



# The LincPIN

**The Lincolnshire Post-Polio Information Newsletter  
Volume 2 - Issue No. 1 - October 1998**

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*This issue includes articles from our online library (our newsletter is distributed by post to many subscribers who do not have Internet access). Rather than duplicate the articles in this online edition of the newsletter, I have instead just included links to the library articles. I have assumed that those of you who already have the articles would prefer not to have to print them again if you wish to print this newsletter for your own use. However, if you are printing copies for further distribution we would ask you to print copies of the articles as well.*



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*Remember the opinions expressed are those of the individual writer(s) and do not necessarily constitute an endorsement or approval by the Lincolnshire Post-Polio Network. Although it does not provide an endorsement, it is provided as a service for those seeking such information. ALWAYS consult your doctor before trying anything recommended in this information or any other publication.*

**Lincolnshire Post-Polio Network**

## Editorial by Hilary Hallam

Here we are in October already. Firstly please accept my apologies for this newsletter being a little late but there has been a lot going on in the past month and as a PPSer I have limited energy.

Welcome to all the new members especially those overseas. The work we do is only possible because of the membership fees and donations received. We have much planned for the future as soon as finances allow. If you are not already a member and reading this then we ask that you consider joining us.

The Annual General Meeting was an excellent day. We were so pleased to welcome many polio survivors and their families from eight other counties in England, four from Wales and two from Scotland. The years reports were read and approved and voting took place. The results are Chairman - Lynn Hobday, Vice Chairman and WebSite Administration - Chris Salter, Treasurer - Jean Tapper, Secretary - Hilary Hallam. Committee Members are Christine Ayre, Jeff Boss, and Phil Bilton. Following the meeting, and over a Buffet Lunch, we were joined by The Mayor, Councillor Bud Robinson and his Lady Mayoress Ruth Robinson and from letters and phone calls received they must have talked to everyone there. Their support, understanding and interest in Post Polio and the problems that we have getting a diagnosis, advice and treatment in the UK was invaluable. We were also delighted that Helena Edwards, Sue and John Wakeing from the Leicestershire Post-Polio Network were able to join us. We would also like to thank Councillor Barry Fppard from the Community Health Council for his presence, interest and assistance. The Mayor opened the afternoon's proceedings with a short address about what they had learned that day and then left to set off a Duck Race for Meningitis.

Lynn Hobday then introduced our speaker saying:

In Dr. Whiteley we have found a consultant sympathetic to our needs for medical help and advice. He has instigated a Post Polio Clinic at Queens Medical Centre. He and his medical team are seeing patients and collecting much information on the problems that polio survivors are having in later life. There is no doubt in my mind, that in time, Dr. Whiteley and his team will be giving help and advice that we all need to cope with post polio problems and his clinic will be respected throughout the world.

You will find [a report on the next page](#) of Dr. Whiteley's talk followed by some of the questions.

Eleven of us joined together for an evening meal at the Halfway House Inn near Swinderby and we talked for hours about all aspects of Post-Polio. I think that the most important point that came out was that those who care for us - our families - are having a equally difficult time in coping with all that is happening. They do not have the condition and can only guess at how we feel and what we are going through and are not always sure what to say and when. As Polio Survivors we must remember this and share with them more about how we feel and listen to how they feel. The medical profession should also take note that the majority of care and treatment that all people with a chronic condition receive is given by our carers and that their needs must be included in plans for the future. This fact is coming out in many PPS Support Groups and at the recent PPS Retreat for the Central Virginia PPS Support Group they had a caregivers workshop. Dave VanAken has written Life with a Polio Survivor (page 13) and shares it with us.

On Saturday 3rd October we had a stand at the Neurological Support Group Conference at Queens

Medical Centre and were surrounded most of the time by delegates requesting information on Post Polio, many who did not know the condition existed.

We would like to take this opportunity to thank all the contributors to our newsletters and for the information that we are able to put up on our WebSite. Special thanks in this issue to Dr. Daria Trojan for another article brought back from trip to Canada in July. To Grace R Young MA, OTR for permission to use her Monthly Tips from her WebSite - next newsletter will all be about tips for coping during holidaytimes. To Mary Clark Atwood from the Los Rancho Amigos PPS Group for sending us her newsletters and permission to print articles she reported on.

Next newsletter - information from PPS Conference in Jena, Germany and more from our members. All contributions financial and items for newsletters always gratefully received.



## Dr. Alan Whiteley, Consultant Neurologist, Queens Medical Centre, University Hospital, Nottingham

### Talk given at our Annual General Meeting

I am honoured to come to speak to you all. It is always very nice for doctors to come and speak to the actual sufferers of the condition. We find it very instructive because we get first hand information.

Now as you know the Post Polio Syndrome is a very mysterious condition. You know it first hand but for the medical profession it has not gained much acceptance in the general medical fraternity, because it is difficult to diagnose and difficult to treat.

The crux of the Post Polio Syndrome is that the sufferer has a polio virus infection, gets better, remains stable over several years and then deteriorates in a number of ways. That is basically how the condition is defined.

The actual infection is a viral infection but we don't know much about the clinical picture at present because it's all history now. We just don't see cases of polio. If a case of polio came to Nottingham there would be panic and pandemonium. I myself have not had first hand experience of the virus.

The virus gets in your mouth and your nose and then it multiplies in your body. Ninety per cent of people don't even know they have had it. Then some people get a sort of flu-like illness, where they feel a bit feverish and a bit off-colour. It's the minority of people that get the paralysing variety. The reason for this is unknown.

The encephalitic type then infects the cells of the brain. It attacks a lot of cells in the nervous system but the peculiar thing is that it attacks the cells called the Anterior Horn Cells or the motor neurones.

The Anterior Horn Cells lie in the spinal cord in the anterior horn. That's why they are called anterior horn cells. These cells control the muscles and it is thought that the virus for some reason gets in the end branches of the cell and then travels up to the cell body and knocks out the cells which causes the paralysis. So when you had an attack of paralytic poliomyelitis, you would get ill, you would feel rotten and then you would notice you were not moving your leg or your arm. You would go to hospital and you would be obviously treated depending on how severe the paralysis was. On the whole you would start recovering.

Recovery would occur if the cell itself had not been killed but just wounded. But if the cell actually died, recovery would occur because another cell would actually take up the muscle fibres of the dead cell by growing new connections.

It's all a question of percentages. If you lose 10% of your Anterior Horn Cells you will recover completely. If you lose 20% you will recover. When you start getting down to over 50% of your

cells then you can't recover that much, so you will notice that the muscle is thin and weak.

I am sure everybody has their own individual peculiarities but I think that you can roughly say there are three types of post polio syndrome.

The first one is the loss of the muscle fibres. That's called post-polio muscular atrophy. The sufferers start losing muscles and become weaker and the muscles become thinner. It usually is in muscles that have been badly affected but it can be in muscles that have only been mildly affected. For some reason there is a process that makes those muscle fibres just not function. And several things can do that.

Firstly the Anterior horn cells just die because of natural aging, or because they are worn out with all the extra use they have been put under or because there is a bit of polio virus still there, that is attacking them still. No-one really knows.

