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Is It Post-Polio – Or Something Else?

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Post-Polio Syndrome – oh, that devilish master of disguises and confusion!

As a polio survivor, I have been fooled more than once. My doctors, too, even the good ones.

When I first developed post-polio syndrome, I erroneously suspected other causes for my problems. Even a neurologist scoffed at post-polio as unlikely.

But eventually post-polio was diagnosed. Then I made the opposite mistake, blaming post-polio as the root of every new problem. Wrong, again.

Take the example of my right groin, which I injured four years ago. Ever since, it was sore and stiff with limited flexibility. The nagging discomfort drastically worsened last summer as my entire leg weakened. I limped and needed a cane, then two canes. I was alarmed.

From the start, my doctors (an excellent primary physician, two locally prominent neurologists and a pioneering post-polio expert) had assumed my groin symptoms were just another part of my late-effects polio. I accepted their assessment.

They were all wrong, and so was I.

By chance, an entirely different diagnosis emerged. A neurologist had sent me to a physical therapist to strengthen my back, after multiple MRIs and x-rays had uncovered spinal arthritis. The doctor's referral didn't even mention my underlying post-polio.

In a 20-minute exam, the therapist could not find enough back pain, weakness or stiffness to warrant treatment. I told him

what I thought my real problems were: post-polio, groin injury and lame leg.

"Have you had a hip x-ray – has anyone ever suggested it?" the therapist inquired. Puzzled, I replied: "No. Why are you asking?" He said: "Your symptoms could be from a bad hip."

How right he proved to be. X-rays and two orthopedic surgeons confirmed severe hip arthritis. A cortisone injection magically banished the pain for weeks, my leg rebounded, and I put my canes aside. The shot did not repair the hip, of course, and the cortisone relief gradually wore off. So later this year I plan to get joint-replacement surgery.

"I may be your first patient who is glad he needs a hip operation," I told the surgeon. "If my problems were caused by post-polio, they can't do much about that."

There's a moral to my hip episode. Correct diagnosis is essential to health care, and polio survivors face a recurring challenge. Whenever a new problem arises, we must grapple with whether it's post-polio syndrome or something else.

We are susceptible to automatically blaming polio. Many of us were ignorant of post-polio or in denial about developing it. But once confirmed, it can bias us to see everything through that lens. Military experts talk about the mistake of "fighting the last war" – misapplying old tactical lessons to new and different situations.

For me – and my doctors – diagnosing polio was tricky from the very beginning.

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While on a family trip at age 8, I started feeling sick. My mother, a registered nurse, feared polio. A local doctor dismissed my symptoms as “probably just a virus.” (Some virus it turned out to be!) Still worried, Mom cut our trip short. Back home, our family doctor was reassuring, saying that many parents were needlessly panicking about polio.

Then one morning, I awakened and swung my legs over the side of the bed to get up – only to crumble to the floor. “Mommy, Mommy,” I cried out. “I can’t walk.” So much for those oblivious doctors.

“At middle age I believed I had escaped post-polio. Years later when I started getting symptoms, I blamed other causes, and a neurologist blamed depression.”

I was taken from our small Ohio town to Children’s Hospital in Columbus. A spinal tap confirmed polio, consigning me to the polio ward for the next few months. At my worst, I was paralyzed from the neck down. Doctors predicted I would never walk again.

Fortunately, they were wrong again. I learned to stand and walk again and led a generally normal life, though I was never athletic, strong or coordinated.

Decades passed. Then in 1985 *The New York Times* reported that some polio survivors were developing renewed problems years after their original infection. Doctors named the condition Post-Polio Syndrome.

At the time I was 42. Concerned, I went to a support group. Other attendees had serious physical complaints. But I had no new symptoms, and my polio was a distant 34 years in the past. My conclusion: I was among the lucky ones dodging the post-polio bullet.

I was wrong. But ignorance can be bliss, and I enjoyed another quarter century of decent health before things went haywire.

At age 67, fatigue bowled me over and I drowsily drifted into long midday naps.

I attributed this to changing springtime allergies. The fatigue forced me to stop my exercise routine of walking up and down 50 flights of stairs three times a week. Then I began to feel stiff and weak. Naturally, I blamed my inactivity. Or maybe this was just “old age.”

It all seemed quite logical, but events proved me wrong.

