



The Post-Polio “Roller Coaster”

A Bruno Byte

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Question: I followed the plan in the [Polio Survivors Handbook](#) and I feel much better. I got a cane, can walk further and my pain and fatigue are much less. I think I'm cured! So, I'm getting rid of the cane and going back the gym to get on the treadmill to lose some weight.

Answer: Sometimes it's actually not helpful for polio survivors to feel better because some go back to denying that they have PPS or are convinced that they have been “cured.” They once again do all the Type A things they'd done before and PPS symptoms return as they ride the “post-polio roller coaster:” Overdoing, crashing, recovering and then overdoing again.

Sometimes our patients intentionally tested their limits, to prove that they actually had PPS, and to see whether they really need to take care of themselves. Other times survivors made a conscious choice to use their energy and risk increasing symptoms, possibly sacrificing some neurons to do something physically taxing. That's their choice. After all, the fundamental tenet of The Post-Polio Institute's program was for polio survivors to turn off their autopilot and decide for themselves what to do with their increased energy, muscle strength and remaining motor neurons. However, it's important to know that remaining, poliovirus-damaged neurons are breakable and that there is no “cure” for PPS, only symptom management.

But, regardless of the reason for overuse, getting off what we call “the post-polio roller coaster” and managing PPS for many polio survivors, if not most, will be the most difficult battle they will ever wage - even more difficult than fighting polio itself. Sadly, it is a battle that some polio survivors will never join. In the early 1990s when PPS was “new,” 12% of Post-Polio Institute patients left the program, overwhelmed by the anxiety and guilt of decreasing activity, the fear of looking disabled and of being abused as they had been as children. We always kept the door open for them to return.

Unfortunately, only 10% of all patients who left treatment returned to The Post-Polio Institute. Typically, they returned about four years later, always in much worse shape than when we first met them. Some of those who limped out were rolling when they returned. Even more unfortunate, 80% of those who returned *quit treatment* again! It will be no surprise to you that these patients were 25% more Type A and 20% more sensitive to criticism and failure than patients who completed treatment.

It's Time to Get off the PPS Roller Coaster.

Warning:

“Looking PPS in the Eye and
Changing your Lifestyle,
Ain't for Sissies.”



Richard L. Bruno, HD, PhD

Bottom line: Getting off “the post-polio roller coaster,” looking PPS in the eye and changing your lifestyle ain't for sissies.

The Encyclopedia of Polio and Post-Polio Sequelae

contains all of [Dr. Richard Bruno's](#) articles, monographs, commentaries
and “Bruno Bytes”

<https://www.papolionetwork.org/encyclopedia.html>

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