

Promoting Positive Solutions

Post-Polio Health International introduces a new column dedicated to questions about relationships and other aspects of living with the late effects of polio.

Question: *I am getting weaker and my friends and family encourage me to find “the answer” and get irritated with me when I say there isn’t one answer. I think they just want me to be like I was.*

Response from Stephanie T. Machell, PsyD: Yes, that’s exactly what they want! It’s hard for them to see you getting weaker. Because there’s nothing they can do to change things, they feel helpless. And because the model most of us have for being sick is one of a “disease” that has a “cure,” a condition like post-polio syndrome is hard to understand.

Their irritation won’t change your condition or improve your relationships, and certainly won’t help them (or you) to feel any better. Tell them this in a nondefensive manner. If you normally use humor, you can say this in a funny way.

Depending on your relationship with them and their coping style, there may be simple things you can do to help them to feel less helpless. You don’t want or need to become the “educator” for your friends and family about post-polio syndrome or disability, but it may help them to have some information.

Talk to them about your own frustrations about what is happening, and empathize with their frustrations. Finding ways of enlisting their sup-

port may help them to feel less helpless, as well as provide you with increased support, and, possibly, assistance that will help you to conserve energy and deal with weakness.

Finding ways to have fun together that don’t further weaken or fatigue you will help you all feel better.

Question: *I recently attended PHI’s 10th Conference in Warm Springs, Georgia, with my spouse. I loved every minute of it. However, since we were in unusual surroundings, he had to assist me more, and I could see how tired he was. He didn’t complain; I felt guilty. We haven’t talked about this, yet. Should we? Do you have any suggestions as to how to approach the topic?*

Response from Rhoda Olkin, PhD: This is a great question, because it incorporates so many aspects of disability into the question. I hear in this question issues about gender, traveling outside one’s own accessible environment, the way disability gets incorporated into the partner relationship, asking for and receiving help, and deciding how to expend one’s precious energy. So let’s tackle these as best we can.

First, women have trouble asking for and accepting help. Studies on gender differences when a spouse incurs a disability indicate that when the male

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Stephanie T. Machell, PsyD and Rhoda Olkin, PhD will answer your questions in future issues of *Post-Polio Health*. Please send them to info@post-polio.org. See page 10 to find out more about Drs. Machell and Olkin.

has the disability, women will try to pick up the tasks that he vacates, but when the female has the disability, the male will hire help. Perhaps males have the right idea? There is a reason why depression in females is twice as common as in males.

Consider the tasks your spouse did for you. How would you feel if you were doing those tasks for him? Would you whine and complain? No, because doing these things – *that's what love is*.

Second, traveling often is a hassle for people with some types of disabilities. All of our issues of weakness, fatigue and pain get brought to the forefront as we're faced with more tasks in inaccessible venues. Then there are the annoyances of other people who don't understand, crowded places with little room to maneuver, lack of places to sit or rest, etc. PHI conferences aim to be hospitable to people with disabilities. And still you needed assistance. Because that's the bottom line – as people with the late effects of polio/post-polio syndrome, we need assistance more than other people might, so we'd better get used to it.

Third, your assistance was from your uncomplaining spouse. You felt guilty. You two didn't talk about it. Should

you? Yes. The best time? Before the trip. The next best time? Anytime. Having trouble starting? *"Hon, you do lots of things for me and for us. When we travel, I notice you have to do even more, and sometimes it tires you. I can't help but wonder if you would tell me if it was too much?"*

There's your opening; after that you're on your own. Just try to believe him when he says he doesn't mind, and remember that your guilt is yours to deal with, not his to make it go away.

Would we ourselves choose to be people with disabilities? Probably not. Would our partners choose for us to experience pain, fatigue and weakness? I would guess not. But this is the hand you (the collective you, i.e., both you and your partner) got dealt. Trust him to make decisions that are wise.

Let me relate a personal experience to illustrate. Recently my two siblings decided to visit Australia without me. I was hurt, but as I thought about it, I realized that a trip to Australia *with me* is a whole different experience for them. Let's face it, I can be a pain – from the whole airport extravaganza of going through security in a wheelchair to finding accessible transportation to hotels with accessible rooms to accessible restaurants, and all that is before we even talk about my reduced energy level. So, although there are things they would never do without me, every once in a while they choose not to include me.

My task is to (a) accept that this is wise for us overall in our relationships and to try not to be hurt, and (b) accept that when they do include me they know the drill and are willing to help me for the privilege of the three of us being together. Your partner also wants the privilege of being with you. ▲

Who is Stephanie T. Machell, PsyD? Dr. Machell is a psychologist in independent practice in the Greater Boston area and consultant to the International Rehabilitation Center for Polio (IRCP), Spaulding-Framingham Outpatient Center, Framingham, Massachusetts. She specializes in working with medical trauma, physical disability and chronic illness. Her father is a polio survivor.

Who is Rhoda Olkin, PhD? Dr. 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. Her book on "What Psychotherapists Should Know about Disability," along with her video "Disability-Affirmative Therapy," are well respected and widely cited. She is a polio survivor and single mother of two grown children.