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# Aging with Cerebral Palsy, Spinal Cord Injury and Amputation: Implications for Life Care Planners

*Nancy Mitchell, MA, OTR/L, CLCP, ATP*

**Editor's Note:** For more information on this topic, the reader may want to refer to a just released book that appears to be a good resource for life care planners. Look to the next issue of the *Journal of Life Care Planning* for a full review of this new resource.

Kemp, B. & Mosqueda, L. (2004). *Aging with disability: What the clinician needs to know*. Baltimore, MD: Johns Hopkins Press. (410) 516-6900.

**Abstract.** *People with disabilities commonly have aging related complications that occur at an earlier age than their peers without disabilities. These complications can lead to a cascade of difficulties which can negatively affect the level of the individual's independence and can impact many components of the life care plan. As a life care planner, it is critical to understand the effects of early aging complications and their potential impact on the life care plan. This article addresses some of the aging implications for individuals with cerebral palsy, spinal cord injury, and amputation.*

## Introduction

For people who have a significant physical disability from a young age, aging related complications come early. Kemp (1996) reported that twenty to twenty-five years after the onset of a disability, most people with significant physical disabilities experience a decline in abilities, early onset of age-related secondary conditions such as arthritis or cardiovascular disease, and resulting emotional, relationship, vocational, and quality of life related issues. Some studies (e.g., Crewe, 1990; Kemp, 1992) have concluded that musculoskeletal issues which include pain, weakness, fatigue, and a subsequent decline in endurance and functional abilities are common complaints across disabilities studied.

The known problems associated with aging with a disability are fairly recent phenomena. Because of medical advances, people with significant disabilities are now living life spans longer than those who lived a generation ago (Crewe, 1990; Kemp, 1996). While life expectancy of all Americans, including people with disabilities, is increasing, Bryan Kemp, director of the Rehabilitation Research and Training Center on Aging with a Disability, has said, "The increase in life expectancy of the disabled isn't accompanied by necessarily good health or good quality of life" (personal communication, Bryan Kemp, American Society on Aging annual meeting, San Diego, CA, March 25, 2000). The fact that most people with even severe disabilities are now living nearly normal life spans has left them, and their health care

professionals, poorly prepared to deal with the accompanying problems of aging with disabilities (Crewe, 1990; Kemp, 1996; Turk & Weber, 1998). Education of people with disabilities, their caregivers, and the health care professionals who serve them, is a critical need. The lack of knowledgeable health care providers and programs offering care across the lifespan, as well as the difficulty of transition from pediatric to adult care, have contributed to discontinuity and even to a lack of care for adults with longstanding disabilities (Crewe, 1990; Currie, Gershkoff, & Cifu, 1993; Kemp, 1996; Sowell, 2000; Turk & Weber, 1998). Historically, children with disabilities such as cerebral palsy and spina bifida, for example, and their parents were educated that their conditions were non-progressive (Turk, Scandale, Rosenbaum, & Weber, 2001; Turk & Weber, 1998). This information has interfered with the implementation of strategies to prevent or lessen the negative effects of early aging for people with disabilities. It also has implied the lack of need for specialized care specific to each disability throughout life. These are important issues for life care planners.

Life care planners have a charge to establish the needed care and costs associated with a person's disability across their lifetime and often a life care plan is developed for a child or young adult. While many conditions seen by life care planners are non-progressive in and of themselves, it is critical that the life care planner have knowledge of what it means to age with a specific disability and the impact of those changes on the life care plan. Research on this topic is more plentiful for some specific disabilities and difficult, if not impossible, to find in others. This article will focus on implications of aging for disability groups most likely in need of a life care plan, including individuals with cerebral palsy, spinal cord injury, and amputations.

**Cerebral Palsy**

Murphy, Molnar, and Lankasky (1995) found that of 101 adults with cerebral palsy recruited from the United Cerebral Palsy Association, more than 90 percent were not having regular health examinations. The same percentage of female participants with cerebral palsy was reported as not having periodic breast or pelvic examinations, mammograms, and papanicolaou (PAP) smear testing. The extra time, expertise, and equipment needed for such exams were seen as barriers to providing this basic level of care. In contrast, Turk, Geremski, and Rosenbaum (2001) reported that 67 percent of women without disabilities receive a pelvic exam on a yearly basis. Murphy, et al. (1995) also found that 90 percent of the male participants reported a lack of prostate examination. Similar lack of care was found in routine testing and follow-up for hypertension, hyperlipidemia, electrocardiogram, and elevated blood sugar. Eighty percent of these 101 adults with cerebral palsy reported a concern that their physicians did not know enough about their disease (Murphy, Molnar, & Lankasky, 2000).

