



## THE LINK-PIN

### Lincolnshire's Post-Polio Informative Newsletter No. 3 - January 1997

#### CONTACTS AROUND THE WORLD NOW TO NUMEROUS TO PUT ON THE MAP

#### Important Message to Polio Survivors Reading our Newsletters

We know that reading these articles will bring back memories of the past, for some these are vivid memories and for others they are just total blanks but the emotional feelings could still be there, as in Lyn's article. For those of you who are now finding things more difficult, we know what you are going through. If you like most of us have been doing the rounds of the Hospital Departments and not getting any answers to your problems, until recently thanks to Dr. McClements, then we know how you feel. The support that we have had by talking to other Polio Survivors, in Lincolnshire and around the World, who understand where we are at has been invaluable. Counselling which can be arranged by your GP has been of tremendous help to some. As you read and learn more, you may like us wish you had known more years ago so that you could have made informed decisions about your work and lifestyle. Yes, I know whether we would have taken the advice that was available then is a moot point, but at least it would have been an informed choice. Would you believe the first noted case was 1875?.....

Ours is a self-help group, and any contributions, whether letters, phone calls, articles, hints and tips, recipes, donations, offers to talk to other members in your area, suggestions of other people to write to for help and sponsorship, reading some of the information received and commenting on it, helping with the office work, whatever, will be gratefully received. If you need to talk then contact us, we did, and we still do, we can all help each other.

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



## **Editorial**

Happy New Year to all our Readers. Lots has happened since our last newsletter and lots more in the pipeline.

The meeting on the 11th January went well with seven attending and five apologies. There was a wealth of information available and it was decided that another meeting should be held in a fortnights time so that some of this could be taken home and read in comfort. This will now be on 25th January at 11.00 (coffee and biscuits) and if anyone else would like to join us then please ring and let me know. John Fotherby was voted in as Treasurer and we gained four new committee members but the post of Chairman is still vacant. This need not be a problem as it is quite in order to elect a chairman for each meeting - to take the meeting - and do this in rotation between some members.

Next it is my happy duty to introduce to Chris Salter, a name on the map last time, but now a member and what a member! He is writing an article all about himself and our Web Site on the Internet for the next newsletter.

Chris lives in Penzance in Cornwall and like us had polio and now has PPS. He found us on one of the Post-Polio Mailing Forums and we corresponded by electronic mail. He said that he would like to work with us and offered us space on his Web Site, which we gratefully accepted. He immediately started this and has been working daily on it, and it is very professionally done. Most of our polio members may have little knowledge of the Internet or what a Web Site is, and I will try to put it simply.

The Internet is a service that anyone world wide can join into if you have a computer and a modem - which connects your phone line to Internet Servers. We pay a monthly charge and then time logged on is charged at local call rate on our phone bill. Next a Web Site, well if you think of it like this; all the people that are connected having the opportunity of writing a 'book' about themselves or the work they do. This book is then able to be read page by page on the computer screen, and printed off on your printer by anyone else connected. You will have noticed at the end of TV programs like Tomorrows World it says visit our Site at - <http://www.bbc.co.uk/tw/>. So for the price of local phone calls we are connected to the World. We talk to Doctors, Post-Polio Support Groups, Polio Survivors etc., and can read other peoples books, the list is endless. So we now have our own 'book' Web Site and it is nearly ready for Public Announcement although it will not be finished for some months as we add other articles and our newsletters. If anyone reading this has

More articles have been picked for this issue which we hope will be of interest to you, out of the many hundreds we now hold. Please can I say once again that the more I learn the more I am able to see what I must do to get the most out of life that I can. I can also see that by using the aids and assistive devices, that I will have less pain, put less strain on joints and muscles, and be able to use the energy I have to the best use. Go back to doing some of those things I am missing out on now, get an electric scooter and go back on those country walks with my friends, etc. I am going to succeed and beat this as I did polio, that did not get the better of me and with knowledge this will not either. Evidence shows that you can get 240% more out of each day by using the aids, pacing, resting, etc. Guess what I am going for? Do you want to join me? Read on.



