POST-POLIO HEALTH

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PHI's mission is supported by its Membership.

Protecting the Future: Lessons from Polio

WE'RE STILL HERE
www.post-polio.org

Each October, Post-Polio Health International's "WE'RE STILL HERE!" campaign gives survivors a platform to share their strength, experience, and hard-earned wisdom with the wider world. This year, under the theme "Protecting the Future: Lessons from Polio," we invited our community to speak directly to the growing concerns around vaccine hesitancy. As national debates over vaccine requirements intensified, many of you stepped forward—not only by sending us your reflections, but also by writing letters to the editor, submitting op-eds, and engaging with local media to remind the public why vaccines remain essential. Your voices carried moral authority and personal insight that no statistic alone can match.

In this issue, we're honored to share a selection of the thoughtful, candid submissions you sent in. These reflections do more than recount the long-term effects of polio, they highlight resilience, purpose, and the determination to use lived experience for the public good. Together, your stories and your advocacy helped counter misinformation and spark meaningful conversations in communities across the country. We thank every survivor who participated in this year's campaign and hope the voices featured here will continue to inspire action and understanding long after "WE'RE STILL HERE!" week has ended.

Vaccines Are Immune System Antiviral Software

Steven Ahrenholz, Union Township, Ohio

I was diagnosed with paralytic spinal polio on August 9, 1955, at 15 months old. My mother had been trying valiantly to get me vaccinated all summer, but my pediatrician's office wasn't administering the Salk vaccine to their patients following the Cutter incident in spring of that year. Vaccinations resumed in June 1955 following confirmation that vaccine stocks from the three other manufacturers followed proper manufacturing processes and their vaccine contained only killed poliovirus. Because of the withholding of the Salk vaccine following the post-Cutter incident resolution by my pediatrician's office, I missed a window of opportunity to be vaccinated.

I have dealt with the aftermath for the past 70 years. Immunization-preventable diseases are just that—they equip the body to prevent or significantly reduce the likelihood of preventable morbidity and mortality.

No one knows what course these infections will take in any one individual until it occurs. If it goes badly, they'll have a lifetime to deal with the residuals, whatever form they take.

Vaccinations play a huge role in protecting ourselves and everyone else. Individuals may have asymptomatic infections where they feel fine but are still shedding the virus to everyone around them who, if they become infected, may develop a severe infection. Individuals may also shed the virus before symptoms appear or for extended periods of time

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following infection, which may then infect others.

Some folks want iron-clad guarantees of safety before getting immunized—not realizing that vaccines are one of the most successful disease prevention measures available. They are one of the most vetted medical and public health interventions in existence. They are ineffective once an infection by a pathogen has hijacked the body's defense mechanisms and disease occurs. Vaccines provide our bodies with an additional tool in its infection defense toolbox. They also defend us against infection from those around us—and you won't necessarily know who those people are.

I remain vigilant keeping ALL my vaccinations current. I promote this message to those around me, who sometimes are surprised to learn I'm living history as a polio survivor, especially when they see me using assistive devices that they haven't seen me use before. Remember, the pathogens don't vanish just because no one seems to be ill.

Reflecting on a Life with Polio

Diane Bouchard Bendahmane,
Lebanon, New Jersey

In August 1940, at age three, I came down with polio. In those days, with no vaccine, it was a parent's worst nightmare. Our family doctor told my parents the only available treatment was to put my legs in steel braces. My mother refused (reasoning that a limb put in a brace would never get stronger), so the doctor told her she might as well take me to Elizabeth Kenny, the Australian nurse famous for her unconventional treatment for polio. Kenny endorsed and demonstrated muscle "re-education"—hot packs followed by exercise.

Fortuitously, that year, Sister Kenny was in Minneapolis, my hometown, working at the Curative Workshop. She was tall and rather gruff, and I remember how frightened I was to be up on a high examination table. That is one of my earliest memories; others are also about polio. For the next six months, my mother applied hot packs to my legs and manipulated them every six hours, night and day. She held firmly to the belief

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Post-Polio Health International's mission is to collect, preserve, and make available research and knowledge to promote the well-being, and independence of polio survivors, home ventilator users, their caregivers and families, and to support the health professionals who treat them.

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that, thanks to Sister Kenny, her little girl could walk. I was left with paralysis in my right leg only. My parents encouraged me by pointing to then-President Franklin Delano Roosevelt, a fellow polio survivor. “You can be anything you want,” they promised.

