

Connections • Winter 2022 Newsletter

We delight in the beauty of the butterfly, but rarely admit the changes it has gone through to achieve that beauty.

- Maya Angelou

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Accessible Technology - Making Life Easier by Paul Snell

In August, I was a presenter at the summer post-polio workshop. Rather than a handout for everyone present, I decided to write a newsletter article that might reach people who could not attend. First, let's talk about your smart phone. Almost everyone in our generation uses their smart phone to make phone calls or to send text messages. Many of us didn't really embrace texting at first, but found that to communicate with the younger generation it was a necessity. As the phones developed, so did the phone's camera and we started taking more and more pictures. Then came the internet on the phone and with that came email. So now we have a great communication device. It really doesn't matter if you have an Apple iPhone or one of the variations with the Android operating system, they both work very well. Now we are discovering that our smart phone is a remarkable control device for our home.

Smart phones have also picked up several very useful "accessibility" functions. When I was first

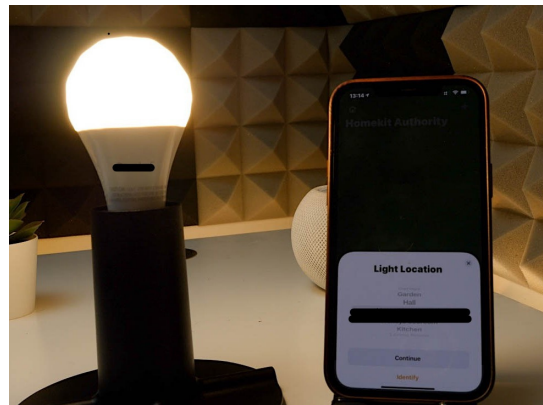


diagnosed with post-polio syndrome, my head seem to dwell for a time on "What if." What if I hadn't had polio, what if my leg would work and didn't hurt, just what if? Gradually I began to change my focus to "What if" I can find ways for technology to make my life better. Phone makers have been doing just that. For example, the iPhone has a terrific "magnifier" that uses the camera and the screen on the phone as an electronic magnifying glass. It is incredibly useful especially if you have limited vision. The iPhone also has multiple functions for those with hearing disabilities. Those can be found under the "Accessibility" section of Settings. There are also multiple assistive functions for people with vision problems. In addition, there are alternative ways to "trigger" the

Accessible Technology - Making Life Easier (Continued)

device depending on if your disabilities are in your hands and arms. These are just a few of the features specifically designed to work for people with disabilities.

Now, let's look to the future. The phone now becomes our primary control device for many products that are specifically designed for persons with disabilities. Let's start with lighting. In the past it has been necessary to select lighting products based on the operating system of your phone. Some products currently work with Siri on Apple phones, others worked with Android operating system on phones such as Samsung, LG and others, and some with Google phones. Some manufacturers have been able to create products that will work with multiple operating systems. Phillips lighting has been a leader, but their bulbs have been very expensive and required an Alexa device to control them. Now the Big Three (Apple, Amazon and Google) have developed a new protocol so that any device can use any product made by third party companies. This will be on the market soon and is great news for consumers. In my



house I have a bulb in my lamp in my living room made by Nanoleaf. The A-19 bulb can be controlled by Android or Apple phones and is very useful. For instance, to turn my lamp on or off, I have to get out of my lift chair, walk around the table just to reach the switch. Now, I push a button on my phone or by voice control and the light comes on. I can also control the color of the bulb (green at Christmas perhaps) as well as controlling the on/off/dimming function. The bulb is only \$20.00. Instead of just a bulb, you can also select a smart plug and control anything that plugs into the wall from your phone. At this time you must select a brand that works with the phone you use. Check the Apple App Store or the Google Play store for products that work with your phone. I also have a "smart"

Accessible Technology - Making Life Easier (Continued)

dead bolt on my front door. It allows me to unlock the door to welcome anyone into my home without having to struggle to get to the door. At the workshop this summer, I talked to several people who have installed “smart” thermostats on the furnace and/or air conditioner. These can “learn” how you want the temperature to be at various times of day. If you want to modify it either up or down, again you can do it by voice control through your smart phone.

Next let’s consider a few other home devices that work really well for those of us with mobility issues or dexterity issues. Several participants in our north-metro support group have serious issues with mobility in their arms and upper body. That makes opening and closing drapes or blinds difficult or impossible. There are now several brands of shades that can be controlled by your phone, by a small remote control or by voice control. These are a game changer for many people. The next really useful device is a Wi-Fi connected garage door opener. This may sound unnecessary but how difficult is it when you need to check the door to

be sure it is down. Or to let a delivery person into the garage. That task is made much easier by just checking your smart phone. Just recently, I saw another incredibly useful Wi-Fi addition for a ceiling fan. Many of us have an impossible task to reach the chains on older fans and a difficult time getting to a fixed switch on the wall. Several very good brands have added Wi-Fi allowing you to control the fan and the light from your chair or bed.

