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# Aging with Early Onset Conditions: Post-polio Syndrome, Spina Bifida, Early Onset Neuromuscular Diseases, Down Syndrome, Brain Injury, and Juvenile Arthritis

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**Abstract**. *An article previously published in the Journal of Life Care Planning (Mitchell, 2004) discussed the effects of aging for individuals with cerebral palsy, spinal cord injury, and amputation. This article will focus on the effects of aging for individuals with a diagnosis of post-polio syndrome, spina bifida, early onset neuromuscular diseases, Down syndrome, brain injury, and juvenile arthritis, by providing a review of literature on these specific diagnoses. In order to effectively and accurately address potential long term care needs for clients with the above-named diagnoses, life care planners should be aware of the issues possibly faced by individuals aging with these disabilities.*

## Introduction

There are currently 12 million people living with early onset disabilities (Kemp & Mosqueda, 2004). This is the "pioneer" generation of people with disabilities to live into the later decades of life. Medical professionals and people with disabilities have little knowledge about the difficulties that could be encountered by this cohort as they age (Kemp & Mosqueda, 2004).

Bryan Kemp and Laura Mosqueda (2004), editors of the book, Aging with a Disability: What the Clinician Needs to Know, discuss three eras of rehabilitation. The first era, 1900-1945, focused simply on surviving from conditions which caused disabilities. This was followed by an era of real rehabilitation efforts which began in the 1940s. The thrust of this era was integration of enabling people with disabilities to become independent with many advances in medicine and equipment for people with disabilities occurring in the 1950s-1960s. The third era emerged in the 1970s and is considered "the era of longevity" (Kemp & Mosqueda, 2004). Kemp & Mosqueda (2004) explain:

"This new era requires us to reevaluate rehabilitation practices and philosophy. Instead of encouraging everyone with a disability to work as hard as possible to enter society and be accepted like everyone else, the "use it or loose it" attitude, we need to help them and their families plan for the long run. A philosophy akin to "conserve it to preserve it" may be more appropriate to the findings of today. The emphasis on achieving maximal functioning probably began around World War II, when a general sense of "you can overcome anything if you just try hard enough" was common. Since society did not openly accept people with disabili-

ties, they were encouraged to fit in or to pass as not disabled. This meant working hard to ambulate, to get a job, to have a family, and to be like everyone else. In a sense, these people needed to be like professional athletes, putting out maximal function every day. Recognition and reward have led this model of behavior to become a way of life for many. However, the philosophy probably has long-term negative consequences (p. 4)."

It can be difficult for life care planners to make life long projections for people with disabilities. Increasing knowledge about the effects of aging with various disabilities will shed some light on future needs that can provide for more successful aging. Life care planners need a heightened awareness of the impact of aging with a disability and the effect on the life care plan. Based on the issues reported in the literature, reflected in this article, and the author's clinical experience, weight control, fitness, and a changing need for assistive technology are important considerations across most disabilities.

**Post-Polio Syndrome**

The Polio Survivors Association published a Poliomyelitis Fact Sheet which reports that while polio has long been eradicated in the United States, 1.1 million survivors exist (2002). Windebank, Litchy, Daube, Kurland, Codd, and Iverson (1991) studied 300 polio survivors who experienced some form of paralysis and found that many now have problems with muscle weakness (often asymmetrical), increased respiratory illnesses, and greater rates of high lipid levels. These symptoms typically occur 20-30 years after the polio occurred. The incidence varies from 22-68 percent of people who have a history of polio.

Willen, Cider, and Sunnerhagen (1999) conducted a study of 32 consecutive patients seen in a post- polio clinic through the use of a questionnaire and a physical examination. They found significantly weaker muscles in the post-polio group when compared to people without a history of polio. In another larger study of 1449 subjects, Wekre, Stanghelle, Lobben, and Oyhaugen (1998) used a questionnaire and reported that 85 percent noted increased weakness in polio affected muscles and 58 percent had weakness in the muscles that had not been affected by polio. Further, in a study of 539 post-polio participants by Halstead and Rossi (1985), similar results were found. Increased weakness in muscles that had been affected by polio was found in 86.6 percent of the patients but weakness in unaffected muscles was reported at 76.8 percent, a significantly higher percentage than found by Wekre, et al. (1998). An earlier study reported that weakness was found only in polio-involved muscles and that a more complete history revealed that people were unaware of the full extent of muscles involved in their illness (Windebank et al., 1991). Many of the participants contracted their illness in childhood and memory of the distant event had faded.