Now I am 88, a retiree. After starting out as a Peace Corps volunteer and staff member in the late-1960s, I went on to have a satisfying career as writer/editor for organizations dedicated to bettering the lives of the poor in developing countries. Most people view me as a strong person who led a successful life despite polio. What they don’t realize is the heartache, obstacles, and humiliation polio has brought me for 85 years. It has been the most defining factor in my personality and temperament.

The day in 1955 when the polio vaccine was announced, my mother was filled with gladness. Never again would a mother have to worry about polio, or watch her child grow more and more crippled, as she had. She would be incredulous to find out that today some people aren’t interested in getting their kids vaccinated. No one should have to live with this terrible disease. Do your kids a favor. Get them vaccinated the first chance you get. If all kids were vaccinated, polio would die out.

Living with the Effects of Polio

Corina Zalace, Niceville, Florida

I have survived over 106 surgeries in the past 77 years, mostly to correct my polio deformities. Since having had polio at age two in Indonesia, where I was born to Dutch parents, my life has been full of adventure and challenges. At age nine, I and my family fled Indonesia to the Netherlands due to a revolution. Two years later we immigrated to California, where better medical care was available for me with my polio problems.

The first thing that happened was that the school nurse in my seventh-grade class called me into her office one morning. She had watched me in the hallways struggling with my walking and asked if I had contracted polio. I said, “Yes.” She then asked if the family and I had been vaccinated for the virus. This was in 1961. Since I was the only one who had gotten polio and no other family member did, my mother told me that everyone else was immune to it. The nurse then told me the shocking news that there are three strains of polio and we all, including me, needed to be vaccinated for all of them. As soon as we learned this, my parents took us all to get vaccinated for all three strains of polio. That made a huge impression on me, and I’ve never forgotten it.

At age twenty, I married my best friend, Stan. We now have three wonderful children, four grandchildren, and one great granddaughter. Our life as a USAF family was a great experience for me because we ended up traveling all over the United States and Europe. I have been permanently in a wheelchair since 1986 when I was 38 years old, but it never stopped me from traveling, even as recently as this month.

I love learning about different cultures and meeting interesting people. But it has not been easy for me. I ended up having to buy a van with a lift or ramp, and insurance does not cover that at all. My body has been through the mill for 75 years since I contracted polio. For years I walked with crutches and a long leg brace, but my legs got weaker and weaker, finally landing me in a wheelchair.

Walking on crutches for years and then pushing a wheelchair has created serious problems in my arms. My left elbow has no more cartilage and is excruciatingly painful and getting very weak. I had my back and neck fused in 2010 from C2-S1 due to severe scoliosis from the polio. My neck hurts all the time, whether I am up or down, to the point of having to take strong pain medications.

Polio has truly been a struggle of pain, weakness, and great difficulty. Always having to learn to adapt to every

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situation, from walking, or actually limping, to watching my body decline year after year and grieving through the whole process, has been difficult and challenging. Now at age 77, I am unable to dress myself, bathe myself, cook, or clean house. Even going to the bathroom is something I require assistance with. I am not happy about it, but life goes on. So, I have a cleaning lady for our house, a caregiver to personally help me, and even several friends who cook for us.

God has blessed us tremendously. My parents were wonderful, always being positive and supportive. Stan has faithfully stood by my side for 57 wonderful years, as have my children. My parents instilled a great positive attitude in me allowing me to be a survivor and overcomer. For that I am extremely grateful. I would not wish this disease of polio on anyone, and I wish the vaccine had been available when I was a child. It is a horrible disease to have to struggle with. So, from personal experience, I am all for vaccinations. ■

To everyone who shared their voice this year—thank you. Your reflections remind us why polio survivors' perspectives matter now more than ever. You can find these stories, along with additional submissions we couldn't fit in this issue, at https://tinyurl.com/2025WSH/.