While life spans for people with disabilities have grown longer, for some with cerebral palsy, excessive mortality continues to be a problem, in part, because of a lack of normal preventative medicine. Strauss, Cable, and Shavelle (1999) reviewed the medical records of 45,292 individuals with cerebral palsy and cited death from breast cancer in adult women with cerebral palsy as nearly three times that of the normal population. They suggested that this population had different and fewer preventative measures or treatment. The study also reported more deaths than would be expected from cerebrovascular and ischemic heart disease, which suggests a lack of preventative care and monitoring for these conditions. They found that heart disease is the primary cause of death in people with cerebral palsy, and pulmonary disease is the second most common cause of death. The Report from the

Roundtable on Aging and Cerebral Palsy (1997) has identified needed areas of research and proposed changes in interventions to improve the process of aging with cerebral palsy with an emphasis on exercise, wellness, and health promotion.

Inadequate dental care and dental treatment for children with cerebral palsy also is reported and often leads to significant dental problems as adults. Seizure medications and difficulty with positioning and cooperation for hygiene were noted as contributing factors (Murphy, et al., 1995; Report from the Roundtable on Aging and Cerebral Palsy, 1997). While the literature did not address the physical difficulty of brushing and flossing teeth for individuals with severe cerebral palsy, the problems in performing good oral care presumably also contribute to dental problems among individuals with cerebral palsy.

Another potential area for problems in adults with cerebral palsy are musculoskeletal pain complaints, typically beginning in the fourth or fifth decade of life (Andersson & Mattsson, 2001; Arcand, 2000; Crawford, 1996; Murphy, et al., 1995; Rapp & Torres, 2000; Report from the Roundtable on Aging and Cerebral Palsy, 1997). Turk & Weber (1998) revealed the incidence of pain in women with cerebral palsy to be as high as 84 percent. This pain can lead to multiple problems including decreased flexibility, increased fatigue, lessened stamina, decreased functional abilities, and depression (Arcand, 2000).

Turk, Geremski, and Rosenbaum (1997) studied the health and function of people with cerebral palsy. Of the 125 participants, 44 percent were residents of a residential facility and the others were recruited from the community. The findings came from an extensive data collection including physical examination, health interview, physical therapy assessment, nutritional habits, and a survey of activities of daily living. Medical records also were reviewed. One fourth to one third of the group studied had an increased need for assistance with activities of daily living (ADL) skills after the age of twenty, depending on the specific ADL. People with less severe disability from cerebral palsy had more pain, particularly in the ambulatory group (Turk, et al., 1997).

Murphy, et al. (1995) reported that many individuals with cerebral palsy who previously walked had stopped walking by the age of 25 because of fatigue and efficiency issues. Another group of ambulators reportedly stopped walking in their forties because of pain complaints. However, the percentage of participants who lost ability to ambulate was not clear from this study. Another study of 72 adults with cerebral palsy, average age of 33, indicated that walking was lost to about 25 percent of participants and for those who continued to walk, distance was compromised (Bottos, Feliciangeli, Sciuto, Gericke, & Vianello, 2001).

Several health challenges increase in frequency as individuals with cerebral palsy age, including contractures (Andersson & Mattson, 2001; Murphy, et al., 1995), bowel and bladder complaints (Arcand, 2000; Murphy, et al., 1995; Rapp & Torres, 2000; Report from the Roundtable on Aging and Cerebral Palsy, 1997) and fractures (Arcand, 2000; Crawford, 1996; Murphy, et al., 1995; Rapp & Torres, 2000; Report from the Roundtable on Aging and Cerebral Palsy, 1997). Andersson and Mattsson (2001), Arcand (2000), Murphy, et al. (1995), and the Report from the Roundtable on Aging and Cerebral Palsy (1997), all cited overuse of joints or physiological burn-out for people with cerebral palsy.

Depression is another reported complaint in this disability cohort. Kemp (1996) reported a relationship between disability and depression and noted that people who were depressed needed more help than those who were not. The impact of the loss of functional abilities and the increased need for assistance as people with cerebral palsy age may contribute to depression and further functional declines.

