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# Post-Polio Syndrome

Post-polio syndrome (PPS) is a disorder of nerves and muscles. It can occur many years after you have polio. It can cause new muscle weakness that gets worse over time. It also causes pain in the muscles and joints, and tiredness. People with PPS often feel exhausted. PPS may cause the muscles to shrink. Over time, muscle weakness can make it hard to breathe.

## What causes post-polio syndrome?

Researchers are still trying to learn more about the possible causes of PPS. It may be caused by the way the nerves have to regrow after polio. This may overwork the nerve cells. The poliovirus may remain in the nervous system and become active again later, causing PPS. Or the immune system may attack the body's own nerves.

Only people who have had polio are at risk for PPS. About a quarter to slightly more than half of people who had polio in the past may develop PPS. You may be more likely to get PPS if:

- You had a severe case of polio.
- You were a teen or adult when you first got polio, instead of as a young child.
- You recovered from most of your polio symptoms.

## Symptoms of post-polio syndrome

PPS affects your nerves and muscles. Symptoms can occur 10 to 70 years after polio, but usually start 20 to 40 years later. Muscle weakness is the main symptom. This weakness may affect one side of your body more than the other. The symptoms may get worse over time and may include:

- Weakness that gets worse (common)
- Fatigue (common)
- Pain in the muscles and joints (common)
- Shrinking of muscles
- Trouble swallowing
- Breathing problems
- Sleep disorders
- Sensitivity to cold temperatures
- Depression

## Diagnosing post-polio syndrome

Your healthcare provider will ask about your health history and your symptoms. They will do a physical exam. You may have tests. Some tests are done to measure your muscle

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strength. Other tests may look for other causes of your symptoms. Tests may include:

- Blood tests, to rule out other causes for your muscle weakness
- Electromyography, to measure the electrical activity of the muscles
- Muscle biopsy, to look for signs of damage in the muscle cells
- MRI or CT scans
- Lumbar puncture (spinal tap) to analyze the spinal fluid

## **Living with post-polio syndrome**

There is no cure for PPS, but treatment can help you manage the condition. The goal of treatment for PPS is to reduce the impact of the condition on your daily life. You may use a cane or walker to save your energy and muscle strength. You may need to make sure you get plenty of rest.

## **Special exercises**

People with PPS may improve muscle strength with low-intensity muscle-strengthening exercises. These are known as non-fatiguing exercises. You may do these exercises in brief cycles. During the cycles, you exercise for a short period of time. Then you rest in between. It's important for people with PPS to avoid too much exertion. Doing these exercises in warm temperatures and in water may help.

## **Other kinds of treatment**

You may get care from a variety of providers. You will work with your healthcare team to create a plan of care. There is currently no medicine shown to stop or reverse the disease. Treatment usually focuses on easing symptoms. Your healthcare team might include a:

- Neurologist
- Physical therapist
- Occupational therapist
- Speech-language therapist
- Respiratory specialist

Some supportive treatments for people with PPS include:

- Assistive devices, like lightweight braces, canes, walkers, scooters, and wheelchairs
- Medicines to relieve pain
- Medicines to treat fatigue
- Physical therapy to keep as much mobility as possible
- Occupational therapy to help with ways to adapt
- Speech-language therapy for swallowing problems

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- Assisted breathing with a positive pressure breathing machine if needed, especially at night
  - Emotional and psychological support

## **Call 911**

Call **911** if you have trouble breathing.

## **When to call your healthcare provider**

Call your healthcare provider right away if you have any of these:

- Trouble swallowing
- New symptoms
- Symptoms that get worse