BOOK CORNER

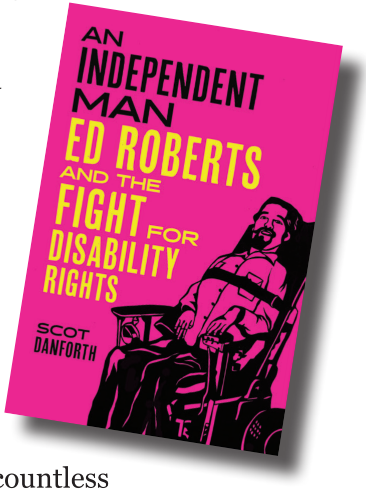
An Independent Man: Ed Roberts and the Fight for Disability Rights

Scot Danforth, University of California Press, 2025

An Independent Man is the first full biography of Ed Roberts, a polio survivor whose life and leadership helped ignite the modern disability rights movement. Author Scot Danforth presents Roberts not simply as an activist, but as a visionary who challenged deeply entrenched assumptions about disability and equality—and then built lasting institutions to turn those ideas into reality.

The book places Roberts' story in the pre-disability rights era, when polio often meant isolation, lowered expectations, and lives defined by dependency. Roberts rejected that fate. He pursued higher education, became a prominent student activist at the University of California, Berkeley, and pushed insistently for the right to live, learn, and work as a full participant in society.

Danforth follows Roberts through his most influential achievements, which include founding UC's Physically Disabled Students Program, which became the model for Berkeley's Center for Independent Living and more than 400 independent living centers across the country; becoming the first California State Director of Rehabilitation with a disability in 1976; and co-founding the Berkeley-based World Institute on Disability in 1983. Throughout the book, Danforth shows how Roberts' belief in the value and agency of those living with a disability helped reshape public policy.



For polio survivors, Roberts' story will likely feel familiar. His struggles with access, autonomy, education, and health care mirror issues many in our community have faced, and his insistence on the value and dignity of disabled lives remains powerfully relevant. By turning ideas into action, Roberts helped lay the groundwork for the rights we enjoy today. The book highlights how one person's vision, amplified by the work of countless advocates, built a movement that advanced opportunity and redefined independence for millions of Americans living with a disability. ■

An Independent Man is available from most major book retailers, though we encourage you to check with your local independent bookstore.

A Tribute to Patricia Ann Morrison

Cyril J. Jardine

Patricia Ann Morrison caught the poliovirus the summer of 1955 when she was eleven, living with her parents and older brother in Richwood, West Virginia. Pat spent the next year in Marmet Hospital learning how to manage the paralysis that affected her muscles from her waist down to her toes. In those days, Marmet was a two-hour hilly drive from Richwood, only attempted on weekends. Pat returned home using a full-body prosthetic that, over a few years, was gradually reduced to leg braces. Elbow crutches provided mobility.

She completed elementary school and graduated from Richwood High School in 1962. Pat received her B.A. from Glenville State College and worked as a Special Education and Reading teacher in Carroll County, Maryland, for thirty years, retiring in 1996.

I met Pat through Match.com in 2013, and we were partners until her death in July 2024. She owned her condo in Westminster, Maryland, and had groceries and anything else she needed delivered. I lived 30 minutes away and spent three to four days a week with Pat.

Pat drove her own car and lived independently until January 2023 when a broken hip took away her independence. She was an expert in managing her post-polio experience and exercised daily with hand and foot weights for strength and stretching routines for flexibility. She was very proud of being able to touch her forehead to her knees at age 79!

Pat had a library of polio and post-polio books and was an avid reader using her Nook e-reader. She was very concerned about her diet and nutrition. I recall driving her to a farm in Pennsylvania to buy organic milk and produce. During her retirement, Pat took yoga classes and tried to volunteer, but was very disappointed that organizations judged her abilities by her appearance.

When Pat and I decided to be partners, I was 70 and she was 69. I almost forgot another significant polio-related issue that Pat managed daily: constipation. Muscles in Pat's abdomen were weakened by the poliovirus which led to a lifetime of constipation. Diet and drugs only partially helped. Pat learned and performed manual extraction, which no one ever wants to talk about. No child should ever get infected by polio.

Personally, I thought Pat was a beautiful woman whom I liked to hang out with. ■

Editor's note: Patricia Ann Morrison, who passed away in July 2024, was a longtime supporter of Post-Polio Health International and made a generous bequest to further PHI's mission. PHI is deeply grateful for her lasting generosity. This remembrance was written by her surviving partner, Cyril Jardine.

