



# The LincPIN

**The Lincolnshire Post-Polio Information Newsletter  
Volume 1 - Issue No. 12 - August 1998**

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

**Lincolnshire Post-Polio Network**

## Editorial by Hilary Hallam

The AGM is on Saturday 19th September 1998 at Ancaster Day Centre, Boundary Street, Lincoln. The format will be a formal meeting starting at 11.30 am prompt. Followed by a buffet lunch (£2 - booking essential) with plenty of time for meeting others. This will be followed at 2pm by a talk by Dr. Alan Whiteley, Consultant Neurologist at Queens Medical Centre plus others with a refreshment break and plenty of time for Questions. We will have a lot of information available on Post Polio Syndrome. This will include a paper copy of the Lincolnshire Post-Polio Library, plus many other medical articles and books. We will also have videos available for watching in another room.

Going south on the A 1434 - Newark Road - Boundary Street is the last street on the right before the Pedestrian Traffic Lights opposite DC Cook. The Day Centre Entrance is on the left about 30 houses down. It is important that you return the enclosed slip whether or not you are able to join us so that we can ensure that we make a success of our first AGM since receiving Charity status. Thank you for your help in this matter. An Evening Meal is being organised with plenty of choice of menu for those who would like to join us. For those travelling some distance and staying overnight and for anyone else who would like to join us, arrangements will also be made for Sunday for those who would like to have a look round Lincoln's famous Cathedral, Castle and the surrounding area. Please contact us for more information.

The Lincolnshire Post Polio Network has come a long way - especially since becoming a Charity at the end of August 1997 - and we have many plans for the future. To achieve this we need more help from individuals in taking on specific areas of the work, and more financial backing, sponsorship and grants. You do not have to live in Lincoln, or have a computer, to help us. Ruth Bridgens in Avon - diagnosed as non paralytic polio - has offered to become our linchpin for all others so diagnosed. She would like to collate your stories about your polio and problems getting diagnosed now and is collecting and reading many medical articles noting references to this. She will be reporting on her findings in the newsletters. We have already put four others in touch with her. Sylvia Dymond in Hampshire has offered to become the linchpin for those who would like a Polio Pen Pal. Christine Ayre in Lincolnshire, a committee member, has offered to be the linchpin for those using respiratory equipment. Please address all letters to these people c/o of our main address on the back page.

An offer came in today from a member in Yorkshire who has collected many leaflets on disability, disability equipment and services to make a list of what is available and the relevant contact information. MaryAnn in Lincolnshire is reading some polio booklets that have arrived and making notes on important points. There are many tasks to do, if you would like to help then please get in touch.

We reported in the last newsletter that Lynn and I were going to visit the States and Canada. This was an extremely successful trip taken at our own expense with some financial help from family and friends. We have returned with over 25 medical articles to add to the Lincolnshire Post-Polio Library, and promises of more to come. Many that we met agreed that more international attendance at conferences where information can be shared and contacts made will enable more discussion to take place on all the intricacies of the problems that polio survivors are finding in later life. If anyone has any contacts that you feel would be willing to provide financial support to enable us to have representatives at more conferences then please get in touch with us.

May I say that over the last two months I have learned how important pacing and resting and using appropriate aids and assistive devices are to enable you to get more out of life. If you allow yourself 10 energy tokens a day - you can cut them in half and quarters - and write out what you would like to do over the next week or two, you can formulate a plan of how you might achieve this. If you borrow tokens from one day or days, then you must store up extra before and/or pay them back later. It is now over a fortnight since returning from America and despite pacing and resting as much as possible during the trip I am still not back to the level of energy that I had before the trip. My cane, electric scooter, driving an automatic car instead of a manual, downstairs bathroom, night-time - 5mg of amitriptyline, Breathe Right Nasal Strip, neck pillow, window open - and now new and well fitting Canadian made brace for my right leg have made a considerable difference to how I manage my life now. Energy used, must be interspersed with rest, for maximum results.

What follows [after Rolling Along] is a much shortened piece about our recent trip to the States and Canada. It will take us a little longer to write this up completely, including photographs of the many Polio Survivors and Post Polio Specialists that we met en route. This will be available in a couple of weeks and at our AGM on September 19th 1998.



## ROLLING ALONG

Grace R. Young, MA, OTR

Many of us who had polio were pushed to exercise vigorously and discard canes, braces, and wheelchairs as quickly as possible. The primary goal was to become "normal" and this meant casting off equipment and doing everything other people did. To us and our families, continuing to use equipment meant that we had not been "cured". Therefore, it is not surprising that we feel a sense of failure if we have to start using wheelchairs or scooters or return to the equipment we left behind many years ago.

Two social workers who are also polio survivors have written about the positive benefits from seeing oneself as disabled ([see reference](#)). These include:

1. allowing yourself to be pleased with whatever you have accomplished.
2. allowing yourself to join support groups which provide an emotional environment for the expression of the painful feelings which accompany physical loss.
3. letting yourself discard the false pride which has prevented you from using equipment which would help you meet the demands of life.

Canes or crutches may suit your needs when you're at home or need to ambulate very short distances. However, using a wheelchair or electric scooter for longer distances or in challenging situations may actually prolong your ability to walk by preventing overuse of your legs. And there are other advantages to using wheelchairs or electric scooters instead of canes and crutches.

Long-term use of crutches or canes can cause secondary complications such as compression of nerves in the neck area (thoracic outlet syndrome) or wrist (carpal tunnel syndrome), which can cause pain and numbness in the arm and hand and eventually affect function in the upper extremity.

Continuous use of crutches or canes can cause gradual weakening of shoulder and arm muscles,

even if these areas did not appear to be affected during the initial attack of polio. Remember that some muscles may have suffered subclinical damage - that is, some motor units were lost during the acute attack but not enough to be obvious during normal usage. The use of canes or crutches over a long period of time can overwork the remaining motor units.

And last - but not least - ambulating uses a tremendous amount of energy when you have considerable weakness in your leg muscles.

### MANUAL WHEELCHAIR VS. ELECTRIC WHEELCHAIR VS. MOTORIZED CART (electric scooter)

The main advantage to a manual wheelchair is its portability. It folds easily and comes as light as 27 lbs., which is too heavy for most polio survivors but could be lifted easily by a non-disabled companion. It fits into most automobile trunks.

The main disadvantage is that long-term pushing may lead to the same problems as using canes and crutches - pain and increasing weakness of the shoulder muscles. Nothing is gained if you conserve your legs but overwork your arms.

There are many factors to consider when deciding between a scooter and an electric wheelchair. Either one is an expensive purchase, so you need to anticipate what your physical condition will be like in the future.

Using an electric cart requires enough leg and trunk strength to transfer on and off the seat. It entails adequate trunk balance and upper extremity strength and endurance as you need to reach forward and maintain a grip on the tiller, which can be fatiguing to the hands and shoulders. If you are experiencing increasing weakness in your shoulders, hands, or upper body muscles, consider whether an electric wheelchair will fit your future needs better than an electric scooter. Electric mobility aids do present a transportation problem. There are many types of lifts available for vehicles, and you need to seek input from a physical or occupational therapist who is experienced with this type of equipment. The main thing to look for in a lift is: can you get the wheelchair or scooter in and out of the vehicle independently and without physical stress.

Reference: Carsey, C. and J. Tepley. 1986. Facing disability. Rehab. Gazette, 27:6-7.

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WebSite <http://www.reocities.com/HotSprings/4713/>

See also the Lincolnshire Post-Polio Library catalogue entry for [Young, Grace R., MA, OTR](#)



## HILS AND LYNN'S TRIP TO THE STATES AND CANADA

Lynn Singleton (a member and Polio Survivor from East Sussex) and I met for the first time at the [Virgin Atlantic](#) Check In Desk at Heathrow Airport on the afternoon of the 30th June 1998. Up to then we had only talked on the phone and corresponded by email. We were primarily going to attend the [Ontario March of Dimes](#) Conference - PPS Solutions for the Future in Toronto. Flying by Virgin Atlantic Jumbo Jet landing at Newark Airport, New Jersey and then hired a car - a Chevrolet Monte Carlo with hand controls fitted free - from [Alamo](#) and drove to and from Newark staying with many of the Polio Survivors and PPS Specialists that we had met on the Internet en route.

Our arrival in the States was just before a massive thunderstorm and we waited inside the building for Chris and her mum Pat Morgan [<THATS-PAT@WEBTV.NET>](mailto:THATS-PAT@WEBTV.NET) to pick us up. We stayed the night with them and next day Chris took us to the Airport so that Pat could fly home to Florida and we could pick up our hire car at Alamo. She led us out onto the Interstate 95 and we were on our way south. First we stopped at Mobility Plus in Highstown New Jersey to pick up the electric

scooter that I had to hire (my own would not fit in the boot of a car) and were soon on the road again to Baltimore in Maryland where we stayed with friends of Hilarys. Brooke Tuft <[BETuft@AOL.COM](mailto:BEtuft@AOL.COM)> called after work the next morning to join us for breakfast. We then drove on via the south of Washington DC to pick up Sheila Tohn <[OldNurse@aol.com](mailto:OldNurse@aol.com)> who was joining us for the next part of our trip. We arrived in Richmond Virginia where we were royally looked after by [Dr. Henry Holland](#) and his wife Brenda <[Henry4FDR@aol.com](mailto:Henry4FDR@aol.com)>. At a cookout the following day on 3rd July we met many of the [Central Virginia Post-Polio Support Group](#) including Linda VanAken <[DVanAken@aol.com](mailto:DVanAken@aol.com)>. Linda Myers <[myersl@POP.EROLS.COM](mailto:myersl@POP.EROLS.COM)> and Phillip Thetford <[Phillipwt@aol.com](mailto:Phillipwt@aol.com)> plus guitar also joined us and met this group for the first time.

