



THE LINC-PIN

Issue No. 9 - January 1998

**WebSite <http://www.zynet.co.uk/ott/polio/lincolnshire/>
Registered Charity No. 1064177**



1998 The Year of the Positive Polio Survivor

**14th February 1998
First Anniversary of our WebSite
now containing over 60 full text medical articles**

Dr. Mandy Bretman, Director of Public Health,
Lincolnshire Health Authority,
chaired the inaugural meeting of the

Neuro Patients Forum
at Lincoln County Hospital on the 19th January 1998
To progress development of a local neurological service.

This was an interesting meeting with many problems being identified by the representatives of the neurological support groups present. The next meeting is on 25th February 1998. A positive step forward for Polio Survivors in Lincolnshire. We will be reporting on the outcome of these two meetings in our next newsletter.

**H.R.H. Queen Elizabeth, the Queen Mother.
Our Very Best Wishes for a Speedy Recovery.**

Many Get Well Messages have arrived in our mail box from around the World....
Here are just a few.....

Many of us Americans remember the courage of the Queen Mum and the King when they refused to leave London during the war. We have tremendous admiration for her and pray for her speedy recovery. *Grace Young.*

Those of us in Florida also add our heartfelt concerns and prayers to all the others for the Queen Mother's recovery. *Barbara Goldstein.*

Even in Alaska we are concerned for the Queen's Mum. Our well wishes and prayers from the north! *Karyl.*

Best Wishes to the Queen Mum, for a speedy recovery. From the folks in Michigan who admire her.
Donnie.

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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

1998 the year of the Positive Polio Survivor. (editorial)

I have at last got a diagnosis for my symptoms. It has taken me nearly three years and following many tests with nothing else found, I now have a letter from Queens Medical Centre, Nottingham stating that they can confidently diagnose the post polio syndrome and treat the symptoms on their

merits.

Many more PPS specialists around the world are giving us permission to add their medical articles to our WebSite for which we thank them.

We are now on the Patients Forum for the Neuroscience's Department at Queens Medical Centre and the new Neuro Patients Forum for Lincolnshire Health Authority. The aim of both groups is to work with recognised neurological support groups to improve on the service provided. Certainly a step in the right direction. We will let you know how things progress as they happen. If anyone has any information on things that have happened to them - good or bad - whilst trying to get medical help in this area then we would be happy to pass the information on. If you live out of our Regional Health Authority then we recommend that you send your stories to the Director of Public Health in your area so that they are kept up to date with problems being incurred by people with neurological conditions.

This newsletter is a **POSITIVE** one. 95% of it written by Polio Survivors. Full of stories, hints and tips and suggestions as to how you might cope better whilst you get your own diagnosis for your many and varied symptoms. Remember PPS is by diagnosis of exclusion of other conditions. It would not be a good idea if Doctors said 'Oh you had Polio, then it must be PPS' and then later you find that you had something else that should have been treated earlier.

Those of us with computers and modems which allow internet access are now able to share information, hints, tips, ideas, and much more with other Polio Survivors and PPS specialists around the World on a daily basis. We can correspond by electronic mail. We can subscribe to Polio discussion lists. We can install computer programs that allow us to 'type-talk' to each other live, and also to speak live via microphone and speakers. All this takes place on the computer, which you have to buy, which is attached to your phone line and you only pay local call rate for all the time online plus a monthly fee to your Internet Service Provider.

We are all different with many different problems, but we are all very inventive. So let's hear your tips, ideas, stories, whatever you would like to tell us. We look forward to hearing from you.

Hilary Hallam, LincsPPN Hon. Sec., Polio Survivor of 1952, aged 5.



PPS SYMPTOMS

by Tom Walter, Polio Survivor Tominical@aol.com

New progressive muscle weakness,
including muscles that were not originally affected by polio.

Unusual fatigue,
Decreased physical endurance,
Breathing difficulties,
Swallowing problems,
Sleep disturbances,
Pain in muscles and joints.

And don't forget about all these POSSIBLE symptoms -

- digestive tract involvement, including constipation and/or diarrhoea;
- genito-urinary involvement;
- weight gain;
- slowing of memory, concentration and attention;
- diminished eyesight and/or hearing when "over" tired;
- falling down more than usual or customary;

- a chronic "itch" in the ear canal;
- muscle twitching and tingling, sharp shooting pains; and
- intolerance for cold (especially) and/or heat.

**Other diseases that may mimic the above
have to be "ruled out" for a diagnosis of PPS.**

Is it possible to have PPS with an EMG that doesn't show the patterns of polio on the unaffected side?

Question asked on the St. Johns Post-Polio-Med List

Residual muscle weakness is one of the hall marks of an attack of paralytic polio. However, some individuals have complete recovery of muscle innervation after paralytic polio. If there was denervation after an attack of polio followed by partial or incomplete recovery there are changes in the EMG that can be detected for a long time. If these changes are not found on EMG it does not rule out the possibility that you had paralytic polio.

As far as diagnosing post polio syndrome with no definitive historical data to support an attack of paralytic polio, there are several alternative approaches.

1. Exclude any known causes for your new symptoms other than post-polio.
2. Do a careful exam of your affected and unaffected sides both clinically and if necessary with an EMG including single fiber EMG to look for changes suggestive of post polio.
3. Observe you periodically for any signs of progression of symptoms.

Regardless of which course you take, I would suggest that you consult a physician knowledgeable in PPS.

Thyagarajan Subramanian, MD - Assistant Professor of Neurology Emery University, USA.



SOUTH AFRICA PAGES

Priscilla Webster writes.....

'I went to count, on my hand, the doctors who accept PPS and then discovered I only had a thumb'

At the moment there is nothing exciting about me because I had polio as a child and really don't remember a thing about it. I was probably one of those for whom it was too traumatic so I buried it in my subconscious. My family reckon I was between 3 & 4 years old. Over the last 11 years I have suffered tremendously in the hands of 'Rocket Scientists' who have diagnosed me with all sorts of weird and wonderful things. One specialist even called me a human freak. Not good for the ego!

In all fairness to the doctors I do also suffer from diabetes, neuropathy, asthma, chronic open angle glaucoma, arthritis, hypertension, epilepsy (non-active) and PPS.

I came out of hospital in early October after having an angiogram and was so humiliated. Anyway as usual too much pain and couldn't sleep so was looking up pain on the Internet when I saw Post-Polio Syndrome. Remembering something my ortho doctor mentioned many years ago I logged in and nearly passed out when I saw all my symptoms. I wrote to my ortho guy and he phoned back to tell me that I definitely had it. (He's just come back from a trip to Canada and was updated by his son! He's 84 and his sons are all ortho surgeons. Wonderful family. This guy still works.)

