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The LincPIN

The Lincolnshire Post-Polio Information Newsletter

Volume 2 - Issue No. 6 - August 1999

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Editorial by Hilary Hallam

This issue is out early as the Annual General Meeting Day with Speakers is fast approaching. This is on September 4th 1999 and at Ancaster Day Centre in Boundary Street, Lincoln. Maps and details of the day are provided with this Newsletter. NB Timings have changed since last newsletter.

Before I tell you more about this day, I would like to thank those of you who returned your surveys about the problems you have had in getting a diagnosis and all the appeals and tribunals you have had to attend. We would still like to hear from those of you who have not yet replied, either on the form, or by letter if you would prefer.

One of our members Sylvia Dymond sent us a copy of an article from 1981 in the Accent on Living Magazine published in Chicago titled *Are Polios Getting Older Faster*. We have received permission to reproduce this in this Newsletter. There is a long quote from Dr. Geoffrey Spencer, St. Thomas Hospital in London (now retired).

> Spencer is very much concerned about those who have had polio and who have had very unhappy experiences with doctors or with hospitals. "They may have had to go into hospitals where their disability was badly understood and they had care which was not appropriate and most of the staff didn’t understand their situation. This is entirely understandable and it gives people with polio a reluctance to seek medical advice when actually they need it. So what I would say is to encourage both people with polio and also the doctors who look after them to take minor medical problems more seriously than they would necessarily take them in the able-bodied because they can be so very much more serious or have more ramifications."

18 years later we are still in the same situation in the UK. Why?

Regarding our presentation to the Government. To date, the Minister of Health is unable to fit us in for a meeting and has not yet replied to the rest of our presentation. The Minister for Social Security Office replied giving us information about the various benefits but did not respond to the questions asked. We have asked Gillian Merron MP to take this up again on our behalf. We will give the latest news at the AGM and in the next newsletter.

The Neurological Patients Forum with Lincolnshire Health Authority will be reconvened later this year with a new format following representation made by ourselves, MESH and SAUK and with the help of the NHS Executive.

Other articles are about Pacing and Resting, Conserving and Preserving (sounds like making jam) and what we can do to help ourselves. We need to manage our lives better and almost every Polio Survivor who starts putting changes into practice says the same thing, 'If only I had known about PPS earlier and what one can do to slow down deterioration and improve the quality of life. Because virtually every new idea I learn about and I put into practice does help.' If you have any tips or stories to tell that have helped you then share them with us.

Reminder - Saturday August 21st 1999. Lincoln ME Self Help Group have invited us to attend a talk given by Dr. Skinner about The Thyroid. This will be from 1.30 to 4.30 at the Ruston Marconi Sports Club on the Newark Road, Lincoln. Read Tears Behind Closed Doors’ by Diana Holmes Avon Books £7.95. A Polio Survivor and Dr. Skinners patient - who did not have ME but an underactive thyroid.

Reminder - Sunday 3rd October 1999. The Falcon Inn, Saltergate, Lincoln will be holding a Truck Pull outside the Pub on this day from 11.00 to 4.00 p.m. Teams of six, 3 ladies and 3 gents, will be pulling a lorry along a measured distance. Each team will donate half their raised money to the LincsPPN - the other half to a Lincoln Charity of their choice. Full details in the next newsletter. They continue to hold various fundraising events and their support is much appreciated. They have already given us £145 collected in the Bar and from various small events for which we are most grateful.

September 3rd, 4th and 5th 1999.

Friday September 3rd will see people arriving from other parts of the country. We will be basing this weekend on the Holiday Inn Express. There will be someone there to welcome those arriving from afar, and we look forward to meeting in the Bar for an informal evening with plenty of time to chat.

It was not possible to hire anywhere nearer to the Hotel than Ancaster Day Centre that had suitable access for wheelchairs and scooters and appropriate toilet facilities. There will be a tail-lift vehicle available on the Saturday (and Sunday if wanted) to transport people who do not have cars or would prefer not to use them that day.

Saturday 4th September the day of the AGM starting promptly at 10.30 a.m. Following this there will be a break for coffee. 12.00 promptly Marcia Falconer PhD, from Ottawa Canada will be our first speaker who will be talking about polio and what happens to our bodies. She co-wrote the article Non Paralytic Polio and PPS that we featured in the January 1999 issue of the LincPlN. We will then have a break for a buffet lunch. The cost of the lunch is £3.00. Booking is essential - please ring or write to book tickets. Pay by cheque beforehand preferably, or on the door. Starting again promptly at 2.00 with Dr. Paul Ballinger, the GP who wrote the Case Study of a patient of his, in Update a magazine for GP's November 1998 and sent out with our December 1998 newsletter. Followed by Sylvia Foster an Orthotist who has worked with Polio Survivors for many many years.

This will be followed by a tea break. During the day there will be question forms available for you to fill out with specific questions you want answering. We will have a Panel of our speakers and at least one other clinician who will be answering as many of these as we have time for ending at 5.00 p.m.

We will then adjourn to the Holiday Inn Express where you can rest up, have a meal at the Pride of Lincoln or any other venue you choose, or have a Take Away sent in to the Hotel. The evening will again be spent in the Bar of the Holiday Inn so that as many of us as possible can get together and share experiences. From past experiences of evenings like this there will be much laughter and many new friendships made. We have reserved rooms for Friday and Saturday nights at the Holiday Inn Express (next to the Pride of Lincoln) which is accessed off the A46 Bypass by turning left on Whisby Road and then first left and left again for the car parks for both Hotel and Pub. The Holiday Inn Express have reduced the cost of each room to £35. (£17.50 for two). This includes a complimentary continental buffet breakfast. You can help yourself to a choice from 3 fruit juices, grapefruit segments and fresh fruit, yoghurts, chocolate and plain croissants, Danish pastries and toast, preserves and cheeses and Tea or Coffee. All the disabled rooms and ground floor rooms have been reserved for us. If you have any queries regarding the Hotel facilities then please telephone them (01522 698333) mentioning the LincsPPN. They do not have a restaurant but a large bar where they serve breakfast and where we will congregate on both Friday and Saturday evenings. Other meals can be taken in the Pride of Lincoln just across the car park, or the hotel can arrange for a Take Away to be sent in.

Sunday 5th September - a day to visit Lincoln. If required we will keep the tail lift vehicle for this day.

Facilities nearby are Whisby Nature Reserve, behind Mike Hazlewood Skiing Lakes and restaurant. Whisby Garden Centre with an excellent cheap cafe, animals and fishing lakes. Jet Skiing is accessed off the A1434 but visible from the A46. There are two leisure centres both about three miles away, North Kesteven Sports Centre on the Al434 and City Sports Centre on Skellingthorpe Road. Also on Skellingthorpe Road is Hartsholme Park with lake and touring Caravan Site and the Swanholme Nature Reserve. Lincoln has roman ruins and our very famous Cathedral - over 900 years otd - visible for miles in most directions. A Castle started in 1068 which also houses a copy of the Magna Carta. The Lawn Visitors Centre, behind the Castle, has many varied interesting exhibits, for children of all ages 3 - 99. The oldest still inhabited house in Lincoln is 1170 which is situated on the left going down Steep Hill and is now an excellently stocked Craft & Sewing shop. Further down are the Readers Book Shops full of second hand books. Then the Jews House and Jews Court and on down to Lincoln's Shopping Centre. You can use the Lincoln Tour Guide Bus to get on and off to see the central Lincoln attractions. Anyone with wheelchairs or scooters wanting to go to any of the places on Steep Hill give me a ring and I will advise of where to park to get to these sideways.