The following day we were taken for a tour round Old Richmond - including seeing the hospital that Dr. Henry was in when he had Polio - and that evening to the 4th July celebrations. We were asked if we minded going and were a little perplexed but the comment 'Well we did beat you' brought much laughter. The music of the 1812, the bells of the carillon in the War Memorial Tower, the Canon fire and the massive firework display at Dogwood Dell were thoroughly enjoyed. The next day we set off for Manassas and the home of Linda Myers where we rested prior to driving to Washington DC for dinner with [Dr. Halstead](#) and his wife Jessica Scheer. Dr. Halstead told us all about how he started learning about PPS, and the conferences he has organised and attended over the years. A very enjoyable and informative time, plus we were able to pick up - hot from the press - some copies of *Managing Post Polio Syndrome* which he has just edited. (See back page for more information.)

We drove back to Manassas for the night and left early the next day for Dayton in Pennsylvania. The home of The Rev's Karen and Gary Utz of the United Methodist Church. Karen <[popette@client.alltel.net](mailto:popette@client.alltel.net)> explained that we had been pronouncing it wrong it is Pope ette and not pop ette. Nancy E <[lynlee@CSONLINE.NET](mailto:lynlee@CSONLINE.NET)> drove 65 miles south from near Franklin to meet us... and we had a delightful time chatting and being driven round the local area to see the Amish Farms and people.

On Wednesday we left for Canada... driving towards Buffalo we were told under no circumstances go on the Interstate through it but to take the road round. However, hearing on the radio that the road round was blocked we turned off and found ourselves driving through Buffalo amidst all the road works and in a torrential rain storm. We could barely see where we were going at one stage the rain was so heavy. Slightly unsure of exactly which bit of the I190 we were on we asked at the toll to this bridge "Where does this road go?" The reply was "To Canada" so on we drove finding out that it was not the bridge we had intended to use but Canada we had reached. We drove on in much better weather to London, Ontario and stayed with Margaret Campbell <[at.campbell@SYMPATICO.CA](mailto:at.campbell@SYMPATICO.CA)>, a special needs teacher, for two nights leaving at 3am to get to the Plaza international Hotel in time to go on Barb Dowds - from OMOD - Coach Trip to Niagara Falls. A wonderful sight. We returned to the Hotel, unpacked, washed and changed and went down to the Hospitality suite where we met with many Polio Survivors. Huge hugs for some that we had talked on the Internet for many months.

The Conference lasted over two days and was filled with very interesting and informative talks and workshops by many eminent medical professionals specialising in PPS. [Dr. Neil Cashman](#), [Dr. Mavis Matheson](#) and [Joan Walker PhD](#) - all of whom have articles on our website - were speakers. (Articles in this issue by [Dr. Mavis Matheson](#) and [Karen Kennedy](#), MSW, CSW from [West Park Hospital, PPS Clinic](#) - more next newsletter). The Saturday Night Murder during the evening meal was great fun and much enjoyed, although by this time of the day our polio fogged brains were not much good at working out 'Who did it'. On the Monday we visited the West Park Hospital, Post-Polio Clinic in Toronto. Wendy Malisani <[wmalisani@westpark.org](mailto:wmalisani@westpark.org)> the co-ordinator showed us round and we had a long talk with Karen Kennedy. An excellent facility and we think a blueprint for all holistic PPS assessment clinics. Diane Gaye <[DianeGaye@aol.com](mailto:DianeGaye@aol.com)> joined us at the Clinic. She was visiting from France with her husband at another conference in Toronto. We then returned to the Hotel and rested. (Dr. Parker and Wendy Malisani from West Park Hospital and [Dr. Daria Trojan](#)

from Montreal Neuro Inst. will be speaking at the [Internationalen Polio-Kongress](#) in Freidrich-Schiller-Universität Jena, Germany from 30 October - 1 November 1998).

Tuesday saw us driving along the Thousand Island Parkway to Montreal. We crossed the Province Line from Ontario into Quebec and found that all the signs were now only in French. We had to bring our schoolgirl French to the fore. I stayed with Sally Aitken <[aitken@accent.net](mailto:aitken@accent.net)> and Lynn with Alice Westcott. We were driven round Montreal, spent an hour in a Board Room at the Montreal Neurological Institute with Dr. Daria Trojan. She then joined us and other members of Polio Quebec for Lunch. Sally then took us on another tour along a very scenic river route followed by dinner with Audrey. The next day, Thursday July 16th, we drove to Ottawa where much to my astonishment I found myself having an appointment with an orthotist, Martin Kraft - The House of Kraft - organised by Marcia Falconer and three hours later walked away with a brace that fitted me, was very comfortable, and the difference in my walking was so noticeable. Swelling and pain in both legs is now considerably reduced. Much concern was raised at the Conference and by the three orthotists we met about the total inappropriateness of the two braces I had been issued with in this country. Thank you Martin and Marcia for making such a difference to my life.

We had a tour round Ottawa, followed by a wonderful meal and much chat and laughter. The next day we had breakfast with Peter Ellis <[pcellis@sprint.net](mailto:pcellis@sprint.net)>, Barry McMahonn <[mcmahonn@home.com](mailto:mcmahonn@home.com)>, Don and Helene Waddell, Linda and Marcia Falconer <[ddf@sce.carlton.net](mailto:ddf@sce.carlton.net)> then returned home and rested and chatted and that evening went out for our first Chinese Buffet. So much to choose from and for a set price. We left next morning and drove out of Canada at Cornwall and through the States of New York, into Vermont and across Lake Champlain by Ferry. We went on through New Hampshire to Massachusetts, such wonderful scenery. We arrived at six o'clock in Brockton south of Boston where we stayed with Judy and her family <[LadyAmulet@aol.com](mailto:LadyAmulet@aol.com)>. Carol Swedberg-Meyer <[CKSwedberg@aol.com](mailto:CKSwedberg@aol.com)> and her husband visited on Sunday and we chatted for hours.

Monday we drove on through Rhode Island and Connecticut to the Bronx and met with Florence Lunde and her husband <[LUNDEFM@aol.com](mailto:LUNDEFM@aol.com)> for a couple of hours and then drove very slowly in heavy traffic towards and across the George Washington Bridge into New Jersey. We made for the Airport and a hotel where we put our feet up, had a good nights sleep and sorted out our things for the journey home. We talked on the phone with Chava Willig Levy <[primerib@ibm.net](mailto:primerib@ibm.net)> as we were out of energy by this time and at the end of 2,700 miles we felt that to attempt the Manhattan traffic on our last day was not a good idea. My hired scooter was collected from the Ramada Hotel by Mobility Plus, for which I am most grateful in view of the fact that the owners Bob Wynn and his wife lost their home a few hours earlier by fire. We returned the car to Alamo... and were taken across to the Departure Lounge where we waited for our overnight flight by Virgin Atlantic to Heathrow Airport.

We returned with over 25 new medical articles for our WebSite - and promises of more to come, with many wonderful memories of meeting many very special people. Learning so much more about PPS by talking with Polio Survivors and PPS specialists. It was a privilege to meet you all, and we thank all of you for your graciws generosity and hospitality.

Hilary <[linpolio@legend.co.uk](mailto:linpolio@legend.co.uk)> and Lynn <[lynn.singleton@virgin.net](mailto:lynn.singleton@virgin.net)>



Elizabeth Lounsbury, Chair of the PPS Committee Ontario March of Dimes, writes.....

I am honoured to have been asked to write an article for the Lincolnshire Newsletter. I am the Chair of the [Ontario March of Dimes](#) Post-Polio Committee. Our organization has it roots in polio. In 1951 it was founded to help polio victims and their families. With the advent of the vaccine and

polio under control we changed our mandate to help find independence for Adults with physical disabilities. In 1985 we established our Post-Polio Program and have been working to educate survivors and professionals. March of Dimes currently has a polio registry of 4800 people that have had polio in Ontario and 1350 interested Health professionals. This registry continues to grow weekly. On an average we mail out seven packages of information weekly to new registrants and Doctors to all corners of the world.

One of the most important things that we do for people contending with Post-Polio problems is hold bi-yearly Post-Polio Conferences. The latest, "Solutions for the Future," was held last month in Toronto. There I met so many wonderful people from all over the world. I became reacquainted with Hilary Hallam, and met Lynn Singleton from Sussex. Both these ladies and I had previously known as Cyberfriends on the Internet. The most important thing we all did at the conference was meet new people, wonderful people all fighting the same battle. No one that attended need ever feel alone again. Many people that had been in complete denial felt so comfortable being with so many others in the same boat that they were finally able to realize that they are in trouble and have to start looking after themselves. Registrants had the opportunity to try out assistive devices such as scooters and realized 'hey this isn't so bad.'

The conference featured such doctors as Dr. Mavis Matheson who spoke on Aging with Post-Polio, and Dr. Cashman. Dr. Cashman spoke on the research into the fatigue medication Mestinon. He stressed that the research was not complete and in fact had not been done properly. The most interesting fact was that at the end of the trials many people decided to stay on Mestinon. People don't take medicine unless it does help. Obviously there are more studies needing to be done. Dr. Vanderlinden, a prominent neurosurgeon, spoke about the options for pain relief in PPS. He discussed medications, nerve stimulation and surgical procedures.

The proceeding will soon be available for ordering from our Head Office. To order your copy e-mail Kim Sialtsis at [ksialtsis@dimes.on.ca](mailto:ksialtsis@dimes.on.ca). This e-mail address will not be working until the end of August. In the meantime anyone is welcome to e-mail me at [loonie@ican.net](mailto:loonie@ican.net). The cost of the proceedings is Cnd \$28.00. I look forward to hearing from all of you that attended the conference and all of you that didn't.



