Conquering Mysterious Foot Pain

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A fter an arduous saga wherein the heroine – me – sought diagnosis, advice and solutions for nearly three years, at long last, the achievement of pain relief and strength was reached in my strong, non-polio foot. I’m starting with the outcome, so that perhaps anyone with similar top of foot pain will be encouraged to read on.

At first, my primary care doc and I thought that perhaps the sharp pain in my overworked strong foot might be the result of taking statins, because I was experiencing pain in my hands and other joints as well. I tried different statins and finally went off them completely in order to test our theory. Most of the pain in other areas subsided dramatically, but I was left with the top of foot pain and pain in my right thumb, which turned out to be arthritis and was treated with corticosteroid shots by a hand specialist.

By this time, I’d had foot pain for well over a year and it was getting worse. Frequently, I woke with stabbing pain in the wee dark hours of the morning. It felt worst upon arising, leading a podiatrist and orthopedist to make an initial diagnosis of a fallen arch, pronation of the ankle, arthritis in the top-most bones of the foot and probable tendinitis as a result of the arthritis.

The fallen arch was addressed with an arch support, and eventually a lightly wrapped Coban™ tape around the arch, which provided some partial relief and assisted in the condition not worsening. I anticipate using the arch support for the rest of my life, and I do arch strengthening exercises that I found in an internet search. (Go to www.post-polio.org/edu/pphnews/PPH28-4-Exercises.pdf to see exercises.)

But arthritis eventually proved to be a misdiagnosis that, unfortunately, drove treatment for about a year.

I saw an excellent post-polio specialist, and, at this point, I was having some new consistent back pain. This was considered to be a more serious problem, and x-rays and MRIs revealed several back issues that I addressed with success (physical therapy, core strengthening, ice and yoga) over many months.

However, the foot pain still worsened, even with use of Lofstrand crutches to improve my gait. (I’ve had to reduce the time I use them: My legs began to weaken in dependency, and my elbows began to have pain – probably arthritis – that improves continued, page 4

Francine Falk-Allen had polio in 1951 at age 3. She is retired after 35 years of running a tax and bookkeeping service. She lives in San Rafael, California, with husband Richard Falk, and two cats. She is also a breast cancer survivor.

One arch exercise involves grabbing a towel with the toes, while keeping the heel on the floor.
WE'RE STILL HERE! ... and We Vote!

On November 6, 2012, we in the United States can go to our respective polling places and vote for the men and women who will make decisions that affect us very personally.

I recall my sense of accomplishment at the passage of the Americans with Disabilities Act in July of 1990. PHI had written articles and distributed many postcards to be sent to Congress in support of a more even playing field for polio survivors. My glee was dampened when a lawyer told me, “None of that had anything to do with it. C. Boyden Gray, the chief counsel to George H.W. Bush, was convinced by his friends. He made it happen.”

Truth be told, both made a difference. Gray may have been the pivotal player but it certainly helped for him to know that hundreds of people with disabilities and their families were watching.

Thanks to those who sent a message during our sixth annual WE’RE STILL HERE! week, in spite of that small voice that might have been saying, “Will anyone read this?”

PHI has noticed an increase in your expression of powerlessness within our health care system. “I made an appointment with a doctor who knows my problems, but instead had to see someone else who was unfamiliar with polio.” “It was agreed I needed to see a cardiologist, but the next available appointment was in eight weeks.”

None of us expect perfection in life, but most of us have noticed longer waiting times, less face-to-face time with the physician and more time with the “documenters.”

What also concerns us all is the continued increase in spending on health care in the United States. In 2011, national health spending is estimated to have reached $2.7 trillion, maintaining the estimated health share of GDP at 17.9 percent.

We know something has to be done, but we feel powerless. Where is the ultimate power? It rests in our elected officials, a group of men and women who currently command very limited respect and confidence from the general public.

The first Tuesday in November will once again give each of us an opportunity to help select these individuals.

Take advantage of it. As aging polio survivors, we will need more and more health care services in the future. Our vote may very well determine our access to affordable, high quality health care. Let's help shape our own future.

