Life Care Planning and Case Management Handbook

Third Edition

Edited by Roger O. Weed and Debra E. Berens
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Edited by

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Foreword

The 2009 edition of the *Life Care Planning and Case Management Handbook* represents the second update or third edition of one of the pillars of reference texts in the practice of life care planning. In the foreword for the 2004 edition, I indicated that a number of important and valuable contributors within the practice of life care planning had been brought together to advance this practice specialty. Dr. Weed has accomplished no less a feat in bringing together specialists in their practice areas to bring us the most important updates to aid us in plan development and case management. Perhaps the most important change is bringing Debbie Berens, PhD, CRC, CCM, CLCP, on board as coeditor. This adds to his text on many important levels, but most importantly it ensures that it will remain available to the life care planning community long into the future.

Dr. Weed and I first met in 1984. This was approximately eight years after I had begun working on the development of the basic tenets, methodologies, and principles of life care planning and three years after the publication of *Damages in Tort Actions*. No one to that point in time had come to life care planning with greater enthusiasm or interest. Since that time, no one has proven to share my vision for life care planning with greater dedication and effort. Dr. Weed has been a dedicated colleague, researcher, writer, lecturer, and teacher, and a tremendous overall contributor to the advanced practice of life care planning. In recognition of his work, he was invited to participate in *A Guide to Rehabilitation* (Deutsch & Sawyer, 1985–2007, Ahab Press, White Plains, NY). That text was retired in 2007, and the *Life Care Planning and Case Management Handbook*, along with Susan Riddick Grisham’s *Pediatric Life Care Planning and Case Management* text, represent the two most comprehensive texts on life care planning and case management currently on the market. He has, without question, been a major moving force in the advancement of life care planning for the past two and a half decades. He has done this by always remaining a team player who stays focused on what is good for life care planning and its practitioners as a whole. We have always shared a philosophy of openly contributing in our lectures and our texts all of the latest information and research we have available. Dr. Weed never holds anything back, and this latest text continues to hold to that philosophy.

The 2009 edition of the *Life Care Planning and Case Management Handbook* will continue to be a necessary desktop reference for every advanced practitioner of life care planning. New chapters on home assessments, vehicle modification, day-in-the-life videos, and elder care law will prove to be exceptionally important to today’s practitioner. The reader will also find that chapters upon which they have depended in the past have been carefully reviewed and updated. In some cases, past contributors have aptly fulfilled this role, but in other instances new contributors with proven, specialized skills and insights have been tapped to provide their insights to completely rewrite or update some of the chapters.
What is most important for readers such as myself is we can still find what we have so depended on in the past. For example:

- In its opening chapters, the text continues to define the roles played by each of the key team members working with the life care planner. It provides life care planners with the insights critical to successful interactions with medical, health-related professionals, and economic team members they are most likely to encounter as they work to build a successful and accurate life care plan.
- The book then goes on to provide up-to-date information on the disabilities most frequently encountered by the life care planner. Most important, we are not just lecturing on current information; we are providing critical resources for being able to bring ourselves up to date on a day-to-day basis. This is what makes this book a critical desktop reference.
- This handbook then moves on to address issues typically left out of similar texts—issues made critical by Daubert v. Merrell Dow in the forensic setting, issues that should be critical even in the nonforensic setting. I refer to ethics, standards, research, and credentials, all of which are thoroughly and professionally addressed within these pages.

It is easy to see that this text continues to illustrate the progression of a career, in which Dr. Weed has both written and edited many other books, chapters, and articles. He has been instrumental in not only helping to develop the advanced practice of life care planning but also helping to develop the market for the product we produce. Once again, I extend my congratulations to Dr. Weed and coeditor Dr. Berens and all of the contributors on an excellent work. I also continue to congratulate those with the insight to be working with a copy of this text on their desktop.

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Introduction

As reported in the first and second editions, life care planning has become a specialty practice unto itself with standards of practice, formal training programs, codes of ethics, professional associations, and (currently) two certifications specific to life care planning. As a health care specialty, it continues to grow and flourish with more training options than ever in existence. Since the last edition of this book, the University of Florida has successfully launched an online distance learning program to join Kaplan University, and there are other companies that offer training onsite as well as online. These authors observe that increasing numbers of physicians and allied health professionals are seeking training. In addition, the *Journal of Life Care Planning*, which was introduced in 2002, as was the Foundation for Life Care Planning Research, have both contributed substantially to the practice of life care planning. Conceptually, the process, methods, and standards associated with future care build upon the foundation of appropriate and coordinated medical and ancillary care for people who have experienced significant medical adversity with lifelong challenges, and the process for identifying needs is described in the following pages.

Purpose

This book is intended to bring together into one publication the many concepts regarding developing life care plans, as well as to offer contemporary thought, beliefs, standards, and procedures. It is the editors’ view that this highly specialized health care practice offers a valuable contribution to managed care and quality-of-life issues for persons with catastrophic disabilities and complex health care needs. Having a solid foundation from which to practice will advance the entire specialty area. The intended audience for the book is anyone who has a role in planning for complex medical care. Families, clients, medical professionals, allied health care professionals, and representatives of the insurance claims industry and legal profession are included. It seems that life care planning is ideal for managed care, if the focus is on quality of care while maximizing the purchasing power of available resources.

Book Structure

The book is presented in four sections. The first chapter represents an overview of the history as well as the current practice of life care planning with a view toward the future. Section I, comprised of Chapters 2 through 11, spotlights various professions commonly associated with developing a life care plan. The professional roles are outlined, and suggestions for planning are offered for those
unfamiliar with the various specialties. Each author was asked to provide an overview of his or her area of specialty as well as identify specific life care planning issues and topics. Obviously, not all contributors who possibly could be life care plan participants are included. For example, dietitians, recreational therapists, music therapists, and various medical specialties that are considered either too closely aligned to the others or not routinely part of the team are not included in the book.

Section II, comprised of Chapters 12 through 21, has been expanded and focuses on selected disabilities for which life care planning has been utilized. Certainly, current practice seems to encompass mostly injury-related disabilities, but the field is slowly expanding into disease and emotional disabilities if the required care is complicated or complex. Two examples are HIV and transplantation care plans. Chapters on mental illness and geriatrics, which were added in the second edition as a result of emerging needs in these areas, were updated. Also, the chapter on audiology, located in Section I, necessarily includes topics relating to a specific disability that overlap with the section on selected disabilities.

Section III, on forensic considerations, is included in the book given that one of the first published uses of the life care plan was through the legal profession. And, although future care planning is much broader in contemporary times, the legal roots are still obvious. This section represents a highly specialized civil litigation enterprise that has different rules with which most people outside of the legal profession are not familiar. The section includes basic concepts and perspectives from both plaintiff and defense attorneys. A unique contribution is the inclusion of the story of a father and a caregiver in a case where the life care plan was instrumental in settling litigation. Most people cannot fully appreciate what it must be like to have a family member involved in a traumatic injury and have to deal with major medical decisions as well as legal issues. Therefore, this chapter is included to offer some personal insight into these areas. Added in this edition are two chapters. The first relates to the rapidly emerging specialty legal practice in elder care, and the second summarizes production-related recommendations for day-in-the-life video production.

The fourth and final section addresses general issues and covers important topics that are not easily aligned with other areas. Ethical issues transcend all categories and probably are the basis for the longevity of the life care planning industry. Ethical life care planners who adhere to a code of conduct will assure the future. Technology also transcends all categories and has immensely impacted the efficiency and professionalism of completing the life care plan. This specialty practice has dramatically changed in the last several years and presents a major challenge for life care planners to keep abreast of new information including products, services, and technology. Life care planning certification information has been revised to reflect a more contemporary practice. Hopefully, voluntary use of qualified life care planners will encourage others to pursue specialized training from the many available options (see information in Chapter 1, “Life Care Planning: Past, Present, and Future”). Along with qualifications and ethics is the concept of basic research associated with the value of life care plans. A chapter that is a reprint of initial research on reliability is a current issue and was included again in this edition. With the establishment of the Foundation for Life Care Planning Research, many more research-related studies are expected to be published in the near future. A chapter on the Americans with Disabilities Act (ADA) as it relates to life care planning has been added to educate the readers about certain specialized ADA topics not previously covered. As was reflected in the second edition, the identification and location of resources comprise a huge obstacle for beginning life care planners. Networking among life care planners clearly reveals the tremendous thirst for data that can be used for planning. Some sources are well known, while others are obscure. The sources listed in this book represent a significant amount of work and sharing of knowledge. Other new chapters are related to elder
care law, home assessments, and transportation. The latter two chapters, coauthored by one of the editors, are reprints of information that initially appeared in the *Journal of Life Care Planning* and are reprinted with permission.

This third edition of the book includes two appendices: the first is the updated Standards of Practice as published in 2006 by the International Academy of Life Care Planners (IALCP); the second is a list of life care planning references. It is our hope that this text will advance the specialty practice of life care planning another level and that the information will assist all who read it by improving their knowledge and professional skills.

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Acknowledgments

There are a number of people who have contributed to helping this book become a reality. Certainly, first to be recognized are the contributors, who represent a major powerhouse of knowledgeable movers and shakers in the life care planning specialty practice from a wide range of specialties. One person, Dr. Paul Deutsch, acknowledged as the father of life care planning, has for many years maintained strong support for our work in this field, and we are honored to have him write the foreword to this edition. The department chair at Georgia State University, Dr. JoAnna White, has been very supportive with our research and writing adventures. We report with sadness that two contributors are no longer with us. Dr. Randy Evans was the author of the neuropsychology chapter in the first and second editions and was a major resource for brain injury treatment programs. Ms. Patti McCollom, a powerhouse and the founder of the International Academy of Life Care Planning, board member of the Foundation for Life Care Planning Research, past chair of the Commission on Case Management Certification, and active in many life care planning and case management organizations and conferences, was a contributor to the elder care chapter. Her husband, Lew Vierling, arranged for long time associate, Dorothy Zydowicz-Vierling, to update her chapter for this edition. Both Randy and Patti are missed.

We also think it is valuable to recognize others who have been instrumental in our careers. From Roger: Of course, my parents have primary credit for my existence as well as urging me to break the mold of local tradition by continuing my education. I was raised in a very small town where high school graduates commonly went to work in the timber industry. In fact, one of my peers could not understand why I would go to college when I could make almost as much money as a college graduate right out of high school. At the time, I did not have a good answer for him. However, the last time I saw him he was “between jobs” due to the massive turndown in the local economy, which is based almost entirely on wood products and logging.

Dr. Timothy Field, who in 1984 was a professor at the University of Georgia, agreed to be my PhD major advisor after a few years of mentoring and advising me in my professional life. I can truly convey that Dr. Field has been a significant positive factor in my professional life. He has opened many doors, been supportive beyond the call of duty, and shown me new horizons. As mentioned, Dr. Paul Deutsch has also been very supportive in my professional career by including me in his life care planning training, writing, and volunteer activities as well as being available for consultation. Julie Kitchen, who is associated with Paul, has also been available for an enormous number of contacts for information, and always is a pleasure with whom to work. I also acknowledge my coeditor, Debbie Berens, who at the time of this edition has, for the past 20 years, been a major cheerleader, editor, organizer, coauthor, and overall superb and talented colleague.
Acknowledgments

Last, but certainly not least, my wife, Paula, has always encouraged me to do professionally whatever I wanted. This support resulted in many moves and job changes for her, and she has never wavered. All in all, I believe that many people have observed more capability in me than I saw in myself. Through good fortune, outstanding resources, and a lot of assistance, this text comes to fruition.

From Debbie: it is thrilling to realize that, for the past 20 years, I have had the incredible experience of mentorship from Roger Weed, my rehabilitation counseling professor back in the days of my master’s degree, and, most recently, my advisor and dissertation chairperson for my doctorate. What ground we have covered in these past two decades! Roger has opened many doors in my professional life and has done so with a generosity of spirit and a belief in my abilities that has brought me to this point, coeditor of this monumental text and an established life care planner. For these past 20 years, Roger has been the epitome of a mentor, vocational rehabilitation counselor, professional confidante, sounding board, and friend, and the consummate example of a researcher, professor, leader, life care planner, and team builder. I certainly hope for another 20 years of professional association.

Another major driving force in my life for the past 22 years has been Mark, my husband, who gets the most credit for endurance and perseverance throughout my professional career. His unfaltering belief in me and unwavering support of all my activities have allowed me to take risks and to grow in professional ways that I would have never imagined. And my two sons, Matthew and Jacob, whose ever present smiles and hugs are the brightest part of my life; there could be no other mom more proud. The many late nights (and early mornings), missed ball games, absent family dinners, skipped vacations, and other sacrifices made over the years can never be replaced, yet I am ever thankful for the joy that my family gives to me and the sense of balance that is so vital. Every step on this journey and every minute spent working on this book have been made with each of you by my side and in my heart.

For my extended family, Mom and Dad, who have stepped in and been there at all the right times throughout my life as only parents know how to do, and to my sisters who always gave their support across the miles, I have each of you to thank for allowing me to share in your lives. My world is so much better with each of you in it.

This book has been the culmination of many contributors within the specialty practice of life care planning. In our daily practices, we are continuously reminded of the good work that goes on in life care planning and the collective energy of life care planning professionals who produce quality work and are committed to advancing the practice. It is our hope that this book will play a small part in continuing the life care planning and case management momentum.

Roger O. Weed
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Editors

Roger O. Weed, PhD, LPC, CRC, CDMS, CCM, FNRCA, FIALCP, professor and graduate rehabilitation counseling coordinator at Georgia State University, is a licensed professional counselor, certified rehabilitation counselor, certified disability management specialist, certified case manager, fellow of the National Rehabilitation Counseling Association, and fellow of the International Academy of Life Care Planners. He has authored or coauthored well over 100 books, articles, and book chapters. He has been honored with several awards for his work, including the 2006 Distinguished Professor Award from the Alumni Association, Georgia State University; Lifetime Achievement Award, International Life Care Planning annual conference; Lifetime Achievement Award, International Association of Rehabilitation Professionals; Outstanding Educator Award, International Association of Rehabilitation Professionals; the 1993 National Professional Services Award from the American Rehabilitation Counseling Association; and the 2003 Research Excellence Award from the College of Education at Georgia State University. In addition, he is listed in several editions of *Who's Who in the World*.

Dr. Weed is the ethics chair for the International Academy of Life Care Planners and an associate editor of the *Journal of Life Care Planning*. He is one of the five founders of the original national training program leading to life care planning certification. He is also a past chair of the Georgia State Licensing Board for professional counselors, marriage and family therapists, and social workers, as well as a past president of the International Association of Rehabilitation Professionals (IARP) (previously known as the National Association of Rehabilitation Professionals in the Private Sector).

Debra E. Berens, PhD, CRC, CCM, CLCP, is a certified rehabilitation counselor, certified case manager, and certified life care planner in private practice in Atlanta, Georgia. Her consulting practice specializes in assessment, research, and development of life care plans for adults and children with catastrophic injuries and disabilities. Dr. Berens also is a part-time instructor in the graduate rehabilitation counseling program at Georgia State University. She is one of the initial developers of course content for Kaplan University’s online professional certificate program in life care planning and is part of the curriculum development team for the University of Florida’s professional certificate in life care planning. In 2001, she completed a five-year term as commissioner on the national Commission on Rehabilitation Counselor Certification (CRCC) and was an active member of the Ethics Committee charged with revising the Professional Code of Ethics for Rehabilitation Counselors (2001), and also served as chair of the Standards and Credentials Committee. She later was a member of the five-person task force responsible for revising the Code of Ethics, Standards of Practice, and Competencies for the International Association of Rehabilitation Professionals (IARP).
A familiar face as moderator of the annual life care planning conferences for the past several years, Dr. Berens is active in both state and national rehabilitation organizations and has actively participated in the planning and facilitation of the biennial Life Care Planning Summits since the original summit in 1997. She is a past president of the Professional Rehabilitation Specialists of Georgia (PRSG), the state chapter of IARP, and in 2007 was awarded the international Outstanding Practitioner award from Chi Sigma Iota Counseling Professional Honor Society. Debbie currently serves on the board of directors of the Foundation for Life Care Planning Research and the Side by Side Brain Injury Clubhouse. She has contributed over the years to writings, publications, and presentations in the fields of rehabilitation, case management, and life care planning, and currently is the managing editor of the *Journal of Life Care Planning*. 
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Paul Amsterdam, ATS, is starting his thirtieth year as a specialist in the field of rehabilitation medical equipment. He comes from a family of three generations in this industry, starting in 1929 with the founding of Amsterdam Bros., one of the country’s first orthotic and surgical supply stores.

Mr. Amsterdam is a nationally certified assistive technology specialist. He has helped to create and has participated in over 100 wheelchair clinics in rehabilitation hospitals, developmental centers, and schools for people with disabilities throughout the New York–New Jersey Metropolitan area. He has been a featured columnist for *Case Manager* magazine and other publications for the last five years.

Mr. Amsterdam is considered an expert in wheelchair mobility and adaptive seating. He makes full assessments of functional needs, designs custom positioning seating systems, and offers alternatives in decubitus prevention as well as manual and power mobility options. He provides complete evaluations for both adults and pediatrics with a wide range of physical disabilities.

Paul is currently working with Sunrise Medical, the manufacturers of rehabilitation mobility equipment, such as Quickie wheelchairs and Jay Seating Products. He also runs his own consulting firm, Rehab Equipment Consulting, which works nationwide with case managers, insurance providers, and life care planners on medical equipment issues. Rehab Equipment Consulting helps create the medical equipment portion of a life care plan, saving time for the planner, and adding veracity and defensibility to that portion of the plan by having it reviewed by a certified specialist in the field. Mr. Amsterdam is also available for expert witness testimony.

Raymond L. Arrona began his career in 1967 as an independent contractor with Wear-Ever Aluminum, Inc., Alcoa Aluminum’s first subsidiary, which marketed Wear-Ever Cookware and Cutco Cutlery. He quickly achieved one of the company’s coveted positions as division manager and relocated from Arizona to Georgia in 1976 where he was president and CEO until 1997 of RASAR Management Services, Inc./dba Vector Marketing, which represents the Cutco Cutlery product. He also operated as Vector’s southern zone division manager for the states of Georgia and South Carolina. In late 1997, he joined a start-up company, QuestCom, which develops websites for businesses. Since the publication of the first edition of this book, he has relocated with his daughter, Anita, to Mesa, Arizona, where he owns Pride of the Valley, an upscale shared direct mail card deck, an affiliate of Pride of the City.

Mr. Arrona experienced every father’s nightmare when his daughter, Anita, was tragically injured in an accident caused by a drunk driver. “The impact of Anita’s accident has been far reaching in all areas of my family’s life, including the personal, financial, spiritual, educational, judicial, professional, and friendship levels. No emotion has been immune from the effects of that tragic day. It is
my wish that by telling Anita’s story, it will in some way help others through similar situations, or assist in allowing life care planners to gain insight into our family as we continue to deal with this life-changing event.”

Dan M. Bagwell, BSN, RN, CLCP, CCM, is chief executive officer of Rehabilitation Professional Consultants, Inc., and president of Dan Bagwell & Associates, both of which are located in San Antonio, Texas. Mr. Bagwell is a registered nurse, licensed in the state of Texas. He received a Bachelor of Science in nursing in 1978 from the University of Mississippi School of Nursing. He is a certified life care planner, certified case manager, and certified disability management specialist. Mr. Bagwell provides adult and pediatric catastrophic case management and life care planning services for individuals in Texas and throughout the United States. His clinical nursing experience spans 30 years, 24 of which have been dedicated primarily to medical case management. In addition to case management, his clinical experience has included critical care nursing and service as an officer in the United States Air Force Nurse Corps and Air Force Reserves. Mr. Bagwell completed the USAF Flight Nurse School in 1979 and performed duties as a medical crew director and flight nurse in Tactical Aeromedical Evacuation. He previously served as president and cofounder of Life Care Personal Living Centers and cofounder and vice president of MediSys Rehabilitation, Inc. Mr. Bagwell has given presentations, lectures, and symposiums concerning life care planning at regional, national, and international conferences. He has authored and coauthored journal articles and textbook chapters in life care planning and organ transplantation. Mr. Bagwell has also served as courtesy faculty with the University of Florida and assisted with the development of educational tracts for the advanced life care planning curriculum concerning solid organ transplantation. He is also a curriculum developer for Kaplan University concerning life care planning and solid organ transplantation.

Richard Paul Bonfiglio, MD, is board certified by the American Board of Physical Medicine and Rehabilitation. Dr. Bonfiglio has previously served as the medical director of several nationally recognized rehabilitation facilities, including the Lake Erie Institute of Rehabilitation and the Bryn Mawr Rehabilitation Hospital. He has also maintained close academic ties, including having served as residency program director at the Schwab Rehabilitation Center.

Dr. Bonfiglio’s clinical practice within the field of physical medicine and rehabilitation has included providing care to children and adults with traumatic brain injuries, spinal cord injuries, amputations, and acute and chronic pain problems. He is an internationally recognized speaker on rehabilitation topics.

Dr. Bonfiglio has been involved for years in the review and critical analysis of life care plans. His interests include the development of a strong medical foundation to enhance the accuracy and reliability of these plans. He is also an expert in life expectancy determinations for individuals following catastrophic illnesses and injuries. He has been on the faculty of the Rehabilitation Training Institute and MediPro Seminars for life care planning.

Dr. Bonfiglio has sustained a strong clinical practice within the field of physical medicine and rehabilitation, providing care to children with a variety of physical and cognitive impairments, and children and adults with traumatic brain injuries, spinal cord injuries, amputations, and acute and chronic pain problems.

Laura Deutsch Brown is a costing specialist with Paul M. Deutsch & Associates in Oviedo, Florida. She has been participating in life care planning research and costing for the company for five years. Laura graduated from Rollins College, Winter Park, Florida, with a degree in psychology.
Terry C. Cox, JD, is an elder law attorney in private practice in Collierville, Tennessee. He has represented individual and business clients in a broad range of civil and criminal cases in various courts, and is committed to providing advice and counsel to elders and their families on issues of aging to help clients protect their interests, plan for their future legal needs, and plan for their future health care needs.

Paul M. Deutsch, PhD, CRC, CCM, CLCP, FIALCP, is a licensed mental health counselor with a PhD in rehabilitation counseling and counseling psychology in his 31st year of practice. He specializes in working with catastrophic disabilities resulting from either birth or a traumatic onset. Dr. Deutsch is best known for having developed the basic tenets, methodologies, and processes of life care planning. He first published on life care planning as a fundamental tool of case management in his 1981 text, *Damages in Tort Actions* (coauthored with Fred Raffa). Dr. Deutsch has contributed twelve volumes and more than fifty peer-reviewed journal articles and chapter contributions, including “A Guide to Rehabilitation,” with Horace Sawyer; “Innovations in Head Injury Rehabilitation,” with Kathleen Fralish; and “Damages in Tort Actions,” with Fred Raffa.

Recently, Dr. Deutsch led a team including Lori Allison, Roger Weed, Patricia McCollom, Debbie Berens, and Terri Winkler in the development of Kaplan College’s life care planning curriculum.

Dr. Deutsch has taught as an adjunct professor at several universities and lectured widely through the United States and Europe. In the 1980s and early 1990s he worked extensively in the former Soviet Union with colleagues of Alexander Romanovich Luria. He has worked extensively in the areas of brain injury and spinal cord injury rehabilitation, among other areas. His experience includes co-ownership and directorship of a brain injury rehabilitation center in the 1980s and later ownership and management of a long-term residential and supported work program for severe brain injury patients.

He has remained active in research efforts and in the past few years has helped to spearhead the formation of the Foundation for Life Care Planning Research along with Dr. Roger Weed; Dr. Christine Reid; Patricia McCollom, MS, RN; and Susan Riddick, RN. The primary work of this foundation is research on the reliability and validity of the life care planning process. Related areas of research may include life expectancy as it is influenced by effective life care planning, as well as case management and all appropriate related life care planning research. In a short time the foundation has forged multiple university relationships and developed successful fund-raising efforts. The results have allowed the foundation to begin funding several doctoral dissertation projects as well as other research efforts.

Dr. Deutsch is active in the profession’s efforts to support and educate nurses and rehabilitation counselors involved in forensic consultation about Daubert-related issues. He has developed the core materials for the profession’s amicus curiae brief that was filed in the Texas Seventh District Court of Appeals and is in the process of developing educational materials to be made available to all interested professionals.

Everett G. Dillman, PhD, an educator and business consultant, is president of International Business Planners, Inc. Dr. Dillman has been active in governmental, business, and financial circles in the Southwest for over fifty years. During this period he has served on the advisory board of the Lubbock Division of the Small Business Administration as well as on the board of directors of several profit and civic organizations. Dr. Dillman has served on the board of directors of the National Association of Forensic Economists and on the Steering Committee for Forensic
Rehabilitation of the National Association of Rehabilitation Professionals in the Private Sector. He has published extensively in both the vocational and economic areas.

Tyron C. Elliott, JD, is a practicing trial lawyer with over thirty years of experience. His practice focuses on the area of neurolaw, which deals with brain and spinal cord injuries. Mr. Elliott primarily represents persons who have received traumatic injuries. He is an adjunct professor at Emory University School of Medicine in Atlanta, where he lectures on legal-medical issues. He is also an advocate member of the American Board of Trial Advocates and has given lectures and programs throughout the United States, Canada, and Mexico. Mr. Elliott is the executive editor of the Neurolaw Letter and has contributed several articles on brain injury and related litigation.

Lisa Engelhart, MS, CRC, was a state vocational rehabilitation counselor and school transitional counselor. She currently teaches special education students in Georgia.

Kevin Foster, MD, MBA, FACS, is the medical director of the Arizona Burn Center and program director, General Surgery Residency as well as director of research of the Department of Surgery, Maricopa Medical Center. Dr. Foster is a graduate of the Medical College of Ohio and completed a general surgery residency at the University of Wisconsin, followed by burn surgery and trauma research fellowships at the University of Washington. He recently completed an MBA at Indiana University School of Business.

Tracy Raffles Gunn, JD, is the founder of Gunn Appellate Practice, PA, in Tampa, Florida. Ms. Gunn is board certified by the Florida Bar as a specialist in appellate practice and is AV rated by Martindale Hubbell. She is chair of the Florida Supreme Court Committee on Standard Jury Instructions in Civil Cases, is an elected member of the American Law Institute, and serves on the Executive Council of the Appellate Practice Section of the Florida Bar. She has been recognized as a one of the “Best Lawyers in America” in the specialty of appellate practice, and was named one of the Top 50 Female Attorneys in Florida by Florida Superlawyers.

Anna N. Herrington, PhD, is a graduate of the rehabilitation counselor training program at Georgia State University and is a counseling psychologist in Atlanta, Georgia.

Carolyn Wiles Higdon, PhD, CCC-SLP, owns and operates a private practice in assistive technology in Georgia. Her practice includes assistive technology for all ages, as well as educational consulting, forensics and life care planning, catastrophic health care of acquired brain injury and trache- and ventilator-dependent patients, and mediation and legal consulting. Dr. Higdon testifies as an expert witness in assistive technology for all ages, is a past chair of the Georgia Board of Examiners for Speech Pathology and Audiology, and is a past chair of Division 12 of the American Speech-Language-Hearing Association (ASHA), the AAC Division. Dr. Higdon is a fellow of the ASHA, is active in multiple professional organizations, and has taught and consulted in Russia, Eastern Europe, Hong Kong, China, Costa Rica, and Thailand. Dr. Higdon is an ASHA consultant to the American Medical Association in the areas of augmentative and alternative communication and current procedural terminology (CPT) codes. Dr. Higdon is the chair of the Department of Communicative Disorders and the director of the Center for Speech
and Hearing Research in the School of Applied Sciences at the University of Mississippi (Oxford), and is an adjunct clinical associate professor at the University of Mississippi Medical Center in Jackson, Mississippi.

**J. Mat Hunt, Jr., CLVS**, in 1982, following years of electronic media experience as a television news and weather reporter, anchor, and documentary producer/writer/editor, founded what is now Huntridge Legal Videography Services in Greenville, South Carolina. In addition to the usual video depositions and day-in-the-life presentations, his settlement documentaries are credited with helping to turn the corner in settlement negotiation and mediation. Permitted works have received multiple Telly Awards and Silver Reels—a rarity in court-related media. An invited guest lecturer with authentic “show and tell” in conferences and continuing legal education seminars, Hunt’s quarter-century profession has been the humanizing of litigation.

**Jim Karl, BS, GC, CEAC, CAPS**, has a degree in Industrial Arts Education with a K-12 certificate and additional hours toward a master’s degree in Course Curriculum Development. Mr. Karl has more than twenty years of hands-on experience in construction and accessible renovations, and is an owner of All In One Accessibility based in Marietta, Georgia (www.allinoneaccess.com). He is a Certified Aging In Place Specialist with the National Home Builders Association, Certified Environmental Access Contractor certification obtained through U.S. Rehab, and a general contractor. He has volunteered his time to several organizations including service on the board of directors of Professional Resources in Management Education, Inc., the previous certifying organization for CEAC now operated by U.S. Rehab. He has consulted nationally on life care plan home assessment and has an extensive speaking resume.

**Sherie L. Kendall, PhD**, received a BA in biology from Indiana University, Kokomo, followed by a doctorate from Indiana University School of Medicine, Indianapolis, Indiana, in medical neurobiology with a minor in anatomy. Eli Lilly Neuroscience Discovery Research Laboratories, Indianapolis, Indiana, awarded her a Women’s Health Internship to study gender differences in models of brain ischemia for her dissertation. As a National Institutes of Health Postdoctoral Fellow at University of Kentucky College of Medicine she received advanced training in Therapeutic and Translational Clinical Research while investigating hormonal neuroprotection and the relationship of HIV-associated dementia to illicit drug use, published in the open access journal, *BMC* (Kendall et al., 2005). Her latest study at University of Kentucky investigating estradiol’s modulation of amphetamine’s effects in young women was recently published in *Pharmacology, Biochemistry and Behavior* (Lile et al., 2007). Dr. Kendall currently serves as assistant professor of biology in the Division of Nursing & Science at Midway College, Midway, Kentucky, where she teaches anatomy and physiology for prenursing students.

As director of research for the Foundation for Life Care Planning Research, Dr. Kendall organizes studies in validation and reliability of life care planning methodology. Publications include contributions to the *Journal of Life Care Planning, A Guide to Rehabilitation, Life Care Planning and Case Management Handbook* (2nd edition), *Case Management for Rehabilitation Health Professionals*, and *NeuroRehabilitation* (Deutsch et al., 2006).

Dr. Kendall is a National Institutes of Drug Abuse Travel Award–winning international speaker, having presented the results of her research at scientific meetings in Europe, Canada, and Puerto Rico, and across the United States. She is active in the Society for Neuroscience, Kentucky Academy of Science, Academy of Southeastern Biologists, Science Advisory Board, and American

Julie A. Kitchen, CCM, CDMS, CLCP, is a certified life care planner with Paul M. Deutsch & Associates in Oviedo, Florida. She has been involved in life care planning research and preparation for thirty years. She is a current faculty member with the University of Florida’s Life Care Planning certificate program, teaching life care planning to others throughout the country. She also works with Kaplan University’s online program in life care planning. She has authored a number of book chapters, articles, and monographs in professional journals. At the 2008 International Symposium of Life Care Planning, Julie was awarded the 2008 lifetime achievement award by her professional peers.

Denise Lester, MD, received her medical degree from the New Jersey Medical School, then completed her residency in anesthesiology as well as pain management training from the Thomas Jefferson University Hospital. Dr. Lester is an assistant professor of anesthesiology at the Medical College of Virginia, Virginia Commonwealth University, and is director of pain management at the Hunter Holmes McGuire Veterans Affairs Medical Center in Richmond, Virginia.

A diplomat of the American Board of Anesthesiology and the American Board of Pain Medicine, Dr. Lester holds specialty certifications in Spinal Cord Stimulation Intraspinal Pump, Radiofrequency Ablation, Percutaneous Discectomy (Dekrompressor), Vertebroplasty, Kyphoplasty, and Spineology Artificial Bone Augmentation.

She has been honored with numerous awards, is a teacher and speaker, as well as a volunteer to various committee and professional organizations. When not working, she is a fitness instructor (yoga, zumba, spinning, kickboxing, water aerobics, and group X).

Robert Litwack, MD, received his medical degree from the University of Minnesota Medical School, then completed his residency in anesthesiology at Boston University Hospital. Dr. Litwack is an assistant professor of anesthesiology at the Medical College of Virginia, Virginia Commonwealth University, and practices anesthesiology and pain management at the Hunter Holmes McGuire Veterans Affairs Medical Center in Richmond, Virginia.

A diplomat of the American Board of Anesthesiology with added qualifications in pain medicine, Dr. Litwack holds specialty certifications in Spinal Cord Stimulation Intraspinal Pump, Radiofrequency Ablation, Percutaneous Discectomy (Dekrompressor), Vertebroplasty, Kyphoplasty, and Spineology Artificial Bone Augmentation.

Patricia McCollom, RN, MS, CRRN, CDMS, CCM, CLCP, was president and nurse consultant for LifeCare Economics, LTD, and Management Consulting & Rehabilitation Services, Inc., and was CEO of the International Academy of Life Care Planners, Ankeny, Iowa. A graduate of the master’s program in rehabilitation, Drake University, Ms. McCollom had extensive experience in care of individuals with head trauma, spinal cord injury, and other catastrophic injury. She was a past national president of the Association of Rehabilitation Nurses, former chair of the National Task Force on Case Management, and past chair of the Commission for Case Manager Certification (CCMC). She was elected by CCMC in 2003 to serve a five-year position on the Foundation for Rehabilitation and Research. At the national level, she taught case management practice and life care planning. She was vice president of the board of directors of the Foundation for Life Care Planning Research. The author of many articles on rehabilitation, case management, and life care planning, Ms. McCollom contributed the chapters on case management, burn
rehabilitation, and cancer rehabilitation to the 2002 Mosby text *Rehabilitation Nursing*, third edition, and the section on life care planning to the 1997 *Advanced Rehabilitation Nursing Practice Core Curriculum*, published by the Association of Rehabilitation Nurses. She coauthored the section on amputations in the Mosby publication *Case Management Clinical Practice Guidelines* and the chapter on life care planning in the September 2001 F.A. Davis text, *The Nurse and the Law*. Ms. McCollom is a coauthor of *The Expert’s Role as an Educator Continues: Meeting the Demands under Daubert* (2002). She was one of the principal developers of the certificate course in life care planning, initiated by Kaplan College in July 2003. Ms. McCollom was the editor of the *Journal of Life Care Planning* from 2002 to 2004 and a 2007 Lifetime Achievement Award recipient from the sponsors of the annual life care planning symposium. (Editors’ note: Sadly, Patti died the day the award was officially granted. However, due to the knowledge of her declining health, arrangements were made to honor her in her hospital room shortly before the conference commenced.)

**Robert H. Meier, III, MD,** is a physiatrist who has provided amputation rehabilitation during the past 34 years for some 3000+ persons with amputations. He previously directed amputee services at The Institute for Rehabilitation and Research in Houston, Texas, and the University of Colorado Health Sciences Center in Denver, Colorado. He received his MD and PM&R residency training from Temple University in Philadelphia. He has served on the faculties of Rehabilitation Medicine at Temple University, Baylor College of Medicine, and the University of Colorado Health Sciences Center. He is now in private practice and is director of the Amputee Services of America, a comprehensive outpatient rehabilitation program devoted solely to the rehabilitation of persons with one or more amputations, located in Thornton, Colorado. In addition, Dr. Meier serves as the manager of the ARMteam, a group of amputation rehabilitation specialists who consult nationally on the needs and most cost-effective services provided for complex amputee problems. Dr. Meier is the director of Medical Rehabilitation Services for Kindred Hospital Denver and is on the active medical staff of the North Valley Rehabilitation Hospital. He also is the rehabilitation consultant for the Institute for Limb Preservation in Denver, Colorado, a multispecialty medical group providing services for persons whose limbs are in jeopardy from cancer or trauma. He speaks nationally and internationally on various rehabilitation and amputation topics and has written many articles and book chapters. His most recent text, *Functional Restoration of Adults and Children with Upper Extremity Amputation*, was coedited with Diane Atkins and published by Demos in 2004. Dr. Meier has been involved with life care planning since 1976.

**Jennifer Milton, BSN, MBA, CCTC,** serves as the administrative director and associate faculty at the University of Texas Health Science Center at San Antonio. Ms. Milton completed her degree in nursing at Russell Sage in Troy, New York. Her experience as a cardiac intensive care unit nurse introduced her to the field of organ donation. She served as a donation coordinator for three years before transitioning into the field of transplantation where she worked at the Medical University of South Carolina for ten years. Ms. Milton oversees the clinical and financial operations of the University Health System/UTHSCSA Transplant Center, which operates programs for end-stage organ failure and transplantation for lung, liver, kidney, and pancreas, and an active living donation program.

**Nancy L. Mitchell, MA, OTR/L, ATP, CLCP, FIALCP,** is an occupational therapist with more than thirty years of experience. She became a certified life care planner in 1998. In addition to her continued clinical occupational therapy practice, she owns Mitchell Disability Assessments & Life Care Planning. Ms. Mitchell completed a master’s degree in gerontology with an emphasis on
aging with a disability. She has presented locally and nationally and is published in the *Journal of Life Care Planning* and the *Journal of Legal Nurse Consultants*.

**William D. Mustain, PhD**, is currently associate professor and chief, Division of Communicative Sciences, Department of Otolaryngology & Communicative Sciences at the University of Mississippi School of Medicine, in Jackson, Mississippi. He also serves as director of the Communicative Sciences Department and the Clinical Vestibular Laboratory, University of Mississippi Health Care, and is an adjunct assistant professor in the Department of Communicative Sciences and Disorders at the University of Mississippi (Oxford). Dr. Mustain received a BA in psychology from the College of William and Mary, and an MEd in deaf education and PhD in audiology from the University of Virginia. He has been involved in evaluation and management of hearing and balance impaired patients of all ages for over thirty years.

**Art Peddle, LPT**, graduated from Georgia State University with a BS in physical therapy, and from David Lipscomb College with a BA in psychology. He has had extensive experience in the field of physical therapy and in multiple disciplines specializing in the areas of industrial occupational medicine, orthopedic physical therapy, sports medicine physical therapy, and neurophysical therapy. He has worked in rehabilitation centers, hospitals, and private practice. His experience has included life care planning and consultation for a variety of physical therapy situations. He presently works with HealthSouth Corporation in Norcross, Georgia. He is a member of the APTA.

**Susan Riddick-Grisham, BS, RN, CCM, CLCP**, maintains a private consulting practice specializing in care coordination for individuals with catastrophic injuries and life care planning. She has authored or coauthored several publications in the area of life care planning and is the editor of the *Pediatric Life Care Planning and Case Management Handbook*. A popular trainer, Ms. Riddick-Grisham has presented educational programs on case management, life care planning, and medical legal consultation.

**Ruth Rimmer, PhD, CLCP**, is director of Psychological/Social Research and Family Service, Arizona Burn Center, and owner of Care Plans for Life, LLC. Dr. Rimmer received her PhD in life span developmental psychology from Arizona State University and a certificate in life care planning from MediPro and the University of Florida. She has been working in the field of burns for over 15 years and has specialized in research associated with the psychosocial and rehabilitation needs of burn survivors, as well as burn prevention. Dr. Rimmer is an active member of the American Burn Association and has served on the Ethics and Rehabilitation committees and as the chair of the Psycho/Social Special Interest Group. She is a published children’s author, an accomplished ventriloquist, and fluent in Spanish.

**David Ripley, MD, MS, CRC, FAAPM&R**, is the medical director of the Rocky Mountain Regional Brain Injury Model System, based at Craig Hospital in Englewood, Colorado. He is board certified in physical medicine and rehabilitation (PM&R) and a fellow of the American Academy of Physical Medicine and Rehabilitation. Prior to entering medical school, Dr. Ripley worked as a vocational rehabilitation counselor and retains his certification (Certified Rehabilitation Counselor). He serves on the board of directors of the Brain Injury Association of Colorado. His clinical practice at the Craig Hospital involves providing medical and rehabilitation care to individuals with brain injury and spinal cord injury.
Anne Sluis Powers, PhD, RN, was an assistant professor of clinical medicine in the department of family medicine and psychiatry at University of Nevada School of Medicine in Reno. Dr. Powers is a licensed psychologist and registered nurse who has coauthored five books regarding life care planning. She provides services clinically to medical patients and those with catastrophic injuries and illnesses.

Amy M. Sutton, PhD, RN, BSN, MA, CLCP, is a certified life care planner and counseling psychologist in private practice. She has her doctorate in neuropsychology from Georgia State University, has received two bachelor’s degrees in psychology and nursing from Purdue University and Indiana University and a master’s degree in psychology from Ludwig Maximillian’s University in Munich, Germany. Dr. Sutton lived and worked as a home health nurse in Germany for 4 years. During her graduate studies in Germany, she conducted a six-week internship/research project in South Africa on AIDS education in the public school system. During her graduate studies in Georgia, Dr. Sutton published several articles and textbook chapters in life care planning as well as publishing the first life care plan validation study. As a registered nurse, she has worked in pediatric critical care, pediatric and adult home health, and inpatient pediatric rehabilitation. She is currently working as a life care planner in Southern California.

Randall L. Thomas, PhD, CRC, is president of the National Center for Life Care Planning. He is a licensed psychologist and certified rehabilitation counselor. He is associated with TecSolutions, a software development company for care management and life care planning activities. He has provided expert testimony in the field of rehabilitation and life care planning in numerous states throughout the United States. He has authored or coauthored numerous articles in the fields of rehabilitation and case management/life care planning software. He is active in the training and education of life care planning. He has served on the Mississippi Board of Psychological Examiners as a member and executive secretary and has also served as a member of the Mississippi Workers’ Compensation Advisory Counsel. He is a member of numerous national organizations and has served as president of the Mississippi chapter of International Association of Rehabilitation Professionals.

Lewis Vierling, MS, NCC, NCCC, CRC, CCM, is president and vocational rehabilitation consultant, for Management Consulting & Rehabilitation Services, Inc., (MCRS) in Johnston, Iowa. A graduate of the master’s program in counseling, Drake University, Mr. Vierling has over 30 years of experience in counseling and vocational services for persons with disabilities. He served as a member of a project team, responsible for the development of a vocational rehabilitation program for a national managed care company.

In June 2006, Mr. Vierling was reelected to serve a second four-year term on the national Commission for Case Manager Certification. He chairs the ethics and professional code committee and serves on the research and examination committee. Mr. Vierling was recently nominated to serve on the Foundation for Life Care Planning Research board of directors and serves on the scholarship committee.

In June 1999, the U.S. Supreme Court cited the results of his vocational evaluation in a landmark Americans with Disabilities Act (ADA) decision, Murphy v. United Parcel Services, Inc. When the Equal Employment Opportunity Commission (EEOC) issued new instructions to address the definition of disability under ADA, Mr. Vierling’s vocational research was cited from the Murphy decision providing examples of “Class of Jobs” relating to work as a major life activity.

Mr. Vierling has recently been invited to contribute periodically a column regarding vocational rehabilitation in the LCA Commentary, a new online publication of the Litigation Counsel of
America, Trial Lawyer Honorary Society. For five years, Mr. Vierling authored an “ADA Update” column for *The Case Manager*, the official journal of The Case Management Society of America, and he is author of *Court Decisions Involving the Americans with Disabilities Act: A Resource Guide For Rehabilitation Professionals*. Mr. Vierling has presented nationally on ADA, catastrophic injury, return-to-work and vocational rehabilitation issues and ethical issues in case management. He was an invited faculty member for the University of Arizona’s Rehabilitation Institute, teaching material regarding the onset of an injury to independence, as well as the implications of ADA court decisions for the rehabilitation professional. Mr. Vierling also presented ADA material at the 2005 and 2006 International Conference on Life Care Planning.

Mr. Vierling was invited to be a faculty member and expert vocational rehabilitation witness at the Defense Research Institutes’ seminar, “Preeminent Lawyers: Superstars of Trial,” in September 2007. Mr. Vierling has published numerous book chapters including, “Disability Case Management” for the second edition of *Case Management Society of America Core Curriculum* and the 2005 update chapter on ADA in Deutsch and Sawyer’s *A Guide to Rehabilitation*. He has contributed a chapter on the ADA in *Damages in Tort Actions*, a Matthew Bender LexisNexis publication and an ADA lesson for the Kaplan College online certificate course in life care planning. Mr. Vierling has contributed numerous journal articles regarding ADA, the dynamics of return to work and catastrophic case management, some of which have appeared in *LNC Resource*, *The Case Manager*, and *RehabPro* publications. In February 2008, GoPubMed, a search engine for biomedical literature, identified Mr. Vierling as an internationally leading author in case management, ADA court decisions and evaluations.

Mr. Vierling was appointed by the governor of Iowa to the Commission of Persons with Disabilities, where he served for ten years. He was elected chairperson of the commission and was invited to attend the signing of the ADA bill at the White House on July 26, 1990.

**Carol Walker, PhD, ABPP-CN, CLCP**, completed her PhD in clinical/medical psychology at the University of Alabama at Birmingham. Her mentor at UAB was Thomas J. Boll, PhD, ABPP, who is a nationally recognized leader in the field of neuropsychology. Her primary interests in her graduate training were neuropsychology, chronic pain, and cardiovascular disease. Dr. Walker completed an internship at the Medical College of Georgia in Augusta, Georgia, where she received specialized training in posttraumatic stress disorder. Her postdoctoral training was completed in an acute rehabilitation hospital setting under the supervision of Dr. Boll.

Dr. Walker is board certified in clinical neuropsychology by the American Board of Professional Psychology (ABPP). She received specialized training in life care planning from the University of Florida/Intelicus, which is known as the most extensive and comprehensive training program for life care planning in the nation. She is a certified life care planner (CLCP), having received her board certification from the Commission on Disability Examiner Certification (now Commission for Health Care Certification). She has eighteen years of combined experience as a clinician treating patients with traumatic brain injury, spinal cord injury, and other catastrophic injuries in an acute rehab setting and currently in full-time private practice. She also provides treatment to patients suffering from cardiovascular accidents, Alzheimer’s disease, and other neurological conditions. Dr. Walker also has an active chronic pain program and furnishes independent medical examinations for patients, insurance companies, and attorneys.

Dr. Walker also serves on the board of The Foundation for Life Care Planning Research and has enjoyed serving on various charitable community boards in Alabama.
She has given numerous invited lectures to a variety of audiences in professional communities not only in Alabama, but at many national conventions. She is also a lecturer for the University of Florida’s online life care planning curriculum, offering specialized expertise to life care planners in the University of Florida’s online training program, proceeds of which Dr. Walker donates to the Foundation for Life Care Planning Research.

**Mamie Walters, CNHP,** pursued a career in music theory and composition until 1981, when she became co-owner and successfully operated a cutlery distributorship for six years. During this period she met Ray Arrona, who was with Vector Marketing Corporation. Her business acumen led to a national promotion as senior assistant to the executive vice president of sales and marketing for the southern zone with Vector. In March 1994, this position ended and Ms. Walters pursued her education full time. In January 1995, she began working as a private hire for Ray Arrona, natural and legal guardian of Anita Arrona for several years. Ms. Walters is a certified natural health professional and is currently enrolled and active in the doctor of naturopathy program. She is also a member of the American Naturopathic Practitioners Association and EarthSave International.

**Terry Winkler, MD, CLCP,** is in private practice as a board-certified physiatrist in physical medicine and rehabilitation and as a subspecialist in spinal cord injury medicine in Springfield, Missouri. He is a past medical director of Cox Hospital Rehabilitation Program and medical director of the Curative Rehabilitation Center, a freestanding outpatient rehab program. His practice focuses on spinal cord injury, acquired brain injury, amputations, and life care planning. Dr. Winkler serves on committees reviewing research grants concerning spinal cord injury, and peer reviews articles for publication in the Archives of Physical Medicine and Rehabilitation. Dr. Winkler has numerous publications regarding life care planning and has contributed to every major text in the field of life care planning, contributed to a college text on rehabilitation record systems, has written on the effects of aging with SCI, and will serve as the medical editor of the new Guide to Rehabilitation (Ahab Press). Dr. Winkler holds an academic appointment as clinical associate faculty at the University of Florida–Gainesville and MediPro Seminars where he teaches life care planning. At Southern Missouri State University in Springfield, Missouri, he teaches differential diagnosis to the master's level physical therapy students. Dr. Winkler's undergraduate training was at Louisiana Tech University. He attended LSU Medical School and then completed residency training in rehabilitation medicine in Little Rock, Arkansas. Past honors include The Americas Award, Alumnus of the Year LA Tech University, “Who's Who among Young Americans,” and the Jean Claude Belot Award from Harvard University health sciences program. In addition to his active medical practice, Dr. Winkler is a certified life care planner, is on the board of the Foundation of Life Care Planning Research, and is on the editorial board of the Journal of Life Care Planning.

**Nicole M. Wolf, MS, CRC, LPC, CPRP,** is a certified rehabilitation counselor, licensed professional counselor, and certified psychiatric rehabilitation practitioner. She works as a quality improvement specialist at United Behavioral Health, where she focuses on improving quality and effectiveness for members in the areas of mental health and substance abuse. Previously she worked as a clinician and research assistant at the Promedica Research Center in Tucker, Georgia. Her research interests include pharmacologic and nonpharmacologic interventions in mental illness and vocational strategies in severe and persistent mental illness.
F. Auston Wortman, III, JD, MPT, has a master’s degree in physical therapy and practices elder law with Terry Cox, JD, in the firm of Cox & Wortman in Collierville, Tennessee.

Dorothy J. Zydowicz-Vierling, RN, BSN, CCM, CDMS, is the director of Operations for Management Consulting & Rehabilitation Services, Inc., (MCRS) in Johnston, Iowa. An honors graduate of Elmhurst College in nursing and psychology, Ms. Zydowicz-Vierling has over twenty-one years of experience in the health care and managed care industries. She is a member of Sigma Theta Tau International Honor Society of Nursing.

In June 2007, Ms. Zydowicz-Vierling was elected to serve a four-year term on the national Commission for Case Manager Certification. She chairs the appeals committee and serves on the new product development committee. Past committee involvement includes exam and research as well as eligibility and compliance.

Ms. Zydowicz-Vierling began her clinical career at Loyola University Medical Center in Maywood, Illinois. She treated patient populations including, but not limited to, trauma, oncology, general surgery, cardiac, infectious disease, gynecology, burn, posttransplant, orthopedics, pediatric, postpartum, renal, psychiatric, peripheral vascular, and neurology. After leaving Loyola, Ms. Zydowicz-Vierling worked in additional specialty fields including as clinical instructor at Triton College in Maywood, Illinois, and as a high-tech infusion nurse in home health care.

Ms. Zydowicz-Vierling has been a case manager and supervisor for third-party administrators, indemnity, union and carrier and self-insured group health, and workers’ compensation clients. In the group health arena, she provided comprehensive secondary, tertiary, and catastrophic group health case management (CM), including utilization management (UM), transplantation services, medical consultation, retrospective and independent medical reviews, disease management and health care benefit consultation.

Ms. Zydowicz-Vierling has been a national quality training consultant in workers’ compensation and over the years has trained executives, managers, clinicians, trainers, clerical and technical staff as well as account, marketing, broker, vendor, and carrier partners. She has trained on topics as diverse as case management, utilization management, marketing, organ transplantation, disability management, system development and deployment, medical cost savings, negotiation techniques, disability management, customer service, clinical ethics, revenue generation, organization and prioritization, and insurance basics.

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Chapter 1
Life Care Planning: Past, Present, and Future

Roger O. Weed

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Introduction
In the first and second editions of this text, I wrote that life care planning has become a major buzzword in the field of professional rehabilitation. Many people who have little knowledge about published concepts in life care planning continue to use the term life care plans to generate business. Several years ago, I recall reading a deposition from a PhD-level “life care planner” who, when asked by the opposing attorney about resources in life care planning, revealed that it was his opinion there were no written resources or training programs in life care planning. This discourse occurred in 1996, after there already existed a national certification in life care planning. It was repeated in 2003 by two “experts,” one of whom claimed there were no training programs but also claimed to be one of the founders of the life care planning practice. Since the second edition, there have been fewer similar occasions, suggesting, in this author’s opinion, that life care planning has become mainstream. Although more professionals are aware of the life care planning concepts, in personal injury litigation, many life care planners have faced deposition and courtroom challenges,
which have further refined the requirements for successful presentation of information (for more information see Weed & Johnson, 2006, as well as the forensics chapter in this text).

Clearly, life care planning continues to be the standard by which other plans are to be measured with regard to the management of catastrophic impairments or complex health care needs. The published methods, concepts, and procedures are an effective means to determine the road map of care as well as to identify reasonable needs and costs associated with an impairment. However, not everyone is demonstrating quality practice; many do not know of existing standards of practice (IALCP, 2006), and many professionals are resisting standardization of the concept. As with previous editions, it is helpful to review the specialty practice of life care planning as a foundation for this book.

The Past

The original issuance of life care plans appeared in a legal publication, *Damages in Tort Actions* (Deutsch & Raffa, 1981), which established the guidelines for determining damages in civil litigation cases. By 1985, the life care plan was introduced to the health care industry in the *Guide to Rehabilitation* (Deutsch & Sawyer, 1985). One of the first nationwide rehabilitation professional training programs was organized by Dr. Paul Deutsch and offered on September 16–17, 1986, in Hilton Head, South Carolina, where more than 100 rehabilitation professionals from throughout the United States assembled to begin the process of learning about life care plans. Initially the training comprised approximately two days to introduce rehabilitation professionals to the overall concepts and the format that was published in the *Guide to Rehabilitation*. It also became evident that many people were practicing life care planning in a variety of ways, some of which appeared to be contrary to the intended goals and purposes of ethical rehabilitation practice. In addition, as previously mentioned, many people were using the term *life care planning* as it became more popular, but had little or no awareness of the appropriate uses or practices associated with this emerging industry.

In the fall of 1992, five rehabilitation professionals, Richard Bonfiglio, MD; Paul Deutsch, PhD; Julie Kitchen, CDMS; Susan Riddick, BS, RN; and Roger Weed, PhD, met to discuss the apparent problems associated with the life care planning industry. Concerned that fragmentation and poor standardization would result in the overall decline of the specialty practice, they decided to develop a concentrated training program consisting of eight 2-day modules representing the various aspects of life care planning.

Module I was a basic overview of life care planning process methods, standards, and formats. Module II was designed to include the vocational aspects of clients whose life care plans appropriately included work-related opinions. Module III addressed effective case management strategies within the complex medical environment. Module IV outlined the various forensic rehabilitation issues to which many rehabilitation professionals, willingly or unwillingly, are subjected. Module V focused specifically on spinal cord injury issues, and Module VI identified brain injury issues. Module VII was an overview of the long-term care issues for other physical and emotional disabilities as well as some disease processes. Module VIII focused more explicitly on business and ethical practices, including the use of technology in life care planning.

Following this process, a management company (Rehabilitation Training Institute) was contracted to set up training programs throughout the United States. Before the first flyers were fully distributed, the first of the organized modules (scheduled for November 1993) was filled. Two introductory courses were developed: one on the West Coast and the other on the East Coast. It appeared obvious that there were a number of rehabilitation professionals who
were interested in pursuing continuing education related to life care planning, and several participants requested official recognition for their educational efforts. Dr. Horace Sawyer of the University of Florida was approached, and he agreed to pursue an official certificate of completion through the University of Florida’s Continuing Education Department. A private-public partnership between the Rehabilitation Training Institute and the University of Florida was formed and named Intelicus. The five founders donated the program content to Intelicus, which was purchased by Medipro Seminars in 2003. However, Medipro has since ceased operations. Most of the founders continue to donate time and services in support of online training through the University of Florida and Kaplan University and the annual life care planning symposium (visit the website for the Foundation for Life Care Planning Research, www.flcpr.org, for the current schedule).

Although an initial description of life care planning was offered by Drs. Deutsch and Raffa in *Damages in Tort Action*, collaboration with leaders and organizations resulted in an agreed upon definition:

A Life Care Plan is a dynamic document based upon published standards of practice, comprehensive assessment, data analysis and research, which provides an organized concise plan for current and future needs with associated costs, for individuals who have experienced catastrophic injury or have chronic health care needs. [Combined definition of the University of Florida and Intelicus annual life care planning conference and the American Academy of Nurse Life Care Planners (now known as the International Academy of Life Care Planners) presented at the Forensic Section meeting, NARPPS annual conference, Colorado Springs, Colorado, and agreed upon April 3, 1998.]

Although the certificate of completion from such programs as the University of Florida and Kaplan University underscored the value of obtaining education specific to this specialized profession, it did not provide the assurance of ethical practice or the professional identity that was desired by people who had invested thousands of dollars and much of their time in the training process. Several certification boards were contacted, with three indicating an interest in leading the way to certification. Eventually the Commission on Disability Examiner Certification (now known as the Commission on Health Care Certification, or CHCC) based in Midlothian, Virginia, and owned by V. Robert May, Rh.D., assumed the responsibility, and the first certifications were offered in the spring of 1996. For nurses who wish to affiliate with an organization that only certifies nurses, the American Association of Nurse Life Care Planners was formed.

Occasionally, there are questions about who did what first. The chronology below is intended to “lay out” the development of the specialty practice of life care planning as is known today. As noted previously, Paul Deutsch, in the mid 1980s, was the first rehabilitation professional to formally teach “life care planning” concepts, methodology, and such. He is considered the “founder” of the life care planning process and was the first one to publish on the topic in the rehabilitation literature (with Fred Raffa) in 1981 (*Damages in Tort Action*).

Susan Riddick-Grisham was the first nurse to formally teach other nurses an organized series of life care planning classes when she was hired by Crawford & Company in the early 1990s. It may be obvious, but she underwent specific life care planning training prior to teaching the methodology to others. She was also the only nurse to help develop the original nationwide training program curriculum launched by the Rehabilitation Training Institute (which later became Intelicus and, through the years, has been reformatted to be today’s life care planning certificate training program offered by the University of Florida).
Patti McCollom was the first nurse to start an organization specifically for nurses and life care planning in the mid 1990s when she founded the American Academy of Nurse Life Care Planners. Under Patti’s direction and at the urging of others, the organization was expanded to include life care planners from disciplines including and outside of nursing (i.e., multidisciplinary), and is now known as the International Academy of Life Care Planners (IALCP). The IALCP later became a section of the International Association of Rehabilitation Professionals. Later, there was another “nurse only” group started by Kelly Lance, known as the American Association of Nurse Life Care Planners (AANLCP).

Finally, life care plans have historically been subject to intense scrutiny in a variety of rehabilitation fields, including managed care, workers’ compensation claims, civil litigation, mediation, reserve setting for insurance companies, and federal vaccine injury fund cases.

**The Present**

At present, the life care planning industry continues to grow, change, and modify the scope of practice associated with catastrophic case management. The International Academy of Life Care Planners is well established and publishes basic standards of practice (IALCP, 2006). The *Journal of Life Care Planning* was launched in 2002. Kaplan University and the University of Florida offer online training programs leading to certification, and Capital Law School’s paralegal program, the Institute for Medical-Legal Education, the International Association of Rehabilitation Professionals, and many other organizations have been preapproved for training related to obtaining or maintaining certification. The Foundation for Life Care Planning Research has been established and supports doctoral student dissertations and other qualified research efforts in the area of life care planning. Several national life care planning summits with endorsements from several organizations have been completed, leading to transdisciplinary and transorganizational consensus on many topics and issues. (At the time of this edition, the primary task of organizing the summits has been assumed by IALCP.)

Although life care planning principles can be used in almost any aspect of care management, it is particularly useful in complex medical cases because the principles and methods that have been developed:

- Provide for needed quality care
- Reduce errors and omissions
- Allow fewer clients to drop through the cracks
- Reduce the failure to take into account various aspects that have an effect on the ultimate outcome of the client’s medical care (Weed & Riddick, 1992; Weed, 1995a)

Complex case management has become a specialty in its own right, and indeed there is the *certified case manager* designation that has emerged as another buzzword. Good case managers—professionals who are able to work consistently in a complex and often adversarial system—are very valuable professionals.

Since the second edition, certification continues to attract a variety of health care professionals and there are now certified life care planners in Canada and just about every state in the United States.

Sometimes arguments continue to be raised that life care planners should be people with nursing backgrounds only (Weed, 1989). In addition, one article proposed that only professionals with at least a doctorate should be considered qualified to develop life care plans (Weed, 1997).
However, in the view of many practicing life care planners as well as the organizers of the initial national life care planning training program, it is the expectation that various professionals are qualified to practice in areas of their knowledge, skills, and abilities. For example, a rehabilitation nurse who has recently graduated from nursing school is ill prepared to effectively manage catastrophic cases. On the other hand, a master’s-level vocational counselor who has spent several years working specifically in spinal cord injury rehabilitation may be extremely qualified to develop life care plans for that population. In addition, it is expected that life care planning members are part of a team, and it is further expected that team members will practice within their knowledge area. Historically, it has been common for vocational counselors and rehabilitation nurses to work together to develop vocational and medical rehabilitation plans (Riddick & Weed, 1996).

In current practice, many organizations and hospitals have adopted life care planning procedures for discharge planning (Weed & Riddick, 1992; Riddick & Weed, 1996; Weed & Field, 2001). There are also health care professionals (such as physiatrists/physicians, occupational therapists, physical therapists, speech/language pathologists, nurses, dietitians, counselors, psychologists, audiologists, etc.) who develop projected care based on the published formats used in life care planning. Although it is important that the various participants in the training have a rehabilitation education and relevant certification in their area of specialty before engaging in the life care planning process, this by itself is certainly not enough; additional education and experience specific to life care planning are necessary (Weed, 1989, 1997). To identify some of the basic methodologies used in the industry and to underscore the relevance of the chapters included in this book, a review of the peer-reviewed current standards, developed in 2001 and revised in 2006, is appropriate (IALCP, 2006). Additionally, life care planning includes various topics that assure the effectiveness of the overall plan. Items included are listed in Table 1.1.

After it is determined that a life care plan is appropriate, locating a qualified life care planner is necessary. Certainly, individuals who have completed the programs through the American Association of Nurse Life Care Planners, University of Florida, Kaplan University, or Capital Law paralegal program, and others who have achieved the national board-certified life care planner designation should be qualified, and visiting the certification boards’ websites (www.ichcc.org and www.aanlcp.org) will provide a list. Further, there are other people who have been practicing in their respective fields for many years and have extensive experience that may supplant the need for a designated or certified life care planner (such as a fellow of the International Academy of Life Care Planners or those with extensive experience). Questions regarding the planner’s qualifications, which include education, work experience, life care planning experience, research knowledge and experience, certifications in legitimate rehabilitation areas, and, in the area of civil litigation, forensic experience, would be relevant (Table 1.2). It may also be important to determine the consultant’s awareness of life care planning with regard to his or her expertise or knowledge about the methodology of life care planning, courses completed on life care planning, references and publications relevant to life care planning, and knowledge of professionals who have been movers and shakers in the life care planning field.

It is also relevant to determine the consultant’s commitment to the profession by inquiring into which organizations he or she participates. Many professionals pay monetary dues to associations but do not participate in professional development, committee work, or other profession-enhancing activities. It is also pertinent to determine if the professional has contributed time and effort by either volunteering to work with clients, speaking on relevant issues, holding office within professional organizations, or writing for relevant publications. Receiving awards, honors, or peer recognition is also pertinent.
### Table 1.1 Life Care Plan Checklist

**Projected Evaluations:** Have you planned for different types of nonphysician evaluations (e.g., physical therapy, speech therapy, recreational therapy, occupational therapy, music therapy, dietary assessment, audiology, vision screening, swallow studies, etc.)?

**Projected Therapeutic Modalities:** What therapies will be needed (based on the previous evaluations)? Will a case manager help control costs and reduce complications? Is a behavior management or rehab psychologist, pastoral counseling, or family education appropriate?

**Diagnostic Testing/Educational Assessment:** What testing is necessary and at what ages? Vocational evaluation? Neuropsychological? Educational levels? Educational consultant to maximize PL 94–142 and/or Individuals with Disabilities Education Act (IDEA)?


**Wheelchair Accessories and Maintenance:** Has each chair been listed separately for maintenance and accessories (bags, cushions, trays, etc.)? Have you considered the client’s activity level?

**Aids for Independent Functioning:** What can this individual use to help himself or herself? Environmental controls? Adaptive aids? Omni-reachers?

**Orthotics/Prosthetics:** Will the client need braces? Have you planned for replacement and maintenance?

**Home Furnishings and Accessories:** Will the client need a specialty bed? Portable ramps? Hoyer or other lift?

**Drug/Supply Needs:** Have prescription and nonprescription drugs been listed, including size, quantity, and rate at which to be consumed? All supplies such as bladder and bowel program, skin care, etc.?

**Home Care/Facility Care:** Is it reasonable for the client to live at home? How about specialty programs such as yearly camps? What level of care will he or she require?


**Transportation:** Are hand controls sufficient or is a specialty van needed? Can local transportation companies be used?

**Health and Strength Maintenance:** What specialty recreation is needed? Blow darts? Adapted games? Row cycle? Annual dues for specialty magazines? (Specialty wheelchairs should be placed on wheelchair page.)

**Architectural Renovations:** Have you considered ramps, hallways, kitchen, fire protection, alternative heating/cooling, floor coverings, bath, attendant room, equipment storage, etc.?

**Potential Complications:** Have you included a list of potential complications likely to occur such as skin breakdown, infections, psychological trauma, contractures, etc.?

**Future Medical Care/Surgical Intervention or Aggressive Treatment:** Are there plans for aggressive treatment? Or additional surgeries such as plastic surgery?

**Orthopedic Equipment Needs:** Are walkers, standing tables, tilt tables, and/or body support equipment needed?

**Vocational/Educational Plan:** What are the costs of vocational counseling, job coaching, tuition, fees, books, supplies, technology, etc.?
# Checklist for Selecting a Life Care Planner

**Professional’s qualifications**

- **Education**, including degrees and continuing education? If doctorate, was the university accredited? (Some have mail-order graduate degrees or diplomas from universities that are less than stellar.)

- **Work** experience?

- **Life care planning** experience?

- **Research** knowledge and experience?

- **Certifications or licenses**? Generally accepted rehabilitation certifications include **CLCP** (certified life care planner), **CRC** (certified rehabilitation counselor), **CDMS** (certified disability management specialist), **CVE** (certified vocational evaluator), **CRRN** (certified rehabilitation registered nurse), **CCM** (certified case manager), diplomat, or fellow **ABVE** (American Board of Vocational Experts).

- **Forensic experience** (if appropriate)? Familiar with the rules pertaining to experts? Have they testified? Do they have a list of cases in which they testified at deposition or trial for the previous 4 years? Plaintiff/defense ratio?

**Prospective consultant’s awareness of life care planning**

- Are they a board-certified or qualified life care planner?

- Have they achieved the **certificate** in life care planning offered through one of the recognized training programs?

- Have they completed **courses** offered by a noted program on life care planning? (e.g., Kaplan University, Intelicus if previous to the 3rd edition of this text, University of Florida, International Association of Rehabilitation Professionals, AANLCP, et al.)

- Can they cite life care planning **references**?

- Do they subscribe to the **Journal of Life Care Planning**?

- Do they know some of the **professionals** associated with life care planning publications and training (e.g., Dr. Debbie Berens, Dr. Terry Blackwell, Dr. Richard Bonfiglio, Dr. Paul Deutsch, Julie Kitchen, Dr. Robert Meier, Dr. Ann Neulicht, Karen Preston, Dr. Fred Raffa, Susan Riddick-Grisham, Dr. Horace Sawyer, Dr. Randall Thomas, Dr. Roger Weed, Dr. Terry Winkler)?

**Commitment to the profession**

- Are they a member of the International Academy of Life Care Planners? What professional and disability-specific **organization**(s) do they belong to? (Are these legitimate or fringe organizations such as a for-profit owned by an individual or group with little recognition or substance?)

- Do they **participate** in professional development?

- Have they **contributed** their time and effort by volunteering services to clients in need, speaking, holding office with professional organizations, writing articles, chapters, or books?

- Have they received **awards, honors, and/or peer recognition**?

**Specialty practice experience?**

- Workers’ compensation or federal Office of Workers’ Compensation Programs?

- Personal injury?

- Social Security?

- State rehabilitation?

(Continued)
Table 1.2  (Continued)

- Longshore workers?
- Jones Act?
- Federal Employees Liability Act (FELA)?
- Long-term and short-term disability?
- Specialize in a particular disability?

**Medical foundation for opinions established**

- Use established published checklists and forms?
- Routinely consult with a physician as part of the team and/or use clinical practice guidelines, medical records, medical depositions, or other recognized sources?
- Include other health professionals as appropriate (e.g., OT, PT, SLT, RT, audiology, neuropsych, etc.)?

**Other**

- What and how do they bill for their services? Do they charge different rates for interview, records review, deposition, or trial?
- Do they have a current curriculum vita?
- History of ethics complaints or arrests?

Other questions to ask may include the consultant’s jurisdictional experience. If the practitioner is expected to work in personal injury litigation, then experience in this arena seems appropriate. Other specialty practices exist and the rules differ, such that it is often extremely important to ensure that the practitioner’s experience covers these specialized fields (Weed, 1994, 1996).

Reviewing a sample life care plan may be appropriate to determine if the prospective professional establishes a foundation for his or her opinions and uses checklists and forms for other health professionals in the specific area of expertise. In general, it is expected that a physician be involved in the plan’s medical opinions, although there are many ways to establish a medical foundation for diagnosis and treatment if a qualified physician is not available. Other types of miscellaneous information may help determine if the consultant has a current vita that outlines his or her experiences, as well as any history of ethics or malpractice complaints.

**Step-by-Step Procedures**

Assuming that the rehabilitation professional is qualified to assess and project a lifetime care plan for a client and is knowledgeable in the topics to be covered, the next step is to begin the process of the life care plan (Table 1.3). First, of course, the referral must be made to the life care planner and basic information, including time frames, billing agreements, retainer information, and information release topics, must be discussed (Weed & Field, 2001). Second, it is important to obtain as complete a copy of the medical records as possible, including nurses’ notes, physicians’ orders, ambulance report, emergency records, consultant’s reports, admission and discharge reports, and laboratory and radiographic reports.

It is also useful to obtain additional information from the client or family in the form of depositions, interrogatories, or other records. Employment records, tax records, and school records are usually helpful if there are vocational issues to be included in the report. If the client is a young
Table 1.3  Step-by-Step Procedure for Life Care Planning

1. **Case Intake:** When you talked with the referral source, did you record the basic referral information? Time frames discussed? Financial/billing agreement? Retainer received (if appropriate)? Arrange for information release?


3. **Supporting Documentation:** Are there depositions of the client, family, or treatment team that may be useful? Day-in-the-life videotapes? And if vocational issues are to be included in report, school records (including test scores), vocational and employment records, tax returns?

4. **Initial Interview Arrangements:** Is the interview to be held at the client’s residence? Have you arranged for all appropriate people to attend the initial interview (spouse, parents, siblings)? Did you allow 3 to 5 hours for the initial interview? (Some consultants or defense experts may not be permitted direct access to the client or treating health care professionals.)

5. **Initial Interview Materials:** Do you have the initial interview form for each topic to be covered? Supplemental form for pediatric cases, CP, traumatic brain injury (TBI), spinal cord injury (SCI) as needed? Do you have a copy of the life care plan checklist? Example plan to show the client? Camera or video camcorder to record living situation, medications, supplies, equipment, and other documentation useful for developing a plan?

6. **Consulting with Therapeutic Team Members:** Have you consulted with and solicited treatment recommendations from appropriate therapeutic team members (if appropriate or able to do so)?

7. **Preparing Preliminary Life Care Plan Opinions:** Do you have information that can be used to project future care costs? Frequency of service or treatment? Duration? Base cost? Source of information? Vendors?

8. **Filling in the Holes:** Do you need additional medical or other evaluations to complete the plan? Have you obtained the approval to retain services of additional sources from the referral source? Have you composed a letter outlining the right questions to assure you are soliciting the needed information, as appropriate?

9. **Researching Costs and Sources:** Have you contacted local sources for costs of treatment, medications, supplies, equipment? Or do you have catalogs or flyers? For children, are there services that might be covered, in part, through the school system?

10. **Finalizing the Life Care Plan:** Did you confirm your projections with the client and family (if appropriate)? Treatment team members (if appropriate)? Can the economist project the costs based on the plan if one is used? Do you need to coordinate with a vocational expert?

11. **Last but Not Least:** Have you distributed the plan to all appropriate parties (client, if appropriate, referral source, attorney, economist, if there is one)?

*Source:* Roger O. Weed and Susan Grisham.

A child with no educational or medical history, then it would be of value to survey in extensive detail the family history, including mother and father, aunts and uncles, and grandparents (Weed, 1996, 2000). In some situations, siblings may have school and other history that may be useful. Occasionally, videotapes of the client prior to the injury or day-in-the-life videos may be compiled...
by the attorney and can be useful, particularly in civil litigation defense cases or insurance consulting where the client is not readily accessible to the consultant.

An initial interview should occur at the client’s residence if possible (whether facility or home), and appropriate people should be invited to the interview, which may include parents, spouse, siblings, or caregivers. In general, initial interviews will last from 3 to 5 hours. When the professional attends the interview, it is important to use interview forms or checklists that will help structure the interview and ensure that topics appropriate to be discussed are covered. There may be supplemental forms for pediatric cases, brain injury, assistive technology, activities of daily living, and others. It is useful to obtain a copy of the life care plan checklist (see Table 1.1) to educate the client and family members as to the purpose of the life care plan and the general components that make up the care plan. It is also recommended that a camera or video recorder be used to record the living situation, medications, supplies, and equipment used for the client. For example, a home may need to be modified and photographs are useful for documentation.

In general, it is useful to consult with the therapeutic team members, if possible. As noted previously, there may be personal injury litigation defense cases or insurance consulting where this is not possible. It is also reasonable to retain the services of a physician or other individuals as appropriate when treatment team members are not available to discuss the case or the caregivers are not specialized. Also, some treating physicians are not experts in the particular disability or are reluctant to provide recommendations, in which case it may be appropriate to arrange for specialty evaluations by other qualified medical professionals.

There is a special note that should be made with regard to medical foundation for cases that have some or many medically based needs. There are people who are not physicians who claim that they need not have any more medical foundation than their own experience. There are others who assert they merely are administratively writing down the notes dictated to them by physicians and are not making independent judgments about the efficacy of recommendations. In this author’s opinion, a qualified life care planner must be a collaborator, participant, and author of the life care plan. For a detailed review of this issue, see “The Life Care Planner: Secretary, Know-It-All, or General Contractor? One Person’s Perspective” (Weed, 2002) as well as additional comments made in the forensic chapter later in this book.

After preliminary life care plan needs are assessed, information should include frequency of the service or treatment, duration of the treatment, cost, source of information, and perhaps vendors for the services or products listed.

It is not uncommon for basic evaluations to reveal various holes that may require additional medical or other evaluations to be appropriate. For example, a neuropsychologist may be required in brain injury cases. It is important that the consultant compose a list of questions that will assist the evaluator in addressing questions that are specific to the life care plan (Blackwell et al., 1994a, 1994b; Weed & Field, 2001). For example, neuropsychologists may do an outstanding job in writing reports and listing the results of tests but may be less than adequate in identifying functional limitations that result from the disability, as well as revealing specific treatment options with costs so that a projection of its estimated value can be determined.

After a life care plan has been completed, it is common for the planner to research the costs of treatment, medications, supplies, and equipment. There are occasions when catalogs will provide the necessary resource, particularly for products that are commonly available through mail order or for remote locations where the services or products are limited. In some states, depending on the jurisdiction (e.g., civil litigation, workers’ compensation, long-term disability, etc.), there may be a need to identify collateral sources. A common collateral source is a “free and appropriate education” often offered through the public school system for eligible students with a qualified
disability under the federal Individuals with Disabilities Education Act (IDEA). There may also be special rules regarding the costs associated with products. One state, for example, requires that costs of products and services for workers’ compensation insurance cases be only a certain percentage above Medicare/Medicaid reimbursement schedules.

As the life care plan is approaching finalization, it may be appropriate to consult with the client and family to determine that historical information is accurate and that the topics included in the life care plan are suitable and reasonable in accordance with the rules of the jurisdiction. Once the life care plan is complete, it is the responsibility of the life care planner to distribute the life care plan to appropriate resources. The life care planner should be mindful of the rules within the jurisdiction to avoid distribution of a plan to inappropriate sources. In the case of civil litigation, the attorney who retains the consultant’s service typically determines the appropriate recipient(s).

One more contemporary task in which some life care planners who are retained by plaintiff’s attorneys in civil litigation participate is to help develop day-in-the-life videos in support of settlement or trial exhibits. In recognition of this growing opportunity, a chapter on this topic has been added to this edition.

The Future

Life care planning continues to realize new horizons. Since the life care plan first emerged in the rehabilitation literature in the 1980s, the concept has grown immensely to represent the most effective case management method within the specialty practice, particularly with regard to complex medically challenging cases (Deutsch et al., 1989b; Kitchen et al., 1989; Weed & Sluis, 1990; Blackwell et al., 1997; Weed, 2007). As this book goes to press, many of the topics that were considered the future of life care planning just a few years ago have already become the present (Deutsch, 1994). Life care planning in the areas of reserve setting for insurance companies, managed care organizations, workers’ compensation, personal injury, facility discharge planning, and government-funded vaccine injury programs have strongly endorsed the concept. In civil injury litigation, the Daubert (1993) and Kumho rulings (Weed & Johnson, 2006) will continue to affect how some professionals develop life care plans by encouraging the practice of using consistent, researched, and critiqued methods of developing opinions (see chapters on forensics and perspectives by defense and plaintiff attorneys for more information).

It was predicted that areas of mental health (especially serious lifelong psychiatric illness such as schizophrenia), geriatrics, mediation, facility-based life care planning, special needs trusts for children, divorce cases, and assisting families with financial and estate planning will increase. However, there is more room for growth in all of these areas. An example was a divorce case where the settlement was based somewhat on the cost of a persistent vegetative-state client living at home; the soon-to-be ex-wife was aware that the child’s father planned to place the client in a facility because it was less expensive and therefore would reduce his obligation for child support. The care planner was initially asked to identify a reasonable care plan. Another example is that attorneys who identify themselves as elder care lawyers are now practicing a recognized specialty, and a chapter has been added to this edition.

In addition, based on participants in recent training programs, experts from a variety of health-care-related occupations (physicians, occupational therapists, physical therapists, and speech and language pathologists) will participate individually as life care planners and as members of a team. Further, life care planners are participating in training programs and certification specific to the development of Medicare set-aside plans used primarily in the workers’ compensation arena. Gaining knowledge and expertise in medical coding procedures for the purpose of determining
medical charges for various services included in a life care plan also appears to be an emerging area, although the extent of this practice is still unknown due to its newness. Health maintenance organizations will use this methodology to assist with the projection of costs for their catastrophically impaired patient population. Managed care is a current phenomenon that has special application to life care planning. If the goal is to manage care, then using life care planning procedures is a viable option. The design is an excellent method to avoid errors and omissions. Unfortunately, the term managed care often really means managed costs. If health maintenance organizations truly wish to enhance care outcomes for their patients, then we will observe many case management professionals involved in training programs focused on life care planning. At least one nationwide case management firm has adopted the basic life care planning procedure to work with insurance companies for catastrophic injuries in an attempt to assist them with overall rehabilitation planning and projection of costs. Structured settlement companies use the life care plan to develop proposals for settlements and estate planning. Facility and hospital discharge planners will use the method for more effective patient and family education as well as for assurance of comprehensive care. Another area that appears on the horizon is provision for the care of children who have complex health care needs and who are in the foster care system, or are adopted. Another exceptionally ripe specialty area has to do with the care of wounded warriors. At the time of this update, there were estimates of more than 35,000 injured military personnel, with huge numbers requiring long-term medical care (Leskin, Lew, Queen, Reeves, & Bleiberg, 2007).

Additionally, life care planning research, already underway (Sutton et al., 2002, and reprinted in this text), has and will continue to increase in number and sophistication with an eye toward underscoring reliability and validity criteria as well as enhancing the standards of practice. At the time this book went to press, the most comprehensive role and function study of life care planning was in the data collection stage, and results are expected to be available through the Foundation for Life Care Planning Research and likely also to be published in the *Journal of Life Care Planning*. For a current list of research projects completed or underway, visit the Foundation for Life Care Planning Research website at http://www.flcpr.org/research.html.

**Conclusion**

Life care planning has emerged as an effective method for identifying and outlining future care needs and costs. The specialty practice continues to grow and develop new horizons. It is of specific importance that a coordinated effort with standardized approaches be promoted so that the practice as a whole progresses and becomes more useful in an ever increasing number of venues. As more professionals, including allied health professionals, become involved in this process, the industry will mature and develop more effective outcome measurements. Some universities are developing doctoral programs to endorse or encompass life care planning procedures and methods. A 2003 unpublished study of accredited graduate rehabilitation counselor training programs revealed that two-thirds offer training in life care planning (Isom et al., 2003). Indeed, in the 2008 accreditation manual by the Council on Rehabilitation Education (CORE), one of the required knowledge areas is life care planning (see C.10 Rehabilitation Services and Resources, at www.core-rehab.org/NonManDocs/corestandards.101708.doc). In civil litigation, both plaintiff and defense attorneys have increasingly turned to rehabilitation professionals to consult on life care planning issues. It is incumbent on the life care planning professional to assure that services offered are consistent with the standards of the profession and the methodologies that have been endorsed by practitioners. Building on the work of others, rather than reinventing the wheel, will assist in achieving this goal.
References


THE ROLES OF LIFE CARE PLAN TEAM MEMBERS
Chapter 2

The Role of the Physiatrist in Life Care Planning

Richard Paul Bonfiglio

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Introduction
A thorough life care plan serves as a road map for the provision of future daily, medical, and rehabilitative care for an individual with significant medical issues and associated impairments (Weed, 2007). However, to best meet the ongoing needs of the individual, the plan should have a solid basis in up-to-date medical science. Inclusion of appropriate medical services must recognize
the fragmentation and specialization of health care. Additionally, making provision for new technologies is important. Changing service provision should also be considered.

An appropriate life care plan guides the provision of ongoing daily, medical, and rehabilitative care for an individual status post catastrophic injury or illness (Bonfiglio, 2004). However, for a life care plan to appropriately provide for all of the needs of an individual, the plan must have a strong medical foundation. All daily, medical, and rehabilitative care recommendations must be medically necessary and appropriate.

The individual’s unique needs, desires, and aspirations should be considered. The long-term implications of care, including preventing secondary complications, enhancing functional outcome, reducing suffering, and improving quality of life, must be considered (Braddom, 1996). The long-term consequences of living with a catastrophic medical condition that causes significant impairments necessitate developing a long-term plan that takes into account the impact of the aging process. The effect of recurrent secondary complications can be cumulative, especially with organs like the kidney and heart. For example, preventing renal failure for a person with a spinal cord injury is extremely important. Dialysis can be fatiguing and cause blood pressure lability for anyone, but is especially difficult to provide for a person with a spinal cord injury, especially if the person experiences orthostatic hypotension or autonomic dysreflexia.

The impact of the aging process on the person’s medical condition stemming from the condition for which the life care plan has been developed can lead to the need for additional supportive services for the individual later in life. A person who can get by with a few hours per day of attendant care when the plan is first implemented may need 24 hours per day care later in life. The life care plan should reflect these different stages in the person’s remaining life.

A life care plan with a proper medical foundation should also consider recent technological advances and changes in health care delivery. For example, the use of functional electrical stimulation to increase strength or replace an orthosis may greatly enhance function. In recent years, there have also been significant improvements in prostheses, wheelchairs, environmental control systems, and other adaptive equipment and assistive technology. Providing the most appropriate and up-to-date equipment can greatly improve function and quality of life. Health care provision is also rapidly changing and not always to the benefit of patients. Shorter hospital stays and increased use of an outpatient setting for surgery should be reflected in a life care plan development. For example, in the past, annual hospitalizations for an individual status post spinal cord injury were routine for bladder management and review of rehabilitation efforts. Such routine admissions no longer occur.

Physicians specializing in the field of physical medicine and rehabilitation (also known as physiatrists) are uniquely trained and qualified to aid in the development and foundation of forward-looking life care plans. Physical medicine and rehabilitation is the medical specialty that focuses on patient long-term functional outcome following catastrophic injuries or illnesses. Additionally, rehabilitation physicians understand the unique physiology of individuals with medical conditions like spinal cord injuries and traumatic brain injuries that cause severe impairments and many potential secondary medical conditions. The team approach that is essential to life care plan development and implementation is also the key to the rehabilitation physician’s approach to patient care.

There is significant legislative and judicial pressure to reduce compensation and limit awards for pain and suffering. Therefore, establishment of the actual losses and ongoing medical and rehabilitative needs becomes increasingly important for litigation (Cooper & Vernon, 1996; Romano, 1996). An individual having suffered a catastrophic injury or illness usually has extensive ongoing lifetime needs. Physiatrists can help prognosticate regarding these ongoing needs and the impact that such care has on life expectancy.
Thus, a sound medical foundation for a life care plan provided by a physician specializing in physical medicine and rehabilitation can help address the patient’s individual medical condition, premorbid medical issues, patient and family preferences, and desired functional outcome, and by that significantly enhance the usefulness of the life care plan. A physiatrist can also help project future care needs based on the impact of the aging process and likely secondary medical complications.

Life Care Planning Implications

Ensuring the availability of appropriate ongoing medical, rehabilitative, and daily care needs has been significantly enhanced by the development of the science of life care planning. However, the foundation for many life care plans is limited by the plan developer’s experience and the frequently marginal input from treating physicians. Especially in developing a plan for an individual with complex health care needs due to a catastrophic injury or illness, the life care planner and the treating physicians may have very little experience in dealing with a person with similar medical issues, especially for a patient with a spinal cord injury, multiple limb amputations, or a severe traumatic brain injury.

Without adequate medical guidance, the life care plan may not provide for all of the unique needs of the individual, including ongoing medical subspecialist visits, diagnostic testing, and treatment options. Additionally, the recommended services, equipment, and supplies may not be adequate over the individual’s lifetime to prevent secondary complications. The recommended services may not allow for recent or reasonably anticipated future developments in medical and rehabilitative care, including technological and service delivery advances. Conversely, the plan may include items that are not necessary to meet the specific needs of an individual patient.

For example, technological advancements and market forces have led to the development of a wide array of adaptive equipment. Environmental control systems allow individuals with virtually any consistent motor activity to control electronic devices and access, and to use computers, including the Internet. There are now numerous wheelchair options. Powered chairs can be navigated with a variety of inputs, and many power chairs have a self-reclining option. There are even power chairs that can climb stairs. Ceiling-anchored lift devices can ease daily care needs. Identifying the most appropriate adaptive equipment for a severely injured individual is aided with the input from a physician in physical medicine and rehabilitation.

There are physicians specializing in physical medicine and rehabilitation who develop life care plans. The insight a physician in this field develops through training and experience may improve the quality of the plan. However, in this author’s experience, nonphysician life care planners often develop more detailed plans with greater patient specificity and more accurate associated cost figures.

Choosing the Right Physiatrist

Physicians specializing in physical medicine and rehabilitation (physiatrists) are uniquely qualified to provide a strong medical foundation for life care planning, based on their training and experience in providing medical and rehabilitative services to individuals with various disabilities (Fletcher, 1992; DeLisa et al., 1993; Sinaki et al., 1993; Downey et al., 1994). Physiatrists are, by their training, experienced in dealing with individuals who have catastrophic functional problems. Additionally, physiatrists are trained to anticipate the long-term needs of their patients.
Rehabilitation care is often essential to maximizing the abilities of individuals with significant disabilities. Rehabilitation physicians generally direct the provision of such services in rehabilitation settings. Relying on these physicians to help develop a long-term plan is a natural extension of their usual practice.

However, in this author’s experience, physiatrists are usually optimists. Obtaining realistic information and projections requires selecting a physiatrist expert appropriately. The following checklist can help with the selection of a physiatrist as an expert witness in a case for an individual with a catastrophic injury or complex health care needs and resultant significant disability:

- Completion of residency from a recognized leading program
- Board certification in physical medicine and rehabilitation
- Training or experience in applicable area of subspecialization (like traumatic brain injury or spinal cord injury)
- Previous publications and national presentations, especially on related topics
- Academic appointment
- Recognized by rehabilitation peers
- Experience with testimony
- Comfort with litigation process
- Reputation for objective, thorough assessment and ethical practice

In this author’s opinion, physicians who combine clinical practice and experience with medicolegal work are usually more credible than those who exclusively provide medical opinions. If the treating physician cannot provide the needed basis and support for a life care plan, an expert physiatrist may be needed. (Editors’ note: In litigation, there are occasions when contacting the treating physician(s) is not allowed.)

Initial contact with the physiatrist should help establish the physician’s accessibility, availability, and ability to articulate the key issues in establishing the extent of the individual’s ongoing needs. Physicians appearing to avoid the attorney’s or life care planner’s contact generally make inadequate witnesses. Review of the physicians’ past testimony, especially regarding comparable cases, may be useful in delineating the physicians’ opinions regarding key areas.

Role of the Physiatrist

Since the physiatrist may be called on to make projections regarding patient life expectancy, which will serve as the medical basis for lifelong care needs, thoroughness in patient evaluations and medical record review is essential. Requesting a sample report is appropriate for judging the physician’s examination and documentation adequacy. Physiatrists are usually team oriented and are willing collaborators because of the nature of the profession. Physiatrists should be identified who consider the life care planner to be part of the patient’s care team.

Hopefully, the involved physiatrist can be educated about the need for financial settlement to facilitate the provision of needed ongoing medical and rehabilitative services for the individual with an injury or complex health care needs. In litigation-related cases, the physiatrist must educate the jury about all aspects of the involved individual’s disabling condition and its implications. Disability not only often results in physical or cognitive limitations, but also may have emotional and psychological implications. The additional energy requirements and time of performing tasks with a disability often take a toll on the patient.
An individual’s disability can also affect the person’s family. New or altered family dynamics may add to the person’s emotional pressure.

Rehabilitation physicians can also play a key role in a team evaluation of an individual with a catastrophic injury or complex health care needs. Evaluations that include measurement of the patient’s functional abilities by various team members, including physical, occupational, and speech therapists; psychologists; vocational counselors; and rehabilitation nurses, are becoming more common. These evaluations serve as a stronger foundation for life care planning development. Physicians in complementary areas of specialization, including neurologists, psychiatrists, neurosurgeons, orthopedists, and urologists, may also be involved. The physiatrist can play a key role in coordinating these evaluations and developing a holistic approach to the resulting clinical impressions and recommendations.

Common Patient Scenarios

Individuals’ Status Post Spinal Cord Injury

Rehabilitation evaluation for a person after a spinal cord injury is particularly important because of the alteration in physiology that accompanies such an injury (Blackwell et al., 2001). Virtually every organ system is affected. As an example, blood pressure maintenance is significantly impacted by higher-level spinal cord injuries, secondary to the loss of central connections for the autonomic nervous system. During the early period after spinal cord injury, especially during spinal shock, hypotension is common. During the early rehabilitation process, orthostatic hypotension can interfere with progress. Orthostatic measures like support stockings and an abdominal binder are important treatment measures. Even during the long course, accommodations may be needed, especially with position changes.

After the initial period of spinal shock, the impaired autonomic control can lead to autonomic dysreflexia or hyperreflexia for individuals with higher-level spinal cord injuries, especially above thoracic level 6. Sensations that in an individual with an intact spinal cord would lead to noxious stimulation can trigger this response. Common triggers are bladder overdistention, excessive skin pressure, constipation, and sunburn. Initial treatment should include elimination of the precipitating factor and changing position, especially elevating the individual’s head. Medication management may also be needed, especially when the condition recurs frequently. If this condition is left untreated, life-threatening blood pressure elevations and cardiac arrhythmias can occur (Blackwell et al., 2001).

Management of the individual with a spinal cord injury’s neurogenic bladder is also essential. Periodic urological evaluations should be included in all life care plans for the spinal cord injured. Additionally, periodic urologic diagnostic testing is needed. At a minimum, this should include regular bladder and renal ultrasound testing, urinalyses, urine cultures, and cystoscopy. Additional tests that may be needed include laboratory testing, including electrolytes, BUN, creatinine, and creatinine clearance.

There are many other alterations in physiology after a spinal cord injury, resulting in conditions like spasticity and impaired thermal regulation. Additionally, there are many possible secondary complications like osteoporosis, contractures, heterotopic ossification, pressure ulcers, urinary tract stones, cancer, reduced respiratory reserve, coronary artery disease, gallstones, hyperlipidemia, and a perforated abdominal viscus. Evaluation of the likelihood or presence of these conditions in an individual case can be done by a physiatrist (see the chapter on spinal cord injury for more details).
Traumatic Brain Injury

Traumatic brain injuries can range from mild to those leading to persistent vegetative state. Although extensive medical and daily care is required for anyone in a persistent vegetative state, the provision of services still should be specific to the individual’s needs and can be influenced by many factors, including the family support system, available community resources, and architectural considerations. Distinguishing between persistent vegetative state and minimally conscious state can be difficult, but is usually very important in legal cases. An individual in a persistent vegetative state is completely detached from the environment, while a person in a minimally conscious state will have some awareness of the surroundings, but the extent of this awareness can be impacted by many factors including acute medical conditions, the effects of medications, and fatigue.

Individuals with severe traumatic brain injuries usually require ongoing medical, rehabilitative, and daily care services (Rosenthal et al., 1990; Ripley & Weed, 2004). A physiatrist can help to delineate the needed care. This medical foundation can aid the life care planner in establishing the medically most appropriate plan. Maximizing the individual’s functional improvement is important. Anticipating potential future complications is also needed (more information is available in the chapter on brain injury).

Even for an individual diagnosed as having a mild traumatic brain injury, the functional implications may be very significant. Neuropsychological testing to determine the extent of these functional effects is important. A physiatrist can help to translate these functional limitations to life care planning effects.

Chronic Pain

Many individuals develop chronic pain because of trauma or illness. Establishing the etiology and relating it to a specific event can be difficult. Additionally, defining the extent of pain and its functional implications can be problematic. Because of the experience of physiatrists in looking at functional implications of disease and disability, they can be helpful in establishing such links. Chronic pain is also a frequent sequela of spinal cord and brain injuries (for additional information, see the chapter on pain).

Amputation

A physiatrist can help determine the appropriate prosthetic device for an individual after an amputation. Recognizing the functional implications of an amputation and appropriate adaptive equipment is also within the experience of physiatrists. Many amputees experience vascular and chronic pain, and physiatrists are appropriate resources for this care as well (also see the amputation chapter). A physiatrist is especially needed to help develop a life care plan for an individual with multiple limb amputations. Care for a person with quadrilateral amputations (both arms and both legs) is particularly complex.

Life Expectancy Determinations

Provision of adequate funding for lifetime medical, rehabilitative, and daily care needs is dependent on an accurate prediction of life expectancy. Unfortunately, there is no medical literature for
individuals with catastrophic injuries that projects life expectancy based on the level of care that is typically outlined in a life care plan. Additionally, the medical literature addressing life expectancy for those with catastrophic injuries or illnesses leading to brain or spinal cord injury has many other flaws. The literature does not generally reflect current health care provision or technological advances. Additionally, such population studies do not address the unique situation of any particular patient. Therefore, in this author’s opinion, an opinion provided by an experienced physiatrist can better predict life expectancy. However, such determinations require a thorough review of available medical records, especially to identify the already existing medical conditions and secondary complications that have occurred. The physiatrist can help determine which complications can be prevented or treated with the services outlined in the life care plan and which are likely to occur despite the recommended ongoing medical and rehabilitative care. The physiatrist can provide an opinion of the effect of the patient’s underlying condition and secondary complications on life expectancy.

Testimony

In litigation-related cases, physiatrists can provide the medical foundation for plaintiff life care plans (Culver, 1990; Cooper & Vernon, 1996; Romano, 1996; Council on Ethical and Judicial Affairs, 1997). Recognizing the unique needs of patients with disabilities is a regular part of the practice of physical medicine and rehabilitation.

Physiatrists can equally well evaluate plaintiff-generated life care plans for medical accuracy and necessity. Determining whether recommended medical services are medically necessary and appropriate is important to the defense.

Physiatrists can also provide testimony regarding the medical basis for life expectancy determinations.

Example Case

Each entry in the life care plan requires certain data. Each recommendation must include the medical specialty, start date, stop date, frequency of service, and duration. A base or procedure cost is added that will allow an economist to estimate the total value of the services or procedures. To provide an example, in the table that follows are a few entries associated with the care of a 73-year-old woman with C5–C6 tetraplegia, which is within the domain of the physiatrist.

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Dates</th>
<th>Frequency</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outpatient spinal cord injury reevaluation to include MD, RN, OT, PT, RT, dietary</td>
<td>2009 to life expectancy</td>
<td>1 time per year</td>
<td>$850–$1200 each</td>
</tr>
<tr>
<td>IVP or renal ultrasound, CBC, UA, and others as needed</td>
<td>2009 to life expectancy</td>
<td>1 time per year</td>
<td>Included in yearly evaluation</td>
</tr>
<tr>
<td>Physiatrist</td>
<td>2009 to life expectancy</td>
<td>4 times per year</td>
<td>$156 per visit</td>
</tr>
</tbody>
</table>

(Continued)
Summary and Conclusions

The appropriate physician expert in physical medicine and rehabilitation can provide opinions regarding:

- Nature and extent of individual patient’s disability and residual abilities
- Patient’s disease and disability past and future natural history
- Potential future medical complications
- Medical basis of vocational potential (functional limitations)
- Delineation of individual’s functional limitations, including physical, cognitive, emotional, and fatigue aspects
- Medical basis of needed equipment, supplies, home modifications, transportation needs, nursing, therapy, and other care services
- Life expectancy

The use of a physiatrist to bolster medical foundation for a life care plan for all venues, and in litigation, can facilitate the jury’s deliberations regarding adequacy of awards. Such decisions are particularly important when the individual requires regular ongoing lifetime care.

Additionally, the physiatrist can help with implementing life care plans by determining the timing and extent of provision of specific medical services. Maximizing functional gains should be a focus of the rehabilitative and life care planning process effort. For a summary of questions that a life care planner might ask, see medical-related topics in the Life Care Plan Checklist in Chapter 1.

References


Chapter 3

The Role of the Nurse Case Manager in Life Care Planning

Susan Riddick-Grisham

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Introduction
The components of the nursing process, a framework for providing care, include assessment, nursing diagnosis, outcome identification, planning, implementation, and evaluation to ensure
a systematic approach for delivering care. These core competencies when applied to the practice of case management involve a collaborative process that assesses, plans, implements, coordinates, monitors, and evaluates the options and services required to meet an individual’s health needs, using communications and available resources to promote quality, cost-effective outcomes (CMSA, 1995). Because of their clinical assessment skills, multidisciplinary communication background, and experience in anticipating and coordinating needed treatment, nurses have remained an invaluable resource to the field of case management. Case management for individuals with catastrophic injury or chronic illness involves a diagnosis with complex medical and psychosocial issues. Life care planning was developed to facilitate the practice of complex health care and catastrophic injury case management by providing a consistent methodology for analyzing the complex needs dictated by the onset of the disability (Weed & Riddick, 1992). Today effective case management and life care planning both rely on the principles of the nursing process to create an integrated continuum with measurable outcomes. Successful lifetime management of the patient with complex medical needs involves ongoing reassessment of clinical, financial, psychosocial, and personal and family/caregiver goals.

Integration of Care Management, Financial Management, and Information Sharing

Following World War II, insurance companies hired nurses and social workers to manage the physical, emotional, and social needs of severely disabled veterans (Blancett & Flarey, 1996). Case management grew as it was widely used in the management of individuals with mental illness. Employers and insurance companies, faced with escalating claims costs, court awards, and rising health care costs, used case management services to assess a claim and set goals and timetables to project costs, all to ensure effective use of their dollars spent.

Today case management continues to play a pivotal role in the evolving health care system by providing patient and family education, decreasing fragmentation and duplication of services, increasing communication and collaboration among all members of the care team, and improving patient adherence to treatment. These actions improve achievement of measurable and durable outcomes, using health care dollars efficiently.

Drs. Paul Deutsch and Horace Sawyer (1985), in A Guide to Rehabilitation, first introduced the concept of life care planning to the rehabilitation professional in 1985. Life care planning was developed as a tool to facilitate case management of catastrophically injured or chronically ill individuals. Life care planning was a direct result of the realization that what was needed was a consistent methodology for analyzing all of the needs dictated by the onset of catastrophic disability through to end of life expectancy. Life care planning offered a methodology that considered the disability, the patient and family, and the process of age and disability combining over time to create phase changes in needs, and further considered the most current research on the disability process. The process also considers the treatment team’s recommendations based on needs-driven considerations.

The life care planning process is a means by which the nurse case manager can develop a consistent, well-organized approach to the management of complex cases. The scope of life care planning has extended to areas such as managed care, insurance reserve setting, discharge planning, elder care, and others. A comprehensive and thorough life care plan (LCP) is designed to allow for an integrated continuum of care addressing the integration of care management, information/communication, and finance mechanisms (see Figure 3.1).
Care and treatment of the catastrophically injured or chronically ill patient often involve multiple treatment providers in a number of treatment settings, all with their own treatment protocols and identified outcomes. Additionally, cases involve insurance adjusters, attorneys, school personnel, home health providers, and other professionals. The nurse case manager is often the sole professional to follow the patient from the point of injury, through transitions from one setting to another, over the patient’s lifetime.

Long after the acute care and medical rehabilitation phases, patients with chronic care needs are often faced with problems that can create challenges. By example, consider the patient, at 20 years post traumatic brain injury, who is suddenly informed that he can no longer drive secondary to vision problems. In order to avoid disruption of the patient’s independent living situation and to relieve the family of the burden of needing to be available to provide transportation, the case manager will identify options for consistent, reliable, and affordable transportation to and from work and community activities such as grocery shopping. Once implemented, the case manager will monitor the situation to determine if the changes are meeting the needs of the patient, family, and employer.

Life care planning provides a consistent methodology for analyzing all of the needs of an individual faced with a chronic medical condition through the lifetime. The life care plan itself
can provide that basis for shared communication and expectations among all care providers, along with the patient and family. The nurse case manager, serving as the implementer of the plan, can act as the liaison of the information, dispensing it to the appropriate individuals at the appropriate times, so as to ensure efficient decision making, appropriate financial expenditures, and planned and measurable outcomes.

The Role of the Nurse Case Manager

Case management in its broadest sense reflects the phases of the nursing process; it is process in action (Blancett & Flarey, 1996). Lydia E. Hall (1963), a rehabilitation nurse, first theorized about the nursing practice in her Core, Care, and Cure Model. In 1973 the American Nursing Association (ANA) legitimized the nursing process. In 1991 and later in 1998 the ANA defined the nursing process to include assessment, diagnosis, outcome identification, planning, implementation, and evaluation.

The nursing process is a framework for providing nursing care to patients, families, and communities. It provides an orderly and systematic approach to defining a plan for patient-centered care that is appropriate to use throughout a lifetime in all settings. Throughout the nursing process the nurse collects and analyzes data to identify health care needs and determine priorities of care goals. The types of data collected can include objective or obvious data, subjective data, variable or changing data, or constant data. The major tasks of the assessment include collection, validation, and organization of data.

The nurse then plans and implements an individualized plan of care with measurable outcomes. This is followed by an evaluation of the patient’s response to the plan, determining whether the patient goals have been achieved. If the patient’s needs change or goals are not achieved, the

Table 3.1 Comparisons of Various Nursing Roles

<table>
<thead>
<tr>
<th>Nursing Process</th>
<th>Case Management Process</th>
<th>Life Care Planning Process</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assessment</td>
<td>Assessment</td>
<td>Data collection includes assessment</td>
</tr>
<tr>
<td>Diagnosis (nursing diagnosis)</td>
<td>Understands primary and secondary diagnoses</td>
<td>Understands primary and secondary diagnoses</td>
</tr>
<tr>
<td>Outcome identification</td>
<td>Outcome identification</td>
<td>Outcome identification</td>
</tr>
<tr>
<td>Planning</td>
<td>Planning/research</td>
<td>Planning/research</td>
</tr>
<tr>
<td>Implementation (involves collaboration)</td>
<td>Implementation</td>
<td>Consulting and possible implementation*</td>
</tr>
<tr>
<td>Evaluation</td>
<td>Monitors/evaluates</td>
<td>Monitors/evaluates</td>
</tr>
<tr>
<td></td>
<td>Collaborates</td>
<td>Collaborates</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Testimony (if forensic)</td>
</tr>
</tbody>
</table>

a. Life care plans that are used in legal cases may not be implemented.
The Role of the Nurse Case Manager in Life Care Planning

nurse modifies the original plan of care. This ongoing continuum of care essentially provides a framework for guiding clinical practice.

Every step of the nursing process is essential to, and is closely interrelated with, the other steps. During the diagnosis and assessment phase, the nurse collects data about the patient from a variety of sources, including the patient, family, significant others, health care personnel, medical records, and literature. This information is used for problem identification so that planning and implementation are appropriate to the patient’s needs.

This step involves formulating diagnostic statements that identify the patient’s health-related problems. Once an assessment is made, the nurse formulates various nursing diagnoses as they pertain to the nursing care model.

The next step of the nursing process involves the development of a nursing care plan that contains patient-centered goals, expected outcomes, and appropriate nursing interventions.

Implementation is the action step of the nursing process. During this step, problem-oriented individualized client care is delivered according to the care plan. This often involves working collaboratively with other members of the health care team.

The last step of the process is evaluation/monitoring. The success of implemented interventions, achievement of expected outcomes, resolution of nursing diagnoses, and accuracy and completeness of assessment data are evaluated. This step provides for the revision of the nursing care plan as necessary.

The entire process is sequential and interrelated. Each step depends on the previous one. The sequence is logical, orderly, and systematic. The plan is established based on patient needs, and nursing care is provided according to the plan.

These core competencies can be applied to the practice of case management that involves a collaborative process that assesses, plans, implements, coordinates, monitors, and evaluates the options and services required to meet an individual’s health needs, using communications and available resources to promote quality, cost-effective outcomes (CMSA, 1995). Case management for the individual with a catastrophic injury or chronic illness involves a diagnosis with complex medical and psychosocial issues. Life care planning was developed to serve as a tool to facilitate the practice by providing a consistent methodology for analyzing the complex needs dictated by the onset of the disability. Case management and life care planning both rely on the principles of the nursing process to create an integrated continuum (see Figure 3.1).

Although a nursing education gives the basic skills used in the life care plan process, a high level of expertise is required to address the complex issues involved in life care planning. Within the life care planning field there are a number of roles that can be filled by a nurse case manager. Those could include but may not be limited to:

- **Life Care Plan Expert:** Develops life care plan. Is prepared to provide expert testimony if the case is in litigation.
- **Life Care Plan Consulting Expert:** Develops life care plans in nonlitigious situations or offers consulting services addressing life care plan critique and analysis to lawyers or insurance companies. Is not expected to provide expert testimony.
- **LCP Research Assistant:** Assists the life care planner in performing medical records analysis or pricing research. Is not expected to provide expert testimony.
- **Life Care Plan Implementer/Trust Case Manager:** Implements the life care plan utilizing traditional case management.
- **Legal Nurse Consultant:** Assists with discovery, conducts research, reviews medical records, identifies standards of care, prepares reports and summaries on the extent of injury or illness, and locates expert witnesses. See Table 3.2 for a medical-legal checklist.
Table 3.2 Medical-Legal Consultation Checklist

<table>
<thead>
<tr>
<th>Medical Records Analysis</th>
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<tbody>
<tr>
<td>Organize and tab; define in layman’s terms; describe number of operative procedures and invasive procedures; use of pain medication; special consultations; number of days in ICU or other special placements; complications experienced; physician names and specialties; discharge disposition.</td>
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<tr>
<th>Medical Research</th>
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<tbody>
<tr>
<td>Relevant articles and books; MEDLINE; software; networking; define content, highlight, organize, and educate attorney.</td>
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<table>
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<tr>
<th>Experts</th>
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<tr>
<td>Location of appropriate experts; coordination of referral to expert; securing services of appropriate experts, including liability, causation, and damage experts.</td>
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</tbody>
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<tr>
<th>Deposition: Review and Summarization</th>
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<tbody>
<tr>
<td>Development of deposition questions and attendance at deposition. Review and summarize deposition to highlight damage and treatment issues.</td>
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</tbody>
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<table>
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<tr>
<th>Case Management</th>
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<tbody>
<tr>
<td>Assessment of medical condition; coordination of medical care and physician referral; coordination of information with attorney, client/family, physician to physician.</td>
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<tr>
<th>Attendance at Medical Exam</th>
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<tbody>
<tr>
<td>Documentation of physician/client interview and assessment.</td>
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<tr>
<th>Demonstrative Evidence</th>
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<tr>
<td>Overheads; charts; graphs; photos; videotape; medical illustration and medical equipment; arrange for day-in-the-life and script; help develop settlement brochures.</td>
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<tr>
<th>Life Care Plan/Life Care Plan Review</th>
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<tbody>
<tr>
<td>Development of a life care plan that identifies appropriate and reasonable care for individuals who have sustained catastrophic injury or chronic illness; review of existing life care plan for overlap and duplication of services; check costs for regional accuracy; assess planner’s potential for bias; check math calculations; review for effective rehabilitation and potential to avoid complications; assure all appropriate topics are included in plan.</td>
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<tr>
<th>Vocational Issues</th>
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<tbody>
<tr>
<td>Identify vocational experts and coordinate evaluation; discuss issues related to placeability, earnings capacity, rehabilitation plan, vocational handicaps, work life expectancy, and related issues.</td>
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</table>

Life Care Planning Organizations

The International Academy of Life Care Planners (IALCP) was established in 1996 as a privately owned professional membership association to serve the advanced practice educational needs of life care planners and to promote the application of Standards of Practice for life care planners in the field (IARP, 2008). Members include nurses, physicians, therapists, psychologists,
The Role of the Nurse Case Manager in Life Care Planning

In August 2005, the IALCP became affiliated with the International Association of Rehabilitation Professionals (IARP).

In 1999 the American Association of Nurse Life Care Planners (AANLCP, 2008) was created to promote a professional practice within nurse life care planning. The philosophy of AANLCP is to be a voluntary association of professional registered nurses concerned with Nurse Life Care Planning. Strategic goals of AANLCP include: being a leader in influencing excellence in nurse life care planning, partnering with other nursing associations, and having a strong, mutually supportive connection with other life care planners. AANLCP’s vision/mission is to recognize the nurse life care planner as the registered nurse who assesses, identifies issues and plans for appropriate interventions, implementation, and evaluation in the nurse life care planning process. AANLCP promotes the professional practice that the registered nurse delivers to the life care planning process. AANLCP also promotes education, collegiality, collaboration, research, and standards as they relate to the practice of nurse life care planning.

AANLCP has developed the following definition of nurse life care planning:

The Nurse Life Care Planner utilizes the nursing process in the collection and analysis of comprehensive client specific data in the preparation of a dynamic document. This document provides an organized, concise plan of estimated reasonable and necessary (and reasonably certain to be necessary), current and future health care needs with the associated costs and frequencies of goods and services. The Nurse Life Care Plan is developed for individuals who have experienced an injury or have chronic health care issues. Nurse life care planners function within their individual professional scope of practice and, when applicable, incorporate opinions arrived at collaboratively with various health care providers. The Nurse Life Care Plan is considered a flexible document and is evaluated and updated as needed.

Life Care Plan Survey Research

In the Life Care Plan Survey 2001, it was noted that 56% of the respondents were registered nurses (Neulicht et al., 2002). Nurses who enter into the practice of life care planning must have an understanding of the medical and rehabilitation issues involved with varying complex medical conditions that they will be asked to address. Another key component of life care planning involves that ability to develop a consistent, valid, and reliable approach to data collection. There are various software programs available to assist in this process. It is important to note that, at the time of this writing, the Life Care Plan Survey has been updated to 2009 and currently is in the data collection process, with the goal of updating the practices, protocols, methodology, and procedures used by today’s life care planners (Neulicht, Riddick-Grisham, Goodrich, & Hinton, working paper).

For those who decide to function in the capacity of a life care plan expert, there is the expectation that one will be required to testify in deposition or trial. These situations are often stressful and time-consuming. In light of recent challenges presented by Daubert or Kumho Tire rulings (see forensic-related chapters for more details), the future of life care planning as a forensic tool may become more powerful if based upon life care plan research focused on identifying quantifiable outcomes and establishing the reliability and validity of the process of life care planning. Nurses
Table 3.3  Desirable Traits for Nurse Life Care Planners

- Know inpatient medical-surgical or acute rehabilitation services
- Have emergency medical experience
- Possess verbal and analytical reasoning skills
- Have the ability to communicate with variety of cultural, educational, and experiential backgrounds
- Possess problem-solving, negotiation, and conflict resolution skills
- Are computer literate for research and communication
- Have knowledge of professional resources and access
- Have the ability to critically analyze literature
- Understand the scope and limitations of medical and allied health fields
- Have pharmacology knowledge
- Know normal laboratory values
- Know drug actions/interactions
- Know pathophysiology of different disabilities
- Have basic abnormal psychology knowledge
- Know the effects of trauma on coping and psychological functioning
- Deal effectively with stress
- Pay attention to details
- Are well organized
- Document the work in the file
- Maintain meticulous files
- See the big picture
- Have self-confidence
- Are objective and professional
- Stay within area of expertise

who act as life care plan experts will be expected to understand basic research methodology. See Table 3.3 for desirable traits for the nurse life care planner.

Providing Life Care Plan Support Services

The nurse case manager may choose a role that is more supportive in nature. Nurses are often hired by the life care plan experts to provide support services, which could include medical record reviews, research, and some of the traditional case management services (Table 3.4).
Providing Legal Support Services

Nurse case managers with life care planning experience are often hired by law firms to act as consultants to assist them in a number of different areas, including medical records review, medical research, identification of experts, and case management. Table 3.5 summarizes topics associated with a comprehensive medical records analysis, which can be an enormous help to lawyers who have limited medical knowledge.

In addition, the attorney may ask a nurse case manager to review a life care plan to evaluate methodological appropriateness of medical conclusions. The forensic and other chapters include suggestions for accomplishing this goal.

Many nurse case managers who perform these support services choose to obtain legal nurse consulting certification, which is offered by the American Association of Legal Nurse Consultants (see resources at the end of the chapter).

For the nurse case manager who is interested in providing expert services, additional training and professional development are recommended. It is important to understand what attorneys are looking for when hiring a qualified life care planner. It is essential to outline the exact nature of the service that will be provided. This is especially true for nurse life care planners. Life care planning often involves the process of developing opinions regarding vocational planning and loss of earnings capacity. For most nurses this is outside the scope of their expertise. It is recommended that nurse case managers clearly communicate what they are prepared to address in the life care plan report. This can be accomplished by the development of a clear, concisely worded referral letter.

It is also important that anyone who serves as an expert develop a basic understanding of the litigation process and the role of the expert witness. In life care planning it is especially important to understand the need for the medical and other evidentiary foundation for each item of the life care plan.

Nurses are bound to practice within the definition of the Nurse Practice Act for the individual state in which they practice. Additionally, the nurse case manager/life care planner is held to the practice standards and code of ethics for each organization joined or certification obtained. Each of these organizations provides opportunities for continued education and growth.
Table 3.5 Checklist for a Comprehensive Medical Records Analysis

- Primary/Secondary Diagnoses: Have you thoroughly reviewed the records to identify primary and other diagnoses?
- Hospitalization Days: List all hospitals and treatment programs. Summarize the dates and days in each. Include the number of days in specialized care such as ICU or rehabilitation.
- Operative Procedures: What operations were performed, on what date, and by whom, and what was the surgeon’s specialty area (orthopedics, neurosurgery, plastic, ophthalmology, etc.)? What kind of anesthesia was used (local or general)? How long was the operation? Were there any complications?
- Medications: What medications were administered? Why were they administered (infections, pain, bowel or bladder program, blood loss, anxiety, etc.)? Include the name, dosage, and route of administration (oral, IV, IM, sublingual, catheter). Note any abnormal reactions and long-term effects.
- Treatment Team: Identify all treating physicians by name, specialty, address, and telephone.
- Consultations: Have you identified all consultations during treatment (e.g., endocrinology, infectious disease, pulmonology, radiology, urology, cosmetic, etc.)?
- Invasive Procedures: Note Foley catheters, intravenous, G-tube feeds, etc. Include length of required treatment and how much.
- Posthospitalization Treatment: What postacute programs or treatment programs were included? Day treatment? Home care? Include dates, purpose, and outcomes.
- Complications: List complications and dates, for example, septic shock, chronic infections such as urinary and respiratory, contractures, skin breakdown, adverse reactions to medications, psychological, etc. Include future risk factors such as bone nonunion, traumatic arthritis, etc.
- Report Writing: Have you explained the medical records so that your reader can understand them (e.g., decubitus = skin breakdown; debride = clean the wound; etc.)?
- Recommendations: Should additional evaluations or treatment be offered? What effect does the incident have on the client’s ultimate functioning or work?

Source: Roger O. Weed and Susan Riddick-Grisham.

Trust Case Management

There are times when the scope of the nurse case manager’s role occurs only after the completion of the life care plan, when the financing mechanisms are in place. This often involves the implementation of the care plan utilizing funds that have been set aside in a trust. Acting as a patient advocate the case manager will work to implement the life care plan by prioritizing patient and family needs. Although life care plans are needs based, many legal awards or family trusts do not provide adequate funding to meet all of the patient’s needs throughout their lifetime. In these instances, the trust case manager must be intimately familiar with alternative funding sources such as the public benefit programs of special needs trusts, Medicare and Medicaid, state rehabilitation services, and various waiver programs.

In this writer’s experience, trust case management is a rapidly growing area. Many major banking institutions now have departments that manage trust assets. These institutions frequently
utilize the services of nurse case managers to work closely with families to provide resource information and to assist in cost-effective decision making that considers the patient and family needs and the available financial resources. For additional information, the reader is referred to the following resources:

- National Academy of Elder Law Attorneys: www.naela.com
- Certified Financial Planner: www.cfp.net
- National Structured Settlement Trade Association: www.nssta.com
- National Elder Law Foundation: www.nelf.org

Related Certifications and Organizations

There are several organizations that offer credentials for case management and related certifications. Some are listed in the following.

- CCM: Certified Case Manager, offered by the Commission for Case Management Certification; (651) 789-3744 or www.ccmcertification.org
- CMCN: Certified Managed Care Nurse, offered by the Board of Managed Care Nursing; (804) 527-1905
- CMC: Case Manager, Certified, offered by the American Institute of Outcomes Case Management; (562) 945-9990 or www.aiocm.org
- RN-NCM: Registered Nurse–Nurse Case Manager, offered by American Nurses Credentialing Center; (800) 284-2378
- CMC: Care Manager Certified, offered by the National Academy of Certified Case Managers; (800) 962-2260
- A-CCC: Continuity of Care Certification, Advanced, offered by the National Association for Certification of Care; (877) 661-0066
- CSWCA: Certified Social Work Case Manager, offered by the National Association of Social Workers Credentialing Center, Specialty Certifications; (800) 638-8799, ext. 409
- COHN/CM: Certified Occupational Health Nurse, offered by the American Board for Occupational Health Nurses; (630) 789-5799

Legal Nurse Certification

- LNCC: Legal Nurse Consultant Certified, offered by the American Association of Legal Nurse Consultants; (877) 402-2562

Life Care Plan Certification

- CLCP: Certified Life Care Planner, offered by the Commission for Health Care Certification; (804) 378-7273 or www.ichcc.org (Editors’ note: although their website includes the www.chccl.com address, at the time of this writing, it is not active. Although the “contact information” notes the name “Commission for Health Care Certification” at the initial website, the name is “International Commission for Health Care Certification,” which probably explains ichcc.org.)
Life Care Plan Organizations

- AANLCP: Certified Nurse Life Care Planner, offered by the American Association of Nurse Life Care Planners; (888) 575-4047 or www.aanlcp.org

Case Management Organizations

- CMSA: Case Management Society of America; (501) 225-2229 or Toll-Free (800) 216-2672
- NACCM: The National Academy of Certified Care Managers; (800) 962-2260
- ARN: Association of Rehabilitation Nurses; (800) 229-7530
- IARP: International Association of Rehabilitation Professionals; (847) 657-6964

Conclusion

The nurse case manager can play a pivotal role in the ongoing management of the catastrophically injured or chronically ill patient. Because of their clinical assessment skills, multidisciplinary communication background, and experience in anticipating and coordinating needed treatment, nurses have remained an invaluable resource to the field. Life care planning was developed to facilitate the practice by providing a consistent methodology for analyzing the complex needs dictated by the onset of disability. Case management and life care planning both rely on the principles of the nursing process to create an integrated continuum.

Within the specialized field practice referred to as life care planning there are many roles that can be served by the nurse case manager. By combining the basic skills of the nursing process with an understanding of life care planning, along with extensive knowledge of the clinical aspects of the presenting disability, an experienced nurse is an excellent professional to provide life care planning services.

Acknowledgment

The author would like to acknowledge Shelene Giles, RN, BSN, BA, MS, CRC, CNLCP, MSCC, Past-President, AANLCP, for her contribution to this chapter.

References


Chapter 4

The Role of the Vocational Rehabilitation Counselor in Life Care Planning

Debra E. Berens and Roger O. Weed

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Introduction

The Dictionary of Occupational Titles (DOT), 4th edition (U.S. DOL, 1991a, p. 52), defines a vocational rehabilitation counselor as one who “counsels handicapped individuals to provide vocational rehabilitation services.” Such services generally include interviewing and evaluating clients, conferring with medical and professional personnel and analyzing records to determine type and degree of disability, developing and assisting clients throughout the rehabilitation plan.
(or program), and aiding clients in outlining and obtaining appropriate medical and social services. The DOT further states that vocational rehabilitation counselors may specialize in a type of disability (e.g., spinal cord injury, traumatic brain injury, amputation, burn, visual impairment, hearing impairment, chronic pain, etc.). The role of the vocational rehabilitation counselor in life care planning expands this definition and is specific to persons who are catastrophically impaired or have complex medical needs and limited access to the labor market. This role has become more defined since the early 1980s, when life care planning was first introduced into the literature (Deutsch & Raffa, 1981). In today’s climate, vocational rehabilitation counselors serve as an instrumental member of the rehabilitation team to coordinate assessments in an effort to measure a person’s aptitude, achievement levels, and transferable work skills. These assessments help determine one’s potential for future work activity, such as full- or part-time employment, sheltered or supported employment, or, in cases where work activity is not a realistic goal, achieving their highest level of productivity or independent living. The essential premise underlying vocational rehabilitation is that involvement in work or some productive, meaningful activity is the goal of one’s rehabilitation program (Marme & Skord, 1993; Weed & Field, 1994, 2001). And if return to work or productive activity is appropriate, then the needs and steps to achieve that goal must be included in the life care plan (Weed, 2007).

Vocational rehabilitation counselors who work within the life care planning arena generally are rehabilitation professionals who have a minimum of a master’s degree in rehabilitation counseling, hold one or more national certifications in the field of rehabilitation, and have extensive training and experience in the areas of evaluation and assessment, catastrophic case management, transferable work skills, earnings capacity analysis, and job placement (Weed & Field, 1994, 2001). Vocational rehabilitation counselors can be credentialed in a number of areas, most notably CRC (certified rehabilitation counselor), CDMS (certified disability management specialist), CCM (certified case manager), CVE (certified vocational evaluator), and ABVE (American Board of Vocational Experts). Credentials can also be obtained from other organizations that, on the surface, appear to be based more on profit making than on advancing the role and function of the rehabilitation professional. While some of these certifications may be valuable, the authors strongly encourage those professionals interested in pursuing further credentials to thoroughly research the history of the organization, assure the credential is founded upon role and function research, and scrutinize the validity of the offer.

Vocational Rehabilitation Counselor as Team Member

Vocational rehabilitation counselors with advanced degrees and appropriate credentials are properly trained, qualified, and fully prepared to complete life care plans. They can be found working in a variety of fields, including workers’ compensation, personal injury, health or disability insurance/managed care, federal Office of Workers’ Compensation Programs, and state vocational rehabilitation agencies. Additionally, many facilities (e.g., specialty centers of excellence such as Shepherd Center in Atlanta, Georgia) employ rehabilitation counselors to assist in the evaluation and, when appropriate, transition of a client into other services for return-to-work assistance or to achieve productivity.

Vocational rehabilitation counselors must be knowledgeable and stay within the accepted standards and guidelines of the particular jurisdiction for which they are preparing the life care plan. For instance, in the workers’ compensation arena, the vocational counselor must work within the established definitions of disability and return-to-work hierarchy (see Weed & Field, 2001, Chapter 3).
This also includes the “odd lot” doctrine that has been defined by case law as “any work that the client may be able to perform which would be of limited quantity, dependability or quality, and for which there is no reasonably stable market for their labor activities” (Gil Crease v. J.A. Jones Construction Company, 1982; Clark v. Aqua Air Industries, 1983). In comparison, vocational rehabilitation counselors within the disability insurance arena, such as long-term disability/short-term disability (LTD/STD), will be expected to provide information on the status of the client’s “any/own occupation,” as well as the client’s vocational potential and the cost of future vocational/educational needs. Similarly, vocational rehabilitation counselors within the personal injury arena will need to determine if the client has vocational potential and to what degree. They will also need to provide information on the cost of the client’s expected future vocational/educational needs in an effort to identify vocational damages associated with the injury or disability.

Regardless of the specific jurisdiction, vocational rehabilitation counselors in life care planning must be able to determine first if a client can work and, if so, what work the client can perform. This determination would include providing information on not only the types of vocational activity a client can be expected to perform, but also the cost, frequency, and duration or replacement of any training or assistance (such as job coach, vocational counseling, rehabilitation technology, modified or custom-designed workstation, supported employment, tuition/books, or other specialized education programs) that may be required to reach the goal (Weed & Riddick, 1992). Depending on the type of disability, the vocational rehabilitation counselor will work with a variety of medical and allied health professionals in determining one’s vocational potential and providing information for the life care plan.

Professionals such as physicians and medical specialists, physical therapists, occupational therapists, speech/language pathologists, recreation therapists, nurses, psychologists, neuropsychologists, audiologists, counselors or other mental health professionals, and, in the case of school-age clients, school personnel, all work with the vocational rehabilitation counselor to provide information for the life care plan. Generally, team members whose primary responsibilities are for cognitive and psychosocial remediation interact more with vocational counselors than do other team members, and interactions are more effective when focused on adaptive work behaviors such as the ability to relate with coworkers and supervisors (Sbordone & Long, 1996). In some cases, the nurse case manager for a client with a catastrophic injury will be the primary author of the life care plan, and the vocational rehabilitation counselor must work in conjunction with the nurse to gather and disseminate vocationally relevant information. It is common for the vocational rehabilitation counselor to rely on the client’s primary physician (if available to the expert based on legal protocol), typically a physiatrist, also known as a specialist in physical medicine and rehabilitation (PM&R), in determining a client’s functional level and potential to perform vocational activity. In appropriate cases, the vocational counselor may request a functional capacity evaluation (FCE), which may also be known as a physical capacity evaluation or functional capacity assessment, to objectively delineate a client’s physical functioning. Although there are arguments about the validity of FCEs, in the authors’ opinion, an appropriately trained examiner can provide objective data regarding the client’s ability to perform various physical demands (lifting, standing, walking, sitting, pushing/pulling, etc.), which are usually performed in a facility that specializes in occupational health information. The FCE provides a snapshot view of a client’s functional abilities on one particular day (although evaluation may be conducted over 2 days), and given the outcome of the testing, the client’s work capacity from a physical standpoint is determined. Additional factors that the vocational rehabilitation counselor must take into consideration in assessing a client’s physical capacities are the client’s ability to perform work activity over time (endurance), the client’s subjective complaints, test validity/reliability (often associated with the examiner as well as the tests), and secondary gain...
issues (Matheson et al., 2002). In summary, the FCE is just one of many pieces of information used by the vocational rehabilitation counselor in assessing a client’s vocational potential.

It is the responsibility of the vocational rehabilitation counselor to maintain a vocational focus on issues related to the life care plan. Most important, the counselor needs to work with the team to establish a medical or psychological foundation to support a client’s work potential opinion. A case in which the authors consulted illustrates the need to establish a medical foundation. The case involved a 50-year-old iron-metal construction worker who fell 70 to 90 feet from scaffolding and received multiple orthopedic injuries. The nurse case manager assigned to the case referred the client for a vocational evaluation to determine his work potential. Results from the vocational evaluation coupled with the client’s reported high motivation to return to work seemed to suggest that he had the capacity to return to work in some area related to his previous work experience. The vocational rehabilitation counselor (not one of the authors of this chapter) then proceeded to conduct a labor market survey to identify actual jobs in his area. Although on the surface it appeared that the case was progressing appropriately (at least from the case manager’s perspective), it was learned through contacts with the client’s treating physician that it was his opinion the client was permanently and totally disabled from work. Indeed, the client applied for and was approved for Social Security Disability Insurance (SSDI) benefits, which supported the doctor’s opinion that the client was disabled from work activity. The physician furthermore indicated that his recommendations with regard to the client’s vocational potential had not been solicited by the vocational counselor. In fact, the physician was unaware that a vocational rehabilitation plan had been developed to return the client to work, and he obviously did not support the plan. This is a clear example of the importance of interacting with a client’s medical care providers (when able) to establish a foundation to support the vocational plan.

Vocational Assessment/Evaluation

The terms vocational assessment and vocational evaluation have been used over the years in rehabilitation literature to generally describe the process of gathering data and determining a person’s potential for work activity. Botterbusch (1987) defines vocational assessment as “more limited in scope” than vocational evaluation and cites the Vocational Evaluation and Work Adjustment Association (1983) definition of vocational evaluation, which “incorporates medical, psychological, social, vocational, educational, cultural, and economic data” (p. 191). In Siefker (1992), it is noted that the two phrases “do not describe a significantly different process and can be considered synonymous” (p. 1). For purposes of this chapter, the phrases will be used interchangeably to describe the comprehensive evaluation of a client’s biographical and social history, education and work history, medical and other pertinent records (employment/personnel records, school records, parents’ school records in pediatric cases, etc.), psychological/neuropsychological records, and actual vocational test results in determining vocational potential.

In compiling data for the life care plan, it is within the role of the vocational counselor to recommend and obtain a formal vocational assessment/evaluation, particularly in the case of a client who:

- Is of working age (generally age 16 to 67)
- Has no or an unclear vocational goal
- Has no work history or a series of short, sporadic jobs
- Has not been determined permanently and totally disabled (i.e., is thought to have some vocational potential)
It may be interesting to note that there has been an increase in the Social Security Administration’s (SSA) determination of full or normal retirement age. The age in which SSA full retirement benefits may begin is now considered to be 67 years old for people born in or after 1960. For individuals born in 1937 or earlier, the full retirement age is 65 and increases incrementally to age 67 for individuals born between 1937 and 1960. Individuals may still begin taking retirement at age 62; however, their SSA retirement benefits will be reduced by an amount greater than for individuals retiring at age 62 today (see www.ssa.gov). Obviously, rules apply to normal SSA retirement benefits, which are different from Social Security Disability Insurance (SSDI) benefits and Supplemental Security Income (SSI) benefits that may be received by some clients with a disability.

For clients who are catastrophically injured, it is important for the vocational evaluation to be as specific as possible and to take into account the client’s personality traits, interests, aptitudes, and physical capabilities so as to adequately identify appropriate vocational options (Weed & Field, 1994, 2001). In their book, Counseling the Able Disabled, Deneen and Hessellund (1986) describe some of the most common reasons for vocational testing. Below is a modified version of the list that is felt to be most relevant to life care planning:

1. Provide information about a person’s interests, mental and physical abilities, and temperament with respect to work.
2. Support, clarify, and document impressions gained during interviews.
3. Discover job interests and potential vocational objectives.
4. Objectively and accurately describe the client’s likes, dislikes, needs, and abilities rather than rely solely on verbal interview information.
5. Observe and evaluate the client’s physical stamina, endurance, agility, and ability as related to work performance.
6. Evaluate the degree to which a particular impairment is a physical disability or handicap.

Vocational assessments can vary depending on the particular jurisdiction in which the case is involved. For example, vocational evaluations performed for workers’ compensation cases typically do not include personality testing in determining suitable employment (Weed & Field, 2001). These evaluations generally focus on aptitudes and physical capacities (and sometimes interests) as well as the client’s demonstrated work history. It is the authors’ opinion that vocational evaluations that do not address personality factors or testing should be closely scrutinized as to why such assessment tools are not included. Is it an oversight on the part of the evaluator? Is the evaluator not qualified to administer personality tests? Is the evaluator relying upon government data associated with the job history as published in the DOT and the Transitional Classification of Jobs (Field & Field, 2004)? Or is there a deliberate attempt not to define personality traits, which may have a positive or negative effect on the client’s vocational potential? Even in workers’ compensation cases, at least one court ruled on appeal that a client’s vocational interests were relevant and necessary (Weed & Field, 1994, 2001).

When referring for a vocational evaluation, the vocational rehabilitation counselor must review the evaluator’s credentials and specify which areas to assess. (Also see the section on referring for neuropsychological testing later in this chapter.) The vocational rehabilitation counselor should be concerned not only with the expertise and experience of the evaluator, but also with the technical or scientific aspects of a particular assessment tool and the way in which the test results will be used (Kapes & Mastie, 1988; Siefker, 1992). In developing a life care plan, the vocational rehabilitation counselor must be able to translate results from the vocational evaluation into requirements for the life care plan (Weed & Field, 1994, 2001; Weed, 2007). Such requirements may include
cost for training, transportation, tuition, specialized or adaptive equipment, and maintenance and replacement schedules of needed equipment (Siefker, 1992; Weed, 2007). For example, the authors were involved in identifying the costs associated with completing a master’s degree and pursuing a PhD for a triple amputee who was a teacher at the time of his electrical injury. Not only were costs included in the life care plan for education requirements, but also costs of transportation, prosthetic devices, maintenance and replacement, clothing allowance (due to increased wear and tear on garments as result of prosthetic use), and computer and other assistive technology needed to assist the client in attaining his vocational goal of education administrator. This case example also demonstrates that a client’s ability to achieve a vocational goal is closely related to other life care plan issues such as ability to perform activities of daily living (ADLs), accessible housing and transportation, psychological adjustment to disability, home/attendant care, wheelchair or mobility needs, and others. This case also provides an example of the inclusive approach the vocational rehabilitation counselor must use in conducting a comprehensive assessment of the client and interrelating realistic occupational goals with all other aspects of the client’s care.

In addition to having a comprehensive evaluation performed, the vocational rehabilitation counselor must be sensitive to how the specific tests are administered. For example, group vs. individual; time, speeded, or untimed; paper and pencil vs. computer administered vs. work sample; short vs. long form; normed vs. nonnormed; and objective vs. subjective, to name a few (see Table 4.1). In general, group tests are not as specific as individual tests (Anastasi, 1982; Siefker, 1992), and speeded or timed tests are usually biased against catastrophically impaired persons. In clients who are motorically or cognitively impaired, tests that are timed may reveal a lower score than is intellectually indicated given that the score is based on speed more so than ability. Additionally, situational or job specific tests that evaluate a person’s ability for work activity in an actual work environment typically are more favorable and yield more accurate results than a work sample assessment in which job tasks are simulated. Some authors suggest that a client’s vocational potential can be most effectively determined when the workplace is used as the primary site of all rehabilitation activity. They further indicate that no other location can be compared to the workplace for face validity and actual job activities (Sbordone & Long, 1996).

Much has been written on the various vocational assessment tools given to persons with a disability (see Vocational Assessment & Evaluation Systems: A Comparison, 1987; A Counselor’s Guide to Career Assessment Instruments, 1988; Vocational Evaluation in the Private Sector, 1992; and A Guide to Vocational Assessment, 2006). The following list is provided to give an overview of some of the more common or well-known tools used in the vocational assessment/evaluation of persons who are catastrophically impaired. The reader is referred to the publications referenced previously for a description of each test and information regarding its usefulness for specific populations of persons with a disability.

### Intelligence:
- Wechsler Intelligence Scales (preschool, child, and adult versions; the standard of the industry)
- Stanford–Binet Scales (child and adult)
- Slosson Intelligence Test (brief and very general)
- Raven Progressive Matrices (emphasis on reasoning ability)

### Personality:
- Minnesota Multiphasic Personality Inventory (MMPI) (also in Spanish)
- 16 Personality Factors (16 PF)
### Table 4.1 Selected Issues Related to Vocational Assessment

<table>
<thead>
<tr>
<th>Speeded, timed, and untimed tests</th>
<th>Speeded and timed tests may be biased against physically impaired clients. Untimed tests may not reveal how competitive a client may be.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual vs. group tests</td>
<td>Usually the group test is offered for economic reasons and is more general. Individually administered tests allow for examiner comment regarding effort and behavioral observation.</td>
</tr>
<tr>
<td>Short “screening” vs. in-depth testing</td>
<td>Vocational evaluators often use short tests for achievement, intelligence, aptitude, and interest screening. Tests such as the Wide Range Achievement Test and current revision (WRAT), Self-Directed Search, General Aptitude Test Battery (GATB), Slosson Intelligence Test, and others are not as precise as more detailed tests (e.g., Wechsler). Many evaluators are not qualified to administer more precise tests.</td>
</tr>
<tr>
<td>Tests vs. on-the-job evaluation</td>
<td>In order of general priority for best assessment:</td>
</tr>
<tr>
<td></td>
<td>• On the job with an employer</td>
</tr>
<tr>
<td></td>
<td>• On the job based on general standard by professional evaluator</td>
</tr>
<tr>
<td></td>
<td>• Work sample</td>
</tr>
<tr>
<td></td>
<td>• Individually administered test</td>
</tr>
<tr>
<td></td>
<td>• Group test</td>
</tr>
<tr>
<td>Leaving out personality factors</td>
<td>It is common in workers’ compensation to leave out interest and personality factors when developing an opinion. Basic information with regard to interests, work values, and personality as it relates to work is recommended.</td>
</tr>
</tbody>
</table>

- Myers–Briggs Type Indicator (MBTI)
- Personality Assessment Inventory (PAI)
- Rorschach Inkblot Test

**Interest:**
- Strong–Campbell Interest Inventory
- Career Assessment Inventory (CAI)
- Self-Directed Search (SDS)
- Kuder Occupational Interest Inventory

**Aptitude:**
- General Aptitude Test Battery (GATB)
- Apticom
Armed Services Vocational Aptitude Battery (ASVAB)
- Differential Aptitude Tests (DAT)
- McCarron Dial System
- Crawford Small Parts Dexterity
- Hester Evaluation System
- Purdue Pegboard

Achievement:
- Wide Range Achievement Test (WRAT as revised)
- Woodcock–Johnson Psychoeducational Battery (as revised)
- Peabody Individual Achievement Test
- Basic Occupational Literacy Test (BOLT)

Work Sample:
- VALPAR
- Jewish Employment and Vocational Service (JEVS)

Assessment of Physical Functioning:
- Vineland Social Maturity Scale
- PULSES (physical condition, upper limb, lower limb, sensory, excretory, support factors)
- Barthel Inventory of Self-Care Skills

In conjunction with objective test results, the vocational rehabilitation counselor should consider the client’s behavior during the interview and test session. Behavioral observation is an integral part of the vocational assessment process and should always be interpreted with the actual test results and client’s history, assuming the test was one that lends itself to such observation (Siefker, 1992). The qualified vocational evaluator is attuned to behavioral issues that may affect test results (e.g., pain behaviors, visual/hearing difficulties, need for medication or rest breaks, fatigue, cultural issues and language barriers, and environmental issues, such as: Is the room too hot or cold? Is it early or late in the day?). Likewise, the client’s behavior may reveal areas of concern or discrepancy that may warrant further investigation (e.g., Was the client late for the testing session? What are the nonverbal behaviors? Are the client’s appearance and grooming appropriate?). Behavior is a valid indication of how one will respond in certain situations, whether it is in a work environment or social/community setting.

In addition to behavioral observations, information about a client’s abilities and skills obtained through educational and work experience may be more valid than test results (Siefker, 1992; Weed & Field, 1994, 2001). For this reason, a transferable skills analysis may be an essential component of the vocational evaluation and for determining a client’s vocational potential. Simply described, a transferable skills analysis is based upon a profile of the worker traits required of a specific occupation. It is used primarily for clients with a documented work history and takes into consideration one’s work experience and residual functional capacities to determine appropriate vocational options. The DOT and Transitional Classification of Jobs (COJ) are necessary to compile a transferable skills analysis, and some experts utilize various computer programs to assist with managing large amounts of data (Truthan, 1997; McCroskey, 2001; Weed & Field, 2001; Gibson,
The Role of the Vocational Rehabilitation Counselor in Life Care Planning

2003). Also, the Occupational Information Network (O*Net) has been designed to replace the DOT eventually; however, the O*Net does not yet offer a way to conduct a transferability analysis that can be reliably used in formulating opinions for Social Security disability determinations and personal injury cases, and the DOT continues to be the vocational resource of choice at the present time. See the vocational resources section later in this chapter for a description of these and other relevant vocational publications.

Neuropsychological Evaluations in Return-to-Work Assessment

Neuropsychological evaluations are performed on clients following a brain injury or neurological disease and are essential in identifying the relationships that exist between one's brain and behavior or, more specifically, between one's actions and abilities and higher-level cognitive processes (Gabel et al., 1986; Evans, 2004). It is within the role of the vocational rehabilitation counselor to refer a client for a neuropsychological evaluation in cases where there is documented or suspected brain injury/impairment. According to Gabel et al. (1986), referral to a neuropsychologist is appropriate to assess problems of a more long-standing nature and includes areas such as visual, auditory, or tactile processing difficulties; constructional apraxia (copying designs or free drawing); abstract reasoning or concept formation; receptive or expressive language deficits; attention/concentration deficits; and short- or long-term memory problems. Neuropsychological testing is valuable not only to assess a client's current behavioral and learning problems (i.e., to establish a functional baseline), but also to establish prognosis, monitor and document changes over time, and assist in the planning of the rehabilitation program (Evans, 1999).

Historically, the focus of neuropsychological testing has been on the determination of brain damage and its location. Over the past decade, there is a growing interest within neuropsychology to focus on the client’s capacity to function in everyday life. The prediction of work behavior is the second most frequent reason for referral to neuropsychological evaluations. However, such evaluations are somewhat limited by a lack of norms based on specific job types and specific client population, and more work is needed in this area (Sbordone & Long, 1996).

Neuropsychologists and vocational rehabilitation counselors generally share the goal of facilitating the client's transition to an active and productive life. Vocationally speaking, neuropsychological evaluations should assist the vocational counselor in identifying the client's vocational capabilities and behaviors and in planning for a successful entrance into an appropriate work environment or, at minimum, to achieve the highest level of functioning/productivity (Sbordone & Long, 1996). For this reason, neuropsychological evaluations are helpful for both adult and pediatric clients and, as with vocational evaluations, must be as specific as possible.

For purposes of life care planning, results from neuropsychological evaluations must relate specifically to the client's function and ability and also provide recommendations for future care needs. Problems in thinking and reasoning, information-processing speed, attention/concentration, and long- or short-term memory are vocational barriers that need to be accurately assessed (Sbordone & Long, 1996). Additionally, psychosocial and interpersonal relationship skills need to be assessed such that there is an obvious need for strong communication and collaboration between vocational rehabilitation counselors and neuropsychologists in the interest of maximizing return to work and identifying life care planning recommendations.

Neuropsychological testing helps determine how much assistance is needed in the home, on the job, at school, and within the community. When referring for a neuropsychological evaluation, it is prudent for the vocational rehabilitation counselor to know to whom a referral is being made and the credentials of the neuropsychologist. Experience has shown that the most qualified
neuropsychologist not only has a PhD in clinical psychology and is board certified as a neuropsychologist, but also has experience in evaluating persons across all levels of severity of brain injury and has demonstrated a commonsense approach to evaluation and test interpretation.

Once a referral is made to a neuropsychologist, it is recommended that the vocational counselor provide specific questions to the neuropsychologist, which, when answered, would provide information needed specifically for the life care plan. The effects of brain trauma can be found in any or all aspects of one’s life, including interpersonal, vocational, educational, recreational, and activities of daily living. It is the role of the neuropsychologist to evaluate the long-term or lifelong effects of brain injury on the client’s ability to function (Weed, 1994; Evans, 2004). Suggested questions specifically pertinent for the life care planning process are listed in Table 4.2.

### Table 4.2 Neuropsychologist Questions

In addition to the standard evaluation report, add the following as appropriate.

1. Please describe, in layman terms, the damage to the brain.
2. Please describe the effects of the accident on the client’s ability to function.
3. Please provide an opinion on the following topics:
   a. Intelligence level? (include pre- vs. post-incident if able)
   b. Personality style with regard to the workplace and home?
   c. Stamina level?
   d. Functional limitations and assets?
   e. Ability for education/training?
   f. Vocational implications on style of learning?
   g. Level of insight into present functioning?
   h. Ability to compensate for deficits?
   i. Ability to initiate action?
   j. Memory impairments (short-term, long-term, auditory, visual, etc.)?
   k. Ability to identify and correct errors?
   l. Recommendations for compensation strategies?
   m. Need for companion or attendant care?
4. What is the proposed treatment plan?
   a. Counseling? (individual and family)
   b. Cognitive therapy?
   c. Reevaluations?
   d. Referral to others (e.g., physicians)?
   e. Other?
5. How much and how long? (Include the cost per session or hour and reevaluations.)

*Source*: Roger O. Weed, partially adapted by R. Frazier.
Rehabilitation counselors should ask neuropsychologists to answer the questions as part of their evaluation for life care planning.

As stated previously, neuropsychological evaluations are useful in both adult and pediatric cases. The interested reader is referred to *Neuropsychological Assessment* (Lezak, 1995) for detailed information on neuropsychological evaluations. According to Lezak (1976), the basic neuropsychological battery contains both individually administered tests and paper-and-pencil tests that are self-administered. The individually administered tests can take up to three hours, and the paper-and-pencil tests can take from three to six hours, depending on the extent of the client's impairment(s). The paper-and-pencil tests typically are not timed; however, the individually administered tests are usually timed. Especially in the case of pediatric clients, neuropsychological evaluations are often given over two sittings in order to avoid fatigue factors. Again, the vocational rehabilitation counselor is cautioned to be sure the neuropsychologist provides a comprehensive evaluation that is sensitive to the client's particular needs and provides information that is relevant for life care planning. Similar to vocational evaluations, neuropsychological evaluations are not done with a single test but instead are a compilation of data based on test results and interpretation and behavioral observations. It is recommended, and good practice, for the vocational counselor to establish a mechanism to meet or speak directly with the neuropsychologist to discuss test results and solicit input for life care planning.

For purposes of this chapter, a brief overview of some of the more common evaluation tools for each age group is given. For additional information, refer to the chapter on the role of the neuropsychologist.

**Pediatric: Neuropsychological Evaluations**

Pediatric cases present many unique challenges for the life care planner (Weed, 2000). One challenge is that there is little, if any, history on which to rely, and practitioners are often hesitant to offer future care recommendations. For this reason, neuropsychological evaluations are particularly helpful with children to qualify and quantify the impact of a child's brain injury on functioning and behavior (Weed, 1996). Although there are many assessment tools to evaluate pediatric clients, the Halstead–Reitan and Luria–Nebraska batteries are the most frequently used in the neuropsychological assessment of children (Gabel et al., 1986).

According to Gabel et al. (1986), perhaps the greatest usefulness of the Halstead–Reitan batteries is the establishment of objective baseline data that can clarify a child’s strengths and weaknesses and be helpful in outlining educational strategies and programs to enhance capabilities. In comparison, the Luria–Nebraska Children's Neuropsychological Test Battery can be administered to children ages 8 to 12 years and focuses on functional systems involved in brain–behavior relationships. A third common assessment battery for children is the Kaufman Assessment Battery for Children (K-ABC) (1983 and revisions), which is individually administered to children ages 2 to 12 years old and measures intelligence and achievement. Also, for academic assessment, it is common for the Woodcock–Johnson Tests of Achievement or Cognitive Abilities test to be administered. Last, a useful tool to assess infants who have experienced brain trauma from age 2 months to 30 months is the Bayley Scales of Infant Development (1969 and revisions). The scales are considered to be the best measure of infant development and provide valuable data regarding early mental and motor development and developmental delay. Other scales of infant developmental attainment are the Cattelle Scales of Infant Development and the Vineland Adaptive Behavior Scales (1984 and revisions).
Adult: Neuropsychological Evaluations

Whereas there are numerous neuropsychological assessment tools from which to choose when evaluating children for life care planning, there are significantly more tests for adult assessments. Below is a brief list of some of the more common neuropsychological tools for adults and areas they evaluate. For more information and descriptions on the listed tests, refer to Lees-Haley’s Last Minute Guide to Psychological and Neuropsychological Testing (1993).

- Wechsler Adult Intelligence Scale, 3rd edition (WAIS-III) (intelligence)
- Wisconsin Card Sorting Test (executive or higher-order functions)
- Boston Naming Test (language)
- Rey Auditory Verbal Learning (memory)
- Wechsler Memory Scale–Revised (WMS-III) (memory)
- Stroop Color Test (mental control)
- Serial 7s or Serial 3s (attention)
- Benton Visual Retention Test (visual memory)
- Gates–MacGinitie Reading Tests (reading academic skills)
- Hooper Visual Organization Test (visual perception)
- Woodcock–Johnson (academic and cognitive assessment)
- Haptic Intelligence Test (intelligence); used for clients with visual impairment
- Leiter Intelligence Test (intelligence); used for clients with hearing impairment
- Hisky–Nebraska Aptitude Test (aptitude); used for clients with hearing impairment

In summary, neuropsychological evaluations for clients with brain impairment are usually essential in the field of life care planning to assess both the near- and long-term effects of brain damage on one’s functioning and developmental levels. Information obtained through neuropsychological testing can be crucial in developing the appropriate future care planning of a client with a traumatic brain injury. Inasmuch as neuropsychological evaluations are vital to life care planning, test results for young children are very variable. Generally, IQ test results are not considered of substantial value until the child reaches school age. Additionally, it is generally more preferable to rely on schoolchildren’s standardized achievement test scores than on actual grades as a true measure of their achievement. In referring a client for neuropsychological testing, the vocational counselor should ensure that the evaluator reviews all available medical and academic records and that the evaluation includes developmental assessments in addition to the standardized test batteries. It is common to include in the life care plan provisions for neuropsychological reevaluations at specific life stages in the client’s development or at specific time intervals throughout one’s life expectancy in order to assess and monitor the client’s functioning abilities. This also applies to the assessment of aging on brain injury or neurological impairment (Weed, 1998).

Wage Loss and Earnings Capacity Analysis

In addition to contributing information relevant to a client’s vocational and educational outlook with regard to life care planning, the vocational counselor also may be asked to assess the client’s loss of earnings capacity. According to one source, future medical care and loss of earnings capacity are directly related to the education and experience of most vocational counselors. The vocational counselor can offer valuable input in three critical areas: lost capacity to earn an income, loss of opportunity to be employed (loss of access to the labor market), and cost of future medical
care (Weed & Field, 1994, 2001; Weed, 2000; Weed, 2002). The first and second areas will be described in this chapter. The third area, establishing the cost of future medical care, is referenced throughout this book and will not be covered specifically in this section. Refer to Table 4.3 for a summary of the relevant factors to consider in establishing a foundation for earnings capacity for both pediatric and adult clients.

With regard to lost earnings capacity, it is first necessary to establish the client’s wages at the time of injury. This can be fairly simple for a client who was working at the time of injury in a job that is considered representative of his or her earnings potential. In pediatric cases or for young clients who may have been working but had not yet established a clear vocational identity, the process can be more challenging. The issue of identifying earnings capacity can be divided into four client populations (Weed, 1996; Weed & Field, 2001):

1. Clients injured at birth or in the neonatal period
2. Clients injured before they reach school age (and have no academic grades or standardized test scores)
3. Clients injured before establishing a career identity
4. Clients injured after having an established work history representative of their vocational potential

Clearly, there are differences in the way the vocational rehabilitation counselor considers information based on the age of the client at the time of injury.

The listed factors can be a good predictor or give a reasonable approximation of what the client could have done prior to the injury (preinjury earnings or capacity). Obviously, the more history

<table>
<thead>
<tr>
<th>Client Age</th>
<th>Factors to Consider</th>
</tr>
</thead>
<tbody>
<tr>
<td>0–1 year of age</td>
<td>Review of family history (i.e., parents, older siblings, aunts/uncles, and grandparents) to include education and work records as a way to establish family patterns.</td>
</tr>
<tr>
<td>2–5 years of age</td>
<td>Same as previous plus daycare records/observations, church school observations, preschool records, pediatrician records, family videotapes, baby books if well maintained by parents, developmental records, neuropsychological evaluations, or other relevant records.</td>
</tr>
<tr>
<td>6–18 years of age</td>
<td>Review of family history, school records (including standardized test scores, academic grades, honors, disciplinary records, and extracurricular activities), pediatrician records, neuropsychological testing, vocational testing, or other relevant records.</td>
</tr>
<tr>
<td>18+ years of age</td>
<td>Review of employment/personnel records, school records, tax records, military records, community/civic involvement, neuropsychological testing, vocational testing, or other relevant information.</td>
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</tbody>
</table>
and documentation there is, the better and more accurate a foundation can be established with regard to earnings capacity.

The vocational rehabilitation counselor must determine the level of the client’s functioning both before the injury (preinjury) and after the injury (postinjury) as it relates to the types of jobs the client could hold now or in the future. In general, wage loss refers to the amount of money (wages) lost by the client as a result of the injury and is based on his or her actual past work history. Earnings capacity, on the other hand, refers to the loss of future earnings related to what would be considered a reasonable estimation of the client’s work potential (capacity) (Weed & Field, 1994, 2001; Weed, 2000).

In some cases, it may be possible to determine that a client is permanently and totally disabled from the workforce based on work history and type of injury. Such an example includes the case of a 58-year-old career truck driver who was involved in a motor vehicle accident and has tetraplegia resulting from a spinal cord injury at C4 level. Although it may be arguable that the client could possibly be employed as a dispatcher or in some other related job in the trucking industry, it is not likely given his advanced age and the fact that he would require extensive job modification and rehabilitation technology, as well as an employer willing to make the modifications and employ the client. In such cases, the actual earnings of the client would be the basis on which to project wage loss (Blackwell et al., 1992).

In other cases, it may be more appropriate to identify a client’s pre- vs. postinjury earnings capacity in categories of jobs rather than specific job titles (Weed, 2000). For example, in cases where the client is a child or young adult with no clearly established work history, the vocational expert can identify categories of jobs that are representative of types of workers (such as skilled or unskilled) and can then identify certain jobs that fall under those categories (such as lawyer or laborer) to determine the client’s earnings capacity. Another alternative is to estimate the client’s pre- vs. postinjury educational capacity. For example, if the client is expected to have the educational capacity of a high school graduate, average earnings representative of a high school graduate can be used. Similarly, average earnings of individuals with a 4-year degree, master’s degree, and doctorate or professional-level degree can be determined based on education level.

To determine wage loss or loss of earnings capacity, the vocational expert essentially evaluates the client’s preinjury and postinjury employability (defined in Weed & Field, 1994, 2001, as possessing the skills, abilities, and traits necessary to perform a job) and compares the two. Once the counselor has evaluated the difference in pre- and postinjury earnings capacity, the economist then calculates the total amount of lost earnings capacity over the client’s work life expectancy (Siefker, 1992). See chapter on the role of the economist in life care planning for further information.

There are many factors and approaches to consider when determining future wage loss and earnings capacity analysis. Of the many approaches, the RAPEL method considers most of the factors (Weed & Field, 1994, 2001). The RAPEL method, developed by Weed (1994), offers a comprehensive approach to determining earnings capacity analysis, particularly in forensic cases. (See chapter on forensic issues for additional information.) The approach incorporates a rehabilitation plan (or life care plan for the client who is more catastrophically impaired), information with regard to the client’s access to the labor market (employability), information with regard to the client’s placeability (defined as the likelihood that the client could successfully be placed in a job), earnings capacity, and labor force participation or work life expectancy. Generally, if there is a reduction in the client’s life expectancy as a result of his or her injury, there also will be a reduction in the work life expectancy. The experienced vocational counselor would express this
reduction in a percentage of loss or number of years lost in the labor market. For more information on the topic of wage loss earnings capacity analysis, refer to Dillman (1987) and the chapter on the role of the economist in this text. The reader is also referred to Neulicht and Berens (2005) for a description of PEEDS-RAPEL, a method for determining wage loss earnings capacity for pediatric clients.

**Labor Market Survey and Job Analysis**

The labor market survey is designed to reveal current information about a specific job market (Weed & Field, 1994, 2001). Questions include:

1. Do jobs of a particular nature exist in the economy?
2. If these jobs exist, are they available locally?
3. If available locally, are these jobs open to my client?
4. What do these jobs pay (including benefits)?

Part of the opinion regarding an adult client’s earnings capacity may be related to the current labor market. Obviously, a pediatric case would not include a specific employer-by-employer analysis; however, data that are collected by the government with regard to the future outlook of an occupation may be included. See Table 4.4 for common topics included in the labor market survey (summarized from Weed & Field, 1994, 2001).

**Table 4.4 Labor Market Survey Checklist**

*Introduction (include the following identifying information for report)*

Name
Age
Date of injury
Type of injury & medical limitations
Work experience
Education
Other historical information
Vocational test results
Method(s) used (What methods were used to obtain the information? Suggest starting with residual employability profile by VDARE for worker traits.)

*Personal contacts (as appropriate) with:*

Personal network
Yellow Pages
City Directory or Haynes Directory
Chamber of Commerce
Professional and trade associations
Job service

*(Continued)*
Table 4.4 (Continued)

<table>
<thead>
<tr>
<th>Vocational rehabilitation</th>
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<tbody>
<tr>
<td>Other</td>
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</table>

Publications

| Wage rates for selected occupations (state) |
| Occupational supply and demand (state Department of Industry and Trade or Labor) |
| State career information systems (or similar) |
| Manufacturing directory (SIC codes) |
| Bureau of Labor Statistics; e.g., Area Wage Survey (federal) |
| Census Bureau (federal) |
| Job Service microfiche/posted jobs (state) |
| Classified ads or job flyers |
| Identified discreet jobs related to client’s experience |
| Labor Market Access Analysis |
| Other                      |

Results

| Employer/s contacted—approximately 10 |
| Job(s) available |
| Wages and benefits (holidays, vacation, sick, medical, dental, personal leave, etc.) |
| Training/education needed |
| Willingness to work with disabled |
| Accessibility/architectural barriers |
| Other                      |

Conclusions (the professional’s opinion)

| Placeability |
| Expected income |
| Other related comments |

It should be noted that the way in which the consultant asks questions could skew the results toward a desired direction. In an example case, a plaintiff’s expert revealed that a client who had chronic pain was unemployable and used as partial justification the results of a labor market survey. She reported that the survey revealed that the client would not be an acceptable candidate for sedentary jobs that were directly in line with her work history. Following the deposition, the defense expert contacted the same employers and distinctly different information was provided. It was hypothesized that the consultant asked questions in a way that solicited support for her conclusions. Ethics, on the part of some consultants, can also be suspect. In another case, contact with the employers listed in another consultant’s notes revealed that no employer on the list recalled
being contacted with regard to a labor market survey, therefore raising the question of whether a survey had actually been performed.

Once a prospective job is located, it may be appropriate to conduct a job analysis (Weed et al., 1991; Blackwell et al., 1992; Weed & Field, 1994, 2001). The analysis is designed to determine if job traits match the worker’s traits and therefore represent a reasonable probability of employment. There are specific guidelines that consultants must follow in order to make sure that they are conducting the analysis according to published standards. Indeed, one successful malpractice lawsuit resulted when a nurse completed a “job analysis” that consisted of less than one page (Drury v. Corvel, as cited by Oakes, 1994). The topics covered in the analysis did not follow published standards. In fact, it appeared as if the nurse was unaware that the government and others have published on this topic.

It is important that the life care planner, who may not be a vocational expert, be aware that when working with the vocational aspects of the plan, the vocational expert must provide a proper foundation for an opinion. For more information, the reader is encouraged to review these topics in the Rehabilitation Consultant’s Handbook (Weed & Field, 1994, 2001), the Revised Handbook for Analyzing Jobs (U.S. DOL, 1991c) and Methods and Protocols: Meeting the Criteria of General Acceptance and Peer Review under Daubert and Kumho (Field, Johnson, Schmidt, & Van de Bittner, 2006).

**Vocational Resources**

The vocational rehabilitation counselor has many resources available to assist in assessing a client’s vocational potential and making appropriate recommendations for the life care plan. The following lists a few of the more valuable reference materials used by the vocational rehabilitation counselor:

- *Transitional Classification of Jobs (COJ)* (2004). Contains worker trait profiles of the 72 U.S. Department of Labor worker traits for each of the 12,741 DOT job titles. The worker traits are assigned a code and rated. Also includes information on the O*Net database.
- *The Enhanced Guide for Occupational Exploration (GOE)* (1991). Provides descriptions of all jobs organized within related job clusters and includes information pertaining to academic and physical requirements, work environment, salary and outlook, typical duties, skills and abilities required, and where to obtain additional information.
Job Analysis and the ADA: A Step-by-Step Guide (1992). This is another option for a comprehensive guide for determining the suitability of a job for clients with disabilities.

O*NET, the Occupational Information Network. A comprehensive database of worker attributes and job characteristics. Contains hundreds of occupational units (OUs) and is intended as the replacement for the Dictionary of Occupational Titles. O*NET will be the nation’s primary source of occupational information. However, it is not usable in its present form for transferability of skill analysis (manual or computerized). Available at http://online.onetcenter.org.

The previously listed resources use data compiled by the federal government, with many published by the government. In addition to the ones listed, there are other state, regional, and local publications specific to occupations found in certain geographic areas. For various approaches to transferable skills analysis, see Weed (2002) and the associated special-issue journal on this subject.

For additional print and computer resources available to the vocational rehabilitation counselor, the following may be useful:

- SkillTRAN (Truthan, 1997). An online and telephonic system of ordering job search and transferable skills information. Also other resources for purchase; (800) 827–2182 or www.skilltran.com.
- Job Accommodation Network (JAN), Office of Disability Employment Policy, U.S. Department of Labor (1984). Offers free consulting service that provides information about job accommodations, the Americans with Disabilities Act (ADA), and the employability of people with disabilities; (800) 526–7234 or www.jan.wvu.edu.

For other websites, see Weed and Field (1994, 2001).

Conclusion

This chapter outlines some of the vocational factors that a life care planner may encounter if a client is expected to have the capability for work activity. If the life care planner does not have the expertise to develop opinions in this specialized area, it may be reasonable to obtain services of a vocational expert and ensure that the vocational expert includes the relevant areas, as described in this chapter, and has sufficient expertise to develop reasonable opinions. Some of the topics included in this chapter are designed to assist the nonvocational expert with an overview so that appropriate questions can be asked in order to enhance the life care plan, reduce overlap or duplication in services, and facilitate the client’s return to employment and achievement of a highest level of functioning. Table 4.5 summarizes some issues, topics, and questions that a life care planner who is not a vocational expert can ask the professional on whom the life care planner is relying for a vocational opinion and recommendations.
Table 4.5  Life Care Planning Questions Regarding Vocational Needs

- First determine if vocational aspects have been considered or are already underway (e.g., already initiated by insurance company or attorney).
- What interview information have you obtained from the client (e.g., work skills, leisure activities, education, work, functional ability)?
- Have you obtained copies of relevant medical records?
- Have you obtained work-related information (such as tax returns, job evaluations, school and test records, training history, and treating MD comments)?
- Does the client need testing before determining vocational potential (e.g., vocational evaluation, psychological, neuropsychological or physical capacities testing)? Also, is the evaluation a quality and valid appraisal?
- If there is work potential, is there a need for justifying a plan by performing a labor market survey? (If LMS, what method is used? e.g., direct contact with employers vs. statistics or publications.)
- What is the client’s expected income, including benefits? (If personal injury litigation, then pre- vs. postinjury capacity.)
- If there is an apparent market for the client's labor, is there a need for a job analysis? (And if an analysis was completed, was it done according to the Americans with Disabilities Act guidelines?)
- What are the estimated costs of the vocational plan?
- Counseling, career guidance? (When does it start/stop, and what are the frequency and cost? e.g., 30 hrs. over 6 months at $65/hr.)
- Job placement, job coaching, or supported employment costs?
- Tuition or training, books, supplies? (Include dates for expected costs, e.g., technical training 2 years @ $400/yr. for 1997–1999.)
- Rehabilitation or assistive technology, accommodations or aides, costs for work, education, and/or training (e.g., computer, printer, workstation, tools, tape recorder, attendant care, transportation—include costs and replacement schedules)?
- What effect, if any, does the injury have on worklife expectancy (e.g., delayed entry into workforce, less than full-time, earlier retirement, expected increased turnover, or time off for medical follow-up or treatment)?

References


Chapter 5
The Role of the Psychologist in Life Care Planning

Randall L. Thomas and Anne Sluis Powers*

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*Dr. Thomas updated Dr. Powers’s 2nd edition chapter.
Introduction

As a member of the interdisciplinary rehabilitation team, the psychologist can play numerous life care planning-related roles. This chapter will consider the roles of inpatient and outpatient psychological services, as well as the ways a psychologist can work with individuals with disabilities, their support systems, and the rehabilitation team (also see the neuropsychologist chapter, which discusses the role of a related specialty). Several different topics will be considered: (1) choosing a psychologist, (2) psychological issues common to rehabilitation, (3) the psychologist’s role in assessment and diagnosis, (4) psychological testing, (5) types of psychological treatment, (6) ethical standards for the psychologist, (7) specialty guidelines for the forensic psychologist, and (8) the interface between the psychologist and life care planner.

Choosing a Psychologist

Following is an overview of the psychological training and preparation of the licensed psychologist. Though psychologists may vary in theoretical orientation, their academic requirements are consistent with the requirements of the American Psychological Association. Rehabilitation professionals should be well informed of the psychologist’s credentials and, in order to make the most appropriate referrals, should be aware of the psychologist’s theoretical orientation.

- A licensed psychologist has typically earned a doctoral degree from an accredited university program or professional school that has been approved by the American Psychological Association (or deemed equivalent, in some cases). Psychologists are required to complete a 1900-hour predoctoral internship in an approved program, followed by a minimum of a 1-year full-time equivalent postdoctoral internship supervised by a licensed psychologist.
- After completion of the previous requirement, the candidate petitions the state board of psychological examiners for the right to take the written examination in professional
psychology, which must be passed within state-legislated parameters. Then the candidate takes
an oral examination based on legal and ethical issues for the state in which the person intends
to practice. Successful passage of both examinations allows licensure within that state. It is
only then that the person may use the title psychologist. Use of the title without proper licensure
constitutes a violation of legal statutes and ethical principles. Please note there are some
exceptions that allow the use of the term psychologist by nonlicensed employees of universities
or state agencies.

- Psychologists practice within the scope of their training and experience, and this training
  may vary widely at the postdoctoral level. It will be important for those engaged in life care
  planning to ascertain whether a psychologist has specific personal and professional experi-
  ence in working with rehabilitation clients and their families. It may be helpful to choose a
  psychologist who has subspecialized in health, medical, or rehabilitation psychology or who
  has additional training as a registered nurse or rehabilitation counselor.

The following is a brief description of widely accepted theoretical orientations used by practicing
psychologists (Altmaier, 1991).

- **Psychoanalytic psychologists** generally follow the theory and principles established by Sigmund
  Freud, including examination of early childhood and familial relationships, along with
  conflicts presumed to originate in early developmental stages.

- **Psychodynamic psychologists** incorporate the theories of those following Freud (Alfred Adler,
  Harry Stack Sullivan, Karen Horney, Erik Erikson, and others). These psychologists also
  focus on aspects of relationships presumed to originate in infancy and childhood.

- **Developmental psychologists** examine cognitive, social, and psychomotor development of indi-
  viduals relative to their age-related peers. Developmental psychologists often evaluate children,
  and their findings may be useful following catastrophic events occurring before adulthood.

- **Behavioral psychologists** analyze environmental and personal factors that can be identified
  and altered in the interest of improving the incidence and frequency of desirable behaviors
  and decreasing the amount of problematic behaviors in an individual.

- **Cognitive-behavioral psychologists** incorporate behavioral principles and also consider the
  roles of thoughts and feelings in acquiring and maintaining certain behaviors. Both behav-
  ioral and cognitive-behavioral psychologists can help develop systematic behavior change
  programs.

- **Health psychologists** tend to adhere to the systems approach: no part of a system operates
  exclusive of others. Therefore, they adhere to the biopsychosocial model. In the rehabilitation
  process health psychologists work with a multidisciplinary team of health professionals (e.g.,
  physicians, nurses, physical therapists, occupational therapists, and case managers) to deter-
  mine the treatment plan and its implementation.

- **Rehabilitation psychologists** practice within the broad field of psychology. Rehabilitation
  psychology is the application of psychological knowledge and understanding on behalf of
  individuals with disabilities and society through such activities as research, clinical prac-
  tice, teaching, public education, development of social policy, and advocacy. Rehabilitation
  psychologists participate in a broad range of activities, including clinical care, program
  development, service provision, research, education, administration, and public policy. The
  American Board of Professional Psychology (ABPP) recognizes rehabilitation psychology as
  a specialty area of practice within psychology.
Industrial psychologists analyze work environments to enhance productivity through the human element. Considerations include management style; environmental factors such as worksite layout, music, and color; employee assistance programs; policy development; attention to group dynamics; and other factors.

It is important to choose a psychologist who appreciates the interdisciplinary team approach and who understands the roles of the various rehabilitation professionals. The psychologist should be properly licensed to eliminate concerns of credibility, and the psychologist’s orientation, when appropriate, should be relevant to the client’s situation from a biopsychosocial-spiritual perspective, addressing the client’s needs holistically.

Psychological Issues Common to Rehabilitation

The Family

Emotional Issues

Following a catastrophic injury or the diagnosis of a life-threatening illness, the issue facing the client and family is that of survival. Will the person live or die? For family members, the initial reaction is usually one of panic. As this response subsides, feelings of disorientation and loss of control are common. It may be very difficult to concentrate, and family members may become confused by what they perceive to be different types of information coming from different sources. Feelings of disequilibrium continue for quite some time in many families, with members feeling in control one day and quite out of control the next. Behaviors that can signal these reactions include anger over both significant and seemingly trivial issues, concrete or very literal thinking, efforts to participate in the loved one’s care in ways that are inappropriate, and neglect of other significant areas of one’s life.

Functional Issues

Once it seems apparent that the client will survive the initial crisis, the focus will shift toward issues of functional abilities and quality of life. Will the client be able to talk, eat, walk, and care for him or herself? Return to normal family roles and responsibilities? Return to school, or earn a living? Different levels of anxiety are associated with the different stages of stabilization and rehabilitation. Family members need a forum for discussing some of these concerns that is private and, if appropriate, separate from the client. In addition family therapy is often very helpful. Family members may need assistance with relaxation strategies, help with prioritizing decisions, or to find as much information as necessary to make good judgments.

Denial

Denial is a defense mechanism that is initially protective, keeping families from feeling overwhelmed by the enormity of a catastrophic event. However, denial of facts often prevents the family from dealing with real issues and consequences that must eventually be addressed. The rehabilitation team treads a fine line, wanting to support optimism and hopefulness, while presenting data about deficits and limitations that may endure. The psychologist or other rehabilitation team members can encourage family members to focus on one day at a time without letting expectations for the
future affect the client’s immediate needs. Gently asking family members, “How does he seem to you?” or asking them to describe how their loved one did things prior to the illness or injury may allow an assessment of the family’s degree of denial or acceptance.

Letting go of denial may lead to expressions, directly or indirectly, of anger. Anger may be expressed toward the client, individuals perceived as responsible for the injury or illness, medical care providers, the legal system, family members, or God. Dealing with anger and frustration effectively may require the assistance of a mental health professional, who will suggest appropriate problem-solving strategies and may assist with various stress management techniques.

Other psychological concerns commonly seen in family members include:

- Fatigue
- Depression
- Sleep disturbance
- Criticisms from other family members and friends regarding care provided for the client
- Feelings of hopelessness, helplessness, and guilt
- Constriction of social activities and opportunities for social support
- Changes in the quality of the relationship with the injured or ill person

At this point, it is important for the rehabilitation team to remember how family may be defined. Certainly where issues of consent are concerned, legal statutes apply. However, the client’s self-defined family may include those with whom no formal, legal ties exist. These relationships may, in fact, be closer than those within the biological family, including relationships with a significant other, close friends, stepfamily members, and so on. Some close relationships may have been defined within legal documents such as durable powers of attorney or living wills; the client’s wishes should be respected and followed within the scope of the law. Extended family members should be supported with mental health services as much as members of the client’s biological family.

It is important to note that psychological issues may surface and then reemerge over and over: developing a relationship with a caring provider that can endure over time, as the need arises, may be essential to a family’s adjustment.

**The Client**

Rehabilitation clients can face tremendous challenges: physically, cognitively, emotionally, behaviorally, financially, and socially. Following traumatic brain injury, disordered and inappropriate features may emerge as a result of altered brain functioning (DeBoskey & Morin, 1985; Ripley & Weed, 2004). For individuals with other types of injuries, it is important to remember that subtle brain injuries may have also occurred. Subtle or obvious problems may become apparent with regard to attention, concentration, memory, problem solving, insight, judgment, affective issues, pain management, and coping.

Problematic behaviors can include the following:

- Agitation
- Irritability
- Outbursts of anger
- Inappropriate statements
- Inappropriate sexual behavior
- Egocentrism
- Concrete thinking
- Impulsivity
- Emotional lability
- Denial of deficits
- Suspicion or paranoia
- Anxiety
- Depression
- Apathy
- Obsessiveness
- Social immaturity
- Dependency
- Eating disorders
- Sleep disorders
- Drug use or abuse

The Behavioral Psychology Approach

When a psychologist with a behavioral orientation is asked to consult regarding these problematic areas, several things will occur. The psychologist will be interested in input from all members of the rehabilitation team in order to determine when problems occur and possible patterns in the problematic behavior (Bellak et al., 1990). The client may be observed during therapies and quiet times for several days while the psychologist notes patterns of behavior. These behaviors will often be charted and used as baseline data.

In general, behavioral interventions will be specifically described and the team will be asked to chart information about client responses. It is common for behavioral problems to increase for a short period of time when the behavioral program is instituted. The psychologist will look for decreases in the frequency, intensity, and duration of problem behaviors over time. Do not become concerned if the behavioral program does not instantly solve behavioral issues: modifications are commonly required, and consistency in application is essential.

The following describes how a behavioral psychologist might work to assist the client in resolving problems.

- The psychologist may be able to identify patterns of events that precede the problem behavior. For example, a client may become agitated when a specific family member visits. Perhaps that family member is doing something that contributes to the problem. In other cases, clients become agitated when the stimulation level in the environment becomes excessive, or when they are fatigued or uncomfortable.

- The psychologist will also try to identify the impact or effect of the client’s behavior. For example, if an inappropriate behavior is followed by an event that the client perceives as reinforcing (e.g., allowed to discontinue an unpleasant physical therapy activity, or being given a milkshake as a distraction), the probability is that the inappropriate behavior will continue or even worsen with time. The psychologist will recommend different ways of responding to inappropriate behaviors that will lessen the likelihood of recurrence. It is important for the entire team to follow the behavioral plan consistently.

- Rehabilitation team members are in a unique position of being able to model ways of interacting with clients. Family members may be at a loss about how to respond to angry
The Role of the Psychologist in Life Care Planning

outbursts or episodes of poor social judgment. The team can show family members how to
simplify language when speaking to someone who cannot think abstractly, how to distract
a client who is focusing inappropriately, and how to ignore certain behaviors in order to
eliminate the reinforcing power of attention.

As a client’s level of awareness and insight improves, it will be important to involve the client
in the setting of behavioral goals. Explaining treatment rationales and getting the client to
take responsibility for his or her own behavioral problem will increase the client’s investment
in the process and, ultimately, in the success of the program. Clients can keep track of prog-
ress on charts, in memory logs, or by other creative ways that measure successes over time.

The Process of Adjustment to Disability

As insight improves, adjustment concerns become central. Individuals follow very similar patterns
of adjustment to disability. Cohn (1961) has described a five-stage process of adjustment. The first
stage is shock, wherein denial or minimization is common. In the second stage, expectancy for recov-
er-y, the client may admit to current deficits but continues to expect a quick and complete recovery.
As the extent of the disability becomes apparent, mourning occurs. Depression, suicidal ideation,
suicidal attempts, and disengagement from or active resistance to the therapy process are common
during this stage and should be identified. During the fourth stage, defense, the adjustment process
begins. The person reaches a critical point where either denial, or movement toward independence,
tends to occur. The final stage, adjustment, occurs when the client has a realistic appraisal of his or
her strengths and/or weaknesses, and begins to focus on moving forward with life.

Posttraumatic Stress Disorder

When traumatic injuries have occurred, posttraumatic stress disorder (PTSD) can result (van der
Kolk, Roth, Pelcovitz, Sunday, & Spinazzola, 2005). According to the American Psychological
Association (1994) in the Diagnostic and Statistical Manual of Mental Disorders, 4th edition, text
revision (DSM-IV, TR, 2000), criteria, PTSD follows from exposure to “an extreme traumatic
stressor … that involves actual or threatened death or serious injury” to the self or someone else,
or finding out about such an event experienced by a loved one (p. 424). The person’s response
must involve “intense fear, helplessness, or horror; a persistent avoidance of stimuli associated with
the trauma; a numbing of general responsiveness; and persistent symptoms of increased arousal”
(p. 424). The symptoms must be present for over 1 month and cause clinically significant distress
or impairment in daily functioning (DSM-IV, TR, 1994). The epidemiology of posttraumatic stress disorder varies, with 50% to 80% of those experiencing a devastating disaster going on
to develop symptoms of the disorder (Kaplan & Sadock, 1991; van der Kolk, Roth, Pelcovitz,
Sunday, & Spinazzola, 2005). The likelihood of developing PTSD correlates positively with the
severity of the stressor.

Therapeutic Strategies

Early intervention programs are being used to encourage clients to talk about their traumatic
experiences in a supportive context. Behavior therapy, cognitive therapy, hypnosis, and some
experimental approaches have been used (Hammond, 1990). Group therapy can be particularly
effective when members of the group have shared similar precipitating events. Family therapy
is often useful because of the high incidence of marital disruption caused by PTSD symptoms.
Medication therapy may be indicated in clients who are seriously affected and are not responding optimally to other therapeutic interventions. Hospitalization may be required during periods of severe symptoms or when there is a risk of suicidal or violent behavior.

It is important to note that clients adjust to disability in highly individual ways. The stages of adjustment within the individual can vary as well. Often, personal stressors will arise that can lead to a revisiting of adjustment issues (e.g., changes in a personal relationship may lead to further examination of the impact of the disability). It may be quite helpful for the client to have a relationship with a psychologist who can be available, repeatedly if needed, for periods of brief therapy.

The Psychologist’s Role in Assessment and Diagnosis

Psychologists are asked frequently to contribute to the initial assessment of a rehabilitation client. Generally, psychologists enter the picture in the rehabilitation facility, rather than during the acute hospitalization. In complex cases, however, it may be helpful to have psychological input during the transitional phase between acute hospitalization and rehabilitation placement.

The psychologist may address the following factors:

- Medical diagnosis
- Preexisting conditions (medical conditions, mental health issues)
- Premorbid health beliefs and behaviors (religious beliefs about health care, degree of compliance with medical treatment in the past, health-related practices, quality of prior relationships with health care providers, use of alternative medicine, degree of faith in medical treatment, etc.)
- Educational background
- Employment history (job titles and stability of employment)
- Medications, including side effects and interactions
- Functional limitations
- Physical rehabilitation potential, from a team perspective
- Premorbid personality characteristics
- Marital status and stability of primary relationship
- Role within family prior to injury or illness (e.g., wage earner status, parenting responsibilities, household management tasks, financial obligations, and relationship with extended family)
- Financial resources
- Extent of social support network
- Substance use and abuse history
- Abuse history (physical, emotional, and/or sexual)
- Legal history
- Coping resources and compensatory strategies
- Community resources
- Adjustment, including stage of adaptation to disability
- Affective status (depression, anxiety, anger, etc.)
- Suicidal potential and lethality
- Insight
- Judgment
Potential for posttraumatic stress disorder
Compliance with treatment
Initiative and motivation
Passivity vs. proactivity
Beliefs about outcomes
Role of spirituality, past and present

Following a psychological evaluation, the team should have a better understanding of who the client was prior to the injury or onset of illness, how the event has impacted the client and his or her support system, and what changes can be anticipated in the future.

Psychological Testing
A number of psychological instruments can provide valuable information when planning care for a rehabilitation client. This section will identify some psychological tests that may be given, along with descriptions of the types of data they will generate.

**Behavioral Assessment of Pain Questionnaire (BAP)**
This 390-item questionnaire investigates issues related to the management of chronic pain (Lewandowski & Tearnan, 1993). Answers reveal the client's perception of pain and its severity, health care use patterns, degree of physical activity and activity avoidance behaviors, spousal influences on pain and wellness, physician influences on pain and wellness, perceived quality of the physician–patient relationship, nonproductive pain beliefs, coping strategies used, mood, and use of medications. Treatment recommendations are generated for managing the physician–patient relationship, reducing pain behaviors, examining pain beliefs, and addressing use of drugs and other substances. A posttreatment questionnaire is available for outcome evaluation. For more information, see [www.painassessmentresources.com/prods/bapwin.html](http://www.painassessmentresources.com/prods/bapwin.html).

**Beck Anxiety Inventory (BAI)**
Twenty-one physical and emotional symptoms are listed in this questionnaire. The client rates whether symptoms experienced within the past week are absent or are mild, moderate, or severe in intensity. Scores indicate whether symptoms of anxiety are within normal range or range from mild to severe. The physical symptoms within the inventory must be evaluated with medical diagnoses in mind: many may be manifestations of disease processes rather than symptoms of anxiety, though the severity of symptoms may be affected by anxiety as well. For more information, see [http://harcourttassessment.com/HAIWEB/Cultures/en-us/Productdetail.htm?Pid=015-8018-400&Mode=summary](http://harcourttassessment.com/HAIWEB/Cultures/en-us/Productdetail.htm?Pid=015-8018-400&Mode=summary).

**Beck Depression Inventory II (BDI-II)**
The inventory contains 21 sets of statements related to depressing thoughts, feelings, and behaviors. The client circles the statement that most accurately describes symptoms during the past week. Scores indicate whether symptoms of depression are within normal range or range from mild to severe. Suicidal ideation, intent, and plan are assessed by one set of statements within the
Coping Resources Inventory for Stress (CRIS)

CRIS measures perceived coping resourcefulness based on transactional models of stress (Curlette et al., 1992). According to these models, stress is the outcome of a perceived imbalance between demands and coping resources. CRIS scales measure self-disclosure, self-directedness, confidence, acceptance, social support, financial freedom, physical health, physical fitness, stress monitoring, tension control, structuring abilities, problem solving, cognitive restructuring, functional beliefs, and social ease. An overall Coping Resources Effectiveness Score is computed, along with primary and composite scales, wellness-inhibiting items, and validity keys.

Geriatric Depression Scale (GDS)

This scale asks 30 yes/no questions about thoughts, feelings, and activities related to depression in older adults. Scores range from normal to severe. For more information, see www.stanford.edu/~yesavage/GDS.html.

Millon Behavioral Health Inventory (MBHI)

This 150-item true/false questionnaire is designed to assess psychological characteristics of patients receiving general medical care or evaluation. It contains 20 scales that provide data regarding coping factors related to the physical health care of adult medical patients. It can help identify possible psychological or psychosomatic complications, and may help predict responses to illness or medical treatment. The inventory takes about 20 minutes to complete and assumes an eighth-grade reading level. The MBHI report generates hypotheses that must be used as one facet of a total patient evaluation. For more information, see www.millon.net/instruments/MBHI.htm.

Millon Clinical Multiaxial Inventory III (MCMI-III)

This self-report instrument contains 175 true/false items designed to assess personality disorders and clinical syndromes described in the Diagnostic and Statistical Manual (DSM-IV, TR). It can assist the clinician in developing individualized treatment plans and help identify potential barriers or obstacles to treatment. The MCMI-III assumes an eighth-grade reading level. For more information, see www.pearsonassessments.com/tests/mcmi_3.htm.

Minnesota Multiphasic Personality Inventory A (MMPI-A)

This inventory is an empirically based test of psychopathology, derived specifically for adolescents (Archer, 1992). It is used primarily to aid in problem identification, diagnosis, and treatment planning in a variety of settings, including hospitals, clinics, school counseling programs, private practice, and correctional facilities. There are 478 true/false items. Administration time takes up to an hour and assumes a sixth-grade reading level. Family problems, eating disorders, and chemical dependency issues are addressed. For more information, see www.pearsonassessments.com/tests/mmpia.htm.
Minnesota Multiphasic Personality Inventory 2 (MMPI-2)

This inventory is the restandardized version of the original MMPI, an empirically based test of adult psychopathology. It is used to measure objectively psychopathology across a broad range of client settings where social or personal adjustment problems are acknowledged or suspected. The MMPI-2 can aid in identifying appropriate treatment strategies and potential difficulties with treatment. The inventory contains 567 true/false test items and assumes a reading level of sixth grade (Greene, 1991).

The MMPI-2 is an extremely sophisticated psychological assessment instrument, and it is beyond the scope of this chapter to present the test in detail. However, the test yields several validity indexes that measure a client’s degree of psychological functioning, as well as attempts to fake “good” psychological health or to present a more deviant picture. Ten basic clinical scales measure symptomatic and characterological symptoms, and numerous subscales assess subtle and obvious aspects of psychological functioning. The consistency of responses and attentiveness while taking the test are also assessed. For more information, see www.pearsonassessments.com/tests/mmpi_2.htm.

Personality Assessment Inventory (PAI)

The PAI is a 344-item inventory that provides a broad-based assessment of mental disorders. The PAI includes 4 validity scales, 11 clinical scales, 5 treatment scales, and 2 interpersonal scales. Clinical scales are clustered in neurotic, psychotic, personality disorders, and behavioral disorders. For more information, see www3.parinc.com/products/product.aspx?Productid=PAI.

State-Trait Anxiety Inventory (STAI)

This inventory was developed to measure the anxiety level of individuals. It consists of two 20-item self-report scales designed to assess anxiety proneness and the current level of anxiety. The test is appropriate for those with a seventh-grade education or higher and requires approximately 15 minutes to administer.

Wechsler Adult Intelligence Scale Revised (WAIS-III)

This test is based upon a definition of intelligence as “the aggregate or global capacity of the individual to act purposefully, to think rationally, and to deal effectively with his environment” (Wechsler, 1944). The subtests evaluate verbal intelligence and performance intelligence. The test is of value for determining intellectual functioning for occupational, educational, and neuropsychological purposes. For more information, see http://harcourtassessment.com/haiweb/cultures/en-us/productdetail.htm?pid=015-8980-727.

Wechsler Intelligence Scale for Children—4th Edition® (WISC-IV)

Wechsler (1944) applied the same definition of intelligence as noted under WAIS-III to the development of a measure of intellectual functioning in children ages 6 years 0 months to 16 years 11 months. Twelve subtests classify verbal intelligence and performance intelligence. The WISC-IV is often administered as part of a neuropsychological test battery. For more information, see http://harcourtassessment.com/HAIWEB/Cultures/en-us/Productdetail.htm?Pid=015-8979-044&Mode=summary.
Wide Range Achievement Test—3rd Edition® (WRAT-3)

This is a norm-referenced test designed to measure current arithmetic, word recognition, and spelling skills. Results provide grade equivalents, standard scores, and percentile rankings for an individual. The spelling and arithmetic subtests can be administered individually or in groups. The reading subtest is individually administered. Jastak and Wilkinson (1984) report greater test–retest reliability on the reading and spelling subtests than on the arithmetic subtest. For more information, see www.minddisorders.com/Py-Z/Wide-Range-Achievement-Test.html.

Woodcock–Johnson® III Test (Achievement and Cognitive Abilities)

The Woodcock–Johnson Test (2001) is widely used by educators and psychologists. It is individually administered and measures achievement in the areas of reading, mathematics, written language, knowledge, and cognitive abilities in the areas of cognitive factors, oral language, and differential aptitudes. The test is divided into two major parts: achievement and cognitive abilities.

Academic achievement is measured in the following areas: mathematics, written language, knowledge, skills, and reading.

Cognitive factors measured include comprehension–knowledge, long-term retrieval, visual-spatial thinking, auditory processing, fluid reasoning, processing speed, and short-term memory. For additional information, see www.riverpub.com/products/wjIIIComplete/index.html.

Types of Psychological Treatment

Different psychotherapeutic approaches have been used with success with those who have had a catastrophic injury or illness. Often an appropriate mixture of therapeutic approaches is needed to provide the client with the maximum benefit. When completing a life care plan, it will be important to include therapeutic modalities that will address the patient’s changing needs over time, and to allow some flexibility so that the patient may enter and exit therapy as life experiences occur.

Individual therapy allows the person to explore issues of a personal nature in a protected and private manner. The individual will need time and privacy to explore the feelings of loss related to the disability or illness. Having a confidential relationship with one therapist over time will facilitate disclosure and allow the therapist and client to develop individualized approaches to treatment issues. The therapist can help the client deal with personal feelings about relationships, manage the fluctuating emotions that emerge, develop plans for behavioral change, troubleshoot potential problem areas, and work on reintegration goals. In many instances, individual therapy can offer the client the opportunity to practice new skills and to bounce ideas off of a caring, neutral party in ways that are potentially less threatening than doing so with a relative or friend.

Individual therapy typically should be requested approximately three times per week during the rehabilitation facility phase. Once the individual is stabilized and participating in outpatient therapies, weekly therapy visits for the first 3 to 6 months are appropriate. Check with the psychologist regarding issues specific to the individual that may require more intensive monitoring (e.g., suicidal ideation).
Biofeedback (Basmajian, 1989) is a helpful modality for many clients as well, particularly those dealing with psychophysiological problems such as hypertension, muscle tension disorders, pain problems, and stress disorders. Biofeedback techniques help the client learn more about his or her individual responses to stressors and ways that he or she can learn to intervene directly, often without using medications or other medical interventions. Physical and occupational therapists have found biofeedback to be a helpful adjunct in neuromuscular reeducation programs.

When adding biofeedback therapy to the life care plan, request approximately 12 hour-long weekly sessions initially, in order to learn and apply the technique. Follow-up visits can be scheduled every 2 weeks for 2 months, then once a month for 2 months. Check with your biofeedback referral source for recommendations.

Hypnotherapy is a somewhat controversial therapeutic technique that can be helpful for some clients. When practiced by a competent therapist, hypnotic techniques can help a client change behaviors he or she is already willing to change (Hammond, 1990). For example, a person who wishes to quit smoking may find hypnotic suggestions regarding smoking cessation to be very powerful in encouraging abstinence. Hypnosis may also be a helpful stress management technique for some.

Family therapy is an extremely important therapeutic modality. A catastrophic injury or illness has profound effects on family functioning, and these effects need to be dealt with by involving the entire family. Changes in role behavior, role expectations, marital relationships, communication pathways, financial status, and family goals will require sensitive support and negotiation (Lezak, 1988). When completing a life care plan, family therapy should be considered when major life transitions are encountered (e.g., a child leaving home, a death in the family, or a major illness diagnosed) by any family member. Family therapy sessions can provide an effective forum for discussing quality-of-life issues, developing living wills and advanced directives, and renegotiating family rules.

Group therapy is helpful for many rehabilitation clients. Group therapy designed specifically for individuals with similar injuries (e.g., spinal cord injuries only) may be beneficial. An important consideration when selecting a group will be the members’ functional communication level rather than functional physical level. Having a mixture of participants who are operating at different stages of adaptation to their disabilities can be helpful in providing newer members with hope and inspiration. A skilled group leader will acknowledge the various stages of adaptation while sensitively encouraging the group to progress to a focus on abilities rather than disabilities, to hope rather than despair.

When completing a life care plan, psychologists will generally include a group therapy modality on a regular basis (some groups meet weekly, others less often) for the first 6 months at least, if the client shows willingness to participate.

Pain management is an important subspecialty area that requires mention. Following catastrophic injury, pain problems are often related to the tissue damage that has occurred. Pain management strategies usually include the use of medications and, hopefully, relaxation techniques (Hanson & Gerber, 1990). As time passes, however, the client will need to reduce his or her reliance on potentially addictive pain medications and to increase independence in managing pain. A pain management specialist can help the client learn
relaxation techniques, cognitive strategies, reactivation steps, and ways of dealing with the psychological components of pain.

If pain continues to be a focus of treatment after physical stabilization has occurred, consider a referral to a pain specialist. Pain is no longer merely a symptom: it has become a problem and needs to be addressed in an intensive manner.

The Interface between Life Care Planner and Psychologist

Most life care planners are familiar with the role of the psychologist. The interface between the life care planner and the psychologist can be productive as the life care planner requests long-term care recommendations. However, there are a number of areas that the psychologist and the life care planner should be aware of to reduce the possibility of miscommunication.

Initially, the life care planner should determine if the psychologist involved is a treating psychologist or has been retained by one of the attorneys to provide expert testimony or provide an independent medical evaluation. In nearly all cases, the psychologist will be either a treating psychologist or a retained expert.

Psychologists often treat individuals with catastrophic injuries, and those clients may become involved in litigation. Therefore, the psychologist may be familiar with the litigation process and should be familiar with requests for records, discovery depositions, and occasionally testifying as a treating psychologist. The psychologist’s office can be expected to have policies and procedures describing how to respond to requests for records and related activities concerning the litigation process.

However, the treating psychologist may not be familiar with the role of life care planners, and an explanation of the life care planning process, along with specific questions, will be helpful. The psychologist may be concerned about your role and why all of these questions are being asked. Perhaps reference to this chapter would be helpful.

Psychologists are generally oriented toward patient care, and the type of information life care planners solicit is familiar to the psychologist. For example:

- What is the client’s diagnosis?
- What is the client’s current treatment program?
- What is the client’s projected course of treatment?
- What is the client’s projected prognosis?

Typically psychologists are comfortable projecting the number of sessions per week or per year and treatment time frame. In addition, they can provide information on charges for psychological services as a part of the life care planning process.

The life care planner communicating with the treating psychologist or retained expert psychologist should inquire regarding specific services. The following is an outline that can aid communication between the life care planner and the psychologist:

1. Projected evaluations (include duration and frequency; consider the effects of aging).
2. Psychotherapy/counseling (consider group, family, and individual sessions). Remember that counseling and psychotherapy are similar and somewhat dependent on the setting. Options may include:
   - Biofeedback
   - Counseling regarding sexual dysfunction (e.g., associated with spinal cord or brain injury)
   - Individual counseling regarding behavioral management
Family counseling for family members’ adjustment
Group counseling
Family consultation (disability education, behavior management)
3. Psychologist/neuropsychological testing, to include intellectual assessment, academic assessment, interest assessment, personality assessment, and neuropsychological functioning. Provide approximate ages at which the assessments should occur.
4. Psychological services related to pain management.
5. Personal care attendant for issues related to mental capacity/incapacity.
6. Recommendations related to restrictive/least restrictive environment.
7. Computer hardware/software related to socialization/independence.
8. Case management related to psychological care.
11. Opinions and recommendations relating to vocational outlook (personality, trauma, intelligence, etc.).
12. Opinions regarding the person’s pre- vs. postinjury functioning.
13. Referral to other professionals such as psychiatrist for medication.

Psychologists can provide valuable information to the life care planner as the life care report is being developed. However, both life care planner and psychologist should clearly be aware of their roles, boundaries, and limitations.

Once the psychologist has provided the list of recommendations, it is suggested the life care planner type up the recommendations and return them to the psychologist for review and signature. This provides the psychologist the opportunity to review for any areas of miscommunication or omission. The written document also provides documentation of the participation of the professionals involved in the planning process.

In addition, the life care planner may request the psychologist to sign the document listing the recommendations. Having a signed form in the file reduces the potential for a challenge of the life care planner’s testimony being based on hearsay since the recommendations were only provided orally and not in a written form. The courts typically allow life care planners significant leeway regarding hearsay. Life care planners solicit oral recommendations from health care members in the normal course of their business (see reference to federal rules 702 and 703 later in this book). However, due to the potential for an error in communication, and the extent to which that error may affect the admissibility of testimony in forensic cases (and the rare occasion where the psychologist may change his or her opinion), the life care planner is well advised to at least request the psychologist to review and sign the list of recommendations. For a summary checklist (that might also be useful to provide to the psychologist), see Table 5.1. (For additional questions, see chapter regarding the neuropsychologist’s role and the chapter on brain injury.)

Ethical/Practice Standards for Psychologists

The primary national association for psychologists is the American Psychological Association (APA) (www.apa.org). Based in Washington, DC, the APA is a scientific and professional organization that represents psychology in the United States. With more than 155,000 members, the APA is the largest association of psychologists worldwide. The 2002 APA Ethics Code was published in the December 2002 issue of the American Psychologist. Electronic copies of the ethics code are available at www.apa.org/ethics/.
For various reasons, some licensed psychologists have chosen to not join the APA. However, most state licensing laws for psychologists incorporate the APA Ethics Code into the licensing law. Therefore, even though a psychologist may not be a member of the APA, he or she is very likely held to the ethical code of the APA based on the specific stature of the state in which the psychologist is licensed.

Psychologists are licensed to practice at the state level, not the national level. Each state has a unique license law that describes the practice of psychology in that particular state.

**Specialty Guidelines for Forensic Psychologists**

The “Specialty Guidelines for Forensic Psychologists” (1991) represent a joint statement of the American Psychology–Law Society and Division 41 of the APA. In addition, the guidelines have been endorsed by a majority vote of the American Academy of Forensic Psychology. The guidelines do not represent an official statement of the APA. They provide assistance to psychologists and others who are interested in the process psychologists will follow when they are involved in a litigation event or retained as an expert witness.

A copy of the “Specialty Guidelines for Forensic Psychologists” may be obtained from www.ap-ls.org/links/currentforensicguidelines.pdf.

**The Individual with Disabilities Education Act**

Since 1975, the federal government has played an important role in ensuring that children with disabilities receive the best possible education through the Individuals with Disabilities Education
Act (IDEA). Reforms in the No Child Left Behind Act made fundamental improvements in elementary and secondary education to enhance the education of children with disabilities by supporting accountability for results, expanded parental choice, a focus on what works, and increased local flexibility.

The life care planner who is developing a pediatric plan should endeavor to contact the school psychologist as a part of the information-gathering process. In many injury cases, school testing may also provide the foundation for preinjury functioning.

**Case Example**

The patient is a 28-year-old female that is 30 months postinjury. She had significant physical injuries, including injury to her brain, in a motor vehicle accident. She has deficits in organizational skills. She tires easily. Neuropsychological testing reveals significant impairment in the ability to maintain attention and concentration. Problem-solving ability is impaired. She is clinically depressed. Memory impairments are present. Short-term and long-term memories are impaired. Auditory and visual memories are also impaired. In addition, she has impaired receptive language and chronic pain.

The life care planner completed a phone conference with the patient’s treating psychologist, Dr. Mary Smith. Following the phone conference, Dr. Smith’s recommendations were typed and sent to her for review and signature. A sample summary with request for confirmation is in the following.

**List of Items and Services**

Recommendations/information from Dr. Mary Smith, psychologist, on April 23, 2008, regarding Ms. Susan Jones:

1. Diagnosis
   - Acquired brain injury, PTSD, impaired mobility, impaired memory, and chronic pain.
2. Psychological Evaluation
   - Annual psychological evaluations for 4 years, then PRN.
   - Neuropsychological exam, one per year for next 3 years, then PRN.
3. Counseling and Psychological Services
   - Counseling two times a week for 1 hour each session for next 3 years, then one session per week for 4 years. She should continue to receive counseling and psychological services because of her ongoing medical and psychological problems. She will need counseling regarding her self-concept and relationship issues.
   - She will need pain management services and cognitive retraining services. If pain continues, additional psychological services of 20 sessions (1 hour per session) per year are recommended until pain levels abate.
4. Counseling for Family
   - Support services and counseling for family for next 2 years. Approximately 50 counseling hours per year.
5. Implications for Current and Future Adjustment to Disability
   - She will need assistance with day-to-day problem solving and planning. I am unable to provide a specific number of hours per day for attendant care, but she may need an attendant 24 hours per day due to cognitive deficits, safety issues, and poor judgment.
6. Case Management Services
She will need a case manager 4 hours per month to coordinate services.

7. Specialized Services
She will need a vocational assessment to determine if she can return to work (which is unlikely) and to assist with avocational activities.

Conclusion
This chapter has reviewed the ways in which a trained, experienced rehabilitation psychologist can participate as a member of the rehabilitation team. In rehabilitation, much attention is given to the preservation and restoration of functioning. Psychological issues can color the work of rehabilitation in subtle and obvious ways and should be carefully considered when planning for the client's care.

It is also important to remember that the relationship a psychologist establishes with a client can continue for many years following the catastrophic injury or diagnosis of illness. As a life care planning professional, you can ensure that your client receives the emotional and behavioral support needed to achieve goals of functional independence.

References


Chapter 6

The Role of the Neuropsychologist in Life Care Planning

Carol Walker

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Introduction

This chapter will address the various roles of a neuropsychologist, particularly as these roles apply to life care planning. The chapter will also address how a life care planner might select a neuropsychologist, the elements of the neuropsychological evaluation, and the methods used by neuropsychologists for interpreting data obtained in a neuropsychological examination. Implications for life care planning will be addressed in terms of ways questions might be posed to a neuropsychologist regarding the functioning of an individual patient.

Ward Halstead set up the first neuropsychology laboratory in the United States in 1935. He used neuropsychological testing to study the effects of different types of brain damage on various cognitive domains as well as sensory and perceptual functioning. Prior to utilizing the testing, he observed individuals with brain damage in a variety of real-world settings in order to determine the types of problems they experienced. He then assembled a battery of 10 tests, which were administered to these patients (Sbordone, Saul, & Purisch, 2007). In collaboration with his
student Ralph Reitan, Halstead created the Halstead-Reitan Battery. This battery remains widely used in the field of neuropsychology. The Boston Approach, which was developed at the Boston VA by Harold Goodglass, Edith Kaplan, and Nelson Butters, focuses on a qualitative strategy. They developed a process approach that relies heavily on behavioral observations during the performance of a task. Another prominent figure in the field of neuropsychology is Alexander Luria. He developed a theory of brain-behavior relationships that postulated complex behavior may be reduced to the individual components and studied to determine what functional system had been damaged (Luria, 1973). In collaboration with Anna-Lise Christensen, a Danish psychologist, his testing method was introduced in the United States. This method utilizes individualized test selection and administration.

Neuropsychology is based on two primary fields of study, neurology and psychometrics (Russell, 1986). Neuropsychology can generally be described as the relationship between the structure and function of the brain, and psychological processes and exhibited behaviors. There has been considerable research in the area of neuropsychology, especially since the 1970s. There are no other areas in psychology where there is a greater empirical research base (Russell, 1986). When the field was initially developed, neuropsychological testing was used as a diagnostic tool. In other words, the goal of the examination was to make a diagnosis of the type and location of a brain lesion using neuropsychological data. While diagnosis has remained a focus of neuropsychological testing, it has been supplanted as a primary diagnostic tool to a large degree by the advent of advanced neuroimaging techniques such as CT and MRI (see Bigler, 1996). However, since neuropsychological testing and evaluation remain the most sensitive measure of brain function, there is continuing utilization of evaluations for measuring function. Even the most sensitive imaging will not provide the nature of behavioral strengths and deficits in a particular case. There are a number of disorders that do not lend themselves to diagnosis through neuroimaging; a primary example of such a disorder is a progressive dementia.

Moreover, as documented in Lezak, Howieson, and Loring (2004), neuropsychological testing can be helpful in discriminating psychiatric versus neurological symptoms, identifying possible neurological disorders, distinguishing between neurological disorders, and providing input regarding localization of lesion site, at least to a hemispheric level. While the role of neuropsychological evaluation in diagnosis has largely been supplanted by advanced neuroimaging, the role in prediction of outcomes and treatment of individuals with neurological disorders has improved with the increasing research-based information available to neuropsychologists. Many patients are referred for neuropsychological evaluation to assess their cognitive strengths and weaknesses, and to obtain information about behavioral alterations and personality characteristics. Assisting with adjustment to an individual’s disability for the patient, their family, and/or their caregiver is also within the roles of the neuropsychologist. Primarily, this consists of educating the family, caregiver, and patient regarding the effects of the neurological condition on the individual’s behavior. This education and a full description of the patient’s abilities, deficits, prognosis, and need for rehabilitation are crucial for the best adjustment of the entire family. Without this information, it is difficult for families and others to make plans for future care, need for supervision, and other management issues for a patient with acquired brain injury or other neurological dysfunction. The neuropsychologist may also answer questions regarding an individual’s capacity to care for himself or herself, ability to follow a therapeutic regimen independently, cognitive capacity to operate a motor vehicle, and ability to manage personal financial matters.

 Provision of information to patients regarding their deficits is also imperative. In those individuals with appreciation of their deficits, there is often depression and mistrust (Lezak, Howieson, & Loring, 2004). In those individuals who exhibit anosognosia, which is a lack of
awareness of deficits (or simply, “I don’t know what I don’t know”), informing their caregivers and others with whom they routinely interact of deficits may allow for improved interpersonal relationships. Those individuals with brain injury and lack of self-awareness are at greatest risk for acting-out behaviors. This lack of self-awareness is not analogous to psychological denial. It is more often a function of frontal lobe/executive dysfunction or other brain lesion.

Follow-up neuropsychological testing allows a determination of changes in the neuropsychological status of an individual. It may also be used to determine the effects of treatment and cognitive remediation strategies. In those individuals whose symptoms are being treated with medications, repeat testing might also help determine the effects of the medication on cognitive functioning. Neuropsychological testing can also be used to assist in educational placement, curriculum planning, and recommendations to maximize learning.

Neuropsychological assessment can also provide information regarding an individual’s ability to participate and, more importantly, benefit from rehabilitation treatment. The questions of whether an individual obtains benefits and of whether that benefit has psychological and social value and is maintained long enough to warrant the cost can be answered by repeat neuropsychological testing (Solberg & Mateer, 1989).

While some neuropsychologists provide assessment only, others provide the treatment to individuals with acquired brain injury, other neurological disorders, chronic pain, and posttraumatic stress disorder. In these cases, one goal is to address the behaviors of the patient with a brain injury. Common postmorbid behaviors including irritability, egocentrism, impulsivity, and other behaviors place high levels of stress on the family. Family members are often included in sessions with the patient, or seen independently, to help them better understand changes in their injured family member and to more effectively cope with the effects not only on the injured patient but on the entire family. Neuropsychologists, who practice in rehabilitation settings, whether acute or postacute, are often involved in education with family members throughout the patient’s admission, to help pave the way for a smoother transition at discharge. They are also part of the rehabilitation team and provide input regarding behavioral and cognitive issues.

Selecting a Neuropsychologist

How should one go about selecting a neuropsychologist for a specific case? Division 40 of the American Psychological Association (APA) published a definition of a neuropsychologist in *The Clinical Neuropsychologist* (March 22, 1989). This definition was adopted by Division 40 Executive Committee and reviewed and accepted again in 1990 to 1996. The necessary education attributes are listed and a definition of a neuropsychologist is given. This definition stressed that attainment of the diplomate in clinical neuropsychology from the American Board of Clinical Neuropsychology “is the clearest evidence of competence as a clinical neuropsychologist assuring that all of these criteria have been met.” A listing of clinical neuropsychologists who have obtained this board certification may be found at www.abpp.org under the Directory of Specialists. The American Board of Professional Neuropsychology, which is another certifying body for neuropsychologists, has a listing of their diplomates at http://abpn.net. Both of these certifying bodies require appropriate education and training for a neuropsychologist to become certified. This is not to suggest that there are not many excellent, well-trained, and experienced neuropsychologists who are not board certified. However, if seeking a neuropsychologist in a particular area, those who are board certified by either the American Board of Clinical Neuropsychology (ABCN), which is affiliated with the American
Board of Professional Psychology, or ABPP, have been evaluated by their peers and their work has been found to meet the established criteria for expertise. This being the case, when there are no personal recommendations available, this allows greater assurance of the training and expertise of the neuropsychologist. It is important to ensure that the neuropsychologist being chosen for referral has not received board certification through a so-called vanity board. These boards provide certifications without regard for competence or training in neuropsychology. Because there are no criteria for determining competency by these vanity boards, any psychologist who holds such credentials should have their qualifications thoroughly assessed before a referral is made to them for an evaluation.

Additional information regarding the necessary education and training in clinical neuropsychology as well as the description of the scope of practice is available at the following resources.


While there are a number of educational requirements for neuropsychologists, the experience each brings to a particular disorder differs. This being the case, it is incumbent when making a referral for a neuropsychological examination to determine the experience of the neuropsychologist in the particular area of interest. In the case of children, it is important that the neuropsychologist have experience in working with children of the same age as the child to be evaluated. In children, not only the disorder but the developmental stage of the child must be considered. While it is helpful to utilize a pediatric neuropsychologist, there is not always an available specialist in every area of the country.

Sbordone, Saul, and Purisch (2007) note that the theoretical orientation of the neuropsychologist influences the outcome of the evaluation. These authors cite information from a 1986 article (Sbordone & Rudd) which reportedly found that psychologists with certain theoretical treatment orientations were less likely to recognize underlying neurological disorders. Sbordone et al. (2007) also report the 1986 study found that the training environment of the neuropsychologists influenced how they viewed cases. These authors further note that many neuropsychologists have little or no experience in the rehabilitation of individuals with acquired brain injury. Because of the lack of experience, opinions regarding the relative permanence of cognitive problems and ability to return to competitive employment, school, or household responsibilities are opined to be often inaccurate or inappropriate. Sbordone and his colleagues further noted that most psychologists are unfamiliar with cognitive rehabilitation techniques and have minimal to no experience training people to use compensatory strategies and techniques to maximize behavioral and cognitive functioning following brain injury. When these neuropsychologists perform evaluations or make recommendations, Sbordone et al. (2007) state the opinions are often overly pessimistic. These authors note that rehabilitation neuropsychologists, on the other hand, may be overly optimistic about the potential for improvement.

Another issue to address in looking at the opinions of a neuropsychologist is that person’s role in the case. This may be particularly important in obtaining information as a life care planner. If the neuropsychologist is the treating neuropsychologist, he or she may have had limited background records, especially preinjury records, and may not have performed as detailed an evaluation as would be the situation if the injured person was referred for a forensic evaluation and the neuropsychologist was acting as an expert. There are a number of differences between the
roles of a treating psychologist and expert psychologist. It is beyond the scope of this chapter to address all of these differences. However, for interested readers, they are delineated in a paper by Greenberg and Shuman (1997).

Overall, when selecting a neuropsychologist it is important to ensure that the individual is appropriately trained and has the skills necessary to evaluate the individual for whom referral is sought. Important issues to consider include the training environment of the neuropsychologist, the experience in clinical neuropsychology as well as experience in the disorder and referral questions, the theoretical orientation of the neuropsychologist, and his or her forensic experience. Board certification, by either ABCN or ABPN, provides external validation that the individual has undergone examination by his or her peers in terms of neuropsychological competence. This is not to suggest they are the only competent neuropsychologists but it gives one greater confidence when referring to a neuropsychologist about whom one knows very little. In many cases it is important that the neuropsychologist understand the medicolegal issues involved in the case. The neuropsychologist should be made aware if a case is involved in litigation to ensure a willingness to become involved.

The Neuropsychological Examination

While most neuropsychologists rely on standardized test data, these data alone do not provide all of the information needed to fully assess an individual. There is a need to consider information from subjective sources, objective sources, and collateral sources. Subjective information includes information provided by the patient, family members, and caregivers, which cannot be verified with other data. It often includes complaints of physical, emotional, and/or cognitive difficulties. Family members and caregivers often relate the patients’ complaints of their feelings or physical distress but may also provide, or be able to provide, with appropriate questioning, objective data. Beyond relating what they have been told about how the patient feels, they may have extensive knowledge of patterns of behavior, sleeping habits, eating habits, personality changes, and interpersonal relationship changes. Other objective information includes information from school records, medical records, vocational records, neuropsychological and psychological test data, and any other data from either before the injury, where possible, or postinjury. The individual’s social history, including educational and work experiences, provides information about premorbid cognitive potential. Marital history also provides relevant information and may tell a great deal about emotional stability, social judgment, and relationship stability over time. Assessment of the individual’s current life circumstances also provides formation about how the individual is currently functioning.

Comparison of an individual’s functioning pre- and postinjury helps to delineate the changes since the injury and help in treatment planning. Medical history and current medical status provide information about the individual’s premorbid history. Medications that have been prescribed may also provide some understanding of how functioning has changed over time. Another important source of information is the observation of the examinee during the testing process. While testing may be performed by a technician or the neuropsychologist, there is often a large amount of information gathered during the examination process, which lasts from several hours to days in some instances. For instance, how an individual approaches a task may give a significant amount of information beyond that provided by the test score alone. For example, while the author was testing an individual on a timed motor task, the examinee stopped performing the task to relate extraneous information about his lunch. While the data were not valid for the task, his behavior...
demonstrated a relative unawareness of the task at hand and involvement in testing. Behaviors of this nature were documented in other aspects of the examination and provided data, outside of the test findings, that were important in understanding his ability to function. Using all available data allows the neuropsychologist to develop a picture of how the person functioned before and after an injury or illness. Failure to consider this information may lead to spurious conclusions by the neuropsychologist. For example, this author tested an individual who reported having completed 12 years of education. The individual further stated he was a high school graduate and an average student. On testing, his intellect was measured to fall in the low end of the borderline range and academic assessment revealed reading in the extremely low range (no school records were available prior to the examination). When school records were provided, it was determined he had not obtained a diploma but a certificate of attendance. He had also been in special education beginning in elementary school. If only the results of testing had been considered, his deficits would have been overstated. The converse may also occur if the neuropsychologist is not aware of past history; an individual with a high level of functioning may not be identified as having changes in cognitive abilities if there is no attempt to determine premorbid level of function.

The assessment dynamics should be predicated on the referral questions (also see example questions to ask the neuropsychologist located in the chapter on the role of the vocational counselor). It is often the case that the referral questions are related to an individual’s ability to work or return to school. Questions regarding the need for competency to manage financial affairs or make other cognitive decisions are also often asked of neuropsychologists. Lezak, Howieson, and Loring (2004) note that examination questions fall into two categories, diagnostic questions and descriptive questions. Diagnostic questions are generally asked when the etiology of cognitive or behavioral problems is unknown. These are usually questions of differential diagnosis. Descriptive questions are those asking about specific abilities and often arise in vocational and educational planning. These authors note these questions are especially important if the planning involves withdrawal or return of normal adult rights and privileges, such as driving or legal competence. In these cases, the neuropsychological examination will focus on the relevant skills and functions. Other areas of assessment include awareness of one’s condition and capacity to incorporate new information and skills.

Tests are typically selected that meet criteria for reliability and validity and have norms appropriate for the individual being assessed. There are some neuropsychologists who use a fixed battery approach; this approach is exemplified by the Halstead-Reitan Battery or the Luria-Nebraska Battery. Most neuropsychologists use a flexible battery approach to address the referral question(s).

Another element of the examination is determining the preinjury baseline of the individual. It is relatively unusual to have someone who has had a previous full neuropsychological examination unless they have suffered a previous injury or neurological illness. Neuropsychologists must try to ascertain how the person might have functioned in the past to develop a benchmark to which current test scores are compared. While most of the population functions in the average range, the individuals whose scores premorbidly fall at the ends of the distribution pose a challenge. If an individual functioned at the upper end of the distribution, even milder changes may affect their ability to function, at least in a vocational sense. For example, a neurosurgeon with mild injuries is likely to have greater difficulty vocationally than one who does not deal with complex life or death issues daily. If an individual was functioning marginally preinjury, then she may have greater difficulty coping than would be the case for someone who functions at a higher level. There are several regression equations that have been developed to estimate premorbid intellect (e.g., the Barona equation). Another method frequently used is reading ability (Johnstone, Callahan, Kapila, &
The Role of the Neuropsychologist in Life Care Planning

Bowman, 1996). There is an obvious difficulty in using this method in cases of premorbid reading difficulties or where the person has sustained damage to reading centers of the left hemisphere. However, given that reading is learned relatively early in development, and is then overlearned as part of the education process, it provides one measure of premorbid abilities in many cases.

Consideration must also be given to factors other than brain damage, which may affect test results. These include motivation, fatigue, pain, depression, anxiety, and litigation. These factors, either singly or in combination, may affect results of testing to varying degrees.

The situation where there is a need for an interpreter is another issue that may impact test results. There are some tests that are available in other languages, for example, Spanish, with appropriate norms for populations of individuals who speak that language. However, the use of an interpreter to administer test questions translated from English into another language should be used judiciously. There is a high likelihood that the test will not render accurate results. The problem is multifactorial; first, the accuracy of the interpretation cannot be determined. Second, the tests often have cultural biases inherent in testing. Third, the norms for the test may not be appropriate for the individual being tested. However, there are situations where it is not possible to find a neuropsychologist who speaks the language of the patient. In these cases, the choice becomes one of either making no attempt to assess the individual or using an interpreter. Some authors have argued there are ethical considerations in testing someone whose language we do not speak (Artiola i Fortuny & Mullaney, 1998); this should be given due consideration before doing so. It is the practice of this author to refer to a neuropsychologist who speaks the language of the patient. If this is not possible, a clinical interview is completed using an interpreter. Tests that have been shown to have limited cultural bias are then administered (Lezak et al., 2004). Even with this caution, the results cannot be considered fully reliable or valid but may provide some useful information regarding function.

There are multiple neurobehavioral variables and diagnostic issues to be considered in the neuropsychological evaluation (Howieson, Loring, & Hannay, 2004). These variables include lesion characteristics, subject variables, and psychosocial variables. For example, there are changes in cognitive abilities related to the aging process. In addition, brain injury has been shown to increase the potential for developing dementia. An individual’s premorbid personality and social adjustment also play a role in outcome. Research has shown that premorbid personality is not so often changed as much as it is exaggerated by brain injury. It is easy to see how the impulsivity, difficulty with anger management, and disinhibition associated with frontal lobe damage are complicated in an individual whose premorbid self-regulation of behavior was poor. Emotional difficulties, such as depression, may also complicate the clinical presentation of an individual with brain injury. It is important that the neuropsychologist identify depression, both premorbid and postmorbid, as it may complicate recovery; in addition, the patient may lack the initiative or cognitive ability to seek help on his own.

It is helpful to have a series of questions for the neuropsychologist to address. Ensuring that they are questions that can be appropriately answered is tantamount to increase the utility of the examination. Receiving a report that documents the potential location of the lesion is not likely to be as helpful in determining life care planning needs as would be a report detailing the functional abilities of the individual with brain injury. One way to obtain the needed information is to ask the neuropsychologist a series of specific questions. For example, Uomoto (2001) states it is easier for a neuropsychologist to answer whether a person can perform a specific task of a specific job than to answer whether they can return to work. One of the most salient issues in answering questions posed has to do with ecological validity of testing. Sbordone (1997) defines ecological validity as the “functional and predictive relationship between the
patient’s performance on a set of neuropsychological tests and behavior in a variety of real-world settings.” Providing the neuropsychologists with information regarding the demands of the environment allows for a better assessment of how the demands interact with the individual’s cognitive strengths and weaknesses, premorbid abilities and skills, and future goals. Without this information, the predictions made based on test data alone have a significant likelihood of being inaccurate. In his article on ecological validity, Sbordone notes the importance of obtaining a detailed history and interviewing collateral sources, the importance of behavioral observations, using appropriate norms, and the relevance of test scores to real-world settings. Sbordone cites the review of Acker in 1990, which examined the question of how neuropsychological tests related to real-world behavior. She found moderate correlations between test results and various functional assessments. She also noted the findings varied according to when during the recovery period the tests were administered. When attempts are made to correlate neuropsychological test results with activities of daily living, the complex tests appear to be better predictors. It seems that the most effective method to increase predictive ability is to ascertain the degree to which test data are consistent with data from other sources (medical records, family observations, academic records, vocational records, and observation of the patient’s behavior in a variety of settings). The degree of agreement between these sources then provides an “operational estimate of our test data” (Sbordone, 1997). If the test data do not fit with the other data, then the ecological validity would be considered low. Neuropsychological test data with a higher level of concordance would be considered to have high ecological validity.

With these considerations, it is possible to obtain ecologically valid predictions from neuropsychological testing. There have been a number of instances where there are questions raised about the value of a neuropsychological examination. In many of those cases, it is likely the neuropsychologist performed a general examination and not one designed to answer specific questions. When a patient is referred by a physician for examination, the examination may not include review of the objective information and supplemental records listed earlier in this chapter. The neuropsychologist is in the role of treating neuropsychologist and will often complete the examination without collateral information other than that provided by a family member who accompanies the patient. It is often the case, particularly early in the recovery process, that the family is overwhelmed by changes that have occurred in their lifestyle. This may lead to faulty information being provided. If the patient lacks insight, his or her view of self has a high probability of being inaccurate. This being the case, records should be provided to the neuropsychologist prior to the testing and reviewed prior to answering the referral questions. Making the questions specific helps the neuropsychologist to answer more helpfully. For example, the individual may be able to sustain attention in an environment with minimal distractions but have difficulty if he is asked to perform in a work cubicle where multiple telephone conversations are taking place simultaneously. Describing the environment to the neuropsychologist is likely to increase his or her ability to make accurate predictions. When asked about the need for supervision, it is often helpful to ask rehabilitation neuropsychologists this question in terms of Functional Independence Measure Scores (FIMS) developed by Smith, Hamilton, and Granger in 1990. For neuropsychologists who are unfamiliar with FIMS, using the descriptions from the scale (e.g., unable to perform an activity or independent in performing an activity) may be useful. It may also be useful to ask about specific tasks that may require supervision such as the administration of medications, ability to be left alone with a young child, ability to manage finances, ability to make financial decisions, or ability to make safety decisions. Another avenue would be to ask questions that would be necessary to answer if the person were being evaluated with regard to civil competence.
In summary, when choosing a neuropsychologist for referral, determine the best person for the referral based on education and expertise in the area of interest. Ask specific questions. Rather than “Can the person return to work?” ask questions about specific tasks and demands in the environment. Also, ask about potential barriers, such as those imposed by fatigue or behavioral issues. When asking about the ability to live independently, focusing on specific areas requiring independence rather than a global question of independence is likely to yield more information.

To avoid receiving a report that does not answer your questions, provide the referral questions before the neuropsychological examination. If not, you may receive a report that describes the person’s strengths and deficits and behavioral deficits, which is not entirely useful for the life care plan recommendations. In many cases, the neuropsychologist may be able to answer your questions after the fact; however, having the questions beforehand may help guide test selection. For example, there are specific tests and techniques employed in evaluations of civil competency; knowing that questions regarding independent living skills will be raised may lead test selection in a different direction.

When should neuropsychological testing be administered for use in a life care plan? Most of the natural recovery following acquired brain injury occurs in the first 6 months after an injury. The degree of recovery is affected by a number of factors including premorbid abilities, age, and family support. It is generally the case that an adult with brain injury is reevaluated every 6 months until the end of 2 years or until the treating neuropsychologist determines the patient’s deficits are unlikely to significantly change. Research tends to support permanence of deficits at the end of 2 years (Lezak et al., 2004). However, there are studies documenting significant cognitive improvement for up to 3 years postinjury when cognitive remediation is provided (Berrol, 1990).

The course of recovery is more complex in children. Children with moderate to severe brain injury have been shown to have cognitive and behavioral deficits that can persist over a span of several years. As the child matures, and additional cognitive skills and behaviors are expected to develop, a secondary impact of the brain injury may become apparent. In these cases, in addition to follow-up for 2 years postinjury, having evaluations completed at academic transition periods is recommended. Specifically, evaluations at the end of third grade, fifth grade, eighth grade, and tenth grade are likely to be helpful in guiding academics. For those individuals for whom postsecondary education is expected, additional neuropsychological examination is recommended after completion of high school. In the situation where a child is in special education, the results of neuropsychological evaluation may help in developing and/or implementing the individualized education program (IEP). The results of testing can also help to determine services needed, beyond those mandated by Individuals with Disabilities Education Act (IDEA) and provided by the school system, to maximize the child’s ability to benefit from education. (For more information on this technical topic, visit www.ed.gov/parents/needs/speced/iepguide/iepguide.pdf.)

Once the patient’s deficits have reached a level where additional change is not anticipated, an additional neuropsychological examination is included as the patient ages. There are changes in cognition that occur as a function of normal aging. In addition to these “normal” changes, those individuals who have experienced a brain injury are at higher risk for developing dementia; the relationship appears to be more pronounced in males (Fleminger, Olier, Lovestone, Rabe-Hesketh, & Giora, 2003).

Psychotherapy, either with a neuropsychologist or other mental health professional with training and experience in acquired brain injury, is likely to be required. In adults, this is likely to be needed periodically through their life expectancy, especially during periods of stress or
when they are confronted with situations that are changed by the impact of their injury and subsequent deficits. An example would be a parent who loses custody of a child because of a brain injury.

The disruptive effect of acquired brain injury has been well documented in the literature (Kreutzer, Marwitz, & Kepler, 1992). Family members and other caregivers, particularly in the cases where there are negative behavioral changes, will require education, support, and therapy to cope. Rosenthal and Geckler (1997) note that the primary focus, until more recently, was on the physical aspects of the injury. The issues of psychosocial and family adjustment issues have since been recognized with regard to the effect on progress in rehabilitation and overall recovery. Family support and preinjury family environment have been shown to have significant effects on outcome in children following traumatic brain injury (Yeates et al., 1997; Max et al., 1999). Anecdotally, it is the experience of this author that families may have a prolonged period of grief related to the changes that accrue following a brain injury. This may result in their attributing deficits in executive function exhibited by the individual who has residual symptoms of brain damage to volitional behavior. Conversely, feelings of guilt, or empathy, may lead them to reinforce negative behaviors to avoid confrontation. There are a myriad of other family and social difficulties where psychological intervention may help improve the quality of life for the patient and family or caregivers.

In the case where the person with the injury is a child, parents benefit from therapy to help with parenting skills as well as help in adjusting to changes in the child’s current behavior and future goals and aspirations. Additional psychotherapy sessions may be needed during puberty and through the teenage years when sexual issues need to be addressed and if no injury or illness had occurred, the child would have been expected to have become increasingly independent.

References


Chapter 7

The Role of the Occupational Therapist in Life Care Planning

Nancy L. Mitchell

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Introduction

Occupational therapists can provide a unique and critical role in the formation of the life care plan. Many of the pages of a life care plan fall under the domain of occupational therapy (OT). The ability to perform daily tasks of self-care, play, school, work, or social participation is the very core of the practice of OT as well as the basis for some of the contents of a life care plan.

The objective of OT is the essence of the purpose of a life care plan. “Occupational therapy helps people live life to its fullest. It does this by helping people of all ages who have suffered an illness, injury or some form of debilitation relearn the skills of daily living. By focusing on the physical, psychological and social needs of its patients, OT helps people function at the highest possible level, concentrating on what’s important to them to rebuild their health, independence and self-esteem” (American Occupational Therapy Association [AOTA], 2008).

Indeed, the AOTA has brought forward a brand to market what OT has to offer consumers. This brand is “Living Life to Its Fullest” (OT Practice, 2008). President of AOTA, Penelope Moyers Cleveland, said, “The key take away we want everyone to have is that living life and occupational therapy are inextricably linked” (p. 7).

Several philosophical assumptions are presented to guide OTs in their profession. The assumptions that parallel those of the life care planner are (Atchinson & Dirette, 2007, p. 3):

- “Each individual has a right to a meaningful existence: the right to live in surroundings that are safe, supportive, comfortable, and over which he or she has some control; to make decisions for himself or herself; to be productive; to experience pleasure and joy; to love and be loved.”
- “Each individual has the right to reach his or her potential through purposeful interaction with the human and nonhuman environment.”
- “The extent to which intervention is focused on the context, the areas of occupational performance or on the client depends on the needs of the particular individual at any given time.”

The Occupational Therapy Practice Framework (2002) reports, “Occupational therapy’s domain stems from the profession’s interest in human being’s ability to engage in everyday life activities.” The broad term that OTs and assistants use to capture the breadth and meaning of “everyday life activities is occupation” (p. 610). The Framework goes on to identify the OT assessment process: “The initial step in the evaluation process provides an understanding of the client’s occupational history and experiences, patterns of daily living, interests, values, and needs, the client’s problems and concerns about performing occupation and daily life activities are identified and the client’s priorities are determined” (p. 614). This is in harmony with the approach of the life care planner in determining numerous contents of a life care plan.

Occupational Therapy Assessment Tools: An Annotated Index (2007) reviews almost 400 instruments used for evaluation by OTs. Evaluation tools reflect the broad scope of OT. The contents of the Index lists assessment tools in the following areas: occupational performance; activities of
The Role of the Occupational Therapist in Life Care Planning

daily living and instrumental activities of daily living; vocation; play; leisure; social participation and quality of life; developmental skills; motor skills; perception; sensory; assessments of social interaction; cognitive assessments; psychological assessments; roles, habits, and routines; coping and adaptive behaviors; assessments of disability status; and assessments of home and work environments (pp. iii–xvi). Clearly, it is beyond the scope of this chapter to review all of these assessment tools. Use of a particular instrument is likely to vary by region of the country and OT subspecialty, and it is unlikely any OT will have expertise in administration and knowledge of interpretation of all of these measures. Some of the more frequently used evaluation tools are provided here:


  Purpose: This individualized clinical outcome measure was designed to detect change in a client’s self-perception of occupational performance over time. The COPM fosters collaboration between the client and the OT to design intervention (Occupational Therapy Assessment Tools: An Annotated Index, 2007, p. 33).

- FIM System and WeeFIM System II (includes 0-to-3 module) (revised from the Functional Independence Measure and Functional Independence Measure for Children) (FIM developed in 1984, version 5.1 in 1997; WeeFIM developed in 1987, version 6.0 in 2006)

  Purpose: The Uniform Data System for Medical Rehabilitation (UDSMR) is a nonprofit organization that promotes uniform documentation of the severity of patient disability and the results of medical rehabilitation. At the core of the UDSMR is the Uniform Data Set, which includes FIM and WeeFIM for assessing severity of disability. They are used as measures of functional status and reflect the impact of disability on the individual and on the human and economic resources of the community. FIM and WeeFIM are designed for clinical evaluation of the individual and to generate group data and analyze the outcomes of rehabilitation in terms of burden of care. The WeeFIM II 0-to-3 Module measures precursors to function in children 0 to 3 years of age as well as changes over time (Occupational Therapy Assessment Tools: An Annotated Index, 2007, p. 80).


  Purpose: This tool is designed to provide a quick and simple evaluation of a person’s ability to perform basic living skills. Although not comprehensive, it can help determine degree of client’s independence and suggest appropriate living situations that will maximize independence (Occupational Therapy Assessment Tools: An Annotated Index, 2007, p. 102).


  Purpose: This WorkWell instrument is designed to identify maximum safe work abilities and any limitations that prevent safe return to work and to provide recommendations to assist safe return to work (Occupational Therapy Assessment Tools: An Annotated Index, 2007, p. 174).

- Bayley Scales of Infant and Toddler Development, 3rd edition (Bayley III; including the Bayley-III Motor Scale and Bayley-III Screening Test) (2005)
Purpose: The comprehensive scales are designed to identify children who have delays in multiple developmental areas, provide baseline information for planning interventions, and follow progress (Occupational Therapy Assessment Tools: An Annotated Index, 2007, p. 244).


Purpose: This motor development program provides in-depth assessment as well as training and remediation of gross and fine motor skills. It can be used for research and to measure a person's motor competence relative to peers, qualitative and quantitative aspects of skills, skill deficits, and progress over time (Occupational Therapy Assessment Tools: An Annotated Index, 2007, p. 329).

- **The Nine-Hole Peg Test (1985)**

Purpose: This tool is used to measure unilateral finger dexterity to determine the extent of fine motor impairment in people experiencing difficulties with functional performance (Occupational Therapy Assessment Tools: An Annotated Index, 2007, p. 324).


