

QUESTION: *As a young polio survivor, I think the hardest thing is having a disease/diagnosis that no longer has a current social context. It is like being caught in the cultural time warp. I have a condition that is relatively cured and eradicated from most parts of the world. While other diseases get a lot of media attention and have cultural support, this is not the case with polio. I find it very hard to get support, generate empathy from others and find others who have gone through similar experiences. Have others expressed this? Do you have suggestions for me?*

Response from Rhoda Olkin, PhD:

Yes, it is true that we are a diminishing breed. But I don't agree that we lack cultural support. It depends on how we think of ourselves. If my identity is as a person with polio, then the media images are rare and public discussion of polio even rarer. But if my identity is as a person with a mobility limitation then I have many counterparts – anyone else using crutches, or a scooter, or a wheelchair. And if I think of myself as a person with a disability I have a whole community. Polio aftereffects and post-polio syndrome have symptoms of pain, fatigue and weakness. Well, that is the disability triad. People with varying conditions experience those same symptoms. I have lots in common with people with spinal cord injury, or multiple sclerosis, or even arthritis (one of the most common causes of disability).

Medical and rehabilitation literature tends to discuss us by our diagnoses. Textbooks typically have chapters on each diagnosis or cluster of diagnoses (such as autoimmune disorders). This is the medical model of disability. It defines groups by medical diagnosis or cause of disability. But in the social model of disability we are defined by the experiences we have in a disabling world, and group ourselves as a community of persons with varying conditions who have common interests (e.g., greater accessibility, pain management, more understanding of

disability by non-disabled people, better enforcement of disability-related laws).

Getting support means asking for support. Frankly, I suck at this. I wonder if you do, too? It can be difficult to ask for help, especially since so many people with polio were raised with the idea of independence and overcoming. But of course as we age with polio things do get harder to manage, and often we need some support. Support is not only one kind of thing. There is material support (e.g., finances, building a ramp), instrumental support (e.g., cleaning the house, carrying in the groceries) and emotional support (a kind word or empathic understanding). The latter is often the hardest to ask for. But it is important to have sufficient people in our lives that provide each of these kinds of support. Take stock, and see where the deficiencies are. Then make a plan to address them.

Regarding empathy, the hard truth is that it is difficult for anyone without a disability to really understand what it is like on a daily basis, unless it is a close relationship. Even then, unless you say things like “I am in pain now” or “I can't take another step” no one will know your experience. So brave the world by saying who you are and what you feel, and keep around you only those who respond how you would like. Some of these others will be persons with disabilities, not necessarily only those with polio.



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.

Response from Stephanie T. Machell, PsyD:

I've heard this from polio survivors of all ages. All of you have had the experience of feeling like survivors of a forgotten war. It is common for others to express shock and surprise over the number of people living with PPS, and to be even more surprised when they find out that cases have occurred in the recent past.

As a young polio survivor you have likely encountered this. Some might even argue that you couldn't possibly have had polio. Some might ask intrusive questions about how you contracted an "eradicated" disease. Some may not even know what polio is and put you in the position of being their "educator." All people with disabilities struggle with how much or how little to explain about their conditions. I advise my clients to develop elevator pitches and sound bites and to consider how (and if) you might answer the "FAQs" that follow. I also recommend planning how you will deal with ignorant and/or intrusive questions and comments about your disability.

As a young polio survivor you face challenges related to your age and stage in life as well as your disability (or current lack thereof). For example, previous generations of polio survivors, not knowing about PPS, could feel more comfortable with pushing themselves and being active in an age-appropriate way because the consequences weren't known. While you benefit from improved accessibility and reduction in (overt) discrimination, society's expectations and "ableism" make it hard to be a young adult with any disability, let alone one lacking a social context.

Even those with disabilities that are well known experience a surprising lack of empathy and support. Fear of rejection due to societal attitudes and your own internalized "ableism" make it feel risky to be vulnerable. Difficult as it is, communicating with others, especially those closest to you, about your experiences and needs is essential to gaining their empathy and support.

Support groups and conferences (like those PHI holds) can provide you with the opportunity to be with others who share the polio experience. It is likely that you will feel a bond with other survivors regardless of age. But because of the particular issues you face in common it would be even better if you and other young polio survivors could connect, either in person or through social media. You could start a Facebook group for polio survivors under a particular age.

You could approach organizations sponsoring major conferences and request programming aimed at your needs, as younger survivors may be more likely to attend if they see at least one session and/or a social hour specifically for them. If you find that there are enough young survivors in your area, you could develop your own support groups or join existing ones. The latter are often in need of new members who can carry on their mission. ■

If you are under 45 and are interested in communicating with others, contact Post-Polio Health International at info@post-polio.org.

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Her father was a polio survivor.