## Permission Giving: Emotional Adjustments and the Late Effects of Polio

Karen Kennedy, MSW CSW, [West Park Hospital](#), Toronto

All of us have encountered situations in life where we have had to seek permission from another person or group in order to complete the task at hand. If that permission is not forthcoming, our efforts may be thwarted and the task halted. In consulting my Collins Gem dictionary, I discover that the word *permission* means authorization, which in turn means to empower, permit or sanction. The word *giving* means elasticity and yielding. The word *give* means to bestow or confer ownership. The task at hand is the ongoing adjustment to life with new fatigue, pain, weakness and general changes in physical and emotional tolerance caused by the late effects of polio.

The ideas of permission giving and adjustments are inseparable. I would like to suggest that the idea of personal emotional permission giving is central to the discussion of adjustment to living with the late effects of polio. The emotional permission giver controls the answer. There will be times when the permission giver may not see the need or may refuse to see the need to give permission - permission to acknowledge reality and initiate purposeful change in order to manage the late effects, instead of being managed by them.

Many of you who live with the late effects of polio, have achieved greatly, worked very hard and sometimes pushed past your pain and physical challenges to accomplish your goals in life. Some of

you have focused your energies on caring for the needs of others, possibly to the exclusion of your own need to set limits. While the discipline, dedication and determination involved, all represent strength in character, the tendency for some has been to tune out their bodies in order to meet these personal goals.

I come to this discussion of permission giving as someone who has not experienced the polio epidemics. I do not live with the daily challenges associated with new weakness, fatigue and pain. I have not been faced with the lifestyle changes, family adjustments and emotional adaptations that are often required. However, I do come to this discussion, as a health care provider who has had the privilege of listening to over 800 individuals who do live with these issues. I continue to learn from these relationships while working to provide support, education and resource contacts to those who come through the Post-Polio Clinic at West Park Hospital.

## The Polio Experience

Rehabilitation medicine became an emerging speciality in the 1940's and 1950's. The polio epidemics of the 30's and 40's challenged the field to expand in order to meet the urgent needs of the polio population at that time. As a result, polio rehabilitation focused on physical recovery with great value being placed on physical exercise and therapy.

Unlike most other neurological diseases, it was possible to replace weakness with strength and build strong limbs. Along with the sense of mastery and control that exercise afforded, was the notion that if one worked hard enough, they could accomplish almost anything. The tendency was to push one's body when there was pain, when the muscles said "No" and when other individuals may have rested. [[\*L.S. Halstead 1\*](#)]

The field of polio rehabilitation did not adequately address the childhood emotional impact of long term hospitalization, separation from family and sometimes invasive treatment experiences. The limited knowledge of polio's late effects and the personal/societal expectations for recovery did not always encourage the expression of feelings. Also, most of you were very young children when you contracted polio and, understandably, your families worked to help you adapt and move on with life.

In the ensuing years, North American society in general wrote polio off as being virtually non-existent until the 80's when research began into the late effects of polio. As a result, many people have been misdiagnosed over the years. Some of you have felt misunderstood and somewhat isolated in relation to your polio experience and have not been accustomed to, nor encouraged to express your polio related needs.

It stands to reason that one's approach to life in general would be affected in some way by certain aspects of the "polio journey". No two life experiences will be the same. Some of you have adjusted all along to visible effects from your childhood polio, while others are just now being faced with new uncharacteristic weakness, fatigue or pain. No matter the experience, the desire to "fight the opponent", is a strong motivator and poses genuine conflict when the body begins to protest the fight. Fighting against the symptoms only tends to intensify them. Previous ways of coping may no longer be the method of choice. This implies the need for change. If the internal permission is lacking or non-existent, adjustment will be more difficult for you and those close to you.

## Permission To Do What?

Many of the following suggestions are a compilation of the insights shared at the Family and Post Polio Syndrome Workshop sponsored by the Post Polio Clinic at West Park Hospital in June 1994.

1. **Make Changes:** Give yourself permission to make changes. Acknowledge your new limitations and adjust your expectations of self. Consider how altering your lifestyle can help you maintain your independence. Conserve your energy by pacing, prioritizing and changing how things are done. Work on receiving new information into your thinking. This may be difficult, as many of you have developed coping approaches which have worked

until recently. Experiment with strategies that work for you and take control. Accept that change is a process that takes time and effort. In your time, allow yourself to feel the loss associated with these changes and explore new interests and roles.

2. **Set Limits:** Dr. Margaret Backman, a psychologist in New York, has considerable experience in working with individuals who live with polio. In her article *Managing Your Needs in Relationships*, [2] Dr. Backman discusses the importance of being an active participant in managing your own needs. She suggests that learning to set limits is key. Learn how and when to ask for help and how and when not to give help. This involves becoming more aware of automatic patterns and finding constructive ways to change them. It is most important to integrate this approach into your lifestyle before your symptoms demand it.

Communication about the reason for limit setting is essential. Families and others can misinterpret this move as being laziness or depression related. The people around you need to be informed so that effective limit setting can take place.

3. **Ask for Help:** Remind people if they need prompting. Don't expect others to always remember or anticipate your needs. [1] Learning to ask for help is seen by some as demeaning and is one of the most difficult tasks in adjustment. Most of you have coped independently for years and are not used to seeking assistance. This often means that roles in families and relationships change and requires a solid commitment to communication and problem solving. Be sensitive to the needs of others in this process. Allow others the joy of helping and learn to graciously receive that help. Work on acknowledging the efforts made by others without feeling guilty or inadequate. During this process, try to focus on what you can do and take pride in your present abilities.
4. **Express And Be Heard:** Openly express your needs, preferences and feelings. This may seem unrealistic for people who are not accustomed to communicating this way. It may start with you seeking out more education or information or asking questions.

### Outcome Of Withholding Permission.

In listening to people, I hear that pride, fear of the future, insecurity in relationships, refusal to accept reality and refusal to give up are some of the blocks that stop people from allowing themselves permission to make needed changes.

Are you noticing any of the following experiences in your own life? Are any of these possibly related to resisting the need to give yourself permission to adjust? (Some experiences listed will be related to other causes.)

- Increased frustration, anger and irritability
- Increased pain and fatigue
- Stressed relationships
- Frustrated family members who are standing by willing to assist
- Increased difficulty accepting suggestions or new ideas for coping
- Energy wasted on fighting the symptoms instead of channelling energy to adapt and take back control
- Fighting against the symptoms tends to increase their impact instead of lessening them
- A survival mentality where there is no reserve energy left at the end of the day for leisure or life
- Decreased social involvement due to fatigue levels and a private approach to the polio issues.

### Support for Change.

Reality is, that if you do not have the supports you need to assist you in this change process, you may need to consider how it can be developed. I often ask people to look at their situation and

identify the existing sources of support that need nurturing, along with new potential avenues for support. Support for change is often nearby if we would recognize it and call upon it. I have singled out four avenues for support, recognizing that you will have your own individual experience of each.

1. **Family and Friends:** Family members and close friends can often provide constructive support and encouragement. The capacity of family members to provide support will vary depending upon how you communicate with each other, the type of relationship you have shared over the years, the level of understanding and acceptance of your polio concerns, and where they live in relation to you. These people can assist to the extent that you are open to explain and speak out your needs.

People often comment on how hard it is for them to accept offers of help from those dear to them. If you have been the caregiver/helper/doer in the family, the idea of delegating more to children or your mate may feel awkward and unnatural both to you and to them. Role adjustments usually happen gradually and it is important not to lose sight of your individual strengths and personhood during this ongoing adjustment.

I would recommend a helpful article entitled *Psychological Issues and Family Relations in Post Polio Survivors* by Dr.s Susan and David O'Grady [3]. The article summarizes a series of family workshops, focusing on how polio survivors can better communicate to their partners and family, what the polio experience is like for them and how partners and family can communicate to the polio survivor what their own experience is like.

2. **Support Groups and Newsletters:** I have observed the role that Ontario March of Dimes, post-polio support groups, conferences and newsletters can play in helping people receive the permission they need to look at their own needs and make necessary changes. The sense of group identity and camaraderie are helpful in adjusting and continuing constructive change. The West Park Clinic strongly believes in the importance of these types of supports and each person through the clinic who is not already registered with the Ontario March of Dimes, is provided with a registration form and information about the support group nearest them.

*(Editors Note. we are in touch with or aware of many support groups or polio survivors around the World. Please contact us for more information.)*

Support groups and newsletters are very helpful in offering informational support as well as emotional support. Being informed is essential in order to have a sense of control in our lives. Many individuals come from experiences where polio information and education has been either nonexistent or inaccurate. So appropriate, credible polio education is a necessary component in giving and receiving support. Community education and information sharing are also effective ways that these groups can assist in developing broader avenues of support for change.

3. **Medical Services:** The health care system is gradually becoming more informed about polio and the late effects, but there is still a large need for increased education. I have met many individuals who are assisting their family practitioners or health care providers by providing them with current articles and research. If you would like a polio information package forwarded to your physician, contact the Ontario March of Dimes Post-Polio Coordinator at 416-425-3463 ext 213 or [omod@inforamp.net](mailto:omod@inforamp.net). (UK - check our WebSite directory or contact the LincsPPN on 01522 888601 or email [info@lincolnshirepostpolio.org.uk](mailto:info@lincolnshirepostpolio.org.uk))

The West Park Hospital Post Polio Clinic is available to Ontario residents (and others now - contact the Clinic for information) and provides a multi-disciplinary team assessment with a physiatrist (physician specialising in rehabilitation medicine), physiotherapist, occupational therapist and social worker. Letters are then sent to the individual and their referring physician, outlining individualised treatment approaches, personal exercise programs,

appropriate adaptive equipment suggestions, and referral or linkage to community resources. If you would like further information, you can link in with the West Park Hospital, Post-Polio Clinic web page at [www.westpark.org/primary/postpolio.html](http://www.westpark.org/primary/postpolio.html)

4. **Community Resources:** It is important to be aware of the services within your community that may provide the type of supports you might be lacking. Consider the areas of support that could simplify your life. What areas can you delegate to others thus freeing up energies for activities that are important to you? Most communities throughout Ontario have a Community Information Centre. These Centres will link you to local, community based agencies that may provide the type of service you are looking for. If you are unable to locate your local centre, call the Province of Ontario information line at 416-326-1234 and ask for the Community Information Centre in your area. If you live in the 613 area code you would call the Ottawa office at 613-238-3630.

