One Person’s Journey into Aging with Cerebral Palsy

A Collection of Writings

By Maureen Arcand
Maureen Arcand has lived over 80 years with the effects of Cerebral Palsy (CP). She started writing about her experience with aging with CP at age 65. This is a collection of what she has written and wishes to share with people with CP, their families, and caregivers.
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*Research and writing began at age 65*
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 on 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 breathe on their own. The focus seems to 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 lifelong 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 whether 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 than 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 caregivers 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 caregivers 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 MECHANISM 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 of 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.
Chapter 2: 
The Journey Begins Slowly (Age 45-65)

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 on 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.
Chapter 3:
The Journey Continues (Age 74-76)

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 overall 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 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 timetable 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.

To be continued……
Chapter 4:
A Bump in the Road (Age 77-78)

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.
Chapter 5:
Cruising Along (Age 78-79)

INTRODUCTION
As I begin writing another chapter in “My Journey into Aging with CP,” friends from the various
phases of my life are being invited to celebrate my eightieth birthday. The birthday has already
happened, but in Wisconsin you don’t plan big parties in the unpredictable weather of January,
so a spring date was chosen. The theme is “Progress and Legacy” and focuses on the changes I
have seen in the lives of people with disabilities and my role in some of those changes.
What makes it even better is that it will be a benefit for an agency whose board I have served on
for a number of years and which helps people with disabilities and their families buy homes.

Needless to say, as a person who has lived with Cerebral Palsy (CP) all my life, I never expected
to live this long. As many of you who have read my previous reports know, I believe I am still
here to share my experiences with others. It has been two years since the last chapter, “A Bump
in the Road,” showed up on the web site of the Wisconsin Council on Developmental
Disabilities. The Council, now known as the Board for People with Developmental Disabilities
(BPDD), continues to support my efforts to share information with people who can use it.

Over the last two years I have spent significant time trying to describe in more detail “how” I did
the things I’ve done. People ask questions like, “How did you have and raise six children?” or
“How did you get involved in advocacy and politics?” My answer has always been, “You do
what you have to do.” When I tried to answer the questions, I found I couldn’t do it in a way
that satisfied me. The temptation was to get way too detailed and more personal than I thought
people needed to know. Since turning eighty and reflecting on those years, I am determined to
share the changes in my life and disability over the last two years, while sharing in a general way
the coping skills which I have used over my lifetime.

CURRENT STATUS
The closing thoughts in the last chapter sum up where I was at that time. I wrote then, “It is still
important for me to be involved in my church and in advocacy on behalf of people with
disabilities. That means going on with my work on the State Developmental Disabilities Council
and as a board member of an agency which makes it possible for people with disabilities to buy
homes. The most important thing is that I can still think, communicate with other people, enjoy
my family, and maybe help others with CP. You can be sure that I will continue to cope with
whatever changes are still ahead and share the adventure of aging with CP.”

As I begin another report on my own experience of aging with CP, I realize that statement is still
true. One of the big questions at the time of the last report was, “Will I be able to stay in my
own home?” The answer to that is that I am still here in my home with the assistance that I need.
There have been changes, many of which are less obvious to other people than they are to me.
My coping skills have been tested over and over. I still have the ability to cope with the physical
changes. In fact, one of the delays in beginning to write again has been my desire to talk more
about my coping skills without going into great detail. I decided to go ahead and describe the
changes and then explain how I cope. Hopefully, writing it this way will allow people to better connect the changes that have occurred with my own coping systems and the application of the coping skills in the real life situations I have faced.

My current situation is that I am still using a manual wheelchair and just beginning to use a motorized chair, primarily outside. My manual chair still works best in the smaller spaces in my home. The accommodations that were made after I fractured my hip and began using a chair are still very effective. They include the walk-in shower, and a low table with a microwave oven. The table and microwave oven are still the primary accommodations in the kitchen where I prepare my own breakfast and lunch. I am still getting Meals on Wheels for my evening meal. Aides come in to assist me mornings and evenings. The routines which I have developed over the years still give me a satisfying degree of independence. The fact that I can stand, swivel, and move myself from the chair to the bed, to my recliner, and in the bathroom is very helpful, and is what allows me to be alone most of the day. As always, my children are close by and can respond very quickly if a special need arises.

