

Guest Editorial

Life Care Planning and Case Management in Brain Injury

This issue examines the special considerations and challenges of life care planning and case management for patients with ABI injuries from a few different perspectives. After a catastrophic brain injury, patients, families, friends and co-workers often struggle to find direction. As the patient moves through the phases of recovery, from rehabilitation to settling into living life with a brain injury, there is a need for a big-picture overview of what can be expected in the future. Because clinical practitioners often have specific roles that are limited to a defined period of time, the baton for a patient's care is passed from care team to care team each with variations in practice patterns, which can confuse the patient and family. Information needs change over time, and in many instances decision-making is focused on the most immediate need rather than on the long-term.

It's important to provide each family with a guide to what to expect in the future – how to access services and resources and how to fund the care and living supports that could be required over a lifetime? We know that each person living with a brain injury is unique and will need a personalized plan of care that addresses cognitive, emotional, and functional deficits, as well as variances in family structures, financial and community resources.

We all want our patients to live healthy, satisfying lives. Decisions and planning will be required to coordinate medical care, legal matters, living supports, and work or other productive activities over the entire lifespan of the injured. Navigating the healthcare maze, moving from clinical provider to clinical provider, finding and establishing local service providers and securing funding can prove frustrating and daunting.

In the early 1980s, specific life care planning methodologies emerged to evaluate and detail the lifelong needs of persons who had suffered ABIs or other catastrophic conditions. The life care plan (LCP) documents future needs of a patient and delineates the cost of

each line item. It provides for ongoing medical care by multiple specialists and clinicians and it includes provisions for long-term caregiver supports such as home health care or residential living. It also accounts for other special provisions, such as a lifetime of medication trials, durable medical equipment, accessible living environments and options for socialization. The LCP is a dynamic document that can require updates over time; it may include considerations for additional rehabilitation for a reduction in disability (as discussed by Lewis & Horn) or supports for changes that are caused by the aging process.

Once in place, the LCP is implemented by a case manager, who acts for the patient as an advocate for quality, patient-centered holistic care that focuses on maximum function and life satisfaction throughout the individual's life. A plan of care is designed to provide a roadmap for the future – a tool that allows for better proactive planning and decision-making, with improved outcomes and the best use of financial resources over time. That plan of care is developed with consideration of factors specific to the individual and current research about what people with similar injuries have experienced over time, such as what is discussed in the Krause et al. article. The plan provides knowledge, and with knowledge comes dignity for all involved, in decisions and in life.

The foundation for the coordination of the life care plan requires that an individual has the requisite expertise for identifying needs associated with medical, psychological, case management and vocational issues. Johnson et al. point out the importance of certification and professional standards of practice in maintaining the integrity and consistency among life care planning practitioners.

In projecting long-term needs of a patient with ABI, there is the critical question of which model to use for analyzing survival prospects: anticipated life expectancy, median survival time, or a full life table.

Day et al. suggest that life care planners have a professional responsibility to consider the possible, or probable, longevity of persons for whom they are planning. Often a life care planner will be expected to work in conjunction with an economist and other experts in valuing a plan, and in determining the best method (life expectancy versus life table) for handling the question of longevity.

Another important aspect of life care planning is the analysis of potential for work or other meaningful activity. When considering the vocational potential of children and adolescents, Neulicht and Berens point out that the needs of a child with an ABI are not a scaled-down version of those required by an adult. Instead, life care planners must examine cognitive, emotional, social, familial, and educational factors, and pre-vocational as well as vocational needs that are unique to children. Young people have developing brains that may recover in irregular ways. PEEDS-RAPEL[®] is presented as a consistent, organized model for analyzing, synthesizing and displaying data as a basis to form reliable opinions. Expanding on that discussion, Reid and Riddick-Grisham note that the inclusion of vocational or meaningful activity requirements in life care plans is not optional; work contributes to an individual's self-worth, quality of life and general health, and is integral to minimizing complications for people living with disabilities.

Life care planning expertise for brain-injured patients is provided in one form or another in many countries around the globe. We also look into the special concerns of several regions outside of the United States, when it comes to long term care plans and case management.

Clark-Wilson and Holloway examine life care planning and the models of rehabilitation, case management and care for ABI patients in the UK. In the UK, immediate acute care is free and accessible, but case management after initial treatment is inconsistent because of the variety of sources for funding. Life care plans, referred to as long-term care reports, are usually prepared by care experts only for the courts for litigated

cases, and funding is a large determining factor in the kind of extended care an individual is likely to receive.

Baptiste et al. studied factors associated with case management service use in people with traumatic brain injury (TBI) in Canada, using a published model for service use. They discovered significant differences between users and non-users of case management services. In particular, users are significantly younger than non-users, as the older the person, the less likely to use the services. Also, users have less education and more severe activity limitations as well as lower community integration. Persons living alone are less likely to use case management. "The Andersen Model" is used most often in Canada to predict use of services.

The use of case management and life care planning services may vary from country to country, but for patients and families living with ABI, the needs are similar in that they must access to services and resources. Life care planning has emerged as a methodology that allows families to have a detailed roadmap of future care needs and the associated lifetime costs. It promotes continuity of care, improved communication between the patient, family and care teams, and informed financial decisions.

The contributing authors have come together in this special edition to give you some insights into the practice of life care planning and case management. These dedicated professionals spend their days contributing to the lives of patients and families living with ABI and other chronic conditions. It has been a privilege and honor working with each of them.

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