

- 1 -

FOR A BETTER UNDERSTANDING OF POST-POLIO SYNDROME



Polio Québec Association

April 2012

Visit our website: www.polioquebec.org

Call us: **514-489-1143 / 1-877-765-4672**

Email us: association@polioquebec.org

Background

As the name implies, post-polio syndrome (PPS) affects people who have had polio.

Poliomyelitis, often called **polio**, sometimes referred to as Heine-Medin disease or infantile paralysis, is an acute viral infection caused by the poliovirus and spreads from person to person.

While in most cases an infection by the poliovirus leads to minor symptoms such as a fever, it can in some cases, lead to more serious symptoms such as severe muscle weakness and can result in permanent paralysis and disability.

The discovery of vaccines by Salk (1955) and Sabin (1962), and subsequent mass immunization campaigns contributed to the eradication of the virus in America, Europe and in the Western Pacific regions. Today, poliovirus is still present in three countries: Nigeria, Afghanistan and Pakistan. India has recently been removed from this list as no new cases of poliomyelitis have been reported in 2011.

Definition

Post-polio Syndrome (PPS) refers to certain symptoms appearing in 50% to 70% of persons who have had polio. The symptoms appear after a period of stability (15 – 40 years) that follows a recovery from poliomyelitis.

PPS is defined as a new weakness and/or a persistent abnormal muscular fatigue, which can also be accompanied by generalized fatigue, muscular atrophy or pain, in persons who have recovered from paralysis due to polio. Terms such as "late effects of polio" or "polio sequellae" are general terms one may encounter.

Symptoms

Several symptoms can be found in Post-Polio Syndrome (PPS). Although no one symptom leads to a diagnosis of PPS, below is a list of the **most common symptoms found in PPS**:

- *new weakness*, instability during walking;
- intense *fatigue*;
- *new pain*, muscular or joint;
- decreased endurance;
- muscle fatigue;
- breathing problems, increased shortness of breath, increased frequency of chest infections;
- sleep disturbances, confusion, especially on waking;
- being cold while others are warm, sometimes accompanied by a burning and tingling sensation;
- lifestyle changes requiring need for assistive devices or a ventilator;
- difficulty swallowing;
- stress, periods of anxiety and depression.

Keep in mind:

- PPS is not always progressive; another period of stability can occur. However, PPS is generally considered to be slowly progressive.
- The non-use or underuse of muscles can mimic PPS symptoms. Inactivity can cause decreased muscle strength and diminished endurance.
- Loss of motor neurons from normal aging can also make the situation worse.

Risk Factors

Not everyone who has had polio will develop PPS. However, some factors can increase the risk of developing PPS:

- having had polio at or after 10 years of age;
- a greater degree of paralysis at the time of the original infection;
- a greater functional recovery after acute polio;
- a longer time since acute polio;
- recent falls, being on bed rest, being hospitalised or having had an accident;
- recent gain weight;
- a new diagnosis , for example: diabetes, or deterioration of an already existing disorder, for example: arthritis;
- a greater age at the time of presentation to a clinic;
- overuse of muscles that were affected during acute polio and have subsequently recovered.

PPS's Important Stages

Original Infection= POLIO

→ Complete or Partial Recovery

→ Reconstruction/Period of stability

→ Degeneration

= Post-Polio Syndrome

Causes

PPS has nothing to do with a reactivation of the poliovirus; it likely results from the consequences of having recovered from acute polio.

The most probable **theory** so far is one which explains that the poliovirus has damaged and destroyed some motor neurons. The motor neurons spared by polio "sprout" to resupply muscle fibres that lost their innervation during polio, like a tree (motor neuron) growing many new branches (sprouts). These new sprouts are thus making up for the loss of motor neurons from polio by taking on an increased load, in addition to carrying on with their regular function of innervating muscle fibers. This explains how some people have recovered almost completely from a paralysis after polio, that may have been partial or complete.