Question: *I'm running into new limits as I get older with post-polio. The physical stuff is mostly manageable. It's figuring out how to stay engaged and active that's tricky. I used to volunteer a lot and be pretty active socially, but that's gotten harder. I don't want to sit around all day, but I also can't keep up the pace I used to. Any advice for staying involved and keeping some structure in my life without overdoing it?*

Response from Rhoda Olkin, PhD:

You are asking about one of the more difficult aspects of aging with polio, which is the noticeable decrement in energy and stamina. The change can be difficult to navigate, especially for those who were quite active in their earlier years. The changes require a renegotiation of what we do. A decision to do something on Saturday might imply a decision to do very little on Sunday. Once we cut out the easy things, harder decisions must be made. Ordering food online, buying more prepared food, maybe hiring a cleaner once a month—these are things that do not change how we define ourselves.

Few will feel diminished by not going to the grocery store every week. But then there are the items that are meaningful and that provide socialization. Both meaning and socialization are vital for good mental health. So, what to do?

This writer says they "volunteer a lot." One idea is to volunteer a little, perhaps no more than one day a week, followed by a slower day at home. They were "pretty active socially"—now be a little active socially. The opposite of lots of volunteering and socializing is not "to sit around all day" but to do mindful planning. I use a physical weekly planner, so that I can open to the coming week and see what activities I have each day.

For example, I see which days I have to get up early and be active right away (hard for me), which days I am seeing friends, check if I have any deadlines coming up. Then once those are clear, I can estimate when I will need down time. This is a busy week for me, so Sunday I am not planning any activities outside the house.

But what about inside the house? I may "sit around," but it might be at my craft table where I make holiday cards or do painting. I might binge-watch a TV show I haven't had time for. I'll do the *New York Times* puzzles and a jigsaw puzzle.

The critical things are to:

(a) plan your energy expenditure over a week, not day by day;

(b) keep seeing people and socializing some each week;

(c) continue doing something that feels meaningful (like volunteering);

(d) program in some fun activities that don't require much energy.

And, here's the hard one: Accept the new reality. Don't fight it, but work within it.

Dr. Rhoda Olkin is a Distinguished Professor of Clinical Psychology at the California School of Professional Psychology in San Francisco, as well as the Executive Director of the Institute on Disability and Health Psychology. She is a polio survivor and single mother of two grown children.

Question: *Technology is supposed to make life easier, but half the time I find myself overwhelmed with online forms, telehealth portals, apps for everything. It's getting harder to keep up. Do you have any suggestions for how us older adults can manage the tech side of life without feeling like we need a full-time tech support person?*

Response from Stephanie T. Machell, PsyD:

Which would surprise you more: that there are young people who hate using technology or that there are older people who love it? Both are true, and more common than stereotypes might lead you to believe. Stereotypes influence our thinking and behavior towards ourselves and others. Internalizing negative stereotypes and assumptions about aging (and disability) can prevent us from trying new things and discovering that we like or are good at them.

Telling yourself that "older" adults find tech difficult to navigate can set you up for failure and frustration. Try changing your self-talk. Remind yourself that you have learned many difficult things over the course of your life and that while learning to use a new app may be challenging, it is far from impossible.

When you make a mistake, remind yourself that learning any new skill involves making mistakes. Remind yourself that there is very little you can do when filling out a form or using an app that will cause irreparable damage to your device or expose you to danger, especially if you have antivirus software installed that is kept up to date and avoid clicking on anything that looks suspect.

If you become frustrated, remember that everyone, regardless of age, encounters frustrating tech issues, including poorly designed forms, hard-to-navigate websites, and unsupportive support people. Take a break and try again later.

It may help to remind yourself that you don't need to know very much about how a device or an app works to use it. For example, you probably read and respond to email, browse the internet, and/or use Facetime or Zoom without knowing about or utilizing every option. However, learning more about your device or an app might help you use it more easily.

For example, if you have vision, hearing, or mobility issues that are making tech use more difficult, learning more about your device's accessibility settings can prove helpful.

Learning more about technology could increase your confidence. Many senior centers and adult education programs offer classes geared to older adults. While learning from younger people seems logical, research shows that peer learning is far more powerful.

Remember, those who are now "older" adults are the ones who were (and in some cases still are) responsible for creating our tech world. Some who once worked in the tech world have transitioned into teaching their skills. Hiring one of them for an hour or so or taking their classes could be money well spent. ■

Dr. Stephanie T. Machell is a psychologist in independent practice in the Greater Boston (MA) area. She specializes in working with those affected by polio and other physical disabilities. Her father was a polio survivor.

