

**QUESTION:** *Sorry NO more Memberships. For years, I have been getting the newsletter and it seems that the same old post-polio stuff keeps coming around. I have been hoping in vain to obtain definitive solutions to either FIX post-polio (I am 80 years old.) or reduce the rate of on-going loss of muscles. Or, I'd like to learn of new medications and/or mechanical devices which can enhance my muscle capability, e.g., help me get up off the ground when I fall. Can you send me something useful? I will become a Member again.*

**Response from Rhoda Olkin, PhD:**

First, the bad news. There is no new cure, no new medicine, no solutions to fix polio/PPS, nor ways to reduce the rate of on-going loss of muscles. In fact, there really isn't much of anything new in the world of polio, other than the focus on eradication worldwide. So yes, we tend to recycle topics, such as light exercise, how to conserve energy, etc. But consider that there are always new members, including those from other countries, many isolated from support groups or others with polio. People with polio in other countries are generally younger than those in the U.S., as polio was still widespread beyond when it was mostly eradicated in the U.S.

And note that polio was 'almost' eradicated in 2000, but fifteen years later the task isn't quite completed, with new polio cases in Afghanistan and Pakistan. In the western hemisphere there were cases as recently as 1979 (and those folks would be about 37 now).

But you do not have to fall. In fact, falling is not a natural part of aging, even when aging with polio/PPS. The purpose of assistive devices is to prevent falls. This is very important, as falls tend to make people feel fragile. When they feel fragile they reduce activities, including socializing, which then often leads to depression. Social support is a key factor in enjoying older age, as is keeping an active mind.

The good news is that there are many devices that can help prevent falls. The simplest are grab bars placed strategically

around the house. Crutches and canes can be used when fatigued, and especially if getting up to use the restroom in the middle of the night. There are knee walkers and four-wheel rolling walkers that have seats. (See, for example, one for under \$60 at Walmart.) And of course there are scooters and manual and electric wheelchairs. Repeated falling is an indication that some device should be used. I had to move to use of a scooter and wheelchair even after just one or two falls a year, because the falls were serious. Certainly if you are injuring yourself when you fall, or have fallen at least once in the past six months, you should consider using an assistive device more.

But let's not assume everything is due to polio/PPS. Be sure you have ruled out other factors that may contribute to weakness or imbalance. Sleep apnea, hypothyroid, inner ear problems — these are just a few of the many factors that might contribute to falling.

Getting up off the ground is difficult. I myself cannot do it without leaning on a chair or other firm support. Scoot on your bottom if need be, to get to a steady support to lean on when you get up, or you can fall again.

Newer very high tech gizmos are being invented, for use by those with paralysis (especially spinal cord injury). Mechanical hands controlled by thought waves, for example, are now being made experimentally, and point towards what might happen in the future. But they are still in the prototype phase.



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

I know that none of this is new, nor is it what you want to hear. There are work-arounds for weakness and falling, but no miracles. Paralyzed muscles are not going to regenerate. But research is ongoing, including that which PHI funds ([www.post-polio.org/res/index.html#awa](http://www.post-polio.org/res/index.html#awa)).

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

At the risk of sounding like the shrink that I am, what I hear is frustration at the lack of a cure for PPS. It is very frustrating that nothing can be done to stop neuronal death or muscle atrophy. And that no one is trying to develop better assistive devices, or medications, or the other things that would make life better for you.

Trust me — when those things happen, you'll find out about it from us. Meanwhile, we'll be writing the same old stuff about bracing and energy conservation. Every so often we'll report something new, or something old in a new way.

Those who see the newsletter or the PHI website for the first time are excited that there is a place for people with polio and PPS. For them, recommendations for improving quality of life feel new and helpful. But for you, and others who've heard it before, it's not enough.

And you definitely don't need me to validate you by saying your frustration is normal. Often when I say this my clients assume I'm telling them they have to "accept" their condition. I'm not. That's not my place. In fact, I believe that for most polio survivors the "ideal" attitude is some balance between acceptance and denial. This balance is ever-changing, meaning that some days it will lean more heavily towards one or the other.

Living with any chronic condition is frustrating. By definition there is no "cure," only ways of managing the condition to maximize quality of life. It is important to maintain good health and treat any other conditions or issues (including psychological ones), because anything that drains your energy will only make things worse.

With chronic illness, finding positive ways of coping with symptoms AND feelings makes a difference (hence the name of this column!). At 80, you have a lot of experience coping with things you can't change. Using those skills to cope with PPS and/or developing new ones reduces helplessness, a major drain on energy.

This doesn't mean you should stifle your negative feelings. It is often said those with chronic illness should avoid negative emotions, but I believe this is unrealistic. It is true that negative emotions can fuel helplessness. But they can also lead to action. For example, frustration over the difficulty of getting up from a fall could lead you to look for a device that helps you get up when you fall. Because none exists, you develop an idea for what you need and either invent it yourself or find someone who can do so (say, in a college biomedical engineering department — often they look for projects like this).

Living well with PPS means knowing what is and isn't helpful. Organizations like PHI and its newsletters can remind polio survivors they're not alone, or they can be a reminder of daily frustration and an unknown future. Only you know which is true for you. But if you unsubscribe, check in sometimes, just in case the news changes. ■

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Her father was a polio survivor.