## **NO MEMORY BUT FEAR..... FROM LYN HOBDAY - Lincoln**

Like Shaun (aged two and a half years) I can recall the homecoming!

Let's go back to when I caught polio (then infantile paralysis). I was four years of age. Was misdiagnosed as having rheumatoid arthritis for three weeks, then after a visit from a specialist was transferred to an isolation hospital. My parents did not (were not allowed) visits for a full year and then I was transferred to another hospital 50 miles from my home. By this time, two very nice strangers bearing gifts plus hugs and cuddles came once a month. After almost four years, I was sent home because I could walk on calipers and because it was August 1939 and the country and the hospitals were preparing for War.

Now the strange thing is I have absolutely no recall of the above events. All these details were told to me by my mother and can only be proved by the odd snapshot taken at the time.

I do recall coming to a house I didn't know, to a sister who did not exist when I left and to the nice people who had visited once a month! The horror and the nightmares I had sleeping in my own bedroom ALONE! After four years sleeping in a ward with 20 others, of the constant presence of the night nurse and of the small light always alight on her desk, the feeling of abandonment and fear is my abiding memory.



Lyn took some articles to read and has asked that we include the following excerpt taken from *Post-Polio Syndrome - The Late Effects of Polio*. An Information Booklet by A. Brownstein, et al - Occupational Therapy, McGill University. Edited by Dr. Neil Cashman, Neurologist and Dr. Daria Trojan, Psychiatrist, and the Polio Quebec Association, brought over to England for us with other books and tapes by Sally Aitken of Polio Quebec. Thanks Sally for all your help.

### **MISCONCEPTIONS**

*PPS is the return of Polio?* **False.** There is not return of the virus. In fact there is no evidence for the presence of a live virus.

*PPS is a rapidly progressive disease?* **False.** The progress of PPS is slow and is measured in years to decades, marked with plateau periods where no progression takes place.

*PPS is untreatable?* **False.** The symptoms can be treated by various methods and early treatment may help alleviate future problems.

*PPS is psychomatic?* **False.** PPS is very real and its effects vary from one person to another and symptom relief requires professional intervention.

*Patients with PPS should exercise vigorously to build up and strengthen muscles?* **False.** In fact, vigorous exercise may weaken muscles even more. Low resistance exercises are favoured so as to prevent atrophy of disuse, and increase strength.

Also included was an excellent Monograph of 52 pages called:-

**Current Trends in Post-Poliomyelitis Syndrome** written by **Daria A Trojan, MD, MSc**, Assistant Professor, and **Neil R Cashman, MD**, Associate Professor from the Montreal Neurological Institute and Hospital, McGill University, Montreal, Quebec. Canada. published in 1996 by Milestone Medical Communications, a division of Ruder-Finn, 301 East 57th Street, New York, NY 10022.



## Dr. Henry writes.....

My name is Henry Holland. I am a retired (on disability due to PPS) physician-psychiatrist. I have learned a lot from reading the postings to the Post-Polio Mailing Lists. I have noticed considerable questioning about medical matters in regard to PPS, various pros. and cons. of medications, and a variety of alternative and non-traditional treatments for PPS which may help some but not others. As a physician, I have observed a fair amount of doctor bashing, much of which may be justified. I have decided to begin posting to possibly be of some help to other PPSers and hopefully to provide some medical balance. I will begin by telling you my abbreviated polio history. I had polio at the age of eleven in 1950 in Richmond, Virginia, where I still reside. I had a severe paralytic case involving motor function damage from the neck down, the right side more severe than the left. After a three month hospitalization and a year of intensive exercise and hot bath treatments at home, I recovered enough function to only require a long leg locking brace on my right leg. During my college and medical school years, I could climb flights of steps, one at a time without a railing and alternating with both legs with a railing. I could walk an 18 hole golf course and ride a bicycle. I could pick myself off the ground when I fell. Towards the end of medical school, my main interests were internal medicine and psychiatry because I enjoyed patient contact. My interest in a medical career was a direct result of my polio experience. I should mention that during my adolescent growing years, I developed scoliosis of the spine with the curvature to the right, my weaker side.