As anyone who has read any of my previous writing knows, I believe that most of my internal organs are affected by CP. Bodily functions such as breathing, bowel and bladder control, and swallowing appear to change very slowly, but can have a major effect. In the last two years, there has been a significant change in the control I have over my tongue. Obviously, this affects my speech, but my major concern is having food go too quickly to the back of my mouth and being swallowed before it is properly chewed. This is especially troubling in taking pills. So far, I have been able to develop an ability to cough things back up before they move too far down my throat and cause choking, but it is something that I need to stay aware of on a daily basis.

In spite of taking Oxybutynin for spastic bladder for many years, I often do not empty my bladder completely. This has been a great concern because it has caused frequent bladder infections. The winter preceding my 80th birthday was one of recurring infections. Between my bladder and my sinuses, I was treating infections most of the time. Antibiotics would seem to take care of either one, but within a few weeks, one or the other would be back. It improved with the warming of the weather and a final lengthy antibiotic treatment. As another winter approached, I was determined to prevent another winter of infections. When advised that cranberry pills might strengthen the bladder, I began taking up to three pills a day. I am happy to report that I am emptying my bladder better and have had no infections this season. Likewise, I was given some preventive measures, primarily taking cranberry pills and drinking a lot of water for my sinus problem. The infections have not come back.

Even my earliest research confirmed that people with Cerebral Palsy would be diagnosed with irritable bowel. For about 15 years, I have had a prescription for Dicyclomine to be taken before each meal. By learning what foods are most irritating and avoiding those, I have been able to minimize irritating attacks, and believe me, they are to be avoided. However, every so often I get careless about eating spicy foods and green vegetables, or eating the same foods within a three-day period. The good thing is that for me, drinking warm Jell-O will usually soothe the irritation. Very seldom do I have to take medicine to end the irritation.
The amazing thing to me is that I am not experiencing a lot of the health problems associated with aging. A whole panel of blood tests done in the fall of my eightieth year showed no heart problems, no diabetes, and a better calcium level than I have had in the past. Since I have never had any symptoms that I could trace to my thyroid problems, I continue to refuse to have surgery or even do more thyroid scans, which are very difficult for me because I’m required to hold still for prolonged periods.

As usual, I have shifted my focus to my physical condition and how it affects my daily living. There is no doubt that my successful coping with these physical changes is the primary reason that I am still in my home and still participating in family and community life. Just as important is the fact that I have maintained my ability to think and solve problems. This is what enables me to carry on my responsibilities as a member of the BPDD, a board member of an agency that assists people with disabilities in buying homes, a County committee planning for the needs of people with disabilities in the case of an emergency requiring evacuation, and my Bishop’s Pastoral Council. All of these activities allow me to advocate for the needs of people with disabilities, which I believe is the reason I am still here.

**MOBILITY**

What does it mean when I say I am using a manual chair? For me, it means using my arms, shoulders and legs to physically propel it. While it is easier to push my chair backwards with my legs to push back, it probably isn’t as safe as going forward and seeing what is ahead of me. It is the loss of balance that makes it necessary to use the chair. The fact that my head continues to pull to the left has a significant impact on my balance. While I can stand to do things at a counter or table, I cannot stand for any length of time or walk without balancing myself against something. The balance problem has been the cause of three falls in the house. In all three instances, I stood and reached for something, throwing off my balance. All my life, except for the fall that broke my hip, I have made every effort to pick myself up. With these three falls, I maintained that habit and wasted a lot of time and energy trying to get myself up from the floor, instead of pushing a button to call for help. In each case, I eventually realized that I could not get up, and pushed the button, and informed the operator that I needed help. With the system that we have in place, designated members of my family are called and made aware of my needs. In all three instances, a family member arrived within a matter of minutes. The last time, when my daughter and two of my grandchildren arrived, I was lying on my back on the kitchen floor.

Upon leaving, after his mother had gotten me back in my chair, my grandson commented that I looked like a beetle on its back. Though I was embarrassed, I wasn’t hurt in any of the falls. It may be worth noting that in many years of falling, my body has always prevented my head from hitting the floor.

