PERSPECTIVES ON AGING WITH LIFE-LONG DISABILITIES

The Collected Writings of Maureen Arcand

Wisconsin Board for People with Developmental Disabilities
201 West Washington Avenue, Suite 110, Madison, WI 53703
608/266-7826 ● FAX 608/267-3906 ● TTY 608/266-6660
Email: bpddhelp@wcdd.org ● Web site: www.wcdd.org

About the Author

Maureen Arcand was born in 1929, and has lived her life with physical disabilities caused by Cerebral Palsy (CP). She raised six children having assumed full responsibility for her family at age thirty-seven. About the same time, she discovered skills that led her into community organizing, advocacy, and local politics first as a volunteer and later in paying positions, including six years on her local county board.

She serves on the board of directors of Movin' Out, a non-profit agency that creates opportunities for people with disabilities and their families to access safe, affordable, and accessible housing. As one of Wisconsin's leading advocates on disability issues, Maureen worked with the Wisconsin Council on Developmental Disabilities on various projects before being appointed to the Council in 2000. She is still serving on the Council and is seen as a role model by younger people with disabilities.

About the Publications

Upon reaching her fifties, Maureen realized that some of her abilities were changing. She attributed the changes to the impact of the aging process on the CP. Seeking information for herself, she found that little was known about the process and people with CP. This seemed to be due largely because people with CP had previously not lived long enough to be concerned about aging, so little was known about what could be expected. It was then that she vowed to learn all she could and share the information with others. This led to the first publication in the collection, *Living and Aging with Cerebral Palsy*. It evolved over several years, as she took this information to the public in the form of trainings and seminars and updated it as she learned more. The final version was completed in 2002. It proved to be important information both for people with CP and for providers of services.

Soon Maureen was hearing from service providers who were asking for more information on how to best serve people with disabilities other than with CP. This led to the next publication, *Serving the Needs of People Aging with Developmental Disabilities*. At the same time Maureen was hearing from people with other disabilities and family members who were concerned about what to expect as they aged. This led to her researching the impact of disabilities on the aging process in general. The outcome of that research was the next publication in the collection, *Are You Living and Aging with a Developmental Disability?* The last two publications, *One Person's Journey into Aging with Cerebral Palsy* and *The Journey into Aging with Cerebral Palsy Continues*, are the personal reflections of Maureen as she has aged. These are meant to be informative and instructional for both people with disabilities, families, and service providers.

We hope these publications and the work Maureen has provided to you helps you to better understand and appreciate what the impact of the aging process has on life-long disabilities.

LIVING AND AGING WITH CEREBRAL PALSY

Presented to Adults with Cerebral Palsy, their Families & Service Providers

November 2002

This publication was funded by the Wisconsin Council on Developmental Disabilities (WCDD) using federal funds provided under P.L, 106-402 through a grant authorized by the Administration on Developmental Disabilities and the U. S. Department of Health and Human Services. The information herein was compiled pursuant to the State Plan on Developmental Disabilities. Grantees undertaking projects under Council sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions expressed do not, therefore, necessarily represent the official position or policy of the Wisconsin Council on Developmental Disabilities.

The report is based in part on two research projects by grant number 90DD0287 from the Administration on Developmental Disabilities (ADD) to the Program on Aging and Developmental Disabilities, Waisman Center UCE, University of Wisconsin-Madison. Gary B. Seltzer, Ph.D., Principal Investigator.

Living and Aging with Cerebral Palsy

An Introduction to Cerebral Palsy

Any discussion of Cerebral Palsy (CP) must be based on an awareness of the uniqueness of this neurological condition that produces a wide variety of physical disabilities. It must be understood that it affects each person differently. Now that people with CP, like other people, are living longer they look back and realize that each person and family has utilized their own coping skills over a lifetime. The degree of coping needed is dependent the degree of disability of each individual. The severity of disability caused by CP can vary from minimal to total incapacitation.

Recently, reports in the media on people with CP have tended to focus on the extremes. Most have been stories about children with the severest disabilities; children unable to walk, talk, even breath on their own. The focus seems be on the small percentage of people with CP who are also mentally retarded. While it is important to understand the needs of those children and their families, it is equally important to recognize that they, and children with less severe disabilities caused by CP, will grow to be adults and live a lifetime with those disabilities.

CP often originates when oxygen is cut off to the motor cells in an infant's brain. The oxygen deprivation may occur just prior to birth, during a difficult birth, because of prematurity, infection or by a brain injury in the first two years of life. Once the damage is done it can not be changed, but early therapy and/or surgery may increase abilities. Disabilities are most often physical, but may be accompanied by a cognitive disability. The physical disabilities vary from very severe to minimal. The degree and type of disability is determined by the location and severity of the damage to the motor cells, and is usually most evident in a lack of muscle control, difficulties in coordinating body movement, and/or paralysis of the lower body.

The activities most often affected are walking, hand and body coordination, speech, and swallowing. The damage may produce disabilities in combinations including any or all of these activities and may be complicated by the impact on internal bodily functions such as breathing and bowel and bladder control.

This brief background introduces the relatively new topic of aging with CP. The same medical advances, which are allowing the general population to live longer, are allowing people with CP to live long enough to experience the aging process. Living more active lives outside of institutions also appears to add years to people's lives. Only in the last fifteen years have people with CP lived long enough to be concerned about the impact of aging on bodies affected by a life long disability.

Waisman Center Research

This report is to share information gathered in two research projects done at the Waisman Center at the University of Wisconsin-Madison in 1994. It is based on research supervised by Dr. Gary Seltzer. One of two projects was a Focus Group Project for which I conducted focus groups and interviews with 20 people ages 34 to 74. The second project was a paper survey of 202 people with CP ages 21 to 74 conducted by graduate student, Amy Ho.

Survey respondents included 93 males and 109 females ranging in age from 21 to 74. A count by age shows 29 people from 21 to 30, 48 from 31 to 40, 58 from 41 to 50, 35 from 51 to 60, 15 from 61 to 70, and 7 over 70. Respondents represented all the varying degrees, types and combinations of physical disabilities usually associated with CP. About 85% reported lack of coordination and control of body movement and/or abnormal muscle tone, while about 60% reported paralysis and/or skeletal deformities. Almost 40% had speech difficulties, and over a quarter of them had swallowing problems. The overlap in numbers indicates combinations of disabilities.

A variety of questions were asked for a variety of reasons, but this report focuses on the reported changes in abilities and functions affected by the CP. Because people were asked to report on changes occurring in the previous twelve months, the information may not reflect changes over a lifetime. Discussion in the focus groups centered on life long changes.

For purposes of the survey abilities and functions resulting for CP were referred to as "conditions". They included those conditions most commonly resulting from CP and experienced over a lifetime including those conditions mentioned above, along with such less obvious affects on fatigue, breathing, swallowing, and bowel and bladder control. People identified each condition they had and weather it was getting better, staying the same, or getting worse. Changes were charted by age groupings and indicate some changes, such as fatigue and arthritis, as early as 30 or 35. Conditions which people saw as getting worse and affecting walking and body coordination increase after age 45, indicating that symptoms of aging may appear somewhat earlier in functions affected CP than in unaffected functions.

Questions were asked about the frequency of general health problems experienced by people as they age. Results for heart conditions, high blood pressure, diabetes, bronchitis, broken hips, dental problems, and women's health problems are shown on the last chart. These problems appear to span all the age groupings, but it does not appear that, except for dental problems, the frequency of these physical conditions occur any more often in people with CP then in the general aging population. These and other answers in the survey and the focus groups indicate that people with CP do not see their disabilities as health problems, and many of them rated their health as good to excellent.

Overview of Projects Results

The survey verified much of the information gathered in the focus groups. Most prominent were the consistent reports of fatigue in both studies. In the focus groups people even in their thirties had said, "I can't do as much as I used to" or "I'm so tired". The condition was referred to as fatigue in the survey. People in every age range reported experiencing fatigue and the percentages increase with age.

Of interest is the fact that people appeared to be less aware of impact on internal bodily functions, such as bladder control and breathing. People in the focus groups tended to deny that impact previous to the discussion, but admitted to it after discussion with others. Survey respondents reported problems with bowel and bladder control in significant numbers that increased to a high of 75% in people over 70.

It is likely that most people expect that their abilities will diminish as they age, and they do all they can to maintain those abilities. People with CP, until recently, have not thought ahead that much. They had not expected to live that long, and they had lived with idea doctors had given their parents that CP is not progressive. They worked hard as young people to gain their own highest level of functioning, and they expected to stay at that level. The non-progressive concept refers to the original damage not to the life time affect on the muscles. As they live longer and begin to experience decreasing control of body movement and more and more fatigue, they may become depressed. Survey results indicate that across all age groups 40% of respondents reported some degree of depression. Focus group participants, all of whom lived in an urban area, had social outlets, and positive living situations, felt they were coping well and did not report depression. The survey does not have enough information to firmly establish reasons for depression, but indicates that isolation and life styles play an important part in the likelihood that people will experience depression.

WCDD Information Project

Review of the information from the Waisman Center research confirmed the importance of getting it to people with Cerebral Palsy (CP), their families, caregivers, and service providers. It became even more important in view of the fact that many more people with CP, including those with severe disabilities, are living in the community and making their own choices about how they live. Having some sense of what they can expect as they age is an important consideration in that planning.