I'm dragging myself up off the ground and making darn sure no other PPS sufferer ever goes through what I went through. At the moment I am working like a lunatic because I am doing it all myself. Thank goodness for wonderful husbands and personal computers. The information off the Internet has helped me tremendously. The South African press is a bit lethargic but we are getting there. Education is going to be very important. I've spent days in hospitals (private ones) where I've had to go without a bath because they will not assist me! No one has been trained to even know about polio.

South African Mail and Guardian,
December 9th 1997
Health

Starting forty or fifty years after childhood polio, victims encounter their disease once more in a different and little understood form called Post Polio Syndrome. Now a South African association has been set up to help survivors says organiser Priscilla Webster..... For more information contact

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The South African Post Polio Syndrome Association,
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**Mike & Yvonne Isaacson
both Polio Survivors
from Cape Town, South Africa.**

Two years ago, my sister who lives in Cambridge found a book on polio and sent it to me. It was "A Summer Plague" by Tony Gould. I found it to be absolutely fascinating and very informative. You see, both my wife and I have polio - I got mine in 1940 and she got hers in 1944. I was affected in both legs and my wife in both legs and one side of the back. That led to a major scoliosis which in turn led to innumerable operations to correct the curvature.

In about 1976 my wife began complaining of a sharp pain virtually following the course of the right radial nerve. X-rays and scans taken over the period of about two years showed that nothing was wrong with the vertebrae or the foramina or the nerve itself and after exhaustive tests, the doctors diagnosed "a residual weakness which was not recognised as such by the orthopaedic specialist. Analgesics and NSAID's were prescribed aplenty and these eventually caused a stomach ulcer, so they had to be stopped and my wife had to just live with the pain. In the meanwhile, the pain "growed and growed" just like Topsy. General fatigue also appeared and my wife had all the classic symptoms of PPS but we still didn't know what it was.

In his book, Tony Gould describes the first appearance, investigations into and eventual acceptance amongst the medical fraternity of what we now know as PPS. Self diagnosis is not to be recommended, but the symptoms described in Tony Gould's book seemed to fit those presented by my wife. We discussed PPS with our General Practitioner, but he had never heard of it and couldn't offer any help, neither was he able to make a diagnosis other than "Well, the body does develop general aches and pains as we all get older.

A cousin of mine who is a Doctor living in Dulwich happened to be on a visit to Cape Town where my wife and I now live. I took him to a plush restaurant, bought him a slice of his favourite cheese cake and a cup of coffee and asked him if he would be prepared to research PPS for me when he got back to Dulwich. The cheese cake must have been good, and he agreed!!

A short time later, he wrote to me enclosing a number of Medical Papers from the Lancet and from the Lincolnshire Post Polio Network, which he had found while browsing on the Internet. Quite frankly, although I knew that it was full of information, the Internet was the very last place that I had ever expected to find anything really useful about Post Polio Sequelae. I didn't even subscribe to the Internet at the time, but eventually did so at my cousin's suggestion. I looked up "polio" and found the Lincolnshire Post Polio Network and was utterly amazed at the wealth of information it contained. I have downloaded and printed quite a few of the Papers in the library and I am studying them and finally finding out how to cope with PPS. I also downloaded one of your recent Newsletters in which I found 'Cilla's e-mail address and I lost no time in contacting her.

Finally, after years in the wilderness, I know that what my wife has is Post Polio Syndrome. I know what it is. I know what it does. And I know how to combat it, all thanks to the Lincolnshire Post Polio Network.....

..... and a slice of cheesecake!!!!!!



Tony Gould's Book can be ordered from www.amazon.com in either hardback or paperback.

UBUNTU (means Humanity)

I take you for who you are
and what you have achieved in life,
not for the colour of your skin.
That is humanity.

Smiling to all who come to my door is Ubuntu.
I do not hold you responsible for pain.

It is difficult being human.
It is difficult for me
to understand your pain and sorrow,
but in your tragedy I tried.

I know it must be difficult for you
to understand my pain.
For you, a perfectly formed human being,
it is almost impossible
to understand the inhumanity of the pain

I suffer twenty four hours a day,
because I have not told you about it.
You cannot understand what it is like
for me to sit up all night
trying to wash away my pain with tears,
because you have slept all night.

How could you know what pain is involved
in me going for a walk,
when you yourself can walk.

I ask not that you pity me,
but that you consider me.

Our lives are intertwined
The poor and the rich
The educated with the uneducated.
Sorrow and joy are ours to share
My respect for you and yours
should ensure your respect for me and mine.
Failure to respect your fellow man,
the laws of the land and the laws of nature
Automatically exclude you from
the membership of Ubuntu.

Priscilla Webster 27th October 1997



FIRE DRILL - by Viola Pahl, White Rock, Canada

This is a serious subject, but I hope this story will not only make you smile, but also ensure that you check your own house/workplace and ensure that you have an escape plan that will work for you.

It was hilarious. The fire drill was conducted every two weeks at the Rehabilitation Centre to see how quickly all handicapped people could be evacuated. I was at the Rehab Centre for six weeks. The many-featured exercise classes were from ten in the morning until three in the afternoon. My strength did not allow me to last all day, so I went to bed right after lunch in a remote room in the Rehab Centre. I'd have about three quarters of an hour's sleep, and then rejoin the group. During the six weeks there, approximately 3 fire drills were held generally right after lunch. The staff forgot about me in the remote room as they hurriedly got everyone out, and the fire marshals (different personnel each time) were in a tizzy, because three times in a row, they could not present a perfect fire drill - there was always ONE burned statistic on paper - namely me. I had either slept through the alarms, or had not reacted swiftly enough to get out of the bed into my chair and into the hallways, or if I suspected it was a drill, I just stayed in bed until the excitement was over. (This was 49 years ago.)

Now we live on the fifth floor of a concrete condo - even the walls in each suite are concrete. I phoned the fire department and asked, "What do I do in the event of a fire? Get out on the open balcony? I might under stress be able to go down a flight of stairs - but if the fire were on that floor - I'd probably never be able to get UP the flight of stairs." The fire marshal advised thus: "First, stay in your suite and phone the fire department and tell them that you are a handicapped person in such and such a suite." If appropriate, he advised I may go out on the open balcony and a fireman would come up a ladder and rescue me. "Sir," I said, "I'd die if I had to be carried down a ladder by a fireman." I am horribly afraid of heights (even pre-polio). He cheerily replied: "Oh no, you wouldn't, madam. We'd look after you." Yeh???? Anyhow, our small city now has a cherry-picker apparatus (is that term familiar to all of you?) and when they were testing it out - hurrah - it was as high as our fifth floor condo. Wow - that would sure beat going down a ladder!

