The Lincolnshire Post-Polio Network
POST-POLIO INFORMATION SERVICE
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The LincPIN

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AGM Saturday 19th September 1998

Two LincsPPN members leave for the States and Canada on June 30th 1998 flying Virgin from Heathrow.
Attending the Ontario March of Dimes Conference
PPS Solutions for the Future - July 10th to 12th in Toronto.
Visiting the West Park Post Polio Clinic in Toronto.
Meeting Dr. Lauro Halstead, Dr. Henry Holland, Dr. Neil Cashman, Dr. Mavis Matheson, Joan Walker PhD PT, Jann Hartman BSc. and more meetings being arranged.
All have articles on our WebSite.
Also meeting many Polio Survivors on a 2000 mile route New York to Virginia into Canada and back to New York via Boston.

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This issue includes articles from our online library (our newsletter is distributed by post to many subscribers who do not have Internet access). Rather than duplicate the article in this online edition of the newsletter, I have instead just included a link to the library article. I have assumed that those of you who already have the article would prefer not to have to print it again if you wish to print this newsletter for your own use. However, if you are printing copies for further distribution we would ask you to print copies of the article as well.

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

Remember the opinions expressed are those of the individual writer(s) and do not necessarily constitute an endorsement or approval by the Lincolnshire Post-Polio Network. Although it does not provide an endorsement, it is provided as a service for those seeking such information. ***ALWAYS*** *consult your doctor before trying anything recommended in this information or any other publication.*
Lincolnshire Post-Polio Network

Editorial by Hilary Hallam

Another two months have gone by and the letters and phone calls for information continue to come in on a daily basis. Once again I ask if anyone has some spare time and would be prepared to take on a share of the work then please get in touch. You do not have to live in Lincoln, or Lincolnshire. There are many little jobs that can be done from home, or locally to where you live. We are having a Stand at the Lincoln City Football Club Gala Day on Sunday 26th July 1998.

Articles included in our newsletter are varied. I choose them to give you a variety of information not only for yourself but for the medical professionals that you are seeing. Many are far too long for inclusion but can be accessed on our WebSite or you can contact us for copies. Updates of new articles added to our WebSite will be included with each Newsletter.

On 17th May 1998 the Scottish Paper, the Sunday Post, printed an article about Post Polio. Janet Boyle their Health Correspondent rang because she had read the Dr. Lauro Halstead article in Scientific American April Issue (now available on our WebSite by kind permission from Dr. Halstead and Scientific American) and could I send her some more information. I sent her a large pack of information, told her about our organisation and explained about our WebSite as the Sunday Post does not have access to the Internet. The article that was published did not mention the excellent Scientific American article or its content. Instead it used words such as dreaded, disease, haunt, crippling and victim. Most of the Polio Survivors who rang said it had really worried them. Our name was quoted incorrectly twice and our WebSite was not mentioned. The picture was incorrectly captioned. No wonder Journalists have such a poor reputation. To date we have received over 80 phone calls for information. Virtually every call was the same story. I have had problems for months to 15 years - and despite having many tests no-one can find any reasons for them and the fact that I had polio has hardly ever been mentioned. A few of the people who have contacted us are getting together to start their own network. We wish them well and look forward to including an article from them in our next newsletter.

Elizabeth Lounsbury, the Chairperson of the Ontario March of Dimes PPS Committee, paid us a flying visit last month and told us about their Toronto Conference July 10th - 12th, PPS Solutions for the Future. The LincsPPN do not have enough money to sponsor attendance at Conferences. However, I personally have to thank some friends and family for their financial support which has enabled me to join Lynn Singleton from Sussex in attending this Conference. We are leaving on June 30th - meeting at the Virgin Airlines Check-in Desk for the first time - and landing in New York. We are hiring a car and our route goes via Baltimore MD, Washington DC, Richmond VA, Dayton PA, Buffalo N.Y., and into Canada. To London, Toronto, Ottawa, Montreal, back into the USA, to Boston and back to New York and home on the 21st July. We wish to thank all the Polio Survivors who have offered us hospitality and organised events to meet many more and without which this trip would be impossible. We also thank the PPS Specialists who have agreed to meet us. I am grateful to the committee members who are stepping into the breach in my absence. All Email, Post and phone calls are being diverted during this time.

Ian Radus, a Polio Survivor from Johannesburg in South Africa, also paid a flying visit to Lincoln whilst visiting London to meet his new Grandson. He also met Lynn Singleton again for the first time in over 30 years. I was type chatting to Lynn on the Internet a month earlier - using ICQ, a communication program downloaded from www.mirabilis.com, - when a chance remark established that she knew Ian. A few weeks later the same thing happened when we were having a three way conversation with Mike & Yvonne in Cape Town - they were stunned to find they knew one another in Rhodesia, also over 30 years ago.

AGM Saturday 19th September 1998

We apologise for having to postpone this but it is now firmly fixed for Saturday 19th September at Ancaster Day Centre, Boundary Street, Lincoln. The AGM will commence at 11.30 am. sharp followed by buffet lunch - £2 - to enable you to get to know each other. Speakers - Dr. Alan M Whiteley, Consultant Neurologist will be the main speaker - at 2.00pm with break for cup of tea and loo visits. The break will be followed by question time. You are welcome to come for all or part of the day. All information, books, videos, etc and photos from trips will be available. We will be arranging an evening meal at another venue for those who wish to join us. There are members coming from long distances and if anyone would be able to offer accommodation then please let us know. Alternatively we have many hotels, motels, and B & B's in the locality.

Post-Polio Pain is a subject of interest to many of us

What is its source? How can I alleviate it? Why do many physicians deny it? What exactly are these unpleasant sensations I feel? Why are they different from other types of pain....and on and on go the questions.

Suffering constant pain is extremely debilitating. In my opinion much more debilitating than needing to use adaptive aids or needing to rest more often. When you are in constant unremitting pain you simply cannot function and enjoy the normal mundane activities that are a part of every life.

One of the problems with the pain of PPS is that physicians often don't understand it. They wonder how the loss of motor nerves (as in ALS) can produce pain. Pain comes from Sensory nerves; not Motor nerves. I have heard physicians deny that the pain is muscle pain due to polio. This can then result in costly and unnecessary further testing to get at the cause of the pain and/or eventually labelling the patient as neurotic.

But Post-Polio muscle pain can be understood in the context of a muscle pain secondary to weakness. Polio patients are unique in so many ways. During recovery we learned to use our bodies and our muscles in different ways. Many muscles that were directly weakened by polio functioned because of reenervation by other neurons during recovery. We got stronger and were stable for many years. But now some of these substitute nerve connections are beginning to fail, slowly. Yet the body plods on and continues functioning the way it always has. The conscious and unconscious muscle movements, embedded in our being over a lifetime of success in movement, continues as if nothing is wrong. Well before we drop from muscle failure many muscles experience a metabolic exhaustion. And this utter fatigue may be felt in a number of ways. Most of it, I believe, is labelled as PAIN.

The pain is described in terms not usually heard by physicians listening to descriptions of pain. "I have a creepy crawly feeling", "The back of my left leg is burning", "I ache like I ran a marathon but didn't do anything". Personally, I remember a feeling akin to intense itching deep inside my right buttock and hamstring. It wouldn't leave. It was with me all the time and caused me to become hyper alert. It lasted for years early on in my post-polio syndrome. I eventually got it under control by swimming and using various drugs that help relax muscles. But it was, by far, the worst thing I've had to deal with.

I believed I would feel better if only I knew other human beings had experienced the same sensations. I didn't know what to call it. I read about parasthesia and thought it must be that. But parasthesia is a pins and needles feeling on the skin's surface. One physician trying to help me told me it was dysesthesia, which essentially means "a feeling that is abnormal". Finally, one day, I described the sensation to a physical therapist as I was talking to her about a wheelchair and the need for it to be comfortable. She said something that made the most sense to me: "it sounds like a fatigue phenomenon". Absolutely! With PPS our problem is fatigue. If our muscles are sore (or in dysesthesia) it is because they are fatigued. And, once muscles are fatigued to the extent that post-polio muscles can become fatigued, it is difficult to get them back to a resting state. I believe this is so because the ordinary muscle tension (contraction of muscles) that exists is exacerbated in an extremely fatigued muscle. This puts us in a cycle of pain, muscle tension, fatigue, and back to pain.

