The LincPIN

The Lincolnshire Post-Polio Information Newsletter
Volume 2 - Issue No. 4 - April 1999

Two important quotes from Irelands First PPS Conference March 10th/11th 1999 in Dublin.

"HOW TO GET THE LATE EFFECTS OF POLIO"

"Push yourself to the limit and a bit more.
Do the same activity again and again.
Don't take any breaks.
Pay no attention to pain and fatigue.
Eat, drink and smoke more than ever.
Avoid assistive devices.
Don't listen to doctors"

NEGATIVE ADVICE
THAT PRODUCED A VERY POSITIVE RESPONSE
from Dr. Lønnberg, PTU Denmark.
Danish Society of Polio and Accident Victims

* * *

To the Government, Minister of Health and all Doctors*

"Your ignorance and stubbornness is costing me my health"
Tina Levy, Polio Survivor, London

* The Lincolnshire Post-Polio Network wishes to acknowledge the interest, concern and co-operation of the many doctors who have contacted us over the last few years. The above quote nevertheless reflects the genuine anger and frustration with the medical profession of a considerable number of polio survivors, arguably the majority of those who seek medical advice in the U.K.

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Editorial by Hilary Hallam, Polio Survivor

Another two months have whizzed by and I cannot believe it is time to publish another newsletter.

Firstly I need to remind members that its **Membership Renewal Time**. If you have not already sent this then please use the renewal slip enclosed with this newsletter. All our work is achieved by membership fees and the generosity of donations. Without these we would not be able to provide the service that we do. Our Information pack, 20+ page bi-monthly newsletters, envelopes and stamps take up a major part of the membership fee of £10 per year. Every penny we receive is spent on providing an information service by newsletter, letter, phone, fax, email and our continually growing WebSite. As with all Charities we need your support to continue to provide the service we do and to improve on it. We also need more physical help in Lincoln if you have time to spare. There is always work to be done, so why not come visit for a day.

A sponsored Truck Pull will take place in Lincoln outside the Falcon Inn within the next couple of months. Unfortunately the date picked clashed with another major event in Lincoln and the Police have asked for a change of date and we are still waiting for confirmation of new date. It will be advertised in the local press.

I attended the very successful **Irish PPS Conference** in March - once again thanks to the generosity of my family and friends in helping me financially. The LincsPPN does not have enough funds to sponsor Conferences. My report of this includes an article written by Catherine Holmquist for the Irish Times. It's about the Chairman of the PPSG, Jim Costello. Another very determined and very successful Polio Survivor against all the odds. Many medical professionals attended and we had many interesting discussions with them including an Irish GP, a Physio from Oxford and an OT from the Wirral. From the Lane Fox Unit at St. Thomas Hospital were Bryony the Physio and Sean, Respiratory Nurse, and Dr. Robin Luff from Kings who works with the new initiative with Dr. Davidson. Dr. Robin Luff agreed that Polio Survivors need Regional Centres for holistic assessment and treatment. He told us there are as many, probably more, people who had polio than there are amputees and they have regional centres.

We are delighted to be able to print **Norman Jones's Report** of the new research by Dr. Davidson and his team at the Lane Fox Unit at St. Thomas Hospital. We will be providing updates on this. It is such a shame that this did not start many years ago.

In the UK over the last ten to fifteen years more and more polio survivors have been seeking medical help for new symptoms. Often these have been in areas where we were not paralysed so we did not think to mention that we had had polio. It comes as a shock to learn there are late effects to having had Polio and that the virus affected nearly all our body. Then we relax because now we believe we will get some help. Then we find that the medical profession knows little about polio and its late effects and there is little help forthcoming. We start to campaign to get services improved but then find that we need to show numbers to get finances spent on our condition.

It always comes down to statistics and finance. Over fifteen months we attended meetings of the Neuroscience Support Group with Lincolnshire Health and were surprised to find they have no idea how many people have neurological conditions, many of them deteriorating ones. They plan their services on the national figures divided by the population. We asked for GP's to be contacted and asked how many patients they have and were told that GP's are independent practitioners and not under their control.

We were told we had input into their neurological report for future services and spent time discussing and preparing a report to be included. Dr. Robert Wilson - Consultant in Public Health Medicine - tells us by letter dated 1st April 1999 that in the original draft of the Service Specification for Neurology he included most of our paper. (He summarised it to make it shorter and altered it slightly to fit the format of the document). However, based on comments he received, he later removed some sections of our paper. (At a meeting on 23rd March 1999 he told us that much of our report was disagreed with, yet they did not see any need to tell or discuss it with us). His letter goes on, "It was felt the specification was too long and had to be made more readable. There are many conditions within neurology and it was felt that the document should reflect the relative importance of the most common conditions. Thus, stroke management should be given top priority because it is the third most common cause of death in Lincolnshire, is a major cause of disability, and many strokes can be prevented." He finishes by saying the recommendations in our paper do still appear in the Service Specification as a separate section, yet we have had no sight of this.

Some conditions mentioned in the report had figures of less than 25. Yet if you take just three conditions, Post Polio, ME and Fibromyalgia we can give a minimum of 500 - probably 2000+ - with symptoms in Lincolnshire but these and other conditions were not even mentioned. Most stroke patients go into hospital and therefore numbers are recorded and they get treated by a multi-disciplinary team. The current waiting list to see a neurologist in Lincolnshire is ONE YEAR said Dr. Bretman, Director of Public Health on 23rd March 1999. Those of us who only attend Hospital as outpatients after many months wait - extended by referrals to other specialists, tests and results - get a diagnosis and there it ends. We still have the symptoms, often much worse. We are still waiting to be properly assessed for aids and equipment. Our condition, our ability to adapt, our energy levels are not understood (article on page 4/5). Money has been and is being wasted year after year on the journey round the hospital departments. Those of us who had Polio and now live in Lincolnshire do not get Quality, Accessibility and Choice from Lincolnshire Health.

We fare little better with Social Services. I get many calls and the latest said "Social Services are offering to send someone round to bath me and cook me a daily meal. Cleaning my house and washing bedding and clothes is not available. That means someone will have to cook for me in a dirty kitchen. Bath me in a dirty bathroom and then I must put my dirty pyjamas back on and get into an unchanged bed. Oh! and they have told me now I am disabled I have to lower my standards. I do not have the money to pay a cleaner. I would rather have a cleaner house, clean sheets and clothes, and use my restricted energy to wash myself as best I can and make my meals. I was a professional business woman at the top of my field. I live in this body, I know what it used to do and how much that is reduced now and how much energy I have. Why can't they give me the money under the Direct Payments Scheme and let me make the decision as to where it will be best spent for quality of my life. There appears to be a severe lack of understanding of disability and little CARE in Care in the Community."

Polio Survivors need regional centres with a multi-disciplinary team assessing us and working with us on the lines of the other Post Polio Clinics in the World and Dr. Davidson's work, and we need them NOW. We need help to slow down our deterioration. Provide us with the aids and assistive devices, correct advice and treatment and we will be able to manage our energy levels and continue to lead productive lives and money will be saved. We ask you wherever you live to let us know how you have fared with your local Health Authority and Social Services. Help us collate more statistics to prove our needs.

AN EXPLANATION OF POLIO SURVIVORS ENERGY LEVELS

by Hilary Hallam

Time and again Polio Survivors are being seen by Health Professionals and Social Services personnel who cannot understand what we mean by our Energy Levels. The following is an explanation of how we 'work'.

We had Polio and over a period of years we 'recovered' to differing levels. We then had a stable period of functioning where we got on with our lives achieving to a high degree. Now we are having problems with daily living, we can see that we are able to do less and less, we have pain, fatigue and weakness. We pretend its not happening to us and push even harder but eventually accept that we are having a problem and we approach our GP for help. We then start the rounds of the Hospital Departments and are referred on to Neurologists, Rehab Specialists, Orthopaedic Surgeons, Rheumatologists, Physiotherapists, Occupational Therapists, Orthotists, Respiratory Specialists, Social Services etc.

Too often you who are assessing us look only at us as we look today. You take no account of who we have been or what we have achieved. You look for a withered limb, a shorter leg, different size feet, a calliper. If you cannot see these things then you wonder if we had Polio. Many of us do not show any easily visible sign of the nerve damage that the Polio virus did to us. You cannot see the 60+% nerve damage where we were paralysed and less than that where we were not.

Our muscles that lost nerves in the initial virus recovered to differing levels. Nerves that were only damaged or unaffected sprouted and sprouted to take over some of the orphaned muscle fibres and with this we 'recovered'.

Your first step is to Manual Muscle Test us. You lie us on a couch and go through a set of push me pull you tests. You write down the results that you get. What you do not take into account is the fact that for a Polio Survivor a muscle testing as 5 is functioning at 60%, 4 at 40%, 3 at 20%, 2 at 10% and 1 at 1 % compared to a person who has not had polio. Weak polio muscles are also supported by others nearby. Quads are the easiest muscles to be substituted by others.

Our muscles have limited energy. They will work for a short time, then they fade. Our body is worked by muscles that are powered by 'Rechargeable Batteries'. Our 'rechargeable batteries' are as old as we are, they are not as good as they were ten years ago. Their ability to recharge is limited. If we were a Torch and you needed to use us right throughout the day you would have to switch us on and off. The time you left us on would have to get shorter as the day went to keep getting some light out of us. If you switched us on first thing in the morning and left us on we would fade after a few hours and then our light would go out. We would be able to do no more that day, until we had recharged over night.

Many of you appear not to realise that to prepare for an appointment/assessment that we have had to input this into our daily and weekly schedule. We probably did very little yesterday to ensure that we would have enough energy to get dressed well, to get to the appointment, and to perform the tasks that you require of us. We know that once home that we will fade and the following day, sometimes two or three days our batteries will not have recharged enough to complete our normal daily energy level.

