



The LincPIN

The Lincolnshire Post-Polio Information Newsletter
Volume 2 - Issue No. 3 - February 1999

14th February 1999

Second Anniversary of our WebSite

The Lincolnshire Post-Polio Library now contains over 90 full text medical articles.

The Falcon Inn

Saltergate, Lincoln.

One of Scottish & Newcastle Retail Ltd 'Who'd a Thought It?' Concept Pubs Have made us their Charity of the Year. Truck Pull and many other events being organised. Watch this space and the local press for details.



<http://www.scottish-newcastle.com/retail/index.html>

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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, Polio Survivor

Welcome to the new members joining us and I have one of them to thank for the idea for this newsletter. A resume of Polio, Post-Polio, and the problems members are having and what information that you need to provide so that you can get an appropriate diagnosis, advice and treatment.

Polio was the dreaded 'Summer Plague' (Summer Plague, by Tony Gould) until the vaccine was discovered. It is now over 40 years in the UK since the vaccine was first used. As soon as Doctors started using the vaccine and the statistics showed fewer and fewer outbreaks, Polio became a condition of the past. Medical professionals stopped researching and lectures became shorter and shorter. The medical and health professionals working today have little to no knowledge of Polio and the effect it had on our bodies.

Non Paralytic Polio and PPS - Some of our members had a diagnosis of 'paralytic polio' and have symptoms in areas that we did not think had been affected by the polio virus. Other members had a diagnosis of 'non-paralytic polio' and have similar symptoms but were being told that if they were not paralysed then they could not have PPS. However the polio virus affected all our body and we did not get paralysis in any area till we got to 60%+ damage. Marcia Falconer, PhD cell biology, is an overseas member of the LincsPPN who had such a diagnosis. I asked her to write us an article and in collaboration with Eddie Bollenbach MA biology, who also has articles on our WebSite, she produced the article Non Paralytic Polio and PPS. We wish to publicly thank you for this. A very important and needed article. I have included this article in this newsletter.

Manual Muscle Testing of Polio Survivors - During the last few weeks - following medical assessments where manual muscle testing grades have been recorded - we have come to realise that this way of testing is faulty. Firstly we are laid on a couch and are able to bring other muscles into play when asked to produce movements against pressure from the tester. Secondly grading muscles with anterior horn cell involvement grossly underestimate the amount of weakness.

Promoting the Awareness of the late effects of Polio and problems such as these need to take place all over the UK. The Lincolnshire Post-Polio Network have for over two years now worked to

address this situation. The fact that the late effects to having had polio was first noted in 1875 by Charcot is incongruous... we are now coming close to a new Millennium. Help us with this task so we can celebrate the new Millennium knowing that Polio Survivors' problems are being addressed in an appropriate way by both the medical profession and government departments. Many Polio Survivors do not have easily visible external signs of having had Polio, and you may find there are people living nearby who would benefit from the knowledge you now have. If you are able, and we do understand that not all of us have relatives and friends nearby to take this on for us, how about holding a coffee morning or fund raising/awareness event where you live. If you would like to do this then give us a ring or drop us a line with your ideas so we can discuss how we might be able to help.

The Falcon Inn, Lincoln has made us their Charity of the Year. I would like to thank my daughter Alison, Assistant Manageress, of the Falcon Inn in Lincoln for their offer to make us their Charity of the Year. Newly refurbished as one of the "Who'd a thought it" Pubs by Scottish & Newcastle Retail Ltd. Events will take place throughout the year and the money raised will make an enormous difference to us. We have had projects on hold due to lack of finance and we will be able to implement these as the money rolls in.

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.

Conference Fee £25. Rooms at £49 (Single, Double and Twin)
Email ppsg@tinet.ie

Members of the Lincolnshire Post Polio Network attending with seats available.

The first Irish PPS Conference is in Dublin on March 12/13 1999, Hilary is travelling from Lincoln by car and ferry to Dublin from Holyhead on Thursday 11th March. Helene McLean is travelling from Scotland by car and Ferry to Northern Ireland and then driving down to Dublin. If anyone would like to join either of us at the moment we have seats available in our cars. Please contact the LincsPPN office as soon as possible. Cost of the Conference is £25 and rooms (single/twin/double) are £49 for the three nights, Thursday, Friday and Saturday (breakfast is not included).



FROM THE CHAIR - (Pun Intended)

Earlier this century if you were unfortunate enough to catch polio then often the GP did not recognise the symptoms initially and you could be treated for anything from gastro-enteritis to rheumatic fever. When correctly diagnosed it was off to isolation, long stays in hospital with many years of operations, physiotherapy and other treatments.

In the 40's and 50's, there were several severe polio epidemics peaking every two or three years. Polio killed and maimed thousands of children and adults. Many children were seen in callipers, on crutches or in wheelchairs. The very word 'polio' struck fear into the hearts of everyone. Polio did not discriminate. It claimed victims throughout all sections of the community - from M.P's to children, from athletes to doctors.

Fear galvanised everyone into action. Guidelines were provided by the Government to local authorities, hospitals, schools and recreational centres. Swimming pools were shut at the height of the epidemic and GP's put on alert. Money was made available to cope with the nation-wide crisis. Polio Hospitals and clinics sprung up in every large town. Research worldwide was intensified to find a way of preventing the dreaded disease.

Then a miracle happened. In the 50's Dr. Salk and Dr. Sabin developed Polio Vaccines and mass vaccinations started. Today we, the polio survivors, need another miracle! Not so dramatic as the last - but just as important. After all, we missed out on the preventative treatment.

