



# The LincPIN

Volume 1 - Issue No. 10 - March 1998

WebSite <http://www.zynet.co.uk/ott/polio/lincolnshire/>

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This Issue is dedicated to the memory of Wendy Roberts (nee Skelcher), who died at the age of 63 in Woonona, New South Wales, 2517, Australia.

She contacted Polio at the age of 13, was nursed at Coleshill Hospital, Birmingham, a great lady, with fantastic strength, so brave, and a great example to us all. There is a great need for more specialist support.

Your forever friend, Jean. MCSP SRP

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



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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

We said that 1998 was the year of the Positive Polio Survivor... Some of our members now have a diagnosis after many years of the rounds of hospital departments. Dr. Whitely will accept referrals from GP's to assess Polio Survivors. There are no tests to say whether you have PPS or not, diagnosis is by exclusion of other conditions and with a past history of polio (records, visible disability, or tests that show polio damage), a stable functioning period and new symptoms.

**Dr. Alan M. Whiteley, Consultant Neurologist,  
Neuroscience's Directorate - Queens Medical Centre,  
University Hospital, Nottingham, NG7 2UH.  
Tel. 0115 924 9924 Fax. 0115 970 9493**

We recommend that you start a file for yourself on your life. Doctors are busy people and any way we can help them by providing information in an easy to read way will we know be appreciated. We also know that writing your polio story can help you adjust and this has helped many of us. Not all of us remember it all, but write down what you can, or what you have been told. This might be an emotional experience for you and for your family. Your parents may be blaming themselves for your catching polio and they, and your siblings, partner and children may be finding your noticeable difficulties as difficult to come to terms with as you are yourself.

We suggest that you have two copies - one a comprehensive document, and another a basic facts only version that a medical professional can scan down, make notes on and keep on your file.

We suggest separate pages on your life, pre-polio, with polio and up to best recovery, your life, work and hobbies since polio, and your symptoms now and when they started and how they affect your life. You can then Photostat this and have copies available for the medical professionals that you come into contact with.

### Membership Fees, Stories Wanted, and Help Needed.

Our membership is growing throughout the Country. We welcome all the new members and ask that you write and tell us your story, tell us your problems, hints and tips that might help others. We would remind you that membership fees are now due for this financial year - £10 -rejoin and receive free copy of 'Changing Lanes' booklet by Michael Creurer. Membership Form enclosed [Readers of this Web version please email [info@lincolnshirepostpolio.org.uk](mailto:info@lincolnshirepostpolio.org.uk) for more information].

We are also looking for more people to help us with our work. You do not have to live in Lincoln or Lincolnshire. Do you have, secretarial, accounting, librarian, medical, journalist, fundraising, etc. skills, the list is endless, then we would like to hear from you. We have a virtual organisation in the planning stage, and there are many tasks to complete. All offers of help will be welcome, however small, and it does not have to be on a regular basis.

### Sponsorship, Grants, Donations.

We would like to thank all those who have supported our work. Donations from members in Hong Kong, America and Britain. Computer and Software for the WebSite from three firms in Florida. Sponsorship from [Diamond Cable](#) who have donated the Rental Costs of our new Business Line. We have plans for improving on the service we provide as soon as we have the funds and would be pleased to hear from anyone who can help us. We have itemised our needs and all donations whether large or small are part of the end result. Maybe you could organise a local event to raise funds. Perhaps you have a hobby and could donate something you have made as a raffle prize. We will also accept any Stores vouchers etc, we can turn these into talking points, air miles for conferences, raffle prizes etc. Stamps are especially welcome. All ideas will be welcomed.

**We offer 20 page Bi-monthly newsletters, 2 leaflets, Copies of medical articles from our WebSite - our most cost effective way of publishing information - telephone, letter, fax and email support. We can ask the worlds experts for help via the Internet. Another aim is to see all Polio Survivors being assessed, advised and treated by Post Polio Clinics in the UK.**



## My Visits to Papworth, and My Infernal Machine

Just over a year ago I paid my first visit to Papworth Hospital, only for an overnight stay to have a sleep study plus lung function tests, x-rays blood tests etc. At that time I was sure PPS had zapped me to such an extent that I would be going home with a respirator, but, it was not to be. I passed all the tests well and was sent home and told to return in a years time.

The year passed, and I returned to Papworth last November for another overnight stay, but, this time the tests were not so good and I was told I would need a respirator for when I was asleep. I was horrified at the time and imagined life as I had known it was over and that I would lead a very difficult and uncomfortable life with a harness on my head. Just imagining trying to sleep with it on, and the noise, nobody I thought could sleep with a noisy machine like that on the bedside table. However, how wrong I was, three months on and I can't imagine being without my wonderful respirator. Life is much better now, gone are the day's when I couldn't stay awake all day, and gone are the nights when I was waking every hour and getting up in the morning 'feeling and looking'

like a Zombie.

I won't pretend that everything is always a bed of roses now but, I don't feel as if PPS has got the better of me, I now have a powerful weapon with which to fight the enemy.

Some of you reading this will know of the problems encountered with a respirator but, not insurmountable problems for the like of us who are the salt of the Earth and can do anything. For those of you who are threatened with a respirator I will say go for it and don't worry about the little problems, these are things everyone suffers so you are not unique. I think the biggest hurdle to overcome is accepting the mask over the nose, it makes one feel rather claustrophobic at first, but, after a few tries it becomes easier and after a few nights sleep life seems a lot rosier. Another problem is the mask itself not the most comfortable thing and can cause a very sore bridge of the nose, and it does take a bit longer to become accustomed to that, but it becomes easier with time. The noise I was so worried about is easy to bear and is quite soothing, I am unable to think for very long when I am using the machine as I tend to drop off to sleep, so thinking is best done in the daytime.

My biggest worry about the machine was how "Ben" my Boxer Dog would react. The first time he saw me wearing the respirator he climbed on the bed and peered into my eyes with a puzzled expression. Now he just accepts it as another of His Mums foibles. He's quite convinced all humans are mad.

The respirator machine itself can be a bit of a pest, the pipes tend to come off just as one is dropping off to sleep. I find the best way to deal with this is to swear at it and threaten to throw it out of the window, or promise to place it on the road in front of the next passing steam roller. This usually does the trick and the infernal machine pulls itself together and the rest of the night passes uneventfully Just be aware of it crouching on the bedside waiting for the next night to try to turn you into a frenzied, swearing, red faced, demented, being.