The aim of permission giving is to take control over the symptoms caused by the late effects of polio in order to make the needed adjustments. You know yourself and your needs the best.

### Lets Take Stock

In conclusion I have listed a few questions that you might want to consider at this point.

1. Has your earlier life experience with polio affected how you approach your present situation? If so, how?
2. In what areas of permission giving are you strong? What areas need attention?
3. Are there signals in your own life or the life of your family that indicate the need for further adjustment?
4. Are there areas where you need further support? Do you know where to find that support, help or information?

I have met many people who have given themselves permission to step into the control seat of their changing health by creatively adjusting their thinking and lifestyle. I know that many of you have been experimenting with these or similar ideas for years. I respect your 'journey' and want to encourage you on your way. As you nurture humour and laughter in your life, you will find the increase perspective and refreshment needed for adjustment

Karen Kennedy, MSW, CSW. Post Polio Clinic. West Park Hospital, Toronto, Canada.

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I would like to hear from others who use or may need to use respiratory equipment.

My respirator has allowed me to do so much more. I hope you like the following story, and would love to hear yours.

## Sweet Dreams

What blissful sleep I have now I have a ventilator, but not so other people. I was greeted at breakfast by my husband this morning with, "How the hell you sleep with all that noise from that machine I will never know". In fact the noise coming from my room in the night must have woken the population of the surrounding Villages, I was told. I must admit I was aware of some noise, but I was dreaming it was someone else making the noise, and I was advising them how to stop making such an awful racket. Such nice sleep on a vent, but when the mask is not tight to the face, one tends to get whistling, and hissing noises, couple that with the snores coming from under the duvet. I had better explain. Well, 'Ben' my Boxer Dog gets so cold in the night he has to get in bed with his Mummy. Not much room in a single bed for him and me but we do manage. He does snore and woof in his dreams, but I do that also, we make a good pair.

I was also told what I looked like while all this noise was going on, lying in my bed with my mask on, and whistling, snorting, blowing, and woofing, with a death grip on the duvet [continental quilt] (how do I do that when I'm asleep?) or else 'Ben' pulls it off. There were four dogs legs sticking out of the side of the bed. With me and a big dog in a single bed something has to hang out. We take it in turns to hang out. How did we both stay in bed fast asleep until nine forty-five was another question?

I must admit Ben as a bed partner has good, and bad sides. On the plus side, is the warmth and softness of him, better than an electric blanket, and also the fact that he is always alert, and listening for the odd noise, or burglar. I know he is alert as when he hears a strange noise he leaves the bed at ninety miles an hour, taking the duvet with him. A definite minus is that he always gets into bed with an assortment of toys, slippers, empty crisp packets, just about anything he can lay his paws on. I think it is a sort of offering for me, payment for getting in my bed. Another minus is when he rolls on his back under the duvet and sticks his legs in the air - all the cold floods into the bed and it's just like being in a tent.

So if you are within a five mile radius of my house any night, don't be disturbed by the woofing, snorting, whistling, and snoring. It's only me and Ben enjoying a peaceful nights sleep.



## AGING WITH POST-POLIO

Dr. Mavis Matheson

[Cartoons shown]

### Aging interventions

Anthropologist Ashley Montague once said "The idea is to die young as late as possible." [*What you really need is a back-up body*] Unfortunately, we don't have back-up bodies. In order to feel young, we must adapt to the changes in our lives. Today, I'd Like to talk to you about making life changes in general and to suggest some options for change in the five areas that are the most effective with the least risk. These areas are, relaxation, nutrition, values and goals, communication and appropriate exercise.

### Making life changes

How often have you said to yourself - "I really should eat better, I need to learn to relax, or I would love to be able to communicate better" and how often have you not made any changes. If you are like most people, you lost count a long time ago. You may even have lost confidence in your ability to make changes. You can make lasting changes. To do so, you need to consider your options, set goals to get started and evaluate your progress.

Before you plan specific changes, figure out why you might want to change an old behavior or add a new behavior. If you want to build relationships, maybe looking better is not as important as

improving your communication skills. What is the best way to get what you really want? Don't base major life changes on the latest self-improvement trend, magazine article, or TV ad. You wouldn't buy a used car from the first salesman you met. Why would you take health care advice from somebody trying to sell you something? Don't rely on individual testimonials. (If you only hear from the guy who wins the lottery, you may believe that a \$1 investment will always get you a million!)

Do your research. Keeping an open mind is a virtue - but as the space engineer James Oberg once said - "not so open that your brains fall out" [*The sign says "Ye Olde wishing well"*] Does a suggestion seem to be reasonable? If it seems too good to be true, chances are it is. Have studies been done? What actually works? Has it been tried with people like you? (If your nerves are burning out, a vigorous exercise program is not for you, no matter how much good it did those university age students.) Let someone else take the risk and find out what doesn't work. Check your "downside risk" before making a change. What are the costs in terms of side effects, money, time and energy? What is the least stressful way to make the improvement you have chosen? The greater the risk to you, the more evidence you need that an intervention is likely to work.

Set goals for change based on what you want out of your life. Your goals should be specific, measurable, realistic, and truthful. Make very specific changes one at a time. What? How? Where? and When? do you want to make this change. Set a definite time and place to get started. To see if you goals are measurable, ask yourself "How will I know if I have succeeded?"

Be realistic, bring modifications into your life gradually. Your body is a wonderful, complex, living system with many checks and balances. Radical changes beget unexpected adaptations. (If you decrease your caloric intake too rapidly, your body will decide you are starving. Your metabolism will slow down. You will burn fewer calories. Not only will this diet not work, but future diets will be less effective!) Keep changes small. Turn one large change into a bunch of small changes.

Be Truthful with yourself about your commitment to this change. Rats live much longer (2 or 3 times normal) on a very low calorie diet (the equivalent of 1000 - 1300 calories a day in humans). On a very low calorie diet, I may or may not live any longer but without the pleasure of food, it will sure seem like it. Ask yourself "Do I want to live with this for the rest of my life?" All change is stressful. Don't waste valuable adaptation energy on something you don't intend to live with for a long time.

Once you have made a change evaluate it regularly. Feel good about what you are doing right. Things won't always go smoothly. [*Monday 8:30 AM: My first attempt to switch Evan to decaf has been a failure.*] Value your accomplishments and appreciate your willingness to try to make changes. If a week goes by and all you have noted are the missed opportunities for change, congratulate yourself on your deepening awareness. Listen to your mind and body. Has the change moved you closer to your goal? No matter how carefully we prepare we will all make mistakes. If something isn't working after 4 months, chances are it is not going to work for you. [*Because I didn't evaluate early, I stayed on a vegetarian diet for 2 years as I became weaker and weaker.*] Learn from the experience, rethink your options and try something else.

When you decide to make your life better, plan your change based on your options. Set a time to make one small, permanent change. Evaluate the change regularly and appreciate the things you are doing right. If it is not working after 4 months rethink your options. "Life is like sex. If it doesn't feel good, you're probably doing it wrong" You can improve your life. Make that change now.

I reviewed many books and articles on aging and Post-polio Syndrome using the criteria I have just discussed. I would love to say that I discovered the magic pill that halts (or better yet reverses) the effects of aging. Unfortunately it just doesn't exist. I was surprised by how many of the medications tried in PPS have been or are being recommended as anti-aging drugs.

Some of the "anti-aging" pills tried and found no better than placebo in Post-Polio Syndrome are Prednisone, Human growth hormone, IGF-1 Insulin-like growth factor (the active agent in Human

Growth Hormone) and Pyridostigmine. Bromocriptine has been somewhat effective in treating fatigue but is only recommended after lifestyle interventions have failed. Large scale testing of Bromocriptine has not yet been done in Post-Polio Syndrome.

What I did find was that the safest and most effective anti-aging interventions will also help with PPS symptoms. They are relaxation, good nutrition, working from your own basic values toward your own goals, improving communication skills and appropriate exercise.

As we go through this handout, mark things you are doing right with a star, options you would consider changing with a check mark. Later, rank the changes you would like to make and start working on the one that is easiest or most important to you.

## 1. Effective relaxation

I have considered marketing a pill to treat PPS. You would take it after lunch. Then you would have to lie down for 1 hour and relax completely. I am sure it would be a very effective treatment. It wouldn't be better than placebo though.

Polio researcher, Dr. Paul Peach pointed out that "Weakness and fatigue are the body's way of telling polio survivors to rest." Drs. Bruno and Frick of the Kessler Institute found that polio survivors who comply with treatment-pace activities, conserve energy, take two 15 minute rest breaks a day, and use assistive devices (a brace, cane, crutches, wheelchair or scooter) have up to 22 percent less pain, weakness and fatigue 18 months after therapy ends.

To treat your fatigue, you need to take time to rest. Nap (if possible) during the day, work fewer hours, and take longer vacations. Rest is the best known treatment for joint and muscle pain. Relaxation is the classic treatment for stress. Using biofeedback techniques, you may learn to control the temperature of your extremities with focused meditation. Learning better breathing techniques may even help with respiratory insufficiency.

