The Lincolnshire Post-Polio Network

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Reception | Library | Networking | Directory | What's New?

The LincPIN

The Lincolnshire Post-Polio Information Newsletter
Volume 2 - Issue No. 9 - February 2000

CONTENTS

Online Reading Navigation Tip - Selecting Cathedral logo will return you to the above contents.

Editorial by Hilary Hallam

Another Year, Decade, Century and Millennium all thrown into one. It's now the year 2000 and 125 years since Polio's late effects was first noted in 1875 in French medical literature Gaz. Med. (Paris) 4: 127-129 and 225-226. Over the last four years we have written numerous letters to the Colleges of Medicine, the Department of Health, the National Health Service Executive, the local Health Authority and have made representation through our MP Gillian Merron to the Ministers of Health and Social Security requesting that the awareness of Polio's late effects is disseminated to all health and benefits professionals.

These are just some of the comments received by letter or phone over the last two months. Why?

- My GP and two Consultants say there is no such thing as PPS.
- My GP has been told there is no treatment for PPS so no need to assess me.
- My neurologist has told my GP, PPS is such that you deteriorate and then you usually stabilise.
- My GP has said there is no NHS money to give you a multi-disciplinary assessment.
- My GP has told me "I don't know anything about polio and its late effects. I will try and find someone who does."
- I failed to gain any more points at my Tribunal for the All at Work Test. I have been medically retired from my job due to my PPS and have full medical reports about my condition. Why do I have to take on extra stress to appeal again?
- I have been granted DLA full mobility but no care component. I have been falling more and more in recent months and functionally the decline in my abilities in the home is considerable and I told the doctor who visited all this. Why have I not been granted any care component?

The amount of our taxes being wasted is still growing. Wasted on inappropriate health appointments, benefits appeals and tribunals. Our health is deteriorating and the stress being put on us is making us worse than necessary. All this could be drastically reduced if the Colleges of Medicine ensured that all new students have a much longer and more detailed lecture on polio and its late effects and provided continuing education to those already qualified and the Government ensured that fuller information on our condition was sent to all Health, Social Services and Social Security personnel. We are working hard with what energy we have to ensure that drastic changes take place this year. Your support is essential. Those in power do not have time to read long letters, but why not write a single A4 page letter to your M.P. itemising the biggest problems you have had in getting appropriate medical help and benefits. Send a copy to us and a copy to Gillian Merron MP for Lincoln.

The next **Lincolnshire Neuroscience's Forum** meeting is on February 10th and we have had added to the agenda the urgent need for the awareness of polio and its late effects to be immediately issued to all health professionals working in the Lincolnshire Health Authority. Why? Our own Chairperson Christine Ayre has been in Lincoln Hospital during January and she rang to say, *'please come and visit me but don't bring flowers or fruit - bring medical articles on PPS'*. It is two and a half years since we approached Lincolnshire Health Authority with our concerns that health professionals were unaware of our condition, and still we have health professionals treating patients saying, *'I know nothing about polio and its late effects. Have you got something I can read?'* Lynn Hobday and I will be attending.

HealthinFocus (http://www.healthinfocus.co.uk/) are hosting a conference in London at the Royal College of Physicians - **'Patient Empowerment in the Digital Age'** on Wednesday 23rd February 2000. "This ground-breaking debate is aimed at bringing the burning issues of patient empowerment, and in particular, the use of the Internet for health information, into the public forum. Indeed, the Government has recently targeted the Internet as a key area in its healthcare strategy." The Keynote speaker is Dr. Liam Fox, the Shadow Health Secretary. Len Van Zyl and I will be attending.

GINI International Polio Conference, June 8 - 10th 2000, in St. Louis, Missouri, U.S.A. (See page 21 for more information). I am doing a 12 minute summary on "Assessing Our Activities to Effectively Manage Our Lives" on June 8th and the full talk on the 10th June assisted by Richard Boone. Any contributions towards the cost of this trip would be greatly appreciated. **Peter Jay who is a Welfare Visitor for the British Polio Fellowship** is also speaking on 10th June on Self Management of Chronic Conditions. He is also a member of the Lincolnshire Post-Polio Network.

Sufferers of Iatrogenic Neglect S.I.N.

S.I.N. or Sufferers of Iatrogenic Neglect is a pioneering UK organisation which is concerened about iatrogenic suffering. This is any suffering which is medically induced. This suffering relates to any disorders, symptoms etc. caused inapropriately by any clinician through his/her diagnosis, manner or treatment. The group recognises that medical care within the NHS is of the highest standard to the majority, but unfortunately, mistakes and poor practice do occur. It is the failure to have these matters impartially addressed and the isolation of individual complainants that have prompted the setting up of S.I.N.

S.I.N. believe that the present procedures are biased against the complainant, and structured to protect the medical profession. The NHS Complaints Procedures urgently need restructuring. At present the Health Service Commissioner can refuse to investigate complaints which are within the time limits and his jurisdiction. There is no right of appeal against the HSC's decision. The group believes that no person should have this arbitrary power which is clearly open to abuse. It is the view of many complainants that the Health Ombudsman is not impartial and fails to implement his powers to ensure quality control within the NHS. This is demonstrated by present statistics. At present there is nothing to deter health professionals from covering up medical mistakes.

S.I.N. believes that,

- there should be an Independent Statutory Authority, set up by the Government, which is given the power to fully investigate complaints within the N.H.S. They believe this authority should also be given the power to take disciplinary action against Doctors and any Health Professionals who fail to fully cooperate, and/or mislead, during the course of investigation. History has shown that self-regulation does not and cannot work!
- Health professionals should be made accountable when mistakes occur. The time has come for the medical profession to learn from mistakes and to stop the accepted culture of cover-up, which currently exists within the NHS and Government.
- A mechanism should be introduced within the NHS to protect patients who complain and/or request a second opinion. There is evidence that complainants are discriminated against by the medical profession when they require subsequent medical treatment. In some cases there is evidence that doctors subsequently deny patients appropriate treatment to coverup their colleagues' incompetence and/or negligent mistakes.

- There should be a change in the law that currently allows doctors to mislead and lie to the relatives of patients who die whilst receiving medical treatment. In response to this judgement, Dr. Brian Goss of the B.M.A. stated "GP's could now put a gloss on the cause of death without fear of litigation."
- There is much concern regarding the securing of medical records. The 1990 Access to Health Records Act is frequently breached by GP's, Health Authorities and Trusts, with no course of redress. Members have experienced long delays. When medical records are finally received, there is on occasion, documents missing, and/or which appear to have been altered. Invariably these documents refer to the incident which gave rise to the complaint, and always place the doctor in a better light. Any subsequent inquiry will accept these notes as being written contemporaneously, and it is almost impossible to prove otherwise. However, some of the group members have secured evidence (some forensic) which support these serious allegations. There is also evidence that, on occasion, additions are made to the medical records to maliciously discredit the complainant. What is needed forthwith is a mechanism which gives automatic and immediate access to health records. Although this may not eradicate the problem, it would certainly make it far more difficult for doctors to alter medical records, to avoid the consequences of their incompetence and/or neglect. This is why S.I.N. believes that medical records should be available after any consultation on request. This would also ensure that genuine mistakes and inaccurate information would not be propagated.
- S.I.N requests that the Department of Health introduces a system by which individual investigating authorities are obliged to compile a list of names and contact details of consenting complainants. This would facilitate communication between individual complainants.

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Post Polio Syndrome
What Does It Mean Orthotically?

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What is post polio syndrome? This becomes a complex question that may have many answers depending on the specifics of a patient's complaints and problems. There was a time that some feared the dreaded disease was coming back and that it would cause additional paralysis in what muscles were left. These issues puzzled patients and physicians alike. Many physicians practicing today have not had the experience of working with the polio population, as many polio patients have been stable for some time. However, after many years of use, muscles and joints seem to be screaming out, "I've had enough, I need relief, I need some rest!" These symptoms consisting of muscle and joint pain come from different parts of the body depending on the affected areas.

First of all, we need to describe exactly what polio is. After entering the body through the gastro-intestinal tract and an incubation period of two weeks, the virus attacks the anterior horn cell of the spinal cord or the brainstem *(1)*. The ventral root, which synapses with a motor nerve, is damaged to the point that it is unable to send messages to the muscle cell through the terminal axon sprouts. This lack of innervation causes muscle weakness or paralysis. If enough damage is done, partial or total paralysis of the lower or upper limbs will result as well as complications and paralysis of the respiratory system. It is believed that some of the terminal axon sprouts are able to branch out to muscle cells, which have been affected and help in innervation. *(2)*. This will allow function of the muscle cell however, that particular muscle probably will be much weaker than a normal group of cell innervation.

There are five main stages of polio. These consist of a prodromal phase lasting two days, an acute illness lasting approximately two months, a recovery or convalescence period lasting up to two years, a stable disability or stage of chronicity and then a post polio syndrome *(3), (4)* which includes symptoms of muscle pain, joint pain fatigue accompanied by additional weakness and atrophy of muscle tissue. Usually the stage of stable disability lasts for 20 to 30 years. These chronic disabilities become increasingly challenging for polio patients trying to keep up a normal pace. The exacerbation of symptoms of the polio patient is classified as "Post Polio Syndrome", a condition composing of a "...cluster of symptoms in individuals who had paralytic polio many years earlier" *(5)*.

From a survey conducted in 1987 by the National Commission on Health Statistics, there were 1.63 million polio survivors with 641,000 having some type of paralysis *(6)*. If you divide this by the approximately 1,000 ABC facilities, there are about 600 patients per facility who will need some manner of care. Even if this number were cut in half, there would still be a substantial population for each facility. A recent problem that has arisen from this group is that many of them who require orthotic care have felt reluctant to confide in their orthotist. Many orthotic professionals have told them that they (polio patients) are hard to deal with, they are set in their ways and take a considerable amount of time to provide care. The orthotic profession must be careful not to prejudge these patients as all difficult type "A" personalities *(7)*. Many of them have expressed offense as they have shared their feeling in the many seminars and support groups which I have had the privilege of presenting. We as professional practitioners, need to take the time to listen and to properly evaluate these patient's conditions. It is imperative that orthotic practitioners become familiar with the polio patient's history. Practitioners need to understand exactly what they are dealing with. Polio survivors are the type of patients that practitioners need to evaluate hands on and to know "first hand" the muscle weakness and range of motion and how the patient is substituting for the weakness to be able to function.

The polio patient is the most important member of his/her rehabilitation team. He/she must be allowed to assist in the design of the orthosis. He/she needs to understand that orthotic practitioners are not sentencing them to 24-hour orthotic wear but are trying to provide a system that will protect and stabilize. Be flexible with these patients. Leave options in the treatment plan. Provide patients with a choice and lead them in the right direction. Let them know that your abilities and expertise can help eliminate unwanted range of motion and allow for a more normal function. By all means, don't lock their joints unless you absolutely have to. If you do, you may find that your carefully designed orthosis will end up in their closet, not because of your design, but because you have taken away from them the simple motions that they use to substitute for muscle weakness and joint deformity.