We have ten energy tokens a day and 70 per week. We have to decide individually what amount of energy each token represents. We have to look at our activities and start charting how long we do them, how much pain and fatigue we get. How long after we have to rest before we can do something else. We then have to keep halving the amount of time until we find a sensible limit that we can work with. We have to do this for all our activities. We can do different tasks for different lengths of time depending on the amount of energy needed to achieve them. So five minutes dusting could be equal to one hour typing or knitting. We are all different. You cannot assume that because one of us can do a task for a length of time that we all can do the same.

Once we have worked out our Token levels then we have to plan our week. We start by putting in things that we have to do. We then work round this and add the other things. Usually only one major task is attempted in any one day. By pacing and resting each day we can actually achieve more. We want to do as much as possible for as long as possible within our limitations. Give us the aids and assistive devices we need to use to prevent overuse and overstraining our muscles and joints and we will manage for longer. We can help ourselves but we can achieve more with your help.

PERSONAL ASSESSMENT OF YOUR ACTIVITY LEVELS.

by Hilary Hallam

This follows on from the previous newsletter ideas of how to help you provide a picture of how your daily abilities are changing. You will need assessing by Physio and OT, but you also need to assess yourself to provide a fuller picture.

We adapted our bodies with polio, with recovery, and now once again we are continuing to make changes. Unless we stop and look at our every day activities, we do not realise what we are doing as its just part of everyday life. It may be a little disconserting seeing the differences in black and white on paper but if you are having trouble getting diagnosed or obtaining the right help, you need to show how you do tasks now and how you used to do them.

You need to look at each area of your life and below are some ideas that might help you. All charts and basic information is now available in a pack and will be sent to all members as they renew.

Bedroom.

- How you get in and out of bed.
- How you sit up in bed.
- How you roll over in bed. (How many separate moves do you make?)
- How you make the bed.

Bathroom.

- How you get in and out of the bath and/or shower.
- How you wash your hair.
- How you wash your feet.
- How you wash your back.
- How you shave, depilate legs etc.
- How you dry yourself.
- How you get on and off the toilet.
- Outside of your own home does going to the toilet present any additional difficulties?.

Kitchen.

- How you stand and/or sit at work surfaces and why.
- How you peel vegetables.
- How you wash up.
- How do you scramble eggs?
- How you cook, bake a cake, make a family meal, prepare a dinner party.
- How you get things out of the fridge or look at what's on a top shelf.
- How you clean the kitchen work surfaces and floor.

Laundry.

- How you manage the washing i.e. getting it to the machine, putting it in, getting it out, putting it where it has to dry, hanging on line, folding it and putting it away.
- How you do the ironing.

Lounge.

- What chair you sit on. How different that is from a few years ago.
- How you rest in the chair.
- Can you sleep comfortably during the day in that room?
- How you vacuum, dust, clean windows, etc.
- The last applies to all housework in main living area.

Dining Room.

- How you lay the table and clear it.
- What cutlery you use.
- Do you adapt ways to cut food?
- How you drink, what sort of utensils you use.

Stairs and steps.

- How you go upstairs.
- How you go downstairs.
- How you do either when you are carrying something.

Decorating.

- How you do the decorating or have others do it for you.

Garden.

- How you do all the gardening activities that need doing or have others do them for you.

Shopping.

- How you shop for food.
- What shops you go to and whether your choice has been affected by access.
- What aids you use.
- Do you get help with shopping?
- How you shop for other items, e.g. clothing.

Social Life and Hobbies.

- What you do and where you go now compared with what you used to do.
- What hobbies you have now and how that compares with the past.
- What sports you participate in now and how that compares with the past.

Finances.

- What percentage of money you now have to pay the same bills as when you worked.

Post Polio Rehabilitation Course

Lane Fox Unit - St Thomas' Hospital
March 1999

The Lane Fox Unit of St Thomas' Hospital in London is committed to researching and understanding the late effects of polio. To call it Post Polio Syndrome is all too easy and confusing.

To quote the words of the Consultant Physician, Dr A C Davidson, who is leading this work

> "There is a good deal of confusion over the use of the term 'post polio syndrome'. For some, it refers to a combination of fatigue, muscle and joint pains and reduced muscle bulk and strength that cannot be explained by specific medical or orthopaedic problems.
>
> Others include the various well recognised long-term sequel of old polio such as loss of function through nerve entrapment, progressive curvature of the spine resulting in pain or respiratory difficulty or instability of joints which have Worn out' through lack of normal muscular support or excessive wear.
>
> Separating out these effects from a possible accelerated ageing effect, coupled with understandable anxiety over the loss of function and fears for the future, have tended to polarise opinions into believers and non-believers of a poorly defined condition -'post polio syndrome'. This is a research interest of the Lane-Fox Unit."

I was privileged to be selected to join nine other polio survivors to attend the Rehabilitation Course which is currently running at Lane Fox, financed by research funding. They are working with 5 groups of 10 survivors (from all parts of the UK) to gather data on the developing late effects of polio. I was part of the second group of ten, with the other three to follow later in the year. The whole programme is scheduled to conclude in March next year with sufficient information to hopefully justify the release of further funding.

The course duration was three days a week for three consecutive weeks and the programme is designed to be of mutual benefit to the Unit and those participating.

And this objective was certainty achieved. Firstly, we were all accommodated in the Simon Hotel, part of the Hospital complex, and this enabled us to not only get to know each other but also talk about common problems, during the evenings. The Florence Nightingale pub, close by the Hospital, was also a popular venue for evening discussions!

During the nine days we covered a variety of topics.

Firstly there were one-on-one physiotherapy assessments to establish a baseline of muscle movement and strength as well as one-on-one sessions with dieticians, occupational therapists and psychiatrists. These sessions were to establish what problems we individually experienced and to give the medical team some insight into how we coped with them.

There were a series of talks on diet, nutrition, exercise, footwear, stretching, sleep disorders, pacing, posture, relaxation, joints, chronic fatigue syndrome, energy conservation, stretching, aromatherapy, work and leisure and finally goal setting. This was interspersed with sessions in the gymnasium, the hydrotherapy pool and numerous group discussions. The latter being one of the more valuable aspects of the programme.

What we learnt we now have to put into practice and then return to the Lane Fox Unit in June for a follow up assessment. In essence, it was mainly obvious, but putting it into practice could be hard for some of us. However the peer pressure from other members of the group and the prospect of returning for reassessment gives that added incentive.

The main theme of their approach is to pace yourself within your own known energy limits, stopping that "5 minute more" way of life. Spread out the use of energy to a more constant level to avoid the work peaks and then the onset of fatigue and muscle pain.

The therapy was aimed at maximising function by improving muscular strength and co-ordination and generally reviewing lifestyle, diet, and daily activities to ensure optimal physical fitness, adequate rest, sleep and appropriate nutrition. Establishing a baseline for exercising and slowly increasing it should produce an overall improvement, given time.

Nobody knows for sure how many polio survivors there are in the UK, especially the non-paralytic ones. Whether it is 30,000 or 300,000, for most the late effects will not be a problem in 50 years time! So no wonder the NHS is not keen to fund any research work. However 50 years, indeed 50 days, is a long time for some of those suffering and I can only hope for each and everyone of us, that the good work being undertaken at the Lane Fox Unit is able to continue. They have my wholehearted support.

Norman Jones - LincsPPN Member
"Norman Jones" <nrjones@globalnet.co.uk>

With thanks to Dr. Davidson for his permission for this to go on general release.

Post-Polio References

1. Lincolnshire Post-Polio Library - Lane Fox
2. LincsPPN Directory - Clinics - Lane Fox
3. LincsPPN Directory - Polio Survivors on the Internet - Norman Jones

THE GIFT OF A WRITTEN NOTE...

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

Lincolnshire Post-Polio Library

Articles added since last newsletter with grateful thanks to the authors

Title: Dr. Henry writes about Polio Literature

FULL TEXT HERE

Author(s): Henry Holland MD

Abstract/Extract: As an infectious disease, historical evidence would indicate that polio has been in existence for over five thousand years. However, over these many centuries, the literature on polio has been limited. In this century there has been more in the medical literature about polio as a result of the epidemics that began in the early part of this century. With the development of the Salk and Sabin vaccines, the medical literature regarding polio quickly vanished. Now, with the reality of Post-Polio Syndrome (PPS), the literature, both medical, non-fiction and fiction has increased in the last decade.

Includes a list of 56 polio and post-polio related book titles with individual title links to a selection of major online bookstores

Title: Gait Analysis Techniques

FULL TEXT HERE

Author(s): JoAnne K. Gronley and Jacquelin Perry.

Original Publication: The Journal of American Physical Therapy Assn. Vol. 63, No. 12, December 1984 1831-1838.

Abstract/Extract: In the gait laboratory at Rancho Los Amigos Hospital, the emphasis is on patient testing to identify functional problems and determine the effectiveness of treatment programs. Footswitch stride analysis, dynamic EMG, energy-cost measurements, force plate, and instrumented motion analysis are the techniques most often used. Stride data define the temporal and distance factors of gait. We use this information to classify the patient's ability to walk and measure response to treatment programs. Inappropriate muscle action in the patient disabled by an upper motor neuron lesion is identified with dynamic EMG. Intramuscular wire electrodes are used to differentiate the action of adjacent muscles. We use the information to localize the source of abnormal function so that selection of treatment procedures is more precise. Force and motion data aid in determining the functional requirement and the muscular response necessary to meet the demand. Determining the optimum mode of locomotion and developing criteria for program planning have become more realistic with the aid of energy-cost measurements. Microprocessors and personal computer systems have made compact and reliable single-concept instrumentation available for basic gait analysis in the standard clinical environment at a modest cost. The more elaborate composite systems, however, still require custom instrumentation and engineering support.