The risks of relaxation are very small. There are no known side effects. It is free or at most the cost of a relaxation tape. It requires a relatively small amount of your time each day. If done correctly, it should give you more energy. This really does sound like the magic pill!

Specifically you need to learn a range of conscious relaxation techniques. There are many ways to achieve deep relaxation but the common ground is slow, full, relaxed breathing, conscious relaxing of the muscles and focusing of the mind on one specific thing so that thoughts and emotions become quieter and less distracting.

Ideally you should learn at least one 20 minute relaxation technique, one 5 minute relaxation technique and one 1 minute relaxation technique. Once you master these relaxation techniques you can learn to recognize difficult, high stress situations and use relaxation techniques to help you to perform better. Use relaxation over the long haul to lower your day-to-day stress level and increase your awareness of your body and your emotions. Your physical and emotional pain is information essential to your health and well-being. Pain is a language, learn to understand it.

Another way to increase relaxation is to incorporate relaxing behaviors into your life. Behaviors like laughter can be very relaxing. It was a seventeenth-century British physician who said "The arrival of a good clown into a village does more for its health than 20 asses laden with drugs." Norman Cousins discovered that ten minutes of the Marx Brothers could reduce tension for as long as 45 minutes.

Dr. William Fry, a Stanford University researcher, conducted studies during the seventies and eighties. He showed that both heart-beat and blood-pressure increase during "mirthful behavior"; (that is, chuckling as well as laughter). After this "excitement phase", a "relaxation phase" sets in. In the case of blood pressure, for example, immediately following laughter both systolic and diastolic pressures return to "lower" levels than the original resting levels before the onset of laughter. He found there is a correlation between degree of relaxation and the intensity and duration of the

laughter (with or without actual delight or entertainment), which demonstrates that the action rather than the mood is responsible for the shift. Forced laughter has the same benefit as real laughter. I need not emphasize the importance of laughing loudly at cartoons whether you think they are funny or not. *[I believe in the healing power of laughter, Doc, but if you try to tickle me again I'm going to belt you.]*

Sleep is an excellent form of relaxation. If you find you fall asleep when you try to do relaxation exercises, it is probably your body telling you just how tired you really are. Music soothes the savage breast. "The Mozart Connection" by Campbell looks at the use of music for relaxation. *[The good news is you have a song in your heart.]* Massage (will be discussed in the healing touch workshop). It is one of the cornerstones of some Post-polio programs. Be careful not to wear yourself out getting to the massage session. Hot tub, hot bath, and whirl pool baths are another very good way to relax. I like the relaxation of a dinner out. I also find listening to tapes very relaxing. I prefer murder mysteries. Loving is an excellent way to relax. It can be anything from petting your cat to hugging to sex. As Richard Bruno suggests, "Turn off your thoughts, turn on your body and JUST DO IT!" Do whatever works for you. *[I'm not pointing any fingers, but all our bubble wrap has been stolen again.]* The important thing is not the behavior itself, but that you find it relaxing and give yourself permission to do it more often.

The reason I have put relaxation first and spent the most time on it is, "When you are up to your ass in alligators it is hard to focus on draining the swamp." In stressful situations like the changes of PPS, blood flows away from the areas of the brain responsible for problem solving and information processing, impairing these faculties. Because of increased adrenaline flow, you will start to have trouble concentrating and difficulty staying still. This doesn't leave you in very good shape to learn new skills or identify your values but you can still learn relaxation techniques.

## 2. Nutrition and Vitamin-mineral supplement

Last October, Dr. Susan Creange, a research fellow at the Post-Polio Institute at Englewood (New Jersey) presented a study of diet in polio survivors. Dr. Creange found that, "Polio survivors often have a 'Type A diet': drinking three cups of coffee for breakfast, not having lunch and eating cold pizza for dinner. When they put polio survivors on a hypoglycemia diet, that requires eating protein at breakfast and small, non-carbohydrate snacks throughout the day, they had a remarkable reduction in nearly all symptoms of post-polio fatigue."

Your body's energy comes from the food you eat, so you want to make sure your food intake is nutritious. Too much weight aggravates stress on joints and muscles and increases pain. *[I see you're developing a hazardous waist.]* Difficulty swallowing may influence the way your food is prepared but makes it even more important that the food you eat is nutrition dense.

I experienced rapid progression of weakness on a vegetarian diet. When I began to eat red meat again, I experienced increased strength, increased muscle endurance and less pain. I also had less fatigue. Dr. L. Halstead described a similar experience when he presented his revised diet principles at the GINI 97 conference. He found that when he increased his protein intake, including more lean meat, nuts, fish, etc. in his diet, he was able to increase calories. He decreased fruit for fruit's sake and nutritionally empty snacks. These changes resulted in improved muscle endurance, diminished muscle pain, and his weight remained steady.

In his book on aging - Dave Barry asks, "Are you willing to commit yourself totally to a program of regular exercise, close medical supervision, and the elimination of all nicotine, caffeine, alcohol, and rich foods, to be replaced by a strict diet of nutrition rich, kelp-like plant growths so unappetizing that they will make you actually lust for tofu?" Many people see nutrition in these terms but it doesn't have to be that Draconian.

The basic principles are:

- Eat a variety of unprocessed (and little processed) foods

- with high nutrient density
- in moderate amounts
- during at **least** three regular meals a day, including breakfast,
- with protein at each meal
- combined with smart snacking patterns (including beverages)
- while drinking at least six glasses of fluid daily, two of them water,
- and taking a broad-based vitamin- mineral supplement.
- I don't recommend megadoses of anything!
- *You have too much Vitamin C in your system. I'm prescribing a cold.*

Because you may be physically inactive, you may be at increased risk for osteoporosis. *[That's not the kind of bone loss we talk about.]* I recommend increasing your intake of dietary calcium. You may want to consider estrogen (Premarin and too many other names to mention). Estrogen replacement in women is probably the nearest thing we have to an effective anti-aging drug. It decreases bone loss, reduces the risk of heart disease, decreases the risk of Alzheimer's disease, reduces the risk of bowel and ovarian cancers, improves the suppleness of the skin and can even improve your sex life. There may or may not be an association between estrogen replacement and an increased risk of breast cancer. When I reach menopause, I plan to start taking estrogen. If you can't tolerate estrogen then ask your doctor about bisphosphonates like Alendronate (Fosamax). These are fairly new drugs that can be used to reduce bone loss.

There are a few other things I would like to suggest under nutrition. I recommend you decrease your caffeine intake so you can monitor your fatigue more accurately. I also suggest you use alcohol in moderation. Alcohol inhibits swallowing, interferes with nutrition, and causes falls and accidents. Alcohol at bedtime interferes with the quality of your sleep. If you smoke, QUIT. *[He doesn't like it much, but it is the only place I let him smoke.]* If you are a smoker, quitting smoking is the most effective anti-aging intervention you can make. If you don't smoke, great.

### 3. Values & Goals Clarification

Gen. Douglas MacArthur said "Nobody grows old by merely living a number of years. People grow old only by deserting their ideals." If you are aware of your major long term values, you can adjust your specific goals to your new limitations without feeling you are losing what is essentially you. Once you clarify your own values, you can set goals within your strength or endurance limits, and avoid going repeatedly to that limit. By doing so, you can reduce the fatigue, joint and muscle pain, muscle weakness, and psychological stresses of Post-polio Syndrome. You and experienced physical or occupational therapists can determine functional losses, assess extremity function, evaluate daily activities, and the need for assistive devices to help achieve the highest level of functioning possible. Even minor adjustments like changes in hobbies or modes of transportation can help. If you are aware of your basic values as you consider possible adaptations to your lifestyle you will find making appropriate adaptations much easier.

*[Can you at least tell me what our company strategy is? No, I don't want you to lose hope.]* This cartoon is funny because we see the futility of working without goals yet many of us do exactly that in our personal lives. When you decide to clarify your values, begin by identifying 5 core values. A core value is an aspect of life that is particularly important to you. It may be something like being confident, learning, being creative, time with family, time with friends, exploring the world, success, helping others, laughing and enjoying, being in attractive surroundings, being independent, getting recognition or being challenged. Be honest with yourself about what matters to you. Don't get trapped into living someone else's values.

A goal is a specific long or short term objective you set for yourself. Find concrete, realistic ways to express core values more frequently in your life. These are your "valued experiences," the things you really love to do. Prioritize your valued experiences and plan for specific action for opportunities to enjoy them. Make small, specific, concrete changes that reflect your core values.

*[The art of free hand drawing.]* This gentleman has found a way to express his creativity in a very difficult situation. It was Katharine Graham who said "To love what you do and feel that it matters - how could anything be more fun?"

#### 4. Self affirming Communication

A satisfying long term relationship is one of the main determinants of a long and happy life. Good communication skills will help you to develop and maintain satisfying long term relationships. *[I interrupt this program for a very brief message.]* Self affirming communication means having the courage to reveal to others who you are and what you want, expressing yourself assertively and listening actively, and replacing self-defeating communication behaviors and styles with self-affirming communication skills.

The four major areas of communication are, nonverbal communication, self-assertive language, giving and receiving feedback, and active listening. *[This makes my face hurt.]* Nonverbal communication includes clear and appropriate voice skills. Your body skills may change with polio or Post-polio Syndrome.

Self-assertive language is used when you say I when you mean I. For example, I want you to... rather than It would be better if you... Use "yes" and "no" not long involved explanations. Don't explain or apologize without reason. Avoid the word "but", it negates whatever you have said before it.

Another very important communication skill is giving and receiving feedback. When you give feedback, avoid value judgements by describing a situation. Be specific with your concerns. Report the impact of a behavior without judging the behavior. The best feedback is solicited, focused on things that can be changed, and immediate. When you are getting feedback, get more than one person's feedback.