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Reprinted with permission from ACCENT on Living. Vol. 26. No. 3 Winter 1981.

Post-Polios and Medical Specialists Meet in Chicago...

ARE POLIOS GETTING OLDER FASTER?

It came across loud and strong! Some polios are experiencing progressive weakness and involvement of muscles not thought previously affected and some are noticing decreased endurance. At the seminar held October 14- 16 ACCENT talked to some of the doctors there, considered by their peers to be experts in the care of post-polios including those with respiratory involvement.

Ernest W. Johnson, M.D., Professor and Chairman of the Dept. of Physical Medicine, Ohio State University, said, "We are involved in some research right now on the aging problem and doing single fiber EMG studies on polios of more than 25 years. We're finding that the jitter or variation in time for the impulse to go to each muscle fiber in that motor unit is greatly increased in old polios and there is much blocking which would mean the muscle would get weaker. It is proposed that this occurs when you normally get old -- we see it in 90-year-old people. We're thinking that some of the anterior horn cells that were attacked and then recovered may have these aging properties too soon. This would account for individuals who had polio earlier, now they're in their 40's, who are now beginning to lose their deltoids or their quadriceps. It's called a benign progression, a late progression of polio in which somebody has it for 15 to 40 years and they gradually go downhill much as if they had the creeping, paralysis of progressive spinal muscular atrophy. I believe, myself, this is due to the early death of an anterior horn cell that was invaded by the polio virus, but recovered at that time. Many times this occurs in people who were in a respirator during their acute phase, but then got up and walked, supposedly recovered. In my opinion, the metabolism of their anterior horn cells has been altered and now these cells are going on to die early."

The question was asked as to the effect of exercise. Is there such a thing as over-exercise? Johnson said "There is much experimental evidence in animals to show if you overwork them, their muscles fragment and are destroyed. There is a case in which an individual had wrist extension and was operating a flexor-hinge splint and got so involved with it, he overworked it. Within one week he lost the function and it didn't come back for six or seven weeks. Dr. Robert Bennett at Warm Springs did document over-work weakness where a muscle which is overworked will get weaker. This is a reversible process though, because if you rest it, it will come back."

Johnson indicated that the best way to stay in as fit a condition as possible was to stay active. "Don't stress your muscles and guide yourself so you don't get exhausted. It is important not to overtire muscles that are weak. If you can, swim. That is the one activity that exercises every muscle."

Ann Bailey, M.D., from the staff of Warm Springs Institute for Rehabilitation, had this to say about the aging problem. "We are investigating this question at this time and really don't have an answer yet. We do definitely think that polio patients are having problems for some reason after approximately 30 years from the time they first had polio. It's not every patient by any means! We don't know at this time what the percentage might be, but there are a fair number of post-polio victims who are having loss of endurance, loss of strength which we are unable to account for by the usual means. We are seeing more patients than before because of the problems they're developing now. We are in the process of doing a survey at Warm Springs, hoping to contact all our previous patients as a follow-up to see just how big a problem it is. We don't have an explanation whether or not the problems are due to aging, whether it's overstressing of muscles, or whether there is some other process going on."

She added, "It's been well known for many years that the polio patient will lose strength and function by overstressing his muscles. While all the muscles should be kept at peak capacity by a reasonable amount of exercise, intensive exercises past the point of fatigue are very bad. You should also avoid chilling if at all possible because cold very definitely adversely affects the polio muscle."

Augusta Alba, M.D., Goldwater Memorial Hospital in New York City when asked what might be done to keep oneself in top physical condition, brought up the necessity of maintaining the compliance of stretchability of your lungs and rib cage. She said, "This is by far one of the most important assets you have in being able to continue to breathe for many hours with residual respiratory muscles. If the lungs and rib cage become stiff, then the amount of muscle power that is there is unable to give you an adequate volume. If they remain compliant, then you’re still able to get an adequate volume with the residual muscle power you have. The way you can keep the muscles of your rib cage and your lungs complaint is by either frog breathing to a maximal inspiration or by using a mouth intermittent positive pressure ventilator for that purpose."

Alba said, "For anyone with respiratory involvement, there is certainly some limitation in vital capacity so it means you cannot fully inflate your lungs with the remainder of your respiratory muscles even though you may be able to breathe perfectly normally both day and night. You need something above and beyond blowing with the amount of air that you’re able to take in, in order to fully stretch your lungs." She feels it would be a wise idea to use a simple machine such as the Zephyr made by Thompson Respiration Products that provides pressure needed to fully inflate your lungs. She tries to encourage everyone to simply learn frog breathing, so they don't need the expense of a machine and, by frog breathing, to inflate the lungs every two to three hours during the day.

Geoffrey Spencer, MB., FFAR, C.S., St. Thomas Hospital in London, England, feels there is definite evidence there is an aging problem with post-polios. He says, "The problem is really very simple. It is that everybody suffers bodily changes as they get older. As a person's lungs and chest wall begin to undergo the normal changes that everybody experiences with age, where previously they had been able to get by without a breathing aid, they may come to need it as their age advances. And given the appropriate simple forms of mechanical breathing aids, the prognosis is excellent." He pointed out that they are finding relatively few, if any, new cases of respiratory polio in England. Inevitably, some of the ones we have are dying. However, the number of polio patients using respirators is rising. This is a direct result of the aging process. It's rising by quite a large number each year as people who have had polio for many years come to need breathing assistance, maybe even for the first time -- even if they didn't need it during the acute phase of the disease."

ACCENT asked Spencer what symptoms one might need to be aware of that could indicate it should be necessary to consult with a doctor. He said, "The difficulty about it is that it's an insidious process and even intelligent doctors don't always recognise it in themselves when it happens to them. The things to watch out for are: loss of mental concentration; headache and drowsiness by day; morning headache, possibly caused by a CO_2 build-up when you aren't breathing as deeply as you do during the day; and a difficulty getting off to sleep."

Spencer also urges breathing exercises. He said, "Any polio patient with significant respiratory weakness who can't yet frog breathe, should try very hard to learn to do so. There is no doubt that if you can blow yourself up like a football, you get in several litres of wind several times a day which has a very useful effect in preventing the chest wall from becoming rigid. A normal person takes a deep sigh about once every 50 breaths. Nobody knows quite why this is, but one of the functions it does have is to keep the chest wall supple. If I can't take a deep breath because half my breathing muscles are paralyzed with polio, then I lose that ability to keep my chest wall supple. It's the chest wall that matters, rather than the lungs -- and it gets stiff. If I blow myself up like a football half a dozen times a day with frog breathing, I keep my chest wall more nearly like a normal, unparalyzed person's chest wall so I stave off the onset of insidious respiratory insufficiency."