When assessing a post polio orthotic patient, consider all design options, which are available. Some of these options may be a combination of two or more orthotic designs. For example, you may have a patient that needs additional knee stability due to weakened quadriceps but is unable to tolerate the weight of conventional designs. One idea is to provide a hybrid orthosis consisting of a leaf spring design orthosis with a pre-tibial shell which provides minimum quadricep support and give just enough feedback to prevent the knee from buckling. Younger and stronger patients [40-60] can accept more aggressive designs and seem to have a willingness to try harder in allowing time for adjustment to new designs. They seem to have a better understanding of what the intended outcome is and will work to make it happen if possible. Older polio ambulatory [60-75] are often more complicated due to additional muscle and joint fatigue. They seem to be more apprehensive about change. Orthotic practitioners need to realize that these older patients have experienced much in dealing with past orthotic challenges. These patients need to lead the way in their orthotic care and are the ones who need options to choose from. Elderly ambulators [75+] usually need lightweight orthoses. They want little change and practitioner listening skills need to be especially keen for this group. You must let these elderly patients know that you care about them and you also must learn to take their criticism with a smile.

What drives many of these patients to their physicians and eventually to orthotic facilities is pain. Polio patients with post polio syndrome will have pain. There is a reason for this pain. Pain is good: it is a tool by which a patient can be protected from further damage if he/she respects it *(8)*. Pain is the, "Personal Awareness of Internal Notification" system. It is important to identify the source of the pain. Orthotic professionals need to focus on the musculoskeletal issues. If possible, joints need to be protected to prevent further damage while allowing the patient to continue to have mobility. By providing stability and more normal biomechanical function, joint destruction and muscle fatigue and stress can be reduced.

Many new and amazing materials are becoming available to orthotic professionals. This allows for lighter and stronger orthotic designs. New techniques are also available through modern technology by surgeons. Some joint deformities can now be improved dramatically, relieving stress and pain around joints and surrounding tissue. Keep your polio patients informed and don't be afraid of the challenges. Many of you have been trained professionally to handle these types of conditions. Please remember that your area of expertise is greatly needed and polio survivors will be relying more on your professional services.

Reference:

1. Atlas of Orthotics, Second Edition, The C.V. Mosby Company, 1955:94.
2. Halstead, LS. Managing Post Polio: A guide to living well with Post-Polio syndrome. Washington, D.C. NRH Press, 1998:9. **[Lincolnshire Library Book Catalogue]**
3. Salter, RB. Testbook of disorders and injuries of the musculoskeletal system. Baltimore, Md. Williams & Williams, 1982:266.
4. Halstead, LS. Opcit, 5.
5. IBID, 7.
6. IBID, 11.
7. Halstead, LS & Grimby. Post-Polio Syndrome, Philadelphia. Hanley & Belfus, Inc. 1994:179.
8. Halstead, LS. Opcit, 122.

Update on members using Ambroise UK Limited orthoses.

Len - I went to see Professor Heatley at Lane Fox Unit, St. Thomas Hospital and he watched me walk with and without my Utx swing. He was very impressed with the difference in my walking.

Hilary - I went back to the Orthotic Department at Lincoln Hospital and mentioned that I was surprised at the difference it had made to my gait and walking. The comment back was "So are we." The support it gives me allows me to walk upright again and without a cane. I can go up slopes easily, but down even slight slopes is still difficult. I cannot stand for any longer without needing to hold on. I cannot walk much further in distance but the benefits of walking normally to my total wellbeing are terrific.

Elizabeth - It's brilliant. I could not stand at all without leaning on crutches and now I just carry a cane in case it locks. My daughter said "In all my life I have never seen my mother stand up straight like that." I feel like a different woman and my partner can hold either hand when we go out.

Wonderful.

These orthoses will not help all Polio Survivors.

October 2005 Update. The UK supplier for UTX is RSLSteeper and their web site has full details of the UTX. According to their web site "for information on our range of orthotic services and products, please contact Mark Tomlinson on 0113 2070435 or email mark.tomlinson@rslsteeper.com". The Dutch manufacturer's web site can be found here (primarily Dutch language).

1. Have you heard about the revolutionary new callipers now available in the UK? **[LincPIN Volume 2 - Issue No. 8 - December 1999]**
2. Len's Story. **[LincPIN Volume 2 - Issue No. 8 - December 1999]**

Polio Biology by Eddie Bollenbach, M.A. Biology.

Eddie Bollenbach has been a long time and valued contributor to several post-polio mailing lists. He is especially noted for his knowledge and skill at communicating the current scientific understanding of the biology and biochemistry of viruses and other scientific topics relating to polio and post-polio conditions. He also keeps a watching eye on developments in scientific research, in particular their potential for opening new lines of investigation that may in the long term increase our understanding of the biological mechanisms underlying polio and post-polio conditions. Eddie has kindly agreed to write an occasional column for the Lincolnshire Post-Polio Library for which we are most grateful bearing in mind his teaching commitments as Professor of Biology at Northwestern Connecticut Community-Technical College.

Non Professional History - Paralytic Polio in May of 1954 at age 7 (was a control (placebo) for Salk vaccine a month earlier in April). Athletic Lifestyle from 1964-1982: Swimming, Cycling, Cross Country Skiing etc. 1982 Post Polio Syndrome. Currently use a motorized scooter for mobility and an adapted van for travel.

- Polio Biology I - An Introduction to the Virus 22nd August 1998.
- Polio Biology II - Post-Polio Syndrome's Elusive Etiology 3rd January 1999.
- Polio Biology III - What About If We Need The Virus Later? 23rd April 1999.
- Polio Biology IV - Polio And Limiting Variables 20th May 1999.
- Polio Biology V - How To Avoid Limiting Variables While Exercising 4th August 1999.
- Polio Biology VI - The Polio War and Vaccine Strategy 6th August 1999.
- Polio Biology VII - Holistic Polio 17th October 1999.
- Polio Biology VIII - Post-Polio Pathogenesis 27th November 1999.
- Polio Biology IX - Peering at Post-Polio Syndrome under the Microscope 25th January 2000.

For the complete list of Eddie's Polio Biology articles including links to recent additions see the Polio Biology Catalogue in the Lincolnshire Post-Polio Library.

N.B. Eddie Bollenbach is also co-author with Marcia Falconer, Ph.D. Non-Paralytic Polio and PPS.

They have also recently compiled a questionairre (50 questions). They are hoping for 1000 plus to be filled in and from around the World. If you would like a copy contact the Office or online got to http://www.angelfire.com/mi/nccc/PoSurvey.htm

Polio Biology IX - Peering at Post-Polio Syndrome under the Microscope

The Microscope is an instrument that revolutionized the study of biology. Before it existed everyone believed the human body was only composed of amorphous flesh. After Galileo and Janssen, the simultaneous inventors of the earliest microscopes at the beginning of the 17th Century, we knew that we were composed of tiny structures called cells. The human body contains about 10 trillion cells, small circumscribed entities with an organized internal anatomy and a complicated biochemistry. These parts together are the essence of life.

In human beings there are cells of many different types. For our purposes we will concern ourselves with just two of the types of cells that are affected, both acutely and persistently by polio: motor nerve cells and, secondarily, striated muscle cells.

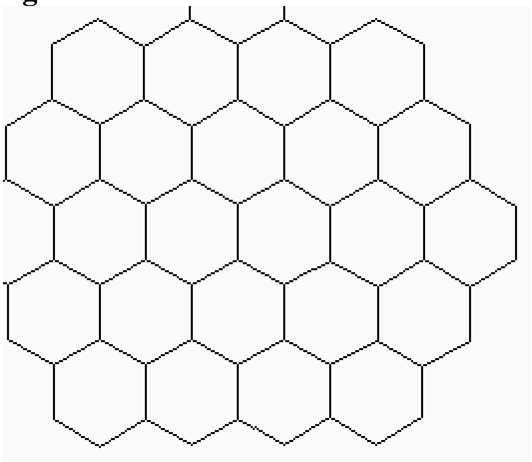
A fairly accurate mental picture of a motor nerve cell can be conjured up by imagining a tree uprooted and cleaned of soil from its roots. The roots of our cell are called dendrites and they would be located inside the spinal cord. Each rootlet would be connected to the branches of another nerve cell above it. Our motor neuron has a branch coming extremely close to a muscle fiber (a long thin cell that can contract (shorten) and elongate).

Picture one nerve cell with 1000 branches, each branch of the cell innervates a single striated muscle fiber. If you can do this you are imagining a "giant motor unit" which is often alluded to in the polio literature. Giant motor units result after acute polio when muscle fibers lose their connection to a branch because the whole tree (nerve cell) dies. Surviving neurons grow extra branches and connect in the process of recovery from polio damage. This giant motor unit consists of a motor nerve connected by end fibers (branches) to 1000 muscle fibers.

When an EMG is performed the technician can tell if muscle fibers are all part of the same motor unit (if there are giant motor units). When the nerve fires, all the muscle fibers connected to it by its end fibers (branches) also fire synchronously. This will show a characteristic pattern recognizable in the EMG.

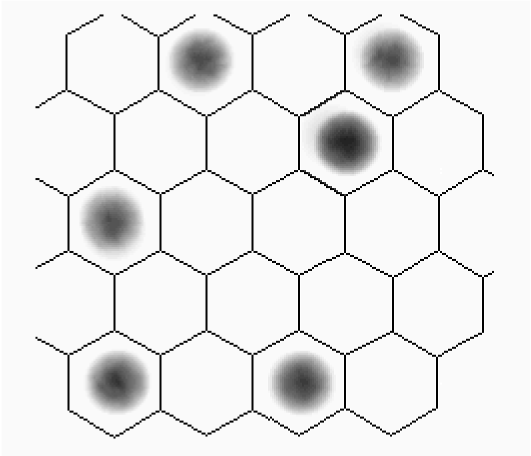
Striated muscle fibers are encased in bundles. I've tried to draw a representation of a group of striated muscle fibers below, although they are not as uniform in shape as my diagram implies. Some are round, some oval, some angular and so on. Anyway, I thought I could make a couple of interesting points about how polio, and post polio syndrome, affect the muscle fibers using these diagrams.

Figure 1.



On the left we have a cross section of a bundle of normal muscle fibers. For the sake of understanding polio we'll suppose that all of them are innervated by healthy nerve cells and are part of the same motor unit. In an individual with Amyotrophic Lateral Sclerosis the entire bundle dies sparing no fibers because the entire nerve cell dies with all of its branches (the entire motor unit.)

Figure 2.



To the left we have a diagram of a muscle bundle but notice that individual fibers (dark centers) are dropping out. It is significant that the entire bundle, with all fibers, is not dying but only a few scattered fibers. This is characteristic of post-polio syndrome under the microscope. It suggests the nerve cell is not dying but rather end fibers are degenerating. It is possible that the fibers dying here could be picked up and reinnervated by another nerve, creating an even bigger giant motor unit. This process is ongoing in patients who have had polio with giant motor units getting bigger and bigger. When a real big one reaches the threshold of cellular exhaustion an entire muscle bundle may die.
At times, under the microscope, muscle biopsies of PPS patients show the loss of entire groups of fibers as happens in ALS. However, in ALS this is the rule while in PPS it is rare. I should add here that the warning against overuse is to spare the muscles and not the neurons. In polio biopsies muscle fibers sometimes appear abnormal with internal nuclei and a ragged shape. These microscopic muscle fiber features are probably due to fewer fibers, because of loss of nerve branches, working harder to maintain function.