I’ve accepted the challenge of learning to use a motorized wheelchair. My desire to be able to go around my neighborhood and into the broader community on my own is what is motivating me to continue to practice so that I can feel safe. I use a joystick to control the chair. I expect to be propelling myself the three blocks it takes to get to the Little League field where two of my
grandchildren play ball.

One of my greatest satisfactions has always been my ability to cook and bake. My ability to stand is allowing me to do those two things in a limited way. For example, I can still bake plain bread by myself, but when I want to make the fancier coffeecakes, I need help. Because this kind of baking has become a tradition with my family, they are willing to provide that help, and I still have the satisfaction of knowing that I can create something. While most of my meal preparation is done in the microwave, I can still stand at the stove long enough to cook some of my favorite meals. This is a good example of my long-standing ability to problem solve and find other ways to get things accomplished. These days, to a larger degree, it means accepting help.

That willingness to accept more help is playing a role in everything I do. The last three years are the first time in my life that I have had to accept help with my personal care. My funding source requires that aides be provided by an agency. While I have no choice in who the aides are, I still have the ability to direct them when they are in my home. For the most part, they have seen the value in using my routines and systems for getting things done. With most of them, I have developed a working but personal relationship. Sometimes I surprise myself at my willingness to accept help when I am out in the community. I find that I am more comfortable when I am going somewhere where I know people will be helpful.

HOW TO PAY FOR THINGS
In my years as an advocate for people with disabilities in the State of Wisconsin, I was very involved in supporting the concept of people living in the community. There were many of us who advocated for a system that we call the Community Options Program (COP). It was designed to keep senior citizens and people with disabilities in their own community and homes. It took getting a Medicaid waiver, but the program has operated successfully for over a decade. This is the source of my funding and it pays for the aides, Meals on Wheels, and equipment. Over the years, it paid for an exterior ramp, bathroom accommodations, and more recently, it has paid for heating duct cleaning and furnace repair. The funding is very flexible and can contribute to almost anything that keeps people out of institutions. Currently, Wisconsin is experimenting with other ways of funding long-term care, so it is possible that the flexibility will not be maintained.

Five months later, as I read what I had written, it seems that I was cruising ahead a day at a time. While describing the ways I have been coping with changes in my abilities in the last few years, I was sharing more of the “how” of my life lived with CP. As in all my writing, I was hoping that my readers would find something to help them in their “Journey into Aging with CP”. Little did I know that there was a “Stop” sign just around the corner. What was around that corner and how I’m dealing with it will be the subject of the next chapter. See you around the corner!
Chapter 6:
A Stop Sign and Beyond (Age 79-81)

After two years of just cruising along, I rounded a corner and was stopped in my tracks. This time it was a broken ankle that provided a detour through rehab. This new chapter in my “Journey into Aging with CP” deals with what stopped me and what it took to get back on course. I’m looking back over six months during which my coping skills and faith were tested once again.

STOP
It happened on April Fools’ Day, a month before my scheduled 80th birthday party. I fell off the edge of my bed, but my memory of what took place is different from what must have actually happened. While taking a nap, I heard a knock at the door. I must have pulled myself up to the edge of the bed without elevating the head of my hospital bed. In doing so, I slid off the bed and landed on my butt with my right ankle twisted underneath me. In my half-asleep state, I thought I had moved from the bed to my wheelchair and then it collapsed. I know that isn’t what took place, but I can still see and feel it in my mind. Fortunately, my housemate was home and was able to get me from the floor into the chair.

The pain in my ankle was severe, but I was convinced that it wasn’t broken and I refused to go to the emergency room. My conviction was based on my previous four ankle fractures. Within minutes, my leg was elevated and on ice. For the next three days, I sat in the living room with my leg elevated. I was visited periodically by my family members who stopped by to ensure that I ate and got to the bathroom. By the third day, I was forced to admit that it was more than a bad sprain, so I arranged to be taken to immediate care. Two breaks were detected in my ankle, so I was transported to a hospital emergency room. Surgery was not deemed necessary, but I was admitted nonetheless because my ankle was too swollen to cast. After two very uncomfortable nights, I met with the hospital social worker to discuss placement in a rehab facility. She named three possible places and I gave her my preference. The next morning, doctors were advising me to stay for two additional days, but the social worker already made arrangements for me to go to the facility of my choice. A light-weight cast was speedily put on my ankle and I was off to rehab.