Anything that can be done to rest painful muscles should be tried. Floating in water, and eventually swimming helped me. Drugs which help you feel more rested should be tried if you are in pain. Some of the antidepressants have been used for this. Elavil improves sleep and helps with polio pain in many cases. I believe that people who have a lot of muscle tension and naturally push themselves may benefit from a Selective Serotonin Re uptake Inhibitor like Paxil. I believe it works, when it does, by slowing down the drive to push on. This may have secondary effects in lessening muscle tension and consequent pain.

Unfortunately, most of the pain relief we experience will derive from our own behaviour and what we learn about our pain. Fortunately the situation is not hopeless.

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REST, PACING AND TIMING

Grace R. Young, MA, OTR <gryoung@.PACBELL.NET>

Fatigue and pain must be respected. Overuse to muscles is not always apparent while it is occurring. Muscle pain is a warning signal that the muscles have been overused. The damage accumulates over a period of time and may not become obvious until you lose the ability to do an activity which was previously possible.

REST

Try to rest at least one hour during the day. If you work and resting at lunchtime is not possible, take a one-hour rest immediately after work. This will make your evening activities more productive and enjoyable.

Lie down to rest so your back doesn't have to support your body weight. Sitting takes 1/3 more energy than reclining. If you want to read, use an overhead book holder so your hand and arm muscles won't stay tense. You can listen to music, practice visualization, or meditate; the point is to allow all the muscles in your body to relax.

PACING

Have you had days when you felt so good that you took on an ambitious project and kept pushing yourself so you wouldn't lose momentum? Were you incapacitated for a few days after that? It is tempting to overdo on your good days. However, you'll be more productive overall if you plan your activities for a balanced lifestyle.

Prolonged activities such as cleaning house or gardening, can leave you exhausted for the rest of the day unless you break them up into short segments with rest breaks in between. Before starting an extended activity, decide how long you will work at it and allow a 15-minute rest break every 30 minutes. Use a kitchen timer to let you know when to stop working and when to start up again.

Alternate light and heavy tasks throughout the week. Split your ambitious projects into daily segments throughout the week, and stick to your plan no matter how good you feel on any particular day. Plan fewer activities for the days when evening activities are on the agenda.

TIMING

You may have different levels of pain and fatigue at various times of the day. Activities which are simple to perform in the morning may be difficult later in the day, or vice versa. For example, if cooking supper in the late afternoon is too stressful, prepare most of it in the morning, to be reheated later.

HOW CAN YOU JUDGE IF AN ACTIVITY IS TOO STRESSFUL?

The easiest sign is a feeling of fatigue while you are in the midst of the activity. This seems obvious but many of us do not pay attention to our body. If the level of fatigue is out of proportion to the level of activity, the activity may be too stressful even if your mind says it should not be.

If there is a change in the quality of movement. For example, you develop a tremor or "jerkiness" in your motions while performing the activity.

If there is a change in the quantity of movement; that is, decreased range of motion. For example, you can usually lift your arm to a certain height but that height lessens as you continue the activity.

If you start to use compensatory movements. For example, you "hunch" your shoulder in order to raise your arm, or you swing your leg out to the side instead of flexing at the hip.

Grace Young WebSite
http://www.reocities.com/HotSprings/4713/

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

Proverbs

Where children have added....
the second half.

Strike while the... bug is close.
Don't bite the hand that ...looks dirty.
A penny saved.... is not much.
Where there is smoke.. there is pollution.
Two's company, three's.. the musketeers.
Children should be seen and not... spanked or grounded.
Laugh and the whole world laughs with you... cry and you have to blow your nose.

HINTS AND TIPS THAT MIGHT HELP YOU TO DIET

collected by Carole Lee - KaroleLee@aol.com

Dieting and not being able to exercise like we used to is difficult. Here are some day-to-day tricks and tips for dieting that I have collected.

Write down the reason for wanting to lose weight. Tape it on your refrigerator door as a constant reminder and incentive. Deal with only one day at a time. Don't become too concerned about tomorrow. Today is your diet day and follow your program to help cut fats and calories.

Set a reasonable goal. Write down how many pounds you want to lose and then aim for it! Goal-setting is a "must" among dieters. It works! Have a positive attitude. Dieting is going to make you look and feel slimmer, younger and healthier. It is NOT a punishment!

There is no getting away from this simple trick: say "NO" to sugar, salt, and excess fat!

Weigh yourself only once a week.

Keep a record of all foods eaten and a weight record will give you encouragement in your program.

Be wary about alcohol, most have too many fat-building calories.

Fiber is important in your program. Improve your intestinal organs and provide bulk to ease feeling of emptiness. You'll have NO stomach growls if you get enough fiber in your diet.

Good sources: whole grain cereals, bran, wheat germ, fresh fruits and vegetables.

Diet doctors insist on having a good breakfast. Wholesome protein and carbohydrate breakfast such as a soft-boiled egg with whole-grain toast helps keep blood sugar in check. It eases craving for sugar, helps avoid mid-morning slump and eases the desire for bigger meals.

Trim fat from meat. Enjoy lean animal foods. Fish is also a good source of protein.

Broil, bake or pan-broil meats without adding extra fat. Use a rack in a roasting pan when broiling or baking meats to render our excess fat.

Keep fresh fruit ready-to-eat in your fridge, along with natural fruit juices. Arrange fresh fruit in crystal bowls around the house.

Enjoy carrot sticks, celery sticks & other raw veggies with low-fat cottage cheese or salt-free peanut butter.

Apple slices spread with salt-free peanut butter or unsweetened apple-sauce with a sprinkling of cinamon is a pleasant snack.

Fresh fruit salads, sprinkled with lemon juice to prevent browning, are always delicious!

Diluted Frozen fruit juices in ice cube trays or popsicle molds are great snacks.

Broiled tomato slices, sprinkled lightly with grated cheese and herbal seasonings and broiled until bubbly, are delightful.

Try frozen banana pops by peeling a banana, cut in half, dip in OJ (orange juice) and roll in bran. Then insert a wooden stick, wrap it and freeze.

Use plain yogurt mixed with fresh fruits, nuts or a little wheat germ. Ready-made fruit-flavored yogurts are higher in calories and often contain sugar.

Hard-boiled or deviled eggs are nutritious snacks.

Chicken or turkey salad, rolled up in a lettuce leaf makes superb snacks.

Baked beans provide excellent and filling protein. Mash them with a little chopped onion and use as a spread on crackers or breads.

Patience, Perseverance and Self-Control with your food plan, make dieting more palatable (little diet humor).

A woman called and asked, "Do airlines put your physical description on your beg so they know who's luggage belongs to who?"
I said, "No, why do you ask?"
She replied, "Well, when I checked in with the airline, they put a tag on my luggage that said FAT, and I'm overweight. Is there any connection?"
After putting her on hold for a minute while I "looked into it" (I was actually laughing). I came back and explained the city code for Fresno is FAT, and that the airline was just putting a destination tag on her luggage.

MOTABILITY

by Joy McDuff - Erith in Kent

My name is Joy McDuff and like many of you suffer from the Late Effects of Polio. I still work a full day at a fairly local Ford car dealership. I must admit that it is getting harder to get up each morning and to suffer a great deal of pain at the end of what now seems a long day. I was hoping to complete my working life at 60, but that may be a few years too far.

I do hope this short article on how to obtain a vehicle using your Disability Living Allowance may be of help to those of you that are not sure of how to use one of the following four ways to become mobile:

1. Outright Purchase
2. Motability Hire Purchase
3. Motability Three Year Contract Hire
4. Used Car Hire Purchase scheme

1. Outright Purchase.

This first method is to buy a new vehicle, at a reduced rate from which ever dealership or franchise you prefer. Usually the dealership will discount the vehicle by approximately 10% - 13%, selling you the car at wholesale price. This means you can pay for the vehicle outright or by using the dealership's own hire purchase/credit system. This way is best if you do not have a full three years allowance, or if you wish to own the car, when it is paid for. You can use this method if you do not receive Disability Living Allowance (DLA), but do have an Orange Badge. Your local dealership will give you more details. If you collect Barclaycard points you can also put them towards the cost of a vehicle bought through the Outright Purchase scheme.