Obviously the loss of muscle fibers is the result of stress on the motor nerve (our tree mentioned by analogy earlier). There is the obvious stress of age changes limiting new sprouting and shifting the dynamic compensation mechanism where denervation and reinnervation continue with the advantage tipping toward loss of nerve branches. And we now know that there is a lot of inflammation in the spinal cords of people who had polio. There are infiltrates of lymphocytes (white blood cells which mediate cellular immunity) and also anti-polio antibodies. Poliovirus RNA has even been found in PPS spinal cords. Obviously all of this is stressing the giant motor units we were left with after recovery from polio. These recent microscopic and ultra-microscopically derived facts still leave us with a mystery: is it one cause or many causes which result in our plight. I believe many.

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Lincolnshire Post-Polio Library - Copy of above article with links to referenced full text and abstracts where available.

Post-Polio Syndrome
From learning it exists through to better managing your life.

You have been having various symptoms of pain in joints and muscles, weakness, fatigue, functional decline etc. for a few years. You have either had no firm diagnosis or been given one like M.E. but you don't feel you fit in with others with the same diagnosis. Then you read a letter or article in a newspaper that there are late effects of having had polio in ones earlier life. The story told and the symptoms mentioned are similar to what you have been experiencing. You start to wonder could this be what is wrong with me? You had polio, or a family member had polio. [One of our members was in a class of 10 where three had paralytic polio - she was never told she had polio, but blood tests have revealed type 1 polio]. What should you do next? [N.B.You cannot have Post-Polio Syndrome if you did not have nerve damage from one of the three Polio viruses.]

The first step is to learn more about the condition. Contact us and the British Polio Fellowship and read through what is sent to you.

You might think the second step is to talk to your GP, actually that is your third step. **Your second step** is to start making a profile of your life. You need a long version for your own use, that you can use to relate back to when asked questions, and a short potted version. You cannot approach busy GP's with armfuls of medical articles that they do not have time to read and expect them to absorb all you want to say in ten minutes. Remember the health professional you are seeing now is probably only seeing you as you are now. He has not seen all you have achieved in your life.

Our Information Pack for many months has included some suggested charts. We suggest that you make up

1. A Time-Line of Your Life colouring in bodies which provides a visual impact of where you had and have problems.
2. An A4 page on yourself that matches those set of diagrams and
3. Our blue leaflet and
4. a good medical article on Polio's late effects.

Your GP will not have time to read your A4 sheet, leaflet or medical article in the ten minutes, so be prepared to offer to come back in a weeks time.

The third step - the visit to your GP. Suggested approach on the lines of *"As you know I have been having problems for some time which we have not been able to put a name to. I have just found out that there is a condition called the Late Effects of Polio/Post Polio Syndrome. I have brought you some literature that you might not have seen about the condition, and have made up this diagram of my life and problems.*

I wonder if my symptoms could be related to the fact that I had polio / my brother had polio / ______. You will see that I had polio / was ill in bed for weeks and could not do sports / ______. I recovered well and did ______ (list qualifications, and sports) and have had no problems till ______ (e.g. five years ago), when I started to have problems as in this diagram. (Mention at least one good example of very evident changes, like up to five years ago I could walk up stairs in a normal fashion, then I realised I was going up one step at a time, and in the last year have had to pull myself up with my arm and restrict the number of times to cut down pain and fatigue).

I gather from the information I have read that PPS is by diagnosis of exclusion and just because I had polio it does not mean every symptom I get is PPS. I do appreciate that I can have other conditions instead of or as well as PPS. Would it be possible for me to come back next week when you have had time to look at this?"

The fourth step which ties in with the second step is that now you have started to look at your life, you must look at exactly how you are doing daily activities. Stop the next time you go to walk upstairs, or get out of a chair, or make a meal, and write down how you are doing each task. You may not have realised you have changed the way you do it. Following Polio we learned substitution of muscles. If we could not do a task one way, then other muscles came into play to help us achieve. Your body has not forgotten this and continually adapts.

The fifth step is what can you do to help yourself whilst you wait for the appointments, tests, diagnosis, advice and treatment. It does not matter what label or how many labels are placed on your symptoms. At the end you can start to make your life more manageable from Day 1. *"Change my lifestyle? What me? Change from being a strong willed, very capable, determined, 'don't need any help thank-you I can manage' (pushing someone aside to move a 56lb sack of spuds) person"* I hear you say. How many Polio Survivors reading this will relate to that statement, and how many carers will say "you have described them perfectly"? There is much you can do. To give you an example what follows is the story of my PPS journey.

How I learned that there were Late Effects of Polio.

In May 1995 I was at the Rotary Disabled Games in Lincoln and heard the comment 'I use a ventilator because I am an old polio.' I thought gulped and said, 'I am an old polio.' 'Oh were you in an iron lung, because if you were then you can get breathing problems in later life.' Big sigh of relief from me. I had waist down paralysis in 1952 but was not in an Iron Lung. There I left it, but filed it away at the back of my mind.

In September '95 - six months into new problems - I had an appointment with an Orthopaedic consultant. He was running late and we had little time to talk. Come back in two weeks for the x-rays. So I wrote a letter to him with more information in it ending it with, 'Does being an old polio have anything to do with this?' X-rays revealed nothing so he sent me for an MRI.

On November 23rd 1995 I went for the results of the MRI scan and saw a different locum Consultant. Without looking up at me he said 'I am glad you are better.' [The results to my MRI scan were essentially normal.] He was a bit stunned when I told him that 'I was not better.' 'I have continued to deteriorate over the last nine months despite adhering to the advice to exercise daily and build on it. I had polio as a child has that got anything to do with this?' He started to look through my file and then turned to me and said, 'There is something called the Late Effects of Polio but I know little about it. I had another patient presenting the same as yourself at my previous hospital. I referred him to a neurologist and will do the same for you.'

I left his consulting rooms and went straight to the Hospital Library and asked for information on the Late Effects of Polio. All that could be found was the old address of the British Polio Fellowship. I did not even know they existed. (The Librarian searched for me some days later on Post Polio Syndrome producing many more article abstracts). I was advised to go to the Health Information Service. There I was given two newspaper articles. GP Newsletter November 1992, Polio returns to haunt GP's, and an Independent Newspaper article about Patricia Rock's life.

Up till now I thought I might have MS and Alzheimers. Now at last, I had something 'on which to hang my hat'. I had had polio with waist down paralysis at the age of 5. I was not mad. I was not imagining it all. Much from my past since falling in 1988 fell into place. Weaker arms and not being able to swim as fast or get myself out of the pool, falling over nothing, constant fatigue etc., there could be a valid reason. I contacted the British Polio Fellowship and joined as a Life Member. I imagined quite wrongly that now I would get assessed, diagnosed and treated. It was such a relief. How wrong I was.

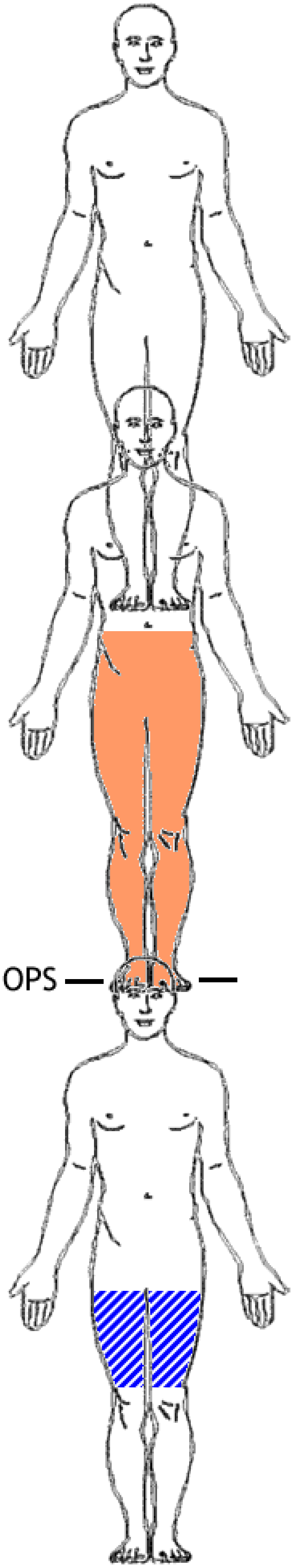
To promote the awareness of PPS and improve medical care for Polio Survivors I founded the Lincolnshire Post-Polio Network. I met Chris Salter and he began our Website in February 1997. A few months later we became a registered charity, and this is our 21st Newsletter.

Just four or the many important facts that I have learned about Polio and its late effects that you and your doctors may not be aware of.

1. The post mortem studies of Professor David Bodian of Johns Hopkins University in the 1940's showed that anyone who had paralytic polio lost on average 50% of their anterior horn cells but required death of more than 60% to demonstrate any paralysis. He also found that at least 90% of all anterior horn cells were in some way affected by the polio infection.
2. Professor WJW Sharrard of England in the 1950's found that in a case of Non Paralytic Polio that 40% damage to the anterior horn cells did not show clinically evident weakness.
3. Dr. Jacquelin Perry from Ranchos Los Amigos Medical Centre, Downey California reports in 1995 that Beasley thirty years ago found that strength rated grade 5 on the basis of manual muscle testing in patients who had had poliomyelitis was equivalent to 53% of the strength in normal controls. In the present study, grade 5 strength of the quadriceps muscle in patients who had had poliomyelitis was equivalent, on the average, to only 59% of the strength in normal controls. Grade 4 strength also tends to be considered to be closer to normal than it is. Both the study by Beasley and the present study showed that the mean strength of the grade 4 muscles was approximately 40% of normal. Muscles of grade 5, 4 or even 3+

strength allow a person to move normally; the greater intensity of effort is unrecognised.

4. Grace Young, OTR reports in 1991 that the therapist must not be misled into expecting adequate endurance for functional activities based on manual muscle testing.



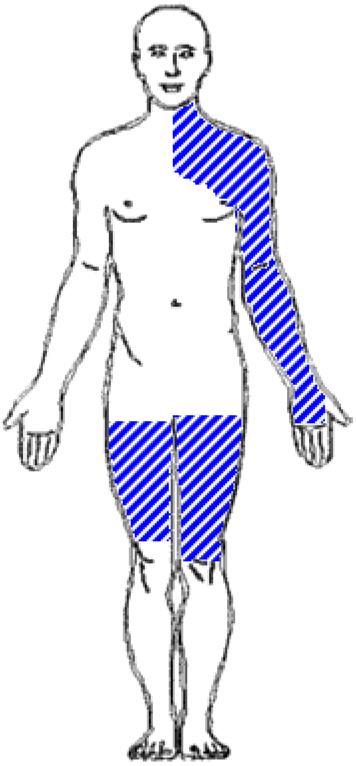
I was born Hilary Ann Foster in March 1947. No known abnormalities.

[At 38 years x-rays revealed congenital abnormalities of the spinal cord. T 11/12 fused and L2/3/4 fused.]

