



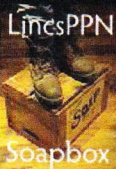
# The LincPIN

The Lincolnshire Post-Polio Information Newsletter  
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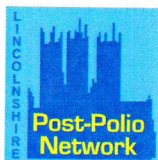


*Congratulations  
Jack & Sheila  
Spencer  
(formerly Dunnett)  
On their Wedding Day  
December 19th 2008*



## **Crisis Treatment is both costly for the NHS and the Polio Survivor.**

Assessments for polio survivors with new symptoms and functional decline after years of stable functioning should be full, base line, multi disciplinary and reviewable yearly. This will help us manage our lives to the best effect and should pick up issues long before they cause a crisis. This will save the government money in the long term.



This publication is provided as a service to those seeking such information. The opinions expressed in this publication are those of the individual authors and do not necessarily constitute endorsement or approval by the Lincolnshire Post-Polio Network. ALWAYS consult your doctor before trying anything recommended in this or any other publication.

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### **Our thanks to the following who have donated funds towards our work**

Jim & Jenny Rayner; JM Deans; Yvonne Grosse;  
Miss C Forrester & Mr. LM Lundblad; Mrs. P Minnitt;  
Mrs. M Pearson; Stuart Tanfield; Claire Colfer; CM Murray;  
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Mrs. E Hobday; SN Jupp; Val Scrivener; CJM & JY Curtis;  
Mrs. BJ Bradley; Margaret Edmonds,  
Robert Price and Dr. E. Goldstein.

Plus all those who work so hard for us for their time, energy  
and financial savings donated to the LincsPPN from their PPS lives.

### **CONTACT INFORMATION IS NOW ON PAGES 18 and 19.**

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## **Editorial by Hilary Boone.**

Richard and I hope that you had a good time over Christmas and that you will be prosperous and as healthy as possible in this New Year, 2009.

Sincere apologies for the delay in your receiving this newsletter. I have to hold my hands up and admit that the struggles to finalise the alterations to our bungalow, and dealing with Social Services have taken a huge toll of our lives in the last nine months. I kept penciling in the newsletter into our plans but yet another member of Social Services staff had to call to get information for their bit of the process. Now I too was experiencing what Lynn Hobday reported in the last newsletter. The stress and additional fatigue that dealing with all this took was, and still is, immense. I would wake and think I should be doing the newsletter today but if I don't get that form filled in. Friday night we move to a local hotel for a week whilst our bathroom is ripped out and a new 1000mm wide bath and toilet and sink that hang on the walls leaving the floor space clear is fitted. It is not going to be easy but it is our last major hurdle. We have had to prove our need for a bathroom not a wet room which was not easy but we did it. See Hints and Tips page 11.

Yesterday I spoke out loud the words that the amount I can manage each day has lessened considerably over the last few years. If you live alone or both of you are less able then life can get pretty tough. PPS was bad enough when it started for me twenty years ago but I am now 61 and am an OLD AGE pensioner! Exciting eh!

Increased fatigue levels and others not understanding the level I was describing led me to research this and I hope the article I have written will help you when trying to explain fatigue. Mary McCreadie asked me to publish Gladys Swensrud's Fourth Year Lessons of her search for answers for her symptoms. With Gladys permission I have added some comments to clarify some of the terms. We hope that you will also find this helpful. We would love to know what you think about the articles.

I attended the Neurological Occupational Therapy Conference in October and listened to presentations, mostly based on MS and Parkinson's [with many speakers research being funded by the charity]. It was an enlightening experience and I am grateful to the COT for donating me a free place. I was also involved in reviewing the final draft of Lincolnshire NHS Neuro-Rehabilitation Commissioning Strategy where some of the funding being requested out of Lincolnshire N.H.S.'s pot of government money was for case managers and specialist nurses for Head Injury, MS and Parkinson's. Whilst we fully accept that these posts are needed there were no posts to support the other neuro conditions. Together with the Lincolnshire Neurological Alliance (LincsNA) we are continuing to have discussions with the relevant government bodies to ensure our 'consulted' views are being considered. We have not seen the final document yet but have been assured that many of the points we raised were taken on board in the final document before it was submitted.

From the varied meetings that we [and LincsNA colleagues] have attended in the last couple of years it would appear that across the board the larger neurological charities with funding to support research/clinics/specialist nurses/etc, - work that is important - are pushing those of us with lesser numbers/smaller charities out into the cold when consultations and discussions take place in the NHS and Local Government. Their own rules state that there must be equality and no discrimination so why do we have to fight our corner so much?



## Message from the Chair

Another year has flown past, leaving us wondering where on earth the time went. All those important things that need to be done - and suddenly you realise that yet another month has disappeared and you **still** haven't completed all the tasks you set yourself. It could be that you've set unrealistic goals; maybe other things have become more important so you've had to prioritise. On the other hand, maybe you're just too tired! PPS takes such a toll on us, and often we don't realise quite how much until it's too late and we've thoroughly overdone it. I can see people casting up their eyes to the heavens and thinking 'Oh no, she's going to yatter on about pacing and resting again!' Right first time!