Based on a review of literature and the clinical experience of the author, implications of

aging with cerebral palsy for the life care plan include:

- Case management is an important consideration for the person with cerebral palsy and case management assistance may be critical even for individuals with normal cognition. For individuals with cerebral palsy, it may be difficult to find or access specialized care and the necessary time and equipment needed for regular preventative care may not be readily available. Case management can provide assistance in these areas.
- Specialized dentistry may be needed lifelong. Special equipment for oral care may be needed.

- Consultation with a dietician at regular intervals will be helpful with problems associated with weight management (over and under weight), which is common in this disability group. According to Amy Johnson, registered dietician at Region's Hospital in St. Paul, Minnesota, individuals with cerebral palsy who are tube fed or have ongoing problems with pressure sores need a nutritional evaluation on an annual basis. Individuals that take more than one hour to feed also need annual assessment. Further, individuals more than 18 years old need nutritional assessments when there has been a greater than 10 percent unplanned loss or gain in weight in one year. Conversely, children with cerebral palsy need dietary/nutritional assessments when they experience a 5 percent loss in weight or show significant changes in their patterns on the growth chart. These children typically are seen yearly until their growth stabilizes (personal communication, Amy Johnson, RD, June 16, 2004).

- Alternative means of mobility should be an early consideration for individuals with any ambulation impairment. Powered mobility may be an important consideration for distance mobility.

- A lifelong fitness routine is critical in maintaining strength, flexibility, endurance, and independence for individuals with cerebral palsy; however, a physical trainer may not have the needed expertise to meet the specialized needs of this population. It is this author's opinion that physical or occupational therapy evaluations every 2-3 years over one's lifetime may be a more appropriate choice.

- Annual assessments by occupational and physical therapy for range of motion measurements and home program updates for individuals with cerebral palsy who have a 20 degree or more joint contracture. These evaluations may be combined with fitness or equipment assessments depending on the therapist or facility.

- Consider increased care needs as the person ages. An increase in assistance with self care after high school was reported in a study of 215 people with cerebral palsy (Turk & Weber, 1998). However, household chores and community daily living tasks were not discussed. In one small study, it was reported that over 83.7 percent of individuals with cerebral palsy age 65 and older needed help with shopping, meal preparation, household chores, finances, and personal cares compared to 65.6 percent of individuals aged 15 to 34 (Crawford, 1996).

- Assistive technology needs can change over time (example: a normal bed may work well in youth but a bed transfer assistive device 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 and ergonomic assessments at life phase changes may be appropriate.

- Pain management, while not needed in childhood, may well become important as a person ages.

- Yearly screening for depression or cognitive decline as part of the physical examination by a family physician beginning in the mid 40s, and yearly psychological assessments are recommended if problems are noted. Previous history of depression will indicate added vigilance (personal communication, M. Suzanne Wright, PhD., ABBP, clinical psychologist, Gillette Lifetime Specialty Care, June 18, 2004).

- Potential aging related complications such as overuse syndrome and potential for falls should also be addressed.

**Spinal Cord Injury**

The life expectancy of individuals with spinal cord injury is increasing (National Spinal Cord Injury Statistical Center, 2003). However, aging with a spinal cord injury brings an increased risk of cardiovascular disease, diabetes, hyperlipidemia (Bauman & Spungen, 1994; McGlinchey-Berroth, Morrow, Ahlquist, Sarkarati, & Minaker, 1995), and hypertension (McGlinchey-Berroth, et al., 1995; Thompson, 1999; Thompson & Yakura, 2001). In a study by examination of 144 people with spinal cord injury, Garland (2001) found increased incidence of osteoporosis which leads to increased risk of fracture. Groah, Weitzenkamp, Lammertse, Whiteneck, and Lezotte (2002) completed a chart review of 3,670 people with spinal cord injury and found significantly increased risk and mortality from bladder cancer. McGlinchey-Berroth, et al. (1995) cited carpal tunnel syndrome, chronic obstructive pulmonary disease, and kidney stones as prevalent in their study of 510 people with a mean age of 50 who had spinal cord injuries.