During my rotating internship, I contracted a severe case of hospital resistant staph pneumonia, was trached, and almost died. I did recover but my lungs were never the same after that. I decided to do my residency in psychiatry because this speciality was mostly mental, could be practiced sitting down, and involved patient contact. However, I continued my interest in internal medicine, attended medical conferences, read medical and psychiatric journals as well as being on the clinical faculty of the Medical College of Virginia for 27 years. During my residency, I experienced repeated episodes of respiratory failure requiring intubation (just as in 'ER' every week) because my arterial CO<sub>2</sub> would increase during sleep due to exhausted respiratory muscles. In 1970, I agreed to a permanent tracheostomy, managed to get a cumbersome Bennett MA-I ventilator at home and my life almost miraculously turned round. I engaged in an active practice for 20 years until I experienced the first signs of PPS. During those 20 years, like many of you, I was a workaholic, had 12-14 hour days, was a dept. chairman, served on executive committees and taught med students and supervised residents. I loved my work. My wife and I had two children before my permanent trach was done and we had another daughter in 1979. If she had been a boy, we might have named her Bennett because that ventilator had extended my life. In 1990 I began to experience unexplained fatigue. I had numerous tests with no new findings. A lady at my church had heard about PPS and told me about a support group that met in Richmond. I went to my first meeting in 1991 and the first meeting was an amazing insight and I discovered an explanation for my problem when I heard the experiences of the other members. I educated my three doctors and they somewhat reluctantly agreed that my fatigue was probably somehow related to PPS. I cut back my hours, bought a scooter and van with a hoist to carry the scooter, my symptoms of fatigue remitted, and I resumed my workaholic practice for another five years. This past summer, the fatigue returned with intensity and was debilitating. I was hospitalized, had \$8,000 worth of tests in two days and nothing new was found. My doctors (the same ones as before) now believed that I had post-polio fatigue. Dr. Richard Bruno's excellent article on [the pathophysiology of central fatigue in PPS](#) was most helpful to these doctors. I have retired on disability and was fairly quickly approved for SSDI. At the worst, the fatigue was so severe that I could not stand, only sit for a few minutes, yet my legs would hold me up and did not feel much weaker motorwise.

I just simply felt like I did not have the energy to walk ten feet. Tom Walter in California has been of immense help to me when I went on-line. The polio chat group on aol, the list services, and my

own local support group have shown me that I am not alone, and that there are numerous polio warriors out there.