I'm probably one of the very worst for not practising what I preach. I have a bit of a mental block about it, I think. If I want to do something, then I want to do it, and if it means paying for it by having to take a few days to recuperate from the exertion, well so be it. It does mean planning a bit more carefully, and being straight about what can and cannot be managed. I know my pride gets totally in the way of common sense sometimes, and I cause myself a lot of aggravation which could have been avoided if only I'd been a little more honest with myself. For me, getting over-tired generally means my temper suffers, and my emotions go into overdrive, which isn't very nice for others to cope with.

My resolutions for the New Year will have to include one that covers being much more sensible about just how much I can do without damaging myself still further. I need to really think about how many times I can cope with getting in/out of the car, how many trips I really need to make to town, and accepting that having someone with me to help get the shopping loaded into the car is a **really good idea!** I've always been independent (some would say, to the point of stupidity!) and having to ask for help goes completely against the grain. In my heart I know that I need help, but my - I think 'ego' is the right word - suggests that of course I can do it. I'm just being idle/stupid/lazy etc. and off I go on the overdoing-it roundabout once again.

The events of the last 8 months since I had that disastrous operation have rather forced me into taking things easier, but I am still fighting against it.... Will I ever learn? I doubt it! Much against my independent streak, I have had to accept that I need Carers to help me. The Carers that come to me are very good - I'd be lost without them, as there are so many things I now can't do for myself. The care is paid for through Direct Payments, which provides me with care night and morning, plus 4 hours a week for shopping or housework. It was a nightmare setting everything up, especially when I was so poorly at the time. Being under the weather makes it so difficult to think straight, and I still don't think they've got it right. I'm going to have to go through the horrible process of contacting the Financial Department at the council, to try to get it sorted out sensibly. I think one of the major problems with Direct Payments is lack of information. I had no end of difficulty trying to get someone to even speak to me about Direct Payments, and when I finally did, I was very suspicious that the person who came to see me didn't really know what she was talking about. Just to get things going, I accepted what I was told, intending to query the financial side later, when I felt a bit better. Sorting out all this sort of thing takes a lot of energy, and puts a lot of stress on you. Hilary has told me that they have



evidence of staff filling out forms who have not read all the rules and regs on the national sites and some not even their own Council. National rules – or Practice Guidance – can be found at [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4005701](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4005701) and local authority rules at sites like <http://www.lincolnshire.gov.uk/> and click on Adult Social Care. If you don't own a computer, then your best bet is to ring your local Social Services Department, and ask them to send you the Department for Work and Pensions document entitled 'Fairer Charging Policies for Home Care and other non-residential Social Services.' I am about to start wading through to find out just exactly what has gone wrong with the financial assessment I had, so that I have chapter and verse to quote at them when I finally get a re-assessment.

As you can see from the front page picture Sheila Dunnett became Sheila Spencer on December 19th 2008. She met Jack at the Dancing Club and they became dance partners and then started to go out together to other events and love blossomed. LincsPPN is very grateful to Sheila for all the work she has done for us, and I'm sure you all will want to join with us to wish her the greatest happiness with her new husband. We gave her a silver plated folding picture frame.

On the back page are pictures of the invention my friend and member Paul Stanton has devised for me. Although once the worst drugs were out of my system I was able to drive, but unless I had someone with me to get the wheelchair in and out of the car, I was absolutely stuck. So Paul got to work on the problem, and ended up devising (of all things!) a shower stool, on which he put large wheels - each one individually braked. This was much more difficult than it sounds, as the legs of the stool are not at 90 degrees to the seat. Somehow he managed to plug each leg with an aluminium rod, which he had especially machined to overcome that problem. The end result is a sturdy, manoeuvrable stool which allows me to get from the front of the car to the back and vice versa, all by myself! I've no doubt it looks a bit strange – judging by the number of people who stare open-mouthed at me when I'm using it! It's not something that everyone could manage, but it suits me fine as you can see in the pictures. I shall never be able to thank Paul enough for restoring some of the independence that ill-fated operation took from me.

As you may know, Mary Kinane has decided to step down from the Expert Panel at the British Polio Fellowship. We are grateful for the effort she put in during her time on the Panel. I have agreed to take over, and attend my first meeting on 27 January. I'm looking forward to the challenge, and am hoping very much that I can contribute something worthwhile to the proceedings – I will certainly be doing my best!

There is much to be done this year in respect of LincsPPN. We have an excellent set of people on our committee and on our Operations Team, who are all committed to doing the very best they can to further our work, and I look forward to another productive and worthwhile and worthwhile year.

Meanwhile, may I wish all our members a happy, and as far as possible, a healthy 2009.

Mary McCreadie, Chair, [mary.mccreadie@lincolnshirepostpolio.org.uk](mailto:mary.mccreadie@lincolnshirepostpolio.org.uk)



## What words do you use to describe your current fatigue levels?

Polio Survivors have years of stable functioning after best recovery with the majority functioning at a high level despite their residual paralysis and weakness. Many report achieving qualifications in a variety of sports and occupations often leading to the response 'you must have had a mild case then'. However, these people include those who had considerable paralysis at the time of their polio infection with some reporting having been in an iron lung or having other respiratory support.

Everyone experiences tiredness, fatigue and exhaustion in their lives and polio survivors are no different.

