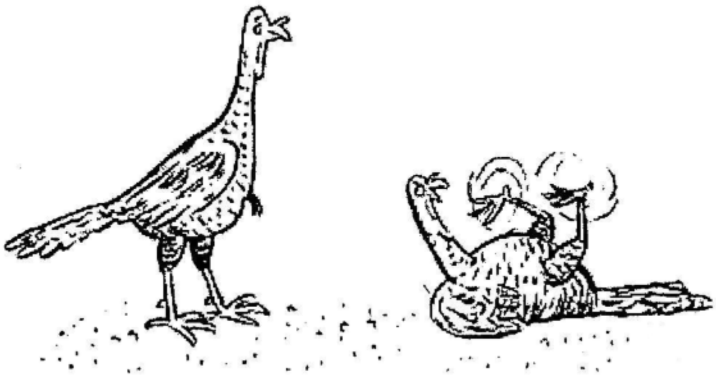
The LincPIN

The Lincolnshire Post-Polio Information Newsletter
Volume 5 - Issue 7 — December 2005

WebSite - http://www.lincolnshirepostpolio.org.uk

Seasons Greetings & A Happy New Year to All our Members their Families and Friends



“What am I doing ! ! ! ? ”
“I am exercising......
and intend to be tough and leathery
by the 24th of December”

We would like to thank the Hawaii Post Polio Network
for permission to use the above cartoon from their November/December 2005 Newsletter
with slightly adapted wording. Contact for this group is Jane Marcum <marcuml001@hawaii.rr.com>

Lincolnshire Post-Polio Network - UK Registered Charity No. 1064177

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WE WOULD LIKE TO THANK THE FOLLOWING FOR DONATIONS RECEIVED TOWARDS OUR WORK.

Agnes Walker, Victor Gabriel, Barbara Bradley, Joy Witheridge, Winnifred Hyam, Anne Williams, Heather Chadwick, Jean Simm, Simon Parritt, Brenda Fleet, Vic Oliver, MR Reece, L Hobday, Barry Branston, I Meade, Mrs John Bowles, Yvonne Webb, Margaret Edmonds, Y Liggins, AT Telford, L Reeves- Hall, Robert Price, Ewan Peddie, Jim & Jenny Rayner, Sylvia Fortune, Sheila Dunnett, Robin & Pauline Butler, Barry & Olivia Branston, Hilary Hallam, Mary Kinane, Denise Carlyle, Chris Salter, Di Newman, Di Brennand, Pat Hollingworth, Margaret Edmonds, Judy Barter and Mary McCreadie.

Lincolnshire Post-Polio Network - UK Registered Charity 1064177
Donations large and small towards our work are always welcome.

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Membership Information

Renewal dates are the first of the Months of Feb, Apr, Jun, Aug, Oct, Dec.
Please make cheques payable to 'Lincolnshire Post-Polio Network'
Post to Membership Sec, UK, 13 Derville Road, Greatstone, New Romney, Kent, TN28 8SX
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Next LincPIN Newsletter - March 2006
Articles for publication 14th February by post or - newsletter@lincolnshirepostpolio.org.uk

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Message from the Chair

Hello Readers, It has been a busy three months since we last went to print. In that time, we have had our Annual General Meeting in Lincoln and the feedback from those attending suggests that our choice of speakers was timely. In particular Dr. Darren Barnes-Heath, BSc, DC, CCEP (a doctor of Chiropractic specialising in neurological conditions) of Newland Chiropractic Clinic in Lincoln gave a fascinating talk and demonstration on how Chiropractic can help those with pps. He has done four years Post Graduate work in neurological conditions with the Carrick Institute and at present is one of seven qualified in the UK. It wasn't the first time I had volunteered to be a 'guinea-pig' for demonstration purposes, and offered myself (but in particular my knees, elbows and eyes!) for a number of reflex and response tests, a study in balance, and a fascinating test on how the left and right sides of the brain work. I hasted to add that none of the tests were invasive in any way and were completely painless. Dr. Barnes-Heath's treatment methods have already helped some PPSers in the Lincoln area to improve function, and I think he had a few more would-be-patients by the end of his talk. We liked the fact that he turned what can be difficult material into a very accessible presentation, and I am glad to quote member and newsletter distributor Barry Branson who said '"That was the best talk I have ever attended." Dr. Barnes-Heath is writing an article for our newsletter but has had to delay this to our next issue as time has run out on him following the birth of his first son, Edward. Congratulations and thanks to his wife for holding off till after the AGM.

Also on that day, we had a talk from Mark Rainey, Carers Service Co-ordinator from the Social Services Directorate of Lincoln County Council—with useful information on developments within Social Services, and how they are set up to respond to Carers needs. Carers in Lincolnshire can now ring his department and ask for an assessment over the phone or at a meeting to ensure that they are in receipt of benefits and help available. It was generally agreed (by those attending) that many carers, especially those who are also disabled/getting older/living with long-term conditions themselves would need to be quite persistent and determined in order to get a prompt response from existing services. We think that in the end, we gave Mr. Rainey a few things to think about from the point of view of aging ppser's. Contact your local Social Services to see if this or a similar service is available and ask for the leaflets. Both speakers were thanked for coming along and giving so freely of their time.

We are disappointed to report that we are not able to help those under 60 with polio and pps to access extra heating allowances.

Here is the reply on the subject from Minister Stephen Timms to Gillian Merron, MP for Lincoln.

POS(3)10865/160 - Dear Gillian,

Mrs. Hallam has written in support of EDM276 which suggest that the Winter

Fuel Payment scheme should be extended to disabled people aged under 60. I have studied carefully the arguments put forward by Mrs. Hallam and others, but remain unconvinced that we should extend Winter Fuel Payments to this group of people.

We introduced Winter Fuel Payments in 1997 to give pensioners reassurance that they could afford to heat their homes in winter. It is paid in a lump sum each winter to ensure that money is available when fuel bills arrive. Older people are targeted because they are more vulnerable to the effects of cold weather during the winter months than other groups.

Not all disabled people suffer from a condition that is directly affected by fluctuating temperatures; for example, people with learning difficulties, or who are profoundly deaf. I do appreciate that disabled people can face extra costs. For example, they may need to spend more on food and transport. Some certainly do need extra heating. By and large, these needs arise all year round and not just during the winter months.

This is why benefits such as Disability Living Allowance and the disability premiums in the income-related benefits were introduced. They provide additional weekly payments and are related to the individuals circumstances. The most severely disabled people receive an additional amount of over £7,000 per year in recognition of their extra needs costs.

I believe that by targeting help to disabled and elderly people in these differing ways we are better able to meet their individual needs.

I would like to assure Mrs. Hallam that we remain committed to tackling fuel poverty. Fuel poverty is caused by a combination of factors, the most common of which include energy inefficient housing, under-occupancy and fuel prices, as well as low incomes. The UK Fuel Poverty Strategy, published in November 2001, set out a comprehensive package of initiatives to ensure that by 2010 no vulnerable household in England should be living in fuel poverty. Warm Front, the Government's main programme for tackling fuel poverty in the private sector in England, has assisted over one million households since its launch in June 2000. The Scheme provides grants for insulation and heating improvements to households in receipt of qualifying benefits. Recent improvements to the Warm Front Scheme mean that all eligible householders will be able to receive full central heating as part of a comprehensive package of measures designed to take, and keep, households out of fuel poverty. There are also comparable Schemes in each of the devolved nations.