The other reason why you can grow weak is because the new connections to the muscles start contracting and the terminal axons die back. It can also be due to a deficiency of the chemical that passes from the end of the nerve to the muscle. We can't treat the actual cells dying but a possible drug would be Riluzole.

We can attempt to increase the acetylcholine by a drug called Mestinon (Pyridostigmine). As far as I know that has not proved to be very affective.

The second type of post-polio is the fatigue, the muscle aching, cold intolerance, sleeplessness, dull brain and those sort of symptoms, it's very difficult to know why those symptoms come about and it could be a different cause from the muscular atrophy. It's understandable in a way because when you have the encephalitis it's not just the anterior horn cells which are damaged. There are a lot of cells which are damaged but at the moment those cells are not understood. There are several thoughts about it. One thought is that there is something wrong with the brain stem. The brain stem is this bit of the brain between the brain and the top of the spinal cord, which is the system that keeps you awake, vigilant and alert. Brain Scans in some people find little spots. It maybe that those spots represent damage. The other thought is that it is something to do with hormones and somehow the polio has affected the pituitary gland.

There is another condition that is very similar to this sort of post polio syndrome and that's Chronic Fatigue Syndrome which is very abundant and thousands of people have it. That again is a complete mystery. If you were to write down your symptoms of PPS and their symptoms of CFS there would not be much difference apart from the fact that you had polio and some of your muscles are wasted. My own view is that CFS will be some sort of disturbance of the chemicals in the brain. The brain is a huge computer and it works on a mixture of electricity and chemicals. These chemicals will set the activity level and if there were a mystery hormone that was out of tune it would cause the CFS condition and likewise with the post polio.

For treatment of fatigue etc, medically all we can suggest is looking after yourself, physiotherapy, etc. The pills are low doses of anti-depressants at night such as amitryptaline and experimentally other hormones such as bromocriptine to stimulate the hormones in the brain are being tried.

The third type of post polio syndrome is associated symptoms causing a deterioration such as arthritis etc. In this category is respiratory failure at night where the breathing can get very slow and you do not get enough oxygen and your carbon dioxide rises. That means you have a very restless sleep and in the morning you feel terrible with a headache and throughout the day you are drowsy and muddle headed. That is quite simply remedied by having a mask on at night to force enough oxygen into your lungs and take away the carbon dioxide. That sort of thing is assessed at specialist units.

### **Question 1.**

*We live in Devon, how do we get in touch with Post Polio specialists when we live in other counties?* Comment. This question is one that comes from nearly everyone who contacts us, "Who

should my GP refer me to?"

This is very much a neurological problem. It depends on the interest of the neurologist and some are going to be interested in muscle disease and some are not and its pot luck whether in your area you are going to find someone that is sympathetic.

**Question 2.**

*What can be done to raise the awareness of PPS generally within the medical profession and more particularly within hospitals?*

Well nagging I suppose is the answer. You just nag away.

**Question 3.**

*We have had consultation, we have had the tests, now we are waiting for the next bit and nothing has happened.*

The next step is you get into a program of maximising the use in the limbs and that to a certain degree can be done by the physiotherapist, but physiotherapy isn't really the whole answer. We really need drugs to correct if your cells are dying off with your hormones. What we need is medical research to get to the problem and treat it effectively.

**Question 4.**

*We feel that Physiotherapists have actually been giving us the wrong advice the wrong treatment and some of us have actually deteriorated from it. There appears to be no training in PPS for physiotherapists. How do you suggest that we get the awareness of our condition to the medical profession? We have written to all the Colleges of GP's, Physiotherapists, OT's etc. promoting the awareness of our Network. The Neurological physios have taken a great interest but what about the rest of the physiotherapists?*

I find physiotherapists very daunting they are usually very powerful women. (Much laughter and memories of their polio physiotherapists). It's a slow process. In the end you have to go and see a physiotherapist and say the recommended treatment by a physiotherapist for PPS is this, what do you think? It's really going to have to be on a one to one basis.

**Question 5.**

*Could we not get a physio from Queens Medical Centre to take an interest?*

Information 15.10.98 is now - Yes, we are making progress here.

**Question 6.**

*I have been referred for an EMG test because a high blood test indicates high muscle destruction. What muscles are tested and what treatment will follow?*

You can measure muscle destruction by an enzyme test that's called a creatine kinase. In some people this enzyme seems to be raised and in others it is not. Myself I don't quite know what that means. You have then to do the EMG. You know what that is, you have probably had them done. They stick a needle into the muscle. You can look for evidence of old polio, sometimes evidence of new muscle disease.

**Question 7.**

*Is there any way to help myself overcome fatigue and tiredness? Is there any way to keep the strength I have left?*

Well, yes that is what you put in your Newsletters and on your Internet Site all the time. You have got to conserve energy, you have got to make sure you do the things that you enjoy doing and not waste your time doing the hoovering or things like that. In the Post-Polio Syndrome there is a concept that if you overtire the muscle that the muscle will die quicker. The thought is that you

should not overtire yourself, that you exercise to within a sensible amount and then you just stop.

**Question 8.**

*There is a problem in that we do not have Occupational Therapists with awareness of PPS who understand the need for this type of equipment. Until we have a diagnosis they will not listen to things like stair lifts, electric wheelchairs and alterations to our houses. We are not getting the medical support that these items are necessary.*

I sympathise.

**Question 9.**

*The trouble is that some of us have gone for 3, 5, 11 or more years trying to get a diagnosis. One member in Scotland has gone through eleven consultants without getting a diagnosis until we sent him information on post-polio. He took this to his GP, he was referred back to the neurologist who said that he had no idea that the condition existed.*

That is a slap on the wrist for neurologists then. There is a sort of inertia in the medical profession. It is a slow process to change attitudes. It's like ME which is only half accepted. There are lots of conditions that don't have a test to prove it. If you don't have a test then it's a matter of opinion and doctors are all different in their opinions.

**Question 10.**

*If a 60 year old man with PPS symptoms for the last 15 years had non paralytic polio diagnosed at the age of 12 came to you would you perform further EMG's and would you want to perform muscle biopsies?*

You can't answer questions like that without seeing the patient and seeing what the old EMG's show. It's very difficult to make diagnoses without seeing the patient.

**Question 11.**

*A member in Lincolnshire has been unable to get an NHS referral to you. What do they do about this? We want you to come out as a PPS specialist so that the doctors will accept that you are the person to take referrals.*

I have done that now, and will be making this information more widely known. There are other GP's in the practice. Doctors take the least line of resistance.

Comment. As most of us have experienced.

**Question 12.**

*Would you write to a neurological publication so that other neurologists know you are specialising?*

I have got to have something to say. It is no good just saying that this condition exists. I will do my best there.

**Question 13.**

*Given that further training in this speciality would be helpful to you and your staff, what other training might you be able to obtain through NHS resources? Is there any way we can help you?*

The usual way, you go to conferences. The best thing would be to have a conference in England.

Comment. There is a 3 day conference in Jena in Germany at the end of October. Is there any possibility of you going?