A word or two now about Papworth Hospital This is the most comfortable, friendly, and laid back Hospital I have ever been in, (and I've been in quite a few). It's just a case of do your own thing most of the time, no set time for getting up, no regimentation, and a thing one may think of as a big problem is soon cut down to size by the staff. If you are visiting Papworth in the near future be warned, the food is not good, so take some eatables with you. Also go with the idea that you won't find a parking space then if you do find one it will be an unexpected bonus.

Anyone reading this who is the proud possessor of one of these infernal machines, and may know a few tips on use etc, please write to me. I would be most grateful for any information, will answer all letters either through the Linc-PIN, or you can apply to Hilary for my address.

Christine Ayre - Lincolnshire.

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# USING YOUR BODY EFFICIENTLY

Grace R. Young, MA, OTR [<gryoung@PACBELL.NET>](mailto:gryoung@PACBELL.NET)

The basic principles of good body mechanics apply to disabled as well as non-disabled individuals. However, polio survivors have individual patterns of muscle weakness and unique ways of compensating, so there are no 'cookbook' rules that apply to everyone. Here are some general principles that apply to most of us.

## GOOD POSTURE

- Good posture uses less energy than 'slumping' and helps prevent muscle tension, fatigue, backaches and neck pain.
- Sitting or standing up straight balances your body on its own bony framework. The further you move from this position, as when you droop or slouch, the more your muscles have to work to counteract gravity.

## SIT INSTEAD OF STAND WHEREVER POSSIBLE

- It takes approximately 25% more energy to perform an activity standing than sitting.
- Sitting decreases the demand on the cardio-vascular system and relieves the weight bearing joints of the lower extremities.
- Sit during meal preparation, while you work on hobbies in the garage, when you shave, apply make up or style your hair, or work in the garden.
- When sitting brings your work surface too high (like preparing meals at the kitchen counter or doing hobbies on a workbench), a drafting chair with a pneumatic lift, a footrest and adjustable backrest works well. The one drawback is that you have to raise the seat before you sit down. Push the chair back into a corner while you get on it so it doesn't roll out from under you.

## LIFTING AND UNLIFTING (SETTING THE LOAD DOWN)

- Incorrect movements squander energy and can cause back injuries. Before starting to lift, assess the situation. How heavy is the load? Will you need to carry it? How far?
- Articles on body mechanics say to lift with the legs, not the back. Many of us can't do that. So if the load is on the floor, sit on a chair and push the load with your foot, crutch or cane to estimate the weight. If it feels ok, get your chair close to it, lift it onto your lap, then place it on a shelf, table or cart next to you. Do not stand up while you are holding the load.
- To lower loads that are above your shoulders, test the weight first by pushing up on it. Keep the load close to your body while letting it slide down, then put onto a shelf, table or cart. Do not lift heavy items over your head; ask for help. For lifting and unlifting, remember to:  
Test the weight first  
Keep it close to the body  
Have a surface ready to receive the load.

## USE MECHANICAL HELP FOR CARRYING

- Carrying objects changes your centre of gravity and can stress your arms and overuse your leg muscles. Here are three inexpensive items which can lessen your energy output.
  1. A kitchen utility cart on casters, available in most houseware departments. Just one trip with the cart can transport dishes, silverware, food to the table and back again. Use the cart to carry laundry or cleaning items. Push it along when you straighten the house, for putting things in their proper place.
  2. A collapsible grocery cart on wheels to keep in your car - use it when no one else is available to bring in the bags.
  3. A lightweight luggage cart is useful for many things besides travelling. Take it to the

mall (shops) to carry your purchases. Use it for transporting articles from room to room and between the house, car, or office. Keep the cart open and in a central location, ready to use at all times.

Grace Young WebSite

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

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

Seen during a Conference:  
For anyone who has children and doesn't know it, there is a Day Centre on the first floor.



## CREATING A USER-FRIENDLY KITCHEN

Grace R. Young, MA, OTR [<gryoung@.PACBELL.NET>](mailto:gryoung@.PACBELL.NET)

Preparing and cleaning up after meals takes a lot of time and energy and has to be done repeatedly. It really helps to organize your kitchen so it is user-friendly.

### STORAGE

- Keep frequently used items stored at a height between the hips and the lips. This avoids unnecessary bending or reaching.
- It seems like whatever you need is always on the bottom or at the back, so store dishes in stacks of their own kind. Do not put small saucers on top of big ones, or small bowls inside of larger bowls. Purchase vinyl-coated wire racks for stacking same-size dishes.
- Stack pots and skillets one layer deep, so you do not have to lift the top items to get at the bottom one. Mail order houses and kitchen specialty shops offer racks for either horizontal or vertical storage of individual skillets or pans.
- If your pantry shelves are deep enough to hold more than one layer, make the second (and third) layer the same as the first. That means you put a can of peaches behind another can of peaches but not behind a can of tomatoes. This way you can see all your supplies at a glance and won't have to pull out objects to get what you want.
- Use Rubbermaid susans for storing condiments in your kitchen cupboards. I have a two shelf lazy susan for small container items like spices and a one shelf lazy susan for taller items like cooking spray, etc. Frequently used items are on the lowest shelf of the cupboard and lesser used items are up higher. A reacher comes in handy for the higher items.
- One and two level sliding racks, bins, baskets, and shelf trays make base cabinets usable for cleaning supplies, food staples cookware, etc, and bring objects within easy reach.
- Have a handyman put your lower kitchen drawers on rollers.
- Utilize stacking storage bins on wheels for potatoes, onions, etc.
- Wire shelf units can be attached to the backs of pantry doors to hold boxes, cans and bottles.
- An angled mirror installed against the wall in back of the stove allows you to see what is cooking on the back burners while you are seated.

### STREAMLINE YOUR WORK

- Store equipment close to the area of first use. For instance, saucepans are usually used first at the sink because you put water in them before taking them to the stove.
- Do not put away the most frequently used pans, skillets or dishes. After each use, wash and

- let pots dry on top of the stove and let the dishes drain in a rack.
- Use lightweight dishes such as Corelle. Stoneware is pretty but too heavy.
  - Use non-stick skillets and pans.
  - Take advantage of dishes that can be used for cooking, serving and storing (such as Corningware). They cut down on many steps as well as dishwashing.
  - An electric knife carves many things besides turkeys and roasts. Use it to slice hard cheese, fruits and vegetables, etc. Keep the knife in a bracket on the wall so it is always ready to use.
  - Use a mini food processor to prepare vegetables. Large food processors require too much clean-up.
  - Chop vegetables with a jar chopper which cuts with pressure from the palm.
  - The one-handed cordless can opener by Black and Decker is very lightweight and requires no pressure to operate once the cutter has been activated.
  - Use a sharp linoleum knife to open cereal boxes. Hold it like a dagger with the blade pointing down and your thumb at the top.
  - Prepare double recipes and freeze half for use at another time.