Title: Pulmonary Dysfunction and Sleep Disordered Breathing as Post-Polio Sequelae: Evaluation and Management

Author(s): John R. Bach, MD and Augusta S. Alba, MD
Original Publication: Orthopedics December 1991 Vol 14 No 12 1329-1337.
Abstract/Extract: Post-polio sequelae can include sleep disordered breathing and chronic alveolar hypoventilation (CAH). Both conditions develop insidiously and can render the post-polio survivor susceptible to cardiopulmonary morbidity and mortality when not treated in a timely and appropriate manner. These conditions can be diagnosed by a combination of spirometry, noninvasive blood gas monitoring, and ambulatory polysomnography Sleep disordered breathing is most frequently managed by nasal continuous positive airway pressure, while tracheostomy ventilation is the most common treatment for ventilatory failure. We report the more effective and comfortable techniques recently made available for managing sleep disordered breathing and the use of noninvasive treatment options for CAH, respiratory failure, and impaired airway clearance mechanisms. One hundred forty-three cases are reviewed.

Title: Pulmonary dysfunction and its management in post-polio patients
Author(s): John R. Bach and Margaret Tilton
Original Publication: NeuroRehabilitation 8 (1997) 139-153
Abstract/Extract: Respiratory dysfunction is extremely common and entails considerable risk of morbidity and mortality for individuals with past poliomyelitis. Although it is usually primarily due to respiratory muscle weakness, post-poliomyelitis individuals also have a high incidence of scoliosis, obesity, sleep disordered breathing, and bulbar muscle dysfunction. Although these factors can result in chronic alveolar hypoventilation (CAH) and frequent pulmonary complications and hospitalizations, CAH is usually not recognized until acute respiratory failure complicates an otherwise benign upper respiratory tract infection. The use of non-invasive inspiratory and expiratory muscle aids, however, can decrease the risk of acute respiratory failure, hospitalizations for respiratory complications, and need to resort to tracheal intubation. Timely introduction of non-invasive intermittent positive pressure ventilation (IPPV), manually assisted coughing, and mechanical insufflation-exsufflation (MI-E) and non-invasive blood gas monitoring which can most often be performed in the home setting, are the principle interventions for avoiding complications and maintaining optimal quality of life © 1997 Elsevier Science Ireland Ltd.

POST POLIO SUPPORT GROUP IRELAND FIRST PPS CONFERENCE. HELD IN DUBLIN MARCH 10/11 1999

REPORT by Hilary Hallam

I must start this report with my Congratulations to Jim Costello, Joan Bradbury and the Conference Committee for succeeding in holding their first PPS Conference and making it the success that it was. This was no mean feat and their initial hoped for attendance went from 120 to nearly 250 with 20% being medical professionals.

To begin with I would like you to read Catherine Holmquist's article in the Irish Times about Jim Costello, the Chairman of the PPSG. One more example of the achievements that Polio Survivors made and are still making in their lives. It shows that with the right aids and equipment we can live very useful and rewarding lives.

The Irish Times Catherine Holmquist writes.

Coping

Fighting for people affected by polio's second blow.

The polio epidemics of the 1940's and 1950's affected an estimated 9,000 people in the State, most of them children. Many recovered to live normal lives, but sadly, in their 40's and 50's, about half of polio survivors are developing post-polio syndrome, a debilitating neurological condition. Jim Costello (56) Chairman of the Post-Polio Support Group, is trying to help.

Being in an iron lung is like lying in a coffin with your head sticking out.

Forty-two years ago, when I was first placed in the iron lung, I was so terrified one of the nurses would open the lung, the pains, and aches were secondary. Pain is secondary to your need to take your next breath.

When the iron lung was opened, you could not breathe. A team of nurses would come to change your sheets or pyjamas so that it would be done very efficiently and fast. They would open the iron lung and you would be lying there going blue, fully conscious, but struggling to breathe. The nurses would be watching your colour so they would know when you needed to get back inside the iron lung, fast.

I was diagnosed with polio in 1958 at the age of 15, which is unusual because 90% of polio's were affected as younger children.

As a child I was a ruffian. My mother used to say if you were looking for me, you'd find me at the top of the nearest high tree. When I got polio, it caused quite a scare because I was one of 360 odd boys in Clongowes school in Co. Kildare, and the diagnosis raised the possibility there was a carrier in the school and others might have been infected. In those days students very seldom got out - once or twice a term if you were lucky.

About two or three weeks before I got polio, I had been at a rugby international between Ireland and Scotland. The doctors reckoned I got the polio from a carrier in the crowd in the main entrance at Lansdowne Road. No one else at Clongowes was affected, My two great interests are rugby and racing and I still go to Lansdowne Road with my lifelong school friend Phil Mooney, who has spent his life in youth rugby training.

The polio paralysed me from the waist up, attacking my lungs and making it impossible for me to breathe. I spent nearly nine months in an iron lung without getting out of it in Cherry Orchard Hospital. The process of recovery was very gradual. I had three years of treatment in hospital - first at Cherry Orchard, then at the world-renowned Nuffield Orthopaedic Centre in Oxford, England. I spent most of those three hospital years in a wheelchair and gradually learned to walk during several years as an outpatient at the Central Remedial Clinic in Dublin. You recover to a certain point and then stop.

Polio is very indiscriminate in the way that it attacks. Some people are affected in one part of the body, then fully recover. Others are affected in the whole of their body, then only partially recover in the upper half, leaving them in a wheelchair, which is the classic image of polio. I'm one of the 'upside down polios' because I was paralysed in the upper body. I can walk normally, but I must wear a brace to support my back and my arms are paralysed.

I have a very slight amount of movement in my left hand. You have to do the most you can with what you have.

In my 20's I worked in the family business, a clothing shop, O'Reilly's in Earl Street. When that was sold I was in the restaurant trade for a while, then dabbled in a small way in the property business.

I still spend 12 - 14 hours a day, about three days a week at Cherry Orchard in an iron lung, which I have had specially adapted so I can use the telephone, the TV, the lights and the radio - all through controls at my feet, one of which operates a telephone headset, which comes down on an electric arm when I need to use it. The entire staff has been most helpful to me over many, many years, getting me through a number of critical illnesses.

The rest of the week I live in my mews in Ballsbridge, which I share with my partner of 15 years, Delia. At home, I use a Nippy portable respirator for 12 - 14 hours a day.

My personal assistant, Trish, is like a pair of arms for me. She dresses me, feeds me and does all the normal things for me that one would normally do with one's arms - dressing, feeding, scratching my nose and even going to the toilet. She carries my briefcase around and helps me with my paperwork.

When I'm lying in the iron lung in Cherry Orchard at night, sometimes my thoughts are racing and I cannot sleep. I have a device which enables me to use the telephone so I can stay in touch with the outside world. I cannot write so when I have an idea in the middle of the night at Cherry Orchard, I leave it on the answering machine in the office of the post polio support group in Carmichael House.

For the past year, with the help of a dedicated committee, I and Joan Bradley, secretary of the Post Polio Support Group, have been organising next weekend's conference, Polio in the 21 st Century. Since 1994 I have worked on a voluntary basis as chairman of the PPSG. Since I cannot use my hands, I use a voice-activated laptop computer to write, correspond through email and surf the Internet.

According to international research some 40 - 60% of polio survivors develop post-polio syndrome some 20 - 40 years after surviving the initial epidemic. They have led useful, independent lives, often with very little contact with the medical profession. Developing the syndrome is a hard blow to someone who is already disabled in that it causes a second disability through one or all of the following symptoms: extreme fatigue; pain in muscles and joints; decline in ability to carry out customary daily activities such as walking. swallowing and respiratory difficulties, which may present as problems relating to sleep.

Diagnosis in people who believed they had recovered may be difficult, because many polio survivors were encouraged to forget they ever had the disease. Polio is not on their current medical records so when they go to their GP's, complaining of symptoms, neither they nor their doctors relate the symptoms to the polio they had as children.

We commissioned a professional survey which found many post-polio people were in urgent need of things such as bathroom adaptations, electric wheelchairs and many other aids and appliances. We have many polio survivors who have worked all their lives but who have earned relatively low incomes - but just above the limit for a medical card. This gives them very little hope because they cannot afford to pay for the appliances, aids and physiotherapy they need. We've been fighting for medical cards for polio survivors for many years without success.

Another problem is that within the community-care system there is a lack of occupational therapists and physiotherapists, so polio survivors may have to wait a year or two just to be assessed for things such as bathroom adaptations. I'm lucky that I am not affected by post-polio syndrome at the moment, and that I have the independent financial means to have a part-time carer and the aids and appliances I depend on. I never worry about my condition. I know lots of lads I was in school with who never had polio and they're dead now and I'm not.

This was my first visit to Ireland and will certainly not be my last. The Irish have such a light hearted way of answering your questions and explaining things that I had to smile so many times, the stress of every situation was reduced considerably. For example, the doors to the Ferry would not open when we arrived in Dublin. Much laughter from the drivers when we were told they had left the key behind and were sending a man over with it in a rowing boat.

Lynn flew in from the south of England and we shared a room and reminisced over our trip to the States and Canada last year. Jeanette and Kim from the Ontario March Of Dimes PPS Committee flew over from Canada. Others included Helena from Leicestershire Post-Polio Network, David Leeks and his wife Chairman, and Dorothy Nattrass Welfare Officer for the BPF. Two ladies from Belgium, Tina from London, Francis from Scotland. We met and chatted with many Polio Survivors from Eire and Northern Ireland and the sharing of information and experiences once again were a positive way forward. I cannot possibly include all that was said and apologise to anyone speaking who I have left out. I have picked out what I consider to be important points that should be taken up in U. K.