To find out more about the Warm Front Scheme, householders should call

0800 316 2028

Yours ever,
Stephen Timms MP
Minister of State for Pensions Reform

Department of Work and Pensions
Richmond House, 79 Whitehall, London, SW1A 2NS
020 7238 0800
Email - ministers@dwp.gsi.gov.uk
www.dwp.gov.uk

About the Warm Front Scheme
http://www.defra.gov.uk/environment/energy/hees/01.htm
and the Grant form and eligibility!!!!!!!!!
http://www.eaga.co.uk/Grants/warm_front.htm

We will continue to support the pressure on government to make Winter Fuel Payments payable to those under 60 years of age, with long-term conditions. However, if you are aged over 60 and living in the UK, contact the government Winter Fuel Payments Helpline on 08459 15 15 15. If you are a member of the British Polio Fellowship, are living on a low income and in the UK, you may apply for the Fellowship winter heating grant by phoning 0800 0180 586.

Stop press in the Sunday Express, Dec 4th by Julie Hartley Brewer, Political Editor, 'The Chancellor is planning to slash winter fuel payments, end free TV licence for the over-75's and scrap the pensions link to earnings, when he is Prime Minister, to save cash. This is the astonishing claim made by Ros Altman, a highly respected independent pensions policy expert who has advised both the Treasury and Number 10 since 1999.' Will be looking into this.

With Mary McCreadie's thoughtful input, (see pages 16 to 22 in this newsletter) as well as Chris Salter's unstinting web support, it is good to see the LincsPPN Members email list so busy at the moment—that's our forum for those who use email to discuss matters online. If you have recently changed your email address, or wish to be subscribed to this list please email mary.mccreadie@lincolnshirepostpolio.org.uk who will check your membership status and get your subscribed so that you too can join in the discussions.

I would also like to thank member Graham Kay who recently wrote to me with fund raising suggestions.

Wishing all our members
A Happy Holiday and Happy New Year.
Mary Kinane, Chair
mary.kinane@lincolnshirepostpolio.org.uk

Please take special note of the Membership Announcement at bottom of page 22.

Compensatory and Recruited Muscle Use by Polio Survivors allows us to ‘cheat’ to achieve actions, but is ‘cheating us’ when we are being assessed.

By Hilary Hallam, December 2005.

A further problem regarding the assessment of Polio Survivors has just come to light. We have already highlighted the fact that Manual Muscle Testing when done to a lesser time/ number of repeats lower than that of the reported start of weakness will not corroborate what is being reported. That it is essential to self assess and give more accurate information. It is the change between how you used to do each action in your daily life and how you do it now that is important information to pass on.

Every time my arms were tested after the fall in 1988 and the start of my new symptoms the following took place.

Reported Symptom	‘My arms are getting weaker, I cannot swim as fast’
First test	Grip strength.
Action	Sustained strong grip for four seconds.
Result	Recorded, muscle strength level 5, normal.

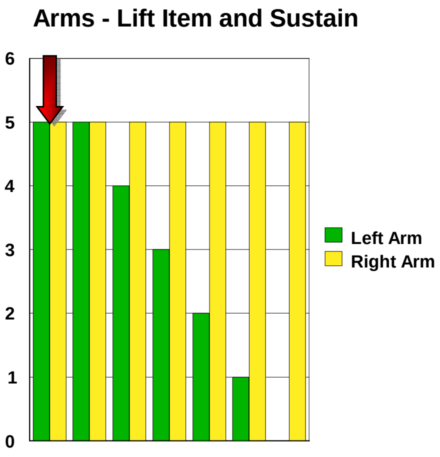

Chart to the left shows at two second intervals my ability to sustain the grip and weight of a saucepan of potatoes for 4 and water. Test above lasted for 4 seconds and did not pick up the decline seen here at six, eight and ten seconds.

Self assessment allows me to change the Reported symptom information to:-

‘I can no longer sustain the grip and weight that I used to. For example, 5 years ago I could lift a saucepan of potatoes for 4 and water, take it to the sink and drain it with no problem. Now I can lift it from the hob to the work-surface - next to one another - but then have to slide it along and take the potatoes out with a slotted spoon.’

To counter any response that a Doctor would realise this, I passed a very stringent medical in 1969 for the Police Force. When I arrived at Training School and saw the Timetable I had to speak to my Sergeant and ask that I be excused from cross country running. Can you imagine their surprise when I told them the reason being that I had never been able to run following my polio at age 5. I could also not rise from a squatting position without using both hands. It was only after receiving the medical report from a Neurologist for the Defence of a Court case in 1998—*on neurological examination of the legs power at the left leg, hip knee and ankle are normal’* [my left leg is my weakest and has never been normal since polio] that this fact came to mind and made me realise that the validity and reliability of single action Manual Muscle Testing has to be faulty. No doctor or health professional would record figures that he did not believe to be true.

The new issue we are raising relates to testing us for reported respiratory symptoms. About five years ago I was approached by a member who had just come back from Papworth Hospital and been told that the figures were fine nothing wrong with her. She replied, ‘but when they tested my breathing ability in a variety of tests they could not do the three repeats wanted at their normal resting times as I did not have the oomph to comply. It took two hours to do fifteen minutes worth of tests.’ I recommended that through her GP she contact the hospital with this further information and believed it had been taken on board.

Ten years and one week after finding PPS existed and bringing the fact that I had had polio as a child into the equation found me at Papworth Hospital for a similar assessment for answers to a list of symptoms. With all the work I have done during this time I was well prepared with a copy of my mid 2004 base line assessment and three pages of typed notes for this visit. Contact details, allergies, intolerances, medicines taken, symptoms, and problems with daily living. To read this as a stand alone document I will set the scene.

In May 1952 at just over five years of age I caught polio when I was in Libya and was initially paralysed waist down with good recovery leaving me with some leg weakness.

In 1958 and 1959 I had tendon transplants in both feet and was able to do more physically. Over the next fifteen years I attempted nearly every sport I could that did not involve running or rising from a squatting position. I did judo, lifesaving, swam for my county, ballroom dancing, rock climbing albeit using strong arms due to leg weakness, canoeing, and at Police Training School completed the 49 mile Lyke Wake Walk across the North York Moors in 18 hours. Polio was part of my past.

My physical abilities prior to a fall in October 1988

- I was working 60+ hours over four jobs, Advanced Swimming Teacher, Senior Lifeguard and Training Officer, paperwork & parts delivery for our garage business.
- Plus an average of 10 hours voluntary work a week and during the summer this was as a Lifeguard at the Chapel St. Leonards Lifeguard Station on the East Coast of England.
- My two children were teenagers and I did all the housework, gardening and decorating.

After the Fall on October 10th 1988, where my foot merely slid on a small wet patch on the handicapped school corridor where I taught swimming in the hydrotherapy pool, I started to have new symptoms and a loss of physical ability. I spent three weeks in neck traction, diligently did all the recommended physiotherapy but the more I did the worse I seemed to get. I could now no longer swim as fast, or pull myself out of the deep end of the swimming pool, or pass even the basic lifeguard award and I lost most of my jobs which was devastating. The testing did not corroborate the weakness I was reporting.

Seven years followed of medically noted yet 'disbelieved' unexplained symptoms with almost no corroboration of what I was reporting. This was despite a continuing and considerable deterioration in my physical ability. I repeatedly had to face that facial expression of 'you are a malingerer, you are not trying hard enough, there is nothing wrong with you'. What was wrong with me, was I mad, MS and Alzheimer's?

On November 22nd 1995, Seven years after the fall and six months after having to give up work through continued deterioration I attended a medical appointment to hear the results of my MRI and at last find out what was wrong with me. I was stunned to be told, 'Glad to see you are better'. I said 'I had polio as a child could that have anything to do with this? The doctor then said, 'Oh there is something called the Late Effects of Polio, I don't know much about it, but I had another patient like you and sent him to a Neurologist.'