What about too much exercise? Spencer was asked to respond to those proponents who feel that the more you exercise, the stronger you're going to get and the better you will be. "Within limits, it's true. However, moderation in all things is pretty sensible. Certainly during the recovery phase, following the acute illness, active exercise is very important. From then on, to maintain the suppleness of joints, passive movement is important. It can be driven too far. There is no point in striving to maintain a tiny flicker of movement in one foot with regular, heroic exercises if that flicker of movement is actually of no practical use at all. It's much better to concentrate on maintaining and preserving and exercising and regularly using those movements and those muscles which are of some practical use. On the whole joints and ligaments have a tougher time in a partly paralyzed person because they are not as well supported by strong muscles all around and people can get joint degeneration, secondary to polio, many years later because they put unfair stresses and strains on their joints. If they deliberately take exercise which is too tough, then actually it can do harm."

Spencer is very much concerned about those who have had polio and who have had very unhappy experiences with doctors or with hospitals. "They may have had to go into hospitals where their disability was badly understood and they had care which was not appropriate and most of the staff didn't understand their situation. This is entirely understandable and it gives people with polio a reluctance to seek medical advice when actually they need it. So what I would say is to encourage both people with polio and also the doctors who look after them to take minor medical problems more seriously than they would necessarily take them in the able-bodied because they can be so very much more serious or have more ramifications."

Other Factors Needing Attention.

During a question and answer session the last day, there were several additional points made deserving special attention.

Good nutrition and weight control are important because increased weight is certainly going to aggravate the work on already weakened muscles. Smoking is a hazard because it adds the additional complication of the changes in the lungs that occur. This includes excessive amounts of mucous and people with residual weakness in their respiratory muscles cannot cough adequately.

Exercise is good, if done carefully. Swimming seems to be a favoured activity, but make sure that it's warm as chilling in water can have a detrimental effect. Be sure to consider getting a flu vaccine every year and also consult with your doctor about the relatively new vaccine to be used every five years to prevent pneumococcal infections such as pneumonia. For those with unusually small veins where lab personnel have difficulty getting blood for tests, ask them to put a hotpack on your arm for up to 20 minutes. This should virtually eliminate the problems of hitting the vein.

The importance of having regular evaluations by your doctor was emphasized repeatedly during the sessions.

March of Dimes and Polio?

ACCENT asked John J. O'Connor, Vice President and General Counsel and Secretary of the March of Dimes Birth Defects Foundation, whether or not they had forgotten about the old polios.

O'Connor said, "Despite belief to the contrary, we have been heavily involved in the polio program by supporting the respirator equipment program for approximately 700 post-polio respirator patients around this country, who are using rocking beds, iron lungs, and portable respirators or various types. This is supported by our respirator equipment pool at the Medical College of Georgia in Augusta who handle all those east of the Mississippi. Those west of the Mississippi are serviced by Lifecare Services of Boulder, Colorado. In our last two fiscal years, this cost the March of Dimes a sum total of over $500,000 per fiscal year -- so you can see we are still heavily involved in this equipment program. We do not provide any out-of-pocket expenditure for living costs. Our program, both for polio and now for birth defects, are limited to patient services, research, professional education, and public health education."

During concluding remarks, O'Connor vowed he would go back to his trustees, asking them to review their programs and the recommendations coming from this conference to see what the National Foundation might add to its programs to satisfy the emerging needs of those who have had polio.

Other needs.

Not all the problems were medical. Others highlighted were the availability of adequate attendant care; a reliable source of information for physicians where they can get technical information on polio care, use of ventilators, etc.; reaching students in medical schools and educating medical personnel about the availability of this specialized kind of information; educating all post-polios as to conditions they should be aware of; availability of reliable information not only on equipment, and last but not least, the need for financial support to help organize, develop, and provide these kinds of services and program.

The conference was put together without federal funds, by Gini Laurie and Allen Goldberg, M.D., who were later joined by the Rehabilitation Institute of Chicago as a co-sponsor. Rehab. Gazette readers contributed the majority of the funds used to organize the meeting. Most participants paid their own expenses.

Photos included in the article were of
E.W. Johnson - Ohio State University, Columbus, Ohio.
Ann Bailey, M.D. - Warm Springs Institute for Rehabilitation, Warm Springs, Georgia.
Gini Laurie (Rehabilitation Gazette)
Allen Goldberg, M.D. Children's Memorial Hospital, Chicago.
Augusta Alba, M.D. Goldwater Memorial Hospital, New York City.
Geoffrey Spencer, M.B., FFARCS. St. Thomas Hospital, London, England.
John O’Connor, March of Dimes, New York City.

Grateful thanks to LincsPPN Member Sylvia Dymond - Polio of 1950 - who sent the above article to us. If you have/or come across any articles on polio and post polio from any newspaper or magazine then do give us a ring to check and see if we have a copy on file.

Sent by Donnie....

There are 18 names of books of the Bible mentioned in the paragraph below. See how many you can find. (A minister found 15 books in 10 minutes. But it took him days to find the others.) For some it takes a while to find them ALL !!! This is also good for the kids. See how you do! Here it is:

I once made a remark about the hidden books of the Bible. It was a lulu, kept the people looking so hard for facts... and for others it was a revelation. Some were in a jam, especially since the names of the books were not capitalized. But, the truth finally struck home to numbers of our readers. To others it was a real job. We want it to be a most fascinating few moments for you. Yes, there will be some really easy ones to spot. Others may require judges to help them. I will quickly admit it usually takes a minister to find one of them, and there will be loud lamentations when it is found. A little old lady says she brews a cup of tea so she can concentrate better. Some might eat a banana, hum a favourite song, or whistle a chorus. See how well you can compete. Relax now, for there really are eighteen names of the books of the Bible in this paragraph. If you happen to fall in a rut, hope and pray for better vision.

THE TEN COMMANDMENTS OF PPS

Dr. Richard L. Bruno and Dr. Nancy M. Frick

After 15 years of searching, archaeologists from The Post-Polio Institute have unearthed the commandments for treating Post-Polio Sequelae (PPS).

1) Listen to Yourself!

Polio survivors often turned themselves off from the neck down after they got polio. The first step in treating PPS is to listen to yourself: to what you feel, physically and emotionally, when you feel it and why. Our most powerful tool in treating PPS is the daily logs our patients keep that relate activities to their symptoms. However, polio survivors sometimes listen too much: to vitamin salesmen saying some herb or spice will "cure" PPS, to other polio survivors who warn that you will eventually have every possible PPS symptom, and to friends and family members (and the voices in you own head) saying you’re lazy and that you must "use it or lose it." Polio survivors need to listen to their own bodies, not to busybodies.

2) Activity is Not Exercise!

Polio survivors believe that if they walk around the block five times a day, spend an hour on the exercise bike and take extra trips up and down stairs, their muscle weakness will go away. The opposite is true: the more you overuse your muscles the more strength you lose. Muscles affected by polio lost at least 60% of their motor neurons; even limbs you thought were not affected by polio lost about 40%. Most disturbing is that polio survivors with new muscle weakness lose on average 7% of their motor neurons per year, while survivors with severe weakness can lose up to 50% per year! You need to substitute a "conserve it to preserve it" lifestyle for the "use it or lose it" philosophy. Stretching may help pain and non-fatiguing exercise for specific muscles can prevent you from losing the strength you have after you get a brace. But polio survivors need to work smarter, not harder.

3) Brake, Don’t Break.