The Minister of State spoke about the healthcare situation in Ireland. How they have indicated a commitment to PPS for rehabilitation and they are loosening the purse strings with some £10 million being committed for physical and sensory disabilities.

Dr. Orla Hardiman Consultant Neurologist at the Beaumont Hospital in Dublin then told us about Polio in Ireland. There are estimated to be 5,000 polio survivors in Ireland with varying degrees of disability. Onset can be gradual or abrupt following long period of bed rest, operation, limb fracture, fall, etc. She heads the new multidisciplinary team and explained what her new clinic was providing. During the two days all her team members spoke about their work in main conference and workshops. Donna Fisher stated that we walk better than anyone should for the amount of weakness we have which is random.

Dr. Jacquelin Perry from the Ranchos Los Amigos PPS Clinic in California and Dr. Lønnberg from PTU in Denmark were the main speakers.

In California, Denmark and Dublin we heard there are multi-disciplinary holistic clinic assessments of Polio Survivors. It is a diagnosis of exclusion, in fact a clinical diagnosis. This approach is necessary to ensure that other conditions are not missed. It is also necessary to properly evaluate the symptoms and provide the necessary support.

Dr. Lonnberg told us that in Denmark the Danish Society of Polio and Accident victims (PTU) runs a nation-wide outpatient clinic and counselling, all services free of charge. The management of polio sequelae and post polio sequelae is conducted by orthopaedists, rheumatologists, orthotic engineers and physiotherapists, 50 employees in total. Each year seven to eight hundred polio survivors benefit from these services, 70% of all patients in the clinic. The Clinic is an integrated cross-professional centre situated in Copenhagen the capital of Denmark. The services offered are: examination and testing by specialists in rheumatology and rehabilitation, physical training and therapy, social and psychological counselling, and counselling for ergonomics and working environment.

In Norway and Sweden several rehabilitation hospitals and medical centres offers evaluation of the late effects of polio and give intensive short period therapy and training to all physical disabled of which the polio survivors are in a minority.

Dr. Lønnberg talked about new weakness in former unaffected muscles, and asked were they unaffected? Is part of the body not affected? You have a febrile child, how do you assess the weakness? You talk about your good leg when maybe you should talk about your better leg?

Dr. Lønnberg talked about the difference between aging and the late effects of polio. With aging from the age of 20-25 we start to lose 1% function per year. With aging there are no biomechanical disadvantages, there is diffuse loss of muscle strength and mass and a slow imperceptible decline in multiple systems. With the late effects we have biomechanical deficits localised in specific areas, focal loss of strength and mass in addition to moderate to serve decline in neuromuscular performance.

With polio, up to 50% of our motor neurones can be lost without the muscle strength showing clinical effects and one single motor neurone instead of serving 1,000 ends can be supporting 10,000 ends. From the age of 20-25 when we start to lose our 1% a year we are starting at a lower figure. The late effects show between 20 and 50 years following polio infection.

Dr. Lønnberg said we need a multi-disciplinary assessment. We then need to be prudent in how we use our energy. That fatigue and weakness MAY be the only signs of respiratory dysfunction.

Dr Perry - who is an orthopaedic surgeon and has seen polio from her early days of working. She has now retired from all work but the Post Polio Clinic. She cautioned us to remember that we are all individuals and our muscles need grading correctly. A grade 3+ muscle can in fact be larger than a grade 4+ muscle. The actual muscle tissue being in sections surrounded by fat. For some of you she said just managing daily living will be as much as you can manage. If you do any activity or exercise and you get pain or fatigue then you are doing too much. You must find your own limits and pace yourself with rests in between.

It is very important to keep as much range of movement as you can. You all have different damage from the polio virus to your muscles and you need professional help to ensure that all your muscles are assessed individually. Exercises can then be tailored to suit your needs, to allow you to keep range of movement, to strengthen muscles that are only slightly weak and to provide some aerobic exercise for your heart and lungs. Although for some of you daily living will be as much as you can manage. Start very gently with small movements and low number of repetitions. Start slowly, take your time and build up from one repetition to more at your pace and for each particular action. You know your body best and what it can manage. One specific suggestion for range of movement for the shoulder was to bend your arm so that your hand is on your chest, like a chicken wing, and raise that arm to shoulder level.

You have to manage your life. Replace anxiety with a plan and remove strain by avoiding overuse. Pace all your activities and stop volunteering for everything (much laughter). To preserve your shoulders and neck, support your arms and avoid overhead reaching. Sit leaning back 15 degrees and try and keep your weight under control. For your lower body, park close to where you are going and avoid stairs. Use orthosis and wheels and again weight control. Limit your fat intake, eat protein at every meal and cut down the portion size.

Where you have need for orthosis these need to be reassessed if already worn and made for those of you who have never worn them or threw them away many years earlier. Just providing you with an orthosis without assessing your muscle weakness, your gait, finding out about your daily life, your home situation and work will not provide you with the orthosis that you need.

Dr. Perry made comment at the end of the conference that many there were wearing orthosis that had not changed since they had had their polio. There are many new and much lighter materials and more specialist joints now on the market. Get properly assessed. An orthosis has to fit you, has to be strong yet light and comfortable and you have to be happy with it.

Dave Allen an Orthotist from Cappagh Hospital, gave an excellent talk which he has agreed to write up and we will include this in our next newsletter.

I was asked to take part in a panel on the second afternoon and spoke about the need for us to show the whole picture of our polio life. Most appointments are very short and we are looked at as we are now with no conception of the achievements we have made at our best recovery. I explained the need to chart your daily activities, to plan the week using energy tokens. I showed our idea of the body charts where you can show different stages in your polio life with possibly just two sheets of paper stuck together. A time line of you from before polio, with polio, different stages of recovery, at best recover, and the stages you are now going through.

Conclusion once again is that the management of late effects of polio is a multi-disciplinary task. Rehabilitation means good management of the whole person. The process involves both consumers and health care providers. We want to achieve as much as possible for as long as possible within our limitations.

We are asking once again for the same facilities in the UK as there are in other parts of the World. To the Minister of Health and local Health Authorities stop wasting money on our rounds of the hospital departments, provide us with Regional holistic assessment centres where we can be case managed back to our local Health Authority. Spend a little money on correct aids and assistive devices now to slow down our deterioration and save money for the future.

Post-Polio References

1. LincsPPN Directory - Organisations - Post Polio Support Group (PPSG)
2. LincsPPN Directory - Organisations - Danish Society of Polio and Accident victims (PTU)
3. Lincolnshire Post-Polio Library - Perry, Jacquelin, M.D., D.Sc. (Hon)
4. Offsite - The Irish Times - http://www.irish-times.com/

BREATHING: ADVICE FOR PEOPLE WITH POST-POLIO OR OTHER NEUROMUSCULAR DISORDERS

Augusta Alba, M.D., Alice Nolan, R.N.
New York University Medical Center,
Department of Rehabilitation Medicine,
Goldwater Memorial Hospital, Franklin D. Roosevelt Island, NY U.S.A.

If you have had polio or suffer from other neuromuscular disorder and have weakness of the neck, upper trunk, or shoulders but are not on a respirator, you may want to evaluate your respiratory needs. Such a disorder may be polymyositis, muscular dystrophy, amyotropic lateral scoliosis, spinal muscle atrophy or spinal cord injury. As you grow older, your respiratory reserves will diminish. A potentially serious problem may develop whereby carbon dioxide is retained and oxygen is decreased in your bloodstream. These changes may be obvious but in most cases they are subtle. You can easily recognise weakness: If you cannot pick your head up off the bed, raise your arms above your shoulders, turn over in bed by yourself, come to a sitting position or sit independently without a back support. However, it is difficult to recognise when the muscles of respiration (the muscles and rib cage that expand and contract your lungs) are not working adequately. When these muscles are impaired a restrictive respiratory problem results. This is different from obstructive pulmonary problems or disorders of the airways.

In the course of normal aging, our lungs and chest wall become less elastic. We do not breathe as deeply. Our vital capacity, the biggest breath we can take into our lungs and ten push out, decreases by 30cc per year (1 oz). Our cough is not as vigorous. Aging and neuromuscular disorder produce more serious changes. These changes are maximized by conditions such as kyphoscoliosis and airway obstruction or chronic bronchitis.

Symptoms which may be associated with failing respiratory reserves are numerous and for the most part non-specific. This means that other medical problems can cause them as well. However, they do serve to alert you to a possible respiratory problem. These symptoms include feeling more tired or becoming exhausted from ordinary activities, and reducing usual activities because of fatigue. Anxiety, inability to fall asleep, restless sleep, awakening during the night with nightmares and awakening in the morning with a headache or slight confusion may occur. Brain functions are altered so depression, inability to concentrate, dizziness, sleepiness during the day and blurring of vision may be present. Vascular symptoms such as peripheral cyanosis or a abnormal sensitivity of the extremities to cold and the tendency to develop high blood pressure or a rapid heart beat maybe caused by respiratory insufficiency, Breathlessness during activity including such a simple task as speaking may occur. Your voice may be lower than it had been. The breaths you take when you are awake may be very shallow and even more shallow when you are asleep. This is why early symptoms usually occur in sleep. Tranquilizers and sedatives will further depress your respiration and should not be taken especially at bedtime or during the night.

For many people, the first changes may be difficulty in raising secretions and feeling congested with frequent colds. Difficulty raising secretions leads to a sealing off of lung tissue from the airways (atelectasis), or to infections of the lung tissue (pneumonia). The work of breathing becomes even harder and respiratory failure occurs more rapidly. With respiratory failure , the right side of the heart fails causing generalized oedema and protein in the urine.

