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Did you have acute poliomyelitis?

An Explanation for Polio Survivors about **Post Polio Sequelae**

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Post Poliomyelitis Sequelae (PPS)

After the poliomyelitis (polio) epidemics in the 1940's and 50's, people like yourself, who were affected by the polio virus, recovered. Half of those affected recovered well, others were left with residual disabilities. Generally, most polio survivors resumed an active lifestyle, your experience with polio thought to be behind you.

What is PPS?

In the 1970s, many polio survivors began reporting new problems. Late effects of polio were first recognized in 1875. Problems include weakness, increased tiredness, sudden onset of fatigue, decreased endurance for activity, painful muscles and possibly, problems breathing, swallowing, or cold intolerance.

How common is PPS?

It is estimated that about 22% of polio survivors develop PPS. You may not develop PPS. Between 1915 and 1961 about 10,000 cases of acute polio were reported. There are an estimated 3000 to 5000 polio survivors in New Zealand (Chetwynd 1993).

Who is at risk for PPS?

PPS tends to be diagnosed some 30 to 40 years after the initial episode of polio. Not everyone who had polio will start developing PPS at this time.

You may develop PPS earlier, later, or not at all.

Your risk is increased if you:

- had extensive paralysis, perhaps needed an iron lung.
- had paralysis of your leg muscles
- were over age ten when you developed polio
- have recently sustained a fall, been confined to bed, had an accident or experienced some kind of stress in your life
- gained weight in the last few months
- have recently developed a medical problem (eg. Diabetes), or an existing problem has worsened (eg. Arthritis).

Recovery from Polio

The polio virus affected cells called motor neurones, primarily in the spinal cord. Sometimes these cells were affected in the lower part of the brain, when it was called 'bulbar paralysis'. These cells send signals along the nerves to your muscles so that you can move. Some of these neurones were unaffected, some recovered, and others were destroyed by the polio virus. Cells that remained attempted to take over the function of the cells that had been destroyed.

This means that your remaining motor neurons have had to supply more muscle fibers than nature originally intended them to supply.

What causes PPS?

There is no evidence that reactivation of the polio virus can occur in man. Both polio affected muscles and nerve cells whether affected or not, have had to work harder than normal to perform your usual activities since your recovery from the initial polio. Over time this may result in exhaustion of the muscle complex.

The symptoms of PPS also can be mimicked by disuse or under use of muscles. Inactivity may result in a loss of strength and a decrease in endurance.

Loss of motor neurons is a normal process with aging. This normal aging process may cause a greater change, perhaps a decrease in function in people like yourself, because polio has already claimed some of your neurons.

What can be done?

Generally, PPS has a slowly progressive course. You can ensure this is so.

It is important to stay in good condition, to avoid stress and take rest when needed.

The important aspects of management are:

- Life style modification
- Weight control and diet
- Assistive devices
- Exercise, individualized

Many symptoms of PPS are due to tired, overworked muscles. The sensible management is to *change your activity level* so that you can do what is important to you. There must be a balance between rest and activities. You may need to rest for twice as long as you were active. You are the person who can best manage and control your life style.

- Keep a diary

Identify the activities and the time spend on those activities that produce symptoms (fatigue, pain etc). Forget the old slogan "no pain, no gain"

Pain is a signal to rest!

Many **devices** can decrease the energy needed to perform daily tasks and lessen strain on your joints. These are items such as electric can openers, jar holders, card holders, walking aids, and for some, electric scooters and wheelchairs. You could

- use a cart and avoid carrying loads
- do tasks in sitting rather than in standing
- take the elevator instead of stairs, even 1 flight!

A careful **exercise program**, such as walking, swimming, cycling, lifting small weights can be beneficial. *Pain on exercise however means stop!* Consult your physiotherapist to plan your exercises and monitor its effects. Some muscles can be exercised, others already used to capacity, may not.

Want to learn more, to talk to someone about PPS?

Contact the Post Polio Support Society (Inc). (see next panel for address). This group is a voluntary organization, run by polio survivors to provide mutual support and to share information and coping mechanisms. There is an annual subscription ($10); newsletters & meetings.

Health professionals, doctors, physical therapists, occupational therapists, & counsellors can provide advice. Most health professionals have not had experience with acute polio, however they have expertise with similar conditions and usually, if they don't know, they will find out.

In summary,

not all polio survivors experience PPS. Keep yourself fit, avoid stress, maintain normal weight, have a 2 to 1 balance between rest and activity. You are sensible and not lazy, if you use devices to avoid fatigue, pain and joint strain.

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