Perseverance
Living with Cerebral Palsy

Change Your Life in 30 Days

Do You Have Any of These 3 Social Troubles?

Defying Challenges Interview Series

Iss. 1, Vol. 1 Sep. 2013
Letter from the Editor

In this issue you will find a delightful mix of stories that will intrigue, inspire and inform you about the lives of individuals with disabilities, specifically those with Cerebral Palsy. I am here to let you know that you are not alone. We can face the challenges of life together. I hope you enjoy my very first issue of Perseverance magazine.

Sincerely,
Jennifer

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Features

Health

Change Your Life in 30 Days  pg. 4

Your Story

Interview Series: Top 5 Challenges  pg. 14
“Change My Life in 1 Minute”

http://www.worldcpday.org/
Imagine a day where you wake up smiling and have a productive, yet relaxing day. When you learn to effectively cope with your anxiety and stress level, you can have days like this.

Today, right here, right now, I want you to make a commitment to yourself. Choose happiness. I know it’s hard and seems easier said than done. Yet it’s one of the best ways to deal with stress and anxiety. I want you to know that all it takes is small steps to a life with less worry and more laughter; more time to be productive and less time distracted.

Especially with the unique situations we face as people with Cerebral Palsy, overcoming stress and anxiety in our lives can seem like it would be easier to dismiss our feelings than seek help to face them.

We are going to choose happiness and find balance in our lives.
I am going to share with you some techniques of coping with stress and anxiety, which should be worked as creating a positive habit for the next thirty days. Try them out. Take one or two and give them time to make a difference in your day-to-day life as they become habit. Give yourself permission to accept your state of mind and stage in life. And then understand that many things in life that are a source of stress can be changed or avoided.

Some of the most common sources of stress are work/school, your health (physically, emotionally and mentally), your relationships, managing your financial budget, and changes in life like moving to a new town. I know that for many people, trying to find balance in your life for all the roles we play is the biggest source of stress. You may be married with a baby on the way but you were just let go from your job. You may be working full-time while going to school and just started a new relationship. You may have to deal with bullies in the cafeteria or in the office. Whatever your particular situation is, there are many ways to help cope with the stress and anxiety associated with handling them.

So, we have a goal in mind. We are going to choose happiness and find balance in our lives. How do we go about doing that?
The first step in finding a solution is to find the problem. Figure out what are the biggest sources of stress in your life and decide which one affects you the most. If you were able to alter the situation, which one would bring the most happiness? For many, their biggest source of stress is mismanaging their health.

The second step is to figure out how you are currently dealing with the source of stress. If you are not taking care of your health, it will damage how well you work in other areas of your life. Did you do your stretching exercises today? Did you remember to take your medicine? Did you look at yourself in the mirror and smile or did you put yourself down? When you are dealing with stress, we often turn to unhealthy coping mechanisms, such as overeating, alcohol abuse, very little sleep, and a feeling of pushing ourselves beyond our capabilities.

The trick is to remember that the goal of relaxation and peace is finding balance. Balance begins with a strong sense of having priorities aligned and in time management. For example, if we make our health our top priority, and plan time throughout the day to address our needs, then the effects of stress in events will have a lesser impact on our reactions and our well-being.

How do you make a conscious effort to reduce stress by improving your health? Make a list of small goals and activities. Divide your list into three categories: physical, emotional, and mental. Evaluate which areas you want to work on first and plan small, manageable stepping stones to get you there. When I completed this exercise in preparation for writing this article, I found that my emotional health needed the most work because my stress was harming my self-image.

Your list is going to be as unique and beautiful as you are, and it will help keep things in perspective. Just remember that any positive change towards happiness is going to reduce stress, so stay confident as you begin the journey to a more balanced life.

Time for Fun: Set aside at least an hour a day to do nothing. It’s your “me” time and nothing is allowed to interrupt it!

Day 17

Journaling helps my mind let go of troubles
Here is my list as an example:

**Physical Health**
*Exercise:* Do my stretching exercises when I wake up and before I go to bed to help alleviate the muscle tension in my legs.
*Nutrition:* Skip the fast food and pack lunch instead!
*Sleep:* Go to sleep half an hour earlier than I usually do to give my mind and body a chance to relax and have restful sleep.