After seven years of brick walls that there was nothing wrong with me I now had a possible name for my condition. My polio was now back in the equation. Now I would get the help that I needed to manage my life, but No…..

Two more years of brick walls. November 1995 to February 1997 and all test results are normal through one hospital. No diagnosis. March 1997 to December 1997 starting all over again at a different hospital system and after a full days tests, *nothing else found so we can confidentially diagnose the post polio syndrome.* The end to the brick walls? NO.

Most test results did not corroborate what I was saying, just a couple of other examples.

- 4 years of medically recorded symptoms of visual problems and testing at two hospitals with nothing significant found, ? Optic neuritis. [Research on Polio lists elicited that it was likely to be weakness of muscles that move the eyes and accommodation. Confirmed by my optician after reading a report from an Australian Optician,]

- Three months attending the ENT department for voice deepening and hoarseness and swallowing problems. Nothing found, you have nothing wrong with you.

In 2004 I was lucky enough to find a new Rehabilitation Consultant Dr. Prasad—out of the area where I lived - who had made a full A4 page of notes on my file, who listened to what I had to say and agreed that with no base line assessment on my records it was difficult to show progression either way of my condition. He referred me for a variety of tests - giving me the waiting times - including to a Physiotherapist for a full assessment. [nine months wait for this appointment]. BUT joy of joys, Senior Physiotherapist Gill Weir was interested in PPS, she listened, she discussed, she observed how I achieved actions, she gave up hours of her own time and worked with me on 'Assessment forms' and by the end of 2004 I had my base line assessment, not only corroborating what I had been saying but finding other new weaknesses. At last now I had this there would be no more brick walls, or ?

In September 2005 I had my yearly appointment with Dr. Prasad and again expressed concern about the fact that some of my symptoms remain unaddressed, e.g. my voice continuing to deepen; getting hoarse after speaking for some time; Richard telling me that I snored very loudly and that I stopped breathing for short times; that I had had swallowing difficulties for over 10 years now; that I choked every time I burst out laughing, I was referred to Dr. Shneerson head of the Respiratory and Sleep Centre at Papworth Hospital. And I was lucky enough to receive an appointment for the end of November.

I was admitted on Monday 30th November 2005 -10 years and one week on from the first time my polio was taken into the equation when assessing me - and now I would find out what was causing all those symptoms and expected that I might have to start using a night time ventilator. I was nervous.

The last thing I expected was another brick wall and I could not believe it was made of the same bricks. The figures from the test results did not corroborate what I was saying. [See the charts on the back page] I did take information with me - my base line assessment and 3 pages of typed notes to be put on my file. Half a page was symptoms relating to the testing that was going to take place. The admitting nurse read this, the admitting doctor skimmed it and passed it back. I tried to discuss the fact that I believed that the way we breathe has something to do with our weakness but got no response. The night time tests took place but the system is such that at 7 a.m. Dr. Shneerson looks at these faxed figures and decides who can go home that day telling the ward staff how many beds are free for new patients. Further tests are to take place that day but you are told you are going to be discharged and you do not get to see the Consultant till after those tests and just as new patients are arriving at 2pm.

I had an x-ray and then went off to the Respiratory Laboratory, [where I was told that they did not see many people with pps, remembering only 2 in the past three months], and met with Roy who was happy to answer questions and discuss any issues. [Roy has also agreed to answer general, not personal, breathing test questions]. As the first test was to repeat three times and take my time between repeats I said 'You are going to record the time taken between tests?' and when told 'NO,' was horrified that this was still happening. Surely not another Brick Wall, test result figures might not show my problems.

To explain. You are asked to take a deep breath, a peg is put on your nose and you are asked to breathe out for as long as you can. Then rest, and then normal resting time of 30 seconds, repeat, rest and repeat again. However, Polio Survivors [and how many others?] are told take your time between tests. So instead of 30 seconds it was 2 minutes and then 4 minutes. Three results almost the same. The next test was the same and so on. Thankfully my tester, 'my bricklayer' was interested. As the testing continued we found that I was recruiting more and more muscles to achieve actions. When trying to hold my breath for ten seconds I ended up pushing hard against the floor with both feet. When asked to lie flat for the last test, twice I raised my head to achieve the action, to be told, 'No, keep your head flat,' and this time requested testing at normal resting times. This showed deterioration on repeat 3 and 4 but we talked for longer between the fourth and fifth repeat and the result started to go back up. Which in itself was very useful as Roy explained it showed that resting for an extra minute showed a higher result and start of recovery from muscle fatigue. When the tests were finished he said that he had added notes on my file and would be taking up what had happened at a staff meeting on Monday. The brick wall that had appeared was now much lower. I was physically exhausted. My ribs ached badly, I was only able to move a little amount of air in and out. I returned to the ward to meet Dr. Shneerson, hear my fate, and be on the road by 1.45 p.m. to get home in daylight.

I did not expect and was surprised to hear that my sleep tests were fine, my oxygen and CO2 levels were within limits [no sleep apnoea] I was asked when did I have polio, what area of my body was paralysed, was I in an iron lung. I replied 'waist down paralysis and no iron lung'. Then the results of my breathing tests, 'these figures are fine,' and the Brick Wall suddenly gains bricks fast. I pointed to the first few words of notes in very small type showing that I fatigued easily to be told 'it was nothing to worry about. I don't need to see you again.' I made a big mistake here. I left, I should have insisted that I have more time to discuss this with him and 'my bricklayer' and asked to stay another night. But I was devastated. How should we approach a Doctor when we believe he is wrong?

In desperation I rang Chiropractor, Dr. Darren Barnes-Heath - who spoke at our AGM - and told him what had happened and asked for his help. I showed him the three pages of information that I prepared and taken with me. Here are just a couple of phrases from a comprehensive report that has now been sent to Papworth. '*Hilary's muscles fatigue very rapidly and so repetitive muscular activity like breathing is constantly at a low level of functionality.' and 'I suspect her palate muscles are fatiguing during her sleep because her medullar output is low and this is causing her reported sleep apnoea.'*

Once again we are able to show that the validity and reliability of this method of testing Polio Survivors [and others with similar neuromuscular problems?] must be faulty. I have not listed at least 45 other brick walls since my fall in 88. So many unproductive appointments with testing not corroborating symptoms. Such a waste of NHS money, time and energy and making me worse than I need to be through stress, frustration, incorrect advice, lack of necessary equipment, treatment, etc.

We will now be revising and updating our Information Pack over the next couple of months. Donations towards the cost of printing and posting would be very welcome. Remember the ball is in your court. You must self assess, you must listen to what your body is telling you. Ask family members and friends to go through your daily activities and help you record the changes. Take that information with you and ask which muscles are you using and ensure that you are tested to the level of your reported decline and that your use of compensatory and/or recruited muscles is taken on board. If you need our help, contact us.

Evidence of issues is critical to our discussions with health professionals to get changes made to the system. Please write and tell us about any similar problems you have had. Remember all the work we do is voluntary, your committee and operations team are giving up time and energy from their limited PPS resources. If you can manage to spare an hour or two then get in touch and see if there is a task that you can help with. Comments from anyone reading this, good or bad, as with all our work is welcome if we are to improve on the services we provide.

Hilary Hallam, Founder, Secretary and Newsletter Editor,
Lincolnshire Post Polio Network—www.lincolnshirepostpolio.org.uk
hilary.hallam@lincolnshirepostpolio.org.uk

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Report from Life Member Jann & John Hartman following their presentation
“Better Eating for Better Health with Family and Friends”
At the PHI Conference in St. Louis, MO June 2005.