Bits of Wisdom from our “Ask the Physical Therapist” Session

This past October, PHI diverted from our usual *Ask the Doctor* format to bring you our first-ever *Ask the Physical Therapist* webinar. During the hour-long session, participants had the opportunity to hear directly from Eric VanHulle, PT, MPT, OMPT, CSCS, and ask him about their physical therapy–related concerns.

Eric is an orthopedic, sports, and post-surgical interventionalist with extensive knowledge of human kinematics. He has spent the last ten years serving as the second in command for Team Rehabilitation in Warren, Michigan, where he works closely with Dr. Daniel Ryan and the post-polio clinic at the Center for Physical Medicine and Rehabilitation. Eric addressed questions that many in our community wrestle with every day: how to stay mobile, manage pain and fatigue, protect vulnerable joints, and work effectively with clinicians who may not fully understand post-polio syndrome. The following excerpts highlight some of the practical, experience-based guidance Eric shared during this informative session.

* * *

Keep in mind that with post-polio, it’s a little bit different than treating any other population because you do have fatigue on the neuromusculoskeletal system. You can’t treat it in such a manner that you’re going to fatigue it further. It doesn’t make sense. You may have heard [the slogan] “no pain, no gain” regarding exercise. That doesn’t hold true with the post-polio population. It really should be, “No pain, no fatigue.”

* * *

With post-polio syndrome, it comes down to trying to do the best work for that particular situation and that function without overtaxing or fatiguing the system. That’s what it really comes down to. Maybe with clinicians that aren’t quite as familiar with post-polio syndrome, they might see muscle weakness and be like, “Well, how do we deal with muscle weakness? Well, in [a typical] population, we exercise and give them progressive overloading exercises.” This is absolutely the wrong thing to do in [the post-polio] population. With this population, it’s really more about stretching, mobility, joint preservation, and energy conservation. What it really comes down to is to plan your day and plan your movements. How can you get done what you need to accomplish and do it [in a manner] where you’re not overtaxing the system?

You don’t want to go crazy and cause significant discomfort to a joint that you’re depending on because your other [polio-affected] joint can’t handle the load. You need to think of yourself as running a marathon—and life is that marathon. If you’re in the last couple of minutes of that marathon, you wouldn’t do something silly like sprinting for the last three minutes. You’d probably pace yourself, make sure that you can finish, and then after you finish, go through a cooldown and you manage your symptoms, manage your fatigue. That’s the same thing with post-polio syndrome. You really need to manage symptoms.

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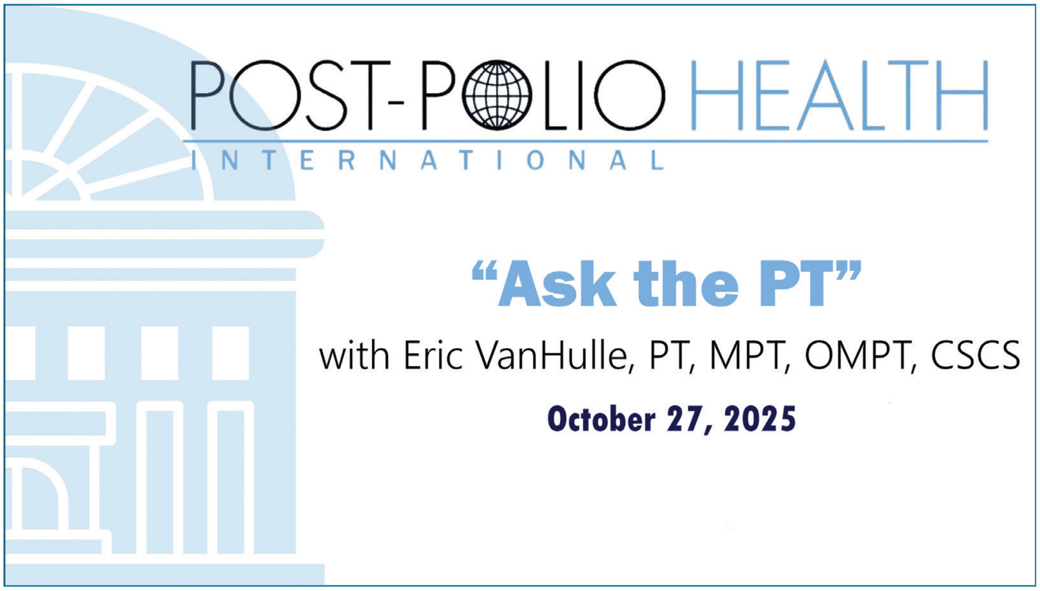


