

QUESTION: *I worked so hard to walk again after acute polio. I have extreme pain in my hip in my weaker leg and since I had a knee replaced, my back pain when standing is also extreme. I use a cane sometimes and I know I should use a scooter or a wheelchair, but I just can't overcome that horrible feeling of being a failure if I do. Besides that I have gained weight and if I don't move some, I will gain even more. Help!*

Response from Rhoda Olkin, PhD:

Ohhhh, been there! I have pain in my knee area, my back hurts, I can't stand for more than a minute, and I spent my formative years doing everything possible to remain ambulatory. Now I use a wheelchair or scooter 90% of the time, crutches the remaining 10%, starting about 10 years ago. My weight gain has been alarming, and I no longer see in the mirror the person I think I am from the inside (who seems to be much younger, cuter, thinner and with great hair!). But I do not see a failure, only flaws that I can address. The flaws do not include the fact that I use a wheelchair, because doing so got me my life back. Pain and limited ambulation were forcing a reduction in activities that narrowed my world.

We get so many messages from everywhere about how walking is good and how the need for any sort of assistive devices is bad. Consider the language often used: "Wheelchair bound" (with the emphasis on the inability to get out of the wheelchair), "non-ambulatory" (not able to walk), "suffers from polio" (as if that's all you are). What if we said "uses a wheelchair" and "fully mobile" (by whatever means!) instead? A wheelchair is not a failure, but a window into a wider world of options. Imagine you lived in a poor country with no access to wheelchairs. In such circumstances people devise their own sets of wheels, and getting a real wheelchair would not represent failure, but wings to fly.

Try an experiment. Go to a big store that has a scooter for customers to use. Do not use it. Go up and down each aisle. Note your level of fatigue and pain. Now go on another day and use the scooter, again going up and down each aisle, and again noting your level of fatigue and pain. What do the results tell you?

Okay, I'm not going to gloss over the significance of using a wheelchair. First, using a wheelchair often means less overall body movement, which can lead to secondary conditions (weight gain, decubitus ulcers, lassitude of some muscles). You have to be careful to avoid these. Since you can walk, do so a bit, or get on the floor and move/exercise, or do chair exercises. (Once a day I walk with crutches from my office to the bathroom and back, a total of 100 steps. I notice I feel better when I do this.) Second, it's a change in body image. People everywhere start reacting to you differently, and that feedback forces some recalibration of the self. Third, it can be harder to maintain or lose weight. Make sure you don't have another condition (hypothyroid, sleep apnea) and then find a balance in intake and output that you can live with. And when you do, write me, so I can use it as well!

Do not let anyone – family, friends, doctors, rehabilitation specialists, physical therapists – lead you to believe using a wheelchair represents failure. It is an alternate means of mobility and does not change the fundamental you.



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: *Sixty years later I still live daily with anxiety stemming from hospital treatment, not abusive but certainly traumatic for a child. Do you have suggestions on how I can reduce the stress of this anxiety?*

Response from Stephanie T. Machell, PsyD:

So many of my clients struggle with this! The hospital experience was indeed traumatic. You had a serious life-threatening disease that in its acute phase included severe pain, a high fever and the inability to move and/or breathe on your own. Your family was absent and often unable to visit even briefly. And the treatments themselves could be painful and at times humiliating.

And no one was explaining why any of this was happening or letting you express your fears. If you tried, you were told to be brave, that big girls and boys don't cry, or something similar. At that time pediatric professionals believed that children didn't experience depression or anxiety and that only disturbed children would suffer long-term emotional effects from polio.

Of course that wasn't true. And because what isn't addressed cannot heal, you like so many others still suffer the aftereffects.

Anxiety can manifest as panic, worry, ruminations, obsessions, compulsions, frightening intrusive memories or nightmares, phobias, fears, a sense that something terrible might happen, avoidance of places or experiences (for example, medical care or wearing heavy clothing). Most likely you have more than one of these symptoms.

There are many self-help techniques for reducing anxiety. Mind-body techniques such as meditation, relaxation, guided imagery, gentle yoga, or tai chi "reset" an overactive autonomic nervous system.

Grounding techniques interrupt panic or flashbacks. For example: Open your eyes.

Feel your feet on the floor and/or your butt in the chair. Breathe steadily. Look at something that reminds you you're safe.

Worriers can set a worry time of 15 minutes at the same time every day. For the other 23 hours and 45 minutes, when you catch yourself worrying, stop and say, "I need to save this for worry time." When worry time comes you MUST worry for 15 minutes. When the time is up, you MUST stop worrying until the next worry time.

Writing can be helpful. Part of what makes trauma traumatic is that it is unspoken and unshared. Putting your experience into words, even if just for yourself in a journal, helps you process and make meaning of your experiences. Others have used art in this way.

Reading about the trauma of polio helps some and overwhelms others, so use your judgment. Along with the many memoirs there are some useful articles about trauma and the polio survivor. The best one, "Bridges to Wellness" by Linda Bieniek, is on the PHI website. The Lincolnshire Post-Polio Library contains some excellent articles. Though not specific to polio there are also workbooks and self-help books for reducing anxiety and other aftereffects of trauma.

Have you seen a psychotherapist? If no one in your area works specifically with polio survivors, look for someone who deals with trauma and/or disability. Many of my clients have found that once they dealt with their trauma, they had a reduction in their PPS symptoms, especially fatigue and cognitive difficulties. Finding a therapist and going through therapy isn't easy. But healing is worth it. ■

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Her father was a polio survivor.

