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Ask Dr. Maynard

Send your questions for Dr. Maynard to info@post-polio.org.

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Question: In your most recent column, you referred with clarity about new pain and fatigue that many polio survivors are experiencing. I have had the same symptoms for 12 years or so, but never with the same intensity and to the same degree as I do now.

I am 74 years old and contracted polio in 1952 at age four. I was in a hospital (Sacred Heart in Norristown, Pennsylvania) for some time. My right leg is completely paralyzed and my left leg partially so below the knee. I use a long leg KAFO on my right leg. I was diagnosed with post-polio syndrome 12 years ago at National Rehabilitation Hospital in Washington, DC, by Dr. Lauro Halstead. Prior to that I got around with the help of a cane. Since then, I have used two crutches.

Until this year, I've had relatively modest PPS symptoms of pain, fatigue and poor balance. These symptoms have become far more pronounced this year, especially the fatigue and pain. With regard to fatigue, I am so exhausted that I nap two hours each afternoon in addition to sleeping eight hours at night. I fall asleep immediately and stay asleep.

My pain issues are twofold. My right shoulder is very painful, particularly when I extend my right arm. Also, my right arm has begun to atrophy and has lost considerable strength. I have limited my one-mile swimming workouts to 2–3 times per week, down from five. I receive cortisone injections every three months and physical therapy twice a week. I'm not seeing much improvement in pain levels. If anything, the pain is getting worse.

The second area of pain relates to my lower back, left side piriformis, and nerve pain down the back of my left leg (the one less affected by polio). The physical therapy has helped tremendously with regard to the lower back pain, but I've noted only very modest improvement with regard to the piriformis muscle and the left leg pain.

I'm not sure where to turn now. Perhaps I should just stay with the PT program, the quarterly cortisone shots, and my reduced physical exercise program. Or perhaps I could consider returning to the post-polio clinic at National Rehabilitation Hospital in Washington to see if they might be willing to re-evaluate me. I've also thought about CBD oils or even medical marijuana. I have no idea whether this last option is advisable or would even begin to bring me any relief.

Dr. Maynard: Before commenting on your pain issues, I want to first say how functional and active you have been over the last 12 year in spite of your PPS. Exhaustion at the end of your day that includes one-mile swimming workouts and walking with two crutches because of 70-year-old childhood polio-related weakness is not surprising! How effortful is your walking? How far can you go before resting at least briefly? Any shortness of breath? Any use of alternative mobility (like motorized carts)? Have you had a thorough general physical that shows no significant heart or lung problems? These could cause more fatigue with the same (or even modestly less) physical activity; and age-related declines in physical exertion capacity frequently become clearly noticeable and impactful in one's 70s.

Regarding the shoulder pain, the first thing to clarify is the diagnosis. If you did not have significant involvement of your arms during the childhood polio, atrophy would not be likely on that basis; it would be a “diagnosis of exclusion,” I would recommend neck X-rays and an EMG study of your right arm. The latter study could also clarify if the atrophy was from old “sub clinical polio.” If it were from old polio, then overuse musculoskeletal shoulder pain from swimming and crutch use would not be surprising and in this case controlling the pain by reducing or modifying activity and/or the use of topical analgesics (including CBD creams) are good strategies.

Regarding the back pain, I would recommend continuing with physical therapy approaches. Perhaps more vigorous stretching of the piriformis would be helpful. Additionally, seeing different therapy practitioners with different backgrounds, training and experience may also prove more helpful.

Finally, I would encourage you to consider a re-evaluation at NRH’s post-polio program because all of your concerns can be best addressed by an in-person interview and detailed neurological and musculoskeletal hands-on examination.

I hope these thoughts and suggestions help you on your continued journey to remain healthy, active and happy as an aging polio survivor.

Response: Thank you so much for your time and for the detailed information you provided to me in your email. I am very appreciative.

I will follow up on each of your suggestions and agree that a re-evaluation of the progress of my PPS at the NRH Post-Polio Clinic is an excellent idea. While my heart and lungs are good and my overall health, aside from PPS, has been very good, I think that a PPS re-evaluation will help me to understand which physical activities to reduce and which assistive devices, such as a wheelchair or scooter, I should consider.

I must tell you that there is a psychological aspect to all these issues. Fitness has been such a key element to my physical and mental health. In addition to my swimming, I am a disabled athlete who has successfully competed in hand cycle (three-wheel cycle) competitions. Last year, I finished with good times in the 26.2-mile Philadelphia Marathon, the Marine Corp Marathon and NYC Marathon. To reduce my cycling and swimming activities has probably become a necessity, but those adjustments will likely be difficult.

In any event, thank you once again for your thoughtful and comprehensive response.

Dr. Maynard: I am pleased that my suggestions were helpful. One further thought about your shoulder pain is to consider having a physical therapist and/or athletics trainer evaluate your swimming stroke for possible modifications to relieve any pain from joint impingement.

Thank you for sharing your psychological challenges resulting from the need to reduce your several vigorous activities (swimming, biking, crutch walking). I have seen or heard from several other polio survivors whose engagement in vigorous (if modified) athletic competitive activities became a psychologically painful loss as they needed to curtail or discontinue them in their older age because of musculoskeletal pain issues. I would encourage you to examine the reasons for your interest in competing because it is common for childhood limitations in physical capacities to drive one to “show or prove” that one is as good or worthy as a non-disabled person.

I would recommend you fully focus on the enjoyment of doing your favorite vigorous activities and on their benefits to your health and well-being. ■