Based on the literature review, pain is a very common complaint for people with post-polio syndrome with muscular pain reported in 80 percent of a study of 79 people with the syndrome and joint pain reported in 77 percent (Agre, 1995). Halstead and Rossi (1985) had very similar findings in their study of 539 participants. They reported 79 percent with joint pain and 80 percent with muscular pain. Willen and Grimby (1998) noted pain, particularly during physical activity, in 50 percent of the 32 people in their study. The data reveal that people who experience pain are less likely to be active which contributes to a cycle of weakness, decreased endurance, and a need for assistance in areas of previous independence.

Decreased endurance and fatigue were consistent problems cited in several studies of patients who had had polio. Reports varied in complaint frequency but were reported as 99 percent of those surveyed (Cosgrove, Alexander, Kitts, Swan, Klein, & Bauer, 1987; Diard,

Ravaud, & Held, 1994; Halstead & Rossi, 1985; Nollet, Beelen, Prins, deVisser, Sargeant, Lankhorst, & deJong, 1999; Thorsteinsson, 1997; Wekre et al., 1998). The research by Cosgrove et al. (1987) was an early study of 183 people and used both questionnaire and an actual examination. More than 99 percent of the participants studied reported decreased endurance. Diard et al. (1994) found that 75 percent of participants complained of fatigue in their study of 248 people with post-polio syndrome. Sixty percent of this group cited changes in leisure and work activities because of the fatigue. Halstead and Rossi (1985) reported fatigue in 87.1 percent of their 539 subjects studied via questionnaire. In another study, 78 percent of the 76 subjects studied reported fatigue which affected the mobility activities of walking outside and stair climbing (Nollet et al., 1999). Wekre et al. (1998) reported fatigue in 80 percent of 1449 subjects in a study by questionnaire. Those subjects noted the fatigue particularly with activity. The decrease in strength and endurance of individuals with post-polio syndrome brings less activity that result in decreases in function. No studies were found to contradict the findings of these studies and the results are also common to other disability groups.

Research from 103 polio survivors seen in a clinic and referred from other hospitals and volunteers who heard about the study indicated that work is the most valued activity and that recreational and social pursuits are sacrificed. Life satisfaction in these areas is compromised (Nollet et al., 1999). Full time workers decreased from 65 percent to 32 percent (Wekre et al., 1998). However, the ages in which these changes occurred were not provided in the study. Consequent difficulties with depression and family stress are expected to occur as work and social activities decrease.

Research on post-polio survivors indicated that an emphasis on non-fatiguing exercise and strengthening is helpful in regaining strength (Agre, 1995). Additionally, weight control is beneficial in reducing workload on joints (Diard et al., 1994). The use of assistive technology such as powered mobility also is encouraged (Wekre et al., 1998). In a study of 183 patients evaluated by questionnaire, Cosgrove et al. (1987) found that individuals with post-polio syndrome have equipment that is very old and in need of change or adaptation. In other research, only 17 percent of people studied were satisfied with public health services although 67 percent had had satisfactory experiences with a thorough examination related to their symptoms. Fourteen percent felt that their doctor was qualified to advise them about their post-polio symptoms and the average time since they had been to a physician visit was seven years (Wekre et al., 1998).

These studies demonstrate a clear need for ongoing specialized care for adults with post-polio syndrome to provide guidance with fitness, weight control, pain management, and potential changes in assistive technology. Increased need for assistance also is possible.

**Spina Bifida**

Spina bifida occurs in less than one of 1,000 births (Spina Bifida Association of America, 2004). Current thinking suggests that it is a birth defect caused by a combination of environmental and genetic factors. People with spina bifida are born with an abnormal development of the spinal cord and surrounding nerves which causes problems with the muscular, urinary, nervous, and skeletal systems. Learning problems also are common (Spina Bifida Association of America, 2004).

Farley, Vines, McCluer, Stefans, and Hunter (1994) provided an extensive list of secondary conditions associated with both spina bifida and cerebral palsy. They included such age-related issues as depression, joint and muscle pain, incontinence, gastrointestinal problems,

obesity, compromised respiratory function, cardiovascular disorders, pressure sores, and spasticity changes. Their study used a questionnaire completed by 380 subjects, with a mean age of 16 years. Pressure sores were cited in 64 percent and burns had occurred in 44 percent of those studied, resulting from a lack of sensation. Forty-two percent of the subjects were unable to walk at all and many of those who identified themselves as ambulators had significant limitations in their mobility (Farley et al., 1994). The subjects in this study were very young and yet significant problems associated with their spina bifida and cerebral palsy were identified. Any of the secondary conditions could have an impact on functional independence because time spent in an inactive period of recovery from pressure sores or burns would likely lead to increased weakness.

