

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 these ideas help. We are all different; we have to work out our own program.

- Listen to and heed our 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 ourselves. Don't get overtired. Stop any activity or exercise – including walking – that causes pain, weakness, or muscle fatigue just before that sets in and rest.
- Do tasks in stages.
- Plan activities ahead for our most productive times.
- Don't use muscles in one position for too long. Change position often to lessen fatigue and stiffness.

- Rest when or before we 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. Including 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 should 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 practicing needed energy conservation.
- Read as much information as you can about PPS and put what you learn into practice and see your lifestyle improve.



Scottish Post Polio Network

Patrons:

**DR RICHARD BRUNO
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**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 30 to 50 years after recovery from
Polio.**

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What are the late effects of Polio Post-Polio Syndrome 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 or even 250,000 for the UK. It 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 a 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, and then forgotten even by Polio Survivors; it was part of our past. 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 of 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 most doctors know virtually nothing about post-polio conditions despite the existence of numerous articles and papers in medical journals world-wide.

They may say 'it's all in your head' 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 aren't 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 understood' is a typical of the type of response we receive from those who read the information we provide. We have all been there, we are learning and finding out what works for us and we are sharing it.

The Scottish Post Polio Network is run by and for people who have had polio. Don't forget we know what you are going through. We are only just ahead of you and a phone call away.

We welcome your questions; you will receive our newsletters. There is updated list of medical consultants who have interest in people who had polio and will take a referral via your GP. There is also regularly updated list of full text medical articles and latest information available from around the world on Lincolnshire Post-Polio Network website www.postpoliosurvivorsnetwork.org or www.post-polio.org or polioplac.org

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