However, once polio survivors start to experience new symptoms and problems with functional activities the symptom we most commonly report is fatigue. We say to health professionals, family members and friends that 'I am so tired all the time, worn out, exhausted, fatigued, etc. How many times have you said something like this and had replies like 'I get exhausted too – I have been at work all day and am tired - you don't have the monopoly on fatigue - just rest and you will be fine - perhaps you need some anti depressants. Did this frustrate you because you felt your level of fatigue was not understood? Think back to your stable years of functioning when you got exhausted/tired/fatigued and compare that with what you are experiencing now. Is it the same? What I experience now is.... Difficult to put in words but a lot more than before.

So what words should we use to define our current fatigue? Here are four excerpts from definitions of fatigue, there are two more further down the article.

### [Fatigue, from Old French, from fatiguer, to fatigue, from Latin fatigare.]

1. noun. weariness or exhaustion from labor, exertion, or stress
2. Temporary loss of strength and energy resulting from hard physical or mental work; "he was hospitalized for extreme fatigue";
3. "Fatigue" is a favorite medical word. When a patient says they have been feeling **unusually tired, "real tired,"** the doctor will usually write down that the patient presents with "fatigue."
4. Fatigue: A condition characterized by a lessened capacity for work and reduced efficiency of accomplishment, usually accompanied by a feeling of weariness and tiredness. Fatigue can be acute and come on suddenly or chronic and persist.

22 years ago I was working 60 hours a week plus about 12 hours as a volunteer lifeguard on top of being a mum, housewife, decorator, gardener, etc. Yes, I got tired and sometimes exhausted and had to rest like everyone else. Now I would define what I experienced during those 25 years of stable functioning as mild and of a temporary nature from which I recovered back to 'normal' after resting.

After my foot slid on a wet patch on the school floor where I was teaching in October 1988 I started to experience new and unexpected functional decline in actions of daily living [ADL's]. I started my quest for answers to these new symptoms. The treatment offered was sessions at the physio gym with plans of increasing repeats



and raised weights. At home I was told to go up and down stairs twice each time I went to strengthen my legs. As a typical polio survivor I thought I would show them and I tried to comply. As the months and years went by instead of improvement I found that I was managing less. Whilst I could do the stairs twice in the morning in the evening I sometimes had to crawl up. I was in more pain and the fatigue was overwhelming and unlike in my stable years a good nights rest was not enough. I thought I had MS from the new weakness and Alzheimers from forgetting things and 'they' thought it was all in my mind, I was malingering and not trying hard enough.

**This statement may help.** "Everyone who exercises realizes that you can't exercise at a high intensity for long before your muscles tire. How long you can go on for depends upon how hard you go."

When looking at your ADL's ask yourself

- 'How many times can I repeat that action, or how long can I sustain that action before the muscles aches so much or runs out of power and I have to stop?
- Am I doing this action like a 'non polio' or am I using any trick movements to achieve this and have I any idea why?
- Have I always done it this way or have I had to change the way I do this [include the position you use and any aids].
- When did this start and what has been the progression?

For example if you have been able to climb stairs since you recovered from polio, have you gone from walking up 'normally, to one step at a time right leg first, then added in using the banister rail to pull up and/or stopping halfway to rest and at some stage had to stop carrying items. [How many of you have thrown washing down the stairs, put stuff on the highest stair you could reach and then go up a few steps and move the stuff up, changed to walking down backwards, etc?]

If you relate these type of changes to a health professional, they should be able to find the new weakened muscles that are the culprit and treatment and maybe the use of some aids and assistive devices can now come into the equation. I know many of you will say you have been doing this but I know from personal experience that you may have to be very specific and physically demonstrate how you do the action now and explain how you used to do it. A couple of photographs or copy of a certificate that prove your earlier level of ability can be very helpful. Remember we all have different levels and combinations of ability levels in muscles throughout our body. There is no set pattern in PPS for health professionals to work to.

A good example - an Australian polio survivor diagnosed with PPS with a weak right leg but still with the ability to go on long walks started to fall. Looking at a clock he would fall towards 2pm and at shorter distances from the start of his walks. He went to see a good pps knowledgeable physiotherapist but her examination of the right side of his body found no new weakness. She said 'while you are here I might as well examine the other side and both were stunned to find that there was new weakness in the left hip muscles. When stronger they had supported the weak right leg but now weaker and tiring earlier were not able to support the weak right leg for as long. The physiotherapist prescribe using a cane to support the weak right leg and that a few short walks would be better than trying to attempt one long one.



When being assessed we are asked 'can you peel vegetables, lift 5lb bag of potatoes, do the laundry, etc. Health, social services and benefits professionals are not mind readers and if you are still in denial or too embarrassed to admit that there are changes in how you do these daily tasks then you are unlikely to get the help you really need.

Sadly, I believe their emphasis on using "can you do ADL's" to assess us without considering what else we have to do to achieve them - let alone what else we can manage that day - reduces the outcomes of the assessment. We do not live our lives doing simple separate actions but combine actions to perform patterns of movement that make up tasks. We have to plan our days and fit in what tasks we can manage. If we push ourselves beyond our limits day after day then is it any wonder we are having more pain, more fatigue, more frustration and are becoming crabby, irritable and find ourselves being unnecessarily sharp to our carers, family and friends. [hands up, I have been there many times]

Fatigue is not just physical, we can also have mental fatigue when we try to concentrate on long meetings, conferences, filling out benefit forms. Plus the more physically fatigued we become the more we notice memory loss, losing track in sentences, trouble finding the right word when overtired, e.g. 'can you pass me the, the, the, short pointy thing that starts with an n, that I hit with this hammer'

Here are two more definitions with words that might help you describe your fatigue.

