

THE POST-POLIO LETTER

Basic facts about PPS for polio survivors' doctors, family & friends.

Dr. Richard L. Bruno

Chairperson, International Post-Polio Task Force
Director, The Post-Polio Institute
The International Centre for Post-Polio Education and Research
Englewood (NJ) Hospital and Medical Center, USA

WHAT ARE POST-POLIO SEQUELAE?

Post-Polio Sequelae (PPS, Post-Polio Syndrome, The Late Effects of Poliomyelitis) are the unexpected and often disabling symptoms -- overwhelming fatigue, muscle weakness, muscle and joint pain, sleep disorders, heightened sensitivity to anesthesia, cold and pain, as well as difficulty swallowing and breathing -- that occur about 35 years after the poliovirus attack in 75% of paralytic and 40% of "non-paralytic" polio survivors. There are about 2 million North American polio survivors and 20 million polio survivors worldwide. The existence of PPS has been verified by articles in many medical journals, including The Journal of the American Medical Association, the American Journal of Physical Medicine and Rehabilitation and The New England Journal of Medicine.

WHAT CAUSES PPS? PPS are caused by decades of "overuse abuse." The poliovirus damaged 95% of brain stem and spinal cord motor neurons, killing at least 50%. Virtually every muscle in the body was affected by polio, as were brain activating neurons that keep the brain awake and focus attention. Although damaged, the remaining neurons compensated by sending out "sprouts," like extra telephone lines, to activate muscles that were orphaned when their neurons were killed. These over sprouted, poliovirus-damaged neurons are now failing and dying from overuse, causing muscle weakness and fatigue. Overuse of weakened muscles causes muscle and joint pain, as well as difficulty with breathing and swallowing.

HOW ARE PPS DIAGNOSED? There is no diagnostic test for PPS, including the electromyogram (EMG). PPS are diagnosed by excluding all other possible causes for new symptoms, including abnormal breathing and muscle twitching that commonly disturb polio survivors' sleep, a slow thyroid and anemia. Other neurological or muscle

ARE PPS LIFE THREATENING? No. But because of damaged brain activating neurons polio survivors are extremely sensitive to, and need lower doses of, gas and intravenous anesthetics and sedative medication. Polio survivors can have difficulty waking from anesthesia and can have breathing and swallowing problems, even when given a local dental anesthetic.

IS PPS A PROGRESSIVE DISEASE? PPS is neither progressive nor a disease. PPS is caused by the body tiring of doing too much work with too few poliovirus - damaged, oversprouted neurons. However, polio survivors with untreated muscle weakness were found to lose about 7% of their remaining, overworked motor neurons each year.

IS THERE TREATMENT FOR PPS? Yes. Polio survivors need to "conserve to preserve," conserve energy and stop overusing and abusing their bodies to preserve their abilities. 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. Also, since many polio survivors are hypoglycemic, fatigue and muscle weakness decrease when they eat protein at breakfast and small, more frequent, low-fat / higher-protein meals during the day.

ISN'T EXERCISE THE ONLY WAY TO STRENGTHEN WEAK MUSCLES? No. Muscle strengthening exercise adds to overuse. Pumping iron and "feeling the burn" means that polio-damaged neurons are burning out. Polio survivors typically can't do strenuous exercise to condition their hearts. Stretching can be helpful. But whatever the therapy, it must not trigger or increase PPS symptoms.

IS TREATMENT FOR PPS EFFECTIVE? Yes. The worst case is that PPS symptoms plateau when polio survivors stop overuse abuse. Most polio survivors have significant decreases in fatigue, weakness and pain once they start taking care of themselves and any sleep disorders are treated. However, because of emotionally painful past experiences related to having a disability, many polio survivors have great difficulty caring for themselves, slowing down and especially with "looking disabled" by asking for help and using assistive devices.

WHAT CAN DOCTORS, FAMILY AND FRIENDS DO TO HELP? Polio survivors have spent their lives trying to act and look "normal." Using a brace they discarded in childhood and reducing overly-full daily schedules is frightening and difficult. So, friends and family need to be supportive of life-style changes, accept survivors' physical limitations and any new assistive devices. Most importantly, friends and family need to be willing to take on taxing physical tasks that polio survivors may be able to do but should not do. Doctors, friends and family need to know about the cause and treatment of PPS and listen when polio survivors need to talk about how they feel about PPS and lifestyle changes. But friends and family shouldn't take control of polio survivors' lives. Neither gentle reminders nor well-meant nagging will force polio survivors to eat breakfast, use a cane or rest between activities. Polio survivors need to be responsible for caring for their own bodies and ask for help when they need it

Whether you had polio or not, please COPY and MAIL this letter to your doctors. With your help every doctor will learn about the cause and treatment of PPS and give polio survivors the care we so desperately need. Thank you!

Mia Farrow, polio survivor

Thaddeus Farrow, polio survivor

Co-Chairpersons **The POST-POLIO LETTER Campaign**

**For more information about the cause and treatment of PPS go
to www.postpolioinfo.com**

POLIO SURVIVORS ARE NO LONGER POSTER CHILDREN.

We are accomplished adults who are being disabled by POST-POLIO SEQUELAE, new fatigue, weakness and pain, affecting the world's 20 million polio survivors.

Yet most doctors don't know PPS exists. Please go to: www.postpolioinfo.com print and then mail THE POST-POLIO LETTER to your doctors.

With your help every doctor will learn about PPS and give polio survivors the care we so desperately need.

Thank you!

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Co-Chairpersons, The POST-POLIO LETTER Campaign

Please, bring this to your local newspaper and ask them to print this public announcement.