John and I had a great time at the Post Polio Conference in St. Louis this past June. First, we always enjoy seeing old friends, like Richard and Hilary as well as making new friends. It was really great getting to know your Mary Kinane and Denise Carlyle. I really enjoyed the many speakers and all the information they so generously shared with us. Denise, Mary, and Hilary had a wonderful presentation that we all enjoyed very much. I also wanted to add that St. Louis has an accessible metro system that we used to get into the hotel from our travel trailer parked over at the casino across the Mississippi River. John and Richard also used the metro for a trip around St. Louis. We hope to get back there again someday and explore more of the St. Louis area on my scooter.

Our topic for the conference was “Better Eating For Better Health With Family and Friends.” Along with up-to-date nutrition information, we wanted to share how we are able to eat well and share the shopping, cooking, and more. We polio survivors are finding out that we must share the chores with others, and that includes cooking. Even if your significant other hasn’t done a lot of cooking in the past, it’s never too late to learn.

My suggestion is to find a child’s cookbook, like the “Junior Cookbook” from Better Homes and Gardens, as they usually have simple to make recipes as well as pictures and other good basic information. Most men enjoy cooking on the grill so that may be a good place to start. It’s really helpful to find something they enjoy like chili or perhaps a hearty soup.

John tends to cook large portions, so he’ll make a really big pot of his spaghetti sauce. We learned to freeze portions to use as needed. It turns out that his quantity cooking was a blessing in disguise. Now, we have a variety of containers to freeze soups and other foods.

It is no surprise that a full 2/3 of polio survivors say they have a weight problem (according to an internet survey). And overweight, inactivity, and age can result in a greater risk of type 2 diabetes. While losing weight is not that easy for most of us, it is something than can be done if it is a priority and we give it enough time. Sorry to say there are no quick diets or easy fixes. It takes a lifestyle change.

We have also found that it is possible to lose weight, even if we can’t do much, if any, meaningful exercising. I have lost a little over 20 lbs. in the past two years. But, John, who is able bodied, lost more weight than I did without really trying. Being active does have its advantages. But, any loss is a step in the right direction.

One of the biggest changes we have made is eating smaller portions of food. Many of the portions served in restaurants today are way too large. That’s why we not only consider carefully what foods we order out, we often share an entrée. Or, if the servings are huge, we will bring home half of it for another easy to heat up meal. And, we stay away from buffets as it has been proven that you will most often overeat when offered such a bounty of foods.

We choose tofu for participants to try, since many people haven’t tasted it or they have tried it and didn’t like it. Tofu is easy to use in cooking and it adds protein to recipes. We served tofu cut into tuna salad (it can be used in place of hard-cooked eggs) and served it on 100% whole wheat crackers. Tofu is really tasty in the right recipe, like Tofu Pumpkin Pie (below).

We also had some plastic bags for the trail mix we had bought in bulk to share. It is always good to have a healthy snack available. And, I believe a nice little extra is adding mini-chocolate chips to snacks. In small portions, they can be a tasty addition to your dietary plan. I usually have some nuts, and a piece of fruit, like an apple with me.

Another easy to use soy product is textured soy protein (tsp) which are dry soy granules. It is often sold as Textured Vegetable Protein (TVP). It needs to be reconstituted with an equal amount of water, or vegetable juice, like V-8. It can be used instead of hamburger in recipes like chili or spaghetti sauce. We also use it half and half to stretch the minced meats in things like barbeque beef for sandwiches.

We also sampled some of the new soy cheeses. Their taste and texture is much better than they used to be. Most everyone thought they could use the cheese slices in things like sandwiches. The idea is to try new foods, and to keep an open mind. You just might find that you enjoy newer, healthier foods. Foods in as close to their natural state as possible are often best. And, you just can't get away from reading labels.

No matter what the latest headline about nutrition says: we still need a good source of lean protein, plenty of fruits and vegetables, a good source of calcium (usually dairy), and 100% whole grains in the proper amounts every day.

No matter where you get your nutrition information, be sure to consider the source. I look for a nutritionist (Registered RD or Licenced LD Dietician) who works with people who have a chronic condition. This is a good person to see, especially if you have access to them through your health services. Or, invite them to your support group meeting. They often bring healthy snacks along with nutrition information and recipes.

Recommended resources:

"The TVP Cookbook: Using the Quick Cooking Meat Substitute" by Dorothy Bates
"Jane Brody's Nutrition Book" by J. Brody (basic nutrition information)
"Power Nutrition for Your Chronic Illness" by Kristine Napier, MPH, RD

More of my book recommendations on my website:
http://www.geocities.com/Heartland/Ranch/5212/bookstore.html

Jann and John Hartman, "on the road" headed for Florida - <arojann@YAHOO.COM>

Tofu Pumpkin Pie

Put all of the ingredients in a blender or food processor:

1 and 1/2 cups canned pumpkin [405gms*]
8 ounces tofu (silky)
2/3 of a cup of sugar (can be part brown sugar) [135gms*]
2 teaspoons pumpkin pie spice
1 teaspoon vanilla extract

Pour into an unbaked pie crust. Bake at 425 degrees for 15 minutes.
Then, bake at 350 degrees for 45 minutes. Chill thoroughly before serving.

Translating US measures to UK measures is not as easy as I thought. Check out the following websites for information—[*hope measures in brackets are right]
http://www.miketodd.net/encyc/cooking.htm
http://www.nal.usda.gov/fnic/foodcomp/search/

Louise L Hay workshop/holiday
“Love Yourself, Heal Your Life” by Member Anne Wood.

14th May. I’m relaxing in my power chair in the shade under a clear, azure sky beside a sparkling blue swimming pool, an iced orange juice in my hand. The air is filled with the sweet scent of honeysuckle, roses and other glorious blooms, the house martins are swooping and diving to catch flying insects for their hungry broods. I’m feeling calm and peaceful.

Carrie Harris www.transabler.co.uk counsellor at the MS Treatment Centre, Southwick, West Sussex BN42 4AB, www.mssussex.com which offers High Dosage Oxygen Treatment (HDOT) and a range of therapies to sufferers of MS and other neurological conditions, is sitting beside me. “I bet if I’d told you when you first came to see me that in 4 months’ time you would be relaxing on a Greek island, you would have thought me crazy.” Yes. Absolutely.

Yet there I was on the Isle of Lesvos, with my daughter Becky as my helper, Carrie and a bunch of other lovely people, all with the same aim – taking part in a “Love Yourself, Heal Your Life” workshop based on the work of Louise L Hay, a metaphysical self-help author http://www.louisehay.com Carrie has a variety of methods to help people overcome their problems and live more happily, and this particular workshop/holiday sounded amazing. I had gone to see her in January this year in great distress as my husband had left me one week before Christmas 2004 after 38 years of marriage. I was distraught – my whole world had collapsed and it was quite impossible to believe I would ever climb out of the black pit of grief and despair I was in. I had been dumped at the age of 60 with a progressive, debilitating disease, I felt unloved and unwanted by the one person I had loved all those years, and I had no future to look forward to.