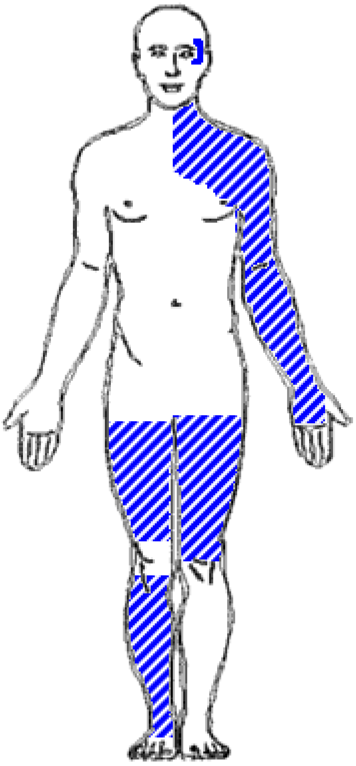
In January 1951 my mother, brother and I sailed to Benghazi, Libya, to join my father who was working with the Army on the telephone system. Shortly after arriving I went down with Whooping Cough (as did my brother) from which I recovered.

May 1952, aged just over 5, I was diagnosed with Paralytic Polio in the Army Hospital in Benghazi. Waist down paralysis. [No known upper body weakness]. After two weeks isolation was put in the Family Ward. A few days later my parents asked would swimming help and amazingly I was allowed out of hospital each afternoon to go swimming in the Mediterranean Sea at the NAAFI beach. Lady Mountbatten was coming to visit me but I never got to see her. We did not expect her to change her itinerary at a moments notice, but then she hardly expected one of the two little girls with polio to be out of hospital swimming. I started to recover and left hospital at six weeks - swimming each afternoon - my mother taking me back each morning for physiotherapy. I learned to walk again but could not run and I was always falling. I used my hands to stand from a chair or get up from the floor. I returned home to the UK had numerous physiotherapy sessions and then in 1961/62 had multiple tendon transfers at Heatherwood Hospital, Ascot by Mr. McFarlane 'Mac the Knife' for my dropped feet.

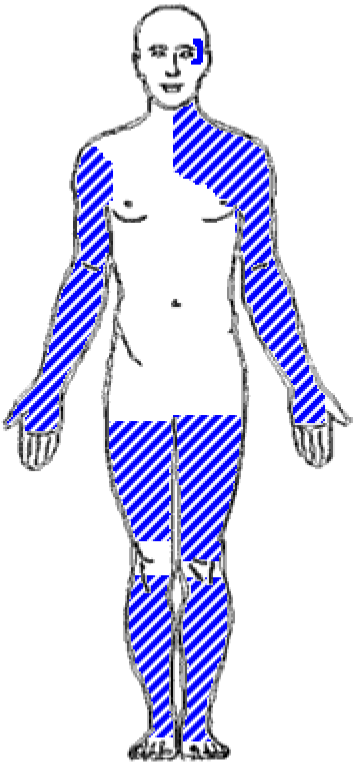
1963. I still could not run but the falling had stopped. I galumphed a bit around the defence area of a Netball court and learned to hit the ball so far in Rounders that I could walk round. I excelled at swimming but it was all arm power as my legs were weak with virtually no leg propulsion in any style but sidestroke. I passed all awards to Distinction in Lifesaving. I started Judo and managed to get to Orange Belt, but no further due to my leg weakness. I went ice skating and still have my white Ice Hockey boots. I learned to canoe. I passed ballroom dancing qualifications. I left school and was a secretary for five years and then a Policewoman for four years with two years in CID. I married moved to Lincolnshire had two children and then divorced. I passed all the RLSS Lifesaving Awards and passed my RLSS and ASA Advanced Teachers Certificates. I voluntarily lifeguarded at the coast weekends from May to September. I remarried and helped my husband run his garage business and held down four other part time jobs, lifeguarding and teaching swimming, working over 60 hours a week. I never stopped.



October 1988 I fell. My foot slid forward in a patch of fluid on the school corridor floor and I landed heavily on my back but more to my left side. I had not fallen this way before. I damaged my neck - whiplashing it - and had some pain in my left arm. Neck collar, physio and pain killers were not enough and 7 weeks later I spent 3½ weeks in neck traction. My nerve conduction studies showed problems with my nerves in both arms, but strangely I had no symptoms in my right arm. X-rays were fine. Orthopaedic and Vascular Consultants could find nothing wrong. 108 days post accident I saw a Consultant Neurologist. He told me 'your x-rays are better than mine' and I was later given two steroid injections in my left shoulder. My left arm was not right, it was weaker but no matter what I said, the standard examination showed nothing wrong. [It's only now that I learn that my diagnosis was an acute cervical radiculopathy - damage to the nerve roots in the neck.] I had lost four jobs whilst off sick I obtained some relief work but 8½ months post accident had to refuse the neurological operation offered. I was now a single parent again and had to be available for work. I could not swim as fast, or pull myself out of the water. I could not pass the lowest necessary lifesaving award to continue lifeguarding and teaching. [I now realise this was because 95% of swimming propulsion was from my arms and Professor Sharrard explained that this new nerve root damage on top of my polio damage meant that I was now functioning at a much lower level.]. I got a full time contract with Social Services in October 1989. I used to come home from work daily, sleep for two hours, totally fatigued. I had not done this pre fall.



1989 - 1994. I had repeated problems with my neck and left arm. I had problems with the vision of my left eye, went through two hospitals, private and NHS appointments but the ?optic neuropathy diagnosis was discounted. [Now diagnosed as weakness of muscles of movement of the left eye]. I started fallling, occasionally breaking toes, but on checking the ground there was nothing to trip over. In 1994 I had a Gynae operation and on getting home from hospital started my daily walk - I got across the road but I had to turn back totally exhausted. Day after day I got a few steps further. I was told it was nothing to worry about and it was not recorded. People would asked me 'Why are you limping?' I did not realise I was. I returned to work. I knew there was something wrong, but if the doctors say there is nothing wrong, what can you do?

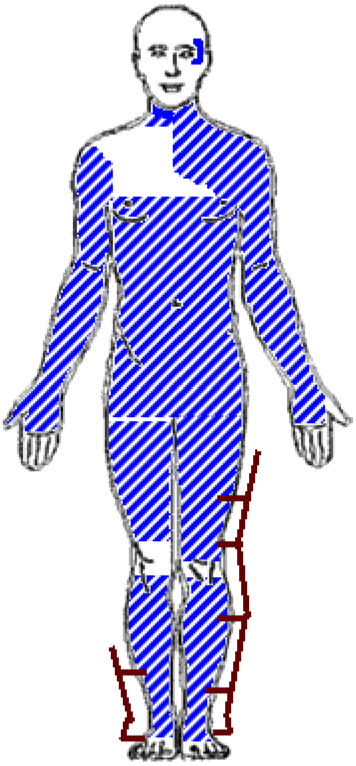


In February 1995 I stood up from a chair and a seering pain went down my left leg. I saw five doctors over the next month and they all said 'It's referred pain from a low back injury.' As far as I knew I had not injured myself and nothing has been suggested. The pain receeded with acupuncture but my leg is left with a 'dead' feeling inside my leg down the path where the nerve pain was. The advice given by my GP was 'it's a low back injury and the latest advice is to exercise and build on it daily.' I did this, or I tried, the more I did the worse I seemed to get, but I was told to keep going. Use it or lose it. I had x-rays. (Not much change from previously). I was now using cane to prevent falling when walking. My legs were weaker I had to use my arms more and now realised they were weaker. On 23rd November 1995 I got my MIRI scan results. *"Essentially normal glad you are better."* I replied *"I am not better, I have deteriorated over nine months, I had polio as a child,"* brought the reply, *"Oh! there is something called the late effects of polio, I know little about it, I will send you to a Neurologist."*

August 1996 - EMG could be lumbar radiculopathy but same results from old polio, no fasciculations so no so-called PPS. Told by Neurologist *"you only have nerve root damage you don't have PPS which is a deteriorating condition, that is if you believe it exists, which I used to, but don't anymore since reading an article six weeks ago."*

February 1997 - *There is not even any documentation of the fact that she had polio as a child and certainly no evidence of any neurological impairment from this, apart from some weakness of the proximal muscles of the legs.*

August 1997 - New Hospital. - EMG. Muscle biopsy, Full Blood and other tests giving a diagnosis in December 1997. *These results mean we can confidently diagnose the post polio syndrome and treat the symptoms on their merits.*



Present Symptoms - many still inadequately or not assessed.

Upper body Polio age 5 with no known upper body weakness. Eye movement problems [move head instead]. Occasionally can't Swallow [relax shoulders, tip head forward and to side] and Voice is still lowering. Laugh loud and choke every time. Cannot cough or sneeze hard without rib muscle pain. Problems with neck extension and left rotation. Can't hold arms up or out for long, change hands on phone frequently. Lifting saucepans etc now have to use two hands. Can't carry handbag in left hand. Can't carry plate of food from kitchen to lounge with left hand, have to use two hands. Can't sustain pushing video fast forward button unless arm resting on arm of chair. Was touch typist but now have to type in phrases and rest wrists [use ergonomic keyboard]. Have to strain arms to get up from floor or out of normal chair causing wrist and shoulder pain.

Lower body (Polio age 5 - waist down paralysis) Legs weakening. Toes now do not bend. Foot drop returned to right leg. Walking distance reduced from miles to yards. Can't drive manual car any more as can't lift left leg up from floor. Can't stand still for more than 30 seconds without needing to hold onto something. Can't get out of bath, have to shower. Experience muscle fatigue when out and have to rest/sleep for couple of hours on return. Sleep, was sleeping badly tossing and turning, mind racing.

Improvements I have made to my life.

1. Mid 1995 - Starting using cane to walk. Less Falls. This is prior to learning PPS existed.
2. Nov 1995 - Found PPS existed and have not stopped searching for information.
3. Dec 1995 - Joined British Polio Fellowship.
4. June 1996 - requested manual wheelchair found to my horror not enough arm strength.
5. July 1996 - started the Lincolnshire Post-Polio Network.
6. August 1996 - Bought much higher bed on 3 years interest free credit. Less strain on arms.
7. September 1996 - Asked GP for counselling. Talked about problems with medical profession and then went through life. This was an eye opener, as I went back through my life I realised why I had done many things, why I had reacted in the way I did. The more I learned about myself, the easier coping with now and the future became. 100% effective treatment.
8. October 1996 - Told by Rehab Registrar to make alterations to house and lifestyle, but could not get Health Service or Social Service Support for this as had NO DIAGNOSIS.
9. March 1997 - Charity purchased me a large 4 wheeled Electric Scooter. It opened up my life, I could now get out to post, to doctors, to shops without needing to ask someone to take me. However, had been badly advised and told it came to pieces for transporting which it did not. Difficult finding people to take me to places out of Lincoln who could get and lift scooter into their car.
10. May 1997 - Took second mortgage and started the following alterations.

    Remodelled kitchen units to make more accessible. Lowered wall cupboards. Kept just a few pieces of crockery for everyday use easily accessible, and put the rest away. If needed someone else could get them out.

    Built in under house. Utility room bringing freezer in from garden shed, washer/dryer by new back door and bought laundry basket on wheels. Clothes airer and rail for hangers. Take washing out of dryer and put on hangers, virtually able to stop ironing. New Bathroom Toilet on tiled block, no need for hand rails. Roll in Shower. Toilet seat on legs type shower stool allows you to wash bits you normally sit on. I wrap myself in a large towel and drip dry. Small storeroom for electric scooter, manual wheelchair [use for times when can't take scooter and to fetch shopping in from car]. Since getting flu in mid December 99 and not coping, my daughter brought my bed down to this unheated room. Four steps from the bed to toilet. Did not realise how beneficial that would be. [Social Services have now agreed to extend this room so that I can get bedroom furniture in it and put central heating in].
11. Started Amitryptaline 5mg at night. Sleep 8-9 hours, wake to go to the toilet and back to bed, no mind racing. This is a very low dose.
12. December 1997 - Got diagnosis of PPS at last. Not referred on, no advice or treatment

offered.