With this in mind the Wisconsin Council on Developmental Disabilities (WCDD) contracted with me to coordinate an Informational Project on CP and Aging. The project was to present the research results to people with CP, their families, and care givers around the state of Wisconsin. Titled "Learning Together" it was designed to provide the available information while learning more from people sharing their personal experiences. Drawing from the research and the learning sessions the project was to produce a series written reports in various formats for appropriate audiences.

Learning sessions focused on the survey information on changes in abilities, bodily functions, and coping skills. The charts summarizing survey results were distributed with a brief written overview. In the belief that people want to know how age related change affects their daily lives I paid special attention to every day concerns including fatigue and its' relationship mobility, the increase in spasticity, the threat of choking, and the importance of good dental care.

People's personal experience verified survey results indicating significant problems swallowing and gagging which can lead to choking and failure to practice good dental care. Participants agreed that the tendency to gag while brushing one's teeth is a prediction of how difficult it would be for them to keep dentures in place making good dental care even more important to the person with CP.

In every group someone asked about choking. It was of grave concern to care givers who were noticing people with severe disabilities having difficulty swallowing food. They felt that the awareness of the possibility of choking is the key to taking precautions such as cutting food in small pieces, not giving too much as once, and eating softer foods. For caregivers it should mean knowing how to assist someone who is choking.

Attendees at the first presentation, a statewide conference on Aging and CP, acknowledged their fatigue and loss of strength. Those who had struggled to walk all their lives knew that they could conserve their energy by using a motorized chair, but their families were resisting and accusing them of "giving up". At that conference Dr. Katherine Frank, Professor of Physical Therapy reported on research she did on energy use by people with CP. Her research showed that people with CP use 100% of their available energy on a daily basis and build up no energy reserve. These results explained why, no matter what their age, people with CP fatigue so easily. In succeeding learning sessions I reported on Dr. Frank's study results and encouraged people to find ways of conserving energy.

One topic, which came up over and over, but about which there is little information available, is exercise for people with CP. People felt that exercise would be of value to them, as it has proven to be for other older people, but they did not know how to exercise with their disabilities. People made it clear that they do not want the kind of physical therapy they had as children. I could only share with them my beneficial experience with a warm water exercise program developed by the Arthritis Foundation and distribute an informational brochure on exercise from the United Cerebral Palsy Research and Educational Foundation.

Somewhat surprising was the fact that in several places more service providers attended than were people with CP. Their questions and comments evidenced a concern for the people they work with, but among them there appeared to be a lack of knowledge of CP. They were eager to learn more about CP in general and made good comments about what they were observing in people they were working with. It may be that observers notice changes in abilities before the person with CP is ready to admit them. These kinds of observations could prove very helpful in future planning and developing coping strategies.

Many people with CP, from the focus groups through the learning sessions, talked about health care providers who know little or nothing about CP. Health care professions must recognize that Cerebral Palsy produces disabilities that can change, and must be dealt with in every stage of life.

The various presentations pointed up the importance of providing basic information to a wide range of people. Participants did learn together. More information was gathered, and continues to be shared. People with CP who attended tended to be those who sought to have their own experiences verified by the research. They were, in a sense, comforted by the fact that the project data reflected experiences very much like their own. People were alerted to what they might expect, enabling them judge the impact of the aging process on their own disability, and to evaluate the changes they are experiencing. With this knowledge they can educate their families, paid caregivers, and professional health care providers.

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Some Conclusions

In a sense this report has evolved over a number of years. There were four years between the Waisman Center research and the WCDD Informational Project, and the various presentations for that project were done over two years. A fact that has become evident during this process is that CP affects the various body systems. Because these systems interact with each other, the studies make us aware that even if it appears that the CP affects a given part of an individual's body, it does in fact affect the whole body. The impact of the CP appears to increase as the person ages.

Most of these affects have been reported in other parts of this report reflecting how and when I heard about them from people experiencing them. It seems wise to call attention to the system wide affects. While some of the information will appear redundant, it seems important to view it as part of the bodily systems.

Issues Associated with the Oral Mechanisms and Systems

The muscles associated with the mouth and throat are good examples of a system that works together in obvious and less obvious ways. Often affected by CP they impact on speech and swallowing with drooling and gagging being the visible results of a person's inability to swallow involuntarily. When the aging process begins to weaken those swallowing muscles, drooling will increase along with increased gagging. I have always gagged easily, and my dental hygienist suggested that bending lower over the sink might reduce the gagging. People began to tell me they were gagging more now than when they were younger. This was making good dental care more difficult. Sharing their concerns helped people realize that the tendency to gag would make it impossible for them to keep a dental plate in their mouth making it imperative that they take care of their teeth. Having this information early on may motivate people to find their own ways of maintaining good dental care.

During the Informational Project people consistently asked if others or I were beginning to choke on food. I had to tell them about the severely spastic woman who choked to death on pizza crust on her 41st birthday. Many of the people reporting choking problems were much less disabled than she. The threat of choking is very real, and we must learn to pay attention to what we put in our mouths. People working with us can help us make wise choices, and should know how to help someone who is choking.

When we speak we use the muscles of the month, lips, tongue, and throat to form words and project sound. Almost 40% of survey respondents reported that CP affected their speech. People's speech can vary depending on the affect of the CP on the oral muscles. People echoed my experience when they said, "talking is harder work". It's harder to get the muscles to work together to form words. People listening to us tend to tell us it doesn't sound different, but if it feels different to the person he/she should be evaluated by a speech therapist. Contrary to what we were told as children, speech therapy can help adults-even aging adults.

I believe that no matter what their age it is vitally important for a person with CP to have is a means of communication. If the ability to speak begins to deteriorate all alternatives should be examined including speech therapy and technical communication systems. In this technical age the possibilities are greater than they have ever been, and we must work to make those opportunity available to everyone who needs it.

Another mouth problem which I have experienced, but which no one had ever mentioned to me until recently is pain in and/or locking of the jaw joint. From time to time over the last thirty years my jaw has locked open. It's a frightening experience. Now two women, both in there fifties, have reported pain and tightening in the jaw joint. Two of us have found relief through Chiropractic care.

Issues Associated with Gastronomic Systems

Problems with chewing and swallowing of food may be the beginning of problems in digestion and assimilation of food. As has been stated people in the focus groups were reluctant to admit that bowel and bladder control was a problem, but a follow-up study of sixteen of them four years later found that eight of them had been diagnosed with spastic and/or irritated bowel or bladder. While four were over sixty, two were under forty, and two over forty.

A doctor who understands the relationship of these functions to CP can prescribe helpful medication.

Issues Associated with Fatigue, Mobility, and Daily Living

In thinking about mobility it is important to know about the thinking that doctors and therapists passed on to parents of children who are now adults over thirty. They stressed walking above all else, and most surgery and therapy was focused on walking. It didn't seem to make any difference what kind a gait they had or how much effort it took to walk on crutches; the desired outcome was that you wouldn't appear as disabled if you could walk.

In the survey 46.5% of respondents reported being fatigued, which I think now may be on the low side. Sixty percent of those from 45 to 55 reported increased fatigue. Forty per cent of those 35 to 45 felt fatigue was getting worse. There have been no efforts to correlate these numbers with the person's method of mobility. However, as soon as I began talking to people again complaints of fatigue were the first thing I heard. It was people over 35 who had walked all their lives who talked most about fatigue. Several people in their fifties have said, "I know I should be using a wheelchair, but my family members say that I'm giving up." I encouraged them to explain to their families that people with CP do not build up a reserve of energy, and not walking is a way of conserving their energy.

While most people related fatigue to walking, it has become obvious that other activities and bodily functions also draw on that limited supply of energy. Individuals need to evaluate all their activities in order to prioritize the use of their energy. All these systems have played a role in whatever degree of independence we have achieved. Because we value that independence, finding ways to conserve energy may seem like giving up some independence. These choices become necessary in the lives of all people as they get older, and are to be expected in the life of a person with a disability. For many people in the follow-up study it had meant accepting help in their home and/or attending adult day programs. Whatever those choices are it is important that we make them ourselves. Hopefully, better knowledge of what they can expect will allow people to better plan for those changes over time.

SERVING THE NEEDS OF PEOPLE AGING WITH DEVELOPMENTAL DISABILITIES

October 2003

The project was funded by WCDD using federal funds provided under P.L, 106-403 through a grant authorized the Administration on Developmental Disabilities and the U. S. Department of Health and Human Services. The information herein was compiled pursuant to the State Plan on Developmental Disabilities. Grantees undertaking projects under Council sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions expressed do not, therefore, necessarily represent the official position or policy of the Wisconsin Council on Developmental Disabilities.

Presentations and reports are based on research done through the Rehabilitation Research Training Center on Aging and Mental Retardation at the University of Illinois at Chicago and funded by U.S. Department of Education, Office of Special Education and Rehabilitation Services.

Serving the Needs of People Aging With Developmental Disabilities

The term Developmental Disabilities, coined in the early 70's, covers people with most forms of Mental Retardation (MR), Cerebral Palsy (CP), and Epilepsy. The term has been expanded through the years to cover other similar neurological conditions. Their need for services prompted their parent advocates to come up with an overall label which would help them secure funding for a service delivery system. As a result, a service delivery system developed to meet their needs as they moved from childhood to adulthood. Now that system must adapt to their changing needs as they age.