The follow-up study of our patients showed that taking two 15 minutes rest breaks per day - that's doing absolutely nothing for 15 minutes - was the single most effective treatment for PPS symptoms. Another study showed that polio survivors who paced activity -- that is worked and then rested for an equal amount of time -- could do 240 percent more work than if they pushed straight through. Our patients who took rest breaks, paced activities and conserved energy had up to 22% less pain, weakness and fatigue. But polio survivors who quit or refused therapy had 21 percent more fatigue and 76% more weakness. For polio survivors, slow and steady wins the race.

4) A Crutch is Not a Crutch...

...and a brace is not a sign of failure or of "giving up." You use three times less energy (and look better walking) using a short leg brace on a weakened leg. Overworked muscles and joints hurt and nerves die after decades of doing too much work with too few motor neurons. So why not use a brace, cane, crutches (dare we say a wheelchair or a scooter) if they decrease your symptoms and make it possible to finally take that trip to Disney World? We know, you'll slow down and take care of yourself "when you're ready." And you'll use a wheelchair "when there's no other choice." Well, you don't drive your car until it's out of gas. Why drive your body until it's out of neurons?

5) Just Say "No" to drugs, unless...

Five studies have failed to find that any drugs that treat PPS. And there have been no studies showing that herbal remedies or magnets reduce symptoms. Polio survivors shouldn't think that they can run themselves ragged, apply a magnet or pop a pill, and their PPS will disappear. Pain, weakness and fatigue are not-so-subtle messages from your body telling you that damage is being done! Masking symptoms -- with magnets or morphine -- will not cure PPS. However, two studies have shown that polio survivors are twice as sensitive to pain as everyone else and usually need more pain medication for a longer time after surgery or an injury (see 10 below).

6) Sleep Right All Night.

The majority of polio survivors have disturbed sleep due to pain, anxiety or sleep disorders, such sleep apnea (not breathing) or muscles twitching and jumping all over your body during the night. However, polio survivors are usually not aware that they stop breathing or twitch! You need a sleep study if you awaken at night with your heart pounding, anxiety, shortness of breath, choking, twitching, or awaken in the morning with a headache or not feeling rested. "Post-polio fatigue" may be due to a treatable sleep disorder.

7) Some Polio Survivors Like it Hot.

Polio survivors have cold and purple polio feet because the nerves that control the size of blood vessels were killed by the poliovirus. Actually, polio survivors nerves and muscles function as if it's 20 degrees colder than the actual outside temperature! Cold is the second most commonly reported cause of muscle weakness and is the easiest to treat. Dress in layers and wear socks made of the silk-like plastic fiber polypropylene (sold as CORTEX or THINSULATE) that holds in your body heat.

8) Breakfast Is the Most Important Meal of the Day.

For once Mom was right. Many polio survivors eat a Type A diet: no breakfast, coffee for lunch and cold pizza for dinner. A recent study shows that the less protein polio survivors have at breakfast the more severe their fatigue and muscle weakness during the day. When our patients follow a hypoglycaemia diet (have 16 grams of low-fat protein at breakfast and small, non-carbohydrate snacks throughout the day) they have a remarkable reduction in fatigue. Protein in the morning does stop your mid-day yawning.

9) Do Unto Yourself as You Have Been Doing For Others.

Many polio survivors were verbally abused, slapped or even beaten by therapists or family members when they had polio to "motivate" them to get up and walk. So polio survivors took control, becoming Type A super-achievers, "the best and the brightest," doing everything for everyone except themselves. Many polio survivors do for others and don’t ask for help because they are afraid of being abused again. Isn't it time that you got something back for all you’ve done for others? Accepting assistance is not the same as being dependent. Accepting assistance can keep you independent. But appearing "disabled," by not doing for others, asking for help or using a scooter, will be frightening. Remember: If you don't feel guilty or anxious you are not taking care of yourself and managing your PPS.

10) Make Doctors Co-operate Before They Operate.

Polio survivors are easily anesthetized because the part of the brain that keeps them awake was damaged by the poliovirus. Polio survivors also stay anesthetized longer and can have breathing trouble with anesthesia. Even nerve bfocks using local anesthetics can cause problems. All polio survivors should have lung function tests before having a general anesthetic. Your complete polio history and any new problems with breathing, sleeping and swallowing should be brought to the attention of your surgeon or dentist - and especially your anesthesiologist - long before you go under the knife.

Polio survivors should NEVER have same-day surgery or outpatient tests (like an endoscopy) that require an anesthetic.

The Golden Rule for Polio Survivors:
If anything causes fatigue, weakness, or pain,
Don’t Do It!
(or do a lot less of it.)
..and...
The Golden Rule for Polio Survivors’ Friends & Family:
See no evil, hear no evil and help only when asked.

Polio survivors have spent their lives trying to look and act "normal." Using a brace they discarded 30 years ago and reducing their super-active daily schedule is both frightening and difficult for them to do. So, friends and family need to be supportive of life-style changes and accept survivors' physical limitations and new assistive devices. Most important, friends and family need to be willing to do the physical tasks a polio survivor should not do, but only when the polio survivor asks. Friends and family need to know everything about PPS but say nothing: neither gentle reminders nor well-meaning nagging will force survivors to use a new brace, sit while preparing dinner or rest between activities. Polio survivors must take responsibility for taking care of themselves and ask for help when they need it.

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Post-Polio References

Articles by both Dr. Bruno and Dr. Frick can be found in our Lincolnshire Post-Polio Library. See the catalogues for:
Bruno, Richard L., Ph.D.
Frick, Nancy M., M.Div, Lh.D.

See also our Directory entries for:
The Post-Polio Institute, Englewood (NJ) Hospital and Medical Center Dr. Bruno
The Harvest Center Drs. Bruno and Frick.

PPS does not just affect the life of the Polio Survivor...

It affects the whole family, friends and work colleagues. You know exactly how you feel, those around you don't. They know how they feel and you don't. The best way round this is for partners, or if you are alone then pick another polio survivor or friend, to share how you both feel about what is happening. Then bring in the whole family and friends. Don't forget if you are working your work colleagues need to talk too.

How often have you, a polio survivor, been doing something and been asked 'Would you like some help' and you have replied 'No, I can do it myself thank you.' Then the next day, you have been struggling with exactly the same job and your partner/family member says nothing. What do you do? You say, 'Why can't you give me a hand with this?'

Share your thoughts and feelings and learn about PPS together. Pacing, resting and planning your week ahead is a good way of coping with all the work that needs doing and more importantly what you want to do. Take a Wednesday morning for example. You can say 'I would like to do so and so' and your partner can say, 'Well I can help you from 10.30 for an hour when I have finished' or 'If we could do it Thursday morning together I am free all morning.' This has to work both ways. If you, a carer, are going to do something that means you won't have hardly any free time one day then tell us so we can plan ahead. It's all a question of talking and sharing your lives.

From personal experience, don't forget your children and family may have questions they want to ask, but decide to keep quiet in case answering stresses you more. Involve them as soon as you can.

What helped me the most was my asking for counselling as advised in the PPS articles. This was arranged by my G.P., and at the surgery.

The first session was 45 minutes and I could say what I felt about the medical profession, it would go no further than these four walls. Wow! Can you believe how much I got off my chest. All those years of not going to the doctors till you really have to. Telling them your symptoms but knowing that most of the time they are going to look at you as if you are a hypochondriac.