Active listening is much easier if you frame the conversation. Try to set limits and impose structure on the information you are receiving. Recognize that disturbance takes precedence if you are not comfortable standing, stop the conversation by explaining you need to sit down, sit down, and then continue the conversation. Try to listen to both verbal and non-verbal messages. Recreate what you are hearing and play it back to the speaker. *[Oh they're very good talkers, but they don't listen worth a damn.]*

#### 5. Appropriate Exercise

Get enough exercise to prevent disuse atrophy, but not enough to produce overuse damage. Many survivors are prescribed or actually ask for the kind of physical therapy they had right after polio: exercising to the point of exhaustion. Several studies show that pumping iron will not increase the strength of muscles that are becoming weaker, and can actually cause an irreversible loss of strength.

After a 1997 study by A.J. McComas of McMaster University in which he actually counted neurons to assess damage, he warned, "Our findings make clear that polio survivors should not be treated using electrical stimulation that causes muscle contraction, nor should they engage in fatiguing exercise or activities that further stress metabolically damaged neurons that are already overworking."

In other words, No free weights, No exercise bikes, No tread mills, No NordicTracs and No Thighmasters for polio survivors. "Feeling the burn" means you are fatiguing your muscles. "Feeling the burn" means nerves are burning out. *[Maybe you should ease up on your exercise program.]*

With all this damage possible, one might ask why a polio survivor might want to exercise? Well, first, it worked for you after your polio infection. You may have been told regularly how much exercise made you strong. I know I was. You may have received a lot of encouragement and reward

for exercising early in life. Lessons learned early in life, tend to be difficult to unlearn. You may hope to increase you life span. Life span is reported to average only 2 years longer in those who exercised as opposed to those who didn't.

Exercise is great if you can do it but remember if you can not exercise, there are other ways to get many of the benefits. Exercise relaxes your body and your mind and releases endorphins. You can get these results through meditation techniques and relaxation. You may want to exercise to ensure better health. To improve heart and lung function, you can use focused breathing. Good nutrition can very effectively control weight, reduce the risk of diabetes and prevent osteoporosis.

A good exercise program has a mix of suppleness, strength and stamina. Muscle stretching and joint range-of-motion exercises are important where there is muscle weakness. Stretching, helps decrease pain and increase range of motion. To improve your suppleness try gentle yoga or other stretching exercises.

Do exercises for strength only with great care. Gentle, non-fatiguing exercises are useful for many polio survivors to maintain muscle strength and tone. If you are experiencing increasing muscle weakness, exercise only under the supervision of a knowledgeable physician or physiotherapist. Discontinue any exercise that causes pain, weakness, or muscle fatigue, including walking. To start an exercise program for strength, first find out which muscles are polio damaged. You build strength in the undamaged muscles using ordinary muscle strengthening methods. For the polio damaged muscles figure out how much weight will fatigue them. Then, lift only 30% of that amount with the damaged muscles. DO NOT FATIGUE the damaged muscles.

To decide if you should exercise for stamina, find out if you can get your heart rate up to training range (220 minus your age) without fatiguing any polio damaged muscles? If you can, get your heart rate into training range for about 20 minutes about 3 times a week for stamina. If you can not get your heart rate up to training range without fatiguing any polio damaged muscles, do not do exercises for stamina. You might want to try laughter. Dr. William Fry found that about 100 laughs a day is equivalent to ten minutes of rowing a boat for its aerobic impact. Sex can also be an excellent aerobic activity. If you only have the stamina for one aerobic activity let this be it! Always remember, with any exercise activity, adapt it to your level to avoid fatiguing you muscles.

There are **many** books on aging. The local library had three columns. Each of the local book stores had a whole section on lifestyle and aging. The books I found most useful are *Your Vitality Quotient*, Earle, R., Imrie, D., & Archibold, R., Random House of Canada Ltd., Toronto, 1989 , *Live Longer - Live Better*, Reader's Digest Assoc. (Canada) Ltd., 1995, and *Reducing your Body Age*, Earle, R., Imrie, D., & Archibold, R. They have a web site: at [www.ivillage.com/bodyage/](http://www.ivillage.com/bodyage/)

We have come together (at this conference) to enjoy contact with and support from others with similar problems and to collect information. The information that we collect is most valuable if it can be used in our day to day lives. (As the conference continues, look for) information on these and other changes that might be valuable to you. Appreciate the things you are doing right. Rank the suggestions in the order that seems right for you. Plan your change. Break it down into small, permanent changes that you can make gradually. This whole conference will be a success for you if you can make just one long term life change using the information you gather here.

"*[If you can't be a good example, then you'll just have to be a horrible warning]*" Catherine Aird.

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## DEFINITIONS

yogurt: Semi-solid dairy product made from partially evaporated and fermented milk. Yogurt is one of only three foods that taste exactly the same as they sound. The other two are goulash and

squid.

recipe: A series of step-by-step instructions for preparing ingredients you forgot to buy, in utensils you don't own, to make a dish the dog won't eat.



## Script you can use to make a 6 Minute Relaxation Tape.

by Dr. Mavis Matheson.

Focused relaxation is an effective exercise for achieving a physically relaxed and mentally alert state.

By focusing your mind on the instructions, you will be able to experience comfortable feelings of heaviness, warmth, and deep relaxation in every part of your body.

With each time you practice, it will become easier and easier to relax whenever you choose.

Begin by laying on your back or sitting comfortably in a chair.

Become aware of sounds inside the room and outside and allow yourself to be separate from them.

Allow your thoughts to come and go.

Give yourself permission to enjoy this time for you relaxation.

As you focus on the instructions, your mind becomes more and more calm as your body becomes deeply relaxed.

(1 minute)

Let go of all physical, emotional and mental tension.

Inhale now and bring the air slowly down into your abdomen. Let your abdomen expand, and then your chest..... Exhale slowly, through your nose.

Once again, inhaling and filling your abdomen more and more, then let your chest expand as you continue inhaling.

Now pause... and exhale, releasing tension from your body.

And continue breathing in this way, consciously allowing the breathing to become slower and deeper.

(2 minutes)

As I count from 5 to 1, allow yourself to move into a deeper and deeper state of relaxation. Picture each number as clearly as you can. By the time I reach 1, your body will be even more relaxed and your mind even calmer. 5..... 4..... 3..... 2..... and 1.....

(3 minutes)

Become aware of how every part of your body feels and know that you can return to this state whenever you chose. Now enjoy this time for your relaxation as you silently repeat your affirmations.

(Possible Silent Affirmations)

I relax at will

I breath fatigue away

I sleep easily and soundly

My food gives me energy  
I choose actions that express me  
I enjoy life fully.

(5 minutes)

Now, as I start to count from 1 to 5, you begin to come back to an awake and alert state. You find yourself rising like a bubble to the surface of a pond. For the rest of today, you will continue to be very alert and very focused. You will notice your body's stress reactions and let them go.

Counting up now ..... 1 ..... 2 ..... 3 ... more and more awake ..... 4 ..... and 5

(6 minutes)

## CONFERENCE IN GERMANY

Bundesverband POLIOMYELITIS e.V.

present an

Internationalen Polio-Kongress

in Freidrich-Schiller-Universität Jena, Germany

from 30 October - 1 November 1998

Post Polio Syndrome - Diagnostic and Therapeutic Opportunities and Potential in the domain of  
Medication/Physiotherapy/Neurology/Orthopaedics and of the Psycho-Social Situation

- Patients Forum -

<http://selbsthilfe.seiten.de/bv/polio/kongr98.htm>

⚠ *Currently Unavailable* ⚠



## SUNDAY MORNING

And now we come  
to Sunday morning,  
faces scrubbed and ready for God.

The week was

the gas bill past due;

The week was

the water leak;

The week was

the neighbor's dog  
digging in the peonies;

The week was

lunch money lost  
and chicken pox.

The week has been depression with

its wistful epic dreams of Eden.

The week has been another savage struggle  
to inherit the earth.

The week will be the weakness  
that may not be exercised;  
the aching that cannot  
be excised or ignored.

The week will be the arm, the leg,  
the mind that falters long before  
its round of chores is done.

For want of more precise and perfect prayers  
we glean from fallen hours our less than original sins;  
collect and sift and sort them into hopeful litanies  
perhaps the Mighty Maker will approve.

And so we come  
to Sunday morning,  
Monday's children every one;  
faces scrubbed  
and ready  
for God.

©The Reverend Phillip W. Thetford, D.Min  
Pastor Ashland Presbyterian Church in Virginia, USA.

## Dear Patients:

We know you've been patiently waiting your turn. Please don't ask us how much longer it'll be; we have no clue. But we do know you've been waiting too long when:

- You actually enjoy reading the magazines.
- Relatives are running over loved ones in the parking lot so they get seen faster.
- The other patients are taking breakfast orders.
- The guy on Long Term Disability has gone back to work.
- Your wife calls and tells you she's had a baby.
- You forgot your name and missed your turn.
- You finish War and Peace for the third time.
- You phone home and and out you are a grandparent.
- You've used up your entire vacation.
- Your fracture's healed.
- Everyone in the room now has the same rash you came in with.
- The bathroom doesn't seem so dirty anymore...

Sent in by Rev. Karen Utz, Dayton PA, USA [popette@client.alltel.net](mailto:popette@client.alltel.net)

**Just for Fun**  
**Food Spoilage Test - How to tell when items are spoiled.**

**EGGS** - When something starts pecking its way out of the shell, the egg is probably past its

prime.

**CARROTS** - A carrot that you can tie a clove hitch in is not fresh.

**FLOUR** - Flour is spoiled when it wiggles.

**POTATOES** - Fresh potatoes do not have roots, branches, or dense, leafy undergrowth.

**FROZEN FOODS** - Frozen foods that have become an integral part of the defrosting problem in your freezer will probably be spoiled (or wrecked anyway) by the time you pry them out with a kitchen knife.



