

POLIO PERSPECTIVE

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Stubborn!

By Millie Malone Lill

Why do polio survivors insist on walking till they can no longer put one foot in front of the other? And why does it bother me so much when they do? It isn't any of my business. Or is it? I am, after all, an advocate. I want people to live long, healthy and fulfilling lives. I want them to do it with the least possible discomfort. I write columns, speak at conferences, counsel other polio survivors. This is what I do, and this is my purpose and my joy.

We were threatened by our physical therapists when we originally contracted polio. I can't even tell you how many times I balked at doing the painful exercises only to be told, "So do you want to end up in a wheelchair?" That was the ultimate outrage, to have to use a wheelchair. So we struggled, we exercised, and we walked. We forced our neurons to put out little sprouts and enervate those muscle fibers that polio had orphaned. We were survivors, by golly, and we could do anything any able bodied person could do.

We overcame polio! It was a point of pride to continue to do anything an able bodied person could do and do it better than they could. Of course, it took us three times as much energy, and we operated mostly on adrenaline after awhile. Exhaustion was our daily companion, but the important thing was that we did it. We lived with pain and were proud of how much we could endure without cracking.

Our parents, our doctors, our physical therapists all encouraged this kind of thinking. They didn't know then that we were setting ourselves up for Post Polio Syndrome. We were no longer the victim of that dreaded disease that killed so many of our peers. Many of us were pre-schoolers when polio attacked us, so we grew up thinking that the only way to live was with pain and determination and exhaustion. Some of us cannot remember ever being fully rested, pain free and full of energy.

Polio survivors are known for being Type A personalities. As a group, we are more likely to have high profile jobs, good educations and long lasting marriages as opposed to other disability groups. It is so hard to be told now that we must conserve to preserve. However, that is what we must do.

Belonging to several online polio groups as well as some support groups that I go to in person, I hear a lot of us saying how proud we are of not 'giving in' to a wheelchair. I see people struggling to continue

to walk as if there were a prize for who stays out of the wheelchair the longest. Well, yes, there is a prize. You will be awarded a set of worn out rotator cuffs that cannot be operated on because you have used your arms to replace your legs for so long that the cuffs are nothing but fringe. You also get hands that are crippled from using crutches for so long. As an additional prize, you might also be eligible for having to hire someone to wipe your butt for you because your hands refuse to work anymore.

Meanwhile, the losers, those of us who ‘gave in,’ will use our power chairs for shopping and be able to actually enjoy rather than just endure the experience. We will be able to hold our grandchildren because we have laps and our arms still function enough for big hugs. At the end of the day, we will have enough energy left to greet our loved ones with a smile instead of a pain filled grimace. We will have the strength to get up out of the chair for those tasks that are too difficult to do while seated, too. We losers have to walk a tightrope to be sure we do just enough to stay active but not so much that we are so fatigued that we are not enjoying our lives. I would not give up my power chair for all the world. Paradoxically, I find that the more I use it, the less I *have* to use it.

POLIO and SHOES:

My Journey from Agony to Acceptance

*Linda Wheeler Donahue
Southbury, Connecticut USA*

Shoes have always had an inordinately large impact in my life.



Growing up, like many of you, I’m sure, I had to wear dark brown ankle high lace up shoes. Even as a little girl, I just knew these were not advancing my fashion im age one bit.

They seemed to stand out like huge brown exclamation marks. Perhaps they were exclaiming, “I HAVE to wear these, but it is not by choice.” As a young girl, I would have far preferred wearing pretty pastel Mary Janes!



When I went away to college, I purchased a pair of shoe protectors called “Drizzle Boots.” These were clear plastic that created a slightly blurred look. Imagine accidentally touching your eyeglasses with baby oil, then donning them and looking at my shoes. That was the obscured image I was going for. It all seems so ridiculous now but I wore those Drizzle Boots for 4 years, rain or shine, never missing a day.



By my first year of teaching, I was wearing orthopedic oxford style shoes that I jokingly referred to as my clodhoppers. Because I took a child’s size, they unfortunately only came in the color red. I did not want to wear them “as is” because it would have drawn too much attention to my feet. So, I bought tan, beige, and black shoe paint and painted my oxfords. This was one more psychological attempt to make my deformed feet disappear. No matter what colors I wore in my clothing, my shoes were instructed to fade away behind their bland color.

One day about twenty years ago, my daughter, Sarah, and I were shopping in a department store. She said, “Come on, Mom; let’s see if you could wear a pair of tennis shoes now that you use a scooter.” So off we went to the shoe aisle, me poohpooing the idea as futility. “This will never work,” I muttered. We arrived in the shoe area and went to the children’s racks, since my shoe size was a 1 on the right foot and a 2 on the left.