I would advise everyone to phone their local fire station and get all the hints possible about how you with your particular limitations might cope with a fire situation. Personally, I pray that I'll never have to flee a fire - the very thought of it sends a chill down my spine as it does to most people, disabled or able-bodied.

For details of Viola's books see [her entry](#) in our [Library Booklist](#)

Randy Riddle writes
Waynesboro Fire Department
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randyr@rica.net

My name is Randy Riddle and I am a Polio Survivor. I am a Small town fire-fighter. I just a while back was off from duty because of second degree burns to my face I received during fighting a fire in which a lady died. This was a lady in her mid 30's, and in good physical shape it seems. So this now has me asking this, if she was in good shape and died what chance do my polio friends have? If you have any disabilities that restrict any movements or your thought making process then you are in grave danger in your own dwelling. You need to start (like yesterday) to draw up a home plan of escape that you can use to help you out in those first minutes of danger (that is all the time you get). The first step you need to take is, get in touch with your local fire department and get all the information that you can. They will be more than glad to help you. The Drs. have helped you with all of the disabilities that have come into your lives, now it is the turn of the local fire departments to help you get out alive. Just remember this, that fire cares not of your lives or cares of any disabilities, it will take your life and all those around you in the time it has taken to read this message.

So PLEASE, PLEASE, PLAN NOW ON HOW TO GET OUT AND STAY OUT ALIVE.

LINCOLNSHIRE FIRE BRIGADE
FIRE SAFETY TEAM ADVISE
01522 582222

Everyone should consider Fire Safety in the Home. If you have any form of disability then it is even more important that you look at your home and decide what you can do to ensure your safety. Make a fire plan.

Early warning of Fire is essential. You should have a smoke alarm on every level of your dwelling. One for every floor and it should be in the Hallway or Landing. These should be properly fitted, and tested on a weekly basis. If you have someone hard of hearing or deaf in the house then you should have flashing light fire alarms fitted as well. You should close all doors at night that separate the areas of possible fire from the escape route.

Escape Route is the next most important point. If you have a problem with mobility, have an electric chair, hoists, stairlift, respiratory equipment then you must consider what is best for you. A *phone is essential in the bedroom* if you have any difficulty in getting out of bed or the room. The Fire Safety Team of any Fire Brigade will be only too pleased to help you work out a specific fire plan for your special needs. Their telephone number will be in the phone book under FIRE and you need to ring the HQ telephone number and ask for the Fire Safety Team.

The following sequence of events that should be followed wherever fire occurs... and in simple terms its Get Out, Get Us Out and Stay Out..... and to expand on that they use the mnemonic FIRES.

- | | |
|----------------------|--|
| F Fires | An actual fire or suspected fire, the smell of burning, fire alarms sounding people shouting fire. |
| I Inform | Ensure that everyone has heard/seen the alarm sounding and has responded, if |

the alarm has not sounded then shout at the top of your voice.

- | | |
|----------------------|---|
| R Retreat | Make sure that you move away from the fire area and close doors behind you. |
| E Evacuate | Evacuate Do not waste time. Keep low in Smoke. Use the SAFEST exit. Once outside phone the fire brigade from a SAFE phone. If doors are locked along your exit route keep a key on a hook near the door, but make sure that it is out of sight and that no-one can reach it through a letter box or see it from a window. Think Security. |
| S Stop Out | Do not go back into the house for anything - not for personal belongings or even pets and do not go back into the house until advised that it is safe to do so by the Fire Officer in attendance. |

Bedroom Phones. Remember that the phone cable may run through the room or rooms which contain the seat of the fire and therefore may be susceptible to fire damage. This may be especially the case where the bedroom phone is an extension linebox or socket cabled to a master socket downstairs. You may want to consider a second phone line and ensure that the cabling comes into the bedroom directly from the outside of the house. Alternatively, a cellular phone kept charged in the bedroom can provide a backup to an internal extension. LincsPPN Administration



You hear the term PPS.....

To have had medical problems for some years that have been medically noted yet unexplained I am sure you will agree has been tough. You know you are an intelligent person, you know you are not imagining things, but if nothing can be found then you are left in limbo. Dare you go to the doctor with yet another problem? Will you be told, it's your age, you are imagining this, maybe you ought to see a psychiatrist..... probably, you think. So no you decide, maybe next month and so you struggle on.

We thought Polio was part of our past lives. Had it. Recovered to a level. Managed. Got on with our lives. End of story. We have all achieved a great deal, many able to go on to highly qualified professional careers, and compete in many sports. Those of us who were left with hardly any easily visible sign have probably not even thought of the word Polio for many years or had little contact with anyone else who had Polio. So it's not surprising that until we hear the words Post Polio do we even consider that the way the polio virus affected our bodies, could have any bearing on our problems.

For example you have a vision problem with one eye. Why on earth should you say I had polio as a child and my legs were paralysed? It would not be relevant, or would it?

Then you have the added problem of your partners, children, family and friends. How are they reacting to your seemingly ever increasing difficulties with no medical answer?

Some Polio Survivors have been given a diagnosis and then had tests to find that they don't have that, so it must be..... and then you are tested for something else and again it's not that, and you do the rounds of the hospital departments. Some have been diagnosed as having Motor Neurone Disease with a very short life span left, only to be told - as they didn't get worse or die in the expected time - that it can't be that. Some have been told that its all in their minds, it's depression, take these tablets. Well, being honest, anyone would become 'depressed' going through this sort of medical minefield.

Then comes the day when you first hear the term Post Polio Syndrome or the Late Effects of Polio.

You start to read some information about it and so many of your symptoms seem to fit. You have to approach this very carefully. There are no tests for PPS, it's by diagnosis of exclusion. It would be terrible if you said to the Doctor, 'I had polio, I have PPS' and other conditions you could have were not looked for.

You feel relieved that there is something else to consider and then worried because you don't know what the future holds. It may also bring back memories of the past, hospitals, operations, being away from parents, not understanding what was going on. This can be quite traumatic and many do not want to even think of PPS, let alone discuss it for this reason. This is quite understandable. You need the support of your GP, your family, and maybe even some counselling to help you bring the past out into the open so that you can cope with now and the future. Nearly all Polio Survivors benefit from the support they can get from talking to other Polio Survivors going through the same problems.

So what is the best way to approach this. Possibly take some information to the Doctor and tell him/her that as you are not medically qualified, you would appreciate him/her looking at what you have found and telling you whether it could be relevant in your case. Doctors are very busy people with a lot of paperwork coming through to read and they won't have time to read much so it's best not to take too much [information]. One comprehensive article or even just a couple of leaflets and a list of the other articles available on our WebSite would give them some starting information, plus a potted history of your life.

