

Post Polio Sequelae Facts



The most important practice for post polio survivors is energy conservation

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What is post-polio syndrome?

Post polio sequelae or syndrome (PPS) affects polio survivors anywhere from 10 to 40 or more years after recovery from the poliovirus attack. PPS include fatigue and weakness in muscles (muscles known to have been affected by polio and those thought to have been unaffected). Rarely, muscle atrophy can occur. Muscle and joint pain are common, as are sleep disorders such as sleep apnea, shallow breathing and muscle twitching in sleep. Polio survivors also have heightened sensitivity to anesthesia, cold, pain, and some have difficulty swallowing and breathing.

The severity of PPS depends on how many neurons the poliovirus killed and damaged during its attack decades ago, and how hard the remaining poliovirus-damaged, neurons have been overworked. Some polio survivors have few and relatively minor symptoms, while others develop severe muscle weakness and fatigue. PPS is not life threatening. The only concern is in patients left with severe respiratory difficulties, who may experience new respiratory impairment and infections. Breathing problems and lung infections in polio survivors need to be addressed quickly.

US Public Health Service estimates that of America's 1.63 million polio survivors, PPS affects at least 25 percent of "non-paralytic" and about 50 percent of paralytic polio survivors. In New Jersey, it is estimated that approximately 50,000 survivors are at risk of PPS.

What causes PPS?

PPS appears to be related to the metabolic failure and sometimes the death of neurons (nerve cells), that activate the muscles and brain nerve that remains after the initial poliovirus attack. This deterioration of individual nerve terminals might be an outcome of the recovery process from the acute polio attack. During this recovery process, in an effort to compensate for the loss of nerve cells (neurons), surviving motor neurons sprout new endings to restore function to muscles. This result is large motor units that may add stress to the neuronal cell body. As a result of this rejuvenation, the individual may have normal-functioning muscles for some time. But after years of overuse, poliovirus damaged, excessively sprouted neurons are not able to maintain the metabolic demands of all their new sprouts. A slow deterioration of the individual terminals and neurons results, causing muscle weakness in the arms, legs, diaphragm and throat. Poliovirus damage to brain activating neurons seems to be the cause of brain fatigue and sensitivity to anesthesia.

Restoration of nerve function may occur in some neurons a second time, especially when polio survivors are forced to rest because of fatigue and muscle weakness. But with consistent overuse, eventually neurons fail and permanent weakness can occur. This hypothesis is consistent with PPS's slow, stepwise, unpredictable course. Polio survivors with untreated muscle weakness are found to lose about 7% of their remaining, overworked motor neurons each year.

How is PPS diagnosed?

PPS is a diagnosis of exclusion. Doctors take a thorough history and may prescribe tests to exclude other conditions that can cause muscle weakness and fatigue, such as anemia, a slow thyroid, heart or lung, disease, and motor neuron diseases, such as amyotrophic lateral sclerosis (ALS). There is no diagnostic test for PPS, including the electromyogram (EMG). PPS is diagnosed by excluding all other possible causes for new symptoms, including a sleep study to rule out abnormal breathing and muscle twitching that commonly disturbs polio survivor's sleep, a slow thyroid and anemia. PPS is usually easy to diagnose.

Once PPS is diagnosed, some patients worry that they have polio again, believing that the virus has been sleeping in their bodies and causing the muscle weakness. PPS is not related to the poliovirus. Further, there is no evidence that the poliovirus can cause a persistent infection in humans. Other neurological or muscle diseases are almost never the cause of PPS symptoms. Other studies have demonstrated that ALS, which progressively weakens muscles, does not occur more frequently in PPS patients, and PPS is not a form of ALS.

How is PPS treated?

Since overuse and abuse is the trigger for PPS, the primary treatment is to "conserve to preserve". Conserve energy and stop overusing and abusing damaged neurons to decrease symptoms and function. Polio survivors must walk less, use needed assistive devices – braces, canes, crutches, wheelchairs – plan rest periods throughout the day, and stop activities before symptoms start. Drug treatments that have been studied – insulin-like growth factor, prednisone, pyridostigmine (Mestinon) and amantadine have not been found not to reduce muscle weakness or fatigue.

Because the signs and symptoms vary case by case, no one treatment has proven to be successful. A common sense approach to treating PPS includes, physical therapy, conservation of energy, speech therapy to assist with swallowing difficulties, occupational therapy to assist with modifying living environment to be safe and convenient, sleep apnea treatment when needed, and use of aspirin and other non-steroidal anti-inflammatory drugs to ease muscle and joint pain if necessary.

What is the role of exercise in the treatment of PPS? There has been much debate about whether to encourage or discourage exercise for polio survivors or individuals who already have PPS. Muscle strengthening exercise adds to overuse. Further, polio survivors typically can't do the strenuous exercise necessary to condition their hearts. The Post Polio Institute in New Jersey has found stretching to be very helpful for treating muscle pain. Whatever the activity, survivors must be careful not to trigger or increase PPS symptoms. A common sense approach that emphasizes safety and effectiveness is recommended. **"The Golden Rule" for PPS: -- if any activity triggers symptoms, polio survivors should do less or none of it** is further recommended.

Is Treatment for PPS Effective?

Yes. In the worst cases of PPS, symptoms plateau when polio survivors stop overusing their damaged neurons. Most polio survivors have significant decreases in fatigue, weakness and pain once they start taking care of themselves and sleep disorders are treated. However, because of the emotionally painful past experiences related to having a disability, many polio survivors have great difficulty caring for themselves. Slowing down and "looking disabled" by asking for help and using assistive devices may be especially difficult for polio survivors.

Can PPS be prevented? PPS specialist recommend that polio survivors listen to their bodies, follow the "Golden Rule", and eat a diet with sufficient amounts of protein for their ideal body weight. Yearly physicals that include blood tests to rule out conditions that can cause fatigue and muscle weakness are also recommended.

Are Immunization still needed?

Before vaccines polio disabled approximately 10,000 residents in the U S per year. Fortunately, vaccines have changed these disturbing numbers. Children receiving recommended doses of inactivated polio vaccine (IPV) at scheduled intervals (2 months, 4 months, 6-18 months, and 4-6 years) have benefited more from IPV and other scheduled vaccines than from any other preventive programs in history. Because polio is still prevalent in many regions of the world, travelers or immigrants can still import the disease. **Continued vigilance against polio and other vaccine preventable diseases is essential to keep New Jersey residents safe from the lingering and debilitating effects of polio and other communicable diseases.**

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