



POST POLIO SEQUELAE

True Answers for Friends and Family

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What is Polio?

'Polio' (or poliomyelitis, infantile paralysis) is a disease caused by three viruses that enter the mouth, grow in the intestines and pass along the nerves into the brain and then the spinal cord. There are 1.63 million American polio survivors.

What damage did the polio virus do?

The polio viruses entered nerves in the brain and spinal cord and took over their 'metabolic factory', causing the nerves to stop working normally just to produce poliovirus. During this invasion, the infected nerves could not function and muscles in the arms, legs, chest, diaphragm and throat became weak or were paralysed. If someone had muscle weakness or paralysis, 90% of their motor nerves were affected by the polio virus and at least 50% were killed. The remaining nerves, although damaged, were able to work again and sent out sprouts (like extra telephone lines) to turn on the muscles that were orphaned when their nerves died.

What are Post-Polio Sequelae (PPS)?

Post Polio Sequelae (PPS) - new fatigue, muscle weakness, joint and muscle pain, cold intolerance and breathing and swallowing difficulty - are the 'sequel' to having had polio and occur in as many as 80% of survivors of paralytic and non-paralytic polio.

What causes PPS?

PPS are caused by 'overuse abuse'. Nerves that were damaged by polio and had sprouted have been overworked for 40 years and can no longer take the strain. So too, overworked muscles ache and joints hurt after decades of doing too much work with too little muscle support.

Is PPS a progressive disease?

No, PPS is neither progressive nor a disease. PPS are just the body growing tired of doing too much work with too few damaged and overworked neurons.

Is there any treatment for PPS?

Yes! Since PPS symptoms are caused by the nervous system equivalent of plugging too many appliances into one electrical outlet, polio survivors simply have to unplug some of the appliances. Polio Survivors must decrease the overuse to stop the abuse of their damaged nerves, weakened muscles and painful joints.

What are the treatments for PPS

Polio Survivors basically need to conserve energy to stop blowing their bodies 'fuses'. Polio survivors must walk less, use needed assistive devices (a brace, crutches, a scooter), stop working before symptoms come on, and plan rest periods throughout the day.

Are treatments for PPS effective?

Yes. The worst case is that patients who stop the overuse abuse will have their PPS symptoms plateau. However, when survivors start taking care of themselves, the overwhelming majority have noticeable decreases in fatigue, weakness and pain.

Isn't exercise the only way to strengthen weakened muscles?

No. Since PPS symptoms result from too many 'appliances' being plugged into an overloaded nervous system, muscle strengthening exercise would be like plugging in a dozen additional toasters. While stretching exercise can be helpful, pumping iron and 'feeling the burn' means that polio damaged neurons are burning out. Also, polio survivors typically can't exercise the way others do to condition their hearts and try to prevent osteoporosis.

What can friends and family do to help?

Polio survivors have spent their lives trying to look and act 'normal'. Using a brace they discarded 30 years ago and reducing their typically super-active daily schedule is both frightening and difficult to do. So, friends and family need to be supportive of life-style changes, accept survivors' physical limitations and their new devices. Most importantly friends and family need to be willing, when asked, to do the physical tasks polio survivors probably could do, but should not do any longer. Friends and family need to know everything about PPS and say nothing. Neither gentle reminders nor well-meaning nagging will force survivors to use a new brace, sit while preparing dinner or rest between activities. Polio survivors must take responsibility for taking care of their own bodies and ask for help when it's needed.

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