

**Cold intolerance and purple “polio feet,”** are caused in part by the muscles around the veins being partially paralyzed by the original polio. Without muscle to control their size, veins fill with blood and cause your feet to appear purple and lack of circulation makes them feel cold.

**Spiritual base:** Having a faith or spiritual base that transcends the daily activities and struggles of this life can be an additional source of personal strength. This pilgrimage is a personal choice, but it often provides another base to work from in creating a greater meaning to challenges faced.

**Never, ever give up:** Maintain a persevering and hopeful attitude to life at all times. Do not give up; it serves no positive purpose, just pace the race.

Additional information and resources are available through the POST POLIO SUPPORT SOCIETY

Freephone - **0800 4 POLIO** (0800 476 546)

Email - [info@postpolio.org.nz](mailto:info@postpolio.org.nz)



[www.postpolio.org.nz](http://www.postpolio.org.nz)

The generous assistance of Freemasons Roskill Foundation in the production of this brochure is gratefully acknowledged.

**Talk to someone:** Polio survivors have spent their lives trying to look and act normal, and not to communicate their needs. However communication is vital to us all so find more information to share with family and friends, and find a support group so you can talk to other people who are in the same situation as you.

**Keep your sense of humour:** Many polio survivors seem to possess a witty sense of humor and an upbeat approach to life, which help you to remain innovative, creative, and positive. We love this characteristic of people with PPS. Keep it working for the world.



# Did you have polio?

*Are you suffering from fatigue & muscle & joint pain?*

It might be post-polio syndrome

# What is Post Polio syndrome?



Post polio syndrome occurs some 40 years plus after an initial occurrence of poliomyelitis.

Polio epidemics used to occur frequently until the mid 1950s, when vaccines were found by Salk/Sabin. Rotary International's 'End Polio Now' campaigns have largely reduced epidemic occurrences but the risk of epidemics remains while un-vaccinated people are still present in society.

75 – 80% of polio survivors now show symptoms of post polio syndrome, or late effects of polio which may include

- Increasing muscle weakness
- Significant levels of fatigue
- Joint and muscle pain
- Cold intolerance
- Breathing and or swallowing difficulties

Post polio syndrome known as PPS, is caused by prolonged overuse of muscles, whose nerve supply, initially damaged in the original

occurrence of polio, can no longer take the strains placed upon them. The overworked muscles then ache and the joints hurt after decades of too much work with too little muscle support, and when the muscles decide that enough is enough PPS results.

*remember if something you do causes fatigue, weakness, or pain, you shouldn't be doing it*

PPS may occur alongside such conditions as diabetes, heart conditions, or cancer, so you may have PPS alone, PPS and another problem or a condition not related to

polio at all. There are no medical tests that can prove you have PPS.

PPS symptoms vary from person to person in severity and multiplicity but understanding PPS and how it affects your body is key to effective treatment and the following may be useful to you.

*Polio survivors must take responsibility for taking care of their own bodies and ask for help when it is needed*

**Pacing:** Understand that your body cannot do as much work as it used to do. The energy you expend must not exceed the energy you have stored, or you will simply run out of muscle power. Learn how long you can work for, and how much rest has to follow, and remember that this varies day to day. Pacing must become a way of life, not just something you do today and forget about tomorrow.

**Exercise:** If exercise kills your muscle power tomorrow, cut your exercise programme by 50%. Doing exercise is important, but over-exercising can be seriously damaging to your muscles while increasing your pain and limiting your functional ability. Remember routine activities such as vacuuming also count as exercise. Exercise is also unlikely to restore function in newly weakened muscles.

**Treatment:** PPS symptoms are caused by the nervous system equivalent of plugging too many appliances into one electrical outlet, polio survivors simply have to unplug some of the appliances.

Polio survivors must decrease the overuse to stop the abuse of their damaged nerves, weakened muscles and painful joints.

**Pain:** Pain and PPS go together, but every effort should be made to diminish pain by reducing activity, increasing rest, and the use of assistive devices, such as walking sticks. Panadol or massage may be helpful, but medical advice should be sought.

**Doctors and therapists:** Find doctors/therapists who know about PPS, are interested in learning more and will listen to you. However, be cautious if a doctor tends to blame all your symptoms on PPS as we are in an age group which is vulnerable to many other medical/surgical problems.

**Nutrition:** Work towards maintaining a constant weight, which is harder to accomplish with a more sedentary lifestyle. Avoid big meals, eat a balanced diet with some emphasis on protein content and maintain good hydration.