Purpose: The MVPT-3 was designed to provide a quick and simple evaluation of visual perception that avoids motor involvement by the subject. It may be used in screening, diagnosis, and research. The third edition was revised to expand the test population to adolescents and adults. The MVPT-V allows evaluation in subjects with spatial deficits due to hemifield visual neglect (HVN) or abnormal visual saccades (Occupational Therapy Assessment Tools: An Annotated Index, 2007, p. 385).

- **Test of Visual-Motor Integration (TVMI) (1996)**

Purpose: The TVMI was designed to be an objective, valid test of visual–motor integration skills, examining how a child interprets, organizes, and replicates physical elements of a stimulus. It can be used for screening, evaluation, research, and diagnostic purposes (Occupational Therapy Assessment Tools: An Annotated Index, 2007, p. 408).

- **Sensory Profile (SP): Adolescent/Adult SP, Infant/Toddler SP (1999; 2006 School Companion)**

Purpose: The SP is designed to measure responses to sensory events in everyday life that support or interfere with function. Children’s versions allow caregiver’s observations to be used in conjunction with other evaluations, reports, and observations from critical members of the team. The version for adolescents and adults allows the subject to identify personal behavioral responses to everyday sensory experiences and patterns and strategies that promote daily function in the environment. The School Companion incorporates the teacher’s perspective on the child’s interaction in an academic environment (Occupational Therapy Assessment Tools: An Annotated Index, 2007, p. 442).

- **Allen Cognitive Level Test (ACL-90) (1990)**

Purpose: The ACL-90 is a brief screening test to estimate the client’s cognitive functioning and capacity to learn and to guide treatment goal setting. Cognitive function categories are based on
Pediatric Evaluation of Disability Inventory (PEDI) (1992)

**Purpose:** The PEDI is a comprehensive clinical assessment of functional capabilities and typical performance in young children with disabilities. It is used to detect functional deficits, monitor progress, or evaluate the outcome of a therapeutic program. PEDI includes a Modifications scale and Caregiver Assistance scale to determine the level of adaptation and assistance required for performance (Occupational Therapy Assessment Tools: An Annotated Index, 2007, p. 698).

### Activities of Daily Living

The performance of activities of daily living (ADL) has long been the cornerstone and domain of the OT. While typical self-care skills of dressing, eating, and bathing are often associated with the profession, the scope of ADL is significantly greater. The Occupational Therapy Practice Framework: Domain and Process (2002) provides the detail (p. 620):

- **Bathing, Showering:** Obtaining and using supplies; soaping, rinsing, and drying body parts; maintaining bathing position; and transferring to and from bathing positions (Uniform Data System for Medical Rehabilitation [UDSMR], 1996, pp. III–20, III–24).
- **Dressing:** Selecting clothing and accessories appropriate to time of day, weather, and occasion; obtaining clothing from storage area; dressing and undressing in a sequential fashion; fastening and adjusting clothing and shoes; and applying and removing personal devices, prostheses, or orthoses.
- **Eating:** “The ability to keep and manipulate food/fluid in the mouth and swallow it” (O’Sullivan, 1995, p. 191, as cited in AOTA, 2000, p. 629).
- **Feeding:** “The process of [setting up, arranging, and] bringing food [fluids] from the plate or cup to the mouth” (O’Sullivan, 1995, p. 191, as cited in AOTA, 2000, p. 629).
- **Functional Mobility:** Moving from one position or place to another (during performance of everyday activities), such as in-bed mobility, wheelchair mobility, and transfers (e.g., to and from a wheelchair, bed, car, tub, toilet, tub/shower, chair, or floor). Performing functional ambulation and transporting objects.
- **Personal Device Care:** Using, cleaning, and maintaining personal care items, such as hearing aids, contact lenses, glasses, orthotics, prosthetics, adaptive equipment, and contraceptive and sexual devices (also see Sexual Activity below).
- **Personal Hygiene and Grooming:** Obtaining and using supplies; removing body hair (use of razors, tweezers, lotions, etc.); applying and removing cosmetics; washing, drying, combing, styling, brushing, and trimming hair; caring for nails (hands and feet); caring for skin, ears, eyes, and nose; applying deodorant; cleaning mouth; brushing and flossing teeth; or removing, cleaning, and reinserting dental orthotics and prosthetics.
- **Sexual Activity:** Engagement in activities that result in sexual satisfaction.
- **Sleep/Rest:** A period of inactivity in which one may or may not suspend consciousness.
- **Toilet Hygiene:** Obtaining and using supplies; clothing management; maintaining toileting position; transferring to and from toileting position; cleaning body; and caring
for menstrual and continence needs (including catheters, colostomies, and suppository management).

Following is one example of an Activities of Daily Checklist used by life care planners that can be completed during the life care plan evaluation and addresses many of the ADLs listed previously.

### Activities of Daily Living

<table>
<thead>
<tr>
<th>NAME:________________</th>
<th>DISABILITY:________________</th>
<th>DATE: ________________</th>
</tr>
</thead>
</table>

CODES: 1 = Can do without difficulty. 2 = Can do with some difficulty. 3 = Can do with great difficulty and/or needs assistance from attendant. 4 = Dependent on someone else to do.

#### Feeding

<table>
<thead>
<tr>
<th>Code</th>
<th>Comments or amount of time required</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fix meal</td>
<td></td>
</tr>
<tr>
<td>Open cans/jars/tubes/boxes</td>
<td></td>
</tr>
<tr>
<td>Open containers/packages/empty contents</td>
<td></td>
</tr>
<tr>
<td>Use manual or electric can opener (note if there is a difference)</td>
<td></td>
</tr>
<tr>
<td>Use microwave</td>
<td></td>
</tr>
<tr>
<td>Use stove/oven (turn on/use)</td>
<td></td>
</tr>
<tr>
<td>Refrigerator/cupboard accessible</td>
<td></td>
</tr>
<tr>
<td>Open refrigerator</td>
<td></td>
</tr>
<tr>
<td>Open drawers</td>
<td></td>
</tr>
<tr>
<td>Transport items short distance</td>
<td></td>
</tr>
<tr>
<td>Use fork/spoon/knife (note if adapted utensils are used)</td>
<td></td>
</tr>
<tr>
<td>Cut with knife</td>
<td></td>
</tr>
<tr>
<td>Butter bread</td>
<td></td>
</tr>
<tr>
<td>Eat soup with spoon</td>
<td></td>
</tr>
<tr>
<td>Make sandwich/light meal</td>
<td></td>
</tr>
<tr>
<td>Reaching meal area</td>
<td></td>
</tr>
<tr>
<td>Eat meal</td>
<td></td>
</tr>
<tr>
<td>Get drink</td>
<td></td>
</tr>
<tr>
<td>Drink from cup/glass with/without adaption</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
</tbody>
</table>

#### Hygiene

<table>
<thead>
<tr>
<th>Code</th>
<th>Comments or amount of time required</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reach sink area</td>
<td></td>
</tr>
<tr>
<td>Activity</td>
<td>Notes</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>--------------------------------------------</td>
</tr>
<tr>
<td>Reach/turn faucets</td>
<td></td>
</tr>
<tr>
<td>Brush teeth</td>
<td></td>
</tr>
<tr>
<td>Wash and dry self (note if there is a difference with hands/face/entire body)</td>
<td></td>
</tr>
<tr>
<td>Use shower (note if roll-in is required)</td>
<td></td>
</tr>
<tr>
<td>Use tub</td>
<td></td>
</tr>
<tr>
<td>Bed bath</td>
<td></td>
</tr>
<tr>
<td>Apply deodorant</td>
<td></td>
</tr>
<tr>
<td>Comb/brush hair</td>
<td></td>
</tr>
<tr>
<td>Shaving</td>
<td></td>
</tr>
<tr>
<td>Makeup</td>
<td></td>
</tr>
<tr>
<td>Shampoo and dry hair</td>
<td></td>
</tr>
<tr>
<td>Nail cutting/cleaning</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
<tr>
<td><strong>BOWEL/BLADDER</strong></td>
<td></td>
</tr>
<tr>
<td>Sitting balance without assistance</td>
<td></td>
</tr>
<tr>
<td>Use catheter</td>
<td></td>
</tr>
<tr>
<td>Irrigate catheter/prepare equipment</td>
<td></td>
</tr>
<tr>
<td>Change catheter/prepare equipment</td>
<td></td>
</tr>
<tr>
<td>Handle urinal</td>
<td></td>
</tr>
<tr>
<td>Empty leg bag</td>
<td></td>
</tr>
<tr>
<td>Leg bag on/off</td>
<td></td>
</tr>
<tr>
<td>Tubing connections on/off</td>
<td></td>
</tr>
<tr>
<td>Bowel care (note if dil, suppository)</td>
<td></td>
</tr>
<tr>
<td>Cleanse self after toileting</td>
<td></td>
</tr>
<tr>
<td>Flush toilet/empty commode</td>
<td></td>
</tr>
<tr>
<td>Manage clothing before/after toileting</td>
<td></td>
</tr>
<tr>
<td>Transfer to/from toilet/commode</td>
<td></td>
</tr>
<tr>
<td><strong>BED ACTIVITIES</strong></td>
<td></td>
</tr>
<tr>
<td>Transfer to/from bed</td>
<td></td>
</tr>
<tr>
<td>Sit up</td>
<td></td>
</tr>
<tr>
<td>Check skin</td>
<td></td>
</tr>
<tr>
<td>Operate bed controls</td>
<td></td>
</tr>
<tr>
<td>Sit at side of bed</td>
<td></td>
</tr>
<tr>
<td>Roll side to side</td>
<td></td>
</tr>
</tbody>
</table>

*(Continued)*
(Continued)

<table>
<thead>
<tr>
<th>DRESSING</th>
</tr>
</thead>
<tbody>
<tr>
<td>Select appropriate clothes and match colors</td>
</tr>
<tr>
<td>Button garment with/without adaptive aid</td>
</tr>
<tr>
<td>Fastenings (slippers, snap, belt)</td>
</tr>
<tr>
<td>Shirt on/off</td>
</tr>
<tr>
<td>Slacks/underpant/skirt on/off</td>
</tr>
<tr>
<td>Corset or binder on/off</td>
</tr>
<tr>
<td>Socks on/off</td>
</tr>
<tr>
<td>Shoes on/off</td>
</tr>
<tr>
<td>Tie shoelaces</td>
</tr>
<tr>
<td>Coat/sweater on/off</td>
</tr>
<tr>
<td>Elastic or TED hose on/off</td>
</tr>
<tr>
<td>Clothes in/out drawers/closet</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>COMMUNICATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Write</td>
</tr>
<tr>
<td>Speak with normal voice</td>
</tr>
<tr>
<td>Summon emergency assistance</td>
</tr>
<tr>
<td>Use telephone, dial/push-button/cordless</td>
</tr>
<tr>
<td>Use word processor/typewriter</td>
</tr>
<tr>
<td>Use augmentative communications</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ENVIRONMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use ECU (note brand/options)</td>
</tr>
<tr>
<td>Effectively control temperature</td>
</tr>
<tr>
<td>Open/close door</td>
</tr>
<tr>
<td>Use keys</td>
</tr>
<tr>
<td>Light on/off</td>
</tr>
<tr>
<td>Use TV/radio/stereo</td>
</tr>
<tr>
<td>Set and/or read clock/watch</td>
</tr>
<tr>
<td>Manipulate newspaper/book</td>
</tr>
<tr>
<td>Use scissors</td>
</tr>
<tr>
<td>Plug in cord</td>
</tr>
<tr>
<td>Pick up things off floor</td>
</tr>
<tr>
<td>Adaptive aids</td>
</tr>
<tr>
<td>Open/read mail</td>
</tr>
</tbody>
</table>
### MOBILITY

<table>
<thead>
<tr>
<th>Activity</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maneuver power/manual wheelchair</td>
<td>(note if Quad pegs/one hand/joystick/sip &amp; puff, etc.)</td>
</tr>
<tr>
<td>Transfer from chair to vehicle</td>
<td></td>
</tr>
<tr>
<td>Wheelchair manipulation</td>
<td></td>
</tr>
<tr>
<td>Utilize and adjust armrests</td>
<td></td>
</tr>
<tr>
<td>Manage leg rests</td>
<td></td>
</tr>
<tr>
<td>Brakes on/off</td>
<td></td>
</tr>
<tr>
<td>Safety belt on/off</td>
<td></td>
</tr>
<tr>
<td>Remove items from wheelchair</td>
<td></td>
</tr>
<tr>
<td>Use lap board/bag/caddy/ashtray</td>
<td></td>
</tr>
<tr>
<td>Utilize cushion</td>
<td></td>
</tr>
<tr>
<td>Do chair maintenance</td>
<td></td>
</tr>
<tr>
<td>Body handling in chair</td>
<td></td>
</tr>
<tr>
<td>Weight shift</td>
<td></td>
</tr>
<tr>
<td>Floor to chair</td>
<td></td>
</tr>
<tr>
<td>Hook arm/reach forward</td>
<td></td>
</tr>
<tr>
<td>Reposition in chair with/without assistance</td>
<td></td>
</tr>
<tr>
<td>Cross/uncross legs</td>
<td></td>
</tr>
<tr>
<td>Negotiate ramps/curbs</td>
<td></td>
</tr>
<tr>
<td>Negotiate rough/smooth terrain</td>
<td></td>
</tr>
<tr>
<td>Chair in/out of car/van</td>
<td></td>
</tr>
<tr>
<td>Drive</td>
<td></td>
</tr>
<tr>
<td>If drive, any adaptations</td>
<td></td>
</tr>
<tr>
<td>Use public transportation</td>
<td></td>
</tr>
</tbody>
</table>

### ORTHOTICS/PROSTHESIS

<table>
<thead>
<tr>
<th>Component</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>Upper extremities orthotics/braces</td>
<td>off/on</td>
</tr>
<tr>
<td>Upper extremities prosthetics</td>
<td>off/on</td>
</tr>
<tr>
<td>Lower extremity prosthetics</td>
<td>on/off</td>
</tr>
<tr>
<td>Lower extremity orthotics/braces</td>
<td>on/off/adjust</td>
</tr>
<tr>
<td>AFOs or KAFO</td>
<td>on/off/adjust</td>
</tr>
<tr>
<td>Splint/sling</td>
<td>off/on</td>
</tr>
</tbody>
</table>

### PERSONNEL/ATTENDANT CARE NEEDS

<table>
<thead>
<tr>
<th>Requirement</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>X if required</td>
<td>Comments</td>
</tr>
<tr>
<td>Independent</td>
<td>(no need)</td>
</tr>
<tr>
<td>Needs</td>
<td>companion for judgment (due to TBI)</td>
</tr>
</tbody>
</table>

(Continued)
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<table>
<thead>
<tr>
<th>Needs guardian (incl. money management)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Occasional (e.g., morning/eve/weekends)</td>
</tr>
<tr>
<td>Live-in attendant (10–12 hours per day and night safety)</td>
</tr>
<tr>
<td>24-hour attendant awake</td>
</tr>
<tr>
<td>24-hour skilled/high-tech awake</td>
</tr>
<tr>
<td>Housecleaning/meals/laundry</td>
</tr>
<tr>
<td>House maintenance interior/exterior</td>
</tr>
<tr>
<td>Errands/doctor appointment</td>
</tr>
<tr>
<td>Other</td>
</tr>
</tbody>
</table>

Source: Roger O. Weed.

Instrumental Activities of Daily Living

Hinojosa and Blout (2004) describe instrumental activities of daily living (IADL) as “complex multi-step activities requiring the integration of higher level cognitive skills (e.g., meal preparation, money management, community travel)” (p. 447). The authors report that these skills are needed to “participate in complex social relationships and societal organizations” (p. 447). The Occupational Therapy Practice Framework: Domain and Process (2002) provides the detail of what is included in IADL (p. 620):

- **Care of others (including selecting and supervising caregivers):** Arranging, supervising, or providing the care for others.
- **Care of pets:** Arranging, supervising, or providing the care for pets and service animals.
- **Child rearing:** Providing the care and supervision to support the developmental needs of a child.
- **Communication device use:** Using equipment or systems such as writing equipment, telephones, typewriters, computers, communication boards, call lights, emergency systems, Braille writers, telecommunication devices for people with deafness, and augmentative communication systems to send and receive information.
- **Community mobility:** Moving self in the community and using public or private transportation, such as driving, or accessing buses, taxi cabs, or other public transportation systems.
- **Financial management:** Using fiscal resources, including alternate methods of financial transaction and planning and using finances with long-term and short-term goals.
- **Health management and maintenance:** Developing, managing, and maintaining routines for health and wellness promotion, such as physical fitness, nutrition, decreasing health risk behaviors, and maintaining medication routines.
- **Home establishment and management:** Obtaining and maintaining personal and household possessions and environment (e.g., home, yard, garden, appliances, vehicles), including maintaining and repairing personal possessions (clothing and household items) and knowing how to seek help or whom to contact.
- **Meal preparation and cleanup:** Planning, preparing, and serving well-balanced, nutritional meals, and cleaning up food and utensils after meals.
Safety procedures and emergency responses: Knowing and performing preventive procedures to maintain a safe environment as well as recognizing sudden, unexpected hazardous situations and initiating emergency action to reduce the threat to health and safety.

Shopping: Preparing shopping lists (grocery and other), selecting and purchasing items, selecting method of payment, and completing money transactions.

The life care planner must be knowledgeable about the performance of IADL of the life care plan recipient. This information is typically not fully included in the medical records and can change over time. The author uses the following checklist of IADL in the process of evaluation for a life care plan.

<table>
<thead>
<tr>
<th>IADL ASSESSMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name: ___________________________ Date: ____________</td>
</tr>
</tbody>
</table>

Indicate percent of time task was performed by person being assessed pre/post disability/illness.

<table>
<thead>
<tr>
<th>Task</th>
<th>Pre</th>
<th>Post</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>LAWN</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mowing</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Watering</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fertilizing</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Aerating</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Seeding</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trimming</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Edging</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bush/tree trimming</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weeding</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Composting</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Raking leaves</td>
<td></td>
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<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Task</th>
<th>Pre</th>
<th>Post</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>GARDEN</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Planting</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hoeing</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weeding</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Watering</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fencing</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Harvesting</td>
<td></td>
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<table>
<thead>
<tr>
<th>Task</th>
<th>Pre</th>
<th>Post</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shovel</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Plowing</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sand/salt application</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Plow maintenance</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Task</th>
<th>Pre</th>
<th>Post</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Storms/Screens</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clean gutters</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wash exterior windows</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stain deck</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exterior painting</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Seal driveway</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A/C maintenance</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Getting mail</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clean deck furniture</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clean garage</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Put in dock</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bird feeding</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pool maintenance</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Boats/snowmobiles</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Landscaping</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exterior holiday decorations</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Take out trash</td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Task</th>
<th>Pre</th>
<th>Post</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Painting/painting prep</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wallpaper/prep</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Plaster/dry wall repairs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Plumbing repairs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Electrical repairs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carpentry</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Ceiling lightbulbs
Water softener
Furnace filter
Smoke alarm testing/batteries

### AUTO MAINTENANCE

<table>
<thead>
<tr>
<th>Task</th>
<th>Pre</th>
<th>Post</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change oil</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rotate tires</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fill fluids</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pump gas</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other car repairs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Change flat tire</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wash car interior</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wash car exterior</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### DRIVING/TRANSPORTATION

<table>
<thead>
<tr>
<th>Task</th>
<th>Pre</th>
<th>Post</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Short distance</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Long distance</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Manual trans.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Public transportation</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### WOOD

<table>
<thead>
<tr>
<th>Task</th>
<th>Pre</th>
<th>Post</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chop</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Split</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stack</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Haul</td>
<td></td>
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</tbody>
</table>

### HOUSEHOLD CHORES

<table>
<thead>
<tr>
<th>Task</th>
<th>Pre</th>
<th>Post</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vacuum</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carpet cleaning</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clean interior windows</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clean floors</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Toilet/tub/sink</td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

(Continued)
### Life Care Planning and Case Management Handbook

(Continued)

<table>
<thead>
<tr>
<th>Task</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clean oven</td>
</tr>
<tr>
<td>Clean refrigerator</td>
</tr>
<tr>
<td>Dusting</td>
</tr>
<tr>
<td>Dishes</td>
</tr>
<tr>
<td>Laundry</td>
</tr>
<tr>
<td>Laundry/fold</td>
</tr>
<tr>
<td>Laundry/put away</td>
</tr>
<tr>
<td>Make bed</td>
</tr>
<tr>
<td>Change sheets</td>
</tr>
<tr>
<td>Flip mattress</td>
</tr>
<tr>
<td>Cooking</td>
</tr>
<tr>
<td>Meal planning</td>
</tr>
<tr>
<td>Baking</td>
</tr>
<tr>
<td>Sewing</td>
</tr>
<tr>
<td>Clothing repair</td>
</tr>
<tr>
<td>Make appointments</td>
</tr>
<tr>
<td>Tax prep</td>
</tr>
<tr>
<td>Pay bills</td>
</tr>
<tr>
<td>Balance checkbook</td>
</tr>
<tr>
<td>Buy gifts</td>
</tr>
<tr>
<td>Wrap gifts</td>
</tr>
<tr>
<td>Indoor holiday decorations</td>
</tr>
<tr>
<td>Send cards/correspondence</td>
</tr>
<tr>
<td>Feed pets</td>
</tr>
<tr>
<td>Pet baths</td>
</tr>
<tr>
<td>Pet walking</td>
</tr>
<tr>
<td>Pet clean-up</td>
</tr>
<tr>
<td>Grocery shopping</td>
</tr>
<tr>
<td>Put groceries away</td>
</tr>
<tr>
<td>Errand running</td>
</tr>
<tr>
<td>Phone calling</td>
</tr>
<tr>
<td>Computer use</td>
</tr>
</tbody>
</table>
The Role of the Occupational Therapist in Life Care Planning

Childcare/Parenting/Grandparenting

Fitness

Hobbies

Relationship

Sexuality

Holidays

Entertaining

Friendships

Sleep

Worship

Source: Distributed by Nancy Mitchell, Mitchell Disability Assessments and Life Care Planning, Apple Valley, MN. Reprinted with permission.
OT Educational Requirements and Specialization

The educational requirements for the OT have expanded over time. Previously, a registered occupational therapist (OTR) needed a bachelor's degree to enter practice, and working therapists with that level of education continue to practice. However, the current requirement of a beginning OT is a master's degree. There has been a more recent movement for OT to obtain a DOT (doctor of occupational therapy) as an entry level of practice. This is a clinical doctorate with an emphasis on enhanced clinical practice. Some experienced therapists are expanding their credentials with this additional education. Certified occupational therapy assistants (COTAs) typically have an associate's degree. OT practitioners are licensed by their individual states.

The OT that treats the person for whom the life care plan is being written is certainly the best first contact for obtaining OT recommendations for the plan. If that therapist is unwilling or unable to make the needed projections, additional OT evaluations may be needed. For example, an individual with a spinal cord injury may have had excellent OT interventions during his or her acute rehabilitation but the treating therapist may not have the expertise to provide input into the life care plan about needed driving adaptations. An additional evaluation from an OT specializing in this area may be needed.

Like many other medical professions, OTs tend to specialize in areas of practice. These include pediatrics, geriatrics, hand therapy, cardiac rehabilitation, physical disabilities, mental health, ergonomics, and health and wellness programming. While more OTs are becoming life care planners, the forensic arena is fairly new for the field. In general, OTs are not trained in litigation and may be reluctant to provide opinions that will be used in a legal setting. An inquiry to the state OT association may be a helpful first step.

In addition, while OTs pride themselves in addressing the needs of the whole person, their consideration of therapy and equipment needs tends to address the short term rather than the lifelong projections that are needed for a life care plan. As a part of therapist training, long-term goals that are a part of the typical therapy plan address needs in a given episode of care, which may mean areas of focus in the weeks or months ahead rather than over a client's entire lifetime. A pediatric therapist treating a child with cerebral palsy, for example, could be encouraged to project therapy and equipment needs throughout childhood and adolescence, but lack the experience or expertise to know what this child will need in his or her adult years. That being said, there are numerous components of the life care plan within the direct expertise of the OT.

Contents of the Life Care Plan and the Role of the OT

OTs are unique in the roles they offer as the health care professional on the team with the knowledge and treatment of allowing people as much independence as possible in their daily lives. Their opinions can include that a person will need the assistance of a caregiver to complete daily activities or for safety and supervision in the home/school/work setting, or the use of equipment for safety or energy conservation. The next section describes many of the sections of a life care plan that could be enhanced with the input of an OT.

In general, costs of an OT evaluation can vary greatly. Medical Fees in the United States (PMIC, 2008) reports that the charge for an OT evaluation is $124 (50th percent) to $190 (90th percent), without geographic modifiers. However, in this author's experience it is not unusual for an OT evaluation at a facility-based practice to be in excess of $400. OTs have direct access in many states to evaluate a person without a doctor's prescription. However, health care facilities require a doctor's order for an OT evaluation as this is needed for payment by insurance providers.
**Projected Evaluations**

The OT should be comfortable providing recommendations for ongoing OT evaluations. However, the therapist may be unwilling or unable to project lifelong needs as this is outside of the typical frame of reference for a given therapy episode of care. In this case, the life care planner can defer to the opinions of the physiatrist who will likely be more comfortable providing projections for lifelong needs. It is typical for the author to include an annual OT evaluation for people with lifelong disabilities such as spinal cord injury, cerebral palsy, or upper extremity amputation.

Of special note for pediatric clients is the Individuals with Disabilities Education Act (IDEA), reenacted in 2004. The IDEA is a federal law ensuring services to children with disabilities who attend public schools throughout the nation. The IDEA governs how states and public agencies provide early intervention, special education, and related services to more than 6.5 million eligible infants, toddlers, children, and youth with disabilities (retrieved June 28, 2008, from http://idea.ed.gov). As part of the law, the IDEA is mandated to provide OT and other therapeutic services that are educationally related to children ages 3 to 21 who attend a public school. The implication for the life care planner developing a life care plan for a child covered under the IDEA is that, for example, a child with a brain injury may have OT evaluation and treatment services written into her individualized education program (IEP) as it relates to their education needs and as provided for by the school system; however, it is important for the life care planner to consider the child’s needs outside the school setting as well. In the author’s opinion, it would be unusual for a child who qualifies for school OT not to need additional OT services external to the school setting.

**Projected Therapeutic Modalities**

The OT should be comfortable providing recommendations for ongoing OT treatment. However, similar to the previous discussion, the therapist may be unwilling or unable to project lifelong needs as this is outside of the typical frame of reference for a given therapy episode of care. Again, input from the treating physician is likely to be invaluable.

**Aides for Independent Function/ADL**

The OT is an expert in daily living activities. The OT should be very helpful in providing specific suggestions of equipment needed to enhance the client’s independence and/or to facilitate the caregiver’s task of providing care for the client. This will allow a life care planner to include specific items in the life care plan that will be of benefit to the client. In this author’s opinion, rather than providing a general allowance for these items, a method often seen in life care plans that probably have not utilized the services of an OT, specific pieces of equipment and replacement schedules, in most instances, can be recommended. This enhances the credibility of the life care plan. However, it is recognized that itemizing numerous low-cost items, such as each adapted eating utensil, plate, and cup, can be unnecessarily detailed. The OT could also be helpful in projecting equipment that, while perhaps not needed currently, will address aging-related factors and enhance abilities as a person ages.

**Wheelchair and Wheelchair Maintenance**

Many OTs perform wheelchair and seating evaluations as a part of their practice. The OT’s input into current and future needs for wheelchairs are likely to be very helpful to the life care planner. The OT who performs these evaluations will be able to make projections about the changing need
for wheelchairs over time such as a child’s ability to benefit from powered mobility or a person’s future need to move to a power-assisted wheelchair.

**Wheelchair Accessories**

The OT is often involved in choosing appropriate cushions, wheelchair backs, carrying bags, cup holders, and other accessories. Their input into this portion of the life care plan could be invaluable.

**Durable Medical Equipment**

The qualified OT is an expert on bath, toileting, and transferring equipment. They may also have significant knowledge of bed, transportation, and ambulation aides.

**Orthotics and Prosthetics**

OTs commonly make splints for the arms, wrists, and hands. They have knowledge about the type of splint that is needed and the frequency of replacement. Many OTs also work with upper extremity amputees in their clinical practice. Prosthetists, however, are likely to have a greater depth of knowledge about prosthetic options, costs, and replacement frequencies.

**Orthopedic Equipment**

OTs will vary in their expertise in this area. Most should have a working knowledge of crutches, canes, walkers, standers, gait trainers, and positioning equipment. Physical therapists are more likely the experts with regard to this equipment.

**Architectural Modifications**

OTs have basic education in accessibility needs for people with disabilities. Some have additional training and may be experts on ergonomics and home modifications. It may be very helpful to obtain an evaluation of a home access specialist to provide the detail needed to get more exact costs and recommendations. This would need to be discussed with the retaining attorney as there will be a cost for this evaluation. Few OTs have this credential (see chapter on home assessment).

**Supplies**

Supplies in the life care plan that relate to adaptive clothing and adaptive feeding generally fall under the expertise of the OT. See also the previous discussion on ADLs.

**Home and Facility Care**

An OT evaluation may be a critical determination of the amount of care and supervision that is needed for a given individual. OTs are trained to evaluate safety and the ability to perform ADLs and IADLs. An OT can also determine when it is important to provide assistance because of limitations due to pain or impaired endurance as well as age-related factors.
**Computer**

Many OTs are experts in computer use and adaptations that are needed to access the computer.

**Health and Strength Maintenance**

OTs often evaluate and suggest home exercise programs and equipment needed to maintain strength and endurance. They can also be a resource to identify camps or special recreation programs or activities for individuals with specific disabilities.

**Transportation**

Some OTs have a Driver Rehabilitation Specialist certification and perform driving evaluations and adapted drivers’ training as part of their clinical practice (see www.driver-ed.org). They can provide invaluable input into the need for driving evaluations and adaptations, costs, and replacement schedules for this equipment.

**Complications**

OTs may be helpful in determining how a given complication may affect functional abilities and the need for equipment in the future. OTs also have knowledge of the risk of overuse injuries for people with disabilities.

**Vocational/Worksite Modifications**

Some OTs specialize in ergonomics and worksite accommodations. They can provide valuable input about injury and overuse prevention and offer suggestions for equipment to enhance success in the workplace.

**The OT as Consultant to the Life Care Planner**

As seen in the preceding section, many of the core components of a life care plan fall under the professional domain of the OT. An evaluation from an OT may be key in making life care plan recommendations. That being said, it will likely be important to communicate to the therapist what information is needed prior to the evaluation. Additionally, an evaluation in the home and, separately, the community may be particularly helpful. The case study at the end of this chapter will illustrate the value of the OT assessment in the formulation of a life care plan.

**Aging with a Disability**

This author (Mitchell, 2004) reported that aging-related complications such as pain, fatigue, decreased strength and endurance, and subsequent loss of functional abilities occurs 20 to 30 years sooner for people with early in life onset disabilities than for their able-bodied peers. This can have significant impacts in the life care plan both for care and equipment. In general, the need for care will increase as functional abilities decline. Changes in equipment and assistive technology are
likely to be needed as a person is less able to function in his or her daily routine, and it is important for the life care planner to anticipate and plan for these changes.

Needs related to aging can vary by disability type. Mitchell (2004) provided the following recommendations to consider when developing a life care plan for individuals who have cerebral palsy, spinal cord injury, or amputation.

Summary of implications for the life care plan for a person with cerebral palsy (Mitchell, 2004, pp. 96–97):

- Case management is an important consideration for the person with cerebral palsy. It may be difficult to find or access specialized care. The necessary time and equipment needed for regular preventative care may not be readily available and case management assistance may be critical even for those people with normal cognition.
- Specialized dentistry may be needed lifelong. Special equipment for oral care may be needed.
- Consultation with a dietitian at regular intervals will be helpful in problems associated with weight management (over- and underweight), which is common in this disability group.
- Alternative means of mobility should be an early consideration for those with any ambulation impairment. Powered mobility is an important consideration for distance mobility.
- A lifelong fitness routine is critical in maintaining strength, flexibility, endurance, and independence. A physical trainer may not have the needed expertise to meet the specialized needs of this population. Physical or OT evaluations every 2 to 3 years over a lifetime may be a more appropriate choice.
- Consider increased care needs as the person ages.
- Assistive technology needs can change over time (e.g., a normal bed may work well in youth but a bed cane or hospital bed may be needed in later decades).
- An ergonomically correct environment in both the home and work setting is critical in preventing injury. Ergonomic assessments at life phase changes may be appropriate.
- Pain management, while not needed in childhood, may well become important as a person ages.
- Periodic psychology assessments may be helpful in monitoring psychological status.
- Potential aging-related complications such as overuse syndrome and potential for falls should be addressed.

Summary of the implications for the life care plan for a person with spinal cord injury are as follows (Mitchell, 2004, p. 99):

- Periodic assessments with a dietitian may be important for weight control.
- Powered mobility should be considered for those needing to travel long distances or on uneven ground (e.g., college campus or rural environment) even with manual wheeling proficiency. Manual assist wheelchairs should typically be introduced 10 to 15 years after injury and powered wheelchairs for spinal cord injured clients using wheelchairs 20 years after injury.
- Other assistive technology needs are likely to change over time. Occupational and physical therapy evaluations to assess assistive technology are recommended.
- An ergonomically correct environment in the home and worksite will minimize injury risk. Periodic assessments at life phase changes may be indicated.
- A lifelong fitness routine is critical in maintaining strength, flexibility, endurance, and independence. A physical trainer may not have the needed expertise to meet the specialized
The Role of the Occupational Therapist in Life Care Planning

needs of this population. Physical or OT evaluations every 2 to 3 years over a lifetime may
well be a more appropriate choice.

- The life care plan should address the potential need for increased care as the person ages and
consider the possible psychological impact of increased dependency.

A summary of the implications for the life care plan for a person with amputation is as follows
(Mitchell, 2004, p. 100):

- An ergonomically correct environment in the home and worksite will minimize injury risk. Ergonomic assessments at life phase changes may be helpful.
- Weight control is important for prosthetic fit and to help from overstressing joints. Periodic assessments with a dietician for those with a potential for weight control difficulties is recommended.
- A fitness program is essential to minimize injuries related to overuse. Input from therapists or a personal trainer may be a benefit to this disability group.
- Alternative mobility may be needed for those with lower-extremity amputations. Age and mobility environment will need to be considered.
- Pain management may not be a concern early in the disability for the person with amputation. However, it can become a problem as the person ages.

Abbreviations Commonly Used in OT

In review of therapy records, a life care planner may have difficulty deciphering abbreviations
used by OTs. While there is a national effort to standardize abbreviations, some may be unique to
therapists and some may even be specific to a given organization. Following is a list of abbreviations that may be found in OT medical records:

AAC Augmentative and alternative communication
AAROM Active assistive range of motion (person needs assistance to complete the full range of motion)
AD Alzheimer’s disease
ADD Attention deficit disorder (now replaced by AD/HD)
ADHD Attention deficit hyperactivity disorder
ADLs Activities of daily living
A/E Above elbow
APD Auditory processing disorder
AROM Active range of motion (person is able to move through the range of motion but may not be able to do so with resistance)
AS Asperger’s syndrome (part of the autism spectrum)
ASD Autism spectrum disorder
AT Assistive technology
B/E Below elbow
B/K Below knee
BMP Behavior management plan
CD Conduct disorder
CGA Contact guard assist (direct contact with the person for safety but no physical assistance)
COTA  Certified occupational therapy assistant (typically an associate degree education)
DCD  Development coordination disorder (DSM-IV 315.4)
DD  Developmentally delayed
FNMES  Functional Neuromuscular Electrical Stimulation (also see TES & TENS)
IADL  Instrumental activities of daily living (activities of daily living beyond self-care such as
money management, meal preparation, child or pet care, telephone or computer use, use of public transportation, driving, and home cleaning and maintenance tasks)
LTG  Long-term goal
OT  Occupational therapist or occupational therapy
OTR/L  Occupational therapist licensed (occupational therapists are registered nationally but licensed by the individual states)
PCA  Personal care attendant
PECS  Picture exchange communication system
PT  Physical therapist or physical therapy
SBA  Standby assistance (no direct contact with the person)
SI  Sensory integration
SID  Sensory integrative (or integration) disorder/dysfunction
SLP  Speech language pathologist
STG  Short-term goal
TENS  Transcutaneous electrical nerve stimulation
TX  Treatment
VC  Verbal cue
WFL  Within functional limits (able to move within the limits needed to perform daily activities but may not have full range of motion or normal strength)

Case Study

A life care planner was asked to evaluate Jane, a 46-year-old woman who was diagnosed with a T7 spinal cord injury resulting in complete paraplegia. The life care planner visited Jane in her rural home. She had completed her in-patient rehabilitation over 2 years ago. The life care planner was concerned because Jane was significantly overweight and complained of severe shoulder pain. Jane was resistant to going into the city for physiatry follow-up and had purchased much of her durable medical equipment over the Internet. Jane was struggling to perform her activities of daily living and relying more and more on her family for assistance. It was clear that some of Jane’s equipment was no longer appropriate for her needs. Jane did agree to have an OT assessment in her home. And the life care planner found a qualified OT to conduct the evaluation.

An OT with spinal cord injury and home accessibility expertise evaluated Jane. Numerous issues that would have relevance to the life care plan were discovered by the OT and needed items were added to the preliminary life care plan:

- Not only had transfers become difficult for Jane; they were in fact unsafe. The OT recommended physical therapy intervention after a physiatry or orthopedic consultation to determine if Jane’s shoulder pain and consequent strength deficits could be improved. If possible, transfer training would need to be retaught. There was an immediate need for a lift. Physical therapy and later PT or personal care attendant hours needed to be increased to eliminate Jane’s need to continue unsafe transfers. See the example life care plan entries in the
The Role of the Occupational Therapist in Life Care Planning

The following. (Note: In an actual life care plan, items would be distributed into the appropriate
categories. For purposes of this chapter, recommendations have been grouped together and
numerous other items not specifically relevant to this chapter have been excluded.)

<table>
<thead>
<tr>
<th>Item/Service</th>
<th>Replacement /Service Frequency</th>
<th>Purpose</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>PM&amp;R or orthopedic visit</td>
<td>1–2x (additional visits are possible)</td>
<td>Evaluate shoulder/ strength and provide recommendations.</td>
<td>$90/visit</td>
</tr>
<tr>
<td>Physical therapy</td>
<td>2–10 sessions</td>
<td>Reassess transfer status, train caregivers in lift use if needed, initiate home exercise program for shoulder. See later in plan for PT or personal trainer long-term follow-up.</td>
<td>$136–$272 per session</td>
</tr>
<tr>
<td>Invacare Reliant battery-powered lift</td>
<td>10 years</td>
<td>Caregiver use when independent or assisted transfers were unable to be performed.</td>
<td>$2369.95</td>
</tr>
<tr>
<td>Lift slings</td>
<td>2–3 years</td>
<td>Slings are needed for use with lift.</td>
<td>$267.95</td>
</tr>
<tr>
<td>Personal care attendant</td>
<td>4–10 hours/day</td>
<td>These hours are needed to assist with personal cares, homemaking tasks, and eliminate independent transfers while shoulder pain is present. It is possible hours will be reduced if shoulder pain is eliminated.</td>
<td>$20–$28/hour</td>
</tr>
</tbody>
</table>

A power wheelchair with an elevating seat was recommended. Jane could access her kitchen cupboards, microwave, and refrigerator with an elevating seat. Without it, the OT noted she used poor ergonomics and put further stress on her shoulders. Powered mobility was recommended sooner than what is typical in Jane’s case because of her pain and mobility in her home. Typically, a power assist wheelchair is introduced 10 to 15 years after a spinal cord injury and a power chair 20 years after injury for the manual chair user (Mitchell, 2004). See the following example of a life care plan entry:
<table>
<thead>
<tr>
<th>Item/Service</th>
<th>Replacement Frequency</th>
<th>Purpose</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Invacare Formula CG Tilt/Elevate for TDX SP base</td>
<td>5 years</td>
<td>A power chair with elevating seat is to fully access kitchen and enhance independence. This chair will need tilt-in-space feature because of inability to perform weight shifts secondary to shoulder pain.</td>
<td>$14,624</td>
</tr>
</tbody>
</table>

**Source:** Lisa Michaels COTA/L, ATS, CRTS, Handi Medical Supply, St. Paul, MN, 2008.

- A power wheelchair would necessitate a van with a lift. Jane had been going into the community less and less because of her transferring inabilities.

<table>
<thead>
<tr>
<th>Item/Service</th>
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<th>Purpose</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2008 Chrysler Town &amp; Country Touring Van with Braun Entervan Conversion</td>
<td>7 years</td>
<td>This van will allow independence in community mobility.</td>
<td>$49,960 (less the cost of an average vehicle in the United States in 2007)</td>
</tr>
</tbody>
</table>

**Source:** HDS Specialty Vehicles, www.hdsmn.com.

- A van with a lift necessitates an oversized garage stall to provide needed maneuvering space for the van, the drop-down lift, and needed clear floor space to roll off the lift and maneuver toward the entrance door. This requires an additional 7 to 9 feet of clear width in one vehicle parking area. Jane has an attached single car garage. It is important to maintain an attached garage for the van so Jane does not have to maneuver through extreme weather elements to reach her van (e.g., snow, rain, ice, etc.) and to acknowledge Jane’s inability to scrape frost off of windows or to remove snow off the vehicle.

<table>
<thead>
<tr>
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<th>Purpose</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Garage modification</td>
<td>1x or may be needed again with additional moves</td>
<td>To allow parking in garage and allow adequate floor space for exit/entry with van lift.</td>
<td>$13,920</td>
</tr>
</tbody>
</table>

**Source:** Jane Hampton CID, CAPS, Accessibility Design, Inc., Minneapolis, MN, 2008.

- The OT offered Jane and her family suggestions about rearranging the kitchen, bedroom, and bathroom to improve access and ergonomics. Some OTs have this expertise but the advice of a home access specialist can also be critical in a life care plan. Although there are several areas in the house to consider, such as vertical access, garage overhead door, access into house, doorways, bathroom, kitchen, hallways, floor surfaces, controls, and so on, for the purpose of this chapter, the kitchen will be addressed to suggest the level of detail and costs appreciated.
- The kitchen did not provide any features to assist Jane in independent or safe meal preparation. The original kitchen layout had not been modified to accommodate needed clear floor space for Jane’s wheelchair or to accommodate the need to approach work areas in a forward approach to get close to the task area. Jane has been relying on her family for most meal preparation and cleanup. See the following example life care plan entry for details:
<table>
<thead>
<tr>
<th>Item/Service</th>
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<th>Cost</th>
</tr>
</thead>
</table>
| Kitchen modifications| 1x (more often may be needed with moves) | • Rearrange cabinet configuration to provide turning space for the wheelchair and approach to each work area.  
• Replace cabinets with new cabinets. Ergonomically, this will be much easier for Jane to use from a seated position.  
• Provide clear knee space at the sink, cooktop, and one mix/work area and incorporate dual pull-out cutting boards.  
• Replace the kitchen sink with a shallower sink to maximize knee clearance height; drains are to be located at the back of the sink to maximize knee clearance depth.  
• Conceal or wrap drainpipes to avoid hot water burns to Jane’s knees.  
• Install single-lever faucet hardware at the sink.  
• Extend the wall cabinet over the dishwasher down to the countertop so dish storage is located within reach range.  
• Replace the gas range with an electric cooktop that offers front controls.  
• Rewire the range fan and light switch located within accessible reach range.  
• Provide a wall-mounted oven with a side-swinging door.  
• Provide a pull-out board below or adjacent to the oven to rest cool items removed from the oven.  
• Incorporate pull-out shelves in base cabinets.  
• Incorporate a pantry, with pull-out shelves.  
• Replace the existing refrigerator with a side-by-side refrigerator that has water and ice in the door, allowing storage for both compartments in reach range.  
• Relocate outlets and switches to the front face of countertops. Provide task lighting at each work area.  
• Replace the kitchen flooring to accommodate newly configured cabinetry and to extend the flooring into each knee space. Ensure the transition to adjacent floor materials is neutral. | $35,000 |

A tub lift was recommended. While Jane had a shower chair, her spasticity and relaxation were improved with warm water. Jane could not get in the tub without a lift. See the following example of a life care plan entry:

<table>
<thead>
<tr>
<th>Item/Service</th>
<th>Replacement Frequency</th>
<th>Purpose</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aqua Tec Beluga RSB with reclining lateral support, wedge cushion, and rotary seat</td>
<td>5 years</td>
<td>Allow for safety and enhanced independence with tub baths.</td>
<td>$2971</td>
</tr>
</tbody>
</table>


Jane’s current wheelchair cushion needed replacement. See the following example of a life care plan entry:

<table>
<thead>
<tr>
<th>Item/Service</th>
<th>Replacement Frequency</th>
<th>Purpose</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infinity Lo Contour FloGel Cushion</td>
<td>3 years</td>
<td>Provide pressure relief, comfort, and positioning.</td>
<td>$418</td>
</tr>
</tbody>
</table>


Jane was educated about shoulder overuse in people with spinal cord injury. Fitness equipment that could be used without harm was suggested. See the following example of a life care plan entry:

<table>
<thead>
<tr>
<th>Item/Service</th>
<th>Replacement/Service Frequency</th>
<th>Purpose</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bowflex Versatrainer&lt;sup&gt;a&lt;/sup&gt;</td>
<td>10–12 years</td>
<td>Upper body strengthening from wheelchair.</td>
<td>$1885</td>
</tr>
<tr>
<td>Dura-Band Exercise System&lt;sup&gt;a&lt;/sup&gt;</td>
<td>2 years</td>
<td>Exercise bands to be used as an alternative to Bowflex or for out of home use.</td>
<td>$37.95</td>
</tr>
<tr>
<td>Personal trainer</td>
<td>4–6 sessions/year</td>
<td>Regular assessment from a personal trainer will be needed to advise re: exercise/strengthening program as medical status changes and with aging. It is possible to get this same advice from a PT but cost is likely to be greater unless accomplished during annual PT evaluation.</td>
<td>$50–$100/session</td>
</tr>
</tbody>
</table>

<sup>a</sup> It is possible that a physical trainer/PT may recommend alternative equipment.
Jane was only 46 years old, 2 years after her injury, and already experiencing shoulder pain. The OT recommended an item, while not currently needed, to be added to the life care plan as Jane aged:

<table>
<thead>
<tr>
<th>Item/Service</th>
<th>Replacement Frequency</th>
<th>Purpose</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bed cane</td>
<td>5 years</td>
<td>This device will assist with bed mobility/transfers. While not currently needed, it should be added to the plan beginning at age 55.</td>
<td>$104.95</td>
</tr>
</tbody>
</table>

Conclusion

Recommendations from the OT may be vital in the development of a life care plan as many components fall under the expertise of the OT. However, the life care planner should remain aware that OTs typically think about a current episode of care and may be unaccustomed to projecting lifelong needs. Additionally, few have forensic experience and may be reluctant to offer an opinion that may be used in a legal setting if they are not experienced or familiar with litigation issues. They may need education about how the information will be used and what it will mean for them to offer an opinion for the life care plan. Therapists also tend to specialize in specific areas of practice and consultation, and more than one OT may be needed for a specific life care plan. Consultation with OTs who specialize in other professional practice areas can bring added depth and detail to the life care plan.

References


Chapter 8

The Role of the Physical Therapist in Life Care Planning

Art Peddle

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Introduction

Physical therapists serve as facilitators of health. They treat patients with a broad range of potential participation from other professionals, family, and friends. An open mind-set to any given patient and situation is crucial to the enhancement and facilitation of health. The treatment of signs and symptoms, pain, irritation, lesions, catastrophic injury, and dysfunction are given viable solutions from the unique perspective of balanced deliverance of effective physical therapy skills. This creates a synergistic application of physical therapy with the patient’s willingness to be responsible toward maximizing health and function. Cooperation with all professionals, financial supporters, family members, and friends contributes to the overall facilitation of health. Insight to innovative and new techniques as applied to a specific patient’s needs is an opportunity to promote physical therapy skills with positive participation by the patient. It is vitally important that the well-being of each patient be considered in long-term and short-term care.

The Life Care Planning Process

In dealing with life care issues, there are fundamental questions and paradigms of thinking to be asked of the physical therapist and others involved in the care of the patient or client, such as the following:

- What was the level of health, function, and lifestyle before the injury, disease, lesion, or dysfunction?
- What level of health, function, and lifestyle can be achieved given the present status of the patient and his or her physiological, social, psychological, financial, and spiritual environment?
- What are the ideal, hopeful goals and plans, balanced with the real goals and plans?
- What are the integrated thoughts on parameters and boundaries of the patient’s thinking in relationship to the process of healing and health?

The physical therapist and all persons involved in life care planning should integrate their plans with the following concepts being interwoven in their health care delivery process:

- “Seek first to understand, before you are understood.” (Covey, 1989, p. 239)
- “Walk a mile in my shoes.” (Song performed by Joe South)
- “Do unto others as you would have them do unto you.” (Matthew 22:39 paraphrased, KJV)
- “Understand the patient’s languages of love—care and receiving”. (Chapman, 1995)

As we examine life care goals and priorities for the patient, we are building a foundation of true principles to develop our skilled delivery of physical therapy. Therefore, we return the patient, as much as possible, to full health and function with basic human dignity, rights, and privileges. If
full health and function are not attainable, then at the very least we should create a plan, delivery, and environment of highest quality and dignity of life, minimizing suffering and creating a door of hope for tomorrow. This also allows us to participate in one of the greater values of life, the opportunity for fellowship and to relate to a person’s unique experience of life, a form of shared enlightenment.

Again, the attitude for delivery is based on how we would want to be treated in any given situation. This attitude counteracts selfish goals and stirs physical therapists to strive for the best scenario and outcome, for the goal is quality of life. This way of life care planning requires commitment to the process. It includes active responsibility and participation of both the physical therapist and the patient.

The Evaluation

The physical therapist has the unique capability of providing a large spectrum of evaluative techniques as well as evaluative protocol. The evaluation process is a multilevel course of action. Full detailed evaluation processes can occur on various levels or may be specific parameters, as well as being appropriate to special situations.

In the general areas of medical studies and patient situations, a physical therapist is presented with a variety of evaluative techniques. These include the areas of orthopedics, neurology, soft tissue dysfunction, wound care, sports medicine, hand therapy, industrial medicine, and catastrophic injury to specific or multiple areas. The physical therapist can also specify evaluative techniques by age groups, including pediatric, youth, adult, and geriatric populations. Besides the areas of physical dysfunction and areas of given diagnostic diseases, lesions, or injury, a comparative evaluation and preparation for return to life evaluations can be delivered. Evaluations that involve return to life skills, including activities of daily living (ADL), function, work-related skills, ergonomic analysis, sports-related skills, and overall total life skills can be offered with the appropriate parameters in order to be specific or holistic in nature.

The evaluation process involves consideration of the adaptability of the patient and the circumstances in which the patient is placed. Evaluations can involve specific areas of spine, extremities, and body systems, as well as specific areas of dysfunction and injury. General areas of consideration and evaluation involve the following.

**Intake Interview**

1. Review the existing medical history and subjective information.
2. Interview the patient. This involves a general subjective overview, including verbal contributions from the patient, type of injury, surgical history, disease process, and dysfunction. Other areas involved in subjective information include present job situation, activity level before and after injury, previous types of physical therapy received, and medical care received.
3. Consider psychosocial questions and interview as they relate to the present dysfunction. Other professionals may have covered psychosocial issues, but it is always appropriate to establish a baseline of understanding of other involved issues in the patient’s dysfunction.
4. As appropriate, communicate with family and friends about observed subjective and objective information.
General Evaluation Input

The subjective information and input obtained from the client are established as the baseline for other evaluation considerations. Pain evaluations using standardized questionnaires as well as various tests have benefits for cross-correlation and reliability of subjective information. These essential baseline data of pain characteristics assist in leading the therapist toward establishing present dysfunction and potential for further dysfunction and other complicating factors.

General characteristic complaints of pain are to be established, such as:

- The location, duration, and frequency of the pain.
- The specific qualities of the pain—constant, intermittent, diffused, localized, sharp, numb, burning, dull, tingling, radiating, quick, or sustained.
- Examples of specific pain (e.g., night pain, pain upon arising in the morning, pain with activity, or pain throughout the day).
- Clarifying the pain intensity by using a scale—0 being no pain and 10 being acute pain.
- Examples of activities that increase pain and activities that decrease pain (e.g., sitting, standing, walking, lying, bending, massage, ice, or heat).
- Is the pain getting better, getting worse, or remaining the same?
- What is the maximum length of time the patient can perform any particular function, such as sitting, standing, walking, and driving?

Pain questionnaires should also reveal relationships between how much function the patient can perform and at what level the pain occurs, such as how much can the patient lift and carry? What provides relief? What positions and body ergonomics or equipment assist in decreasing pain and promoting function? Pain drawings and various standard pain scales are other informative tools to be utilized for comparative information, with coordination of other data.

Past medical history and personal information also are important to understanding the direction of evaluation, treatment, and plans for function and health care. The new standards and parameters established under the Health Insurance Portability and Accountability Act (HIPAA) have to be considered in all aspects of care and planning.

Referral questions such as return to work, work duty load, time load, consistency testing, and impairment ratings are also directional in the evaluative and care process.

Objective Evaluation

An objective evaluation will analyze basic functional activities, such as the patient’s gait; sitting, standing, and rolling activities; and appropriate supportive devices.

Observation of the basic structure of the anatomy, weight-bearing capabilities, and appropriate body landmarks is an essential part of this examination. One should note appropriate posture, compared to the correct anatomical position, and specific noted deviations. Considerations for historical body habits, adaptive shortening, and contractures are important data. Also note the self-limiting or compensated functions and adaptations the patient has made. These can occur voluntarily or involuntarily.

Other observations should include:

- Basic soft tissue evaluation
- Appropriate understanding of joint position
Special tests can target specific examination of any given extremity or body part. These tests rule out various complications and evaluate appropriate function and dysfunction.

Other appropriate evaluations include:

- **Intervertebral movement**
- **Normal joint movement**
- **Range of motion (ROM), including cardinal and diagonal planes**
- **Gait analysis**
- **Flexibility**
- **Manual muscle testing**
- **Strength testing with technologies and instruments**
- **Functional test**
- **Sensory tests**
- **Special tests**

Special tests can target specific examination of any given extremity or body part. These tests rule out various complications and evaluate appropriate function and dysfunction.

Other appropriate evaluations include:

- **A neurological exam** would include basic reflexes as well as appropriate strength measuring, with manual muscle testing and sensory examination. It should be noted that during the evaluation any cross-correlation with a basic generalized assessment can be made with more specific evaluations, including functional aspects of a work capacity assessment (WCA), functional capacity assessment (FCA), and isokinetic, neurological, and balance testing and sensation tests.

- **Joint mobility evaluations** include the normal ROM, correct anatomical position, appropriate accessory movements, and physiological movements.

- **Soft tissue evaluations** include palpation of tissue, noting restrictions, trigger points, pliability, and plastic and elastic responsiveness. The evaluation of soft tissue and tender points should include restrictive qualities and tenderness nature and the response of the tissue (Jones et al., 1995). The evaluation of articular structures should include pain, irritation, and inflammation status as well as movement patterns being evaluated. The functioning of soft tissue and joint structures as a synergistic pattern should be noted. Functioning activities such as sit to supine and return, rolling to supine, side lying and return, and overhead reach are part of the evaluation. The evaluation of functional positions and assuming positions, including the quality of movement as well as any centralization or peripheralization of pain, signs, and symptoms should be considered in this process.

- **Other palpation skills** include evaluating muscle play, restriction, guarding, reflex contractions, soft tissue restrictions, trigger point, and referred pain. **Intervertebral movement evaluation** is based on a numerical scale set between 0 and 6, with 0 being ankylosed and 6 being unstable; 3/6 is normal. The intervertebral movement can also be classified as hypomobile, hypermobile, and painful. The general evaluation can be broad or specific.

**Work Capacity Assessment (WCA) and Functional Capacity Assessment (FCA)**

The terms work capacity assessment and functional capacity assessment are sometimes used synonymously (Polinsky, 1983; Blankenship, 1989). They can also be more definitive, with WCA being an evaluation used for baseline of work capacities. The FCA would involve a more direct study of basic, functional activities of daily living, with the potential of also evaluating work-related activities. The WCA/FCA can be done at the beginning, middle, or end of any
treatment evaluation process, or as part of a total perspective of life care planning depending on what is needed. There can also be varying degrees of specific details in the WCA, since the parameters are determined by the physical therapist’s understanding of the goals of the evaluation process. The WCA/FCA can occur during the initial stages of the life care planning process or can be extended throughout the span of the life care plan. Follow-up assessments are to upgrade and adjust the goals and plans for the patient, as well as to update the baseline data for reevaluation. All physical therapy evaluations are done in coordination with other professionals and their evaluations. Integrating the results of other health professionals’ assessments into the physical therapy plan allows for a more holistic approach in achieving the goals for the individual patient.

There are a number of evaluative techniques in the areas of WCA and FCA that are effective and appropriate for any given situation in the life care planning process. According to Blankenship (1989, p. 122), “the WCA or the FCA is an evaluation of physical capabilities and limitations as they relate to work, recreation, and ADL. It describes the optimum and maximal capabilities in terms of strength, endurance, related joint problems, fine and gross motor coordination, limiting factors and methods of functional and task performance.” Therefore, in order to make a more accurate assessment, the WCA/FCA should involve measurements of different activities.

**Nonmaterial Handling and Positional Tolerance**

General areas tested in basic functioning include:

- Lifting, which includes level lift, floor to table, and carrying
- Pushing to maximum tolerance
- Pulling to maximum tolerance
- Standing, sitting, and kneeling tolerance
- Bending, stooping, and squatting
- Walking, climbing, and balance
- Coordination activities, including the upper and lower extremities with gait analysis and gait function
- Pivots, forward reach, overhead reach, etc.

The evaluation often requires an assessment of time and repetitive parameters specifically defined as not required, occasional (up to one-third of the time), frequent (one-third up to two-thirds of the time), and constant (over two-thirds).

**Material Handling, Lifting Tests, and Strength Tests**

These tests can take on specific work or functional aspects. Various lifting tests have been developed to improve consistency, reliability, validity, and standardization of data to be applied to evaluation and supportive conclusions, results, and directions of rehabilitation.

Isometric lift test, strength test with one repetition, repetitive loads, dynamic and static, grip test, and other integrated techniques utilizing new technologies, programs, and standardized techniques and databases are part of the evaluative tools available. These tests are also cross-correlated often to arrive at reliability, validity, and consistency of effort parameters. Many tests, for example, EPIC (Employment Potential Improvement Corporation, developed by Matheson, available at www.epicrehab.com), have criteria and standards for application, databasing, and analysis.
Activities of Daily Living (ADL)

Establishment of proper body ergonomics and posture during functional ADL, as well as work-related activities, is important not only in establishing and facilitating present health, but also in preventing further dysfunction and injury. It is important that ergonomics be applied in the evaluation process as a tool to determine the patient’s capabilities (physically and mentally) in comprehending the issues of proper body mechanics. In the evaluative functional capacity/work capacity arena, proper ergonomics and posture will need modifications based on equipment handling capabilities and the use of adaptive equipment.

Functional aspects of ADL, such as personal grooming, hygiene, and dressing, are issues that are often considered in the FCA (also see Chapter 7 on the occupational therapist’s role). Areas of nutrition and speech can also be evaluated by a qualified physical therapist with appropriate training. Some aspects of the FCA, as well as other aspects of WCA, are often overlapped in the expertise area with the occupational therapist, speech therapist, recreational therapist, ergonomic specialist, and appropriate physician specialist. In any evaluative process, standard body mechanics are to be evaluated by the therapist during the lifting task portion, as well as basic functional activities task, in order to ensure the most advantageous body mechanics for handling basic ADL functions and work functions.

Evaluation for sports and other specific recreational skills needs to be considered in the evaluative process. There is a correlation between functional skills, work skills, and sports or recreation skills. Collating these concepts provides for efficiency of movement, as well as promoting correct body function and health, within the parameters of the given dynamics of the patient’s physical challenges.

Evaluation of body mechanics is crucial to determine potential for wear and tear on the patient. Appropriate alternatives, suggestions, and varying procedures and skills for handling any given dysfunction should be understood. Full comprehension of these procedures and skills will enhance the development of proper use of strength, as well as minimize irritation and pain. Also, with proper evaluation of the patient’s present knowledge and skill, the need for further training or education can be developed. The role of the physical therapist from the basic evaluative process or WCA/FCA can essentially be refined or specified for any catastrophic impairment.

When performing the evaluative process and listing objective findings, substantial data are important to assist the delivery of health care to the patient. Gathering of data and information in the objective format also plays an important role in defending the patient’s present situation and in presenting the plan for future services. Skilled assessment is vital in giving direction for the best possible outcome for the patient’s return to health, as well as providing long-term care. It is appropriate to develop parameters allowing for changes in the patient’s function and health and in the patient’s environmental situation and basic home lifestyle. Adaptability and changes in preparing the patient for return to work or work activities are crucial in understanding the format for performing the evaluative FCA or WCA.

Isokinetic Testing

Isokinetic testing provides a technologically advanced approach to human performance testing, rehabilitation, and exercise. The test allows all major joints of the body, including the upper extremities, lower extremities, and trunk, to be evaluated and compared. Bilateral testing, as well as comparative testing, can differentiate between muscle groups in the isokinetic test. Isokinetic exercise is performed at a constant speed throughout the range of motion. As the muscle applies
force, it is resisted by appropriate proportional opposing force. Therefore, the speed of movement is kept constant. The isokinetic evaluation process or exercise provides an excellent means of qualifying many aspects of movement and function, including muscle torque, work, fatigue, ROM, and peak torque levels. As the sophistication of technology improves, more accurate and appropriate measuring devices will allow for basic data and parameters in which to assess body function. The isokinetic test can also be used in a cross-correlation with functional measurements being taken, as well as manual muscle testing and basic lifting capabilities. This cross-correlation can help define the patient’s present level of activity and assist in determining symptom magnification and inappropriate illness behavior parameters.

Neurological Evaluation

As in the general evaluation given earlier, the neurological examination can be an expanded appraisal involving specific parameters. It involves specific emphasis on neurological and neuromuscular mechanisms of the body, including muscle test and evaluations, sensory tests, functional and neuromuscular developmental sequencing and evaluations, and specific injury evaluations to the central nervous system or peripheral nervous system. Associated dysfunction as in gait, transfers, dressing, grooming, hygiene, sports, and work can also be neurologically evaluated.

Cardiovascular Fitness Evaluation/Cardiovascular Profile

Cardiovascular fitness evaluations incorporate a range of specifically applied stress testing under the supervision of the physician and appropriate professionals, including a physical therapist. The cardiovascular appraisal is often involved in the FCA/WCA, which establishes a minimal level of conditioning protocol that could include treadmill, bicycle ergometer, or step-climbing evaluations. All these tests have basic guideline parameters. Often a cardiovascular clearance evaluation is needed before other evaluations, WCA, and FCA can be performed. The pertinent physician or professional may give appropriate parameters under which the cardiovascular system may be stressed or tested.

Neuromuscular, Balance, and Coordination Evaluations

The neuromuscular skeletal function is evaluated in specific areas or systems and holistic body systems and functions. This evaluation can involve the study of the balance system of the body in relationship to gait and functional activities. Proper consideration for a proprioceptive feedback system in static and dynamic functional activities is measured. This evaluation can involve specific job activities, sports activities, and ADL, with coordination, balance, and skill being integrated into foundation data. The criteria involve general standardized tests, as well as specific tests designed by the physical therapist to the given situation based on age, developmental sequencing, and specific goals of the functional or life care demands.

Gait Evaluation

Gait evaluation involves specific or general evaluations of the patient’s ambulatory status in a variety of environment situations. Consideration for adaptive equipment, tools, and prosthetics is part of this evaluative process.
Return to work and physical demand categories as published by the Department of Labor, in combination with consistency of performance, positional tolerances, and lifting tests and other evaluative procedures, create a viable tool to have a “systematic process of measuring and developing an individual’s ability to perform meaningful tasks on a safe and dependable basis” (Hanoun Medical, 2002).

**Evaluation Recommendations**

The role of the physical therapist as a facilitator in health care is to treat, train, condition, and assist in the direct structure and setting of goals for the patient. Basic communication to the patient, family, professionals, and financial parties serves as a primary directive of achieving the life care planning process. It should be understood from the physical therapist’s point of view that his or her establishment of feedback into the life care planning process is crucial in developing a long-term solution for the patient’s care. Proper structured treatment, evaluation, follow-up physical therapy, and training involve clear communications among the professionals involved so that all forms of facilitation to functioning are utilized.

**The Lifelong Physical Therapy Plan**

An attitude of openness and understanding should be the goal while preparing the patient for the highest level of independence. This same directive should be applied when providing options for those who will need long-term or lifelong physical therapy. Examples of this attitude and structure are as follows: a patient who is in need of a wheelchair and is dependent upon the wheelchair for most of her life will develop other dysfunctions. Typically there is greater wear and tear on the upper extremities, cervical, neck, thoracic, and spine, due to having to handle a greater load of total body function in the upper extremities and upper trunk and neck areas. It is important to understand that lower extremities that are not functioning do not provide support and therefore cannot be used in functional skills. This greater demand of activity and function is placed on the remaining working cardiovascular, neuromuscular, and skeletal systems. These patients or clients are susceptible to greater breakdown of all involved systems and structures. Effective planning involves addressing the immediate dysfunction in preparing the patient to develop a higher level of independence and future preparation. It should also be understood that the patient would in all probability have an increased ratio of wear-and-tear factors and greater susceptibility to further lesions and insult in his remaining systems and structures.

The dysfunctional areas of the body and mind will still need suitable care and support. These would include areas of strength, ROM, hygiene, wound care, tissue function, and basic vascular and neurological functional considerations. Sometimes injured areas become hypersensitive, even though not functional. Phantom and referred pain can occur in the dysfunctional area.

As in any treatment or evaluation process, the therapist should be open-minded and aware of any new studies or opportunities to increase the function and promote the facilitation of health in the injured area. This especially applies for adaptive equipment. The progressive use of equipment, awareness of advanced technology, and foresight to predict need are essential. For example, a lower-level tetraplegic patient would commonly require a primary power wheelchair for basic ambulating. However, there are occasions in which an additional manual wheelchair would provide the patient with a variety of sitting postures, backup to the power chair, and an opportunity for the wheelchair to be used as a piece of exercise equipment. The manual wheelchair provides an
excellent source of exercise potential and opportunity for the patient to develop some control and direction in ambulating.

Thoughtful modifications and supplements to the patient and the given situation, with appropriate equipment, should be considered for both short-term and long-term care. This allows the physical therapist and the life care planning team to develop a full perspective in returning the patient to the highest level of independence and an appropriate, dignified lifestyle. Motivating, encouraging, and challenging the patient to use equipment and supportive devices are part of the evaluative, training, and treatment process.

Financial considerations include original equipment, maintenance, modifications, and replacement equipment. All these factors are to be considered over the patient’s life span. As the patient changes and various challenges are presented, considerations for equipment should be appropriate to the life care plan and goals. Financial support for equipment and the evaluative process should be based on the highest goals and principles presented.

**Physical Therapy Treatment**

In the life care planning process, an evaluation establishes the baseline for treatment throughout the process. In many situations, specific treatment by the physical therapist is required and involves not only therapy, but also ongoing evaluation. Physical therapy treatment may involve eight basic categories:

1. Education
2. Conditioning
3. Physical medicine treatment
4. Function-specific and ADL-specific treatment
5. Occupational and industrial physical therapy
6. Sports physical therapy
7. Total life relationship skills and integration treatment
8. Boundaries and communication skills

*Education* involves an emphasis on ergonomic principles applied to posture and body mechanics, and essential principles for carrying out assisted or independent programs of conditioning, strengthening, ROM, and functional care. Education in ADL, functional, sports, and work-related skills is delivered to all parties involved. It is important that these skills are developed in the patient’s real-world setting and that there is ample opportunity to implement them in an appropriate manner—with supervision, leading toward independence as a baseline goal. The appropriate support of professionals and family members in the real-world setting will require adaptive thinking.

Establishment of specific patient potential in any given area needs to be determined and understood by the patient and team members. An understanding of the patient’s situational lifestyle, critical work demands, task analysis, functional activities, and recreational plans is important. The patient’s understanding of educational information presented and the development of a functional delivery by the patient in handling basic nonmaterial ergonomics and essential material ergonomics should be considered. Material handling and nonmaterial handling ergonomics are matters not just of work-related issues, but also of functional ADL and the total environment.
Integration into the whole aspect of the patient’s life care with the life care planning team on an as-needed and program-developmental basis will be required. This will probably require the physical therapist to coordinate with the patient/client, other professionals, and family members to follow through with essential concepts of physical therapy education.

**Conditioning** involves aerobics, cardiovascular, and physiological conditioning. It should be noted that in conditioning, appropriate adaptations to the patient’s/client’s needs will be made and evaluated, as well as developed into a working solution by the physical therapist. Strengthening, which will incorporate specific muscle dynamics, will be used to increase strength levels for performing functional activities, work activities, sports activities, and ADL. Specific areas of strengthening can involve techniques in cardinal and diagonal planes, which can involve singular movements or multidirectional movements. The physical therapist has at his disposal the use of many strengthening techniques, including isometrics, isotonics, isokinetics, plyometrics, and proprioceptive neuromuscular facilitation (PNF). Strengthening could involve rotational, multidirectional facets to prepare the patient for a variety of lifestyle situations. Mobility, stretching, and flexibility categories are used synonymously to describe appropriate mobility exercises to ensure basic principles of full functional ROM in both physiological and accessory patterns. Using balanced concepts of strengthening without strain or further injury is of vital importance in designing a program specific to the individual patient and situation.

The integration of all conditioning factors with functional skills, ADL skills, work skills, and sports skills should be considered and integrated into life care planning. Specific neuromuscular, balance, and coordination activities allow the integration of the central nervous system and the peripheral nervous system to handle ADL, functional, work, and sports activities. Ballistics and dynamics are stresses to be applied to prepare the patient to handle a variety of velocity forces and changes that occur in any lifestyle situation. This can involve specificity of training at various speeds and various levels of physical performance.

**Physical medicine treatment** includes the use of appropriate medications, modalities, manual therapy, and specific exercises. Physical therapy medicine is used for basic signs and symptoms, which may include pain management, wound care, and improving function. Physical medicine includes the areas of specialized program development or treatment, which could include relaxation techniques, weight control, and appropriate uses of supportive devices, equipment, and braces.

**Function-specific and ADL-specific treatment** are specific treatment programs the physical therapist can use to encourage increased functional capabilities, such as in gait, transfers, personal hygiene and grooming, speech, and general ADL.

**Occupational and industrial physical therapy** involves the process of creating a situation in which a patient/client may progress from a beginning level of handling any job task to the actual performance of the job. The job-specific program can involve a program starting in the clinic and being transferred to the on-site job location. Work hardening, work conditioning, and work start are synonymous terms to describe this process.

**Sports physical therapy** involves the direct relationship of physical therapy in establishing appropriate conditioning and training, structure, and protocol. This skilled development of parameters and goals creates an atmosphere that develops independent training techniques, as well as independence to continue higher levels of sport or sports-specific performance.

**Total life relationship skills and integration treatment** involves the physical therapist working with the patient, family, and total environmental in developing a workable plan structured for assisting the patient in facilitating her full health at the highest level possible. This total life care integration involves a coordination of all previous physical therapy treatments and evaluations with the potential for upgrading, changing, and adapting any given treatment plan and program.
Boundaries and communication skills involve personal and relationship effort and education, utilizing appropriate psychological consultation and study. The skills and techniques gained will enhance the positive effectiveness of a caring serving professional.

Exit Program and Care Resolution

Preparing the exit program involves a combination of compiling all previous evaluations, treatment, data, and observation processes in communication with the associated team members to arrive at a conclusion of the involvement process in the patient/client. During the exit program, appropriate recommendations and postdischarge plans are made from the physical therapist’s point of view with preferred sequencing, as well as postdischarge plans for status to returning to full lifestyle situations. Options and variations of any program, as well as reentry into a program, are open for consideration, as is proper application of newly found situations.

Follow-up care resolution is a broad category involved in interpreting the appropriateness and efficacy of the evaluative and treatment process from the patient’s perspective. It also involves the physical therapist’s perspective in the areas of physical ergonomic integration into basic life, concepts of preventative physical medicine, appropriate concerns for future update and recheck, and any issue of compliance. This involves a process of communication between the patient and all team members in restoring the patient to the highest level of function and a dignified lifestyle.

Symptom Magnification

Symptom magnification or inappropriate illness behavior is an issue that can be present in the life care process and involves many complications and issues. Physical therapists, as well as other professionals, have attempted to arrive at appropriate systems, tests, and evaluative procedures for giving suitable feedback and baseline data to establish appropriate behavior in any given situation. General considerations for inappropriate illness behavior and symptom magnification are behaviors that are out of proportion to the impairment. It should be understood that symptom magnification is a behavior that is improper but does not implicate a reason or motive for that behavior. Furthermore, it should also be understood that there could be a psychosocial basis for some behaviors that do not necessarily originate from a physiological or organic basis.

In determining symptom magnification or inappropriate illness behavior it should be understood that there are often degrees and levels at which it is expressed. Some of these levels are extreme and can impede the appropriate fair process of assisting a person to achieve a healthy lifestyle. In addition, there are forms of symptom magnification that exist on a low level that are intrinsic to basic lifestyle teachings. Therefore, appropriate considerations for establishing objective information, as well as objective treatment, require skill and fitting consultation from the team of life care planners and associated professionals.

If the physical therapist is involved in the identification of the type of symptom magnifier, which could be classified in the areas of an experimenter, a refugee, a game player, and a psychogenic type of magnification, consultation with the appropriate professional should be performed and used (Blankenship, 1989). Appropriate test questionnaires and scales administered by the physical therapist, or previously by associated professionals, can be considered as part of the evaluative
process. It should also be noted that in understanding, evaluating, and commenting on appropriate and inappropriate illness behavior, one should have an open mind and be alert to cross-correlation factors in the evaluative and treatment processes.

An example of this would be a patient being asked to perform a cardinal plane ROM by lifting his arm over his head, but the patient states or demonstrates that he cannot lift his arm above 70° of shoulder flexion. Then when asked to take off his shirt, he is able to demonstrate taking his shirt off over his head, thus demonstrating his ability to flex his shoulders above 100° or more of shoulder flexion. Cross-correlation of specific evaluative techniques and functional techniques assists in determining the reliability and validity of the patient’s status. In communicating this information, the physical therapist should use the expression “The data presents itself.” Another way to express performance is to use the phrase “The patient demonstrated (this or that).” Therefore, the therapist avoids conjecture and judgment when communicating.

Physical Therapy Charges

Basic rates in physical therapy for services rendered are wide and varied. Each profession and professional has his or her requirements and specific insights into delivery of any evaluation and treatment process. The following numbers are given as a broad perspective and are estimates for considering lifelong life care planning issues and are subject to change with all basic life situational economics, as well as specific professional demands.

- Basic physical therapy treatment and conditioning range from $65 to $200 per hour.
- General evaluative techniques, depending on the extensiveness of the techniques, range from $60 to $1000.
- These techniques could involve anything from a beginning basic physical therapy evaluation of $65 (average charge) to more specific exams running $200.
- WCAs and FCAs range from a modified WCA/FCA costing $200 to a more extensive WCA/FCA costing $1000.

Again, there is such a wide variety in pricing that it is best to be specific to the physical therapist involved in the analysis, evaluation, and treatment processes to determine the best life care planning situation. As in other life care planning areas, considerations for “how I would like to be treated” and what is fair should be a basis for appropriate structuring for financial reimbursement.

Establishing a Knowledge Base

The physical therapist should establish an appropriate information system in order to accomplish the following:

1. Provide a means of examining the specific case issues as a professional.
2. Establish appropriate correlations between injury and patient types.
3. Establish appropriate protocol for returning the patient to his or her lifestyle and life situation.
4. Establish appropriate modifications for further patient assistance and study.
Case Study

The client, a 23-year-old female, suffered a burst fracture of the first vertebrae in her lumbar spine (L1) resulting in a conus medullaris (spinal cord) injury following an exercise-related injury. She is ambulatory (although impairment is obvious) but uses a cane when outside of the home for stability and safety. She participated in a functional capacity evaluation, which was completed over a 2-day period due to the client's fatigue and reduced endurance.

Results of the evaluation are as follows:

- Unable to complete Kasch Step Test due to fatigue in lower extremities.
- Unsteady balance while stepping when fatigued.
- After 15 minutes of continuous walking, client was visibly fatigued with decreased control of lower extremities and trunk during ambulation.
- Difficulty with crouching (consistently lost balance).
- No difficulty sitting for 30 to 40 minutes at one time.
- No difficulty crawling.
- Difficulty with higher-level coordination/balance activities.
- Validity of the isometric strength testing reflects decreased strength/balance.
- Dynamic progressive lifting test discontinued after client lifted 24 pounds due to rating of very heavy load.
- Functioning in sedentary–light physical demand category due to lack of endurance.
- Significant postural, lower extremity strength, balance, and endurance deficits.
- Highly motivated client with “enormous potential to improve.”
- Recommend 6-week rehabilitation therapy program to address deficits, night splinting to prevent further deformity of toes, and vocational counseling.

Results of the muscle skeletal evaluation are as follows:

- Significant increase in thoracic kyphosis (outward curvature of the spine at the top of the back) with scoliosis (sideways deviation of the spine)
- Left shoulder three-quarter inch lower than right shoulder; right iliac crest one-quarter inch higher than left
- Posture in forward-head, rounded-shoulder stance
- Decreased muscle mass in gastrocnemius and lower leg area with increased toe flexion

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<th>Projected Evaluations</th>
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<td><strong>Recommendation (by whom)</strong></td>
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Conclusion

The role of the physical therapist is vital in life care planning in many cases. There exists the opportunity to facilitate good health, to minimize suffering and pain, and to restore patients or clients to the highest functional level of life. The experienced physical therapist is capable of being an effective leader and director of life care planning. The physical therapist, as a responsible leader, accepts the challenges of encouraging responsibility in the patient and team members. When participating in the life care planning process, if the physical therapist seeks to apply the principles of “seek first to understand before you are understood” (Covey, 1989, p. 239) and “do unto others as you would have them do unto you” (Matthew 22:39 paraphrased, KJV), the outcome will be an integration of the spiritual and physical worlds. This philosophy offers an appropriate balance of structure, goals, and priorities to enhance the life care planning paradigm.

Acknowledgments

The author wishes to acknowledge all the educators, mentors, associates, and work professionals, as well as friends and family, who have contributed in the past to my profession as a physical therapist. Some of the material in this chapter was based on readings from Polinsky Rehabilitation, Keith Blankenship’s Industrial Rehabilitation, The Five Love Languages by Chapman, and Strain-Counterstrain by Jones et al. Other conceptual contributors are Health South’s Rehabilitation, Gordon Cummings, Stanley Paris, and John Barnes. This chapter seeks to introduce the general

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<th>Projected Therapeutic Modalities</th>
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<td><strong>Recommendation (by whom)</strong></td>
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<td>Rehabilitation therapy to address posture, strength, balance, and endurance deficits (includes physical therapy and occupational therapy) (PT)</td>
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<td>Health and strength maintenance via supervised exercise program by PT at a model spinal cord injury center’s fitness center</td>
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\(^a\) Expected Costs included in this example are for illustration purposes only. Actual cost information will vary based on client’s specific therapy needs, geographic area, provider, and other factors.
population of professionals who are involved in life care planning, with a general overview of insights to physical therapists and their role in the life care planning process. It encompasses information I have read and received from a variety of sources, integrating those ideas and resources with my experience and opportunities in providing life care planning in the past and present. There are many excellent sources of further specific details, evaluations, and treatments available to those concerned. It is of vital importance that we apply our skills, training, and knowledge with appropriate understanding balanced with growth.

References


Chapter 9

The Role of the SLP and Assistive Technology in Life Care Planning

Carolyn Wiles Higdon

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Introduction

Individuals with communication disorders present complex, confusing, and often frustrating challenges to the life care planner. Communication is defined as the transmission or exchange of thoughts and information from one individual to another, whatever the means (e.g., speech, manual sign, gestures, or other graphic symbols). Communication may be linguistic or nonlinguistic. Communication itself is an abstract concept, with disorders in communication, defined by brain-monitoring technology, sophisticated differential diagnoses, and an ability to understand normal and abnormal human speech and language. The best-qualified person to evaluate and make recommendations in this specific area is the speech-language pathologist (SLP). The area of study is accurately referred to as communication sciences and disorders, which includes speech-language pathology and audiology. Speech-language pathology includes cognitive communication, speech, language, and swallowing.

As we begin the second century of neuroscience, we have embarrassingly little information about how speech and language develop in the normal human brain, and understanding of how these processes can be disrupted is also extremely primitive. To a large extent, this predicament results from severe technological limitations in the study of human anatomy and physiology that have prevailed until recently. Either techniques have been too invasive for use with human subjects or, for those less invasive techniques (conventional electroencephalography), the information generated is difficult to interpret, particularly with regard to normal function.

Brain imaging refers to a group of radiological techniques that differentiate abnormal from normal brain structures. Newer imaging techniques permit examining live brain tissue integrity without cranial penetration, now allowing SLPs to gather very sophisticated information about the brain and communication. Brain imaging is divided into static and dynamic techniques. Static techniques identify the anatomical structures of the brain and include computed tomography (CT) and magnetic resonance imaging (MRI). Dynamic techniques examine brain functional anatomy or physiology and include regional cerebral blood flow, single-photon emission computed tomography (SPECT), and positron emission tomography (PET).

In addition to imaging techniques, several other diagnostic techniques may be chosen to gather cognitive and language function information from the brain. The electroencephalogram (EEG) is a graphic representation of the potential differences between two separated points on the scalp surface that represent brain-transmitted electrical potentials or the electrical activity generated by brain cells. Electrical potentials are called brain waves. Brain electrical activity mapping represents a topographic mapping of the temporally recorded EEG activity of the electrical potentials from the brain. Brain electrical activity mapping provides greater clinical insight into brain physiology than an EEG (Bhatnagar, 2008).

Electromyography (EMG) is the visual record of muscular electrical activity during spontaneous and voluntary movements. Electromyography is used to determine the nerve or muscle pathology
when clinical evidence is either absent, equivocal, or needs confirmation. An examination of the quality, speed, and magnitude of electrical impulses in muscles can help detect nerve or muscle damage. It can also differentiate among muscle disease (myopathy), atrophy of spinal motor neurons (neuropathy), interruption of nerve supply (denervation), and neuromuscular (myoneural) problems.

Evoked potentials refer to normal electrical activities of the central nervous system that occur in response to specific and controlled sensory stimulation. Whether the sensory stimulus is visual, somatosensory, or auditory, evoked brain responses are recorded using electrodes referred to the spinal cord, brain stem, and scalp. Visual evoked potentials are used to evaluate electrical conduction along the optic nerve, optic tract, lateral geniculate, optic radiations, and visual cortex. Somatosensory evoked responses are elicited by simulation of contralateral peripheral nerves. Clinical conditions in which somatosensory evoked potentials are of diagnostic value include multiple sclerosis, brain injuries, brain death, posterior column spinal cord lesions, and lesions of the peripheral nerves. Evoked response audiometry is the electrophysiological assessment of auditory functions. It measures changes in neural activity that occur in the auditory acoustic stimuli. Evoked response audiometry is used for assessing the functioning of the auditory neural pathway to predict hearing thresholds in patient populations that are difficult to test. In evoked response audiometry, the most commonly measured responses are the auditory brain stem responses (brain stem auditory evoked response).

Dichotic listening is a noninvasive neuropsychological tool that involves auditory stimuli and is commonly used for assessing cerebral dominance. It involves presenting simultaneous but partially different auditory stimuli to both ears. The attention factors are minimized by requiring subjects to simultaneously attend to both ears and report the stimuli they perceive. When the linguistic material presented in both ears is largely similar and spoken in the same voice, attending to the stimuli from both ears poses processing difficulties. The neurolinguistic implications of these findings are that right ear performance can serve as an index for determining degrees of language lateralization. Strong support for the stronger contralateral auditory projections in dichotic listening came when the dichotic testing results were supported by the observation of the left language lateralization by hemispheric infusion of sodium amobarbital.

The lumbar puncture (spinal tap) is used for diagnosing various infections and hemorrhages of the central nervous system that are not observable from the CT scan. Chemical analysis of the obtained cerebrospinal fluid helps in the differential diagnosis of multiple sclerosis, neurosyphilis, Guillain–Barre syndrome, carcinomatous meningitis, and neuropathies. Lumbar puncture is contraindicated in cases of increased intracranial pressure because of the possibility of a brain stem herniation (Bhatnagar, 2008). These are a few commonly used radiological diagnostic techniques that directly apply to the management of neurological patients who are commonly seen by practicing SLPs, primarily in medical settings.

Improvements in computers during the last two decades have significantly enhanced our ability to study aspects of human anatomy and physiology otherwise inaccessible (e.g., deep structures of living brains), and to consider sophisticated experimental questions (e.g., the temporal course of neural function and the nature of individual differences). Thus, in many ways these techniques have placed us on the threshold of the first century of human neuroscience.

Neuroscience is significant in the process of life care planning because it allows life care planners the critical, and now more measurable, information to make projections about disability related to the communication disorders, as well as provides thoughtful input into the long-term medical, educational, clinical, rehabilitative, psychosocial, recreational, vocational, and technology needs of the individuals. Access to neuroscientific information also mandates that the life
care planner carefully identify the SLP in the life care planning process, to ensure that the SLP demonstrates the knowledge and skills necessary to provide irrefutable information that will stand up under scrutiny of other team members in the life care planning process, as well as from other medical, legal, and funding sources.

This chapter will discuss the role of the SLP and the advanced areas of training and preparation needed to demonstrate the level of knowledge and skills in communication sciences and disorders necessary in life care planning. Qualifications and credentials of a SLP are reviewed (ASHA, 1989), along with the assessment process and funding and economic considerations that impact the area of speech-language pathology (ASHA, 1991). Neurolitigation considerations for the SLP expert are discussed in the second half of the chapter. The whole concept of taking a role in the life care planning process is a new consideration for the SLP, who will provide an integral part in the development of the life care plan for individuals with communication or swallowing deficits. The credibility and complexity of communication disorders are just beginning to be recognized, as well as the impact that deficits in communication disorders have on multiple parts of the life care plan. If the life care planner recognizes that an individual has a communication deficit, the SLP may furnish information in the areas of cognitive communication, vocational, educational, aids to independent living, psychosocial, speech, language, swallowing, medical complications, and future medical planning.

The Role of SLP in Life Care Planning

The purpose of a life care plan is to identify the comprehensive and individualized needs of a person as they relate to a disability or chronic illness with relevant associated cost considerations. These needs are the operational components of a life care planning process. They should never be compromised or manipulated. The costs assigned to these needs are determined by the geographical consumer rate for the identified services and equipment. The costs can be developed through understanding the range of available funding streams, creative and innovative ways of negotiating, available resources, and the cost projection analyses that accompany such planning.

The SLP must be well grounded in the theory of normal development in all ages, in any previous learning or developmental problems affecting the individual, and in the current status of the individual, and must be able to predict future functioning of the individual. Many times SLPs will practice in the treatment of either the pediatric or the adult population. This frequently precludes the SLP from being able to look backward or beyond to make accurate recommendations about future functioning needs.

It is always useful for the SLP, who is consulting in the life care planning process, to be able to actively engage in the clinical treatment of individuals and their families. This enhances the SLP’ credibility, because the SLP should have realistic estimates of current needs and prognostic predictions. However, it is also imperative that the consulting SLP have a fluid understanding of the current literature and research that directly or indirectly impacts the area of communication

Person-First Language

Students as well as professionals in speech-language pathology (and audiology) must keep in mind that the problems individuals experience do not define who they are. People are not their problems; problems are something people experience. Therefore, as clinicians and researchers we follow the “client/person first” conventions as closely as possible; in other words, we refer to “a boy with an articulation disorder,” “a girl with a hearing impairment,” “a woman with a voice disorder,” and so on. Professionally, we avoid phrases such as “He’s an articulation client,” “She’s hearing impaired,” “She’s a voice case,” and so on, because the wording implies that the person’s problem is his or her identity. It is easy to slip into the habit of referring to the problem that the person has rather than to the person who has a problem. We need to learn early and maintain our vigilance to always use person-first language.
Qualifications and Credentials of an SLP for Life Care Planning Purposes

The generally accepted national standard for practice in speech-language pathology (communication sciences and disorders) is the American Speech-Language-Hearing Association (ASHA) certificate of clinical competence in speech-language pathology (CCC-SLP). The ASHA CCC-SLP requires a master’s degree in speech-language pathology, completion of a 1-year clinical fellowship, and successful passage of the national examination. For states with licensure (50 for audiology and 47 for speech-language pathology), the legal right to practice will vary with the individual licensing acts. Most licensure laws were modeled after the ASHA CCC standard (ASHA, 1996). Licensure, unlike certification, is mandatory for those states that regulate the practice of audiology and speech-language pathology. In many states, licensure requirements parallel those of ASHA certification. Further, ASHA certification will satisfy many of the requirements of state licensure when you apply for reciprocity. Table 9.1 shows the states with licensure of SLPs and audiologists. See the chapter on audiology in this text for additional information on audiology licensure.

Table 9.1 State Licensure for SLPS and Audiologists

<table>
<thead>
<tr>
<th>Alabama</th>
<th>Kentucky</th>
<th>Ohio</th>
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<tr>
<td>Alaska</td>
<td>Louisiana</td>
<td>Oklahoma</td>
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<tr>
<td>Arizona</td>
<td>Maine</td>
<td>Oregon</td>
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<tr>
<td>Arkansas</td>
<td>Massachusetts</td>
<td>Pennsylvania</td>
</tr>
<tr>
<td>California</td>
<td>Michigan*</td>
<td>Rhode Island</td>
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<tr>
<td>Colorado*</td>
<td>Minnesota</td>
<td>South Carolina</td>
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<tr>
<td>Connecticut</td>
<td>Mississippi</td>
<td>South Dakota*</td>
</tr>
<tr>
<td>Delaware</td>
<td>Missouri</td>
<td>Tennessee</td>
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<tr>
<td>District of Columbia</td>
<td>Montana</td>
<td>Texas</td>
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<tr>
<td>Florida</td>
<td>Nebraska</td>
<td>Utah</td>
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<td>Georgia</td>
<td>Nevada</td>
<td>Vermont</td>
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<tr>
<td>Hawaii</td>
<td>New Hampshire</td>
<td>Virginia</td>
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<tr>
<td>Idaho</td>
<td>New Jersey</td>
<td>Washington</td>
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<tr>
<td>Illinois</td>
<td>New Mexico</td>
<td>West Virginia</td>
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<tr>
<td>Indiana</td>
<td>New York</td>
<td>Wisconsin</td>
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<tr>
<td>Iowa</td>
<td>North Carolina</td>
<td></td>
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<tr>
<td>Kansas</td>
<td>North Dakota</td>
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</tbody>
</table>

* Does not regulate the profession of speech-language pathology.
These individuals may hold additional credentials through their state education agency. Often, the state education agency requirements do not equate to the national standard, requiring only a bachelor’s degree and education certification in a state to practice. Twelve states require school-based audiologists and SLPs to be licensed (Connecticut, Delaware, Hawaii, Kansas, Indiana, Louisiana, Massachusetts, Montana, New Mexico, Ohio, Texas, and Vermont). SLPs with specific interests may hold additional certifications determined by societies and organizations interested in developing credentials to define expertise in a particular area, such as the Rehabilitation Engineering and Assistive Technology Society of North America (also known as RESNA) or the special-interest divisions of ASHA. The special-interest divisions within ASHA are listed in Table 9.2.

Codes of ethics for all organizations in which an individual holds membership must be acknowledged and followed. Ethics is defined as “the study of standards of conduct and moral judgment … and the system or code of morals of a particular profession” (ASHA, 2003). When applied to a field or professional area, such as augmentative communication, or a profession, such as audiology or speech-language pathology, the ethical conduct of practitioners is embodied both in a code (or canons) of ethics and in standards of practice. SLPs and audiologists must comply with the code of ethics for their discipline. The code of ethics for a discipline is typically developed by the professional association serving it. The ASHA code of ethics sets forth the fundamental principles and rules considered essential to the preservation of the highest standards of integrity and ethical conduct to which members of the profession of speech-language pathology and audiology are bound. All professional activity must be consistent with the code of ethics. The Principle of

<table>
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<tr>
<th>Table 9.2 ASHA Special Interest Divisions</th>
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<td>15</td>
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<td>16</td>
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</table>
Ethics II, Rule B, especially important in the area of assistive technology, states “individuals shall engage in only those aspects of the profession that are within their competence, considering their level of education and training” (ASHA, 2003a).

When funding is available, third-party intermediaries in most instances require the ASHA CCC and licensure. The national certification standards are generally tied to the ASHA CCC for both funding by third-party intermediaries and for service delivery. On the other hand, other certifications in existence, such as the education agency certification, traditionally do not equate to the CCC. If you are not familiar with an individual and his or her credentials, it is wise to contact ASHA and the state licensing board to determine his credentials. It is also important to note that licensing laws usually relate to direct patient assessment and treatment in the state where the service is provided, but do not address review of records or expert testimony. The national certification is a generic certification whereby the individual has met the minimum entry-level requirements across a broad spectrum of knowledge areas in communication sciences and disorders. When funding is available, third-party intermediaries use as a guideline the requirements for service delivery established by Medicare and Medicaid (i.e., ASHA CCC-SLP) and, where applicable, a current state license.

SLPs who have the expertise to provide information in their area must also understand and participate in transdisciplinary integrated assessment and treatment models; have knowledge of funding streams and creative funding; be knowledgeable about state and federal policy, laws, and changes in these laws and policies; and be knowledgeable of collaborative sources and how to build them. They must also be able to provide clear, concise, understandable documentation that is written in a defensible but understandable format with functional milestones and goals available. For a complete communication assessment and many of the services related to delivery of care for individuals exhibiting communication and swallowing difficulties described in this chapter, it is advisable that the consulting SLP hold a doctoral degree with emphasis in the areas of assistive technology. (See Appendixes 9.1 and 9.2 for an outline of relevant information.)

**SLP Training and Preparation**

The competent SLP has received preparation in the following areas, as they relate to human communication, swallowing, and development across the life span:

- Theories and processes of normal development and aging, including motor, cognitive, social-emotional, and communication
- Physiology of speech production and swallowing, including respiration, phonation, articulation, resonance, and the vocal/aerodigestive tract
- Embryological, genetic factors in development, including the development of craniofacial structures and the nervous system
- Anatomic structures, neuroanatomy, and neurophysiology supporting speech, language, hearing, swallowing, and respiration
- Organic etiologies of disorders of communication and swallowing
- Psychological and psychosocial influences on communication and swallowing
- Neurolinguistic, linguistic, cultural, and social influences on communication
- Theories of speech perception and production, language development, and cognition
- Ethics related to diagnosis, treatment, and professional conduct
Basic computer theory and systems applications, including frequently used software and input and output devices, as they relate to evaluation and treatment of language, cognitive communication, augmentative and alternative communication (AAC), swallowing, voice disorders (see Table 9.3), and central auditory processing disorders.

**Table 9.3  Voice Disorders Addressed by the SLP**

<table>
<thead>
<tr>
<th>Functional</th>
<th>Neurological</th>
<th>Organic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diplophonia</td>
<td>Ataxic dysarthria</td>
<td>Cancer</td>
</tr>
<tr>
<td>Falsetto</td>
<td>Essential tremor</td>
<td>Congenital abnormalities</td>
</tr>
<tr>
<td>Functional aphonias</td>
<td>Guillain-Barré syndrome</td>
<td>Contact ulcers</td>
</tr>
<tr>
<td>Functional dysphonia</td>
<td>Hyperkinetic (spasmodic dysphonia, essential tremor)</td>
<td>Endocrine changes</td>
</tr>
<tr>
<td>Muscle tension dysphonia</td>
<td>Hypokinetic (Parkinson's disease)</td>
<td>Granuloma</td>
</tr>
<tr>
<td>Nodules</td>
<td>Lower motor neuron (LMN)</td>
<td>Hemangioma</td>
</tr>
<tr>
<td>Phonation breaks</td>
<td>Mixed (amyotrophic lateral sclerosis, TBI, multiple sclerosis)</td>
<td>Hyperkeratosis</td>
</tr>
<tr>
<td>Pitch breaks</td>
<td>Myasthenia gravis</td>
<td>Infectious laryngitis</td>
</tr>
<tr>
<td>Polyps</td>
<td>Resonance disturbance</td>
<td>Laryngectomy</td>
</tr>
<tr>
<td>Reinke’s edema</td>
<td>Spasmodic dysphonia</td>
<td>Leukoplakia</td>
</tr>
<tr>
<td>Traumatic laryngitis</td>
<td>Spastic dysarthria</td>
<td>Papilloma</td>
</tr>
<tr>
<td>Ventricular dysphonia</td>
<td>Unilateral dysarthria</td>
<td>Pubertal changes</td>
</tr>
<tr>
<td>Vocal cord thickening</td>
<td>Upper motor neuron (UMN)</td>
<td>Sulcus vocalis</td>
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<tr>
<td></td>
<td>Vocal fold paralysis</td>
<td>Webbing</td>
</tr>
</tbody>
</table>

- Interpersonal Communication, Human Learning, Counseling Theories and Practices, and Family Systems and Systems Theory

The SLP who is consulting on a life care plan should demonstrate an advanced knowledge and understanding of health care and educational facility practices; the common diseases and conditions affecting human communication, swallowing, and development across the life span; and medical, educational, surgical, and behavioral treatment as they relate to communication disorders, including knowledge of:

- Medical terminology
- Physicians’ orders, confidentiality, legal issues in medical practices, and information and data systems management
- Elements of the physical examination and vital sign monitors
- Medical and laboratory tests and their purposes
- Medical record documentation practices
- Pharmacologic factors affecting communication and cognitive processes, development, and behavior
- AT, AAC approaches, and the range of bioengineering adaptations used in medical settings
The Role of the SLP and Assistive Technology in Life Care Planning

- Concepts of quality control and risk management
- Concepts in medical setting environmental safety (such as universal precautions, procedures, and infection control principles; radiation exposure precautions; and the Safe Medical Devices Act)
- Team processes
- Performance improvement processes
- Theories, concepts, and practices in outcomes measures
- Theories and concepts related to the impact of psychosocial and spiritual needs and the individual’s cultural values on health care services
- Voice and laryngeal health and disorders
- Respiratory functions, tracheostomy tubes, and respiratory support requirements
- Neuroanatomy, neuropathology, and the neurophysiological support of swallowing, speech, language and related cognitive abilities (Table 9.4), and the effects of diseases and disorders of the nervous system
- Concepts in human nutrition and hydration needs and their disorders
- Methods and interpretations in neuroimaging and other forms of anatomic imaging
- Esophageal, oropharyngeal, laryngeal, and neurologic tumors
- Concepts in neuropsychology and psychiatric and psychosocial disorders
- Common medical conditions
- Educational terminology
- Federal mandates related to education
- Broad understanding of curricula and literacy
- Educational philosophy of state education agencies
- Medical and surgical management of communication and swallowing

The SLP should be able to demonstrate advanced skills and abilities in diagnostics, treatment, and service delivery. The SLP should be able to review medical records and conduct succinct clinical case histories and interviews to gather relevant information related to communication and swallowing, and to select and administer appropriate diagnostic tools and procedures and treatment for communication and swallowing disorders that are functionally relevant, family centered, culturally sensitive, and theoretically grounded.

<table>
<thead>
<tr>
<th>Language</th>
<th>Cognition</th>
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<tbody>
<tr>
<td>Phonology</td>
<td>Attention</td>
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<tr>
<td>Morphology</td>
<td>Memory</td>
</tr>
<tr>
<td>Lexicon</td>
<td>Orientation</td>
</tr>
<tr>
<td>Syntax</td>
<td>Organizing</td>
</tr>
<tr>
<td>Semantics</td>
<td>Planning</td>
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<td></td>
<td>Reasoning</td>
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<td></td>
<td>Problem solving</td>
</tr>
</tbody>
</table>

Note: This table lists the areas of language and cognition the SLP assesses and treats.
The SLP should be able to:

- Obtain a representative sample and describe articulation and voice production in meaningful, accurate, and reliable terminology that addresses intelligibility and the audio-perceptual judgments of quality, tension, pitch, loudness, variability, steadiness, oral and nasal resonance, and severity of the disorder.
- Interpret a range of acoustic and physiologic measures of voice production (see Table 9.3).
- Understand acquired communication disorders to include aphasia, apraxia, dysarthria, traumatic brain injury, locked in syndrome, and progressive deteriorating central and peripheral nervous system diseases.
- Demonstrate skills in instrumental assessments (acoustic, aerodynamic, electrolaryngographic, electromyographic, manometric, and ultrasonic measures).
- Apply techniques that ensure validity of signal processing, analysis routines, and elimination of task or signal artifacts.
- Understand assessment and treatment of autism spectrum disorders and pervasive developmental disorders.
- Use one or more techniques for imaging the larynx, vocal tract, and nasopharynx (flexible/rigid endoscopy, ultrasonography, or stroboscopy).
- Select and implement training and treatment procedures appropriate for speech prostheses and orthotics (tracheoesophageal puncture prosthesis, electrolarynges, speaking trachs and one-way valves, palatal lifts, voice amplifiers, voice output communication aids, obturators, and palatal augmentation prostheses).
- Conduct an oropharyngeal swallow examination accurately identifying abnormal structures and functions; identify symptoms, medical conditions, and medications pertinent to dysphagia; interpret and document examination findings; use instrumental techniques for screening and diagnosis of oropharyngeal dysphagia and for biofeedback in dysphagia management.
- Conduct reliable and accurate modified barium swallow procedures following a standard protocol that includes identification of structural abnormalities; swallowing motility disorders; presence, time, and etiology of aspiration; and appropriate treatment techniques (posture, maneuvers, bolus modification).
- Determine patient management decisions regarding oral/nonoral intake, diet, risk precautions, candidacy for intervention, and treatment strategies.
- Select and appropriately apply aided and unaided communication, including both linguistic and nonlinguistic modes and methods.
- Locate and access assistive technology (AT), services, and funding sources.
- Work effectively with interpreters and translators and use assistive listening devices when needed for patient care.
- Communicate findings and treatment plans in a manner that is fitting and consistent with health care facility procedures.
- Counsel and educate patients and families and work within family systems to elicit participation in the treatment plan and work as a member of a health educational care team. (See also Table 9.5 for a description of the types of physical and communication impairments that may need AAC or AT evaluation by a SLP.)

In December 1995, Jean-Dominique Bauby, the 43-year-old editor of the French magazine *ELLE* (published in many languages), suffered from a severe stroke in his brain stem that left him permanently paralyzed from head to toe, although his mind was intact—a victim of locked-in syndrome. Where once he had been renowned for his gregariousness and wit, Bauby now found himself imprisoned in an inert body, able to communicate only by blinking his left eye. It is remarkable that in doing so he was able to compose an eloquent memoir, which was published 2 days before his death in 1996 and went on to become an international bestseller. Bauby was able to accomplish this time-consuming and tedious task through the help of an assistant from his publisher: for each letter of every word of the 132-page book, the assistant would begin with the letter A and proceed through the alphabet until she reached the correct letter, at which time Bauby would make his only possible responses, the blink of his left eye, to indicate that was the letter he wanted. In this manner he dictated his memoir, *The Diving Bell and the Butterfly*. (Adapted from Bauby, 1996/Fogle 2008)
The SLP will need to consider all of the following categories, regardless of the age of the individual, in the development of information for the life care plan: an oral and pharyngeal swallowing (dysphagia) assessment to include modified barium swallows, videostroboscopy evaluation, prostodontic intervention, and palatal prostheses; cognitive communication information; auditory processing information to include central auditory processing, augmentative communication assessment information, AT assessment information, voice and vocal information including videostroboscopy, and Botox assessment information; oral peripheral motor information; hearing acuity information; assistive listening device; and cochlear implant information.

The critical information obtained from a thorough communication sciences and disorders assessment must be considered within all the parameters of the life care plan itself. In other words, any and all areas that are impacted by deficits in communication and swallowing must be addressed with recommendations, if deemed appropriate by the evaluating SLP. These parameters include projected evaluation, projected therapeutic modalities, diagnostic testing and educational assessment, mobility (including accessories and maintenance of mobility technology), aids for independent functioning, orthotics and prosthetics, home furnishing and accessories, pharmacology needs, home/facility care, future medical care, transportation, health and strength maintenance, architectural renovations, potential complications, orthopedic equipment needs, vocational/educational planning, AT in the areas of sensory deficits, cognitive challenges, and communication disorders (including Jenny Craig, the well-known cofounder of weight-loss centers, had a bizarre accident in 1995. She was watching television while sitting on a couch with no headrest. She fell asleep and her head fell forward with her chin on her chest. A loud noise from the TV startled her and her head jerked up, causing the mandible to snap over her maxilla. She had to pry her teeth apart, and began to speak with a lisp as a result of trying to keep her lower teeth from hitting her upper teeth. She immediately saw her dentist, who referred her to a temporal mandibular joint (TMJ) specialist who told her that she had dislocated her jaw. The TMJ specialist recommended she try dental appliances, none of which helped. Her speech problem became worse and chronic. She was diagnosed with focal dystonia of the mandible (involuntary muscle contractions that induce abnormal movements and postures caused by the trauma of the sudden jerking of her mandible). She received Botox injections in her cheeks, which had no beneficial effect on her speech. Three years after the accident, she saw a reconstructive surgeon who specialized in cleft lip and palate and was able to repair some of the damaged muscle tissue that had been caused by the years of abnormal mandibular movements. In addition, the surgeon was the first person to recommend speech therapy. Craig began working with an SLP 5 days a week, 1 hour per day plus speech exercises in between appointments. Although her speech is not the same as it had been before the unusual accident, Craig is thankful she can communicate with people. (Fogle, 2008)

<table>
<thead>
<tr>
<th>Table 9.5 Physical and Communication Impairments That May Need AAC or AT</th>
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<tbody>
<tr>
<td>Developmental disabilities such as cerebral palsy, Down’s syndrome</td>
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<tr>
<td>Autism spectrum disorders and pervasive developmental disorders</td>
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<tr>
<td>Childhood apraxia of speech</td>
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<tr>
<td>Aphasia</td>
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<tr>
<td>Apraxia</td>
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<tr>
<td>Dysarthria</td>
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<tr>
<td>Traumatic brain injuries (closed and open)</td>
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<tr>
<td>Locked-in syndrome</td>
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<tr>
<td>Progressive deteriorating central and peripheral nervous system diseases (Parkinson’s disease, ALS, multiple sclerosis, Guillain-Barré syndrome, dementias, and Alzheimer’s)</td>
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</table>
hearing and processing difficulties needing assistive listening devices). (See Appendix 9.2 for an outline.)

**Terminology in the Field of Communication Sciences and Disorders**

The importance of terminology relative to our communication with other professionals and the general public, as well as the very special needs of international and transdisciplinary communication and development, has become increasingly apparent. In addition to improved consistency in the use of terms, there is the need to carefully examine what meanings the developing jargon may have to other individuals who rely primarily on a dictionary and common sense. Although many people in the field may know what is meant by a given term, others may not share the same meaning. Some terms used by many people in one country may not easily translate into other languages. Even more apparent, with the diversity of people in the world today, care must be exercised to consider multiple interpretations of a term, sometimes affected by the perspective of one's culture.

Because of the transdisciplinary nature of the medical-legal-clinical world, there are also problems of various disciplines using other jargon to describe essentially the same phenomenon, act, or characteristic. These problems reflect the need for an emerging field like life care planning to develop an internally consistent and logical terminology that will facilitate the international and transdisciplinary development of the field. It is important to actively educate individuals on the life care planning team concerning specific terminology that defines and describes areas of assessment and treatment within the field of communication sciences and disorders. The author refers you to Appendix 9.13 for a list of communication sciences and disorders (both audiology and speech-language pathology acronyms).

**The SLP Review of Records and Intake**

The SLP must perform his own case intake, consisting of talking with the referral source, determining the time frames needed to complete testing, arranging the financial and billing agreements, and arranging for a release of all pertinent information. Additional testing needed may be identified at this time or during the initial interview arrangements.

The SLP will then review a copy of the medical records to include:

- Nursing notes
- Doctor’s orders
- Other services’ reports
- Educational information
- Vocational information
- Day-in-the-life videos
- Other relevant documentation, depending on the etiology and diagnosis

A thorough assessment battery is then administered, gathering information from the spouse, family, or other relatives, including the clients themselves. This step may also include the opportunity for the SLP to consult and interview other team members whose information may have a bearing on final recommendations of the SLP. At this time, if additional medical, clinical,
vocational, or educational information or evaluations are needed, requests for these additional information-gathering steps should be submitted to the referral source. A letter may be composed outlining the correct questions with supporting data to ensure that the SLP has the opportunity to solicit the needed information.

At the completion of the assessment, the SLP must be able to provide a written report, documenting the test results, observations, and conclusions with clear recommendations. These recommendations must be detailed to include a projection of future care costs, frequency of service or treatment, duration, base cost, source of information, and recognized vendors or manufacturers, current prices, collaborative sources, and categories of information. It is recommended that the consulting SLP be knowledgeable about the local sources and costs of these recommendations, either through direct contact with suppliers or through catalog and desktop-computerized research. Recommendations from the SLP should be discussed with the client and family, treatment team members, and other life care team members if they directly impact the final recommendations and the cost analysis of the plan by the economist. Any coordination and agreement needed between team members including the economist should occur at this time.

A draft of the communication sciences and disorders assessment and recommendations report should be written and distributed to the life care planner for review relative of the accuracy and completeness of the information. The SLP must be able to explain, from a life care planning perspective, the reasons and rationales that are relative to their recommendations. These must be lifelong recommendations and objectives, developed in an integrated format. Once the document is correct and complete, a final draft should be compiled and distributed to the life care planner and the referral source. It should be determined, by these two parties, whether the written documentation should be sent to other internal life care planning team members, including the family and client, and to external individuals.

**Assessment Process**

There are four methods of gathering and interpreting quantitative and qualitative information about the client that should be used in the communication sciences and disorders assessment process by the SLP. These four measures are a collection of the initial database, interview procedures, clinical assessment, and formal assessment procedures (Dunn & Dunn, 1991). Often more than one method is used to gather information about the same aspect of a client’s skills and abilities, the context, the activity, or the use of technology or equipment. Information collected should include the reason and need for referral, medical diagnosis, and educational and vocational background information. This information is collected during the referral and intake phase, and its purpose is to provide preliminary data for planning the assessment. The interview takes place during the identification phase as a means of gathering information regarding the consumer and her needs. It is important that the consumer, family members, rehabilitation or education professionals, and other care providers be interviewed.

Formal assessment procedures are administered in a prescribed way and have set methods of scoring and interpretation. Therefore, they can be duplicated and analyzed. They may or may not be standardized. Clinical assessment techniques involve skilled observation of the consumer and are used throughout the assessment process. These techniques may be structured so that a series of steps is followed to determine specific skills, or they may be intentionally left unstructured to see what takes place. Observation can be done during a simulated task in a clinic setting or in a context familiar to the consumer such as a classroom or workplace. Differential diagnosis is an
ongoing and essential component of the assessment process and one that requires an advanced level of understanding and perspective about the trauma or injury.

**Pediatric and Adolescent Assessments**

Evaluating children (pediatric and adolescent) presents complex and challenging issues, complicated by the catastrophic nature of the disease, disability, or trauma and frequently challenged by the almost insurmountable task of planning a child’s life. For these reasons, it is critical to make accurate and thorough projections and careful analysis of the disability, educate team members and caregivers about the pediatric disabilities, and develop a differential diagnostic therapeutic approach to service delivery to the child. The list of pediatric and adolescent considerations in the communication sciences and disorders assessment is lengthy, detailed, and can be complex. It is important to disclose that the list is not all-inclusive, because changes occur as research and science enhance the process. Readers should see Appendix 9.14 for a basic speech and language checklist for birth to 24 months.

There are areas that warrant consideration when performing a communication evaluation for a pediatric or adolescent individual that are not considered, or at least not in the same detail, when evaluating an adult. Chronological age and pretrauma development are used as the normal benchmarks against which to measure the disability issues. Routine medical needs must be addressed to the pediatric specialists who would provide the information that impacts a child’s communication development. These include pediatric physiatry, otolaryngology, pediatric neurology, developmental medicine, audiology, dental/orthodontic, prosthodontist, and pediatric neuro-ophthalmology and ophthalmology. It should be noted here that there is a trend in the medical specialty fields to identify specialists who work solely with adolescents. Additional cognitive and educational information is gathered from the following sources:

- Educational consultants to private and public educational programs
- Personal caregivers and attendants
- Pediatric neuropsychological assessment
- Occupational and physical therapy
- Vision and hearing specialists
- Evaluators of driving
- Programs for the development of social and pragmatic skills
- Prevocational and vocational training programs

One area receiving an increased amount of attention at this time is autism. Autism (autistic disorders) is within the broader diagnostic category of autism spectrum disorder (ASD). Other diagnoses in the category include Asperger’s syndrome, pervasive developmental disorder (PDD) (sometimes referred to as PDD-NOS), and childhood disintegrative disorder. All of these disorders occur in males approximately four times more often than in females. In earlier years, autism affected 1 in 500 children; however, with the explosive increase in the United States (and apparently in other countries), whether because of better diagnoses or actual increases in cases, it is now estimated that 1 in 150 children ages 10 and younger are classified as having some form of ASD (Bishop, 1989; Gillberg, 1991; Tonge, 2002; Owens, 2004). SLPs are aggressively involved in treating children and adolescents with ASD.
Federal Mandates and Policies

The SLP, as an outcome of the assessment results, frequently provides AT or augmentative and alternative communication (AAC) recommendations. AT is defined as any technology used to enable individuals to perform tasks that are difficult or impossible due to disabilities (Lloyd et al., 1997). AAC itself is defined as the supplement or replacement of natural speech or writing using aided or unaided symbols, and the field is referred to as the clinical/educational practice to improve the communication skills of individuals with little or no functional speech (Lloyd et al., 1997). It is important to be knowledgeable about the laws and policies that support the use of AT or AAC. The list of federal mandates that relate to the use of AT, the development of AT services (evaluation and therapy), and the integration of AT devices and services into medicine, education, independent living, and vocational arenas is lengthy. The partial list of mandates as shown in Table 9.6 continues to change (and improve) and is not considered to be inclusive. It is included to give readers an idea of the growing list of political directives that acknowledge the consumer’s need for AT devices and services.

Industrial advancements and competition have driven the recent development of AT devices, but the development of services and service delivery in the United States has been influenced significantly by federal legislation. Over the last 40 years, the federal government has enacted a series of bills and initiatives requiring federal agencies, states, and private industry to support the employment of people with disabilities. Milestones over the 40 years include the following most recent legislation.

The Rehabilitation Act of 1973 mandates reasonable accommodation in federally funded employment and higher education for AT and services. This act has established several important principles upon which subsequent legislation has been based. These include *reasonable accommodations* in employment and in secondary education. The act mandates that employers and institutions of higher education receiving federal funds seek to accommodate the needs of employers

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<th>Table 9.6 Federal Mandates</th>
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<td>Section 504 of the Rehabilitation Act of 1973</td>
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<td>Individuals with Disabilities Education Act (IDEA), PL 101-476</td>
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<td>Technology-Related Assistance for Individuals with Disabilities Act of 1988, PL 100-407</td>
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<tr>
<td>Technology-Related Assistance for Individuals with Disabilities Act Amendments, PL 103-218</td>
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<td>Americans with Disabilities Act (ADA) of 1990, PL 101-336</td>
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<td>Goals 2000: Educate America Act, PL 103-85</td>
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<td>Improving America's Schools Act, PL 103-382</td>
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<td>Telecommunications Act of 1996, PL 104-104</td>
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<td>Telecommunications for the Disabled Act of 1982</td>
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<td>Telecommunications Accessibility Enhancement Act of 1988</td>
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<td>Rehabilitation Act, Section 508</td>
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and students who have disabilities. It specifically prohibited discrimination in employment or admission to academic programs solely on the basis of a handicapping condition. Sections 503 (educational institutions) and 504 (employers receiving federal funds) of this act describe both reasonable accommodations and least restrictive environment (LRE), a term relating to the degree of modification in a job or academic program that is acceptable. Many of the efforts to achieve accommodations in the least restrictive environment involved the use of assistive technologies.

The Education for All Handicapped Children Act (EHA) of 1975 extends reasonable accommodations for students from ages 5 to 21, providing a free, appropriate public education (FAPE). This act initiated procedures to ensure that each public school system identifies and provides all children with disabilities with an education. States were also mandated to establish procedures for enforcement. AT plays a more significant role in gaining access to educational programs. The act created the individual education plan (IEP) to be made for all students with disabilities. This act, also known as PL 94-142, established the right of all children to a free and appropriate education, regardless of handicapping condition. When PL 94-142 passed, children with disabilities who were not in school programs or those who were but who were not receiving services began individual education plans (IEPs) with measurable goals, AT, and services. Lack of local services or lack of funding was not a reason to deny services. The impact of this law has been far reaching. Devices ranging from sensory aids (visual and auditory) to augmentative communication devices to specialized computers have been utilized to provide access to educational programs for children with disabilities. Several additional acts leading up to PL 94-142 gave the foundation for the passage of this act.

The passage of the Elementary and Secondary Education Act (PL 89-10) in 1965 to improve quality of education for individuals and the passage of Elementary and Secondary Education Amendments for Children with Handicaps (PL 89-313) established the foundation for future legislation dealing with children with handicaps. The zero reject principle is the principle developed out of EHA, stating that all children, regardless of the severity of their disability, have a right to special education services. These services are provided by the local education agency (LEA) in the LRE. The Handicapped Infants and Toddlers Act of 1986 extended the preceding act to children ages 5 and under, expanding emphasis on educationally related AT.

Assistive technology (AT) includes both devices and services. The Individuals with Disabilities Education Act (IDEA) (reauthorized in 2004) defines an AT device as any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities. Devices can replace a missing limb, help prevent the worsening of a condition, improve physical functioning, increase a person’s capacity to learn, or strengthen a physical or other weakness. AT services support people with disabilities or their caregivers to help them select, acquire, or use AT devices. Such services also include functional evaluations, training on or demonstration of devices, and purchasing or leasing devices. Specifically, AT services include the following:

- Evaluating the needs of an individual with a disability, including a functional evaluation of the individual in the individual’s customary environment
- Purchasing, leasing, or otherwise providing for the acquisition of AT devices by individuals with disabilities
- Selecting, designing, fitting, customizing, adapting, applying, maintaining, repairing, or replacing of AT services
- Coordinating and using other therapies, interventions, or services with AT devices, such as those associated with existing education and rehabilitation plans and programs
Training or technical assistance for an individual with disabilities or family of an individual with disabilities

Training or technical assistance for professionals (including individuals providing education and rehabilitation services), employers, or other individuals who provide services to, employ, or are otherwise substantially involved in the major life functions of individuals with disabilities

AT can help people learn, compete in the work environment, achieve independence, or improve quality of life. Although the use of AT is not an end in itself, it is part of an ongoing therapeutic process to improve functional capabilities.

Examples of AT

Aids for Daily Living: Self-help aids for use in activities such as eating, bathing, cooking, dressing, toileting, home maintenance, and so on. Examples include modified eating utensils, adapted books, pencil holders, page turners, dressing aids, and adapted personal hygiene aids.

Aids for Hearing Impaired: Aids for specific populations including assistive listening devices (infrared, FM loop systems), hearing aids, TTYs, visual and tactile alerting systems, and so on.

Aids for Vision Impaired: Aids for specific populations including magnifiers, Braille or speech output devices, large-print screens, closed-circuit television for magnifying documents, and so on.

Augmentative and Alternative Communication (AAC): Electronic and nonelectronic devices that help persons with speech and/or hearing disabilities communicate: communication boards, speech synthesizers, modified typewriters, head pointers, and text-to-voice software.

Computer Access Aids: Headsticks, light pointers, modified or alternate keyboards, switches activated by pressure, sound or voice, touch screens, special software, and voice-to-text software that enable persons with disabilities to use a computer. This category includes speech recognition software.

Environmental Controls: Electronic systems that help people control various appliances, switches for telephone, TV, or other appliances activated by pressure, eyebrows, or breath.

Home/Workplace Modifications: Structural adaptations that remove or reduce physical barriers: ramps, lifts, bathroom changes, automatic door openers, and expanded doorways.

Mobility Aids: Devices that help people move within their environments: electric or manual wheelchairs, modifications of vehicles for travel, scooters, crutches, canes, and walkers.

Prosthetics and Orthotics: Replacement or augmentation of body parts with artificial limbs or other orthotic aids such as splints or braces. There are also prosthetics to assist with cognitive limitations or deficits, including audiotapes or pagers (that function as prompts or reminders).

Recreation: Devices to enable participation in sports, social, cultural events. Examples include audio description for movies, adaptive controls for video games, adaptive fishing rods, cuffs for grasping paddles or racquets, and seating systems for boats.

Seating and Positioning: Adapted seating, cushions, standing tables, positioning belts, braces, cushions and wedges to maintain posture, and devices that provide body support to help people perform a range of daily tasks.

Service Animals: The Americans with Disabilities Act defines a service animal as any guide dog (for visually impaired and blind individuals), signal dog (for hearing impaired or deaf individuals), or other animal individually trained to provide assistance to an individual with a disability.
Vehicle Modifications: Adaptive driving aids, hand controls, wheelchair and other lifts, modified vans, or other motor vehicles used for personal transportation.

The 1986 amendment to the Rehabilitation Act of 1973 required all states to include provision for AT services in the rehabilitation plans of the state vocational rehab agencies. Section 508 mandates equal access to electronic office equipment for all federal employees. Technology-Related Assistance for Individuals with Disabilities Act (Tech Act) of 1988 mandates consumer-driven AT services and system changes in the states. This act created the development of the Tech Act programs throughout the country. The act was reauthorized in 1994. This legislation authorized funds for states to establish and implement a consumer-responsive, statewide program of technology-related assistance for individuals with disabilities, including identification of barriers to administering this assistance. Table 9.7 lists the priorities for the continuation of Tech Act activities and Appendix 9.15 lists the State Assistive Technology Programs.

The Americans with Disabilities Act (ADA) (PL 101-336) of 1990 (reauthorized in 2002) prohibits discrimination based on disability in employment, transportation, and telecommunications. The ADA furthers the goal of full participation of people with disabilities by giving civil rights protection to individuals with disabilities that are like those provided to individuals on the basis of race, sex, national origin, and religion. It guarantees equal opportunity for individuals with disabilities in employment, public accommodations, transportation, state and local government services, and telecommunications. President George H. W. Bush signed the ADA into law on July 26, 1990. Copies of the full Americans with Disabilities Act of 1990 may be obtained at no cost from the U.S. Subcommittee on Disability Policy, 113 Hart, Senate Office Building, Washington, DC 20510. The ADA Private Transportation hotline is (202) 224-6265.

The IDEA of 1991 (Public Law 105-17 and the reauthorization of PL 94-142), which became the Individuals with Disabilities Improvement Act (IDIA) of 2003, mandates that all local educational agencies provide AT devices and services to benefit students with disabilities. The IDEA mandate includes that local educational agencies be responsible for providing AT devices and services if these are required as part of the child’s educational or related services or as a supplementary aid or service. AT devices are identified in the IDEA as “any item, piece of equipment

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<th>Table 9.7 Tech Act Priorities</th>
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<td>To promote public awareness of AT at the national level</td>
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<td>To provide training and education about AT on a national basis for stakeholders, including other national social service and business organizations, members of the insurance and health care industry, and public office holders/policy makers</td>
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<td>To develop positions on a full range of national AT- and disability-related issues and to share these positions with other organizations or policy makers, as needed, to ensure that the views of the states and territories and their consumers with regard to AT service delivery are adequately represented</td>
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<tr>
<td>To provide a forum for exchanging information and promoting the system change accomplishments and activities of the Tech Act projects</td>
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<tr>
<td>To identify the need and opportunities for the development of nationally conducted activities to increase access to AT</td>
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<tr>
<td>To develop and promote a national agenda</td>
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or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of children with disabilities” (Section 300.5). The IDIA was also aligned with the No Child Left Behind (NCLB) Act of 2001. Refer to www.asha.org for additional information on IDEA, IDIA, and NCLB.

The definition of an AT device, as provided in the IDEA, is very broad and gives IEP teams the flexibility that they need to make decisions about appropriate AT devices for individual students. AT includes a range of low and high technology, hardware and software, and technology solutions that are generally considered instructional technology tools if they have been identified as educationally necessary and documented in the student’s IEP. The need for AT is determined by the student’s IEP committee as educationally necessary. AT service is any service that directly assists a child with a disability in the selection, acquisition, and use of an AT device. The term includes (1) the evaluation of the needs of a child with a disability, including a functional evaluation of the child in the child’s customary environment; (2) purchasing, leasing, or otherwise providing for the acquisition of AT devices by children with disabilities; (3) selecting, designing, fitting, customizing, adapting, applying, retaining, repairing, or replacing AT devices; (4) coordinating and using other therapies, interventions, or services with AT devices, such as those associated with existing education and rehabilitation plans and programs; (5) training and technical assistance for a child with a disability or, if appropriate, that child’s family; and (6) training or technical assistance for professionals (including individuals or rehabilitation services), employers, or other individuals who provide services to employ or are otherwise substantially involved in the major life functions of children with disabilities (Section 300.6). The rules and regulations for special education in each state may also address the provision of assistive devices and services in various sections of the state’s educational policy and regulations, including the definition of assistive devices, the definition of service, within what parts of the IEP AT may be included (related services, supplemental aids and services, etc.), whether AT is needed to provide the student a FAPE, whether an AT assessment is needed, if AT is needed for the student to participate in local or state testing, and whether the technology is needed in a nonschool setting.

The reauthorization of the Rehabilitation Act of 1973 (1992) (1997) mandates rehabilitation technology to be a primary benefit to be included in the rehabilitation plan for the state rehabilitation agencies. The rehab plan was required to include how AT will be used in the rehabilitation process of each individual client. In 1992, Congress passed the reauthorization of the Rehabilitation Act of 1973. This legislation (PL 102-569 in 1992 and PL 105-17 in 1997) makes the rehabilitation act consistent with the principles of self-determination of the ADA, and it is more consumer responsive than the original version. Rehabilitation technology is defined in this law to include rehabilitation engineering and AT devices and services. Under this legislation each state must specify how AT devices and services or work site assessments are to be provided. The individualized written rehabilitation plan (IWRP, but now referred to as the Individual Work Plan, or IWP) must include the provisions of rehabilitation technology services to assist in the implementation of intermediate and long-term objectives, and rehabilitation technology is exempt from what are termed comparable benefits funding considerations. The latter concept means that vocational rehabilitation monies are considered to be the first source of funding for purchase of AT regardless of whether the individual has other funding sources. Also included within the mandate of this legislation was the continuation of rehabilitation engineering research centers, which focus on one or more core areas of research and development.

The Ticket to Work and Work Incentive Improvement Act of 1999 provides consumer choices for the provision of vocational rehabilitation and job training and other support services. The Ticket to Work and Work Incentive Improvement Act of 1999 has a number of incentives that can
be offered to benefit recipients to help them reintegrate into the workplace. Agencies that provide employment training and job placement to people with disabilities will receive a fixed portion of that person's prospective Social Security case benefit when the individual goes back to work and in the first few years during the individual's employment.

The New Freedom Initiative (February 2001) increases funding for research and development of AT resources nationwide. Although not legislation, this initiative also promotes full access to the community for people with disabilities through expanded transportation options, educational opportunities, and greater integration into the workforce. Readers should refer to Appendix 9.4 for funding terminology information.

SLPs (and audiologists) must address the unique privacy concerns, both ethical and regulatory, that confront individuals who rely on AT and the SLPs and other practitioners who provide them with services (Blackstone et al., 2002). The Health Insurance Portability and Accountability Act of 1996 (HIPAA) was created by Congress to provide guidelines for the protection of health care information and to establish standard formats for the electronic transmission of clinical data such as claims, referrals, explanation of benefits (EOB), remittance advices (RAs), and others. Although there are nine separate elements to the HIPAA legislation, the Department of Health and Human Services (DHHS) has thus far promulgated three in the form of final regulatory rules, the privacy rule and the transaction and code set rules, and the security of health care data as they are generated and stored by providers and others who have access to this protected information.

The privacy rule of HIPAA is intended as a federal floor to protect the privacy of individually identifiable health information contained in a patient's medical record. The protected information includes a patient's name, address, Social Security number, financial data, or any other identifying information in addition to the medical record itself. The rule creates substantial new compliance issues for covered entities, which include virtually all health care providers, health plans, health information clearinghouses, and those business associates who engage directly or through contractual arrangements with any of those. It also covers paper files containing this protected information that is not yet in electronic form. In short, it covers all information, including both hard and soft files. The compliance date for the privacy rule was April 14, 2003. Substantial civil and criminal penalties, up to and including jail time, can be assessed for noncompliance.

The final HIPAA privacy rule covers all individually identifiable health care information in any form, electronic or nonelectronic, that is held or transmitted by a covered entity such as a health care provider, a third-party payer, or any of their business associates who come into contact with these data. Under HIPAA, there are legal penalties for covered entities that receive or use unauthorized information intentionally. SLPs, by transmitting personal health information (PHI) in electronic form, are regulated by HIPAA. The following points about HIPAA and AT should be followed to remain compliant.

SLPs should consider assistive devices that facilitate the security of PHI by providing essential design features, vocabulary, and training that emphasize the rights to privacy and informed consent of individuals who rely on assistive devices, strategies, and techniques. The SLP is responsible for making sure the PHI is not openly accessible. New devices offer both text and audio-data logging. These logs potentially put the user at risk if they are available to others. All AAC users should receive a copy of the provider’s Notice of Privacy Practices. The Notice of Privacy Practices explains how the provider will use the individual’s PHI and outlines the provider’s confidentiality program. SLPs should educate themselves on HIPAA regulations, should conduct a gap analysis of their practice policies and procedures, and should undertake a compliance implementation program. The privacy and safety of individuals using communication boards and AAC devices
should be considered when including personal information (name, address, phone number, religion, political affiliation, etc.). Remember that not all AT users understand the privacy issues, either. Eavesdropping, communication partners speaking loudly to interpret the message, and people reading what is on the screen are all potential violations of privacy. AT users need training to learn to protect their privacy and need help selecting vocabulary such as “Please do not read my display.” AT users also need training to coordinate their speech output to conform to public expectations of conversations, help to lower the volume of their device, password protection and encryption of the message buffer and data logging system in the AT device to protect the user's content, and privacy/confidentiality training for their communication partners. Table 9.8 has HIPAA helpful websites.

**Speech-to-Speech Relay System**

**Background**

Speech-to-speech (STS) is one form of Telecommunications Relay Service (TRS). TRS is a service that allows persons with hearing and speech disabilities to access the telephone system to place and receive telephone calls. STS enables persons with a speech disability to make telephone calls using their own voice (or an assistive voice device). Like all forms of TRS, STS uses specially trained operators—called communications assistants (CAs)—to relay the conversation back and forth between the person with the speech disability and the other party to the call. STS CAs are specially trained in understanding a variety of speech disorders, which enables them to repeat what the caller says in a manner that makes the caller's words clear and understandable to the called party.

**Who Uses STS?**

Often people with speech disabilities cannot communicate by telephone because the parties they are calling cannot understand their speech. People with cerebral palsy, multiple sclerosis, muscular dystrophy, and Parkinson's disease, and those who are coping with limitations from a stroke or traumatic brain injury, may have speech disabilities. People who stutter or have had a laryngectomy may also have difficulty being understood. In general, anyone with a speech disability or anyone who wishes to call someone with a speech disability can use STS.

**Using STS**

A special phone is not needed for STS. You simply call the relay center by dialing 711, and indicate you wish to make an STS call. You are then connected to an STS CA who will repeat your spoken words, making the spoken words clear to the other party. Persons with speech disabilities may also receive STS calls.
Alternatives

Persons with speech disabilities may use a TTY to make a TRS call, but many such people have some type of physical limitation that makes typing into a text input device difficult. STS offers an alternative to a TTY or other text input device when the only other option would be not to communicate via telephone at all. Some STS providers also offer STS service for Spanish-to-Spanish callers.

Mandatory Minimum Standards for STS

The FCC imposes mandatory minimum standards on providers of all forms of TRS, such as ensuring user confidentiality, making service available 24 hours a day, 7 days a week, and answering 85% of calls within 10 seconds. The FCC also imposes certain additional requirements on STS providers. For example, STS CAs must remain with a call for a minimum of 15 minutes. In addition:

- An STS CA may, at the request of the user, retain information from a particular call in order to facilitate the completion of consecutive calls. The user may ask the TRS CA to retain such information, or the CA may ask the user if she wants the CA to repeat the same information during subsequent calls. The STS CA may retain the information only for as long as it takes to complete the subsequent calls.
- STS providers must offer STS users the option to maintain at the relay center a list of names and telephone numbers that the STS user commonly calls. When the STS user requests one of these names, the CA must repeat the name and state the telephone number to the STS user. This information must be transferred to any new STS provider.

For further information on the TRS mandatory minimum standards, go to www.fcc.gov/cgb/consumerfacts/trs.html.

Filing a Complaint with the FCC

If you have a problem with STS Relay Service, first try to resolve it with the provider. If you are unable to resolve it directly, you can file a complaint with the FCC. There is no charge for filing a complaint. You can file your complaint using the online complaint Form 2000C found on the FCC website at www.fcc.gov/cgb/complaints.html. You can also file your complaint with the FCC's Consumer Center by e-mailing fccinfo@fcc.gov, calling 1-888-CALL-FCC (1-888-225-5322) voice or 1-888-TELL-FCC (1-888-835-5322) TTY, faxing 1-866-418-0232, or writing to: Federal Communications Commission, Consumer & Governmental Affairs Bureau, Consumer Inquiries and Complaints Division, 445 12th Street SW, Washington, DC 20554.

Manufacturers’ Roles

Manufacturers’ roles in AT are often disputed and discussed. The responsibility of the manufacturer/vendor/representative varies depending on the expertise of the AT team and the expertise of the SLP. Devices are designed into a prototype device to convert it to a version that can be
fabricated in small quantities and tested with potential users. Testing of this production prototype is commonly referred to as alpha testing and is normally conducted as an in-house function by the manufacturers. Once the device appears to be functioning properly, several additional replicas are fabricated. During this development stage, the manufacturer is able to determine potential problems that may develop during the manufacturing phase and the prototypes can be evaluated more extensively by several individuals, usually clinicians and consumers simultaneously (beta testing). This accomplishes the identification of potential problems in the product, evaluation of product documentation to ensure that it is clear and useful, and evaluation of the product with a variety of individuals with disabilities to identify the target population as accurately as possible. Manufacturing then occurs, by which a working prototype of the AAC device is converted into a device that is then produced. For a list of vendors, please refer to Appendix 9.5 and Appendix 9.15, which contain a wealth of AAC and AT resources.

**Funding and Economic Issues**

There are a variety of financing and funding options (see Appendix 9.3 for some examples) for services and technology needs that a qualified SLP could recommend for support in the life care planning process. It is the consulting SLP responsibility to understand where and how to access this information on collateral funding sources. These include public programs such as maternal and child health, education, vocational rehabilitation, developmental disability programs, Department of Veterans Affairs programs, and Older Americans Act programs. There are alternative funding sources such as loans, libraries, foundations, and charitable organizations, as well as understanding options under the U.S. tax code, and the issues of civil rights, universal access, and telecommunications. A recommended outline for a funding request is shown in Appendix 9.17.

Information on current initiatives and emerging promising best practices related to the funding and acquisition of technology and services is also available and should be considered in the development of the life care plan for the areas of speech-language pathology and AT. Knowledge of policy and funding information (Appendix 9.4) adds credibility and strength to this portion of the life care planning process. Frequently, recommended technology and services in the areas of communication sciences and disorders/speech-language pathology are costly and require a lengthier and more complex plan of treatment than some other areas of the plan. If the consultant in this area can show an ability to understand and develop funding options and plans, the success of this portion of the plan is strengthened. The SLP who is involved in the life care planning process must have a current and accurate analysis of the marketplace with regard to the cost of services and technology or other goods needed in his portion of recommendations in the life care process. This also directly relates to potential policy changes in health care and education that may directly affect specific recommendations in the areas of communication sciences and disorders and current funding terminology (Appendix 9.4).

**Medical Coding**

Medical coding is useful to life care planners and SLPs (Table 9.9) for documentation and billing purposes. *Current Procedural Terminology, 4th edition (CPT)*, is a systematic listing and coding of procedures and services performed by physicians, based upon the procedure being consistent with contemporary medical practice and being performed by many physicians in clinical practice
<table>
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<tr>
<th>CPT</th>
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<tr>
<td><strong>Swallowing Function</strong></td>
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<tr>
<td>92526</td>
<td>Treatment of swallowing dysfunction and/or oral function for feeding</td>
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<tr>
<td>92610</td>
<td>Evaluation of swallowing function</td>
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<tr>
<td>92611</td>
<td>Motion fluoroscopic evaluation of swallowing function</td>
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<tr>
<td>92612</td>
<td>Flexible fiber-optic endoscopic evaluation of swallowing</td>
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<td>92613</td>
<td>With physician interpretation and report</td>
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<tr>
<td>92614</td>
<td>Flexible fiber-optic endoscopic evaluation laryngeal sensory testing by line or video recording</td>
</tr>
<tr>
<td>92615</td>
<td>With physician interpretation and report</td>
</tr>
<tr>
<td>92616</td>
<td>Flexible fiber-optic endoscopic evaluation of swallowing and laryngeal sensory testing</td>
</tr>
<tr>
<td>92617</td>
<td>With physician interpretation and report</td>
</tr>
<tr>
<td><strong>Speech and Language</strong></td>
<td></td>
</tr>
<tr>
<td>92506</td>
<td>Evaluation of speech, language, voice, communication, and/or auditory function</td>
</tr>
<tr>
<td>92507</td>
<td>Treatment of speech, language, voice, communication, and/or auditory processing disorder, individual</td>
</tr>
<tr>
<td>92508</td>
<td>Group, two or more individuals</td>
</tr>
<tr>
<td>97532</td>
<td>Development of cognitive skills to improve attention, memory, problem solving, direct one-on-one patient contact by the provider, each 15 minutes</td>
</tr>
<tr>
<td>97533</td>
<td>Sensory integration techniques to enhance sensory processing and promote adaptive responses to environmental demands; each 15 minutes</td>
</tr>
<tr>
<td>92511</td>
<td>Nasopharyngoscopy with endoscope</td>
</tr>
<tr>
<td>92520</td>
<td>Laryngeal function studies</td>
</tr>
<tr>
<td>92626</td>
<td>Evaluation of auditory rehabilitation status, first hour</td>
</tr>
<tr>
<td>92627</td>
<td>Each additional 15 minutes</td>
</tr>
<tr>
<td>92630</td>
<td>Auditory rehabilitation; prelingual hearing loss</td>
</tr>
<tr>
<td>92633</td>
<td>Auditory rehabilitation; postlingual hearing loss</td>
</tr>
<tr>
<td>96105</td>
<td>Assessment of aphasia with interpretation and report, per hour</td>
</tr>
<tr>
<td>96110</td>
<td>Developmental testing; limited, with interpretation and report</td>
</tr>
<tr>
<td>96111</td>
<td>Extended, with interpretation and report, per hour</td>
</tr>
<tr>
<td>96125</td>
<td>Standardized cognitive performance testing (e.g., Ross Information Processing Assessment) per hour of qualified health care professional’s time, both face-to-face time administering tests to the patient and time interpreting these test results and preparing the report</td>
</tr>
</tbody>
</table>
### The Role of the SLP and Assistive Technology in Life Care Planning

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>31575</td>
<td>Laryngoscopy; flexible fiber-optic; diagnostic</td>
</tr>
<tr>
<td>31579</td>
<td>Laryngoscopy; flexible or rigid fiber-optic, with stroboscopy</td>
</tr>
</tbody>
</table>

#### Augmentative and Alternative Communication

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>92597</td>
<td>Evaluation for use/fitting of voice prosthetic device to supplement oral speech</td>
</tr>
<tr>
<td>92605</td>
<td>Evaluation for prescription of non-speech-generating augmentative and alternative communication device</td>
</tr>
<tr>
<td>92606</td>
<td>Therapeutic service(s) for the use of non-speech-generating augmentative and alternative communication device, including programming and modification</td>
</tr>
<tr>
<td>92607</td>
<td>Evaluation for prescription for speech-generating augmentative and alternative communication device; face-to-face with the patient; evaluation, first hour</td>
</tr>
<tr>
<td>92608</td>
<td>Evaluation for speech device; each additional 30 minutes</td>
</tr>
<tr>
<td>92609</td>
<td>Therapeutic services for the use of speech-generating device, including programming and modification</td>
</tr>
<tr>
<td>V5336</td>
<td>Repair/Modification of AAC devices (excluding adaptive hearing aids)</td>
</tr>
</tbody>
</table>

#### Other Procedures

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>92700</td>
<td>Unlisted otolaryngological service or procedure</td>
</tr>
<tr>
<td>99366</td>
<td>Medical team conference with interdisciplinary team of health care professionals, face-to-face with patient or family present, 30 minutes or more, participation by qualified health care professional</td>
</tr>
<tr>
<td>99368</td>
<td>Medical team conference with interdisciplinary team of health care professionals, face-to-face with patient or family not present, 30 minutes or more, participation by qualified health care professional</td>
</tr>
</tbody>
</table>

in multiple locations. Each procedure is identified with a five-digit CPT code. International Classification of Diseases-9-Clinical Modification (ICD-9-CM) is an indexing of medical information by disease and operations. V codes are codes within the ICD-9CM classification system that may be used in any health care setting. V codes may be used as either a first listed (principal diagnosis code in the inpatient setting) or secondary code, depending on the circumstances of the encounter. V codes indicate a reason for an encounter and are not procedure codes. A corresponding procedure code must accompany a V code to describe the procedure performed. Readers should refer to the American Medical Association’s bookstore website (www.amabookstore.com) for current manuals or software with up-to-date listings of all CPT, ICD-9 codes, and V codes. Table 9.9 lists all the speech-language pathology CPT codes as of time of publication. Table 9.10 lists the newest ICD-9-CM SLP codes in 2008. The Model Superbill for SLPs (Appendix 9.12) (ASHA, 2008) at the end of this chapter is another point of reference for SLP medical coding.

In January 2003, five CPT codes specifically for AAC services were developed through the CPT Code Committee of the American Medical Association (AMA). These codes and definitions are listed in Table 9.10. These codes are used specifically for all AAC services (evaluation, reevaluation,
Table 9.10  New 2008 ICD-9-CM SLP Codes

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>315.34</td>
<td>Speech and language developmental delay due to hearing loss</td>
</tr>
<tr>
<td>787.20</td>
<td>Dysphagia, unspecified</td>
</tr>
<tr>
<td>787.21</td>
<td>Dysphagia, oral phase</td>
</tr>
<tr>
<td>787.22</td>
<td>Dysphagia, oropharyngeal phase</td>
</tr>
<tr>
<td>787.23</td>
<td>Dysphagia, pharyngeal phase</td>
</tr>
<tr>
<td>787.24</td>
<td>Dysphagia, pharyngoesophageal phase</td>
</tr>
<tr>
<td>787.29</td>
<td>Other dysphagia</td>
</tr>
</tbody>
</table>

and therapy). Readers should be cautioned in two regards. First, readers should refer to the *AMA CPT Code Manual* (2008) and the ASHA website (www.professional.asha.org) for clarification of the AAC codes or for further information on any of the speech, language, and hearing codes. Medical codes are always subject to updating and changes, so clinicians should stay current with medical coding terminology. Second, readers need to remember that there are Level II HCPCS national codes for speech-generating and non-speech-generating devices (Medicare terminology for an AAC device), called E codes (Table 9.11). The device codes (Level II HCPCS E codes) are specifically for devices, accessories, and software. The AAC CPT codes are for evaluation and treatment services. Readers will also find a wealth of resources in Appendix 9.7 (Toll-Free Phone Numbers and Hotlines), Appendix 9.8 (Internet Resources), Appendix 9.10 (International Sites), and Appendix 9.11 (Periodicals and Newsletters).

Note that as this edition was going to press, a pivotal announcement was made concerning private insurance coverage of augmentative communication devices for individuals with autism. Premera Blue Cross rescinded their exclusion policy on SGDs/AAC devices for individuals with ASD. Prior to this announcement (ASHA, March 2008), Premera excluded coverage of autism-related speech-language disorders on the basis that it considered SGDs and AAC devices for autism to be “investigational.” Premera would only cover those devices as “medically necessary” if they were used to treat speech-language impairments that are not “primarily” due to autism or other pervasive developmental disorders. Premera’s policy change will result in coverage under the same criteria for SGDs/AAC devices to treat speech-language disorders, regardless of whether they are related to autism or of other etiologies. Hopefully, other agencies of funding will follow the same course, now that the precedent has been set.

Neurolitigation

Following the development of the complete plan by the life care planner, it is possible that the plan will become part of neurolitigation. Success in neurolitigation frequently depends on the quality and quantity of expert evidence, which directly relates to the presentation of the life care plan, especially during medical malpractice cases and traumatic brain injury and spinal cord injury cases. Courts may admit the life care plan into evidence and rely on those plans as the predicate for compensatory damage awards when a well-qualified rehabilitation specialist prepares those plans. Included should be a list of treatment interventions that are reasonable and necessary and that show the real need for the individual to incur the expenses noted in the plan, and accurate, reasonable,
Table 9.11 Medicare Funding of AAC Technology—Fee Schedule (2008)

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>E2500 (formerly K0541)</td>
<td>Speech-Generating Device</td>
<td>E2502 (formerly K0615)</td>
<td>E2504 (formerly K0616)</td>
<td>E2506 (formerly K0617)</td>
<td>E2508 (formerly K0543)</td>
<td>E2510 (formerly K0544)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Speech Output</th>
<th>Digitized</th>
<th>Digitized</th>
<th>Digitized</th>
<th>Synthesized</th>
<th>Synthesized</th>
<th>Synthesized</th>
</tr>
</thead>
<tbody>
<tr>
<td>Codification</td>
<td>E2500</td>
<td>E2502</td>
<td>E2504</td>
<td>E2506</td>
<td>E2508</td>
<td>E2510</td>
</tr>
<tr>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Message Type</th>
<th>Prerecorded messages</th>
<th>Prerecorded messages</th>
<th>Prerecorded messages</th>
<th>Message formulation</th>
<th>Message formulation</th>
<th>Message formulation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Code</td>
<td>E2500</td>
<td>E2502</td>
<td>E2504</td>
<td>E2506</td>
<td>E2508</td>
<td>E2510</td>
</tr>
<tr>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Recording Type</th>
<th>Less than or equal to 8 minutes</th>
<th>Greater than 8 minutes but less than or equal to 20 minutes</th>
<th>Greater than 20 minutes but less than or equal to 40 minutes</th>
<th>Greater than 40 minutes</th>
<th>N/A</th>
<th>N/A</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Code</td>
<td>E2500</td>
<td>E2502</td>
<td>E2504</td>
<td>E2506</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Access Method</th>
<th>Multiple access methods</th>
<th>Multiple access methods</th>
<th>Multiple access methods</th>
<th>Direct physical contact with SGD</th>
<th>Multiple access methods</th>
<th>Program for personal computer or PDA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Code</td>
<td>E2500</td>
<td>E2502</td>
<td>E2504</td>
<td>E2506</td>
<td>E2508</td>
<td>E2510</td>
</tr>
<tr>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Message Formulation Technique</th>
<th>Multiple access methods</th>
<th>Multiple access methods</th>
<th>Multiple access methods</th>
<th>Direct physical contact with SGD</th>
<th>Multiple access methods</th>
<th>Program for personal computer or PDA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Code</td>
<td>E2500</td>
<td>E2502</td>
<td>E2504</td>
<td>E2506</td>
<td>E2508</td>
<td>E2510</td>
</tr>
<tr>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Fee Schedule Amount</th>
<th>$391.06</th>
<th>$1195.80</th>
<th>$1577.42</th>
<th>$2312.96</th>
<th>$3576.61</th>
<th>$6768.25</th>
</tr>
</thead>
<tbody>
<tr>
<td>Code</td>
<td>E2512</td>
<td>E2599</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(formerly K0546)</td>
<td>(individually priced)</td>
<td>(individually priced)</td>
<td>(individually priced)</td>
<td>(individually priced)</td>
<td>(individually priced)</td>
<td>(individually priced)</td>
</tr>
</tbody>
</table>

Note: The fee schedule amounts for each code are dependent on the current Medicare Fee Schedule. A speech-generating device (SGD) is the Medicare terminology for an AAC device.
and conservative costs for future care. SLPs participating in the life care planning process need to appreciate these requirements and understand their possible role in neurolitigation. It is possible that the consulting SLP will have to give testimony in a deposition concerning her area within the life care plan, or may be considered as an expert witness if the case goes to trial. The SLP will be responsible for answering questions and explaining her portions of the life care plan.

Regardless of particular knowledge, skills, experience, training, or education, the expert who is able to clearly articulate his opinions and conclusions, who understands the dynamics of the litigation process, and who comports with commonsense techniques for presenting testimony is the expert the attorney wishes to use to advance the client's cause. Obviously, the expert must be both professional and knowledgeable in demeanor and appearance, must be familiar with the various types of rehabilitation programs and therapeutic services available, must possess an in-depth knowledge of the current literature, and understand and be able to explain intervention strategies employed at all levels of treatment. Being able to explain the complexities involved in extremely specialized fields of expertise, without appearing to condescend to lay jurors, is particularly important.

The following is a list of general considerations that SLPs who function as experts for the purpose of explaining their part of the life care planning process should espouse. The chapter author considered whether to leave this section in at time of revision, but based on input from life care planners and SLPs who may review this prior to deposition or trial, she decided to include it.

1. Tell the truth. Then you will not have to remember what you said.
2. Phrase your answers with care. Be conscious of what they will look like in black and white.
3. Answer only the question asked; do not volunteer information.
4. Do not answer a question that you do not understand. It is not up to you to educate the examiner, and if he misuses words common in your profession, do not explain distinctions or ask questions as to what he means; it is up to him to formulate an intelligible question.
5. Do not guess, speculate, or assume anything. You only know what you have seen or heard; there is a difference between what you know and whether you have information concerning a particular subject.
6. Do not be positive about a subject unless you are; it is no crime to fail to remember or to be vague if that is the truth.
7. Do not adopt the examiner's phraseology or conclusions. If the question contains a false assumption (“Isn't it true that all communication tests are conducted in this manner?”) or terms that are not precisely correct (“So you frequently performed this treatment for this patient?”), point out the language you do not wish to accept and stick to the facts. Beware of questions that start with “Isn't it fair to say” or that attempt to paraphrase or summarize your previous testimony on a particular point.
8. Do not explain the manner in which you reached your answer, because such tactics invariably involve facts other than those concerning what you have been asked.
9. Do not testify concerning a document that is an exhibit until you have read it over thoroughly. Do not discuss documents that are not exhibits unless specifically asked about them, and then do not be positive about their content unless you are certain of your answer. Make no assumptions about documents.
10. Never get upset, explain, or argue with the examiner. You are liable to say things that are not correct, and in any event, it is not your duty to help him in this task.
11. If an objection to a question is made by counsel who retains you, listen very carefully, as it may provide information as to some underlying snare.
12. Avoid small talk, levity, ethnic or derogatory slurs of any kind, and even the mildest obscenity. Better to come across as formal than as a nonserious or offensive person.

13. If at any time during the deposition you realize you previously said something that was a mistake or incorrect, correct the error as soon as possible. Do not waive your right to read and sign a deposition. Should a realization of an error arrive after the deposition has been completed, you should make such correction on the errata sheet that will be supplied to you at the time you are asked to sign off on the deposition as transcribed.

Presentation of testimony by selected members of the rehabilitation team in litigation can be of immense benefit to counsel, the court, and lay jurors in furthering the understanding and costs associated with present and future needs and care and treatment, and in providing a framework on which an insurer or jury can justify a substantial settlement or award. One’s abilities to be effective in this regard are aided by a clear understanding of one’s role as an expert witness and the ability to interact with others and clearly articulate one’s specialized knowledge in the areas at issue, placed in the context of a full understanding of the dynamics of the litigation process and an awareness of the techniques of proper presentation.

Hot Topics in Speech-Language Pathology Update

The following is a list of hot topics in the field of speech-language pathology/communication disorders. These topics will continue to develop over the next several years, affecting recommendations in life care plans. Life care planners are encouraged to monitor these topics and to be assured that they are always on the cutting edge of this information as they develop strong well-written and well-researched life care plans.

- Development of assessment and treatment guidelines for autism spectrum disorders
- Development of assessment and treatment guidelines for central auditory processing disorders
- Development of specific treatment guidelines in neurological treatment of communication disorders (e.g., cognitive communication, aphasia, apraxia, dysarthria, and dementia)
- Development of research in gastroesophageal reflux disease (GERD)
- Efficacy and evidence-based studies to determine what treatments are effective
- Development of a stronger presence with funding streams and sources
- Improving treatment outcomes with all areas of treatment
- Development of instrumentation to improve diagnostic and treatment measures (fiber endoscopy, e-stimulation, cervical auscultation, deep pharyngeal stimulation)
- Increased inclusion as a member of medical surgical teams for management of head and neck issues (e.g., laryngectomees, palatal surgeries, vocal cord surgeries) and brain surgeries (e.g., removal of tumors, control postcerebral vascular accidents, seizure controls)
- Increased research and treatment of progressive neurological diseases such as Parkinson's, dementia, Alzheimer's, and multiple sclerosis
- Increased research participation with neurotrophic cortical electrode implantation
- Increased research with speech-language treatment post cochlear implants
- Research with pharmacological therapeutic interventions to improve communication in patients with communication disorders
- Use of Vital Stimulation to correct swallowing problems
- Collaborative surgical and prosthetic intervention for craniofacial anomalies
With the increased awareness and concern about individuals with blast-related and other brain injuries, ASHA members need comprehensive knowledge and practical skills to provide optimal services. To assist professionals working in rehabilitation settings, the Joint Committee on Interprofessional Relations Between the American Speech-Language-Hearing Association (ASHA) and the American Psychological Association’s (APA) Division 40 (Clinical Neuropsychology) has developed resources now available to ASHA members. Speech-language pathology and neuropsychology are two of the professions involved in the assessment and treatment of children and adults with cognitive-communication and language disorders resulting from congenital or acquired brain impairment. Since its insemination, the committee has produced several documents to assist professionals engaged in brain injury rehabilitation. Policy documents are accessible at ASHA Practice Policy (www.asha.org) and include:

- 1990 position statement on the value of interdisciplinary practice
- 2003 report examining commonalities and variations in education standards for both professions

Also available are two peer-reviewed articles:

- A 2002 article in the *Journal of Head Trauma Rehabilitation* on cognitive rehabilitation
- A 2007 article in the *American Journal of Speech-Language Pathology* on theoretical and clinical contributions to the assessment of memory

**Case Study**

The client, Sam Hall, age 22, sustained a brain injury following a motor vehicle accident. His traumatic brain injury (TBI) resulted in physical and mental deficits that required AT. A complete series of tests were administered, including cognitive and oral–motor (results will not be included in this brief example) assessments as appropriate, and the client clearly appeared capable of participation in speech and language therapy, as well as swallowing therapy and therapy to address his AT needs. The rehabilitation plan shown in the following was part of a comprehensive life care plan; however, only the appropriate topics for the SLP are included.

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Medical Needs</th>
<th>Dates</th>
<th>Frequency</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Swallow study with fiber endoscopy</td>
<td>2008–2010</td>
<td>Every 6 months through 2010, then optional depending on complications and need.</td>
<td>$250</td>
<td></td>
</tr>
<tr>
<td>Swallow study with MBS</td>
<td>2009–2028</td>
<td>Yearly for life.</td>
<td>$450</td>
<td></td>
</tr>
<tr>
<td>Otolaryngology</td>
<td>2008–2028</td>
<td>Yearly for life, more if additional respiratory complications occur.</td>
<td>$400</td>
<td></td>
</tr>
<tr>
<td>Nutrition consult</td>
<td>2008–2028</td>
<td>Yearly for life because of the traumatic injury. Nutrition is a crucial part of the lifelong plan.</td>
<td>$150</td>
<td></td>
</tr>
</tbody>
</table>
## The Role of the SLP and Assistive Technology in Life Care Planning

### Recommendation Medical Needs  Dates  Frequency  Expected Cost

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Dates</th>
<th>Frequency</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Audiological evaluation</td>
<td>2008–life</td>
<td>Yearly for life expectancy, because of the traumatic injury and then later to aging.</td>
<td>$820</td>
</tr>
<tr>
<td>Optional: pulmonology</td>
<td>Only if complications</td>
<td>Unknown</td>
<td>Unknown</td>
</tr>
</tbody>
</table>

### Home and Accessories

<table>
<thead>
<tr>
<th>Home and Accessories</th>
<th>Dates</th>
<th>Frequency</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Environmental control unit</td>
<td>2008–life expectancy</td>
<td>Replace every 5 years.</td>
<td>$1200 plus $100 per year maintenance and updates</td>
</tr>
</tbody>
</table>

### AT Equipment and Supplies

<table>
<thead>
<tr>
<th>AT Equipment and Supplies</th>
<th>Dates</th>
<th>Frequency</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Augmentative and alternative communication</td>
<td>2008–life expectancy</td>
<td>Replace or upgrade every 5 years for life. Initial AAC device may need to be basic, but the system will either have to increase in complexity with the client’s recovery or be replaced with a new device of increasing complexity.</td>
<td>Initially, $1500, later at $5000</td>
</tr>
<tr>
<td>Wheelchair mount and latching system for AAC</td>
<td>2008–life expectancy</td>
<td>When power chair is replaced but at 5 years as a maximum replacement time.</td>
<td>$1500</td>
</tr>
<tr>
<td>Computer, desktop, and printer</td>
<td>2008–life expectancy</td>
<td>For integration of the AAC device, to increase communication and therapy options initially, later for independent living purposes.</td>
<td>$2500</td>
</tr>
<tr>
<td>Assisted listening device to include earphone, speaker's microphone</td>
<td>2008–2018</td>
<td>For auditory processing in therapy and in the community, enhancing listening ability and minimizing “noise” in the environment.</td>
<td>$800</td>
</tr>
<tr>
<td>MyoTrac 2 biofeedback portable unit for swallowing and motor speech</td>
<td>2008–2012</td>
<td>For biofeedback of swallowing, motor speech in therapy.</td>
<td>$1600 every 5 years (with 1 year warranty), pack of 10 sensors $65 (replace one every 3 years)</td>
</tr>
</tbody>
</table>

(Continued)
(Continued)

<table>
<thead>
<tr>
<th>Item</th>
<th>Timeframe</th>
<th>Description</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low-technology and no-technology assistive devices for communication and cognition</td>
<td>2008–life expectancy</td>
<td>For quick communication (basic AAC devices) for attention, to communicate immediate needs quickly.</td>
<td>$200 per year</td>
</tr>
<tr>
<td>Memory aids</td>
<td>2008–life expectancy</td>
<td>Initially will start with low-tech device such as a card, simple voice output, then progress to an electronic calendar and organizer.</td>
<td>$200 per year</td>
</tr>
<tr>
<td>Adapted phone for AAC</td>
<td>2009</td>
<td>One time only, but upgrades in the technology will be needed. Phone: $500 with upgrades at $200 every 5 years</td>
<td>Phone: $500 with upgrades at $200 every 5 years</td>
</tr>
<tr>
<td>Work/study station (electronic)</td>
<td>2008–2037</td>
<td>Update every 5 years, needs to be electronic with the necessary adapted equipment. $8000 for initial, then $1000 every 5 years for electronic upgrade and $300 per year for maintenance of the electronics on the desk.</td>
<td>$8000 for initial, then $1000 every 5 years for electronic upgrade and $300 per year for maintenance of the electronics on the desk.</td>
</tr>
</tbody>
</table>

**Speech Pathology Services**

<table>
<thead>
<tr>
<th>Item</th>
<th>Timeframe</th>
<th>Description</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assessment to include swallowing, cognition, speech (motor), auditory processing, and reading/writing</td>
<td>2008–life expectancy</td>
<td>Yearly assessment (reassessment) until 2013, then every 5 years for life.</td>
<td>$1000–$1500 per year</td>
</tr>
<tr>
<td>Assessment for augmentative communication system and additional AT</td>
<td>2008–life expectancy</td>
<td>Yearly reassessment until 2013, then every 5 years for life. Note: the SLP evaluation and the AT evaluation may be combined, completed by one person; however, the expected cost should then be combined (i.e., $2000–$3000) yearly, etc.</td>
<td>$1000–$1500</td>
</tr>
<tr>
<td>Service</td>
<td>Time Period</td>
<td>Description</td>
<td>Frequency</td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>----------------------</td>
<td>------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>SLP therapy</td>
<td>2008–2016, then</td>
<td>First year: 5 hours per week. Second year: 3 hours per week. Third year: 2</td>
<td>$175 per hour</td>
</tr>
<tr>
<td></td>
<td>dependent upon the</td>
<td>hours per week. Fourth/fifth years: 1 hour per week if progress continues</td>
<td></td>
</tr>
<tr>
<td></td>
<td>reevaluation every</td>
<td>without further complications (illnesses, other accidents, etc.).</td>
<td></td>
</tr>
<tr>
<td></td>
<td>5 years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SLP (AT/AAC) technology training</td>
<td>2008–2016, then</td>
<td>First year: 5 hours per week. Second year: 3 hours per week. Third year: 2</td>
<td>$175 per hour</td>
</tr>
<tr>
<td></td>
<td>dependent upon the</td>
<td>hours per week. Fourth/fifth years: 1 hour per week if progress continues</td>
<td></td>
</tr>
<tr>
<td></td>
<td>AT reevaluation and</td>
<td>without further complications (illnesses, other accidents, etc.). Will need</td>
<td></td>
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<tr>
<td></td>
<td>the AT devices</td>
<td>2 hours per week for 4 weeks every 5 years if new technology is introduced</td>
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<tr>
<td></td>
<td></td>
<td>and/or when aging issues complicate the use of the technology (typically at</td>
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<tr>
<td></td>
<td></td>
<td>age 50 and 70 for someone with a disability).</td>
<td></td>
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<tr>
<td></td>
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</tr>
<tr>
<td>Vocational program and independent living</td>
<td>2012–2037</td>
<td>Job training, and/or independent living training.</td>
<td></td>
</tr>
<tr>
<td>program</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rehabilitation engineering: tech support</td>
<td>2028–2047</td>
<td>Technology support, home modifications as needed, transportation modifications</td>
<td>$100 per hour</td>
</tr>
<tr>
<td>and home/transportation access</td>
<td></td>
<td>as needed. First year: 10 hours per month; second year: 4 hours per</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>quarter (16 years for the year); third/fourth/fifth years: 10 hours per</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>year. Every year after 2013, 5 hours as needed.</td>
<td></td>
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</tbody>
</table>
Conclusion

The opportunity to participate in the life care planning process should not be taken lightly. It has been one of the most rewarding parts of the profession of speech-language pathology for this author. It requires professionals who are respected among their peers for their hard work, diligent study, research, data collection and use, expert testimony, and even ability to explain their results and information in written form. Standards must be placed on what the industry expects from its consultants when the consultants provide strong, useful assessments and recommendations. It is time for life care planners to set a level of accountability, responsibility, and recognition for the consultants that they use to develop the communication and swallowing areas of the life care plan, and it is time for SLPs to empower themselves for this process.

References

Appendix 9.1  Communication Sciences and Disorders/SLP Assessment Process

1. **Who** is a qualified SLP for life care planning purposes?
   - A. Training, licensure, certification, and practice settings
   - B. Ability to network
   - C. Integrated transdisciplinary model
   - D. Knowledge of funding streams and creative funding
   - E. Knowledge of state and federal policy, laws, and procedures
   - F. Knowledge of the development of collaborative sources

2. **What** will a qualified SLP need?
   - A. Review of all pertinent medical, vocational, educational, pharmacological, and sociological information
   - B. Differences between a staff speech-language pathology evaluation and the type of data needed to support a life care plan and to support the medical-legal challenges
   - C. Time needed to complete a communication sciences and disorders assessment
   - D. Understanding of related professional information and how it impacts and affects the speech-language information and plans
   - E. An ability to understand future trends and their application to the life care plan

3. **Components** of a communication disorders assessment
   - A. Oral and pharyngeal swallowing (dysphagia) assessment to include modified barium swallows, videostroboscopy evaluations, prostodontic intervention, and palatal prostheses
   - B. Cognitive communication information
   - C. Audiological information to include central auditory processing information
   - D. Augmentative communication assessment information
   - E. AT (assistive technology) assessment information
   - F. Voice (to include videostroboscopy, Botox assessment information, etc.)
   - G. Oral peripheral motor information
   - H. Hearing acuity information
   - I. Assistive listening device or cochlear implant information

4. **Written** documentation prepared in a defensible but understandable plan with functional milestones and goals
   - A. Ability to determine lifelong goals and functional outcomes
   - B. Ability to understand how to develop services and technology needs over time
   - C. Ability to explain how decisions within other areas of the life care plan will impact assessment, treatment, and technology needs within the communication sciences and disorders part of the plan
   - D. Ability to explain present data in terms of future impact
Appendix 9.2  Communication Sciences and Disorders: Checklist for Life Care Planning

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<table>
<thead>
<tr>
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<tbody>
<tr>
<td><strong>1.</strong></td>
<td>Does the funding source understand the purpose and usefulness of a complete evaluation from an SLP?</td>
</tr>
<tr>
<td><strong>2.</strong></td>
<td>Check qualifications, credentials, and areas of expertise of the SLP you have selected to provide the information.</td>
</tr>
<tr>
<td><strong>3.</strong></td>
<td>Does the SLP understand the concepts of the life care planning process and how the information provided by him will be used?</td>
</tr>
<tr>
<td><strong>4.</strong></td>
<td>Is the SLP aware of the professional content areas within communication sciences and disorders that must be included/considered in the report to the life care planner?</td>
</tr>
<tr>
<td></td>
<td>A. Expressive language</td>
</tr>
<tr>
<td></td>
<td>B. Receptive language</td>
</tr>
<tr>
<td></td>
<td>C. Cognitive communication</td>
</tr>
<tr>
<td></td>
<td>D. Oral and pharyngeal dysphagia</td>
</tr>
<tr>
<td></td>
<td>E. Augmentative communication</td>
</tr>
<tr>
<td></td>
<td>F. AT (assistive technology)</td>
</tr>
<tr>
<td></td>
<td>G. Hearing and auditory processing as it relates to communication</td>
</tr>
<tr>
<td></td>
<td>H. Voice and voicing aspects</td>
</tr>
<tr>
<td></td>
<td>I. Fluency and rate</td>
</tr>
<tr>
<td><strong>5.</strong></td>
<td>Can the SLP provide the results in a timely manner that meets deadlines?</td>
</tr>
<tr>
<td><strong>6.</strong></td>
<td>Has the SLP been provided access to all available and necessary records, including medical, educational, vocational, and specialized testing?</td>
</tr>
<tr>
<td><strong>7.</strong></td>
<td>Are the client and family available for a thorough test battery? Are there access restrictions?</td>
</tr>
<tr>
<td><strong>8.</strong></td>
<td>Once information is gathered, is the SLP able to provide thorough written documentation with clear recommendations?</td>
</tr>
<tr>
<td><strong>9.</strong></td>
<td>Have the questions in the following areas been considered during the communication sciences and disorders assessment?</td>
</tr>
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</table>

*Evaluations/Assessments*

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<tbody>
<tr>
<td>**   **</td>
<td>Have all the necessary assessments in the areas of communication sciences and disorders (language, speech, swallowing, augmentative communication, AT, hearing, central auditory processing, videostroboscopy, modified barium swallow studies) been considered?</td>
</tr>
<tr>
<td>**   **</td>
<td>When will reassessments be scheduled?</td>
</tr>
<tr>
<td>**   **</td>
<td>At what ages or levels of functioning will these reassessments (or additional assessments) be considered?</td>
</tr>
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*Therapy*

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<tbody>
<tr>
<td>**   **</td>
<td>How will necessary therapies be identified?</td>
</tr>
<tr>
<td>**   **</td>
<td>How will collaborative sources be used?</td>
</tr>
</tbody>
</table>
### AT

- How will technology recommendations for augmentative communication be integrated with other AT recommendations or other AT that is already present?

- Consider the use of low and high technology to include wheelchairs, environmental controls, vision equipment, hearing aids, computers, adaptive aids, and assistive listening systems.

- Have maintenance schedules, maintenance contracts, extended warranties, and replacement schedules been considered?

- What is the range of AT that is needed?

- Have the following been considered: computers, means of access, size of screens, assisted listening, low-technology communication needs, high-technology communication needs, memory aids, swallowing program equipment, necessary software, ancillary battery power, systems to integrate augmentative communication with computers for complete system development, adapted phones, variety of synthetic and digitized voices, amount of memory needed in computerized systems, and positional items for mounting and portability?

### Home Furnishing/Accessories

- How will AT within the existing home and environment be included?

- Have probable vs. potential environmental changes been considered?

### Drug Supplies and Needs

- Is there a need for medications for saliva control?

- Have all pharmacological interventions been recommended for motor control (ataxia, tremors, etc.), for memory enhancement, for seizure control?

- Have potential side effects of drugs or pharmacological intervention plans been considered in relationship to all areas of communication, swallowing, or auditory processing? These drug recommendations directly impact treatment recommendations and must be aggressively considered in the plan.

### Future Medical Care

- What annual evaluations will be needed?

- What specialties will need to repeat the evaluations for specific treatment needs and recommendations?

### Potential Complications

- What complications could potentially occur as a result of poor treatment or no treatment in the areas where recommendations have been made?

- What complications in speech, language, swallowing, communication, cognitive communication, oral–motor, hearing, and processing could occur with this etiology during the life span?

### Vocational Planning

- How will communication, hearing, and language/speech recommendations as well as augmentative communication and AT recommendations integrate with vocational plans and needs at this time and in the future?

(Continued)
### Appendix 9.2 (Continued)

**Educational Planning**

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<table>
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<tbody>
<tr>
<td></td>
<td>How will communication, hearing, and language/speech recommendations as well as augmentative communication and AT recommendations integrate with educational plans and needs at this time and in the future?</td>
</tr>
<tr>
<td></td>
<td>What systems and equipment are available within educational programs (primary, secondary, and postsecondary)?</td>
</tr>
<tr>
<td></td>
<td>Is the software appropriate for cognitive needs and projections in the future?</td>
</tr>
<tr>
<td></td>
<td>Have specialized camps, summer training programs, specialized preschools, and specialized short-term programs for upgrading and improvement as well as further training needs in the future been considered?</td>
</tr>
<tr>
<td></td>
<td>10. Is the SLP able to explain from a life care planning perspective the reasons and rationales relative to the recommendations?</td>
</tr>
<tr>
<td></td>
<td>11. Does the SLP understand how to develop lifelong recommendations and objectives? An integrated plan?</td>
</tr>
<tr>
<td></td>
<td>12. Is the SLP able to give detailed specific evaluations that allows the life care planner the ability to develop life care plan specifics (i.e., vendors, dates, current prices, specific individuals, collaborative sources, and categories of information)?</td>
</tr>
<tr>
<td></td>
<td>13. Once the draft of the life care plan is complete, is the SLP furnished a draft for careful review relative to the accuracy and completeness of the information?</td>
</tr>
<tr>
<td></td>
<td>14. Is the SLP aware that the data collection and analysis (evaluation) information may be presented to an insurance carrier, in testimony through deposition, or at a trial?</td>
</tr>
</tbody>
</table>

### Appendix 9.3 Funding and Financing

**Public Programs**

**Medicaid and Medicare**

- Required and optional services
- Intermediate care facilities for persons who are mentally retarded (ICFs/MR)
- Early and Periodic Screening, Diagnosis, and Treatment (EPSDT)
- Section 2176 Home- and Community-Based (HCB) waivers
- Community-supported living arrangements

**Maternal and Child Health**

- Maternal and child health block grant
- Children with special health care needs
- Special Projects of Regional and National Significance (SPRANS)

**Education**

- Individuals with Disabilities Education Act (IDEA) state grants (Part B)
IDEA: Programs for Infants and Toddlers with Disabilities and Their Families (Part H)

<table>
<thead>
<tr>
<th>State-operated programs (89–313)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vocational education</td>
</tr>
<tr>
<td>Head Start</td>
</tr>
<tr>
<td><strong>Vocational Rehabilitation</strong></td>
</tr>
<tr>
<td>State grants</td>
</tr>
<tr>
<td>Supported employment</td>
</tr>
<tr>
<td>Independent living (Parts A, B, and C)</td>
</tr>
<tr>
<td><strong>Social Security Benefits</strong></td>
</tr>
<tr>
<td>Title II: Social Security Disability Insurance (SSDI)</td>
</tr>
<tr>
<td>Title XVI: Supplemental Security Income (SSI)</td>
</tr>
<tr>
<td>Work Incentive Programs</td>
</tr>
<tr>
<td><strong>Developmental Disability Programs</strong></td>
</tr>
<tr>
<td><strong>Department of Veterans Affairs Programs</strong></td>
</tr>
<tr>
<td><strong>Older Americans Act Programs</strong></td>
</tr>
<tr>
<td><strong>Alternative Financing</strong></td>
</tr>
<tr>
<td>Revolving loan fund</td>
</tr>
<tr>
<td>Lending library</td>
</tr>
<tr>
<td>Discount program</td>
</tr>
<tr>
<td>Low-interest loans</td>
</tr>
<tr>
<td>Private foundations</td>
</tr>
<tr>
<td>Service clubs</td>
</tr>
<tr>
<td>Special state appropriations</td>
</tr>
<tr>
<td>State bond issues</td>
</tr>
<tr>
<td>Employee accommodations program</td>
</tr>
<tr>
<td>Equipment loan program</td>
</tr>
<tr>
<td>Corporate-sponsored loans</td>
</tr>
<tr>
<td>Charitable organizations</td>
</tr>
<tr>
<td><strong>Funding Options through Private Insurance</strong></td>
</tr>
<tr>
<td>Health insurance</td>
</tr>
<tr>
<td>Workers’ compensation</td>
</tr>
<tr>
<td>Casualty insurance</td>
</tr>
<tr>
<td>Disability insurance</td>
</tr>
<tr>
<td><strong>Funding Options through the U.S. Tax Code</strong></td>
</tr>
<tr>
<td>Medical care expense deduction</td>
</tr>
</tbody>
</table>

(Continued)
Appendix 9.3 (Continued)

<table>
<thead>
<tr>
<th>Business deductions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employee business deductions</td>
</tr>
<tr>
<td>ADA credit for small business</td>
</tr>
<tr>
<td>Credit for architectural and transportation barrier removal</td>
</tr>
<tr>
<td>Targeted jobs tax credit</td>
</tr>
<tr>
<td>Charitable contributions deduction</td>
</tr>
</tbody>
</table>

Appendix 9.4 Funding Glossary

**Access**: Generally refers to an individual's ability to obtain public or private health insurance coverage. Also used to indicate an individual's ability to easily obtain health services. That ability may be affected by restrictions on enrollees' distance from health care, waiting time to receive services, or individual's capability to communicate with providers, as well as to comprehend and carry out treatment instructions. Access may also be impacted by restrictions imposed on the physicians' choice of treatment options and various cost-containment strategies.

**Accountable health plans (AHPs)**: Under leading health reform proposals, vertically integrated organizations of providers and insurers that offer a standard benefit package approved at the national level by Congress and a federal board or commission. AHPs would be certified by the states and would be required to publish reports on their prices, patient satisfaction, and health outcomes. These health plans would fully integrate the financial, managerial, clinical, and preventive aspects of health care. Accountable health plans are also referred to as certified health plans, alliance health plans, accountable health partnerships, and qualified health plans under current reform bills.

**Actual acquisition cost**: The pharmacist's net payment made to purchase a drug product, after taking into account such items as purchasing allowances, discounts, rebates, and the like.

**Actual charge**: The amount a physician or other provider actually bills a patient for a particular medical service, procedure, or supply in a specific instance. The actual charge may differ from the usual, customary, prevailing, or reasonable charge.

**Acute care**: Medical care for health problems or illnesses that are short-term or intense in nature.

**Administrative costs**: The costs assumed by a managed care plan for administrative services such as claims processing, billing, and overhead costs.

**Adverse selection**: Among applicants for a given group or individual program, the tendency for those with an impaired health status, or who are prone to higher than average utilization of benefits, to be enrolled in disproportionate numbers and lower deductible plans. See community rating.

**Aged**: For purposes of Medicare enrollment, persons 65 years of age or over are considered to be aged. Medicaid eligibility is determined on the basis of financial need for people who meet Supplemental Security Income eligibility criteria (aged, blind, or disabled individuals) and Aid to Families with Dependent Children criteria (adults and children). Eligibility determinations are made for an entire economic unit or case (sometimes a family) based on whether one member of a case meets the criteria. For example, an aged case could consist of a 66-year-old male and his 63-year-old wife. In contrast, a disabled enrollee could be over 65 years of age.
**Agency for Health Care Policy and Research (AHCPR):** The agency of the Public Health Service responsible for enhancing the quality, appropriateness, and effectiveness of health care services.

**Allied health professionals:** Nonphysician health workers, including, but not limited to, nurses, pharmacists, respiratory therapists, phlebotomists, pulmonary therapists, occupational therapists, recreational physical therapists, lab technicians, social workers, and dental hygienists.

**All-payer system:** A reimbursement setup where all insurers reimburse providers using the same accounting system.

**Alternative delivery system:** A phrase that describes nontraditional health insurance programs that finance and provide health care to members. These include health maintenance organizations (HMOs) and preferred provider organizations (PPOs).

**Ambulatory care:** Health care services provided on an outpatient basis. No overnight stay in the hospital is required. The services of ambulatory care centers, hospital outpatient departments, physicians’ offices, and home health care services fall under this heading.

**Ambulatory surgery:** Any minor surgical procedures that can be performed at any type of medical facility on an outpatient basis—not requiring an overnight stay.

**Claim:** The formal demand by the insured to collect reimbursement for a loss covered under an insurance policy.

**Claims clearinghouse system:** System that allows electronic claims submission through a single source.

**Claims review:** The method by which an enrollee’s health care service claims are reviewed before reimbursement is made. The purpose of this monitoring system is to validate the medical appropriateness of the provided services and to be sure the cost of the service is not excessive.

**Clearinghouse capability:** Company capable of submitting electronic and paper claims to several third-party payers.

**Clinical indicator:** A tool used to monitor and evaluate care to assure desirable outcomes and to explain or prevent undesirable outcomes.

**Clinical practice guidelines:** Guidelines that specify the appropriate course(s) of treatment for specified health conditions.

**Closed-panel HMO:** Employment system in which physicians staffing an HMO are employed solely by the HMO.

**Coinsurance:** A cost-sharing requirement under a health insurance policy that provides that the insured will assume a portion or percentage of the costs of covered services. After the deductible is paid, this provision forces the subscriber to pay for a certain percentage of any remaining medical bills—usually 20%.

**Community rating:** A method health insurers use to determine the premium costs for a group it is planning to insure. Under this system, the insurer bases the premiums on the average health care costs of the community, not the age, sex, occupation, or health of individual subscribers.

**Competitive medical plan (CMP):** An organization defined by the federal Medicare program that provides enrolled members with physician, hospital, and laboratory services on a capitation basis. These services are provided primarily by physicians who are under contract, employed by, or partners in the CMP. A CMP has fewer restrictions imposed than a federally qualified health maintenance organization, but may be a state-licensed HMO.

(Continued)
### Comprehensive major medical coverage
A form of health insurance that combines the coverage of basic medical expense contracts and specialized medical care contracts into one comprehensive plan. These plans have both a deductible and coinsurance.

### Consolidated Omnibus Reconciliation Act (COBRA)
Federal law enacted in 1985. It permits an employee who has been terminated or has a reduction in work hours to continue her health insurance coverage for a period of up to 18 months. This law also covers the employee’s dependents.

### Continuous quality improvement (CQI)
A quality model that incorporates statistical tools to analyze processes and improvement in quality care.

### Contract
An agreement by which the insurer agrees to provide insurance benefits, to protect against losses, and to provide a written statement outlining the insurance provisions. The insured agrees to pay the insurer a set fee, called a premium, and other considerations.

### Contributory
A general term that describes any employee insurance plan where the employee pays part of the premium.

### Copayment
Copayments are a type of cost-sharing under Medicaid whereby insured or covered persons pay a specified flat amount per unit of service or unit of time, and the insurer pays the rest of the cost.

### Cost-per-case limits
Reimbursement limits imposed by the government on each Medicare admission to hospitals.

### Cost sharing
The general set of financing arrangements whereby the consumer must pay out of pocket to receive care, either at the time of initiating care or during the provision of health care services, or both. Cost sharing can also occur when an insured pays a portion of the monthly premium for health care insurance.

### Cost shifting
A practice by health insurers to increase premiums for one group of business to offset costs from another line of business, like Medicare and Medicaid recipients.

### Exclusivity clause
A part of a contract that prohibits physicians from contracting with more than one health maintenance organization or preferred provider organization.

### Expenditures
Under Medicaid, expenditures refers to an amount paid out by a state agency for the covered medical expenses of eligible participants.

### Experience rating
A system where an insurance company evaluates the risk of an individual or group by looking at the applicant’s health history.

### Extended care
Long-term care, ranging from routine assistance for daily activities to sophisticated medical and nursing care for those needing it. The care, covered under certain insurance policies, can be provided in homes, daycare centers, or other facilities.

### Family planning services
Family planning services are any medically approved means, including diagnosis, treatment, drugs, supplies and devices, and related counseling that are furnished or prescribed by or under the supervision of a physician for individuals of childbearing age for purposes of enabling such individuals freely to determine the number or spacing of their children.
**Federally qualified HMOs**: HMOs that meet certain federally stipulated provisions aimed at protecting consumers, e.g., providing a broad range of basic health services, assuring financial solvency, and monitoring the quality of care. HMOs must apply to the federal government for qualification. The process is administered by the Office of Prepaid Health Care of the Health Care Financing Administration (HCFA), Department of Health and Human Services (DHHS).

**Fee-for-service**: The traditional way of billing for health care services. Under this system, there is a separate charge for each patient visit and the service provided.

**First-dollar coverage**: Health policies that pay all medical expenses up to a predetermined limit, without a deductible charge.

**Fiscal agent**: A fiscal agent is a contractor that processes or pays vendor claims on behalf of the Medicaid agency.

**Fiscal intermediary**: The agent (e.g., Blue Cross or an insurance company) that has contracted with providers of service to process claims for reimbursement under health care coverage. In addition to handling financial matters, it may perform other functions such as providing consultative services or serving as a center for communicating with providers and making audits of providers’ records.

**Fiscal year**: Any 12-month period for which annual accounts are kept. The federal government’s fiscal year extends from October 1 to the following September 30.

**Fixed fee**: An established fee schedule for pharmacy services allowed by certain government and private third-party programs in lieu of cost-of-doing-business markups.

**Formulary**: A list of selected pharmaceuticals and their appropriate dosages felt to be the most useful and cost-effective for patient care. Organizations often develop a formulary under the aegis of a pharmacy and therapeutics (P&T) committee. In HMOs, physicians are often required to prescribe from the formulary.

**Freedom of choice**: Legislation restricting or eliminating the right of insurers to narrow the subscribers’ selection of providers in return for a price discount.

**Freestanding hospital**: Any hospital that is not affiliated with a multihospital system.

**Gatekeeper**: A component of an independent practice association HMO that requires a subscriber to see a primary physician and get the physician’s approval before seeing a specialist about a medical condition.

**Generic substitution**: Substituting a generic version of a branded off-patent pharmaceutical for the branded product when the latter is prescribed. Some HMOs and Medicaid programs mandate generic substitution. Mandatory generic substitution within the Medicare program is currently being debated in Congress.

**Global budget**: A budget that would determine the total amount of money that a geographic area could spend each year for health care. Under a global budget, providers and hospitals receive predetermined payments. As an enforcement mechanism for staying within budget, providers and hospitals will not receive additional funding if their costs exceed their budgeted payments.

**Infant mortality rate**: Deaths in the first year of life per 1000 births. The U.S. rate in 1990 was 9.1, 19th among developed countries. According to the U.S. General Accounting Office, 50% of these deaths are due to lifestyle factors, 20% due to environmental factors, 20% due to biological factors, and 10% due to inadequate health care.

(Continued)
**Inpatient hospital services**: Inpatient hospital services are items and services furnished to an inpatient of a hospital by the hospital, including bed and board, nursing and related services, diagnostic and therapeutic services, and medical or surgical services.

**Intensive care**: Skilled nursing services prescribed by a physician, delivered with the guidance of a registered nurse. Scope of care is provided to individuals with serious medical conditions that persist for long periods of time.

**Intermediate care facility**: An intermediate care facility is an institution furnishing health-related care and services to individuals who do not require the degree of care provided by hospitals or skilled nursing facilities as defined under Title XIX (Medicaid) of the Social Security Act.

**Job-lock**: The inability of an individual to change employers for fear of losing health coverage, particularly if the employee or a dependent has a preexisting condition.

**Laboratory and radiological services**: Professional and technical laboratory and radiological services ordered by a licensed practitioner, provided in an office or similar facility (other than a hospital outpatient department or clinic) or by a qualified lab.

**Legend drug**: A drug product that cannot be dispensed legally without a prescription.

**Long-term care**: Continuous health care delivered by a hospital or other health care institution to a patient for 30 days or more.

**Magnetic resonance imaging**: State-of-the-art machine used as a diagnostic tool, using magnetic waves to produce comprehensive pictures of the anatomy.

**Managed care**: A term coined originally to refer to the prepaid health care sector, e.g., HMOs and CMPs, where care is provided under a fixed budget and costs are managed. Increasingly, the term is being used by many analysts to include PPOs and even forms of indemnity insurance coverage that incorporate preadmission certification and other utilization controls.

**Maximum allowable cost, or reasonable cost range**: A maximum cost is fixed for which the pharmacist can be reimbursed for selected products, as identified in a formulary.

**Medicaid**: A government program that covers medical expenses for the poor and certain other classes of uninsured people, established by Title XIX of the Social Security Act. Each state administers its own program. Medicaid is funded by both the state and federal governments.

**Medicaid buy-in**: A provision in certain health reform proposals whereby the uninsured would be allowed to purchase Medicaid coverage by paying premiums on a sliding scale based on income.

**Medicaid Management Information System**: Federally developed guidelines for computer system design to achieve national standardization of Medicaid claims processing, payment, review, and reporting for all health care claims.

**Medically needy**: Under Medicaid, medically needy cases are aged, blind, or disabled individuals or families and children who are otherwise eligible for Medicaid and whose income resources are above the limits for eligibility as categorically needy but are within limits set under the Medicaid state plan.

**Medical savings accounts (MSAs)**: An account into which individuals can contribute a limited amount to cover medical costs or to buy insurance. Contributions to the accounts are sometimes tax deductible. MSAs are often cited as an incentive to limit health spending. Also called medical IRAs.
**Practice variation:** An assessment of the patterns of a practitioner’s practice to determine if the practitioner provides care that is significantly different from others with similar practices. If there is a significant difference, the practitioner’s practice is analyzed to determine the reasons for the variation and whether that practitioner’s practice patterns should be modified.

**Preferred provider organization (PPO):** Type of health insurance program where a limited group of physicians and hospitals provide a broad range of medical care for a predetermined fee. Patients using the group providers usually have their health care expenses covered in full. Those covered under the PPO who do not use the preferred providers for care usually have to pay for a portion of their medical expenses.

**Prepaid group practice plans:** Organized medical groups of essentially full-time physicians in appropriate specialties, as well as other professional and subprofessional personnel, who, for regular compensation, undertake to provide comprehensive care to an enrolled population for premium payments that are made in advance by the consumer or their employers.

**Prescribed drugs:** Prescribed drugs are drugs dispensed by a licensed pharmacist on the prescription of a practitioner licensed by law to administer such drugs, and drugs dispensed by a licensed practitioner to his own patients. This item does not include a practitioner’s drug charges that are not separable from his other charges, or drugs covered by a hospital’s bill.

**Preventative care programs:** Often called wellness programs, these programs use exercise and health education and promotion as vehicles to keep people healthy and good insurance risks.

**Primary care:** General medical care that typically deals with common injuries and illness.

**Prior authorization:** The approval a provider must obtain from an insurer or other entity before performing certain procedures using certain medical products or admitting a patient electively, in order for the service to be covered under the plan.

**Prospective financing:** Financing for health care services based on prices or budgets determined prior to the delivery of service. Payments can be per unit of service, per member, or per time period. In all its forms prospective financing differs from cost-based reimbursement, under which a provider is paid for costs incurred.

**Prospective Payment Assessment Commission (ProPAC):** A 15-member commission, appointed by the director of the Office of Technology Assessment, that makes recommendations to the secretary of the Department of Health and Human Services on various aspects of the diagnosis-related group system of Medicare reimbursement.

**Providers:** Physicians, hospitals, and other health care organizations that treat individuals for illness and injuries.

**Rate setting:** A form of financing under which hospitals or nursing homes are paid prices that are prospectively determined, generally by a state agency. Prospectively determined prices may be paid by all payers for all covered services, as in all payer systems, or by only some payers. The unit of payment can be service, patient, or time period. See prospective financing.

**Rational drug therapy:** Prescribing the right drug for the right patient, at the right time, in the right amounts, and with due consideration for relative costs.
### Reasonable charge
In processing claims for supplementary medical insurance benefits, carriers use HCFA guidelines to establish the reasonable charge for services rendered. The reasonable charge is the lowest of the actual charge billed by the physician or supplier, the charge the physician or supplier customarily bills her patients for the same services, and the prevailing charge that most physicians or suppliers in that locality bill for the same service. Increases in the physicians’ prevailing charge levels are recognized only to the extent justified by an index reflecting changes in the costs of practice and in general earnings.

### State plan
The Medicaid state plan is a comprehensive written commitment by a Medicaid agency to administer or supervise the administration of a Medicaid program in accordance with federal requirements.

### Stop loss
That point at which a third party has reinsurance to protect against the overly large single claim or the excessively high aggregate claim during a given period of time. Large employers, who are self-insured, may also purchase reinsurance for stop-loss purposes.

### Supplemental Security Income (SSI)
SSI is a program of income support for low-income aged, blind, and/or disabled persons established by Title XVI of the Social Security Act.

### Therapeutic substitution
A practice entailing a pharmacist’s dispensing a drug felt to be therapeutically equivalent to the drug prescribed by a physician without obtaining permission from the prescribing physician. Generally, the P&T committee of an HMO will formally approve therapeutic substitutions that it feels are permissible, and only those so designated can be made by the pharmacist dispensing for the HMO.

### Third-party administrator
Individual or company that contracts with employers who want to self-insure the health of their employees. They develop and coordinate self-insurance programs, process and pay the claims, and may help locate stop-loss insurance for the employer. They also can analyze the effectiveness of the program and trace the patterns of those using the benefits.

### Third-party liability
Under Medicaid, third-party liability exists if there is any entity (i.e., other government programs or insurance) that is or may be liable to pay all or part of the medical cost or injury, disease, or disability of an applicant or recipient of Medicaid.

### Total quality management (TQM)
See continuous quality improvement.

### Universal access
The availability of affordable public or private insurance coverage for every U.S. citizen or legal resident. There is no guarantee, however, that all individuals will actually choose to, or have the funds to, purchase coverage. See universal coverage.

### Universal coverage
The guaranteed provision of at least basic health care services to every U.S. citizen or legal resident. See universal access.

### Usual, customary, and reasonable charges
Method of reimbursement used under Medicaid by which state Medicaid programs set reimbursement rates using the Medicare method or a fee schedule, whichever is lower.

### Utilization review
A tool used by providers, health care organizations, and insurance companies to influence the use of health care resources with the objective of containing costs.

### Vendor
A medical vendor is an institution, agency, organization, or individual practitioner that provides health or medical services.
Vendor payments: In welfare programs, direct payments are made by the state to such providers as physicians, pharmacists, and health care institutions rather than to the welfare recipient himself.

Waiver: A rider or clause in a health insurance contract excluding an insurer’s liability for some sort of preexisting illness or injury. Also refers to a plan amendment, such as an HCFA waiver or plan modification.

Waivers (Section 1115 or 1915(b)): Section 1115 of the Social Security Act grants the secretary of Health and Human Services broad authority to waive certain laws relating to Medicaid for the purpose of conducting pilot, experimental, or demonstration projects. Section 1115 demonstration waivers allow states to change provisions of their Medicaid programs, including eligibility requirements, the scope of services available, the freedom to choose a provider, a provider’s choice to participate in a plan, the method of reimbursing providers, and the statewide application of the program. Projects typically run 3 to 5 years. States cannot change the federal Medicaid assistance percentage through a waiver.

Appendix 9.5 Vendor List

Ablenet, Inc.
1081 Tenth Ave. SE
Minneapolis, MN 55414-1312
Telephone: 800-322-0956
E-mail: customerservice@ablenetinc.com
Website: www.ablenetinc.com

Adamlab
55 East Long Lake Rd.
Mailstop PMB-337
Troy, MI 48098
Telephone: 248-594-6997

Adaptivation
2225 W 50th St., Suite 100
Sioux Falls, SD 57105-6525
Telephone: 800-723-2783
E-mail: info@adaptivation.com
Website: www.adaptivation.com

Applied Human Factors, Inc.
P.O. Box 228
Helotes, TX 78023
Telephone: 888-243-0098
E-mail: sales@ahf-net.com
Website: www.ahf-net.com

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### Appendix 9.5 (Continued)

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<thead>
<tr>
<th>Company Name</th>
<th>Address</th>
<th>Telephone</th>
<th>Email</th>
<th>Website</th>
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</thead>
<tbody>
<tr>
<td>Assistive Technology, Inc.</td>
<td>7 Wells Ave, Newton, MA 02459</td>
<td>800-793-9227</td>
<td><a href="mailto:customercare@assistivetech.com">customercare@assistivetech.com</a></td>
<td><a href="http://www.assistivetech.com">www.assistivetech.com</a></td>
</tr>
<tr>
<td>Dyanavox Systems, L.L.C.</td>
<td>2100 Wharton, Suite 400, Pittsburgh, PA 15203-1942</td>
<td>800-344-1778</td>
<td><a href="mailto:sales@dynavoxsys.com">sales@dynavoxsys.com</a></td>
<td><a href="http://www.dynavoxsys.com">www.dynavoxsys.com</a></td>
</tr>
<tr>
<td>Enabling Devices/Toys for Special Children</td>
<td>385 Warburton Ave, Hastings on Hudson, NY 10706</td>
<td>800-832-8697</td>
<td><a href="mailto:customer_support@enablingdevices.com">customer_support@enablingdevices.com</a></td>
<td><a href="http://www.enablingdevices.com">www.enablingdevices.com</a></td>
</tr>
<tr>
<td>Enkidu Research, Inc.</td>
<td>247 Pine Hill Rd, Spencerport, NY 14559</td>
<td>800-297-9570</td>
<td><a href="mailto:info@enkidu.net">info@enkidu.net</a></td>
<td><a href="http://www.enkidu.net">www.enkidu.net</a></td>
</tr>
<tr>
<td>Hearit, L.L.C.</td>
<td>8346 North Mammoth Dr, Tucson, AZ 85743-1046</td>
<td>800-298-7184</td>
<td><a href="mailto:hearitllc@hearitllc.com">hearitllc@hearitllc.com</a></td>
<td><a href="http://www.hearitllc.com">www.hearitllc.com</a></td>
</tr>
<tr>
<td>Madentec LTD.</td>
<td>9935-29A Ave, Edmonton, Alberta T6N 1A9, Canada</td>
<td>877-623-3682</td>
<td><a href="mailto:sales@madentec.com">sales@madentec.com</a></td>
<td><a href="http://www.madentec.com">www.madentec.com</a></td>
</tr>
<tr>
<td>Company Name</td>
<td>Address</td>
<td>Phone Number</td>
<td>Email Address</td>
<td>Website URL</td>
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<tr>
<td>Mayer-Johnson, Inc.</td>
<td>P.O. Box 1579, Solana Beach, CA 92075-7579</td>
<td>800-588-4548</td>
<td><a href="mailto:mayerj@mayer-johnson.com">mayerj@mayer-johnson.com</a></td>
<td><a href="http://www.mayer-johnson.com">www.mayer-johnson.com</a></td>
</tr>
<tr>
<td>Poppin and Company</td>
<td>P.O. Box 176, Unity, ME 04988</td>
<td>207-437-2746</td>
<td><a href="mailto:poppin@uninets.com">poppin@uninets.com</a></td>
<td><a href="http://www.poppinandcompany.com">www.poppinandcompany.com</a></td>
</tr>
<tr>
<td>Prentke Romich Company</td>
<td>1022 Heyl Rd., Wooster, OH 44691-9744</td>
<td>800-262-1984</td>
<td><a href="mailto:info@prentrom.com">info@prentrom.com</a></td>
<td><a href="http://www.prentrom.com">www.prentrom.com</a></td>
</tr>
<tr>
<td>Tash, Inc.</td>
<td>3512 Mayland Court, Richmond, VA 23233</td>
<td>800-463-5685</td>
<td><a href="mailto:tashinc@aol.com">tashinc@aol.com</a></td>
<td><a href="http://www.tashinc.com">www.tashinc.com</a></td>
</tr>
<tr>
<td>Toby Churchill, LTD.</td>
<td>20 Panton St., Cambridge, CB2 1HP, United Kingdom</td>
<td>011-44-1223-576117</td>
<td><a href="mailto:sales@toby-churchill.com">sales@toby-churchill.com</a></td>
<td><a href="http://www.toby-churchill.com">www.toby-churchill.com</a></td>
</tr>
<tr>
<td>Turning Point Therapy &amp; Technology Inc.</td>
<td>P.O. Box 310751, New Braunfels, TX 78131-0751</td>
<td>877-608-9812</td>
<td><a href="mailto:support@turningpointtechnology.com">support@turningpointtechnology.com</a></td>
<td><a href="http://www.turningpointtechnology.com">www.turningpointtechnology.com</a></td>
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<th>Phone</th>
<th>Email</th>
<th>Website</th>
</tr>
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<tbody>
<tr>
<td>Words+, Inc.</td>
<td>1220 West Ave. J</td>
<td>800-869-8521</td>
<td><a href="mailto:support@words-plus.com">support@words-plus.com</a></td>
<td><a href="http://www.words-plus.com">www.words-plus.com</a></td>
</tr>
<tr>
<td>Zygo Industries, Inc.</td>
<td>P.O. Box 1008</td>
<td>800-234-6006</td>
<td><a href="mailto:ZYGO@zygo-usa.com">ZYGO@zygo-usa.com</a></td>
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## Appendix 9.6  Selected AAC Websites

<table>
<thead>
<tr>
<th>Communication Aid Manufacturers</th>
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<tbody>
<tr>
<td>1. AbleNet</td>
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<tr>
<td><a href="http://www.ablenetinc.com">www.ablenetinc.com</a></td>
</tr>
<tr>
<td>AbleNet produces a variety of communication aids, switches, and other adaptive devices. It will loan a package of equipment with an accompanying training script for in-service training. The website offers links for the products catalog, AAC news, frequently asked questions, and other AAC-related websites.</td>
</tr>
<tr>
<td>2. Adaptivation</td>
</tr>
<tr>
<td><a href="http://www.adaptivation.com">www.adaptivation.com</a></td>
</tr>
<tr>
<td>Adaptivation distributes AT to persons with disabilities. Adaptivation products include the Chipper, Voice Pal, and many other related devices and the accessories that go with them. The website includes links for its product catalog, domestic and foreign dealers, upcoming workshops, and other AAC-related websites.</td>
</tr>
<tr>
<td>3. Adaptive Switch Laboratories, Inc.</td>
</tr>
<tr>
<td><a href="http://www.asl-inc.com">www.asl-inc.com</a></td>
</tr>
<tr>
<td>Adaptive Switch Laboratories, Inc., is a company that makes and sells a variety of switches and mounting kits. Its products are compatible with a variety of wheelchairs. Product catalogs and price lists can be found on its website. The ASL website also includes information about educational seminars and leasing programs.</td>
</tr>
<tr>
<td>4. AMDi</td>
</tr>
<tr>
<td><a href="http://www.amdi.net">www.amdi.net</a></td>
</tr>
<tr>
<td>AMDi designs electronic devices for governmental, industrial, and commercial customers. Some of its products include the Tech/Speak, Tech/Talk, and Tech/Four. Its website provides the product catalog and price list.</td>
</tr>
</tbody>
</table>
5. Assistive Technology, Inc.
   www.assistivetech.com
   Assistive Technology, Inc., is the manufacturer of the Gemini AAC device and universally accessible Macintosh computer, suited to a range of input methods. Assistive Technology also produces LINK, a talking keyboard. The website includes links to its products catalog and upcoming tradeshows and conferences.

6. Aurora Systems, Inc.
   www.aurora-systems.com
   Aurora Systems, Inc., is a company that provides computer software for people with learning disabilities, augmentative communication needs, and speech disabilities. The Aurora Systems, Inc., website contains purchasing information and a support system center for its products.

7. Communication Devices, Inc.
   www.comdevices.com
   Communication Devices, Inc., is the manufacturer of the Holly.com line of augmentative communication devices. This website also has links to other AAC websites.

8. Consultants for Communication Technology
   www.ConCommTech.com
   Consultants for Communication Technology products include the KeyWi and KeyWi2 lines of software, which enable a laptop computer to become a complete communication device without the need for an external synthesizer. Other products include an environmental control system. The website includes links for the company’s product catalog, downloads of a demo of its software, and the opportunity to hear the synthesized voices that are included with the KeyWi software.

9. Crestwood Communication Aids, Inc.
   www.communicationaids.com
   Crestwood Communication Aids, Inc., has a variety of light-tech products that are easy to use and affordably priced. Its website includes links to its catalog.

10. DynaVox Systems
    www.dynavoxsys.com
    Products by DynaVox Systems include the DynaMyte 3100, the DynaVox 3100, and the DynaVox line of software by both Macintosh- and IBM-compatible computers. The DynaVox Systems website includes links for tech tips, upcoming trade shows, and finding a DynaVox representative in your area.

11. Electronic Speech Enhancement, Inc.
    www.speachenhancer.com
    The entrepreneurs at Electronic Speech Enhancement, Inc., developed a technology called speech enhancement to combat the challenge of making speech clearer, not just louder. The ESE website includes links for its products and its ordering process.

12. Enabling Devices
    www.enablingdevices.com
    Enabling Devices, a division of Toys for Special Education, Inc., is dedicated to providing affordable learning and assistive devices for the physically challenged. The website for enabling devices includes links to its products catalog and an online shopping option. This website also includes links to many other related websites.

(Continued)
### 13. The Great Talking Box Company
www.greattalkingbox.com
The Great Talking Box Company distributes affordable communication devices such as EasyTalk, DifiCom 2000, and e-talk, along with accessories. The Great Talking Box Company website has other useful information such as trade show and sales information.

### 14. Gus Communications, Inc.
www.gusnic.com
Some of the products offered by Gus Communication, Inc., include a software package that is compatible with any Windows-based personal computer. The Gus Communications, Inc., website includes links for its products, ordering, and demos of its products that can be downloaded onto any IBM-compatible computer.

### 15. IntelliTools
www.intellitools.com
IntelliTools develops and markets computer products for special education. The company’s mission is to help children with educational challenges (physical and cognitive) and optimize their social and academic participation and success. Products by IntelliTools include Creativity Tools, Curriculum Resources, and SwitchIt! software. Along with information about its products, the IntelliTools website also includes links for tutorials and training, technical support, product demos, and links to other AAC-related websites.

### 16. LC Technologies, Inc.
www.eyegaze.com
LC Technologies, Inc., is a company that manufactures the Eyegaze Communication System, a system that “empowers people to communicate with the world by only the movement of their eyes.” Its website includes product brochures and prices. In addition, it also provides papers and presentations by individuals who have used or worked with Eyegaze Communication Systems.

### 17. Luminaud, Inc.
www.luminaud.com
Luminaud, Inc., is a manufacturer and supplier of a wide range of electronic speech equipment and tracheostomy products. Some of its products include Minivox, Chattervox, and other voice amplification products. Its website includes its products catalog and price lists and links to other AAC-related websites.

### 18. Madentec
www.madentec.com
Madentec is a company that distributes products such as the computer enhancer Tracker 2000, a head-pointer access system. In addition, it sells a variety of electronic aids for environmental control. The Madentec website also includes frequently asked questions and links that provide games to play using Tracker 2000.

### 19. Mayer-Johnson, Inc.
www.mayer-johnson.com
Mayer-Johnson, Inc., offers products for special needs and education. Products by Mayer-Johnson, Inc., include Picture Communication Symbols, BoardMaker software Picture Communication Symbols,* and many other AAC-related devices and materials. Its website includes links to other AAC websites and the product catalog, as well as upcoming conferences and tech support for the Mayer-Johnson line of products. *Picture Communication Symbols (PCS) are copyrighted © 1981–2000, Mayer-Johnson, Inc. All rights reserved.
<table>
<thead>
<tr>
<th>20. Prentke Romich Company</th>
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<tr>
<td><a href="http://www.prentrom.com">www.prentrom.com</a></td>
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<tr>
<td>Prentke Romich Company (PRC) produces a number of devices that take advantage of Minspeak semantic compaction. This vocabulary system features over 4000 vocabulary words available on a single overlay. Prentke Romich Company has a variety of training options, including video conferencing and web-based modules. The PRC website offers links to its product catalog, product representatives, training seminars, and conferences, as well as a link to other AAC-related websites.</td>
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<tr>
<th>21. RJ Cooper &amp; Associates</th>
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<tr>
<td><a href="http://www.rjcooper.com">www.rjcooper.com</a></td>
</tr>
<tr>
<td>RJ Cooper &amp; Associates makes products for persons with special needs, including special software and hardware adaptations. RJ Cooper &amp; Associates also sells a variety of switches and related devices, including the Big Baby Switch especially designed for babies. Its website includes a single-switch arcade game that can be downloaded to a computer as well as links to its TechWeek vacation, lectures, and workshops.</td>
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<tr>
<th>22. Saltillo Corporation</th>
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<tr>
<td><a href="http://www.saltillo.com">www.saltillo.com</a></td>
</tr>
<tr>
<td>Saltillo Corporation is a company that distributes communication products for nonspeaking individuals. Its products are designed to be easy to use by the communicator and her support staff. The Saltillo Corporation website contains details and purchasing information about ChatBox and its accessories, among other AAC devices. The website also contains helpful technical support, distributor locations, and its rental policies.</td>
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<tr>
<th>23. Slater Software, Inc.</th>
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<tr>
<td><a href="http://www.slatersoftware.com">www.slatersoftware.com</a></td>
</tr>
<tr>
<td>Slater Software, Inc., is the producer of the Picture It, Pixreader, and Pixwriter software packages that teach literacy skills to children with special needs. Its website includes descriptions of products along with Adaptive Plays and Interactive Books. It also includes a link to the products catalog.</td>
</tr>
</tbody>
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<table>
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<tr>
<th>24. Synergy</th>
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<tbody>
<tr>
<td><a href="http://www.speakwithus.com">www.speakwithus.com</a></td>
</tr>
<tr>
<td>Synergy is a company that makes AAC/computer systems and a wide range of software and adaptive inputs. Synergy offers an AAC/functional computer system for both Macintosh- and IBM-compatible computers. Its website includes links for funding assistance, frequently asked questions, and upcoming workshops and lectures.</td>
</tr>
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<tr>
<th>25. Tash, Inc.</th>
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<tr>
<td><a href="http://www.tashinc.com">www.tashinc.com</a></td>
</tr>
<tr>
<td>Tash, Inc., is the manufacturer of a variety of switches, adaptive devices, and mounting devices. Its website offers online shopping and the option of requesting a catalog.</td>
</tr>
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</table>

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<tr>
<th>26. Words+, Inc.</th>
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<tbody>
<tr>
<td><a href="http://www.words-plus.com">www.words-plus.com</a></td>
</tr>
<tr>
<td>Words+, Inc., is a company dedicated to improving the quality of life for people with disabilities. Its products include computer software, the Freedom 2000, and the Message Mate line of products. The Words+, Inc., website includes links for its products catalog, upcoming workshops, and links to other AAC-related websites.</td>
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Appendix 9.6 (Continued)

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<thead>
<tr>
<th>27. ZYGO Industries, Inc.</th>
<th><a href="http://www.zygo-usa.com">www.zygo-usa.com</a></th>
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<tbody>
<tr>
<td>ZYGO Industries, Inc., is the manufacturer of the Macaw family of digitized AAC systems. ZYGO Industries, Inc., also manufactures a variety of other AT devices. It has a CD-ROM and videotape that contains samples of its products. Its website includes links to its product catalog and a link to information about funding for AT.</td>
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<tr>
<th>AAC Associations</th>
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<tbody>
<tr>
<td>Home page for Special Interest Division 12 (AAC). Available once you register at the ASHA website: <a href="http://www.asha.org/speech/disabilities/disabilities.cfm">www.asha.org/speech/disabilities/disabilities.cfm</a> This page is user-friendly and available to the public. It is a good reference for those beginning to learn about AAC. This page provides general information about AAC, including information about putting together an AAC team and selecting a device.</td>
</tr>
</tbody>
</table>

| 29. International Society for Augmentative and Alternative Communication (ISAAC) | www.isaac-online.org |
| ISAAC is an international organization devoted to advancing augmentative and alternative communication (AAC). The mission of ISAAC is to improve communication and the quality of life for people with severe communication impairments. ISAAC does this by facilitating information exchange and focusing attention on work in the field. The ISAAC website provides links to AAC resources, publications, events, and conferences. |

| 30. U.S. Society for Augmentative and Alternative Communication (USSAAC) | www.ussaac.org |
| USSAAC is a national chapter of ISAAC devoted to advancing augmentative and alternative communication (AAC) in the United States. The mission is to improve communication and the quality of life for people with severe communication impairments by facilitating information exchange through its conferences and a quarterly newsletter titled Speak UP! |

<table>
<thead>
<tr>
<th>Education Sites</th>
</tr>
</thead>
<tbody>
<tr>
<td>The AAC-RERC is dedicated to assisting individuals who use AAC by advancing and promoting AAC technologies and supporting individuals that use, manufacture, and recommend them. The AAC-RERC is funded by the National Institute on Disability and Rehabilitation Research (NIDRR, Grant H133E980026). The website includes current information on Medicare funding policies, research on improving AAC technologies for young children, and links to vendor websites and university AAC sites.</td>
</tr>
</tbody>
</table>

| 32. AAC at Penn State | http://aac.hhdev.psu.edu/Research.htm |
| The website describes current research in AAC, including some on improving AAC technology for young children. It also describes research programs directed toward improving clinical practice and enhancing outcomes for individuals who use AAC. Penn State is also a partner in the AAC-RERC (Augmentative and Alternative Communication-Rehabilitation Engineering Research Center on Communication Enhancement; see #31). |
33. AACworld at Purdue
   www.soe.purdue.edu/aac
   In addition to information about augmentative and alternative communication (AAC) and assistive technology (AT) courses at Purdue, this website provides several types of resource material for researchers and practitioners, including abstracts of master's and doctoral theses, recent AAC research at Purdue, and links to other sites of potential value, including the Assessment Research Center (which includes information about the electronic alternate assessment procedures developed at Purdue as Indiana’s response to PL 105-17) and universities with which Purdue is currently collaborating, such as the Centre for Augmentative and Alternative Communication (CAAC) at the University of Pretoria, South Africa, and the University of Cologne, Germany.

34. California State University–Northridge

35. Closing the Gap
   www.closingthegap.com
   This website includes product information on new hardware and software and current issues involving AT and AAC. It also has links to newsletter articles and how to subscribe to the bimonthly newsletter.

36. Communication Aids for Language and Learning (CALL) Centre, University of Edinburgh
   http://callcentre.education.ed.ac.uk
   The CALL Centre is a Scottish National Resource and Research Centre located within the University of Edinburgh’s Department of Equity Studies and Special Education, in the Faculty of Education.

37. Trace Research and Development Center
   www.trace.wisc.edu
   This website provides information on all types of AT, including AAC. The comprehensive nature of the site provides students with the broad perspective they will need to work effectively with clients who require technology beyond a communication device. The front page is organized into four headings: New and Highlighted Items, Designing a More Useable World, Cooperative Electronic Library (Co-Net), and Publications and Media Catalog. The last two sections relate to AAC most directly. Co-Net includes information on products, people, and services; publications and media; and also text documents. For the most up-to-date product information, the website directs the user to the ABLEDATA website (see #40).

38. The University of Nebraska–Lincoln AAC website
   www.aac.unl.edu
   The University of Nebraska–Lincoln (UNL) AAC website contains academic and clinical training information, as well as vendor information for people working with AAC. It also provides a variety of links to AAC and other speech-language pathology sites.

(Continued)
### Other AAC Resources

<table>
<thead>
<tr>
<th>Number</th>
<th>Resource Name</th>
<th>Website</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>39.</td>
<td>AAC Intervention.com</td>
<td><a href="http://www.aacintervention.com">www.aacintervention.com</a></td>
<td>AAC Intervention.com is a website that sells products to aid in making overlays for early intervention with AAC. It also provides helpful information on how to begin using AAC with a nonspeaking child. This website has some unique features such as local and national presentation/conference dates and tips of the month.</td>
</tr>
<tr>
<td>40.</td>
<td>ABLEDATA</td>
<td><a href="http://www.abledata.com">www.abledata.com</a></td>
<td>ABLEDATA is a federally funded project whose primary mission is to provide information on AT and rehabilitation equipment available from domestic and international sources to consumers, organizations, professionals, and caregivers within the United States. Its website includes links for resource centers, product information, and other AAC-related websites.</td>
</tr>
<tr>
<td>41.</td>
<td>Augmentative Communication, Inc.</td>
<td><a href="http://www.augcominc.com">www.augcominc.com</a></td>
<td>Augmentative Communication, Inc., publishes <em>Alternatively Speaking (AS)</em> and <em>Augmentative Communication News (CAN)</em>, newsletters that together provide the latest information on hot topics in the field, discussion of vital issues for AAC stakeholders, and news from the AAC community. The Augmentative Communication, Inc., website also provides links for presentations, articles in the publications, and other AAC-related websites.</td>
</tr>
<tr>
<td>42.</td>
<td>Communication Independence for the Neurologically Impaired (CINI)</td>
<td><a href="http://www.cini.org">www.cini.org</a></td>
<td>Founded by SLPs, people with ALS, and family members, CINI is the only not-for-profit organization solely devoted to improving the quality of life for persons with ALS/MND (Lou Gehrig's disease). The organization disseminates information about the communication technology that can help them. The website includes pages on frequently asked questions, related resources and links, a glossary, publications, and names of manufacturers.</td>
</tr>
</tbody>
</table>

### Additional Resources

Additional resources can be obtained by:

- Checking references and appendices in the four original texts cited and the other publications cited (e.g., the Lloyd et al. text has extensive appendices on developers, manufacturers, vendors, and associations as of 1997).

- Checking websites with the typical cautions used when one browses websites.

- Subscribing to the ASHA SID 12 newsletter in particular and specific volumes, including *Augmentative and Alternative Communication Newsletter*, June 2001, Vol. 10, No. 2, pp. 32–33 (an issue devoted to a bibliography of AAC books, chapters, and journals).

- Subscribing to ISAAC’s official journal—*Augmentative and Alternative Communication*.

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## Additional Links to Other AAC-Related Sites

<table>
<thead>
<tr>
<th>Link</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>AAC-RERC</strong></td>
<td>AAC-RERC is the Rehabilitation Engineering Research Center on Communication</td>
</tr>
<tr>
<td><a href="http://aac-rerc.com">http://aac-rerc.com</a></td>
<td>This is one of a network of RERCs funded by the National Institute on Disability and Rehabilitation Research (NIDRR) of the U.S. Department of Education.</td>
</tr>
<tr>
<td><strong>ABLEDATA</strong></td>
<td>ABLEDATA is a federally funded project whose primary mission is to provide information on AT and rehabilitation equipment available from domestic and international sources to consumers, organizations, professionals, and caregivers within the United States.</td>
</tr>
<tr>
<td><a href="http://www.abledata.com">www.abledata.com</a></td>
<td></td>
</tr>
<tr>
<td><strong>ACOLUG</strong></td>
<td>ACOLUG is a listserv created to exchange ideas, information, and experiences on augmentative communication by people from all over the world. By using e-mail, people who use augmentative communication and their friends and families discuss issues related to augmentative communication, such as equipment, funding, learning techniques, and supports. Anyone can join, and there is no cost.</td>
</tr>
<tr>
<td><a href="http://www.temple.edu/inst_disabilities/acolug">www.temple.edu/inst_disabilities/acolug</a></td>
<td></td>
</tr>
<tr>
<td><strong>Apraxia-Kids</strong></td>
<td>The Apraxia-Kids Internet Resources provides comprehensive information regarding Childhood Apraxia of Speech. The site, which is appropriate for both families and professionals, includes expert articles on diagnosis, treatment, AAC, related disabilities, an e-mail discussion list, a monthly online newsletter, message boards, and resource listings. Additionally, there is a research section with the latest news on apraxia research.</td>
</tr>
<tr>
<td><a href="http://www.apraxia-kids.org">www.apraxia-kids.org</a></td>
<td></td>
</tr>
<tr>
<td><strong>ASHA</strong></td>
<td>ASHA is the American Speech-Language-Hearing Association. ASHA is the professional organization of SLPs and audiologists. SLPs are the primary service providers for people who rely on AAC and are generally the best resource on an AAC team for addressing language issues. ASHA has a special interest division, SID-12, that addresses AAC.</td>
</tr>
<tr>
<td><a href="http://www.asha.org">www.asha.org</a></td>
<td></td>
</tr>
<tr>
<td><strong>ATIA</strong></td>
<td>ATIA is the Assistive Technology Industry Association. ATIA organizes an annual conference on AT.</td>
</tr>
<tr>
<td><a href="http://www.atia.org">www.atia.org</a></td>
<td></td>
</tr>
<tr>
<td><strong>Augmentative Communication, Inc.</strong></td>
<td><strong>Augmentative Communication News and Alternatively Speaking</strong> provide the latest information on hot topics in the field, discussion of vital issues for AAC stakeholders, and news from the AAC community.</td>
</tr>
<tr>
<td><a href="http://www.augcominc.com">www.augcominc.com</a></td>
<td></td>
</tr>
</tbody>
</table>
### Appendix 9.6 (Continued)

<table>
<thead>
<tr>
<th><strong>C.H.E.R.A.B.</strong></th>
<th><a href="http://www.apraxia.cc">www.apraxia.cc</a></th>
</tr>
</thead>
<tbody>
<tr>
<td>The Communication Help, Education, Research, Apraxia Base Foundation websites are for anyone who cares for a child that has delayed speech, a speech disorder, is a late talker, etc., as well as for those who care for a child that has received a diagnosis of apraxia.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Childhood Apraxia of Speech Association of North America (CASANA)</strong></th>
<th><a href="http://www.apraxia.org">www.apraxia.org</a></th>
</tr>
</thead>
<tbody>
<tr>
<td>The Childhood Apraxia of Speech Association is a not-for-profit organization whose mission is to strengthen the support systems in the lives of children with apraxia so that each child is afforded his best opportunity to develop speech.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Consortium for Assistive Technology Outcomes Research (CATOR)</strong></th>
<th><a href="http://www.atoutcomes.org">www.atoutcomes.org</a></th>
</tr>
</thead>
<tbody>
<tr>
<td>CATOR conducts research dedicated to improving measurement science for assistive technology (AT), reducing barriers to the use of AT outcome measures, and understanding the processes for AT adoption and abandonment.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>CSUN</strong></th>
<th><a href="http://www.csun.edu/cod">www.csun.edu/cod</a></th>
</tr>
</thead>
<tbody>
<tr>
<td>California State University–Northridge (CSUN) Center on Disabilities organizes the annual Conference on Technology and Persons with Disabilities. CSUN also offers the Assistive Technology Applications Certificate Program.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>CTG</strong></th>
<th><a href="http://closingthegap.com">http://closingthegap.com</a></th>
</tr>
</thead>
<tbody>
<tr>
<td>Closing the Gap organized an annual conference on computer technology for people with disabilities and publishes a newsletter.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>ISAAC</strong></th>
<th><a href="http://www.isaac-online.org">www.isaac-online.org</a></th>
</tr>
</thead>
<tbody>
<tr>
<td>ISAAC is the International Society for Augmentative and Alternative Communication. Membership is open to anyone interested in AAC. ISAAC activities include a biennial conference and sponsorship of <em>AAC Journal</em>. Many ISAAC national chapters address more local interests.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>PEC</strong></th>
<th><a href="http://www.toolcity.net/~coonster/shout">www.toolcity.net/~coonster/shout</a></th>
</tr>
</thead>
<tbody>
<tr>
<td>The Pittsburgh Employment Conference for Augmented Communicators is the largest gathering in the world of people who rely on AAC. Topics of interest to employment-age individuals are addressed at the annual conference.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>RESNA</strong></th>
<th><a href="http://www.resna.org">www.resna.org</a></th>
</tr>
</thead>
<tbody>
<tr>
<td>RESNA (Rehabilitation and Assistive Technology Society of North America) is an interdisciplinary association of people with a common interest in technology and disability. Its purpose is to improve the potential of people with disabilities to achieve their goals through the use of technology. It serves that purpose by promoting research, development, education, advocacy, and the provision of technology and by supporting the people engaged in these activities. RESNA was founded in 1979 as a not-for-profit organization. There are currently over 1600 individual and 150 organizational members.</td>
<td></td>
</tr>
</tbody>
</table>
USSAAC
www.usaac.org
USSAAC (U.S. Society for Augmentative and Alternative Communication) is the U.S. chapter of ISAAC.

WheelchairNet
www.wheelchairnet.org
WheelchairNet is a community for people who have a common interest in (or in some cases a passion for) wheelchair technology and its improvement and successful application. WheelchairNet is a virtual community—a community that exists only in cyberspace. Cyberspace is just a way of referring to the Internet. It's a community organized along the lines of a real town. This virtual town is inhabited, visited, and managed by people who have an interest in wheelchairs and how wheelchairs can best serve the needs of people who use them. WheelchairNet is operated by the RERC on Wheeled Mobility at the University of Pittsburgh.