Finally, let’s look back at the phone. Its function has obviously changed a lot. I’m thinking about my grandparents’ phone that had no dial, no buttons, and to make a call you simply picked up the receiver, an operator answered and connected your call. This is quite a change in our lifetime. The important thing to remember is that we now have a powerful tool that will continue to evolve and provide additional assistance to those of us with disabilities.



***Mark your calendar for
August 13-17 of 2023 for
the next Colorado Post-Polio
Rocky Mountain Getaway!***

Post-Polio Basics - 2022

What is Post-Polio Syndrome (PPS)?

- Late effects -- any long-term effects from polio, whether a person has PPS or not
- PPS affects up to 50% of polio survivors
- Criteria for diagnosis of PPS --
- Prior polio validated by exam, history, or electrodiagnostic tests (EMG)
- Period of physical stability for at least 15 years
- No other diagnosis to explain the symptoms (see **Symptoms of PPS**)

PPS is a diagnosis of exclusion!!

What Causes PPS?

An exact cause has not been determined. Possible causes include: decades of “overuse and abuse” of the body, motor neurons damaged by polio begin to fail, effects of aging on top of effects of polio.

Are There Medications That Help PPS?

There are NO medications that address PPS problems directly. Some medicines commonly used to treat arthritis or nerve pain may help some pain.

What Are Some of the Symptoms of PPS?

- New weakness in muscles -- both those

originally affected and those thought unaffected by the poliovirus

- Breathing or swallowing difficulties because of new muscle weakness or scoliosis
- Pain in muscles and/or joints
- Unaccustomed, unexplained fatigue-either rapid muscle tiring or feeling total body exhaustion
- New or increasing muscle atrophy
- Functional decline, more than would be expected from aging
- Wear and tear arthritis in joints
- Nerve compression problems

What Can Be Done?

- Determine what causes “overuse” and adjust activities to avoid/minimize overuse.
- “Conserve to preserve” but still maintain activity.
- Use assistive devices to maintain independence.
- Join a post-polio support group (in-person or on-line).
- Control weight while maintaining nutrition--adequate protein is essential; limit added sugars.
- Physical therapy, with goal to maintain function.
- Get professional mental health help if needed.

Post-Polio Basics - 2022 (Continued)

What About Breathing Problems?

Breathing problems can be due to diaphragm or chest muscle weakness because of prior polio, especially when the person needed respiratory assistance during the acute polio illness or had/have severe scoliosis.

Lung conditions such as COPD or asthma can cause breathing problems.

Pulmonary function tests (PFTs) can determine whether a cause of the breathing problem is restrictive (decreased chest movement such as from polio-weakened muscles) or obstructive (narrowing of the airways inside the lungs).

Treatment of each condition (restrictive/obstructive) is different. A person can have both restrictive and obstructive issues.

What About Swallowing Problems?

Swallowing problems, if not addressed, can lead to weight loss, malnutrition, and aspiration

pneumonia. They can be caused by weakened throat muscles, problems in the esophagus or a combination of both.

One test that can not only determine the cause, but possibly provide treatment tips is a modified barium swallow study (MBSS), done by a speech therapist and radiologist. Most hospitals have the capability to do this test.

Many speech therapists have the skills needed to determine the cause and provide treatment because people who have had strokes often have similar swallowing problems.

What To Do About Pain?

- Look at activity -- if pain is from overuse abuse of tissues, adjust activities.
- Use heat and/or ice on painful area(s).
- Massage the area.
- Try warm water therapy.
- Use assistive and adaptive aids to reduce stress on muscles, joints.
- Use topical medications before taking pills, ex. Salon-Pas, Ben-Gay, over-the-counter creams containing Lidocaine 4%, or diclofenac (brand name: Voltaren gel).

Post-Polio Basics - 2022 (Continued)

- Consider trial of CBD (if legal in your state, country, location).
- Use pain medication only as directed by your healthcare provider.