For over two years now The Lincolnshire Post-Polio Network has been working, with limited energy and financial resources, to bring the late effects of having had polio to the attention of Government, the medical profession and the public at large.

Polio Survivors have already coped once with the effects of Polio, to have to cope with its late effects unexpectedly when it was first recognised in 1875 is not fair. We know life's not fair, but this is ridiculous!

- When Government fear a situation is out of control - they take action.
- Thousands of those who caught polio in the past are with us today.
- We need help with the new symptoms that cause
 - muscle and joint pain,
 - fatigue both physical and mental,
 - reduction in mobility,
 - respiratory and sleep difficulties,
 - and the frustration and depression that follows loss of activity and confidence.

Requests made by the LincsPPN to improve medical provision for Polio Survivors are being ignored or brushed aside.

In mid '97 we found a neurologist who would listen - Dr. Alan Whiteley at Queens Medical Centre, Nottingham. We experienced a great lift of spirit, because we thought that at last something would be done. After a physical examination and discussion of problems, after the tests, we get the diagnosis and wait for the next step. And we wait and wait and nothing happens. We are told there is no finance available to train the therapists needed for a PPS Clinic. Physiotherapist, Occupational Therapist, Social Worker. Input will also be necessary from Orthotists, Speech and Respiratory Therapists.

From where I sit (and I do mean sit), I appeal on behalf of all the Lincolnshire Post-Polio Network members and Polio Survivors in the UK to Mr. Frank Dobson, Minister of Health, to listen to us. Yes you are a busy man and the National Health Service is reeling with lack of nurses, funding etc. But, you have been appointed to be the peoples advocate on health and we are some of the people you serve.

Lynn Hobday, Chairman.



Article from our [Online Library](#)

The following article is 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 article as well and attach it to the newsletter.

Title: [Non-Paralytic Polio and PPS](#)



Author(s): Marcia Falconer, Ph.D. cell biology and Eddie Bollenbach, M.A. biology

Original Publication: Lincolnshire Post-Polio Library Publication, January 1999

Abstract/Extract: An increasing number of medical doctors no longer dismiss symptoms of fatigue, pain, and increasing weakness when presented by a person with a documented history of paralytic polio. This is so even though there is no objective test available to diagnose Post-Polio Syndrome (PPS) nor is there agreement on, or a clear understanding of, the etiology of this disease. However, people with PPS symptoms and a history of non-paralytic polio have great difficulty receiving a diagnosis of PPS.



Snowprints

I remember those days
as a wee little boy,
When the snow on the ground
Filled my heart full of joy.

I would put on my jacket
My gloves and my hat,
Throw snow at my sisters
They'd call me a brat.

We'd run like the dickens
And roll in the snow,
Make snowmen - and angels
All lined in a row.

But soon I would tire
And loose all my pep,
The others kept playing
While I lost my step.

So I'd head back home
To get warm by the fire,
But I'd turn and look back
Where my heart felt desire.

Then I'd notice my footprints
Lined up in a row,
One big one - one small one
How can this be so?

I must cover those snowprints
So no one would know,
My tracks were not even
I'd brush them with snow.

And the joy in that lad
Was torn once again,
By those damn little footprints
Uneven as sin.

But now I look back
At my tracks one and all,
For I no longer care
That ones big and one small.

January 10,1947....

Researchers at Stanford University reported they have isolated the virus that causes poliomyelitis (polio).. sometimes deadly disease that reached epidemic status in the USA in the early 1900's.



I'M A SENIOR CITIZEN

I'm the life of the party...even when it lasts 'till 8 pm.
I'm very good at opening childproof caps with a hammer.
I'm the first one to find the bathroom wherever I go.
I'm awake many hours before my body allows me to get up.
I'm smiling all the time because I can't hear a word you're saying.
I'm positive I did housework correctly before my mate retired.
I'm sure everything I can't find is in a secure place.
I'm wrinkled, saggy and lumpy, and that's just my left leg.
I'm having trouble remembering simple words like....uh....
I'm now spending more time with my pillows than with my mate.
I'm sure they are making adults much younger these days.
I'm wondering if you're only as old as you feel, how could I be alive at 150?
I'm anti-everything now: anti-fat, anti-smoke, anti-noise, anti-inflammatory.
I'm supporting all movements now - by eating bran, prunes and raisins.



Interesting thoughts.....

If a man is standing in the middle of the forest speaking and there is no woman around to hear him, is he still wrong?
If a deaf person swears, does his mother wash his hands with soap?
Is there another word for synonym?
Isn't it a bit unnerving that doctors call what they do 'practice'?
Why isn't there mouse-flavored cat food?
What do you do when you see an endangered animal eating an endangered plant?
Would a fly without wings be called a walk?
Why don't sheep shrink when it rains?
Can vegetarians eat animal crackers?
If the police arrests a mime artist, do they tell him he has the right to remain silent?



SOME PEOPLE CANT TAKE A HINT

During the summer when the power mower was broke, and wouldn't run, I kept hinting to my husband that he ought to get it fixed, but somehow the message never sunk in.
Finally I thought of a clever way to make the point. When my husband arrived home that day, he

found me seated in the tall grass, busily snipping away with a tiny pair of sewing scissors.

He watched silently for a short time, then went into the house ... he was gone only a few moments, and when he came out again he handed me a toothbrush. "When you finish cutting the grass," he said, "you might as well sweep the sidewalks."