**Emotional Health**
*Relationships*
  *Significant Other:* Take time to enjoy each other’s company, and not burden them with everyday stresses so they can relax too. Share how much you love him in little ways.
  *Friends:* Text, Facebook, Call them! Keep in touch so you don’t lose them to time and distance
  *Family:* Your family is your rock when things get rough. Make time to hang out and catch up.
*Self-Image:* Practice positive self-talk and smile!
Keep a journal to reflect on life changes.

**Mental Health**
*Sleep:* Don’t worry about the to-do list, just listen to some meditation music and dream away!
*Time for Fun:* Set aside at least an hour a day to do nothing. It’s your “me” time and nothing is allowed to interrupt it! Listen to music. Take a bath. Chill out!
*Reduce Schedule:* Prioritize and organize. Say no to events and activities that do not justify the energy spent on them.
Why Coping with Mobility Challenges Makes You Braver
Walking braces (commonly called DAFO’s), shoe brace inserts, wheelchairs, crutches, adaptive driving, the list goes on. Some of the most challenging aspects of having CP deals with the range of our mobility. I have a form of cerebral palsy that allows me to be able to walk, and drive a car. The kind of CP I have affects the right side of my body and causes extreme tension in my calf muscle and Achilles tendon, which makes me walk on my toes, mostly on my right foot, sometimes both feet, depending on my level of stress and fatigue.

“Walking on your toes” is also called “Excessive Plantarflexion” according to dafo.com. When I was a child I wore two types of walking braces, one that was a shoe insert, and another that stabilized my lower leg to try to get me to walk “heel-toe” instead of just on the ball of my foot.

Just because it is a feeling of “hey, I’m not alone in the world,” I am always intrigued when I meet someone with CP or a similar disability.
One of my friends in elementary school, Kyle, had the same disabilities as me (A VP shunt and CP) except that his CP was much more severe. He mostly used a wheelchair, but sometimes he was able to use brace crutches to walk. He was one of the nicest people I knew and was always joking and laughing with his friends. He had a really difficult time managing the symptoms of his condition, and his body kept rejecting the help the doctors would give him, like a more modern shunt and shots to help relax his muscles. I’ve had two shunt revisions (which is major surgery) and he had 22 revisions by the time he graduated high school.

Unfortunately, he passed away over the summer after he graduated, and I will always miss him, and wonder what life would be like for him if medical technology was better equipped to help him and others make the best of the short lives we have. One thing that showed his strength of character is that despite his severe cerebral palsy, he was a strong student and had a good social life. He went to Homecoming and Prom with his girlfriend, and hung out with his friends just like any kid his age.

I’ve met one other person with CP and her situation is more mild like mine. She is a few years older than me, and was a co-worker at my internship a few years ago. Ashby went to college, is able to drive and lead a normal social life. My social skills need a lot of work but she helped me learn how to talk to people about our situation without it being awkward. She is quick to smile and make you laugh and help when needed. We are just people that need love, respect and understanding like anyone else.

One thing I learned from her relating to mobility issues is adaptive driving. She uses a hand brake in her car instead of a foot brake. Because of the way her arms and legs are postured from the muscle tension, using a hand brake is easier for her to grasp and manipulate. It helps her concentration while driving and reduces anxiety because instead of worrying about her foot slipping to switch over to the brake, she can use her foot for the gas and her hand for the brake. She challenged herself to get her driver’s license when she was still a teenager. I think she is brave for doing that because I had anxiety attacks every time I tried to drive, and didn’t get my license until age 25.

There are many ways to cope with mobility challenges, with the help and support of assistance devices and the support of family and friends.

Sources:
http://www.dafo.com/patient-groups/excessive-plantarflexion/
http://lifeofthedifferentlyabled.com/2013/shoes-does-anyone-else-struggle/#comment-73506
http://www.richard-driving.co.uk/Pages/MobilityTraining.aspx
Do You Have Any of These Social Troubles?