2. Motability Hire Purchase.

This scheme enables the disabled customer to purchase virtually any new car (though some dealerships exclude racy models). Repayments are met by handing over all or part of the Higher Rate Motability Component of the DLA to Motability Finance Ltd for four or five years - you decide how long. This scheme enables you to fit personal adaptations and not have to have them transferred to a new vehicle after three years, and you decide when you want to buy a newer model. A one year RAC breakdown cover and one year warranty is included with Ford vehicles. You would have to ask if this is the same with other franchises. As with scheme one, with this scheme you are responsible for all maintenance, servicing and insuring your vehicle. Again Barclaycard points can be used towards the cost of a car through the Motability Hire Purchase scheme.

3. Motability Three Year Contract Hire.

Over 95% of those using their allowance to obtain a vehicle opt for this scheme. It is an economical option which provides a package of after sales service to take all the worry out of your motoring.

You can exchange your allowance (and pay an initial deposit, if there is one) for a brand new car of you choice. This car will be serviced, maintained and insured for three years. There is an excess payment of £75 on any crash claim put through the insurers. You are covered by a full RAC membership, so there is no need to worry if you do breakdown, you will have roadside assistance on a new dedicated Motability telephone number direct to the RAC. After the initial deposit (if there is one) you only have to pay for fuel and oil. However excess mileage charges are payable if the annual 12,000 miles is exceeded.

If you need help to raise the initial deposit, you may be able to get financial assistance from Motability's special charitable fund or from one of the other charities.

Most Ford dealerships have a full list of vehicles available on this scheme, many with no deposit, and this includes automatic transmissions. I would think that other dealerships do something similar. If adaptations are fitted to a Contract Hire vehicle they must be removed (or transferred to your new vehicle) when the vehicle is returned at the end of the three years. Most of my customers (some of them are now good friends) come in to choose their new vehicle about 4 - 6 months before their lease runs out. This means they can have their new car waiting for them on the day the old one returns. I also make sure that any adaptations are fitted to the new car or that the mechanic is available to transfer the adaptations over to the replacement car while we sign the paperwork. When applying for a vehicle on this scheme you will have to show your Drivers Licence and a copy will be taken for Motability Finance, and the same with your award notice. You can also obtain an exemption from paying Road Fund Licence (Road Tax) if you use any of these schemes and the vehicle is used for the benefit of the disabled person. You do not have to be the driver, you can nominate a member of your family or a friend to drive for you.

4. Used Car Hire purchase scheme.

All the above schemes deal with brand new cars. This as it's title shows is for used cars. To qualify for this scheme you must have the Higher Rate Motability Component of the DLA for at least two years. M.F.L. will provide a fixed sum on finance for two or three years towards the purchase of a used car, subject to an AA inspection and valuation report. Your chosen vehicle should be less than five years old and have covered less than 60,000 miles. You will have to provide any shortfall between the price of the vehicle and the amount of finance provided. Again you will be responsible for all servicing, maintenance and insurance.

If any of the above schemes appeal to you, but you have not driven for a while, and are unsure whether you still can, there are assessment centres dotted all over the British Isle's that for a small fee will put you into specially adapted vehicles and simulators to assess your ability to drive. This not only puts your mind at rest and sorts out the adaptations you might need; it lets the rest of the family know that you are quite capable, able and willing to go out on your own.

Disabled youngsters can drive from the age of 15. Motability have a scheme which pays for their driving lessons.

With Ford vehicles there is also the offer of a free mobile phone (you pay the monthly charge and your call charges), to take with you in the car in case of problems. There is one button dialling for the RAC.

If you would like more information you can write to me, land post I'm afraid, not connected to the intemet (yet!), or phone 01279 635666 and ask for an application pack for Motability. If you have an allowance book there is a blue page inside that you can post off, this again will bring the application pack to your door. I hope this will help you choose a vehicle for yourself and although I deal mainly with Fords, there are many franchises to choose from. So, go for it, get mobile, and enjoy the freedom and independence.

If any members would like to write to me then ring the Office for my address.

Articles from our Online Library

The following articles are reprinted in full in the edition of this newsletter distributed via the postal services. If you are printing this web edition for further distribution, please print the library articles as well and attach them to the newsletter.

Title: Henry Holland MD - Medical Credentials

FULL TEXT HERE

Title: Dr. Henry writes about Normalcy

FULL TEXT HERE

Author(s): Henry Holland MD

Abstract/Extract: In trying to understand something about the psychological effects of polio, we have often heard how most polio victims exercised and worked vigorously to regain a sense of being normal. In a general sense, this usually meant trying to achieve a level of physical function and social function that was nearly equal to the pre-polio level of function and achievement. Many times this goal was unreachable in measurable physical function. For example, President Franklin Roosevelt firmly believed that he would walk again after his initial polio attack. He actively engaged in physical therapy for seven years trying to walk again. He never walked again, but he did manage to walk for short distances with the assistance of two long leg braces, a cane, and a companion's arm. A mystery does arise in attempting to explain the psychological impact that this tremendous effort made on the psyche and personalities of hosts of young polio victims.

A Husbands story

Her New Scooter and how I could not keep up

My wife had been getting increasingly frustrated. Her almost new scooter had only made a couple of trips to the warehouse discount store and a short business trip to Atlanta. She had thought that the scooter was her ride to freedom. What she didn't count on was my inertia and the continued stress and depression that my job situation was causing. She wanted to go to Disneyworld, Niagara Falls, or the Smithsonian. I wanted to stay in my chair.

Finally, I relented and agreed to seek out a mountain trail to hike and ride. The ranger at the gate to the National Park suggested a trail that was totally accessible 64 miles up the road. My wife was itching to find a trail closer to the gate. After some "discussion", we found a possible nature trail. After we crossed the road, we decided to take a trail to a campground. The nature trail appeared far too rough for a 3-wheel scooter.

Immediately after the nature trail branched off, our trail began to steadily climb. My wife's scooter climbed without problems. I however became quickly exhausted. The moderate slope was continual. But I continued when I saw her eyes; the gleam that had been missing for years had returned.

Then I remembered the bears! I stopped and was completely trapped by my memories of the PBS and Discovery Channel documentaries on bear attacks. My wife offered to turn back. I could not think of ending her fun and continued the climb despite the bears. A few yards later I saw movement in the middle of the trail. yelled, "it could be a snake". My wife eagerly rode ahead and saw that it was only a big butterfly. She laughed. Obviously, my 6 years of country living hadn't erased my fears of nature.

The climb continued. I complained of my rapid pulse and sat down on a rock water fountain. My wife just continued to glow. She offered a few words of encouragement. I told her that the Park Service should place more benches along the path. She chuckled. I estimated that we had walked at least a couple of miles; she disagreed. I continued my crawl; the scooter continued its ride. I stopped and studied the map. I saw a small road on the map that connected to the main road and prayed that it would be there. I then thought we had almost reached the summit, but after a curve I saw that the moderate climb was still seemingly endless. My body was aching, my heart was pounding, and I was panting. My wife, however, was cruising.

Finally, I saw the connecting road ahead. I quickened my pace. She was a little disappointed but agreed to take the road back down to our van. We were not going to make the campground. I turned and was suddenly startled by a big animal. I hollered, " Bear". My wife laughed. It was just a large deer.

I walked and she rolled quickly and quietly down the hill. She needled me a little about the animals (real and imagined) that we had encountered along the trail. She was happy. I was exhausted. When we reached the car, I headed toward the store. At the door we saw a sign saying that sodas were available at the campground store 1 mile up the road. I cringed. I had thought we had to have walked 4 miles. My wife said I was dreaming. We drove the car up the road that paralleled the trail. I hit the odometer a few times. It just couldn't be working. The place where we ended our climb was only 0.75 miles up the road.

As we drove away, I realized that the tables had been completely turned on this hike. My wife was fresh and happy, I was completely beat. I must have felt exactly like she had felt on all of the walks that I had begged her to take or that she had had to take in the years prior to her scooter. As we wound down the mountains, I understood post-polio a little better than I had before my hike.

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PPS Dictionary

Electric Scooter - Shoes with wheels and a seat.
Cane - Third leg for balance.
Electric Wheelchair - Freedom to do things I couldn't before.

