

Question: *I'm a 58-year-old woman who contracted polio when I was three. My family was living at the time in Vietnam. A couple of years later, we emigrated to the United States. My parents told me not to mention to the other kids that I had had polio. (My case wasn't severe. I recovered with few obvious physical effects, so I guess I'm what some would call a "passer.") Perhaps they wanted to spare me from any stigma of having had polio, but I think I really internalized it as shame, and I've carried that with me through all of my adult life. Now, as I've aged into a disability, I find myself struggling with these feelings more and more. My parents are still living, and we have a good relationship, but they often try to change the subject or dismiss me when I bring it up.*

Response from Rhoda Olkin, PhD:

It is not unusual for any of us who survived polio to internalize the pervasive stigma we experienced. That stigma comes from messages about disability in media, from peers, in advertising, and even from our own families. It is perhaps the stigma that comes from our own parents that is hardest to shake. So, the inclination is to try to change our parents. Unfortunately, this is highly unlikely to be successful for many reasons. Some countries put a premium on qualities of children that make them more able to work and to marry. Disability, inasmuch as it detracts from these qualities, is seen as decreasing the value of the person.

Another view your parents may hold is the moral model of disability. This is a common model in many Asian countries. In the moral model, the disability is seen as a reflection of the inner character of the person and even of the family. On the negative side of the moral model that reflection is a blemish—evil thoughts, bad character, moral indiscretions. It carries great shame and stigma. (There is a positive side to the moral model as well, i.e., that one can be blessed with a

disability; that is something for another discussion another time.)

If you cannot change your parents, and in fact they don't even want to discuss it, I suggest you not waste energy trying for the unlikely chance of breaking through. Instead, work on eroding the sense of stigma and shame that you internalized. There are several avenues that might help: polio support groups, groups that include many types of disabilities, reading of all types (biographies by people with disabilities; about the models of disability; studies about disability and stigma), and of course professional therapists who practice disability-affirmative therapy.

This journey towards greater self-acceptance does not happen all at once. Start by no longer trying to 'pass.' Use any assistive device that helps you. Be matter-of-fact about your disability with others. Casually mention it in conversations with your parents (e.g., "I didn't go to the outing because of my polio-related fatigue") so that it is out in the open (but without expecting them to respond). You are a person who survived polio, so be loud and proud.



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Response from Stephanie T. Machell, PsyD:

It was common for polio survivors, especially those who could “pass” as nondisabled, to be told not to talk about having had polio. Not only was polio stigmatized, but those with disabilities of any kind faced barriers to full participation in American society. Passing permitted access to educational or work opportunities while minimizing the likelihood of experiencing disability-related bullying or microaggressions.

Passing comes at a price. The need to pass means that the true self is unacceptable and stigmatized. Though the passer appears outwardly successful, she internalizes the shame attached to the stigmatized identity. Maintaining a passing identity involves deception and the constant risk of being exposed.

For you, as for many other polio survivors, exposure came via the late effects of polio. New or worsening disability may cause passers to feel betrayed, both by their bodies and by those who encouraged them to pass. Memories and feelings related to the polio experience may return, sometimes intensely.

It’s natural that you want to speak with your parents about this. Before you do, it’s best to address the ways you internalized shame about having had polio and the effects this has had on your life with supportive but uninvolved others. Online or in-person polio support groups help reduce the isolation shame creates by allowing you to connect with others who are dealing with the same issues. Therapy that focuses on disability and identity can help you heal your internalized shame

and develop skills for aging well with a disability.

Once you’ve done this work you may decide you no longer need to talk to your parents about your experiences. If you still want to do so, think about what you want from the conversation. Consider how you will feel if they continue to minimize your issues or try to defend their actions. You might speak first with siblings and/or supportive family members to enlist their help. Those who are older may have valuable insight into how your family coped with your illness.

After you’ve prepared, prepare your parents. Let them know you want to find a time to talk about your polio experience. Be clear that it’s not your intention to blame them and that though you understand some of what you will say may be hard for them to hear you hope they will hear you out. If you want an ally present, ask their permission for this, and ask them if there is anyone they would like to invite. Sharing this column with them and/or suggesting they browse the PHI website will help them understand your experience better while also recognizing that it is a common one for polio survivors and their families.

If they refuse, respect their wishes. You can ask again in the future. Or you can suggest they let you know when they’re ready to talk. They may need more time. Or they may never be ready. Painful as it may be, forcing the issue could damage the good relationship you have. ■

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.