I still have my brain and can communicate. Yes, I do have some word finding problems at times. A lot of daily rest has restored some energy to where I can leave the house for a few hours depending on the temperature outside. I am convinced that the original polio infection involved areas of the brain (particularly the Reticular Activating System) in the spinal and bulbar-spinal types that probably went undetected unless the patient died and evidence was found at autopsy. Now this area and probably other areas have worn out, contributing to central fatigue. The theories on motor neuron fatigue and related muscle or joint pain make sense and are more easily accepted in medical centres as being related to PPS. I find that the central fatigue when it is debilitating causes sleep disturbance, a feeling of being constantly tired even when one wakes up and tends to become more severe in the late afternoon. Everyone with PPS has tried to find what works best for them, and there is much variety. I remind myself that the polio virus was very specific in where it did its damage, but no two cases of acute polio were exactly alike. Consequently, although there are many similarities in the symptoms of PPS (that is why it is called a 'syndrome'), the manifestations of PPS are never EXACTLY the same in any two of us. As a result, the medical profession is puzzled as to what to do even when medical people are knowledgeable about PPS. Do you exercise or not? Do you prescribe pain meds and contribute to someone attempting to resume activity and further weaken motor function? Do you prescribe antidepressants since some surveys indicate 1/4 to 1/3rd of PPSers meet the diagnostic criteria for Major Depression? But what dose do you prescribe since most PPSers respond to lower doses if they respond, and it seems most PPSers are more sensitive to side effects than just depressed patients. Is the PPS itself causing a depletion of serotonin and catecholamines leading to biological depression or is the depression simply secondary to the sense of loss of purpose and usefulness that many PPSers experience. I think many of us have used denial and are prone to be so called type A personalities. A better term might be driven obsessive-compulsive overachievers who find it difficult to change and deal with anger. I think PPS has stirred up both our repressed anger (from the past) and allowed our conscious anger about PPS to be felt. I have noticed as a group that most of us are perceptive, but also sensitive to the reactions of others and even project our anger onto others. This usually indicates that the individual is angry with himself or herself. But we also seem to be equally caring, apologetic, and forgiving. We are all in this together. If not for PPS, we would have had no reason to find each other. If there is a blessing in all of this for us, it is that we have rediscovered ourselves and each other through a variety of interpersonal methods. Until 1991, I knew only one other person who showed a residual of polio. Now, I know hundreds, and the potential is thousands. During my professional career, I treated the usual mental disorders that most psychiatrists treat, but I maintained an interest in the emotional problems or defenses of people with chronic medical illnesses (diabetes, colitis, arthritis, chronic pulmonary disease, cerebral palsy, chronic fatigue syndrome, fibromyalgia, etc.) I also tried to stay abreast of psychopharmacology and the interaction of drugs. I have learned a lot about ventilators since I have used one for 27 years. I found that many times the least treatment is the best, especially with the elderly and chronic disorders, but I also believe in relieving pain. I can confess that doctors are fearful of state boards of medicine and their power, fearful of losing their federal narcotic license, and are under scrutiny from review by private insurance companies, Medicare, Medicaid and HMO's (Health Money Organizations --- only joking), who will punish you if you happen to have a 'sick' practice, meaning a lot of patients with chronic disorders.

We often do order unnecessary tests in defensive fear of malpractice claims. It used to be that if something had happened, you could deal with it when you knew that you had done nothing wrong, but now the doctor gets a letter in the mail for his records from a lawyer or a subpoena for records from the court over something that may have happened over a year before. I can tell you that such an event can distract your attention and attitude towards our many grateful patients.

I have said enough, I would like to respond to inquiries about PPS, medications, various treatments, and yes, I am interested in alternative treatments and have tried a few myself. Ironically, the Salk

Vaccine put an abrupt end to all the research on the natural course of polio. Now, we, hopefully, the last polio generation in the USA, will perhaps renew some research and provide answers about the natural course of polio, and hopefully, in time to be of some help to ourselves. I graduated from med school in 1966, and my class did get a one hour lecture on polio, now it is mentioned in much the same way the bubonic plague or leprosy is mentioned. You need to know about it to answer quiz questions, but you do not expect ever to see a case of it.

What I have said in regard to medical and psyche dynamic issues is only my opinion, just that. I have had vast experience as a doctor and a patient. I do not claim to be an expert, I am one of you, but I am willing to be of any help I can.

*Henry Holland, Richmond., Virginia, USA. [Henry4FDR@aol.com](mailto:Henry4FDR@aol.com)*

Dr. Henry will respond to any questions put to him from any Polio Survivor, so ask away.



### **KISSING FROGS BY TANIA IN USA - (Sound familiar?)**

Thanks to this Newsgroup and other Internet resources (I finally self-diagnosed myself as PPS). Been to see my General Practitioner, and she agreed and sent me to a Neurologist. Neurologist, very nice, wanting to learn but less knowledgeable than I am, From there to a Physical Therapist, also nice, but not knowledgeable either, Requested a Physician, got another darling doctor who didn't know much either.

So after kissing all these well meaning frogs.....

I have decided on my own course of action, the least intrusive possible.

Absolutely no pharmaceuticals at this point.

Physical therapy in a WARM pool (we're fortunate to have one in town)

Acupuncture and Chinese herbs, good vitamins and supplements.



### **BOOKS - which may be of interest to you.**

We will add to this list each time. We have copies of both of Granny's out on loan as I type.