I contacted Katy Fetters, the founder of Teen Cerebral Palsy Blog, and she gave me some comments on the challenges she faces with CP and how she stays positive.

Note from the Editor:
Katy Fetters is one of those people that even when you don’t know her in person, just by what you read, she inspires you to better yourself. I contacted her to comment on how her blog has impacted her and others with CP. Reaching out to others for support is a huge deal, especially in a community like ours. This is her reply:
“Hi Jennifer,

Thanks for contacting me. I’m glad you found my blog helpful for your research, and I think it’s great what you are doing! I actually filmed a small interview for TGIS TV show last winter and you may find it helpful to you as a resource. I talk about having my blog; about CP in general. 1) I will add though that a big struggle for me personally (I think this could be CP related) is just having CONFIDENCE!

2) I often feel shy because of the way I walk and I try not to make myself feel awkward in certain social/dating situations. I try not to discourage myself, but I have a hard time letting go of the fact that I can never really hide from my CP, so I am still learning to accept it for what it is day by day. I kind of touch on that on the show.

3) Also, just the physical challenges that it presents makes CP stressful. I wish I could be a runner but its too hard on my legs and I have to wear a brace on my leg to loosen my leg muscles. My family is so active so its always been hard to keep up.

Here is a link to the piece: www.vimeo.com/connection3/llwkatyfetters
If you also want to see more, my roommate and I have made a few videos too--you can see them here: http://www.teencerebralpalsy.com/teencp-video-blogs/
Let me know what you think! Thank you for reaching out to me and doing what you do to spread CP awareness!”

Katy
Story 1: Fred

Interview Series:
What are the Top Five Challenges You Face in Life?

Your Battle Against

Discrimination
The top five challenges....let me just say that my biggest challenge was to be independent. That was the most important to me and there were many road blocks placed by myself and from many I interacted with through out my life.

“You are the captain of your soul.”

1. Family. Although my family was supportive, it was some what of a struggle for them to understand I wanted a life as other able-bodied people experienced, most took this for granted. Being protective was a knee-jerk reaction and justified in some cases but it can become a barrier also.

2. Discrimination....by far that is the most formidable barrier. The “D” word can take many forms and I did not know how it affected me and how others viewed me till I was about 37 years old, yes incredible. I could right a book about it, but the greatest antidote to it is yourself. People with CP have a god given inner determination that is beautiful. The thing to do is challenge yourself daily to overcome all the things people say are not possible and prove them wrong. This is what makes life worth living.

3. Never turn away from your family, no matter what obstacles present themselves. Always try to love and communicate that from your soul. I think CP enables that anyway, it tends to be a two way street. Many people will communicate this later in life to you.

4. Be mindful that you are different and can be used and taken advantage of. This just comes with the territory.

5. Be good to yourself, life is short. Find a way to exercise. I used a stationary bike and rowing machine, very good for self esteem.

6. Good friends are like gold.

I am a mirror twin and both my brother and I have CP. We both are 60 years old and have led productive lives working for 30 years and self employed for ten of those years, running a small business, with sales of 5 million and many satisfied customers.

You can live your dreams, just remember you are the captain of your soul. Good luck and a good long life with the good sense to live it.

Sincerely,
Fred

I hear “You were my hero” many times from long time friends. What god takes away he gives in other ways. Be strong, be an oak, but be compassionate and loving always.
Story 2: Ashby

Look Within: Secrets to Challenging Your Comfort Zone

How learning the value of self-esteem and friendship can give you courage to live your life.
“My attitude about my disability had to change if I was going to make it in this world.”
Life with a disability has been an interesting journey! Tough at times and still tough even as an adult...but rich. Would I trade it if I could? I’m not sure, but I do know that I have an empathy and insight that is deeply developed and directly related to my experiences.

For the majority of my life, I have been in hiding. In elementary school I wasn’t teased too much, I always had a small handful of friends, and lost myself in books. I had an uncanny ability to live in my own little world. I felt different, but I shoved those feelings aside and didn’t want to confront difference, even as a child.