When you look fit and well and tell them that you can't climb stairs like you used to, can't carry bags as heavy, can't walk as far, etc., you get examined, lift your leg, bend your knee. That's OK. Take these tablets, it's arthritis, it's your age, and the worse remark of all, ‘It’s all in your mind’.

Then over the next sessions I was encouraged to talk about my life starting from being a baby. After 8 sessions I had come to terms with my past and was ready to cope with now and the future. I learned so much about myself, e.g. I suddenly realised why I hated buying shoes.

Back in a rush came the vision and smells of that specialist shoe shop I was taken to at the age of 13 following my tendon transplant operations. They specialise in shoes for awkward feet, my mother was told. Following the measuring came the appearance of the shop assistant through that curtain. 'I am sorry, but these are all we have to fit you.' Dark Brown Men's Jesus Sandals... and I was 13 and a teenager.

I realised then why I had freaked out in a shoe shop in Nottingham when going to buy some flat shoes to wear with my very pale blue wedding dress. The shop assistant appeared through the curtain saying, 'The only size 9's we have are these...' Dark Brown Walking Shoes!!!!!!

I was so angry and told the shop manager what I thought of her staff. Now of course I realise that her statement was perfectly ok. They were the only shoes she had in a 9. But to me who had always had trouble buying shoes the thought of them and my wedding dress...

Now, I don't mind wearing the shoe boxes.

Hilary Hallam - Polio of 1952, aged 5.
linpolio@legend.co.uk

Anita writes...

Hils, about your observation that many of us polio survivors are about a foot shorter than you. I was surprised to find out during my PPS exam that according to the doctor, I would have been about 59" instead of 52" if I hadn't had polio. So now I can truthfully say, I'm not overweight, just undertall.

Anita Bjorling - Polio of 1952
<anitabjorling@hotmail.com>
http://eurekaherald.com/users/angel/anita/anitapage.htm
⚠ *Currently Unavailable* ⚠

SOME THOUGHTS FROM A WHEELCHAIR.

By Chris and Chas Mackinnon

I've always been small, around five feet tall,
But, now that I'm wheelchair bound,
I'm beginning to find that I really don't mind
Being only three feet from the ground.
I used to think I'd be sad, but there’s good points and bad
About being sat down and on wheels,
I can take out a roast or recover the post
Without bending, how clever that feels!
When the grandchildren visit, you can see them think "Is it
A train or a cart and a horse,
Or it may be a great big red bus just for us?"
But it's never a wheelchair of course.

When nursing my pets, think how easy it gets,
With no effort they jump on my knee,
And wherever I go, I certainly know
There's always a chair there for me.
When things are too high on the shelf I don't cry,
That's just one of those things, I agree,
And when nobody sees me, that doesn't displease me,
Till they nearly end up on my knee.
It can be a real bind, but I've learned not to mind
When people talk over my head,
But when they ask, "Does she take... ? I think *for God's sake,*
Why the hell don't they ask me, instead?

I’ve learned not be hurt, when my prettiest skirt
Can no longer be seen as it should,
When the colour and swirl can't be shown with a twirl,
Tears no longer come in a flood.
It's often a bind in new places, I find,
I'm enjoying a nice drink or two,
When it always occurs, it is down or upstairs,
"What is?" you ask, Why, the loo.
I've programmed my brain to put up with the strain
Of being stuck here in this chair,
And I don't really mind all the things that I find
That would get in most other folks hair.

But I've got one pet hate, I'll tell you all straight,
And it really is driving me nuts,
I seem to spend hours not smelling the flowers,

But all shapes and sizes of butts.

Chris - Polio of 1952
earthborne@cableinet.co.uk

There are three signs of old age.
The first is your loss of memory, the other two I forget.
Middle age is when you have stopped growing at both ends, and have begun to grow in the middle.
At my age, "getting a little action" means I don't need to take a laxative.
The cardiologist’s diet: if it tastes good, spit it out.

In a country of free speech, why are there phone bills?

If the pen is mightier than the sword, and a picture is worth a thousand words, how dangerous is a fax?

Why do banks charge you a "insufficient funds" fee on money they already know you don't have?

If all the world is a stage, where is the audience sitting?

Why is the alphabet in that order? Is it because of that song?

If I melt dry ice, can I take a bath without getting wet?

How does a Thermos know if the drink should be hot or cold?

What happens to an 18-hour bra after 18 hours?

Why didn't Noah swat those two mosquitoes?

When your pet parakeet sees you reading the newspaper, does he wonder why you're just sitting there, staring at carpeting?

Inside some of us is a thin person struggling to get out, but she can usually be sedated with a few pieces of chocolate cake.

It is bad to suppress laughter; it goes back down and spreads to your hips.

Amazing! You just hang something in your closet for a while, and it shrinks two sizes.

I had to give up jogging for my health. My thighs kept rubbing together and setting my pantyhose on fire.

Freedom of the press means no-iron clothes.

SOME HELPFUL TIPS
USE YOUR BODY EFFICIENTLY

Grace R. Young, MA, OTR

Maintain good posture both sitting and standing. Correct seating is critical.

- Correct depth.
- Low back and feet supported, knees lower than hips.
- Sit whenever possible.

Use correct methods for lifting:

- Test the weight of the load.
- Keep it close to the body.
- Have a surface ready to receive it.

Use mechanical help for carrying:

- Kitchen cart on casters.
- Luggage cart.
- Collapsible grocery cart.

PROTECT YOUR JOINTS.

Use the largest joints available for any activity. The joints closest to the body are the largest and strongest. Change positions frequently. Maintaining joints in one position causes muscles to fatigue. Use a telephone head set, card holder, book holders, etc. Prevent pressure on the thumb side of your fingers. Using hands incorrectly pushes the fingers away from the thumb into a deforming position. For example, hold purses and bags on the forearm instead of with the fingers.

REST, PACING AND TIMING.

Rest at least an hour a day, but as frequently as needed. Some people need intermittent rest periods throughout the day. Break up stressful activities into smaller work periods. For example, work no longer than 30 minutes, rest 15 minutes, etc., depending upon the activity and your own strengths and weaknesses. For some people these work, rest periods may be as short as 2 or 3 minutes work and 2 or 3 minutes rest. Pace yourself. It is tempting to overdo on your good days but you’ll be more productive over-all if you plan ahead.

Alternate light and heavy activities throughout the week. Don't do a heavy activity if you're going out in the evening. Try using Day-at-a-Glance and Week-at-a-Glance books to help you plan ahead. Timing can make a difference in how you feel. You may have different levels of pain and fatigue at various times of the day. Example if cooking supper late in the afternoon is stressful, prepare most of it in the morning, to be reheated later.

ELIMINATE AND DELEGATE JOBS.

What can be eliminated? Bedmaking, ironing for example. Use a comforter (quilt/duvet) with a cover instead of a top sheet, blanket, and bedspread. The comforter could be straightened up while still in bed.

Purchase permanent-press clothes that can be hung up after partially drying in the dryer.

Delegate. Simple chores which can be assumed by others include caring for pets, disposing of trash and garbage, setting the table for breakfast the night before, folding laundry. Assign to others larger jobs including vacuuming, mopping, cleaning bathrooms.

HOME MODIFICATIONS.

- Drafting chair for meal preparation.
- Cutting board on a pulled out drawer.
- Two-shelf utility cart with lower shelf folded up to allow for leg room.
- Hospital overbed table.

