

QUESTION: *I was recently asked why I never attended post-polio meetings unless I speak and why I didn't ask questions of the internet groups of polio survivors. I immediately knew the answer—those situations make me feel vulnerable, so I avoid them. Is this a healthy way of coping?*

Response from Stephanie T. Machell, PsyD:

There's no one healthy way of coping. Some people thrive on information and group interactions. Others don't. I know many polio survivors who don't attend support groups. Usually this is because they have experienced groups that became negative, either judging/scape-goating certain members or spending the majority of group time complaining and never discussing solutions. Groups like that, whether in person or online, would make anyone feel vulnerable!

Limiting your exposure to information can be healthy. It's important to know your limits so you don't become overwhelmed by the volume and/or repetition of information. Knowing groups and meetings cause you to feel vulnerable means you can control your exposure to them.

Then again, it depends on what you mean by vulnerable. Vulnerability, as in openness to experience and/or others, can be a way of making connections. It requires trust that your experience and limits will be respected. Again, if this hasn't been your experience in groups it is understandable why you wouldn't want to be vulnerable in them.

If you mean that the information you receive, or the condition of others attending the group, bring up fears about the future that cause you to feel personally vulnerable, avoidance may still be healthy—to a point. I often tell my clients that the "healthiest" stance for a polio survivor is a combination of acceptance and denial,

in varying proportions. If your avoidance keeps you from dealing with important or necessary issues, meeting people who could be friends and allies, or from learning about things that could improve your quality of life, it isn't helpful, and it probably isn't healthy.

Rather than avoiding groups altogether, it might be useful to consider what you lose by not going, and what you might gain by participating. If choosing to go only when you are presenting helps you to feel in control, and lack of control is part of what makes you feel vulnerable, is there another way to control the situation?

For example, you might ask questions of trusted others in private messages rather than exposing yourself to the entire online forum, or only attend meetings where information you need will be shared. You could sit in the back and leave if things feel too overwhelming, or take breaks and return. If you're worried what others will think, you can develop a "sound bite" speech to explain that you are pacing yourself/practicing good self-care/drank too much coffee and needed the bathroom/in denial (if the person asking is a fellow polio survivor, he/she will likely laugh).

It's also all right to decide groups really aren't your thing and you'd rather not waste precious energy on dealing with them. Those who use groups and forums aren't better adjusted or coping better—they're coping differently. Obtain information in ways that make you comfortable and you will be coping just fine! ■



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.

QUESTION: Every day I find there is something that annoys me—a truck parked in front of a ramp, someone without a handicapped sticker parked in the handicapped spot, a store counter that is too high, someone remarking on how well I drive my scooter. How do I decide which to respond to, and how to respond?

Response from Rhoda Olkin, PhD:

This is a great question as it is one that faces everyone with a disability. The experiences you are describing are called ‘microaggressions.’ These are everyday insults, put-downs, slights, due to your disability status. The intent of the speaker (“I was only joking.”) is not what is important in a microaggression, but the impact on the recipient.

For example, sometimes when I back into an elevator in my wheelchair someone will say to me “you drive that thing really well.” Why should this bother me? First, because each person believes they are the first to remark on this amazing skill of mine, when in fact I hear it a lot. Second, it means they are primarily noticing me as a wheelchair user, not a person. And third, of course, I drive the wheelchair well—I’ve had lots of daily practice. I don’t comment on how well people use their legs!

But what about the store counter that is too high? How can I be upset about that, it’s nobody’s fault. Well, of course it is. Think of how many people were involved in the design of a store, who signed off on the plan, and the number of employees who see the height of the counter and don’t think about its accessibility. The counter represents the failure of many professionals to recognize that people with disabilities will need to be served at a counter that is too high.

These are things you notice, that upset you, that you encounter very frequently. The sheer number can get you down. Plus, each time you have to decide if and how you are going to respond. That uses emotional energy. So what’s a person to do? Here are a few guidelines I’ve developed.

List priorities. For example, Itzhak Perlman, the renowned violinist who had polio and walks with crutches, has made accessibility at concert halls his priority. What would be your priority?

Have responses ready. When someone says to me “you drive that really well,” I say “yes I do,” and let it go. It is not worth the energy. But when someone says “you’re going to get a speeding ticket in that thing!” I am more irritated, so I say “and you’ll get one when you run.” Maybe this will make them think about it a bit.

Target the right person. There is absolutely no point in yelling at the 19-year-old part-time worker behind that too-high counter. He has no power. If you are going to take action, call for the manager or write to the headquarters of the company.

Choose battles wisely. There are many battles out there. Try to choose those that fit your priorities, and, importantly, those you can win. ■

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.

