



Life Care Planning – An International Perspective

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Imagine building a house with no framework or design; you would not have a home. The Life Care Planner is often likened to a housing contractor and architect, because just as your home, a life care plan needs to be well planned, designed and constructed. Because of the diversity of needs and challenges that can follow brain injury (BI), many people are involved in the life care plan “building process.” Support needs and costs following BI are often life-long and go beyond direct medical care. It is especially important to understand the resources required to promote function and performance over the person’s lifespan.

Life Care Planning, as it is practiced by Certified Life Care Planners (CLCP) in Canada, Care Experts in the United Kingdom (UK), and CLCP’s in the USA, all adhere to a specific methodology involving standards of practice, scope of practice, and Codes of Ethics. This enables life care plans that are comprehensive and consistent with well-reasoned practice and evidence. Key practices include careful review of all available records; meeting with the person experiencing disability; talking with treating professionals, consulting professionals and family, as appropriate; identifying personally appropriate and accessible services, along with associated charges; and practicality in recommendations relative to personal capacities and lifestyle. Effective plans delineate the objectives, steps, resources, and timing associated with all services and supports required for the person’s life.

Given the notable differences in health service delivery systems, it is not unusual for people to ask why a life care plan is needed for individuals with disability due to BI in Canada and the UK. Both Canada and the UK have access to basic

healthcare that is funded via public rather than private means. All hospital and most primary services are universally available to all citizens and permanent residents of each country; essentially from the beginning to the end of life. Because of this public funding, the “patient” does not see a bill for hospital treatment or medical monitoring visits at a doctor’s office (Health Canada, 2016). Access to such healthcare is considered a basic right; much like primary and secondary education is in our mutual countries. Hence, in both Canada and the UK, no one “goes broke” if they have a serious health condition, or less.

In this article, we describe our two “sister” systems in Canada and the UK. This includes how life care planning is practiced as a professional sub-specialty of rehabilitation in these two countries, and why uncovered care costs can still be substantial and need to be discerned, despite “universal” access.

The Functional Approach

Adding the concept of function as a key component of what constitutes a “health condition” was a fundamental part of international changes that the World Health Organization (WHO) instituted in 2001. The WHO’s International Classification of Function (ICF) frames health issues as those that occur beyond hospitals and direct medical care (World Health Organization, 2001). The ICF considers activities a person can or cannot perform and the person’s participation level (domestic chores, childcare, intimate relations, school, work and community association participation). Importantly, function was framed to include personal and environmental factors, nested within the grouping called “contextual factors;” considered an integral component of health. This means that

the psychosocial, behavioural, relationship and environmental components of BI, as well as specific challenges emanating from such factors are all part the functional approach in a life care plan. Typically, these are mostly the “invisible” areas of performance following BI and are too easily neglected when care costs focus strictly on physical function.

This systematic analysis of functional factors provided by the ICF is universally available to all professionals seeking an evidence-based direction (Law 2002). This improves the homogeneity of emerging life care planning research. Multiple functional losses and/or capacity variations following BI result in notable life changes that often require a variety of supports that can incur significant cost. These costs are medically justified but not specifically “medical” in nature. More often than we like to acknowledge, the responsibility for addressing these functional losses are carried by family, friends and other community members especially for people with disability following BI who are based in the community. When these long-term needs and costs are overlooked, the person with BI risks future safety concerns, secondary complications (including social marginalization, mood disorders, and addictions) as well as re-injury. The “chain of risks” frequently needs to be mediated by access to long-term supports. Otherwise, one problem or situation can lead to another. For example, the risk of a fracture from a fall due to balance issues, or addiction due to impulse-management problems.

Canadian Care Costing

By definition a life care plan is “dynamic” (Weed and Berens, 2010), likewise, Canada’s publicly funded health care system is dynamic. The overall term for the Canadian care system is “Medicare,” not to be confused with Medicare programs in the USA. There have been a number of changes since Medicare was introduced in 1968 and changes will likely continue in response to changes within medicine and throughout society. Concurrently, this evolution also occurs in the field of life care planning at both individual and at systems levels. Regardless of the dynamic features of Medicare, the basics for Canada’s healthcare remain the same, i.e., universal coverage for medically necessary health care services is provided on the basis of need, rather than the ability to pay (Health Canada, 2016).