13. January 1998 - Asked GP to organise Ankle Foot Orthosis for right foot now dropped. [This must be made to measure and by an Orthotist who understands about Polio and PPS, and who listens to what you say.] UK first two were unsuitable but Canadian made one in three hours changed life drastically. 95% reduction in pain and swelling in ankle, knee and hip. Driving distance increased 10 fold.
14. October 1998 - Took possession of Motability Car fitted with Electric Hoist - took two months to find one that fitted my body for driving. VW Sharan 2.0SE automatic. Very comfortable to drive. Front seats swivel to get in and out. Arm rest for left arm, foot plate for left leg. Power steering little movement needed. High enough can get in and out without using arms. Hoist lifts scooter up and down, have to push in and out which means finding flat level to park on, or turn car round. Could not afford electric mechanism to do this. In fact being honest could not really afford to get the car, but having control of my life back far outweighed the increased financial burden.
15. September 1999 - Father bought me an electric rise leg raise chair. Bliss. Less pain in shoulders and wrists from not having to strain to get in and out of chair. That arm energy now available to prepare food in kitchen. Legs up and relax, weight of body now on whole body and not just bottom muscles, less pain. Able to rest more during day.
16. Four Charities purchased lightweight 3 wheel electric scooter. Bruno Supercub which is very stable even for heavyweights like me.
17. KAFO - Knee Ankle Foot Orthosis. - Utx swing from Ambroise UK Limited, Dutch made very lightweight caliper. The company found us from the PPS article in Nursing Times. I now stand straight when I walk, I walk with a normal pattern, I find it easier without a cane but have to concentrate on where I am walking. I carry my collapsible cane with me. Slopes up are no problem, but even slight slopes down for me are difficult - walk down sideways.
18. I ACHIEVE MORE EACH DAY NOW I have learned to pace and rest my activities. I breakdown what I do into sections, preventing much overstraining of muscles and joints. I use any aid or assistive device that helps with this. I plan my week ahead. [OK, I don't always stick to it, but at least its an informed decision.]

The Nature of Things and the PPSer

by Lili in Georgia, U.S.A.

I was stricken with the polio virus along with my sister and nephew in the summer of 1946 at age 6. I wore a leg brace and a back brace for several years after my hospital stay. By my teens, I was free of all bracing and there were no signs of ever having had polio. I was a passer until I was diagnosed with PPS in the summer of 1993. At the time, I was aware I was losing stamina and was jogging to regain my strength. I had little knowledge of any late effects of polio. I was active in sports. Swimming and gardening were especially important in my life.

After many tests and blood studies done in 1993, I was referred to a wonderful neurologist who has been a great help to me, helping me understand how to manage my energy with as few script meds as possible. I also go to Shepherd Clinic in Atlanta Georgia for their loving care in the out patient polio clinic. They have advised me, fitted me with an electric wheelchair and approved new bracing as well as excellent physical therapy.

I rested for approximately two years with many warm soaks in the tub a day. Slowly I came back to a level of pain I could manage and an understanding of how important it is to be as aware as possible when my body tells me, 'Listen, I need to rest'. Not waiting until I was hanging onto the bathroom sink, brushing my teeth, unable to hold myself up and then realize I guess I'm tired now. I've learned to keep my days as structured as possible. I keep a journal for recording what I am doing on a given day that may cause me to be in more pain. I also plan with Day at a Glance my schedule for the week. There is a digital read out clip on clock with an alarm for the days my brain is running away with me. This is excellent to keep track of time and when the alarm sounds, I can move on to something else.

Stress is a killer for 'All' PPSers. With stress we will decline if we don't get a handle on how much we can deal with it and how to avoid it as often as possible. Many times we cannot avoid a stressful situation as it may be sadness in our own family. This is when time taken to meditate daily pays off. I am always practising my technique to bring my mind to a very relaxed state. In the beginning this can be difficult but do not give up. You can do it. Only then can I concentrate and contemplate whatever the problem may be. Finally I am able to analytically think about this stressful problem and reach an understanding within me in a realistic way. I work at being totally honest with myself as I am assessing my life at any given time.

In order to bring happiness to my life and the lives of my family and friends, I look at the time I spend carefully to make certain it will bring positive results. The human body is so fragile and vulnerable. For PPSers, our life has changed from being active and strong to a new weakness we remember from so long ago. Often we suffer with much pain. As we continue to learn about our limits, accepting the reality of the situation, remember we can have a good and productive life. We must choose where we wish to spend our energy daily and to discover things that will benefit us now.

Awareness of the reality of our new body is, I believe, a step toward our eliminating our suffering. This second time around, suffering the late effects of polio is a kick in the teeth no question. It has been a major benefit to me to share with others via the Internet and support groups who suffer in the same way I do. We inevitably develop more kindness and compassion toward others. This has helped me to develop a strong desire to do what is necessary to be as free of suffering as possible.

With friendship, I send to all PPSers my warmest wishes for peace of mind with no emotional or physical pain.

Truly yours, *Lili in Georgia*
lili g <sophia_7777@yahoo.com>

Swallowing Problems

PETER ELLIS who lives in Ottawa, Canada and who had acute Bulbar Polio in 1951 has written some very comprehensive articles about his PPS. My Experiences with Progressive Oropharyngeal Dysphagia written in August 1998 and My 2nd Bedside Swallowing Assessment by my Speech Language Pathologist at the Rehabilitation Centre. January 24th 2000. These contain very detailed information including advice he has been given. If anyone is having problems in this area and would like copies of these articles please write or give us a ring. Or contact Peter by email.

"PETER ELLIS" <pcellis@sympatico.ca>

What's for Breakfast or Lunch? When there is no time or energy to cook!

by Jann Hartman, B.Sc

Tuna Sandwich on rye bread.

English Muffin Pizzas: spaghetti sauce on toasted muffins, top with grated cheese, and microwave or bake until cheese melts.

Egg Salad on Toast.

Quiche: mix up the night before and pop in the oven in the morning. Or make anytime, and freeze the leftovers. Heat in a microwave.

Leftovers: meatloaf, stew, a hearty soup or chowder. Toasted cheese sandwich (good with tomato soup, if desired).

Burritos (scrambled eggs, grated cheese, taco sauce rolled up in a flour tortilla) or Bean Burrito (bean dip, cheese, salsa in a tortilla).

Cold chicken (as is, or dip in salsa or lowfat sour cream and onion).

Bread or rice pudding (with raisins or other dried fruits).

Yogurt "sundae": Vanilla yogurt topped with fruit, and for a little extra crunch try adding a little cereal (like Grapenuts).

Cottage cheese: topped with fresh berries or other fruits.

Pie: fruit or pumpkin/sweet potato. Fruit pies can be heated in the microwave and eaten with milk poured over the slice of pie in a bowl.

French toast: make ahead and freeze. Pop in toaster, and use maple syrup or fresh fruit (bananas are good).

Frozen waffles: top with fruit and vanilla yogurt.

Breakfast Shake: 1 cup yogurt and 1 cup fresh (or canned) fruit in blender. Or try a soy smoothie: soy milk and fruit. Or blend up Silky tofu and fruit (banana, kiwi, and berries are great!).

The Elvis special: Peanut Butter and sliced bananas on whole wheat toast. (OK, his was fried in butter, and on white bread, but this is the "better" version and still tastes great).

Bagel with low-salt ham and cheese. Or use a tomato slice, onion and pepper (optional). Or try a lower fat cream cheese spread.

Fruit cobblers, like an Apple Crisp (cut up apples, sprinkle with brown sugar or maple syrup, stir in some cereal -- I like raisin bran flakes). Eat with milk, if desired.

Try a Baked Potato (or microwave one), and top with: leftover or frozen vegetables and heat; or add salsa; or use low fat sour cream and soy "bacon" bits.

Use your own imagination, but don't skip breakfast! And these are also good for protein snacks. Good for the whole family.

Easy Magic Quiche - Can be Frozen.

This is a quick and easy quiche recipe that needs no crust. It can be made with eggs or egg substitutes, whatever you prefer.

1 cup grated swiss cheese (or any combination of cheeses)
4 eggs, or the equivalent egg substitutes
1 can low-fat evaporated milk (or 1½ cups milk)
½ cup flour
½ cup or more any leftover or frozen vegetables (I like to use broccoli, cauliflower, onion; use whatever you like best).

Spray a 9" pie pan with Pam (low fat spray), and put in vegetables.
Sprinkle the grated cheese over the vegetables.
In a bowl, beat eggs, milk, and flour.
Pour egg mixture into the pie pan, and let set 5 minutes.
Bake at 325 degrees for 50 minutes, or until a knife inserted in the center comes out clean and the

eggs are cooked.
Salt and pepper to taste.

Leftovers can be frozen and heated up in the microwave for breakfast or a snack. It is a family favorite, so easy and versatile.

CREAMY TOFU PUDDING

10½ oz. pkg. Japanese-style firm silken tofu, cubed
¼ cup honey
½ tsp. vanilla extract
1/8 tsp. cinnamon
Chopped fresh or dried fruit (optional)

Combine all ingredients, except fruit, in a blender or food processor. Top each service with fruit, if desired. Makes 1 and 1/3 cups.

VARIATIONS: For chocolate pudding prepare as directed above, omitting cinnamon. Add 2 tablespoons unsweetened cocoa. You can add ¼ teaspoon almond extract and top with chopped nuts or miniature chocolate chips, if desired.

Nutrition information per 2/3 cup serving:
220 cal; 11 gm. protein; 4 gm. total fat (0.5 Sat. fat); 39 gm. carb; 0gm. cholesterol; 55 mg. sodium; 0 gm. fiber.

BOTTOM LINE: Put tofu, honey, vanilla, and cocoa in blender and mix well. Pour into dishes and serve. That's it! As fast or faster than instant pudding!

Smoothies to make in your Blender

1. Pina Colada Smoothie Serves 2

    2 bananas

    1½ cups pineapple (fresh or canned)

    1½ cups vanilla-flavored soy milk

    2 or 3 dates (optional)

    1-2 tablespoons shredded coconut

    2 tablespoons maple syrup

    ice cubes

2. Coffee Lover's Smoothie Serves 2

    1 ½ cups vanilla-flavored soy milk

    ½ cup cold coffee

    2-3 ice cubes

    2 bananas

    a dash of cinnamon

3. Two Berry Smoothie Serves 1-2

1 banana

1/3rd cup dried cranberries

1/2 cup fresh halved strawberries

½ cup vanilla-flavored soy milk

4. Easy Tropical Fruit Smoothie Serves 1-2

This shake is made with canned tropical fruit salad, a good solution when fresh fruits are unavailable.

1 cup canned tropical fruit salad, drained of juice

½ cup vanilla-flavored soy milk

5. Summer Smoothie Serves 1-2

Try this shake in the summer when peaches are in season.