Based on the author's literature review, the long term implications of the conditions associated with spina bifida seem not to be researched or are often coupled with the diagnosis of cerebral palsy. Most of the work in the area of aging with spina bifida was found in the proceedings of a 1994 conference in Crystal Beach, Virginia titled "Preventing Secondary Conditions Associated with Spina Bifida or Cerebral Palsy: Proceedings and Recommendations of a Symposium"(Leibold, 1994). Research data was not provided but the information presented was in agreement with research done in aging with spinal cord injury. In her presentation at the symposium, "Achieving and Maintaining Body Systems Integrity and Function: Personal Care Skills" (1994), Leibold's main emphasis was the need for weight control and fitness. Bergman (1994) reported that repetitive trauma caused from walking with abnormal biomechanics can lead to bursitis and arthritis and issues associated with being overweight, a common problem for individuals with spina bifida, contributes to these concerns. The need for appropriate assistive technology also was suggested (Leibold, 1994).

In adults with spina bifida, shoulder pain is seen at times when the individual reaches their 20s and, very often, when they reach their 30s and 40s (Cathy McMillin OTR/L, personal communication, July 12, 2004). McMillin conducts a clinic for adults with spina bifida and reports that surgical repair due to shoulder problems for individuals with paraplegia can be devastating because independence often is lost with post-surgical limitations. She states that these individuals are left with three options: nursing home admission for rehabilitation; a greatly increased need for family members to assume heavy personal cares; or the hiring of outside help while they are unable to perform self transfers. McMillin further reports that the frequent prescription of manual assist wheelchairs to those with paraplegia while in their 30s may be a helpful factor in reducing pain and contributing to overuse syndrome of the shoulder from long term manual wheelchair use.

Another problem associated with people with spina bifida is an increased incidence of latex sensitivity whose consequences can be deadly. Research reveals that repeated latex exposure leads to adverse reaction, and adults with spina bifida may have more problems than children (Klingbeil, Baer, & Wilson, 2004; Wright, Alderson, Ash, & Short, 2001; Obojski, Chodorski, Barg, Medrala, Fal, & Malolepszy, 2002). Special supplies which do not contain latex may be an important consideration for this population.

Overall, obesity, pressure sores, pain, and fatigue are problems that are preventable and the education of individuals with spina bifida on nutrition, weight control, and exercise will be critical in the health promotion of this group of individuals (Simeonsson, McMillen, & Huntington, 2002). Additionally, Farley et al. (1994) reported that 57 percent of 380 people studied had special education services, and learning disabilities associated with this group of individuals will generally bring challenges in patient education and follow-through. However, the lack of research in this area causes concern and long term studies regarding the effects of

aging with spina bifida are needed. Based on the literature review and what has been learned from other disability groups, life care planners must be aware of the need for weight control, fitness, possible increases in the need for care, potential shoulder problems, and the subsequent need for changing assistive technology for individuals with spina bifida. Latex free products also may be a critical addition to the life care plan.

**Neuromuscular Disease**

Neuromuscular diseases affect the muscle fibers, motor neuron cells of the spinal cord, and junction of the nerves and muscles. Although there are numerous conditions that fall into this category, this section will focus on childhood onset neuromuscular disorders. Based on the review, very little has been written about aging with neuromuscular diseases such as muscular dystrophy and spinal muscular atrophy. Given that these conditions are progressive in nature, several years ago, the prognosis for an individual living into the adult years with these conditions was very poor. Although such disorders continue to cause mortality at young ages, medical and technological advances are allowing others to live much longer lives.

Carol Sowell (2000), writing for Quest, a publication for the Muscular Dystrophy Association, wrote the following about aging with neuromuscular diseases:

"People over 40 with neuromuscular diseases can celebrate the greater longevity and better quality of life these changes have afforded. But what their doctors didn't know decades ago was that middle age often brings a new set of medical and functional challenges to those with long-term mobility disorders. Like everyone else in the middle and later years, people aging with neuromuscular disease face predictable health risks, such as heart disease, diabetes, osteoporosis, arthritis, hypertension, and loss of acuity in sight and hearing, but for those with early-onset mobility impairments, these changes may have come much earlier in life. And, because of long-term effects of a disabling condition, the changes will be met with what one researcher calls "a narrow margin of health," that is, less resiliency for accommodating to the change (p.1)."