Organize your kitchen:

- Store every day dishes in stacks of their own kind.
- Use vinyl coated wire racks.
- Stack pots and skillets one layer deep.
- One-motion storage of pantry items.
- One and two level sliding racks, bins, baskets and shelf trays.
- Keep supplies close to the area of first use.
- An angled mirror against the wall over the stove allows you to see what's cooking on the back burners while you're seated.

Throughout the house:

- Place electric outlets at least 18" from the floor.
- Install light switches near the entryway to each room.
- Install telephone extensions in the most used rooms or get a portable phone.

Minimize trips:

- Store towels, sheets and pillowcases in each room where they are used instead of a central linen closet.
- Put duplicate supplies in each area where used.

SIMPLIFY YOUR WORK .

- Don't put away the most frequently used pans or skillets.
- Some recipes double easily. Prepare double recipes and store half for use at another time: meat loaves, muffins, etc.
- Use convenience foods such as prepared salads and vegetables from the supermarket salad bar.
- Do chores the same way each time. Repetition increases efficiency.
- When marketing (shopping), have groceries bagged according to category.

USE ENERGY-EFFICIENT EQUIPMENT.

- Electric knife for hard cheese, vegetable, fruits, etc.
- Jar chopper for onions, peppers, etc.
- Cordless lightweight can opener by Black and Decker.
- Corelle dishes instead of stoneware.
- Lightweight non-stick skillets.
- Reachers for high and low objects.

Grace Young gryoung@pacbell.net
WebSite http://www.reocities.com/HotSprings/4713/

See also the Lincolnshire Post-Polio Library catalogue entry for
Young, Grace R., MA, OTR

Acceptance with Laughter & Tears.

Accepting PPS does not mean giving up, does not mean quitting.

It just means "accepting" the changes, the adjustments. So today you're having a bad day huh? Then be good to yourself. Anything you can't get done today can wait until tomorrow, or the next day, or the next week, or even the next month!

Watch a movie - even though you probably won't stay awake for all of it.

Read a book - even though you probably won't remember what it's about.

Write a letter to a friend - just think of the fun they'll have trying to decipher it (of course I had to look up decipher).

Laugh at the silly things you do rather than get upset about them...

So what if you just spent $200 at the grocery store and bought nothing of value - you got there right? And, even better, you got back home!

So what if you left the clothes in the washer for over a week? You washed them, just forgot to dry 'em.

So what if you put that hot cup of tea you just made in the fridge - you'll find it the next time you go there for the dishwashing soap.

When you're walking and you trip over (nothing), whoever saw you, just tell them you're a clutz.

When you set up the VCR for your hubby's favourite show (bravo just for that) and you recorded the weather channel, just tell him you wanted him to be informed for his golf league.

Big deal that you got more eggshells in that "special new recipe" - even the best of chefs do that.

Your cats are acting very strange - FEED THEM before they bring you their gift (mouse, bird, etc.)

If you're on the net and in chat and you suddenly forgot what you were going to say, just pretend there's a lag. If you get really lost in your thoughts (kinda comatose), just say you got disconnected.

Remember that it's okay to fall. just brush yourself off and get right back up.

Cry when you need to, laugh whenever you can, take it one day at a time.

Set a goal, no matter how small it seems; the success of reaching that goal is worthwhile.

Rev. Karen Utz, Dayton Ohio - Polio Survivor
popette <popette@ALLTEL.NET>

Focusing the Mind

by Christine Ayre.

Polio survivors are a tenacious lot, they have had to be to get over polio in the first place, so changing your way of life to take into account PPS is not a thing easily accepted. I am no exception, I admit could have done a lot of things sooner, to make life a bit easier, when I have made that change wonder why I have not done it a long time ago.

A couple of years ago I bought a scooter, mainly so that I could resume walking my dogs. I thought this would be the ideal thing and so it has proved to be, the dogs soon learnt to trot at the side and four miles an hour is nothing to "Ben". "Aster", being older, sometimes finds it a bit much, so jumps on the scooter and has a ride.

The other thing I thought of when I bought the scooter was taking it in my car, thinking then the world would be my oyster, that I could once again go anywhere and do anything. With this in mind I bought scooter ramps, called "suitcase ramps", they fold in half and fit in the car nicely. These would have been ideal for an Olympic weight lifter, also they are wonderful finger trappers. For me they are useless, so having the scooter in the car and driving off into the sunset has just not happened. I often think looking around at the aids on sale for disabled people, maybe a chimpanzee could have designed better.

I will tell you what happened to force me to sort out the scooter in the car problem.

A couple of weeks ago my partner 'John' and I decided we would go into the nearby town to do a bit of shopping and look round the market. Although the day was grey and overcast we set off. I planned to go into just two shops, then to totter up to the marketplace where I would meet up with John and walk back to the car together. We parted company in the car park and I set off to the first shop. Walking for me is not too bad for about the first fifty yards, after that my feet start to act as if they are wearing flippers. They start to flip and flop about, my arms don't seem to be part of me and I feel like a zombie.

Before I got to the first shop the rain started. Although still in sight of the car, flippering my way back to get an umbrella was out of the question, so I battled on. I reached the first shop, got what I wanted, crossed the road to the other shop, the rain quite fast by now, completed my shopping and set off for the market at my usual sub-slug pace. The rain by now was bucketing down.

I scrabbled in my handbag for something to cover my head. All I had that was waterproof was a bag for collecting dog poo, not big enough for my head. I dodged into "Boots" to buy one of those plastic rainhat things, only to be told "oh we don't sell those anymore". Back I went into the rain.

The next thought was, take shelter, which I did in a bookshop. I slugged up and down the shop a few times while I thought about getting back to the car. I gazed at a rack of envelopes for so long that the shop assistant asked me if I wanted to buy any. I said no, I just like looking at them. All the time the rain got worse and worse. I decided the best thing I could do was to slide along as close to the shop windows as possible and maybe get a bit of shelter as I went along. This went quite well at first, until I caught sight of my feet.

I was wearing sandals bought a few weeks ago. The sales assistant had conned me into buying waterproof polish for the sandals. It wasn’t until I got home and was applying the polish that I realized feet wearing sandals would get wet anyway. Seeing my feet now wearing the sandals, the rain pouring in the top and out of the sides I remarked on how lucky I am to be wearing waterproof sandals. I found the whole thing rather amusing and this caused me to start laughing hysterically. I had to lean up a wall to laugh in comfort. People were giving me a wide berth, thinking maybe that I was drunk, or had water on the brain. I caught sight of John rushing back to the car, he always ignores me when I get an attack of laughing. I did eventually get back to the car, but wet to the skin.

The drenching I received that day served to focus my mind. I decided I would have to address the scooter in the car problem.

I thought if the ramps were lighter maybe I could manage. With this in mind I approached my brother "Barry". He is able to do most things, Building Boats, repairing Traction Engines, Rebuilding Machines, nothing is impossible for him. So I said can you make these ramps so that I am able to lift them? I should have known what he would say "what did you buy this rubbish for? I can build you a set of ramps, lighter and stronger". "OK", I said "do it", and he did it.

Now I can get my scooter in and out of the car. It's wonderful. I went into town for the first time this week with the scooter. What freedom! Zoomed round "Woolworths", people jumped out of the way when they saw me coming. I find it amazing how many people walk along not looking where they are going. In the past I have been nearly knocked over quite a few times. Now things have changed.