Vote!

Joan L. Headley, Executive Director, PHI
A bout 25 polio survivors participated in the 2012 Paralympic Games in London a month ago. Two of the athletes were members of the U.S. Team: Zena Cole, at 55 the oldest member of the women's track and field team, won a bronze medal in the discus, and Dennis Ogbe, who contracted polio in his native Nigeria, participated in the shot put and discus.

Other polio survivors represented Great Britain, Kenya, Ghana, Nigeria, India, Pakistan and South Africa. These athletes were among the 4,250 athletes from a total of 164 nations who competed in 21 sports and won 1,992 medals. China, Russia and Great Britain topped the medal table, with the United States ranking sixth.

Few people in the United States saw any of the Paralympic Games on television. NBC, which saturated the airwaves with Olympic coverage, devoted only five and a half hours of coverage of the Paralympics, mostly on cable channels.

Other countries fared better with hundreds of hours of coverage aired in Britain, Europe, Africa and Asia. And the British public bought more tickets to these Paralympics than any other in the past.

Among those who did not catch much of the Paralympics was Steve Goldman. But, too, he was getting ready to hit the road in another of his beloved road trips.

Steve feels some nostalgia for the Paralympics. He was very athletic growing up in New York as a polio survivor. A wheelchair racer, he even held a couple of world records for a while.

In 1972, Steve was on the U.S. Team that participated in the Paralympics in Heidelberg, Germany. That was the year the Olympic Games were bloodied by terrorists in Munich. It was only later that the Olympics and Paralympics were linked, a major step in raising the profile and visibility of the Paralympics.

About 1,000 athletes from 43 countries participated in 10 sports at Heidelberg. Many were polio survivors with the majority of the rest being individuals with spinal cord injuries. The U.S. Paralympic Team comprised 45 athletes, as Steve remembers, with about 30 of them polio survivors. Were you one of them?

Because of his involvement in wheelchair sports, Steve met his future wife and found his way into a career in the Durable Medical Equipment industry. Now retired and on his own

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Steve Goldman at the 1972 Paralympics.

Steve Goldman shows his silver medals for the 100-meter dash and the wheelchair slalom to his parents on arriving home from the Paralympics in 1972.
when I do not use the crutches or lean heavily on a cane.)

Deep tissue massage of the foot, which sounded like a great idea, produced electrical-like shooting pain that went off every 15 to 30 seconds for days. I pushed for an MRI, and finally it revealed, in agreement with a foot x-ray, no arthritis, definite tendinitis, tendonosis and tenosynovitis, or irritation of the tendon sheath, in my posterior tibial and anterior tibialis tendons where they attach to the joint on my foot. The tenosynovitis was the primary culprit in the sharp pain.

What Didn’t Work
Solutions we tried without success were immobilization in a removable plastic cast (which caused my limp to be worse and worsened my back pain) and a (very painful) plasma injection, which several experts recommended, because it nearly always speeds tendon healing. I had to immobilize the foot again, and after six weeks, it was evident that the process had unfortunately and unpredictably worsened my condition.

I tried an ankle-foot orthotic to give the tendons a rest (I walked like Frankenstein), and I tried an air cast, used for sprained ankles, which gave a small amount of relief as it helped prevent pronation of the ankle and foot. I was becoming quite depressed at what seemed to me a definite progression of debilitation.

At one of my post-polio doctor visits, I broke down and cried, feeling that I had travelled a long hard road that led only to a dead end. The tendon pain and the nerve pain of the tenosynovitis made it hard to trust my footing, and I depend so deeply on the stability of this strong, trusted foot. I now was told that it was probable that I had had some vestige of polio effect in the strong foot, as polio rarely strikes one side of the body exclusively.

One doctor commented, “We all face these kinds of problems as we age; it’s not just polio patients.” Non-polio friends told me they also struggled with fallen arches, yet, they did not have an opposing paralyzed leg to deal with. I just could not accept that nothing could be done.

My post-polio doctor gave me one last prescription for physical therapy directed specifically at the tendon issues in my foot. I saw a new PT who had had foot problems herself, and knew the long road back to tendon health. Tendons heal very slowly and need specific attention.