Appendix 9.7 Toll-Free Phone Numbers and Hotlines

<table>
<thead>
<tr>
<th>Organization</th>
<th>Phone Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>AMC Cancer Information Line</td>
<td>800-525-3777</td>
</tr>
<tr>
<td>American Association on Mental Retardation</td>
<td>800-424-3688</td>
</tr>
<tr>
<td>American Council of the Blind</td>
<td>800-424-8666</td>
</tr>
<tr>
<td>American Diabetes Association, Inc.</td>
<td>800-232-3472</td>
</tr>
<tr>
<td>American Foundation for the Blind</td>
<td>800-232-5463</td>
</tr>
<tr>
<td>American Liver Foundation</td>
<td>800-223-0179</td>
</tr>
<tr>
<td>American Paralysis Association</td>
<td>800-225-0292</td>
</tr>
<tr>
<td>American Parkinson Disease Association</td>
<td>800-223-2732</td>
</tr>
<tr>
<td>American Speech-Language-Hearing Association</td>
<td>800-638-8255</td>
</tr>
<tr>
<td>American Spinal Cord Injury</td>
<td>800-962-9629</td>
</tr>
<tr>
<td>American Trauma Society</td>
<td>800-556-7890</td>
</tr>
</tbody>
</table>

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Appendix 9.7 (Continued)

<table>
<thead>
<tr>
<th>Organization</th>
<th>Phone Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arthritis Foundation</td>
<td>800-283-7800</td>
</tr>
<tr>
<td>Association for Retarded Citizens of the U.S. (ARC)</td>
<td>800-433-5255</td>
</tr>
<tr>
<td>AT&amp;T National Special Needs Center</td>
<td>800-833-3232</td>
</tr>
<tr>
<td>Beginnings</td>
<td>800-541-4327</td>
</tr>
<tr>
<td>Better Hearing Institute Hearing Helpline</td>
<td>800-EAR-WELL</td>
</tr>
<tr>
<td>Blind Children's Center</td>
<td>800-222-3566</td>
</tr>
<tr>
<td>The Candlelighters Childhood Cancer Foundation</td>
<td>800-366-2223</td>
</tr>
<tr>
<td>Captioned Films for the Deaf</td>
<td>800-237-6213</td>
</tr>
<tr>
<td>Center for Special Education Technology</td>
<td>800-873-8255</td>
</tr>
<tr>
<td>c/o Council for Exceptional Children</td>
<td></td>
</tr>
<tr>
<td>Consumer Product Safety Commission</td>
<td>800-638-2772</td>
</tr>
<tr>
<td>Cornelia deLange Syndrome Foundation</td>
<td>800-535-3323</td>
</tr>
<tr>
<td>Dial a Hearing Screening Test</td>
<td>800-222-3277</td>
</tr>
<tr>
<td>Disabilities AT&amp;T, National Special Needs Center</td>
<td>800-233-1222</td>
</tr>
<tr>
<td>Dyslexia Society, Orton</td>
<td>800-222-3123</td>
</tr>
<tr>
<td>Easter Seal Society</td>
<td>800-221-6827</td>
</tr>
<tr>
<td>Organization</td>
<td>Phone Number</td>
</tr>
<tr>
<td>-----------------------------------------------------------</td>
<td>-----------------------------------</td>
</tr>
<tr>
<td>Educators Publishing Service, Inc. Specific Language Disabilities</td>
<td>800-225-5750</td>
</tr>
<tr>
<td>Epilepsy Foundation of America</td>
<td>800-332-1000</td>
</tr>
<tr>
<td>ERIC Clearinghouse on Adult Career and Vocational Education</td>
<td>800-848-4815</td>
</tr>
<tr>
<td>Family Support Network</td>
<td>800-852-0042</td>
</tr>
<tr>
<td>Federal Hill-Burton Free Care Program</td>
<td>800-638-0742</td>
</tr>
<tr>
<td>Federal Internal Revenue Service</td>
<td>800-829-1040</td>
</tr>
<tr>
<td>Financial Aid for Education Available from the Federal Government</td>
<td>800-333-INFO</td>
</tr>
<tr>
<td>Georgia Assistive Technology Project (Atlanta)</td>
<td>800-497-8665</td>
</tr>
<tr>
<td>Georgia Assistive Technology Project (Warm Springs)</td>
<td>800-578-8665</td>
</tr>
<tr>
<td>Georgia Relay Center</td>
<td>800-255-0135 (Voice to TT)</td>
</tr>
<tr>
<td></td>
<td>800-255-0056 (TT to Voice)</td>
</tr>
<tr>
<td>Guide Dog Foundation for the Blind</td>
<td>800-548-4337</td>
</tr>
<tr>
<td>Handicapped Media, Inc.</td>
<td>800-321-8708</td>
</tr>
<tr>
<td>Handicapped Travel Divisions, National Tour Assoc.</td>
<td>800-682-8886</td>
</tr>
<tr>
<td>Head Injury Foundation, National</td>
<td>800-444-6443</td>
</tr>
<tr>
<td>Health Resource Center</td>
<td>800-544-3284</td>
</tr>
<tr>
<td>Hearing Helpline</td>
<td>800-327-9355</td>
</tr>
<tr>
<td>Hearing Information Center, Senior Hearing Aids</td>
<td>800-622-3277</td>
</tr>
</tbody>
</table>

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Appendix 9.7 (Continued)

<table>
<thead>
<tr>
<th>Organization</th>
<th>Phone Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Higher Education and Adult Training of People with Handicaps (HEATH Resource Center)</td>
<td>800-54-HEATH</td>
</tr>
<tr>
<td>Huntington's Disease Society of America</td>
<td>800-345-4372</td>
</tr>
<tr>
<td>IBM National Center for Person with Disabilities</td>
<td>800-426-4832</td>
</tr>
<tr>
<td>International Shriners Headquarters</td>
<td>800-237-5055</td>
</tr>
<tr>
<td>Job Accommodations Network (JAN)</td>
<td>800-526-7234</td>
</tr>
<tr>
<td>Job Opportunities for the Blind (JOB)</td>
<td>800-638-7518</td>
</tr>
<tr>
<td>John Tracy Clinic on Deafness</td>
<td>800-522-4582</td>
</tr>
<tr>
<td>Juvenile Diabetes Foundation Hotline</td>
<td>800-223-1138</td>
</tr>
<tr>
<td>Kidney Foundation, National</td>
<td>800-622-9010</td>
</tr>
<tr>
<td>Kidney Fund, National</td>
<td>800-638-8299</td>
</tr>
<tr>
<td>The Lighthouse National Center for Vision and Aging</td>
<td>800-334-5497</td>
</tr>
<tr>
<td>Lupus Foundation of America</td>
<td>800-558-0121</td>
</tr>
<tr>
<td>Medicare, Hotline</td>
<td>800-672-3071</td>
</tr>
<tr>
<td>Medigap, U.S. Department of Health and Human Services</td>
<td>800-638-6833</td>
</tr>
<tr>
<td>Modern Talking Picture Service, Inc.</td>
<td>800-237-6213</td>
</tr>
<tr>
<td>Muscular Dystrophy Association</td>
<td>800-358-7240</td>
</tr>
<tr>
<td>Muscular Sclerosis, Georgia Regional Office</td>
<td>800-822-3379</td>
</tr>
<tr>
<td>Organization</td>
<td>Phone Number</td>
</tr>
<tr>
<td>------------------------------------------------------------------------------</td>
<td>--------------------</td>
</tr>
<tr>
<td>National AIDS Hotline</td>
<td>800-342-AIDS</td>
</tr>
<tr>
<td>National Alliance for the Mentally Ill (NAMI)</td>
<td>800-950-NAMI</td>
</tr>
<tr>
<td>National Association for Parents of the Visually Impaired</td>
<td>800-562-6265</td>
</tr>
<tr>
<td>National Association for Rehabilitation Facilities</td>
<td>800-368-3513</td>
</tr>
<tr>
<td>National Association for Sickle Cell Disease, Inc.</td>
<td>800-421-8453</td>
</tr>
<tr>
<td>National Cancer Institute Information Service</td>
<td>800-4-CANCER</td>
</tr>
<tr>
<td>National Center for Sight</td>
<td>800-221-3004</td>
</tr>
<tr>
<td>National Committee for Citizens in Education</td>
<td>800-NETWORK</td>
</tr>
<tr>
<td>National Council on Aging</td>
<td>800-424-9046</td>
</tr>
<tr>
<td>National Cystic Fibrosis Foundation</td>
<td>800-344-4823</td>
</tr>
<tr>
<td>National Down Syndrome Congress</td>
<td>800-232-6372</td>
</tr>
<tr>
<td>National Down Syndrome Society</td>
<td>800-221-4602</td>
</tr>
<tr>
<td>National Eye Care Project Helpline</td>
<td>800-222-EYES</td>
</tr>
<tr>
<td>National Headache Foundation</td>
<td>800-843-2256</td>
</tr>
<tr>
<td>National Head Injury Foundation (NHIF)</td>
<td>800-444-6443</td>
</tr>
<tr>
<td>National Health Information Center (NHIC)</td>
<td>800-336-4797</td>
</tr>
<tr>
<td>National Hearing Aid Society Hearing Aid Hotline</td>
<td>800-521-5247</td>
</tr>
</tbody>
</table>

(Continued)
Appendix 9.7 (Continued)

<table>
<thead>
<tr>
<th>Organization</th>
<th>Phone Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Information Center for Children and Youth with Disabilities (NICHCY)</td>
<td>800-999-5599</td>
</tr>
<tr>
<td>National Information Clearinghouse for Infants with Disabilities and Life-Threatening Conditions</td>
<td>800-922-9234, ext. 201</td>
</tr>
<tr>
<td>National Information System Vietnam Vets/Children</td>
<td>800-922-9234</td>
</tr>
<tr>
<td>National Insurance Consumer Hotline</td>
<td>800-942-4242</td>
</tr>
<tr>
<td>National Library Service for Blind &amp; Physically Handicapped</td>
<td>800-424-8567</td>
</tr>
<tr>
<td>National Multiple Sclerosis Society</td>
<td>800-624-8236</td>
</tr>
<tr>
<td>National Organization for Rare Disorders (NORD)</td>
<td>800-447-6673</td>
</tr>
<tr>
<td>National Organization on Disability</td>
<td>800-248-ABLE</td>
</tr>
<tr>
<td>National Parkinson Foundation</td>
<td>800-327-4545</td>
</tr>
<tr>
<td>National Rehabilitation Information Center (NARIC)</td>
<td>800-346-2742</td>
</tr>
<tr>
<td>National Retinitis Pigmentosa Foundation</td>
<td>800-638-2300</td>
</tr>
<tr>
<td>National Reye's Syndrome Foundation</td>
<td>800-233-7393</td>
</tr>
<tr>
<td>National Sexually Transmitted Diseases Hotline</td>
<td>800-227-8922</td>
</tr>
<tr>
<td>National Spinal Cord Injury Association</td>
<td>800-962-9629</td>
</tr>
<tr>
<td>National Stroke Association</td>
<td>800-367-1990</td>
</tr>
<tr>
<td>National Tuberous Sclerous Association</td>
<td>800-CAL-NTSA</td>
</tr>
</tbody>
</table>
Appendix 9.8  Internet Resources

About elder law
www.naela.com/naela/hotlinks.htm#ElderlawResources

Adaptive Solutions
Assistive Technology Tracker
www.adaptive-sol.com

Alexander Graham Bell Association for the Deaf
www.agbell.org

(Continued)
<table>
<thead>
<tr>
<th>Organization</th>
<th>Website</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alliance for Technology Access</td>
<td><a href="http://www.ataccess.org">www.ataccess.org</a></td>
</tr>
<tr>
<td>ALS Association</td>
<td><a href="http://www.alsa.org">www.alsa.org</a></td>
</tr>
<tr>
<td>American Association on Mental Retardation</td>
<td><a href="http://www.aamr.org">www.aamr.org</a></td>
</tr>
<tr>
<td>American Foundation for the Blind, Technology Center</td>
<td>wwwafb.org</td>
</tr>
<tr>
<td>American Medical Association</td>
<td><a href="http://www.ama-assn.org">www.ama-assn.org</a></td>
</tr>
<tr>
<td>American Physical Therapy Association</td>
<td><a href="http://www.apta.org">www.apta.org</a></td>
</tr>
<tr>
<td>American Speech-Language-Hearing Association</td>
<td><a href="http://www.asha.org">www.asha.org</a></td>
</tr>
<tr>
<td>Americans with Disabilities Act Document Center</td>
<td><a href="http://janweb.icdi.wvu.edu">http://janweb.icdi.wvu.edu</a></td>
</tr>
<tr>
<td>Assistive Technology, Inc.</td>
<td>wwwassistivetechcom/info-faq-funding.htm</td>
</tr>
<tr>
<td>Assistive Technology Tracker</td>
<td>wwwadaptive-solcom</td>
</tr>
<tr>
<td>Audible, Inc.</td>
<td>wwwaudiblecom</td>
</tr>
<tr>
<td>Augmentative Communication</td>
<td>wwwaugcommcom/productshtml</td>
</tr>
<tr>
<td>Augmentative Communication On-Line User Group (ACOLUG)</td>
<td><a href="http://www.templeedu/inst_disabilities/acolug">www.templeedu/inst_disabilities/acolug</a></td>
</tr>
<tr>
<td>Blissymbolics Communication International</td>
<td><a href="http://home.istarca/~bci/">http://home.istarca/~bci/</a></td>
</tr>
<tr>
<td>Brain Actuated Technologies, Inc.</td>
<td>wwwbrainfingerscom</td>
</tr>
<tr>
<td>California Relay Service</td>
<td>800-735-2929</td>
</tr>
<tr>
<td>California State University–Northridge, Center on Disabilities</td>
<td>wwwcsunedu/cod</td>
</tr>
</tbody>
</table>
CALL Center, University of Edinburgh
http://callcenter.education.ed.ac.uk

Center for International Rehabilitation Research Information and Exchange (CIRRIE)
http://cirrie.buffalo.edu

Centers for Disease Control and Prevention
www.cdc.gov

Centers for Disease Control Morbidity and Mortality Weekly Report
www.cdc.gov/epo/mmwr/mmwr.html

Clinical Research Abstract
www.med.upenn.edu/cra

Communication Aids Manufacturers Association
www.aacproducts.com

Communication Aids Manufacturers Association (CAMA)
www.aacproducts.org

Communication Independence for the Neurologically Impaired (CINI)
www.cini.org

Council for Exceptional Children
www.cec.sped.org

Council for Licensure Enforcement and Regulation (CLEAR)
www.clearhq.org

Cyberlink Interface
www.brainfingers.com

Department of Veterans Affairs
www.va.gov

Design to Learn
www.designtolearn.com

Division of Vocational Rehabilitation
State of New Mexico Department of Education
www.state.nm.us/dvr/vragencies.htm

Doug Dodgen and Associates
AAC Feature Match Software
www.dougdodgen.com

Dragon Dictate Systems
www.dragonsys.com

(Continued)
Apple
www.apple.com

Battelle
www.battelle.org

Center for Ethics and the Global Economy
http://www.theglobal-economy.org

Conscious Touch
www.touch-central.com

Customer, Care, and Technical Support
www.activecare.com

Direct Relief
www.directrelief.org

Dutchess County Department of Community and Family Services
www.dcf.com

Eisenhower National Clearinghouse for Math and Science Education
www.enc.org

Equal Access to Software and Information (EASI)
www.rit.edu/~easi/

Eye/Muscle Operated Switch (EMOS)
www.mctos.com

Food and Drug Administration
www.fda.gov

GMR Labs
www.aimnet.com/~roark/

Guillain-Barré Syndrome Disability Resources
www.adsnet.com/steinhi/html/gbs/gbsabel.html

Harris Communications
15159 Technology Dr.
Eden Prairie, MN 55344-2277

Health Care Financing Administration
www.hcfa.gov

Health care law
www.arentfox.com/telemedicine.html

HMS School for Children with Cerebral Palsy
Philadelphia, PA
www.hmsschool.org

Human Factors and Ergonomics Society (HFES)
HFES is one of the major professional organizations for practitioners and researchers in ergonomics and human factors.
http://hfes.org

Institute of Medicine
www.nas.edu/iom

International Society for Augmentative and Alternative Communication (ISAAC)
www.isaac-online.org

Internet Disability Resources
Mary Barros-Baily and Dawn Boyd
Ahab Press, Inc.
2 Gannett Dr., Suite 200
White Plains, NY 10604-3404
E-mail: AHAB4@aol.com
<table>
<thead>
<tr>
<th>Organization</th>
<th>Website</th>
</tr>
</thead>
<tbody>
<tr>
<td>ISAAC</td>
<td><a href="http://www.isaac-online.org">www.isaac-online.org</a></td>
</tr>
<tr>
<td>Keyboard Alternatives and Vision Solutions</td>
<td><a href="http://www.keyalt.com">www.keyalt.com</a></td>
</tr>
<tr>
<td>Krown Manufacturing, Inc.</td>
<td><a href="http://www.krowntty.com">www.krowntty.com</a></td>
</tr>
<tr>
<td>Kurzweil Applied Intelligence</td>
<td><a href="http://www.kurz-ai.com">www.kurz-ai.com</a></td>
</tr>
<tr>
<td>LifeSpan Access Profile</td>
<td></td>
</tr>
<tr>
<td>Don Johnston Company</td>
<td></td>
</tr>
<tr>
<td><a href="http://www.donjohnston.com">www.donjohnston.com</a></td>
<td></td>
</tr>
<tr>
<td>List of disability sites</td>
<td></td>
</tr>
<tr>
<td><a href="http://www.nde.state.ne.us/ATP/listsites.html">www.nde.state.ne.us/ATP/listsites.html</a></td>
<td></td>
</tr>
<tr>
<td>Madentec</td>
<td><a href="http://www.madentec.com">www.madentec.com</a></td>
</tr>
<tr>
<td>Muscular Dystrophy Association (MDA)</td>
<td><a href="http://www.mdusa.org">www.mdusa.org</a></td>
</tr>
<tr>
<td>Nathaniel H. Kornreich Technology Center</td>
<td><a href="http://www.kornreich.org">www.kornreich.org</a></td>
</tr>
<tr>
<td>National Easter Seal Society</td>
<td><a href="http://www.easter-seals.org">www.easter-seals.org</a></td>
</tr>
<tr>
<td>National Federation of the Blind (NFB)</td>
<td><a href="http://www.ngb.org">www.ngb.org</a></td>
</tr>
<tr>
<td>National Information Center for Children and Youth with Disabilities (NICHY)</td>
<td><a href="http://www.nichy.org">www.nichy.org</a></td>
</tr>
<tr>
<td>National Information Center for Children and Youth with Handicaps (NICHCY)</td>
<td><a href="http://www.nichcy.org">www.nichcy.org</a></td>
</tr>
<tr>
<td>National Institutes of Health</td>
<td><a href="http://www.nih.gov">www.nih.gov</a></td>
</tr>
<tr>
<td>National Organization for Competency Assurance (NOCA)</td>
<td><a href="http://www.noca.org">www.noca.org</a></td>
</tr>
<tr>
<td>National Organization on Disability</td>
<td><a href="http://www.nod.org">www.nod.org</a></td>
</tr>
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</table>
## Appendix 9.8 (Continued)

<table>
<thead>
<tr>
<th>Organization/Resource</th>
<th>Website</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Spinal Cord Injury Association</td>
<td><a href="http://www.spinalcord.org">www.spinalcord.org</a></td>
</tr>
<tr>
<td>National Technical Institute for the Deaf</td>
<td><a href="http://www.rit.edu/~418www/">www.rit.edu/~418www/</a></td>
</tr>
<tr>
<td>Net Connection to CD &amp; S</td>
<td><a href="http://www.mankato.msus.edu/dept/comdis/kuster2/welcome.html">www.mankato.msus.edu/dept/comdis/kuster2/welcome.html</a></td>
</tr>
<tr>
<td>Oklahoma Able Tech</td>
<td><a href="http://www.okstate.edu/wellness/at-home.htm">www.okstate.edu/wellness/at-home.htm</a></td>
</tr>
<tr>
<td>PennTech-Central Instructional Support Center</td>
<td><a href="http://www.cisc.k12.pa.us">www.cisc.k12.pa.us</a></td>
</tr>
<tr>
<td>Pittsburgh Employment Conference (PEC)</td>
<td><a href="mailto:SHOUT@agi.net">SHOUT@agi.net</a></td>
</tr>
<tr>
<td>Prentke Romich Company (PRC)</td>
<td><a href="http://www.prentrom.com">www.prentrom.com</a></td>
</tr>
<tr>
<td>Quality Indicators for Assistive Technology Services</td>
<td><a href="http://www.qiat.org">www.qiat.org</a></td>
</tr>
<tr>
<td>Rehabilitation Engineering and Assistive Technology Society of North America (RESNA)</td>
<td>RESNA is an interdisciplinary association of people with a common interest in technology and disability. This association promotes research, development, education, advocacy, and the provision of technology. <a href="http://www.resna.org">www.resna.org</a></td>
</tr>
<tr>
<td>RESNA Credentialing Examination in Assistive Technology</td>
<td><a href="http://www.resna.org/certify/index.html">www.resna.org/certify/index.html</a></td>
</tr>
<tr>
<td>Social Security Disability Administration Disability Information</td>
<td><a href="http://www.ssa.gov">www.ssa.gov</a></td>
</tr>
<tr>
<td>Special Interest Division 12</td>
<td><a href="http://www.professional.asha.org/sidivisions/sid_12.htm">www.professional.asha.org/sidivisions/sid_12.htm</a></td>
</tr>
<tr>
<td>Speech to Speech</td>
<td><a href="http://www.stsnews.com">www.stsnews.com</a></td>
</tr>
<tr>
<td>Technical Assistance Project</td>
<td><a href="http://www.resna.org/taproject/at/statecontacts.html">www.resna.org/taproject/at/statecontacts.html</a></td>
</tr>
<tr>
<td>Resource</td>
<td>Website/Contact Information</td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>The Arc (of the United States)</td>
<td><a href="http://www.thearc.org">www.thearc.org</a></td>
</tr>
<tr>
<td>Trace Center—University of Wisconsin–Madison</td>
<td>gopher://trac.wisc.edu:70/1/netmenus/fintech</td>
</tr>
<tr>
<td>Trace Research and Development Center</td>
<td><a href="http://trace.wisc.edu">http://trace.wisc.edu</a></td>
</tr>
<tr>
<td>Training and Technical Assistance Center</td>
<td><a href="http://tac.elps.vt.edu/htmldocs/augcom.html">http://tac.elps.vt.edu/htmldocs/augcom.html</a></td>
</tr>
<tr>
<td>Turning Point Technologies</td>
<td>877-608-9812</td>
</tr>
<tr>
<td>United Cerebral Palsy, Funding for Assistive Technology</td>
<td><a href="http://www.ucpa.org">www.ucpa.org</a></td>
</tr>
<tr>
<td>United Way of America home page</td>
<td><a href="http://www.unitedway.org">www.unitedway.org</a></td>
</tr>
<tr>
<td>University of Nebraska–Lincoln</td>
<td>AAC Vendors Information</td>
</tr>
<tr>
<td>University of Nebraska–Lincoln</td>
<td><strong>UW AugComm</strong></td>
</tr>
<tr>
<td>Upshaw Institute for the Blind</td>
<td><a href="http://depts.washington.edu/augcomm">http://depts.washington.edu/augcomm</a></td>
</tr>
<tr>
<td>U.S. government site for Medicare information</td>
<td><a href="http://www.medicare.gov">www.medicare.gov</a></td>
</tr>
<tr>
<td>USAAC (U.S. Chapter of ISAAC)</td>
<td><a href="mailto:USAAC@aol.com">USAAC@aol.com</a></td>
</tr>
<tr>
<td>Wisconsin Assistive Technology Initiative</td>
<td><a href="http://aac-rerc.com">http://aac-rerc.com</a></td>
</tr>
<tr>
<td>World Health Organization</td>
<td><a href="http://www.who.ch">www.who.ch</a></td>
</tr>
</tbody>
</table>

(Continued)
### Appendix 9.8 (Continued)

<table>
<thead>
<tr>
<th>Wynd Communications</th>
</tr>
</thead>
<tbody>
<tr>
<td><a href="http://www.wyndtell.com">www.wyndtell.com</a></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>YAACK (Augmentative Communication Connecting Young Kids)</th>
</tr>
</thead>
<tbody>
<tr>
<td><a href="http://www.mrtc.org/~duffy/yack/index.html">www.mrtc.org/~duffy/yack/index.html</a></td>
</tr>
</tbody>
</table>

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### Appendix 9.9  Online Assistive Technology Resources

<table>
<thead>
<tr>
<th>Ability Hub</th>
</tr>
</thead>
<tbody>
<tr>
<td>AbilityHub.com’s purpose is to help users find information on adaptive equipment and alternative methods available for accessing computers. Ability Hub’s founder is Dan Gilman, a certified ATP (assistive technology practitioner) with RESNA.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ABLEDATA</th>
</tr>
</thead>
<tbody>
<tr>
<td>A national database of information on more than 17,000 products that are currently available for people with disabilities.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Access Board</th>
</tr>
</thead>
<tbody>
<tr>
<td>An independent federal agency. Contains information on Section 508 of the Rehabilitation Act, as amended requiring that electronic and information technology developed, procured, maintained, or used by the federal government be accessible to people with disabilities. In 1998, the board established an Electronic and Information Technology Access Advisory Committee (EITAAC) to help the board develop standards under Section 508.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Accessible Website Design Resources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Connects to a Government Services Administration (GSA) site with links to several organizations with “how-to’s” on designing websites for accessibility for people with disabilities, including a link to “Top Ten Mistakes in Web Design.”</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Alliance for Technology Access</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provides location information for the Alliance for Technology Access regional centers. The Alliance assists individuals with disabilities in accessing technology, mainly through computer resources.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Apple’s Disability Solutions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information on computer access solutions for individuals with disabilities.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Assistive Technology Funding and Systems Change Project (ATFSCP)</th>
</tr>
</thead>
<tbody>
<tr>
<td>AT funding and systems change information.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>AT Quick Reference Series</th>
</tr>
</thead>
<tbody>
<tr>
<td>This TechConnections resource provides quick reference guides for work-related accommodations, such as Voice Input Systems, accessible calculators, mouse alternatives, one-handed keyboards, and other assistive technologies.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>AZtech, Inc.</th>
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</thead>
<tbody>
<tr>
<td>Information on transforming inventions into products for individuals with disabilities.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Breaking New Ground Resource Center</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>
The Role of the SLP and Assistive Technology in Life Care Planning

| Provides information and resources on AT for agricultural workers and agricultural worksites. In 1990, the Outreach Center of Breaking New Ground became a part of the USDA AgrAbility program. |
| Center for Information Technology Accommodation (CITA) |
| Legislation and policies on information systems accessibility, including the Assistive Technology Act of 1998. |
| Closing the Gap |
| Closing the Gap’s role is to provide information on microcomputer materials and practices that can help enrich the lives of persons with special needs. |
| Consortium for Citizens with Disabilities (CCD) |
| CCD is a working coalition of more than 100 national consumer, advocacy, provider, and professional organizations working together with and on behalf of the 54 million children and adults with disabilities and their families living in the United States. The CCD has several task forces on various disability issues, such as employment and training, developmental disabilities, health, Social Security, long-term services and supports, telecommunications and technology, rights, etc. |
| Cornucopia of Disability Information (CODI) |
| A wealth of information relating to disabilities, including topics such as aging, statistics, computing, centers for independent living, and universal design. This site is based at the State University of New York–Buffalo. |
| CPB/WGBH National Center for Accessible Media |
| “Making Educational Software Accessible: Design Guidelines, Including Math and Science Solutions.” These guidelines represent an ambitious initiative to capture access challenges and solutions and present them in a format specifically designed to educate and assist educational software developers. The detailed guidelines and solutions specific to math and science are unique to this document. This work is the result of a 3-year project funded by the National Science Foundation’s Program for Persons with Disabilities. The CPB/WGBH National Center for Accessible Media developed this document with input from a distinguished board of advisors with expertise in accessible design, AT, and the education of students with disabilities. |
| DISABILITY Resources on the Internet |
| This site was created and is maintained by Jim Lubin, a person with quadriplegia. |
| Do-It Internet Resources |
| Resources are listed in many categories, including general resources, education, technology, legal, social, and political issues. |
| EPVA Assistive Technology |
| The Eastern Paralyzed Veterans Association (EPVA) launched a website for AT in 2002. Available at this site are product reviews on wheelchairs and cushions and a tech guide on driving aids, transfer devices, and exercise equipment. |
| Equal Access to Software and Information (EASI) |
| EASI is part of the Teaching, Learning, and Technology Group, an affiliate of the American Association of Higher Education. EASI’s mission is to promote the same access to information and resources for people with disabilities as everyone else. |

(Continued)
Appendix 9.9 (Continued)

<table>
<thead>
<tr>
<th>Website/Source</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>IBM Special Needs Solutions</td>
<td>Information on IBM computer access solutions for persons with disabilities.</td>
</tr>
<tr>
<td>International Center for Disability Resources on the Internet</td>
<td>The center will collect and present best practices in areas related to disability and accessibility issues. The center will collect disability-related Internet resources, including resources that may be helpful to the disability community.</td>
</tr>
<tr>
<td>Job Accommodation Network (JAN)</td>
<td>A service of the U.S. Department of Labor’s President’s Committee on Employment of People with Disabilities, JAN provides information about job accommodation and the employability of people with functional limitations. Publishes quarterly reports on the number of cases handled by information and ADA-related concerns, among many other outcome data statistics.</td>
</tr>
<tr>
<td>National Clearing House of Rehabilitation Training Materials (NCHRTM)</td>
<td>Download AT-related documents from this site. Sample titles include “Assistive Technology: Practical Intervention Strategies”; “ADA: Train the Trainer Program”; and “Reasonable Accommodations in the Workplace.”</td>
</tr>
<tr>
<td>National Rehabilitation Information Center (NARIC)</td>
<td>NARIC is a library and information center on disability and rehabilitation. More than 50,000 National Institute on Disability and Rehabilitation Research (NIDRR)-funded, other federal agency, and private disability-related publications are held and abstracted by NARIC in its REHABDATA database, searchable online.</td>
</tr>
<tr>
<td>National Institute on Disability and Rehabilitation Research (NIDRR)</td>
<td>NIDRR, part of the U.S. Department of Education, manages and funds more than 300 projects on disability and rehabilitation research, including 56 state and U.S. territory AT projects and several Rehabilitation Engineering Research Centers.</td>
</tr>
<tr>
<td>On a Roll—Talk Radio</td>
<td>Talk Radio focusing on life and disability news, updated daily. While at the site, check out the RealAudio archives of this award-winning radio talk show.</td>
</tr>
<tr>
<td>One-Hand Typing</td>
<td>Information on free downloads, how-to manuals, therapists, and more.</td>
</tr>
<tr>
<td>TeamRehab Report</td>
<td>A monthly magazine for professionals in rehabilitation technology and services.</td>
</tr>
<tr>
<td>Trace Research &amp; Development Center</td>
<td></td>
</tr>
</tbody>
</table>
The Trace Center conducts research aimed at improving technology that can benefit individuals with disabilities by making it more accessible in four main areas: communication, control, computer access, and next-generation communication information and transaction systems.

<table>
<thead>
<tr>
<th>West Virginia Rehabilitation Research and Training Center (WVRRRT)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information resources on vocational rehabilitation, including links to the Job Accommodation Network and Project Enable.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>WheelchairNet</th>
</tr>
</thead>
<tbody>
<tr>
<td>WheelchairNet is a continuously developing resource for a broad community of people who are interested in wheelchairs: consumers, clinicians, manufacturers, researchers, funders. It contains resources for lifestyle, wheelchair technology and research developments, discussions, products, industry product standards, funding, services, etc.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>World Wide Web Consortium (W3C)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The W3C, an international industry consortium, was founded in October 1994 to lead the World Wide Web to its full potential by developing common protocols that promote its evolution and ensure its operability. The W3C also includes the World Accessibility Initiative, which provides guidelines on website accessibility.</td>
</tr>
</tbody>
</table>

**Appendix 9.10 International Sites**

<table>
<thead>
<tr>
<th>AAATE</th>
</tr>
</thead>
<tbody>
<tr>
<td><a href="http://www.fernuni-hagden.de/FTB/AAATE.html">www.fernuni-hagden.de/FTB/AAATE.html</a></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ARATA</th>
</tr>
</thead>
<tbody>
<tr>
<td><a href="http://www.iinet.net.au/~sharano/arata">www.iinet.net.au/~sharano/arata</a></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>International Center for Disability Resources on the Internet</th>
</tr>
</thead>
<tbody>
<tr>
<td>The center will collect and present best practices in areas related to disability and accessibility issues. The center will collect disability-related Internet resources, including resources that may be helpful to the disability community.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Untangling the Web: Where Do I Go for Disability Information?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lists websites in many categories, including general information resources, disability legislation, employment resources, and more.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Yuri Rubinsky Insight Foundation: webABLE!</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contains an accessibility database that provides links to an extensive list of Internet resources related to disability and accessibility. Resources include mailing lists, websites, and newsgroups.</td>
</tr>
</tbody>
</table>
### Appendix 9.11 Periodicals and Newsletters

<table>
<thead>
<tr>
<th>Periodical/Newsletter</th>
<th>Address</th>
<th>Telephone</th>
<th>Fax</th>
<th>Website/E-mail</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alternatively Speaking</td>
<td>Augmentative Communication, Inc., 1 Surf Way, Suite 237, Monterey, CA 93940;</td>
<td>408-649-3050; Fax: 408-646-5428; newsletter.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Closing the Gap Resource Directory</td>
<td>P.O. Box 68, Henderson, MN 56044;</td>
<td>612-248-3294.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Conn SENSE Bulletin</td>
<td>Special Education Center, Technology Lab, The University of Connecticut, U-64, Room 227, 249 Glenbrook Rd., Storrs, CT 06269-2064;</td>
<td>203-486-0172.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The ISAAC Bulletin</td>
<td>49 The Donway West, Suite 308, Toronto, ON M3C 3M9, Canada;</td>
<td>+1-416-385-0351; Fax: +1-416-385-0352; E-mail: <a href="mailto:secretariat@isaac-online.org">secretariat@isaac-online.org</a>; Website: <a href="http://www.isaac-online.org">www.isaac-online.org</a>.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>REACH/Rehabilitation Engineering Associates</td>
<td>Telephone: 800-485-5040; newsletter.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SpeakUp!</td>
<td>c/o Beatrice Bruno, P.O. Box 21418, Sarasota, FL 34276; Telephone: 941-312-0992; Fax: 941-312-0992; E-mail: <a href="mailto:usaac@comcast.com">usaac@comcast.com</a>; Website: <a href="http://www.usaac.com">www.usaac.com</a>.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Voices</td>
<td>Hear Our Voices, Newsletter Department, 1660 L St. NW, Suite 700, Washington, DC 20036; Telephone: 205-930-9025.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>WorkTech</td>
<td>Seaside Education Associates, Inc., P.O. Box 6341, Lincoln Center, MA 01773; newsletter.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Appendix 9.12 Model Superbill for Speech-Language Pathology

The following is a model of a superbill that could be used by a speech-language pathology practice when billing private health plans. This sample is not meant to dictate which services should or should not be listed on the bill. Most billable codes are from the American Medical Association (AMA) Current Procedural Terminology (CPT), © 2007. Prosthetic and durable medical equipment codes, such as speech-generating device codes, are published by the Centers for Medicaid and Medicare (CMS) as Healthcare Common Procedure Codes.

The superbill is a standard form that health plans use to process claims. For the professional rendering services, it provides a time-efficient means to document services, fees, codes, and other information required by insurance companies (i.e., certification and licensure). The patient uses this form to file for health plan payment.

**Note:** This is only a model; therefore, some procedures, codes, or other pertinent information may not be found on the following model. For a complete list of CPT and ICD-9 code, the ASHA Health Plan Coding & Claims Guide is available through ASHA's Billing & Reimbursement web site or by calling ASHA's Product Sales at 1-888-498-6699.
<table>
<thead>
<tr>
<th>CPT</th>
<th>Procedure</th>
<th>Charge</th>
</tr>
</thead>
<tbody>
<tr>
<td>92526</td>
<td>Treatment of swallowing dysfunction and/or oral function for feeding</td>
<td>_____</td>
</tr>
<tr>
<td>92610</td>
<td>Evaluation of swallowing function</td>
<td>_____</td>
</tr>
<tr>
<td>92611</td>
<td>Motion fluoroscopic evaluation of swallowing function</td>
<td>_____</td>
</tr>
<tr>
<td>92612</td>
<td>Flexible fiber-optic endoscopic evaluation of swallowing;</td>
<td>_____</td>
</tr>
<tr>
<td>92613</td>
<td>with physician interpretation and report</td>
<td>_____</td>
</tr>
<tr>
<td>92614</td>
<td>Flexible fiber-optic endoscopic evaluation laryngeal sensory testing by line or video recording;</td>
<td>_____</td>
</tr>
<tr>
<td>92615</td>
<td>with physician interpretation and report</td>
<td>_____</td>
</tr>
<tr>
<td>92616</td>
<td>Flexible fiber-optic endoscopic evaluation of swallowing and laryngeal sensory testing;</td>
<td>_____</td>
</tr>
<tr>
<td>92617</td>
<td>with physician interpretation and report</td>
<td>_____</td>
</tr>
<tr>
<td>92506</td>
<td>Evaluation of speech, language, voice, communication, and/or auditory processing.</td>
<td>_____</td>
</tr>
<tr>
<td>92507</td>
<td>Treatment of speech, language, voice, communication, and/or auditory processing disorder, individual</td>
<td>_____</td>
</tr>
<tr>
<td>92508</td>
<td>group, two or more individuals</td>
<td>_____</td>
</tr>
<tr>
<td>97532</td>
<td>Development of cognitive skills to improve attention, memory, problem solving, direct one-on-one patient contact by the provider; each 15 minutes</td>
<td>_____</td>
</tr>
<tr>
<td>97533</td>
<td>Sensory integrative techniques to enhance sensory processing and promote adaptive responses to environmental demands; each 15 minutes</td>
<td>_____</td>
</tr>
<tr>
<td>92511</td>
<td>Nasopharyngoscopy w/ endoscope</td>
<td>_____</td>
</tr>
</tbody>
</table>

(Continued)
### Appendix 9.12 (Continued)

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
<th>Unit</th>
</tr>
</thead>
<tbody>
<tr>
<td>92520</td>
<td>Laryngeal function studies</td>
<td></td>
</tr>
<tr>
<td>92626</td>
<td>Evaluation of auditory rehabilitation status, first hour</td>
<td></td>
</tr>
<tr>
<td>92627</td>
<td>each additional 15 minutes</td>
<td></td>
</tr>
<tr>
<td>92630</td>
<td>Auditory rehabilitation; prelingual hearing loss</td>
<td></td>
</tr>
<tr>
<td>92633</td>
<td>Auditory rehabilitation; postlingual hearing loss</td>
<td></td>
</tr>
<tr>
<td>96105</td>
<td>Assessment of aphasia with interpretation and report, per hour</td>
<td></td>
</tr>
<tr>
<td>96110</td>
<td>Developmental testing; limited, w/ interpretation and report</td>
<td></td>
</tr>
<tr>
<td>96111</td>
<td>Extended, with interpretation and report, per hour</td>
<td></td>
</tr>
<tr>
<td>96125</td>
<td>Standardized cognitive performance testing (e.g., Ross Information Processing Assessment) per hour of a qualified health care professional's time, both face-to-face time administering tests to the patient and time interpreting these test results and preparing the report</td>
<td></td>
</tr>
<tr>
<td>31575</td>
<td>Laryngoscopy; flexible fiber-optic; diagnostic</td>
<td></td>
</tr>
<tr>
<td>31579</td>
<td>Laryngoscopy; flexible or rigid fiber-optic, with stroboscopy</td>
<td></td>
</tr>
</tbody>
</table>

#### Augmentative and Alternative Communication

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
<th>Unit</th>
</tr>
</thead>
<tbody>
<tr>
<td>92597</td>
<td>Evaluation for use/fitting of voice prosthetic device to supplement oral speech</td>
<td></td>
</tr>
<tr>
<td>92605</td>
<td>Evaluation for prescription of non-speech-generating augmentative and alternative communication device</td>
<td></td>
</tr>
<tr>
<td>92606</td>
<td>Therapeutic service(s) for the use of non-speech-generating augmentative and alternative communication device, including programming and modification</td>
<td></td>
</tr>
<tr>
<td>92607</td>
<td>Evaluation for prescription for speech-generating augmentative and alternative communication device; face-to-face with the patient; evaluation, first hour</td>
<td></td>
</tr>
<tr>
<td>92608</td>
<td>Evaluation for speech device; each additional 30 minutes</td>
<td></td>
</tr>
<tr>
<td>92609</td>
<td>Therapeutic services for the use of speech-generating device, including programming and modification</td>
<td></td>
</tr>
<tr>
<td>V5336</td>
<td>Repair/modification of AAC device (excluding adaptive hearing aid)</td>
<td></td>
</tr>
</tbody>
</table>

#### Other Procedures

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
<th>Unit</th>
</tr>
</thead>
<tbody>
<tr>
<td>92700</td>
<td>Unlisted otorhinolaryngological service or procedure</td>
<td></td>
</tr>
<tr>
<td>99366</td>
<td>Medical team conference with interdisciplinary team of health care professionals, face-to-face with patient and/or family present, 30 minutes or more, participation by qualified health care professional</td>
<td></td>
</tr>
<tr>
<td>99368</td>
<td>Medical team conference with interdisciplinary team of health care professionals, face-to-face, patient and/or family not present, 30 minutes or more, participation by qualified health care professional</td>
<td></td>
</tr>
</tbody>
</table>

#### TOTAL CHARGES

---

---
I HEREBY AUTHORIZE DIRECT PAYMENT OF BENEFITS TO SPEECH SERVICES, INC.
SIGNATURE: ____________________________

I HEREBY AUTHORIZE IRENE SMITH, M.A. - CCC-SLP TO RELEASE ANY INFORMATION ACQUIRED IN THE COURSE OF TREATMENT.
SIGNATURE: ____________________________

IRENE SMITH, MA, CCC-SLP
SPEECH SERVICES, INC.
555 ANYWHERE ROAD ANYWHERE, CA 55555
(555) 555-5555

<table>
<thead>
<tr>
<th>SS #000-00-0000</th>
<th>Tax ID #00-000000</th>
<th>California License #0000</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Speech-Language Pathology</td>
<td></td>
</tr>
<tr>
<td>White copy: Office</td>
<td>Canary copy: Insurance</td>
<td>Pink Copy: Patient</td>
</tr>
</tbody>
</table>

Appendix 9.13  Key Acronyms and Phrases Used in Communication Sciences and Disorders

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AAA</td>
<td>American Academy of Audiology</td>
</tr>
<tr>
<td>AAS</td>
<td>American Auditory Society</td>
</tr>
<tr>
<td>ABD</td>
<td>All but dissertation</td>
</tr>
<tr>
<td>ACPCA</td>
<td>American Cleft Palate Craniofacial Association</td>
</tr>
<tr>
<td>ADA</td>
<td>Americans with Disabilities Act</td>
</tr>
<tr>
<td>AIC</td>
<td>Asian Indian Caucus</td>
</tr>
<tr>
<td>ANCDS</td>
<td>Academy of Neurological Communication Disorders and Sciences</td>
</tr>
<tr>
<td>APA</td>
<td>American Psychological Association</td>
</tr>
<tr>
<td>API</td>
<td>Asian Pacific Islander</td>
</tr>
<tr>
<td>ARO</td>
<td>Association for Research in Otolaryngology</td>
</tr>
<tr>
<td>ASA</td>
<td>Acoustical Society of America</td>
</tr>
<tr>
<td>ASHA</td>
<td>American Speech Language Hearing Association</td>
</tr>
<tr>
<td>ASHF</td>
<td>American Speech Language Hearing Foundation</td>
</tr>
<tr>
<td>ASL</td>
<td>American Sign Language</td>
</tr>
<tr>
<td>AuD</td>
<td>Doctorate of audiology</td>
</tr>
<tr>
<td>BA</td>
<td>Bachelor of arts</td>
</tr>
<tr>
<td>BBS</td>
<td>Bachelor of health sciences</td>
</tr>
<tr>
<td>BHSM</td>
<td>Better Hearing and Speech Month</td>
</tr>
<tr>
<td>BS</td>
<td>Bachelor of sciences</td>
</tr>
</tbody>
</table>

(Continued)
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>CAOHC</td>
<td>Council for Accreditation in Occupational Hearing Conversation</td>
</tr>
<tr>
<td>CAPCSD</td>
<td>Council for Academic Programs in Communications Sciences and Disorders</td>
</tr>
<tr>
<td>CCC</td>
<td>Certificate of clinical competence</td>
</tr>
<tr>
<td>CEU</td>
<td>Continuing education unit</td>
</tr>
<tr>
<td>CF</td>
<td>Clinical fellowship</td>
</tr>
<tr>
<td>CLD</td>
<td>Culturally and linguistically different</td>
</tr>
<tr>
<td>CSD</td>
<td>Communication sciences and disorders</td>
</tr>
<tr>
<td>CV</td>
<td>Curriculum vitae</td>
</tr>
<tr>
<td>DIVISIONS</td>
<td>Special interest divisions</td>
</tr>
<tr>
<td>EB</td>
<td>Executive board</td>
</tr>
<tr>
<td>EC</td>
<td>Executive council</td>
</tr>
<tr>
<td>FAFSA</td>
<td>Free Application for Federal Student Aid</td>
</tr>
<tr>
<td>GPA</td>
<td>Grade point average</td>
</tr>
<tr>
<td>GSF</td>
<td>Graduate school fair</td>
</tr>
<tr>
<td>GUR</td>
<td>General university requirement</td>
</tr>
<tr>
<td>IDEA</td>
<td>Individuals with Disabilities Education Act</td>
</tr>
<tr>
<td>IEP</td>
<td>Individual education plan</td>
</tr>
<tr>
<td>IRB</td>
<td>Institutional Review Board</td>
</tr>
<tr>
<td>LC</td>
<td>Legislative council</td>
</tr>
<tr>
<td>LSA</td>
<td>Linguistic Society of America</td>
</tr>
<tr>
<td>MA</td>
<td>Master of arts</td>
</tr>
<tr>
<td>MS</td>
<td>Master of science</td>
</tr>
<tr>
<td>NAFDA</td>
<td>National Association of Future Doctors of Audiology</td>
</tr>
<tr>
<td>NAPP</td>
<td>National Association of Preprofessional Programs</td>
</tr>
<tr>
<td>NBASLH</td>
<td>National Black Association for Speech–Language Pathology and Hearing</td>
</tr>
<tr>
<td>NBGSA</td>
<td>National Black Graduate Student Association, Inc.</td>
</tr>
<tr>
<td>NESPA</td>
<td>National Examination in Speech-Language Pathology and Audiology</td>
</tr>
<tr>
<td>NIH</td>
<td>National Institute of Health</td>
</tr>
<tr>
<td>NSF</td>
<td>National Science Foundation</td>
</tr>
<tr>
<td>NSSLHA</td>
<td>National Student Speech–Language–Hearing Association</td>
</tr>
<tr>
<td>OT</td>
<td>Occupational therapist or occupational therapy</td>
</tr>
<tr>
<td>PAC</td>
<td>Political action committee</td>
</tr>
<tr>
<td>PET</td>
<td>Positron emission topography</td>
</tr>
<tr>
<td>PhD</td>
<td>Doctorate of philosophy</td>
</tr>
<tr>
<td>PT</td>
<td>Physical therapist or physical therapy</td>
</tr>
<tr>
<td>----------</td>
<td>----------------------------------------</td>
</tr>
<tr>
<td>Quals</td>
<td>Qualifying examinations</td>
</tr>
<tr>
<td>RC</td>
<td>Regional counselor</td>
</tr>
<tr>
<td>SHS</td>
<td>Speech, language, and hearing scientist</td>
</tr>
<tr>
<td>SLP</td>
<td>Speech-language pathologist</td>
</tr>
<tr>
<td>SLP-A</td>
<td>Speech-language pathology assistant</td>
</tr>
</tbody>
</table>

### Appendix 9.14  How Do I Know if My Child Is Reaching the Milestones?

<table>
<thead>
<tr>
<th>Birth to 5 months</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reacts to loud sounds.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Turns head toward a sound source.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Watches your face when you speak.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vocalizes pleasure and displeasure sounds (laughs, giggles, cries, or fusses).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Makes noise when talked to.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>6 to 11 months</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Understands “no-no.”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Babbles (says “ba-ba-ba” or “ma-ma-ma”).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tries to communicate by actions or gestures.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tries to repeat your sounds.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>12 to 17 months</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Attends to a book or toy for about 2 minutes.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Follows simple directions accompanied by gestures.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Answers simple directions nonverbally.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Points to objects, pictures, and family members.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Says two or three words to label a person or object (pronunciation may not be clear).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tries to imitate simple words.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>18 to 23 months</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Enjoys being read to.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Follows simple commands without gestures.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Points to simple body parts such as “nose.”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Understands simple verbs such as “eat,” “sleep.”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Correctly pronounces most vowels and n, m, p, b, words. Also begins to use other speech sounds.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 9.14 (Continued)

<table>
<thead>
<tr>
<th>Names of the State</th>
<th>E-mail Addresses</th>
<th>Websites</th>
</tr>
</thead>
<tbody>
<tr>
<td>ALABAMA Alabama Statewide Technology Access and Response Project (STAR) System for Alabamians with Disabilities</td>
<td><a href="mailto:pbloom@rehab.state.ak.us">pbloom@rehab.state.ak.us</a></td>
<td><a href="http://www.rehab.state.al.us/star">www.rehab.state.al.us/star</a></td>
</tr>
<tr>
<td>ALASKA Alaska Assistive Technology Program</td>
<td><a href="mailto:sean_obrien@labor.state.ak.us">sean_obrien@labor.state.ak.us</a></td>
<td><a href="http://www.labor.state.ak.us/at/index.htm">www.labor.state.ak.us/at/index.htm</a></td>
</tr>
<tr>
<td>AMERICAN SAMOA American Samoa Assistive Technology Service Projects (ASATS)</td>
<td><a href="mailto:apisap26@yahoo.com">apisap26@yahoo.com</a></td>
<td></td>
</tr>
<tr>
<td>ARIZONA Arizona Technology Access Program (AZTAP)</td>
<td><a href="mailto:jill.sherman@nau.edu">jill.sherman@nau.edu</a></td>
<td><a href="http://www.nau.edu/ihd/aztap">www.nau.edu/ihd/aztap</a></td>
</tr>
<tr>
<td>ARKANSAS Arkansas Increasing Capabilities Access Network (ICAN)</td>
<td><a href="mailto:bmvuletich@ars.state.ar.us">bmvuletich@ars.state.ar.us</a></td>
<td><a href="http://www.arkansas-ican.org">www.arkansas-ican.org</a></td>
</tr>
<tr>
<td>CALIFORNIA California Assistive Technology System (CATS)</td>
<td><a href="mailto:rdevylde@dor.ca.gov">rdevylde@dor.ca.gov</a></td>
<td><a href="http://www.atnet.org/resources/about_cats.htm">www.atnet.org/resources/about_cats.htm</a></td>
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<tr>
<td>COLORADO Colorado Assistive Technology Project</td>
<td><a href="mailto:cathy.bodine@uchsc.edu">cathy.bodine@uchsc.edu</a></td>
<td><a href="http://www.uchs.edu/atp">www.uchs.edu/atp</a></td>
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<tr>
<td>CONNECTICUT Connective Assistive Technology Project</td>
<td><a href="mailto:dawn.lambert@po.state.ct.us">dawn.lambert@po.state.ct.us</a></td>
<td><a href="http://www.techactproject.com">www.techactproject.com</a></td>
</tr>
<tr>
<td>DELAWARE Delaware Assistive Technology Initiative (DATI)</td>
<td><a href="mailto:dati@asel.udel.edu">dati@asel.udel.edu</a></td>
<td><a href="http://www.asel.udel.edu/dati/">www.asel.udel.edu/dati/</a></td>
</tr>
</tbody>
</table>

Says 8 to 10 words (pronunciation may still be unclear).

Asks for common foods by name.

Makes animal sounds such as “moo.”

Starts to combine words such as “more milk.”

Begins to use pronouns such as “mine.”
<table>
<thead>
<tr>
<th>DISTRICT OF COLUMBIA</th>
<th><a href="mailto:ajohns@uls.dc.com">ajohns@uls.dc.com</a></th>
<th><a href="http://www.atpdc.org">www.atpdc.org</a></th>
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<td>Georgia Tools for Life</td>
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<th><a href="http://www.atrc.org">www.atrc.org</a></th>
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<th><a href="mailto:rseiler@uidaho.edu">rseiler@uidaho.edu</a></th>
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<th><a href="mailto:infotech@uiowa.edu">infotech@uiowa.edu</a></th>
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<tr>
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<td>---------------------------</td>
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<tr>
<td>MARIANA ISLANDS</td>
<td><a href="mailto:straid@cnmiddcouncil.org">straid@cnmiddcouncil.org</a></td>
<td><a href="http://www.cnmiddcouncil.org">www.cnmiddcouncil.org</a></td>
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<td>Commonwealth of the</td>
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<td>Northern Mariana Islands</td>
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<td>Assistive Technology</td>
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<tr>
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<td><a href="mailto:mdtap@mdod.state.md.us">mdtap@mdod.state.md.us</a></td>
<td><a href="http://www.mdtap.org">www.mdtap.org</a></td>
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<td><a href="mailto:matp@matp.org">matp@matp.org</a></td>
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<tr>
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<td>MICHIGAN</td>
<td><a href="mailto:cbair@match.org">cbair@match.org</a></td>
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<tr>
<td>MINNESOTA</td>
<td><a href="mailto:star.program@state.mn.us">star.program@state.mn.us</a>/</td>
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<tr>
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<td><a href="mailto:contactus@msprojectstart.org">contactus@msprojectstart.org</a></td>
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<tr>
<td>MISSOURI</td>
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<td>MONTANA</td>
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<td>NEBRASKA</td>
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<td>NEW HAMPSHIRE</td>
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<td>NEW MEXICO</td>
<td><a href="mailto:AWinnegar@state.nm.us">AWinnegar@state.nm.us</a></td>
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<td>OKLAHOMA</td>
<td>Oklahoma ABLE Tech</td>
<td><a href="mailto:linda.jacol@okstate.edu">linda.jacol@okstate.edu</a></td>
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<tr>
<td>OREGON</td>
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<td><a href="mailto:laurie@accesstechnologiesinc.org">laurie@accesstechnologiesinc.org</a></td>
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<tr>
<td>PENNSYLVANIA</td>
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<td><a href="mailto:piat@temple.edu">piat@temple.edu</a></td>
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<td>VIRGIN ISLANDS</td>
<td>U.S. Virgin Islands Technology-Related Assistance for Individuals with Disabilities (TRAID)</td>
<td><a href="mailto:yhabtey@uvi.edu">yhabtey@uvi.edu</a></td>
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(Continued)
### Appendix 9.15 AT Resource Directory

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<td><a href="http://www.acsw.com">www.acsw.com</a></td>
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<td><a href="http://www.AcademicTherapy.com">www.AcademicTherapy.com</a></td>
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<td><a href="http://www.accessiblebookcollection.org">www.accessiblebookcollection.org</a></td>
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<tr>
<td>Acoustic Magic, Inc.</td>
<td><a href="mailto:Bob@Acousticmagic.com">Bob@Acousticmagic.com</a></td>
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<tr>
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</tr>
<tr>
<td>Company</td>
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<td>Website</td>
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<tr>
<td>-------------------------------</td>
<td>--------------------------------</td>
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<td><a href="http://www.adamlab.com">www.adamlab.com</a></td>
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<td><a href="http://www.adaptivation.com">www.adaptivation.com</a></td>
</tr>
<tr>
<td>Adaptive Solutions</td>
<td><a href="mailto:sherry@adaptive-sol.com">sherry@adaptive-sol.com</a></td>
<td><a href="http://www.adaptive-sol.com">www.adaptive-sol.com</a></td>
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<td>Adaptive Technologies Research, Inc.</td>
<td><a href="mailto:info@adapt-tech.com">info@adapt-tech.com</a></td>
<td><a href="http://www.adapt-tech.com">www.adapt-tech.com</a></td>
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<td>Advanced Multimedia Devices, Inc.</td>
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<td><a href="http://www.amdi.net">www.amdi.net</a></td>
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<td>AGS Publishing</td>
<td><a href="mailto:brian@agsnet.com">brian@agsnet.com</a></td>
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<td>The Conover Company</td>
<td><a href="mailto:sales@conovercompany.com">sales@conovercompany.com</a></td>
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<td>The Great Talking Box Company</td>
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<td>The School Board Co., Inc.</td>
<td><a href="mailto:sennil04@earthlink.net">sennil04@earthlink.net</a></td>
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<td>Thinking Publications</td>
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<td>Tiger DRS, Inc.</td>
<td><a href="mailto:tiger-electronics@att.net">tiger-electronics@att.net</a></td>
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Appendix 9.17 Outline for Funding Request

1. Demographic Information
   Patient’s name, date of birth, medical diagnosis, date of onset, patient’s contact information, physician’s contact information, SLP contact information, patient’s primary support contact information, and date of SLP evaluation.

2. Current Communication Impairment
   a. Impairment and Severity
      This section should explicitly demonstrate how the medical condition results in severe expressive speech impairment. Include ICD-9 codes as appropriate. Describe the impairment severity, as well as the type of communication disorder (dysarthria, aphasia, apraxia, aphonia).
   b. Anticipated Course of Impairment
      This section should demonstrate the current status and the expected course of the speech impairment as it relates to the underlying disease/condition. Staging scales may be used.

3. Comprehensive Assessment
   a. Hearing Status
      This section should explicitly provide information about the person’s hearing status as it relates to a SGD and accessories. If the hearing ability is not an issue, it should be stated. Include information about the communication partners, information about acuity, localization, understanding of natural speech, and understanding specific SGDs.
   b. Vision Status
      This section should explicitly provide information about the person’s visual status as it relates to using a SGD and accessories. If the person’s vision is not an issue, it should be stated. Describe the vision using an SGD, including acuity, visual fields, lighting needs, angle of view, contrast, color, detail, and spacing.
   c. Physical Status
      This section should provide information about the person’s physical skills and abilities as they relate to using an SGD and accessories. The report should state that the patient possesses the physical abilities to effectively use an SGD and required accessories to communicate. Describe pertinent considerations such as motor skills, ambulatory status, positioning needed, how scanning will occur if needed, selection options, and if accommodations may assist with physical access.

(Continued)
Appendix 9.17 (Continued)

d. Language Skills
This section should explicitly provide information about the person's language skills and abilities as they relate to using an SGD and accessories. Describe the level of linguistic impairments (mild to severe language impairment), performance on any language assessment (e.g., BDAE, WAB, picture descriptions), competency or ability to develop skills (e.g., form, content, use), type of symbol use will be required, or whether a combination of different types of symbols.

e. Cognitive Skills
This section should explicitly provide information about the person's cognitive skills and abilities as they relate to the use of an SGD and accessories. If cognitive/linguistic abilities are not an issue, it should be stated. Discuss the level of cognitive impairment, if significant impairment, how it relates to a person's need for an SGD, describe a person's attention, problem-solving skills as they relate to, enhance, or develop daily, functional communication skills.

4. Daily Communication Needs
   a. Specific Daily Functional Communication Needs
      This section should list the person's daily functional communication needs in areas described. Supplement the categories by considering daily communication situations, environments, partners, and specific messages. Include specific daily communication needs that may encourage increased independence, such as access to telephone.

   b. Ability to Meet Communication Needs with Non-SGD Treatment Approaches
      This section should document why the patient is unable to fulfill daily functional communication needs using natural speech (or speech aids) and non-SGD treatment approaches including a statement that states that daily functional communication needs cannot be met using natural communication methods or low-tech/no-tech AAC techniques because of ______________ (specific). Discuss communication prognosis without an SGD, the individual's ability to use strategies and natural modes of daily communication, why high-tech instead of low-tech strategies, show explicitly what other forms have been considered and ruled out, and mention issues related to communication partners and caregivers.

5. Functional Communication Goals
   This section should state the daily functional communication treatment goals that will be met using a SGD. This is a very important section. Functional goals are key to demonstrating the need for ongoing treatment. They are also key to demonstrating positive outcomes with SGD use and why a particular SGD will benefit the individual and enable her to achieve functional communication goals. SLPs should prepare immediate-term, short- to mid-term, and long-term functional goals. Include a timetable.

6. Rationale for Device Selection
   This section will explain why certain device features are required based on the person's skills and abilities as described in the daily communication needs. This section provides data that lead first to the selection of a specific device code and, second, to a specific device within that code, as well as specific accessories. At this point, SLPs work with rehab engineers, physical therapists, occupational therapists, and use AAC devices with simulations or clinical trials.
The Role of the SLP and Assistive Technology in Life Care Planning

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<th>a. General Features of Recommended SGD and Accessories</th>
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<td>Direct selection, scanning, and encoding access techniques are considered, as are message characteristics and features (type of symbols, storage capacity, vocabulary expansion and rate enhancement). Output features to include voice output, visual display, and feedback and other features such as portability (size and weight, transportation requirements) and battery time required are other considerations.</td>
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7. Recommended Device and Accessory Codes

| The coverage limitations and issues related to whether a manufacturer/supplier will accept assignment need to be considered, with reference to the SGD category chart. |

8. Description of Equipment and Procedures Used During Any Demonstrations of the Recommended SGD and Any Other SGDs and Accessories

| Evidence that the individual participated in the assessment process needs to be noted with some prediction of outcomes with the use of the SGD device. |

9. SGD and Accessories Recommended

| At this point, the individual's ability to achieve his functional communication goals requires the acquisition and use of the (name of the device) and (name the specific accessories) needs to be noted. The identified SGD should represent the clinically most appropriate device for (name of beneficiary). Specific SGD and accessories are listed in this section as well as why they enable the individual to achieve functional communication goals. |

10. Patient and Family Support of the SGD

| Discuss participation of the family/caregivers/client state they agree to the selected SGD equipment and its use for daily communication. |

11. Physician Involvement Statement

| Confirmation that the treating physician (name, address, phone number) on ___(date) saw the report and concurred with it, thus writing a prescription for the recommended SGD and accessories (date the report was forwarded to the physician should be before the date of the prescription). |

12. Treatment Plan

| Frequency of therapy, functional goals with dates, type of treatment (individual vs. group), follow-up recommendations, projected frequency of reassessment, and possible examples of a treatment plan. |

13. Functional Benefit of Upgrade

| This section is required only if the SLP is requesting an upgrade of equipment. The features or capabilities of the upgrade recommendations are included, plus additional communication goals that can be achieved with the upgraded equipment and the importance of the patient's ability to complete these communication goals. |

14. SLP Assurance of Financial Independence and Signature

| The statement confirming that the SLP performing this assessment is not an employee of and does not have a financial relationship with the supplier of an SGD. This disclaimer statement, the SLP's name, ASHA certification number, and state license number complete the report. |

(Continued)
## Appendix 9.18 AAC Organizations

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<tr>
<td>Autism Society of America</td>
<td><a href="mailto:info@autism-society.org">info@autism-society.org</a></td>
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<td>CAST, Inc.</td>
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<tr>
<td>Center for Assistive Technology &amp; Environmental Access (CATEA)</td>
<td><a href="mailto:catea@coa.gatech.edu">catea@coa.gatech.edu</a></td>
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<tr>
<td>Center for Best Practices in Early Childhood</td>
<td><a href="mailto:L-Robinson@wiu.edu">L-Robinson@wiu.edu</a></td>
<td><a href="http://www.wiu.edu/thecenter">www.wiu.edu/thecenter</a></td>
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<td>Center for Computer Assistance to the Disabled, Inc. (C-CAD) UC P of Metropolitan Dallas</td>
<td><a href="mailto:atinfo@ucpdallas.org">atinfo@ucpdallas.org</a></td>
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<tr>
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<td><a href="mailto:ctrdis@csun.edu">ctrdis@csun.edu</a></td>
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<td><a href="mailto:info@cprf.org">info@cprf.org</a></td>
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<td><a href="http://www.ldaamerica.org">www.ldaamerica.org</a></td>
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<tr>
<td>Minnesota Governor’s Council on Development Disabilities</td>
<td><a href="mailto:mary.jo.nichols@state.mn.us">mary.jo.nichols@state.mn.us</a></td>
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<tr>
<td>National Council on Disability</td>
<td><a href="mailto:ebriggs@ncd.gov">ebriggs@ncd.gov</a></td>
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<td>National Information Center for Children and Youth with Disabilities (NICHCY)</td>
<td><a href="mailto:nichcy@aed.org">nichcy@aed.org</a></td>
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<td>National Institute for Rehabilitation Engineering (NIRE)</td>
<td><a href="mailto:nire@theoffice.net">nire@theoffice.net</a></td>
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<td>National Lekotek Center</td>
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<tr>
<td>Porter Sargent Publishers, Inc. (Directory for Exceptional Children)</td>
<td><a href="mailto:info@portersargent.com">info@portersargent.com</a></td>
<td><a href="http://www.porter.sargent.com">www.porter.sargent.com</a></td>
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<td>Publications &amp; Information Dissemination</td>
<td><a href="mailto:clearinghouse.infotogo@gallaudet.edu">clearinghouse.infotogo@gallaudet.edu</a></td>
<td><a href="http://www.clerccenter.gallaudet.edu">www.clerccenter.gallaudet.edu</a></td>
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<td>Recording for the Blind &amp; Dyslexic (RFB &amp; D)</td>
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<td>Sensory Access Foundation</td>
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<td>Technology and Media (TAM)</td>
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<td><a href="http://www.frostig.org">www.frostig.org</a></td>
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<td>United Cerebral Palsy Associations, Inc. (UCPA)</td>
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<td>United States Society for Augmentative &amp; Alternative Communication (USSAAC)</td>
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<tr>
<td>Western Center for Microcomputers in Special Education</td>
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Chapter 10

The Role of the Audiologist in Life Care Planning

Carolyn Wiles Higdon and William Mustain

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Introduction

Audiology, an autonomous profession that encompasses both health care and educational professional areas of practice, is involved with the study of hearing and balance and their related disorders. The audiologist is the independent hearing health care professional who provides comprehensive diagnostic and habilitative/rehabilitative services for all areas of auditory, vestibular, and related disorders. These services are provided to individuals across the entire age span from birth through adulthood, which is in concert with the goals of a life care plan; to individuals from diverse language, ethnic, cultural, and socioeconomic backgrounds; and to individuals who have multiple disabilities (ASHA, Spring 1996). Within life care planning, the audiologist should be involved in pediatric and adult rehabilitation efforts when clients experience decreased hearing sensitivity, auditory processing problems, auditory neuropathy (auditory dys-synchrony), or balance problems. Clients may experience auditory deficits, due to genetic or natural aging...
factors, ear disease, brain injury, auditory processing dysfunction, environmental noise exposure, or reactions to medications that are ototoxic or vestibulotoxic.

Life care planners seeking information on current audiology preferred practices, technical papers, position statements, reimbursement codes, standards, and certification and licensure (Appendix 10.1) will find the American Speech-Language-Hearing Association (ASHA) web-portal (www.professional.asha.org or www.asha.org) the most comprehensive site for peer-reviewed documentation of practice issues and currency of reimbursement codes. The ASHA Code of Ethics (ASHA, 2003), revised January 1, 2003; scope of practice (ASHA, Spring 2004); preferred practice patterns for the profession of audiology (ASHA, 2006); Joint Audiology Committee Clinical Practice (1999) statements and algorithms; and current reimbursement code funding are documents (ASHA, 2007) of significant interest to life care planners seeking best practices information and quality hearing health care for their clients. The information is also available on the ASHA webportal.

Services provided by audiologists include the ability to

- Test and diagnose hearing and balance disorders
- Select, fit, and dispense hearing aids and assistive devices
- Provide audiologic/aural (re)habilitation services
- Educate consumers and professionals on prevention of hearing loss
- Participate in hearing conservation programs to help prevent workplace-related and recreational hearing loss
- Consult for federal, state, and local agencies in reducing community noise
- Conduct research

Audiology services are available in the following work settings:

- Colleges and universities
- Public and private schools
- Hospitals
- Community-based hearing and speech centers
- State and local health departments
- Private practices
- Rehabilitation centers
- Nursing care facilities
- Industry
- State and federal governmental agencies
- Military

Audiology can be categorized by either the setting in which one practices or the population one serves. Bess and Humes (1995) identified the following specialty areas in which audiologists generally practice (see Figure 10.1). The pediatric audiologist concentrates on the audiologic management of children of all ages. The pediatric audiologist is often employed in a children’s hospital or a health care facility primarily serving children. The medical audiologist works with patients of all ages and is more concerned with establishing the site and cause of a hearing or balance problem. Medical audiologists are typically employed in hospitals as part of either a hearing and speech department or a department of otolaryngology (i.e., ear, nose, and throat). Some audiologists who work in a medical environment perform intraoperative monitoring, which involves monitoring central and peripheral
nerve function during surgical procedures. The rehabilitative/dispensing audiologist focuses on the management of children or adults with hearing impairment. Rehabilitative audiologists are often in private practice and may specialize in the direct dispensing of hearing aids in addition to offering other audiological rehabilitation services. Rehabilitative audiologists are also employed by a variety of health care facilities (e.g., hospitals and nursing homes). The industrial audiologist provides consultative hearing conservation services to companies whose workers are exposed to high noise levels. The industrial audiologist may be in private practice or work on a part-time basis. The forensic audiologist serves as an expert witness in legal issues related to hearing and balance. The forensic audiologist may serve as an expert witness for the plaintiff or defense in compensation cases and may also serve as a consultant in community or environmental noise issues. Finally, the educational audiologist serves children in the schools and is employed or contracted by the educational system. Many audiologists, not just those in academic environments, engage in basic and applied research that is not only essential to understanding human auditory function but also necessary in order to develop testing materials and procedures and improved amplification systems.

**Basic Audiologic Procedures**

When referring a patient to an audiologist for a basic audiological assessment, one may expect certain basic procedures to be conducted to quantify and qualify hearing loss on the basis of responses to acoustic stimuli and to screen for other associated communication disorders. These include a pure tone hearing test (ASHA, 1978), speech audiometry (ASHA, 1988), and acoustic immittance (ASHA, 1991b) procedures accomplished in accordance with American National Standards.

**Clinical Process for a Basic Audiologic Assessment**

The clinical process for a basic audiologic evaluation includes the following (ASHA, 1999):

- A case history
- Otoscopic evaluation
- External ear canal examination and cerumen management, if necessary
- Assessment, which includes:
  - Air conduction and bone conduction threshold measures with appropriate masking (pure tone testing)
  - Speech recognition thresholds or speech awareness thresholds with appropriate masking
  - Word recognition (speech discrimination) measures with appropriate masking
  - Acoustic immittance testing (tympanometry, static compliance, and acoustic reflex measures)
  - Other procedures, which include, but are not limited to, otoacoustic emissions screening, speech and language screening, communication inventories, and screening for APDs and other related auditory disorders

**External Ear Canal Examination and Cerumen Management**

The external ear canal examination is performed to remove debris from the ear canal to allow the audiologist to perform the assessment or to perform rehabilitative or hearing aid procedures. The need for cerumen (ear wax) management is required when there is an accumulation of debris that would preclude the audiologist from obtaining valid and reliable assessment results and, in many cases, improve auditory sensitivity. Established procedures include the following (ASHA, 1991a; Roeser & Crandell, 1991; Ballachandra & Peers, 1992):

- Mechanical removal
- Irrigation
- Suction

It should be noted that in some states, cerumen management is not within the scope of practice of audiologists. Reimbursement for the service varies by state and region and also from third-party payers.

**Pure Tone Testing**

An audiologist using a calibrated electronic device called an audiometer measures hearing. An audiogram is a graphic representation of hearing. It relates intensity (loudness) as a function of frequency (pitch). Frequency, measured in hertz (Hz), is plotted along the abscissa, and intensity, measured in decibels (dB), is plotted along the ordinate. For a simplistic explanation of the various sounds and definitions of hearing loss, see Figure 10.2.
A person wears earphones and the audiologist presents tones at varying frequencies and intensities for each ear. When the individual hears the tone, she responds by raising her hand. When the tone is heard at the lowest intensity level two out of three times, the audiologist records this intensity level for each frequency on the audiogram. This level is called threshold. Thresholds for the left ear are plotted with a blue X and thresholds for the right ear are plotted with a red O. Normal hearing is considered to be between –10 and +15 dB HL. Hearing level (HL) is the number of decibels relative to normal hearing, which is 0 dB HL on the audiogram. The example audiogram indicates normal hearing in the left ear and a hearing loss in the right ear.

The area enclosed by the two wavy lines is called the speech banana. This area represents the frequencies and intensities of spoken English and assists the audiologist in explaining how a hearing loss may affect a person’s ability to understand speech. In the example audiogram, the person will not be able to hear speech sounds above 1000 Hz in the right ear because his thresholds are out of the speech banana. Were this person to have this degree of hearing loss in both ears, he may be expected to have difficulty understanding high-frequency speech sounds such as s, f, th, p, t, k, sh, and ch, for example. In addition, he may be expected to have considerable difficulty understanding conversational speech in the presence of background noise, such as in a cafeteria.

Audiograms (Figure 10.3) are very important because they can indicate whether a person has a hearing loss and also the type and degree of loss she has. There are three principal types of hearing loss directly associated with the peripheral auditory mechanism: conductive (a problem
in the outer or middle ear), sensorineural (a problem in the inner ear or the eighth cranial nerve, which carries the auditory signals to the brain), and mixed conductive and sensorineural loss. Other nonperipheral auditory deficits may include auditory processing disorders and an auditory neuropathy (auditory dys-synchrony).

**Speech Audiometry**

A second part of the basic testing includes speech audiometry where the audiologist evaluates how well a person can hear and understand speech. Speech audiometry consists of speech threshold and word recognition (understanding) or speech discrimination testing. Speech threshold testing determines how soft a speech sound a person can recognize, whereas word recognition testing tells the audiologist what percentage of conversational speech is correctly understood at a particular intensity level. One method of obtaining a word recognition/speech discrimination score is called the articulation gain function (Figure 10.4) (or performance intensity/phonetic balance function). This method assures that the patient’s maximum score possible will be identified (ASHA, 1988).

Most people understand conversational speech maximally at approximately 40 dB above their speech threshold. The evaluator starts by presenting the speech level at 40 dB above the patient’s speech threshold and reading a list of 50 single-syllable words with the person instructed to repeat back each word.

The percentage correct score at 40 dB above a person’s threshold is then plotted. If 100% correct is not achieved, the test is repeated using a similar list of words at 50 dB above the person’s threshold, and that score is plotted. This procedure is repeated until the person’s best score is obtained. The score in the example graph indicates that the person will understand speech 90% of the time as long as it is 60 dB above threshold.
Acoustic Immittance

Acoustic immittance, sometimes referred to as acoustic impedance, measures the mobility of the middle ear system. The middle ear is basically a vibratory system consisting of the eardrum and the three middle ear bones: the malleus, incus, and stapes. The middle ear is responsible for taking acoustic energy (sound) and transferring it via mechanical energy from the outer ear to the fluids in the inner ear. The functioning of the middle ear affects the way people hear. Tympanometry is a measure of the mobility of the middle ear (compliance) as a function of middle ear pressure, measured in dekapascals (daPa). The results are displayed on a graph called a tympanogram (Figure 10.5), and interpretation of these results can help indicate the site of the lesion or what is causing a hearing loss (ASHA, 1991b).

An electroacoustic immittance meter is used to measure the middle ear function. A plug is inserted into the ear canal, and the instrument takes the measurements and graphs the information.

There are five basic types of tympanograms:

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<td>Type A</td>
<td>Middle ear pressure is between +100 and 150 daPa. Compliance is normal.</td>
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<td>Type Aₐ</td>
<td>Middle ear pressure is normal. Compliance is reduced.</td>
<td>Otosclerosis</td>
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<td>Type Aₜ</td>
<td>Middle ear pressure is normal. Compliance is increased.</td>
<td>Disarticulation</td>
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<tr>
<td>Type</td>
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<td>-------</td>
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<tr>
<td>B</td>
<td>Middle ear pressure cannot be measured due to fluid.</td>
<td>Middle ear effusion</td>
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<tr>
<td></td>
<td>Compliance is reduced.</td>
<td></td>
</tr>
<tr>
<td>C</td>
<td>Middle ear pressure is reduced.</td>
<td>Eustachian tube dysfunction</td>
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Figure 10.5 Tympanograms.
Although these procedures are typically conducted during an audiologic evaluation, they may be modified to meet the special needs of children and other difficult-to-test patients. For patients who cannot or will not tolerate earphones, test signals (tones and speech) can be presented through loudspeakers strategically placed within the sound-attenuated test booth. The patient will either look toward the sound or be taught to place a peg in a board, ring on a peg, block in a box, and so on, in response to the sound. At that moment, the patient’s positive response behavior will be reinforced. Successive trials will enable the audiologist to establish threshold or an acceptable estimate of hearing level.

### Pediatric Audiologic Assessment

Pediatric audiologic assessment is usually conducted on infants and young children (under 5 years of age) (ASHA, 1993) and other individuals whose developmental levels preclude the use of standard adult audiologic assessment procedures. The assessment typically requires an audiologist skilled in pediatric assessment and will involve multiple office visits. The clinical process is essentially the same as that for a basic audiologic assessment prior to attempting to obtain test results. The assessment may include one or more assessment tools (acoustic immittance measures, audiologic (re)habilitation and education needs assessment, otoacoustic emissions (OAE), electrophysiologic assessment, and other developmentally appropriate behavioral procedures). Behavioral testing measures include the following:

- **Visual Reinforcement Audiometry (VRA)**
- **Conditioned Play Audiometry**
- **Tangible Reinforcement Operant Conditioning Audiometry (TROCA)**
- **Visual Reinforcement Operant Conditioning Audiometry (VROCA)**
- **Behavioral Observation Audiometry (BOA)**
- **Prenatal Causes of Hearing Loss**

Prenatal causes refer to adverse effects on the cochlea during embryological and fetal development, resulting in congenital hearing loss. Development of the external, middle, and inner ear takes place between the fourth and eighth weeks of gestation. Some infants have hereditary factors that put them at risk for hearing loss. Genetic abnormalities such as a variety of sensorimotor impairments; difficulty with balance and coordination; mental retardation; musculoskeletal anomalies; thyroid disorders; abnormal skin pigmentation; visual disorders; cleft palate; and skull, facial, and external ear deformities may accompany the hearing loss. Combinations of these various disorders are referred to as syndromes, and a combination of genetic and in utero environmental factors is referred to as multifactorial genetic consideration.

Teratogens are environmental agents that result in malformations and anomalies of specific organs and systems that are undergoing rapid development in the embryo or fetus. Exposure to teratogens may result in major congenital anomalies. Some of these teratogens and infectious diseases are drugs (alcohol, cocaine, cigarette smoke), congenital HIV and AIDS, rubella, cytomegalovirus (CMV), herpes simplex-type virus, toxoplasmosis, congenital syphilis, and thalidomide (the most notorious teratogen in history). Table 10.1 summarizes categories of risk factors for hearing loss in infants and young children.
Newborn Hearing Screening

Many children are born with significant hearing impairments but are not identified and provided appropriate intervention (Folge, 2008). These children lose their ability to acquire fundamental speech, language, cognition, and social skills required for later schooling and success in society. Early intervention is needed for them to develop communication skills on par with their normal hearing peers (Hayes & Northern, 1997; Vaughn, 2005). Hearing screening may be a luxury in many nations, but it is becoming increasingly important in nations with the resources to provide the procedures. Hayes and Northern (1997) stated that the prevalence of significant hearing disorders in newborns may be as high as 6 in every 1000 live births. Simmons, McFarland, and Jones (1980) found hearing loss in 1 out of 50 infants who had been discharged from neonatal intensive care units. Infants with low Apgar scores are considered at risk for hearing impairments. Some newborns may pass a hearing screening and still be at high risk for hearing loss, therefore it is important to perform regular follow-up hearing screenings for at least several months (Mann, Cuttler, & Campbell, 2001). Readers are referred to Table 10.2.

ASHA has a model bill for states, called the Early Hearing Detection and Intervention (EHDI) advocacy campaign, designed to help states reduce the number of infants lost to follow-up after hearing screening, expand early intervention services, and promote culturally sensitive family support programs.

Launched in 1999, ASHA’s Phase I EHDI campaign, developed in 2000 and revised in 2004, focused on federal seed grants and state legislation to expand universal newborn screening and other policies to build the infrastructure to support state EHDI programs. Since then, the number of infants screened for hearing loss has increased from 20% to 92% nationwide. Although not all states mandate hearing screening for all newborns, all states have a hearing screening program in place.

### Table 10.1 Risk Factors for Hearing Loss in Infants and Young Children

<table>
<thead>
<tr>
<th>Risk Factor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family history of childhood hearing loss</td>
</tr>
<tr>
<td>Congenital infections (TORCH)*</td>
</tr>
<tr>
<td>Craniofacial anomalies</td>
</tr>
<tr>
<td>Low birth weight (less than 3.5 lbs or 1.6 Kg)</td>
</tr>
<tr>
<td>Hyperbilirubinemia requiring blood exchange</td>
</tr>
<tr>
<td>Bacterial meningitis</td>
</tr>
<tr>
<td>Asphyxia</td>
</tr>
<tr>
<td>Ototoxic medication</td>
</tr>
<tr>
<td>Mechanical ventilation of more than 10 days</td>
</tr>
<tr>
<td>Syndromes that include hearing loss</td>
</tr>
</tbody>
</table>

*TORCH is an acronym describing congenital perinatal infections, including toxoplasmosis, other infections (like syphilis), rubella, CMV, and herpes simplex
The Phase II advocacy campaign builds on the principles of the 2007 Joint Committee on Infant Hearing (JCIH) Statement and the Early Hearing Detection and Intervention Act of 2007 (H.R. 1198 and S.N. 1069). ASHA’s goal is to have the federal EHDI legislation passed in 2009.

The EHDI model bill focuses on follow-up services. It calls for an enhanced tracking system to monitor newborns and infants with hearing loss. It also provides the following:

- A broad range of early intervention services, including family support programs
- Comprehensive insurance coverage for intervention services and devices for children with hearing loss
- Coverage for children with mild, moderate, and unilateral hearing loss

Although the majority of infants are screened for hearing loss, almost 60% of infants who do not pass the screening are lost to follow-up, either because they do not receive follow-up services or because their follow-up is not tracked effectively. In addition, services recommended in Phase II—early intervention services, family support programs, and devices—are either not provided or

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### Table 10.2 Birth to 24 Months: Red Flags

<table>
<thead>
<tr>
<th>Birth to 28 days</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. An illness or condition requiring admission of 48 hours or greater to a NICU.</td>
</tr>
<tr>
<td>2. Stigmata or other findings associated with a syndrome known to include sensorineural or conductive hearing loss.</td>
</tr>
<tr>
<td>3. Family history of permanent childhood sensorineural hearing loss.</td>
</tr>
<tr>
<td>4. Craniofacial anomalies, including morphological anomalies of the pinna and ear canal.</td>
</tr>
<tr>
<td>5. In-utero infection such as cytomegalovirus, herpes, toxoplasmosis, or rubella.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>29 days to 24 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. All of the above, plus the following.</td>
</tr>
<tr>
<td>2. Parent or caregiver concern regarding hearing, speech, language, developmental delay, or a combination of these.</td>
</tr>
<tr>
<td>3. Postnatal infections associated with sensorineural hearing loss, including bacterial meningitis.</td>
</tr>
<tr>
<td>4. Recurrent or persistent otitis media with effusion for at least 3 months.</td>
</tr>
<tr>
<td>5. Neonatal indicators—specifically, hyperbilirubinemia at a serum level requiring blood exchange transfusion, persistent pulmonary hypertension of the newborn associated with mechanical ventilation, and conditions requiring the use of extracorporeal membrane oxygenation.</td>
</tr>
<tr>
<td>6. Syndromes associated with progressive hearing loss such as neurofibromatosis, osteoporosis, and Usher’s syndrome.</td>
</tr>
<tr>
<td>7. Neurodegenerative disorders such as Hunter’s syndrome, kyphosis, gargoylism, or sensorimotor neuropathies such as Friedreich’s ataxia and Charcot-Marie-Tooth syndrome.</td>
</tr>
<tr>
<td>8. Recurrent or persistent otitis media with effusion for at least 3 months.</td>
</tr>
<tr>
<td>9. Head trauma.</td>
</tr>
</tbody>
</table>
not covered by health plans. ASHA’s model legislation addresses that gap by calling for improved tracking systems and by mandating insurance coverage for early intervention services, family support programs, and devices.

The model legislation is structured so that states can adapt it to fit their needs and availability of resources. Some states, such as Rhode Island and Virginia, already mandate coverage for early intervention services, and at least nine states mandate hearing aid coverage for children.

One important aspect of the Phase II follow-up and early intervention services requires states to mandate that family information and support are timely, culturally competent, and family centered. Phase II stipulates that families receive unbiased information and are offered the full range of early intervention services and treatment options available for children with hearing loss.

At press time of the third edition of this text, the following update on EDHI is available. New state laws are on the books in Maine and Tennessee that enhance early hearing detection and intervention (EHDI) efforts, reflecting a national trend to improve EHDI programs.

Maine’s governor approved legislation on April 17, 2008, to help ensure that newborns with suspected or confirmed hearing loss receive the necessary follow-up care in a timely manner from qualified professionals. The legislation implements the recommendations of a working group that studied the effectiveness and timeliness of early identification and intervention for children with hearing loss.

The new law requires a hospital or birthing center to schedule a newborn whose screening result is “refer” for a follow-up audiology appointment. Parental approval is necessary. The appointment must be scheduled prior to discharge, and the hospital or center must notify the newborn’s primary care provider in writing of the screening result and appointment prior to discharge. In addition, the Maine Department of Health and Human Services’ Newborn Hearing Program must report to a joint standing committee of the legislature about barriers to access to audiologists for the continued evaluation of hearing loss in newborns.

Tennessee’s governor signed legislation on April 21, 2008, to enhance the state’s newborn hearing screening program by mandating hearing screenings and follow-up care for all newborns. Claire’s Law requires that every newborn infant in Tennessee be screened for hearing loss before discharge from the hospital, unless the child’s parents object on religious grounds. For children born outside of a hospital setting, or in a hospital that does not provide screening, the attending health care professional must refer the child to the Department of Health or to an appropriate provider for a hearing screening. In addition, any medical or audiologic provider performing follow-up tests must report the results. Children who do not pass the hearing screening test are then referred to the Tennessee Early Intervention System (TEIS) of the Department of Education for follow-up. Children who have been identified with hearing loss or are at high risk for hearing loss must also be referred to the TEIS. Finally, the law requires certain insurance plans to cover hearing screenings.

**Perinatal Causes of Hearing Loss**

Perinatal causes of hearing loss are those that occur during the birth process. Infants who must be admitted to neonatal intensive care units (NICUs) are 20 times more likely to have hearing problems than infants in normal newborn nurseries (Simmons et al., 1980). Hearing loss in infants who were in NICUs is often associated with the identifiable disorders that caused the need for the NICU or treatment for the disorders. Respiratory distress syndrome (RDS/hyaline membrane disease) is the most common respiratory disease in premature infants. Infants with RDS receive treatment by invasive procedures such as intubation and suctioning, putting them at an additional
risk of infections. If infants become septic (generalized infection), general treatment is with antibiotics with potential ototoxic properties, placing them at a higher risk for hearing loss.

Congenital heart disease (CHD) is among the most common birth defects, affecting as many as 1 in 100 newborns (Fogle, 2008), and may exhibit cyanosis, respiratory distress, congestive heart failure, or a combination of these. In addition, these infants frequently exhibit failure-to-thrive and feeding problems. CHD is often associated with syndromes such as growth deficiencies, mental retardation, Down syndrome, and external ear anomalies. Again, ototoxic drugs may be needed to fight the infections.

Central nervous system disorders may have hearing loss as one component of the disorder, including cerebral hemorrhage, hydrocephalus, hypoxic encephalopathy, and neonatal seizures. Any individual who experiences hypoxia may have compromised neurological status and hearing abilities.

**Postnatal and Childhood Causes of Hearing Loss**

Postnatal causes of cochlear hearing loss are factors occurring after birth. These include bacterial meningitis, measles, mumps, chicken pox, influenza, and viral pneumonia. Most viral-producing hearing losses are bilateral, except for mumps. The body’s natural reaction to infection is elevation of temperature; however, when fever becomes excessive, cellular damage can occur, including cells of the cochlea. Treatments may warrant ototoxic antibiotics. Diabetes mellitus and kidney disease have been implicated in sensorineural hearing loss, as have head traumas, which cause both neurological disorders and hearing loss (Fogle, 2008). Table 10.1 lists some of the risk factors for hearing loss in infants and young children.

In older children (and adults), one of the most preventable is noise-induced hearing loss. Most people will have reduced hearing as they grow older (especially after the age of 60); however, there are things individuals can do to try to preserve their hearing. Noise-induced hearing loss, once called “blacksmith’s deafness” from the continual clanging of metal on metal, dates back hundreds of years. During World War II it received much more attention because of the heavy artillery used in the war. Acoustic trauma from a single exposure may cause permanent hearing loss. Gradual hearing loss from repeated exposure to excessive sound can damage or destroy the delicate hair cells in the cochlea. Hearing conservation programs and hearing research programs (ASHA 2006) have developed public education campaigns to alert people, especially adolescents and teenagers, to the damage caused to hearing with loud music. Wearing ear plugs or ear muffs to help block the loud sounds or music, limiting the time of an iPod session with breaks to allow your hearing to rest, and keeping the volume reduced are just a few suggestions included in a hearing conservation program. Table 10.3 shows the readers the decibel levels of some of the most common environmental sounds, and Table 10.4 lists the decibel levels of some musical instruments as well as some types of music. Table 10.5 shows the noise exposure of sound in decibels for certain periods of time that may create hearing risk.

**Pressure-Equalizing (PE) Tubes**

Many infants and children have repeated ear infections requiring pressure-equalizing (PE) tubes. The surgical procedure is called a myringotomy, performed with a small surgical incision into the tympanic membrane to relieve pressure and release fluid or pus from the middle ear. A small suction device may be inserted through the incision to delicately suction out the fluid and pus. Antibiotics are given before and continued afterward to manage infection (Mosby, 2006).
The Role of the Audiologist in Life Care Planning

Table 10.3 Decibel Levels of Common Sounds

<table>
<thead>
<tr>
<th>Decibels</th>
<th>Sound</th>
</tr>
</thead>
<tbody>
<tr>
<td>130+</td>
<td>Jet takeoff, gunfire (pain threshold)</td>
</tr>
<tr>
<td>120+</td>
<td>Rock concert speaker sound, sandblasting, thunderclap, fireworks, pneumatic drill</td>
</tr>
<tr>
<td>110+</td>
<td>Dance club, snowmobile, powerboats, hammering metal</td>
</tr>
<tr>
<td>90+</td>
<td>Subway trains, motorcycle, workshop tools, lawn mower</td>
</tr>
<tr>
<td>80+</td>
<td>Heavy city traffic, factory noise, vacuum cleaner, garbage disposal, Niagara Falls</td>
</tr>
<tr>
<td>70+</td>
<td>Dog barking, noisy restaurant, busy traffic</td>
</tr>
<tr>
<td>60+</td>
<td>Ringing telephone, baby crying, alarm clock 2 feet away</td>
</tr>
<tr>
<td>50+</td>
<td>Quiet automobile 10 feet away</td>
</tr>
<tr>
<td>40+</td>
<td>Everyday conversation</td>
</tr>
<tr>
<td>30+</td>
<td>Quiet street at night with no traffic</td>
</tr>
<tr>
<td>20+</td>
<td>Whispered conversation</td>
</tr>
<tr>
<td>10+</td>
<td>Soft rustle of leaves, birds singing, dripping water faucet</td>
</tr>
<tr>
<td>0</td>
<td>Just audible sound</td>
</tr>
</tbody>
</table>


Table 10.4 Decibel Levels of Musical Instruments

<table>
<thead>
<tr>
<th>Decibels</th>
<th>Instruments</th>
</tr>
</thead>
<tbody>
<tr>
<td>60–70</td>
<td>Normal piano practice</td>
</tr>
<tr>
<td>70</td>
<td>Fortissimo singers 3 feet away</td>
</tr>
<tr>
<td>75–85</td>
<td>Chamber music in small auditorium</td>
</tr>
<tr>
<td>84–111</td>
<td>Flute</td>
</tr>
<tr>
<td>85–114</td>
<td>Trombone</td>
</tr>
<tr>
<td>106</td>
<td>Timpani and bass drum rolls</td>
</tr>
<tr>
<td>120–137</td>
<td>Symphonic music peak</td>
</tr>
<tr>
<td>150</td>
<td>Rock music peak</td>
</tr>
</tbody>
</table>

Source: Adapted from HeadWize, www.headwise.com/articles/hearing_art.htm.

Following the myringotomy and cleaning of the middle ear, the otolaryngologist may insert a PE tube through the incision in the tympanic membrane. The tube is plastic, tiny, and hollow with a flange on each end that prevents the tube from falling into the middle ear or falling out of the tympanic membrane prematurely. The tube allows direct ventilation of the middle ear and
functions as an artificial Eustachian tube to maintain normal middle ear pressure. The tube may remain in place from several weeks to several months, after which time it extrudes (pushes out) naturally into the external auditory canal, usually without the child noticing. Newer-designed tubes may remain in place indefinitely.

### Multicultural Considerations

Gallaudet Research Institute has conducted an Annual Survey of Deaf and Hard-of-Hearing Children and Youth for more than 30 years. The survey represents the largest database of information on deaf and hard-of-hearing children in the United States (if not the world). For more than 10 years, prematurity, heredity, and meningitis have been identified as the three primary causes of hearing loss across all racial and ethnic groups (Holden-Pitt & Diaz, 1998).

Over the years, there have been a disproportionate number of African American and Hispanic children who are born premature or develop meningitis. Research (Van Naarden & Decouflé, 1999) seems to show that African American children weighing less than 2500 grams (5.5 pounds) had much higher rates of hearing impairment than their Caucasian peers. In addition, the prevalence rates of hearing impairment for normal birth weight and borderline birth weight were higher for both male and female African American children than for Caucasian male and female children.

Differences have been found in the incidence of otitis media among racial groups, with American Indians and Alaskan Eskimos having the highest and African Americans having the lowest (National Center for Health Statistics, 1994). The differences may be attributed to the variations in structure and function of the Eustachian tubes among the various racial groups (Doyle, 1977; Spivey & Hirschhorn, 1977; Beery, Doyle, & Cantekin, 1980).

### Table 10.5 OSHA Regulations 1910.95—Occupational Noise Exposure (Adapted)

<table>
<thead>
<tr>
<th>Decibels</th>
<th>Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>90</td>
<td>8 hours</td>
</tr>
<tr>
<td>92</td>
<td>6 hours</td>
</tr>
<tr>
<td>95</td>
<td>4 hours</td>
</tr>
<tr>
<td>97</td>
<td>3 hours</td>
</tr>
<tr>
<td>100</td>
<td>2 hours</td>
</tr>
<tr>
<td>102</td>
<td>1.5 hours</td>
</tr>
<tr>
<td>105</td>
<td>1 hour</td>
</tr>
<tr>
<td>110</td>
<td>0.5 hour</td>
</tr>
<tr>
<td>115</td>
<td>0.25 hour or less</td>
</tr>
</tbody>
</table>

*Note: When 2 or more periods of noise exposure occur, the combined effect should be considered rather than the individual effect of each. Exposure to impulse or impact noise should not exceed 140 dB peak sound pressure level.*
Differences in rates of hearing loss based on gender and race have been found in industrial noise-exposed populations. White males show the greatest effects of noise on auditory thresholds, followed by black males, white females, and then black females (Jerger, Jerger, Pepe, & Miller, 1986). La Ferriere, Kaufman-Arenberg, Hawkins, and Johnson (1974) found that in addition to more melanin (responsible for tissue pigmentation) content in the skin and eyes, individuals with darker skin have more melanin in their inner ear. The temporary threshold shift in hearing was inversely related to the skin pigmentation: the least pigmented subjects showed the greatest temporary threshold shift, and the most pigmented subjects showed the least shift (Barrenas & Lindgren, 1990). The hypothesis is that melanin in the inner ear may, in some unknown way, protect the ear from excessive noise. The National Center for Health Statistics (1994) and the National Institute of Deafness and Communication Disorders (2002) found that as hearing acuity declines with advancing age (presbycusis), white females have better hearing than white males, and both black males and females hear better than white male and female individuals. There is no explanation for these differences until further research can be done.

Socioeconomic status also plays a role in the incidence of hearing loss. In general, individuals with lower incomes (below $20,000 per year, i.e., “low-lower” income level) and less education (no high school diploma) are more likely to have a hearing loss than individuals with higher income (more than $50,000 per year, i.e., “low-middle” income level) and a high school diploma (National Council on Aging, 1999).

**Comprehensive (Advanced) Audiologic Assessment**

The comprehensive audiologic assessment includes the measures utilized in a basic audiologic assessment, but further encompasses specific procedures or batteries of specific procedures that are viewed as separate entities for purposes of service delivery.

**Otoacoustic Emissions (OAEs)**

OAEs are acoustic signals generated by the inner ear of healthy ears in normal-hearing individuals. The acoustic signals are by-products of the activity of the outer hair cells in the cochlea. The clinical significance is that they are evidence of a vital sensory process arising in the cochlea, and OAEs only occur in a normal cochlea with normal hearing. OAEs are a powerful diagnostic tool that assist audiologists in ruling out unusual auditory disorders, where there are unexplained differences in hearing between two ears, when a sudden hearing loss occurs, in medical-legal cases, and in cases of questionable validity of hearing test results.

The OAE evaluation is relatively quick (approximately 5 minutes per ear) and is noninvasive. A soft rubber tip is inserted in the ear canal and a series of comfortably loud tones or clicks are presented. No response is necessary from the patient; he only needs to sit quietly while the test is being conducted. OAEs can be completed at any age from shortly after birth to above 90.

**Auditory Evoked Response (AER)**

An AER assessment describes the clinical status of the auditory neural pathway and associated sensory elements, and assists in differential diagnosis and in estimating threshold sensitivity. The assessment may also be conducted with patients who are difficult to test by conventional
behavioral methods for the purposes of site of lesion identification or in resolution of conflicting data (ASHA, 1999).

Patients are prepared for the assessment by placement of recording electrodes on the head, and they wear earphones for introduction of stimuli. The AER procedures may include the following:

- Electrocochleography (EcohG)
- Auditory brain stem response (ABR)
- Auditory middle latency response (AMLR)
- Auditory late (long latency) response (ALR)
- P300 response
- Mismatched negativity (MMN) response

**Neurophysiologic Intraoperative Monitoring**

Neurophysiologic intraoperative monitoring involves continuous direct or indirect electrophysiologic measurement and interpretation of myogenic and neural responses to intraoperative events or modality-specific, controlled stimulation in the course of surgery on or in the vicinity of those structures. The important aspect of intraoperative monitoring is the online moment-to-moment correlation between the changes in neurophysiologic responses and intraoperative events.

The principal objectives of neurophysiologic intraoperative monitoring are (1) to avoid intraoperative injury to neural structures, (2) to facilitate specific stages of the surgical procedure, (3) to reduce the risk of permanent postoperative neurological injury, and (4) to assist the surgeon in identifying specific neural structures (ASHA, 1992).

**Balance (Vestibular) System Assessment**

The clinical assessment process may include some or all of the following:

- **Electronystagmography (ENG):** Surface electrodes are placed around the eyes in order to record vestibular initiated eye movements (nystagmus), in particular the vestibular ocular reflex (VOR). These electrodes record changes in the electrical potential between the cornea and the retina, which are used to measure eye movement. Subtests of the ENG battery include tests of coordinated eye movement (saccadic eye movement, smooth pursuit eye movement, and optokinetic-induced eye movement) and tests for the presence of nystagmus under a variety of conditions (horizontal and vertical gaze, static head and body position change, and rapid position change). A physical stimulus, usually cool and warm water or air, is also presented to each in order to generate a VOR and determine the relative strength of response from each ear (bithermal caloric test).

- **Videonystagmography (VNG):** Most clinical vestibular laboratories no longer use surface electrode recording of eye movement, but rather employ newer, computerized, video-based recording techniques. The patient wears goggles that house an infrared camera. This camera sends a real-time video recording of the eyes to a computer where eye movement analysis is performed. This technology provides a more precise measurement of eye movement and also allows video storage for later analysis, consultation with colleagues, and teaching purposes. The subtests for VNG are the same as those for ENG assessment.
Rotary Chair: Video technology is used to record eye movements in response to computer-controlled chair rotation around the Earth's vertical axis. This rotation provides stimulation of the vestibular system and produces a VOR, which is computer analyzed with regard to gain, phase, and symmetry.

Computerized Dynamic Posturography (CDP): Postural stability can be assessed under simulated real-life conditions using dynamic forceplate technology. The patient stands on a pressure-sensitive forceplate, which measures lateral and vertical forces. This can be used to quantify postural sway under static and dynamic conditions. The Sensory Organization Test (SOT) isolates the principal components of balance (vestibular, visual, and somatosensory) and analyzes the patient's ability to use each alone and in combination in order to maintain standing posture. The Motor Control Test (MOT) evaluates a patient's ability to react to unpredictable surface perturbations (up, down, backward, and forward).

CDP is helpful in evaluating patients with complaints of unsteadiness or disequilibrium, neurologically or orthopedically compromised patients, or patients with negative or equivocal findings on VNG/ENG assessment. It can also be used as a quantitative method for evaluating the efficacy of vestibular rehabilitation.

Cochleotoxic Drug Therapy (Audiologic Management)

Permanent hearing loss or balance disorders caused by ototoxic drugs can have serious vocational, educational, and social consequences. These effects may be minimized or even prevented if the ototoxic process is detected early in treatment. Any drug with the potential to cause toxic reactions to structures of the inner ear, including the cochlea, vestibule, semicircular canals, and otoliths, is considered ototoxic (Govaerts et al., 1990). Drug-induced damage affecting the auditory and vestibular systems can be called, respectively, cochleotoxicity and vestibulotoxicity. Over 200 drugs have been labeled ototoxic (see list in Lien et al., 1983; Rybak, 1986; Govaerts et al., 1990). Different ototoxic drugs can cause either permanent or temporary structural damage of varying degree and reversibility (Brummett, 1980; Bendush, 1982). The actual frequency of cochleotoxicity associated with specific drugs is unclear because of inconsistencies in reported data (Powell et al., 1983; Kopelman et al., 1988; Pasic & Dobie, 1991).

Although the role and responsibility for designing and implementing an auditory monitoring program for cochleotoxicity rest with the audiologist, the implementation and continuation of such a program require a collaborative effort between the audiologist, physician, and other medical center personnel. The relationship between cochleotoxicity and drug administration parameters such as dosage, duration of treatment, and serum concentration is highly variable (Barza & Lauermann, 1978; Schentag, 1980; Fausti et al., 1992, 1993). An attending physician, therefore, cannot rely solely on dosage or serum concentration to predict the risk of ototoxicity. The prospective assessment of hearing function remains the only reliable method for detecting the presence of cochleotoxicity prior to symptomatic hearing loss. Evidence suggests that high-frequency audiometry is the method of choice for the earliest detection of ototoxic hearing loss (Laukli & Mair, 1985; Fausti et al., 1990; Frank, 1990; Frank & Dreisbach, 1991; Valente et al., 1992).

The basic cochleotoxicity monitoring program requires the following (ASHA, 1994):

- Specific criteria for identification of toxicity
- Timely identification of at-risk patients
Life Care Planning and Case Management Handbook

- Pretreatment counseling regarding potential cochleotoxic effects
- Valid baseline measures (pretreatment or early in treatment)
- Monitoring evaluations at sufficient intervals to document progression of hearing loss or fluctuation in sensitivity
- Follow-up evaluations to determine posttreatment effects

If ototoxic hearing loss results in a communication deficit, the audiologist will recommend audiology rehabilitation (including amplification if necessary), assistive listening devices, speech reading, and so on. Audiologic rehabilitation management should begin as soon as possible after the hearing loss is identified.

**Audiologic (Aural) Rehabilitation Assessment**

Audiologic rehabilitation assessment evaluates and describes the receptive and expressive communication skills of individuals with a hearing loss or related hearing disorders. Individuals of all ages are assessed on the basis of results from the audiology assessment, hearing aid or assistive system/device assessment, fitting, or orientation; sensory aid assessment; and communication needs or preferences.

The assessment includes an evaluation of the impact of the loss of hearing on the individual and her family/caregiver. The assessment may result in the development of a culturally appropriate audiologic rehabilitation management plan, including, when appropriate (ASHA, 1997):

- Fitting and dispensing recommendations, and educating the consumer and family/caregivers in the use of and adjustment to sensory aids, hearing assistive devices, alerting systems, and captioning devices
- Counseling relating to psychosocial aspects of hearing loss and processes to enhance communication competence
- Skills training and consultation concerning environmental modifications to facilitate development of receptive and expressive communication
- Evaluation and modification of the audiologic management plan

**Audiologic (Aural) Rehabilitation Management**

Audiologic rehabilitation is provided to persons of all ages who have any degree or type of hearing loss on the basis of the results of the audiologic rehabilitation assessment. Audiologic rehabilitation facilitates receptive and expressive communication of individuals with a hearing loss or related hearing disorders, and results in achievement of improved, altered, augmented, or compensated communication processes. Performance in both clinical and natural environments is considered. The family/caregiver plays an integral part of the rehabilitation process.

Short- and long-term functional communication goals and specific objectives are determined from assessment and direct the framework for treatment. They are reviewed periodically to determine continued relevance and appropriateness (ASHA, 1995b, 1997, 2002).

When it comes to dealing with hearing loss, some think that simply obtaining hearing aids or other listening devices is the rehabilitation. Audiologic rehabilitation, however, is a much broader concept. It focuses on reducing difficulties related to hearing loss and listening. The overall goal is to maximize communication success in everyday environments and situations.
Audiologic rehabilitation services may include the following:

- Learning how to listen
- Learning how hearing loss affects speech
- Learning skills in speech reading (lip reading, facial expression, gestures, body language)
- Building confidence in handling communication situations
- Learning what to do when you do not get the message
- Learning how to use your hearing aids or cochlear implant
- Learning about different kinds of technology to improve communication
- Learning how to advocate for yourself
- Learning what your rights are under various laws
- Promoting family and caregiver understanding and support of your needs
- Learning how you can make it easier for your family to communicate with you

Audiologists and speech-language pathologists often collaborate in delivering aural rehabilitation services. Depending on the patient’s particular need, one or the other professionals may take a lead. For example, the audiologist:

- Would be responsible for fitting and dispensing hearing aids, sensory aids, and assistive listening devices, and training you how to use them
- Can provide counseling about your hearing loss and processes to enhance communication
- Can provide skills training concerning environmental modifications to facilitate development of receptive and expressive communication
- Can conduct aural rehabilitation assessment and design a management plan

The speech-language pathologist:

- Would be responsible for evaluating receptive and expressive communication skills and providing services to develop or improve receptive and expressive communication
- Can provide treatment focusing on comprehension of language in oral, signed, or written modes
- Can provide treatment dealing with speech and voice production
- Can provide treatment such as auditory training and speech reading
- Can provide training in communication strategies (www.asha.org/hearing/rehab/gen_aur_rehab.cfm)

**Audiologic (Re)habilitation for Children**

Specific services for children depend on individual needs as dictated by the current age of the child, the age of onset of the hearing loss, the age at which the hearing loss was discovered, the severity of the hearing loss, the type of hearing loss, the extent of hearing loss, and the age at which amplification was introduced. The audiologic rehabilitation plan is also influenced by the communication mode the child is using. Examples of communication modes are speaking/listening/looking, cued speech, manually coded English, total communication, auditory-oral, auditory-verbal, and American Sign Language.
The most debilitating consequence of onset of hearing loss in childhood is its disruption in learning speech and language. The combination of early detection of hearing loss and early use of amplification has been shown to have a dramatically positive effect on the language acquisition abilities of a child with hearing loss. In fact, infants identified with a hearing loss by 6 months can be expected to attain language development on a par with hearing peers if appropriately managed. Audiologic habilitation/rehabilitation services for children typically involve the following:

- **Training in auditory perception.** This includes activities to increase awareness of sound, identify sounds, tell the difference between sounds (sound discrimination), and attach meaning to sounds. Ultimately, this training increases the child’s ability to distinguish one word from another using any remaining hearing. Auditory perception also includes developing skills in hearing with hearing aids and assistive listening devices and in how to handle easy and difficult listening situations.

- **Using visual cues.** This goes beyond distinguishing sounds and words on the lips. It involves using all kinds of visual cues that give meaning to a message such as the speaker’s facial expression, body language, and the context and environment in which the communication is taking place.

- **Improving speech.** This involves skill development in production of speech sounds (by themselves, in words, and in conversation), voice quality, speaking rate, breath control, loudness, and speech rhythms.

- **Developing language.** This involves developing language understanding (reception) and language usage (expression) according to developmental expectations. It is a complex process involving concepts, vocabulary, world knowledge, use in different social situations, narrative skills, expression through writing, understanding rules of grammar, and so on.

- **Managing communication.** This involves the child’s understanding the hearing loss, developing assertiveness skills to use in different listening situations, handling communication breakdowns, and modifying situations to make communication easier.

- **Managing hearing aids and assistive listening devices.** Because children are fitted with hearing aids at young ages, early care and adjustment are done by family members or caregivers. It is important for children to participate in hearing aid care and management as much as possible. As they grow and develop, the goal is for their own adjustment, cleaning, and troubleshooting of the hearing aid and, ultimately, taking over responsibility for making appointments with service providers.

Services for children occur in the contexts of early intervention (ages birth to 3) and school services (ages 3 to 21) through the Individuals with Disabilities Education Act (IDEA). In early intervention, an individualized family service plan (IFSP) is developed and may include audiology services, speech-language pathology services, the services of teachers of the deaf and hard-of-hearing, and the services of other professionals as needed. When the child turns 3, an individualized education program (IEP) is developed. The services provided are designed to maximize the child’s success in the general education environment. Again, the IEP may specify audiology services, speech-language pathology services, and the services of teachers of the deaf and hard-of-hearing. Each professional has a role to play in the child’s educational achievement and success.

**Assistive Listening Devices (ALDs)**

An ALD is any type of device that can help a person function better in day-to-day communication situations. An ALD can be used with or without hearing aids to overcome the negative effects
of distance (sound fades as distance increases, or speech may become unintelligible for someone with a hearing impairment), background noise (classrooms and meeting areas tend to be noisy, and noise can come from within the room such as heating and cooling or from outside the room such as hallways and traffic), and poor room acoustics (reverberation: sound waves reflect off walls and hit other walls repeatedly, and multiple reflection/reverberation disrupts speech understanding by causing echoes). So even though a patient has a hearing aid, assistive listening devices can offer greater ease of hearing (and therefore reduced stress and fatigue) in many day-to-day communication situations (www.asha.org/hearing/rehab/assist_tech.cfm).

Examples of ALDs include the following:

- Personal frequency-modulated (FM) systems are like a miniature radio station operating on special frequencies assigned by the Federal Communications Commission. The personal FM system consists of a transmitter microphone used by the speaker and a receiver used by you, the listener. The receiver transmits the sound to your hearing aid either through direct audio input or through a looped cord worn around your neck. A personal FM system does not require any wire so mobility is greatly enhanced. FM systems/auditory trainers have been standard equipment for children with hearing loss in educational settings for many years. Audiologists are the uniquely qualified professionals to select, evaluate, fit, and dispense FM systems. Before selecting an FM system for personal use, it is necessary to assess auditory capacity and the current level of auditory and communication function and to identify other factors related to device use. The issue of potential damage to the auditory mechanism should be considered when fitting any assistive listening device. This is of special concern when considering the fitting of a self-contained FM system to a person with near-normal hearing, mild hearing loss, or fluctuating hearing loss (ASHA, 2002). All amplification equipment is subject to failure; therefore, daily monitoring is required (Bess, 1988). Periodic comprehensive monitoring of the FM system by the audiologist includes electroacoustic analysis, probe microphone measurements, and other in-depth troubleshooting measures. In addition, the periodic assessments of hearing and of performance with the FM device are necessary to monitor stability of hearing, appropriate device settings, function, and degree of benefit. The evaluations should be performed at least annually for adults and children 5 years of age and older. For children under 5 years of age and for individuals with fluctuating or conductive hearing loss, the follow-up evaluations should be much more frequent.

If a self-contained FM system is going to be used, decisions must be made relative to the gain, frequency response, input/output functions, and saturation sound pressure level requirements for the individual listener. During the preselection process, assessments may include, but are not limited to, audiological assessment, observation of auditory performance in representative settings, consultation with the user or others knowledgeable about the user’s performance, questionnaires and scales, hands-on demonstration, and a trial period. Other factors to be considered in the preselection process include the following (ASHA, 2002):

- The person’s ability to wear, adjust, and manage the device
- Support available in the educational setting (e.g., in-service to teachers, classmates)
- Acceptance of the device
- Appropriate situations and settings for use
- Time schedule for use
- Compatibility with personal hearing aids and other audio sources as well as options for coupling
Individual device characteristics and accessories
- External source interference (e.g., pagers, radio stations, computers, etc.)
- Cost and accessibility
- Legislative mandates

Personal FM systems are useful in a variety of situations such as listening to a travel guide, in a classroom lecture, in a restaurant, in a sales meeting, to a book review, in nursing homes, in senior centers, and so on.

*FM systems* are also used in theaters, places of worship, museums, public meeting places, corporate conference rooms, convention centers, and other large areas for gathering. In this situation, the microphone/transmitter is built into the overall sound system. Patients are provided with an FM receiver that can connect to their hearing aid or to a headset.

Personal FM systems are also especially useful for children with auditory processing disorders or ADD/ADHD who are distracted by classroom noise or other background noise. The teacher wears the microphone, taking the sound of her voice directly into the child’s ears.

- **Infrared systems** are often used in the home with TV sets. They, like the FM system, are also used in large-area settings like theaters. Sound is transmitted using infrared light waves. The TV is set at a volume comfortable for family members. The infrared system transmitter transmits the TV signal to the receiver, which can be adjusted to a desired volume. Thus, TV watching as a family becomes pleasurable for all. It is not blaring for family members with normal hearing.

- **Induction loop systems** are most common in large-group areas. They can also be purchased for individual use. An induction loop wire is permanently installed (perhaps under a carpet) and connects to a microphone used by a speaker. (In the case of individual systems, a wire loop is laid on the floor around the listener and the speaker.) The person talking into the microphone creates a current in the wire that makes an electromagnetic field in the room. When the patient switches his hearing aid to the T (telecoil/telephone) setting, the hearing aid telecoil picks up the electromagnetic signal and the patient can adjust its volume through the hearing aid.

- **One-to-one communicators** are sometimes used in a restaurant, a nursing home, or when riding in a car, when the patient wants to be able to easily hear one person. Or perhaps she is delivering a lecture or running a meeting and a person in the audience has a question. The person with the question is given a microphone to speak into. The sound is amplified and delivered directly into the speaker’s hearing aid (or headset if she does not have a hearing aid), and the speaker can adjust the volume to her comfort level. When using the one-to-one communicator, the speaker does not have to shout, private conversations can remain private, and, when in a car, her eyes can remain on the road.

There are many other assistive listening devices such as telephone amplifying devices for cordless, cell, digital, and wired phones; amplified answering machines; amplified telephones with different frequency responses; paging systems; computers; wake-up alarms; and so on.

There are also **alerting devices** that signal when a sound occurs. For example, there are doorbell, knock-at-the-door, or phone alerting devices; fire alarm/smoke alarm devices; baby-cry devices or room-to-room sound alerting systems; vibrating clock alarms; vibrating paging systems; vibrating watch alarms; and so on. Many use strobe light or conventional light to alert; others use vibrating systems to alert.

There are other assistive listening devices such as closed captioning, a device for an individual with a hearing impairment used to provide written text to match spoken words on a TV program (Fogle, 2008). A telephone text (TTY) transmits text messages through the
The Role of the Audiologist in Life Care Planning

telephone line. A telecommunication device (TDD) has a visual display of typed messages over the phone, available also for printed messages. Text messaging through the cellular phone is easy, convenient, and gaining in popularity.

Hearing Aid Selection and Fitting

**Myth:** Hearing aids restore hearing to normal just as an eyeglass prescription can restore vision to 20/20.

**Fact:** Hearing aids do not restore hearing to normal. Just as eyeglasses do not cure vision problems, hearing aids do not cure hearing loss. Like eyeglasses, hearing aids provide benefit and improvement. They can improve hearing and listening abilities, and they can substantially improve quality of life.

Any individual who subjectively reports and audiometrically demonstrates hearing loss of a degree that interferes with communication should be considered for fitting with amplification. The clinical process is initially the same as that for a basic audiologic assessment. The complete audiologic assessment and needs assessment is necessary to initiate a treatment plan that may include amplification. The process of the hearing aid selection in conjunction with determination of the treatment plan is necessary prior to initiating the selection regimen.

The patient must be counseled to include an explanation of the potential benefits and limitations associated with personal amplification. The fitting of a personal amplification system and verification of its appropriateness for the communication needs of the patient, family, and caregiver are necessary requisites. There must be validation of the benefit to and satisfaction of the patient, family, and caregiver. In many cases it is necessary to demonstrate a support system is in place to assist in maximizing the use and maintenance of the personal amplification system. The clinical decision-making process is based on professional judgment and individual patient characteristics that may significantly influence the nature and course of the selection and fitting process. The process may vary by audiologist and may vary based on the patient needs, cooperation, comprehension, and process setting. The procedures listed in the following require the completion of an audiologic assessment within the prior 6 months. (Most audiologists will require their own assessment at the time of the hearing aid selection process.)

The audiologic clinical process may include, but is not necessarily limited to, the following (ASHA, 1998, 1999) (the components are not designed to be all-inclusive):

- Recent history of auditory function
- Appropriate physical examination (e.g., otoscopy)
- Cerumen (ear wax) management
- Sprathreshold loudness measurements
- Ear impressions
- Hearing aid selection procedure
- Hearing aid performance verification in 2 cc coupler and in the real ear for quality control
- Individual or group orientation to amplification
- Unaided/aided communication inventory
- Individual or group hearing aid follow-up
- Qualitative assessment of amplification
- Measurement of satisfaction and benefit
- Unaided and aided speech recognition measures
Hearing aids differ in design, size, the amount of amplification, ease of handling, volume control, and the availability of special features. But they do have similar components, which include:

- A microphone to pick up sound
- Amplifier circuitry to make the sound louder
- A receiver (miniature loudspeaker) to deliver the amplified sound into the ear
- Batteries to power the electronic parts

Some hearing aids also have ear molds (earpieces) to direct the flow of sound into the ear and enhance sound quality.

**Styles of Hearing Aids**

*In-the-canal (ITC) and completely-in-the-canal (CIC) aids* are contained in a tiny case that fits partly or completely into the ear canal. They are the smallest aids available and offer cosmetic and some listening advantages.

All parts of *in-the-ear (ITE)* aids are contained in a shell that fills in the outer part of the ear. These aids are larger than canal aids and, for some people, may be easier to handle than smaller aids.

All parts of *behind-the-ear (BTE)* aids are contained in a small plastic case that rests behind the ear; the case is connected to an ear mold by a piece of clear tubing. This style is often chosen for young children for safety and growth reasons.

Contralateral Routing of Signal (CROS) hearing aids are used for patients with one unaidable ear, due to the severity of loss, and one normal hearing ear on the contralateral side. A microphone is placed at the ear level of the “bad” side and the signal picked up by this microphone is “routed” (either through a hardwire or an FM transmitter) to the receiver in the ear level hearing aid on the “good” or normal ear. If the better ear also has a hearing loss, the arrangement is called BICROS, indicating that a microphone and an amplifier are also placed on the side of the better ear.

Bone-Anchored Hearing Aids (BAHA) as a part of advanced technology should also be considered as an alternative option to a traditional CROSS hearing aid for patients with profound unilateral hearing loss and, of course, patients with bilateral atresia (missing ear canal). The majority of hearing aids sold today are canal hearing aids and ITE hearing aids.

There are also special hearing aids built to handle very specific types of hearing losses such as aids that can be built into glasses for individuals who need that type of fitting. There are hearing aids available that can accommodate virtually any kind of hearing loss.

**Types of Hearing Aids**

Hearing aids are distinguished by their technology or circuitry. In the early days, hearing aid technology involved vacuum tubes and large, heavy batteries. Today, there are microchips, computerization, and digitized sound processing used in hearing aid design.

- *Conventional analog hearing aids* are designed with a particular frequency response based on your audiogram. The audiologist tells the manufacturer what settings to install. Although there are some adjustments, the aid essentially amplifies all sounds (speech and noise) in the same way. This technology is the least expensive, and it can be appropriate for many different types of hearing loss.
Analog programmable hearing aids have a microchip that allows the aid to have settings programmed for different listening environments such as quiet conversation in your home, noisy situations like a restaurant, or large areas like a theater. The audiologist uses a computer to program the hearing aid for different listening situations depending on the individual hearing loss profile, speech understanding, and range of tolerance for louder sounds. Some aids can store several programs. As the listening environment changes, a wearer can change the hearing aid settings by pushing a button on the hearing aid or by using a remote control to switch channels. The aid can be reprogrammed by the audiologist if hearing or hearing needs change. These aids are more expensive than conventional analog hearing aids, but generally have a longer life span and may provide better hearing in different listening situations.

Digital programmable hearing aids have all the features of analog programmable aids but use digitized sound processing to convert sound waves into digital signals. A computer chip in the aid analyzes the signals of your environment to determine if the sound is noise or speech and then makes modifications to provide a clear, amplified distortion-free signal. Digital hearing aids are usually self-adjusting. The digital processing allows for more flexibility in programming the aid so that the sound it transmits matches a specific pattern of hearing loss. This digital technology is the most expensive, but it allows for improvement in programmability, greater precision in fitting, management of loudness discomfort, control of acoustic feedback (whistling sounds), and noise reduction.

Special Features for Hearing Aids

Many hearing aids have optional features that can be built in to assist in different communication situations. Some options are

- **Directional microphone.** Some hearing aids have a switch to activate a directional microphone that responds to sound coming from a specific direction, as occurs in a face-to-face conversation. A patient can switch from the normal nondirectional (omnidirectional) setting, which picks up sound almost equally from any direction, to focus on a sound coming from in front. When the directional microphone is activated, sound coming from behind is reduced.

- **Telephone switch.** Some hearing aids are made with an induction coil inside. You can switch from the normal microphone “on” setting to a “T” setting to hear better on the telephone. (All wired telephones produced today must be hearing aid compatible.) In the T setting, environment sounds are eliminated, and the patient only picks up sound from the telephone. Furthermore, he can talk without his hearing aid “whistling” because the microphone of the hearing aid is turned off.

- The T setting can also be used in theaters, auditoriums, houses of worship, and so on, that have induction loop or FM installations. The sound of the talker, who can be a distance away, is amplified significantly more than any background noises. Some hearing aids have a combination M (microphone)/T (telephone) switch so that while listening with an induction loop, the wearers can still hear nearby conversation.

- **Direct audio input.** Some hearing aids have a direct-audio-input capability that allows them to plug in a remote microphone or an FM assistive listening system, connect directly to a TV, or connect with other devices such as a computer, CD player, tape player, radio, and so on (www.asha.org/hearing/rehab/hearing_aids.cfm).
Federal and state regulations may require a medical evaluation and clearance from a licensed physician prior to hearing aid purchase.

Advances in digital signal processing in recent years have opened the way for digital hearing aids to become the standard of current audiologic practice. The current emphasis for research and development is on specific features such as directional technology and digital noise reduction to maximize speech understanding and sound quality. The introduction of digital noise reduction (DNR) has provided greater ease of listening for many hearing-impaired individuals based on subjective measures. The challenge remains to develop algorithms that separate speech from noise. Notable technological developments are also being made in the field of implantable hearing devices. Apart from the more commonly employed cochlear implant technology, there has also been growth in the use of middle ear implants and, more recently, bone-anchored hearing aids suitable for single-sided hearing loss.

**Auditory Processing Disorders Assessment (as Performed by an Audiologist)**

Auditory processing disorders (APDs) is the current terminology for what was referred to in earlier literature as central auditory processing disorders (CAPDs). With current research and improved diagnostic tools, we now know that not all APDs can be related to a central origin. An APD assessment helps to define the functional status of the central auditory nervous system (CANS) and central auditory processes.

The assessment is indicated for individuals of all ages who have symptoms or complaints of hearing difficulty with documented normal peripheral auditory function, have a central nervous system (CNS) disorder potentially affecting the central auditory system, or have learning problems possibly related to the auditory difficulties. The APD assessment requires a team approach and is to be conducted with other audiologic, speech, and language tests, as well as neuropsychological tests, to evaluate the overall communication behavior, including spoken language processing and production, and educational achievement of the individual (ASHA, 1999).

ASHA (1996) in the *American Journal of Audiology* defined (central) APDs as a problem in one or more of six areas:

1. Sound localization and lateralization (knowing where in space a sound source is located)
2. Auditory discrimination (usually with reference to speech, but the ability to tell that one sound is different from another)
3. Auditory pattern recognition (musical rhythms are one example of an auditory pattern)
4. Temporal aspects of audition (auditory processing relies on making fine discriminations of timing changes in auditory input, especially differences in timing by the way input comes through one ear as opposed to the other)
5. Auditory performance decrements with competing acoustic signals (listening in noise)
6. Auditory performance decrements with degraded acoustic signals (listening to sounds that are muffled, missing information, or for some reason not clear—the best example is trying to listen to speech taking place on the other side of a wall; the wall filters or blocks out certain parts of the speech signal, but a typical listener can often understand the conversation)

The interpretation of results is derived for multiple tests; there is no single test to determine the presence of an APD. The APD battery of tests may involve a series of appointments over a period
of time. The test results will be measured against age-appropriate norms and knowledge of the CANS in normal and disordered states. The procedures in an APD battery should be viewed as separate entities for purposes of service delivery and reimbursement.

The clinical process is as follows:

- Appropriate communication, medical, and educational history is taken.
- Assessment is typically part of an intradisciplinary (audiology and speech-language pathology) approach.
- Assessment of peripheral hearing sensitivity to assure normal hearing sensitivity.
- Patient is prepared for behavioral and electrophysiologic assessment of the CANS.
- Types of central auditory behavioral tests include
  - Tests of temporal processes
  - Tests of dichotic listening
  - Low redundancy monaural speech tests
  - Tests of binaural interaction

Central auditory electrophysiologic tests include

- Auditory brain stem response (ABR)
- Middle latency evoked response (MLR)
- N1 and P2 (late potentials) responses (P300)
- Mismatched negativity (MMN)
- Middle ear reflex
- Crossed suppression of otoacoustic emissions

**APDs Management (as Performed by an Audiologist)**

The comprehensive rehabilitation of and management of APDs may include interventions directed to acoustic signal enhancement, improvement of language and cognitive capacities, skills development, use of compensatory strategies, employment of listening strategies, and improvement of the listening environment (ASHA, 1990, 1996). Management (treatment) is conducted to improve auditory processing, listening, spoken language processing, and the overall communication process. Improvements in auditory processing and listening can benefit learning and daily living activities.

APD management is recommended when there is a likelihood of improving communication behavior in any age group. Any individual who is documented to have an APD after completion of the APD test battery, and who is impaired or compromised on the basis of the results, is a candidate for management (treatment). Generalization of skills and strategies is enhanced by extending practice to the natural environment through collaboration among key professionals (ASHA, 1999).

The clinical process may be, but is not limited to, the following (ASHA, 1999):

- A treatment plan is formulated based on the patient’s complaints, symptoms, history, central auditory test results, and functional performance deficits.
- Treatment may be conducted in an intradisciplinary (audiology and speech-language pathology) and interdisciplinary manner.
The treatment plan should incorporate several major approaches:
- Auditory training and stimulation
- Communication and educational strategies
- Metalinguistic and metacognitive skills and strategies
- Assistive listening devices
- Acoustic enhancement and environmental modifications of the listening environment

Tinnitus Management

Tinnitus, more commonly spoken of as ringing in the ear or head noise, has been experienced by almost everyone at one time or another. It is defined as the perception of sound in the head when no external sound is present. In addition to ringing, head noises have been described as hissing, roaring, pulsing, whooshing, chirping, whistling, and clicking. Ringing and head noises can occur in one ear or both ears and can be perceived to be occurring inside or outside the ear. Tinnitus can accompany hearing loss. It can exist independent of a hearing loss.

Tinnitus cannot be measured objectively. Rather, the audiologist relies on information provided in describing the tinnitus. The audiologist will ask questions like:

- Which ear is involved? Right? Left? Both?
- Is the ringing constant? Do you notice it more at certain times of the day?
- Can you describe the sound or the ringing?
- Does the sound have a pitch to it? High pitch? Low pitch?
- How loud does it seem? Does it seem loud or soft?
- Does the sound change or fluctuate?
- Do you notice conditions that make the tinnitus worse (e.g., when drinking caffeinated beverages, when taking particular medicines, or after exposure to noise)?
- Does the tinnitus affect your sleep? Your work? Your ability to concentrate?
- How annoying is it? Extremely so? Not terribly bothersome?

Knowing the cause of tinnitus is a relief, instead of having to live with the uncertainty of the condition. When tinnitus is demystified, stress level (which can make tinnitus worse) is frequently reduced, and there is a feeling of greater control.

The most effective treatment for tinnitus is to eliminate the underlying cause. Because tinnitus can be a symptom of a treatable medical condition, medical or surgical treatment can take place to correct the tinnitus.

Unfortunately, in many cases the cause of tinnitus cannot be identified, or medical or surgical treatment is not the appropriate course of action. In these cases, the tinnitus itself may need to be treated.

Drug therapy, vitamin therapy, biofeedback, hypnosis, electrical stimulation, relaxation therapy, counseling, habituation therapies, and tinnitus maskers are among many forms of management available. Audiologists and otolaryngologists routinely collaborate in identifying the cause and providing treatment. A treatment that is useful and successful for one person may not be appropriate for another.

Nonmedical management of tinnitus has traditionally involved masking or covering up the patient’s internally produced head noises with externally generated sound. This can take the form of enhanced environmental sound provided by traditional hearing aids, since most patients with handicapping tinnitus also have hearing loss. If there is no hearing loss, or if hearing aid use is not
appropriate, a tinnitus instrument, similar in appearance to a hearing aid, can be used to provide a masking sound. The particulars of the masking sound used will vary according to information provided by the patient, such as the loudness, pitch, and quality of the tinnitus. More recent treatment protocols for tinnitus involve habituation to rather than covering up of the tinnitus. This is known as Tinnitus Retraining Therapy (Jastreboff, 1990). This treatment approach involves directive counseling designed to remove negative associations attached to the tinnitus. Sound therapy is also used, but not to cover up the tinnitus. Instead an emotionally neutral sound, such as white noise, is paired with the tinnitus in order to facilitate habituation. Tinnitus Retraining Therapy takes 12 to 18 months, but its proponents cite significant relief from annoying tinnitus in over 80% of patients treated (Jastreboff, 1996).

The scope of practice of audiologists is described in the following and should demonstrate the breadth and depth of knowledge and skill audiologists possess.

**American Speech-Language-Hearing Association (ASHA) Audiology Scope of Practice**

The practice of audiology includes the following (ASHA, 2004):

- Activities that identify, assess, diagnose, manage, and interpret test results related to disorders of human hearing, balance, and other neural systems
- Otoscopic examination and external ear canal management for removal of cerumen in order to evaluate hearing or balance, make ear impressions, fit hearing protection or prosthetic devices, and monitor the continuous use of hearing aids
- Conducting an interpretation of behavioral, electroacoustic, or electrophysiologic methods used to assess hearing, balance, and neural system function
- Evaluation and management of children and adults with central APDs
- Supervision and conducting of newborn hearing screening programs
- Measurement and interpretation of sensory and motor-evoked potentials, electromyography, and other electrodagnostic tests for purposes of neurophysiologic intraoperative monitoring and cranial nerve assessment
- Provision of hearing care by selecting, evaluating, fitting, facilitating adjustment to, and dispensing prosthetic devices for hearing loss, including hearing aids, sensory aids, hearing assistive devices, alerting and telecommunication systems, and captioning devices
- Assessment of candidacy of persons with hearing loss for cochlear implants and provision of fitting, programming, and audiological rehabilitation to optimize device use
- Provision of audiological rehabilitation, including speech reading, communication management, language development, auditory skill development, and counseling for psychosocial adjustment to hearing loss for persons with hearing loss and their families and caregivers
- Consultation with educators as members of interdisciplinary teams about communication management, educational implications of hearing loss, educational programming, classroom acoustics, and large-area amplification systems for children with hearing loss
- Prevention of hearing loss and conservation of hearing function by designing, implementing, and coordinating occupational, school, and community hearing conservation and identification programs
- Consultation and provision of rehabilitation to persons with balance disorders using habituation, exercise therapy, and balance retraining
Designing and conducting basic and applied audiologic research to increase the knowledge base, to develop new methods and programs, and to determine the efficacy of assessment and treatment paradigms; dissemination of research findings to other professionals and to the public

- Education and administration in audiology graduate and professional education programs
- Measurement of functional outcomes, consumer satisfaction, effectiveness, efficiency, and cost–benefit of practices and programs to maintain and improve the quality of audiological services
- Administration and supervision of professional and technical personnel who provide support functions to the practice of audiology
- Screening of speech-language, use of sign language (e.g., American Sign Language and cued speech), and other factors affecting communication function for the purposes of an audiologic evaluation or initial identification of individuals with other communication disorders
- Consultation about accessibility for persons with hearing loss in public and private buildings, programs, and services
- Assessment and nonmedical management of tinnitus using biofeedback, masking, hearing aids, education, and counseling
- Consultation to individuals, public and private agencies, and governmental bodies, or as an expert witness regarding legal interpretations of audiology findings, effects of hearing loss and balance system disorders, and relevant noise-related considerations
- Case management and service as a liaison for the consumer, family, and agencies in order to monitor audiologic status and management and to make recommendations about educational and vocational programming
- Consultation with industry on the development of products and instrumentation related to the measurement and management of auditory or balance function
- Participation in the development of professional and technical standards

Credentials Held by Audiologists

As health professionals concerned with the welfare of the patients they serve, audiologists must possess certain credentials to practice audiology. These credentials signify a specific level of education and competence that serve to protect consumers. Certification and licensure are the two most common credentials possessed by audiologists. Table 10.6 delineates the characteristics of certification and licensure.

In order to be certified by ASHA and licensed/registered/certified by a particular state regulatory board or agency to practice audiology, one must possess a doctoral degree earned from an accredited college or university audiology graduate (doctoral) program (note: this requirement is relatively new, so one may encounter audiologists who do not possess doctoral degrees). College and university graduate audiology programs seek accreditation from the Council on Academic Accreditation of the American Speech-Language-Hearing Association. This ensures that graduates of these programs are eligible for the certificate of clinical competence (CCC) issued by the Council for Clinical Certification of ASHA. The U.S. Department of Education and the Council on Recognition of Postsecondary Accreditation have approved ASHA as a credentialing agency. The standard on which the certificate of clinical competence in audiology (CCC-A) is based has served as the foundation for most states’ licensing
### Table 10.6 Characteristics of Certification and Licensure

<table>
<thead>
<tr>
<th>Purpose</th>
<th>Grants recognition to practitioners who have met certain qualifications</th>
<th>Protects the public’s life, health, safety, or economic well-being</th>
</tr>
</thead>
<tbody>
<tr>
<td>Function</td>
<td>Restricts the use of the designated title to individuals who choose to meet the qualifications</td>
<td>Restricts scope of practice so that it is illegal for unlicensed individuals to provide the services</td>
</tr>
<tr>
<td>Qualifications</td>
<td>Formal education, experience, personal characteristics, and completion of examination</td>
<td>May piggy back on qualifications required for certification</td>
</tr>
<tr>
<td>Establishment of Regulations</td>
<td>Developed and approved by members of the association</td>
<td>Developed by regulatory body and approved according to the state’s Administrative Procedure Act</td>
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<td>Provider</td>
<td>Usually a private association</td>
<td>State agency</td>
</tr>
<tr>
<td>Status</td>
<td>Voluntary</td>
<td>Mandatory</td>
</tr>
<tr>
<td>Penalties for Violation</td>
<td>• Rescind membership • Rescind certification</td>
<td>• Admonishment • License revocation • Monetary fine • Restrictions on practice • Incarceration • License suspension</td>
</tr>
<tr>
<td>Continuing Education</td>
<td>Certifying entity may sponsor continuing education opportunities for members; may be required for recertification</td>
<td>May be required for licensees to renew</td>
</tr>
</tbody>
</table>

Source: ASHA State Policy Division 10/10/95-aew

laws. ASHA’s national certification standards have undergone costly scientific tests of validity (ASHA, 2004b). ASHA-certified audiologists possess specific knowledge and competencies and must pass a national examination as well as maintain currency through continuing education.

Additionally, most states require audiologists to be licensed, registered, or certified in order to practice audiology in that particular state. Each state’s licensing or regulatory board has specific educational and competency requirements, which are assessed through examination. Renewal of state credentials usually requires maintenance of currency through continuing education.

### Referral Considerations

Referrals to audiologists can be made directly by contacting the office, center, hospital, or facility in which the audiologist is employed. ASHA, at (301) 897-5700; the American Academy of Audiology, at (703) 790-8466; or a state speech-language-hearing association can provide the names of audiologists practicing in specific geographic areas. ASHA maintains a referral source (PROSERV) on its consumer website at www.asha.org.
It is important and helpful to be aware of the types of test procedures and terminology used by audiologists. This will assist the case manager in making appropriate referrals and in conversing knowledgeably with the audiologist. The following is some of the test procedures and terminology used by audiologists.

**Types of Hearing Loss**

*Conductive:* Abnormalities of the outer or middle ear  
*Sensorineural:* Abnormalities of the inner ear  
*Mixed:* Combination of conductive and sensorineural  
*Central:* Abnormalities of the central auditory nervous system

**Assessment Procedures**

*Behavioral Observation Audiometry (BOA):* Controlled observation of responses (i.e., changes in behavior such as quieting, arousal from sleep, eye shift, eye widening, eyebrow raising, body movement, and head turn) to acoustic stimuli  
*Visual Reinforcement Audiometry (VRA):* Reinforcement with lighted toys when the child turns toward the sound source  
*Conditioned Play Audiometry (CPA):* Conditioning the child to respond to the stimulus through game playing  
*Conventional Audiometry:* Hand-raising or button-pushing response to stimulus  
*Auditory Evoked Potentials (AEPs):* Measurement of changes in electrical activity of the auditory nervous system in response to acoustic stimuli  
*Otoacoustic Emissions (OAEs):* Measurement of sound generated by motion of the outer hair cells  
*(Central) Auditory Processing Evaluation (APDs):* Assessment of the central auditory system to process complex auditory stimuli

**Mode of Presentation**

*Soundfield:* Testing via loudspeakers; does not allow a unilateral or asymmetrical hearing loss to be ruled out  
*Air Conduction:* Testing via earphones; allows each ear to be evaluated in isolation  
*Bone Conduction:* Testing via a bone vibrator; directly stimulates better cochlea function

**Test Battery**

*Frequency-Specific Information:* Absolute vs. minimum response  
*Speech Awareness Threshold (SAT):* Lowest intensity level at which there is awareness of speech  
*Speech Reception Threshold (SRT):* Lowest intensity level at which a spondee word can be repeated 50% of the time  
*Word Recognition Ability:* Percentage of monosyllabic words repeated correctly when presented at a comfortable listening level  
*Acoustic Immittance:* Previously explained  
*Tympanometry:* Measurement of the mobility of the tympanic membrane/middle ear system as a function of varying degrees of air pressure in the external ear canal
a. *Static Compliance:* Mobility of the tympanic membrane/middle ear system
b. *Equivalent Volume:* Ear canal volume

*Acoustic Reflex Measurements:* Observation of the contraction of the muscles of the middle ear in response to loud sounds

### Outcomes of Audiology Services

Outcomes of audiology services may be measured to determine treatment effectiveness, efficiency, cost–benefit analysis, and consumer satisfaction. Specific outcome data may assist consumers to make decisions about audiology service delivery. The following list describes the types of outcomes that consumers may expect to receive from an audiologist:

- Interpretation of otoscopic examination for appropriate management or referral
- Identification of populations and individuals with or at risk for hearing loss or related auditory disorders:
  - With normal hearing or no related auditory disorders
  - With communication disorders associated with hearing loss
  - With or at risk of balance disorders, and tinnitus
- Professional interpretation of the results of audiological findings
- Referrals to other professions, agencies, or consumer organizations
- Counseling for personal adjustment and discussion of the effects of hearing loss and the potential benefits to be gained from audiological rehabilitation and sensory aids, including hearing and tactile aids, hearing assistive devices, cochlear implants, captioning devices, and signal/warning devices
- Counseling regarding the effects of balance system dysfunction
- Selection, monitoring, dispensing, and maintenance of hearing aids and large-area amplification systems
- Development of culturally appropriate, audioligic, rehabilitative management plans, including, when appropriate:
  - Fitting and dispensing recommendations, and educating the consumer and family/caregivers in the use of and adjustment to sensory aids, hearing assistive devices, alerting systems, and captioning devices
  - Counseling relating to psychosocial aspects of hearing loss and processes to enhance communication competence
  - Skills training and consultation concerning environmental modifications to facilitate development of receptive and expressive communication
  - Evaluation and modification of the audioligic management plan
- Preparation of a report summarizing findings, interpretation, recommendations, and audioligic management plan
- Consultation in development of an individualized education program (IEP) for school-age children or an individualized family service plan (IFSP) for children from birth to 36 months of age
- Provision of in-service programs for personnel and advising school districts in planning educational programs and accessibility for students with hearing loss
- Planning, development, implementation, and evaluation of hearing conservation programs
Impact of Hearing Loss on Communication

Life care planners and other individuals should be aware of the impact that hearing loss can have on communication. Generally speaking, a conductive (outer or middle ear) hearing loss, which cannot be medically remediated, can be adequately benefited through amplification. It must be cautioned that young children commonly experience conductive hearing loss due to ear and upper respiratory infections. Although these episodes are usually self-limiting or respond to medical intervention when necessary, some children persist with conductive hearing loss, which may affect their speech and language development. These children should be referred to an audiologist as well as a speech-language pathologist.

An individual with a sensorineural (inner ear) hearing loss, however, can be expected to experience some degree of difficulty understanding speech, particularly when the listening environment is less than ideal. This means that when a person with a sensorineural hearing loss is greater than 3 to 4 feet from the source of the sound or when there is noise in the background (there almost always is some noise in the background), that person will likely misunderstand some of what is being said. This is because the pattern of hearing with a sensorineural hearing loss is typically worse in the high frequencies or pitches and better in the low frequencies or pitches. In order to understand speech clearly, we must hear all the pitches equally well. The vowels are generally low in pitch (and loud) compared to consonants, which are high in pitch (and soft).

A properly fitted hearing aid can be extremely beneficial. However, it is important for all to recognize that even with appropriate amplification, individuals with sensorineural hearing loss might still have difficulty understanding what is being said, particularly with noise in the background.

How to Communicate with People Who Are Hard of Hearing

The following suggestions are examples of effective strategies for communicating with individuals with hearing impairment:

- **Positioning:**
  - Be sure the light, whether natural or artificial, falls on your face. Do not stand with the sun to your back or in front of a window.
  - If you are aware that the hard-of-hearing person has a better ear, stand or sit on that side.
  - Avoid background noise to the extent possible.

- **Method:**
  - Get the person’s attention before you start talking. You may need to touch the person to attract attention.
  - Speak to the hard-of-hearing person from an ideal distance of 3 to 6 feet in face-to-face visual contact.
  - Speak as clearly as possible in a natural way.
  - Speak more slowly to the hard-of-hearing person. Pausing between sentences will assist the listener.
  - Do not shout. Shouting often results in distortion of speech and it displays a negative visual signal to the listener. Do not drop your voice at the end of the sentence.
  - If the person does not understand what you said, rephrase it.
  - When changing the subject, indicate the new topic with a word or two or a phrase.
- **Physical:**
  - Do not obscure your mouth with your hands. Do not chew or smoke while talking.
  - Facial expressions and lip movements are important clues to the hard-of-hearing person. Feelings are more often expressed by nonverbal communication than through words.

- **Attitude:**
  - Do not become impatient.
  - Stay positive and relaxed.
  - Never talk about a hard-of-hearing person in his presence. Talk to them, not about them.
  - Ask what you can do to facilitate communication.

### How to Communicate with People Who Are Deaf

The following is a list of suggestions for communicating with someone who is deaf.

- **DO** be facially expressive when communicating.
- **DO NOT** break eye contact when communicating with people who are deaf. Lack of eye contact is considered rude when communicating with a visually oriented person.
- **DO** get the attention of a person who is deaf by tapping the shoulder.
- **DO NOT** take offense at direct questions regarding qualifications or personal life. Direct questions between one person who is deaf and another person who is deaf are culturally quite common and can spill over into interactions with hearing people with no attempt to be rude.
- **DO** be conscious of hearing-loss terminology. Within the culture of the deaf, the norm is profound deafness and a mild hearing loss may mean “hard of hearing” to the person who is deaf.
- **DO** while a person who is deaf is signing, **DO NOT** touch her hands.
- **DO** define individuals who are deaf by their abilities, rather than their disabilities.
- **DO NOT** talk with another hearing person in the presence of a person who is deaf without signing or ensuring a clear line of sight for speech reading. Just as those with acquired hearing loss may be suspicious when they do not understand what others are saying, so may individuals who are deaf. Use sign language, written communication, or ensure the individual who is deaf can speech read (lip read) what is said.
- **DO** attempt to use sign language with an individual who is deaf. Any attempt is appreciated, but if you are not fluent, the services of an interpreter should be obtained.
- **DO NOT** use the term *oral* as it implies oral ideologies (oralists). Rather, use the term *spoken English* or *spoken communication*. Similarly, *communication training* may be preferred to *aural rehabilitation* because the former implies improvements in aspects of communication, such as written communication, that are not aurally based.

### First Aid for Hearing Aids

The following are some suggestions for troubleshooting minor hearing aid difficulties. If the problem is not resolved, the hearing aid may require factory repair and should be returned to an audiologist or hearing instrument specialist (preferably the same who dispensed the aid).
Symptom Solution

Hearing aid dead:

- Assure aid turned on.
- Assure battery inserted correctly.
- Try new battery.
- Clean battery contacts with pencil eraser.
- Assure earmold not clogged with wax (BTE aid).
- Assure receiver port not clogged with wax (ITE aid).

Hearing aid weak:

- Replace battery.
- Clean receiver port (ITE aid).
- Clean earmold tip.
- Assure microphone port not occluded (ITE aid).

Aid distorted:

- Replace battery.
- Clean receiver port (ITE aid).

Aid whistles:

- Assure tight fit of earmold (BTE) or ITE aid.
- Assure ear canal free of cerumen.

Causes, Tests, and Remedies

2. Cause: Battery reversed in holder so that positive end is where negative end should be. Test: Examine. Remedy: Insert battery correctly.
3. Cause: Poor contacts at cord receptacle of battery holder due to dirty pins or springs. Test: With hearing aid turned on, wiggle plugs in receptacles and withdraw and reinsert each plug and the battery. Remedy: Rub accessible contacts briskly with lead pencil eraser, then wipe with clean cloth moistened with dry-cleaning liquid. Inaccessible contacts usually can be cleaned with a broom straw dipped in cleaning fluid.
4. Cause: Internal break or near-break inside receiver cord. Test: While listening, flex all parts of cords by running fingers along entire length and wiggle cords at terminals. Intermittent or raspy sounds indicate broken wires. Remedy: Replace cords with new ones. Worn ones cannot be repaired satisfactorily.
5. Cause: Plugs not fully or firmly inserted in receptacles. Test: While listening, withdraw and firmly reinsert each plug in turn. Remedy: Insert correctly.
6. Cause: Ear tip not properly seated in ear. Test: With the fingers, press the receiver firmly into the ear and twist back and forth slightly to make sure that the ear tip is properly positioned. Remedy: Position correctly.

7. Cause: Ear tip plugged with wax or with drop of water from cleaning. Test: Examine ear tip visually and blow through it to determine whether passage is open. Remedy: Disconnect ear tip from receiver, then wash ear tip in lukewarm water and soap, using pipe cleaner or long-bristle brush to reach down into the canal. Rinse with clear water and dry. A dry pipe cleaner may be used to dry out the canal; blowing through the canal will remove surplus water.

8. Cause: Insufficient pressure of bone receiver on mastoid. Test: While listening, press the bone receiver more tightly against the head with the fingers. Remedy: Bend the receiver headband to provide greater pressure. Your audiologist who is more skilled in maintaining conformation with the head preferably does this.

10. Cause: Receiver close to wall or other sound-reflecting surfaces. Test: Examine. Remedy: Avoid sitting with the fitted side of the head near a wall or other surfaces. Such surfaces tend to reflect the sound from the receiver so that it is more readily picked up by the microphone, thus causing whistling.

11. Cause: Microphone worn too close to receiver. Test: Try moving instrument to provide wider separation between it and the receiver. Remedy: Avoid wearing microphone and receiver on same side of body or close together.

12. Cause: Plastic tubing not firmly seated at hearing aid or ear tip ends, or tubing so sharply bent as to block the passage of sound through it. Test: Examine and check for tightness at ends. Remedy: Push tubing ends firmly onto nubs. See that there is no kink or sharp bend. Replace the tubing if necessary.

Behaviors of Children at Risk for Auditory Disorders

Certain characteristic behaviors by children should alert parents and teachers to be concerned about their hearing. Some of the signs are

- Often misunderstands what is said
- Constantly requests that information be repeated
- Has difficulty following oral instructions
- Gives inconsistent responses to auditory stimuli
- Turns up the volume of the television, radio, or stereo
- Gives slow or delayed response to verbal stimuli
- Has poor auditory attention
- Has poor auditory memory (span and sequence)
- Is easily distracted
- Has difficulty listening in the presence of background noise
- Has poor receptive and expressive language
- Has difficulty with phonics and speech sound discrimination
- Learns poorly through the auditory channel
- Has reading, spelling, and other learning problems
- Exhibits behavior problems
- Says “Huh?” or “What?” frequently
Indicators Associated with Hearing Loss

Some common indicators associated with hearing loss include:

- Family history of hearing loss
- \textit{In utero} infection (e.g., cytomegalovirus, rubella, syphilis, or toxoplasmosis)
- Craniofacial anomalies, including those with morphological abnormalities of the pinna and ear canal
- Birth weight less than 1500 grams (3.3 pounds)
- Hyperbilirubinemia at a serum level requiring exchange transfusion
- Ototoxic medications, including, but not limited to, chemotherapeutic agents, or aminoglycosides used in multiple courses or in combination with loop diuretics
- Bacterial meningitis and other infections associated with sensorineural hearing loss
- Severe depression at birth with Apgar scores of 0 to 4 at 1 minute or 0 to 6 at 5 minutes
- Prolonged mechanical ventilation 5 days or longer (e.g., persistent pulmonary hypertension)
- Stigma or other findings associated with a syndrome known to include a sensorineural or conductive hearing loss
- Parent/caregiver concern regarding hearing, speech, language, or developmental delay
- Head trauma associated with loss of consciousness or skull fracture
- Recurrent or persistent otitis media with effusion for at least 3 months
- Neurofibromatosis type II and neurodegenerative disorders
- Anatomic deformities and other disorders, which affect eustachian tube, function

Costs Related to Amplification

The cost of hearing aids varies from approximately $500 to $2500 per instrument depending upon type and options. A single behind-the-ear instrument may be as little as $500, while a digital instrument will typically cost $2100 to $2500. Middle ear implantable instruments may run $25,000, plus $5000 per year for technical support. Many patients with disabilities may need manufacturer support to ensure they are capable of operating the volume control and other instrument options. Digital hearing aids often have an external control much like a television remote control. Care must be given to ensure appropriate fitting and follow-up services. Pitfalls that must be avoided are indiscriminate fitting of patients with amplification not appropriate for their loss and insufficient follow-up and audiologic/aural rehabilitation.

- A hearing aid should be effective for 3 to 5 years before replacement is necessary. It is wise to purchase replacement and repair warranties.
- A standard factory warranty will be 1 to 2 years.
- Battery costs may vary depending on the severity of the hearing loss and the power required of the hearing aid. A package of six batteries will cost $4 to $5. The average life expectancy for a battery is approximately 10 days to 2 weeks when the instrument is worn during waking hours. If an instrument is out of warranty, the cost of repair is approximately $150 to include a 1-year warranty.

Children under 21 are entitled to mandatory hearing services, including hearing aids, under Medicaid. Hearing aid coverage for adults is optional and varies from state to state. A list of state Medicaid office contacts can be found at http://cms.hhs.gov/medicaid/tollfree.asp.
Although Medicare does not pay for hearing devices in fee-for-service plans, hearing aids may be covered by Medicare+Choice plans, such as health maintenance organizations. The Centers for Medicare and Medicaid Services (CMS) clarified in 2001 that Medicare carriers should pay for diagnostic audiologic tests regardless of a hearing aid recommendation.

**Funding Issues Related to Audiological Services**

Obviously, people with the financial resources to pay privately for these devices and services will be able to obtain what they need. However, most rely upon alternative funding and specific issues are mentioned in the following:

- **Medicaid**: States must cover hearing aids for children through the Early and Periodic Screening, Diagnosis, and Treatment Program. Coverage for adults is optional and rarely included in a state plan.
- **Medicare**: Medicare does not cover hearing aids or tests related to hearing aids. Social health maintenance organizations (SHMOs) are part of a demonstration project that includes some long-term care. All SHMOs cover hearing aids. As risk HMOs enter the Medicare market, many are providing partial coverage of hearing aids. For example, the Medicare HMO might cover $500 of a hearing aid. Some states and regional third-party payers allow balance billing—check in your state and with your dispensing audiologist.
- **Private Health Plans**: Most do not cover hearing aids unless there is a labor union contract such as the United Automobile Workers (UAW), which covers the costs related to one hearing aid every 3 years. The benefit is not limited to automobile workers but is found in many contracts negotiated by the UAW. Another example of a union contract is the California Public Employees Retirement System, which offers a hearing benefit to retirees enrolled in Medicare managed care plans. Some private plans such as Blue Cross and Blue Shield may cover a hearing aid if the need is related to an accident or illness.


**Special Issue: Cochlear Implants**

Cochlear devices have been implanted in nearly 10,000 children and adults who are profoundly hearing impaired or deaf due to genetic factors, ototoxic drugs, meningitis, rubella, and head trauma. A criterion for candidacy (Table 10.7) primarily requires that the auditory nerve must not be destroyed. General guidelines include the following:

- Be at least 1 year of age (with anticipation of even younger in near future).
- Have severe to profound bilateral sensorineural deafness.
- Demonstrate no significant benefit from traditional amplification.
- Have strong family support.
- Have no medical contraindications to surgery.
- For children, have a supportive school system.
- For adults, have appropriate expectations.
- Have the ability to pay for the device and services—the total cost of an implant in 2008 was more than $60,000, not including replacements (see example case in the following).
With regard to children, there appears to be a controversy regarding the device. Although promoters report that children can more effectively learn language with the implant, they are neither a normal-hearing person nor deaf. The child may not fit in the deaf subculture and may experience ridicule from others that can adversely affect social development. On the other hand, individuals who became deaf before learning language commonly do not read higher than the third- or fourth-grade level. This barrier, of course, can significantly affect their vocational outlook.

**Cochlear Implant Centers**

There are various cochlear implant centers around the country. Teams of professionals work together with adults and children from start to finish. Team members include an audiologist, otologist/surgeon, medical specialists as needed, psychologist, counselors, and speech-language pathologists. They work with potential candidates and their families to determine candidacy for an implant, perform the surgery, and provide follow-up care both through the center and through local agencies or school districts near the cochlear implant recipient.

**The Clinical Process**

Once a person is referred to the cochlear implant center, extensive testing is done to determine if the person is a suitable candidate. This evaluation usually includes extensive audiologic testing,
psychological testing, examination and tests performed by the surgeon, x-rays, magnetic resonance images, physical examination, and counseling to assure suitability and motivation to participate in the process. It is important that the candidate understands what the implant will and will not do and the commitment required for care and follow-up services.

Once the decision is made to go ahead, the surgery is done. Sometimes it involves an overnight stay in the hospital, and sometimes it is done on an outpatient basis.

About 4 to 6 weeks after surgery, the person returns to the center to be fitted with the microphone and speech processor and to activate and program (called mapping) the implant. The initial fitting process is done over several days and may include additional visits over several months, because as each electrode in the cochlea is activated, it must be adjusted and programmed into the speech processor. As the person develops skill in using the implant, further adjustments and reprogramming are required. Once the optimum program is obtained, fewer visits are required. Usually there are annual visits to the center for checkups.

Both children and adults are involved in extensive rehabilitation services from an audiologist, speech-language pathologist, teachers, and counselors as they learn to listen, improve speech, use speech reading, and handle communication. They are taught how to use the implant and how to respond to the sounds they are receiving. If one has heard before, sounds through the cochlear implant may seem unnatural at first. If a person has never heard, they must be taught what the sounds are.

**Cochlear Implant Mechanism**

Cochlear implants have external (outside) parts and internal (surgically implanted) parts.

The *external parts* include a microphone, a speech processor, and a transmitter. The *microphone* looks like a behind-the-ear hearing aid. It picks up sounds—just like a hearing aid microphone does—and sends them to the speech processor.

The *speech processor* may be housed, with the microphone, behind the ear, or it may be a small box worn in a chest pocket. The speech processor is a computer that analyzes and digitizes the sound signals and sends them to a transmitter worn on the head just behind the ear.

The *transmitter* sends the coded signals to an implanted receiver just under the skin.

The *internal (implanted) parts* include a receiver and electrodes. The *receiver* is just under the skin behind the ear. The receiver takes the coded electrical signals from the transmitter and delivers them to the array of electrodes that have been surgically inserted into the cochlea. The *electrodes* stimulate the fibers of the auditory nerve, and sound sensations are perceived (www.asha.org/hearing/rehab/cochlear_implant.cfm).

**Types of Counseling**

Counseling individuals with hearing loss or those who are deaf, as well as counseling family members, work associates, and friends of the individuals depend on the type of counseling needed at a specific time. Several types of counseling, the definition of the type of counseling, and the proposed outcomes are listed in Table 10.8. Successful counseling requires skill as well as knowledge about the individual type of hearing loss and is most successful when done by a qualified audiologist.
<table>
<thead>
<tr>
<th>Type of Counseling</th>
<th>Definitions</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informational</td>
<td>To provide education.</td>
<td>For the person and family to understand hearing loss, to be knowledgeable about appropriate technology, and to increase their willingness to participate in aural rehabilitation.</td>
</tr>
<tr>
<td>Rational Acceptance</td>
<td>For individuals to learn ways to manage their hearing losses and their communication difficulties.</td>
<td>For the individual to optimally use communication strategies, to structure the listening environment to maximize communication, to increase willingness to participate in aural rehabilitation.</td>
</tr>
<tr>
<td>Adjustment</td>
<td>To help individuals work through their negative feelings about their hearing loss and increase their sense of self-worth.</td>
<td>For the individual to begin viewing the hearing impairment as separate from self-concept and self-image, and to improve both of these, and to become more willing to participate in aural rehabilitation.</td>
</tr>
<tr>
<td>Psychosocial</td>
<td>To facilitate emotional adjustment in the context of the aural rehabilitation plan. Usually small groups with communication partners are encouraged to attend.</td>
<td>Self-acceptance, increased self-confidence, and more effective communication strategies.</td>
</tr>
<tr>
<td>Assertiveness Training</td>
<td>Incorporated into the aural rehabilitation sessions, to learn the differences among aggressive behavior, which involves the violation of other people's rights; passive behavior, which involves allowing others to violate their rights; and assertive behavior, in which individuals protect their rights without violating those of other people (Hull, 2001). Also teaching individuals how to anticipate communication situations in advance and figure out ways to minimize difficulties.</td>
<td>Emphasis is on language and choice of words, and consequences of behaviors. Learning to anticipate communication situations and to learn repair strategies that may help the individual with a hearing loss (so that the individual may request one of the repair strategies).</td>
</tr>
</tbody>
</table>
## Example Case

Following is an example *portion* of a plan for a 6-year-old child, with a severe sensorineural hearing loss due to meningitis at the age of 1, who met the criteria for a cochlear implant. His parents were very bright based on educational achievements and testing. Both were employed by the school system. The child and an older sibling were both judged to be intellectually gifted.

<table>
<thead>
<tr>
<th>Area</th>
<th>Recommendation</th>
<th>Dates</th>
<th>Frequency</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical/ Surgery</td>
<td>Cochlear implant device</td>
<td>2008</td>
<td>Replacement 1x in life.</td>
<td>$40,000.</td>
</tr>
<tr>
<td></td>
<td>Overnight hospital stay</td>
<td>2008</td>
<td>1x.</td>
<td>$925.</td>
</tr>
<tr>
<td></td>
<td>Surgeon fees</td>
<td>2008</td>
<td>1x.</td>
<td>Included in the device cost.</td>
</tr>
<tr>
<td></td>
<td>Audiologist fees</td>
<td>2008</td>
<td>1x for the implant itself.</td>
<td>Included in the device cost.</td>
</tr>
<tr>
<td>Assessment/ Therapy</td>
<td>Speech pathology</td>
<td>2008 to 2033</td>
<td>Intensive speech perception training and additional language and speech therapy for the first 5 years, then weekly until age 22.</td>
<td>Provided by school system under IDEA for school year, 5x/week for 5 years. If private pay during summer months, expected cost at $150 per hour.</td>
</tr>
<tr>
<td>Area</td>
<td>Audiology for programming, mapping, adjustments, general maintenance, tuning</td>
<td>2008 to life</td>
<td>Seen after the first 4–6 weeks for calibration, then seen monthly for the year, then yearly recheck, unless complications.</td>
<td>$150 per hour.</td>
</tr>
<tr>
<td></td>
<td>ENT</td>
<td>2008 to life</td>
<td>First 4–6 weeks, seen weekly, then monthly for the first year, then yearly thereafter for life unless complications.</td>
<td>$300 per visit.</td>
</tr>
<tr>
<td></td>
<td>TTY (text phone); SuperPrinter 4425 recommended (includes printer, auto answer, ring, and flasher)</td>
<td>2008 to life</td>
<td>Every 10 years.</td>
<td>$500 (includes 1-year warranty).</td>
</tr>
</tbody>
</table>

(Continued)
<table>
<thead>
<tr>
<th>Area</th>
<th>Recommendation</th>
<th>Dates</th>
<th>Frequency</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>TTY paper refill (3 pack of 2.5 inch thermal paper)</td>
<td>2008 to life</td>
<td>Every 3 months or as needed depending on the use.</td>
<td>$16 per year (estimate).</td>
<td></td>
</tr>
<tr>
<td>TTY batteries (6)</td>
<td>2008 to life</td>
<td>Yearly or more depending on use.</td>
<td>$20 for a pack of two.</td>
<td></td>
</tr>
<tr>
<td>Sonic Alert or Silent Call Alerting System, including receiver, transmitters, and rechargeable battery</td>
<td>2008 to life</td>
<td>Sonic Alert: 1x only. Silent Call: every 10 years.</td>
<td>Sonic Alert: $260 with 1-yr warranty. Silent Call: $540 with vibrating unit and 2-yr warranty.</td>
<td></td>
</tr>
<tr>
<td>Door knock signaler with light</td>
<td>2008 to life</td>
<td>Every 10 years.</td>
<td>$65.00 for package.</td>
<td></td>
</tr>
<tr>
<td>Portable smoke detector</td>
<td>2008 to life</td>
<td>Every 10 years.</td>
<td>$175.</td>
<td></td>
</tr>
<tr>
<td>Allowance for batteries, lightbulbs, etc.</td>
<td>2008 to life</td>
<td>Batteries: monthly. Bulbs: yearly depending on use.</td>
<td>$50 per year (estimate).</td>
<td></td>
</tr>
<tr>
<td>Baby cry alerter (assumes child)</td>
<td>Estimate 2032</td>
<td>1x (assumes child).</td>
<td>Sonic Alert: $40 (may also be used as smoke detector).</td>
<td></td>
</tr>
<tr>
<td>Replacement cords and batteries for implant device</td>
<td>$1000 to life</td>
<td>Every 3 months for two cords at $10 each. One time per year for 2 pack batteries at $10/per year.</td>
<td>$90 per year.</td>
<td></td>
</tr>
<tr>
<td>Replacement headset</td>
<td>2010 (after 3-year warranty to life)</td>
<td>Project 3–4 upgrades over life.</td>
<td>$500 every 3 years.</td>
<td></td>
</tr>
<tr>
<td>Upgrade external processor</td>
<td>2023</td>
<td>1x.</td>
<td>$6000.</td>
<td></td>
</tr>
<tr>
<td>Silent Call or Sleep Alert charger unit</td>
<td>2008</td>
<td>Every 10 years.</td>
<td>$110.</td>
<td></td>
</tr>
<tr>
<td>Service contract for external speech processor and headset (internal device has a 99-year warranty)</td>
<td>2008 to life</td>
<td>Every 2 years.</td>
<td>$750 for 2 years (after 3-yr manufacturer warranty expires).</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td>Public school</td>
<td>2008 to 2022</td>
<td>School year.</td>
<td>$0 provided under IDEA.</td>
</tr>
</tbody>
</table>
The Role of the Audiologist in Life Care Planning

Conclusion

In many life care plans, audiological services can be a critical component. In personal injury litigation, common sequelae from head trauma can destroy or reduce hearing, disrupt balance, and produce serious ringing in the ears (tinnitus). In medical illness, malpractice, or mistakes, the audiologist is commonly an important member for diagnosis and treatment of hearing dysfunction. Of particular interest is the role the audiologist can play with regard to children. Hearing deficits can seriously hamper educational achievement that can lead to poor social adjustment and a poor vocational outlook. Indeed, many deaf children are initially diagnosed mentally retarded and do not receive services during critical developmental periods. This chapter assists the life care planner with information related to the roles and responsibilities of the audiologist and provides resources for information, services, and products.

References


**Appendix 10.1 State Requirements for Audiologists (2008)**

Thirty states permit audiologists to dispense hearing aids under an audiology license by virtue of amending the hearing aid dealers’ licensure law, the audiology licensure law, or both.

<table>
<thead>
<tr>
<th>Alabama</th>
<th>Mississippi</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alaska</td>
<td>New Mexico**</td>
</tr>
<tr>
<td>Arkansas</td>
<td>New York</td>
</tr>
<tr>
<td>Colorado</td>
<td>Oklahoma</td>
</tr>
<tr>
<td>Connecticut*</td>
<td>Ohio</td>
</tr>
<tr>
<td>Florida</td>
<td>Rhode Island</td>
</tr>
<tr>
<td>Georgia</td>
<td>South Carolina</td>
</tr>
<tr>
<td>Idaho</td>
<td>South Dakota</td>
</tr>
<tr>
<td>Illinois</td>
<td>Tennessee</td>
</tr>
<tr>
<td>Indiana</td>
<td>Texas*</td>
</tr>
<tr>
<td>Louisiana</td>
<td>Utah</td>
</tr>
<tr>
<td>Massachusetts</td>
<td>Vermont</td>
</tr>
<tr>
<td>Maryland</td>
<td>Washington</td>
</tr>
</tbody>
</table>
The Role of the Audiologist in Life Care Planning

Notes: *Certain conditions apply.

** Audiologists must obtain an endorsement to dispense hearing aids.

The following 20 states and the District of Columbia require audiologists to hold HAD (Hearing Aid Dispenser) licensure to dispense hearing aids.

<table>
<thead>
<tr>
<th>States</th>
</tr>
</thead>
<tbody>
<tr>
<td>Michigan</td>
</tr>
<tr>
<td>West Virginia</td>
</tr>
<tr>
<td>Minnesota</td>
</tr>
<tr>
<td>Wisconsin</td>
</tr>
<tr>
<td>Arizona</td>
</tr>
<tr>
<td>Nebraska</td>
</tr>
<tr>
<td>California</td>
</tr>
<tr>
<td>Nevada</td>
</tr>
<tr>
<td>Delaware</td>
</tr>
<tr>
<td>New Hampshire</td>
</tr>
<tr>
<td>District of Columbia</td>
</tr>
<tr>
<td>New Jersey</td>
</tr>
<tr>
<td>Hawaii</td>
</tr>
<tr>
<td>North Carolina</td>
</tr>
<tr>
<td>Iowa</td>
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<tr>
<td>North Dakota</td>
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<tr>
<td>Kansas</td>
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<tr>
<td>Oregon</td>
</tr>
<tr>
<td>Kentucky</td>
</tr>
<tr>
<td>Pennsylvania</td>
</tr>
<tr>
<td>Maine</td>
</tr>
<tr>
<td>Virginia</td>
</tr>
<tr>
<td>Missouri</td>
</tr>
<tr>
<td>Wyoming</td>
</tr>
</tbody>
</table>

Appendix 10.2 Degree of Hearing Loss

<table>
<thead>
<tr>
<th>Hearing Level</th>
<th>Hearing Ability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal (~10 to 10 dB)</td>
<td>Can hear speech normally</td>
</tr>
<tr>
<td>Minimal (10 to 25 dB)</td>
<td>Has difficulty hearing faint speech in a noisy place</td>
</tr>
<tr>
<td>Mild (25 to 40 dB)</td>
<td>Has difficulty hearing faint or distance speech, even in a quiet environment</td>
</tr>
<tr>
<td>Moderate (40 to 55 dB)</td>
<td>Hears conversational speech only at a close distance</td>
</tr>
<tr>
<td>Moderately severe (55 to 70 dB)</td>
<td>Hears loud conversational speech</td>
</tr>
<tr>
<td>Severe (70 to 90 dB)</td>
<td>Cannot hear conversational speech</td>
</tr>
<tr>
<td>Profound (&gt;90 dB)</td>
<td>May hear loud sounds; hearing is not the primary communication channel</td>
</tr>
</tbody>
</table>

Appendix 10.3 Resources

Harc Mercantile
Kalamazoo, MI
800-438-4272 (V)
800-413-5245 (TTY)
www.harcmercantile.com
Harris Communications
Eden Prairie, MN
800-825-6758 (V)
800-825-9187 (TTY)
www.harriscomm.com

Hear-More, Inc.
Farmingdale, NY
800-881-4327 (V/TTY)
www.hearmore.com

Hitec
Burr Ridge, IL
800-288-8303
www.hitec.com

MVM Technical Corporation
1 Union Square West, Room 210
New York, NY 10003
212-741-1967

Potomac Technology
Rockville, MD
800-433-2838
www.potomactech.com

Soundbytes
New York, NY
800-667-1777
www.soundbytes.com

United TTY Sales
Olney, MD
866-889-4872
www.UnitedTTY.com

Weitbrecht Communications
Santa Monica, CA
800-233-9130 (V/TTY)
www.weitbrecht.com

Some Other Distributors of Assistive Listening Devices

Audio Enhancement
www.audioenhancement.com

Centrum Sound
members.aol.com/centrumweb

Hear You Are, Inc.
Stanhope, NJ
201-347-7662 (V)
201-347-7662 (F)
hearyouare@aol.com
Heidico
Reno, NV
702-324-7104 (V/TTY/F)

Hello Direct
www.hello-direct.com

Radio Shack
www.radioshack.com

Sound Associates
www.soundassociates.com

Sound Remedy
New York, NY
212-242-1036 (V/F)

There are also many centers across the country where individuals can examine the types of assistive listening devices available in order to determine which products to purchase. To locate an assistive device demonstration center in your area, call the American Speech-Language-Hearing Association’s Action Center at 800-638-8255, e-mail actioncenter@asha.org, or call Self Help for Hard of Hearing People, Inc. (SHHH) at 301-657-2248 (voice) or 301-657-2249 (TTY).

Selected Resources for Information, Services, and Products

Information
Alexander Graham Bell Association for the Deaf
3417 Volta Place, NW
Washington, DC 20007
202-337-5220 (V/TTY)

American Academy of Audiology
11730 Plaza America Dr., Suite 300
Reston, VA 20190
703-790-8466

American Association for the Deaf-Blind
814 Thayer Ave., Room 302
Silver Spring, MD 20910
301-588-6545 (V/TTY)

American Association for Deaf Children
10th and Tahlequah Streets
Sulfur, OK 73086
800-942-ASDC

American Athletic Association for the Deaf
3607 Washington Blvd., #4
Ogden, UT 84403
801-393-5710 (V)
801-393-7916 (TTY)
American Speech-Language-Hearing Association  
2200 Research Blvd.  
Rockville, MD 20850  
Members: 800-498-2071  
Nonmember: 800-638-8255  
Fax: 301-296-8580

Helen Keller National Center for Deaf-Blind Youths and Adults  
111 Middle Neck Rd.  
Sands Point, NY 11050  
516-944-8900 (V)  
516-944-8637 (TTY)

National Association for the Deaf  
814 Thayer Ave., Room 302  
Silver Spring, MD 20910  
301-587-1788 (V)  
301-587-1789 (TTY)

National Information Center on Deafness  
Gallaudet University  
800 Florida Ave. NE  
Washington, DC 20002

Products/Services  
Canines  
Paws with a Cause  
1235 100th St. SE  
Byron Center, MI 49315  
800-253-PAWS

Cochlear Implant  
Cochlear Corporation  
Suite 200  
61 Inverness Dr. East  
Englewood, CO 80112  
800-523-5798

Interpreters  
Registry of Interpreters for the Deaf  
9719 Colesville Rd., Suite 310  
Silver Spring, MD 20910  
301-608-0050 (V/TTY)

General Products  
HARC Mercantile, LTD.  
1111 West Centre Ave.  
P.O. Box 3055  
Kalamazoo, MI 49003  
800-445-9968 (V)  
800-413-5245 (TTY)
Appendix 10.4 Model SuperBill for Audiology

The following is a model of a superbill that could be used by an audiology practice when billing private health plans. This sample is not meant to dictate which services should or should not be listed on the bill. Most billable codes are from the American Medical Association (AMA) Current Procedural Terminology (CPT), 2007. Prosthetic and durable medical equipment codes, such as hearing aid codes, are published by the Centers for Medicaid and Medicare (CMS) as Healthcare Common Procedure Codes. The superbill is a standard form that health plans use to process claims. For the professional rendering services, it provides a time-efficient means to document services, fees, codes and other information required by insurance companies, (i.e., certification and licensure). The patient uses this form to file for health plan payment.

NOTE: This is only a model, therefore some procedures, codes, or other pertinent information may not be found on the following model. For a complete list of CPT and ICD-9 codes, the ASHA Health Plan Coding & Claims Guide is available through ASHA's Billing & Reimbursement website or by calling ASHA's Product Sales at 1-888-498-6699.

(Continued)
### MODEL AUDIOLOGY SUPERBILL

<table>
<thead>
<tr>
<th>Procedure</th>
<th>CPT</th>
<th>Fee</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Audiological Assessment Procedures</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Screening test, pure tone, air only</td>
<td>92551</td>
<td></td>
</tr>
<tr>
<td>Pure tone audiometry (threshold); air only</td>
<td>92552</td>
<td></td>
</tr>
<tr>
<td>Pure tone audiometry; air and bone</td>
<td>92553</td>
<td></td>
</tr>
<tr>
<td>Speech audiometry; threshold</td>
<td>92555</td>
<td></td>
</tr>
<tr>
<td>Speech audiometry w/speech recognition</td>
<td>92556</td>
<td></td>
</tr>
<tr>
<td>Comprehensive audiometry threshold evaluation and speech recognition</td>
<td>92557</td>
<td></td>
</tr>
<tr>
<td>Audiometric testing of groups</td>
<td>92559</td>
<td></td>
</tr>
<tr>
<td>Bekesy audiometry; screening</td>
<td>92560</td>
<td></td>
</tr>
<tr>
<td>Bekesy audiometry; diagnostic</td>
<td>92561</td>
<td></td>
</tr>
<tr>
<td>Loudness balance test, alternate binaural or monaural</td>
<td>92562</td>
<td></td>
</tr>
<tr>
<td>Tone decay test</td>
<td>92563</td>
<td></td>
</tr>
<tr>
<td>Short increment sensitivity index (SISI)</td>
<td>92564</td>
<td></td>
</tr>
<tr>
<td>Stenger test, pure tone</td>
<td>92565</td>
<td></td>
</tr>
<tr>
<td>Tymanometry</td>
<td>92567</td>
<td></td>
</tr>
<tr>
<td>Acoustic reflex testing</td>
<td>92568</td>
<td></td>
</tr>
<tr>
<td>Acoustic reflex decay test</td>
<td>92569</td>
<td></td>
</tr>
<tr>
<td>Filtered speech test</td>
<td>92571</td>
<td></td>
</tr>
<tr>
<td>Staggered spondaic word test</td>
<td>92572</td>
<td></td>
</tr>
<tr>
<td>Lombard test</td>
<td>92573</td>
<td></td>
</tr>
<tr>
<td>Sensorineural activity test</td>
<td>92575</td>
<td></td>
</tr>
<tr>
<td>Synthetic sentence test</td>
<td>92576</td>
<td></td>
</tr>
<tr>
<td>Stenger test, speech</td>
<td>92577</td>
<td></td>
</tr>
<tr>
<td>Visual reinforcement audiometry (VRA)</td>
<td>92579</td>
<td></td>
</tr>
<tr>
<td>Conditioning play audiometry</td>
<td>92582</td>
<td></td>
</tr>
<tr>
<td>Select picture audiometry</td>
<td>92583</td>
<td></td>
</tr>
<tr>
<td>Electrocochleography</td>
<td>92584</td>
<td></td>
</tr>
<tr>
<td>Auditory Evoked Potentials, comprehensive</td>
<td>92585</td>
<td></td>
</tr>
<tr>
<td>Auditory Evoked Potentials, limited</td>
<td>92586</td>
<td></td>
</tr>
<tr>
<td>Procedure</td>
<td>Code</td>
<td></td>
</tr>
<tr>
<td>---------------------------------------------------------------------------</td>
<td>--------</td>
<td></td>
</tr>
<tr>
<td>Evoked otoacoustics emissions, limited</td>
<td>92587</td>
<td></td>
</tr>
<tr>
<td>Evoked otoacoustics emissions, comprehensive</td>
<td>92588</td>
<td></td>
</tr>
<tr>
<td>Evaluation of central auditory function, with report; initial 60 minutes</td>
<td>92620</td>
<td></td>
</tr>
<tr>
<td>each additional 15 minutes</td>
<td>92621</td>
<td></td>
</tr>
<tr>
<td>Assessment of tinnitus (includes pitch, loudness matching, and masking)</td>
<td>92625</td>
<td></td>
</tr>
</tbody>
</table>

**Hearing Aid Assessment and Fitting Procedures**

<table>
<thead>
<tr>
<th>Procedure</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hearing aid exam and selection; monaural</td>
<td>92590</td>
</tr>
<tr>
<td>Hearing aid exam and selection; binaural</td>
<td>92591</td>
</tr>
<tr>
<td>Hearing aid check; monaural</td>
<td>92592</td>
</tr>
<tr>
<td>Hearing aid check; binaural</td>
<td>92593</td>
</tr>
<tr>
<td>Electroacoustic evaluation for hearing aid; monoaural</td>
<td>92594</td>
</tr>
<tr>
<td>Electroacoustic evaluation for hearing aid; binaural</td>
<td>92595</td>
</tr>
<tr>
<td>Ear protector attenuation measurements</td>
<td>92596</td>
</tr>
<tr>
<td>Intraop nerve test add-on</td>
<td>95920</td>
</tr>
<tr>
<td>Somatosensory testing</td>
<td>95925</td>
</tr>
<tr>
<td>Visual evoked potential test</td>
<td>95930</td>
</tr>
<tr>
<td>H-reflex test, amplitude and latency study</td>
<td>95934</td>
</tr>
<tr>
<td>H-reflex test, not g/s muscle</td>
<td>95936</td>
</tr>
<tr>
<td>Neuromuscular junction test</td>
<td>95937</td>
</tr>
</tbody>
</table>

**Balance System Assessment Procedures**

<table>
<thead>
<tr>
<th>Procedure</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spontaneous nystagmus, including gaze</td>
<td>92531</td>
</tr>
<tr>
<td>Positional nystagmus</td>
<td>92532</td>
</tr>
<tr>
<td>Caloric vestibular test, each irrigation (binaural, bithermal stimulation constitutes four tests)</td>
<td>92533</td>
</tr>
<tr>
<td>Optokinetic nystagmus</td>
<td>92534</td>
</tr>
<tr>
<td>Spontaneous nystagmus test, including gaze and fixation nystagmus, with recording</td>
<td>92541</td>
</tr>
</tbody>
</table>

**Sample Audiology Superbill**

<table>
<thead>
<tr>
<th>Procedure</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positional nystagmus test, minimum of four positions</td>
<td>92542</td>
</tr>
<tr>
<td>Caloric vestibular test, each irrigation (binaural, bithermal stimulation constitutes four tests), with recording</td>
<td>92543</td>
</tr>
<tr>
<td>Optokinetic nystagmus test, bidirectional, foveal or peripheral stimulation, w/ recording</td>
<td>92544</td>
</tr>
<tr>
<td>Oscillating tracking test, with recording</td>
<td>92545</td>
</tr>
</tbody>
</table>

(Continued)
### Sinusoidal vertical axis rotational testing
- Code: 92546

### Use of vertical electrodes in any or all of the above tests
- Code: 92547

### Computerized dynamic posturography
- Code: 92548

### Vestibular and Balance Rehabilitation Services

#### Neuromuscular re-education of movement, balance, coordination, kinesthetic sense, posture, and proprioception
- Code: 97112

### Cerumen Management Services

#### Removal of impacted cerumen, one or both ears
- Code: 69210

#### Auditory Implant Services Cochlear implant follow-up exam < 7 years of age
- Code: 92601

#### Reprogram cochlear implant <7 years of age
- Code: 92602

#### Cochlear implant follow-up exam >7 years of age
- Code: 92603

#### Reprogram cochlear implant > 7 years of age
- Code: 92604

#### Diagnostic analysis with programming of auditory brain stem implant, per hour
- Code: 92640

### Habilitative and Rehabilitative Services

#### Evaluation of speech, language, voice, communication, and/or auditory processing
- Code: 92506

#### Treatment of speech, language, voice, communication, and/or auditory processing disorder; individual group, two or more individuals
- Code: 92507

#### Evaluation of auditory rehabilitation status, first hour
- Code: 92626

#### Evaluation of auditory rehabilitation status, each additional 15 minutes
- Code: 92627

#### Auditory rehabilitation; prelingual hearing loss
- Code: 92630

#### Auditory rehabilitation; postlingual hearing loss
- Code: 92633

### Hearing Aids (HCPCS Level II Codes)

#### Assessment for Hearing Aid
- Code: V5010

#### Fitting/Orientation/Checking of Hearing Aid
- Code: V5011

#### Repair/Modification of a Hearing Aid
- Code: V5014

#### Conformity Evaluation
- Code: V5020

#### Hearing aid, Monaural, body worn air conduction
- Code: V5030

#### Hearing aid, Monaural, bone conduction
- Code: V5040

#### Hearing Aid, Monaural, in the ear
- Code: V5050

#### Hearing Aid, Monaural, behind the ear
- Code: V5060

#### Glasses, air conduction
- Code: V5070
<table>
<thead>
<tr>
<th>Description</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Glasses, bone conduction</td>
<td>V5080</td>
</tr>
<tr>
<td>Dispensing fee, Unspecified Hearing Aid</td>
<td>V5090</td>
</tr>
<tr>
<td>Hearing Aid, bilateral, body worn</td>
<td>V5100</td>
</tr>
<tr>
<td>Dispensing fee, bilateral</td>
<td>V5110</td>
</tr>
<tr>
<td>Binaural, body</td>
<td>V5120</td>
</tr>
<tr>
<td>Binaural, in the ear</td>
<td>V5130</td>
</tr>
<tr>
<td>Binaural, behind the ear</td>
<td>V5140</td>
</tr>
<tr>
<td>Binaural, glasses</td>
<td>V5150</td>
</tr>
<tr>
<td>Dispensing fee, binaural</td>
<td>V5160</td>
</tr>
<tr>
<td>Hearing Aid, CROS, in the ear</td>
<td>V5170</td>
</tr>
<tr>
<td>Hearing Aid, CROS, behind the ear</td>
<td>V5180</td>
</tr>
<tr>
<td>Hearing Aid, CROS, glasses</td>
<td>V5190</td>
</tr>
<tr>
<td>Dispensing fee, CROS</td>
<td>V5200</td>
</tr>
<tr>
<td>Hearing Aid, BICROS, in the ear</td>
<td>V5210</td>
</tr>
<tr>
<td>Hearing Aid, BICROS, behind the ear</td>
<td>V5220</td>
</tr>
<tr>
<td>Hearing Aid, BICROS, glasses</td>
<td>V5230</td>
</tr>
<tr>
<td>Dispensing Fee, BICROS</td>
<td>V5240</td>
</tr>
<tr>
<td>Dispensing Fee, Monaural Hearing Aid</td>
<td>V5241</td>
</tr>
<tr>
<td>Hearing Aid, Analog, monaural, CIC (completely in the ear canal)</td>
<td>V5242</td>
</tr>
<tr>
<td>Hearing aid, analog, monaural, ITC</td>
<td>V5243</td>
</tr>
<tr>
<td>Hearing aid, digitally programmable analog, monaural, CIC</td>
<td>V5244</td>
</tr>
<tr>
<td>Hearing aid, digitally programmable analog, monaural, ITC</td>
<td>V5245</td>
</tr>
<tr>
<td>Hearing aid, digitally programmable analog, monaural, ITE (in the ear)</td>
<td>V5246</td>
</tr>
</tbody>
</table>

**Sample Audiology Superbill**

<table>
<thead>
<tr>
<th>Description</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hearing aid, digitally programmable analog, monaural, BTE</td>
<td>V5247</td>
</tr>
<tr>
<td>Hearing aid, analog, binaural, CIC</td>
<td>V5248</td>
</tr>
<tr>
<td>Hearing aid, analog, binaural, ITC</td>
<td>V5249</td>
</tr>
<tr>
<td>Hearing aid, digitally programmable analog, binaural, CIC</td>
<td>V5250</td>
</tr>
<tr>
<td>Hearing aid, digitally programmable analog, binaural, ITC</td>
<td>V5251</td>
</tr>
<tr>
<td>Hearing aid, digitally programmable, binaural, ITE</td>
<td>V5252</td>
</tr>
<tr>
<td>Hearing aid, digitally programmable, binaural, BTE</td>
<td>V5253</td>
</tr>
<tr>
<td>Hearing aid, digital, monaural, CIC</td>
<td>V5254</td>
</tr>
<tr>
<td>Hearing aid, digital, monaural, ITC</td>
<td>V5255</td>
</tr>
</tbody>
</table>

(Continued)
### Appendix 10.4 (Continued)

<table>
<thead>
<tr>
<th>Description</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hearing aid, digital, monaural, ITE</td>
<td>V5256</td>
</tr>
<tr>
<td>Hearing aid, digital, monaural, BTE</td>
<td>V5257</td>
</tr>
<tr>
<td>Hearing aid, digital, binaural, CIC</td>
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### Other Procedures

- Otorhinolaryngological service or procedure: 92700

---

**Steven Smith, AuD, CCC-Aud**  
Audiology & Hearing Center, Inc.  
999 Anywhere Street  
Rockville, MD 00000  
Federal ID #00-00000 (999) 999-9999

**Audiological Diagnosis:**  

**ICD-9 Code:**  

**Hearing Aid/Earmold Defect:**  

**Previous Balance:** $ _____  
**Today’s Fee:** $ _____  
**Total Due:** $ _____  

**Amount Paid:** $ _____  
**Balance:** $ _____

**Today’s Payment Paid By**  
Cash: _____  
Check: _____  
Credit card: _____

**White copy: Office**  
**Canary copy: Insurance**  
**Pink copy: Patient**
Chapter 11
The Role of the Economist in Life Care Planning

Everett G. Dillman

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Introduction
An economist is frequently called upon to compute the present value of the future medical and care costs set forth in a life care plan prepared by a specialist. Although the economist generally will have little or no input in the development of the plan, the economist does have an
interest in how the plan is structured and what it contains. This chapter examines the content of life care plans from the point of view of an economist and identifies some areas of potential concern.

The structure of the life care plan, including what elements are covered, will differ to some extent from author to author. Experience has shown, however, that there are a number of consistent patterns that emerge, some of which will cause difficulty for economic analysis (Dillman, 1987, 1988). The areas of concern from an economic point of view include (1) cost categories, (2) items that should be included, (3) timing of the items, (4) the use of actual or annual averages, and (5) the emphasis placed on trivial items. Each of these elements is discussed in more detail.

**Categories of Costs**

In making the economic evaluation, the economist must consider the fact that the costs of the various items included in the plan will not remain static over time but can be expected to increase with inflation. The historical rates of increase will differ depending upon the particular item, as the prices of some things tend to increase faster than others. For instance, the inflation of doctors’ fees and hospital costs has historically been much greater than the inflation for such items as bandages, hospital beds, and other commodities.

In considering future inflation, the economist generally looks at the past inflation of the type of good being evaluated. Although it may be possible to develop data series for many individualized items, the economic analysis will generally place the items into the broad classifications of medical services, nonmedical services, medical commodities, and nonmedical commodities.

Two of the categories, medical services and medical commodities, are subsets of the Consumer Price Index (CPI) and are defined by the Bureau of Labor Statistics (www.bls.gov/cpi/cpifact4.htm). These definitions as well as those for the other two categories follow.

**Medical Services**

This category involves professional and hospital services. Included are payments for physicians, dentists, and other professionals such as optometrists, ophthalmologists, opticians, psychologists, chiropractors, nurse practitioners, and therapists. The category of hospital services includes nursing home care. Hospital services for inpatients, such as pharmacy, laboratory tests, radiology, short-stay units, ambulatory surgery, physical therapy, and emergency room fees billed by the hospital, also fall into this category. This category also includes fees paid to individuals or agencies for the personal care of invalids, elderly, or convalescents in the home including food preparation, bathing, light housekeeping, and other services.

**Medical Commodities**

The medical commodities classification includes the following:

- Prescription drugs and medical supplies. This includes all drugs and medical supplies dispensed by prescriptions. Also included are all prescription-dispensed over-the-counter drugs, that is, those drugs that are obtained over the counter but are prescribed by the doctor and dispensed by the pharmacist.
Internal and respiratory over-the-counter drugs. This includes all nonprescription medication taken by swallowing or inhaling, as well as suppositories or enemas.

Topicals and dressings. Includes all nonprescription medicines and dressings used externally.

Medical equipment for general use. Includes nonprescription medical equipment not worn or not used for supporting the body. Included in this group are nonprescription male and female contraceptives. Whirlpools and vaporizers are also included.

Supportive and convalescent medical equipment. This category includes all supportive and convalescent medical equipment and auxiliaries to such equipment. Also included are prostheses, crutches, wheelchairs, and associated accessories.

Hearing aids. Includes all types of hearing aids and the cost of testing and fitting of the hearing aid.

**Nonmedical Services**

The nonmedical services category is concerned with all personal services that are not included in medical services. Examples would include services such as housecleaning, home maintenance, lawn care, and auto repair. Some services that are medically related will fall into this group, such as wheelchair repair and maintenance of a van wheelchair lift. Nonprofessional attendant care (when not provided through a health care provider) can be classified as a nonmedical service.

Since the long-term inflation rate of nonmedical services is less than that for medical services, when there is doubt as to the correct classification, the conservative approach would be to place the service item in the nonmedical services category.

**Nonmedical Commodities**

The nonmedical commodities category includes all the commodity (i.e., nonservices) items that do not fall under medical commodities. Such items might be specialty foods, housing, and alterations to housing, automobiles, games, bedding, and computers.

The historical inflation rates of each of these categories are given by the appropriate subseries of the CPI, or, in the case of nonmedical services, the average increase in hourly wages in the private nonagricultural economy. These are shown in Table 11.1 to Table 11.6.

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### Table 11.2 Consumer Price Index for Medical Commodities: All Urban Consumers

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What Should Be Included

The life care plan, in personal injury litigation, should include all medical and care items (both services and commodities) that will be, or should be, incurred because of the incident in question. Which specific items to include is usually not a question for the economist. The economist needs to make sure that only marginal costs are considered, that is, those items that normally would not be purchased from earnings absent the injuries.

In addition, the value of the items or services should be evaluated even if provided at no cost by family members, significant others, or some other collateral source. Each of these concepts will be briefly discussed.

Marginal Costs

A marginal cost, as it pertains to a life care plan in personal injury litigation, can be defined as an additional or extra cost that is incurred because, and only because, of the injury in question. For instance, the entire cost of a new car (every 3 years or so) would generally not be considered a marginal cost. The individual would normally need transportation even if not injured. Under
Table 11.3  Consumer Price Index for Medical Services: All Urban Consumers

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(Continued)
normal circumstances the transportation would have been paid for out of the individual’s earning capacity, which is, of course, usually another element of potential damage. What would be appropriate, however, is the additional cost required by the nature of the limitations. A van rather than a regular car might be necessary to transport a client in a wheelchair. If so, the additional cost of a van instead of a regular car would be appropriate. Any special modifications such as a lift or special controls would also qualify as a marginal cost. To obtain the marginal cost, one would subtract the cost of a normal item (i.e., a compact car) from the cost of the recommended item.

The life care planner should not include the value of any trade-in toward transportation. The value of a trade-in is an asset owned by the individual. The value of the vehicle to be traded in is no different than a down payment taken from savings. The measure is how much more does the new vehicle cost, given the requirements necessitated by the injury, than the type of vehicle that normally would have been purchased by the injured party. For instance, assume an individual owned a sedan with a trade-in value of $2,000. A new similar sedan could be purchased for $15,000, without trade-in, or $13,000 with trade-in. However, the nature of the injury is such that a van with lift is necessary at a cost of $25,000. The marginal cost would be $25,000 minus $15,000 or $10,000. The trade-in is completely irrelevant.

The same concept holds true for equity received in the sale of a home necessitated by the purchase of new facilities necessary to accommodate the injuries. Only the additional cost should
Table 11.4 Consumer Price Index for Hospital Services: All Urban Consumers

<table>
<thead>
<tr>
<th>Year</th>
<th>Hospital and Related Services 1982–1984 = 100.0</th>
<th>Hospital Services December 1986 = 100.0</th>
<th>Inpatient Hospital Services December 1986 = 100.0</th>
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</table>

(Continued)
be included in the life care plan. That cost can be estimated by the difference between the market price of the old home and that of the new one. Any equity held in the old home is irrelevant.

The case of a renter is somewhat different. If the life care plan includes the cost of the recommended facility as well as the rent currently paid, the economist can compute an inputted value to the stream of rental payments. That is, the economist can estimate the value of the rented home and thus determine the marginal cost of the recommended facility.

Items such as television sets, radios, and books are often set forth in life care plans. In some cases, the inclusion of such items may be justified because of the specifics of the case, but often the items are duplications of what the individual would normally have purchased without the injury and therefore are not a marginal cost and should not be a part of the plan. Marginal costs, however, may be included in the rare case where no compensation for lost earning capacity is included in the total damage estimate.

**Value of the Items**

Care must be taken to include the type and extent of all additional commodities and services necessitated by the injury, even if these have been, or are expected to be, provided without direct out-of-pocket cost to the client. For example, an injured party may require 24-hour, 7-days-a-week attendant care, which has been provided in the past by family members. Even if the family members are able and willing to continue to provide the services, from an economic point of view the value of the services should be estimated and included as a part of the life care plan. In economics, this is called the *opportunity cost* (Dillman, 1988).

The concept of marginal cost may also come into play when assigning a value to some of the services provided. That is, some of the services provided by the family member would have been provided even without the injury and consequently should not be double counted. For instance, if the injured party is a young child who requires constant care, only the additional care necessitated by the injury should be considered. The normal and customary care a mother and other family members would provide the child should not be considered an additional cost necessitated by the injury.

In some life care plans an attendant or aide is priced at the going rate, as if one were to directly hire and become the employer. In other plans, the service is considered to be provided by a home care provider. If the direct-hire approach is to be recommended, consideration must be given to the following:

- The hourly wage must be at least the federal minimum wage.
- The employer (i.e., the client) will be responsible for the withholding and payment of all Social Security taxes. Arrangements must be made for the filing of all reports in a timely fashion.

---

**Table 11.4 (Continued)**

<table>
<thead>
<tr>
<th>Year</th>
<th>Hospital and Related Services 1982–1984 = 100.0</th>
<th>Hospital Services December 1986 = 100.0</th>
<th>Inpatient Hospital Services December 1986 = 100.0</th>
<th>Outpatient Services December 1986 = 100.0</th>
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Table 11.5  Historical Hourly Earnings for Nonagricultural Wage and Salary Employees, 1947–2001

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<th>Year</th>
<th>Hourly Wages</th>
<th>Year</th>
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- Provision must be made for vacations, sickness, or other unavailability of the employee.
- The client will be responsible for hiring and training. The turnover of such employees can be expected to be very high.

The administrative tasks necessary when an employee is used may prove too burdensome for the client, who is, after all, injured or at least in need of assistance. Although family members may assume the responsibility for these administrative matters, it is not incumbent upon them to do so. In most cases, the preferred treatment would be to assume that attendant costs would be provided by a home care agency. (Editors’ note: For a detailed explanation of costs associated with private hire, see R. Thomas & J. Kitchen, 1996, Private hire: The real costs, Inside Life Care Planning 1: 1, 3–5.)
Delivery Period and Amount

In computing the present value of the life care plan, the economist must know the timing of each cost element as well as the length of time the element will be needed. There are two separate considerations concerning the delivery period: when the element will be needed (including replacements) and for how long it will be needed.

The life care planner should attempt to be as specific as possible as to exactly when a procedure or item will be required. Estimates such as “when needed” or “as required” are often seen in life care plans but cannot be evaluated by the economist.

Statements such as “two operations will be required over her lifetime” are less precise than the economist would prefer but can be used and evaluated. In such a case, the economist may make the estimate by assuming that the procedures will occur at equal time intervals over the life expectancy. As an alternative, the economist may total the costs for all like procedures and divide by the number of years of life expectancy to give an annual amortized cost. This would represent the average annual cost for the procedures. If the delivery times are given as a range (e.g., every 3 to 5 years), the economist may space the delivery at the mean (e.g., 4 years) or, again, compute an annual average. Using an average per year is slightly less accurate than using given amounts in specific years, however. The problem is that in many cases, the exact timing is not known.

Statements such as “an operation will be needed within the next 10 years” are very imprecise but still may be evaluated. The most conservative evaluation would place the timing at the beginning of the period if the inflation rate is expected to exceed the discount rate, or at the end of the period if the interest rate is expected to exceed inflation. A compromise evaluation may be made by timing the procedure at the midpoint of the stated duration or by averaging the cost over this period and using an annual average.

The duration of the delivery period is also a very important consideration. The life care plan should note when the element is to start (usually identified by age or year) and when it is to end. Statements such as “these costs will continue until he reaches adulthood” provide little information.

Care must be exercised in assigning a range of values to the items (as opposed to a range of delivery times). Ranges in values may occur for two reasons. If the item is identical from two different vendors, the lowest cost should be the only one included. Identical, however, refers both to

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<th>Cost Category</th>
<th>Data Series</th>
<th>Average Annual Rate of Increase (1970–2007)</th>
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</thead>
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<td>Medical care services</td>
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<td>Nonmedical services</td>
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<td>Nonmedical commodities</td>
<td>All items (CPI)</td>
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Source: Table 11.1 to Table 11.5.
the characteristics of the item as well as its availability. If there is some difference in the characteristics that is not identical, only the preferred one should be recommended. It is incumbent upon the life care planner to make that recommendation. In other words, ranges in values should not be included in the plan.

A life care plan frequently includes items such as wheelchairs, hospital beds, or other medical equipment that may have to be replaced periodically. In some cases, some trade-in value may be present. If so, the life care plan should only include the out-of-pocket cost of the replacement equipment. This pertains only to equipment initially purchased through funds provided by the life care plan and not to a residual value of things already owned by the individual.

Some equipment items may have been purchased prior to funding the life care plan. In such a case, this expense would have been included in past damages and should not be included in the life care plan, which provides for future medical and care needs.

Life care plans often include costs of institutional care where, of course, food and lodging are provided by the facility and thus are included in the cost. Economists differ as to whether the “normal” per diem costs of this food and lodging should be an offset against the total cost. The argument for such an offset is that these expenditures would be made anyway and paid for out of earning capacity. The argument against such a deduction is that the type and quality of lodging and food are not the same as the individual would otherwise expect. In any event, the decision whether to deduct should be left to the economist.

Many of the elements identified in the life care plan will be delivered over the life expectancy of the injured party. The question may arise as to what is the life expectancy of the client given the medical condition. A change to the life expectancies set forth in the typical mortality table is not an economic determination but rather a medical one. The economist should be made aware of any modifications to a normal life expectancy made by a specialist. It should be emphasized that the client's life expectancy should be based on the assumption of quality care, as set forth in the life care plan. For this reason, data from studies of the mortality rates of patients with like conditions but who did not have the advantages of quality care should not be used, uncritically, as evidence of a changed life expectancy for the client.

**Actual or Average Annual**

The costs of the various items may be stated in terms of a specific value in 1 or more years or may be stated in terms of an average cost per year. For instance, assume a medical item costs $12,000 and will have to be replaced every 4 years. The life care planner may opt to average the expenditures as $3,000 per year. The present value of items listed in these two ways will differ slightly because of the math involved. If the initial costs and the replacement periods are known exactly, then analyzing the data based on a specific amount in a given year will be slightly more accurate than using the average per year. The problem in most cases, however, is that both the initial costs and the length of the replacement periods are estimates, averages, or ranges. When this is the case, little accuracy will be lost by allocating the costs on an average basis.

**Economy of Effort**

A comprehensive life care plan will contain a large number of items, some of which cost little and some of which cost a great deal. Experience has shown that most of the costs are concentrated in
just a relatively few items, usually those elements associated with care, such as the costs of doctors, hospitals, nurses, LPNs, or attendants. The total value of the commodity items generally represents only a small proportion of the total costs.

Many life care plans set forth trivial commodity items in minute detail. Some go as far as to estimate the number of additional boxes of facial tissue that will be used annually. On the other hand, the same plan may set forth two or more care options that differ by many thousands (or even hundreds of thousands) of dollars per year. In many cases, the care options will be assigned a cost, but detailed discussion as to the relative benefits of each option will not be given. The reader of the plan will have little or no idea of the relative advantages or disadvantages of the various care options.

The life care plan would be strengthened if the major research, development, and discussion were concentrated on needs that make the greatest impact on total costs. That is, the important items should be emphasized. In many cases, even if the marginal costs of the trivial items (such as facial tissue) were eliminated from the analysis, there would be little difference in the final total cost of the life care plan.

**Total Lifetime Values**

The only important total cost, over the life expectancy, that needs to be considered in a life care plan is the total present value. This is the number the jury will be asked to consider to provide for the lifetime medical and care needs of the client. Present value considers the rates of price inflation as well as the earning power of money (i.e., interest).

When a life care planner gives a total lifetime value of the recommended items by adding all of the items over life expectancy, the results may be confusing and even misleading. If such a total is intended to represent present value, the implicit assumption is that inflation and interest will cancel out. Unless the economist uses the total offset discounting method, the present value calculation will always differ from the lifetime total. These differences will invariably cause confusion.

**Complications**

Life care plans frequently enumerate complications that may arise during the individual’s life expectancy. However, complications that only rise to the level of potential do not meet the criterion of probable as defined in the legal sense. That is, the chance of a complication occurring should be at least over 50% to be included. From a purely statistical point of view, any potential complication could be evaluated if the probability of it occurring were known, but unless that probability exceeded 50% it would, in all likelihood, not be allowed into evidence.*

**Conclusion**

When an economist is called upon to compute the present value of the future medical and care costs set forth in a life care plan prepared by a specialist, the economist must rely on the accuracy of data, including the need, the dollar values, the timing, and the duration. Since the life care

---

* A probability is nothing more than the number of times something occurs to the number of times it could possibly occur. For instance, a lung transplant is needed in one out of four cases, so the probability of it happening is 1 divided by 4, 1/4 or 25%.
plan is the foundation for the economic analysis, the economist has an interest in how the plan is presented. This chapter has looked at life care plans from the economist’s point of view and has made a number of recommendations.

References


SELECTED DISABILITIES:
TOPICS AND ISSUES
Chapter 12

Life Care Planning for the Amputee

Robert H. Meier, III

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Introduction

The physiatrist has been trained in the team approach to provide rehabilitative care to persons with simple and complex disabilities. The physiatrist should serve as an ally with the life care planner in determining the ideal outcome of rehabilitative care. In addition, if the physiatrist has been the care provider throughout the active rehabilitation treatment phase, they also will have insights into the psychosocial issues of the person with the disability that will enhance the life care plan. The physiatrist can also medically case manage the variety of health professionals and treatments that are necessary, especially in cases of catastrophic disability. The physiatrist is an excellent resource to provide rehabilitative care and determine equipment costs.

For the person with an amputation, the physiatrist should have the ability to provide meaningful information for the life care plan, especially in the following areas:

- Point of maximum medical improvement
- Life expectancy
- Expected functional outcomes
- Costs of prosthetic devices
- Frequency of prosthetic replacement
- Quantity and types of rehabilitation services and their costs
- Adaptive equipment needs and costs
- Architectural modifications for function
- Attendant care hours and level of service
- Psychosocial needs
- Vocational and avocational expectations and modifications
- Work restrictions
- Future medical needs
- Future surgical needs

If the local physiatrist is unable to provide useful life care planning information, there is a network of specialized physiatrists who have years of experience in working with the rehabilitation of specific areas of disability. These physiatric specialists can be located through the life care planner network. They should have extensive experience in providing health care for a person with an amputation. The physiatrist can be of great service to the life care planner in indicating the appropriate level of functional outcome to be achieved and the future needs for the amputee.
Phases of Amputation Rehabilitation

The loss of a body part(s) is an emotionally traumatic experience. Yet most persons who sustain an amputation can look forward to a fulfilling life of meaningful function using contemporary prosthetic designs. The key to successful prosthetic rehabilitation is having an understanding of the desired functional outcome and the rehabilitative process necessary for achieving that outcome. In addition, the physiatrist should provide a time framework for the achievement of the ideal outcome. The physiatrist can also outline the most cost-efficient array of rehabilitative services to achieve the desired rehabilitation goals.

To understand the rehabilitative process for a person with an amputation, it is best to consider the following phases of amputation rehabilitation. These phases, while somewhat artificial, do interweave and flow from one to the next. By knowing the phase of the amputation rehabilitative process, the life care planner can identify the issues to be considered in each phase and assist the amputee toward the next phase. The hallmarks of each phase can be used to determine if the amputee is successfully moving through the phases or is delayed in a phase. Being delayed in a phase of rehabilitative care can detract from the best functional or psychosocial outcome and can also add to the costs of health care.

The phases for amputation rehabilitation staging and the setting in which they are usually accomplished in today’s health systems are

OUTPATIENT
1. Preoperative

INPATIENT
2. Surgical
3. Acute postsurgical (some inpatient and some outpatient)

OUTPATIENT
4. Preprosthetic
5. Prosthetic prescription and fabrication
6. Prosthetic training
7. Community reentry
8. Vocational/avocational
9. Follow-up

Hallmarks of each phase have been assigned to measure the progress of the person with an amputation from one phase to the next (Table 12.1). There is usually some overlap from one phase to the next, and the person may move more quickly through one phase than another (Meier, 1994). The focus throughout all these phases is on the needs and desires of the amputee. The person’s ability to adapt to an altered body image and, in some cases, an altered lifestyle is essential for achieving the idealized outcome. Paying attention to and providing service for their psychosocial well-being are paramount to successful rehabilitative outcomes.

Preoperative

On a few occasions, the patient is delayed in the decision for an amputation. This is an ideal time for the rehabilitation team to assess and begin a treatment plan focusing on function of the remaining extremities. This is also an appropriate time to practice preventive care to maintain full range of
motion and strength in the proximal limb muscles of the side to be amputated and also in the intact limb. An aerobic conditioning program should be provided during this phase since this type of exercise will hasten the postoperative functional recovery, especially in the use of a leg or arm prosthesis.

Amputation Surgery and Reconstruction Phase

Amputation surgery should proceed as a reconstructive surgery that will provide a residual limb with the best function, whether or not a prosthesis is likely to be prescribed. A reconstructive philosophy of amputation is best accomplished by a surgeon who has performed a number of amputations and understands contemporary prosthetic options and ideal functional outcomes.

In some cases, further reconstructive surgery for the residual limb will be necessary in order to achieve the best prosthetic function and the ideal outcomes following prosthetic fitting. This type of surgery may include both plastic and orthopedic surgery in order to improve the bony elements of the residual limb or surgery to enhance the quality of soft tissue coverage. The costs of this surgical reconstruction would need to be included in the life care plan.

Acute Postoperative Phase

This is a time for wound healing and pain control. Usually there is wound care necessary until the sutures are removed. The rehabilitation focus is on the remaining limbs and instructing the
amputee in preventive exercise for the amputated limb and the intact limbs. Psychosocial support is essential during this period of loss for the individual.

**Preprosthetic Phase**

This period is usually accomplished on an outpatient basis. Once the sutures are removed, attention is paid to shaping and shrinking the residual limb in preparation for prosthetic casting. This is a good time to educate the amputee and the family regarding the prosthetic options available, and to develop and review the rehabilitation plan, if it has not previously been accomplished. At this time, careful therapeutic attention should be paid to aerobic conditioning and strength training. Emotional stresses should be anticipated that surround change in body image, function, family roles, and income. Empowering amputees to view themselves as healthy individuals and regaining the locus of control in their life are important components of this phase.

**Prosthetic Fabrication**

At this phase, the team, including the amputee, should decide on a prosthetic prescription that best meets the person's needs and desires (Meier, 1995). More and more, the prosthetic prescription is also dependent on what a third-party payer will sponsor. It is preferable that a prosthetist who is frequently experienced in fitting the specific level of amputation be used to fabricate the prosthesis. The time framework from prosthetic casting until final fitting of the prosthesis should be presented to the amputee and the rehabilitation team for planning purposes.

In this author's experience, prosthetic prescription is often determined by the prosthetist with little input from other team members, including the patient. There is a great new array of prosthetic components with sophisticated technology continuing to be brought to the market. However, this newer technology is usually more expensive than preexisting components with little to no research to demonstrate when it is most appropriate to use them. In addition, there is meager research to indicate whether it is cost-effective or efficacious to utilize in the prosthetic prescription.

As a general rule, the lower-limb amputee should be fitted within 8 weeks of amputation and the arm amputee fitted within 4 to 6 weeks of amputation surgery. If the upper-limb amputee is delayed in fitting, the chances of using a prosthesis for bimanual activities decreases significantly. They become accustomed to performing activities in a one-handed manner and, therefore, do not find the prosthesis to be of much assistance in performing their daily activities.

**Prosthetic Training**

This phase is most often accomplished in an outpatient therapy setting with therapists who have trained many amputees with similar levels of amputation and similar types of prosthetic components. It is important that the therapist have worked with the types of prosthetic components included in the prosthesis. Today's prosthetic technology is changing so quickly that it is important that the treating therapist keep abreast of the latest componentry and understand the biomechanics of each component. This phase should continue until the expected level of functional outcome has been achieved. The length of treatment time will vary depending on the level of amputation, the amputee's health, level of function prior to the amputation, associated injuries, and medical problems. The rehabilitation team should proceed with gradual prosthetic wearing.
and functional training with the goal of achieving the idealized functional outcomes listed in Tables 12.2, 12.3, and 12.4. The rehabilitation treatment plan should focus on the level of function necessary for community reintegration and for vocational and avocational outcomes.

It should be noted that some amputees choose to not wear a prosthesis and function quite well. Many of these non-prosthetic-wearing amputees develop a meaningful quality of life that suits them. A prosthesis may not always be appropriate to include in a life care plan.

**Community Reintegration**

Persons with the amputations should begin to resume their roles in the family and the community as quickly as possible following the amputation. Prosthetic training can assist with community reintegration by restoring meaningful function. A psychologist or social worker should assist the amputee in developing productive social interactions with family, friends, peers, and other persons in the community. This reintegration demonstrates a positive emotional adaptive process from the amputee with the motivation to achieve an optimal quality of life. There are some amputees who, for whatever their individual reasons, have not developed a positive emotional adjustment and do not relate a positive quality of life. This maladaptation is more frequently seen in persons who have chronic pain that has not been adequately addressed or who have been depressed or anxious without appropriate counseling.

**Table 12.2  Functional Expectations for the Below-Knee Amputee**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Wears the prosthesis during all waking hours</td>
</tr>
<tr>
<td>2.</td>
<td>Walks on level and uneven surfaces</td>
</tr>
<tr>
<td>3.</td>
<td>Climbs stairs step over step</td>
</tr>
<tr>
<td>4.</td>
<td>Drives a car (if desired)</td>
</tr>
<tr>
<td>5.</td>
<td>Can fall safely and arise from the floor</td>
</tr>
<tr>
<td>6.</td>
<td>Can run (if cardiovascular status permits)</td>
</tr>
<tr>
<td>7.</td>
<td>Can hop without the prosthesis</td>
</tr>
<tr>
<td>8.</td>
<td>Participates in avocational interests</td>
</tr>
<tr>
<td>9.</td>
<td>Has returned to same or modified work</td>
</tr>
<tr>
<td>10.</td>
<td>Does not use any gait aid</td>
</tr>
<tr>
<td>11.</td>
<td>Performs aerobic conditioning exercise (if cardiovascular system permits)</td>
</tr>
<tr>
<td>12.</td>
<td>Knows how to inspect skin of the amputated and nonamputated legs and foot</td>
</tr>
<tr>
<td>13.</td>
<td>Knows how to change stump socks to accommodate for soft tissue changes</td>
</tr>
<tr>
<td>14.</td>
<td>Knows how to buy a correctly fitting shoe for the remaining foot</td>
</tr>
<tr>
<td>15.</td>
<td>Independent in ADL</td>
</tr>
<tr>
<td>16.</td>
<td>Understands the necessity of follow-up</td>
</tr>
</tbody>
</table>
### Table 12.3  Functional Expectations for the Above-Knee Amputee

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Wears the prosthesis during all waking hours</td>
</tr>
<tr>
<td>2.</td>
<td>Walks on level and uneven surfaces</td>
</tr>
<tr>
<td>3.</td>
<td>Climbs stairs step over step (some may do one step at a time)</td>
</tr>
<tr>
<td>4.</td>
<td>Drives a car (if desired)</td>
</tr>
<tr>
<td>5.</td>
<td>Can fall safely and arise from the floor</td>
</tr>
<tr>
<td>6.</td>
<td>Can hop without the prosthesis</td>
</tr>
<tr>
<td>7.</td>
<td>Participates in avocational interests</td>
</tr>
<tr>
<td>8.</td>
<td>Has returned to same or modified work</td>
</tr>
<tr>
<td>9.</td>
<td>Does not use any gait aid (some may need a cane)</td>
</tr>
<tr>
<td>10.</td>
<td>Performs aerobic conditioning exercise (if cardiovascular system permits)</td>
</tr>
<tr>
<td>11.</td>
<td>Knows how to inspect skin of the amputated and nonamputated legs and foot</td>
</tr>
<tr>
<td>12.</td>
<td>Knows how to buy a correctly fitting shoe for the remaining foot</td>
</tr>
<tr>
<td>13.</td>
<td>Independent in ADL</td>
</tr>
<tr>
<td>14.</td>
<td>Understands the necessity of follow-up</td>
</tr>
<tr>
<td>15.</td>
<td>A few can run with high-level training</td>
</tr>
</tbody>
</table>

*Greater energy expenditure than for below-knee prosthetic use*

### Table 12.4  Functional Expectations for the Above- and Below-Elbow Amputee

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Independent in donning and doffing the prosthesis</td>
</tr>
<tr>
<td>2.</td>
<td>Independent in activities of daily living</td>
</tr>
<tr>
<td>3.</td>
<td>Can write legibly with remaining hand</td>
</tr>
<tr>
<td>4.</td>
<td>Has successfully switched dominance (if necessary)</td>
</tr>
<tr>
<td>5.</td>
<td>Drives (if desired)</td>
</tr>
<tr>
<td>6.</td>
<td>Has returned to work (same or modified job)</td>
</tr>
<tr>
<td>7.</td>
<td>Can tie laces with one hand or with the remaining hand and the prosthesis</td>
</tr>
<tr>
<td>8.</td>
<td>Uses a button hook easily</td>
</tr>
<tr>
<td>9.</td>
<td>Has prepared a meal in the kitchen</td>
</tr>
<tr>
<td>10.</td>
<td>Has been shown adaptive equipment for the kitchen and ADL</td>
</tr>
<tr>
<td>11.</td>
<td>Has performed carpentry and automotive maintenance (if desired)</td>
</tr>
<tr>
<td>12.</td>
<td>Wears prosthesis during all waking hours</td>
</tr>
<tr>
<td>13.</td>
<td>Uses the prosthesis for bimanual activities</td>
</tr>
<tr>
<td>14.</td>
<td>Understands the necessity of follow-up</td>
</tr>
</tbody>
</table>
**Vocational Rehabilitation**

The physiatrist should be closely involved during this phase of amputee rehabilitation. The physiatrist is most knowledgeable in the expected level of prosthetic use in a variety of vocational settings. The physiatrist is also best suited to place the work restrictions in relationship to the level of amputation and functional outcome. Working as a team, the case manager, the physiatrist, and the vocational rehabilitation specialist can provide an excellent support system for the amputee and enhance a successful return to the workplace.

While vocational rehabilitation should begin shortly following the amputation, return to the workplace may require a functional capacity evaluation, worksite evaluation, and perhaps worksite modification. Generally, it is ill advised to provide a vocational prognosis until the person has achieved maximum functional outcome with or without use of a prosthesis.

**Follow-Up**

In order to ensure the most appropriate level of prosthetic function, prevent prosthetic problems, and address emotional adjustment to amputation, a regular and periodic program of rehabilitation follow-up should be provided for the amputee. Once the ideal level of function has been achieved and the amputee is wearing a definitive prosthesis, the person should be seen in regular follow-up on an annual or every-other-year basis. This schedule permits measurement of the functional outcomes of amputation rehabilitation. It also serves to enhance the education of the amputee regarding preventive care and further prosthetic needs.

Restoration of meaningful function, body compensation and emotional adaptation to an amputation take a significant time from the amputation until the patient is well stabilized. For most patients with a unilateral leg amputation, the process of amputation and its rehabilitation will generally take the majority of 12 to 18 months. Certainly prosthetic fitting and training take less than the 12 to 18 months but the true return to a full life cannot be hurried and the achievement of maximum medical improvement (MMI) falls within this 12 to 18 month framework. In the person with a unilateral arm amputation, this process of rehabilitation to MMI is more likely to occur in 6 to 9 months from the onset of the amputation (Meier & Atkins, 2004). Of course, if there are significant comorbid factors or there is bilateral limb loss, achieving MMI may take a longer period of time.

**Demographics of Limb Amputation**

Amputation of the leg is more common than amputation of the arm and occurs in a 3:1 ratio. The leg amputee is usually a person in the sixth or seventh decade of life who sustains the amputation because of occlusive arterial vascular disease. Often this person also has associated diabetes mellitus. In addition to the vascular disease in the legs, there is often accompanying arterial disease in the coronary and cerebral arteries. With associated diabetes, the complications can include peripheral neuropathy, renal disease, and diminished eyesight. All of these comorbid factors can diminish the functional outcomes expected from prosthetic rehabilitation.

The arm amputee is usually a young man who has sustained a work-related injury. The amputation most frequently involves the right arm and most often results in a below-elbow (transradial) amputation of the dominant arm. The arm amputee, unlike the leg amputee, can function independently with the use of one arm. Full-time functional prosthetic use in the arm amputee is less likely to occur than in the leg amputee.
Phantom and Residual Limb Pain

This phenomenon occurs in most patients immediately following the amputation surgery and usually subsides during the first 4 to 6 weeks after the amputation. In only a few amputees does phantom limb pain become so problematic that it interferes with the quality of life. Phantom pain should not be treated with narcotics other than during the acute postoperative period. Today, a variety of medications can be used to alleviate this pain. Popular at this time are pregabalin (Lyrica), gabapentin (Neurontin), dexromethorphan, tricyclic antidepressants, and carbamazepine (Davis, 1993). These medications affect the way the body processes pain messages in the peripheral and central nervous systems. Other physical modalities have been utilized but have met with varied success depending on the individual amputee. If the phantom pain interferes greatly with the quality of life and/or prosthetic function, an amputee pain specialist should be consulted. Often, pain in the amputee is related to the level of anxiety, depression, and altered sleep that is present. Posttraumatic stress disorder is often present and may contribute to the level of perceived pain. Problematic pain in the amputee must be approached using emotional counseling and not just medications or modalities.

Pain in the residual limb should be differentiated from phantom pain. Often, residual limb pain is caused by a poorly fitting prosthesis and can be alleviated with socket modifications. Residual limb pain may also be caused by the development of a neuroma from a peripheral nerve that was severed at the time of the amputation. There are a variety of conservative and surgical methods to attempt to decrease the pain from a neuroma (Sherman, Sherman, & Gail, 1980).

On a few occasions, neuromodulation through the use of peripheral nerve or central neural stimulation is warranted.

Levels of Limb Amputation

In general, the longer the length of the residual limb, the better the prosthetic function that can be expected. In the leg, amputation below the knee (transtibial) provides for lower energy expenditure than the use of an above-knee (transfemoral) prosthesis. Salvaging the leg at a below-knee
level is now the goal of leg amputation surgery in the United States (Moore & Malone, 1989). Disarticulation levels for the arm and leg have certain relative contraindications and should be carefully considered on an individual basis. Full thickness skin and soft tissue coverage are also helpful in achieving ideal prosthetic functional outcomes. However, with the new gel liner interfaces, scarred skin and poor soft tissue coverage can be dealt with in a more satisfactory manner than in the past.

In today’s reconstructive surgery for the amputee, very short residual limbs can be lengthened using bone allograft or Ilizarov techniques. In addition, poor scar and soft tissue coverage can be replaced with full thickness skin and overlying muscle using a pedicle or free flap tissue transfer.

**Prosthetic Prescription**

There has been an explosion of available prosthetic components in the past 10 years, and it is hard to keep up with the constant barrage of new options for the amputee. As noted previously, most of the new components have added to the expense of the prosthesis without scientific demonstration that they have enhanced functional outcome. Many of the new components are lighter weight and therefore more comfortable to wear. New prosthetic foot designs have added the ability to run and jump, and these desired functions were not previously possible with the older component designs (Esquenazi & Torres, 1991). The use of electric components for the arm amputee has not been universally applied in the United States. This technology remains less frequently prescribed than the conventional body-powered designs. The prices of prostheses, especially those using the new socket designs and components, have risen dramatically. A high-tech above-knee prosthesis frequently will cost between $20,000 to $86,000, while an above-elbow myoelectric arm can cost $40,000 to $150,000. With costs at these levels, it is imperative that the amputee be treated in a comprehensive interdisciplinary center of amputation rehabilitative excellence.
The usual components required for a prosthetic leg include the socket, a foot/ankle complex, and a means of suspension. Of course, for the above-knee prosthesis, a knee component is also prescribed.

For the arm amputee, there is a socket that fits onto the residual limb and for the below-elbow amputee, a wrist joint, a terminal device, and a suspension system are required elements of the prescription. Terminal devices can be a hook or a hand (Sears, 1991). The hand can be passive, or it can move. For the above-elbow amputee, an elbow joint is prescribed. In considering the arm prosthetic prescription, the team needs to consider the three basic prosthetic designs available. They are a passive prosthesis that provides mainly cosmetic restoration, one that is cable controlled by body power, or one that has electric moving parts. A comparison of these types of arm prostheses is presented in Table 12.5 (Esquenazi, Leonard, Meier, et al., 1989).

### Table 12.5 Advantages and Disadvantages of Various Upper-Limb Prostheses

<table>
<thead>
<tr>
<th>Type</th>
<th>Pros</th>
<th>Cons</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cosmetic (passive)</td>
<td>Most lightweight</td>
<td>High cost if custom made</td>
</tr>
<tr>
<td></td>
<td>Best cosmesis</td>
<td>Least functional</td>
</tr>
<tr>
<td></td>
<td>Least harnessing</td>
<td>Low-cost gloves stain easily</td>
</tr>
<tr>
<td>Body powered</td>
<td>Moderate cost</td>
<td>Most body movement to operate</td>
</tr>
<tr>
<td></td>
<td>Moderately lightweight</td>
<td>Most harnessing</td>
</tr>
<tr>
<td></td>
<td>Most durable</td>
<td>Least satisfactory appearance</td>
</tr>
<tr>
<td></td>
<td>Highest sensory feedback</td>
<td></td>
</tr>
<tr>
<td>Externally powered (myoelectric and switch control)</td>
<td>Moderate or no harnessing</td>
<td>Heaviest</td>
</tr>
<tr>
<td></td>
<td>Least body movement to operate</td>
<td>Most expensive</td>
</tr>
<tr>
<td></td>
<td>Moderate cosmesis</td>
<td>Most maintenance</td>
</tr>
<tr>
<td></td>
<td>More function-proximal levels</td>
<td>Limited sensory feedback</td>
</tr>
<tr>
<td>Hybrid (cable elbow/electric TD)</td>
<td>All cable excursion to elbow</td>
<td>Electric TD weights forearm (harder to lift)</td>
</tr>
<tr>
<td></td>
<td>Increased TD pinch</td>
<td>Good for elbow disarticulation (or long above elbow)</td>
</tr>
<tr>
<td>Hybrid (electric elbow/cable TD)</td>
<td>All cable excursion to TD</td>
<td>Least cosmesis</td>
</tr>
<tr>
<td></td>
<td>Low effort to position TD</td>
<td>Lower pinch force for TD</td>
</tr>
<tr>
<td></td>
<td>Low-maintenance TD</td>
<td></td>
</tr>
</tbody>
</table>

This level of amputation can be handled in several ways. Many partial-hand amputees choose to not wear any prosthetic restoration. However, if cosmesis is desired, a cosmetic glove can be fabricated. This is usually made from a mold taken of the residual hand. A custom-made silicone glove that is hand-colored can provide excellent cosmesis and is reasonably durable. However, if it is worn at work, a protective glove should be worn. Another manner to prosthetically handle this level is to make an opposition bar that can provide improved prehension between the prosthetic bar and the residual moving parts of the hand. If the thumb has been amputated, an excellent prosthetic thumb can be fabricated. The functional and cosmetic results from this prosthesis often decrease the need for surgical reconstruction of the amputated thumb.
Life Care Planning for the Amputee

Figure 12.5 “I-Hand” without coverage of a cosmetic glove. Individual fingers move using myoelectric signals

**Wrist Disarticulation/Below Elbow (Transradial)**

The below-elbow prosthesis is usually composed of a double-walled plastic laminate socket that fits intimately over the residual limb. A locking, quick-change wrist unit is commonly prescribed through which the terminal device is attached to the forearm shell. This wrist unit permits ease of change of various terminal devices and locks the terminal device in a position of function when handling heavier objects. For most men who will return to heavy-duty work, a body-powered prosthesis will be useful. For the businessman or white-collar worker, a myoelectric or a passive cosmetic prosthesis may be preferable (Meier, 1996).

A newer hand with isolated finger motion (I-Hand) is now commercially available for myoelectric control, and it permits individual finger motion with articulation of the usual finger joints.

**Elbow Disarticulation/Above Elbow (Transhumeral)**

The prosthetic options at this level of restoration are body-powered or electric control. The electric prosthesis is many times the expense of the body-powered arm. For a very short above-elbow level of amputation, an electric prosthesis may be the only functional restoration that is reasonable.

**Shoulder Disarticulation**

This level can be fitted with a lighter weight endoskeletal design with a passive elbow joint and a moving terminal device. At this proximal level of amputation, an electric prosthesis will permit more functional motion of the component parts. However, it is heavier to wear and much more costly.

**Partial/Hindfoot**

Often this level of amputation can be fitted with a full-length insole with toe filler that fits inside the shoe. This insole can usually be interchanged between various shoes. The bottom of the shoe may need to be modified to provide a more normal gait pattern.
Below Knee (Transtibial)

The prosthesis that is currently used for this level of amputation was popularized in the mid-1950s. It is called a patellar tendon bearing (PTB) design. It was originally designed to place superincumbent body weight on the remaining anatomic landmarks that were pressure tolerant. It relieves pressure from the pressure-intolerant areas of the residual stump. For this level, the prosthetic prescription includes the design of the prosthetic socket, a foot/ankle complex, and a means of suspending the prosthesis on the residual leg. A current popular suspension design is called the triple “S” system or the silicone suction suspension. A silicone sleeve is worn against the skin and a knurled pin extends from the distal end. This pin locks inside a coupling in the distal end of the prosthetic socket. The silicone sleeve provides additional padding to the inside of the socket against the skin. Other types of gel liners are in vogue today and have made prosthetic leg wearing more comfortable. These liners reduce the number of skin problems seen with prosthetic wear and function.

Knee Disarticulation/Above Knee (Transfemoral)

The contemporary socket design for the above-knee amputee has changed in the 1980s and 1990s (Leonard & Meier, 1993). There are a number of designs available, but the one in greatest use is a narrow mediolateral, ischial containment design. New socket designs also include thermoplastic

Figure 12.6 One example of the several microprocessor knee units for above knee amputation prosthetic restoration. This example is a “C leg” manufactured by Otto Bock.
inner liners that have improved the comfort of prosthetic wearing. Gel liners are also available for this level of amputation. A variety of knee units are also available that provide differing degrees of knee stability and cosmesis with gait.

Today, a computerized knee unit is available. Some amputees find they have to think less about walking to ensure knee stability with one of these knee units. Also, the knee is less likely to bend, causing a fall, than some of the prior knee units that were totally controlled by the amputees themselves. These computerized knees are significantly more expensive than their passive counterparts.

**Hip Disarticulation**

This is a difficult level to fit comfortably and to have the amputee walk successfully with the prosthesis. This level of amputation should be handled by a prosthetist who makes 10 or more of this type of prosthesis a year. More importantly, for the best success, this amputee should have rehabilitation in a center that has trained a number of amputees to wear this type of prosthesis with good results.

**Prosthetic Complications**

A well-fitted prosthesis is in intimate contact with the skin of the residual limb. There are shearing forces applied to the skin in arm and leg prostheses. In the leg amputee, there are also direct pressures applied from the prosthesis to the skin of the residual leg. These forces can create skin pressure problems. These issues are usually addressed with prosthetic socket modifications or the use of gel-skin interfaces. A differing socket design may also be necessary to change the forces applied to the skin.

**Prosthetic Costs**

Because of the high cost of prosthetics, a team of experienced amputee rehabilitation specialists should develop a prescription. To have the prosthetist develop the prescription in a vacuum is almost a conflict of interest and should be avoided.

When assembling the prosthetic costs of the life care plan, it is essential that the life care planner understand what estimate the prosthetist is providing. There are at least three ways of pricing a prosthesis. There is a usual and customary cost of a prosthesis. This cost would be the full, nondiscounted, non-Medicare allowable cost that usually will have significant markup built into the numbers provided from the prosthetic laboratory. Almost never is this price paid to the prosthetist for the final prosthetic device. The more appropriate number to use for prosthetic costs is the Medicare allowable reimbursement. This is the usual amount at which a prosthesis will be paid. Some managed care and insurance providers will discount from the Medicare allowable fee schedule or will provide an add-on amount that will be a specific percentage above the Medicare allowable reimbursement schedule.

Also, if the life care planner is obtaining price quotations from a variety of prosthetic facilities, it is imperative that the same L codes be utilized when comparing the various pieces of the prosthesis. The L code is the Medicare system of providing specific numbers for specific prosthetic components. If specific L codes are not used in obtaining the variety of quotes, it will be like comparing apples and oranges. However, it may be of benefit to obtain a variety of prosthetic price quotes and provide a range in the life care plan using a high estimate, a low estimate, and
the median price. Prosthetic pricing does vary from laboratory to laboratory for the exact same prosthesis. Prosthetic price quotes also can vary dramatically from one region of the United States to another.

**Prosthetic Replacement**

Within the first 2 years following the amputation, several socket changes are usually necessary to accommodate the rapid soft tissue changes that occur. These changes improve the prosthetic fit and comfort of wearing. Usually after this time, a prosthesis should last the amputee from 3 to 5 years before a replacement prosthesis is prescribed. Certainly, the level of activity in using the prosthesis will affect the frequency with which these replacements are needed. Modifications to the prosthesis are usually needed once every 6 months on average. An estimate for routine prosthetic maintenance should be obtained from a prosthetic facility but on average, it is estimated that 10% of the original cost of the prosthesis be provided once the warranty of the prosthesis has expired.

Complete replacement of a leg prosthesis is generally felt to be essential for the active prosthetic wearer every 3 to 5 years. This provides a mean of 4 years between new prosthetic fabrication.

For the conventional, body-powered arm prosthetic user, the same replacement schedule is provided as for the leg. For the electric arm prosthesis, the replacement schedule increases to every 7 years.

**Aging with an Amputation**

As the amputee matures and reaches ages 60 to 65, it is expected that prosthetic use will decrease. This decreased use should increase the length of time between essential prosthetic replacement. It is likely that an average replacement for a new prosthesis would occur every 5 years instead of the previously recommended 4 years. As functional use of the prosthesis decreases, it should also be expected that additional assistance for essential household function should be provided in the life care plan. In the male amputee, this sort of assistance would include outdoor home maintenance and yard work. For the female amputee, additional assistance with the heavier housework would be appropriate. This would include items such as bed making, laundry, housecleaning, mopping, and vacuuming. Also, the incidence of low back pain in the more mature amputee has been found in about 75% of lower-limb amputees. This pain is generally secondary to biomechanical issues but should be evaluated and treated on a regular basis.

Also, aging with a disability research has shown the onset of additional disabling changes in body systems within 20 to 30 years from the onset of the initial disability. In the amputee, issues of overuse and biomechanical stress and strain do occur over years of altered biomechanics. Often, changes are seen in the extremity opposite to the amputated one and also in the more proximal body segments, which take additional stress and strain to compensate for the amputation.

**Life Care Planning with the Physiatrist**

There are three differing scenarios for physiatric involvement with life care planning. The best scenario is when the physiatrist to be involved with the life care plan has been the treating physiatrist
throughout the individual’s rehabilitation process. In this scenario, the physiatrist has become quite involved with developing and facilitating the amputee’s rehabilitation treatment goals and plan. Having worked with the amputee through the phases of amputation rehabilitation, this physiatrist can give the most useful prognostic information for the life care plan. The physiatrist will have a clear picture of the amputee’s psychosocial support system, needs, and desires, as well as the amputee’s preamputation lifestyle and how likely it will be to achieve the desired quality of life postamputation.

Another scenario is the physiatrist who has been asked to participate in a life care plan but has never been involved with the amputee’s rehabilitation program. This physiatrist should evaluate the individual to provide meaningful information for a life care plan. Often, this requires a visit from the amputee to the physiatrist for a thorough assessment. This may be accomplished from one to several days, depending on the complexity of the case. Almost always, this evaluation will be performed during an outpatient visit. The evaluation usually includes the physiatric assessment and visits with an occupational therapist, a physical therapist, a psychologist, and a prosthetist. Other rehabilitation professionals and consultants may be included in this evaluation, depending on other areas of disability or comorbid factors that are present. The product of this evaluation should be a report that provides all the information that a life care planner will find useful in developing the final plan. For this reason, it is essential that the life care planner pose all of the important questions he or she wishes the physician to address before the evaluation process begins.

The evaluation process by the physiatrist should include the following elements that are clearly delineated during the evaluation and the physiatrist’s opinions that are to be included in the life care document.

These items should include

- History
- Past medical history
- Review of systems including thorough assessment of pain
- Medications
- Psychosocial history
- Activity status—before the amputation and at the time of the evaluation
- Vocational history
- Avocational history
- Prosthetic history
- Adaptive equipment used
- Achievement of maximum medical improvement
- Future needs
  - Prosthetic
  - Emotional
  - Rehabilitative
  - Medical
  - Surgical
  - Equipment
  - Architectural modifications
  - Attendant care
  - Vocational options
Follow-up plan
- Health maintenance and preventive care
- Specifically stated goals obtained from the amputee for the future

A third manner for physiatric involvement in life care planning is the “curbside consultation.” In this instance, the physiatrist does not have the advantage of evaluating the amputee but instead reviews the case records and provides input into the life care plan based on the physiatrist’s experience with similar patients. This manner of physiatric involvement can be very useful to the life care planner in helping to assure that important life care planning issues for a person with an amputation are not overlooked.

**Potential Complications**

Potential complications are dependent on the reason for the amputation (trauma, electrocution, diabetes, cancer, cardiovascular disease, etc.), fit of prosthesis (if one is used), work demands, living environment, quality of medical treatment, and other factors. However, common considerations include the following (Weed & Sluis, 1990):

- Some of the most common complications are psychological. In many cases, psychological counseling will be provided while the client is an inpatient and may be continued following discharge from acute care. If psychological counseling is offered, the costs for this should be placed on the “Projected Therapeutic Modalities” page. In the example case, the client experienced significant depression, was hospitalized for suicidal ideation, and had undergone a significant amount of psychological counseling following discharge. In this case, the family unit fell apart and a number of family counseling issues were raised.
- In the event of amputations where the client wears a prosthesis, one would expect the probability of occasional skin breakdown. In one case, the client suffered amputations as a result of an electrocution injury. In this situation, the skin loses its integrity due to the burn. The client may require surgical intervention in order to repair skin breakdown.
- Bone spurs occasionally become a problem and may require surgery.
- Phantom pain or sensations are very common, at least during acute recovery, and may need some sort of treatment.
- Other complications include osteoarthritis, which may be experienced in the knees and lower back, as well as back pain that may be experienced due to an abnormal gait. Fit of the prostheses is of paramount importance to avoid these kinds of complications. In addition to proper fit, specific gait training to educate the client as to proper body mechanics will be important.
- Another often overlooked complication has to do with weight gain. Weight gain affects the fit of the prostheses, requiring either adjustment or a complete refabrication of the socket.
- Complicated recoveries from other injuries may be a result of the inability of the client to manage self-care during periods of injury or illness. For example, an individual who is a triple amputee (bilateral below knee and dominant arm at the shoulder) may be unable to take care of herself for even bowel and bladder care or other survival needs should she injure her other arm.
Knee problems when not wearing the prosthesis is often a complication for bilateral below-knee amputees. It is sometimes much easier to avoid the time it takes to put on a prosthesis by simply walking on one’s knees in order to get around the house, such as going to the bathroom at night or trying to get out of the house in case of an emergency. After years of using this method to move around, it is not uncommon for clients to experience knee problems.

While working in hot environments or having to exert considerable effort to walk or engage in physical activity with a prosthesis, sweating can become an irritating problem. Prostheses tend to feel heavy and awkward and will require an approximate 10% increase in energy for a single below-knee amputation and much more energy expenditure with multiple amputations (Friedmann, 1981). It does not take an educated observer to understand that a bilateral above-knee amputee will expend considerable energy simply getting from one place to another. In fact, many amputees may prefer to use a wheelchair to do things quicker. In addition, an upper-extremity amputee, such as a shoulder disarticulation, requires the addition of a mechanical arm or a Utah arm, which also requires considerable effort. This may result in excessive sweating and irritation as well. In addition, working in a hot environment, such as outdoors in the summertime in the U.S. South or in a boiler room indoors, may become intolerable.

Neuromas are also fairly frequent and can be quite irritating if the prosthesis impacts the area where the neuroma resides. Often surgery is the treatment of choice.

Case Study

Mr. M. was a 57-year-old male at the time of his motorcycle accident in 2001, when he sustained multiple injuries to his body. He was air-lifted to a trauma unit, where he was stabilized and intubated. It was decided that his left leg was not viable, and a left mid-length above-knee amputation was performed. This incision healed without incident, and the scar has matured well. He was unconscious for a period of 1 week and was determined to have a closed head injury that cleared slowly. Since the injury, the apparent sequelae from the head injury are mild short-term memory deficit and quick change of mood and temper. He also sustained a fractured larynx and had to be intubated for a prolonged period of time. When the tube was removed, he continued to have a hoarse voice with vocal cord paralysis on one side. Since the amputation, he has received a well-fitted prosthetic leg and taught himself to walk using the prosthesis. He has little time for health professionals and always seems to know what is best for his care needs. He now lives independently in a two-story home. He has intermittent pain in the residual leg and also phantom pain. The pain is exacerbated with weather changes that occur frequently where he lives in the Pacific Northwest.

He wants to return to riding motorcycles and remain in his current two-story home. He is currently divorced but has an adult son who checks on his well-being a couple of times a week. He feels that his home would better suit his needs if an elevator were installed since negotiating steps is a hassle even though he can climb them independently and safely.