1 peach, cut

1 kiwi, peeled and cut

½ banana

½ cup vanilla-flavored soy milk

6. Mango Nectarine Smoothie Serves 1-2

1 nectarine, cut

1 banana

½ cup mango pieces

½ cup vanilla-flavored soy milk

7. Pear Smoothie Serves 1

2/3rd cup canned pears, drained

2/3rd cup vanilla-flavored soy milk

8. Cantaloupe Banana Smoothie Serves 1

2/3rd cup diced cantaloupe

1 banana

½ cup vanilla-flavored soy milk

9. Nectarine Blueberry Smoothie Serves 1

1 nectarine, cut

½ cup blueberries

½ cup vanilla-flavored soy milk

10. Prune Banana Smoothie Serves 1

6 dried prunes

1 banana

½ cup vanilla-flavored soy milk

Jann Hartman, Baltimore, MD, U.S.A.
Jann <jann@home.com>

1. Lincolnshire Post-Polio Library - Nutrition and Post Polio Syndrome - Janice Hartman.
2. Lincolnshire Post-Polio Directory - Polio Survivors on the Internet - **Janice Hartman** Jann's PA Dutch Kitchen

Mixed Drinks

Once upon a time there lived a boiler maker. He was rather Stout, and he had several Double Gins. But his manner was always ale and hearty. One day he went to his local Inn, where he was known as a good mixer. And there he met a-Brandy-legged barmaid, and she was just the tonic he needed. He took her for a spin on his motorbike, but suddenly the side-car began to Wine, and he had to fix it with a Screwdriver.

They became good friends. He was Brown and she was Pale, and they went together like Black and Tans. One day he said: "I'd like to Whiskey off to Malibu." But she said: "I can't go because of my ale-ments." So he went alone, and she thought Absinthe would make his heart grow fonder. But the Rum bounder didn't come back, and she was be-Cider herself with grief. And she became a Twisted Bitter Lemon. Which just goes to show - you should never mix your drinks!

Sent to us by Steven Carrett
steve@carrett.freeserve.co.uk

If to get one pair

DLA Question "No. 137"
Q. When you go shopping to Asda how far can you walk?
A. As far as the Baked Beans.

BUILDING IMMUNITY

By Vicki McKenna

As winter sets in we need to pay attention to our immune systems and ensure that immunity is improved to thus ward off 'flu's and colds. Poor diet can lower our defences so this is the first area to set to rights. In addition to this avoid pollution as far as possible and pesticides.

There are currently 60,000 chemicals being used commercially. 3,000 of these are used as food additives and 800 are found in drinking water. Traffic fumes, factory emmissions, chemicals used domestically, food farmed and grown with the use of pesticides and antibiotics - all of this affects our immunity and makes us more vunerable to disease. To support your natural defence system reduce your exposure to as many of the above pollutants as you can and eat organically grown foods where possible.

Make sure that you include the following daily supplements to boost immunity;

- Vitamin C; 1,000 -3,000mgs per day. This is antibiotic and antibacterial. It is the strongest antioxidant known and in research has been shown to promote longevity. It is water soluble and so an excess is excreted. Stagger your intake into 3 doses of 1,000 mgs each. Citrus fruits and rosehips are good natural sources.
- Vitamin E; Another powerful antioxidant, this vitamin protects from free radical damage and research shows it has antiageing properties. It is invaluable for the immune system. Natural sources are vegetable oils, leafy vegetables and egg yolk. Take 100 - 200 i.u's of this vitamin per day.
- Zinc; This is a crucial antioxidant for the functioning of the immune system. It also helps to

detoxify lead and other toxins from the body . Do not take more than 50 mgs of this per day.

- A Multivitamin is an essential daily supplement. Brands such as "Quest" and "FSC" will contain high amounts of vital vitamins such as A and B whereas cheaper supermarket brands often have less of these and more "filler".
- Above all else remember that "laughter is the best medicine". Research shows that laughing lowers blood pressure and boosts the immune system by causing us to relax, let go of our cares and worries and so allows the body and thus its defence system to normalise leaving us feeling happier and healthier.

Bibliography;

1. "THE NUTRITIONAL HEALTH BIBLE" by L. Lazarides.
2. "A BALANCED WAY OF LIVING; Practical and Holistic Strategies for Coping with Post Polio Syndrome" by Vicki McKenna.

   Send Cheque for £10 or $30 (inc. P&P) to Vicki McKenna, 42 Regent Park Square, Glasgow G41 2AG Scotland.

1. Lincolnshire Post-Polio Library Book Catalogue - **A Balanced Way Of Living** Practical and Holistic Strategies for Coping with Post Polio Syndrome

- My grandmother started walking five miles a day when she was 60. She's 97 now and we don't know where the heck she is.
- The only reason I would take up jogging is so that I could hear heavy breathing again.
- I joined a health club last year, spent about 400 bucks. Haven't lost a pound. Apparently you have to show up.
- I have to exercise in the morning before my brain figures out what I'm doing.
- I don't exercise at all. If God meant us to touch our toes, he would have put them further up our body.
- I like long walks, especially when they are taken by people who annoy me.
- I have flabby thighs, but fortunately my stomach covers them.
- The advantage of exercising every day is that you die healthier.
- If you are going to try cross-country skiing, start with a small country.
- I don't jog. It makes the ice jump right out of my glass.

Sent in by Suz O'Kelly. New York State.
"SOK' <okellysj@email.msn.com>

Is William H Remaley in Pennsylvania the oldest living Polio Survivor?

My father, William H. Remaley, was born in a small town called Parryville, Pennsylvania in 1904. He was stricken with polio in 1905 just when he was taking his first steps. Over the next few years his father had to work and his mother did not take care of him. His legs atrophied backwards to the point he walked with his hands and dragged himself to get around. His father eventually divorced his mother and he brought my father to the Good Shepherd Home in 1911. At that time the home was a house on 6th & St. John Sts. in Allentown, Pennsylvania run by Mama and Papa Raker. They took my father in and cared for him. He played the trombone in the home's band and they travelled to different places on a bus. He went to Jefferson Elementary School and was pulled in a wagon to get there. He went thru to 8th grade (at that time that was all).

A few years later Mama & Papa Raker sent my father to Children's Hospital in Philadelphia where he had surgery on his legs to straighten them out - that stay was 17 weeks. A few years later, in fact when my father was 19 years old, he had another operation at the same hospital that kept him there 9 weeks. The good thing was he walked for the first time in his life with braces and crutches. He went to business school for a while with a few other residents but they used to skip and they were caught. He then worked for the Good Shepherd Home as supervisor of the laundry. For about 6 years when I was little they shut the laundry down and made my father the night security guard !!! He would go from building to building making sure doors were locked, find residents (especially the old folks) who would wander out of the buildings or off their floor. He even caught a robber by putting his crutch out when he ran by and got his name in the paper. Then the home reopened the laundry and made him supervisor again and he did that job until 1982 when he retired at 79 years old. That is 56 years (54 years according to Social Security). During his career at the Good Shepherd Home he met my mother who was a practical nurse. They were married in the home's chapel by Dr. Conrad Raker, the son of Mama & Papa Raker.

My mother and father were married 56 years last May 8, 1999. My mother passed away January 22, 2000. My mother was sixteen years younger than my father and I never thought he would make it through losing my mother. A few years ago I asked him about my mother being sixteen years younger than him and was that proper back then - his answer - "I married a younger women so that when I got old she would take care of me and she is doing a great job"!

I can't even begin to tell you how proud I am of my father - when I was young my mother worked so much at the Good Shepherd Home, weekends, double shifts, split shifts, that my father who worked regular hours was always there for me.

My memories of my father back in the 50's and 60's being handicapped are in my mind forever. My father loved to go shopping with me when my mother worked. I remember walking along Hamilton Street (the shopping area at that time) and his crutch became stuck on a lollipop that someone threw on the ground and he fell down, a little girl walked by and asked her mother "what is wrong with that man". I looked at her in disbelief because in my mind there was nothing wrong with my father. My father could not teach me how to ride a bike but he would watch me from the front window. When I would go out front and sleigh ride he would be waiting for me to come in frozen and have hot chocolate and warm pyjamas waiting for me. He could not believe that I taught myself how to swim at the local free pool. He baked every birthday cake for me until I moved out on my own. But the most memorable thought I have is that he let me fall asleep in his arms almost every night even though he couldn't carry me upstairs to put me to bed, my mother or a friend would do that.

Today my sister and myself are taking care of him at home in his own house and with my sister having only three years to retire. If I never go back to work until he's gone I will never regret it - my father's mind is amazing and goes back to 1910 and his stories keep us going.

For everyone out there with a handicap this man should be an inspiration to keep going. His only request now is not to be left alone and my sister and I will make sure he isn't! He has not had any problems with PPS as far as we can tell.

If there are any Polio Survivors of my fathers era who would like to write and tell him about their early polio lives please email me or send them via the LincPIN address. I would enjoy reading them to him and he is really looking forward to getting a copy of this newsletter and hoping to hear from some British Polio Survivors.

My Adventure in Paradise

by Christine Ayre

I'm not easily scared, or so I tell myself. Spooks and things that go bump in the night leave me unmoved. I have been known to shudder when I see a giant spider, teeth and eyes flashing, lurking in the bath, but even that can be trapped in a sponge and dropped out of the window. What about the polio dragon? I hear you cry. As I said before nothing scares me!!!! Brave words and I'm fooling myself, I was scared once, so this is my confession.

A few years ago, my partner John was working in Singapore. I had visited the previous year and was enchanted by this beautiful place. Eager to return I set off the next year, planning to spend Christmas and the New Year in paradise.

The first time I went to Singapore we had also spent some time in Penang. This is a wonderful tropical island and I was hoping to pay a return visit. Alas this was not to be, all the Hotels were fully booked and so we had to make do with going to another, smaller Island further up the coast of Malasia, called Langkowi. First we had to fly to Penang, about half an hour flying time from Singapore, then await a flight to Langkowi.

While awaiting our flight in Penang we decided to have a meal. Our table overlooked the runway of the airport and gave us a perfect view of aircraft taking off and landing. In true Brit style I had ordered chicken and chips for lunch. I was in the process of inspecting the rather strange looking chicken and had come to the conclusion that it was a whole baby chicken, pressed flat and coated in breadcrumbs, when I looked up and saw coming down the runway, a little aeroplane, shining white in the sunlight and painted with exotic pink and purple orchids. It was doing a little dance, as if it could hardly wait to become airborne again. The pilot managed to calm it down and it disappeared from view. I remarked on the wildness of the plane and that only a fool would risk his life in that.

After lunch we headed for the departure lounge to await our flight. Our number was called and we were, with about ten more people, herded out onto the tarmac. To my amazement, there standing waiting for us was the little white plane. The pilot and his co-pilot, looking very smart in their Malasian Air Systems uniforms boarded the plane and I, fool that I am, climbed in the little door at the side, taking care not to hit my head on the ceiling. I settled into the seat behind the pilot. The only concession to comfort was a wickerwork fan, which was greatly appreciated as the plane was like an oven. We set off bumping and jolting down the runway, the little plane raced along and shot into the air as if fired from a cannon. This was no lumbering jet, or jumbo, this was the Red Rum of the air. This little plane could twist and turn, swoop and glide, as if it were a bird.