Serendipity! Success!
She suggested exercises, but they aggravated the pain. Then she had a serendipitous thought: try Kinesio® Tex Gold tape on the affected area, to relieve the irritation in the tendon sheath. The tape only has to be changed every five days or so. (Several athletes in the 2012 summer Olympics, particularly the swimmers, used this tape.)

Miraculous! Along with the use of gel ice packs, within a few days, I was having less pain, and the swelling at the tendon attachment point was reduced. Over several weeks, the swelling was gone (except when I was
on my feet too much), indicating that the inflammation had subsided if not been eliminated. I iced the area, at least once a day, especially in the evening after I’d been stomping around all day, which helped reduce inflammation. Then, because the tendon sheath was less irritated, I was able to do the exercises she gave me.

Using wide stretchy rubber therapy bands, starting with the least resistance and increasing to the maximum resistance, I did these exercises at first with five repetitions once a day, then twice daily, then gradually increased to 15 repetitions twice in a session, with two sessions daily. (Go to www.post-polio.org/edu/pphnews/PPH28-4-Exercises.pdf to see exercises.)

I have finally achieved real healing in this long-maligned tendon, and many days I have NO pain in my foot, after a few years of daily and sometimes constant, stabbing pain. If I do too much walking, I pay the price both in my foot and back, and get out the ice packs and rest for a couple of days.

My therapist also recommended that after nearly a year of wearing the Kinesio tape, I gradually wean myself from it, by taking it off for a day or two, wearing it for three days, then off again, etc., until it does not feel like it makes a difference to wear it. I am still in this process and find that some days I am fine without it, and some days, I just want the extra support.

**Hard Work Pays Off**

Here’s the part you already know but don’t want to hear: If you back off on repetitions after achieving considerable success, and have not come to a complete rehabilitation, you will backslide and probably experience renewed pain. I did this, which often happens about 80 to 90 percent of the way through rehab. So, I am bringing myself back to the regular two sets of 15 repetitions, twice a day. As one doctor pointed out, “You’re motivated ...” and we said in unison, “... by pain.”

If you have experienced pain in a supposedly “non-polio” extremity and it can be traced to a tendon issue, I encourage you to pursue a good physical therapist who has been trained in the use of Kinesio tape and tendon rehab. The hard work is so very worth it.
Question: I have a question regarding differential diagnosis specifically utilizing electromyography (EMG, a test that measures the electrical activity of muscles at rest and during contraction). I am 63 with a family history of stenosis. I have low back pain, sometimes radiating diagonally to the hip/thigh region and increasing in intensity, leading to sudden inability to rise from sitting to a standing position from my wheelchair.

An MRI shows L4-5 stenosis. My right leg has always been very weak. The neurologist attempted EMG in the right leg but said there is no electrical response and so there is no way to identify nerve root involvement for possibly repairing the problem. Is there another way to do an EMG on an essentially flaccid leg or another test to diagnose the origin?

A: The potential usefulness of EMG study of a severely long-term paralyzed post-polio leg is indeed limited. There are no other tests to really substitute for it, but I would offer the following thoughts that may be helpful in deciding what is happening with your back and leg (diagnosis) and what to do (treatment).

EMG study could be done on your stronger leg, because spinal stenosis is commonly, although not always, bilateral. If you have had any new loss of sensation in your right foot or leg, this would suggest the stenosis is significant and producing sensory nerve damage.

Your history of radiating pain down the right leg when getting up/changing position/bending suggests a radiculopathy, or pinched nerve problem, in your low back is more the problem than the spinal stenosis, a narrowed central spinal canal space.

You may want to consider a spinal epidural steroid injection. These injections are usually helpful if there is a chronic pinched nerve or spinal stenosis problem causing your symptoms. Even if the problem is not cured, a temporary improvement is helpful and would support the suspected diagnosis. Injections can also be repeated and help avoid surgery, which has significant risks and unpredictable results.