It wasn’t until late high school/early college that I faced the fact I even had C.P. If people made fun of me, I was oblivious to it. I didn’t want to see it. It would have broken me then. Whether it be that I was ashamed, in denial... one thing I know--I was morbidly afraid of being different, stigmatized or pegged as a person with a disability--so I just hid it away the best I could. It was unimaginably hard. It was like a huge secret that was blatantly obvious to everyone around me...one that I wish could have just gone away.

When I was getting ready to head to college I had a melt down. I had MANY MANY friends and one day I went WAY out of my comfort zone ask one of them (whose sister had a disability) why no one wondered about me? I asked if my friends saw it and if it bothered them deep down.
Did they feel awkward about it and just didn’t say anything? She responded that they just realized that it was something I didn’t talk about so they didn’t talk about it either. Everyone adopted that stance early on in their friendships with me. The next thing my friend said stuck with me....”You don’t have a hidden disability Ash, it must be crazy hard to live as if you do.” Her statement, to this day, had profoundly impacted me.

As I went off to college life got more complicated and mobility got tougher as I aged. No longer could I manage a step between levels alone and hikes and woods were next to impossible without an arm. Can you imagine how difficult this is when you are terrified to ask for help?

“...they would not abandon me if I shared my CP with them.”
I harbored a mixture of anger, fear, pride and ‘what if’s’ in my every day. It was very difficult emotionally.

Some time in latter college I realized that I couldn’t hide behind my parents (who were wonderful and supportive always!) anymore and that I was my only advocate. My attitude about my disability had to change if I was going to make it in this world. I realized very gradually, that people loved me for me and they would not abandon me if I shared my CP with them.

In fact, me being open with them helped them to relax and it was always in my best interest to be forthright. Interestingly, if I brought it up, my friends open up and ask more questions. The more comfortable I was, the more comfortable they were. This discovery was a TREMENDOUS relief to me. In fact, I realized it really wasn’t fair of me to make assumptions about how they would react--I had zero faith!

Today I am 34. I am much more accepting and patient with myself. I share about my CP a bit more

“This gives me an anchor and perspective in times of struggle. It is because of this hope, that I press on!”
willingly, especially since I have had to lean on people a little bit more (literally). I am learning to trust. I still hate when people stare at me because I walk differently, I cannot stand feeling marginalized and am a bit sensitive to condescension. I think I have a ways to go before accepting myself the way I need to, but I am well on my way.

Professionally, I am a former special education teacher who is currently in seminary for counseling. In addition to my friends and family helping me in this process, my faith in God has propelled me forward, Believing that I am loved unconditionally in spite of my imperfections gives me tremendous purpose and a hope in my future. I firmly believe that I live in a plan that is unfolding that is richer than one I could draw up on my own! My disability is being used in some greater way.

This gives me an anchor and perspective in times of struggle. It is because of this hope, that I press on!
Story 3: Lauren

Proven Methods to Get Your Confidence Back

Dealing with Cerebral Palsy as a teenager
“It’s hard to make new friends and other relationships when people are afraid to talk to you.”

The top 5 challenges I think we face are acceptance from others, acceptance from ourselves, coming to terms with the fact that there will probably be something we can’t do that others can, not focusing on the negatives and building relationships.

Anybody who is different in the eyes of others will have a hard feeling accepted from others which, in turn, leads to them thinking they aren’t good enough. Sometimes because of my CP I get stuck in my negative thoughts and I only think about what I can’t do versus all the good things my life has to offer. I cope with my daily challenges through talking with my family.

I don’t know what I would do without them because they are a great support system and its hard to make new friends and other relationships when people are afraid to talk to you. I’m completely open about anything anyone wants to talk to me about and I wish people could see past the wheelchair. But also I think sometimes people with disabilities become shy and don’t try new things and don’t try to talk to new people so, in my case, it’s just as much my fault that I have difficulties making new relationships as it is others who simply are afraid to talk to me.

And also, being a teenage girl, there is a lot of crying involved to get through the rough times. I try not to keep my emotions bottled up anymore because when I do I get very angry towards anyone just trying to be nice and help.

I’ve started coping with stress by exercising. I feel great afterwards and it helps me burn off some steam. Also, yet again, I talk to my family and sometimes my friends to get it out of my system.