The people we are talking about are the first people with DD to experience the aging process. The same medical advances that have extended the lives of non-disabled people are enabling people with disabilities to live longer than they ever expected. A person over fifty probably hasn't thought about what it would mean to get older, and someone younger may be learning for the first time that they can expect to become senior citizens.

I am one of those people. I have lived over seventy years with physical disabilities caused by CP. I never expected to live this long and until I began to notice changes in my capabilities, I never questioned how getting older might affect my disability. In the beginning there were few answers, but I knew that whatever answers I found I would share with others.

It has been less than 15 years since researchers began looking at the impact of the aging process on people with Developmental Disabilities (DD). Early research focused on Mental Retardation and learning whether people with MR would age differently than the normal population. About the same time other practitioners began to look at the impact of aging on physical disabilities caused by Cerebral Palsy.

By 1997, the results of this research were being reported, but were not widely circulated. Some of the first conclusions were that people with DD experienced symptoms of aging at an earlier age than the non-disabled population. By this time, it was recognized that there are different forms of MR which account for differences in when those symptoms appear. Most obvious is the fact that people with Down Syndrome begin to age earlier and that the process goes faster than with other forms of MR. Much of the research, especially that on CP, focused on age-related physical changes.

Across-the-board expected age-related changes in vision, hearing, and mobility were reported. Changes in bodily functions such as breathing, digestion, and bowel and bladder control were most common in people with CP. It became obvious that the parts of the body which had always been affected by CP were impacted on to the greatest degree. While people with CP reported fatigue and lack of endurance as early as their late 30's, people with only MR may be somewhat older before fatigue becomes a problem.

It is important that we do not frighten people at the same time we are helping them identify changes in their disabilities. When it comes to aging, I have found that people with DD can relate to the fact that they are like everyone else. I have had people reflect on their aging family members or acquaintances. They are better able, then, to accept the changes they are experiencing. Some people respond favorably to the fact that they are one of the first people with disabilities to get to be as old as they are. Like everyone else, they appreciate the fact that they are still alive.

These are some general facts which give us a partial picture of people aging with DD. Without a doubt, the aging of people being served present new challenges for service providers. If care givers are going to help people identify changes, they must be aware of their abilities, behavior, and ongoing health. This can be difficult when staff turns over so quickly. Residential and employment providers need to find both general and more specific ways of assessing and accommodating changing needs.

Among the general concerns are those of health and safety. It is important that the entire agency adopt common sense precautions, such as good lighting, mobility aids, and elimination of barriers. These kinds of precautions can help people stay safe.

All around us these days, people are being given advice about how to live longer and enjoy life. A wide variety of prevention and intervention strategies are being proposed. There is an emphasis on good nutrition and exercise. This is probably even more important to people with DD since the research shows an even higher rate of obesity among people with MR than in the general population. This is especially true of women with MR. For a variety of reasons, they may not have developed good eating habits, or been encouraged to exercise. Research shows that overweight people with DD face the same risk for health problems and death as other overweight people, and that the risk drops if the level of physical fitness can be improved. An easy measure of physical fitness is whether an individual can get through the normal workday and not be too tired for leisure and household activities.

Obviously, it is never too late to introduce and encourage better eating habits and exercise. Walking, swimming, and structured exercise classes are good beginnings. Most people, as they age, turn to health care professionals for advice, which is often more difficult for people with DD and those working with them. Most doctors know very little about the impact of MR or CP on the person's health. They often fail to recognize a person's capabilities and fail to establish good communication. Service providers find themselves having to educate the healthcare system.

What Developmental Disability Service Providers Need to Know About the Changing Needs of People as They Age

People often identify the signs of aging as loss of abilities such as sight, hearing, and mobility, and the development of serious health problems such as heart problems, diabetes, and cancer. If they are professionals involved in providing services to people with developmental disabilities (DD), there's a good chance that they have observed those same changes in people with DD, but in their thirties and forties. Can these be symptoms of aging? Does this mean that most people with lifelong disabilities begin to age earlier than people without disabilities? The answer to both questions is yes.

These facts produce a whole series of other questions which have been addressed by researchers in the last 15 years and are now being addressed by service providers. The questions and answers are complicated by the variety of disabilities of people being served, because the aging process impacts differently on different disabilities.

What are Some of those Differences?

A major difference occurs between Down Syndrome and other forms of mental retardation (MR). People with Downs begin to age earlier and faster than others. Their abilities may change in their thirties and early forties, and lead to dementia and serious health problems including heart problems.

The aging process is gradual and is not usually noticeable in people with other forms of MR until the early forties. However, many of these people are overweight and face the same health problems faced by all overweight people.

People with Cerebral Palsy (CP) often notice fatigue in their late thirties and changes in their physical abilities in their forties. Bodily functions and activities always affected by CP, such as mobility, speech, coordination, swallowing, breathing, and bowel and bladder control, gradually decline over time.

What are Some General Considerations in Assessing Changing Needs?

People are individuals and may experience aging differently, so their service needs will be more individualized. Factors which determine the impact of aging include: type and severity of disability, combinations of disabilities, past abilities, and health problems. Taken as a whole, these factors will determine changing service needs. Personal preferences should be considered along with health and safety issues. It goes without saying that the availability of staff and resources will be major factors in choosing more beneficial services.

What are Some Specifics which may be Signs of Aging?

Fatigue: At the end of a work day a person is too tired to participate in leisure and/or household activities.

Loss of coordination and balance: Mobile person falls more.

Onset of Arthritis: Joint pain and swelling.

More difficulty in speaking: In people with CP, speaking takes more effort and gradually becomes harder to understand.

Increasing behavior problems: People who are feeling changes but are not able to verbalize may act out in frustration.

Any signs of illness or deterioration of health.

Changes in cognitive abilities including memory loss.

What Preventative Measures might a Provider Implement?

Promotion of successful aging is much the same for people with DD as for the general population, but may be more difficult to achieve. For example, a larger percentage of people with DD are overweight than in the general population, and it is harder for them to exercise. Many of them have poor eating habits. Beginning to promote exercise and good nutrition as early as possible can help avoid many of the illnesses associated with aging.

Staying alert to what is happening to people is most important. This means, of course, that staff need to know people well enough to observe and record change. Communication needs to be such that people feel they will be listened to when they express concerns about what they're experiencing.

What is Needed to Better Serve People as they Age?

More flexibility in meeting individual needs.

More intensive staff availability and personal care.

More support for direct service providers.

Appropriate daytime activities for people no longer able or wanting to work.

Availability of health care including needed therapies, such as physical, occupational, and/or speech.

Better coordination and communication with health care providers.

ARE YOU LIVING AND AGING WITH A DEVELOPMENTAL DISABILITY?

October 2003

This paper was funded by the Wisconsin Council on Developmental Disabilities (WCDD) using federal funds provided under P.L, 106-402 through a grant authorized by the Administration on Developmental Disabilities and the U. S. Department of Health and Human Services. The information herein was compiled pursuant to the State Plan on Developmental Disabilities. Grantees undertaking projects under Council sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions expressed do not, therefore, necessarily represent the official position or policy of the Wisconsin Council on Developmental Disabilities.

Presentations and reports are based on research done through the Rehabilitation Research and Training Center on Aging with Developmental Disabilities (RRTC), University of Illinois at Chicago which is funded by the U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Research (Grant No. H133B980046).

Are You Living and Aging with a Developmental Disability?

I am a person with a developmental disability. My disability is from Cerebral Palsy (CP). I am over 70 years old. When I was in my 50's, what I could do changed. I couldn't walk as far and as fast, I fell more often, and I had pain in my neck from arthritis. When I went to the doctor, he said I was getting older. No one could tell me much, because before that, people with CP had died before they were 50 years old. I knew then that I would have to find the answers for myself, and that I would share those answers with other people with disabilities. That is what I'm doing now.

As people with developmental disabilities, including <u>most</u> forms of Mental Retardation (MR), Cerebral Palsy (CP), and Epilepsy, we have always known our disabilities would be part of our whole lives. If we are now over 50 years old, we didn't think we would live to be that old. We are pioneers, because we are the first people with these kinds of disabilities to live long enough to wonder about getting older. Now many of us are 50, 60, 70, and even older. Here are some things we need to know.

It is important to know that our disabilities make a difference in how we age. We are all different, so what happens to us will be different and may happen at different times. Knowing what to watch for can help us understand what is happening. What kind of disability we have makes a big difference. We know now that there are different kinds of Mental Retardation. Autism and Down Syndrome are two kinds, and there are other syndromes. If you have Down Syndrome, you may begin to age in your 40's, but if you have another kind of MR you may be in your 50's before you feel changes in what you can do.

Some of us with Cerebral Palsy may begin to feel tired and not be able to do as much as before, when we are around 35 years old. Sometimes it is a good idea for us not to use all our energy to walk. Using a wheelchair to get around may mean we have more energy to do other things.

Living longer should be a good thing---something to be proud of. Not only are we living longer than people with DD ever did before, but we have had more chances to live in the community, to have jobs, to have friends, and do things we like to do. We can keep doing these things even when we get older. We should not be afraid of getting older. Knowing that we can get older should help us take better care of ourselves. It's important that we tell people close to us when we feel changes in how we feel and what we can do.

The answers on the next two pages should help you as you live the years ahead of you. I have put the information in simple terms to show you what might happen. Some of it is what I have learned myself and some is from what other people learned from talking to people with disabilities like ours. Use them to help you enjoy your life.