He has no intention of returning to work with his multiple disabilities following the motorcycle accident. However, before his accident, he worked doing outdoor construction, and the employer and the insurance carrier would like him to pursue some type of gainful employment.
### LIFE CARE PLAN AMPUTEE EXAMPLE

#### Routine Future Medical Care—Physician Only

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Frequency and Duration</th>
<th>Purpose</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Otolaryngology (per Dr. XYZ at U. WA Med Ctr.)</td>
<td>59/2011</td>
<td>Reconstructive surgery of the trachea and larynx with a temporary tracheostomy.</td>
<td>$30,000 total for staged procedures</td>
</tr>
<tr>
<td>Physiatry (R. Meier, MD)</td>
<td>1x year</td>
<td>Monitor prosthetic function, evaluate right foot and proper footwear.</td>
<td>$175 per year</td>
</tr>
<tr>
<td>Orthopedic Surgery (R. Meier, MD)</td>
<td>1x year</td>
<td>Evaluate low back pain that is expected to begin at age 65 years related to abnormal gait associated with prosthetic walking.</td>
<td>$350 per year beginning at age 65 years</td>
</tr>
<tr>
<td>MRI (R. Meier, MD)</td>
<td>At least every 5 years once back pain has begun, expected age 65</td>
<td>Same as above.</td>
<td>$1,300–$1,500 (avg.) every 5 years beginning at age 65 years</td>
</tr>
<tr>
<td>Endocrinology (R. Meier, MD)</td>
<td>Every 6 months</td>
<td>To monitor diabetes and its associated complications.</td>
<td>$175 per year</td>
</tr>
</tbody>
</table>

#### Projected Evaluations—Nonphysician (include all allied health evaluations)

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Year Initiated/ Suspended</th>
<th>Frequency/Duration</th>
<th>Expected Cost</th>
</tr>
</thead>
</table>

See next section, “Projected Therapeutic Modalities.”

### Projected Therapeutic Modalities

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Year Initiated/ Suspended</th>
<th>Frequency/Duration</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical therapy to upgrade prosthetic skills as new components are used (R. Meier, MD)</td>
<td>57/2009</td>
<td>Every 4 years for four sessions</td>
<td>$125 per session</td>
</tr>
<tr>
<td>Recommendation</td>
<td>Year Initiated/Suspended</td>
<td>Frequency/Duration</td>
<td>Expected Cost</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------------</td>
<td>--------------------------</td>
<td>--------------------</td>
<td>---------------------</td>
</tr>
<tr>
<td>Neuropsychology battery for possible head injury at time of the accident</td>
<td>59/2011</td>
<td>One-time battery</td>
<td>No cost included</td>
</tr>
<tr>
<td>(R. Meier, MD, and an unnamed PhD)</td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Year Purchased</th>
<th>Frequency/Duration</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Motorized scooter for long-distance walking and access in the community</td>
<td>Age 65 years</td>
<td>Every 7 years</td>
<td>$3500</td>
</tr>
<tr>
<td>(R. Meier, MD, and Rocky Mountain Medical Equipment)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Year Purchased</th>
<th>Frequency/Duration</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Manual wheelchair (Quickie II) to negotiate places that the motorized scooter</td>
<td>Age 65 years</td>
<td>Every 10 years</td>
<td>$2500</td>
</tr>
<tr>
<td>cannot travel (R. Meier, MD, and Rocky Mountain Medical Equipment)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Year Purchased</th>
<th>Frequency/Duration</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scooter lift for car to carry the scooter on the car rather than to disassemble</td>
<td>Age 65 years</td>
<td>Every 7 years</td>
<td>Range $2795–3195</td>
</tr>
<tr>
<td>and lift into the car trunk (R. Meier, MD, and Adaptive Automotive, Thornton,</td>
<td></td>
<td></td>
<td>(including installation)</td>
</tr>
<tr>
<td>Colorado)</td>
<td></td>
<td></td>
<td>depending on vehicle used to which it is installed</td>
</tr>
</tbody>
</table>

(Continued)
### Wheelchair Maintenance and Accessories

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Year Purchased</th>
<th>Frequency/Duration</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Motorized scooter maintenance (R. Meier, MD)</td>
<td>Age 65 years</td>
<td>Every 7 years</td>
<td>Maintenance once a year at 10% of the base price of the wheelchair. Begins 1 year after purchase when under warranty.</td>
</tr>
<tr>
<td>Manual wheelchair maintenance (R. Meier, MD)</td>
<td>Age 65 years</td>
<td>Every 2 years</td>
<td>10% of the base cost of $2500 for every 2 year maintenance or $125 per year.</td>
</tr>
</tbody>
</table>

### Aids for Independent Function and Orthopedic Equipment Needs

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Year Purchased</th>
<th>Frequency/Duration</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assorted adaptive equipment for the kitchen and bath (recommended by PT and OT)</td>
<td>57/2009</td>
<td>1x year</td>
<td>$100 (avg.) per year</td>
</tr>
<tr>
<td>Crutches to use when walking without wearing the prosthesis (R. Meier, MD)</td>
<td>57/2009</td>
<td>Every 5 years</td>
<td>$275 for ergonomic grips and heavy-duty tips</td>
</tr>
</tbody>
</table>

### Orthotics/Prosthetics

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Year Purchased</th>
<th>Frequency/Duration</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Main walking leg with “C” knee and dynamically responsive foot (R. Meier, MD, and an unnamed CP)</td>
<td>57/2009</td>
<td>Every 3–5 years Average of 4 years</td>
<td>High quote—$46,427 (prosthetic lab A) $35,117 (prosthetic lab B) Low quote—$29,264 (prosthetic lab C)</td>
</tr>
<tr>
<td>Shower leg (R. Meier, MD, and an unnamed CP)</td>
<td>57/2009</td>
<td>Every 5 years for lifetime</td>
<td>High—$9215 (prosthetic lab A) Low—$7680 (prosthetic lab B)</td>
</tr>
<tr>
<td>Sports prosthesis for wind boarding (R. Meier, MD, and an unnamed CP)</td>
<td>59/2011</td>
<td>Replace every 3 years until age 65 years</td>
<td>High—$27,430 (prosthetic lab A) Low—$22,858 (prosthetic lab B)</td>
</tr>
</tbody>
</table>
**Clothing allowance**

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Year Purchased</th>
<th>Frequency/Duration</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clothing allowance for excessive wear and tear on clothing imposed by prosthetic leg wearing (R. Meier, MD)</td>
<td>57/2009</td>
<td>1x year allowance</td>
<td>$716 per year per VA clothing allowance, <a href="http://www.vba.va.gov/BLN/21/Rates/special1.htm">www.vba.va.gov/BLN/21/Rates/special1.htm</a></td>
</tr>
</tbody>
</table>

### Home Furnishings and Accessories

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Year Purchased</th>
<th>Frequency/Duration</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shower grab bars for safety and ease of function using the tub shower (R. Meier, MD)</td>
<td>57/2009</td>
<td>Every 10 years</td>
<td>$400 installed</td>
</tr>
<tr>
<td>Wheelchair ramps to ingress and egress between the garage and the interior of his home using ADA code standards for pitch of ramp (R. Meier, MD, and local contractor)</td>
<td>57/2009</td>
<td>1x only</td>
<td>$750</td>
</tr>
</tbody>
</table>

### Drug/Supply Needs

Drug and supply needs and costs are representative of the client’s current need and may change from time to time.

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Purpose</th>
<th>Cost per Unit</th>
<th>Cost per Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>No medication taken in relationship to amputation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Insulin (endocrinologist)</td>
<td>To control blood sugar that is elevated secondary to diabetes mellitus</td>
<td>No cost included</td>
<td>No cost included</td>
</tr>
</tbody>
</table>

(Continued)
### Home/Facility Care

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Initiated/Suspended</th>
<th>Hours/Shifts/Days</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attendant service for meal preparation, bathing and hygiene assistance—no health care training necessary (R. Meier, MD)</td>
<td>65 years to lifetime</td>
<td>4 hours per day, 7 days per week</td>
<td>$15–$20 per hour (avg.) for CNA level of attendant service. Note: Cost of attendant may be reduced if negotiated with home health agency for long-term contract, through private hire, or if family members provide some or all of the care. Differences in hourly rate also may be due to geographic differences. Be sure to survey local area where the client lives.</td>
</tr>
<tr>
<td>Home maintenance and painting for routine home maintenance and painting every 5 years (R. Meier, MD)</td>
<td>57/2009 to lifetime</td>
<td>2 hours per week</td>
<td>$20 per hour</td>
</tr>
<tr>
<td>Yard work for lawn mowing, weeding, raking, fertilizing, and snow removal that occurs over 12 months of the year (R. Meier, MD)</td>
<td>57/2009 to lifetime</td>
<td>3 hours per week for 7 months during the growing season and then 1 hour per week for the 5 winter months</td>
<td>$20 per hour</td>
</tr>
</tbody>
</table>

### Transportation

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Year Purchased</th>
<th>Frequency/Duration</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vehicle with automatic transmission for general transportation (R. Meier, MD)</td>
<td>57/2009</td>
<td>Every 7 years</td>
<td>Generally, an additional $800 above the cost of a standard transmission. Some vehicles with automatic transmission are considered standard and bear no additional cost above that of manual transmission.</td>
</tr>
</tbody>
</table>
Motorcycle for recreation (R. Meier, MD, and Adaptive Automotive) 57/2009 Every 7 years Cost of modification related to amputation

Health and Strength Maintenance (Leisure Time Activities)

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Year of Purchase</th>
<th>Frequency/Duration</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aerobic conditioning program for the remainder of his life (R. Meier, MD)</td>
<td>57/2009</td>
<td>Annual membership for club or every 5 years for exercise equipment</td>
<td>Range $500–$1800/year for YMCA, health club, or home exercise equipment</td>
</tr>
<tr>
<td>ACA membership with InMotion magazine subscription (R. Meier, MD)</td>
<td>57/2009</td>
<td>Annual membership</td>
<td>$30 per year</td>
</tr>
</tbody>
</table>

Architectural Considerations

The client requires some architectural changes to his existing home that include replacing the banister to the second floor so he can grasp it for safety reasons when going up and down the flight of stairs, the countertop in his bathroom should be raised about 6 inches to provide better standing posture, a ramp should be permanently installed from the garage into the kitchen, the master bathroom should have an elevated commode installed with side rails, fire alarm, and smoke detectors installed, and shower rails/grab bars in bathroom. All of these items should cost $5000.

When the client reaches approximately 70 years of age, he will require further architectural changes to his existing home in order for him to function using both floors of his home. The following figures were provided by Goldwal Construction in Vancouver, WA:

- Kitchen $35,781
- Bath $25,558
- Interior doorway modifications $5725
- Exterior doorway and ramping modifications $15,335
- Stair glide for access to the second floor of the existing home $8500

Vocational/Educational Plan

Deferred to vocational expert.

Future Medical Care, Surgical Intervention, Aggressive Treatment

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Year Initiated/Suspended</th>
<th>Frequency</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Revision of current above-knee amputation stump (R. Meier, MD)</td>
<td>59/2011</td>
<td>1x only</td>
<td>Surgeon: $3000 Hospital: $17,000 Anesthesiology: $630 Total: $20,630</td>
</tr>
</tbody>
</table>

(Continued)
(Continued)

<table>
<thead>
<tr>
<th>Potential Complications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Potential complications are included for information only.</td>
</tr>
<tr>
<td>No frequency or duration of complications is available.</td>
</tr>
</tbody>
</table>

- Low back pain at age 65 years. See prior recommendations for orthopedic surgeon visits and MRI evaluations.
- Degenerative changes in the right hip, foot, and ankle from more than usual stress and strain imposed on the remaining foot due to the amputation of the opposite leg that also is compounded by having diabetes and its long-term consequences.
- Musculoskeletal problems including altered gait, back problems, and back pain related to abnormal gait, osteoarthritis, neuromas, heterotopic ossification, myositis ossificans, or bone spurs on stump, all of which may become significant and require additional diagnostic tests, treatment, or more surgery than projected. At risk for overuse syndrome of upper extremities (shoulders and wrists) related to crutch use and manual wheelchair propulsion over time that may require additional diagnostic tests for upper extremities (EMGs, nerve conduction tests, X-rays, etc.) or splints and/or other treatment if complications occur.
- Psychological problems related to adjustment to disability including self-esteem, self-image, self-confidence, difficulty with relationships, reduced functional abilities, adjustment to permanency of disability, depression, etc.
- Increased risk for falls and reinjury due to impaired physical/mobility skills and increased fatigue associated with AK prosthesis use.
- Weight changes including significant gain, loss, stump shrinkage, or atrophy, which affect prosthesis fit and require more frequent replacements or adjustments than expected.
- More extensive or expensive medical care and equipment than expected due to expected reduced function and physical decline as one ages. Failure to maintain prosthesis or do proper skin care can result in increased prosthesis maintenance costs or more frequent replacement than expected. Stability and durability of prosthesis also can affect functional abilities and long-term outcomes. Additionally, pain may increase as one ages due to prolonged prosthesis use such that daily prescription of nonsteroidal anti-inflammatory medications may be needed.
- Skin breakdown on stump due to prosthesis use may result in additional treatment or surgery.
- Excessive sweating that affects fit of prosthesis, requiring medical treatment and possible medication.
- Vascular compromise or other vascular or circulatory issues related to AK amputation.

**Conclusion**

The physiatrist should play a valuable role in assisting in the development of the life care plan for the person who has sustained an amputation. An emphasis should be placed on the amputee achieving the ideal level of function with an appropriate rehabilitation program. Just providing a
prosthesis is not the same as providing an integrated rehabilitation program that includes a prosthesis. The emphasis should be placed on the needs and desires of the person with amputation. Measuring the functional outcome, the success of community reintegration, and the individual’s emotional adaptation to the changes are important in developing an accurate life care plan. The physiatrist should serve as an invaluable collaborator with the life care planner in order to develop the most accurate and comprehensive life care plan.

References
Chapter 13

Life Care Planning for Acquired Brain Injury

David L. Ripley and Roger O. Weed

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Introduction

Traumatic brain injury (TBI) is one of the leading causes of neurological impairment in the United States and in 2004 accounted for over 1.4 million visits to the emergency room each year with 50,000 deaths, 235,000 admissions to the hospital, and 1.1 million being treated and released (Centers for Disease Control, 2008a). Further, the Centers for Disease Control (CDC) in 2008 estimated that approximately 5.3 million Americans have a lifelong need for care. Acquired brain injury (ABI) is the leading cause of neurological impairment for individuals between the ages of 16 and 30 years of age. ABI technically includes brain injury as a result of cerebrovascular disease (or stroke), but for the purposes of this chapter, the focus will predominately be on brain injury of traumatic etiology (Kraus et al., 1984).

Creating an appropriate life care plan for an individual with ABI can be a formidable challenge. The brain, as the neurological control center for the body, affects almost every aspect of physiological functioning. Injury to the brain therefore can affect almost every function (Rosenthal, 1990; Kraus, 1991; Kaufman et al., 1993; Macciocchi et al., 1993; Piek, 1995). Practitioners in the field of brain injury rehabilitation must be prepared to deal with problems in essentially every organ system in the body, as well as a variety of cognitive and behavioral problems (Wood, 1987; Uomoto & Brockway, 1992).

Because the majority of people who sustain a brain injury are young at the time of their injury, in the time of their lives when career goals are being set and established, it is difficult in many circumstances to estimate lifetime earning capacity and needs (Wehman et al., 1988; Stapleton et al., 1989; Corthell, 1993; Dikmen et al., 1994; Goodall et al., 1994; Ip et al., 1995; Horn & Zasler, 1996; Zasler, 1997). Additionally, as acute trauma management and medical and rehabilitation care improve, the survival of patients with these injuries continues to increase (High et al., 1996; Kreutzer et al., 2001). The result is that many more people survive with increasingly complex medical and rehabilitation problems (Centers for Disease Control, 2008). Due to the variability in recovery following TBI, life care planners are often forced to develop, in a sense, multiple care plans to accommodate the different potential outcomes that may occur in a single individual.

Definitions

Due to a variety of descriptions used by medical professionals throughout the years, and the problems this caused with communication, the American Congress of Rehabilitation Medicine (ACRM) in 1993 proposed a uniform nomenclature for brain injury. The following definitions are part of the ACRM’s recommendations (American Congress of Rehabilitation Medicine Head Injury Interdisciplinary Special Interest Group, 1993):
- **Acquired brain injury**: Injury to the brain that occurs after the brain has developed; may be due to trauma, surgery, intracranial bleeding, ischemia, or tumor.
- **Traumatic brain injury**: Injury to the brain caused by trauma. One form of acquired brain injury.
- **Coma**: Specific diagnostic term indicating lack of arousability, including loss of sleep–wake cycles on EEG, and lack of meaningful interaction/response to the environment.
- **Vegetative state**: Patients who have no meaningful response to the environment after their eyes are open.
- **Persistent vegetative state**: A vegetative state that persists longer than 3 months, or 1 year if due to trauma.
- **Locked-in syndrome**: A condition in which patients are awake, capable of communication, aware of their environment, but unable to move or speak.
- **Minimally responsive**: Patients who are no longer comatose or vegetative but remain severely disabled (used for patients who are demonstrating inconsistent responses to stimuli yet have some meaningful interaction with the environment).

**Epidemiology**

As noted previously, it is estimated that approximately 1.4 million TBIs occur in the United States each year. Also, as noted in 2005, there were an estimated 235,000 hospitalizations for a primary diagnosis of TBI. The U.S. Centers for Disease Control and Prevention (2008a) have determined that the annual combined total incidence for TBI is estimated to be 102 cases per 100,000 people. It is useful to break down the incidence of TBI based on injury severity. Various methods of rating injury severity are used and will be discussed later in the chapter. However, the incidence when breaking down by injury severity is 14 per 100,000 for severe TBI, 15 per 100,000 for moderate TBI, and 131 per 100,000 for mild TBI.

There are several factors associated with a higher risk for TBI. Males are more than twice as likely as females to sustain a TBI (CDC, 2008b). Additionally, patients with brain injury tend to be from lower socioeconomic groups, have a history of substance use or abuse, and have a history of engaging in risky behaviors. Additionally, brain-injured patients are more likely to live in an urban area. Alcohol is frequently involved in accidents resulting in brain injury and is considered to be the most common preventable cause of TBI. Education about safety, such as wearing seatbelts and bicycle helmets, and not driving while intoxicated, seems to have contributed to a slight decline in the incidence of hospitalization following TBI in recent years.

Brain injury generally follows a bimodal distribution with respect to age. The largest peak is in late adolescence and early adulthood, when individuals are more likely to engage in high-risk activities. The later peak begins for individuals older than age 65, when falls become more common. Because the largest peak occurrence is in the period of time from late adolescence to early adulthood, life care planning for this group is particularly challenging, as lifelong concerns must be taken into consideration, including aging and aging issues, education, vocational rehabilitation, and community reintegration. Age may also be correlated with outcomes, as older individuals (over age 65) tend to have a slower recovery following brain injury.

**Costs**

The costs associated with treating TBI are estimated to be $48.3 billion annually. Costs associated with hospitalization were estimated to be $60 billion in 2000, the most current data available...
Life Care Planning and Case Management Handbook

(Finkelstein, Corso, Miller, & Associates, 2006, as cited by the CDC, 2008a; Brown, Elovic, Kothari, Flanagan, & Kwasnica, 2008).

Review of model systems data for 2007 reveals that the average cost for inpatient treatment of a case of TBI was approximately $154,000 (Traumatic Brain Injury Model Systems, 2008). This estimate was based on the cost for acute hospital care and acute inpatient rehabilitation and does not include rehabilitation efforts (which were reported to be an additional $56,901 after the patient has left the hospital); it also does not include physicians’ fees.

Etiology

ABI of nontraumatic etiology may include cerebrovascular accidents (stroke), bleeding within the brain, infections, tumors, or surgery. A cerebrovascular accident (CVA), commonly called a stroke or a brain attack, usually occurs as a result of thromboembolic phenomenon, usually as a result of vascular disease. A thrombus is a clot of fibrin, platelets, and blood cells that can form on the inner lining of blood vessels. This thrombus may embolize, or travel from the location where it was formed to another area, where it can become lodged, blocking blood flow. Nontraumatic ABIs may also occur as a result of lack of oxygen getting to the brain due to problems with the lungs, heart, or bleeding. Some ABIs are due to hemorrhage within the brain due to vascular disease or aneurysms that have ruptured. Another significant cause of ABI is due to tumors, both benign and malignant. Additionally, injury to the brain may occur as sequelae from intracranial surgery.

Traumatic brain injuries can occur as a result of trauma from a number of causes. The most frequent cause is from motor vehicle accidents, accounting for almost two-thirds of all injuries. The second most frequent cause is falls. Falls are the most common cause of TBI in the elderly and very young. Assaults are the third most common cause overall, and in urban areas, assaults may actually be a greater cause than falls. Other less common causes of TBI include sports and recreational injuries, work-related injuries, and miscellaneous injuries, such as being struck by falling objects. At least half of all traumatic brain injuries involve alcohol consumption in one way or another, and alcohol represents the single most preventable cause of TBI in the United States (CDC 2008b; Traumatic Brain Injury Model Systems, 2008).

Anatomy of the Brain

Coverings

The brain is protected by a number of layers of differing tissue. A layer of skin is the outermost covering, followed by a layer of connective tissue and muscle. The bony calvarium, or skull, provides the greatest protection of the brain. Fractures of the skull are present in a number of brain injuries and are generally associated with a more severe injury. Under the skull are three distinct layers that provide the direct cover of the brain. The outermost, thickest layer is called the dura mater and is attached to the inner layer of the skull in many places. Underneath this layer is the arachnoid mater, which derives its name from its similarity in appearance to a spider web. The arachnoid mater follows the surface of the brain closely, but does not follow the surface down deep into the crevices, or sulci, on the surface of the brain. The innermost layer of covering is called the pia mater, and this layer does follow the brain into the sulci.

Cerebral Cortex

The outer surface of the brain is called the cerebral cortex. There are many convolutions of the surface of the brain, which serve to increase the surface area of the outside of the brain. The bulges
Gyri and sulci

Are referred to as gyri, and the involutions are referred to as sulci. The origination of neural messages to the rest of the body, for the most part, occurs on the surface of the brain. In most cases, seizure activity also originates at the level of the cortex.

The cortex of the brain is divided into lobes (see Figure 13.1) that represent areas of specific functioning. The frontal lobe is responsible for higher cognitive processes, such as planning, organization, and problem solving. It is also the part of the brain responsible for control of impulsive...
and instinctual behavior (Grafman et al., 1996). Lastly, the origination of motor activity occurs in the most posterior portion of the frontal lobe.

The parietal lobe is predominately concerned with the registration of sensory information, particularly the ability to sense when something has touched the skin. Other types of sensory information are processed in this area, and the parietal lobe gives us the ability to orient objects in space, follow a map, and appreciate music. Individuals with injury to the parietal lobe will often exhibit neglect, or lack of awareness of part of their own body.

The temporal lobes are located on the sides of the brain. These lobes are critical in the registration of auditory information and are critical in the understanding and formulation of language. The inner portion of the temporal lobes also contains structures that are responsible for memory formation, as well as the origination of emotions. Individuals with seizures most frequently have injury to their temporal lobe.

The occipital lobe is located on the most posterior aspect of the brain. Visual information is registered and processed here. Individuals with injury to this area may have cortical blindness, which is an inability to see because of failure of the brain to recognize the neural signals sent from the eyes.

**Midbrain**

The midbrain (Figure 13.2) contains a number of structures whose predominant activities are to receive signals transmitted from other parts of the brain or from elsewhere in the body, and to modify the signal before transmitting it on to where it ultimately will register. Structures within the midbrain help to control movement, interpret sensory information, and also help with such activities as controlling our level of consciousness. Patients who are comatose or who are in a persistent vegetative state have impaired functioning in the midbrain.

**Brain Stem**

The brain stem (Figure 13.2) is the most inferior portion of the brain and is not always considered a part of the brain at all. However, this part of the brain is critical for basic life-sustaining functions, as it is responsible for regulating breathing and heart rates. Most of the cranial nerves exit here, so the brain stem is intimately involved in the transmission and reception of sensory and motor information of the head, such as tongue movement, facial movement, and sensation. Because all sensory and motor information to and from the body and brain must travel through the brain stem, even a very small area of injury to the brain stem can have devastating effects on the person with the injury.

**Cerebellum**

The cerebellum is an area of the brain that facilitates coordinated motor movements. There are extensive neural pathways between the cerebellum and other areas of the brain concerned with motor movement. Individuals with injury to the cerebellum exhibit ataxia, or lack of control of smooth, coordinated movements. Interestingly, patients with ataxia often have no problems with strength and often have the muscle strength to carry out any activity you ask. However, they lack an ability to control their limbs’ movements, such that it is often difficult or impossible for them to perform basic activities like picking up a glass or walking.
Brain Injury Classification

Brain injuries can be classified by a number of methods (Marshall et al., 1992; Teasdale et al., 1992). ABIs are generally classified as traumatic, anoxic/hypoxic-ischemic, vascular, or other.
Anoxic or hypoxic-ischemic brain injuries occur when areas of the brain do not receive enough oxygen. This is frequently the cause of secondary injury after a traumatic injury, but may also occur independently of trauma. The most frequent cause of hypoxic-ischemic brain injury is secondary to myocardial infarction or heart failure. During resuscitative efforts for a heart attack, the brain may be deprived of oxygen for several minutes. Vascular brain injuries, commonly called strokes, most commonly occur as a result of thromboembolic phenomena. However, other types of vascular brain injuries include aneurysms, arteriovenous malformation, and spontaneous intracranial hemorrhages. Finally, injury to the brain may occur as a result of viral or bacterial infections, metabolic derangements, or tumors.

Traumatic brain injuries, the broadest category of ABI, may be further subdivided a number of ways. One of the most basic methods of subcategorization is to divide them between open or closed. Open injuries are those injuries in which there is disruption of the scalp and skull, creating the possibility that the brain may be contaminated by material from the outside environment. Penetrating brain injuries are a type of open injury, in which a foreign body (such as a bullet) passes through the skull and outer coverings of the brain into the brain tissue itself. Closed head injuries are those in which the skull remains intact and the brain is not exposed to the outside environment, although significant injury may occur from the impact of the brain against the inner part of the skull, or from shearing of axons secondary to rotational forces.

Medical professionals caring for survivors of brain injury will also classify the injuries based on severity. The most common, widely utilized method of classification is the Glasgow Coma Scale, a method that classifies injuries based on clinical presentation (see Table 13.1). A medical professional will rate the patient’s response in three separate areas: eye opening, motor response, and verbal response. The scale gives scores for each of the areas, which are summed to give a total score that can be used to rank the severity of the injury. Individuals who score 3 to 8 are said to have a severe injury, from 9 to 12 a moderate injury, and from 13 to 15 a mild injury. This information may be useful to predict the outcome and likelihood of long-term impairments (Clifton et al., 1993; Zafonte et al., 1996; Teasdale et al., 1998).

Another broad categorization of brain injury is to divide between diffuse and focal brain injuries. Diffuse injuries are generally due to shearing injury of the axons and generally occur across a broad area of the brain. Focal injuries occur with trauma to one specific region of the brain. These two types of injury may occur concomitantly. In general, focal injuries result in shorter periods of unconsciousness than diffuse injuries. Individuals with diffuse injury, sometimes referred to as diffuse axonal injury (DAI), may have prolonged periods of unconsciousness from several days to weeks. In general, individuals with DAI have a prolonged recovery period compared to those with focal injuries (Bontke & Boake, 1991; Berker, 1996).

**Initial Treatment**

When a patient presents to the emergency room following TBI, the initial activities focus on life preservation. Often, concomitant injuries preclude addressing the brain injuries until later in the
Table 13.1 The Glasgow Coma Scale

<table>
<thead>
<tr>
<th>Patient’s Response</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Eye opening</strong></td>
<td></td>
</tr>
<tr>
<td>Spontaneously</td>
<td>4</td>
</tr>
<tr>
<td>To voice</td>
<td>3</td>
</tr>
<tr>
<td>To painful stimulus</td>
<td>2</td>
</tr>
<tr>
<td>No eye opening</td>
<td>1</td>
</tr>
<tr>
<td><strong>Motor</strong></td>
<td></td>
</tr>
<tr>
<td>Follows commands</td>
<td>6</td>
</tr>
<tr>
<td>Localizes to pain</td>
<td>5</td>
</tr>
<tr>
<td>Withdraws from pain</td>
<td>4</td>
</tr>
<tr>
<td>Flexor response</td>
<td>3</td>
</tr>
<tr>
<td>Extensor response</td>
<td>2</td>
</tr>
<tr>
<td>No motor response</td>
<td>1</td>
</tr>
<tr>
<td><strong>Verbal</strong></td>
<td></td>
</tr>
<tr>
<td>Oriented</td>
<td>5</td>
</tr>
<tr>
<td>Converses but disoriented</td>
<td>4</td>
</tr>
<tr>
<td>Inappropriate words</td>
<td>3</td>
</tr>
<tr>
<td>Incomprehensible verbal utterances</td>
<td>2</td>
</tr>
<tr>
<td>Not vocalizing</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
</tr>
<tr>
<td>(Sum of score from each of three areas)</td>
<td>(3–15)</td>
</tr>
</tbody>
</table>

Injury classification:

- Severe: 3–8
- Moderate: 9–12
- Mild: 13–15

*Note:* A score with a T (e.g., 8T) means the patient was intubated for airway purposes and may be unable to fully respond.

course of treatment. However, for those patients with severe injuries, the initial protocols involve rating the patient’s level of arousal using the Glasgow Coma Scale, and some form of neuroradiographic imaging. At this time, CT scan remains the preferred type of image, due to the relatively faster speed with which images can be obtained and the fact that the types of injury that require emergency surgical intervention show much more readily on CT than MRI. However, there is some discussion about whether newer MRI techniques are more sensitive to intracranial injury.
Once the patient is stabilized, a more detailed assessment of the injury will occur, and further treatment may be recommended. For severe injuries, assessment by a neurosurgeon will usually occur. If there is evidence of specific, severe types of bleeding or increased pressure inside the head, surgery will be performed to evacuate the blood or alleviate the pressure. Sometimes an intracranial pressure monitor will be placed to accurately measure the pressure inside the brain.

Patients frequently require assistance with basic life functions. They may be placed on a mechanical ventilator to help them breathe. For prolonged management, sometimes a tracheotomy is performed to facilitate prolonged ventilator support. Additionally, for patients that are unconscious for prolonged periods of time, a feeding tube may be surgically introduced. Many patients with severe injury will also sustain injuries to other parts of their body as well. Surgical attention is often necessary during the early hospitalization to address fractures, damaged internal organs, internal bleeding, and other medical concerns.

**Initial Rehabilitation Care**

While patients are still in the hospital, physical and occupational therapy referrals should occur to maintain joint range of motion and strength and to begin working on activities of self-care. The more severely injured patients should be referred to a rehabilitation facility following their acute hospitalization to begin the work of trying to be restored to their highest level of functioning. An assessment by a physiatrist, a medical doctor with training in physical medicine and rehabilitation (PM&R), is important during this phase to facilitate the coordination of services and medical treatment to promote the best outcome following TBI (Rosenthal, 1990; Almli & Finger, 1992; Bontke et al., 1993; Berker, 1996; Semlyen et al., 1998).

Patients will often require further medical and rehabilitation care after medical issues are stabilized (Cope, 1995). Several different levels of rehabilitation care are possible, and the best appropriate level of care depends on the acuity of the concomitant medical issues as well as the level of functioning of the patient (Evans, 1992; Mazmanian et al., 1993; Hall & Cope, 1995; Schmidt, 1997). Patients who cannot participate or tolerate several hours of therapy each day are most appropriately sent to a subacute rehabilitation program until they can tolerate a more aggressive therapy program. The most common level of rehabilitation care is *acute inpatient rehabilitation*, where patients receive 3 or more hours of therapy a day from several different therapy disciplines (i.e., physical therapy, occupational therapy, speech therapy), as well as ongoing medical attention (Malec & Basford, 1996). Once patients are medically stable and safe to be managed at home, therapy efforts transition to an outpatient setting. *Rehabilitation day programs* are therapy programs designed for individuals who still need therapy from several different disciplines in a team format, but no longer need as close medical attention as individuals in the acute inpatient setting. Some individuals will not need the interdisciplinary model of therapy, but only require therapy from one or two disciplines; then single-service outpatient therapy is indicated.

**Medical Complications**

An adept life care planner who works with survivors of brain injury must be aware of the potential medical complications that arise following brain injury and their impact on recovery,
long-term function, and reintegration in the community. As the brain is the control center for all neurological processes in the body, injury to the brain can result in complications to almost every organ system. It is beyond the scope of this chapter to discuss all complications, although there are several common complications that we will describe (Kraus, 1984, 1991; Corrigan & Mysiw, 1988; Bigler, 1989; Bloomfield, 1989; Russell-Jones & Shorvon, 1989; Uomoto & Brockway, 1992; Bontke et al., 1993; Jore et al., 1993; Katz & Alexander, 1994; Kaufman et al., 1994; Piek, 1995; Cifu et al., 1996a).

**Cranial Complications**

Injury to the cranial nerves frequently occurs following TBI. As a result, patients may have difficulty with basic sensory functions, such as vision, hearing, smell, and taste. Facial paresis is frequently seen, with resultant difficulty in oromotor functions, as in speaking, resultant dizziness, and balance disorders. This by itself may lead to problems with standing, walking, and transfers. It is very common for the olfactory nerve, the cranial nerve that controls sense of smell, to be damaged due to its structure, sometimes resulting in problems with eating and appetite. Fractures of the temporal bone, a part of the skull, can result in disruption of the cranial nerve associated with hearing, resulting in hearing impairment.

Many patients will have significant difficulty with vision problems following brain injury. Problems may range from inability to see objects in certain parts of the field of vision (sometimes referred to as a field cut) to blurry or double vision. This may be due to injury to the visual pathways within the brain, to injury to the nerves that control eye movements, or to injury to the eye itself. An evaluation by a neuro-ophthalmologist, a physician with training in neurological disorders that affect vision, is sometimes very helpful.

**Endocrine Disorders**

Endocrinology is the study of hormones and their function. Many hormones are regulated or secreted by the pituitary gland, a structure at the base of the brain. The pituitary can frequently be damaged during injury to the brain due to its location and structure. Common endocrine disorders following brain injury include syndrome of inappropriate diuretic hormone (SIADH), growth hormone deficiency, and irregularities of gonadal steroid production. Endocrinopathies are much more evident in women, because menstrual irregularities, as a result of altered pituitary-gonadal axis functioning, may persist for a year or longer after brain injury. This may also be a source of problems with infertility following injury.

**Pulmonary Complications**

Patients with severe TBI frequently have respiratory failure as sequelae of the initial trauma. As a result, patients often require mechanical ventilation with a breathing machine (ventilator). Sometimes physicians must perform a tracheotomy, or a surgically created hole, to allow the patient to breathe and to help prevent complications from prolonged ventilator management. Patients who are immobile for prolonged periods of time are at a higher risk for developing pneumonia. A pulmonary embolus, or a blood clot that lodges in the blood vessels of the lungs, is also a potential complication of prolonged immobility.
Cardiovascular Complications

Direct effects of brain injury on the cardiovascular system are infrequent. However, immobility may lead to secondary complications over time. The most common is the formation of deep vein thromboses (DVTs) or blood clots in the veins. These clots can be potentially life threatening, as they can break free and lodge in the lung vessels causing a pulmonary embolus, as noted previously. DVTs may also result in postphlebitic syndrome, or a painful condition of inflammation of the veins. Another complication that may lead to cardiovascular injury is called central storming, in which abnormally high levels of stimulant hormones are released into the bloodstream, resulting in fevers, high heart rates, and high blood pressure. This phenomenon can result in heart injury to people who are susceptible.

Neurological Complications

Typical neurological problems include weakness, sensory deficits, and the previously mentioned cranial nerve problems. Individuals who have had a brain injury are at increased risk for developing seizures. The presence of a penetrating brain injury, skull fracture, or significant amounts of subarachnoid blood increases the risk for seizures. The upper motor neuron syndrome is possibly the most frequently seen neurological complication after all forms of brain injury, with its constellation of symptoms of weakness, spasticity, and increased reflexes. Spasticity is a velocity-dependent increase in motor tone that is seen frequently following injury to motor nerves in the central nervous system. This is such a profound problem after brain injury that it will be discussed in detail later in the chapter. Additionally, cognitive and behavioral problems are frequent neurological complications and will also be discussed in more detail later.

Gastrointestinal Complications

Patients frequently exhibit dysphagia, or impairment in the ability to swallow, as a result of weakness of the pharyngeal muscles. Often, patients require the placement of a feeding tube to prevent aspiration of food and to allow for feeding while the pharyngeal muscles remain weak. Additional gastrointestinal problems may include incontinence secondary to neurological impairment of the muscles controlling bowel function or alternatively from cognitive impairment. Constipation is frequently seen due to the same alteration in neurological functioning of the bladder, or often due to medications.

Genitourinary Complications

Neurological control of the bladder may be impaired, resulting in incontinence. However, most cases of incontinence following brain injury are a result of disinhibition instead of true neurological impairment. Patients with neurological impairment of bladder function may retain urine, which can lead to other problems, including frequent infections of the urinary tract, infection of the kidneys, and renal and bladder stones. Sexual dysfunction may also be an issue, although, again, these problems are predominately behavioral as opposed to physiological impairment of sexual functioning. Frequently, sexual inhibition may occur as a result of altered body image due to impairments such as weakness, spasticity, or changes in physical appearance due to the injury, although more frequently, patients become sexually disinhibited due to injury to the areas of the brain responsible for control of impulsive behavior (Kreuter et al., 1998). Sexual functioning is an area that is
frequently overlooked by medical professionals. In women, infertility may occur secondary to the endocrine changes mentioned earlier.

**Musculoskeletal Complications**

Musculoskeletal complications are very common following brain injury. Injury to the motor nerves in the brain may result in the upper motor neuron syndrome, which consists of the constellation of symptoms of spasticity, weakness, and hyperreflexia. Areas of weakness can vary depending on where the injury is located in the brain. Due to the brain’s structural organization, injury on one side of the brain results in weakness on the opposite side of the body. Additionally, the weak side is frequently associated with spasticity. If unchecked, spasticity and immobility may ultimately result in contractures, which is tightening of the soft tissues and shortening of tendons around a joint resulting in a reduction in the patient’s mobility. As a result of associated trauma, patients with brain injuries also frequently have associated fractures, peripheral nerve injuries, or soft tissue injury that can also make rehabilitation difficult. An interesting musculoskeletal problem that sometimes occurs following TBI is heterotopic ossification, a condition in which bone is formed inappropriately in soft tissue areas. This problem, if left untreated, can result in ankylosis, or fusion of a joint, such that moving it is impossible. Extremity pain may also be a problem, due to inherent injury to the extremity or from neurological damage to the sensory pathways.

**Cognitive Problems**

Injury to the brain can result in any number of changes in mental function, including changes in personality. The specific changes, of course, depend on the specific structures damaged. Very commonly, brain-injured patients experience problems with memory, attention, and arousal, as well as difficulties with language and communication (Seel et al., 1997). Even patients who experience a relatively good recovery will often have subtle cognitive deficits that make returning to work or living independently difficult. A list of potential cognitive problems after TBI can be found in Table 13.2 (Groswasser & Stern, 1998).

**Recovery from TBI**

Recovery from brain injury is a highly variable process. Severely injured patients recover in general along a set of stages, classified as the Rancho Los Amigos Scale of Cognitive Functioning (see Table 13.3). Patients do not always progress through each stage in a stepwise fashion; some

<table>
<thead>
<tr>
<th>Table 13.2 Potential Cognitive Problems after TBI</th>
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<tbody>
<tr>
<td>Apathy</td>
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<tr>
<td>Depression</td>
</tr>
<tr>
<td>Forgetfulness</td>
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<tr>
<td>Anxiety</td>
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<tr>
<td>Anasognosia</td>
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<tr>
<td>Stage</td>
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<tr>
<td>-------</td>
</tr>
<tr>
<td>Level I</td>
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<td>Level II</td>
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<td>Level III</td>
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<td>Level IV</td>
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<td>Level V</td>
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<tr>
<td>Level VI</td>
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<tr>
<td>Level VII</td>
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<tr>
<td>Level VIII</td>
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patients may skip one or more stages. This scale has its greatest usefulness in communicating with other team members about the condition of the patient, although at times it is helpful for family members, particularly when patients are in an agitated state. Some families find it somewhat comforting to know that the agitated state is part of a normal recovery process following TBI.

Most sources indicate that full neurological recovery of the brain following a severe injury takes approximately 1 year. Although this is a good estimate for most patients, there are certainly exceptions, and some patients have demonstrated significant recovery even after 1 year. Researchers are learning more about the process of neuroplasticity and factors affecting better outcomes (Ginsberg et al., 1997; Pike & Hamm, 1997).

### Long-Term Impairments

Impairments following brain injury may include almost any complication imaginable. However, there are certain impairments that occur with such regularity after TBI that they warrant special mention. These impairments are the main issues that cause long-term problems after brain injury. Any life care plan for a patient who is traumatically severely injured should be sure to address these particular issues.

- **Weakness**: Injury to the motor cortex or motor pathways may lead to weakness. Severe enough injury will result in paralysis. Weakness is usually the biggest factor affecting a person’s ability to perform activities of self-care, such as dressing, grooming, and feeding. It

<table>
<thead>
<tr>
<th>Stage</th>
<th>Name</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level IX</td>
<td>Purposeful-appropriate: standby assistance on request</td>
<td>Able to independently shift back and forth between tasks and complete them accurately for at least 2 consecutive hours. Uses memory devices appropriately when reminded; may be able to initiate and carry out steps in familiar household, work, and leisure tasks with assistance when requested. Aware of and acknowledges impairments and disabilities when they interfere with task completion and takes appropriate corrective action with supervision when requested. May continue to have low frustration tolerance, irritability, and depression, but able to monitor social interaction more appropriately with only standby assistance. May be able to think about consequences of actions or decisions when requested.</td>
</tr>
<tr>
<td>Level X</td>
<td>Purposeful-appropriate: modified independent</td>
<td>Able to handle multiple tasks simultaneously in all environments but may require periodic breaks. Able to independently procure, create, and maintain own assistive memory devices. Independently initiates and carries out self-care, household, community, work, and leisure tasks, but may require more time or compensatory strategies to complete them. Able to independently think about the consequences of decisions or actions but may require more than the usual amount of time or compensatory strategies to select the appropriate decision or action. Social interactions are fairly consistently appropriate.</td>
</tr>
</tbody>
</table>
may also impair an individual’s ability to walk and move about and, in extreme cases, may lead to the necessity of assistance with transfers.

- **Spasticity**: Spasticity, defined as “velocity-dependent increase in motor tone,” as mentioned earlier in the chapter, often remains a huge obstacle to independence after a brain injury. Spasticity is manifested clinically as an involuntary “tightening” of the muscles, resulting in difficulty moving a joint through normal range of motion. Spasticity is often associated with weakness and further complicates the patient’s ability to move and perform activities of self-care. Furthermore, severe spasticity places the patient at risk for a number of other complications, such as contractures and skin breakdown. Much of the medical treatment following TBI centers around the prevention and treatment of spasticity. A number of medical interventions in the treatment of spasticity have become available in recent years. Aside from oral medications and therapeutic interventions such as splinting, casting, bracing, and range-of-motion exercises, patients are frequently treated with a variety of injections for spasticity. These may include nerve blocks using ethanol or phenol or, more commonly now, botulinum toxin injections. A newer treatment device, the intrathecal pump, may be surgically implanted to provide a higher concentration of medicine for spasticity directly at the level of the spinal cord, where it is most effective. The advantage to this technique is that it allows greater control over the administration of medicine, while avoiding many of the side effects associated with oral administration of medication. This treatment is not for everyone, however, and should be discussed with the patient’s doctor. Finally, various surgical techniques may be used, usually as last-resort efforts, for treatment of spasticity. These include various tendon-lengthening procedures, rhizotomy, or cordotomy.

- **Behavioral problems**: Although other issues may be more of a focus of medical treatment, it is often behavioral issues that prevent successful community reintegration and return to gainful employment. Patients may have low frustration tolerance, impaired judgment, and, in many cases, emotional lability or frank aggression that hinder successful rehabilitation outcomes. Behavioral problems are usually addressed on a number of levels, including psychological counseling, behavior modification plans, medications, and, in worst cases, inpatient neurobehavioral treatment programs.

- **Cognitive**: Several studies have examined the frequency of patients’ complaints following TBI. The most common complaint in all studies is problems with memory. Areas of the brain associated with memory formation are particularly susceptible to injury following trauma, due to their proximity to bony protuberances inside the skull. Additionally, these structures are particularly susceptible to anoxic injury as well, which can occur secondarily following trauma. Deficits in attention, motivation, and sensory input can also secondarily result in memory problems.

- **Aging**: As noted below in the vocational category, aging with a brain injury can result in a faster than average decline physically as well as cognitively. Reduced physical skills and judgment can also result in additional injury as time passes. Indeed, once a person has experienced a brain injury, he or she is much more likely to have a second injury than people without a brain injury. Also, for some mild to moderately brain-injured clients, social isolation and awareness of deficits eventually erode the hope and optimism that occur while progress is being made, and behavior and emotional problems may rise several years after the original insult. These problems are not as much related to aging as to the passage of time and the slow realization that they will never achieve their preinjury levels and may be unable to enjoy normal social and love relationships (Trudel & Purdum, 1998).
Community Reintegration

Successful return to the community remains a significant challenge given all of the potential barriers a patient may face due to the impairments sustained as a result of the injury (Berens, 2008; Smith-Knapp et al., 1996; Wall et al., 1998). With changes in personality, and behavioral problems, interpersonal relationships often become difficult. Many patients require ongoing supervision for safety reasons, which interferes with social activities. Driving a motor vehicle is a significant concern, and a formal driving evaluation should be performed by a therapist trained to look for the specific problems that may interfere with safe driving.

An additional issue frequently seen is return to recreational activities. A high percentage of brain injury patients engaged in high-risk activities prior to their injury (Chesnut et al., 1993). In fact, it is often engagement in high-risk activities that led to the brain injury in the first place. It is extremely important that individuals protect themselves against a second injury, particularly while the brain is healing. The second impact syndrome, in which a person healing from one injury is exposed to a second injury, may result in exponentially worse or even fatal outcomes, even with a relatively minor second injury. It is therefore extremely important that the patient be restricted from engaging in activities that may place him or her at risk for another injury. A therapeutic recreation specialist may be helpful in identifying and developing appropriate leisure interests after brain injury as well as helping develop techniques to pursue those interests when physical and cognitive impairments make them difficult. In addition, substance abuse may adversely affect recovery and ultimate outcome, further complicating the vocational and life care planning needs (Corrigan, 1995).

Vocational Rehabilitation

Return to gainful employment after brain injury remains a significant challenge (Dikmen et al., 1994; Goodall et al., 1994; Ip et al., 1995; Wehman et al., 1988, 1993; Stapleton et al., 1989; Cifu et al., 1997; Zasler, 1997). Most studies indicate that following a brain injury, approximately one-quarter to one-third of individuals return to work within a 1- to 2-year period following the injury (Traumatic Brain Injury National Data and Statistical Center, 2004). Even with milder brain injuries, work-related issues often become the major problem due to significant problems with interpersonal relationships and behavioral changes (Baker, 1990; Chwalisz, 1992; DePompeo & Williams, 1994). Most TBIs occur in individuals between the ages of 16 and 30, a time in most people’s lives when education is being completed and career goals established. For those who have completed their education, the cognitive problems often prohibit the use of previously gained knowledge. Additionally, memory problems may make further education or training impossible, in the worst cases.

It is strongly recommended that individuals undergo a neuropsychological evaluation to determine their capacity for education and work (Weed, 1996, 1998; Macciochi et al., 1998). A proper, thorough neuropsychological evaluation will give information about how the patient learns and processes information, and will help the vocational rehabilitation counselor in establishing appropriate return-to-work goals (also see Table 13.4 for a checklist of questions to the neuropsychologist, which, although also included in the vocational chapter of this book, appears relevant enough to include in this chapter). Many clients, in fact, are unable to return to competitive employment due to their impairments, or need significant support and assistance to do so. Many patients have no difficulty obtaining employment, but have a great deal of trouble maintaining employment.
Research regarding employment suggests that the most difficult to place long term are people with mental illness and brain injury.

In order to adequately assess the vocational and life planning needs of a person with a brain injury, it is recommended that, as clinical judgment dictates, other allied health professionals be considered. The occupational therapist may be an appropriate referral for an assessment for seating and positioning, adaptive aids, and other vocationally related issues. For some clients, activities of daily living training, including household safety, would be included. The speech and language pathologist will be instrumental in determining augmentative communications and assistive technology for clients with more severe injuries, as well as in providing an assessment of receptive and expressive speech and language. They also often offer cognitive remediation strategies. A physical

<table>
<thead>
<tr>
<th>Table 13.4  Neuropsychologist Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>In addition to the standard evaluation report, add the following as appropriate:</td>
</tr>
<tr>
<td>1. Please describe, in layman terms, the injury to the brain.</td>
</tr>
<tr>
<td>2. Please describe the effects of the accident on the client’s ability to function.</td>
</tr>
<tr>
<td>3. Please provide an opinion to the following topics:</td>
</tr>
<tr>
<td>a. Intelligence level? (include pre- vs. postincident if able)</td>
</tr>
<tr>
<td>b. Personality style with regard to the workplace and home?</td>
</tr>
<tr>
<td>c. Stamina level?</td>
</tr>
<tr>
<td>d. Functional limitations and assets?</td>
</tr>
<tr>
<td>e. Ability for education/training?</td>
</tr>
<tr>
<td>f. Vocational implications—style of learning?</td>
</tr>
<tr>
<td>g. Level of insight into present functioning?</td>
</tr>
<tr>
<td>h. Ability to compensate for deficits?</td>
</tr>
<tr>
<td>i. Ability to initiate action?</td>
</tr>
<tr>
<td>j. Memory impairments? (short-term, long-term, auditory, visual, etc.)</td>
</tr>
<tr>
<td>k. Ability to identify and correct errors?</td>
</tr>
<tr>
<td>l. Recommendations for compensation strategies?</td>
</tr>
<tr>
<td>m. Need for companion or attendant care?</td>
</tr>
<tr>
<td>4. What is the proposed treatment plan?</td>
</tr>
<tr>
<td>a. Counseling? (individual and family)</td>
</tr>
<tr>
<td>b. Cognitive therapy?</td>
</tr>
<tr>
<td>c. Reevaluations?</td>
</tr>
<tr>
<td>d. Referral to others? (e.g., physicians)</td>
</tr>
<tr>
<td>e. Other?</td>
</tr>
<tr>
<td>5. How much and how long? (include cost per session or hour and reevaluations)</td>
</tr>
</tbody>
</table>

Source: Roger O. Weed, with acknowledgment to Robert Frasier for some content.
therapist is often the most appropriate referral to determine the client’s true physical capabilities by compiling a functional capacity assessment (or physical capacity assessment) that is more detailed than most physicians can report. For the young adult or pediatric case, an educational consultant can be very important to maximize the client’s educational potential. Under the Individuals with Disabilities Education Act (IDEA), the public school system is responsible for providing specialized services to children with disabilities. However, many of these clients are unserved for a variety of reasons. One reason is that the client has not been adequately assessed in order to identify deficits that would meet the criteria for specialized education. Another reason is that the client may meet the definition, but the school’s funding is inadequate and the school will fail to provide appropriate support. Educational consultants who are familiar with the rules often can negotiate the appropriate education protocol.

Several methods of vocational assistance have been developed, including sheltered workshops and supported employment. The supported employment model involves a job coach who spends time with the patient at the worksite and assists with training the patient for the job, accommodations of the workspace if necessary, and helping with problems that may occur if needed. Much of the support involves educating the employer about the nature of brain injury (McMahon & Shaw, 1991; Wehman et al., 1993).

In addition, the effects of aging with a brain injury may affect work life expectancy (Weed, 1998). Data reveal that many clients with a brain injury cognitively or physically deteriorate at a faster rate and appear years older than their chronological age; it is not uncommon for clients to depart from work (i.e., retire early) at an age younger than that of most able-bodied workers. Reduced physical skills from the initial injury mean the person has less of a reserve than the average person, so as he or she ages, he or she may reach the threshold of dependence at an earlier age. There also may be an increased risk of Alzheimer’s disease at an earlier age, leading to loss of independence earlier than with the average person (Chandra et al., 1989; Gedye et al., 1989; Rosenthal, 1990; Cifu et al., 1996b; Thompson et al., 1997). For example, it may be appropriate to phase out work and phase in a day program or volunteer activities by the time the client is in his or her fifties. The decline in work life can also be a result of moving from full-time to part-time work as well as earlier retirement.

Case Study
A 32-year-old client was riding a motorcycle that was hit by a car. At the time of the interview, 3 years postinjury, he stated that he did not remember the incident or anything a couple of weeks prior to the incident. Following the incident, his first consistent memory is approximately 2 to 3 months later. He was treated for 2 months in an acute care hospital and then for 5 months in a brain injury rehabilitation hospital. The client was diagnosed with severe TBI with physical and cognitive deficits, including ventriculoperitoneal shunt and orthopedic injuries requiring extensive care.

Neuropsychological testing results concluded that the client had sustained a very severe TBI. Testing revealed reduced intellectual capacity of one standard deviation, perhaps slightly more, below preinjury levels. His primary deficit is in visual/motor problem solving. He is able to sight read beyond a high school level. He has significant deficits in mathematical calculations, with overall performance at a level much lower than expected given his preinjury educational level. No anomia was noted, and he is able to mildly retrieve words without perseveration or intrusive errors. He has
significant difficulty with fine motor coordination, with reduced range in the left upper extremity. He has significantly improved executive function from prior testing, which is the most promising part of the overall evaluation, although he continues to exhibit occasions of temper outbursts. He has moderately to severely impaired short-term memory, especially with verbal short-term memory given the absence of consolidation of information. He has a positive affect, although he has times of unhappiness/frustration, and is basically functioning in a more adaptive manner.

He has a young daughter and must be supervised when with her. His wife is supportive and has quit work to be his caregiver. He must have someone available for assistance with judgment, safety, food preparation, and financial commitments. Work is not a reasonable goal, although volunteer activities part-time would be therapeutic.

<table>
<thead>
<tr>
<th>LIFE CARE PLAN</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Note:</strong> For purposes of this plan, the following initials are placed in parentheses according to their respective recommendations:</td>
</tr>
<tr>
<td>JP = Jeffrey Preston, MD, physiatrist</td>
</tr>
<tr>
<td>MC = Michael Cathy, MD, psychiatrist</td>
</tr>
<tr>
<td>RH = Robert Hampton, MD, ophthalmologist</td>
</tr>
<tr>
<td>IR = Ian Raston, MD, hand surgeon</td>
</tr>
<tr>
<td>WW = William White, MD, internist</td>
</tr>
<tr>
<td>AP = Amy Passy, PT, physical therapist</td>
</tr>
<tr>
<td>JH = John Hurry, PsyD, neuropsychologist</td>
</tr>
<tr>
<td>RW = Roger Weed, PhD, life care planner</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Routine Future Medical Care—Physician Only</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Recommendation (by whom)</strong></td>
</tr>
<tr>
<td>-----------------------------------------</td>
</tr>
<tr>
<td>Physiatrist (JP) X-rays: left hip, knee, or shoulder (JP)</td>
</tr>
<tr>
<td>Head CT scan (JP) Head MRI (JP) EEG (JP)</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
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<tr>
<td></td>
</tr>
</tbody>
</table>

**Note 1:** Cost for physiatrist does not include one-time new patient evaluation at $100 to $150 required by one physiatrist.

**Note 2:** Costs for x-rays, CT scan, MRI, and EEG include both diagnostic study and physician interpretation fee. Cost range for MRI depends on whether the study is done with or without contrast. If done with contrast, an additional fee for the contrast dye will incur.
<table>
<thead>
<tr>
<th>Neurologist (JP)</th>
<th>2 times/year to life expectancy</th>
<th>Monitor neurological status</th>
<th>$148–460/year at $74–115/visit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Orthopedic surgeon (JP)</td>
<td>2 times/year to life expectancy</td>
<td>Monitor orthopedic status and development of expected degenerative joint disease</td>
<td>New patient: $180, 1 time only Follow-up: $120–160/year to life at $60–80/visit</td>
</tr>
<tr>
<td>Note: See also expected future left knee and hip replacement surgery recommended by Dr. Preston.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neuro-ophthalmologist (RH)</td>
<td>2 times/year to life expectancy</td>
<td>Monitor visual impairments</td>
<td>$160/year at $80/visit</td>
</tr>
<tr>
<td>Note: Economist to deduct cost of routine ophthalmology or optometry follow-up since it is recommended for the general population.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychiatrist (MC)</td>
<td>4–6 times/year for 2–3 years, then 2–3 times/year to life expectancy</td>
<td>Medication management</td>
<td>$288–432/year for 2–3 years, then $144–216/year to life at 72/visit</td>
</tr>
<tr>
<td>Hand surgeon (IR)</td>
<td>1 time/year to life expectancy</td>
<td>Monitor left-hand problems related to neurological disorder</td>
<td>$60/year to life expectancy</td>
</tr>
<tr>
<td>Internist (WW)</td>
<td>4 times/year to life expectancy</td>
<td>General medical care and treatment</td>
<td>$424/year at $106/visit</td>
</tr>
<tr>
<td>Note: The internist reports the client is expected to require more frequent visits and at a higher level per visit than typically expected of the general population. Visits included in the plan are over and above recommendations for the general population.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Note: The client also may need evaluation and follow-up by specialists, including neurosurgeon, urologist, and others as needed depending on complications and at the discretion of his treating physicians. See also Potential Complications.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Projected Evaluations—Nonphysician**  
(Include all allied health evaluations)

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Dates</th>
<th>Frequency/Duration</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical therapy evaluation to assess gait changes (JP)</td>
<td>2001 to life expectancy</td>
<td>1 time/year to life expectancy</td>
<td>$200–250/year to life expectancy</td>
</tr>
<tr>
<td>Note 1: According to the records, the client was discharged from physical therapy in April 2001 and transitioned to a home exercise program. The therapist recommended physical therapy reevaluation in 3 to 4 months to determine maintenance of his function and carryover of skills.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Note 2: See also Health and Strength Maintenance for ongoing fitness program.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational therapy evaluation to evaluate for and monitor adaptive equipment needs (JP)</td>
<td>2001 to life expectancy</td>
<td>1 time/year to life expectancy</td>
<td>$300–350/year to life expectancy</td>
</tr>
</tbody>
</table>

(Continued)
(Continued)

**Note:** According to the physiatrist, speech therapy does not appear to be indicated for the client and no recommendations are made for yearly speech evaluations or therapy to monitor his status and provide recommendations depending on needs.

<table>
<thead>
<tr>
<th>Home accessibility evaluation by qualified occupational therapist (RW)</th>
<th>2001</th>
<th>1 time only</th>
<th>$200 (average) for in-home occupational therapy evaluation with recommendations</th>
</tr>
</thead>
</table>

**Note:** Although the client’s home generally appears appropriate for him at this time, a home accessibility evaluation is reasonable and appropriate to evaluate the home and make recommendations for additional modifications to ensure the client maintains his highest level of independence and function in his home, especially given an expected further decline in physical functioning as he ages.

### Projected Therapeutic Modalities

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Year Initiated</th>
<th>Frequency/Duration</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical therapy to develop, monitor, and supervise fitness program and home exercise program (JP)</td>
<td>2001</td>
<td>4 times/year to life expectancy</td>
<td>$988/year to life for four 1-hour sessions/year at $247/session</td>
</tr>
</tbody>
</table>

**Note:** See also Health and Strength Maintenance for ongoing fitness program.

| Neuropsychologist consultation for coping strategies, adjustment issues, cognitive remediation, and behavior management strategies (JH) | 2001 | 4–6 times/year to life expectancy | $392–840/year to life at $98–140 (depends on length of visit) |

**Note 1:** It is likely the client also will need counseling episodically throughout his lifetime, especially during transitional times in his life (i.e., mid-30s, middle age, elderly, etc.), as well as during life-changing events that may occur (i.e., birth of second child, expected in January 2004, etc.). Frequency and duration of counseling are unknown, and no additional cost is included in plan totals.

**Note 2:** The client’s wife/family also may need counseling as needed throughout their life expectancy depending on circumstances. The neuropsychologist states he is available to the client and wife as needed, typically for telephonic intervention related to various issues/questions that arise, at no additional cost to the client. The physiatrist also states the client’s family/wife may need counseling intervention at some time in the future.

| Case manager experienced in working with clients with a brain injury to problem solve, coordinate care, client advocate, etc. (RW) | 2001 | 2 hours/month (average) to life expectancy | $1800–2136/year (average) to life expectancy at $75–89/hour (does not include mileage to appointments and to meet with client) |

---
Financial planner/consultant (JH) | 2001 to life expectancy | 2 hours/month (average) | $1920–2400/year (average) to life expectancy at $80–100/hour (estimate)

**Note:** The client requires assistance and oversight with legal and business contracts, budgeting, financial planning, major decision making, and other money management decisions. Although his wife currently performs these activities, it is recommended a financial consultant, independent from the family, be utilized.

### Diagnostic Testing/Educational Assessment

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Year Initiated</th>
<th>Frequency/Duration</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neuropsychology evaluations (JH)</td>
<td>2020–2025 (50–55 years of age), then repeat 5 years later</td>
<td>2 times over course of lifetime</td>
<td>$1200–1600 total at $600–800/evaluation</td>
</tr>
</tbody>
</table>

### Wheeled Mobility Needs, Accessories, and Maintenance

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Year Purchased</th>
<th>Replacement Schedule</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Power scooter (JP) Scooter maintenance (RW)</td>
<td>2001 to life expectancy 2002</td>
<td>Scooter: Every 5 years (average) Batteries: 1 time/year (average) to life expectancy 1 time/year after warranty expires</td>
<td>Scooter: $2700–2900 every 5 years average Batteries (2): $180/year at $89.95 each Maintenance: $100/year (average estimate)</td>
</tr>
</tbody>
</table>

**Note 1:** The physiatrist recommends a power scooter for prolonged mobility assistance and extended outings in the community. See also scooter lift for vehicle in the following sections.

**Note 2:** The client states (and records confirm) that he previously used a manual wheelchair for mobility assistance and no longer requires the chair. For purposes of future care planning, it is presumed the wheelchair is available in the home for his use in the future, if needed, and no cost for replacement is included in plan totals.

### Home Furnishings/Aids for Independent Function

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Year Purchased</th>
<th>Replacement Schedule</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shower/tub bench with back (JP)</td>
<td>2001 (already has)</td>
<td>Every 5 years (average) to life expectancy</td>
<td>$48.95–59.95 every 5 years (average) to life expectancy</td>
</tr>
<tr>
<td>Elevated toilet seat (JP)</td>
<td>1997 (already has)</td>
<td>N/A; see note</td>
<td>N/A; see note</td>
</tr>
</tbody>
</table>

**Note:** The client states he no longer uses this item; however, for purposes of future care planning, it is presumed the elevated toilet seat is available in the home for his future use, if needed, and no cost for replacement is included in plan totals.

(Continued)
(Continued)

<table>
<thead>
<tr>
<th>Allowance for daily planner/scheduler, memory book and other compensatory tools, handheld shower, cordless phone, etc. (JH, RW)</th>
<th>2001 (already has some items)</th>
<th>1 time/year allowance to life expectancy</th>
<th>$50/year (average) to life expectancy</th>
</tr>
</thead>
</table>

**Orthotics/Prosthetics**

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Year Purchased</th>
<th>Replacement Schedule</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Custom left ankle, foot orthosis (AFO) (JP)</td>
<td>2015 or 2020 (age 45 or 50)</td>
<td>Every 2–3 years (average) to life expectancy</td>
<td>$600–1000 every 2–3 years (average) to life expectancy (includes measuring, molding, casting, fittings, and adjustments)</td>
</tr>
</tbody>
</table>

**Note 1:** The physiatrist states the client also may benefit from custom insoles or orthopedic footwear due to his altered gait; however, no information is available regarding specific type or kind of orthopedic supply and no additional cost is included in plan totals. See Potential Complications.

**Note 2:** The orthotist suggests replacement every 1 to 2 years (average) depending on wear and tear, maintenance, and need or changes in the client’s mobility and musculoskeletal structure.

**Orthopedic Equipment Needs**

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Year Purchased</th>
<th>Replacement Schedule</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cane with offset handle (JP, WW)</td>
<td>2001 (already has)</td>
<td>Every 10 years (average) to life expectancy</td>
<td>$20–25 every 10 years (average) to life expectancy</td>
</tr>
<tr>
<td>Standard folding walker (JP, WW)</td>
<td>2000 (already has)</td>
<td>Every 10 years (average) to life expectancy</td>
<td>$70–85 every 10 years (average) to life expectancy</td>
</tr>
</tbody>
</table>

**Note 1:** The client currently uses a cane with offset handle for mobility assistance primarily in the community. The physiatrist recommends both a cane and walker be available to him throughout his life expectancy. If a rolling walker is needed, cost is $200 to $270 each.

**Note 2:** The physiatrist also recommends a power scooter for long-distance outings in the community (see scooter).

**Drug Needs**

*Drug needs and costs are representative of the client’s current need and may change from time to time.*

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Purpose</th>
<th>Cost per Month</th>
<th>Cost per Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clonazepam (Klonopin), 0.5 mg, 2 times/day (MC)</td>
<td>Seizure prevention</td>
<td>$21.12–43.59 for 60 tablets/month</td>
<td>$257–530/year to life expectancy</td>
</tr>
<tr>
<td>Oxybutynin (Ditropan), 5 mg, 3 times/day (WW)</td>
<td>Bladder control and management Reduce</td>
<td>$17.11–25.79 for 90 tablets/month</td>
<td>$208–314/year to life expectancy</td>
</tr>
<tr>
<td></td>
<td></td>
<td>$34.27–42.59 for</td>
<td>$730–907/year to life expectancy</td>
</tr>
</tbody>
</table>
Zanaflex, 4 mg, $\frac{1}{2}$ tablet in A.M., $\frac{1}{2}$ tablet at noon, 1 tablet at bedtime ($1\frac{1}{2}$ tablets/day) (WW) Baclofen, 20 mg, 3 times/day (WW) Propranolol LA (Inderal), 60 mg, 2 times/day (WW) spasticity/ataxia spasticity/ataxia 30 tablets/month $25.92–47.69$ for 90 tablets/month $47–61.79$ for 60 tablets/month $315–580$ per year to life expectancy $572–752$ per year to life expectancy

**Note:** According to the physiatrist, the client is expected to require these or similar medications throughout his life expectancy. The internist also states medications are expected to be needed throughout his lifetime.

**Supply Needs**

Supply needs and costs are representative of the client’s current need and may change from time to time.

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Purpose</th>
<th>Replacement Schedule</th>
<th>Cost per Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prism glasses (RH)</td>
<td>Reduce double vision</td>
<td>Expect replacement every 1–2 years (average)</td>
<td>$283$ for frames and lenses every 1–2 years (average) to life expectancy</td>
</tr>
</tbody>
</table>

**Note 1:** According to the ophthalmologist, the client's vision impairment as related to the brain injury is expected to remain the same over his lifetime. He states there will probably be no new problems with his vision assuming no additional or further ocular trauma occurs. See also Potential Complications.

**Note 2:** The client states he does not use other supplies related to injuries received in the incident.

**Home/Facility Care**

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Year Initiated/Suspended</th>
<th>Hours/Shifts/Days of Attendance or Care</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Competent companion for assistance, safety, and supervision in the home (JP, JH) Child care assistance (JP, JH)</td>
<td>2001</td>
<td>10–12 hours/day, 7 days/week, 365 days/year to life expectancy As needed</td>
<td>$35,953–65,700$ per year to life expectancy at $9.85–15$/hour Defer to economist for loss of child care services</td>
</tr>
</tbody>
</table>

**Note 1:** The client's wife currently performs the function of a live-in caregiver.

**Note 2:** Of the nine home health agencies contacted in the client's local area, only one agency offered a live-in caregiver and the service currently was not available due to staffing shortages and difficulty in hiring and retaining live-ins. When and if available, live-in at the one agency is $139.20/day.

**Note 3:** The neuropsychologist states the client does not require overnight awake care and should be able to summon emergency assistance if needed.

**Note 4:** Both the neuropsychologist and physiatrist state the client is expected to have difficulty with child-raising activities with his 2-year-old daughter and his expected second child

(Continued)
in January 2004 and requires child care assistance. Economic value of time that a father normally spends in child-rearing and child-raising activities and that which is lost due to the client's injury are deferred to the economist.

**Note 5:** The cost of in-home care may be reduced through negotiation with the home health agency for long-term contract, private hire, or if family or friends assume some of the care.

<table>
<thead>
<tr>
<th>Yard care and interior/exterior home maintenance and repairs (per interview)</th>
<th>2001</th>
<th>N/A</th>
<th>Defer to economist as part of loss of household services</th>
</tr>
</thead>
</table>

**Note:** The client’s home is in obvious need of repair due to injury caused by maneuvering the wheelchair in the home (i.e., injury to doorways, flooring, walls, etc.). The client states he is unable to do the repairs and is unable to paint or do other interior/exterior home maintenance tasks since the injury.

### Transportation

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Year Purchased</th>
<th>Replacement</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cellular telephone for emergency communication (RW)</td>
<td>2000 (already has)</td>
<td>Every 5 years (estimate)</td>
<td>N/A (had preinjury)</td>
</tr>
<tr>
<td>Scooter lift for vehicle (RW)</td>
<td>2001 or when scooter purchased; see scooter</td>
<td>Every 5–7 years (average) to life expectancy or at time of vehicle replacement</td>
<td>$2500 every 5–7 years (average) for hoist arm scooter lift</td>
</tr>
</tbody>
</table>

**Note:** Although the client received satisfactory scores in the behind-the-wheel adapted driving evaluation in July 2001, the neuropsychologist opines that driving is not recommended due to judgment impairments and slow processing that impair his ability to act quickly or in emergencies.

### Health and Strength Maintenance (Leisure Time Activities)

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Year of Purchase or Attendance</th>
<th>Replacement or Attendance Schedule</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fitness program: Option 1 Gym membership (JP) Option 2 Home exercise equipment to include treadmill, parallel bars, and multistation exercise machine</td>
<td>2001 to life expectancy</td>
<td>N/A; already has equipment; plan for 2-time replacements (estimate) over his lifetime</td>
<td>N/A; no additional cost over general population 2011: $3000 (estimate) 2021: $3000 (estimate)</td>
</tr>
</tbody>
</table>
Note 1: The physiatrist recommends a physical conditioning/exercise program under the supervision of a physical therapist to monitor and oversee/supervise fitness program. See also physical therapy for recommended four times/year physical therapist supervision.

Note 2: The physical therapist suggests a recumbent stationary bicycle also may be useful for the client.

<table>
<thead>
<tr>
<th>Membership to National Brain Injury Association and local support groups/networking (RW)</th>
<th>2001 to life expectancy</th>
<th>Yearly membership</th>
<th>$35/year to life expectancy</th>
</tr>
</thead>
</table>

**Vocational/Educational Plan**

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Year Initiated/Suspended</th>
<th>Purpose</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Computer with monitor, printer, Internet access, software package, and other features (RW)</td>
<td>1-time-only replacement estimated in 2002 (approximately 4 years after purchase of current computer in 1998)</td>
<td>Increase independence for educational and recreational activity</td>
<td>$2000 (average) for 1-time-only replacement in approximately 2002</td>
</tr>
</tbody>
</table>

Note 1: Dr. Preston states in his deposition that a personal computer is medically indicated for the client to include possible access for environmental control unit (ECU) or adaptive devices integration in the future.

Note 2: A one-time-only replacement cost for computer and related equipment/supplies is included in plan. Replacement after that is presumed to be consistent with use of a personal computer by the general population.

Note: The client has no competitive vocational potential. Volunteer activity is a best option for him to increase his sense of productivity and self-worth, and provide a sense of purpose. If professional services are required in the future to develop or cultivate an alternate volunteer program for the client, expect 20 to 40 hours for vocational counseling and related services, including vocational evaluation, labor market research, job site analysis, etc., at $75 to $89/hour. However, costs for these services are not included in the plan.

**Architectural Considerations**

(List considerations for home accessibility and modifications.)

The client currently lives with his wife and 2-year-old daughter in a ranch-style house that has been modified to accommodate him and generally appears appropriate for his current needs. A ramp has been constructed to the back door, which is the entrance the client uses to enter and exit the home, and grab bars have been installed in the bathroom. The front entrance has steps leading to the front door, although no handrail is available and the client demonstrates he generally is able to ascend and descend the stairs with difficulty in a modified fashion and with altered gait.

The client requires a one-story home with accessibility features and minimal, if any, stairs. If stairs, he requires handrails. See also home accessibility evaluation for one-time-only evaluation to assure the home is accessible both now and for the future as he ages and experiences an expected reduction in his physical capabilities.

(Continued)
### Future Medical Care, Surgical Intervention, Aggressive Treatment

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Year Initiated</th>
<th>Frequency</th>
<th>Expected Cost*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eye muscle surgery (RH)</td>
<td>2002–2003 (age 32–33)</td>
<td>1 time only, if successful</td>
<td>$5000 (approximate)</td>
</tr>
<tr>
<td>Left total knee replacement (JP)</td>
<td>2020 (age 50)</td>
<td>Replacement in approximately 2020: $30,948</td>
<td>Replacement in approximately 2020: $30,948 1st revision: $35,608 2nd revision: $34,378</td>
</tr>
<tr>
<td>Left knee revision (JP)</td>
<td>Approximately 2030–2032 and every 10–12 years (average) thereafter to life expectancy</td>
<td>Initial knee replacement in 2020, then every 10–12 years (average) knee revision to life expectancy</td>
<td></td>
</tr>
<tr>
<td>Left hip revision (JP)</td>
<td>Approximately 2030–2032 and every 10–12 years (average) thereafter to life expectancy</td>
<td>Initial hip replacement in 2020, then every 10–12 years (average) hip revision to life expectancy</td>
<td></td>
</tr>
</tbody>
</table>

*Expected cost for knee and hip replacement/revision includes surgeon fee and average hospital charges and does not include surgeon assistant fee, if applicable, anesthesiologist fee, or sub-acute or rehab unit stay. One case of a client similar in age to this client with diagnosis of degenerative joint disease required total knee replacement at a cost of $40,733, inclusive.

**Note 1:** The physiatrist states he expects the client to require joint replacement in both left hip and left knee due to altered gait and increased wear and tear on his lower-extremity joints as well as expected degenerative joint disease. He states the severity of the degenerative joint disease depends on maintenance of the client’s weight and overall health and fitness.

**Note 2:** According to one orthopedic surgeon who performs knee and hip replacement surgeries, knee and hip prostheses last on average 10 to 12 years (based on geriatric population); however, the client may require more frequent revision due to his young age at time of projected initial replacement and expected increased activity level (more so than geriatric activity level). See also Potential Complications.

**Note 3:** For purposes of future care planning and based on the physiatrist’s recommendation for initial hip and knee joint replacement at approximately age 50, presume two hip and knee revisions over the client’s lifetime at approximately age 60 to 62 and age 72 to 74.

**Note 4:** The orthopedic surgeon states joint revision surgeries are more difficult than the initial replacement surgery and each subsequent revision is more difficult than the previous one. Recovery also tends to take longer. However, no additional cost for extended recovery is included in plan totals for revision surgeries.

**Note 5:** Pain medication is expected to be needed following each joint revision surgery as well as probable anti-inflammatory medication. Exact kind, dose, and duration of medication are unknown and no additional cost for medications is included in plan totals.

**Note 6:** Orthopedic visits following joint replacement/revision generally include one post-op visit (at no cost) plus three other visits at 3, 6, and 12 months postreplacement/postrevision at $60 to $80/visit. Routine follow-up also includes AP and lateral x-rays of hip at $174.25/x-ray and knee at $261.25/x-ray at each post-op visit. Additional medical needs following joint replacement/revision likely include postoperative physical therapy and
probable long-term need for cane or walker for mobility assistance. Aqua therapy also may be indicated following joint replacement/revision.

<table>
<thead>
<tr>
<th>Procedure</th>
<th>Description</th>
<th>Note 1</th>
<th>Note 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ventriculoperitoneal (VP) shunt revision (JP)</td>
<td>Approximately 2011 (15 years after initial shunt placement)</td>
<td>1 time only, assuming no complications</td>
<td>Expected cost for VP shunt revision includes surgeon fee and hospital charges only and does not include diagnostic studies that may be needed such as abdominal x-rays or head CT scan, or anesthesiology charges. See head CT scan, which may be used for diagnostic purposes at time of shunt revision.</td>
</tr>
<tr>
<td>Neurosurgeon evaluation: $286</td>
<td></td>
<td>Revision surgery: $28,927</td>
<td></td>
</tr>
</tbody>
</table>

**Note 1:** The client was released from the care of his neurosurgeon in February 1998 to be followed by the physiatrist and return as needed if there were complications with his shunt or changes in his neurologic status. The physiatrist states it is probable the client will require at least one shunt revision over his lifetime due to expected complications.

**Note 2:** Expected cost for VP shunt revision includes surgeon fee and hospital charges only and does not include diagnostic studies that may be needed such as abdominal x-rays or head CT scan, or anesthesiology charges. See head CT scan, which may be used for diagnostic purposes at time of shunt revision.

**Potential Complications**

- Neurologic problems, including increased risk for seizures, shunt complications, increased spasticity that is expected to get worse over time, etc., which require aggressive treatment (including Botox injections), diagnostic tests, and prescription medication.
- Psychological difficulties, including poor adjustment to disability, anger, aggression, irritability, depression, poor social behavior, increased social isolation, increased risk for suicide if not getting adequate care, etc., which could require medication and psychotherapy or hospitalization to treat. The psychiatrist states the client is at higher risk for affective symptoms. Additionally, the neuropsychologist states an anger management program may be an option in the future.
- Increased risk for early onset of dementia due to the effect of TBI and the aging process, as well as more prone to earlier onset of memory problems and overall decline in cognitive abilities associated with aging.
- Increased risk for falls and additional injuries (i.e., bone fractures, secondary brain injury, etc.) due to spasticity, impulsivity, poor balance, and reduced physical abilities. The physiatrist states there is a very high probability of the client experiencing falls with resultant fractures. The neuropsychologist states a second brain injury would be devastating and the client would not recover to the extent he has recovered from the primary brain injury.
- Musculoskeletal and mobility problems due to altered gait. May require custom orthopedic footwear and insoles. May also experience additional hand problems, depending on his neurological status, that require surgical correction. May require more frequent hip or knee revisions than normally expected or have longer than expected recovery following joint revisions.
- Urology problems if Ditropan medication becomes ineffective and urology services are needed, including evaluation, diagnostic studies, other medications, surgery, etc.
- Visual problems, including additional or further ocular trauma or need for other aggressive treatment/surgery to correct or improve his double vision caused by left trochlear nerve palsy and partial oculomotor palsy.
- More extensive or expensive medical care and equipment than expected.
- Adverse reaction to long-term use of medication(s).
Conclusion

Thousands of our citizens experience a brain injury each year. The more knowledgeable one is about this specialized industry, the better equipped one is to obtain effective treatment while controlling costs and complications. Life care plans can effectively help ask the right questions and guide the individual, family, and funding source through the complex maze of rehabilitation and long-term care. Effective vocational rehabilitation can help integrate the person back into the community, perhaps as an employed, productive individual. In order to accomplish these monumental tasks, numerous professionals and family members must work together in a collaborative fashion to achieve common goals.

References


Chapter 14

Life Care Planning for the Burn Patient

Kevin N. Foster and Ruth B. Rimmer

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Introduction

A well-documented and thorough life care plan plays an important role in the long-term recovery of a burn-injured individual. Serious burns cause a significant interruption of the patient's life, including physical, social, emotional, and financial stability. Therefore, it is vitally important that the life care plan for the burn patient is holistic and addresses concerns regarding the client's medical, emotional, social, and financial needs and well-being.

Burn care has evolved dramatically over the past 20 years. Acute burn medical care has improved greatly and has resulted in dramatically higher survival rates (Brusselaers et al., 2005). Persons, especially children, with a large percentage of total body surface area burns (% TBSA) survive routinely (Wolf et al., 1997). While it is encouraging that mortality has declined, an individual’s survival of serious burn injury often results in lifelong challenges and complications for the burn patient and the family. Recovery often necessitates post-acute care rehabilitation, future reconstructive surgeries with accompanying therapies, home health care, as well as the need for assistance with psychological, social, educational, and vocational rehabilitation issues. A well-thought-out and comprehensive life care plan can provide the survivor and the family with a vital road map that will assist them in navigating the long and arduous road to recovery.

Burn care is a highly specialized field of medicine. The burn care team is multidisciplinary and is made up of an extensive array of medical professionals. A burn injury is complex and complicated from both a physical and a psychological standpoint and survivors benefit from a multifaceted team approach to their care (Demling, 1995).

In the acute hospital setting, the patient is cared for by a team of burn care professionals, which includes burn surgeons, physician’s assistants, nurses, burn techs, physical and occupational therapists, nutritionists, respiratory therapists, psychologists, social workers, and case managers. Patients often require additional care from specialists such as plastic/reconstructive surgeons, hand surgeons, cardiologists, neurologists, psychiatrists, and speech therapists. The acute medical care setting for burn patients is labor intensive, and the care is expensive. It takes tremendous effort on the part of the entire burn care team, as well as an immense effort on the part of the patient and the patient’s family for basic survival to occur (Herndon & Blakeney, 2007). Rehabilitation begins in the hospital and is often extended in a specialized rehabilitation facility after discharge from the acute burn care setting for weeks or even months postdischarge.

Life care planners and medical case managers should be familiar with the prevalence, etiology, and pathophysiology of burn injury. Over the past two decades there has been a notable reduction in the total number of burn injuries in the United States; however, every year approximately 700,000 persons in the United States continue to require medical attention for their burn injuries (Brigham, 2005). It is estimated that approximately 40,000 of those injured will be hospitalized and that approximately 3,500 individuals will die from their burns (Pruitt, 2007). Survival is
Life Care Planning for the Burn Patient

The severity of the burn is determined by a number of factors including the size of the burn injury, the need for skin grafting, and the presence or absence of an inhalation injury. The larger the percentage of TBSA (total body surface area) burned, the less favorable the outcome is likely to be. The depth of the burn, including the degree of the burn, also influences the ultimate outcome, with deeper burns resulting in a less favorable prognosis and the need for the patient to receive skin grafts. Inhalation injury is another factor, which often contributes to poorer outcome. Burns may present with other trauma, which can also complicate survival and future care needs. Premorbid medical conditions can also have a negative influence on the patient's outcome (Hartford, 2007). All of these details are important to consider when developing the life care plan or managing a burn case; therefore, a thorough review of the patient's medical records and familiarity with the patient's medical history are imperative.

**Burn Injury Prevalence**

The risk of being burned, as well as the etiology of the burn, is related to a person's age, type of employment, economic status, type of recreational activities in which one engages, and location of residence. Although the specific number of burn injuries in the United States is unknown, individuals suffer from far more minor than major burns. It is estimated that only 3% to 4% of burn-injured persons reporting to emergency rooms are admitted or transferred to a burn center/unit. However, burn injuries are still a significant problem and an expensive injury. In 2003, fire/flame-related burns and inhalation injury continued to rank as the sixth leading cause of unintentional death due to injury in the United States and fires/flames caused the fifth largest number of injury-related deaths in the home (National Safety Council, 2003). The economic cost of burn injury is high with hospital bills for severe burns ranging from many thousands to millions of dollars for one patient. Ongoing reconstruction and rehabilitation are also costly, which is another reason why an accurate life care plan is important.

While burns can be caused in a variety of ways, the most prevalent causes of burn injuries requiring admission to the hospital are fire/flame, scalds (most common in young children and the elderly), and chemical, electrical, and radiation burns. Flame and scald burns account for the vast majority or approximately 79% of all reported cases (Pruitt et al., 2007). The arms and hands, head and neck, and lower extremities are the areas of the body most likely to sustain burns. Of nonfatal burns, 45% involve the hand and arm, 25% involve the neck and head, and 16% result in burns to the leg and foot (Pruitt et al., 2007). The face, limbs, hands, and feet are vital to both physical and social function, and burns to these body parts, especially scarring across the joints, can be disfiguring as well as disabling (Demling & LaLonde, 1989).

**Classification of Burns**

The treatment of burns is often determined by the classification of the injury. Burn injuries are typically classified by etiology, depth of the burn (layers), location of the burn, and the percentage of total body surface area burned (% TBSA). Burn depth, which refers to the layers that have been damaged, is classified as superficial (first degree), superficial partial thickness (second degree), deep
partial thickness (second degree), full thickness (third degree), and deep full thickness (fourth degree). Physicians will often defer the classification of a burn injury for several days, in order to correctly determine the true depth of the burn.

- Superficial (first-degree) burns involve only the superficial epidermis and usually require 3 to 7 days for healing with no scarring.
- Superficial partial-thickness (second-degree) burns involve the epidermis and the dermis excluding hair follicles, sweat glands, and sebaceous glands and should heal in less than 21 days with minimal scarring.
- Deep partial-thickness (also second-degree) burns involve the epidermis and most of the dermis, requiring more than 21 days for healing, and may develop severe hypertrophic scarring.
- Full-thickness (third-degree) burns result in total destruction of the skin, both epidermis and dermis and hypodermis, and may involve additional tissue. Full-thickness burns of any significant size require skin grafting.
- Deep full-thickness (fourth-degree) burns involve fat, nerve endings, muscle, and/or bone and are usually a result of prolonged contact with heat or an electrical injury and may require flap coverage or amputation (Fisher & Helm, 1984).

Burns are also categorized by the percentage of TBSA involved. It is customary to establish the percentage of partial- and full-thickness burns separately. The American Burn Association (ABA) classifies burn injuries as mild, moderate, and major. Moderate and major burns require hospitalization.

- Minor burns are those that involve less than 15% TBSA and are partial thickness. In the elderly and pediatric populations 10% or 2% full thickness is considered minor unless the eyes, ears, face, hands, or perineum are burned.
- Moderate burns include a total body surface area of 15% to 25% (10% to 20% for pediatric patients less than age 10 or adults over age 40) without regard to the depth and 2% to 10% full-thickness burns unless the eyes, ears, face, or perineum are burned.
- Major burns include those partial-thickness burns that cover more than 25% of the body (20% for children and adults less than the age of 40); or those full-thickness burns that cover more than 10% of the total body surface area as well as all burns to the face, eyes, ears, feet, and perineum. Burns sustained from electricity or lightning or those involving inhalation injury are also considered major. Burns with comorbid trauma and all burns that present with premorbid illness or are in the very young or the elderly are also labeled as major burns (Hartford, 2007).

**Majors Problems Associated with Burn Injury**

**Role of the Skin**

The skin plays a major role in sustaining life since it makes up the largest organ system of the body. The main functions of the skin follow:

- Protective barrier
- Regulates body temperature
Life Care Planning for the Burn Patient

Fluid conservation
- Receives environmental stimuli
- Excretory gland
- Absorbs Vitamin D
- Determines identity

Human skin is made up of several layers: the epidermis (10%), which is the outer layer, and the dermis (90%), which is the inner layer. The average thickness of adult skin is 1 to 2 millimeters. The top layer contains cells that determine skin color and make up the protective layer of skin. The dermis is found beneath the epidermis. The dermis contains connective tissue, capillaries, collagen, and elastic fibers. This layer supplies structure and nutrition to the epidermis, provides elasticity of the skin, and contains the hair follicles and excretory glands including the sweat and sebaceous glands. There are sensory nerve endings found throughout the skin; therefore, deeper burns may cause permanent changes in a person's capacity to sense pain, touch, and temperature (Cromes & Helm, 1993).

When both layers of the skin, the epidermis and dermis, are destroyed, the patient loses hair follicles, sweat and sebaceous glands. A layer of fat and connective tissue is found under the dermis, and muscle, bone, and tendons are beneath this layer. Sensory nerve endings are distributed throughout the skin and subcutaneous layer. Therefore, burn injury, depending on the depth, may result in a permanent change in the burn victim's capacity to sense pain, touch, and temperature (Fisher & Helm, 1984).

Wound care is a key component of acute and rehabilitative burn care. Wounds must be maintained in a manner that facilitates and at the very least does not impede re-epithelialization of the skin. This includes care designed to minimize infection, remove dead tissue, reduce heat loss, and prevent further tissue loss. A typical approach to wound care involves cleaning the wound and debriding it twice daily. Donor site dressings must also be changed once or twice a day. Wound care is extremely painful for the patient. If reconstructive surgery is a future recommendation for a patient, a provision for home health care will likely be necessary.

Common Surgical Procedures

There are a number of common surgical procedures in burn care. If the burn injury is circumferential, the skin can become very tight and stiff and stop the blood flow to the areas below the burn. An escharotomy, a cut made down through the burned skin (the eschar), may be performed. A faciotomy, which is a deeper cut into the tissue below the skin (fascia), may also be performed, in order to expose the muscle. Medical records will document these procedures.

Grafting is a surgical procedure that involves the transplantation of skin. Grafting becomes necessary when the patient has burns that will not heal spontaneously. There are several types of skin grafts. The first is an autograft, which is created when the individual's own skin is taken from an unharmed part of the body (donor site) and placed over the burned area.

If the burned area is not ready for an autograft, a temporary skin covering may be used, allograft (homograft) or a xenograft (pigskin). This thin temporary covering is placed over the wound and allows for better pain control and provides a barrier to infection. These temporary grafts stick to the skin, but will be removed when the area is ready for a permanent skin graft (autograft). Skin grafts may take after the first surgery but sometimes they fail and the patient must be returned to the operating room, possibly several times, until all of the dead, burned skin has been removed (debrided or excised). A dermal replacement may also be used because it provides an outstanding...
barrier for infection, is easy to apply, and adheres well to lesions. It can be very costly, so be sure to inquire if dermal replacement will be necessary for any reconstructive surgeries (Khosh, 2008).

It is important to note how many surgeries the burn patient has undergone in the narrative portion of the life care plan. It helps to illustrate just how burdensome and difficult the patient’s acute care stay was.

**Reconstruction**

A seriously burned patient, especially a child, may need a great deal of post-acute care reconstructive surgery. The purpose of burn reconstruction is to provide the patient with function, comfort, and improved appearance. In children, reconstruction may also be done to allow for growth. The burn patient is likely to have a lifelong relationship with a reconstructive surgeon (Barret, 2008).

It is customary for definitive correction of burn scars to be postponed for at least a year or more. Scars mature over time, and some scars through the use of pressure garments and splints may not need surgical correction. Scar contractures can be uncomfortable as well as unsightly. They may also impede function. It is important for life care planners to inquire as to which reconstruction procedures will be necessary and how often it is probable that they will be repeated over the life span. It is especially important to address those scar contractures that are present over joints, and skeletal deformities also need to be considered.

Once the surgery has been performed, the patient will likely need home health care, physical or occupational therapy, and pressure garments. These items are all important to the long-term success of any reconstructive surgery. The surgeries may also need to be repeated multiple times over the life span, especially when the burn is sustained in early childhood.

**Pressure Garments and Splints**

Burn injuries that destroy dermis also cause elimination of the normal pressure that these layers of skin provide. Absent this pressure, hypertrophic scars can form, causing deformities and impairment of function. Pressure garments help to prevent and control the formation of hypertrophic scars by applying counterpressure to the wounded area. They also aid in reducing the effects of hypertrophic scarring, itching, and increased circulation to the area (Lisares, 1972). Pressure garments are fitted by a specialist, which is usually done prior to discharge from acute care.

Pressure garments can play a vital role in the proper healing of wounds and reduce the effects of scarring, but for the garments to perform their job properly, they need to fit tightly and be in good condition. Patients often wear their garments for anywhere from 12 to 24 months after initial discharge. They typically must be worn 23 hours per day. Therefore patients are prescribed two sets with each fitting. Patients will often be fitted for new garments after reconstruction procedures.

Positioning is also very important for the burn patient. Patients are often sent home with splints. They are also often ordered after reconstruction. The life care planner should inquire into the need and frequency of both garments and splints when discussing projected surgeries.

**Prosthetics**

A very severe burn, a fourth-degree or circumferential third degree burn, may result in an amputation. This may involve a digit, hand, limb, or even a nose or ears. A prosthetist can provide
information regarding the cost, replacement schedule, and need for other accessories for the patient. An anaplastologist, an individual who has the ability to create and customize highly individualized prosthetics for the face, can be consulted for information regarding prosthetic eyes, ear, noses, fingers, and so on.

**Nutritional Issues**

Burn injuries affect the body’s metabolic rate, and burn patients suffer from posttraumatic hypercatabolism. This well-known phenomenon causes the breakdown of tissue and exhausts the body’s energy stores. The magnitude of the problem is defined by the total body surface area and severity of the burns. Glucose uptake is compromised, cholesterol and lipoprotein concentrations are decreased, and protein catabolism causes patients to lose protein content. The increased metabolism is amplified by pain, anxiety, hypovolemia, and infection, as well as loss of body heat (Gallal & Yousef, 2002). Burn patients’ nutritional needs are of key importance, and patients are often given enteral feedings with a high caloric content to promote healing. Supplements are often prescribed after discharge from acute care as well as after reconstructive procedures to insure proper healing.

**Rehabilitation**

Patient-specific rehabilitation services begin immediately during acute burn injury care and continue after, often long after, the patient is discharged from initial hospitalization. The literature suggests that recovery from a major burn may take several years to return a patient to a satisfactory level of function (Brown, Helm, & Weed, 2004; Warden & Warner, 2007). The depth and location of the burn are key factors in determining the type and goals of immediate and aggressive therapeutic intervention. The preservation of function and mobility are the short-term goals of rehabilitation. Long-term goals involve returning the patient to independence through the ability to perform activities of daily living, compensation for functional loss, management of scars and pain, and reintegration into the home and community (Serghiou, 2007).

It is important to remember that discharge from the hospital does not mean that the patient is restored to good health. A burn patient’s wounds have been covered, but they may have to return to the hospital for additional surgeries and will likely have orders for outpatient physical therapy and/or occupational therapy, burn clinic visits, pain management, psychological care, as well as the need for pressure garment fittings. Ongoing wound care, as mentioned previously, is also a facet of the rehabilitative phase of burn recovery.

Rehabilitation should begin immediately so that the scars do not mature and cause more severe contractions and limitations, which can increase complications, diminish function, and result in additional treatment and a greater cost of care. Burn scar maturation can vary from 6 to 18 months and longer. During this period it is important to mobilize the burn area to decrease the likelihood of contractures, deformities, and hypertrophic scarring. Once scar maturation has occurred, correction of most deformities and cosmetic abnormalities involves costly surgical procedures with physical/occupational therapy, home health care, and burn clinic or doctor office follow-up in order for functional gains to be maintained (Cromes & Helm, 1993).

**Massage Therapy**

Scar massage has been found to be beneficial to burn patients and provides several important functions, including the promotion of collagen, the remodeling of scars, decreased itching, decreased
anger, and decreased anxiety while providing moisture and pliability to the burned areas and donor sites (Field et al., 1998). It may be recommended by the physician after scar revision surgeries or for ongoing pain and scar management.

**Outpatient Services**

Over 60% of the 40,000 patients who are hospitalized annually for their burn injuries are admitted to the 125 hospitals that have burn centers or units (National Hospital Discharge Survey, 2003). Many of these specialized care centers are regional in nature. Therefore, patients must sometimes relocate, temporarily, to a burn center in order to receive ongoing and appropriate outpatient burn and rehabilitation care (Hartford, 2007).

A comprehensive burn rehabilitation course may require as much as 6 hours of therapeutic intervention per day, 5 days per week. The frequency usually decreases gradually to three times per week and eventually to two times per week. The patient often requires attendant care from a family member or health care provider for dressing changes, exercise routines, and activities of daily living. A severely burn-injured individual may have need of assistance for weeks or even months. If parents, spouses, or other family members are providing attendant care or transportation, an estimate of compensation for their time and effort should be considered for inclusion in the life care plan.

Physician follow-up visits are needed approximately every 1 to 2 weeks in the initial outpatient stage, with frequency decreasing to once or twice per month as long as the patient is on physical therapy or occupational therapy treatment, and for the first few weeks after treatment is stopped. Typically treatment lasts for anywhere from 12 to 16 weeks. To make sure the patient is maintaining function after therapy has stopped, typical physician follow-up should continue but gradually decrease to once every 3 months for 12 to 18 months, then biannually for another 12 to 18 months, then annual visits, unless unforeseen complications arise. However, the number of weeks or months and the actual physician follow-up plan is always specific to the patient; therefore, a physician should make the actual recommendation.

**Pediatric Life Care Plans**

Life care plans for severely burn-injured children can be very complicated. Pediatric patients often need multiple reconstructive surgeries as they grow. Children may have cognitive problems due to trauma and/or inhalation injury, and there will be great demand placed on their parents and family in order to support them in their need for ongoing care. Educational needs also should be considered. Summer burn camp is a rehabilitation program that can bring great benefit to a burn-surviving child and should be considered for inclusion in the life care of a pediatric burn-survivor. The World Burn Congress, an annual event sponsored by the Phoenix Society, can also be beneficial for children and their families and can be extremely helpful for adult burn survivors and their families as well.

**Psychological Issues**

Psychological adjustment to a severe burn injury can often be profound (Smith, 2006). A significant number of burn-injured patients will suffer from posttraumatic stress disorder and experience intrusive memories related to the event during the acute care phase (Ehde, 1999). Depression and
anxiety on the part of the patient and/or the family may also occur. Psychological intervention may have begun in the burn center during the acute care stage of hospitalization, if it was available. However, not all burn centers or units have psychological services available as a regular part of their care protocol.

The medical chart should be reviewed to ascertain what psychological problems may have arisen during inpatient care and what psychiatric or psychological services, if any, were delivered. Supportive services and crisis management care are often offered to patient’s families in the burn center; however, as basic survival becomes the major goal during the initial phase of hospitalization, psychological matters may not have been addressed, or may have been addressed inadequately.

Acute stress disorder may be diagnosed during acute hospitalization. Posttraumatic stress disorder, a complication which longitudinal studies have found to affect up to 45% of adults who were hospitalized for their burn injury 1 year postburn and nearly a third of burn patients within 2 years of their burn, cannot be diagnosed until at least 30 days after the initial traumatic event (Perry, Difede, Musngi, Frances, & Jacobsberg, 1992; Wiechman et al., 2001). Therefore, it is important to address psychological issues of both the patient and the family, not only during the inpatient stay, but after discharge from the burn center or burn unit as well.

Many burn-injured patients persist with periods of fear and anxiety. These symptoms often recur when the patient has to return to the hospital for reconstructive surgeries. Adults may express their anxiety through physical symptoms such as palpitations, perspiration, nausea, and shaking. Children may become clingy or fearful, cry often, have headaches and stomachaches, or become disruptive and angry. The psychological impact of burn injury has become a major focus of burn care. “Health care professionals are increasingly recognizing that they cannot neglect the psychological and social dimensions both for patients and their families. Research has shown that patients and clients who receive psychosocial support as part of their rehabilitation are more likely to adjust positively to living with a disfigurement” (Partridge, 2008).

A psychosocial survey should be performed for the patient. As mentioned earlier, the patient and the patient’s family may have been unable to address psychological and social issues such as posttraumatic stress disorder, financial pressures, or depression before discharge from acute care. They may be experiencing new problems at home such as sleep disturbance, anxiety, sexual concerns, body image problems, itching, identity issues, inability to return to work or school, and unresolved pain issues. If the patient or the family expresses concerns regarding any or all of these matters, there should be an evaluation by a psychologist or psychiatrist. A neuropsychology evaluation, used to examine brain function and possible impairments, is often recommended for severely burned pediatric patients and may be ideal for any burn patient who has experienced an inhalation injury or trauma to the head concomitant with the burn injury.

Life care planners should make inquiries regarding any currently prescribed psychotropic drugs and the length of need for such medications. If medication is needed on an ongoing basis through life expectancy, it is likely that the patient will need ongoing visits with a psychiatrist. Consideration should be made for immediate psychological intervention if problems are occurring, as well as for the need for ongoing psychological care during major life shifts and periods of reconstructive surgery. Play therapy for children, individual therapy for adolescents and adults, and couples counseling for both spouses and parents should be considered as well.
Vocational Rehabilitation

There is limited literature available on the details surrounding return to work following a serious burn injury. One study revealed that the majority of burn survivors do return to work within 2 years with an average of 17 weeks off the job (Byrch et al., 2001). However, there are a number of reported factors that tend to impede return to work. The most common risk factors associated with longer durations of work absence following serious injury and found to increase the unlikelihood of returning to work include the patient’s admission to intensive care units, a lengthy hospitalization, and a low education level. These are not unusual circumstances for individuals who have sustained severe burn injuries.

Other factors impeding return to work, which are related directly to burn injury, include total body surface area, length of hospitalization, thickness of burns, number of surgeries, age, presence of hand burns, reduced endurance, alcohol or drug dependence, and prior psychological or psychiatric problems. The longer the time lapse since the burn injury, the higher the likelihood of returning to work. Positive factors for likelihood of returning to work include pre-employment status, age, good coping skills, and higher level of education. However, having more full-thickness burn injuries was associated with a lower likelihood of returning to work (Dyster-Aas et al., 2007).

Several studies have shown that burn patients who are able to return to work report more satisfaction and a better overall quality of life than those who remain unemployed. Therefore, vocational rehabilitation issues should be taken into consideration during the early part of outpatient rehabilitation. Employers should be contacted on a regular basis to keep them updated on the status of the patient, in order to encourage a good relationship, and to diminish the patient’s fears that former employment will be lost. A comprehensive job description can be utilized to determine therapy needs in order to assist the patient in maintaining job skills. Part-time employment or light duty should be discussed in order to diminish financial stress and to avoid establishing a pattern of dependency (Weed & Berens, 2005).

A majority of burn patients are able to return to work but they are often unable to return to the job they had prior to their burn injury (Byrch et al., 2001). If job modifications or return to the same type of employment is unlikely, vocational evaluation and training should be considered as soon as the patient is healthy enough to begin. Research from the University of Washington revealed that only 37% of survivors, 2 years out from their injury, had gone back to the same job, and to the same employer without accommodation. Almost 50% had received disability, not gone back to work, or had some degree of employment interruption (Brych et al., 2001).

Those individuals who have been deemed permanently impaired will benefit from the assistance of a knowledgeable rehabilitation counselor (a board-certified rehabilitation counselor/CRC is preferred) who has the necessary background to conduct an assessment of the person’s physical, cognitive, and emotional functioning levels. A vocational evaluation by a certified vocational evaluator may be justified. A psychological assessment and functional capacity evaluation should also be considered.

A burn patient’s ability to return to work is highly individualized. The infirmity can range from no loss of function to living with an amputation and the need to adjust to a prosthesis. Life care planners are often confronted with electrical burns, which may have resulted in amputation,
cognitive and emotional impairment, and vision problems. One study, which involved patients who had endured amputation from electrical burns and had been cared for at a burn center of excellence, reported a superior return-to-work rate than people with disabilities in general (Weed & Atkins, 2004). Productivity is a highly valued personal characteristic; therefore, helping clients with their return to work or assisting them in finding a new vocation or different form of recreation is a vitally important outcome.

**Complications**

Complications after burn injury can be extensive and wide-reaching. They may affect any or many body systems (Warden & Warner, 2007). It is important to ask the treating physician what the potential complications are for a particular patient. The following chart includes common complications associated with burn injury. They have been divided by body systems with recommendations for intervention, and the likely frequency and duration of treatment, and surgical options. The list includes the most significant and usual burn-injury-related complications. The most common treatment options are also included.

**Burn Injury: Damage Assessment Checklist**

Serious burn injuries are considered catastrophic injuries. There is usually significant cost associated with the recovery and rehabilitation of the burn patient, which can necessitate lifelong care. Pediatric burn patients often require extensive reconstruction and rehabilitation, especially during but not limited to their growth and developmental years. A burn injury impacts the entire family system, so it is important to consider the family’s needs as well.

Patients may need a variety of physicians to care for them including but not limited to plastic reconstructive surgeons, physiatrists, orthopedic surgeons, pediatric intensivists, cardiologists, internists, pulmonologists, and psychiatrists for lifelong care.

Allied health care, including psychological, physical, occupational, and vocational therapies, as well as the need for case management are important items to consider. In-home assistance, respite care, home maintenance and cleaning services, and assisted living in advanced years are also often a necessity.

Patients often have an ongoing need for pain medications, moisturizers, pressure garments, prosthetics and orthotics, splints, special makeup, and other supplies. Transportation and mobility assistance as well as exercise for optimum function should also be considered.
<table>
<thead>
<tr>
<th>Skin Complications</th>
<th>Clinical Presentation</th>
<th>Diagnosis</th>
<th>Nonsurgical Options</th>
<th>Surgical Options</th>
<th>Additional Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Nonhealing wounds: acute</strong></td>
<td>Open, painful, wounds, often with bleeding or exudate</td>
<td>Clinical exam</td>
<td>Debridement of devitalized tissue and local wound care with a plethora of wound care products; improved nutrition; treatment of infections (which may not be clinically obvious); hyperbaric oxygen therapy (unproven)</td>
<td>Primary wound closure; partial thickness skin grafting; full thickness skin grafting; soft tissue rotation or flaps</td>
<td>Wound care is an art, not a science: what works for one patient may not work for another. A key element is patience. Assume wound closure of about 1 cm per month of therapy.</td>
</tr>
<tr>
<td><strong>Nonhealing wounds: chronic</strong></td>
<td>As in previous entry; nonhealing or lack of progression over weeks or months; breakdown of a previously healed wound</td>
<td>Clinical exam; wound culture; noninvasive vascular studies</td>
<td>As in previous entry; antibiotics; good nutrition is key</td>
<td>As in previous entry</td>
<td>As in previous entry</td>
</tr>
<tr>
<td><strong>Skin blistering</strong></td>
<td>Superficial, pink, moist painful open wounds on a site that had been previously healed</td>
<td>Patient history; clinical exam</td>
<td>Local wound care with a variety of wound care products</td>
<td>Rarely requires split-thickness skin grafting</td>
<td>Usually heals with conservative care</td>
</tr>
<tr>
<td>Skin Complications</td>
<td>Can occur anywhere on burned, grafted, or donor site skin. Most often is poorly vascularized areas, areas under tension, or areas of contact or friction.</td>
<td>Open, painful, wounds, often with bleeding or exudate</td>
<td>Clinical exam</td>
<td>Debridement of devitalized tissue and local wound care with a plethora of wound care products; improved nutrition; treatment of infections (which may not be clinically obvious); hyperbaric oxygen therapy (unproven)</td>
<td>Primary wound closure; partial thickness skin grafting; full thickness skin grafting; soft tissue rotation or flaps</td>
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<tr>
<td>Nonhealing wounds: acute</td>
<td>As previous entry; often associated with infections such as MRSA or vascular insufficiency.</td>
<td>As in previous entry; nonhealing or lack of progression over weeks or months; breakdown of a previously healed wound</td>
<td>Clinical exam; wound culture; noninvasive vascular studies</td>
<td>As in previous entry; antibiotics; good nutrition is key</td>
<td>As in previous entry</td>
</tr>
<tr>
<td>Nonhealing wounds: chronic</td>
<td>May occur anywhere; most often seen in freshly healed wound or donor sites.</td>
<td>Superficial, pink, moist painful open wounds on a site that had been previously healed</td>
<td>Patient history; clinical exam</td>
<td>Local wound care with a variety of wound care products</td>
<td>Rarely requires split thickness skin grafting</td>
</tr>
<tr>
<td>Skin blistering</td>
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<tr>
<td>Complication</td>
<td>Location</td>
<td>Clinical Presentation</td>
<td>Diagnosis</td>
<td>Nonsurgical Options</td>
<td>Surgical Options</td>
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<tr>
<td>Pigmentation changes</td>
<td>Can occur anywhere; most often seen in grafted skin especially on the face and head; may see in healed burns; rarely seen in healed donor sites.</td>
<td>Skin that is darker (more common) or lighter (less common) than normal</td>
<td>Clinical examination</td>
<td>Makeup: can be difficult to locate and expensive to use</td>
<td>Tattooing and other pigmentation procedures; most only partially correct the abnormality</td>
</tr>
<tr>
<td>Hypertrophic scars</td>
<td>Can occur anywhere; most often seen in grafted areas, but common in healed burns also; rarely seen in donor sites’ deeper burns, burns that were open for a longer period of time, or burns that were infected tend to form worse hypertrophic scars. More common in persons with greater skin pigmentation.</td>
<td>Thick, red, or purple, hard, nonpliable, raised scars; often itchy and/or painful</td>
<td>Clinical exam</td>
<td>Custom-fitted compression garments reduce and improve almost all of the symptoms associated with hypertrophic scars; silicone sheeting under the compression garment often is synergistic; custom plastic masks may be effective for face scars; garments must be worn 23 1/2 hours per day to be truly effective; a variety of topical medications may improve symptoms: aloe, diphenhydramine lotion, aspirin cream, calcium channel blocker cream, ketamine lotion and many others; some systemic medications may help: antihistamines, nonsteroidal anti-inflammatory drugs, and others; other therapy such as massage, ultrasound, etc., may be useful in selected cases</td>
<td>Scar excisions with primary closure; sequential excision and closure of a scar; excision and grafting; excision and soft tissue coverage following skin expansion</td>
</tr>
<tr>
<td>Complication</td>
<td>Description</td>
<td>Examination/Therapy</td>
<td>Outcome</td>
<td></td>
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<tr>
<td><strong>Keloids</strong></td>
<td>As in previous entry; tend to form in persons with high levels of skin pigmentation</td>
<td>Clinical examination</td>
<td>As in previous entry; steroid injection and/or radiation therapy may be useful</td>
<td></td>
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</tr>
<tr>
<td><strong>Painful scars</strong></td>
<td>Can occur anywhere. More common on extremities than on torso or head.</td>
<td>Painful scars, most sensitive to touch, heat, or cold; can be unpredictable in extent and manifestation of pain; typically burning, may be sharp</td>
<td>Scar excision may be helpful, but usually only temporarily, if at all, effective; surgery should be avoided if at all possible</td>
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<tr>
<td></td>
<td>Clinical examination of scar: palpation, and range of motion</td>
<td>As previously, for hypertrophic scars; desensitization and neuropathic pain medications may be useful (neurontin, amitriptyline)</td>
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<tr>
<td></td>
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<td></td>
<td>This complication is very difficult to manage. Complete resolution is unusual; most patients have residual pain for many years.</td>
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</table>

**Wound contracture**
- Can occur anywhere that has been burned; usually seen with deep burns that have healed or been grafted. Most common: neck, axilla, hands, elbow, knees.
- Skin tightness, especially with extension, decreased range of motion, and decreased functionality
- Clinical examination, and range of motion measurements

Aggressive physical or occupational therapy to prevent and treat; splinting in progressive extension or flexion; massage, ultrasound may be useful adjuncts
- Generally depend upon therapy to prevent and treat; persistent contractures that interfere with function can be released surgically, with local soft tissue transfer or skin grafting
- Wait until scar is mature and physical therapy and occupational therapy have been maximized before considering surgery. Therapy is very important after surgical release.

*(Continued)*
### Microstomia (small mouth)

- **Location**: Mouth
- **Clinical Presentation**: Face, lip, and neck burns, typically; neck and chest burn wound contracture can pull down on the lip, also
- **Diagnosis**: Clinical exam, mouth opening measurements
- **Nonsurgical Options**: Prevention with a microstomia appliance; as in previous entry for hypertrophic scars; aggressive occupational therapy
- **Surgical Options**: Can be released surgically; usually quite successful
- **Prevention**: Prevention is key. A microstomia appliance must be worn at all times to effectively prevent or treat.

### Ectropion (contraction of scar tissue of the eyelid or eversion of the eyelid caused by contraction of facial skin)

- **Location**: Occurs with deep facial burns or burns to the eye area; usually becomes obvious during acute hospitalization.
- **Clinical Presentation**: Inability to close the eyes, thereby causing corneal damage due to drying
- **Diagnosis**: Clinical exam, ophthalmology consult
- **Nonsurgical Options**: Therapy, including scar massage and stretching
- **Surgical Options**: Daily therapy until problem resolves
- **Additional Comments**: Surgical intervention for release and skin grafting is usually indicated.

### Skin infection

- **Location**: Can occur anywhere. May result from infection of ingrown hairs, ingrown glandular secretions, clogged pores, poor vascularization. Often caused by streptococcus or staphylococcus (including MRSA).
- **Clinical Presentation**: Skin redness, pain, erythema, swelling; may see pustules (especially with MRSA) or frank pus; may be subclinical
- **Diagnosis**: Skin examination and wound culture
- **Nonsurgical Options**: Local wound care, pus drainage, debridement of devitalized tissue, removal of foreign body (staple or suture)
- **Surgical Options**: May require aggressive debridement, drainage, excision in the operating room
- **Additional Comments**: Don’t forget to look for infections that are not obvious in wounds that are not healing.
<table>
<thead>
<tr>
<th>Condition</th>
<th>Description</th>
<th>Examination</th>
<th>Treatment</th>
<th>Procedures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fingernail loss</td>
<td>Occurs with deep hand burns. May see fingernail loss without regrowth, deformed nails, jagged nails</td>
<td>Clinical exam</td>
<td>Meticulous nail trimming and cleansing; massage</td>
<td>Can use toenails for reconstructive and cosmetic procedures</td>
</tr>
<tr>
<td>Hair follicle loss</td>
<td>Usually full thickness burn to scalp with follicle destruction.</td>
<td>Clinical exam</td>
<td>Creative hair dressing, wigs, hairpieces, hats, glasses; no effective medications</td>
<td>Reconstruction with tissue expansion in nearby hair-bearing area with subsequent wound excision and soft tissue transfer</td>
</tr>
<tr>
<td>Ingrown hairs</td>
<td>Occurs on hair-bearing areas of the body that have been burned and grafted.</td>
<td>Clinical examination</td>
<td>Local wound care, drainage of pus, topical antibiotics; may require systemic antibiotics</td>
<td>Surgical excision of the offending hair; may require reconstruction or skin grafting</td>
</tr>
<tr>
<td>Loss of sebaceous and/or sweat glands</td>
<td>Almost always associated with deep burns that have been grafted; may occur in deep healed burns.</td>
<td>Clinical examination</td>
<td>Local wound care with lubrication creams/lotions/ointments</td>
<td>No effective surgery</td>
</tr>
</tbody>
</table>

(Continued)
### Complications

<table>
<thead>
<tr>
<th>Eye and Ear Complications</th>
<th>Eye and Ear Complications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inability to close eyes; dry eyes; frequent tearing</td>
<td>Ectropion (eversion of the eyelid)</td>
</tr>
<tr>
<td>Tarsorrhaphy sutures</td>
<td>Usually occurs on upper or lower lid after serious facial burn</td>
</tr>
<tr>
<td>Ophthalmologic examination</td>
<td>Ophthalmologic examination</td>
</tr>
<tr>
<td>Massage and passive stretching may help</td>
<td>Deteriorating visual acuity</td>
</tr>
<tr>
<td>Excision and grafting is usually required</td>
<td>Occurs following electrical injury</td>
</tr>
<tr>
<td>Ophthalmologic examination</td>
<td>Usually none</td>
</tr>
<tr>
<td>Clinical examination</td>
<td>Screening eye examination should be done on all patients with electrical injury</td>
</tr>
</tbody>
</table>

### Marjolin's Ulcer

- Typically develops in a healed or grafted burn that is chronically open; typically occurs 10–30 years after injury.
- Nonhealing wound with associated mass or growth.
- Wound biopsy

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- Nonhealing wound with associated mass or growth.
- Wound biopsy

### Cataract

- Occurs following electrical injury.
- Usually none

### Sensory Testing

- Reassurance of patient; wait for function to return; compression garments, silicone, massage may all help; avoid irritation, trauma; padded clothing.

### Life Care Planning and Case Management Handbook

- Loss of or decreased skin innervation
  - Almost always associated with deep burns that have been grafted; may occur in deep healed burns.
  - Requires life-long treatment, typically.
  - Relatively rare; occurs in far less than 1% of patients.

### Marjolin's Ulcer (squamous cell carcinoma)

- Typically develops in a healed or grafted burn that is chronically open; typically occurs 10–30 years after injury.
- Nonhealing wound with associated mass or growth.
- Wound biopsy

### Cataract

- Occurs following electrical injury.
- Usually none

### Screening eye examination should be done on all patients with electrical injury.
<table>
<thead>
<tr>
<th>Loss of ear cartilage</th>
<th>Full-thickness burn to ear.</th>
<th>Loss of normal anatomic appearance and contour of ear</th>
<th>Clinical examination</th>
<th>Massage and passive stretching may help minimally</th>
<th>Usually requires bone graft and skin grafting; occasionally requires soft tissue transfer</th>
<th>Cosmetic deformity primarily; hearing usually not affected.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Lung and Heart Complications</strong></td>
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</tr>
<tr>
<td><strong>Tracheal stenosis</strong></td>
<td>Tracheal narrowing as a result of prolonged intubation.</td>
<td>Difficulty breathing; poor exercise tolerance; stridor</td>
<td>Clinical examination; bronchoscopy, laryngoscopy computerized tomography</td>
<td>Dilation</td>
<td>Usually requires surgical correction</td>
<td>Usually present at time of discharge from initial hospitalization.</td>
</tr>
<tr>
<td><strong>Pulmonary insufficiency</strong></td>
<td>Results from inhalation injury (toxic effect of breathing products of combustion); may be exacerbated by pulmonary infections while hospitalized.</td>
<td>Poor exercise tolerance; easy fatigability; frequent pulmonary infections; cough</td>
<td>Clinical examination; pulmonary function testing; bronchoscopy</td>
<td>Exercise; bronchodilators</td>
<td>None</td>
<td>May not manifest until years after initial injury; usually present to some degree at time of discharge from initial hospitalization.</td>
</tr>
<tr>
<td><strong>Cardiac dysrhythmias, cardiac dysfunction, coronary artery disease</strong></td>
<td>Occurs following electrical injury.</td>
<td>Chest pain, shortness of breath, poor exercise tolerance</td>
<td>Clinical examination, ECG, echocardiogram; Holter monitor</td>
<td>Exercise, diet, medications</td>
<td>Usually none; may rarely require coronary artery bypass grafting</td>
<td>Very rare complication seen only after electrical injury.</td>
</tr>
</tbody>
</table>

(Continued)
<table>
<thead>
<tr>
<th>Complication</th>
<th>Location</th>
<th>Clinical Presentation</th>
<th>Diagnosis</th>
<th>Nonsurgical Options</th>
<th>Surgical Options</th>
<th>Additional Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neuroma</td>
<td>Nerve or nerve ending that becomes hypersensitive following a burn; usually the result of the nerve or nerve ending getting caught up in the inflammatory process.</td>
<td>Specific hypersensitive or painful and/or tender area usually on an extremity; may be hypersensitive to hot or cold or both</td>
<td>Clinical examination</td>
<td>Compression garments, silicone, topical analgesics, massage, ultrasound</td>
<td>May surgical require excision</td>
<td>Tends not to respond completely regardless of treatment modality.</td>
</tr>
<tr>
<td>Reflexive Sympathetic Dystrophy (RSD)</td>
<td>Idiosyncratic pain syndrome that is poorly defined; usually occurs following serious burn; more common in extremities, especially lower extremity.</td>
<td>Hypersensitive, painful, stiff, inflammatory skin; intolerance of cold or heat or both; may see redness and swelling; exam may be completely normal</td>
<td>Clinical examination</td>
<td>Compression garments, aggressive occupational or physical therapy; ganglion block may be helpful; a variety of medications have been used</td>
<td>Usually none</td>
<td>Difficult to diagnose—typically a diagnosis of exclusion; very difficult to treat successfully.</td>
</tr>
<tr>
<td>Musculoskeletal Complications</td>
<td>Heterotopic ossification</td>
<td>Usually seen in large joints of burned extremities; elbow is the most commonly involved joint.</td>
<td>Decreased range of motion; usually diagnosed by occupational therapists</td>
<td>Clinical examination; x-ray; bone scan</td>
<td>Passive and active range of motion to prevent and treat; dynamic and passive splints or casting; continuous passive range-of-motion devices</td>
<td>Excision and removal of heterotopic bone; postoperative therapy is very important</td>
</tr>
<tr>
<td>Joint subluxation</td>
<td>Typically seen in the small joint in hands, fingers, feet, and toes on burned extremities.</td>
<td>Obvious deformity; decreased function and decreased range of motion</td>
<td>Clinical examination and x-rays</td>
<td>Prevention with range of motion and strengthening, splinting</td>
<td>Surgical release and reconstruction</td>
<td>Wait until scar is mature to surgically correct.</td>
</tr>
<tr>
<td>-------------------</td>
<td>------------------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------</td>
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<td>----------------------------------------------------------</td>
<td>-------------------------------</td>
<td>-------------------------------------------------</td>
</tr>
<tr>
<td>Boutonniere deformity of finger</td>
<td>Dorsal aspect of burn hands involving extensor tendon.</td>
<td>Obvious deformity; decreased function and decreased range of motion</td>
<td>Clinical examination and x-rays</td>
<td>Prevention with range of motion and strengthening, splinting</td>
<td>Surgical release and reconstruction</td>
<td></td>
</tr>
<tr>
<td>Swan neck deformity of finger</td>
<td>Contracture of hand muscles and tendons.</td>
<td>Obvious deformity; decreased function and decreased range of motion</td>
<td>Clinical examination and x-rays</td>
<td>Prevention with range of motion and strengthening, splinting</td>
<td>Surgical release and reconstruction</td>
<td></td>
</tr>
<tr>
<td>Mallet finger deformity</td>
<td>Deep burns to the dorsum or back of hand: involves extensor tendons.</td>
<td>Obvious deformity; decreased function and decreased range of motion; inability to extend the distal interphalangeal joint of finger</td>
<td>Clinical examination and x-rays</td>
<td>Prevention with range of motion and strengthening, splinting</td>
<td>Surgical release and reconstruction with tendon repair</td>
<td></td>
</tr>
</tbody>
</table>

(Continued)
<table>
<thead>
<tr>
<th>Complication</th>
<th>Location</th>
<th>Clinical Presentation</th>
<th>Diagnosis</th>
<th>Nonsurgical Options</th>
<th>Surgical Options</th>
<th>Additional Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exposed tendons</td>
<td>Deep burns, usually of hands or feet.</td>
<td>Obviously exposed tendons with decreased function</td>
<td>Clinical examination</td>
<td>Local wound care; protection of tendon from dessication</td>
<td>Soft tissue transfer and reconstruction</td>
<td>Usually requires surgery; may use skin substitutes.</td>
</tr>
<tr>
<td>Shortened extremity</td>
<td>Burn scars on extremities prevent normal bone growth.</td>
<td>Obviously shortened extremity with decreased function</td>
<td>Clinical examination</td>
<td>Aggressive physical and occupational therapy</td>
<td>May require reconstruction for severe limitation of function</td>
<td>Usually requires wound contracture release simultaneously.</td>
</tr>
<tr>
<td>Limb amputation</td>
<td>Full thickness burns of extremities; often with compartment syndrome and/or vascular insufficiency.</td>
<td>Obvious loss of extremity</td>
<td>None</td>
<td>Preoperative planning, if possible; immediate postoperative prosthesis if possible; maintenance of joint above amputation in neutral position; stump care; strengthening and balance training</td>
<td>Stump may require revision for chronic wound and/or poor soft tissue padding</td>
<td>Involvement of patient and family in care vital to success.</td>
</tr>
</tbody>
</table>
The following checklist can be utilized when meeting with care providers and considering future care needs.

**Burn Life Care Plan Checklist**

<table>
<thead>
<tr>
<th>Annual Evaluations</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Physicians/Surgeons</td>
<td></td>
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<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Primary Care</td>
<td></td>
</tr>
<tr>
<td>Surgeries related to growth or aging:</td>
<td></td>
</tr>
<tr>
<td>Contracture Releases</td>
<td></td>
</tr>
<tr>
<td>Dermabrasion</td>
<td></td>
</tr>
<tr>
<td>Hand Surgeries</td>
<td></td>
</tr>
<tr>
<td>Hypertrophic Scarring</td>
<td></td>
</tr>
<tr>
<td>Heterotropic Ossification</td>
<td></td>
</tr>
<tr>
<td>Tissue Expansion</td>
<td></td>
</tr>
<tr>
<td>Scar Excision</td>
<td></td>
</tr>
<tr>
<td>Emergency Room Visits</td>
<td></td>
</tr>
<tr>
<td>Physical Discomfort</td>
<td></td>
</tr>
<tr>
<td>Pain Control</td>
<td></td>
</tr>
<tr>
<td>Itching</td>
<td></td>
</tr>
<tr>
<td>Skin Breakdown</td>
<td></td>
</tr>
<tr>
<td>Range-of-Motion Issues</td>
<td></td>
</tr>
<tr>
<td>Sleep Problems</td>
<td></td>
</tr>
<tr>
<td>Aesthetic Issues:</td>
<td></td>
</tr>
<tr>
<td>Eyebrows</td>
<td></td>
</tr>
<tr>
<td>Nipples</td>
<td></td>
</tr>
<tr>
<td>Fingernails</td>
<td></td>
</tr>
<tr>
<td>Eyelashes</td>
<td></td>
</tr>
<tr>
<td>Special Makeup</td>
<td></td>
</tr>
<tr>
<td>Breast Implants</td>
<td></td>
</tr>
<tr>
<td>Special Bra</td>
<td></td>
</tr>
<tr>
<td>Breast Prosthesis</td>
<td></td>
</tr>
<tr>
<td>Pressure Garments</td>
<td></td>
</tr>
<tr>
<td>Face Mask</td>
<td></td>
</tr>
<tr>
<td>Arms</td>
<td></td>
</tr>
<tr>
<td>Trunk</td>
<td></td>
</tr>
</tbody>
</table>
Back
Legs
Hands/Gloves
Zippers
Silicone Sheeting
Splinting
Occupational Therapy Needs
Physical Therapy Needs
Speech Therapy Needs
Massage Therapy
Lotions
Dressing Change Materials
Sun Protection Needs
Sunscreen
Special UV-Protective Clothing
Nutritional Needs
Case Management
Psychological Interventions
Psychiatry
Play Therapy
Neuropsych Testing
Family Therapy
Individual Psychotherapy
Support Group
Burn Camp
World Burn Congress
Hypnosis
Educational Needs
Private School
Tutoring
IEP Assistance
Vocational Needs
Job Training
Vocational Counseling
Work Hardening
Workplace Reintegration
Recreational Issues
  Recreation Therapy ____________________

Home Care
  Home Health ____________________
  Respite Care for Parents/Spouse ____________________
  Aids to Daily Living ____________________
  Assisted Living Needs ____________________
  Housekeeping ____________________
  Handyman ____________________

Mobility
  Wheelchair ____________________
  Scooter ____________________
  Walker ____________________
  Prosthetics ____________________

Pulmonary Issues
  Pulmonologist ____________________
  Breathing Treatments ____________________
  Humidifier ____________________
  Dressing Change Materials ____________________
  Pain Medications ____________________
  Other Medications ____________________
  Conservatorship ____________________

Case Study
The following is a case study and resulting life care plan for a 46-year-old man who was severely burned at age 44. The names and dates have been changed, but the details of the case are real.

Summary
Jonathon Doe is currently a 46-year-old male who sustained severe flash and flame burns to approximately 85% of his body, including his face, hands, neck, trunk and back, bilateral upper and lower extremities, ankles, and feet, at the age of 44. He was hospitalized at Anytown Burn Center for 6 months. He was then transferred to Anytown Rehabilitation for therapy for a total of 55 days due to his considerable and severe burn injuries.
Life Care Plan for Jonathon Doe

Narrative Summary

Summary

Jonathon Doe is a 46-year-old male who sustained severe flash and flame burns to approximately 85% of his body, including his face, hands, neck, trunk and back, bilateral upper and lower extremities, ankles, and feet, at the age of 44. He was hospitalized at Anytown Burn Center for 6 months. He was then transferred to Anytown Rehabilitation for therapies for 55 days for his considerable and severe burn injuries.

Life Expectancy

Life expectancy according to the Vital Statistics of the United States 2000 Life Tables indicated that a 46-year-old American male should live another 31 years.

Medical Overview

Mr. Jonathon Doe is a 46-year-old Caucasian male, who was burned over 85% of his body, with a majority of the burns being third degree, as a result of a hotel fire. When EMS arrived he was outside, alert, and oriented, but in severe distress. There was no reported loss of consciousness. Mr. Doe suffered an 85% TBSA thermal burn injury with concurrent inhalation injury.

Records were reviewed of Jonathon’s hospitalization at Anytown Hospital Burn Center, where he remained inpatient for 6 months.

Jonathon sustained burns of mostly third-degree burns (85%) to his face, neck, bilateral arms and hands, knees, torso, both legs, back, and feet. He required extensive skin grafting with mostly cultured epithelial cells to all of these areas during his acute hospitalization.

Jonathon was hospitalized for surgical care of his burn wounds, fluid resuscitation, respiratory distress, multiple therapies, and pain management. Outpatient issues were continuing burn care, psychological counseling for posttraumatic stress disorder and depression, heterotopic ossification, development of hypertrophic and contracture scars, open wounds, and pain management.

Emergency Department

Jonathon Doe is a 44-year-old Caucasian male. He arrived at Anytown Hospital via ambulance after sustaining an estimated 85% total body surface area (TBSA) thermal burn injury. Jonathon was burned in a hotel fire.

Jonathon’s severe burn injuries were such that he was at serious risk for the development of burn shock. There is a chain reaction of events that occur in large burns and that result in the shift of intravascular fluid into the surrounding tissues, thus putting the individual at risk for shock. To treat this, IV access was obtained and fluid resuscitation with normal saline was started. A Foley catheter was placed to closely monitor urine output, which is used as one guide for volume status. Vital signs were closely monitored.

Multiple surgeries included escharotomies of burns, debridement, and ultimately the placement of allograft and split-thickness skin grafts by Dr. Burn Surgeon. Mr. Doe was followed by Dr. Breath for pulmonary issues. Dr. Germs followed Jonathon for infectious disease. The following surgeries were performed to close Mr. Doe’s extensive burn wounds:
Life Care Planning for the Burn Patient

Full Face/Portion Neck/Upper Chest—Debridement of burned skin.
Arms—Split-thickness skin grafting to right hand/wrist/forearm/upper arm and hand and wrist.
Chest/Abdomen—Skin grafts and cultured skin/cultured epidermal autografts (CEAs).
Back/Flanks/Bilateral Buttocks—Application of CEAs and subsequent split-thickness skin grafting.
Heels and Portions of Feet—Application of CEAs.
Legs—Application of CEAs—subsequent skin graft behind knees.

Mr. Doe had many complications associated with his severe burn injury. These included the following:

- Respiratory failure necessitating mechanical ventilation. He remained on the ventilator for 32 days.
- Compartment syndrome requiring the following escharotomies:
  - Medial and lateral bilateral upper extremities
  - Dorsum of hands
  - All fingers and toes bilaterally
  - Feet (very deep circumferential burns of legs and particularly feet and ankles)
  - Medial and lateral legs
  - Left and right chest
- Right lower lobe pneumonia
- Acute Respiratory Distress Syndrome (ARDS)
- Hypothermia
- Sepsis (multiple episodes of positive blood cultures)
- Acidosis
- Hypoalbuminemia
- Elevated liver enzymes
- Narcotic withdrawal; at one point was on morphine. Weaning was a long laborious process involving the use of methadone
- Seizures—probably related to high-dose morphine
- Multiple wound infections (both bacterial and fungal)
- Multidrug resistant pseudomonas infections. Varying degrees of loss of range of motion in all joints

Current Status and Disabling Problems

Jonathon Doe remains disabled secondary to his severe burn injuries. Current issues include range-of-motion problems with bilateral elbows and bilateral axillae; hypertrophic ossification to bilateral elbows; contractures of bilateral popliteals, bilateral shoulders, and bilateral hands; daily pain; and contractures of the right foot.

Medical History

Up to the point of the accident, Jonathon reports that he was in excellent health. He was a smoker at the time of the injury. He reports that he continues to smoke approximately five cigarettes a day. He was an active person and an avid soccer player prior to sustaining severe burns.
Marital History
Jonathon is single. He states in his deposition that he has a very close relationship with a woman who he has been seeing for 5 years.

Family History
Jonathon grew up in Anytown, USA. His parents, Mr. and Mrs. Tom Doe, continue to reside in Anytown. He has two sisters, who also reside in Anytown, USA.

Social History
Jonathon was extremely socially and physically active and was independent in self-care, financial, and household management. He seemed to have fairly good coping skills and had strong spirituality, as well as a support system that included his family and church.

Educational History
Jonathon attended school in Anytown, USA, and graduated from Anytown in 1980. He was self-employed as a carpenter.

Employment History
Jonathon has worked throughout his adult life. He has been unable to return to his former employment due to range-of-motion problems and loss of feeling in his hands and wrists. His psychologist reports that his accomplishment in his job was “a key part of his identity.” His doctor said he will never be able to return to his former job as a carpenter.

Current Social Activities
Jonathon has shared that he continues to be in pain since his discharge from the hospital. He is unable to sleep and reports suffering from feelings of incompetence and hopelessness.

Medical Course
Jonathon will likely require surgeries to his bilateral elbows, axillae, and bilateral posterior knees; dermabrasion to the face; possible other contracture releases; and possible corrective surgeries for his hands. He will continue to require pain management, occupational and physical therapy, mobility assistance, splinting and pressure garments, and psychological interventions for a number of years. The recommendations of his treating physician follow in the life care plan tables (see Charts 2 and 3).
### Chart 2  Life Care Plan for Jonathon H Doe

Primary Disability: 85%–Mostly 3rd-Degree Burns  
Date of Injury: March 10, 2004  
Date of Birth: March 12, 1959  
February 8, 2009  
Ruth B Rimmer, PhD, CLCP  
2145 East Glencove  
480-612-2994

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#### Option 1

<table>
<thead>
<tr>
<th>Projected Evaluations</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Plastic Surgeon</strong></td>
</tr>
<tr>
<td><strong># Start Year/Age</strong></td>
</tr>
<tr>
<td>2006/46</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon  
Purpose: Evaluate for necessary surgical treatment for the coming year.  
Comment: Plastic Surgeon who is a burn specialist like Dr. Fixit.

<table>
<thead>
<tr>
<th><strong>Internal Medicine</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong># Start Year/Age</strong></td>
</tr>
<tr>
<td>2006/46</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon  
Purpose: Have an annual evaluation to determine how major body systems, stressed by the burn injuries, are doing.
### Burn Surgeon

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2016/56</td>
<td>2037/77</td>
<td>1 Time/ 2–3 Years</td>
<td>$250.00 to $400.00</td>
<td>$83.33 to $200.00</td>
<td>22</td>
<td>$141.67</td>
<td>$3,116.74</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Should continue to see a burn surgeon after his major reconstructive and contracture release surgeries are done every 2–3 years.

### Physiatrist

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2037/77</td>
<td>1 Visit/ Year</td>
<td>$250.00 to $300.00</td>
<td>$250.00 to $300.00</td>
<td>32</td>
<td>$275.00</td>
<td>$8,800.00</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Evaluate for rehab needs

### Dietician

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2015/55</td>
<td>1 Time/ Year</td>
<td>$125.00 to $150.00</td>
<td>$125.00 to $150.00</td>
<td>10</td>
<td>$137.50</td>
<td>$1,375.00</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Evaluate for nutritional needs.

Comment: Assist through surgical procedures—help maintain healthy weight.

### Dermatologist

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2037/77</td>
<td>1 Visit/ Year</td>
<td>$125.00 to $150.00</td>
<td>$125.00 to $150.00</td>
<td>32</td>
<td>$137.50</td>
<td>$4,400.00</td>
</tr>
</tbody>
</table>
Recommended By: Dr. Burn Surgeon

Purpose: Evaluate for skin cancer, skin condition.

**Occupational Therapy**

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2037/77</td>
<td>1 Per/ Year</td>
<td>$200.00 to $250.00</td>
<td>$200.00 to $250.00</td>
<td>32</td>
<td>$225.00</td>
<td>$7,200.00</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Evaluate for upper body range of motion and mobility.

**Otolaryngologist**

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2015/55</td>
<td>1 Time/ Year</td>
<td>$100.00 to $300.00</td>
<td>$100.00 to $300.00</td>
<td>10</td>
<td>$200.00</td>
<td>$2,000.00</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Monitor airway.

Comment: To be seen during years he has surgery.

**Physical Therapy**

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2037/77</td>
<td>1 Time/ Year</td>
<td>$300.00</td>
<td>$300.00</td>
<td>32</td>
<td>$300.00</td>
<td>$9,600.00</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Evaluate for range of motion and mobility issues.

(Continued)
<table>
<thead>
<tr>
<th>Professional</th>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychiatrist</td>
<td>2006/46</td>
<td>2015/55</td>
<td>1 Time/ 3 Years</td>
<td>$350.00 to $500.00</td>
<td>$100.00 to $166.67</td>
<td>10</td>
<td>$1,416.70</td>
</tr>
<tr>
<td>Psychologist</td>
<td>2006/46</td>
<td>2011/51</td>
<td>1 Per/ Year</td>
<td>$200.00 to $250.00</td>
<td>$200.00 to $250.00</td>
<td>6</td>
<td>$1,350.00</td>
</tr>
<tr>
<td>Podiatrist</td>
<td>2006/46</td>
<td>2037/77</td>
<td>1 Time/Year</td>
<td>$150.00 to $175.00</td>
<td>$150.00 to $175.00</td>
<td>32</td>
<td>$5,200.00</td>
</tr>
</tbody>
</table>

**Recommended By:**
- Dr. Burn Surgeon
- Mary Psychologist, PhD

**Purpose:**
- Psychiatrist: Evaluate for PTSD, depression, etc. Dispense medication if necessary
- Psychologist: Evaluate for PTSD and/or depression. Comment: Allows him to have regular session as he moves through the surgical phase.
- Podiatrist: Evaluate condition of feet, special shoes, nail care. Comment: He continues to have loss of sensation in his feet; had infection from ingrown toenails; needs special shoes.
### Ophthalmologist

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2037/77</td>
<td>1 Visit/Year</td>
<td>$150.00 to $165.00</td>
<td>$150.00 to $165.00</td>
<td>32</td>
<td>$157.50</td>
<td>$5,040.00</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Monitor for vision problems.

### Recreational Therapy

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2037/77</td>
<td>1 Time/5 Years</td>
<td>$160.00</td>
<td>$32.00</td>
<td>32</td>
<td>$32.00</td>
<td>$1,024.00</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Assess Jonathon's productive usage and engagement in leisure activities.

Comment: Assist with integration back into art work and improve psychological well-being.

### Dental Evaluation

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2012/52</td>
<td>1 Time/Year</td>
<td>$250.00 to $350.00</td>
<td>$250.00 to $350.00</td>
<td>7</td>
<td>$300.00</td>
<td>$2,100.00</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Evaluate dental condition after burn injury.

### Psychologist

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2012/52</td>
<td>2037/77</td>
<td>1 Time/3–4 Years</td>
<td>$380.00 to $450.00</td>
<td>$95.00 to $150.00</td>
<td>26</td>
<td>$122.50</td>
<td>$3,185.00</td>
</tr>
</tbody>
</table>

Recommended By: Mary Psychologist, PhD

Purpose: Evaluate during life changes, aging issues, etc.

(Continued)
### Psychiatrist

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2016/56</td>
<td>2037/77</td>
<td>1 Time/5–7 Years</td>
<td>$350.00 to $500.00</td>
<td>$50.00 to $100.00</td>
<td>22</td>
<td>$75.00</td>
<td>$1,650.00</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon, Mary Psychologist, PhD

Purpose: Evaluate for life changes and aging issues.

---

#### Projected Therapeutic Modalities

**Occupational Therapy**

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011/51</td>
<td>2037/77</td>
<td>24–36 Times/4 Years</td>
<td>$150.00 to $175.00</td>
<td>$900.00 to $1,575.00</td>
<td>27</td>
<td>$1,237.50</td>
<td>$33,412.50</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Intermittent therapy to maintain range of motion and mobility.

**Physical Therapy**

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011/51</td>
<td>2037/77</td>
<td>12–24 Times/3–4 Years</td>
<td>$150.00 to $225.00</td>
<td>$450.00 to $1,800.00</td>
<td>27</td>
<td>$1,125.00</td>
<td>$30,375.00</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Intermittent therapy to maintain range of motion and mobility.
### Hypnotherapy

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2010/50</td>
<td>4–6 Times/Year</td>
<td>$100.00 to $125.00</td>
<td>$400.00 to $750.00</td>
<td>5</td>
<td>$575.00</td>
<td>$2,875.00</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Assist with pain control and anxiety reduction.

### Individual Psychotherapy

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2007/47</td>
<td>48 Visits/ Year</td>
<td>$150.00</td>
<td>$7,200.00</td>
<td>2</td>
<td>$7,200.00</td>
<td>$14,400.00</td>
</tr>
</tbody>
</table>

Recommended By: Mary Psychologist, PhD

Purpose: PTSD management; evaluate for depression.

### Massage Therapy Intermediate

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2015/55</td>
<td>24–32 Times/Year</td>
<td>$75.00 to $100.00</td>
<td>$1,800.00 to $3,200.00</td>
<td>10</td>
<td>$2,500.00</td>
<td>$25,000.00</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Massage therapy for scar management and suppleness of skin.

### Massage Therapy Ongoing

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2016/56</td>
<td>2037/77</td>
<td>12 Times/Year</td>
<td>$75.00 to $100.00</td>
<td>$900.00 to $1,200.00</td>
<td>22</td>
<td>$1,050.00</td>
<td>$23,100.00</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Massage therapy for scar management and pain control.

(Continued)
### Chart 2 (Continued)

#### Disabled Driver Training

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2006/46</td>
<td>3–5 Hours/Year</td>
<td>$120.00</td>
<td>$360.00 to $600.00</td>
<td>1</td>
<td>$480.00</td>
<td>$480.00</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Address special driving needs.

#### Individual Psychotherapy

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2010/50</td>
<td>24 Visits/Year</td>
<td>$150.00</td>
<td>$3,600.00</td>
<td>5</td>
<td>$3,600.00</td>
<td>$18,000.00</td>
</tr>
</tbody>
</table>

Recommended By: Mary Psychologist, PhD

Purpose: Psychotherapy for PTSD every two weeks until major surgeries are behind him.

#### Individual Psychotherapy

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011/51</td>
<td>2037/77</td>
<td>12–24 Times/4 Years</td>
<td>$150.00</td>
<td>$450.00 to $900.00</td>
<td>27</td>
<td>$675.00</td>
<td>$18,225.00</td>
</tr>
</tbody>
</table>

Recommended By: Mary Psychologist, PhD

Purpose: 3–4 months of sessions during major life changes.

#### Vocational Rehabilitation Evaluation

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2007/47</td>
<td>2007/47</td>
<td>1 Time/Year</td>
<td>$1,000.00 to $1,500.00</td>
<td>$1,000.00 to $1,500.00</td>
<td>1</td>
<td>$1,250.00</td>
<td>$1,250.00</td>
</tr>
</tbody>
</table>
Recommended By: Dr. Burn Surgeon
Purpose: Evaluate for potential and appropriate job opportunities.

<table>
<thead>
<tr>
<th>Scooter</th>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wheelchair(s)/Mobility/Maintenance</td>
<td>2006/46</td>
<td>2037/77</td>
<td>1 Per/7–10 Years</td>
<td>$2,620.00 to $2,935.00</td>
<td>$262.00 to $419.29</td>
<td>32</td>
<td>$340.64</td>
<td>$10,900.48</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon
Purpose: Mobility
Comment: Mr. Doe tires easily. This would allow him longer periods of activity outside the home.

<table>
<thead>
<tr>
<th>Scooter Batteries</th>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2037/77</td>
<td>2 Per/5 Years</td>
<td>$46.00</td>
<td>$18.40</td>
<td>32</td>
<td>$18.40</td>
<td>$588.80</td>
<td></td>
</tr>
</tbody>
</table>

Purpose: Allows for longer outings. Back-up batteries.

<table>
<thead>
<tr>
<th>Scooter Maintenance</th>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2037/77</td>
<td>1 Time/2 Years</td>
<td>$125.00 to $150.00</td>
<td>$62.50 to $75.00</td>
<td>32</td>
<td>$68.75</td>
<td>$2,200.00</td>
<td></td>
</tr>
</tbody>
</table>

Purpose: Maintain the scooter, tires, etc.

(Continued)
### Scooter Canopy

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2037/77</td>
<td>1 Time/10 Years</td>
<td>$196.62</td>
<td>$19.66</td>
<td>32</td>
<td>$19.66</td>
<td>$629.12</td>
</tr>
</tbody>
</table>

**Purpose:** Protect from sun and create barrier against rain, etc

---

### Wheelchair, 4-Wheel Drive Power

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2037/77</td>
<td>1 Per/ 7–10 Years</td>
<td>$2,600.00 to $3,000.00</td>
<td>$260.00 to $428.57</td>
<td>32</td>
<td>$344.29</td>
<td>$11,017.28</td>
</tr>
</tbody>
</table>

**Recommended By:** Dr. Burn Surgeon

**Purpose:** Mobility. He has limited stamina for long outings.

---

### Maintain Power Wheelchair

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2037/77</td>
<td>1 Time/2 Years</td>
<td>$125.00 to $150.00</td>
<td>$62.50 to $75.00</td>
<td>32</td>
<td>$68.75</td>
<td>$2,200.00</td>
</tr>
</tbody>
</table>

**Purpose:** Maintain wheelchair, tires, etc.

---

### Power Wheelchair Batteries

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2037/77</td>
<td>2 Per/ 5 Years</td>
<td>$46.00</td>
<td>$18.40</td>
<td>32</td>
<td>$18.40</td>
<td>$588.80</td>
</tr>
</tbody>
</table>

**Purpose:** Extra backup batteries

---

Option 1 Wheelchair(s)/Mobility/Maintenance Subtotal $28,124.48
<table>
<thead>
<tr>
<th>Orthotics/Prosthetics</th>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th># Total Number</th>
<th>Cost Per Year</th>
<th>Cost Per Year</th>
<th>Average</th>
<th>Total Cost</th>
<th>Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Compression Garments/Arms</td>
<td>2006/46</td>
<td>2037/77</td>
<td>8–10 Times/Year</td>
<td>$69.99</td>
<td>$559.92 to $699.90</td>
<td>32</td>
<td></td>
<td>$629.91</td>
<td>$20,157.12</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recommended By: Dr. Burn Surgeon</td>
<td>Purpose: Assist with circulation, prevent DVTs.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Compression Garments—Legs</td>
<td>2006/46</td>
<td>2037/77</td>
<td>8–10 Per/Year</td>
<td>$79.61</td>
<td>$636.88 to $796.10</td>
<td>32</td>
<td></td>
<td>$716.49</td>
<td>$22,927.68</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recommended By: Dr. Burn Surgeon</td>
<td>Purpose: Assist with circulation, prevent DVTs. Comment: 2–3 sets per year.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Silicone Face Mask</td>
<td>2006/46</td>
<td>2007/47</td>
<td>1 Per/Year</td>
<td>$1,800.00 to $2,000.00</td>
<td>$1,800.00 to $2,000.00</td>
<td>2</td>
<td></td>
<td>$1,900.00</td>
<td>$3,800.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recommended By: Dr. Burn Surgeon</td>
<td>Purpose: Scar compression, decrease itching. Comment: May need after facial dermabrasion.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(Continued)
<table>
<thead>
<tr>
<th>Compression Garments—Gloves</th>
<th>2006/46</th>
<th>2015/55</th>
<th>4–6 Per/Year</th>
<th>$214.00</th>
<th>$856.00 to $1,284.00</th>
<th>10</th>
<th>$1,070.00</th>
<th>$10,700.00</th>
</tr>
</thead>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Scar compression, increased circulation, decreased itching.

Elbow Splint

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2008/48</td>
<td>2–4 Times/1–2 Years</td>
<td>$111.78</td>
<td>$111.78 to $447.12</td>
<td>3</td>
<td>$279.45</td>
<td>$838.35</td>
</tr>
</tbody>
</table>

Recommended By: Mr. Moveit, OT

Purpose: Splinting after surgery

Elastomer

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2008/48</td>
<td>2–4 Times/1–2 Years</td>
<td>$58.50</td>
<td>$58.50 to $234.00</td>
<td>3</td>
<td>$146.25</td>
<td>$438.75</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Material for under splint.

Long Leg Splint

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2006/46</td>
<td>2 Times/Year</td>
<td>$122.78</td>
<td>$245.56</td>
<td>1</td>
<td>$245.56</td>
<td>$245.56</td>
</tr>
</tbody>
</table>

Recommended By: Mr. Moveit, OT

Purpose: Needs after popliteal correction surgery.
<table>
<thead>
<tr>
<th>Elastomer</th>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2006/46</td>
<td>2006/46</td>
<td>2 Times/ Year</td>
<td>$58.50</td>
<td>$117.00</td>
<td>1</td>
<td>$117.00</td>
<td>$117.00</td>
</tr>
</tbody>
</table>

Recommended By: Mr. Moveit, OT

Purpose: Used under splint.

<table>
<thead>
<tr>
<th>Axilla Splint</th>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2006/46</td>
<td>2012/52</td>
<td>4 Times/ 6 Years</td>
<td>$1,800.00 to $2,000.00</td>
<td>$1,200.00 to $1,333.33</td>
<td>7</td>
<td>$1,266.67</td>
<td>$8,866.69</td>
</tr>
</tbody>
</table>

Recommended By: Mr. Moveit, OT

Purpose: Use splint after axilla release surgeries.

<table>
<thead>
<tr>
<th>Elastomer</th>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2006/46</td>
<td>2012/52</td>
<td>4 Times/ 6 Years</td>
<td>$58.50</td>
<td>$39.00</td>
<td>7</td>
<td>$39.00</td>
<td>$273.00</td>
</tr>
</tbody>
</table>

Recommended By: Mr. Moveit, OT

Purpose: Used under splint.

Option 1 Orthotics/Prosthetics Subtotal $68,364.15
<table>
<thead>
<tr>
<th>Option 1 Orthopedic Equipment Subtotal $9,810.00</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Orthopedic Equipment</strong></td>
</tr>
<tr>
<td><strong>CPM</strong></td>
</tr>
<tr>
<td># Start Year/Age</td>
</tr>
<tr>
<td>2006/46</td>
</tr>
<tr>
<td><strong>Recommended By: Dr. Burn Surgeon</strong></td>
</tr>
<tr>
<td><strong>Purpose:</strong> Used daily for 3–4 months after elbow surgery.</td>
</tr>
<tr>
<td><strong>Option 1 Orthopedic Equipment Subtotal $9,810.00</strong></td>
</tr>
<tr>
<td><strong>Aids for Independent Function</strong></td>
</tr>
<tr>
<td><strong>Button and Zipper Aid</strong></td>
</tr>
<tr>
<td># Start Year/Age</td>
</tr>
<tr>
<td>2006/46</td>
</tr>
<tr>
<td><strong>Recommended By: Dr. Burn Surgeon</strong></td>
</tr>
<tr>
<td><strong>Purpose:</strong> Assist in buttoning and zipping.</td>
</tr>
<tr>
<td><strong>Adaptive Clothing</strong></td>
</tr>
<tr>
<td># Start Year/Age</td>
</tr>
<tr>
<td>2006/46</td>
</tr>
<tr>
<td><strong>Recommended By: Dr. Burn Surgeon</strong></td>
</tr>
<tr>
<td><strong>Purpose:</strong> SUV protection.</td>
</tr>
<tr>
<td><strong>Long-Handled Bath Brush</strong></td>
</tr>
<tr>
<td># Start Year/Age</td>
</tr>
<tr>
<td>-----------------</td>
</tr>
<tr>
<td>2006/46</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Better able to shower independently.

---

**Reacher**

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2037/77</td>
<td>1 Time/ 4–5 Years</td>
<td>$9.95</td>
<td>$1.99 to $2.49</td>
<td>32</td>
<td>$2.24</td>
<td>$71.68</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Helps to reach things independently.

---

**Shower Chair**

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2037/77</td>
<td>1 Per/ 4–5 Years</td>
<td>$40.00 to $45.00</td>
<td>$8.00 to $11.25</td>
<td>32</td>
<td>$9.63</td>
<td>$308.16</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Avoid falls in shower.

---

**Jar Opener**

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2037/77</td>
<td>1 Per/ 4–5 Years</td>
<td>$12.25 to $14.00</td>
<td>$2.45 to $3.50</td>
<td>32</td>
<td>$2.98</td>
<td>$95.36</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Open jars independently.
<table>
<thead>
<tr>
<th>Item</th>
<th>Start Year/Age</th>
<th>End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th>Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Shower, Handheld</strong></td>
<td>2006/46</td>
<td>2037/77</td>
<td>1 Per/ 5 Years</td>
<td>$34.95</td>
<td>$6.99</td>
<td>32</td>
<td>$6.99</td>
<td>$223.68</td>
</tr>
<tr>
<td>Recommended By: Dr. Burn Surgeon</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Purpose: Better able to shower by himself.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Long Shoehorn</strong></td>
<td>2006/46</td>
<td>2037/77</td>
<td>1 Per/ 5 Years</td>
<td>$24.00</td>
<td>$4.80</td>
<td>32</td>
<td>$4.80</td>
<td>$153.60</td>
</tr>
<tr>
<td>Recommended By: Dr. Burn Surgeon</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Purpose: Helps to put on his own shoes and socks.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Tub Transfer Brush</strong></td>
<td>2006/46</td>
<td>2037/77</td>
<td>1 Per/ 5 Years</td>
<td>$129.00</td>
<td>$25.80</td>
<td>32</td>
<td>$25.80</td>
<td>$825.60</td>
</tr>
<tr>
<td>Recommended By: Dr. Burn Surgeon</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Purpose: Transfer out of tub.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Commode with Padded Seat</strong></td>
<td>2006/46</td>
<td>2037/77</td>
<td>1 Per/ 5 Years</td>
<td>$38.00</td>
<td>$7.60</td>
<td>32</td>
<td>$7.60</td>
<td>$243.20</td>
</tr>
<tr>
<td>Recommended By: Dr. Burn Surgeon</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Purpose: Padded seat with arms.</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Medication Organizer/Box

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2037/77</td>
<td>1 Per/ 3–4 Years</td>
<td>$3.00 to $6.00</td>
<td>$0.75 to $2.00</td>
<td>32</td>
<td>$1.38</td>
<td>$44.16</td>
</tr>
</tbody>
</table>

Recommended By: Ms. Healthy, Burn Nurse Practitioner

Purpose: Keep medicines organized.

<table>
<thead>
<tr>
<th>Option 1 Aids for Independent Function Subtotal</th>
<th>$32,586.56</th>
</tr>
</thead>
</table>

### Bandage Scissors

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2015/55</td>
<td>1 Per/ Year</td>
<td>$6.00 to $9.00</td>
<td>$6.00 to $9.00</td>
<td>10</td>
<td>$7.50</td>
<td>$75.00</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Dressing changes.

### Dressing Change Materials

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2012/52</td>
<td>4 Times/ Year</td>
<td>$400.00 to $450.00</td>
<td>$1,600.00 to $1,800.00</td>
<td>7</td>
<td>$1,700.00</td>
<td>$11,900.00</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Dressing change materials postsurgery.

(Continued)
### Gloves, Latex

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2015/55</td>
<td>2 Per/ Year</td>
<td>$6.00</td>
<td>$12.00</td>
<td>10</td>
<td>$12.00</td>
<td>$120.00</td>
</tr>
</tbody>
</table>

**Recommended By:** Ms. Healthy, Burn Nurse Practitioner

**Purpose:** For dressing changes.

### Ensure

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2010/50</td>
<td>1080–1440 Per/ Year</td>
<td>$2.00 to $2.12</td>
<td>$2,160.00 to $3,052.80</td>
<td>5</td>
<td>$2,606.40</td>
<td>$13,032.00</td>
</tr>
</tbody>
</table>

**Recommended By:** Dr. Burn Surgeon

**Purpose:** Nutritional boost during years of surgery.

### Aloe First Spray

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2037/77</td>
<td>12 Per/ Year</td>
<td>$12.00</td>
<td>$144.00</td>
<td>32</td>
<td>$144.00</td>
<td>$4,608.00</td>
</tr>
</tbody>
</table>

**Recommended By:** Dr. Burn Surgeon

**Purpose:** Helps maintain dry skin and reduce itching.

### Aloe Vera Lotion

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2037/77</td>
<td>3–4 Per/ Month</td>
<td>$12.00</td>
<td>$432.00 to $576.00</td>
<td>32</td>
<td>$504.00</td>
<td>$16,128.00</td>
</tr>
</tbody>
</table>

**Recommended By:** Dr. Burn Surgeon
### Life Care Planning for the Burn Patient

**Purpose:** Helps maintain dry, cracking skin.

**Lip Balm**

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2037/77</td>
<td>24 Per Year</td>
<td>$5.00</td>
<td>$120.00</td>
<td>32</td>
<td>$120.00</td>
<td>$3,840.00</td>
</tr>
</tbody>
</table>

**Recommended By:** Dr. Burn Surgeon

**Purpose:** Helps for dry, cracking lips.

**Aquaphor**

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2037/77</td>
<td>48–60 Times/Year</td>
<td>$16.99</td>
<td>$815.52 to $1,019.40</td>
<td>32</td>
<td>$917.46</td>
<td>$29,358.72</td>
</tr>
</tbody>
</table>

**Recommended By:** Dr. Burn Surgeon

**Purpose:** Dry sensitive skin.

**Maderma**

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2012/52</td>
<td>10–12 Per Year</td>
<td>$28.99</td>
<td>$289.90 to $347.88</td>
<td>7</td>
<td>$318.89</td>
<td>$2,232.23</td>
</tr>
</tbody>
</table>

**Recommended By:** Dr. Burn Surgeon

**Purpose:** Scar management.

Option 1 Supplies Subtotal $81,293.95

(Continued)
<table>
<thead>
<tr>
<th>Medications</th>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neurontin</td>
<td>2006/46</td>
<td>2037/77</td>
<td>11 Per/Year</td>
<td>$460.59</td>
<td>$5,066.49</td>
<td>32</td>
<td>$5,066.49</td>
<td>$162,127.68</td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ibuprofen</td>
<td>2006/46</td>
<td>2037/77</td>
<td>2 Per/Year</td>
<td>$14.99</td>
<td>$29.98</td>
<td>32</td>
<td>$29.98</td>
<td>$959.36</td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pepcid AC Tablets</td>
<td>2006/46</td>
<td>2037/77</td>
<td>12 Per/Year</td>
<td>$17.99</td>
<td>$215.88</td>
<td>32</td>
<td>$215.88</td>
<td>$6,908.16</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Pain control—1 bottle has 300 tablets. Need about 270 a month.

Comment: Will likely need this medication for life.

Purpose: Pain control.

Comment: 500 tablets per bottle—200mg.

Purpose: Acid reduction.
<table>
<thead>
<tr>
<th></th>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tylenol 500 mg</td>
<td>2006/46</td>
<td>2037/77</td>
<td>4–5 Times/Year</td>
<td>$12.99</td>
<td>$51.96 to $64.95</td>
<td>32</td>
<td>$58.46</td>
<td>$1,870.72</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>Recommended By:</td>
<td>Dr. Burn Surgeon</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Purpose:</td>
<td>Pain control</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Artificial Tears</td>
<td>2006/46</td>
<td>2037/77</td>
<td>12 Times/Year</td>
<td>$11.00 to $13.00</td>
<td>$132.00 to $156.00</td>
<td>32</td>
<td>$144.00</td>
<td>$4,608.00</td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recommended By:</td>
<td>Dr. Burn Surgeon</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Purpose:</td>
<td>For dry eyes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benadryl</td>
<td>2006/46</td>
<td>2015/55</td>
<td>12 Per/Year</td>
<td>$14.99</td>
<td>$179.88</td>
<td>10</td>
<td>$179.88</td>
<td>$1,798.80</td>
</tr>
<tr>
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<td></td>
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<td></td>
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<td></td>
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</tr>
<tr>
<td>Recommended By:</td>
<td>Dr. Burn Surgeon</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Purpose:</td>
<td>For itching</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Multivitamin</td>
<td>2006/46</td>
<td>2037/77</td>
<td>6 Per/Year</td>
<td>$6.95 to $8.95</td>
<td>$41.70 to $53.70</td>
<td>32</td>
<td>$47.70</td>
<td>$1,526.40</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recommended By:</td>
<td>Dr. Burn Surgeon</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Purpose:</td>
<td>Nutritional purposes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Sunscreen

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2037/77</td>
<td>10–12 Per/Year</td>
<td>$8.00 to $10.00</td>
<td>$80.00 to $120.00</td>
<td>32</td>
<td>$100.00</td>
<td>$3,200.00</td>
</tr>
</tbody>
</table>

**Recommended By:** Dr. Burn Surgeon  
**Purpose:** Prevent skin cancer.  
**Comment:** Higher incidence of skin cancer in burn injury patients.

### Stool Softener

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2037/77</td>
<td>10 Per/Year</td>
<td>$10.50 to $12.00</td>
<td>$105.00 to $120.00</td>
<td>32</td>
<td>$112.50</td>
<td>$3,600.00</td>
</tr>
</tbody>
</table>

**Recommended By:** Dr. Burn Surgeon  
**Purpose:** Need with narcotics he will be taking indefinitely.

### Bacitracin

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2010/50</td>
<td>2–3 Times/Year</td>
<td>$17.40</td>
<td>$34.80 to $52.20</td>
<td>5</td>
<td>$43.50</td>
<td>$217.50</td>
</tr>
</tbody>
</table>

**Recommended By:** Dr. Burn Surgeon  
**Purpose:** For dressing changes postop at home.

---

Option 1 Medications Subtotal: $186,816.62
### Home Care/Facility Care

<table>
<thead>
<tr>
<th>Case Management</th>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2006/46</td>
<td>2037/77</td>
<td>48–60 Hours/Year</td>
<td>$100.00 to $120.00</td>
<td>$4,800.00 to $7,200.00</td>
<td>32</td>
<td>$6,000.00</td>
<td>$192,000.00</td>
</tr>
</tbody>
</table>

**Recommended By:** Dr. Burn Surgeon  
**Purpose:** Assist with monitoring all medical care relating to the burn injuries.  
**Comment:** Some years he will need more hours, some less, so it should even out. He will have yearly evaluations and medications that he can use assistance with.

<table>
<thead>
<tr>
<th>Housekeeping Services</th>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2008/48</td>
<td>2019/59</td>
<td>52 Visits/Year</td>
<td>$60.00 to $80.00</td>
<td>$3,120.00 to $4,160.00</td>
<td>12</td>
<td>$3,640.00</td>
<td>$43,680.00</td>
</tr>
</tbody>
</table>

**Recommended By:** Dr. Burn Surgeon  
**Purpose:** Assist with housekeeping duties.

<table>
<thead>
<tr>
<th>Interior/Exterior Home Maintenance</th>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2008/48</td>
<td>2019/59</td>
<td>144 Hours/Year</td>
<td>$50.00 to $80.00</td>
<td>$7,200.00 to $11,520.00</td>
<td>12</td>
<td>$9,360.00</td>
<td>$112,320.00</td>
</tr>
</tbody>
</table>

**Recommended By:** Dr. Burn Surgeon  
**Purpose:** Assist with maintenance of home.
<p>| Lawn Care |</p>
<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2008/48</td>
<td>2019/59</td>
<td>50 Visits/Year</td>
<td>$75.00 to $100.00</td>
<td>$3,750.00 to $5,000.00</td>
<td>12</td>
<td>$4,375.00</td>
<td>$52,500.00</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon
Purpose: Assist with outside work.

<p>| Assisted Living Facility |</p>
<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2007/47</td>
<td>12 Times/ Year</td>
<td>$3,395.00</td>
<td>$40,740.00</td>
<td>2</td>
<td>$40,740.00</td>
<td>$81,480.00</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon
Purpose: Assisted living arrangement includes housekeeping, health and wellness, and two meals a day.
Comment: Mr. Doe needs a number of surgeries in the next two years. Assisted living would be a big help during that time period.

<p>| Assisted Living Facility |</p>
<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2020/60</td>
<td>2037/77</td>
<td>12 Times/ Year</td>
<td>$3,450.00</td>
<td>$41,400.00</td>
<td>18</td>
<td>$41,400.00</td>
<td>$745,200.00</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon
Purpose: Mr. Doe is likely to age more quickly than the average person.

<p>| Daily Attendant |</p>
<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2011/51</td>
<td>3500 Hours/ Year</td>
<td>$20.00 to $22.00</td>
<td>$70,000.00 to $77,000.00</td>
<td>6</td>
<td>$73,500.00</td>
<td>$441,000.00</td>
</tr>
</tbody>
</table>
### Daily Attendant

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2012/52</td>
<td>2037/77</td>
<td>3650 Hours/Year</td>
<td>$20.00 to $21.00</td>
<td>$73,000.00 to $76,650.00</td>
<td>26</td>
<td>$74,825.00</td>
<td>$1,945,450.00</td>
</tr>
</tbody>
</table>

### Future Medical Care Routine

#### Physiatrist

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2015/55</td>
<td>3 Visits/Year</td>
<td>$160.00 to $180.00</td>
<td>$480.00 to $540.00</td>
<td>10</td>
<td>$510.00</td>
<td>$5,100.00</td>
</tr>
</tbody>
</table>

#### Internal Medicine

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2037/77</td>
<td>2–3 Times/Year</td>
<td>$175.00</td>
<td>$350.00 to $525.00</td>
<td>32</td>
<td>$437.50</td>
<td>$14,000.00</td>
</tr>
</tbody>
</table>

(Continued)
### Blood Work, Chemistry

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2037/77</td>
<td>2–4 Times/Year</td>
<td>$78.50</td>
<td>$157.00 to $314.00</td>
<td>32</td>
<td>$235.50</td>
<td>$7,536.00</td>
</tr>
</tbody>
</table>

**Recommended By:** Dr. Burn Surgeon

**Purpose:** Check electrolytes, renal function, and liver enzymes.

**Option 1**

**Future Medical Care Routine Subtotal:** $26,636.00

### Transportation

**Van, Adaptive with Lift**

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2037/77</td>
<td>1 Time/ 8–10 Years</td>
<td>$45,000.00 to $50,000.00</td>
<td>$4,500.00 to $6,250.00</td>
<td>32</td>
<td>$5,375.00</td>
<td>$172,000.00</td>
</tr>
</tbody>
</table>

**Purpose:** Transport scooter or wheelchair.

### Mileage

**Mileage**

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2012/52</td>
<td>500–750 Per/Year</td>
<td>$0.45</td>
<td>$225.00 to $337.50</td>
<td>7</td>
<td>$281.25</td>
<td>$1,968.75</td>
</tr>
</tbody>
</table>

**Purpose:** Mileage to appointments.

**Mileage**
<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2008/48</td>
<td>2020/60</td>
<td>1 Time/ 7 Years</td>
<td>$45,000.00 to $50,000.00</td>
<td>$6,428.57 to $7,142.86</td>
<td>13</td>
<td>$6,785.71</td>
<td>$88,214.23</td>
</tr>
</tbody>
</table>

Recommended By: Ms. Healthy, Burn Nurse Practitioner

Purpose: Allows for architectural changes for home he lives in every 7 years, which is the average number of years Americans live in their homes.

Comment: He is slated to be in assisted living for the next 2 years and then back in such a situation after age 60.

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2030/70</td>
<td>12 Times/ Year</td>
<td>$30.00</td>
<td>$360.00</td>
<td>25</td>
<td>$360.00</td>
<td>$9,000.00</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Regular exercise for function and mobility.
### Acute Medical Intervention

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2007/47</td>
<td>2 Times/ 2 Years</td>
<td>$5,000.00</td>
<td>$5,000.00</td>
<td>2</td>
<td>$5,000.00</td>
<td>$10,000.00</td>
</tr>
</tbody>
</table>

**Recommended By:** Dr. Burn Surgeon

**Purpose:** Keep heterotropic ossification of elbow from returning.

**Comment:** This price is the minimum price that was quoted by the radiation centers called.

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2037/77</td>
<td>1–2 Visits/ Year</td>
<td>$1,250.00 to $1,800.00</td>
<td>$1,250.00 to $3,600.00</td>
<td>32</td>
<td>$2,425.00</td>
<td>$77,600.00</td>
</tr>
</tbody>
</table>

**Recommended By:** Dr. Burn Surgeon

**Purpose:** ER visits after surgery for skin breakdown and/or respiratory issues.

### Surgical Intervention

**Repair heterotropic ossification of left elbow**

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2006/46</td>
<td>1 Time/ Year</td>
<td>$4,000.00</td>
<td>$4,000.00</td>
<td>1</td>
<td>$4,000.00</td>
<td>$4,000.00</td>
</tr>
</tbody>
</table>

**Recommended By:** Dr. Orthopedic Surgeon

**Purpose:** Remove calcified bone impeding movement of joint.

**Comment:** Done by an orthopedic surgeon.
### Integra—Dermal Replacement

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2006/46</td>
<td>1 Time/ Year</td>
<td>$4,537.50</td>
<td>$4,537.50</td>
<td>1</td>
<td>$4,537.50</td>
<td>$4,537.50</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Skin substitute.

Comment: Mr. Doe has limited donor sites.

### Anesthesia Fee

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2006/46</td>
<td>1 Time/ Year</td>
<td>$1,500.00 to $1,750.00</td>
<td>$1,500.00 to $1,750.00</td>
<td>1</td>
<td>$1,625.00</td>
<td>$1,625.00</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Surgery performed under general anesthesia.

### OR/Surgery Suite

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2006/46</td>
<td>1 Time/ Year</td>
<td>$10,000.00 to $12,500.00</td>
<td>$10,000.00 to $12,500.00</td>
<td>1</td>
<td>$11,250.00</td>
<td>$11,250.00</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Surgery done inpatient under general anesthesia.

(Continued)
## Chart 2 (Continued)

### Grafting

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2006/46</td>
<td>1 Time/Year</td>
<td>$2,908.00</td>
<td>$2,908.00</td>
<td>1</td>
<td>$2,908.00</td>
<td>$2,908.00</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Grafting to axilla wounds.

Comment: This is the second surgery to repair for heterotopic ossification.

### Anesthesia Fee

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2006/46</td>
<td>1 Time/Year</td>
<td>$1,125.00 to $1,250.00</td>
<td>$1,125.00 to $1,250.00</td>
<td>1</td>
<td>$1,187.50</td>
<td>$1,187.50</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Surgery done under general anesthesia.

### OR/Surgery Suite

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2006/46</td>
<td>1 Time/Year</td>
<td>$7,500.00 to $9,250.00</td>
<td>$7,500.00 to $9,250.00</td>
<td>1</td>
<td>$8,375.00</td>
<td>$8,375.00</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Place graft on axilla.

### Postop Therapy

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2006/46</td>
<td>36–48 Visits/Year</td>
<td>$150.00 to $175.00</td>
<td>$5,400.00 to $8,400.00</td>
<td>1</td>
<td>$6,900.00</td>
<td>$6,900.00</td>
</tr>
</tbody>
</table>
**Recommended By: Dr. Burn Surgeon**

**Purpose:** Therapy to maintain benefits of surgery—range of motion.

**Postop Home Health**

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2006/46</td>
<td>24–36 Visits/Year</td>
<td>$120.00</td>
<td>$2,880.00 to $4,320.00</td>
<td>1</td>
<td>$3,600.00</td>
<td>$3,600.00</td>
</tr>
</tbody>
</table>

**Recommended By: Dr. Burn Surgeon**

**Purpose:** Daily dressing changes for 4–6 weeks.

**Comment:** Nursing care 6 days a week with one dressing change at burn clinic.

**Repair heterotropic ossification of right elbow**

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2006/46</td>
<td>1 Time/Year</td>
<td>$4,000.00</td>
<td>$4,000.00</td>
<td>1</td>
<td>$4,000.00</td>
<td>$4,000.00</td>
</tr>
</tbody>
</table>

**Recommended By: Dr. Orthopedic Surgeon**

**Purpose:** Remove calcified bone impeding movement of joint.

**Integra—Dermal Replacement**

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2006/46</td>
<td>1 Time/Year</td>
<td>$4,537.50</td>
<td>$4,537.50</td>
<td>1</td>
<td>$4,537.50</td>
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</table>

**Recommended By: Dr. Burn Surgeon**

**Purpose:** Skin substitute

(Continued)
<table>
<thead>
<tr>
<th>OR/Surgery Suite</th>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2006/46</td>
<td>2006/46</td>
<td>1 Time/ Year</td>
<td>$10,000.00 to $12,500.00</td>
<td>$10,000.00 to $12,500.00</td>
<td>1</td>
<td>$11,250.00</td>
<td>$11,250.00</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon
Purpose: OR, Facility Fees, and Recovery

Anesthesia Fee

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2006/46</td>
<td>1 Time/ Year</td>
<td>$1,250.00 to $1,500.00</td>
<td>$1,250.00 to $1,500.00</td>
<td>1</td>
<td>$1,375.00</td>
<td>$1,375.00</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon
Purpose: Surgery done under general anesthesia.

Grafting

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2006/46</td>
<td>1 Per/ Year</td>
<td>$2,908.00</td>
<td>$2,908.00</td>
<td>1</td>
<td>$2,908.00</td>
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</table>

Recommended By: Dr. Burn Surgeon
Purpose: Skin graft

Anesthesia Fee

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2006/46</td>
<td>1 Time/ Year</td>
<td>$1,125.00 to $1,250.00</td>
<td>$1,125.00 to $1,250.00</td>
<td>1</td>
<td>$1,187.50</td>
<td>$1,187.50</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon
Purpose: Surgery done under general anesthesia.
### OR/Surgery Suite

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2006/46</td>
<td>1 Time/ Year</td>
<td>$7,500.00 to $9,250.00</td>
<td>$7,500.00 to $9,250.00</td>
<td>1</td>
<td>$8,375.00</td>
<td>$8,375.00</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: OR, Facility Fees, and Recovery

### Postop Therapy

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2006/46</td>
<td>36–48 Visits/Year</td>
<td>$150.00 to $175.00</td>
<td>$5,400.00 to $8,400.00</td>
<td>1</td>
<td>$6,900.00</td>
<td>$6,900.00</td>
</tr>
</tbody>
</table>

Purpose: Therapy to maintain benefits of surgery—range of motion.

### Postop Home Health

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2006/46</td>
<td>24–36 Visits/Year</td>
<td>$120.00</td>
<td>$2,880.00 to $4,320.00</td>
<td>1</td>
<td>$3,600.00</td>
<td>$3,600.00</td>
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</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Daily dressing change, monitor graft.

### Dermabrasion

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2008/48</td>
<td>2013/53</td>
<td>2 Times/ 6 Years</td>
<td>$12,000.00 to $14,000.00</td>
<td>$4,000.00 to $4,666.67</td>
<td>6</td>
<td>$4,333.33</td>
<td>$25,999.98</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Even out scarring and color on the face.

(Continued)
### Grafting of bilateral poplitreals (behind knees)

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2006/46</td>
<td>2 Times/Year</td>
<td>$2,160.00 to  $4,320.00</td>
<td>$4,320.00 to $8,640.00</td>
<td>1</td>
<td>$6,480.00</td>
<td>$6,480.00</td>
</tr>
</tbody>
</table>

**Recommended By:** Dr. Burn Surgeon  
**Purpose:** Jonathon still has open wounds behind his knees.

### Anesthesia Fee

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2006/46</td>
<td>1 Per/Year</td>
<td>$1,500.00 to  $1,750.00</td>
<td>$1,500.00 to $1,750.00</td>
<td>1</td>
<td>$1,625.00</td>
<td>$1,625.00</td>
</tr>
</tbody>
</table>

**Recommended By:** Dr. Burn Surgeon  
**Purpose:** Surgery done under general anesthesia.

### OR/Surgery Suite

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2006/46</td>
<td>1 Time/Year</td>
<td>$10,000.00 to $12,500.00</td>
<td>$10,000.00 to $12,500.00</td>
<td>1</td>
<td>$11,250.00</td>
<td>$11,250.00</td>
</tr>
</tbody>
</table>

**Recommended By:** Dr. Burn Surgeon  
**Purpose:** OR, Facility Fees, and Recovery

### Postop Therapy

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2006/46</td>
<td>36–48 Per/Year</td>
<td>$175.00 to  $200.00</td>
<td>$6,300.00 to $9,600.00</td>
<td>1</td>
<td>$7,950.00</td>
<td>$7,950.00</td>
</tr>
</tbody>
</table>

**Recommended By:** Dr. Burn Surgeon
Purpose: Therapy to maintain benefits of surgery—range of motion.

Postop Home Health

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
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</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2006/46</td>
<td>24–36 Visits/Year</td>
<td>$120.00</td>
<td>$2,880.00 to $4,320.00</td>
<td>1</td>
<td>$3,600.00</td>
<td>$3,600.00</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Dressing changes, monitor healing.

Contracture Release Axilla

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2013/53</td>
<td>4 Times/ 5–7 Years</td>
<td>$5,800.00</td>
<td>$3,314.29 to $4,640.00</td>
<td>8</td>
<td>$3,977.14</td>
<td>$31,817.12</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Release contracture to improve range of motion.

Comment: He needs the surgery on each axilla, and it is likely this surgery will be repeated at least once on each side due to contractures.

Integra—Dermal Replacement

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2011/51</td>
<td>4 Times/ 5–7 Years</td>
<td>$4,537.50 to $9,075.00</td>
<td>$2,592.86 to $7,260.00</td>
<td>6</td>
<td>$4,926.43</td>
<td>$29,558.58</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Skin substitute

(Continued)
<table>
<thead>
<tr>
<th>OR/Surgery Suite</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong># Start Year/Age</strong></td>
<td><strong># End Year/Age</strong></td>
</tr>
<tr>
<td>2006/46</td>
<td>2013/53</td>
</tr>
</tbody>
</table>

**Recommended By:** Dr. Burn Surgeon

**Purpose:** OR, Facility Fees, and Recovery

---

<table>
<thead>
<tr>
<th>Anesthesia Fee</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong># Start Year/Age</strong></td>
<td><strong># End Year/Age</strong></td>
</tr>
<tr>
<td>2006/46</td>
<td>2013/53</td>
</tr>
</tbody>
</table>

**Recommended By:** Dr. Burn Surgeon

**Purpose:** Surgery done under general anesthesia.

---

<table>
<thead>
<tr>
<th>Postop Home Health</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong># Start Year/Age</strong></td>
<td><strong># End Year/Age</strong></td>
</tr>
<tr>
<td>2006/46</td>
<td>2013/53</td>
</tr>
</tbody>
</table>

**Recommended By:** Dr. Burn Surgeon

**Purpose:** Daily dressing change, monitor graft.

---

<table>
<thead>
<tr>
<th>Grafting</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong># Start Year/Age</strong></td>
<td><strong># End Year/Age</strong></td>
</tr>
<tr>
<td>2006/46</td>
<td>2013/53</td>
</tr>
</tbody>
</table>
### Anesthesia Fee

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2013/53</td>
<td>4 Time/ 5–7 Years</td>
<td>$1,125.00 to $1,250.00</td>
<td>$642.86 to $1,000.00</td>
<td>8</td>
<td>$821.43</td>
<td>$6,571.44</td>
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</table>

### OR/Surgery Suite

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2013/53</td>
<td>4 Times/ 5–7 Years</td>
<td>$7,500.00 to $9,250.00</td>
<td>$4,285.71 to $7,400.00</td>
<td>8</td>
<td>$5,842.86</td>
<td>$46,742.88</td>
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</table>

### Postop Home Health

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2013/53</td>
<td>24–36 Visits/ 7 Years</td>
<td>$120.00</td>
<td>$411.43 to $617.14</td>
<td>8</td>
<td>$514.29</td>
<td>$4,114.32</td>
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</table>
### Chart 2 (Continued)

#### Postop Therapy

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2013/53</td>
<td>144–192 Times/5–7 Years</td>
<td>$150.00 to $175.00</td>
<td>$3,085.71 to $6,720.00</td>
<td>8</td>
<td>$4,902.86</td>
<td>$39,222.88</td>
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</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Therapy to maintain benefits of surgery—range of motion.

Option 1 Surgical Intervention Subtotal $404,818.76

#### Potential Complications

##### Arthritis

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
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<td>0/0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

##### Commissuroplasty—release of contractures around mouth

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>0/0</td>
<td>0/0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

##### Contractures

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>0/0</td>
<td>0/0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

##### Major Depression

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Condition</td>
<td># Start Year/Age</td>
<td># End Year/Age</td>
<td>Frequency</td>
<td>Cost Per Unit</td>
<td>Cost Per Year</td>
<td>Total Cost</td>
<td>Cost Per Year Average</td>
</tr>
<tr>
<td>----------------------------</td>
<td>------------------</td>
<td>----------------</td>
<td>-----------</td>
<td>---------------</td>
<td>---------------</td>
<td>------------</td>
<td>------------------------</td>
</tr>
<tr>
<td>Decrease Range of Motion</td>
<td>0/0</td>
<td>0/0</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Decubitus Ulcers</td>
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<td>0/0</td>
<td>1</td>
<td>1</td>
<td></td>
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<tr>
<td>Heterotopic Ossifications</td>
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<tr>
<td>Osteoporosis</td>
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<td></td>
</tr>
<tr>
<td>Peptic Ulcer Disease</td>
<td>0/0</td>
<td>0/0</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Seizures</td>
<td>0/0</td>
<td>0/0</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(Continued)
<table>
<thead>
<tr>
<th></th>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Infection</strong></td>
<td>0/0</td>
<td>0/0</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Skin Breakdown</strong></td>
<td>0/0</td>
<td>0/0</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Chronic Pain</strong></td>
<td>0/0</td>
<td>0/0</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Respiratory Complications</strong></td>
<td>0/0</td>
<td>0/0</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Surgical Complications</strong></td>
<td>0/0</td>
<td>0/0</td>
<td></td>
<td></td>
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<td>1</td>
<td></td>
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</tbody>
</table>

Option 1 Potential Complications Subtotal $0.00
### Option 1: Life Care Planning for the Burn Patient

#### Home Furnishings

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2037/77</td>
<td>2 Per/ 1–3 Years</td>
<td>$19.99 to $29.99</td>
<td>$13.33 to $59.98</td>
<td>32</td>
<td>$36.65</td>
<td>$1,172.80</td>
</tr>
</tbody>
</table>

Recommended By: Ms. Healthy, Burn Nurse Practitioner

Purpose: Keep air moist for skin.

#### Chair, Lift Reclining

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2020/60</td>
<td>2037/77</td>
<td>1 Time/ 5–7 Years</td>
<td>$450.00 to $600.00</td>
<td>$64.29 to $120.00</td>
<td>18</td>
<td>$92.14</td>
<td>$1,658.52</td>
</tr>
</tbody>
</table>

Recommended By: Ms. Healthy, Burn Nurse Practitioner

Purpose: Assist in getting up and out of chair.

Option 1 Home Furnishings Subtotal $2,831.32

---

### Hospital Days

#### Med-Surg Days

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2011/51</td>
<td>45–70 Times/ 5 Years</td>
<td>$1,092.00</td>
<td>$9,828.00 to $15,288.00</td>
<td>6</td>
<td>$12,558.00</td>
<td>$75,348.00</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Inpatient days–5–14 days per procedure. Based on 1.5 procedures per year over 5 years.

Comment: Surgeries requiring excision and grafting will be 5–7 days x 2.

(Continued)
### X-Rays and Diagnostic Services

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2011/51</td>
<td>2.5–3 Times/Year</td>
<td>$750.00 to $1,250.00</td>
<td>$1,875.00 to $3,750.00</td>
<td>6</td>
<td>$2,812.50</td>
<td>$16,875.00</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Postsurgery in-patient testing.

### Dressing Supplies

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2011/51</td>
<td>15–21 Times/Year</td>
<td>$250.00</td>
<td>$3,750.00 to $5,250.00</td>
<td>6</td>
<td>$4,500.00</td>
<td>$27,000.00</td>
</tr>
</tbody>
</table>

Recommended By: Ms. Healthy, Burn Nurse Practitioner

Purpose: Dressing change materials and nursing charges.

### Medications and IV Fluids

<table>
<thead>
<tr>
<th># Start Year/Age</th>
<th># End Year/Age</th>
<th>Frequency</th>
<th>Cost Per Unit</th>
<th>Cost Per Year</th>
<th># Total Number of Years</th>
<th>Cost Per Year Average</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/46</td>
<td>2011/51</td>
<td>2.5–3 Times/Year</td>
<td>$1,000.00 to $1,500.00</td>
<td>$2,500.00 to $4,500.00</td>
<td>6</td>
<td>$3,500.00</td>
<td>$21,000.00</td>
</tr>
</tbody>
</table>

Recommended By: Dr. Burn Surgeon

Purpose: Inpatient meds and IV fluids.
<table>
<thead>
<tr>
<th>Therapies Inpatient</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td># Start Year/Age</td>
<td>2006/46</td>
</tr>
<tr>
<td># End Year/Age</td>
<td>2011/51</td>
</tr>
<tr>
<td>Frequency</td>
<td>45–75 Times/ 5 Years</td>
</tr>
<tr>
<td>Cost Per Unit</td>
<td>$300.00</td>
</tr>
<tr>
<td>Cost Per Year</td>
<td>$2,700.00 to $4,500.00</td>
</tr>
<tr>
<td># Total Number of Years</td>
<td>6</td>
</tr>
<tr>
<td>Cost Per Year Average</td>
<td>$3,600.00</td>
</tr>
<tr>
<td>Total Cost</td>
<td>$21,600.00</td>
</tr>
</tbody>
</table>

Recommended By:  Dr. Burn Surgeon

Purpose: Psychotherapy, occupational therapy, and physical therapy.

Option 1 Hospital Days Subtotal $161,823.00

Option 1 Grand Total $5,217,430.26
Life Care Plan
for
Jonathon H. Doe

Anytown, USA

Date of Birth: March 12, 1959
Event Date: March 10, 2004
Primary Disability: 85%—Mostly 3rd-Degree Burns

Preparation Date: July 24, 2008

Ruth B. Rimmer, PhD, CLCP

2145 East Glencove
Mesa, AZ 85213

480-612-2994

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### Chart 2  Life Care Plan for Jonathon H. Doe, Anytown, USA

<table>
<thead>
<tr>
<th>Items/Services</th>
<th>Age</th>
<th>Year</th>
<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Cost/Unit</th>
<th>Cost/Year</th>
<th>Comments</th>
<th>Recommender</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1 Plastic Surgeon</strong>&lt;br&gt;Option 1</td>
<td>Beginning***&lt;br&gt;46 2006</td>
<td>1 Visit/Year</td>
<td>Evaluate for necessary surgical treatment for coming year.</td>
<td>Cost/Unit $400.00 to $400.00</td>
<td>Plastic surgeon who is a burn specialist like Dr. Fixit.</td>
<td>Dr. Burn Surgeon</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>2 Internal Medicine</strong>&lt;br&gt;Option 1</td>
<td>Beginning***&lt;br&gt;46 2006</td>
<td>1 Per/Year</td>
<td>Have an annual evaluation to determine how major body systems, stressed by the burn injuries, are doing.</td>
<td>Cost/Unit $300.00 to $350.00</td>
<td>Cost/Year $300.00 to $350.00</td>
<td>Dr. Burn Surgeon</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>3 Burn Surgeon</strong>&lt;br&gt;Option 1</td>
<td>Beginning***&lt;br&gt;56 2017</td>
<td>1 Time/2–3 Years</td>
<td>Should continue to see a burn surgeon after his major reconstructive and contracture release surgeries are done every 2–3 years.</td>
<td>Cost/Unit $250.00 to $400.00</td>
<td>Cost/Year $83.33 to $200.00</td>
<td>Dr. Burn Surgeon</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Cost/Year Average = ($300.00 + $350.00) ÷ 2 = $325.00

Cost/Year = $250.00 × 1 ÷ 2 = $125.00

Cost/Year = $250.00 × 1 ÷ 3 = $83.33

Cost/Year = $400.00 × 1 ÷ 2 = $200.00

Cost/Year = $400.00 × 1 ÷ 3 = $133.33

Cost/Year Average = ($83.33 × $200.00) ÷ 2 = $141.67
<table>
<thead>
<tr>
<th>Option 1</th>
<th>4 Physiatrist</th>
<th><strong>Beginning</strong>*</th>
<th>1 Visits/Year Evalue for rehab needs</th>
<th>Cost/Unit $250.00 to $300.00</th>
<th>Cost/Year $250.00 to $300.00</th>
<th>Dr. Burn Surgeon</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>46</strong></td>
<td><strong>6</strong></td>
<td><strong>2006</strong></td>
<td><strong>77</strong></td>
<td><strong>2037</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Cost/Year Average = ($250.00 + $300.00) ÷ 2 = $275.00</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>5 Dietician</strong></td>
<td><strong>Beginning</strong>*</td>
<td>1 Time/Year Evaluate for nutritional needs</td>
<td>Cost/Unit $125.00 to $150.00</td>
<td>Cost/Year $125.00 to $150.00</td>
<td>Assist through surgical procedures — help to maintain healthy weight.</td>
<td>Dr. Burn Surgeon</td>
</tr>
<tr>
<td>46</td>
<td>55</td>
<td>2006</td>
<td>2015</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Cost/Year Average = ($125.00 + $150.00) ÷ 2 = $137.50</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>6 Dermatologist</strong></td>
<td><strong>Beginning</strong>*</td>
<td>1 Visit/Year Evaluate for skin cancer, skin condition</td>
<td>Cost/Unit $125.00 to $150.00</td>
<td>Cost/Year $125.00 to $150.00</td>
<td></td>
<td>Dr. Burn Surgeon</td>
</tr>
<tr>
<td>46</td>
<td>77</td>
<td>2006</td>
<td>2037</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Cost/Year Average = ($125.00 + $150.00) ÷ 2 = $137.50</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>7 Occupational Therapy</strong></td>
<td><strong>Beginning</strong>*</td>
<td>1/Year Evaluate for upper body range of motion and mobility.</td>
<td>Cost/Unit $200.00 to $250.00</td>
<td>Cost/Year $200.00 to $250.00</td>
<td></td>
<td>Dr. Burn Surgeon</td>
</tr>
<tr>
<td>46</td>
<td>77</td>
<td>2006</td>
<td>2037</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Cost/Year Average = ($200.00 + $250.00) ÷ 2 = $225.00</strong></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td><strong>8 Otolaryngologist</strong></td>
<td><strong>Beginning</strong>*</td>
<td>1 Time/Year Monitor airway.</td>
<td>Cost/Unit $100.00 to $300.00</td>
<td>Cost/Year $100.00 to $300.00</td>
<td>To be seen during years he has surgery.</td>
<td>Dr. Burn Surgeon</td>
</tr>
<tr>
<td>46</td>
<td>55</td>
<td>2006</td>
<td>2015</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Cost/Year Average = ($100.00 + $300.00) ÷ 2 = $200.00</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Items/Services</td>
<td>Age</td>
<td>Year</td>
<td>Frequency/ Replacement</td>
<td>Purpose</td>
<td>Cost</td>
<td>Comments</td>
</tr>
<tr>
<td>---------------</td>
<td>-----</td>
<td>------</td>
<td>------------------------</td>
<td>---------</td>
<td>------</td>
<td>----------</td>
</tr>
<tr>
<td>9 Physical Therapy</td>
<td>46</td>
<td>2006</td>
<td>1 Time/Year</td>
<td>Evaluate for range of motion and mobility issues.</td>
<td>Cost/Unit $300.00 to $300.00</td>
<td></td>
</tr>
<tr>
<td></td>
<td>77</td>
<td>2038</td>
<td></td>
<td></td>
<td>Cost/Year $300.00 to $300.00</td>
<td></td>
</tr>
<tr>
<td>10 Psychiatrist</td>
<td>46</td>
<td>2006</td>
<td>1 Time/ 3 Years</td>
<td>Evaluate for PTSD, depression, etc. Dispense medication if necessary.</td>
<td>Cost/Unit $350.00 to $500.00</td>
<td></td>
</tr>
<tr>
<td></td>
<td>55</td>
<td>2015</td>
<td></td>
<td></td>
<td>Cost/Year $116.67 to $166.67</td>
<td></td>
</tr>
<tr>
<td>11 Psychologist</td>
<td>46</td>
<td>2006</td>
<td>1/Year</td>
<td>Evaluate for PTSD, and or depression.</td>
<td>Cost/Unit $200.00 to $250.00</td>
<td>Allows him to have regular session as he moves through the surgical phase.</td>
</tr>
<tr>
<td></td>
<td>51</td>
<td>2011</td>
<td></td>
<td></td>
<td>Cost/Year $200.00 to $250.00</td>
<td></td>
</tr>
<tr>
<td>12 Podiatrist</td>
<td>46</td>
<td>2006</td>
<td>1 Time/Year</td>
<td>Evaluate condition of feet, special shoes, nail care.</td>
<td>Cost/Unit $150.00 to $175.00</td>
<td>He continues to have loss of sensation in feet, had infection from in-grown toenail, needs special shoes.</td>
</tr>
<tr>
<td></td>
<td>77</td>
<td>2037</td>
<td></td>
<td></td>
<td>Cost/Year $150.00 to $175.00</td>
<td></td>
</tr>
</tbody>
</table>

Cost/Year Average = ($350.00 + $500.00) ÷ 2 = $425.00

Projected Evaluations

Cost/Year = $350.00 x 1 ÷ 3 = $116.67

Cost/Year = $500.00 x 1 ÷ 3 = $166.67

Cost/Year Average = ($116.67 + $166.67) ÷ 2 = $141.67

Cost/Year Average = ($200.00 + $250.00) ÷ 2 = $225.00

Cost/Year Average = ($150.00 + $175.00) ÷ 2 = $162.50

(Continued)
<table>
<thead>
<tr>
<th></th>
<th><strong>Opthamologist</strong></th>
<th></th>
<th></th>
<th></th>
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</thead>
<tbody>
<tr>
<td></td>
<td><strong>Option 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>Beginning***</td>
<td>46</td>
<td>2006</td>
<td>1 Visit/Year</td>
<td>Monitor for vision problems.</td>
</tr>
<tr>
<td></td>
<td>Ending***</td>
<td>77</td>
<td>2037</td>
<td></td>
<td>Cost/Unit $150.00 to $165.00</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Cost/Year $150.00 to $165.00</td>
</tr>
<tr>
<td></td>
<td><strong>Dr. Burn Surgeon</strong></td>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

Cost/Year Average = ($150.00 + $165.00) ÷ 2 = $157.50

<table>
<thead>
<tr>
<th></th>
<th><strong>Recreational Therapy</strong></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Option 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>Beginning***</td>
<td>46</td>
<td>2006</td>
<td>1 Time/5 Years</td>
<td>Assess Jonathon's productive usage of and engagement in leisure activities.</td>
</tr>
<tr>
<td></td>
<td>Ending***</td>
<td>77</td>
<td>2037</td>
<td></td>
<td>Cost/Unit $160.00 to $160.00</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Cost/Year $32.00 to $32.00</td>
</tr>
<tr>
<td></td>
<td><strong>Dr. Burn Surgeon</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Cost/Year = $160.00 x 1 ÷ 5 = $32.00

<table>
<thead>
<tr>
<th></th>
<th><strong>Dental Evaluation</strong></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Option 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>Beginning***</td>
<td>46</td>
<td>2006</td>
<td>1 Time/Year</td>
<td>Evaluate dental condition after burn injury.</td>
</tr>
<tr>
<td></td>
<td>Ending***</td>
<td>52</td>
<td>2012</td>
<td></td>
<td>Cost/Unit $250.00 to $350.00</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Cost/Year $250.00 to $350.00</td>
</tr>
<tr>
<td></td>
<td><strong>Dr. Burn Surgeon</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Cost/Year Average = ($250.00 + $350.00) ÷ 2 = $300.00

<table>
<thead>
<tr>
<th></th>
<th><strong>Psychologist</strong></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Option 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>Beginning***</td>
<td>52</td>
<td>2012</td>
<td>1 Time/3–4 Years</td>
<td>Evaluate during life changes, aging issues, etc.</td>
</tr>
<tr>
<td></td>
<td>Ending***</td>
<td>77</td>
<td>2038</td>
<td></td>
<td>Cost/Unit $380.00 to $450.00</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Cost/Year $95.00 to $150.00</td>
</tr>
<tr>
<td></td>
<td><strong>Mary Psychologist, PhD</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Cost/Year = $380.00 x 1 ÷ 3 = $126.67  
Cost/Year = $450.00 x 1 ÷ 4 = $112.50  
Cost/Year Average = ($95.00 + $150.00) ÷ 2 = $122.50
<table>
<thead>
<tr>
<th>Items/Services</th>
<th>Age</th>
<th>Year</th>
<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Cost</th>
<th>Comments</th>
<th>Recommender</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychiatrist</td>
<td>56</td>
<td>2017</td>
<td>Beginning*** 5–7 Years</td>
<td>Evaluate for life changes and aging issues.</td>
<td>Cost/Unit $350.00 to $500.00</td>
<td></td>
<td>Dr. Burn Surgeon, Mary Psychologist, PhD</td>
</tr>
<tr>
<td>Option 1</td>
<td>77</td>
<td>2038</td>
<td>Ending***</td>
<td></td>
<td>Cost/Year $50.00 to $100.00</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Cost/Year = $350.00 x 1 ÷ 5 = $70.00
Cost/Year = $500.00 x 1 ÷ 7 = $71.43
Cost/Year = $350.00 x 1 ÷ 7 = $50.00
Cost/Year Average = ($50.00 + $100.00) ÷ 2 = $75.00

(Continued)
## Chart 2 (Continued)

<table>
<thead>
<tr>
<th>Items/Services</th>
<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Cost/Unit</th>
<th>Cost/Year</th>
<th>Comments</th>
<th>Recommender</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Occupational Therapy</td>
<td>Beginning*** 51 2012</td>
<td>24–36 Times/ 4 Years</td>
<td>Intermittent therapy to maintain range of motion and mobility.</td>
<td>$150.00 to $225.00</td>
<td>Cost/Year = $150.00 x 24 ÷ 4 = $900.00 Cost/Year = $175.00 x 36 ÷ 4 = $1,575.00 Cost/Year Average = ($900.00 + $1,575.00) ÷ 2 = $1,237.50</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ending*** 77 2038</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Dr. Burn Surgeon</td>
</tr>
<tr>
<td>2 Physical Therapy</td>
<td>Beginning*** 51 2012</td>
<td>12–24 Times/ 3–4 Years</td>
<td>Intermittent therapy to maintain range of motion and mobility.</td>
<td>$150.00 to $225.00</td>
<td>Cost/Year = $150.00 x 12 ÷ 3 = $600.00 Cost/Year = $225.00 x 12 ÷ 4 = $675.00 Cost/Year = $225.00 x 24 ÷ 3 = $1,800.00 Cost/Year Average = ($600.00 + $675.00 + $1,800.00) ÷ 3 = $1,125.00</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ending*** 77 2038</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Dr. Burn Surgeon</td>
</tr>
<tr>
<td>3 Hypnotherapy</td>
<td>Beginning*** 46 2006</td>
<td>4–6 Times/ Year</td>
<td>Assist with pain control and anxiety reduction.</td>
<td>$100.00 to $125.00</td>
<td>Cost/Year = $100.00 x 4 = $400.00 Cost/Year = $125.00 x 6 = $750.00 Cost/Year = $100.00 x 6 = $600.00 Cost/Year Average = ($400.00 + $750.00) ÷ 2 = $575.00</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ending*** 50 2010</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Dr. Burn Surgeon</td>
</tr>
</tbody>
</table>
### Projected Therapeutic Modalities

<table>
<thead>
<tr>
<th>Items/Services</th>
<th>Age</th>
<th>Year</th>
<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Cost/Unit</th>
<th>Cost/Year</th>
<th>Comments</th>
<th>Recommender</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>4 Individual Psychotherapy</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Option 1</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Beginning*** 46 2006</td>
<td></td>
<td></td>
<td>48 Visits/Year</td>
<td>PTSD management. Evaluate for depression.</td>
<td>Cost/Unit</td>
<td>$150.00 to $150.00</td>
<td></td>
<td>Mary Psychologist, PhD</td>
</tr>
<tr>
<td>Ending*** 47 2007</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Cost/Year</td>
<td>$7,200.00 to $7,200.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>5 Massage Therapy Intermediate</strong></td>
<td></td>
<td></td>
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<tr>
<td>Option 1</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Beginning*** 46 2006</td>
<td></td>
<td></td>
<td>24–32 Times/Year</td>
<td>Massage therapy for scar management and suppleness of skin.</td>
<td>Cost/Unit</td>
<td>$75.00 to $100.00</td>
<td></td>
<td>Dr. Burn Surgeon</td>
</tr>
<tr>
<td>Ending*** 55 2015</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Cost/Year</td>
<td>$1,800.00 to $3,200.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>6 Massage Therapy Ongoing</strong></td>
<td></td>
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<td>Option 1</td>
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<td></td>
</tr>
<tr>
<td>Beginning*** 56 2017</td>
<td></td>
<td></td>
<td>12 Times/Year</td>
<td>Massage therapy for scar management and pain control.</td>
<td>Cost/Unit</td>
<td>$75.00 to $100.00</td>
<td></td>
<td>Dr. Burn Surgeon</td>
</tr>
<tr>
<td>Ending*** 77 2038</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Cost/Year</td>
<td>$900.00 to $1,200.00</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Cost/Year** = $75.00 x 24 = $1,800.00
Cost/Year = $100.00 x 32 = $3,200.00
Cost/Year Average = ($1,800.00 + $3,200.00) ÷ 2 = $2,500.00
Cost/Year = $75.00 x 32 = $2,400.00

(Continued)
<table>
<thead>
<tr>
<th>Chart 2 (Continued)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>7 Disabled Driver Training</strong></td>
</tr>
<tr>
<td><strong>Option 1</strong></td>
</tr>
<tr>
<td><strong>Beginning</strong>*</td>
</tr>
<tr>
<td>46 2007</td>
</tr>
<tr>
<td><strong>Cost/Year = $120.00 x 3 = $360.00</strong></td>
</tr>
</tbody>
</table>

| **8 Individual Psychotherapy** |
| **Option 1** |
| **Beginning*** | **Ending*** | **24 Visits/Year** | **Psychotherapy for PTSD every 2 weeks until major surgeries are behind him.** | **Cost/Unit** | **Cost/Year** | **Mary Psychologist, PhD** |
| 46 2006 | 50 2010 | | | $150.00 to $150.00 | $3,600.00 to $3,600.00 |
| **Cost/Year = $150.00 x 24 = $3,600.00** |

| **9 Individual Psychotherapy** |
| **Option 1** |
| **Beginning*** | **Ending*** | **12–24 Times/4 Years** | **3–4 months of sessions during major life changes.** | **Cost/Unit** | **Cost/Year** | **Mary Psychologist, PhD** |
| 51 2012 | 77 2038 | | | $150.00 to $150.00 | $450.00 to $900.00 |
| **Cost/Year = $150.00 x 12 ÷ 4 = $450.00** | **Cost/Year = $150.00 x 24 ÷ 4 = $900.00** | **Cost/Year Average = ($450.00 + $900.00) ÷ 2 = $675.00** |
## Diagnostic/Educational Testing

<table>
<thead>
<tr>
<th>Items/Services</th>
<th>Age</th>
<th>Year</th>
<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Cost</th>
<th>Comments</th>
<th>Recommender</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Vocational Rehabilitation Evaluation</td>
<td>47</td>
<td>2008</td>
<td>Beginning***</td>
<td>Evaluate for potential and appropriate job opportunities.</td>
<td>Cost/Unit $1,000.00 to $1,500.00</td>
<td>Cost/Year $1,000.00 to $1,500.00</td>
<td>Dr. Burn Surgeon</td>
</tr>
<tr>
<td>Option 1</td>
<td>47</td>
<td>2008</td>
<td>Ending***</td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

(Continued)
## Wheelchair(s)/Mobility/Maintenance

<table>
<thead>
<tr>
<th>Items/Services</th>
<th>Age</th>
<th>Year</th>
<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Cost</th>
<th>Comments</th>
<th>Recommender</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1 Scooter</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Option 1</strong></td>
<td>46</td>
<td>2006</td>
<td></td>
<td><strong>Beginning</strong>*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Scooter</strong></td>
<td></td>
<td></td>
<td><strong>1 Per/ 7–10 Years</strong></td>
<td>Mobility</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Ending</strong>*</td>
<td>77</td>
<td>2037</td>
<td></td>
<td><strong>Cost/Unit</strong></td>
<td></td>
<td></td>
<td>Dr. Burn Surgeon</td>
</tr>
<tr>
<td><strong>Option 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Frequency/Replacement</strong></td>
<td><strong>Cost/Unit</strong></td>
<td><strong>Cost/Year</strong></td>
<td><strong>Comments</strong></td>
<td><strong>Recommender</strong></td>
<td><strong>Cost/Year</strong></td>
<td><strong>Cost/Year Average</strong></td>
<td></td>
</tr>
<tr>
<td><strong>1 Per/ 7–10 Years</strong></td>
<td>$2,620.00 to $2,935.00</td>
<td>$262.00 to $419.29</td>
<td></td>
<td>$2,620.00 x 1 ÷ 7 = $374.29</td>
<td>$2,935.00 x 1 ÷ 10 = $293.50</td>
<td>($262.00 + $419.29) ÷ 2 = $340.64</td>
<td></td>
</tr>
</tbody>
</table>

**2 Scooter Batteries**

<table>
<thead>
<tr>
<th>Items/Services</th>
<th>Age</th>
<th>Year</th>
<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Cost</th>
<th>Comments</th>
<th>Recommender</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Option 1</strong></td>
<td>46</td>
<td>2006</td>
<td></td>
<td><strong>Beginning</strong>*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Scooter Batteries</strong></td>
<td></td>
<td></td>
<td><strong>2 Per/ 5 Years</strong></td>
<td>Allows for longer outings. Backup batteries.</td>
<td></td>
<td></td>
<td>Dr. Burn Surgeon</td>
</tr>
<tr>
<td><strong>Ending</strong>*</td>
<td>77</td>
<td>2037</td>
<td></td>
<td><strong>Cost/Unit</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Option 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Cost/Year</strong></td>
<td>$18.40 to $18.40</td>
<td>$18.40</td>
<td></td>
<td>$46.00 x 2 ÷ 5 = $18.40</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**3 Scooter Maintenance**

<table>
<thead>
<tr>
<th>Items/Services</th>
<th>Age</th>
<th>Year</th>
<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Cost</th>
<th>Comments</th>
<th>Recommender</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Option 1</strong></td>
<td>46</td>
<td>2006</td>
<td></td>
<td><strong>Beginning</strong>*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Scooter Maintenance</strong></td>
<td></td>
<td></td>
<td><strong>1 Time/ 2 Years</strong></td>
<td>Maintain the scooter, tires, etc.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Ending</strong>*</td>
<td>77</td>
<td>2037</td>
<td></td>
<td><strong>Cost/Unit</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Option 1</strong></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Cost/Year</strong></td>
<td>$62.50 to $75.00</td>
<td>$62.50</td>
<td></td>
<td>$125.00 x 1 ÷ 2 = $62.50</td>
<td></td>
<td>($62.50 + $75.00) ÷ 2 = $68.75</td>
<td></td>
</tr>
</tbody>
</table>
### Wheelchair(s)/Mobility/Maintenance

<table>
<thead>
<tr>
<th>Items/Services</th>
<th>Age</th>
<th>Year</th>
<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Cost/Unit</th>
<th>Cost/Year</th>
<th>Comments</th>
<th>Recommender</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>4 Scooter Canopy</strong></td>
<td></td>
<td></td>
<td></td>
<td>Protect from sun and create barrier against rain, etc.</td>
<td>$196.62 to $196.62</td>
<td>$19.66 to $19.66</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Option 1</td>
<td>Beginning*** 46</td>
<td>2006</td>
<td>1 Time/ 10 Years</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ending*** 77</td>
<td>2037</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

Cost/Year = $196.62 x 1 ÷ 10 = $19.66

| **5 Wheelchair, 4 Wheel Drive Power** |       |      |                       | Mobility. He has limited stamina for long outings. | $2,600.00 to $3,000.00 | $260.00 to $428.57 | Dr. Burn Surgeon |
| Option 1       | Beginning*** 46 | 2006 | 1 Per/ 7–10 Years    |         |           |           |          |             |
|                | Ending*** 77 | 2037 |                       |         |           |           |          |             |

Cost/Year = $2,600.00 x 1 ÷ 7 = $371.43
Cost/Year = $2,600.00 x 1 ÷ 10 = $260.00
Cost/Year = $3,000.00 x 1 ÷ 7 = $428.57
Cost/Year Average = ($260.00 + $428.57) ÷ 2 = $344.29

| **6 Maintain Power Wheelchair** |       |      |                       | Maintain wheelchair, tires etc. | $125.00 to $150.00 | $62.50 to $75.00 |          |             |
| Option 1       | Beginning*** 46 | 2006 | 1 Time/ 2 Years      |         |           |           |          |             |
|                | Ending*** 77 | 2037 |                       |         |           |           |          |             |

Cost/Year = $125.00 x 1 ÷ 2 = $62.50
Cost/Year = $150.00 x 1 ÷ 2 = $75.00
Cost/Year Average = ($62.50 + $75.00) ÷ 2 = $68.75

| **7 Power Wheelchair Batteries** |       |      |                       | Extra backup batteries. | $46.00 to $46.00 | $18.40 to $18.40 |          |             |
| Option 1       | Beginning*** 46 | 2006 | 2 Per/ 5 Years      |         |           |           |          |             |
|                | Ending*** 77 | 2037 |                       |         |           |           |          |             |

(Continued)
<table>
<thead>
<tr>
<th>Items/Services</th>
<th>Age</th>
<th>Year</th>
<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Cost/Unit</th>
<th>Comments</th>
<th>Recommender</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1 Compression Garments – Arms</strong></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Option 1</td>
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<td></td>
</tr>
<tr>
<td>Beginning***</td>
<td>46</td>
<td>2006</td>
<td>8–10 Times/Year</td>
<td>Assist with circulation, prevent DVTs.</td>
<td>$69.99 to $69.99</td>
<td></td>
<td>Dr. Burn Surgeon</td>
</tr>
<tr>
<td>Ending***</td>
<td>77</td>
<td>2037</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cost/Year Average = ($559.92 + $699.90) ÷ 2 = $629.91</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>2 Compression Garments – Legs</strong></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Option 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Beginning***</td>
<td>46</td>
<td>2006</td>
<td>8–10 Per/Year</td>
<td>Assist with circulation, DVT prevention.</td>
<td>$79.61 to $79.61</td>
<td>2–3 sets per year.</td>
<td>Dr. Burn Surgeon</td>
</tr>
<tr>
<td>Ending***</td>
<td>77</td>
<td>2037</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cost/Year Average = ($636.88 + $796.10) ÷ 2 = $716.49</td>
<td></td>
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</tr>
<tr>
<td><strong>3 Silicone Face Mask</strong></td>
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<td></td>
</tr>
<tr>
<td>Option 1</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Beginning***</td>
<td>46</td>
<td>2007</td>
<td>1 Per/Year</td>
<td>Scar compression, decrease itching.</td>
<td>$1,800.00 to $2,000.00</td>
<td>May need after facial dermabrasion.</td>
<td>Dr. Burn Surgeon</td>
</tr>
<tr>
<td>Ending***</td>
<td>47</td>
<td>2008</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Orthotics/Prosthetics

<table>
<thead>
<tr>
<th>Items/Services</th>
<th>Age</th>
<th>Year</th>
<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Cost/Unit</th>
<th>Cost/Year</th>
<th>Comments</th>
<th>Recommender</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Compression Garments – Gloves</strong></td>
<td>46</td>
<td>2007</td>
<td>4–6 Per/Year</td>
<td>Scar compression, decrease itching.</td>
<td>$214.00</td>
<td>$856.00</td>
<td></td>
<td>Dr. Burn Surgeon</td>
</tr>
<tr>
<td><strong>Elbow Splint</strong></td>
<td>46</td>
<td>2006</td>
<td>2–4 Times/1–2 Years</td>
<td>Splinting after surgery.</td>
<td>$111.78</td>
<td>$223.56</td>
<td></td>
<td>Mr. Moveit, OT</td>
</tr>
<tr>
<td><strong>Elastomer</strong></td>
<td>46</td>
<td>2006</td>
<td>2–4 Times/1–2 Years</td>
<td>Material for under splint.</td>
<td>$58.50</td>
<td>$117.00</td>
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<td>Dr. Burn Surgeon</td>
</tr>
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</table>

Cost/Year = $214.00 x 4 = $856.00
Cost/Year = $214.00 x 6 = $1,284.00
Cost/Year Average = ($856.00 + $1,284.00) / 2 = $1,070.00

Cost/Year = $111.78 x 2 = $223.56
Cost/Year = $111.78 x 4 ÷ 2 = $223.56
Cost/Year Average = ($111.78 + $447.12) ÷ 2 = $279.45

Cost/Year = $111.78 x 4 = $447.12
Cost/Year = $58.50 x 2 = $117.00
Cost/Year = $58.50 x 4 ÷ 2 = $117.00
Cost/Year Average = ($58.50 + $234.00) ÷ 2 = $146.25

Cost/Year = $58.50 x 4 = $234.00

(Continued)
<table>
<thead>
<tr>
<th>7 Long Leg Splint</th>
<th>Option 1</th>
<th>Beginning*** 46 2006</th>
<th>2 Times/Year Needs after popliteal correction surgery.</th>
<th>Cost/Unit $122.78 to $122.78</th>
<th>Cost/Year $245.56 to $245.56</th>
<th>Mr. Moveit, OT</th>
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<tbody>
<tr>
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<td>Ending*** 46 2006</td>
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<tr>
<td><strong>Cost/Year = $122.78 x 2 = $245.56</strong></td>
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<td>8 Elastomer</td>
<td>Option 1</td>
<td>Beginning*** 46 2006</td>
<td>2 Times/Year Used under splint.</td>
<td>Cost/Unit $122.78 to $122.78</td>
<td>Cost/Year $245.56 to $245.56</td>
<td>Mr. Moveit, OT</td>
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<tr>
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<td>Ending*** 46 2006</td>
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<tr>
<td><strong>Cost/Year = $58.50 x 2 = $117.00</strong></td>
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<tr>
<td>9 Axilla Splint</td>
<td>Option 1</td>
<td>Beginning*** 46 2006</td>
<td>4 Times/6 Years Use splint after axilla release surgeries.</td>
<td>Cost/Unit $1,800.00 to $2,000.00</td>
<td>Cost/Year $1,200.00 to $1,333.33</td>
<td>Mr. Moveit, OT</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Ending*** 52 2012</td>
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</tbody>
</table>
| **Cost/Year = $1,800.00 x 4 ÷ 6 = $1,200.00**
| **Cost/Year = $2,000.00 x 4 ÷ 6 = $1,333.33**
<p>| <strong>Cost/Year Average = ($1,200.00 + $1,333.33) ÷ 2 = $1,266.67</strong> |
| 10 Elastomer     | Option 1 | Beginning*** 46 2006 | 4 Times/6 Years Used under splint.               | Cost/Unit $58.50 to $58.50  | Cost/Year $39.00 to $39.00   | Mr. Moveit, OT |
|                  |         | Ending*** 52 2012    |                                                  |                             |                                |                 |
| <strong>Cost/Year = $58.50 x 4 ÷ 6 = $39.00</strong> |</p>
<table>
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<tr>
<th>Items/Services</th>
<th>Age</th>
<th>Year</th>
<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Cost/Unit</th>
<th>Cost/Year</th>
<th>Comments</th>
<th>Recommender</th>
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<tbody>
<tr>
<td>1 CPM Option 1</td>
<td>45</td>
<td>2006</td>
<td>180–240 Times/2 Years</td>
<td>Used daily for 3–4 months after elbow surgery.</td>
<td>$26.00 to $35.00</td>
<td>Average = ($2,340.00 + $4,200.00) ÷ 2 = $3,270.00</td>
<td>Dr. Burn Surgeon</td>
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<tr>
<td></td>
<td>47</td>
<td>2008</td>
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Cost/Year = $26.00 x 180 ÷ 2 = $2,340.00
Cost/Year = $35.00 x 240 ÷ 2 = $4,200.00
Cost/Year Average = ($2,340.00 + $4,200.00) ÷ 2 = $3,270.00
Cost/Year = $26.00 x 240 ÷ 2 = $3,120.00

(Continued)
## Aids for Independent Function

<table>
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<tr>
<th>Items/Services</th>
<th>Age</th>
<th>Year</th>
<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Cost/Unit</th>
<th>Cost/Year</th>
<th>Comments</th>
<th>Recommender</th>
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<tbody>
<tr>
<td><strong>Button and Zipper Aid</strong></td>
<td></td>
<td></td>
<td></td>
<td>Assist in buttoning and zipper.</td>
<td>$5.95 to $5.95</td>
<td>$1.19 to $1.98</td>
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<td>Dr. Burn Surgeon</td>
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<tr>
<td>Option 1</td>
<td></td>
<td></td>
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<tr>
<td>Beginning***</td>
<td>46</td>
<td>2006</td>
<td>1 Per/3–5 Years</td>
<td></td>
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<tr>
<td>Ending***</td>
<td>77</td>
<td>2037</td>
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<tr>
<td><strong>Adaptive Clothing</strong></td>
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<td>SUV protection.</td>
<td>$900.00 to $1,000.00</td>
<td>$950.00</td>
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<td>Dr. Burn Surgeon</td>
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<tr>
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<tr>
<td>Beginning***</td>
<td>46</td>
<td>2006</td>
<td>1 Per/Year</td>
<td></td>
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<tr>
<td>Ending***</td>
<td>77</td>
<td>2037</td>
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<tr>
<td><strong>Long-Handled Bath Brush</strong></td>
<td></td>
<td></td>
<td></td>
<td>Better able to shower more independently.</td>
<td>$19.95 to $19.95</td>
<td>$3.99 to $6.65</td>
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<tr>
<td>Beginning***</td>
<td>46</td>
<td>2006</td>
<td>1 Per/3–5 Years</td>
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<tr>
<td>Ending***</td>
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<td>2037</td>
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<tr>
<td><strong>Reacher</strong></td>
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<td></td>
<td>Helps to reach things independently.</td>
<td>$9.95 to $9.95</td>
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<td>Beginning***</td>
<td>46</td>
<td>2006</td>
<td>1 Time/4–5 Years</td>
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<tr>
<td>Ending***</td>
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<td>2037</td>
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<tr>
<td>Items/Services</td>
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<td>Year</td>
<td>Frequency/Replacement</td>
<td>Purpose</td>
<td>Cost/Unit</td>
<td>Cost/Year</td>
<td>Comments</td>
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<tr>
<td><strong>Shower Chair</strong></td>
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<tr>
<td>Option 1</td>
<td>45</td>
<td>2006</td>
<td>1 Per/ 4–5 Years</td>
<td>Avoid falls in shower.</td>
<td>$40.00 to $45.00</td>
<td>$10.00</td>
<td>$8.00 to $11.25</td>
<td>Dr. Burn Surgeon</td>
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<td></td>
<td>77</td>
<td>2038</td>
<td></td>
<td></td>
<td>$12.25 to $14.00</td>
<td>$2.45</td>
<td>$2.45 to $3.50</td>
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<td><strong>Jar Opener</strong></td>
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<td>46</td>
<td>2006</td>
<td>1 Per/ 4–5 Years</td>
<td>Open jars independently.</td>
<td>$12.25 to $14.00</td>
<td>$3.06</td>
<td>$2.80</td>
<td>Dr. Burn Surgeon</td>
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<td>77</td>
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<td>$14.00 to $16.00</td>
<td>$3.50</td>
<td>$2.98</td>
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<td><strong>Shower, Handheld</strong></td>
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<tr>
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<td>46</td>
<td>2006</td>
<td>1 Per/ 5 Years</td>
<td>Better able to shower by himself.</td>
<td>$34.95 to $34.95</td>
<td>$6.99</td>
<td>$6.99</td>
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<td>$34.95 to $34.95</td>
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<td>$6.99</td>
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<th>Items/Services</th>
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<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Cost/Unit</th>
<th>Cost/Year</th>
<th>Comments</th>
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<tbody>
<tr>
<td><strong>8 Long Shoehorn</strong></td>
<td>46</td>
<td>2006</td>
<td>1 Per/5 Years</td>
<td>Help to put on his own shoes and socks.</td>
<td>$24.00 to $24.00</td>
<td>$4.80 to $4.80</td>
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<td><strong>9 Tub Transfer Brush</strong></td>
<td>46</td>
<td>2006</td>
<td>1 Per/5 Years</td>
<td>Transfer out of tub</td>
<td>$129.00 to $129.00</td>
<td>$25.80 to $25.80</td>
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<td>Dr. Burn Surgeon</td>
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<tr>
<td><strong>10 Commode With Padded Seat</strong></td>
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<td>2006</td>
<td>1 Per/5 Years</td>
<td>Padded seat with arms.</td>
<td>$38.00 to $38.00</td>
<td>$7.60 to $7.60</td>
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<tr>
<td><strong>11 Medication Organizer/Box</strong></td>
<td>46</td>
<td>2006</td>
<td>1 Per/3–4 Years</td>
<td>Keep medications organized</td>
<td>$3.00 to $6.00</td>
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<td>Ms. Healthy, Burn Nurse Practitioner</td>
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<tr>
<td>Items/Services</td>
<td>Age</td>
<td>Year</td>
<td>Frequency/Replacement</td>
<td>Purpose</td>
<td>Cost/Unit</td>
<td>Comments</td>
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<tr>
<td>1 Bandage Scissors</td>
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<td>2006</td>
<td>1×/ Year</td>
<td>Dressing changes.</td>
<td>$6.00 to $9.00</td>
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<td>Dr. Burn Surgeon</td>
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<tr>
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<td>55</td>
<td>2015</td>
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Cost/Year Average = ($6.00 + $9.00) / 2 = $7.50

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<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Cost/Unit</th>
<th>Comments</th>
<th>Recommender</th>
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<tbody>
<tr>
<td>2 Dressing Change Materials</td>
<td>46</td>
<td>2006</td>
<td>4×/ Year</td>
<td>Dressing change materials postsurgery.</td>
<td>$400.00 to $450.00</td>
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<td>52</td>
<td>2012</td>
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Cost/Year Average = ($1,600.00 + $1,800.00) / 2 = $1,700.00

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<th>Age</th>
<th>Year</th>
<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Cost/Unit</th>
<th>Comments</th>
<th>Recommender</th>
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<tbody>
<tr>
<td>3 Gloves, Latex</td>
<td>46</td>
<td>2006</td>
<td>2×/ Year</td>
<td>For dressing changes.</td>
<td>$6.00 to $6.00</td>
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<td>Ms. Healthy, Burn Nurse Practitioner</td>
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<td>2015</td>
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Cost/Year = $12.00
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<th>4</th>
<th><strong>Ensure</strong></th>
<th><strong>Option 1</strong></th>
<th><strong>Beginning</strong>* 46 2006</th>
<th><strong>Ending</strong>* 50 2010</th>
<th><strong>1080–1440 Per/Year</strong></th>
<th><strong>Nutritional boost during years of surgery.</strong></th>
<th><strong>Cost/Unit $2.00 to $2.12</strong></th>
<th><strong>Cost/Year $2,160.00 to $3,052.80</strong></th>
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<tr>
<td>Cost/Year = $2.00 x 1080 = $2,160.00</td>
<td>Cost/Year = $2.12 x 1080 = $2,289.60</td>
<td><strong>Cost/Year Average = ($2,160.00 + $3,052.80) ÷ 2 = $2,606.40</strong></td>
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<tr>
<td>Cost/Year = $2.00 x 1440 = $2,880.00</td>
<td>Cost/Year = $2.12 x 1440 = $3,052.80</td>
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<th>5</th>
<th><strong>Aloe First Spray</strong></th>
<th><strong>Option 1</strong></th>
<th><strong>Beginning</strong>* 46 2006</th>
<th><strong>Ending</strong>* 77 2037</th>
<th><strong>12 Per/Year</strong></th>
<th><strong>Helps maintain dry skin and reduce itching.</strong></th>
<th><strong>Cost/Unit $12.00 to $12.00</strong></th>
<th><strong>Cost/Year $144.00 to $144.00</strong></th>
<th><strong>Dr. Burn Surgeon</strong></th>
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<tbody>
<tr>
<td>Cost/Year = $12.00 x 12 = $144.00</td>
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<th>6</th>
<th><strong>Aloe Vera Lotion</strong></th>
<th><strong>Option 1</strong></th>
<th><strong>Beginning</strong>* 46 2006</th>
<th><strong>Ending</strong>* 77 2037</th>
<th><strong>3–4 Per/Month</strong></th>
<th><strong>Helps maintain dry, cracking skin.</strong></th>
<th><strong>Cost/Unit $12.00 to $12.00</strong></th>
<th><strong>Cost/Year $432.00 to $576.00</strong></th>
<th><strong>Dr. Burn Surgeon</strong></th>
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<tbody>
<tr>
<td>Cost/Year = $12.00 x 3 x 12 = $432.00</td>
<td>Cost/Year = $12.00 x 4 x 12 = $576.00</td>
<td>Cost/Year Average = ($432.00 + $576.00) ÷ 2 = $504.00</td>
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<tr>
<th>7</th>
<th><strong>Lip Balm</strong></th>
<th><strong>Option 1</strong></th>
<th><strong>Beginning</strong>* 46 2006</th>
<th><strong>Ending</strong>* 77 2037</th>
<th><strong>24 Per/Year</strong></th>
<th><strong>Help for dry cracking lips.</strong></th>
<th><strong>Cost/Unit $5.00 to $5.00</strong></th>
<th><strong>Cost/Year $120.00 to $120.00</strong></th>
<th><strong>Dr. Burn Surgeon</strong></th>
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<td><strong>Items/Services</strong></td>
<td><strong>Age</strong></td>
<td><strong>Year</strong></td>
<td><strong>Frequency/Replacement</strong></td>
<td><strong>Purpose</strong></td>
<td><strong>Cost</strong></td>
<td><strong>Comments</strong></td>
<td><strong>Recommender</strong></td>
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<tr>
<td>8 Aquaphor</td>
<td>Beginning***</td>
<td>46</td>
<td>2006</td>
<td>48–60 Times/Year</td>
<td>Dry sensitive skin.</td>
<td>Cost/Unit $16.99 to $16.99</td>
<td>Dr. Burn Surgeon</td>
<td></td>
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<tr>
<td>Option 1</td>
<td>Ending***</td>
<td>77</td>
<td>2037</td>
<td></td>
<td></td>
<td>Cost/Year $815.52 to $1,019.40</td>
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<tr>
<td>Cost/Year = $16.99 x 48 = $815.52</td>
<td>Cost/Year = $16.99 x 60 = $1,019.40</td>
<td>Cost/Year Average = ($815.52 + $1,019.40) ÷ 2 = $917.46</td>
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<tr>
<td>9 Maderma</td>
<td>Beginning***</td>
<td>46</td>
<td>2006</td>
<td>10–12 Per/Year</td>
<td>Scar management.</td>
<td>Cost/Unit $28.99 to $28.99</td>
<td>Dr. Burn Surgeon</td>
<td></td>
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<tr>
<td>Option 1</td>
<td>Ending***</td>
<td>52</td>
<td>2012</td>
<td></td>
<td></td>
<td>Cost/Year $289.90 to $347.88</td>
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<tr>
<td>Cost/Year = $28.99 x 10 = $289.90</td>
<td>Cost/Year = $28.99 x 12 = $347.88</td>
<td>Cost/Year Average = ($289.90 + $347.88) ÷ 2 = $318.89</td>
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<tr>
<th>Items/Services</th>
<th>Age</th>
<th>Year</th>
<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Cost/Unit</th>
<th>Comments</th>
<th>Recommender</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Neurontin</strong></td>
<td></td>
<td></td>
<td><strong>Beginning</strong>* 46 2006</td>
<td>11 Per/Year</td>
<td>Pain control—1 bottle has 300 tablets. Need about 270 per month.</td>
<td>Cost/Unit $460.59 to $460.59</td>
<td>Will likely need this medication for life.</td>
</tr>
<tr>
<td><strong>Ibuprofen</strong></td>
<td></td>
<td></td>
<td><strong>Beginning</strong>* 46 2006</td>
<td>2 Per/Year</td>
<td>Pain control.</td>
<td>Cost/Unit $14.99 to $14.99</td>
<td>Dr. Burn Surgeon</td>
</tr>
<tr>
<td><strong>Pepcid AC Tablets</strong></td>
<td></td>
<td></td>
<td><strong>Beginning</strong>* 46 2006</td>
<td>12 Per/Year</td>
<td>Acid reduction.</td>
<td>Cost/Unit $17.99 to $17.99</td>
<td>Dr. Burn Surgeon</td>
</tr>
<tr>
<td><strong>Tylenol 500 mg</strong></td>
<td></td>
<td></td>
<td><strong>Beginning</strong>* 46 2006</td>
<td>4–5 Times/Year</td>
<td>Pain control.</td>
<td>Cost/Unit $12.99 to $12.99</td>
<td>Dr. Burn Surgeon</td>
</tr>
</tbody>
</table>

Cost/Year = $460.59 x 11 = $5,066.49

Cost/Year = $14.99 x 2 = $29.98

Cost/Year = $17.99 x 12 = $215.88

Cost/Year = $12.99 x 4 = $51.96

Cost/Year = $12.99 x 5 = $64.95

Cost/Year Average = ($51.96 + $64.95) ÷ 2 = $58.46
<table>
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<tr>
<th>Items/Services</th>
<th>Age</th>
<th>Year</th>
<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Cost/Unit</th>
<th>Cost/Year</th>
<th>Comments</th>
<th>Recommender</th>
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<tbody>
<tr>
<td><strong>Artificial Tears</strong></td>
<td>46</td>
<td>2006</td>
<td>Beginning***</td>
<td>For dry eyes.</td>
<td>Cost/Unit $11.00 to $13.00</td>
<td>Cost/Year $132.00 to</td>
<td>Dr. Burn Surgeon</td>
<td></td>
</tr>
<tr>
<td>Option 1</td>
<td>77</td>
<td>2037</td>
<td>Ending***</td>
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<tr>
<td><strong>Benadryl</strong></td>
<td>46</td>
<td>2006</td>
<td>Beginning***</td>
<td>For itching.</td>
<td>Cost/Unit $14.99 to $14.99</td>
<td>Cost/Year $179.88 to $179.88</td>
<td>Dr. Burn Surgeon</td>
<td></td>
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<tr>
<td>Option 1</td>
<td>55</td>
<td>2015</td>
<td>Ending***</td>
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<tr>
<td><strong>Multivitamin</strong></td>
<td>46</td>
<td>2006</td>
<td>Beginning***</td>
<td>Nutritional purposes.</td>
<td>Cost/Unit $6.95 to $8.95</td>
<td>Cost/Year $41.70 to $53.70</td>
<td>Dr. Burn Surgeon</td>
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<tr>
<td>Option 1</td>
<td>77</td>
<td>2037</td>
<td>Ending***</td>
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<tr>
<td><strong>Sunscreen</strong></td>
<td>46</td>
<td>2006</td>
<td>Beginning***</td>
<td>Prevent skin cancer</td>
<td>Cost/Unit $8.00 to $10.00</td>
<td>Cost/Year $80.00 to $120.00</td>
<td>Dr. Burn Surgeon</td>
<td></td>
</tr>
<tr>
<td>Option 1</td>
<td>77</td>
<td>2037</td>
<td>Ending***</td>
<td></td>
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</table>

