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Guidelines

for people who have had polio

BASED ON MARCH OF DIMES
INTERNATIONAL CONFERENCE ON
Post-Polio Syndrome



Guidelines for People who have had Polio

Post-Polio syndrome (PPS) is a disorder of the neuromuscular system that affects many people who had poliomyelitis many years earlier. However, most people who had polio do not develop PPS. PPS usually develops 15 or more years after an acute polio virus infection that resulted in some degree of temporary or permanent paralysis. The new problems arise after many years of stable muscle function. All told, as many as 250,000 U.S. polio survivors may have PPS.

What are the symptoms of PPS?

The main symptom of PPS is new muscle weakness that gradually worsens. It is often accompanied by decreased muscle endurance during activities, muscle and joint pain, muscle wasting and severe fatigue. These problems usually come on gradually, but may start suddenly if you have undergone surgery, or been hospitalized or confined to bed. Even muscles that were believed to be unaffected by the previous bout with polio may be affected. Less frequently, breathing difficulties and swallowing problems may occur. If these problems persist for at least one year, you may have PPS.

However, even if you have one or more of these symptoms, you may not have PPS. A complete medical evaluation may show that you have arthritis, tendonitis or cartilage damage, all of which can occur in the aging process, but are more common when movement and weight-bearing have been altered by the effects of weakened muscles. Various other conditions also cause progressive muscle weakness or fatigue.

If you think you might have PPS, you should consult your physician, who may refer you to a neurologist or other specialist, preferably one having experience with PPS. In addition to the neurological examination, doctors often recommend tests, such as imaging studies (computerized tomography and magnetic resonance imaging), to rule out other disorders with similar symptoms; however, there is no definite test for PPS. Continuing care, if indicated, is usually supervised by a neurologist or specialist in rehabilitative medicine.

What causes PPS?

The causes of PPS are not thoroughly understood. Many researchers believe that PPS symptoms result, at least in part, from the unusual stress placed on surviving nerve cells. During the initial attack of polio, some of the nerve cells in the spinal cord that control muscles (called motor neurons) are damaged or destroyed. Without impulses from these nerve cells, a muscle cannot function. Fortunately, some motor neurons usually survive the polio attack and send out new nerve connections to the orphaned muscle cells in an attempt to take over the function of the nerve cells that were destroyed. This process enables an individual to regain at least some use of affected muscles. However, after many years, the overburdened nerve cells may begin to fail, resulting in new muscle weakness.

Some research suggests that the normal aging process may also play a role. After the age of 60, most people have a decrease in the number of motor neurons in their spinal cords. Persons who have not had polio can lose a considerable number of motor neurons as they age without experiencing any serious muscle weakness. However, among polio survivors who already have lost a considerable number of motor neurons, this age-related loss may contribute to new muscle weakness. Both overuse and underuse of muscles may also contribute to muscle weakness.

How is PPS treated?

While there is no specific treatment for PPS, post-polio experts can help you develop a management plan that should lessen or eliminate some of your symptoms. To date, no medication has proven helpful in reducing the muscle weakness and fatigue associated with PPS.

Most people with PPS can benefit from some form of exercise. An appropriate, non-fatiguing exercise program may help improve muscle strength and functioning. Fatigue is best treated with lifestyle changes, including regular rest periods and daytime naps. If you have muscle fatigue limited to specific muscle groups, you should pace yourself carefully,

interspersing bouts of physical activity with rest periods. Some individuals may benefit from weight loss. Assistive devices, such as braces and intermittent use of wheel chairs or motorized scooters for long distances also can help conserve energy. These lifestyle changes may also help ease muscle and joint pain, as can use of moist heat, ice, massage, and when necessary, medications.

Individuals with breathing problems may benefit from nighttime breathing assistance to help improve sleep and energy levels. Instruction on special swallowing techniques and diet alterations can make eating easier and safer for those with swallowing problems.

What research is needed on PPS?

An international steering committee made up of leading PPS researchers, convened by the March of Dimes, recommends additional research on the causes, symptoms, prevalence, diagnosis and treatment of PPS—with the goals of improving diagnosis and treatment of the disorder. For example, studies that provide more information on the typical course of symptoms in PPS should help distinguish the disorder from other conditions that may have similar symptoms, and thereby improve diagnosis of PPS. A thorough evaluation of current management approaches used to lessen PPS symptoms should help identify the approaches that are most beneficial, and so lead to more effective treatment. Drug treatment also may benefit some PPS individuals, but more studies are needed to evaluate the effectiveness of several potential drug treatments. In order to improve patient care, the committee also recommends creation of regional centers or networks of providers with expertise in all aspects of PPS.

For additional information:
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www.post-polio.org

Suggested Reading:

Halstead, L.S. (ed.). *Managing Post-Polio: A Guide to Living Well with Post-Polio Syndrome*.

Washington, DC: NRH Press, 1998.

Jubelt, B., Agre, J.C. Characteristics and management of postpolio syndrome. *Journal of the American Medical Association*, 2000, volume 284, pages 412-414.

Maynard F.M., Headley, J.L. (eds.). *Handbook on the Late Effects of Poliomyelitis*. St. Louis, MO: Gazette International Networking Institute, 1999.

Post Polio Information Package for Health Care Professionals. Toronto: Ontario March of Dimes, 2000.

Post-Polio Syndrome: Identifying Best Practices in Diagnosis and Care. White Plains, NY: March of Dimes, 2001. [This report was the basis for the guidelines in this brochure and derives from a May 2000 International Conference on PPS, sponsored by the U.S. March of Dimes in collaboration with the Roosevelt Warm Springs Institute for Rehabilitation. The report and this brochure are available on-line at www.modimes.org/Programs2/International.]

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