



Frederick M. Maynard, MD

Question: *I am 69 and had polio in my right foot when I was 20 months old. I have had tendon transplants, heel cord lengthening surgery, and some toes fused. I wore a short leg brace following surgeries when I was eight years old at Warm Springs in Georgia. I had five children and have always been active, e.g., marched in the band, rode horse-back, biked, skated and swam, and usually did it better and faster than the others. (I was still “different” though.)*

I have had rheumatoid arthritis since age 30 and now have osteoarthritis. I noticed at age 40 that I was getting much weaker and more unstable on my feet. My right calf is much smaller than my left one. All the tricks I used to hide my limp failed me. Since a total hip replacement, I tire much more easily and walk with a cane. (I have a 1-7/16 inch difference in leg length.) I also go to a pain clinic for spinal stenosis. Should I walk as much as possible (30 minutes or so a day) or “save my strength,” and pray tell, save it for what? NAME WITHHELD

A: Thank you for sharing your story. It illustrates the challenges faced by people with moderately severe polio-related residual weakness who have led surprisingly active lives. You, as have many others, faced declining strength already in middle age. You next confronted age-related and, possibly, overuse-related complications, such as hip arthritis. Rheumatoid arthritis and spinal stenosis would be considered unrelated medical conditions (also known as “co-morbid medical conditions”) that complicate and compound your post-polio condition. I would advise you stay as active as you can while not aggravating your pain problems. You may wish to consider water exercise workouts to

maintain fitness and vitality, rather than walk “as much as possible.”

I identify with your rhetorical question of “save my strength, and pray tell, for what?” You should use what strength you still have to fulfill your life’s priorities requiring motor function as best you can. You should not obsess about saving your energy for unknown future needs. Please, just don’t push yourself to such a degree that you hasten the day when you can’t even walk at all or do transfers by yourself. Post-polio life requires constant rebalancing, like walking a tightrope!

Question: *I am a male age 60 who contracted polio at age six months and Guillain-Barré syndrome at age 40. I was diagnosed with post-polio syndrome at age 55. Four weeks ago I had testosterone pellets implanted when I found out I had a major testosterone deficiency. What happened four weeks later, as reported to my naturopathic doctor who prescribed it, was simply amazing.*

My legs, hips, hands, arms, chest and stomach muscles are beginning to look like they did as a younger man when I was body building. My balance is 100% changed. I avoided hugging people because it knocked me off balance. I normally could not step off a curb due to weakness in my good leg. Now I just do it! I am walking upright instead of hunched over for fear of falling. I feel “solid” again.

I have zero fatigue. My joint pain, other than the left knee, is gone. My right

ankle is a bit sore in the morning, and it takes a step or two to warm it up. Of course, that is because I am walking around now. I've lost weight, and more importantly, lost inches off my waist. I am able to sleep 6-7 hours without medication. My mind is clearing; my enthusiasm is off the charts. I own and run several corporations and had pretty much given up on the future of any normal activity. I don't have to fake optimism.

I felt compelled to write to you and describe the results in hope that you may pass them along. I have no logical answer other than the testosterone replacement. I have been confounded, and somewhat discouraged, by the lack of response from my mail to physicians and researchers around the world that explained how my post-polio syndrome symptoms have disappeared since I had the testosterone pellets implanted. While my results may be too good to be true, they are true nonetheless. Can you explain the lack of response? MR. HALSETH

A: Your story nicely illustrates how post-polio symptoms can be confused with other diseases. Given the dramatic reversal of your muscle atrophy, and the complete resolution of other symptoms within one month of treatment with testosterone, I have no doubt the primary diagnosis was low testosterone, not post-polio syndrome.

In answer to your second question about the lack of response from doctors and researchers, it is likely a result of professional skepticism. One person's story of dramatic improvement attributed to a "treatment" does not prove that the "treatment" was the cause of the improvement, as opposed to another unknown coincidental cause, or even a placebo effect. Only a well-designed study can prove this, and all

doctors and researchers are literally trained to be skeptical about claims of improvement. Therefore, they are rarely impressed by or responsive to undocumented miracle stories.