It would be best to have it in Britain if you want British doctors to go. If you make the conference attractive enough? Aim it at neurologists. Doctors have to attend a certain amount of lectures to practice.

**Question 14.**

*If you have an EMG that shows old polio and the GP writes to you for diagnosis and or help to manage the illness what would you advise?*

You have to see a patient, have hands on to make a diagnosis, so you must ask your GP to refer you to me.

### **Question 15.**

*We do now know that you can get referral from one health authority from another.*

They are going to change the way the health service is funding next March. All this paying may just disappear.

*For Queens Medical Centre contact information see the entry for [Dr. Alan M Whiteley, Consultant Neurologist](#) in our Directory of Clinics and Health Professionals.*



## **QUOTABLE QUOTES**

### **ON POETIC LOVE**

When an eel bites your thigh  
And the sting makes you cry  
That's a moray.

### **ON PUBLISHING OR PERISHING**

I am returning this otherwise good typing paper  
to you because someone has printed gibberish  
all over it and put your name at the top.  
*English Professor, Ohio University*



## **Control Your Destiny II With Dr. Jacquelin Perry**

Reprinted with permission from Rancho Los Amigos Post-Polio Support Group  
Newsletter September 1998

*Reported by Mary Clarke Atwood*

World renowned polio specialist Dr. Jacquelin Perry was the featured speaker at the Rancho Los Amigos Post-Polio Support Group meeting on December 6th 1997.

Since retiring after 40 years of dedicated, full time county service, Dr. Perry continues her work at Rancho but in a new capacity - as a volunteer. Because she continues to believe that post-polio syndrome is under-treated by the general medical community, the Rancho Post-Polio Clinic remains open and she continues as chief of Post-Polio Services. Dr. Perry also volunteers as medical consultant for the Rancho Pathokinesiology Lab. When the opportunity arises for her to speak at worldwide conferences or lectures, Dr. Perry uses the occasion to educate other medical professionals about PPS. We appreciate this annual opportunity for her to educate us, the polio survivors.

As time passes it is becoming more and more clear to Dr. Perry that we as polio survivors have more control over our future than anyone else. Therefore, she chose to repeat last year's title for this talk, "Control Your Destiny II".

This presentation was based upon questions submitted to Dr. Perry. The following report focuses on her response to one question concerning the natural progression of postpolio syndrome. In succeeding issues we will present Dr. Perry's answers to the other questions from this meeting.

**Question:** *What is the natural progression of post-polio syndrome? Will a person return to the same degree of paralysis that was experienced at onset?*

**Answer:** When focusing on the natural progression of PPS it is important to understand that muscle function depends on three systems:

1. Control from the brain.
2. Sensation from the periphery, the lower motor system from the spinal nerve cell (anterior horn cell) down to the muscle.
3. The third system is the most important for people with PPS because if you lose the nerve, you lose the muscle. We talk about muscle weakness, but polio is actually a nerve disease that damaged or killed anterior horn cells. This makes a lot of difference in terms of exercise, etc.

## Acute Polio

During the acute phase of polio some spinal nerve cells died while others were injured but later recovered. Some people had paralysis - others did not. The effects were like spatter paint. If you had a lot of "paint" you had a lot of damage, while others were just touched lightly. But all survivors were left with a damaged neuro-muscular system.

## Recovery

Recovery from polio entailed all three methods of recovering function:

1. Neuro recovery.  
Between 12% - 91% of the nerve cells that were injured - not killed - by the polio virus recovered.
2. Axon sprouting.  
New branches of the remaining nerve cells were sent out to adopt the orphaned muscle fibers. The result was that each nerve was then doing 50% more work or even up to four times as much as normal.
3. Hypertrophy.  
The muscles enlarged themselves up to about 400% so they could increase function.

It is not known how much a survivors recovery was due to spontaneous nerve generation, how much could be credited to patching by the axon sprouting, and what amount was due to hypertrophy. Upon recovery polio survivors had a random disability in regard to the amount of paralysis. The amount of muscle weakness a person had was pure chance; it depended upon the amount of polio virus a person had and where it went. Some survivors remained paralysed, while others looked or felt normal although they were not.

## Research

During the 1940s Bodian traced the polio virus in the motor nerve cells of monkeys. He found that polio, a systemic disease, affected 95% of these cells by either injuring or destroying them.

Research confirms that there is some obvious weakness as a result of polio:

- Agre found that polio survivors with no current symptoms had only 80% of normal muscle strength. Symptomatic survivors had 60% or less muscle strength compared to the normal group.
- Following a four year study Grimby reported a normal 2% - 5% loss of muscle strength in asymptomatic polio survivors, but for symptomatic survivors this loss may be as high as 13%.
- A study by Grimby confirms that weaker muscles work longer and twice as hard.

This research says that it is necessary to protect this overused muscle system. The muscles that are grade 3, 3+, and some 4s are getting all the exercise they can tolerate. In order to maintain this function these muscles must be protected from overuse.

## Now

For many, many years polio survivors have been working with a damaged neuro-muscular system that keeps working harder than ever to meet normal demands. We need to appreciate the fact that



each anterior horn cell innervates several hundred muscle fibers and the surviving horn cells have been doing 50% more work than normal. Plus it appears they don't like being overworked.

Because of this over-use of the neuromuscular system, new weakness is now developing. Survivors may develop new weakness not only in "polio" muscles but also in other muscles that did not seem to be involved during the acute phase.

Although the amount of weakness a polio survivor develops in later life depends upon the original involvement, age is also a factor. Anterior horn cells do not have infinite durability - they begin aging at about 60 years of age. So polio patients aged 70 and up have a natural weakness just from age that needs to be appreciated and put in perspective also.

### Advice

At least half of the 1.5 million people who had polio have post-polio syndrome. Nothing has been added, PPS is a loss of function. The problem is that a survivor's lifestyle now exceeds his physical ability.

Dr. Perry advises, "Don't push the system". She believes a polio survivor can control loss of function by controlling overuse of muscles. The way to do this is by making lifestyle changes, modifying activities, and pacing.

Polio survivors should know their own muscle strengths and plan accordingly. A study by Agre related to exhaustive fatigue confirms that:

- a person with normal muscles will recover fully from muscle fatigue in five minutes.
- an asymptomatic polio survivor will recover in ten minutes.
- a symptomatic polio survivor will have partial recovery in five minutes but then have further loss.

So it becomes necessary to make lifestyle modifications. Dr. Perry advises patient to:-

1. Figure out what you don't have to do.
2. Get others to do the heavy work.
3. Break up work periods with rest periods.
4. Don't pride yourself on working harder.
5. Pain is a sign of injury and overuse, so just don't let it happen. Figure out what causes your pain and don't do it again.

### How You Can Help Yourself

Dr. Perry's general activity guideline is that a polio survivor can do anything as long as it causes:-

1. NO PAIN and
2. NO FATIGUE THAT LASTS LONGER THAN 10 MINUTES.

Survivors can control their destiny by avoiding muscle overuse strain. But, she cautions: **Polio survivors who overuse muscles will lose strength.**

If you are experiencing new weakness, fatigue, or pain you can help yourself now by changing your lifestyle and pacing yourself.