5. The word fatigue is used in everyday life to describe a range of afflictions, varying from a general state of to a specific work-induced burning sensation within one's muscles. It can be both physical and mental.
6. At its highest level is defined as an overwhelming, debilitating, and sustained sense of exhaustion that decreases one's ability to carry out daily activities, including the ability to work effectively and to function at one's usual level in family or social roles.

### **Pitfalls that you might fall into when asked single action questions.**

[Energy Tokens, we have £10 of energy tokens a day and £70 a week.  
The value to the tokens is personal, only we can work them out.]

**Action - Peeling potatoes.** 'Can you peel a potato?' If you answer 'Yes' and the assessment [could be a verbal question or on a form or survey] stops with that answer then have you given them the full picture of energy you use to do this?

*If we say peeling one potato takes 10 pence of energy, then would it be correct to say 'she is able to peel potatoes'. What about four potatoes, would this be 40 pence of energy and would it be correct to still say 'she can peel potatoes'.*

First we have to get to the place where we are going to peel the potatoes and here are just a few examples of how we might do this.

- 1.1 Stand from chair and walk normally.
- 1.2 Push up from chair on arms and walk with a cane.
- 1.3 Rise using electric rise chair and wearing aids and using arm crutches.
- 1.4 Manually wheeling to kitchen.
- 1.5 Electrically wheeling to kitchen.
- 1.6 Other method.



Next step is to get out all of the equipment needed. Pans, potatoes, knife and peeler. How would you do this?

- 2.1 Stand to do this normally.
- 2.2 Sit on chair, perching stool or wheelchair [can you reach all the items or has someone left them out for you].
- 2.3 Lean against the work surface to use both hands, hold with one to use the other and have to stand because your arms only work well when angled down at 45 degrees and with elbows in as short arm levers.
- 2.4 Other method.

Now we have to turn on the water, wash the potatoes, peel them, cut them into pieces and put them in saucepan. Which answer would you pick?

- 3.1 Can do this.
- 3.2 Wash and peel them but not cut.
- 3.3 Wash and cut them but cannot peel [different wrist actions].
- 3.4 Someone else has done them and left them in water in saucepan for you.
- 3.5 Or maybe another combination.

Now we have to go and wait whilst they cook and return to the kitchen.

4. Answers as section 1.

Now they are cooked they need draining, and then putting on the plate as they are, or maybe mashing them. Which answer/s would you pick?

- 5.1 Do whatever needs doing as normal.
- 5.2 Because I cannot now lift the saucepan full of potatoes and water
  - A. I slide the saucepan across the work surface and tip potatoes into colander placed in sink,
  - B. or use a fish fryer basket in the saucepan,
  - C. or use slotted spoon to lift them out,
  - D. or use a stove top or electric steamer.
- 5.3 Am able to mash them.
- 5.4 Can squash them a bit with a masher but not mash.
- 5.5 Have to eat as they are because I cannot mash or squash.
- 5.6 Other method.

You now have to go to the place where you are going to eat these potatoes.

6. Answers as section 1.
7. You now have to chew the food, swallow it.
8. Take the plates back to the kitchen and wash them up and put them away.

Potatoes alone are not a meal, add cutting and cooking the meat, making gravy.

I have great difficulty peeling, cutting and mashing due to new wrist and arm weaknesses. I now have direct payments and my 'help' does the veg and cuts meat for the crock pot etc. I worked out that if I had to do each of the parts of this task that it would take about £1.40 worth of my days energy tokens just for the potatoes! Remember every bit of energy you can save can be used elsewhere. See overleaf how to work out your energy tokens.



## How to work out your energy tokens.

Use your 'My Polio Life' list of actions of daily living to help you.

Write down what you need to do in the home. Things like getting in and out of bed, getting dressed and undressed, bathing and washing hair, shaving, getting meals, doing any items of housework/laundry that you can manage, hobbies, crafts, projects in your workshop, etc.

Then think about the actions when you go out of the house. Going shopping locally or in town, to see GP or hospital appointment, visit library, exercise class, walking the dog, bit of gardening, do you do the driving, get the wheels in and out of the car, use your electric wheelchair or scooter, push yourself manually, someone pushes you.

You have ten pounds of energy tokens a day and seventy a week. You now need to allocate money amounts to each action, e.g. getting dressed 50 pence, but adding 20 more pence if going out. You might be able to drive for an hour on a motorway in light traffic for £1.00, but say you live in Cornwall and the roads are all winding and hilly then with a lot more arm movement for steering and a lot more accelerator brake changes you might only manage 15 minutes for £1.00. Many of us have pajama days because getting dressed and undressed takes energy and if no one is visiting and we can use this energy to do something else why shouldn't we? We are not being lazy we are managing our lives to the best effect. [Am in my pj's now]

Once you have given token amounts to all the items then it will help you plan your week. Remember it is your choice what you do each day. If you want to use more than ten pounds of tokens for one of the days then that is fine, just remember when planning this week that you will have less for other days.