IT'S GOOD TO TALK

Having been forced to give up work two years ago due to late effects of polio, I am now able to take stock of my life. With positive thinking I have come to the conclusion that life is not so bad after all. Gone are the days when I had to get up at six o'clock and rush round getting ready, and then spend half an hour driving to work. After work doing shopping, cleaning, dog walking etc, with not a moment to spare. Now I am unable to do the housework, so I watch someone else making a much better job of it than I ever did. I don't even walk the dogs in the same way, now I go on my electric scooter and the Bonzo's run at the side. This has left me with time to spare to do the things I never had time for before. I now go to art classes, and computer classes. I do a lot of reading and have the time to spare looking for the books that are really of interest and if I now have a sleepless night its not a problem. I spend the night reading, drinking cocoa and delighting in the fact that I don't have to get up early in the morning. I no longer go out on a horse, risking my neck on a cold winter morning trying to hold on to a horse who thinks he's a cross between Red Rum and a bucking bronco. Instead I lie in bed with my Boxer Dog Ben at my side and listen to the intrepid riders going past on the road outside. This is a wonderful thing in the depths of Winter. By now you will have come to understand my positive way of thinking. Why not try for yourself? Don't mourn the past, look to the future instead.

One of the ways I have found of having a bit of fun involves the telephone. How mad I used to get at the frequent phone calls I received from window, kitchen, bathroom, vacuum cleaner, and survey Companies. I now actually look forward to getting a call. I will give a rough outline of how I answer these calls and maybe you can try it for yourself.

Always be ready when you pick up the phone, expect it to be a salesman. When I pick up the phone they say,'Is that Mrs Ayre?" I say "Who dear?" When they repeat the name I say "Will you speak up as I'm a bit deaf". They then repeat the name, and I welcome them as a long lost friend or relation and start to tell them all sorts of rubbish about an imaginary family. Things like Uncle Fred having his leg off, the cat having kittens and would they like one, the secret is to keep talking and not let them get a word in.

Another way I deal with a phone call is pretend I'm an answering machine. I live on the site of a Gilbertine Abbey*, so I use this as a theme for the call. I say this is a recorded message, The Abbess cannot answer at the moment but, if you require a prayer for the day press 1, for information about joining our order press 2, to make a donation press 3, to order from the Abbey shop press 4.

The calls from people doing surveys are even more fun. I feed them all sorts of way out information. One such caller asked me if I had Asthma? I replied "no but I have a corn on my foot", then went on to tell of all the ailments of my imaginary family. When I was asked "did I have any pets?" I said yes, I have six dogs, fourteen cats, a donkey with three legs, ten chickens, one duck, fifty goldfish, and a Viet- namese pot bellied pig, and did the caller want to know all of my pets names? Why did she ring off? Was it something I said?

My other frequent caller is a wrong number when a woman calls she always asks for Rita. When the man gets the wrong number, he thinks he has Rita and launches straight into the conversation. Once he said, "are you coming round for a cup of tea and a piece of cake?". So I said "yes where do you live?" Another time he started with, "I'll meet you in the market place tomorrow at twelve o'clock"."Oh good" I said, "how will I know you?" His reaction is always the same, a few seconds of silence and then, "Rita is that you?" I wonder what Rita is like, she seems to have an exciting life.

One wrong number caller I had at six o'clock one morning was not appreciated. A mans voice said, "Has he gone?" I said 'Who?" He said "Charlie". I said "Who's Charlie?" That call has me a bit worried, why did he want to know if Charlie had gone, have I missed out on something? Surely not at six o'clock in the morning.

I'm now waiting for someone to call, does anyone want to ring me and make me an offer I can't refuse? Don't forget its good to talk.

Christine Ayre, Catley Abbey, Lincolnshire.

Members can get my telephone number by ringing our Secretary. I will be on the Internet soon.

Historical Note

GILBERT OF SEMPRINGHAM, founder. B. at Sempringham, *c*. 1085; d. there, 1189; cd 1202; f.d. 4 February. The founder of the only specifically English religious order. Being regarded as unfit for ordinary feudal life, he became parson of Sempringham in Lincolnshire, where his father was lord of the manor. In 1131 Gilbert oganized a group of young women of his parish into a religious community, under the Benedictine rule. Laysisters and brothers were added, a second house was founded, and in 1148 Gilbert provided chaplains for his nuns by establishing a body of canons following the Augustinian rule. This order grew rapidly, having men's and women's houses side by side and also monasteries of canons only, with leper hospitals and orphanages. As master general of it, St Gilbert set an admirable example of abstemious and devoted living, but the later years of his long life were seriously disturbed. When he was about eighty he was arrested and charged with sending help to St Thomas of Canterbury, who had taken refuge abroad from King Henry II; eventually the charge was dropped, although Gilbert refused to deny it on oath. Later still there was a revolt among his laybrothers, who grievously slandered the old man; the case was taken to Rome, where it was decided in his favour. St Gilbert lived to be over a hundred and passed his last years nearly blind, as a simple member of the order he had founded and governed. The Gilbertine Order came to an end when all its houses, over twenty in number, were suppressed by King Henry VIII.

Source: The Penguin Dictionary of Saints by Donald Attwater; revised and updated by Catherine Rachel John. ISBN 0 14 051123 7.

LincsPPN Web Administration

POLIO CHILD

Dear PPS Family, You are the only people that I know who might understand this poem and why I wrote it.

A child is softly crying, she's maybe five or six.

The Doctor says no problem, your hurt we're going to fix.
Her eyes plead to her mother, but her mother does not see.
She is talking to the Doctor, of the things that are to be.

This child is listening to the words, but understanding not.
Why does she have to leave her house, and her little puppy Spot.
She does not know what she did wrong, she is sorry she is sick.
Mommy's always fixed her hurts before, with a visit that was quick.

But now she has to go away, to a place she hears them say.
It is called a Children's Hospital, they must go this very day.
She strains to listen as they talk, they've forgotten she is there.
In her little voice she says, "Please NO", but they do not seem to care.

At home as they get ready, she begs, "Please let me stay."
Her Mommy says "Now sweetie, you'll be better in a day."
The Doctor says that you must go, or you will not get well,
Now you be brave her Mommy says, your Dad we must tell.

She wants to please her Mommy, and please her Daddy too,
But she is very frightened, and does not know what to do.
And so she thinks a game she'll play, pretend it is not her,
That's going to the hospital, but her little friend named Zer.

This little friend, you understand, is only make believe,
And thus begins the fantasy this little girl will weave.
To shut out all the fear she feels, a new life she begins,
And Zer will be the child outside, to protect the girl within.

The weeks and months that Zer endures, the loneliness and pain,
The doctors saying to behave, and be good for the nurse Jane.
All the yelling of the nurse, and threats if she should cry,
Why'd my mommy send me to this place, am I supposed to die.

The man that was to help me swim, is taking off my clothes,
He tells me not to be afraid, he wants to see me pose.
If that is true, the words he says, then why's he touching me,
And why is he undressing too, and saying this must be.

Zer knows that he was very wrong, but he says it was play,
He tells her that about this day, she should never ever say.
That night when it is time to sleep, she turns and hides her eyes,
Why have the big people done this, she says and then she cries.

Today is Sunday and the day, her family she will see,
And maybe if she's really good, and quiet as a bee.
They'll see that she is different, and nice to be around,
And maybe want to take her home, if she doesn't make a sound

The time has come for them to leave, she holds her Daddy tight,
She prays that she's been good enough, and smiles so very bright.
She looks into her Mommy's eyes and says can I come, please,
But they just smile and say good bye, her little hand they squeeze.

They tell her that she should be good, and do what she is told,
And that will make the doctors glad, so they won't have to scold.
The team are running down her cheeks, the nurse is holding tight,
Why won't my Mommy and Daddy, just take me home tonight.

This is a dream, the woman says, as she sits up in bed,
But still she feels the horror that keeps running thru her head.
For years her mind protected her, no memory of those years,
This dream is like a haunting, of a childhood filled with fears.

To all who read my poem and.especially other Polio Survivors who may have been through similar experiences.

I have found that writing seems to help me. I have also noticed that where I have read something that I could relate to then I have been better able to talk about my own memories knowing I was not the lone ranger. I guess that is one of the reasons that I wrote this poem.

I guess there is also a third reason .... a way to reach the "normals", who I truly believe just do not know. Our society has always kept very quiet about anything that is out of the norm or not politically correct.

I did feel somewhat better after I wrote this, and I know that it will take a long time before I can think of those times without crying and wondering why.