Facts About Aging for People with Developmental Disabilities

If you have Mental Retardation, Autism, Down Syndrome, Cerebral Palsy (CP), Epilepsy, or any combination of those, you have a Developmental Disability (DD). Throughout life, everyone gets older, and if they live long enough, they will experience the aging process. All people are living longer than they used to, and so are people with all kinds of disabilities. Living longer should be a good thing. People with DD have lived with our disabilities all our lives, and know that in some ways our lives have been different than other people's. For the first time, we have to ask if what happens to us when we get older will be different than what happens to other people.

RESEARCH

For about 15 years, people who cared about us have been studying these questions, and have found out some things which can help us.

They have found out that the changes that happen to all people when they are over 50 begin to happen to people with DD earlier---<u>sometimes</u> in their 40's. These changes often happen to people with Down Syndrome even earlier.

<u>Here are some of those changes:</u>

1. We get tired easier and quicker.
2. We don't see and hear as well.
3. Walking may be harder work.
4. We may lose our balance easier and fall.
5. We may have to go to the bathroom more often.
6. We may have more trouble remembering things and figuring things out.

For <u>some</u> of us, the changes begin in our 40's, which is earlier than for people without disabilities.

Here are Some Ways these Changes may be Different because our Disabilities are Different:

1. People with CP notice changes in all parts of the body which have been affected by the CP, such as walking, talking, breathing, swallowing, and bowel and bladder control.
2. Changes happen to people with Down Syndrome earlier.
3. People with CP may have Arthritis in their 30's.

Here are Some Ways we are like People without Disabilities:

1. We are living longer than people ever have before.
2. People with DD can have the same health problems that happen to all older people, such as Heart Disease, Diabetes, and Arthritis.
3. Many people with mental retardation are overweight, especially women. This adds to their health problems.

What Should we be Doing to Make our Lives Easier and Healthier as we get Older?

1. We should be exercising as much as we can. Walking, swimming, and exercise classes are all good ways.
2. We should eat food that is good for us, like fruits and vegetables instead of fast foods and sweets. This helps us lose weight.
3. We should take care of our teeth.
4. We should tell someone if we're feeling stressed out or sick.

IT IS IMPORTANT TO KNOW OUR OWN BODIES, SO THAT WE KNOW WHEN SOMETHING CHANGES.

ONE PERSON'S JOURNEY INTO AGING WITH CEREBRAL PALSY

October 2003

This paper was funded by the Wisconsin Council on Developmental Disabilities (WCDD) using federal funds provided under P.L, 106-402 through a grant authorized by the Administration on Developmental Disabilities and the U. S. Department of Health and Human Services. The information herein was compiled pursuant to the State Plan on Developmental Disabilities. Grantees undertaking projects under Council sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions expressed do not, therefore, necessarily represent the official position or policy of the Wisconsin Council on Developmental Disabilities.

Presentations and reports are based on research done through the Rehabilitation Research and Training Center on Aging with Developmental Disabilities (RRTC), University of Illinois at Chicago which is funded by the U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Research (Grant No. H133B980046).

A listing of available publications can be found at the RRTC web site. Many can be downloaded at no cost. Web site: http://www.uic.edu/orgs/rrtcamr

One Person's Journey into Aging with Cerebral Palsy

My journey with Cerebral Palsy (CP) began the day I was born and continues as I approach my 75th birthday. The journey into aging began in my early forties, but then I did not see it that way. Like people with disabilities caused by CP before me, I did not expect to live to grow older. Now it has become important to me to recall the "hows" and "whens" of the aging process and their impact on my abilities and my life. This attempt to record my experiences is being made in the hope that other people with CP can benefit from knowing something about what has happened to me over the last thirty some years.

A description of my disability seems appropriate. Because CP is so individualized and can be so different from person to person, it may be helpful for readers to have some understanding of the degree of disability I have lived with. For my purpose here, the cause and growing-up years are not so important, so where I was at age 40 seems to be the place to start.

My disabilities are all physical but not severe. All four of my extremities are to some degree affected, as is my balance and coordination. I have walked unaided since the age of three and have always found ways to do what I needed and wanted to do, including all self-care. At age forty I was a working mother of six children, a homemaker, and a community activist. As a divorced single mom and homeowner, I was responsible for all decisions. Physically, I was able to walk six to ten blocks, type (always with one finger), cook and bake, care for my children, and maintain my home. My speech was very understandable, and had in fact improved as I became more involved in community affairs and spoke in public.

This was my life at age forty and the background on which symptoms of aging would begin and gradually impact my life. My energy remained high, but between the ages of 40 and 45 there began to be signals of coming changes. The first was a fall in front of a bus I was running to catch. That convinced me that I couldn't run anymore, and accepting that was a psychological turning point for me.

The year I turned 45, I began to experience neck pain with pressure up into my head. I know now that it was the beginning of the deterioration of my neck and its muscles from years of involuntary head motion, but then it felt like something was growing at the base of my skull. Doctors could not account for the pressure until I sought out a chiropractor.

I had never forgotten that it was chiropractic care that got me walking as a child, so going back to it seemed logical. It proved to be a wise decision for me, and I have been treated in the same clinic for almost 30 years. The original finding was that the pressure in my head was because my upper spine was pushing upward.

After a few adjustments, the pressure was released and the pain subsided. However, there was the recognition that the process of deterioration and the development of arthritis had begun. The chiropractor and I were committed to slowing down the process. Twenty years ago when my head began to pull to one side, we developed a series of neck exercises which, along with adjustments as needed and other interventions, have significantly delayed the process.

I want to stress that change has been gradual and at times barely detectable. Because the physical change was so gradual it did not inhibit my ability to fill my life with good and meaningful activities. I saw my children grow into adulthood and welcomed the arrival of grandchildren. There was a series of full time satisfying jobs, one of which began at age 55 and from which I retired from full time employment after nine years. My community activities continue to this day and included six years as an elected County Board member.

Over the years, I realized that all the parts of my body that had always been affected by CP were responding to the aging process. The response in onset and severity were different from one bodily function to another. There have been occurrences that were occasional, while other functions stayed at a certain level of ability for a long time before declining to another level and staying there.

An example of an occasional occurrence is the locking of my jaw. The first time was in my early 40's, and was a very frightening experience. My mouth would not close, there was significant pain, and emergency room staff was not sure how to deal with it. Since I could not close my mouth, swallowing was difficult, and I was afraid of choking. The experience made me realize that for me, swallowing was not as involuntary as it should be, and is almost impossible with my mouth open. The locking of the jaw happened only five times in twenty years. I have learned to sense a misalignment and have it adjusted by the chiropractor.

Swallowing, tongue movement, and chewing are functions of the mouth which have changed, gradually staying at certain levels for extended periods of time before declining again. I found it important to view these functions together because they all contribute to the possibility of choking and the quality of speech. For me it has meant that moving my tongue, whether to form words or move food around in my mouth, has become harder work. I am less able to control my swallowing, so I drool more, and food can slip down my throat before it is properly chewed. The acknowledgment that this puts me in danger of choking has forced me eat slower and find ways to dislodge food from my throat.

The impact on my speech becomes more and more of a concern. I did not pay close enough attention when it first began to become harder work to form and get words out. People said they couldn't tell the difference, and under certain circumstances it was more understandable. At one point I rejected the suggestion that I have speech therapy. Presently, I can see people having more difficulty understanding me.

A recent consultation with a speech therapist indicated that the major factors are my breathing and tongue control. I must slow down and take breaths more often. Pausing briefly allows me to swallow and for my listener to catch up with what I'm saying. I have begun tongue exercises in the hopes I can gain some control. That would help both the speech and the movement of food in my mouth. I am finding the idea of being better understood and maintaining my speech are real motivators.

There is one part of the mouth I haven't mentioned---the teeth. I learned the hard way that because of a lack of hand coordination and strength along with an active gag reflex, I had not taken adequate care of my teeth. By the age of 60, I had a serious gum infection, the cure of which was very costly, and brought the realization that should I lose my teeth, the gag reflex would prevent me from keeping a plate in my mouth. At some expense I have maintained my remaining teeth, and am determined to keep them.

As I have stated, my first realization of change was in my ability to run. It was a foreshadowing of the gradual but persistent loss of balance and endurance. Walking is one of those functions which stayed much the same for even a number of years before declining to another level. The loss of balance, which increased the tendency to fall, was always the most obvious change. At age 64, I began a warm water exercise program designed by the Arthritis Foundation. It really slowed down the loss of balance and helped keep my legs strong enough to prevent some falls and enable me to get myself up when I do fall. In acknowledgment of what was coming, I did get a walker at age 70, using it first only when I walked distances. Use of the walker has increased gradually since. I seldom use it in the house, but use it more and more away from the house.

Hand strength and coordination is another example of gradual levels of decline. My hands have also been impacted by the Arthritis in my neck and a rotator cuff injury sustained in a fall in my early 60’s. The warm water routine includes finger and wrist exercises, which have proved very helpful. My own ability to find less stressful ways of doing things keeps me typing, cooking, and taking care of myself.

In all my conversations with other people with CP, I find that the last things they want to talk about are what I call internal bodily functions. Most of us must admit that our breathing, digestion, and bowel and bladder control involve muscles, which are affected by the CP. The reality of that becomes more obvious as we age. In my early 50’s I began having repeated bladder infections. The Urologist kept telling me I didn't empty my bladder, to which I always wondered if my bladder was spastic. To make a long story short, it took him four years to tell me I had a spastic bladder and to prescribe Oxybutynin. I've been taking it ever since, maintaining satisfactory control and eliminating infections.