Tom Conrad / Judy Conrad

[<tlcon@OZCOOLCOM>](mailto:tlcon@OZCOOLCOM)



A Résumé of Polio and Post-Polio

Compiled by Hilary Hallam

What is Poliomyelitis?

Poliomyelitis is an acute viral infection with a wide range of manifestations. It is an enterovirus which invades the body through the mouth and then moves on through the intestinal tract, can get into the blood and moves to other areas and then into the Central Nervous System. The extent of damage depended on how far the virus went in our bodies and how much damage it did. It could be as little as a non-specific minor illness or could progress through weakness to paralysis of limbs and even death.

A non-specific minor illness would be a slight fever, headache, sore throat and vomiting which develop 3 to 5 days after exposure and recovery occurs within 24 to 72 hours.

The major illness which can take 7 to 14 days to appear will show with a fever, severe headache, stiff neck and back, deep muscle pain. There may be no further progression from this picture of an aseptic meningitis or the disease may go on with loss of selective tendon reflexes and assymetric weakness or paralysis of muscle groups.

To obtain a diagnosis of Poliomyelitis, virus isolation from throat or faeces or a demonstration of a rise in specific antibody was necessary to confirm the diagnosis.

Diagnosis was then Non-Paralytic Polio or Paralytic Polio. This was not two different diseases, but the extent of the damage that took place in our nervous system. Paralysis did not take place until damage in that area had reached over 60%. Less than 60% damage in the whole body meant no paralysis, just weakness. (See new LincsPPN article written by an overseas member Marcia Falconer, PhD and Eddie Bollenbach, MA - [Non Paralytic Polio and PPS](#)).

Factors that predisposed serious neurological damage included increasing age, recent tonsillectomy, inoculations (most often Diphtheria, Tetanus and Whooping Cough Vaccine) and physical exertion at the same time as onset of the Central Nervous System phase.

How it affected us.

The nerve damage that took place remained. It was the sprouting of undamaged nerves that allowed us to recover. Nerves sprouted and sprouted sometimes as many as 8 to 10 times and these axonal sprouts took up the orphaned muscle fibres. Paralysis occurred after 60% damage and recovery depended on how many nerves were left. As the muscle obtained axonal sprouted nerves to support it and this increased over 40% then the muscle changed from paralysis to weakness. Without this marvellous recovery system we would have remained at our worst scenario.

Recovery.

To complicate matters for the medical profession we are all different. We were damaged in different areas, and differing degrees of recovery took place. We then had different doctors with different ideas of treatment, operations, and assistive aids. There were Iron Lungs, Body Plaster Casts and Corsets, Spinal and other Fusion's, Tendon Transplants, Braces, Callipers, Built up shoes, Crutches,

Walking Sticks, Wheelchairs. Hot wet wool blankets wrapped on muscles, physiotherapy, contraptions that we put our feet into and pulled levers to give us electric shocks, the lists is endless. All manner of weird and wonderful contraptions. What appears not to be realised is that our bodies adapted in ways not thought possible. If one muscle did not work very well, then others took over a share of the work. If we could not do something one way, then we found another. We have been very inventive and continue to do so.

Following recovery we have done different things with our lives and our bodies adapted in different ways. So there is no one set of facts for our symptoms now, we have to be treated individually.

Criteria for a Diagnosis.

- A diagnosis of Paralytic Polio or Non Paralytic Polio where nerve damage took place.
- A period where you recovered.
- A stable period of functioning.
- New symptoms for which no other explanation can be found.

Symptoms.

- Fatigue often overwhelming. Both physical and mental.
- Loss of muscle strength and/or use, also in muscles thought not to be polio affected.
- Pain in muscles and joints.
- Trouble breathing and/or swallowing.
- Problems sleeping.
- Intolerance for cold, causing muscle weakness, and sometimes burning pain and/or discoloration in affected limbs.
- There may be other symptoms that are related to your old polio.

Diagnosis.

- It's purely a clinical diagnosis by exclusion of other conditions.
- There are no tests to show PPS.

Tests that are being used to assess us.

- Obtaining our previous medical history.
- List of current symptoms.
- Physical examination.
- Manual Muscle Testing.
- X-rays and MRI scans.
- Blood Tests.
- EMG - Electromyography.
- NCS - Nerve Conduction Studies.
- Muscle biopsy.
- Swallowing tests.
- Sleep Study.

The full picture is not often seen.

The full picture is not often seen. Health Professionals seeing you now did not see you before or when you had Polio, or how you recovered, or what you have achieved in the intervening years. Health Professionals seeing us now have rarely seen polio as it happened. Lectures on polio and its effects are minimal or not given. Polio is considered to have been eradicated in this country by the vaccine. Its late effects are little known about. They have no idea how you have adapted your body and continue to do so to achieve.

Actions we once found easy, are now becoming more difficult. We know our own bodies well and we can tell when things are changing. You may not realise that you are doing things differently. You just continue to adapt. It might not always be easy to describe these changes. Toothache in the bones, a 'numb' feeling inside my leg, it just does not work like it used to, are some of the comments made to us.

Medical Professionals are busy people and appointments are short and you need to be able to show not just your current symptoms but also your whole life story. It's all relevant to what you are experiencing now. Pictorial information can make more of an impact than a long list of problems. We have produced some charts that we hope might be useful in providing the information.

Holistic Assessment.

As in most other Post Polio Clinics in other parts of the World this should be a full holistic examination and assessment preferably by a Neurologist, Physiotherapist, Occupational Therapist and a Social Worker with knowledge of Polio and its late effects. Other specialist Therapists may also be necessary such as Respiratory, Speech and Orthotists. The above tests and results will give part of the picture.