The flight for me was magical. We were soon thousands of feet in the air, but yet I was able to see clearly everything on the ground. On the shimmering blue sea were hundreds of little boats. When flying over land I saw jungle and rivers and smoke coming up from countless fires. As we neared our destination the sea started to be dotted with more and more little Islands and soon we spied one larger than the rest and knew we were nearly at our destination. The little plane danced us down the runway and into an enchanted land of palm and banana tree's, thick jungle and brightly coloured birds. Lazy water buffalo eyed us as we passed.

We had a half hour drive to reach our Hotel, the only one on the Island. The Hotel overlooked a wide bay dotted with little volcanic islands, a perfect place for smugglers in the olden days. The Hotel and grounds were on a series of terraces stretching down to the sea and the whole of the Hotel was covered with multicoloured bourganvillia. The food was wonderful, giant prawns, crabs, lobster and my favourite, fillets of snapper grilled to perfection.

Our days were spent wandering round the Hotel grounds and down to the sea. Not much of a beach, but instead a long pier stretching out to sea with seats to rest my weary bones and soak up the sun and warmth.

It was on the way back from the pier that it happened, something I will never forget.

We were walking back from the pier and on leaving the beach had to walk round a large boathouse. I was walking in front as the path was narrow and boarded on one side by the boathouse and on the other by a thick screen of bushes and palm trees. Nearing the corner of the boathouse I heard footsteps, loud, slow, slapping, sort of footsteps.

I called to John to say we will have to make room for someone to pass, turned the corner and came face to face with a giant monitor lizard (sometimes called dragons). At the same instant I realized John wasn't with me.

Anyone who has been to the tropic's will know there is no such thing as silence, there is so much wild life and it is very vocal. On meeting this monster I heard nothing of the wild life, only the pounding of my heart. My limbs had turned to water and had the feeling that I was looking out of a fish bowl, the only thing I could see was the giant lizard.

He was huge, blue grey in colour, legs like tree trunks, sharp claws and a big head with little gleaming piggy eyes. We looked each other up and down. I could see him weighing me up, no doubt thinking I looked a scrawny unappetising Brit and a case of heartburn waiting to happen.

He shook his great head opened his mouth and displayed a set of sharp teeth, which would have been greatly improved with a bit of Colgate and a good brush. He swished his tail and lumbered off into the bushes. At that moment John came round the corner. He asked what was wrong with me and said he had been watching a monkey on the beach. I gabbled, 'I've nearly been eaten by a crocodile, it was on the path, it had big teeth and piggy eyes, it nearly got me.' 'Don't be silly' he said 'there are no crocodiles here, you have been in the sun too long.'

On returning to the Hotel I told one of the staff of my encounter with the monster and was told I was very lucky to escape. These dragons don't have flames, instead they have a poisonous bite and have been known to kill small children.

On a recent television programme about these dragons, I learnt that the bite is so dangerous because the dragons teeth are filthy from rotting food and are alive with bacteria. One bite gives potentially fatal blood poisoning.

Oh yes I was scared, that is another one of my nine lives gone.

After all that the Polio Dragon seems more of a pussycat.

Christine Ayre - catley@tesco.net
Chairperson Lincolnshire Post Polio Network

Post-Polio
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PPS Whispered

On my recent stay in hospital I was very careful to let everyone know that I have post polio syndrome. Just imagine my surprise when other people treat it as a deadly secret. It happened this way.

When the nurses were changing shift, one nurse in charge was most careful of my feelings. She would walk round the ward telling the nurse on the next shift, what was wrong with each patient.

When she got to my bed she would say, 'this is Christine,' then in a whisper she would say, 'she has post polio syndrome.' The first time it happened I stared open mouthed. The second time I was ready and said, 'I'm not ashamed of having it, I don't mind who knows.' She said 'Well it's not nice for everyone to hear.' Bless her heart, she was so nice and was only thinking of sparing my feelings. I do appreciate the thought, but when will we get it through to people that we want our condition to be known. The word can't be passed in whispers, it must be shouted from the rooftops, then maybe the medics will start to listen. We have many emotions to deal with, despair, anger, frustration, depression, fright and now this! Jokingly, in future when I crawl out from under my stone to do a bit of shopping, I'll wear a Tesco carrier on my head. I would hate anyone to recognise me and know what I suffer from.

Christine Ayre - catley@tesco.net
Chairperson Lincolnshire Post Polio Network

* * *

HEART'S EASE

Deep in the night I seek surcease from pain
cascading o'er my darkened windows still
warm spring rain trinkles down the opaque pane
rain, like human tears, continues to spill

'til dawn brings sights banishing last night's chills
eradicating grief... sad thoughts... remain...
purple pansies populate window sills
wand'ring memories echo their refrain

I tread the dewy meadow, my eyes fill
with flowers of the field who don't complain.
Are greenest pastures heav'ns own window sill
clean scoured now from last night's tepid rain?

God's blessings bring gentle rain from above;
a benediction of heart easing love.

LaVonne Schoneman - Vonnejo@aol.com
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* * *

A Recipe for Happiness

Take twelve whole months. Clean them thoroughly of all bitterness, hate, and jealousy. Make them just as fresh and clean as possible.

Now cut each month into twenty-eight, thirty or thirty-one different parts, but don't make the whole batch at once. Prepare it one day at a time out of these ingredients.

Mix well into each day one part of faith, one part of patience, one part of courage, and one part of work. Add to each day one part of hope, faithfulness, generosity, and meditation, and one good deed. Season the whole with a dash of good spirits, a sprinkle of fun, a pinch of play, and a cupful of good humor.

Pour all of this into a vessel of love. Cook thoroughly over radiant joy, garnish with a smile, and serve with quietness, unselfishness, and cheerfulness. You're bound to have a Happy New Year.

Sent in by Mary-Lou.Whitaker@kinfolk.org

Kuna (Pronounce Q'na), Idaho

STRENGTH

We don't always have to be strong to be strong. Sometimes our strength is expressed in being vulnerable. Sometimes we need to fall apart to regroup and stay on track.

We all have days when we cannot push any harder, cannot hold back self-doubt, cannot stop focusing on fear, cannot be strong. There are days when we cannot focus on being responsible.

Occasionally, we don't want to get out of our pajamas. Sometimes we cry in front of people. We expose our tiredness, irritability, or anger. Those days are okay. They are just okay.

Part of taking care of ourselves means we give ourselves permission to "fall apart" when we need to. We do not need to be perpetual towers of strength. We ARE strong. We have proven that.

Our strength will continue if we allow ourselves the courage to feel scared, weak, and vulnerable when we need to experience those feelings.

Today, help me to know that is it okay to allow Myself to be human. Help me not to feel guilty or punish myself when I need to "fall apart".

Author unknown - sent in by Rev. Karen Utz, PA.
<popette@alltel.net>

I'm Very Well Thank You

There is nothing the matter with me,
I'm as healthy as I can be,
I have arthritis in both my knees,
And when I talk - I talk with a wheeze.
My pulse is weak, and my blood is thin,
But - I'm awfully well for the shape I'm in.

Arch supports I have for my feet,
Or I wouldn't be able to be out in the street,
Sleep is denied me night after night,
But every morning I find I'm alright.
My memory is failing, my head's in a spin,
But - I'm awfully well for the shape I'm in.

The moral is this - as my tale I unfold,
That for you and me who are getting old,
It's better to say "I'm fine" with a grin,
Than to let folks know the shape we are in.
How do I know that my youth is all spent?
Well, my 'get up and go' has got up and went,
But I really don't mind when I think with a grin,
Of all the grand places my got up' has bin.

Old age is golden I've heard it said,
But sometimes I wonder as I get into bed,
With my ears in a drawer, my teeth in a cup,
My specs on a table until I get up,

As sleep overtakes me I say to myself,
Is there anything else I could lay on the shelf.

When I was young my slippers were red,
I could kick my heels right over my head,
When I was older my slippers were blue,
But I still could dance the whole night through,
Now I am old my slippers are black,
I walk to the shop and puff my way back,
I get up each morning and dust off my wits,
And pick up the paper to read the obits.
If my name is still missing I know I'm not dead,
And so I have breakfast - and go back to bed.

Author Unknown
from Kathleen Burrell, Lincolnshire. Polio of 1917.

Branson, Missouri, U.S.A.
June 10-13 2000 - 2nd Internet Reunion

There is going to be a Reunion of Polio Survivors, who have met on the Internet, in Branson following the GINI Conference. Branson is 4/5 hours drive south of St. Louis. The Lawrence Welk Resort is now taking bookings. All Rooms are $55. This is a get-together to share stories, information, real live hugs and will be full of laughter Opportunities to visit local attractions. Contact us or **"Tommy"** <tlcon@webound.com>.

EIGHTH INTERNATIONAL POST-POLIO AND INDEPENDENT LIVING CONFERENCE 2000
SAINT LOUIS, MISSOURI, U.S.A.

Preliminary Program - In response to feedback from previous conferences, the program offers multiple tracks of information with many interactive sessions for both health professionals and consumers. Each participant can choose from a variety of topics. Sponsored in part by the March of Dimes Birth Defects Foundation.

N.B. The following is excerpted from the 7 pages provided to wet your appetite. Full details on our WebSite World-Wide Conference and Seminar Diary - Card No. 6. Or ring us. For Registration forms write or fax to:-

Gazette International Networking Institute (GINI)
4207 Lindell Boulevard, #110, Saint Louis, Missouri 63108-2915, U.S.A.
Fax +1 314 534 5070

Thursday June 8th 2000 11.30 - 1.00 Opening Luncheon.
Welcoming Participants and Honoring Dr. Augusta S. Alba and Dr. Jacquelin Perry.

1.30 - 2.45 A Multidisciplinary Team: Evaluation and Treatment of Polio Survivors
Anne Gawne, MD; Pima McConnell, PT, ATP; Linda Palmer, OTR; Melvin Hale, CO.
followed by 12 minute summary - Assessing Our Activities to Effectively Manager Our Lives
Hilary Hallam - Lincolnshire Post-Polio Network.
[there are six other options at the same time]

Saturday June 10th 2000 - 10.30 - 11.30
Assessing Our Activities to Effectively Manage Our Lives
Hilary Hallam, Richard Boone. Lincolnshire Post-Polio Network.
and at the same time
Self Management of Chronic Conditions
Peter Jay - British Polio Fellowship [and Lincolnshire Post-Polio Network Member]
[there are four other options at the same time]

Ends Saturday June 10th 2000 at 4.30 p.m.

ALSO - A Seminar for Physical and Occupational Therapists and Assistants
Friday June 9th 2000, through Saturday noon, June 10th 2000, during the above Conference. Registrants must attend both days to receive the full 9½ hours credit and are encouraged to attend the entire conference.

Costs. [NB. These are just an excerpt for an idea of costs]

Full Registration -	before May 1st	-	After May 1st.
Individual with disability	$160	-	$190
Individual with disability and one attendant/family member	$220	-	$250
Health Professional and Others (Includes PT/OT Seminar)	$250	-	$280
PT/OT Seminar (June 8 8.00 - 4.45 and June 9 8.00 - 11.45)	$160	-	$190

Meals.
The complete meal package fee of $105 per person (meals are separately priced as well) includes Thursday Lunch, Friday Lunch, Friday dinner and Saturday lunch. (Full registration fee includes Thursday's dessert bar and continental breakfasts on Friday and Saturday.)

