

POLIO PERSPECTIVE
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IN THIS ISSUE

My Polio Story
by Leigh Lewis Trimble

A Letter to People With a Chronic Illness or Disability
by Mary Puglisi

In Search of the Perfect Brace
by William M. DeMayo, MD

...And Over She Goes
by Millie Malone Lill

Web Corner

Polio Newsletters

A Little Bit of Humor

My Polio Story
by Leigh Lewis Trimble

I found something that I wrote about being diagnosed with Post Polio. For all of you who are worried about having Post Polio. This is long But it might help some one.

Post Polio no way, that was my attitude when I first heard the talk over the radio as I was standing in my gift shop. There was no way that I would have Post Polio. I would out smart it. The buzz was that people who had polio had a re-occurrence of polio. They brought this on by their active

life style being type "A" individuals. Well I was a type "A" personality. At that time I ran a gift shop with my husband outside of Williamsburg, Virginia and I took care of my home and three sons. This was in the early 80's.

I had polio as a child, when I was four years old. That was in 1948. I had already had polio over thirty years. I was an active mother of three boys, and although I walked with crutches and wore a brace on my left leg I managed to do almost everything that all the other young mothers did. In fact I did more. My husband, and I had bought an established gift shop. I ran the shop doing the buying, and managing the sales crew. There were days just after Thanksgiving, where I never had a moment to sit down. I remember that my good leg hurt up to my knee from being on my feet all day long. These boom days just before Christmas were just too good to miss and I was one of my best sales ladies.

During this time, as if I did not have enough on my plate, I even took oil painting classes at William and Mary College. I would work all day and then come home to be with the boys and fix dinner. Little wonder that I never had the energy to clean up after dinner. I thought that I was just lazy.

It was during this time that my back started to bother me. I had scoliosis that began to develop during my teens. It was a result of the polio. I went to my GP doctor, who asked for X rays and when they came back he was amazed and wanted me to go immediately to see a specialist. He was afraid that if I had a bad fall that I might just end up having to sit in a wheelchair the rest of my life. The Doctor he sent me too referred me to the Scoliosis clinic in Minneapolis. My husband and I flew out for an appointment with Dr Bradford, who was there at the time and considered to be the best scoliosis doctor. He recommended surgery to straighten my back. Waiting for an appointment, I dieted.

Five months later we went out for the surgery. Now that I think about it this was more than likely the beginnings of my onward battle against post polio. My recovery was slower than for someone "normal." My husband and I became estranged. I stayed with my parents to recover.

My life went on but everything had changed. My two sons and I stayed with my parents, and my oldest son went to College near by.

I tried to not over use my good leg by sitting occasionally in a wheel chair. I swam at the local YMCA to keep my weight down and to get exercise. I got too enthusiastic and felt so good that I pushed myself too much. I clearly remember one day after swimming that I had an unusual weak feeling in my arms. I wondered about that. I had that feeling reoccur after sitting out in the sun in Virginia Beach watching the surf with friends. Why did I have trouble with the steps? I felt so tired. I began to wonder if I had MS. I had a friend who had been diagnosed with MS in her thirties. Could that be what these periods of weakness were?

Needless to say, all I did was wonder. I did try to conserve my strength by sitting in my chair some. The effect was that it became harder and harder to keep my weight down. I have always been fairly careful about my diet, eating the right kinds of food. However, with the little weight that I gained I resorted to some fad diets. With each fad diet I would inevitably gain a few extra pounds. I was in my mid 40's.

Steps which had never been a problem in the past became more and more difficult. I thought this

might have been due to the back surgery. Fast forward to my mid fifties, there was definitely something wrong. I fell going up the stairs to a friend's party. I was so embarrassed. I have always brushed off falls in the past saying that I knew how to fall. I fell so many times without hurting myself. But that time was different. I should not have fallen then. I became afraid to go places without one of my sons or a friend. My life became more and more restricted. Finally, I looked into getting a scooter. That would enable me to do more. My son and I were now doing antiques and in order to find our merchandise I needed to be able to get around to find the items to sell. You can not order antiques out of a book.

Finally a friend insisted that I find out if I indeed had Post Polio. I found a doctor in Richmond Virginia, Dr. Wooten and was diagnosed with post polio. I had lost the battle 50 years after first getting polio. She advised me not to walk or to use my regular wheel chair as my arms were also effected by the polio. I needed a power chair, or scooter. I had gotten the scooter, but now I needed to use it full time. My Dad helped me get a van that had hand controls and a lift for my scooter.

