



**Avoiding PPS:
"A Pound of Prevention Is Worth a Ton of Therapy"**
A Bruno Byte
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Question: Forty years ago I had polio. I'm told that the virus killed more than half of the nerves in my spinal cord and brain stem. I've learned that surviving nerves were damaged by the virus but have been doing 10 times the work to make up for nerves that were killed. Even though my leg has been paralyzed for forty years, I have always been very hard-driving and am constantly busy: I own my own company, have five kids, take care of my 90-year-old mother and mother-in-law who lives with me. I also volunteer at a homeless shelter and raise money to "Save the Whales" in my spare time. Other people who caught this virus are also very busy all the time and are having severe problems with fatigue, new muscle weakness, and pain. However, I feel fine right now-except for daily headaches. Should I change my lifestyle to try to prevent the new problems others are having?

Answer: There has never been a real longitudinal study in polio survivors who have no symptoms that looks at the emergence of Post-Polio Sequelae (PPS), the unexpected and often disabling symptoms -- overwhelming fatigue, muscle weakness, muscle and joint pain, sleep disorders, heightened sensitivity to anesthesia, cold intolerance, and difficulty swallowing and breathing -- that occur decades after the acute polio infection when the reduced number of remaining, poliovirus-damaged neurons "brownout" or fail due to overuse. However, each time polio survivor surveys are conducted, the percentage of individuals reporting PPS goes up. The first population-based study in 1983 found that 22% of paralytic polio survivors reported PPS symptoms. The 1987 National Health Interview Survey estimated that of America's 1.63 million polio survivors, 58% who had paralytic polio and 28% who had non-paralytic polio had PPS. In England, where they don't even "believe" in PPS, 78% of polio survivors are reporting new symptoms. Something must be going on that causes more and more polio survivors to report PPS as the years go by. But what?

A 1985 survey found that PPS developed in those who were at least 10 years old when they had had polio and in those who had had a more severe infection, i.e. those who had been hospitalized at polio onset and had had more limbs paralyzed. A 1988 study found that it wasn't just the severity of the polio but how much you recovered in the succeeding years that predicted new symptoms. That is the more damage the poliovirus did and the more muscle strength you recovered, the more stress was placed on the remaining, polio-damaged motor nerves. The more muscle strength you had to lose, the more likely you were to have PPS, an example of "The bigger they are, the harder they fall."

Then, our 1985 and 1990 international Post-Polio Surveys found that both physical overexertion and emotional stress trigger PPS. Further, polio survivors who were "Type A" (hard-driving, pressured, time-conscious, perfectionistic and overachieving) were more likely to develop PPS. It appears that both physical and emotional stress on a polio-damaged and overworked central nervous system lead to the development of PPS. This conclusion is supported by our 1991 Post-Polio Institute clinical follow-up study

showing that, in individuals who already have PPS, fatigue, weakness and pain just get worse if patients don't follow their therapists' recommendations to decrease physical and emotional stress.

So what do polio survivors like you do if you don't currently have symptoms? We now know that all polio survivors have a smaller number of polio-damaged and severely overworked neurons and are at risk for developing symptoms, especially if they constantly stress themselves, physically and emotionally. Doesn't it make sense to take the load off your remaining, poliovirus-damaged neurons so that you don't get to the point where you stress your neurons to death?

Will all polio survivors eventually develop PPS? After more than 30 years of experience with more than 6,000 polio survivors, I think every polio survivor will develop some symptom that can be related to the fact that they had polio. Will all polio survivors develop all post-polio sequelae, from fatigue through swallowing problems? Certainly not. But just as people who've had a heart attack are advised to reduce stress, why shouldn't polio survivors try to protect their quality of life by decreasing physical and emotional stress through the moderation and pacing of activities, use of appropriate assistive devices (especially those that were discarded so many years ago) and by reducing hard-driving, Type A behavior?

Will these self-care activities prevent the onset of PPS? We know that our patients' clinical reports and two follow-up studies clearly show that the progression of PPS symptoms is at least halted, if not markedly reduced, when patients start to take care of themselves. So it's hard to imagine that self-care won't have some preventative effect with regard to PPS. And if prevention is possible, it would certainly be a lot less difficult and expensive than the physical, occupational and psychological therapy that are necessary to treat PPS.

But what if self-care merely holds PPS off for a while, or reduces the severity of symptoms when they do occur? Why should polio survivors spend their lives beating up their bodies and their spirits by taking care of everyone around them without even spending a moment during the day thinking about -- let alone caring for -- themselves?

Polio survivors often say, "Self-care is selfish! I feel too guilty to take care of myself." Self-care, moderation and reduced stress have been recommended as the foundation for a peaceful and even happy life for nearly 2,500 years, since the time of the Buddha. Taking care of yourself *isn't* selfish, say the Buddhists; it is "The Middle Way" between sloth and excess. Buddhists say that, since compassion for everyone is the basic principle that leads to peace and happiness, people cannot be peaceful or happy if they spend their days exhibiting compassion for the whole world with the exception of just one person: themselves.

So start having compassion for yourself. Then go save the whales.

The Encyclopedia of Polio and Post-Polio Sequelae

contains all of [Dr. Richard Bruno's](#) articles, monographs, commentaries and "Bruno Bytes" (Questions & Answer articles).

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