## Sylvia Dymond from Hampshire, UK

It was in 1953 that I returned to work after contracting polio in June 1950. The GPO kept my job open for me during my long stay in hospital and physiotherapy as an out patient. My concern was how I would return to work, and how I would be able to get there. I wondered if I would be able to get on a bus, so as my father worked for London Transport he arranged for an old bus to be put in the grounds of the hospital I was attending near to the physiotherapy department, and I and other polio's who wanted to try to get onto the bus did so. I eventually went back to my job at the local telephone exchange. I literally pulled myself up three flights of stairs with a calliper on one leg and a spinal support. My job as a GPO telephonist helped me to recover, stretching as I had to on the switchboard helped my left arm to strengthen.

However.... now I tell a different story. I feel I am one of the forgotten Polio's as far as the NHS are concerned. I was not getting anywhere with my collapsing body so I decided to get some private appointments. Taking my PPS information I first made an appointment with an orthotist who had a surgical support made for me which has made a considerable difference. Then a physio, who said that with the support on I should not remain sitting for much more than an hour at a time, lying down in between. She is also sorting out a set of gentle exercise to help me. So it seems that we can get the right help if we pay. Its such a shame that most in the NHS these days know so little about the polio damage that was done and the problems we are getting now.

I have a few tips for those who suffer from the overwhelming fatigue. I invested in a powered adjustable bed with single massager in 91 but have just got a new one from a company called BAKARE where the massage effect has five choices. I could not now exist without such a bed. Not all beds raise up from the floor, mine does.... I could whitewash the ceiling if my arms were not so weak.

I have a separate massage pad in my armchair which also goes away with me, although going away is rare in this climate and we have to be certain that there is 24 hour heating. Many places now - even specialist homes - still turn their heating off in the summer and some at night as well. Polio's with cold intolerance just cannot manage like this. I have aromatherapy oils which I rub into my arms and knees, although I could do with a live in massager!! Couldn't we all ladies?



Diane now living in France <[DianeGaye@aol.com](mailto:DianeGaye@aol.com)>

When I was 3, my grandfather died. My mother was very close to him and, since we were living in

Indiana and my grandparents near Albany New York, my parents went "East" for the funeral, leaving me and my sister with neighbors. This was in '52. My earliest memories date from just before this - picking strawberries next to railroad tracks, pretty ladies in pink dresses with pink clouds around them (a wedding in an orchard), and so on. You'll see why I mention this a little later. From what I have been told, we all went swimming. And sometime later I woke up from my nap, not being able to walk. Here all memories stop. Completely. Until I reached the age of 4½. I don't remember all the horrors of being in the hospital. I don't remember throwing toys out of the bed. I don't remember not eating. I don't remember rubbing chocolate pudding in my hair. And strangely enough, even though I remember my little brother as a baby (born when I was 4), I don't remember those 5 years of daily exercises on the dining room table. From what I have read and have been told, this is probably a good thing.

So, for as long as I can remember, I have always had a brace on my left leg. But that never stopped me from climbing trees (and falling out of them, breaking the brace!), playing kickball (like baseball, but kicking a basketball instead of using a bat and ball) except that there was always someone to run the bases for me ("Diane's at bat, who's running?" - it was always so natural). I roller skated with one skate. Couldn't ride a bike though, in spite of Daddy trying everything he could imagine, including tying me on! The other kids were just other kids, my friends. I had more problems with some adults. I will never forget or forgive a Mr. Maleski, my teacher in 4th and 5th grades. HE decided I couldn't square dance with the others during gym. HE decided I shouldn't play ball or go out to recess with the others, making me go to the infirmary to "lie down". And my friends all thought this was unfair too!

Like most other polio survivors, there were the operations and such. When I was 6, I had a rather serious one (can't remember exactly what, not that it matters). In the hospital, I was in a children's ward with maybe 8 to 10 other kids, many of them much sicker than I. All of a sudden, I broke out in spots, like little pimples, all over my body. The doctors and nurses went wild. What on earth was happening? Post-operative shock? Followed blood tests and examinations and so on and they couldn't find out what was wrong. When along came a young intern who took one look at me a cried "Chicken pox"!! And here I was in a ward with all those other children with an extremely contagious disease!. I was whipped out of that ward so fast that it would make your head spin. And so fast that they didn't even tell my mother!!

Later, in high school, I babysat, went to the dances, looked after my brother and my sisters when Mom was too busy (I'm the oldest of 5), dated, went over the state line to go drinking (legal age 21 in Connecticut, 18 in New York), and everything else everyone else did in the 60's. Graduated 4th in my class and went on to college in Pittsburgh where I met Henri, got married, dropped out, worked, followed him to France, had two kids, held down several jobs and finally became a translator. Uninteresting, full, satisfying life.

What am I trying to prove with all this "normality"? I don't really know. I think my polio was harder on my mother than on me. She was the one who had to stand there when I fell and say "Get up by yourself". She was the one who felt guilty all her life. I got pretty fed up with that guilt business about 20 years ago. So I said "Do you like me as a person? Yes? OK, the polio made me what I am, so just cut it out". A friend here in France once said that my biggest handicap isn't the brace but my American accent. Another said that just looking at a picture of me makes him want to smile.

The problem is that now, I get exhausted when I try to do housework (fortunately, I have a cleaning lady twice a week). I can't stand to iron Henri's shirts anymore. I can't walk around Paris (or any other city) with him anymore. Grocery shopping is possible as long as I am the one to push the cart. Is this the polio or is this just being nearly 50? A part of me is trying to convince myself that I am just getting old (and fat!) and out of shape, denying that this brace on my leg is making any difference.

So there you are. When I read about other polio survivors, I feel as though I am reading about myself, in a way. I feel as though I am waking up out of some kind of dream and finally having to

face the fact that I did have polio and that maybe I will have to do something about it. I feel better having written it.



## Dealing With My Fear, Anger, And Negative Thinking

Those of us with PPS often have to deal with a lot more than our pain, brain fog, and the shock of suddenly being disabled after years of living and working hard. We have to deal with our fears, anger, and negative thoughts about our new situation in life. I know because I've been there!

With PPS I've had lots of fear haven't you? Whenever a fear gets my attention: my first response is to run and hide. However, admitting my fear is always the best thing I can do. Admitting it, talking about it, and asking questions about it disempowers the fear's grip on me and puts me in the drivers seat. Keeping the fear locked inside myself, on the other hand, is extremely toxic. I know that it will eventually eat me up; at the very least, I will waste more of my precious energy on it.

All of us with PPS have similar fears, and I for one never look forward to something that is going to bring me pain or insist that I have to design a new lifestyle for myself. But it all doesn't have to be done today. That would be too overwhelming. All we have to do is take it just one minute at a time. I've come to the realization that I must keep things simple and find easy ways of doing things. That makes my life manageable.

I've felt a lot of anger, too, in not being able to do everything that I used to be able to do. Haven't you experienced this? My anger was consuming me at such a rapid rate a few years ago that finally I had 2 choices: let it kill me or reach out for help. Since then I've been in therapy and sought help from 12-Step meetings, where I heard people who'd been there for a while talk about all of their gratitude. Gratitude! I didn't want to hear about that! What did I have to be grateful for? I was filled with rage, and the fact that somebody sitting next to me was filled with gratitude made me even angrier!

I kept showing up at the meetings though, and every week I visited my therapist. Very gradually the anger started to fade, making room for some self-love and joy for the first time in my life since I was 7, when I had polio. The healing took lots of time, commitment, desire, and work. Healing from childhood traumas, including the effects of polio, is a full-time job for me, but I'm \*GRATEFUL \* today!

Have you heard the saying that if you change your thoughts you can change your world? Well, my thoughts and my world were very dark and negative for a long time. Negative thoughts almost killed me. They certainly depleted my energy, held me prisoner, and robbed me of my joy. They kept me stuck in a very unhappy space.

I had to learn how to deal with the reality of my PPS. Yes, I had pain! Yes, I struggle all of the time to catch my breath! No, I can't do a lot of things that I wish I could still do! This is what my reality is; but today I choose to face it, accept it, and not let it stop me from life. In spite of the physical problems that I must confront every single minute of the day, I am aware that I'm enveloped in all kinds of blessings and miracles each second of my existence. I don't want to cloud my vision and my mind with "poor me" thinking any more. I've wasted enough of my life living that way. Today I want to be able to laugh, sing, and enjoy my daughter's smile and my husband's hug ... as well as the bright, wan sunshine. And I know how to do that today.

The blessings are there for our taking and enjoying right this very minute. In the midst of our PPS pain, there they are; but the only way we can realize them is to anchor ourselves in the moment, open our hearts, remove the self-pity from our eyes and minds, and then ... watch out! Life will radiate with richness, fullness, and joy!

PS. I have had a tracheostomy for eight years now.

Carol Swedberg Meyer - 74 Prescott Dr. N. Chelmsford, MA 01863-1942 USA  
<[CKSwedberg@aol.com](mailto:CKSwedberg@aol.com)>



## Martyn Bailey LincsPPN member from Derbyshire visits Eugenia Provence in Seattle.

Thank you so much for letting me know that Martyn Bailey and his family from Derbyshire were coming. They flew to Vancouver, then drove to Seattle, where they met up with his brother and sister-in-law.

Martyn said his PPS was diagnosed about a year ago, and is very fortunate because his employers are providing him with a car adapted with hand controls, as well as a power wheelchair. Like all of us, he's still coming to terms with the need to make these accommodations.

I gave him copies of some tips on occupational and physical therapy that my PPS specialist, Dr. Stanley Yarnell, had given me, so that he could share these with his doctor. His doc doesn't sound very aware, because he has a plan for (what sounds like much too strenuous) physical therapy when Martyn returns.