We deeply appreciate Dr. Perry's responding to all of our questions during and following her talk. As a small token of our appreciation, a poinsettia plant was presented to her before the meeting.

*Articles by Dr. Perry and biographical details can be found in the Lincolnshire Post-Polio Library in the catalogue entry for [Perry, Jacquelin, M.D., D.Sc. \(Hon\)](#).*



Conserve To Preserve PPS Muscles

Reprinted with permission From Rancho Los Amigos Post-Polio Support Group  
Newsletter September 1998

*Reported by Mary Clarke Atwood*

An enlightening program on muscle care was presented at the February 28th 1998 meeting of the Rancho Los Amigos Post-Polio Support Group in Downey, California. The featured speakers were members of the Rancho Los Amigos Physical Therapy Department: Jennifer Fitzpatrick, SPT, and Katy Schultz, SPT, under the supervision of Maureen Jennings, PT, from the Rancho Polio clinic and Eirik Blydt-Hansen, PT, APT.

The primary focus of post-polio rehabilitation is to eliminate strain on muscles, joints, and ligaments. In this report, polio survivors will learn how to monitor activity levels and achieve these goals with lifestyle modification, stretching exercises, and using functional devices when necessary. These strategies will help preserve muscle function. "Conserve to preserve" is the name of the game.

### Lifestyle Modification

The key for people with PPS is to understand that 'pushing through' pain and fatigue is no longer acceptable. Rather, it is important to realise that pain and fatigue are signs that an activity is too stressful for the muscles and may lead to permanent damage and weakness. Prolonged or repetitive high demand activities which result in pain and fatigue must be moderated or discontinued.

One way to monitor muscle overuse is by keeping a log of daily activities. This will help pinpoint activities causing excessive fatigue and which may need to be moderated or avoided.

A survivor may be able to continue performing some activities but with frequent rest periods and monitoring. Studies have shown that resting for twice as long as the activity time may result in improved endurance and avoidance of fatigue. If these changes are made early, strength may be recovered enough to bring the muscles up to a more useful level but not for excessive strain. [Dr. Jacquelin Perry's activity guideline is that a polio survivor can do anything as long as it causes (1) No pain and (2) No fatigue that lasts longer than ten minutes.]

### Exercise ???

Many people with PPS want to exercise to strengthen weak muscles, but in most cases this is contraindicated. PPS muscle weakness is not usually due to lack of exercise but rather from damage due to overworked muscles in everyday activities. In rare cases, minimal strengthening exercises have been beneficial in some muscles once major lifestyle changes have reduced the strain from everyday activities. Although there have not been any studies on stretching for PPS, most sources advocate maintenance of normal range of motion to preserve function.

### Stretching Exercises

Muscle weakness and tightness vary in each person with PPS, so there is no general program appropriate for all - an individually tailored program is best. Stretching exercises should be gentle and focus on tight, overworked muscles.

It is important to understand that all contractures (joint or muscle tightness) are not bad. For instance, calf tightness can help increase stability during walking for persons with weak calf muscles. If this tightness were stretched out, it might decrease stability and result in the need of a brace.

A common contracture that is not beneficial is hip flexion tightness (inability to fully straighten the hip). An elective exercise would be lying on the stomach for 15 minutes each day to reduce existing hip flexion tightness and help prevent new or increasing tightness.

Gentle range independently of motion exercises performed or with assistance can be beneficial for

most survivors. These consist of gently moving each joint through its available range - avoiding fatigue or pain. The following general range-of-motion exercises are an example. Each exercise may not be appropriate for all individuals. If appropriate, each exercise should be performed SLOWLY and very gradually. A survivor might start with as little as one repetition and gradually work up to as many as 5 to 10 repetitions daily, spread throughout the day if necessary. The keys are avoiding fatigue, increased weakness, and pain.

- Make circles with each ankle while sitting or lying down.
- While sitting, straighten one knee, lifting the foot from the floor, then lower slowly. Alternate left and right legs.
- Slide/raise one knee up towards the chest, then lower slowly. Alternate left and right legs.
- Slide one leg out straight to the side, then return it to the middle. Alternate left and right legs.
- Bend hands up towards the shoulders then straighten arms back down to your sides.
- Shrug shoulders up towards your ears, then slowly lower.
- Lift one arm straight out in front, then lower. Alternate left and right arms. (This is easier to do lying down.)
- Lift one arm out to the side then slowly lower. Alternate left and right arms.
- With elbow bent and held at your side, slowly rotate hand in toward stomach and then out to the side. Alternate left and right arms.

### Functional Devices

Many polio survivors find it difficult to return to the functional devices they worked so hard to get rid of in childhood. But many of these devices can help take the strain off muscles and joints:

- **Orthosis or brace**

This can provide protection and assistance to specific weak or painful muscles and joints, and may allow the person to continue walking.

- **Walking Aids**

Crutches and canes are good ways to protect painful overused leg muscles and joints. These can provide a way to transfer some of the body weight to the arms and decrease the work of the legs, hips, and the lumbosacral spine. However, if there is any pain or weakness in a person's arms, these walking aids are inappropriate because they may lead to overuse and further weakness.

- **Mobility Aids**

Motorized wheelchairs and scooters can provide independent mobility. However, some scooters can be hard on arms and shoulders.

Manual wheelchairs are rarely prescribed for polio survivors because of the high strain they put on the arm muscles.

- **Reachers**

A variety of reaching devices can be helpful for a person with weak arms.

All of these devices decrease demands and help protect weakened muscles thus prolonging the person's ability to perform functional activities.

### Anti-Inflammatory Medications

Overuse of muscles can cause swelling and inflammation. These may be reduced by the use of Non-Steroidal Anti-inflammatory Drugs such as Ibuprofen. (*Consult your physician before taking any medications.*) But keep in mind that these drugs only mask the pain, they are not a cure. Dr Perry

says, "Pain is a sign of injury and overuse, so don't let it happen. Try to determine what causes your pain and avoid it."

## Conclusion

Unfortunately, the popular phrase "Use it or lose it" does not apply to PPS. Polio survivors must reprogram their minds to think "Conserve to Preserve."

Think of your muscles as money. You have a certain amount that is available for use each day, which is based on your income. The actual amounts you use during each day are your expenditures. You also have a savings account or reserve of muscles. If your lifestyle continuously exceeds your daily income, then you begin depleting your savings account until there is no reserve. Continuing at this pace will lead to decreases in function as your muscles are "repossessed" - one by one.

Lifestyle modification is the way to protect your muscles so they will last. Functional devices can help take the strain off weak muscles and joints if appropriate. Remember, a muscle has only so many contractions within its lifetime, and once used up, there is no turning back.

For More Information, Contact:

Rancho Los Amigos Medical Center  
Physical Therapy Department  
7601 E. Imperial Hwy.  
Downey, California 90242-3496  
Tel. (562)401-6847  
Fax. (562)401-6052

An audio tape of this complete presentation is available for \$7.00 including US postage from Ken Baragar - 817 Irving Place, Anaheim, CA 92805-5025 Tel 714/535-2710.



