

International Encyclopedia of Rehabilitation

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Life Care Planning: Introduction to

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Introduction

Life care planning is a relatively new sub-specialty originating in the United States, that has experienced tremendous growth in the last 30 years. This growth is due in part to the utilization of life care plans within the rehabilitation, insurance, and legal professions. More significantly, life care plans have proven to be valuable tools in managing catastrophic injury and illness.

The tenets and methodologies of life care planning emerged from a combination of case management practices and catastrophic disability research in the mid-1970s. The first published reference to life care planning can be found in *Damages in Tort Actions* (1981), a multi-volume text written by Paul M. Deutsch Ph.D. and Fred Raffa Ph.D. The methodology of life care planning provided professionals with a consistent process for analyzing the immediate and lifelong needs of patients necessitated by the onset of a disability.

With its foundation in rehabilitation, life care planning attracts board certified and/or licensed professionals from diverse fields of practice, including rehabilitation counseling, rehabilitation nursing, rehabilitation psychology, physiatry, case management, and an other allied health professions. In addition to achieving certification or license in their primary disciplines, many professionals choose to pursue board certification in life care planning (CLCP) which is currently granted in the U.S. by the Commission on Health Care Certification or one specific to nurses offered by the American Association of Nurse Life Care Planners (CNLCP).

This article presents an overview of the historical roots of life care planning, including the underlying philosophies and research, that guided its development along with the eventual establishment of its tenets and methodologies.

Theoretical Basis of Life Care Planning

Life care planning originates from the integration of three distinct fields of practice: experimental analysis of behavior, developmental psychology, and case management.

Experimental Analysis of Behavior

Experimental analysis of behavior, which unites the specialties of experimental and clinical psychology, involves the scientific study of behavior and changes in behavior. By understanding the mechanisms of behavior, researchers attempt to define how and why individuals react to specific situations in specific ways.

Inherent in this specialty are the principles of learning theory and behavioral psychology, that rely upon the counting and charting of discrete behaviors in order to document changes over time. Complex behaviors are deconstructed into specific actions that can be

quantitatively measured and analyzed in relation to the presentation of various stimuli or as an individual reacts to given situations.

The techniques that drive behavior analysis are also critical elements of life care planning. Planners must be able to identify the short-term and long-term goals and acute needs of patients, and then clearly communicate these details to all parties involved in the case. Just as behavior charts serve as documentation of behavior change over time, life care plans serve to account for all of the medical, care, and rehabilitation needs of individuals with catastrophic injuries.

Developmental Psychology

Developmental psychology involves the study of social, cognitive, and physical changes that occur throughout the developmental years and beyond. This area of study has defined several critical periods in human development, which, in part, determine future attitudes, behaviors, relationships, and sense of well-being. Developmental psychology attempts to identify the effects of aging by conducting longitudinal and cross-sectional research and recognizes that the human life cycle is comprised of many phases, not just childhood and adolescence.

This focus on the life cycle and phase changes throughout the aging process provide a philosophical basis for life care planning. A comprehensive plan provides continuity of care while accounting for the patient-specific characteristics that will interact with the effects of disability over time.

In addition to providing a theoretical basis for life care planning, developmental psychology played a practical role in the development of the subspecialty. In the early stages of its history founding researchers in life care planning were conducting research with children who were diagnosed with cerebral palsy. When reviewing the recommendations for future care with families, practitioners noticed that it was difficult to adequately communicate the information because of the overwhelming complexity of the children's needs. Parents, therapists, educators, physicians, and others involved in the child's care needed a structured, systematic reference tool that summarized the recommendations and provided a roadmap to follow in the future. Over time, the framework for the life care plan was laid.

The life care plan became a document that allowed practitioners to clearly identify the critical periods of need as children progressed through the developmental phases of the life cycle. This, combined with the functional limitations of the disability, guided the composition of an individualized life care plan.

Case Management

A concept emerged in the United States in the early 1970s, as theorists in the field of case management recognized the importance of integrated, coordinated services for those with long-term medical, support care, and rehabilitation needs. The life care plan presented the necessary format for presenting comprehensive yet exceptionally detailed information regarding the manifold needs of patients with catastrophic injuries. In doing so, case

managers were in a better position to offer assistance and effective, proactive strategies for patients' health and well-being.

The practices and basic principles inherent within rehabilitation counseling, rehabilitation nursing, rehabilitation psychology, and case management culminated in the establishment of the standards, tenets, and methodologies of life care planning.