It was so wonderful to be able to share experiences, and he's persuaded me to get the disabled parking permit I've been resisting for so long. Also, has given me hopes that I can still do long trips. I believe I convinced him that power wheelchair would be the best thing that he ever did. Or I hope I did!



## LINCOLNSHIRE POST POLIO NETWORK - ANNUAL GENERAL MEETING.

11.30 A.M. SATURDAY 19TH SEPTEMBER 1998

Chairman - Lynn Hobday    Vice Chairman and Web Administrator - Chris Salter

Treasurer - Jean Tapper    Secretary - Hilary Hallam

Committee members    Christine Ayre, Phil Bilton

ANCASTER DAY CENTRE BOUNDARY STREET - LINCOLN

11.30 a.m. prompt

followed by BUFFET LUNCH - approx 12.30 p.m. (£2 - booking essential)

SPEAKERS AT 2.00 P.M.

including Dr. Alan Whiteley, Consultant Neurologist, Queens Medical Centre.

REFRESHMENT BREAK

QUESTION TIME

A full copy of the Lincolnshire Post-Polio Library will be available plus lots of other information, including photos of polio survivors (please bring photograph with you) and PPS Newsletters from around the World. Videos on Polio and PPS will be shown in another room.

INFORMAL EVENING

Join us at the Halfway House, on the A46 at Swinderby - 7.00p.m. onwards. Large choice of menu available 7.00 - 8.30 p.m.

**SUNDAY TOUR THE CATHEDRAL, CASTLE, LAWN VISITORS CENTRE,  
LINCOLNSHIRE LIFE MUSEUM AREA.**

Contact us for Information on B & B in the area 01522 888601  
There is a caravan park in Hartsholme Park, Skellingthorpe Road, Lincoln.

**Please Fill in the Slip below**

I/We:		
will attend the AGM	YES/NO	
Buffet Lunch (£2.00 per person) <i>Vegetarians catered for.</i>	YES/NO	No:
Speakers Session at 2.00 p.m.	YES/NO	
Informal Evening - 7.00 p.m. onwards Halfway House Inn, A46 Swinderby	YES/NO	No:
Sunday late morning visit in Lincoln Cathedral Area.	YES/NO	

Nominations for Committee Members

I am a paid up member of the Lincolnshire Post-Polio Network and

I would like to nominate \_\_\_\_\_ for the post of \_\_\_\_\_

I would like to nominate \_\_\_\_\_ for the post of \_\_\_\_\_

I would like to nominate \_\_\_\_\_ for the post of \_\_\_\_\_

I would like to nominate \_\_\_\_\_ for the post of \_\_\_\_\_

Please use a separate sheet if you wish to make more nominations.



**Lincolnshire Post-Polio Library**

Articles added since last newsletter with grateful thanks to the authors

**Title:** [Muscle Recovery in Poliomyelitis](#)



**Author(s):** W. J. W. Sharrard, London, England

**Original Publication:** The Journal of Bone and Joint Surgery, Vol 37 B, No. 1, February 1955:63-79.

**Abstract/Extract:**

1. The results of a three-year study of recovery in 3,033 lower limb muscles and 1,905 upper limb muscles in 142 patients are presented.
2. The rate of recovery of partly paralysed muscles is the same in all muscles and muscle groups in the lower or upper limb. Clinical differences in the ability of individual

muscles to recover depend upon the proportions of their number that remain permanently paralysed.

3. The rate of recovery is slowest in adults and most rapid in young children.
4. The amount of further recovery to be expected in a muscle can be predicted from knowledge of its grade at any time after one month from the onset of the paralysis. Fourteen-fifteenths of the total amount of recovery takes place by the beginning of the twelfth month; with rare exceptions individual muscle recovery is complete after twenty-four months.
5. Ninety per cent of muscles that are still completely paralysed after six months remain permanently paralysed.
6. The prognosis of a completely paralysed muscle is related to the level of paralysis in muscles supplied by the same spinal segments.
7. Deterioration in power in a muscle is uncommon and, when it occurs, is associated with the presence of the strong opposing force of antagonist muscles or of gravity.
8. The application of these findings to the management of cases of paralytic acute anterior poliomyelitis is discussed.

**Title:** [The Distribution of the Permanent Paralysis in the Lower Limb in Poliomyelitis](#) A Clinical and Pathological Study



**Author(s):** W. J. W. Sharrard, London, England

**Original Publication:** The Journal of Bone and Joint Surgery, Vol 37 B, No. 4, November 1955:540-558.

**Abstract/Extract:**

Though a striking feature of the paralysis that may result from an attack of poliomyelitis is its diversity, the belief that some order exists in the apparently irregular distribution of the permanent paralysis has been expressed by several authors. Wickman (1913) stated that "although a great variety of combinations of paralyses are found, certain types appear more often than others; in the leg the peroneal group and certain muscles of the thigh -- in my experience the quadriceps femoris especially -- tend to be implicated." Lovett and Lucas (1908), Lovett (1915, 1917), Jahss (1917), Mitchell (1925) and Legg (1929, 1937) showed tables indicating the relative frequency of paralysis and paresis in the muscles of the lower limb. All show a high incidence of paralysis in tibialis anterior, tibialis posterior, the long extensors of the toes and the peronei. A lower incidence of paralysis but a greater combined total of paralyses and pareses is shown in the quadriceps and in the gluteal muscles. No satisfactory explanation has yet been offered to account for these findings

It is the object of this paper to review the distribution of paresis and paralysis in the muscles of the lower limb, to account for its disposition in terms of the destruction of motor nerve cells in the lumbo-sacral spinal cord, and to indicate the practical application of the findings in the management of poliomyelitis.

**Title:** [Anticholinesterases in Post-Poliomyelitis Syndrome](#)



**Author(s):** Daria A. Trojan and Neil R. Cashman

**Original Publication:** The Post-Polio Syndrome: Advances in the Pathogenesis and Treatment Volume 753 of the *Annals of the New York Academy of Sciences* May 25, 1995

**Abstract/Extract:** Our studies indicate that a proportion of fatigued post-poliomyelitis patients can experience an amelioration of defects in neuromuscular junction transmission and of clinical fatigue with anticholinesterases. Because S-SFEMG response was significantly associated with clinical response to anticholinesterases, fatigue in PPS may be caused by defects in neuromuscular junction transmission in a proportion of patients.

Preliminary studies in a small group of patients indicate that anticholinesterases may produce their clinical neuromuscular response by producing an increase in isokinetic strength in a proportion of patients. Our studies provide a physiological rationale for the use of anticholinesterases in PPS for the symptom of fatigue. However, further randomized, placebo-controlled, double-blinded trials are needed to establish definitively the benefits and risks of these agents.

**Title:** [Dr. Henry writes about Ambien](#)



**Author(s):** Henry Holland MD

**Original Publication:** SJU Polio mailing list. [Note this Library edition has been updated].

**Abstract/Extract:** I have personally prescribed Ambien for patients for longer than one month time periods, but in PPSers, one must be convinced that the Ambien is not hiding an underlying respiratory or sleep apnea problem and that the Ambien is not contributing to an underlying respiratory problem. If there is an existent sleep apnea problem or respiratory difficulties, Ambien should be used with caution and only under the supervision of a physician familiar with PPS as it may intensify the existent problem.



## Managing Post-Polio A Guide to Living Well with Post-Polio Syndrome

Edited by Lauro S. Halstead, M.D.

Published by NRH (National Rehabilitation Hospital) Press

"An all new guide to living with post-polio from NRH Press 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.

Excerpt from Chapter 13, written by Anne C Gawne and Tom Walter on page 189.

The Lincolnshire Post Polio Network site can be found at the following WWW home page address <http://www.zynet.co.uk/ott/polio/lincolnshire/>. It is maintained by the post polio support group in Lincolnshire, England and is a good place to start your search for information. Resources include a library of up-to-date articles, medical information and general facts about PPS.

Available Now - 256pp, 6 x 9 - Paperback (Hardback edition also available) \$11.95

If you are in the UK and would like to order a copy through us then write and place your order as soon as possible. Cost including postage and packing is £10.00

[More details about the book](#) including the full text of the Introduction can be found in the Booklist section of our library.



## LINCOLNSHIRE POST-POLIO NETWORK

# Registered Charity No. 1064177

LincsPPN MEMBERS - Offering support in specific areas.

**LincsPPN members are now offering support in specific areas. Ruth and Christine would like to collate your stories and information on their subjects - articles to appear in the LincPin. If you would like a polio pen pal then Sylvia has offered to help with this. Please send all letters, c/o of the LincsPPN or email Ruth and Christine directly. Any other offers - history of polio/calipers/people with young children/ read and write synopsis of stories on polio. In fact if you have an ideas of how you can help then please contact us.**

NON PARALYTIC POLIO	Ruth Bridgens in Avon	<a href="mailto:pb.rb@virgin.net">pb.rb@virgin.net</a>
RESPIRATORY SUPPORT	Christine Ayre in Lincolnshire	<a href="mailto:catley@tesco.net">catley@tesco.net</a>
PEN PALS	Sylvia Dymond in Hampshire, UK.	

**Articles for publication by September 25th - Publication date September 30th 1998**

**MEMBERSHIP for this financial year is £10.00 - includes 6 Newsletters**

**Life Membership £100 - 20 x £5 per month**

**All Membership fees now payable by Standing Order**

**All donations will be gratefully received.**

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

**The Secretary, Lincolnshire Post-Polio Network  
PO Box 954, Lincoln, Lincolnshire, LN5 5ER United Kingdom**

**Telephone: +44 (0)1522 888601**

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**[info@lincolnshirepostpolio.org.uk](mailto:info@lincolnshirepostpolio.org.uk)**

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