Unfortunately, Sowell's comments are not supported by research specific to neuromuscular disease, but are generalized from literature on adults with chronic conditions. Her conclusions also are supported by this author's observations in her clinical practice. Research specific to neuromuscular disease is sadly lacking except for some data on life expectancy from research conducted outside of the United States (Eagle, Baudouin, Chandler, Giddings, Bullock, & Bushby, 2002).

Eagle et al. (2002) studied 197 subjects by chart review and concluded that the use of mechanical ventilators has significantly lengthened the lives of people with Duchenne muscular dystrophy. Work by Jeppesen, Green, Steffensen, and Rahbek (2003) supports this. Eagle et al. (2002) demonstrated that the mean age of death from Duchenne muscular dystrophy in the 1960s was 14.4 years but has risen to 25.3 years. It is clear that this cohort does not live long enough to experience many other long term effects of their typically sedentary lifestyle.

The fact that people with neuromuscular diseases use power wheelchairs because of weakness generally leads to a more inactive lifestyle. Sowell (2000) reported an early onset of respiratory decline, cardiac conditions, osteoporosis, and diabetes as well as an increase in fatigue, weakness, and pain which in turn brings functional changes. Changes in independence can negatively alter work and family relationships.

The research on financial, emotional, and physical impact of early aging associated with childhood onset neuromuscular disease is sorely lacking. The studies on other disabilities

which indicate a need for fitness, weight control, assistive technology, and transition to lifelong follow up by specialty care may need to be applied to this diagnostic group for promotion of maintenance of independence for as long as possible.

**Down Syndrome**

The etiology for Down syndrome (DS), a chromosomal abnormality, is unknown and although it has been linked to babies of mothers of older maternal age, it occurs in children of mothers of all ages. Data reveal that DS occurs in one of every eight hundred births and people with Down syndrome are now living significantly longer than in previous generations (Benke, Carver, & Donahue, 1995). In the author's experience, some degree of developmental disability always results from the syndrome, but many individuals with DS reach some level of employment and a supervised living arrangement. However, early onset of Alzheimer's disease is becoming increasingly associated with Down syndrome (Tyler & Shank, 1996).

The National Down Syndrome Society estimates that 25 percent or more of people with Down syndrome will have signs of dementia beginning at age 35. Incidence increases with age and the likelihood of a person with Down syndrome developing Alzheimer's disease is three to five times more likely than that of the general public (Lott, 2004).

Schupf, Kapell, Nightingale, Rodriquez, Tycko, and Mayeux (1998) demonstrated that of 111 adults with Down syndrome studied, Alzheimer's disease was developed ten to twenty years earlier than in people without the syndrome. Men had an earlier onset than women. This was a randomly selected, community based sample that consisted of caregiver interviews and medical record reviews. While statistics were not provided, the sample had larger numbers of people with severe mental retardation than would be expected of a general sample of adults with Down syndrome. In spite of this, no correlation of level of mental retardation was equated with development of Alzheimer's disease. Schupf et al. (1998) speculated that the earlier incidence of Alzheimer's disease in people with Down syndrome, when compared to the normal population, was due to differences in hormonal function in the two groups.

A longitudinal study of 100 people with Down syndrome by Lai, Kammann, Rebeck, Anderson, Chen, and Nixon (1999) did find a gender difference and indicated that women are 1.77 times more likely than men to develop Alzheimer's disease. Holland, Hon, Huppert, Stevens, and Watson (1998) reported evidence of dementia in individuals with Down syndrome 30 or 40 years earlier than the general population. Schupf et al. (2003) studied a community based sample of 163 women with Down syndrome, past the age of menopause. They found that women who reached menopause at age 46 or younger had an increased risk and earlier onset of Alzheimer's disease compared to a group with menopause after age 46.

Tyrrell, Cosgrove, McCarron, McPherson, Calvert, Kelly, McLaughlin, Gill, and Lawlor (2001) studied 285 people with Down syndrome and found the increased incidence of Alzheimer's disease was associated with seizure disorder, brain injury, and myoclonis (abnormal muscle contracture indicative of neurological injury). Mean age of occurrence of dementia was age 54.7. Based on this data, and the author's clinical experience, changes in behavior and level of independence in activities of daily living that can occur with Alzheimer's disease potentially can have a profound effect on the level of care, medical intervention, medication, and potential need for equipment for the individual aging with Down syndrome.