Cost/Year Average = ($132.00 + $156.00) ÷ 2 = $144.00

Cost/Year Average = ($179.88 + $179.88) ÷ 2 = $179.88

Cost/Year Average = ($41.70 + $53.70) ÷ 2 = $47.70

(Continued)
<table>
<thead>
<tr>
<th>9 Stool Softener</th>
<th>Beginning***</th>
<th>10 Per/Year</th>
<th>Needed with narcotics he will be taking indefinitely.</th>
<th>Cost/Unit</th>
<th>Cost/Year</th>
<th>Dr. Burn Surgeon</th>
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<tbody>
<tr>
<td>Option 1</td>
<td>46 2006</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>77 2037</td>
<td></td>
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<tr>
<td></td>
<td>Cost/Year = $10.50 x 10 = $105.00</td>
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<tr>
<td></td>
<td>Cost/Year = $12.00 x 10 = $120.00</td>
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<tr>
<td></td>
<td>Cost/Year Average = ($105.00 + $120.00) ÷ 2 = $112.50</td>
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<table>
<thead>
<tr>
<th>10 Bacitracin</th>
<th>Beginning***</th>
<th>2–3 Times/Year</th>
<th>For dressing changes postop at home.</th>
<th>Cost/Unit</th>
<th>Cost/Year</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>Option 1</td>
<td>46 2006</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td></td>
<td>50 2010</td>
<td></td>
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<tr>
<td></td>
<td>Cost/Year = $17.40 x 2 = $34.80</td>
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<tr>
<td></td>
<td>Cost/Year = $17.40 x 3 = $52.20</td>
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<td></td>
<td>Cost/Year Average = ($34.80 + $52.20) ÷ 2 = $43.50</td>
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<tr>
<td>Items/Services</td>
<td>Age</td>
<td>Year</td>
<td>Frequency/Replacement</td>
<td>Purpose</td>
<td>Cost/Unit</td>
<td>Cost/Year</td>
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</tr>
<tr>
<td>Case Management</td>
<td>46</td>
<td>2006</td>
<td>Beginning*** 46-60</td>
<td>Assist with monitoring all medical care relating to the burn in juries.</td>
<td>$100.00 to $120.00</td>
<td>$4,800.00 to $7,200.00</td>
</tr>
<tr>
<td>Option 1</td>
<td>77</td>
<td>2037</td>
<td>Ending***</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Housekeeping Services</td>
<td>48</td>
<td>2006</td>
<td>Beginning*** 52 Visits</td>
<td>Assist with housekeeping duties.</td>
<td>$60.00 to $80.00</td>
<td>$3,120.00 to $4,160.00</td>
</tr>
<tr>
<td>Option 1</td>
<td>59</td>
<td>2020</td>
<td>Ending***</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interior/Exterior</td>
<td>48</td>
<td>2009</td>
<td>Beginning*** 144 Hours</td>
<td>Assist with maintenance of home.</td>
<td>$50.00 to $80.00</td>
<td>$7,200.00 to $11,520.00</td>
</tr>
<tr>
<td>Home Maintenance</td>
<td>59</td>
<td>2020</td>
<td>Ending***</td>
<td></td>
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<table>
<thead>
<tr>
<th>Chart 2 (Continued)</th>
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<tbody>
<tr>
<td><strong>Cost/Year = $50.00 x 144 = $7,200.00</strong></td>
</tr>
<tr>
<td><strong>Cost/Year Average = ($7,200.00 + $11,520.00) ÷ 2 = $9,360.00</strong></td>
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<table>
<thead>
<tr>
<th><strong>4 Lawn Care</strong></th>
<th><strong>Beginning</strong>* 48 2009</th>
<th><strong>50 Visits/Year</strong></th>
<th><strong>Assist with outside work.</strong></th>
<th><strong>Cost/Unit $75.00 to $100.00</strong></th>
<th><strong>Dr. Burn Surgeon</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Option 1</strong></td>
<td><strong>Ending</strong>* 59 2020</td>
<td></td>
<td></td>
<td><strong>Cost/Year $3,750.00 to</strong> $5,000.00</td>
<td></td>
</tr>
<tr>
<td><strong>Cost/Year = $75.00 x 50 = $3,750.00</strong></td>
<td><strong>Cost/Year = $100.00 x 50 = $5,000.00</strong></td>
<td><strong>Cost/Year Average = ($3,750.00 + $5,000.00) ÷ 2 = $4,375.00</strong></td>
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<table>
<thead>
<tr>
<th><strong>5 Assisted Living Facility</strong></th>
<th><strong>Beginning</strong>* 46 2006</th>
<th><strong>12 Times/Year</strong></th>
<th><strong>Assisted living arrangement includes housekeeping, health and wellness, and two meals a day.</strong></th>
<th><strong>Cost/Unit $3,395.00 to $3,395.00</strong></th>
<th><strong>Mr. Doe needs a number of surgeries in the next 2 years. Assisted living would be a big help during that time period.</strong></th>
<th><strong>Dr. Burn Surgeon</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Option 1</strong></td>
<td><strong>Ending</strong>* 47 2007</td>
<td></td>
<td></td>
<td><strong>Cost/Year $40,740.00 to $40,740.00</strong></td>
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<tr>
<td><strong>Cost/Year = $3,395.00 x 12 = $40,740.00</strong></td>
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<thead>
<tr>
<th><strong>6 Assisted Living Facility</strong></th>
<th><strong>Beginning</strong>* 60 2022</th>
<th><strong>12 Times/Year</strong></th>
<th><strong>Mr. Doe is likely to age more quickly than the average person.</strong></th>
<th><strong>Cost/Unit $3,450.00 to $3,450.00</strong></th>
<th><strong>Dr. Burn Surgeon</strong></th>
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</thead>
<tbody>
<tr>
<td><strong>Option 1</strong></td>
<td><strong>Ending</strong>* 77 2039</td>
<td></td>
<td></td>
<td><strong>Cost/Year $41,400.00 to $40,740.00</strong></td>
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<tr>
<td><strong>Cost/Year = $3,450.00 x 12 = $41,400.00</strong></td>
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<tr>
<td>Items/Services</td>
<td>Age</td>
<td>Year</td>
<td>Frequency/Replacement</td>
<td>Purpose</td>
<td>Cost/Unit</td>
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</tr>
<tr>
<td>7 Daily Attendant</td>
<td>46</td>
<td>2006</td>
<td>3500 Hours/Year</td>
<td>CNA to help with medications, lotions, meals, and laundry.</td>
<td>$20.00 to $22.00</td>
</tr>
<tr>
<td>Option 1</td>
<td>51</td>
<td>2011</td>
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<tr>
<td>8 Daily Attendant</td>
<td>52</td>
<td>2013</td>
<td>3650 Hours/Year</td>
<td>CNA to help him with daily activities.</td>
<td>$20.00 to $21.00</td>
</tr>
<tr>
<td>Option 1</td>
<td>77</td>
<td>2038</td>
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Cost/Year = $20.00 x 3500 = $70,000.00
Cost/Year = $22.00 x 3500 = $77,000.00
Cost/Year Average = ($70,000.00 + $77,000.00) ÷ 2 = $73,500.00

Cost/Year = $20.00 x 3650 = $73,000.00
Cost/Year = $21.00 x 3650 = $76,650.00
Cost/Year Average = ($73,000.00 + $76,650.00) ÷ 2 = $74,825.00

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<table>
<thead>
<tr>
<th>Items/Services</th>
<th>Age</th>
<th>Year</th>
<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Cost/Unit</th>
<th>Cost/Year</th>
<th>Comments</th>
<th>Recommender</th>
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<tbody>
<tr>
<td>1 Physiatrist</td>
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<td></td>
<td>Dr. Burn Surgeon</td>
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<tr>
<td>Option 1</td>
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</tr>
<tr>
<td></td>
<td>Beginning***</td>
<td>46</td>
<td>2006</td>
<td>3 Visits/Year</td>
<td>Monitor rehab, pain medication, and mobility issues.</td>
<td>$160.00 to $180.00</td>
<td>$480.00 to $540.00</td>
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<tr>
<td></td>
<td>Ending***</td>
<td>55</td>
<td>2015</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td><strong>Cost/Year = $160.00 x 3 = $480.00</strong></td>
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<tr>
<td></td>
<td><strong>Cost/Year = $180.00 x 3 = $540.00</strong></td>
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<td></td>
<td><strong>Cost/Year Average = ($480.00 + $540.00) ÷ 2 = $510.00</strong></td>
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<tr>
<td>2 Internal Medicine</td>
<td></td>
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<td>Dr. Burn Surgeon</td>
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<td>Option 1</td>
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</tr>
<tr>
<td></td>
<td>Beginning***</td>
<td>46</td>
<td>2006</td>
<td>2–3 Times/Year</td>
<td>Monitor health as it relates to medications and burn injuries.</td>
<td>$175.00 to $175.00</td>
<td>$350.00 to $525.00</td>
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</tr>
<tr>
<td></td>
<td>Ending***</td>
<td>77</td>
<td>2037</td>
<td></td>
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<tr>
<td></td>
<td><strong>Cost/Year = $175.00 x 2 = $350.00</strong></td>
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<tr>
<td></td>
<td><strong>Cost/Year = $175.00 x 3 = $525.00</strong></td>
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<tr>
<td></td>
<td><strong>Cost/Year Average = ($350.00 + $525.00) ÷ 2 = $437.50</strong></td>
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<tr>
<td>3 Blood Work, Chemistry</td>
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<td>Dr. Burn Surgeon</td>
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<tr>
<td>Option 1</td>
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</tr>
<tr>
<td></td>
<td>Beginning***</td>
<td>46</td>
<td>2006</td>
<td>2–4 Times/Year</td>
<td>Check electrolytes, renal function, and liver enzymes.</td>
<td>$78.50 to $78.50</td>
<td>$157.00 to $314.00</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ending***</td>
<td>77</td>
<td>2037</td>
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<td></td>
<td><strong>Cost/Year = $78.50 x 2 = $157.00</strong></td>
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<tr>
<td></td>
<td><strong>Cost/Year = $78.50 x 4 = $314.00</strong></td>
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<tr>
<td></td>
<td><strong>Cost/Year Average = ($157.00 + $314.00) ÷ 2 = $235.50</strong></td>
<td></td>
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</tr>
<tr>
<td>Items/Services</td>
<td>Frequency/Replacement</td>
<td>Purpose</td>
<td>Cost</td>
<td>Comments</td>
<td>Recommender</td>
<td></td>
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</tr>
<tr>
<td>1 Van, Adaptive with Lift</td>
<td>Beginning*** 46 2006</td>
<td>1 Time/8–10 Years</td>
<td>Transport scooter or wheelchair.</td>
<td>Cost/Unit $45,000.00 to $50,000.00</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Option 1</td>
<td>Ending*** 77 2037</td>
<td></td>
<td></td>
<td>Cost/Year $4,500.00 to $6,250.00</td>
<td></td>
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</tr>
<tr>
<td>2 Mileage</td>
<td>Beginning*** 46 2006</td>
<td>500–750 Per/Year</td>
<td>Mileage to appointments.</td>
<td>Cost/Unit $0.45 to $0.45</td>
<td></td>
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</tr>
<tr>
<td>Option 1</td>
<td>Ending*** 52 2012</td>
<td></td>
<td></td>
<td>Cost/Year $225.00 to $337.50</td>
<td></td>
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</tr>
<tr>
<td>3 Mileage</td>
<td>Beginning*** 53 2015</td>
<td>250 Per/Year</td>
<td></td>
<td>Cost/Unit $0.47 to $0.47</td>
<td></td>
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</tr>
<tr>
<td>Option 1</td>
<td>Ending*** 77 2039</td>
<td></td>
<td></td>
<td>Cost/Year $117.50 to $117.50</td>
<td></td>
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</table>

Cost/Year = $45,000.00 x 1 ÷ 8 = $5,625.00  
Cost/Year = $50,000.00 x 1 ÷ 10 = $5,000.00  
Cost/Year = $4,500.00 x 1 ÷ 10 = $4,500.00  
Cost/Year Average = ($4,500.00 + $6,250.00) ÷ 2 = $5,375.00  
Cost/Year = $50,000.00 x 1 ÷ 8 = $6,250.00  

Cost/Year = $0.45 x 500 = $225.00  
Cost/Year = $0.45 x 750 = $337.50  
Cost/Year Average = ($225.00 + $337.50) ÷ 2 = $281.25  

Cost/Year = $0.47 x 250 = $117.50  

(Continued)
<table>
<thead>
<tr>
<th>Items/Services</th>
<th>Age</th>
<th>Year</th>
<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Cost</th>
<th>Comments</th>
<th>Recommender</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Architectural Renovations</td>
<td></td>
<td></td>
<td>1 Time/7 Years</td>
<td>Allows for architectural changes for home he lives in every 7 years, which is the average number of years Americans live in their homes.</td>
<td>Cost/Unit $45,000.00 to $50,000.00</td>
<td>He is slated to be in assisted living for the next two years and then back in such a situation after age 60.</td>
<td>Ms. Healthy, Burn Nurse Practitioner</td>
</tr>
<tr>
<td>Option 1</td>
<td>48</td>
<td>2009</td>
<td></td>
<td></td>
<td>Cost/Year $6,428.57 to $7,142.86</td>
<td></td>
<td></td>
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<tr>
<td>Ending***</td>
<td>60</td>
<td>2021</td>
<td></td>
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</table>

Cost/Year = $45,000.00 x 1 ÷ 7 = $6,428.57  
Cost/Year = $50,000.00 x 1 ÷ 7 = $7,142.86  
Cost/Year Average = ($6,428.57 + $7,142.86) ÷ 2 = $6,785.71
<table>
<thead>
<tr>
<th>Items/Services</th>
<th>Age</th>
<th>Year</th>
<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Cost</th>
<th>Comments</th>
<th>Recommender</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gym Membership</td>
<td></td>
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</tr>
<tr>
<td>Monthly Fee</td>
<td>46</td>
<td>2006</td>
<td>12 Times/Year</td>
<td>Regular exercise for function and mobility.</td>
<td></td>
<td></td>
<td>Dr. Burn Surgeon</td>
</tr>
<tr>
<td>Option 1</td>
<td>70</td>
<td>2030</td>
<td></td>
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</table>

Cost/Year = $30.00 x 12 = $360.00

(Continued)
# Chart 2 (Continued)

<table>
<thead>
<tr>
<th>Items/Services</th>
<th>Age</th>
<th>Year</th>
<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Cost/Unit</th>
<th>Comments</th>
<th>Recommender</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1 Radiation to elbow</strong></td>
<td>46</td>
<td>2006</td>
<td>2 Times/ 2 Years</td>
<td>Keep heterotropic ossification of elbow from returning.</td>
<td>$5,000.00 to $5,000.00</td>
<td>This price is the minimum price that was quoted by the radiation centers called.</td>
<td>Dr. Burn Surgeon</td>
</tr>
<tr>
<td><strong>Option 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>47</td>
<td>2007</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>2 Emergency Room Visits</strong></td>
<td>46</td>
<td>2006</td>
<td>1–2 Visits/ Year</td>
<td>ER visits after surgery, for skin breakdown and respiratory issues.</td>
<td>$1,250.00 to $1,800.00</td>
<td></td>
<td>Dr. Burn Surgeon</td>
</tr>
<tr>
<td><strong>Option 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>77</td>
<td>2037</td>
<td></td>
<td></td>
<td>$1,250.00 to $3,600.00</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Cost/Year = $5,000.00 x 2 ÷ 2 = $5,000.00  
Cost/Year = $1,250.00 x 2 = $2,500.00  
Cost/Year = $1,800.00 x 2 = $3,600.00  
Cost/Year Average = ($1,250.00 + $3,600.00) ÷ 2 = $2,425.00
<table>
<thead>
<tr>
<th>Items/Services</th>
<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Cost/Unit</th>
<th>Comments</th>
<th>Recommender</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Repair heterotopic ossification of left elbow</td>
<td>Beginning*** 46 2006</td>
<td>1 Time/Year Remove calcified bone impeding movement of joint.</td>
<td>Cost/Unit $4,000.00 to $4,000.00</td>
<td>Done by an orthopedic surgeon.</td>
<td>Dr. Orthopedic Surgeon</td>
</tr>
<tr>
<td>Option 1</td>
<td>Ending*** 46 2006</td>
<td></td>
<td>Cost/Year $4,000.00 to $4,000.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 Integra—Dermal Replacement</td>
<td>Beginning*** 46 2006</td>
<td>1 Time/Year Skin substitute.</td>
<td>Cost/Unit $4,537.50 to $4,537.50</td>
<td>Mr. Doe has limited donor sites.</td>
<td>Dr. Burn Surgeon</td>
</tr>
<tr>
<td>Option 1</td>
<td>Ending*** 46 2006</td>
<td></td>
<td>Cost/Year $4,537.50 to $4,537.50</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 Anesthesia Fee</td>
<td>Beginning*** 46 2006</td>
<td>1 Time/Year Surgery performed under general anesthesia.</td>
<td>Cost/Unit $1,500.00 to $1,750.00</td>
<td></td>
<td>Dr. Burn Surgeon</td>
</tr>
<tr>
<td>Option 1</td>
<td>Ending*** 46 2006</td>
<td></td>
<td>Cost/Year $1,500.00 to $1,750.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 OR/Surgery Suite</td>
<td>Beginning*** 46 2006</td>
<td>1 Time/Year Surgery done inpatient under general anesthesia.</td>
<td>Cost/Unit $10,000.00 to $12,500.00</td>
<td></td>
<td>Dr. Burn Surgeon</td>
</tr>
<tr>
<td>Option 1</td>
<td>Ending*** 46 2006</td>
<td></td>
<td>Cost/Year $10,000.00 to $12,500.00</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Cost/Year Average = ($1,500.00 + $1,750.00) ÷ 2 = $1,625.00

Cost/Year Average = ($10,000.00 + $12,500.00) ÷ 2 = $11,250.00

(Continued)
<table>
<thead>
<tr>
<th></th>
<th><strong>Grafting</strong></th>
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</thead>
<tbody>
<tr>
<td></td>
<td><strong>Option 1</strong></td>
<td><strong>Beginning</strong>*</td>
<td><strong>1 Time/Year</strong></td>
<td><strong>Grafting to axilla wounds.</strong></td>
<td><strong>Cost/Unit</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>46 2006</strong></td>
<td></td>
<td><strong>$2,908.00 to $2,908.00</strong></td>
<td><strong>Cost/Year</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Ending</strong>*</td>
<td></td>
<td></td>
<td><strong>$2,908.00 to $2,908.00</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>46 2006</strong></td>
<td></td>
<td></td>
<td><strong>This is the second surgery to repair for heterotopic ossification.</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Dr. Burn Surgeon</strong></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

**Cost/Year Average = ($2,908.00 + $2,908.00) ÷ 2 = $2,908.00**

<table>
<thead>
<tr>
<th></th>
<th><strong>Anesthesia Fee</strong></th>
<th><strong>Option 1</strong></th>
<th><strong>Beginning</strong>*</th>
<th><strong>1 Time/Year</strong></th>
<th><strong>Surgery done under general anesthesia.</strong></th>
<th><strong>Cost/Unit</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td><strong>46 2006</strong></td>
<td></td>
<td></td>
<td><strong>$1,125.00 to $1,250.00</strong></td>
<td><strong>Cost/Year</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Ending</strong>*</td>
<td></td>
<td></td>
<td><strong>$1,125.00 to $1,250.00</strong></td>
<td><strong>Cost/Year</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>46 2006</strong></td>
<td></td>
<td></td>
<td><strong>$1,125.00 to $1,250.00</strong></td>
<td><strong>Dr. Burn Surgeon</strong></td>
</tr>
</tbody>
</table>

**Cost/Year Average = ($1,125.00 + $1,250.00) ÷ 2 = $1,187.50**

<table>
<thead>
<tr>
<th></th>
<th><strong>OR/Surgery Suite</strong></th>
<th><strong>Option 1</strong></th>
<th><strong>Beginning</strong>*</th>
<th><strong>1 Time/Year</strong></th>
<th><strong>Place graft on axilla.</strong></th>
<th><strong>Cost/Unit</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td><strong>46 2006</strong></td>
<td></td>
<td></td>
<td><strong>$7,500.00 to $9,250.00</strong></td>
<td><strong>Cost/Year</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Ending</strong>*</td>
<td></td>
<td></td>
<td><strong>$7,500.00 to $9,250.00</strong></td>
<td><strong>Cost/Year</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>46 2006</strong></td>
<td></td>
<td></td>
<td><strong>$7,500.00 to $9,250.00</strong></td>
<td><strong>Cost/Year</strong></td>
</tr>
<tr>
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<td></td>
<td><strong>Cost/Year Average = ($7,500.00 + $9,250.00) ÷ 2 = $8,375.00</strong></td>
<td><strong>Dr. Burn Surgeon</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th><strong>Postop Therapy</strong></th>
<th><strong>Option 1</strong></th>
<th><strong>Beginning</strong>*</th>
<th><strong>36–48 Visits/Year</strong></th>
<th><strong>Therapy to maintain benefits of surgery—range of motion.</strong></th>
<th><strong>Cost/Unit</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td><strong>45 2006</strong></td>
<td></td>
<td></td>
<td><strong>$150.00 to $175.00</strong></td>
<td><strong>Cost/Year</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Ending</strong>*</td>
<td></td>
<td></td>
<td><strong>$5,400.00 to $8,400.00</strong></td>
<td><strong>Cost/Year</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>45 2006</strong></td>
<td></td>
<td></td>
<td><strong>$5,400.00 to $8,400.00</strong></td>
<td><strong>Dr. Burn Surgeon</strong></td>
</tr>
</tbody>
</table>

**Cost/Year Average = ($5,400.00 + $8,400.00) ÷ 2 = $6,900.00**
<table>
<thead>
<tr>
<th>Items/Services</th>
<th>Age</th>
<th>Year</th>
<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Cost</th>
<th>Comments</th>
<th>Recommender</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>9 Postop Home Health</strong></td>
<td></td>
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<tr>
<td>Option 1</td>
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</tr>
<tr>
<td></td>
<td>45</td>
<td>2006</td>
<td>Beginning***</td>
<td>Daily dressing changes for 4–6 weeks.</td>
<td>Cost/Unit $120.00 to $120.00</td>
<td>Nursing care 6 days a week with one dressing change at burn clinic.</td>
<td>Dr. Burn Surgeon</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Ending***</td>
<td></td>
<td>Cost/Year $2,880.00 to $4,320.00</td>
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</tr>
<tr>
<td><strong>10 Repair heterotropic ossification of right elbow</strong></td>
<td>46</td>
<td>2007</td>
<td>1 Time/Year</td>
<td>Remove calcified bone impeding movement of joint.</td>
<td>Cost/Unit $4,000.00 to $4,000.00</td>
<td></td>
<td>Dr. Orthopedic Surgeon</td>
</tr>
<tr>
<td>Option 1</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Beginning***</td>
<td></td>
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<tr>
<td></td>
<td>46</td>
<td>2007</td>
<td>Ending***</td>
<td></td>
<td></td>
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<tr>
<td><strong>11 Integra—Dermal Replacement</strong></td>
<td></td>
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<tr>
<td>Option 1</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Beginning***</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>46</td>
<td>2007</td>
<td>Ending***</td>
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</tbody>
</table>

Cost/Year = $120.00 x 24 = $2,880.00
Cost/Year = $120.00 x 36 = $4,320.00
Cost/Year Average = ($2,880.00 + $4,320.00) ÷ 2 = $3,600.00

(Continued)
<table>
<thead>
<tr>
<th>Option 1</th>
<th>Beginning***</th>
<th>1 Time/Year</th>
<th>OR, Facility Fees, and Recovery</th>
<th>Cost/Unit</th>
<th>Dr. Burn Surgeon</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>46 2007</td>
<td></td>
<td></td>
<td>$10,000.00 to $12,500.00</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Ending</strong>*</td>
<td></td>
<td></td>
<td>Cost/Year</td>
<td></td>
</tr>
<tr>
<td></td>
<td>46 2007</td>
<td></td>
<td></td>
<td>$10,000.00 to $12,500.00</td>
<td></td>
</tr>
</tbody>
</table>

Cost/Year Average = ($10,000.00 + $12,500.00) / 2 = $11,250.00

<table>
<thead>
<tr>
<th>Option 1</th>
<th>Beginning***</th>
<th>1 Time/Year</th>
<th>Surgery done under general anesthesia.</th>
<th>Cost/Unit</th>
<th>Dr. Burn Surgeon</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>46 2007</td>
<td></td>
<td></td>
<td>$1,250.00 to $1,500.00</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Ending</strong>*</td>
<td></td>
<td></td>
<td>Cost/Year</td>
<td></td>
</tr>
<tr>
<td></td>
<td>46 2007</td>
<td></td>
<td></td>
<td>$1,250.00 to $1,500.00</td>
<td></td>
</tr>
</tbody>
</table>

Cost/Year Average = ($1,250.00 + $1,500.00) / 2 = $1,375.00

<table>
<thead>
<tr>
<th>Option 1</th>
<th>Beginning***</th>
<th>1/Year</th>
<th>Skin graft</th>
<th>Cost/Unit</th>
<th>Dr. Burn Surgeon</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>46 2007</td>
<td></td>
<td></td>
<td>$2,908.00 to $2,908.00</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Ending</strong>*</td>
<td></td>
<td></td>
<td>Cost/Year</td>
<td></td>
</tr>
<tr>
<td></td>
<td>46 2007</td>
<td></td>
<td></td>
<td>$2,908.00 to $2,908.00</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Option 1</th>
<th>Beginning***</th>
<th>1 Time/Year</th>
<th>Surgery done under general anesthesia.</th>
<th>Cost/Unit</th>
<th>Dr. Burn Surgeon</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>46 2006</td>
<td></td>
<td></td>
<td>$1,125.00 to $1,250.00</td>
<td></td>
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<tr>
<td></td>
<td><strong>Ending</strong>*</td>
<td></td>
<td></td>
<td>Cost/Year</td>
<td></td>
</tr>
<tr>
<td></td>
<td>46 2006</td>
<td></td>
<td></td>
<td>$1,125.00 to $1,250.00</td>
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</tbody>
</table>

Cost/Year Average = ($1,125.00 + $1,250.00) / 2 = $1,187.50
<table>
<thead>
<tr>
<th>Items/Services</th>
<th>Age</th>
<th>Year</th>
<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Cost</th>
<th>Comments</th>
<th>Recommender</th>
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</thead>
<tbody>
<tr>
<td>16 OR/Surgery Suite</td>
<td>46</td>
<td>2006</td>
<td>Beginning***</td>
<td>1 Time/Year</td>
<td>Cost/Unit</td>
<td>$7,500.00 to $9,250.00</td>
<td>Dr. Burn Surgeon</td>
</tr>
<tr>
<td>Option 1</td>
<td></td>
<td></td>
<td>Ending***</td>
<td></td>
<td>Cost/Year</td>
<td>$7,500.00 to $9,250.00</td>
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<td></td>
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<td></td>
<td></td>
<td>Total Cost/Year Average = ($7,500.00 + $9,250.00) ÷ 2 = $8,375.00</td>
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</tbody>
</table>

| 17 Postop Therapy | 46 | 2006 | Beginning*** | 36–48 Visits/Year | Therapy to maintain benefits of surgery—range of motion. | Cost/Unit | $150.00 to $175.00 | Dr. Burn Surgeon |
| Option 1 | | | Ending*** | | Cost/Year | $5,400.00 to $8,400.00 | |
| | | | | | Total Cost/Year Average = ($5,400.00 + $8,400.00) ÷ 2 = $6,900.00 | |

<p>| 18 Postop Home Health | 46 | 2006 | Beginning*** | 24–36 Visits/Year | Daily dressing change, and monitor graft. | Cost/Unit | $120.00 to $120.00 | Dr. Burn Surgeon |
| Option 1 | | | Ending*** | | Cost/Year | $2,880.00 to $4,320.00 | |
| | | | | | Total Cost/Year Average = ($2,880.00 + $4,320.00) ÷ 2 = $3,600.00 | |</p>
<table>
<thead>
<tr>
<th>Procedure Description</th>
<th>Option 1</th>
<th>19 Dermabrasion</th>
<th>Beginning*** 48 2008</th>
<th>2 Times/6 Years</th>
<th>Even out scarring and color on the face.</th>
<th>Cost/Unit $12,000.00 to $14,000.00</th>
<th>Cost/Year $4,000.00 to $4,666.67</th>
<th>Dr. Burn Surgeon</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Ending*** 53 2013</td>
<td></td>
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<tr>
<td>Cost/Year = $12,000.00 x 2 ÷ 6 = $4,000.00</td>
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<tr>
<td>Cost/Year = $14,000.00 x 2 ÷ 6 = $4,666.67</td>
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<tr>
<td>Cost/Year Average = ($4,000.00 + $4,666.67) ÷ 2 = $4,333.33</td>
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</tr>
<tr>
<td>Procedure Description</td>
<td>Option 1</td>
<td>20 Grafting of bilateral popliteals (behind) knees</td>
<td>Beginning*** 46 2006</td>
<td>2 Times/ Year</td>
<td>Jonathon still has open wounds behind his knees.</td>
<td>Cost/Unit $2,160.00 to $4,320.00</td>
<td>Cost/Year $4,320.00 to $8,640.00</td>
<td>Dr. Burn Surgeon</td>
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<td>Ending*** 46 2006</td>
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<tr>
<td>Cost/Year = $2,160.00 x 2 = $4,320.00</td>
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<tr>
<td>Cost/Year = $4,320.00 x 2 = $8,640.00</td>
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<tr>
<td>Cost/Year Average = ($4,320.00 + $8,640.00) ÷ 2 = $6,480.00</td>
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<tr>
<td>Procedure Description</td>
<td>Option 1</td>
<td>21 Anesthesia Fee</td>
<td>Beginning*** 46 2006</td>
<td>1/ Year</td>
<td>Surgery done under general anesthesia.</td>
<td>Cost/Unit $1,500.00 to $1,750.00</td>
<td>Cost/Year $1,500.00 to $1,750.00</td>
<td>Dr. Burn Surgeon</td>
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<td>Ending*** 46 2006</td>
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<tr>
<td>Cost/Year Average = ($1,500.00 + $1,750.00) ÷ 2 = $1,625.00</td>
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<tr>
<td>Items/Services</td>
<td>Age</td>
<td>Year</td>
<td>Frequency/Replacement</td>
<td>Purpose</td>
<td>Cost/Unit</td>
<td>Comments</td>
<td>Cost/Year</td>
<td>Recommender</td>
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</tr>
<tr>
<td>22 OR/Surgery Suite</td>
<td>46</td>
<td>2006</td>
<td>Beginning***</td>
<td>1 Time/Year</td>
<td>OR, Facility Fees, and Recovery</td>
<td>$10,000.00 to $12,500.00</td>
<td>Cost/Year Average = ($10,000.00 + $12,500.00) ÷ 2 = $11,250.00</td>
<td></td>
</tr>
<tr>
<td></td>
<td>46</td>
<td>2006</td>
<td>Ending***</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>23 Postop Therapy</td>
<td>46</td>
<td>2006</td>
<td>Beginning***</td>
<td>36–48 Per/Year</td>
<td>Therapy to maintain benefits of surgery—range of motion.</td>
<td>Cost/Unit $175.00 to $200.00</td>
<td>Cost/Year Average = ($6,300.00 + $9,600.00) ÷ 2 = $7,950.00</td>
<td></td>
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<tr>
<td></td>
<td>46</td>
<td>2006</td>
<td>Ending***</td>
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</tr>
<tr>
<td>24 Postop Home Health</td>
<td>46</td>
<td>2006</td>
<td>Beginning***</td>
<td>24–36 Visits/Year</td>
<td>Dressing changes, and monitor healing.</td>
<td>Cost/Unit $120.00 to $120.00</td>
<td>Cost/Year Average = ($2,880.00 + $4,320.00) ÷ 2 = $3,600.00</td>
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<tr>
<td></td>
<td>46</td>
<td>2006</td>
<td>Ending***</td>
<td></td>
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</tbody>
</table>

Cost/Year Average = ($10,000.00 + $12,500.00) ÷ 2 = $11,250.00

Cost/Year = $175.00 x 36 = $6,300.00
Cost/Year = $200.00 x 48 = $9,600.00
Cost/Year Average = ($6,300.00 + $9,600.00) ÷ 2 = $7,950.00
Cost/Year = $120.00 x 24 = $2,880.00
Cost/Year = $120.00 x 36 = $4,320.00
Cost/Year Average = ($2,880.00 + $4,320.00) ÷ 2 = $3,600.00
<table>
<thead>
<tr>
<th>Option 1</th>
<th>Beginning***</th>
<th>4 Times/ 5–7 Years</th>
<th>Release contracture to improve range of motion.</th>
<th>Cost/Unit</th>
<th>Cost/Year</th>
<th>He needs the surgery on each axilla, and it is likely this surgery will be repeated at least once on each side due to contractures.</th>
<th>Dr. Burn Surgeon</th>
</tr>
</thead>
<tbody>
<tr>
<td>25 Contracture Release Axilla</td>
<td>46 2006</td>
<td>4 Times/ 5–7 Years</td>
<td></td>
<td>$5,800.00 to $5,800.00</td>
<td>$3,14.29 to $4,640.00</td>
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<tr>
<td></td>
<td>Ending***</td>
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<tr>
<td></td>
<td>53 2013</td>
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<tr>
<td>Cost/Year = $5,800.00 x 4 ÷ 5 = $4,640.00</td>
<td>Cost/Year = $5,800.00 x 4 ÷ 7 = $3,314.29</td>
<td>Cost/Year Average = ($3,314.29 + $4,640.00) ÷ 2 = $3,977.14</td>
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</table>

<table>
<thead>
<tr>
<th>Option 1</th>
<th>Beginning***</th>
<th>4 Times/ 5–7 Years</th>
<th>Skin substitute</th>
<th>Cost/Unit</th>
<th>Cost/Year</th>
<th>Cost/Year Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>26 Integra—Dermal Replacement</td>
<td>46 2007</td>
<td>4 Times/ 5–7 Years</td>
<td></td>
<td>$4,537.50 to $9,075.00</td>
<td>$2,592.86 to $7,260.00</td>
<td></td>
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<tr>
<td></td>
<td>Ending***</td>
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<tr>
<td></td>
<td>51 2012</td>
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</tr>
<tr>
<td>Cost/Year = $4,537.50 x 4 ÷ 5 = $3,630.00</td>
<td>Cost/Year = $9,075.00 x 4 ÷ 7 = $5,185.71</td>
<td>Cost/Year Average = ($2,592.86 + $7,260.00) ÷ 2 = $4,926.43</td>
<td></td>
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</tr>
<tr>
<td>Cost/Year = $4,537.50 x 4 ÷ 7 = $2,592.86</td>
<td>Cost/Year = $9,075.00 x 4 ÷ 5 = $7,260.00</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Option 1</th>
<th>Beginning***</th>
<th>4 Times/ 5–7 Years</th>
<th>OR, Facility Fees, and Recovery</th>
<th>Cost/Unit</th>
<th>Cost/Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>27 OR/Surgery Suite</td>
<td>46 2006</td>
<td>4 Times/ 5–7 Years</td>
<td></td>
<td>$9,250.00 to $10,500.00</td>
<td>$5,285.71 to $8,400.00</td>
</tr>
<tr>
<td></td>
<td>Ending***</td>
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<tr>
<td></td>
<td>53 2013</td>
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</tr>
</tbody>
</table>
### Life Care Planning for the Burn Patient

**Prepared by:** Ruth B. Rimmer, PhD, CLCP

<table>
<thead>
<tr>
<th>Items/Services</th>
<th>Age</th>
<th>Year</th>
<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Cost</th>
<th>Comments</th>
<th>Recommender</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Surgical Intervention</strong></td>
<td></td>
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<tr>
<td><strong>Cost/Year = $9,250.00 x 4 ÷ 5 = $7,400.00</strong></td>
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<tr>
<td><strong>Cost/Year = $9,250.00 x 4 ÷ 7 = $5,285.71</strong></td>
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<tr>
<td><strong>Cost/Year = $10,500.00 x 4 ÷ 5 = $8,400.00</strong></td>
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</tr>
<tr>
<td><strong>28 Anesthesia Fee</strong></td>
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<tr>
<td><strong>Option 1</strong></td>
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</tr>
<tr>
<td><strong>Beginning</strong>*</td>
<td>46</td>
<td>2006</td>
<td>4 Times/5–7 Years</td>
<td>Surgery done under general anesthesia.</td>
<td>Cost/Unit $1,250.00 to $1,500.00</td>
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</tr>
<tr>
<td><strong>Ending</strong>*</td>
<td>53</td>
<td>2013</td>
<td></td>
<td></td>
<td>Cost/Year $714.29 to $1,200.00</td>
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<tr>
<td><strong>Cost/Year = $1,250.00 x 4 ÷ 5 = $1,000.00</strong></td>
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<tr>
<td><strong>Cost/Year = $1,250.00 x 4 ÷ 7 = $714.29</strong></td>
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<tr>
<td><strong>Cost/Year = $1,500.00 x 4 ÷ 5 = $1,200.00</strong></td>
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<tr>
<td><strong>Cost/Year Average = ($714.29 + $1,200.00) ÷ 2 = $957.14</strong></td>
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<tr>
<td><strong>29 Postop Home Health</strong></td>
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<td><strong>Option 1</strong></td>
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</tr>
<tr>
<td><strong>Beginning</strong>*</td>
<td>46</td>
<td>2006</td>
<td>96–144 Times/5–7 Years</td>
<td>Daily dressing change, and monitor graft.</td>
<td>Cost/Unit $120.00 to $120.00</td>
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</tr>
<tr>
<td><strong>Ending</strong>*</td>
<td>53</td>
<td>2013</td>
<td></td>
<td></td>
<td>Cost/Year $1,645.71 to $3,456.00</td>
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<tr>
<td><strong>Cost/Year = $120.00 x 96 ÷ 5 = $2,304.00</strong></td>
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<tr>
<td><strong>Cost/Year = $120.00 x 96 ÷ 7 = $1,645.71</strong></td>
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<tr>
<td><strong>Cost/Year = $120.00 x 144 ÷ 5 = $3,456.00</strong></td>
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<tr>
<td><strong>Cost/Year Average = ($1,645.71 + $3,456.00) ÷ 2 = $2,550.86</strong></td>
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<tr>
<td><strong>31 Grafting</strong></td>
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<td><strong>Option 1</strong></td>
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</tr>
<tr>
<td><strong>Beginning</strong>*</td>
<td>46</td>
<td>2006</td>
<td>4 Times/5–7 Years</td>
<td>Autograft wound.</td>
<td>Cost/Unit $3,384.00 to $3,384.00</td>
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<tr>
<td><strong>Ending</strong>*</td>
<td>53</td>
<td>2013</td>
<td></td>
<td></td>
<td>Cost/Year $1,933.71 to $2,707.20</td>
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</tbody>
</table>

(Continued)
**Cost/Year = $3,384.00 × 4 ÷ 5 = $2,707.20**
**Cost/Year = $3,384.00 × 4 ÷ 7 = $1,933.71**

Cost/Year Average = ($1,933.71 + $2,707.20) ÷ 2 = $2,320.46

<table>
<thead>
<tr>
<th>32 Anesthesia Fee</th>
<th>Option 1</th>
<th>Beginning***</th>
<th>46</th>
<th>2006</th>
<th>Cost/Unit $1,125.00 to $1,250.00</th>
<th>Ending***</th>
<th>53</th>
<th>2013</th>
<th>Surgery performed under general anesthesia.</th>
<th>Cost/Year $642.86 to $1,000.00</th>
</tr>
</thead>
</table>

Cost/Year = $1,125.00 × 4 ÷ 5 = $900.00
Cost/Year = $1,125.00 × 4 ÷ 7 = $642.86
Cost/Year = $1,250.00 × 4 ÷ 7 = $714.29
Cost/Year Average = ($642.86 + $1,000.00) ÷ 2 = $821.43

<table>
<thead>
<tr>
<th>33 OR/Surgery Suite</th>
<th>Option 1</th>
<th>Beginning***</th>
<th>46</th>
<th>2006</th>
<th>Cost/Unit $7,500.00 to $9,250.00</th>
<th>Ending***</th>
<th>53</th>
<th>2013</th>
<th>OR, Facility Fees, and Recovery</th>
<th>Cost/Year $4,285.71 to $7,400.00</th>
</tr>
</thead>
</table>

Cost/Year = $7,500.00 × 4 ÷ 5 = $6,000.00
Cost/Year = $7,500.00 × 4 ÷ 7 = $4,285.71
Cost/Year = $9,250.00 × 4 ÷ 7 = $5,285.71
Cost/Year Average = ($4,285.71 + $7,400.00) ÷ 2 = $5,842.86

<table>
<thead>
<tr>
<th>34 Postop Home Health</th>
<th>Option 1</th>
<th>Beginning***</th>
<th>46</th>
<th>2006</th>
<th>Cost/Unit $120.00 to $120.00</th>
<th>Ending***</th>
<th>53</th>
<th>2013</th>
<th>Daily dressing change, and monitor graft.</th>
<th>Cost/Year $411.43 to $617.14</th>
</tr>
</thead>
</table>

Cost/Year = $120.00 × 24 ÷ 7 = $411.43
Cost/Year = $120.00 × 36 ÷ 7 = $617.14
Cost/Year Average = ($411.43 + $617.14) ÷ 2 = $514.29
<table>
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<tr>
<th>Items/Services</th>
<th>Age</th>
<th>Year</th>
<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Cost</th>
<th>Comments</th>
<th>Recommender</th>
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<tbody>
<tr>
<td>35 Postop Therapy</td>
<td>46</td>
<td>2006</td>
<td>Beginning*** 144–192 Times/5–7 Years</td>
<td>Therapy to maintain benefits of surgery—range of motion.</td>
<td>Cost/Unit $150.00 to $175.00</td>
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<td>Option 1</td>
<td>Ending*** 53</td>
<td>2013</td>
<td>Cost/Year $3,085.71 to $6,720.00</td>
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Cost/Year = $150.00 x 144 ÷ 5 = $4,320.00  
Cost/Year = $150.00 x 144 ÷ 7 = $3,085.71  
Cost/Year = $175.00 x 144 ÷ 5 = $5,040.00  
Cost/Year = $175.00 x 144 ÷ 7 = $3,600.00  
Cost/Year = $150.00 x 192 ÷ 5 = $5,760.00  
Cost/Year = $150.00 x 192 ÷ 7 = $4,114.29  
Cost/Year = $175.00 x 192 ÷ 5 = $6,720.00  
Cost/Year = $175.00 x 192 ÷ 7 = $4,800.00  
Cost/Year Average = ($3,085.71 + $6,720.00) ÷ 2 = $4,902.86
## Potential Complications

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<th>Year</th>
<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Cost</th>
<th>Comments</th>
<th>Recommender</th>
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<td>1 Arthritis</td>
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<td>***</td>
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<td></td>
<td>Dr. Burn Surgeon</td>
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<td>Cost/Year</td>
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<tr>
<td>3 Commissuroplasty—Release of Contractures Around mouth</td>
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<td>***</td>
<td></td>
<td>Cost/Unit</td>
<td></td>
<td></td>
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<tr>
<td>Option 1</td>
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<td>Cost/Year</td>
<td></td>
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<td>4 Contractures</td>
<td>Beginning</td>
<td>***</td>
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<td>Cost/Unit</td>
<td></td>
<td></td>
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<tr>
<td>Option 1</td>
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<td>Cost/Year</td>
<td></td>
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<td>4 Major Depression</td>
<td>Beginning</td>
<td>***</td>
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<td>Cost/Unit</td>
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<td>Cost/Year</td>
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<td>5 Decrease Range of Motion</td>
<td>Beginning</td>
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<td></td>
<td>Cost/Unit</td>
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<tr>
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<td>Cost/Year</td>
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<td>6 Decubitus Ulcers</td>
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<td>***</td>
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<td>Cost/Unit</td>
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<tr>
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<td>0</td>
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<td></td>
<td>Cost/Year</td>
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<td>Potential Complications</td>
<td>Frequency/Replacement</td>
<td>Purpose</td>
<td>Cost</td>
<td>Cost/Unit</td>
<td>Cost/Year</td>
<td>Comments</td>
<td>Recommender</td>
</tr>
<tr>
<td>-------------------------</td>
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<td>-----------</td>
<td>-----------</td>
<td>----------</td>
<td>-------------</td>
</tr>
<tr>
<td>7 Heterotopic Ossifications</td>
<td>Option 1</td>
<td>Beginning***</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>Ending***</td>
<td>0</td>
</tr>
<tr>
<td>8 Osteoporosis</td>
<td>Option 1</td>
<td>Beginning***</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>Ending***</td>
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</tr>
<tr>
<td>9 Peptic Ulcer Disease</td>
<td>Option 1</td>
<td>Beginning***</td>
<td>0</td>
<td>0</td>
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<td>10 Seizures</td>
<td>Option 1</td>
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<td>0</td>
<td>0</td>
<td>0</td>
<td>Ending***</td>
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</tr>
<tr>
<td>11 Infection</td>
<td>Option 1</td>
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<td>0</td>
<td>0</td>
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<td>0</td>
<td>0</td>
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(Continued)
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<tr>
<th>Chronic Pain</th>
<th>Respiratory Complications</th>
<th>Surgical Complications</th>
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<td>Option 1</td>
<td>Option 1</td>
</tr>
<tr>
<td>Beginning***</td>
<td>Beginning***</td>
<td>Beginning***</td>
</tr>
<tr>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Ending***</td>
<td>Ending***</td>
<td>Ending***</td>
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**Chart 2 (Continued)**
### Home Furnishings

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<th>Items/Services</th>
<th>Age</th>
<th>Year</th>
<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Cost</th>
<th>Comments</th>
<th>Recommender</th>
</tr>
</thead>
<tbody>
<tr>
<td>Humidifier</td>
<td>Beginning***</td>
<td>46</td>
<td>2 Per/1–3 Years</td>
<td>Keep air moist for skin.</td>
<td>Cost/Unit $19.99 to $29.99</td>
<td>Cost/Year $13.33 to $59.98</td>
<td>Ms. Healthy, Burn Nurse Practitioner</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2006</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Ending***</td>
<td>77</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>2037</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chair, Lift Reclining</td>
<td>Beginning***</td>
<td>60</td>
<td>1 Time/5–7 Years</td>
<td>Assist in getting up and out of chair.</td>
<td>Cost/Unit $450.00 to $600.00</td>
<td>Cost/Year $64.29 to $120.00</td>
<td>Ms. Healthy, Burn Nurse Practitioner</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2021</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Ending***</td>
<td>77</td>
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<tr>
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<td>2038</td>
<td></td>
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Cost/Year = $19.99 x 2 = $39.98  
Cost/Year = $19.99 x 2 ÷ 3 = $13.33  
Cost/Year = $29.99 x 2 = $59.98  
Cost/Year = $450.00 x 1 ÷ 5 = $90.00  
Cost/Year = $600.00 x 1 ÷ 7 = $85.71  
Cost/Year = $450.00 x 1 ÷ 7 = $64.29  
Cost/Year Average = ($64.29 + $120.00) ÷ 2 = $92.14  
Cost/Year = $600.00 x 1 ÷ 5 = $120.00
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<tr>
<th>Items/Services</th>
<th>Age</th>
<th>Year</th>
<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Cost</th>
<th>Comments</th>
<th>Recommender</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Med-Surg Days</td>
<td></td>
<td></td>
<td></td>
<td>Inpatient days–5–14 days per procedure. Based on 1.5 procedures per year over 5 years.</td>
<td></td>
<td>Surgeries requiring excision and grafting will be 5–7 days x 2.</td>
<td>Dr. Burn Surgeon</td>
</tr>
<tr>
<td>Option 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td></td>
<td>Beginning***</td>
<td>46</td>
<td>2006</td>
<td>45–70 Times/5 Years</td>
<td>Cost/Unit $1,092.00 to $1,092.00</td>
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<td></td>
<td>Ending***</td>
<td>51</td>
<td>2011</td>
<td></td>
<td>Cost/Year $9,828.00 to $15,288.00</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>Cost/Year = $1,092.00 x 45 ÷ 5 = $9,828.00</td>
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<td></td>
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<td></td>
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<td></td>
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<tr>
<td></td>
<td>Cost/Year = $1,092.00 x 70 ÷ 5 = $15,288.00</td>
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<tr>
<td></td>
<td>Cost/Year Average = ($9,828.00 + $15,288.00) ÷ 2 = $12,558.00</td>
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<td>2 X-Rays and Diagnostic Studies</td>
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<td></td>
<td>Post-surgery in-patient testing.</td>
<td>Cost/Unit $750.00 to $1,250.00</td>
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<td>Dr. Burn Surgeon</td>
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<td>Cost/Year $1,875.00 to $3,750.00</td>
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<td></td>
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<td>46</td>
<td>2006</td>
<td>2.5–3 Times/Year</td>
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<tr>
<td></td>
<td>Ending***</td>
<td>51</td>
<td>2011</td>
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<td></td>
<td>Cost/Year = $750.00 x 2.5 = $1,875.00</td>
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<td></td>
<td>Cost/Year = $1,250.00 x 3 = $3,750.00</td>
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<tr>
<td></td>
<td>Cost/Year Average = ($1,875.00 + $3,750.00) ÷ 2 = $2,812.50</td>
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<tr>
<td>3 Dressing Supplies</td>
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<td>Dressing change materials and nursing charges.</td>
<td>Cost/Unit $250.00 to $250.00</td>
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<td>Ms. Healthy, Burn Nurse Practitioner</td>
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<td>Option 1</td>
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<td></td>
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<td>Cost/Year $3,750.00 to $5,250.00</td>
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<td></td>
<td>Beginning***</td>
<td>46</td>
<td>2006</td>
<td>15–21 Times/Year</td>
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<tr>
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<td>51</td>
<td>2011</td>
<td></td>
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<tr>
<td></td>
<td>Cost/Year = $250.00 x 15 = $3,750.00</td>
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<td>Cost/Year = $250.00 x 21 = $5,250.00</td>
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<td></td>
<td>Cost/Year Average = ($3,750.00 + $5,250.00) ÷ 2 = $4,500.00</td>
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<td></td>
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</tr>
<tr>
<td>Items/Services</td>
<td>Age</td>
<td>Year</td>
<td>Frequency/Replacement</td>
<td>Purpose</td>
<td>Cost</td>
<td>Comments</td>
<td>Recommender</td>
</tr>
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<td>Medications and IV Fluids</td>
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<td>2006</td>
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<td>Inpatient meds and IV fluids.</td>
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<td>2.5–3 Times/Year</td>
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<td>$1,000.00 to $1,500.00</td>
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<tr>
<td></td>
<td>51</td>
<td>2011</td>
<td>Ending ***</td>
<td></td>
<td>Cost/Year</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>$2,500.00 to $4,500.00</td>
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<td>Therapies Inpatient</td>
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<td>2006</td>
<td>Beginning ***</td>
<td>Psychotherapy, occupational therapy, and physical therapy.</td>
<td>Cost/Unit</td>
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<td>Dr. Burn Surgeon</td>
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<td>Option 1</td>
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<td></td>
<td>45–75 Times/5 Years</td>
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<td>$300.00 to $300.00</td>
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<tr>
<td></td>
<td>51</td>
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<td>Ending ***</td>
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<td>Cost/Year</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>$2,700.00 to $4,500.00</td>
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</table>

Cost/Year = $1,000.00 x 2.5 = $2,500.00
Cost/Year = $1,500.00 x 2.5 = $3,750.00
Cost/Year = $1,000.00 x 3 = $3,000.00
Cost/Year = $1,500.00 x 3 = $4,500.00
Cost/Year Average = ($2,500.00 + $4,500.00) ÷ 2 = $3,500.00
Cost/Year Average = ($2,700.00 + $4,500.00) ÷ 2 = $3,600.00
### Chart 3

**Roll-Up Summary for Jonathon H. Doe**  
**Anytown, USA**

<table>
<thead>
<tr>
<th>Categories</th>
<th>Totals</th>
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<tr>
<td>Projected Evaluations</td>
<td>$71,857.44</td>
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<tr>
<td>Projected Therapeutic Modalities</td>
<td>$165,867.50</td>
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<tr>
<td>Diagnostic/Educational Testing</td>
<td>$1,250.00</td>
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<td>Wheelchair(s)/Mobility/Maintenance</td>
<td>$28,124.48</td>
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<td>Aids for Independent Function</td>
<td>$32,596.19</td>
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<td>Supplies</td>
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<td>Medications</td>
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<td>Home Care/Facility Care</td>
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<td>Future Medical Care Routine</td>
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<td>Transportation</td>
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<td>Architectural Renovations</td>
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<td>Health and Strength Maintenance</td>
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<td>Acute Medical Intervention</td>
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<td>Surgical Intervention</td>
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</tr>
<tr>
<td>Potential Complications</td>
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</tr>
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<td>Home Furnishings</td>
<td>$2,831.32</td>
</tr>
<tr>
<td>Hospital Days</td>
<td>$161,823.00</td>
</tr>
</tbody>
</table>

*Grand Total $5,217,439.89*
Resources

Books

Total Burn Care, 3rd Edition (2007)
Edited by David N. Herndon, MD
Published by Saunders Elsevier

Juan P. Barret-Nerin, MD and David N. Herndon, MD
Published by Marcel Dekker, Inc., ISBN: 0824754530

Burn Care (1999)
Steven E. Wolf, MD and David N. Herndon, MD
Published by Landes Bioscience, 810 S. Church Street, Georgetown, Texas 78626 ISBN:
1-57059-526-7

Burn Unit: Saving Lives after the Flames (Hardcover)
by Barbara Ravage

Journeys through Hell: Stories of Burn Survivors’ Reconstruction of Self and Identity
by Dennis J. Stouffer, ISBN: 084767892X

Rising from the Flames: The Experience of the Severely Burned
by Albert Howard Carter, Jane A. Petro, Albert Howard III Carter
ISBN: 0812215176

Severe Burns: A Family Guide to Medical and Emotional Recovery
by Andrew M. Munster. The Baltimore Regional Burn Center
ISBN: 0801846536

Journals

Journal of Burn Care & Research: www.journalofburnsandwounds.com
Journal of Burns & Wounds: www.burncarerehab.com
Burns: Elsevier.com

Burn Survivor Websites

Burn Survivors Online (www.burnsurvivorsonline.com)
Phoenix Society for Burn Survivors (www.phoenix-society.org/community/)

Conclusion

Major burn injury is associated with deformity, extreme emotional and physical pain, financial
hardship, and extensive rehabilitation. Recovery from a major burn can take a lifetime. Life care
planners and case managers can help the patient and the patient’s family navigate the rocky road
of recovery by insuring that the care they receive will help to improve function and diminish complications over the patient’s life span.

The fight for survival begins during the acute care phase but extends long after discharge from the hospital. The patient must continue to follow through with ongoing therapies, proper usage of splints and pressure garments, and ongoing exercise programs, and receive the necessary psychological and physical care associated with his or her burn injuries for maximum recovery. Allowing patients to have some measure of control of appropriate options (dressing change schedule, treatment schedule, etc.) can assist them in reducing their anxiety and help them to become more independent in their care.

The rehabilitation process for a burn patient can be overwhelming not only to the patient but to family and friends as well. The importance of addressing their psychosocial needs is paramount and is a very important component of the rehabilitation process. It will allow for a smoother transition to home, school, the workplace, and more successful reentry into the community at large (Helm & Cromes, 1995). By and large, burn rehabilitation is multifaceted, costly, and time consuming. It takes great courage and endurance on the part of the client and the client’s support system to persevere. A thorough life care plan, coupled with effective case management, can help to decrease the complications associated with burn injuries and increase the likelihood of an ongoing yet successful recovery.

References


Chapter 15

Life Care Planning for the HIV/AIDS Patient

Sherie L. Kendall

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Introduction

It has been nearly 30 years since the first case of what would be called acquired immunodeficiency syndrome (AIDS) was described (CDC, 1981). The Centers for Disease Control and Prevention (CDC) began reporting an unusually high incidence of an uncommon pneumonia, *Pneumocystis carinii* (PCP), now named *Pneumocystis jiroveci*, but still referred to as PCP (Stringer et al., 2002). A rare cancer, Kaposi’s sarcoma, was also being seen in the same population, young gay men in San Francisco, New York, and other cities. Thus, AIDS was initially considered a male, homosexual disease that spared heterosexual males, females, and children. Then the number of new cases began increasing rapidly among persons with hemophilia A and other recipients of blood transfusions. A third distinct population of victims emerged from the intravenous drug users’ (IDUs’) community. Prognosis at that time was imminent death, the cause and prevention of which were unknown. Because AIDS was appearing in diverse populations, an infectious agent was suspected as the cause. The mode of transmission seemed to be through sexual contact or blood product exposure (Prusiner, 2002).

By 1983–1984 the pathogen responsible for the progressed disease state of AIDS was identified as human immunodeficiency virus (HIV). Within the next 2 years blood tests became available commercially for diagnosing HIV infection, thus safeguarding the blood supply, allowing the extent of the epidemic and individual infection to be defined and forecast, and eventually the evaluation and monitoring of therapeutic interventions (Montagnier, 2002). The mode of infectious transmission has been delineated as being only via exchange of bodily fluids. Present therapies have extended the life span for the treated HIV patient. Still, neither an absolute cure nor a preventative vaccine (Fauci et al., 2008) has yet been developed and so mortality remains virtually 100%.

Since new infections, at the rate of 6500 per day (Fauci et al., 2008), continue to exceed the number of HIV-related deaths, the population living with HIV infection is burgeoning. UNAIDS estimated that at the end of 2007, 33 million people were living with HIV worldwide (2008).
However, the pandemic is not expected to peak for another 40 to 50 years (Stine, 2008, p. 280). The face of AIDS is changing as the pandemic advances. Heterosexuals now comprise about 95% of all those in the world living with HIV infection (Stine, 2008, p. 175). It follows naturally that “the percentage of women among people living with HIV has remained stable at 50% for several years” (UNAIDS, 2008). In 2007, the portion of the population infected with HIV was comprised of sex workers (60.4%), IDUs (46.1%), and men who have sex with men (MSM) (40.1%) (UNAIDS, 2008). It is now evident that the face of HIV/AIDS is changing from the initial perception that AIDS was a male, homosexual disease to the current reality that HIV is an infection spread by heterosexual contact in the mainstream of society.

Now in the third decade since identification, HIV/AIDS has become a pandemic rivaling the Black Death of the fourteenth century’s bubonic plague. This modern plague is unique among prior bacterial and viral scourges that preferentially afflicted the weak, the very young, and the elderly. AIDS ravages the healthy, young to middle-aged adult population, which is not surprising because HIV is transmitted by exchange of body fluids, primarily during sexual contact. The impact on society is also unique in that this pandemic decimates the workforce and leaves a generation of orphans without a cultural structure to support them.

**Epidemiology of HIV/AIDS in the United States**

Human immunodeficiency virus type 1 (HIV-1) has been clearly identified as the primary cause of AIDS, which results from the destruction of CD4+ T lymphocytes of the immune system. Another strain of the human retrovirus found primarily in western Africa, HIV-2, also causes AIDS. Unless specifically stated as HIV-2, future references to HIV in this chapter will be to HIV-1. HIV is classified into clades based on genetic diversity of the strain, and further classified by subtype of clade (Kitchen, 1995). The three clades are lettered M, for Main with subtypes A through K, and the relatively rare O for Outlier, and N for non-M non-O clades primarily found in western Africa (Bartlett & Gallant, 2005; Stine, 2008). Genetic variants have arisen, not because HIV replicates with a higher rate of mutation than is common, but because HIV generates 10 billion virions per day. At this rate, every possible mutation in the HIV genome can be produced every day in every victim. The genetic versatility of HIV permits the virus to become drug resistant and avoid antibody detection by vaccines and disease-screening tests (Johnson, 1998).

Clade M, subtype B, is the most prevalent in the United States, causing 98% of all HIV infections (Weidle et al., 2000). However, another distinguishing characteristic of the modern pandemic is that international travel facilitates communication of the different varieties of HIV to all world regions. The prevalence of strain, clade, and subtype of HIV in every world region can be expected to continue changing over time, making effective treatment regimes, testing protocols, and future vaccines obsolete in record time.

As early as 1983, the U.S. Department of Health and Human Services (DHHS) declared the HIV epidemic to be the nation’s foremost health priority (National Institute of Mental Health, 2000). National vital statistics data are discerning measures of HIV-related mortality and how HIV-related deaths have changed over the course of the HIV epidemic. Currently, HIV is the fifth leading cause of death for Americans between the ages of 25 and 44. This represents a decline in AIDS-related deaths by 70% from the mortality peak in 1995 when HIV was the leading cause of death in this age group (National Center for Health Statistics, 2002; CDC, 2002b). The decline in mortality coincides with the emergence of new HIV therapies in the past two decades. Unfortunately, the rate of new infection has not been similarly reduced. It is estimated that more than 56,000 people in the United States acquire HIV annually. The CDC further reported that
an alarming 1.1 million persons were living with HIV by the end of 2006. Perhaps 21% of them were unaware of their infection (2008a, 2008b). These numbers represent a substantial health care burden, loss of work time and resources, and significant case management responsibilities for this population.

The face of the epidemic in the United States in 2006 differed from the world as a whole. The majority of persons who contract HIV infection in the United States are MSM (48%). IDUs represent 19% of those infected, and females who engage in high-risk heterosexual contact account for 18%. In the United States, only 25% of those living with HIV are female. Racial minority communities are disproportionately represented among the infected population, especially blacks, followed by Latinos. Blacks are nearly eight times more likely to become infected than whites, while Latino/Hispanics are almost three times as likely to become infected (CDC, 2008a, 2008b). However, like the global HIV+ population, adults ages 25 to 49 years comprise 70% of those infected in the United States. Historically, pediatric HIV infection is almost entirely due to mother-to-child transmission either before or during birth, or after birth by breastfeeding (CDC, 2002b). This is also true globally.

**Natural History**

Transmission of HIV occurs through exchange of body fluids, particularly blood, breast milk, and genital secretions. Risk of transmission is present in sexual encounters, infected needle sticks, blood product and tissue reception, birth, and breastfeeding. Because a vaccine against HIV is not anticipated in the foreseeable future, prevention of new infection cases is limited to behavior modification of high-risk behaviors such as injection drug use and unprotected sexual intercourse and minimizing other risk factors such as genital ulcers, multiple sex partners, and history of sexually transmitted diseases. Postexposure prophylaxis (PEP) is moderately effective in reducing the rate of transmission and generally recommended after a significant intravenous exposure or sexual exposure and to reduce mother-to-child transmission for the fetus of an infected woman who becomes pregnant (Dolin, Masur, & Saag, 2003).

After HIV has been transmitted to a person, there ensues an incubation period of 2 to 3 weeks. The subsequent acute retroviral syndrome lasts 1 to 3 weeks; however, only 50% to 90% of patients are symptomatic in this stage. The range and severity of symptoms in primary HIV infection vary considerably, with an acute mononucleosis-like illness developing in about 40% of patients (Bartlett, 2001). Generally, it is characterized (percent prevalence of symptomology) by fever (96%), adenopathy (swollen lymph nodes, 74%), rash on the body (70%), myalgias (54%), and weight loss (13%). Gastrointestinal disorders include pharyngitis (70%), diarrhea (32%), nausea/vomiting (27%), hepatosplenomegaly (14%), and oropharyngeal candidiasis (thrush, 12%). Neurological symptoms may appear as headache (32%) and other indications such as meningitis, meningencephalitis, peripheral neuropathy, facial palsy, Guillain-Barré syndrome, brachial neuritis, and cognitive/affective disorders (12%) (Bartlett & Gallant, 2005).

With recovery from the acute retroviral syndrome, an antiviral immune response occurs (seroconversion) and a state of chronic HIV infection is entered that may be clinically asymptomatic, or minimally symptomatic before the development of overt immunodeficiency. This clinical latency period is marked by viral replication within lymphoid tissues and declining numbers of CD4+ lymphocyte cells in the immune system. In an untreated patient, the asymptomatic stage usually continues for 7 to 10 (average of 8) years. However, for reasons that are only beginning to be understood, the disease progresses differently in some people such that slow and rapid progressors to the symptomatic and AIDS stages have been seen clinically. Long-term nonprogressors (LTNPs)
comprise about 5% to 10% of the HIV seropositive population and appear not to progress to AIDS status (Stine, 2008, p. 162).

The onset of symptomatic HIV infection may present with any of the previously noted or other conditions indicative of cell-mediated immune deficiency such as, but not limited to, bacillary angiomatosis, pelvic inflammatory disease (PID), idiopathic thrombocytopenic purpura, oral hairy leukoplakia, and herpes zoster involving two episodes or two dermatomes and listeriosis (Bartlett & Gallant, 2005). In addition to these direct effects of viral infection, tumors such as Kaposi’s sarcoma and some rather virulent opportunistic infections (OIs) can appear at this time even though the immune system is only moderately suppressed (e.g., bacterial pneumonia and tuberculosis). Chronic skin conditions such as seborrheic dermatitis, persistent oral or vulvovaginal candidiasis, and herpes simplex may be seen (Powderly, 2001). The immune system is progressively impaired as CD4+ cell counts continue to decline, allowing the clinical expression of an AIDS indicator condition.

In the untreated patient of HIV infection, survival from time of HIV infection is about 10 years. The average time from the diagnosis of an AIDS-defining condition to death is 16 months. For the HIV-positive patient receiving current antiretroviral (ARV) therapy and prophylaxes against OIs, survival and quality of life are appreciably better than those of the untreated HIV patient recounted in this natural history of HIV infection. However, the ARV treatments introduced in the last decade have not been used therapeutically long enough to predict the extended survival they provide (Bartlett, 2001; Masci, 2001; Stine, 2008). It is important to remember that no one ever recovers completely, even though the LTNP’s seem not to progress to AIDS. The management of chronic HIV infection is not analogous to the management of chronic pathological, noninfectious conditions such as type II diabetes or hypertension, which do not necessarily result in mortality per se.

**Classification**

The classification, surveillance, and reporting of HIV/AIDS are based on the case definitions for adults and children over the age of 18 months that have been developed by the CDC. The CDC has developed special criteria for infants less than 18 months of age that take into account mother-to-child transmission. The AIDS surveillance case definition was revised in 1985, 1987, and 1993 to incorporate additional illnesses that were found to be associated with HIV infection. The current case definition of AIDS recognizes the following AIDS indicator conditions in adults (CDC, 2008).

**AIDS-Defining Conditions (CDC, 2008c)**

- Bacterial infections, multiple or recurrent*
- Candidiasis of bronchi, trachea, or lungs
- Candidiasis of esophagus†
- Cervical cancer, invasive‡
- Coccidioidomycosis, disseminated or extrapulmonary
- Cryptococcosis, extrapulmonary
- Cryptosporidiosis, chronic intestinal (greater than 1 month’s duration)
- Cytomegalovirus disease (other than liver, spleen, or nodes), onset at age greater than 1 month
- Cytomegalovirus retinitis (with loss of vision)†
- Encephalopathy, HIV related
Herpes simplex: chronic ulcers (greater than 1 month’s duration) or bronchitis, pneumonitis, or esophagitis (onset at age older than 1 month)

Histoplasmosis, disseminated or extrapulmonary

Isosporiasis, chronic intestinal (great than 1 month’s duration)

Lymphoid interstitial pneumonia or pulmonary lymphoid hyperplasia complex†

Lymphoma, Burkitt (or equivalent term)

Lymphoma, immunoblastic (or equivalent term)

Lymphoma, primary, of brain

*Mycobacterium avium* complex or *Mycobacterium kansasii*, disseminated or extrapulmonary†

*Mycobacterium tuberculosis* of any site, pulmonary,†‡ disseminated,† or extrapulmonary†

*Mycobacterium*, other species or unidentified species, disseminated† or extrapulmonary†

*Pneumocystis jirovecii* pneumonia†

Pneumonia, recurrent†‡

Progressive multifocal leukoencephalopathy

*Salmonella* septicemia, recurrent

Toxoplasmosis of brain, onset at age older than 1 month†

Wasting syndrome attributed to HIV

The 1993 revision (CDC, 1992) added immunologic parameters of CD4+ lymphocyte counts less than 200 cells/mm³ or a CD4+ percentage of total lymphocytes of less than 14% as diagnostic of AIDS for HIV-infected adults and adolescents. By 1993 and 1994 this immunologic criteria, rather than AIDS-defining conditions, resulted in almost half of the AIDS cases reported (Sande & Volberding, 1999). An expansion of the case definition for HIV/AIDS stages the progression of HIV according to the patient’s clinical condition categories (A, B, and C) and CD4+ cell count classes (1, 2, and 3). Because class 3 is an AIDS indicator condition, HIV-positive patients staged as A3 and B3 as well as C1–C3 are defined as having progressed to AIDS (Bartlett, 2001; Bartlett & Gallant, 2005).

**Clinical Conditions Categories (CDC, 1992)**

A. Category A consists of one or more of the conditions listed in the following in an adolescent or adult (greater than or equal to 13 years) with documented HIV infection. Conditions listed in Categories B and C must not have occurred.

- Asymptomatic HIV infection
- Persistent generalized lymphadenopathy
- Acute (primary) HIV infection with accompanying illness or history of acute HIV infection

* Only among children less than 13 years of age (CDC, 1994 revised classification system for human immunodeficiency virus infection in children less than 13 years of age, *MMWR* 1994; 43 [No. RR-12]).
† Condition that might be diagnosed presumptively.
‡ Only among adults and adolescents equal to or greater than 13 years of age (CDC, 1993 revised classification system for HIV infection and expanded surveillance case definition for AIDS among adolescents and adults, *MMWR* 1992; 41 [No. RR-17]).
B. Category B consists of symptomatic conditions (not A or C) in an HIV-infected adolescent or adult that are not included among conditions listed in clinical Category C and that meet at least one of the following criteria:

a. The conditions are attributed to HIV infection or are indicative of a defect in cell-mediated immunity; or

b. The conditions are considered by physicians to have a clinical course or to require management that is complicated by HIV infection. Examples of conditions in clinical Category B include, but are not limited to:
   - Bacillary angiomatosis
   - Candidiasis, oropharyngeal (thrush)
   - Candidiasis, vulvovaginal; persistent, frequent, or poorly responsive to therapy
   - Cervical dysplasia (moderate or severe)/cervical carcinoma in situ
   - Constitutional symptoms, such as fever (101.3 degrees) or diarrhea lasting greater than 1 month
   - Hairy leukoplakia, oral
   - Herpes zoster (shingles), involving at least two distinct episodes or more than one dermatome
   - Idiopathic thrombocytopenic purpura
   - Listeriosis
   - Pelvic inflammatory disease, particularly if complicated by tubo-ovarian abscess
   - Peripheral neuropathy

C. AIDS indicator condition present (see list of AIDS-defining conditions). Once a Category C condition has occurred, the person will remain in Category C.

**CD4 Count Classification (CDC, 1992)**

1. Greater than or equal to 500 cells/μl
2. 200 to 499 cells/μl
3. Less than 200 cells/μl

**Laboratory Criteria**

The most recent revision (CDC, 1999) incorporated “the reporting criteria for HIV infection and AIDS into a single case definition.” The definition of HIV infection implemented in 1993 was revised to include HIV screening tests as laboratory evidence of HIV with regard to AIDS-defining conditions for adults, adolescents, or children greater than or equal to 18 months of age. A reportable case of HIV infection must meet at least one of the following criteria:

- Positive result on a screening test for HIV antibody, for example, repeatedly reactive enzyme immunoassay, followed by a positive result on a confirmatory (sensitive and more specific) test for HIV antibody, for example, Western blot or immunofluorescence antibody test
- Positive result or report of a detectable quantity on any of the following HIV virologic (nonantibody) tests:
   - HIV nucleic acid (DNA or RNA) detection, for example, DNA polymerase chain reaction (PCR) or plasma HIV-1 RNA
   - HIV p24 antigen test, including neutralization assay
   - HIV isolation (viral culture)
Clinical or Other Criteria

If the previous laboratory criteria are not met, then one of the following must be met:

- Diagnosis of HIV infection, based on the previous laboratory criteria, that is documented in a medical record by a physician
- Conditions that meet criteria included in the case definition for AIDS (CDC, 1992)

Clinical Management of HIV Infection

Objectives of Clinical Therapy

The aim of HIV therapy is threefold. The first objective is to lower viral load to undetectable levels and hold it there. Lowering viremia protects the immune system from depletion of CD4+, which is the second goal of therapy because a functioning immune system protects against OIs. Ultimately, the purpose of therapy is to preserve the overall health of the patient at optimal status. Therapeutic failure can emerge as worsening of virologic, immunologic, or general clinical status of the patient.

HIV Lab Studies/Blood Analysis

HIV testing and diagnosis should always be carried out under the CDC Guidelines for Counseling, Testing, and Referral (CDC, 2001). The patient's best interest requires early diagnosis to preserve the broadest possible range of treatment options in managing the disease. Once antibody testing establishes diagnosis, two other tests for markers of HIV infection are important in managing the illness. Viral load tests of the amount of virus in the bloodstream indicate the expected rate of disease progression. The higher the viral load, the faster the disease is expected to progress. White blood cell tests for counts of CD4+ lymphocyte cells or percent of CD4+ cells in the total lymphocyte cell population indicate how far the disease has progressed in suppressing the immune system. These tests are used to determine when to initiate therapy, relative success of therapy, and when to change therapy. Both viral load tests and CD4+ cell counts are recommended upon diagnosis of HIV seropositive status to establish a baseline, at initiation of ARV therapy, 4 weeks later, and then every 3 to 4 months thereafter. Resistance testing is used to determine the optimal therapy choice either prior to initiation of therapy or when current therapy fails.

HIV Antibody Detection and Antigen Identification Tests

Screening for HIV infection is by the detection of antibody specific to the virus in the blood by the reactive enzyme-linked immunosorbent assay (ELISA). A second positive ELISA followed by a positive Western blot detection of several HIV antibodies confirms diagnosis. The patient is termed HIV seropositive because the blood analysis or serology is positive for HIV.

If acute HIV infection is suspected, a negative ELISA may be followed by a Western blot and a plasma HIV RNA test. Acute HIV infection, which precedes seroconversion, is defined by detection of HIV RNA in the plasma on the same day as a negative Western blot for antibodies (Princeton, 2003). Seroconversion should be verified 3 to 4 months later by an ELISA. Sensitivity and specificity of these tests are greater than 98%; however, indeterminate results can be obtained.
Patients with high-risk exposure should be retested in 2 to 3 months. Patients with indeterminate serology and a low-risk behavior history are almost never positive, and retesting is optional.

The ELISA and Western blot test processes are time- and labor-intensive. The consequence of the delay in producing test results is a low return rate of patients to obtain the test outcomes. Some other serologic tests have been developed to speed the return of results to 20 minutes or less after testing. The Food and Drug Administration (FDA) approval of both a urine sample and a saliva sample test (OraQuick ADVANCE®) has improved consumer acceptance of testing because needle sticks are not required and the tests can be administered in a community setting. All of these tests must be administered by clinical personnel. However, one FDA-approved home test kit is on the market, Home Access® Express HIV Test. The test sample may be taken by anyone, but must be mailed to a laboratory for analysis. Results are available within 3 days to a month. Importantly, detection of the HIV antigen, p24, can be made as early as 16 days after infection, before antibodies to HIV are produced by the immune system. Since August 1995, all blood and plasma donations have been screened for p24 to better insure the safety of blood product transfusions in compliance with an FDA mandate (Stine, 2008).

**Viral Load Testing**

Viral load tests are used for evaluating and monitoring the effectiveness of ARV therapy. Lower levels of virus in the blood are associated with reduced risk for progression to AIDS status, infection, transmission, and death. Successful ARV therapy will diminish or stabilize viral load. An increasing viral load while on ARVs is indicative of virologic failure and possibly the emergence of viral resistance. The sensitivity of tests for viral load has been improving rapidly. Currently, the HIV-1 DNA PCR test can detect as few as 1 to 10 copies of HIV proviral DNA (Bartlett & Gallant, 2005). The most desirable range of viremia is undetectable. An undetectable viral load is prognostic of the best clinical outcome, but it does not mean that HIV has been eradicated. Viremia is a measure of HIV in the blood only. Other reservoirs of virus reside in lymph tissues, bone marrow, the brain, genital secretions, and within the cells of the immune system. The FDA recognizes three quantitative determinations of viral load: one is reverse transcriptase-PCR (RT-PCR), the branched-chain DNA assay (bDNA), and, most recently, nucleic acid sequence-based amplification (NASBA) (Bartlett & Gallant, 2005). These assays give different numbers for the same patient sample because the bDNA detects more viral subtypes than the RT-PCR and may differ from NASBA results as well. Therefore, it is inappropriate to compare results from the different tests.

**CD4+ Cell Testing**

Counts of CD4+ lymphocytes are an indicator of immune system health. Increased level of CD4+ cells correlate well with decreased risk of OIs and tumors. Immunologic failure is indicated by diminished CD4+ counts and correlates well with increased risk of OIs. Normal CD4+ cell counts are 800 to 1050/cubic milliliters (mm$^3$), but even a count of 500/mm$^3$ is considered high for the HIV-positive patient. In the high cell count range, there is no immediate danger. In the medium range of 200 to 500/mm$^3$ serious symptoms are uncommon, but there is an increased risk for shingles, thrush, skin infections, and bacterial pulmonary infections. In the medium to low range of less than 350/mm$^3$ ARV is offered to the patient, and preventative treatment, or prophylaxis, for some major infections is usually initiated (Bartlett & Gallant, 2005). A CD4+ cell count of less than 200/mm$^3$ is an AIDS-defining condition.
Resistance Testing

When HIV can replicate in the presence of an ARV drug, it has the opportunity to mutate to avoid the drug’s activity. If a drug is unable to completely suppress HIV replication, viral resistance can emerge. Incomplete suppression can occur in a number of ways. The drugs prescribed may not be completely effective against the patient’s strain of HIV, or the patient may have difficulty adhering to the treatment regimen and miss doses of the drugs. Resistance testing can help in the selection process for an effective therapeutic treatment strategy. Two kinds of resistance testing are available: phenotypic and genotypic. In phenotypic testing, a sample of the patient’s HIV is exposed to various drugs, and the relative effectiveness of the drugs against that strain of HIV is measured. In genotypic testing the genetic structure of the patient’s HIV is determined and compared to the structure of ARV targets. Mutations in the patient’s HIV structure that are known to thwart ARV targets are identified. A rational choice for a salvage ARV regimen can be based on the results of this resistance testing. Phenotypic testing is the most diagnostic and will identify drugs that lack efficacy against the specific host’s mutant HIV strain, but is time consuming and costly ($800 to $1,000 per test). Genotypic testing is faster and less costly ($400 to $500 per test) than phenotypic testing, but will only identify the mutation of the host’s strain (Stine, 2008). Even though no therapies are tested, genotypic tests give an indication of which drug therapies may be successful.

Antiretroviral Therapy

The progress medical science is making toward eradicating HIV is encouraging. While it must be understood that antiretroviral agents (ARVs) cannot be considered a cure, they do represent viable, potent interventions for this infectious disease. A positive HIV test is not good news, but with these drugs, it is no longer an imminent death sentence. The advent of the newest pharmaceutical agents is too recent to know the duration of their clinical efficacy. Many HIV-positive people are living 15 years or longer with proper case management.

The first ARV, a nucleoside reverse transcriptase inhibitor (NRTI), was released in 1986. Therapeutic research during the 1990s developed two new classes of ARVs: protease inhibitors (PIs) and nonnucleoside reverse transcriptase inhibitors (NNRTIs). Studies of treatment with combinations of three to four of these drugs were found to slow progression of HIV infection to AIDS status and improve survival. The multidrug therapies are termed highly active antiretroviral therapy (HAART). The goal of anti-HIV therapy is to suppress viremia in order to preserve or restore immune function and to prevent the emergence of drug resistance and OIs by patients adherence to treatment regimen.

Since many ARVs were expedited through the development process, investigation of their long-term adverse effects, toxicities, and drug interactions must be continued. Some toxicities have become well recognized such as abnormal fat redistribution (dyslipidemia) and metabolic disorders, for example, glucose intolerance, hyperlipidemia, lactic acidosis, and hepatic steatosis (Princeton, 2003). Patient adherence is difficult to maintain since the treatment regimens are complex and laden with minor, but troubling, side effects. Complete patient compliance with therapy is vitally important because viral resistance to the drugs emerges as adherence diminishes (Masci, 2001).

The standard of care of the HIV+ patient changes with the accumulation of knowledge and the development of new drugs. Therefore, it is sometimes prudent to delay making therapeutic changes in anticipation of future drug development. The U.S. DHHS (October 10, 2005) as reported by Bartlett and Gallant (2005, p. 59) has revised the guidelines for initiation of anti-HIV
treatment based on a combination of clinical symptomology, viral load, and CD4+ count. These guidelines are tiered in four levels:

1. When the patient is asymptomatic, CD4+ cell count is above 350/mm³, and plasma HIV RNA is below 100,000 c/mL, most clinicians would delay initiating treatment and observe.
2. When the patient is asymptomatic, CD4+ cell count is 200 to 350/mm³, and plasma HIV RNA is at any value, the recommendation is to offer treatment. However, the recommendation's strength is based on the patient's interest in initiating therapy and the prognosis of disease-free survival.
3. When the patient is asymptomatic, CD4+ cell count is less than 200/mm³, and plasma HIV RNA is at any value, the recommendation is to begin treatment.
4. When the patient is symptomatic (e.g., sick, AIDS, OI, fever, etc.), the recommendation is to treat regardless of CD4+ cell count and plasma HIV RNA level.

HAART is the cornerstone of anti-HIV therapy. The use of only two ARVs or any monotherapy is not recommended because these therapies may not completely suppress HIV replication, thus allowing viral resistance to emerge. The hallmark of successful therapy is a 5- to 7.5-fold drop in viral load within 4 weeks and a 10-fold decrement within 8 weeks. The long-term goal of HAART is to maintain viral load that is below the limits of detection, that is, undetectable. Even when achieved, an undetectable viral load is not indicative of eradication of the virus. The purpose of suppressing the viral load is to permit the immune system to recover. This recovery is measured by an increase in CD4+ cells and improvement in the patient's overall health status. The durability of the initial treatment regimen is predicated upon the efficacy of the drugs against the virus, their tolerability by the patient, and ultimately by the patient's adherence to the regimen.

At the present time, there are at least 24 antiretroviral medications approved either individually or in co-formulation for HIV therapeutic intervention. These drugs are classified in three categories: reverse transcriptase inhibitors (RTIs), either nucleoside/nucleotide analogues (NRTIs), or non-nucleoside compounds (NNRTIs); HIV protease inhibitors (PIs); and HIV entry or integrase inhibitors. They include the following:

The DHHS guidelines of October 6, 2005, as reported in Bartlett and Gallant (2005, p. 61), provide for Preferred and Alternative Initial Regimens for HAART as outlined in the chart below.

<table>
<thead>
<tr>
<th>Drug Trade Name (Class)</th>
<th>Generic Names</th>
</tr>
</thead>
<tbody>
<tr>
<td>Atripla™ (NRTI)</td>
<td>sustiva, viread, and emtriva</td>
</tr>
<tr>
<td>Combivir® (NRTI)</td>
<td>lamivudine and zidovudine</td>
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<tr>
<td>Emtriva® (NRTI)</td>
<td>emtricitabine (FTC)</td>
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<td>Epivir® (NRTI)</td>
<td>lamivudine (3TC)</td>
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<tr>
<td>Epzicom™ (NRTI)</td>
<td>epivir and zidovudine (ZDV), azidothymidine(AZT)</td>
</tr>
<tr>
<td>Hivid® (NRTI)</td>
<td>zalcitabine (ddC)</td>
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(Continued)
Preferred HAART offers two options:

1. efavirenz + (lamivudine or emtricitabine) + (zidovudine or tenofovir DF) – except for pregnant women or women with pregnancy potential
2. lopinavir/ritonavir (co-formulated as Kaletra®) + (lamivudine or emtricitabine) + zidovudine

<table>
<thead>
<tr>
<th>Drug Name</th>
<th>Description</th>
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<tr>
<td>Trizivir™ (NRTI)</td>
<td>abacavir sulfate with lamivudine and zidovudine</td>
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<tr>
<td>Truvada™ (NRTI)</td>
<td>emtricitabine and tenofovir</td>
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<td>Videx® and Videx® EC (NRTI)</td>
<td>didanosine (ddl)</td>
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<td>Viread™ (NRTI)</td>
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<td>Ziagen® (NRTI)</td>
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<td>Rescriptor® (NNRTI)</td>
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<td>Sustiva™, Stocrin (NNRTI)</td>
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<tr>
<td>Crixivan® (PI)</td>
<td>indinavir sulfate (IDV)</td>
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<tr>
<td>Fortovase® (PI)</td>
<td>saquinavir (SQVsgc) discontinued 2006</td>
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<tr>
<td>Invirase® (PI)</td>
<td>saquinavir mesylate (SQVhgc)</td>
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<tr>
<td>Kaletra® (PI)</td>
<td>lopinavir and ritonavir (LPV/r)</td>
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<tr>
<td>Lexiva® (PI)</td>
<td>fosamprenavir (FPV)</td>
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<td>Norvir® (PI)</td>
<td>ritonavir (RTV)</td>
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<tr>
<td>Prezista® (PI)</td>
<td>Darunavir</td>
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<tr>
<td>Reyataz® (PI)</td>
<td>atazanavir (ATV)</td>
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<td>Viracept® (PI)</td>
<td>nelfinavir mesylate (NFV)</td>
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<tr>
<td>Fuzeon® (entry inhibitor)</td>
<td>enfuvirtide (ENF)(T-20)</td>
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<tr>
<td>Selzentry (Celsentri)® (entry inhibitor)</td>
<td>Maraviroc</td>
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<tr>
<td>Raltegravir® (integrase inhibitor)</td>
<td>MK 0158</td>
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Alternative HAART offers 10 recommendations, which may be preferred in select patients:

- efavirenz + (lamivudine or emtricitabine) + (didanosine or abacavir or stavudine) – except for pregnant women or women with pregnancy potential†
- nevirapine + (lamivudine or emtricitabine) + (zidovudine or stavudine* or tenofovir or didanosine or abacavir) (avoid for initial therapy in women with CD4 counts > 250/ mm³ and men with CD4 counts > 400/ mm³ due to high rates of hepatotoxicity)
- fosamprenavir + (lamivudine or emtricitabine) + (zidovudine or stavudine* or abacavir or tenofovir or didanosine)
- fosamprenavir/ritonavir‡ + (lamivudine or emtricitabine) + (zidovudine or stavudine* or abacavir or tenofovir or didanosine)
- atazanavir + (lamivudine or emtricitabine) + (zidovudine or stavudine* or abacavir or didanosine) or (tenofovir + ritonavir 100 mg/d)
- indinavir/ritonavir‡ + (lamivudine or emtricitabine) + (zidovudine or stavudine* or abacavir or tenofovir or didanosine)
- lopinavir/ritonavir (co-formulated as Kaletra) † (lamivudine or emtricitabine) + (zidovudine or stavudine* or tenofovir or didanosine)
- nelfinavir + (lamivudine or emtricitabine) + (zidovudine or stavudine* or abacavir or tenofovir or didanosine)
- saquinavir (Invirase)/ritonavir‡ + (lamivudine or emtricitabine) + (zidovudine or stavudine* or abacavir or tenofovir or didanosine)
- abacavir † lamivudine + zidovudine – only when an NNRTI- or a PI-based regimen cannot or should not be used

Since HIV can become resistant to all drugs, future treatment options could be limited by the initial and secondary drug choices. The medical follow-up of individuals on any pharmacological therapy must be maintained, as well as diligent case management, to closely monitor the patient’s condition and changing needs. Case management/medical issues associated with the use of these drugs include routine follow-up with general chemistry and hematological evaluations on a schedule established by the physician as well as monitoring of viral load and CD4+ counts.

There are several reasons to change the components of a drug therapy including virologic, immunologic, and clinical failure of the therapy. The DHHS Guidelines for Changing Antiretroviral Regimens (April 2005), as reported in Bartlett and Gallant (2005, pp. 75–76), include assessing several characteristics of the treatment regimen, including the assessment of

- Adherence
- Convenience
- Tolerability
- Pharmacokinetic issues
- Drug interactions
- Resistance

* Notes: Higher incidence of lipoatrophy, hyperlipidemia, and mitochondrial toxicities reported with stavudine than with other NRTIs.
† “Women with child-bearing potential” includes women who want to conceive or who are not using effective contraception.
‡ Low-dose (100–400 mg) ritonavir.
Drug Profiles, by Class and Generic Name

Nucleoside/Nucleotide Reverse Transcriptase Inhibitors (NRTIs) (n = 8, plus 5 in combination formularies)

This class of drugs provided the first efficacious antiretroviral treatment. They are analogs of the nucleosides or nucleotides used to build the DNA of the virus. When the reverse transcriptase enzyme uses an analog in the replication process, an incomplete virus is produced that is non-functional. Adverse reactions common to this class of drugs include lactic acidosis with or without hepatomegaly, and steatosis. Viral resistance to these drugs usually evolves from point mutations in the virus specific for the particular drug so that cross-resistance between drugs is usually incomplete.

Abacavir sulfate (ABC)

The trade name is Ziagen®. The limiting adverse effect to this drug is a hypersensitivity reaction, which can be fatal. The reaction usually occurs within the first 6 weeks of drug administration, but resolves after discontinuation of the drug. Abacavir is one of three drugs comprising Trizivir™. It is also co-formulated with 3TC as Epzicom™. There are no food restrictions.

Didanosine (ddl)

The trade names are Videx® and Videx EC®. Using this medication can cause painful chronic peripheral neuropathies that produce a mild, reversible, stocking-and-glove pattern of discomfort in about 10% of individual users. Pancreatitis may occur in 1% to 2% and may be severe, even fatal. Toxicities can include headache, insomnia, rash, and gastrointestinal disturbances. The drug should be taken 1 hour before or 2 hours after a meal. Do not combine with d4T.

Emtricitabine (FTC)

The trade name is Emtriva®. This drug may be taken once per day. Toxicity is minimal, but can manifest as hyperpigmentation. It has no food effects or drug interactions. It is co-formulated with TDF as Truvada™ and taken once per day. When combined with sustiva and viread, it is marketed as Atripla.

Lamivudine (3TC)

The trade name is Epivir®. Resistance to this drug can develop rapidly if monotherapy is used or if viral replication is not completely suppressed. There are no food restrictions and minimal toxicity. The drug is generally well tolerated, but side effects can include nausea, diarrhea, anemia, low white blood cell count, and pancreatitis (especially in children). Renal failure would require the dosage to be decreased. Lamivudine is one of three drugs comprising Trizivir™. It has also been approved for use with Zidovudine and marketed as Combivir®. It is co-formulated with ABC as Epzicom.

Stavudine (d4T)

The trade name is Zerit®. A dose-related peripheral neuropathy occurs in 19% to 24% of individuals with advanced disease and in 14% of those with less advanced HIV disease. Other adverse
effects may include headache, lipoatrophy, gastrointestinal disturbances, anemia, neutropenia, pancreatitis, and elevated hepatic transaminases. Renal failure would require the dosage to be decreased. The drug may be taken without regard to food. Avoid combining with ddi, especially during pregnancy.

**Tenofovir (TDF)**

The trade name is Viread®. This is the only nucleotide analog currently approved for clinical use. The nucleotide analog does not require intracellular phosphorylation for activation, as do the nucleoside analogs. It may have broader activity than the other drugs of this class. Minimal toxicity but nephrotoxicity may occur. Adverse effects can include elevations in creatine kinase, hepatic transaminases, and triglycerides, neutropenia, fatigue, headache, and worsening of peripheral neuropathies. The drug has no food effect. It is combined with FTC as Truvada. When combined with sustiva and emtriva, it is marketed as Atripla.

**Zalcitabine (ddC)**

The trade name is Hivid®. The major adverse effect is peripheral neuropathy presenting as a burning sensation. Other side effects include lactic acidosis, lipoatrophy, rash, stomatitis, fever, ototoxicity, anemia, leukopenia, and thrombocytopenia. Pancreatitis is rare, but can be fatal. Renal failure would require the dosage to be decreased. Do not take with didanosine. There are no food restrictions but cannot be taken with antacids.

**Zidovudine (AZT, ZDV)**

The trade name is Retrovir®. Therapy-limiting effects may include bone marrow suppression resulting in anemia and leucopenia. Other side effects are headache, fatigue, lactic acidosis, lipoatrophy, rash, nausea, gastrointestinal disturbances, and seizures. A reversible myopathy may appear with prolonged use. This drug has been shown to decrease mother-to-child transmission. Zidovudine is one of three drugs comprising Trizivir™. It has also been approved for use with Lamivudine and marketed as Combivir®. The drug may be taken without regard to food.

**Nonnucleoside Reverse Transcriptase Inhibitors (NNRTIs) (n = 3)**

This class of drugs differs structurally from the NRTIs. Rather than substituting a dysfunctional component in the DNA-building process, they actually bind to the reverse transcriptase, thus inactivating the enzyme of synthesis. Viral resistance to this class of drugs evolves rapidly if any single drug is used as a monotherapy. Broad cross-resistance between agents in this class is common. Many drug treatments for non-HIV conditions are incompatible with NNRTIs, and drug interactions must be checked before prescribing.

**Delavirdine (DLV)**

The trade name is Rescriptor®. Rash, headache, fatigue, and gastrointestinal disturbances are the common adverse effects. Other side effects include insomnia, myalgia, elevations in uric acid, transient elevations in liver functions, anemia, neutropenia, and thrombocytopenia. The drug has no food effects.
Efavirenz (EFV)

The trade name is Sustiva®. Rash commonly occurs early in treatment and then resolves within the month. Cholesterol may increase by 10% to 20% in some patients. Because this drug penetrates the blood–brain barrier, some central nervous system (CNS) disturbances may occur, including dizziness, changes in sleep and dreams, abnormal thinking, and difficulty concentrating. These symptoms typically resolve within a month. Delusions, abnormal behavior, depression, and elevated liver enzymes may also occur. Taking the drug at bedtime minimizes the drug effects on activities of daily living. Avoid taking the drug with high-fat meals and preferably on an empty stomach. The drug may be teratogenic. Avoid taking in first trimester. When combined with viread and emtriva, it is marketed as Atripla.

Nevirapine (NVP)

The trade name is Viramune®. Rash occurs in 7% to 15% of patients and is more common in women, but can usually be tolerated with antihistamine use. Other common adverse effects are headache, depression, and hepatitis—less commonly, fatigue, nausea, diarrhea, fever, myalgia, elevated liver function, and mean corpuscular volume. This drug is not compatible with oral hormone contraceptives. There are no food restrictions.

Protease Inhibitors (PIs) (n = 11, including 1 in a combination formulary)

This class of drugs inhibits HIV protease, the enzyme that cleaves viral polyproteins to functional HIV proteins. When protease is inhibited, infectious HIV virions are not produced. Toxicities generally appearing in this class of drugs are metabolic effects on lipids and glucose and body composition changes. Complete cross-resistance of the virus to PIs does not evolve initially. However, cross-resistance may broaden over time as mutations in the virus accumulate so that sequential use of PIs may not be possible. Many drug treatments for non-HIV conditions are incompatible with PIs, and drug interactions must be carefully checked before prescribing. The PIs are potent, but toxic, drugs; thus, their prescription is controversial in terms of cost-benefit analysis even though they are now considered standard of care. They have been shown to save lives, but at a price of damaged organ systems that may ultimately shorten lives (Stine, 2008).

Amprenavir (APV)

The trade name is Agenerase®. The only formulations still available are pediatric capsules and oral solution. Fosamprenavir (Lexiva) is now preferred. The most common side effects are rash, paresthesia, and gastrointestinal disturbances. Because this drug is a sulfonamide, it must not be taken by those with hypersensitivity reactions to sulfa. This drug is not compatible with oral hormone contraceptives. Vitamin E supplements should not be taken. Amprenavir interacts with several other drugs, elevating serum levels of some drugs and itself being reduced in serum by others. A thorough reference should be consulted before prescribing. The drug should be taken an hour apart from antacids and didanosine. Avoid taking the drug with high-fat meals.

Atazanavir (ATV)

The seventh protease inhibitor was approved on June 20, 2003. Reyataz® (PI)/atazanavir is noteworthy for being given in a single pill, once per day, with food. As with all drugs in this class, a
significant safety concern is hyperlipidemia. Bristol-Myers Squibb Company of Princeton, New Jersey, produces it. The side effects include gastrointestinal intolerance, jaundice, and increased transaminases.

**Daranavir**

The trade name is Prezista®. In mid-2006 this drug received accelerated FDA approval as a salvage regimen when taken in combination with ritonavir. Prezista may be effective against HIV resistance developed to other PIs. In 2008 the FDA approved darunavir taken with ritonavir as an initial therapy. The drug must be taken with food and has many drug interactions.

**Fosamprenavir (FPV)**

The trade name is Lexiva®. This is the pro-drug to APV and is now the preferred form. The most common side effects are gastrointestinal disturbances, rash, and increased transaminase. Unlike APV, it has no food effects.

**Indinavir sulfate (IDV)**

The trade name is Crixivan®. Adverse effects that are noteworthy include nephrolithiasis, which occurs infrequently and requires a temporary interruption of treatment for 1 to 3 days. Adequate hydration is critical. Other side effects include rash, nausea, thrombocytopenia, headache, diarrhea, insomnia, stomatitis, asymptomatic hyperbilirubinemia, and elevated hepatic transaminases. Indinavir interacts with several other drugs, elevating serum levels of some drugs and its own serum level being reduced by others. A thorough reference should be consulted before prescribing. The drug dose should be taken with water either 1 hour before or 2 hours after a meal.

**Lopinavir (LPV/r)**

Lopinavir is co-formulated with ritonavir to elevate its plasma concentration to therapeutic levels and marketed as Kaletra®. Adverse effects may include elevated triglycerides, cholesterol, hepatic enzymes, and glucose. Other side effects may be asthenia, headache, rash, diarrhea, nausea, and vomiting. Lopinavir inhibits the P450 CYP3A metabolic path and like other PIs has many drug interactions. A thorough reference should be consulted before prescribing. The drug dose should be taken with food.

**Nelfinavir mesylate (NFV)**

The trade name is Viracept®. Side effects are generally mild and are primarily diarrhea, but can include nausea, rash, depression, asthenia, and mild fatigue. Nelfinavir inhibits the P450 CYP3A metabolic path and like other PIs has many drug interactions. A thorough reference should be consulted before prescribing. The drug dose should be taken with food and can be dissolved in water.

**Ritonavir (RTV)**

The trade name is Norvir®. The most common side effects are gastrointestinal: nausea, diarrhea, vomiting, anorexia, abdominal pain, and taste perversion. Other adverse effects may include
paresthesias, elevated cholesterol, and elevated hepatic enzymes. Ritonavir binds to several cytochrome P450 isoforms, and interacts with several drugs. It will reduce levels of oral contraceptives and theophylline, among others. A thorough reference should be consulted before prescribing. Refrigeration is recommended. The drug should be taken with food.

**Saquinavir (SQV)**

The trade name is Invirase for the hard gel capsule and Fortovase for the soft gel capsule. Fortovase was discontinued as of February 2006. Adverse effects are generally mild and include diarrhea, nausea, and abdominal discomfort. Other side effects may include jaundice, elevated liver function, headache, confusion, seizures, rash, asthenia, and paresthesia. Saquinavir is metabolized by CYP3A4, and interactions with other drugs that affect that metabolic path are common. A thorough reference should be consulted before prescribing. The drug dose should be taken within 2 hours of a full meal.

**Tipranavir (TPV)**

The trade name is Aptivus®. Adverse effects are generally mild and include diarrhea, nausea, and abdominal discomfort. Other side effects may include elevated liver function, and rash, especially in women. The drug dose should be taken with a full meal.

**HIV Entry or Integrase Inhibitors (n = 3)**

These are new classes of drugs whose development was aimed at different viral targets from the RTIs and PIs. These drugs aim to block the virion’s entry to the immune cell (entry or fusion inhibitors) and its activation after synthesis (integrase inhibitors) (Ritchie, 2001).

**Enfuvirtide**

The first of the fusion inhibitor (FI) class of medications received accelerated approval on March 13, 2003. Fuzeon® (FI)/enfuvirtide is remarkable because it is effective against HIV infection resistant to other currently available drugs, thus adding a new component to HIV therapy. The drug is given by subcutaneous injection. Adverse reactions may include allergic reaction, especially at the injection site, and increased risk for pneumonia. Roche Pharmaceuticals of Nutley, New Jersey, will distribute the drug under a license from Trimeris, Inc., of Durham, North Carolina.

**Maraviroc**

The trade name is Selzentry®. This drug mechanism of action is to block the CCCR5 co-receptor, thus inhibiting entry to the CD4+ immune cell. It received FDA approval in August 2007. It is deemed useful for salvage therapy. Of importance, this drug is administered orally. Drug failure is anticipated to occur when the virus switches to using a different entry receptor.

**Raltegravir (MK 0158)**

This drug received FDA approval in October 2007. It blocks HIV DNA from entering or fusing with human DNA, thus it is an integrase inhibitor. As with other new classes of anti-HIV drugs, it will be used primarily for salvage therapy.
Investigational Drugs

Although HAART may durably suppress HIV replication without the emergence of viral resistance, the HIV variants hosted by a particular patient may still develop reduced susceptibility to current drugs through incomplete adherence to treatment regimen. Sometimes declines in immune function develop in the presence of viral suppression. The possibility also exists that the current HAART drugs will prove too toxic to be used indefinitely. Furthermore, HIV is known to be sequestered in memory cells of the immune system and harbored in other privileged sites in the body that are inaccessible to ARV therapeutics so that HIV cannot be eradicated from the body. New therapeutics will be required to facilitate salvage therapy. Ongoing basic and clinical research is aimed at addressing the need for superior drug efficacy, improved patient adherence, reduced toxicity, better tolerance, and more treatment options (Feinberg, 2002).

The antiretroviral agents currently approved for therapeutic intervention act to inhibit either the reverse transcriptase or the protease enzyme of viral synthesis or by barring HIV’s entry to the cell or to human DNA. New classes of drugs under current development are aimed at different viral targets, including disrupting HIV replication with zinc fingers and anti-sense drugs, assembly inhibitors and maturation inhibitors to interfere with HIV functioning (Stine, 2008). Early-access programs are available for qualifying patients to participate in studies of investigational drugs through the pharmaceutical company. Usually the primary care physician must initiate the recommendation of the patient to the program.

Opportunistic Infections and Malignancies

By weakening the immune system, HIV permits the opportunity for infectious disease and malignancy to attack any organ system. HIV is also known to alter the natural progression of several common infections such as syphilis and hepatitis B (HBV) and C (HCV). Most HIV/AIDS-related mortality is caused by these comorbid conditions. The incidence of OIs varies between different transmission exposure populations such as MSM or IDUs. Prevalence of certain OIs varies with geographical region such as histoplasmosis, which is endemic to the Ohio and Mississippi River Valleys. However, the CD4+ cell count is a reliable marker for incidence of specific OIs. When the CD4+ cell count falls to between 250 and 500/mm3, HIV-positive individuals usually experience minor OIs such as oropharyngeal candidiasis (thrush) and the development of active tuberculosis disease. Cryptosporidiosis and tumors of Kaposi’s sarcoma or lymphoma may emerge with CD4+ cell counts between 150 and 200/mm³. When the CD4+ cell count range is between 75 and 125/mm³, more severe OIs such as Pneumocystis jiroveci pneumonia (PCP), Mycobacterium avium complex (MAC), herpes simplex virus (HSV), toxoplasmosis, cryptococcosis, and esophageal candidiasis may appear. Cytomegalovirus (CMV) retinitis occurs with CD4+ counts of less than 50/mm³. Prolonged survival has been shown with MAC and PCP prophylaxis as well as with HAART (Sande & Volberding, 1999). The U.S. Public Health Service and the Infectious Diseases Society of America developed guidelines for preventing OIs among persons infected with HIV in 1995 and updated them in 1997, 1999, and 2002. The major changes in the 2002 update primarily address the discontinuance of prophylaxis upon reconstitution of the immune system. Overall, as of this revised chapter, HAART is still recognized as the most effective approach to OI prevention. The guidelines address 19 OIs (CDC, 2002a). The more frequently reported HIV/AIDS-related malignancies and OIs and their preventions and standard treatments are described here.
Vaccinations

Vaccination with influenza vaccine and pneumococcal vaccine is recommended for all HIV-infected adults. Hepatitis vaccination for HBV is the standard of care. Vaccination for hepatitis A (HAV) is recommended for those who have HCV or chronic liver disease or are sexually active and are seronegative for HAV. Diphtheria/tetanus vaccine should be boosted every 10 years. Other vaccines that should be administered in those not previously vaccinated include measles, mumps, and rubella, as well as inactivated polio. All live virus vaccines are contraindicated (Sande & Volberding, 1999; Bartlett, 2002; Princeton, 2003).

Opportunistic Infection,Suppressive Therapy, and Treatment

Pulmonary disease is a major source of morbidity and mortality in HIV-infected individuals. The number one life-threatening OI for HIV-infected patients is PCP, which is suppressible with the prophylactic use of trimethoprim-sulfamethoxazole (TMP/SMX) (Bactrim or Septa), Dapsone, aerosolized pentamidine (NebuPent), or Atovaquone (Mepron). Bactrim has the advantage of also being prophylactic against Toxoplasma gondii and some other bacterial infections. Patients who are at risk of PCP are those with CD4+ counts of less than 200; those with oropharyngeal candidiasis; those with persistent fever of more than 2 weeks; and those who have had prior PCP. Treatment medications include TMP/SMX, Dapsone, pentamidine, Clindamycin/Primaquine, and Atovaquone (Mepron). Recurrent bacterial pneumonia is an AIDS indicator condition. Pneumococcal vaccination with Pneumovax is the standard of care. Empiric treatment should not be commenced until the infecting bacteria are characterized. Although penicillin-resistant strains are appearing, effective treatment can be made with second- and third-generation cephalosporins or TMP/SMX.

Mycobacterium tuberculosis (TB) is a frequent but treatable cause of morbidity and mortality in the HIV-positive population. Most HIV-associated TB disease is the result of activation of dormant TB infection and can emerge even in the presence of CD4+ counts in excess of 300. Biannual TB skin testing by purified protein derivative (PPD) is recommended. HIV infection alters the natural history of TB so that those who are HIV positive are far more likely to contract TB. Latent TB may be suppressed by isoniazid (INH) therapy given for 12 months. Although many strains of TB are becoming antibiotic resistant, TB can be treated and cured with a multidrug regimen usually commencing with four drugs, then reducing the number of drugs over the course of treatment. Some of the more common drugs of treatment include INH, rifampin (Rifadin), rifabutin (Mycobutin), ethambutol (Myambutol), and pyrazinamide (PZA).

Another frequently occurring, serious OI is Mycobacterium avium complex. MAC is a term for two related bacteria: Mycobacterium avium and Mycobacterium intracellulare (MAI). When CD4+ counts drop below 50, MAC can become disseminated, seriously eroding quality of life and reducing survival. MAC bacteremia is associated with fever/sweats, progressive anemia, painful joints, gastrointestinal cramping, nausea/vomiting, diarrhea, and wasting. Prophylaxis should be considered, after excluding TB, when the CD4+ count falls below 100. Azithromycin (Zithromax) is the preferred prophylactic, but two other drugs are also approved—clarithromycin (Biaxin) and rifabutin (Mycobutin)—for all HIV-infected patients with CD4+ counts of less than 100.

Fungal infections seen in HIV/AIDS patients include candidiasis, cryptococcosis, histoplasmosis, coccidioidomycosis, and aspergillosis. Candidiasis is the most commonly seen OI in HIV/AIDS patients and is seen at all stages of immunosuppression. Vaginal candidiasis (yeast), followed
by oropharyngeal (thrush) and esophageal candidiasis, is the usual order of presentation of this infection. Candidiasis is routinely being treated topically with ketoconazole (Nizoral), clotrimizole (Nystatin, Gyne-Lotrimin), or miconazole (Monistat 3) when possible, reserving the systemic drugs such as fluconazole (Diflucan), amphotericin, and itraconazole (Sporanox) for more severe fungal infections. Cryptococcus neoformans is the most frequently occurring life-threatening fungal infection, usually affecting those with CD4+ counts below 50. Cryptococcosis most often presents as disseminated disease. Cryptococcal meningitis is the most common manifestation, but pneumonia is also seen. This infection should be treated aggressively with amphotericin, followed by suppressive therapy with fluconazole. Histoplasma capsulatum is endemic to the Midwestern United States and found in bird droppings. It causes acute pulmonary disease. The preferred therapy for disseminated histoplasmosis is amphotericin. Coccidioides immitis is endemic to the Southwestern United States and Mexico. Most patients with this infection have CD4+ counts under 250. The clinical presentation of coccidioidomycosis is acute pulmonary infection. Disseminated disease should be treated with amphotericin, followed by suppressive therapy with ketoconazole or fluconazole for life. Aspergillosis is seen infrequently and usually only in advanced AIDS. The lungs are most commonly involved, and secondarily the brain. The treatment of choice is amphotericin.

Cytomegalovirus (CMV) infection is a common HIV-related pathogen causing retinitis, colitis, and encephalopathy. Most people are infected with dormant CMV, but active disease emerges in 20% to 40% of HIV/AIDS patients, particularly in those with CD4+ counts of less than 50. CMV retinitis accounts for the 75% to 85% of CMV disease and is the leading cause of blindness in AIDS patients. Symptoms include blurry vision, light flashes, and floaters. A therapy specific for CMV retinitis is surgical implantaion of a ganciclovir pellet (VitraSet) in the affected eye together with oral Ganciclovir. The implant is effective for several months, but will not protect the other eye from CMV (Princeton, 2003). CMV colitis presents with abdominal pain, diarrhea, anorexia, weight loss, and fever. CMV encephalopathy is usually seen as radiculopathy. This occurs as a spinal cord syndrome with lower-extremity weakness, spasticity, areflexia, urinary retention, and hypoesthesia. Subacute encephalitis caused by CMV also occurs in AIDS patients. Personality changes, difficulty concentrating, headaches, and sleepiness frequently are present. The best prophylaxis is effective ARV therapy to restore the immune system. Initial acute therapy is with IV Ganciclovir. Maintenance therapy throughout the life of the patient is critical for CMV retinitis because the virus is only suppressed by Ganciclovir and not eliminated. Oral Ganciclovir is nearly as effective as IV Ganciclovir was at delaying reactivation of CMV retinitis. Toxicity and viral resistance may limit Ganciclovir therapy. Foscarnet and Cidofovir may provide alternate therapies (Sand & Volberding, 1999).

Herpes viruses cause a number of symptoms in immunocompetent people and are responsible for substantial morbidity in immunosuppressed HIV/AIDS patients where their symptoms are more severe and of longer duration. This family of viruses includes CMV, described previously, as well as herpes simplex viruses I and II and herpes zoster. Herpes simplex virus I produces cold sores or fever blisters primarily around the mouth, but they can also occur on the genitalia. Other symptoms include fever, fatigue, swollen glands, and muscle pain. Herpes simplex virus II produces painful ulcers on the genitals or anus. Symptoms preceding an outbreak are similar to influenza. Herpes zoster (shingles) causes a painful rash along a particular dermatome, which is a reactivation of previous chicken pox infection. Suppression and treatment are accomplished with acyclovir (Zovirax), famciclovir (Famvir), or valacyclovir (Valtrex).

Toxoplasma gondii is associated with cerebral toxoplasmosis in the majority of patients. It is the second most common OI of the eye. It may also cause pneumonia. T. gondii is one of the most common tissue parasites found in humans and is hosted by the domestic cat as well as many
other mammals and bird species. Humans can become infected by coincidental exposure to cat feces or by eating raw or undercooked meat. In an immunocompetent individual, the parasite is usually dormant, causing no signs or symptoms; however, in the patient with depressed cellular immunity, the parasite may become activated and cause full-blown disease. Among individuals with AIDS, 3% to 40% develop toxoplasmic encephalitis (Smith, 1994). Persons with \textit{T. gondii} are at risk for developing toxoplasmosis and should begin suppressive therapy when their CD4+ count falls below 100. The most common regimens are TMP/SMX (Bactrim or Septa), pyrimethamine in combination with sulfadiazine, and Dapsone plus pyrimethamine (Daraprim). Patients with toxoplasmosis encephalitis must be on chronic suppressive therapy for life.

\textit{Cryptosporidium parvum} is a serious parasitic OI. Cryptosporidiosis causes profuse, watery diarrhea with cramping, abdominal pain, fatigue, anorexia, and nausea/vomiting. CD4+ cell counts under 200 facilitate this illness. The infection is easily transmitted by contact with feces. Handwashing is the best protection against contamination. Cryptosporidiosis is not cured, only suppressed, and is more likely to reappear as the immune system is progressively impaired. Symptoms may be reduced by paromomycin, spiramycin, or erythromycin and other antidiarrheal agents.

\textbf{Malignancies}

Kaposi’s sarcoma, non-Hodgkin’s lymphomas (NHLs), and invasive cervical cancer are malignancies indicative of AIDS in HIV-infected individuals (Krown, 1996). Squamous carcinoma conjunctiva is known as an AIDS-associated cancer. Other neoplasms that are likely AIDS associated include Hodgkin’s disease, plasmacytoma, leiomyosarcoma (pediatric), and seminoma (Sande & Volberding, 1999). Both males and females with prolonged immunodeficiency exhibit a high frequency of noninvasive intraepithelial lesions (warts) of the anogenital squamous epithelium that may be precursors to invasive cancer. The sexually transmitted human papillomaviruses (HPVs) are suspected of causing these lesions and neoplasms. AIDS-associated malignancies may increase in frequency as their long latency periods are exceeded by prolonged survival provided by HAART.

\textbf{Life Care Planning Considerations for the HIV/AIDS Patient}

The approval in 1996 of several antiretroviral drugs and tests for quantifying viral load transformed the care of HIV patients. Case management strategies in the past primarily addressed cost-effective treatment of the primary disease for a relatively short time horizon. The new primary disease treatment protocols have significantly slowed the progression of HIV infection and prolonged survival in many patients. The extension of life span has broadened case management guidelines for the HIV-infected patient in scope, direction, and responsibilities. One new facet of case management is the psychosocial adaptations of living long-term with HIV/AIDS. This not only includes the psychological health of HIV-positive persons and their families, caregivers, and health-related professionals, but also the immense financial and job market accommodations that are required.

Life care planning for the individual living with AIDS or symptomatic HIV can cover a wide array of needs. To be as inclusive as possible in outlining the potential areas of needs, a checklist may prove helpful. The following checklist is for planning purposes. In the interest of space, not every possible concern has been detailed. However, this checklist will guide the interested party in the systematic thought process needed to comprehensively consider the need areas (Kitchen, 1995).
Life Care Planning: Needs Checklist for the HIV/AIDS Patient

Physical impairment/considerations:
- Hemiplegia
- Loss of balance
- Loss of strength
- Paralysis
- Coordination
- Fatigue (extreme in some cases)
- Weakness
- Clumsiness
- Ataxia
- Reduced functional capacity
- Pain
- Visual acuity
- Physical stamina and endurance
- Loss of bowel control
- Arthralgia
- Arthritis
- Fibromyalgia

Cognitive impairment/neuropsychological considerations:
- Depression
- Dementia
- Intellectual impairment
- Inattention
- Forgetfulness
- Reduced concentration
- Expressive/receptive speech
- Aphasia
- Dysarthria
- Adjustment disorder
- Apathy
- Disorientation
- Social isolation
- Delirium
- Manic disorder
- Psychotic disorder
- Anxiety disorder
- Adjustment disorder

Respiratory considerations:
- Bacterial infection
- Lymphoma
- Fungi
Mycobacteria
Pneumocystis
Kaposi’s sarcoma
Viral infections
Tuberculosis

**Gastrointestinal considerations:**
- Abdominal pain
- Painful elimination
- Hepatomegaly
- Cholecystitis
- Colitis
- Enteritis
- Megacolon/colon perforations
- Pancreatitus
- Intestinal obstruction
- Mucosal biopsy

**Neurological considerations:**
- Meningitis
- Focal CNS lesions
- Encephalitis
- Headache
- Myelopathy
- Cranial nerve palsies
- Seizures
- Peripheral neuropathy
- Demyelinating neuropathy

**General health considerations:**
- Diarrhea
- Painful elimination
- Apathy
- Anorexia
- Dysphagia
- Poor intake (painful mouth/throat)
- Medication reaction/interaction
- Adverse drug reactions
- Chronic pain
- Esophageal disease
- Fever
- Malnutrition
- Weight loss
- Malabsorption
- Wasting syndrome
Candida (oral/esophageal/vaginal)
Sleep disorder

**Hematologic considerations:**

- Anemia
- Leukemia
- Bone marrow disorders
- Leukopenia
- Thrombocytopenia

**Cardiovascular considerations:**

- Pericarditis
- Pulmonary hypertension
- Myocardial involvement
- Vascular abnormalities
- Arrhythmias
- Venous thrombosis and pulmonary embolism

**Endocrinologic considerations:**

- Hypothalamic-pituitary
- Adrenal
- Glucocorticoid hormones (Cortisol)
- Mineralocorticoid hormone deficiency (renal sodium wasting, hypotension, hypokalemia, and metabolic acidosis)
- Thyroid
- Gonad
- Pancreas
- Mineral homeostasis
- Lipid metabolism
- Wasting syndrome

**Renal considerations:**

- Fluid imbalance
- Electrolyte imbalance
- Acid–base disturbance
- Acute tubular necrosis
- Metabolic acidosis
- HIV-associated nephropathy
- Hemolytic uremic syndrome
- Dialysis

**Dermatologic considerations:**

- Infections
- Shingles
Herpes virus infection
Hairy leukoplakia
Neoplastic disease
Seborrheic dermatitis
Hypersensitivity rashes

Oral considerations:
- Candidiasis
- Gingivitis
- Periodontitis
- Herpes simplex
- Herpes zoster
- Bacterial lesions
- Cytomegalovirus ulcers
- Hairy leukoplakia
- Warts

Neoplastic disease:
- Kaposi’s sarcoma
- Lymphoma
- Carcinoma
- Recurrent aphthous ulcers

**Life Care Planning: Recommendations Checklist**

**Allied health evaluations:**
- Physical therapy
- Occupational therapy
- Speech therapy
- Respiratory therapy
- Recreational therapy
- Psychology
- Neuropsychology
- Vocational/educational
- Financial planning
- Seating/mobility
- Adaptive driving

**Medical (evaluations and follow-up):**
- Physiatry
- General medicine
- Dental
- Podiatry
- Oncology
- Dermatology
Neurology
Rheumatology
Anesthesiology (pain control)
Nutritional
Gynecological/obstetrics
Psychiatry
Gastroenterology
Urological
Plastic/reconstruction
Pulmonary
Cardiology
Ophthalmology
Diagnostics, such as TB testing, MRI, CT scans, Pap smear, etc. (see list in the following)
Routine preventative immunizations (i.e., pneumonia vaccine, hepatitis B)

**Laboratory testing (Bartlett, 2001):**

- HIV serology
- CBC
- CD4 count
- Quantitative plasma HIV RNA
- Chemistry profile, including renal function and liver function tests
- Toxoplasma serology (immunoglobulin G, or IgG)
- Chest X-ray
- PPD
- STD screen; syphilis and Chlamydia urine screen (women)
- Baseline fasting lipid profile and glucose in all candidates for HAART therapy
- Hepatitis screen: HAV and HBV (to determine candidates for vaccine), HCV (in all injection drug users), and active hepatitis screen by determination of transaminase levels
- Pap smear (if none in the past year)

**Optional tests:**

- CMV serology
- HAV antibody
- Varicella antibody
- G6PD (sometimes done at baseline in those with high risk—African Americans and men of Mediterranean heritage)

**Sequential tests:**

- HIV RNA plasma levels: baseline confirmatory test at 2 to 4 weeks, then every 3 months if stable, or more frequently with initiation of antiretroviral therapy or change in therapy
- CD4 count: baseline and then every 3 to 6 months +/- confirmatory test if outlier results
- PPD: annual in high-risk patients with persistently negative results
- RPR: annual syphilis test in sexually active patients
- Pap smear: baseline and 6 months, then annually if negative
- CBC: baseline and every 3 to 6 months (as a component of CD4 count)
Therapeutic drug monitoring:

AZT-CBC every 3 months or more frequently
ddC, ddI, d4T—peripheral neuropathy
Nevirapine—liver function tests, especially during first 6 weeks
Protease inhibitors +/- NNRTI—fasting lipid profile at baseline and in 3 to 6 months; subsequent frequency depends on risks and test results
Fasting levels necessary for triglycerides that are used to determine LDL; should be done after 8- to 12-hour fast

Therapeutic modalities:

Physical therapy
Occupational therapy
Speech therapy
Respiratory therapy
Recreational therapy
Therapy/counseling (group, individual)
Career guidance/counseling
Staff training
Family counseling
Family education
Patient education
Driver’s education (with adaptations)
Legal/financial counseling
Spiritual support/counseling
Caregiver support
Case management
Leisure pursuits

Equipment considerations:

Mobility equipment (wheelchairs/scooters, etc., manual/power)
Equipment repairs/maintenance
Emergency call equipment (Wander guard/cell phone, Call Alert, other safety systems)
Home furnishings (to conserve physical energy)
Lift recliner
Accessible setting
Mobile stools
Reachers
Environmental control devices/maintenance and repair
Ramping
Stair glide
Elevator
Hospital bed/mattress
Special-size linens/blankets
Washer/dryer (for excess laundry requirements)
Feeding pumps (parenteral/enteral feeding)
Scale
Handheld shower
Shower bench
Handrails

**Medical equipment:**
- Suction machine
- Apnea monitor
- Oxygen concentrator
- Liquid oxygen
- Ventilator
- Humidifier

**Miscellaneous supplies (medical):**
- Catheters
- Feeding bags
- Suction catheters
- Syringes
- Diapers
- Bed pads
- Gloves
- Creams/powders
- Gauze/tapes
- Masks
- Thermometers
- Blood pressure monitors
- Garbage bags
- Wipes
- Paper towels
- Antibacterial soaps

**Architectural renovations/medical retrofitting:**
- Barrier-free design
- Grab bars in bathroom
- Temperature guards
- Call system

**Orthotics:**
- As prescribed

**Orthopedic equipment:**
- (For strength maintenance and mobility)
- Walkers
- Parallel bars
Canes
Crutches
Bath seat

**Aids for independent function:**

- Built-up plates/utensils
- One-handed equipment
- Voice-activated computer/software
- Adaptive clothing

**Infection control devices:**

- Sharps/needle/contaminant storage and destruction
- Decontaminant cleaners

**Medications:**

- Antiretrovirals
- Protease inhibitors
- Palliative care
- Pain treatment
- Oral
- IV
- Feeding supplements
- Dietary supplements
- Vitamin therapy

**Attendant/nursing care:**

- Respite care
- Caregiver support
- Hospice care
- Home health aide
- Driver
- Nursing care
- Home maintenance (interior/exterior)

**Surgical/aggressive intervention:**

- Ports for total parenteral nutrition (TPN) access
- Plastic surgical repairs
- Pain control devices (implanted)
- Surgical treatment of complications
- Tumor removal

**Complications:**

- Hospital care
- Clinic care
- Secondary infections
Falls
Accidents
Medical complications (myriad)
Financial

Costs of Care

There is one certainty when considering the costs of care for the HIV/AIDS patient: there is no way to predict the costs of care with certainty. In this author’s opinion, the medical management of the HIV/AIDS patient cannot be projected beyond the near future because the course of the disease and complications vary widely between patients. New treatment therapeutics and regimens, which are continuously being introduced to the treatment protocol, can change the treatment plan repeatedly. Although one can become knowledgeable about the most frequently encountered complications and the range of care and associated costs, with current research it is not possible to state within a reasonable degree of rehabilitation probability the frequency of occurrence, the severity of occurrence, the duration of a complication, or its best treatment strategy at some future time. Therefore, a practical way to predict a treatment course, project its costs, and feel comfortable that adequate services and funding have been identified may not exist. This effectively limits the amount of information for quantifying the costs of treatments that can be provided in a life care plan. The following tables present the costs of the choices for various antiretroviral therapies (ARTs) used as primary treatments of HIV infection. Table 15.1 summarizes annual costs for nucleoside analog medicines. Annual costs for nonnucleoside compounds are shown in Table 15.2. Protease inhibitor drug costs are summarized in Table 15.3. The new drug classes of entry inhibitors and integrase enzyme inhibitors annual costs are presented in Table 15.4. The costs of interventions for some of the more common OIs are summarized in Table 15.5, while Table 15.6 presents some other customary health care expenses. Also refer to Table 15.7 for ARV costs presented within a composite cost of care study.

More extensive primary disease therapies used over lengthier periods of time and the concomitant extension in life expectancy for the HIV patient that has occurred over the past decade have increased costs of care significantly compared to life care plans prepared 10 years ago. In addition to the costs for treating the primary HIV infection, common complications in HIV disease management must be considered in projecting the costs of care. The most common complication of HIV disease is the occurrence of OIs, which can substantially influence the total sphere of costs. Improved prophylaxes and treatment protocols for more OIs result in the prescribing of more drugs over the course of the disease, which also raises the costs of care.

Opportunistic infection management can be a major expenditure, especially when one factors in the ongoing prophylactic treatment after the initial acute infection has subsided or when the patient’s condition indicates prophylaxis be commenced. For example, the routine use of Diflucan for persons with CD4+ counts of less than 100 would cost almost $100,000 for each major infection prevented. Another example to consider is the medication for CMV infections. Oral Ganciclovir as a prophylaxis of CMV disease reduced the rate of CMV disease by nearly 50%; however, oral Ganciclovir costs approximately up to $20,000 per year. At higher CD4+ counts, health care costs are principally due to primary disease therapy and typically notOI management. The primary treatment therapy remains the most expensive cost consideration, however; costs for prophylaxis and treating complications increase as the CD4+ counts decrease. Table 15.5 presents the costs of agents recommended for prophylaxis or treatment of the more frequently encountered OIs among adults with HIV.
The medical management of the HIV/AIDS patient is not limited to primary disease treatment and control of OIs. Other health care resources such as consultations with specialists, tests, particular procedures, and health care facility usage are regularly employed to monitor and manage the course of the disease and its complications. Table 15.6 presents some health care resource costs. The costs are presented in 2003 dollars as econometrically updated from the originally reported 1995 dollars (Gable et al., 1996). The 1995 dollar costs were revised to represent 2003 dollar costs based on the cumulative increase in the medical care component of the U.S. Department of Labor’s Consumer Price Index, 1995 (annual) versus June 2003.

These tables do not present home care costs such as attendants or nursing services that the patient may periodically require. The cost of attendant or skilled nursing care will vary by the severity and duration of the specific episode of the complication. In early disease stages the patient may only need outpatient treatment, while in later stages the patient may require intermittent hospitalization or home-based attendant care with visiting skilled nursing. Eventually disease progression may necessitate skilled nursing care and perhaps home-based hospice care.

**Table 15.1 Antiretroviral Therapy: Nucleoside Analogs (Reverse Transcriptase Inhibitors)**

<table>
<thead>
<tr>
<th>Name</th>
<th>Cost/yeara</th>
</tr>
</thead>
<tbody>
<tr>
<td>Zidovudine, ZDV (Retrovir)/AZT</td>
<td>$4,340.18</td>
</tr>
<tr>
<td>Didanosine, ddI (Videx)</td>
<td>$3,686.85</td>
</tr>
<tr>
<td>Zalcitabine, ddC (Hivid)</td>
<td>$3,013.89</td>
</tr>
<tr>
<td>Stavudine, d4T (Zerit)</td>
<td>$4,061.28</td>
</tr>
<tr>
<td>Lamivudine, 3TC (Epivir)</td>
<td>$3,818.75</td>
</tr>
<tr>
<td>Combivir (Zidovudine/lamivudine)</td>
<td>$7,940.61</td>
</tr>
<tr>
<td>Abacavir (Ziagen)</td>
<td>$4,930.75</td>
</tr>
<tr>
<td>Trizivir (Ziagen/Retrovir/Epivir)</td>
<td>$12,895.71</td>
</tr>
<tr>
<td>Tenofovir (Viread)b</td>
<td>$5,198.00</td>
</tr>
<tr>
<td>Emtricitabine (Emtriva)</td>
<td>$3,625.56</td>
</tr>
<tr>
<td>Truvada (emtricitabine/tenofovir)</td>
<td>$9,683.45</td>
</tr>
<tr>
<td>Emzicomc (Epivir/Ziagen)</td>
<td>$10,151.88</td>
</tr>
<tr>
<td>Atripla (Sustiva/ Viread/Emtriva)</td>
<td>$13,800.00</td>
</tr>
</tbody>
</table>


Note: Nucleoside analog reverse transcriptase inhibitors (NRTIs) are potent in combination with other drugs; used alone, they lead to HIV resistance, ZDV (AZT), d4T, 3TC, and abacavir penetrate the blood–brain barrier. Common side effects: lactic acidosis. Seven new nucleoside analogs are in some phase of testing in the United States.c

a Cost is based on average prescription prices found in Jacksonville, FL, pharmacies, 2006.

b Tenovir is the first nucleotide analog approved for HIV treatment. It blocks HIV replication similar to the nucleoside analogs.

c Prevents the viral proteins from assembling into the HIV capsid that houses viral RNA, enzymes, etc.
Table 15.2 Antiretroviral Therapy: Nonnucleoside Compounds (Nonnucleoside Reverse Transcriptase Inhibitors)

<table>
<thead>
<tr>
<th>Name</th>
<th>Cost/Year&lt;sup&gt;a&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nevirapine (Viramune)</td>
<td>$4,395.36</td>
</tr>
<tr>
<td>Delavirdine (Rescriptor)</td>
<td>$3,842.13</td>
</tr>
<tr>
<td>Efaviruz (Sustiva, Stocrin)</td>
<td>$5,258.69</td>
</tr>
</tbody>
</table>


Note: Non-nucleoside analog reverse transcriptase inhibitors (NNRTIs) may interact with other *Cytochrome p450-preceed drugs*: protease inhibitors, oral contraceptives, etc. NNRTIs have a mixed ability to penetrate the blood–brain barrier. Common side effect: mild rash. Some doctors build up drug doses slowly to avoid rash; the other worry is that dose building increases risk of drug resistance.

<sup>a</sup> Cost is based on average prescription prices found in Jacksonville, FL, pharmacies, 2006.

When computing the potential cost of attendant care services, it is important to include volunteer or nonpaid hours in the total costs of care. It is common for the patient’s family, significant other, spouse, or other volunteers to provide health care services when sufficient funding to acquire paid help is lacking. Particularly in determining costs of care in the life care planning (forensic) arena, these volunteer hours must be accounted for in the total cost of care. In other words, the services that a spouse, friend, or volunteer provide have a value. The proper method to assess the value of such services is to determine what it would cost to replace these services in the labor market. These service-related costs are typically obtained by contacting a home health agency to evaluate the level of care required based on the home health regulations in a specific state.

This discussion of costs also leads to a consideration of the availability of funding for the proper treatment of early intervention and prophylaxis for OIs. As is typical in the general population, funded health care has been proven to reduce overall costs of health care since preventative steps can be taken that reduce actual costs per incidence of medical need. That is true in the HIV/AIDS population as well. If funding is not available for primary disease medications or for preventative treatment of OIs, costs can escalate due to complications and OIs, resulting in more hospital stays and a foreshortened life expectancy.

Other considerations in providing care for the HIV patient include social services, palliative treatment (i.e., pain management), psychological support, and home health requirements. Home health requirements can include services provided and arranged through an agency (home health agency), private home health hires, friends, family services, community or church volunteers, and local service programs. A central aspect of home health care is providing a stable environment in which adherence to the treatment regimen can be maintained to avoid the possibility of viral resistance even if directly observed therapy becomes necessary.

The economic impact on the individual through loss of work productivity, quality of life, self-esteem, and will to live merits consideration in assessing the costs of living with HIV infection. Services must be provided to empower the HIV/AIDS individual in all spheres of life.

The first report of annual health care expenditure per HIV+ patient in the United States was published by Chen et al. (2006). Their study, “Distribution of health care expenditures for HIV-infected patients,” was conducted in the University of Alabama at Birmingham outpatient
Table 15.3  Antiretroviral Therapy: Protease Inhibitors

<table>
<thead>
<tr>
<th>Name</th>
<th>Cost/Year$^a$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Saquinavir mesylate (Invirase)</td>
<td>$5,233.39</td>
</tr>
<tr>
<td>Ritonavir (Norvir)</td>
<td>$9,001.32</td>
</tr>
<tr>
<td>Indinavir (Crixivan)</td>
<td>$6,310.46</td>
</tr>
<tr>
<td>Nelfinavir (Viracept)</td>
<td>$8,641.23</td>
</tr>
<tr>
<td>Saquinavir (Fortovase)</td>
<td>$2,954.93</td>
</tr>
<tr>
<td>Amprenavir (Agenerase)</td>
<td>$4,372.71</td>
</tr>
<tr>
<td>Kaletra (Lopinavir/Novir)</td>
<td>$8,040.05</td>
</tr>
<tr>
<td>Atazanavir (Reyataz)</td>
<td>$9,959.88</td>
</tr>
<tr>
<td>Fosamprenavir (Lexiva)</td>
<td>$7,800.00</td>
</tr>
<tr>
<td>Tipranavir (Aptivus)$^c$</td>
<td>$3,340.68</td>
</tr>
<tr>
<td>Darunavir (Prezista)</td>
<td>$9,125.00</td>
</tr>
</tbody>
</table>


Note: Protease Inhibitors (PIs) are very potent and may interact with other drugs using cytochrome p450 metabolic pathways. Potentially life-threatening if taken with Seldane, Hismanal, Propulsid, Halcion, or Versed. Avoid rifabutin, Nizoral, rifampin. Poor absorption may affect potency. Common side effects: liver toxicity, hypoglycemia, flatulence, bloating, lipodystrophy (fat distribution). Seven new protease inhibitors are now in some phase of testing in the United States. In addition, there are at least 28 other antiretroviral drugs being investigated.

$^a$ Cost is based on average prescription prices found in Jacksonville, FL, pharmacies, 2006.
$c^c$ Prevents the viral proteins from assembling into the HIV capsid that houses viral RNA, enzymes, etc.

Viatical Settlements

A unique financial resource, a viatical settlement, is available to individuals who are HIV+. This process, which is called viatification, allows individuals to sell their life insurance policy for cash. A viatical settlement provides a valuable financial resource to help patients pay for the cost of hospitalization, treatment, home care, or other expenses, including day-to-day living expenses. The proceeds of a viatical settlement can facilitate options the patient might not otherwise have had, such as noninsured or experimental medical treatments, and can restore the patient’s control over the conduct of daily life.

Viatical settlement is not a new concept. The term comes from the Latin *viaticum*, meaning “provision for a journey.” Viatica were the supplies that Roman soldiers were given in preparation for their journeys into battle (presumably journeys from which they might not return). In essence,
a viaticum was the provision a soldier needed for the closing phase of his life. The analogy is that a person wishing to viaticate is preparing for the closing phase of life.

Initially, the viatical settlement industry was comprised of an informal network of small insurance settlement companies serving primarily the AIDS community. Many insurance settlement providers are active in the field today, and the process has expanded to include persons with other life-threatening illnesses such as cancer or Alzheimer’s disease. In fact, in this author’s experience, the selling of an insurance policy no longer requires any justification. Any person can sell any policy and use the proceeds as desired, even to take a vacation.

Viatical settlements are available in all 50 states. There are no restrictions on how the funds may be used, which restores some control to the patient for making decisions as personally deemed necessary. All types of insurance policies, including term, whole life, universal life, or group (employer paid) policies, may be sold. Policy values of just $10,000 to well over $1 million have been sold as viatical settlements. The viatification process is initiated with a relatively simple application and usually takes 3 to 6 weeks to complete. Some viatical investment companies will offer to buy the policy directly; others will seek offers to purchase from other funding sources. For cautions, see www.sec.gov/answers/viaticalseettle.htm. Also, the National Association of Insurance Commissioners posts a link of companies including those deemed unsuitable. For example, see

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### Table 15.4  Antiretroviral Therapy: Entry Inhibitors and Integrase Enzyme Inhibitors

<table>
<thead>
<tr>
<th>Name</th>
<th>Cost/Year^a</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Entry Inhibitors</strong></td>
<td></td>
</tr>
<tr>
<td>T-20 (Enfuvirtide, Fuzeon)</td>
<td>$20,000 (WAC)^d</td>
</tr>
<tr>
<td>Maravirocc (Selzentry)^e</td>
<td>$13,200</td>
</tr>
<tr>
<td><strong>Integrase Inhibitors</strong></td>
<td></td>
</tr>
<tr>
<td>Raltegravir (MK 0158)^e</td>
<td>$12,133.08</td>
</tr>
</tbody>
</table>


Note: Entry inhibitors bar HIV from entering immune cells. *Integrase inhibitors prevent HIV DNA from entering human DNA.* All lettered notes for Tables 15.1–15.4 are summarized below:

^a Cost is based on average prescription prices found in Jacksonville, FL, pharmacies, 2006.

^b Tenovir is the first nucleotide analog approved for HIV treatment. It blocks HIV replication similar to the nucleoside analogs.

^c Prevents the viral proteins from assembling into the HIV capsid that houses viral RNA, enzymes, etc.

^d Atazanavir is the first once-a-day PI for use with other anti-HIV drugs. Fuzeon, on launch day (USA) 2003, cash and carry price was $2200/month or $26,400/year. In 2006 the price was $2335/month or $28,020/year. Wholesale acquisition cost (WAC) was $20,000. In May 2003, of the 142 largest insurers, 94% agreed to cover Fuzeon, as have Medicaid programs in 48 states. There are now drugs that interfere with at least nine different mechanisms in the process by which HIV attaches itself to specific cell types, enters them, enters the cells’ DNA, makes copies of itself, and exits the cell.

^e Maraviroc is the second FDA entry inhibitor drug, but the first CCR5 coreceptor inhibitor. Raltegravir is the first FDA HIV integrase enzyme inhibitor drug. Both drugs will be used in salvage patient therapy, that is, patients resistant to current antiretroviral therapy.
Table 15.5  Wholesale Acquisition Costs of Agents Recommended for Preventing Opportunistic Infections among Adults Infected with HIV

<table>
<thead>
<tr>
<th>Pathogen</th>
<th>Drug/Vaccine</th>
<th>Dose</th>
<th>Estimated Annual Cost/Patient US$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pneumocystis carinii</td>
<td>Trimethoprim-sulfamethoxazole</td>
<td>160/800 mg daily</td>
<td>135</td>
</tr>
<tr>
<td></td>
<td>Dapsone</td>
<td>100 mg daily</td>
<td>72</td>
</tr>
<tr>
<td></td>
<td>Aerosolized pentamidine</td>
<td>300 mg every a.m.</td>
<td>1185</td>
</tr>
<tr>
<td></td>
<td>Atovaquone</td>
<td>1500 mg daily</td>
<td>11,627</td>
</tr>
<tr>
<td>Mycobacterium avium complex</td>
<td>Clarithromycin</td>
<td>500 mg twice daily</td>
<td>2843</td>
</tr>
<tr>
<td></td>
<td>Azithromycin</td>
<td>1200 mg weekly</td>
<td>3862</td>
</tr>
<tr>
<td></td>
<td>Rifabutin</td>
<td>300 mg daily</td>
<td>3352</td>
</tr>
<tr>
<td>Cytomegalovirus</td>
<td>Ganciclovir (oral)</td>
<td>1000 mg 3 times/day</td>
<td>17,794</td>
</tr>
<tr>
<td></td>
<td>Ganciclovir implant (lasts 6–9 months)</td>
<td></td>
<td>5000</td>
</tr>
<tr>
<td></td>
<td>Ganciclovir (IV)</td>
<td>5 mg/kg of body weight daily</td>
<td>13,093</td>
</tr>
<tr>
<td></td>
<td>Foscarnet (IV)</td>
<td>90–120 mg/kg of body weight daily</td>
<td>27,770–37,027</td>
</tr>
<tr>
<td></td>
<td>Cidofovir (IV)</td>
<td>375 mg every other week</td>
<td>20,904</td>
</tr>
<tr>
<td></td>
<td>Fomivirsen (intravitreal)</td>
<td>1 vial every 4 weeks</td>
<td>12,000</td>
</tr>
<tr>
<td></td>
<td>Valganciclovir</td>
<td>900 mg daily</td>
<td>21,582</td>
</tr>
<tr>
<td>Mycobacterium TB</td>
<td>Isoniazid</td>
<td>300 mg daily</td>
<td>23/9 months of therapy</td>
</tr>
<tr>
<td></td>
<td>Rifampin</td>
<td>600 mg daily</td>
<td>294/2 months</td>
</tr>
<tr>
<td></td>
<td>Pyrazinamide</td>
<td>1500 mg daily</td>
<td>194/2 months</td>
</tr>
<tr>
<td>Fungi</td>
<td>Fluconazole</td>
<td>200 mg daily</td>
<td>4603</td>
</tr>
<tr>
<td></td>
<td>Itraconazole capsule</td>
<td>200 mg daily</td>
<td>5340</td>
</tr>
<tr>
<td></td>
<td>Itraconazole solution</td>
<td>200 mg daily</td>
<td>5673</td>
</tr>
<tr>
<td></td>
<td>Ketoconazole</td>
<td>200 mg daily</td>
<td>1230</td>
</tr>
<tr>
<td>Herpes simplex virus</td>
<td>Acyclovir</td>
<td>400 mg 2 times/day</td>
<td>1384</td>
</tr>
<tr>
<td></td>
<td>Famiclovir</td>
<td>500 mg 2 times/day</td>
<td>5311</td>
</tr>
<tr>
<td></td>
<td>Valacyclovir</td>
<td>500 mg 2 times/day</td>
<td>2538</td>
</tr>
<tr>
<td>Toxoplasma gondii</td>
<td>Pyrimethamine</td>
<td>50 mg weekly</td>
<td>49</td>
</tr>
<tr>
<td></td>
<td>Leucovorin</td>
<td>25 mg weekly</td>
<td>888</td>
</tr>
<tr>
<td></td>
<td>Sulfadiazine</td>
<td>500 mg 4 times/day</td>
<td>1490</td>
</tr>
</tbody>
</table>
### Pathogen Drug/Vaccine Dose

**Streptococcus pneumoniae**  
23-valent pneumococcal vaccine  
One 0.5-ml dose intramuscularly  
13

**Influenza virus**  
Inactivated trivalent influenza vaccine  
One 0.5-ml dose intramuscularly  
3

**Hepatitis A virus**  
Hepatitis A vaccine  
Two 1.0-ml doses intramuscularly  
124

**Hepatitis B virus**  
Recombinant hepatitis B vaccine  
Three 10- to 20-μg doses intramuscularly  
70

**Bacterial infections**  
Granulocyte-colony-stimulating factor (IV)  
300 μg 3 times/week  
29,406

**Varicella-zoster virus**  
Varicella-zoster immune globulin  
Five 6.25-ml vials  
562

**Source:** Wholesale acquisition costs of agents recommended for preventing opportunistic infections among adults infected with human immunodeficiency virus, *Drug Topics Red Book*, Medical Economics, Montvale, NJ, 2000. With permission; as noted in *CDC-MMWR Recommendations and Reports*, June 14, 2002/51(RR08), 1–46; *Guidelines for Preventing Opportunistic Infections among HIV-Infected Persons—2002; Recommendations of the U.S. Public Health Service and the Infectious Diseases Society of America.*

www.insurance.ca.gov/0100-consumers/0030-licensee-info/0040-viatical-settlements/viatical-settlement-companies.cfm#top.

The value of the insurance policy (the amount paid to the policy owner) is determined by several factors, including prevailing interest rates, premium obligations, and projected life expectancy. The National Association of Insurance Commissioners (NAIC) has established pricing guidelines. Viators (patients) generally receive between 30% and 80% of the face value of the insurance policy. Generally, the longer the life expectancy, the less the viatical settlement.

### Table 15.6  Cost of HIV+/AIDS: Health Care Resource Use Costs

<table>
<thead>
<tr>
<th>Resource Use</th>
<th>Unit of Treatment</th>
<th>Cost per Unit ($)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amikacin levels</td>
<td>Tests</td>
<td>201</td>
</tr>
<tr>
<td>Barium swallow</td>
<td>Procedure</td>
<td>312</td>
</tr>
<tr>
<td>Blood chemistries</td>
<td>Test</td>
<td>47</td>
</tr>
<tr>
<td>Blood culture</td>
<td>Test</td>
<td>235</td>
</tr>
<tr>
<td>Blood gas</td>
<td>Test</td>
<td>79</td>
</tr>
<tr>
<td>Bone marrow biopsy</td>
<td>Procedure, physician, laboratory tests</td>
<td>1158</td>
</tr>
<tr>
<td>Bone marrow</td>
<td>Test</td>
<td>287</td>
</tr>
</tbody>
</table>

(Continued)
Table 15.6 (Continued)

<table>
<thead>
<tr>
<th>Resource Use</th>
<th>Unit of Treatment</th>
<th>Cost per Unit ($)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bone marrow and culture (MAC)</td>
<td>Test</td>
<td>634</td>
</tr>
<tr>
<td>Brain biopsy</td>
<td>Procedure, hospital (3 days), laboratory tests, physician</td>
<td>15,576</td>
</tr>
<tr>
<td>Bronchoscope</td>
<td>Procedure</td>
<td>2181</td>
</tr>
<tr>
<td>Catheter placement</td>
<td>Procedure</td>
<td>3116</td>
</tr>
<tr>
<td>CD4+ cell count</td>
<td>Test</td>
<td>3116</td>
</tr>
<tr>
<td>Chest radiograph</td>
<td>Test</td>
<td>211</td>
</tr>
<tr>
<td>Colonoscopy (biopsy)</td>
<td>Procedure</td>
<td>156</td>
</tr>
<tr>
<td>Complete blood count test</td>
<td>Test</td>
<td>89</td>
</tr>
<tr>
<td>Consultation (oncologist)</td>
<td>Visit</td>
<td>232</td>
</tr>
<tr>
<td>Cryptococcal antigen titer</td>
<td>Test</td>
<td>935</td>
</tr>
<tr>
<td>CT scan/CAT</td>
<td>Procedure</td>
<td>467</td>
</tr>
<tr>
<td>CT scan (noncontrast)</td>
<td>Procedure</td>
<td>381</td>
</tr>
<tr>
<td>CT chest, abdomen, head</td>
<td>Procedure, contrast material</td>
<td>2804</td>
</tr>
<tr>
<td>Dermatologic biopsy</td>
<td>Procedure</td>
<td>391</td>
</tr>
<tr>
<td>Detached retina</td>
<td>Treatment, hospitalization</td>
<td>4673</td>
</tr>
<tr>
<td>Dilantin level</td>
<td>Test</td>
<td>70</td>
</tr>
<tr>
<td>Electroencephalogram</td>
<td>Test</td>
<td>779</td>
</tr>
<tr>
<td>Endoscopy (biopsy)</td>
<td>Procedure</td>
<td>779</td>
</tr>
<tr>
<td>Emergency room visit</td>
<td>Visit</td>
<td>391</td>
</tr>
<tr>
<td>Foscarnet administration induction</td>
<td>Treatment</td>
<td>9615</td>
</tr>
<tr>
<td>Foscarnet administration maintenance</td>
<td>Treatment</td>
<td>1561</td>
</tr>
<tr>
<td>Foscarnet induction monitoring</td>
<td>Test/cycle</td>
<td>760</td>
</tr>
<tr>
<td>Foscarnet maintenance monitoring</td>
<td>Test/cycle</td>
<td>913</td>
</tr>
<tr>
<td>Ganciclovir administration induction</td>
<td>Treatment</td>
<td>6255</td>
</tr>
<tr>
<td>Ganciclovir administration maintenance</td>
<td>Treatment</td>
<td>1444</td>
</tr>
<tr>
<td>Ganciclovir induction monitoring</td>
<td>Test/cycle</td>
<td>140</td>
</tr>
<tr>
<td>Ganciclovir maintenance</td>
<td>Test/cycle</td>
<td>278</td>
</tr>
<tr>
<td>Home (drug) administration</td>
<td>Visit</td>
<td>156</td>
</tr>
<tr>
<td>Home care</td>
<td>Visit</td>
<td>350</td>
</tr>
<tr>
<td>Resource Use</td>
<td>Unit of Treatment</td>
<td>Cost per Unit ($)</td>
</tr>
<tr>
<td>-------------------------------------------</td>
<td>--------------------------------------------------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>Hospital physician visit</td>
<td>Visit</td>
<td>195</td>
</tr>
<tr>
<td>Hospitalization</td>
<td>Day</td>
<td>1544</td>
</tr>
<tr>
<td>Intensive care unit</td>
<td>Day</td>
<td>3087</td>
</tr>
<tr>
<td>Induced sputum</td>
<td>Procedure</td>
<td>547</td>
</tr>
<tr>
<td>Indwelling catheter</td>
<td>Procedure</td>
<td>3087</td>
</tr>
<tr>
<td>Infected catheter</td>
<td>Treatment and replacement</td>
<td>3739</td>
</tr>
<tr>
<td>Intraleisional injections</td>
<td>Procedure</td>
<td>156</td>
</tr>
<tr>
<td>Lipase and triglycerides</td>
<td>Test</td>
<td>55</td>
</tr>
<tr>
<td>Lumbar puncture</td>
<td>Procedure, laboratory tests</td>
<td>733</td>
</tr>
<tr>
<td>Lumbar puncture</td>
<td>Associated tests</td>
<td>342</td>
</tr>
<tr>
<td>Lymphoma biopsy</td>
<td>Procedure, hospital (1 day), physician, laboratory tests</td>
<td>3894</td>
</tr>
<tr>
<td>Magnesium test</td>
<td>Test</td>
<td>31</td>
</tr>
<tr>
<td>Magnetic resonance imaging</td>
<td>Procedure</td>
<td>1869</td>
</tr>
<tr>
<td>Office visit (physician)</td>
<td>Visit</td>
<td>79</td>
</tr>
<tr>
<td>Ophthalmology examination</td>
<td>Test</td>
<td>312</td>
</tr>
<tr>
<td>Ophthalmology examination (follow-up)</td>
<td>Test</td>
<td>235</td>
</tr>
<tr>
<td>PPD skin test</td>
<td>Test</td>
<td>15</td>
</tr>
<tr>
<td>Pulmonary function test</td>
<td>Test</td>
<td>71</td>
</tr>
<tr>
<td>Radiation therapy, 2 to 3 weeks</td>
<td></td>
<td>17,133</td>
</tr>
<tr>
<td>Serum amylase</td>
<td>Test</td>
<td>24</td>
</tr>
<tr>
<td>Specialized test battery</td>
<td>Tests</td>
<td>1558</td>
</tr>
<tr>
<td>Sputum smear and culture sensitivities</td>
<td>Test</td>
<td>326</td>
</tr>
<tr>
<td>Toxoplasmosis titer</td>
<td>Test</td>
<td>55</td>
</tr>
<tr>
<td>TPN</td>
<td>TPN material and home infusion charges (9 days)</td>
<td>577</td>
</tr>
<tr>
<td>TPN laboratory work</td>
<td>Test</td>
<td>125</td>
</tr>
<tr>
<td>Transfusion</td>
<td>Each</td>
<td>779</td>
</tr>
<tr>
<td>Wasting syndrome diagnostic workup</td>
<td>Clinical tests</td>
<td>3116</td>
</tr>
</tbody>
</table>


Notes: 2003 dollars econometrically updated from 1995 dollars; CT = computerized tomography.
company is likely to pay for that individual’s policy because the company must assume responsibility for maintaining the policy for a longer period of time. The proceeds from a viatical settlement may, however, impact certain means-based entitlement programs such as Medicaid. Furthermore, under current law, the proceeds from a viatical settlement are taxable as income for federal tax purposes. However, several states have adopted or are considering specific regulations or provisions, which may include the following:

- State and city tax-free treatment of viatical settlement proceeds to encourage the use of these settlements
- Prevention of the brokering of life insurance policies to individual investors who are looking for speculative returns without due regard for the policy owner’s welfare
- Requiring viatical companies to maintain a minimum level of capital or surety bond to fund the purchase of life insurance policies as part of the viatical settlement process to help ensure that companies can fund settlements and to prevent the involvement of viatical settlement companies that may put people at financial risk
- Requiring licenses and other strictly enforced reporting mechanisms for viatical settlement companies and limiting licenses to companies with well-established operations (Editor’s note: The Viatical Association of America identified in previous editions is no longer active.)

Table 15.7 Mean Annual Expenditure per Patient by Cost Component and CD4+ Cell Count Category for 635 Patients from the University of Alabama at Birmingham HIV Outpatient Clinic

<table>
<thead>
<tr>
<th>CD4 Cell Count Category</th>
<th>No. of Patients</th>
<th>Total Cost</th>
<th>Antiretroviral Medication</th>
<th>Non-ARV Medication</th>
<th>Hospital Costs</th>
<th>Other Outpatient Costsa</th>
<th>Physician/Clinic Costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;50 cells/μl</td>
<td>62</td>
<td>$36,352 (100)</td>
<td>$10,855 (30)</td>
<td>$14,882 (41)</td>
<td>$8353 (23)</td>
<td>$1909 (6)</td>
<td>$533 (1)</td>
</tr>
<tr>
<td>50–199 cells/μl</td>
<td>99</td>
<td>$23,864 (100)</td>
<td>$11,862 (50)</td>
<td>$6685 (28)</td>
<td>$3369 (14)</td>
<td>$1416 (6)</td>
<td>$532 (2)</td>
</tr>
<tr>
<td>200–349 cells/μl</td>
<td>143</td>
<td>$18,274 (100)</td>
<td>$11,935 (65)</td>
<td>$3452 (19)</td>
<td>$1186 (7)</td>
<td>$1365 (7)</td>
<td>$336 (2)</td>
</tr>
<tr>
<td>&gt;350 cells/μl</td>
<td>331</td>
<td>$13,885 (100)</td>
<td>$9407 (68)</td>
<td>$1855 (13)</td>
<td>$1408 (10)</td>
<td>$930 (7)</td>
<td>$285 (2)</td>
</tr>
<tr>
<td>All 635</td>
<td></td>
<td>$18,640 (100)</td>
<td>$10,500 (56)</td>
<td>$4240 (23)</td>
<td>$2342 (13)</td>
<td>$1199 (6)</td>
<td>$359 (2)</td>
</tr>
</tbody>
</table>

Source: Chen et al., Clinical Infectious Diseases, 42, 1003–1010, 2006. With permission.

Notes: Cost per patient per year (% of total cost) by category.
a Other outpatient costs include outpatient radiological examination, laboratory tests, procedures, and home health care.
Case Management: A Critical Component

Case management of individuals with HIV/AIDS is vitally important—not only in managing the case from a direct economic standpoint, but also from managing the case from an early intervention/prevention standpoint. It is imperative that case managers keep themselves informed on the scope of knowledge available on HIV/AIDS, on new treatment modalities and their uses, on resistance issues, and on side effects. In addition, the case manager must be able to communicate effectively with physicians and to address nutritional issues, adherence of patients to therapy, financial issues, and psychological issues such as loss of identity and self-esteem.

Because the field is changing rapidly, the effective case manager will subscribe to professional journals that are devoted to the subject, for example, the *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology* (www.jaids.com), and learn to browse the Internet efficiently. Suggested websites include national health hotlines, government agencies, and professional organizations; private-sector AIDS services, information, and advocacy groups; AIDS lobby/watchdog groups; and other AIDS-related information sources. Information from the Centers for Disease Control and Prevention (CDC) is also available on the Internet.

When case managing HIV/AIDS clients, the health professional should encourage patients to become self-advocates. This will empower the person with HIV/AIDS to become involved with the treatment of the disease, rather than being a victim of the disease. Delays in treatment are not only costly, but also life threatening. Some suggested activities for both the case management professional and the patient are as follows:

- Join the local AIDS organization, the county AIDS consortium, and the state board.
- Attend conferences on AIDS, arming oneself with information to share.
- Call local health departments or HIV/AIDS organizations for information.
- Seek out pharmacists who have taken the time to become familiar with the new treatment modalities.
- Become involved in local support groups.

There are a multitude of state and federal programs that can be of assistance if one is willing to invest the time and energy to become involved and informed. Additional information can be found by contacting entities listed in the resources section of this chapter. These include AIDS hotline numbers (national and state level), government health agencies and professional societies, private-sector services and advocacy groups, AIDS lobby/advocacy/watchdog groups, other AIDS-related information sources, patient assistance programs made available through pharmaceutical companies, and pharmaceutical information.

Conclusion

The AIDS epidemic continues to present unrelenting challenges to the medical profession. While medical science has made progress in reducing the frequency and duration of complications, improving quality of life of those affected and extending survival, finding an absolute cure or preventative vaccination remains elusive. The progression of this disease is unpredictable, which presents significant obstacles to the life care planner, since, unlike most diseases, complications and the course of the illness cannot be accurately anticipated. The life care plan will rely heavily on the recommendations of the individual’s physician and relevant research. The life care planner who chooses to specialize in the HIV/AIDS arena must be aware of the myriad complications and
remain contemporaneous with evolving HIV/AIDS medical research. Accordingly, the life care planner must also be committed to regularly updating the plan based on the client’s ever-changing circumstances and emerging information.

Acknowledgments

The author thanks Julie A. Kitchen, CCM, CLCP, of Paul M. Deutsch & Associates for significant contributions to the text. Her professional expertise and perspective were invaluable for the life care planning considerations for the HIV/AIDS patient, viatical settlements, and case management critical components sections.

Sherie Kendall, PhD, is supported by a Founder’s Award from the Foundation for Life Care Planning Research. Dr. Kendall is currently employed by Midway College, Midway, Kentucky.

Resources

HIV/AIDS Hotlines—United States

Johns Hopkins
www.hopkins-hivguide.org/resources/hiv_aids_hotlines/hiv_aids_hotlines_u.s.html?contentInstanceId=37932&siteld=7151

Government Agencies/Professional Societies

AIDSinfo
P.O. Box 6303, Rockville, MD 20849-6303; Tel: 800-448-0440; Outside United States: 301-519-6616; TTY number: 1-888-480-3739; http://aidsinfo.nih.gov

American Medical Association (AMA)
535 Dearborn Street, Chicago, IL 60610; Tel: 312-645-5000

American Public Health Association (APHA)
1015 Fifteenth Street, Washington, DC 20005; Tel: 202-789-5600

American Red Cross
1750 K Street NW, Suite 700, Washington, DC 20006; Tel: 202-973-6025

American Red Cross AIDS Education
1730 D Street NW, Washington, DC 20006; Tel: 202-737-8300

American Social Health Association (ASHA)
P.O. Box 13827, Research Triangle Park, NC 27709; Tel: 800-227-8922

The Americans with Disabilities Act Information and Assistance Hotline
800-949-4232 V/TTY

Business & Labor Information Service (CDC NAC)
800-458-5231 or 1-800-243-7012 (Deaf/TDD). Links business organizations and labor groups with resources for developing HIV/AIDS in the workplace programs.
Centers for Disease Control [and Prevention] (CDC)
1600 Clifton Road NE, 26 Executive Park, Atlanta, GA 30333; Tel: 404-639-3311
National Prevention of Disease Hotline: 800-343-AIDS or 800-342-2437; www.cdcnpin.org

The Centers for Disease Control and Prevention (CDC) National AIDS Information Clearinghouse “Materials Catalogue” and “Business Responds to AIDS” Resource Services
P.O. Box 6003, Rockville, MD 20849-6003; Tel: 800-458-5231 (in Maryland: 301-763-5111)
9 a.m. to 7 p.m. M–F; additional numbers: 800-243-7012 (TDD/Deaf Access); 301-217-0023 (international)

Department of Health and Human Services
(see also listing for U.S. Public Health Service) Office of the Secretary, 200 Independence Avenue NW, Room 615-F, Washington, DC 20201; Tel: 202-245-6296

Experimental Treatment Infoline
(see also New York listings) 800-633-7444 (New York State only); 212-239-5523 (other states). Provides up-to-date information on experimental treatments via touchtone

Food and Drug Administration (FDA)
5600 Fishers Lane, Rockville, MD 20857; Tel: 301-443-2410

FDA Center for Drug Research
Office of the Director, 5600 Fishers Lane, Rm. 13B-45, Rockville, MD 20857; Tel: 301-443-2894

Hemophilia and AIDS/HIV Network for the Dissemination of Information (HANDI)
110 Greene Street, Suite 303, New York, NY 10012; Tel: 212-431-8541 or 800-42-HANDI

Intergovernmental Health Policy Project (IHPP) at George Washington University AIDS Policy Center
2021 K Street NW, Suite 800, Washington, DC 20006; Tel: 202-872-1445

National Adoption Information Clearinghouse
301-231-6512

National AIDS Hotline
800-342-2437 (24 hours a day, daily); 800-243-7889 (TTY/TDD); 800-342-AIDS (English);
800-344-SIDA (Spanish); 301-217-0023 (international)

National Clearinghouse for Alcohol and Drug Information’s Center for Substance Abuse Prevention (CSAP)
800-729-6686

National Indian AIDS Hotline
800-283-2437

National Institutes of Health (NIH)
Office of the Director, Bldg. 1, Room 344, 6003 Executive Blvd., Bethesda, MD 20892; Tel: 301-496-4000 (main information number). For information on AIDS clinical trials at the NIH Clinical Center: 800-AIDS-NIH (800-243-7644), 12 p.m. to 3 p.m. (EST), M–F

National Library of Medicine (NLM)
The National Library of Medicine provides numerous AIDS informational resources, including three online AIDS databases: AIDSLINE, AIDSDRUGS, and AIDSTRIALS. To obtain a free
information packet, call 800-638-8480. National Institutes of Allergy and Infectious Diseases (NIAID) Office of Communications, Bldg. 31, Room 7A-32, Bethesda, MD 20892; Tel: 301-496-5717. National Cancer Institute (NCI), Bldg. 31, Room 11A-48, 6003 Executive Blvd., Bethesda, MD 20892; Tel: 301-496-4000

**National Hemophilia Foundation (NHF)**
212-219-8180

**National Herpes Hotline**
919-361-8488 (9 a.m. to 7 p.m. EST, weekdays)

**National Minority AIDS Council (NMAC)**
1931 Thirteenth Street NW, Washington, DC 20009; Tel: 202-483-6622; 202-544-1076; Fax: 202-483-1135; 202-544-0378

**National Native American AIDS Prevention Center (NNAAPC)**
3515 Grand Avenue, Suite 100, Oakland, CA 94610; Tel: 510-444-2051

**National Pediatric & Family HIV Resource Center**
30 Bergen Street, ADMC #4, Newark, NJ 07103; Tel: 973-972-0410 or 800-362-0071; Fax: 973-972-0399; www.pedhivaids.org

**National Sexually Transmitted Diseases HOTLINE/CDC**
800-227-8922 (8 a.m. to 11 p.m. EST, weekdays)

**Rural AIDS Network (RAN)**
1915 Rosina, Santa Fe, NM 87501; Tel: 505-986-8337

**Substance Abuse and Mental Health Services Administration’s (SAMHSA)—Drug Abuse Information and Treatment Referrals Hotline**
800-662-HELP

**Teen AIDS Hotline**
800-283-2473 (AIDS info and grief counseling, 8:30 a.m. to 1 p.m., and 2 to 5 p.m., M–F)

**U.S. Conference of Mayors**
1620 I Street NW, 4th floor, Washington, DC 20006; Tel: 202-293-7330

**U.S. Public Health Service (PHS)**
200 Independence Ave. SW, Washington, DC 20201; Tel: 202-472-4248

**Health Resources and Services Administration (HRSA)**
HRSA AIDS Program Office, 5600 Fishers Lane, Parklawn Building, Rockville, MD 20857; Tel: 301-443-4588.

**Substance Abuse and Mental Health Services Administration (SAMHSA)**
SAMHSA Office on AIDS, 5600 Fishers Lane, Room 12C-10, Rockville, MD 20857; Tel: 301-443-5305. USPHS Public Affairs Office H. H. Humphrey Bldg, Rm. 725-H (same zip, etc.) Tel: 202-245-6867

**U.S. Agency for International Development (USAID) HIV/AIDS Division/AIDS Control and Prevention Project (AIDSCAP)**
Room 1200, SA-18, Washington, DC 20523-1817; Tel: 703-875-4494
Visual AIDS [U.S. government effort to increase AIDS awareness through image, video, etc.]
131 West 21st Street, 3rd floor, New York, NY 10011; Tel: 212-206-6758

Private-Sector Services and Advocacy Groups

ACT UP
Local Chapter Contacts (within ARIC’s PWA Resource Guide) www.critpath.org

AIDS Action Council [AIDS legislative watchdog group]
1875 Connecticut Avenue NW, Washington, DC 20009; Tel: 202-986-1300 (ext. 47); Fax: 986-1345.
Contact: Winnie Stachelberg, Derek Hodel

AIDS Project Los Angeles (APLA)
6721 Romaine Street, Los Angeles, CA 90038; Tel: 213-962-1600. Contact(s): Stephan Korsia, Stephen Bennett (CEO). Available publications: Heard It through the Grapevine newsletter

AIDS Research Information Center, Inc. (ARIC, Inc.)
20 South Ellwood Avenue, Suite 2, Baltimore, MD 21224-2241; Tel: 410-342-ARIC; Fax 410-342-2742. Contact: Lee Hardy. Available publications: ARIC’s AIDS Medical Glossary—a 500 page medical reference in layman’s language (donation requested). The DIRT (on AIDS) newsletter

AIDS Treatment Data NETWORK
611 Broadway, Suite 613, New York, NY 10012; Tel: 800-734-7104; 212-260-8868; Fax: 212-260-8869. Contact(s): Ken Fornataro, Joel Beard. Available publications: Treatment Review newsletter. Simple Facts Information Sheets (information on drugs and diseases in AIDS in plain language). AIDS/HIV Experimental Treatment Directory (a directory of trials for NY, NJ, CT, Philadelphia, and Washington, DC) [Note: these and other materials are available in Spanish]

American Foundation for AIDS Research (AmFAR)
Up-to-date information on HIV drugs, treatment strategies and toxicities, clinical trials, HIV-related conditions, and resources for HIV-positive people and health care providers. Also features the Treatment Insider, a newsletter on HIV therapy and prevention. http://web.amfar.org/treatment/index.asp

American Lung Association (of South Alleghenies) [TB & AIDS info]
634 Main Street, PO Box 67, Johnstown, PA 15907; Tel: 814-536-7345; Fax: 539-5919; Contact: Philip J. Cynar

Carl Vogel Foundation
2025 I Street NW, Suite 917, Washington, DC 20006; Tel: 202-289-4898; Contact: Ron Mealy, exec. director

Center for Natural and Traditional Medicine
P.O. Box 21735, Washington, DC 20009; Tel: 202-387-3645 or 234-9632; Fax: 332-2132 (dedicated); Contact: Kaiya Montacean, codirector

Community Research Initiative on AIDS (CRIA)
275 7th Avenue, 20th floor, New York, NY 10001; Tel: 212-924-3934; Fax: 924-3936; Contact: Bette Smith
**Direct Action for Treatment Access (DATA)** [Alternative/Holistic AIDS treatment advocacy]
Consumer Coalition for Health Choices, PO Box 60391, Palo Alto, CA 94306-0391; Tel: 415-321-6670 (9 a.m. to 9 p.m.); Fax: 323-3864 (W): 415-323-6051; CompuServe account # 71702.760 [71702.760@compuserve.com] Contact: Steven Wm. Fowlkes

**Direct AIDS Alternative Information Resources (DAAIR)** [Alternative/Holistic treatments information]
31 East 30th Street, Suite 2, New York, NY 10016; Tel: 212-689-8140; Contact: Fred Bingham

**Drug Reform Coordination Network (DRCNet)**
4455 Connecticut Ave. NW, Suite B-500, Washington, DC 20008-2302; Tel: 202-362-0030; Fax: 202-362-0032

**Gay Men’s Health Crisis (GMHC)**
129 West 20th Street, New York, NY 10011; Tel: 212-807-6664; Fax: 337-3565; GMHC AIDS Information hotline: 212-807-6655 (M–F 10 a.m. to 9 p.m., Sat 12 p.m. to 3 p.m.). Available publications: *Treatment Issues* newsletter

**Human Rights Campaign Fund** [Gay/Lezian Rights + AIDS issues lobby group]
1012 14th Street NW, Suite 607, Washington, DC 20005; Tel: 202-628-4160; Fax: 202-347-5323; Contact: Tim McFeeley

**Mobilization Against AIDS (MAA)**
415-863-4676; Fax: 415-863-4740; Contact: Ben Carlson

**National Association of People w/ AIDS**
1413 K Street NW, 7th floor, Washington, DC 20005; Tel: 202-898-0414; 800-673-8538; Fax: 202-898-0435; NAPWA-Link computer BBS: 703-998-3144 (8-N-1)

**National AIDS Network**
729 Eighth Street SE, Suite 300, Washington, DC 20003

**National AIDS Treatment Advocacy Project**
72 Orange Street, #3C, Brooklyn, NY 11201; 718-624-8541; Fax: 718-624-8399; Contact: Jules Levin

**National Council of Churches/AIDS Task Force**
475 Riverside Drive, Room 572, New York, NY 10115; Tel: 212-870-2421

**N.C.C./ Minority Task Force on AIDS**
475 Riverside Drive, Room 456, New York, NY 10115; Tel: 212-749-1214

**National Gay/Gayian Health Foundation**
1638 R Street NW, Suite 2, Washington, DC 20007; Tel: 202-797-3708; Contact: Bill Scott

**National Gay and Lesbian Task Force (NGLTF)** [Gay/Gayian Rights + AIDS lobby group]
1734 14th Street NW, Washington, DC 20009-4309; Tel: 202-332-6483

**National Women’s Health Network**
1325 G Street NW (Lower Level), Washington, DC 20005; Tel: 202-347-1140

**Parents and Friends of Lesbians and Gays (P-FLAG)**
P.O. Box 27605, Washington, DC 20038-4605; Tel: 202-638-4200; Book offer: *Family AIDS Support Notebook*, basic information for the families of people with HIV/AIDS

**The People with AIDS Coalition Hotline**
212-532-0568 or 800-828-3280
Pharmaceutical Research and Manufacturer’s Association [drug information]
1100 Fifteenth Street NW, Washington, DC 20005; Tel: 202-835-3400; Contact(s): Gerald Mossinghoff; John Petricciani, MD. Available publications: AIDS Medicines in Development, annual report on new AIDS drugs and vaccines in development. Free!

Project Inform
205 13th Street, Suite 2001, San Francisco, CA 94103-2461; Tel: 415-558-9051; 800-822-7422; Contact: Martin Delaney. Available publications: PI Perspective newsletter, Wise Words (by and for women with HIV), and other treatment information

PWA Health Group
31 West 26 Street, New York, NY 10010; Tel: 212-532-0289. Available publications: Notes From the Underground newsletter

The Sheridan Group
Tel: 202-462-7288; Fax: 202-483-1964; Contact: Tom Sheridan

Test Positive Aware Network
1340 West Irving Park Road, PO Box 259, Chicago, IL 60613; Contact: John Krotz, director. Available publications: Positively Aware newsletter

Treatment Action Group [offshoot of ACTUP Treatment and Data Committee, now independent] 147 Second Avenue, #601, New York, NY 10003; Tel: 212-260-0300

Treatment Action Network [Project Inform’s treatment activist organization]
147 Second Avenue, #601, New York, NY 10003; Tel: 415-558-8669; 415-626-7231; Fax: 415-558-0684; Contact: Anne Donnelly, Tom Wonsiewicz, David Lewis

Women Alive
800-554-4876. This is a new national hotline staffed by HIV+ women volunteers. This hotline is geared for HIV+ women who would like peer support or treatment information. Open Mon., Wed. & Fri. 11 a.m. to 6 p.m. (Pacific time) 2 to 9 p.m. (Eastern time)

Women and AIDS Resource Network (WARN)
P.O. Box 020525, Brooklyn, NY 11202; Tel: 718-596-6007

Women’s AIDS Resource Movement (WARM) [a part of Tampa AIDS Network]
P.O. Box 8333, Tampa, FL 33674; Tel: 813-237-6455

Women Organized to Respond to Life Threatening Diseases (WORLD)
P.O. Box 11535, Oakland, CA 94611; Tel: 510-658-6930. Available publications: WORLD/MUNDO newsletter

Palliation

Alliance for Cannabis Therapeutics (ACT) and Marijuana/AIDS Research Service (MARS) [advocacy for the use of marijuana]
P.O. Box 21210, Kalorama Station, Washington, DC 20009; Tel: 202-483-8595; Fax: 797-9543

American Chronic Pain Foundation [info on coping with chronic pain]
P.O. Box 850, Rocklin, CA 95677

International Pain Foundation [info on pain research/treatment]
909 NE 43rd Street, Suite 306, Seattle, WA 98105
Roxane Pain Institute Association Doleur France-Amerique (France-USA Pain Society)
Michel Dubois, MD, Pres. Cancer/AIDS Pain HOTLINE (24 hrs/day): 800-335-9100

Family and Population Planning Planned Parenthood Federation of America (PPFA) [HIV info + safe sex education]
810 Seventh Avenue, New York, NY 10019; Tel: 212-541-7800

The Population Institute [info on how overpopulation helps spread disease worldwide]
110 Maryland Avenue NE, Washington, DC 20002

State AIDS Info Hotlines
Alabama 800-228-0469
Alaska 800-478-AIDS; nationwide 907-276-4880
Arizona 602-420-9396
Arkansas 800-364-2437; nationwide 501-661-2408
California (Northern) 800-367-2437; nationwide 415-863-2437; TTY/TDD 415-864-6606;
Southern California 800-922-2437; TTY/TDD 800-553-2437; Los Angeles 213-876-2437
Colorado 800-252-AIDS; Denver only 303-782-5186
Connecticut 800-342-AIDS
Delaware 800-422-0429
District of Columbia 202-332-AIDS; within metro DC and VA 800-322-7432
Florida 800-352-AIDS; Haitian Creole 800-243-710; Spanish 800-545-SIDA
Georgia 800-551-2728; nationwide 404-876-9944; Atlanta 404-876-9944
Hawaii 808-321-1555; nationwide 808-922-1313
Idaho 800-677-AIDS
Illinois 800-243-AIDS; TTY/TDD 800-782-0423
Indiana 800-848-AIDS; TTY/TDD 800-972-1846
Iowa 800-445-AIDS
Kansas 800-232-0040
Kentucky 800-654-AIDS
Louisiana 800-992-4379; nationwide 504-944-2437; TDD 944-2492
Maine 800-851-AIDS; nationwide 800-775-1267
Maryland 800-638-6252; Baltimore 410-945-AIDS; metro DC & VA 800-322-7432; Hispanic AIDS hotline 301-949-0945; Baltimore only TTY area 410-333-2437
Massachusetts 800-235-2331; nationwide 617-536-7733; TTY/TDD 617-437-1672
Michigan 800-872-AIDS; Spanish 800-826-SIDA; TTY/TDD 800-332-0849; teen line 800-750-TEEN; health care workers 800-522-0399
Minnesota 800-248-AIDS; nationwide 612-870-0700
Mississippi 800-826-2961
Missouri 800-533-AIDS
Montana 800-235-6668; Eastern Montana AIDS hotline 800-675-2437; Western Montana AIDS hotline 800-663-9002
Nebraska 800-782-AIDS
Nevada 800-842-AIDS
New Hampshire 800-752-AIDS
New Jersey 800-624-2377; TTY/TDD 201-926-8008
New Mexico 800-545-AIDS
New York 718-638-2074; counseling 800-872-2777 (M–F 2 p.m. to 8 p.m., Sat/Sun 10 a.m. to 6 p.m.). Taped information, 24 hrs. 800-541-2437 (counselors: M–F 8 a.m. to 8 p.m., Sat/Sun 10 a.m. to 6 p.m.). Treatment information 800-633-7444; Spanish 800-233-7432
GMHC AIDS hotline 212-807-6655 (M–F 10 a.m. to 9 p.m., Sat 12 p.m. to 3 p.m.); GMHC TDD 212-645-7470
Long Island AIDS hotline 516-385-AIDS (M–F 9 a.m. to 9 p.m., tape after hours). Albany 800-233-SIDA
Long Island People With AIDS hotline 516-225-5700
Mothers of PWAs [outside of NY] 800-828-3280 (available MWF 2 p.m. to 6 p.m.)
NY State Gay/Lesbian Task Force AIDS Information hotline 800-221-7044 [funded by Gay/Lesbian Task Force, New York 212-807-6016]
People With AIDS Coalition hotline 212-647-1420 (Staffed by HIV+ people)
North Carolina 800-342-AIDS
North Dakota 800-472-2180; nationwide 701-224-2376
Ohio 800-332-AIDS; TTY/TDD 800-332-3889
Oklahoma 800-535-AIDS
Oregon 503-223-AIDS; within area codes 503, 206 and 208: 800-777-2437
Pennsylvania 800-662-6080; Critical Path AIDS Project hotline 215-545-2212; 215-463-7160 (publications orders)
Puerto Rico 800-981-5721; Linea de Infor SIDA y Enfermedades de Transmission Sexual; nationwide 809-765-1010
Rhode Island 800-726-3010; Spanish 800-442-7432
South Carolina 800-322-AIDS
South Dakota 800-592-1861
Tennessee 800-525-AIDS
Texas 800-299-AIDS
Utah 800-366-AIDS; nationwide 800-487-2100
Vermont 800-882-AIDS
Virginia 807-773-AIDS
Virginia 800-533-4148; Hispanic line 800-322-7432
Washington 800-272-AIDS
West Virginia 800-642-8244
Wisconsin 414-273-AIDS; 800-334-2437
Wyoming 800-327-3577

Note: Physicians and other health care professionals are encouraged to consult other sources and confirm the information contained in the Johns Hopkins website listed in the following because no single reference or service can take the place of medical training, education, and experience. Consumers are cautioned that this site is not intended to provide medical advice about any specific medical condition they may have or treatment they may need, and they are encouraged to call or see their physician or other health care provider promptly with any health-related questions they may have.

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Chapter 16

Life Care Planning for Depressive Disorders, Obsessive-Compulsive Disorder, and Schizophrenia

Nicole M. Wolf

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Introduction

The impact of mental illness on the cost of health care and productivity has been largely underestimated. Mental illness affects about one in four adults or about 26.2% of Americans ages 18 and older (Kessler et al., 2005). According to the National Institute of Mental Health (NIMH), when this prevalence rate is applied to the 2004 U.S. Census results, an estimated 57.7 million adults have a mental illness (NIMH, n.d.). Of the 10 leading causes of disability in the United States, 4 are mental disorders: major depression, bipolar disorder, obsessive-compulsive disorder, and schizophrenia (Murray & Lopez, 1996). Psychiatric illness programs have not traditionally used life care planners. However, life care planning for mental illness can be considered an untapped market since the disease is lifelong and requires reasonably predictable care (Hilligoss, 2003). The prediction of expected care can be summarized in a life care plan (Weed, 1999; Weed & Field, 2001). In order to provide an accurate life care plan, it is important to consider the complexity of mental illness, including symptoms, treatment, and impact on functioning. The following sections
provide an overview of major depressive disorder, bipolar disorder, obsessive-compulsive disorder, and schizophrenia. At the end of the chapter, implications for life care planning are considered, including a checklist to help create the life care plan and an example of a life care plan for an individual with schizophrenia.

**Major Depressive Disorder**

The leading cause of disability worldwide in individuals ages 5 years and older (measured in the number of years lived with a disabling condition or illness) is major depression (Murray & Lopez, 1996). In the United States, major depressive disorder is reported as the foremost cause of disability in people ages 15 to 44, affecting 14.8 million people (NIMH, n.d.; World Health Organization [WHO], 2004). In any given year, it is estimated that 18.1% of the adult U.S. population have a mood disorder and 6.7% have major depressive disorder specifically (Kessler et al., 2005). The term mood disorders includes major depressive disorder (MDD), dysthymic disorder, and bipolar disorder (see bipolar disorder section). MDD and dysthymia share similar clinical features; however, they differ in duration and severity. Dysthymia is characterized by mild depressive symptoms with a duration of at least 2 years (American Psychiatric Association [APA], 2000a). MDD is associated with greater impairment and severity of symptoms; therefore, it will be the focus of the rest of the section.

**Epidemiology and Course of Illness**

The Epidemiologic Catchment Area Study (ECA) sponsored by the National Institutes of Health estimated, in adults, the 1-month prevalence of MDD at 2.2% and a lifetime prevalence of 5.8% (Robins & Reiger, 1991). However, other studies have found significantly higher lifetime prevalence estimates, with a 26% rate in women and a 12% rate in men (APA, 2000a). A major depressive episode often occurs after an individual experiences a severe psychosocial stressor such as divorce or the death of a loved one. MDD can occur at any age, but the average age of onset is in the late twenties. The disorder may develop suddenly or take days or weeks to become clinically diagnostic. The duration of MDD is varied, and untreated episodes typically last 6 months or longer (APA, 2000a). Some individuals will later develop bipolar disorder after experiencing a hypomanic or manic episode. It is estimated that 50% to 85% of individuals with MDD will have another episode (Mueller et al., 1999). Typically, functioning returns to baseline after an episode resolves, but 20% to 35% of individuals will have some residual functional impairment (APA, 2000a). There appears to be a genetic component in the development of MDD, with higher prevalence rates among first-degree relatives (APA, 2000a).

**Symptoms**

MDD is characterized by one or more major depressive episodes, with an absence of any hypomanic, manic, or mixed episodes. The fundamental feature of a major depressive episode is a persistent depressed mood that lasts at least 2 weeks or loss of interest or pleasure in almost all activities. Other symptoms of a major depressive episode include changes in sleep, appetite, weight, or psychomotor activity; lack of energy; feeling guilty or worthless; decreased ability to focus, think, or make decisions; and thoughts of death or suicidal thoughts, plans, or attempts (APA, 2000b). At least four of these symptoms must be present and last for at least 2 weeks in
in order to meet the criteria of a major depressive episode. MDD can range from mild to severe, with a corresponding range in loss of functioning. Individuals with MDD can have psychotic features where delusions (false, irrational beliefs) and hallucinations are present. Catatonic features may also be present, where there is a severe change in motor movements and behavior (e.g., an individual may remain motionless, engage in bizarre postures, or become mute) (APA, 2000b).

**Treatment**

The American Psychiatric Association has established treatment guidelines for MDD (APA, 2000a) and has conceptualized treatment into three phases: (1) the acute phase, during which the goal is to induce remission; (2) the continuation phase, during which the goal is to preserve remission; and (3) the maintenance phase, during which the goal is to prevent future episodes. Both pharmacotherapy and psychotherapeutic interventions are used to meet these goals. Treatment recommendations will vary based on the severity and characteristics of the depressive episodes and response to treatment.

**Pharmacotherapy**

**Antidepressants**

Antidepressant medications are utilized during all phases of treatment. Commonly prescribed antidepressants include selective serotonin reuptake inhibitors (SSRIs) and serotonin norepinephrine reuptake inhibitors (SNRIs). Older agents such as tricyclics and monoamine oxidase inhibitors (MAOIs) may also be prescribed, most often when individuals fail first-line treatments. SSRIs include fluoxetine, fluvoxamine, sertraline, paroxetine, and citalopram. SSRIs are generally as effective as other classes of antidepressants and pose a significantly less threat of fatality in overdose than tricyclics (APA, 2000a). Common side effects of SSRIs include sedation, insomnia/agitation, gastrointestinal distress, sexual side effects, and weight gain (Pies, 1998). SNRIs include venlafaxine and duloxetine. Common side effects of SNRIs include nausea, decreased appetite, headache, gastrointestinal distress, and dizziness (Keller et al., 2007; Wohlreich et al., 2007). Tricyclic agents include amitriptyline, clomipramine, doxepin, and imipramine. Studies estimate that about 50% to 75% of individuals respond to tricyclics, compared with a placebo response rate of 25% to 33% (Klerman & Cole, 1967; Klein et al., 1980; Depression Guidelines Panel, 1993; Potter et al., 1998). Common side effects of tricyclics include cardiac or autonomic (e.g., orthostatic hypotension, dizziness), anticholinergic (e.g., dry mouth, urinary retention, blurred vision), and neurobehavioral (e.g., memory impairment, psychomotor stimulation, tremors) symptoms (Pies, 1998). MAOIs include phenelzine and tranylcypromine. In 2006, the U.S. Food and Drug Administration (FDA) approved the first transdermal patch for treating depression (selegiline or Emsam®), which is an MAOI antidepressant (FDA, 2006). MAOIs have similar efficacy in treating MDD as tricyclics (APA, 2000a). Individuals taking MAOIs must avoid certain foods and beverages such as aged cheese and meats, fava beans, and red wine because a serious, life-threatening interaction (hypertensive crisis) may occur (Pies, 1998). The selegiline patch does not require the same dietary restrictions if prescribed at the lowest dose (FDA, 2006). Common side effects of MAOIs include orthostatic hypotension, weight gain, sexual impairment side effects, and neurological effects such as headache and insomnia (APA, 2000a).
Adjunctive Medications

If an individual does not have an adequate response to antidepressant medications, other agents such as mood stabilizers and antipsychotics may be added in hopes of greater efficacy. Lithium has demonstrated efficacy in up to 50% of individuals who do not respond to antidepressant therapy alone (Price et al., 1986). Individuals with psychotic symptoms are often prescribed antipsychotic agents. Additionally, one antipsychotic agent, olanzapine, has shown efficacy when combined with fluoxetine in treatment-resistant depression (Shelton et al., 2001). Last, electroconvulsive therapy (ECT) may be considered in moderate to severe depression and in depression with psychotic features. ECT has shown superior efficacy over antidepressant therapy (Janicak et al., 1985) and may be helpful in individuals who have not responded to antidepressants (Lam et al., 1999).

Psychotherapeutic Interventions

Cognitive-behavioral therapy has the most evidence of any psychotherapy approach in treating MDD successfully (APA, 2000a). The goals of cognitive therapy are to identify and change irrational beliefs and distorted attitudes, thereby reducing depressive symptoms. Additionally, other theoretical orientations that may be used in MDD include behavior therapy, interpersonal therapy, and psychodynamic therapy. Individuals with MDD often have marital and family issues, so therapy with the spouse or family may be helpful. Group therapy may also be beneficial to individuals with MDD.

Vocational Impact of MDD

Individuals who are depressed may have decreased motivation, poor initiative, lack of drive, and low energy (Fischler & Booth, 1999). These symptoms can make it difficult to learn new skills. Individuals with MDD may have irritability that negatively affects relationships with coworkers. They may be overly sensitive to criticism and have difficulty coping with others. The symptoms of MDD can make it difficult for an individual to stay on task or complete a project. Stress tolerance is decreased in MDD; therefore, a high-stress, fast-paced work environment may be inappropriate.

Reasonable Accommodations

Accommodations for an individual with MDD will depend on the severity of symptoms. It is important to offer flexibility in scheduling to allow for appointments for medication management or therapy. A quiet workstation away from distractions may improve attention and focus. A predictable routine can help minimize stress and maintain stamina. Hourly goals can help with maintaining work pace. Working in a team may decrease feelings of loneliness. Lastly, new information or new job skills may require extra instruction and additional time to learn. Providing written instructions can help to improve accuracy and aid in retention.

Costs of MDD

Major depressive disorder is a costly illness in terms of both direct costs (e.g., hospitalizations, doctor’s visits, medications) and indirect costs (e.g., missed work, reduced productivity, quality of life). The annual cost of MDD in 2002 was estimated at $43 billion, and missed work accounted for $17 billion, according to the American College of Occupational and Environmental Medicine.
MDD has been shown to be equivalent to coronary heart disease in terms of reduced productivity, and it is estimated that people with MDD function at an even lower rate than people with hypertension, diabetes, or arthritis (ACOEM, 2002). In terms of cost of treatment, SSRIs may be cost-effective over tricyclic agents, even though SSRIs have higher up-front acquisition costs (Frank et al., 2001). Factors that contribute to the cost-effectiveness of SSRIs include higher rates of compliance and reduced rates of physician visits, laboratory monitoring, and hospitalizations (Conner et al., 1999). SSRIs show comparable costs across the various agents (Crown et al., 2001).

**Bipolar Disorder**

Clinical classifications on bipolar disorder first appeared around the turn of the century, when Emil Kraepelin divided psychotic disorders into two major categories: manic-depressive insanity and dementia praecox (Wyatt, 2001). These terms are the predecessors of bipolar disorder and schizophrenia, respectively. According to the *Diagnostic and Statistical Manual of Mental Disorders, IV, text revision* (DSM-IV-TR) (APA, 2000b), there are two classifications of bipolar disorder: bipolar I and bipolar II. Individuals with bipolar I have experienced at least one episode of mania, while individuals with bipolar II have not. Instead, they experience a milder form of mania termed hypomania. Both of these mood states will be further explained in the symptoms section. Bipolar I is typically more severe and disabling than bipolar II. Unless otherwise stated in the text, in the following sections the term bipolar disorder refers to bipolar I.

**Epidemiology and Course of Illness**

The Epidemiologic Catchment Area Study estimated the prevalences of bipolar I and bipolar II disorders in the adult population at 0.8% and 0.5%, respectively (Robins & Reiger, 1991). In any given year, about 2.6% of the population or about 5.7 million American adults have bipolar disorder (Kessler, 2005). The ECA study reports the mean age of onset at 21 years of age (Robins & Reiger, 1991). Disturbingly, it is estimated that almost 70% of individuals with bipolar disorder who seek help are misdiagnosed, commonly with unipolar depression (Hirschfeld et al., 2003). There are generally an equal number of men and women affected with bipolar disorder, although their course of illness may be different. Women tend to have more depressive than manic episodes, while in men manic episodes typically equal or exceed depressive episodes (APA, 2000b). Current research indicates that bipolar disorder is likely a result of a genetic predisposition combined with environmental influences, including stressful events (Rush, 2003).

Bipolar disorder can have a devastating impact on quality of life. When left untreated, an individual may experience 10 or more episodes of mania and depression over a lifetime (Goodwin & Jamison, 1990). As many as 60% of individuals with bipolar disorder experience chronic interpersonal and occupational impairments (APA, 2002). The divorce rates among these individuals are two to three times higher than those of the general population (Manning et al., 1997). The ECA study found that individuals with bipolar disorder were the most likely of all of the mentally ill groups to have a history of previous suicide attempts. In fact, 25% to 60% of all individuals with bipolar disorder will attempt suicide at least once in their lifetime, and 18.9% succeed (Robins & Reiger, 1991).

The course of illness in most individuals is chronic, often with alternating periods of depression and mania. Symptoms typically reduce for a period of time between these episodes; however, 20% to 30% of individuals continue to have residual mood symptoms (APA, 2000b). About
10% to 15% of individuals with bipolar disorder have rapid cycling, which is defined as four or more episodes of mania, mixed mania, hypomania, or depression occurring in a 12-month period (Bowden, 1996). Rapid cycling is more common in women than in men (APA, 2000b).

**Symptoms**

Symptoms associated with bipolar disorder include mania, hypomania, depressive, and mixed states. Psychotic features may occur with all of these states except hypomania. Psychotic features are defined as a break with reality characterized by delusions and hallucinations. The DSM-IV-TR (APA, 2000b) criteria for each of these mood states are detailed in the following.

**Mania**

The characteristics of mania include the following:

- Mood disturbance for at least 1 week: abnormal and persistently elevated, expansive, or irritable mood
- Pressured speech: talkative, with pressure to keep talking, difficult to interrupt
- Distractibility: difficulty maintaining attention, distracted by irrelevant information or stimuli
- Flight of ideas: racing thoughts, frequently changing subjects
- Inflated self-esteem or grandiosity: an exaggerated sense of self-importance or of one’s status, accomplishments, wealth, talents, or beauty
- Decreased need for sleep: sleeps very little or not at all, may deny need for sleep
- Impulsivity: difficulty controlling impulses and may engage excessively in pleasurable activities without regard for potential consequences (e.g., gambling, sexual activity with strangers, or lavish spending of money)
- Increase in goal-directed activity or psychomotor agitation

**Hypomania**

Hypomania and mania share the same characteristics. However, in hypomania the symptoms are not severe enough to cause significant vocational or social impairment or to warrant hospitalization. Additionally, psychotic features are never present during a hypomanic episode (APA, 2000b).

**Depressive Episode**

To meet the criteria for a depressive episode, each symptom must be present nearly every day (e.g., not occurring occasionally). The criteria for a depressive episode are as follows:

- Depressed mood occurring most of the day for at least 2 weeks
- Significantly reduced interest or pleasure in all or almost all activities occurring most of the day
- Significant weight loss or weight gain or change in appetite
- Insomnia or hypersomnia
- Psychomotor agitation or retardation that is observable by others
Feelings of worthlessness or excessive/inappropriate guilt, which may take on a delusional quality
- Fatigue or lack of energy
- Decreased ability to think or focus or make decisions
- Recurrent thoughts of death and/or suicidal ideation, plan, or attempt

**Mixed Episode**
A mixed episode occurs when the criteria for both a manic and depressive episode are met at the same time nearly every day for at least 1 week (APA, 2000b). A mixed episode causes severe impairment and may lead to hospitalization. During a mixed state, it is common to have agitation, difficulty sleeping, significant changes in appetite, psychosis, and suicidal thoughts.

**Treatment**
The APA *Practice Guidelines for the Treatment of Patients with Bipolar Disorder* provide the following treatment guidelines and goals (APA, 2002):

- Perform a thorough diagnostic evaluation.
- Evaluate the safety of the patient and others and determine a treatment setting.
- Establish and maintain a therapeutic alliance.
- Monitor the patient’s psychiatric status.
- Provide psychoeducation about bipolar disorder.
- Enhance treatment compliance.
- Promote regular patterns of activity and sleep.
- Anticipate stressors.
- Identify new episodes early.
- Minimize functional impairments.

To achieve these goals, a combination of pharmacologic and psychotherapeutic interventions is required.

**Pharmacotherapy**
Medications are used to treat acute manic symptoms, alleviate depression, and prevent future episodes. Common categories of drugs that are used to treat bipolar disorder include mood stabilizers/anticonvulsants, antipsychotics, and adjunctive agents. While lithium has been the most commonly prescribed medication for the treatment of bipolar disorder for decades, the use of other mood stabilizers and atypical antipsychotics as first-line treatments has become increasingly common due to their perceived greater tolerability and mounting evidence of efficacy.

**Lithium**
Lithium has been the mainstay of bipolar pharmacologic treatment. It was first found to have antimanic properties in 1949 (Cade, 1999) but was not widely prescribed for bipolar disorder in the United States until the mid-1960s (Jefferson et al., 1987). Lithium demonstrates efficacy in the treatment of acute mania, depressive episodes, and prevention of recurrent episodes (Goodwin &
Side effects are reported in up to 75% of individuals that take lithium (Jefferson et al., 1987; Goodwin & Jamison, 1990). Side effects of lithium include excessive thirst, excessive urination, memory problems, tremor, weight gain, and drowsiness/tiredness (Lenox & Husseini, 1998). Rates of noncompliance range from 18% to 53%, and the side effect most often reported as the reason for discontinuing lithium is memory problems (Goodwin & Jamison, 1990). Toxic effects and overdose can occur and are more common with high serum levels. Monitoring of serum plasma levels is an important aspect of lithium treatment. Initially, close serum monitoring is required to find the optimal therapeutic dose and to avoid toxicity. It is recommended that renal and thyroid functions be tested regularly because lithium use may disrupt these processes (APA, 2002).

Other Mood Stabilizers

Valproate, an anticonvulsant, is another agent commonly used in the treatment of bipolar disorder. Valproate has demonstrated efficacy in the treatment of acute mania and some evidence of effectiveness in acute bipolar depression and maintenance (APA, 2002). Common side effects of valproate include sedation, gastrointestinal distress, tremor, increased appetite, and weight gain. There may be life-threatening adverse reactions, but such events are rare. Dosing is established through blood serum monitoring. Toxicity and overdose are not common with routine dosing. It is recommended that liver function and hematologic measures be assessed on a regular basis (APA, 2002). Other commonly prescribed mood stabilizers include carbamazepine and lamotrigine.

Antipsychotics

Beginning with olanzapine in 1999, all of the atypical antipsychotics have FDA approval for the treatment of bipolar disorder with the exception of paliperidone. This includes aripiprazole, ziprasidone, risperidone, and quetiapine. The conventional antipsychotic chlorpromazine also is indicated for the treatment of bipolar disorder. Traditionally, antipsychotics have been used to treat acute mania and psychotic symptoms. However, some agents such as quetiapine, olanzapine, and aripiprazole are also indicated in treating depressive symptoms and in preventing future episodes (Gutman & Nemeroff, 2007). Unlike lithium and valproate, atypical antipsychotics do not require serum monitoring. Atypical antipsychotics have various side effects depending on the agent; some are sedating while others are activating, some have weight gain while others are weight neutral, and some may induce metabolic problems, including hyperglycemia. Common side effects associated with the use of atypicals include drowsiness, sedation, dry mouth, constipation, dizziness, orthostatic hypotension, nausea, and possibly extrapyramidal symptoms (but reduced in comparison with conventional antipsychotics).

Adjunctive Medications

Other medications that are used in bipolar disorder include benzodiazepines/tranquilizers, antidepressants, and other anticonvulsants. Benzodiazepines or tranquilizers are also used to treat acute mania because of their sedative effects. Antidepressants are used for bipolar depression; however, caution and close monitoring are required because these agents may induce mania (APA, 2002). There have been investigations into the use of other anticonvulsants such as topiramate and gabapentin in treating bipolar disorder (Wang et al., 2002; Vasudev...
et al., 2006). More research is needed to better quantify the beneficial effects of adjunctive medications.

**Psychotherapeutic Interventions**

The APA practice guidelines for the treatment of bipolar disorder (2002) recommend the use of psychoeducation and psychotherapeutic interventions. The primary goals of these treatments are to decrease distress, improve functioning, and reduce the risk and severity of future episodes. While psychotherapeutic interventions alone are typically not effective in the treatment of acute mania, they do demonstrate efficacy with bipolar depression (Zaretsky et al., 1999). Treating bipolar depression without antidepressants can be especially beneficial to individuals who have antidepressant side effects, antidepressant-induced mania, or rapid cycling. In addition to individual therapy, individuals with bipolar disorder may also benefit from family therapy, group therapy, and support groups.

**Vocational Impact of Bipolar Disorder**

Bipolar disorder can result in significant difficulties in the workplace. Hirschfeld and colleagues (2003) found that employment rates of individuals with bipolar disorder dropped from 49% in 1992 to 40% in 2000. During a manic phase, symptoms such as grandiosity, distractibility, poor judgment, and excessive or inappropriate motivation can result in severe consequences on the job. A person experiencing manic symptoms has reduced interpersonal functioning, poor time management, difficulty maintaining attention, and may be distracting to coworkers. The individual may be unpredictable, unreliable, and irrational. At the most extreme, the individual experiencing mania can be dangerous to herself and to others in the workplace. An individual experiencing a depressive episode may have lack of motivation, lack of energy, social withdrawal, and decreased ability to attend and focus (Fischler & Booth, 1999).

**Reasonable Accommodations**

Functional limitations and reasonable accommodations will vary according to the individual based on differences in episode, symptom severity, and effective coping strategies. Accommodations could include job sharing or job restructuring, putting all workplace communications in writing, and allowing time off for appointments and hospitalization, if needed. Increasing the structure of the workday and developing hourly goals can also be helpful. It is important to provide regular feedback on both job performance and interactions with others. Providing a quiet workstation with minimal distractions can improve attention and focus. Educating a supervisor or coworker about the early signs of mania could also be helpful in providing appropriate interventions early in the episode, thereby reducing functional impairment.

**Costs of Bipolar Disorder**

Bipolar disorder is a costly illness, in terms of both economics and impact on quality of life. The most costly intervention for bipolar disorder is hospitalization. Begley and colleagues (1998) report that the average cost per person with a single manic episode is $11,720. This estimate rose to $624,785 for individuals with chronic episodes. It is estimated that 64% of individuals with
bipolar disorder are noncompliant, meaning they do not take their medications as prescribed (Li et al., 2002). Direct health care costs rise in individuals who delay or do not take mood stabilizers during their first year of treatment (Li et al., 2002). Medication noncompliance can lead to relapse and rehospitalization—a costly cycle. While newer medications may be more expensive, there is some evidence that shows that they help to reduce overall costs, due to improved efficacy (Namjoshi et al., 2002).

**Obsessive-Compulsive Disorder (OCD)**

Worry, doubts, and superstitious behavior are often a part of everyday experiences. Many people spend some time worrying, especially when psychosocial stressors are high. When worries become excessive or irrational or when certain actions are perceived as necessary to counteract these thoughts, then OCD is suspected. Important clinical features of OCD are that the thoughts and actions must be time-consuming (greater than 1 hour per day), cause marked distress, and significantly impair everyday activities (APA, 2000b).

**Epidemiology and Course of Illness**

OCD was once considered to be a rare disease by mental health professionals. People with OCD often did not seek treatment. OCD came to be recognized as a more common illness when the National Institute of Mental Health found that more than 2% of the population has OCD, which makes it more common than bipolar disorder and schizophrenia (U.S. Department of Health and Human Services [U.S. DHHS], 1996). People with OCD come from all ethnic backgrounds, and men and women are affected in equal numbers. Generally, the onset of OCD is any age between preschool and adulthood. Most people develop OCD by the age of 40 years (March et al., 1997). Up to 50% of individuals with OCD report that their symptoms began during childhood (March et al., 1997). OCD often goes unrecognized even after an individual seeks treatment. It is estimated that the average person with OCD sees three to four different doctors and spends 9 years seeking treatment before the correct diagnosis is made (March et al., 1997). OCD appears to have a genetic component and is linked to tic disorders (U.S. DHHS, 1996). The symptoms are most likely due to a reduction in the levels of serotonin in the brain or other neurotransmitter dysfunctions such as levels of dopamine (U.S. DHHS, 1996; March et al., 1997; Denys, Zohar, & Westenberg, 2004). OCD symptoms are often chronic, although there may be periods of time when the symptoms are less severe.

**Symptoms**

Most people with OCD have both obsessions and compulsions. Obsessions are thoughts, images, or impulses that are persistent and perceived by the individual as unwanted, intrusive, and beyond control (APA, 2000b). However, the individual with obsessions is able to recognize that these thoughts are a product of his own mind. The obsessive thoughts are perceived as disturbing and result in high levels of distress and anxiety. Individuals experiencing obsessions often cope by ignoring or suppressing the thoughts or attempting to neutralize them through another thought or behavior, which is a compulsion. Therefore, compulsions are repetitive actions or thoughts that an individual performs in order to make obsessions go away. Compulsive behaviors in OCD are not
pleasurable, but are used to reduce or prevent anxious feelings or worries (APA, 2000b). Common obsessions include the following (APA, 2000b):

- Fear of contamination (e.g., by touching a doorknob or shaking hands)
- Repeated doubts (e.g., wondering if the stove was left on or if a check was signed)
- A need to have things in a certain order or organized a certain way, often symmetrically (e.g., lining up shoes a certain way, positioning canned goods according to size, type)
- Aggressive or horrifying images (e.g., slapping someone, shouting obscenities at work)
- Sexual imagery (e.g., pornographic images)

Common compulsions include the following (APA, 2000b):

- Repetitive behaviors (e.g., hand washing, ordering, checking, touching, hoarding)
- Repetitive mental acts (e.g., praying, counting, repeating words or phrases)

**Treatment**

Treatment of OCD includes both medications and psychotherapeutic interventions. Most people require the use of both modalities, as only 20% experience symptom remission with medications alone (March et al., 1997). The *Expert Consensus Guidelines for the Treatment of Obsessive-Compulsive Disorder* (March et al., 1997) divides treatment into two phases: acute and maintenance. The respective treatment goals during the acute and maintenance phases are to end the current OCD episode and prevent future episodes. Most treatment occurs on an outpatient basis, as hospitalization is rarely necessary for the treatment of OCD.

**Pharmacotherapy**

**Antidepressants**

Serotonin reuptake inhibitors (SRIs) are the mainstay of pharmacologic treatment of OCD. SRIs include clomipramine (a tricyclic antidepressant) and SSRIs such as fluoxetine, fluvoxamine, paroxetine, sertraline, and citalopram. Antidepressants that do not have serotonergic properties are typically not effective in the treatment of OCD (Pies, 1998). If OCD symptoms do not diminish after an SRI is initiated, it is recommended that the dosage be increased to the maximum dose for at least 4 to 6 weeks. If the response is still inadequate, the ineffective SRI should be discontinued and another SRI initiated (March et al., 1997).

**Adjunctive Medications**

If symptoms do not respond to conventional treatment, then another strategy is the use of adjunctive medications. Commonly used adjunctive medications include clomipramine, benzodiazepines (e.g., clonazepam, alprazolam, lorazepam), antipsychotics (e.g., haloperidol, pimozide, risperidone), and buspirone (an antianxiety agent) (March et al., 1997). Adjunctive medications are not used alone, but added on to the existing medication regime. It is important to monitor for increased medication side effects or interactions when using multiple agents. Sedation is a common side effect of these medications, so it may be necessary to take them at bedtime.
Psychotherapeutic Interventions

Cognitive-behavioral therapy (CBT) is recommended for all individuals with OCD (March et al., 1997). CBT techniques utilized in the treatment of OCD include exposure and response or ritual prevention. Exposure consists of having the individual come into contact with a feared stimulus (e.g., dirty objects, shaking hands, etc.). The goal of this technique is to reduce anxiety with each exposure session. Response or ritual prevention is another key element to this process. This technique is defined as preventing the individual from any actions that are used to reduce anxiety when exposed to the feared stimulus (March et al., 1997), for example, not permitting the individual to wash her hands after touching something perceived as contaminated. Other CBT techniques used in OCD include thought stopping, distraction, and contingency management.

Individuals with OCD may also benefit from psychoeducation about the illness and ways to manage symptoms. Also, support groups can be helpful because they provide an outlet for individuals to share experiences and receive peer support.

Vocational Impact of OCD

OCD can have a devastating impact on vocational functioning. Commonly, individuals with OCD will work at a slow pace as a result of coping with obsessions and compulsions. An individual may feel compelled to check and recheck his work or a need to do certain rituals while working that make ordinary tasks take an extended period of time to complete. Individuals with OCD have a lower tolerance for stress. Everyday occurrences such as shaking someone’s hand or counting money might induce obsessive thoughts and compulsive behaviors. Also, a stressful work environment can contribute to the severity and frequency of OCD symptoms. Distractibility can occur because the individual with OCD is often preoccupied with symptoms, detracting from the ability to concentrate and focus (Fischler & Booth, 1999).

Reasonable Accommodations

An individual with OCD will work better in an environment that offers predictability and routine. This can help keep stress levels to a minimum and reduce the need to make decisions throughout the day, which may prove difficult, especially when symptoms are moderate to severe. It may be helpful to allow some flexibility in the setup of the workspace. Providing hourly goals may help establish pace of work. A workstation that is not in close proximity to coworkers may decrease anxiety and distractibility. Lastly, flexible scheduling should be offered to accommodate medication management and CBT appointments.

Costs of OCD

Although hospitalization is generally not required in the management of OCD, it remains a costly illness from both an economic and quality of life perspective. In 1990, the total costs of OCD were estimated to be $8.4 billion, which was 5.7% of the estimated costs of all mental illnesses combined for that year ($147.8 billion) (Dupont et al., 1995). More research is needed to better quantify the costs of OCD. In regards to quality of life, individuals with OCD have dysfunction in all areas. OCD has a negative impact on an individual’s interpersonal relationships, and significant others may become part of the destructive symptom cycle by enabling rituals. In these cases, it is especially important to include significant others in the treatment plan, including the use of marriage and family therapy.
Schizophrenia

In 1896, Emil Kraepelin provided the first descriptions of the disease known today as schizophrenia (Wyatt, 2001). After decades of studying the mentally ill, Kraepelin began to categorize individuals by their course of symptoms. He used the term *dementia praecox* to describe individuals whose psychotic symptoms began early in life and continued on a deteriorating course (Wyatt, 2001). In 1911, Eugene Bleuler coined the term *schizophrenia* for the illness that Kraepelin called dementia praecox, because he thought it was a more fitting description of the illness. The word schizophrenia means a splitting (schizo) of the mind (phrenia), and not a split personality, which is a common public misperception about the illness (Wyatt, 2001).

Early treatments for schizophrenia such as hypoglycemic coma, seizure therapy, and frontal lobotomies were typically unsuccessful and even harmful for the patient. Schizophrenia treatment was revolutionized in the early 1950s with the introduction of the first antipsychotic agent, chlorpromazine (*Thorazine*), allowing many patients to be treated in the communities instead of in hospitals (Siegfried et al., 2001). In the early 1990s, pharmacotherapy entered another more promising phase with the introduction of the first atypical antipsychotic agent, clozapine. The atypical agents offer increased efficacy and reduced serious side effects when compared with the older, conventional agents.

**Epidemiology and Course of Illness**

The ECA study found the annual prevalence rate for schizophrenia to be about 1.3% of the population (Robins & Reiger, 1991), translating into about 2.2 million people in the United States. The incidence rate is similar across diverse geographical, cultural, and socioeconomic categories. The onset of schizophrenia can be gradual or sudden, but many individuals display signs that something is wrong (e.g., decreased sociality, withdrawal, and unusual behavior) before actual psychotic symptoms are apparent (U.S. DHHS, 1999). The age of onset is typically adolescence to early adulthood, with men typically having an earlier onset than women. It is unusual to develop schizophrenia after the age of 40 (McEvoy et al., 1999). Earlier onset is associated with poorer outcomes, which may be attributed to the loss of age-appropriate milestones in the areas of education, interpersonal relationships, and employment (U.S. DHHS, 1999). The course of schizophrenia is often chronic and disabling. Individuals may have periods of acute psychosis alternating with periods of symptom remission or a constant level of residual symptoms that can greatly impair functioning. Schizophrenia subtypes (based on symptoms) include paranoid, disorganized, catatonic, undifferentiated, and residual (APA, 2000b).

Schizophrenia is primarily a problem of brain functionality rather than brain structure. While the role of dopamine imbalance has been well documented, other neurotransmitters appear to be involved in schizophrenia as well, including serotonin, acetylcholine, norepinephrine, glutamate, and GABA. While the causes of schizophrenia are unknown, scientists believe it is a combination of genetic predisposition and environmental factors that most likely occur *in utero* during the development of the brain (U.S. DHHS, 1999).

**Symptoms**

The two main categories of symptoms in schizophrenia are positive symptoms and negative symptoms. The term *positive* refers to occurrences that are added to one’s ordinary experience, while the term *negative* refers to aspects of life that are taken away from one’s ordinary experience.
Positive Symptoms

Positive symptoms include hallucinations, delusions, disorganized speech, and disorganized or catatonic behavior. Hallucinations can occur in all sensory modalities, but the most common are auditory. Auditory hallucinations are usually in the form of voices. A voice may provide a running commentary on a person’s actions or thoughts; there may be two or more voices talking to each other or a single voice that commands a person to do things such as pray out loud or hide in the basement.

Delusions are false beliefs and may take on a bizarre quality such as believing one is from another planet or that one has two heads. Common categories of delusions include the following:

- Paranoid (believing one is being tracked by the CIA, is the victim of a communist plot, etc.)
- Grandiose (believing one is the president, a rock star, a religious prophet, etc.)
- Referential (believing that a song on the radio or popular novel is about oneself, etc.)
- Thought broadcasting (believing that one’s thoughts are broadcasting out loud so that others can hear them)
- Somatic (believing one’s teeth are soft or loose, that one’s body is shrinking, etc.)

Negative Symptoms

Negative symptoms include flat affect (facial expressions of emotion are absent), alogia or poverty of speech (fluency and amount of speech are markedly reduced), avolition or lack of motivation or drive (decreased ability to initiate and continue goal-directed behaviors, little interest in any activity), anhedonia (loss of ability to feel pleasure, emptiness), anergia (lack of energy), and asociality (social isolation and withdrawal).

Associated Symptoms or Features

Other symptoms often found in schizophrenia include cognitive dysfunction (e.g., impaired memory, executive functioning, concentration, abstract thinking, etc.), inappropriate affect, dysphoric or depressed mood, anxiety, odd psychomotor activities (e.g., rocking, pacing), odd mannerisms or behaviors, and sleep disturbances. Common comorbid conditions include substance abuse, anxiety disorders, personality disorders, and other medical conditions/illnesses. It is important to note that treatment noncompliance is very common and further complicates the clinical picture of schizophrenia. It has been reported that 75% of individuals with schizophrenia stop taking their medication within 2 years of leaving a hospital or treatment program, which greatly increases the risk of relapse and rehospitalization (Weiden et al., 1994).

Treatment Phases of Schizophrenia

There is no cure for schizophrenia. Treatment involves a broad range of interventions, both pharmacotherapy and psychosocial, designed to reduce the frequency and severity of symptoms and to improve functioning. The American Psychiatric Association has established treatment guidelines for schizophrenia (APA, 1997) and has conceptualized the treatment of schizophrenia into three phases: (1) acute phase, (2) stabilization phase, and (3) stable phase.
The acute phase is characterized by florid psychosis, where an individual has severe delusions, hallucinations, negative symptoms, and disorganized thinking. Individuals in this stage are often unable to care for themselves and may be violent, homicidal, or suicidal. The goals of treatment during the acute phase are to reduce the acute symptoms and improve functioning. Clients should receive care in the least restricted environment that will preserve safety and allow for effective treatment. Treatment should include the implementation of antipsychotic medication, as well as nonpharmacologic treatments aimed at reducing stress and overstimulation and establishing a therapeutic relationship between the client and treatment team. Psychoeducation about schizophrenia should be provided at this phase to both clients and their families.

The stabilization phase typically lasts 6 months or more after the onset of the acute episode. Although the severity of the psychotic symptoms is reduced, symptoms are still present and can fluctuate in intensity. Functioning is improved, but some impairment remains. Treatment goals during the stabilization phase include minimizing stress, minimizing the likelihood of relapse, improving community functioning, and continued reduction of symptoms. During this phase, it is important to provide clients with psychoeducation regarding the importance of medication in reducing relapse. Pharmacologic interventions include the continued use of antipsychotics and other agents to reduce symptoms and relapse. The APA expressly discourages the reduction in dose or discontinuation of effective medications for at least 6 months after the resolution of the acute phase (APA, 1997). Psychotherapeutic interventions include psychoeducation, social skills training, group therapy, and prevocational training.

The stable phase is characterized by relatively stable symptoms that are less severe than those experienced during the acute phase. Residual symptoms may be more nonpsychotic in nature, such as circumstantial thoughts or speech, overvalued ideas rather than delusions, and mild to moderate negative symptoms. Treatment goals during the stable phase include optimizing functioning and quality of life, minimizing the risk of relapse, and monitoring for medication side effects. Pharmacologic interventions include maintenance therapy of effective medications (antipsychotics and others) while minimizing medication side effects. Nonpharmacologic interventions include independent living skills training, social skills training, cognitive rehabilitation, and vocational rehabilitation (APA, 1997).

Treatment Refractory Schizophrenia
A substantial portion of individuals with schizophrenia are considered treatment refractory or resistant. The criteria for treatment refractory schizophrenia are as follows: (1) persistent, moderately severe, positive symptoms; (2) at least a moderately severe illness overall; (3) poor social/occupational functioning during the last 5 years; and (4) drug refractory, that is, lack of improvement on at least two conventional antipsychotics (Kane et al., 1988). Treatment refractory individuals are often highly symptomatic, with higher rates of service use and rehospitalization. The reported prevalence rates of refractory schizophrenia range from 20% to 40% to 60% or greater when the definition of refractory is broadened to include social, vocation, and cognitive dysfunction (Prein & Cole, 1968; Hegarty et al., 1994; Essock et al., 1996). Adjunctive medications or higher antipsychotic dosing are often used in refractory individuals.

Pharmacotherapy
Antipsychotics
The expert consensus guidelines (McEvoy et al., 1999) recommend that atypical antipsychotics be employed as first-line therapies over conventional antipsychotics unless a client is having
good results with minimal side effects on a conventional agent or if the client does not take oral medications regularly (nonadherent); then a depot formulation (long-acting shot) should be used. At this time, there is one depot formulation available that is an atypical antipsychotic and several that are in the conventional antipsychotic class. Conventional antipsychotics are associated with troublesome and serious side effects such as tardive dyskinesia (abnormal, involuntary movements commonly of the mouth, face, or extremities) and extrapyramidal symptoms (restlessness, tremors, muscle contractions, and rigidity). Many atypical agents have shown equal efficacy in positive symptoms as conventional agents and superior efficacy in the treatment of negative symptoms and cognitive symptoms (McEvoy et al., 1999). The atypical agents are not without side effects. Common side effects associated with the use of atypicals include drowsiness/sedation, dry mouth, constipation, dizziness, orthostatic hypotension, nausea, extrapyramidal symptoms (but reduced in comparison with conventional antipsychotics), and weight gain.

Adjunctive Medications

Polypharmacy is becoming increasingly common in psychiatry, including the use of more than one antipsychotic agent (Stahl, 1999). The rationale for the use of multiple agents is the desire to target different neurotransmitter receptor sites thought to be part of the disease process in schizophrenia. However, there is little controlled research on the efficacy of combination therapy. Clark and colleagues (2002) examined New Hampshire Medicaid pharmaceutical claims from 1995 to 1999 and found the following information about changes in prescription practices in the treatment of schizophrenia and schizoaffective disorder: (1) prescriptions of multiple antipsychotics increased from 5.7% to 24.3%; (2) prescriptions for antidepressants increased from 18.5% to 35.6%; (3) prescriptions for antianxiety medications increased from 19.9% to 33.5%; and (4) prescriptions for mood stabilizers increased from 17.7% to 30.0%.

Anticonvulsants/Mood Stabilizers

Commonly prescribed anticonvulsants/mood stabilizers include valproate, carbamazepine, and lithium. These agents have shown some evidence of augmenting antipsychotic response, improving mood, and reducing agitation, aggression, and irritability (APA, 1997; Fein, 1998). Dosing is generally the same as the dosing that would be used in seizure or mood disorders (APA, 1997). Anticonvulsants are generally well-tolerated agents. Carbamazepine may interact with other drugs, including reducing the serum levels of antipsychotics and benzodiazepines (antianxiety medications). Common side effects of anticonvulsants include neurological symptoms (e.g., double vision, blurred vision, fatigue) and gastrointestinal distress (e.g., nausea, indigestion, vomiting, and diarrhea) (Keck & McElroy, 1998).

Antidepressants

It has been noted for many years that a large portion of people with schizophrenia exhibit depression-like symptomatology. Estimates of the prevalence of depression in this population range from 7% to 65% (Bartles & Drake, 1988; DeLisis, 1990). The expert consensus guidelines (McEvoy et al., 1999) recommend utilizing an SSRI (e.g., fluoxetine, paroxetine, sertraline, etc.) as first-line treatment. SSRIs may increase the serum concentrations of certain antipsychotics. Common side effects of SSRI treatment include gastrointestinal distress, insomnia, and sexual dysfunction (Tollefson & Rosenbaum, 1998).
Benzodiazepines/Anxiolytics

Benzodiazepines (e.g., lorazepam, diazepam, clonazepam, etc.) are often implemented during acute psychosis and may augment antipsychotic response and decrease agitation and anxiety (APA, 1997). Additionally, patients with certain motor disturbances, such as akathisia, may show improvement with the use of benzodiazepines (Siegfried et al., 2001). Generally, benzodiazepines have few drug interactions. Common side effects of benzodiazepines include sedation and drowsiness (Ballenger, 1998).

Anticholinergics

Anticholinergic medications (e.g., benzotropine mesylate, trihexyphenidyl hydrochloride, amantadine, etc.) are used to prevent and treat extrapyramidal side effects. It is commonly necessary to use anticholinergics in individuals that are prescribed conventional agents. The use of these agents should be reconsidered whenever a change in the antipsychotic dosage is made, as lower dosages may have reduced side effects (APA, 1997). Anticholinergics generally do not interact with other drugs. Side effects of anticholinergics include dry mouth, dry eyes, urinary retention, constipation, and memory disturbances (Stanilla & Simpson, 1998).

Vocational Impact of Schizophrenia

Employment is a critical aspect of reintegration into the community. In recent years, the importance of employment among individuals with schizophrenia has received renewed interest, and more supported employment programs are available. However, most people with severe and persistent mental illness remained unemployed, at a rate as high as 85% to 100% (Anthony et al., 1990; National Organization on Disability, 1998; Rosenheck et al., 2006). There are many factors that contribute to such low rates of employment, including residual positive and negative symptoms, interpersonal skills deficits, cognitive impairments, relapse, lack of appropriate vocational programs, and stigma. However, the benefits of paid employment are far reaching, including an association with total symptom improvement, lower rates of hospitalization, and decreased rates of emotional discomfort (Bell et al., 1996). Another recent study investigating the effects of paid work in individuals with schizophrenia found improvements in quality of life including increased motivation, sense of purpose, and empathy and decreased anhedonia (Bryson, Lysaker, & Bell, 2002).

Functional Limitations and Reasonable Accommodations

Functional limitations will vary according to the individual based on differences in symptoms (both severity and domain) and effective coping strategies. Positive symptoms can make it difficult for clients to concentrate, handle stress, and interact with others. Negative symptoms can result in lack of motivation and energy, difficulty with initiating and completing a work task, and impaired social skills. Cognitive symptoms have a negative impact on concentration, attention, memory, and ability to problem solve or learn new information. Additionally, cognitive symptoms can cause difficulties in a client’s ability to prioritize, filter out irrelevant information, and function socially.

Reasonable accommodations for clients with schizophrenia will vary according to individual needs and may change over time. Typically accommodations are not costly, as they are not usually structural. Common categories of accommodations (Manusco, 1990; Pratt et al., 1999) include the following:

- Human assistance (e.g., job coach, additional training, coworker mentoring)
- Changes to the physical environment (e.g., room dividers to decrease distractions or enclosed office space)
Changes in workplace policy (e.g., job sharing, job restructuring, schedule flexibility to accommodate medical/therapy/rehabilitation appointments)
Changes in workplace communication (e.g., putting all work requests in writing, scheduling daily planning sessions to develop hourly goals)

Vocational Programs

Vocational program models include clubhouse programs, transitional employment, agency-sponsored or consumer-operated businesses, and supported employment. A review of 17 studies of various employment programs found supported employment to have the best outcomes, with 58% of individuals in supported employment obtaining jobs, compared with a rate of 21% of individuals in traditional programs (Bond et al., 1997). A more recent multisite, randomized trial found similar results where participants in supported employment were more likely to find competitive employment than those in the service as usual programs (55% vs. 34%, p <.001), and they were more likely to work 40 or more hours in a given month and earn more money (Cook et al., 2005). The basic tenet of supported employment is that any client can hold a job in the competitive workforce if provided the proper supports. Important features of supported employment include integration with treatment; client choice; ongoing, time-unlimited supports on- or off-site; and integrated settings.

Costs of Schizophrenia

It is estimated that schizophrenia costs the United States about $32.5 billion per year (NIMH, 2003a). When measured in disability adjusted life years (DALYs), the impairment of active psychosis is equal to tetraplegia (quadriplegia) (NIMH, 2003b). The largest portion of the cost of schizophrenia is generated from hospitalizations for initial episodes and relapses (Thieda et al., 2003). Half of the relapses are a result of medication nonadherence, and the other half are due to lack of treatment efficacy (Weiden & Olfson, 1995). Decreasing hospitalization rates and utilizing outpatient programs instead of inpatient treatment could reduce the economic burden of schizophrenia. One older study found that intensive outpatient treatment resulted in a savings in hospital costs of about $8000 per client (Dickstein et al., 1988). This program resulted in annual savings of $272,767, based on reductions in hospitalization rates.

Since atypical antipsychotics came onto the market, there has been evidence that treating individuals with schizophrenia with these newer agents instead of conventional antipsychotics can help reduce overall costs, despite the fact that the initial costs of the atypical agents are significantly higher than conventional drugs (Davies et al., 1998; Finley et al., 1998; Palmer et al., 1998; Hamilton et al., 1999). A review of 22 studies found that in most cases, the atypical antipsychotics were at least cost-neutral and may be cost-effective when compared with conventional agents (Hudson et al., 2003). However, the National Institute of Mental Health recently published a study finding similar efficacy of a conventional antipsychotic (perphenazine) with several atypical antipsychotics (risperidone, ziprasidone, quetiapine) (Lieberman et al., 2005). In this study, one atypical antipsychotic (olanzapine) did have better outcomes in terms of efficacy than the conventional agent. It is important to note that overall a majority of the individuals in this study (74%) discontinued their assigned antipsychotic before 18 months, which was included as part of the outcomes measure (Lieberman et al., 2005). Additionally, it is notable that this trial does not include all of the atypical antipsychotics. Clearly, more investigation is needed to better quantify the cost-effectiveness, efficacy, and quality-of-life benefits of the atypical antipsychotics in comparison with the older agents.
Case Study

John is a 40-year-old single man who was diagnosed with schizophrenia at the age of 17. He has been hospitalized five times and attempted suicide at the age of 20. His primary symptoms include auditory hallucinations and delusions. The voices he hears often instruct him to do things such as “Don’t go outside!” or “Don’t eat that food, it’s poisoned!” His delusions are mostly of a paranoid nature. He believes that he is monitored by the CIA through a chip implanted in his ear. When he walks down the street, he feels like others are staring at him. Sometimes he thinks that people are speaking in code about him at the supermarket. John also has a lack of motivation and drive. On a bad day, he stays on the couch for hours, barely moving. He sometimes has difficulty keeping up his hygiene. John often has trouble with his concentration and memory. To overcome this, he carries a small notebook with him everywhere he goes to remind him of things he needs to do such as appointments, grocery shopping, and laundry.

John takes many medications on a daily basis and requires the use of a medication organization box to keep track of them. Despite this, sometimes he still forgets his medication. John occasionally has delusions about his medications, believing that they are poisoned or hurting his body in some way. He sees his psychiatrist once a month for medication management. He also attends individual and group therapy once a week. John has received social skills training, psychoeducation, and vocational counseling in the past. He lives independently with a roommate. Previously, he lived in a group home.

Although he had his first break at 17, John did complete high school. He has not had any other formal education. His work history is sporadic, with long periods of unemployment. He has worked as a grocery bagger, stocker, fast-food worker, pizza deliverer, and landscaper. He has morning sedation from his medications and is often late if he has to be at work before 11:00 a.m. His chronic lateness resulted in several job terminations. John is currently unemployed but wants to work. He wants to try vocational counseling again because he is having a hard time finding a job on his own.

John receives Social Security Disability Insurance (SSDI) payments and has Medicare. His parents also contribute substantially to his living costs. John's parents want funds set up for when they are deceased, so that John will continue to receive appropriate treatment. They want to hire a life care planner to help them create these plans. Table 16.1 provides a sample life care plan for schizophrenia based on the format published in Deutsch and Sawyer (2004).

Table 16.1 Example Life Care Plan for John for Estate Planning

<table>
<thead>
<tr>
<th>Description</th>
<th>Purpose</th>
<th>Frequency/ Duration</th>
<th>Costs per Visit</th>
<th>Costs per Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychiatry</td>
<td>Medication management</td>
<td>Minimum of 1 time/month to life (may be 1 time/week during acute phase)</td>
<td>$100–175</td>
<td>$1200–2100</td>
</tr>
<tr>
<td>Dentist/teeth cleaning</td>
<td>Many psychotropic medications cause dry mouth, which may lead to dental problems</td>
<td>2 times/year to life</td>
<td>$90</td>
<td>$180</td>
</tr>
</tbody>
</table>
### Primary care physician/general medical care

Monitoring of overall health; increased prevalence of comorbid conditions such as obesity, hypertension, insulin resistance, diabetes, STDs

| 1 time/year, average | $150–300 (depending on tests required, does not include lab fees) | $150–300 |

### Psychotherapeutic Interventions

<table>
<thead>
<tr>
<th>Therapy</th>
<th>Age/Year Initiated</th>
<th>Age/Year Discontinued</th>
<th>Treatment Frequency</th>
<th>Base Cost per Session</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual</td>
<td>1985</td>
<td>Lifetime</td>
<td>1 time/week for 6 months (stabilization phase), then 1–2 times/month average</td>
<td>$100/session</td>
</tr>
<tr>
<td>Group</td>
<td>1985</td>
<td>Expect lifetime</td>
<td>1 time/week up to 6 months (stabilization), then 1–2 times/month average</td>
<td>$60/session</td>
</tr>
<tr>
<td>Psychoeducation</td>
<td>1985 as needed</td>
<td>Expect 6 months, then unknown</td>
<td>2 times/month for 6 months; follow-up sessions as needed</td>
<td>$40/session</td>
</tr>
<tr>
<td>Social skills training, group format</td>
<td>Age of onset/stabilization phase/as needed</td>
<td>Expect 6 months, then unknown</td>
<td>1 time/week during the stabilization phase, then less frequent depending on symptoms, level of social dysfunction, and ability to learn new skills</td>
<td>$40/session</td>
</tr>
<tr>
<td>Case management</td>
<td>Age of onset/stabilization phase</td>
<td>Expect 6 months, then unknown</td>
<td>1 time/week during stabilization phase, then less frequent</td>
<td>$65/session</td>
</tr>
</tbody>
</table>

(Continued)
<table>
<thead>
<tr>
<th>Medication/Supply Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Medication/Supply</strong></td>
</tr>
</tbody>
</table>
| Antipsychotic | 1985 | Lifetime | Atypical = $300–650/month  
Conventional = $100–150/month |
| Anticonvulsant/mood stabilizer | 2003 | May be lifetime | $165–300/month  
Lab costs = $100–150/lab |
| Antidepressant | 1988 | Minimum 9 months, then reevaluate | $30–250/month, then unknown |
| Benzodiazepine | 2003 | 6 months, then reevaluate | $25–150/month |
| Anticholinergic | In conjunction with conventional antipsychotic, possibly with atypical antipsychotic | Unknown, dependent on symptoms | $20–150/month |
| Medication organizer | Age of onset | Lifetime | Nominal (about $5); replace as needed |

### Acute and Facility Care

<table>
<thead>
<tr>
<th>Facility Description</th>
<th>Description/Purpose</th>
<th>Length of Treatment</th>
<th>Costs per Day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospitalization</td>
<td>Inpatient treatment; indicated if individual is a threat to himself or others; initiate medications and provide stabilization</td>
<td>Expect 2–4 weeks for stabilization; additional hospitalizations may be indicated in future</td>
<td>$700+/day</td>
</tr>
<tr>
<td>Option 1 Residential treatment</td>
<td>Supervised housing + day treatment; indicated if individual is unable to complete activities of daily living (including taking medications as prescribed) without high level of assistance</td>
<td>Same as above</td>
<td>$500+/day</td>
</tr>
<tr>
<td>Option 2 Partial hospitalization/day treatment</td>
<td>Day treatment; does not include housing; indicated if individual needs increased daily structure</td>
<td>Same as above</td>
<td>$250+/day</td>
</tr>
<tr>
<td>Option 3 Group home</td>
<td>Living quarters and meals; no treatment is provided</td>
<td>Same as above</td>
<td>$45+/day</td>
</tr>
</tbody>
</table>
### Diagnostic Testing

<table>
<thead>
<tr>
<th>Diagnostic Recommendation</th>
<th>Age/Year Initiated</th>
<th>Age/Year Discontinued</th>
<th>Frequency</th>
<th>Base Cost per Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>MRI (brain)</td>
<td>2008</td>
<td>2008</td>
<td>Expect 1 time only</td>
<td>$2000</td>
</tr>
<tr>
<td>Psychological evaluation/ testing</td>
<td>2008</td>
<td>2008</td>
<td>Expect 1 time only</td>
<td>$400–600</td>
</tr>
</tbody>
</table>

### Vocational/Education Plan

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Age/Year Initiated</th>
<th>Age/Year Discontinued</th>
<th>Frequency</th>
<th>Costs per Session</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vocational counseling</td>
<td>2008</td>
<td>2009</td>
<td>1–2 times/week average, 48 weeks</td>
<td>$75/session</td>
</tr>
<tr>
<td>Vocational testing</td>
<td>2008</td>
<td>2008</td>
<td>1 time only</td>
<td>$750</td>
</tr>
<tr>
<td>Supported employment—may include job coaching, telephone contact, workplace visits, and meetings with employer</td>
<td>2008</td>
<td>2008</td>
<td>2 sessions or more per week, for 48 weeks, then less frequent as indicated</td>
<td>$40–75/session</td>
</tr>
</tbody>
</table>

### Potential Complications

- Poor compliance due to side effects of medications or other factors leading to relapses and hospitalizations
- Adverse reactions to medications (e.g., drowsiness, dry mouth, constipation, dizziness, orthostatic hypotension, sedation, nausea, and weight gain)
- Job placement difficulties that require more than one occasion of support
- Loss of family support (e.g., death of one or both parents) resulting in relapse, requiring more psychological support than planned
- Movement disorders (such as tardive dyskinesia (TD) or extrapyramidal symptoms (EPS), which can be permanent and debilitating
- Dental complications from long-term use of medications

### Conclusion

It is important to understand the complexity of mental illness when creating a life care plan. Factors to consider include the expected course of illness, chronicity of symptoms, and response to treatment. The most costly treatment modality is hospitalization. Individuals with a chronic, disabling course of illness may require multiple hospitalizations or longer-term stays. Treatment
Table 16.2  Life Care Plan Checklist for Mental Illness

- Psychotherapeutic Interventions: What types of therapy will be needed? Are there family or marriage issues that need to be addressed? How complex is the treatment plan? Will a case manager be needed to coordinate care? Are support groups available? Is substance abuse present? If so, what treatments will be needed?