STARTING AGAIN
I knew almost immediately that I made a good decision. I was impressed with the attitude of staff, the cleanliness of the facility, and the expertise of the therapy staff. Following the evaluation of my needs, I began physical therapy (PT) and occupational therapy (OT). Each person who received therapy had a specific therapist assigned to them. Even though many of us were in the therapy room at the same time, I always had a sense that I had the undivided attention of my therapist. This was a welcomed change from the facility I was in after I broke my hip.
In the years of reporting on my journey, I have never really talked about the importance of my Catholic faith, but it was such an important part of the next two months, that I feel compelled to share it. During the first week of rehab, I discovered the Catholic television channel. It made me think a lot more about how important my faith has been throughout my life. I have always been influenced by the fact that I am survivor, even though I had been expected to die the day I was born. It seemed to me that I had been spared for a purpose, and at this point I had become quite satisfied that I was still living out that purpose, part of which was the sharing of information on aging and cerebral palsy (CP). What I heard on the Catholic television channel made me ponder how well I had actually fulfilled that purpose.

My days in rehab were busy. Each day I had both PT and OT twice a day, I ate three excellent meals, and I did whatever else I could to take care of myself. During the first two weeks, the PT was aimed at strengthening both of my legs and the goal of my OT was to strengthen my arms and upper body. There were regular routines in PT, but in OT I was able to select activities that would improve the coordination in my hands and relieve some of the tension in my shoulders and neck.

AN ADDED PROBLEM
Even before I broke my ankle, I had been aware that I was coughing more and more. While in rehab, I began to realize that the cough was getting worse and I was not feeling very well. I had to come to terms with the fact that there was something wrong with my respiratory system and eventually one morning I was too sick to go to therapy. When my daughters came in that morning, they, too, realized that there was something seriously wrong. Hospital staff were alerted to my condition and they suggested that I could go to the emergency room (ER). I declined the trip to the ER but requested oxygen, hoping it would make breathing easier. While the oxygen did improve my breathing, it was suspected that I had pneumonia. In this case, I was actually hoping it was pneumonia, because we would know what to do about that.

Well, it wasn’t pneumonia and I was having more and more difficulty swallowing. A speech therapist evaluated my swallowing problem and recommended that I eat pureed food and that my pills be crushed into pudding. Even though I knew this would help, I really didn’t like it. Rather than embarrass myself by coughing in the dining room, I stayed in my room to eat my meals. The appointment with my doctor was only days away, so I decided to not make any additional changes until then. I continued with therapy and it was often interrupted by my harsh coughing, which became somewhat of a joke.

When I finally met with my doctor, it didn’t take long for him to diagnose severe bronchitis, prescribe antibiotics, and suggest the use of a nebulizer at least three times a day to help break up the congestion. For a person with cerebral palsy, coughing really doesn’t bring anything up. While using the nebulizer up to six times in a twenty-four hour period did make me more comfortable, it took two weeks before the treatment loosened the congestion enough for me to cough anything up.
MORE AFFECTS OF CP
My doctor was concerned about the sinus drainage that I had been experiencing, so I met with a specialist who put a camera down my throat to capture images of my vocal cords. For years I had periods of hoarseness which affected the quality of my speech and I had long harbored fears that my vocal cords were damaged. This was a chance to find out for sure, but the images showed no damage and I felt relieved.

As I have reported before, my drooling had become more excessive as I aged. I never thought I would see the day when I would be unhappy because I couldn’t drool, but it happened and it wasn’t very pleasant. Various medications dried out my mouth and throat to the point that I really had no saliva. I began taking a gel-like substance before eating to stimulate the creation of saliva. It seemed so ironic that we think that drooling is such a nuisance, but I was happy when I could drool again. It took about a week before I was back on regular food, but it took longer than that for the saliva to come back and for me to be able to swallow my pills again. It was really the first sign that I was getting better, and through it all, I was able to continue my therapy.

I met with a speech therapist and the option of speech therapy and its potential benefits generated a lot of discussion. As I described in the past, my speech had become increasingly hard work as I got older. After analyzing my speech, the therapist attributed my difficulty with speech to a loss of muscle control in my tongue and lips, and also to my breathing problems. The good news regarding my vocal cords led the therapist to think we could do something about my voice quality. She felt that certain exercises could strengthen the control of my tongue and my ability to project my voice. I felt it was certainly worth a try, so we began working together three days a week. I began doing the exercises immediately and my therapist was delighted with how hard I would work. The fear of not being able to speak at my birthday party – which was fast approaching – proved to be a fantastic motivator.