Grace Young WebSite

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

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

Rev. Warren J. Keating, Pastor of the First Presbyterian Church of Yuma, Arizona,  
says that the best prayer he ever heard was,  
'Lord please make me the kind of person my dog thinks I am.'



## **PAIN IN POST-POLIO SYNDROME**

By C. Vandenakker, MD

### **A. CAUSES OF PAIN IN THE POLIO SURVIVOR**

Causes of pain are numerous, but those specific to post-polio syndrome appear to be related to overuse of weak muscles along with abnormal joint and limb biomechanics and degenerative changes.

Pain syndromes can be classified into:

#### **1. Post-polio muscle pain**

This pain affects the muscles affected by polio. It is a deep or superficial aching pain, similar to the pain of acute polio. It is often associated with muscle cramps, twitching, or crawling feeling. It often occurs at night or the end of the day. It is exacerbated by physical activity stress, and cold.

#### **2. Overuse pain**

This includes injuries to soft tissues: muscle, tendons, bursa, and ligaments. Common examples are rotator cuff tendonitis, medial or lateral epicondylitis, trochanteric bursitis and myofascial pain. This would include all strains, sprains, or overuse of the 'strong' limb. Most of these occur due to poor body mechanics, abnormal positioning or changes in posture. Overuse symptoms are very common in the upper extremities of crutch/cane users.

#### **3. Biomechanical pain**

Change in normal body biomechanics as well as normal wear and tear on joints results in degenerative joint disease (arthritis), degenerative changes in the spine(disk degeneration and worsening of curvature of the spine), and nerve compression syndromes.

Changes in body mechanics due to the weakness from polio makes joints very susceptible to wear and tear or degeneration - both in the strong limbs where there is often increased weight bearing and in the weak limbs where prolonged strain on unstable joints, protected only by ligaments, results in stretching of ligaments and increasing deformity. Those who rely on wheelchairs or crutches often show the wear and tear in the joints of the upper extremities. The joint pain may or may not be associated with swelling. X-rays usually show extensive degenerative changes.

The nerve compression syndromes include carpal tunnel syndrome, ulnar neuropathy at the elbow or wrist, brachial plexopathy and cervical or lumbar radiculopathies. These syndromes occur when there is pressure on a nerve, either due to degenerative changes that result in bone spurs, or enlargement of tendons or ligaments due to over-stressing, disk herniations in the spine, or a combination of factors. Neuropathies can be very painful and are often characterized by burning, tingling, and sensory loss, as well as weakness.

#### 4. Bone pain

Most often the cause of bone pain in a polio survivor is severe osteoporosis or fractures. Fractures may be due to trauma (most commonly falls) or simply collapse of bones or compression fractures due to severe osteoporosis.

### **B. EVALUATION OF PAIN**

#### 1. Evaluation starts with assessment of the pain.

Where is the pain? How would you describe it?

How long has it hurt? Is it constant?

What seems to aggravate it? What alleviates it?

Is it associated with other symptoms?

How does it limit your activities?

Have you tried any treatments?

What? Has it helped?

Pain drawing may be helpful!

#### 2. Thorough medical assessment including history, physical exam, and appropriate diagnostic studies are used to identify the source. Studies that may be used include:

X-rays

Special imaging, i.e. CT scan, MRI, or bone scan

Nerve conduction studies/EMG

### **C. MANAGEMENT OF PAIN**

#### 1. Basic principles:

Improve body mechanics

Correct or minimize postural and gait deviations mechanically

Protect and support weak muscles and joints

Promote lifestyle modifications

Adjust work load on muscles and joints to match capacity

Control inflammation and muscle spasm

#### 2. Therapies utilized:

Modalities

Medications - most commonly non-steroidal anti-inflammatories or low dose anti-depressants

Behavior modification - pacing

Bracing or assistive devices, positioning aids  
Spray and stretch or trigger point injections  
Joint injections  
Surgical intervention  
Weight loss  
SAFE exercise

### 3. Avoiding the 'pain cycle'

Pain > inactivity > increased weakness and loss of flexibility > frustration and depression > overexertion > damage to relationships with friends and family

Learn to accept your condition

Learn to relax

Let your feelings and needs to be known

Problem solve / find new ways of remaining involved and active in relationships

**In essence, pain is part of the post-polio syndrome and we have to learn how to deal with it as effectively as possible. We need to review any recommendations and incorporate them into our own individual lifestyles.**

*Reprinted from The Florida East Coast Post-Polio Support Group [Newsletter Volume 5 No. 4 January /February 1998](#).*



## Post-Polio Research: The State of the Art, 1998

NEW MOBILITY, April, 1998

Re-printed with permission from Dr. Richard Louis Bruno

1997 was a year of discovery for researchers studying post-polio sequelae (PPS) - the disabling fatigue, muscle weakness and pain experienced by 76 percent of polio survivors decades after the poliovirus has come and gone. Some of the new findings are disappointing, and others are even disturbing. But new understanding from this research will become the platform for future treatments, so there's every reason for survivors to keep themselves well informed.

### Brain Waves and Fatigue

During the past eight years, my team at the [Post-Polio Institute at New Jersey's Englewood Hospital and Medical Center](#) has been studying the cause of post-polio fatigue, the most common and disabling PPS. Post-polio fatigue has been found to be associated with a severe inability to focus attention and a marked reduction in the brain-activating hormone, ACTH. Magnetic resonance imaging reveals damage to the brain-stem neurons responsible for activating the brain, damage also found during autopsies of polio survivors done 50 years ago.

A study to be published this spring in the Journal of Chronic Fatigue Syndrome describes our measurement of polio survivors' attention, brain waves and the hormone prolactin. Prolactin increases in the blood when there is too little of the most important brain-activating neurochemical, dopamine. Our finding that polio survivors with the worst fatigue had the highest prolactin levels and the slowest brain waves suggests that survivors do not have enough dopamine to fully activate their brains. A dopamine shortage may explain their difficulty focusing attention, and other symptoms of post-polio "brain fatigue." This conclusion is supported by our 1996 finding that bromocriptine - a drug that substitutes for dopamine in the brain - reduces the symptoms of post-polio brain fatigue in survivors who do not respond to the treatments of choice for fatigue reducing physical and emotional stress, using assistive devices, conserving energy, resting and pacing activities.