If any PPS group would like to use my poem in a Newsletter then they have my permission.

Brooke near Baltimore, Maryland USA

Personal Perspectives through the Polio Experience

Marian in Florida - <pelican9@WEBTV.NET>

Now that I have stopped denying my polio and begun accepting it, I believe I am a happier person. No longer must I prove that I am stronger than this disease. For years I denied this disease as though it was something outside myself -- like dirt on my body that would wash off with enough scrubbings. But, of course, polio and its effects simply do not disappear. Polio is part of me, like a piece of my body. However, I am not polio. Does this make sense?

I do not choose to think of this malady in a positive or negative manner. I wish to simply accept it pragmatically. Of course, I would not wish it for myself. If it was a choice, then I'd rapidly choose, no thanks. Has it made me stronger? I doubt it. I simply lived the life that was dealt in the manner that my priorities dictated at the time. What would I be like IF polio had not attacked my body at 13 months old? Ah! That big IF. Who can say? I'll never have a chance to find out. However, I must believe that my background and mindset would have sent me on a similar path -- college, careers, marriage, children, supermom. Exploring the current feelings finds no anger, more or less satisfaction with life dealt.

I have come to believe that all people have disabilities of some kind. No one is without problems of some sort. This realisation has finally allowed me to understand that I am a good person, and begin to like myself regardless of the physical problems.

POLIO - THEN, NOW AND THE FUTURE

From a Polio Survivors Perspective

We, who had Polio in our earlier lives, had a huge struggle. Most of us were taken from our homes as tiny children to have many tests performed and treatments to follow. Lumbar punctures, isolation, Iron lungs, callipers, spinal corsets and braces. Steaming hot wet wool wrappings rung out and placed on muscles, with sheets of rubber placed over that and then wool blankets placed over that to hold in the heat. Straight jackets at night. Plaster casts from head down to goodness knows where. Arms and legs positioned out at strange angles and plastered in place. Tied to bed frames. Electrical treatments. The list is endless.

If we were very young we probably did not even realize who our parents were. How were we to know that the Nurses we saw every day were not the parents that the other children talked about. Who were those people that came maybe every Sunday, maybe only once a month? Some parents could not manage to travel more than once a year. When we saw them the next time, did we even recognize them. Who were they? Then came the operations, often during the school holidays, and the teasing at school. We were always the odd one out. We couldn't join in, we couldn't run. We weren't able to go on that school trip 'it's more than you can manage.' On Sports Day we could finally be included but in the obstacle race, because everyone is slow in that.

'No Pain, No Gain.' How many times did we hear that, in those years when we had endless exercises to do, endless operations and endless physiotherapy. So what did we do? We pushed ourselves, we achieved. Many of us threw away those callipers, crutches and corsets. We hid our disability. We passed exam after exam. We went to colleges, universities and got all sorts of white collar jobs that required more education than average. We worked hard, we had to prove to the world that we were as good as anyone else. Most of us got married, had families, and on we pushed.

What does a polio survivor look like? Well, if we are wearing a calliper then it's easy. That half hour lecture that most health professionals have covering 'contagious diseases' tells you that's what polio looks like. It put us in callipers, and wheelchairs. But what about those of us that do not show an easily visible sign of having had polio. We don't have a withered limb or a shorter leg or callipers. We probably don't have any medical records from those earlier years. We have moved again and again, and records that should have been sent on were not. Hospitals closed or decided that after so many years there was no need to keep old records and they were destroyed.

Then we get to NOW. We are very positive go getting types who are always on the go, never stopping. Working full time, doing volunteer work, sports, and being involved with organizations of all sorts. We develop a problem that takes us to the doctor. These problems begin with increased pain and overall body fatigue. We begin doing less in our home lives so we can function at work. Some notice that all of a sudden we are having more incidents of choking when we eat. Many of us have to go back and pick up that cane or dig out that old calliper because we begin to fall more easily. Now, however, our bodies are no longer young and the falls hurt more and do more damage. We never had to ask for help before, and asking for help now comes at a great emotional price We find that a cold or the flu turns into life threatening pneumonia. We begin to notice that a good nights sleep is hard to come by, as muscle pain and bone pain take over our lives. We tell our physicians and are told we need to lose weight and exercise more. OK, we'll concede that we are overweight, and all our lives exercise was the thing that keep us functioning. Now we find exercising only makes us feel more on the verge of collapse, makes our legs feel more out of control and increases our pain levels. First we get a few pills, then we might get some hospital tests. Nothing is found. We are in limbo. We know we have a problem, but it's suggested that as nothing physical has been found, maybe it's psychological, all in our head. We are imagining it. So a few more months, which tum into years go by. We have more problems, more pills, more tests, and still no reason can be found. Three, five, ten or even more years of problems. If we are lucky and hear about Polio Survivors having new problems then we look for more information. The story is nearly always the same. 'My problems have been Medically Noted yet remain Unexplained.

Polio, is hardly ever taken into the equation by the medical providers. It's your age, it's the old polio, it's psychological are the suggestions. Get more exercise is often the response. Typically you will try very hard at this. You become more and more fatigued. but you push harder and harder. You become frustrated. Not depressed in a clinical sense most of the time, but frustrated. You know you have a problem, or problems. You know your body did not work like this before but you cant get any answers. What are you to do? You can't do as much at home. You start having problems with falling asleep in the chair. Your family and often you yourself think you are being lazy. You are 60, 50 even 40 and you can't climb the stairs without pulling yourself up by the rail. You go to walk up hills that you walked up 2 years ago, and you can't do it. You can't manage to rearrange a room at one go, or garden like you used to. You start to use convenience foods as you can't stand for as long in the kitchen. You go to a dance, and you manage a couple and sit out the rest. A few years earlier you could dance all night. What is happening to you?

Health Professionals, we know that there are no tests to show Post Polio Syndrome. We know that you can only make a diagnosis by exclusion of other conditions. We certainly don't want you to say "You had Polio, it's PPS", and miss something else we might have. We know we are getting older. But we do know our own bodies and how they were in the past, what we have achieved with them, and we can see that something is happening.

All we are asking is that you take the fact that we had Polio into the equation when diagnosing our symptoms. That you listen to our story of when we had polio even though we have no records. That you leam more about what Polio is and what it did to our bodies. That you go back to those medical articles of the 50's and 60's. That you look at the mass of information about Post Polio Syndrome that there is available from those specialists in PPS.

We ask that you understand that we will still want to push ourselves to the limit. That we might not want to talk about what could be happening to our bodies. We will not want to think about the future, and we might have blocked out what happened to us in the past. We will not want to use aids and assistive devices. We will not want to have to go to part time work, or to take early retirement. Ask us if we can manage to do something, like shop in a supermarket and the majority of us will say, 'of course'. Ask 'can you go shopping in a supermarket and then go home and clean one room', and we are likely to reply,'Oh No, if I did that then I would not be able to cook a meal, or do the washing. I have to do the shopping one day, the washing the next, and I have someone come to mow my lawn'. Then ask us what we did five years ago. 'Oh all of it, plus I used to go out to work, and take the children to their clubs and.....and.....and.....'

There is much work to be done in the UK to promote the awareness that Polio Survivors can have new problems in later life. Considering it was first noted in 1875, it's incongruous that here we are nearly into the 21st Century and we are having to ask you - the Health Professionals in the UK - to look at the information we have collected. It's not easy. No Medical professional wants a patient to bring information to them that they know little about.

We want to ask this of each health professional that comes upon a patient that has had polio. Examine us holistically, listen to what we have to say. Then, make an informed decision as to what to do next. If you have not come across this problem before, then look at the information that is available from around the World, and talk to others who are now starting to specialize in the problems that Polio Survivors can have in later life.

Diagnose our symptoms into categories. Advise, treat and refer us on when necessary. Help us come to terms with having to change our lifestyle from doing everything and more at a fast rate, to slowing down and doing tasks in stages, resting in between. Help us come to terms with having to walk with a cane, use an electric scooter or wheelchair to conserve our energy. OT's help us see that if we alter our houses a little such as, a downstairs toilet, a walk-in shower, a higher bed, etc that we can begin to stop wasting the energy that we do have. Physio's work with us individually to find a gentle set of exercises that will help us keep range of movement, even if it's only one repetition a day of some movements. Dietitians help us to work out a balanced menu that will take into account the much reduced energy we are able to expend. Counsellors help us talk out all our past that has been blocked away, help us cope with now and move on to a future.