This universal access is mostly perceived as social advancement by Canadians, as it reflects this country’s values of fairness and equity and is fundamentally similar to the UK with regard to healthcare access. However, we are aware that universal health coverage has been an area of political and social struggle in the US. More recently, threats to the Canadian public health system by multinational corporations and private clinics bankrolled by business interests have also become regarded as a real risk (Canadian Doctors for Medicare, 2016).

What happens when health problems continue beyond the direct medical needs and negatively impact a person’s life trajectory and future function? In Canadian law, there were a series of cases in 1978, known as “the trilogy” where the Supreme Court outlined Canadian law on costs of future care (Klinger, et al., 2004). The court stated that the award for future care is based on what is reasonably necessary to promote the mental and physical health of the plaintiff (Slater, 2012).

Geographic location, such as what province a person lives

in is always a factor. In Canada, each province individually administers, implements, plans, and negotiates fees separately while meeting the national principles set out under the Canada Health Act (Canada Health Act, 2016). Whenever, a region within that province has disparity with regard to available services (such as low density populations or physically restrictive areas) it adds another factor for the life care planner to consider.

Support needs in Canada fall under supplementary supports and not direct medical care. Typically, home and continuing care services are not covered by the Canada Health Act; however, the provinces and territories provide and pay for certain home and continuing care services. These include services for seniors, children, low income residents; and range from dental/prescription to physical therapy. The federal department of Veterans Affairs Canada provides home care services to certain veterans if they are not available through their province or territory. In addition, the federal government provides home care services to First Nations people living on reserves and to Inuit in certain communities (Health Canada, 2016).

Even with available primary medical coverage, as well as some rehabilitation coverage, there are often other substantial lifetime supports that a person with BI needs in order to function in the community. Typically, these are not part of the province’s health plan. Overall, public funding for supplementary supports is not available on a consistent or long-term basis and eligibility needs to be routinely proven. These recurring assessments preclude the establishment of long-term support planning through public sources. As a result, such supports are clearly identified within a Canadian life care plan and costed at market rates. In general, gratuitous supports by family and friends offer no guarantees of appropriate or enduring services, and are therefore not considered a valid approach for life care planning.

Much as in the USA, life care plans provide a disciplined and valued approach in TORT actions, but can also be used for non-TORT purposes, since they provide articulate long-term blueprints following any catastrophic health condition. In both situations, they specifically identify needed treatments and services, as well as reliable providers.

In Canada, as in the USA, each life care planner is required to complete structured training in the basic methodology and tenets required to prepare a comprehensive plan and then pass certification examinations. Canadians who received certification after 2005, are classified as a Canadian Certified Life Care Planner (CCLCP), while those certified before 2005 are typically classified as a Certified Life Care Planner (CLCP).

The UK Experience

Citizens of the UK proved themselves demonstrably proud of their National Health Service (NHS) when London hosted the summer Olympics. However, the vast majority of people who enter NHS services as a patient are often completely unaware of the clinical pathway they enter. The appointed pathway guides them through treatment programmes and then back into the community. For those with long-term care needs, the National Framework for NHS, continuing Healthcare and NHS-Funded Nursing Care are key. This is not only a vehicle for long term care, but it is also important as an interface to a number of other care pathways across health and social care services.

Following hospitalization, patients are discharged home and often provided with limited services. Vital therapy is invariably provided on a minimum session basis for a fixed period of time. The patient is then discharged to the care of his or her general practitioner who will refer them back for additional services if needs change. Quite often, this turns into a vicious cycle of “toing and froing” through healthcare provision.

For individuals who experience disability following BI, accessing specialist treatment is often equivalent to a “post code lottery” (like a zip code in the USA), as required community-based services are either not available or insufficiently available. Some counties have local specialist units and community professionals such as occupational therapists, physiotherapists, speech and language therapists, and case managers experienced in the needs of people with BI. However, the number of sessions that specialist therapists provide are limited, which often truncates treatment efficacy. If a patient is pursuing a claim for damages, a joint agreement for privately funding services can be made via the Rehab Code (The Rehabilitation Code, 2016). In non-forensic cases the insurer, typically vehicle insurance or professional indemnity, will directly fund these services. When liability has been agreed in favour of the claimant in a lawsuit, the client then often has the means to privately pay for services above and beyond what is available via NHS and Local Authority.