### Two Drugs Flunk the Test

Last fall, the results of two multi-center drug studies were announced. Robert Miller, of San Francisco's Columbia Pacific Medical Center, led a study of recombinant insulin-like growth factor-1 (IGF-1) in polio survivors. Why study IGF-1? Because a 1995 study at the Milwaukee V.A. Medical Center had found that male polio survivors with "difficulties in the activities of daily living" had abnormally low blood levels of IGF-1. IGF-1 normally increases muscle size, stimulates extra neuronal growth (a process called sprouting) and slows the progression of amyotrophic lateral sclerosis. So an IGF-1 "menopause" in polio survivors was considered a possible cause of post-polio muscle weakness, and the replacement of IGF-1 was thought to be a potential treatment. Miller and his colleagues measured several variables before and after three months of twice-daily under-the-skin injections of either IGF-1 or a placebo: subjective fatigue, ability to function, the force of a maximal muscle contraction after a fatiguing exercise, and the amount of muscle strength recovered 15 minutes after the exercise. Unfortunately, the study found that IGF-1 had no effect on subjective fatigue, functional ability or muscle strength, although muscle force after the 15 minute rest was 13 percent higher. The improved muscle force "was statistically significant for those who received IGF-1," says Miller. But, he adds, "We are not sure how clinically meaningful this would be nor do we understand the mechanism of this finding."

Another multi-center, placebo-controlled study was headed by Neil Cashman, now at the University of Toronto. Cashman and his colleagues gave polio survivors a placebo or pyridostigmine (Mestinon), a drug that prolongs the action of acetylcholine, the chemical released by motor nerves to make muscles contract. In an earlier study in which subjects knew they were taking the drug, pyridostigmine was found to decrease survivors' "general fatigue" by 56 percent. But the controlled study of pyridostigmine was disappointing. After six months, says researcher Daria Trojan, there was "no significant impact on quality of life, fatigue or muscle strength."

IGF-1 and pyridostigmine join amantadine, an anti-viral drug, and prednisone, a powerful steroid, as once-promising drugs that have not been found to reduce post-polio muscle weakness or fatigue in placebo-controlled studies.

## Magnets for Pain?

If current drugs are not effective treatments for PPS, might less conventional approaches be helpful? Carlos Valbona, of the Baylor College of Medicine, thought so. He and his colleagues tested the effects of magnets on pain in polio survivors. Valbona identified subjects' "trigger" points, places on the body that hurt when pressed. He then caused pain "by firm application of a blunt object approximately one centimeter in diameter," asking subjects to rate the pain on a scale from zero to ten. On average, the pain was rated about a 9. Researchers then placed either a magnet or a non-magnetic pad, indistinguishable from the magnets, over the painful trigger point and waited. After 45 minutes, the blunt object was again pressed into the trigger point. Subjects treated with a magnet rated their pain a 4 on average after the second push. Those treated with the non-magnetic pads rated their pain an 8.

Valbona's methods cannot be faulted. Double-blind, placebo-controlled studies like this one are the gold standard of research. Sadly, the media quickly reported that magnets are a "cure for post-polio pain." Pushing a blunt object into a trigger point does not produce post-polio pain, but rather an experimentally-induced pain that is not at all typical of the chronic muscle and joint pain reported by about 75 percent of polio survivors. Without another study, it is not clear that magnets will decrease chronic pain in polio survivors.

It is also unclear why magnets would have any effect on even experimentally induced pain in polio survivors. Valbona implies that the pain-reducing effect of magnets in his study may be related to The Post-Polio Institute's 1985 finding that polio survivors have double the pain sensitivity of those who have not had polio. This heightened pain sensitivity may be related to a 50-year-old finding that the poliovirus kills brain neurons that produce endorphins, the body's own morphine.

But regardless of how magnets might have decreased pain in this study, polio survivors shouldn't

think they can run themselves ragged, apply magnets to treat pain, and be just fine. Future studies may indeed show that magnets are helpful for pain. But pain in polio survivors means damage is being done to the body. Masking discomfort - with magnets or morphine - is not a cure for polio survivor's pain.

## The Damage Done

The most important and sobering finding of 1997 was a study by A.J. McComas of Canada's McMaster University. McComas and his group tested the most widely accepted hypothesis for late-onset muscle weakness in polio survivors: that motor neurons are breaking down and sometimes dying as a result of the initial poliovirus damage and decades of overuse abuse.

McComas actually performed two studies. First, using a technique he developed and has used for 25 years, he counted the number of motor neurons in polio survivors. Muscles known to have been affected by the original polio were found to have lost 59 percent of their motor neurons. Sixty-five percent of muscles thought not to have been affected had lost 40 percent of their motor neurons. These percentages mirror precisely the findings of pathologist David Bodian, who 50 years ago showed that at least 60 percent of motor neurons had to be killed by the poliovirus for a muscle to show any weakness, and argued that there was no such thing as an "unaffected muscle" in someone who had had paralytic polio.

McComas' second study was equally revealing but more disturbing. He counted motor neurons in 18 subjects, then followed them for two years. At follow-up, 78 percent of the subjects reported a decrease in muscle strength and had lost an average of 13.5 percent of their motor neurons, approximately twice the rate of loss expected in healthy subjects. Most alarming was the finding that the two survivors who reported the greatest decrease in strength had each lost 50 percent of their motor neurons during the two years. While these findings are frightening, they are also a guide to a rational treatment for PPS. "Our findings make clear that polio survivors should not be treated using electrical stimulation that causes muscle contraction, warns McComas, "nor should they engage in fatiguing exercise or activities that further stress metabolically damaged neurons that are already overworking."

## Typically Type A

In a study presented last October, Dr. Susan Creange, a research fellow at the Post-Polio Institute, reported that polio survivors with blood sugar levels in the low normal range have as much difficulty focusing attention as do diabetics who have extremely low blood sugars from taking too much insulin. "Polio survivors," Creange says, "often have a 'Type A diet:' drinking three cups of coffee for breakfast, not having lunch and eating cold pizza for dinner. When we 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 the symptoms of post-polio fatigue.

The question for Creange was not only why polio survivors appear to be hypoglycemic - which she thinks is related to polio survivors' brain-activating neurons being metabolically damaged - but also why they often eat a "Type A diet" and have such difficulty taking care of themselves.