When I tried on an adorable pair of sneakers, you should have heard the exclamations of delight coming from the two of us. “Oh WOW! These are so cute, they fit, and I can wear them now that I am seated.” It was a happy day indeed and the beginning of a long progression of joyful shoe shopping to come.

I had always wished I could wear feminine, slip-on style flats or pumps, but slip-on shoes fall off my feet because I lack the muscles necessary to grip the shoes with my toes. So for decades I wore the lace-up oxfords to assure that the shoes clung to my feet. It wasn’t until I began to use a wheelchair fulltime that I was finally able not only to wear the tennis shoes, but also to wear other attractive shoe styles. And what a thrill that has been. Now, I joyfully overcompensate for all those years in bland shoes with footwear in every color of the rainbow. My closet overflows!

There are many benefits to using a wheelchair or scooter, but this shoe advantage is by far the most fun. I can wear fashion-forward styles in every shape and color . . . shoes I could never walk a step in, but that look attractive perched atop my wheelchair footrest.

Now in my older years, my feet have widened and I cannot get away with the dainty flats anymore, however I no longer hide in beige. I have to adapt to my changing body, but I now know I can still let my personality shine through. In fact, bright red shoes have actually become my trademark. I never would have believed that when I was dyeing my original red clodhoppers beige! It took a long time to accept the parts of myself that are associated with my disability.

Now, when I go to a meeting or an event, if I choose to slip on red shoes, I consider this color choice my Declaration of Acceptance. I accept myself, polio feet and all, and take pride in donning bright red shoes or even my double-wide added depth lace-up therapeutic footwear. No drizzle boots are needed to defuse the look. No beige color calls upon my feet to vanish.

I have traveled the road from agony to acceptance, and I celebrate my journey with color.

Photos: Top Left, Linda age 6; Lower photo on Right: Drizzle Boots over red shoes; Lower Left, Linda in her manual wheelchair ready to attend a wedding. The lace-up orthopedic shoes are always a part of any formal outfit.

About the Author:

Professor Emeritus of Arts and Humanities, Linda Wheeler Donahue, is a polio survivor, a disability activist, writer, and speaker. Many of her essays deal with the psychological and social consequences of disability, and with ways to prevent and resolve problems associated with the aftermath of polio.

POLIO and SHOES:

An Examination of our Unique Footwear Challenges

Linda Wheeler Donahue

“Boots and shoes are the greatest trouble of my life. Everything else one can turn and turn about, and make old look like new; but there’s no coaxing boots and shoes to look better than they are.”

The words above were written by English novelist, George Eliot (1819-80). Hyperbole aside, I daresay many of us can identify with that opening phrase “... shoes are the greatest trouble in my life.” So sit down, pull off your shoes, curl up and read about easing the footwear burdens in your life.

Correctly fitted shoes can ease walking discomfort for people who had polio. Shoes are also part of our presentation to the world and therefore contain an emotional component that cannot be denied. The subject of shoes has always interested me, frustrated me, perplexed me, and occasionally, thrilled me. I have spent inordinate time and energy in my search for the right shoes.

No exploration of the subject of shoes for polio survivors is possible without first conducting an inquiry into the complex dynamics of human locomotion. It is because we polio survivors have pathological gait patterns that our feet require specialized footwear. I find the excellent work of Dr. Jacquelin Perry particularly helpful in understanding polio gait deviations. In my opinion, all health care professionals involved in musculoskeletal patient care should carefully study Dr. Perry’s research.

In 1995 a study was done by the Biomedical Engineering Department at Perdue University examining the gait kinematics and dynamics of polio survivors utilizing newly developed graphical and analytical tools. The researchers detected abnormal patterns in the kinematics of the polio gait.

Nine healthy subjects and seventeen polio survivors were involved in the project. Significant increases in the knee extension and ankle plantar flexion of polio patients were observed during the weight acceptance phases of their gait. Polio survivors also exhibited highly noticeable excessive hip flexion during the late swing phase of their ambulation. Not surprising, the people who had polio walked less symmetrically and less stably than people who did not have polio. In addition, weaknesses in lower extremity muscles of polio folks were found to be an important factor that affected stable ambulation.

Doctors who Specialize in Feet

A rule of thumb is that it is not normal for anyone to experience foot pain, not even polio survivors. If you have pain in any area of your feet, it is wise to visit a health care professional who specializes in the medical treatment of the foot. A good podiatrist will study pathological mechanisms of your polio gait and will take into account your foot deviations, as well as knee gait abnormality, hip gait deviations, pelvis and trunk pathological gait, all of which, many of us have. Here are three categories of professionals trained to treat feet.