If you have any of the signs and symptoms described above, you should make an appointment to see your doctor. Your breathing can be evaluated by simple tests. One of these is measuring your vital capacity (the maximum amount of air that can be moved into the lungs and then forcibly exhaled). If your vital capacity is reduced but is still above 50% of a predicted value for your age and sex, it is unlikely that your symptoms are related to your diminished breathing capacity except in three situations; marked obesity, partial obstruction of the throat during the night in deep sleep, and the presence of an intrinsic lung disease such as an old tuberculosis or emphysema. If your doctor considers it necessary, he will refer you to a pulmonary specialist.

The pulmonary specialist will do screening pulmonary function tests, more comprehensive function tests if he finds them necessary and arterial blood gases. He may not find it necessary for you to have a ventilator but may wish to follow you on a regular semi-annual or annual basis, or to see you immediately if you develop an intercurrent respiratory infection. If he suggests mechanical respiratory support, you need not be alarmed. Such support is an insurance policy for your well being.

The respirator will help you sign your lungs (stretching or range of motion). It will help you to cough, speak and even regain energy that had to be funnelled into the increased work that you expended in breathing prior to the use of the respirator.

Reprinted from East Coast Florida PPS Group Newsletter March/April 1999. Barbara Goldstein - bgold@america.com
Originally in 'The Boomerang', South Bay Post Polio Support Group, Torrance, California, July/ August 1998.

Editors note: We would ask those testing us to remember that our energy levels are not constant. We may be able to do an action a few times but then our energy levels are depleted and we lose the ability to continue at the same rate. We ask that testing is not done after we have sat around for some time doing very little, but that we do some activity just prior to testing or are using up as much energy on this day of testing as we would at home.

Post-Polio References

1. Lincolnshire Post-Polio Library - Alba, Augusta S., MD
2. Lincolnshire Post-Polio Library - Newsletters - Florida East Coast Post-Polio Support Group

AIR MANAGEMENT EQUIPMENT

Harry Davies <hdavies@lightspeed.net>
President of the Post Polio Support Group of Fresno, California.

When your doctor tells you that you need a C-PAP or that you should be on a BI-PAP machine, the first thought that comes to you is, what are they and what do they do?

C-PAP is a machine that can be adjusted by your Respiratory Therapist to supply different amounts of air pressure. This pressure is a steady pressure that opens up your throat and makes it easier for you to breath. The air under pressure is pushed into your lungs when you take in a breath . So when you take a breath of air it is so much easier to breath in. But that pressure never changes and you have to exhale against that pressure. This is the down side of this type of machine. But, once you get used to it, you would be surprised how much help you are getting. The C-PAP is used for many different types of breathing problems. Apnea being one of major causes for the C-PAP machine use.

BI-PAP, this machine is much like the C-PAP but it has two levels of pressure. When you take 'in a breath of air the machine gives you the higher pressure, then when you exhale the machine senses this and drops to a lower pressure for you to exhale without the high back pressure. These pressures are set by your Respiratory Therapist. Note, the doctor should send you for a sleep study before you start on any program of air management. These pressures have to be checked while you are awake and while you are asleep.

Both of these machines can come with a computer built in that after you go to sleep they adjust to your breathing speed and the amount of air you are taking in.

These two machines can be used with a mask of sorts, they have mask that covers your mouth and nose, they have mask that just covers your nose, and they have nose pillows that fit inside your nose. The choice of mask is usually up to the individual. Some people have trachs that they hook the machine up to. It all depends on your needs and what the doctor prescribes for your condition.

There is another machine, the Ventilator. This style of machine can force air into your lungs and then helps you get rid of the exhaled air. It is a more complicated machine. Usually all the controls are right on the front of this machine where they can be adjusted by the individual. This machine has high and low alarms. You can adjust the breathing rate per minute, how much time in-between breaths, and the pressure at which the machine will cycle for breathing. Normally this type of machine is used by a person who has a trach. But there are groups that use non-invasive ways to use this machine, Non-invasive would be using a mask. I found out that with the mask I would get air into my stomach along with my lungs. I finely switched to the trach and have not had any more trouble with the bloating.

Last but not least, when using these machines you more than likely will need a heated humidifier. This will put the moisture into your throat and lungs. Dry air will cause you a lot of discomfort. The most important item to remember is, it takes time to get use to using any one of these machines. But the rewards are the best when you get that first nights sleep where when you wake up the next morning feeling like a person again!

Editors note: Christine Ayre, LincsPPN Committee member, has a Bi-pap and would be happy to share her experiences of testing and using it. Contact her via LincsPPN.

Post-Polio
References

1. Lincolnshire Post-Polio Library - Bach, John R., MD

RULES OF ETIQUETTE FOR POLIO SURVIVORS.

PERSONAL HYGIENE.

1. Decisions about which body part to wash depend on which doctor you're seeing today, i.e., face/ears for the ENT; feet for the podiatrist; arms for blood tests; etc
2. Proper use of toiletries can forestall bathing for several days. However, if you live alone, deodorant is a waste of good money.
3. Read labels carefully. Ever notice how much the can of room freshener resembles the can of deodorant?
4. Remember to warn your spouse before kissing if you've just taken your herbal remedies, since your breath now smells like grass.

IN THE KITCHEN.

1. If you can't remember what it is you're cooking in the pot, whatever it is, it can probably use more salt.
2. Do not toss that cold cup of coffee into the dryer or set the iron in the refrigerator to cool off, no matter how good an idea it may seem at the time.
3. When your husband tells you 'Don't worry about dinner, just throw some frozen chicken in the oven and forget it", DON'T forget it.
4. When everything INCLUDING the can opener is dirty, it may be time to wash some dishes.
5. It's bad manners to fall asleep at the table, especially in the food.
6. If you're having a bad day, there's nothing better than pizza and quiet.

DRIVING ETIQUETTE.

1. Always place a Post-it Note on the dash-board telling you where you're going. And when you get there, place another on the dashboard that says HOME.
2. Never relieve yourself from a moving vehicle, especially when driving.
3. Always carry an electronic homing device in your car and with you so you can find your car in the parking lot.

TIPS FOR ALL OCCASIONS.

1. If you have to vacuum the bed, it's time to change the sheets.
2. If you take the dog for a walk, make sure he brings you back.
3. Nevermind about taking one day at a time. Just stick to one thing at a time.
4. Try to spend at least 45 minutes each morning doing one get-up.
5. Work at learning something new everyday, like sitting up, for example.
6. Remember to breathe when napping. It's unnerving to wake up and see vultures staring at you.
7. Learn to understand your "body language":

- Joints - "I ache! It's going to rain!"
- Stomach - "You're getting me upset!"
- Nose - "Oh, oh, I'm getting a cold!"
- Head - "Stop it, all of you! I'm getting a migraine!"

Another gem from Donnie <mickiemc@FRONTIERNET.NET>

* * *

Friend American and Polioians lend me your ears I will gladly repay you the second Tuesday of next week with a nose thrown in for interest. I have come to bury Polio not to praise it.... To Polio, or not to Polio that is the question. Whether it is nobler in mind to spit in the eye of popular opinion or to sleep per chance to dream. Ah! there be the rub do dreams come is such a sleep. Hark, what light through yonder monitor screen breaks... it is an e-mail from the east, it is Raghnall, alas I knew him well ..... Oh, heck, at least I thought I did.... Oh damn it anyway, cry havoc or whatever, and let slip the dogs of war [bark bark] and with fiery tongue delight not the fainted heart, but rather avenge the murdered soul and bare witness to the conflict that left it so ..... And then and only then shall peace,. sweet peace, over thy countenance flow.

From: Randel Harvey <goldendragon@ddaccess.net>

and Sylvia from Hampshire asks...

Has anyone any other idea for washing between their toes than a soft toothbrush taped to a Dyno Drain Cleaning Rod?

COMPUTER COMFORT

Grace R. Young, MA, OTR

If you're reading this, you're on the internet which means you probably spend a fair amount of time at your computer. This can put you at risk for a lot of problems. Carpal tunnel syndrome, tendonitis, bursitis - all result from chronic, continuous, overuse of the hands and arms. Neck and back pain, headaches, eyestrain, tension and fatigue can also come with the territory.

Before computers, people who typed for a living didn't develop these conditions. What has changed?

For one thing, we type much faster on a computer keyboard - thousands of keystrokes per hour. And there are no breaks - we don't have to stop at the end of each page to insert fresh paper. These fast, repetitive motions take their toll on your body. The problem is compounded if your computer workstation doesn't fit you.

So here are some risk-reducing recommendations from ergonomics, the science of arranging and adjusting your work environment to fit you and your body. They won't all apply to everyone, but you can utilize whatever fits your situation.

BODY AND ARM POSITION.

Shoulders need to be relaxed and elbows kept close to the body. Place the computer keyboard at elbow height or 1" below elbow height to keep your forearms parallel to the floor and wrists in neutral position. A too-high keyboard is one of the most frequent flaws at computer workstations. If your keyboard height is not adjustable, change the chair height.

Be sure your chair depth is correct for you. If it is too shallow your thighs won't be supported. If it is too deep, it won't support your back.

Make sure your feet are supported. If your feet don't reach the floor use a foot rest or a 3-ring notebook binder.

You also don't want your hips flexed so much that your knees are higher than your hips. This interferes with blood flow to the legs. If you can, move your feet forward so your knees are lower than your hips and straighter than 90 degrees.

Use a lumbar pillow or a small rolled-up towel to support your low back.

To avoid over-stretching to reach objects you use often, make a semicircle with one arm to determine your comfort zone and place frequently-used objects within that area.

YOUR MONITOR.

The most comfortable distance for the monitor screen is 18-25 inches from your eyes.