However, year after year, the increased demand placed on the remaining motor neurons can lead to deterioration of the neuromuscular unit. Over time, premature ageing and the excessive demands placed on the remaining motor neurons leads to the destruction of the neuronal sprouts. The muscles then lose their innervation (nerve supply), resulting in gradual weakness over time. This degenerative process can also produce neuromuscular junction transmission defects (difficulties in communication between the nerve and muscle) which may be the cause of muscular fatigue. It is therefore common to see persons who have recovered from polio experience new problems with their legs, arms, breathing or level of energy even after many years of complete autonomy.

Compared to the general population, certain conditions are more likely to occur in people with previous polio:

- ***Sleep Apnea (breathing problems during sleep)***
 - **Can produce** significant daytime fatigue or drowsiness, morning headaches, nightmares, snoring, impaired concentration, and irritability.
 - **Can be diagnosed** in a sleep clinic, and is treatable.
- ***Fibromyalgia***
 - **Can produce** chronic, generalized pain.
 - **Can be treated** with certain medications, aerobic exercise, and other measures.
- ***Osteoporosis (loss of bone mass)***
 - **Increases** risk of fractures.
 - **Can be treated** with several medications.

Diagnosis and treatment of these disorders associated with polio, can result in an improvement of symptoms.

Finally, it is important to not forget the psychological impact of PPS on an individual. PPS can be the reason for personality changes such as increased: introversion, isolation, anxiety and frustration because:

- symptoms occur unexpectedly;
- their cause is often unknown;
- the person has to deal with an **important lack of knowledge and understanding of the condition in the medical and allied health professions** (example: incorrect diagnoses, health care professionals diminishing the importance of symptoms brought to them by a patient,...);
- it is sometimes difficult to face reality with a new set of limitations.

Diagnosis

It is difficult to establish a diagnosis for PPS because:

- the diagnosis is determined by excluding other possible conditions that produce similar symptoms.
- PPS is still a relatively unknown diagnosis among physicians.
- several symptoms can mimic normal aging.

In 2001, a working group organised by the *March of Dimes* (USA), identified the following as diagnostic criteria for PPS:

- 1) A credible history of acute paralytic polio confirmed by neurological exam and EMG testing.
- 2) A period of partial or complete functional recovery, followed by a period of neurological stability (usually 15 years or more) after the original polio infection.
- 3) New muscular weakness, or abnormal, persistent muscular fatigue with or without generalized fatigue, muscular atrophy, or joint or muscle pain.
- 4) The above symptoms persist for at least one year.
- 5) Exclusion of other orthopedic, neurological or medical causes that can explain the new symptoms.

During the diagnostic process, the doctor proceeds to a thorough physical examination, where the strength of all the muscles is tested as well as the amount of movement at each joint. Motor neuron loss due to the acute polio can be confirmed by electromyography (EMG) testing. It is important to note that EMG testing cannot confirm the presence of post-polio syndrome.

Prevention

There is no cure for PPS to this day. But you can try to slow down the process and relieve the symptoms.

- ***Respect your body.***
- **Rest** often and regularly to avoid an important decrease in your abilities.
- **Avoid stress.**
- Use aids and tools to avoid fatigue and pain. Make **realistic goals**.
- **Stay in shape**, but without exercising excessively. Keep this in mind. « Take care of yourself to live longer. »
- Stay informed about **medications** that can help you to relieve the pain, but beware of their side effects.
- If you have to undergo a surgery with **anaesthesia**, make sure your doctor knows about your situation.
- Use of assistive devices such as crutches, braces, wheelchairs or other household adapted devices may facilitate daily functioning.
- ***Sleep well and eat well.***
- ***Stay positive.***

Keep in mind that among people who have had polio, those who overuse their weakened muscles and who do not rest when they feel tired are more at risk of experiencing an important decrease in their abilities. This means living with greater amounts of fatigue, weakness and persistent pain.