Going back to, or using for the first time, aids and assistive devices, filling out DLA forms etc., are extremely stressful times. We have fought all these years not to be 'disabled' and now we have to admit that we are 'less able'. It's a total turn round. It's not easy. It's not something we would choose. This is a new phase in our lives. Help us - now - and we will be as successful in this phase - the future - as we have been in the past.

From Polio Survivors all over the World.

Hilary Hallam

Kathleen's Story - Lincolnshire In October 1917

In October 1917 six young children and myself contracted Infantile Paralysis (as polio was then known). We all lived in a small Lincolnshire village.

The six children had comparatively mild attacks, progressed well and with little lasting effects. I was five and a half and not so lucky - my attack was more severe. In the early stages I was without use in any of my limbs. After some months I regained enough strength to sit up and was able to feed myself. For three years I received little or no treatment. A stay of six weeks in the local hospital proved of no benefit.

A decision was taken that once the Great War was over and bombing in London ceased, I should be admitted to the National Hospital, Queen's Square, London. However, I was eight years old when a bed became available. During the waiting period our family doctor recommended that, during the day, I should lie on a wooden door like frame on top of a sofa. My bad left leg to be tied at the ankle at the higher end with my head at the lower end. The reasoning for this being that the weight of my body would stop the ligaments from drawing up my leg. This did not work and my leg became bent. On admission to the National the ligaments were cut in order to release the knee. During my twenty six weeks there treatments included massage, exercises and electric shock treatment (how I dreaded the latter). I was fitted with a plaster cast from toes to thigh on my bad leg, which was taken off each night and put back in the morning. It was open down the front end and fastened by hooks and a long lace. A spinal support was also fitted and made from a quarter inch thick strong stiff material, with steel supports down the sides, which was extremely hot in summer. After not walking for three and a half years I had to be retaught to do so, but only indoors and in the garden, with a wheelchair made for the street.

After a year the leg plaster began to break at the ankle. I was then sent for a replacement to the Kensinaton War Supply Department. After another year I was again admitted to the National Hospital for a completely new appliance, where I stayed for a further twenty four weeks - with the same treatment.

At eleven and a half I again went to the National for seven weeks only. I was then fitted with a steel and leather calliper and steel and canvas spinal jacket with small crutches attached for shoulder support. I have worn a similar type of appliance since then (74 years). Anyone who has worn this type of'jacket' will appreciate the discomfort it brings.

My muscles were never strong enough to allow me to take a job away from home, but I managed to do many household tasks including cooking. For a time I ran my own dressmaking business. For some years I drove a Ministry of Health small car. Eventually the Ministry decided my arms were no longer strong enough to control it. That was when I began to realise they were right and I now know that PPS started at that time and has continued ever since. This would be about twenty five years ago. My legs also began to deteriorate. For some years I persevered until I had to use a walking stick in the house and later a walking frame with three wheels. Six years ago I had to resort to an indoor electric wheelchair. Needless to say, the struggle to keep on my feet had been so great that it came as a relief to give up walking altogether.

Although I now have to rely on carers and friends to do so much for me, my life is by no means all gloom. There are many things of interest to be seen from my windows, watching the birds and the flowers in my garden, and with plenty of things that are manageable sitting down.

As a point of interest, I would like to know whether any other polio sufferers were patients at the National Hospital, particularly during the nineteen twenties. If so, I wonder whether they have thought of comparison with the present day hospitals. My memories are of bare wooden floors, which had to be scrubbed weekly, and a daily menu of bread and margarine for breakfast and tea, washed down with a thick mug of tea, lunch of minced beef, watery cabbage end potatoes, followed by milk pudding, to say nothing of the strict discipline that was imposed, especially when matron and doctors were due on their rounds. Visiting was Thursday and Sunday afternoons for two hours only. After a time one became used to the routine and made the best of it.

Kathleen B. - Lincolnshire.

If you would like to write to me, please do so care of the LincsPPN address and I will enjoy getting your letters and replying in person.

Other Polio Survivors' memories

On the theme of "memories" I wonder how many of us have lifelong "hilarious" memories of the stay in a hospital polio ward, in contrast to the predominantly scary memories. I just turned 4 when I got polio in July 1943 in Seattle. It was in a polio ward at "Children's Orthopedic Hospital" (now renamed "Children's Hospital and Medical Center") in Seattle, Washington, USA. Seattle is my birthplace. One day we were all brought spaghetti for dinner; one of us started throwing the spaghetti (not me, of course :-)) and all at once we were all throwing spaghetti at each other. It is one of my most vivid of all my childhood memories. I STILL see the big, big mess and the faces of the angry nurses! (Smiley face :-) if you look at it sideways)

Jack Schwartz Jack_Schwartz@ITLNET.NET
P.O. Box 1971 Weatherford, Oklahoma 73096-1971

Hi Jack, Different class 1953 but same thread. The food was so cold by the time it was brought to our out building, that it was nearly frozen. One day I decided, I had 3 room mates younger, I was 17, that we should butter the pancakes and toss then on the walls and ceiling. We did and for a brief moment in our despair there was a roar of laughter as they flopped to the floor, and when the nurse came she didn't have a clue as to how they got all over the floor!

PAT Dog lover from N.J.
now living in Tampa Bay area of Fla.

Wanting to pee and being told to wait. Oh I know what that was like. I was not embarrassed but couldn't get anyone to bring me the bed pan so I peed in the empty milk bottle and dumped it out the window that my bed was by - no easy task - the milk bottle opening was not that big and trying to sit on it was a feat in itself. If you could have seen me it would have been even funnier. A little 6 year old trying to balance on a milk bottle to pee. But you know what, I didn't spill a drop - G - (Grin) I think one reason we polio's are so resourceful is that we have had to improvise so many times in our lives that we became creative. When in need of an answer or solution to a problem my family always says "ask Nana - she will know".

Betty <Bettylive@aol.com>

When I was 15 I had bilateral knee surgeries and 2 stages of spinal fusions done. I wound up in this cast that was like armour (from the neck all the down to the toes). At night, during the nurses break, the kids that could walk would sneak down the boys end and pass notes. The kids that couldn't get out of bed would get their cigarettes out and smoke and if a nurse returned sooner than she was supposed to cigarette butts got stuck down bed posts. It's incredible no bed ever wound up leaking the smoke! We certainly were never bored.

Erika <EINK@AOL.COM>

It's not what's being said though, it's the memories that are being stirred up inside. I was three and a half in 1949 when polio reared its ugly head in my back yard. I don't remember my spinal tap but other memories haunt me. I remember not being able to move and thinking that it was the hot, wet wool that was holding me down. I later worked in a hospital as a radiographer and one day (I was about 30 years old) during a snow storm I had to do a chest x-ray on a sweet little 3 year old, wrapped in the cloying jolter of memories - wet wool. As she screamed as I reached to take her from her mother's arms, I became weak in the knees and had to leave the room and have someone else complete the exam for me. I sat myself down on a bench in the hall, covered with sweat and shaking as I remembered lying in a white crib, draped in wet wool - the crib stood next to a window and I saw my mother and father outside of the window - my mother stood to the side of the window where I could barely see her and I saw that she was crying and I remembered crying myself and calling to them and wondering why they would not come into the room and hold me, cuddle me, make me feel all better. Instead I thought I must have done something very bad, very bad. Why would they ever leave me alone with all of these strangers that did all these terrible, hurting things to me. Ah, the tempests that were unleashed by that little three year old and her winter's wet wool. I remember the ache of being homesick and I don't think I have ever experienced such an intense emotional pain again - I think I built up walls that helped me not to feel many things with the intensity that they, perhaps, deserve. My Raggedy Andy came to the hospital and never came home. I think we all went into the hospital with much that we never brought home - our sense of innocence for one. We all seemed to have come home with something extra as well, a spirit that we lived with and that touched the lives of the many that came in contact with us during our lives. The fight that enabled many of us to spit in polio's face and work until we could get just a little stronger - that fight will always sustain us Enough! ....but I'll be back!