A few weeks into my sessions with Carrie she mentioned that she was arranging this course, and suggested I give it some thought. But it was a crazy idea – I had a fear of flying and hadn’t been near a plane for 21 years, hadn’t been abroad for at least 10 years when I didn’t even need a stick to help me walk, and anyway I always had my husband to help me. I have to use an electric wheelchair when out, can’t climb stairs and can’t get up from seats and beds without electric equipment. In my fragile emotional state it was much too big to contemplate. I couldn’t do it. However, Becky saw Carrie’s flyer and immediately volunteered to give up a week’s earnings and be my support and mainstay, despite not fully recovered from 10 years of CFS/ME. She talked me into it… Then began the long process of first of all checking that the hotel was wheelchair-friendly, and whether there was some way of transporting my power chair between the airport and hotel, an hour’s drive. The latter took a good 3 weeks for the hotel to arrange. Would the airline accept the chair batteries which had to be sealed ones otherwise they would explode in mid-air? Would they let me take my essential chair charger, the battery-operated cushion lift www.mangar.co.uk/products/cushion (also mains-operated), large toilet seat extension, and two crutches into the cabin with me? Carrie made umpteen lengthy phone calls to the travel company, airport and airline who asked so many questions regarding the descriptions and dimensions of everything, that eventually I said it would be easier if I dealt with it all myself. I didn't anticipate it being as stressful as I found it during the next few weeks, with all the information I had to gather or give, and because at quite a late stage I realised I hadn't sorted out travel insurance and the long-stay car parking at London Gatwick Airport. I decided to take my manual chair as well as I didn't know the terrain on Lesvos, and in case the electric one was damaged en route. I got in quite a state arranging and double-checking everything, feeling panicky and frequently wishing I had never agreed to go.

On The Day we left our homes at 7am. I had to take my own car to the airport so that my chair could be hoisted in, but with two wheelchairs and room for just two people it became clear that our luggage and equipment had to go in another car. Thankfully Becky's fiancé, Dan, did the honours there. I booked the parking company for the "Meet and Greet" service (approx £90), and they met my car, helped us unload everything then took the car and parked it. Dan stayed with us up to the gate, constantly reassuring me that everything was fine, then Becky took over jollying me along.

My big toilet seat had to be accessible at all times for a "sit-down job", and I had searched the internet for a female urinal that I could discreetly tuck into my bag, and found several suitable ones, www.whizaway.com , www.woodstockit.com/products/Uribag courtesy of the NHS, and I bought a third kind myself, www.traveljohn.co.uk . I packed one of each. The cushion lift was essential on the plane as the seats were very low, and on the hotel bed as it was impossible for me to get up unaided.

For my own sanity I had double-checked every arrangement, leaving nothing to chance, making sure that all the organizations involved knew of my disability, that I was taking two wheelchairs, essential cabin equipment – all of which was carried free and I could still take the maximum hand luggage – that I would need assistance getting on to the aircraft, and that I was scared. In the event, I was allowed to keep my power chair right to the cabin door, having been hoisted in it on to a large hydraulic lorry and driven 1½ miles to the plane.

Once we had taken off I was able to relax for a few hours, and was so pleased that all the rigorous planning had worked out well. The week before we left I had a final session with Carrie to help get over my nerves about the flight, and I also took a Valium tablet. She met us at the airport in Mytilene and helped Becky who was struggling with the luggage and my equipment, then guided us outside to where a taxi and my wheelchair transport were waiting. This was a rather beaten up little truck driven by a very jolly Greek gent who assured me, as he and the taxi driver hauled my 1½ cwt power chair on to the back, along with the manual, that the flimsy bits of rope were more than adequate, and not to worry. The hour's stunning drive to the hotel was up and down steep and winding roads, through the olive groves, and I was thrilled to bits.

The newly built Aegean Sun Hotel, www.aegeansun.gr 1.5km from Plomari, and minutes from the sea was very accessible and our room was right by reception. The wet room was great and I could shower in safety. The staff were very helpful and most spoke English. They must have chuckled when I emailed them to ask if there were cutaway kerbs for my wheelchair…… they were just "plain car roads" as they put it…..yes, and rugged, fast and winding, not ideal for a wheelchair, but we made it into Plomari twice, 30 mins each way. The picturesque, seaside town is built on a hillside with rough, steep steps everywhere, tumbledown houses, cobbled roads, etc, and we didn't see anyone else in a wheelchair. I guess any disabled locals either stayed in or were carried around.

We arrived on a Thursday, and the workshop weekend began with dinner on Friday evening and getting to know each other. We were a party of ten: Carrie's colleague, complementary therapist Heather Drummond, two had come just for the holiday, so there were six of us for Carrie and Heather to work with. We weren't expected to explain our particular reasons for going, we just had to be willing to take part in as much as we felt comfortable with. We did meditations, drew and talked about healing body parts which hurt, gave and received massage for a few minutes, we sang affirmations, thought about negatives and positives learned from our parents, discussed forgiving others, learned about loving ourselves, how to change our ways of thinking, etc. It was pretty emotional at times, and sometimes quite hard work. At the end, Carrie asked us to write a few words of encouragement on heart-shaped post-it notes to give to everyone, and I was touched and flattered by the many compliments given to me.

The next few days we were free to do as we wished, and Carrie and Heather made themselves available to anyone who wanted to talk privately or have some complimentary therapy from Heather, such as a massage or ear candling. One day the others went on a coach and boat trip to Turkey, so I just relaxed in the shade and read the course book "You Can Heal Your Life", by Louise L Hay.

One evening we all trouped down to a local beach restaurant and had an uproarious time – I couldn't remember when I had laughed so much……what a tonic that was. For the first time Carrie saw another side to me, and I rediscovered the joy of making others laugh…..a wonderful feeling.

All too soon it was time to leave, reluctantly in my case as I had felt so good on the island and I was going back to bleak despair. It was sad saying goodbye to everyone but I had so many happy memories that I knew would stay with me. The trip home took a nightmarish 11½ hours due to a stop-over on the Greek mainland and complete disembarkation. Becky and I arrived at the equivalent of 1.30am, it was pouring with rain, very cold and we were exhausted.

After I picked up from the expected slump into depression, I definitely felt the benefit of the workshop/holiday. It was a turning point, without doubt. Thanks to Carrie, Heather, Becky and the others I met, I proved to myself that I did have the courage to leap into the unknown, overcoming fears and breaking the chains I thought were there, that I am loveable and that I can be happy again. My confidence has grown and I aim to see more of the world now. I am indebted to Carrie for helping me this far, and to Becky for her constant support during the worst period of my life. Now I must practise my affirmations and learn to love myself.

PENSIONS IN THE UK

By Phone Team Member, Margaret Edmonds.

Having just achieved the early release of my occupational pension on medical grounds, I was asked by Hilary to start a discussion of our experiences of getting pensions paid before ‘official’ retirement.

Everybody’s situation is unique and getting the pension depends on the combination of individual health problems and the provisions of the particular pension scheme. In my case, it was a ‘frozen’ pension from local government employment that finished eighteen years ago and small as it is, it’s a welcome addition to my part-time earnings. When making the application I had to keep remembering that the criterion is that if I was still doing the job I used to do for them, I wouldn’t be able to do it any more. If you are still working for the employer who runs the scheme, it’s likely to be fairly obvious if you are running into difficulties at work, but I had to not only make the point that I’d left the earlier job because fatigue was already catching up with me, but also show that I was now ‘failing’ in the much more straightforward job I’d recently taken on. If it had been the other way round and I was now in a more demanding job than I was eighteen years ago, it might have been more difficult to make out the case for ill-health retirement. Added to this was the need to ‘prove’ my own diagnosis of PPS – not always easy.

If you are still working, the best route is referral to the occupational health doctor (or a doctor providing a similar service if you work for a private company) via the personnel/human resources department and then, whether you are still working or not, agreement from the GP to support the application if asked. The medical practitioner giving the supporting report doesn’t have to be a specialist or consultant.