Notes on tests being done now that may be helpful.

Manual Muscle Testing. This testing is somewhat subjective - dependant on the tester and their strength.

Dr. Perry, Rancho Los Amigos PPS Clinic, California, USA, reports that in 1953 Professor WJW Sharrard from Britain found that clinicians failed to identify any weakness unless more than half the anterior horn cells were gone.

In 1961, Beasley reported his quantitative studies of muscles with anterior horn cell involvement, demonstrating that such muscles graded 5 were really only about 65 % of 'true normal' and those graded 4 were really only about 40% of 'true normal'.

Dr. Perry's measurements of muscle force and EMG analysis confirm that manual grades of good (4) and normal (5) grossly underestimate the amount of weakness that there is in affected muscles - that is these grades are registered by strengths that are only 40 to 60% of 'true normal.'

| GRADE | NAME | % TRUE NORMAL |
|-------|--------|---------------|
| 5 | Normal | 60% |
| 4 | Good | 40% |
| 3 | Fair | 20% |
| 2 | Poor | 10% |
| 1 | Trace | 1% |

EMG - The Polio virus damages nerves and others not damaged sprout to take over orphaned muscle fibres and this varies throughout the body depending on the amount of anterior horn cell damage. The results will depend on where the needles are inserted as to what damage will be seen. A negative EMG for damage from old polio is therefore not conclusive.

Muscle Biopsy - Taking a biopsy from an already compromised muscle could result in further damage and is not undertaken in most PPS Clinics of some standing unless necessary for a specific reason.

Respiratory Tests - The current testing, we believe should also have added to it, lying on either side in case one dome of the diaphragm is affected where lying on the back would not show this. Testing should also take into account the amount of energy spent in the last hour or so. If the Polio

Survivor has been resting then energy could be available that would not be if the person, for instance, had just walked along a corridor, or pushed themselves some distance in a wheelchair.

Sleep Study - We believe should be done following a days normal activities and in as near as possible situation that relates to home.

Sample Chart - A sample page has been added to give you an idea how you can show all this. Don't restrict yourself to a number of bodies, pick specific years in your life that will show your achievements as well as your symptoms. Add photos if you think they will help.

Compiling a Personal Profile of your Life.

This may not be easy. As you start entering information on forms or writing your story you will start to remember the past, either as fact or just an emotional feeling. It is not easy coping with the knowledge that having recovered from Polio that possibly some of the problems you are now experiencing could be related to the fact that you had Polio in your earlier life. Talking and thinking about things that you thought were fixed in your past and expected them to stay there is not going to be easy. Filling in Incapacity Benefit, Disability Living Allowance, Attendance Allowance and other forms can be very difficult. You have not considered yourself disabled at all, or for many years, and you don't really want to fill in these forms. The British Polio Fellowship will also be able to help with the filling in of the forms, writing letters on your behalf. 0171 842 1898.

You may remember all that happened, you may remember nothing, but you are likely to still have emotional memories and feelings of incidents that have occurred throughout your life that will come to the fore as you start to consider what is happening. Tears are a release of emotion and it does not matter how strong willed and capable you have been all your life it is not a weakness to cry but a process of moving forward. We have to move at our own pace and we suggest that you ask others to allow you to do this. It is a step by step process.

Your parents, if they are still alive, and siblings will also have memories of your earlier polio life and it may not be easy for them to talk either. Parents often blame themselves for our catching polio. However it was not their or anyone's fault. It's just the same as any other virus. Most of us are extremely grateful for all they did for us following what must have been a very traumatic time for them. We would not be who we are now without it.

Your partners, children, work colleagues and friends also have problems in knowing what to say. Lack of awareness of the existence of our condition does not help. You may live alone and have few family and this might be much more difficult for you. (We can put you in touch with other Polio Survivors of a similar age - If you would like to offer to become a pen/phone pal then please get in touch). We are aware that not all GP's are sympathetic and part of this could be that they have little knowledge of Polio and its late effects. You probably already know more than they do. GP's work very hard and cannot possibly know all there is to know about every condition, and as they are our first line of medical help we must try and help them understand how our lives have altered. Hopefully you will be able to discuss this with your GP who might consider as an early treatment some counselling to come to terms with what is happening, regardless of diagnosis at the end. You have symptoms and they must be treated on their merits. It has helped many of us.

Use the charts and diagrams we have provided, or make up your own. Write your story, add photographs, it's up to you. You could make it quite comprehensive and then make a potted version, or just a few simple charts that will visibly show your symptoms.

How you can start to make the changes.

We find that we cannot do things that a few years ago were easy. We tend to struggle on and not ask for help. We do not necessarily see the gradual changes. After all, we have proved over and over again that the doctors and other people are wrong when they told us that we would not be able to do something. So we don't want to change. However, this is just a new phase in your life. You have succeeded in all the previous phases and you can achieve in this one and the next just the same.

By planning your life week by week and taking advantage of the aids and assistive devices, alteration to your house and office you should find that you can cope much better. There is less stress and frustration. Energy saving in one area allows energy for another. Why waste energy doing a mundane task that can be done by others which prevents you from doing something you enjoy. Preventing further damage by using the aids so that you don't continue to overstrain could also give you more energy to do other things more beneficial to you. This isn't easy, it takes time, but you should find that as you begin to make changes life gets easier and you can see a way forward. Try looking at what you have achieved in the day as a success and try not to think about what you could not do. Think positively.