As you go through the list of daily activities it might be helpful to underline or note where you now use aids or assistive devices or someone else has to help or do it for you. You may need this information to answer questions from Social Services or Benefits Doctors. You need to take your full day into account when answering. You may be able to walk to your neighbours for a cup of coffee but if you fail to say that there are two seats on this journey and you have to use a cane and stop and rest for ten minutes twice each way they will assume you are doing it in one hit and therefore can walk that far.

When filling in forms do not attempt to answer them in pen straight away. Photocopy the forms and write your answers on a copy and get someone else – preferably someone with experience of the forms – to help you word your answers accurately. When none of the choices fit your particular circumstances then add another box with comment. A good idea if you have not seen the form before is to get someone else to read it first and let you know which documents you will need to get out to answer the financial parts. When you start involving Social Services you will find that one visit spawns another from someone else and then another and you find yourself having to answer the same questions over and over again. It is very STRESSFUL. If you can have someone with you. More on this next newsletter.

Do not waste energy on something that can be done by someone else or can be made easier by using aids and equipment. Be energy efficient. Plan ahead, get the most out of your energy tokens. Live to the best of your ability and get lots of laughs



## Tip bits

**Tip 1. Aiding digestion** Last time we saw our Chiropractor, Dr. Darren Barnes-Heath who specialises in neurology we flippantly asked if there was any way he could help our increasing and droopy stomach size.

We were stunned when he said, 'Yes I can' and explained that now we are not walking as much our muscles don't move so much, reducing how much they stimulate the cerebellum which in turn helps to stimulate the digestive system. The brainstem influences the tone of the gut muscles and the release of all the different digestive enzymes. [When he assessed Mary Kinane and spoke at our AGM a few years ago many were surprised at the methods he used to see how the brain and the muscles were talking to one another, including eye movements and smell]. Firstly we can gargle two to three times a day for a minute. Secondly, he said that often the cerebellum can be activated by eye muscles to help stimulate the digestive system. Ideally he says you should be seen by a Chiropractor who specialises in neurology who will assess you doing these exercises but we could do all the pathways to see if it helped us.

**Sitting.** Close your eyes. With your head still and moving your eyes slowly and smoothly in an X shape go from top left to bottom right and then top right to bottom left. It sounds simple to do but it is not to begin with, so try looking in a mirror with your eyes open to start with. Repeat this 3 times 3 times a day.

**Sitting** looking forward focus on a spot in front of you and keeping your eyes focusing on the spot move your head to the side but remember your eyes must stay focusing forwards. Go from one side back to the middle, then the other side, then up and down in a + shape. Repeat this 3 to 5 times 3 times a day.

Remember start with one or two repeats and if you have any problems trying this then stop and get further advice.

Whilst this might sound strange I can confirm that our monthly appointments over the last four years of 20 minutes each have kept us going and most of our problems have been improved by his treatment. One day I had a very stiff left side of my neck and shoulder and he advised the second exercise 4 times to the right only 4 times a day. Within days it eased and when it starts up again, mostly when driving long distances, I do a few of the exercises and the muscle tension subsides.

**Tip 2.** Good Calcium in green vegetables. When we told him we were taking calcium because Richard could not have dairy products he told us we could get enough calcium from eating green vegetables each day.

**Tip 3. Changing the bathroom.** If you are moving or contemplating changing your bathroom a Wet Room might not be what you really want/need. 10 years ago I took Social Service advice and had a wet room put in. It did not work for me, and it did not work for Richard. We were unable to deal with our legs below our knees. Sitting on a shower stool or seat one still has to balance as you move about to try and get water over all your bits. Relaxing in a bath [although you lose four inches of water from the bath lift] is wonderful. Being able to clean your lower legs and feet, shave legs if you need to, rub off hard skin, clean between those toes feels so good Remember if you need handrails now or in the future or you want to fix toilet and sink without pedestals to the wall you might need to have the wall strengthened with board. Our bathroom is being totally refitted next week, more next issue.



Editors note - [Medical terminology and other notes added at end]

## Fourth and Final Installment

### Post Polio Syndrome - Fourth Year Lessons Feb 2004 to Feb 2005

By Gladys Swensrud, San Diego, [swensrud@pacbell.net](mailto:swensrud@pacbell.net)

One important thing I believe all polio survivors must keep in mind as they try to understand their personal issues related to old polio is: Each and every problem could have another origin beside PPS. The most difficult part is to separate them into the two different categories of PPS related and OTHER. I, personally, have had a tremendous problem doing that, and I can only guess other survivors have had the same trouble. When I look at my situation living with: ongoing muscle fasciculation and fibrillation, Bulbar issues like - loss of gag-reflex, unprovoked/silent reflux, and Mixed Sleep Apnea - daily muscle exhaustion (from simple use of my muscles, which may be explained by my EMG as having severe chronic neurogenic changes), neuropathy in my toes, bilateral Hoffman's signs, brisk reflexes, muscle issues related to imbalance in my musculature, etc., I am not certain where to apply responsibility aside from old polio.