Looking back now, my birthday party seems like a miracle. I was still on oxygen when the big night came. Almost 200 people that I’ve gotten to know throughout the years attended my 80th birthday celebration. Some of the people who attended were friends and colleagues whom I hadn’t seen for years, and to my surprise, they stood in line to talk to me. I’m still amazed that I was not just able to talk to them individually, but also able to speak to the entire crowd during the presentation of a Lifetime Achievement Award. It was even more memorable because I had been so sick.

MOVING AHEAD
Now one month after my fall and almost done with the antibiotics for my Bronchitis, I was still using the nebulizer. I still had to cough very hard to produce any mucus. Once I was back to eating regular food in the dining room, I made social connections with some of the other residents. I was still having trouble swallowing pills, even though I could take them by myself. My ankle had already been recast once and I was able to do leg exercises while standing up.

I had been watching the Catholic TV channel all the time I had been there, and I was questioning
how well I had achieved what I thought was my purpose in life. I was questioning some specific circumstances in which I might not have done the right thing and I felt the urge to talk with someone who shared my faith. Each Sunday that I was been in rehab, Communion had been brought to me. When it was delivered by a fellow parishioner whom I knew, we talked at length and discovered that we had a lot in common and even shared many of the same concerns about our pasts. Our discussion was tremendously helpful to me and it concluded with her commenting that she was looking for an inexpensive place to live. Well, as luck would have it, I was looking for someone to live with me. It seemed to both of us that it was meant to be, and I began talking to my family about the possibility of sharing my home with this person.

LOOKING TOWARD HOME
My children made it clear that they didn’t want me to go home unless there would be someone in the house with me, especially at night. Hearing about my prospective housemate eased their minds, and one of my daughters spoke with my friend and showed her the house. Everyone was confident it would work, so my family helped to prepare my home for my new housemate, who moved in shortly thereafter.

Therapy staff convened a care conference, which included everybody involved in my situation - one of my daughters, my case manager, therapy and nursing staff, my housemate, and me. At the conference, therapy and nursing staff informed me that I would be able to return home within a month. My case manager reported that the agency providing my home aides would be changing, and within days a nurse visited me to evaluate my needs at home. My occupational therapist and I went to my house to review the accommodations I already had in place, and she confirmed that I would be able to manage in the house. Her only suggestion was to change the way I would get in the shower.

While my PT and OT continued, and plans were being made for my return home, I had really gotten into the speech therapy. With the possibility of improved speech as a motivator, I was determined to work as hard as I could. The therapist identified three primary problem areas: my breathing, my lack of tongue control, and the way I forced words from the back of my throat. To address these problem areas, she developed a therapy routine which consisted of breathing, lip, and tongue exercises. I began doing these exercises first thing every morning and I also worked with the therapist three times a week. My word formation improved almost immediately, and this inspired me to work even harder.

As the coughing decreased and my conditions improved, I was able to pay more attention to the people around me and the activities that were available for residents. I ate most of my meals with various groups of women and they made me feel especially comfortable. And, the better I felt, the more helpful I could be to other residents. Something else that provided comfort to me throughout my stay was Mass, which was celebrated every Tuesday morning. I scheduled my therapies around Mass and toward the end of my stay, I even began going to my own church on Sunday mornings. To attend Mass and my medical appointments, I utilized the local para-transit system. This resource has helped me get where I’ve needed to go for years. My health continued to improve and the better I got, the less my children visited. When someone noticed that my
children’s visits were less frequent, I explained that they are always there when I really need them.

The PT routines were just that – routines. Each day started with leg exercises, which included sitting in the wheelchair and then moving to the mat where the therapist was more involved in moving my legs. Finally, the last part of the routine had me standing at a bar and doing exercises that focused on balance. From the beginning, I was concerned about the ability of my legs to work together. After I broke my hip, it took a tremendous amount of work to get my legs to move together, step by step. Lo and behold, my fear was unjustified and the first time I got between parallel bars I was able to step forward using both legs! It was a huge relief and I began practicing with a walker. What was most surprising was that I was able to stand and pivot even better than before.