On my 68th birthday I treated myself to an Asian music concert. After settling into my center seat, I belatedly realized that I had misread my ticket and was in the wrong row. By now other people had filled the seats on my left and right, and I did not want to disturb them by squeezing past.

I only needed to go back two rows, which were still empty. So I clumsily climbed over the back of my seat to the next row, then again to the row behind that. No problem.

I thought that this exertion might make me a bit stiff or sore the next couple days. Instead, I was hunched over in pain and immobility for weeks, having a hard time getting up and down from a chair and in and out of my car.

As my symptoms piled up, I went to my doctor. We drafted a list of possibilities, including chronic fatigue, Epstein-Barr, fibromyalgia, low testosterone, hypothyroid, Lyme disease, cardiomyopathy, rheumatoid arthritis – and post-polio syndrome.

As tests eliminated other causes, post-polio loomed as the likely culprit. But a neurologist was highly skeptical, saying I was simply depressed and suffering psychosomatic symptoms. He was wrong. After electromyography and skin conduction tests, he grudgingly confirmed post-polio.

He was not much help, unaware of books on post-polio or support groups. I found both on my own. From Post-Polio Health International’s *Post-Polio Directory*, I contacted the excellent clinic at the MedStar National Rehabilitation Hospital in Washington. It assessed me, designed calibrated exercises and made other

recommendations. About the same time I also was diagnosed with sleep apnea, a common disorder in post-polio, and began using a breathing machine at night.

It all helped, and for a couple of years I was stabilized, albeit at a lower plateau of energy and strength.

But suddenly last summer, pronounced fatigue and napping returned. My right leg weakened drastically, requiring canes. It was obvious to me that this was a big new decline in the progression of post-polio.

Once again, I was wrong.

A sleep doctor found that I had neglected to change the silicone liner of the face mask for my breathing machine, so it weakened and leaked air, reducing the pressure needed to ease breathing. As soon as I changed the liner, the fatigue and long naps disappeared.

For my walking difficulties, I went to a second neurologist. She focused on my spine and diagnosed neck and lumbar arthritis. She sent me to the physical therapist whose fortuitous hunch about my hip joint – the one I had strained at the concert four years before – proved to be a real breakthrough.

Ironically, the groin injury that was the last straw prompting my original post-polio diagnosis apparently wasn't caused by post-polio after all.

My doctors and I have been wrong many times. They thought I didn't have polio to begin with. Once it was diagnosed, they predicted I would never walk. At middle age I believed I had escaped post-polio. Years later when I started getting symptoms, I blamed other causes, and a neurologist blamed depression.

And what appeared to be alarmingly worsened post-polio last summer turned out to be fatigue caused by a breathing mask defect, and a limp caused by hip arthritis that doctors and I had missed for four years.

An old medical adage advises: "When you hear hoofbeats, think of horses, not

zebras." In other words, in making a diagnosis first look for common illnesses, not exotic ones. By that metaphor, post-polio is exotic. And the maxim needs a corollary: "But if you have a zebra and hear new hoofbeats – don't rule out horses."

What I have learned is to take nothing for granted, neither medical expertise nor my own guesses and assumptions. Keep an open mind, explore possibilities, question everything, get more tests and second and third opinions, keep searching and welcome serendipitous insights like my physical therapist's hunch. ■

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Social Security Disability Benefits

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braces, canes, crutches, walkers, wheelchairs or pulmonary support. The reduced ability to sustain customary activities, including work, may result. A previously stable functional capacity may be further diminished. Many individuals with medically severe polio residuals have worked despite their limitations. The new onset of further physical or mental impairments (even though they may appear to be relatively minor) in polio survivors may result in further functional problems that can limit or prevent their ability to continue work activity. Postpolio sequelae may effectively alter the ability of these individuals to continue functioning at the same level they maintained for years following their initial polio infection."

You can find these rules on Social Security's website: www.ssa.gov. Look for Social Security Ruling 03-1p: "Policy Interpretation Ruling Titles II and XVI: Development and Evaluation of Disability Claims Involving Postpolio Sequelae." If you are interested in hiring a lawyer for representation with your initial application or with any level of appeal following that, NOSSCR's referral service can provide contact information to an attorney in your area. ■

Nancy G. Shor is Senior Policy Advisor at the National Organization of Social Security Claimants' Representatives (NOSSCR). NOSSCR maintains a national referral service for claimants seeking Social Security lawyers; the toll-free telephone number is 800-431-2804. Visit NOSSCR's website at www.nosscr.org.