Most of my life I have had some sense that the muscles of my bowel were affected, but it was never a real problem. I was in my late 50’s when I had my first full-fledged attack of irritated bowel. I have had to learn that certain foods are irritants, which can cause pain and diarrhea. I suspect this may be individualized, but for me, some foods don't bother me unless I eat them at successive meals. Apparently, Oxybutynin is often prescribed for irritated bowel, but doubling my dosage to take care of both the bladder and bowel produced a severely dry mouth, which affected my speech. I rely on careful eating and over-the-counter medications when it does happen.

When I experienced a shortness of breath after age 65, a breathing test uncovered the fact that my lungs fill only to 75 per cent of their capacity. It has not proved to be a problem, but I am sure again that it is because of muscles affected by CP. It may be that as all my muscles slow down, the breathing can keep up.

I have mentioned some interventions that have helped me, but I should also say that I have made accommodations along the way. Since I lost strength in my arms and legs, I have had a raised toilet seat and a motorized recliner. These and the walker are for my safety and comfort. There are lots of smaller things and I know there will more in the future.

As was my intent when I started this, I have attempted to describe changes in those abilities affected by my CP. My desire is not to frighten people, but to alert them to the fact that the aging process does have a somewhat different impact on people living with CP. For each of us, CP is very individualized, so it becomes important that we know our own bodies, abilities and disabilities, so that we can be aware of change. This will enable us to work with those around us to make accommodations as they become appropriate for us.

UPDATE:

Recently I have had a peek at the future. It was set off by a bladder infection which I denied having for a couple days. It weakened my whole body, affecting my balance and coordination, and resulted in a fall from my bed. I was unable to get myself up and had to call for help. The antibiotics given me for the infection made me sicker and further affected the CP-affected functions. With a change in medication, it took about ten days to restore balance and coordination. As it was coming back, I saw the Neurologist, who told me that any illness might trigger that kind of a loss.

This series of events has prompted the elimination of some barriers in the house and the addition of some safety measures, including Life Line, which would allow me to push a button worn on my person to call for help. It stimulated family discussions of alternative ways of doing things and of possible care options in the future.

THE JOURNEY INTO AGING WITH CEREBRAL PALSY CONTINUES

December 2006

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The Journey into Aging with Cerebral Palsy Continues

Background and Perspective:

The last time I shared in writing the experiences of my journey into aging with Cerebral Palsy (CP) I was seventy four years old. Now I am 77, and the adventure has been varied, sometimes difficult, but always interesting. Through it all, is always the desire to share my experiences with others in the hope it will help them on their journey. Always in my mind is the knowledge of how individualized the disabilities caused by CP can be from one person to another. Although, I have spoken with others about the impact of the aging process on their CP affected bodies, this is written primarily from my own experience.

In my previous piece, One Person's Journey into Aging with Cerebral Palsy, I described my disability at age forty when I first noticed changes which I attributed to the aging process. Then I said, "My disabilities are all physical. All four of my extremities are to some degree affected, as are my balance and coordination. I have walked unaided since the age of three, and have always found ways to do things I needed or wanted to do, including all self-care. Physically I was able to walk six to ten blocks, type (always with one finger), cook and bake, care for my children, and maintain my home. My speech was very understandable, and had in fact improved as I became involved in community affairs and spoke in public." That was how it was when I was forty.

At age 74, I reported neck problems, including arthritis, loss of balance and coordination, loss of muscle control in my mouth, leading to the increased possibility of choking, increased drooling, some difficulty forming words. Also I had become much more aware of the affects of CP on internal bodily functions such a bladder and bowel control and breathing. I discussed at some length how these changes had occurred gradually over time, usually leveling off and staying at a given level of ability for considerable lengths of time. The interventions being employed were warm water exercise, chiropractic care, medication for spastic bladder, and occasional use of a walker. That was how it was mid-way through my 75th year.

The last three years have brought significant changes and some alarming experiences, especially relative to my neck and head as well as my balance. It has meant experimenting with new interventions and making changes in how I do things. Interestingly, in spite of changes in my abilities my general health has remained excellent. I am only a little less independent, and am involved with my family and as a volunteer in advocacy activities on the behalf of people living with life-long disabilities.

Still my greatest interest is in sharing information on aging with people with CP no matter what their age and having them share their experiences with me. Hopefully we can help others. Those of us who are now senior citizens are among the first people with CP to live long enough to claim that title. It is with a sense of pride that I now describe what is happening to me and how I and those around me are coping.

Reacting to Change:

So I begin in the fall before my 75th birthday when my body gave me a sense of what might be coming. A bladder infection weakened my whole body affecting my balance and coordination. For the first time I was not able to pick myself up after falling and had to call for help. I was not injured, and with treatment the infection subsided and the balance and coordination returned almost to the level I had been enjoying. The frustration I felt at not being able to get up stayed with me and prompted an evaluation of my situation. Changes in the arrangement of my room were made immediately to make it safer.

More importantly this preview of what might be coming convinced me to apply for the Community Options Program (COP) waiver which helps older people in Wisconsin stay in their homes. I had been on a waiting list, and knew that I was eligible. Through COP I was enrolled in the Life Line Program, which allows me to push a button worn on my person to call for help. As yet I have not had to use it. Over time COP has provided a ramp, a new walker, an accessible shower, and more recently help with heavier housekeeping tasks. In short, it has allowed me to maintain my independence in the community.

Choosing Botox:

During this period my biggest problem was the arthritis and pressure in my neck. My head pulled to one side, making the muscles very tight and creating pressure on the nerve going from my neck into my head. The resulting discomfort made it hard to hold my head up and affected my balance. For some months I got by with chiropractic care, a pain reliever, and wearing a foam rubber collar. These helped while I was awaiting an appointment with an Orthopedist specializing in CP at the University of Wisconsin Hospitals. A month before my 75th birthday he evaluated my over all condition and concluded that I was doing very well except for my neck. He recommended that I increase the pain reliever, and outlined how he would treat the neck with Botox shots.

It seemed to me there was an element of risk involved in doing the Botox shots. Shooting a foreign substance into my neck which was so deteriorated from arthritis and affected by of years of involuntary head motion concerned me a lot. I also perceived this course of treatment to be the rather experimental. At that point in time I did not feel that the discomfort was significant enough to take the risk that I felt Botox was. We agreed that I could monitor the pain, and inform him at any time I was ready to have the shots.

As I went through the next two months, including the holidays and my 75th birthday, the discomfort varied from day to day, but moved toward being a "flaring" pain that would spread across the base of my skull. It is hard to describe the sensation. Not only did it change from day to day, but from time to time in the same day. I made the appointment for Botox shots which were done a month after my birthday. We discussed the fact that the shots would have to be carefully placed. We did not want them to relax the muscles affecting my speech or breathing. Having the shots was not especially painful. He used half the maximum amount of Botox available in six spots all in the left side of my neck. I was given a time table for what I could expect and the suggestion that I wear the collar to help my head pull back to the right when the muscle began to relax.

Within three days there was a difference. Over the next two weeks the tight muscle gradually relaxed , and the right side had to adjust to the change. It was like a tug of war between the neck muscles until my head began to straighten up. The flaring pain subsided, and my balance was better because my head wasn't pulling to one side. I kept wearing the collar, while going about my normal activities including the warm water exercises. As the pain was eliminated, I felt that the Botox had done what was expected. What a relief!

Shortly after having the Botox shots the doctor offered to refer me for physical therapy. I rejected his offer of hands on therapy at this time. But as it happened, my daughter who is a therapist, had worked out some exercises for me to do at home. Although I did them quite faithfully, and my daughter checked my progress periodically, I know now that I should have taken it more seriously and gone to a therapist to work with me directly.

Taking Care of Myself:

Needless to say the aging process was continuing to affect other parts of my body while all this was going on. I was seeing an Internist, who was aware of the CP but did not blame everything on that. He continued to monitor me for problems usually experienced in people my age, such as heart problems, high cholesterol, and diabetes. He ran tests to check on symptoms as they occurred. The tests usually came back negative.

Long before this I had been diagnosed with spastic bladder and bowel, both of which are affected by the CP. I had been on medication for the bladder for a long time, and at that time was pretty well able to control the bowel with diet and over the counter medication. As time went by I noticed that I had less control of my tongue especially when taking pills and moving food around in my mouth. My tongue began to hump up as it never had before, and I was drooling more.

During the three months that the effects of the Botox peaked, evened off, and then began to decline I continued exercising the neck and going to the warm water pool. I wore the collar a lot of time and when asked why, I said, "to keep my head on straight". I was able to keep up with my regular activities, including the cooking and baking that mean so much to me. One major change was that I began taking the walker wherever I went. A rather frightening incident at church convinced me that the decline in my balance made it unsafe to walk outside or in group settings without something to hang on to.

This was a real concession on my part, and became a consideration when I was invited to participate in a meeting of adults with CP held in Washington. I was hesitant to fly by myself and change planes, even though I had done it successfully in the past. With the help of my family I was able to go without changing planes. Everything went well, and at 75 I was the oldest person there. My sense of satisfaction was in the fact that I had done it myself, while helping younger people with CP understand that they can live longer than they may have expected.