The civil service pension scheme is similar to local government but other organisations with money purchase based pension schemes may have different criteria. If you have a privately purchased pension you may want to get advice from a financial expert, although they may charge a fee. The drawback is that pension benefits paid early are often reduced and you may want to weigh present need against future need. Early payment of pensions is subject to Inland Revenue regulations and pensions are taxable, although lump sum payments are not.

Perhaps we could put our ideas and experiences of all kinds of pensions together.

Email:- Margaret Edmonds <pme.pme@virgin.net>
or
Write to me c/o the Lincolnshire Post Polio Network, main address and I will put all the responses together in another article.

The LincPIN welcomes Mary McC
Our new Facilitator

Some of you may already know my name, but for those who don't, I'm Mary McCreadie – non-paralytic polio in 1959 – ex-piano teacher/performer – PPS diagnosed in 2000. 2005 – heading for the wheelchair at a terrifying rate!

I've just joined the Operations Team as a Facilitator – which is a grand term for someone who is prepared help with posing questions for our E-Mail forum, and to collect and collate pictures and text from all members, for publication in The LincPIN. I am very much looking forward to working with everyone, and hope that I can rely on you, our members, to provide as much grist for our particular mill as possible! The wealth of experience amongst you can be of immeasurable benefit to those who have just been diagnosed with PPS, and are frightened, lonely, or simply uncertain how to manage daily life – or indeed to old hands who simply 'never thought of that – what a wonderful idea!'

To that end, we are looking for hints on living to pass on to others – how do you manage to do your ironing? How do you wash the dishes when you're stuck in a wheelchair? How do you cut vegetables when you can't hold the knife? I know that there are some amazingly innovative ideas out there – and it would be wonderful if we could share them.

We are also looking for any stories about your experience with Polio and PPS – both in childhood and as an adult. Pictures too, would be most welcome!

Please send any ideas by post to:

Mary McCreadie, c/o Lincolnshire Post-Polio Network,
69 Woodvale Avenue, Lincoln, LN6 3RD, UK.

Or by e-mail to: mary.mccreadie@lincolnshirepostpolio.org.uk

The E-mail Forum

As most of you will know, we have an e-mail discussion list which is available to any member who is able to get on-line. It is a marvellous way of connecting people who otherwise might find themselves very isolated and feeling alone. Being able to 'talk' to people who know exactly what Polio and PPS is all about, having been there, done that AND have the T-shirt, is often a great help!

There is a wealth of knowledge and expertise amongst members on just about every problem any of us might experience, and being able to ask someone who has already been through it cuts out a lot of unnecessary angst!

Over the last few weeks a number of subjects have been aired, and what follows is a brief taste of some subjects we've been discussing, with a few of the answers given.

THERE IS HELP OUT THERE! - ………… Mary McCreadie.

One of the worst things when you have PPS or something like it, apart from simply coping with daily life, is being short of money. Nothing is more certain to give you sleepless nights than worrying about paying bills!

There IS help out there - but you need to know how to access that help. There is a wealth of information on the Internet – as long as you know how to search for it. But for those who are not well enough, or not yet connected, just finding out what is available and what you may be entitled to can be a nightmare. You may be missing out on funds that you desperately need. Over the next few issues, we will be giving you information on various kinds of benefits, and how to apply for them.

An agency I had never heard of – until the day I had a Care-Line installed by my local authority – is the Care and Repair Agency. This agency is sometimes known as ‘Staying Put’ or ‘Home Improvement’ and the work they do can be invaluable to those on low-incomes. Unfortunately, as is often the case with Government departments, whilst most local authorities have an office which deals with these things, titles are not universal, and they do not always advertise what they do. Consequently, the very people who need them most know absolutely nothing about them! (The logic of this quite escapes me!)

The following information has been taken directly from www.foundations.uk.com . The web-site is easy to navigate, and the information well presented.

What Are Home Improvement Agencies?

Home Improvement Agencies are small, locally based not-for-profit organisations. They help homeowners and private sector tenants who are older, disabled or on low income to repair, improve, maintain or adapt their homes. They provide people-centred, cost effective assistance, and help to tackle poor or unsuitable housing, enabling clients to remain in their own home, safe, secure, warm and independent.
HIAs currently operate in over 300 local authority areas. They are sometimes referred to as 'Care & Repair' agencies or 'Staying Put' schemes. They are usually managed by:

- Housing Associations
- Local Authorities
- Charities
- Independent Management Committee

MISSION STATEMENT OF H.I.A.’s.

"To enable those in need of support to maintain their independence in their chosen home for the foreseeable future. This may include older people, people on low incomes, disabled people and other groups determined by local circumstances. This would usually be in the private sector, however, local needs may require more flexibility.

This outcome would normally be achieved by supporting people throughout the repair, adaptation or improvement process, so that the individual is able to remain in their own home in a warm, safe and secure environment. This could also include the direct provision of repair and maintenance services, preventative initiatives, and providing advice on accessing appropriate, including private, finance."

CORE H.I.A. ACTIVITIES.

Advice and Advocacy: HIAs assist people identify what the real problems may be with their home and how these issues may be addressed. This includes a review of all housing options open to the client including advice on legal entitlements, welfare benefits, financial matters and other support services which the client may need to enable them to remain in their home

Financial Matters: HIAs offer a broad overview to clients of the financial implications of pursuing their chosen option. Whilst for many people, the cost of any repairs or improvements will be covered by a grant from the local housing authority, HIAs also offer support to clients to access alternative sources of income, including raising loans against the equity of their property, ensuring that people receive appropriate independent financial advice.

Technical Issues*:* Many clients of a HIA are apprehensive about housing repairs carried out to their own home. It is, therefore, a critical role of the HIA to offer both guidance to clients on the required work and assurance that any repairs undertaken will be completed satisfactorily, to budget and on time. Jobs undertaken can range from the very small (such as minor plumbing repairs) to major renovations or the construction of adaptations or extensions for a disabled person. The building work is specified, competitive estimates are sought from good quality vetted contractors and the whole work is overseen by the agency's technical staff in order to ensure that the finished result meets the needs and wants of the client.

Additional Home Improvement Agency Services

- **Hospital Discharge Projects**: Provide a rapid response team to enable older people to be safely discharged from hospital into their own home through carrying out essential repairs and adaptations.
- **Handypersons Schemes:** Carry out small repairs to the homes of mainly low income, older and disabled people to enable them to maintain their properties and live in greater comfort and security.
- **Aids and Adaptations:** These schemes organise the fitting of a range of small adaptations in the older and disabled persons home to assist independent living.
- **Home Security Schemes:** To install measures such as door and window locks, door chains, viewers, external lighting and related security features to vulnerable peoples homes.
- **Energy Efficiency Projects:** Help vulnerable people to identify measures that can be taken to improve energy efficiency in their homes and provide practical help and assistance to implement.
- **Home Safety Schemes:** Offer HIA clients the option of having a detailed check carried out to identify 'risk factors' that could result in an accident in the home and recommend remedial action.
- **Disabled Persons' Housing Service:** Aims to achieve appropriate and

affordable housing solutions for people with disabilities through the provision of a range of services which help with access to adaptable rented and owner-occupied housing, and adapting properties to meet the needs of people with disabilities.

o **Home Maintenance Project:** Aims to emphasise the importance of regular maintenance work in order to avoid crisis or major works at a later date.

HIAs may also provide the following services

- Unsolicited Calls Helpline
- Disabled Persons' Project
- Integrated Home Maintenance
- Painting & Decorating Project
- Gardening Services
- Decorating Services
- Community Alarm Services

Daily Living Support - How Home Improvement Agencies Contribute To Housing, Health and Social Care Services

HIAs have been innovative and creative in developing and expanding their services to work across housing, care and health sectors involving many partners, professionals and individuals. This includes local authority housing and grant officers, occupational therapists, health workers, social services and many others.