Write about when you had polio, how it affected you and how you recovered. Some Polio Survivors remember everything, some of us remember nothing. It's difficult for elderly relatives to remember back 40 or more years, and they might also find this difficult. Our Parents, siblings and relatives must have been devastated when we caught Polio and will have gone through quite traumatic times, and they could easily find this an emotional experience as well.

Write a short history of your life, your education, your occupation (including being a mum and bringing up your children), your hobbies and sports and what levels you achieved. Now you have some basic information to refer to.

So what can you do whilst you wait for your GP to read the information and arrange for you to see a relevant specialist for your current problems.

You have been a Doer all your life, never given up, managed to pack 36 hours into every 24, refused help as you can manage, haven't you? We haven't found a Polio Survivor who does not agree with this statement - yet! When relatives ring me in the first instance, I always smile when they say 'you have described my wife/husband exactly.'

The best advice is that you have got to change. You won't like it at first, we didn't, but we know it works. As a Polio Survivor, it doesn't really matter what they find wrong with you, you need to look at your lifestyle, your weight and diet, your work, your house, your hobbies, in fact everything that you do. Involving the whole family and getting them to join with you in this and look at their lives as well, is a good idea.

Where are there places that you could do things to make life better for yourself? Where can you save energy and use it more wisely to do the things you want to do? There are many questions you could ask yourself. Many Polio Survivors will tell you that when this is first suggested to them that they replied that I am not that bad yet, I don't need to think about any of this yet. However, most of us later agree that the earlier you start looking and changing your lifestyle then the easier things are and you are able to have a better quality of life.

These ideas are not to get you to stop doing what you like, but to save you as much energy as possible to allow you to use what you have to do what you want. If you pace yourself throughout the day, with work and rest periods you can do much more than if you get up and do too much in the morning and then can do nothing for the rest of the day. If you know that tomorrow is going to

be a busy day, then ensure that today and the day after are days of more rest.

Ask yourself:-

- Is there any way I can alter things at work to save me energy?
- Is my computer monitor at the right height, would an ergonomic keyboard (keyboard split and angled) help?
- Should I still be lifting heavy weights, can I use a trolley, get someone else to do it, split the amounts to more manageable levels?
- Maybe a rucksack-type bag distributing the weight more evenly would make it easier to carry things?
- Could someone else dig the garden this year?
- Am I overweight?
- Do I eat a balanced diet?
- Am I wearing the right sort of shoes?
- I feel the cold more now, so should I get a hat and some gloves to wear when out?
- Is my bed the right height and comfortable?
- Can I get out of my armchair easily?
- Could I alter my kitchen cupboards so that I can easily reach the items?
- Would rails in the bathroom help me to get up off the toilet, into or out of the bath/shower?
- Maybe a downstairs toilet would save me many trips up and down stairs?
- Would a cane help me to walk better?
- Would an electric scooter or wheelchair allow me to get out more and do more?
- In sports, could I split this into smaller episodes, one game instead of two?

There will be many more questions that you can think of.

Keep a diary each day of what you eat, the drugs and vitamins you take. How much pain and fatigue you have. What you do and how you feel. Have a Pain Chart, an Activity Chart, etc. numbering from 1 - 10 and working out your own criteria for the numbers. Write your criteria down defining what each number represents. Like 1 = pain free: 2 = twinges of mild pain occasionally through out the day, etc. Post these criteria in the front of your diary. We tend to have 'brain fog' and it helps to refer back to your criteria so your observations remain constant with the criteria. Also if you ever show your diary to your doctor he can see the definition of what a 1 or a 5 means to you. This will help in your communication with your physician and will result in better understanding on his part and better care of your medical condition for you.

The final most important thing is that you must remember that your Partner, Siblings, Children, Relatives, Friends and Work Colleagues will not know about PPS and your problems unless you tell them. Share it with them, share how you feel, ask them how they feel. Tell them what you are doing and you might be surprised at their reaction. They can't help you if you don't tell them.

Remember it's your body, it's your decision, and it has to be made when you are ready to make it.

Hilary Hallam



Energy Presents

I discovered that if I count my energy presents like people who are dieting count their calories and fat grams I have much less problem with fatigue. During this busy holiday I am sure all of us can use the reminder that we need to use our energy wisely.

Imagine yourself with a basket of presents everyday. In the basket are 5-10 presents. Each present is

a Unit of Energy. As you go through your day you will use a present for every task you perform. When you take a shower and dress for the day you will need an energy present. If you run errands, for each place you stop may require a whole energy present just getting to and from the buildings. I have discovered for every 45 min I sit at the computer I use a present. If you prepare a meal that will take a present. Others may use more or less depending on your abilities and fatigue levels. Obviously it does not take long to use up that basket of presents in a normal day. So make sure that each of you use your gifts wisely. It requires rest (sleep) to refill the basket. Once the basket is empty there are no reserves and you must sleep to recharge and wait for the basket to refill.

It is possible to hoard some of your presents and save them for a special occasion. But please remember these presents are very perishable so will not keep very long. If you have a big event coming up then you must rest more and use less presents for several days prior, so that you are capable of withstanding the extra demands you may put on your body with a special activity. Should you exceed your box of presents for a special occasion, you may discover that the basket has fewer gifts inside for several days following. Thus instead of 10 presents you may only have 5 or 6. We are not the energizer bunnies and cannot keep going and going and going. We need to find ways of managing our energy use so that we can reduce our fatigue. It is difficult to determine how much energy you can expend in any given day without suffering ill affects from overdoing. However, I do believe we can manage our lives if we are aware of how much we exhaust ourselves just doing our daily chores.

It takes 3 times the energy to stand as to sit. It requires 3 times the energy to sit as to lie down. So keep this all in mind and rest often. Sit to do whatever projects you can and eliminate unnecessary activities. Oh and I always suggest that you save at least one energy present every day for something you enjoy doing. We deserve to indulge ourselves and need those positive reinforcements in our lives.

Linda Van Aken - DVanAken@aol.com



Sharing with your family

I had the problem of falling easily and worrying about shoes and things being left in the middle of the floor. I raised my daughter to be aware of making sure nothing was left ever in the middle of the floor but I did find I had to learn how to deal with unaware people when she started dating and her boyfriends would come over and leave shoes etc. in the middle of the floor. The best way to deal with it is, immediately when you come across something left where it could cause you to fall, call in a loud pleasant voice "whoever left these 'shoes' in the middle of the floor, please come immediately and move them, I cannot afford to fall anymore because I could get hurt so badly". Then wait for them to come and show them where to put the article, like along the wall somewhere, and do not move until this has been accomplished. You will not have to do this very many times. They will see quickly how important it is to you, and your problem of stuff left in the middle of a path will disappear.