One of my biggest fears is ending up alone. I’m afraid that I will push away anyone who tries to show any love or emotion towards me because it makes me nervous and uncomfortable. I feel like no one will like me because of my CP. I’m trying really hard to get past that because if I feel that way, why should I expect anyone else to think differently?

My joys are spending time with friends and family. I love crafting and crocheting. I also love reading. I have also come to enjoy exercising. I used to go to therapy all the time and they would only tell me what I was doing wrong so it feels great to just be able to exercise the way I do. Not everyone is the same so who knows the right way of anything.

What inspires me? People who push the boundaries and do the unexpected inspire me. I know they had a lot of struggles to get where they are and I struggle everyday with everyday tasks so I believe I can do the unexpected as well.
How do you cope with the challenges of Cerebral Palsy?

I think the top 5 challenges people with CP face are:

1. Physical limitations caused by CP- not being able to physically run, jump, climb stairs, do the things you want to do, etc.

2. Societal/attitudinal barriers- many times, society views people with disabilities as being less capable than those who are “normal.” They may pity or baby people with CP, creating lower expectations for them and preconceived notions of what they can and cannot do. This undermines the person with CP’s sense of self-worth and can lead to learned helplessness. Overall, it devalues people with CP by treating them as lesser human beings.

3. Inaccessible buildings/environments- stairs without railings, no elevators, etc. This is how society disables people.

4. Pain- not everyone with CP deals with this one, but for those who do, it can significantly impact quality of life and a person’s activities.

5. Social stigma/trying to fit in- this one relates a lot to #2, but especially for those of us on the mild side, there’s kind of this gap between the “normal” world and the “disabled” one, and we kind of fall through the cracks. There’s always this feeling of being different from everyone else, of having people stare, and sometimes wanting to just be “normal,” to try and hide your CP (if possible) and just fit in, to be able to keep up with friends and do whatever they’re doing.

I would say that I cope with these challenges by trying to make the most of my physical abilities (stretching, PT, going to the gym), and also by trying to self-advocate and have confidence in myself whatever I do. Sometimes I feel like I have to try twice as hard as the average person just to combat stereotypes, to prove to the world that people with CP are just as capable as everyone else, even though I might limp or hold my hand a little bit funny, but I guess that’s life.
I look at everything I’ve accomplished in the past, even when others have said I couldn’t do things, and that gives me hope for the future. I have an internal motivation to prove others wrong, I guess, and to prove to myself what I can do.

**How do you cope with stress?**

The same way anyone else does, I guess. Except for me, when I’m stressed, my spasticity tends to increase, so then I trip more and have a harder time doing things, and then I just get more stressed and the whole thing turns into a vicious cycle. Usually I try to take breaks, listen to music, read, relax, or just take deep breaths and remind myself that everything is going to be okay. I try to balance my priorities, since I know it takes longer for me to do some things, and if I have enough time to get from place to place and do things, it usually works out.

**What are your fears and joys? What inspires you?**

In the context of CP, sometimes I fear what will happen to me in the future. There isn’t a whole lot of research out there being done on adults with CP, so sometimes it’s like I’m staring into this blank chasm when it comes to what happens next. Will I always be able to walk? Will I get arthritis someday? Will I age faster than the general population? Will I be in more pain as I get older?

There are a whole bunch of questions out there that I would like to have the answers to, but nobody really seems to know any definite answers, even the doctors. Sometimes it’s kind of scary contemplating the future, because there’s just so much I’m not sure about.

Again, in the context of CP, my joys usually involve being able to do something I once thought was impossible, or just really feeling good about myself and my body. I never thought I would ever be able to climb up 2 stairs without holding onto a railing, but now I can, and that’s awesome. Sometimes I don’t like the way CP has transformed my body- my twisted hips, turned in legs, and crooked feet- especially with society’s notions of what is “beautiful”, and I don’t fit that- but when I sit back and reflect on all it can do for me, I have a new perspective.

