

**QUESTION:** *As I get older with polio, my friends and family get older and have new ailments. They see me as just another person with a cane, but I think of it differently. I feel isolated and misunderstood. What are your thoughts?*

**Response from Rhoda Olkin, PhD:**

I hear you! It can be frustrating when our contemporaries see us as just another aging person with typical aches and pains and mobility issues. But there is a difference between having a disability and then aging, and aging then acquiring a new impairment.

Some of those differences are positive: we are used to coping, we have developed compensatory mechanisms, we are more likely to be open to using assistive technology, and we have insider knowledge about accessibility and assistive devices. Many of us have joined support groups, and taken steps in the home for fall prevention.

But some of those differences are not so positive: we are starting the aging process with weakness and fatigue already in effect, our incomes might be less due to retiring earlier or cutting down work hours, our expenses might be more from housing modifications and assistive device purchases and upkeep, and additional impairments compound existing limitations.

For polio survivors in particular, we have the issue of diminishing numbers, and less familiarity with polio on the part of the public. And we may feel less sympathetic with our peers who have new ailments (“You’ve lived with this for all of five minutes, quit whining!”).

They didn’t experience childhood with a disability, adolescence with a disability, dating, partnering and parenting with a disability. They don’t have early medical experiences, some of which were traumatic. They haven’t faced the daily

microaggressions people with disabilities experience. And when someone asks them “What happened to you?” the answer garners sympathy, not the quizzical or frozen looks that we get when we say “I had polio.”

But all of this leaves you feeling isolated and misunderstood. Truthfully, it is very hard for those without disabilities to really understand what the experience is like. The ones with new ailments may think they get it, but inside you know they really don’t, and this alienates you.

There are no easy answers to this, but there are ways to cope. First, don’t expect friends to get it. They won’t; they can’t. This is why there are support groups for polio survivors, this newsletter and PHI.

Second, take time to admire in yourself the strengths you have built from surviving polio. Are you more resilient? Better able to cope with pain? Do you have more knowledge about managing fatigue?

Third, remember that socialization is a part of living well longer. Friends may not be able to supply the kind of understanding we think we need, but stay social. Have different groups for different activities – the one you talk to when you are blue, the one you go to movies with, the one who will get you a few things at the farmer’s market, the one who asks how you are.

Fourth, volunteer to help others. Studies suggest that altruism is one of the traits associated with happiness. For example, in one study people were given money, and those who spent it on someone else had reduced heart rates, compared to those who spent the money on themselves.



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She is a polio survivor and single mother of two grown children.

Fifth, consider getting a kitten! Despite their reputation for aloofness, they like to snuggle, give you unconditional positive regard, and are fairly low maintenance.

**Response from Stephanie T. Machell, PsyD:**

Because the outward appearance of your post-polio syndrome and their normal aging is similar, your family and friends may be doing what everyone does – assume we know based on our own experience how another person feels. When it works it allows us to feel we understand and support others and are in turn understood and supported. It works best if our experiences really are the same.

Of course, no two people have the exact same experiences. If the differences are small, setting them aside is easy. As the differences grow, so does the possibility that what was meant to be reassurance that you are part of the community of your (aging) peers ends up with you feeling the other person not only doesn't have a clue but is dismissing your experience – and you.

Your family member or friend may also be threatened by the changes he or she sees in you, especially if those changes affect your relationship. For example, the spouse who enjoyed physical activities with you wants to believe that the exercise will be equally good for both, rather than facing the possibility that afterwards you'll need a week to recover. The friend who now uses a cane but can still shop for hours wants to believe you can do the same. Either or both might believe that telling you about their experience of aches and pains will act as encouragement for you to try harder and to act and feel more "normal."

Instead it, like the empathic mismatch, leaves you feeling isolated and misunderstood. When their well-meaning efforts fail to provide comfort and support, or to cajole you into engaging in your previous activities, your family member or friend may feel confused and frustrated, maybe even angry. Unaddressed, the feelings grow on both sides and may jeopardize the relationship.

Once you've been misunderstood you may be reluctant to try to share more about your experiences. But doing this is key to overcoming your isolation and to maintaining the relationships. Because you are likely to feel even more vulnerable now, it's even more important to be mindful of remaining nondefensive and using "I" statements to explain the ways your experiences differ from the assumptions your significant others are making.

But even if you are able to communicate clearly and calmly, not everyone in your life will be equally willing or able to listen. Some may never get it, and you may have to decide how or if you can have a relationship with someone who is unwilling or unable to understand your experience.

If that person is someone whose understanding is critical, like a spouse, you can try bringing him or her to appointments. Hearing a medical provider or therapist explain the ways PPS differs from normal aging can be easier and less threatening than hearing it from you. Reading the same information from an objective source like PHI's *Post-Polio Health* and websites might give your family member time to metabolize and integrate it into their worldview. ■

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Her father was a polio survivor.