- Diagnostic Testing: Often other illnesses need to be ruled out before a diagnosis of mental illness is made, especially in cases where symptoms might overlap with brain abnormalities (e.g., tumors). What tests are needed to rule out other illnesses? Will a psychological battery be needed? What level of education has the individual completed? Is separate educational testing needed as well?

- Medication/Supply Needs: Medication regimens can consist of multiple medications at various dosages. Some require blood serum monitoring, which will add to the overall cost. What medications are indicated (including daily dosages and how supplied)? Are they available in generic?

- Routine Medical Care: How often will the individual need to see a psychiatrist? In what kind of treatment setting will medication management take place? Will there be regular monitoring by other staff such as nurses? Comorbid conditions are common in people with mental illness. Will annual health checks be performed by medical personal, including laboratory assessments?

- Acute and Facility Care: Is the illness at an acute stage where inpatient treatment is required? What is the expected course of illness? Are multiple hospitalizations likely? What impact do symptoms have on functioning? Is family present in the individual’s life? Is the individual capable of independent living? If not, what level of support is required?

- Vocational/Education Plan: What is the individual’s work history? What vocational services are offered in her geographical area? Has vocational potential been assessed? What are the costs of supported employment?

Nonadherence is a major issue to consider, given that it is a widespread phenomenon and is associated with poorer outcomes and higher costs.

Despite the differences among various mental illnesses in symptoms, treatment, and degree of disability, there are common areas to consider when creating a life care plan for this population. The checklist provided in Table 16.2 can help the life care planner cover the various areas required to create a plan for individuals with mental illness. Given the high costs of mental illness in both direct costs and quality-of-life issues, life care planning is definitely a needed but untapped resource.

References


Chapter 17

Life Care Planning for People with Chronic Pain*

Denise D. Lester and Robert Litwack

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Introduction

Significant pain can be experienced as a result of a multitude of medical problems. Chronic pain syndrome refers to pain that lasts more than 6 months, worsens with time, and is associated with

The most common pain complaint is associated with low back pain, an affliction experienced by 80% of the population sometime during their lifetime (Cailliet & Helberg, 1981; Moreo, 2003). Objective definitions of pain have eluded researchers (Weed, 1987). No pain literature available to these writers has been able to satisfactorily define pain objectively. Pain appears to be a subjective experience measured by self-report (Merskey, 1964, 1972; Sternbach, 1968, 1974; Engel et al., 1970; Melzack, 1973; Skinner, 1974; Fordyce, 1976; Shealy, 1976; Bresler, 1979; IASP, 1979; Ramsey, 1979). Research indicates that the pain threshold is similar from person to person and culture to culture, but pain tolerance can vary dramatically (Shealy, 1976). Sternbach (1968) has simply stated that “pain is a hurt we feel” (p. 1). It is defined by the International Association for the Study of Pain (IASP) as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage.”

Monitoring the severity and duration of pain improves patient care. It is widely accepted that pain is a complex experience involving sensory, emotional, psychological, and sociologic factors. The subjective nature of pain explains the difficulty with measurement. The same standards should not be used to measure pain in all circumstances. Alanmanour (2006) described an algorithmic approach to pain assessment varying from the basic interventional formal structured inventories. Pain tools are either unidimensional or multidimensional. The latter take into consideration the motivation and affective dimensions of pain and are typically used when there is (1) persistent acute pain, (2) mixed acute and chronic pain elements, (3) significant psychosocial dysfunction, (4) initial chronic pain evaluations, and (5) disability evaluation addressing the role of sickness impact.

A brief listing of unidimensional and multidimensional pain measurement tools would include (Ramamurthy, Alanmanou, & Rogers, 2006):

Unidimensional: Verbal Descriptor Scale, Visual Analogue Scale, Numerical Rating Scale and Pain Relief Scale

Multidimensional: McGill Pain Questionnaire, Brief Pain Inventory, Dartmouth Pain Questionnaire, the Minnesota Multiphasic Personality Inventory, West-Haven–Yale Multidimensional Pain Inventory and the Quebec Back Pain Disability Scale

The psychological and emotional impact of chronic pain varies among individuals. The impact may be severe, resulting in depression/sense of hopelessness and disruption of family and social roles.

For purposes of this chapter, chronic pain can be described as daily pain that has lasted anywhere from 6 months to 1 year after the original pain incident. Although there is controversy regarding definitions, most physicians agree that acute pain is from the date of onset to 1 month, subacute pain is defined as daily pain lasting from 1 to 6 months, and chronic pain can thereafter be defined as lasting 6 months or longer (National Institute of Disability and Rehabilitation, 1993).

Chronic pain and the subsequent costs to society, however, do not necessarily include all individuals who have had pain of some type or another for longer than a year. In general, the diagnosis of chronic pain becomes broader as it includes the psychological stress and disruption to the everyday quality of life of individuals who suffer from it. There are an estimated 30 to 40 million adults (representing 15% to 20% of the population) in this country who suffer from chronic pain (Brownlee & Schaf, 1997; Moreo, 2003). Each year millions of people seek relief at hospitals or pain clinics. The overall cost in lost workdays, medical treatment, and additional psychological counseling can be enormous. If directly related to back pain, the cost is estimated at $25 billion.
Counting back pain, migraine and headache pain, osteoarthritis, rheumatoid arthritis, fibromyalgia, failed surgical fusion lumbar or cervical spine, reflex sympathetic dystrophy, causalgia, diabetic neuropathy, and cancer pain, estimates exceed over $40 billion annually. Of the workforce, complaints of pain and related complications of pain result in one-quarter of all the sick days taken, or to put it another way, over 50 million lost workdays per year are due to pain (Beecher, 1959; Davis, 1975; Brownlee & Schaf, 1997).

The history of pain management actually probably dates back to the first known practicing doctors. It has been said that 80% of patient problems prompting a visit to a physician are the direct result of some form of pain—acute, subacute, or chronic. However, most recently, with the advent of chronic pain management programs, more comprehensive multidisciplinary team management for chronic pain and the associated disability/psychological stress/depression and subsequent functional loss have sprung up. Now there are pain management centers in nearly every major metropolitan area in the United States. Pain management has become a subspecialty recognized by the American Medical Association, and numerous societies offer continuing medical education, seminars, legislative lobbying assistance, and national boards of directors to oversee the problems associated with the disease state now classified as chronic pain. Beginning in 1911, workers’ compensation laws were enacted to require employers to assume the cost of occupational disability without regard to fault (Weed & Field, 2001). These laws have dramatically altered the recovery of the individual injured in the workforce since that time. However, additional aspects involving litigation have become more prevalent in the last 20 to 30 years. Because of litigation, an adversarial role between the workplace and the injured worker often develops.

Also of interest are the recent efforts to reduce health care costs by any and all means. Thus, again, injured workers suffering chronic pain ailments are often given little, if any, direct assistance, and anecdotally it appears that legal assistance through litigation has become necessary to allow the patient to pursue more comprehensive treatment of his or her chronic pain condition. It can be said that if a patient truly has significant chronic pain, it will disrupt every aspect of his or her life. This includes vocational as well as avocational pursuits, sleep, and routine daily activities such as dressing, bathing, hygiene, and self-care. Exercise, relationships, sexual relationships, and financial stresses will all ensue. In this way, a comprehensive approach to the treatment of the chronic pain patient embodies all the aforementioned areas, as it focuses attention on restoring the patient to a level of independence to the extent that it is possible. The long-range goal is to achieve a degree of independence of the patient from the health provider. Recent studies seem to indicate that those individuals suffering from chronic pain that are not seeing physicians or receiving constant medical attention may do better.

**Diagnostic Efforts in Workup**

The first thing necessary for any patient suffering from pain of 6 months’ duration or longer is to review what medical and psychological attention he or she has been receiving. This includes review of diagnostic evaluations, medical and psychological consultations, laboratory, radiological, and surgical intervention. It is important to ensure that indeed the patient’s diagnosis is one of a chronic painful disease rather than an untreated acute pain. In the latter, it is prudent to determine if all acceptable treatment options have been offered or failed before considering the palliative symptomatic management of a chronic painful illness. This is important because the pain pathways and pathophysiology of chronic pain is very different from acute pain, thus the acute pain signal could be alerting the patient that a serious consequence of tissue injury is imminent.
An example would be the dilemma of the acute pain syndrome known as recurrent acute angina with the propensity for a myocardial infarction requiring extensive cardiac evaluation with each episode of crushing chest pain, versus the chronic pain syndrome known as chronic intractable angina, which although has similar symptoms is typically treated palliatively. The scope of diagnostic evaluations of the patient with chronic pain is quite numerous. There are numerous pain management diagnostic and therapeutic algorithms as well as clinical practice guidelines available to the pain provider. The authors of this chapter often refer to several resources—*Decision Making in Pain Management, the International Spine Injection Society: Guidelines for Diagnostic & Therapeutic Spine Injections, and Interventional Techniques in the Management of Chronic Spinal Pain: Evidenced Based Practice Guidelines*. Typically, diagnostic strategies will depend upon the painful area to be evaluated but usually include detailed medical history (including medical record review of all previous evaluations of chronic painful disease and detailed medication history), detailed psychiatric/psychological history, comprehensive physical examination (including signs of nerve injury), laboratory review, radiological review (including magnetic resonance imaging, or MRI, of the affected area; (Note: MRI is not appropriate in all patients, e.g., those with pacemakers and/or ferromagnetic foreign bodies); computed tomography, or CT, scanning; plain-film x-rays; and/or myelograms), electromyographic muscle examinations, and nerve conduction velocity. Radiologic imaging can be overused and costly. The following diagram is an adaptation from Ramamurthy and Alvarado (2006) that simply outlines the use of radiographs in a cost-effective algorithm.

![Cost-effective imaging in chronic pain evaluation](image)

Often more invasive procedures will be necessary to support or refute a chronic painful diagnosis such as laparoscopic surgical evaluation, or diagnostic spine injections (discography, facet joint injections, nerve root injections) in the diagnosis of axial and radicular skeletal-related cervical, thoracic, or lumbar spine pain.

Occasionally multiple specialty consultations are required to achieve such thorough evaluations in our present era of medical specialties. Inclusive of this would be a psychologist for determination via psychological testing, such as with the Minnesota Multiphasic Personality Inventory or other assistive testing, to determine a patient’s psychological status as it pertains to his or her pain...
Life Care Planning for People with Chronic Pain

Evaluation of the chronic pain patient

- Medical record review
- Questionnaire
  - Medical history
  - Pharmacotherapy
  - Surgical procedures
  - Family and social history
- Interview
  - Pain description
  - Sleep, psychiatric and substance abuse history
- Physical examination
  - Neurological: gait, joint ROM*, pain reproduction
  - Pain behavior: nonorganic signs
- Investigations
  - Review prior tests: MRI, EMG, psychological
  - More tests needed
  - Differential diagnostic nerve blocks
  - Psychological: MMPI and other tests needed
- Functional evaluation: disability assessment

Anatomic
- Facet joint
discogram nerve blocks

Pharmacologic
- Placebo
local anesthetics opioids and reversals sedatives
- Pentathol, propofol

Intravenous
- Exam under sedation

Impairment
- Orthotics
- Disability

Activities of daily living
- Peripheral origin
- Nonperipheral origin

Benefits of having several specialists evaluate the patient will be that significant overlap of observations, including questionable symptom magnification with litigious patients with secondary gain in mind, will be noted from a variety of clinicians’ vantage points. Despite being a suspicious point of view to include in an evaluation of the patient with pain, it is nonetheless necessary, as certainly questions will arise later regarding the authenticity of the patient’s symptoms. Occasionally it will be difficult to show from the objective testing standpoint that pain has an organic cause that is immediately observable with the aforementioned testing (Beecher, 1959). In these instances, chronic pain management specialists can add a further backdrop from which to define and further assess the patient’s pain complaints. There are a number of sensory feedback loops to the central nervous system, including the sympathetic nervous system, bones, joints, ligaments, muscles, and, ultimately, the dermatomes of the peripheral nervous system. Despite the insurance company’s desire to be shown where the pain is coming from, many times pain resulting
from trauma does not reveal the presence of a herniated disk, fracture, or ruptured ligaments. In these instances, additional documentation or proof as to the nature of the patient's pain complaints will be required. Ramamurthy and Alvarado (2006) provided a very basic, easy-to-follow algorithm for the evaluation of the chronic pain patient. The insert is an adaptation of his algorithm.

**Approaches to Management of Pain**

Once complete reviews of all of the aforementioned diagnostic evaluations are performed, a complete list of differential pain diagnoses can be formulated. Although it would be more simple if all of the pain complaints were generated from a chronic painful illness of the same structure (e.g., a single herniated spine disc), it is more common that multiple different pain generators contribute to a single chronic pain complaint. For example, axial back pain can exist on one side of the patient's low back and the patient may fixate on his or her knowledge that he or she indeed has a herniated disc at that level—but more likely the pain is the result of a combination such as facet joint spine arthritis, with myofascial disease and possibly sacroiliac joint disease. Additionally, the pain generators may be of different pathophysiology. Using the example of chronic foot pain patients, they indeed may have neuropathic pain from nerve injury resulting from chronic diabetic ischemic foot injury—but also may have coexisting nociceptive (tissue injury) pain from arthritis of the foot bones. Identifying the type of pain pathophysiology (nerve injury pain vs. tissue injury pain) will direct the most appropriate types of pain management interventions for treatment. It is often difficult to differentiate which symptoms and signs are from which types of pain etiologies. This has led to increased referrals to pain management clinics. An anesthesiologist or physiatrist (and occasionally a neurologist or psychiatrist) with special postresidency training in pain management (pain algologist) typically manages these clinics. The pain management clinic is typically comprehensive in its evaluation and treatment of pain and often utilizes interdisciplinary specialists either by referral or directly within its clinic such as psychiatrists, psychologists, physical therapists, and social workers. The majority of these clinics function in an outpatient setting or in the confines of a local hospital. The algologist has been trained to perform diagnostic injections of local anesthetic agents into different tissue regions, thereby blocking the local neuroanatomy and allowing for the cessation of the pain symptom complex. If performed properly (with minute volumes of local anesthetic and into the correct tissue planes), the patient will have a potential pain generator numbed—and if the pain is relieved, that will indirectly alert the provider that this anesthetized structure contributes to the patient’s pain. Of note, there typically is a large placebo effect when performing injections of any type and therefore the provider often will perform two separate diagnostic injection trials with different local anesthetic duration of actions in order to be certain there is a true cause and effect relationship. Depending upon the nature of the pain, its etiology, and its potential for catastrophic bodily injury (e.g., impending spinal cord injury), the patient may require surgical intervention bypassing more conservative treatment options. The most common surgeons involved in spine ailments, including cervical and lumbar spine pain, are the neurosurgeon and the orthopedic surgeon. Specialists in these areas in most major metropolitan regions are familiar with causes and treatment of pain and will offer surgical remedies for their relief. In addition, in this setting in select patients, the pain management clinic algologist or the surgeon also offer minimally invasive spine interventions. Examples include percutaneous discectomy (the Dekompressor procedure), which is a needle aspiration of a spinal disc to decrease a symptomatic disc herniation.

Another resource for the initial treatment for chronic pain would be the less aggressive, more conservative outpatient rehabilitation or physiatrist office. In this setting, the comprehensive
nature of the pain is addressed from a number of areas, including medications, sleep restoration, diet and exercise, orthotics, physical therapy, behavioral modifications (back school), electrical stimulation devices, and other neurological diagnostic workups. The decision as to which resource to employ is often selected by the patient.

The majority of patients in the authors’ outpatient pain clinic has been injured for over a year and has already been evaluated by either a neurosurgeon or orthopedic surgeon. These patients typically have been referred to an algologist by a primary care physician or surgeon because of extensive comorbidity (e.g., significant psychiatric disease, substance abuse, or end-of-life issues) or have been unmanageable despite standard of care conservative therapy. Many of them have already undergone surgical intervention and that the algologist will evaluate and employ an interdisciplinary treatment plan. Before describing each of the specific aspects of interdisciplinary therapy, it is important to note that goal setting is the important initial step in the development of the treatment plan. Goal setting is bidirectional, meaning that both the pain provider and the patient–family unit participate in defining the goals of the interdisciplinary pain plan. These goals are very patient specific and can vary greatly from patient to patient. For example, a patient who was highly functional prior to an injury and has full brain function and mobility but cannot use his or her dominant upper extremity secondary to pain may establish goals of using that upper extremity in the future to return to work (e.g., typing, lifting, etc.) or perform activities of daily living that utilize the dominant upper extremity (e.g., dressing, brushing teeth, writing). On the other hand, a patient who has had a significant cervical spinal cord injury with tetraplegia (also known as quadriplegia) and severe spasm and pain of the lower extremities may have just the goal of enough relief of pain and spasm to accept the appropriate lower extremity positioning for urinary bladder catheterizations several times per day. Simply stated, the first case represents a highly physically functioning patient’s rehabilitation requests and goals versus the second case of little to no physical functioning rehabilitation goals. The issue of goal setting is not just for patient and provider satisfaction but also for cost-effectiveness. If the goals are not set or are unrealistic, excessive, unfounded treatments or unnecessary repeated diagnostics (e.g., MRI studies) may be provided that escalate costs and present potential harm to the patient. Goal setting is a dynamic process and must be reevaluated (and often readjusted) after the success or failure of each pain treatment.

The interdisciplinary treatment plan typically includes simultaneous introductions of medication management, interventional therapies, physical therapy, and psychosocial therapies. Medication management must take into consideration that while many medications will relieve pain and suffering for a short period, many of these medications can have inappropriate side effects or consequences when delivered over a lifetime of chronic pain. Therefore, it is of utmost importance that not only the most effective pain reliever be considered but also the most safe analgesic over the expected lifetime of the chronic disease. These authors often explain this issue to patients with the following analogy: “Inhaled anesthetic gasses can certainly relieve your pain for the short time— but would also require a ventilator and a breathing tube and therefore are not an option for your long-term pain strategies. In the same manner, high-dose injectable Ketorolac will certainly assist you with a pain exacerbation in the emergency room but would not be appropriate after more than a few days of your pain exacerbation because of bleeding risks.” The decision to utilize specific types of oral analgesics often follows specific algorithms, such as the Analgesic Ladder on the following page, adapted from the World Health Organization Pain Relief Ladder (World Health Organization, 2009).

The intervention strategies include any treatments that are not considered an oral medication, but in the algologist setting they typically refer to minimally invasive injections of nerve, muscles, or painful structures of the spine. Therapeutic injections are categorized into those that modulate
painful tissues and those that neurolyse.* Modulation of pain via therapeutic injections includes injecting local anesthetics and long-acting steroids into spine structures (e.g., epidural space, facet joints, sacroiliac joints, and spinal nerves), and injecting narcotics and other types of analgesics into various tissue planes (e.g., spinal fluids, brachial plexus, epidural space). Additionally, modulating therapeutic types of injections include all types of electrical stimulation therapies for pain including implantable spinal cord stimulators, which are electrical wires implanted into the spine to control pain. Because neurolytic injections are often irreversible, they are provided after much consideration of the risk–benefit ratio. Examples of neurolytic injections include killing with heat (radiofrequency ablation of nerves or tissues), killing with cold (cryotherapy), or killing with chemicals (alcohol, phenol, glycerol, Sarapin tissue injections). A newer minimally invasive spine procedure provided by algologists and surgeons, includes vertebral augmentation for bony spine fractures. In this technique algologists place cement or cement-like substances into the spine fracture via a needle and typically render a severe chronic pain cured with immediate resolution of pain. There are a myriad of additional interventional procedures that can assist with the therapy of chronic pain. One additional class of therapies is the implantable devices for pain. As introduced previously, these devices comprise two groups: implantable drug delivery systems (IDDS) and implantable electronic neuromodulation systems (IENS). The IDDS is a small catheter that is implanted into the spinal fluid and tunneled to the abdominal wall to a pump reservoir. This pump has a computerized motor that delivers minute amounts of opioids, local anesthetics, and

* Neurolyse: to kill tissue.
other analgesics to the spinal fluid to control pain and limit side effects. It is typically considered in a very select group of patients who have failed all conservative therapies and have a life expectancy greater than 6 months. It is costly and additionally has the risk of infection of the spine, granuloma of the spine, or pump malfunction as well so it is placed only in a very select population of patients. It is totally implantable and requires, about every 3 months, a refill through a needle puncture through the skin. The IENS is also totally implantable and is a small wire that is placed
into the epidural space and is connected to a microcomputer that is indwelling in the abdominal wall or the scapula. The patient can manipulate the amount of electricity through a remote device through the skin. Again this is a costly therapy that has its own associated risks and should only be considered after failing more conservative therapy and after several days of a trial period.

Physical therapy interventions are often felt to be the strength of any good comprehensive pain management plan. In the authors’ practice the patients are expected to continue physical therapy (aquatic based or land based) as a lifestyle to remain an active patient in the pain clinic. While this is labor intensive to monitor for compliance, it has been demonstrated that those patients who remain compliant with physical therapy continue to maintain or restore physical function and have less additive pain syndromes related to the cycle of immobility associated pain. Physical therapists may also employ other low-risk strategies such as transcutaneous electrical nerve stimulation (TENS units, which are devices that use electrical skin surface patches to remove pain), ultrasound therapy, cold, moist heat, traction, and paraffin wax therapy.

If an individual has already undergone several surgeries and a number of injections, then a physician may be reluctant to send him or her back for more invasive procedures. It is important that each patient undergo a thorough evaluation of his or her present condition to determine the etiology of the pain. If a patient’s pain has not been evaluated for 2 or more years, despite a thorough documentation of the presence of a nonoperative lesion from the past, then it is quite possible that further evaluation and diagnostic x-ray information of perhaps a new pain problem may be necessary. There are many pain management algorithms and guidelines in existence that can assist pain providers with implementing therapies in an appropriate manner. The following diagram is an adaptation from King (2006) and is an example of a cost-effective algorithmic approach to the management of low back pain.

**Life Care Planning and Chronic Pain**

Individual types of pain are especially variable and are almost beyond the scope of this short chapter. A listing of types of injuries that can result in chronic pain requiring lifetime medical care would include the following:

- Spinal cord injury: cervical, thoracic, lumbar with paraplegia, or tetraplegia (also known as quadriplegia)
- Cervical, thoracic, lumbar, or sacral spine bony traumatic injury (e.g., fractures, dislocations)
- Cervical, thoracic, lumbar, or sacral spine arthritis and degenerative disease states (e.g., degenerative disc disease, facet joint disease, spondylosis, disc herniations)
- Deafferentation pain syndromes (loss of sensation secondary to nerve injury with increased pain traffic: e.g., postherpetic neuralgia, phantom syndromes, post thoracotomy syndrome, diabetic neuropathies, HIV neuropathy, alcohol neuropathy, multiple sclerosis, central pain)
- Central nervous system and spinal cord infarctions (post stroke pain)
- Neuropathy (peripheral neuropathies, plexus neuropathies, cranial nerve neuropathies)
- Complex regional pain syndromes type 1 (reflex sympathetic dystrophy)
- Chronic regional pain syndrome type 2 (causalgia)
- Multiple orthopedic fractures and subsequent claudication injuries
- Cancer of any organ or any tissue type
- Traumatic brain injury
- Abdominal problems (e.g., inflammatory bowel disease, Crohn’s disease, chronic pancreatitis)
Genital/urinary problems (e.g., interstitial cystitis)
- Pulmonary problems
- Osteoarthritis
- Rheumatoid arthritis
- Systemic lupus erythematosus
- Fibromyalgia
- Trigeminal neuralgia
- Motor vehicle accidents
- Failed spinal surgeries
- Orthopedic joint replacement surgery, including hip and knee surgeries
- Vascular injuries, including angina
- Peripheral vascular injuries
- Peripheral vascular ischemia with crush injuries
- Headaches, including migraine, cluster, and tension headaches
- Pelvic inflammatory disease
- Environmental toxins and exposure

The medical needs and future care for these conditions run the gamut and require a coordinated effort of services that are individually determined. Some of the considerations include the following.

Psychological Considerations

In the comprehensive management of chronic pain, psychological testing and treatment for depression, anxiety, and stress are all components required for maximum improvement. All chronic pain patients should have psychological counseling and psychological testing somewhere in the course of their pain diagnosis or management. The family will also require assistance in coping with the patient’s pain problems, as it is very disruptive to the normal activities of family life following an injury or illness that causes chronic pain. Depending upon when the life care planner becomes involved in the case, an evaluation by a psychologist is commonly recommended, as well as subsequent further recommendations of biofeedback and stress management on a weekly basis for at least 1 year to improve the patient’s ability to initiate and maintain a program that will benefit him or her for the lifetime of the complaint.

There are numerous additional resources from which the chronic pain patient can draw. Self-help groups and certain newsletters are available for individual diseases that the patient can access through the Internet. Local chapters, usually located by Internet searches, of the larger disease diagnoses that cause chronic pain may be available. These include rheumatoid arthritis foundation groups, fibromyalgia groups, spinal cord injury and recovery groups, brain injury recovery groups, multiple sclerosis groups, local diabetes foundations, and others.

It should be noted that self-treatment through alcohol or illicit drug use is a common feature of our society, which probably increases with the advent of chronic pain. Recently, additional guidelines have been released by the American Academy of Pain Medicine (www.painmed.org), the World Institute of Pain (www.-iapsar.org/WIP/WIP-base.htm), and the American Academy of Pain Management (www.aapainmanage.org). All entities now recognize the therapeutic use of chronic narcotic analgesia for chronic pain. However, medical societies in local as well as state medical boards are concerned about the use of chronic narcotic analgesia for chronic pain. This view seems to reflect our fears of addiction and the subsequent costs and problems that addiction has caused in our society. As this may be a national resource book for life care planning, it...
is likely that the reader may find in his or her locality a remaining bias toward the avoidance of use of chronic narcotic analgesia for the treatment of chronic pain. The following two diagrams from Marrero (2006) and Alanmanou (2006) demonstrate algorithmic approaches to concerns of addiction and decisions regarding opioids analgesia implementation.

Multidisciplinary pain programs that employ psychologists, social workers, anesthesiologists, orthopedic surgeons, neurosurgeons, neuropsychologists, physiatrists, and allied health professionals are often quite familiar with the local political flavor of the area and will be one of the better resources in determining what a patient’s needs are in general, as well as giving him an understanding of what the trends throughout the nation are at that time.

**Opioids in noncancer pain**

Oral: first choice  
Alternate route: second choice

Add adjuvants early  
Treat side effects

Relief?

Yes  
No relief or intolerable side effects

Periodic reassessment  
Opoid rotation

Relief  
No relief

Periodic reassessment  
Other approaches to manage pain
Additional Considerations for Chronic Pain Management

As mentioned previously, a multidisciplinary team is the best resource for thorough and comprehensive management of chronic pain. Typically the needs of the patient will require five or six comprehensive measures to maximize the outcome of the patient's ability to manage his or her own condition after a period of 6 months to a year. Most outpatient treatment of a chronic pain patient will result in a very brief 1- to 2-month period of intense evaluation and management followed by a middle period of 3 to 6 months of continued weekly monitoring or monthly monitoring and establishing of a management program that will fit the patient's needs. Biofeedback, stress management, counseling, psychological testing, and family counseling will be included. Additional areas for maximizing the patient's independence will include diet, weight loss, and exercise. Normally, most patients with chronic pain have a hard time functioning in the upright position and the normal gravity environment. For that reason, exercise programs, especially ones employing a pool, are very popular and quite prevalent and seem to best suit the needs of the chronic pain exercise program prescription.

A six-step comprehensive program in the treatment of chronic pain patients has been published in the prior edition of this text and is included below. Note that this program occurs in the rehabilitation setting, since the majority of the patients seen in this setting have already undergone pain clinic and surgical options. A comprehensive, conservative chronic pain management program would consist of the following areas:

- **Exercise:** A program including a pool for both strength conditioning and checking the effects of the central nervous system related to exercise with serotonin and norepinephrine release. Additional cardiovascular and pulmonary conditioning for weight-loss assistance is also a key element.

- **Diet:** A thorough review is usually achieved with a dietary journal kept by the patient for 2 weeks. After the journal is reviewed, recommendations are made with specific restrictions of foods that are clearly harmful to the patient's diet. For additional help with diet, reading materials and instructions are added for food selection, and a basic understanding of carbohydrates, fats, and protein is taught. Subsequently, the patient's weight is taken on a weekly basis for his next several visits and further assistance and encouragement are given.

- **Sleep restoration:** Patients cannot handle the daily stress of chronic pain without adequate sleep. Sleep achieves a degree of relaxation and resets the thermostat of the central nervous system. Deep sleep has also been shown to be the period in which growth hormone is released and significant tissue repair and restorative processes take place. Paradoxically, deep sleep is often shortened in the chronic pain patients, and very often the sleep additive medications paradoxically decrease deep sleep as well. The sleep-deprived patient will have more difficulty responding to minute-to-minute changes in his or her day and thereby will be much less adaptable to his or her chronic pain condition than those who are sleeping through the night. Pharmacological agents for this are often needed to restore the patient to a restful night's sleep. Of note, several studies suggest that psychological strategies (e.g., progressive relaxation) for managing the insomnia of the chronic pain patient are more effective than most prescribed sleep agents. Additional concerns would be for patients who have sleep apnea or other obstructive forms of sleep disturbance, which may require expensive equipment (BiPAP devices) to remedy the insomnia. Sleep centers are usually run and directed by a pulmonologist or neurologist and are available in most metropolitan areas. These physician authors have used these clinics as an assistive consultation in helping the patient return to a more restful night's sleep.
Pharmacological agents: The recitation of all medications that are prescribed and used in current pain management would be beyond the scope of this short chapter. There are five basic categories:
- Antidepressants for pain relief (e.g., Duloxetine, Amitriptyline, Nortriptyline) and anxiolytics.
- Medications for the resolution of nerve pain, which consist of Pregabulin, Gabapentin, Tegretol, Dilantin, and Depakote.
- Muscle relaxants, consisting of Soma, Skelaxin, Robaxin, Flexeril, Baclofen.
- Nonsteroidal antiinflammatory drugs (NSAIDs) or other non-narcotic analgesics that also assist with the reduction in inflammatory joint changes. These would consist of ibuprofen (Advil, Motrin, and others), Releve, Relafen, Oravail, Tramadol, etc.
- Narcotic analgesia. This would depend on efforts of resolving the pain from all other measures and would follow the World Health Organization ladder to analgesics (previously cited in this chapter). Examples include Methadone, Oxycodone, Morphine, Fentanyl Patch, Levorphanol, etc.
- Side effects. All of these commonly have side effects that affect patient compliance and comfort. For example, NSAIDs can cause gastrointestinal upset, ulcers, and liver and kidney damage. Opioids often result in physical dependence and cause dizziness, fatigue, concentration impairments, drowsiness, nausea, impaired vision, and constipation. Also, some of the newer medications can reach $100,000 per year in cost.

Physical therapy and outpatient modalities: Usually patients who have chronic pain also have a sedentary lifestyle as a consequence of trying to avoid pain. A brief burst of physical therapy for 2 to 4 weeks following the intake of a new patient may prove useful. This is usually aimed at providing the modality that may have already been used in other efforts of physical therapy. The difference with the use of physical therapy at this time is to try other physical therapy prescriptions and also to allow patients the use of transcutaneous electric nerve stimulation (TENS) or percutaneous electrical stimulation (PES) units, or other locally available stimulation units to attempt to decrease their pain. Further sessions of physical therapy throughout the course of the patient’s lifetime may also be necessary depending upon brief or prolonged periods of inactivity, which will result in a loss of strength and function. In general, the nature of the comprehensive, conservative measures implemented for chronic pain management attempts to keep the patient from losing significant degrees of function for prolonged periods of time by instituting an exercise program. Nonetheless, a once-per-year physical therapy evaluation may be necessary to forestall more remedial forms of functional loss.

For back pain and other selected central-nervous-system-generated pain, injections into the spinal canal area can provide relief, but often must be repeated regularly and can cause numerous side effects (e.g., nausea, vomiting, headache, transient weight gain, and infections).

Orthotics and other adaptive equipment: These products can usually be procured at the local orthotics or prosthetist or durable medical equipment supplier. There are a number of self-care adaptive aids, such as long-handled reachers, button hooks, and assistive devices for eating, grooming, and daily household tasks. In addition, under this heading would fall the grouping of spinal orthoses such as cervical pillows or orthopedic braces for sleeping and comfort in sitting, driving, walking, and moving about. From this standpoint, electric mobility devices, power chairs, assistive bathing devices, and personalized aids could all be considered for prescription. Throughout it should be mentioned that the patient’s condition is not presumed to be static. Occasional retesting and obtaining x-rays and, in some cases, other surgical, neurosurgical, or orthopedic surgery interventions may be required.
In addition to the previously listed items, various surgical options may be available for structurally identifiable reasons and well-selected patients. Intrathecal morphine pumps, spinal cord stimulators, and repeat surgery are examples. However, there are high failure rates, and costs are substantial (Moreo, 2003). Spinal fusions can total $18,000 to $25,000. Implanted pumps can cost $15,000 to $32,000 for the surgery, an average of $300 per month for medication and other follow-up charges, and $10,000 to $21,000 for pump replacement. Spinal cord stimulation initially can be expected to reach $15,000 to $20,000 or more, and then another $2500 per year for follow-up.

**Determining Patient's Functioning Level**

The patient’s needs, at the time of intake as a chronic pain patient and throughout life, can be ascertained most effectively through an outside source of local physical therapy where functional capacity evaluations are performed. A functional capacity evaluation (FCE) (also referred to as a physical capacity assessment) is usually an 8-hour assessment that is typically performed over a 2-day period. During this assessment the patient’s autonomic functions are evaluated, including heart rate, respiratory rate, and skin temperature. Other measurements, such as a visual analog scale of pain, may also be performed.

The majority of the testing includes performance of a variety of tasks that are observed and are also repeated in a number of different fashions to ascertain the patient’s reliability from one task to the next. Typically, insurance companies and other health care providers will request these, as will the workplace at the time of a patient’s disability. They are useful for disability determination, but are typically not adequate for disability rating. Disability ratings come under a different evaluation. Many times the consultants who have been working with the patient throughout the months are not capable or are not interested in performing disability evaluations. Determining individuals who are willing and capable to perform these assessments can be the source of difficulty in bringing the patient’s legal problems to a close. The reader should be aware that the validity of FCE results has been challenged, particularly in litigation settings, and the value of the results may be only as good as the equipment used and the evaluator’s expertise (King et al., 1998).

**Life Care Planning and Chronic Pain and Future Concerns**

In making preparations in the life care plan for the needs of a patient with chronic pain, it becomes necessary to take into consideration all of the measures listed previously. To this end, identifying someone who will follow the patient and participate in a comprehensive chronic pain management multidisciplinary team approach is preferred. If, however, that is not possible, then the needs from a chronic pain future life care plan would include all of the steps mentioned in the evaluation and treatment of a chronic pain patient at the initial intake. It should be noted that from a chronic pain standpoint, efforts are directed at making the individual with chronic pain self-reliant and avoiding constant medical intervention. Although this is the desired outcome, it is very time-consuming to achieve this goal, and as with any long-term disease problem, it becomes necessary for routine reevaluations and upgrades in the individual program. Cost estimates for chronic pain include medication and equipment repair and replacement, and 1- to 2-year reevaluations with x-rays, blood work, and consultations of the individual specialists will be necessary. It may also be necessary to include physical therapy and psychological counseling reevaluations. As the patient with chronic pain ages, additional evaluations and treatments with upgrades in equipment and possible surgical interventions may also be required. It once again becomes necessary to include in
an exhaustive fashion a comprehensive listing of the patient's problems and some future prognosis as to the deterioration of these diagnostic considerations.

**Case Study**

The following example is a life care plan for a patient in the authors' clinic who traumatized her lower limbs after a massive saddle pulmonary embolus led to ischemic injury of both her lower limbs while she was on active military duty. This trauma eventually led to the development of complex regional pain syndrome type 1, and over time involved all four extremities. Initial attempts at conservative treatment and surgery were accomplished on several occasions with poor results over the years. Additionally, a multitude of pain specialists from a variety of disciplines (neurosurgery, anesthesiology, physiatry, neurology, and orthopedics) were consulted, and diagnostic and treatment strategies were implemented. Attempts at aggressive physical therapy typically failed because the patient was so hyperesthetic and dysesthetic to light touch in all four extremities. Her baseline pain management consisted of combinations of opioid medications, adjunctive antidepressant and anticonvulsant medications, physical therapy and psychotherapeutic strategies. She was referred to a specialist for a dorsal column stimulator, which failed to provide long-term relief. The patient had received mixed risk recommendations regarding spinal fluid pump placement because she required extensive anticoagulation. She later decided to defer that option of treatment for risk of spinal hematoma and worsening paralysis. At the time of the plan, she was completely a functional paraplegic requiring an electric wheelchair, and she remained essentially nonfunctional and did not drive, work, or clean her home. Her bed was relocated to the living room to avoid stairs or excessive movement. Her husband was supportive and actively assisted in her rehabilitation efforts.

**Life Care Plan**

*Jane Doe*

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## Life Care Plan

**Client Name:** Jane Doe  
**Date of Birth:** 1/1/62  
**Date of Injury:** 7/7/2005  
**Date Prepared:** 8/27/2007

### Projected Therapeutic Modalities

<table>
<thead>
<tr>
<th>Therapy</th>
<th>Age/Year at Which Initiated</th>
<th>Age/Year at Which Suspended</th>
<th>Treatment Frequency</th>
<th>Base Cost per Year</th>
<th>Growth Trends</th>
<th>Recommended by</th>
</tr>
</thead>
</table>
| Pain support group; individual, couples, and crisis therapy; medication supervision | 43/2005 | Life expectancy | Group at $50/week for 48 therapeutic weeks. Individual at $125, 1 to 2 times/week for 2½ yrs., then 25 sessions/year (average) for life expectancy | $2400 (group)  
$6000–12,000 (individual)  
$3125 year to life expectancy | To be determined by economist | Dr. Lester and Dr. Litwack |
| Pain management program | 43/2005 | 43/2005 | 3½ weeks | $7000–8000 | To be determined by economist | Dr. Lester and Dr. Litwack |
| Occupational therapy; included as part of inpatient pain program | 43/2005 | 3–4 months | 2 times per week, 1 hour per session as part of pain program | See pain program above | N/A | Dr. Lester and Dr. Litwack |
| Physical therapy | 43/2005 | 3–4 months | 2 times per week, 1 hour per session following pain program | $1920–3200 at $80–100/hour | To be determined by economist | Dr. Lester and Dr. Litwack |

**Source:** Format reproduced with permission of Dr. Paul M. Deutsch. Adapted from the *Guide to Rehabilitation.* LCare_2_DOC
### Diagnostic Testing/Educational Assessment

<table>
<thead>
<tr>
<th>Diagnostic Recommendation</th>
<th>Age/Year at Which Initiated</th>
<th>Age/Year at Which Suspended</th>
<th>Per Year Frequency</th>
<th>Base Cost per Year</th>
<th>Growth Trends</th>
<th>Recommended by</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological testing, IQ and psychological status testing</td>
<td>43/2005</td>
<td>43/2005</td>
<td>Psychological evaluation</td>
<td>$500–600</td>
<td>To be determined by economist</td>
<td>Dr. Lester and Dr. Litwack</td>
</tr>
</tbody>
</table>
| Laboratory studies:  
(1) Opioid compliance  
(2) Assessment of therapeutic window for adjunctive analgesics | 43/2005                    | Lifetime                     | 4 times per year | $600/year | To be determined by economist | Dr. Lester and Dr. Litwack |
| Radiologic studies: MRIs | 43/2005                    | Lifetime                     | Range 1/year to 1 X every 4 years and as clinically appropriate | $5000 total | To be determined by economist | Dr. Lester and Dr. Litwack |

### Wheelchair Needs

<table>
<thead>
<tr>
<th>Wheelchair Type</th>
<th>Age/Year at Which Purchased</th>
<th>Replacement Schedule</th>
<th>Purpose of Equipment</th>
<th>Base Cost</th>
<th>Growth Trends</th>
<th>Catalog or Supplier Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Three-wheel power chair, rear-wheel drive (e.g., Pride)</td>
<td>43/2005</td>
<td>Every 5 years</td>
<td>Mobility, independence, and avoiding complications</td>
<td>$3000–3500</td>
<td>To be determined by economist</td>
<td>Adaptive Equipment Specialists</td>
</tr>
<tr>
<td>Wheelchair Accessories and Maintenance</td>
<td>Age/Year at Which Purchased</td>
<td>Replacement Schedule</td>
<td>Purpose</td>
<td>Base Cost</td>
<td>Growth Trends</td>
<td>Catalog or Supplier Reference</td>
</tr>
<tr>
<td>----------------------------------------</td>
<td>-----------------------------</td>
<td>----------------------</td>
<td>---------</td>
<td>-----------</td>
<td>--------------</td>
<td>-------------------------------</td>
</tr>
<tr>
<td>Maintenance, carry bags, wheelchair batteries, and charger</td>
<td>43/2005</td>
<td>Yearly</td>
<td>Maintenance and supplies</td>
<td>$100/year average</td>
<td>To be determined by economist</td>
<td>Sammons-Preston</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Aids for Independent Function</th>
<th>Age/Year at Which Purchased</th>
<th>Replacement Schedule</th>
<th>Equipment Purpose</th>
<th>Base Cost</th>
<th>Growth Trends</th>
<th>Catalog or Supplier Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reachers or other aids</td>
<td>43/2005</td>
<td>Yearly</td>
<td>Aides for independent functioning</td>
<td>$50/year average</td>
<td>To be determined by economist</td>
<td>Sammons-Preston or other supplier</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Orthotics/Prosthetics</th>
<th>Age/Year at Which Purchased</th>
<th>Replacement Schedule</th>
<th>Equipment Purpose</th>
<th>Base Cost</th>
<th>Growth Trends</th>
<th>Supplier</th>
</tr>
</thead>
<tbody>
<tr>
<td>Right leg ankle/ foot orthosis Straps</td>
<td>43/2005</td>
<td>Every 3 years</td>
<td>Support body weight, avoid falls, reduce complications Attach ankle-foot orthosis (AFO) to leg</td>
<td>$406.64</td>
<td>To be determined by economist</td>
<td>Butte Limb and Brace</td>
</tr>
<tr>
<td></td>
<td>44/2006</td>
<td>Every 8–12 months</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Drug/Supply Needs</th>
<th>Drug (Prescription)</th>
<th>Purpose</th>
<th>Per Unit Cost</th>
<th>Per Year Cost</th>
<th>Growth Trends</th>
<th>Recommended by</th>
</tr>
</thead>
<tbody>
<tr>
<td>Methadone, 10 mg, 3 times/day Ativan, 2 mg, 3 times/day</td>
<td>Pain control Antianxiety</td>
<td>$9.76/30 $12.62/90</td>
<td>$356 $153 Total = $509</td>
<td>To be determined by economist</td>
<td>Dr. Lester and Dr. Litwack</td>
<td></td>
</tr>
</tbody>
</table>

Note: Medications listed are representative of current and future needs. Specific prescriptions may change.
### Home/Facility Care

<table>
<thead>
<tr>
<th>Facility Recommendation</th>
<th>Home Care/Service Recommendations</th>
<th>Age/Year at Which Initiated</th>
<th>Age/Year at Which Suspended</th>
<th>Hours/Shifts/Days of Attendance or Care</th>
<th>Base Cost per Year</th>
<th>Growth Trends</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Companion, psychological support, aide, and house maintenance</td>
<td>2005</td>
<td>Life expectancy</td>
<td>Husband performs these functions; expect 2 days/week at $36/day if hired</td>
<td>$0 if continued marriage or $3744/year if hired</td>
<td>To be determined by economist</td>
</tr>
</tbody>
</table>

### Future Medical Care—Routine

<table>
<thead>
<tr>
<th>Routine Medical Care Description</th>
<th>Frequency of Visits</th>
<th>Purpose</th>
<th>Cost per Visit</th>
<th>Cost per Year</th>
<th>Growth Trends</th>
<th>Recommended by</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychiatrist follow-up</td>
<td>As needed</td>
<td>Review of medications</td>
<td>See projected therapeutic modalities</td>
<td>N/A</td>
<td>N/A</td>
<td>Dr. Lester and Dr. Litwack</td>
</tr>
<tr>
<td>Neurological/orthopedic follow-up (not including x-ray, lab, or other diagnostic costs, e.g., MRI = $1000–1200)</td>
<td>1 time/year to life expectancy</td>
<td>Prescribe braces, follow-up to back surgery, and prevent complications</td>
<td>$100 (average)</td>
<td>$100/year (average)</td>
<td>To be determined by economist</td>
<td>Dr. Lester and Dr. Litwack</td>
</tr>
</tbody>
</table>

### Transportation

<table>
<thead>
<tr>
<th>Equipment Description</th>
<th>Age/Year at Which Purchased</th>
<th>Replacement Schedule</th>
<th>Equipment Purpose</th>
<th>Base Cost</th>
<th>Growth Trends</th>
<th>Catalog or Supplier Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Option 1</td>
<td>43/2005</td>
<td>Every 5–7 years (trade-in value to be determined by economist)</td>
<td>Mobility and independence</td>
<td>$42,000–45,000</td>
<td>To be determined by economist (reduce by cost of average vehicle or by cost of client’s vehicle trade-in)</td>
<td>Handicapped Services, Inc.</td>
</tr>
<tr>
<td>Option 2</td>
<td>Car with trunk lift and hand controls</td>
<td>43/2005</td>
<td>Every 5–7 years</td>
<td>Mobility and independence</td>
<td>$1200–1750 ($400–550 hand controls; $1000–1200 trunk lift; car must be equipped with power steering and brakes)</td>
<td>To be determined by economist</td>
</tr>
</tbody>
</table>

### Health and Strength Maintenance

<table>
<thead>
<tr>
<th>Equipment Description</th>
<th>Special Camps or Programs</th>
<th>Age/Year of Purchase or Attendance</th>
<th>Replacement or Attendance Schedule</th>
<th>Base Cost</th>
<th>Growth Trends</th>
<th>Catalog or Supplier Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Universal gym with physical conditioning components/ stationary bike/ weights</td>
<td></td>
<td>2005</td>
<td>1 time only</td>
<td>$500–1500</td>
<td>To be determined by economist</td>
<td>Sports Town</td>
</tr>
</tbody>
</table>
### Architectural Renovations

<table>
<thead>
<tr>
<th>Accessibility Needs</th>
<th>Accessibility Needs</th>
<th>Costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ramping</td>
<td>X</td>
<td>Bathroom</td>
</tr>
<tr>
<td>Light/ environmental controls</td>
<td>X</td>
<td>Sink</td>
</tr>
<tr>
<td>Floor coverings (if wheelchair is used inside)</td>
<td>X</td>
<td>Cabinets X</td>
</tr>
<tr>
<td>Hallways</td>
<td>X</td>
<td>Roll-in shower X</td>
</tr>
<tr>
<td>Doorways</td>
<td>X</td>
<td>Temperature control guards</td>
</tr>
<tr>
<td>Covered parking</td>
<td>X</td>
<td>Heater</td>
</tr>
<tr>
<td>Kitchen</td>
<td></td>
<td>Fixtures</td>
</tr>
<tr>
<td>Sinks/fixtures</td>
<td></td>
<td>Door handles</td>
</tr>
<tr>
<td>Cabinets</td>
<td></td>
<td>Additional electrical outlets</td>
</tr>
<tr>
<td>Appliances</td>
<td></td>
<td>Central air/heat</td>
</tr>
<tr>
<td>Windows</td>
<td></td>
<td>Therapy/equipment storage</td>
</tr>
<tr>
<td>Electric safety doors</td>
<td></td>
<td>Attendant bathroom</td>
</tr>
<tr>
<td>Fire alarm</td>
<td>X</td>
<td>Single-story home; no steps</td>
</tr>
</tbody>
</table>

### Potential Complications

<table>
<thead>
<tr>
<th>Complications</th>
<th>Estimated Costs</th>
<th>Growth Trend</th>
</tr>
</thead>
<tbody>
<tr>
<td>Re-hospitalized for psychological/psychiatric care and crises management; electroconvulsive therapy costs approximately $1000 each treatment</td>
<td>No duration or frequency available; costs not included in plan</td>
<td></td>
</tr>
<tr>
<td>Failed back with additional surgery required</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Falls and reinjury</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adverse reactions to medications</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Vocational/Educational Plan**

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Age/Year at Which Initiated</th>
<th>Age/Year at Which Suspended</th>
<th>Purpose</th>
<th>Base Cost</th>
<th>Growth Trends</th>
<th>Recommended by</th>
</tr>
</thead>
<tbody>
<tr>
<td>Client appears unemployable; final determination deferred to vocational rehabilitation specialist based on progress in treatment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Future Medical Care Surgical Intervention or Aggressive Treatment Plan**

<table>
<thead>
<tr>
<th>Recommendation (Description)</th>
<th>Age/Year Initiated</th>
<th>Frequency of Procedure</th>
<th>Per Procedure Cost</th>
<th>Per Year Cost</th>
<th>Growth Trends</th>
<th>Recommended by</th>
</tr>
</thead>
<tbody>
<tr>
<td>Based on history, client likely to be rehospitalized for psychological reactions to disability.</td>
<td>Date unknown</td>
<td>Implanted pain drug delivery system 1 time.</td>
<td>$50,000</td>
<td>$150 for 5 times per year for refills?</td>
<td></td>
<td>Dr. Lester &amp; Dr. Litwack</td>
</tr>
</tbody>
</table>

*Source:* Format reproduced with permission of Dr. Paul M. Deutsch. Adapted from the *Guide to Rehabilitation.*

**Conclusion**

Chronic pain has the ability as a diagnostic entity to cause as much disruption in patient care as do the functional, psychological, and social losses involved in the original injury. It should be noted that as a specialty, chronic pain is developing and should be available in its broadest sense from the multidisciplinary approach nearly everywhere in the United States. A carefully arranged initial intake with subsequent development of the six categories outlined should place the life care planner in the position to expertly assess and recommend the appropriate level of care for patients with chronic pain. However, as with all diseases, individuals with chronic pain will suffer variable outcomes based upon their individual application of the programs outlined for them. The responsibility of the patient in chronic pain is not unlike that of a diabetic, who, although having undergone a comprehensive study and treatment program, nonetheless is left on a daily basis to provide the right type of treatment for his or her own condition. It is incumbent upon the patient to adopt new lifestyle measures, restrict activities, and habituate certain aspects such as...
biofeedback and relaxation, and not just do the easy thing, which is to take a pill or apply a TENS unit. Patient compliance in this regard is key, and assistance through psychological counseling and frequent monitoring is often the best hope for achieving some degree of success in modifying a patient’s former lifestyle to include measures necessary for a chronic pain management program. The goal of chronic pain planning, therefore, is not to reduce the pain to the level it was before the injury, but to modify the pain such that the patient can enjoy an enhanced quality of life and maintain a reasonable degree of function. It is also pertinent to note that a comprehensive treatment plan that uses all six outlined areas will offer the best chance of success, rather than a patient selectively using two or three modalities. The goal is to reduce the patient’s perceived level of pain to where certain activities that were prohibitive or restrictive are now possible. Clearly this does not necessarily mean that the patient will be able to perform all activities. It is along these lines that the compromise between where the patient was and where the patient is now needs to be identified. In this context, the patient can be encouraged to achieve some degree of compromise with the condition of chronic pain and a future activity level that is beyond where he or she has been functioning. In light of these issues, the life care plan can be a valuable adjunct to assist the chronic pain patient.

References


Chapter 18

Life Care Planning for Spinal Cord Injury

Terry Winkler, Roger O. Weed, and Debra E. Berens

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Introduction

Spinal cord injury (SCI) historically has been described by physicians as one of the most catastrophic conditions in medicine (Kennedy, 1986). In ancient Egyptian times, it was considered a condition not to be treated since patients died and the demise reflected on the physician’s ability if attempts to cure them failed. Clinical features were first described in great detail by Hippocrates around 400 B.C. Paraplegia and neurogenic bowel and bladder were observed. However, since complications were poorly understood and modern medications were unavailable, an early death was the common result. It was not until the twentieth century that significant strides were made based on medical research begun, particularly in England in 1944 at the Stoke Mandeville Hospital. In the United States, the first federally funded research program was established in Arizona in 1970. Since its early beginnings, the research center has been moved to the University of Alabama with contributing support by 14 SCI model programs throughout the United States. Research data are now available regarding a plethora of issues, and life expectancy as well as quality of life for individuals with SCI have significantly improved. Fortunately, there have been many positive changes in health care and in society for people with SCI. Technology is rapidly changing and continues to provide positive changes in community access, mobility, and independent living for individuals
with SCI. However, even with these improvements, these still exist some physicians and health care providers who continue to hold a pessimistic view of spinal cord injury. Indeed, as late as 1947, Dr. William Asher described the paralyzed patient as follows:

Picture the pathetic patient lying long abed, the urine leaking from his distended bladder, the lime draining from his bones, the blood clotting in his veins, the flesh rotting from his seat, the scybala stacking up in his colon, and the spirit draining from his soul. (Asher, 1947, p. 967)

One goal of this chapter is to provide the background information that life care planners need to prevent this portrait from developing in a spinal cord-injured person’s life. In these authors’ opinion, the rehabilitation professional should become involved with the spinal cord injury patient immediately after the acute hospital care (Winkler, 1997). The life care planner must have a thorough working knowledge of the physiological effects, the most common side effects, and proper medical interventions of spinal cord injury. He or she must work with other health professionals to provide counseling for the patient and the family, and offer suggestions for environmental modifications, equipment, and services for the patient that offer greater mobility and independence. This chapter is intended to provide a foundation of basic medical knowledge of spinal cord injury, vocational information, functional abilities of people with spinal cord injury, and future medical and nonmedical needs, and to serve as an introduction to life care planning and spinal cord injury (Blackwell et al., 2001). It is imperative that the life care planner go beyond this chapter to the references cited to develop a deeper understanding of the issues that have an impact on life care planning in spinal cord injury.

Prevalence of Spinal Cord Injury

One of the more current discussions of epidemiological factors of spinal cord injury can be found in Go et al. (1995). The model systems data provide good information on general trends in spinal cord injury; however, it should be pointed out that the model systems data perhaps are skewed toward individuals who have a higher level of lesion and an adequate funding source. Individuals who have lower-level or incomplete spinal cord injuries or who do not have adequate funding for extended hospital stays tend to be treated at a local hospital or facility rather than referred to the model systems. Krause and colleagues (1975) found an incidence of spinal cord injury of 32 cases per million per year who survived or reached a hospital, with an additional 21 cases per million per year dying prior to reaching the hospital. Griffin and colleagues (1985) describe an incidence that approached 55 per million, with 35 cases per million surviving to reach the hospital.

The incidence of spinal cord injury has been reported as low as 29 cases per million to a high of 60 cases per million in various studies. There appears to be some variability from state to state regarding the exact rate of spinal cord injury. However, overall the annual rate of hospitalized individuals with spinal cord injury is approximately 40 cases per million (National SCI Statistical Center, 2008). This would correspond with 12,000 new cases of spinal cord injury per year in the United States. The prevalence or number of people who were alive in the United States in 2007 who have SCI has been estimated to be approximately 255,702 persons, with a range of 227,080 to 300,938 persons based on incidence and prevalence statistics obtained from several studies (National SCI Statistical Center, 2008).
Causes of Spinal Cord Injury

Gibson (1992) has described the four leading causes of spinal cord injury as motor vehicle accidents, falls, violence, and sports injuries. Data from the National SCI Statistical Center (2008), regarding the etiology of SCI since 2005, is outlined in Table 18.1.

Automobile crashes remain the number one cause of traumatic spinal cord injury, but a decline has been reported. The peak incidence occurred between 1978 and 1980 at 47% and dropped to as low as 38% reported in 1990. This reduction in motor vehicle crashes and spinal cord injury may be attributed in part to the improved safety features of some automobiles as well as the increased use of safety seatbelts as virtually all 50 states have made not wearing a seatbelt while riding in an automobile either a primary or secondary offense. Another interesting trend is the reduction of sports-related spinal cord injuries that has occurred over the last 15 years. Spinal cord injuries as a result of falls have increased by 7% in the same period of time, and spinal cord injury as a result of violence has almost doubled from 1978 to 1990. In some areas, violence is the number two cause of spinal cord injury. Louisiana ranks it as the number two cause, resulting in 32% of its reported cases of spinal cord injury (Lawrence et al., 1992).

Go et al. (1995) pointed out that the etiology of spinal cord injury differs substantially by age, gender, and race. Previously, the most common age of injury was approximately 19 years old, with a range of 16 to 30 years old. The mean age at the time of spinal cord injury from 1973 through 1992 has increased by 4.9 years, with the mean age of 28.5 years increasing to a mean age of 33.4 years. Since 2005, the average age at time of SCI is 39.5 years (National SCI Statistical Center, 2008). This trend has important implications. Since older persons with spinal cord injury tend to have more preexisting major medical conditions and are more likely to have tetraplegia (previously known as quadriplegia), they therefore develop a higher rate of secondary complications and more frequent hospitalizations than their counterparts (Roth et al., 1992; Go et al., 1995). With regard to gender, males account for approximately 77.8% of all spinal cord injuries since 2000, although there has been a slight trend toward a decreasing percentage of males with SCI from 81.8% prior to 1980. Ethnic patterns of individuals with SCI since 2000 reveal 63% are Caucasian, 22.7% are African American, 11.8% are Hispanic, and 2.4% are from other racial/ethnic groups (National SCI Statistical Center, 2008).

As perhaps expected, there are seasonal variations, with the lowest number of spinal cord injuries occurring during the winter months, particularly February. The highest number of spinal cord injuries occurs during the summer months, with July having the highest incidence. Half of all spinal cord injuries occur on a weekend day, with 20% occurring on Saturday, which is nearly double the rate of spinal cord injury occurring during weekdays.

Table 18.1 Causes of Spinal Cord Injury

<table>
<thead>
<tr>
<th>Injury Source</th>
<th>Percentage of Total Injuries</th>
</tr>
</thead>
<tbody>
<tr>
<td>Motor vehicle crashes</td>
<td>42</td>
</tr>
<tr>
<td>Falls</td>
<td>27.1</td>
</tr>
<tr>
<td>Violence</td>
<td>15.3</td>
</tr>
<tr>
<td>Sports</td>
<td>7.4</td>
</tr>
<tr>
<td>Other/unknown</td>
<td>8.1</td>
</tr>
</tbody>
</table>

Data from the model SCI systems since 2000 reveal that, of all people with spinal cord injuries, the most frequent neurologic category at time of hospital discharge is in individuals with incomplete tetraplegia (34.1%), followed by complete paraplegia at 23%, complete tetraplegia at 18.3%, and incomplete paraplegia at 18.5% (National SCI Statistical Center, 2008). Tetraplegia is defined as paralysis or partial paralysis in four extremities, with paraplegia being paralysis or partial paralysis in two extremities. Between 50% and 55% of all spinal cord injuries have some sparing of sensation, motor function, or both sensation and motor function and can be classified as incomplete. Over time, the percentage of individuals with incomplete tetraplegia has increased slightly while the percentage of both complete paraplegia and complete tetraplegia has decreased slightly (National SCI Statistical Center, 2008).

Functions of the Spinal Cord

Spinal cord injury is a traumatic insult to the spinal cord that can result in alterations of normal motor, sensory, and autonomic function (Staas et al., 1993; Blackwell et al., 2001). For purposes of this chapter, the discussion will be confined to traumatic spinal cord injury; however, the principles will apply to spinal cord injury of all etiologies.

The spinal cord has three basic functions:

- It serves as a conduit to bring sensory messages from the body and internal organs to the brain, where the brain can monitor activities of all structures and act as a central processing unit to interpret messages from the body.
- In a similar fashion, it carries messages from the brain to the effector organs or structures in the body. In this regard, the spinal cord can be viewed as a series of cables or connections between the brain and the body.
- It provides protective and coordination function whereby reflex mechanisms protect the body (e.g., withdrawal reflexes) and other centers facilitate or coordinate some bodily functions, such as urination, which is controlled by the micturition center in the sacral cord.

This is, of course, a simplification of the spinal cord. The spinal cord is a tremendously complex structure with literally hundreds, if not thousands, of functions being performed. Many of the body’s autonomic functions are coordinated and regulated at least in part in the spinal cord, and we have learned that the modulation and control of pain is in part based in the spinal cord. There is a very complicated group of interneurons and proprioneurons in the spinal cord whose roles are to facilitate or inhibit the activity of other neurons in the spinal cord. There is virtually no bodily function occurring below the level of the foramen magnum that is not influenced in some way by the integrity of the spinal cord. Therefore, the number of complications and problems that occur as a direct result of spinal cord injury are enormous, with implications for almost every body system (Schoenen, 1991).

The Spinal Column: Basic Anatomy

The spinal column consists of 33 vertebrae, intervertebral disks, and ligaments (Blackwell et al., 2001). The vertebrae provide a weight-bearing structure, the spinal column that houses and protects the spinal cord. In addition, the vertebral column allows a great deal of flexibility in the
cervical and lumbar spines. There is a relatively high degree of rigidity in the thoracic spine, easily identified by the ribcage, which provides support and protection for the internal organs.

The vertebrae are divided into five segments:

- Seven cervical vertebrae (neck): These support the head and provide a great deal of mobility. There are eight spinal nerves, C1 through C8. This is accomplished by the first cervical vertebra having a spinal nerve exiting above and below it, with each vertebral body from that level down having a spinal nerve exiting below the vertebra.
- Twelve thoracic vertebrae support the ribs.
- Five lumbar vertebrae (lower back) allow flexion and extension, some rotation, and side bending.
- Five sacral vertebrae provide a base of support and attachment for the pelvis.
- Four coccygeal vertebrae are fused together and form the tailbone.

Each vertebral body is separated by an intervertebral disk that is made of cartilage and acts as a shock absorber and cushion for the spinal column. The intervertebral disks make up one-fourth of the total height of the spinal column and allow a great deal of flexibility between vertebral bodies. The vertebral disks have the ability to herniate and can cause injury to the spinal cord or nerve root in cases of severe herniation.

Numerous ligaments are responsible for maintaining the integrity of the spinal column and its alignment. Two of the most important are the anterior longitudinal ligaments on the front of the vertebral bodies and the posterior longitudinal ligaments on the back of the vertebral bodies. If either of these ligaments is torn, the column is said to be unstable and this greatly increases the likelihood of spinal cord injury or damage.

The central nervous system is made up of the brain and the spinal cord. It is completely encased in a very strong protective membrane, the dura mater, and is bathed in cerebrospinal fluid. The spinal cord begins at the base of the skull, the foramen magnum, and extends to the L1 or L2 vertebral level, ending in the shape of a cone called the conus medullaris. From the conus medullaris down, nerve roots continue down through the spinal canal to exit at their proper levels. These nerve roots are referred to as the cauda equina.

It is important to note that there is a disparity between the bony level and the neurological level. For example, the nervous segments that are adjacent to the L1 vertebral body in the spinal canal are S2, S3, and S4. Therefore, an injury to the L1 vertebral body would result in damage to S2, S3, and S4 nerves. This is a very important concept in life care planning. When developing a life care plan, it is extremely important that it be developed for the neurological level of injury, not the bony level of injury.

**Spinal Cord Damage**

Spinal cord damage can occur in several ways, some of which include the following (Blackwell et al., 2001):

- Overstretching or tearing of the nervous tissue of the spinal cord.
- Direct pressure on the spinal cord from bony fragments, bulging disks, or hematoma.
- Swelling and edema can produce increased pressure and decreased blood flow in the area of the spinal cord injury, leading to further damage.
The initial spinal cord injury usually does not result in a complete disruption of the cord, and it is generally felt that high-dose steroids, such as methylprednisolone, given within 4 hours of the spinal cord injury may have some beneficial effect, although there are conflicting reports in this regard. Intense research in spinal cord injury treatment and intervention may hold the most promise of providing some relief from the effects of injury. However, to date there is no cure for spinal cord injury and none foreseeable in the near future.

It is possible to determine the mechanism of injury in spinal cord injury by reviewing x-rays and computed tomography (CT) scans. Axial compression alone, such as from a diving accident, will result in a burst-type fracture. Rotation combined with flexion is the most damaging type of force on a spinal column, and it will result in disruption of the posterior ligamentous structure (Staas et al., 1993). Central cord syndromes are the result of a hyperextension injury. Injury to the thoracic spine requires much greater forces due to the protective effect of the ribcage and the stability of the spine. These are usually only involved in very high-speed vehicular-type traumas or accidents that involve very high forces. They also can occur when the occupant is ejected from the vehicle (Zigler & Field, 1992).

Distraction forces placed at a vertebral body can result in a Chance fracture. This type of injury is observed in motor vehicle accidents where only a lap belt is worn. This can be prevented with the use of a shoulder harness belt in addition to the lap belt. A similar injury occurs in automobiles that are provided with passive restraints in which the shoulders are restrained but the hips are not. A collision can result in the person's hips moving forward, causing a hyperflexion of the neck and resultant spinal cord injury at a higher level. Another recent reported phenomenon is high tetraplegia to children and smaller adults as a result of airbag deployment.

The stability of the spinal column is determined by the intactness of the anterior and posterior longitudinal ligaments as well as the vertebral body and will dictate whether surgery is needed. Surgical decompression even a number of years after the spinal cord injury can result in improvement. This issue is of the utmost importance in cervical spinal cord injury where, for example, a late decompression can result in a person with C5 motor function having an improvement in C6 motor function, which would make a tremendous difference in his functional outcome. In general, for the lower-level spinal cord injury, decompression is not as crucial. Acute spinal cord injury surgical management may include traction, halos, bracing, Harrington or similar rods, and fusion.

### Spinal Cord Injury Classifications

It is important to establish a worldwide standard for the nomenclature and classification of spinal cord injury. Without this, it is impossible to perform meaningful spinal cord injury research from center to center or country to country. Likewise, it is impossible to view spinal cord injury in terms of life care planning and to critique and review and make recommendations in life care planning without a standardized classification system.

In response to this need, the American Spinal Injury Association (ASIA) and the International Medical Society of Paraplegia developed a worldwide nomenclature system (American Spinal Injury Association/International Medical Society of Paraplegia, 2000). This system of classification gives key sensory levels to identify dermatomes of injury and key muscle levels to identify the levels of muscle functions. Spinal cord injuries may be complete or incomplete with partial sparing. The ASIA classification system includes a level for the sensory impairment and a level for the motor impairment, as well as a letter designation for the degree of completeness (also see Blackwell et al., 2001).
The scale, once known as the modified Frankel classification system and now as the ASIA Impairment Scale (also see Figure 18.1), is used to describe completeness, with five classes being recognized:

Class A: Complete spinal cord injury: no motor or sensory function is preserved in the sacral segments S4–S5.

Class B: Incomplete spinal cord injury: sensation but not motor function preserved below the level of injury; includes the sacral segments S4–S5.

Class C: Incomplete spinal cord injury: motor function is preserved below the neurological level, and more than half of the key muscles below the neurological level have a muscle grade of less than 3 (grades 0 to 2). No functional motor strength.

Class D: Incomplete spinal cord injury: motor function is preserved below the neurological level, and at least half of the key muscles below the neurological level are graded at 3 or more. The person may be able to use the motor function, for example, for a brief transfer, or ambulate short distances.

Class E: Complete return of all motor and sensory function below the level of the lesion, but may have abnormal reflexes.

**Figure 18.1** Standard neurological classification of spinal cord injury. (From American Spinal Injury Association, 2000, 2002.)
**Examples of Incomplete Syndromes**

The following are specific types of incomplete syndromes:

- **Central cord syndrome:** Central cord syndrome is said to be present when the individual has paralysis greater in the upper extremity than the lower extremities, and sacral sensory sparing.

- **Brown–Sequard syndrome:** Brown–Sequard syndrome is a hemisection of the spinal cord and is characterized by ipsilateral paralysis with contralateral sensory loss from two segments below the level of the lesion down.

- **Cauda equina syndrome:** Cauda equina syndrome is an injury to the lumbosacral nerve roots within the neural canal below the conus medullaris resulting in a loss of bowel and bladder control and weakness of the lower extremities or paralysis.

- **Conus medullaris syndrome:** An injury to the spinal cord at the level of the conus and the lumbosacral nerve roots, which results in areflexic bladder and bowels and lower-limb paralysis.

- **Anterior cord syndrome:** A lesion that produces variable loss of motor function and sensitivity to pinprick and temperature while preserving proprioception.

**Functional Effects**

Spinal cord injury is considered to be a permanent condition, with very few people experiencing significant long-term recovery from the disability. Individuals with complete spinal cord injury have very little improvement in general; only 2% will improve to an ASIA Class D. Of those who present with an ASIA Class B, 20% will improve to an ASIA Class D or E. For ASIA Class C, 50% will improve to an ASIA Class D or E. The length of time since spinal cord injury is also a factor in prognosis. Individuals who have had no improvement within the first 6 months to 1 year are considered to have permanent injury with no likelihood for significant functional improvement.

Upper motor neuron (UMN) lesions, in general, refer to a lesion in the spinal cord that occurs at the T11 or T12 level or higher. Individuals with tetraplegia have a UMN lesion. UMN lesions are characterized by increased spasticity with intact reflex bladder and bowel functioning and sexual functioning, in general.

Lower motor neuron (LMN) injuries occur at T12 or below, usually seen in individuals with paraplegia, especially cauda equina syndromes. In general, LMN lesions have impairment of the reflex arcs that control bowel and bladder functioning and sexual functioning. These individuals will have flaccid bowel and bladder functioning, which results in much greater difficulty controlling bowel and bladder incontinence. In general, erectile function in the male is impaired.

Individuals with intact reflex voiding mechanisms of the bladder and the bowel may experience less complications, infections, and incontinent episodes.

**Potential Complications of Spinal Cord Injury**

Numerous physiological changes occur in almost every system of the body as a result of spinal cord injury (Blackwell et al., 2001). In addition, there are a host of complications that occur as a result of spinal cord injury. A comprehensive discussion of these factors and issues is beyond the scope of this chapter. However, an introduction to the topic is useful and necessary to understand
Cardiovascular

Normal physiological control of the arteriovenous system and the heart is lost in spinal cord injury from the injured vertebral level down. The portion of the spinal cord that controls the heart directly ranges from T1 to T7. Injuries at this level or above result in altered cardiovascular physiology, not only of the vasculature but also of the heart proper.

Hypotension

Loss of blood pressure (BP) control is a very common problem in individuals with spinal cord injury. Higher-level spinal cord injuries result in orthostatic hypotension in which the individual experiences a drop in blood pressure and an elevating heart rate in response to attempting to sit up. These episodes tend to improve with time; however, a select group of individuals may continue to have this throughout the remainder of their lives and require very aggressive management in order to tolerate a sitting posture. Orthostatic hypotension is most commonly seen in individuals with a spinal cord injury at T6 or above. It can be quite severe and result in a patient having a fainting episode or loss of consciousness. Numerous techniques to assist in the management of this are available, including compression hose, abdominal binders, reclining chairs, and elevating leg rests. Physical therapists address this complication by progressive elevation with a tilt table. Medications useful in the management of orthostatic hypotension include ephedrine, tyramine, flocrine, and ergotamine. Newer medications such as Proamatine (midodrine), an alpha-adrenergic vasoactive agent, are more effective. The orthostasis will interfere with the number of hours a person can be in a wheelchair and with his or her ability to be out in the community for vocational or social activities.

Arrhythmias

High-level spinal cord injuries can result in bradyarrhythmias that can lead to cardiac arrest and standstill during tracheal suction. Patients at risk for this may require atropine or possibly placement of a pacemaker. A highly skilled caregiver who is capable of responding to such emergencies should be available.

Deep Vein Thrombus (DVT)

DVT has been recognized as a significant cause of morbidity and mortality in individuals with spinal cord injury. The incidence of DVT ranges from 47% to 100%, increasing the initial cost of hospitalization by 35%, and the annual direct cost of hospital care alone is estimated by DeVivo to be $178 million; these figures do not take into account the economic cost of lives lost to DVT (Consortium for Spinal Cord Injury, 1997b). One recent tragic loss occurred when a Kansas City Chiefs football player died after developing a DVT secondary to SCI. In SCI without prophylaxis, DVT is likely to occur in well over 80% of cases (Waring & Karunas, 1991). The use of heparin has been demonstrated to be effective in reducing the incidence of DVT. Spasticity and its effects on the development of DVT have been studied. There are varying reports in the literature; however, overall, it is felt that increased spasticity may result in a decreased incidence of DVT in the acute sitting (Bors et al., 1954). Chin (personal communication, 1997) has studied DVT and the use
Life Care Planning for Spinal Cord Injury

of Lovenox (a low-molecular-weight heparin) in the prevention of DVT and has documented that Lovenox is extremely effective in reducing the acute incidence of DVT. The Consortium for Spinal Cord Injury (1997b) publication Prevention of Thromboembolism recommends low-molecular-weight heparin to prevent DVT in SCI.

Of those individuals who develop DVT, approximately one-third can develop pulmonary embolus. Pulmonary embolus can be a life-threatening condition and result in death in a number of individuals. Venous Doppler studies and venograms are necessary to follow the DVT as are serial laboratory studies, such as Protimes. Once a DVT has developed, an individual will be treated for 6 months to 1 year, depending on clinical response. A small number of people with spinal cord injury will develop a chronic DVT and require lifelong management with anticoagulation therapy. Some individuals with DVT and other comorbidities or injuries may require the placement of a vena cava filter to protect them from risk of pulmonary embolus. Of those individuals who do not develop DVT during the acute hospital stay, there is approximately 14% to 20% risk of developing a DVT at some point during their lifetime. The period of greatest risk for development of DVT seems to occur within the first 3 months of injury (Staas et al., 1993). If the person is 1 year out from the development of DVT and experiences increased swelling and temperature when anticoagulation is stopped, this likely represents a permanent condition and will require lifelong anticoagulation treatment. Individuals who have experienced a DVT are twice as likely to develop a blood clot again in the same extremity at some point later in their life (Wyngaarden et al., 1988).

**Autonomic Dysreflexia (AD)**

AD is a life-threatening complication. The incidence of AD is 48% to 98% of people with tetraplegia and high paraplegia (Esmail et al., 2002) and most commonly occurs in individuals who have a spinal cord injury at T6 or above. The Consortium for Spinal Cord Injury has a comprehensive discussion of this condition and its treatment in Acute Management of Autonomic Dysreflexia (“Adults with SCI Presenting to Health-Care Facilities,” 1997, as cited in Esmail et al., 2002), which defines a systolic blood pressure at or over 150 as a hypertensive urgency. It is important to remember that higher-level SCI uniformly leads to low blood pressure, and a BP reading ordinarily felt to be within normal limits would be elevated for an individual with tetraplegia. AD is characterized by one or more of the following:

- Flushing or redness of the skin that develops above the level of the spinal cord injury
- General malaise
- Severe headache
- Elevated blood pressure
- Increased heart rate
- Occasionally, slowed heart rate

While AD commonly occurs at T6 or above, with the right type of stimulus (such as giving birth), it can occur at lower levels of spinal cord injury. This condition is extremely uncomfortable and can be life threatening. The patient may feel as if he or she is dying, and the sequela can cause an extreme and diffuse malaise. Individuals that have frequent and recurring autonomic dysreflexia or who tend to have alarmingly high blood pressures (i.e., diastolic pressure over 120 mmHg or systolic pressure over 200 mmHg) require ongoing use of medications such as Dibenzyline and Procardia. In addition, they will require a fail-proof emergency response system to ensure that
they obtain required urgent care. The danger lies in the elevated blood pressure that can result in stroke and death. The life care plan should be designed in such a fashion as to make every effort to prevent the episodes by providing adequate supplies for frequent catheterization and bowel programs. Additionally, personal care attendants should be trained to properly assist in preventing the autonomic dysreflexia, or recognizing and treating it.

In incomplete spinal cord injuries, AD is generally not a significant problem. AD occurs as a result of some noxious stimulus, the most common being distended bowel or bladder. Other causes may be occult fractures, decubitus ulcers, infections, and abdominal lesions (ulcers or choledolithiasis). Improper positioning in the chair, as well as tight clothing or wrinkles in the clothing, have been reported to cause episodes of AD. In individuals who are experiencing increasing autonomic dysreflexia, a complete and thorough medical workup is indicated to determine the etiology of the AD.

AD is treated by identifying and relieving the noxious stimulus. In the case of bowel and bladder, the complication can be reduced or eliminated by emptying the bowel or bladder. In refractory cases of AD, medications such as Dibenzyline may be required. In acute episodes of AD, calcium channel blockers such as Procardia are indicated to gain control of the blood pressure while the underlying etiology is determined. Recent reports reveal that Captopril given sublingually may be a safer alternative (Esmail et al., 2002). Some centers are using Nitroglycerin paste on the chest wall as an alternative to Procardia.

The patient with SCI is also at higher risk for developing peripheral vascular disease, both arterial and venous disease (Lee, 1991). There is also evidence that individuals with spinal cord injuries experience a greater rate of coronary artery disease and myocardial infarction. When all other risk factors are controlled for, such as gender, age, family history, and lifestyle, the individual with a spinal cord injury is twice as likely to develop coronary artery disease as the able-bodied counterpart (Duckworth, 1983; Kesseler, 1986; Yehutil, 1989; Dorey, 1990; Bauman et al., 1994). Schmitt et al. (1995) have pointed out that the leading cause of death for persons with neurologically incomplete paraplegia is ischemic heart disease.

**Pulmonary**

Individuals with spinal cord injuries below T12 have virtually no impairment of their pulmonary system. As the spinal cord injury levels rise from T12 to T5, there is a progressive loss of abdominal motor function and chest wall function that impairs expiration and cough. As the level rises further from T5 to T1, intercostal muscle function is impaired and inspiratory and expiratory function are impaired. Jackson and Groomes (1991) have reported that approximately 70% of individuals with new spinal cord injuries experience respiratory complications, with one-third developing pneumonia.

The most critical level for pulmonary function is C3, C4, and C5, the neural segments that supply the phrenic nerve and the diaphragm. With injuries at this level and above, the individual is at high risk for relying upon a ventilator for pulmonary function. Spinal cord injury at levels C3 and above will result in total dependency on ventilators (Blackwell et al., 2001). These individuals require a whole host of support to maintain them, including high-level attendant care and frequent physician follow-up visits. In a select group of these individuals, phrenic pacers (although expensive) may be indicated and will result in a more physiological breathing mechanism. It can be expected that individuals with phrenic pacers will experience fewer respiratory complications, have an improved quality of life, and have improved longevity. Benefits include improved speech and smell, ease of transfers and mobility, reduced respiratory infections, reduced secretions, and possibly closing the trach site (Gittler et al., 2002). In high levels of spinal cord injury, careful monitoring
of the pulmonary status is absolutely essential and problems must be reported immediately to the treating physicians. Individuals with vital capacities below 10 to 5 ml/kg are at greatest risk for respiratory failure and may require some assisted ventilation to prevent complications. Devices and techniques such as abdominal or quad coughs, abdominal binders, mechanical insufflation–exsufflation, high-frequency chest wall oscillation, incentive spirometry, and abdominal weights may be required (McKinley et al., 2002). Medications that may be required are antibiotics, updraft agents, theophylline, mucolytic drugs, and beta-agonist inhalers. Oxandrin, an oral anabolic steroid, has been shown to improve pulmonary function (Spungen et al., 1999).

Upper respiratory tract infections and pneumonias can be expected to occur at a higher frequency and require aggressive preventive care in order to limit morbidity and mortality. Individuals with tetraplegia should receive annual influenza vaccinations and a pneumococcal vaccination. The winter months are likely to be the most troublesome and may require daily respiratory therapy treatments in order to prevent complications.

Individuals with high-level spinal cord injury will require a host of equipment, including ventilators, respiratory monitors, suctioning equipment, and pulse oximetry. Additional emergency equipment will include a backup ventilator, a home generator system in the event of prolonged power failure, and an Ambu bag.

Additional factors that can complicate respiratory status in individuals with spinal cord injury are a progressing scoliosis, increasing spasticity, and syringomyelia. High spinal cord injury in females who become pregnant may also experience a worsening pulmonary status and require additional support during pregnancy.

**Sleep Disturbances**

Braun and colleagues (1982) have reported an increased incidence of sleep apnea in patients with SCI. Consideration of monitoring of their condition is required in patients with symptoms of sleep apnea, particularly in patients who are overweight.

**Gastrointestinal (GI)**

Individuals with spinal cord injury experience a number of physiological changes in the function of their GI tract. There is a slowing of transient time through the GI system, and gastric acid secretion may increase (Consortium for Spinal Cord Injury, 1998).

**Peptic Ulcer Disease**

There is an increased risk and rate of development of peptic ulcer disease connected with a spinal cord injury. Almost all individuals with acute spinal cord injury will have gastritis or peptic ulcer disease (Kewalramani, 1979; Epstein, 1981). GI bleeding is a very common early complication in spinal cord injury. The risk for GI bleeds and ulceration is higher in individuals with spinal cord injury at T6 and above. Prophylactic use of H2 blockers is common and medically appropriate. The GI bleed frequently result in anemia after spinal cord injury (Gore et al., 1991).

**Cholelithiasis**

Individuals with spinal cord injury have an increased risk and rate of development of gallstones. Reports have suggested an increased rate from 3 to 11 times more likely to develop gallstones than
the able-bodied population. It is generally believed that this may be related to a relative stasis in the gastrointestinal tract, an overproduction of bile by the gallbladder, or decreased gallbladder motility (Apstein & Dalecki-Chipperfield, 1987; Stone et al., 1990).

Individuals with UMN lesions may have an unaltered defecation reflex and respond to digital stimulation of the rectum with a reflex defecation. Individuals who do not have an intact anorectal reflex (LMN lesions) for defecation have a much more difficult time controlling bowel incontinence.

Dietary factors are used to assist in controlling bowel incontinence by maintaining a proper consistency of the stool. In addition, rectal suppositories such as Dulcolax, Enemeez (formally known as Therevac, Mini Enemas), and Magic Bullet may be necessary. Oral medications such as Metamucil, Colace, or Peri-Colace also may assist in bowel management. Miralax is also an agent that appears to be very effective for SCI constipation.

Individuals with spinal cord injuries experience a high rate of hemorrhoids and rectal fissures that will require the assistance of gastroenterologists and colorectal surgeons. Patients with SCI who have intractable diarrhea and difficulty controlling their incontinence may be candidates for a colostomy. Bowel incontinence poses serious social, recreational, and vocational limitations for individuals with SCI. Individuals with high-level spinal cord injuries are dependent on others for assistance and management of their bowel incontinence. In addition, individuals with low-level spinal cord injury or paraplegias will require the assistance of an attendant during times of illness for management of their bowel program, and a personal care attendant will be required during times of illness that result in GI upset or diarrhea. Management of the neurogenic bowel can be quite time-consuming and require from 30 minutes to 3 hours or more for each event.

**Metabolic Changes**

Metabolic changes are numerous after spinal cord injury and can result in altered nutritional requirements, hypercholesterolemia, and dyslipidemia. Nutritional counseling and changes in the diet may be required to assist the patient with learning how to manage these complications. Exercise has been demonstrated to be beneficial in assisting and restoring a desirable HDL-to-LDL ratio.

**Diabetes Mellitus**

Diabetes mellitus (adult onset) is clearly related to spinal cord injury. Several studies have well established the glucose intolerance of individuals with spinal cord injury. There may be a relative insulin resistance present. Other factors may also include the decreased ability of the individual with SCI to exercise and maintain fitness and the tendency to gain weight due to decreased activity (Duckworth, 1983; Bauman & Spungen, 1984; Formal, 1992).

**Anemia**

Anemia after spinal cord injury develops early. It was originally generally believed to represent only an acute incidence of blood loss and acute gastrointestinal problems. There are, however, individuals who continue to have ongoing difficulty with anemia that is clearly related to their injury. The exact etiology of the anemia remains elusive, although there are reports that there is decreased erythropoietin produced at the kidneys. It is clear that persistent anemia is likely a multifactorial problem (Hirsch et al., 1990). Treatment requires multivitamins, vitamin C, iron supplements, and occasionally Epogen.
**Urinary Complications**

Spinal cord injury results in a neurogenic bladder (urinary incontinence) in most people. The management program required depends on the level of spinal cord injury and the patient’s unique bladder function or dysfunction. Upper motor neuron lesions may be managed with an external catheter if an intact reflex voiding mechanism is present. This technique is by far the most desirable if it is functional for the patient. It should be recognized that as a male patient ages or changes occur with the spinal cord injury, the external condom catheter may not continue to be an effective method of urinary control.

Most patients with spinal cord injury will require intermittent catheterization (IC) performed four to six times daily. Males with SCI with low-level lesions are the best suited for intermittent catheterization. Intermittent catheterization becomes increasingly more difficult in females, obese individuals, and individuals with high-level lesions. Indwelling Foley or suprapubic catheters may be required to manage the neurogenic bladder for these patients.

Detrusor-sphincter dyssynergia is common in SCI and leads to poor bladder emptying, urinary reflux, and, if unrecognized or not treated, renal failure. It is screened for with renal ultrasounds diagnosed with urodynamic studies. Treatment includes anticholinergic medications, sphincterotomy, and frequent intermittent catheterization (Wyndaele, 2002). Pudendal nerve blocks with Botox or Phenol are also effective (Tsai et al., 2002).

Individuals with spinal cord injury experience an increased rate of urinary tract infections and urosepsis and will require urinalysis, urine culture and sensitivities, and intermittent antibiotics. The cost of antibiotics in a population utilizing sterile IC is 43% of the cost of those using nonsterile IC, and using hydrophilic catheters reduces the risk for strictures (Wyndaele, 2002). Some individuals may require lifelong use of prophylactic antibiotics to reduce the incidence of urinary tract infections. Bladder and renal calculi are a common complication of spinal cord injury that should be screened annually and will require a urologist to manage. Bladder cancer is much more common in SCI, especially in those who use an indwelling Foley catheter. For SCI, the risk of bladder cancer is 25 times higher, and the risk of mortality is 70 times higher than age- and gender-matched populations in general. Looking at the SCI population, an indwelling Foley increases the risk of bladder cancer fivefold over other methods of bladder management (Groah et al., 2002). Urinary incontinence may lead to skin breakdown in the perineal area and result in decubitus ulcers that require expensive surgery. High-level spinal cord injury will mandate the assistance of a personal care attendant.

The individual with spinal cord injury will likely require catheters, leg drainage bags, night drainage bags, gloves, tape, Betadine, and other supplies. Follow-up evaluations will require renal ultrasounds, intravenous pyelograms (IVPs), urinalysis, urine cultures and sensitivities, urology visits, and urodynamic studies.

Goals of neurogenic bladder management include maintaining continence, preserving renal function, and reducing morbidity. A change in management of the system during the patient’s lifetime may be required (Cardenas, 1992).

**Musculoskeletal**

A host of physiological changes occur after spinal cord injury, including body composition, lipid metabolism, energy expenditure, nutritional parameters, glucose and calcium metabolism, thermoregulation, and soft tissue changes (Yarkony, 1996). All of these affect the musculoskeletal system.
Approximately 40% of individuals with SCI will have multiple fractures below the level of the injury. In addition, due to the extensive osteoporosis from the level of the lesion down, it can be anticipated that many individuals with SCI will experience at least one long bone fracture during their lifetime. Long bone fractures below the level of the lesion are slow to heal or may not heal at all, resulting in a nonunion. Such fractures have to be evaluated carefully; they may require future surgical interventions or prolonged care and treatment. These fractures can be a source of ongoing pain and can produce autonomic dysreflexia symptoms in a patient. Fractures below the level of the spinal cord injury can result in the development of a nonunion or heterotopic ossification, both of which would require extended periods of treatment.

Fractures above the level of the lesion or in the upper extremities can interfere with rehabilitation care and make the patient more dependent on personal care services until the fracture and the resulting sequela have resolved.

Heterotopic ossification (HO) is a common complication of spinal cord injury by which the body begins making ectopic bone in an area where bone should not exist. Typically, this bone is formed in the soft tissues around a joint, most commonly in the hips, knees, shoulders, elbows, and ankles. The condition rarely occurs in small joints of the hands or feet. It is reported to occur in as many as 20% to 30% of patients with SCI and can result in limited range of motion (ROM) of a joint. HO can lead to complications such as repeated skin breakdown, or it interferes with positioning and activities of daily living (ADL). Triple-phase bone scan is the earliest and most sensitive test to diagnose HO. Additional useful tests includes serum alkaline phosphatase and x-rays.

HO must be treated by a physical therapist with range of motion to prevent ankylosing of a joint. Medications that are useful include Indocin and Didronel and may require from 6 months to 1 year of treatment. When active HO is present, frequent follow-ups with a physiatrist, serial bone scans and x-rays, and serum phosphorus levels are required.

After HO has matured and has no longer been active for at least 1 year, and if the HO is causing interference with ADL, positioning, or skin breakdown, it can be surgically removed. Refractory HO that is not responsive to medication may benefit from radiation treatment, although there are conflicting reports in the literature regarding the efficacy of radiation treatment.

Once patients with SCI have experienced HO, they have an approximate 50% chance of reactivating the disease sometime during their lifetime. Factors that will result in reactivation of the HO include fractures, infection, kidney stones, decubitus ulcers, and surgeries. Reactivated HO is treated the same as the original episode of HO, requiring Indocin, Didronel, physical therapy, and possibly radiation treatment. It also requires physician follow-up, bone scans, x-rays, and frequent laboratory evaluation.

**Poikiothermia**

Poikiothermia is related to a decreased ability to maintain body temperature. In an able-bodied person, body heat is generated through shivering and vasoconstriction and body heat is reduced through sweating and vasodilatation. These mechanisms are impaired in the patient with a spinal cord injury. The higher the level of injury, the more significant the poikiothermia. This loss of ability to regulate body temperature can be life threatening in individuals with spinal cord injury and require adequate safeguards to assist in maintaining body temperature. This includes central heating and air systems in their homes as well as good, functioning air-conditioning systems in their vehicles. Cellular telephones are required so that in the event the vehicle breaks down, the person can summon help. Individuals with SCI are at risk for skin injury from exposure to extreme heat or cold and may, in fact, suffer life-threatening complications if exposed to the extremes of either temperature for longer than a brief period of time.
Osteoporosis

Osteoporosis is a common complication of spinal cord injury because as much as 50% of the bone mineralization may be lost within the first few months of the injury. This puts the patient at greater risk of fractures below the level of the lesion. In addition, it has been reported that fractures below the level of the lesion are much slower to heal or may not heal at all. Bone mineralization loss continues with aging, raising the risk of skeletal complications with the length of time from spinal cord injury onset.

Overuse Syndromes

Overuse syndromes and chronic pain of the upper extremities, shoulders, elbows, and wrists are common sequelae of spinal cord injury and can result in a decreased functional status of the patient. Up to 75% of patients may experience the development of peripheral nerve entrapment such as carpal tunnel syndrome and ulnar nerve entrapments at the wrists and elbow. Davidoff et al. (1991) have reported the incidents to be as high as 86%. Decreased shoulder functioning and increasing pain have been reported with aging. Rotator cuff impairment and tendinitis of the shoulders are common problems associated with spinal cord injury. At least one study reports upper-extremity complications occur earlier in females (Pentland & Twomey, 1991). Upper-extremity pains are commonly reported to exist in 75% of the spinal cord injured (Sie et al., 1992). Females seem to have greater difficulty with upper-extremity and shoulder pain than males. Musculoskeletal repetitive trauma injuries occur commonly in long-term SCI, but can be prevented with appropriate lifestyle or equipment modifications. Also, living independently without assistance increases the opportunity for repetitive use injuries (Groah et al., 2002).

Spasticity

Spasticity, an involuntary rhythmic contraction of a muscle, can result in increased disability by interfering with transfers, activities of daily living, and positioning in the chair, as well as interrupting sleep and causing pain. However, there also are some beneficial effects of spasticity such as assisting with weight shifts, improving circulation, helping to reduce skin breakdown, and at times use for functional purposes, such as a transfer.

Increasing spasticity can result from sitting on a foreign object, skin breakdown, infections, kidney stones, ingrown toenails, bony fractures, or other painful stimuli. Syringomyelia, a cyst in the spinal canal that can raise the level of injury if not treated, is a diagnosis that must be excluded when no other source of the increasing spasticity can be found.

Spasticity is treated by providing full range of motion to all involved joints at least twice a day with prolonged terminal stretch by the therapist. Standing in a standing frame or tilt table can help reduce spasticity. Avoiding extreme temperature changes, whirlpool treatments, and preventing bladder infections, constipation, and skin breakdown will also help.

Medications that are commonly useful in the treatment of spasticity include Baclofen, Dantrium, and Valium. Xanaflex is a newer antispasticity medication that is an alpha-blocker and can be helpful in cases not responding to other oral agents. In severe cases, the patient may require an intrathecal Baclofen (ITB) pump. Sudden withdrawal from ITB has been reported to have resulted in at least six deaths, and life-threatening syndromes in many others, which is felt to be an underrepresentation of the actual adverse events (Coffey et al., 2002). The authors report that noncompliance, human error, and mechanical malfunction occur, leading to these problems, and that any patient with ITB infusion is theoretically at risk. Such reports emphasize the duty of life care planners to develop plans that assure high-quality timely follow-up care and access to health care providers.
Surgery such as a rhizotomy may be considered. The patient may require motor point blocks or nerve blocks using phenol, alcohol, or Botox. Spasticity has been reported to increase with aging in spinal cord injury (Menter, 1995).

The results of increased tone and decreased range of motion are well-known complications of spinal cord injury. They can require surgical intervention, treatment with physical therapists, range of motion, standing frames, whirlpool treatments, peripheral nerve or motor point blocks, and splinting.

**Decubitus Ulcers**

Decubitus ulcers are a common and perhaps the most costly complication of spinal cord injury. It is reported that most individuals with SCI will experience at least one decubitus ulcer. In the SCI population, the annual incidence of decubitus ulcers is 23% to 30% (Byrne & Salzberg, 1996). Ulcers may be classified according to their level of involvement:

- **Grade I** is redness and induration of the skin.
- **Grade II** is superficial breakdown of the dermis.
- **Grade III** extends through the entire subcutaneous tissue but not into the muscle.
- **Grade IV** involves deep ulceration that extends into muscle tissue and to underlying bone.
- **Grade V** results in widespread extension of the ulcer into adjacent body joints or cavities.

The best management for decubitus ulcer is prevention; however, this is not always possible. Given the very best level of care, individuals can still develop decubitus ulcers. It particularly becomes a problem as the individual with spinal cord injury ages. Adequate seating systems and positioning in the chair with proper cushions are crucial in maintaining skin integrity and reducing the incidence of decubitus ulcers. In addition, adequate personal care attendants for hygiene and assistance in transferring and positioning are also necessary. Nutritional support is beneficial at reducing the risk of decubitus ulcers and at helping decubitus ulcers to heal.

Once decubitus ulcers have developed, a variety of treatments may be appropriate, including antibiotic ointments, debridement preparations, whirlpool treatments, and surgery. Recent wound care advancements include Regranex gel, Oxandran, electrical stimulation, and vacuum system to promote wound healing (McKinley et al., 2002). A scar is left in the area of a decubitus ulcer after healing and predisposes this area to further breakdown in the future. This complication can be a very expensive and time-consuming event. One model spinal cord injury treatment center reported that the cost of treatment for decubitus, where hospitalization was required (Stage III or IV), was $14,000 to $23,000 for U.S. hospitals, and a few of the more complicated cases at a model spinal cord injury center have topped $100,000 (Arthur Simon, M.D., personal communication, November 1999).

Infections are common complications that may be a direct result of skin breakdown, be it from virulent organisms transmitted to the patient by others via poor sterilization procedures or from community-acquired bacteria. Review of past medical records to determine the number of infections and the types of infections that the patient has experienced will serve as a useful guide for making projections about the future rates and types of infections the person is most likely to experience. In addition, the severity of the infections should be assessed to determine the level of care that will likely be required. For example, a patient who has had numerous infections with highly resistant organisms requiring hospitalizations and IV antibiotics is likely to continue to require that level of care.
Sexual Functioning

Spinal cord injury has a significant impact on sexual functioning in males and females. Sipski and Alexander (1992) reported that in males with UMN injuries, reflex erections are present in 70% to 90%. Ejaculation occurs in only 4% of these patients. In males with LMN lesions, approximately 20% achieve an erection, with 20% of these achieving ejaculation. Females with spinal cord injury have reported higher levels of reflex lubrication and psychogenic lubrication, with 50% to 75% reporting orgasm.

Male fertility is impaired in spinal cord injury. Techniques such as vibratory stimulation and electroejaculation may be used to harvest sperm for artificial insemination. Success rates vary from center to center but may approach 50%. In general, it is felt that the earlier the sperm is harvested after spinal cord injury, the greater the likelihood of successful pregnancy. Recent studies suggest the viability of sperm does not decline over time as previously thought (Brackett et al., 1998).

Males with SCI may require assistive techniques for erectile dysfunctions such as prostaglandin penile injections, vacuum tumescence pumps, or penile implants. In general, penile implants are discouraged in the spinal cord injury population since they can lead to erosion and skin breakdown in the perineum. A newer treatment for erectile dysfunction is MUSE, an intraurethral suppository. Viagra, Lavita, and Cialis have proven useful to treat erectile dysfunction in SCI. Caverjet penile injections are required for some men with SCI.

Stiens reports that vibratory ejaculation and electrical stimulation result in semen retrieval in 67% to 97% of men with SCI. Assisted reproduction technologies available in order of complexity include intravaginal insemination, intrauterine insemination, in vitro fertilization, gamete intrafallopian transfer, and intracytoplasmic sperm injection, with costs ranging from $1000 to $14,000 (Blackwell et al., 2001).

In females with SCI, half will not miss a menstrual cycle. Of those who have a delayed menses, all will generally begin normal menstruation within a 3- to 6-month period. The female with SCI typically has no change in her fertility. Birth control becomes a major problem since the female is at high risk for development of DVT and birth control pills are known to increase the risk of DVT. It is generally recommended that birth control pills not be utilized. The Norplant implant is not recommended if there has been a preexisting history of DVT. Condom usage may be the method of choice for prevention of pregnancy in the female with SCI.

Women with spinal cord injuries who become pregnant have a higher incidence of premature and low-birth-weight infants (Sipski & Alexander, 1992). In addition, females during the last trimester of pregnancy may experience more difficulty with urinary tract infections, decubitus ulcers, edema, autonomic dysreflexia, transfers, and self-care. Due to these complications, admission to the hospital during the 32nd week of pregnancy may be required. Breastfeeding for those with tetraplegia may be difficult due to positioning or due to its triggering autonomic dysreflexia. SCI mothers may require assistance with child rearing. The SCI mom will require a power wheelchair to assist her mobility with the infant and diaper bag. This need will continue until childbearing years are over or until the family growth is complete and the youngest child is old enough to be mobile and follow parents’ requests. It has been reported that having a disability increases a woman’s likelihood of physical, mental, or sexual abuse, with as many as 40% having experienced abuse (Ridington, 1989; Nosek et al., 1998; Harness-DiGloria, 1999).

Individuals with spinal cord injury should have access to counseling regarding their sexuality and relationships with others. Counseling can provide sex education to assist the couple in resuming sexual activity and to teach alternate techniques for giving and receiving sexual pleasure with the presence of a spinal cord injury.
Factors to Consider in Life Care Planning

A thorough and comprehensive review of the medical records from the acute care hospital stay and the initial rehabilitation stay should be performed to obtain the most accurate information available regarding the medical history and treatment of the client from time of injury as well as the complications the client has experienced that can have an impact on future medical needs. In addition, a thorough review of the most recent records from physical therapy, occupational therapy, and other providers will provide valuable clues to the person’s current functional status and equipment needs and will occasionally reveal complications. When reviewing the medical records, there are key items that should be searched for, since they can and do alter the future medical needs of the patient. In addition to the complications noted previously, the following is intended to be a partial list of important topics and issues to glean from records that can have an effect on life care plan entries.

Neurological Level

Knowing the neurological level of the patient is crucial as a starting point to determine future medical needs. Therefore, careful review of the records should be performed to determine the exact neurological level and completeness of the spinal cord injury. If this cannot be determined from the records, then the life care planner must obtain an accurate neurological level from a knowledgeable physician. In addition, knowing and describing accurately the neurological level of the patient serves as a baseline in the event that there is a change in the person’s neurological status so that the change can easily be recognized by the caregivers.

Comorbidities

Comorbidities and other medical complications and problems of the patients are extremely important and can impact the life care plan. Complications such as coronary artery disease, peripheral vascular disease, preexisting renal disease, chronic obstructive lung disease, and diabetes mellitus have a significant interplay with the effects of spinal cord injury. Preexisting conditions can become much worse when combined with spinal cord injury and dictate that a higher level of care be provided. Some conditions, although not related to the traumatic spinal cord injury, are seriously complicated by the traumatic spinal cord injury and therefore mandate that the life care plan provide a higher level of care as a result of the spinal cord injury. For example, the insulin-dependent diabetic who becomes tetraplegic requires an increased level of attendant care to monitor blood sugar and give insulin injections, even though diabetes is not directly related to the spinal cord injury.

Preexisting disabilities combined with spinal cord injury can have a synergistic effect and require higher levels of care than would be required by the presence of either disability alone. For example, the blind individual who becomes paraplegic will require a much higher level of attendant care than the average paraplegic.

Functional Independent Measures (FIMs)

FIM scores are used to communicate the level of independence of the patient in many areas. The scores generally are obtained while the patient is in an inpatient rehabilitation setting or
participating in a rehabilitation program. The scale ranges from Level 7, fully independent, to Level 1, which requires total assistance. The rehabilitation record typically will reflect FIM scores in several areas, including dressing, bathing, grooming, transfers, medications, bowel and bladder, and mobility. If the FIM score is 5 or less in any category, then attendant care is needed to assist the patient in that area. While FIM scores are not the only way to determine what personal care services are needed by the individual, they are an excellent way to establish a baseline and provide objective documentation of the need. FIM scores considered along with level of SCI, and many other factors, will help determine need for personal assistance services (PAS). (Also see the following discussion.)

**Equipment**

Review of the records can also determine in part what equipment needs the patient has and what equipment needs have been met at that point. It is not necessary to recommend the exact same type and style of equipment that was recommended by the hospital, but it is important to review what has been provided to the patient and when it was provided prior to making any future recommendations. The equipment provided to or recommended for the individual may be a function of resources available rather than what was indicated or needed.

Various types of durable medical equipment (DME) will be required, although the amount and style depend on the level of injury and the competence of the patient. A life care plan should address wheelchair needs, home and ramp modifications, environmental control systems, equipment maintenance, security systems, transportation needs, cellular phones, and other appropriate equipment.

Position and posture are important variables affecting SCI performance. Problem solving and seating recommendations require a good working knowledge of physical impairment, wheelchair adaptation, seating systems, and the person’s needs. Due to the complexity of the issue, an analytical working method is required (Bolin et al., 2000).

Equipment should also be provided to allow the individual to maintain an active exercise program. Persons with higher-level spinal cord injuries, who are unable to voluntarily move their muscles, may be appropriate for functional electrical stimulation units to perform this activity for them. Functional electrical stimulation (FES) equipment has been around more than 20 years and has undergone significant refinement in recent years. Gittler (2002) provides a brief discussion of indications and costs of several options. Phrenic pacers improve pulmonary function with the basic hardware cost of $50,000. Vocare is designed to improve bowel and bladder emptying, with a hardware cost of $40,000. The Freehand II system, the Handmaster, and the Tetron Glove provide grasp, or key grip and release function, for individuals with C5–C6 tetraplegia, costing approximately $50,000 each. Although the Freehand system is apparently no longer manufactured, a number of units are reportedly available for implantation.

See http://www.aetna.com/cpb/medical/data/300_399/0378.html, which reports that the Freehand system is approved for coverage by this major insurance carrier effective February 1, 2000, and was last reviewed on July 29, 2008. See also www.neurotechreports.com/pages/SCImarket.html, which suggests that neither the Freehand nor VoCare are available anymore. Each of these FES systems will require surgical or nonsurgical placement, training in its use, and ongoing maintenance/replacement cost. A variety of FES devices are useful in maintaining cardiovascular health and improving lipid profiles in spinal cord injury (Wheeler et al., 2002).
Psychological and Social Adjustment

The rehabilitation and acute care records should provide information on family support and the patient’s psychological adjustment to the disability. Patients who cope poorly or fail to complete initial rehabilitation are at much higher risk for experiencing complications and problems and will require a more intensive level of service in the life care plan. In addition, identifying social activities that were important to the patient prior to the spinal cord injury and establishing alternative ways to participate in these activities for the newly injured person are important goals of a life care plan.

Future Needs

Functional Outcomes

Data from current SCI model systems show that the trend for acute inpatient care for individuals who sustain a SCI has significantly decreased. From 1974 to 2005, there had been a 40% reduction in length of hospital stay (from average 25 days to average 15 days), and an even further reduction in days in the rehabilitation unit from an average of 115 days to 36 days (National SCI Statistical Center, 2008). The implications of this for the life care planner are that individuals who receive a traumatic SCI are being discharged sooner from the hospital and rehabilitation unit than previously, with an expected result in less functional outcomes. Therefore, the functional status of the patient is crucial in projecting future equipment needs and, specifically, personal assistance services needs. Careful consideration to the needs of a patient must be given and every attempt made to accurately represent the number of personal care hours that are required. PAS needs can represent the single most expensive part of the plan for individuals with higher-level injuries. For example, individuals who are ventilator-dependent tetraplegics require 24-hour care. If PAS are purchased through an agency, care that is at least on the level of a licensed practical nurse (LPN) will be provided. In many cases, there are no LPNs trained in ventilator care, in which case an RN will be required (check with the agency within each state with regard to its policies on this topic). At the other extreme, an individual with lower-level paraplegia may be self-sufficient with a few hours of homemaker services. Underrepresentation of PAS needs will result in the patient not having adequate services to maintain him or her throughout his or her lifetime and will likely lead to a higher rate of complications and hospitalization and, in extreme cases, reduced life expectancy. Overestimating the PAS needs will result in an inaccurate, unjustifiable, and more expensive plan that is unfair to all parties involved.

There are a number of tables that can be used to provide a starting point on what a person’s functional level is anticipated to be given his or her neurological level of spinal cord injury. Comprehensive tables available include those published in Blackwell et al. (1994), Staas et al. (1993), and Braddom (1995). A more complete discussion of these issues can be found in Blackwell et al. (2001) and Harrell and Krause (2002).

These references and their corresponding tables are intended to serve only as guides in making projections about the types of support an individual will need. There are patients who will function with less care and others who will require much greater care, given their unique sets of circumstances; thus, each person must be evaluated individually. Failure of a patient to meet the projected level of independence does not necessarily mean the patient is not trying, is poorly motivated, or is malingering. The tables referred to are general starting points. However, there are specific areas in each of these tables that these authors have serious disagreements with, and we
do not, by noting them here, suggest that we wholeheartedly agree with the recommendations in these publications.

It is well recognized that the most expensive component of present and future care is the area of support services or personal assistance services for individuals with SCI. PAS includes attendant care, homemaker services, driver services, and home/lawn maintenance. Several studies have attempted to identify the average charges or expense for these services (Berkowitz et al., 1992, 1998; Devivo et al., 1995). These studies have attempted to identify cost of PAS as an average in cohorts, with questionable success. The studies do not in any way represent the actual needs for PAS. Data from these studies are not intended to apply to a specific individual. In addition to limitations of the studies, the authors warn that the data should not be used to project the future needs of an individual. The life care plan is a needs-based assessment and must be written to reflect the actual need of the person with SCI. Harrell and Krause (2002) specifically state that “it would be irresponsible, and a breach of our professional duties and responsibilities as life care planners, not to endeavor to articulate this need.” Many factors affect the number of hours of PAS required as well as the level of training required. Some include the level of SCI, age at onset of SCI, gender, comorbidities, SCI complications, duration of SCI, effects of aging with SCI, obesity, cognitive ability, compliance, and level of psychological adjustment. Guidelines for hours of PAS have been published by the Consortium for Spinal Cord Injury (1999), Outcomes Following Traumatic Spinal Cord Injury. This has been adapted by Blackwell et al. (2001) and is presented with permission in Table 18.2. The guidelines are not intended to be prescriptive, but are a guide to understand PAS needs in individuals with SCI. In addition, it should be recognized that projections are based on the average SCI case (i.e., young, healthy, and male).

Relying on family members to provide PAS is inadequate and leads to adverse effects on the family. Burnout, fatigue, exhaustion, stress, loss of intimacy, and social isolation are some of the more common problems (Blackwell et al., 2001). Families serving as caregivers do so at considerable cost to themselves, increasing their own risk for health problems. Caregivers who find that role stressful have a mortality risk 63% higher than noncaregivers over a 4-year period (Schulz & Beach, 1999). Private hire of PAS has hidden costs and problems described in the article by Thomas and Kitchen (1996), “Private Hire: The Real Cost.” Harrell and Krause (2002) report that the reality of self-managed care can be burdensome and suggest, “It is often difficult to find appropriate caregivers … the identification and screening of appropriate assistant candidates is difficult even for professionals.”

In cases where a high level of PAS is required, recommending nursing home placement absent compelling reasons is considered at the very least inadequate and likely unethical. Harrell and Krause’s (2002) comments earlier about the life care planners’ obligation to develop a needs-driven report speaks to this issue. Nursing home placement typically results in a reduced quality of life for people with SCI (Duggan et al., 2002; Harrell, 2002). Duggan et al. (2002) indicate that in today’s managed care environment, a focus on cost containment has resulted in the population of individuals with SCI being discharged earlier and more likely facing nursing home placement. The national SCI model system database reveals a significant increase in discharges to nursing homes from 3% in 1977 to 6% by 1993, and such discharges may be in excess of 8% today. The authors state that “the typical skilled nursing home facility may not be equipped to provide the necessary level and intensity of SCI care demanded” (Duggan et al., 2002). The study identified numerous problems in nursing home care, such as

- Failure of staff to answer call buzzers
- Insufficient attention to personal privacy
Absence of routine self-care activities, or self-care that was provided haphazardly or irregularly

- Failure to give bowel and bladder care in a timely manner, with bowel and bladder routines virtually disappearing
- Functional gains made in rehab lost
- Verbal and physical abuse by staff
- Increased rates of complications experienced by the cohort
- Repeat hospitalizations, and an overall pattern of instability
- Lack of economic power as the reason for nursing home placement

The Supreme Court on June 22, 1999, decided *Olmstead v. L.C.* (527 U.S. 581, 1999), ruling that institutionalization of a person with a disability when a physician deems community treatment equally beneficial “is properly regarded as discrimination based on disability.” President George W. Bush in his New Freedom Initiative committed to signing an order supporting the most integrated community-based settings for individuals with disabilities (Bush, 2001). In addition, the Department of Health and Human Services prepared a report for the Congress that indicates

<table>
<thead>
<tr>
<th>Level of Injury</th>
<th>Assistance Required</th>
<th>FIM&lt;sup&gt;a&lt;/sup&gt;</th>
<th>NSCISC Median&lt;sup&gt;b&lt;/sup&gt;</th>
<th>NSCISC Interquartile Range&lt;sup&gt;c&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>C1–C3</td>
<td>24-hour attendant care, to include homemaking</td>
<td>24 hours/day</td>
<td>24 hours/day</td>
<td>12–24 hours/day</td>
</tr>
<tr>
<td>C4</td>
<td>24-hour care, to include homemaking</td>
<td>24 hours/day</td>
<td>24 hours/day</td>
<td>16–24 hours/day</td>
</tr>
<tr>
<td>C5</td>
<td>Personal care: 10 hours/day Homemaking: 6 hours/day</td>
<td>16 hours/day</td>
<td>23 hours/day</td>
<td>10–24 hours/day</td>
</tr>
<tr>
<td>C6</td>
<td>Personal care: 6 hours/day Homemaking: 4 hours/day</td>
<td>10 hours/day</td>
<td>17 hours/day</td>
<td>8–24 hours/day</td>
</tr>
<tr>
<td>C7–C8</td>
<td>Personal care: 6 hours/day Homemaking: 2 hours/day</td>
<td>8 hours/day</td>
<td>12 hours/day</td>
<td>2–24 hours/day</td>
</tr>
<tr>
<td>T1–T9</td>
<td>Homemaking: 3 hours/day</td>
<td>2 hours/day</td>
<td>3 hours/day</td>
<td>0–15 hours/day</td>
</tr>
<tr>
<td>T10–L1</td>
<td>Homemaking: 2 hours/day</td>
<td>2 hours/day</td>
<td>2 hours/day</td>
<td>0–8 hours/day</td>
</tr>
<tr>
<td>L2–S5</td>
<td>Homemaking: 0–1 hours/day</td>
<td>0–1 hours/day</td>
<td>0 hours/day</td>
<td>0–2 hours/day</td>
</tr>
</tbody>
</table>


Notes:<sup>a</sup> Expected FIM instrument outcomes based on expert clinical consensus.
<sup>b</sup> Median FIM estimates, as compiled by NSCISC.
<sup>c</sup> Interquartile range for NSCISC FIM data.
<sup>d</sup> Personal care includes hands-on delivery of all aspects of self-care and mobility, as well as safety interventions.
<sup>e</sup> Homemaking activities include meal planning and preparation and home management.

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90% of nursing homes do not have enough workers to properly care for patients (Pear, 2002). The preliminary implications by Kathryn Allen, director, Health Care—Medicaid and Private Health Insurance Issues, are available from the U.S. General Accounting Office in publication GA001-1167T, *Implications of Supreme Court’s Olmstead Decision Are Still Unfolding*. Nursing homes have been implicated as reservoirs of multiple antibiotic-resistant bacteria (Wiener et al., 1999). *JAMA* (September 1998), in its medical news and perspectives section, discusses unacceptable nursing home deaths, and reports that two-thirds of deaths where autopsy was done revealed that the causes were treatable. In addition, 3113 nursing home residents died avoidable deaths from malnutrition, dehydration, urinary tract infection, bowel obstruction, or bedsores in 971 nursing homes in 1993 alone. Clearly, recommending nursing home placement absent compelling reasons in this physician author’s opinion is unacceptable life care planning practice.

**Psychological and Vocational Rehabilitation Issues**

Adjustment to disability and community reintegration are crucial factors that have an effect on quality of life and longevity. Clinical depression is five times more common in the SCI population than the general population (Kemp et al., 1999). Sufficient attention must be provided in this area in the life care plan to ensure that an adequate adjustment to disability is achieved by the patient, and that he or she can resume a functional role in the community.

Vocational goals should be assessed when appropriate and require the expertise of a vocational rehabilitation counselor who is knowledgeable in spinal cord injury. Rehabilitation engineering or assistive technology also may be very useful to the client’s successful return to productivity (Weed & Field, 2001). Recreational activities have an important impact not only on the patient but on his or her family as well and attempts should be made to assess the person’s important preinjury recreational activities and to reintegrate them into these activities to the extent possible and appropriate given the injury level. For example, an outdoor enthusiast who hunted frequently may be accommodated with an all-terrain vehicle and appropriate hunting-assisted devices. Some activities may have specific benefits. For example, an individual with tetraplegia may exercise the pulmonary system with blow darts.

As previously noted, sexual adjustment and marital relationship issues must be considered in the life care plan. Berkowitz et al. (1992) reports that the rate of divorce in individuals with SCI is twice as high as in the general population. Females with SCI reported a lack of meaningful relationship, and sexuality counseling is frustrating (Pentland et al., 2002). Appropriate counseling should be provided to both the individual with the spinal cord injury and the spouse or significant other. This may require consideration for family adjustment, which is frequently an issue after spinal cord injury. All members of the family, including the children, have suffered losses and may need to have available some level of support and counseling to assist with their readjustment. Further, for individuals who either are too young or do not have a significant other at the time of SCI, consideration should be made for counseling and adjustment needs as future relationships develop.

The life care plan must ensure that the patient’s highest functional level is achieved and maintained throughout his or her lifetime. The support services that are provided have a major impact in this area. Patients should have adequate access to individuals who can assist in improving and maintaining their strength, endurance, and range of motion. They should be given the opportunity to learn advanced wheelchair skills and improved community mobility.
**Medical Follow-Up**

The patient with SCI will require physician evaluations and treatment over the course of his or her lifetime. The required physician specialties and evaluations will depend on the patient’s level of injury and individual situation. In general, every individual with SCI should have a physiatrist if one is available in the local community. Additional physicians and specialties based on individual needs that often are periodically required include urology, internal medicine, neurosurgery, orthopedics, pulmonary medicine, podiatry, and plastic surgery. Laboratory evaluations will include complete blood counts (CBCs), sequential multiple analysis (SMAs), urinalyses (UAs), urine cultures and sensitivities (UC&S), renal ultrasounds, intravenous pyelograms (IVPs), electrocardiograms (EKGs), x-rays, and magnetic resonance imaging (MRI).

In most cases, periodic physical therapy and occupational therapy evaluations will be required. Additional support services may include respiratory therapy, particularly for individuals with a higher-level injury. Biannual, annual, or semiannual spinal cord injury evaluations (depending on individual needs) by a team of experts should be provided in order to reassess the patient’s functional status, evaluate medication needs, train new caregivers, introduce new equipment and technology to the patient, reduce the likelihood of complications, assess changes over time related to aging, and improve the level of overall care provided to the patient. These evaluations can be provided in a specialty spinal cord treatment center or by a local team that is particularly knowledgeable and expert in providing these services. A systematic assessment by an interdisciplinary team knowledgeable in SCI is essential (Whiteneck & Menter, 1993). Based on the authors’ experience in developing life care plans for individuals with SCI, a potential trend in recent years has been that a comprehensive, interdisciplinary SCI evaluation at a model SCI center may no longer be the standard for every patient. Instead, an evaluation by the SCI physiatrist generally is performed with recommendations and referral for further evaluation by the various specialties. In at least one model SCI center, the physiatrist evaluation generally is scheduled first, with the client returning to the center for additional evaluations as recommended by the physiatrist. However, this does not mean to imply that the life care plan should not include recommendations for regular evaluations by qualified professionals in SCI medicine and rehabilitation, and the astute life care planner should be able to obtain costs for each of the expected evaluations separately in order to provide the comprehensive evaluation. One life care planner recently posted researched costs from a model SCI center for a client who had high-level tetraplegia and was ventilator dependent to include a total of over $21,000 for the various specialties typically included in a comprehensive, inpatient, interdisciplinary evaluation (electronic post to LCPforum, retrieved December 22, 2008, www.careplanners.net).

**Transportation**

Transportation to medical appointments, work, recreation, or shopping can be a significant issue for patients with spinal cord injuries. Initially, lower-level paraplegics may do well with an automobile and hand controls. A Braun car topper may be adequate for wheelchair storage, or a patient may be able to store the wheelchair behind the driver’s seat. Individuals with tetraplegia or clients with paraplegia who are aging may require an accessible van with a wheelchair lift. In general, parking should be covered since protection from the elements is important for transfers into and out of the vehicle. Some vans are designed to fit into a standard garage; however, most have a raised roof that may prevent the use of standard carports or garages.
Supplies/Medications

As the life care planner probably expects, supplies can be a major part of the life care plan. Catheters and bladder-management-related items, chux pads, bowel program supplies, skin care products, dilatation sticks, latex gloves, sanitation supplies, and so on will be required. A strategy to assess this need is to obtain a list of suppliers and request a printout of the products obtained over the past 6 months. This list will usually provide a complete picture, including amount, size, usage, and cost. Often lists of medications from the pharmacist will reveal forgotten complications that should be considered in the life care plan. The plan should include provisions for changes for additional supplies in the future.

Vocational Considerations

Many individuals with a spinal cord injury will be able to enter the labor market (Devivo et al., 1995; Krause, 1996; Krause & Anson, 1996). The number one factor for successful employment is amount of education. As one may expect, the higher the education level, the more likely the individual with SCI is able to find employment (Krause, 1996; Krause & Anson, 1996). Other influences include level of injury, with paraplegics more likely to be employed than tetraplegics. Ethnicity also seems to play a role, with Caucasians typically finding employment more often than individuals from minority groups. With regard to ethnicity, it is interesting to note that current research reports that minority women are more likely to be employed than minority men, but Caucasian men are more likely to be employed than Caucasian women (Krause & Anson, 1996). With regard to age, people with SCI in the age group of 41 to 50 were more likely to be employed than cohorts who were younger or older. One study reports that people working at the time of their injury had a better chance of finding employment than people who were not working (Devivo et al., 1995). Of interest, only 74% of the participants in one study were working at the time of their injury (Krause & Anson, 1996). Their employment rate was 25% at the time of the study. However, even if they were not currently working, 42% of Caucasians and 23% of minorities reported working at some point since their injury. It is also noted that it may take several years to adequately recover from injury and obtain employment skills. The employment rate continued to rise for more than 8 years postinjury. Krause (1996) also notes that clients who are socially active have a better chance of employment.

Earning capacity is another related issue. Even though the client may be employed, he or she may not be working full-time. In addition, clients’ ability to choose jobs, ascend up the promotion ladder, and otherwise maximize their earning potential is likely compromised. They may also retire earlier or miss workdays due to medical treatment for complications or periodic evaluations. The comprehensive life care plan will reduce the potential for complications and provide vocational support that enhances the potential for suitable employment.

With input from a qualified vocational rehabilitation professional, the life care plan should address the costs for assisting clients with SCI in preparing for employment if work is a reasonable option for them. Potential costs to be outlined in a life care plan could include

- Tuition and fees.
- Books and supplies.
- Computer technology designed to reduce physical effort (such as IBM voice type, Dragon Dictate, Kurzweil, Voice Master, smaller keyboards, keyboard panel, head points, etc.).
- Workstations (such as AbleOffice, produced by the Center for Assistive Technology and Environmental Access, Georgia Institute of Technology, Atlanta, GA).
Vocational evaluation, vocational counseling, job placement assistance, job coaching, and related costs. Postplacement assistance for those clients who successfully obtain employment may also be a consideration for the life care plan in order to assure continuation of employment.

Many life care planners are not vocational experts and may easily overlook or fail to include support for this important quality of life issue. It is suggested that the life care planner include a vocational expert to address this area as a part of the team.

Aging with Spinal Cord Injury

Numerous changes occur as an individual ages, and people with spinal cord injury are no exception. In fact, there is evidence that the individuals with spinal cord injury tend to age faster or experience some of the changes commonly associated with aging earlier than the population of individuals without SCI. The life care plan should anticipate the change in functional status of the person due to SCI, and reflect changing equipment and PAS needs. A model of aging with SCI is useful in projecting functional decline (Menter, 1993). (See Figure 18.2.)

Essentially the graph has three components in terms of level of independence achieved, rate of decline, and length of maintenance phase. First is the level of functional recovery achieved with rehab after onset of SCI. Second is a maintenance phase of variable length in time from a few months to 20 years or more. The last identified phase is the declining phase due to aging, SCI complications, and comorbidities. The slope of this curve, or the rate of decline, is variable from person to person. Many individualized factors affect each component or phase of Menter’s model of aging with SCI. Thompson and Kemp have described the effect of one variable, the age of the person at onset of SCI. When the person is older at onset of SCI, the maintenance phase is shorter in a linear inverse relationship (see Figure 18.3).

This phenomenon is a function of both the absolute age of the individual and the number of years the individual has had the disability. As a result, the patient has changing needs throughout the course of his or her lifetime. The life care plan should reflect this change in needs by

Figure 18.2  Model of aging and physical disability in SCI. (From Menter, R. R., in Aging with Spinal Cord Injury, G. G. Whiteneck et al., eds., pp. 1–8. New York: Demos, 1993. With permission.)
incorporating appropriate services and equipment to meet the anticipated need as the individual ages. For example, it can be anticipated that an individual who has had a spinal cord injury for 20 to 25 years and has been using a manual wheelchair will have more difficulty with upper-extremity pain and complications and may consider switching to a power wheelchair. Similarly, the patient may have more difficulty with transfers and self-care needs and require a higher level of attendant care.

Secondary conditions of SCI are common. As life expectancy has increased for people with SCI, so has morbidity from secondary conditions. In a survey of 117 people with SCI with a mean proportion of 35 disabled life years, respondents reported having experienced, in the year prior to interview, a mean of 6.5 of 17 secondary conditions. The most prevalent were spasms, 87%; UTIs, 73%; skin breakdown, 66%; fatigue, 64%; chronic pain, 49%; bowel problems, 47%; autonomic dysreflexia, 46%; anxiety, 43%; and depression, 42%. Difficulty with independence with regard to activities of daily living and with access to medical care was significantly associated with reports of more secondary conditions (Meyers et al., 2000). Seekins and Ravesloot (2000) conducted a similar survey on 73 rural SCI survivors in Montana who averaged 11 years since the onset of SCI, reporting an average of 16 secondary conditions. This “suggests that many people with disabilities living in rural communities are faring far more poorly than might be expected” (Seekins & Ravesloot, 2000). Surveys of secondary conditions in veterans show a similar prevalence, confirming that serious but preventable secondary conditions are common and take an important toll on people living with SCI (Prysak et al., 2000).

Women aging with SCI have concerns unique and distinctive from males. Pentland has completed a review and describes the concerns felt to be essential for women with SCI to plan and prepare for their later years. Women are more likely to face the aging process alone. They report heavier menstrual flow with age, and wheelchair transfers cause “flooding” by creating surges in menstrual flow. Many in their early forties report menopause symptoms. Frequency of UTIs and incontinence episodes increase, as do bowel care needs. Worsening upper-limb pain interferes with ADL and sleep. Most experience fatigue and reduced stamina, making napping necessary. Those with partners report they are increasingly relying on them for PAS, which is perceived as both a threat and loss to both parties. Many report more “down” days, increased anxiety, marked

Figure 18.3  Decline after SCI relationship to age of onset of SCI. (From Kemp, B., Long-term outcomes with disability, Rancho Los Amigos Seminar, Sept 1998. With permission.)
absentmindedness, and tearfulness. The age-related changes exacerbate the need for continual adjustment. The women indicated that well-trained attendants who are knowledgeable about SCI can play a significant role in averting medical problems (Pentland et al., 2002). Women in general required more PAS than men (Berkowitz et al., 1992).

For research regarding aging and spinal cord injury, excellent sources include Menter (1995), Stover (1995), Whiteneck et al. (1991), and Yarkony et al. (1988). Menter has described general physiological changes that occur with aging, such as

- Loss of muscle mass
- Decreased strength
- Decreased range of motion
- Increasing osteoarthritis
- Increasing problems with urinary and bowel management

These aging-related risks in combination can lead to increased pain and decreased functional status. When these effects occur in individuals with SCI, they are additive and accelerate the decline of the person’s functional status. Menter’s (1993) model of aging predicts a functional decline that will begin between 15 and 20 years postinjury for the average person with SCI. Some of the specific problems associated with aging include the following:

- Pain has been reported to occur in over 90% of individuals with a spinal cord injury (Melzack, 1978). There are several types of pain that can increase with time. One type is musculoskeletal pain from overuse of the upper extremities, osteoarthritic changes, and other causes. Another type is a central pain from the spinal cord injury that is usually described as a burning dysesthetic-type pain that has been reported to increase with aging. A neurological pain can develop due to poor posture, arthritic changes at the spinal column, or peripheral nerve entrapments that will further deteriorate the patient’s functional status. Woozly and Young (1995) have reported that pain is frequently a major lifelong management issue in patients with traumatic myelopathy. Potential sources of the pain include bones, ligaments, spinal meninges, cauda equina, and the spinal cord itself (Schmitt et al., 1995). Local pain at the level of the spinal cord injury may be addressed with surgical procedures even after having been present for a number of years (Bohlman et al., 1994). In one report the cervical and shoulder pain in a cape-like distribution common in tetraplegia is felt to be related to an associated orthostatic hypotension (Cariga et al., 2002). Persistent pain is a prevalent problem of community-residing people with SCI and likely to affect activity levels (Widerstrom-Noga et al., 2002). Pain control techniques such as physical therapy, TENS unit, electrical stimulation, and whirlpool therapy should be considered. In some cases, the individual may require an inpatient pain management program.

- Spasticity has been reported to increase with time and can become quite problematic and difficult to control. As an individual ages, he or she may no longer tolerate the medications to treat the spasticity and require the placement of an intrathecal Baclofen pump. Spasticity may require additional physical therapy, whirlpool treatments, or electrical stimulation to control.

- Because as a person ages he or she has a decline in strength and increasing weakness, it is not surprising that fatigue has been reported as one of the most common problems affecting lifestyle and quality of life and is a difficult problem to treat. Contrary to popular belief, wheelchair propulsion and other functional activities such as transfers do not significantly
increase upper-extremity strength (Kotajarvi et al., 2002). Fatigue can best be addressed by providing more assistive equipment, reducing the level of activity, or providing additional personal care services.

- There is mounting evidence that there are physiological and hormonal changes in individuals with SCI that contribute to aging at a faster rate than that of the able-bodied population. Tsitouras and colleagues (1995) have documented abnormally low levels of serum testosterone, growth hormone, and insulin-like growth factors in individuals with spinal cord injuries that predispose the individual to age-related changes. Over time there is little doubt that other changes will be discovered that correlate with Menter’s theory that individuals with SCI age at a faster rate.

**Spinal Cord Injury and Life Expectancy**

A common question asked of the physician is related to the effects of the injury on life expectancy. Although treatment for complications has improved dramatically over time, available statistics continue to reflect a generally reduced life expectancy for individuals with SCI. However, life expectancy is clearly improving as care improves and complications are effectively managed, but is still somewhat below life expectancies for individuals without SCI (National SCI Statistical Center, 2008). Some physicians who specialize in spinal cord treatment have opined that clients, particularly paraplegics, who have access to excellent care such as outlined in a life care plan may achieve normal life expectancy. Further, they argue, research data are not available for these clients. Morbidity and mortality associated with SCI are due not to the neurological deficits per se but to its complications, and survival rates greatly improved with systematic prevention and treatment of SCI complications. The National SCI Statistical Center (2008) suggests that mortality rates are significantly higher during the first year after injury than during subsequent years, particularly for severely injured persons. Catz et al. (2002) found that surviving 5 years or longer predicts a long life expectancy. Figure 18.4 illustrates the trend of improving longevity.

![Figure 18.4 Life expectancy of people with SCI. (From Kemp, B., Long-term outcomes with disability, Rancho Los Amigos Seminar, Sept 1998. With permission.)](image-url)
In general, research demonstrates that the higher the injury, the more the loss. For example, a 40-year-old male with tetraplegia who is ventilator dependent will statistically die sooner than a similar male with tetraplegia who is not on a ventilator. And a 40-year-old male with paraplegia will statistically have a longer life expectancy than both patients with tetraplegia noted previously. Two discussions of life expectancy in SCI are provided in recent publications (DeVivo, 2002; Krause, 2002). DeVivo (2002) indicates that tables can only provide rough estimates of life expectancy, as categories are broad data with considerable variability within each category. Also, factors such as gender, race, time since injury, the trend toward longer life expectancy, and preexisting medical conditions should be considered. Krause (2002) argues that standard approaches to estimating life expectancy are inadequate, do not consider important social variables, and result in the most conservative estimates. In addition, Krause (2002) reports that individuals with Medicaid or Medicare as the primary sponsor of care have a 1.47 to 2.31 greater likelihood of mortality than individuals who have care funded from other sources. Further, individuals having adequate access to care and PAS are going to have a lower rate of mortality, and Krause (2002) concludes that income is a major factor to be considered in life expectancy.

**General Considerations**

It is difficult to rely on statistics for specific clients since many elements can affect longevity. There are several factors to consider, such as the following:

- **Diagnosis**: The type and level of injury have the most obvious impact.
- **Intelligence**: The ability to comprehend, comply, and participate in the management of their injury directly affects quality of care. A patient with severe mental retardation or with a brain injury and a spinal cord injury is less able to assist in his or her own care or recognize complications than someone who does not have a cognitive impairment.
- **Education**: This probably is related to intelligence and refers to understanding the educational value of learning about their situation to prevent complications or to accommodate the disability.
- **Quality of care**: Poor quality of care can lead to unobserved complications that can be life threatening. Good medical follow-up can intervene in complications before they become expensive or life threatening.
- **Compliance**: Lack of compliance in medicine is a well-known problem. For example, a poor weight shift schedule can lead to serious and expensive skin breakdown care.
- **Personality and psychological state**: Also related to compliance is the person’s ability to train and get along with caregivers. Good and assertive communicators are better able to convey their needs than shy, ineffective patients. Also, clients with poor psychological adjustment may be harmful to themselves.
- **Family support**: Another well-known and researched attribute is the client’s family support system. Overall, the better the support, the better the recovery and adjustment.
- **Home vs. institution**: The client’s place of residence can have an effect by subjecting the patient to virulent diseases if in a nursing home. Also, staff who work for the facility are often less responsive to patients than staff whose paychecks come directly from the client. In addition, staff who work for a facility may have several patients to manage, whereas clients at home usually are the attendant’s only responsibility.
Risk Factors

As with the general population, there are risk factors that the physician must consider when opining about the patient’s life expectancy:

- **Age**: As noted previously, aging leaves patients with reduced ability to rebound from illness and complications.
- **Gender**: Males generally are expected to have a shorter life span. (This is consistent with mortality rates among males in the general population.)
- **History of complications**: Some patients have a history of problems that can be serious with regard to life expectancy. Upper respiratory infections, skin breakdown, and serious spasticity are just a few examples.
- **Diseases**: As noted previously, patients with diabetes pose greater problems than patients without this disease. Preexisting cancer, diabetes, cardiovascular disease, or other diseases may be a factor.
- **Smoking**: Smoking is a well-known life-reducing activity. Individuals with tetraplegia with already impaired respiration may be at even more risk.
- **Substance abuse**: Alcoholism or drug addiction can significantly affect the patient’s basic physical well-being, as well as detrimentally affect his or her judgment. For example, one patient who became a paraplegic from an automobile crash after drinking was rendered a tetraplegic when he had another motor vehicle crash after drinking.
- **Good or bad genetics**: Family history has been linked to longevity.

In summary, to project the patient’s life expectancy, the life care planner should consult a qualified physician with regard to this topic in order to consider the individual’s unique factors. A strong caution must be given on attempting to apply generalized statistics to a specific person with a spinal cord injury. Deutsch and Sawyer (1996) have an excellent discussion on the problems of “mindless use of data.” The available information must be reviewed and interpreted by a physician experienced and knowledgeable in the field of spinal cord injury. Currently available data, in all likelihood, underrepresent true life expectancy of individuals with SCI.

For patients who appear to have higher risk factors for shortened life expectancy, the life care planner should make fair and reasonable attempts to provide a level of care in the plan to reduce the risk to the extent possible while also enhancing the client’s optimal level of functioning and quality of life.

Case Study

This 46-year-old Missouri client was injured in a motor vehicle crash resulting in mild brain injury and C4–C5 spinal cord injury. The client demonstrates no functional capabilities with three of his extremities, although he has enough motion in his right upper extremity to control his wheelchair. He wears a tracheostomy (trach) as a result of his inability to cough appropriately, and suctioning of his secretions reportedly is required several times per day. Additionally, he speaks with the aid of a Passy Muir speaking valve that is attached to his trach. The client has experienced several complications, and the future medical care requirements are more detailed than most. The life care plan follows.
### Life Care Plan

**Note:** For purposes of this plan, the following initials are placed in parentheses according to their respective recommendations:
- **RE** = Reedi Eates, MD, gastroenterologist
- **RW** = Roger Weed, PhD, life care planner
- **TW** = Terry Winkler, MD, consulting physiatrist

#### Routine Future Medical Care—Physician Only

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Year Initiated and Frequency</th>
<th>Purpose</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Physiatrist (TW)</strong></td>
<td>3 times/year to life expectancy</td>
<td>Assess medical status to address/prevent complications.</td>
<td>$300–600/year at $100–200/visit (depends on length of visit and complexity of exam)</td>
</tr>
<tr>
<td><strong>Urologist (TW)</strong></td>
<td>2 times/year to life expectancy Every other year to life expectancy 1 time/year to life expectancy</td>
<td>Monitor neurogenic bladder and urological functioning.</td>
<td>$200–400/year at $100–200/visit Ultrasound: $235–280 Cystoscopy: $325–400</td>
</tr>
<tr>
<td><strong>Pulmonologist (TW)</strong></td>
<td>3–6 times/year to life 1–2 times/year (average) to life expectancy 1–2 times/year (average) to life expectancy</td>
<td>Monitor respiratory status and tracheostomy.</td>
<td>Initial: $100–400 (includes x-ray and pulmonary function tests) Follow-up: $65–170/visit $65–100 each (depending on single view, etc.) $65–300 each (depending on specific tests needed)</td>
</tr>
<tr>
<td><strong>Orthopedist (TW)</strong></td>
<td>1 time/year to life expectancy</td>
<td>Monitor heterotopic ossification formation and reduce or prevent complications.</td>
<td>$100–200/year depending on length and complexity of visit</td>
</tr>
</tbody>
</table>

**Note 1:** Costs do not include cultures of trachea secretions to survey for pathogens or other diagnostic tests that cannot accurately be determined at this time.

**Note 2:** The client continues to require a tracheostomy (trach). Presume trach and related supplies will be needed to life expectancy. See also related medical equipment and related supplies.

**Note:** Cost does not include x-rays or other diagnostic tests that cannot accurately be determined at this time.
### Life Care Planning for Spinal Cord Injury

Podiatrist (TW)  
3 times/year (average)  
Toenail care and cutting.  
Initial: $45–130 (depending on length of visit)  
Follow-up: $44–46/visit

Plastic surgeon (TW)  
2–4 times/year (average) to life expectancy  
Monitor skin care and prevent/manage skin breakdown.  
$164–328/year to life expectancy at $82/visit (2009)

Internist/general practitioner (TW)  
Annual influenza vaccination (TW)  
Pneumococcal pneumonia vaccine (TW)  
2–4 times/year over and above general population  
1 time/year  
1 time only  
General medical care and treatment of acute complications.  
$120–320/year at $60–80 for Level III visit (2009)  
$20/year (2009)  
$25, 1 time only (2009)

Note 1: The frequency of routine future medical care assumes the client's complications are well controlled. It is expected that the client will experience complications; however, the frequency, type, and severity are difficult to predict. Also see Potential Complications.

Note 2: The client may also need evaluation and/or follow-up by other specialists, including gastroenterologist, pulmonologist, and others as needed depending on complications and at the discretion of his primary physician.

### Projected Evaluations—Nonphysician

*Include all allied health evaluations*

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Year Initiated</th>
<th>Frequency/Duration</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical therapy evaluation (TW)</td>
<td>2002</td>
<td>1 time/year to life expectancy</td>
<td>$150–352 for initial 30- to 60-minute evaluation, then $150–180/year thereafter to life expectancy</td>
</tr>
<tr>
<td>Occupational therapy evaluation (TW)</td>
<td>2002</td>
<td>1 time/year to life expectancy</td>
<td>$150–352 for initial 30- to 60-minute evaluation, then $150–180/year thereafter to life expectancy</td>
</tr>
<tr>
<td>Nutritional/dietary evaluation (TW)</td>
<td>2002</td>
<td>1 time/year to life expectancy</td>
<td>$60–70/year for 1-hour consultation</td>
</tr>
<tr>
<td>Psychological evaluation (RW)</td>
<td>2002</td>
<td>1 time only</td>
<td>$125–175 (depending on specific tests administered)</td>
</tr>
</tbody>
</table>

*Note:* One of the psychologists contacted stated that he sees the client for a 1-hour initial visit at $125 to obtain a thorough case history and then will recommend psychological testing, if appropriate, based on the initial evaluation. If indicated, cost for testing is $300 to $400 at $100/hour for 3 to 4 hours of testing (approximately).
Therapeutic recreation evaluation with report and recommendations (RW) | 2002 | 1 time only. | $176–352 for 30- to 60-minute evaluation
---|---|---|---
Home accessibility evaluation (see also Architectural Considerations) | 2002 (or when move to new home) | 1 time only. | $250 (average estimate) for 1-hour in-home OT evaluation (2009)

**Note:** An occupational therapist with experience and expertise in home accessibility and assistive technology is recommended to evaluate the client’s home as well as make recommendations for assistive technology devices for in-home use.

### Projected Therapeutic Modalities

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Year Initiated</th>
<th>Frequency/Duration</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical therapy (in addition to daily range of motion by caregivers) (TW)</td>
<td>2002</td>
<td>3 times/year to evaluate in-home program and make recommendations</td>
<td>$270–333/year at $90–111/visit</td>
</tr>
<tr>
<td>Counseling (individual and/or couple) for adjustment to disability, coping strategies, problem solving, etc. (RW)</td>
<td>Unknown*</td>
<td>Unknown*</td>
<td>Unknown*</td>
</tr>
</tbody>
</table>

**Note:** The client's need for and frequency of counseling will be dependent upon outcome of psychological evaluation.

| Sexual evaluation/ counseling (TW) | 2002 | 1-time evaluation | $0; included in urological evaluation |

**Note 1:** Dr. Winkler suggests options that may be appropriate for the client include a trial dose of Viagra, an Erectaide device, and/or Prostaglandin injections; however, occurrence and frequency depend on outcome of urological evaluation. See also Potential Complications.

**Note 2:** Sexual counseling also may be a component of the comprehensive rehabilitation day program at the spinal cord injury rehabilitating center.

| Case manager to problem solve, coordinate care, client advocate, hire caregivers, oversee case, etc. (RW) | 2002 (immediate need) | 4 hours/week (average) for 1 year, then 4 hours/month (average) to life expectancy | $15,600–16,432 for first year, then $3600–3792/year (average), thereafter at $75–79/hour |

### Diagnostic Testing/Educational Assessment

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Year Initiated</th>
<th>Frequency/Duration</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Optional neuropsychological evaluation (RW)</td>
<td>2002</td>
<td>1 time only</td>
<td>$2000 (average) with report and recommendations</td>
</tr>
</tbody>
</table>
### Wheelchair Needs

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Year Purchased</th>
<th>Replacement Schedule</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Invacare Action Arrow power wheelchair with joystick controls, recline system, elevated leg rests, arm rests, head rest, etc. (TW)</td>
<td>4/8/98 (already has)</td>
<td>Every 4–5 years depending on use</td>
<td>$16,074 retail (negotiated cost at $13,341)</td>
</tr>
<tr>
<td>Reclining manual wheelchair for backup mobility (TW)</td>
<td>2002 (immediate need)</td>
<td>Every 10 years (estimate) depending on amount of use</td>
<td>$3000 (average)</td>
</tr>
<tr>
<td>Shower wheelchair for bathing and hygiene (assumes accessible bathroom) (TW)</td>
<td>2002 (immediate need)</td>
<td>Every 4–5 years depending on wear and tear</td>
<td>$1500 (average)</td>
</tr>
<tr>
<td>Tilt table for stand-up capability (TW)</td>
<td>2002–2020 (age 65)</td>
<td>Every 10 years (estimate) depending on amount of use to 2020</td>
<td>$1184–3799 for manual table or electric/manual combination table (2001)</td>
</tr>
</tbody>
</table>

### Wheelchair Accessories and Maintenance

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Year Purchased</th>
<th>Replacement Schedule</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Roho wheelchair cushion (TW) 2 cushion covers</td>
<td>2000 (already has)</td>
<td>Every 2 years (average) 1 time/year</td>
<td>$399</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>$50/year</td>
</tr>
<tr>
<td>Note: It is recommended the client have two cushion covers—one to be used as backup when the primary cover is being laundered or otherwise unable to be used.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 gel batteries for wheelchair (TW)</td>
<td>1998</td>
<td>1 time/year</td>
<td>$350 for pair</td>
</tr>
<tr>
<td>Note: According to the client’s wheelchair vendor, a battery charger comes with the purchase of a wheelchair and, if properly used and maintained, should not need replacement sooner than the wheelchair. Replacement cost, if needed, is $450.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Power wheelchair maintenance (TW)</td>
<td>2002</td>
<td>1 time/year and as needed after 1-year warranty</td>
<td>Expect 10% cost of chair/year. Note: Do not include maintenance on years wheelchairs are replaced. See also next entries.</td>
</tr>
<tr>
<td>Manual wheelchair maintenance (TW)</td>
<td>2003 (or 1 year after purchase of manual backup wheelchair)</td>
<td>1 time/year and as needed after 1-year warranty</td>
<td>Expect 10% cost of chair/year.</td>
</tr>
</tbody>
</table>
## Orthotics/Prosthetics

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Year Purchased</th>
<th>Replacement</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bilateral resting hand splints (TW)</td>
<td>2002</td>
<td>1–2 times/year (average)</td>
<td>$33–60 standard (Sammons Catalog)</td>
</tr>
<tr>
<td>Bilateral resting ankle splints (TW)</td>
<td></td>
<td>Every 2 years (average)</td>
<td>$40–65 standard (Sammons Catalog)</td>
</tr>
</tbody>
</table>

## Assistive Technology/Aids for Independent Function

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Year Purchased</th>
<th>Replacement Schedule</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobile Arm Support Feeder with elevating forearm mechanism that attaches to wheelchair to assist with right-hand feeding (TW, RW) Training by occupational therapist in proper use (TW, RW)</td>
<td>2002 (upon completion of intensive and comprehensive rehabilitation program) to life expectancy</td>
<td>Every 5 years (average)</td>
<td>$325 (includes instruction manual and reclining wheelchair feeder bracket); if Winsford Feeder is needed, cost = $2960 (2001) $0; it is presumed training can be provided by the OT during the rehabilitation program and monitored by the OT during annual evaluations</td>
</tr>
<tr>
<td>Allowance for assistive technology devices/aids for independent function such as mouth sticks, page turner, tabletop docking station, swivel docking station, pillow splints, handheld shower, etc. (RW)</td>
<td>2002</td>
<td>1 time/year to life expectancy</td>
<td>$100/year (average)</td>
</tr>
<tr>
<td>Computer system, printer, and Internet access (RW)</td>
<td>2002</td>
<td>Life expectancy</td>
<td>No cost over general population</td>
</tr>
<tr>
<td>Rehabilitation technology evaluation to develop in-home workstation (RW)</td>
<td>2002</td>
<td>1 time only to determine modifications and develop accessible work area for home use</td>
<td>$4000 (estimate) for evaluation and custom-designed area</td>
</tr>
</tbody>
</table>
### Home Furnishings and Accessories

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Year Purchased</th>
<th>Replacement Schedule</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Invacare Hospital Bed (semielectric) Excel 8000 air flotation mattress Maintenance (to include mattress covers, etc.)</td>
<td>1998 (already has) 1999 (already has) 2002</td>
<td>Frame: 1-time-only purchase (see Note 2) Every 10 years (estimate) depending on wear and tear 1 time/year or as needed after warranty and depending on wear and tear</td>
<td>$2030 (actual retail cost of current bed) $1798 (actual retail cost of current mattress) $100/year (estimate)</td>
</tr>
</tbody>
</table>

**Note 1:** If skin breakdown continues to be a problem, the client will require a high-technology skin pressure relief bed system (such as Clinitron or similar). Cost is up to $100/day or $36,500/year.

**Note 2:** An option to allow the client and his wife to sleep in the same bed is a queen-size adjustable bed by Invacare. Cost is $2100.

<table>
<thead>
<tr>
<th>Overbed table (TW)</th>
<th>2002</th>
<th>Every 15 years (estimate)</th>
<th>$100–200</th>
</tr>
</thead>
<tbody>
<tr>
<td>Power Patient Lift System with split sling (TW)</td>
<td>2002 (immediate need)</td>
<td>Lift: 1 time only Sling: Every other year</td>
<td>Lift: $2604–3703 Sling: $165–198</td>
</tr>
</tbody>
</table>

**Note 1:** Dr. Winkler recommends a more advanced lift system that will be easier for the caregivers to use and will transfer the client in a safer way. The new lift also does not require the client to sit on the sling all day, which could potentially reduce the complications he has with skin breakdown.

**Note 2:** It is recommended the client have two lift slings—one to be used as backup when the primary sling is being laundered or otherwise unable to be used.

<table>
<thead>
<tr>
<th>Portable ramps (TW)</th>
<th>2002</th>
<th>1 time only</th>
<th>$300–330</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allowance for accessories such as lift maintenance, batteries for speaker telephone, urinals, transfer board, etc. (RW)</td>
<td>2002</td>
<td>1 time/year</td>
<td>$100/year (average)</td>
</tr>
</tbody>
</table>

### Medical Equipment

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Year Purchased</th>
<th>Replacement Schedule</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vacumax Suction Machine Suction machine canister</td>
<td>1999 (already has) N/A</td>
<td>Every 5 years 1 time/month (average)</td>
<td>$800 $109.20/year at $9.10 each</td>
</tr>
<tr>
<td>Humidifier</td>
<td>1999 (already has)</td>
<td>Every 5 years</td>
<td>$30–50</td>
</tr>
</tbody>
</table>

**Note:** If the client requires a more advanced humidifier or air purifier system, cost could be up to $445.

(Continued)
(Continued)

<table>
<thead>
<tr>
<th>Item</th>
<th>Year</th>
<th>Frequency</th>
<th>Cost per Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nebulizer with compressor</td>
<td>1999</td>
<td>Every 5 years</td>
<td>$165</td>
</tr>
<tr>
<td>Air compressor for tracheostomy</td>
<td>1999</td>
<td>Every 5 years</td>
<td>$800</td>
</tr>
<tr>
<td>Oxygen concentrator</td>
<td>1999</td>
<td>Every 5 years</td>
<td>$3500</td>
</tr>
<tr>
<td>Pulse oximeter (TW)</td>
<td>2002</td>
<td>Every 5 years</td>
<td>$1850 (Handheld) or $2000 (Handheld with printer) or $3000 (Standard)</td>
</tr>
</tbody>
</table>

**Note 1:** The client states the oxygen equipment is used on an as-needed basis and more during winter months and/or times of complications.

**Note 2:** Dr. Winkler reports that based on a telephone conversation with the client and review of available records, it is presumed the client will require the trach and supplies as well as supplemental oxygen and equipment to life expectancy. For purposes of future care planning, the cost of the trach and related supplies/equipment is included to life.

### Drug Needs

Medications will change over time and are representative of the client’s current needs.

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Purpose</th>
<th>Cost per Unit</th>
<th>Cost per Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cytotec, 200 mcg, 1 time/day</td>
<td>Prevent ulcers</td>
<td>$128.49/120 tablets</td>
<td>$390.82/year</td>
</tr>
<tr>
<td>Albuterol solution, 2.5 mg/3 ml, 2 times/week average</td>
<td>Aid in breathing</td>
<td>$22.49/month (approximately)</td>
<td>$76.90/year (average) at 2 times/week (average)</td>
</tr>
<tr>
<td>Dulcolax (Bisacodyl), 10 mg, every other day (TW)</td>
<td>Bowel program</td>
<td>$5.41/30 tablets</td>
<td>$32.91/year</td>
</tr>
<tr>
<td>Baclofen, 10 mg, 4 times/day (TW)</td>
<td>Decrease spasticity</td>
<td>$23.49/90 tablets</td>
<td>$381.06/year</td>
</tr>
<tr>
<td>Robitussin, cf. syrup, 5 ml, every 4 hours as needed</td>
<td>Expectorant and cough medication</td>
<td>$7.69/bottle</td>
<td>$184.56/year at 2 bottles/month (average estimate)</td>
</tr>
<tr>
<td>Ultram, 50 mg, 2 times/day (per client interview, 12/13/01)</td>
<td>Pain relief</td>
<td>$47.70–71.79 for 60 tablets</td>
<td>$580.35–873.45/year (2009)</td>
</tr>
<tr>
<td>Tylenol, 500 mg, 2 times/day (TW)</td>
<td>Pain relief</td>
<td>$12.78/120 tablets</td>
<td>$77.75/year</td>
</tr>
<tr>
<td>Vitamin C, 500 mg/day</td>
<td>Vitamin supplement</td>
<td>$1.49/60 tablets</td>
<td>$9.06/year</td>
</tr>
<tr>
<td>Zinc sulfate, 220 mg, 2 times/day</td>
<td>Mineral supplement</td>
<td>$14.49/60 tablets</td>
<td>$176.30/year</td>
</tr>
</tbody>
</table>
Allowance for additional as needed medications, i.e., Propulsid, Theravac mini-enemas, Bean-O, autonomic dysreflexia medication, etc.

<table>
<thead>
<tr>
<th>Purpose</th>
<th>N/A</th>
<th>Cost per Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gastrointestinal difficulties, bowel management, abdominal gas, episodes of autonomic dysreflexia</td>
<td>$50/year (estimate)</td>
<td></td>
</tr>
</tbody>
</table>

**Note 1:** Antibiotics also are prescribed on a regular basis for infections. See Future Medical Care, for expected yearly cost of antibiotic treatment.

### Supply Needs

Supplies will change over time and are representative of the client’s current needs.

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Purpose</th>
<th>Cost per Unit</th>
<th>Cost per Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>#16 Foley catheter insertion tray, changed monthly (includes catheter and drainage bag)</td>
<td>Bladder management</td>
<td>$16.43/kit</td>
<td>$230.02/year (see following note)</td>
</tr>
</tbody>
</table>

**Note:** According to Dr. Winkler, the client’s Foley catheter may need to be changed more frequently during times of urinary tract infections or other complications. Expect approximately 14 catheter changes/year (average).

<table>
<thead>
<tr>
<th>Purpose</th>
<th>N/A</th>
<th>Cost per Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Colorectal tube, approximately 1/month (RE)</td>
<td>Relief of distended abdomen</td>
<td>$0; client no longer uses; see Potential Complications</td>
</tr>
<tr>
<td>Adult diapers, 1/day (average)</td>
<td>Bowel incontinence</td>
<td>$77.44/case of 72</td>
</tr>
<tr>
<td>Chux bed underpads, 4/day</td>
<td>Incontinence</td>
<td>$56/case of 150</td>
</tr>
<tr>
<td>Power-free gloves, 3/day</td>
<td>Hygiene</td>
<td>$8.50/box of 100</td>
</tr>
<tr>
<td>Tracheostomy collar, 1/month</td>
<td>Respiration</td>
<td>$3</td>
</tr>
<tr>
<td>Disposable nebulizer, as needed</td>
<td>Respiration/airway clearance</td>
<td>$3</td>
</tr>
<tr>
<td>Oxygen cannulas, approximately 10/week Oxygen mask Oxygen adapter for portable oxygen</td>
<td>Respiration</td>
<td>$8/week $3 each $1.50 each</td>
</tr>
</tbody>
</table>

(Continued)
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(Continued)

<table>
<thead>
<tr>
<th>Trach supplies, including trach tube holders and trach drain bags Suction supplies, including canisters, tubing, 14 Fr catheters, etc., as needed Aerosol tubing (100 feet)</th>
<th>Aid in breathing Pulmonary care and aid in suctioning</th>
<th>Expect 1/month depending on frequency of use Estimate 4 times/year depending on use</th>
<th>$44.80/year $16.25/year $76/year at $19 each</th>
</tr>
</thead>
<tbody>
<tr>
<td>Passy–Muir speaking valve</td>
<td>Aid in speaking with tracheostomy</td>
<td>Expect 2 times/year (estimate)</td>
<td>$240/year at $120 each</td>
</tr>
<tr>
<td>Blood pressure cuff (purchased in 1998)</td>
<td>Monitor blood pressure</td>
<td>$85 (average) up to $120 (average) for digital every 10–15 years (estimate)</td>
<td>$5.67–12/year</td>
</tr>
<tr>
<td>Stethoscope (purchased in 1998)</td>
<td>Monitor heart rate</td>
<td>$15 every 15 years (estimate) or $50 for kit (includes blood pressure cuff and stethoscope)</td>
<td>$1/year or $3.33–5/year for both (note: If kit purchased, eliminate separate cost for blood pressure cuff above)</td>
</tr>
<tr>
<td>Porta-Cath</td>
<td>IV access for antibiotics</td>
<td>N/A</td>
<td>$0; do not expect catheter replacement unless complication</td>
</tr>
<tr>
<td>Allowance for sterile gauze pads, kerlex tape, 4 x 4 sponges, Q-tips, 1/2-inch Dakin strips, foam heel protectors, TED hose for swelling, syringes, contact precaution gowns, rubbing alcohol, hydrogen peroxide, antiseptic wipes, various skin creams, donut ring, etc.</td>
<td>Wound and skin care</td>
<td>N/A</td>
<td>Expect $200/year (average)</td>
</tr>
</tbody>
</table>

| Health and Strength Maintenance (Leisure Time Activities) |
|---|---|---|---|
| Recommendation (by whom) | Year of Purchase or Attendance | Replacement or Attendance Schedule | Expected Cost |
| Daily range of motion to extremities See also Assistive Technology/Aids for Independent Function | 2002 to life expectancy | 7 days/week, 365 days/year | $0; provided by in-home caregiver |
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<table>
<thead>
<tr>
<th>In-home care (TW)</th>
<th>2002 to life expectancy</th>
<th>24 hours/day care, 365 days/year</th>
<th>LPN: $24–31/hour weekdays, $24–32/hour weekends</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Minimum LPN level of care at 3 shifts/day; see also note 6</td>
<td>Note: One agency ($31 and $32/hour) bills holidays at 1 1/2 time</td>
</tr>
</tbody>
</table>

**Skilled nurse visit, i.e., RN (TW)**

| 2002 to life expectancy | 2–6 hours/month (average) | RN: $28–37/hour or $90 (2001) to $105/visit (1999) |

**Note 1:** According to Dr. Winkler, the client requires 24 hours/day care, including nighttime awake care for suctioning, positioning/turning, and emergencies. The agencies, based on needs, specify minimum LPN level.

**Note 2:** The client's caregiver must also provide transportation to medical appointments and errands, housekeeping, laundry, meal preparation, bathing, personal care, range-of-motion exercises, and respite to family members who currently provide most of the care.

**Note 3:** Dr. Winkler reports that the client's home health needs will increase during times of illness, infections, or other complications and states the client will require 24-hour RN care for increased level of in-home skilled care due to expected complications. According to Dr. Winkler, estimate 7 days/year for 24-hour RN care for increased level of in-home skilled care due to expected complications. Cost of RN care at $28 to $37/hour for weekdays and $28 to $40/hour for weekends, 7 days/year. Economist to deduct cost of LPN care for 7 days/year while RN care is provided.

**Note 4:** Economist to deduct the cost of 6 to 12 weeks of in-home nursing care on a one-time-only occurrence for the time in which the client is expected to be in the intensive rehabilitation program. Economist also to deduct expected 4 to 9 hospitalization days/year; see Future Medical Care entries.

| Interior/exterior home maintenance (wife will do homemaker tasks) (TW) | 2002 to life expectancy | Expect 2 hours/week (average) | $1040/year at $10/hour (average) |

**Transportation**

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Year Purchased</th>
<th>Replacement Schedule</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wheelchair-accessible van with automatic lift, raised roof, wheelchair tie-downs, etc. (TW)</td>
<td>2002 (immediate need)</td>
<td>Every 7–10 years or 70,000–80,000 miles</td>
<td>$42,000 (estimate) and $256/year mileage to appointments</td>
</tr>
<tr>
<td>Van accessibility maintenance (RW)</td>
<td>2003</td>
<td>1 time/year or as needed depending on wear and tear</td>
<td>$50/year average</td>
</tr>
<tr>
<td>Cellular telephone for emergency communication (RW)</td>
<td>2002</td>
<td>Every 5–7 years (estimate)</td>
<td>No additional cost over general population</td>
</tr>
</tbody>
</table>

(Continued)
(Continued)

### Architectural Considerations

List considerations for home accessibility and/or modifications.

He requires a single-level, barrier-free home with widened hallways and doorways, smooth floor coverings, accessible bathroom to include roll-in shower and grab bars in wet areas, wheelchair ramps to front and back entrance/exit, equipment/storage room, and other accessibility features. His home also requires a backup generator in the event of a power failure. Although his oxygen and respiratory equipment are not used on a daily basis, an alternate or backup power source is recommended in the event of power failure when the equipment is in use. Estimated cost for standard generator is $2000, including installation (will not power home air-conditioning).

Current home is not modifiable. If a new home is constructed, expect cost to be 8% to 12% above the cost of the average home in the local area. Moving expenses to move the client's belongings from his current residence to a new residence are estimated at $5000. Economist is to deduct the value of an average home in the client's local area.

### Future Medical Care, Surgical Intervention, Aggressive Treatment

<table>
<thead>
<tr>
<th>Recommendation (by whom)</th>
<th>Year Initiated</th>
<th>Frequency</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antibiotic treatment for complications related to urinary tract infections, indwelling Foley catheter, upper respiratory infections, etc. (TW)</td>
<td>2002</td>
<td>Oral antibiotics 1–2 courses/year (average) (estimate 3 tablets/day, 10 days average/course) IV antibiotics 1- to 2-week course (average) every 2–3 years (average) to life expectancy</td>
<td>Oral antibiotics $129–590/year to life at $129–295/course (2009) (range includes Ceftin to Levaquin antibiotics) IV antibiotics $1567–3134 every 2–3 years at $223.89/day for medications (2001) plus $1260–2520 for RN to administer IV antibiotics 2 times/day (average) at $90/visit for 1–2 weeks (average) every 2–3 years (average) to life (2009)</td>
</tr>
</tbody>
</table>

**Note 1:** According to Dr. Winkler, the client is expected to have on average 4 to 9 days/year of hospitalization for urinary tract infections, upper respiratory infections, skin breakdown, and other complications related to his spinal cord injury at an average of $1200/day.

**Note 2:** At the time of Dr. Winkler’s examination, the client reportedly had a Grade II decubitus ulcer on his right ischial tuberosity that required immediate attention, and chronic osteomyelitis in his left ischial tuberosity. Information received subsequent to Dr. Winkler’s evaluation reveals that the client has seen the plastic surgeon regarding his pressure sores and underwent aggressive wound care.

**Note 1:** According to Dr. Winkler, the client is expected to require oral antibiotic treatment on a yearly basis and IV antibiotics on an intermittent basis for various complications related to the spinal cord injury throughout his life expectancy.

**Note 2:** The client states that he was prescribed oral Ceftin and Levaquin for his most recent infections and informs that he generally is no longer prescribed Cipro or Augmentin antibiotics. According to the infusion company, his last IV antibiotics were Vancomycin and Cefazidime, administered in July 2000, and cost is based on his history of infusion therapy.
Comprehensive rehabilitation day program, including physiatry, nursing, respiratory therapy, PT, OT, seating and positioning, education/training, vocational services, community reintegration, etc. (TW) 2002 (immediate need) 6- to 12-week program (actual length of program will be determined following evaluation by rehabilitation team) $21,120–42,240 at $704/day for 5 days/week program
Airfare to treatment center: $268 (2009) round-trip (for client plus 1 attendant; see following note)
Accessible ground transportation to/from Atlanta airport: $180–190 at $90–95/trip for 20 miles one way (approximately)
Lodging is included in per diem

Note 1: Economist is to deduct therapeutic evaluations, i.e., PT, OT, and dietary, for the year in which the client participates in the intensive rehabilitation program.

Note 2: Additional physicians and specialty services may be added to the day program (i.e., urology, psychology, sexual counseling, plastic surgery, etc.) depending on the client’s needs and outcome of initial team evaluation. Type and amount of services, if any, cannot accurately be determined and no additional cost is included in plan.

Note 3: Assumes the client’s wife will accompany him to the evaluation and will be his attendant.

Potential Complications

Note: Potential complications are included for information only. No frequency or duration of complications is available. No costs are included in the plan.

Skin breakdown/decubitus ulcers that could require surgery to correct. The client has a history of skin breakdown and hospitalizations for wound care with surgical intervention. Recent statistics regarding pressure sore treatment at a specialty spinal cord treatment center include $62,000 for 6-week hospitalization up to $92,000, including physician and operating room charges (source: Arthur Simon, MD, plastic surgeon, 10/20/99).

Increased risk for respiratory complications, including pneumonia, embolus, lung collapse, upper and lower respiratory infections, etc., due to spinal cord injury and tracheostomy use, which could require extensive diagnostic studies, aggressive pulmonary treatment, or hospitalization. The client has a history of hospitalizations for pneumonia and has other respiratory problems.

Cardiovascular problems, including heart disease, high cholesterol levels, inflammation of veins with clots, deep venous thrombosis, electrolyte imbalance, heart irregularities, and feet/leg circulation problems.

Urological problems, including urinary tract infections, bladder/kidney stones or blockage, higher incidence of bladder cancer related to indwelling catheter, kidney failure, autonomic dysreflexia, etc. Additionally, the client may be a candidate for medications and/or devices for his erectile dysfunction.

Musculoskeletal problems, including poor posture, myositis ossificans, osteoporosis, pain especially in upper extremities, fractures, spinal column instability, contractures, heterotopic ossification, traumatic arthritis, etc., which could require x-rays, bone scans, and/or other diagnostic studies and aggressive treatment, including surgery. The client discloses daily pain in his upper extremities as well as a burning pain sensation in the back of his knees and calves.

(Continued)
Conclusion

Spinal cord injury represents a complex array of medical challenges to the client, health care professionals, and the life care planner. Fortunately, enough research exists to reasonably and effectively plan for the patient’s needs with regard to care, products, supplies, and equipment. A detailed analysis of the individual’s situation, review of medical records, and knowledge of the available literature, as well as the participation of a qualified physician and other providers as appropriate, will assist the life care planner with a quality and effective road map of care that will enhance the life of an individual with a spinal cord injury.

References


Chapter 19

Life Care Planning for Organ Transplantation

Dan M. Bagwell and Jennifer Milton

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Introduction

More than 50 years have passed since the first successful kidney transplant in 1954. In the decades that have followed, organ transplantation has emerged from an experimental process to a well-established medical science with just over 28,000 people receiving a transplanted organ in 2007 alone. Despite the success rates of transplantation and continued improvements in graft and patient survivals, the number of potential recipients has steadily climbed due to a stagnant organ donation rate. As such, the waiting times and waiting list mortality have increased in tandem with the survival rates after transplantation.

Until 1984, the allocation of organs for transplantation in the United States was largely unregulated and primarily coordinated by local organ banks scattered throughout the country. The scenario prompted congressional intervention with the first major legislative act concerning transplantation occurring in 1984, when Congress passed the National Organ Transplant Act. From this act, the Task Force on Organ Transplantation was formed, resulting in the development of initial transplantation guidelines. Public Law (P.L.) 98-507 authorized the creation of qualified organ procurement organizations (OPOs), along with formation of the Organ Procurement and Transplantation Network (OPTN) and the Scientific Registry for Transplant Recipients (SRTR). The OPTN is comprised of a partnership between public and private sectors that serves as a systemwide link for all professionals involved in the system of donation and organ transplantation nationwide. The primary goal of the OPTN is to ensure the effectiveness, efficiency, and equity of organ sharing through a national system of organ allocation and to increase the supply of donated organs available for transplantation. The SRTR was established to ensure accurate and up-to-date transplant morbidity and mortality information. Through a contract with the Health Resources and Services Administration of the U.S. Department of Health and Human Services, the OPTN and SRTR were maintained by the United Network for Organ Sharing (UNOS). UNOS has maintained the OPTN contract for more than 20 years with five successive contract renewals. UNOS performs many valuable functions, but it is best known as the “holder of the list”: the nation’s list of patients awaiting cadaveric organ transplantation.

All pretransplant and posttransplant patients are registered with UNOS along with their health status. Laboratory results, rejection incidence, infections, and other data are reported to UNOS at periodic intervals throughout the life of the patient. The SRTR collates this information and maintains an elaborate informational database providing statistical information, such as waiting lists by organ type, graft and patient survival by individual transplant center, and volume and types of organs transplanted. The SRTR is provided data from the OPTN, whose staff of scientists and statisticians is responsible for relevant evaluation of the scientific and clinical state of solid organ transplantation in the United States. The SRTR contract is maintained by Arbor Research Collaborative for Health with the University of Michigan. The body of statistical outcomes and analysis produced and published by the SRTR plays a critical role in OPTN policy development.

The entire organ transplant system benefits from transparency, consensus, and cooperation among all interested parties including the public, the SRTR, the OPTN, the Health Resources
and Services Administration (HRSA), and the Advisory Committee on Organ Transplantation (ACOT). The current level of outcome transparency in the transplantation process is unparalleled in the national medical community. The data produced through these collaborative efforts are available to the public in a manner that allows for national, regional, or transplant center-specific review (www.ustransplant.org). The availability of this information allows members of the medical community, potential organ recipients, insurers, and managed care companies the opportunity for transplant center-specific research. Typical information frequently researched includes:

- Average length of time transplant candidates spend on the waiting list by blood group, race, transplant center, and region
- Number of organs accepted at a particular transplant center
- Number of organs declined at a particular transplant center and reasons declined
- Volume of transplants performed nationally and by transplant center
- Survival rates at 1 and 3 years; nationally, center specific, by diagnosis, by age of recipient, and by length of time awaiting receipt of an organ

As of July 1, 2007, the number of UNOS-certified transplant centers in the United States was just over 250 (UNOS, 2008). UNOS certification is provided for transplantation programs that meet its strict standards for patient and graft survival rates, transplant volumes, surgeon and physician training, and nursing, laboratory, and hospital criteria. These standards are monitored through the OPTN to ensure that certified programs maintain compliance with certification criteria. Transplant centers are required to obtain and maintain certification for each transplant program it operates to include kidney, pancreas, pancreas islet cell, liver, intestine, multivisceral, heart, lung, and heart–lung transplantation (UNOS, 2008).

On March 28, 2007, the Centers for Medicare and Medicaid Services (CMS) published revised conditions of participation for transplant centers in the United States. While transplant programs can perform transplants as an abiding member of the OPTN, CMS approval is today viewed by most as a fundamental requirement for transplant programs. The CMS conditions of participation provide intense structure and requirements along with a reapplication process and onsite audit at 3-year intervals to maintain this highly regarded certification.

As of March 2008, the number of people awaiting organ transplantation in the United States was 98,624. However, in the prior calendar year, only 28,354 transplants (solid organ) were performed (UNOS, 2008). With less than 30% of those awaiting transplantation actually receiving an organ each calendar year, it is easy to understand the dilemma of a compounding effect of demand outpacing organ donation and why many people do not live to receive an organ. More than half of those on the waiting list are diagnosed with end-stage renal disease (ESRD) and are awaiting kidney transplantation. It is notable that the prevalence of ESRD in the U.S. population has risen from 1321 per million in 2002 to 1585 in 2005 (USRDS, 2007).

Primary etiologies of kidney failure are diabetes, hypertension, and glomerulonephritis. Hepatitis C and alcoholic cirrhosis account for most liver failures requiring liver transplantation. Chronic obstructive lung disease and pulmonary fibrosis represent the most common etiologies for the 2127 individuals awaiting lung transplantation. Those awaiting heart transplantation are estimated at 2692 with an equal distribution of primary disease caused by coronary artery disease and cardiomyopathy. The vast majority of people in the United States that comprise the national waiting list for all organs are adults, although the majority of intestinal transplants performed are pediatric transplant recipients.
Life Care Planning in Transplantation

Developing life care plans for individuals with end-stage organ disease requires a thorough understanding of organ-specific disease processes. The patient’s candidacy for organ transplantation must be determined, or at least projected within a reasonable degree of medical certainty, such that a logical projection can be made that transplantation will occur within the average waiting time for a suitable organ (cadaveric). While awaiting transplantation, the transplant candidate requires life-sustaining medical treatment and care. Depending on the specific organ involved and the extent of the disease, time can be an extremely important factor of patient survival. Those with ESRD can usually be kept alive for many years on renal dialysis; however, those with liver failure and advanced heart and lung disease do not have the same opportunity. As such, some of these individuals will die while awaiting transplantation. In the general transplant population, individuals younger than 30 are expected to live more than four times longer than comparably aged dialysis patients. Transplant patients fare much better, with expected residual life expectancies approximately two-thirds that of the general population in the United States (USRDS, 2007).

To address the issue of deaths while awaiting transplantation, the OPTN seeks to allocate organs to those who need them the most. In the case of liver, heart, and lung failure, organs are allocated using a mortality risk score corresponding to the degree of medical urgency. Once candidacy is determined, comprehensive evaluations and ongoing follow-up are required until transplantation.

The Transplant Candidacy Process

Patients in need of transplantation are referred to transplantation centers in many different ways. Generally, referrals are made through physicians specializing in end-organ disease such as nephrologists, gastroenterologists, cardiologists, or pulmonologists. Patients may also be referred by claims representatives of health insurance companies who have developed contractual relationships with various centers of excellence or transplant institutes. Individuals may also refer themselves to transplant programs by way of the Internet (UNOS, 2008).

Prior to scheduling an initial evaluation, medical records are forwarded to the transplant center for review by a physician and a transplantation nursing coordinator. Patients are assigned to a pretransplantation nurse coordinator at the time of referral to begin the process of determining candidacy through a program’s transplantation evaluation protocols. The pretransplant nurse coordinator is an invaluable resource to the life care planner, for he or she can assist in the analysis of program-specific medical evaluations and diagnostic protocols in preparation for transplantation.

Indications for transplantation (UNOS, 2008):

- End-stage organ failure not amenable to medical therapy
- Psychological stability and family support to sustain the patient through the transplant and complex postoperative regimen
- Age parameters: neonate to mid-70s (varies greatly from center to center)

Contraindications for transplantation:

- Morbid obesity (greater than 35–40% body mass index)
- Metastatic cancer
Uncontrolled systemic infection
Pregnancy
Psychological instability that will make compliance difficult
Ongoing illicit substance abuse (past substance abuse generally requires a period of at least 6 months abstinence and relapse prevention training or counseling)
Positive for human immunodeficiency virus (HIV), except in some select centers
Cardiac ejection fraction less than 20% (unless patient is a heart or combined heart-lung transplant candidate)

The underlying disease etiology is an important consideration, as certain disease processes may recur and threaten the transplanted organ. Membranoproliferative glomerulonephritis and focal segmental glomerulosclerosis have fairly high recurrence rates (25% to 50%) and represent a major challenge for transplant physicians (Crosson Transplantation Proceedings, 2007). For liver transplantation, the distribution of diagnoses at listing has been very stable since 2000. Non-cholestatic liver disease remains the largest single diagnostic category, representing about 72% of the waiting list. Hepatitis C is not cured by liver transplantation and recurs after transplantation, with 30% to 70% of patients exhibiting complications during the first postoperative year (Ohler & Cupples, 2008). Graft hepatitis may lead to fibrosis and cirrhosis in up to 30% of patients.

Following the initial interview and evaluation, transplant candidates will undergo rigorous medical testing to ensure the best possible outcomes during and following the transplant procedure. Typical diagnostics routinely performed during the pretransplantation evaluation period for all transplant candidates include the following:

- **Routine Laboratory:** Blood type, white blood cell count (WBC), chemistry profile, serology studies, hepatitis A, B, and C; HIV; rapid plasmin reagin (RPR), histocompatibility leukocyte antigen (HLA) typing, 24-hour creatinine clearance (except for kidney transplant patients already on dialysis), and viral titers; and cytomegalovirus (CMV), varicella, Epstein-Barr virus (EBV), HgbA1C
- **Other Basic Diagnostics:** Skin testing for tuberculosis, chest x-ray (posterior–anterior (PA) and lateral), electrocardiogram, and peripheral vascular studies such as duplex venous Doppler
- **Cardiac Evaluation** (based on symptomatology or per protocol): echocardiogram, cardiac stress test, and possibly cardiac catheterization
- **Dental Consultation** (to rule out infectious agents)
- **Standard Cancer Screening:** Pap smear (women over age 18, or younger if sexually active), mammogram (women over age 40, or younger with positive family history), prostate-specific antigen (PSA) levels (men over age 40), and colonoscopy for men and women over age 50
- **Social Services Consultation with Possible Psychiatric Consultation**

### Additional Organ-Specific Diagnostics

- **Kidney:** Voiding cystourethrogram (optional) for diabetics or those with a history of urinary tract infections
- **Pancreas:** C-peptide to ensure Type I diabetes
- **Liver:** Abdominal computed tomography (CT) scan or magnetic resonance imaging (MRI) to rule out hepatocellular carcinoma, evaluate the portal vein, and measure the size of the liver
Heart: Cardiac catheterization for all patients to determine filling pressures and pulmonary resistance

Lung: Ventilation perfusion scan of each lung to determine the specific lung to be removed during transplantation; pulmonary function tests to establish pretransplant baselines; CT scan of the chest to rule out lung cancer

Additional diagnostics may be required for further evaluation or interim treatment of a health problem prior to transplantation, if the typical diagnostics performed yield abnormal findings. Cardiac abnormalities found during echocardiography or cardiac stress testing may require cardiac catheterization for definitive results and treatment plans. Even in the absence of abnormal noninvasive cardiac testing, many transplant centers have begun to require cardiac catheterization to evaluate for small vessel disease and thus improve perioperative success. This is not an infrequent occurrence, as persons with end-stage organ failure often have multiple organ system problems.

Completion of the initial evaluation period may take a few days to months. Following the evaluation period, the patient’s data are collected and presented to a committee, review board, or perhaps individual physician for review and determination of transplant candidacy. Once approved, the prospective transplant recipient is notified, and his or her data are forwarded for placement on the national waiting list for a cadaveric organ, or a living donation transplant is performed.

Living donation has increased dramatically from 2425 in 1991 to 7003 in 2004 (SRTR, 2006). This increase in living donation rates in more recent years has been the result of unrelated donors from spouses and friends. There has also been an increase in the number of good samaritan donors, also referred to as nondirected living donors. There are networks that now offer paired exchange, which allows an incompatible donor and recipient pair to be matched with another incompatible donor and recipient pair. Through this process, both recipients are able to receive living donor transplant.

The options for living donation are presented to most kidney and liver pretransplant patients and may also be offered to prospective lung, intestine, and pancreas transplant candidates at select programs. There were 322 living donors in 2004 compared with 321 in 2005 (SRTR, 2006). The primary mission for programs offering living donation is to first “do no harm” to the potential donor in an effort to help the recipient. This requires a thorough assessment of the living donor to ensure that he or she is in optimal health.

The donor evaluation will generally include the following studies:

- **Laboratory:** Blood type, WBC, chemistry profile, serology studies (hepatitis A, B, and C; HIV; and RPR), HLA typing with donor–recipient cross-match for kidney donation, and viral titers; CMV, varicella, EBV, urinalysis with urine culture, 24-hour creatinine clearance (two times), and, optimally, a glofli study to assess creatinine clearance for potential kidney donors.

- **Other Basic Diagnostics:** Skin testing for tuberculosis, chest x-ray (PA and lateral) and electrocardiogram, CT scan or arteriogram to evaluate renal arteries/veins, anatomy of kidneys, and CT or MRI scan of the liver for potential living liver donors; a liver biopsy is often requested by the transplant physician for prospective liver donors.

- **Cardiology Evaluation:** Based on the age of the donor, this may include echocardiogram and a cardiac stress test.
Social Services and Psychiatric Consultation

Throughout the donor evaluation process, transplant centers are required to provide an independent donor advocate or independent donor advocate team (IDAT) to ensure that the donors’ rights are represented and they remain free from coercion. The members of the IDAT have a legal responsibility to remain independent of the transplant program. Following the donor evaluation, the results are often reviewed by a neutral physician that is not associated with the prospective transplant recipient. If the donor meets the requirements and is cleared for donation, then surgery is scheduled and performed.

Living donation remains a better choice for most patients, as shorter waiting times decrease morbidity and mortality. When the donor of a living related kidney and the recipient share histocompatibility antigens, significant improvements in long-term graft survival are seen.

Awaiting Transplantation

Median waiting times in the United States by organ type are presented below in Table 19.1. The life care planner should consider that mean waiting times can be significantly impacted by blood type. For example, the waiting time for a kidney in 2004 for blood type O was 1881 days and 1207 days for blood type A (OPTN, 2006). Waiting times may be extremely long for patients who are sensitized or patients with a significant degree of preformed antibodies for which the risk of immediate rejection is considerably high. Unfortunately, these antibodies are formed when an individual is exposed to other human antigens such as pregnancy, prior blood transfusions, and prior transplantation. Newer protocols have been established to enhance the opportunities for these sensitized patients through the use of gamma-globulin infusion and plasmapheresis, a process that helps to remove problematic antibodies from the blood. Some success has been seen with this process, but it has not been broadly adopted for general clinical utilization, as it remains constrained by the high cost of the therapy, which is not a covered service by Medicare and most managed care companies.

Kidney

Renal patients awaiting transplantation are followed at close intervals by their nephrologists through their respective dialysis units and nephrology offices. While awaiting transplantation, pre-kidney transplant patients will have blood specimens forwarded to the histocompatibility laboratories (HLA) at periodic intervals (at least monthly) for cross-matching with prospective cadaveric kidney donors and for monitoring of antibodies associated with rejection. This represents an ongoing cost borne by the recipient candidate until transplantation is accomplished. Likewise, the costs of donor evaluations and eventual organ procurement are assumed by the organ recipient. Patients on hemodialysis will continue to dialyze three times weekly for a period of 3 to 4 hours with each dialysis. Home hemodialysis has become more popular over time, with nightly hemodialysis taking place in the patient’s home.

Liver

Waiting periods for individuals with end-stage liver failure are variable and are determined on the basis of medical acuity of the prospective recipients. UNOS has assigned a methodology for rating liver transplant patients on the waiting list, referred to as MELD, or the model for end-stage
liver disease. MELD is a “continuous disease severity scale that is highly predictive of the risk of dying from liver disease for patients waiting on the transplant list” (UNOS, 2006). This model incorporates the patient’s bilirubin, international normalized ratio (INR), and creatinine in an equation that results in a patient score of up to 40 points. Liver organ candidates with higher scores are moved forward on the waiting list, thereby increasing their opportunity to receive an organ and hopefully reducing the number of deaths due to liver failure while awaiting transplantation. Exception points are available for certain conditions such as hepatocellular carcinoma (HCC). HCC is a growing indication for liver transplantation provided that the combined tumor size is below a specific threshold (generally 9 cm). In the setting of HCC, time is of increased significance, as the liver tumors may grow too large for transplantation to remain an option.

MELD laboratory values must be repeated at regular intervals and entered into the national waiting list for the patient to maintain his or her place on the list. When the patient has 25 points or greater, he or she must have laboratory studies drawn every 7 days, and the results must be entered into the UNOS database within 48 hours of laboratory draws. Liver organ recipient candidates with lower scores will have laboratory draws with frequencies ranging from every 30 days to as long as 12 months. Liver candidates may be followed medically by their own gastroenterologist in conjunction with a transplant center, or they may be followed solely by the transplant center.

**Lung**

Recently, the allocation of lungs was transitioned to an acuity model called the Lung Allocation Scoring (LAS) system. Candidates ages 12 and older are prioritized for donated lung offers by the LAS (UNOS Bylaws, 2008), which is calculated using the following:

- Wait list urgency measure (expected number of days lived without a transplant during an additional year on the wait list)
- Posttransplant survival measure (expected number of days lived during the first year posttransplant)
- Transplant benefit measure (posttransplant survival measure minus wait list urgency measure)

Wait list urgency measure and posttransplant survival measure (used in the calculation of transplant benefit measure) are developed using Cox proportional hazards models. Individuals suffering from end-stage lung disease are among the most acutely ill patients awaiting transplantation. Prior to transplantation, exacerbations of chronic obstructive lung disease may require frequent hospitalizations. Extended intubation and ventilation requirements are poor prognostic indicators for transplantation. A surgical approach is generally predetermined based on etiology, single-lung transplant versus bilateral lung transplant, and projected outcomes.

**Heart**

Heart transplant candidates are ranked through a status criteria system with designations as 1A, 1B, 2, or 7 (UNOS Bylaws, 2008). To qualify as a status 1A, the recipient candidate must require mechanical circulatory support, mechanical circulatory support with objective medical evidence of significant device-related complications, mechanical ventilation, or continuous infusion of high-dose intravenous inotropic agents, or have an estimated life expectancy without a heart transplant of less than 7 days. To qualify for status 1B, heart transplant recipient candidates must have a left
and/or right ventricular assist device in place and require intravenous inotropic medication. Those classified as status 2 do not meet the criteria for status 1A or 1B. Status 7 is applied to those patients deemed temporarily unsuitable for transplantation and are maintained in an on-hold status. The wait time for most adult heart transplant candidates is in excess of 1 year. As with patients awaiting lung transplantation, heart transplant candidates are also acutely ill and frequently require hospitalizations prior to transplant. It is not uncommon for these patients to require mechanical bridges to transplant, such as aortic balloon pump therapy or ventricular assist devices.

Individuals awaiting heart and lung transplants may have to relocate to live near their transplant centers, as the donor organs have a relatively short ischemic time and should be transplanted within 4 hours of organ procurement. If these organ recipient candidates reside at distances 2 or more hours from their transplant facility and do not have 24-hour coverage capability for emergency flight arrangements, then relocation to an area within the vicinity of the transplant center is necessary. At least one caretaker will need to be with the patient at all times to care for him or her, drive him or her to appointments, and be present at the time of transplant.

Finally, average waiting times for access to suitable organs vary from region to region, due to the length of the waiting lists and the volume of organs procured by each organ bank. The recipients’ blood type is also a significant factor in the projected waiting times with regional variability. The life care planner should research information available through the SRTR to review the transplant program where a specific patient is registered. Each organ procurement organization computes its data on average waiting times for each organ type.

Median waiting times (in days) by organ type for candidate information obtained from the OPTN waiting list (1999 to 2004) were as follows are listed in Table 19.1.

**Organ Procurement**

Organs may be procured locally or regionally. The cost associated with cadaveric organ acquisition and procurement varies by the organ procurement organization with established standard acquisition costs (SAC). SAC fees are approved through the Medicare intermediaries of each state. These fees include charges from the donor hospital for testing of a donor after he or she has been declared brain dead. Typical charges include screening for infectious diseases, basic laboratory work, chest x-rays, hospital costs for use of the operating room and associated expenses for organ removal, surgical fees for organ removal, transportation of teams to outside hospitals by land (ambulance) or chartered air service, and the OPO’s procurement coordinators and supplies. These SAC fees

<table>
<thead>
<tr>
<th>Organ Type</th>
<th>Median U.S. Waiting Time (Days)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heart</td>
<td>176</td>
</tr>
<tr>
<td>Intestine</td>
<td>123</td>
</tr>
<tr>
<td>Kidney</td>
<td>1314</td>
</tr>
<tr>
<td>Kidney/Pancreas</td>
<td>562</td>
</tr>
<tr>
<td>Liver</td>
<td>278</td>
</tr>
<tr>
<td>Lung</td>
<td>539</td>
</tr>
<tr>
<td>Pancreas</td>
<td>464</td>
</tr>
</tbody>
</table>

can be obtained by contacting the OPO in the region where the patient is listed for transplantation. For example, in south Texas, the OPO SAC fees excluding surgical fees and transportation charges are

- Kidney: $23,500
- Liver: $26,800
- Heart: $28,500
- Single lung: $21,000
- Bilateral lung: $42,000
- Pancreas: $21,000
- Small bowel: $15,300


Transplantation continues to be a very successful treatment for end-stage liver disease. The number of liver transplants has increased steadily over the last decade, with 6441 procedures performed in 2005. This growth may reflect a larger number of deceased donors, especially in the expanded donor criteria (ECD) and donation after cardiac death (DCD) categories. Although the long-term outcomes for these recipients remain unclear, short-term benefits have been clearly identified. Patient and graft survival for recipients of DCD grafts have continued to improve, with 1-year survival rates for recipients of DCD grafts in 2004 virtually identical to those seen for recipients of standard criteria grafts.

The DCD donor is not declared brain dead, but has generally suffered a massive traumatic brain injury. Either the patient appears to be lapsing into a persistent vegetative state or has lost all brain function except for some minimal brain stem activity, or the family does not wish to proceed with life support in the setting of such a devastating head injury. The family opts to withdraw life support, and the medical team pronounces death with the cessation of cardiorespiratory function. At the moment death is declared by the trauma or neurology team, the transplant team proceeds with organ recovery.

An ECD donor is defined as age 60 or older, or between the ages of 50 to 59 with at least two of the following conditions: history of hypertension, a serum creatinine level of greater than 1.5, or the cause of death was from a cerebrovascular accident. Long-term outcomes are not as good with DCD and ECD. However, faced with certain death of individuals in the absence of a transplant, many transplant centers and patients accept the higher risk.

Transplantation

When a suitable donor becomes available, matching recipient candidates on the waiting list are notified and asked to come to the hospital. Upon arrival, consent forms are signed, blood work is drawn (CBC, chemistry profiles, HIV, hepatitis screens, CMV status, and HLA cross-matches for patients needing kidney transplants), a chest x-ray and EKG are performed, and a loading dose of immunosuppression is often given prior to transplantation. Frequently patients will be admitted and undergo these workups only to have the transplant cancelled, due to problems with the donor organ.

The diseased organ for transplanted patients involving the liver, lung, and heart will be removed (or, in the case of single-lung transplantation, one diseased lung removed) and the new organ transplanted in its place. In the instance of kidney transplantation, the native kidneys
remain in place unless they are removed for reasons of infection or intractable hypertension. The newly transplanted kidney is placed retroperitoneal in the lower abdomen adjacent to the bladder through an incision of the same location as an appendectomy. This position allows for fewer urological complications from ureter attachments and offers easier posttransplantation biopsy. In children, kidneys are placed intraabdominally. Hearts are sometimes being left in place when less optimal hearts are used for transplantation.

Immediately upon arrival to the ICU, extensive and specific postoperative monitoring is begun to include laboratory work, hemodynamic monitoring, fluid assessment, and administration of immunosuppressive medications, generally cyclosporine or Prograf. Daily drug levels will be drawn to monitor cyclosporine or Prograf levels in the blood. Patients receiving liver, lung, or heart transplants will remain on mechanical ventilation for at least a few hours. For many lung transplants, mechanical ventilation is required for as long as 3 days.

Organ-Specific Postoperative Management

Following kidney transplant, postoperative care focuses upon monitoring urine output, replacing fluids, and maintaining normal electrolyte values. Foley catheters will be maintained for 3 to 5 days postoperatively. Transplanted kidneys may begin to function immediately, producing copious amounts of urine. Acute tubular necrosis may be seen, resulting from ischemia of the kidney tubules. Acute tubular necrosis necessitates an increased length of stay, along with dialysis for resolution and preservation of the patient’s health.

Surgical complications from kidney transplantation are categorized into vascular, urologic, or lymphatic. Overall, surgical complications occur in less than 5% of kidney transplanted patients. Vascular complications include renal artery or vein thrombosis. The more common urologic complications seen postoperatively include ureteral obstruction, urinary leakage at the graft, and the occurrence of lymphoceles. These complications can involve a return to surgery for repair, although lymphoceles and obstructions caused by hematoma most often resolve with percutaneous drainage and sometimes without intervention (Ohler & Cupples, 2008). Renal artery thrombosis represents a very serious complication that may threaten graft survival. Ultrasonography of the new kidney is performed within the first 48 hours of transplantation to assess the status of the renal artery and vein and check for signs of ureteral obstruction.

Liver transplant patients begin their immediate postoperative period in much the same fashion as kidney transplants, although the focus of postoperative monitoring centers on the function of the new liver. Considerable blood loss and fluid shifts may have occurred in the operating room, often a result of the patient’s pretransplant medical condition. Signs and symptoms of hemorrhage will be carefully monitored, and coagulopathies may be corrected with fresh frozen plasma. In addition to the standard Foley, nasogastric tubes, and venous access lines seen with all transplanted patients, liver transplant patients will arrive with at least two Jackson–Pratt drains placed for drainage hemodynamically, and the patients may have difficulty with hypertension and electrolyte imbalance. Typical vascular complications include hepatic artery and portal vein thrombosis and occur in approximately 10% of liver transplantation cases. These may require a return to surgery for repair.

Two to 3 days of mechanical ventilation can be expected following lung transplantation. When sufficient tidal volume is reached along with an adequate spontaneous ventilatory rate and an alert mental status, the lung transplant recipient can be extubated. Chest tubes placed during surgery are generally removed postoperatively between days 6 and 8. Complications following
lungs. The reimplantation response; a combination of ischemia, reperfusion, and injury; and lymphatic discontinuity that may contribute to pulmonary edema (Ginns et al., 1999). Ventilatory management is much the same as usual postoperative management, except for those who are transplanted for chronic obstructive pulmonary disease (COPD). These patients, who will continue with one hyperinflated lung in their chest, may be positioned with their native lung down to decrease mechanical pressure from the hyperinflated lung. Minimizing fluid intake is critical for these individuals, so as to reduce risk of pulmonary edema while maintaining hemodynamic stability.

Heart transplant recipients generally recover more quickly than patients undergoing open-heart surgeries. The hemodynamic monitoring and support of the transplant patient are similar to open-heart care. Bradycardia and junctional rhythms are not unusual in the transplant patient, and most patients will have pacing wires placed during the transplant procedure. Patients will also require small amounts of inotropic support for the first 2 to 3 days postoperatively. After a relatively short stay in the ICU for postoperative monitoring, the heart transplant patient can be moved to a general transplant ward for the remaining recovery period, typically 4 to 5 days. At the end of the first postoperative week, the patient will undergo an initial endomyocardial biopsy to monitor for rejection. The biopsy is performed in the cardiac catheter suite. The right internal jugular vein is catheterized, and biopsy samples are advanced into the right ventricle for biopsy.

Throughout the entire hospitalization for patients receiving transplanted organs, transplant coordinators, social workers, and discharge coordinators are planning for and organizing a smooth transition to the home or alternative setting at the time of discharge. The average length of stay for transplant recipients has continued to shorten, as improvements in the entire transplantation process have been seen. Managed care influences have also contributed to shorter hospitalization stays. As a result, many transplant centers begin formal postoperative teaching classes prior to transplantation.

Complications of Organ Transplantation

Organ rejection and postoperative infection represent major complications following organ transplantation. Many other potential complications are also seen, and these are primarily the result of direct and indirect side effects of many of the necessary medications required for immunosuppression. Medical management of these individuals requires somewhat of a balancing act for transplant physicians, who strive to maintain viability of a transplanted organ through immunosuppressive therapy, while also attempting to reduce other potentially serious side effects these agents produce.

Rejection continues to represent one of the most common causes of graft failure. With an intact immune system, the body’s natural response to a newly transplanted organ is rejection. Specific lymphocytes within the immune system recognize the genetic blueprint of anything that is not native to the recipient. As a result of advances in HLA typing and cross-matching, hyperacute rejection today is almost extinct, although chronic rejection remains a serious unsolved complication. Organs donated and received between identical twins are the only transplants that are widely accepted as not requiring comprehensive immunosuppression. Research continues on reaching immune tolerance through immunosuppressive withdrawal, as well as bone marrow transplantation at the time of solid organ transplant. A wide spectrum of improved immunosuppressive agents that have contributed significantly to a drastic reduction in the incidence of acute cellular rejection for most transplanted organs is now available. The diagnosis and treatment of rejection varies by organ type. Table 19.2 identifies common signs and symptoms of rejection by organ transplant type and the most common diagnostics utilized to identify early rejection.
Immunosuppression

Advances in organ transplantation have been largely due to improvements in and the general availability of immunosuppressants. Fifty years ago, total body irradiation was the only form of immunosuppression available following transplantation. High-dose irradiation was required to prevent rejection, and most patients died from secondary marrow aplasia or overwhelming infection. Azathioprine was introduced in the early 1960s, representing a major advance in kidney transplantation. With prolonged graft survival demonstrated, a dramatic increase in the number of kidney transplant units was seen throughout the world. Steroids were soon added in combination with azathioprine to treat rejection and subsequently for prevention of rejection. This regimen was typically followed during the 1960s and 1970s, until cyclosporin became readily available in the early 1980s. With the introduction of cyclosporin, another dramatic breakthrough in allograft survival was seen. Graft and host survival were improved not only in kidney transplantation, but in liver and heart transplants as well. Many new immunosuppressant agents are currently under investigation that are promising for yet further dramatic improvements in transplantation outcomes. The production of monoclonal antibodies that recognize different cell surface markers on lymphocytes expands the opportunity for increased specificity of immunosuppression.

Transplant recipients will require immunosuppressive therapy throughout their lives or the life of the graft. Most will receive at least dual-agent therapy, although protocols vary to include triple and quadruple therapy, along with a variety of other medications. Immunosuppressants represent a significant proportion of the long-term outpatient expenses incurred by transplanted individuals beyond the first 12 months following transplantation. The cost of standard immunosuppression alone typically ranges from $8000 to $13,000 per year (2006 dollars) (UNOS, 2007). Legislation expanded Medicare’s coverage of immunosuppression through Part B, and the advent of Medicare part D coverage is having a tremendous impact on recipients’ ability to afford transplant medication.

Table 19.2  Signs and Symptoms of Rejection by Organ Type and Commonly Employed Diagnostics in the Detection of Rejection

<table>
<thead>
<tr>
<th>Transplant Type</th>
<th>Signs and Symptoms of Rejection</th>
<th>Common Diagnostics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kidney</td>
<td>Flank tenderness; diminished urine output; weight gain; edema; increased serum creatinine</td>
<td>Chemistry profile, specifically serum creatinine; immunosuppressive levels; kidney biopsy</td>
</tr>
<tr>
<td>Liver</td>
<td>Increased bilirubin and GGT; tenderness at operative site; usually asymptomatic of pain or discomfort</td>
<td>Bilirubin levels; GGT; immunosuppressant levels; liver biopsy</td>
</tr>
<tr>
<td>Lung</td>
<td>Increasing shortness of breath; infiltrates on chest x-ray; decreased FEV1; FEF 25–75 (PFTs)</td>
<td>Chest x-ray; exercise oximetry; pulmonary function tests; diagnostic bronchoscopy with bronchial lavage</td>
</tr>
<tr>
<td>Heart</td>
<td>Fatigue; peripheral edema; S3 gallop; pericardial friction rub; decreased ECG voltage</td>
<td>Rejection can only be monitored by endomyocardial biopsy</td>
</tr>
</tbody>
</table>
Managing immunosuppressant therapy can be a clinical challenge. Careful consideration is given to other necessary medications a patient may require for conditions other than end-stage organ disease. For example, there is increased metabolism of cyclosporine when administered with other medications such as phenytoin and Phenobarbital, thus decreasing its antirejection qualities. Conversely, drugs such as erythromycin and certain antifungal agents impair cyclosporin metabolism; therefore, dosing must be adjusted accordingly. One of the major goals of the immunosuppressive regimen is to be nephron sparing.

Maintenance immunosuppressive agents commonly employed in today’s transplant programs are listed in Table 19.3 and are identified by category, function, common side effects, and standard dosing.

Beyond maintenance immunosuppression, monoclonal or polyclonal antibodies add a new dimension to immunosuppression therapy and are utilized for induction therapy, as well as treatment of moderate to severe rejection (Table 19.4). These drugs are generally initiated in the hospital setting following transplantation, where patient response can be monitored. If well tolerated, they may be continued after discharge in the outpatient setting, although usually administered over

### Table 19.3 Maintenance Immunosuppression

<table>
<thead>
<tr>
<th>Immunosuppressant</th>
<th>Category</th>
<th>Function</th>
<th>Common Side Effects</th>
<th>Maintenance Dosage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prograf (Tacrolimus, FK 506)</td>
<td>Calcineurin inhibitor</td>
<td>Inhibits T cell function by impairing release of interleukin-2 (IL-2); binds to immunophilin FKBP (acute or cellular rejection prevention)</td>
<td>Hypertension, Tremor, Nephrotoxicity, Diarrhea, Hyperkalemia, Insomnia, Hyperglycemia</td>
<td>0.1–0.3 mg/kg/day; generally given orally; may be given intravenously</td>
</tr>
<tr>
<td>Neoral (cyclosporine)</td>
<td>Calcineurin inhibitor</td>
<td>Inhibits T lymphocyte response by binding cyclophilin; also impairs IL-2 (acute or cellular rejection prevention)</td>
<td>Hypertension, Tremor, Nephrotoxicity, Hirsutism, Gingival hyperplasia, Hypokalemia</td>
<td>5–15 mg/kg/day given in two divided doses</td>
</tr>
<tr>
<td>CellCept (Mycophenolate mofetil, or MMF)</td>
<td>Selective antimetabolite</td>
<td>Blocks synthesis of guanosine, thus blocking T and B cell proliferation (acute and possibly humoral rejection prevention)</td>
<td>Diarrhea, Nausea, Abdominal discomfort, Leukocytosis</td>
<td>1–3 g daily divided every 12 hours</td>
</tr>
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<td>Hypertension, Tremor,</td>
<td>0.1–0.3 mg/kg/day; generally given</td>
</tr>
<tr>
<td>FK 506)</td>
<td>inhibitor</td>
<td>binds to immunophilin FKBP (acute or cellular rejection prevention)</td>
<td>Nephrotoxicity, Diarrhea</td>
<td>orally; may be given intravenously</td>
</tr>
<tr>
<td>Neoral (cyclosporine)</td>
<td>Calcineurin</td>
<td>Inhibits T lymphocyte response by binding cyclophilin; also impairs IL-2</td>
<td>Hypertension, Tremor,</td>
<td>5–15 mg/kg/day given in two divided</td>
</tr>
<tr>
<td>CellCept (Mycophenolate</td>
<td>Selective</td>
<td>Blocks synthesis of guanosine, thus blocking T and B cell proliferation</td>
<td>Diarrhea, Nausea, Abdominal</td>
<td>doses</td>
</tr>
<tr>
<td>mofetil, or MMF)</td>
<td>antimetabolite</td>
<td>(acute and possibly humoral rejection prevention)</td>
<td>discomfort, Leukocytosis</td>
<td></td>
</tr>
</tbody>
</table>

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Immunosuppressant | Category | Function | Common Side Effects | Maintenance Dosage
---|---|---|---|---
Imuran (Azathioprine) | Antimetabolite | Inhibits T and B lymphocyte proliferation by inhibiting DNA and RNA synthesis | Leukopenia Thrombocytopenia Alopecia Anorexia Toxic hepatitis | 1–3 mg/kg/day in a single daily dose
Rapamune (Sirolimus) | Macrolide antibiotic | Impairs capacity of cytokines to trigger T cells to enter cell division; inhibits B cell proliferation (possibly cellular and humoral rejection prevention) | Anemia Thrombocytopenia Leukopenia Hypertension Hypercholesterolemia | 2–5 mg/day
Prednisone (Methylprednisolone, Solu-Medrol) | Corticosteroid | Inhibits lymphocyte proliferation; nonspecific anti-inflammatory agent | Increased appetite Cushingoid syndrome Hypertension Hyperglycemia Insomnia Mood swings GI upset Acne Osteoporosis Cataracts | 5–10 mg/day for the treatment of acute rejection; may be given in doses up to 1–2 mg/kg IV

a relatively short course (7 to 14 days). Should long-term monoclonal or polyclonal antibodies be required, a substantial increase in the cost of immunosuppression is seen with a single dose; average wholesale costs range from approximately $400 to as much as $1700.

**Infection**

Infection is a major cause of morbidity and mortality for transplanted patients. It has been estimated that more than 60% of transplanted patients encounter some type of infection within the first posttransplant year (Rubin, 1999). Clearly, the risk of infection is exceptionally high with an immunocompromised host.

Within the first month following transplantation, bacterial infections are most common and are generally related to the surgery and invasive procedures such as intravenous lines, drain tubes, and indwelling catheters. Prophylactic antibiotic coverage begins preoperatively at most transplant centers. Beyond the first postoperative month, the effects of sustained immunosuppression predispose the patient to viral infections, such as CMV, EBV, and hepatitis B and C. Postoperative CMV infection is common and represents a serious problem and concern.
in organ transplant patients. The host patient can be infected with this virus when CMV mismatched organs are transplanted such that a CMV-positive donor organ is transplanted into a CMV-negative recipient. CMV has been cited as a risk factor for acute rejection (McLaughlin et al., 2002) and chronic rejection (Weinberg et al., 2001). Most centers will preferentially treat with an intravenous antiviral agent for up to 30 days, then convert to an oral agent for long-term treatment or prophylaxis (Rubin, 2000). In combination with antivirals, CMV hyperimmune globulin may also be administered at periodic intervals. Opportunistic infections are also seen beyond 6 months postoperatively.

Prevention of bacterial, viral, and fungal infections is critical for graft and host survival. Therefore, prophylactic treatment, primarily for the first 3 months following transplantation, is standard practice. Thereafter, antibiotics and other antimicrobials are frequently prescribed with the onset of fever or other symptoms of potential infection.

Bactrim is a mainstay for most transplant program protocols for prevention of pneumocystic pneumonia. For those sensitive to sulfa preparations, pentamidine inhalation treatments are administered in an outpatient setting on a monthly basis. CMV prophylaxis (ganciclovir/valganciclovir) is usually administered for the first 3 to 12 months following transplantation, as is acyclovir for herpes zoster prophylaxis. Candida prophylaxis (fluconazole, itraconazole) is also generally prescribed for the first 3 months after transplantation.

### Table 19.4 Monoclonal and Polyclonal Antibodies (Immunosuppressive Induction and Rescue Agents)

<table>
<thead>
<tr>
<th>Agent</th>
<th>Category</th>
<th>Function</th>
<th>Common Side Effects</th>
<th>Dosage</th>
</tr>
</thead>
<tbody>
<tr>
<td>OKT3 (Muromonab-CD3)</td>
<td>Monoclonal antibody</td>
<td>Alteration of T cells by binding of CD3 T cell (treatment of acute rejection when conservative therapy fails)</td>
<td>Fever Body aches/chills Pulmonary edema Nausea/vomiting Diarrhea Tremors Aseptic meningitis</td>
<td>5 mg/day for 7–14 days according to center protocol</td>
</tr>
<tr>
<td>Simulect (Basiliximab)</td>
<td>Monoclonal antibody</td>
<td>Binds receptors of interleukin-2 (IL-2) complex; inhibits IL-2-mediated T lymphocytes</td>
<td>May predispose patients to infection or PTLD</td>
<td>Day of transplant: 20 mg IV Postoperative day 4: 20 mg IV</td>
</tr>
<tr>
<td>Zenapax (Daclizumab)</td>
<td>Monoclonal antibody</td>
<td>Binds receptors of IL-2 complex; inhibits IL-2-mediated T lymphocytes</td>
<td>Nausea/vomiting May predispose patients to infection or PTLD</td>
<td>1 mg/kg given every 14 days for a total of 5 doses</td>
</tr>
<tr>
<td>Thymoglobulin</td>
<td>Polyclonal immunoglobulin</td>
<td>Antibody may adhere to cell receptors, which reduces the amount of circulating T lymphocytes</td>
<td>Fever/chills Thrombocytopenia Leukopenia Myalgia Headaches</td>
<td></td>
</tr>
</tbody>
</table>
Other Complications

In approximately 75% of renal transplant recipients, hypertension is a problem following transplantation. Blood pressure monitoring is an integral part of follow-up. Patients are taught to monitor their own blood pressure and are sent home with blood pressure monitoring equipment. Commonly prescribed antihypertensives utilized by transplant centers include nifedipine, Norvasc, atenolol, clonidine, and hydrochlorothiazide.

Hyperlipidemia is commonly seen in many transplanted patients, with rates of occurrence ranging from 29% to 62% posttransplantation (Backman & Morales, 2000). Cardiovascular disease remains the leading cause of late mortality in renal transplant patients. A cholesterol-lowering agent, such as Pravachol, Lipitor, or Lopid, is usually included in the medication regime. There is also a high incidence of gastrointestinal ulcers, and many transplanted patients require long-term use of H2 receptor antagonists such as Pepcid, Zantac, Prilosec, Prevacid, Nexium, or Protonix.

Many patients require short-term insulin use following transplantation, and a small percentage will remain insulin dependent. The highest incidence of insulin dependency following transplantation is in the African American and Hispanic population groups. The reported incidence of new-onset diabetes after transplantation has varied between 2% and 53%, whereas the prevalence of diabetes in the general population is estimated at 4% (Montori, 2002).

Transplanted patients also have a significantly heightened risk for malignancies. A 21-fold increased incidence of skin cancer has been reported in the transplanted population relative to the general population at large, along with a 28- to 49-fold increased incidence of lymphoproliferative disease (Penn, 2001). UNOS requires follow-up and mandatory tracking of all cancer and tumor incidents posttransplantation.

Long-Term Follow-Up

After discharge from the acute care setting, patients immediately begin their transplant clinic follow-up. With each clinic visit, laboratory studies are obtained to include CBC, chemistry profile, and immunosuppressant levels. Some transplant centers routinely biopsy transplanted kidneys annually or as indicated to monitor for rejection, while other centers biopsy within the first 12 months and only when there are demonstrable signs of rejection thereafter. Biopsies may be performed in an outpatient surgery setting under the guidance of ultrasound or through inpatient admission.

Heart transplant patients will undergo endomyocardial biopsy and follow-up chest x-rays. Heart biopsies begin at 7 to 10 days postoperatively. This is followed by weekly biopsies for 2 to 3 weeks, then monthly for 2 to 3 months, progressing to 60-day intervals, quarterly intervals, semiannual intervals, and, ultimately, biopsies on an annual basis.

Outpatient clinical follow-up with lung transplant patients will include laboratory monitoring, chest x-rays, and pulmonary function tests. Postoperative clinic visit intervals for these patients are generally scheduled weekly for 4 weeks, followed by 2-week intervals for approximately 8 weeks, monthly for 3 to 4 months, 60-day intervals for at least 4 months, and then quarterly. Patients are discharged with a handheld spirometer to encourage daily monitoring of pulmonary function.

Most transplant patients will average 20 to 35 outpatient transplant clinic visits during their first postoperative year. Assuming relative medical stability, clinic visits may be reduced and typically range from 5 to 15 per year thereafter. Hospital readmission is most common for infection or rejection, with the highest incidence of readmission for transplant complications following lung and kidney transplantation.
Graft and Patient Survival

Both graft and patient survival continues to improve in all transplant organ categories, despite the necessity of transplantation from donors with less than optimal HLA compatibilities due to a growing waiting list of individuals needing organs and a plateau in the number of donors. This has been particularly true for kidney transplantation, where the results of living donor kidney transplants continue to be superior to those achieved with cadaver donors. Longer-term graft and patient survival continues to be greatest for kidney transplants, while lung and combined liver and intestinal transplants have the shortest patient survival. Kidney transplanted patients also have the advantage of return to dialysis if the graft fails, and many have an opportunity for subsequent transplantation(s).

The annual report of the U.S. Organ Procurement and Transplantation Network provides extensive and timely reports concerning graft and patient survival rates, as well as other valuable information concerning the transplantation and organ donation process in the United States. These reports are available to the general public and include specific data by transplant center, region, state, and nation. Table 19.5 provides 1- and 5-year organ-specific patient survival statistics following transplantation in the United States. OPTN data can also be researched extensively to extrapolate customized life expectancy projections by cohort to include the primary disease resulting in organ failure (Table 19.6).

Estimated Transplantation Costs

Hospitalization costs for organ transplantation can vary substantially, and this variation is usually complication dependent (postoperative), with varying lengths of stay. Standard deviations

Table 19.5 Unadjusted 1- and 5-Year Patient Survival by Organ

<table>
<thead>
<tr>
<th>Organ Transplanted</th>
<th>1-Year Survival (%)</th>
<th>5-Year Survival (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Kidney</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Deceased donor</td>
<td>94.7</td>
<td>80.7</td>
</tr>
<tr>
<td>Living donor</td>
<td>98.0</td>
<td>90.4</td>
</tr>
<tr>
<td>Pancreas alone</td>
<td>94.9</td>
<td>90.2</td>
</tr>
<tr>
<td>Pancreas after kidney</td>
<td>95.5</td>
<td>83.6</td>
</tr>
<tr>
<td>Kidney-pancreas</td>
<td>95.1</td>
<td>85.8</td>
</tr>
<tr>
<td><strong>Liver</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Deceased donor</td>
<td>86.9</td>
<td>73.4</td>
</tr>
<tr>
<td>Living donor</td>
<td>91.2</td>
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<td>50.2</td>
</tr>
<tr>
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<td>73.7</td>
</tr>
<tr>
<td>Lung</td>
<td>84.9</td>
<td>51.6</td>
</tr>
<tr>
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<td>43.6</td>
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</table>

Source: OPTN/SRTR 2006 Annual Report, Table 1.13.
Table 19.6 One-, 3- and 5-Year Survival by Etiology of Organ Failure

<table>
<thead>
<tr>
<th>Organ</th>
<th>Cause of Organ Failure</th>
<th>Percent Survival</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heart/Lung</td>
<td>Cardiomyopathy</td>
<td>1 Year *</td>
</tr>
<tr>
<td>Heart/Lung</td>
<td>Congenital Heart Disease</td>
<td>1 Year 61.1</td>
</tr>
<tr>
<td>Heart/Lung</td>
<td>Coronary Artery Disease</td>
<td>1 Year *</td>
</tr>
<tr>
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<td>Cardiomyopathy</td>
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</tr>
<tr>
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</tr>
<tr>
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</tr>
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<td>1 Year 82.1</td>
</tr>
<tr>
<td>Heart</td>
<td>Coronary Artery Disease</td>
<td>1 Year 87.1</td>
</tr>
<tr>
<td>Heart</td>
<td>Cardiomyopathy</td>
<td>3 Year 81.1</td>
</tr>
<tr>
<td>Heart</td>
<td>Congenital Heart Disease</td>
<td>3 Year 73.6</td>
</tr>
<tr>
<td>Heart</td>
<td>Coronary Artery Disease</td>
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</tr>
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<td>Short Gut Syndrome</td>
<td>1 Year 77.3</td>
</tr>
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<td>Functional Bowel Problems</td>
<td>3 Year 53.3</td>
</tr>
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<td>Short Gut Syndrome</td>
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</tr>
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<td>Short Gut Syndrome</td>
<td>5 Year 47.0</td>
</tr>
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<td>Retransplant/Graft Failure</td>
<td>1 Year 95.5</td>
</tr>
<tr>
<td>Kidney</td>
<td>Congenital, Rare, Familial</td>
<td>1 Year 98.0</td>
</tr>
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<td>Diabetes</td>
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<td>Glomerular Disease</td>
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<td>Kidney</td>
<td>Hypertensive Nephrosclerosis</td>
<td>1 Year 95.8</td>
</tr>
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<td>Neoplasms</td>
<td>1 Year 97.5</td>
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<td>Polycystic Kidneys</td>
<td>1 Year 97.6</td>
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<td>Renovascular and Other Vascula</td>
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<td>Tubular and Interstitial Disease</td>
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<td>Other</td>
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(Continued)
Table 19.6 (Continued)

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<th>Percent Survival</th>
</tr>
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<td>Diabetes</td>
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<td>Glomerular Disease</td>
<td>3 Year 94.2</td>
</tr>
<tr>
<td>Kidney</td>
<td>Hypertensive Nephrosclerosis</td>
<td>3 Year 89.7</td>
</tr>
<tr>
<td>Kidney</td>
<td>Neoplasms</td>
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</tr>
<tr>
<td>Kidney</td>
<td>Polycystic Kidneys</td>
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<td>Renovascular and Other Vascula</td>
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<td>Tubular and Interstitial Disease</td>
<td>3 Year 90.8</td>
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<td>Kidney</td>
<td>Other</td>
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<td>Kidney</td>
<td>Diabetes</td>
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<td>Polycystic Kidneys</td>
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<td>Benign Neoplasms</td>
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</tr>
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</tr>
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<td>Malignant Neoplasms</td>
<td>1 Year 86.2</td>
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<td>Cause of Organ Failure</td>
<td>Percent Survival</td>
</tr>
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<td>3 Year 69.4</td>
</tr>
<tr>
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<td>Congenital Heart Disease</td>
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(Continued)
Table 19.6 (Continued)

<table>
<thead>
<tr>
<th>Organ</th>
<th>Cause of Organ Failure</th>
<th>Percent Survival</th>
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<tr>
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<td>Diabetes</td>
<td>1 Year 95.9</td>
</tr>
<tr>
<td>Pancreas</td>
<td>Cancer</td>
<td>1 Year *</td>
</tr>
<tr>
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<td>Other</td>
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<td>3 Year 90.9</td>
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<td>Diabetes</td>
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<tr>
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<td>Pancreas</td>
<td>Diabetes</td>
<td>5 Year 84.5</td>
</tr>
<tr>
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<td>Cancer</td>
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</tr>
<tr>
<td>Pancreas</td>
<td>Other</td>
<td>5 Year 42.6</td>
</tr>
</tbody>
</table>

reported by reliable databases are generally in excess of $100,000. The sections in this chapter have
included pertinent information needed by the life care planner to develop a comprehensive life
 care plan for individuals suffering from the most common forms of end-stage organ diseases and
 awaiting organ transplantation.

As with other diagnostic groups, life care planning in transplantation must be individualized for
each person, with consideration given to specific parameters applicable for the individual. Specific fac-
tors that should be considered in developing the life care plan include patient age, gender, blood type,
transplant status, and transplant center, as these factors can affect recipient candidacy and specific wait-
ing times for transplantation. Likewise, preoperative and postoperative protocols can vary from one cen-
ter to the next, although most OPTN-certified transplant centers are similar. Center- and organ-specific
immunosuppressant protocols do tend to vary, which over time can have a significant impact on cost.

Table 19.7 provides an estimate of average first-year billed charges per transplant in the United
States for the year 2007.

Table 19.7 Estimated U.S. Average 2007 First-Year Transplant Costs

<table>
<thead>
<tr>
<th>Transplant (Solid Organ)</th>
<th>Estimated Number of Transplants</th>
<th>Estimated First-Year Billed Charges</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heart Only</td>
<td>2118</td>
<td>$658,800</td>
</tr>
<tr>
<td>Single Lung Only</td>
<td>783</td>
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</tr>
<tr>
<td>Double Lung Only</td>
<td>844</td>
<td>$557,400</td>
</tr>
<tr>
<td>Heart-Lung</td>
<td>38</td>
<td>$874,800</td>
</tr>
<tr>
<td>Liver Only</td>
<td>6504</td>
<td>$519,600</td>
</tr>
<tr>
<td>Kidney Only</td>
<td>17,015</td>
<td>$246,400</td>
</tr>
<tr>
<td>Pancreas Only</td>
<td>490</td>
<td>$297,300</td>
</tr>
<tr>
<td>Kidney-Pancreas</td>
<td>924</td>
<td>$368,600</td>
</tr>
<tr>
<td>Intestine Only</td>
<td>81</td>
<td>$908,600</td>
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<tr>
<td>Intestine with Other Organs</td>
<td>155</td>
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</tr>
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</tr>
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</tr>
<tr>
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</tr>
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<td>Cornea</td>
<td>31,166</td>
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</tr>
<tr>
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<td>4442</td>
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</tr>
<tr>
<td>Bone Marrow-Allogenic Unrelated</td>
<td>2848</td>
<td>$602,200</td>
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</table>

Case Study

**Abbreviated Life Care Plan**

Jane S. Doe is a 36-year-old, single female who underwent aortic valve repair at the age of 18 months. At 9 years of age, she was returned to surgery for aortic valve replacement. This procedure went well, and Ms. Doe was free of cardiac or other health complications for many years. A decision was made to explant and replace the valve when Ms. Doe was 31 years of age due to concerns for a valve defect and associated high mortality rate. Unfortunately, Ms. Doe developed multiple serious complications postexplantation to include a conduction disorder with severe dysrhythmia and damage to the tricuspid valve resulting in right heart failure. When the dysrhythmia failed to respond to multiple conservative interventions, an implantable cardioverter defibrillator was placed for concerns of sustained ventricular arrhythmias.

Ms. Doe now suffers from progressive heart failure. She will require extensive and comprehensive cardiac follow-up, diagnostic surveillance, and treatment. In addition to the need for tricuspid valve replacement and the associated risks with this procedure, it is anticipated that Ms. Doe’s cardiac health will continue to deteriorate such that the need for a heart transplant is deemed probable within 5 years.

After completing a comprehensive evaluation, review of the medical records and consultation with the team of cardiologists and cardiothoracic surgeons involved with Ms. Doe’s treatment plan, a life care cost analysis was developed.

**LIFE CARE COST ANALYSIS**
**FOR**
**JANE S. DOE**

<table>
<thead>
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<th>Date of Report: 02/03/07</th>
<th>Diagnoses:</th>
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<td>Date of Birth: 01/05/71</td>
<td>Aortic Valve Repair (18 months)</td>
</tr>
<tr>
<td>Current Age: 36 Years</td>
<td>Aortic Valve Replacement (Age 9)</td>
</tr>
<tr>
<td>Gender: Female</td>
<td>Chronic Anticoagulation Therapy</td>
</tr>
<tr>
<td>Race/Ethnicity: Caucasian</td>
<td>Aortic Valve Explantation/Replacement (Age 31)</td>
</tr>
<tr>
<td>Average Residual Life Expectancy: 46.0 Years</td>
<td>S/P Implantable Cardioverter Defibrillator</td>
</tr>
<tr>
<td>Projected Residual Life Expectancy: 25 Years</td>
<td>Progressive Right Heart Failure 20 Tricuspid Valve Damage</td>
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</table>

<table>
<thead>
<tr>
<th>Service/Item</th>
<th>Begin at Age</th>
<th>Duration Years</th>
<th>Frequency per Year</th>
<th>Average Unit Cost</th>
<th>Annual Cost</th>
<th>Lifetime Cost</th>
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**Pretransplant Services**

**Therapeutic Services**

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**Pretransplant Medication**

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<td>Cultures/Viral Titers</td>
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**Transplantation and First Postoperative Year**

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**Diagnostics**

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Medication
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<th>Frequency per Year</th>
<th>Average Unit Cost</th>
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<th>Lifetime Cost</th>
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<td>Duration Years</td>
<td>Frequency per Year</td>
<td>Average Unit Cost</td>
<td>Annual Cost</td>
<td>Lifetime Cost</td>
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<td>--------------------------------------</td>
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**Home Health Care and Essential Services**

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<th>Begin at Age</th>
<th>Duration Years</th>
<th>Frequency per Year</th>
<th>Average Unit Cost</th>
<th>Annual Cost</th>
<th>Lifetime Cost</th>
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<tr>
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**Potential Care Needs**

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<th>Annual Cost</th>
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**COST ANALYSIS SUMMARY**

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(Continued)
(Continued)

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<th>Service/Item</th>
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<td>Transplantation and First Postoperative Year</td>
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**Transplantation Centers**

As of March 21, 2008 (www.transweb.org/reference/sites/centers.htm):
Bert Fish Medical Center Kidney Transplant Program
Brigham and Women’s Hospital
British Columbia Transplant Society
Children’s Hospital of Los Angeles
Cleveland Clinic Foundation Transplant Center Clínica Ruiz
Emory University Division of Transplantation
Fairview University Children’s Hospital
Howard University Transplant Center Jackson Memorial Hospital
Johns Hopkins Comprehensive Transplant Center King’s College Hospital Liver Transplant Programme
Lied Transplant Center
London Health Sciences Center Multi-Organ Transplant Program (Canada)
Loyola University Medical Center Transplant Programs
Medical College of Georgia Medical College of Virginia Hospitals of the VCU Health System
The Methodist Hospital Multi-Organ Transplant Center
Midwest Eye-Banks and Transplantation Center
National Institute of Transplantation
New York Presbyterian Hospital–Cornell Medical Center Organ Preservation Unit
New York University Medical Center Division of Transplant Surgery
Northwestern University Division of Organ Transplantation
Ochsner Multi-Organ Transplant Center
Oregon Health Sciences Center transplant program
Porter Transplant Service
St. John Health System Transplant Specialty Center
Stanford University Medical Center Transplant Program
State University of New York at Stony Brook transplant program
Texas Heart Institute
Texas Transplant Institute
Thomas E. Starzl Transplantation Institute
Transplantation Program at Albany Medical Center
Tulane Multi-Organ Transplant Center
University Hospitals of Cleveland Transplant Program
University of Arizona Medical Center transplant program
University of California at Davis Transplant Center
University of California at San Diego’s Heart Transplant Program
University of Florida South Health Sciences Center Transplant Surgery
University of Iowa Hospitals and Clinics
University of Kentucky Transplant Center
University of Michigan Transplant Center—Michigan Transplant
University of Maryland Transplant Services
University of Minnesota Transplant Surgery
University of Oklahoma Health Sciences Center Transplant Program
University of Pennsylvania Health System transplant services
University of Southern California Liver Transplant Program
University of Tennessee (Memphis) Transplant Program
University of Texas Division of Immunology & Transplantation
University of Texas Health Science Center at San Antonio (organ transplantation program)
University of Toronto Multi Organ Transplant Program (Canada)

Resources

Selected Organizations
United Network of Organ Sharing (UNOS)
P.O. Box 2484
Richmond, VA 23218
(804) 782-4800
www.unos.org

Donate Life America
700 N. 4th St.
Richmond, VA 23219
(804) 782-4920
www.donatelife.net

Transplant Speakers International, Inc.
P.O. Box 6395
Freehold, NJ 07728
(877) 609-4615
www.transplant-speakers.org

National Foundation for Transplants
5350 Poplar Ave.
Suite 430
Memphis, TN 38119
(800) 489-3863 or (901) 684-1697
www.transplants.org
The James Redford Institute for Transplant Awareness  
10573 West Pico Blvd., #214  
Los Angeles, CA 90064-2348  
Ph: (310) 559-6325; Fax: (310) 559-6370  
email: web@jrifilms.org

National Donor Family Council  
c/o National Kidney Foundation  
30 East 33rd St.  
New York, NY 10016  
(800) 622-9010  
www.kidney.org/recips/donor/index.cfm

References


Chapter 20

Life Care Planning for the Visually Impaired

Terry Winkler and Roger O. Weed

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Introduction

Visual impairment can have a devastating effect on an individual, personally, emotionally, socially, and vocationally. Younger and Sardegna (1994) have pointed out that an individual’s personality, past experiences with blindness, education, social and financial factors, mobility, occupation, cultural background, general physical condition, psychological readiness, and family support system will affect how she is able to deal with vision loss. The consequences of vision loss or impairment are all-encompassing, impacting every area of an individual’s life. This demands that the rehabilitation professional develop a carefully thought out life care plan that meets the needs of the individual over a lifetime through all of the various areas affected. In addition, vision impairment encompasses a continuum of problems from low vision to total blindness. The level of preserved vision will affect the recommendations of the life care plan. Technology is rapidly changing and continues to provide interventions that have a tremendously positive effect on a visually impaired person’s life and vocation.

The goal of this chapter is to provide background information that the life care planner will need to initiate a life care plan for visually impaired individuals. In addition, and perhaps more important, the chapter provides references to assist in locating resources for the visually impaired. The life care planner must have a thorough working knowledge of visual impairment, its effect and impact, and expertise regarding the types of equipment and technological advances for the visually impaired.

Definitions

Visual impairment may be divided into two main categories: low vision and blindness. Low vision is much more common than total blindness. From an educational standpoint, blindness is defined as visual acuity in both eyes of less than 20/200 or visual field of less than 20°, despite the best correction with glasses (Social Security Administration [SSA], 2009). In education, low vision is defined as visual acuity better than 20/200 but worse than 20/70 with correction (PL101-476, The Individuals with Disabilities Education Act). Additional important terminology distinctions are severe visual impairment and legally blind. Severe visual impairment is defined by Nelson and Dimitrova (1993) as the self- or proxy-reporting inability to read ordinary newspaper print even with the best correction of glasses or contact lenses. In other words, severe visual impairment is not based on test of visual acuity. Rather, it measures perceived visual problems. Legally blind is used to indicate entitlement to certain government and private agency services. Low vision is defined by the American Academy of Ophthalmology (2003) to exist if ordinary eyeglasses, contact lenses, or lens implants do not give clear vision. People with low vision still have useful vision; however, this vision can be improved with visual aid devices. In addition, vision impairment is defined as having 20/40 or worse vision in the better eye even with eyeglasses. In most states, 20/40 is the point at which people can no longer obtain unrestricted driver’s licenses (NIH, 2003).

Epidemiology

A variety of estimates are available at various sources regarding the numbers of individuals with low vision or blindness. Definitions of blindness and low vision vary with different authors or sponsoring organizations. This results in some variability of the numbers that are reported. The Prevention of Blindness Database estimates that in 1990 38 million people worldwide met the definition of blind (Tielsch et al., 1990) and more than 1 million in the United States (NIH, 2003). This was more than double the population reported in 1972 of 10 to 15 million. Thylefors
et al. (1995) reported that 4.6% of the U.S. population met the definition for blindness and 14.4% met the definition of low vision. Nelson and Dimitrova (1993) reported a total number of U.S. citizens with blindness among civilian noninstitutionalized population of 4.3 million. They went on to say that they believed this number represented approximately half of all the individuals with visual impairments in the United States. Nelson and Dimitrova’s (1993) discussion of severe visual impairment revealed that the five states with the highest number of individuals meeting the definition were California, New York, Texas, Pennsylvania, and Florida. Florida had the highest rate of severe visual impairment at 22.6 persons per 1000. It was estimated that approximately 1,000,000 to 1,250,000 were of working age between 18 and 64. For persons ages 40 or older, Iowa, South Dakota, and North Dakota had the highest prevalence (NIH, 2003). In the national picture in 1990, more than 17 of every 1000 persons in the civilian noninstitutionalized population of the United States were severely visually impaired. Slightly over half a million met the definition of blindness in both eyes, with approximately 100,000 children meeting the definition of severely visually impaired. The National Information Center for Children and Youth with Disabilities estimates that for individuals under the age of 18, 12.2 per 1000 have visual impairments and 0.06 per 1000 have severe visual impairments, that is, either legally or totally blind (Teplin, 1995). Some studies indicate that visual problems are strongly linked to race. For example, Tielsch et al. (1990) and the NIH (2003) reported that legal blindness is more common among black Americans than whites, and Hispanics have a higher prevalence of vision impairment than other races (NIH, 2003).

Etiology

A variety of conditions can lead to visual impairment. The most common causes of visual impairment vary with the age of the individual. Deutsch and Sawyer (2003) pointed out that the leading causes for children under the age of 5 include retrolental fibroplasia, neoplasm, infections, and injuries. The same is true for individuals ages 5 to 19. Over age 20, cataracts become the most common cause. During the 1970s, glaucoma was the second-leading cause of blindness. However, 1992 data indicate that the most common causes of blindness in the United States are cataracts, trauma, amblyopia, and macular degeneration, respectively. This likely reflects a greater awareness, early detection, and treatment of glaucoma.

Low vision may occur from a variety of causes, which include birth defects, inherited diseases, injuries, diabetes, dacryoma, and cataracts. The most common cause is macular degeneration, which is a disease of the retina and causes damage to the central vision. Peripheral vision, however, is not affected. There are different types of low vision according to the American Academy of Ophthalmology (2003). Reduced central or reading vision is the most common; however, decreased peripheral vision may occur, or a loss of color vision, or the ability to adjust to light, contrast, or glare. The different types of low vision may require different kinds of assistance.

Traumatic etiology of eye injuries occurs in a variety of ways. They may be the result of chemical or ultraviolet burns, direct penetrating wounds, abrasions, lacerations, or violent shaking-type injuries, which can damage the retina. Burns to the eye, lacerations, and corneal abrasions can result in significant visual impairment. However, later scar tissue development can also be a complicating factor that leads to deteriorating vision. Detached retina can lead to blurred or altered vision, flashes of light, or total blindness in an eye.

Some medical conditions that are undiagnosed or not treated properly can lead to severe visual impairment. These include eye infections, glaucoma, cataracts, hydrocephalus, and vascular disease. The central causes of visual impairment would include stroke, traumatic brain injury, hydrocephalus, and tumors. A significant limitation to vision can occur from ocular motor injuries.
Functional Outcomes

The degree of visual loss may vary significantly with the more severe visual impairments leading to the most profound types of functional deficits. The age of onset and level of development before loss of sight occurs are critical factors in a person’s ability to acquire skills and concepts. Vision may actually fluctuate or be temporarily influenced by factors such as fatigue, light glare, or inappropriate lighting. An understanding of the types of visual impairment is important, but generalizations about a person’s visual functioning cannot be made solely on the basis of a diagnosis. Assessment of functional and vocational implications must be conducted on an individual basis, which in turn affects the nature of the final life care plan (LaPlant et al., 1992; Bristow, 1996).

The types of interventions that are required vary, depending on the nature of the visual impairment. For example, if peripheral vision is damaged, the person has tunnel vision and requires different interventions than an individual with macular degeneration, which would result in the loss of central vision with relative sparing of the peripheral vision. Or an individual may have night blindness where she has very little vision in dimly lit areas such as in retinitis pigmentosa, or there is photosensitivity where vision is severely impaired in the bright sunlight.