Seeing other people who are less fortunate than me, or others with CP who are similar to me accomplish things, really inspires me. I don’t think that’s much different than the general population. Just knowing that there are others out there like me who have done amazing things, and that I’m not alone, really helps.
Facing Your Fears

Coping with Cerebral Palsy as a Young Adult

How do you cope with the challenges of CP?

Physical struggle: Balance, coordination, delayed motor skills... often could not be as athletic as I wanted to be so I put that energy into academics in high school.

Confidence: I always felt like people noticed the way I walk right away and that they judged me or thought less of me...I have to remind myself that I am my own person, and I have a powerful voice, doing good for others makes me feel like a better, more confident individual.

Feeling feminine: I often want to feel cute wearing dress and getting all dolled up but I can’t wear heels, or I have a brace on... and I sometimes wish for pretty feet and evenly toned legs, but I am learning
to be more comfortable in my own skin like anyone else in their 20’s by staying as fit and healthy as I can.

Feeling alone: As much as my family tries to be sympathetic to my CP, no one close to me fully understands what it is like and that makes it hard to be struggling alone sometimes (even with an online community).

Education/Awareness: people mistake severe CP for a mental disability, but it is entirely the opposite. I feel so much love and admiration for those who have more severe CP-- the need for education is imminent to normalize CP and other disabilities alike. I feel like if people knew what was “wrong” we wouldn’t feel so different or talked about for the way we move our bodies.

How do you cope with stress?

I cope with most stress by keeping a journal: it’s a way to keep things private, and still get the negative energy out of me. I like to be outside, go sit under the sun or moon, or just do something active to get all my stress out of my head and my body.

What are your fears and joys? What inspires you?

I fear feeling like I won’t be as healthy as I am now, when I am old. I fear not being able to support myself financially, emotionally etc...

I find joy in being outside, being at the beach, being with my family and anyone who can make me laugh.

I am inspired by my parents at their love, their dedication to our family and their business. I am inspired by anyone who is fearless and always does good for others. I am inspired by the beauty of our world, and by creative people.
Better Your Future:

Living with Cerebral Palsy as an Adult
The Road Ahead

*Note: Names have been changed to protect privacy.

There is not much documentation out there about living with Cerebral Palsy as an adult. There are two articles I’ve seen in my research that even begin to approach the subject. And I’ve read on a few forums and blogs about teens and young adults that are terrified of growing old, because we don’t know how our bodies will change as we age, as affected by our disabilities, and whether or not the symptoms will worsen with time. It’s not just the physical aspect of being an adult that presents a challenge. There are social, emotional and mental concerns as well. Through online research and connecting with a few people with CP (Cerebral Palsy) on blogs and forums, there are common themes in what people experience in dealing with their type of CP and aging.

Social Concerns

Dealing with discrimination is a major concern, for example, in trying to find (and keep!) a job, as well as people seeing you as less of a person because we’re “different.” One recent case of discrimination happened to a customer on an airline called Jetstar in Australia, on June, 3, 2013. There was a 21 year old woman with Cerebral Palsy that was refused her flight by the airline, to visit her family because the airline thought she couldn’t understand the pre-flight demonstration of “in-case-of-emergency” instructions (To read more, check out the link at the bottom of the article). It saddens me to see situations like this happen. I think a lot of it has to do with the average person’s fear, ignorance, and tendency to belittle anything that is different than themselves.

Building friendships and relationships as you get older is also a challenge. Depending on the severity of CP for the individual relates the kinds of classes they took in school, whether or not they can go to college (relating factors being financial situation and level of independence), learning how to drive or take public transportation, finding a job. Building social skills and helping people to see you as a person with a life and goals and dreams, not just that strange guy with a stutter and a twisted hip. Able-bodied (AB) people either pity or ignore us in many cases.

Another concern that is closely related to the need for independence is if you can live alone or with some assistance/caregivers (family or professional). Through my research online, I have connected with two people (Fred* and Larry*) who are 60 years old twins with spastic diplegia CP and have lived together their whole lives. Fred’s CP is involved
on his left side and his brother’s is on his right side. They were born in 1953 and as children had multiple surgeries including fusing joints in the hip and foot on the affected side. As they grew up and became adults, becoming independent from their parents was difficult because of the need for some assistance in daily tasks. They got their driver’s licenses at age 20 and went on to live on their own and eventually owned a business together.