The top of the screen should be at eye level. If you wear bifocal or trifocal glasses the screen will need to be somewhat lower to keep your head in an upright position.

Place a document holder next to the monitor at the same height and distance as the screen. Typing from a document lying on the desk causes repetitive neck motion.

TAKE FREQUENT BREAKS AND STRETCHES.

Blink often. Optometric studies have shown that people tend to blink less and open their eyes wider when looking at a computer screen. This causes dryness that can lead to fatigue, a burning sensation, difficulty focusing and headaches.

Stretch your wrists and fingers. Stretch your wrists backwards until you feel a mild pull, then stretch forward. Make a fist, then stretch the fingers outward.

Put your hands on your hips and lean backwards gently, then bend side to side. Do this sitting down so you won't lose your balance.

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

Editors note: Ergonomic Keyboards. These are split keyboards and allow your wrists to stay in line with your arms and reduces wrist strain. Also have a platform in front where you can rest palms. In some models Backspace and Tab keys are also duplicated in the middle. Takes a couple of days to get used to them.

BOOKS AVAILABLE FROM THE LincsPPN.

MANAGING POST-POLIO - A Guide to Living Well with Post-Polio Syndrome

Edited by Lauro S. Halstead, M.D.
Published NRH Press - Available Now - 256pp, 6 x 9 - Paperback

"An all new guide to living with post-polio from NRH Press edited by Lauro S. Halstead, M.D., internationally renowned post-polio expert and polio survivor, Managing Post-Polio provides polio survivors, family members, support group members, and health care professionals with a long-needed tool to assist individuals with post-polio syndrome to live healthier, fuller lives.

This easy-to-read, consumer-orientated guide is designed to help with day-to-day living with this often misdiagnosed and debilitating condition. Managing Post-Polio deals directly and openly with the issues that confront polio survivors as this condition develops, and provides assistance and support for the ongoing management of their problems."

None of the authors or contributors will profit financially from sales of the book, profits are being set aside for use in the PPS Clinic at the NRH, headed up by Dr. Halstead.

More Details...

UK Members £8.00 inc. postage. UK Non members £10.00 inc. postage.
Overseas Members contact for additional postage amount.

HEALING THE BLUES - DRUG-FREE PSYCHOTHERAPY FOR DEPRESSION

Dorothea Nudelman & David Willingham, MSW

Written in two personal voices, patient (Polio Survivor) and therapist, this is the gripping story about the depression of a brave woman who faced her own despair and transformed it into a creative renewal of her life.

HEALING THE BLUES is also a guidebook to a drug-free approach to healing depression. Depression robs us of the enjoyment of life. Increasingly, drugs are seen as a quick solution. This book suggests an alternative approach: "Listening to the depression" for what it is telling us about our life. What's not working? What needs to be understood and changed?

More Details...

Signed copies of the hardback edition 235pp (now out of print) are available from the Lincolnshire Post-Polio Network at a price of £10 including postage.

A BALANCED WAY OF LIVING
Practical and Holistic Strategies for Coping with Post Polio Syndrome

Vicki McKenna BA. Lic Ac

Vicki McKenna is a member of the Lincolnshire Post Polio Network and has written this book using her personal experiences of polio, its late effects and her training in acupuncture and Chinese medicine. It can take an inordinately long time in the UK to go from GP through the rounds of the Hospital Departments before we get the assessment, diagnosis, and treatment that we need. Time and again we hear from Clinics abroad that Polio Survivors must be assessed and treated holistically. We can start to make a difference to our health by assessing our lifestyle as soon as we learn there are late effects to having had polio. We should not wait for diagnosis because any improvement we can make to our health, lessen the pain and fatigue we are experiencing will be of benefit, regardless of the diagnosis at the end.

Vicki's book takes you through an overview of PPS. Then moves on to looking at your life with a new perspective. Read ways of letting go of the old attitudes and trying new ones. Relaxation, gentle exercise, diet and the most important factor conserving energy so that you can you do things you want to do when you want to do them.

The next article in this newsletter is the complete text of Chapter 7, reproduced with the permission of the author.

To Order Your Copy send £10 UK - £12 Europe - $US25 Outside Europe. Prices inclusive of postage and packing (airmail outside Europe). Payment by cheque, postal order or money order (please contact Vicki or LincsPPN for $US payment address in USA). Please allow 14 days for delivery.

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CONSERVING ENERGY

The complete text of Chapter 7 from "A BALANCED WAY OF LIVING Practical and Holistic Strategies for Coping with Post Polio Syndrome" by Vicki McKenna BA. Lic Ac

Earlier we saw the importance of making changes in our attitude towards life. We may not choose to have PPS but we can choose how to cope with it. By seeing PPS as an opportunity for change and growth we learn to come to terms with it and find ourselves in control of our lives once more.

We have seen how we can build energy by practising certain techniques and watching what we eat. In this way we protect ourselves from becoming stressed and damaging our sensitive nervous systems. Finally we need to focus on our outer environment and start to make changes in our homes and at work that will also help the process of sustaining and conserving energy.

If we pay attention to intuition - the teacher within that I wrote about earlier, we will find ways of doing this. Always ask your inner wisdom for guidance - through prayer, meditation, dreams, we can find solutions that prompt easier, more harmonious ways of doing the things that presently drain us. The suggestions that follow are merely suggestions - if you feel uncomfortable with them put them to one side - always, always listen to your own heart - be guided by its wisdom.

The model of Chinese philosophy provides us with a path that helps us to lead a balanced , harmonious life. This path shows us the basic foundations that we need to pay attention to in order to live this life of balance and harmony. Some of these have been written about in earlier chapters; the practise of breathing exercises and meditation, the need to let go and flow with the energy of life. It remains to be said that the wise man in Chinese philosophy traditionally cultivates a lifestyle that teaches us the following three things. Firstly we need to understand that although we seemingly lead separate lives, we are all linked and we all affect each other. Because of this we need to care for our fellows and be cared for by them. In other words, to use twentieth century terminology, we need to feel supported, In this way the human heart and spirit are fed and nourished. Secondly we need to live lives of simplicity and make our environment easy and stress free to live and work in. We do this by careful planning and organising. Thirdly we need to ground ourselves in a calming sense of routine which brings rhythm and stability to our days. In this way we can feel energised and uplifted - able to live our lives fully. Let us look more closely at each of these three areas.

SUPPORT

As polio survivors we need to be supported in many ways. Crucially we need the emotional support of those around us but practically speaking we also need financial and physical support to assist us in our lives.

A Support Network

Marjorie often feels despair now that PPS has limited her mobility and finds it hard to ask for help. She has written a piece called Isolation which she has kindly allowed me to quote from; "It's a lonely word, isolation, on bad days it seems to envelop me like a smothering blanket cutting off sustaining air. Once I liked to be alone with my books and music, then, private time away from people and pressures provided nourishment for my soul.... Solitude was precious because it balanced the pressures of days spent dealing with people ... Now ... at times I feel imprisoned, like Rapunzel in the castle tower, without the advantage of long hair to slide down.... It is difficult obtaining help when one is proud and independent". Marjorie feels excluded and lonely and is finding it hard to tackle life without a support network.

Stressors can be endured more easily when you have a strong supportive network of family and friends. Research shows that good health depends on a support system. Ethnic communities often do not have the same stress related diseases that the rest of us do simply because they are composed of close knit communities.

As Polio survivors we need to learn that it is OK to ask for help and accept the support and encouragement that others can give. We have taught ourselves to push on independently of others - we can manage fine on our own. Here again we need to see ourselves as disabled and feel positive about it. We do not need to be ultra brave and strong - just realistic. We need to accept our disability pragmatically and trust others to help us. Many of us have support networks set up, others need to construct them. The key to support is communication - we need to be able to clearly express what help we need. In this way we will not feel that we have lost control of our independence.

Dorothea Nudelman, polio survivor, mother and author of "Healing the Blues" (a very moving account of Dorothea's experience of psychotherapy which I highly recommend especially for anyone thinking of going through the process of psychotherapy) found that PPS allowed her to make many changes in her life but she writes, 'the most complex and far reaching changes I need to make lie in communication with my spouse, my daughter and my close friends - people I interact with on a daily basis and who are closest to me. I think that for polio veterans to move forward in developing significant relationships with children, spouses and friends, we must abandon our silences and voice our needs more openly and directly. While the need to "ask for help" seems self evident, it is difficult to do when the lessons of silence were tied to independence and self reliance throughout our recovery years. Though silence served as strong motivation in our initial recovery, it is futile and destructive when used inappropriately. If we now need to rely somewhat on others for the full enjoyment of our lives, not to ask for help exhibits false pride and recklessness".

Dorothea then goes on to describe a conversation with her daughter that reveals clearly how communication is indeed the key., "Offhandedly I asked her, 'What memories about my coping with polio are vivid for you now as you look back?' Without hesitation she answered; 'Your never relaxing, never stopping when you worked at something until it was done. I always knew when the end came when you'd say; 'Okay. Now I've got to go and put my feet up.' It wasn't until recently that I knew your legs hurt you. It was that, knowing about the pain, that got my attention. I felt bad when I learned it hurt. I understood 'hurt'. Had I understood earlier, I think I'd have been a lot quicker to do things, to help. At first it made me angry, that I didn't know. Now it just makes me sad, you never said anything.' "

Dorothea was amazed that her daughter saw her mother's silence from this perspective. "I'd never seen it this way. Silence was the very thing I'd practised so as not to leave her burdened. But this 'protection' didn't serve her well any more than it had served me. Once I realised that, the floodgates of conversation opened easily. Since then, I have been entirely honest and direct with her. And she has said its so helpful, all the time, to know what's going on with me. Speaking for herself and her dad she said, "That's the best way for us to help you. The best, the easiest, the fastest Way for us to know where you're at - open communication without demanding".