My OT activities primarily targeted my upper body. I chose what I wanted to work on and my decisions were based on whether the exercise was doing good or causing harm. For example, I had to stop performing a pulley exercise that was designed to strengthen my shoulders and upper arms because it was putting too much pressure on my arthritic neck and shoulders. It was important to me to work on hand coordination, so the therapist would put small objects into Play-Doh and I would search for them and work them out with my fingers. We eventually decided that it would be a good idea for me to be able to stand and do things with my hands at the same time. As I stood at a table, I kept my balance while performing exercises with peg boards and other games. My plan was to use my motorized chair more than I had previously, so my occupational therapist watched me operate the chair and evaluated my ability to control it. She was pleased – and even a little surprised – at how well I did.

It was time to see the orthopedist again and he was very encouraged with how well my ankle had healed. Even though his written instructions didn’t reflect what he told me – he said I could put more weight on my ankle – we went ahead anyway and I continued to progress rather quickly. There was a general consensus that I would be able to leave the facility well ahead of my next scheduled appointment with the doctor. The therapist felt so strongly that I would be ready to leave within two weeks that she scheduled an earlier appointment for me. At the appointment the cast was removed and the doctor said that I could leave whenever the therapist deemed it appropriate.

That same day I had an appointment with my cerebral palsy specialist. We were both very concerned about the positioning of my head. The entire time I was in rehab my head was pulling to the left. This by itself was nothing new, but now my head was really pulling toward my shoulder. Understanding that this comes with arthritis and the deterioration in my neck, the doctor recommended additional PT for my neck and shoulders.

I proudly told him about the success of my speech therapy and he commented that he could hear a difference, especially in my voice quality. I also notified him of the fact that I had been given permission by the orthopedist to return home as soon as my physical therapist thought it was appropriate. I explained that I thought my situation at home would be better with a new
housemate. We had our usual conversation about how my abilities were changing and how I
would cope and I left his office with written recommendations for additional PT and speech
therapy.

The next morning, both of the therapists involved were happy to see my doctor’s
recommendations and they began the process to get approval from Medical Assistance. We
discontinued the OT but I had PT and speech therapy all the way up to the day before I went
home. My discharge was tentatively scheduled to take place in less than two weeks and I was
feeling better physically and I was quite confident about going home. I had already been home
one Saturday to help sort out my belongings and prepare the house to have all the carpets
cleaned. My new housemate had already moved in and was enjoying living there. Staff and
residents were happy for me, but the people I had gotten to know at the rehab facility told me
they would miss me. My daughter began taking my belongings home and, when my discharge
day came, I said my “goodbyes” and returned home.

AT HOME
When I arrived home, I was pleased to find my new housemate and a very clean carpet. What I
wasn’t thrilled with was the fact that some of my things did not get put back in their proper place
after the carpet cleaning. It was somewhat frustrating to have to search for my things. It took me
nearly a month to get reorganized and to arrange things so I could get to them. As the days
passed, my housemate and I found that we had even more in common, and this included similar
ways of doing things and a belief in having systems to get tasks accomplished.

Once home, I established a relationship with the new agency that was to provide my personal
care. Soon people were coming to my home to provide services. I gave each of them a crash
course in Cerebral Palsy and told them how I like to have things done. Most of them understood
that I knew what was best for me. The only outside help I really need is an hour in the morning
and an hour in the evening. During this time, the personal care workers help me get dressed,
shower, administer eye drops, and they also do some very light housekeeping. For the most part,
I was happy with the personal care workers and some of them are still with me, except for one
person that I had trouble communicating with. I did not hesitate to suggest that the agency not
send her back.

While I was in the house I used my manual chair a lot and my motorized chair wasn’t getting
much use. My housemate was my primary source of motivation to get outside and use the
motorized chair. She would accompany me outside and she paid close attention to how I used the
joystick. We found ourselves evaluating curb cuts in the neighborhood and on a few occasions
we really had to work hard to get me out of a tight situation. As I became more proficient with
the chair, we began to make trips downtown where I could practice navigating amidst groups of
people. When I began to get to places where I really wanted to go, I became more and more
brave. Now I go around the neighborhood with ease.