Special issues occur in very young children with visual impairment (Dodson-Burk & Hill, 1989; Teplin, 1995; Matthews, 1996). In fact, the child’s development depends upon the severity of the visual impairment, type of visual loss, and age at onset of the vision deficit. The National Information Center for Children and Youth with Disabilities reports that a young child with visual impairment has little reason to explore interesting objects in the environment and misses opportunities to have experiences to learn. This lack of exploring will continue until learning becomes motivating or until intervention begins. Children with visual impairment may be unable to imitate social behavior and understand nonverbal cues because they are unable to see peers or parents. This creates obstacles to a growing child’s independence. It is imperative that children with visual impairment be assessed early and receive appropriate interventions. They will require ongoing assessment as they grow and develop. An interdisciplinary approach will be beneficial in teaching self-care and daily living skills, as well as approaching educational and vocational issues. Deutsch and Sawyer (2003) have pointed out that even relatively minor impairment can result in vocational handicaps that limit the range of job alternatives available to an individual and reduce earning capacity. An example is color blindness, which can reduce the range of job opportunities that would otherwise be available. The degree to which total blindness results in permanent impairment and loss of earning capacity varies with the individual and depends on many personal and vocational factors. An infant or young child who has sustained the loss of an eye will require multiple careful follow-up appointments with the placement and replacement of an ocular prosthesis and conformer to promote development of the orbit. Failure to do this will result in some deformity of the forehead and face and will not allow placement of a cosmetic prosthesis.

Psychological Impact

Few conditions are as feared as blindness. As stated in the introduction, an individual’s reaction is affected by personality, past experience, education, social and financial factors, mobility, occupation, cultural background, general physical condition, psychological readiness, and family support. Common psychological reactions include anxiety, depression, anger, and, perhaps the most limiting of all, fear. The individual may experience the five emotional stages of loss as defined by Dr. Elizabeth Kübler-Ross (1975): denial, anger, bargaining, depression, and finally acceptance. While not all individuals will experience each of the stages, and the length of time per stage may vary a great deal, some part or all of these reactions may occur.
Deutsch and Sawyer (2003) described a variety of sensory distortions that can occur early on, including a loss of position sense such as a sensation of floating. This disorientation is often exacerbated by the psychological problems that accompany visual impairments. In addition, an individual who has a sudden onset of total visual impairment may have more acute or severe psychological reactions than an individual who has had a slow onset of blindness and has had time to adjust along the way. Varying degrees of independence will be lost, with some individuals experiencing a high degree of dependence on others. This cannot be viewed as a lack of motivation on an individual’s part. It should be recognized, as previously stated, that there are multiple factors involved that dictate the ultimate functional outcome from visual impairment. Most will experience a great deal of social isolation, frequently having difficulty in establishing relationships. Some individuals have a substantial difficulty in communicating with sighted people after the onset of their visual impairments. If the visual impairment occurs at a very young age, certain concepts such as visual spatial arrangements can be extremely difficult to grasp.

Psychological counseling will be crucial for individuals with visual impairment to assist in dealing with the impact of the disability. In addition, a variety of specialized training and equipment can be utilized to help improve the person’s independence, which will have a positive psychological effect.

**Aids to Independent Function and/or Durable Medical Equipment for the Visually Impaired**

This need can be divided into two broad general categories: high-technology and low-technology devices. Devices exist to help individuals with low vision and individuals with total blindness. A low-vision device is an apparatus that improves vision. The American Academy of Ophthalmology (2003) cautions that no one device restores normal vision in all circumstances, so that different devices may be required for different purposes. Bristow (1996) reports that a rehabilitation professional should consider three types of aids for the visually impaired: tactile, auditory, and visual aids. Low-vision devices can be divided into optical and nonoptical devices. Optical devices use a lens or combination of lenses to produce magnification. There are five categories: magnifying spectacles, hand magnifiers, stand magnifiers, telescopes, and closed-circuit television. Nonoptical low-vision devices include large-print books, check-writing guides, large playing cards, large telephone dials, high-contrast watch faces, talking clocks and calculators, and machines that can scan print and read out loud.

Lighting is extremely important to individuals with low vision (Panek, 2002). As one ages, the need for light to perform a task increases. On average, a 60-year-old person will need twice as much illumination as he needed at age 20. A person who is visually impaired may require complete renovation or modification of the entire lighting system in her home or office in order to best accommodate her disability. In some cases, having light sources that can be portable or moved close to the work area, such as high-intensity lights on adjustable arms, are beneficial. Hat brims or visors can be useful in blocking annoying overhead light, and absorptive lenses, which can help control glare, should be considered.

Gail Pickering, an assisted technology specialist, has published an excellent chapter regarding assisted technology for the visually impaired in the 1996 edition of *A Guide to Rehabilitation* by Deutsch and Sawyer. This chapter provides a comprehensive discussion of low-technology and high-technology devices and concludes with an exhaustive list of resources for obtaining the devices and information about their cost and use. Also see the resources list at the end of this chapter and the related chapter on assistive devices in Weed and Field (2001). With the vast improvements in search techniques and logic via the Internet, the use of Google or another search engine to locate current assistive technology is easier than ever.
Examples of low-technology devices that should be included in a life care plan include check-writing guides, watches that can indicate time by voice, tactile clues or feeling, Braille, tape recorders, labels, timers, cooking cups, measuring cups, cooking devices, rulers, large-dial telephones, and so on. High-Marks is a liquid paste that hardens to make colored fluorescent raised lettering for writing notes or labeling items that can be easily seen or easily felt by someone with normal hand sensation. Label makers can make labels that are large print, Braille, or talking labels that will allow a person to organize her closets and wardrobes, among other uses. Pill splitters and liquid medication guides and measuring spoons are available. Individuals with diabetes and visual impairment will benefit from insulin-measuring devices that are accessible or perhaps a computerized insulin pump. Numerous kitchen devices are available, such as liquid-level indicators, elbow-length oven mitts to prevent burns, and vegetable- and meat-slicing guides. There are self-threading needles, magnetic padlocks (that do not require a combination or a key to open but use a magnetic sensor), typewriters, and letter-writing templates.

Higher-technology devices include portable money handling, accounting, and identification machines, portable Braille note takers, refreshable Braille displays that can integrate with TDD devices, and optical character reader devices such as the Optacon. This device will scan printed material and convert it to a tactile display. Similar devices can be obtained that will convert the printed material to a computer file or voice synthesizer. Descriptive video services are available that will allow a visually impaired person to receive narrative descriptions of the visual portions of a television program. In order to receive this service, the person must have stereo VCR, DVD, or TV and a second audio program channel to receive the descriptive video service. These devices should be considered in every life care plan for a visually impaired person. Computers can be modified or adapted, such as utilizing a screen reader, a speech synthesizer to allow a visually impaired or blind person to access computer programs. Screen readers are available from Microsoft that will read the graphical portion of a computer program. Electromagnetic ovens can be used to heat food without flames or heating elements to reduce the risk of burns. Kurzweil readers, a computerized camera that scans print media and converts it to voice-synthesized output, are available.

Closed-circuit TV will allow the person who is visually impaired to modify printed text to an enlarged image or to an image that has enhanced contrast so that it may be easier to read. Software programs are available that will scan books on disk for individual words or combinations of words.

Mobility devices are the most common aid, and the simplest is a cane. The proper length is important. The individual should flex the shoulder until the upper limb is parallel with the floor. The distance from the hand to the floor is the proper length for the cane. The cane should be lightweight, flexible, and easily collapsible, and the end of the cane is painted red to indicate to others that the individual has a visual impairment. High-technology mobility devices include a laser cane; examples are the Pathsounder, the SonicGuide, and the Mowat Sensor. These devices operate either by sonar or by light beams. Walkmate is an electronic mobility device that vibrates to indicate when an obstacle is in the path. Some individuals will benefit from the Night Vision Aid, which will provide improved vision by amplifying available light. Aids are available that will help to orient an individual or familiarize a person with the environment that she is in (Galvin & Caves, 1996). Examples would be three-dimensional maps or tactile aids, verbal recordings, and sight descriptions of travel routes. A contemporary high-technology device for mobility that has improved significantly in function since the second edition is a Global Positioning Systems (GPS) device, which can literally help a person locate his position on the Earth accurate to within a few feet. These devices are available with verbal directions and are available in models that can be installed in cars or be handheld. If the individual has turned the wrong way, the device will
alert her to this fact. Digitized compasses are available also. Some areas or cities have transmitters in public areas such as telephones, restrooms, street signs, ATM machines, elevators, and so on, which transmit information about the location.

Guide dog services are extremely beneficial for some individuals who are visually impaired. Most organizations provide a guide dog at no out-of-pocket cost to the person who qualifies. These organizations often have long waiting lists and fairly stringent criteria as to who may qualify to receive the animal. Although there may be no direct cost, there clearly are numerous expenses associated with a guide dog, including the cost of transportation to obtain the guide dog, training on how to use the animal, and lost wages if the individual is employed. The training varies from a couple of weeks to 6 to 8 weeks in length. Once the guide dog has been obtained, there are costs associated with maintaining the animal’s health, tick and flea control, food, grooming, veterinarian care, and kennel stays. In addition, there may be some increased costs to maintaining the home. Appropriate modifications such as a fenced-in yard to allow the guide dog the opportunity to be out of the home during times when not working are essential. Periodic replacement of the guide dog’s harness will also be required.

The individual with visual impairment typically will choose not to own a private vehicle and utilize public transportation or taxicab services for community mobility. Such costs must be included in the life care plan, though in personal injury litigation, a deduction for damages received for loss of earnings capacity will be appropriate. If a private vehicle is maintained or the person lives in a town that has limited public transportation, then the cost of hiring a driver should be determined.

There are times and situations where the individual with a visual impairment requiring community mobility is best assisted by using a sighted companion as a guide. Some individuals do not adapt well to canine guides or the use of assistive mobility devices. There may be emotional or cognitive factors (such as a brain injury) that demand a companion assist the visually impaired person with her community mobility. Indeed, in many cases, dependent on the activity level of the person, career choice, environment, and so on, all of the mobility aids mentioned will be required or used.

**Personal Care and Homemaker Services**

There are numerous activities that are required to maintain a home or to live with a measure of independence in the community. The life care planner must carefully evaluate the individual’s unique situation and functional abilities and keep foremost in mind the safety of the person for whom the plan is being developed. In addition, it is important to recognize that marked changes in the person’s functional status can occur with what would be otherwise relatively minor illnesses for sighted people. The life care plan should have adequate funding for personal care services and homemaker services to cover this eventuality. The individual who is visually impaired will benefit from some assistance in areas such as personal banking; identifying and marking bills for payments; labeling clothing; food shopping and storage; marking settings on the furnace, washing machine, microwave, and stove; some housecleaning; maintaining the home, lawn, and yard; and many other tasks.

When attending school, college, or seminars, note takers and readers may be required and should be considered in the life care plan (Hazekamp & Huebner, 1989; Panek, 2002). In most public school settings, these services may be provided by the school system with funding from the Individuals with Disabilities Education Act (IDEA). There are also funding sources available
through state, federal, and nonprofit resources if the person qualifies (Mendelson, 1987). Such funding can vary with jurisdiction and congressional funding.

Mobility training, available in many metropolitan areas, is essential for persons who are visually impaired and requires a time-intensive initial training period and then updates on an annual or as-needed basis. Mobility instructors will be required when there are any changes in the individual’s life such as a new home or home modifications, a new job or change in one’s present job, a move to a new city, or orientation to new stores and businesses that develop in the community. Changes in public transportation systems or bus routes may also require an additional training period. This is separate from orientation training that is required on an ongoing basis. For example, a visually impaired person will have times when strangers are required to be in the home, such as for home repairs, servicing for utilities, deliveries, and so on. Having a trusted sighted companion present in the home during these times provides an extra measure of safety for the visually impaired person and his personal belongings.

**Formal Rehabilitation**

For the newly blind or for a person who is severely visually impaired, a formal rehabilitation program should be undertaken. Topics that should be addressed at a minimum include communication with the sighted world, training in personal management and household tasks, accessing printed material, meal preparation and consumption, in-home and community mobility, and other activities of daily living. Mobility training should be refreshed at least on an annual or as-needed basis and is somewhat dependent on changes in the person’s life. Additional areas to be addressed would include Braille instructions, typing lessons, vocational training, and psychological counseling or adjustment.

**Case Study**

The following excerpts of a life care plan are for a 49-year-old woman injured in a motor vehicle accident. She experienced a mild brain injury as well as blindness from a blood clot on her brain. The following is for illustration purposes only and does not constitute the complete life care plan.

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Dates</th>
<th>Frequency</th>
<th>Expected Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Aids for Independent Function</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arctic Business Vision software</td>
<td>2009–2033</td>
<td>Replace every 5 years</td>
<td>$1895</td>
</tr>
<tr>
<td>Arctic transport synthesizer</td>
<td>2009–2033</td>
<td>Replace every 5 years</td>
<td>$1295</td>
</tr>
<tr>
<td>Braille &amp; Speak portable note taker</td>
<td>2009–2033</td>
<td>Replace every 3 years</td>
<td>$1794</td>
</tr>
<tr>
<td>Braille printer</td>
<td>2009–2033</td>
<td>Replace every 3 years</td>
<td>$3995</td>
</tr>
<tr>
<td>Duxbury Braille Translator</td>
<td>2009–2033</td>
<td>Replace every 5 years</td>
<td>$495</td>
</tr>
<tr>
<td>DUXWP Translator</td>
<td>2009–2033</td>
<td>Replace every 3 years</td>
<td>$295</td>
</tr>
<tr>
<td>Optic scanner</td>
<td>2009–2033</td>
<td>Replace every 5 years</td>
<td>$1500</td>
</tr>
<tr>
<td>Description</td>
<td>Years</td>
<td>Frequency</td>
<td>Cost</td>
</tr>
<tr>
<td>-----------------------------------------------------------------------------</td>
<td>-------------</td>
<td>--------------------</td>
<td>---------------------------</td>
</tr>
<tr>
<td>Personal computer with voice control (JAWS and software only)</td>
<td>2009–2033</td>
<td>Update every 2 years</td>
<td>$1000, then $300 per 2 years</td>
</tr>
<tr>
<td>Refreshable Braille display</td>
<td>2009–2033</td>
<td>Replace every 5 years</td>
<td>$14,495</td>
</tr>
<tr>
<td>Talking money identifier</td>
<td>2009–2033</td>
<td>Replace every 5 years</td>
<td>$685</td>
</tr>
<tr>
<td>Maintenance for equipment</td>
<td>2010–2027</td>
<td>Yearly with deduction for warranty</td>
<td>$500 per year average</td>
</tr>
<tr>
<td>Mobility training</td>
<td>2009–2010</td>
<td>1 time only</td>
<td>$45,000</td>
</tr>
<tr>
<td>Seeing eye dog</td>
<td>2009–2033</td>
<td>Every 12 years</td>
<td>$0 for dog $1500 per year for food, grooming, veterinarian, and flea and tick treatments</td>
</tr>
<tr>
<td>Allowance for aids such as canes, talking clock, watch, kitchen timer, blood pressure cuff, travel alarm, scale, yardstick, writing guide, garment labeler, talking books, etc.</td>
<td>2009–2033</td>
<td>Yearly</td>
<td>$300 per year</td>
</tr>
<tr>
<td><strong>Home Care</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Housekeeper</td>
<td>2009–2033</td>
<td>Weekly</td>
<td>$2080 per year</td>
</tr>
<tr>
<td>Handyman</td>
<td>2009–2033</td>
<td>Weekly</td>
<td>$2080 per year</td>
</tr>
<tr>
<td>Lawn maintenance</td>
<td>2009–2033</td>
<td>Seasonally (32 weeks)</td>
<td>$700 per year</td>
</tr>
<tr>
<td>Personal assistance for shopping, etc.</td>
<td>2009–2033</td>
<td>10 hours per week</td>
<td>$6240</td>
</tr>
<tr>
<td>Home security</td>
<td>2009–2033</td>
<td>1 time only</td>
<td>$1500 + $25 per month maintenance and monitoring</td>
</tr>
<tr>
<td><strong>Future Medical Care—Routine</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physiatrist</td>
<td>2009–2033</td>
<td>3 times per year</td>
<td>$204 per year</td>
</tr>
<tr>
<td>Neurologist</td>
<td>2009–2033</td>
<td>1 time per year</td>
<td>$54 per year</td>
</tr>
<tr>
<td>Ophthalmologist</td>
<td>2009–2033</td>
<td>2 times per year</td>
<td>$224 per year</td>
</tr>
<tr>
<td>Lab tests, including UA, Tegretol, and blood</td>
<td>2009–2033</td>
<td>2 times per year</td>
<td>$156–578 per year</td>
</tr>
<tr>
<td><strong>Transportation</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Taxi</td>
<td>2009–2033</td>
<td>As needed</td>
<td>$600 per month average; economist to deduct average cost of car expense</td>
</tr>
</tbody>
</table>
Conclusion

Visual impairments can be caused by disease, injury to the eye or brain, or the natural process of aging. Although total blindness is relatively rare, low vision or vision disturbance (such as neglect or field cuts) can adversely affect the person’s ability to live independently or work. This chapter is designed to suggest life care planner topics and services that need to be considered when developing a comprehensive plan. Since the causes of visual impairment are varied, and specific functional limitations and medical care are individual, the life care planner should either have education or training in this specialized area or associate with someone who does. Fortunately, many resources and adaptive aids (see the following) have been developed for enhancing the person’s quality of life as well as productive functioning.

Selected Resources

General Information

American Academy of Ophthalmology
P.O. Box 7424
San Francisco, CA 94120-7424
(415) 561-8500, ext. 223
www.aao.org

American Foundation for the Blind
11 Penn Plaza, Suite 300
New York, NY 10001
(800) 232-5463 (hotline)
(212) 502-7600
(212) 502-7662 (TDD)
www.afb.org

Center for Assistive Technology and Environmental Access
Georgia Institute of Technology
490 10th St.
Atlanta, GA 30318
(404) 894-4960 (V/TTY)
Fax: 404-894-9320
www.catea.org

Glaucoma Research Foundation
200 Pine St., Suite 200
San Francisco, CA 94104
(800) 826-6693
(415) 986-3162
Fax: 415-986-3763
www.glaucoma.org
Lighthouse, International, Information and Resource Service (I&R)
111 East 59th St.
New York, NY 10022-1202
(212) 821-9200
(800) 829-0500
(212) 821-9703 (TTY)
Fax: 212-821-9707
www.lighthouse.org

National Association for Visually Handicapped
22 W. 21st St.
New York, NY 10010
(212) 889-3141
Fax: 212-727-2931
www.navh.org

National Eye Institute
Building 31, Room 6A32
31 Center Dr., MSC 2510
Bethesda, MD 20892-2510
(301) 496-5248
Fax: 301-402-1065
www.nei.nih.gov

VISIONS/Services for the Blind and Visually Impaired
Nancy D. Miller, Executive Director
500 Greenwich St., 3rd Floor
New York, NY 10013-1354
(888) 245-8333
(212) 625-1616
Fax: 212-219-4078
www.visionsvcb.org

Recorded Reading Materials
American Printing House for the Blind
1839 Frankfort Ave.
P.O. Box 6085
Louisville, KY 40206-0085
(800) 223-1839
(502) 895-2405
Fax: 502-899-2274
www.aph.org
Associated Services for the Blind
919 Walnut St.
Philadelphia, PA 19107
(215) 627-0600
Fax: 215-922-0692
www.libertynet.net/tildaasbinfo

Books On Tape, Inc.
P.O. Box 7900
Newport Beach, CA 92658-7900
800-626-3333
www.booksontape.com

Braille Circulating Library
2700 Stuart Ave.
Richmond, VA 23220-3305
(804) 359-3743
Fax: 804-359-4777
http://bclministries.org

Jewish Braille Institute of America, Inc.
110 East 30th St.
New York, NY 10016
(800) 433-1531
(212) 889-2525
Fax: 212-689-3692
www.jewishbraille.org

Library of Congress
National Library Service for the Blind and Physically Handicapped
1291 Taylor St. NW
Washington, DC 20542
(800) 424-8567
(202) 707-5100
(202) 707-0744 (TDD)
Fax: 202-707-0712
http://lcweb.loc.gov/nls

Recording for the Blind & Dyslexic
The Anne T. Macdonald Center
20 Roszel Rd.
Princeton, NJ 08540
(800) 221-4792
(609) 452-0606
Fax: 609-520-7990
www.rfbd.org
Large-Print Reading Materials

American Bible Society
1865 Broadway
New York, NY 10023
(212) 408-1200
www.americanbible.org

American Printing House for the Blind
1839 Frankfort Ave.
P.O. Box 6085
Louisville, KY 40206-0085
(800) 223-1839
(502) 895-2405
Fax: 502-899-2274
www.aph.org

Blindskills, Inc.
P.O. Box 5181
Salem, OR 97304-0181
(503) 581-4224
(800) 860-4224
Fax: 503-581-0178
www.blindskills.com

Doubleday Large Print Home Library
Membership Services Center
6550 East 30th St.
P.O. Box 6325
Indianapolis, IN 46206
(317) 541-8920
www.DoubledayLargePrint.com

John Milton Society for the Blind
475 Riverside Dr., Room 455
New York, NY 10115
(212) 870-3336
Fax: 212-870-3229
www.jmsblind.org
National Association for Visually Handicapped
22 West 21st St.
New York, NY 10010
(212) 889-3141
Fax: 212-727-2931
www.navh.org

New York Times/Large Type Weekly
229 W. 43rd St.
New York, NY 10036
(800) 631-2580 (large-type weekly subscriptions)
(212) 556-1734 (office)
Fax: 212-556-1748
LargeTypeWeekly

TIME Large Edition
TIME Inc.
Time & Life Building
Rockefeller Center
New York, NY 10020-1393
(800) 552-3773
www.time.com

Ulverscroft Large Print (USA), Inc.
P.O. Box 1230
West Seneca, NY 14224-1230
(800) 955-9659
(716) 674-4270
Fax: 716-674-4195
www.ulverscroft.co.uk

Optical Reading and Illumination Devices

Bossert Specialties
3620 East Thomas Rd., Suite D-124
Phoenix, AZ 85018
(602) 956-6637
(800) 776-5885
Fax: 602-956-1008
http://bossertspecialties.com

Eschenbach Optik of America, Inc.
904 Ethan Allen Highway
Ridgefield, CT 06877
(203) 438-7471
(800) 396-3886
www.eschenbach.com
National Association for Visually Handicapped
22 W. 21st St.
New York, NY 10010
(212) 889-3141
Fax: 212-727-2931
www.navh.org

Membership Organizations
American Council of the Blind
1155 15th St. NW, Suite 1004
Washington, DC 20005
(800) 424-8666
(800) 424-8666
(202) 467-5081
Fax: 202-467-5085
www.acb.org

Blinded Veterans Association
477 H St. NW
Washington, DC 20001-2694
(800) 669-7079 (message)
(202) 371-8880
Fax: 202-371-8258
www.bva.org

National Federation of the Blind
1800 Johnson St.
Baltimore, MD 21230
(410) 659-9314
Fax: 410-685-5653
www.nfb.org

Consumer Organizations
American Foundation for the Blind
National Technology Center
11 Penn Plaza, Suite 300
New York, NY 10001
(800) 232-5463
(212) 502-7773 (CTIB)
www.afb.org

Association for Macular Diseases, Inc.
210 East 64th St.
New York, NY 10021
(212) 605-3719
www.macula.org
The Foundation Fighting Blindness
Executive Plaza I, Suite 800
11350 McCormick Rd.
Hunt Valley, MD 21031-1014
(888) 665-9010
(800) 683-5555
(800) 683-5551 (TDD)
(410) 785-9687 (TDD)
(410) 785-1414
Fax: 410-771-9470
www.blindness.org

Glaucoma Support Network
Glaucoma Research Foundation
200 Pine St., Suite 200
San Francisco, CA 94104
(800) 826-6693
(415) 986-3162
www.glaucoma.org

The Institute for Families of Blind Children
Mail Stop #111
P.O. Box 54700
Los Angeles, CA 90054-0700
(323) 669-4649
Fax: 323-665-7869
www.instituteforfamilies.org

Lighthouse International
111 E. 59th St.
New York, NY 10022-1202
(212) 821-9200
(800) 829-0500
(212) 821-9703 (TTY)
Fax: 212-821-9707
www.lighthouse.org

Macular Degeneration Foundation, Inc.
P.O. Box 9752
San Jose, CA 95157-9752
(408) 260-1335
Fax: 408-260-1336
www.eyesight.org

National Association for Parents of Children with Visual Impairments, Inc.
P.O. Box 317
Watertown, MA 02471
(800) 562-6265  
(617) 972-7441  
Fax: 617-972-7444  
www.spedex.com/napvi

National Association for Visually Handicapped  
22 West 21st St.  
New York, NY 10010  
(212) 889-3141  
Fax: 212-727-2931  
www.navh.org

National Organization for Albinism and Hypopigmentation (NOAH)  
P.O. Box 959  
East Hampstead, NH 03826-0959  
(800) 473-2310  
Fax/voice: 603-887-2310  
www.albinism.org

**Adaptive Equipment Catalogs**

National Federation for the Blind  
Product Center  
1800 Johnson Street  
Baltimore, MD 21230  
(410) 659-9314  
www.nfb.org

LSS Group  
P.O. Box 673  
Northbrook, IL 60065  
(800) 468-4789  
www.LSSgroup.com

Maxi-Aids  
P.O. Box 3209  
Farmingdale, NY 11735  
(800) 522-6294  
www.maxiaids.com

**Dog Guide Resources**

Eye Dog Foundation for the Blind  
512 North Larchmont Blvd.  
Los Angeles, CA 90004  
(213) 626-3370  
www.eyedogfoundation.org
References


Chapter 21

Elder Care Management Life Care Planning Principles

Patricia McCollom and Dorothy Zydowicz-Vierling

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Introduction

This is a time of sweeping change and opportunity in the field of aging, health, and long-term care. Significant progress in the technology available to improve health care, increased focus on prevention strategies, and the growing importance of home and community-based care are just three key factors transforming the landscape of health and long-term care delivery (Modernizing Older Americans Act Programs U.S. Administration on Aging, 2006).

By the year 2030, the percentage of persons 65 and older is expected to double from 35 million to 70 million, growing from 12% in 2000 to over 20%. Additionally, the population 85 years of age and older is projected to grow to 8.9 million in the year 2030 (U.S. Department of Health and Human Services, Administration of Aging, 2008).

As this age shift occurs and retirement is frequently postponed, physiological aging is delayed, as compared to a century ago. With advances in medical treatment, persons are living longer and
healthier into the sixth, seventh, and eighth decades, with greater periods of time in what is considered old age.

Aging is often compounded by the onset of chronic illnesses and disabling conditions, bringing with it the increased likelihood of functional loss and disability. As a result, costs for care and services increase. One study has reported that approximately 20% of community-dwelling older adults have some difficulty with activities of daily living, and this percentage doubles for persons who are more than 85 years old (Cohen & Van Nostrand, 1995). The effects of age-related changes on functional activities are summarized in Table 21.1.

Review of Table 21.1 demonstrates that the aging process itself results in expected physiological change. Coupled with lifestyle, nutrition habits, physical environment, work history, and extended retirement, expected physiological change varies. For those with chronic conditions, prescribed medications add an additional variable that impacts long-term health needs. For example, individuals with elevated blood pressure may be prescribed medication that increases susceptibility to falls as a result of orthostatic hypotension. Facing long-term health needs, elders requiring care management can benefit from development of a life care plan. The life care plan becomes a distinct written resource for the individual and family, listing community resources, payer sources, contacts, and eligibility variables. Using this tool in elder care management benefits the individual, the family, and the case/care manager, as services are provided over a continuum of care.

In many cases, a life care plan is developed for litigation. In geriatric care, however, it most likely is compiled for long-term care planning or family education. A life care plan in elder care management is distinguished from life care planning for litigation support in three ways:

- The life care plan is an outcome of elder care/case management services.
- The life care plan is developed in collaboration with the individual and family without regard to personal injury legal parameters.
- The life care plan identifies community resources and health care options from which the individual and family may choose.

Benefits for Life Care Planning in Elder Care

The life care plan created to support elder care is a living document. It is intended to be useful to all parties involved in the individual’s care, including family, friends, support services, community resources, and caregivers among the health care team.

Benefits for life care planning in elder care may be specified in five areas. First, a life care plan for elder care management enhances individual and family education. Information in the plan includes physician appointments, procedures, medications, needed diagnostic or monitoring tests, home health care services, and chosen options for ongoing services. The document clearly and concisely lists needed information that can be readily accessed.

Consider, for example, Robert R., age 81, who was diagnosed with lung cancer, with metastasis to the lumbar spine. His primary caretaker was an 85-year-old brother. His physician prescribed over 17 medications to address Mr. R.’s health care needs. In the elder care management process, a life care plan was developed that included all medications, the reason for prescription dosage, time for administration, and side effects to note. The pharmacist’s name, address, and telephone number were included for reference. Over the remaining 7 months of Mr. R.’s life, he and his brother used the life care plan medication list several times daily, as a support tool, to answer questions and confirm accuracy of administration.
### Table 21.1 Age-Related Changes on Functional Activities

<table>
<thead>
<tr>
<th>Body System</th>
<th>Expected Change</th>
<th>Disease/Illness</th>
<th>Functional Consequences</th>
</tr>
</thead>
<tbody>
<tr>
<td>Senses</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vision</td>
<td>Degenerative change to pupils, iris, sclera, retina; decreased elasticity, opacity, and flattening of lens</td>
<td>Macular degeneration; cataracts</td>
<td>Need for increased lighting; sensitivity to glare; diminished adaptation to light/dark; poor eye coordination; decreased peripheral vision; decreased visual acuity; decreased depth perception</td>
</tr>
<tr>
<td>Hearing</td>
<td>Thickening of ear drum; decreased sensory receptors Auditory nerve degeneration; extended exposure to sound/damage</td>
<td>Deafness; chronic vestibular effects</td>
<td>Diminished ability to participate in conversation; safety problems; social withdrawal</td>
</tr>
<tr>
<td>Smell/taste</td>
<td>Decreased sensitivity of neuroreceptors</td>
<td>Health impairments related to poor nutrition</td>
<td>Decreased appetite; safety problems</td>
</tr>
<tr>
<td>Touch</td>
<td>Decreased sensitivity of neuroreceptors</td>
<td>Impaired skin integrity related to pressure, pain, burns</td>
<td>Decreased response to tactile stimuli; safety problems</td>
</tr>
<tr>
<td>Musculoskeletal</td>
<td>Decreased muscle mass; loss of elasticity; decreased bone density; deterioration of articular cartilage; altered motor neuron conduction</td>
<td>Arthritis; muscle atrophy; bone fractures; chronic pain</td>
<td>Immobility; decreased strength and endurance; postural changes; impaired balance and coordination; decreased speed of movement and reaction time; body flexibility</td>
</tr>
<tr>
<td>Neurological</td>
<td>Decreased short-term memory; decreased processing of information; slowed reflexes; decreased response time; sleep pattern changes</td>
<td>Decreased cerebral blood flow; stroke; dementia; depression</td>
<td>Decrease in adapting to new information; decreased ability to problem solve and integrate new information; difficulty in remembering or memorization; need for rest periods; changes in ability to drive decreasing autonomy</td>
</tr>
</tbody>
</table>
Cardiopulmonary | Decreased pumping force of heart; blood pressure changes; weakening of respiratory muscles; decreased elasticity of cardiac valves; reduced chest wall function and vital capacity | Orthostatic hypotension; hypertension; cardiac failure; myocardial infarction; pulmonary infection | Reduced ability to exercise, work; need to pace energy; increase in fatigability; decreased endurance; shortness of breath

Integumentary | Decreased skin vascularity and thickness; diminished sweat glands; decreased thermo-regulatory control; nails thicken and become brittle; increased corns, callouses, and nevi | Frequent bruising, skin tears; delayed healing time; infection of skin and nails; skin cancer | Poor body temperature control; susceptible to tissue damage

Gastrointestinal (GI) | Changes in teeth, gingivae; decreased saliva, gastric juices; decreased bowel motility; decreased blood flow to liver, pancreas, bowel | Nutrition deficits; dysphagia; constipation; elevated liver enzymes; weakening of wall of GI system; hiatal hernia; gastroesophageal reflux disease (GERD) | Decreased ability to maintain intake; swallowing problems; alternations in medication metabolism; change in protein metabolism

Endocrine | Reduced insulin secretion; decreased glucose tolerance; changes in hormone, enzyme production; Impaired thyroid function | Diabetes; hypoglycemia | Decreased endurance; monitoring of blood sugar necessary; specific nutritional intake required; prescription medication necessary

Genitourinary | Decreased renal blood flow; decreased muscle tone; decreased glomerular filtration, resulting in changes in acid–base balance | Electrolyte imbalance; recurrent urinary tract infection; urinary retention | Frequency of urination; stress incontinence; severe systemic effects with nausea, vomiting, or diarrhea

Second, a life care plan in elder care management facilitates integration of services. Multiple options may exist for a given program to meet a specific need. When developing the plan in collaboration with the family, options are identified and choices regarding services are made. Services are therefore not duplicated.

In the life care plan of Mr. R., noted previously, supplemental nutrition services were needed, since he did not have the strength or endurance to prepare meals. Working with the family, a cooking and food-shopping plan was developed with neighbors, to assure food met his tastes and
appetite. Use of a community program was declined, due to institutional-style meals, with little fresh fruit or vegetables included.

Third, use of a life care plan in elder care management results in decreased stress for the individual and family. The plan not only delineates care and services, but also associates costs, identifying the payer source. Prepared in a concise, clear form, the structure of the plan allows the individual and family to locate specific information related to needs, and to review the rationale for treatment and services.

In our example, Mr. R.’s extended family lived in a distant state. The life care plan’s costs section assisted the family in supporting Mr. R.’s brother in decision making regarding home care assistance. Further, a plan was developed that included homemaker services and increased services, as his condition worsened.

Fourth, the life care plan in elder care management provides a continuing resource to the family through delineation of needs, rationale and outcomes for programs and services, and measureable goals for evaluation of services.

With implementation of the life care plan for Mr. R., the recommendation was for homemaker services once weekly. Listed within the plan was the expected outcome for this recommendation: laundry and household cleaning completed. Evaluation of this service by the care manager demonstrated lack of achievement of the outcome at 4 weeks. Services were increased to three times weekly, which demonstrated outcome achievement.

Finally, access to community resources is facilitated through life care planning in elder care management. The life care planner must locate and identify community resources consistent with the individual’s needs and present the resources as options to consider.

When homemaker services were recommended to assist Mr. R. to remain in his home, such services were not covered by Medicare. Community options were identified and selection for services was made based upon comprehensive review of available options, rather than referral by hospital social service only.

The development of a life care plan in elder care management is based upon individual rights, choice, individual/family values, comprehensive assessment, appropriate resource use and planning, and implementing, monitoring, and evaluating recommended services. The plan is developed with the individual’s informed consent or that of a guardian/conservator. By addressing an individual’s rights, values, and preferences, the life care plan is removed from a litigation model to a model recognizing individual autonomy. Individual preferences, community resources, and financial abilities determine the plan.

**Assessment**

A life care plan used in elder care management is driven by clinical data about the individual, which provide a rationale for resource use. A systematic assessment of the individual’s functional skills, cognitive status, limitations, needs, strengths, abilities, and resources (personal and community) is required.

An assessment of functional skills is critical to life care plan development. During an assessment interview, consider questions about lifestyle, such as how does the individual spend the day and what activities take place outside of the home (McCollom, 2000). Further questioning should define how the client shops and carries out financial and household management. It is often appropriate to consider and include formal functional evaluations performed by care providers.

Environmental assessment must be integrated with functional assessment, to provide safety-related recommendations in the life care plan. External risk factors may include social isolation, lack of a support system, degree of integration in the community, issues with transportation,
or current geographic location. Internal risk factors for consideration in a life care plan include cognitive status, medications, depression, comorbidities, and mobility.

Life care planning in elder care often involves more than medical issues. The life care planner must be able to assess the individual's risk factors, potential problems, barriers, and options. Funding, community resources, geographic barriers, or family/cultural variables may make autonomy difficult.

Lifestyle and cultural implications must be considered. Life care planners must recognize when their values may come in conflict with the individual or family’s preferences and beliefs. They must strive to maintain objectivity to facilitate patient advocacy.

Ultimately, the outcomes of an individually driven life care plan include improvements in patient and family satisfaction, education, and understanding of care options. Individual participation also increases involvement in care and service evaluation, which allows the individual some level of autonomy and control over a difficult circumstance. Furthermore, self-reliance and self-determination are promoted. For the patient and family to receive the best care possible, a well-directed multidisciplinary approach is essential (Zydowicz, 2008).

Table 21.2 provides an assessment tool for use in life care planning in elder care management.

Table 21.2  Elder Care Management Life Care Plan Assessment Tool

<table>
<thead>
<tr>
<th>1. Records review</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Contacts</td>
</tr>
<tr>
<td>3. Guardian/conservator</td>
</tr>
<tr>
<td>4. Health status</td>
</tr>
<tr>
<td>Past medical history</td>
</tr>
<tr>
<td>Review of systems</td>
</tr>
<tr>
<td>Medications</td>
</tr>
<tr>
<td>Pharmacist</td>
</tr>
<tr>
<td>Program medications</td>
</tr>
<tr>
<td>Nutritional status/eating habits</td>
</tr>
<tr>
<td>Cultural specifications</td>
</tr>
<tr>
<td>Illness impact</td>
</tr>
<tr>
<td>Protein needs</td>
</tr>
<tr>
<td>Height, weight</td>
</tr>
<tr>
<td>5. Functional skills</td>
</tr>
<tr>
<td>Self-care</td>
</tr>
<tr>
<td>Cognition</td>
</tr>
<tr>
<td>Communication</td>
</tr>
<tr>
<td>Behavior</td>
</tr>
<tr>
<td>Mobility</td>
</tr>
<tr>
<td>Elimination</td>
</tr>
<tr>
<td>Safety</td>
</tr>
<tr>
<td>Household management</td>
</tr>
<tr>
<td>Community involvement</td>
</tr>
<tr>
<td>Evaluations completed</td>
</tr>
</tbody>
</table>
### 6. Psychosocial status
- Family/friends
- Patient/family values
- Community support
- Mood, affect
- Coping mechanisms
- Level of education
- Stressors
- Substance use/abuse
- Sleep patterns

### 7. Environment
- Architectural barriers
- Health hazards
- Sanitary conditions
- Modification needs
- Transportation
- Community resources used

### 8. Financial status
- Income
- Assets
- Monthly costs
- Insurance
- Power of attorney
- Living will

### 9. Risk factors
- External
- Internal

---

**Plan Implementation and Monitoring**

Implementation of the life care plan reflects action based upon information analysis and synthesis. The plan identifies formal and informal support mechanisms and encourages family involvement in the plan. Ongoing assignments are made to family, providers, or other resources for evaluation of ongoing needs and the efficacy of all services. Remember that the life care plan is a living document requiring constant assessment and reevaluation.

**Maximizing Resources**

Life care planning in elder care management typically involves budgeting from limited financial resources and the creative use of community resources. Care and service options may include community or service/church groups; volunteers; private, personal pay; or alternative family resources.
Support services needed may include health screening through parish nurse programs or recreation programs. Respite care may be located through church or diagnosis-specific organizations. Long-term-care insurance policies may provide alternative services support, such as adult day care, which may be incorporated into the life care plan. Creativity in resource use and allocation must be incorporated in the plan and evaluated for continued usefulness.

<table>
<thead>
<tr>
<th>SAMPLE LIFE CARE PLAN</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Life Care Planning in Elder Care Management (Edited Version)</strong></td>
</tr>
<tr>
<td><strong>Patient:</strong></td>
</tr>
<tr>
<td><strong>Address:</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Date of Birth:</strong></td>
</tr>
<tr>
<td><strong>Telephone:</strong></td>
</tr>
<tr>
<td><strong>Medical Diagnosis:</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Physician:</strong></td>
</tr>
<tr>
<td><strong>Telephone:</strong></td>
</tr>
<tr>
<td><strong>Hospital:</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Telephone:</strong></td>
</tr>
<tr>
<td><strong>Primary Caregiver:</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Telephone:</strong></td>
</tr>
<tr>
<td><strong>History:</strong></td>
</tr>
</tbody>
</table>
**Status at Time of Life Care Plan Development:** Mr. R. was in a weakened condition, with poor nutritional status. He was isolated socially and unable to participate in household management. His 85-year-old brother was the primary caretaker. The brother was recovering from chemotherapy for treatment of non-Hodgkin's lymphoma. The brother's role was medication administration, transportation to physician appointments, and grocery buying. Elder care management was instituted on a private-pay basis by extended family, living in a distant state, to monitor health status and to promote quality of life.

<table>
<thead>
<tr>
<th>MEDICAL CARE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care/Need</td>
</tr>
<tr>
<td>Monitoring by cancer specialist as scheduled by the doctor; weekly appointments are scheduled during chemotherapy</td>
</tr>
<tr>
<td>Monthly appointments with heart doctor, J.B. White, M.D. (972-555-7212)</td>
</tr>
<tr>
<td>Laboratory studies/ blood samples; hemoglobin; mematocrit; comprehensive metabolic profile</td>
</tr>
<tr>
<td>Nutritional status evaluation</td>
</tr>
</tbody>
</table>
### MEDICATIONS

**Pharmacist: Dot Harvey, Harvey Pharmacy, (972) 555-7312**

<table>
<thead>
<tr>
<th>Medication/Dose</th>
<th>Why Prescribed</th>
<th>Times</th>
<th>Cost</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oxycontin, one tablet every 12 hours</td>
<td>Pain relief</td>
<td>8 A.M. 9 P.M.</td>
<td>$71.91/month (60 tablets)</td>
<td>This is a strong medication that will relieve pain and cause drowsiness.</td>
</tr>
<tr>
<td>Oxycodone, one or two tablets every 3–4 hours for increasing pain</td>
<td>Pain relief</td>
<td>11 A.M. 3 P.M. 7 P.M. Midnight 4 A.M.</td>
<td>$146.86/month (120 tablets)</td>
<td>This medication is for break-through pain and should be taken on an as-needed basis; if patient becomes dizzy, confused, or constipated, talk with Dr. Smith.</td>
</tr>
</tbody>
</table>

**Note:** This approach was repeated for all medications prescribed for Mr. R. The pharmacy he used was selected by Mr. R. and his brother because (1) pricing was competitive, (2) the pharmacy provided home delivery, and (3) a senior discount was provided to persons with greater than four long-term prescriptions. Cost was an issue, since total noncovered medications totaled approximately $700/month.

### HOME CARE ASSISTANCE

<table>
<thead>
<tr>
<th>Care/Need</th>
<th>Rationale</th>
<th>Outcome</th>
<th>Costs</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meal planning/ preparation</td>
<td>Poor intake; poor appetite</td>
<td>Increased intake; improved energy levels; improved function and improved healing</td>
<td>$0</td>
<td>Neighbors have organized to provide 15 meals/week; Mrs. K. will meet with patient on Thursdays at 10:00 a.m. to prepare a grocery list; Kurt R. will complete shopping.</td>
</tr>
<tr>
<td>Homemaker services</td>
<td>Decreased strength has limited patient's ability to care for his home as he wishes it to be done.</td>
<td>Laundry and cleaning completed</td>
<td>$45/week</td>
<td>Patient requested 3 hours, once weekly, at $15/hour; interviewed two persons from his church and selected one to hire; outcomes will be monitored by the care manager.</td>
</tr>
</tbody>
</table>
Conclusion

Life care planning benefits at-risk geriatric populations (see Table 21.3). Those who are identified after assessment in medium- to high-risk categories are prime candidates for life care planning. As an outcome of care/case management, life care planning enhances individual/patient education, facilitates integration of services, decreases stress, and encourages use of and access to community resources. With an aging population, life care planning offers a valuable tool for those facing long-term health care needs resulting from catastrophic injury or chronic illness.

<table>
<thead>
<tr>
<th>Category</th>
<th>High Risk</th>
<th>Medium Risk</th>
<th>Low Risk</th>
</tr>
</thead>
<tbody>
<tr>
<td>Characteristics</td>
<td>75 years or older, assisted living, 2 or 3 comorbidities, major functional limitations, 2 or more acute inpatient stays in past 12 months, multiple physician contacts, dialysis, day treatment, home health services</td>
<td>Newly diagnosed chronic illness, 2 or 3 comorbidities, lifestyle change</td>
<td>Lifeline, support system in place, compromised financial status</td>
</tr>
<tr>
<td>Case management</td>
<td>Intensive</td>
<td>Active</td>
<td>Maintenance</td>
</tr>
<tr>
<td>Frequency</td>
<td>2 weeks or more</td>
<td>Monthly</td>
<td>6–8 weeks</td>
</tr>
</tbody>
</table>

Mr. R. died peacefully at his home, surrounded by friends and family.

Resources

AARP: Coping with Grief and Loss
www.aarp.org/griefandloss

Accessible Home Modification Page
www.homemods.org

Administration on Aging—Department of Health and Human Services
www.aoa.gov

Aetna Intelihealth
www.Intelihealth.com
Agency for Health Care Research and Quality
http://ahcpr.gov

Aging Network Services
www.agingnets.com

Aging Research & Training News
www.bpinews.com/hr/pages/art.htm

AGS Foundation for Health in Aging
www.healthinaging.org

Allscripts Care Management Solutions
www.extendedcare.com

Alzheimer’s Association
www.alz.org

Alzheimer’s Disease Education and Referral Center at the National Institute of Aging
www.nia.nih.gov/Alzheimers

American Association for Geriatric Psychiatry
www.aagpgpa.org

American Association for Homecare
www.aahomecare.org

American Association of Homes and Services for the Aging
www.ahhsa.org

American Association of Retired Persons (AARP)
www.aarp.org

American Bar Association Commission on the Legal Programs of the Elderly
www.abanet.org

American Cancer Society
www.cancer.org

American Geriatrics Society
www.americangeriatrics.org

American Society on Aging
www.asaging.org

Andrus Foundation
www.andrus.org
ARCH National Resource Center for Respite Care and Crisis Care Services
www.chtop.org/arch.html

Arthritis Foundation
www.arthritis.org

Assisted Living Federation of America
www.alfa.org

Association for Gerontology in Higher Education
www.aghe.org

Benefits Checkup
www.benefitscheckup.com

Brookdale Center for Health and Longevity
www.brookdale.org

Cancer Center
www.cancercenter.com

Cancer Net
www.cancer.net

CaregiverZone.com
www.caregiverzone.com

Caregiving Online
www.caregiving.com

Caregiving Supplies—The Boulevard
www.blvd.com
www.coast-resources.com
www.dynamic-living.com

Careguide@Home—Elder Care
www.eldercare.com

CarePlanner—Clinical Tools
www.careplanner.org

Care There
www.carethere.com

Case Management Resource Guide
www.cmrg.com/index.htm
Centerwatch
www.centerwatch.com

Children of Aging Parents
www.caps4caregivers.org

Clinical Trials
www.clinicaltrials.com

Consumer Consortium on Assisted Living
www.ccal.org

ElderCare Online
www.ec-online.net

Elderhostel
www.elderhostel.org

Elder Support Network
Association of Jewish Family & Children Agencies
www.ajfca.org

Elderweb—Center for Eldercare
www.elderweb.com

Estronaut—A Forum for Women’s Health
www.womenshealth.org

Family Caregiver Alliance—National Center on Caregiving
www.caregiver.org

Fisher Center for Alzheimer’s Research Foundation
www.alzinfo.org

Friends and Relatives of the Institutionalized Aged
www.fria.org

Gerontological Society of America
www.geron.org

GriefNet
www.griefnet.org

Guide to Retirement Living
www.retirement-living.com/main.html

Health and Age
www.healthandage.com
Health Answers Education
www.healthanswers.com

Health A to Z
www.healthatoz.com

Health Care Financing Administration
www.os.dhhs.gov

Healthfinder
www.healthfinder.gov

Health Policy and Management
www.hpm.umn.edu

Home Health
www.e-homehealth.com

Hospice Foundation of America
www.hospicefoundation.org

Long Term Care Insurance Buyer’s Advocate Alliance
www.prepsmart.com

Mature Mart
www.maturemart.com

Mayo Clinic
www.mayo.edu

MedBank of Maryland, Inc.
www.medbankmd.org

Medicine Program
http://themedicineprogram.com

MEDLINEplus
www.nlm.nih.gov/medlineplus

MedSite from WebMD
www.medsite.com

National Academy of Elder Law Attorneys
www.naela.org

National Academy of Social Insurance
www.nasi.org
National Academy Press
www.nap.edu

National Advisory Council for Long Term Care Insurance
www.longtermcareinsurance.org

National Asian Pacific Center on Aging
www.napca.com

National Association for Hispanic Elderly
www.anppm.org

National Association of Area Agencies on Aging
www.N4A.org

National Association of Geriatric Education Center
www.hcoa.org/nagec

National Association of Professional Geriatric Care Managers
www.caremanager.org

National Association of State Units on Aging
www.nasua.org

National Cancer Institute
www.cancer.gov

National Caregivers Library
www.caregiverslibrary.org

National Center on Elder Abuse
www.ncea.aoa.gov/ncearoot/Main_Site/index.aspx

National Clearinghouse for Alcohol and Drug Information
www.ncadi.samhsa.gov

National Committee to Preserve Social Security and Medicare
www.ncpssm.org

National Council on the Aging
www.ncoa.org

National Family Caregivers Association
www.nfcacares.org

National Health Information Center
www.health.gov/nhic
National Hospice and Palliative Care Organization
www.nho.org

National Hospice Foundation
www.nationalhospicefoundation.org

National Institute on Aging
(800) 222-2225
www.nih.gov/nia

National Library of Medicine (PubMed)

National Policy Resource Center on Nutrition Physical Activity and Aging
www.nutritionandaging.fin.edu

National Rehabilitation Information Center
www.naric.com

National Senior Citizen’s Law Center
www.nsclc.org

National Senior Sports Association
www.amgolftour.com

Nursing Home Information Site
www.angelfire.com

Nutrition Analysis Tool 2.0
www.nat.uiuc.edu/mainnat.html

Patient Care Technologies Inc.
www.ptct.com

SeniorCom
www.senior.com

SeniorLaw Home Page
www.seniorlaw.com

SeniorLink
www.seniorlink.com

SeniorNet
www.seniornet.org

Senior Options
www.senioroptions.com
Senior Sites
www.seniorsites.com

Social Security Administration Online
www.ssa.gov

TheHelpWeb
www.thehelpweb.com

The Homecare Directory
www.thehomecaredirectory.com

Thirdage.com
www.thirdage.com

Today’s Care Given
Caregiver Survival Resources
www.caregiver911.com

Visiting Angels Living Assistance Services
www.angelsinwestpalm.com

Web of Care
www.webofcare.com

References


Chapter 22

Forensic Issues for Life Care Planners

Roger O. Weed

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Introduction

This chapter will summarize some of the issues that the life care planner must consider in order to practice in the area of forensic rehabilitation and may offer a somewhat different perspective than that offered in the chapters authored by attorneys. Clearly, the life care plan (LCP) is used for more than litigation (Weed, 1994; Riddick & Weed, 1996; Weed & Field, 2001; Deutsch & Sawyer, 2003; Weed, 2003, 2007). Historically, the care plan has been used in setting reserves for insurance companies, assisting workers’ compensation companies with assessing future care costs associated with work-related disabilities, estimating the cost of future care for health care
insurance companies, and providing the client and family with an outline of future care (Weed & Field, 2001; Deutsch & Sawyer, 2003). In the event that inadequate funding is available, the life care plan can become the road map for prioritizing care. In many instances, the future care plan may not be fully funded; therefore, the LCP can be used to prioritize treatment so that available funding is used most appropriately. In a simplistic way, the LCP is used to identify needs that can be translated into a budget so that the most important items are given the highest priority.

Since LCPs are used in a variety of jurisdictions, the appropriate “rules” must be considered. Probably the most comprehensive setting is in personal injury litigation (Weed & Berens, 2002). In the litigation arena, the LCP must consider the entire person and his or her situation. Only items that have economic value are included. For example, hedonic damages, such as the loss of pleasure of life or choice, are not included in this format. This chapter is not intended to provide a comprehensive analysis for items and issues that do not lend themselves to economic projections; the reader is referred to Brookshire and Smith (1990) for a more detailed discussion of this specialized area. It must also be recognized that many states have different legal rules with regard to evidence and testimony. Indeed, federal rules are interpreted differently across the United States. This chapter is intended to address common issues and topics associated with civil litigation as applied to life care planning or forensic rehabilitation.

According to Black’s Law Dictionary (Black, 1990), forensic rehabilitation refers to the practice of rehabilitation principles in legal settings. This short dissertation will discuss the relationship between rehabilitation and the courts, expert witness roles, and selected terms that may be important to the rehabilitation consultant working within the legal system.

Rehabilitation experts are relatively new to the courtroom. Indeed, rehabilitation counselors historically were trained specifically to work in public agencies and were often shielded from acting as expert witnesses in personal injury litigation (Weed & Field, 2001). The first entry into the rehabilitation private sector, which involved nurses, was initiated on a larger scale in the late 1960s, when International Rehabilitation Associates, which later became Intracorp, was formed by an insurance company to help process and manage insurance claims. By the 1990s, private sector rehabilitation had extended into almost all areas of disability care, including workers’ compensation, long-term disability, Social Security disability insurance, health insurance, railroad (Federal Employees Liability Act), longshore workers, Jones Act, and personal injury litigation (Weed & Field, 2001). Although there is considerable similarity across jurisdictions, there are a number of differences the rehabilitation expert should know before stepping into court, and even before beginning work on a case within a particular legal jurisdiction.

For example, the word disability is defined differently in various systems. In public rehabilitation, disability usually refers to the medical condition, which establishes eligibility for services, indicating that the client is able to perform work and benefit from vocational rehabilitation services (Weed & Field, 2001). When Social Security determines a person is disabled, the person is deemed unable to perform “substantial gainful activity” and may qualify for government support. In workers’ compensation systems, some states have provision for disability that may be permanent or temporary, as well as partial or total. As with the word disability, terminology can make a significant difference and it is important for the rehabilitation expert to understand the meaning of words used in the various disability systems and the courtroom.

Although this author recommends that the rehabilitation expert possess credentials related to life care planning consulting and testimony, it is not necessary for the rehabilitation professional to be certified or possess a certain level of education to be considered an expert. According to legal precedence (Kim Manufacturing v. Superior Metal Treating, 1976), an “expert witness is one who by reason of education or specialized experience possesses superior knowledge respecting a subject
about which persons having no particular training are incapable of forming an accurate opinion or deducing correct conclusion.” Therefore, an attorney may retain someone for personal injury litigation who would not necessarily be considered an expert in some states for workers’ compensation or as a vocational expert (VE) for the Social Security system, but who fits this definition of expert witness.

**Earnings Capacity Analysis**

Often one element of damages is the loss of earnings capacity (Dillman, 1987; Field & Weed, 1988; Weed & Field, 2001; Weed, 2002b). If the life care planner is not independently qualified to opine about this aspect of the case either by education, training, or credentials, he or she may wish to associate with a vocational expert. In order to provide an expert opinion regarding the loss of potential earnings, the expert must be prepared to provide an assessment of the person’s earnings capacity. Although a separate chapter addresses the details for what must be evaluated to arrive at a vocational opinion, generally accepted methods for determining loss of earnings capacity include the following:

- The most common method assumes the client has a work history. The rehabilitation professional scrutinizes vocational and medical records, perhaps supplemented by testing, and provides a professional opinion regarding preincident and postincident earnings capacity. See Table 22.3 for a description of the RAPEL methodology useful in determining earnings capacity. Obviously, this is not useful for a client who is too young to be of working age or for a client with limited or no work history.

- The Labor Market Access method, developed by Field and Field (1992), uses federal data regarding worker traits and the Dictionary of Occupational Titles (DOT) (U.S. Department of Labor, 1991). Although the Labor Market Access program is no longer available, a computer program (such as OASYS at www.vertekinc.com, or SkillTRAN at www.skilltran.com) can accomplish the same goal and can be used to help sort through more than 70 worker traits for the more than 12,000 job titles preincident versus postincident. This process identifies the number of preincident versus postincident jobs, preincident and postincident average earnings, and other information that can be used as a basis for the expert opinion. It is important to be aware that the O*Net (http://online.onetcenter.org) developed by the federal government has replaced the DOT for most career counseling purposes. However, at the time of this publication, there are numerous problems associated with using the O*Net in Social Security and personal injury pre- vs. postinjury opinions, and the aging DOT remains the resource of choice.

- To determine earnings capacity for children and others who may not have ample work history, an extensive review of the client’s background is useful. This may include school records, scrutiny of the parents and extended family with regard to work and education, and educational or neuropsychological testing. An extension of the RAPEL methodology, called PEEDS-RAPEL, has been developed to address factors specific to generating earnings capacity opinions for children (Neulicht & Berens, 2005). In acquired brain injury pediatric cases, preincident versus postincident ability to be educated can also be applied (Weed, 2000b).

- Another method, known as L-P-E, identifies the client’s probability of life (L), probability of labor force participation (P), and probability of employment (E). For more information on this method, the professional is directed to Economic/Hedonic Damages: The Practice Book for Plaintiff and Defense Attorneys, by Brookshire and Smith (1990).
A more contemporary methodology developed by Michael Shahnasarian (2007), is the Earnings Capacity Assessment Form, which has identified 14 factors to consider when developing opinions. At the time of this edition, little independent research has been conducted to assess the reliability and validity of the method, but the concept seems reasonable.

A more detailed explanation of some of these topics can be found in The Rehabilitation Consultant’s Handbook (Weed & Field, 2001), the Encyclopedia of Disability and Rehabilitation (Weed, 1995), and chapters in this book relating to the roles of vocational expert and economist.

Hedonic Damages

Another domain that some rehabilitation experts address is the loss of pleasures or choices in life, known as hedonic damages. Methods include describing to the jury the client’s situation regarding pain, loss of access to the labor market, psychological effects, loss of consortium, and other factors to provide the jury with guidelines. However, since hedonic damages cannot be specifically or directly translated into a dollar amount, this item is rarely a part of the LCP report.

The Life Care Plan (LCP)

Regardless of the topic, the expert must be able to quantify damages in a way that provides the economist, if one is used, or the jury, with the necessary information to project costs over time (Dillman, 1987; Weed, 2007). These data are used to help determine the amount of award to the client, if the party against whom the suit is lodged is found at fault. To ascertain the needs and costs of future care, particularly for serious medical conditions and catastrophic injuries, the LCP was originally published by Deutsch and Raffa in Damages in Tort Action (1981). This method organizes topics according to various categories (see Chapter 1 for an overview and Tables 22.1 and 22.2) that outline expected treatment, start and stop dates, costs, and other information that will provide the jury with an understanding of the treatment plan. The format is designed to develop a comprehensive rehabilitation plan that includes the necessary information to project the expense, usually with the help of an economist, in order to arrive at a “bottom-line” figure.

Report Writing

Some general report-writing issues are discussed in other chapters. One important item to note here is that a potential shift in terminology has recently emerged within the area of forensic

Table 22.1 Elements for Future Care Damages

- When does treatment start?
- What is the frequency of sessions?
- What is the cost per session (if relevant)?
- When does treatment stop?
- Additional costs such as evaluations, tests, laboratory, or medications?
- Any other needs/costs?
evaluations such that “the person who is the subject of the objective and unbiased evaluation” (Barros-Bailey et al., 2008, p. 7) should be referred to as the evaluee rather than client. Of other special interest, in this author’s view, is the 1993 ruling known as the Daubert decision (Daubert v. Merrell Dow). This decision implied that any testimony in federal court offered by a scientific expert must be founded on a methodology or underlying reasoning that is scientifically valid and can be properly applied to the facts of the issue. Considerations included whether the theory or technique has been subjected to peer review and publication. This theory was extended to expert opinions by the Kumho Tire opinion (1999). (Some states have adopted this federal court ruling, so experts may face a Daubert challenge in state court cases.) Although this topic has been addressed in preceding chapters, it is important to emphasize that proper foundations must be provided to a plan. Since many life care planners unfortunately either have failed to undergo specific training or do not follow published guidelines, the importance of continuing education, developing standards and methodologies, and publishing guidelines specific to our industry is underscored (Feldbaum, 1997; Choppa, Field, & Johnson, 2005; Field, Johnson, Schmidt, & Van de Bittner, 2006; Weed & Johnson, 2007).

One important aspect of the report is inclusion of appropriate details for the jury to determine the cost of future care and effects on vocational opportunities, including earnings capacity. Assuming that an expert has developed all of the necessary data and opinions relative to damages in a personal injury case, it is appropriate to offer a rationale to encompass the issues that should be addressed in a written report. The RAPEL methodology (Table 22.3) is designed to address

<table>
<thead>
<tr>
<th>Table 22.2 Example Entry for Future Care Damages</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Psychological evaluation in June 2008 at $600</td>
</tr>
<tr>
<td>• Expect counseling to begin in July 2008 at 1 time/week, 1-hour session, for 26 weeks at $100/hour, then expect group counseling for 2 years (48 sessions) at $40/session</td>
</tr>
<tr>
<td>• Expect medication, Prozac, 1 tablet of 20 mg/day for life expectancy, at $53.86 per month</td>
</tr>
<tr>
<td>• Expect psychiatrist follow-up for medication 4 times/year beginning January 2009 at $150 for the initial visit, then $75 for each visit thereafter to life</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Table 22.3 The RAPEL Method: A Commonsense Approach to Life Care Planning and Earnings Capacity Analysis*</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Rehabilitation plan</strong></td>
</tr>
<tr>
<td>Determine the rehabilitation plan based on the client’s vocational and functional limitations, vocational strengths, emotional functioning, and cognitive capabilities. This may include testing, counseling, training fees, rehab technology, job analysis, job coaching, placement, and other needs for increasing employment potential. Also consider reasonable accommodation. A life care plan may be needed for clients with catastrophic injuries or complex health care needs.</td>
</tr>
<tr>
<td><strong>Access to the labor market</strong></td>
</tr>
<tr>
<td>Determine the client’s access to the labor market or employability for jobs that exist in the labor market without regard to current economic or other conditions. Methods include the transferability of skills (or worker traits) analysis, disability statistics, and experience. Some professionals use computer programs to help manage large amounts of data. Access loss may also represent the client’s loss of choice and is particularly relevant if earnings potential is based on very few positions.</td>
</tr>
</tbody>
</table>

(Continued)
Table 22.3 (Continued)

| **Placeability** | This represents the likelihood that the client could be successfully placed in a job whereas employability or access to the labor market does not consider currently available jobs. This is where the “rubber meets the road.” Consider employment statistics for people with disabilities, employment data for the specific medical condition (if available), economic situation of the community (may include a labor market survey), and availability (not just existence) of jobs in chosen occupations. Note that the client’s attitude, personality, and other factors will influence the ultimate outcome. |
| **Earnings capacity** | Based on the previous points, what is the preincident capacity to earn compared to the postincident capacity to earn. Methods include analysis of the specific job titles or class of jobs that a person could have engaged in pre- vs. postincident, the ability to be educated (sometimes useful for people with acquired brain injury), family history for pediatric injuries, and computer analysis based on the individual’s worker traits. Special consideration applies to children, women with limited or no work history, people who choose to work below their capacity (e.g., highly educated persons who are farmers), and military trained. |
| **Labor force participation** | This represents the client’s work life expectancy. Determine the amount of time that is lost, if any, from the labor force as a result of the disability or retraining time. Issues include longer time to find employment, part-time vs. full-time employment, medical treatment or follow-up, earlier retirement, etc. Display data using specific dates or percentages. For example, an average capacity of working 4 hours a day due to a brain injury may represent a 50% loss. |


* In litigation the word evaluate may be more appropriate than “client.” For a discussion on this related topic, the authors suggest reading Barros-Bailey, M., Carlisle, J., Graham, M., Neulicht, A., Taylor, R., & Wallace, A. (2008). Who is the client in forensics? Boise, ID: Authors (Contact Dr. Barros-Bailey at barrosm2002@yahoo.com).

the relevant topics for personal injury litigation in a rational and commonsense way as well as provide a format for displaying the information to the jury. A narrative description of each letter represented in RAPEL is in Table 22.3. Table 22.4, which describes PEEDS-RAPEL, an earnings capacity analysis specific to pediatric cases. See Neulicht and Berens (2005) for a full description of PEEDS-RAPEL.

**Rehabilitation Plan**

This section includes the LCP that comprehensively outlines the expected future medical and related care of the client (see previous chapters for topics or Life Care Planning: A Step by Step Guide, Weed, 2007). This section may also include, as applicable, additional future testing, counseling, training fees, rehabilitation technology, labor market survey costs, job analysis, job coaching, placement, and other needs for improving the client’s potential for employment.

For expert testimony, the life care planner is expected to follow established procedures and ethics (see Appendix I for peer-reviewed Standards of Practice published by the International Academy of Life Care Planners in 2002 and revised in 2006). Experts who elect not to be specifically certified in life care planning (such as CNLCP or CLCP) may not be subject to complaints that can be reviewed or disciplined by the certification board (Weed, 2001a). For example, one expert completed an updated life care plan for a client with a brain injury. Although the client
Table 22.4 PEEDS-RAPEL Is Adapted for Pediatric Issues

<table>
<thead>
<tr>
<th><strong>Parental/Rental/Family Occupations</strong></th>
<th>Obtain family work history (occupations and skill levels). Include information from parents, older siblings, aunts/uncles, grandparents, or those adults that are likely to provide a role model for the child. Also include military experience, volunteer/community service, and/or avocational activities. Consider vocational assessment of parents, as appropriate, to determine a pattern of aptitudes or trait profile.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Educational Attainment</strong></td>
<td>Establish family patterns of educational attainment including information from the immediate and extended family. Determine not only the academic level/degrees earned, but the skills obtained through education and training. Administer or coordinate a referral for achievement, and/or intellectual assessment of parents as needed.</td>
</tr>
<tr>
<td><strong>Evaluation Results</strong></td>
<td>Determine the child’s functional capacities through interviews and formal assessment of physical, cognitive, emotional, and vocational capacity. Consider academic skills, interests, aptitudes, personality, assessment of independence/ADLs, and family patterns of hobbies/leisure activities. When appropriate, compare to preinjury status and function.</td>
</tr>
<tr>
<td><strong>Developmental Stage</strong></td>
<td>Consider the normal developmental tasks of a particular age (e.g., ADLs, career development). Determine the effects of a disability on function and ability to achieve developmental milestones. Provide recommendations for remediation and/or accommodations to facilitate the optimum level of function for the child.</td>
</tr>
<tr>
<td><strong>Synthesis</strong></td>
<td>Integrate results of the interview, parental/family occupations, educational attainment, evaluation results, developmental stage, and opinions regarding functional capacities to determine the impact of the disability and the likely options that are, within reasonable probability, available to the child.</td>
</tr>
<tr>
<td><strong>Rehabilitation Plan</strong></td>
<td>Determine the rehabilitation plan based on the client’s vocational and functional limitations, vocational strengths, emotional functioning, and cognitive capabilities. This may include testing, counseling, training fees, rehabilitation technology, job analysis, job coaching, placement, and other needs for increasing employment potential. Also consider reasonable accommodation. A life care plan may be needed for catastrophic injuries.</td>
</tr>
<tr>
<td><strong>Access to the Labor Market</strong></td>
<td>Determine the client’s access to the labor market. Methods include use of computer programs for transferability of skills (or worker trait) analysis, disability statistics, and experience. This may also represent the client’s loss of choice and is particularly relevant if earnings potential is based on very few positions.</td>
</tr>
<tr>
<td><strong>Placeability</strong></td>
<td>This represents the likelihood that the client could be successfully placed in a job. This is where the “rubber meets the road.” Consider the employment statistics for people with disabilities, employment data for the specific medical condition (if available), economic situation of the community, availability (not just existence) of jobs in chosen occupations. Note that, where appropriate, the client’s or family’s attitude, personality, and other factors will influence the ultimate outcome.</td>
</tr>
<tr>
<td><strong>Earnings Capacity</strong></td>
<td>Based on the previous points, what is the preincident capacity to earn compared to the postincident capacity to earn? Consider categories and examples of occupations (e.g., unskilled, semiskilled, or skilled as a result of elementary/middle school, high school, technical school, or college educational attainment) that are representative of the type of occupations a child could reasonably have been expected to perform pre- and postinjury. Determine the ability to be educated (sometimes useful for people with acquired brain injury). Utilize relevant research data and computer analysis, as appropriate, based on family work patterns or client’s worker traits.</td>
</tr>
</tbody>
</table>

(Continued)
Labor Force Participation

This represents the client’s work life expectancy. Determine the amount of time that is lost, if any, from the labor force as a result of the disability. Issues include additional time to find employment, part-time vs. full-time employment, medical treatment or follow-up, earlier retirement, etc. Display data using specific dates or percentages. For example, an average of 4 hours a day may represent a 50% loss.


had measurably improved from the first plan to the second, the updated plan (authored by the same person) was approximately double the cost of the first. Upon deposition, one explanation offered was that he, the life care planner, was simply acting in an administrative role by writing down what the medical professionals told him. The second plan included opinions from a new expert, and the LCP author did not ask questions, collaborate, or otherwise participate in the development of the LCP (in either the first or second plan). As a result, at least one plan (and maybe both) was not an accurate representation of needs. Essentially, the life care planner reported that the attorney should depose the experts on whom he relied to try and ferret out the reasons for substantial changes from the first LCP to the next. This stance seems to be an abdication of one of the major roles the qualified life care planner is expected to play. The qualified life care planner is expected to know what questions to ask, have enough knowledge about the disability to have a sense of what is reasonable, and be an active participant in the process. Further, according to one peer-reviewed article on the reliability of LCPs, professionals who conduct their life care planning practice according to published procedures should not observe significant differences between original and updated LCPs (Sutton et al., 2002; also see chapter of reprint on this topic).

In a second example, the plaintiff’s life care planner compiled a future care plan without consulting, collaborating with, or soliciting recommendations from treating professions to which she had access. As a result, when the physicians were deposed, their recommendations were very different from those in the written plan. When deposed, the expert proclaimed that she had been doing LCPs for many years and did not need to consult with others.

In summary, the qualified life care planner is neither a secretary nor a know-it-all. (See Weed, 2002a, “The Life Care Planner: Secretary, Know-It-All, or General Contractor? One Person’s Perspective,” for a more comprehensive discussion on this topic.) The expert needs to understand life care planning procedures, have knowledge about specific disabilities, and adhere to the profession’s standards and ethics to develop a comprehensive and reliable LCP. When conducted properly, the LCP is a valuable road map of care that can also be utilized to resolve disputes.

Although ethics is covered in another chapter, there are LCP-specific issues and topics that may be relevant in this section. Certainly, within a reasonable range, professionals in the practice of life care planning can have differing opinions and philosophies. Some, particularly people who choose not to pursue specific life care planning education and training, seem to be most likely to push the boundaries (Berens & Weed, 2001). Indeed, in the Life Care Planning Summit of 2000, sponsored by several organizations and many different life care planning professionals, there were many topics that achieved consensus by all 100-plus participants present and was endorsed by seven participating organizations (Weed & Berens, 2001). One item that has wide acceptance is the need for a medical foundation for relevant plan entries. First, it must be explicitly noted that
every LCP entry is not medical. Certainly nursing, allied health, vocational, psychological, case management, and other opinions can be offered by professionals who have the credentials to do so. However, many LCP needs are within the realm of physicians to prescribe. The ways to obtain a medical foundation are many. The most obvious is to collaborate with a qualified physician (or several if differing specialties are required). Other options include soliciting recommendations via letter or fax (keeping careful documentation), requesting the attorney to ask the physician questions in deposition if one does not have access to the physician (such as consulting for the defense), relying upon published medical research or clinical practice guidelines specific to the disability for standards and guidelines, and searching the client’s medical records for documented recommendations.

Another issue common to life care planning is the methodology of the research conducted related to identifying costs for the needs identified in the document. It is common for facts and data on which the author of the LCP relies will come from a variety of sources such as physicians, allied health care professionals, consultants, catalogs, suppliers, pharmacies (actual patient records, online, and brick and mortar), and others. It is also common for the author of the LCP to employ or subcontract a qualified individual who completes the necessary research. One caution is that the LCP author should provide specific direction to the person and supervise the research methodology so the document is reliable and can be effectively communicated by the author of the LCP within a litigation context. If one retains an independent consultant (rather than employing someone to help with the research), one must assure that the consultant is competent and willing to testify since it infers that the author of the LCP has delegated the duties to another person without the necessary oversight to fit the “direction and supervision” criteria. For example, in some life care plans, the durable medical equipment list may be extensive and complicated. In this instance, it may be reasonable to retain an expert consultant who can competently testify to the specifications, replacement schedules, and costs. On the other hand, researching the costs of medications may be within the realm of the life care planner’s expertise, who may direct and supervise an employee or independent contractor on sources to contact and what information to obtain. Checklists and forms are helpful in this regard, as well as having clear and thorough documentation of the research conducted, contacts made, date of contact, name of resource and contact person, phone number or e-mail/web address, and so on.

When consulting with attorneys about another individual’s LCP, one recommended strategy to help organize data and reveal the foundation for recommendations is a matrix of data containing a minimum of three columns. The first column is for each life care plan recommendation by the other expert, the second is for supporting documentation (medical records, depositions, report contents, interview information, day-in-the-life videos, etc.), and the third is for comments made based on the available information (see Table 22.5 for a basic example). In some cases, it may be appropriate to add a column for research-related information. It may also be useful to add a column when the expert’s plan being reviewed has been updated. This will allow the reader to see at a glance what the changes are for each category from the initial plan to the updated plan. Also to be included are general comments at the end.*

For occasions where comparison of two opposing LCPs is desirable, the two plans can be displayed side by side, with a column for foundation. See Table 22.6 for a limited example where the plaintiff’s life care planner did not collaborate with, or utilize, existing medical records and testimony from the treating physician for the LCP.

* Thanks to Debbie Berens for the layout design for Tables 22.5 through 22.7.
Table 22.5  Example Basic Matrix for Determining the Foundation for Life Care Plan Recommendations

<table>
<thead>
<tr>
<th>Plan Entry</th>
<th>Recommendation Based on Records Review</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Counseling 1 time/week for 2 years</td>
<td>No recommendation found in records.</td>
<td>Unknown psychological foundation; the nurse consultant is not certified or licensed in a counseling field.</td>
</tr>
<tr>
<td>Physiatrist 4 times/year to life</td>
<td>Dr. Doodue's deposition of May 10, 2003, p. 33, line 20, says 2 times/year to life.</td>
<td>Dr. Doodue is the treating physiatrist and reported that she was not contacted with regard to her recommendations.</td>
</tr>
<tr>
<td>Attendant care 4 hours/day to age 60, then 8 hours/day</td>
<td>Dr. Doodue's deposition of May 10, 2003, p. 49, lines 18–20, says the L2 spinal cord injury (SCI) client will require “some attendant care for household activities.”</td>
<td>SCI research for anticipated attendant care for an L2 level is 0–1 hour/day; see Blackwell et al., 2001, p. 246 (copy included).</td>
</tr>
</tbody>
</table>

Note: Records reveal a recommendation for ankle-foot orthoses (AFOs) for both legs, which was not included in the life care plan.

A third potential review technique is to compare the other expert’s procedures (to the extent possible) with the published procedures. See Table 22.7 for the general outline.

**Access to Labor Market (Employability)**

In many litigation cases, an individual may very well be able to return to a job that is custom-designed around his or her disability or, as in the case of traumatic brain injury, with an

Table 22.6  Example Comparison Matrix of Future Care Recommendations

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Penny Money, PhD (Plaintiff’s LCP)</th>
<th>Roger Weed, PhD (Defense LCP)</th>
<th>Medical Records/Deposition of Boat Dock, MD (Treating Physiatrist)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physiatrist</td>
<td>2 times/year</td>
<td>1–2 times/year average to life expectancy</td>
<td>1–2 times/year for medication management</td>
</tr>
<tr>
<td>Primary care physician</td>
<td>Internist: 1 time initially, then 2 times/year to life expectancy</td>
<td>4–5 times/year to life expectancy (deduct average yearly medical care for general population)</td>
<td>4–5 times/year for general medical care (which includes a preexisting condition)</td>
</tr>
<tr>
<td>Orthopedic evaluation</td>
<td>1 time initially (by surgeon), then 1–2 times/year to life expectancy</td>
<td>Optional for complications, if any; year initiated and frequency unknown</td>
<td>May need if develops degenerative spine/joint disease and/or scoliosis; no need at present</td>
</tr>
<tr>
<td>Medical testing</td>
<td>No reference</td>
<td>Yearly lab tests to life expectancy Renal function studies every 3 months to life expectancy</td>
<td>Routine diagnostic testing Renal function studies every 3 months</td>
</tr>
<tr>
<td>Published Step-by-Step Procedures for Life Care Planning (Derived from Step-by-Step Procedure for Life Care Planning, Table 1.3 of this volume.)</td>
<td>Comments Regarding Expert’s Procedures (Based on records, report, deposition transcript, etc.)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>
| **Case Intake:**  
1. When you talked with the referral source, did you record the basic referral information?  
2. Time frames discussed?  
3. Financial/billing agreement?  
4. Retainer received (if appropriate)?  
5. Arrange for information release? |  |
| **Medical Records:**  
1. Complete copy requested including lab reports and X-rays |  |
| **Supporting Documentation:**  
1. Are there depositions of client, family, or treatment team that may be useful?  
2. Day-in-the-life videotapes  
3. And if vocational issues to be included in report—school records (including test scores)?  
4. Vocational and employment records?  
5. Tax returns, if appropriate? |  |
| **Initial Interview Arrangements:**  
1. Is the interview to be held at the client’s residence?  
2. Have you arranged for all appropriate people to attend the initial interview (spouse, parents, siblings)?  
3. Did you allow 3–5 hours for the initial interview? |  |
| **Initial Interview Materials:**  
1. Do you have the initial interview form for each topic to be covered?  
2. Supplemental form for pediatric cases, CP, traumatic brain injury (TBI), and spinal cord injury (SCI) as needed? |  |

(Continued)
Table 22.7 (Continued)

<table>
<thead>
<tr>
<th>Consulting with Therapeutic Team Members:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Have you consulted with and solicited treatment recommendations from appropriate therapeutic team members (if appropriate)?</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Preparing Preliminary Life Care Plan Opinions:</th>
<th></th>
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<tbody>
<tr>
<td>1. Do you have information that can be used to project future care costs?</td>
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<tr>
<td>2. Frequency of service or treatment?</td>
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<td>3. Duration?</td>
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<td>4. Base cost?</td>
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<td>5. Source of information?</td>
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<td>6. Vendors?</td>
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<tr>
<th>Filling in the Holes:</th>
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<tbody>
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<td>1. Do you need additional medical or other evaluations to complete the plan?</td>
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<tr>
<td>2. Have you obtained the approval to retain services of additional sources from the referral source?</td>
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<tr>
<td>3. Have you composed a letter outlining the right questions to assure you are soliciting the needed information?</td>
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<tr>
<th>Researching Costs and Sources:</th>
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<tbody>
<tr>
<td>1. Have you contacted local sources for costs of treatment, medications, supplies, and equipment?</td>
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<tr>
<td>2. Or do you have catalogs or flyers?</td>
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<tr>
<td>3. For children, are there services that might be covered, in part, through the school system under IDEA?</td>
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employer who is interested in helping an employee with mild to moderate cognitive deficits (Weed, 1988; Weed & Field, 1994/2001). However, the client may not have access to the same level of vocational choices he did prior to the incident. In essence, the client might appear to have no particular loss of earnings capacity, but at the same time be at high risk for losing a job and then having a significant problem locating suitable employment. As noted earlier in this chapter, access to the labor market can be determined through a variety of means. OASYS and SkillTRAN are two computer programs used as tools to assist in determining, based on worker traits, the client's ability to choose in the labor market. For example, one client may have a 50% personal loss of access to the labor market and another individual may have a 95% personal loss of access to the labor market. Obviously, an individual who has personal access to 5% of the labor market should be employable or placeable; however, the difficulty factor for suitable or sustained employment has increased significantly. By placing a loss of access percentage to the labor market, one can sensitize the reader or jury to the potential difficulty for placement. Generally, this is described in a particular percentage loss of access to the client's personal labor market rather than to the national labor market. Few unimpaired people have access to 100% of the labor market, and this is a common error assumed by the uneducated observer (Woodrich & Patterson, 2003).

**Placeability**

This represents the likelihood that the client will be successfully placed in a job with or without rehabilitation support or rehabilitation consultant assistance. One may need to conduct a labor market survey, job analysis, or, in pediatric cases, rely upon statistical data to opine about ultimate placeability. The economic condition of the community may also be a factor. It is important that the rehabilitation consultant recognize that the client's personality, cognitive limitations, and other factors certainly influence the ultimate outcome. For adults, the rehabilitationist may find that it is useful to include an opinion about jobs that are available

<table>
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<tr>
<th>Finalizing the Life Care Plan:</th>
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<tr>
<td>1. Did you confirm your projections with the client and/or family?</td>
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<tr>
<td>2. Treatment team members (if appropriate)?</td>
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<tr>
<td>3. Can the economist project the costs based on the plan?</td>
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<tr>
<td>4. Do you need to coordinate with a vocational expert?</td>
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<tr>
<th>Last but Not Least:</th>
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<tr>
<td>1. Have you distributed the plan to all appropriate parties (client [if clinically appropriate], referral source, attorney, and economist, if there is one)?</td>
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(actual openings) in addition to jobs that exist but are not currently available to the client (employability)—if it is likely that the client will have worker traits that match various job titles. Matching to a job title does not suggest that the person can indeed be placed in a particular occupation. Other factors, such as location, experience, education, and personality, can adversely impact placement. Also, many jobs that may be appropriate for the client are difficult to obtain. The vocational opportunity may be highly competitive or there may be very few positions available. On the other hand, jobs may exist that the client with a disability may be able to do, even though on paper (through review of worker traits based on government statistics) it would appear to the contrary.

**Earnings Capacity**

Based on the rehabilitation plan, access to the labor market, and placeability factors, the client may or may not be employable in the labor market. If placement in a job is likely, an estimate of the earnings potential is important. In general, the difference between wage loss and earnings capacity analysis for an individual is that which he or she can reasonably attain and hold. For example, consider a 17-year-old who delivers papers for an income when he is catastrophically impaired and is never able to work again. Certainly, the earnings history from the paper delivery does not represent the individual’s capacity. On the other hand, a 55-year-old union truck driver may exhibit an earnings history that is consistent with his capacity. Considerations include whether the individual is a child or an adult and, if an adult, the industry for which he or she is best suited. For example, a drywall hanger of marginal intelligence may very well reach his earnings potential by the time he reaches his late twenties or early thirties. On the other hand, an attorney may not reach her potential until late in his or her career.

**Labor Force Participation**

This category represents an opinion about the client’s anticipated work life expectancy. Usually an individual who has a reduced life expectancy will also be expected to have a reduced work life expectancy. At the other end of the spectrum, the client’s participation in the labor force may be unchanged. An individual may also be expected to work 6 hours per day after the injury rather than 8 hours per day, which represents a 25% loss of normal work life expectancy. Some clients have demonstrated consistent extra income by working overtime, and this situation can be considered in this arena as well. Generally speaking, the consultant will express the opinion of loss by percentage or perhaps a number of years. It is usually the economist who makes the actual economic projections. This particular area is quite complicated, and most vocational counselors are not prepared to address the subtleties and complexities of economic projections (Dillman, 1987). However, for additional general information, though an aging resource, the consultant can obtain information about worklife estimates in *Worklife Estimates: Effects of Race and Education* (Bulletin 2254, U.S. DOL, 1986). Other privately produced worklife tables exist but, in this author’s experience, controversy surrounds their usage so caution is urged.

In order to assure that experts cover the relevant areas and have the background to offer opinions, two checklists have been developed (see Tables 22.8 and 22.9).
### Table 22.8 Checklist for Review of Life Care Plans

| ✓ | Was a complete set of medical and other relevant records provided with referral? Did narrative report accompany LCP? Deposition transcripts of client, family, and/or treatment team provided? Day-in-the-life or other videotapes of client? Photographs of client? Deposition of life care planning expert? |
| ✓ | Does LCP follow published standards and procedures? Refer to IALCP website (www.IALCP.com) for published standards for life care planners. Use of published or standard checklists, forms, charts, etc.? Collaborative effort? Potential complications referenced on appropriate page and not included in LCP? |
| ✓ | Are entries in LCP appropriate for disability/injury? Input obtained from treatment team or consulting physician(s), if appropriate? Medical, psychological, or neuropsychological foundation established? Standards of care for the specific disability referenced, if applicable? Life care planner’s recommendations within his area of expertise? Medical/therapeutic recommendations within respective providers’ area of expertise? Preventive and rehabilitative goals? All areas related to disability included? Costs related to disability only and not related to general or routine care or preexisting conditions? Costs based on geographic area or other appropriate database? |
| ✓ | Overlaps? Are same or similar services listed more than once under different categories? Can one provider accomplish two recommendations and be more cost-effective (e.g., qualified speech therapist or occupational therapist to also do assistive technology evaluation, primary care physician to also do urinalyses, etc.)? Time frames for services chronological or mutually exclusive? |
| ✓ | In-home/facility care? For in-home pediatric care, are adjustments made for time child is at school and for time parents normally are expected to be available to parent a child? Adjustments made as child gets older and normally would require less assistance? Level of care appropriate to client’s needs? (In general, minimum LPN for G-tube management, bowel/bladder program, trach care, medication administration, and cut/clean toenails; CNA/PCA/HHA for activities of daily living (ADL), meal preparation, laundry, housekeeping, driving, and safety/supervision at home. Also refer to each state’s Nurse Practice Act for specific requirements.) Do agencies surveyed provide CNA II or have state authorized special rules that allow trained CNAs to provide some skilled care under supervision of RN/LPN? Consideration made to potential negotiated cost reduction with home health agency if long-term contract? Parents/family expected to provide some of the care? Lawn/yard care and exterior/interior home maintenance included as adult? For residential community living program/facility, is average yearly cost of individual room and board deducted from per diem rate (if loss of earnings capacity is also a part of damages)? |
| ✓ | Appropriate cost deductions made or noted to economist with regard to general expenses incurred without disability? For wheelchair-accessible van, cost of average vehicle or trade-in value of family vehicle deducted if loss of earnings capacity is also a part of damages? Accessible home, cost of average home in local area deducted? Dental/medical care, cost of routine care recommended for general population deducted? Adaptive clothing allowance, average yearly cost of clothing for general population deducted? Adaptive leisure equipment allowance, average yearly cost of recreation/leisure activities of general population deducted? Total enteral nutrition, average yearly cost of food consumption for general same-age population deducted? Alternatively, is a distinction made that the recommended services in the plan are over and above those that are recommended for the general population? |

(Continued)
### Table 22.9 Checklist for Review of Life Care Planner Qualifications and Practices (aka Checklist for Selecting a Life Care Planner)

| ✓ | Are costs calculated correctly? Is the math correct? Source of cost information known or documented? If economic calculations are included, is life care planner qualified to make such calculations? Are costs of as-needed services/items included in plan? Are costs of potential complications included? |
| ✓ | Vocationally relevant items? Are vocational issues addressed or deferred to qualified vocational specialist for vocational considerations? |
| ✓ | Plan confirmation? Plan or relevant entries reviewed/confirmed/endorsed by physician(s) and/or treatment team, if access is available? Client/family, if access available? Future updates expected? |
| ✓ | Aesthetics? Are plan entries easy to read, follow, and understand? Does plan overall look professional and make sense? Minimal to no typographical errors or date errors? Is the information presented clearly, logically, and with sufficient detail? Consistency between narrative report, records, and plan entries? |

**Source:** Debra E. Berens and Roger O. Weed.

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### Table 22.8 (Continued)

| ✓ | Professional’s qualifications? |
| ✓ | Education, including degrees and continuing education? If doctorate, was the university accredited? (Some so-called experts have mail-order degrees or diplomas from universities that are not accredited.) |
| ✓ | Training specific to life care planning? |
| ✓ | Work experience? |
| ✓ | Life care planning experience? |
| ✓ | Research knowledge and experience? |
| ✓ | Certifications or licenses? Generally accepted rehabilitation certifications include CLCP (certified life care planner), CNLCP (certified nurse life care planner), CRC (certified rehabilitation counselor), CDMS (certified disability management specialist), CVE (certified vocational evaluator), CRRN (certified rehabilitation registered nurse), CCM (certified case manager), diplomat or fellow ABVE (American Board of Vocational Experts), and CLNC (certified legal nurse consultant). |
| ✓ | Forensic experience (if appropriate)? Familiar with the rules pertaining to experts? Have they testified? Do they have a list of cases for which they testified at deposition or trial for the previous 4 years? Plaintiff/defense ratio? |
| ✓ | Prospective consultant’s awareness of life care planning? |
| ✓ | Are they certified in an area relevant to life care planning? Refer to Commission on Health Care Certification website (www.ichcc.org) or contact the American Association of Nurse Life Care Planners (www.aanlcp.org) for list of life care planners who are certified through either organization. |
- Have they achieved the **certificate** in life care planning offered through one of the past or existing training programs such as Rehabilitation Training Institute, Intelicus, University of Florida, Kaplan University, Capital Law paralegal program, etc.?

- Have they completed **courses** or **continuing education** offered by past or present noted programs on life care planning (e.g., Rehabilitation Training Institute, Intelicus, Medipro, University of Florida, IARP, IALCP, Care Planners network, et al.)?

- Can they cite life care planning **references**?

- Do they know some of the **professionals** associated with life care planning publications and training?

- Do they belong to professional **organization(s)** with focus on life care planning such as International Academy of Life Care Planners (IALCP), www.IALCP.com? Do they belong to a disability-specific organization? (Are they legitimate or fringe organizations such as a for-profit owned by an individual or group with little recognition or substance?)

- Do they **participate** in professional development?

- Have they **contributed** their time and effort by volunteering services to clients in need, speaking, holding office with professional organizations, writing articles, chapters, or books?

- Have they received **awards, honors, or peer recognition**?

- **Commitment** to the profession?

- Workers’ compensation or federal Office of Workers’ Compensation Programs?

- Personal injury?

- Social Security?

- State rehabilitation?

- Longshore workers? Jones Act? Federal Employees Liability Act (FELA)?

- Long-term and short-term disability?

- Specialize in a particular disability?

- **Medical foundation** for opinions established?

- Use established published **checklists and forms**?

- Routinely consult with a **physician** as part of the team or have medical literature/clinical practice guidelines relevant to client?

- Include other **health professionals** as appropriate (e.g., OT, PT, SLT, RT, audiology, neuropsychology, etc.)?

- **Other**?

- What and how do they **bill** for their services? Do they charge different rates for interview, records review, deposition, trial time, or rush cases?

- Current curriculum **vitae**?

- History of **ethics complaints or arrests**?

*Source: Original checklist developed by Roger O. Weed, revised by Debra E. Berens, 2002.*
Conclusion

This chapter builds upon the following chapters offered by experienced plaintiff and defense attorneys. Since the previous edition, numerous cases of successful and unsuccessful court challenges have appeared. Extensive summaries of examples up to 2006 are available in *Life Care Planning in Light of Daubert and Kumho* (Weed & Johnson, 2006) punctuated with comments, conclusions, and helpful hints. Examples include experts who have substantial experience but have been excluded based not on their work experience and background, but what they are planning on testifying about. In some cases, there appeared to be little or no foundation for opinions. Commonly, the expert failed to include a medical basis for recommendations. In other cases, the recommendations offered by the plaintiff’s expert were contrary to the treating or plaintiff’s medical expert’s opinions.

The booklet by Weed and Johnson (2006) also includes examples of professionals who were deemed qualified. In general, successful experts utilized published standards of practice, adhered to published and peer-reviewed methodology, had evidence of training or continuing education specific to life care planning, and were able to show clear foundation for opinions and recommendations.

Other recommended publications related to the chapter topics are

- *Daubert Challenge: From Case Referral to Trial* (Choppa, Field, & Johnson, 2005)
- *Methods and Protocols: Meeting the Criteria of General Acceptance and Peer Review under Daubert and Kumho* (Field, Johnson, Schmidt, & Van de Bittner, 2006)

In summary, this chapter has outlined many of the topics and issues that the life care planner must consider when developing opinions for civil litigation cases. The expert is in an excellent position to assist in resolving litigation by soliciting information that addresses almost all of the damage aspects of the case. Knowing the health care industry and effectively analyzing the needs and researching the future care and costs associated with a complex injury are specialized services that offer a true enhancement to the profession. When completed objectively and professionally, the care plan will assist the jury with a clear understanding of the needs of the client as well as provide the road map of care for the client and family or a client trust.

References


Chapter 23

A Personal Perspective of Life Care Planning

Raymond L. Arrona and Mamie Walters, as told to Anna N. Herrington

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Introduction

This chapter is a brief telling of Anita Arrona's story. On September 7, 1987, Anita was returning home from visiting her boyfriend when a drunk driver hit her. Her injuries were profound and included open brain trauma, severe brain contusion of the left and right frontal lobes, supraorbital fractures of her left and right eyes, multiple blunt trauma to the chest, hydrocephalus, pleural effusion of the left lung, fractured right clavicle, and severe spasticity with minimal control of bodily functions. By October 5, 1987, infected frontal lobe brain tissue was removed and a shunt was inserted to drain off excess fluid. Her left eye was unsalvageable. After 3 months and multiple surgeries, it became evident that Anita would never achieve independence, and the family’s attorney retained the services of a life care planner to develop an outline of future expected care. Over the years, although severely brain injured, hemiparetic, and blind in the left eye, her medical situation has stabilized and she has learned to speak a few words. She resides in a wheelchair, which requires an attendant’s service to move her. She is totally dependent on others for her well-being.
Anita’s journey since her injury in 1987 has involved many factors: family and friends, high moral standards and strong values, and a solid plan. Anita’s father, Ray Arrona, has been and continues to be her warrior in the many battles that must be fought to obtain what she needs. Mamie Walters, a family friend who has turned professional caregiver, has been devoted to seeking out creative therapeutic methods to enhance Anita’s abilities and is committed to her growth. Anita and Ray have had strong coping resources based on deep-rooted beliefs in optimism, honesty, perseverance, stubbornness, hard work, and faith in God. Last, on Anita’s journey has been the pragmatic vehicle— the life care plan. Anita’s life care plan has been the essential road map, though detours are sometimes taken, of her often arduous journey.

Ray Arrona: My Daughter’s Story

Let me begin with one of the codes by which I live my life: be responsive. A story I heard at a recent conference illustrates this well. There was a first mate that came to his captain advising him that the ship was going to be under attack and inquiring as to what to do. The captain told the first mate to run and get his (the captain’s) red shirt. So he got the red shirt, they engaged in battle, and they won. About a week or two passed and the first mate returned to the captain and warned him of a pending battle with pirates. Once again the first mate asked, “What do you advise?” Again the captain replied, “I want you to bring my red shirt.” So, they engaged in battle and wiped out all the pirates. When putting everything away the first mate was curious and asked the captain, “Can you please tell me about this red shirt? Every time you put this red shirt on we seem to do well. I wonder if there is some point in this.” The captain told him that it “was the leadership thing.” The captain explained that if he happens to get stabbed while under attack or is hit by a volley, “I don’t want the men to see me get hurt and bleed so I can continue to lead them through the battle.” That’s pretty wise. Another month passes and the first mate rushed to the captain shouting, “Captain, Captain, I have news of yet another battle. There are pirates on starboard, on the bow, and on the port side! What shall I do?” So the captain says, “Will you please get me my brown pants?”

I tell this story to express the importance of a quick and smart response. I have found that being ready for the battle has been of immense importance in my life. I was born and raised in Miami, Arizona, a copper-mining community about 80 miles east of Phoenix. Being Hispanic, I grew up in a strict and disciplined home. At home I learned the importance of a good attitude. I learned about making good choices and taking responsibility for those choices. I learned to believe strongly in myself. Now, I am 50 years old and I know these early lessons have assisted me through my life. I worked while attending college at Arizona State University and had plans to pursue a pre-med curriculum. That was in 1964. However, my plans changed when I met Anita’s mother in 1965. Soon we were married and a year later, in November 1966, Anita was born.

I continued to work with my college employer, Wear-Ever, Inc., the first subsidiary of Alcoa, and later transferred to another subsidiary, Cutco. I have been associated with these two companies for nearly 30 years, though many changes have occurred. Our second child was another daughter, Andrea, who was born just about 11 months after Anita. Little did we know how short a time we would have with Andrea who, at 11 months, drowned in the bathtub. It was terrible. This tragedy was our first to experience as a family. I am not sure whether it prepared us for the future, but it certainly tightened the family.

Then there was the aftermath and our struggles. We had a son, my namesake, who was born on Christmas Day. You may remember the Apollo moonshot; it was somewhere around that time
in 1968. Ray Jr. was 18 at the time of Anita’s injury. (Ray is now married and has two children. He is in the Navy and lives in Seattle, Washington.) For many different reasons, our marriage did not work and we were divorced in 1971.

I later met and married (October 1974) Sheri, the love of my life. We just recently celebrated 22 years of marriage. At the time of Anita’s accident, Sheri was 38 years of age. My employer offered me a promotion to a position that required transferring across the country to Atlanta, Georgia. We moved in 1976. Alyson was born to Sheri and me a year later in May 1977. Alyson, Anita’s younger sister, was 10 years old and was in fifth grade at the time of the injury. Alyson probably has the most anger in the family about Anita’s disaster, even to this day. Ryan, whom Anita used to take care of often, was born four years later in October 1981. At the time of the accident, he was 5 and not really aware of what was happening.

It was during this period of time (1979) that Anita moved in with my parents in Miami, Arizona, because of difficulties she was having with her mother. However, Anita did not realize how strict her grandparents would be, and we soon realized that it might be best for her to move to Atlanta to be with me. Anita moved in with us and enrolled as a junior at North Cobb High School in Kennesaw, Georgia. She graduated in May 1984. Anita is a very determined person—she has not lost this trait. She is a hard worker and has not lost that drive, either. After school she worked several jobs with the goal of eventually attending court-reporting school. During this time she saved enough money to buy her dream car: a new, red, 1986 Toyota GT. Anita would not let anyone else drive or even touch that car. She loved that car.

It was Labor Day 1987, and since I am a football fanatic, I was glued to the television. At the end of the evening, the news detailed Labor Day highway accidents. According to the report, the number of accidents was less than predicted. I thought, *This is really great.* Then the phone rang. The phone call was very similar to the one I received when I was working in Tucson and heard the news from an official at a local hospital about Andrea’s accident. Although they would not say what was going on, I knew that something was terribly wrong. Anita had been visiting with her boyfriend, Dan, that evening of Labor Day and was on her way home. I called Dan and asked him what was going on. He did not know. Dan lived about half a mile from the hospital, and I asked him if he would please join me there. Upon arrival at the hospital, I was escorted into a private conference room, and as I walked in, I saw Dan talking with two professional men dressed in white. Later, I learned those were the neurosurgeons who were preparing for a lengthy, all-night operation on Anita. They informed me that Anita had been involved in a terrible auto accident that had crushed her skull. They said she was critical and was given only about a 20% chance to survive.

I felt all numb inside, as if I was living through a bad dream. That night was spent making emergency phone calls trying to find out what was happening because there was no information. I had a lot of support from Dan and his family; we prayed the rosary all night long together. We prayed that God would take care of Anita. The next morning the doctors came in and told us Anita had made it through the evening, but it was still touch-and-go. I was shocked when I went into the room. Tubes were inside of her, IVs, multiple machines that I had no idea what they were for, lights, monitors. I could barely find Anita because her body was very swollen. I felt a feeling of helplessness, not knowing what to do. I was overcome with feelings of despair, feelings of sorrow. As fate would have it, my mother had passed away the year before and Anita was planning to take a trip on that Labor Day to see my father. But the trip was postponed because of an American Legion conference that my dad, a veteran and an avid American Legion member, wanted to attend. So, there was this anger about why things could not have been different. There was a lot of grief.
During the next few weeks, I was not really aware of what was taking place. There were many visitors and everyone was trying to understand what happened. I can recall staying up all night, sleeping on the floor, and waiting to be awakened for any news that we would have of Anita. There were many life-threatening decisions on Anita’s behalf that needed to be made. She had edema, which at that time I had no idea what that was. There was pressure being caused by the cerebral spinal fluid because it was not draining properly; so we learned what edema was. It was to plague us throughout the next several months. There were several needed operations that required removing part of the brain to relieve building pressure. We learned what a shunt was—something that was where the fluid needs to drain back—and we learned what operation that was going to take. We learned what the left brain does and what the right brain does. Throughout several months we were just hoping that all parts of her body would work. We were hopeful that she would have movement on the right side of her body. We did see that, and it gave us a lot of hope that things were going to be all right and that Anita could return, by the grace of God, to the original Anita. However, many problems continued to appear. So, the hope for survival was in and out, in and out, and the prognosis changed day by day. She had good days and bad days.

Many people told us that quite often in a crisis, your emotions and intelligence do not work together. All I know is that we learned to measure gains in inches and seconds and minutes. Anita was in the hospital ICU for 9 months. Everyone was distraught; there was a lot of sadness, but the family pulled together. The many prayers and visits from my extended family were invaluable. I believe in prayer. It brought hope to our family. We had so much support: from our family, church, friends, and business associates sending cards, making visits and calls, and saying prayers. The hospital staff was supportive, especially the ICU nurses and the physicians. We had legal and financial support. We were truly blessed.

However, our family was under tremendous stress. Our family had changed. Most of the attention was on Anita. All talk was Anita. Being a husband had to go by the wayside. Though I did the best I could, being a father to all my children was sacrificed. I really did not have any idea how it would affect the other children. There was a different schedule that was imposed upon us. New schedules, new decisions, and emotions we had not experienced before. As parents, we were obligated to take care of Anita, even though she was an adult. We had a lot of bills to pay, unaware of where the money would come from. My business is commission based and, therefore, dependent on my being in the field to produce. Because I had become an independent contractor, I no longer had health insurance with the company. Our private-pay insurance did not cover Anita since she was not a full-time student. There were going to be a lot of things that were unclear to me. There were increased workloads for everyone in the family; we were stressed to the limit. We had no idea what was ahead of us.

So what caused the accident? I can recall the second night that I was in ICU and a police officer came and talked to me. I thought he was very considerate to find out how Anita was doing. However, that was not his intention at all. The purpose of his visit was to serve me with a ticket, intended for Anita, for running a red light. Fortunately, there was an eyewitness who revealed the truth: Anita was broadsided by a college-age drunk driver who had run a red light. He was also on drugs at the time, and unfortunately, this was his third DUI offense.

I had no idea what was going to take place as far as Anita’s litigation. The physician who had done the operation asked me if I had someone in mind, and I said no. He recommended an attorney who is very good with personal injury cases. However, I did not know he was good, I had never heard of him. My mind went through many things. I was unsure who to select and what to do, so I did what I was accustomed to doing and sought out other attorneys to see what
their prices would be. I was told it would not cost me anything; however, it would be one-third of whatever was awarded on a contingency basis. That blew my mind. I thought, *Anita needs all of this money*. I certainly can have an appreciation in retrospect. I did look for another attorney. I described the situation and he was willing to do it for a fixed cost and a certain percentage that was lower. However, as I talked with him, he thought we could make the records look like Anita was going to school at the time and work out something with the insurance. There was a part of me that was tempted to listen to that because I was desperate to find a way to preserve as many funds as I could. Thank God, I did not hire that individual. I found a good attorney, and it has worked out well in our case.

I learned how our courts work. There was to be a criminal trial and a civil trial. The criminal trial came first, and I do not know what effect the criminal trial had on our civil trial, but it was an ordeal. I came to the conclusion that our court system was not a justice system but an injustice system. Eyewitnesses had to be sought out to put together the actual scene of the accident, and we soon discovered the drunken driver who hit Anita was out of town on a vacation. He was out on bail. He never even spent one night in jail.

It was really hard for our family to sit in a courtroom with the man who hit Anita. He showed no remorse, and neither did his family. That made it hard. Not once did they come and say they were sorry or anything at all. There were so many coincidental things that happened that would literally blow me away. One of the things is that the attorney that represented the defendant was a close friend of Anita's boyfriend. He did not know that Anita was the girl who had been hit, so he took the case. He happened to be an excellent attorney and I could not believe how things could be done in a way to make the innocent look guilty. There was a young lady in ICU who really gave a lot of care to our daughter. She worked in another hospital and was a close friend of Dan's family. She transferred to Kennestone. As fate would have it, her brother was working for the defendant. It was very emotional and distressing. After about a week of trial, the defendant decided to plead guilty. We never had a civil trial. That was settled out of court. The young man was sentenced to 5 years for a third offense, and we heard later that he was given 2 years to serve and after about 18 months was up for parole. We took an active role to ensure he served his full 2 years.

Based on the life care plan, a settlement was reached with the defendant and I was made Anita's legal guardian. I opted to select an irrevocable trust. The reason I did so is that if something happened to me, I could pretty much dictate who would be in charge of the financial affairs for Anita and also avoid temptations by either myself or anyone else to misuse those funds. I have used the trust, my attorney, and the professional rehabilitation consultant as my second conscience. The professional rehabilitation consultant/professional expert was very involved in the life care plan. It is amazing how many things he was right on target with and how important that was in supporting Anita's case.

Would Anita be better off now if she had not lived through the accident? What is her life going to be like? That almost seems unfair. There was a lot of anger in dealing with this situation and probably always will be. Will we ever totally recover from the catastrophic effects to our family, let alone Anita? Since the accident, my daughter Alyson has had to deal with much residual anger. A positive aspect is that time and being vocal have helped to dissolve much of that anger. My dad is from the old school and wanted to be a vigilante and come and shoot the drunk driver. Many times the emotions speak instead of the intelligence. Occasionally I pop in and out of that anger. Dealing with the resentment is hard, too. Why Anita? A beautiful person, a bright future, why us? My Alyson cries for the sister she lost, and I grieve for my daughter.

It was becoming evident that Anita was coming to the end of her hospital stay. The people at the hospital were telling me to look for a long-term facility. That is when I started doing research
and making trips. I have a whole bunch of files on everything. I went to Tennessee to Rebound and was impressed. I went to Florida to see a program they had there. I had heard about Peachtree Re-entry here in Atlanta, but I was told they would not take her. I visited Texas, but that was too far away. We settled on a facility near Birmingham, Alabama.

Because of Anita’s condition at the time of transfer, she went into a Birmingham hospital and was later transferred to an Alabama facility. The quality of care went down. My gut feeling after awhile was that she was not getting the care we wanted. The people seemed to be superficial. That was the feeling I got. I was advised to get a case manager. I would offer the same advice. If you are ever in a similar situation, I urge you to hire an independent person or case manager that is your advocate and not use the facility’s advocate.

Our case manager expressed dissatisfaction with the treatment that Anita was receiving and suggested we visit a brain injury program in Louisiana. We asked our initial life care planner to go with us and give us his professional opinion. We liked what we saw, so we moved Anita to Louisiana. Anita made many gains at the treatment facility. In fact, the first thing she ate since her accident was a communion, which was a great sign. A minister who worked at the facility administered this holy food. That is when Anita started eating.

A new facility had opened in Atlanta and I began to investigate the possibility of Anita returning “home.” With the assistance of the initial life care planner, I obtained another case manager to study this possibility. When Anita was in Louisiana, it seemed as though the accident did not happen because she was a long distance away. Although I made trips, they could only be occasional, and we had to rely on and trust the quality of care of the facility. The family visitations were strained and the family seemed to be embarrassed of being with Anita in public. The involvement was guarded, and still is, though it is gradually getting better. A lot of it has to do with each family member maturing in his or her process of acceptance, as well as everyone remembering how much fun it is to be around Anita.

I have been very pleased with the things that I have obtained in the institutional setting, but I wanted something better for our daughter. We decided Anita’s quality of life would improve if she lived in her own home. We tried to work with the doctors to set up a facility. There were many conflicts of interest that came about here in Georgia with doctors recommending clients to their own facilities, and we were hopeful that there would be a home environment. In trying to check out all our options, our life care planner and I made some more investigative trips. As it happened (God does work in mysterious ways) I was aware of a friend from work who had recently been outsourced (due to corporate downsizing). In fact, I was sending her resumes out throughout Atlanta trying to help her find a position because I was so convinced of her capabilities. Lightning struck my brain: What if I could convince our friend, Mamie Walters, to come to Atlanta and help us start a new program? Have Anita come out of Meadowbrook and go into her own home? Could we do this? Could we afford paying her? I confirmed the financial feasibility. We approached Mamie with the concept, and she was interested. She came to Atlanta, and it has made a phenomenal difference.

There is hope for the future. One of the things we do in our business is to make measurable gains in a reasonable amount of time. That is by charting things, charting sales. We look for behavior that is going to enhance that increase. It requires positive thinking. Mamie and Anita have positive attitudes, and it is evident by the progress Anita has made. She is tipping her chart.

So what about the future? Our long-term plans include the establishment of a licensed home with a home environment. However, as one might expect, there are obstacles (or a more positive interpretation is challenges). We want a home with a family atmosphere, a high quality of life, and a healthy, natural nutritional diet for the occupants. We are trying new ideas and approaches.
I always laugh when I see Mamie coming up with something new and natural and noninvasive. I am so often humbled when her alternative therapies produce great results. Certainly there are going to be changes that are going to take place as time goes on. There are also many challenges that remain.

In conclusion, I would like to emphasize how much we all have learned from Anita during this whole ordeal. She has brought deeper meaning to perseverance, faith, determination, and love. One of the things that I always have done in my life is target areas in which there is control and in which there is potential for progress. I can look and find possibilities anywhere. I also like to identify areas in which there is no control and learn how to make adjustments or accept this lack of control. This concept is captured so well in the prayer of serenity.

God grant me the serenity to accept the things that I cannot change,
The courage to change the things that I can, and
The wisdom to know the difference.

— Saint Francis of Assisi

It is this prayer that has guided me throughout this ordeal and continues to be a source of comfort to me on my journey as Anita’s dad.

Mamie Walters: My Journey with Anita

I remember one day a contractor was building a ramp at my home for Anita and he made the comment to me that if this accident had happened to him, he would just want to be dead. He could not see himself in this position, going through what Anita goes through and having people do for her what has to be done. My answer to him was, “You don’t get to be dead. You just deal with this every day. You just live with it. You have to adjust to it because you did survive.” And that is what I have seen Anita do. What an inspiration she has been to me.

My children’s father had passed away (1994), and it was our first holiday (Thanksgiving) without their dad. Ray’s family, being the dear family that they are, invited us to their home. We had a wonderful time. It was about 11:00 on Thanksgiving evening and just out of the blue Ray started discussing the possibility of me moving to Atlanta and working with Anita. Even though I had never worked with this type of client before, I had worked with Ray for many years and knew that we have had great success in the past in what we tried to achieve. I decided if he was willing, so was I. If it did not work out, we would both know we gave Anita our best effort and that was what really counted.

Once I made this decision, I returned to Orlando. One of the assignments Ray and I had given ourselves was to set our goals and objectives for the program and for Anita. At our next meeting, in January, we compared notes. As it turned out, our goals and objectives were almost identical, including the time frames. That was really exciting. Our original plan was to have Anita in her own home by the end of the year (1995). We actually had her home in 6 months.

I had experience in corporate forecasting for a number of years, and Ray is one of these math wizards. He also had been doing forecasting for about 30 years. We knew what we were doing. However, I believe the key to our progress was being of the same mind-set. Our singular vision allowed us to focus our energies and to be expedient in the pursuit of our goals.

One of the first things we did was to arrange for me to come to Meadowbrook and work with Anita. I did so for 6 weeks. I wanted to observe Anita’s care and have some supervised hands-on
experience. This observation and experience were vital in preparing for Anita’s weekend visits with me. When I first began working with Anita, and the facility staff was in agreement, I noticed that Anita was very depressed. She had no initiative. Her arms were always folded and her head stayed down unless she was watching television. If she liked you, she smiled.

This was the Anita that I met. Her speech therapist said she just did not try to do any work. Her interpretation was that Anita felt like there was no reason to bother. There was not a lot of progress at Meadowbrook. We believed that there were many things that are possible in a home environment that are either not possible or practical or just not done in an institution. Ray and I were very excited about the possibilities.

In March 1995, I brought Anita home 2 days a week; in April, we increased to 3 days a week, and we continued this schedule through the end of June. I would bring her home from Friday night until Monday morning. In March, I was doing the care, the meals, everything. In April, I realized with the increase of 3 days that I might not be able to handle the care alone. My 17-year-old daughter, Ana, helped out and soon became very interested in assisting with Anita’s care. Anita’s total transition time from institutional care, including her hospital stay, was 7 years. She has been home for almost 2 years now (Fall 1996).

My first objective for Anita, once she was home, was to increase her self-esteem. Without high self-esteem, she had little confidence. Without confidence, she had no initiative, and so it goes. I began by giving her control. Anytime I could give her control, I did. I bought different colored sheets so she could choose what color she wanted on her bed. I gave her a TV remote and CDs to choose for music. With more choice and independence, she began to have some self-respect and self-dignity. I let her know she was loved. As we worked together she gained trust and knew the things we were doing were for her own good (even the range-of-motion exercises, which she hated).

One of the challenges that Anita had was to drink enough fluids. She did not drink fluids. As a result, problems occurred. We wanted to increase her fluids. She drank V-8 juice but refused water and all other drinks, except sometimes a little pineapple juice. Currently Anita is drinking approximately 30 ounces of fluid a day, and she has been doing that for quite some time, and most of this is water. She has really come a long way with positive reinforcement and increased control. We took shopping trips so she could pick out some special drinking glasses for her water. Her favorite color is green, so we went on a shopping trip for green glasses. So simple, yet so effective.

Since Anita had a brain injury, I really did not know what she was capable of doing. I knew what I had been told. I knew that there was, supposedly, no place for her to go in her rehabilitation and progress. Her dad had taught her the word hi, and that was all she could say for about a year. Anita had not learned how to tap into her real voice, so her voice sounded really breathy. I would take her to the computer, and she enjoyed it. I experimented and knew she could read. We made it fun. She has learned to type some words strictly from memory. This was a major accomplishment for Anita.

I believe this learning became possible with self-control, self-confidence, and the initiative to work. Once she started working and saw she could actually do things, she became more confident and more enthused about continuing to work. At this time she is reading a large number of words. We have organization skills activities where she will group flash cards using the words in categories. Her proficiency is about 85% to 90%, sometimes better. Anita presently has a vocabulary of about 20 different words and syllables that she speaks with her true voice. This is something I felt could happen. She has worked very hard.

Her grandfather was coming for a visit from Arizona, and Anita dearly loves her grandfather. She is crazy about him. I asked her if she would like to greet her grandfather when he arrives. She nodded that she would work with me. In working with Anita I have learned how much she loves
Elvis. We would practice to Elvis music. I did not know what I was going to get. We were having fun, and were working at it. She started getting the “pa pa pa pa.” From this we put a short sentence together. This was a giant step for Anita because of her severe apraxia. She eventually could say, “Hi, Papa” and “Bye, Papa.” I wondered if she would remember this when she saw her grandfather. A few weeks went by and we kept practicing. Her grandfather arrived and she said, “Hi, Papa,” and when he got ready to leave she said, “Bye, Papa.” There are some things money cannot buy because they are priceless, and that moment was one of them.

One of her words she learned was hi. We were working on the pie sound, and I told her if she learned the word pie I would take her out to get some pie. I let her order it from the waitress. Her most current word is sly. That is because she is in love with Sylvester Stallone. Sometimes motivation gets easier and easier. Elvis is her romantic guy, and Sylvester is her macho, hero guy. I told her if she could learn sly, I would take her to the movies. She worked and she said it, and so we went. I think it is important that if you do offer a reward, that it is given quickly. In her case, it has kept her going.

We have a Christian home where Anita lives. I believe that the mind, spirit, and body are intricately joined to make up the human being. In working with Anita I felt like the ball had been dropped in her spirituality. This is something Ray and I wanted to address. Today she enjoys Mass. She truly gets very excited about going to Mass. She loves gospel music. We try to address the spiritual side of Anita as a holistic approach to her care. Anita is very strong in her spirit, and she is a survivor. I do not require my staff to go around saying Hail Mary’s all day. They do not walk around with rosaries. We only provide for spiritual requests if the client wishes. I do ask the staff to play a rosary audiotape at nighttime for Anita because this is what she likes to hear. She likes gospel music, so they put in the tapes so she can hear that. These are the ways we are addressing her spiritual life. It is the belief in the importance of balancing the mental, the physical, and the spiritual.

When Anita came back to a home environment, her family visits increased. She dearly loves her family. Her strongest bonds are with her dad, her grandfather, her aunt, and her former boyfriend, Dan, who still comes to see her. Anita is quite social now and loves their visits. She also enjoys our emphasis on games, recreational outings, and community involvement.

Our home promotes prevention. One of the strongest results of our prevention approach has been the vast improvement in Anita’s health through our nutritional program. Anita was plagued with upper respiratory infections, urinary tract infections, chronic conjunctivitis, and such. Now Anita experiences very few infections. Basically, we use only real food. There are no canned goods, no processed foods; our kitchen is stocked with fresh fruits and vegetables. We have eliminated meats, dairy products, and sugars from Anita’s diet. Anita does not have a problem with swelling, her circulation is good, and she has had no skin breakdown since her return home. Her attention span has increased, her energy level has increased, and her stamina has improved. This has really helped with her therapy sessions.

If I had to select one aspect of the program that is essential, it would have to be teamwork. Teamwork started with the life care plan. That was our road map for Anita. When I came on board, it was essential that I have the life care plan available because my expertise is not in the medical field. I am not a certified case manager, rehabilitation specialist, or nurse. The life care plan was and is a main reference for Anita’s life care. Also, the life care plan has been key in our financial success. We provide excellent care for minimal funds. The type of care we are providing costs approximately $250 to $300 per day. This does not include doctor visits, supplies, or medications. It does include 24-hour nursing care, bed pads and briefs, personal care for the individual, housekeeping duties, recreational and occupational reinforcement, and scheduled outings. We provide better care than the larger institutions with less money for this type and level of client.
Another vital aspect of our program is staff education and staff appreciation. If I explain to the staff the importance of why things need to be done, I find the job performance is good and their attitude is positive. I believe in staff recognition. The attitude at the home and the attitude of the staff is one of respect. We respect each other, we respect the clients, and we respect the guests coming into the home. We show a lot of dignity. The staff takes pride in what they are doing because they can see the results. We try to encourage each other; we try to encourage the client and not criticize.

We find that this attitude permeates the home and affects Anita’s spirit. Although she continues to receive therapies and improvements are observed, the bottom line is that Anita is home—where she belongs.

Editor’s Note
Since this account was initially published, in the first edition of this book, the family has moved back to Arizona, where they are closer to family. Anita continues to successfully live at “home” with 24-hour care. This story underscores the value of a dedicated and supportive family. The family, particularly the father, was thrown into a complex arena with little preparation. The event has irrevocably changed the family’s and Anita’s lives. Without the caring and unwavering problem-solving dedication, as well as diligent pursuit for improving Anita’s life, it is unlikely that progress in her situation would have occurred.
Chapter 24

A Plaintiff’s Attorney’s Perspective on Life Care Planning

Tyron C. Elliott

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It is better to judge a man by his questions than by his answers.

— Voltaire

Introduction

Plaintiff’s attorneys define themselves by their ability to ask the right questions, not only of their opposition, but also of themselves and their own clients. In the catastrophic case, the plaintiff’s attorney understands that a myriad of questions may and should be asked about the future. Yet that same attorney is buffeted by thoughts that no real answers can be given. He or she fears that all attempts to probe the future or assist the trier of fact in probing the future will slide into that murky realm of the possible and away from the safe ground of the probable, where he or she must remain to prove a case. The attorney also knows that the more specific the questions become, the more difficult they are to answer. The safe thing to do then seems to be to generalize about future care and future needs and thus avoid these pitfalls.

Following this course leaves the attorney and his or her client ill-equipped to stand before the trier of fact and ask for specific compensation for the special damages for future medical and rehabilitation needs. The attorney knows the judge or jury will be asking the next obvious question: What will those needs be, and how much can we expect that they will reasonably cost? The modern plaintiff’s attorney must and should provide the judge or jury with all the evidence that exists on those issues.

As plaintiff’s attorneys, we are accustomed to marshaling all our own evidence, tracking down its sources, and shaping our cases so that they can be fairly and clearly presented to the judge or jury. We are reluctant to say that in the catastrophic case, the medical and rehabilitation needs are too complex for us to attempt that marshaling of evidence. We do not know where to begin. We do not know what questions to ask.

Fortunately, we now have the life care plan and qualified persons able to prepare it. This specialization is being followed more and more by various rehabilitation professionals and nurses who, using their background training, become proficient at the business of working out a plan for the future medical and rehabilitation needs of the client. In working with the professional life care planner, the attorney does not abdicate the attorney’s traditional role as the one who asks the critical questions and who marshals the evidence to prove a point. The attorney joins with the life care planner to make sure the right questions are asked. The skilled plaintiff’s attorney recognizes that he or she needs the assistance of an equally skilled life care planner to identify those questions (Elliott, 1993).

Roles of the Forensic Expert

There are generally two areas that the attorney must address in litigation: liability and damages. When a party is found liable, that party is determined to be at fault. The next task is to prove damages, or the costs associated with the incident. The rehabilitation professional may act as a consultant, which implies that he or she will work behind the scenes to assist the attorney with developing a case or reviewing the work of others (Weed, 1995; Riddick & Weed, 1996; Weed &
Field, 2001). Although psychologists, rehabilitation counselors, neuropsychologists, physicians, therapists, and others offer these services, this seems to be a unique role for rehabilitation nurses and life care planners. Indeed, many larger law firms employ consultants on staff to conduct medical research, locate experts, develop deposition and trial questions, summarize medical records and depositions, and provide other litigation support services.

A more common role for the rehabilitation professional is to act as the expert and develop opinions, which will be offered as testimony. The rehabilitation expert will generally participate in the damages portion of litigation by assisting in establishing the cost of future care and the significance of the incident with regard to the person’s ability to perform work (earnings capacity). Most life care planners are not qualified to offer opinions in the areas of future medical care costs and earnings capacity loss. Therefore, two experts will usually be retained to opine about these separate damages.

**Life Care Plans in the Catastrophic Case**

There are other very specific reasons why the plaintiff’s attorney should use a life care plan in the catastrophic or neurolegal setting. It is an essential tool for settlement and trial preparation since it gives the insurance company and its counsel a clear look at what will be presented to the jury (Elliott, 1993; Taylor, 1996). It gives the plaintiff’s attorney the comfort of knowing that those things that could be addressed have not been left to chance and uncovers items of damages that were not thought of by the attorney (Sbordone & Shepherd, 1991).

**Potential Problems**

Life care plans are becoming more and more acceptable to different courts, and they are increasingly required in specialized situations such as pediatric neurolitigation (Sellars, 1996). There are pitfalls, however, that must be watched for by the plaintiff’s attorney. The attorney cannot assume that the life care planner in every instance understands the legal system to the extent that the planner can know what will or will not be properly received into evidence. It is tempting to assume that because you have found the life care planner, as a trial attorney, your job is over in that area. Nothing could be further from the truth (see Weed & Johnson, 2006, for several summarized life care planning litigation related cases).

The attorney must make sure that the life care planner understands the need for a medical evidentiary foundation for each item in the plan. There have been cases where the entire plan was thrown out, and the award with it, because the attorney, and perhaps later the initial trier of fact, took the life care plan as the word of the life care planner and did not show or prove that the various items in the plan were there because they were authorized by medical personnel. In the case of *Diamond R. Fertilizer, et al. v. Jimmy L. Davis*, the court found that the lower court had approved a treatment plan that allowed the rehabilitation company that prepared the plan to determine the treatment needed. The court held that the authority for the plan must rest with the physicians, and it disallowed the plan. With no showing of medical necessity or physicians’ orders, the plan provided for a TV, a VCR, a specially equipped van, a whirlpool, a hydraulic lift, and an environmental control unit for the client. The court found no justification and denied all of these items.
Insurance Concerns

Another area of care in crafting life care plans that the attorney must follow is in those cases where the funding is structured in dependence upon a specific health care policy and not upon general medical necessity. In the case of *Dempsey v. United States of America*, the plan provided for daily attendant home care. The lower court had mistakenly assumed that such care had been provided by the existing CHAMPUS policy that had to be offset. A close scrutiny by the appeals court showed that such care was not provided and the life care plan with that provision was approved. The attorney not only must see that the plan provides necessary care, but also must often prove that it is covered by insurance.

Logical Consistency of Life Care Plan

The attorney must also assume that the plan he or she uses may be scrutinized by the opposition or by the court for logical consistency. If there is illogic in its premises and if it is inconsistent, the plan may be considered flawed and not adopted at all. The plaintiff’s attorney does not have to be a life care planner to read the plan in light of its logical underpinnings. For example, if a therapy, such as speech therapy, is proposed to terminate at a certain age and yet speech evaluations are proposed to continue beyond that age, there should be a very logical reason why the evaluations continue after the therapy is discontinued. This also applies to areas such as physical therapy and particularly applies to pediatric issues. If a child is to receive certain therapy only through childhood, evaluations that are pediatric in nature should not continue under the plan past childhood without specific explanation.

In the case of *Brewer v. Secretary of Health and Human Services*, the court applied just such a fine-toothed comb to the plan. Among other things, the court found that all parties and their life care planners had misread and miscalculated the dosage and amount of antiseizure medication. The court took it upon itself to research the issue and to determine the dosage of medication and the proper cost. The court also found that the replacement of assistive communicative devices was not coordinated to their useful life and that no proof was given for the number and type of devices. Finally, the court approved an award for counseling for siblings and parents, citing reasons of well-being for the patient, not the family itself, which the court based on an article from the *Journal of Head Trauma Rehabilitation*. None of these reasons had been advanced by the plaintiff.

The Role of the Plaintiff Attorney in the Life Care Plan

From the plaintiff’s perspective, the life care plan is an integral tool in the proof of damages in neurolitigation or any other catastrophic injury. The attorney must continue to play an active role in making sure the plan fits the parameters for admission into evidence and that the plan meets the test of logic. The life care planner and the attorney must work as a team in reaching this goal. The plan cannot simply be drafted by the life care planner and then handed to the attorney, who, in turn, tenders it into evidence. It is not a chain letter to be passed on. It is a part of the mosaic of the case and must be viewed as such.

The life care planner also brings a new analysis and a fresh look to the legal case. If the plaintiff’s attorney is open to examining new perspectives, new things are discovered about the damages aspect of the case. Some may be good for the case, such as an element of damages that should
be sought but has been overlooked. Some may be bad for the case, such as the discovery of some exaggeration of an aspect of damages by the client, well intentioned or not. The life care planner is searching for different information than the attorney and, in reviewing the same material, will shed a new light on it for the attorney.

The level of objectivity of the life care planner is therefore very important. It is essential that the person doing the life care plan give the information to the attorney without sugar coating and without bias so that the attorney can adjust the theory of the case to the facts that are developed and not vice versa. This is particularly true in the area of employability. By using devices such as the functional capacities assessment and other tools, the vocational assessment as a component of the life care plan becomes the foundation for credibility. The jury can see what jobs the plaintiff may reasonably expect to perform in the future, how they are suited to the client, and why he or she cannot perform the tasks that would allow other employment. All this is integral to the solid life care plan. It shows thoroughness on the part of the plaintiff’s team in bringing the facts to the decision maker on the other side, be that person an adjuster or a juror. The pitch that the plaintiff has compensation neuroses fades before the plain facts of what he or she can do, what he or she cannot do, and how this will affect life in the future (Elliott, 1999).

Special Forensic Considerations

It is useful for the rehabilitation expert to be sensitive to special rules and issues related to civil litigation. A few are listed in the following.

Hearsay

The ethical rehabilitation professional who practices in forensic settings provides a valuable contribution by establishing a reasonable treatment plan, helping to settle personal injury litigation, and providing the jury with information on which to base an award. Offering testimony is fraught with obstacles such as (1) introducing hearsay evidence and (2) developing appropriate exhibits for the courtroom. In general, hearsay refers to relying on information from another person that may be unreliable or inappropriate. Hearsay taken to the extreme can be applied to your personal identity. For example, you are likely to know your name because someone (your parent) told you your name many years ago. Rules of evidence (with special emphasis on 702 and 703) have been developed to address this problem (see Table 24.1 and www.law.harvard.edu/publications/evidenceiii/rules/702.htm).

Table 24.1 Reducing Hearsay Challenges

| • Are you qualified as an expert? |
| • Are you offering opinions that are in your area of expertise? |
| • Are you relying on facts and data that you and others in your professional field commonly rely upon? |
| • Are people employed or retained by you working under your direction and supervision? |
| • Have you provided a foundation for medical opinions by utilizing physicians for medical diagnosis? |
As a result of *Daubert v. Merrell Dow*, Federal Rule of Evidence 702 has been amended to address the tests for admissibility of expert testimony. The new rule states,

If scientific, technical, or other specialized knowledge will assist the trier of fact to understand the evidence or to determine a fact in issue, a witness qualified as an expert by knowledge, skill, experience, training, or education, may testify thereto in the form of an opinion or otherwise, if (1) the testimony is based upon sufficient facts or data, (2) the testimony is the product of reliable principles and methods, and (3) the witness has applied the principles and methods reliably to the facts of the case. Effective, December 1, 2000.

In order to seek a uniform approach to the adoption of Rule 702 by the various states, the National Conference of Commissioners on Uniform Laws drafted what has been designated Uniform Rule 702 with the goal of creating a more uniform expert testimony admissibility standard across state jurisdictions (available at www.law.upenn.edu/bll/ulc/ure/evid1200.htm). The rule reads,

(a) *General Rule.* If a witness testimony is based on scientific, technical, or other specialized knowledge, the witness may testify in the form of an opinion or otherwise if the court deems the following are satisfied:

1. the testimony will assist the trier of fact in understanding evidence or determining a fact in issue;
2. the witness is qualified by knowledge, skill, experience, training, or education in the scientific, technical, or other specialized field;
3. the testimony is based upon principles or methods that are reasonably reliable, as established under subdivisions (b), (c), (d), or (e);
4. the testimony is based upon sufficient and reliable facts or data; and
5. the witness has applied the principles or methods reliably to the facts of the case.

(b) *Reliability deemed to exist.* A principle or method is reasonably reliable if its reliability has been established by controlling legislation or judicial decisions.

(c) *Presumption of reliability.* A principle or method is presumed to be reasonably reliable if it has substantial acceptance within the relevant scientific, technical, or specialized community. A party may rebut the presumption by proving that it is more probable than not that the principle or method is not reasonably reliable.

(d) *Presumption of unreliability.* A principle or method is presumed to be not reasonably reliable if it does not have substantial acceptance within the relevant scientific, technical, or specialized community. A party may rebut the presumption by proving that it is more probable than not that the principle or method is reasonably reliable.

(e) *Other reliability factors.* In determining the reliability of a principle or method, the court shall consider all relevant additional factors, which may include:

1. the extent to which the principle has been tested;
2. the adequacy of the research methods employed in testing the principle or method;
3. the extent to which the principle or method has been published and subjected to peer review;
(4) the rate of error in the application of the principle or method;  
(5) the experience of the witness in the application of the principle or method;  
(6) the extent to which the principle or method has gained acceptance within the relevant scientific, technical, or specialized community; and  
(7) the extent to which the witness’s specialized field of knowledge has gained acceptance within the general scientific, technical, or specialized community.

At the time of this publication, the updated Uniform Rule 702 has been slow to catch on; it would be wise for the practitioner to use this more detailed rule in preparation for Daubert challenges or to make the same, since it is the most comprehensive pronouncement on admissibility standards under Daubert that we have seen. It appears that most states are waiting until further clarification appears at the federal level before adopting these rules in their entirety. Even Uniform Rule 702 does not provide a clear method for making the determinations required under Daubert, and so far life care plans have not reached the level of serious challenge. If they become more critical to large verdicts with a cap on noneconomic damage, that may change. (For an excellent discussion on Daubert-related issues for the life care planner, see Countiss & Deutsch, 2002.)

Although the following discussion is based on federal rules, most states have either adopted these rules in some form or established precedent through previous legal cases. The old Rule 702 states that a witness qualified as an expert by knowledge, skill, experience, training, or education may testify by offering an expert opinion. Rule 703 allows the expert to rely on facts or data, which are not entered as evidence, if the information is commonly relied upon by experts in the field. Practically, this is demonstrated in two ways. First, the consultant may hire a subcontractor or use an employee to develop research, assist in report writing, and summarize medical records. As long as these professionals are qualified and they work under direction and supervision by the lead consultant, the information should be allowed in the courtroom. Second, it is common for life care planners to rely upon physicians for treatment plans, vendors or catalogs for costs, and other sources for the foundation of the plan. The key issue is related to what the consultant and others in the field commonly do to conduct business (see Weed & Field, 1994, for more federal rules of evidence information).

Written Opinions

In most rehabilitation settings, it is expected that consultants will provide written reports with conclusions and opinions. The same standard should apply to the role of the expert witness. Attorneys may occasionally ask the expert to act as an expert but not provide a written report. Although narratives may be optional, conclusions, recommendations, and opinions should be provided in writing. In this author’s opinion, failure to follow the standards of the expert’s industry reflects badly and ultimately damages the profession as a whole. Experts who play the game of challenging the attorney to guess what they will say at trial through depositions are shortsighted. This has become enough of an issue that some jurisdictions now require a written report.

Disclosing Prior Expert Testimony

A recent rule has been added to federal and other cases that may require revealing cases in which the consultant testified in deposition or trial during the previous 4 years (referred to as Rule 26; see www.law.cornell.edu/rules/frcp/Rule26.htm). Data should include the case caption, the date
of the deposition or trial, and the state in which the case was filed. This disclosure does not apply
to cases where the life care planner was acting as a consultant or the expert did not testify.

**Collateral Source**

Collateral source rules vary from state to state and jurisdiction to jurisdiction (i.e., federal vs. state
cases). In practical terms, collateral sources refer to rules that require a personal injury award be
offset by reasonable available services and products. Generally, this is represented in pediatric cases
by including the free services that are available in the school system through the Individuals with
Disabilities Education Act (IDEA). This may include special education, occupational therapy,
physical therapy, speech and language therapy, aide services, and specialized equipment and sup-
plies. Other options may include offsets for Medicaid or Medicare. The consultant is advised to
discuss this issue with the attorney prior to rendering an opinion.

**Interrogatory**

An interrogatory is a list of questions that is submitted through an attorney usually to the client
but sometimes to an expert. A series of questions is asked that is expected to elucidate the reason
you were called as an expert. This is usually a prelude to a deposition. Generally the other side is
attempting to discover what will be entered as evidence at a trial. This is a formal procedure that
should not be taken lightly.

**Deposition**

The rehabilitation consultant’s role at the deposition is similar to his or her role at a trial. The
primary difference is the location and the lack of the presence of a judge. The deposition can be
conducted at the office of the expert, at a court reporter’s office, in the office of the attorney, and
occasionally by telephone. A judge is not present to preside or to rule on objections by the counsels
for plaintiff or defense. While clients may attend, their presence is uncommon.

There are two types of deposition that the expert is likely to face. One is an evidence deposi-
tion. The evidence deposition generally is called by the side that retained the expert. In this situ-
ation, either the attorney believes there is good reason to attempt to settle the case, or the expert
will not appear live at trial. Both attorneys present their case similar to how it would be presented
at trial. In some cases the expert may be videotaped, although more often than not, the deposition
will be transcribed from an audiotape or other court recording method. Many physicians utilize
this method. Another type of deposition is the discovery deposition. In this case the other side
is attempting to uncover or discover what evidence is expected to be offered at trial. Usually the
attorney that retains the expert being deposed does not ask questions of the specialist since the
attorney does not want to give away any more information than necessary.

The attorney who requested the deposition initiates direct examination. Cross, redirect,
and recross examination may follow. A certified court recorder records (and later transcribes)
the entire testimony. Since a judge is not present to control the proceedings, objections by
either side are stated. The rationale for such objections are given and discussed. The judge,
prior to the submission of the testimony, will make a ruling on each objection into evidence at
a trial. The rehabilitation expert should be aware that although the deposition appears to be a
much more informal process, its content is equally important to that of the formal courtroom
testimony. The entire deposition, or selected portions of its contents, may be read at the formal hearing or trial.

Note that some professionals find themselves in awkward positions. Many times opposing attorneys ask questions of experts that would not be allowed in trial when a judge is present. The experienced expert can usually set boundaries, but professionals new to the industry may not know what is proper. Seeking training in this specialized area is recommended in order to avoid compromising your reputation or offering opinions contrary to forensic rules. There may also be occasions where the expert is bordering on saying something that documents malpractice, such as incorrectly disclosing records that have been subpoenaed or providing confidential information about other clients. Remember, the attorney that retains the expert is not representing the expert. An expert should not expect personal legal advice from the attorney who hired him or her; if an expert makes this assumption, he or she is treading on dangerous legal territory. The expert is advised to consult his or her attorney if there are legal questions.

**Subpoena**

A subpoena is a formal legal request for records or appearance at a deposition or trial. It may or may not be a proper request. For example, the expert receives a subpoena for confidential records of a client. It happens to be a difficult client who is involved in litigation. Should the records be sent? The expert may decide that he must comply with the threatening warrant. However, the expert must first be clear on confidentiality. The expert should know that a judge does not usually review a subpoena for records. If the client has not signed a release, the expert should check with his own attorney before releasing the records. Recently, this author had a personal injury defense attorney subpoena him for a deposition. The expert was to appear at a specific date and time, but if he submitted records, the deposition would be canceled. The author contacted the attorney to tell him records would be released when a release of information was received. Ultimately, the deposition and the requested records were canceled when the request was disclosed to the client’s attorney since the expert was not being called to testify. Another example involves a rehabilitation counselor who received a subpoena from a defense attorney for her records on a client. The counselor felt compelled to send the records only to learn that the client’s attorney was furious since she had also provided the other side with attorney work product, which was privileged communication. Generally, it is best for the rehabilitation professional to agree to provide information once the appropriateness is determined. This is accomplished by writing to the attorney who requested or subpoenaed the information and explaining that as soon as proper releases or a judge’s order is received, the information will be provided promptly.

On the other hand, a subpoena for appearing in court as a witness carries a different expectation. If the individual is to appear as a witness to the event or accident, then it is expected that he or she appear or suffer possible warrant for arrest. On the other hand, if the individual is to appear as an expert witness, it is generally accepted that one cannot be forced to provide an expert opinion even though one may be required to appear.

**Trial by Jury**

The primary difference in a jury trial and other settings is the courtroom. At the jury trial, the expert is called to testify at the time the attorney deems to be the most critical for such testimony.
The life care planner most frequently testifies without the benefit of hearing live testimony (referred to as sequestering), although in some courts the expert is allowed to sit in and listen to others testify. The presence of a jury and the necessity to sit in the witness chair add an air of sophistication and formality that matches no other legal setting. It becomes very easy to do those things that one should not and to forget to do those things that one should. The consultant should realize that the jury will not remember most of the testimony presented. What is remembered is the impression they held of the expert. Therefore, it is very important to avoid confrontation with the cross-examining attorney and become an advocate for one side over another. Remaining as objective as possible is vital but very difficult in the heat of the battle.

One more suggestion is to speak to the jury since the lawyer probably already knows the answer to the question. This is harder than it sounds. However, many juries have been sitting for days in a boring (usually) courtroom and may “doze off” at times. Speaking directly to the jury will help keep them on task and perhaps leave them with a better impression. There are several ways to display evidence to a jury to help convey your opinion in a more interesting way. For example, you may choose to write figures on a flip chart, blow up the life care plan or vocational opinions on a large chart that can be seen by the jury and others, use transparencies, make slides of the evidence, and, as has occurred more recently, utilize computer-based displays. In general, it is recommended to use an educational approach by teaching the jury. This will be more interesting to the jury and will allow the expert to stand up and move around.

**Recent Trends in Life Care Plan Value**

There is a perception among plaintiff’s attorneys that the relentless pursuit of a cap on noneconomic damages in civil cases will eventually bear some fruit and that, in most jurisdictions, they will be faced with a cap on the recovery of items such as pain and suffering. At both the federal and state level these issues are being renewed with new majorities in the U.S. House and Senate. As a consequence, many attorneys are already beginning to refocus their efforts on the maximization of economic losses to compensate for this change in the landscape. It is easy to see how the attorney must rethink the approach to catastrophic cases if a limit is to be applied for noneconomic losses. The juries will be asked, more than ever, to apportion their verdicts so that they must identify or allocate an amount to each category. Such a new approach means that life care plans become more important than ever as the keystone of an adequate recovery in the view of the plaintiff’s attorney.

A variation on this theme is found in one of the recent federal cases to discuss a life care plan. In *Lebron v. United States*, No. 00-51101, 5th Circuit, decided January 5, 2002, the 5th Circuit Court of Appeals was reviewing a Federal Tort Claims Act case in which a life care plan had been used. In such cases the plaintiff must make a demand before filing suit. The demand is considered to set the limit of recovery and any recovery in excess of the demand in the principal case must be written down to the extent it exceeds the demand. In this case the demand was $20 million. The recovery was $20.6 million. The plaintiffs, in seeking to avoid the stricture of this rule, argued that they could not have known about certain damages at the time they filed the demand, citing the life care plan as it was later developed in proof of that fact. The court did not agree and reduced the award to the $20 million demand, pointing out that the case was known to be very complex from the beginning and nothing new developed after the demand was filed. The fact that the life care plan as produced was greater than anticipated was not adequate reason to change the rule as
the court saw it. Had the focus been on the life care plan from the beginning, perhaps the result would have been different. Indicators are that life care plans will be involved in such catastrophic cases in the very early stages since so much more may be riding on them.

Conclusion

In the final analysis, the person receiving the life care plan for review or hearing it in testimony will filter that information through his or her own life experiences. If it contains items that just simply do not seem reasonable and necessary, those items will not be accepted. It will create an aura of skepticism about the entire plan. It is the job of the attorney working with the life care planner to analyze the plan and to search for items that may be perceived in this fashion. In many instances, the remedy is simply a matter of giving a proper explanation of why the item is needed, rather than an oblique reference to the source. Some items speak for themselves. Some require explanation if they are esoteric or very technical. It must be remembered by everyone involved in the process that communication is primary and essential.

The plaintiff's attorney in every case is sending a message in two parts: the attorney (1) must convince the opposing side of its obligation to pay money for damages, and (2) then must convince the opposing side how much it should pay. If the attorney is not certain about the future needs of the client, the attorney cannot maintain ardor in seeking that amount. To be effective, the attorney first must be convinced of the truth of the case and then must convince the opposing side. The life care plan is indispensable to that process. Properly done, the life care plan convinces the attorney. Properly presented, the life care plan convinces the jury. When the file is closed, the attorney will have to reflect on whether what was done was all that could be done to see that the client's life, all of the remainder of that life, was cared for in the best possible manner. It is often the life care plan that makes that reflection a source of satisfaction rather than regret.

References

Countiss, R., & Deutsch, P. (2002). The life care planner, the Judge and Mr. Daubert. Journal of Life Care Planning, 1, 35–43


Chapter 25

A Defense Attorney’s Perspective on Life Care Planning

Tracy Raffles Gunn*

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* Much of the information for this chapter appeared in the 2nd edition chapter coauthored by Tracy Gunn and Lee Gunn.
Introduction

Counsel defending against serious injuries is likely to confront a life care plan presented by the plaintiff’s attorney in an effort to quantify the various impacts upon the injured party’s activities of daily living and quality of life. A defendant must prepare early and thoroughly to rebut the plaintiff’s various claims and identify areas of overreaching or weakness in the plan. This chapter will address the defense perspective on life care planning in terms of both attacking the plaintiff’s life care plan and retaining a defense life care planning expert, either as a nontestifying consultant or to testify at trial.

Attacking the Plaintiff’s Life Care Plan

Qualifications

The first step in attacking the plaintiff’s life care plan is to determine whether the plaintiff’s life care planner is, in fact, qualified to present the plan. This is a critical issue because an unqualified witness will not be accepted as an expert and will not be permitted to testify at trial. Thus, a successful attack on the plaintiff’s life care planner’s qualifications will result in the planner’s entire testimony, and the plan itself, being kept from the jury’s consideration.

There are two levels of qualification that will be required of a life care expert presenting a life care plan. First, the expert must be qualified generally in the area of life care planning. Second, the expert must be qualified to substantiate, to the degree required under the particular jurisdiction’s substantive law, the need for each element of care provided in the plan.

Qualifications as a Life Care Planning Expert Generally

Under the Federal Rules of Evidence, a witness may establish his or her qualification as an expert by reason of “knowledge, skill, experience, training, or education.” The use of the disjunctive “or” in this list of the grounds for determining a proposed expert’s qualification has been consistently held to permit qualification as an expert based on any one of these five factors. Thus, a properly qualified expert may have no practical experience in the particular area about which he or she testifies. Similarly, a witness may qualify as an expert in a field in which he or she has no formal

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* The Federal Rules of Evidence apply only in federal courts, and different requirements may apply in certain state courts. However, the majority of states have patterned their rules of evidence after the federal rules and have adopted the case law interpreting the federal rules as persuasive in their respective jurisdictions.

† Federal Rule of Evidence 702, which governs the admissibility of expert testimony, provides as follows: “If scientific, technical, or other specialized knowledge will assist the trier of fact to understand the evidence or to determine a fact in issue, a witness qualified as an expert by knowledge, skill, experience, training, or education may testify thereto in the form of an opinion or otherwise.” Rule 702 serves several distinct functions. It establishes the authority to use expert testimony in general, sets forth the standard for admissibility of expert testimony in a given case, and addresses the qualifications necessary to accord a witness status as an expert. See generally Coleman v. Parkline Corp., 844 F.2d 863, 865 (D.C. Circuit 1988); and Sterling v. Velsicol Chemical Corp., 855 F.2d 1188, 1208 (6th Circuit 1988).


A Defense Attorney’s Perspective on Life Care Planning

training, education, degree, or certification. In fact, at least one court has held that a skilled witness on a medical subject need not be duly licensed to practice medicine.’ The determination of whether an individual qualifies as an expert is a decision for the trial court pursuant to Federal Rule of Evidence 104(a). This determination is left to the sound discretion of the trial court and will not be reversed on appeal absent an abuse of that discretion.†

Because life care planning is a relatively new profession, there are few written court decisions addressing the degree of experience, education, or other qualification required to properly establish a proposed witness as an expert life care planner. At least one court has held that attending two seminars on life care planning and compiling 25 life care plans are not sufficient to qualify an individual as an expert in life care planning.‡ Another court has determined that a rehabilitation consultant who prepared 200 to 225 life care plans per year and held a bachelor’s degree in psychology, a master’s degree in rehabilitation counseling with a minor in behavioral psychology, and a PhD in counseling psychology and a minor in rehabilitation counseling, with a subspecialty in severe orthopedic disabilities, was qualified by both his education and practical experience to testify as a life care planning expert.§,¶

Between these two extremes, the lack of case law precedent on the issue leaves a gray area that will give rise to debate concerning the qualifications of a proposed life care planning expert. A life care planner seeking to testify for the plaintiff should be prepared to establish her qualifications by relevant training, education, or experience. A defense life care planning consultant can assist her client not only in analyzing the elements of the life care plan, but also in determining whether the plaintiff’s proposed life care planning expert is in fact qualified as such.

Qualification to Present the Particular Life Care Plan

Rule 702 was written as a general grant of authority for the use of expert testimony and is therefore permissive in nature.” Therefore, in many applications of the expert witness rule, the threshold issue is whether the field of expertise is proper for expert testimony in court. Expert testimony is generally proper in any scientific field that has reached a level of general acceptance. Most courts have at least implicitly recognized that life care planning itself has reached such a degree of general

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§ In 1996 the Commission on Health Care Certification (previously known as the Commission on Disability Examiner Certification) created a life care planner certification (CLCP). Later, the American Association of Nurse Life Care Planners was formed offering a similar certification (CNLCP) for nurses only. Such certifications presumably assures a threshold of knowledge and experience. Failure to be certified will not likely preclude the expert from testifying, but will serve as an important factor in arguing the respective weight to be given to competing life care plans. For information, see www.ichcc.org or www.aanlcp.org.
¶ This perspective derives from the fact that expert testimony is treated as an exception to the general rule requiring witnesses to testify to facts instead of opinions. See generally McCormick, EVIDENCE 12, at 30 (3d ed. 1984).
** Note, however, that this general acceptance requirement can also impact the admissibility of a particular life care plan if the scientific bases for any elements of the plan are not generally accepted. This specific issue is discussed in more detail infra at notes 20 to 23 and accompanying text.
acceptance as to be the proper subject of expert testimony. Thus, there should not usually be any question that expert testimony is generally permitted in conjunction with a life care plan. *

Conversely, however, the particular substantive law controlling a given case may require expert testimony regarding a certain issue. In these cases, expert testimony is not only permitted by rule 702 but also, in fact, required by the relevant substantive law. † For example, in cases involving claims of personal injury, courts around the country generally hold that expert testimony is required on the issue of whether treatment claimed as damages is medically necessary. Under this rule, many elements of a life care plan will often require qualified medical expert testimony in order to be properly presented to the jury as a claimed element of damages. In the vast majority of cases, this foundation requires testimony of a physician.

In many cases, plaintiffs seek to present a life care plan to the jury supported only by the testimony of a rehabilitation consultant or certified life care planner. The defense will likely take the position, and several courts have held, that each element of the life care plan must also be independently supported by a separately qualified expert’s testimony as to that element’s reasonableness and necessity in the given case. As one court stated, “The responsibility for establishing a treatment plan rests with a claimant’s authorized physicians.” ‡ Unless such requirements are enforced, the use of the life care planning expert will enable the plaintiff to circumvent the threshold for admissibility of each claimed element of damages in the plan. Thus, once the life care planner is properly

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* See generally International Brotherhood of Teamsters v. United States, 431 U.S. 324, 97 S.Ct. 1843, 1851, 52 L.Ed.2d 396, 407 (1977) (recognizing that expert testimony is required in medical malpractice cases); Randolph v. Collectramat Inc., 590 F.2d 844, 848 (10th Circuit 1979); and Huddell v. Levin, 537 F.2d 726, 726 (3d Circuit 1976).

† Diamond R. Fertilizer v. Davis, 567 So.2d 451, 455 (Fla. 1st DCA 1990). In Diamond Fertilizer, the court held that it was reversible error to adopt a life care plan that was established by a rehabilitation counselor and that gave the counselor the discretion to oversee and supervise the claimant’s medical and nursing home care, where the plan was supported solely by the counselor’s own testimony without the testimony of any treating physician. The court emphasized that each element of a life care plan must be medically necessary and that, in most cases, medical expert testimony is required to establish medical necessity (567 So.2d at 455).

‡ See Fairchild v. United States, 769 F.Supp.964, 968 (W.D. La. 1991) (recognizing that each treatment element recommended by the life care planner must have independent record support); First National Bank v. Kansas City Southern Railway Company, 865 S.W.2d 719, 738 (Mo. App. 1993) (holding that a life care planner’s testimony regarding the need for and costs of future attendant care should have been excluded due to the lack of a medical doctor’s testimony establishing the need for such care on a medical basis) (analyzing the issue in terms of impermissible speculation on the question of damages); and Timmons v. Mass. Transp. Authority, 591 N.E.2d 667, 67071 (Mass. 1992) (holding that admission of vocational rehabilitation expert’s opinion of future loss of earnings was prejudicial error because the expert assumed that the injury was permanent and this assumption was not supported by evidence). See also Hobbs v. Harken, 969 S.W.2d 318 (Mo. App. 1998); Hines v. Sweet, 567 S.W.2d 435, 438 (Mo. App. 1978). But see National Bank v. Estate of Bollmeyer, 504 N.W.2d 59, 65 (Minn. App. 1993) (holding that a qualified life care planner who has reviewed the plaintiff’s medical records can testify to the plaintiff’s need for future personal care services, and rejecting the argument that a medical doctor must testify regarding such need; the court did not state whether the medical evidence relied on by the life care planner established the plaintiff’s need from a medical standpoint in the first instance). It should be noted that an appellate court may permit a trial court less discretion in determining the scope of the life care planner’s expertise than in permitting the expert to testify in the first instance. See, e.g., First National Bank v. Kansas City Southern Railway Company, 865 S.W.2d 719 (Mo. App. 1993) (allowing the trial court broad discretion in qualifying the expert but holding that the trial court committed reversible error in permitting the qualified life care planner to testify to matters requiring medical expertise).
qualified as an expert in the field of life care planning generally, the court will next consider whether the proposed expert is qualified as an expert in the relevant field for each element of the life care plan that is not supported by other evidence or another expert’s testimony.

Failure by the plaintiff to properly limit the scope of the life care planner’s proposed expertise may result in the entire plan and the planner’s entire testimony being precluded or stricken. A life care planner testifying for the plaintiff must therefore ensure not only that he is qualified to testify as a life care planner generally, but that he is qualified to testify concerning the necessity of any individual elements of the plan that are not independently supported by appropriate medical or other expert testimony. In many cases the plaintiff’s life care planner can best serve the client by enlisting the services of the proper medical experts, rather than by attempting to support the plan based on his testimony alone. A defendant’s life care planning consultant can be of great assistance in helping defense counsel to identify any weaknesses in the plaintiff’s proposed expert’s qualifications to testify regarding the need for any given treatment element in the plan.

In general, a rehabilitation or habilitation expert will attempt to translate the physical or mental impairment into a disability in order to assess the effect upon the injured party’s ability to participate in activities of daily living. It is the role of the physician to establish the existence of a physical or mental impairment, and it is inappropriate for a rehabilitation consultant to present opinion testimony as to the existence of a medical condition or its likely progression. Rather, the foundation for the impairment must be laid by a physician, including any expected complications or progression. This medical opinion can then be translated by the rehabilitation consultant into the disabling effects.

It should be noted that there may also be limitations on the authority of a life care planner to oversee and supervise the plaintiff’s treatment. In one case, the court reversed an award that placed a rehabilitation counselor in charge of supervising the claimant’s medical and nursing home care where there was insufficient independent medical evidence to support the award:

The award is patently erroneous insofar as it purports to give a rehabilitation company authority to oversee and supervise claimant’s medical and nursing care. Such responsibility rests with a claimant’s treating physicians. Furthermore, although [the rehabilitation expert] was apparently competent to testify concerning his rehabilitative services, his testimony was not sufficiently substantial to provide the sole support for such a far-reaching award of rehabilitative oversight and authority.

* See Reddish v. Secretary of the Department of Health and Human Services, 18 Cl. Ct. 366, 375 (U.S. Claims Court 1991) (noting that life care plan incorporated needs outlined by treating physicians); Neher v. Secretary of the Department of Health and Human Services, 23 Cl. Ct. 508 (U.S. Claims Court 1991) (damage award reversed because elements of life care plan were speculative and were duplicated by other award); and Ainos’ Custom Slip Covers v. Delucia, 533 So.2d 862 (Fla. 1st DCA 1988) (reversing an order awarding the medical and nursing home services outlined in a life care plan where the testimony of the rehabilitation consultant was the sole support for the award and the medical witnesses testified that the claimant’s current care was sufficient).

† Ainos’ Custom Slip Covers v. Delucia, 533 So.2d 862, 864 (Fla. 1st DCA 1988), review denied, 544 So.2d 199 (Fla. 1989). See also Alpha Reins Corp. v. Townsend, 606 So.2d 506 (Fla. 1st DCA 1992) (court retained jurisdiction to determine which elements of the life care were medically necessary).

‡ In Department of Health and Rehabilitative Services v. J.B., 675 So.2d 241 (Fla. 4th DCA 1996), the plaintiff’s attorney represented to the defendant and to the court that he would not introduce a life care plan at trial, and subsequently attempted to introduce such a plan at trial. The court precluded the plaintiff from using the plan.
**Foundational Objections, the Frye Standard, and Other Preclusions**

In addition to challenging the plaintiff’s expert’s general and specific qualifications, defense counsel should be aware of other potential grounds to exclude the testimony. For example, an untimely disclosure of the intent to use a life care plan can bar its introduction at trial.

Likewise, even where there is no question regarding the expert’s qualifications, the expert’s opinion must be supported by an adequate factual foundation. The expert’s proper role is to provide opinion testimony based on facts that are of record in the case. The lack of an adequate factual foundation requires that the expert’s testimony be stricken as based on speculation. Such an issue may arise if, for example, the life care planner intends to testify regarding the cost of certain treatment but no medical evidence has been proffered to indicate that such treatment is reasonable, necessary, or caused by the relevant accident. Such foundational objections should be considered in cases where similar objections to the life care planner’s qualifications have been overruled.

The speculative nature of a life care plan can also preclude its admissibility if the plan involves new or experimental treatments or novel theories of causation. *Frye v. United States* (the Frye rule) mandates that expert testimony deduced from a scientific principle or discovery is only admissible if the principle or discovery is “sufficiently established to have gained general acceptance in the particular field in which it belongs.” While the U.S. Supreme Court has since adopted a slightly broader standard for admissibility of scientific evidence in federal courts, all courts will apply some threshold requirements to the admissibility of novel scientific evidence. If the life care plan is based on a scientific theory that does not meet the threshold requirements, it can be excluded in whole or part. A *Frye* analysis can be applied not only to test the viability of the types of treatment and services claimed in the life care plan, but also to challenge the theory that the condition itself could have been caused by the particular event.

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† American Bearing Co., Inc. v. Litton Industries, Inc., 729 F.2d 943, 947 (3d Circuit 1984), cert. denied, 469 U.S. 854, 105 S.Ct. 178, 83 L.Ed.2d 112 (1984); Twin City Plaza, Inc., v. Central Surety and Insurance Corporation, 409 F.2d 1195, 1200 (8th Circuit 1969) (“When basic foundational conditions are themselves conjecturally premised, it behooves a court to remove the answer from one of admissible opinion to one of excludable speculation”); and Polk v. Ford Motor Company, 529 F.2d 259, 271 (8th Circuit 1976), cert. denied, 426 U.S. 907, 96 S.Ct. 2229, 48 L.Ed.2d 832 (1976) (an expert’s opinion must be based on matters sufficient “to take such testimony out of the realm of guesswork and speculation”). In Randolph v. Laeisz, 896 F.2d 964, 968 (5th Circuit 1990), for example, the court held that a properly qualified economist’s testimony was inadmissible where the testimony was based on insufficient foundation. The economist had testified that lost wages should be reduced by a certain percentage due to market conditions. The court held that because such market conditions did not appear in the record, there was insufficient foundation for the expert’s testimony. The court found that the testimony was improperly admitted because the expert’s testimony served as substantive evidence rather than opinion interpreting facts in evidence.
‡ 293 F. 1013 (D.C. Circuit 1923).
§ 293 F. at 1014.
\** For example, in Black v. Food Lion, Inc., 171 F.3d 308, 31213 (5th Circuit 1999), the plaintiff’s expert opined that her fibromyalgia resulted from a slip-and-fall accident. The defendant presented medical literature indicating that the scientific community had been unable to determine that trauma could be the cause of fibromyalgia. The court excluded the testimony even under the more liberal *Daubert* test, holding that “mere conjecture does not satisfy the standard for general acceptance” (171 F.3d at 313).
\†† See infra for a detailed discussion of the use of life care planning by the defense.
Of course, defense counsel is advised not only to keep these potential exclusionary arguments in mind in analyzing the plaintiff’s proffered life care plan, but also to ensure that any defense life care plan complies with each of these requirements and will be admissible.

Cross-Examination of the Plaintiff’s Expert

As courts increasingly relax the formal requirements for qualifications of expert testimony, and as scientific advances render more elements of a life care plan generally accepted, it may not be possible to completely exclude the expert from testifying. Where the threshold requirements for qualification are met, any deficiency in the witness’s knowledge, education, training, or experience is relevant only to the weight to be given her testimony, and not the admissibility of that testimony. Courts will often hold that a proposed expert of marginal qualification should be permitted to testify and the opposing party required to elicit the defects in his qualifications on cross-examination, rather than barring the testimony completely. Thus, when a life care expert is permitted to testify over defense objection, the expert should expect any weaknesses in his qualifications to be explored in detail on cross-examination.

Defense counsel will determine whether the plaintiff’s expert is state certified in rehabilitation, habilitation, vocational rehabilitation, workers’ compensation, or other form of counseling. A defendant will also find it helpful to determine whether the plaintiff’s expert is a medical case manager. Often, plaintiffs will retain vocational rehabilitation consultants who have expanded their forensic practice into life care planning. Many plaintiffs’ experts have never actively served as a patient advocate or coordinator of health services on behalf of an injured party. Establishing that the plaintiff’s expert has done nothing more than read books and look at other life care plans in order to present a particular life care plan can be crippling to the plaintiff’s case, even if the court finds the expert qualified to testify. A life care expert hired by the defendant to assist in preparing the defense case can assist his or her client by being familiar with all available training or education in the field, and making defense counsel aware of any such training or education that does not appear on the plaintiff’s life care expert’s resume.

Financial Bias

After the plaintiff’s life care planner has overcome any qualification issues, the planner must avoid additional potential pitfalls. Financial bias is a common ground for defense efforts to discredit the plaintiff’s experts, including the life care planner. The obvious financial bias of any expert is

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† In the instance of rehabilitation, an individual has a known ability that is lost due to the impairment, creating a disabling affect. In the art of habilitation, the counselor is seeking to develop skills unknown to the injured party prior to the impairment. Accordingly, the techniques required to rehabilitate persons differ from those to habilitate individuals. In this chapter the term rehabilitation counselor refers to both rehabilitative and habilitative counseling, unless noted to the contrary.
‡ It should be noted that even where the relevant substantive law would permit compensation to the plaintiff for the fees of persons whose services were enlisted to obtain the award, a life care planner’s fees may not be compensable. See *Southern Industries v. Chumey*, 613 So.2d 74 (Fla. 1st DCA 1993) (holding in a workers’ compensation context that the life care planning services of a rehabilitation counselor and psychologist were not reasonably necessary to the procurement of benefits and therefore were not compensable expenses); *Frederick Electronics v. Pettijohn*, 619 So.2d 14 (Fla. 1st DCA 1993) (rehabilitation counselor and psychologist who developed life care plan did not qualify as a health care provider, and his services were therefore not reimbursable expenses in workers’ compensation case).
that he or she is being paid to present opinion testimony on behalf of the plaintiff. Beyond the bias that all retained experts have, defense counsel will likely inquire about the amount of money received by the expert for litigation support services generally. Many jurisdictions require that the expert give a best estimate of the amount of money or percent of income received from litigation services as a whole. Under the Federal Rules (commonly referred to as Rule 26), the expert must disclose publications for the last 10 years, compensation paid for the study and testimony, and a listing of cases for which testimony was given in the last 4 years. Prior retention by the plaintiff’s law firm is often a fruitful source of showing an ongoing business relationship that the life care planner presumably would not want to jeopardize by presenting conservative plans.

Another source of financial bias impeachment is the appearance of impropriety created by recommended self-referral. Some life care planners are involved in owned and operated rehabilitation centers. Where the life care plan is centered around such a program, this creates the appearance of a financial incentive on the part of the life care planner. In some egregious cases, defense counsel can successfully establish that the life care planner has engaged in self-referral of prior plaintiffs who have received settlements or judgment awards and entered into the life care planner’s own facility programs. It can be devastating to the plaintiff’s case for the jury to learn that the life care planner may receive a substantial amount of the life care plan funding by payment to a medical facility in which he or she owns a substantial interest.

Defense counsel should also be aware that the elements offered in the plaintiff’s life care plan can impact other evidence and discovery in the case. For example, at least one court has held that where the plaintiff’s life care plan included professional help to manage her assets, the plaintiff had put her economic condition at issue and was required to produce her personal financial records, which ordinarily would have been unavailable to the defense.

**Purpose of Retention**

It is useful to establish why the rehabilitation consultant was retained by plaintiff’s counsel. The obvious purpose is to support the plaintiff’s litigation by providing a life care plan that can be used by an economist as a foundation to support a present value of economic loss.

Rather than sharing such candor, some rehabilitation consultants will attempt to present themselves as an advocate for the client, who is allegedly seeking advice regarding his or her future care needs and how they can be met. Defense counsel will establish carefully the extent to which the rehabilitation consultant has furthered advocacy of the client beyond obtaining the information necessary to prepare the plaintiff’s life care plan. In the usual instance, nothing has been done to advocate on behalf of the client beyond the preparation of the life care plan report. For example, rarely will the plaintiff’s expert have contacted an insurer or public assistance program in order to qualify the client for services. Such a line of inquiry can be most effective in instances where an insurer, the public school system, or other resource has provided a medical case manager who has not recommended the various therapies or other aspects of the plaintiff’s life care plan.

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* See *Compton v. West Volusia Hosp. Auth.*, 727 So.2d 379, 381 (Fla. 5th DCA 1999).

† Such issues apparently do not create enough speculation to preclude admissibility of the plan itself. See *Ballance v. WalMart Stores, Inc.*, 178 F.3d 1282 (unpublished disposition), 1999 WL 231653 (4th Circuit 1999) (trial court properly admitted life care plan testimony, despite defendant’s claim that the life care plans are speculative because they are contingent upon future events and choices, such as whether the plaintiff has surgery and whether it is successful).
Another area of recent aggressive attack is the failure of the life care planner to look at the injured party’s circumstances in any real-world sense. Defense counsels are increasingly inquiring of the history of the life care planner’s clients who actually follow through with the life care plan after a court recovery or large settlement.* Often, the catastrophic case takes several years to resolve. Life care planners need to be prepared to respond to defense counsel inquiry as to how the injured party is being presently cared for and the current economic cost for that level of care. Obviously, the life care planner must be prepared to explain why the proposed life care plan markedly differs from the current care plan and thereby justify the increased costs of the more intensive care.†

The Basis of the Opinions

The basis of an expert’s opinions is another potential area for criticism and cross-examination. In the discovery deposition, defense will establish the entirety of the work performed by the rehabilitation consultant in order to prepare the report and should determine that the work on the case is complete. Inquiry will be made regarding any interviews conducted and any authoritative text relied upon. A well-prepared life care expert will be able to demonstrate that he or she is familiar with all the relevant facts of the case.

Counsel should also determine at the time of the deposition that the rehabilitation consultant is not attempting to interpret any of the medical, psychological, or therapeutic assessments made, unless the rehabilitation consultant is qualified to do so. If the inclusion of some therapy, medical examination, diagnostic testing, or other aspect of the plan requires the opinion of a physician, psychologist, or other expert, it must be determined whether such a person has been contacted to validate those aspects of the life care plan. The more experienced rehabilitation consultant who is not a physician will have the life care plan reviewed by a physician in order to verify the inclusion of the various prescribed modalities. On the other hand, a life care planner who is a physician may very well require the support of a case manager, vocational counselor, psychologist, or other specialist if he or she cannot show specialized training in the area of damage-related opinions. If this is not done, it can be a fertile source of cross-examination and perhaps for striking some elements of the plan for lack of proper predicate.

Base Costing and Duplication

In most instances, the plaintiff’s life care planner will attempt to identify a current cost for each aspect of the plan. Defense counsel will review the plan carefully to determine the reasonableness of the costs proposed. Defense counsel’s counsel frequently contacts experts to review the proposed life care plans in order to determine whether the proposed costs are reasonable. Furthermore, the life care planner needs to be conversant regarding the stress being placed upon the current caregivers, especially when they are a spouse or parents, or some other family member. While the economist may talk about the economic cost to that caregiver, the role of the life care planner is to provide insight into the propriety of the care being given. In many instances, the life care planner will find that the parent or spouse is perfectly capable of giving adequate care with additional training and respite. In those situations, the life care planner should make that concession and remain objective. It is the role of the economist to extrapolate the cost to the family member of this type of care. In most jurisdictions, the court will allow evidence of the value of these services being provided by the family member and the jury will thus be able to consider the dollar value of this care in making an award.

† However, a defendant may be precluded from introducing evidence of the cost of an annuity to fund future medical expenses. See North Broward Hospital District v. Bates, 595 So.2d 578 (Fla. 4th DCA), rev. denied, 605 So.2d 1265 (Fla. 1992) (although evidence of the cost of an annuity to compute present value may be admitted in cases involving loss of future earning capacity and loss of support in wrongful death actions, the jury could not utilize an annuity approach in determining future medical damages).
of each of these base cost assumptions. The defense rehabilitation consultant should also review
the plan and point out any areas of weakness. Fertile ground for attack usually involves the failure
of the plaintiff’s plan to recognize the availability of bulk purchasing and long-term contractual
rates. Many plaintiffs’ plans will set forth an hourly rate for home health aides, nursing services,
and household services. Such hourly rates are then extrapolated by the plaintiff’s economist, result-
ing in exorbitant annual costs. It is not unusual to be able to demonstrate that the annual cost of
hourly services is more than double the cost of negotiated contract rates.*

Plaintiffs’ life care plans also commonly provide for many duplications of services and sup-
portive items. Duplication not only is a basis for attack of the life care plan in argument to the
jury, but also may result in the court striking all or part of the plan.† All costs of the life care
plan should therefore be carefully assessed and a determination made of whether the plaintiff is
recognizing the fixed costs that would not be relatable to the injury event. For example, where a
plaintiff’s injury requires a special diet, the cost of the special diet should be offset by the normally
expected food cost incurred by any individual. In instances of special transportation requirements,
it is important to establish whether the plaintiff’s plan has offset those transportation expenses
that would have been normally incurred. Where group home residency is being recommended,
the plaintiff’s plan should set off for typical housing costs. The group home rate often includes
laundry, food, and other expenses that may also be included in some other aspect of the plaintiff’s
economic analysis, such as lost earnings capacity.

Defense counsel should also explore with the plaintiff’s expert any consideration given to
the availability of public programs or collateral sources.‡ It should be noted that the collateral
source rules of the particular jurisdiction may impact the permissible scope of such evidence.§
In most states, the collateral source rule has been modified to allow defendants to set off insurance
benefits provided without lien rights and benefits provided or available under public assistance
programs from the damages awarded. The defendant’s rehabilitation consultant should
assist defense counsel in pointing out those matters called for by the plaintiff’s plan for which
there may be a government agency or other funding source not considered in the plaintiff’s
economic analysis.

For example, states receiving federal funds may be required to provide comparable education
opportunities to severely handicapped children up to age 22. The public school system also makes
available those therapies that are required to further the educational opportunities of the student.
Therefore, the public school program is an excellent resource for cases of catastrophic injury to
infants and young children. Defense counsel should establish the plaintiff’s rehabilitation consul-
tant’s position with respect to the consideration of these public programs and be prepared to rebut
the plaintiff’s expected contention that such programs are substandard and inappropriate for the
particular client. The failure of a plaintiff’s life care planner to recognize and take into account the

* Neher v. Secretary of the Department of Health and Human Services, 23 Cl. Ct. 508 (U.S. Claims Court 1991)
damage award reversed because elements of life care plan were speculative and were duplicated by other award).
† See generally Cates v. Wilson, 361 S.E.2d 734 (N.C. 1987) (noting that the plaintiff’s life care planner testified
both in the plaintiff’s case in chief and on cross-examination by the defense regarding the availability of public
facilities to meet the needs outlined in the life care plan).
‡ See generally Cates v. Wilson, 361 S.E.2d 734 (N.C. 1987).
§ Life care plans are subject to the same requirements for pretrial disclosure as are applied to other evidence
in the particular jurisdiction, and the life care plan may be stricken for failure to comply with such pretrial
discovery requirements. See Department of Health and Rehabilitative Services v. Spivak, 675 So.2d 241 (Fla.
4th DCA 1996).
availability and suitability of charitable and other publicly funded programs can cast doubt on an otherwise objectively prepared analysis.

**Licensing Issues**

To this author’s knowledge, no state has any specific licensing requirements for persons who author life care plans. As the majority of life care planning probably involves the medicolegal context, the lack of any standardized requirements and licensure makes the area fertile ground for those persons who wish to claim expertise for sale on the open market. Unlike recognized specialties that are subject to licensing requirements, the field is open to the unscrupulous expert who views the life care plan as a device to sell in the forensic marketplace. Without licensure, it is impossible to self-police those who are claiming to be life care planners. The long-term solution is the creation of a national standards organization that becomes recognized by the states and lobbies for enactment of statutory licensing. (Editor’s note: As noted previously there are certifications with ethics and standards. There is also the International Academy of Life Care Planners, which publishes *Standards of Practice* guidelines. Visit www.ialcp.org and see separate chapters in this text.)

In the absence of separate licensure, life care planners must be mindful of the limitations that are imposed by related and existing state licensure laws. In most states, persons are required to hold one or more licenses before they may prescribe or perform various therapies. For example, a licensed vocational rehabilitation counselor is not qualified in the State of Florida to prescribe or perform physical therapy. Moreover, therapists licensed to perform physical therapy may only do so subject to intermittent physician reviews. Life care planners must therefore be mindful not to misrepresent to the client or the jury the ability to recommend the various treatment modalities that the life care planner is not independently qualified to opine as reasonable and necessary.

Due to the minimal organization within the life care planning profession, a myriad of qualifications are typically seen on the life care planner’s resume. The life care planner’s formal training may be as a vocational rehabilitation counselor, nurse, certified case manager, mental health counselor, psychologist, occupational therapist, physical therapist, physician, or some combination of these and other professions. Thus, the ability of the life care planner to give specific opinions for care will vary with the type of case presented. For example, a vocational rehabilitation counselor who has no training in case management or nursing is not qualified to render a life care plan assessing the medical needs of a child with catastrophic birth-related injuries. The same life care planner may, however, be perfectly qualified to render a life care plan in the case of a less catastrophically injured plaintiff who simply requires modality seeking to reasonably accommodate the client in the workforce throughout his or her remaining work life. Conversely, a certified case manager with nursing experience in the long-term care of persons with impaired mobility would be well suited to the evaluation of the life care needs of the catastrophically injured child, and ill equipped to assess the needs of the less catastrophically injured worker. Thus, the life care planner seeking to provide services in a medicolegal context should assess his or her own limitations and accept cases accordingly.

Moreover, a certified case manager may be very well qualified to opine as to future durable goods requirements and perhaps the nursing care coverage required for the type of injury presented. This same case manager would, however, be required to defer to a qualified physician the issue of future surgeries and attendant complications, prescription medication, and prescribed therapies. Similarly, this life care planner should defer to an orthotist for the type of orthopedic...
bracing required and the various therapists involved in the care for the form and frequency of therapy provided. As the clinical care of the catastrophically injured person involves a multidisciplinary approach, the life care planner should not be hesitant to interact with and gain insight from these disciplines when creating a plan. In fact, the greatest service the life care planner can provide to a retaining attorney is to express the limitations of the planner to give opinions and encourage the retaining party’s use of other experts to ensure a credible and legally sufficient foundation for the admission of the life care plan.

Many life care planners are unwilling to accept their own limitations for fear that it will erode their role. Such persons are encouraged to look at the other fields that are called upon to participate in the legal system. For example, economists were called upon to render opinions concerning future economic loss in catastrophically injured cases long before the assistance provided by life care planners was available. In order to properly perform this assessment, the economist would frequently review the opinions of the health care providers, the costs provided therein, and the extrapolations required based upon this foundation of information.

The life care planner’s role is to take this analysis to the next step and include a more holistic approach. The weakness of the economist’s analysis historically was that it was incomplete in its scope. It is submitted that the life care planner is best able to assist the legal professional by using experience to dictate the probable needs that will be involved with a patient’s future care. This ensures that the life care planner and attorney will research and consider all aspects of care in creating the life care plan. Just as most of the economist’s report of future economic losses is predicated by facts gained from others, there is no weakness in a life care planner’s relying upon information gained from other sources. Such reliance may make the difference between admissibility and inadmissibility of the life care planner’s testimony.

The Decision to Retain a Defense Rehabilitation Consultant

Because cases that are appropriate for plaintiff’s use of a life care plan typically involve catastrophic physical injury or significant brain damage, the defense counsel is well advised to retain a defense rehabilitation consultant early in the case. Often courts do not require disclosure of experts’ opinions until the months immediately preceding the trial.* As such, much of the discovery will be completed before the defendant has an opportunity to receive the plaintiff’s life care plan.

In order to be properly prepared to rebut the plaintiff’s plan and to determine whether to present a defense plan, it is vital that much of the groundwork be laid in the early portions of the case discovery. A defense rehabilitation consultant can provide early assistance by suggesting the various records that should be requested and identifying persons to be deposed in order to make the determinations necessary to evaluate the injured party’s life care needs. In most cases, the defense rehabilitation consultant will not need to spend a significant amount of time or money to provide this initial assistance. Moreover, the dividends returned on this initial investment are paid in the form of easing the inevitably compressed final preparation toward trial.

The actual selection of a particular rehabilitation consultant requires a basic understanding of the types of injuries involved in the case and an investigation of those experts available and qualified to support the defense. The qualifications of any proposed rehabilitation consultant should

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be reviewed carefully by defense counsel. Most defense counsels will want to review the potential rehabilitation consultant’s current curriculum vitae and rate sheet. Defense counsel will likely request referrals from other attorneys who have hired the counselor, in order to confirm both the expert’s qualifications and his or her abilities as a witness.

Ultimately, defense counsel must exercise judgment in determining the practical interplay of the retained rehabilitation expert with the overall theme of the defense and the other experts. For example, if the plaintiff has no in-state experts, then the defendant’s theme may be to retain only local experts on all issues in order to point out the need for the plaintiff to go to other jurisdictions to get experts to support the case. As with the selection of any expert, the overall picture of the case must not be lost and the rehabilitation expert must make a good fit.

The Testifying Defendant Rehabilitation Consultant

The initial scope of retention is usually limited to service as a consulting expert to assist defense counsel in the rebuttal of the plaintiff’s life care plan. In some cases, the defendant may want to take the next step and hire his or her own life care planning expert to testify at trial. The decision of whether to call a defense rehabilitation consultant at trial is troublesome and must be made on a case-by-case basis. Several factors affect this decision. First, a credible life care planner, even though testifying for the defense, will likely validate at least some of the plaintiff’s plan. Defense counsel must weigh the price of validation of some or all of the plaintiff’s plan with the benefit of attacking the credibility of those portions with which the defense rehabilitation consultant has substantial disagreement. Just as a defendant intends to elicit substantial concessions from the plaintiff’s rehabilitation consultant on cross-examination, so too the plaintiff’s counsel anticipates being able to reinforce much of the plaintiff’s theory of the case through cross-examination of the defense expert.

A second and perhaps more important factor in deciding whether to call a defense rehabilitation consultant as a testifying expert is the impact of this decision on the discoverability of the expert’s work and opinions. In most jurisdictions, the contributions of consulting experts who do not testify at trial are protected by the work-product privilege. For example, under the Federal Rules, a party can discover facts known or opinions held by another party’s consulting experts only upon showing “exceptional circumstances under which it is impracticable for the party seeking discovery to obtain facts or opinions on the same subject by other means.” Absent such a showing of exceptional circumstances, which is extremely rare, the expert’s work is protected from discovery.

However, such protection is usually not afforded to experts expected to testify at trial. Thus, in instances where the rehabilitation consultant may be called upon to testify, both defense counsel and the life care expert should be aware that matters that would have been protected as work product if prepared by a consulting expert may be stripped of that protection. Notes, memorandums, research, and other matters held by the consulting expert may, by the decision to have the expert testify at trial, be transformed into the discoverable file materials of a testifying expert.† These materials may outline a great deal of the defense theory of the case. The cost of disclosing these materials to the plaintiff prior to trial may outweigh the benefit of having a defense life care planner testify at trial.

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Furthermore, under the Federal Rules, a party must automatically disclose the identity of all testifying experts, and each testifying expert must provide the opposing party with a report that contains the following:

A complete statement of all opinions to be expressed and the basis and reasons therefore; the data or other information considered by the witness in forming the opinions; any exhibits to be used as a summary of or support for the opinions; the qualifications of the witness, including a list of all publications authored by the witness within the preceding ten years; the compensation to be paid for the study and the testimony; and a listing of any other cases in which the witness has testified as an expert at trial or by deposition within the preceding four years.∗

This report must be provided 90 days prior to the trial date or at such other time as the court requires.† Additionally, the opposing party may depose any testifying expert, and the opposing party is entitled to take that deposition after the disclosure of the expert’s report.‡ Such disclosure requirements and discovery opportunities are a substantial consideration in determining whether to retain a testifying life care expert for the defense.

In instances where the defense rehabilitation consultant will testify, it is imperative that a physical examination of the injured party occur, or that the court be requested to allow such an examination. Otherwise, the plaintiff will make the often persuasive argument that the defense expert has not even seen his or her client. As the provision of care to severely injured persons continues to become more complex and specialized, it is essential to recognize a multidisciplinary approach and to allow the defense rehabilitation consultant access to the depositions and, if possible, the actual persons involved in the care and treatment of the injured party.

In catastrophic injury cases, it is advisable for defense counsel to work with the rehabilitation consultant to engage the services of the specialized physicians and therapists necessary for the overall assessment of the life care plan. However, many jurisdictions have patient–physician or other privileges that preclude defense-retained experts from meeting with the plaintiff’s physicians and therapists.§ Additionally, many treating physicians and therapists do not want to become involved in litigation and therefore refuse to be informally interviewed by a defense-retained rehabilitation consultant. In such situations, compiling a defense team is the only approach that will ensure a complete evidentiary foundation for a defense life care plan. Plaintiffs obviously have a distinct advantage in having access to treating physicians. The defense must minimize this advantage by putting together its own team of experts and, if permitted under the laws of the relevant jurisdiction, explaining to the jury why such assembly was necessary.

‡ See McCormick, EVIDENCE, 98 at 244 n. 5 (noting that more than 40 states recognize a physician–patient privilege).
§ Life care planning testimony may be relevant and helpful in cases other than personal injury cases. See, e.g., Urbanek v. Urbanek, 484 So.2d 597 (Fla. 4th DCA 1986) (using life care testimony in a marital dissolution case to analyze the wife’s changed circumstances in setting alimony amounts). Life care plans are often used to establish reserves in workers’ compensation claims.
Practical Considerations: The Effect on the Jury

It must be remembered by both plaintiff and defendant that the life care plan will not be presented in a vacuum. Issues of liability and causation can be affected by the credibility of the plaintiff’s life care plan. Both plaintiff and defendant must be certain that they retain a well-qualified, knowledgeable rehabilitation or habilitation expert who will present an objective life care plan. Although the economic incentive to prepare an overreaching life care plan can be tempting to the plaintiff, the presentation of such a plan to the jury will often have a spillover effect on the overall view of the case. It may offend the jury and thereby swing a close liability case in favor of the defense. Defense counsel must therefore be prepared to take full advantage of the overreaching life care planner.

Conversely, the requirements of care for the injured party that are set forth in the life care plan directly affect the economic costs of the injury and indirectly affect the noneconomic losses by the life care plan’s efforts at improving the quality of life. Defense counsel must therefore be cognizant that an attack on any aspect of the plan may be viewed as insensitive to the efforts at improving the plaintiff’s quality of life. Just as the overreaching plaintiff can alienate a jury, the insensitive attack on elements of a plan for the benefit of the injured party can offend juries.

Conclusion

Defense counsel involved in the catastrophic injury case in which the plaintiff relies upon a life care plan is advised to aggressively attack damages. This attack begins with early retention of defense experts, including a rehabilitation consultant. At a minimum, the defense rehabilitation consultant will be instrumental in the preparation of early discovery and effective cross-examination of the plaintiff’s expert. In instances where the plaintiff’s life care plan warrants, the presentation of an alternative defense life care plan, and the early involvement and careful presentation of the defense rehabilitation consultant as a testifying expert, can enhance the overall credibility of the defendant’s case and provide the jury with a more reasonable economic alternative.
Chapter 26

Life Care Planning and the Elder Law Attorney*

Terry C. Cox and F. Auston Wortman, III

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Introduction

The practice of life care planning is familiar to members of the International Academy of Life Care Planners and others who regularly read their publication the Journal of Life Care Planning; however, the practice of elder law as related to life care planning may not be as familiar. This chapter provides a description of and historical overview of the elder law forensic life planning function (not to be confused with life care planning as provided by the professional life care planner). For purposes of this chapter, rehabilitation professionals who practice life care planning are referred

* Note: This chapter is in large part a reprint of the authors’ article of the same name which appeared in the 2008 Journal of Life Care Planning, 6(3–4):105–112. Reprinted with permission.
to as professional life care planners. In comparison, the life planning function of attorneys who concentrate in the field of elder law is referred to as forensic life planning. Beneficial collaboration between elder law attorneys who practice life planning and professional life care planners is discussed. Ethical considerations are also addressed.

History and Development of Elder Law

The practice of law can be traced to the arguments and rhetorical speeches echoing through the halls of the Greek courts. Cicero, the Greek intellectual and philosopher, vividly describes the scenes of this primitive form of law practice (Sutton & Rackham, 1942). Since the days of Cicero, the practice of law has evolved into numerous areas of specialized practice.

Relatively speaking, elder law, as an identified area of practice concentration, is in its infancy in comparison to bedrock subjects including the law of property, crimes, torts, and contracts. Elder law became formally recognized as a specialty practice in 1988 with the founding of the National Academy of Elder Law Attorneys, Inc. (National Academy of Elder Law Attorneys, n.d.). The NAELE serves as the “professional association of attorneys dedicated to improving the quality of legal services to the elderly” (NAELE, n.d.). In addition to facilitating the enhancement of elder law practice, the NAELE serves as an interdisciplinary link between practicing elder law attorneys and those in other professions that serve the elderly.

In furtherance of its organizational mission, the NAELE board of directors formed the National Elder Law Foundation (NELF) in 1993. The NELF exists to improve the professional competence of elder law attorneys and to seek recognition of the specialty area of elder law practice by judicial authorities and the bar in general. To that end, the NELF created a program to certify qualified practitioners as elder law specialists. The specialty practice of elder law was officially recognized by the American Bar Association’s House of Delegates in February 1995 (NELF, n.d.).

The Nature of Elder Law Practice

As defined by the NELF,

Elder Law is the legal practice of counseling and representing older persons and their representatives about the legal aspects of health and long term care planning, public benefits, surrogate decision-making, older persons’ legal capacity, the conservation, disposition and administration of older persons’ estates and the implementation of their decisions concerning such matters, giving due consideration to the applicable tax consequences of the action, or the need for more sophisticated tax expertise. (NELF, Rules and Regulations, n.d.)

Further, it is fundamental that elder law attorneys be capable of identifying, coordinating, and triaging issues that arise, or may arise, while advising and representing older persons. Elder law attorneys must be proficient in matters of health and life insurance, contracts, long term care, employment, retirement, and housing. Elder law attorneys address, from the forensic perspective, issues that arise during an elder’s life transitions. These life transitions arise when the elder ceases to be solely in charge of health care, housing, personal care, and business decision making in favor of a team approach to life management involving a combination of persons involving the caregiver, the attorney, the professional life care planner, and the geriatric care manager.
According to the board of certification of the NELF, an elder law attorney’s knowledge must be broad; the attorney must know an assortment of topics, including, but not limited to, the following:

- Health and long-term care planning
- Public benefits (includes Medicaid, Medicare, and Social Security)
- Surrogate decision making (includes powers of attorney and guardianship)
- Older persons’ legal capacity
- The conservation, disposition, and administration of the older person’s estate (includes wills, trust, and probate of an estate) (Needham, n.d.)

As part of the forensic life planning function, an elder law attorney offers counsel on various subjects that arise in the context of the aging process:

- Health and personal care planning, including the preparation and use of custom-designed advance medical directives (medical powers of attorney, living wills, and health care declarations), and providing counsel to older persons, attorneys-in-fact, and families about medical and life-sustaining choices, and related personal life choices
- Pre-mortem legal planning, including the drafting and execution of wills, trusts, general powers of attorney, financial powers of attorney, real estate ownership, gifting, and the financial and tax implications of related transactions
- Fiduciary representation, including the provision of counsel to one serving as executor, personal representative, attorney-in-fact, trustee, guardian, conservator, representative payee, or other formal or informal fiduciary
- Legal capacity counseling, including advising how capacity is determined and the level of capacity required for various legal activities, and representing those who are or may be the subject of guardianship/conservatorship proceedings or other protective arrangements
- Public benefits advice, including planning for and assisting in obtaining Medicaid, Supplemental Security Income, and veterans’ benefits
- Advice on insurance matters, including analyzing and explaining the types of insurance available, such as health, life, long-term care, home care, COBRA, Medigap, long-term disability, burial/funeral policies, and dread disease coverage, which under certain life policies allow for advance payment of a portion of the death benefit when the insured develops certain fatal conditions or which under certain annuity contracts allows for accelerated payment of a portion of the accumulated value of the contract under such circumstances
- Resident rights advocacy, including advising patients and residents of hospitals, nursing facilities, continuing care retirement communities, assisted living facilities, adult care facilities, and those cared for in private homes of their rights and appropriate remedies in matters such as admission, transfer and discharge policies, quality of care, and related issues
- Housing counseling, including reviewing the options available and the financing of those options such as mortgage alternative, renovation loan programs, life care contracts, and home equity conversion
- Employment and retirement advice, including pensions, retiree health benefits, unemployment benefits, and other benefits
- Income, estate, and gift tax advice, including consequences of plans made and advice offered
Life Care Planning and Case Management Handbook

- Public benefits advice, including planning for and assisting in obtaining Medicare, Social Security, and food stamps
- Counseling with regard to age or disability discrimination in employment and housing
- Litigation and administrative advocacy in connection with any of the previously listed matters, including will contests, contested capacity issues, elder abuse (including financial or consumer fraud), fiduciary administration, public benefits, nursing home torts, and discrimination

The future of elder law practice portends dynamic change in two aspects. First, the scope of issues that confront the elder continues to grow with the increasing variety and complexity of the health care delivery system, housing options, personal financial products, and asset protection strategies. Second, the needs of the elder client group have come to be recognized as largely comparable to those of persons with disabilities. Accordingly, some elder law attorneys are beginning to identify themselves as special needs counsel, a phrase that serves as an umbrella descriptor for any attorney who serves persons affected by aging or disability.

**Elder Law as an Emerging Specialty**

Given trends in contemporary society and based on the authors’ opinion, the next 50 years of elder law practice in the United States will be driven by two phenomena: the rapid increase in the elderly population and the corresponding increased concentration of wealth among that generation. In the first phenomena, data from the U.S. Bureau of the Census and the U.S. Administration on Aging foretell a startling rate of growth in the older population. In 2011, the baby boom generation will begin to turn 65, and by 2030, it is projected that one in five people will be ages 65 or older. It is expected that by the year 2030, there will be approximately 70 million Americans ages 65 or older (U.S. Census Bureau, 2000). In the second phenomena, in 1995, the median net worth of persons ages 65 to 69 was $106,408, the highest median net worth of any age group. It has been estimated that during the first decade of the 21st century, $6 trillion in wealth will change hands from parents to their baby boomer children (Takacs, 2007).

Despite increased wealth and longevity, the reality of the aging population is that “increases in life span do not guarantee a commensurate improvement in quality of life” (Takacs, 1998, p. 2). It has been hypothesized that the most prominent health problems for the elderly will likely be chronic conditions, such as heart disease, neuropsychiatric illness, and cancer. According to a study by Dr. Olafur Aevarsson (1996) reported in the *Journal of the American Geriatrics Society*, almost 10% of persons ages 85 to 88 will develop dementia each year. Dr. Aevarsson stressed that the danger of the elderly developing dementia is substantial (Aevarsson, 1996). The need to evaluate, assess, plan, and care for persons with dementia is, therefore, imperative.

Based on available data, the nursing home will be the residence for three out of every four elderly persons at some point during their lives (Takacs, 1998). The duration of nursing home stay for half of the elderly persons in a nursing home will be 6 months or less. The other half will, on average, stay in a nursing home 5 years or more. At any given time, 4.41% of the 65 and older population in the United States is in a nursing home. Recently, in the State of Minnesota, that number reached 7.95% (Takacs, 1998).
The Holistic Approach (Forensic Life Planning)

Statistics confirm what common sense inherently tells us: the elderly have a higher risk of poor health, disability, loss of income, and incapacity than the population in general. In recent years, the federal government and state governments have enacted legislation on almost a continuous basis in an effort to protect the elderly and expand benefits available to them. The elderly have become more aware of the benefits available to them. In this regard, the elderly and their caregivers have sought attorneys to assist them in planning matters to seek the benefits that are available and to advocate for the rights of the elderly.

While the typical attorney–client relationship generally involves two parties, the elder–client relationship is usually a three-sided affair, involving the elder, the attorney, and the family or caregiver, who often serves as the catalyst for engaging the attorney. In many cases, elder law attorneys welcome, and depend upon, the family's or the caregiver's participation in planning for the elder person. While this configuration presents obvious ethical challenges, such as identifying the elder as the client and serving the client's best interest even when that duty departs from the preferences of the caregiver, it recognizes the reality that effective assistance to elders requires a team effort, a multidisciplinary treatment, and a holistic approach.

Attorneys who follow the holistic approach characterize their practice model as a collaborative effort among the elder, the attorney, the geriatric care manager, the family, and various health care facilities and professionals, with the elder always being the primary focus. “Elder Law attorneys use a holistic, multi-disciplinary approach to help seniors, people with disabilities and their families in a caring, compassionate way that seeks to preserve dignity for such individuals” (NAELA, n.d.). These attorneys have become affiliated in the newly organized Life Care Planning Law Firms Association.

Most elder law practitioners that employ the forensic life planning model customarily represent the client over the balance of the client’s lifetime. The forensic life planning process generally followed by elder law practitioners typically involves an evaluation, assessment, and continued reassessment of the following areas during the representation of an elder client or a client with a disability:

- Housing arrangements: An assessment is performed to determine the level of care a client needs. The spectrum of living arrangements for clients varies from residing in the home to receiving skilled care in a nursing home. Between these two living arrangements lay home health care, continuing care retirement communities, independent living facilities, and assisted living facilities.
- Asset protection strategies: An assessment of a client’s assets is usually performed to determine what, if any, public benefits can be made available to a client. Strategies seeking Medicaid and Veterans Administration benefits eligibility are developed and reviewed with the client and implemented according to the client’s desires.
- Health care delivery assessment: A geriatric care manager assesses the client’s current health status and care needs. In this regard, the geriatric care manager monitors the delivery of health care and anticipates future health care needs.
- Financial management strategies: The client’s monthly income and expenses are analyzed to maximize beneficial use of income and to control costs.
- Estate planning assessment: An assessment of the estate planning strategies is necessary in order to maintain continued eligibility for public benefits. It is imperative to avoid any seemingly benign transaction that may nonetheless impair the client’s eligibility for public benefits.
Advocacy and general representation: Often, it is necessary for an attorney to engage in the traditional legal role of advocating for the client. Advocacy skills are most important when communicating with benefits providers and insurance companies in order for the client to obtain the best possible outcome.

It has been insightfully observed that elder law is the only area of law practice that is identified by the unique legal needs of a particular client group and not necessarily by a body of substantive law, hence the need for comprehensive, personalized planning. The critical distinctive common to elder law practitioners who provide forensic life planning services is that they directly engage care managers in the development and execution of their plan. Prototypically, the practitioner utilizes the services of a care manager to meet with clients in their residential settings, assess clients’ health care and housing needs, and assist and implement care plan decisions that are made. A former president of NAELA considers that his elder law practice addresses the personal, emotional, and legal needs of the client. He describes the goal of his practice as assisting clients in maximizing the quality of their lives (Takacs, 2007).

Table 26.1 provides a matrix that describes a holistic approach to life care planning for elderly clients. This distinctive, holistic approach recognizes care managers as professionals who bring a quality-of-life component to the process of developing and implementing a client’s life care plan. It has been said, “The elder law attorney who practices life planning defines a satisfactory professional relationship with clients not in terms of resolving legal issues but . . . in how effective[ly] he [or she] has enabled his [or her] clients to ‘maximize the quality of their lives’” (as cited in Takacs, 2007, pp. 1–21).

**Ethical Considerations**

In addition to the many ethical obligations inherent in the discharge of the professional duties of the professional life care planner and the elder law attorney, a body of complex ethical issues may arise when the life care planning/forensic life planning dichotomy is examined. Specifically, these issues, in their various fact-specific permutations, can spring from the dilemma of the impact of funds availability on future care planning. Elder law attorneys typically approach the forensic life plan from the standpoint of first quantifying existing financial resource availability and then developing a plan within the parameters of those financial constraints. Accordingly, forensic life plans for three clients with identical personal needs would be markedly different in light of the resource availability for each client. Where continuing court oversight of a plan of care is contemplated, as in the case of an adult under conservatorship or a minor under guardianship, the judge in charge of the case will take a balance sheet approach to approval of a proposed plan and to review of action taken in the implementation of an existing plan.

In sharp contrast is the ethical obligation of the professional life care planner to develop a care plan that is needs based rather than funds based (Commission on Health Care Certification, 2007). In such circumstances, the challenge for the elder law attorney who collaborates with the professional life care planner is twofold: first, to educate the party having authority to approve and oversee the implementation of a life care plan as to the wisdom of the needs-based approach; and, second, to advocate for the incorporation of flexibility in the evaluation of care plans. The professional life care planner can become a critical partner to the party having approval authority in defining the success of the care plan and, in so doing, can maintain adherence to the attendant professional standards and ethics of professional life care planners.
### Table 26.1 Professional Life Care Planner’s Matrix for Collaboration with Forensic Life Planner Observing the Holistic Practice Model

<table>
<thead>
<tr>
<th>Activity</th>
<th>Attorney</th>
<th>Caregiver(s)</th>
<th>Client</th>
<th>Health Care Provider(s)</th>
<th>Skilled Care Representative</th>
<th>Social Worker</th>
<th>Geriatric Care Manager</th>
<th>Life Care Planner</th>
</tr>
</thead>
<tbody>
<tr>
<td>Initial Consultation</td>
<td>X</td>
<td>X</td>
<td>X (if the client is mentally able to participate)</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Physical Baseline Examination</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Financial Status Review</td>
<td>X</td>
<td>X</td>
<td>X (if the client is mentally able to participate)</td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Pre-Admission Evaluation</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Strategic Asset and Resource Placement</td>
<td>X</td>
<td>X</td>
<td>X (if the client is mentally able to participate)</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Residential Placement</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Continuing Health Care Interventions</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Quarterly Residential Placement Review</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Periodic Review of Asset and Resource Placement Strategy</td>
<td>X</td>
<td>X</td>
<td>X (if the client is mentally able to participate)</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>
Elder Law Attorneys and Professional Life Care Planners: The Perfect Match

In consideration of the foregoing, it would appear that professional life care planners and elder law attorneys are positioned to work collaboratively to effectively assess, plan, advocate for, and deliver services to enhance or maintain the best possible quality of life for elderly persons or persons with disabilities.

Throughout the United States, local laws require that certain transactions involving legal awards of money to or for the benefit of persons who are under disability due to age or mental or physical infirmity must be court approved. Professional life care planners provide an invaluable service to the courts and the parties in developing an appropriate plan for the long-term uses of the funds awarded. Anecdotal information provided by experienced professional life care planners suggests that, at times, life care plans, even though court approved, unfortunately are not always fully implemented. One of the stated reasons for this dilemma is that there sometimes is no one on the care planning team who can help structure the plan so that it is legally enforceable and so that there is continuing accountability for implementation. The involvement of an attorney in the creation of the plan can contribute to the development of a strategy that will ensure that the plan is carried out long term. Another potential reason is that life care plans are often not fully funded and a qualified professional life care planner can be invaluable with prioritizing needs as well as attempting to locate alternative funding sources in the implementation of the plan.

As observed previously, the typical contexts in which the elder law attorney provides forensic life planning services generally are those that arise from the occurrence of a traumatic or acquired brain injury or other dementia where family involvement is a dependent element in successful planning. Elder law attorneys are not generally presented with the opportunity to serve persons with other disabling conditions (i.e., spinal cord injury, amputations, etc.) for whom personal independence in all aspects of life is a central issue and for whom there may be little, if any, involvement of family caregivers. The elder law attorney can provide much needed forensic life planning services for this population, particularly in the area of advocacy under state and federal statutory provisions ensuring accommodation and access in workplace, employment, and public facility settings. Professional life care planners working with such clients can add a dimension to the services they render by incorporating the assistance of a legal advocate.

The professional life care planner often does not have a means of reaching many in the potential client population who have need for life care planning. Within the forensic arena, the professional life care planner is typically engaged as a consequence of a catastrophic injury and the engagement typically is initiated by a liability insurance carrier, an insurance defense attorney, or a plaintiff personal injury attorney. Of course, there are other uses of life care planning outside the forensic arena such as hospital or nursing home discharge planning, estate planning, workers’ compensation issues, and others. However, within the forensic setting, the term of the engagement generally is for the amount of time necessary to assess the injured person’s needs and to design and present the plan for care; thereafter, the engagement of the professional life care planner typically ceases. The elder law attorney, however, is in contact with a vast pool of persons coping with issues related to aging and disability who have voluntarily sought the attorney’s services for a long-term planning and management function.

In conclusion, the prospect of collaboration between the elder law attorney and the professional life care planner provides each the opportunity to expand the scope of his or her practice and the concomitant challenge to each to address serious and complex questions within the framework of his or her respective professional discipline. The attorney who seeks to provide forensic life planning
Life Care Planning and the Elder Law Attorney

Case Study

Facts: Carl and Imogene have been married for 40 years. Carl was a Navy veteran in World War II. Upon discharge, Carl began civilian employment. Imogene has a history of mental health problems. Her mental issues have at times strained their marriage. Imogene has, on more than one occasion, threatened Carl with a knife. When Imogene threatens Carl, he leaves the home and lives with a relative, usually one of their daughters.

Their assets include a jointly owned residence worth approximately $235,000 and joint bank accounts of less than $200,000. Carl's income consists of a retirement pension and Social Security. Imogene only receives Social Security. Together their income totals approximately $2,700 per month. Their joint expenses total approximately $2,500 per month, including groceries, utilities, insurance, mortgage, and other miscellaneous expenses.

At this time, Imogene has experienced a health downturn due to a stroke. She requires 24-hour at-home care. A daughter has taken Imogene into her home, where a home health care agency provides needed care. This caregiving arrangement has worked due to a long-term care insurance policy that Imogene purchased many years ago.

Issues presented:

1. Financing Imogene's nursing home care. Imogene's health continues to decline. The caregivers, Carl and his daughters, based upon the recommendations of the geriatric care manager and the life care planner, have decided to place Imogene in a skilled nursing facility. The average cost of skilled care can range from $170 to $225 per day. Even though Imogene's long-term care insurance policy will cover a portion of her skilled nursing cost, there will still be a difference to be paid by someone. As we can see from Carl and Imogene's financial portfolio, their current income will not cover the cost of Imogene's skilled care in a residential setting. Also, it would appear that Carl and Imogene's assets would render Imogene financially ineligible to qualify for public benefits through the Medicaid program or through the Veterans Administration to defray the cost of such care. The threshold considerations relative to placement in a skilled nursing facility are as follows:
   - In considering an appropriate skilled nursing facility placement, it is imperative to consider Imogene's past behavioral issues. Many facilities may decline to accept her as a resident due to her past behavioral issues.
   - Carl does not drive very much and cannot travel very far from their home to visit Imogene in the skilled nursing facility.
   - Carl and Imogene's assets must be repositioned in forms that will cause those assets not to be categorized as countable resources under Medicaid criteria. Because a Medicaid benefits applicant can only have $2,000 in countable resources, the remainder of the assets must be allocated, spent, or invested in ways that are Medicaid compliant and thus are not included as countable resources when a Medicaid benefits application is considered. In the case of Carl and Imogene, several methods of asset repositioning should occur. The following asset repositioning strategy could be adopted to establish Medicaid benefits eligibility; it must be noted, however, that because the Medicaid program is administered in each state under state-specific rules and regulations, the calculations herein are representative only.
i) A portion of the couple’s assets may be allocated exclusively to Carl:

- Standard maintenance amount: $1,711
- Mortgage payment: $1,200
- Property taxes: $167.33
- Homeowners’ insurance: $97.67
- Utilities amount: $160
- Total shelter cost (steps 2 through 5): $1,625
- 30% of standard maintenance amount ($1,711 × .3 =): $513.30
- Excess shelter amount ($1,625 – $513.30 =): $1,111.70
- Total need of community spouse ($1,111.70 + $1,711 =): $2,822.70
- Total of community spouse’s noninvestment income: $900
- Total of institutionalized spouse’s noninvestment income: $1,800
- Personal needs allowance: $40
- $1,800 – $40: $1,760
- $2,822.70 – ($900 + $1,760): $162.70
- $162.70 × 12: $1,952.40
- $1,952.40 / .3 (interest rate): $6,508.00

The amount of Imogene’s assets allocated to Carl is $6,508.00.

ii) Next, a portion of Imogene’s income may be allocated to Carl to cover his living expenses. Carl can request a fair hearing before the state agency charged with responsibility for administering the Medicaid program during which he can present proof of his living expenses so that a portion of Imogene’s income may be allocated to him. It is possible for a portion of Imogene’s income to be allocated to Carl so that his imputed income for purposes of Medicaid eligibility $1,711, that is, the current standard maintenance amount. Thus, Imogene’s imputed monthly income would be $989 and Carl’s would be $1,711. The $989 amount that is allocated to Imogene under this calculation is the amount that must be paid to the skilled nursing facility as her personal contribution to the cost of her residential care. Medicaid will pay the remainder of the monthly cost of her residential care. The remainder of Carl and Imogene’s monthly income in excess of the $989 amount may be retained by Carl and spent on his personal monthly living expenses.

2. Seeking supplemental income for Carl. Based upon Carl’s military service, he may be eligible for Veterans Administration benefits because of Imogene’s medical needs. If her medical needs are sufficient and if their assets can be positioned to establish benefits eligibility, Carl could qualify to receive roughly $1,000 per month, which could be spent on his living expenses or on Imogene’s care. If Carl qualified for the VA benefit and if Imogene qualified for the Medicaid benefit, the Medicaid benefit for Imogene would be reduced by the amount of the VA benefit. The criteria and the corresponding calculations under which eligibility for VA benefits is determined are different from those that apply to establish Medicaid eligibility. A methodology similar to that set forth in Step 1 would be employed using the benchmarks set forth under separate and distinct VA eligibility criteria.

3. Accommodating Carl’s rehabilitation from his anticipated surgery. Carl is scheduled to undergo hip replacement in the near future. This will impact his ability to visit Imogene and will create a temporary need for skilled nursing care for Carl. Care should be given to determine whether the skilled nursing facility selected for Imogene has the capability to care for Carl
during his rehabilitation so that he may stay in Imogene’s room during that time. Such arrangements can sometimes be made, resulting in economy in cost of rehabilitative care and reduction of demands upon family caregivers during Carl’s convalescence.

References


State Statutes
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Delaware: DEL. CODE ANN. Tit.12 §3901(k).

Florida: FLA. STAT. ch. 768.25.

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Nevada: NEV. REV. STAT. 42.030.

New Mexico: N.M. STAT. ANN. §39-1A-4.


Virginia: VA. CODE ANN. §8.01-424.


Chapter 27

Day-in-the-Life Video Production in Life Care Planning

J. Mat Hunt, Jr.

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Introduction

Moving Visuals Move People . . . Especially if One Can Also Hear What’s Moving

In this author’s opinion, the day-in-the-life video can be one of an attorney’s most effective tools to substantiate a client’s injury, demonstrate ongoing difficulty, and put a name and a face on a case number. It is a legitimate opportunity to show what must be shown in a way that protects a client’s dignity. Furthermore, videos can assert admiration in place of pity or misunderstanding, and can educate the viewer about very real circumstances in ways verbal or print communication rarely can. Indeed, video productions portray the essence of the client . . . within a reasonable amount of time, in order to convey the message.

But it is not a cookie-cutter task, is rarely completed in a day, and some of the creative and emotional elements most people may believe would be the content of such a video just will not
fly. Some content might just get thrown out if over the prejudicial line, so it is best to know where not to go, and then to not even go there. But first, one needs to know where to go, by determining the priorities necessary to be in the content. The single, most important planning tool to help accomplish this goal is a good life care plan.

After a number of years as a news feature reporter/producer/editor at a “#1-in-the-market” network affiliate television station, and after a couple of subsequent private sector years in the video business, mostly doing productions for ad agencies and businesses, I received my first opportunity to do a day-in-the-life video in 1984. I did not know the attorney at the time, but for some reason he believed I was the guy to call, and ever since then, it has been an evolving, fine-tuning mainstay of our company that is taken very seriously . . . because it truly matters to somebody. Many other attorneys have increasingly called upon our company over the years to provide this service, and each product is usually an improvement over the last. These demonstrative exhibits are considerably better when a life care planner is involved at the outset, but at the time of my initial assignment, I did not even know what a life care planner was. It was totally new territory, and there was much to learn in order to be credible.

Sharing some of that first experience may be a useful introduction for this chapter, because it is unforgettable. And I may be the only person who watched all of it, as many cases settle before the visuals are even put together. However, if the visuals are there, reality can be preserved in the event it is needed, and it is good to be prepared ahead of time. You may only get one take.

This first client was almost 300 miles away, in the middle of nowhere, and our work involved documenting the end result of an elderly minister’s having been robbed and shot through his neck as he and his wife stopped to spend the night in a motel, on their way for him to preach in a revival in yet another state. He was medically unable to travel for court appearances in the resulting civil and criminal actions in another state’s jurisdiction, due to his spinal injury and the resulting complications.

The Height of Bad Things Happening to Good People

Yes, we had a location light kit . . . we had a fine broadcast camera . . . and there was enough feature work experience to know something about doing a “warm and fuzzy” video in somebody’s home. But there was much more to consider, and many of the creative things learned in the TV and ad business needed to be cast aside, because everything was potentially discoverable. In that planning process, there was the need to learn about the myriad of health care necessities that should be included in this video, in order to help a jury understand the difficulty and resulting expense. It had to be videotaped and later assembled in a way that made sense for the viewer . . . eventually consistent with somebody’s live testimony. Writing a voiceover and presenting a self-contained narrated video in court was not an option. These visuals needed to substantiate testimony we did not yet have.

In producing day-in-the-life videos, nothing is staged. It is not necessary to stage, because the action is real. We did the location work, we got different angles, and we observed the client eating, taking his meds, the architectural modifications, therapy, the whole nine yards. I thought we had completed the important part, and was personally moved that nobody was angry, especially under the circumstances. The client and his family had already dealt with that, and all their energy was devoted to day-to-day survival. Our being there made our client’s day even more exhausting and difficult. Concentration fatigue was very real, as everyone was working together to find solutions in dealing with this tragedy, and to set up specific shots in a way that made sense to a viewer who could not be there. In producing this video, at the time, there really was not an established
standard or known precedent for reference. We found ourselves helping to set that standard as we developed the day-in-the-life video.

The next day was a secondary reason to justify the trip from my perspective, as it was not part of the day-in-the-life production. It was a simple video deposition at bedside to get our client’s sworn de bene esse testimony for the criminal case. Both the public defender and prosecutor were present with the securely transported accused gunman, in order for him to be identified face-to-face as the assailant. This was simple, yet uneasy. Three attorneys, a court reporter with equipment, a videographer with more equipment, a handcuffed defendant, and yes . . . the client, bedside in a double-wide, with an added-on wheelchair-accessible bathroom.

After identifying the party who fired the shot that permanently disabled the client . . . a procedural necessity . . . the client did the sort of thing that makes a lawyer cringe when a client does such things: he forgave the man who shot him, right there on the spot . . . and on video.

No, he did not condone the action . . . there was no let-him-go-free mentality . . . but in this gentleman’s pain, suffering, and permanently life-altering consequences, he freed himself of a burden . . . and likely cleared the way to get on with it for everybody. He also injected a strong dose of humanity in this procedural exercise. This client was Number One. Unforgettable.

Now it is not really known what settled the case, but in this first day-in-the-life, with no real guide to follow in the process, although the video work was an important process, it was not as important as the reality of this client. And in this case, the video was never needed to be used.

**Admiration . . . Not Pity**

In preparing a day-in-the-life video, the client’s best interests are the first priority. The client should never be made an emotional star in an exciting, flashy video. In my opinion, after doing this work for 25 years, flashy is not good, and totally unnecessary. The work should credibly show what is really there. And to be credible, staging is unnecessary. Give the viewer the opportunity to be smart . . . and FEEL what is really there, without messing with it to attempt to create a picture.

But that does not mean we should go with the flow with no planning. It does not mean don’t move some furniture. And it does not mean no tripod, no lighting, and a quick overview with an attorney’s son’s consumer camera, because it seems so easy when first discussed elsewhere.

When asked to produce a day-in-the-life video, especially if the initiating attorney has never retained a professional to complete one (or, occasionally, has never actually even seen one), is to get on the same terminology page. **Make sure what we think we’re being asked to do is what the attorney really wants.** For example, one may be asked to do a day-in-the-life video in a wrongful death case . . . and obviously, the client is no longer among the living. One may be asked to do a day-in-the-life video as if it were for trial, when it is really needed very quickly for a mediation just scheduled. Or the day-in-the-life term may be used to indicate settlement documentary . . . meaning one can more flexibly use music, photographs, unsworn interviews, and other demonstrative media to make it more interesting and credibly self-contained. The end use is usually a matter of editing. The day-in-the-life location work with the client is essentially the same, and ideally the videographer will be capturing credible visuals that can be used in many ways. The original location video can be the source media for a brief mediation visual, a segment in a settlement documentary, and/or a trial exhibit. Finding out what the attorney means procedurally can be more important than what the videographer is first told. **And one must ask.** One must ask specific visual questions that address what can realistically be covered in a video, and that can vary between legal processes and different jurisdictions.

When I am asked to produce a day-in-the-life video, the first question out of my mouth is “Do you have a life care plan?” In my opinion, the life care plan is the single most important
startup tool for day-in-the-life video work, for without it you run the risk of missing the most important aspects of the client's life. It may be wise to actually delay location work until a life care planner becomes involved, even if there is not a finished plan in time to meet the video deadline. The videographer can at least have some significant recommendations, a draft, or an outline from the life care planner with which to organize priorities. In the event a life care plan has not yet been drafted, at a minimum a telephone conference call can be a useful alternative in order to assess the life care planner's impressions and recommendations. This, of course, presumes that the life care planner has already met with the client and conducted at least an initial evaluation and assessment. An exception, of course, is if there is a need to document present reality, in anticipation of changes in condition before a life care planner is able to become involved.

Regardless of the tips and recommendations provided in this chapter, a day-in-the-life video is not a cookie-cutter project, and at this point there is no known, accredited, specific higher education course or templates on the Internet to tell the reader everything to consider when working on such a video. What we have at the time of this writing are some basic acceptable standards and precedents to make sure the work is likely to be admitted in court, so it does not become a useless, expensive exercise in frustration. There are numerous, sometimes conflicting, court rulings on admissibility, and these standards vary from state to state. Therefore, we will not reference specific rulings for purposes of this chapter. Instead, we will paint this chapter with a broad brush by stating some parametric considerations, and, along the way, offering some practical thoughts as to how to make it happen in the real world based on our experiences.

Basically, key consideration goals are as follows:

- Authentication
- Relevance
- Nonprejudicial portrayal
- Accurate portrayal

Within those goals, it is helpful to establish a chronology, including:

- Baseline: normal life prior to life-changing event
- Event: visuals that can substantiate or transition to the present
- Reality: present-day life care visuals
- Conclusion: the final thought that summarizes the effects of the event

The baseline may be the most overlooked opportunity to make a day-in-the-life video effective. In order to show what a client has lost, establishing what they had to lose is key to making it real. For example, if the client was a computer technician, excelled in his work, got along with everybody, and made his boss a lot of money, with the resulting personal earning capacity. . . . and then a head injury impaired his ability to do the computer work, and also took away the most important purpose and enjoyment of everyday life. . . . Some qualified expert can write that conclusion in a report or testify to damages, like a college professor.

But wouldn’t it be more effective to the jury pool, or a mediator, if you had pictures of the client working on computers? Better yet, some home, training, or corporate video, where one could also hear how swiftly he moved a keyboard, and possibly articulated expertise. He may look the same, and may even present quite normally. But a cognitive decline can be communicated much better if there is a baseline for comparison. Credentials, certificates, accepting performance
awards, along with economic information can also visually help establish not only where the client was, but project where he would likely be now without the difficulty, and where he could have been expected to progress in the future.

The event may need to be communicated through testimony or documents, but production of a day-in-the-life is an opportunity to make that event more real with TV news reports one can hope the attorney or client has obtained. This can be very effective in mediation, and can possibly have some limited use in trial. If the event was an accident and had some media coverage, these may be some of the most useful visuals one has. But often they are not just a phone call away.

In order to have access to this footage, an attorney may need a subpoena to obtain it, if indeed it was even archived. Most news operations will require a subpoena to protect themselves, plus reasonable fees for their time to run it down and produce it. However, it is unlikely that the attorney will be able to get anything that did not air or was not published. Original footage, even if saved, will be procedurally difficult to obtain, even with a subpoena. Pushing for unedited footage that did not air may not be worth the risk of delaying production of aired video, which can be reviewed and used. In any event, the source should be properly credited with a brief graphic when used, if there is not already a station ID superimposed on the material.

Reality started after the event, and the videographer or editor may have become involved months or years into the process. Although family members have been stressed out for a long time while dealing with their new reality, some may have had the presence of mind to videotape coming home from the hospital, or some of the earlier days of recovery. Although the quality may not be as good as one would want, a few well-selected seconds can be a big help in substantiating real difficulty in the passing of time. That is something that may need to be requested repeatedly, and it is a good idea to inquire about videos that may be in the possession of friends. Still photographs are better than nothing, but moving video also gives the viewer ambient audio, and audio is often the foundation for feeling what is seen.

Another source of visuals, in addition to family members, is rehabilitation. Many rehabilitation facilities routinely videotape progress for such functions as walking, and, with the help of the attorney, that can probably be obtained. This adds to the chronology.

It is now timely to address some of the day-in-the-life production that the reader may have thought was all there was to this process. But hopefully, after absorbing this chapter up to this point it is apparent there is more to a successful video than perhaps was first thought. Here are some suggestions in checklist form:

- This may sound self-serving on the part of the writer, but it is not a good idea for an attorney to hire a cousin, child, or neighbor to do this work, unless they are experienced. Neither should it be assumed that somebody who shoots sports or weddings is a good choice without some help. A National Court Reporters Association (NCRA) Certified Legal Video Specialist (see www.ncraonline.org) experienced in legal work beyond depositions should be a minimum requirement. And, if he or she has a broadcast television news background, that is even better. That person will know what a deadline is, and is less likely to accumulate more material than you can manage. Long is not good.
- There should be at least two people involved on site, regardless of how the responsibilities are divided. The videographer needs to be able to totally concentrate on what is being documented, and another party should be producing . . . by anticipating what is next, and dealing with family or other caregivers. The target is always moving, and the content being documented may be discoverable. Plus, there are some medical or rehabilitation procedures that must be captured correctly in one take.
No home video, except archives from family. Day-in-the-life work should be produced with professional equipment by experienced professionals. Minimal camera requirements should be 3-Chip Broadcast or Industrial Camera, with at least a 10:1, preferably a greater, ratio optical lens. While some cameras have digital zoom capabilities, they can create artifacts that can distract from the closer shots that require a zoom ratio in the first place. Also, digital zooms are difficult to accomplish smoothly.

Professional lighting is a must in order to assure normal skin tones in mixed- or low-light environments. It may not be needed for every element, but it should be available with the expertise to use it. If a potential videographer says he does not have lighting because he does not need it, call someone else who is willing to work harder to get it right, because this is probably the most important video in the client’s life. Simply bouncing a light off the ceiling does not change reality, yet it may help eliminate color temperature discrepancies that detract. Remember, day-in-the-life videos are competing for an attention span with million-dollar-an-hour television programming that comes into everybody’s home, every day. Keeping it clean and natural does make a difference, even if the viewer does not think about it. If the end result is natural, one does not have to make excuses for it or think about it.

The production professionals may be told “No sound.” That is not what it means. The intended meaning is likely no narration, or don’t have the client or the caregiver stand there and explain what they are doing because it likely cannot be used in court that way. Do record natural sound at all times, and make sure the levels are not too hot (audio recording where microphone volume is set too high), or on auto. This is especially important with the newer digital cameras, for the equipment is less forgiving than analog when levels are too high. Distortion occurs more easily, and it cannot be fixed later. To be safe, audio levels should peak no higher than 12 dB, and one needs a camera with VU Meters in order to visually monitor audio levels. Good audio gives visuals presence. The viewer should hear machinery, somebody brushing her teeth, and a crutch hitting the floor if the client accidentally drops it. The crew should advise everybody that natural sound is being recorded, so unnecessary commentary is not taped. Always be aware that original footage may have to be produced to the other side.

Whoever does day-in-the-life work should also be an experienced editor, and the attorney should see examples of his or her work before assuming competence. Reading magazines and knowing the language of the business are not good enough for what probably is the most important video in someone’s life. A good editor is more likely to be on the lookout for what matters in the field. Be aware that editing is not cutting things out as much as it is putting in material that tells a story in a way that makes sense to and captivates the viewer. Editing is everything when there are hours of material and an under-20-minute attention span. The importance of a talented, competent editor throughout the entire process cannot be understated. And everything that goes into editing should be time budgeted at about 2 hours per finished minute. This is not a process to be rushed.

The location video process will be very tiring for a client. Those involved should be advised up front that eating, bathing, and other forms of caregiving may take three times as long as the usual painstakingly long time.

Since this process is tiring for the client, restful downtime should be built into the anticipated schedule. It always takes longer than anticipated.

Find something fun. Even though the situation at hand may be very sad, videos are works within an entertainment medium. If all the content is horrific, it is a tune out. The production crew should find and plan something fun that the client can do for enjoyment of life, and take
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advantage of any light moments to contrast and balance the negatives. This will humanize
the end product, will allow the viewer to relate, and may be one of the more beneficial things
anybody does for the client’s feelings.

After obtaining permission to speak directly with the client or caregiver, establishing a trust-
ing relationship is important. While the client may have been through years of personal
intrusion . . . and while one may be very familiar with a video process . . . coming into
someone’s home or facility with a camera, equipment, and unknown people is a very big,
potentially stressful event. It is not unlike going to court for the first time. Making people
comfortable, and helping them understand that they do not have to clean up for company,
can go a long way to pave the way to success. That may be complicated by a requirement in
some jurisdictions that the other side be notified and allowed to be present. Fortunately, most
judges do not consider day-in-the-life videotaping to be an inspection, and the intrusion of
opposing counsel can usually be avoided. The intrusion of too many people is especially dif-
ficult if the client is in a hospital or nursing home (see next point).

Day-in-the-life location work in a facility means numerous hurdles to proactively overcome
before the production crew arrives. Not only is the client likely to be confined to one room,
possibly semiprivate, but also access to even the least cramped of facilities can be a challenge.
One cannot assume that because some family member said some nurse said it was okay for
you to come make a video that it is okay to appear with your equipment when it suits the
family. Regardless of whether it is a public or a private facility, there is likely an administrator
who must run it by risk management, and risk management may be halfway across the
country, if not on vacation. If the professional waits until the last minute to cross that
bridge, the easiest immediate answer from risk management is always no, so in the process
of asking for access, it is sometimes helpful to assert at the outset that (ideally) the facility is
not a defendant, and the production crew is part of the process to obtain funding for care.
Before being told that other residents or patients cannot be included, the facility should be
informed that residents or patients will not be recorded. In fact, some facilities may prohibit
including the participation of caregivers employed by the facility.

Visuals should not be limited to someone lying still in a bed, as feeding, bathing, therapy,
and other forms of care need to be part of the story. So if videotaping employees is not
feasible, perhaps family members or independent caregivers or therapists can be available.
In any event, releases should be executed for each person appearing on camera, including
family members.

If facility access is problematic, an additional persuasion one may offer (with consent of the
client’s attorney) is to provide the facility with a “time code window” copy of all the video
shot in the facility for their review prior to editing. This may need to be produced for the
other side anyway, so proactively making it available to the facility should not be a problem.
It then becomes a simple matter for those in charge of the facility to confirm for their
records that the footage is within reason, and if there is anything in doubt, they can advise
in writing, referencing the on-screen numbers. It is probable that the attorney will not want
to use any potential problem segment(s) anyway, so this process should be a positive exercise
to accomplish what is needed. The writer has found that suggesting this safeguard, with
consent of counsel, is useful in totally lowering the facility’s shield. Most administrators
truly want to help their patients . . . they just need to make sure their facility is protected,
and that the video crew is not 60 Minutes doing a hidden camera story on their type of
facility. And if one ever needs to go back to the same facility in another case, trust is already
established, and the process is made a lot smoother.
More than likely, a day-in-the-life video will require significant videography in the home. A site check with no camera is time well-spent to prepare the needs of the environment. If the videographer has come a long distance, perhaps a visit on the day of arrival, with no equipment, will break the ice and lower the shield of anxiety. It is a good opportunity to bond with the family by listening to their story first, and then showing them a cleared example of some of the professional’s work product. Providing an example not only lowers anxiety and creates confidence, but also opens a dialogue for practical suggestions to plan your location work. Then the crew can hit the ground running the next day, after anxieties are cleared and, hopefully, everyone has had a good night’s rest. That’s right . . . tell them to go to bed early.

The site check also is a good time to plan the order of visuals and solicit the caregiver’s input as to unique circumstances that might be important to know. One might plan a purpose for dressing by also planning a place to go, such as a doctor’s office, the grocery store, bowling alley, church, or wherever the client may actually go or enjoy going. This gives purpose for getting dressed and going out the door, and the documented arrival somewhere else does not necessarily have to be the same day. Under those circumstances, it is wise to plan for continuity by suggesting that the same outfit be worn each day.

If a doctor visit or therapy appointment can be or is scheduled during the location work, that is yet another opportunity for a practical visual. Like any health care facility, getting clearance up front is a must, and the attorney or paralegal may be able to cut through the procedural red tape before the shoot. Again, if the client says the doctor will say it is okay, that does not necessarily mean it is okay. If permission is obtained ahead of time, that doctor or therapy visit is a great opportunity to substantiate how much difficulty the client has in accomplishing more basics than most people even need to consider. On-camera releases are still a must.

If the field trip opportunity the client was dressed for is the grocery store, one may also need to obtain permission for interior location work. Frankly, it may not even be necessary to go inside a store. Getting in and out of a vehicle in the parking lot may sufficiently make the point.

Most of what has been addressed to this point is active and moving. But the videographer with a good eye will also obtain visuals of the client doing nothing, possibly resting, possibly bored, possibly helpless. That is part of the day as well, and when that moment comes, a good videographer will know it, and will not need to stage it. Also throughout the process, there should be cutaways. Close-ups of medications, health care supplies, wipes, tubes, and machinery may have their place as visuals later in the edit. If there is a special bed, it is an expensive piece of equipment to document and justify. While it is tempting to want to show a lot of emotion, tight shots of extreme facial grimacing, too many noises, and anything that may be interpreted as overly dramatic should be avoided. If it is there, it’s there, and one will know it without having to create it. The expectation is admiration, not pity.

The videographer with a good eye and a heart will also be thinking about what a client can do, or perhaps can do with difficulty. For example, the client with carpal tunnel syndrome may have difficulty opening a jar, but should be given the opportunity to open one, possibly with some help. Hugging children or grandchildren, or the inability to hug children or grandchildren, are visuals worth the effort. Not staged. . . . Natural . . . they know how to do it . . . or try to do it as best they can.

This subject could have endless pages of different stories and situations, along with specific visuals that make the point. But since this is not a cookie-cutter process, a good videographer or editor will know what works without a checklist. However, there is also a need to be mindful of the legal process and what is within the bounds of those first priorities.
Authentication: Make sure the party who did the work, or participated in the work, is credible, is available, and has integrity. Make sure the visuals accurately depict reality. No conflicts of interest.

Relevance: Stay on point with purpose. Connect the baseline with the present situation, and relate it to the event.

Nonprejudicial portrayal: Prejudicial visuals are invitations for exclusion.

Accurate portrayal: One should not make up or stage anything. Keep it real. Real is good, and it captivates. “Just the facts” increases admissibility.

In other words, the professional retained to develop the day-in-the-life video should use good judgment, exercise appropriate restraint, and save the creative, misleading, morphing effects for political commercials.

A day-in-the-life video is about substantiating something very real to somebody, and does not need all the tricks that videographers know that they can do. But some modern-day effects are appropriate in order to protect the client’s dignity, such as fuzzing or blurring out private areas in the edit, if they must be in the shot to communicate necessary care. The client deserves integrity, the best quality, the professional’s concentration, and respect for dignity.

This type of personal yet professional work . . . documenting the difficult . . . may not be the most lucrative work one may produce, but it may very well be the most memorable and rewarding. It may or may not even be used, as the case may be resolved sooner than expected. But win or lose, one has accomplished something that truly matters, and the videographer may have done more to validate and help somebody get through a tragedy than any other professional brought into the mix, other than a caregiver. The product will have shared and seriously documented important personal time in a personal space.

So in short, how does one do a day-in-the-life video?

It should be done the way one would like someone else to do it for somebody dear to them.
Chapter 28

Ethical Issues for the Life Care Planner

Roger O. Weed and Debra E. Berens*

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Introduction

According to Black's Law Dictionary (Black, 1990), ethics is defined as (1) a set of principles of right conduct, (2) a theory or a system of moral values, or (3) the rules or standards governing the conduct of a person or members of a profession. A variation of this definition is found in Merriam-Webster's Dictionary (2009a), which defines ethics as (1) the discipline dealing with what is good and bad and with moral duty and obligation, (2) a set of moral principles or values, (3) a theory or system of moral values, (4) the principles of conduct governing an individual or a group, or (5) a guiding philosophy.

According to at least one study (Swartz et al., 1996), ethical decision making undergirds all aspects of rehabilitation. This statement certainly holds true for the practice of life care planning

as well, and this chapter will focus on ethics issues specific to the life care planner with suggestions for minimizing potential problems. Also included in this text is the standards-related document from the International Academy of Life Care Planners (IALCP) (see Appendix I). According to Merriam-Webster’s Dictionary (2009b), a standard is defined as (1) something established by authority, custom, or general consent as a model or example; (2) something set up and established by authority as a rule for the measure of quantity, weight, extent, value, or quality; and (3) something that applies to any definite rule, principle, or measure established by authority. As can be expected from a review of these technical definitions, the interplay of ethics and standards is somewhat difficult to separate. However, based on the definitions, ethics-related observations directly related to life care planning are as follows.

**Right Conduct:** This premise is perhaps the most understandable. Most professionals know right behavior from wrong behavior, yet many influences are exerted on the life care planner when faced with insurance referrals, client advocacy, biased information provided by an attorney, and so on (Banja, 1994). The attorney, for instance, is hired as an advocate for one side of the case or the other (i.e., plaintiff vs. defense); however, the life care planner is ethically bound to be an objective professional who develops a future care plan based on the client’s needs regardless of which side is paying the bill. It is especially relevant to clarify one’s role at the outset, which can be done in the form of providing a professional disclosure statement. Some professionals provide professional disclosure verbally and some by handing out printed information fact sheets or statements about the role and function of the life care planner and what the person with the disability can expect from an evaluation. For example, in personal injury litigation, the life care planner might be retained as a defense expert to conduct an independent evaluation, or as a plaintiff’s expert to provide life care planning opinions without any expectation of implementation. In either instance, disclosure of the life care planner’s role at the beginning of a case will help to minimize potential problems due to a lack of the client’s understanding or expectations of services provided. The Standards of Practice for Life Care Planners state that “Life Care Planners are expected to . . . adequately advise clients of the role of the Life Care Planner.” Further, the standards state, “Each client should be fully informed about the role of the Life Care Planner” (IALCP, 2006). The code of professional ethics developed by the Commission on Health Care Certification (CHCC), under its principles and associated rules section, states that “life care planners are obligated to clarify the nature of their relationship to all involved parties when providing services at the request of a third party.” “[L]ife care planners retained by third party referral sources will clearly define through written or oral means, the limits of their relationship, particularly in the areas of informed consent and legally privileged communications, to all involved individuals” (CHCC, 2007, R2.3).