Integration of Practice

Following are several of the factors that precipitated the development of life care planning methodology:

1. **The need for a summative statement.** Individuals and their families, particularly in pediatric cases, needed to have a concise summary of a long-term plan that could be reviewed following a comprehensive evaluation, then referred to as a guideline in future.
2. **A tool of communication.** In most catastrophic or complex care cases, many professionals are involved in the care and rehabilitation effort. The effectiveness of these efforts depends upon the coordination, cooperation, and communication between all parties involved in the rehabilitation process. The life care plan provides a format for a clear, concise, and sensible presentation of the complex needs of the patient.
3. **Forethought of planning.** One of the foundations of catastrophic case management asserts that proactive, preventative measures must guide the planning process. Otherwise, crisis situations, which are neither healthy for the patient nor optimal decision-making circumstances, will dictate the resultant care plan.
4. **Analysis of complex concerns into basic components.** Life care planning methodology establishes that the most basic components of each recommendation be identified and accounted for within the plan. Once outlined, the prevention of complications becomes a more manageable goal.
5. **Plans are individualized to meet the unique needs of each patient.** Life care plans are not generic formulas applied to a patient according to their diagnosed disability or injury. Integral to the process of life care planning is a review of patient-specific records; a clinical interview; and extensive evaluation of the injury/disability, the individual's goals and preferences, the needs of the family, and an analysis of the geographical area of residence.
6. **Needs, rather than funding sources, drive the planning process.** At no time during the plan development process should budgetary concerns influence care and rehabilitation recommendations. The life care plan was designed with the intention of citing all of the items and services made necessary by the onset of a disability/injury. Once the implementation phase of the process begins, planners

Applications of Life Care Planning

With the basic methodology of life care planning established, it became a tool for use in consultation with patients, families, rehabilitation professionals, and catastrophic case managers. As the standards and methods gained acceptance outside of the general rehabilitation circle, insurance carriers, worker's compensation judges, circuit court judges, federal court judges, attorneys, and others involved in litigation have called upon life care planners as experts in long-term disability management. Courts, primarily in the United States and Canada with participation by professionals in other countries, have sought the specialized knowledge of life care planners so that they, and juries, are better able to understand the long-term effects of catastrophic injuries and the associated economic damages of such cases.

As may be imagined, once applied outside of the immediate arena of consultation, life care planning has experienced tremendous growth and is recognized as a valuable means of disability analysis. The research and development of life care planning effectively bridged the gap between acute care plans, ongoing catastrophic case management, and the provision of appropriate long-term care and rehabilitation services.

A Team Approach

Life care planners do not work in isolation, but depend upon the skills and knowledge of other professionals to collaboratively determine the immediate and future needs of patients. A thoroughly researched life care plan is based upon both case management principles and medical foundations. In order to meet the standards established within the subspecialty, each of these components is necessary.

It is encouraging to note that in the U.S. during the early 1990s, six federal district appeals court rulings redefined the concept of the Independent Medical Examination (IME). Now, rehabilitation psychologists, nurses, and counselors were recognized as professionals qualified to conduct an evaluation and assert an opinion regarding the effects of an individual's disability, their functional limitations, and future needs. These were important rulings because they symbolized the fact that case management and rehabilitation professionals possess a unique set of skills in analyzing disability and in educating those involved in litigation. Growing recognition of the subspecialty has induced interest in life care planning and prompted many practitioners to pursue board certification in this area.

Original Definition of Life Care Planning

The original definition of life care planning is as follows:

"A consistent methodology for analyzing all of the needs dictated by the onset of a catastrophic disability through to the end of life expectancy. Consistency means that the methods of analysis remain the same from case to case and does not mean that the same

services are provided to like disabilities." (Deutsch and Raffa 1981; Deutsch and Sawyer 2002)

Two components of the definition deserve additional discussion: the concepts of a consistent methodology and needs-driven recommendations.

A Consistent Methodology

In order to most effectively, and accurately, analyze the needs of patients, life care planners must employ a consistent methodology and approach to the task. Rather than becoming overwhelmed by the complexity of the process, life care planners deliberately and methodically organize, evaluate, and interpret patient-specific information. When data is systematically collected and managed, each detail of the patient's circumstance may be identified. Preventative measures may then be effectively applied in an effort to thwart potential medical complications, incongruencies in care, inappropriate equipment/supply recommendations, and unrealistic rehabilitation programs.

As stated earlier, there are acute care situations which cannot be foreseen, but the goal of life care planning is to minimize such occurrences. When reacting to a crisis, the patient, family, and involved professionals often do not have an opportunity to judiciously consider consequences of decisions, but must take immediate action to resolve a threatening situation. In fact, most often there is little choice involved in the actions required in order to stabilize or maintain a patient's status.