It was over four months after the Botox shots when I saw the doctor again. The affects had worn off, and there was the beginning of tightening in the neck and pressure in my head. I was told that what I had experienced was what he had expected. Feeling the procedure had produced the desired results, we talked about how we would do it again if the real pain came back. We agreed that I would make the decision when I felt the need. Beyond the neck the doctor was pleased that I was using the walker and felt I was doing well.

For the next two months I was able to do the things I wanted to do as long as I did the neck and water exercises and saw the chiropractor every couple weeks. Our main concern was my right shoulder. Sometime in my mid sixties I fell and injured that rotator cuff. I was told that after sixty a rotator cuff does not heal. It affected the upward movement of my shoulder and right arm. The chiropractor was able to relax it, but I was using my left arm more and more. Over the years the left arm has gradually gained strength and flexibility enabling me to do more with it.

During this period I was having frequent attacks of irritated bowel, with more and more foods irritating it. The Internist added a prescribed medication to the over the counter meds I had been using. He recommended having a colonoscopy. I agreed and had it done by the specialist who originally diagnosed the irritated bowel. She confirmed that the CP is a factor, but said my symptoms were very much like most of her older patients, and that I was taking the right medications. She suggested increasing the amount I was taking.

Botox Again:

Six months after the first shots I was uncomfortable enough to schedule a second one. The tightness, pressure, and pain in my head were all back, and I had confidence that I would get relief again. We agreed that the same amount would be used, but a quarter of it would be put in the right side rather than all in one side. For the two days following the shots the tug of war was back in the two sides of my neck just as before. What was different is that my head fell forward. I began wearing the collar most of the time. Not being able to hold my head up once again affected my balance. It became obvious that the muscles were not reacting as they had the first time.

A week after the shot I had to acknowledge there was something else wrong. I was weak and hot. There were other symptoms typical of a bladder infection. A trip to Urgent Care confirmed the infection and Sulfa was prescribed. I had reactions to the Sulfa, and to the increased bowel medication. I saw my regular doctor who changed the Sulfa and said to cut back on the bowel medication. The infection cleared quickly, but I was short of breath and aware that I was not responding to the Botox as I had before.

On the morning of the 15th day after the second Botox shots, I had trouble getting my breath and was very hot. On the phone I described my symptoms to the Internist's nurse and feared I might be having a heart attack. She considered sending me to the Emergency Room, but decided they could do tests in the clinic. After a morning of tests, X-rays, and blood work, we knew it wasn't my heart. We were left wondering if some how it could be the Botox.

The doctor took time to contact the CP specialist. After hearing what I was experiencing and what tests had been done, he admitted that the Botox might have "migrated" to my lungs. He said the Botox was probably at its' peak, and would begin to wear off. They agreed that there was nothing to do except wait and see. I was told to take it easy for a week and then come in. That was what I did, and as the days went by my breathing got easier. By the time I went in my breathing was back to what is normal for me, but my neck was far too relaxed. We were convinced it had been the Botox.

A New Pattern Being Set:

I had been scheduled to begin Physical Therapy (PT) about a month after the second shots. When I went into the Rehab Clinic to begin PT, the CP specialist wanted to talk to me. He was anxious to know how I was and was concerned that I had such a different reaction to the Botox. Meeting with PT for the first time was very reassuring. She was sure that we could strengthen my neck with a hands on exercise routine. After assessing my neck, we agreed on a three day a week schedule of tensing and relaxing movements for my head and neck. For a month I went three times a week and did the routine every day at home. The next two months I went twice a week. The benefits motivated me to stay with it. By my 76th Birthday I was going once a week, and soon I was doing them entirely on my own. My neck was much stronger, and the affects on the rest of my body were very positive.

Now I was back to my usual activities, and had come through another holiday season able to do the things that mean the Holidays to me. I was also back to my warm water exercise, which was good because it always helps my balance. For safety's sake I was wearing the collar a lot of the time and taking the walker wherever I went. A pattern was being set for my 77th year and beyond. Doing the neck exercises kept my neck relaxed enough, so the pain did not come back. At one point there was concern that the Bextra prescribed for the arthritis might not be safe. So I began and continue to take Aleve twice a day. It keeps me comfortable most of the time. I had a bone density test which indicated a calcium deficiency. It is being treated with a calcium supplement with vitamin D, and is being closely monitored. A key factor has been getting enough rest; not only a good night's sleep, but resting during the day when I feel the need.

General Health:

The greatest blessing is my general health, which remains excellent. There was a period of distress that proved to be delayed menopause. It took some time to realize that I needed to go back to hormone therapy, but it only took three days to eliminate the symptoms and boost my energy level. When we wanted to be sure my heart was OK, I had a nuclear perfusion stress test rather than putting me on tread mill. It was an interesting process and the results were positive. I am checked periodically for the things that all older people should be checked for, and so far have none of them. As I have said before, I am fortunate to have an Internist who will pay attention to my whole body and work with the specialist who is so knowledgeable about CP.

My 77th birthday in January proved to be the beginning of a three month period of feeling exceptionally well. I was telling people that I woke up surprised every morning at how good I felt. The pain in my head had not come back and so I wasn't worried about having to have Botox again. If I neglected my neck exercises and didn't wear the collar, there was some pulling in my neck. My balance was a real concern and kept me trying to get to warm water exercises at least twice a week. By now I was convinced that I needed the walker whenever I went away from the house.

I began to notice that I fell more frequently if I was stepping backwards. After analyzing what was happening, I started some exercises to strengthen my upper thighs. I found that just being conscious of stepping backwards made me more careful and cut down on the falls. Some time previous to that, I had reported numbness in my fingers and hands to the CP Specialist. He suggested wearing wrist splints to bed. The pain and numbness were greatly reduced.

It was the spring of 2006 and I was 77 years old and in good general health. As is usual for me, I was anticipating the joys of family over the summer and hoping that I would be able to pick up on the follow-up for my previous research project. The next few months proved to bring enough change in my abilities and health to warrant a future report on my journey into aging with Cerebral Palsy.

This ends my report on the 74th, 75th, and 76th years of my journey. As always, I remind you that I am reporting primarily on my experiences. Knowing how individualized the disabilities caused by Cerebral Palsy can be, people need to take from this report what seems relevant and useful to them. As I have often said, knowing our own bodies and abilities is key to evaluating changes caused by the aging process and finding ways of coping that work for each of us.

The journey continues……

THE JOURNEY CONTINUES:
A BUMP IN THE ROAD

January 2008

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The Journey Continues: A Bump in the Road

A Brief Look Back

The last chapter of my journey into aging with cerebral palsy (CP) promised that it would be continued. At the time it was written, I was already experiencing new changes in my abilities and in my general health. As I report again, over a year has gone by. I have now reached the age of 78. The year has been one of significant changes and important decisions. Before beginning to talk about the physical changes I have experienced, I need to summarize where I was and what my expectations were during the spring of 2006.

Thinking back further to when I first began noticing physical changes that were age-related, I know I tried to plan ahead to meet my changing needs. When I realized that I needed help to stay in my home, I took advantage of a local Home-Share program. Over six years, three young women shared my home in return for doing some household tasks, while I took care of my personal needs. Another time, I realized I needed some home accommodations. I was able to go on a Medical Assistance waiver program called the Community Options Program or COP. This program aim to keep people in their own homes and communities by providing them with the supports they need. With COP funding, I was able to install a ramp and a walk-in shower, and purchased a four-wheel walker.

In the Spring of 2006, I was 77 years old and rejoicing in my relative excellent health. The walker was essential to my getting out of the house and around the community. As is usual for me, I was anticipating the joys of summer and having family over. I even had begun a follow up study to my previous research on aging and cerebral palsy.

At the time in 2006 when I made the commitment to continue these reports, the biggest changes I would have acknowledged would have be in my mouth and throat. I was losing more control of my tongue, making it harder to control food in my mouth. Food would slip to the back of my throat before it was properly chewed. It would often stick in the upper part of my throat. I adjusted by developing a technique for coughing it back up. In addition, I noticed my drooling pattern was changing. I was drooling more, and could go from having a dry mouth to drooling in a couple of minutes. I carried a supply of men's handkerchiefs wherever I went.

Previously, I reported that I had a bone density test, which confirmed that I had osteoporosis along with arthritis. The role of vitamin D in processing calcium in my thyroid and its effect on the bones was explained to me, and they began monitoring my calcium and vitamin D levels. The levels of calcium fluctuated over a four-month period, so I was advised to see a thyroid specialist. They confirmed that I had Parathyroidism and I was told that I should see a surgeon. I did and surgery was recommended. I had a complete pre-surgery physical which did not uncover any other health problems. The surgery was more complicated than expected, because they discovered that I had six parathyroid glands instead of the normal four. Four of them were not functioning, so they were removed. I recovered quickly, and there were no after-effects, positive or negative, that I could detect.

In all my writing about aging and CP, I have urged people with CP to know their own bodies and pay close attention to any changes. Now I must admit that a year ago I was not completely practicing what I preached. I felt so good physically, was so confident, and I was doing the things to preserve my abilities that I wasn't paying any attention to changes in my walking. I felt so comfortable taking the walker wherever I went. I even used it more in the house. Unfortunately, I just did not realize that my right leg was starting to drag. Weakness in my lower back has always effected my walking, so I wasn't paying close attention to how much my lower spine was starting to deteriorate. Over the years chiropractic care slowed down the deterioration. But, I hadn't faced the fact that my lower back continued to weaken which had an impact on my legs. While at the same time, arthritis increased in my neck and shoulders.