When you start looking at the tasks you do and how you do them, you could find that you have adapted your own personal way. If you can't bend your legs then it's easier to see what is in the fridge if you stand with your back to it and look in. If whisking eggs normally etc is becoming more difficult then you might find you are holding your arm against your body. You go upstairs one step at a time, and possibly pull yourself up with one arm. Things also change as you the day proceeds. Make a list of your activities including how you have adapted the action, this might help others.

One huge concern is who pays for all the adaptations and equipment you need. If you do not have the finances to pay for them then it will all have to go through Social Services. The most important fact is that the earlier a little money is spent so that we can avoid overstraining and overdoing then the longer we will be able to manage within our limitations. They will need information from the medical professionals who have assessed you and will also want to visit to see how you cope in your home. They will need financial information and it would help to have some information prepared. They will also want to know if you belong to any organisations that might be prepared to help towards the costs.

Sample Forms

The following forms are offered in two versions. The gif images are a compromise between file size and definition. You will need to resize the gif format image to your paper size as standard paper sizes vary between countries. The appearance of the HTML version may be altered via font types/sizes and margins depending on the configuration options of your particular browser. All the forms should be printed as Landscape apart from the Daily Activity Diary.

Symptoms recorded by year.
[Form 1 - 1000 x 694 x 8 gif](#) Size = 36K
[Form 1 - HTML](#)

Symptoms recorded by year inc body outline chart.
[Form 2 - 1000 x 650 x 8 gif](#) Size = 32K
[Form 2 - HTML](#)

| DIARY OF EACH DAY'S ACTIVITIES - DATE..... | | | | | |
|--------------------------------------------|------|------------|-----------|------------|---------|
| Notes: | | | | | |
| ACTIVITY | TIME | TIME DOING | TIME REST | PAIN LEVEL | COMMENT |
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Diary of each day's activities.
[Form 2 - 669 x 1000 x 8 gif](#) Size = 30K
[Form 3 - HTML](#)

Finally, a variation of Form 2 as an example of how some very basic information may be recorded.

| KEY | | PRE POLIO | POLIO | RECOVERY | PROBLEMS NOW |
|-----------------|----|-----------|-------------------|---------------|------------------|
| PARALYSIS | | | | | |
| MILD WEAKNESS | | | | | |
| WEAK | | | | | |
| VERY WEAK | | | | | |
| HEAD/NECK | OK | OK | No Known Weakness | | REDUCED MOVEMENT |
| ARMS | OK | OK | No Known Weakness | | WEAK |
| RESPIRATORY | OK | OK | No Known Weakness | | WEAKNESS |
| ABDOMEN | OK | OK | PARALYSIS | | WEAK |
| RIGHT UPPER LEG | OK | OK | PARALYSIS | WEAK | VERY WEAK |
| LEFT UPPER LEG | OK | OK | PARALYSIS | MILD WEAKNESS | VERY WEAK |
| RIGHT LOWER LEG | OK | OK | PARALYSIS | | VERY WEAK |
| LEFT LOWER LEG | OK | OK | PARALYSIS | | WEAK |



emPOWER

The Charities Consortium of Users of Prosthetics, Orthotics, Wheelchairs, and Electronic Assistive Technology - emPOWER campaigns for a 'National Look' based on individual needs.

Wheelchair Users' Charter

Here is emPOWER's Charter for Users of Wheelchairs. In this rapidly changing world we do not regard it as written on tablets of stone. If you have any comments/suggestions please let us know.
Joe Hennessy OBE Vice Chair, emPOWER.

1. A partnership.

In publishing this Charter for Users of Wheelchairs, we understand that to communicate effectively, we must concentrate on salient points; every fine detail cannot be covered. The Charter brings with it an obligation on Users and on Carers to collaborate reasonably, and in a non-discriminatory manner, with all those professional staff at each Wheelchair Service Centre who provide the skilled services which enable us to achieve and maintain our maximum personal independence. The correct supply, care and use of a Wheelchair depends significantly on the shared co-operation of each User in his/her on-going treatment and rehabilitation programme. The National Health Service is a Partnership. In particular Users should:

- keep appointments or advise their Centre when this is impossible
- properly care for and maintain equipment, and promptly advise their Centre of wear and tear, thereby avoiding undue emergencies.

Throughout this Charter the expression "User" implies "User & Carer", where appropriate. The role of the Carer may be, and often is, as vital as that of the User.

2. Disability Discrimination Act.

This Charter should be read within the context of the Disability Discrimination Act 1995 which makes it illegal to discriminate against people with disabilities in the provision of and access to goods and services, and in employment.

3. A modern and dependable service.

This Charter supports the continuing development and sustenance of a Modern and Dependable NHS, and of the well-being of the one million staff who work in it. Users seek to help:

- raise standards
- abolish waste and unnecessary bureaucracy
- break down barriers between health, social care, education and employment
- guarantee equality, quality, excellence and efficiency
- share best practices openly for the benefit of all
- create and nourish Centres of Excellence.

4. Effectiveness.

The User will assess the Service by its Effectiveness - the extent to which, and the quality with which, it meets Users' needs. Effectiveness requires the Service to be organised and run around the health needs of individual Users, rather than for the convenience, budgetary or otherwise, of any system or institution. Professional staff should advise the User of the optimum solutions to needs, and such advice should not be compromised by resource constraints, realistic though recognition of the latter must be.