My life actually changed for the better. I was no longer restricted to making sure I had someone with me. I had the freedom to go as I pleased. Of course there were those places that a chair or scooter could not go. I was still able to stand and walk some with my crutches. I could do the grocery shopping without help for the first time in my life. There were benefits. The doctor prescribed medicine to calm my nerves. Once I got used to living this way I was not as worried. After a few months I no longer needed the medication. She also prescribed medication for pain. After a while the pain I had felt in my arms and good leg lessen and I started using only pain medicines that were sold over the counter when needed.

I now realize that muscle soreness that felt like the flu was also Post polio. By pacing myself and trying not to over do has really helped. It is amazing that I can still be a type "A" personality in a wheel chair. Even with post polio, I used to paint daily producing a vast amount of oil painting. For the past nine years, I have run first an Antique mall and now a Twentieth Century Design Shop with my youngest son from a power chair. I care for my aging mother, that sometimes pushes the limits, but I can do it for now anyway. I just pace myself. I do believe in living life to the fullest.

A Letter to People With A Chronic Illness or Disability

by Mary Puglisi

YOU ARE NOT A BURDEN

“You are not a burden. You have a burden, which by definition is too heavy to carry on your own.”

To everyone living with a chronic or invisible illness or disorder: You are not a burden.

You are a miracle. God gave you the gift of life. He chose you to be here, wandering this mysteriously gorgeous Earth.

You are a friend. Make a list of the people who invite you on adventures, who have a hundred beautiful, ridiculous, embarrassing yet awesome pictures with you in them, and who you share endless pizza dinners (lunch, breakfasts, snacks, don't lie) with. The people you make laugh when they want to cry and whose aid you go running to when they're facing a hard time. You are a friend to so many.

You are a daughter, son, sister, brother, granddaughter, grandson, niece, nephew, aunt, uncle. Think

back to every holiday being surrounded by the few or many special people who you know you can always run home to, no matter what. The ones who you share your best memories with and experienced your biggest arguments with. You are their family. Without you, they would be one less.

You are a gift. When you shine your light on this world and share yourself with the people in it, I promise you that you are presenting something unique that no one else is able to. You have a purpose here—a purpose designed solely for you.

You are a warrior. The physical pain you endure every day, some days worse than others, is a pain not many could endure. Every day you're getting stronger, even when it feels like you're weakening. You fight through the aching, throbbing, pulsing, nauseating, piercing, and everlasting horrific sensations that are indescribable to others who don't know what it feels like to be in your body.

You are a fighter. You fight through that pain, and somehow continue to keep moving forward in your journey. You fight on, whether it's getting through the work day without having to call out early due to a worsening symptom or it's biting your lip to fight the pain during your hundredth unsuccessful IV insertion. You fight through the frustration, sadness, anxiety, loneliness and helplessness that come along with your physical pain. Your fortitude is immeasurable in size.

You, my dear friend, are not a burden. Your illness is a burden.

It is your burden. But even being solely yours, it cannot be carried by you and you alone.

Because you are a friend, family member, gift, warrior and fighter, the chances are that you have a support system to help you carry that burden. Do not be afraid to ask for help. For the ones who are meant to stick around, will ask how they can help lift that burden whenever they can.

You are not a burden and you were not made to carry this burden alone."

In Search of the Perfect Brace with Perfect Fit

By William M. DeMayo, M.D.

DeMayo's Q & A Clinic <http://www.papolionetwork.org/demayos-q--a-clinic.html>

Proper fit of a custom brace (orthotic) is absolutely essential. Often individuals who are not very knowledgeable about custom orthotics will give up on this treatment option because they are unaware that a good orthotist will continue to modify a brace until it fits perfectly. Ideally, the orthotist, the prescribing physician, and the patient should form a team to decide on the type of brace and postproduction modifications necessary to achieve this goal. I have been blessed to work with outstanding orthotists who work collaboratively. I regularly meet with the orthotist and the patient together. The patient is always at the center of this discussion and is educated from the start regarding all biomechanics and potential functional goals.