Sudden Change

Three weeks later, I was feeling so well that I attended a two-day out-of-town meeting. At that time, I was using my four-wheel walker. As we left the hotel for dinner, I lost control of the walker on a curb cut, and it went one way and I went the other. As soon as I hit the pavement, I knew I had broken my hip, and immediately said, "Don't move me." Laying on the hotel driveway, I was surrounded by DD Council members and staff, one of whom had my daughter on the phone even before the ambulance arrived. Two of the staff followed the ambulance as I was transported to a small local hospital. There X-rays confirmed that my left hip was broken. I was told immediately that they didn't have an orthopedic surgeon on staff. I was reassured when they asked me which hospital in my home area I wanted to go to.

There was ongoing communication with my children and of course they were anxious to have me brought back to my home area. The search for an orthopedic surgeon and a hospital bed began immediately. That evening the local doctor reported that she had found a surgeon back home but not a bed and she would continue her efforts. After a night of drug induced sleep I was informed the next morning that two hospitals in my home area did not have a bed available. It was made clear to me and my family at home that the longer I waited for surgery the more dangerous my condition became. Getting the surgery done quickly now became the top priority, even if that meant it would be done away from home. Had I been alone it would have been very frightening, but one of the Council staff stayed with me. By noon a surgeon had been found at a larger hospital in the area, and arrangements were made for me to go there by ambulance that afternoon.

Again two of my friends followed the ambulance, and three of my children were at the hospital when I arrived. I went into surgery almost exactly 24 hours after the fall. After the surgery we were told that it had gone well and that a rod and pins had been put in my hip. We were told immediately that I would need to go into a facility for rehabilitation. Two of my daughters, one of whom is an Occupational Therapist, spent the night in the hospital. The next day they returned home to research and choose a rehabilitation facility, and a third daughter came to be with me. I was being kept reasonably comfortable, but it was good to have a family member there partly to help hospital staff understand how the CP affects everything I do.

By the time I left the hospital three days later I had been in three different hospitals in less than a month; one small and medium sized hospital with my hip and the big University Hospital for the thyroid. In all three hospitals, my daughters and I found ourselves educating hospital staff about Cerebral Palsy, and how it affects the way I do things. In all three places, my daughters had to explain the importance of keeping my mouth moist because of the effect of a dry mouth on my swallowing. Also affected is my ability to take pills, and I found myself having to demonstrate how I put the pill into the back of my throat. Maybe more important than these specifics was the general lack of knowledge about C P and the desire of nurses to know more about it. I never missed an opportunity during this month of medical procedures to explain what CP is. It is always important to me to have medical professionals understand how individualized C P is and how it can impact so differently from one person to another. In all three hospitals, I found people really interested in knowing more.

The Rehab Experience

My OT daughter had chosen a rehabilitation facility in our area, and my internist had agreed by phone to provide the medical follow along that was required by the facility. After five days of excellent hospital care, I was transported by ambulance to a rehabilitation center and nursing home a few miles from my home. That ride had an interesting twist when an ambulance crew member entered my room and said, "You have CP. So does my daughter." Of course I took the opportunity to converse with him during the ride. It made for a most interesting ride.

I had been given a significant amount of pain relievers to be able to tolerate the nearly two hour ambulance ride. That may be why I don’t remember clearly my first night in the rehabilitation facility. I do know that two of my children were there to greet me. I was taken to a two-person room and met a lovely woman who had been admitted earlier in the day, and we began our adventure together.

The next morning, an Occupational Therapist came to my bedside and did an evaluation that would determine my therapy and care needs. I asked for her advice when I realized that I was going to get wet every time I drank out of the available water cup. She modified a smaller cup with a cover and a straw, and my problem was solved.

I stayed in my room the first day. On the second morning, I was wheeled in a wheelchair first to the dining room where most of the residents ate their meals, and then to the Physical Therapy room. I was immediately reminded of my childhood physical therapy, as much of the equipment was the same. I was introduced to the physical therapist (PT) who would direct my therapy. We began with exercises lying on a mat and/or while sitting in the wheelchair. It involved movement in both legs and ankles. Those early exercises were intended to maintain flexibility that would allow me to walk when the hip was healed enough to bear weight.

In the middle of that night I began to wonder what I would allow myself to accept. A friend who visited on Sunday helped me put three options in writing. I described the ideal as being able to use the two wheeled walker both inside and outside the house, or at least some combination of the walker and a manual wheelchair. But I also realized I might have to accept the complete use of a manual chair. During that first two weeks, I really had to face the fear that my mobility might well be less than it had ever been.

I shared these options and concerns with my PT on Monday morning when she introduced me to a PT Intern who would be providing my therapy under her direction. The three of us discussed briefly our expectation that I would be able to use the walker, and they liked my idea of setting a weekly goal. We planned for another week of therapy before I attempted to stand up. That meant two hours of physical therapy a day and one hour of occupational therapy (OT).

The occupational therapy was aimed more at the disabilities from CP and arthritis in my upper body and neck. Much of it was similar to exercises I did as a child to improve my hand coordination and strengthen my upper body. I was able to include the neck exercises I had been doing for some time. It was the OTs who helped me learn to use a manual wheelchair. As time went on they showed me the safest ways of doing things from the chair. There was a social aspect to the therapy sessions, since there were other people in the room doing the same exercises. We worked together and encouraged each other.

The time came when we felt I was ready to stand on both legs and walk. In the previous days I had been standing briefly, but now I was to walk forward between parallel bars. I felt comfortable and balanced standing at the bars. Then I attempted my first steps. I was shocked when I tried to pick up and move what had been my good right leg forward. My heel would go up, but that was all. Along with my therapists everyone in the room was watching not knowing what to think. All I could say was, "It feels like that leg has a mind of its own." It was a surprise to the therapists, my family, and I. What to do? There seemed to be nothing to do but to go back to the exercises. I had to have an answer for myself, and finally presumed that it was because of the Cerebral Palsy, and that the disconnection was in the motor cells directing my legs. The only thing I could think of to do was to tell my leg what to do. So, I began to give my leg the verbal command, "Shift and lift", with each attempted step.

This was the most frustrating time for me and my children. I continued to stand up every day and talk through each attempted step. The daughters who visited most often began to visit at therapy time to watch for progress. One day as they were leaving, I looked up from the parallel bars and saw my nine year old grandson lingering in the doorway. I noticed his questioning eyes watching me, as if he wanted to will my leg to pick up. Feeling what it meant to him made me work even harder. Within days I moved from the bars to the two-wheeled walker. The leg had begun to move forward, and everyone was encouraged.

The fact that my hip surgery had been done in another area of the state complicated things a bit. It had been almost six weeks since I had surgery and entered rehab. The normal procedure would have been to return to the surgeon, who did the operation, to check on the healing of the hip. Because of the distance involved this was not possible, so my CP Specialist referred me to an orthopedic surgeon in town. I went from the facility to the hospital where X-rays were taken of the hip. These showed that it was healing well. The new surgeon had some concern about the pin holding the rod in place being very close to my knee. He expressed some reluctance to touch another surgeon's work should there be a need for a second surgery. He advised that we continue with the therapy and check back with him in six weeks.

A Change in Attitude

As therapy progressed, I began to realize that I might not meet my goal of being able to walk in the house even with the walker, because my progress was so slow. A series of questions went through my mind. How much help would I need if a manual wheelchair was my primary means of mobility? How would I function in my home? Could I feel safe? Would enough help be available? Knowing that my children had been fearful about my safety before, I realized they would be even more fearful now. I had to ask myself if I should be thinking about going into an assisted living situation. Choosing to do that would mean selling the home in which I had raised my children.

As each of them came to visit over the next few weeks, I talked to them about their fears for me, about what our home meant to them, and what it would mean to them if I sold the house. They were very open about their fears for me and the fact that they had no personal reluctance to having the house sold. They confirmed what they have always said; that I had worked hard to pay for the house, and if the profits from the house could be used for my care, they were alright with that. In the end, they all acknowledged my need to go home and try it before we made any other decisions. Hearing each one say almost the same thing prompted a change in my own attitude. While I knew I had to go home and try, I would be better prepared to accept selling our home if I wasn't able to make it there.

Progress and Planning

As I approached my third month in rehab, my right leg was picking up and moving forward allowing my legs to move as they should. It was time to think about what would happen after rehabilitation. What is called a "care meeting" was convened by the facility social worker. I met with my therapist, my COP case manager, my therapy daughter, and the social worker. Though there was some discussion of a nursing home, we talked mostly about what it would take for me to function at home. My daughter explained what accommodations had already been made in the house as well what would need to be added. The meeting concluded with a decision to try to get me home in two weeks. However, it was understood two week extensions were possible if the therapists felt I could make more progress at the facility.

The next step toward getting me home was to set up a staff home visit. That brought both Physical and Occupational Therapists into my home with me. I took them on a tour of the first floor and showed them the accommodations I already had, which included the outside ramp, a walk-in shower, bathroom grab bars, a hospital bed, and pullout shelves in the kitchen. They had me try going from room to room in a wheelchair, transferring to the toilet, bed, and recliner. They identified barriers that would need to be removed if I was going to be able to navigate by myself throughout the first floor. In the end they evaluated my existing accommodations and made excellent recommendations for improvements.