And here is the problem in easy to see terms

**A. Muscle Fasciculation** [1] I know occasional muscle fasciculation is not uncommon for healthy people, such as in that twitching eyelid, but my fasciculation problems are found throughout my body each and every day. They are clearly the most numerous in each muscle determined by my EMG to be identified as having old polio. They are also in several spots that make me suspect those muscles are the next to begin to cause problems. When I awaken in the morning, often muscle fasciculation is the first thing I notice about the day. This indicates to me that my muscles are tight while sleeping, and some times, in fact, I awaken with my muscles so tight that I must mentally work to make them relax. It is these days when I am especially grateful that I use Neurontin [2]

I have read time and again, if you restrict activities, the muscle fasciculation problem is much better - to that I am a major skeptic. Even on days when I have been sedentary, if I tighten my muscles to move my legs - even just to change positions - a giant motor fasciculation will move across one of my quads to remind me in spades that they are there. And sometimes, for no apparent reason on sedentary weeks, my fasciculations are particularly active.

One interesting piece of information I learned this year is that fasciculation in a muscle can be large. Perhaps some of the myoclonus muscle movements [3] I thought I felt were actually just giant fasciculation. I try to assess by thinking whether or not my leg actually is forced to move by the force of the contraction. It is hard to know because when they happen to you, they surprise you and always feel powerful. [4]

**B. Bulbar issues** - Loss of gag reflex - [The gag reflex is elicited by stroking the pharyngeal mucosa (back of the throat—smile) with a tongue depressor. A gag reflex can be elicited in most normal persons.] Add to that a clear diagnosis of a Mixed Sleep Apnoea breathing deficit, {Mixed is OSA and CSA [5] which is likely to be caused by polio weakened neck and breathing muscles - compounded by the fact that my brain may not always be reminding me to breathe. Then layered on that



is the vulnerability of unprovoked, silent reflux, and this all looks a bit more complicated.

### **C. Muscle exhaustion is easily understood for those who experience it.**

My friend, Sandy, who is in her second round of treatment with ovarian cancer, really hit the mark when she said, "Now I understand what you mean by muscle exhaustion." I think she interpreted it perfectly! She was correlating how she feels on chemotherapy to how I feel when my muscles are weary from any overuse and produce that flu-like feeling. The basic problem is that our brain sends the signal to move, but the body is just too tired to listen.

### **D. The inability to stand for long because of leg muscle weakness.**

Clearly defined muscle issues in both legs from my EMG.

Neuropathy in my toes - the "ill-defined sensory symptoms of paresthesia (burning, prickling sensations) or focal pain." (From the book Amyotrophic Lateral Sclerosis, A guide from Patients and Families) (Explained in detail below!) {ALS is known as Motor Neurone Disease - MND - in the UK}

**E. Bilateral Hoffmann's signs** [6] Anyone who has had a thorough neurological exam has had this easy test. This reflex is triggered by the quick release that occurs after the forceful flexion of the joint at the tip of the middle finger. A reflex inward flexing of the thumb on the same hand is a positive response." Yet, to confuse me further in trying to separate PPS from OTHER, it could also be said "bilateral positive reflexes may not be abnormal because they are not unusual in healthy young individuals." (From the book Amyotrophic Lateral Sclerosis, A guide from Patients and Families)

### **F. Brisk Reflexes**

I digress just slightly here because my brisk reflexes and how they fit a Post Polio diagnosis have baffled me since the inception of my PPS problems. Typically polio presents with paralysis, muscle atrophy and hyporeflexia (a decreased reflex response), and ALS presents with muscle atrophy, fasciculation and hyperreflexia [defined as overactive or over-responsive (brisk) reflexes]. How did I get caught between the two? I had many questions and absolutely no answers. While doing some peripheral reading, I stumbled upon reference to a book titled, Clinical Neuroanatomy made ridiculously simple by Stephen Goldberg, M.D. In reading it I learned a tremendous amount about the brain and how it works to direct the functions our bodies perform. What I was specifically reading to learn was: What part of the brain controls reflexes? What I actually learned was the brain is central to all the issues surrounding Post Polio Syndrome. It added credence in my mind to the approach Dr. Richard Bruno took in his book, which I recommended in my Year 2 summary, The Polio Paradox, What You Need To Know.

Since I could not pinpoint the exact reason for my hyper reflexes, I contacted, Dr. Susan Perlman, a well-known and respected neurologist in the southern CA area, who is Director of the Post-Polio Center at UCLA. I posed a thoroughly clear picture of my problem to her. Her response was, "It appears that some polio survivors may develop what are known as upper motor neuron signs in the context of a classically lower motor neuron problem (PPS). The original polio was "poliomyelitis" - the myelitis part referring to an inflammation in the spinal cord (home of the upper motor



neuron pathways). I suspect that the original infection did inflame the adjacent upper motor neuron pathways (perhaps causing the severe painful spasms some patients experienced) and left these pathways scarred in some way and open to future changes (like brisk reflexes)."

Because of Dr. Perlman's response, at long last I had reached the point where I could stop frantically searching for answers to the Upper Motor Neuron (UMN) symptoms, which took so much of my time and energy. And her explanation fit perfectly into the chasm of information that bewildered Dr. Munsat and other researchers at one point in his book. I will always be thankful that Dr. Perlman was so accessible to answer questions because this one answer enabled me to finally find comfort with a possible solution to this issue, which had plagued me for four years. It allowed me to move on to do other, more constructive things with my time.