## How a ppsr avoids upper body pain

I have been able to solve my problems of arm, shoulder, and neck pain by keeping my muscles well supported and by listening to my body. As soon as I feel any pain in these areas I stop what I am doing and lie down. Usually it takes about 20 minutes rest and my muscles are back to normal (as possible).

Here are the ways I support my upper body muscles:

- Whenever possible I sit in a chair that has arms and a high back. The arms on many chairs are too low to provide good support. I noticed I would lean my upper body toward the armrest for support. To solve this problem I had two 3x3x12 inch cushions made to increase the arm height and provide better support for my arms and shoulders. When the cushions will not fit properly on top of the armrest, I just place the cushions diagonally across my lap.
- A lumbar pillow (Jay Active backrest) provides additional back support. A small pillow could also be used.
- For car travel I had two 4x4x14 inch cushions made. I attach one to the center armrest with a strap and I place the other one diagonally across my lap. When I ride in a car that has no center armrests, I place both cushions across my lap.
- Neck support is also very important in the car. I had a neckroll made with straps and Velcro to attach to the headrest. The correct size was determined by rolling up a hand towel, securing the ends with rubber bands, and then attaching it to the headrest with more rubber bands. (I experimented with towels of different thickness to find the size that gave the most comfortable support.)

I have found that the arm cushions and neckroll are wonderful to use when traveling by airplane

too. I always carry them with me.

## A Heated Rice Bag

I created the following device to provide heat for aching muscles or cold feet.

- A heated rice bag feels so good on aching muscles or to warm your cold feet. For neck or shoulder pain place one on your pillow and lay on it.

What is a rice bag? How can I get one? Easy - - All you need is a hand towel (about 15x24 inches) and 6 cups of uncooked rice (about 2 ½ pounds) and a sewing machine. [Crocheting can substitute for the sewing.]

Directions:

1. Fold towel in half lengthwise.
2. Double stitch across center to form two sections.
3. Double stitch midway across each half to create 4 sections in all.
4. Next fill each pocket with 1 ½ cups uncooked rice.
5. Double stitch outside edge from top to bottom (hold rice back in pocket).

Heat in microwave for 2-3 minutes. Do NOT get it wet. Take care before putting on skin ensure that it is not too hot.

Mary C Atwood,

[marwoodca@JUNO.COM](mailto:marwoodca@JUNO.COM)

Rancho Los Amigos Post Polio Support Group.

Email [RanchoPPSG@hotmail.com](mailto:RanchoPPSG@hotmail.com)



## Life with a Polio Survivor

from Dave VanAken ([DVanAken@aol.com](mailto:DVanAken@aol.com))

[Central Virginia PPS Support Group](#)

Weekend Retreat - Sept 26-27 1998

The first PPS retreat was a success for both the survivors and their partners. During one of the breakout sessions, the partners met and discussed life with a Polio survivor. As far as I know, this was the first time the partners met and discussed how we dealt with PPS and the impact it was having on our lives.

Many of us did not realize the existence of PPS when we first entered our relationships. Yes, we all knew our partners had suffered from polio, some more than others. In my case, my bride was what is referred to as a "passer." We danced, took long walks, talked most of the night away, and enjoyed the intimacy and love of a new relationship. Polio was talked about, and the possible consequences later (much later) in life. I, as most of us did, respected and admired our survivors, as they had overcome and achieved so much in their life, which added to our love.

We, the Polio survivors and partners, share many common concerns and fears. We are frustrated and angry with this disease that has impacted so much of our lives. Personally, I am frustrated with the disease because it has forced my wife have to choose how she lives her life. Lifestyle management, energy management, and continual choices have become so much a part of our daily lives. Some of this would have come with advancing age anyway, but the PPS has accelerated this change in our lives. My wife speaks of having limited energy presents to use in a day, and she now chooses them wisely, or suffers the consequences. While I am not the one who physically suffers when she overdoes or overextends herself, I am impacted by her choices. Fortunately, she is wise and often

saves a present or two for us to enjoy together.

For those caregivers who also work, the additional burdens of a career or a job add to an already full plate. We, too, have limited energy presents to use, and can get overwhelmed by it all. Who can we say "no" to? Not to our life partners, not to our bosses, so too often it is to ourselves. There have been times when we have overdone, and the caregiver relationship shifts, the survivor must take care of the caregiver. Instead of accepting this shift, the caregiver feels guilty and often presses on. The shift in caregiving is natural and should be accepted as the gift of love that it is.

We fear the future. What will it be like 5 years from now? What if something happened to our partner? Both the survivors and partners fear this the most. For the survivor, this is a terrifying possibility. In some cases, the survivor is extremely dependent - physically, emotionally, or both - on the caregiver partner. The loss of the partner carries not only the significant loss of a life's partner, but someone who has unselfishly worked to enhance the quality of life lived. Who or how would this void be filled?

From a partner's perspective, a gaping hole would open in our lives. We have willingly spent our physical and emotional reserves enabling our survivor to enjoy a quality of life. Often we have forgone "outside" activities so the survivor isn't left behind. Is there enough left in our "life" to be able to cope with this loss and continue?

So how do we move forward? In the strongest of any relationships, the key is communication. Open communication without guilt identifies the fears, concerns, and needs we all have. We must be able to share these openly in order to deal with them. In this open environment, we must take the emotions out of the topic, and talk about the situation, but not the individual. It is important that both partners respect the needs of their partner to express these strong feelings. We have expectations of each other, but do we agree with them? Where I work, we openly speak of our expectations and obligations to other parts and people in our organization. This ensures everyone is on the same page, and we all understand our roles. We can then successfully satisfy the needs and desires in our work relationships. Shouldn't we have the same levels of respect in our personal relationships?

The PPS support group fills a vital role in helping our survivors cope with and deal with the realities of the disease. The purpose of a support group is to help find a way forward, deal with common problems, concerns, and fears. While we are welcome at the survivor's meetings, the caregiving partners haven't had a similar forum. We think this type of support group can help, just as the Survivor's group helps the survivors. We would like to meet at the same time as the Survivors group - the first Saturday of each month at Sheltering Arms. I encourage both Survivors and partners to attend the support meetings. As my wife keeps telling me, we gain strength from others in similar situations.

If you can't join us but are Internet active, Gary Utz, a caregiver in Pennsylvania, has started a caregiver internet group, and would welcome your insights, concerns, and questions. To subscribe to the caregiver list, send an e-mail to [PPS-cg-subscribe@egroups.com](mailto:PPS-cg-subscribe@egroups.com) or to the list owner at [gutz@alltel.net](mailto:gutz@alltel.net).

Once we start talking and sharing, the burden becomes lighter for all.

**If you are a carer and would like to contribute to a Carers Page in this Newsletter then please write to Marie c/o the [LincsPPN address](#).**



GRACE R YOUNG, MA, OTR

As a polio survivor, I have had to make numerous adjustments to my lifestyle for many years. As an occupational therapist at KaiserPermanente in Southern California I had the opportunity to develop

and teach educational programs to several hundred polio survivors over a period of several years. Much of the material was gleaned from solutions applied in my own life, and I also learned a great deal from the participants in the classes.

