

We can do something about it

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 between recovering from Polio and the appearance of these new symptoms. Only this time we need a different 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 and Preserve' theory. We've learned that these ideas help. We are all different, we have to work out our own program.

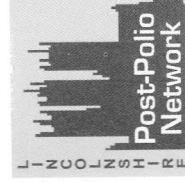
- Listen to and heed your body's warning signals.
- Get periodic evaluations and proper therapy from health professionals who know about PPS.
- Set priorities. Decide what is truly important. Forget the rest. We can't do everything.
- Learn how to pace yourself. Don't get overtired. Stop any activity or exercise — including walking — that causes you pain, weakness, or muscle fatigue just before that sets in and rest.
- Do tasks in stages.
- 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 when or before you get tired. Stop for a 15 to 30 minutes rest maybe several times a day.
- Don't smoke, drink or take drugs that interfere with respiratory function or reduce co-ordination.
- Eat a sensible diet. Include bulk producing fibre and watch those calories. Extra weight makes extra problems for weakened muscles.
- Avoid getting chilled. Wear leg warmers, hat and gloves in cold weather. Carry an extra sweater.
- Work out an exercise program with people knowledgeable about PPS. Swimming in relaxed manner in warm water could help.
- Make full use of the best appropriate devices. A cane, new bracing and perhaps a motorised scooter or chair can allow you to do much more.
- Be sure to have the best body positioning and support — while awake and asleep. Protect against flu and get early treatment for respiratory illness
- Don't be afraid to ask for help. This isn't giving in; it's practising much needed energy conservation.
- Discuss problems and opportunities with other Polio Survivors, your families and friends.
- Read as much information as you can about PPS and put what you learn into practice and see your lifestyle improve.

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

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



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Includes The Lincolnshire Post-Polio Library
- over 100 full text medical articles

What are Post-Polio Syndrome, the Late Effects of Polio, Post-Polio Sequelae?

The diagnostic terms in use vary in their specificity but they all describe new symptoms following our recovery from Polio earlier in our lives.

Figures are estimated as 30,000 and 50,000 and even 250,000 for the UK. It just depends on which survey and whose statistics you look at. Some researchers believe as many as three quarters of us are experiencing what we think is the result of chronic overuse of our polio-weakened joints and muscles. These may have aged prematurely due to lack of reserve capacity. The medical community offers few answers to what we shall call PPS.

Common symptoms

- ◆ Fatigue, often overwhelming
- ◆ Loss of muscle strength or use, even in muscles thought not to be polio affected
- ◆ 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

Remember Polio?

It was the dreaded disease wiped out by vaccines, then forgotten even by Polio Survivors; it was part of our past. We had polio, past tense. With grit and determination, we came back. Lots of us 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 full normal function, or so we believed, and some we did not even realise were affected by Polio.

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. And doctors aren't sure what's causing our new problems, much less what we should do about them. In fact, many doctors know very little about post-polio conditions (despite the existence of numerous articles and papers in medical journals worldwide). They may give inappropriate prescriptions and advice, or send us on costly, needless referrals, and in some cases deny it exists.

We hate to admit we now find it hard to do things we used to handle with ease. Even those closest to us don't understand what we are going through. No wonder we retreat into ourselves, pretend nothing is wrong or lash out in fear, anger, frustration and loneliness.

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 from those who read the information we provide. We've all been there, we're learning and finding out what works for us, and we are sharing it.

The Lincolnshire Post-Polio Network is run by and for people who have had polio and their families and friends. Don't forget we know what you are going through, we are only just ahead of you.

We welcome your questions. Receive our bi-monthly newsletter; regularly updated list of full text medical articles on our Website, which you can order. We will keep you in touch with the latest information available from around the World.

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