By Viola Pahl (alias Granny) Polio at age 22 and 7 months pregnant. Vancouver, Canada.

*Gold in Life's Hourglass* her life story .... is \$4 plus postage (special price)

*Granny's Love Hate Affair with a Computer* is \$7 plus postage (only 300 printed)

By Lavonne Schoneman - author of a series of books on coping with polio and disability from a laypersons view. She wrote LaVonne's Coping Column for Polio Survivors Newsletter of the Pacific Northwest for 5 years (out of print 3 years ago).

HOW TO COPE [1] Practical Tips for Polio Survivors [2] More Practical Tips for Polio Survivors [3] More Choices for Polio Survivors and [4] More Choices for Polio Survivors and Others. The set sells at \$24 plus postage. We will have a set shortly.



### **THE LAUGHTER PAGE - THE BEST MEDICINE AVAILABLE, Take Twice a Day.**

#### **A FEW FACTS ABOUT MEN (With apologies to the chaps)**

1. Men like to barbecue. Men will cook if danger is involved.

2. Men who have pierced ears are better prepared for marriage. They've experienced pain and bought jewellery.
3. All men hate to hear 'We need to talk about our relationship'. These seven words strike fear in the heart of even General Schwartzkopf.
4. Men have higher body temperatures than women. If your heating goes out in winter, I recommend sleeping next to a man. Men are like portable heaters that snore.
5. Most men hate to shop. That's why the men's department is usually two inches from the door.
6. Male menopause is a lot more fun than female menopause. With female menopause you gain weight and get hot flushes. Male menopause - you get to date young girls and drive motorcycles.

A man once counselled his son that if he wanted to live a long life, the secret was to sprinkle a little gunpowder on his cornflakes every morning. The son did this religiously, and he lived to the age of 93. When he died, he left 14 children, 28 grandchildren, 35 great grandchildren, and a 15 foot hole in the wall of the crematorium.

Granny's Favourite - taken from *Granny's Love Hate Affair with a Computer* written by Viola Pahl, Vancouver, [see page 6](#).

Why do they say **Amen** instead of **Awoman**?

Because they sing **hymns** not **hers**.

There are two theories as to how woman came to be.....

1. God made Adam, and woman was just an afterthought.
2. After God made Adam, He took a good look at him and said,  
Wow! I can do better than that.

Sign on Granny's Computer (also on my works Banda machine, purple memories.. 25 years ago)

**ACHTUNG! ALLES LOOKENPEEPERS!** Dies machine is nicht fur gefingerpoken und mitten graben. Ist easy schnappen den springenwerk, blowen-fusen und poppen corken mit spitzensparksen. Iss nicht fur gewerken by dass dummkopfen. Das rubber necken sightsee-ers keepen hands in das pockets - relaxen und wadtchen das blinken lights. (Author unknown)

**Conundrums** - Answers next newsletter - Items wanted for this page please.

What do you go into a shop for, pay for it, but come out without it?

What costs 10p for one, 20p for 10, and 30p for a 100?

What goes up a chimney down but can't go up a chimney down?

What gets wetter as its drying?



## POST-POLIO AND PHYSICAL THERAPY

### Susan L Fish MAPT

During recent years, I have had the opportunity to meet and work with patients experiencing the late effects of polio. Many times I have detected some frustration and anger regarding my professionals lack of experience in treating Post-Polio patients. I write this brief article now for two reasons.

1. to explain and help you understand this lack of knowledge on the part of many of my colleagues.
2. to provide some guidelines regarding Do's and Don'ts when seeking physical therapy.

Most Physical Therapists (PT's) (Physiotherapists in UK) working today weren't even alive during

the major polio epidemics. Their formal education regarding poliomyelitis was more historical than factual, with little more than definitions of pathology and no clinical experience. Post-Polio Syndrome is only recently being recognised and its existence is still questioned in some medical circles. Both acute polio and post polio syndrome present clinical pictures which are unlike any other neuromuscular condition. Without the experience of working with acute polio patients and with little documented information regarding the treatment of Post-Polio Syndrome, it is not surprising to find professionals lacking in knowledge.