5. User needs.

The User has several needs, which should be identified and addressed initially through a comprehensive assessment. These include:

- **Consultation and Choice:** At assessment and throughout his/her treatment, the User should be consulted about the type of wheelchair which will best meet his/her needs, and to have flexibility of choice, of adaptation, and of venue of service provision.
- **Comfort and Support:** The Wheelchair prescribed should provide adequate postural support to enable the User to be comfortable and achieve maximum possible function and independence.
- **Control and Manoeuvrability:** the controls and the manoeuvrability, within limitations imposed by the environment, should meet the agreed assessed needs of the User.

- **Capability and Maintenance:** the Wheelchair must be mechanically safe and require relatively low maintenance appropriate to the User's individual lifestyle and other requirements.
- **Cosmesis:** the wheelchair should be cosmetically acceptable to the User. If not, s/he will feel self-conscious and may not take full advantage of it;
- **Caring:** Caring is the catalyst.

All these compatible requirements should be achieved within the time scale required for swift and sustained rehabilitation, and without undue occupational stress. Following assessment, the service should provide the wheelchair most appropriate to the individual User's clinically assessed needs.

6. Commissioning.

Commissioners should create and sustain a culture in which contracts reflect clinical, rather than financial, needs. They should encourage and facilitate direct communication between themselves, Users and Providers.

7. Providers.

The Provider should promote, for new and for existing Contractors, equitable competitive opportunities in a viable commercial climate, in which quality of service is encouraged and rewarded.

8. Independence for life.

Needs change over time, through at least 'seven stages', from the new-born babe to the senior citizen. To foster Independence for Life, and to avoid crises, each User should be entitled when his/her needs change to request review by his/her clinical rehabilitation team. Adequate time and skilled resources must be available for the learning of new skills, and the provision of new or redesigned equipment. There should be one named focal point of contact for the user, enhanced in cross-boundary situations by flexible sharing of funding across budgetary and organisational boundaries.

The User should have easy access to beneficial equipment, treatments, therapies, and services, and full and up-to-date information about new equipment and technology, including access to manufacturers' catalogues at each Centre.

The User has first-hand knowledge of his/her requirements for independence in day-to-day living, and needs assurances that his/her views will be taken into account.

The Occupational Therapist, the Physiotherapist and the Rehabilitation Engineer, in consultation with other members of the Rehabilitation Team, are the lead experts in matching design and delivery with User requirements. They also need assurances that their views will be taken into account.

9. Freedom of choice.

The User and Professional Staff benefit from continuity of relationships. They need time to get to know each other and to continue to develop mutually optimum solutions as the User's needs change. Where possible (and where there is more than one Therapist), the User's ability to choose his/her Occupational Therapist or Physiotherapist should be respected. Every effort should be made to secure continuity of care.

Where required to meet the User's needs for specialist services promptly and comprehensively, it should be seen as commendable management practice for funding to follow the User and to cross organisational boundaries swiftly and without undue bureaucracy.

A nation-wide listing of the wheelchair services and of types of wheelchair on general issue (including those under the voucher scheme partnership option) should be published annually by the

NHS Executive.

10. User consultation.

There should be regular opportunities for Users to consult with Staff and with Commissioners. Where practicable, this should involve the creation of a User Consultative Committee, concerned with the well-being of Users and of Staff. No topic concerning the Service should be deemed not to be of interest to Users. The Chair of the Committee should preferably be a User, and the Committee or other mechanism for liaison should contain a representative balance of Users and Staff. A clear and simple procedure for expressing satisfaction or dissatisfaction should be agreed, and should be on permanent public display, including the opportunity of eventual recourse to a Health Authority Ombudsman, after the procedure has been fully explored.

11. Information.

Each Centre should publish widely, by non-discriminatory means and in accessible formats, information about the services and facilities it provides, and the benefits and services provided by other relevant agencies, as well as information about the standard NHS complaints procedure. All emergency hotlines should incorporate a Minicom service.

12. Education and training.

The success of the service creates and enhances demands for highly trained and skilled personnel. With the emphasis on national quality standards, from NVQ to degree level, adequate resources must be available to institutions of education and training, in order that the requisite numbers and high quality of professional staff may be achieved.

Curricula should be consultatively designed to deliver competencies which meet User needs and priorities.

During each undergraduate year, from the outset, adequate clinical training/experience should be programmed and practised, so that the necessary levels of independent competence have been achieved before graduation. Users should see it as art of their role to participate in such "hands-on" clinical training/experience.

All professional staff should feel able to request, receive and help organise accredited training for their continuing professional development, including disability equality training, to expand and fulfil their potential.

Contracts should provide adequate protected time for all professional staff to undertake, to the required standard of excellence, agreed responsibilities for clinical tuition and supervision of students.

13. Research and development.

Consultation should continue to ensure that Research and Development proposals and programmes, both Centre-based and National, focus on User needs. Worthwhile innovations in technology and practice should be introduced effectively with minimum delay. And beneficial, developments and knowledge achieved locally should be made available to Users nationally.

14. Clinical audit & quality assurance.

Adequate resources should be guaranteed by Commissioners to Providers for Clinical Audit and Quality Assurance programmes. Participation of Users in the development and in the operation of such programmes is essential to their effectiveness and should be facilitated, whilst respecting the requirement to safeguard patient confidentiality Reports to Health Authorities should be made available to User Consultative Committees.

Note: Terms used in this Charter have the following meanings:

"User" means a person of any age who needs a Wheelchair and is entitled to NHS provision.

"Commissioners" are responsible for assessing and determining the health needs of their resident population and for commissioning services to meet those needs. "Providers" are responsible for providing services to the local population to the standard and level specified by Commissioners. "Contractors" provide services, through competitive tender, to the requirements of Providers who do not wish to provide an element of service or services directly.

