As a polio survivor, you need to know that Social Security has special instructions for examiners who evaluate disability claims that involve postpolio sequelae.

Let’s quickly review the general rules. The Social Security Administration has a five-step evaluation process, known as the “sequential evaluation” process. The first question is whether the claimant is working at full-time employment; if yes, the claim is usually denied at this step. The second step is whether the impairment involved is considered “severe;” if it isn’t, the claim is generally denied. The third step is whether the impairment meets SSA’s criteria at Listing #11.11. If it does, the claim is awarded here. If not, the claim proceeds to step four. Here, the decision is made as to whether the individual can return to his or her former job. If not, the claim goes to step five to consider whether the claimant can perform other work on a full-time, competitive basis.

And now, let’s look at the special rules that Social Security applies to disability claims involving postpolio sequelae. The source is Social Security Ruling 03-1p. It states, “Disorders that may manifest late in the lives of polio survivors include postpolio syndrome (also known as the late effects of poliomyelitis), early advanced degenerative arthritis, sleep disorders, respiratory insufficiency and a variety of mental disorders. Any one or a combination of these disorders, appropriately documented, will constitute the presence of ‘postpolio sequelae’ for purposes of developing and evaluating claims for disability on the basis of postpolio sequelae under Social Security disability. Even though some polio survivors may have had previously undetected motor residuals following the acute polio infection, they may still report progressive muscle weakness later in life and manifest any of the disorders listed above.”

The diagnosis of postpolio sequelae is, by itself, not enough to qualify for Social Security disability benefits. The claims examiner is looking for the ways this condition limits your ability to do the kinds of activities that jobs demand. What kinds of “functional limitations” are often found?

Social Security Ruling 03-1p states, “Individuals experiencing postpolio sequelae may complain of the new onset of reduced physical and mental functional ability. Complaints of fatigue, weakness, intolerance to cold, joint and muscle pain, shortness of breath and sleep problems, mood changes, or decreased attention and concentration capacity may hallmark the onset of postpolio sequelae. Weakness, fatigue or muscle and joint pain may cause increasing problems in activities such as lifting, bending, prolonged standing, walking, climbing stairs, using a wheelchair, transferring from a wheelchair (e.g., from wheelchair to toilet), sleeping, dressing and any activity that requires repetition or endurance. Changes in attention, cognition or behavior may be manifested by reduced capacity to concentrate on tasks, memory deficits, mood changes, social withdrawal or inappropriate behavior.”

SSR 03-1p continues, “Many polio survivors who had been in a stable condition may begin to require new or additional assistive devices, such as
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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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.

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