Hotel Rooms - Saint Louis Marriott Pavilion Downtown.
All rooms are $119. Single, Double (two people one bed) and Double Double (two people two beds).

N.B. It is important that you use the GINI Registration Forms and Hotel Registration Forms to ensure that you are aware of all costs and cancellation details.

* * *

My Private War

by June Millard 1.4.26 - 8.8.92

[Part 1].

This article was written by the late June Millard whose sister is Wendy Grimmitt, a new member from Grantham who caught polio at the same time as June and now has PPS.

Life in the late summer of 1940 to a fourteen year old girl was an exciting and scaring one. The battle of Britain was being fought in the skies, and every day the wireless gave the score. As the numbers of German losses increased so did our hero-worship of the boys in blue.

The autumn came and the enemy bombers found Birmingham. Going to college became an adventure of dodging fire hoses and rubble. Often our train couldn't get into the main station, and we had to walk about a mile into town. Soon the days brought their news of human tragedy and loss, and we realised life wasn't as thrilling or exciting as we had thought.

During this time two friends and I made plans to join the Land Army at sixteen and a half, little knowing that by the end of November I would be fighting a private war, not against the Germans, but against the polio virus and its after affects. Within three days, from being a very athletic girl, I was reduced to a helpless log.

The ambulance sped, its bell clanging, to the Queen Elizabeth Hospital, where the doctors were waiting with oxygen and pins to stick into my limbs. I couldn't feel anything. Total paralysis. An iron-lung had been brought from another hospital as the Q.E. was awaiting delivery of its own, and that night with the electric pump thumping and the pressure of air forcing my reluctant rib-cage to work, I became their first iron-lung patient.

A fortnight later when their machine arrived, I was transferred to it, and it became well and truly christened - in more ways than one. No-one was more thankful than I to Lord Nuffield for this marvellous gift, and I did my best to thank him when I met him two years later in Woodlands Hospital.

Unable to turn my head, all I could see was the sky with its ever changing patterns, and the birds flew by. At that time a popular tune was 'If I only had Wings', and in my imagination I flew with the birds to far away places.

One night Jerry hit the local electricity supply, and while the hospital emergency supply was organised the porters pumped by hand to keep me alive. How their arms must have ached next day!

Time passed, and my Mother came every day through the terrible weather to see me and to encourage me to keep on fighting. My day wasn't from morning to night, but was measured from Mother's goodbye kiss to her smile and 'hallo'.

Not realising how complete the paralysis was, I pleaded to be let out, and gradually they let me 'out'. One, two, three minutes. So the periods grew, till one day - one wonderful day - I was on a real bed for two whole hours. After that my determination grew to leave my 'prison' completely.

There followed twenty four nerve-wracking hours for the doctors and nurses, and - I had made it! Though three times they prepared the iron-lung, but, noticing, I said, 'I'm not going back in there', and I didn't.

After 'coming out' my weight was only about four stone. I was so emaciated that the Teaching Sister used to bring her students to see a bone in my foot. Whenever she moved the foot it could be seen working; a demonstration impossible on a skeleton.

Though it was winter in wartime my small ward was a flower box, and Mother used always to bring two bunches of violets. While I was in my Lung they used to be attached to the plate that held the rubber collar. Later they were put in a little vase, arranged so that though I still couldn't move my head - I could always see them. They meant so much to me, a promise of better things to come.

In a week or so it was decided that I could go into the main ward. My nurses were needed elsewhere as there were lots of wounded soldiers in the top wards. It was good to be back amongst people again, and they were very nice to me considering the thump of the iron-lung which kept a lot of them awake day and night.

Christmas came, with its choir of nurses at midnight, and laughter at a stern Sister who slipped on her behind while holding the plum pudding aloft; and sadness too. One of our elderly diabetics resented 'them nurses who wouldn't let her have her oranges'. So while visitors were there she ate two 'to beat em'. That night 'them nurses, fought a hard battle for her life, and lost.

One day, sweeping through the doors of the ward, came the professor on his rounds with his puppies (students) at his heels, and Sister, Staff and Junior Nurses joining the retinue. He was a pompous little man, who thought his word indisputable. Waving an immaculate hand in my direction he pronounced, 'This patient will never recover the use of her body, and as for her ever walking, well, that is an impossibility.'

In the pause, a weak voice - mine - said, 'You are a liar. Of course I will'. The effect was immediate. A gasp from some, giggles from others. All he could say was, 'Why?' I explained I could never imagine not being able to walk. He just smiled pityingly, and moved along the ward.

Sister told me off, but I swore I could make him eat his words no matter how long it took, my only wish being that, he would die of old age first.

Before long an Orthopaedic surgeon took over my case. He specialised in the treatment of infantile paralysis, as polio was then called. The first thing he ordered was that the sandbags be pushed up between my sides and arms, as the muscles were beginning to shorten. It was very painful, but I found that if I was asleep, the staff didn't adjust them at night after they had slipped. It was amazing how well I slept 'dead to the world' the moment sister made her rounds.

In the late spring I was moved to the Orthopaedic Hospital. If anyone had told me it as to be my home for the next two and a half years I would have given up there and then. The Q.E. was centrally heated, and the colour schemes were bright and cheerful. The predominating colour of my new ward was a dismal brown, and one side was open to the elements. The place looked horrid, and I hated it. But I was trapped.

The Sister was a harsh disciplinarian. Everyone from the patients to the doctors were scared of her. She ruled the ward like a camp boss, and many a good nurse gave up a promising career because of her and a few weeks in her ward.

Her favourite patients fared better, though the pats she gave them on the cheek sounded more like slaps to me. Needless to say, I was not among the favoured few. I wasted too much time when her nurses could have been polishing and cleaning. They had to feed me and, because of my bed-sores, a lot of time had to be spent on treatment strictly on 'doctor's orders'.

There was a marvellous lady in the physio department, who gave me treatment and allowed me to stay in her department all afternoon, treating me as a human being. But for her my spirit would have been broken.

One good thing did come from all this. I became a fighter against all bullies; not with fists or strength - hadn't any - but with words of silence. Strange how a stony stare can be as effective as a blazing row.

While the German planes were finding the motor works nearby, the sirens would go howling and the ward would awake. Amongst us were many very small children who were more frightened than we older ones. We would start to sing, the louder the better, to cover the noise of the bombs, or at least make them sound less. The little ones would join in, and soon fell asleep from sheer exhaustion. Our reward for this was hot cocoa, and, if our rendering was extra good, hot toast.

During this time I was splinted and on a frame, and one of my Houdini tricks was to wriggle my hand from its plaster case to relieve the ache in my shoulder. I explained it away by saying it happened in my sleep. This didn't fool anyone, but they let me get away with it.

The big day of the year was Founders Day when Dame Elisabeth Cadbury and her guests came to hear our songs and see our plays. These were performed from our beds, and had been rehearsed again and again. The beds were pulled into a semi-circle facing this small audience and so began our performance.

We rehearsed 'Nymphs and Shepherds' till I loathed it. I still do. We sang 'Greensleeves' too, and whenever it comes on the radio even now I can't get it switched off quickly enough. These tunes bring back too vividly unhappy memories of that time.

That first summer a new-comer arrived in the ward complete with chicken-pox, and the ward was put into quarantine for three weeks which meant no visitors. The visiting time was Sunday afternoon only. Now we missed our folks more than ever.

After this we had just one visit. Then german measles followed by mumps swept the wards, and there were more weeks of being closed away from the small family world that kept me going. Instead of being grateful to have missed those germs, I felt resentful at having been cut off for nothing.

Then, a year later, our martinet was moved to a male ward. She didn't last long there. A new sister came, and we patients thought we had died and gone to heaven she was so kind.

At about this time we heard that people outside were collecting to 'buy a bomb', so the girls helped by making woolly golliwogs to wear on a coat. As my bed had a bar on the top I was the 'sales lady'. We didn't put a price. People gave whatever they liked or could afford. In all we made over £20 and sent the money off.

By now some use had returned to my left arm, and though it was a struggle, I could feed myself. At times more fell off my spoon than stayed on it. Lying perfectly flat and seeing the plate through a mirror didn't help, but it's surprising what one gets used to.

To try to restore movement in muscles can at times be painful, though there are lighter sides to the treatment. In the first cold winter there were two joys: the heat lamps and the heated swimming pool. This pool was a fairly new addition to the Department, and while the local pool was in use we had many visitors. Occasionally there were so many people that it was difficult to get at the cupboard which housed the controls. A few times when we surfaced we were a delicate shade of pink, but at least we were really warm. That we enjoyed.

I dreaded the bath in the ward. Having no control over any part of my body, and being a lightweight, the only way to keep me above water was to wedge my head between the taps. The bath was longer than I was, and I was afraid of coming unstuck. I knew really they wouldn't let me drown, but the fear stayed with me.

A little use now returned to my feet, and the first time my ankle moved to my command was quite a day. Slowly, oh so slowly, odd muscles began to respond - hardly a flicker at first, but the thrill of seeing them get stronger made one fight on, though by now the realization of what was in front of me was very plain. The trouble was that no one believed that it would be possible for me to walk, and - to be fair - by all the medical books it was not.

Most polio's limbs, go very limp and floppy but for some reason mine stiffened, and in the right hip and knee osteo-arthritis set in and calcified the cartilege. This was most uncomfortable but an unexpected bonus later on.

About 1943, after repeated requests, my specialist said, 'She seems so determined to stand. Get her ready in Physio tomorrow and I'll come down.' Next morning, in new pink slippers, and wearing a pretty blue dressing gown, I lay and waited for the 'moment'. At last the specialist arrived with two other doctors and what seemed to be half the hospital staff. My physio lady gave me an encouraging smile, and two of the nurses slid me off the plinth into an upright position, and my feet were on the ground for the first time in two and a half years. I could look at people, instead of up to them.

Looking at the specialist I said, 'Please let me go'. He nodded at the nurses, and for one glorious moment I stood alone. As he turned away he said. 'Get her some crutches. She might yet'.

When on crutches my stiffness saved me from having to wear calipers. Admittedly there were only two positions to be in: flat on my back, and upright. To say I walked would be laughable. The left foot moved forward about four inches and the other followed up to it. But I didn't care; I was on my feet, and moving - just.

The muscles in both my thumbs had gone completely, so the surgeon decided to try a brand new operation; transplanting part of the muscle of the third finger like a rubber band around the back of the thumb, then threading it through a hole bored in the bone and stitching it down. I believe this was the first op of its kind in the Midlands.

The left hand was a great success. The right hand failed after two tries, much to the disappointment of the surgeon. Within two days I knew both times that the op on my right hand had failed. There was not any soreness after all the cutting and stitching compared with what there had been in the left hand. I knew by the lack of pain that there was no hope.

Before the second op I was lying there all dressed ready, my mouth dry from the injection, and rather scared. I was watching the time drag round to 9 am., dreading to feel the mask on my face - no prick in the arm and oblivion in those days - when into the ward came Snow White, as we called the porter, grinning all over his face. He had come to inform me that my waiting was in vain, as the surgeon wouldn't be back from his holidays for another week. So I disrobed and was given plenty to drink, and to add insult to injury I was stung on the hand which was to be operated on by an angry wasp.

To be continued next Newsletter.

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