POST-POLIO HEALTH
INTERNATIONAL

"Ask the PT"
with Eric VanHulle, PT, MPT, OMPT, CSCS
October 27, 2025

You are your best advocate. Nobody owns your body but you. Nobody's going to be as interested in preserving it as you are. So, you should use your voice, and you should be very forward with not only yourself but also with the people treating you. You might be like, "Hey, this might be a little bit too much for me, and I'm significantly fatigued an hour and a half after I leave here." You can't complete the rest of the day, you are going to bed two hours early, or whatever it might be. Or the next day, you don't feel well. It is well within your rights to tell your physical therapist, "Yes, this is a little too much." There are very well-intentioned therapists out there, very well-intentioned physicians, but they don't live in your skin and in your body. You are the one that knows your limits.

* * *

If we're going to do an exercise prescription for you, we're going to make sure that that limb is always cared for in the right way; that it is exercised in the right way so that you don't injure cartilage. Most of the population that's dealing with PPS is older, right? The longer you're on the planet, the more you're in a gravity environment, and the more that cartilage tends to wear. We do have to be very conscious of that. Always make sure you're communicating with any practitioner you're dealing with and that you're not overtaxing that limb. You should leave therapy or your exercise prescription thinking, "Hey, I've done some good here," and not, "Hey, this really is bothering me." There are times when we'll do an exercise, and it just doesn't agree with you. Maybe it worked for ten other people, but you're the one person who it doesn't work for. Then we have to put our brain power together and say, "Okay, well, what else can we do to accomplish this task and not exacerbate that joint?"

* * *

These selected insights offer just a glimpse of the thoughtful, patient-centered advice Eric VanHulle shared during the webinar. To hear his full responses, explanations, and additional questions from PHI members, we encourage you to watch the complete *Ask the Physical Therapist* session on PHI's YouTube channel at https://tinyurl.com/AskPT-OCT25. Whether you are living with the late effects of polio, supporting someone who is, or working as a health professional, the full video provides valuable perspective on pacing, self-advocacy, and long-term joint and muscle care. ■

NETWORKING

Ask the Doctors

QUESTION: *I had polio as a child, which left me with a deformed left shoulder blade. In addition, my left lung was damaged, and my left arm has always been weak, though I do have full use of it. Within the past few years, I've developed difficulty swallowing and find that I have to eat more slowly and take my large medications by opening the capsules. Could this possibly be an effect of my polio?*


Marny Eulberg, MD

Answer from Marny Eulberg, MD: Swallowing difficulties *can* be a result of weakness in the throat muscles caused by polio and is more common in people who had breathing muscles or upper extremity muscles affected by polio. Most often, in neuromuscular conditions, the swallowing problem is worse with thin liquids like water or juices, but it can also be for things like dry bread or pills.

However, swallowing problems can also be caused by other conditions that also happen in people as they age, even if they didn't have polio. In my experience with polio survivors that have swallowing problems, when they were tested, it turned out that about 40% of the time the problem was related to weakness of their throat muscles. The other 60% of the time it was caused by problems lower down in their esophagus, such as scarring in their esophagus causing a narrowing, a malfunction of the normal squeezing of the muscles in the esophagus that happens with aging called "presbyesophagus," or some kind of growth that was partially blocking the esophagus.

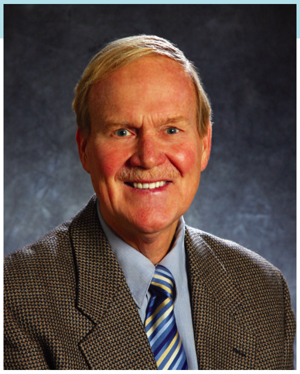
The best tests to determine the cause of your problems swallowing are either a fiberoptic endoscopic evaluation of swallow (FEES) or a modified barium swallow study (MBSS). Any medium-sized hospital that has speech therapists on staff should be able to do a modified barium swallow study. It is done in the X-ray department with both a speech therapist and a radiologist present. They watch as you swallow a thin liquid containing barium, then a thicker liquid with barium (like milkshake consistency), and finally, the barium mixed with something solid like crunched up cookies or mini marshmallows.