Historically, when resources were not available, a person with BI could end up in a unsuitable long term placement. The recent Care Act 2014, however, now gives local authorities clearer guidance as to their responsibilities to provide long-term care to patients with complex needs (Canada Health Act, 2016). To ensure that assessment is carried out in an appropriate and proportionate manner, the local authority must regard: (a) the wishes and preferences of the individual to whom it relates; (b) the outcome the individual seeks from the assessment; and (c) the severity and overall extent of the individual’s needs (Reg. 3(2)). This new approach is outcome oriented and requires assessment techniques that are “flexible and can be adapted to best fit with the person’s needs, wishes and goals.” In situations of private funding, local authorities are still expected to provide an independent overview to ensure that clients are not being deprived of their liberty, and that their wishes and choices are taken into account.

Even when all services are covered via private funding, insurers providing services through the rehab code and other payment sources historically fell into the trap of thinking that a fixed amount of sessions could be enough, without considering long-term support and maintenance programmes that may continue to be required. To prevent this, case managers are now often secured to pursue continuing assessment and manage ongoing treatment needs. In the process, case management has become an integral part of both public and private long-term care systems in the UK.

Unlike the USA and Canada, the term “Life Care Planner” is not recognized in the UK and the same role is fulfilled by what is known as “Care Experts.” Care Experts are the main Registered Nurses or Occupational Therapists with experience in the field of Brain Injury.

Case Example

A 14 year-old-girl who went into hospital for a routine tonsillectomy in 2003 suffered hypoxic brain damage during

the surgery. This left her physically impaired, unable to manage any element of her daily life, limited limb function, unable to mobilise, fed via a stomach tube, incontinent and unable to communicate verbally. After a year of funded hospital care, she was discharged home to the care of her mother. Her mother was limited by her own disability as she was wheelchair dependent due to paraplegia. Public funds provided a day centre during weekdays with transportation. It also commissioned a care agency to provide awake staff care at night and 2-1 coverage in the morning and evening for her hygiene needs when she was not at the day centre. Unfortunately, the agency frequently couldn’t fulfil the care plan services. When this occurred, the burden of care constantly fell on the mother, which increased the mother’s own health concerns.

A case was brought against the hospital for medical negligence and settled in 2014. As part of the compensation process, a case manager was initially appointed to try and improve the situation by liaising with the agency and sourcing house adaptations. Then, in October 2014, a Personal Health Budget (PHB) scheme was introduced nationally which enabled the young woman to appoint a provider who could employ a dedicated care team for her. The care plan, including cost of care, was approved by a government body. Services were expanded from this initial plan using compensation money from the lawsuit so that staff could double up during the evenings and weekends to enable her to attend youth clubs, take days out with her mother and have holidays. Needless to say, this young lady and her mother’s quality of life has been improved greatly.

Conclusion

In both Canada and the UK, effective life care planning involves consideration of the multiple public and private funding streams that may be required in a case. It equally involves identifying available specialty resources with requisite knowledge about BI. As a result, both life care planners and case managers face significant challenges. Whereas case managers may principally focus on a client’s immediate needs, the life care planner, much like an architect, provides a longitudinal map that envisions the composite situation including changing needs across life stages and associated with aging.

Public systems cannot and will not manage these integrated needs without the input of skilled professionals, and experienced and certified life care planners / care experts often fill this gap. Unfortunately, there are many areas where people still fall between the cracks in our systems and effective advocacy and service delivery can be an overwhelming task. Here, comprehensive life care plans can be one of the most valuable tools to individualize care needs for the person who experiences disability following BI, as well as for their families.

In summary, long term care needs and supports that enable safe and effective function over a lifetime, and are within reason, can be a significantly costly component of healthcare for BI that is not covered through any public health plan in Canada or the UK. It is within this context that our countries share challenges for ensuring reasonable remuneration with strong and credible life care plans. Life care plans need to consider the context of the person’s particular life over their anticipated

lifespan, possible changes and challenges to their condition over time, including possible degeneration, and the nature, culture, and personally relevant circles of support that define life quality.

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