Each month there will be a new topic relating to conserving your energy, simplifying your work, protecting your joints, or modifying your surroundings - anything which might help to lessen the symptoms of pain and fatigue.

So please bookmark my website and check it every month. Then check out the resource list and explore my favorite websites. And, finally, please e-mail me with your comments and suggestions, [gryoung@pacbell.net](mailto:gryoung@pacbell.net)

## MONTHLY TIP SUPPORTING WEAK JOINTS

Along with wheelchairs, nothing conjures up as much dread as the idea of having to start wearing braces or splints. We may feel that these devices signal "disabled" almost as much as more obvious mobility aids. Yet external devices can compensate for weakness and offer so much relief from pain and unstable joints that it makes a big difference in our energy level. Here are a few examples:

When the quadriceps muscle at the front of the knee is too weak to support the weight of the body during ambulation, the knee may hyperextend ("back-knee") so that ligaments instead of muscles are providing much of the support during weight bearing. Weakness of other knee muscles can cause medial-lateral instability, where the knee shifts sideways during weight bearing. Problems like these lead to gradual deterioration of the knee joint. Once joints are damaged, they will not be able to regain their original function. Wearing a long leg brace (KAFO - knee, ankle, foot orthosis) can keep the knee joint from shifting during ambulation and prevent further damage.

Weak muscles at the front of the ankle can cause a "foot drop" where you cannot bring your toes upward so your heel hits the ground first. To keep from stubbing your toe and possibly falling, your leg has to lift higher than normal with each step. In this case, a short leg brace (AFO - ankle, foot orthosis) keeps the ankle in a good position, allowing the heel to strike the ground first.

When one leg is shorter than the other, your center of gravity changes with each step you take. This is fatiguing unless the discrepancy in leg length is compensated by a lift, either inside of outside the shoe.

In the hand, weakness in the wrist or thumb muscles can cause you to compensate by moving your arm in ways which quickly fatigue the whole upper extremity, including the elbow and shoulder muscles. Hand splints such as a wrist support or a thumb "opponens" splint place the wrist or thumb in a functional position.

In these and other instances, a properly fabricated brace or splint can support weak joints, maintain normal joint alignment, prevent deformities and joint damage, eliminate compensatory movements, and minimize pain.

If you are concerned about how braces and splints look to others, consider this: Muscle weakness, unstable joints, uneven gait, shifting your center of gravity with each step all cause compensatory motions which make us look disabled. Our difficulties with ambulating, using our arms, etc., appear less conspicuous when the joints are properly supported and held in a functional position.

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WebSite <http://www.reocities.com/HotSprings/4713/>

See also the Lincolnshire Post-Polio Library catalogue entry for  
[Young, Grace R., MA, OTR](#)

You know you're getting older  
when you stoop to tie your shoes  
and wonder what else you can do whilst  
you are down there.

Lili in Georgia. [tweety7777@webtv.net](mailto:tweety7777@webtv.net)



## Articles from our [Online Library](#)

*The following articles are reprinted in full in the edition of this newsletter distributed via the postal services. If you are printing this web edition for further distribution, please print the library articles as well and attach them to the newsletter.*

**Title:** [Fibromyalgia Is Common in a Postpoliomyelitis Clinic](#)



**Author(s):** Daria A. Trojan, MD, MSc, Neil R. Cashman, MD

**Original Publication:** The Archives of Neurology June 1995 Volume 52 620-624

**Abstract/Extract:**

**Objective:** To determine prospectively the occurrence and clinical characteristics of fibromyalgia in patients serially presenting to a postpolio clinic. Fibromyalgia may mimic some of the symptoms of postpoliomyelitis syndrome, a disorder characterized by new weakness, fatigue, and pain decades after paralytic poliomyelitis.

**Design:** Case series.

**Setting:** A university-affiliated hospital clinic.

**Patients:** One hundred five patients were evaluated with a standardized history and physical examination during an 18-month period. Ten patients were excluded because of the absence of past paralytic poliomyelitis.

**Interventions:** Patients with fibromyalgia were treated with low-dose, nighttime amitriptyline hydrochloride or other conservative measures.

**Main Outcome Measures:** Patients with fibromyalgia had diffuse pain and 11 or more of 18 specific tender points on examination (American College of Rheumatology criteria, 1990). Patients with borderline fibromyalgia had muscle pain and five to 10 tender points on physical examination.

**Results:** Ten (10.5%) of 95 postpolio patients met the criteria for fibromyalgia, and another 10 patients had borderline fibromyalgia. All patients with fibromyalgia complained of new weakness, fatigue, and pain. Patients with fibromyalgia were more likely than patients without fibromyalgia to be female (80% vs 40%,  $P < .04$ ) and to complain of generalized fatigue (100% vs 71%,  $P = .057$ ), but were not distinguishable in terms of age at presentation to clinic, age at polio, length of time since polio, physical activity, weakness at polio, motor strength scores on examination, and the presence of new weakness, muscle fatigue, or joint pain. Approximately 50% of patients in both the fibromyalgia and borderline fibromyalgia groups responded to low-dose, nighttime amitriptyline therapy.

**Conclusions:** (1) Fibromyalgia occurs frequently in a postpolio clinic. (2) Fibromyalgia can



mimic some symptoms of postpoliomyelitis syndrome. (3) Fibromyalgia in postpolio patients can respond to specific treatment.

**Title:** [Dr. Henry writes about Debilitating Fatigue](#)



**Author(s):** Henry Holland MD

**Abstract/Extract:** As you may recall, several months ago, I wrote about the problems that many polios face with fatigue. Many experience peripheral muscle fatigue which may manifest itself with muscle weakness and/or pain, and others may experience central fatigue which may be experienced with mental fatigue, increased sleep requirement, difficulty maintaining wakefulness, difficulty with word finding, and emotional factors such as difficulty with anxiety and depression. I mention all this because I feel that central fatigue has been my most difficult problem, and yet this type of fatigue is probably the least understood.



## Contributions from Polio Survivors

A tourist in Vienna is visiting old graveyards. Suddenly he hears music. There is no one else around so he starts to look for the source of the music. He finally locates the sound coming from a grave with a headstone marked "Ludwig van Beethoven" 1770-1827. As he listens, he realizes this is the Ninth Symphony but it is being played backward. He leaves and returns with a friend he has persuaded to see for himself this strange happening from Beethoven's grave. This time it is the Seventh Symphony that is playing but again, it is playing backward. Puzzled, they decide to search out a music scholar and after doing this, they return the following day. By now word has spread and a throng has gathered as the crowd is listening to Beethoven's Second Symphony, being played backward. Just then the graveyard caregiver ambles up to the group around the grave. Someone asks, "What do you make of this?" He replies, " Don't you get it?"

Guess now before reading further?

No idea? Look [here](#)..

from "Lili in Georgia" [tweety7777@webtv.net](mailto:tweety7777@webtv.net)

An English woman, while in Switzerland, looked at several rooms in a large apartment house. She told the schoolmaster who owned the house that she would let him know about renting one of the rooms later. However, after she arrived back at her hotel, the thought occurred to her that she had not asked about the water closet (bathroom). She immediately wrote a note to the schoolmaster asking about the "W.C.," being too bashful to write out the words "water closet." The schoolmaster, who was far from being an expert in English, did not know what the initials "W.C." meant. He asked the parish priest, and together they decided that it meant Wayside Chapel. The schoolmaster then wrote the following letter to the very surprised woman.