Thompson (1999) conducted a study of 150 people with spinal cord injury as part of a larger cross-sectional study of the effects of aging the by Rancho Los Amigos National Rehabilitation Center, a leader in the study of aging with a disability. The participants were patients at the Center's outpatient clinic. When interviewed, individuals in their middle 40s and early 50s reported increased need in assistance with bathing, transfers, dressing, and household chores. An 18-20 year average time since injury correlated with this need for more assistance and the older the person was at the time of their injury, the shorter the duration of time before more assistance was needed. Thompson (1999) also found that individuals with tetraplegia needed more assistance at an earlier age than those with paraplegia. In another study of 150 individuals with spinal cord injury, Thompson and Yakura (2001) found that aging related changes of pain, fatigue, decreased muscle strength, weight gain, and an increased incidence of urinary tract infections and pressure sores make performing ADLs more

difficult.

Aging related changes in patients with spinal cord injury were found by Thompson and Yakura (2001) to have occurred 15-20 years earlier than those expected of persons without a disability. They proposed that these changes occurred at a younger age because, on a daily basis, the person is working at full capacity and this leaves them with little reserve. Regular physical assessments may allow for interventions to slow or prevent functional changes.

The older age of the individual and the longer the time post-injury was found to be predictive of increased care needs (Charlifue, Weitzenkamp, & Whiteneck, 1999; DeVivo, Shewchuk, Stover, Black, & Go, 1992; Gerhart, Bergstrom, Charlifue, Menter, & Whiteneck, 1993; Thompson, 1999; Thompson & Yakura, 2001). The research by Charlifue, et al. (1999) was helpful in that it studied 439 individuals through the use of a questionnaire and physical examination at five, ten, and fifteen years after the time of injury. The study demonstrated that increased age was associated with the need for more physical assistance. The exact nature of the increased need for assistance was not specified in the study but was measured by use of the Functional Independence Measure (FIM). The study by DeVivo, et al. (1992), with a large sample of 11,117 participants with spinal cord injury, was less significant to the author of this article because participants were, on average, less than five years post injury. In another study of individuals with spinal cord injury who had an average of 13 years from the time of injury, nearly two thirds of the 150 participants who have had these functional changes also reported decreased social activities (Thompson & Yakura, 2001).

Petland and Twomey (1994) found that of 52 individuals studied with long term paraplegia and manual wheelchair use, mean age of 44 years, arm pain was noted as a common problem and there were consequent functional declines that affected the individuals' abilities to perform daily living tasks. Individuals with spinal cord injury who use their shoulders and upper extremities for transfers and bed mobility are typically unable to adequately rest injured/overused arms and shoulders and this can lead to chronic problems. In another study by Gellman, Sie, and Waters (1988), almost 68 percent of 84 people with paraplegia reported pain in their upper extremities and pain complaints increased with length of time since injury. These participants were seen when receiving routine follow-up care at least one year after injury. The prevalence of pain complaints highlights the need for fitness, adaptive equipment, and prevention of unusual stresses, weight control, and an appropriate ergonomic environment for individuals with spinal cord injury.

Gerhart, et al. (1993) conducted a study of 279 people with long term spinal cord injury. The participants were long established patients receiving follow-up care for their injuries and were more likely to have appropriate equipment and care than their counterparts who did not receive such follow-up for their disability. These individuals with spinal cord injury had been discharged from rehabilitation and functioned independently in all ADLs, but showed an increased need for attendant care as they aged. The individuals who needed additional help had a lower perceived quality of life (Gerhart, et al., 1993).

In a study conducted by Thompson and Yakura (2001) of 150 participants with spinal cord injury, assistive technology could have reduced the functional losses of persons with spinal cord injury due to aging but only ten percent of the 150 participants could identify this need themselves. When seen by a physical therapist, 78 percent of the participants needed new equipment and Thompson and Yakura (2001) reported an increased need for equipment over time. This underscores the need for regular and long term follow-up for individuals with spinal cord injury.

Based on a review of literature and the clinical experience of the author, implications of

aging for individuals with spinal cord injury for the life care plan will vary by level of injury but generally include:

- Periodic assessments with a dietician may be important for weight control and frequency will depend on genetic predisposition to weight problems, activity level, level of injury, and potential to be active. Amy Johnson, registered dietician, indicated annual nutritional assessments for individuals experiencing a 10 percent weight gain in one year are recommended until the issues with excessive weight are managed or stabilized (personal communication, Amy Johnson, RD, June 16, 2004).

- Yearly screen for depression as part of physical examination by family physician beginning on average twenty years after injury with yearly psychological assessments if problems are noted. Previous history of depression will indicate added vigilance (personal communication, M. Suzanne Wright, PhD., ABBP, clinical psychologist, Gillette Lifetime Specialty Care, June 18, 2004).