Although, there may be reasons for a lack of knowledge, a responsible professional should **NOT** treat any condition that he or she is not confident and knowledgeable in treating. You may be able to direct a PT to appropriate resources. Please see the resources at the end of this article and I would be happy to help also.

Reasons for seeking physical therapy will vary. You may be referred to a PT to help you with your Post-Polio Syndrome. You may be referred for rehabilitation following corrective surgery for a polio related condition. You may also be referred for a condition not necessarily related to polio at all such as arthritis, bursitis, tendonitis, fractures, osteoporosis, low back pain, stiff neck, etc, etc. Your physical therapist is well trained to treat these other conditions. However, your post polio status should be taken into consideration when designing a program. Here is some advice.

### **Do's and Don'ts to keep in mind when going for physical therapy.**

**Do** trust yourself and the knowledge you have gained over the years about your body.

**Do** be willing to alter your lifestyle.

**Do** avoid fatigue.

**Do** get enough rest.

**Do** pace your activities rather than discontinuing them.

**Do** conserve energy. It may make more sense to spread your activities out, allowing for rest periods, rather than eliminating interests and activities.

**Do** recognise that your body is aging and some physical changes will occur which are not related to post-polio. There IS a normal aging process even though post-polio may be a part of it.

**Do** respect your feelings. This may be a difficult adjustment time for you; seeking emotional as well as physical guidance may be a wise thing to consider.

**Don't** follow advice regarding physical exercise if you become fatigued while doing it.

**Don't** become short of breath with exercise.

**Don't** do more than your body feels comfortable doing.

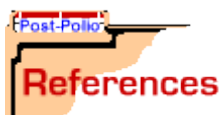
**Don't** cause pain with activity or exercise.

**Don't** gain weight.

**Don't** reject using aids and assisting devices without giving them serious thought. (They are meant to conserve energy and preserve anatomical structures, i.e. joints, muscles, tendons, cartilage and ligaments.) Most are delighted and surprised by the increased endurance and energy they have with the use of canes, wheelchairs, motorised scooters or the many other easily found assisting devices.

### **Resources**

1. Dean, Elizabeth. *Clinical Decision Making in the Management of Late Sequela Poliomyelitis*. Physical Therapy Oct 1991, Vol 71; 10 752 - 761
2. Weiss, Marianne R. *Becoming an intelligent Consumer of Physical Therapy Services*, Polio Network News Winter and Spring 1993, Vol. 9 Nos. 1 and 2.



Lincolnshire Post-Polio Library - [Copy of above article](#) with links to referenced full text and abstracts where available.





# TELLING YOUR FAMILY AND FRIENDS ABOUT PPS

## SONDRA LUCHTS IN AMERICA

I am a psychologist, but even my training does not make this day to day adjustment caused by pps easy - either to accept or to communicate to my husband, family and friends.

I recently gave each of my circle a short article about PPS that began with a concise discussion of the reasons for PPS as we believe them to be and then centered on the subject of fatigue and pacing. I mailed the article to each person with a short handwritten note that simply said:-

I expect that you might have noticed some differences in my behaviour - and maybe even my attitude - so I thought as my friend you deserved to know what is going on. As I change with this devil PPS, sometimes I am angry, lots of time I am embarrassed and sometimes I am just plain sad. This note is a direct result of being afraid that you may think my decreased activity level is because I have become just plain-out lazy. Sometimes I think the same thing. After reading the enclosed article you will know almost as much about PPS as I do and I hope you will ask me about whatever you are curious about just as you would if I had a cold or changed jobs.

Please be forewarned that I am still me and, as you know, that means I still need to know everything, give advice you never knew you wanted, or needed, and think much of life is a huge joke played on us by a giant Snoopy. And, know also that my friends and family continue to be the valued core of meaning in my existence - perhaps even more than ever. And finally, thank you for being my friend.