Research in this area continues to be published and life care planners who serve this diagnostic group must keep current on research on the link between Down syndrome and

Alzheimer's disease. Very significant needs for care and assistive technology can occur in individuals with Down syndrome who develop Alzheimer's disease. In the author's opinion, a baseline neuropsychological evaluation in the early 30s may be a helpful tool for assistance with the diagnosis should it be needed.

**Traumatic Brain Injury**

The Centers for Disease Control and Prevention (2004) estimates that 80,000-90,000 people in the United States experience significant long term and even life long disabilities resulting from traumatic brain injury each year. Over 5 million people in the United States live with these problems (Thurman, Alverson, Dunn, Guerrero, & Sniezek, 1999). Problems resulting from brain injury can include cognition, personality, movement, and vision deficits (Thurman et al., 1999).

There is conflicting opinion in the literature that those individuals with moderate to severe brain injury have a much greater risk of developing Alzheimer's disease. Rasmusson, Brandt, Martin, and Folstein, (1995) observed that mild brain injury does seem to cause an earlier onset of Alzheimer's disease Subjects of their study were 68 patients followed by an Alzheimer's disease research center. All subjects had a capable spouse to provide the needed history. The people with Alzheimer's disease were compared to 34 volunteer participants without dementia who were matched by age, sex, and level of education. The study found pre Alzheimer's disease brain injury in 29.4 percent of the subjects and in only 2.9 percent of the control group. Fleminger, Oliver, Lovestone, Rabe-Hesketh and Giora (2003) reviewed the databases of 43 case controlled studies and found excessive incidence of Alzheimer's disease in those with previous brain injury. However, other research contradicts their findings. Mehta, Ott, Kalmijn, Slooter, van Duijn, Hofman, and Breteler (1999) also looked at mild brain injury and its connection to Alzheimer's disease. Their study of 6,645 subjects who were dementia free found that mild brain injury was not a major risk factor for Alzheimer's disease or dementia. Likewise, a review of the medical records of 1283 people with traumatic brain injury suggested that while Alzheimer's disease is not caused by brain injury, the time of onset is earlier for them than for the general population (Nemetz, Leibson, Naessens, Beard, Kokmen, Annegers, & Kurland, 1999).

Levin (2000) reported that the link between Alzheimer's disease and previous brain injury is unclear. He cited a study by Klein, Houx, and Jolles (1996) which indicated that senior citizens with previous history of brain injury did have more neuropsychological impairment, declined more rapidly, and were less able to adapt to these changes than the general population. Levin (2000) indicates that brain injury makes aging more difficult because there seems to be less "reserve" to be helpful with aging changes in the brain.

The need for more research on aging with brain injury is clear. There is not yet consensus on the issue and with that, the implications for life care planners about what it means to age with brain injury is not definitive.

**Juvenile Idiopathic Arthritis**

Arthritis is typically thought of as a disease of the elderly, but currently 300,000 children in the United States have some form of rheumatic disease or type of arthritis. Additionally, 8.4 million people aged 18-44 have arthritis (Arthritis Foundation, 2004). Until the 1990s, studies reported that "80 percent grow out of their juvenile rheumatoid arthritis and have a good out-

come" (Dr. Vehe, pediatric rheumatologist at Gillette Children's Specialty Health Care, personal communication, February 4, 2003).

According to Dr. Vehe (personal communication, February 11, 2004), juvenile rheumatoid arthritis was a diagnosis previously used in the United States and the Europeans used a different term. Vehe also reported that there is now common language and the appropriate terminology world wide is juvenile idiopathic arthritis (JIA). Literature reviewed for this project used both terms but for the purposes of this article, JIA will be the terminology used.

Several recent studies were reviewed. One hundred and five children with JIA were studied after hospital admission from 1980-1985 following a mean disease duration of 14.2 years. Osteopenia, the precursor to osteoporosis, was noted in 41 percent of adolescents eleven years after early onset (mean age of 2.8 years) of the disease (Lien, Flato, Haugen, Vinje, Sorskaar, Dale, Johnston, Egeland, & Forre, 2003). This study was biased in that it looked at children admitted to the hospital. While hospital admissions in the 1980s were more prevalent than current practice, these children most likely had more severe disease than their non-hospitalized counterparts. It is unknown what the impact of osteopenia will mean for them as adults and in their elder years and long term follow-up of this group is clearly needed.

