

We can do something about PPS

We didn't think we'd have to, but we can and must learn to adjust - again. We can live rewarding lives despite PPS, just as we have done in those stable years following recovery. However, this time we need a new strategy.

No longer should we push our residual strength to the limits. The 'No Pain, No Gain' theory is out and in comes the 'Conserve to Preserve' theory. We've learned that these ideas work. We are all different and we have to work out our own program.

- Listen to your body's warning signals.
- Get periodic evaluations and relevant to you therapy from health professionals who have knowledge and experience of working with polio survivors.
- Set priorities. Decide what is truly important to you. Forget the rest. We can't do everything.
- Learn how to pace yourself.
- Do tasks in stages. Take each action of daily living and keep halving the amount of time you do [and then rest] till you find an optimum schedule that works for you. Surprisingly this allows you to do more of the action overall.
- Plan activities ahead for your most productive times.
- Don't use muscles in one position for too long. Change positions often to lessen fatigue and stiffness.
- Rest a few minutes before you get tired and then you can do the action again.

- Don't smoke or drink or take medications that interfere with respiratory function or reduce co-ordination. An occasional celebratory drink is ok.
- Eat a sensible diet. Include bulk producing fibre and watch those calories. Check out low glycemic load foods. Look at what you eat and swap high glycemic foods for low ones.
- Avoid getting chilled. Wear leg warmers, hat and gloves in cold weather. Carry an extra sweater.
- Work out an exercise program with health professionals knowledgeable and experienced in polio and post polio. Stretching and/or swimming gently in warm water can help.
- Make full use of the best appropriate devices. A cane, arm crutches, rollator, new bracing and an electric scooter or wheelchair can allow you to do much more with less pain and fatigue.
- Be sure to have the best body position and support - whilst awake and asleep. Protect against flu and get early treatment for any respiratory affected illness.
- Don't be afraid to ask for help. This is not giving in, it is practicing much needed energy conservation.
- Discuss problems and opportunities with other Polio Survivors, your families and friends. Two minutes each and listen to how they feel about what is happening to you.
- Read more information about PPS and put what you learn into practice and see your lifestyle improve.



POST POLIO MATTERS

If you had POLIO

and are experiencing
New Pain
New Weakness
Functional Decline
then you are not alone

**The Late Effects of Polio
Post-Polio Syndrome
Post-Polio Sequelae
Post-Poliomyelitis Syndrome**

Terms for new symptoms
being experienced by
Polio Survivors
10 to 50 years
after recovery from Polio



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What do these terms mean?

Late Effects of Polio [LEOP]

Post-Polio Syndrome

Post-Polio Sequelae

Post-Poliomyelitis Syndrome.

The diagnostic terms in use vary in their specificity but all relate to having had Polio in our earlier lives. LEOP tends to refer to symptoms following recovery, whereas the others refer to NEW symptoms after a stable period of functioning most commonly known as PPS.

In the UK actual figures for many neurological conditions have not been recorded for decades. Sadly Polio is included in this list. The currently used figure is about 120,000 out of a population of 66 million. Less than 5 in 100,000 is considered to be a rare disease.

Common symptoms

Fatigue, often overwhelming

Loss of muscle strength or use, even in muscles thought not to have been affected at the time of polio

Pain in muscles and/or joints

Trouble breathing or swallowing

Problems sleeping

Intolerance for cold, causing muscle weakness, and sometimes burning pain and/or discolouration in affected limbs.

Slowly moving digestive system.

Our old polio can also affect how we react to other conditions, medications and anaesthetics.

Remember POLIO?

It was the dreaded disease wiped out by vaccines in the UK and the developed world, then forgotten even by Polio Survivors; it was part of our past. With grit and determination, we came back. Lots of us never used or left behind wheelchairs and braces. We've been living full and productive lives. But now something new is happening.

Many who survived acute POLIO 40 to 70 years ago are experiencing new muscle problems or hitting a wall of fatigue. We feel weakness in some muscles that responded to therapy and returned to normal function, or so we believed, and other muscles we did not even realise were affected by the polio virus at the time of infection.

Without knowing why, we who had polio suddenly find our mobility threatened. The ways we have been compensating for our paralysed or weakened muscles are no longer working.

We have learned many health professionals have been taught nothing or just a few basic facts about Polio during their training. A few photos of withered limbs and polio survivors in iron lungs gives a very restricted understanding of how well some of us recovered.

We were brought up to 'Use it or Lose it' and did we. Strong willed, determined, succeed at everything possible, help everyone we can describes nearly all of us. Is there any wonder we find it hard to listen to suggestions to 'pace and rest our actions' start using aids and assistive devices, ask others for help? We can turn down help one minute and then moan that no-one offers to help the next.

You're not alone anymore

Let us share the latest information with you.

If you had Polio and are experiencing new symptoms, we urge you to get in touch with us. "For the first time, I feel somebody really understands" is typical of the type of response we receive by those who contact us.

Polio Survivors Network - originally named and still registered as Lincolnshire Post-Polio Network - is run by and for people who have polio, and their families. For 23 years now we have shared information with other PPS Groups around the world. The most common response by new folks seeking information is 'But I am not there yet'. We are honest and admit that we too said exactly the same thing at the start of our journey.

We are pleased to tell you that the more we learned and tried the suggestions out there the better we started managing our lives. We will also admit that occasionally we still overdo, those habits of a lifetime hard to change.

MEMBERSHIP is now FREE thanks to a legacy from member Ms. Brown.

POST POLIO MATTERS - our quarterly newsletter is available by post [UK only] and by email as a PDF. Members will receive their newsletter two weeks before we make them available online.

DONATIONS towards our work will always be gratefully received, by post or PayPal.