Start printing out some of the stuff that people talk about here that pertains to you and start talking about it with your family. You can open a conversation by saying, "You know, I was wondering why I was having this particular problem, and look what I have found on the Internet", then use that as a platform to start to educate them on what problems you are finding difficult to deal with. I found most of my problems disappeared when I finally started communicating with my family. They cannot read your mind and they do not realize what things are beginning to be difficult for you until you tell them about it. You can do this in a light manner. Your family probably does not realize how afraid you are, even though you probably think the whole world can see it. We have got so good at learning to cope and adapt, lots of things you think should be apparent to them, they have got used

to thinking you can take care of yourself.

I remember the first time I had to make an issue of getting my husband to follow me into work and help me get across the ice covered street into the building. I had got more and more afraid of walking on ice and scared of falling, that when I knew it was going to be icy in the morning getting into work, I would get physically sick to my stomach and either force myself to go and creep across the street with my heart up in my throat, or I would call in sick, not even telling my husband of my fear.

Finally one day, I could not call in sick again, and I could not face the fear of getting myself across the street, and so I told him I need him to help me get into the building. But I didn't explain the mornings of fear I had faced and I didn't confess my days of sickness were due to being afraid to walk in on the ice so the first couple of times I asked him to help me he grudgingly came along and helped. Then finally one evening when I knew it was going to be bad in the morning and I told him I needed him to follow me into work, he blew up and hurt my feelings and I cried and finally told him of all the times of cold fear I had faced walking on the ice. He was just dumbfounded I had never told him before and I never had to ask him again to follow me into work. He always volunteered before I could ask. The point being, I had never shared my fear with him. I just tried to cope until could not any more, and then somehow, I felt he should just know what was going on in my head and all about my fear, when I had never shared it with him.

Start sharing what things are becoming difficult with your family. It will be kind of hard to begin but you will find that they will begin to understand and even start to try to be more of help to you with things you find difficult. And you will find that it is not so scary when you have someone to share it with.

by Shirley from Kansas, USA.

swhisman@earthlink.net



Grace R Young, MA, OTR and Polio Survivor writes about muscles...

Even though you were told that you had "nonparalytic" polio, this doesn't mean that you didn't lose some motor units during the acute attack. It means that there was no clinical weakness. A muscle can lose as much as 50% of its motor units and still not show clinical weakness. However, the remaining motor units are working harder and longer. After many years of overworking, some of the remaining motor units start to give out.

During the acute attack most of the spinal cord is affected, even though much of it might recover within a few weeks. But we don't really know whether or not there is subclinical damage to some of the muscles. That's why many of us have new weakness in areas that we didn't think were affected.

I have seen similar comments throughout the medical literature. However, after evaluating and treating almost 400 polio survivors over several years, I have to disagree. Many people with minimal residual weakness worked so hard to "pass" as normal they are presenting with greater losses proportionately than those with more severe effects who were not able to be "over-achievers".

I have even seen patients who state they never had polio (but someone in their family did when they were children) and now present with new muscle weakness and atrophy, and were diagnosed as PPS following EMGs. We know that almost the entire spinal cord is affected in the acute attack, even though muscle weakness is not obvious. A muscle can lose up to 50% of motor units and still test as 4 or 5, but the remaining motor units are working harder and longer. A muscle testing as 5 may have

only 75% of motor units as a non-polio, and a 4 may have only 40% of motor units as a non-polio. So even very mild cases can and do develop the late effects.

about fatigue...

I think most of us can relate to delayed fatigue. We overdo on good days and then are sidelined for several. It helps if you can identify right when the fatigue starts and stop for a rest before you reach the "point of no return" (easier said than done). Here are a few ideas:

1. Stop when you feel a little tired. This sounds simplistic, but most of us were taught to ignore pain and fatigue, so we don't notice until the fatigue overwhelms us.
2. Decreased quality of movement. Stop if motions that are usually done smoothly develop a tremor or become shaky.
3. Decreased quantity of movement. Stop if your range of motion declines while you are working.
4. Stop if you start using compensatory motions. For instance, you start having to "hunch" your shoulder in order to raise your arm, or your leg starts swinging out to the side instead of flexing at the hip when you walk.

If you stop in time, you can usually resume the activity after you rest for a while (you may need more than one rest period). This is much more productive than being out of commission for several days afterward.

about scooters...

Each vendor only carries certain brands of wheelchairs and/or scooters and naturally want you to buy one of theirs, so do some research and find what's best for you.

I am on my third electric scooter and have some suggestions about features to look for.

1. A sturdy base which can't be tipped over.
2. The brakes should lock automatically as soon as you stop (no hand brakes).
3. Make sure the tiller is not stationary and can easily be pushed forward out of your way.
4. Armrests which can be pushed up or down (no fixed armrests).
5. Enough power to go up steep inclines.
6. Large enough tires (tyres) to go over rough terrain. Test various models outdoors on many different surfaces in addition to testing inside your house.
7. Can your hand operate the tiller while your elbow is supported on the armrest - if not, your shoulder muscles will become fatigued.
8. Practice getting on and off different types of seats. Although most brands have swivel seats, I found that bucket seats were difficult for me.

about joint replacement...

One contraindication to joint replacement is weak muscles around the joint. You need strong muscles for a good result.

For information on energy conservation visit Grace Young's web site
<http://www.reocities.com/HotSprings/4713/>

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Several of Grace Young's articles, originally published in peer reviewed medical journals, can be found in our [online library](#). See the catalogue entry for [Young, Grace R., MA, OTR](#)



MRI Scans

Magnetic Resonance Imaging, MRI, is one test that you are likely to be offered. Firstly check around and see if there are any sideless MRI and CAT scanners in your area. Some Polio Survivors do not like to be in closed-in areas. They like the window open at night, like the air blowing on their faces when travelling in cars, do not like wearing tight clothing round the neck. This fact may therefore make this particular test a daunting experience. From personal experience and from reading the many stories on the Internet, I offer you the following suggestions which I wish I had been given prior to mine.

Talk to your GP about your concerns and ask him to let the Unit know. Maybe they have an advice leaflet you can read. You are not being a wimp admitting that this. Maybe it could be arranged for you to go and see the machine.

Suggestions on the internet, are to tell the staff how you feel. Ensure that you are comfortable as the test takes some minutes. Take a favourite cassette with you, or ask them to tune the headphones in to your favourite radio station. You can still hear the staff's voices over the headphones. Ask them to let you know what they are doing. Maybe take Margaret from Florida's suggestion...

Try spending a million pounds.....