Pat from NH
Robert & Patricia Saisi <saisi@SRNET.COM>

Hi! My name is Lillie Jennings. I am 55 years old come Tuesday. I am married 25.5 years to a good man who doesn't quite know how to deal with all that's happening with my body as a result of PPS. I was pretty strong for most of our marriage but now I can't do much of anything if it involves walking any distance, standing any length of time, or lifting much weight. He does about everything in the house now but you know what I hate the most is not being able to go shopping by myself.

I had bulbar polio at age 14; was in hospital in Vanderbilt University Hosp. in Nashville, Tennessee for 15 months; in iron lung for 2 months; missed 3 years of high school but did finish. For almost 30 years I enjoyed almost a normal life and then out of the blue I began to have back aches and weakness. It's been downhill from there. I fought it as long as I could and then started having a pinched nerve and severe coldness in my lower extremities. When the pain got too bad I had to do something. My regular Dr. treated me for sciatica to no avail. I just recently saw an orthopedic (hope I spelled that right) Dr. and he sent me to a neurosurgeon yesterday and I am going to have a series of steroid shots in my lower back done at a pain management clinic but the neurosurgeon said he doesn't think it will do much good. I'll try anything, tho, just on the off chance that it might work. He also said that he would not push for surgery (forgot to mention that have a herniated disc that is aggravating my problem and I have osteoarthritis in my spine) but there again the surgery probably wouldn't alleviate the pain so why cut till they have to? I have a follow-up appt. with him in 3 months and he is going to write a recommendation for a scooter for me and I will once again be mobile on my own.

I was so surprised to find him knowledgeable about PPS, and he was young. Even the older Drs. freely admit they don't know anything about polio let alone PPS. I am beginning to experience increasing weakness in my lungs and constant hoarseness. I am not complaining tho because so many of my fellow patients in the hospital died or had to be institutionalized because either the parents did not want or could not care for them. I had great parents who cared for me and encouraged me in everything I tried. I have a 33 year old son and am very blessed. I am a Christian and I teach Sunday school. My church family is very supportive. I love to talk (bet you would have never have guessed that on your own! LOL (Laughing out Loud) If anyone would like to write who is not on the internet, then send it to Hilary and she can send it on to me. I would love to hear from someone in England.

Lillie Jennings, Fayetteville, North Carolina, USA.

Those who do not share our conflict

In many ways we are similar to warriors who fought (and are fighting again) in a war to conquer the enemy, the polio Dragon. As Churchill once said in a famous speech, 'we must never surrender'. Since we know, that this enemy cannot be defeated, at best we can keep it at arm's length; we must be relentless and vigilant to watch its every move, and to ensure we take steps to curtail or remove any opportunity to allow it to advance or close in and destroy the remains of our ravaged systems. Those who do not share our conflict, have no idea of the toll in pain and suffering we have endured in this battle against the dragon. Individually, we could not stand a chance. But united together with our global allies we are a force to be reckoned with. We are fighting on two fronts. The most immediate one being keeping the dragon on the other side of the wall, and the other front we fight is convincing outsiders, that the dragon is not a myth. Let not the outsiders turn us from the warriors we are into feeble worriers.

Patrick Ross <pross@npiec.on.ca> Canada

A family story I love:

Great Great Grandmother from Georgia saddled a horse and rode 12 miles to see a Doctor. She'd never seen one. She rode back disappointed and reported "it was only a man."

Richard in Florida

Member from Scotland writing a book asks:

I am a polio survivor and a traditional acupuncturist and am writing a book on practical strategies for coping with PPS. I would like to include case histories of those experiencing PPS and would be most grateful to any readers who want to write to me with an account of how PPS has changed their lives. I would also like to know if readers with PPS feel that a type A stressful lifestyle helped contribute to their symptoms. Please email:

Vicki McKenna <Steve@thoughtware.demon.co.uk>
or phone +44 (0)1414236249. Confidentiality assured.

Maurice Rampley Maurice_Rampley@msn.com is writing a fiction book about polio and would like to hear from people their thoughts, recollections and experiences of pregnancy, childbirth, parenting, treatment, clinic visits and schooling. 7 Cedars Way, Linslade, Leighton Buzzard, Bedfordshire, LU7 7PD.

POLIO SURVIVORS COMMUNICATING AROUND THE WORLD

Those of you without Internet access must wonder how we are able to include so many bits from other Polio Survivors around the World. There are Email Lists and Newsgroups for nearly every subject you can think of on the Internet. Lists work by subscribers sending in their message to a central point from where the messages are redistributed via email to all the subscribers for that particular list. Newsgroups work in a slightly different way but the end result is the same. If you want to answer you can reply to a subscriber privately by emailing them directly or you can reply via the mailing list. It is the latter approach that effects 'public' discussion and debate between the list subscribers, each one being given the opportunity to add their comments to yours. A great deal of support is given. It's wonderful to be able to write about your problems and know that those reading the messages understand what you are going through.

The St. Johns University Polio list, one of several polio related mailing lists, is a private subscription based forum. Prvate in the sense that subscription requests have to be approved by the List owners. Although it is not a moderated list where every message is read by a human list moderator before redistribution, subscription to the list is conditional on accepting and working within a set of guidelines provided at the time of subscription. The intent of the list is to "Serve two purposes: To supply information, and to provide support and friendship in an informal and friendly environment."

To subscribe send an e-mail to listserv@maelstrom.stjohns.edu with a blank subject line and **sub Polio (yourfirstname yourlastname)** in the body of the message. There are other lists, newsgroups, and all the information on how to access ail this can be found on our Web Site at http://www.zynet.co.uk/ott/polio/lincolnshire/directory/forums.html.

There are also applications that enable you to hold conversations in real time by typing messages at the keyboard which appear on the other parties screen. They may be an individual or a number of people at different locations. Many of these applications offer additional facilities such as whiteboards, i.e. areas of the screen where you can write information for all the participants to see, much as you would at a meeting, conference or tutorial. If your computer has sound capabilities, which are more or less standard on today's machines, you can also hold voice conversations over the Internet.

Hilary Hallam
Chris Salter

Seppo Utriainen <Seppo.Utriainen@prodycon.fi> from Finland Polio Association wrote..

This is the best time of my life, when I have the opportunity to communicate with all you polio's and PPS's in the Western Hemisphere.

Patrick Ross <pross@npiec.on.ca> from Canada replied....

Seppo you are so right...This is a communications revolution that we are in the midst, and it comes at a time when our ability to get around physically is being restricted by P.P.S. So, it makes it all the sweeter for us, and for me too, and I'm sure for most of us hit with P.P.S. This is the best of times to have this ability to communicate with an almost telepathic capability here on the NET. There you are in Finland, many thousands of miles away, and yet we can know each other's feelings and thoughts. It is somewhat ironic, that at a time when our body's communications systems is rapidly breaking down, we are compensated by a rapidly growing global communications network. Let us together, celebrate this blessing of new technology, and embrace it, for it will make our world closer, and allow us to share so much.

Travel Agent stories...

I got a call from a man who asked, "is it possible to see England from Canada?" I said, "No." He said "but they look so close on the map.

A nice lady just called. She needed to know how it was possible that her flight from Detroit left at 8:20am and got into Chicago at 8:33am. I tried to explain that Michigan was an hour ahead of Illinois, but she could not understand the concept of time zones. Finally I told her the plane went very fast, and she bought that!

STRANGE OLD LADY

A very weird thing has happened. A strange old lady has moved in to my house. I have no idea who she is, where she came from, or how she got in. I certainly didn't invite her. All I know is that one day she wasn't there, and the next day she was.

She's very clever. She manages to keep out of sight for the most part; but whenever I pass a mirror, I catch a glimpse of her there; and when I look into a mirror directly to check my appearance, suddenly she's hogging the whole thing, completely obliterating my gorgeous face and body. It's very disconcerting. I've tried screaming at her to leave but she just screams back, grimacing horribly. She's really rather frightening.

If she's going to hang around, the least she could do is offer to pay rent. But no. Every once in a while I do find a couple of dollar bills on the kitchen counter, or some loose change on my bureau or on the floor, but that certainly isn't enough.

In fact, though I don't like to jump to conclusions, I think she steals money from me regularly. I go to the ATM and withdraw a hundred dollars, and a few days later, it's gone. I certainly don't go through it fast, so I can only conclude that the old lady pilfers it. You'd think she'd spend some of it on wrinkle cream. God knows, she needs it.