When I started traveling around in the motorized chair by myself, one of the first places I went
was back to the rehab center for outpatient PT and speech therapy. The PT was for my neck and
shoulders and the primary concern was how much my head was pulling to the left. A combination of ultrasound and massage were used to relax the muscles in my shoulders and neck. As the muscles relaxed, I was able to gain some control of my neck and head; however, this is something I still have to cope with every day. That means wearing a foam collar at least part of the day and always when I ride in a vehicle. When I got to a point where it was obvious that no further improvement could be made, PT was discontinued.

The speech therapy was a different ball game because my improvement was continuous. The diagnosis the therapist made while I was in rehab was correct and we continued to do the breathing and tongue control exercises, adding to them as we went along. Because speaking was not as difficult as it had been in the last few years, I was, and am, really motivated to continue the exercises every day. I asked people if they could hear any difference and, for the most part, they mentioned the improvement in my voice quality. For years I had been forcing the sounds from the back of my mouth and throat, so I worked hard to project the sound from the front of my mouth. I had always had problems making sounds that required moving my tongue up to the back of my upper teeth. The therapist gave me exercises specifically designed to gain additional control of my tongue and lips, and we were happy with every bit of progress I made. I always say none of my kids have names that begin with the letter L because it was always the hardest sound for me to make. Now I am able to get my tongue up to the back of my teeth to make any necessary sounds. Initially, I went back to therapy twice a week, then once a week, and for the final two sessions I went every-other week. At that point, we both felt that my speech improvement had probably reached its pinnacle and that I had the tools required to do the exercises at home to maintain this new level of speech quality. Now, five months later, these breathing and tongue and lip exercises are a daily priority for me because it is so good to not have to work at getting words out.

Earlier I mentioned that while in rehab I discovered a spiritual component when I found a Catholic TV channel. While my faith had always been very important, I started asking myself new questions. I started discussing these questions with my housemate and it was natural for the two of us to continue on this spiritual journey together. This journey has changed my prayer life, as well as my TV viewing. We spend a lot of time watching and talking about the programs available on EWTN. I have given up other TV shows – soap operas and cop shows – and I am ready to get involved in the pro-life movement to raise awareness about the abortion of children suspected of having disabilities. I am not sure how involved I will be in this issue but I do think that the problem deserves more attention.

After five months at home, I have established routines and made decisions about how to use the limited energy I have. I have been able to assume my responsibilities as an officer of the State Developmental Disabilities Council and as a Board member for the agency that benefitted from my birthday party. As always, I am involved with family activities and I rely on them as needs arise.

The most significant change in my abilities is numbness in my right hand. For many years I have had some numbness but not enough to really affect the use of my hand. Now there are times
when my entire hand is numb and other times when it is only the thumb and forefinger. This makes getting pills into my mouth very difficult. To further complicate matters, my tongue often humps up and throws the pill to the front of my mouth. I am experimenting with chewable pills and I have also found that I can place small pills closer to my throat. I accomplish this by wetting my finger, sticking the pill to my finger and pushing it back to where it can be swallowed. The CP Specialist is not sure if the numbness is due to the pressure on the nerve in my neck and/or Carpal Tunnel in my wrist. Even though I will not put myself through surgery, testing will be done to determine what is causing the numbness. It is interesting to watch how much my left hand tries to compensate for my right hand. I experienced a similar phenomenon when I injured my rotator cuff and gained strength in the other arm and shoulder.

There is a significant change to report that is not CP related – for a number of years, there has been a cataract growing in my right eye. In the last two months, reading has become very difficult and cataract surgery was the only solution. Rather than just give me a sedative, the doctors decided to put me to sleep for fear that if they didn’t I might involuntarily move my head during the surgery. This was a wise decision and I appreciated their acknowledgment of the effects of my CP.

This seems like a good place to end this chapter of my journey. I am very curious about what lies ahead and how much time I may still have. Will I lose ability more quickly or will it continue to be a gradual process? At age 81, can I expect to maintain my good physical health and further improve my spiritual life? I know one thing – I will want to continue to share information on aging with CP. For twenty years I have felt that my purpose for being here is to share my experiences with other people with CP. I hope that my efforts have helped you enough that you will continue to watch for my reporting.