

LIFE CARE PLANNING: YESTERDAY AND TODAY

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YESTERDAY...

The term "life care plan" was introduced into the legal literature in 1981 by Drs. Paul Deutsch and Fred Raffa in the publication, *Damages in Tort Actions*. The publication identified guidelines for specifying damages in civil litigation cases. In 1985, Drs. Paul Deutsch and Horace Sawyer introduced the concept to the profession when they published the classic *Guide to Rehabilitation*. Within that text, which is updated yearly, a life care plan was identified as a part of rehabilitation evaluation to project the impact of catastrophic injury on an individual's future.

As rehabilitation professionals identified the value of life care planning, the need for education regarding this "new tool" became apparent. One of the first education opportunities for rehabilitation professionals was headed by Dr. Deutsch, September 16-17, 1986, in Hilton Head, South Carolina. The two-day program focused upon the concept of life care planning and the format, which had been published in *Guide to Rehabilitation*. Also, in 1986, the first rehabilitation professional peer reviewed journal article on life care planning appeared in the *Journal of Private Sector Rehabilitation*.

By 1989 it became evident that professionals needed additional resources for training and a series of booklets were introduced covering common disabilities observed in workers' compensation and personal injury litigation. They are;

- Deutsch, P., Weed, R., Kitchen, J. & Sluis, A. (1989). Life care plans for the head injured: A step by step guide. Athens, GA: E & F Vocational Services.
 - Deutsch, P., Weed, R., Kitchen, J. & Sluis, A. (1989). Life care plans for the spinal cord injured: A step by step guide. Athens, GA: E & F Vocational Services.
 - Weed, R. & Sluis, A. (1990). Life care plans for the amputee: A step by step guide. Tampa FL: CRC Press.
 - Kitchen, J., Cody, S., & Deutsch, P. (1989). Life care plans for the brain damaged baby: A step by step guide. Orlando, FL: PMD Press
 - Kitchen, J., Cody, S., & Morgan, N. (1990). Life care plans for the ventilator dependent patient: A step by step guide. Orlando, FL: PMD Press
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Over the next several years, it became apparent that professionals in various health care fields were developing documents known as "life care plans". In an effort to promote standardization and professional practice, in the fall of 1992, a group of rehabilitation professionals came together to develop a concentrated curriculum for the life care planning process. Paul Deutsch, PhD, Julie Kitchen, CDMS, Richard Bonfiglio, MD, Susan Riddick, RN, and Roger Weed, PhD, created an eight-track program including tenets, process, methods, medical basics in catastrophic cases, forensic issues, and business and ethical practice. Initial courses were offered on the East and West coasts as a "trial balloon" to survey if other professionals perceived similar needs.

With introductory courses on both coasts successful, the group sought recognition for course completion for participants. As a part of this process the five founders gave the program to the University of Florida where Dr. Horace Sawyer assisted with development of a joint public-private relationship between the Rehabilitation Training Institute and the University (known as Intelicus), resulting in a certificate from the University of Florida in life care planning. The University continues to oversee the curriculum and Intelicus acts as marketer and conference manager.

As educational opportunities began to increase for life care planners, the need for a specific practice identity began to emerge. Certification was identified as a viable option for practitioners, to establish minimum standards for entry into practice and to offer the public a means for evaluating credentials of those offering life care planning services. Leaders in life care planning discussed development of a certification process for life care planners with a number of certifying bodies. In 1994, the Commission on Disability Examiner Certification (CDEC) began research and development for life care planning certification and in the Spring of 1996, the first exam was administered. Unlike many other certification exams, there was no "grand fathering." All applicants were required to submit documentation showing at least 120 hours of continuing education as well as certification in a health care related area before being allowed to apply.

During this time period, the literature regarding life care planning processes began to expand. Notable references include (see list of almost 200 references elsewhere in this journal for a more complete record.):

- Deutsch, P. & Sawyer, H. (eds) (1985). Guide to rehabilitation. New York, NY: Mathew Bender (updated yearly and now available through Ahab Press)
- Deutsch, P., Sawyer, H., Jenkins, W., & Kitchen, J. (1986). Life Care Planning in catastrophic case management. Journal of Private Sector Rehabilitation, 1(1), 13-27.
- Blackwell, T., Weed, R., Powers, A. (1994) Life Care Planning for Spinal Cord Injury, Elliott & Fitzpatrick, Athens, Georgia
- Blackwell, T., Powers, A., Weed, R. (1994) Life Care Planning for Traumatic Brain Injury, Elliott & Fitzpatrick, Athens, Georgia
- Weed, R. & Field, T. (1994). The rehabilitation consultant's handbook. Athens, GA: Elliott & Fitzpatrick

- Weed, R (Ed.) (1999). Life Care Planning and Case Management Handbook. Boca Raton, FL: St. Lucie/CRC Press.