STOP PRESS

**Frontline
Journal for Physiotherapists
21st January 1998**

Small article giving information of the Lincolnshire Post Polio Network has already produced three enquiries from Physiotherapists for information.

Jackie Dearing, MGCP, BABTAC,
32 Chiltern Road, Lincoln, LN5 8SE

Fully Qualified Aromatherapist,
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Discount for LincsPPN members.



I know I have PPS when:

- I go to bed at night and discover that my night-gown or pyjamas are in another room, so I heave a sigh and rather than spend the energy to get the night clothing, I opt to go to bed in my undergarments.
- As I walk with crutches or wheel down the street, I spot a \$10 bill on the sidewalk. I am too tired to pick it up.
- I spend time teaching the cat how to use a can opener so it can get its own food.
- I teach the dog to lick the stamps and envelopes of my outgoing mail.
- I ask for a fork instead of chopsticks when I'm in a Chinese restaurant.

- I'm too tired to lift my head, so my spouse always kisses me on the forehead.
- I press the "delete" button before I even read the Polio Digest.
- I now cook macaroni instead of spaghetti because I can't cope with the long, stringy, unmanageable pasta.
- I never buy shoes with laces any more - just slip-ons.
- Instead of taking half a day to do nothing, it now takes me all day to do nothing. *Added by Kathy* - and I have to rest up the next day from the exertion!
- I avoid drinking liquids so I won't have to clamber out of my recliner to go to the bathroom.
- I have learned a new way to wipe up spills - drop a towel on the floor and rub it over the spill with my foot. Then push it into a corner for someone else to pick up later.
- I only buy paper-back books.
- I use the magnet (for pain) to drop on the floor and pick up the paper clips I drop at work, so that I don't have to bend down to pick them up.
- I use a curved toilet brush to wash my back, honest... it's just the right shape and nearly like a loofah.
- I only buy non iron clothing.
- I use my walking stick to get items out of cupboards.
- I can shut my eyes and imagine myself back walking back downstairs to where I was so that I can remember what it was that I came upstairs for.
- I lay out my outfits for the week in advance so I don't have to make any early morning decisions.
- I wash my hair in the kitchen sink so I can rest my arms on the drainboards.
- I shop at the closer more expensive market rather than drive the few extra miles for better prices.
- When I count my change and drop some I just leave it there rather than try to pick it up.
- I wear winter gloves when pumping gas, (petrol) even in the summer because my hand gets so numb and cold.
- I decide to move to the desert so I never have to see snow, leaves or grass again!
- I turn down an invite to dinner at a Chinese restaurant because I know I'll fall asleep in their birds nest soup.
- I would rather eat nails than sit through the entire showing of Titanic!
- I tell my spouse or family and friends that they never have to worry what to get me for a gift - all I ever want are gift certificates for a massage!
- I decide to make myself a healthy breakfast - I prepare instant oatmeal and leave it to "set" a few minutes. I return at lunch time and realize it's still sitting there! (brain fog)

Isn't it great to know we are all doing these things TOGETHER.

Brain Fog - a term used by Polio Survivors to explain why they can't remember why they started a conversation or what the word they want to use is, yet have no problem telling you what it means.

Central Fatigue (Brain Fog) may affect some people at some times more severely than as described above, i.e. it may impact thought processes not just memory. For example, it's not just words that are forgotten but the ability to order your thoughts is reduced. LincsPPN Web Administration.

The above was started by Viola Pahl, with additions from Kathy, Jean and Abby.

Viola Pahl <violapahl@iname.com>

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INCREASED WEIGHT AND PPS

People who have PPS tend to move around less but perhaps eat the same amount of food as before not realizing of course that this puts on weight because less calories get burned up. With polio people, it is twice as hard to lose weight, get over illness, recuperate from illness etc., as it is for a normal person. This information came from my doctor and from my own personal experience. I used to be extremely active physically before PPS set in but then it hit me and I got scared and luckily did the correct thing of cutting back on activity. The only drawback of course was putting on extra weight. It is taking me a long time to get the pounds off me as I cannot exercise strenuously.

*Dagmar
birdman <birdman@CMC.NET>*

I was told to check suggested serving size...and then to put what I thought was that size of the item [like ½ cup of rice] on a plate. Then, measure out exactly the portion called for and put that on the plate. The comparison right there might surprise you. I'm not one to measure or weigh my food, but doing that for a week is an eye opener. I'm a bit too generous with my portions.

However, my problem is lack of incentive. found I have had to give up so many pleasures since PPS that eating good food is one of my few indulgences that I have left. I know I can maintain if not lose weight if I am very careful with what I eat. And yet I have such a hard time being disciplined enough to actually get results.

* THE NAKED TRUTH ABOUT DIETING *

A great way for us to lose weight is to eat naked in front of a mirror. That way restaurants will almost always throw you out before you can eat too much.

Can anyone speak Finnish?

Seppo Utriainen of the Finish Post Polio Association has sent us a copy of their 55 page magazine *Poliolehti*. It's all in Finnish. Anyone help? Thank you Seppo.

Tip for Leg Brace (calliper) wearers.

I wear a right long leg brace and it has never exactly opened by itself but before I had the leather knee joint guards put on the brace, my pants (trousers,) skirt etc., would keep it from catching all the way. I would not be aware of it and sometimes my brace would bend and I'll fall. After the guards were applied I don't have that problem now. I always listen for the "click" and if I don't hear it; I'll pull it again until I hear it. I've broken both feet in the past 5 years and can't be too careful.

Barbara Robinson
<brobin@network-one.com>

Surveys on Post Polio Syndrome

We have been sent some copies of three surveys from Medical Professionals in America. They relate to the incidence of anxiety and depression - osteoporosis - and for polio survivors still working. If any Polio Survivor would like copies, to be returned direct to the medical professionals themselves, then [ring or write](#).

The Twelve Gifts I Wish for you In this special season

and all the year through

Happiness. Deep down within.

Serenity. With each sunrise.

Success. In each facet of your life.

Family. Beside you.

Close and caring friends.

Health. Inside you.

Love. That never ends.

Special memories. Of all the yesterdays.

A bright today. With much to be thankful for.

A path. That leads to beautiful tomorrows.

Dreams. That do their best to come true.

Appreciation. Of all the wonderful things about you.

God bless you all.

Rev. Karen Utz - popette@mail.twd.net



Sylvia in Welling, Kent, UK dictated the following stories

Some 30 years ago my mum and I were invited to dinner at a friends house opposite to ours. It was winter and it had been snowing. They said dress up nice and we will do the main meal, you do the sweet.