**Moral Values:** The previous dilemma regarding maintaining objectivity regardless of whether the plaintiff or defense side has retained the services of a life care planner can be further influenced by the life care planner’s view of the world. For example, a life care planner retained by the plaintiff may privately hold the belief that insurance companies are thieves that deprive people of their rightful recovery and there is a need to get as much as one can for the client. Conversely, a life care planner retained by the defense may believe that plaintiff’s attorneys get rich off the unfortunate circumstances of people with injuries and too many frivolous lawsuits are filed. These biases must be held in check with extra vigilance to ensure the life care planner provides a proper and objective evaluation and conclusion.
Rules or Standards of the Specialty Practice: In an attempt to rectify some personal biases, industries and professions have developed agreed-upon rules or standards to govern professionals’ behavior. Within the preview of the life care planner, there are many ethics codes and licensure laws that include rules regarding personal conduct. An example is the Standards and Code of Professional Ethics presented by the CHCC, which include rules of professional conduct that are “exacting standards which provide guidance in specific circumstances” (Standards and Code of Ethics, CHCC, 2007, available at www.ichcc.org/CHCC%20Standards%20and%20Guidelines%20Manual%202008.pdf). Another example mentioned earlier in this chapter is the Standards of Practice for Life Care Planners developed by the IALCP (2006).

General Professional Duties within Health Care

Many ethics guidelines overlap with each other, and others have significant differences in detail. However, there are several concepts that appear to apply across the board. According to Banja (1994, p. 86) and Blackwell (1999), the four commonalities are as follows:

- **Autonomy**: The client’s right to information and voluntary decision making.
- **Nonmaleficence**: The client’s right not to be harmed.
- **Beneficence**: The client will receive appropriate care or services.
- **Justice**: The client’s right to receive unbiased and nonprejudicial treatment.

In accordance with these constructs, Shaw and Sawyer (2000) further divide the concepts into counseling and forensic environments. Although written for the certified rehabilitation counselor (CRC), several precepts apply to the life care planner. With regard to ethical priorities, Shaw and Sawyer (2000) assert that professionals who practice in the counseling environment emphasize autonomy, nonmaleficence, and beneficence, whereas the forensic counselor emphasizes justice. They also observe that there are many other variations in roles that can constitute challenges. In general, confidentiality does not exist in the legal case, but failure to maintain confidentiality in a counseling relationship is a clear breach of ethics. Within the legal environment, the consultant must be accountable to the jurisdiction in which the case is pending; whereas in the counseling environment, one is responsible to the client. The counseling relationship is expected to be supportive, whereas in the forensic setting the consulting relationship is evaluative in nature.*

Further, based on the authors’ experiences and review of the literature, several scenarios are regularly observed. The first is associated by going **outside of the area of expertise**. This can take the form of offering medical opinions, life expectancy projections, or economic valuations (distinguishing between economic summaries from present value calculations) without adequate knowledge, education, or foundation. Life care planners unfamiliar with the forensic setting may be seduced into offering opinions outside their area of expertise that can damage their credibility and, in a roundabout way, damage the case. In the event of a plaintiff’s expert, this action also can cause harm to the client.

A second scenario is associated with the life care planner who develops a relationship with the attorney such that he or she becomes the **hired gun**. This relationship can be cultivated with

* For a discussion on this related topic, the authors suggest reading Barros-Bailey, M., Carlisle, J., Graham, M., Neulicht, A., Taylor, R., & Wallace, A. (2008). Who Is the Client in Forensics? Boise, ID: Authors (Contact Dr. Barros-Bailey at barrosm2002@yahoo.com).
either plaintiff or defense attorneys where potential future referrals may be forthcoming. Also, some attorneys may be adept at providing biased information to the expert, or inviting the expert to company parties or dinners just to form a more friendly or social relationship rather than a professional, working relationship. This statement is not intended to suggest that a life care planner must not have a working lunch with a referral source, but that the ethical consultant should be aware of influences that may shade his or her professional opinion or give the perception of something other than a professional, nonbiased working relationship. In one case, a neuropsychologist admitted in deposition that she had invited the attorney who retained her services to her home for a lunch and swim party and that they had attended several personal social events together. In another case, a rehabilitationist compiled a plan for an injured worker during the same time frame that she was also married to the client's attorney. A third example is the case of a rehabilitation counselor who publicly claimed he was going to “kick the defense counsel’s butt” in an upcoming trial. Although the reports and opinions by these professionals may very well have been appropriate and accurate, these statements and scenarios cast a shadow over the objectivity of the consultant’s work.

A third scenario is the potential for errors and miscommunication because of unclear expectations. This is particularly a problem for the inexperienced life care planner who may take instruction from the referral source rather than have clear boundaries about his or her role. In general, it is more effective for the life care planner to assertively outline for the referral source what he or she is or is not qualified to do. In these writers’ experience, it is better for the life care planner to clearly outline what the expectations are without relying on an attorney to direct the planner’s activity and potentially influence the life care planner’s objectivity.

Life care planners need to exercise due care by diligently reviewing case materials, seeking appropriate research and information, and following a process consistent with standards of the specialty practice that results in credible opinions and conclusions. Many consultants do not know what the established standards are (mostly because they are not members of the IALCP, are not certified in an area relative to the specialty practice, and do not attend conferences that offer life care planning topics), and therefore fail to follow the standards. It is reasonable to observe that a growing professional practice area, such as life care planning, will attract entrepreneurs who will learn through trial and error; however, this method of learning can damage the specialty practice unless effective intervention can occur, including education about accepted standards and procedures. (A wise person once said, if one learns by trial and error, they are likely to go on trial for one of their errors.)

Life care planners who are new to the specialty practice need to learn the specialty area (aka, literacy). Unfortunately, many beginning care planners are seriously deficient in this area. There is a specialized methodology, vocabulary, and knowledge base that must be learned and understood in order to be an effective life care planner. Also, different jurisdictions have different rules with regard to the life care plan. For example, in forensic and workers’ compensation areas, differences exist between state laws and regulations as well as between state and federal rules of evidence, and it behooves the life care planner to be cognizant of the differences within the various jurisdictions in which he or she provides services. A case that the authors reviewed involved a life care plan developed as a result of a breach of contract lawsuit. Upon review of the plan and consultation with the attorney, it became apparent that the life care planner was not aware of, or perhaps not familiar with, the rules specific to breach of contract law such that the plan included recommendations and costs that were not allowable under this particular jurisdiction, and this raised the question of accuracy of the life care plan and credibility of the life care planner who prepared it.

Another issue for the life care planner, even for the most experienced professional, is the potential problem with dual relationships (also related to dual roles or multiple relationships or roles). The term dual implies that the professional not only serves in his or her primary role, but also
establishes a second (or multiple) role with the client that may be viewed as harmful (Cottone, 2003). Although the issue of dual relationships historically has been a common topic in the ethics literature and is specifically addressed in the Standards of Practice for Life Care Planners (IALCP, 2006, reprinted in Appendix I), more recently the term multiple relationships has gained favor and implies two or more relationships with clients that could impair professional judgment or increase the risk of exploitation (AAMFT Code of Ethics, 2001, subprinciple 1.3, as cited in Cottone, 2003). In the practice of life care planning, it may be common for the expert to develop a future care plan while also providing some case management and coordination services. Indeed, the scope of practice/applications section of the Standards of Practice for Life Care Planners states that “the life care planner … may temporarily assume a peripheral role in the management of the case” (IALCP, 2006). Further, “[T]he life care planner must take care to keep the life care planning function separate from caregiver and case manager functions” (III.A). In other situations, life care planners may use counseling skills to facilitate information gathering and reduce the client/family’s psychological pain/anxiety when the real purpose is to obtain information to develop an expert opinion. In one example, a rehabilitation counselor proclaimed she was going to offer her services free to help an acquaintance in her divorce action because the acquaintance’s “s.o.b. husband” was (in her opinion) mistreating her friend.

Shaw and Sawyer (2000) urge the life care planner to clarify the relationship, purpose, and roles at the outset. In the literature, such disclosure is referred to as professional disclosure. Berens and Weed (2001) assert that a written professional disclosure statement signed by the client is preferred and one of the best ways to uphold the life care planner’s ethical obligation to inform clients of the process and ensure the client understands and gives consent to participate. The authors point out that professional disclosure such as this obviously applies to cases in which the life care planner has access to the client and his or her designee. In cases where the life care planner does not have client access or is serving as a consultant where no client interaction is allowed or expected, professional disclosure generally is not made or required. (See discussion at the beginning of this chapter regarding professional disclosure as promoted by the IALCP Standards of Practice and CHCC code of ethics.)

Example Ethical Brushes

Court rulings provide insight into ethical issues related to rehabilitation professionals providing expert testimony (Weed, 2000). For example, in Fairchild v. United States, 769 R. Supp. 964 (W.D. L.A., 1991), the court awarded a sum of $150,000 instead of the $1.74 million requested because the rehabilitation plan was prepared by someone not considered an expert. The so-called expert reportedly had attended two conferences on rehabilitation counseling and had prepared only 25 life care plans. No other training or education within the field of rehabilitation counseling or life care planning had been completed.

In Elliott v. United States, 877 F. Supp. 1569 (M.D. GA., 1992), the defense expert’s opinion was disregarded because the expert had been a rehabilitation consultant for only a short time, had completed only five life care plans, and had never implemented a plan. Additionally, the care plan reportedly did not include a physician contact or a conservative view.

In Norwest Bank, N.A. and Kenneth Frick v. K-Mart Corporation, U.S. District Court, Northern District of Indiana, South Bend Division (1997), the rehabilitation expert’s opinion with regard to future care was excluded in part due to a lack of medical foundation, as well as an inability to produce evidence that the methodologies used to forecast the cost of future care were based on anything other than personal experience.
In a workers’ compensation case, Maria Teresa Palmer, guardian ad litem for J. Carmen Fuentes v. W. Brent Jackson d/b/a Jackson’s Farming Company (I.C. No. 859146, North Carolina),

the life care planner did not travel to Mexico to evaluate plaintiff’s home circumstances and was not familiar with the medical facilities which may be in the vicinity of plaintiff’s home. Therefore, specific findings could not be made with respect to renovations which may be necessary to plaintiff’s dwelling or specific medical and durable supplies and equipment. Further, while plaintiff would benefit from placement in a brain injury facility, there is insufficient evidence in the record on which any specific finding may be made of whether an appropriate facility is available for plaintiff.

However, in light of the unique contribution of the published procedures of a life care plan, the workers’ compensation commission in this case concluded that a complete, current, and comprehensive life care plan would be beneficial.

In addition to published cases, there are other examples based on deposition testimony that are not readily available to the general reader. At least two recent cases reveal life care planners who admit no previous education specific to life care planning, few or no publications related to life care planning in their libraries, and no membership in professional organizations specific to life care planning. When asked about certification, at least one of the individuals claimed she does not need to be certified as a life care planner since she has years of experience and is certified in a related field. However, further examination of her credentials revealed she achieved certification as a case manager (CCM) and rehabilitation counselor (CRC) at the time the respective certifications were initially offered. Therefore, it may be presumed the individual was actually grandfathered in (i.e., took the certification exam but did not have to pass it in order to become certified).

Other examples of deponents’ testimony include those that express claims that life care planners are only serving an administrative function where they, similar to a secretary, simply record what someone tells them (see also Weed, 2002, and Weed & Johnson, 2006, for many more examples). At the other extreme is the professional (who is not a physician) who asserts that he or she can develop a complex life care plan without consultation with medical or treating professionals (if he or she has access to them). Or a physician that develops a life care plan, including case management, nursing, vocational, and psychological opinions, without adequate corroborating foundation.

As noted in the Weed (2002) article, the competent life care planner is neither an administrative recorder nor a know-it-all. A better analogy may be a general contractor or one who knows the big picture and which questions are relevant to ask of which professionals while building the care plan from a sound foundation to a completed comprehensive structure.

Suggestions for Success: Global

In order for the life care planning specialty practice to thrive and expand, it is incumbent upon each individual life care planner to assume control and responsibility over his or her actions and to practice within the ethical boundaries of the industry. Some suggestions to enhance the life care planner’s ethical practice include the following:

- Join a professional organization specific to life care planning that includes ethics and standards of practice (e.g., IALCP). Belonging to organizations that primarily are nursing, rehabilitation counseling, or related professions are useful but may not be helpful
for specific issues associated with providing an ethical foundation in life care planning. Professional organizations specific to life care planning also offer a process by which life care planners can be held accountable to ethics and standards within the industry.

- Consider certification as a life care planner or become certified in an area related to life care planning. (Another option is to become a fellow of the IALCP.) Although it is a voluntary process, certification affirms that the professional has completed the requisite education, experience, and training and has passed an exam that demonstrates he or she possesses a minimum competency to provide services. Also, certification offers a process for ethics complaints. Having this process will assist the life care planner in maintaining a continuing focus on life care planning professional ethics and standards of practice specific to the industry.

- Follow established standards of practice and ethics (see appendices at end of book) published by the IALCP or other organizations specific to life care planning.

- Expand one’s knowledge base by attending conferences, summits, and specialty training specific to life care planning. Not only will the life care planner be kept current on the industry and acceptable practices (this is especially true if the consultant is not certified and has no continuing education requirements), but also leaders in the field will become part of his or her professional network.

- Subscribe to the *Journal of Life Care Planning* to stay current with contemporary issues in life care planning. (Available by contacting the publisher at 706-548-8161 or www.rehabpro.org/ialcp/journal.)

- Be active in the specialty practice. Join a committee for program planning, offer an article to the *Journal* or other relevant publications, or conduct or participate in research projects, for example, do something that will enhance life care planning and give back to the profession.

- Develop a protocol for disclosing to clients the various role(s) one might assume during the life care planning process.

### Suggestions for Success: Malpractice Insurance Related

The following suggestions were offered by National Professional Group, a malpractice insurance carrier, as cited in Weed et al. (2003, pp. 47–54). Although there are many overlapping topics, these are specific to avoiding ethical brushes with insurance claims.

- **Role with Account:** It is very important for hiring parties to clearly define the rehabilitation professional’s role and the type of evaluation or services being requested. It is preferable that these assignments be in writing.

- **Role with Client:** In cases where the consultant is hired by the insured party’s insurance carrier, professional disclosure must be made with the client and documented. The client must clearly understand the role of the consultant (e.g., to evaluate and assist the client with return to work, to case manage, or to develop a life care plan).

- **Written Documentation:** Many times the individual retaining the consultant may send a cursory retention letter outlining services requested. If not, it is incumbent for the consultant to get the necessary information verbally and follow up with a written confirmation to the hiring party.

- **Scope of Service:** Misunderstandings can develop over the scope of service. Thus, the more accurate the consultant’s documentation, the easier it is for a review committee or court to determine that the consultant acted appropriately.
Objectivity: The consultant must remain objective and unbiased in the delivery of services and shall not accept assignments if the individual who retains the consultant’s services attempts to influence the objectivity or outcome of the evaluation.

Contingency Fees: Consultants shall not provide services on a contingency basis to prevent the appearance that the consultant’s objectivity has been compromised at the prospect of financial gain.

Professional Fees: If the consultant provides trial and deposition testimony, he or she will be cross-examined about professional fees. Fees should be standard for the services provided; exorbitant fees will compromise the consultant’s credibility.

Communication: Proper communication at all levels is critical, and it is important for the consultant to provide a clear explanation of what should be expected and the possible outcomes. Other areas of communication include ongoing progress, internal communication, external communication, fees, and fee structure. The consultant shall not tell a client that a coworker made an error that caused the client’s injury or that the client’s problem could be worse.

Terminology: Professionals have their own set of technical terminology, and it is easy to forget that laypeople may not completely understand those terms. It is important for professionals to use common terminology with clients and maintain a speaking manner that ensures the client is treated respectfully and that he or she understands what is being communicated. Provide booklets and pamphlets to encourage greater understanding among clients and to encourage clients to ask questions to avoid any confusion. Remember, the better the client is educated and understands the role of the consultant, the lower the chances for lawsuits.

Colleague Collaboration: Quality collaboration helps detect areas of weakness in one’s practice. An outside quality assessment from another professional perspective may help the consultant to recognize procedures that could be changed to benefit service delivery and potentially protect himself from malpractice claims.

Continuing Education: It is important to keep abreast of new advances in technology within a particular area of specialty. Therefore, continuing education, whether required by any board or certification, is crucial.

Common Sense: Good common sense always is valuable in dealing with people referred for services and in maintaining good solid business practice.

Records: Do not alter a client’s record under any circumstances. Be careful about documentation and include the rationale for services or why in some cases a decision is made not to do something. Make sure to follow one’s own policies and procedures in every case.

Client Respect: Always treat clients properly and with respect. Never let the client feel he or she is unimportant or insignificant.

Consent: Always obtain written informed consent from the client.

Confidentiality: Be extraordinarily careful about confidential information. Oftentimes, rehabilitation professionals may be in an environment where unsuspecting family members or others may overhear the content of information that potentially could be damaging to the client. Be aware of and comply with HIPAA guidelines as they apply to the practice of life care planning.

Conclusion

In summary, the case examples described earlier in this chapter underscore the need to adhere to ethics and standards that are agreed upon and followed by competent life care planning professionals.
Ethics statements represent judgments about morality, what is right or wrong, good or bad, and how to deal with everyday situations. All possible situations or scenarios cannot be anticipated, and the life care planner with a solid ethics foundation will be able to approach those situations in a more ethical or correct manner, which likely will preserve his or her reputation and credibility while also minimizing the potential for ethics breaches or malpractice claims. As time passes, ethics statements seem to become more important. The Code of Professional Ethics for Rehabilitation Counselors (CRCC, 2001, and, at the time of this edition, under revision for expected release in 2010) essentially doubled in length from the previous code in an apparent continued attempt to address more issues based on a combination of ethics complaints, the evolution and growth of the rehabilitation industry, and anticipated problems. Additionally, continuing education requirements to maintain CRC certification historically were based solely on rehabilitation-related topics requirements; however, effective July 1999, standards for recertification were made stronger in the area of ethics, and now 10 clock hours of ethics continuing education are required for CRC recertification.

On a related issue, professional nurses are bound to a code of professional practice, promulgated by the American Nurses Association (ANA). Similarly, certified case managers (CCM) sign an agreement to practice under the code of professional conduct published by the Commission for Case Manager Certification (Patricia McCollom, personal communication, September 6, 2002). Life care planning professionals undergoing Daubert challenges or malpractice claims often will be held accountable to existing standards of practice regardless of whether they are certified or belong to an appropriate organization. On the other hand, if a life care planner commits an ethical violation but is not certified in a professional area related to life care planning, the certification board has no jurisdiction even if a complaint is lodged. Certainly, life care planners will face ethical dilemmas and having knowledge and awareness of the accepted and published ethics as well as a network of knowledgeable colleagues to call upon to work through problems will reduce the risk of serious error. Indeed, knowledge reduces risk and fear.

A visual image one might keep in mind with regard to ethics is if the news crew from 60 Minutes showed up at your office for an interview, would you feel comfortable with your opinions? Or, is your life care plan written so that experts from within the life care planning specialty practice will conclude that your work is reasonable and proper? Did you conduct yourself in a way that you would expect others to act toward you? If you can answer yes to these questions, perhaps many pages of ethics statements will be unnecessary.

In closing, ethics is a critical area for life care planners and one that has evolved concurrently with the evolution of life care planning itself. With the advent of electronic communications, new considerations regarding dual (or multiple) relationships, HIPAA regulations regarding client health information and confidentiality, and other contemporary events in life care planning, it is imperative for life care planners to regularly review their respective codes of ethics and standards of practice to maintain an ethical focus and remain current on ethical service delivery.

References


Chapter 29

Reliability of Life Care Plans: A Comparison of Original and Updated Plans*

Amy M. Sutton, Paul M. Deutsch, Roger O. Weed, and Debra E. Berens

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Introduction

This exploratory study examines the reliability of life care plans by comparing original and updated versions of 65 life care plans. The 65 anonymous participants, with varying diagnoses and backgrounds, each had an original and updated life care plan developed for them. The time between the original life care plan and the updated plan ranged from 1 to 5 years, with an average of

1.8 years. All life care plans were provided by two experienced and board-certified life care planners who follow the established standards and procedures within the industry, and the samples chosen included all applicable cases within the 5 years preceding the time the study began in the spring of 2002. The home/facility care and routine medical care subsections of the life care plans were compared by assigning current year (2002) costs to the projected needs and then analyzing using a chi-square statistical analysis. These subsections were selected since virtually all cases had entries in these two areas. Results reveal that the chi-squares for both home/facility care and routine medical care between the original and updated life care plans were found to be not significant at the .05 level. These results provide further evidence of reliability over time of life care planning in the areas of home/facility care and routine medical care when using established procedures.

Reliability of Life Care Plans: A Comparison of Original and Updated Plans

To formulate an accurate depiction of an individual’s current and future health care needs, a life care planner must integrate hundreds of pieces of information. This requires commitment to a consistent and unbiased process and reliance on fact, research, and expertise to formulate a plan that can predict future needs with accuracy and reliability. A life care plan has been defined as “a dynamic document based upon published standards of practice, comprehensive assessment, data analysis and research, which provides an organized, concise plan for current and future needs with associated costs, for individuals who have experienced catastrophic injury or have chronic health care needs” (combined definition, 1998, as cited in Weed, 1999, p. iii).

According to Deutsch (1994), the development of life care plans came as a response to multiple professional concerns. First, persons with disabilities and their families need a concise summary to plan for future needs. Second, a communication tool is needed with which all parties involved in a catastrophic injury case will be informed of these needs. Third, a planning approach in the field is needed rather than the traditional reactionary approach. Fourth, through the life care planning process, disabilities could be broken down into basic components to more carefully identify complex concerns. Finally, concerns specific to the person with a disability and his family, such as geographic location, preferences, and personal goals, need to be incorporated into a plan of care to ensure a realistic implementation. In response to these concerns, life care plans have become important tools in a number of different settings, including complex disease management, establishing insurance reserves, workers’ compensation case management, health insurance managed care, resolution of personal injury claims, and facilitating client and family understanding of the long-term costs and effects of injuries and illnesses (Weed, 1994). To meet the demands of preparing such a plan, certain skills provided by life care planning training and certification programs, in combination with expertise in numerous areas, are recommended. Brodwin and Mas (1999) outline 12 areas of expertise: medical aspects of disability, foundations of rehabilitation counseling, case management, psychosocial aspects of disability, behavioral interventions, preventative care, equipment and supplies, educational and vocational implications of disability, assessment and evaluation, community resources and services, rehabilitation facilities, and expert witness testimony. Similarly, the published life care planning model includes several subsections that should be addressed in a life care plan in order to provide the most comprehensive plan possible. Subsections include the following (Weed, 1998):

- Projected evaluations
- Therapeutic modalities
Reliability of Life Care Plans: A Comparison of Original and Updated Plans

- Diagnostic testing
- Wheelchair needs, accessories, and maintenance
- Aids for independent functioning
- Orthotics
- Home furnishings and accessories
- Medications and supplies
- Home/facility care
- Routine medical care
- Transportation
- Health and strength maintenance
- Architectural renovations
- Potential complications
- Aggressive treatment or surgical intervention
- Orthopedic equipment needs
- Vocational planning

It is from this knowledge foundation that life care planning professionals are able to make future projections and confer with multiple care providers to develop the most accurate care plan possible.

As the field of life care planning has become more defined through training programs, publication, and widespread use, a need for research that examines the reliability and validity of life care plans has emerged (Countiss & Deutsch, 2002). Although much research involving case management exists and numerous articles have been written on life care planning, little research has been conducted specifically to evaluate the reliability and validity of life care plans. Reliability is expected from a life care plan due to its influential role in the clients’ future care management. Demonstrating reliability of life care plans also provides a foundation for establishing predictive validity. Due to the comprehensive and predictive nature of a life care plan and the extreme variability of the population served (e.g., varying diagnoses, age differences, available support systems, treating professionals, etc.), it is a challenge to measure the reliability of a life care plan (Deutsch, 2002). However, one study, by McCollem and Crane (2001), surveyed 10 clients with spinal cord injuries who had a life care plan developed for them several years prior to the study. The authors concluded that a clear consistency was found between projected and actual needs. In comparison, the study presented in this article measures life care plan reliability by evaluating existing life care plans of clients who, for a variety of reasons, have had a second life care plan written 1 to 5 years after the first plan was completed. These second life care plans were updated and revised versions of the original life care plans based on the status of the client and the interventions, services, and complications that arose following the original life care plan. By comparing the two plans and determining what had been revised, a measurement of change can be generated that provides professionals with information regarding those areas of a life care plan that likely are not subject to change and those areas that are sensitive to the passage of time. The two major areas analyzed in this study include home/facility care and routine medical care. These areas were targeted for two reasons: (1) they are common among virtually all life care plans and (2) they comprise the bulk of the needs that can be tied to measurable data and costs in nearly every life care plan. Based on a review of the literature, the following two hypotheses were formulated:

- **Hypothesis 1**: There will be no significant difference between the home/facility care costs of the original life care plans and the updated life care plans.
Hypothesis 2: There will be no significant difference between the routine medical care costs of the original life care plans and the updated life care plans.

Method Participants
A total of 130 life care plans from 65 anonymous cases were obtained and analyzed. Each case had an original life care plan (LCP 1) and an updated life care plan (LCP 2). The diagnoses for the participants included a wide range of traumatic as well as chronic medical conditions such as acquired brain injury, spinal cord injury, birth defect, and pain syndromes. There were 44 males and 21 females of various ethnic backgrounds. Ages of participants ranged from 2 to 75, with an average age of 28 years. The years between LCP 1 and updated LCP 2 were 1 to 5, with an average of 1.8 years. The life care plans were obtained from two experienced and certified life care planners in private practice, both of whom maintain a policy of strict adherence to published life care planning processes, procedures, and standards. Due to the limited number of cases available, all life care plans that fit the criteria were included in the study. To maintain anonymity to the researcher, all life care plans were purged of names and replaced with case numbers. The study methodology was submitted to the Institutional Review Board (IRB) of Georgia State University for approval of human subjects research. Approval was obtained before the study was initiated.

Procedure
Once all life care plans were reviewed, the projected needs outlined in the in-home care and routine medical care subsections were extracted from each. A master list of all projected needs was generated, and costs were assigned to the needs. The costs were obtained from a database of current health care costs from one specific region in the southeast United States during one specific time frame (2002). By using a consistent economic reference, all plans shared a common denominator with which they could be compared. As an example, the need for a home health aide was included in several life care plans, and an hourly rate for home health aide was determined from the database. Once all needs were assigned a cost, each life care plan was again evaluated. If a life care plan recommended a home health aide 5 days a week for 3 hours a day, 15 hours was multiplied by the cost from the database and then multiplied by the number of weeks per year the client was to receive the service. Finally, a total cost per year for the home health aide recommendation was determined. This methodology was followed for each recommendation in the home/facility care and routine medical care subsections until a complete list of annual costs for the two subsections was obtained. The costs were then totaled to create an overall annual cost for the subsection comprising the variables Home/Facility Care Costs 1, Home/Facility Care Costs 2, Routine Medical Care Costs 1, and Routine Medical Care Costs 2.

While executing the aforementioned method, a number of challenges became apparent. First, many recommendations were presented as a range rather than a specific number. For example, follow-up visits with a neurologist were recommended four to six times per year. For the purposes of data analysis, recommendations were averaged in each case. The entry for neurologist visits from the previous example was then recorded as five times per year. Second, some of the recommendations were reported as less frequent than annually. For example, if magnetic resonance imaging (MRI) was recommended once every 1 to 2 years, it was averaged on a yearly basis that equates to 0.66 MRIs per year. As each life care plan is a unique plan that is tailored to the individual, other challenges materialized. Often, life care plans make recommendations for time periods such
as “from age 20–30, age 31–55, and age 56 to life expectancy.” For this study, one specific time frame was chosen so that data analysis was consistent across all plans. The time frame in the study was determined to be the first year immediately following the updated life care plan regardless of when the original life care plan was created, because some recommendations would have been concluded before the second plan was completed. As such, recommendations that were one time only (i.e., urology consult—one time only) were included in the annual calculations only if the recommendation was to occur in the first year following the second life care plan. This eliminated the concern that certain recommendations in the first plan may have been completed before the second plan was developed, thereby creating an inaccurate discrepancy in the cost between plans. Finally, many life care plans offer multiple options within a subsection. For example, within the home/facility care subsection, Option 1 commonly relates to the client being cared for at home and Option 2 for the client to be cared for in a long-term-care facility. Statistical problems with averaging or totaling these different options, and the fact that some plans did not include both options, consequently led to the decision to consider only Option 1 in this analysis. With these procedural problems addressed, the data corresponding to the previously identified variables were analyzed using the Statistical Package for the Social Sciences (SPSS) and Excel. Three researchers, to ensure accuracy, performed the data extraction and data entry.

Results

Data points for the dependent variables did not fall into a normal distribution. Consequently, parametric tests such as analysis of variance, $t$-test, and repeated measures could not be used. Figures 29.1 and 29.2 demonstrate this lack of normal distribution with the example of in-home care and routine medical care for the original life care plans (LCP 1). In particular, the distributions for each of the

![Figure 29.1 Distribution of actual costs for home/facility care in ranges for original life care plans (LCP 1).](image-url)
variables were skewed to the left, indicating that the majority of costs fell in lower-cost portions of the distribution, rather than the higher-cost ends. For this reason, the chi-square goodness-of-fit test is the most appropriate means of analyzing data that do not meet the normal distribution criteria. This test compares distributions and determines significant differences between the distributions. Costs were categorized into 10 bins according to frequency, and these were then analyzed. It was necessary to use these 10 categories due to the large range of the variables as well as the fact that absolute zeros were present in two of these ranges (see Table 29.1). The chi-square for home/facility care variances between LCP 1 and LCP 2 was not significant at the .05 level (chi-square = .85, df = 9, p > .05). The chi-square for routine medical care variances between LCP 1 and LCP 2 also was not significant at the .05 level (chi-square = 5.04, df = 9, p > .05). The critical value for both

![Figure 29.2](image)

**Figure 29.2** Distribution of actual costs for routine medical care in ranges for original life care plans (LCP 1).

<table>
<thead>
<tr>
<th>Variable</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home/Facility Care (LCP 1)</td>
<td>0.00</td>
<td>378,870.00</td>
<td>101,059.60</td>
<td>105,137.57</td>
</tr>
<tr>
<td>Home/Facility Care (LCP 2)</td>
<td>0.00</td>
<td>365,512.00</td>
<td>104,645.50</td>
<td>102,713.20</td>
</tr>
<tr>
<td>Routine Medical Care (LCP 1)</td>
<td>80.50</td>
<td>13,429.00</td>
<td>3212.75</td>
<td>29,13.67</td>
</tr>
<tr>
<td>Routine Medical Care (LCP 2)</td>
<td>215.00</td>
<td>16,795.00</td>
<td>3566.89</td>
<td>3354.20</td>
</tr>
</tbody>
</table>
hypotheses was set at 16.919. These data indicate that differences between original and updated life care plans are not significant.

**Discussion**

Any number of complications or technological advances, which are relatively impossible to predict and plan for, may affect a client’s prescribed needs and components of the life care plan. Some degree of change, therefore, is entirely probable. However, an overall reliability is expected from a life care plan due to the large psychosocial, medical, and financial investments entrusted in the plan. The results of this study indicate that for the two subsections analyzed, life care plan needs are resistant to the effects of time and therefore are reliably predictive. Although projections made by the life care planner cannot be specifically validated by this study, projections remained consistent even after 1 or more years had passed. In order to specifically validate life care plan entries, the various recommendations relied upon would be subject to further research design and analysis across multiple life care planners. However, it is clear from these data comparisons of LCP 1 and LCP 2 that agreement on entries implies that over time recommendations were appropriate. It is also clear that the results of this study alone do not imply the reliability of all life care plans, especially for uncertified professionals or those who fail to use established procedures; however, the study can be a springboard from which more research can be conducted. Another interesting finding is that total costs for the subsections home/facility care and routine medical care tend to fall in the less expensive direction of the distributions. This finding supports the proposition that life care plans are needs driven rather than cost driven, with a tendency toward conservative estimates of expenditures as opposed to liberal or inflated costs. One limitation of the study is that there were only two life care planners providing cases for review. Additionally, both of the life care planners are considered experts in the field and may not be representative of all life care planners. Both assert that they remain consistent in their approach and committed to following published standards and methodology. Similar studies in the future will be more valuable if a larger sample of certified life care planners with varying levels of experience who also adhere to the published standards of practice participate. Future research should also include a large enough sample to evaluate plan reliability based on diagnoses, gender, and age, among other factors. Other studies may take a similar approach as this investigation but look at other subsections of the life care plan, particularly if enough samples can be identified for similar disabilities or gender, and to distinguish differences between children and adults.

Although a few of the updated life care plans in the study had marked variations from their original life care plans, these variations did not affect the overall results of the study. For future research, these cases could be investigated from a qualitative perspective to determine why these updated plans reflected greater change. Change may occur for any number of reasons, such as the development of another medical condition, complications due to unforeseen events, failure to comply with the life care plan, changed physician recommendations, and so on. Finally, a retrospective study to examine validity by determining what services were actually provided, what was needed, and what was projected would be valuable to determine recommendation validity.

This study underscores the effectiveness of future care forecasting where individual needs are identified and comprehensive treatment recommendations are documented when based on published
models and procedures of life care planning. It appears that life care planners will benefit their clients by adopting a standardized approach to developing life care plans that is based on existing protocol designed for this specialized industry.

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Chapter 30

Americans with Disabilities Act (ADA): From Case Law to Case Management and Life Care Planning Practice

Lewis E. Vierling

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Introduction

The Americans with Disabilities Act (ADA) of 1990 is undergoing a major transition, particularly as a result of the amendments of 2008. The purpose of this chapter is to provide a framework for understanding the transition the ADA is going through, especially in defining what it means to have a disability under the Act. The rehabilitation professional, whether case manager, life care planner, or vocational expert, is encouraged to have an understanding of this transition to best serve as an advocate for individuals with disabilities.

There has been a transition in the intent of ADA as well. Congress’ original intent was that the Act should provide a clear, comprehensive mandate for the elimination of discrimination for individuals with disabilities. At the time of enactment, they suggested that the ADA should be a civil rights law that is inclusive and broadly interpreted. However, through its review by the Supreme Court, decisions have evolved to a very narrow interpretation. In fact, the Court stated in the *Toyota v. Williams* decision that the ADA should be “interpreted strictly to create a demanding standard for qualifying as disabled” (Vierling, 2002d).

The court’s struggle with the definition of disability under the law is not necessarily a new issue. A recent search of the U.S. Code, which is the official compilation of federal statutes that are currently in force, identified 67 places where disability is defined. Of the 67 places, there were 26 references to definitions contained in other code sections. However, the definition of disability under the ADA has evolved from other disability legislation that had been consistently applied in the court system until the ADA was challenged in court. As a result of these decisions, advocates have introduced and passed legislation to restore the protection Congress intended. The ADA Amendment Act (ADAAA) signed by President Bush on September 25, 2008, was the result of those efforts and will be discussed in the context of the transition of the ADA.

The unique nature of this transition is the more than 16 years of developing case law surrounding the 1990 ADA. The ADAAA was effective January 1, 2009. It is being speculated that the range of coverage and protection for individuals with disabilities will expand significantly. While it is essentially effective immediately, it is expected that areas of the ADAAA will be challenged, resulting in new case law. The case law regarding the ADAAA will take several years to develop in the court system, thereby extending this already protracted transition.

*Bringing an ADA Perspective to the Practice of Case Management and Life Care Planning*

Catastrophic injury/illness does not necessarily equal disability under the 1990 Americans with Disabilities Act (ADA) as has been interpreted by the courts. After more than 16 years of enforcement and litigation, the courts have struggled with the problem of proving whether an individual has a covered disability under ADA, and therefore is protected against discrimination. In fact, in
the words of a judge at the First Circuit Court of Appeals in a written decision, the word *disability* is considered to be a “term of art” (Heyburn, 2002). This clearly demonstrates the difficulty and subjectivity that have developed in defining disability under ADA.

Even though four prominent pieces of legislation were influential in forming the basis of ADA, there has been no unified consensus concerning the meaning of a disability. For example, the Rehabilitation Act of 1973 (PL 93-112) provided for vocational rehabilitation services on a national scale to qualifying persons with disabilities. It also mandated employment of persons with disabilities in federal government jobs and most federally funded programs. Section 504 of the Rehabilitation Act, one of four sections, is considered to be “the underpinnings for the ADA” (Blanck, 1999). In summary, the section provides that people with disabilities have equal employment opportunities and prohibits the exclusion based on disability of otherwise qualified disabled persons from participation in any program or activity receiving federal financial assistance.

The Education for All Handicapped Children’s Act, PL 94-142 (updated by PL 105-17 and termed the Individuals with Disabilities Education Act, or IDEA), had a strong influence in propelling the disabilities rights movement forward and was designed to educate and train children with severe disabilities who are likely to be placed into institutions (Blanck, 1999). Another important piece of legislation was the 1978 amendments to the Developmental Disabilities Assistance and Bill of Rights Act (PL 95-602). This legislation not only established a nationwide system of protection and advocacy, but also created a program of comprehensive services for persons with developmental disabilities. The Fair Housing Amendment Act of 1988, 42 USC 3601-3631, made it illegal to discriminate on the basis of disability in housing, real estate transactions, zoning, and the operation and services of apartments and condominiums. Despite the fact that the road to ADA has a long legal history that includes over 27 pieces of legislation (NCD, 1997), there was still no social consensus regarding what it means to be disabled by 1999 (Diller, 1999).

Each year, the U.S. Supreme Court grants review to approximately 80 to 90 cases. The Supreme Court has heard and provided decisions on 21 specific ADA cases since the law went into effect through the 2007 to 2008 term. They have reviewed numerous other ADA cases from lower courts and opined that the lower courts’ decisions should stand, referred to as *stare decisis* (let the decision stand). Five of the 21 cases have dealt with clarifying the definition of disability. As interpreted by the Supreme Court, however, it has been absolutely clear that a medical diagnosis is not automatically considered to be a disability under the ADA. There has been an inherent paradox in how the courts have opined regarding the definition of disability. For example, individuals who are severely ill or disabled and unable to perform the essential functions of a job under Title I of ADA have not been protected. If an individual can do a particular job, he or she has not been considered disabled and therefore is not protected (Vierling, 2000a, 2000b, 2000c, 2000d, 2001a, 2001b, 2002a, 2002b, 2002c, 2002d).

**National Council on Disability and ADA**

In 1984, Congress established the National Council on Disability (NCD) to make recommendations to promote equal opportunity for persons with disabilities. In 1986, the NCD issued a report, “Toward Independence,” recommending that a comprehensive law be passed. The NCD issued a follow-up report in 1988 entitled “On the Threshold of Independence,” and the council published the draft bill of what was to become the ADA. A revised ADA bill was sponsored by Senator Tom Harkin and Representative Tony Coelho in 1989. President George H. Bush signed into law on July 26, 1990, the ADA before an audience of more than 3000 American leaders from
disability rights movements gathered on the White House lawn (Editor’s note: The author of this chapter was an invitee).

**ADA Definition of Disability and the Five Titles**

Disability, as defined in the ADA, is a physical or mental impairment that substantially limits one or more major life activities; a record of such impairment; or being regarded as having an impairment (as cited in Vierling, 2002d). The Equal Employment Opportunity Commission (EEOC) issued guidelines for complying with the ADA law. Within the EEOC’s regulations was an expansion of the definition that was within the ADA legislation. The Supreme Court, however, has narrowed that definition considerably.

The ADA took effect July 26, 1992, 2 years after the signing by President George H. Bush. Title I of the ADA prohibits private employers, state and local governments, employment agencies, and labor unions from discriminating against qualified individuals with disabilities in job application procedures, hiring, firing, advancement, compensation, job training, and other terms, conditions, and privileges of employment. The following is a review of each major emphasis under all five titles and is not meant to be a full description of Titles I through V (Vierling, 2002d):

1. Title I: Employment—affected employers having 15 or more employees
2. Title II: Public services—affected all activities of state and local governments, with Subtitle B applicable to transportation provided by public entities
3. Title III: Public accommodations and services operated by private entities—affected privately operated public accommodations, commercial facilities, and private entities offering certain examinations and courses
4. Title IV: Telecommunications—affected telecommunications relaying services and closed captioning
5. Title V: Miscellaneous provisions—including the relationship of ADA to other laws, the requirements for technical assistance, the role of the Architectural and Transportation Barriers Compliance Board, the coverage of Congress, and some additional definitions regarding coverage

**ADA Restoration Act**

Because of the Supreme Court decisions limiting the scope of the ADA, there have been several attempts to restore the law’s intended coverage by proposing numerous legislative changes through Congress. Twin versions of an ADA Restoration Act, S. 1881 and H.R. 3195, were introduced into Congress. The Restoration Act sought to address the problems with the ADA’s definition of disability by eliminating the “substantial limitation” on a major activity requirement and prohibiting courts from considering whether a person uses mitigating measures.

The NCD concluded in a series of comprehensive reports, *Righting the ADA* (2002–2004) that the Supreme Court’s interpretation of the definition of disability altered the scope and coverage of the ADA. They concluded that “the majority of people with disabilities have no federal legal recourse in the event of discrimination, particularly in instances of employment discrimination.” It was hoped that the Restoration Act would restore Congress’ original intent.
when it enacted the ADA in June 1990, that it should be a civil rights law that is inclusive and broadly interpreted.

**The ADA Amendments Act of 2008**

A compromise bill, the ADA Amendments Act of 2008, or ADAAA (S. 3406), was passed by both houses of Congress and on September 25, 2008, signed by President George W. Bush. The ADAAA significantly broadens the scope of protection intended by Congress to be available under the 1990 Act, but had been severely limited by Supreme Court decisions over the last 10 years.

The purpose of the ADAAA was stated in the first line of the bill, “to restore the intent and protections of the Americans with Disabilities Act of 1990.” The ADAAA was effective on January 1, 2009. The Act retains the ADA’s basic definition of *disability* as an impairment that substantially limits one or more major life activities, a record of such an impairment, or being regarded as having such an impairment. In terms of who is covered under the ADAAA, employers with 15 or more employees are going to be required to comply with the new amendments.

The ADAAA focus specifically on several main issues that have been narrowly interpreted by the courts. First, and most important, is the definition of disability. It retains the ADA’s basic definition, but changes the way the statutory terms are interpreted (i.e., substantially limited and major life activities). It also addresses the controversial decisions regarding the use of mitigating measures. It clarifies that an impairment that is episodic or in remission is a disability if it would substantially limit a major life activity when active. The new law addresses “regarded as” cases and whether the medical conditions are transitory and minor and whether reasonable accommodations should be provided to those individuals determined to be regarded as disabled. Finally, Congress emphasized that the definition of *disability* should be interpreted broadly.

Congress found that the current EEOC ADA regulations defining the term “substantially limits” as “significantly restricted” are inconsistent with congressional intent by “expressing too high a standard.” Therefore, EEOC has been instructed to issue new regulations redefining “substantially limits” from its current definition (“significantly restricts”) to comply with the Act’s broader view. Various other agencies such as the U.S. Attorney General’s Office and the Department of Transportation have been instructed to issue revised regulations to serve as guidance in responding to the ADAAA.

Other changes include expanding the definition of *major life activities* (MLA) that have been delineated in the regulations by the EEOC and many activities that have not been recognized by the EEOC, for example, reading, bending, and communicating. The second list of major life activities in the new law includes those identified as major bodily function, for example, functions of the immune system, normal cell growth, and digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions.

The ADAAA took a major departure from the five Supreme Court decisions related to considering the use of mitigating measures in determining whether an individual is disabled under the law. The new law states that mitigating measure (medications, prosthesis, medical supplies, equipment, and other auxiliary aids or services) should not be considered in the determination of whether an individual has a disability. The exception is that prescription eyeglasses and contact lenses may still be considered in assessing whether an individual is “substantially limited.” The ADAAA also states that an impairment that is episodic or in remission is a disability if it would substantially limit a major life activity when it is active.
Under the ADAAA, Congress has declared that it provide a “clear and comprehensive national mandate for the elimination of discrimination” and “clear, strong, enforceable standards addressing discrimination” by reinstating a broad scope of protection. The law also defined the standard for being “regarded as disabled.” That standard is defined as “establishing that the individual has been subjected to action prohibited under the ADAA because of an actual or perceived physical or mental impairment whether or not the impairment limits or is perceived to limit a major life activity.” In “regarded as” cases, employers do not need to provide reasonable accommodation to individuals who are considered to be regarded as or perceived to be disabled. The individual must now show that the employer perceived them as having a physical or mental impairment, not that the impairment substantially limits a major life activity. This is a major change from the case law surrounding “regarded as” cases.

The amendments also state that “regarded as” claims cannot be based on impairments that are transitory and minor. *Transitory* is defined as an actual or expected duration of 6 months or less.

It is clear that the expanded definition of disability under the amendments will have an increasing effect on the number of individuals who will be considered “protected” by the new law. It is being assumed that there will be less emphasis on the assessment of whether an individual is “qualified” under the law and more on whether an employer had unlawfully discriminated against that individual. Some have speculated that with the all-expansive list of what qualifies as MLAs, the employer would be better off to assume that an impairment qualifies as a disability.

Providing reasonable accommodations will become even more important for the employer. In doing so, the employer will need to consider not only the current effects of an impairment, “but also what the effects would be if the impairment were in an active state.” The employer will find it even more advantageous to engage in the interactive process. Employers should be prepared to engage either applicants or employees in conversations related to providing reasonable accommodations to qualified individuals to enable them to perform the essential functions of the job in question.

### Major Life Activities and the Burden of Proof

The five specific cases that have dealt with the definition of disability are *Bragdon v. Abbott; Sutton v. United Airlines; Murphy v. UPS; Albertsons, Inc., v. Kirkingburg; and Toyota v. Williams* (Vierling, 2002d). The precedent that has been established by the Supreme Court has been that there needs to be clear evidence to assist the court with a three-part analysis to determine whether a plaintiff has shown that he or she is substantially limited in a major life activity. After hearing the plaintiff’s evidence in his or her burden-of-proof phase, the court has applied the three-part analysis as follows (Vierling, 2002d):

1. The court must determine whether the plaintiff has an impairment under ADA.
2. It must identify the life activity on which the plaintiff relies in his or her case and determine if it constitutes a major life activity.
3. It must decide whether the impairment in question substantially limits the major life activity identified by the plaintiff.

It is important to note that the plaintiff must assert that he or she is substantially limited in a specific major life activity. Then it is apparent that the plaintiff must articulate with precision the impairment alleged and how that major life activity is affected by that impairment. In addition, the courts have considered a number of other specific factors in their decision-making process.
For example, when evaluating whether an impairment substantially limits a major life activity, the lower courts were guided by Supreme Court decisions to consider the nature and severity of the impairment; the duration or expected duration of the impairment; and the permanent or long-term impact or the expected permanent or long-term impact of, or resulting from, the impairment. However under the ADAAA, there will be less emphasis on the assessment process and more on whether the employer met its legal obligations.

The courts have required an individual assessment on a case-by-case basis. In this author’s opinion, this means that both a case management plan and a life care plan must specifically address issues that are related to the definition of a disability. Those issues have been clearly delineated by the EEOC following clarification by the U.S. Supreme Court. For example, as a direct consequence of the Sutton, Murphy, and Kirkingburg decisions (Vierling, 2002d), the EEOC issued instructions for field offices regarding the analysis of ADA complaints and addressing the use of mitigating measures in considering whether a person is disabled (EEOC, 1999). These instructions changed the procedure for field office staff investigating individual complaints and appeared in the Federal Register in June 2000. The instructions to field offices summarized and explained how the Supreme Court cases impact the process of charges filed under ADA. The instructions emphasized “the individualized analysis that must be used in determining a charging party has a disability as defined by ADA and whether a person is qualified” (as cited in Vierling, 2002d).

However with the new law, there will be less emphasis on the evaluation or assessment of a defined disability. It is unknown at this time what the new regulations will state, how the court decisions will view this process, and what case law will develop surrounding the assessment process.

Another important aspect of the developing ADA case law has been that individuals are protected under ADA, not specific disabilities. Therefore, the court has stated that each individual has to be evaluated on a case-by-case basis to determine if the individual has a disability and is therefore protected. But under the new amendments, there will be less emphasis on this inquiry and more on whether acts of discrimination occurred.

Understanding the Development of Case Law

Precedent versus Persuasive Authority

A distinction needs to be made between precedent versus persuasive authority. In a legal sense, a precedent is “an earlier decision relevant to a case to be decided” (Elias & Levinkind, 1999). Once a court decides how a law should be applied to a particular set of facts, this decision controls later decisions by that and other courts. It is only a precedent as to a particular set of facts and the precise legal issues decided in light of those facts. The more the facts of legal issues vary between two cases, the less the effect of the precedent. If the circumstances of a current case match an earlier one, the previous case is considered a precedent and binding on the court.

Persuasive authority, on the other hand, is not binding on other courts, but if a case contains an analysis of legal issues and provides guidance for any court referring to it, it has persuasive authority. Generally speaking, the higher the court level, the more persuasive a decision may be on other courts in similar types of cases.

In rendering an opinion, a court may apply the prevailing interpretation of similar cases to the case being heard in its court. These cases are said to establish a precedent. The principles that are derived from other court cases make up the body of case law applied in new cases. This is part of the legal tradition of common law.
As previously noted, applying the principles from an earlier decision is the doctrine of *stare decisis* (Vierling, 2002d). These principles are extracted from court decisions at a variety of levels. These decisions are pertinent to the field of rehabilitation. Case law further evolves as court cases are resolved.

**The Effects of Supreme Court Decisions on Lower Courts**

U.S. Supreme Court cases are precedent for all courts with respect to decisions involving the U.S. Constitution or any other aspect of federal law. Also, Appellate Court and Supreme Court cases are precedent with respect to future decisions by the same court. The U.S. Court of Appeals’ cases are precedent for U.S. District Courts within their 12 circuits, plus a Federal Circuit Court. Opinions of the U.S. District Courts are never precedent for other courts. However, the decisions may have persuasive authority on other district courts’ decisions. As noted previously, the higher the court level, the more possibility for persuasive authority. State Supreme Court cases are precedent for courts only within that state.

**From Case Law to Practice: Integrating Court Decisions into the Practice of Case Management and Life Care Planning**

**The Role of Mitigating and Corrective Measures in Determining Disability**

In June 1999, the Supreme Court rendered opinions on a trilogy of ADA cases that have had a major impact on determining who is disabled (Vierling, 2002d). These decisions provided a new legal standard that has been used for defining disability under the ADA. However, with the passage of the 2008 ADA amendments, new case law will preclude the standard. The most significant issue that the Supreme Court dealt with was affirming the use of mitigating measures such as medications, corrective lens, prosthetic devices, and the body’s ability to compensate for an impairment to determine disability. As noted, this inquiry will be of less concern especially since the passage of the ADAAA. Now the inquiry is to be made without regard to the use of mitigating measures except for ordinary eyeglasses or contact lenses.

**Single Job versus Class of Jobs**

If a plaintiff is relying on demonstrating a substantial limitation in the major life activity of work, EEOC regulations and current case law have stated that he or she will need to satisfy this definition: he or she must be significantly restricted in the ability to perform either a class of jobs or a broad range of jobs in various classes compared to the average person having comparable training, skills, and abilities. To satisfy this definition, the plaintiff and his or her representative who is preparing either a vocational evaluation or a life care plan has been required to present information on the number and types of available jobs from which he or she is disqualified that use similar training, knowledge, skills, or abilities and are within a reasonably accessible geographic area. This information has helped the trier of fact to decide whether the individual’s impairment rises to the level of a disability and, therefore, falls within the protected class under ADA. Clearly, it
has been crucial that the rehabilitation professional provide very specific information well beyond the medical diagnosis or medical information from a physician. The rehabilitation professional is encouraged to review upcoming governmental agencies’ new regulations, specifically the EEOC as it relates to work as a major life activity with the passage of the ADAAA.

**Toyota v. Williams Supreme Court Decision**

In the *Toyota v. Williams* case (2002), the question before the Supreme Court was: what is the proper standard for determining whether an individual is substantially limited in performing manual tasks? Performing manual tasks is a specific major life activity. As a part of her case, Ms. Williams claimed that she was covered under ADA because her cumulative trauma injury prevented her from doing tasks associated with certain types of manual jobs. However, the Supreme Court said that the proper test for assessing whether an individual was substantially limited in performing manual tasks is whether the impairment prevents or restricts performing tasks that are of “central importance to most people’s daily lives.” In this decision, Justice Sandra Day O’Connor also made the distinction that routine or minor injuries not of a permanent or long-term nature are not protected under ADA.

Congress was very specific in the ADAAA in addressing the issues in the *Toyota v. Williams* decision. The Act stated that the decision in the *Williams* case “further narrowed the broad scope of protection intended to be afforded by the ADA.” Congress’ intent with the ADAAA was to restore a broader scope and expand the coverage that had been narrowed by this decision.

In the *Williams* case, work as a major life activity was again questioned by the Supreme Court. The court’s response to work as a major life activity has diminished the value of claiming it as an issue in an ADA claim. In addition, the Supreme Court said that the plaintiff must prove a disability by offering evidence that the limitation is substantial in terms of her own experience, reinforcing the standard that such assessments must be on a case-by-case basis. This, of course, reemphasizes that a full evaluation, whether it is a case management report, vocational evaluation, or life care plan, must be made by the rehabilitation professional. This decision supports the legal standard relating to alleging a protected disability under ADA, if claiming a substantial limitation in the major life activity of performing manual tasks. Rehabilitation professionals will need to assess and review in their plan the individual’s level of ability in performing manual tasks in his or her personal life. Manual tasks could include such things as ability to perform activities of daily living (ADL), housekeeping chores, and the ability to care for self and other family members. These are the types of real-world activities that the courts have been looking to assess. It is unknown at this time what the impact of the ADAAA will be on the assessment of performing manual tasks.

In the *Williams* decision, published in January 2002, the Supreme Court stated that ADA should be “interpreted strictly to create a demanding standard for qualifying as disabled” (*Toyota v. Williams*, 2002). As noted, this case law is refuted in the ADAAA, but may indeed be challenged in future cases as the assessment process continues to be in transition because of the status of the ADA.

**Other Important Supreme Court Decisions**

There are two other decisions that have created case law for which rehabilitation professionals should be familiar. In June 1999, the Supreme Court published its opinion in the *Olmstead Commissioner, Georgia Department of Human Resources v. L.C.* case, which has particular relevance to life care planners. In this case, the question presented to the Supreme Court was whether the
public service portion of ADA compels the state to provide treatment and habilitation services for persons with mental disabilities in community placement when appropriate treatment and habilitation can also be provided to them in state and mental institutions? The second issue was that if ADA does include providing treatment and habilitation in community placement, does that exceed the enforcement power granted to Congress?

In a vote of 6 to 3, the Supreme Court determined that states are required to place people with mental disabilities in community settings rather than in institutions when the state’s treatment professionals have determined that community placement is appropriate. This would also be under the condition that transfer from institutional care to a community-based program would not be opposed by the individual and that the placement can be reasonably accommodated. The state must also take into consideration the resources available and the needs of other individuals within the state facility.

On June 18, 2001, President George W. Bush signed Executive Order 1.3217, titled “Community-Based Alternatives for Individuals with Disabilities.” This order provided assistance from the federal government to states to implement the Supreme Court decision in Olmstead. The goal of these grants was to assist people with disabilities to do the following (Rubinger & Gardner, 2002):

1. Live in the most integrated community setting appropriate to their individual support requirements and preferences
2. Exercise meaningful choices about their living environments, the providers of services they receive, the types of support they use, and the manner by which services are provided
3. Obtain quality services in a manner as consistent as possible with their community preferences and priorities

As part of this initiative, President Bush proposed an increase in funding to help transition Americans with disabilities from institutions to community living. This is clearly another example of the integration of case law in providing valuable resources for rehabilitation professionals to assist their clientele.

The next decision to be discussed from the Supreme Court was Cleveland v. Policy Management Systems Corporation (1999). In this case, the question before the court was whether the application for, or receipt of, Social Security disability benefits precludes a person with a disability from bringing an ADA claim. The court recognized that there may be many situations in which the claim for Social Security disability benefits and an ADA claim may exist side by side. The court stated that because the qualification standards for Social Security benefits and ADA are not the same, an application for receiving Social Security benefits is not inconsistent with being a qualified individual with a disability under ADA. The court, however, did state that the plaintiff must provide an explanation that he or she can still perform the essential functions of the job with or without reasonable accommodations. The Cleveland case demonstrates to the rehabilitation professional the importance of providing reasonable accommodation under ADA. The rehabilitation professional should also be aware that there is the possibility that an individual receiving Social Security benefits would still be protected under ADA.

Court Decisions and Their Impact on Rehabilitation and Life Care Planning Practice

Whether rehabilitation professionals are serving in an advocacy role or as an objective evaluator, they have the responsibility to provide as accurate an assessment of the needs of the client as
possible. Courts have provided specific guidelines in the form of case law to assist in making informed decisions in future cases. The life care planner needs to be knowledgeable about the case law to effectively provide appropriate data, particularly for vocational and expected future need opinions.

As already noted, court decisions affect EEOC’s guidelines. The trilogy of ADA decisions in 1999 was the impetus for the publication of new instructions to the field offices regarding analyzing charges addressing disability and who is qualified under ADA. It was also the impetus for Congress to restore the protection afforded under the ADA that had been narrowed by the Supreme Court through the amendment legislation. Another example is the EEOC issuing new “Enforcement Guidelines on Reasonable Accommodation and Undue Hardship” under the Americans with Disabilities Act on October 17, 2002. These guidelines were a direct result of the Supreme Court decision in the 2001–2002 term on U.S. Airways, Inc. v. Barnett (2002). The updated enforcement guidelines revised the standard for reasonableness. The reasonableness of an accommodation is now evaluated by whether it is considered not only effective, but also feasible or plausible for the typical employer. In the Barnett decision, the Supreme Court suggested the possibility that special circumstances may exist for providing reasonable accommodations to an individual despite the seniority system. Without the existence of any special circumstances, the court determined that it would be unreasonable for an employer to reassign an employee to another job, which would violate the seniority system.

Under the standards from the Barnett decision, the plaintiff has the burden to prove that an accommodation is reasonable. Then the burden shifts to the employer to provide case-specific evidence proving the accommodation would cause an undue hardship. The guidelines also provide examples of what would be reasonable and unreasonable accommodations. The rehabilitation professional can be a valuable asset by understanding the ADA case law and new legal standards. Following are examples of case law pertaining to providing reasonable accommodations.

- Seniority systems prevail over reasonable accommodation. However, employees may identify special circumstances that lead to the employer providing reasonable accommodation.
- The concept of providing reasonable accommodation is to accommodate a person’s disability rather than accommodate the person with the disability.
- The employer must make reasonable accommodations to the limitations of the disability rather than for those limitations.
- Reasonable accommodation applies to obstacles exclusively related to the workplace.
- Accommodations must be reasonable, feasible, and plausible.
- Employers have a mandatory obligation to engage in an interactive process with employees regarding making reasonable accommodation.
- The employer’s obligation to be involved in the interactive process goes well beyond the first attempt and should continue when the employer is aware that the accommodation is not working.
- The duty to accommodate is a continuing duty that is not exhausted by one effort.

**Outcome of ADA Title I Cases**

The rehabilitation professional should be aware that courts have decided in favor of employers in most ADA litigation cases. In a survey identifying court decisions from the year 2007, the American Bar Association’s Commission on Mental and Physical Disability Law Reporter shows that employees prevailed in less than 5% of the cases. It has also been noted that 80% of all employment cases are
dismissed in motions for summary judgment. A motion for summary judgment is granted when
the court believes no genuine issue of material fact exists. The party filing the motion is entitled
to prevail as a matter of law. As a result, 80% of the ADA Title I cases never reach a jury. When
they do, the vast majority of cases are won by employers. Since the period from 1992 to 2006, the
average win for employers is 95.4%.

Comparison of the 1990 ADA and the ADA Amendments Act

Following is a comparison of five specific issues addressed by Congress in its effort to restore the
intent and protections afforded individuals with disabilities under the 1990 ADA:

<table>
<thead>
<tr>
<th>Issue</th>
<th>ADA (As Construed by the Courts)</th>
<th>ADA Amendments Act (As Amended)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mitigating measures</td>
<td>To be considered in the process of determining whether a person has an impairment that is substantially limiting.</td>
<td>Not to be considered in determining whether a person has an impairment that is substantially limiting except for ordinary eyeglasses or contact lenses.</td>
</tr>
<tr>
<td>“Substantially limits”</td>
<td>Impairment substantially limits an MLA if it prevents or severely restricts the individual from performing the activity.</td>
<td>EEOC and Supreme Court have incorrectly interpreted—should be rewritten to provide a broader scope of coverage.</td>
</tr>
<tr>
<td>The “major life activity” requirement</td>
<td>Must be an activity that is “of central importance” to most people’s daily lives.</td>
<td>Expanded list of major life activities to also include the operation of major bodily functions.</td>
</tr>
<tr>
<td>Episodic conditions and multiple major life activities</td>
<td>Some courts have held that individuals must be limited in more than one major life activity. Other courts have held that episodic or intermittent impairments are not covered under the law.</td>
<td>An impairment that substantially limits one major life activity is sufficient. Impairments that are episodic or in remission are disabilities if limiting when the condition is considered active.</td>
</tr>
<tr>
<td>Regarded as having a disability</td>
<td>Covers individuals who are “regarded as” disabled. Courts have required individuals to show what employers were thinking.</td>
<td>Can establish coverage under the “regarded as” section by showing that they were subjected to an action prohibited by ADA based upon an actual or perceived impairment. No accommodations for those found to be “regarded as.”</td>
</tr>
</tbody>
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Summary and Conclusions

As of the 2007–2008 term, the Supreme Court has heard and provided decisions in 21 specific ADA cases (Albright, 2007). Five of the cases involved the definition of disability. These decisions have led to Congress passing the ADA Amendments Act of 2008 that seeks “to restore the intent and protections of the Americans with Disabilities Act of 1990.” The ADA amendments focus specifically on several main issues that have been narrowly interpreted by the courts. First and most important is the definition of disability. It retains the ADA’s basic definition, but changes the way the statutory terms are interpreted, for instance, substantially limited and major life activities. It also addresses the controversial decisions regarding the use of mitigating measures. It clarifies that an impairment that is episodic or in remission is a disability if it would substantially limit a major life activity when active. The new law addresses “regarded as” cases and whether they are transitory and minor and whether reasonable accommodations should be provided to those individuals determined to be regarded as disabled. Finally, Congress emphasized that the definition of disability should be interpreted broadly.

Of particular relevance is the Olmstead case, which may have implications for lifelong care of people with mental and developmental disabilities, since community-based programs may be legally required over institutional care. In addition, the vocational aspects of a life care plan may require a knowledgeable expert to ensure opinions are defensible.

These Supreme Court decisions have altered and, in many cases, narrowed the definition of disability and, consequently, who is protected under ADA. Matthew Diller, Fordham University law professor, has stated, “The courts have seized upon the definition of disability as a way to stop cases, and in effect, shield an employer’s conduct from scrutiny” (1999). The courts have taken the position that ADA should be strictly interpreted, creating a demanding standard for qualifying as disabled. The records indicate that was not the intent of the Congress. As demonstrated, only a very small number of cases dealing with the actual discrimination issues are heard by a judge or jury. The ADA Amendments Act was meant to correct this situation.

The plaintiff has had the burden to prove that he or she has a disability as a gateway step to presenting his or her case before a judge or jury. This has proven to be a difficult step. Congress’ legislative goal with the ADAAA was to correct this and focus the emphasis on the possible act of discrimination rather than the assessment of whether the individual has a disability. The courts have provided very specific guidelines for presenting information within an evaluation to assist all parties concerned to understand the circumstances and needs of the plaintiff. In practice, a detailed assessment based upon guidelines provided by ADA case law can be a valuable source of information for the judge or jury in adjudicating ADA cases. Some of this case law has been precluded by the ADA Amendments Act, adding yet another chapter to the intent of Congress to “provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities and provide broad coverage.” It has been demonstrated in this chapter that protection of people with disabilities under ADA has not been automatic, even if one is in a catastrophic impairment situation.

The unique nature of the ADA transition is the more than 16 years of developing case law surrounding its effective date of July 1992. The ADAAA was effective January 1, 2009. It is being speculated that the range of coverage and protection for individuals with disabilities will expand significantly. While it is essentially effective immediately, it is expected that areas of the ADAAA will be challenged, resulting in new case law. The case law regarding the ADAAA will take several years to development in the court system, thereby extending this already protracted transition.
References


*Mental and Physical Disability Law Reporter* 32.


*Toyota Motors v. Williams.* (2002, January 8). No. 00-1089.


**Supreme Court Decisions**

*Barnes v. Gorman,* No. 01-682, June 17, 2002.
*Chevron v. Echazabal,* No. 00-1406, June 10, 2002.
*Toyota Motors v. Williams,* No. 00-1089, January 8, 2002.

**Important Websites**

Department of Justice—ADA Home: www.usdoj.gov/crt/ada/adahom1.htm
The Federal Judiciary: www.uscourts.gov
Law News: www.law.com
The National Council on Disability: www.ncd.gov/index.html
U.S. Supreme Court Collection: www.supct.law.cornell.edu:8080/supct
U.S. Supreme Court—Multimedia Media Database: http://oyez.nwu.edu
U.S. Supreme Court of the United States: www.supremecourtus.gov
Washington Post for Supreme Court News: www.washingtonpost.com
Chapter 31

Technology and Life Care Planning

Randall L. Thomas

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Introduction

Integrating emerging technology with professional skills provides a powerful tool for a successful life care planning practice (Thomas, 1992, 1994; Weed, 1995, 1996a, 1996b, 1996c). Today, the
life care planner can access a wider scope of available resources and information to ascertain the most appropriate recommendations for the client. Previously, the professional did not have access to all possible resources, and existing data usually required considerable time and effort to obtain. With today’s technology and access via the Internet, the professional can maximize efficiency and organization to produce a quality life care plan that best benefits the client’s needs. This chapter presents guidelines for integrating today’s emerging technology into a life care planning practice and provides practical information every life care planner should know.

As the Internet expands and more and more resources are made available to the general public via the Internet, the resources available to people with disabilities and those who work with them have also grown tremendously (Barros & Boyd, 1997). Because of rapid changes in technology, especially computer processors, hard drive capacity, and the Internet, integration of technology can be confusing and problematic to the life care planner. For example, determining which computer system to purchase, selecting the appropriate software and network capability, training staff, and knowing how to maintain the integrity of the data on the computer system are only a few of the critical decisions in this often difficult process. Therefore, integrating computer technology into a life care planning practice is not easy, and the temptation to avoid the transition may exist. Fortunately, emerging technology offers much more capability, convenience, and stronger computer hardware configurations that should remain functional and productive for the next 2 to 5 years. The professional can limit confusion regarding technology and take advantage of this increased ability by identifying needs within the practice and obtaining a better understanding of today’s technology.

**Initial Steps**

The life care planner must first determine the professional and business goals in the practice before purchasing computer equipment. If the goal is to complete a maximum of two or three life care plans a year, including narrative and tabular printing of recommendations with associated charges, many of the commercially available word-processing, spreadsheet, and database programs will suffice. The life care planner can construct simple databases to track information and resources. Commercial databases such as Microsoft Access and FileMaker Pro are readily adapted to provide simple, flat-file databases for resources and contacts. With professional programming, the databases can be customized to provide comprehensive relational databases for the life care planner.

On the other hand, if life care planning is to comprise a significant part of the practice, existing computer system and software may require upgrading. Computer hardware and software are now available that are reliable and cost-efficient. Access to this technology is essential because it allows production of a quality product that reflects current clinical knowledge and superior organization of information. This technology also enables the life care planner to create a summary table for costs during the client’s lifetime, or on a year-by-year basis, while making the most productive use of staff time.

In short, technology impacts the life care planner in the following ways:

- Enhances the ability to organize professional contacts and resources in a logical, easy-to-find method
- Enhances the ability to organize client data to reference deposition dates, trial dates, referral source, and search for conflicts of interest before accepting a new referral
Diminishes staff time for specialized reports or printouts
- Allows greater control over data integrity with less dependence on external computer experts and resources
- Increases ability to customize reporting formats and invoicing to referral sources
- Simplifies access to the Internet for research (provides capability to search the Internet from within a dedicated LCP program)
- Enables access to state and national databases via the Internet (e.g., Health Care Utilization Project data for inpatient hospital charges)
- Send and receive large electronic files of medical records (i.e., ≥100 MBs)
- Accesses and distributes information via personalized web pages on the Internet

The successful life care planner should be prepared to incorporate the previous changes in a proactive manner to reach optimal efficiency (Thomas, 1994, 2004). Following are useful concepts that will enable the professional to begin these proactive responses and take charge of integrating technology into the life care planning process.

Use of Computers in a Life Care Planning Practice

Computers have become an essential tool for the life care planner. The recent generation of computers with very fast processors gives significant computing power to the small- or medium-size business. Current computers with their speed and improved operating systems allow the small company or solo practitioner to execute very sophisticated programs that were beyond consideration a few years ago.

Now it is possible to use software programs to accumulate all case management information resources and easily identify specific vendors, recommendations, and costs for items in a life care plan. Once resources and vendors are identified in an informational database, faxes can be quickly generated that allow the professional to contact potential vendors for current charges. Upon obtaining the specific descriptions with charges and other pertinent information, these items can be easily translated into the traditional life care plan tables or into a customized life care plan report, depending upon the professional’s preference. Retyping redundant information such as the recommendation and vendor is minimized (Thomas, 1994, 2004).

Because there are a variety of report requests, the life care planner is able to provide a report that meets the standards of life care planning as well as the requests of the referral source. For example, a referral source may wish to have a summary of the items and, in some cases, a summary of charges over the lifetime of the client. In the past, the life care plan narrative may have been completed in a word-processing program. If a cost summary involving mathematical calculations were required, it would likely be completed in a spreadsheet such as Excel, or calculations would have been completed manually using a calculator. Now, all of this information can be completed at the same time in one software program.

Once appropriate software is installed, the professional will also become more familiar with multiple life care planning resources available on the Internet. E-mail communication has increased the sharing of information and the development of listservs has become an instantaneous help desk for the life care planner. By using the appropriate computer hardware and software, the life care planner will have a significant professional advantage. However, before the next hardware and software purchase, review the following guidelines in order to make wise decisions.
Computer Purchase Guidelines*

1. Purchase a computer with a processor speed of at least 2.4 gigahertz (GHz).
2. Purchase a minimum hard drive capacity of 500 gigabytes (GB).
3. Purchase a minimum RAM (random access memory) of 4 gigabytes (GB) and 6 MB L2Cache.
4. Purchase, at a minimum, a 19-inch flat panel monitor. A “square” monitor as opposed to a “landscape” model is recommended. For more efficient use of computer software, consider using two “side by side” monitors. Be sure to have an adequate video card installed.
5. Purchase a laser printer with capability for networking. Most laser printers have this feature at the present time. If color photos or text is included, inkjet printers have excellent quality and are relatively cheap. Because of the cost per page, it may be reasonable to have two printers: one laser for prints and speed, and the other for color needs. Also, some all-in-one machines might be useful for color copies, color printing, scanning to .pdf files or photo files, and faxes.
6. Utilize a DSL line or cable modem for access to the Internet.
7. Network your computers at the office or home with an Ethernet network. Consider using the wireless networking referred to as Wi-Fi. But remember to have encryption on your Wi-Fi system.
8. The most popular operating system is Windows XP or Vista. There has been much discussion regarding the Vista system, and many people have chosen to stay with XP “until the next OS come out.” Have your staff trained on the Windows XP or VISTA operating system.
9. Purchase an uninterruptible power source (UPS), which usually costs between $100 and $200. The UPS prevents sudden power outages on the computer and network equipment. Sudden power outages can result in loss or corruption of data. The UPS also serves as a surge protector.
10. Select a quality company from which to purchase computer and software products. Choose either (1) a reputable company, preferably one that will offer a 30-day, no-questions-asked, money-back guarantee; or (2) mail order through a national company. Mail order companies such as Dell (800-424-1370) and Gateway (800-846-2059) offer a wide variety of products. Consider a 3-year support contract that includes toll-free 24-hour technical support. The cost of this additional service is approximately $200 and, in this author’s opinion, is a very good investment.
11. Select a good data backup system and have a thorough understanding of its use. Some users install the data backup system with the hope it will never be used. Unfortunately, the user may not test the backup system until the dreaded hard drive crash occurs. One important quality of a backup system is that it is convenient and easy to use for both storing and restoring data. Utilizing a DVD burner is one method to archive data on your computer. Another is to purchase a USB portable hard drive, which could easily have the capacity to be a complete duplication of the main desktop computer. This option also offers the opportunity to take your “computer” with you by attaching it to a laptop. And don’t forget to have an offsite copy of your data.
12. Also, have a regular backup schedule for your data files and place the data in an offsite location, such as a safety deposit box, on a periodic basis. This may seem excessive, but I strongly recommend this consideration.
13. In choosing your backup medium, use caution if you purchase a dedicated backup external hard drive with a proprietary compression or encryption system. Such systems work well today, but in 5 years the proprietary encryption system may no longer be supported.

* See Appendix A for terminology definitions.
A DVD burner holds approximately 4.6 GB (or 8.5 GB) of information (approximately 6 to 12 regular CDs). One of its advantages is that the DVD can easily be read by other computers. This allows the user to save large files and then place the DVD in a safe location. Also, the professional can use a DVD or CD to mail data to other locations when it would not be practical to e-mail a 60- or 80-MB file. Another advantage of the DVD is that it allows instant access to archived files. A DVD reader/burner is typically a part of the computer system. Successful life care planners recognize the ongoing need to protect their investments with appropriate staff training and data backup technologies.

**Software**

Software used to assist professionals is abundant in today’s technology. Word-processing programs such as Microsoft Word are a necessity for any office. Database programs that allow the user to design templates are also becoming popular. Such database programs include Microsoft Access and FileMaker Pro. The professional may also explore spreadsheet capability and presentation software such as PowerPoint if the practice needs these. In addition, software programs incorporating the CPT codes (copyright by American Medical Association) are available on CD from many publishers. A simple “CPT code software” Google search quickly yielded thousands of hits referencing companies with products for sale.

While much of the software currently available is designed for home health agencies, specific software for case management and life care planning is now available.

Several software programs are available for the life care planner:

- Ann Maniha offers a life care planning program designed to work with Microsoft Word or WordPerfect. Contact e-mail is ann.maniha@att.net.
- Computer Methods offers an online program for report writing. See www.LIFECAREWRITER.com.
- LCPStat software for life care planning was introduced in 1993 by TecSolutions, Inc. and recently released version 7. See www.LCP3.com.
- SaddlePoint Software, LLC offers PlannerPro! Plus, a program that provides tools for the life care planner. See www.saddlepoint.net.
- Total Life Care (TLC) software by Compensation Economic Information Systems was made available for purchase in 2003. See www.rehabserv.com/tlc.htm.

These programs should be carefully reviewed by the life care planner considering a specialty software package for life care planning. The program should offer the user the ability to organize data and generate reports in an efficient and reliable manner. Such programs would also be a business advantage to those individuals using technology and life care planning. As with any software used in forensic settings, the user should be aware of any Daubert implications and be prepared to answer questions about the software from a Daubert standpoint (see the chapters in this volume by the plaintiff and defense attorneys).

Another type of software that would be advantageous for the life care professional is a voice recognition technology (VRT) program. VRT is not a new concept; however, it has become popular because tremendous strides have been made in VRT, and computer hardware and software programs are now available at reasonable costs. VRT programs allow the professional to speak
into a microphone and the computer will “type” at a rate of 50 to 125 words per minute with approximately 95% accuracy, increasing efficiency and reducing overhead in this high-technology approach to office tasks. Most VRT products are compatible with the major word-processing, spreadsheet, and database programs. Feedback from life care planners reflects the general history of VRT—it is a mixed review. Some life care planners give a favorable report on the use of VRT; others have had a poor experience. One issue is that words are occasionally misspelled. Actually, the word is spelled correctly, but the VRT understood a different word than was intended! Therefore, editing a report is more challenging.

Also, Internet-related software includes a variety of programs such as Real Audio, a software program that allows the user to listen to music or speech from an Internet site. The audio capacity will become more important as continuing educational programs and distance-learning strategies are introduced by professional associations and universities.

**Computer Operating Systems**

Most life care planners will be using the Windows XP/Vista operating system by Microsoft. Some of the software used by life care planners can be used on either the Macintosh or Windows operating system. However, most life care planners utilize the Microsoft operating system. With any of the new generation of operating systems from Microsoft and Apple, the user can access the Internet, receive e-mail, download files, and research the various databases. Although there has been concern over the future of the Macintosh computer and Apple Corporation, based on relatively recent product announcements, it is probable that the Macintosh operating system will remain a viable operating system for many years to come.

**Networking**

Networking refers to the ability for several computers, in an office or at separate locations, to be electronically connected. The decision to network has become an easier one to make. Prior generations of computers were difficult to network. Windows XP/Vista and Macintosh have significant network capability built into their operating systems. For offices that have four or more people using the Internet or sharing the same life care planning databases, establishing a local area network is essential.

Once the decision to network is made, establishing the network should be relatively straight-forward. A cable specialist will run cables, and a software specialist will set up the protocols for the computers to talk to each other. The user should be certain to ask that firewalls be installed to prevent unauthorized access to the computers via the Internet. Your computer consultant can advise on the most appropriate firewalls (protection from computer hackers and viruses). And the user should be careful to save the various passwords associated with the modem and firewalls in a safe and secure location.

There will be a moderate cost for the initial network installation and associated hardware and software. There are also other costs involved such as ongoing maintenance and upgrades. In addition to the costs for the initial technology purchase (i.e., specific hardware or software products), there is also a commitment to staff training and development in the use of the network.
Using the Internet as a Resource

The Internet continues to grow in both volume and quality of information. It has become a useful medium for life care planners to locate medical specialists and resources (Thomas, 1996b, 2004). In addition, most medical centers have home pages that allow users to learn of services offered by specific facilities and to contact persons in these businesses. Data regarding specific medical fees/charges by CPT code have become easier to obtain over the Internet. Charges by DRG can be obtained but less useful in many cases than would be charges by CPT codes.

For life care planners that have already attempted to find information on charges, there are software programs that provide charge by CPT codes. PMIC offers Medical Fees in the United States 2008, an eBook in .pdf format. See http://pmiconline.stores.yahoo.net/mefeinunst203.html.

Medical charge information is often proprietary, and the publishers charge a premium price for the information in both printed form and access over the Internet. It is probable that databases with medical charges will eventually become available on the Internet. For example, one experienced professional has developed a Web-based site to assist with sharing of life care planning data in partial answer to this problem (www.careplanners.net). In addition, TecSolutions, Inc. offers a CPT lookup database that reflects CPT descriptions, Medicare allowable fees, and Medicare allowable payments to ambulatory surgical centers and outpatient hospital surgery departments (see www.LCP3.com). Note that CPT is a registered trademark of the American Medical Association.

Since the CPT codes and descriptors are copyrighted by the American Medical Association and are not in the public domain, all companies that utilize the CPT codes have to pay a royalty to the AMA.

The Internet will continue to expand access to medical and legal databases. Some of these databases, such as HCUP (www.ahrq.gov/data/hcup), have excellent medical charge information that is free of charge, whereas other databases are proprietary (see www.ahd.com/subscriptiondetails.html) and have an associated fee. A general rule of thumb is that any printed information requiring payment will also require payment when obtained over the Internet.

Two useful websites are

- Healthcare Cost and Utilization Project (HCUP). (For inpatient hospital charges based on ICD 9 Cm procedure codes or ICD 9 Cm diagnosis codes; http://hcupnet.ahrq.gov.)

Internet Access Providers or Internet Service Providers

Internet service providers (ISPs) are prevalent in nearly all areas of the United States. Use of ISP has become easier with the introduction of DSL and cable modem service. DSL and cable modem services provide unlimited access to the Internet, but with limits on how much data the user can upload. DSL providers typically limit the upload speed and allow higher download speeds. In contrast, cable modems typically do not cap the upload speeds; therefore, at times you may have fast download and fast upload speeds. But cable modems are similar to a telephone party line—if several people in your neighborhood log on to their cable modem, the download and upload speeds will diminish. In addition, companies such as Verizon and AT&T offer wide-area wireless broadband service for laptops in most metropolitan areas.
Internet Search Engines

Search engines are proprietary software programs that are accessed via the Internet and allow the user to list and enter keywords for topics to be researched on the Internet. The search engine will review its database of Internet sites and provide the life care planner with domain names and uniform resource locators (URLs) of sites on the Internet that have information related to the keywords. The life care planner can access a particular site by clicking on the site name. There is no charge to use the more popular search engines such as Google.com and Wikipedia.com.

E-Mail Communication

E-mail is another primary use of the Internet and most life care planners are well familiar with this technology. E-mail means sending an electronic message to someone else that has an Internet or other e-mail address. This approach offers many advantages. For example, even though the U.S. Postal Service can deliver the same message, the exchange via e-mail occurs in a matter of seconds. Therefore, sending e-mail is essentially instantaneous, and typically there is no per message charge for e-mail. Also, once an account with the Internet provider is established, the user can send unlimited messages (Thomas, 1996a). Most Internet e-mail programs limit the size of attachments. This can affect sending large documents or high-resolution photos. For documents that exceed your Internet e-mail attachment limits, companies such as YOUSENDIT (see www.yousendit.com) offer the ability to send large documents (up to 2 GB) for a fee of about $10 per month (Pro Account).

Videoconferencing

Videoconferencing has become readily accessible to most Internet users in the past few years. As life care planners continue to purchase computers with faster processor and Internet access speeds, video compression programs are also becoming more effective. As a result, acceptable-quality videoconferences are available over the Internet. Video quality will not be that of a television, but video on the computer screen will provide acceptable viewing for communication.

Significant commercial value has been placed on videoconference software. Corporations (and life care planners) spend a significant amount of money for staff traveling to face-to-face meetings. The value placed on the face-to-face meeting is so significant that the life care planner and others will pay premium prices for reliable videoconference software and hardware.

For a summary of suggestions related to the previous text, please refer to Table 31.1.

Conclusion

In summary, technology has a significant impact on the life care planning process. Technology continues to evolve that will allow more efficient and accurate completion of life care plans for individuals with catastrophic injuries. Computer hardware and software will allow quicker processing of reports and locating of appropriate resources. Use of software such as word processing, specialized programs for life care planning and case management, sources of information, and data on CD-ROM/DVD/Internet will continue to increase.

Implementing the use of computers and software into life care planning is more than simply buying a computer. There must also be an appropriate computer system, including hard drive capacity, processor speed, software, backup system, software/hardware maintenance, and staff
Table 31.1 Practical Technology Hints for the Life Care Planner

- Make sure you have firewall protection. If you have a full-time connection to the Internet with a DSL or cable modem, there may be several hundred attempts each day to access your computer.

- Make sure you have virus protection—and keep it up to date.

- Do not open e-mail attachments unless you are sure of their content. Even if the e-mail is from someone you know, attachments often are infected.

- The monthly cost for a DSL or cable modem ($40 to $70) is worth the expense for the increased productivity.

- New computers have adequate processing speed to run the numerous programs the life care planner will utilize.

- A DVD burner or a portable USB hard drive is a useful tool for backing up files for the life care planner.

- Adobe Acrobat is a very useful tool for sending reports by e-mail that are printer ready. The full cost is approximately $200.

- When buying a new computer system, purchase at least 4 GB of RAM and 500 GB hard drive.

- Use www.whatismyip.com to identify the IP number for your computer when it is logged on to the Internet.

- Use a router, not a hub, on your office Ethernet connection to the Internet. The router allows greater security measures.

- Wi-Fi is a wireless Ethernet connection that should be considered when networking your office.

- A reasonable monthly fee to pay a company for Web hosting is $45 to $65 per month.

- A reasonable cost to pay a Web developer to develop a website with approximately 10 web pages would be $500 to $1000.

- A reasonable cost, on an annual basis, to pay a Web developer to update your website three to four times per year would be $75 per hour, with approximately 4 hours of update time per year.

- Do not allow your Web developer to own your specific domain name. Perform a search on www.whois.com and discover who owns your domain name.


- Typically, you register your domain name for 3 years and mark your calendar to renew the subscription. If your domain name registration expires, another company can purchase your domain name.

- The approximate cost per year for registering and owning a domain name is $15 to $25.

Training. Since data that are becoming available are more comprehensive, additional computing power will be required to process this data at a speed acceptable to the life care planner. This chapter contains guidelines and other information to encourage the successful integration of technology and life care planning and to provide the life care planner with necessary information.
References


Appendix A: Selected Technological Definitions

E-mail (electronic mail)
Messages, usually text, sent from one person to another via computer. E-mail can also be sent automatically to a large number of addresses such as a mailing list.

FAQ (frequently asked questions)
Document that lists and answers the most common questions on a particular subject. There are hundreds of FAQs on subjects as diverse as pet grooming and cryptography. FAQs are usually written by people who are tired of answering the same questions over and over.

FTP (file transfer protocol)
A very common method of moving files between two Internet sites. FTP is a special way to log in to another Internet site for the purposes of retrieving or sending files. There are many Internet sites that have established publicly accessible repositories of material that can be obtained using FTP, by logging in using the account name “anonymous.” Thus, these sites are called anonymous FTP servers.

IP number
An identifier for a computer or device on a TCP/IP network. Networks using the TCP/IP protocol route messages based on the IP address of the destination. The format of an IP address is a 32-bit numeric address written as four numbers separated by periods. Each number can be zero to 255. For example, 1.160.10.240 could be an IP address. An IP number is a unique number consisting of four parts separated by dots (e.g., 165.113.245.2). Every machine that is on the Internet has a unique IP number. Most machines also have one or more domain names that are easier for people to remember.

ISDN (Integrated Services Digital Network)
Basically this is a way to move more data over existing regular phone lines. ISDN is rapidly becoming available to much of the United States and in most markets. It can provide speeds of roughly 128,000 bits per second (bps) over regular phone lines. In practice, most people will be limited to 56,000 or 64,000 bps.
ISP (Internet service provider)
A company that provides access to the Internet. For a monthly fee, the service provider gives you a software package, username, password, and access phone number. Equipped with a modem, you can then log on to the Internet and browse the World Wide Web and USENET, and send and receive e-mail.

TCP/IP (transmission control protocol/Internet protocol)
This is the suite of protocols that defines the Internet. Originally designed for the UNIX operating system, TCP/IP software is now available for every major type of computer operating system. To be truly on the Internet, the user’s computer must have TCP/IP software.

URL (uniform resource locator)
The standard way to give the address of any resource on the Internet that is part of the World Wide Web (WWW), for example, www.matisse.net/seminars.html or telnet://well.sf.ca.us. The most common way to use a URL is to enter into a WWW browser program, such as Netscape or Lynx, and enter the URL address.

Wi-Fi (wireless fidelity)
Wi-Fi is the popular term for a high-frequency wireless local-area network (WLAN). The Wi-Fi technology is rapidly gaining acceptance in many companies as an alternative to a wired LAN. It can also be installed for a home network.

WWW (World Wide Web)
The whole constellation of resources that can be accessed using FTP, HTTP, and some other protocols.

Appendix B: Software Vendors

Elliott and Fitzpatrick
800-843-4977
706-548-8161
www.elliottfitzpatrick.com

IMA Technologies, Inc.
Case management software such as CaseTrakker
800-458-1114
www.casetrakker.com

Life Care Writer
Computer Methods
510-824-0252
www.lifecarewriter.com

O*Net (Occupational Information Network)
The automated online replacement for the Dictionary of Occupational Titles
http://online.onetcenter.org
SaddlePoint Software, LLC
256-535-2322
www.saddlepoint.net

TecSolutions
LCPSTAT Case Management and Life Care Planning software for Windows and Macintosh
601-946-0646
www.LCP3.com

TIMESLIPS Corporation
Time and billing software
877-816-7829
www.timeslips.com

Total Life Care Software
Compensation Economic Information Systems
305-271-0012
www.rehabserv.com/tlc.htm
# Chapter 32

## Life Care Planning Resources

Julie A. Kitchen and Laura Deutsch Brown

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Introduction

A plethora of information has been written over the years about resources that can and should be used in life care planning. As life care planners, we know that the person with the most accurate, accessible, and thorough resources is the winner in the life care planning arena. Without proper resources that are easily accessible, understandable, and updateable, the task of completing a competent, thorough, and accurate life care plan can be formidable. In the authors’ experience, most life care planners spend the majority of their time researching information for the plan, rather than actually formulating the specific components for the plan. Therefore, the life care planner with the competitive edge is the one who has a multitude of data from a variety of sources, encompassing a large pool of information, rather than just the basics involved in setting up the outline for the recommendations for the life care plan.

There is an operative word that must be spoken and understood here, and that word is accessible resources. Just having the information available somewhere in the office is not enough. This will not help the expert during the stress of a deposition when asked to pull that source, or during a telephone conference with a referral source, asking for specifics on something referenced in the life care plan. Additionally, there are many topics not specifically covered in the life care plan itself that must also be readily available for conferencing, speaking, training, testifying, networking, and case managing. Remember that our role as life care planners is as educators—well-prepared, knowledgeable educators with an almost unlimited fund of knowledge and resources.

This chapter will outline some resources (which will in turn lead the reader to other resources) that will enable life care planners to expand their horizons and base of information. This chapter is not designed to outline specific individual sources for a specific problem. This chapter will globally outline information that will provide the life care planner/case manager with the fact source(s) needed to be well rounded and knowledgeable in all facets of the life care planning area of practice and that will provide a foundation upon which one can continually build a broad knowledge base.

Just as the key to comprehensive life care planning is to develop and maintain a consistent methodology to analyze and process catastrophic cases, the key to resourcing and maintaining a database is just as important, and a consistent methodology must be used to obtain and maintain those sources. Otherwise, the professional will be mired in a deluge of information that is virtually useless if it is not accessible, updated, and maintained in such a fashion that the professional can have immediate access.

As professionals, we must keep abreast of technology available so as to benefit fully from what it can offer. This means being willing to investigate new technology, new data storage
and retrieval systems. This is not to say that one cannot stay with a proven, successful method of data collection, retrieval, and so on, but the professional must keep an open mind as to alternatives that are continually being developed. The professional is encouraged to seek out and evaluate a number of currently available software programs to determine which system (for case management, life care planning, resource data storage and retrieval, etc.) will best fit specific needs.

This chapter is also designed to make the task of researching easier and more user friendly. We will begin by starting at the beginning of the research process involved in the life care planning arena.

The process of researching requires the life care planner to do the following:

- Identify and define needed information.
- Cultivate effective resources to locate information.
- Organize, store, and retrieve valuable information.

Therefore, let us break this down further by narrowing the scope a bit to make it more manageable. In order to identify and define needed information, the life care planner must look at the client specifics:

- Injury/disability
- Environment/location

Client needs based on the disability:

- Medical services
- Nursing/assistance
- Residential needs
- Education/vocation
- Miscellaneous services
- Supplies/equipment
- Allied health services

Defining client needs goes hand-in-hand with identifying those areas for inclusion in the life care plan. The authors like to refer to the Area Cost Analysis Request form (see the following) as a blueprint for the life care plan. It is in using this form that the planner begins mentally constructing the plan as the requested costing information is outlined. By checking off those items that require costing research, the planner is also constructing the various recommendations contained within the plan (also see Appendix A for a sample facility questionnaire).

<table>
<thead>
<tr>
<th>Area Cost Analysis Request</th>
</tr>
</thead>
<tbody>
<tr>
<td>Client: ____________________________</td>
</tr>
<tr>
<td>Plaintiff: ___ Defense: ___ Age: ___ Sex: M F</td>
</tr>
<tr>
<td>Disability:__ Area Code: ____________</td>
</tr>
<tr>
<td>City: ___ Nearest Metro Area: ______________________</td>
</tr>
<tr>
<td>Today’s Date:__ Date Due: ______________________</td>
</tr>
</tbody>
</table>

(Continued)
Allied Health Professionals:

- Dentist
- Gastroenterologist
- GP/internist
- Neuro-ophtalmologist
- Neurologist
- Neuropsychologist
- Neurosurgeon
- Ophthalmologist
- Orthopedist
- Orthosurgeon
- Otolaryngologist
- Pain specialist
- Pediatrician
- Physiatrist
- Plastic surgeon
- Podiatrist
- Psychiatrist
- Psychologist
- Pulmonologist
- Rheumatologist
- Urologist
- Other: ______________________________

Home Health: (See links to home health agencies)

Therapy: ____ PT, ____ OT, ____ ST, ____ Respiratory
Invasive procedures required? (Yes/No) Such as:
- Catheter
- Suction
- IV therapy
- Trach care
- Tube feeding
- Bowel program

Staffing:

<p>| | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>HHA</td>
<td>____ Hourly, ____ Visit</td>
<td></td>
<td></td>
</tr>
<tr>
<td>LPN</td>
<td>____ Hourly, ____ Visit</td>
<td></td>
<td></td>
</tr>
<tr>
<td>RN</td>
<td>____ Hourly, ____ Visit</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

__ Live-in (available/definition/last time staffed this level?)
### Facility-Based Outpatient Therapy:

- PT
- OT
- ST
- Respiratory therapy
- Aquatic therapy
- Therapeutic riding
- Recreational therapy
- Work hardening program
- Disabled driver
- Augmentative communication
- Assistive technology
- Other:
  - Other:
  - Other:

### Miscellaneous Services:

- Handyman service
- Health club
- Home modification
- Housecleaning
- Massage therapy
- Nutritionist
- Support group
- Other:

### Educational Programs:

- Public school
- Summer program
- Private school
- College aid
- Tutor
- Camp
- College: AA BA
- Vocational/technical: _________________

### Vocational Services:

- Vocational evaluation
- Vocational counseling
- Job coaching
- Sheltered work
(Continued)

- Supported work
- Day/activity program

Wage data research required (if providing a loss of earnings report):

**Occupation:**

<table>
<thead>
<tr>
<th>Programs/Facilities:</th>
<th>Facility Care Level:</th>
</tr>
</thead>
<tbody>
<tr>
<td>___Adult day care</td>
<td>Level of disability</td>
</tr>
<tr>
<td>___Day program ___ABI ___MR</td>
<td># Hours of supervision</td>
</tr>
<tr>
<td>___Assisted living facility</td>
<td>ADLs:</td>
</tr>
<tr>
<td>___Other: ___</td>
<td>Cues:</td>
</tr>
<tr>
<td>___ICF/MR or group home</td>
<td>Aggressive</td>
</tr>
<tr>
<td>___Long-term head injury</td>
<td>Ambulatory</td>
</tr>
<tr>
<td>___Skilled nursing facility</td>
<td>Continent</td>
</tr>
<tr>
<td>___Supported living</td>
<td>Verbal</td>
</tr>
<tr>
<td>___Transitional living ___ SCI ___ABI</td>
<td>PVS</td>
</tr>
<tr>
<td>___Neurobehavioral inpatient</td>
<td>Trach</td>
</tr>
<tr>
<td>___Chronic pain ___Inpatient ___Outpatient</td>
<td>Vent dependent</td>
</tr>
<tr>
<td>___SCI rehab: ___Inpatient ___Outpatient</td>
<td>Tube fed</td>
</tr>
<tr>
<td>___SCI evaluation: ___Inpatient ___Outpatient</td>
<td>Bowel program</td>
</tr>
<tr>
<td>___Other</td>
<td>Day program</td>
</tr>
<tr>
<td></td>
<td>Work program</td>
</tr>
</tbody>
</table>

**Diagnostics:**

- EEG
- EKG
- Evoked potential ___Audio ___Visual
- Pulmonary functions
- Renal scan
- Renal ultrasound
- Sleep study
- Swallow study
- Urodynamic studies
- CT:
  - MRI:
  - X-ray:
    - Bronchoscopy
    - Colonoscopy
    - Cystoscopy
    - Endoscopy

**Labs:**

- Cardiac profile
- CBC (with diff.)
Comprehensive metabolic panel
Creatinine
C&S
LFT
Lipid panel
UA
Chemical levels (what medication): ________________

Surgeries/Procedures:

Botox
Biofeedback
FES
Epidural block
SCI fertility program: M F
Gastrostomy
PEG tube
Trach revision
Shunt revision
Hip subluxation
Hip replacement
Knee replacement
Baclofen pump
Morphine pump
Spinal stimulator
Scoliosis surgery
Diskectomy (cervical/thoracic/lumbar)
Laminectomy (cervical/thoracic/lumbar)
Spinal fusion (cervical/thoracic/lumbar)
Scar revision (length of scar: ___)
Stump revision
Arthroscopy
Contracture release
Tendon release
Hardware removal

(Continued)
This table illustrates a sample form that can be used as a blueprint for the life care plan. Once the needs are known, then researching the cost is in order. The Internet has certainly changed and shaped the way we research costs, but the telephone is still an important link when specific information needs to be acquired. E-mail is another valuable tool, and actually, some of the same tips on the art of obtaining telephone information is valuable in obtaining information via e-mail, since both, ideally, will be answered by a human on the other side. Do not underestimate the power of the spoken word. An outline of instrumental tips is located in the following.

**The Art of Obtaining Information by Telephone**

*First Impressions Count:* Do not be demanding, but be humble, and with sincerity ask your questions.

*Be Optimistic and Positive:* Do not let the person on the other end try to dismiss you by indicating he or she does not know the answer. Assume the person does; he or she just might not know he or she knows. Be persuasive, but kind and optimistic.

*Be Complimentary:* “I understand you are the area expert on such and such.”

*Be Persistent and Patient:* Do not give up. Continue to follow up on your contacts and respect their time requirements, if possible. (Beg when necessary.)

*Be Personable:* No one enjoys talking to someone who is very stiff and all business. Throw in a bit of small talk to make both of you feel at ease. If the other person can feel your pain, so to speak, you have a much better chance of acquiring the needed information.

<table>
<thead>
<tr>
<th>Equipment:</th>
</tr>
</thead>
<tbody>
<tr>
<td>ECU</td>
</tr>
<tr>
<td>Standers</td>
</tr>
<tr>
<td>Cushions</td>
</tr>
<tr>
<td>Ramp/lift</td>
</tr>
<tr>
<td>Van conversion</td>
</tr>
<tr>
<td>Assistive technology</td>
</tr>
<tr>
<td>Augmentative communication device</td>
</tr>
<tr>
<td>Pediatric equipment</td>
</tr>
<tr>
<td>Orthotics</td>
</tr>
<tr>
<td>Prosthetics</td>
</tr>
<tr>
<td>Visual aids</td>
</tr>
<tr>
<td>Wheelchair</td>
</tr>
<tr>
<td>Specialized equipment: ________________________</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Supplies:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medications:</td>
</tr>
<tr>
<td>DME:</td>
</tr>
</tbody>
</table>
Be Flexible: Go with the flow. If you are referred to yet another number to call, do so cheerfully. Eventually you will end up rewarded.

Now that we have reviewed the essential points involved with the art of obtaining information via telephone, let us look at some of the more practical matters in terms of locating information.

**Locating Health Care Professionals**

When working outside of your geographical area, using the Web, go to the online Yellow Pages to begin your search for medical professionals or allied health professionals. Two examples are:

- InfoSpace: www.infospace.com
- The Real Yellow Pages: http://yp.yahoo.com or www.yellowpages.com

To find certain specific specialists, such as a pain specialist, physiatrist, neuro-ophthalmologist, neuropsychologist, neurosurgeon, or nutritionist, special research tools are required. A useful tool to use to find specific specialists is the *National Trade and Professional Associations*. This text provides detailed contact and background information on over 7600 trade associations, professional societies, technical organizations, and labor unions in the United States. It is available from:

Columbia Books, Inc.
8120 Woodmont Avenue, Suite 110
Bethesda, MD 20814
(888) 265-0060
Fax: (202) 464-1675
E-mail: info@columbiabooks.com

Another good general source includes the *Case Management Resource Guide* (www.cmrg.com). This guide can provide information for a number of programs and facilities, such as:

- Home care
- Rehabilitation
- Subacute care
- Nursing facilities
- Assisted living facilities
- Hospice
- Long-term acute care
- Hospitals
- Psychiatric and addiction

The following links will guide you to home health agencies. Always look to the national agencies first when researching costs. If there are no national agencies available, contact the closest agency for assistance. Many times, a national agency will service out-of-town areas for an additional transportation/travel charge.

Websites for specific agencies can direct you to specific offices in geographic locations served.
Home Health Links

Interim Home Health: www.interimhealthcare.com
ResCare (formerly Kelly Assisted Living): www.rescare.com
Maxim Home Health: www.maximhealthcare.com
Nurse Finders: www.nursefinders.com

Other Useful Links

Brain Injury Facility Locator: www.biausa.org
United Cerebral Palsy Direct Services: www.ucp.org
Spinal Cord Injury Rehabilitation Centers: www.spinalcord.uab.edu
Commission on the Accreditation of Rehabilitation Facilities: www.carf.org
Shepherd Spinal Cord Injury Program: www.shepherd.org
Rosomoff Comprehensive Pain Center or Miami Pain: www.rosomoffpaincenter.com
National Spinal Cord Injury Association: www.spinalcord.org

Locating Miscellaneous Services

Search online Yellow Pages for:
Health club
Wellness program
Massage therapy

Locating Schools/Educational Services

Preschools, public schools, private schools, school boards—online Yellow Pages:
www.infospace.com
Colleges and universities, by state: www.50states.com/college
Tutor locator—Sylvan Learning Centers: (800) Educate or www.educate.com
Special needs camp: www.acacamps.org

Vocational Rehabilitation Resources

Department of Vocational Rehabilitation Offices by state: www.parac.org/svrp.html

Geographically Specific Wage Data

Bureau of Labor Statistics: www.dol.gov/ (yearly metropolitan-area occupational employment and wage estimates); or just www.bls.gov
Occupational Outlook Handbook: www.bls.gov/oco/

Federal Information

Federal government: www.usa.gov
Medicaid phone numbers: http://cms.hhs.gov
Social Security Administration: www.ssa.gov
Web Resources

National Clearinghouse of Rehabilitation Training Materials: http://ncrtm.org
National Center for Dissemination of Disability Research: www.ncddr.org

Storing and Retrieving Information—Database

A life care plan database is an important aspect of what any successful life care planner/case manager will require. Following are several choices of products available. (Be sure to look in the technology chapter of this text for additional explanation.)

**LCPStat version 7** (TecSolutions, Inc., PO Box 2446, Madison, MS 39130)

CONTACT PERSON: Randall Thomas PhD, 601-946-0646; Fax: 601-605-5812

The program is designed for case management, life care planning, and Medicare set-aside reports. The program includes multiple report formats for life care plan reports and summary of cost reports.

Also included is a resource database that allows the user to maintain resources (items and services) with unit costs or costs range. The user may identify a specific vendor, vendor address, and vendor city/state/zip code or geographical location. The user can also identify the specific medical impairment for which the item would be appropriate. The user can select specific items from resources and import those items into a life care plan.

Screen shots of interest sites can be stored in LCPStat v7, or the user can store .pdf or Word documents.

LCPStat v7 is designed for use on Windows 2000/XP/Vista and Macintosh operating systems. LCPStat v7 also includes CPT lookup capability. (CPT codes are copyrighted by the American Medical Association.)

Also include are databases for literature review and a contacts database.

Life Care Planning for the PC

*Life Care Planning for the PC* is authored and copyrighted by Ann Maniha, RN, CLCP, CMC. The life care plan format is created in Word and WordPerfect file formats. The narrative and tables are all in one document. The software has the ability to be completely individualized to specific preferences. The software also has the ability to calculate in the tables. The format layout is easily understood and is reasonably priced. Instructions are included; you will receive both a CD and an instruction manual.

Contact: Ann Maniha, RN, CLCP, CMC, Certified Life Care Planner, Certified Medical Coder; Telephone: 713-861-7633; 713-861-8617; Fax: 713-861-3255.

PlannerPro! Plus, developed by SaddlePoint Software, LLC, is a complete package not only for the professional life care planner, but for the Medicare set-aside allocator and workers’ compensation medical cost projectionist as well.


Features of the software include built-in calculation capabilities, reusable data, including reusable vendor databases, and many print format combinations. Different font sizes and complete report customization are newly added features. Report print options include the ability to define all fields within the printouts, including header, footer, title, and descriptive verbiage for the report fields.
The software also has the capability to export life care plans, Medicare set-asides, and medical cost projections created within the software into a Microsoft Word document or to .pdf-formatted documents. The print options for Word document exports include the ability to set the fonts and font characteristics of the output to Word, and the ability to define and set the types of tables into which the numeric output is inserted. Word options also include the ability to combine numeric data within the narrative, allowing the full editing capacity of Word to be employed within the plan. The same ability to personally define the descriptive fields exists within the Word export option as well as the standard report option. PlannerPro! Plus’s capability to export life care plans into .pdf documents allows the quick and easy delivery of life care plans, Medicare set-asides, and medical cost projections via the Internet, e-mail, or CDs. CPT codes, Level I HCPCS codes, and ICD-9 codes are available for PlannerPro! Plus, in a searchable database, allowing complete and accurate item/services/procedure descriptions in life care plans, Medicare set-asides, and medical cost projections.

CPT is a registered trademark of the American Medical Association (https://catalog.ama-assn.org/Catalog?jsessionid=VGDSQWFR1PCRLA0MRPVX5Q?_requestid=813320).


It is extremely important to be well documented in your research and to be thorough and sure of the quality of information that was obtained. Make sure your definitions of job descriptions (e.g., live-in care) are consistent with the agency’s definition. Considerable anxiety and wasted time will be spared if you set up and follow a strict, structured methodology of information retrieval, collection, and storage.

**Selected Specific Resources**

Examples that have proven valuable in the past are the following.

**Paralyzed Veterans of America (PVA)**

PVA is another great source of information on a variety of topics related to long-term-care planning/case management of catastrophic disabilities. PVA publishes guides for the benefit of veterans with disabilities to help them understand the requirements for receiving benefits, services, equipment, and so forth, from the U.S. Department of Veterans Affairs (VA). The guides explain who is eligible to receive services and equipment and the process of application. It also describes the number and kinds of equipment that are available to veterans, depending upon their entitlement status. This includes wheelchairs, prosthetic and sensory aids, automotive grants/allowances, clothing allowances, and a multitude of other benefits. Of particular relevance to spinal cord injury are the monographs published under the title *The Consortium for Spinal Cord Medicine, Clinical Practice Guidelines* (administrative and financial support provided by PVA). Topics include the following:

- Depression following SCI: A Clinical Practice Guideline for Primary Care Physicians
- Prevention of Thromboembolism in SCI
- Neurogenic Bowel Management in Adults with SCI
- Acute Management of Autonomic Dysreflexia: Adults with SCI Presenting to Health-Care Facilities
- Prevention of Thromboembolism in SCI
- Neurogenic Bowel: What You Should Know
- Outcomes following Traumatic SCI: Clinical Practice Guidelines for Health-Care Professionals
Contact the Paralyzed Veterans of America at:
Paralyzed Veterans of America
801 18th St. NW
Washington, DC 20006-3517

PVA National Headquarters: 800-424-8200
PVA Publications Distribution Center: 888-860-7244
www.pva.org
E-mail: info@pva.org

**Title 38: Veterans’ Benefits**

www4.law.cornell.edu/uscode/
www.access.gpo.gov/uscode/title38/title38.html

To download these documents, scroll to “Federal Register Documents in the News” on the GPO Access Federal Register Page. You can also locate them by searching GPO’s online *Federal Register* for the topic entry shown previously.

To purchase a single copy or annual subscription of the *Federal Register*, contact:

You can also refer to copies of the *Federal Register* at any federal depository library and see page II for order information.

**Special Needs Trust**

Special needs settlements trusts have been in common usage since 1993 and have been used on behalf of individuals with disabilities in litigation since 1978. The trusts have received extensive attention lately and will continue to spark debate or changes over time.

Most trusts are established by court order for settlement or judgment proceeds received on behalf of a litigating party who is severely disabled. The trust’s two basic purposes are:

- To provide an ongoing management vehicle for the settlement proceeds to ensure that the funds allocated to the claimant with the disability are not subject to exploitation or waste
- To preserve the claimant’s eligibility (when properly drafted and in the appropriate situation) for local, state, or federal benefit programs, including Supplemental Security Income, under Title XVI, and Medicaid under Title XIX, of the Social Security Act (42 USC)

Congress amended the Medicaid statute in the 1993 Omnibus Budget Reconciliation Act (OBRA), now codified at 42 USC 396p(d)(4)(A), to expressly recognize the use of such trusts as a means of preserving Medicaid eligibility if certain conditions are met.

Part of the intrigue of a trust is the Medicaid lien. The medical needs of a person with a disability are often funded in part by Medicaid after, say, an accident and before the resolution of the case. Medicaid may be the only source of payment while liability is being contested. All attorneys should know that the Medicaid lien must be satisfied and discharged as part of the settlement process. Usually this process was left to the end of a suit, with the hopes that Medicaid will offer a substantial discount (often 30% to 50% or more of the actual lien). However, this discount may no longer be available. One can no longer leave the treatment of the Medicaid lien
to the conclusion of a case. The Health Care Financing Authority (HCFA) appears to be taking a rather hard line of no compromise of the federal financial participation amount of Medicaid liens. Thus, to avoid the parties discovering at the end of a case that almost the entire recovery could go to the Medicaid lien, this lien must be examined at the front end of a case.

All of this is quite confusing. Each state is handled differently, so there is no blanket answer to questions often posed. The authors suggest that the case manager/life care planner obtain additional information from William L.E. Dussault, Esq., William L.E. Dussault, P.P., Inc., 219 East Gales St., Seattle, WA 98102; phone: 206-324-4300. Mr. Dussault was one of the first to publish data on the special needs trusts and has a network of professionals that specialize in this area.


University of Washington Spinal Cord Injury Update

This newsletter is supported by a grant from the National Institute of Disability and Rehabilitation Research, U.S. Department of Education, to the Northwest Regional Spinal Cord Injury System, one of the model SCI care systems nationwide. The newsletter is issued several times per year and is packed full of information that is a must for all life care planners/case managers.

This newsletter covers topics related to spinal cord injury (SCI) for both health care providers and consumers. Contact: http://sci.washington.edu. Subscribe: scirehab@u.washington.edu.

National Council on Disability

The *NCD Bulletin*, a monthly publication of the National Council on Disability (NCD), is free of charge and is also available in alternative formats on the Internet (www.ncd.gov). It brings you the latest issues and news affecting individuals with disabilities. Contact:

National Council on Disability
1331 F St. NW, Suite 850
Washington, DC 20004-1107
202-272-2004 (Voice)
202-272-2074 (TT)
Fax: 202-272-2022
www.ncd.gov

Information from HEATH National Clearinghouse on Postsecondary Education for Individuals with Disabilities

This newsletter is published three times a year. Contact:

The George Washington University
HEATH Resource Center
2121 K St. NW, Suite 220
Washington, DC 20037
202-973-0904 (Voice/TTY)
800-544-3284
Fax: 202-973-0908
E-mail: askheath@heath.gwu.edu
Viatical Settlements

A viatical settlement is a unique financial resource that allows individuals facing a life-threatening illness to sell their life insurance policy for cash, which can then be utilized for treatment and resources required as a result of the disability. For more information:

- American Council on Life Insurance
  1001 Pennsylvania Ave. NW
  Washington, DC 20004-2599

- National Association of Insurance Commissioners
  444 North Capitol St. NW
  Washington, DC 20001

- National Viatical Association
  1200 G St. NW, Suite 760
  Washington, DC 20005
  www.nationalviatical.org

- North American Securities Administrators Association
  10 G St. NE, Suite 710
  Washington, DC 20002
  www.nasaa.org

- Viatical Association of America
  1200 19th St. NW, Suite 300
  Washington, DC 20036

- Viatical and Life Settlement Association of America
  viatical@cfl.rr.com
  www.sec.gov/answers/viaticalsettle.htm

Through the Looking Glass: Resources for Parents with Disabilities

Persons with disabilities still experience discrimination when it comes to everyday issues, even such basic issues as the human rights associated with reproduction. The ability of mothers with a disability to care for their babies is questioned by health care professionals and the general population. Through the Looking Glass is a nonprofit organization founded by Megan Kirschbaum in Berkeley, California, in 1982. It focuses on preventative services, professional training, and research concerning families with a disability or medical issue for either parent or child. Contact:

- Through the Looking Glass
  2198 Sixth St., Suite 100
  Berkeley, CA 94710-2204
  800-644-2666
  TLG@lookingglass.org
Telecommunications Accessibility

With the advent of the ADA, each state was required to implement a telecommunications system that is accessible to people with disabilities. In Florida, for example, Florida Telecommunications Relay (FTRI) is a not-for-profit organization that administers a statewide Specialized Telecommunications Equipment Distribution Program for hearing-impaired, dual-sensory-impaired (hearing and vision), and speech-impaired Florida citizens. The equipment provided through this program is loaned to all qualified citizens for as long as they need it, at no charge. The FTRI program provides basic access to the telecommunications network as mandated by the Telecommunications Access System Act of 1991 (TASA), Chapter 417, Section III, Florida Statutes.

Every state must have some type of system in place to provide accessible telecommunications. Contact your local telephone service information system, usually located inside the front cover of your local telephone book.

To learn more about Telecommunications Relay Service (TRS), visit the FCC’s website at www.fcc.gov/cgb/dro/trs.html. You can also contact:

Federal Communications Commission
Consumer & Governmental Affairs Bureau
445 12th St. SW
Washington, DC 20554
888-CALL-FCC (888-225-5322)
888-TELL-FCC (888-835-5322) (TTY)
www.fcc.gov/cgb/

Directory for Exceptional Children

The Directory for Exceptional Children is an excellent resource that reflects the growing recognition of the multidimensional needs of exceptional children. Since the organization’s beginning in 1954, each subsequent edition has grown. This is a resource for both families and professionals, with listings encompassing the entire range of developmental, organic, and emotional handicaps. Each listing conforms to a standardized format, making it convenient for referencing and easy comparison of programs.

The 16th edition of the Directory (2007–2008) is a comprehensive survey of 2200 schools, facilities, and organizations across the United States serving children and young adults with developmental, emotional, physical, and medical disabilities. With indexes cross-referencing a range of disabilities, this work is an invaluable aid to parents and professionals seeking the optimal environment for special needs children.

Directory for Exceptional Children, 16th edition
$75, 1152 pages, 2007–2008
Porter Sargent Publishers Inc.
Book Sales and Customer Service
400 Bedford Street, Suite 322
Manchester, NH 03103
800-342-7470
Fax: 603-669-7945
info@portersargent.com
Guide to Summer Camps and Summer Schools

The 31st edition covers the broad spectrum of recreational and educational summer opportunities. Facts from 1700 camps and schools make the Guide a comprehensive and convenient resource.

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c/o IDS
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Manchester, NH 03101
800-342-7470
www.portersargent.com

General Information Sources

Topics in Spinal Cord Injury Rehabilitation

This journal is published quarterly by Thomas Land, www.thomasland.com. This is a peer-reviewed topical journal devoted to multidisciplinary commentary on the management of persons with disability because of an insult to the spinal cord. The topics presented are current on the treatment of patients with spinal paralysis. A special issue on life care planning, coedited by Terry Winkler, MD, and James S. Krause, PhD, is Volume 7, Number 4, published in Spring 2002.

Exceptional Parent: The Magazine for Families and Professionals

Yearly technology/communication/education issues are included with a subscription to the Exceptional Parent. This magazine is a must for any professional working with pediatrics. Not only are the magazines stocked with informative articles, but also the resource sections alone are worth a subscription.

The Neurolaw Letter

This monthly newsletter is a must-read for attorneys and health care professionals involved in brain injury litigation. Each month, The Neurolaw Letter provides practice points, trial techniques, marketing strategies, and hands-on tips that are of immediate benefit to practitioners in this emerging area of jurisprudence. Issue after issue, some of the most respected legal and medical professionals in the field of brain injury offer their insights to recognizing, evaluating, and litigating these challenging cases. Subscription includes a three-ring binder. The annual subscription rate is $96 (12 monthly issues). Contact: www.braininjurybooks.com/legal.html.

Other Sources

The sources mentioned in this chapter are certainly not a complete list of all resources available. The authors’ goal was to present some sources of information that may not be commonly known among life care planning/case management professionals. Not mentioned, of course, are the vast
resources available through the Internet. There have been entire books written on the sources that can be obtained through the Internet.

A chapter on sources would not be complete without mentioning some of the authoritative data available pertaining to life care planning/case management. Certainly, *A Guide to Rehabilitation*, by Paul M. Deutsch and Horace Sawyer cannot be overlooked. This book was formerly published by Ahab Press, but is now out of print. It will be replaced by *Deutsch’s Guide to Life Care Planning and Disability Management*, edited by Paul M. Deutsch. The book is anticipated to be released in 2009 or 2010 by DC Press, 2445 River Tree Circle, Sanford, FL 32771, 407-688-1156.

**Journal of Life Care Planning**

This journal is the only peer-reviewed professional journal dedicated to the practice of life care planning. It is published by Elliott & Fitzpatrick, Inc., Athens, GA (www.elliottfitzpatrick.com or 706-548-8161). Life care planning has evolved into a complex and advanced specialty practice. The goal of this journal is to serve as a vehicle for promoting education and advanced practice. (Managing Editor: Debbie Berens, PhD, debra.berens@comcast.net or 770-978-9212.)

**Certification in Life Care Planning**

Certification for life care planners (i.e., certified life care planner, or CLCP), was the first certifying body for life care planners, and issued the first life care planner certification examination in March 1996. The certification is through the Commission on Health Care Certification (CHCC), now known as the International Commission on Health Care Certification, www.ichcc.org or (804) 378-7273. Later, a nurse only certification formed and is available through the American Association of Nurse Life Care Planners, www.aanlcp.org.

**Conclusion**

This chapter on resources is designed to provide the life care planner with basic information to be prepared for the circumstances that occur in our profession. The heart and soul of the life care planning process is the ability to quickly and efficiently locate resources. Preparedness is the key to a successful life care planning experience.

**Appendix A**

Appendix A is designed to be a questionnaire format used when querying home health agencies on the services available and the related costs.

<table>
<thead>
<tr>
<th>Nursing Research Format</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Provider:</strong></td>
</tr>
<tr>
<td>Telephone: _____________ Fax:</td>
</tr>
<tr>
<td>Contact: _______________ Title:</td>
</tr>
</tbody>
</table>
## Areas of Service (Counties):

Is there a mileage charge in addition to hourly? ___Yes ___No. If Yes: ____/Mile

### Rates: (Private-pay rate for all costs: ___Yes ___No)

<table>
<thead>
<tr>
<th>Service</th>
<th>Rate 1</th>
<th>Rate 2</th>
<th>Rate 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>HHA/hour</td>
<td>$____</td>
<td>$____</td>
<td>$____</td>
</tr>
<tr>
<td>HHA/visit</td>
<td>$____</td>
<td>$____</td>
<td>$____</td>
</tr>
<tr>
<td>LPN/hour</td>
<td>$____</td>
<td>$____</td>
<td>$____</td>
</tr>
<tr>
<td>LPN/visit</td>
<td>$____</td>
<td>$____</td>
<td>$____</td>
</tr>
<tr>
<td>RN/hour</td>
<td>$____</td>
<td>$____</td>
<td>$____</td>
</tr>
<tr>
<td>RN/visit</td>
<td>$____</td>
<td>$____</td>
<td>$____</td>
</tr>
</tbody>
</table>

Minimum # of hours per visit: _________

Live-in: ___Yes ___No  Daily rate: $____

Number of hands-on care hours per day with a live-in: ______

Number of uninterrupted sleep hours for a live-in per night: _____

Definition of live-in services as defined by this specific agency:

When was the last time this agency actually supplied a live-in?

### Case Manager: $____/hour

### Therapies:

<table>
<thead>
<tr>
<th>Therapy</th>
<th>Yes</th>
<th>No</th>
<th>Rate/visit</th>
</tr>
</thead>
<tbody>
<tr>
<td>PT</td>
<td>___</td>
<td>___</td>
<td>$____/visit</td>
</tr>
<tr>
<td>OT</td>
<td>___</td>
<td>___</td>
<td>$____/visit</td>
</tr>
<tr>
<td>ST</td>
<td>___</td>
<td>___</td>
<td>$____/visit</td>
</tr>
</tbody>
</table>

Recreational therapy: ___Yes ___No $____/visit

### Other:

Transportation:

Can staff member transport patient? ___Yes ___No

Personal car? ___Yes ___No  Patient’s car? ___Yes ___No

### Skill Responsibilities:

#### Can Aide Level:

Administer medications: ___Yes ___ No
Perform bowel stimulation: ___Yes ___ No
Administer G-tube feeds: ___Yes ___ No

(Continued)
(Continued)

<table>
<thead>
<tr>
<th>Insert catheter:</th>
<th>___ Yes ___ No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trim finger/toe nails:</td>
<td>___ Yes ___ No</td>
</tr>
</tbody>
</table>

**Can LPN Level:**

<table>
<thead>
<tr>
<th>Perform trach care:</th>
<th>___ Yes ___ No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perform vent care:</td>
<td>___ Yes ___ No</td>
</tr>
<tr>
<td>Trim finger/toe nails:</td>
<td>___ Yes ___ No</td>
</tr>
</tbody>
</table>

An agency may have a policy that aides, trained by RNs, can do certain invasive procedures such as bowel stimulation, catheter changes, etc. Under this arrangement, it is the specific RN training the aide who is ultimately liable and responsible for the activities of the aide. Therefore, in this agency, in practice, are the aides performing such services in their day-to-day activities?

<table>
<thead>
<tr>
<th>Is RN Supervision (included with):</th>
</tr>
</thead>
<tbody>
<tr>
<td>Live-in or aide care: one visit/_________ (week/month/quarter)</td>
</tr>
<tr>
<td>LPN care: one visit/_________ (week/month/quarter)</td>
</tr>
</tbody>
</table>

Is there an extra charge for the RN supervision visit? ___Yes ___ No

If Yes: $_____/visit

**Comments:**

Research by: ______________________________  Date:
Chapter 33

Medical Equipment Choices and the Role of the Rehab Equipment Specialist in Life Care Planning

Paul Amsterdam

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Introduction

The importance of medical equipment in the life care plan has always been a function of the physical impairment of the individual client. The greater one’s physical impairments, the more dependent he or she will be on medical equipment and other assistive technology.

This chapter will address the need for accurate assessments of rehab medical equipment in a life care plan. It discusses the various factors that must be considered in choosing the correct models and types of equipment. Common errors of equipment planning are noted from the author’s experience in reviewing life care plans, with some solutions toward achieving more accurate results. The role of the rehab equipment specialist (rehab technology supplier or assistive technology supplier [RTS or ATS]) is also discussed as a beneficial tool to the life care planner.

Medical equipment has parameters different from other factors of a life care plan. In almost all cases of permanent disability, if there is a need for certain medical equipment at the start of the plan that expense will continue throughout the client’s life expectancy. Medical equipment choices are a very dynamic function of a life care plan as well. Allowances must be made for changes in the type of equipment that will be needed. Some of these changes in equipment will be due to the aging of a client, while others will be from expected physical deterioration of the client. A good example of the latter is the overuse syndrome that becomes common in spinal cord injury clients after years of propelling a manual wheelchair (O’Leary & Sarkarati, 2000).

Allowances must also be made for the repair and eventual replacement of each piece of equipment. Maintenance and replacement schedules vary for different types of equipment, and factors such as manufacturer’s warranty, daily expected usage, and a client’s environment will all play a part in assessing these variables. Maintenance and replacement schedules will be addressed later in this chapter.

Medical equipment is only one area of assistive technology that should be considered for an individual client. According to the Technology-Related Assistance for Individuals with Disabilities Act of 1988 (the Tech Act), an assistive technology device is “any item, piece of equipment, or product system, whether acquired commercially, off the shelf, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities.” Other areas of assistive technology, such as augmentative and assistive communication systems, environmental control units, computer interface technology, and visual impairment technology, may also be needed and considered for the client, but are not primarily discussed in this chapter.
Factors in Choosing Medical Equipment

The predominant factor in choosing the correct medical equipment will be the client’s diagnosis and overall medical assessment. A chronic lumbar sprain requires little in the area of assistive technology, whereas a spinal cord injury resulting in some level of paralysis may require considerable equipment depending on the extent of the injury. The need for equipment is somewhat commensurate with the level of the spinal cord injury. The higher the overall break in the neurological pathway, the more severe the client’s physical involvement; consequently, there will be greater reliance on assistive technology to solve mobility, activities of daily living (ADL), and other day-to-day independent functions.

Another factor in equipment needs is the age of the client. As previously noted, equipment will change as an individual ages, not only due to physical deterioration, but also as an individual’s lifestyle changes. The 4-year-old born with cerebral palsy may start childhood using a therapeutic stroller for mobility, grow into a pediatric tilt-in-space manual wheelchair, and then, through increased function, graduate into a motorized wheelchair.

This also leads to another factor in determining correct equipment. What are the mobility needs for a particular client? Is the client able to manually propel a manual wheelchair, or is powered mobility going to be the primary option for independence? If an attendant must push the client, will a standard wheelchair frame meet his or her needs, or will he or she require something more specialized, such as a reclining or tilt-in-space wheelchair frame?

Often overlooked factors in determining the correct choice in equipment are the environment and lifestyle of an individual client. The equipment required for a T2 paraplegic who is living independently in a rural or urban environment, and has a full-time vocation, will be vastly different than that for a client with the same level of injury who resides in a skilled nursing facility with no occupation. Environment and lifestyle must also be considered when estimating correct replacement schedules for a client’s wheelchair, which will be discussed later in this chapter.

Common Errors in Equipment Recommendations

The author has reviewed many life care plans for several years. The two most common errors found in the equipment recommendations are omissions and exaggeration of need.

Omissions

Omissions of equipment in a life care plan, especially in the plan created for the plaintiff, will hurt the client twofold. Primarily, by not including a needed type of equipment, the cost allowance for that equipment is not included in the client’s immediate assistive technology needs. The omission is then multiplied as many as five times the current amount, by not being part of the economist’s computations for replacements of the omitted item.

Omissions hurt the client in another way. A good life care plan is not just a list of medical costs but, as stated in the Life Care Planning Survey of 2002, is “a comprehensive plan for meeting the individualized and complex service needs resulting from the onset of a disability” (Neulicht et al., 2002). An omission of a certain type of assistive technology may lead a client away from a certain therapeutic road. For instance, the omission of any standing therapeutic aid from the plan for a quadriplegic may never guide the client toward a type of therapy that can be an important part of his or her daily life. As the benefits of standing have been shown to lessen the possibilities of skin
breakdown, osteoporosis, and urinary tract infection, among other things (Stewart, 1992), the omission of the equipment needed for this therapy may very well alter the client’s future physical health and need for additional medical services.

It should be noted that an omission in the plaintiff’s plan does not necessarily mean the equipment should then be omitted in the defense plan. On the contrary, an objective plan should include all needed equipment necessary for proper functioning for the client, regardless of which side created the plan. In Glynn and Davis’s (2001) article on physician-directed plans, they state there should be “no more variation from case to case” (whether plaintiff or defense requested).

**How Do You Avoid Omissions?**

A good first source to help objectively set some equipment choices for a life care plan is the expected functional outcomes tables assembled by the Consortium for Spinal Cord Medicine (1999). These tables delineate between different spinal cord levels of injury and what probable equipment would be needed for a variety of functional activities. These tables, however, are specifically limited to spinal cord diagnoses, and equipment choices are made in general terms, not specific ones.

Another way life care planners can avoid costly omissions in the type of equipment needed is to trace a day-in-the-life-of for their client. The idea here is to try and picture how the client must go through every aspect of his or her day.

When he or she wakes up in the morning, can he or she lift him/herself out of bed? If so, how?

Does he or she require any sort of assistance, either a trapeze bar or safety rail, off the side of the bed?

Can transfers be done independently with the use of a transfer board, or is a caregiver required to use a hydraulic patient lift and sling?

Can he or she dress herself, button his or her own shirts and zip his or her own pants? How does he or she get to the closet or drawers to get the clothes in the first place?

Specific questions should be asked as the client goes into every room in his or her house. Functional mobility, independence in ADL, transportation, and bathroom safety must all be reviewed as the client goes through his or her daily routine. Vocational and quality of life interests must also be addressed to avoid costly omissions. Pressure relief issues, both in sitting and in the bed, must be reviewed; in addition, possible adjunct home exercise and therapies should be addressed. As each area of functional dependence is noted, there are a variety of equipment choices that can then be made.

**Problems in Wheelchair Choice**

The most common instances for omissions occur in the area of wheelchair choice. Because of the amount of complex variables when evaluating a client for a wheelchair, the lifetime choices of models and needed accessories must be examined carefully. There are many different types of manual wheelchairs: standard frames, lightweight, ultralight frames, and rigid ultralights. This does not include the more specialized frames such as recliners, super-low hemi-frames, and adult and pediatric tilt-in-space wheelchairs.

Motorized wheelchairs also are incredibly varied in model and overall function. As an example, in the year 2008, the three largest manufacturers of motorized wheelchairs in this country had over 40 distinct models (source: order forms from Invacare Corporation, Sunrise Medical,
and Pride Mobility). The price of these chairs ranged from $3000 to $30,000. If you are creating a plaintiff’s plan, do all your clients with spinal cord injuries get a $30,000 chair? Likewise, can the defense hold that the least expensive $3000 chair will meet all clients’ power mobility needs?

The answer, of course, is that neither side should delegate choice of model by overall cost. Every client has a range of correct possible wheelchair models that must suit his or her physical and mobility needs. It is a function of the life care planner to determine either through his or her own research or the use of outside experts the correct types of wheelchairs needed and to be able to defend those choices.

Wheelchair Choices

For the purpose of funding durable medical equipment, the federal government’s Medicare program created different allowances with numerical procedure codes and product groups to describe (and pay) for the different types of wheelchairs. These descriptive codes and group designations have now been almost universally used by most of the managed care organizations as a basis for their method of payment for wheelchairs. The codes (although we are not interested in the allowable prices associated with them) are a good method of breaking down wheelchairs into different descriptive categories for the life care planner to utilize as well. The planner should make an examination of his or her particular client’s physical limitations, in regard to the choice of the correct wheelchair category. See also Tables 33.1 and 33.2 for manual and motorized wheelchair considerations.

Table 33.1  Manual Wheelchair Bases

<table>
<thead>
<tr>
<th>Code Type</th>
<th>Description</th>
<th>Utilization</th>
<th>Samples/Price Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>K0001—Standard wheelchair</td>
<td>Weight = 36 pounds Width = 16 or 18 inches Depth = 16 inches Arms = fixed or detachable Footrests = fixed or swing-away</td>
<td>Clients who ambulate or are capable of standing pivot transfer; inexpensive choice for those who are not dependent on a wheelchair as their primary means of mobility, or must be pushed by caregiver</td>
<td>Standard frame from all manufacturers — Invacare Tracers, E&amp;J Vista, and Traveler From $300–$700</td>
</tr>
<tr>
<td>K0002—Hemi (low-seat) wheelchair</td>
<td>Weight = 36 pounds Seat height = 17 or 18 inches Width = 16 or 18 inches Depth = 16 inches Arms = fixed or detachable Footrests = swing-away</td>
<td>Primary need for clients with hemiplegia; enables client to propel chair with one or both feet</td>
<td>Invacare Tracer EX From $500–750</td>
</tr>
</tbody>
</table>

(Continued)
Table 33.1 (Continued)

| K0004 — High-strength lightweight frame | Weight = <34 pounds Width = variable Depth = 14 or 16 inches Lifetime warranty on side frame and cross-braces Back height = adjustable | For individuals who are unable to functionally propel a standard manual frame; excellent choice for older client or for nonpropellers with older caregivers who must lift chair | Invacare 9000 XT Quickie Breezy Series From $850+ |
| K0005 — Ultralight frame | Weight = <30 pounds Width = variable Depth = variable Lifetime warranty on side frame and cross-braces Adjustable rear-axle system | For highly active wheelchair user; spinal cord injuries, spina bifida, or any other client using a manual wheelchair as the primary means of mobility | Quickie 2 Quickie GPV and R2 Invacare MVP Invacare A4 and A6 All Tisport/Tilite Wheelchairs From $1600+ |
| K0009 — Other manual wheelchair bases | May include tilt-in-space wheelchair frames or other custom-designed frames to meet individual needs | Clients with significant positioning issues, pressure issues, limitations in range of motion | Invacare Solara Quickie TS Freedom Design Libre From $3000+ (does not include a seating system) |

Table 33.2 Motorized Wheelchair Bases

<table>
<thead>
<tr>
<th>Power Groups</th>
<th>Description</th>
<th>Utilization</th>
<th>Samples/Price Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 1 — Motorized wheelchairs</td>
<td>Frame = portable Electronics = little adjustability or programmability</td>
<td>Client is not able to functionally ambulate or propel a manual wheelchair; client should have good upper-extremity control without cause for future progression</td>
<td>Invacare ATM</td>
</tr>
<tr>
<td>Group 2 — Motorized wheelchair with programmable controls</td>
<td>Consumer Power chair group electronics must have limited programmability to adjust parameters for speed, tremor dampening, acceleration, and braking. This group does not allow for advanced switch options. Majority in this group have captain or van style seating.</td>
<td>Clients with orthopedic or respiratory conditions that present overall weakness. They are unable to self propel a manual wheelchair.</td>
<td>Invacare Pronto Series Wheelchairs Pride Jazzy models From $6000+</td>
</tr>
</tbody>
</table>
Group 3 — Motorized wheelchairs

| Allow for advanced electronics; single or multiple power seating functions such as power tilt and recline. | Clients with neuromuscular or progressive disorders that require more involved mobility functions and alternative drive controls. The client with poor trunk control or at a higher risk of skin breakdown is common. | Invacare TDX SP   Quickie PULSE 6 or Rhythm models   Permobil C300   Pride Quantum Series |

Group 4 — Motorized wheelchair bases

| High-performance model motorized wheelchairs with advanced electronics and increased speed, designed for more outdoor use. | For the highly active clients utilizing their chairs as much or more outdoors than inside. (Note: these chairs are not approved for funding by Medicare.) | Invacare Arrow   Quickie P-222 and S646   Permobil C500   Omega Trac Innovations in Motion 4 x 4 |

Questions to Consider

- Can the client functionally propel a manual wheelchair?
- Will the use of a lighter-weight frame benefit overall mobility?
- Before advancing to a motorized chair, will the use of the manual wheelchair provide the client with the most probable means toward daily exercise, continued range of motion, and easier accessibility throughout the home and workplace, and via transportation?
- Will the client require customized programming or the use of specialized switches (e.g., sip and puff, or head arrays) that necessitate a motorized wheelchair with higher-end electronic capabilities?
- Would the need for power-actuated positioning systems such as power recline, power tilt in space, or a standing frame be substantiated, or would these functions be generally unused by the client and perhaps just make the chair overly heavy and cumbersome (not to mention far more expensive)?

Accessories Required

By far the greatest omission seen in life care plans for wheelchair considerations is in the area of accessories. All of us have had the experience of wanting to buy a large item, such as an automobile. We may first be attracted to an ad claiming a very low sticker price. After going to the retailer, reviewing options and accessories, you could not drive out of the showroom without the automobile, now costing you sometimes thousands of dollars more. There is little difference when having to purchase a new wheelchair, only in the case of the wheelchair, many of those options may truly be a medical necessity for the overall function of your client. These accessories fall into the following adjunct consideration categories.

**Pressure Reduction**

There are currently over 200 different wheelchair cushions on the market today. The prices of these may range from $20 to $2000. In my experience, few will benefit from the quality of a
$20 cushion, but just as few would ever require cushions in the $2000 category. One excellent guide to proper cushion choice is the use of a skin assessment system, such as the Braden scale. When skin risk is determined, the range and type of possible cushion choices can be both narrowed down and substantiated.

When noting a cushion for the life care report, like the wheelchair itself, a replacement schedule must be set up. Inexpensive foam cushions will have a far shorter replacement life than some of the more expensive pressure equalization cushions, such as a Roho or Jay 2. It should be noted that many of the higher-priced cushions have far longer warranties as well. On many life care plans, I have often seen replacement of a Roho cushion after only 2 years, when the manufacturer fully warranties this product for the same 2 years. Additional cushion covers should also be taken into account. Providing an extra cover initially with a cushion will substantially extend the overall replacement needs for the cushion, as well as provide for needed cleanliness issues.

Custom Therapeutic Seating Systems

Many clients require the use of therapeutic seating in the wheelchair. Limits in range of motion, weaknesses or excessive muscle tone, trunk instability, or spinal deformities may all necessitate adding some range of customized seat and back systems. This may include other features, such as thoracic or pelvic supports, abductor wedges, chest harness, specialized head supports, or upper-extremity support trays.

How much therapeutic seating an individual client will need may be something the life care planner should research with that client’s former therapists or other rehab technology seating specialists, before noting it in the life care plan. (Also see section on utilizing references and outside experts at the end of this chapter.)

Prices for seating systems may be as low as $400 or over $6000. In many cases it is equal to or more than the frame of the wheelchair. It should require references to modifications for growth, repairs, and replacements. Consequently, this is one aspect of the equipment report that cannot be omitted.

Mobility and Accessibility Features

Many of the features we commonly see on a wheelchair, such as the armrests and footrests, are not necessarily included in the base price of the wheelchair. Some chair models may include some of these as standard features, but there is a good chance the accessories needed by your client will not be the standard styles provided. A particular model of ultralight wheelchairs may have as many as six to eight different armrests or footrest configurations to choose from. This may add an additional $175 to $400 to the price of the chair.

The choice of wheels will vary from molded composite to lightweight spoke wheels. The choice of tires and front casters can make significant changes in both a wheelchair’s performance and cost. Standard hand rims are made of either chrome or aluminum, but vinyl- or plastic-coated ones are also available. Projection hand rims in both vertical and offset styles may be a medical necessity for clients with limited fine-motor coordination. As noted on an ultralight wheelchair order form from TiSport Corporation, there is currently a set of ultralight, highly durable wheel spokes under the brand name Spinergy that will add over $600 to the base price of a wheelchair, but may greatly enhance the suspension and mobility for some active clients.
Some mobility and accessibility features for motorized wheelchairs are not so obvious. One particular feature commonly recommended is a swing-away joystick mount. Without this device, most clients using a motorized wheelchair would be unable to bring the chair up to a dining table or desk. The device will in turn add an additional $300 to $400 to the base price of the power chair. Some clients may also benefit from a power seat actuator. At the push of a lever, this system will allow the seat of the power chair to raise about 8 to 11 inches from its standard height to enable the client to reach items that would normally be inaccessible.

**Safety Features**

Most accessories needed for wheelchair safety are usually not that expensive, but one would be negligent to omit them in the wheelchair order. Seatbelts and chest harnesses may be the first items that come to mind, but certainly most common is a pair of rear anti-tipping levers. As wheelchairs have gotten lighter and more adjustable, the anti-tippers have become more of a safety necessity. Clients who are amputees may also benefit from a chair that has been modified with amputee adapters to change the center of gravity on the rear wheels.

**Convenience and ADL Features**

There are many accessories that may not be considered medical necessities, yet greatly enhance a person’s ability to carry on with normal activities of daily living. One must remember that a life care plan should reflect all necessary items and that services reflect their needs with consideration for the jurisdiction.

Some items that come to mind are backpacks and seat pouches for the client to easily carry items. Also available are fold-up luggage carriers and cup holders. For those who use a pair of crutches or cane for short-distance ambulation, a crutch or cane holder becomes a needed feature. One item overlooked in many life care plans for clients who actively propel wheelchairs is a good pair of wheelchair gloves. As the active user will wear out gloves quickly, at least two pairs per year should be allowed for in a plan.

**Exaggeration of Needs**

The second common error regarding equipment choices in a life care plan is exaggeration of needs. Gass and Gonzalez (2001) in their article discuss the overall effects of gross exaggeration to a life care plan. Where omissions may affect a plan by not allowing for certain needed equipment or specific features, gross exaggerations of equipment needs may affect the overall credibility of the entire life care plan.

A life care planner is not necessarily basing his or her equipment choices strictly on medical necessity, but must be able to justify these choices in relationship to the functional needs and abilities of the client. For example, it would be difficult to justify a $12,000 alternating-pressure/low-air-loss mattress replacement system for a client with full skin sensation, ability to independently weight shift and transfer, and no previous history of skin breakdown. Likewise, an expensive high-performance ultralight titanium wheelchair is not the proper choice for a client who does not have the cognitive ability to self-propel a manual wheelchair.

As previously noted, the choices and price range of motorized wheelchairs are enormous. Unfortunately, this seems to encourage some in life care planning to pick only from the top end of this range, without regard to true individual need. This author has had to write an opinion
on a plaintiff’s life care plan that recommended a $30,000 motorized wheelchair with a power-actuated standing frame for a client who independently stands and ambulates with forearm crutches throughout his or her residence. It would only take a few examples of this type of gross exaggeration for a defense attorney to question the credibility of all the equipment choices and perhaps the credibility of the life care planner.

Setting Standards of Protocol for Replacement Schedules of Medical Equipment in a Life Care Plan

One controversial factor in life care plans has been the replacement schedule allowances for medical equipment (R. Weed, personal communication, April 20, 2002). As it is fundamental that all equipment have a usable life expectancy when listing medical equipment for a life care plan, it is likewise fundamental that each piece of equipment has a noted replacement schedule. This is especially true of the more major purchases such as beds, pressure support systems, and wheelchairs.

How crucial is the accuracy of the figures? As an example, consider the case of a 25-year-old tetraplegic who has a life care plan that lists a motorized wheelchair with a power-actuated tilt-in-space system and standing features, programmable controls, and other needed accessories. The manufacturer’s list price is noted at $31,000. One life care planner projects replacement of the chair every 4 years, while the other life care planner says every 5 years. Based on a life expectancy of 69 years, the former planner allows for 10 replacement chairs; the latter only 8. The overall difference between the life care plans would be $62,000. This of course is not discounted to present value and does not take the economist’s adjustments for inflation into account.

Even with less expensive equipment, such as a Jay pressure relief cushion with a list price of $425, the differences in replacement allowances can show some significant variances. In reviewing plans, the author has observed that replacement for these cushions ranges from 2 to 5 years. Continuing to use the previously noted client as an example, the 5-year allowance equates to eight replacement cushions at a total plan cost of $3400. The 2-year allowance equates to 20 replacement cushions at a total price of $8500 (not discounted to present value), for a difference of $5100 between the two plans.

Even more problematic than the variance in costs between plans is the lack of any accurate standards to compute replacement allowances. This lack of any prescribed standards can easily allow an attorney to question not only the accuracy of the replacement costs of a particular plan, but also the accuracy of the methods of computation for all other medical equipment costs and allowances.

So what factors must be taken into account when figuring replacement schedules for equipment? The first factor to consider is the manufacturer’s warranty of the particular piece of equipment being recommended. The implied expectation of any warranty is that the piece of equipment will last throughout the length of the warranty period. If the equipment is defective, the warranty allows for replacement or compensation with little to no cost to the user. In our homes most of us utilize equipment far beyond the expiration of the manufacturer’s warranty. It is not uncommon to have the same refrigerator, stove, or washer for over 10 years, while the warranty on these items may expire after only 1 year.

In the author’s experience, many life care plans include replacements of certain items that do not even meet or barely exceed the manufacturer’s warranty of the product. The aforementioned Jay cushion has a complete replacement warranty (other than the cover) for up to 2 years, and if properly maintained (occasional cleaning and kneading of the gel pad and replacements of covers), the cushion’s life expectancy should at least double the warranty.
Most items referred to as durable medical equipment are well described. That is to say, they are quite durable. Most standard commodes, tub rails, tub benches, and folding walkers have a lifetime warranty; however, it should be noted that a lifetime warranty does not preclude a replacement allowance for these items. Over a period of time, any of these items will show excessive wear and tear. This is particularly true of any items with many moving parts that will become shaky with time, or items that have padding that can eventually tear or wear out. Some pieces of equipment such as a trapeze bar attached to a floor stand are so durable and their everyday usage sufficiently limited that their replacement can safely be expected to last 10 years or more.

In addition to the warranty and its relationship to replacement allowances, the life care planner must also take into account the need for repairs and maintenance to a piece of equipment. A pair of forearm crutches should last a client 3 years, but the crutch tips will have to be replaced perhaps twice a year. The Jay pressure relief cushion previously referenced has a longer life than many allow for, but the removable covers should be replaced yearly. (A better strategy is to allow for the purchase of two covers when first buying a cushion, in order to alternate their use while cleaning, and then allow for twice the replacement time, i.e., 2 years for each cover.)

Repairs versus replacement becomes a far more complicated equation when one is considering more complex pieces of equipment with more parts, such as manual wheelchairs or power-actuated products, like electric hospital beds, air-powered support surfaces, and motorized wheelchairs.

When including a hospital bed in a life care plan, it is important to note that hospital beds have a lifetime warranty on all the welds of their frame (Invacare Corporation and Graham-Field, Inc., product warranty information, 2002). It is extremely rare for these frames to require repairs. Conversely, the mechanisms for adjustment, such as the shafts, motors, and hand controls, will require repair or replacement, and an allowance for maintenance should be made. Likewise, the mattress should be replaced every 4 to 5 years. There are certain factors that must be taken into account, such as the weight of the client, the daily usage of the bed (for less active clients), and the use of higher-end support surfaces or flotation mattresses that either put less stress on the mattress itself or entirely replace the standard hospital bed mattress. (The author has seen a number of life care plans allowing for replacement of hospital bed mattresses when the client is using none.)

Wheelchairs categorized as high-strength lightweight or ultralight must have a lifetime warranty on the side frame and cross-braces (Centers for Medicare and Medicaid Services, 2002). The other working parts of the chair are usually covered by a limited warranty of 1 year, excluding wear and tear or abuse. (The manufacturer many times upon return of a broken or defective part will determine if there was abuse of the product.) Likewise, there is a minimum of a 5-year-to-lifetime warranty for the frame of a motorized wheelchair, and the electrical components all have a life expectancy minimum of 1 to 2 years (Invacare Corporation, Sunrise Medical, and Pride Mobility Products Corporation product warranty information, 2002). When recommending either a manual or motorized wheelchair, the life care planner should include maintenance and repair allowances, but after time must consider that the frequency of repairs and the overall wear on the frame will necessitate a replacement of the equipment.

Determining the replacement allowance for a wheelchair is a process that currently seems to lack any standardization or protocol. In Kendall and Deutsch’s (2002) article on research methodology, the authors state that life care planning is a “standardized process” (p. 158). They further assert, “If Life Care Planning is a reliable tool in Case Management and the provision of patient care, then the results of a given LCP can be consistently replicated” (p. 157).

However, in reviewing life care plans, the author has observed that similar models of wheelchairs may be assigned a replacement with as little as 2 years or as great as every 10 years. Although there may be a valid reason for the 10-year replacement, such as a rarely used backup chair, the plan...
rarely includes any notation as to the justification for a replacement number given. As shown in the examples given earlier in the chapter, these variances, when multiplied by a young client’s life expectancy, can add up to significant cost differences in opposing plans.

There are a variety of factors that will have an effect on the replacement allowance for a wheelchair. Some of these factors will reduce the life of a chair, while others will add to its life. It is necessary for the life care planner to consider which factors are inherent in an individual client’s lifestyle and account for those factors in the life care plan. By using a standardized format, taking the factors noted in the following into a weighted scale for replacement allowance, both greater reliability for the individual life care plan and greater consistency, reliability, and validity for the life care planning process as a whole should be achieved.

**Contributing Factors to Replacement Time for Wheelchairs**

**Age**

The age of the client is the first contributing factor. Everyone’s general activity level differs throughout different age ranges. The greater the activity level of an individual, the more wear and tear on the frame of a wheelchair.

Most children (4 to 16 years) are very active, and those children who are wheelchair dependent are no exception. They usually are attending school 5 days a week, and when not in classrooms, most are playing with other children. Athletic programs now include children in wheelchairs in a large variety of games and events. The Special Olympics and other athletic associations for children with disabilities are a part of many school and recreation programs nationwide.

Moreover, children grow. Growth is a factor that must be addressed in each child on an annual basis. This is not to say a child will require a replacement of the wheelchair each year, because the majority of pediatric wheelchair frames are built with adjustability for growth. A qualified RTS or ATS will always try to allow for a maximum amount of growth in relationship to the current measurements of a child. Sometimes, a child’s measurements fall between two sizes of wheelchair frames, and less growth must be allowed for proper propulsion of a manual wheelchair. This is less of a concern in motorized wheelchairs, where the ability to reach a joystick is far more adjustable than the ability to properly reach two hand rims. In the author’s experience, pediatric wheelchair frames generally will last the child from 4 to 5 years, with growth being modified and accounted for.

Growth also must be accounted for not just in the frame of a wheelchair, but also in any custom seating system for children. This too is easily accomplished through quality evaluations performed by rehabilitation professionals when first designing the seating system. All seating systems should have about 4 to 5 years of growth built into them. One exception to this rule is custom-molded seating systems, such as Contour U or the Otto Bock OBSS systems. As these systems are created utilizing an actual body mold of the child, there is far less available growth that can be built into them.

Young adults (ages 16 to 30) are also highly active, and from the teens through the early twenties, the average individual is still attending school. Many are propelling for longer distances, especially throughout college campuses. In general, this age group is far less sedentary, and the population who are wheelchair dependent are now spending far more of their time with able-bodied friends and out in the community than ever in the past. Most are in the same wheelchair for as much as 18 hours per day, 7 days per week. Some also have become involved in wheelchair sports on a far more aggressive level (although the more serious of these athletes will probably purchase or utilize a separate sports wheelchair for their particular game). Again, the greater the activity level, the more wear on the wheelchair overall.
Adults (ages 30 to 65) in general will tend to have a bit lower activity level. Many wheelchair-dependent individuals will be married, have families, and spend more time at home. Many who are working in offices are indoors in more confined spaces throughout the day, putting far less stress on the wheelchair frame. This is not to say that many individuals of this age range are not active in the community or their careers, but the stress on the wheelchair in this type of lifestyle is far less.

Senior citizens (over 65) as a rule have a lower activity level. Many who are using manual wheelchairs (even lightweight frames) may not have the endurance or strength as they age to manually propel the chair long distances or in more difficult outdoor environments. Many may not be able to self-propel at all and are pushed by an attendant. With such a lower activity level, the replacement schedule for the wheelchair should obviously decrease.

**Environment**

Where the wheelchair is being used will also affect its replacement allowance. A suburban and urban environment where there are mostly paved sidewalks, graded curb cuts between streets, and, thanks to the Americans with Disabilities Act, far more wheelchair-accessible buildings puts only limited fatigue on the wheelchair.

Clients who live in a more rural environment, with far less of the previously noted accommodations, will fatigue the frames of their chairs quicker. Hills, rocks, and soft earth not only put more wear and tear on the frame, but also require more frequent repairs to the chair.

On the other hand, individuals who live in a skilled nursing facility will put far less stress on the wheelchair. The linoleum floors, fully accessible environment, and inferred lower activity level will increase the overall lifetime of the wheelchair.

**Behavior**

How an individual behaves in a wheelchair can greatly influence its replacement. This factor is more relevant for those in manual wheelchairs, as an individual with uncontrolled behavioral problems should probably not be driving a motorized wheelchair. The first instance to consider is whether your client can self-propel a manual wheelchair at all. If the client does not self-propel, due to either physical or cognitive deficits, his or her overall activity level in the wheelchair will usually be far less than that of those who functionally propel their chairs.

Some individuals may exhibit hyperactive, athetoid, or extreme self-stimulation behavior. All of these behaviors, which may result from developmental delays or clients with serious head injuries, will stress parts of a wheelchair frame. The author works with a large population of institutionalized clients who all incessantly perform some type of self-stimulation behavior in their wheelchairs. For example, they may slam their bodies back and forth in a rocking motion for hours while seated in a chair, and others, if not controlled, may beat the sides of the wheelchair with their fists, or, in transferring, will forcefully propel themselves into or out of the chairs. Any of these extreme behaviors will have an effect on the lifetime of the chair.

**Body Type**

Clients who are obese or are close to the weight limitations of a certain wheelchair frame will obviously put more overall wear on the chair. Most wheelchairs come with a 250-pound weight limitation; however, there are custom bariatric frames that are capable of supporting an individual
weighing between 600 and 1000 pounds. Obviously, the higher the weight limitation, the more it will compensate for this weight factor.

**Lifestyle**

How the client spends the majority of each week is another factor that should be considered. Does the client spend most of each day at home, or does he or she go into an office or a school 5 days a week? If so, how is the client transported? It should be noted that the very act of securing a wheelchair onto a van or school bus twice a day for a long ride will lead to some wear, as the vibrations on the frame will eventually cause the bolts to oval out the holes in the frame. Wheelchair manufacturers and research facilities routinely test their frames in a double-drum vibration sled to count how many cycles will lead to frame damage (Johnson, 1996; Vitek et al., 2001).

Lifestyle must also be reflected when choosing the appropriate model of wheelchair for the client. If the client is an active self-propeller, the chair prescribed should be a high-strength ultralight frame. Various studies have tested the durability and cost comparisons of different wheelchair frames, and it has been shown that ultralight rehabilitation wheelchairs are the most cost-effective over the life of the wheelchair, costing 3.4 times less (dollars per life cycle) than depot (standard frame) wheelchairs and 2.3 times less (dollars per life cycle) than the lightweight wheelchairs tested in the study (Cooper et al., 1997). Likewise, if the client is obese or exhibits self-stimulation behavior, a heavy-duty or even custom-reinforced frame is required. Similar appropriateness of correct model selection must be assured in calculating the replacement of a motorized wheelchair.

One note in considering a lifestyle should be when your client has both a motorized and manual wheelchair. In most cases, the manual wheelchair will be used as a backup, so consequently its overall use may be far more limited than the use of the motorized wheelchair throughout the week. This too must be taken into account when projecting replacement schedules.

**Replacement Allowance Worksheets**

The author first introduced the following worksheets to participants of the Life Care Planning Summit in Chicago, Illinois, on May 18, 2002. At that time, first drafts of the worksheets, based on available data, were sent to over 20 life care planners throughout the country for their comments on both accuracy and ease of use. Initial changes were made, and the worksheets were then sent to another eight volunteers for additional comments. Responses from the life care planning community from both mailings were about 20% of all those sent.

It is hoped by the author that the worksheets will be considered a tool to improve the overall reliability of life care plans in the area of wheelchair replacement. By accounting for the factors described in this chapter, the assigning of a replacement value for a wheelchair can be better defended with a more objective basis. It is further hoped that this tool can be adjusted and improved with time by communication with the author as various life care planners utilize and perhaps supplement the worksheets based on the uniqueness of their individual cases.

**Estimated Replacement Schedule Assessment Form**

**Manual Wheelchair**

All medical equipment will eventually wear out and must be replaced. The frequency of replacement is dependent on the individual using the equipment and various factors in his or her life. Two assumptions must be made for this worksheet:
1. The wheelchair frame is appropriate for the lifestyle of the client (i.e., if he or she is an active self-propeller, this should be a high-strength ultralight frame). If the client is obese or exhibits self-stimulation behavior, a heavy-duty reinforced frame may be required.
2. Routine maintenance is done on an annual or as-needed basis.

The following worksheet will assist the rehabilitation consultant with evaluating the factors and how they affect the overall replacement schedule of each item. Each of the factors will either add to or subtract from the life of the equipment being used.

Identify factors that affect your client, and then apply them to the chart based on the *value* instructions. The adjusted replacement time in the lower-right-hand corner will be the estimated weighted replacement schedule for the particular piece of equipment.

<table>
<thead>
<tr>
<th>Additional Determining Factors</th>
<th>Value</th>
<th>Effect on Replacement Time</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age:</strong> If client is …</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4–16 years</td>
<td>–1 year</td>
<td></td>
</tr>
<tr>
<td>16–30 years</td>
<td>–0.5 year</td>
<td></td>
</tr>
<tr>
<td>30–65 years</td>
<td>No change</td>
<td></td>
</tr>
<tr>
<td>&gt;65 years</td>
<td>+1 year</td>
<td></td>
</tr>
<tr>
<td><strong>Environment:</strong> If client lives in …</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Suburban or urban</td>
<td>No change</td>
<td></td>
</tr>
<tr>
<td>Rural environment</td>
<td>–0.5 year</td>
<td></td>
</tr>
<tr>
<td>Skilled nursing facility</td>
<td>+1 year</td>
<td></td>
</tr>
<tr>
<td><strong>Behavior:</strong> If client …</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can self-propel</td>
<td>No change</td>
<td></td>
</tr>
<tr>
<td>Cannot self-propel</td>
<td>+1 year</td>
<td></td>
</tr>
<tr>
<td>Has self-stimulation, athetoid, or other hyperactive behavior</td>
<td>+2 year</td>
<td></td>
</tr>
<tr>
<td><strong>Body Type:</strong> If client is …</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Over 250 pounds</td>
<td>–0.5 year</td>
<td></td>
</tr>
<tr>
<td><strong>Lifestyle:</strong> If client …</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is highly active adult</td>
<td>–0.5 year</td>
<td></td>
</tr>
<tr>
<td>Locks wheelchair into a van or school bus several times per week</td>
<td>–0.5 year</td>
<td></td>
</tr>
<tr>
<td>Is using manual chair as a backup for a power chair</td>
<td>+2 years</td>
<td></td>
</tr>
</tbody>
</table>

**Adjusted replacement time** =
Estimated Replacement Schedule Assessment Form

Motorized Wheelchair

All medical equipment will eventually wear out and must be replaced. The frequency of replacement is dependent on the individual using the equipment and various factors in his or her life. Two assumptions must be made for this worksheet:

1. The appropriate model of motorized wheelchair has been chosen to meet the lifestyle, environment, and weight capacity of the client.
2. Routine maintenance is done on an annual or as-needed basis.

The following worksheet will assist the rehabilitation consultant with evaluating the factors and how they affect the overall replacement schedule of each item. Each of the factors will either add to or subtract from the life of the equipment being used.

Identify factors that affect your client, and then apply them to the chart based on the value instructions. The adjusted replacement time in the lower-right-hand corner will be the estimated weighted replacement schedule for the particular piece of equipment.

<table>
<thead>
<tr>
<th>Client Name: ______________________________  Date of Birth: _____________</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Additional Determining Factors</strong></td>
<td><strong>Value</strong></td>
<td><strong>Effect on Replacement Time</strong></td>
</tr>
<tr>
<td><strong>Age:</strong> If client is …</td>
<td>Then +/- from 5 years</td>
<td></td>
</tr>
<tr>
<td>4–14 years</td>
<td>–1 year</td>
<td></td>
</tr>
<tr>
<td>14–30 years</td>
<td>–0.5 years</td>
<td></td>
</tr>
<tr>
<td>30–65 years</td>
<td>No change</td>
<td></td>
</tr>
<tr>
<td>&gt;65 years</td>
<td>+1 year</td>
<td></td>
</tr>
<tr>
<td><strong>Environment:</strong> If client lives in …</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Suburban or urban</td>
<td>No change</td>
<td></td>
</tr>
<tr>
<td>Rural environment</td>
<td>–0.5 year</td>
<td></td>
</tr>
<tr>
<td>Skilled nursing facility</td>
<td>+1 years</td>
<td></td>
</tr>
<tr>
<td><strong>Body Type:</strong> If client is …</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Over 300 pounds</td>
<td>–0.5 years</td>
<td></td>
</tr>
<tr>
<td>Very ataxic or has high muscle tone of upper extremities</td>
<td>–0.5 years</td>
<td></td>
</tr>
<tr>
<td><strong>Lifestyle:</strong> If client …</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is highly active adult</td>
<td>–0.5 year</td>
<td></td>
</tr>
<tr>
<td>Locks wheelchair into a van or school bus several times per week</td>
<td>–0.5 year</td>
<td></td>
</tr>
</tbody>
</table>

Adjusted replacement time =
Use of References and Specialists

There are a variety of sources life care planners can use to create their list of the most optimal equipment and most accurate prices for their clients. One of the most common methods is to obtain the original list of equipment a client was provided when he or she left the rehab facility after the injury. Although this is an excellent first step, it may be far from a complete list of all the client’s equipment needs. Some of the flaws with this method that must be recognized are as follows:

- **Time Factor:** If a great deal of time has passed since the original equipment was provided to your client, his or her physical condition may have changed (either better or worse).
- **Environment or Vocational Changes:** The client may have moved to a different home that requires other types of equipment, or the life care plan may be providing for a new, more accessible environment, which may change some of the equipment choices. Current or future vocational options must be considered as well.
- **Funding Issues:** When the original equipment was provided, the client’s funding source may not have allowed for higher-quality models, or a large segment of equipment, such as independently controlled ceiling lifts, environmental controls, or computer interfaces built into the power wheelchair. The life care plan must address all equipment to provide the client with the highest possibility of independent function.

Prices for medical equipment are another area of possible contention in the report. As previously noted, by omission of various accessories, the price of a particular wheelchair may be vastly inaccurate. A more important point is what source a life care planner uses to acquire prices. The author has seen a variety of different sources used for price submission to the plan:

- Catalogs
- Internet sites
- Calls to medical equipment providers in the client’s local area

There is a possible problem utilizing any of the previous sources to obtain prices. Many catalog and Internet sites are quoting extremely discounted prices for equipment. Some of these prices may be a result of overstocked merchandise or a particular price passed on by a manufacturer. When the client finally (possibly years later) receives a judgment on the case, and must now purchase his or her own equipment, he or she may not be able to receive an equivalent discount as to what was originally quoted. Likewise, when a life care planner calls a local vendor and requests a price, he or she may not be sure if the price has been discounted or possibly increased.

It has been the author’s contention in past articles and lectures (Amsterdam, 2001, 2002) that the most objective price that should be used for a life care plan is the manufacturer’s suggested list price (MSLP). As this price is provided by every manufacturer and is consistent throughout all 50 states, it provides the only true objective basis for accurate pricing. The MSLP is also always a price that the client should be able to obtain from any reputable equipment provider.

The Use of Rehabilitation Equipment Specialists as Consultants

If a client’s physical disabilities are more involved, it may be beneficial to consult with a rehab equipment specialist. It is important to realize that the medical equipment industry, like all other
branches of health care, has many areas of specialization. There are medical equipment companies that specialize in respiratory supplies, others strictly in the enteral or IV therapy business, and some whose primary income are as physician or hospital suppliers. Any of these companies can buy and distribute wheelchairs and other durable medical equipment, although they may have little, other than cursory, knowledge in proper evaluation of a rehab client.

Rehab equipment suppliers (RTS) are individuals who specialize in the needs of clients with permanent disabilities. They are usually employed in a firm that is in the primary business of rehab medical equipment evaluation and distribution. An RTS can go through a national certification or credentialing process; the most recognized curriculum was developed through RESNA (the Rehabilitation Engineering and Assistive Technology Society of North America). Those passing this certification process attain the credentials of ATS (assistive technology supplier). A therapist who passes the same curriculum attains the credentials of ATP (assistive technology practitioner). If the individual is also a member in good standing with NRRTS (the National Registry of Rehabilitation Technology Suppliers; 2003), he or she may also be recognized through the trademarked credential of CRTS (certified rehab technology supplier). RESNA and NRRTS both provide a directory of certified specialists on their websites.

Certified ATS/CRTS specialists are working in rehabilitation hospitals, state developmental centers, and schools for children with disabilities, evaluating clients for equipment needs on a daily basis. Utilizing the expertise of a certified ATS will help you get the best idea of your client’s current and future equipment needs. He or she can provide you with accurate pricing based on MSLP if requested, as well as help add greater defensibility to the equipment section of the overall plan.

Conclusion

For many with permanent disabilities, the lifetime use of rehabilitation medical equipment, such as a custom wheelchair, may be the one aspect that separates their lives from the rest of the able-bodied world. As technology improves, providing lighter materials and more functionality, new models of equipment will be continually introduced, and the job of the life care planner to include the correct type of equipment in a plan will only get more difficult. When equipment costs are a large segment of a particular life care plan, costly errors of omission and tendencies to exaggerate medical needs can be used by opposing attorneys as focal points of contention. Better systems of protocols must be used for replacement schedules, as well as the ascertaining of accurate prices. The use of rehab equipment experts is increasing in the life care planning industry, and life care planners who are working without such expertise may have a harder time defending their choices in a court of law.

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Chapter 34

Home Assessment in Life Care Planning*

Jim Karl and Roger O. Weed

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Introduction

Of the originally published life care planning format, two pages or categories, Home Furnishings and Accessories, and Architectural Renovations, were dedicated to addressing requirements associated with living at home for clients with catastrophic injuries or complex chronic health care needs (Deutsch & Raffa, 1981; Deutsch & Sawyer, 1985). The category related to home furnishings is generally understood to incorporate equipment and supplies, typically of a “medical” nature, such as with durable medical equipment and other required equipment. Examples include specialized beds and skin care mattresses, patient lift systems, and portable ramps (Deutsch & Sawyer, 1985; Weed & Field, 2001; Weed & Berens, 2006). Similarly, the category related to architectural renovations provides for permanent alterations or modifications to a structure. Examples include accessible bathrooms, accessible entrances, wider doorways, modified kitchens, changed floor coverings, and so on. However, in many situations, an existing structure may require such extensive modifications that the task is impossible to achieve or the cost–benefit analysis results in a decision to design and build a new home that more appropriately fits the client’s needs.

The life care planner must also recognize that some clients will not have the funding to fully achieve recommended modifications or housing design, and such home furnishings and architectural renovations recommendations should be prioritized based on the level of necessity to achieve maximum value. This chapter will offer an overview of a suggested life care planning process for home assessments, including the recommended qualifications of the professional on whom the life care planner may rely for appropriate home assessment recommendations.

Home Assessment in Life Care Planning

Qualified life care planners are trained to evaluate a client’s needs for specialized housing and home modifications in addition to future medical care and other factors (Deutsch & Sawyer, 1985; Weed & Field, 2001; Grisham, 2004; Weed, 2004). Example conditions that may merit evaluation for specialized home equipment, renovations, or environmental requirements include spinal cord injury (Ford & Duckworth, 1987; Winkler & Deming, 2004; Winkler & Weed, 2004a), amputation (Meier, 2004; Meier & Weed, 2004), brain injury (Ripley & Weed, 2004; Savage, Klingbeil, & Fawber, 2004; Weed & Berens, 2006), burns (Brown, Helm, & Weed, 2004; Sheridan & Fox, 2004), cerebral palsy/neurodevelopmental disabilities (Neufeld, Monasterio, Livingston, Taylor, Grisham, & Taylor, 2004), visual impairments (Winkler & Weed, 2004b), geriatrics/elder care (McCollom, 2004), and any other disability or condition that impairs daily living functioning. Requirements can range from relatively inexpensive equipment to a complete rebuild of the home.

Selection of Qualifying Professional or Company to Perform the Home Assessment

In the authors’ opinion and based on their professional experiences, the assessment of home needs can be one of the most critical areas of the life care plan and can potentially be one of the most expensive. Proper design for function, safety, hygiene, independence, attendant care, transfer, and other activities need to be taken into full consideration. A general contractor, without appropriate
knowledge, may look at the home and see the need for door widening, ramping, and possible roll-in shower, but likely will miss fire safety exits, adequate door header height for accessible van for covered transfer, interior flooring issues, accessible kitchen, office areas, client mobility and function, and so on.

In many cases, if not most, the entire home will need to be designed specifically to accommodate the client, giving consideration to their function, range of motion, and abilities. (Note: There may be occasions when a client will not require access to a second floor or a basement, so in some circumstances it may be justifiable to limit the assessment to the client’s main living area.) Although the bathroom could be designed with a roll-in shower, the size of the shower will depend on the size of the individual, the type of shower chair, care attendant assistance requirements, and other factors. However, if the recommendation for the client is to include warm water therapy, then an overhead transfer system and bathtub sized to accommodate the client would be the best option rather than a roll-in shower. Another option may be the Shower Trolley, the latest bath item for individuals who are tetraplegic who require full bathing assistance (see Figure 34.1). The Shower Trolley lays flat and will allow an attendant to turn the client on each side for full bathing and skin inspection. The trolley, which retails for $7,995, requires a larger space and a different bathroom design than a roll-in shower or overhead transfer system, and the person performing the home assessment must be cognizant of such options.

As the reader may begin to understand, selecting a professional or company knowledgeable of all the options for home modifications and design is critical. Equally important is the professional’s ability to have proper understanding of the client’s situation in order to support their assessment report and defend it, particularly if the life care plan is utilized in personal injury litigation or workers’ compensation cases. Suggested credentials for a home assessment professional include a Certified Environmental Access Contractor/CEAC (note: the company responsible for this credential reportedly has recently discontinued issuing additional CEAC certifications), or Certified Aging in Place Specialist/CAPS (information and directory available at www.nahb.org). There are also some architects and licensed general contractors (GC) who specialize in handicap accessible renovations or construction. Networking with peers who have had positive experiences with successful home assessments/modifications also may reveal good choices.

Figure 34.1  Shower Trolley. (Photo by Jim Karl.)
Home Assessment Process

The home assessment should consist of a full overview of all of the required modifications. To focus solely, as some less knowledgeable consultant might, on the bathroom and ingress or safety exits will leave one with a home that is not properly designed for the individual’s function, safety, independence, and general mobility. One way to achieve a proper assessment is to consider that teamwork is a must. In these authors’ opinion, it is important that the life care planner supply the home assessment consultant with as much information as possible, describing the client’s physical functioning and range of motion, relevant mental or cognitive considerations, medical care recommendations, type of equipment used or recommended, level of home attendant care required, hobbies, and any other pertinent information. This information will assist the consultant in comprehensively surveying the home for function and safety. The home assessment should be discussed with the client and available family members, whenever possible, to insure that all relevant details regarding individual needs are considered and included. In the event that the client is temporarily residing elsewhere, such as a hospital or extended care facility, it is recommended that a meeting with the individual be arranged prior to the home assessment. A family member of the client, life care planner, case manager, occupational therapist, and, in some cases, an assistive technology expert and the client’s attorney also may be included in the assessment process. Typically, the assessment will take on the form of questions and answers for each design area as to function, space, usable design, safety, independence, and attendant care assistance. In these authors’ view, all home areas that do not require modification for the client should be so noted in the assessment so that the reader will understand that the room or potential modification was not overlooked.

Based on the first author’s experience, the usual time required for completion of a comprehensive onsite assessment generally will range from 2 to 4 hours. The typical assessment charged by the first author ranges from a flat rate of $1,800 to $2,800 and includes the time required for an onsite evaluation as well as researching design specifications and a written report. The difference in cost relates to the complexity and design sophistication requirements. When charging by the hour, the estimated range in the metropolitan Atlanta, Georgia, area is $150 to $180 per hour.

As the reader can imagine, trying to modify an existing home can be very challenging and, if the home is too small, adding on or designing a new home to properly allow maximum function, safety, and independence may be more cost effective. However, with today’s pricing, in the first author’s experience, approximately 30% of the remodeling costs are for demolition and restructure to allow for the new modifications. In many cases, the funds directed toward demolition would be better spent on new construction since renovations and modification often have trade-offs and do not entirely meet the needs of the client. In addition, some homes, when modified, become much more expensive than other houses in the neighborhood and this can complicate recapturing the home’s value when resold. That is, the same modified home in a “better” neighborhood potentially would sell at a higher price.

General Assessment Overview

The following is a guide to a general overview of a home assessment and suggests possible modifications for each area. As noted earlier, client specifics will ultimately determine the actual home assessment report and the project cost range for each area. The authors note that the following list provides examples and is not inclusive of all options available to create the most accessible home.
I. Entrance to Home, Covered Transfer Areas, and Fire Safety Exit

A. Ramps

Areas with a rise of 30" or less are appropriate for ramping. Several types of ramping can be developed and will be dependent on the style of home, location of ramp, and homeowners’ association requirements, if applicable. Aluminum ramping with handrails is preferred to wooden ramping for longevity, ease of maintenance, and safety. Other types of ramping include concrete and other solid surface products. The general cost consideration for ramping is $150 per foot installed plus any additional site preparation work that may be required.

B. Porch Lifts

Areas over 30” in height or with limited space, such as inside of a garage, can be modified by using a porch lift (see Figure 34.2). When using a porch lift, it is important to always have a permanent type of ramp that can be used as an emergency exit in the event the porch lift malfunctions or the power supply is cut. The cost of the porch lift is approximately $6,800 or more depending on height and site preparation.

C. Fire Safety Exits

Exits that require access through a kitchen, carport, or garage, or past a gas furnace that is sometimes located in a hall will not qualify as safety exits, as these areas are the most likely to be

Figure 34.2  Mac's Porch Lift. (Photo from www.macleslift.com.)
involved in a fire. A preferred location is directly out of the bedroom or within 25’ of the bedroom where the client sleeps. The cost to install a fire safety exit varies widely depending on exterior door installation requirements (moving electrical wire in walls, structural supports, brick or block exterior rather than wood or stucco, etc.), amount and style of ramping, and site preparation. At the low end, an uncomplicated exterior door installed would be about $2,400.

D. Covered Transfer Areas

The size of the client’s van will determine the door header height of the garage. Keep in mind the size of the chair and age of the client as well. If the size of the chair or function of the client will change or limit the movement of the head, the style of van and correspondingly the size of the covered structure (carport or garage) may change. In general, the garage door height should be designed for the taller van and would typically require at least a 9’ door header. Also, should the home be sold, the taller door header will open up the market to all clients with similar needs. Another consideration is that, due to the size of many handicap-accessible vans, additional concrete for backing up and parking likely will need to be installed to accommodate the reduced maneuverability of larger vehicles. Further, the van that has a side-landing platform will limit the availability of another car in the garage and the entry door location into the home will also determine the function of the van in the garage.

II. Access throughout the Home

A. Type of Mobility Equipment Used for Assistance

The type of floor covering, width of hall, width of door openings, and location of doors are considerations for using mobility equipment in the home. Not all areas of the home can be widened. Following is a description of possible options for in-home access.

B. Two-Story or Basement Access Required

Possible options for home access include stair lifts inside the home (see Figure 34.3), incline platform lifts, and elevators or porch lifts. As mentioned earlier, there should be a direct exit out of the client’s living area without having to use the mechanical device for maximum safety.

C. General Maneuvering around the Home

The size of rooms will depend on the type and style of furniture, space for transfers, flooring, width and length of hallways and any turns, trip hazards, throw rugs, extension cords, and location of required controls (i.e., thermostats). Automatic door openers will provide major improvements for independence. Additionally, some clients will require voice-activated home automation systems (see, for example, assistive technology in the following for more on this topic).

III. Bedroom

The size and layout of the client’s bedroom will be directly affected by the type of equipment required, size of the client’s wheelchair, level of attendant care, and method of transfers. Following are some considerations to be addressed:
A. Adequate space by the bed is the first consideration because transfers can be assisted, unassisted, or involve specialty requirements that could increase the complexity of the room design. This would in turn necessitate extra special attention to room specifications.

B. Attention to possible specialty lighting requirements, additional heat source, or additional electrical outlets for the client’s equipment, and the location of each.

C. Some clients, such as one who is ventilator dependent, will require a backup generator for emergency power to operate equipment during a power outage.

D. Overhead transfer systems exist that can reduce the number of people needed to transfer a client to a chair, bathroom, or other locations in the home (see Figure 34.4). Certain designs allow for moving from room to room even with doorways between the rooms. Some lift systems have a hand control that a client with adequate function can use without assistance. Overhead lifts start at about $5,200 installed but will increase in cost based on the complexity of installation (such as ceiling supports and doorways), track, and run.

E. For clients with adequate functional ability, clothing storage to include accessible closet and custom-designed dresser drawers will be needed. The dresser can be designed with easy pullout drawers at wheelchair height and hanging rods that can be lowered or reinstalled in the closet at wheelchair height. The cost of the glides to be added to a drawer costs about $50 per pair. Closets that incorporate motorized technology to reduce physical effort or enhance access can also be employed.

F. If extra space is required to accommodate therapy equipment that has been recommended by the OT and physician, a fold-down therapy table is an option that will reduce the amount of space needed. Cost of a fold-down therapy table depends primarily on size and can be expected to range from $850 to $1,800.

G. The home should have a fire safety exit that does not require going through the kitchen, through a garage, or by a furnace room. If a functional fire safety exit is not possible, a new home that provides a safe environment is strongly recommended. Many clients require substantially more time to exit a home (especially if in bed) or need an attendant to transfer. A plan for safe egress cannot be emphasized enough.

H. General room design to include a 14’ x 16’ room size is a good reference point. Small rooms can limit wheelchair function beside the bed and access to storage in addition to increasing safety issues in patient transfers.
IV. Bathroom

The bathroom, like the bedroom, will require specific design modifications such as adequate room size, type of equipment, bathing options, and required assistance that is individualized to the client’s specific needs. All of these variables need to be discussed with the client, health care providers, and probably family members (especially if the client is a child) to develop the bathroom design and safety of function required by the client. The type of bathing and equipment required, such as a tilt-back shower chair, a Shower Trolley (see Figure 34.1), and specialized care when bathing (i.e., clients who are ventilator dependent), all have an effect on the size and design of the bathroom. Due to convection cooling, a wet client who has reduced ability to regulate body temperature (such as a client with a spinal cord injury) likely will benefit from overhead infrared heat lamps if it is possible to install these. The cost of a tilt-back shower chair begins at about $2,100, and a Shower Trolley retails for $7,995. Following are some additional considerations to be addressed in the bathroom:

A. Independence, or need for assistance and the level of functional ability, will affect the room dimension requirements. A rule of thumb is the more assistance that is required, the larger the room size. Additionally, the presence and location of specialized equipment for optimum use can dictate room dimensions.
B. Grab bars, if needed, will require careful assessment of their locations. Further, most walls will require the installation of backing to properly anchor the bar. The standard grab bars range about $50 to $60 and decorative models can cost up to $300, not including installation. Note that installation costs for most of the entries are not included because every situation is different. For example, a grab bar cannot be bolted to an older plastic tub or shower. Therefore, a rebuild of the tub or shower would be added to the cost of the grab bar.

C. Toileting Options
1. High-rise toilets can be stand-alone (expect about $285 plus installation) or specialized products that fit over existing toilets (cost ranges from $85 to $200). Also, electric toilet lift seats that help a client rise to a standing position can be helpful to someone who has reduced function (e.g., elderly) and range in cost from $750 to $1,800.
2. The amount of space required for the client’s wheelchair to be placed next to the toilet will be determined by method of client transfer. For example, a client with a spinal cord injury at, say, the T12 level, will likely be able to transfer herself with the aid of grab bars by placing the wheelchair alongside the toilet. A client who needs some personal assistance such as “stand and pivot” to the toilet may need less room, but benefit from at least one grab bar. A client who utilizes a Hoyer or overhead lift will need enough room for two people (also see #3).
3. There are specific floor lifts that are designed for assisting caregivers with client toileting. The lift is designed to provide for seated to seated transfers with the function of the lift to raise the individual to a partial standing position. These specialty lifts greatly assist with the removal of garments in toileting and are known as standing aid lifts. The cost, at the low end, is in the neighborhood of $3,800. The Barrier Free lift is another option and lists for about $6,800.
4. Open-bottom shower chairs have proven popular for double duty as a toileting aid as well as shower assist. Cost begins at $980.
5. Overhead transfer systems may reduce attendant care requirements (previously mentioned since they can be useful in many areas of the home).

D. Bathing Options
1. A walk-in bathtub with a high built-in seat adds increased safety for elderly persons or those with limited mobility/balance. However, the individual must have enough function to make a 3” step into the unit. Cost is approximately $6,500 plus installation.
2. Roll-in showers are popular but the dimensions will depend on the size of the client, required assistance in bathing, and type of shower chair. The minimum size is 4’ x 5’. The shower unit by Best Bath is a modular unit that has several full roll-in model sizes available and has a ¾” plywood reinforced wall structure to allow for installation of grab bars. Prices vary according to size and style, but could be budgeted beginning at $4,400 plus installation costs.
3. If therapy bathtubs are recommended, the installation of an overhead transfer system is usually required for safe transfers. The system track design can be developed to allow for direct transfers from bed to therapy tub, thereby providing maximum ease, safety, and function.
4. As mentioned earlier, the newest item for bathing that facilitates client positioning and reduces attendant requirements is the Shower Trolley. This equipment allows care assistants to fully bathe and inspect all areas for skin breakdown and achieve maximum hygiene for individuals requiring this level of care. Due to the size and function of this unit, special attention is required during the bathroom design process to assure adequate room to maneuver the device with a client in a prone or supine position.
E. Additional storage area(s) for personal items, supplies, and equipment is a common need for individuals with a disability. An additional storage area should be designed for ease of independent usage, as appropriate, or according to the client’s or caregiver’s capabilities.

F. Roll-under Sink and Vanity Area: The vanity area should have a cultured marble vanity top with a built-in sink to provide a smooth, flat surface to set and reach items as well as a sink location. Cultured marble allows for a specific design and placement of the sink, which is an integral part of the product (no seams) and can be fabricated for clearance for roll-under access. The vanity should have full pullout drawers for easy access, and the faucet can be located to the side of the sink if limited reach is an issue. Typically recommended is a single-lever faucet or an automatic turn-on faucet with a longer spout and angle to direct the water flow toward the center of the sink for easier water flow onto hands. The vanity mirror should be positioned to allow for seated viewing.

G. Flooring
Nonslip floor tile is the ideal surface as tile will generally withstand a wet environment without damage. Vinyl floors typically will develop mold and mildew, as well as other problems, if not properly sealed and maintained.

H. Minimum bathroom size is 10’ x 10’, although most bathrooms designed for clients are larger.

V. Kitchen
The kitchen is an area that can be designed to provide for full function or a special function depending on the client’s capabilities. The size of the kitchen will vary depending on the client’s needs as well as on the adjacent room. If the area is combined with, say, an eat-in kitchen and with open access, the kitchen may not require as much room as one that is in a room that is self-contained. In general, an open space of 5’ is needed for maneuverability and access. If the kitchen is self-contained, expect at least a size of 9’ x 14’. Areas of consideration for the kitchen are as follows:

1. Roll-under sink for clients who are wheelchair reliant but have enough functional abilities for independence.
2. Lowered food preparation surfaces so that clients can perform tasks from a seated position.
3. Roll-under electric cooktop is preferred. For safety reasons, a gas stove is not recommended for use by individuals with a disability or mobility impairment. The style of cooktop that is recommended by the first author is one by Fisher Paykel, which will contain a spill of a half-gallon of liquid over the surface. This is an obvious major safety feature when cooking. Also, for clients who are able to cook, the controls must be located on the side so the person does not have to reach over the burners to operate the stove. The cost for a Fisher Paykel cooktop is about $1300.
4. A raised dishwasher for easier function or the Fisher Paykel dish drawer unit, which pulls out like a drawer, is recommended. The cost for a single-drawer model is about $1100, and the two-drawer model is about $1600.
5. A built-in oven with a side-opening door that is located at proper seated height (rather than a standard pull-down oven door) may be indicated depending on the client’s abilities. Expect to pay about $850.
6. Base cabinets with full pull-out extension drawers with taller than typical sides provide ease of access for clients. These are designed for dish and cooking utensil storage and pantry items and often have built-in guides for organizing utensils and dishes.
7. Switch controls for garbage disposal, lights, and so on, at the front of the cabinet for seated height may be indicated.
8. Solid surface countertops for movement of items such as heated items and water may be required.
9. Adequate floor space and movement radius are critical and are dependent on client size, functional needs, and other factors.

VI. Laundry Room

This area can be designed for wheelchair function or for care attendant function, or can be left as standard.

Type of possible modifications:

1. Raised front-loading washer and dryer units have become mainstream, and several models and features are available. Expect to pay about $2,000 or more for a pair, not including delivery. Pedestal style may be extra.
2. Lowered roll-under folding surface to allow client to sort and fold clothes from a seated position may be indicated.
3. Wheelchair-accessible hanging rack so client can reach and hang clothes to dry.
4. Accessible storage area for cleaning items.
5. Adequate floor space for ease of movement.

VII. Assistive Technology

The utilization of technology-based items can give independence back to individuals for specific functions that would otherwise not be possible (for more information on this topic, visit the Center for Assistive Technology and Environmental Access at www.catea.org). Environmental control units (ECUs), sometimes referred to as electronic aids for daily living (EADLs), are designed to allow individuals to perform daily routines and operate various household items in their home via technology-based products (Gilman, 2007). The technology, when incorporated with a computer system, can allow for complete home automation. Available computer system software packages can accommodate individual function including voice activation and automation, character recognition, control of household items, and much more. Some examples of independence through technology that can be achieved include turning on and off lights, dialing and answering the telephone, typing letters or other documents, sending a fax, taking care of personal finances, controlling the TV/DVD/CD player/stereo, opening outside doors, and adjusting the bed. By utilizing assistive technology, the client’s level of independence not only reduces attendant care needs but also increases the client’s self-worth and self-esteem as major benefits. Costs range from a few hundred dollars to more than $13,000 for the Multimedia Max system with all available options (www.abilityhub.com/ecu/index.htm).

Conclusion

The proper design of a client’s living environment is critical for independence, function, safety, hygiene, care attendance, as well as general enjoyment and quality of life. Sometimes an existing home will not accommodate the required modifications or the expense for renovations will be unreasonable when considering demolition expenses or the house value after...
modification in relation to other homes in the neighborhood. On those occasions, the design of a new home will be more cost-effective and will provide for a much better level of safety and function. The new or modified home, depending on the client’s specific factors and requirements, may be the home in which they reside to old age, and the areas listed in this article may have the additional need to be designed to allow for the client’s aging and deteriorating functional abilities.

In addition to aging considerations, the client’s home, especially for one who has significant limitations, likely will be the environment in which most of his time will be spent. For this reason alone, safety, function, and comfort are of paramount concern. Adequate assessment not only provides the foundation to improve or modify the client’s environment to meet essential needs, but can reduce the cost of care, decrease complications, provide safer surroundings, and improve one’s quality of life and well-being, even as the client ages. This chapter was intended to familiarize the life care planner on the importance of utilizing an appropriately certified or qualified home assessment consultant who will consider and incorporate, as part of a comprehensive assessment, the topics and issues presented in this chapter.

References


Chapter 35

Vehicle Modifications: Useful Considerations for Life Care Planners*

Roger O. Weed and Lisa R. Engelhart

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Introduction

Most people with catastrophic injuries or complex health care needs that impact mobility will require specialized transportation adaptations. The needs range from minor modifications to very high tech and custom designed modified vans. This article, primarily based on a case study, will

Safety Factors from a Historical Perspective

In order to understand the basic history of vehicle modifications, Michael Dresdner, an industry expert, was interviewed for this chapter. A snapshot from the history of the U.S. mobility equipment industry highlights safety as a prime factor in the cost of modified vans generally and structurally modified vans in particular (M. Dresdner, personal communication, December 21, 2004).* When adaptive equipment companies emerged as garage shop operations during the Vietnam War era, they primarily served veterans with disabilities, many of whom were willing to gain mobility by means that probably would be unimaginable today. For example, a person might have unsafely reclined his or her wheelchair to enter a vehicle and slouched to see through the windshield, or, moreover, did not have any mechanism for securing the wheelchair inside the vehicle. According to Dresdner, the Veterans Administration (VA) originally was the sole funding source for early vehicle modifications and they, along with some state vocational rehabilitation agencies, began to develop safety guidelines as early as 1972. However, regulation was inconsistent and slow to emerge. From the early 1970s to the mid-1980s, there were no significant changes in the way that a wheelchair driver accessed a vehicle. In the 1980s, the standard vehicle in the mobility industry was the full-size Ford Econoline van, modified either by adding a powered floor pan or by structurally lowering the floor. In 1992, Ford replaced the Econoline’s dual front and rear fuel tanks with a single tank located in the center of the chassis to provide more crash protection. This precluded lowering the floor in 1992 and newer Ford E-series vans. Reportedly, to avoid the appearance of ambivalence toward the disability community, Ford introduced an aft-of-axle fuel tank kit that allowed modifications, including lowered floors. Thus, for the first time in the history of the mobility industry, vehicle builders were able to use a

* Michael Dresdner is the president of Handicapped Driver Services, Inc. (HDS); a former board member of the National Mobility Equipment Dealer’s Association (NMEDA); and the current president of the Adaptive Driving Alliance.
crash-tested fuel system that complied with Federal Motor Vehicle Safety Standards (FMVSS). In addition, they were becoming increasingly aware of how essential these standards were to consumers’ safety (M. Dresdner, personal communication, December 21, 2004). Nevertheless, as the federal government improved accident data collection, it revealed the extent to which the mobility industry still was noncompliant with the FMVSS. The National Mobility Equipment Dealers Association (NMEDA) responded by developing a structural modifier certification and a quality assurance program, and by conducting crash tests of structurally modified vehicles. Since then, regulation has steadily increased, not only because of the availability of accident data and crash safety testing, but also due to the growing involvement of major automobile manufacturers and conversion van specialists in the structural modification of vehicles. As a result, all types of modified vehicles are becoming safer, although their cost reflects the expense of compliance with rapidly evolving safety standards.

It is important to note that improving regulation and compliance has created a paradox, as reported in a recent Wall Street Journal article (Schatz, 2005) that cited “The Exemption from the Make Inoperative Prohibition.” This 2001 National Highway Traffic Safety Administration (NHTSA) rule created limited exceptions to the “Make Inoperative” statute, which prohibits the alteration or removal of motor vehicle safety equipment or features that are required pursuant to the FMVSS (Exemption from the Make Inoperative Prohibition, 2002). In other words, known safety devices cannot deliberately be altered or removed from a vehicle under ordinary circumstances. However, this exemption allows otherwise prohibited modifications, which, in essence, effectively allow people with disabilities to purchase adapted vehicles. The paradox is that while consumers can now enjoy the independence that mobility affords, their safety may be at stake. This is why it is essential for case managers and life care planners to identify the most technically knowledgeable and dependable modifiers, even though the cost of their products and services may be greater (M. Dresdner, personal communication, December 21, 2004).

**Structural Factors**

For purposes of the following discussion, definitions are provided as related to vehicle modifications:

- **Alterers** are companies, such as automobile manufacturers, and other parties that specialize in high-volume, mobility-related structural modifications that are made prior to a vehicle’s first retail sale.
- **Dealers** are mobility equipment retailers who sell vehicles directly to consumers.
- **Structural modifications** generally mean lowered floors, raised doors, and raised roofs.
- **Nonstructural modifications** include, but are not limited to, wheelchair lifts, mechanical or electronic driving aids, wheelchair restraint systems, and interiors.
- **Driver rehabilitation specialist (DRS)** signifies one who plans, develops, coordinates, and implements driver rehabilitation services for individuals with disabilities (ADED, 2005). If one is a certified driver rehabilitation specialist (CDRS), he or she has met minimum education and experience requirements and has passed an examination offered by the Association for Driver Rehabilitation Specialists relating to this specialty area (see also the resources at the end of this chapter).

Most of the vehicles sold by today’s mobility dealers are lowered-floor full-size vans and lowered-floor minivans, which dealers purchase from alterers who typically use base vehicles manufactured
by major automakers such as Ford, Toyota, Chrysler, Dodge, and GM. These products include Braun Corporation’s Entervan and Rampvan,* the Toyota Sienna with a Rampvan conversion, and Vantage Mobility International’s (VMI) NorthStar and Summit models (M. Dresdner, personal communication, December 21, 2004).

Mobility dealers sell these vehicles either as-is or with additional nonstructural modifications that are completed by the dealer to meet customers’ unique needs as recommended with the help of a CDRS. Some dealers also continue to perform their own structural modifications, thereby customizing the vehicle for a particular person. Although mobility dealer-built full-size vans offer certain features that currently may not be available when purchased from alterers, Dresdner notes the practice is rapidly becoming economically impractical due to liability exposure and the complexities of compliance with new safety standards, which are the result of continuing vehicle crash tests.

Structural modifications, whether performed by alterers or dealers, involve removing the original equipment manufacturer’s (OEM) floor and repositioning the original body mounts that support the body of the vehicle on the frame and maintain its structural integrity. Base vehicles often are heavy-duty vans, like the Ford E-250, which better compensate for the weight of a larger person in a power chair who must be lifted from one side of the vehicle and positioned off-center inside. In fact, in 2003 Ford issued an advisory to inform mobility vehicle builders that the lighter E-150 van is not recommended if structural modifications are required because the combined weight of the structural components and passenger load could exceed the maximum allowable weight for the front and rear axles (Jowa, 2003). Therefore, even though a lowered-floor minivan might work, a CDRS could reasonably recommend a structurally modified, full-size van for a larger person who uses a powered wheelchair with rehabilitation aids.

In preparation for this chapter, one of the authors followed van modifications for a 6’2” client with a brain stem injury, whose seated height in his power wheelchair is 56”. Modifications were followed from initial fitting to final delivery of the van and training for the client. In determining which vehicle would be most appropriate for the client, vehicle alternatives were considered, including a Ford full-size van and a Dodge Caravan minivan, one of the base vehicles on which a lowered-floor Entervan might be built. However, without the addition of a raised roof and door, a 6” lowered floor in the Ford would only provide a 52½” clear door opening and only 54” in the Entervan with a 10” lowered floor. Either would have been too small to accommodate the client in this particular case. The Entervan, or other lowered-floor minivans, may be more appropriate for shorter individuals who use nonpowered wheelchairs, and could accommodate some powered wheelchairs that do not have the complex power-tilt/recline type features and mid-wheel drive with which this client’s chair was equipped.

Due to the client’s specific needs (seated height, weight, visibility, and desire to ride in the front passenger position), and in consultation with a CDRS, the Ford E-250 van was selected and modified with a 6” lowered-floor, as well as a raised door and roof, which together allowed as much as a 62” clear door opening, or approximately 6” larger than the client’s minimal requirements for door size.

**Customization and Design Issues**

The higher cost of a structurally modified van relates in part to the amount of time that engineers and mechanics spend on design requirements. Dresdner (personal communication, December 21, * Independent Mobility Services (IMS) built the Rampvan prior to acquisition by Braun Corp. in July 2004.
reports that a customer purchasing a vehicle that requires complex modifications will need 20 to 40 hours of presale counseling, including a comprehensive driver evaluation and a 2 to 3 hour preliminary fitting by a CDRS. Furthermore, once structural modifications are complete, the process of fitting the person to the vehicle is complex and time consuming, but critical to ensuring maximum safety and utility. Dresdner cautions, “A quarter of an inch in [the] location [of mechanical or electronic driving aids] can make a huge difference for [a person with a disability].” Therefore, driving aids must be positioned precisely to suit the physical capabilities of a person who may have limited strength or limited range of motion, or both, and even though a passenger vehicle may not present the complexities of a driver vehicle, the person still must be fitted to the vehicle.

The delivery fitting can last from 2 to 3 days and may include adjustments such as replacing the original equipment manufacturer’s shoulder belt, or installing a new upper anchorage point for the shoulder belt if the door was raised, or if it required relocation due to the client’s size or positioning of the wheelchair. One of the authors observed several hours of a delivery fitting for a passenger vehicle, during which two expert modifiers tediously made changes and added technology. For example, the vehicle had an automatic electric wheelchair lock-down device and because the client used a powered Permobil wheelchair that had complex rehabilitation aids, the modifier spent 2 hours partially disassembling the wheelchair to install a bracket on the bottom. Additional time was required to install the device to the vehicle floor to allow precise placement of the client in his wheelchair.

Modifiers provide another essential service by training all users of both driver and passenger vans: the person with a disability must learn how to get in and out of the vehicle and use equipment specially designed for him or her, and caregivers must be instructed about normal, as well as emergency, use of all equipment. This education process includes reviewing owner’s manuals and completing comprehensive delivery checklists, which ensures that the modifier has provided the purchaser with complete and accurate instructions.

Considering the complexities of customization and modification, mobility equipment dealers cannot simply charge a fraction over a vehicle’s cost. By definition, modifiers are low-volume/high-expertise businesses and if they were to apply the standard automobile dealers’ high-volume/low-margin distribution model, they could not deliver the customized service that today’s mobility customers demand. In addition, as Dresdner notes, carrying product liability insurance is a significant consideration these days, even if a vehicle has not undergone extensive modification.

**Selected Cost Estimates**

According to *Consumer Reports*, the cost of an average vehicle is approaching $28,000 (“Up Front: News, Trends, Advice,” 2005). A person with limited arm use may only require a spinner knob for less than $50. Similarly, hand controls may be the only adaptation needed and the expected cost is between $600 to $800, although they rapidly are becoming more expensive due to FMVSS compliance issues and insurance costs. One often-overlooked detail is that a person driving with hand controls may also have spasticity (e.g., paraplegia) and a pedal block may need to be installed to prevent inadvertent acceleration or braking, or accidental entrapment of the person’s foot under the brake pedal, thus preventing operation of the braking hand control. This additional expense is about $375, plus installation.

A person with C5 tetraplegia who can drive independently generally will require low-effort steering, a servo gas-braking system, and a lowered floor in addition to the standard passenger devices, at a $20,000 to $30,000 higher cost. A person with a C4-5 injury typically will require
servo steering and servo gas brakes, at an estimated $30,000 to $50,000 more than the base cost. Dresdner estimates that it could cost up to $110,000 to modify a vehicle for an independent driver who uses the full spectrum of high-tech driving aids, such as a hand-operated joystick system and electronic touchpad.

Overall, the annual maintenance costs for a high-tech passenger vehicle will only be slightly higher than for a more conventional vehicle. According to Dresdner, when the equipment is new and under warranty in years one to three, there should be no cost unless the vehicle experiences extraordinarily hard service. In year four, an owner might pay $500 more for maintenance. Maintenance and repairs in year five could be an additional $800 should lift repairs be necessary; however, most problems are likely to be minor. Maintenance and repair costs in year six will depend on mileage and driving conditions, particularly if the lift and tie-down are exposed to dirt, and then costs could be considerably higher. Note: Some of the equipment, such as lifts and servo driving systems, have a service life expectancy and, due to liability issues, companies will not reinstall them into new vehicles even if they appear to be in good condition, nor repair them if they are beyond the service limits. Reportedly, new requirements for lift systems include cycle counters and a specific maintenance schedule.

Case Study

The client in this case study, Rick (permission was granted to use his real name and photos found later in this article), acquired a disability and associated inability to drive that resulted from a brain stem injury, which functionally limits him equivalent to a high-level tetraplegic. He also cannot turn his head past midline in one direction. If able to stand, Rick is approximately 6’2” and uses a Permobil power chair, in which his seated height is 56”. In his previous van, he was positioned behind the front seat and the tie-downs for his chair were hand-secured. To enter the vehicle, Rick had to recline his chair to get through the 47” doorway, and once in position inside, he would return his chair to its upright position. As a result, his views through the windshield and the side windows were obstructed because he sat so high inside the raised roof. The main reason Rick was unable to ride up front was that his vehicle did not have a lowered floor, which allows a person to ride further forward in the passenger position. Another reason was that the platform of his lift, which encroached on passenger space, blocked his forward access.

After 16 years, almost 200,000 miles, and numerous maintenance problems, Rick ordered a new van. As previously stated, a Ford E250 Econoline van was selected because the combination of his body weight and the weight of his power chair demanded that the vehicle have a heavy-duty suspension. Therefore, a minivan was contraindicated. The vehicle was delivered after a delay of several months due to new crash testing requirements for the modified fuel system (to accommodate the substantial modifications, the fuel system also had to be modified). Once the company capable of doing the modifications received the base vehicle, it undertook extensive dismantling, including removal of the roof, floor, and interior, and structural redesign of the chassis (see Figure 35.1). In addition, the floor was lowered 6”, and the door and roof were raised to allow for installation of the custom doors (see Figure 35.2).

In order to limit the loss of interior space to the lift supports/arm, the modifier selected a Braun cassette-style lift that, when not in use, is stored under the van floor (see Figure 35.3). Although the lift generally is protected, it extends far enough below the van that rough roads or careless driving could damage the mechanism; therefore, it is not appropriate for all users, but generally is considered a very reliable device with excellent lifting capacity.
Accessory items included a rear air conditioner for Rick and an automatic wheelchair locking system for the primary caregiver, his wife, to relieve her from having to wrestle with his chair and manual tie-down straps. Although the EZ Lock docking system necessitated modifications to the wheelchair on the day of delivery, the result is that Rick can maneuver into the passenger position and automatically lock into place. A modified seatbelt was added and, in the event that the passenger front seat is needed, the design allows for temporary replacement of the seat.

After all the structural modifications were completed, another subcontractor added the interior. At time of delivery, Rick was asked to arrive early in the morning and did not leave until early evening. Among the final fitting projects were wheelchair modifications—the attachment of a bracket for the EZ Lock system—and precise placement of the locking mechanism on the floor of the van, which was performed by two skilled technicians who measured and wired the device after numerous trials with Rick and subsequent revisions. Custom seatbelts also were installed and adjusted.
to fit Rick’s dimensions in his wheelchair. Final modifications of the interior and client/caregiver training about all of the vehicle’s features completed the project. The photo in Figure 35.3 was taken during training on the day of delivery and illustrates the finished project. One interesting note is that Rick, who has impaired voice quality, reported that for the first time in 16 years, he can talk with his wife while they are driving, not only because he essentially is riding up front with her—he only sits about 12” behind her—but also because the new van is relatively quiet. His wife, on the other hand, retorts that she now has a backseat driver and perhaps a quiet vehicle is not as desirable as it would seem!

A summary of costs associated with this project can be viewed in Table 35.1. Note that high-tech aids, which a person with a high-level spinal cord injury generally would use, are not included in this example. As previously noted, the cost of that type of project could easily exceed $100,000.

Below is an outline of general topics for the life care planner or case manager to consider when providing for transportation needs for a client with mobility impairment.

### Table 35.1 Vehicle Modifications for Case Study: Rounded Costs

<table>
<thead>
<tr>
<th>Equipment</th>
<th>Costs Rounded</th>
</tr>
</thead>
<tbody>
<tr>
<td>Base Van, Ford E250</td>
<td>$27,300</td>
</tr>
<tr>
<td>Interior Conversion, Hi-Top</td>
<td>$7750</td>
</tr>
<tr>
<td>Roof Support Structure</td>
<td>$1300</td>
</tr>
<tr>
<td>Executive Top</td>
<td>$2000</td>
</tr>
<tr>
<td>Custom Tall Side Doors</td>
<td>$3000</td>
</tr>
<tr>
<td>Braun 603A Cassette Lift</td>
<td>$9600</td>
</tr>
<tr>
<td>6” Dropped Floor</td>
<td>$8000</td>
</tr>
<tr>
<td>EZ Lock/Tie Downs/Custom Seatbelt</td>
<td>$2000</td>
</tr>
</tbody>
</table>
Checklist for Adaptive Driving and Passenger Equipment

A. Evaluation:
1. Certified driver rehab specialist (CDRS) evaluation
2. CDRS prescription for adaptive driving and passenger equipment

B. Prescription:
1. Type of vehicle
   a) Lowered-floor minivan
   b) Lowered-floor full-size van (by alterer)
   c) Lowered-floor full-size van (by mobility equipment retailer-modifier)
2. Primary driving aids (if client able to drive)
   a) Mechanical driving aids
   b) High-tech (servo) driving aids
3. Secondary driving aids (e.g., touchpad systems)

C. Client:
1. Passenger/driver
   a) Weight
   b) Seated height in wheelchair (on properly inflated cushion)
2. Type of wheelchair
   a) Nonpowered
      i) Rigid
   b) Collapsible powered
      i) Seated height of client in wheelchair (on properly inflated cushion)
      ii) Weight of client in wheelchair
      iii) Features, e.g., powered-recline, powered-seat, vent equipped, etc.
3. Additional medical devices
   a) Patient lift system, e.g., Hoyer
   b) Portable ventilator
   c) Oxygen
   d) Refrigerator (to preserve medication)
4. Level of independence (driver)
5. Lifestyle considerations (full-size van)
   a) Outdoor activities and rural use might preclude under-vehicle lifts due to limited ground clearance
   b) Unobstructed doorway allows able-bodied access to cargo area (people and service animals)
   c) Privacy issues, e.g., window blinds if performing self-catheterization
   d) Vocational/avocational activities
   e) Additional equipment to be transported based on lifestyle considerations

<table>
<thead>
<tr>
<th>Item</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wheelchair Dropped Floor Front</td>
<td>$600</td>
</tr>
<tr>
<td>Air Conditioning, Back</td>
<td>$850</td>
</tr>
<tr>
<td><strong>TOTAL (not including tax)</strong></td>
<td><strong>$62,400</strong></td>
</tr>
</tbody>
</table>

Note: Does not include high-tech aids or other custom modifications.
Conclusion

With the improvement in survival rates and life expectancy of individuals with catastrophic disabilities as well as the increased aging population, accessible vehicles are becoming more commonplace and new products are appearing virtually monthly. The entry of several vehicle manufacturers in this once very specialized field has allowed many people with impaired mobility to go to dealers, select a vehicle from among several on a lot, and drive home the same day. However, there continues to be a need for modification of available transportation choices and when structural modification is needed, many, many hours of consultation may be necessary before and during the construction process, which could potentially increase the cost of the vehicle by thousands of dollars. Most life care planners and case managers will not have the knowledge to evaluate clients’ adaptive driving equipment needs because this technical area is extremely specialized. Pediatric client needs, although not specifically included in this chapter, present additional deliberation since size of the child, seriousness of the effects of the disability on mobility, and growth factors will determine selection of a vehicle and appropriate modifications. For example, a child who relies on a wheelchair as a positioning seating system will likely require an accessible van earlier than one who can travel comfortably in a booster seat.

Dresdner stresses the importance of teamwork, including consultation with a CDRS who can help to ensure that recommendations are appropriate and that competent vendors properly implement the specified modifications (M. Dresdner, personal communication, December 21, 2004). However, as with any professional specialty area, the life care planner needs to assure competent recommendations with the client’s or family’s participation, when possible. Many life care planners may have the knowledge, experience, and expertise necessary to make transportation-related recommendations; however, regardless of the source of the recommendations, given the increasingly complex nature of this area, life care planners and case managers are encouraged to refer clients to accredited modifiers who comply with NMEDA standards, participate in the NMEDA QAP program, and are members of the Adaptive Driving Alliance.

Resources

1. The Association for Driver Rehabilitation Specialists (formerly the Association of Driver Educators for the Disabled, or ADED, the acronym by which it is still known): a nonprofit professional organization for those working in the field of driver education, driver training,
and transportation equipment modifications for persons with disabilities. Offers the Driver Rehabilitation Specialist Certification Exam (CDRS).

711 S. Vienna St., Ruston LA 71270
800-290-2344
www.driver-ed.org

2. National Mobility Equipment Dealers Association (NMEDA): a nonprofit trade association of mobility equipment dealers, driver rehabilitation specialists, and other professionals dedicated to broadening the opportunities for people with disabilities to drive or ride in vehicles modified with mobility equipment.

3327 Bearss Avenue, Tampa, FL 33618
800-833-0427
www.nmeda.org; nmeda@aol.com

3. Adaptive Driving Alliance (ADA): a nationwide group of vehicle modification dealers providing van conversions, hand controls, wheelchair lifts, scooter lifts, tie-downs, conversion van rentals, paratransit, and other adaptive equipment for drivers with disabilities and passengers.

4218 W. Electra Lane, Glendale, AZ 85310
623-434-0722
www.adamobility.com


400 Seventh St. SW, Washington, DC 20590
888-327-4236
www.nhtsa.dot.gov/cars/rules/adaptive

5. Society of Automobile Engineers (SAE): an international organization of engineers, business executives, educators, and students who share information and exchange ideas for advancing the engineering of mobility systems.

SAE World Headquarters, 400 Commonwealth Drive, Warrendale, PA 15096-0001
724-776-4841
www.sae.org

6. The Braun Corporation: the Braun Corporation purchased Independent Mobility Systems (IMS) in July 2004, creating the world’s largest mobility products company. IMS, a business unit of The Braun Corporation, continues to manufacture and support the Rampvan brand minivan conversion. The Braun Corporation sells the Entervan brand of mobility vehicles.

800-THE-LIFT
www.ims-vans.com; www.entervan.com; askbraun@braunlift.com

Accessibility Services Plaza
1310 Kennestone Circle NW, Marietta, GA 30066
877-HDS-VANS (432-8267); 770-422-9674 (local)
www.hdsvans.com; info@hdsvans.com

References
Chapter 36

Credentialing and Other Issues in Life Care Planning

Roger O. Weed and Debra E. Berens

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Introduction

Credentialing in support of one’s professional work in health-care-related fields has exploded with an apparent increasing array of certifications, licenses, educational degrees, and registrations available. Many credentials are backed by research, accreditation, and role and function studies, while others seemingly appear overnight with no apparent foundation for establishing credibility. Included in the previous statement is the nonaccredited and, in some instances, bogus degrees (doctorates included). Nonetheless, life care planners seem to be attracted to enhancing their list of credentials and willingly pay the associated costs. Further complicating this issue is the apparent diversity of professional disciplines that is represented by the life care planners observed over the years (e.g., physicians, psychologists, certified rehabilitation counselors, nurses, occupational therapists, speech pathologists, social workers, and others). While this short chapter will not include a list of credible versus noncredible credentials, some hints or issues will be offered.
Credentialing: General

In the beginning, counselors, psychologists, and most other professions were unregulated. One could hang out a shingle advertising that he or she was, for an example, a barber and dentist. As time passed, more and more people formed organizations and set professional standards (T. Field, personal communication, November 7, 2007) or promoted protecting practice through implementation of laws or establishing certifications that would hopefully be required for employment in targeted settings. States began implementing laws intended to protect the welfare of their constituents. For example, all states require licensure to practice in the life care planning–relevant professions of physicians, nurses, and psychologists. Many states have licensure requirements for counselors, allied health therapists, prosthetists and orthotists, and others. However, there is no state that requires one to be licensed, registered, or certificated to prepare life care plans, though some businesses may require specific credentials.

Licensure

Licenses, the most restrictive credential for rehabilitation professions, are issued by government entities and are expected to protect the health and welfare of citizens (Matkin, 1995). Licenses are typically thought of as being issued by states, but the federal government also grants licenses (such as the FCC). For purposes of life care planning, no state issues a license for life care planners, but an individual’s credential may require licensure, such as physician, nurse, or psychologist. A few states require rehabilitation counselors to be licensed if they offer services within the scope of practice as defined by the state. Although most professionals reading this chapter will know whether they are covered by licensing laws and regulations, one will need to determine if there are different requirements with moves from one state to another state. The primary issue is that, unlike certification or registration, one who is required to be licensed to practice, but is not, can be denied the opportunity to work within his or her profession. However, a person who completed medical school, for instance, but is not licensed as a physician could seemingly potentially be qualified to work as a life care planner as long as he or she does not practice medicine as defined by law. Note that some states have a title protection act and others have a practice protection act. In the State of Georgia, professional counseling has a practice protection law, which means that if one performs services as defined in the law as professional counseling, one must be licensed. In a title protection state, one may practice psychology, but may not call himself or herself a licensed psychologist unless licensed by that state.

Certification

Certification is described as a process by which an organization (governmental or nongovernmental) recognizes an individual for having met certain predetermined professional qualifications (Matkin, 1995). Organizations that certify individuals can be profit, nonprofit, or governmental but are not regulated by the government (CRCC, 2009a). The organizational structure can run the gamut from being governed by a single individual or controlled by a group overseen by an outside organization. Some certifications can be related to meeting extensive qualifications and passing a written or oral examination, or can be as simple as related to the work setting. For example, the first author is a certified educator by the National Council on Rehabilitation Education (NCRE), which means that he is employed 20 hours or more in an educational institution teaching rehabilitation counseling. (Note: the website, www.rehabeducators.org, on January 2, 2009 states,
“Membership structure is currently being revised. New information and application materials will be posted at the end of July, 2008,” so changes may be revealed soon, though 6 months later than indicated, no news was posted.) The NCRE may presume that for one to be employed by an institution of higher learning, the person’s credentials meet the intended criteria so no additional scrutiny is necessary.

Some organizations are structured such that the board or commissioners are elected or appointed representatives from groups that support the certification. For example, the Commission on Rehabilitation Counselor Certification (CRCC) consists of appointees from nine organizations and one public member (CRCC, 2009b). Also, in terms of history, the CRC, established in the mid-1970s, is one of the oldest certifications in the rehabilitation consulting arena, predating the nationally certified counselor (NCC), among other well-established credentials. At the other extreme, some certifications are offered by organizations that are effectively controlled by one person, which may or may not have a board or a group of commissioners.

The point of this discussion is that most, if not all, life care planners possess at least one certification, and the person may acquire highly valued certifications with a substantial history, with an extensive research base (including role and functions studies), and which enjoy a credible reputation throughout the membership or by stakeholders. Or, one may pay for a certification which has no real foundation or value when closely scrutinized. In the authors’ opinion, one way to assure basic credibility is to determine if the organization is accredited by the National Organization for Competency Assurance (NOCA), the parent company for the National Commission for Certifying Agencies (NCCA), which accredits certification organizations complying with its standards. As stated, “The mission of NCCA is to help ensure the health, welfare, and safety of the public through the accreditation of certification programs/organizations that assess professional competence” (NOCA, 2007, p. 1). In these authors’ opinion, it seems that if an organization is accredited by NCCA, then there is a mechanism by which the organization’s standards, by-laws, policies and procedures, and overall credentialing process have been determined satisfactory (approved) and there is ongoing review and evaluation by NCCA for reaccreditation. There may be other accrediting bodies that support a certification, but one would be advised to make sure the statement “accredited by” has validity and is not simply another shell of an organization that is intended to give the impression of legitimacy. The authors recognize that other evidence of credibility can be located and the expectation is that the reader will exercise due diligence before paying fees. One further note: certification does not stop one from practicing a profession, but does prohibit what one can call himself or herself. For example, one may practice rehabilitation counseling, but may not call himself or herself a Certified Rehabilitation Counselor (CRC) unless the Commission on Rehabilitation Counselor Certification’s requirements are met and the individual has been granted certification status through the CRCC.

In general, the authors summarize the previous information within a checklist format in Table 36.1.

<table>
<thead>
<tr>
<th><strong>Registration</strong></th>
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Registration is a term that can refer to someone who is either licensed or simply registered with an organization that represents a particular profession (e.g., licensing related to Registered Nurse or Occupational Therapist/Registered). As Matkin (1995) observes, “Registration is closely related to certification and licensure, in that once these forms of credentials are issued, the professional becomes listed by name and other pertinent information among other similarly designated members of a specialty. Thus a registry is a document that assists the public to identify qualified practitioners.
or businesses to perform specific services” (pp. 396–397). At one time, the primary author was registered within a state professional organization as a “qualified rehabilitation professional.” The purpose was to establish the basic credentials of rehabilitation counseling in a state that did not require licensure and to encourage insurance companies to only pay for the services of people who joined the voluntary registry. Although there was no examination, in order to be called a qualified rehabilitation professional certain credentials had to be met. At the time, numerous people of dubious qualifications were attempting to claim that they were qualified to work with people who were injured at work in order to be paid through the state’s workers’ compensation system. Another example in the State of Georgia is the “registered rehabilitation supplier” list maintained by the Georgia State Board of Workers’ Compensation, which indicates that individuals (both nurses and rehabilitation counselors) who are registered with the state (and pay an annual fee) have had their credentials reviewed and are deemed eligible to provide rehabilitation services to injured workers who are receiving Georgia state workers’ compensation benefits.

<table>
<thead>
<tr>
<th>Table 36.1 Basic Questions before Seeking a Certification (with authors’ comments)</th>
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<tbody>
<tr>
<td>✓ Is the organization not-for-profit or for-profit? (Comment: not-for-profits on the surface enjoy an appearance of better credibility or face validity than for-profit organizations. However, that business structure by itself is not a determining factor.)</td>
</tr>
<tr>
<td>✓ Is the organization owned by an individual (profit or not-for-profit)? (Comment: an entity owned by an individual is less desirable.)</td>
</tr>
<tr>
<td>✓ Is the organization run by elected or appointed commissioners, or is it effectively run or controlled by an individual? Do the commissioners serve “at the pleasure of” the owner? (Comment: an independent board or group of commissioners is desirable.)</td>
</tr>
<tr>
<td>✓ Is the certification based upon research and a reliable role and function study? (Comment: preferably with approval and oversight by a university institutional review board.)</td>
</tr>
<tr>
<td>✓ Does one need to pass a legitimate examination to become certified? (Comment: whether oral or written, there should be evidence that the exam, if one is required, is based on research. Attention should also be given to certificants who were “grandfathered” at the time they were certified, which implies they did not have to pass an examination to obtain certification.)</td>
</tr>
<tr>
<td>✓ Do organizations that offer continuing education recognize the certification such that they offer credits for training? (Comment: if one attends several conferences and there are no available continuing education credits for a particular certification, it may mean that the credential is not valued.)</td>
</tr>
<tr>
<td>✓ Are policies and procedures accessible to review before seeking certification, and do they protect stakeholders by providing for due process? Or can the owner, board, or commissioners take action for purported transgressions without notice to, or participation of, the certified professional? (Comment: it seems reasonable to expect that a consistent due process policy is in force, and NCCA standards require due process. See next question.)</td>
</tr>
<tr>
<td>✓ Is the certification accredited by the National Commission for Certifying Agencies (NCCA) or another legitimate accreditation-related entity? (Comment: although the authors do not believe that this provision is a necessity, the oversight is desirable for organizations that offer certifications.)</td>
</tr>
</tbody>
</table>
Gianforte (1976, as cited in Matkin, 1995) noted that there can be state or national registries, with the advantage that national registration leads to reciprocity throughout the country whereas state registries may not extend beyond the borders of the respective state.

**Accreditation**

Accreditation can refer to educational institutions or other organizations. As noted previously, NCCA accredits organizations that meet certain standards. The operative word here is organization since the program or educational offerings are accredited whereas certification applies to individuals. Within educational institutions, accreditation can be numerous. For example, the university where the authors teach is accredited not only as a university, but the specific rehabilitation counseling program is also accredited by the Council on Rehabilitation Education (CORE). Further, some of the classes also meet the requirements for accreditation in school counseling, professional counseling, and school psychology. With regard to life care planning, the standards of rehabilitation counselor training identify knowledge content areas that include the mandate to teach life care planning elements as part of the rehabilitation counselor training program (CORE, 2008).

At the other extreme of programs accredited by well-established accreditation agencies are sham degrees offered by so-called universities that deliver, for a price, an impressive degree including, in some cases, transcripts (Bear & Bear, 2004). The degree may appear to be from an impressive university like Harvard, or a name very close to a recognized educational institution (in spelling or perhaps a slightly different name). Other such degrees are obtained through highlighting one’s experiences or attending a few classes that somehow meet the requirements for a doctorate. It is not uncommon for bogus degrees to claim they are accredited by equally bogus accreditation agencies. For anecdotal examples, the following is offered.

Several years ago, one rehabilitation-related organization began offering a doctorate but when the state officials in which the business was located were notified, an investigation revealed that state requirements for an educational institution were not met and they were forced to close. In another case, a person who claimed that he possessed a degree from a university and had several years of testifying to such achievement was pressed to provide proof. As it turned out, he did not have the degree to which he testified, which unraveled several settled litigation cases. Last, another testifying expert listed a PhD, which, when evaluated, was from an unaccredited program and the purported coursework additionally was not related to rehabilitation consulting or the area to which the PhD was claimed.

The authors hasten to add that in spite of some of the problems and issues listed previously, there are trustworthy and fully accredited undergraduate, graduate, and doctoral programs, including emerging and established distant learning and online educational offerings.

In summary, accreditation defines the requisite knowledge content areas to be offered by training and educational programs responsible for preparing individuals to enter an occupation (Matkin, 1995).

**Conclusion**

For the specialty practice of life care planning, certifications abound and are not regulated by governmental agencies. Each has its own requirements—and costs—which in some cases simply constitute an economic enhancement to the person(s) who owns the business. Others are substantial,
well-researched, long-standing certifications from organizations that are NCCA accredited or are well recognized within the rehabilitation profession. (For example, CORE requires that a CRC coordinate accredited graduate rehabilitation counseling programs.) Further, registries and educational institutions may or may not be legitimate and, in some ways, “caveat emptor,” or let the buyer beware. Historically, in these authors’ opinion, one could assert certain achievements and perhaps successfully work without being caught. However, with the vast improvements in searching the Internet and increasing abilities of rehabilitation professionals, attorneys, and others to discover these data, it seems increasingly difficult for life care planners to fudge their credentials. Before one commits to a certification, registration, or degree program to support one’s contention that they are qualified as a life care planner, it is suggested that some of the concerns, guidelines, observations, issues, and such items as previously listed be considered.

References
Appendix I

Standards of Practice for Life Care Planners*

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I. Introduction

A. Definition of Life Care Planning

The Life Care Plan is a dynamic document based upon published standards of practice, comprehensive assessment, data analysis, and research, which provides an organized, concise plan for

current and future needs with associated cost for individuals who have experienced catastrophic injury or have chronic health care needs.

**B. Historical Perspective**

The development of a comprehensive plan of care has always been considered an integral part of the medical and rehabilitation process. This type of plan has historically been used by multiple disciplines. Rehabilitation professionals create a rehabilitation plan. Nurses develop a nursing care plan. Physicians define a medical treatment plan, and other professions develop plans specific to their practice. Pursuant to rapid growth in medical technology and an increased emphasis on the cost of care, including concepts of managed care, information regarding the specific cost of care has become an increasingly important aspect of health care. This process of developing a comprehensive plan and delineating costs has evolved over an extensive period of time and is now utilized by case managers, counselors, and other professionals in many sectors. This concept represents an acceptable and pragmatic approach to the delivery of services within myriad sectors of the health care delivery system.

The concept of rehabilitation/life care plans has been utilized in a variety of health care and legal settings to provide information and documentation regarding the cost of services related to long-term care. These plans are also provided as valuable tools for rehabilitation planning, geriatric services implementation, management of health care funds, discharge planning, educational planning, and long-term managed care, among other areas.

**C. Transdisciplinary Perspective**

Life care planning is a transdisciplinary specialty practice. Each profession brings to the process of life care planning practice standards that must be adhered to by the individual professional, and these standards remain applicable while the practitioner engages in life care planning activities. Each professional works within specific standards of practice for his discipline to assure accountability, provide direction, and mandate responsibility for the standards for which he is accountable. These include, but are not limited to, activities related to quality of care, qualifications, collaboration, law, ethics, advocacy, resource utilization, and research. Moreover, each individual practitioner is responsible for following the standards of practice for life care planning in addition to the standards for the qualifying profession.

In addition, the individual practitioner must examine her qualifications as applied to each individual case. Therefore, a thorough knowledge of the medical diagnosis, disability, and long-term care considerations, by virtue of education and experience, is a necessary component of the practitioner’s competency for each individual case.

**D. Education/Preparation/Certification**

The life care planner must:

1. Possess the appropriate educational requirements as defined by his professional standards; e.g., nurses should possess the requirements to acquire licensure, rehabilitation counselors should possess the requisite master’s degree, and other health professionals should possess the required degree for their field.
2. Maintain current professional licensure or national board certification within a professional health care discipline.
3. Demonstrate completion of an accredited program in nursing or a baccalaureate or higher-level educational program in a professional health care field. Fields may include, but are not limited to, nursing, rehabilitation counseling, medicine, physical, occupational or speech therapy, or psychology.
4. Demonstrate professional discipline that provides sufficient education and training to assure that the life care planner has an understanding of human anatomy and physiology, pathophysiology, the health care delivery system, the role and function of various health care professionals, and clinical practice guidelines and standards of care.
5. Participate in specific continuing education, required to maintain the individual practitioner’s licensure or certification within her profession.
6. Obtain continuing education and/or training to remain current in the knowledge and skills in the field.

II. Philosophical Overview/Goals of Life Care Planning

The life care plan should be a working document that provides accurate and timely information, which can be easily used by the client and interested parties. It should be a document that can be updated and serve as a lifelong guide to assist in the delivery of health care services in a managed format. It is appropriate, if possible, for the care plan to be a collaborative effort among the various parties and should reflect goals that are preventive and rehabilitative in nature. As a dynamic document, the life care plan will require periodic updating to accommodate changes and should have as its goal quality outcomes.

Goals / Life Care Plans:
A. To assist the client in achieving optimal outcomes by developing an appropriate plan of prevention of complications and restoration. This may include recommendations for evaluations or treatment that may contribute to the client’s level of wellness or provide information regarding treatment requirements.
B. To provide health education to the client and interested parties, when appropriate.
C. To develop accurate and timely cost information and specificity of service allocations that can be easily utilized by the client and interested parties.
D. To develop options for care that may be necessary for alternative situations.
E. To communicate the life care plan and objectives to the client and interested parties, when appropriate.
F. To develop measurement tools, which can be used to analyze outcomes.
G. To routinely develop comprehensive assessments of the projected goals of the life care plan, whenever possible.

III. Role and Functions of Life Care Planning

A. Scope of Practice/Applications

As a member of a health care profession, the life care planner must remain within the scope of practice for that profession as determined by state or national bodies. The functions associated
Appendix I

with performing life care planning are within the scope of practice for health care professionals, or evidenced by assessment.

Research analysis of data and evaluation of care recommendations are key elements in the functions of life care planning. In performing these elements, the life care planner will communicate with a variety of health care professionals regarding a case. The life care planner does not assume decision-making responsibility beyond the scope of her own professional discipline.

B. Specialization Features

The life care planner must have skill and knowledge in understanding the health care needs addressed in a life care plan. Consultation with others and obtaining education are expected when the life care planner must address health care needs that are new or unfamiliar. The life care planner must be able to locate appropriate resources when necessary. The life care planner provides a consistent, objective, thorough methodology for constructing the life care plan, while relying on appropriate medical and other health-related information, resources, and personal expertise for developing the content of the life care plan. The life care planner relies on state-of-the-art knowledge and resources to develop a life care plan.

Specialized skills are required to successfully develop a life care plan. These include, but are not limited to, the ability to research, critically analyze data, manage and interpret large volumes of information, attend to details, demonstrate clear and thorough written and verbal communication skills, develop positive relationships, create and use networks for gathering information, work autonomously, and demonstrate a professional demeanor and appearance.

C. Functions

1. Assessments: Assessment is the process of data collection and analysis involving multiple elements and sources.
   a. Collects data that is systematic, comprehensive, and accurate.
   b. Collects data about medical, health, biopsychosocial, financial, educational, and vocational status and needs.
   c. Obtains information from medical records, client/family/significant others (when available or appropriate), and relevant treating or consulting health care professionals. If access to any source of information is not possible (e.g., denied permission to interview the client), this should be so noted in the report.

2. Plan Development Research: The determination of content and the cost research components of life care planning require a consistent, valid, and reliable approach to research, data collection, analysis, and planning. The life care planner:
   a. Determines current standards of care and clinical practice guidelines from reliable sources, such as current literature or other published sources, collaboration with other professionals, education programs, and personal clinical practice.
   b. Researches options and costs for care, using sources that are reasonably available to the client.
   c. Considers appropriate criteria for care options such as admission criteria, treatment indications or contraindications, program goals and outcomes, whether recommended care is consistent with standards of care, duration of care, replacement frequency, ability of the client to appropriately use services/products, and whether care is reasonably available.
d. Uses a consistent method to determine available choices and costs.
e. When available and/or helpful in providing clarity, uses classification systems (e.g.,
ICD-9, CPT) to correlate care recommendations and costs.
f. Maintains knowledge of care standards, services, and products through continuing
education, literature, exhibits, etc.
3. Data Analysis
   a. Analyzes data to determine client needs and consistency of care recommendations with
      standards of care.
   b. Assesses need for further evaluations or expert opinions.
4. Planning
   a. Follows a consistent method for organizing data, creating a narrative life care plan report
      and cost projections.
   b. Develops and uses written documentation tools for reports and cost projections.
   c. Develops recommendations for content of the life care plan cost projections for each
      client and a method for validating inclusion or exclusion of content.
5. Collaboration
   a. Develops positive relationships with all parties.
   b. Seeks expert opinions, as needed.
   c. Shares relevant information to aid in formulating recommendations and opinions.
6. Facilitation
   a. Maintains objectivity and assists others in resolving disagreements about appropriate
      content for the life care plan.
   b. Provides information about the life care planning process to involved parties to elicit
      cooperative participation.
7. Evaluation
   a. Reviews and revises the life care plan for internal consistency and completeness.
   b. Reviews the life care plan for consistency with standards of care and seeks resolution of
      inconsistencies.
   c. Provides follow-up consultation to ensure that the life care plan is understood and
      properly interpreted.
8. Testimony
   If the life care planner engages in practice that includes participation in legal matters, the
   life care planner:
   a. Acts as a consultant to legal proceedings related to determining care needs and costs.
   b. May provide expert sworn testimony regarding development and content of the life
      care plan.
   c. Maintains records of research and supporting documentation for content of the life
      care plan.

IV. Standards of Performance
A. Ethical

Ethics refers to a set of principles of “right” conduct, a theory or a system of moral values, or the
rules or standards governing the conduct of a person or members of a profession. The primary
goal of ethics is to protect clients, provide guidelines to practicing professionals, and enhance
the profession as a whole. Within the life care planning specialty, all practitioners are members of one or more professional disciplines or are licensed or certified. It is expected that life care planners follow appropriate, relevant, ethical guidelines within their areas of professional practice and expertise.

Life care planners are expected to maintain appropriate confidentiality, avoid ethically conflicting dual or multiple relationships, adequately advise clients of the role of the life care planner, and maintain competency in the profession.

1. Confidentiality: Appropriate confidentiality is a sensitive and important concept. Some professionals will have communications protected by “privilege,” which is statutorily based in each state. For example, although no life care planners under that title alone are currently covered by privilege, many may be professional counselors, licensed psychologists, or others who have the additional statutory protection. Litigation has the additional component of attorney work product that may have an effect on what information may be disclosed. The life care planner must be thoroughly informed on this topic.

2. Dual or multiple relationships: A personal relationship with a client is not appropriate during the course of service. Developing life care plans for friends, coworkers, professional colleagues, or anyone where the objectivity and professionalism of the care plan is questioned should be avoided. Serving in dual or multiple professional roles, such as case manager or treater, is permitted as long as the simultaneous roles are not used for the purpose of providing benefit to the professional (e.g., recommending continued use of the professional without justification).

3. Client advisement of role: Each client should be fully informed about the role of the life care planner. For example, the client should be fully informed about who is requesting the life care plan as well as the confidentiality of communications. Also, life care planners who have dual role responsibilities should clarify that the life care planning role is separate and should clarify what the limits of their participation might be. Editor’s Note: For purposes of litigation or forensic evaluations, the person with the disability may be referred to as “evaluatee.” See Barros-Bailey, M., Carlisle, J., Graham, M., Neulicht, A., Taylor, R., & Wallace, A. (2008). Who is the client in forensics? *Journal of Life Care Planning, 7*(3), 125–132.

4. Competency: The life care planner is expected to accurately represent any information received for a particular case. Recommendations are to have medical, rehabilitation, psychological, and case management foundations with appropriate medical specialist and treatment team collaboration when possible, with support from medical recommendations, clinical practice guidelines, research, and other current literature.

Research information that the life care planner has obtained should be readily available for review and reflected within the life care plan.

Each case is unique, and the life care plan must demonstrate professional judgment in bringing together data, supporting documentation, and the individual characteristics of the person addressed within the plan.

The life care planner should possess knowledge of professional legal requirements including the legal principles of consent and confidentiality, including HIPAA requirements.

5. Life care planners are professionals, from varying educational backgrounds, who maintain professional conduct when addressing opposing life care plan consultants. Life care plan consultants should focus upon methodology of plan development, supporting documentation for recommendations, and plan content.
B. Research

The life care plan will have as its basis the scientific principles of medicine and health care. The involvement of the life care planner in the area of research should include, but not be limited to, the following objectives:

1. The life care planner will strive to identify and participate in research independently or in collaboration with others, utilizing research tools and activities that will promote quality outcomes.
2. The life care planner will critique literature for application to life care planning.
3. The life care planner will use appropriate research findings in the development of life care plans.
Appendix II

Bibliography of Life Care Planning and Related Publications

Note: The amount and scope of life care planning literature have mushroomed since the second edition, so it is not feasible to include a current listing. The references listed here represent the foundation of the specialty practice. To explore current publications, two sources are of particular note. The Journal of Life Care Planning is an excellent outlet; subscriptions are available at 706-548-8161. The Foundation for Life Care Planning Research helps fund research, which, when published, is available on the website at www.flcpr.org/research.html.


Dempsy v. United States, 32 F.3d 1490 (11th Circuit 1994).


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