Polio survivors are typically very independent people but we need to realise that asking for help does not constitute 100% dependence! As we reach out to others, we find we can still be in the driving seat. Taking the decision to clearly ask for help will improve the quality of our fives rather than trying to do everything alone and getting exhausted into the bargain.

Asking for help is hard but one way of doing this is to gather together all those who are connected with you - family, friends and explain to them how PPS is affecting you and what your needs are now. You may be needing more help with getting out and about shopping and socialising or with housework. If everyone is put in the picture they will be more able to help you.

Do not expect others to anticipate your needs you need to ask. Allow others to help and give them recognition and thanks for doing so. Often people want to help but are often put off by the feisty determined attitude of a polio survivor, Instead of wasting energy pushing support away and coping in type A style, we need to learn to ask for help and welcome it when it is given. We needed to be type A's in the past in order to survive with our disabilities - now we need to give ourselves permission to relax and reach out to others whom we trust to help us.

A trained councillor can also be part of a support network. Marjory found counselling very helpful "because many of us don't want to burden friends and family with our worries." Since the stressful period when she wrote Isolation (see above), Marjory has come a long way towards accepting her limitations and allowing others to help.

I experienced several months of therapy and it helped me enormously to know that there was someone I could offload to and who would listen as I voiced my fears. With my therapists support I learned to cope better with the changes in my life. If you see a councillor try to find someone who is not stuck on or inclined to take a "psychosomatic" view. Your therapist needs to be informed that PPS is a real organic illness and not the result of a depression!

Support groups

Support groups are also very useful in helping us to cope with living with PPS. The British Polio Fellowship and the Lincolnshire Post Polio Network can both open up the world for polio survivors who feel isolated and unsupported. (See addresses in resources section). These are larger groups where the emphasis is on disseminating information and working very often for social and political change.

There are also groups of the larger, information oriented type, that are not concerned solely with polio survivors but which represent the disability movement generally. The British Council of Disabled People is one such group and was set up in 1981 as the first umbrella organisation run by and for the disabled. Many groups now talk about the "social model of disability" - that the real problem for disabled people lies in the attitudes of society rather than in us. They therefore advocate amongst other things reeducating the public to become more aware of their responsibility to make access available in the environment for the disabled. The issue of access thus becomes a civil rights issue rather than a problem that needs to be solved with charitable gestures. This is a particularly relevant issue in the light of the Governments "back to work" scheme. As one disabled activist said; "how can you get to work if you can't even get on a bus?" The importance of groups such as these lies in their positive acceptance of disability and in their encouragement to assert ones needs openly.

My own view, based on the Chinese model, is that change in the outer world needs to be brought about firstly through changes in ones own being - ones own attitudes and perceptions. When we work on ourselves and develop a calm and centred approach then we are ready to make changes that will be positive and beneficial out in the world. These processes can go along side each other - whilst working on issues of self development, we can work for social change.

We are all part of the world we live in and it is the responsibility of us all - able bodied and disabled to ensure that we work together to make changes to our collective well-being. Thus we need to ensure that buildings are erected with access for the disabled, that we no longer tolerate discrimination against the disabled and that financial benefits are fully and easily available to the disabled. But all this work of creating change in the social and political arena needs to come from the development of a calm, centred and compassionate view.

It is important not to blame others and make the world wrong for when we do we become victims to the externals in our lives. Much better to turn inwards for our solutions and trust our inner guidance. In this way we take responsibility for, and become empowered to make the necessary changes in the outer world. We then assert our needs from centredness rather than anger and bitterness and in this way will be more able to convince others of the need for change and encourage others to help us implement such changes.

Smaller self help groups usually have less emphasis on working for social and political change but will, very often, like the larger groups, be concerned with the dissemination of information regarding PPS. Generally though, these groups are more about mutual support and sharing of ideas. Through contact with other survivors you can see how they are managing their symptoms, and pick up tips for coping with your own. The risk in support groups is of reinforcing each others negative experiences of PPS. The aim of a good support group should be to create a safe space in which to share negative experiences but also to focus on finding solutions for the problems of PPS.

To set up a small support group you can contact your local newspaper with a press release outlining the date, time and place of the meeting with a brief description of PPS and the organisers phone number. Stick flyers up in local libraries and community centres etc. When you meet decide who will lead the group, who will take up roles of treasurer, secretary etc. Clarify what the groups goals will be and determine the maximum number of members. Discuss also the issue of confidentiality.

At the first meeting people can offer a brief life history along with any concerns. Inform all members of larger groups such as the Lincolnshire Post Polio Network so that they are all aware of the data that such groups have access to and the social/political work that such groups do. You could then share views and feelings on topics such as the emotional impact of PPS, coping strategies, the effect of PPS on relationships. Keep the focus positive and upbeat.

Community Support

Your local Citizen's advice centre, library, social services and doctors surgery should also provide a supportive service with information concerning the type of help you may need. Through such agencies you could, for example find out about transportation programmes such as the "dial-a-ride bus" service and the taxi card facility that is available in many cities. Useful phone numbers; The National Federation of Shopmobility; 0190 561 7761. Tripscope (advise on travelling including wheelchair and scooter hire) 0345 585 641. Disabled Living Foundation; 0171 289 6111.

Giving Support

We need to be aware that as much as we need to be supported we are also capable of giving support. The stress pioneer - Hans Selye found that the best way to be loved was to act lovingly towards others. He described this as "altruistic egoism". Whatever we put out is mirrored back to us - when we extend love and care we will receive the same in return. Often it helps to focus on others problems rather than our own. This can be done by campaigning for civil rights, by being involved in a support group or in any number of other ways.

Marjorie has set up a small maternity agency that she runs part time from home - providing a service for others helps her feel good. Jennifer finds it hard to do the things she previously took for granted but manages to find the time to be a volunteer carer at a local nursery for children from deprived backgrounds. We can all do something, in our own way, to reach out and make a difference to the world. Taking the focus off ourselves and spending time loving others helps us to feel valued and included.

Supportive Equipment

Our bodies now tire more easily and our limbs are weaker than they were. We may need to use equipment such as calipers and wheelchairs where previously we managed without. Giving ourselves permission to appear disabled by using such equipment is hard for those of us who passed for able bodied but it is crucial that we let go of pride and denial if we are to help ourselves and move forward. Many of us, particularly those not obviously affected by polio, have been able to hide a polio affected arm or leg under clothing and in this way minimise our disability. We may now feel a great resistance to using aids such as calipers or crutches for the first time. For those of us who have used these kinds of support the idea that we may now have to use a wheelchair may fill us with dread. Some of us may have problems with breathing but are resistant to the idea of using a ventilator to help with breathing at night.

It is hard to admit that we may now need more help - we fought the battles of polio and felt we had conquered the affects of the disease forever. For many of us it feels almost like a backward step into failure to start having to use assistive aids.

It is hard to acknowledge that we may need more in the way of aids than we have for many years now that we are experiencing the weakness of PPS but sticks, crutches and calipers may make all the difference to our lives. Those who have already relied on equipment such as this may now find that using a wheelchair for long distances can make mobility less of a problem. Jim, on first using a ventilator says he felt "as if I have been given a new start to life". He feels that the machine is well worth the hassles involved in learning to use it and of upkeeping and maintaining it for with it he has his life back.

To push on without the right kind of help can mean wearing out weak and vulnerable muscles - particularly those that were not obviously damaged by polio but were none the less affected. Once we let go of pride we can start to enjoy life as we zip along on our electric scooters! Adapting to change is never an easy process but as we have seen earlier - we need to let go of struggling and focus on whatever it takes to help is cope more effectively so that we may move on in our lives and start to enjoy ourselves again.

Financial Support

Developing PPS may mean an end to stable employment and being forced onto benefits. Most people I spoke to have had to take early retirement or revert to part time work. This may mean a decrease in their standard of living and a precarious financial future. Clare found she had to sell her flat and move out of London to live somewhere cheaper. She realised she would not be able to continue to pay her mortgage after having to stop work due to PPS. I found myself in a similar situation and like Clare moved cities to make our financial situation easier. Changes such as these are never easy but neither is living with the stress of a demanding job and PPS. Try to sort out your financial situation before you work yourself into the ground and are forced to retire. Sharron denied her symptoms of PPS for a long time before she realised; "I couldn't cope. I ended up going on sick leave and couldn't handle the thought of going back to any of my jobs mentally or physically" With the help of a councillor, Sharron began to make the changes necessary to lead a more relaxed lifestyle and now reports that her life is manageable once more.

The Benefits System in the UK

Try to change lanes as easily as possible - sit down and work out now how to manage finances working part time or not at all. This may mean going on benefits. Phone the Benefits Agency for more information on 0800 882 200. You may find that you are entitled to Incapacity Benefit, Disability Living Allowance or Severe Disablement Allowance.

Incapacity Benefit is for people under state pension age who cannot work because of illness and have paid sufficient NI contributions in the correct years.

Disability Living Allowance is a cash benefit for people under 65 who need help with personal care or for getting around. DLA does not depend on your income, savings or NI contributions. There are two components to DLA; the care component is for help with things like washing, dressing, cooking; the mobility component is for those who cannot walk or have difficulty in walking because of their illness. If you have a DLA higher level mobility award you will probably be entitled to a disabled orange parking badge which you can get from your local authority.