Aging with Polio - Safety Issues

Normal aging can impact muscle strength, balance, and mobility. To live safely with polio, **prevent falls!**

- Keep home spaces open for easy navigation and floors clear of rugs.
- Use assistive devices such as canes, crutches, walkers/rollator walkers at home and when venturing out.
- Equip bathrooms with tub or shower chairs and grab bars, including by the toilet.
- Physical therapy can improve these issues and teach ways of coping.
- A physical therapist can teach you how to fall more safely and how to get up and recover from falls.
- Have a way to get help if you fall and cannot get back up. Some phone apps detect falls then notify certain persons, and/or having a medical alert device.
- **Insure you always have a cordless/cell phone with you -- even when moving around your own home.**

Did You Know?

People still get polio, but as of 2021 there were less than 600 cases in the entire world!

There are post-polio clinics and support groups scattered across the globe. Post-Polio Health International (PHI) has a directory at www.post-polio.org.

Financial resources help with some types of equipment needed by polio survivors—check with CPPO or PHI.

Since 1988, Rotary International clubs have been actively working to eradicate polio. This would be only the second human disease to ever be totally eradicated!

Where Can I Find More Information?

Post-Polio Health International (PHI)

St. Louis, MO, 314.534.0475,
www.post-polio.org

*Adapted from information provided
by Polio Epic, Inc. Tucson, AZ.*

*Revised and updated February 2022
by Marny Eulberg, M.D.*

Have you ever wished for a crystal slipper that you could actually walk in? by Marny Eulberg, MD



During my childhood I remember dreaming about shoes that were anything other than brown or black leather orthopedic shoes that a brace could be attached to. It was a big day when I got a pair of black and white saddle shoes! But I dreamed of black or white patent leather Mary Janes, like other girls wore when they were dressed up, and I longed for a pair of red shoes!

I hate to think of how much money I have spent on shoes that I hoped would work for me to only discover that they made me too unstable, hurt my foot, or did not work with my brace(s).

For anyone with an abnormal gait/way of walking the best shoe is one that has a sole that is flat or nearly flat from side to side and from the heel to the toe (see image).

A shoe that has a wide toe box is more stable than one with a narrow-pointed toe. Stability is enhanced if the bottom the sole is slightly wider than where the sole meets the shoe. A leather sole provides the least amount of traction which are less likely to cause tripping on thick carpet or can be great for dancing. A rubber or similar material provides the best traction but may make it more likely to trip when walking on carpet. Examples of shoes that have flat or nearly flat soles are skateboard shoes (think Vans, etc.), court shoes – either for playing basketball or tennis such as Converse, or boat shoes used by those walking around the decks of slippery boats.

The ideal shoe to wear with a brace fits closely around the brace and the foot, holding you snugly and comfortably within it. It has a sole that sets flat on the ground, including around the edges, in order to provide maximum stability when standing and walking. Your foot, the shoe, and the brace should function as one solid unit.

Have you ever wished for a crystal slipper that you could actually walk in? (Continued)

If you are a new brace wearer, the shoe you need on your braced foot may need to be ½ to 1 shoe size larger and/or wider than the shoe you wore on your foot before it was braced. Frequently, one can get more room in the shoe by removing the insole(s). For some polio survivors, this may mean you now can wear the same size shoes on both feet! You may be able to get the orthotist to make the foot plate on your brace the same size as your larger foot so you can wear the same size shoes on both feet. Sometimes it means getting all new shoes and, at times, beginning a frustrating, time-consuming, and sometimes expensive process of finding shoes that will fit around the brace and serve your needs.

For those who need mis-mated shoes (one size on one foot and another size on another foot), some options may be: getting shoes from Nordstrom's. As long as there is at least 1 ½ shoe size difference between the two shoes, Nordstrom's will only charge you the price of one pair for shoes that each are a different size. If you ask, some shoe



stores may discount the second pair with or without some restrictions. You may be able to find mis-mated shoes from an organization such as National Odd Shoe Exchange (www.oddshoe.org). In addition, there is a website, <https://www.abilityhacker.com/where-to-buy-shoes-when-your-feet-are-two-different-sizes/> that lists resources for mis-mated shoes. There is also a website www.oddshoefinder.com that lists single shoes or mis-mated shoes for sale offered by persons with extra shoes for others who wear those sizes to purchase. If you have purchased two pairs of shoes and have the extra mis-mated shoes that you cannot wear, you can offer them for sale on the Odd Shoe Finder website or donate them to N.O.S.E. (the National Odd Shoe Exchange).

Have you ever wished for a crystal slipper that you could actually walk in? (Continued)

You will need to pay the postage/shipping to N.O.S.E. but the cost of the one donated pair and any shipping costs are tax-deductible as a charitable donation.