The speech therapist will be most interested in how the muscles of your tongue and throat work, and the radiologist will be most interested in your esophagus as it goes down into your chest and ultimately to your stomach. The speech therapist, in addition to trying to find the cause of your swallowing problem, can also tell you something to do that will make swallowing easier and less likely to be a problem. They may also set you up with a series of exercises to help the muscles work better. The speech therapist does not need to have had a lot of experience with polio survivors because many people who have had a stroke also have swallowing problems, and there are enough people having strokes that the speech therapist will have developed expertise that can help you, too.

Emptying your capsules out and taking the powder either by itself or sprinkling on applesauce, jam or jelly, or ice cream is one way to deal with difficulty swallowing capsules. There are some medications—often having the initials LA, XR, etc., after their name—that should not be crushed or dumped out of the capsule because they need to remain intact until they get past your stomach and into the intestines. You might consult your physician or pharmacist about whether that is true for any of your medicines. Sometimes the medications that you take are also available as a liquid or chewable tablet (often when they are given to children) and you might be able to get your particular medication in a form that would be easier for you to swallow.

Additional remarks from Frederick Maynard, MD: Your new difficulties with swallowing most certainly could be as a result of your polio history. Your description of left shoulder and lung involvement suggests a "bulbar polio" pattern of greatest involvement by the polio viral infection in your childhood. Later life swallowing problems are more common in polio survivors, especially those with shoulder and diaphragm involvement.

I would recommend evaluation by a speech/language pathologist who specializes in swallowing problems. You will need a radiographic test known as a "three-phase swallowing test" with an opaque dye done under a fluoroscope in a radiology department. It is ideal if the speech/language pathologist is present during the procedure in order to identify some of the best treatment recommendations to manage your symptoms and prevent complications. You can read some more about post-polio swallowing problems in PHI's *Handbook on the Late Effects of Poliomyelitis* at https://post-polio.org/late_effect_polio/swallowing/.



Frederick M. Maynard, MD

QUESTION: *Having contracted polio in 1949 at the age of two, my life growing up was physically challenging—a drop foot, leg length discrepancy, and limping my way through school. I lived a life of "no's." No sports. No dancing lessons. No nursing school. ("Too much walking.")*

My current problem is constant pain in my Achilles tendon, shooting up through the calf. The joint and space connecting my hind hip to my leg is constantly in pain and cannot be ignored. X-rays show age-appropriate arthritis. I'm getting a new AFO in December because my leg has considerable atrophy. Besides resting and using pain creams, what recommendations do you have?

Answer from Frederick Maynard, MD: We are sorry to learn of your problematic pain. From your detailed description, I am concerned that your pain is "nerve pain" (referred to by doctors as "neurogenic pain"). Nerve pain is typically constant, often shooting, and hard to localize or provoke repeatedly in the same way. It could be coming from a pinched nerve in your back or the sciatic nerve in the medial buttock area. The first order of business would be to have an electrodiagnostic evaluation performed by a qualified doctor (AAEM-certified), typically a physiatrist or a neurologist.

If the test does not show any signs of nerve impingement or new nerve damage (beyond what would be expected because of your polio history), then it might be necessary to do more detailed tests on your tendons, muscles, and joints in the painful leg, including provocative maneuvers to produce the pain. Sometimes muscle tightness can lead to surprisingly severe pains. If your new AFO is comfortable and corrects the foot drop well but doesn't reduce the leg pains, then I would say the pain is likely neurogenic. You will need a referral to have the electrodiagnostic tests (these are described in our *Handbook on the Late Effects of Poliomyelitis* at https://post-polio.org/late_effect_polio/electromyography/). ■

Have a medical question about the late effects of polio? PHI's Medical Advisory Committee is here to assist. Just fill out the form at https://post-polio.org/ask-the-doctor/, and one of our volunteer physicians will be in touch. Please allow up to five business days for a response.

DISCLAIMER: PHI offers this program as an educational service but it in no way is a substitute for medical care by a personal healthcare provider. Our physicians/other healthcare providers can only make suggestions that you, in turn, will need to discuss with your healthcare provider. They cannot treat you or write prescriptions for you. Interactions in writing, verbally, or even by video, cannot replace the value of an in-person evaluation.

In Appreciation

Thank you for recognizing your friends and loved ones with contributions to the activities of PHI and IVUN and for your generous Membership contributions.

Please contact us if we made an error.

Contributions to PHI's education, advocacy, and networking activities

In Memory of
Joyce Anderson
Winnie Baden Schinitsky
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