For a study published in 1997, Creange mailed anonymous surveys to all patients who had been evaluated by the Post-Polio Institute team. Patients were asked about their PPS symptoms and completed surveys that measured loneliness, self-concept and how Type A - hard-driving, pressured, time-conscious, perfectionistic and overachieving - they were. Patients were also asked how often they rested during the day, asked for help from others, and used braces, canes, crutches, wheelchairs or scooters.

"Patients with a high Type A score were less likely to take rest breaks, a cornerstone of the treatment of PPS," says Creange. "Patients who used wheelchairs were more lonely and had a poorer self-concept, crutch users also had poorer self-concept, while those who asked co-workers

for help had a more positive self-concept." Further, the most Type A patients were the loneliest; the lonelier they were, the poorer their self-concept.

"Polio survivors will not rest, use assistive devices or ask for help if they feel badly about themselves, says Creange. "Friends and family members must help polio survivors feel better about themselves if they are to slow down, accept lifestyle changes and use the new assistive devices needed to treat their PPS.

### Abuse: Then and Now

Another study presented last year also asked why polio survivors are so Type A and take such poor care of themselves. The 1995 International Survey, performed by Dr. Nancy Frick of Harvest Center in Hackensack, N.J., surveyed more than 1,700 polio survivors and nondisabled controls. Frick, a polio survivor herself, measured Type A behavior and sensitivity to criticism and failure, and asked whether polio survivors had been evaluated or treated for their PPS. The survey also asked about experiences surrounding the original polio, including hospitalization, surgeries and emotional and physical abuse by family members, peers and medical professionals. "As in our two previous post-polio surveys," says Frick, "polio survivors were 21 percent more Type A and 15 percent more sensitive to criticism and failure as compared to nondisabled controls." A more upsetting finding was that polio survivors reported 34 percent more emotional abuse and 94 percent more physical abuse than did controls. "All of the 'extra' abuse was related to polio survivors appearing obviously disabled, says Frick. Polio survivors who were abused were at least 15 percent more Type A and sensitive to criticism than those who were not abused.

"It is no mystery why polio survivors today refuse assistive devices that make them look more disabled," says Frick. "Using crutches or a wheelchair feels like painting a bullseye on your chest above the words, 'Abuse me, I'm disabled!'" Frick's findings may also explain why polio survivors are so reticent about even being evaluated for PPS. "About 78 percent of polio survivors said they were not treated with concern by the medical staff when they had polio," she says. Polio survivors who were treated well by medical personnel are significantly less Type A and less sensitive to criticism than those who were treated poorly. Those who were not treated well became more Type A and more sensitive to criticism and failure as adults. Frick's research suggests that Type A behavior developed as a protection against criticism and failure, and that polio survivors who are most Type A today are most likely to refuse evaluation or treatment for their PPS. Frick concludes, "Type A polio survivors refuse to treat their PPS and use assistive devices as a protection from the kind of abuse they experienced as children."

### Treatment of Choice

Research during the past decade has shown that conservative treatments for PPS - reducing physical and emotional stress, using assistive devices, conserving energy, resting and pacing activities - are very effective. The problem is that polio survivors have such difficulty applying these simple measures. "The treatments for PPS may sound simple but they are not," says Frick. "Polio survivors have to deal not only with their bodies giving out on them again, but also with their long-buried emotional pain." And it is those painful experiences of the past, the fear of giving up "protective" Type A behavior, and a terror of looking disabled that stop polio survivors from treating their PPS. The most difficult aspect of treating PPS is not deciding whether a short or long-leg brace will be most helpful. The challenge is helping polio survivors face the pain of their abusive pasts and accept appearing more disabled now - by slowing down, asking for help and using new adaptive equipment - so they won't become more disabled later in life.

Dr. Richard Louis Bruno is Director of the Post-Polio Institute at Englewood (New Jersey) Hospital and Medical Center and is Chairperson of the International Post-Polio Task Force. Papers describing the research performed at the Post-Polio institute can be found in the on-line PPS Library at <http://members.aol.com/harvestctr/pps/polio.html>

Dr. Bruno <[PPSENG@AOL.COM](mailto:PPSENG@AOL.COM)>

See also the Lincolnshire Post-Polio Library catalogue entry for  
[Bruno, Richard L., Ph.D.](#)



## Articles from our [Online Library](#)

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

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



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

**Original Publication:** SJU Polio mailing list.

**Abstract/Extract:** Many of the posters on this list have mentioned being in comas for a few days, having double vision, breathing and swallowing difficulties, etc with the original infection. Most of us had headaches and tender necks (meningeal irritation) and these symptoms would be compatible with an encephalitis at the time of the original infection.

**Title:** [Dr. Henry writes more on Post Polio Brain Fatigue](#)



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

**Original Publication:** Central Virginia (Richmond) PPS Support Group Newsletter.

**Abstract/Extract:** I have written in the past about post-polio brain fatigue. This symptom complex that many of us experience involves a feeling of total body fatigue, difficulty remaining alert, word finding problems, concentration difficulties, and occasional forgetfulness. These problems are usually absent when we are well rested. In the November/December issue of the newsletter of the Florida East Coast Post-Polio Support Group, there is an article written by Donald Peck Leslie, MD, of the Shepherd Center, Inc. of Atlanta, Georgia entitled "*POST-POLIO FATIGUE: WHAT IS IT? WHAT CAN WE DO ABOUT IT.*" It is a lengthy article that summarizes the development of PPS and many of the theories regarding the causes of PPS. I was particular interested in some of the information relating to PPS brain fatigue and will attempt to relate it to you.

### ROTARY DISABLED GAMES IN BARNSELEY SUNDAY 19TH APRIL 1998

Free Transport 7am to 9pm from Lincoln.  
Snooker, Bowls, Boccia, Swimming, Archery, Table Tennis, Rifle Shooting, Darts, Weight Lifting, Wheelchair Dash and Wheelchair Slalom  
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# The Transforming Power Of Illness

by Vicki McKenna, BA Lic Ace MBAC

[<steve@thoughtware.demon.co.uk>](mailto:steve@thoughtware.demon.co.uk)

LincsPPN Member in Glasgow

Last year I was under a lot of stress with a major house/city move. I had been experiencing poor health for the past few years - aches and pains and gastric symptoms to name a few of the mysterious ailments that had entered my life.

