



Stephanie T. Machell, PsyD

Promoting Positive Solutions

QUESTION: *I am a polio survivor, single, and currently work as an elementary school teacher. I have several years until retirement. Whenever I think of the future, I can get easily overwhelmed wondering “How long can I work? Will I have to go on disability? Who is going to take care of me?” My brother urges me to “live in the moment” and not worry myself, but I can’t seem to let it go. Help!*

**Response from
Stephanie T. Machell, PsyD:**

Dr. Stephanie T. Machell is a psychologist in independent practice in the Greater Boston area and consultant to the International Rehabilitation Center for Polio, Spaulding-Framingham Outpatient Center, Framingham, Massachusetts. Her father was a polio survivor.

Please send questions for Drs. Machell and Olkin to info@post-polio.org.

It’s understandable that you would worry about the future. You don’t say anything about your current physical condition, so I don’t know if your concerns are about specific changes you’re experiencing or about the fear that you may experience them. Either way, most people feel less fearful when they have more information. It might be helpful to see your post-polio doctor or to obtain a consultation even if it involves traveling. A post-polio doctor and his or her team can answer your questions and provide you with the information you need. Don’t allow your fears to keep you from going. If there is something wrong, more can be done if it is addressed early than if you wait. You may even receive good news about how you are doing.

Your post-polio doctor can help you answer questions about whether it would be helpful for you to go out on disability. At our clinic, polio survivors are usually advised that they can continue to work if they aren’t experiencing pain, weakness or fatigue that interferes with the demands of their jobs. Those who are finding that their pain and fatigue are getting worse and that working drains their energy are advised to think about going on disability. This can be a difficult and painful decision that can bring up many issues. In my work with polio survivors I’ve found that even those who were most reluctant to stop working don’t regret having made the decision

to stop when they find that they have more energy and less pain as a result.

Many polio survivors fear that they will decline and become fully dependent on others. Based on the elderly polio survivors I have known, this is not typical. Overall, people – including polio survivors – are healthier and independent to older ages than at any time before. Fewer people die in nursing homes, and there are more community-based options for care available. Unfortunately, no one knows how they will age. And while you may be fearful of being left alone due to being single, there are no guarantees that those with spouses and children will be cared for by them.

There are techniques for reducing worries that you can try on your own. When you feel worried, try doing relaxation techniques or journaling. A more complicated technique involves scheduling a “worry time” of about 15 minutes a day. When you catch yourself worrying tell yourself you will save that worry for worry time. When worry time comes you must worry about something for the entire 15 minutes. Over time it becomes harder to do this and the worries may fade.

It might help to discuss your concerns with a mental health professional who is knowledgeable about disability issues. Many of the polio survivors who consult me come specifically to address the issues you are raising. It can be helpful to have a safe place where your fears can be acknowledged and discussed openly.



Rhoda Olkin, PhD

QUESTION: *I have been living with PPS for over 4 years now. I use AFO (ankle-foot orthotic) devices and have to be mindful of rest and energy conservation. At family gatherings, my cousin tends to pick places with stairs and restaurants that require extra walking. He knows I have limits, but I feel like a nag to keep reminding him to include my needs in the plans. I am angry that he does not get it. How can I deal with this? I want to look forward to family gatherings, but now I tend to dread them.*

Response from Rhoda Olkin, PhD:

Wow, I so get it! These incidents you describe are what psychologists refer to as “microaggressions” – small daily acts or events or comments in which your status as a person with a disability is made both paramount and denigrated. Microaggressions related to race or sexual orientation have been shown to cause psychoemotional symptoms in the subjects. Interestingly, no one has done studies about microaggressions related to disability, but I am sure from my own experiences and those of my students and friends with disabilities that microaggressions occur daily, and that they inflict an emotional toll. It is even more difficult when the microaggression is perpetrated by someone close to us – it carries more weight, and we might find ourselves thinking s/he should know better!

The truth is, your cousin probably does not get it. It is very hard for people not intimately involved with disability in themselves or a close family member to understand two concepts. The first concept is disability fatigue. The word fatigue is used by everyone, and they usually mean they need a

good night’s sleep. But it means something different when a person with polio talks about fatigue. For us, fatigue means that muscles have started to give out, simple acts like going from the bedroom to the kitchen can seem like too much, our minds feel fuzzy, and we are in greater danger of falling. We want to avoid getting over-fatigued because it brings our lives to a halt. Thus it is necessary to pay attention to the entire shape of one’s week, not only what one is doing on Saturday, but what one is doing for the week prior, and the few days after. Others – even family members – might advise us to go to bed early when recuperation from fatigue takes more than that.

The second concept other people often do not understand is the daily assault of inaccessibility. So many of these are out of our control, that when they occur within the family (such as your cousin picking places with stairs), it is tempting to blow up. But he probably does not know what accessible means for you. He probably does not know your capabilities or limits. What is “extra walking” to you might seem trivial to him. He doesn’t have a yardstick to use.

So you know what you have to do. You have to call your cousin or go to lunch with him, and lay out the problem. Do this unrelated to any upcoming event, so you are not mad about a current issue. Say something like, “I realized that you might not know what my limits are in terms of physical abilities. Thus, without meaning to, you sometimes pick places that are very hard for me to go to. I find myself getting angry, but in fact I have never told you what I can and cannot manage. So let me explain ...” ▲

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.