Needs-Driven Recommendations

When a consistent methodology is followed, research regarding patient outcomes may be accessed throughout the life care planning process. Recall that experimental analysis of behavior, one of the building blocks of the subspecialty, contributed the procedure of charting behaviors as one means of disability analysis. Changes in patient behaviors are used as a measure of the positive/negative effects of environmental factors, medical interventions, and rehabilitation techniques.

This type of research allows life care planners to compile an outcomes database according to the patient-specific limitations and needs identified. In addition to outcomes, short-term treatment/rehabilitation goals may be determined based on what has been established to be effective within the research literature. Nursing/attendant care needs, equipment requirements, maintenance levels of therapy, and many similar areas may be more reliably determined if based upon established research findings.

Recommendations within the life care plan must have a basis in known medical and rehabilitation outcomes as documented within research literature. Recommendations based upon any factor other than patient need are bound to failure. This is not to suggest that unforeseen complications will not occur, but the incidence of such crises may be minimized through adherence to the established methodologies. Life care plans based upon funding considerations may endanger the health and well-being of patients who require more care, equipment, or services than financial resources allow.

Reality must impose itself at some point in the process. The plan implementation phase allows case managers to work collaboratively with professionals from numerous disciplines and community agencies to creatively resolve funding issues and identify collateral sources of support. Plan implementation is most effectively accomplished through a team approach, with consideration given to all possible avenues of funding.

Foundational Development of the Life Care Plan

As Life Care Planning has evolved over the past thirty years it has been influenced by extensive research much of which has been sponsored by the Foundation for Life Care Planning Research. In the most recent years it has become recognized that plans must be well supported through the development of a strong Foundation in four critical areas as appropriate to the specific recommendations involved:

1. Medical foundation
2. Rehabilitation foundation
3. Case management foundation
4. Psychological foundation

The steps involved in establishing medical foundation include the following:

1. Establishing direct links between the medical records and recommendations in the plan.
2. Writing the Medical and Allied Health treatment team members with plan questions not answered in the existing records.
3. Utilizing consulting specialists.
4. Utilizing Clinical Practice Guidelines.
5. Utilizing research literature.

The steps in establishing the rehabilitation foundation are similar:

1. Effective use of the medical and rehabilitation records through careful linking of this information to plan recommendations.
2. Writing the Medical and Allied Health treatment team members with plan questions not answered in the existing records.
3. Utilizing consulting specialists.
4. Utilizing Clinical Practice Guidelines.
5. Utilizing research literature.

The steps in establishing the case management foundation are as follows:

1. Effective use of the medical and rehabilitation records through careful linking of this information to plan recommendations.
2. Writing the Medical and Allied Health treatment team members with plan questions not answered in the existing records.
3. Writing the current case manager on the file.

4. Utilizing consulting specialists.
5. Utilizing Clinical Practice Guidelines.

The steps in establishing the psychological foundation are as follows:

1. Effective use of the medical and psychological records through careful linking of this information to plan recommendations.
2. Writing the Medical and Allied Health treatment team members with plan questions not answered in the existing records.
3. Writing the current psychologist or licensed mental health counselor on the file.
4. Utilizing consulting specialists.
5. Utilizing Clinical Practice Guidelines.

Regardless of the Life Care Planners specialty, it must be understood that no single practitioner of this sub-specialty has the expertise to complete a Life Care Plan without drawing upon the skills of experts from a broad range of professionals through consultation, interaction with the treating physicians and allied health team members and use of both clinical practice guidelines as well as the research literature. Individuals with a disability interact during acute treatment and rehabilitation with a broad range of medical specialist and many different allied health team members. To expect that one single physician, rehabilitation counselor, nurse or psychologist or other professional working on a plan can independently determine all of the needs of any given disability without utilizing all of these treating professionals and without taking advantage of all of the available literature is to underestimate the complexity and purpose of the Life Care Planning process.

Recognition of Life Care Planning as a Subspecialty of Practice

The current definition of life care planning is as follows:

"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 costs for individuals who have experienced catastrophic injury or have chronic health care needs." (International Academy of Life Care Planners 2003)

Professional Organizations

The subspecialty of life care planning is built upon the contributions of experimental analysis of behavior and developmental psychology, but it draws most heavily upon the principles of case management. Because life care planning is transdisciplinary, many professional organizations recognize this area of practice as a vital component of the future health and well-being of patients.

International Academy of Life Care Planners (IALCP)

The International Academy of Life Care Planners (IALCP) has taken a leadership role in the development of standards. It began as the American Academy of Nurse Life Care

Planners which became the IALCP in November 1997. Membership was open to all practitioners so that those from divergent disciplines could come together in promoting the welfare of patients. The IALCP first published the Standards of Practice for peer review in 2000.