I sipped foul tasting Chinese herbs, rested, meditated and experienced a taste of my own medicine by having acupuncture. I swallowed vast quantities of vitamins pills, thought positively, got in touch with my feelings and in short did all that I could to get well. Some months later - still unwell and by now chronically fatigued with accompanying symptoms of mental confusion, poor concentration, and memory problems, I was labelled an M.E. sufferer by my G.P.

It was then remembered having read something about post-polio syndrome in the past and started to research as much as I could about the subject. I had had polio as a baby and to this day use a full length caliper to get around. Like most polio survivors I ignored my disability and got on with my life. Now it seemed that polio was back to haunt me.

Elizabeth Kubler-Ross writes about the first stage of bereavement being denial and I think this could be applied to the first stage of illness. Certainly for me denial was the immediate reaction to the realisation that I was chronically ill. I have experienced poor health in the past but sheer bloodymindedness has always seen me through and pushed me on. Suddenly these tactics did not work. My body now rebelled if I did too much with joint pains, headaches, and overwhelming fatigue. I was very frightened but battled on refusing to slow down and acknowledge these symptoms. Weeks of frustration followed as I realised that my luck had run out and this time I was not going to bounce back.

My life has dramatically altered during this time. I have had to cut back on work and play and it has not been easy to accept that this is how it needs to be. Slowly I am coming to a place of acceptance which I hope will strengthen my understanding of illness - my own and that of others who experience this crucible of ill health.

Although I have practised Chinese acupuncture for the past fifteen years, I am like most of us, a child of twentieth century western culture and have in the past been treated with allopathic, chemical medicine. Western medicine looks for the instant cure and seemingly works well with acute illnesses - for example bacterial infection is successfully treated with antibiotics. Many times I have longed for this kind of "quick fix" but sadly this approach is useless when it comes to long term, chronic illness. Western medicine is at a loss when faced with diseases such as M.E. and post polio syndrome and although there are treatments to help ease the symptoms - pain killers for the muscle aches and antidepressants for the accompanying mood swings, there is no instant cure.

The goal of Western medicine seems to be to blast disease out of existence and I think medics feel thwarted and embarrassed at their apparent "failure" when it comes to chronic illness. This repressive attitude towards sickness comes I believe from our modern culture which has no place for the weak or slow in the twentieth century scheme of things. Life in the present day is lived at a hectic pace and productivity is the great god to be worshipped. We have to be seen to be achieving at home, at school, at work, in all aspects of life until we reach the (often early!) grave.

Chemotherapy and radiotherapy can bomb and blitz cancer in the battle field of the sick body. The term "heroic" surgery is used to invoke the idea that we are valiantly striving against suffering and disease. Illness is seen as the enemy - a thief in the night coming to steal away our busy, productive lives. We put the chains on the door to protect ourselves by doubling our doses of vitamin C, exercising frantically and eating fibre, morning, noon and night. We suppress the first sign of a cold

with a dose of aspirin and carry on with a purposeful air. Illness is seen by society as a threat to productivity and a sick person is seen as one who is not able to contribute to the whole. The vulnerable pack of cards we call "society" is threatened by illness and fears it may tumble down. How many times have we experienced the G.P. hastily scrawl out a prescription so that we may return, post-haste, to work.

The Cartesian view of the universe - that mechanistic, scientific view widely held by medicine today, looks at the body as a machine that can be repaired. And who would not want to be "fixed" if it meant feeling fit and well again? The instant cure is very seductive to be healthy is something no-one would spurn and yet chronic diseases are here and are not always "fixable". Further more there is a price to be paid for this quick fix approach. When we see the body as a machine that is broken and needs mending we ignore the possibility that sickness is a cryptic message sifting up through the symptoms of blood, sweat and tears to tell us that we are out of balance in our lives. We ignore this at our peril. When symptoms are superficially alleviated the message is crushed beneath the surface only to rise again at some future time and place of illness.

Illness can be seen as an opportunity to take stock. In Ancient Greece there were temples which contained rooms for sick people to retreat into to be healed by the gods and goddesses. This was a time of quiet introspection based on the understanding that illness is a sacred space for inner work to be done so that healing may come from the core of our being. This means that the goal of healing is peace of mind and whether the body is "fixed" or not, is irrelevant. It is then a bonus to find the body rejuvenated but it is not the primary focus.

The late effects of polio have made me review my life and this has been a painful process. Having had polio as a child I needed to overcome my disability in order to be on a par with the able-bodied world. I viewed the world as challenging and felt I needed to prove myself as good as the next (able bodied person) person. An addiction to challenge followed and a pursuit of overcoming obstacles. I strove for myself and also to contribute to the world as mother and as therapist. My attitude was to pack in as much as I could - working, socialising, exercising - it was all grist to my mill and of no surprise to others when I developed the symptoms of post polio syndrome.

Frustration, fear and despair descended on me at that time and I felt I would never be able to enjoy my life again. How could I if I was not the capable productive woman I had always been? In my mind there was no room for change - I wanted to get back to that busy life style that felt so rewarding. Slowly I had to face and accept the fact that my catalogue of symptoms was not going to vanish away and my old life and identity needed to change.

To see that there is a purpose to suffering is not to romanticise it but it does make it more bearable and, hopefully, understandable. It seems to me possible that Life chooses for some of us to be active, healthy achievers in order for work to be done out in the world. It could also be possible that life chooses for some others of us to be sick in order that deeper work of growth is done on behalf of the collective. I believe that we are all part of a web of life - each a part of the whole. I therefore believe that I as part of you experience this illness in order to contribute to our wholeness. What I have to contribute now is perhaps not as tangible as the work I was able to do when I was well but I feel that the work of growth is as valid as my previous contribution. I am now able to look at my life with more of an overview and hopefully my insights might help others.

It seems to me that the part the late effects of polio have played in my life to help bring about transformation, is to have me learn to let go of old outmoded ways of thinking and feeling and behaving. Attachment to achieving, pushing on through life without regard for mind or body has placed much stress on my immune system. I have perceived the world as a challenge and myself as a warrior woman ready to take on the battle it presents. I have seen life as a struggle in which I need to prove myself, an exam in which I need to come out top. I do not believe that illness is solely due to one's attitude in life. There are many components involved both genetic and environmental but attitude it seems to me is the clincher. I may have a predisposition to post polio syndrome but by cultivating a relaxed and easy approach to life I could perhaps have avoided the full blown traumas

of it.

Slowly I have come to realise that I need to change my perception of life and start to see the world as a place to appreciate - full of potential delight. Even though I may be unwell and cannot work as I used to, I can still choose to live as the Buddhists might say with an attitude of "Mindfulness".