HIAs have proven to be model organisations in "joint working" to help to deliver the objectives of the following national and local strategies:

♦ **Housing:** Working in partnership with local housing authorities to target the most vulnerable older, disabled and low-income people living in the worst housing conditions and provide them with advice and assistance to maintain, repair or adapt their homes to meet their needs.

♦ **Community Care:** Enabling older and disabled people to remain living independently in their own homes in greater comfort, security and safety.

♦ **Crime and Safety:** Addressing the safety and security aspects relating to vulnerable peoples' homes.

♦ **Energy Efficiency and Fuel Poverty:** Identifying measures that can be undertaken to improve energy efficiency and reducing fuel bills in the homes of those in highest need in the private sector.

♦ **Health:** Contributing to the Health Improvement Programme and other health strategies by addressing cold, damp housing conditions, reducing the risk of accidents and contributing to hospital discharge planning.

♦**Neighbourhood Renewal Strategy:** Improving the poor housing of the most vulnerable people to help narrow the gap between the most deprived neighbourhoods and the more affluent areas. Contributing to improving health, security and the physical environment and helping towards neighbourhood renewal.

The most important thing to do first, is to ring your local authority, and ASK!!! Your Occupational Therapist will know who to put you in touch with, or if you don't have one, simply speak to the lady on the switchboard at your local office.

mary.mccreadie@lincolnshirepostpolio.org.uk

Obtaining suitable wheel-chairs through Social Services/NHS what’s the best way to go about it?

To others having problems with Social Services, I got myself a booklet from the local disability equipment shop and picked out all the things I thought would be useful to me and then asked the OT's things like "is there anything that would help me with ...." feigning ignorance and got mostly everything I needed.

Just a few thoughts about wheelchairs. All the OT said to me was, "What are your needs?" I'd barely seen a wheelchair before! It certainly helps to be knowledgeable before hand with brochures, and having checked out wheelchairs somewhere else first, like a shop or Disabled Living Centre.

The Dept. of Health's National Service Framework for Long-term Conditions, OBLIGES the NHS wheelchair clinics/assessment centres to supply wheelchairs ACCORDING TO NEED, and not according to fixed supply, as has been the case to now. Applying for a powered indoor chair is your first step - if you have a powered indoor chair you can then apply for a powered outdoor chair - that's the way the system is set up. So putting your needs in writing is definitely worth the effort. The NSF leaflet can be obtained by logging onto: www.dh.gov.uk/longtermnsf

Sheltered Housing – or stay at home?

I understand your dilemma ...it's important to stick up for what you want, but obviously very stressful. I don't know if anyone's already mentioned this, apologies if to them if they have, but there is a charity called 'Care and Repair' which offers help and advice with housing for older people and disabled people. They are supposed to be able to help with adaptations. Their website is www.careandrepair-england.org.uk/

I know some of you do not feel that you want to be on a retirement type place but believe me in some ways it could be better, as people look out for you more. It is difficult if it is away from your friends and family but true friends will be there wherever you live and you would soon make new ones.

Tips for making life easier in the house:

I've had all my low level cupboard shelves removed and replaced with sliding chrome baskets and a carousel under the sink area. What a difference it has made. I'm able to walk around the bungalow so this has helped me keep my balance when trying to reach into cupboards. Also with limited use of only one hand it helps when trying to lift things onto the surfaces. My son's friend has raised both my fridge and freezer units about 2feet, fitting small cupboards under them. This is a great success - I can now clean them without falling into them!! I've a small trolley to put items on to transfer from fridge or freezer to surfaces.

We have a Wet room downstairs. Fully tiled floor and walls. Floor slopes in to the shower drain. Shower stool to sit on. Toilet is up on a breeze block base tiled the same as the floor... so no plastic rise toilet seat!!!!!

I have an ironing board fitted into a drawer, another polio I know and uses a wheelchair had hers fitted into the middle drawer.

I find my worktops too high too! Until I can have a new fantastic kitchen (in my dreams!) I sit on my perching stool, open the cupboard door and put my feet on the lowest shelf. I find this makes chopping etc easier. Hilary can work more efficiently standing as her arms need to work down at 45 degrees. So she works at the sink, leans against work surfaces, and can rest one arm against sink side whilst using other, etc. sitting on a perching stool did not work.

Another disabled lass I know had her units on raise and lower so that she could use them at her height and her husband at his..... Still its really a good idea to sit in a wheelchair and practice doing all the actions you might have to do and see what might be necessary for the long term. Try before you buy or get given equipment. Why not go with at least one other disabled person to a Disabled Living Centre and giggle and try out all the stuff available. Its so much easier than doing it on your own.

Joint replacement and PPS

With regard to Larry's [USA] question about joint replacement, I would "shop" around and find out what a surgeon's reputation is, much like going into your nearest superstore and reading the labels on the packet before buying your food. With all the appropriate courtesy which we can muster, we must ask medical professionals what their success rates are with hip, knee and ankle replacements - some of these specialists actually don't mind being asked these questions - if they do - it may be a sign to go elsewhere! Assertiveness pays off in the long-run, and we do for others as well as ourselves, when we ask reasonable questions of health care providers. Ask how many Polio Survivors they have operated on.

I am having the same reservations as you as this is something I am supposed to have done. I did note in a Canadian PPS newsletter someone wrote that they had had a hip done and asking others about knees and hips many said they wish they had not had it done.

My Doctor is good and I asked for a surgeon that specialises in knee replacement Ops and he recommended this one at the Orthopaedic hospital in Birmingham. Although I have seen registrars etc on the last two visits I have had it agreed that if I go for the Op the surgeon himself will do it because of the complications with PPS.

Through experience I have found always ask to be referred to a specialist who actually specialises in your complaint. Ring the hospital when you have the appointment to make sure you are on his list, if not ask for another appointment.

It is imperative to get your muscles strength accurately assessed. Manual testing will not provide accurate results. If you do not have the muscle sustaining and repetitive power to sustain the post operative therapy you could have problems. Ask to be assessed by the Post Operative Therapist before the operation. Ensure that they watch you stand from chair, get up from bed, get out of car, etc. Remember we use trick movements and other muscles to assist us and its so much easier on both patient and therapist if you do this pre op and practice having that limb out of action, what exercises you are going to have to do. Remember we take four to five times longer to recover. It might also be helpful to visit the ward pre-op so they can see how you do things and you can see what the bathrooms etc are like.

Alas, there’s no space to quote from every subject discussed! Suffice it to say that the conversation also ranged from health to floor-coverings, and many points in between. Questions invariably lead on to other subjects, which in turn raise further questions and suggestions, just as in good conversation.

The E-Mail forum is a superb way of disseminating and obtaining information about everything and anything that affects us. I know that not everyone has a computer, but for those that do, it would be wonderful to hear from you, so that our discussions can be even fuller and more varied. Any questions or ideas would be warmly welcomed – whether it's about general health, Social Services, equipment, attitudes from the public or the NHS – we need to hear from YOU!

Join the LincPIN e-mail forum: Email mary.mccreadie@lincolnshirepostpolio.org and I will confirm your membership status and get you subscribed.

NOT ON THE INTERNET? — JUST DROP ME A LINE.

But we would not want anyone who doesn't have a computer to feel left out! We need your input too. Your questions can be discussed on the forum, and copies of replies sent to you by post, and/or published in the next issue.

Polio and Post-Polio News—A service we provide.

