

QUESTION: *My husband, like myself, was a polio survivor. He passed away last summer. I wouldn't say I'm depressed, but I feel lonely a lot. I have kids and grandkids nearby that still visit regularly. I have couple of good friends who I still get together with for breakfast every few weeks. I'm grateful for the love and support they bring me. But sometimes I feel like they don't really understand what it was like to have had polio, or what it's like to deal with the late effects of polio. I didn't have to explain these things to my husband. He knew what it was like. I live in a fairly small town in Kentucky and don't know any other polio survivors. I've looked for support groups in your Directory, but sadly, there aren't any near me. My kids tell me to use Facebook, but I don't use the computer much and didn't really like Facebook when I tried it. I guess my question is: how do I keep from feeling so isolated? How do I find others that might know what I'm going through?*

Response from Rhoda Olkin, PhD:

How might we think about friendships? How many do we need? How do we get more? To explore this, do an exercise with me.

- (a) Draw a circle in the middle of the page. Put the names of your most intimate people in that circle. It might be a partner, a parent, kids and grandkids.
- (b) Now draw a second circle surrounding the first. In this circle write the names of the people you call when you need to talk, or who you would tell when something bad happens. If your partner dies, who do you reach out for?
- (c) Next, draw a third circle around the second circle. In this circle put the names of those you might have lunch or go to a movie with. You talk to each other, maybe even a lot, but not about deeply personal or painful topics.
- (d) Keep drawing these concentric circles until you have run out of people in your life.

The inner circle is generally the smallest. Even those with large extended families are usually closest to only some of them. Which circle could use more people in it? You can't just go out and make a new best friend on demand. But you can increase the people in that third circle, the ones to go with you to a restaurant or event. I used to think the first two inner circles were the most important. My litmus test was would I rather stay home and watch TV or go see this person? But this is a really bad litmus test for an introvert such as myself; I would always rather stay home! However, as a psychologist I know the research on socializing—it is vital for a longer and more fulfilled life.

For me, the people in circle number two tend to be people who have personal disability experience in themselves or family, or who have worked in the disability community. It does really help when friends 'get it' without much explanation. But all of my friends are disability-affirmative, i.e., they consider my disability needs in any outings, never make me feel I am holding them back, and are open to talking frankly about disability.



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.

It is the third circle where you can have some control. Joining a group of some sort is one way. For example, I joined a writing group that meets once a month. So now I have seen these people about a dozen times over the last year. It isn't intimate, but we now have a shared history, and a common interest in writing. Whether it's gardening, quilting, ceramics, reading, art history—join (or even start) a group.

Response from Stephanie T. Machell, PsyD:

No wonder you feel lonely at times. You lost not just a husband, but a comrade who understood the polio experience from the inside. Of course, you want to be around others who get it.

Finding those others may not be easy, but it will be worth the effort. And they may not live that far away. Often, I meet one or more polio survivors who live in the same small town, each of whom will tell me there are no other polio survivors in the area. Unless they participate in support groups, most of the polio survivors I know don't know any other polio survivors personally.

So how might you find them without using the computer? Network! Ask everyone you feel comfortable asking if they know any and, if so, would they introduce you. Don't assume that they would have mentioned it before. And don't assume their friends and friends of friends don't and ask them to ask, and so on.

You could broaden your search by organizing a gathering for area polio survivors. All you need is a meeting space and a time you can use it. Often churches,

libraries, senior centers or hospitals will have space you can use.

Make up a simple flyer and send it to medical providers (don't forget your own), ministers, and senior centers and other community organizations within however many miles of your town you want to cover. Post it on community bulletin boards and advertise in the events section of your local paper(s).

The initial gathering can be a social time with a brainstorming session for ways people might like to connect both formally (support groups or regularly scheduled gatherings) or informally (exchanging contact info and keeping in touch).

What if you do all this and still don't find any other polio survivors? Others aging with disabilities face many of the same issues. You could try connecting with them in the ways mentioned above and see if they will provide the support you're seeking.

Or you could give Facebook another try, this time for the specific purpose of connecting with other polio survivors. You can follow and/or join only polio-related groups, where you can post requests for those who live in your area to contact you. You can post a similar request on the PHI website, and/or advertise that you are starting a support group if you decide to do so. The internet may never become your favorite way of communicating. But being able to connect with polio survivors from all over the world might win you over. ■

Dr. Stephanie T. Machell is a psychologist in independent practice in the Greater Boston (MA) area. She specializes in working with those affected by polio and other physical disabilities. Her father was a polio survivor.