Physical Concerns

I have read many comments in my research about people with CP from ages 28 to 60, that they have increased difficulty in mobility, fatigue, pain and other ailments, which gives them a sense of premature aging causing such things as loss of balance, motor skills, arthritis, and overall body functioning which makes the CP seem worse. Doctors either prescribe muscle relaxers and Advil or do not take them seriously because Cerebral Palsy itself isn’t supposed to be progressive or degenerative over time.

When talking with Fred and Larry, they were very open to expressing what their lives have been like. One of the questions I asked was “As you have aged, have the symptoms of CP gotten worse over time?” And this is Larry’s response: “Unfortunately they have, as you age your muscle structure, cartilage, and tendons are prone to fatigue. It has affected my walking I can’t walk long distances anymore. My feet have changed the most in that the surrounding muscle structure has broken down making me flat footed with no arch so to speak. That in itself has been tough because I have stress fractures that are tiny they don’t hurt so much but I can’t walk barefoot on hard surfaces anymore. I suffer hip pain although recently went on Balcofen tablets and it has made living much better, no hip pain anymore.

I fall a lot more I don’t know why but over time something has happened to me it is the most frustrating thing with bruised knee’s and ribs being the worst of it so far. I thank God I have my brother with me to help me get up.

The need to relax and take a nap I have noticed tiring as I have aged. Although I was very active between ages 10-40 I still can’t believe what I did physically then. Probably the best advice is exercise when young 20-40 then pace yourself thereafter.

To be honest symptoms is a word that is not the right way to approach CP as I don’t know any different. I have always had these ailments it seems as you age they become more noticeable. If we were able bodied
“The limits that you put on your self other than what bad luck or your mental state or CP physical limits are, is up to you.”
to be confined to a wheel chair in a caretaker setting. We were blessed that way. I know many people who are not and that is something I am grateful for.”

Fatigue, and increased muscle spasticity and stiffness results in higher levels of pain throughout the body, as well as the body not being able to repair itself as fast as it did when they were younger. This leads to falls and other injuries. Depending on the type of CP a person has, the amount of energy spent by the spasming muscles and activity level of the person (through lifestyle, physical therapy and exercise) can affect their nutritional needs, calorie intake and metabolism.

It is important for everyone to be mindful of healthy eating and stretching, exercising and sleeping well. But the importance of leading a healthy life is stressed even more for people with disabilities because complications can arise so quickly from our bodies not being strong.

This includes things like a significant weight loss or gain can be an issue as a result, for many adults with CP. According to Fred, “In the last 20 years weight gain has been my biggest hurdle. In high school as a senior I weighed about 175 lbs. At 50 I weighed 225 and I then developed sleep apnea, I ballooned up to 280 and then after treatment dropped to 225-230 again. I currently weigh 227 and my goal is to be 195 by the end of the year. Larry has always been then I would have a marker so to speak to go from.

The foot and it’s deteriorating muscle structure and bunions etc is something I would address at a young age before 30. If a person has such problems. My brother Fred had this done on both feet but I did not and I regret that. Fred is much better on his feet than I am, walking etc. Weight I can’t stress this enough stay slim that is the most troubling of all for a person with CP. As you age with the extra weight on knees, ankles, feet it is compounded with CP. Stay slim!

Don’t do a lot of pounding exercises: running, jumping etc. This wears your body down physically. Do ride a stationary bike invest in a good one similar to a Bally’s Liftcycle or better yet join a Gym and cardio on the bike and do light weight training “Pneumatic” air operated machine are best. I trained for years on these bikes and weight machines. It made a huge difference in my walking and people didn’t even notice my CP. They nicknamed me “Doc” for my limp, God love them.

Now cooking and taking care of myself has never been a problem. You see I was brought up as a “you’re on your own child” My parents worked long hours and was mostly brought up by my sister who was 5 years older. I was cooking at age 9 had a large paper route at 12. Most people with CP are Survivors as well they should be. My CP is much less and I am fortunate not
embarrassed to ask for help because your mental health is just as important. Whether you are 20 or 70, get the help you need. It could save your life.