The natural history of people with imaging-demonstrated spinal stenosis is that after one year one-third get better without specific treatment, one-third stay the same and one-third get worse.

Pain going down a leg when making transitional movements, such as standing up, can be a referred pain that originates from an inflammation in the muscles, joints or ligaments of the lower back, pelvis and hips. Evaluation and treatment by a hands-on physical therapist, massage therapist or chiropractor may also be helpful for either resolving the problem or clarifying the true cause.
**Question:** I have lower left leg PPS atrophy. Since hernia surgery recently, I haven’t been able to walk or bicycle as I regularly used to do. I've sometimes noticed worrisome foot edema that is more pronounced and sustained since the surgery. Other than trying not to sit for too long, cutting back on salt and elevating the leg more, is there anything else I should be thinking about or doing for this?

**A:** Hernia surgery could aggravate dependent edema in your polio-affected lower limb in several ways. Sometimes it is the result of salt/water imbalances that follow anesthesia, medications taken before and after surgery and the decreased activity surgery imposes.

Another problem is the swelling in the groin around the hernia repair site because one of the major veins that drains blood from the leg goes through that same area.

In addition, with more sitting and less walking, there is less normal pumping action from leg muscles to cause blood to flow back out of the legs. If any or all of these are the reasons for what you are experiencing, the swelling should largely be gone in the morning after having the leg elevated all night – it can be put on one pillow overnight.

You are doing the right thing by limiting salt, but wrapping the leg and/or elevating it when sitting can also minimize prolonged swelling. You can also wiggle toes and move your ankle muscles up and down while sitting.

There should also be no pain or redness in the leg. The one concern is whether during the surgery you had a new blockage of any veins in your leg. This is known as venous thrombosis. If the leg is red, warm and tender, it may be thrombophlebitis. The former can be silent and resolve with the above simple suggestions. If the latter, and occasionally with the former, there is a possibility that the blocking vein thrombosis (blood clot) can grow, and a piece may break off to cause a pulmonary embolism if a piece of clot travels to the lungs. This can be very serious and occasionally fatal. Generally a blood clot in the leg will be diagnosed by tests, ultrasound and/or scans, and if found, then treated with anti-coagulants.

If you are concerned about having a thrombosis or phlebitis, you should see your doctor immediately or be seen in an urgent care/walk-in clinic.
QUESTION: I am a polio survivor, single, and currently work as an elementary school teacher. I have several years until retirement. Whenever I think of the future, I can get easily overwhelmed wondering “How long can I work? Will I have to go on disability? Who is going to take care of me?” My brother urges me to “live in the moment” and not worry myself, but I can’t seem to let it go. Help!

Response from Stephanie T. Machell, PsyD:

It’s understandable that you would worry about the future. You don’t say anything about your current physical condition, so I don’t know if your concerns are about specific changes you’re experiencing or about the fear that you may experience them. Either way, most people feel less fearful when they have more information. It might be helpful to see your post-polio doctor or to obtain a consultation even if it involves traveling. A post-polio doctor and his or her team can answer your questions and provide you with the information you need. Don’t allow your fears to keep you from going. If there is something wrong, more can be done if it is addressed early than if you wait. You may even receive good news about how you are doing.

Your post-polio doctor can help you answer questions about whether it would be helpful for you to go out on disability. At our clinic, polio survivors are usually advised that they can continue to work if they aren’t experiencing pain, weakness or fatigue that interferes with the demands of their jobs. Those who are finding that their pain and fatigue are getting worse and that working drains their energy are advised to think about going on disability. This can be a difficult and painful decision that can bring up many issues. In my work with polio survivors I’ve found that even those who were most reluctant to stop working don’t regret having made the decision to stop when they find that they have more energy and less pain as a result.

Many polio survivors fear that they will decline and become fully dependent on others. Based on the elderly polio survivors I have known, this is not typical. Overall, people – including polio survivors – are healthier and independent to older ages than at any time before. Fewer people die in nursing homes, and there are more community-based options for care available. Unfortunately, no one knows how they will age. And while you may be fearful of being left alone due to being single, there are no guarantees that those with spouses and children will be cared for by them.