Through a self-report questionnaire of the quality of life of 82 adults with a history of JIA and a mean disease duration of 21 years, researchers found that 39 percent had active disease. The older the subjects were and the longer the duration of the disease, the greater the correlation with more body pain and decreased function (Foster, Marshall, Myers, Dunkley, & Griffiths, 2003). It is important to note that the subjects had significantly more advanced disease than would be expected in a random sample of subjects. Another study with a sample size of 215 subjects, having a disease median duration of 16.5 years, showed that half of the cohort had continued active disease and/or changes in body structures. Functional limitations were reported in one third of the subjects studied but less than 10 percent reported severe limitations (Minden, Niewerth, Listing, Biedermann, Bollow, Schontube, & Zink, 2002). The subjects studied were still young adults. Long term impact of JIA remains unknown. Packham and Hall (2002) studied 246 subjects with disease duration of 28.3 years and found a more serious picture. While under half had active disease clinically, more (54.4 percent) had laboratory evidence of disease. Severe disability was cited in 42.9 percent of those studied. The duration of the disease in the subjects studied was almost 18 years longer than in the Minden et al. (2002) study. This appears to support other evidence that the longer the duration of the disease, the more likely the long term negative consequences. The need for planning for transition to adult care while in the teen years also is clear.

Remission from JIA is defined as lack of disease activity without intervention for six months (Fantini, Gerloni, Gattinara, Cimaz, Arnoldi, & Lupi, 2003). Studies vary greatly on the remission rate for JIA. The range is from 6-60 percent and depends on the type of JIA studied (Fantini et al, 2003; Flato, Aasland, Vinje, & Forre, 1998; Flato, Lien, Smerdel, Vinje, Dale, Johnston, Sorskaar, Moum, Ploski, & Forre, 2003; Oen, Malleson, Cabral, Rosenberg, Petty, & Cheang, 2002). Fantini et al. (2003), in a study of 683 subjects, reported that delay in obtaining appropriate care negatively affected remission rates.

For those people not in remission, troublesome problems persist. Flato et al. (2003), in a study of 268 randomly selected subjects with JIA, cited 24 percent with joint erosions and 36 percent of those studied reporting impaired function. Flato et al. (1998) found joint erosions in 25 percent of 72 subjects studied and noted 60 percent with a report of no disability. The study suggested the early and aggressive use of treatment as important. Oen et al. (2002), in a study of 392 subjects who met a selection criteria of five years of onset and were a minimum of eight

years of age, found joint replacement was needed in 13-57 percent of those with JIA after 15 years with the disease. Predictors of continued problems were female sex, hip joint involvement, and long duration of an elevated sedimentation rate (a laboratory test of inflammation). In a small sample of 26 cases, 70 percent of those with oliogoarthritis JIA (arthritis affecting 1-4 joints in the first six months of the disease) gave low back pain as a problem (Narayanan, Rajendran, Porkodi, & Shanmuganandan, 2002). These subjects had a mean disease duration of 11.4 years. Again, the need for long term follow-up is demonstrated.

In a patient group of individuals with JIA which was studied with a mean of 24.7 years after diagnosis, researchers found more disability, pain, fatigue, decreased functional abilities, and a diminished perception of health when compared to a control group (Peterson, Mason, Nelson, O'Fallen, & Gabriel, 1997). Controls were matched by sex and age. Longitudinal studies on this diagnosis are lacking and more research into what lies ahead for this cohort is needed. New and more aggressive drug therapies given to this patient group in the 1990s may significantly change the future for aging for individuals with juvenile idiopathic arthritis. The effects of aging for those who received this drug therapy may be different, and hopefully more positive, than those of their predecessors. With current data, it appears that those with inactive disease seem to age with good functional outcomes. Individuals with ongoing disease have poorer functional outcomes. In the author's opinion, the impact on aging with JIA on the life care plan is unclear. It is important to note the potential for long term disability.

## Conclusions

It is clear from the literature that aging with a disability presents significant challenges at a younger age than for people without disabilities. Mosqueda (2004) wrote:

> Olympic athletes are among the small percentage of people who push their bodies to their highest possible level of functioning. Perhaps people with disabilities share this characteristic with elite athletes; but instead of pushing their bodies to the limit during training in the quest for a gold medal, they must do so every day just to accomplish their daily activities and fulfill their social roles (p. 37).

The research is sorely lacking in some disability groups in what it means to age with a disability, and more plentiful and emerging in others. Life care planners need to be aware of the difficulties ahead and make allowances for the potential consequent changes in care, medical intervention, and assistive technology.

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