

FROM
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Avoiding PPS: "A Pound of Prevention Is Worth a Ton of Therapy"

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Dear Aggie:

Forty years ago I caught a virus that killed more than half of the nerves in my spinal cord and brain stem. The nerves that survived were damaged by the virus but have been doing double the work to make up for the 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 work two jobs, have ten kids, take care of my 90-year-old mother and mother-in-law who live with me, volunteer at a hospital and 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?

"Symptomless in Seattle"

There has never been a longitudinal study that looks at the emergence of Post-Polio Sequelae (PPS) -- new fatigue, muscle weakness, joint and muscle pain, cold intolerance and sleep, breathing and swallowing difficulty -- in polio survivors who have no symptoms. However, each time someone surveys polio survivors, the percentage of individuals reporting PPS goes up. The first population-based study in 1983 found that 22.4% of paralytic polio survivors had PPS. 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 polio virus 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.

Then, the 1985 and 1990 National 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 the 1991 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 "Symptomless in Seattle" do if they don't currently have symptoms? Well, it doesn't take "Dear Aggie" or even a post-polio specialist to figure out that people with a smaller number of polio-damaged and severely overworked neurons are at risk for developing symptoms, especially if they constantly stress themselves, physically and emotionally stress. A 1997 study found that motor nerves actually die at a rate of 7% each year in polio survivors who have muscle weakness. Doesn't it make sense to not get to the point where the motor nerves start giving up the ghost?

Will all polio survivors eventually develop PPS? Many PPS experts think so. 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, shouldn't polio survivors without PPS try to protect their damaged and overworked nerves?

We advise all polio survivors to follow "The Golden Rule:"

**IF SOMETHING YOU DO CAUSES FATIGUE, WEAKNESS, OR PAIN,
DON'T DO IT!**

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, the 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? No one knows. Both our patients' 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.

What if self-care merely holds PPS off for a while, or reduces the severity of symptoms when they do occur? Or what if self-care has no long-term effect on PPS? Why should polio survivors spend their lives beating up their bodies and their spirits by taking care of everyone around them, to the point where they don't even spend a moment of the day thinking about -- let alone caring for -- themselves?

Polio survivors 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.

Dear "Symptomless:"

I don't know anything about viruses. But I do think it makes sense for you to start taking better care of yourself. Why is it so hard for us to take care of ourselves? Why should you be doing for everyone else and ignoring and abusing yourself? Don't you at least deserve not to have your head hurt all the time? Why don't you start by doing one thing for yourself for each thing you do for someone else? Maybe you won't prevent new physical problems. But the worst that could happen is that other people will still be helped and you'll feel better. Why should you "Save the Whales" and not save yourself?

Aggie

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