There are techniques for reducing worries that you can try on your own. When you feel worried, try doing relaxation techniques or journaling. A more complicated technique involves scheduling a “worry time” of about 15 minutes a day. When you catch yourself worrying tell yourself you will save that worry for worry time. When worry time comes you must worry about something for the entire 15 minutes. Over time it becomes harder to do this and the worries may fade.

It might help to discuss your concerns with a mental health professional who is knowledgeable about disability issues. Many of the polio survivors who consult me come specifically to address the issues you are raising. It can be helpful to have a safe place where your fears can be acknowledged and discussed openly.
QUESTION: I have been living with PPS for over 4 years now. I use AFO (ankle-foot orthotic) devices and have to be mindful of rest and energy conservation. At family gatherings, my cousin tends to pick places with stairs and restaurants that require extra walking. He knows I have limits, but I feel like a nag to keep reminding him to include my needs in the plans. I am angry that he does not get it. How can I deal with this? I want to look forward to family gatherings, but now I tend to dread them.

Response from Rhoda Olkin, PhD:
Wow, I so get it! These incidents you describe are what psychologists refer to as “microaggressions” – small daily acts or events or comments in which your status as a person with a disability is made both paramount and denigrated. Microaggressions related to race or sexual orientation have been shown to cause psychoemotional symptoms in the subjects. Interestingly, no one has done studies about microaggressions related to disability, but I am sure from my own experiences and those of my students and friends that microaggressions occur daily, and that they inflict an emotional toll. It is even more difficult when the microaggression is perpetrated by someone close to us – it carries more weight, and we might find ourselves thinking s/he should know better!

The truth is, your cousin probably does not get it. It is very hard for people not intimately involved with disability in themselves or a close family member to understand two concepts. The first concept is disability fatigue. The word fatigue is used by everyone, and they usually mean they need a good night’s sleep. But it means something different when a person with polio talks about fatigue. For us, fatigue means that muscles have started to give out, simple acts like going from the bedroom to the kitchen can seem like too much, our minds feel fuzzy, and we are in greater danger of falling. We want to avoid getting over-fatigued because it brings our lives to a halt. Thus it is necessary to pay attention to the entire shape of one’s week, not only what one is doing on Saturday, but what one is doing for the week prior, and the few days after. Others – even family members – might advise us to go to bed early when recuperation from fatigue takes more than that.

The second concept other people often do not understand is the daily assault of inaccessibility. So many of these are out of our control, that when they occur within the family (such as your cousin picking places with stairs), it is tempting to blow up. But he probably does not know what accessible means for you. He probably does not know your capabilities or limits. What is “extra walking” to you might seem trivial to him. He doesn’t have a yardstick to use.

So you know what you have to do. You have to call your cousin or go to lunch with him, and lay out the problem. Do this unrelated to any upcoming event, so you are not mad about a current issue. Say something like, “I realized that you might not know what my limits are in terms of physical abilities. Thus, without meaning to, you sometimes pick places that are very hard for me to go to. I find myself getting angry, but in fact I have never told you what I can and cannot manage. So let me explain ...”
Obesity not only affects the health of older adults, it also affects their everyday lives. Older adults who are obese report more activity limitations and more feelings of sadness and hopelessness than those who are not obese.

The key to healthy aging is maintaining a healthy body weight throughout adulthood as well as later in life. As we age, our body gradually shifts. We lose muscle and gain fat. This shift slows our metabolism, making it easier to gain weight. In addition, some people become less physically active as they get older, increasing the risk of weight gain. For people aging with chronic conditions who have mobility limitations, maintaining a healthy weight can be even more challenging as finding types of physical activity and exercise that work for you and your body becomes more difficult.

There has been little research on the weight of people who were aging with a chronic condition. People with post-polio syndrome (PPS) who participated in our survey may recall answering a question about weight, height and waist circumference. The RRTC studied this data and recently published findings in the Disability and Health Journal.