### **G. Weak muscles that cause a domino effect elsewhere in your body.**

In my case, weak shoulder muscles that imbalance the bones in my shoulder and arm. Clearly a muscle issue in my polio-weakened left bicep and triceps determined by my EMG could play a part in this muscle riddle.

I suspect each of the above is old polio related, but of course there is no way for me, or anyone else to tell. When you see a neurologist, they note things like bilateral Hoffmann's signs may indicate abnormality, but they may not be abnormal because they are not necessarily unusual in healthy young individuals. Or they will relate to you that neuropathy in your toes can indicate a problem, but it also isn't unusual to find them in healthy elderly people. However (to confuse the lines of division between PPS and other even more), as stated in Amyotrophic Lateral Sclerosis, by Hiroshi Mitsumoto, M.D. and Theodore L. Munsat, M.D., on page 32,

"In our studies nearly 20 percent of patients with motor neuron disease (180 with ALS and 36 with progressive muscular atrophy) had ill-defined sensory symptoms of paresthesia (burning, prickling sensation) or focal pain. However, sensory examination showed no abnormalities except a decreased sensitivity to vibration in the toes, {which is not unusual in healthy elderly people." [7]

My dilemma is: Along with everything else, how do I categorize the problem of burning in my toes, and, as verified by my doctor, decreased sensitivity to vibration; how, exactly, can I explain these along with each of my other neuromuscular concerns in one body? Are these PPS issues or OTHER? It just all blends together. And what, exactly, is OTHER?

I have filled this year with research, investigations [as my interest in Creatine Kinase (CK) levels] [8] and my quest to give back to the world a little for all I have been given. My connection to, and volunteer time with, the San Diego Neuro Network (SDNN), a collaboration of fourteen neurologic and neuromuscular agencies in the San Diego area, has been a tremendous positive in my life. I have met so many wonderful people, whose life's purpose is to find solutions to the suffering others endure with neurologic and neuromuscular disorders and diseases.

I have filled many wonderful hours making blankets for Children's Hospital, knowing they will bring warmth and joy to every child that receives one. I spend a great deal of time watching the ads and sorting through bolts of fabric to find just the right ones for children in the 10-18 age categories. As my best friend, Kathy O'Neill, and I have



learned: fabric shopping and making blankets can be addictive; we find ourselves spending Saturdays driving from shop to shop for just the color or pattern we want to complete a blanket, but at the same time, we are creating a wonderful memory together by sharing this adventure as best friends!

I am delighted that my work this year to bring more books on Post Polio Syndrome to the San Diego area libraries was successful. Rotary International in the San Diego area has paid for 4 new titles to be added to the San Diego Public Library system. The books will be tracked to see whether or not they are utilized, and if there is a great demand for them, Rotary International has agreed to fund more books in the coming year. And, at the same time, the San Diego Neuro Network has been generous with their book gifts this year as well. We, as a group, donated books from each agency to the county library system; then working closely with the San Diego City Library staff, we culminated this effort, by delivering books representing our agencies to the San Diego City Public Library system.

Special kudos are assigned this year to my wonderful hand surgeon, Dr. DeLois Bean. I adore her! One of the unrelated PPS issues, which I would identify in the other column, although it too could be PPS related (but was not in my case), was impending carpal tunnel surgery. Dr. Bean is the ultimate professional! She identified the problem, discussed options with me, made me feel confident my choice was the correct one in my case, scheduled surgery in short order, and the outcome was magnificent. Once again, as with Dr. Lamantia and Dr. Murray, it is a team effort that creates the best result.

The time invested this year in managing my health issues was, in retrospect, a bit overwhelming. This is partially due to my tenacity in trying to bring the breathing issues of PPS to the attention of my HMO.[9] It was also due to my interest and investigation of CK, but mainly it was attributable to keeping my physical issues in check. When I was first diagnosed, I remember a neurologist intimating I should go home, learn to accept this new challenge and spend my time doing other things I enjoy and not wasting it on doctor visits. Perhaps that would work if, when you first went to see a doctor, they understood all the issues related to Post Polio Syndrome and could address all facets of your concerns correctly. Unfortunately we have no such comprehensive clinic in place at this time in San Diego. But, if I had followed that doctor's advice, how long would it have taken for my undiagnosed breathing deficit to slowly and methodically rob my body and mind of life giving oxygen. the point to which I was headed. and for me to just quite thriving completely? Until Post Polio knowledgeable doctors are in place in the San Diego area, those of us with PPS must be ever vigilant!

As I begin year five, I will continue to work toward more recognition within my Health Maintenance Organization about the breathing issues surrounding PPS and other neuromuscular disorders.[10] I realize I pose a real challenge to them, and they are far from appreciative that I continue to solicit their help! Whether or not you win, sometimes, certain issues are just worth the fight!

With thanks to each doctor that was named in this year's summary for his or her help and assistance. As in my summaries from years 1 - 3, I sent each doctor I named in Year 4 a copy of Post Polio Syndrome - Fourth Year Lessons. I sought and obtained permission from each of them to use their names prior to printing this



summary. They have been, and continue to be, the best support system a patient experiencing the late effects of polio could ask for! I feel so fortunate to be in their care &/or in contact with them!

### **Gladys.**

Contact and additional information can be found at [www.swensrud.com/postpolio](http://www.swensrud.com/postpolio) or approval to copy this in its entirety can be obtained by emailing Gladys Swensrud at [swensrud@packbell.net](mailto:swensrud@packbell.net).