Dear Madame,

I take great pleasure in informing you that the W.C. is located seven miles from the house in the center of a beautiful grove of pine trees. It is capable of holding 229 people and is open on Sunday and Thursday only. I recommend that you come early, although there is plenty of standing room. This is an unfortunate situation, especially if you are in the habit of going regularly. You will no doubt be glad to hear that a good number bring their lunch and make a day of it, while others who can afford it go by car and arrive just in time. I would especially suggest that your ladyship go on Thursday when there is social music. Acoustically, the place is excellent.

It may interest you to know that my daughter was married in the W.C., and it was there she met her husband. I can remember the rush there was for seats. The newest attraction is a bell donated by a wealthy resident of the district. It rings joyously every time a person enters. A bazaar is to be held to provide plush seats for all, since the people think it is a long-felt need. My wife is rather delicate and does not go regularly. Naturally, it pains her very much not to attend more often. If you wish, I shall be glad to reserve the best seat for you where you will be seen by all. Hoping I have been of service to you, I remain, [the schoolmaster]

from Fred Stoermer, Tacoma, WA, USA

God grant me the Senility  
to forget the people  
I never liked anyway,  
the good fortune  
to run into the ones I do,  
and the eyesight  
to tell the difference.

from Maureen [MHenrik107@aol.com](mailto:MHenrik107@aol.com)

When I contracted polio and was in the isolation hospital, my parents were told by the doctor, that all the patients he was treating came from clean homes, and that children from dirty homes did not get polio. In the village near where I live, there is a family with the dirtiest kid I have ever seen, they are only washed once a year, and that is done in the stream. Last year when they went to the stream to be washed, there were some geese on the water, so the kids had to go without the wash that year, but these kids never suffer a days illness.

I'm now just collecting my soap, and sponge, I'm off up to the stream for my yearly bath, I'll beat this illness thing, even if it kills me.

from Christine

He's decomposing. he he he he...



**It's not me that has the problem It's my shoes. !!!!!**

My walking boots used to do 9 miles three years ago but they tell me now that they only want to keep my feet warm in bad weather.

My dancing pumps are nearly as bad. They could go on all night long, discoing the night away, and now after one disco dance where I barely move my feet, they start complaining and ask me to sit down again.

My flip flops tell me they get so cold now they want me to wear thick warm socks to help keep them warm.

My flippers and ice skates have left me a note to say they have left home, but I think they are together up in the attic. Goodness knows what they are doing up there together.

My trainers, well they complain and moan if I use them too much, but you should see the smile on their little faces when I get on my scooter. Great big grins, they sit there up front looking out on the world and smiling at all who pass.

Oh and I forgot my walking boot socks. Well they seem to be happier now. They tell me that they used to hate it inside my walking boots, where it was dark, hot, sweaty and their fluffy bits were

squashed. Now they can see the world and keep their fluffy bits fluffy as I wear them to walk round the house and they love keeping my toes warm as toast.

So you see folks..., it's not me that can't do what I used to before - it's my shoes - but they do seem happier now that I have understood them.

Hilary [linpolio@legend.co.uk](mailto:linpolio@legend.co.uk)

## Salad Dressings and Chili Recipe

Vinaigrettes - Basically, you can use any vinaigrette and cut the oil WAY down. If it's too strong tasting then add a little water. Sometimes I don't use any oil. I often crumble a small amount of blue cheese on a salad and then use plain Balsamic vinegar & soft & pepper. Another idea is to use a good salad vinegar (I use Heinz Gourmet Salad Vinegar), then add to some dry parmesan cheese which is low in calories, salt & pepper, and a variety of tasty ingredients such as; sweet red pepper, purple onions, a few green olives, pickled corn or okra, sliced jalapeno peppers, etc.

### Chili - 8 to 10 servings

1 bowl has 250 calories, 18 grams of protein and 7 grams of fat.

½ pound dry pinto beans

½ pound dry kidney beans

1 pound hamburger meat

3 cans diced tomatoes

2 onions, diced

2 green bell peppers, diced

4 teaspoons chili powder

4 teaspoons cumin

1 teaspoon salt

about 2 Tablespoons of flour and some water in a jar with a lid (for thickening)

Rinse and drain beans separately, and soak in water overnight in separate pots.

Drain beans and cook separately as they take different amounts of time. I get the beans ready a day ahead and store them in the fridge.

Cook ground beef in skillet, breaking up chunks. Drain in a colander and rinse with hot water....this removes most of the fat.

Put tomatoes in large pot, add 2 + cups of water and the chopped peppers & onions. Cook covered until vegetables are tender. Add seasonings and taste....sorry, but again most of my recipes aren't exact. Shake up the water and flour and add slowly to slow boiling mixture in the pot.....stir as you do this until achieving desired consistency of gravy. Then you have to correct the seasonings again.....usually needs more cumin and salt. When this is done, add the cooked meat and the beans.

Recipe makes 8 to 10 servings. I freeze 2 portion servings in plastic ziplock bags which can be easily thawed for quick meals... with flour tortillas & a salad. The chili freezes so well that you can't tell the difference from when it's fresh cooked.

from Peggy, our member from New Orleans [terpeg@mindspring.com](mailto:terpeg@mindspring.com)



## Lincolnshire Post-Polio Library

Articles added since last newsletter with grateful thanks to the authors

**Title:** [You are going to have surgery - A Guide for Polio Survivors](#) LEAFLET

**Author(s):** J. M. Walker, PhD, PT.



**Original Publication:** Originally written for Nova Scotia Polio Survivors Support Group. 1996.

**Abstract/Extract:** Discusses *Why preparation for any surgery may be important, For what types of surgery is this important?, and What to do when surgery is required.*

**Title:** [Polio Survivors as Patients - Guide for Emergency Care & Surgical Health Workers](#)  
LEAFLET



**Author(s):** J. M. Walker, PhD, PT, C. McGowan & G. Vardy.

**Original Publication:** Originally written for Nova Scotia Polio Survivors Support Group. 1966.

**Abstract/Extract:** Discusses *Concerns of Polio Survivors that may require attention, Response to Medications, why special attention is needed, Special Considerations for the patient who is a polio survivor & especially those with PPS and Important questions to ask of patients in the Emergency Care setting.*

**Title:** [Did you have acute poliomyelitis? An Explanation for Polio Survivors about Post Polio Sequelae](#) LEAFLET



**Author(s):** J. M. Walker, PhD, PT, C. Grant, BSC(Physio)

**Original Publication:** Originally written for Post-Polio Support Society NZ (Inc). Revised 1966.

**Abstract/Extract:** Discusses *What is PPS?, How common is PPS?, Who is at risk for PPS?, Recovery from Polio, What causes PPS? and What can be done?.*