**For further information please contact: emPOWER Charities Consortium,
c/o Muscular Dystrophy Group, 7-11 Prescott Place, London SW4 6BS**

emPOWER members include:- Age Concern, Aim Hi, Arthritis Care, Association for Spina Bifida and Hydrocephalus, British Computing Society Disability Group, British Diabetic Association, British Polio Fellowship, Brittle Bone Society, Contact A Family, Council for Disabled Children, Disability Action (N.I.), Disability Sports England, FAST, Leonard Cheshire Limbless Association, Motivation, Murray Foundation, Muscular Dystrophy Group, National Federation of Shopmobility, RADAR, REACH, SCOPE, STEPS, Spinal Injuries Association, SSAFA & FHS, Whizzkidz and Workable.

N.B. We have contacted emPOWER and flagged up our interest in their work. We are asking you to write to us with your comments on this Charter.

Disabled Living Centres Council - The Vassall Centre, Gill Ave, Fishponds, Bristol, BS16 2QQ.

We have also contacted the Disabled Living Centres Council and are being asked to bring forward to their attention any aids and equipment problems members are having. If you have a Centre in your area then you might like to make an appointment to see all the equipment there is available and get some ideas from their experienced staff as to what might help you save energy.



SOME INTERESTING FACTS

The longest one-syllable word in the English language is "screched."

"Dreamt" is the only English word that ends in the letters "mt".

The dot over the letter 'i' is called a tittle.

The word "set" has more definitions than any other word in the English language.

"Underground" is the only word in the English language that begins and ends with the letters "und."

There are only four words in the English language which end in "-dous" - tremendous, horrendous, stupendous, and hazardous.

The longest word in the English language, according to the Oxford English Dictionary, is pneumonoultramicroscopicsilicovolcanoconiosis. The only other word with the same amount of letters is pneumonoultramicroscopicsilicovolcanoconioses, its plural.

The longest place-name still in use is

Taumatawhakatangiangaauotamateaturipukakapikimaungahoronukupokaiwenuakitanatahu, a New Zealand hill.

Los Angeles's full name is "El Pueblo de Nuestra Senora la Reina de los Angeles de Porciuncula" and can be abbreviated to 3.63% of its size, "L.A."

A cat has 32 muscles in each ear.

An ostrich's eye is bigger than its brain.

Tigers have striped skin, not just striped fur.

Alfred Hitchcock didn't have a belly button. It was eliminated when he was sewn up after surgery.

Donald Duck's middle name is Fauntleroy.

The muzzle of a lion is like a fingerprint - no two lions have the same pattern of whiskers.

There is a seven letter word in the English language that contains ten words without rearranging any of its letters, "therein" the, there, he, in, rein, her, here, ere, therein, herein.

Duelling is legal in Paraguay as long as both parties are registered blood donors.

A goldfish has a memory span of three seconds.

It was discovered on a space mission that a frog can throw up. The frog throws up its stomach first, so the stomach is dangling out of it's mouth. Then the frog uses its forearms to dig out all of the stomach's contents and then swallows the stomach back down again.

Cranberries are sorted for ripeness by bouncing them; a fully ripened cranberry can be dribbled like a basketball.

The male gypsy moth can "smell" the virgin female gypsy moth from 1.8 miles away.

The name for Oz in the "Wizard of Oz" was thought up when the creator, Frank Baum, looked at his filing cabinet and saw A-N, and O-Z, hence "Oz."

The microwave was invented after a researcher walked by a radar tube and a chocolate bar melted in his pocket.

'Stewardesses' is the longest word that is typed with only the left hand.

To "testify" was based on men in the Roman court swearing to a statement made by swearing on their testicles.

The combination "ough" can be pronounced in nine different ways. The following sentence contains them all "A rough-coated, dough-faced, thoughtful ploughman strode through the streets of Scarborough; after falling into a slough, he coughed and hiccoughed."

The only 15 letter word that can be spelled without repeating a letter is uncopyrightable.

Facetious and abstemious contain all the vowels in the correct order, as does arsenious, meaning "containing arsenic."

Emus and kangaroos cannot walk backwards, and are on the Australian coat of arms for that reason.

Cats have over one hundred vocal sounds, while dogs only have about ten.

The word "Checkmate" in chess comes from the Persian phrase "Shah Mat," which means "the king is dead".

The reason firehouses have circular stairways is from the days of yore when the engines were pulled by horses. The horses were stabled on the ground floor and figured out how to walk up straight staircases.



NEW BOOK - A Balanced Way of Living (practical and holistic strategies for coping with PPS)

by Vicki McKenna Acupuncturist, Polio Survivor and LincsPPN Member.

Post Polio Syndrome includes a range of symptoms experienced by the polio-survivor. These include chronic fatigue, pain in muscles and joints, weakness, and problems with concentration and memory.

Vicki McKenna is an acupuncturist and polio survivor with many years experience of working with

Chronic Fatigue Syndromes such as ME and PPS.

This book explores current research into PPS and, drawing on the tradition of Chinese Medicine,, includes practical and holistic strategies for coping with the symptoms. It covers the following:

- Symptoms and causes of PPS.
- Personal experiences of polio survivors.
- How to let go of old attitudes and be empowered by new ones.
- A mind - body programme of relaxation techniques, exercise and diet.