Articles about life care planning began to appear in The Case Manager, Inside Life Care Planning, Journal of Rehabilitation, Journal of Private Sector Rehabilitation, and Rehabilitation Nursing Journal.

During 1996, Intelicus presented the first Annual Life Care Planning Conference, drawing over 200 life care planners from across the nation. Their conferences continue annually, bringing practitioners together to share best practices and current knowledge and to create a one-of-a-kind networking opportunity.

Also in 1996, the first professional association of life care planners was formed. Originating as the American Academy of Nurse Life Care Planners, the group's purpose was to provide advanced practice educational programs and to provide leadership for standards development. In 1997, Roger Weed proposed a dialogue with the organization to discuss open membership to all practitioners. Following a meeting in Atlanta, Georgia, the AANLCP Advisory Panel voted to change the group's name to the International Academy of Life Care Planners and to open membership to all professionals engaged in the practice. The IALCP has since participated in the development of the nationally accepted definition of a life care plan and has developed and published National Standards of Practice for Life Care Planners.

On April 12, 2000, the first Life Care Planning Summit was held to address life care planning topics and issues, with the goal of achieving consensus among practitioners in five focus areas. The focus areas were: (1) professional preparation; (2) basic procedures for the life care planning process; (3) ethics; (4) reliability and validity; (5) information dissemination. The attendees participated in focus groups, using a modified nominal group technique, to establish the priority issues under each focus area. A summary of consensus findings agreed to by all participating organizations was published and is available from Elliott & Fitzpatrick, 706/548-8161, for a nominal charge.

During 2000-2001, leaders in life care planning began to see the need for joint efforts, to address issues in life care planning, including validity, research methodology and education for others. The National Coalition of Life Care Planners was formed with representation from IARP, AALNC, CMSA, Intelicus, CDEC and IALCP. The group is available for dialogue regarding issues which impact the overall practice. In addition, the second Life Care Planning Summit will be held in Chicago on May 19, 2002.

TODAY...

The practice of life care planning continues to evolve evidenced by the almost 200 references on life care planning, and multiple universities and organizations training students in the procedures. A definition of a life care plan has been published widely, ethics are established and the Scope of Practice and Standards of Practice have been peer reviewed, field reviewed, published and disseminated. (They are available for all at internationalacademyoflifecareplanners.com).

Life care planning has expanded into elder care management, discharge planning, special needs trusts and Medicare set-aside trusts. The practice has become accepted as a valuable tool for the prediction of costs and for patient/family education, with catastrophic injury or chronic health care needs. It now becomes incumbent upon practitioners to work together to promote quality, evidence-based plans, consistent with expectations of professional behavior and with Standards of Practice, established by peers.

Table 1, Chronology of Selected Life Care Planning Events

Year	Event
1981	Life Care Planning concept first appeared in the legal literature in the book <i>Damages in Tort Action</i> , Volumes 8 & 9
1985	Life Care Planning introduced to the rehabilitation literature in the book <i>Guide to Rehabilitation</i>
1986	First national conference held at Hilton Head Island First article appeared in rehabilitation literature in the <i>Journal of Private Sector Rehabilitation</i> , volume 1, number 1.
1989	Series of booklets launched for training.
1992	First comprehensive curriculum developed consisting of 8 tracks, 2½ days each by Paul Deutsch, Richard Bonfiglio, Susan Riddick-Grisham, Julie Kitchen and Roger Weed.
1993	University of Florida on November 14 th , agrees to offer a certificate in Life Care Planning.
1994	University of Florida assumes responsibility for curriculum.
1996	The Commission on Disability Examiner Certification administers the first certification exam in March leading to Certified Life Care Planner designation. First annual Life Care Planning conference is held. First association specific to life care planning formed - American Academy for Nurse Life Care Planners (not to be confused with the American Association of Nurse Life Care Planners).
1997	The American Academy for Nurse Life Care Planners evolved into the International Academy of Life Care Planners and professional membership expanded beyond nursing.
1998	Life Care Planning definition agreed upon by several groups.
2000	First Life Care Planning Summit is held on April 12. Standards of Practice for Life Care Planners published.
2002	Second Life Care Planning Summit is scheduled for May 19