A few companies have begun to recognize and respond to some of the challenges experienced by those with limited hand/arm function or wearing braces to put on standard shoes. Shoes with Velcro closures have been available for several years. There now are some additional options including shoes that flex at the heel when putting the shoe on and then pop back up so the need to tie shoelaces may be avoided—examples: Kizik, Zeba, and Nike FlyEase. The shoes of BILLY Footwear, www.billyfootwear.com, incorporate a zipper that go along the outside and around the toe, allowing the upper of each shoe to open and fold over completely. Thus, the wearer can place his or her foot onto the footbed unobstructed. Then with a tug on the zipper-pull the shoe closes and secures overtop the user's foot. All of these companies have some limited size/width options.

Are these ideas going to help everyone—no, but they may help many of the readers who struggle finding shoes. The biggest challenges will be for those who wear an adult sized shoe on one foot and child or youth size on the other foot, those who wear a woman's size on one foot and man's size on the other, those needing a very wide or very narrow shoe, those who need a custom-made shoe, and finding styles other than casual shoes.

Individuals who use a brace that attaches directly to the shoe or uses a stirrup built into the heel of the shoe are having increased difficulty finding leather shoes, especially women's leather oxford type shoes. If it still can meet a person's needs, it may be useful to talk to an orthotist about converting the brace to one that has a footplate, one design is called a UCB (University of California, Berkeley) footplate, that goes around your foot and heel and will fit inside a shoe eliminating the need to have a leather heel on the shoe.

Disclaimer: I have never needed to shop for or purchase men's shoes or unusual sizes, so likely I did not discuss all the challenges faced by men, those who need custom shoes, or wear the more limited sizes.

Food for Thought - "Sensible" Shoes by Margaret Hinman



Feet are amazing apparatuses. That intricate combination of bones, joints, and muscles allow us to stand, walk, run, and climb, and provide us with stability, balance, and mobile dexterity. Shoes were originally invented to keep those feet warm and safe in environments they had to navigate. Then culture and individual differences in taste created those shoes in different styles, some great and some, like stilettos, not so great in terms of the basic purposes for shoes.

From the time I started to walk, I have been doomed to wearing "sensible" shoes, starting with those laced oxfords that were sturdy, durable and always purchased one size larger so I

could grow into them over time and so they would last longer. That way, I could get by with one, maybe two pairs of shoes a year, particularly if I spent the summer going around barefooted. I like pretty, chic, stylish shoes and always wanted those sandals and those flats, but when my very practical, sensible parents had to shoe seven pairs of little feet, those options were at most times out of the question.

I could hardly wait until I was old enough to wear high heels, but polio struck when I was eleven and before I was old enough to wear them. As luck would have it, my grandmother had a play-clothes box at her house and in it was a pair of small sized high heels from my aunt so in the year before I got polio, I felt so grown-up strutting around in those high heels, my one and only chance to wear any.

In the fifties, wearing a brace definitely meant wearing sensible shoes, oxfords or saddle shoes with heels that could be removed so the orthotist or the cobbler could rivet

Food for Thought - "Sensible" Shoes (Continued)

the metal stirrup of the brace onto the sole of the shoe. My one exception to the mundane was a pair of red and white saddle shoes which allowed me a touch of being cool.

When in high school, I ditched my brace because that locked knee apparatus was heavy, uncomfortable, and Inconvenient, and I could walk without it although logic, good sense and how polio impacted my knee and foot should have prevented it as a possibility. So, for about 20 years, I was able to wear "cool" shoes, flats, moccasins, sandals, and others, some of which were not the best choices in terms of stability, balance, and mobility.

By the time pain in my knee forced me back into a brace, technology and materials had advanced, not only in bracing but also in shoes styles. Aluminum, graphite, titanium, plastics, hook-and-loop straps, electronic assists, and braces that fit into shoes, as well as custom braces that correct some deformities opened a whole new world for those of us who need that kind of assistance in navigating our

environment. And whether we need a brace or not, "sensible" shoes abound, designed for specific needs and function, in a variety of materials, shapes, styles and colors.

Now, our "maturity" has to be factored into the equation when choosing shoes. The normal aging process which includes a decline in strength, balance and mobile dexterity, coupled with the after-effects of polio can make us more vulnerable to falling. We can wear fashionable, "sensible" shoes that will help prevent that from happening, shoes with a flat, wider outer sole that allow our feet to have the maximum contact with the ground. Mature wisdom has also produced two other conditions when getting those sensible shoes: shoes need to be comfortable when you walk out of the store and do not need to be broken in, and when you find shoes that work well for you, get an extra pair because they may not be available in the future when you want another pair.

Just some food for thought!