To Order Your Copy send £10 UK - £12 outside UK/Eire - cheque or Postal Order inc. post & packing USA \$20 - (please contact Vicki OR LincsPPN for payment address in USA) Please allow 14 days for delivery. **Orders to:**

Vicki McKenna
42 Regent Park Square
Glasgow
Scotland. G412AG

Vicki McKenna <Vicki@share.force9.co.uk>

<http://www.share.force9.co.uk/>

⚠ *Currently Unavailable* ⚠



MedicAlert - YOUR LIFELINE.

Imagine being in an accident and not being able to speak.

Membership and contact details updated 21st February 2010..

One in three people in this country has a hidden medical condition, Diabetes, Asthma, Epilepsy, Food Allergies and Heart Conditions. We have Post Polio Syndrome and there is specific information regarding drugs and anaesthetics that it is extremely important that medical professionals know about should anything happen to you. We are in touch with MedicAlert and have forwarded information on the late effects of Polio to them. They will be adding PPS information to their WebSite shortly. Your personal information will be recorded by your GP/Consultant.

Medic Alert - a registered Charity (No. 233705) provides protection in the form of emergency identification bracelets and necklets and the back-up of a 24 hour emergency telephone service. Membership to the MedicAlert® service - including a tailored-made Emblem - starts at just £19.95 plus the first year's Membership at £25. As a registered charity, The MedicAlert Foundation can also provide free membership to individuals on a limited income. There are various bracelets and necklets including a sports version available at different prices.

Application forms are available free of charge from ourselves, from your Doctors Surgery or direct from:

Medic Alert Foundation
1 Bridge Wharf 156 Caledonian Road, London, N1 9UU.
Telephone 0800 581 420
Fax 020-7278 0647

<http://www.medicalert.org.uk/>

An application form can be downloaded from their web site.



Lincolnshire Post-Polio Library

Articles added since last newsletter with grateful thanks to the authors

Title: [Postpoliomyelitis Syndrome: Assessment of Behavioral Features](#)



Author(s): Donald L. Freidenberg, David Freeman, Steven J. Huber, Jacquelin Perry, Armin Fischer, Wilfred G. Van Gorp and Jeffrey L. Cummings.

Title: [The Postpolio Syndrome - An Overuse Phenomenon](#)



Author(s): Jacquelin Perry, M.D., Gregory Barnes, B.S., R.P.T. and JoAnne K. Gronley, M.A., R.P.T.

Title: [Dr. Henry writes about Polio Spouses](#)



Author(s): Henry Holland MD

Title: [Non-Paralytic Polio and PPS](#)

Author(s): Marcia Falconer, Ph.D. cell biology and Eddie Bollenbach, M.A. biology.

THE FULL TEXT WAS INCLUDED IN THE PRINTED VERSION OF THIS NEWSLETTER. [SEE ABOVE.](#)

Title: [An Open Trial of Pyridostigmine in Post-poliomyelitis Syndrome](#)



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

Title: [Polio Biology II - Post-Polio Syndrome's Elusive Etiology](#)



Author(s): Eddie Bollenbach, MA.



ODDS AND ENDS

Lap Top Computer needed. We would like to be able to take our WebSite with us to meetings and Conferences so that we can demonstrate the wealth of information that we now hold on our main resource. If you know anyone who would be prepared to donate us an older version Lap Top Computer with Windows 95 on it then we would more than grateful. Our paper copy of the Library - now over 90 full text medical articles - is getting very heavy to transport.

Chris Adams, a member in Birmingham asks, "Do you know of anyone with a Ulysee or other car with a semi auto clutch, I would like to communicate with them?" [<c.w.adams@bham.ac.uk>](mailto:c.w.adams@bham.ac.uk)

Pat Roe a member from Sheffield has sent us three lovely crocheted knee rugs, 5 foot square. If any member would like one of these for a donation towards our work then please get in touch. Thank you Pat for all the bits you have made for us to sell to raise funds. Your hard work is appreciated.

Klaus in Berlin asks is there someone in England who speaks very good German to be a pen pal to a PPSer in Germany. [<KlausinB@aol.com>](mailto:KlausinB@aol.com)

How to make Rice Bags
to heat for aching muscles or Cold Feet.

From Carole... KaroleLee@aol.com

Items Needed;

One hand towel about 15x24 inches

6 cups of uncooked rice (2 ½ lbs.)

A sewing machine.

Directions:

1. Fold towel in half lengthways.
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 wet.....ENJOY



Membership Fees

Our Membership Year runs with the Financial Year and Fees are due from the end of March. Thank you to the three members who have already paid us. Membership Fee is £10 per year. Payment can be made by Standing Order direct to our Bank Account, or by cheque or Postal Order. Life membership is £100 and can be paid as a one-off cheque or by monthly standing order of £5 per month. Membership includes six bi-monthly newsletters. For our American members or those wishing to pay in \$US, payment is \$20 a year or \$200 for Life Membership and payment can be made direct to our US accountant. Please contact us for details. Membership includes the six bi-monthly newsletters for that year. Membership Cards will be issued with the next newsletter.

Our work would not be possible without membership fees and the donations that we receive. Thank you.



LINCOLNSHIRE POST-POLIO NETWORK

Registered Charity No. 1064177

Articles for publication by March 20th - Publication date April 5th 1999

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Document preparation: Chris Salter, [Original Think-tank](#), Cornwall, United Kingdom.

Primary Document Reference: <URL:<http://www.ott.zynet.co.uk/polio/lincolnshire/linkpin/lincpinvol02issue03.html>>

Alternate Document Reference: <URL:<http://www.zynet.co.uk/ott/polio/lincolnshire/linkpin/lincpinvol02issue03.html>>

Last modification: 21st February 2010.

Last information content change: 21st February 2010.