Gateaux would be nice I thought and I spent £3.00 (US\$4.80), a fortune in those days, on ingredients. Four layers, cream and fruit in the layers and more cream and fruit on top. Licking my lips even thinking about it again. It looked wonderful. So mum and I were ready and off we set across the road. Dressed all posh in long skirts. Carefully does it across the road because of the snow, mum opens the gate and off I set up the path. Lynn and Rick have opened the door.... yes, you guessed, my legs gave way and down I went on my knees, and desperately I tried to save the gateaux, but splosh it went on the lawn.... the cream coming out sideways.... I called myself all the stupidest silly..... (that's the way I cope and then I get the giggles) Here I was in a long skirt with a wet bum... mouthing expletives, my mother standing behind me bless her heart, shocked at her daughter using this language.... Lynn and Rick were standing at front door howling with laughter and trying so hard to apologise for laughing but they said it was like watching a slow motion film.... and that the look on my face was unbelievable...

We managed to get two layers onto a plate and had this for sweet. We looked out later and the birds and a cat were having a wonderful meal, so my £3.00 was not all wasted.

Another time...

I was going to visit a friend but I had no car so I caught the bus to Erith in Kent. Picture the scene, a queue of folks just left work at the bus-stop opposite and an elderly gent passing by, cloth cap on head.

As I got off the bus my legs went, I went round in a circle and grabbed this poor old man pushing him to the ground and I ended up sitting on his shoulders. The bus conductor could not stop laughing, even though he was trying hard to keep a straight face. I could not get up, so the bus conductor got off the bus and lifted me off this poor old gent. Was he injured, angry, upset? He did not seem to be, all he kept saying was 'Where is my cap, I can't find my cap?' He must have been 60 and I was only 30 and all he was concerned about was his cap, not worried about the fact that I was sitting on top of him.

Another time...

Again a long time ago, well I am nearly 70 - oh and I don't feel 70, I still feel 21 in my head, but my polio surviving body some days makes me feel 90 - well, there I was waiting to cross the road, it was icy, and my work colleagues used to help me walk across the ice... well, there was this fellow and he was coming across the road towards me and (*she is laughing so much now that I can hardly type for laughing along with her*) and you know the sand dance, well that's what he looked as if he was doing. One leg forward, and one back, hands all over the place, trying desperately to save himself from falling. Well, I could not help laughing, he was nearly doing the splits and I laughed so much I wet myself. The two girls with me that were helping me across the road thought I was wicked, they were trying to help me and I dared to laugh at this poor man, they were so embarrassed. I was not laughing at him, but having a disability myself and having been in that situation many times, I was laughing with him.

Editors note. Sylvia has a sister in Minden, in the Haliburton Highlands, Ontario, and is going to visit her for a month later on this year. I mentioned this on the Internet that night and Marcia, Margaret and Elizabeth, all living in different areas of Ontario, hope to meet her and introduce her to many polio survivors. Sylvia can't wait to hear your stories and bring back photos and information.

Rosemary Burrows Does anyone remember me?

Rosemary Burrows, aged 5, Wymeswold near Loughborough, Leicester in 1947.... think it was the Summer of 1947 that I contracted polio and went into Harlow Wood. I had my left leg affected and remember having a bandage tied to my foot and I was supposed to be moving it a lot, but I got tired of doing it. I would love to correspond with anyone from that area, or who went to Harlow Wood as I can't remember much at all and I would love and value someone else's impressions.

Me now, well I am married to Rolland Roy and I now live in Victoria, British Columbia, Canada and I am now aged 56. I had to give up work in 1990 due to fatigue and increasing weakness, now happening in my arms and "good" leg.

Rosemary rroy@islandnet.com

Suzanne Rourke, Cairns, Australia.

I am so pleased to have been able to get in contact with you all. In less than 1 week feel like I have made firm friendships I never would have believed possible. Thank God for this wonderful Internet invention, and for all you caring PPS people. Life is going to be so much more enjoyable now we have contact outside our group. In Cairns we are virtually isolated from the rest of Australia. Now we can converse with South Africa, the U.K., the States and the rest of the world. Its mind boggling, though a very comforting feeling. I would just like to say a very warm hello from David and Lois, 'Ned' Kelly and his wife, Margaret, Cynthia, Cheryl and from the rest of our Nth. Far Queensland group. Am looking forward to communicating with you all.

suzie97@cairns.net.au

My visit to the UK - John Bennett

I rented a Toyota Corolla from Wheelchair Travel in Guildford, Trevor Pollitt (wheelchair.travel@cableol.co.uk), for the period 4 Sept.- 18 Sept. The charge was £578 for 14 days, + £28 for delivery at a hotel near Heathrow on the 4th, + £28 for return including a ride to Heathrow on the 18th. This is expensive compared to the normal Hertz rental, but Hertz (or other agencies we checked) no longer rent cars with hand controls in the UK (though they and all the other agencies do in the US.) There was no mileage charge for the 1600 miles we drove, though we

paid for petrol (a substantial expense). The car was fine, and the service was good.

We read about accommodations and B&B's in the book "*Accessible Holidays in the British Isles*" (ordered by fax from *Holiday Care*). Given our itinerary, we stayed for the most part at [Travel Inns](#) and occasionally at Travel Lodges. Both chains have rooms that are generally well set up for wheelchair access.

We were able to make reservations and enjoyed staying at the Scatterbrook Farm, Hinam Cross, Dulverton, [Somerset](#) for three nights (p. 261 in the book). The roads up steep hills from Dulverton are not for the faint of heart (paved, one lane, no room to pass for the most part), but Jill and Harry Aldridge are friendly and accommodating hosts. I used the accessible shower. The house is on a power generator that shuts off at about 10pm (battery operated bedside lights), so (as the guide books say), "check for special arrangements before booking" if there are such requirements.

I am a fan of restored steam railroads, and we rode the West Somerset at Bishop Ledard and the [Bluebell](#) at Sheffield Park. Both lines were wheelchair accessible, and the personnel were friendly and helpful. We also visited abbeys and cathedrals at Tewkesbury, [Hereford](#), Gloucester, Exeter, Salisbury, [Winchester](#), and Canterbury. They were (for the most part) accessible, and people were helpful with parking and with finding the way around.

At the [Greenwich Maritime Museum](#) in East London the lift to the store was in operation, but the lift to the museum itself was unfortunately out of order. We found the [Victoria and Albert](#) quite accessible.

It was a great trip, and thanks for your suggestions that assisted our planning. If I could look up things here via email messages, I would be happy to see if I could assist people from the UK with information on access in our area.