Question: *Often we polio survivors have very few options that are helpful in understanding our circumstances and what direction to take. Thank you for being available to provide this important service. Here is my question in three parts. When I read The Polio Paradox by Richard L. Bruno, PhD, he assured us that post-polio syndrome (PPS) is not life threatening. Is this still a valid statement? Is there any evidence to the contrary? Secondly, will the effects intensify and cause weakness to the level that one experienced during acute polio? Also, does PPS affect the brain's ability to function normally in speech, sight or thought processes (through stress or brain lesions)?* MR. MALIGIA

A: There is no evidence that PPS is "directly" life threatening. PPS symptoms can become sufficiently disabling to "indirectly" shorten one's life, such as by imposing a fearfully sedentary lifestyle that leads to hypertension, obesity, high cholesterol and heart disease. If severe post-polio breathing and swallowing problems develop and are not treated appropriately, critical life functions can also be put in jeopardy.

A clear answer to your second question is more difficult. Theoretically, at least, one could again become as weak as one was at the time of initial recovery from the acute polio infection. In my clinical experience of 25 years, this never happens. While severe worsening may happen TO a post-polio person, it does not result FROM post-polio syndrome as defined by a consensus

continued, page 10

statement of medical researchers (March of Dimes Birth Defects Foundation, 1999, *Identifying Best Practices in Diagnosis & Care*, Warm Springs, GA: March of Dimes International Conference on Post-Polio Syndrome). Certainly, PPS will not be more debilitating than acute polio, because it develops slowly and does not suddenly challenge all critical life functions like an acute infection does. Additionally, small changes in motor function can and should be treated with appropriate rehabilitative strategies, such as use of compensatory devices and making activity changes.

Last, PPS does not directly affect the brain's capacity to see, talk or think, but it can at times affect those functions temporarily if its symptoms (such as severe fatigue or pain) are so intense that they overwhelm one's concentration and/or alertness. When well rested, all brain functions will return to their normal state.

Follow-up Question: In Vol. 25, No. 1 (page 3), Dr. Maynard responded to a question about "using my toes more than my whole foot to walk now." He explained that the anterior tibialis muscle is the primary contracting muscle that normally picks

up the foot at the ankle joint to help your toes clear the floor as you pick up your leg. To compensate for weakness in this muscle, adjacent muscles (toe extensors) that act to move the toes upward also contribute to picking up the foot. In fact, one is not walking more on the toes, but with the over activity, the toe extensor muscles, and the big toe in particular, are in an abnormal "cocked-up" position during the swing phase of walking. Ms. Toher asked, "What can I do about this?"

A: If the toes are rubbing on your shoe tops, a "high toe box" shoe design may be helpful. It wouldn't hurt to try taping the toes. If the muscles continue to weaken, a lightweight short brace may become necessary. There are several new designs that may be satisfactory, including ones that merely attach to the back of a shoe's counter and are hardly visible. A high-topped shoe or hiking boot might solve the problems on unlevel ground. Some people also do much better with very lightweight soft moccasin footwear, at least when weather and walking surfaces permit. Seeing a good orthotist and/or working with an experienced post-polio physician to find a feasible individual solution would be your best option. ▲

Donations in Recognition of Others

Post-Polio Health International extends a heartfelt thank you to its many Members and friends who financially support its mission by recognizing loved ones.

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

In Memory of

Marshall D. Baugher
Carol Bernardo
Abbie Bondurant
Ray R. Boyce

Phyllis L. Brink
Bill Buckingham
Paul Dunleavey
Gerald Hughes Gaines
Patrick Gibbons

Harley Clare Headley
Lee Holloway
Jere Howe
Sam Kargel
Virginia Kawamura

continued ...