Another concern that people have as they age (especially if they have a disability and their body is wearing down) is their mental sharpness, focus and memory. Having hobbies, getting a small, non-strenuous part-time job, or maybe taking a community college class and hanging out with friends are some great ways to exercise your brain and body.

Emotional Concerns

Fred also expressed concerns about what life would be like without Larry: “My greatest fear is that one of us, my brother or I will die alone. That is why my focus now is improving my overall health and staying in touch with friends. I at 60 now still have goals....I want to relocate some day to a 10 acre ranch just south of where I live now. I will have to wait till my dad passes because he is alone now and me and my brother is all he has. We all spend time together everyday.” Improving your relationships heals your social and emotional health, and helps you to be a happier individual.

Mental Concerns

Anxiety and depression can affect anyone at any age. If someone you know is experiencing symptoms of these mental disorders, it is very important to help them get professional assistance. It can be particularly difficult for someone with a disability to express themselves and their feelings, because of physical and/or mental communication barriers. Be attentive to any changes in behavior, mood swings, eating habits and unusually quiet or sad appearance because these may be signs there is a problem.

Someone might be depressed because they can’t be as active as they were when they were young, or need to rely on others for help even more than usual, and especially considering how people with disabilities (including CP) can seem to age faster physically than others, it is important to not feel ashamed or lighter, thus more mobile; he is 185 lbs at present. I mention all this because weight gain has a profound effect on both my mental and physical well being. For me my biggest problem is depression and is directly tied mainly to my degree of mobility. Of course there has been other causes, relationships, family and business. But for me it is my weight.”

“We love to travel...... good for the soul.... it makes us feel alive.”

https://sites.google.com/site/perseverancemagazine/
Fred continues, “Me and Larry have recently found a woman doctor who is very CP knowledgeable and has prescribed the drug Baclofen in pill form. This has really helped me as I no longer suffer from hip pain on my right side or back spasms that would make me immobile for up to 2 days. This is due to the muscle imbalance that is part of CP. It has been a wonder drug for me, as I get around so much better.”

Major components of having a strong emotional well-being are enjoying life, being loved, and finding happiness. What matters is taking care of yourself and being confident and focusing on your strengths.

Some other words of wisdom from Fred: “The limits that you put on your self other than what bad luck or your mental state or CP physical limits are, is up to you. CP does not degenerate as far as I can tell but you must get exercise and eat well. No soda pop, or concentrated fruit juices, less bread and carbs, only drink pure fresh water and eat healthy… fresh fruit, veggies, chicken and fresh water fish, lean meats. Watch your weight and get out and enjoy nature. Do not overdo, take rests when you get tired, and you will later as you age, nothing wrong with taking a nap or having quiet times.

Hobbies especially ones that you are passionate about are essential. Me and Gary both love to listen to music and the associated electronics. We both target shoot which gets us out of the house. Love to BBQ and cook Italian, French, Chinese, and anything else we can dream up. Collect and drink wine, mostly French, Italian, Chilean, and Napa Valley, though we have scaled back our intake. Alcohol can have a profound impact on motor skills, being always in control is the utmost importance. I know this from experience….. especially after I hit 45 so just a word to the wise.

We love to travel…….good for the soul….it makes us feel alive.”

For More Information:

http://www.cpirf.org/stories/465

http://www.medhelp.org/posts/Cerebral-Palsy/are-there-any-adults-here-with-mild-CP/show/1331785
Experience, Education and Vision for quality care for persons with cerebral palsy.

http://www.uclaccp.org/
Perseverance

1. Steady persistence in a course of action, a purpose, a state, etc., especially in spite of difficulties, obstacles, or discouragement.

2. Theology. Continuance in a state of grace to the end, leading to eternal salvation.


Cerebral Palsy

cer-ebral pal-sy
noun
Pathology.

1. a form of paralysis believed to be caused by a prenatal brain defect or by brain injury during birth, most marked in certain motor areas and characterized by difficulty in control of the voluntary muscles.