Mindfulness involves letting go of old conditioned attitudes and perceptions in order to appreciate what is and so allow the flow of life's energy. How to let go? It seems to me that letting go is not truly possible unless it is a movement towards or into another state of being. We cannot let go of the familiar ways of reacting and behaving however undermining they may be to health unless we have the promise of a different and better way of being. Gautama Buddha over two thousand years ago talked of attachment as the root of all suffering. When we hang onto old emotional states such as anger, grief, anxiety, or fear we suffer. Buddhism suggests that freedom from attachment to these states arises when we let go of them and move towards an acceptance of what is. This means the calming of the fearful and frenzied mind so that it may value, appreciate and enjoy whatever life brings.

When we start to trust that there is enjoyment to be found in the small details of life - a conversation with a friend, the warm smell of the dinner cooking, the play of sunlight on leaves then we are letting go to live in a calm appreciation of this moment. When we do this we are giving the body and mind the chance to deeply relax and in this space healing can take place. At this point we are flowing with the energy of life rather than against it. This then is the opportunity of illness - the chance to be mindful of the moment so that mind and body can heal. Physical symptoms may not vanish away - tissue damage may have taken place and will not heal instantaneously but a process has started of letting go and relaxing to focus on absorbing the every day pleasures that are accessible in the here and now.

We are more than our symptoms - we have the awareness to choose to take the opportunities life presents and appreciate and value the gifts the senses bring. The simple pleasures of enjoying the summer rain or sitting by a roaring fire in the depth of winter can be lost in a busy world whose prime concern often seems to be the cultivation of the material rather than the spiritual. For me these pleasures allow me to feel fully alive even when sick and tired.

I am by no means out of the woods of post polio syndrome and I do not wish to sound like Pollyanna and give the impression that illness is a wonderful thing. Most days I am frustrated, saddened and scared by the symptoms experience but the antidote that helps me out of the dark tunnel is there should I choose to access it. Firstly I become aware and tune into the thoughts and feelings that I am identifying with, then I let go of them by turning my attention to appreciate something in my environment in this moment. This is a choice still available to me in spite of everything and through the choosing comes a healing.

This attitude of "mindfulness" does not mean ignoring the darker forces of the external world. I am only too well aware for example of the damage done to our immune systems through pollution and the over use of pesticides. Illness is not an event that happens in isolation - we are all interconnected and we are all affected by poisoned air and water.

Appreciative acceptance of our immediate environment cannot mean we avert our gaze from these atrocities and think beautiful thoughts. Instead we determine to ensure that we can value our world even more fully by helping it to heal collectively. This may mean campaigning for organic farming, getting involved in a charitable organisation, signing a petition against the fluridisation of our water - whatever it takes. The more we contribute to the wellbeing of the collective and are absorbed in something beyond our own complaints the more we open to life and heal ourselves as individuals.

Post polio has given me the time and space to try to understand a little more about the purpose and the meaning of my life. Let me be clear - if I could choose to be sick or well I would wave the magic wand for wellness any day! I have however been dealt this particular hand of cards and I am grateful that it has allowed me to understand the importance and the need to learn to smell those

roses along the way. I still take my herbs and vitamins and take (gentle) exercise but the difference now is that I no longer strain to get well in order to simply carry on living my life in the stressful way I used to live it. Instead I am able more and more to aspire towards an attitude of acceptance and appreciation of my life as it is. The gifts are there - the comfort of a friend, listening to music, appreciating silence, reading a good book - they all bring pleasure in this moment. And in that moment healing grows.



## Changing Lanes

by Michael Creurer <[mpcreurer@pacificcoast.net](mailto:mpcreurer@pacificcoast.net)>

I have published a booklet titled Changing Lanes...a guide to help when ageing, illness or disability forces us into the Slow Lane. I write from the perspective of a polio survivor who has experienced many changes because of disability. The booklet contains personal stories combined with psycho-educational concepts which people can use in their own lives.

The booklet has been very well received by my local organization, the Post Polio Awareness and Support Society of British Columbia.

### **LincsPPN Members to receive free copy**

All new members and those renewing membership for the year April 98 - March 99 will receive a free copy of this booklet.

See also the Lincolnshire Post-Polio Network Library Booklist catalogue entry for [Michael Creurer](#)



## Today I Smiled

Author Unknown

Today I smiled, and all at once  
Things didn't look so bad.  
Today I share with someone else,  
A bit of hope I had.  
Today I sang a little song,  
And felt my heart grow light,  
And walked a happy little mile,  
With not a cloud in sight.  
Today I worked with what I had  
And longed for nothing more,  
And what had seemed like only weeds,  
Were flowers at my door.  
Today I loved a little more,  
Complained a little less,  
And in the giving of myself,  
Forgot my weariness.

from Linda Boudreau

Kings County Post Polio Support Group Go-Ordinator - Nova Scotia.

<[sheralee@glinx.com](mailto:sheralee@glinx.com)>

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## How lucky I am

On the basis of what I have observed in life or learned from others: It's like some people see themselves as a victim of circumstance, while others see themselves as a survivor. Can as opposed to Can't! "Imagination is greater than knowledge." (Einstein) It's realising while I'm bundled up in a patio chair, sitting on the front deck of my house on the bay, no longer able to walk the beaches, or hike the trails, or work six to seven days a week in the classroom..... how lucky I am to have the opportunity to sit here and observe the wildlife and their wonderful sounds, right here all around me. Seven bald eagles are screeching their shrill calls as they come and go from the tree next door. The goldey-eyed, black and white ducks who look like they've just slicked back their hair on top, are quietly and patiently swimming on the clear, tranquil waters, waiting for feed to swim by. A couple of mallards land and hunt for mussels in the shallow waters, while a larger flock of Canadian Geese hum swiftly and lowly over the bay. Would I have the opportunity to observe this gift of peace, beauty, and order in the colours of a spectacular sunset, God's magnificent creations, if I were still thrusting my life in the battles of public education and traffic when I was choosing to 'take on the world'?

Karyn Lindegaard, Alaska  
<[elindega@ptialaska.net](mailto:elindega@ptialaska.net)>

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## How to Lie to the Bathroom Scales

Weigh yourself with clothes on, after dinner. And then again in the morning, without clothes, before breakfast because its nice to see how much weight you've lost overnight.

Never weigh yourself with wet hair.