Scope of Practice

Today the IALCP, in addressing the scope of practice of the life care planner, notes:

"Life Care Planning is an advanced practice which is collaborative in nature and includes the patient, family, care providers and all parties concerned in coordinating, accessing, evaluating and monitoring necessary services." (IALCP, 2003)

The Standards continue:

"The IALCP believes professionals who develop life care plans must:

1. Have a foundation of knowledge and practice.
2. Have an appropriate experience base.
3. Conduct an active practice, which demonstrates application of the appropriate professional processes.
4. Perform specific methodologies demonstrating advanced practice.
5. Participate in professional organizations.
6. Participate in community and national organizations." (IALCP, 2003)

"Life care planning is a multidisciplinary specialty of practice within a professional discipline. Each discipline brings to the function of life care planning standards of practice, which must be adhered to by the individual professional. Each professional works within specific standards of practice for his or her discipline to ensure accountability, provide direction, and mandate responsibility for the standards for which he or she 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, individual practitioners must examine their qualifications as applied to each individual case. Therefore, a thorough knowledge of the 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" (IALCP, 2003).

Other Professional Organizations

The IALCP is not the only professional organization supportive of life care planning. Others of note include the following:

- International Association of Rehabilitation Professionals (IARP):
http://www.rehabpro.org/iarpindex_msie.html

- Commission on Health Care Certification (CHCC), formerly known as the Commission on Disability Examiner Certification (CDEC): <http://www.ichcc.org>
- Case Management Society of America (CMSA): <http://www.cmsa.org/>
- American Association of Legal Nurse Consultants: <http://www.aalnc.org>
- American Association of Nurse Life Care Planners: <http://aanlcp.org>

The IALCP, IARP, AALNC, CHCC and CCMC joined together to sponsor the Life Care Planning Summit 2000 (see below).

Life Care Planning Summit 2000

The purpose of the Life Care Planning Summit 2000 was to join planners from across the U.S. in a think tank concentrated upon the following topics:

- Professional preparation
- Basic tenets and procedures
- Reliability and validity of life care planning
- Continuing education and information dissemination

The Summit was a resounding success and underscored the collaborative, interactive spirit inherent within life care planning. Those new to the subspecialty should be encouraged by the fact that, in the 25 years since its origin, life care planning has emerged into a transdisciplinary collective, committed to providing quality care and case management for individuals with various disabilities. The Life Care Planning Summit 2002, which met with equal success and has contributed significantly to the field, followed the original Summit.

The Rehabilitation Professional's Role as an Educator

Aside from the responsibilities incurred throughout the life care plan development process, rehabilitation professionals are first and foremost educators. As educators, planners must be able to clearly communicate the nature of a patient's disability, the residual functional limitations, and the effects of the disability throughout the patient's life expectancy.

The life care planner has a responsibility to educate others regarding:

- The physical and psychosocial sequelae of the injury or illness.
- What can be expected when the effects of an injury or illness combine with the aging process over time.
- The impact of the injury or illness on the family.

Individuals and family members rely upon this information in order to make well-informed decisions, understand the phase changes expected as the patient ages, and plan for future needs. Recall that the life care plan is a communication tool, that relates a large volume of complex information in a concise, readable format.

The role of educator extends into the courtroom. Judges, juries, attorneys, insurance administrators, and others rely upon the life care planner to offer an explanation regarding the effects of an injury or illness, residual functional limitations, future needs, potential complications, and other issues to clarify with precision how the life of the patient has been impacted. The life care planner does not simply present the "bottom line" dollar figure associated with the patient's case, but educates all involved in the process so that jurors can arrive at the appropriate economic damages award.

The life care planner is an educator and the life care plan is a tool for communicating the necessary services, time frames for implementation of each recommendation, associated costs, and potential complications of the injury/illness or noncompliance with medical and rehabilitation prescriptions. Without a clear understanding of these elements of the plan, patients and families may not feel confident in their ability to make responsible, reasonable choices.

Conclusion

Upon completion, each life care plan should reflect the unique needs of the patient. The established methodology allows planners to consistently follow a specific sequence of tasks throughout the development process while, at the same time, customizing each plan according to the realities of a patient's circumstance." Thus, proving the patient, treatment team, and all involved parties with an organized and comprehensive document detailing the needs dictated by the onset of a catastrophic or complex disability. Currently, life care plans are being utilized in the United States, Canada, the United Kingdom, and Australia.

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