Podiatrist

A podiatrist, or doctor of podiatric medicine, is a health care professional whose total training focuses on the foot, ankle and related body systems. As a specialist in foot care, the podiatrist receives training in the diagnosis, treatment and prevention of foot and ankle disorders by medical and surgical means. After obtaining an undergraduate degree, the podiatric doctor spends four years in a college of podiatric medicine to obtain a doctorate degree. In addition, many podiatrists further their education by participating in a post-graduate residency program at an approved hospital or university. Following their doctorate degree, each podiatrist must pass national and state examinations in order to be licensed by the state in which he or she will practice.

Orthopaedist

An orthopaedic surgeon is a doctor who corrects congenital or functional abnormalities of the bones with surgery, casting, and bracing. Orthopaedists also treat conditions of the feet. It is the branch of surgery broadly concerned with the skeletal system (bones). The orthopaedist deals with the prevention or correction of injuries or disorders of the skeletal system and associated muscles, joints, and ligaments.

Pedorthist

Ever hear of a pedorthist? I did not know this specialty existed until I began my research for this article. A certified pedorthist fits patients for shoes and orthoses that are well-made and well-fitting; they often work closely with a podiatrist and are adept in creating footwear solutions for problem feet.

Their goal is to get your feet into shoes that are appropriate for your diagnosis and lifestyle. They understand how therapeutic footwear affects a person's biomechanics. The pedorthist will begin by measuring both feet, since one foot is commonly larger than the other, and especially so in people who had polio. The pedorthist will determine if the shoe is wide enough and that the widest part of the foot rests comfortably in the widest part of the shoe. The length of the shoe is important; there should be about a thumb's width between the longest toe and the front of the shoe.

The style of the shoe will be determined by your activity level and the desired effect of the footwear, such as protection, accommodation, support and stability. The pedorthist will usually recommend shoes made of leather which allow the foot to breathe and can also be easily stretched. The best shoes for people who had polio are often ones with thick, cushioned soles, however, this is not always the case. When I was walking, I needed a rigid leather sole. A cushy sole rocked and rolled too much and did not support my weak feet and ankles. Now that I am a full-time wheelchair user, I love the comfort of a soft sole, extra padding in the tongue, and softness around the top line of the shoe. A good pedorthist will listen to you carefully and take into account your individual needs.

Shoe Shopping

Finding a shoe that fits properly can be a frustrating and time-consuming course of action. Because many of us have subtle and not-so-subtle abnormalities of our feet, the process of finding a proper fitting shoe can be difficult. There are a few simple guidelines that, if followed, can make the process a bit more tolerable.

When purchasing shoes, it is always a good idea to have the salesman measure your feet. It is also important to have both feet measured, because in many instances there may be a difference in the size of your feet.

Shopping online? Since there are many more diabetics than polio survivors, it is helpful to put the word "diabetic" in your search parameters. Stores that feature footwear for diabetics are more likely to offer shoes that will work for people who had polio.

It is useful to familiarize yourself with some basic terminology. Footwear meeting these types of requirements may be eligible for partial reimbursement from Medicare through the Therapeutic Shoe Bill.

Molded shoes - A custom-molded shoe is one that 1) is constructed over a positive model of the patient's foot, 2) is made from leather or other suitable material of equal quality, 3) has removable inserts that can be altered or

replaced as the patient's condition warrants and 4) has some form of shoe closure. This includes a shoe with or without an internally seamless toe.

Orthopedic Shoes -

"Orthopedic shoes" are shoes that are specially constructed to aid in the correction of a deformity of the muscular skeletal structure of the foot. These shoes often have a Goodyear welt, steel shank and elongated medial counter which are modified to compensate for an abnormality of the foot. Various modifications, such as wedges, can be applied to or put inside this basic orthopedic shoe.

Orthoses -

These are used to support, align, prevent or correct deformities or to improve the functions of movable parts of the body. A primary function of the orthosis is to reduce pressures at potential problem sites. Custom orthotics are fabricated from an impression or 3 dimensional laser scan of the foot. Once the orthoses have been fitted and rechecked, they will need to be properly maintained, which includes periodic replacement.

Shoe Inserts –

Shoe inserts are devices usually constructed of plexiglass, hard plastic or other rigid material fashioned for the individual foot by a laboratory. An orthotic device is fabricated according to the specifications written on the prescription by the client's physician.

Extra-Depth Shoes - Extra-

depth therapeutic footwear refers to shoes that are roomier inside the toe box, instep, arch, and heel. They are characterized by their adaptable features, including modifiable uppers and soles, extra space and removable inlays, which allow the shoes to accommodate numerous types and styles of orthotics and other inserts. Even if you do not use orthotics, the extra room can provide a good level of roomy foot comfort.

Mismates

"Mismatched shoes" are one pair of orthopedic shoes in which one shoe is a whole size and/or width larger than the other.

Many polio survivors have different size feet. This can present quite a challenge in finding comfortable footwear. A rule of thumb is to fit the longest foot. Then you can take up the slack for the smaller foot by adding a sponge shoe insole, soft lamb's wool padding, or even tissues to stuff the toe of the shoe for the smaller foot.