- Powered mobility should be considered for individuals with paraplegia for use on prolonged or extended community outings and/or to travel on uneven ground even when the individual is proficient in maneuvering a manual wheelchair. Based on this author's experience, manual assist wheelchairs should be introduced 10-15 years after injury and powered wheelchairs for clients with spinal cord injury using manual wheelchairs 20 years after injury.

- Assistive technology needs are likely to change over time and occupational and physical therapy evaluations to assess assistive technology are recommended.

- An ergonomically correct environment in the home and work site will minimize injury risk. Period ergonomic assessments at life phase changes may be indicated.

- A lifelong fitness routine is critical in maintaining strength, flexibility, endurance, and independence for individuals with spinal cord injury; however, a physical trainer may not have the needed expertise to meet the specialized needs of this population. The author recommends physical or occupational therapy evaluations every 2-3 years over lifetime may well be a more appropriate choice.

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

**Amputation**

There is relatively little research about the long term effects of living with an amputated limb. Studies reviewed had generally small sample sizes and no statistics were found on children and young adults with congenital or acquired limb loss. The research available regarding aging issues for individuals with amputation indicated an early onset of pain and arthritis symptoms in the non-amputated limb due to overuse and stress of the normal extremity. For example, Lemaire and Fisher (1994) reported a significant increase in

osteoarthritis in the non-amputated leg of twelve individuals with lower extremity amputation with an average age of 71.8 years. This is thought to be due to an increase of workload to the normal leg when compared to individuals without leg amputations.

Not surprisingly, a study of 11 individuals without amputations found that there was better symmetry of gait compared to those with below knee amputations (Hurley, McKenney, Robinson, Zadravee, & Pierrynowski, 1990). Gait analysis in the study was done but over half of the subjects were young and not long term prosthetic users. An asymmetrical gait over a long period of time is likely to lead to wear and tear injury, pain, and potentially greater disability.

Individuals with upper extremity amputation experience similar overuse problems and Jones and Davidson (1999) noted that 50 percent of 46 upper extremity amputees had problems such as pain, arthritis, shoulder impingement, and epicondylitis. The location of the injuries varied and seemed to be dependent on vocational and lifestyle activities. Although the time since amputation was difficult to determine from the study results, this factor is important because upper extremity amputations tend to occur at younger ages than lower extremity amputations (Dillingham, Pezzin, & MacKenzie, 2002). The long term impact of overuse of the intact limb is the prime issue in aging in this disability group.

Based on a review of literature, the author suggests that the life care plan for an individual with amputation includes:

- An ergonomically correct environment in the home and work site will minimize injury risk. Ergonomic assessments at life phase changes may be helpful.

- Weight control is important for prosthetic fit and to help from over-stressing joints. Periodic assessments with a dietician for those with a potential for weight control difficulties are 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, other than for phantom pain, may not be a concern early in the disability for the individual with amputation. However, it can become a problem as the person ages because of problems associated with overuse.

**Conclusions**

Individuals with childhood and young adult onset disabilities are living significantly longer and, along with that, a new set of potential obstacles has been discovered. More literature about aging with a disability is available for some diagnoses and sorely lacking in others. In the literature reviewed, there is a common theme of pain, fatigue, and potential for overuse injuries across disabilities. This can lead to weakness, decreased endurance, and an overall decline in functional abilities. For individuals who have worked hard to be as independent as possible in their lives, this is a difficult discovery. For life care planners, this

can mean a change in projections for care and assistive technology as a person ages. It is important for life care planners to utilize practice guidelines and obtain input from physicians with disability specific expertise when possible.

It is clear that aging with a disability is significantly more difficult than it is for the general public population. Individuals with disabilities themselves are learning the hard way about what it means to grow older. In many instances, they have been told that their disabilities were static but in fact, new problems occur as their body's age and there is need for education and ongoing specialized care. Concrete preventative measures need to be planned to maximize independence when aging with a disability and the life care planner is in a unique position to identify those measures for inclusion in the life care plan.

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**About the Author**

Nancy Mitchell, MA, OTR/L, CLCP, ATP, is an occupational therapist with 30 years of experience. She became a certified life care planner in 1998. In addition to her continued clinical 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 and was a founding team member of a clinic developed for adults with early onset disabilities.