Severe Disablement Allowance is for people aged 16 or over who have not been able to work for 28 weeks consecutively because of illness and who cannot get IB because they have not paid enough NI contributions. You need to be classified as 80% disabled to qualify. The Community Care Act of 1997 has given disabled people the right to make their own care arrangements via a direct payments scheme. Under the act, local authorities are allowed to give people with disabilities the cash to employ care assistants to help with meal times, washing or cleaning, instead of providing them with care directly. Only 31 local authorities have established this scheme but hopefully more will take it up. As you are probably aware, the benefit system is under review. If the benefit you are entitled to is queried by a review body remember to seek advice from a support groups such as the LincsPPN or BPF (address in the back.).

SIMPLICITY

When we stop pushing ourselves and start to slow down, it helps if we simplify our environment. In this way we empower ourselves by taking control of our daily lives and conserving energy. All it takes is some planning and organising plus a little help from friends and family in the first instance. Here are some of the ways you can alter things around the home so that you have energy left to enjoy life!

- Let go of being houseproud - life is not only too short to stuff a mushroom, it is just not long enough to bother with energy sapping activities such as ironing or drying dishes! I leave the dishes to drain and anyone who wants ironed clothes in my house knows to do it themselves! A bit of dust never hurt anyone and there are many more interesting things to do with your time than spend it hoovering all day! If you can afford it get a cleaner in a couple of hours a week to do the heavy cleaning. If money is a problem find out if your local authority can provide you with a home help.
- Plan a housework timetable. I clean the bathroom and the kitchen 2x per week. I reckon these rooms are top priority - the rest gets done 1x per fortnight.
- Make sure cleaning materials are on each floor to avoid going up and down for them. Get a dryer or a couple of clothes horses to eliminate having to hang out washing.
- Get a downstairs loo put in if possible to save trips upstairs.
- Standardise menus and shopping lists as much as possible.
- Always use a trolley when shopping.
- Never lift heavy objects if you can help it. Ask someone and failing that drag or slide the object.
- Use lightweight equipment around the house e.g. hoovers, cooking utensils etc.

- Use long handled tools to avoid bending and stretching.
- Put items frequently used within easy reach to avoid reaching up to a top shelf etc.
- Use devices such as jar openers to conserve energy.
- Work at a comfortable height preferably whilst sitting.
- Tilted desks lessen strain on the upper back.
- Pack a lightweight camping seat to take out with you.
- Raised flower beds and pots can be used for growing flowers and vegetables.
- Use remote controlled devices such as for the TV, and invest in an answer machine to save hurrying to answer the phone! Install several phones all over the house. Get food delivered as much as possible. have an organic vegetable delivery 1x a week.
- Your local health food shop may have details of a similar system. Your local supermarket may also accept orders by phone. Iceland, the frozen food chain, offer a delivery service; 0800 328 0800.
- Use a rucksack to distribute weight more easily.
- Make lists. Short term lists define the goals for today. Put on the top of the list that which really needs to be done. Now cut that list by half by crossing out everything you have classified as non essential!
- Learn to ask for help and learn to say no!
- All of these are ways to make life easier by cutting down on unnecessary expenditure of energy. Boots and the Disabled Living Foundation have created a catalogue "Active and Independent". There are many devices displayed to make life easier. To get a copy phone 0800 371221. For more specialist help e.g. to adapt your bathroom with a raised toilet or bath seat, you need to get a referral to an occupational therapist. He/she can advise you about foot operated taps if your arms are weak, lifting devices to get wheelchairs on and off the roof of the car, aids to help you get in and out of bed etc.

STABILITY

We need to see energy as a bank account - if you keep drawing on your energy without replenishing it you will wind up with an empty account. We need to live lives where we give equal weight to rest and activity for in this way we keep the bank account balanced and in the black. PPS is an opportunity to let go of lifestyles that exhaust us so that we can start to live on more of an even and balanced keel.

Chinese medicine always stresses the importance of a lifestyle that adapts to life's changing circumstances and often refers to the changing seasons as the best teacher on how to "go with the flow". When it is winter we all need to accept a reduction in activity and take more rest, as plant life does, than in the summer when everything grows and flourishes.

With PPS we may have to encourage ourselves to be more often in "winter mode" and take plenty of rest. We need to learn to value this time and see purpose in it. Just as seeds need to be dormant before developing into shoots so the daydreams and reveries of our resting time can allow us to develop helpful insights. In this way we connect with the deep wisdom of our inner selves and build energy so that we can be more active when necessary. Here are some of the ways that we can pace ourselves and lead more harmonious and enjoyable lives.

- Always plan at least 2 rest periods per day. I do meditation, chi-gung and breathing exercises in the morning for an hour and have a one hour nap in the afternoon. Resting must mean a total break from all distraction and noise. I turn off the phone and tell everyone not to play music or disturb me. Call me an old grouch if you like but I know what helps me to feel better!
- Alternate periods of activity with breaks. Break activities up into chunks and do a little at a time. If I work on the word processor for an hour 1 will then take 15 minutes to recover the energy expended.

- "Have to" and "should" need to be used rarely. In this way we cut back on tasks involving duty and increase on the level of pleasure! I now avoid loading myself with situations that I used to push myself through. If they cannot be avoided then I get on with the task in hand but I focus on the fact that this stressful activity will soon be over and meantime it is an opportunity for growth - a chance to practise mindfulness, going with the flow and breathing techniques!
- A stable life is one that has clear boundaries. I have routines that enable me to choose how and when I expend and conserve energy. Sometimes this means that I have to say "no" or "maybe" to friends. I have planned my life to enable me to do the things I want to do, when I want to do them. That may sound selfish but it is actually a matter of survival! If I were to live a life of abandoned spontaneity, I would be exhausted and of no use to myself or anyone else!
- Obviously flexibility is important - there are times when this schedule of rest and activity needs to be interrupted but then I try to make up for unexpected expenditure by having an extra long nap after the event! In this way I am in charge of the bank account and ensure that energy is spent on a) necessary tasks and b) enjoyment. The crucial element here is to have a balance of work and play!
- Ideally an average day in a balanced life needs to be composed of a variety of activities. Many of us will need to continue working but hopefully this will be part time and so there will be a balance of work and play. Some time needs to be spent in pursuit of hobbies and other leisure activities. Creative expression can release frustration and through activities such as painting or writing we can let go of our feelings. We do not need to be experts in these skills - the point is to see them as therapeutic tools. Include time with friends and family sharing how the day/week has been - getting together and connecting with others is an important part of the day. Periods of relaxation are the foundations of a balanced day - we need to be alone with ourselves to contemplate and regenerate. This is the time to do gentle exercise and practise meditation, to take a nap or simply sit in the garden or local park and absorb the pleasures of nature.

Post-Polio References

1. LincsPPN Directory - Disability Living

Motability Roadshow
at the Transport Research Laboratory,
Crowthorne, Berkshire
25th, 26th & 27th June 1999

10.00 am - 6.00 pm Friday & Saturday, 10.00 am - 4.00 pm Sunday

Wide range of adapted vehicles to test drive.
Over 200 exhibitors of outdoor mobility products, advice & information services.
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For further information Free Entry Leaflet, Visitors Guide and Prize Draw contact Mobility Choice on:
Tel: 01344 770946 Fax: 01344 770950 Email: choice@gtnet.gov.uk

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POLIO AS I UNDERSTAND IT

by Jeanne W Houghton, Annandale, Virginia
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Here's my personal polio spiel. Since I learned about anterior horn cells and axon sprouts and god-knows-what-other medical jargon, I've come up with this image. The anterior horn cells are not the posterior ones. They're in FRONT (of the spine), and shaped like HORNS. And they are motor nerve cells, not sensory, so they carry messages about moving, not about feeling. They are what got damaged -- or killed -- when we got polio. The dead ones didn't come alive again, but those remaining managed to recuperate a bit, some more than others. Some anterior horn cells never got damaged at all and kept us going while we had the disease (god bless'em all).

Now I have the image of a long telephone cord -- the nerve cell -- going all the way from my spine to whatever muscle it's supposed to "talk to." At the end of the line there are apparently a number of extension phones (axon sprouts) on the one main line, each with a muscle fiber listening carefully and ready to jump when notified. I think of the muscle fibers as football players energetically jogging in place waiting enthusiastically for a MESSAGE! But the phone line is down, and they get tired of being ready, and they sit down, and over the years they atrophy into next to nothing because nobody ever CALLS! All the football players on the one main line, the one nerve cell, peter out, since none of the extensions works unless the main line works. Meanwhile, they complain, at first, and the neighboring nerve fiber phone line adds a lot more extensions, so the abandoned football players can get a message. The football players never got sick- They just never got a message! Some never did get a new phone extension, and they probably did dry up and disappear. But a lot of those abandoned football player muscle fibers got rehooked. The other phone lines heard them wailing and set about adding extensions to their own main lines, and lo and behold, one main line could get the message, via those extension lines, to triple or quadruple the original number of football players (i.e. muscle fibers). And voila - we became normal again!!!

(Or some of us got to the appearance of normal. Some of us couldn't keep enough phone lines up to keep even the minimal requirement of football players jumping, and those of us, friends, died. Just gotta keep those breathing muscles going one way or another, and god bless the geniuses who invented iron lungs and all the better variations we have now, or a lot of us on this list wouldn't be here to enjoy postpolio syndrome.)

We didn't get "Normal" again, of course. That phone system was never meant to work with so many extensions, and the lines just can't hold up. Actually, I don't think they know whether the problem is at the main switch back in the spine, or along the main line itself, or where the extensions are connected, or where the football players listen in. But in any case we don't have the original communication system and the alterations don't seem to be built to fast a lifetime.

OK, that's my personal metaphor for the first polio recuperation (damaged phone fines repaired themselves, and both they and undamaged ones added new extension lines) and now post polio degeneration. I personally don't think the undamaged phone lines are going to quit on us. I think all that additional overgrowth just can't make it. But no one knows how much tinkering a rested-up, well-paced post polio body can do to keep the old thing going. We're all still practicing!

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