### **Editors Notes.**

1. Fasciculation - (or "muscle twitch") is a small, local, involuntary muscle contraction (twitching) visible under the skin arising from the spontaneous discharge of a bundle of skeletal muscle fibers.
2. Neurontin or Gabapentin - an anticonvulsant used to control partial seizures in adults with epilepsy and also certain types of nerve pain.
3. Myoclonus - 'sudden, brief, jerky, shock-like involuntary movements'.
4. Reducing leg fasciculations - A Cambridgeshire Physiotherapist explained to me that our foot muscles are the pump to get the blood back to the heart. Paralysed and weak muscles and a reduction in exercise restrict this happening. Raising legs when sitting can assist the return of blood and the removal of waste products. This advice has considerably reduced my leg fasciculations and peripheral neuropathy - burning pains.
5. OSA and CSA - Obstructive Sleep Apnea and Central Sleep Apnea. USA spelling is apnea, UK spelling is apnoea. Sleep apnoea can be caused by either complete obstruction of the airway (obstructive apnoea) or partial obstruction (obstructive hypopnea—hypopnea is slow, shallow breathing), both of which can wake one up. Central Sleep Apnoea - during sleep, a person with central sleep apnea does not receive the stimulus to breathe; the respiratory musculature fails, breathing stops, and the person wakes up to resume breathing. Mixed sleep apnoea is a combination of both which Richard has and he has a bi-level Res Med VPAP III S/T machine. S stands for spontaneous when he breathes and T for Timed when his brain has not triggered a breath. Remember published in LincPIN [9] CPAP's - C stands for continuous pressure for both in and out breaths] should not be used for polio survivors who have weak respiratory muscles and cannot breathe out against the same Inspiratory pressure. Richards machine is set at pressure 15 in, and 7 out and a back up rate of 10 breaths per minute (for the Timed part of the sequence).
6. Hoffmans sign - a neurological sign in the hand which is an indicator of problems in the spinal cord. It is associated with loss of grip.
7. At age 41 I could not feel the vibration of the tuning when placed on my feet, but could further up my legs.
8. Creatine Kinase - See article by Gladys Swensrud in LincPIN, v.5.4 June 2005.
9. Respiratory - See article by Gladys Swensrud in LincPIN v5.9 June 2006.
10. HMO - Health Maintenance Organisation.



## 'OLD' IS WHEN...

- Your sweetie says, 'Let's go upstairs and make love,' and you answer,  
'Pick one; I can't do both!'
- Your friends compliment you on your new alligator shoes and you are barefooted.
- A sexy babe catches your fancy and your pacemaker opens the garage door
- Going braless  
pulls all the wrinkles out of your face.
- You are cautioned to slow down by the doctor  
instead of by the police.
- 'Getting a little action'  
means you don't need to take any fibre today.
- 'Getting lucky' means  
you find your car in the parking lot.
- And 'all nighter' means  
not getting up to use the bathroom.

## AND 'OLD' IS WHEN...

You are not sure these are jokes?

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Two large hairy caterpillars were sitting  
on the garden path  
having a great chat  
when a butterfly flew past.

One caterpillar says to the other  
'You'll never get me up in one of them'.

## 80th Birthday Drink

An old lady goes to the bar on a cruise ship and orders a scotch with two drops of water.

As the bartender gives her the drink she says,

'I'm on this cruise to celebrate my 80th birthday and it's today.'

The bartender says, 'Well, since it's your birthday, I'll buy you a drink. In fact, this one is on me.'

As the woman finishes her drink, the woman to her right says, 'I would like to buy you a drink, too.'

The old woman says, 'Thank you.

Bartender, I want a Scotch with two drops of water.'

'Coming up,' says the bartender

As she finishes that drink, the man to her left says, 'I would like to buy you one, too.'

The old woman says, 'Thank you.

Bartender, I want another Scotch with two drops of water.'

'Coming right up,' the bartender says.

As he gives her the drink, he says, 'Ma'am, I'm dying of curiosity.

Why the Scotch with only two drops of water?'

The old woman replies, 'Sonny, when you're my age, you've learned how to hold your liquor.

Holding your water, however, is a whole other issue.'

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why not support our work by joining us

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who know where you are coming from  
is a HUGE stress reliever**

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If you do not wish to cut the newsletter  
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A Post-Polio Information Service for Polio Survivors and Medical Professionals  
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## Newsletters - The LincPIN - Next Issue February 2009

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**REMEMBER - DONATIONS TOWARDS OUR WORK, LARGE OR SMALL, ARE WELCOME**





Wheelchair nearly in the car



Scooting myself backwards to the front of the car



Safely in the driving seat, pulling the wheelie-stool after me

Paul's invention means I can go out by myself. It costs me an awful lot of energy tokens to do, which means that I have to ration myself to one or perhaps two trips in a week. In terms of independence, my contraption is worth its weight in gold.

How many Polio Survivors do you know who have slowed down their level of functional decline, reduced pain and fatigue levels and become less stressed by telling it like it really is? Who have learned to pace and rest and accepted that those aids and assistive devices that you feel come with a DISABILITY or 'REALLY OLD PEOPLE USE THIS' label, can actually made a huge difference to the way we manage our lives?