Still on the subject of computers – did you know that Lincolnshire Post-Polio Network has another e-mail distribution list of articles from around the World related to polio, post polio and disability issues to which you can subscribe?

It is known as PandPPNews. Summaries of all the articles and links to the source can be found at the Polio and Post Polio News web site http://mt.lincolnshirepostpolio.org.uk/pandpp-news/. To subscribe to the email notification service follow the *Choose and Subscribe* link in the left hand column.

Announcement to Members.

A change is being made to the LincPPN's Annual General Meeting date, moving it from its present timing in October forward to June, and it is hoped to implement this change by the end of February 2006. As a consequence of this, a change in the current 2005/2006 financial year from 12 months to 8 months must also be made as the accounts have to be audited in advance of the AGM. The reason for both these changes is to make the AGM more accessible to more members, at what we think we will be an easier time of year for many members to travel, with daylight hours being the longest. After considered discussion and consultation of our LincPPN's constitution, this adjustment does not require a constitutional change. This matter was discussed both at Committee on October 21st and at our AGM on October 22nd, 2005 with members in attendance. At that AGM, those attending were largely in favour of the change, and saw no reason for not implementing this as soon as possible.

We respectfully request that if any member has an objection to this change, they should write giving their reasons by February 28th, 2006, when they will, of course, be considered by the committee. In the long-term, we think that the membership will welcome this change for the better.

With thanks,
Mary Kinane
Chair.

Ferrules (Crutch/walking stick tips)

Anyone using a stick or crutch will know that sickening feeling you get as your stick starts to slide out from under you at break-neck speed when there is the slightest drop of water about. Ferrules supplied by your Physio. Department will normally be the standard grey ones - which are positively lethal in bad weather, or when there's a wet floor to be negotiated. But did you know that there are different types of ferrules – ones that are designed especially for wet weather, or icy conditions? I didn't, until one of our members told us about them in one of our e-mail discussions. He kindly gave us the address for a company in America who will supply especially crafted ferrules which are guaranteed to be safer in the wet than the ordinary ones:

www.fetterman-crutches.com - certainly worth a visit, especially for those of you in America. Their goods are a touch on the expensive side, but look pretty effective. From the US, you can call them Toll-free on 1.888.582.5544 for information. There are also quite a few UK sites, and I contacted the one which seemed to supply what I needed: www.bnow.co.uk (Benefits Now, 20 Lark Rise, Newport, Isle of White, PO30 5YJ. Tel: 01983 539954) The ferrule is called the 'Ingrid Convex' – there are several more, including one with a fold-away ice spike.

They supplied me very quickly with the best ferrules I've had in 10 years of using an elbow-crutch! They're made of black rubber, and have what looks like a spiral tyre tread. (picture on back page) So far, I've been able to test them in both wet and icy weather, and felt much more secure than at any time previously. I even felt more secure using the stick in the house. Obviously, I can't yet say how long they will last in comparison with the usual ones, but it looks as if they'll wear well. I'll let you know! The ferrule is called the 'Ingrid Convex' and there are several other designs in this range, including one with a fold-away ice spike.

At just over £5.00 each, they cost twice as much as the ordinary ones (if you buy them in the shops) – but what's a few pounds compared with your safety?

I spoke to my local Physiotherapy. Department today, and they have never heard of *any* ferrule other than those slippery grey ones! They expressed great interest in my new ones, and have actually asked me to pop in and show them. I'm hoping very much that the 'interest' will actually result in more people being at least told about these 'wet-weather' ferrules, so saving a few broken or sprained legs or arms!

My wheelchair repair guy said he had sort of good news for me...
"We've found the problem....
Your battery needs a new wheelchair!"

A guy walks into the doctor's office and says, "Doctor, you've got to help me. I pass gas HUNDREDS of times a day." He tells the doctor that it's silent and odorless. Then he says, "Doctor, you won't believe this but I've passed gas ten times while we've been talking."

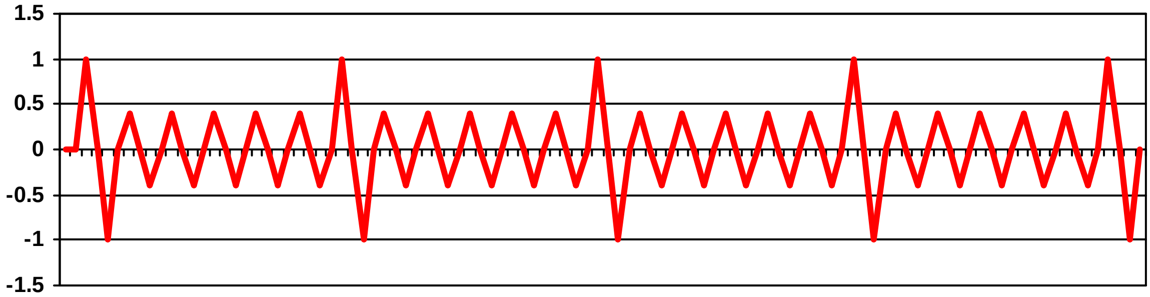
So the doctor gives him some pills, "Here, take two of these every day and come see me in two weeks."

The guy comes back in one week complaining, Doctor, what's in these pills? I still have the gas, it's still silent, but now it smells absolutely TERRIBLE!"

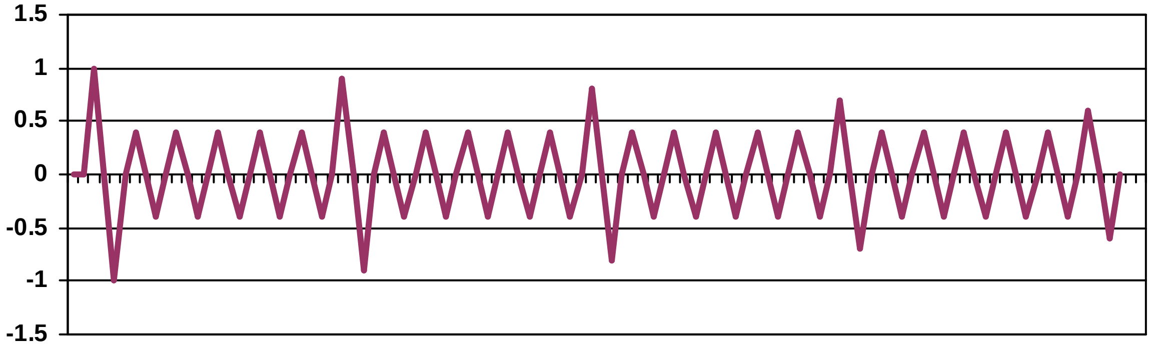
The doctor says, "Well that takes care of your sinus problem, now let's work on your hearing."

Schematic of Breathing Tests [Article pages 6 - 9 refers]

The top chart in red is the results from a Non Polio who takes in a deep breath and blows it out steadily and then breathes normally for five breaths and then repeats the deep breath in and blows it out steadily.



The middle chart - purple - is a schematic of the likely results if a Polio Survivor who is reporting breathing and sleep problems due to muscles fatiguing was asked to repeat the tests at the same time intervals. NB the depth of breath in/out reduces each time.



The bottom chart - blue - is a schematic of the results of a test done at Papworth Hospital 31st November 2005 where the Polio Survivor was asked to do the same test as the top chart in red, BUT was told to repeat this when they were ready, take the time you need to recover to do the test again to the same level. The same method was used for all the tests. The amount of resting time between tests was not recorded, although the tester did agree to add notes to the test results showing that the patient fatigued easily. The figures recorded on the final form - all virtually the same result - were read by the Consultant as 'fine', there is no need to see you again. Pacing and resting works - but if we still have problems doing this then they need addressing.