Polio feet may also have width differences or the double-whammy of length *and* width differences. This problem can force a delicate balancing act. If there is a length and width difference, you may want to fit the longer length and narrower width to balance both feet.

If your foot size differential is more than a size and a half or if there is a substantial width difference, you should purchase mismates. One option is if you are an 8 on the left foot and a 5 on the right, for example, you may be able to find a mismates shoe buddy. I met a friend online with feet sized opposite of mine and we exchange the extra pair of shoes when we need to buy two pairs. It is always a happy surprise to get a package in the mail from her.

If you have Internet access, you can register your mismate sizes at this website: <http://www.mermade.homestead.com/ped-pals.html>. By adding your name to this free listing service, you may just find your "sole-mate." Some retail outlets have policies regarding purchasing mismates. Here are three.

Nordstrom

Nordstrom stores have a policy whereby you can purchase two different sized shoes and pay only for the price of one pair. However, their ruling is that the size differential must be 2 sizes or more. This policy was established by Mrs. Nordstrom, a polio survivor herself. For more information or to request a free catalog, call 1-800-285-5800. The Nordstrom website is <http://www.nordstrom.com/>.

Comfort Corner

Perhaps you receive a small catalog in the mail called Comfort Corner. Wendy H. Morrison, co-founder of Comfort Corner, in describing her company's mission says: "Each and every item is chosen for its ability to bring everyday comfort and ease into your life." Their policy on mismates is to charge full price for one pair of shoes and half price for the second pair. Unlike Nordstrom, they do not require a 2 size differential. For more information, call 1-800-735-4994 or visit their website at: www.comfortcorner.com.

Comfort Shoe Specialists

While I do not have personal experience with this company, I am intrigued by their willingness to alter shoes. They write: "We can take any shoe and customize the uppers in many beautiful ways! We can add straps, remove straps, change the color, or even put on a larger sole to make a shoe bigger!" For more information, call 314-822-3300 or visit their website at:

<http://www.comfortshoe.com/custom.html>

Psychosocial Aspects of Podiatry

In researching this subject, I was very encouraged to discover that podiatry professionals recognize the emotional aspect of foot problems. Like other bodily attributes such as one's hair, weight, or facial features, for polio survivors, feet often carry a heavy psychosocial price tag. For us, feet are not just feet; they are a sensitive and emotional issue.

When selecting a podiatrist or pedorthist, it is helpful to find a compassionate one who understands the social issues relative to feet and footwear as well as simply the practical side of the subject. Correctly fitted shoes can ease walking discomfort for people who had polio. Many of us have pathological gait patterns that make the task of walking quite precarious and place great stress on our mechanical and metabolic systems. We use a complex series of structural and functional compensations to accomplish the delicate mission of walking. The stresses placed on nerves, muscles, and joints in a polio survivor are in many cases several times those experienced by other people.

There is no such thing as a typical polio gait pattern since polio survivors are unique and creative with compensations to maintain their walking function. Common problems affecting gait include lower-limb flaccidity, contracture, dropfoot, hip flexor weakness and abdominal weakness leading to curvature of the spine. Surgical interventions such as fusions, osteotomies and tendon transfers can create altered skeletal mechanics that further influence overall movement pattern. Fortunately, there are medical professionals who are familiar with these issues and can be helpful in guiding your choice of shoes. A critical factor in determining your shoe selection is to recognize your unique process of ambulation. Shoes should bring comfort and support while stabilizing your gait. People who had polio can benefit greatly from properly fitting shoes. Their shoes should provide stability, comfort, support and, to the extent possible, even be aesthetically pleasing. Optimally, the right shoes will do no less than enhance your overall quality of life.

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Linda Wheeler Donahue

About the Author

Linda Wheeler Donahue, Professor Emeritus of Arts and Humanities, is a polio survivor, writer, and speaker.

She is President of *The Polio Outreach of Connecticut* and is a frequent presenter at conferences, focusing on the social/emotional complexities of disability.

Linda's essays dealing with the aftermath of polio, have been published worldwide. She welcomes feedback and can be reached at LinOnnLine@aol.com.

WEB CORNER

Here are a few interesting web sites:

Take a virtual tour of the Holy Land via this website. According to a friend who just visited there, many places are not accessible. Going via the internet takes care of that problem.

<http://www.p4panorama.com/panos/HOLYLAND/index.html>

For easier computing, check out this site:

<http://www.arthritisselfmanagement.com/health/daily-living/easier-computing>

Polio Health International has added a new feature, Ask Dr. Maynard.

<http://www.post-polio.org/edu/askdrmay.html>

Here is a handy little gadget that might help some of us:

<http://www.paraladder.com/>