Their written recommendations became a family action plan. My children gathered at my house on a Saturday to begin eliminating barriers and rearranging furniture to create a barrier free passage. For example, they moved a tall cupboard from the kitchen to the bedroom giving me an open path into the kitchen, while providing an accessible place for my clothes. Other changes in the kitchen were the placement of the microwave, toaster, and small drawers on a new low table and reversing the refrigerator door handles, making it possible for me to make simple meals for myself. These kinds of accommodations meant the elimination of some of my possessions, which I would probably have insisted on keeping, if I had been there.

More Decisions

Up until this point, I had been using wheelchairs belonging to the facility. The visit home determined that I needed a smaller chair. I was aware of an agency which rehabilitated wheelchairs and made them available for a small donation. My therapist daughter was able to find an appropriate manual chair, for which I made a personal donation. Knowing that I had a chair of my own which I could operate, gave me a better sense of independence. It also assisted the OT in teaching me how to do things like picking things up off the floor. On the advice of the therapists, I was given my first two-week extension just before Thanksgiving. I left the facility for Thanksgiving with my family and saw for the first time the new openness that my family had created in my house.

At this point, everyone except my Case Manager was pretty well convinced that I would be able to be at home with some additional services. The Case Manager was still talking nursing home. It took a face-to-face meeting with me and one of my daughters to convince her that we were not going to accept a nursing home placement at this time. Once convinced of that, she made arrangements for twice-daily Home Health Aide services and Meals on Wheels seven days a week. She assured me that these services could be paid for by the COP Waiver Program. With these assurances and the progress that I was making in therapy, I was granted one more two-week extension.

During that last two-week extension, I was able to stop my prescribed pain medication and do more of my personal care. It was also time to go back to the surgeon for a twelve-week x-ray. The x-ray confirmed that the hip had healed well, but there was still concern about the pin which held the rod in place being so close to my kneecap. I was very much relieved when the surgeon said that if I had problems, I could come back to see him.

Final Plans

The final two weeks in therapy were aimed at my being able to walk as far as possible with a two-wheeled walker. By then, my right leg was picking up and extending in an almost normal step. It was expected that I would take the two-wheeled walker home and not even think about using my four-wheeled one. My hour of occupational therapy every morning centered on skills I would need to be safe at home. It was drilled into me that I must evaluate the safety of anything I thought about doing.

By this time, I had been evaluated by a nurse from Independent Living, an agency which serves older people. It was planned that COP funding would pay for a home health aide in the morning and evening, and Meals on Wheels in the evening. COP funding requires that services be purchased from an agency, not an individual. While I chose to have evening meals rather than noon meals, I did not have much choice in whom the home health aides would be. The physical therapist had ordered a two-wheeled walker, which arrived the day before I went home.

One thing I was determined to have a choice in was when I would go to bed in the evening. I knew I would not want to go to bed as early as when the health aide would come to get me ready. I felt sure that with the hospital bed a system, much like I was using in rehab, a better time could be worked out. A friend offered to stay with me all night the first few nights and help work out a system. While this planning was going on, my family was making final preparations at home.

Going Home

My discharge date was a week short of my having been in rehab for three months. It was eight days before Christmas. I went home confident that I would be able to maintain a somewhat different level of independence, but I was ready to accept the help that was going to be available. My family had renovated the house to make it safer and more barrier-free. I found that I could navigate quite well in the wheelchair, and was well able to transfer. As I had expected, my friend and I came up with a bedtime routine that first night. It involved using the hospital bed with its grab bars, a commode near the bed, and my ability to pivot and transfer. It took two more nights before we both felt comfortable with the system, and I stayed alone.

The Health Aide who arrived the first morning was a young woman I liked immediately. She was efficient and respectful and eager to learn how I wanted things done. It was important to me that the aides understood that I was directing my own care. She fit the bill very well, but I understood that others would be coming at other times. Over time I evaluated each aide by the same criteria, and found I could adapt to different people without much difficulty. But I felt all along that I found my main caregiver that first morning. It was my first experience needing help with personal care like showering and dressing, and I felt I was adjusting quite well to having someone else do my personal care along with household tasks I had always enjoyed doing.

Meals on Wheels started the second night, and it was good to know that I did not have to be concerned about a main meal. I was well able to prepare my breakfast and lunch at the lowered table which had been installed in the kitchen. Everything I needed was there, and the pull-out cupboard shelves were stocked with food, dishes, and utensils that I could get to myself.

The fact that Christmas was so close really motivated me to try and do more things. In order to do at least some of my normal preparations for the holidays, I concentrated on what I could do from the chair, rather than brooding about the fact that I could not bake my holiday specialties.

My out-of-town daughter and her partner came for the holidays and stayed with me, so the entire family was together for our traditional Christmas Eve celebration. They saw to it that I got to church Christmas morning, and the three of us spent a lovely two days together. The holiday showed me that my family still expected that I would do as many of the things I always enjoyed as I felt I could do.

The early weeks of the New Year were a time of adjusting to new limitations, getting used to having someone come in twice a day to help with routines that I had always done myself, getting to know the people who were coming into my home, and just a general atmosphere of acceptance. I was faithfully doing the exercises I had been doing in physical therapy and practicing walking with the walker a couple times a day.
For the most part I was happy with Meals on Wheels in the evening, and liked the challenge of finding new ways to use the microwave. I began to feel really good about how I was getting around the house in the chair and doing as much as I could for myself. There were times that I would think of something that I really wanted to do and would have to remind myself that I couldn't just stand up and walk to do it.

Real New Year

My real new year began on January 9th, my 78th birthday. I kept my appointment with the CP specialist. It was the first time he had seen me since before I broke my hip. He surprised me by telling me that the disconnection of my right leg was not because of the CP but from the nerves in my spine being squeezed by the deterioration and arthritis in both my neck and lower back. At that time, he stated that an MRI would be the only way to know exactly what was causing it. He stated that if it were from the neck, surgery could be done, but there would only be a 30 percent chance of improvement. I told him, as I had before, that I would never have back or neck surgery. As he always does, he reminded me that I was lucky to have had the mobility I did as long as I did. We agreed to wait three months and see what happened, but I knew that I would consult my Chiropractor. I came away not sure of whether he had given me good news or bad news. Although it did make sense, it made me rethink about what I might expect.

I took the news to the Chiropractor, who surmised that it was the lower back, and he took X-rays, which confirmed that my tail bone was pushed back, and there was a gap which meant that nerve impulses were not getting to my legs properly. He thought that additional damage had been done in the fall. For two weeks, I had chiropractic adjustments three times a week, followed by two weeks of twice a week. At first he said not to try and walk, but as it felt better, I was able to walk more and swing the right leg forward. But walking came with back pain, which became more significant the more I walked. At one point, the pain was really severe, and I stopped trying to walk, although I continued to be able to stand and pivot to transfer. Another series of adjustments relieved the pain. However, I found that when I stood for any length of time, I felt it in my lower back. My realization that I was not going to be able to stand and walk as I had hoped prompted more reliance on the chair. Thankfully, the balance did improve. This allowed me to stand for a limited time and do things at the counter or the sink.

I realized in January that I had neglected any follow-up on my Parathyroid condition, and made an appointment with the Endocrinologist. The lab work indicated that the parathyroid glands which had been left in were not functioning correctly, and an appointment was made for a thyroid scan. When I had the scan four weeks later, I was able to hold still for 35 minutes. The next day I was notified by telephone that the scan confirmed that my remaining glands were not working. I was advised that I needed a Vitamin D supplement to be taken three days a week for a month, and then once a month after that, and that I was to go back to see the thyroid surgeon.

When I went back to see the surgeon, he wanted me to have two more scans, because they were still not sure if the remaining glands were functioning or not. I realized that he had no idea how hard it was for me to hold still for the scan. Because I felt so good physically, I was totally confused and very reluctant to go through more scans or any further surgery. I finally got that message to the surgeon himself, who agreed that I should continue taking the calcium and vitamin D and see what happens.

In the interim, I had seen the eye doctor, who confirmed that cataracts were still developing in both eyes, but it would be at least two years before he would recommend surgery. I was pleased when he stated that whenever such surgery was done, I would be put out, because he realized that I wouldn't be able to hold still.

As much as I have preached about the importance of people with CP taking care of their teeth, this too was neglected over these months. I'm now having to have some extensive dental work, as I'm determined to be able to eat with my own teeth.

Closing Thoughts

For me it is still important to me to be involved in my church and advocacy on the behalf of people with disabilities. That means going on with my work on the State DD Council and as a board member of an agency which makes it possible for people with disabilities to buy homes. To this end, while still in rehab, I changed my status with our Para-transit system to door to door service as a wheelchair user traveling on accessible buses. This was rather different for me since I had ridden one taxi company for forty years, but it meant that I could get away from the facility on my own. It continues to enable me to get where I need to go.

Even now, months after coming home, I find myself evaluating the safety of each thing I think about doing. Within the house I feel safe with the systems and the help we have put in place. This will allow me to stay in my house for now. There are places that I know well and where I know help will be available that I go without hesitation. I must admit, there are other places I've been too fearful to try going on my own, but I keep gradually moving forward. The most important things to me are that I can still think, communicate with other people, enjoy my family, and maybe help others with CP. You can be sure I will continue to cope with whatever changes are still ahead and share the adventure of aging with CP.