I am invincible, I am woman,
I am scooter person, I feel a song coming on,
as I race up the highstreet 0 to 4 mph in seconds.
There is just one thing missing.
Anyone got one of those caps with the peak at the back?

Barry will make scooter ramps to order if anyone is interested. Contact me through the Lincolnshire Post-Polio Network.

Christine Ayre - Polio of 1950.
<Catley@tesco.net>

GIFTS WE CAN GIVE EACH OTHER.

1) THE GIFT OF LISTENING...

But you must REALLY listen. No interrupting, no daydreaming, no planning your response. Just listening.

2) THE GIFT OF AFFECTION...

Be generous with appropriate hugs, kisses, pats on the back and handholds. Let these small actions demonstrate the love you have for family and friends.

3) THE GIFT OF LAUGHTER...

Clip cartoons. Share articles and funny stories. Your gift will say, "I love to laugh with you."

4) THE GIFT OF A WRITTEN NOTE...

It can be a simple "Thanks for the help" note or a full sonnet. A brief, hand-written note may be remembered for a lifetime, and may even change a life.

5) THE GIFT OF A COMPLIMENT...

A simple and sincere, "You look great in red," "You did a super job" or "That was a wonderful meal" can make someone's day.

6) THE GIFT OF A FAVOUR...

Every day, go out of your way to do something kind.

7) THE GIFT OF SOLITUDE...

There are times when we want nothing better than to be left alone. Be sensitive to those times and give the gift of solitude to others.

8) THE GIFT OF A CHEERFUL DISPOSITION.

The easiest way to feel good is to extend a kind word to someone, really it's not that hard to say, Hello or Thank You.

Friends are a very rare jewel indeed.

They make you smile and encourage you to succeed. They lend an ear, they share a word of praise, and they always want to open their hearts to us.

Show your friends how much you care.

You may want to share this with everyone you consider a FRIEND.

Author Unknown.

Attention Children:

The Bathroom Door is Closed! Please do not stand here and talk, whine, or ask questions. Wait until I get out. Yes, it is locked. I want it that way. It is not broken, I am not trapped. I know I have left it unlocked, and even open at times, since you were born, because I was afraid some horrible tragedy might occur while I was in there, but it's been 10 years and I want some PRIVACY.

Do not ask me how long I will be. I will come out when I am done. Do not bring the phone to the bathroom door. Do not go running back to the phone yelling "She's in the BATHROOM!" Do not begin to fight as soon as I go in. Do not stick your little fingers under the door and wiggle them. This was funny when you were two. Do not slide pennies, Lego's, or notes under the door. Even when you were two this got a little tiresome.

If you have followed me down the hall talking, and are still talking as you face this closed door, please turn around, walk away, and wait for me in another room. I will be glad to listen to you when I am done.

And yes, I still love you. Mom

Author Unknown.

Lincolnshire Post-Polio Library

Articles added since last newsletter with grateful thanks to the authors

Title: Survey of the Late Effects of Polio in Lothian

Author(s): B. Pentland, D. J. Hellawell, J. Benjamin, R. Prasad
Original Publication: Rehabilitation Studies Unit, Charles Bell Pavilion, Astley Ainslie Hospital, 33 Grange Loan, Edinburgh EH9 2HL. January 1999
Abstract/Extract: The Edinburgh Branch of the British Polio Fellowship (BPF) expressed the concern of members that the medical and related professions often appeared unfamiliar with the late consequences of polio and that services were not meeting their needs. In an attempt to determine the number of people affected and the nature of their experience, this postal survey was done in 1998. A set of questionnaires were sent to 221 people, in Edinburgh and the Lothians, who had been identified as suffering polio in the past from those known to the BPF and hospital records. There were 125 replies which constituted the study population: 60% were female; the median age was 59 years; and the median time since original diagnosis was 51 years.

Title: National Rehabilitation Hospital Limb Classification for Exercise, Research, and Clinical Trials in Post-Polio Patients

Author(s): Lauro S. Halstead, Anne Carrington Gawne, and Bao T. Pham
Original Publication: The Post-Polio Syndrome: Advances in the Pathogenesis and Treatment Volume 753 pp 343-353 of the Annals of the New York Academy of Sciences May 25, 1995.
Abstract/Extract: A need exists for an objective classification of polio patients for clinical and research purposes that takes into account the focal, asymmetric, and frequent subclinical nature of polio lesions. In order to prescribe a safe, effective exercise program, we developed a five-level (Classes I-V) limb-specific classification system based on remote and recent history, physical examination, and a four-extremity electrodiagnostic study (EMG/NCS). Class I limbs have no history of remote or recent weakness, normal strength, and a normal EMG. Class II limbs have no history of remote or recent weakness (or if remote history of weakness, full recovery occurred), normal strength and EMG evidence of prior anterior horn cell disease (AHCD). Class III limbs have a history of remote weakness with variable recovery, no new weakness, decreased strength, and EMG evidence of prior AHCD. Class IV limbs have a history of remote weakness with variable recovery, new clinical weakness, decreased strength, and EMG evidence of AHCD. Class V limbs have a history of severe weakness with little-to-no recovery, severely decreased strength and atrophy, and few-to-no motor units on EMG. In a prospective study of 400 limbs in 100 consecutive post-polio

patients attending our clinic, 94 (23%) limbs were Class I, 88 (22%) were Class II, 95 (24%) were Class III, 75 (19%) were Class IV, and 48 (12%) were Class V. Guidelines for the use of this classification in a clinical/research setting are presented along with sample case histories and class-specific exercise recommendations.

Title: Correlation of Electrophysiology with Pathology, Pathogenesis, and Anticholinesterase Therapy in Post-Polio Syndrome

FULL TEXT HERE

Author(s): Neil R. Cashman and Daria A. Trojan
Original Publication: Reprinted from The Post-Polio Syndrome: Advances in the Pathogenesis and Treatment Volume 753 [pp 138-150] of the Annals of the New York Academy of Sciences May 25, 1995
Abstract/Extract: A great deal of data has been generated on PPS, and a great deal more will be generated before we understand the pathophysiology of this common and disabling disorder. Perhaps now, to guide future work and direct therapeutic approaches, it is best to think of the symptoms of PPS as due to two lesions of the motor unit: a "progressive lesion" and a "fluctuating lesion."

Title: Pain And Post-Polio Syndrome - An Overview

FULL TEXT HERE

Author(s): Paul E. Peach, MD.
Original Publication: Unknown. Received from Dr. Peach July 1999.
Abstract/Extract: Polio survivors, not unlike the general population, will likely experience pain at some points in their lives due to a myriad of reasons. Unlike the general population, however, polio survivors are somewhat more likely to experience pain as a consequence of the residual paralysis or paresis of chronic polio. If a polio survivor is experiencing pain, this does not necessarily mean that the pain is a symptom of post-polio syndrome. Taking this yet one step further, even if a polio survivor has been appropriately diagnosed with post-polio syndrome and is experiencing pain, this does not necessarily mean that the pain is due to the symptoms of post-polio syndrome. If pain is being experienced, it is essential that an appropriate medical evaluation be made because the pain could be due to any number of factors ranging from very benign to quite serious.

* * *

Two articles by Frankie Campling who has ME.