## EXERCISE - WHAT IS RIGHT FOR YOU.

### Mavis J. Matheson. MD. April 1995.

Many people with a history of polio can improve muscle strength and cardiovascular conditioning with an exercise program [1] [2]. One of the problems that people with Post-Polio Syndrome face is how much exercise they should be doing. We have all been told to conserve our energy. We know that too much exercise will further damage already weak muscles. We also know that if a muscle is not exercised it will loose strength. So what should we be doing.

Determining how much we should do isn't easy. We must learn to recognize fatigue. We must learn which pains mean overworked muscle and which are part of normal aging. We need to pay attention to our bodies and use pain and fatigue as signals. We have to let go of the 'no pain, no gain' philosophy we learned while we were recovering from polio. We must also learn to use how we feel today to assess yesterday's activity and plan for tomorrow. Dr. Agre and Dr. Rogdriquez have shown that polio survivors can assess their own muscle fatigue [3]

The key to exercise for people with Post-Polio Syndrome is to suit the activity to the amount of damage to the muscle. This damage may be a result of the original polio and from post-polio overuse. Different researchers use different methods of determining just how much a muscle or group of muscles is damaged and what exercises are appropriate [1] [4]

After consulting with our doctors to assure ourselves that we don't have some disease process other than PPS causing our problems, we must decide how much to do. What can we do when we don't have a Post-Polio Clinic and physicians willing and able to do four limb EMG's? Without using EMG, we can still look at our histories and we can feel how we are doing now. Using this information we can try to set up or get the physiotherapists (many of whom have little or no

knowledge of post-polio syndrome) to set up appropriate exercise programs for us. I suggest you try to figure out what each of your limbs should do based on your experience with that limb.

For each limb, ask yourself "What is the most severely involved muscle in this limb?" "is that muscle weak?" and "Am I noticing signs of increasing weakness in that muscle?" Increased pain in the muscle, twitching, decrease in quality of movement, being able to walk shorter distances, having more trouble with stairs, more difficulty standing, muscle wasting, difficulty holding your arm up, driving, dressing and tiring with fewer and fewer repetitions during your regular exercise routine are common signs of increased weakness in a muscle or limb. Do you know of any reasons other than PPS why that muscle may be weak? For example has the muscle been immobilised recently?

A limb that does not have any weakness is classed as no clinical polio [1] and you can use it like any normal limb. These are the limbs you can use to get a good workout for your heart and lungs (cardiovascular workout). Be active 3 - 4 times a week for at least 20 minutes getting your heart rate up to 60 - 80% of maximum. You can exercise these limbs like normal limbs. It is also sensible to do gradual exercises to maintain strength and flexibility. If you notice any signs of increasing weakness, you must reevaluate your limb and your exercise program for that limb.

If your muscle is mild to moderately weak but shows no sign of increasing weakness, the limb would be classed as clinically stable polio [1]. You can exercise these muscles with care. They should probably not be significantly fatigued. Try exercising 3 times per week for periods of 10 - 20 minutes with frequent rests. Progressive resistance exercises (also called non fatiguing strengthening exercises) with gradually increasing weights may be used to maintain and possibly gain strength. Monitor yourself carefully while you exercise and if you notice any signs of increasing weakness, you must reevaluate your limb and your exercise program for that limb.

If your muscle is severely weak, the limb is probably appropriately classed as severely atrophic polio [1]. Active exercise of the limb is likely impossible. Passive range of motion exercises may be used to maintain flexibility.

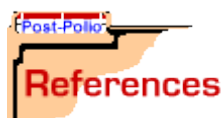
If your muscle is weak and showing increasing weakness, ask yourself, "Am I doing too much or too little?" Unless the limb has been immobilized recently (for example, in a cast or on bed rest) you are probably doing too much. The limb should be classed as having clinically unstable polio [1]. You should try decreasing the amount of activity that limb is doing, use energy conservation, and get your rests. Those are the muscles that are being damaged by overuse. You must not fatigue them. It is probably a good idea to stretch to maintain flexibility and range of motion. If the limb has been getting too little activity, you can try a carefully graduated program of non-fatiguing exercises. Monitor yourself carefully while you exercise and if you notice any signs of increasing weakness, reevaluate your exercise program for that limb.