Introducing: Colorado Post-Polio Statewide and Beyond Quarterly Zoom Informational Meetings

Meetings will be held via Zoom.

Social half hour from 10:30 to 11:00 a.m. MST

Presentation of Topic from 11:00 a.m. to 12:00 p.m. MST

Question & Answer Session from 12:00 to 12:30 p.m. MST

These meetings will be held on the fifth Saturdays of the year with 2022 dates being:
April 30th, July 30th, and October 29th.

Contact Mitzi Tolman at mtolman@eastersealscolorado.org to be included.



2022 Advisory Council Members

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2022 Advisory Council Meetings

Members are always welcome.

Zoom at 4:30 p.m.

April 20, July 20, October 19, 2022



Colorado Post-Polio Support Group Schedules

Support Groups are beginning to meet in-person with appropriate social distancing. Others still meet virtually. Please stay in touch with your facilitator for further information.

AURORA

Meets the 4th Thursday of every month from 11:00 a.m. to 12:30 p.m.

Meeting in-person at New Hope Community Church, 17699 E Hampden Ave.

Facilitator: Myrna Schmidt, 608.790.5755 or myrnaschmidt1@yahoo.com

COLORADO SPRINGS

Meets the 1st Wednesday of every month from 10:00 a.m. to Noon, with a few exceptions.

Meeting in-person at Rock Family Church, 4005 Lee Vance Dr.

Facilitator: Hal Goldberg, 303.212.0017 or halgoldberg@halgoldberg.net

GRAND JUNCTION

CPPO will host an information meeting and traveling clinic on the Western Slope in Spring 2022. Please contact Mitzi Tolman at 720.940.9291 or mtolman@eastersealscolorado.org for more information.

LAKESWOOD

Mitzi will host a lunch in April 2022 to discuss the group's future. Please contact Mitzi Tolman at 720.940.9291 or mtolman@eastersealscolorado.org for more information.

NORTH AREA

Meets the 3rd Saturday of every month from 10:00 a.m. to Noon.

Meeting via Zoom. *Members outside of the North Area are welcome to attend.*

Facilitator: Jill Eelkema, LCSW, 720.675.9902 or jille@westerncarepartners.com

NORTHERN COLORADO (Fort Collins)

Meets the 4th Saturday of every month from 10:00 a.m. to Noon.

Facilitator: Peter Way, 970.460.6164 or NOCOPolio@gmail.com

PUEBLO

Meets the 3rd Saturday of January, April, July and October.

Next meeting April 16, 2022 at 1:00 p.m.

Facilitator: Jill Eelkema, LCSW, 720.675.9902 or jille@westerncarepartners.com

SOUTH DENVER

Meets the 1st Tuesday of every month from 11:00 a.m. to Noon.

Meeting via Zoom. *Contact Hal for the meeting link.*

Facilitator: Hal Goldberg, 303.212.0017 or halgoldberg@halgoldberg.net

 **Donations**

If you would like to donate to support Colorado Post-Polio efforts, **please complete this form, detach and mail it to Mitzi Tolman at Easterseals Colorado.** To ensure that we receive 100% of your donation, contributions should be **payable to Easterseals Colorado** with **"POST-POLIO" written in the memo line.** Your contribution will be gratefully acknowledged. Thank you again!

NAME: _____

ADDRESS: _____

CITY, STATE, ZIP: _____

PHONE: _____

E-MAIL: _____

MAIL TO:

Easterseals Colorado
Attn: Mitzi Tolman
393 S Harlan St, Suite 250
Lakewood, CO 80226
Memo line: POST-POLIO



**FREE MATTER FOR
BLIND OR DISABLED**



This Is YOUR Newsletter – *Connections* is the official news publication of the Colorado Post-Polio Program. The opinions are those of the individual contributors, and do not necessarily constitute an endorsement or approval by either the Colorado Post-Polio Council or Easterseals Colorado. **(Always check with your personal physician for all medical questions and concerns.)**

We invite not only your comments about this newsletter; tell us what topics you want to read about in future issues. If you have article ideas or suggestions, are willing to write a short article, tell your personal story or you'd like to review a book, please call **Mitzi Tolman** at **720.940.9291** or email her at mtolman@eastersealscolorado.org, or write to: Easterseals Colorado, Attn: Mitzi Tolman - Colorado Post-Polio *Connections*, 393 S Harlan St, Suite 250, Lakewood, CO 80226.

If you prefer to receive this newsletter online or change your mailing information, please contact Mitzi Tolman at Easterseals Colorado at 720.940.9291 or mtolman@eastersealscolorado.org.