WHAT ARE YOU GETTING RIGHT?

One of the ways of managing your ME could be to ask yourself questions like *"What am I doing wrong?"* or *"Why did I do such-and-such which I knew was a bad idea?"* I don't think that that is always helpful. There are far too many people around who are only too ready to point out your mistakes without you joining in the chorus. A much more constructive way might be to ask *"What am I getting right?"* If you can get better at recognising the things that work for you, the times when you manage yourself well, then you can start to build on your successes.

Thinking well of yourself is important. If you concentrate on what you might be doing wrong, you are likely to have a much lower opinion of yourself than if you give equal time and attention to the ways in which you are being successful. If you can identify the things that really do work for you, you can begin to build on them. You could try keeping a diary for a few weeks in which you only record successful events and good moments. Once you can see what they were and how you achieved them, you could plan to include more of them.

'Getting things right' can come in a variety of forms. Some of them can seem to be rather small and trivial, but even a crumb of a good idea can be a foundation for more. Some of the things to look out for could include:

- The times when you paced yourself really well and didn't allow yourself to be pushed off course.
- The realistic goal that you set yourself and managed so that you got a sense of achievement.
- The small treat you gave yourself as a reward for achievement.
- The times when you communicated really well with the people around you.
- The moments when you were able to distract yourself from being worried or anxious.
- The flash of happiness you experienced and acknowledged in spite of feeling ill.

You are unique, so your successes will always be somewhat different from those of other people with ME. However, if you give it some thought, I am sure that you could identify the times when you would class yourself as a success at managing your ME. What was different about those times? What helped you to 'get it right' in a way that you don't always manage? What are the things that you are confident you usually do well? How could you do more in the same sort of way?

What about making *"I'm going to give myself credit for all the things I'm getting right"* one of your New Year resolutions.

BEING ILL DOESN'T MEAN NOT HAVING RIGHTS

It is all to easy to slip into the trap of feeling that we have stopped having rights since becoming ill. We do still have rights, no more and no less than the people around us, even if we can't do all the things we once did. We will communicate better with family, friends, doctors and officials if we can be quietly assertive, but that assertiveness has to be based on the belief that we still have rights.

I have found it very helpful to think carefully about what my own rights are now, taking my illness into account, and to balance them against the rights of the people around me. This is the list I’ve worked out for myself.

I believe that I have the right:

- to ask anyone for anything, while respecting their right to say no;
- to say no myself without feeling guilty;
- to choose whether or not to get involved in the problems of someone else;
- to look after myself and not to be pushed into doing something that might jeopardise my health or wellbeing;
- to use a reasonable amount of my available energy for having pleasure;
- to have different abilities and needs depending on the fluctuations of my illness;
- to choose what help I will accept;
- to be consulted about decisions that will affect me;
- to give as well as to receive;
- to have emotions and mind about what has happened to me;
- to change;
- to be confused;
- to be kind and forgiving to myself when I make mistakes;
- to believe that being is as important as doing;
- not to feel guilty about being ill.

Could you work out a list for yourself that takes account of your particular circumstances?

<frankie@campling.force9.co.uk>

AGM Followed by Speakers - Saturday 4th September 1999. Ancaster Day Centre, Boundary Street, Lincoln.

Building is open from 9.30 am.
AGM Starts promptly at 10.30 a.m for about an hour.
Coffee Break.

12.00 Marcia Falconer, PhD from Ottawa, Canada.
Co-author of Non-Paralytic Polio and PPS.

12.45 - 2.00 Buffet Lunch and time to meet each other.
Buffet Lunch is £3.00 - Booking is essential.
Ring or write to book lunch tickets.
Cheques would be welcome beforehand or pay on the door.

Afternoon Session.
2.00 Dr. Paul Ballinger, author of Unusual Cases - Post Polio Syndrome
and Sylvia Foster, Orthotist.

Tea Break.
Panel of Speakers and Other Clinicians for Questions.

End by 5.00p.m.

Informal Evening in the Bar of the Holiday Inn Express, Lincoln.
Friday and Saturday Nights 3rd and 4th September 1999.

Ancaster Day Centre
Boundary Street, Lincoln. Off the A1434.

Coming into Lincoln from the A46 go straight across onto the A1434 then keeping on this road go through 5 sets of Traffic Lights. D C Cook (VW Cars) is then on your right. Boundary Street is the first left after the next set of pedestrian lights. Hairdressers on corner. Entrance is immediately after the 30 terraced houses on your left. Coming from the other direction on the A15 after the South Park Roundabout onto the A1434 and it is the last street on the right before the first set of Pedestrian lights. Hairdressers shop on corner.

The Holiday Inn Express is just off the A46. Coming from the south on the A46 take the A46 Lincoln Bypass north and Whisby Road is the first road on the right. The Pride of Lincoln (Hotel, Bar and large restaurant) is visible from the A46 and the Holiday Inn Express is next to this. Entrance to both is the first road on the left down Whisby Road and take the first left off that. Coming from the North Whisby Road is the first road on the left after the roundabout junction with the B1188 Doddington/Lincoln.

Annual General Meeting
September 4th 1999 - Ancaster Day Centre, Boundary Street, Lincoln. 10.30 am. prompt.

Nominations for all posts* are requested in writing by the 30th August 1999.

Chairman - Lynn Hobday is standing down as Chairman.
Vice Chairman - no one in post.
*Vice Chairman with specific responsibility for the WebSite will remain with Chris Salter.
Secretary - Hilary Hallam and prepared to stand again.
Treasurer - Jean Tapper and prepared to stand again.
4 Committee Members - Christine Ayre and Phil Bilton and prepared to stand again.

Meetings are held every two months in the Lincoln area to suit those attending. If any members or family members are interested in joining the committee - and you would be most welcome - and would like more information about the work involved then please get in touch. We have already received the following nominations.

Chairman or Vice Chairman - Christine Ayre - I am a Polio Survivor of 1950. Live in between two small Lincolnshire villages with my two dogs. I use a Nippy ventilator at night. I have a stairlift, electric scooter and motability car which has enabled me to manage my life much better. I am a Committee member of the Lincolnshire Post-Polio Network and author of articles in the LincPIN.

Chairman or Vice Chairman - Councillor Bud Roy Robinson - Bracebridge Ward, Lincoln. Bud is aged 64 and married with 8 children, 16 grandchildren and one great grandchild. He was in the R.A.F. for 5 years as an Air Traffic Controller. He has been a Councillor since 1986. Has 12 years experience of working with people with housing needs for a housing association. Chairman of the Housing Committee for 10 years. He was part of the Steering Committee set up for Citizens Advocacy now called CALL and has been involved with Share the Care, and the Social Services committee. He was Mayor of Lincoln 1998 - 1999 and opened our last AGM.

Committee Member - Myra McManus - a Polio Survivor living in Lincolnshire.

The hardcopy edition of the Newsletter that was posted to all members contained a Nomination/Voting form at this point.

LINCOLNSHIRE POST-POLIO NETWORK
Registered Charity No. 1064177

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MEMBERSHIP for this financial year is £10.00 - includes 6 Newsletters
Life Membership £100 - 20 x £5 per month
All Membership fees now payable by Standing Order
All donations will be gratefully received.

All enquiries, book requests, medical article requests, membership fees, items for newsletters and donations to
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