**Title:** [Post Polio Sequelae: An Explanation for Health Professionals](#) LEAFLET



**Author(s):** J. M. Walker, PhD, PT, K. Sweet, BSC(Physio)

**Original Publication:** Originally written for Nova Scotia Polio Survivors Support Group. Revised 1966.

**Abstract/Extract:** Discusses *What is post polio syndrome?, Who is more at risk for PPS?, Why may some polio survivors develop PPS? and What can be done?.*

**Title:** [Fibromyalgia Is Common in a Postpoliomyelitis Clinic](#) (In this Newsletter)

**Author(s):** Daria A. Trojan, MD, MSc, Neil R. Cashman, MD

**Title:** [Management of post-polio syndrome](#)



**Author(s):** Daria A. Trojan, Lois Finch

**Original Publication:** NeuroRehabilitation 8 (1997) 93-105

**Abstract/Extract:** Many patients with post-poliomyelitis syndrome can benefit from a management program. When a post-polio patient presents with new symptoms, it is first essential to identify and treat other medical and neurological conditions which could produce these symptoms. New weakness can be managed with exercise (stretching, strengthening, and aerobic), avoidance of muscular overuse, weight loss, orthoses, and assistive devices. Fatigue can be managed with energy conservation techniques, lifestyle changes, pacing, regular rest periods or naps during the day, amitriptyline to improve sleep, and possibly pyridostigmine (trial in progress). The management of pain is dependent upon its cause. The treatment of post-polio muscular pain can include activity reduction, pacing (rest periods during activity), moist heat, ice, and stretching, use of assistive devices, and life style modifications. Fibromyalgia can be treated with amitriptyline, cyclobenzaprine, and aerobic exercise. Joint and soft tissue abnormalities can be managed with modification of extremity use, physiotherapy, orthoses, assistive devices, non-steroidal anti-inflammatory medications, and rarely steroid injections and

surgery. Superimposed neurological disorders may produce pain, and should be identified and treated. The identification and treatment of pulmonary dysfunction in a post-polio patient is an important aspect of management, and is discussed elsewhere in this issue. Dysphagia can be managed with diet changes, use of special breathing and swallowing techniques, monitoring fatigue and taking larger meals earlier and smaller meals later, and avoiding eating when fatigued. The management of psychosocial difficulties usually requires an interdisciplinary approach, and may include a post-polio support group, social worker, psychologist, and psychiatrist. © 1997 Elsevier Science Ireland Ltd.

**Title:** [Anticholinesterase-responsive neuromuscular junction transmission defects in post-poliomyelitis fatigue](#)



**Author(s):** Daria A. Trojan, Daniel Gendron and Neil R. Cashman

**Original Publication:** Journal of the Neurological Sciences, 114 (1993) 170-177

**Abstract/Extract:** Disabling generalized fatigue and muscle fatiguability are common features of post-poliomyelitis syndrome (PPS). In 17 fatigued PPS patients, we measured jitter on stimulation single-fiber electromyography (S-SFEMG) for at least 3.5 min before and after i.v. injection of 10 mg edrophonium. We observed reduction in jitter (defined as a significant difference in jitter means before and after edrophonium, unpaired *t*-test  $P < 0.05$ ) in 7 patients, no change in 8, and a significant increase in 2 patients. Blinded to their edrophonium results, the 17 patients were treated with pyridostigmine 180 mg/day for 1 month, with a subjective improvement of fatigue in 9 patients, and with a significant reduction in mean Hare fatigue scores in the entire group of 17 patients (pre=2.71, and post=1.71; Wilcoxon signed rank sum test,  $P < 0.05$ ). Edrophonium-induced reduction of jitter on S-SFEMG was significantly associated with pyridostigmine-induced subjective improvement of fatigue (Fisher's exact test,  $P < 0.04$ ). A significant reduction in fatigue with pyridostigmine was observed only in the 7 patients who experienced a significant reduction in jitter with edrophonium (Wilcoxon signed rank sum test,  $P=0.03$ ). In addition, the 9 pyridostigmine responders experienced a significant reduction in jitter means pre- and post-edrophonium (100% vs. 88%, Bonferroni corrected,  $P < 0.01$ ). We conclude that neuromuscular transmission as measured by jitter on S-SFEMG can improve with edrophonium in a proportion of PPS patients, and that generalized fatigue and muscle fatiguability in some patients with PPS may be due to anticholinesterase-responsive NMJ transmission defects.

**Title:** [Pathophysiology and diagnosis of post-polio syndrome](#)



**Author(s):** Daria A. Trojan, Neil R. Cashman

**Original Publication:** NeuroRehabilitation 8 (1997) 83-92

**Abstract/Extract:** Post-poliomyelitis syndrome is defined as a clinical syndrome of new weakness, fatigue and pain which can occur several decades following recovery from paralytic poliomyelitis. The cause of this disorder is still unclear, and many possible etiologies have been proposed. The most widely accepted etiology was first proposed by Wiechers and Hubbell, which attributes PPS to a distal degeneration of massively enlarged post-polio motor units. Other probable contributing factors to the onset of this disease are the ageing process, and overuse. Currently, there is no specific diagnostic test for PPS, which continues to be a diagnosis of exclusion in an individual with symptoms and signs of the disorder. © 1997 Elsevier Science Ireland Ltd.

**Title:** [Polio Biology I - An Introduction to the Virus](#)



**Author(s):** Eddie Bollenbach

It may surprise you to know that we don't understand where viruses originally came from. Yet for every life form on the planet there is some virus

somewhere that can penetrate and infect its cells. All viruses infect by following a similar process: they attach to a cell, penetrate it, reproduce, and propagate. The propagation step often involves bursting and killing the infected cell and the release of hundreds of new viruses. Polio does this to the cells it infects.

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## CONFERENCE IN GERMANY

Bundesverband POLIOMYELITIS e.V.  
present an  
Internationalen Polio-Kongress  
in Freidrich-Schiller-Universität Jena, Germany  
from 30 October - 1 November 1998

Post Polio Syndrome - Diagnostic and Therapeutic Opportunities and Potential in the domain of Medication/Physiotherapy/Neurology/Orthopaedics and of the Psycho-Social Situation  
- Patients Forum -

<http://selbsthilfe.seiten.de/bv/polio/kongr98.htm>

 *Currently Unavailable* 

Post-Polio Support Group (Ireland)  
Carmichael Centre, North Brunswick St., Dublin 7.  
Telephone + 00353 (0)1-873 0338

Medical Conference and AGM  
Friday 12th and Saturday 13th March 1999  
Green Isle Hotel, Nass Road, Dublin 22.

More information will be available by the time of the next newsletter.  
**Jim Costello, Chair-person - "Jim " <[jjcos@indigo.ie](mailto:jjcos@indigo.ie)>**

American Association for Respiratory Care  
11030 Ables Lane, Dallas, Texas, 75229-4593

7th International Conference  
Noninvasive Ventilation : Across the Spectrum from Critical Care to Home Care.  
March 14 to 17 1999 in Orlando, Florida, USA

More than 1,000 people are expected to gather March 14 - 17 1999 in Orlando to participate in a

program for anyone involved with noninvasive ventilation  
- from physicians, respiratory therapists, and nurses to ventilator users and their families.  
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