I never prescribe a brace unless the patient understands the potential significant improvement they can have by using it. Once the brace has been fabricated, we meet again to discuss modifications that would improve the brace. It is important to remember that modifications created in the office do not always perform perfectly in a community. Therefore, it is essential that the patient be aware and "speak up" in between office visits by calling the orthotist for further adjustments should there be problems with the fit. So to start, let's list issues with fit that are clearly unacceptable and require intervention by the orthotist

. These include:

- Pressure Ulcers
- Gapping (should be total contact)
- Excessive width (difficult to don shoe)
- Skin indentations
- Redness
- Pain

Achieving a perfect fit can be quite a challenge in individuals with foot deformities, atrophy, and excessive muscle tightness (for example calf tightness can cause excess pressure on the ball the foot due to lack of flexibility). Additionally, gait deviations in polio survivors often require further customization such as lifts, flaring/posting of the heel, decreased or support and metatarsal pads (to address hammer toes or painful metatarsals). The polio survivor should continue to describe any difficulties with the brace so that the prescribing physician and orthotist can address them. This may take multiple trials in a challenging case.

Occasionally the brace needs to be recast in the process and redone from the start. This is often because of unintended movement during the initial casting process (poor position prior to drying of the casting material). It is important to note that a skilled orthotist can flare a plastic brace, add custom padding, change the alignment, and redistribute weight within the brace. It is not uncommon for a polio survivor, who has perhaps problem solved thousands of times in the past, to try and implement a “do-it-yourself fix”. This is often a mistake.

As an example, individuals who experience pressure over a bony prominence will often time try to insert a “pad” between the brace and the sore area. Typically this is a problem since it may cause some transient decrease in pain, but actually increase the pressure between the bone and the brace. (Adding any material into a tight space always increases the tightness/pressure in that area. And orthotist will usually heat the brace and move it away and/or pad above and below the painful spot to distribute weight more evenly. There are many other approaches to brace modifications that are beyond the scope of this article yet, are routine for a good orthotist.

A patient and physician can develop a relationship with an orthotist over time that allows for an increase understanding of their skills. Armed with this information, the patient will be much more likely to collaborate with the orthotist and call for any problems with fit or function. It is important to remember that not all braces are custom. Some braces can be sold as a stock item and improve function in simple cases. This is typically not the case in polio survivors. Also, there does exist a marketing movement towards carbon fiber braces. Proponents speak of and often exaggerate “energy storing function” and other claims, yet they do not discuss a significant disadvantage. The structure of carbon fiber braces cannot be modified once it is fabricated and they are extremely expensive to “redo” if initial casting is not perfect.

The function of the prescribed custom AFO can vary widely depending on the the individual need and design variations will then impact the fit of the brace. Some braces must control pronation/supination of the foot. This can increase or decrease the likelihood of pressure on certain bones of the foot and ankle. Other braces may be focused on preventing drop foot or stabilizing the knee. While “Fit” is essential, optimal “Function” is the actual purpose of any brace. Often times, there appears to be a trade-off between the two. Nevertheless, persistence and collaboration can almost always achieve both. In this light, it is important to remember that polio survivors often times have been using braces for many manyyears.

While newer technologies and materials may be optimal for some patients, an individual who has

functioned best with a brace that they have used for decades and who is not having any new problems is often best served by re-fabricating the exact same brace. At the same time, lighter/smaller custom plastic braces sometimes provide additional benefits and should be considered by individuals who are in need of a change. Significant discussion and communication is often needed between the physician, orthotist, and polio survivor to decide on the ideal approach.

The ideal brace will do three things.

Meet the functional goal (e.g., preventing foot drop, stabilizing ankle, improving balance, or improving the stability);

Be weightless and

Be absolutely comfortable.

While this ideal may never be perfectly reached, healthy collaboration between the physician, orthotist and patient usually results in an outcome that comes close.

...And Over She Goes *by Millie Malone Lill*

As a polio survivor, I've often thought of my health as a huge game of Jenga, that game where you stack little blocks up till they nearly fall over, then you remove one block at a time till it collapses. As a typical Type A person, I hate giving up anything that I've always done and that I still enjoy. My Jenga is about as high as it can go, so now, due to progressing PPS issues, I have to start removing blocks.

Which one can I live without? Well, let's see. If I get a new brace to replace the disaster that my current brace has become, maybe I won't have to remove the Walking block. I called the local hospital in an attempt to get an appointment with the orthotist who is supposed to be there twice a month. No answer, so I left a message with my request for an appointment and my phone number. That was a week ago. I'll call again tomorrow.