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Why We Can't Get Any Better - Jon Schoen, Polio Survivor

Science is dumfounded. Age, depression, fatigue and the inability to find solutions, is bringing our improvement to a standstill. It is a much larger picture than we want to admit. The uphill battle is beyond our single minded conception. This is the ultimate form of denial, that we just can't change things. Education has always been the answer, since the industrial revolution. We are retarded in the confines of age and endurance. Hobbled bodies may never improve and the odds are they'll worsen. We are not equal in this battle for the strong to come to our aid, so intelligence will prevail. With the resources spread so thin, the weakest will suffer intensely, because the powerful minds don't look back. Does this all seem negative and irrational? Well it is and it isn't. For the individual with faith in a higher power, looking over us, it's fact and reality. For those with no faith in a higher power, you have to certainly deny these facts and call them irrational.

PPS people have 'A' personalities, which is counter productive to pacing, resting, learning and peace of mind. Here is one list of characteristics found at the Strong Institute web site:

http://ourworld.compuserve.com/homepages/strong_nlp/STRESS.HTM#person

The above site no longer exists at the specified server. LincsPPN WebAdministration - 9th January 1999

Could you be the 'A' Type personality?

1. Move, walk, eat rapidly....
2. Hurry others when they are talking.....

3. Impatient in traffic, restaurants, queues, laborious tasks.....
4. Feel guilty when you relax.....
5. Challenge anyone else who is competitive.....
6. Work to very tight schedules.....
7. Often do more than two things at once.....
8. Complete others' sentences.....
9. Impatient when rare events happen....
10. Take over conversations.....
11. Frequently pound table or hand to make a point.....
12. Belief that success is dependent on you getting more done faster.....
13. Often clench your jaw or grit your teeth.....
14. Fear of failure.....
15. So busy accumulating, no time to just be.....
16. Judge yourself and others by accomplishments rather than personality traits.....
17. Emphasis on key words in your sentences.....
18. Evaluate your accomplishments and those of others in numerical terms.....
19. Inability to accept limiting personal defects or emotional problems.....
20. Take over others' work because they are not completing the tasks fast enough.....

This is one thing PPS people have control over, the ability to change. Type'A' behaviour will bring us to the mercy of Post Polio Syndrome at such an accelerated rate, we can't imagine, rendering us useless to our family and support circle. We all know the answer. How many times do we tell others to slow down, pace, rest and be good to our inner selves? Why can't we seem to do it for ourselves? One reason, it is terribly hard to give up control. We feel this is all we have in a complicated, competitive society. Our thoughts are:- if the glass ceiling isn't broken today, I will never have a chance. Maybe one more push, with all my possible strength, will break through the confines of Polio.

In our process to keep this control, unconsciously we hurt others, who should be partners in conquering a dragons hold. Rather it be an overbearing desire to show our capabilities, or isolation into small groups critical of the disconcerted selves who want answers now.

We do things many people impose on the weak, like isolating the less intelligent and make judgements of emotional character. Patience is not a virtue, so mainstreaming anyone with less than tolerable finites is difficult. In simple terms, our nerves are shot, so we can't allow the childlike into our circle. We form groups of closed minds to the very ones we should hold up and give the most care to.

I am guilty. My simple desire for recognition and love makes me do things that keep people down, not recognizing the wearing of my soul into disconnection of human needs. The fact I may be more creative, or intelligent than others, gives me pride of superiority. Not being as smart as others, especially the young, mentally strong, makes me hateful and depressed. The mere fact that time worries and controls me, makes my body hurt more than it would. Muscles tense at the thought of the work before me. Fatigue sets in, before I can start the battle to a material security, which doesn't even exist.

This is the double edged sword we have to live with. Wanting more than the average person to succeed, but nerve endings, muscles, minds and endurance that couldn't possibly be competitive. If I only see these things, accept them, let god take control and hold out my hand to those brothers and sisters who need what I can offer, then I am more fortunate than any Totally Abled Bodied Person alive. I am very lucky, being forced by a terrible disease to see how salvation can be achieved. Looking deep into myself and others, I can find the good souls shine through. Giving up the need to criticize my family and friends can be a relief. Forgiving the worst of PPS emotional reactions is freedom for the hidden mind.

Could it be we are asking for the wrong thing, in wanting a haven away from stress and difficulties?

Is it possible the haven, peace and solitude is right in front of me? Letting my mind be free to enjoy the good in others could just be the answer. This is not me today. I am compelled to lash out, again, at those who seem to thrive on domination and hurt. If there isn't pain, many look for it, like it's a habit of mental need. It can be like a daily fix, for finding trouble, before it finds us. We want to root out evil, even if it doesn't exist. Compelled to get even, for the oral and mental lambasting impuned upon us, feeds hate. Eventually we need to feed this desire, increasing our pain, confusing ourselves worse, obscuring any good in others whatsoever and sapping what little energy left in not so pretty bodies.

To achieve half of the cure for PPS, it doesn't cost a dime. When many of us get better, we can pull the others up. With clear minds the battle can be won, not through blind fighting, but personality changes. There is a good chance many have had so few kind words, the light will scare us back into ourselves.

We are certainly not the first people facing such challenges. History is fascinating to look at, but god knows we wouldn't want to be there. With a higher power taking care of the things keeping us apart, we can grow for each other. Let go, it's the only way.

Jon A. Schoen



My memories of the day that London was silent - 6.9.97.

I was in the Lane Fox Unit at St. Thomas Hospital on the day of Princess Diana's funeral and I have never experienced anything like it before in my life.

The Lane Fox Unit is right by Westminster Bridge Road and the Houses of Parliament and the silence in London was incredible. You could actually feel the silence. It was so... I cannot describe the feeling, it was uncanny, all we could hear was the birds singing..... it was tangible. It affected everyone. You could see people walking across the bridge but you could hear nothing. Even the river seemed as if it knew, you couldn't even hear the lapping of the waters of the River Thames. Our whole unit was in silence. When the nurses came on duty, they whispered as they spoke. They told of stations closed, and no trains, and London so full of people yet so quiet, and the sadness and the silence. The hospital had few visitors and those that came whispered too.

I was not able to go to the route of the funeral but experiencing this really made sure that we were part of it. A day in my Polio life that I will remember forever.

P.S. I am a young 69 with a body that still wants to be 21 when PPS will let it. I am still involved in many voluntary projects and would love to hear from other Polio Survivors in my age range, which means anyone. Being able to talk to other polio survivors is the best medicine I have found for PPS, it really lightens the load. I am not alone anymore.

Sylvia Fortune, Welling, Kent.



[Computer CD on Post Polio Syndrome](#) available from the

[Gazette International Networking Institute \(G.I.N.I.\)](#)

co-ordinator of the International Polio Network

and the International Ventilator Users Network

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**Annual General Meeting - Details still being finalised for April.
Members will be notified by post shortly.**



**LINCOLNSHIRE POST-POLIO NETWORK
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