Based on the answers received, we calculated Body Mass Index (BMI), which is weight divided by height, that results in a number commonly used to categorize if a person is underweight, normal, overweight or obese. In our research, we compared the data we collected to a larger sample of the general population from National Health and Nutrition Examination Survey (NHANES) that assesses the health and nutritional status of U.S. adults and children. We also looked at BMI by chronic condition (multiple sclerosis, post-polio syndrome, muscular dystrophy and spinal cord injury), age group and gender.

Our findings:

◆ The average BMI for both men and women with PPS across all age groups was greater than 25, which is the standard for overweight.

◆ In comparison to people with multiple sclerosis, spinal cord injury and muscular dystrophy, people with PPS, on average, had a higher BMI.

◆ In comparison to the NHANES Survey group, on average, people with PPS had lower BMI, except for women in the youngest age group (40-59 years of age). In other words, people aging with PPS are in better shape compared to the general population aging in the United States.

◆ BMI was positively associated with age, years since diagnosis, mobility and interactions of some of these factors. For example, you are more likely to have a higher BMI if you are older, you've lived with your condition longer, and you have more severe mobility limitations.

◆ No differences were found for waist circumference, which is unusual. There is much debate over the best ways to collect information on weight, height and waist circumference. Ideally, actually weighing someone on a scale and measuring height and waist circumference in-person is best rather than asking someone to report this on a survey, as we did.

◆ To calculate your BMI, go to www.cdc.gov/healthyweight/assessing/bmi/.

References and Resources:
www.cdc.gov/healthyweight/assessing/bmi
www.cdc.gov/healthyweight/calories
www.cdc.gov/healthyweight/losing_weight/eating_habits.html
www.cdc.gov/nchs/nhanes.htm
www.post-polio.org/edu/pphnews/pph19-2a.html
Thank you

For recognizing your friends and loved ones with contributions to support the unique mission of PHI and IVUN. PHI strives to publish an accurate list. Please contact us if we made an error.

Contributions to PHI’s educational, advocacy, and networking activities ...

In Memory of
Shirley Ann Callahan        Robert T. O’Brien
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Joseph Kohn                  Sherman Sklar
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Polio Survivors and the Paralympics
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again, he’s indulging his passion for packing up his car and touring the country.

A lot has changed in 40 years. Technology has vastly improved. Steve says in 1972, U.S. athletes used regular E&J chairs, but that the Europeans had more advanced equipment. Training has gotten better and more sophisticated, and other disabilities are represented.

But polio remains a part of the Paralympics. There are still plenty of younger polio survivors in parts of the world where polio eradication is perhaps in its last lap. They are likely to be competing in Brazil in 2016. And, hopefully, we’ll be able to see more of their efforts in the U.S. media. Steve Goldman will try to watch, even if he’s on the road. ▲
SON HAS POLIO. PROGNOSIS POOR.

So read the telegram received by Lauro Halstead’s parents in August 1954. Their 18-year-old son was hitchhiking around Europe following his first year in college when he contracted polio that would leave his right arm totally paralyzed.

Nearly six decades later, Lauro Halstead, MD, MPH, has announced his retirement after a distinguished career that includes 20 years on the medical faculties of the University of Rochester and Baylor College of Medicine and 26 years as director of the Post-Polio Program and medical director of the Spinal Cord Injury Program and the Male SCI Fertility Program at MedStar National Rehabilitation Hospital in Washington, D.C.

Following his own rehabilitation, Dr. Halstead went on to earn a medical degree from the University of Rochester School of Medicine and a Masters Degree in Public Health from Harvard University. In the early 1980s, he began to experience new symptoms of weakness which led him to organize a conference of health care professionals at Warm Springs, Georgia. At about this time, the term post-polio syndrome was introduced and quickly became the unofficial designation for the new problems polio survivors were experiencing.

Dr. Halstead became internationally known for his work on the late effects of polio and male SCI fertility and has written or edited seven books. He has published widely in the areas of spinal cord injury, post-polio syndrome and rehabilitation methods and philosophy. In retirement, Dr. Halstead says he will have a limited private practice for people aging with a disability and continue to write, act as a consultant to medical facilities, travel and re-learn to speak Italian.