The problem with trying to save the Walking block from being pulled out of the stack is the orthotist. No particular orthotist, just the process of getting the appointment, getting the prescription, and starting the process. This aint my first rodeo, so I know that is going to be exhausting. I've been wearing a brace since my 40s and that was not last week, folks, so I am very familiar with the drill. It involves at least a dozen trips to get the brace made, and fitted, and refitted and the obligatory assurance from the orthotist that I will "get used to this slight discomfort." My discomfort can vary from a truly slight bit of pain to a feeling of walking on Legos. The orthotist, needless to say, is feeling not even the slightest discomfort and what little he does feel is soon assuaged by my hefty co-pay.

Okay, now for the sake of getting on with it, let's say the new brace, the orthotist, and my polio affected limb agree that this is The Perfect Brace. Now I have to convince my hips and back to go along with this assessment. After a couple of months, the Walking block is safe.

Now let's work on trying to remove that pesky Weight Gain block that wedged itself in there because of the bad brace. I don't want to cut out too much protein, but my favorite protein comes in the form of meat. I didn't claw my way up to the top of the food chain so I could gnaw on turnips! Perhaps I could cut out sugar, which is not something I'm addicted to anyhow. More veggies, yes, that's a good idea. Of course, I hate to cook for one person, so maybe I'll stick to my Meals on Wheels program with maybe a salad for supper.

Now, in theory, I have lost weight and can remove that block. The tower starts to wobble because now my brace no longer fits! I better find another block I can remove that will re-balance the whole thing. I don't want to exercise and lose what few motor neurons are still at the party. Maybe I could remove the Staying Up Reading All Night block. My favorite block!

Back to the orthotist to refit the brace. Maybe a little more walking, not too much, just to keep the weight down a little. I know! I'll go back to the pool! Well, no, I guess not. It seems that I have lost enough muscle in my polio affected leg to make walking in the pool impossible. I don't have enough strength in that floppy appendage to hold it down in the water. It floats behind me like seaweed.

You know what? I don't like this game anymore. I'm switching to Scrabble.

Web Corner

Plant based polio booster vaccine

<https://news.upenn.edu/news/penn-led-team-develops-plant-based-polio-booster-vaccine>

Lab grown cartilage

https://medlineplus.gov/news/fullstory_159956.html

All it needs is a touch

https://medlineplus.gov/news/fullstory_159956.html

Radio interview with Dr. Bruno

<http://www.papolionetwork.org/new-stories-of-interest.html>

Travel confidently with Accessibility Info you need

<http://abc-med-2257141.hs-sites.com/blog/travel-confidently-with-accessible-info-brettapproved>

Healthy Aging and Physical Disability

<http://agerrtc.washington.edu/info/summaries>

Indian Boy Who Saw the World Wrong Side Up

<http://www.transfermaster.com/blog/view-post/The-Indian-Boy-Who-Saw-The-World-Wrong-Way-Up>

An Ode to Determination

<http://www.transfermaster.com/blog/view-post/An-Ode-to-Determination>

Rising Tide of In Home Care for Seniors

<http://www.newswise.com/articles/view/656745/?sc=mwhn>

Wheelchair Superman

<http://www.transfermaster.com/blog/view-post/Wheelchair-Superman>

Polio Newsletters

Atlanta Post Polio Association

<http://www.atlantapostpolio.com/APPA News-2016-spring-final.pdf>

Post Polio Health International

<https://www.facebook.com/Post-Polio-Health-International-PHI-173414896052885/?fref=nf>

Pennsylvania Polio Survivors Network

<http://www.papolionetwork.org/>

Polio Survivors Network

http://www.poliosurvivorsnetwork.org.uk/iama_poliosurvivor.html

A Little Bit of Humor

Walking through Chinatown, a tourist is fascinated with all the Chinese restaurants, shops, signs and banners. He turns a corner and sees a building with the sign, "Hans Olaffsen's Laundry."

"Hans Olaffsen?" he muses. "How in hell does that fit in here?" So he walks into the shop and sees an old Chinese gentleman behind the counter.

The tourist asks, "How did this place get a name like 'Hans Olaffsen's Laundry?'" The old man answers, "Is name of owner."

The tourist asks, "Well, who and where is the owner?" "Me...is right here," replies the old man.

"You? How did you ever get a name like Hans Olaffsen?"

"Is simple," says the old man. "Many, many year ago when come to this country, was stand in line at Documentation Center. Man in front was big blonde Swede. Lady look at him and go, 'What your name?' He say, 'Hans Olaffsen.' Then she look at me and go, 'What your name?'"

"I say Sem Ting."