Whatever your exercise program, continue to make changes to help you conserve energy. Pay attention to fatigue and rest when you are tired (before you are exhausted). If you are overweight you need to lose weight. Dr. Peach and Dr. Olejnik found that patients who successfully control the factors responsible for neuromuscular overuse did not lost muscle strength [5].

## Resources.

1. Gawne AC: *Strategies for Exercise Prescription in Post-Polio Patients*. In Halstead LS, Grimby G (eds). *Post Polio Syndrome* (1995) pp 141 - 164.
2. Fillyaw MS, Badger GJ, Goodwin GD, Bradley WG, Fries TJ, Shukla A: *The effects of Long -Term Non Fatiguing Resistance Exercises in Subjects with Post-Polio Syndrome*. *Orthopedics* (1991) vol. 14: 1253 - 1256
3. Agre JC, Rodriquez AA: *Neuromuscular Function in Polio Survivors*. *Orthopedics* (1991) vol. 14 No. 12: 1243 -1347
4. Feldman RM: *The use of EMG in the differential Diagnosis of muscle weakness in post-polio syndrome*. *Electromyogr. Clin. Neurophysiol.*, (1988) 28: 269 -272.

5. Peach PE, Olejnik S: *Effect of treatment and non-compliance on Post Polio Sequelae*. Orthopedics (1991) vol 14. 1199 - 1203



Lincolnshire Post-Polio Library - [Updated version \(2005\) of above article](#) with links to referenced full text and abstracts where available.



## **USEFUL INFORMATION PAGE. - Disability Resource Centres.**

These can be very useful in getting some idea of what aids and assistive devices are available. Scooters, Wheelchairs, Electric Rise leg raise chairs, and many other items that can make life easier. Two that I have visited and found extremely helpful are:-

**The Mary Marlborough Centre, Nuffield Orthopaedic Centre, Headington, Oxford. OX3 7LD Telephone 01865 227600.**

The Centre used to be a Polio Hospital. For instance the Garden Centre devises many items to cope with individual problems, like one handed secateurs that hold the clipped branch in them, and many have now been marketed for the general public. Well worth ringing to arrange a visit if you are in the area. Referral can be made by your GP for assessment but there is a small fee involved. If you would like any more information then please ring.

**Disability Information Trust, Mary Marlborough Centre, Nuffield Orthopaedic Centre, Headington, Oxford, OX3 7LD. Tel. 01865 227592 or Fax 01865 227596.**

Provides books detailing items that have been assessed. We have three \*\* titles are:-

Wheelchairs, *Outdoor Transport* \*\*, Communication and Access to Computer Technology, Clothing and Dressing, Home Management and Housing, Parents with Disabilities, Personal Care, Gardening, *Furniture* \*\*, Walking Aids, Children with Disabilities, *Hoists Lifts and Transfers* \*\*, Arthritis - an equipment guide, Employment and the Workplace. For more information ring.

### **Doncaster Disability Resource Centre**

Soverign House, Heavens Walk, Doncaster, DN4 5HZ.  
Telephone 01302 769219 and Fax 01302 327778

Here I was able to look at, and try, different scooters and electric rise leg raise chairs. The OT's were extremely helpful, and have sent me further information from other companies. If anyone would like to visit then please ring to make an appointment and for further information on what they have for you to look at.

**Disabled Living Centres, ring 0171 8200567 for your nearest Centre.**

Not visited yet, but will do, nearby Centres in Nottingham, Hull and Leicester.



**Articles for publication by March 11th please.  
Publicity date anticipated about 20th March 1997**

**Bibliography of all articles and newsletters we hold now available please send sae if you want a copy. About six pages of A4. Please remember that we are running on a shoe string whilst we apply for grants. Any donations will be gratefully received.**

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**We are only a phone call, fax or email away and we do want to hear from you.**

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