And, the money isn't the only thing she's taking. Food seems to disappear at an alarming rate. Especially the good stuff - ice cream, cookies, candy - I just can't keep them in the house. She really has a sweet tooth. She should watch it; she's really putting on the pounds. I think she realizes that, and to make herself feel better, I know she is tampering with my scale so I'll think that I'm gaining weight, too.

For an old lady, she's really quite childish. She also gets into my closets when I'm not home and alters all my clothes. They're getting tighter every day. Another thing: I wish she'd stop messing with my files and the papers on my desk. I can't find a thing anymore. This is particularly hard to deal with because I'm extremely neat and organized; but she manages to jumble everything up so nothing is where it's supposed to be. Furthermore, when I program my VCR to tape something important, she fiddles with it after I leave the room so it records the wrong channel or shuts off completely.

She finds innumerable, imaginative ways to irritate me. She gets to my newspapers, magazines and mail before me - and blurs all the print; and she's done something sinister with the volume controls on my TV, radio, and phone. Now all I hear are mumbles and whispers. She's also made my stairs steeper, my vacuum cleaner heavier, all my knobs and faucets hard to turn and my bed higher and a real challenge to climb into and out of.

Furthermore, she gets to my groceries as soon as I shelve them and applies super glue to the tops of every jar and bottle so they're just about impossible to open. Is this any way to repay my hospitality? I don't even get any respite at night. More than once her snoring has awakened me. I don't know why she can't do something about that. It's very unattractive.

As if all this isn't bad enough, she is no longer confining her malevolence to the house. She's now found a way to sneak into my car with me and follow me wherever I go. I see her reflection in store windows as I pass, and she's taken all the fun out of clothes shopping because her penchant for monopolizing mirrors has extended to dressing rooms. When I try something on, she dons an identical outfit - which looks ridiculous on her and then stands directly in front of me so I can't see how great it looks on me.

I thought she couldn't get any meaner than that, but yesterday she proved me wrong. She had the nerve to come with me when I went to have some passport pictures taken, and she actually stepped in front of the camera just as the shutter clicked. Disaster! I have never seen such a terrible picture. How can I go abroad now? No customs official is ever going to believe that crone scowling from my passport is me.

She's walking on very thin ice. If she keeps this up, I swear, I'll put her in a home. On second thought, I shouldn't be too hasty. First, I think I'll check with the IRS and see if I can claim her as a dependent.

Rev. Karen Utz. Pennsylvania, USA.
"popette" <popette@client.alltel.net>

PPS Dictionary

Vent - Extra set of lungs that can be used at night so that you can sleep and your breathing muscles can take a nap too.

Lincolnshire Post-Polio Library

Articles added since last newsletter with grateful thanks to the authors

G - Grimby, MD.

Title: Endurance Training Effect on Individuals With Postpoliomyelitis

FULL TEXT HERE

Author(s): Brian Ernstoff, MD, Hakon Wetterqvist, MD, PhD, Henry Kvist, MD, PhD, Gunnar Grimby, MD, PhD
Original Publication: Arch Phys Med Rehabil 1996;77:843-8.
Abstract/Extract:

Objective: To determine the effects of an endurance training program on the exercise capacity and muscle structure and function in individuals with postpolio syndrome.

Design: Preexercise and postexercise testing was performed with muscle strength evaluations using isokinetic testing as well as hand-held Myometer. Muscle fatigue was determined by use of isokinetic testing, and endurance was determined by exercise testing. Enzymatic evaluation was performed with muscle biopsies taken at the same site; preexercise and postexercise muscle cross-sectional area was measured by computed tomography. Disability

and psychosocial evaluation was performed by a Functional Status Questionnaire.

Title: Muscle Function, Muscle Structure, and Electrophysiology in a Dynamic Perspective in Late Polio

FULL TEXT HERE

Author(s): Gunnar Grimby, MD, PhD, Erik Stålberg, MD.
Original Publication: Reprinted from POST-POLIO SYNDROME, edited by Halstead & Grimby, © 1995 Hanley & Belfus, Inc., Philadelphia, PA. Chapter 2, pp 15-24.

Abstract/Extract: The muscular impairment in patients with a history of polio varies from none to severe. The relationship between the degree of initial involvement and the effect of various compensatory mechanisms determines the clinical picture, which changes dynamically. Early and late recovery after poliomyelitis depend on a number of factors. Clinical improvement that appears within a *few weeks* after the acute phase is probably due to recovery in the excitability of functional, but not degenerated, motor neurons. Degeneration of neurons, causing peripheral denervation, is compensated by collateral sprouting, i.e., by nerve twigs branching off from surviving motor units overlapping with the denervated ones. This is most likely the main factor explaining recovery within the *first 6-12 months*. Another late compensatory process is the increase in size of the muscle fibers. As a result of these processes, normal muscle strength and presumably normal muscle volume can be seen despite a calculated loss exceeding 50% of the number of motor neurons.

Dr. Henry Writes...

Dr. Henry writes about Falling
Dr. Henry writes about Debilitating Fatigue
Dr. Henry writes about Massive Denial
Dr. Henry writes about Normalcy(In this newsletter)
Dr. Henry writes about the Time and Contrast
Dr. Henry writes about The Virtue of Self Denial

West Park Post-Polio Clinic - Toronto

Title: Physiotherapy Management of The Late Effects Of Polio

FULL TEXT HERE

Author(s): Christine Uriadka
Original Publication: Revised transcript of presentation given by the author in Winnipeg, Canada April, 1997

Abstract/Extract: I am a physiotherapist currently working in the Post-Polio Clinic at West Park Hospital, a rehabilitation and specialized continuing care hospital in Toronto, Ontario, Canada. In my discussion, I will touch upon several broad areas related to post-polio issues. I'll begin by discussing why it is essential for clinicians to be aware of how to manage the late effects of polio. I will go on to provide a general profile of the physical symptoms and functional difficulties that arise in the post-polio population, and talk about how these new concerns develop. This description would not be complete without addressing the emotional coping issues and lifestyle adaptations that accompany the physical changes. I would then like to discuss a number of symptom management approaches, from the physiotherapy perspective. After this, I will provide an overview of the structure of the Post-Polio Clinic at West Park Hospital.

- Why do Clinicians Need to Know about the Late Effects of Polio?
- The Late Effects of Polio

- Development of Post-Polio Symptoms
- Functional Changes
- Impact on Accustomed Roles
- Coping with Lifestyle Modifications
- Emotional Impact
- Management of Post-Polio Symptoms
- Exercise Guidelines for the Post-Polio Population
- Prescription of Cardiovascular Exercise
- Benefits of Aquatic Exercise
- Considerations regarding Aquatic Exercise
- Prescription of Strengthening Exercises
- Prescription of Stretching Exercises
- Energy Conservation
- Postural Correction
- Strategies to Correct Postural Alignment
- Adaptive Equipment: Benefits of Orthotic Prescription
- Factors Affecting Bracing Requirements
- Purposes of Ambulation Aid
- Considerations for Ambulation Aid Prescription
- Pain Management Strategies
- Client Education
- Post-Polio Clinic Role and Structure
- Client Care Process
- Access to Clinicians at West Park Hospital
- Outcomes
- Post-Polio Educational Kit
- Suggestions and Approaches for Health Care Professionals

Copies available from LincsPPN Office at £1.00

Article from our Online Library

The following article is reprinted in full in the edition of this newsletter distributed via the postal services. If you are printing this web edition for further distribution, please print the library article as well and attach it to the newsletter.

Title: A Look At Feet (for people with the late effects of polio)

FULL TEXT HERE

Author(s): Beth Rose, B.A., B.Sc.(O.T.). Post Polio Clinic, West Park Hospital, Toronto, Ontario.

Abstract/Extract: Many people with the late effects of polio demonstrate foot problems. Some are mild problems, while some are more severe. Harley said that Polio may have affected some, but not all, of the muscles of the lower extremities. This partial paralysis can therefore create a muscular imbalance between opposing muscle groups of the foot and ankle, often leading to a Pes Planus (flat foot), Pes Cavus (high arched foot), abnormal pronation, abnormal supination, and gait abnormalities. Various other problems can then ensue, such as calluses, corns, Hammer toes, or Hallux Valgus... Proper fitting, supportive footwear and custom-made foot orthoses can alleviate many of the problems seen with the feet, such as calluses, corns, plantar fasciitis, metatarsal problems and bunions.

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