When weighing remove everything, including glasses. In this case, blurred vision is an asset. (Don't forget the earrings, those things add at least a pound.)

Use cheap scales only, never the medical kinds, because they are always five pounds off ... To your advantage.

Always go the bathroom first.

Stand with arms raised, making pressure on the scales lighter.

Don't eat or drink in the morning until AFTER you 've weight in, completely naked of course.

Weigh yourself after a haircut, this is good for at least half a pound of hair (hopefully).

Exhale with all your might first BEFORE stepping onto the scale (air has to weigh something, right?)

Start out with just one foot on the scale, then holding onto the towel rack in front of you, slowly edge your other foot on and slowly let off the rack. Admittedly, this takes time, but it's worth it, you will weight at least two pounds less than if you'd stepped on normally.

Penny O'Leary  
<[oleary.ocs@worldnet.att.net](mailto:oleary.ocs@worldnet.att.net)>

### CONTACTS IN YOUR AREA

Lincolnshire Post Polio Network and Leicestershire Post Polio Network now have members in many counties throughout the UK. If you would like to be put in touch with those in your area

please ring and let us know. Your name will not be given out unless you contact us.



Thoughts on:

## **In the Shadow of Polio : a Personal and Social History by Kathryn Black**

Clarissa Lassaline

Librarian, [OMOD](#), Post Polio Library Sudbury Chapter, Ontario, Canada

This is a brave and tender reconstruction of one family's dark tale of polio interwoven with the story of the polio years of the 40s and 50s in general. It is an exposure of the human sacrifice and devastation, a gentle probe of wounds and suffering through the wall of society's silence and indifference, a testimonial to the all-but-forgotten polio-stricken, and especially those who were severely handicapped.

In this tale, a little girl loses her mother to polio, and her family too. That child now grown must delve into the collective past to better perceive the utter severity of polio's ravages and the mechanisms by which life with severe disability was remade. She comes to understand how these changes affected not only the polio patient but also the entire family. With each new aspect explored, there is a greater grasp of the stark reality of her mother's life as a respiratory quadriplegic and a better comprehension of why she was not able to live with her polio-changed self, as many others, just as severely handicapped, did. It is here that Ms. Black explores the very essence of the polio experience. It seems there is not a feeling too complex, a thought too personal that she has not turned over and over and examined in a thousand ways in her need to reach back and understand what happened to her mother. She does this gently, with sensitivity. She does it with infinite tenderness, as if in each polio person there is a little bit of the mother she is trying to find.

This personal quest drives the author to examine in fair detail the era encompassing her own mother's harsh polio experience so that those dark months of long ago can be recreated minute by minute, week by week. This need to revisit that time in her family's history that changed their lives irrevocably is paramount. It is visceral. Many other polio survivors too young at the time of the disease to have their own memories of what happened will perhaps recognize this need. Many may recognize as well the silences and voids left by a world that managed to put polio completely from its mind.

If the very scope of this search is one of the great strengths of the book, it is in large part due to the openness of the author and her unjudgemental probing. Ms. Black has chosen not to obscure personal or familial traumas but rather to clarify the devastation wrought from severe paralysis by examining it in all its aspects. Many polio survivors, many severely handicapped, have come to her aid with their stories and thoughts. These recollections strike a deep cord for all of us with a polio past, not least of which those too young to remember the original polio now dealing with the late effects and experiencing, perhaps for the first time, what it means to be handicapped. Guilt, belief in mind over matter, accomplishment in the face of adversity all come rushing back from a very dim past. The mantra of never complaining and the chasm of silence fall back into place. And what of the hope, unspoken, grasped and clung to? Whomsoever polio cut down will recognize these things and must know, from their on personal experience of it, or intuitively, that 'the amount of adaptation and acceptance that the severely handicapped from polio had to cope with is staggering'. Not only the crushing enormity of the limitations of severe paralysis had to be dealt with but so did the

prevailing attitudes of a society which believed in overcoming the impossible and which clearly approved those who made an effort to fit back into the norm again. Not all could. This collective 'refutation of what polio really did to people and their lives', writes Ms. Black, '...diminished the profound experience of many patients'.

There were moments of alienation initially for this reader whenever the focus shifted from the young mother lying motionless in her iron lung to the healthy little girl who didn't know where her mother was, until gradually it became impossible to separate the one from the other. More often than not the polio experience, in our recollections, is considered solely in terms of the person stricken with the disease. This book is the family's tale of polio, inseparable. All were deeply affected by it, their lives shook up in a profound way. Polio touched Ms. Black just as surely as it did the mother it took away from her, as it did so many other families who were all changed by it. And it is in this sense that she answers yes to the question asked by a respiratory quadriplegic: are you one of us?

Ultimately, the author must conclude that her mother, and her family, were not able to overcome the obstacles that polio presented. That sometimes when the cards are heavily stacked against us, it really isn't possible to change our life stories, to replace the person we were with a new one. It is a measure of the author's deep compassion to have been able to explore fully, without in any way minimizing the individual polio experience, the insurmountable odds that could, and sometimes did, win out.

**In the Shadow of Polio : a Personal and Social History by Kathryn Black. Addison-Wesley Publishing Co., 1996.**



*Kathryn Black's Book can be ordered from [www.amazon.com](http://www.amazon.com) in paperback.*



## **Healing the Blues**

Drug Free Psychotherapy for Depression.

by Dorothea Nudelman Polio Survivor and David Willingham, MSW

"This book packs a wallop! I have read hundreds of books about psychotherapy, but I cannot remember one that so thoroughly describes what actually happens in the therapy hour.... For anyone who has ever wondered how, and even if, psychotherapy works, read this book! You will become a believer!"

*Carol Zimbleman, MSW, Stanford University Employee Assistance Program, Private Practice.*

We still have a few copies of this hardback autographed book of 235 pages donated to us by Dorothea <[dnudelman@earthlink.net](mailto:dnudelman@earthlink.net)> to help us raise funds. It is excellently written and many of us have found that we can relate to what Dorothea went through and it can help us and our families to come to terms with our present difficulties.

We recommend that it is read by partners, families and friends. One husband rang to say "For the first time since my wife started having problems I now have some understanding of what she has been and is going through, it has been of great help to me, and has allowed us to talk more freely, thank you for making this available to us in this country."

Price in the UK is £10 including postage.

See also the Lincolnshire Post-Polio Network Library Booklist catalogue entry for [Dorothea Nudelman & David Willingham, MSW](#)



## **POST POLIO SYNDROME**

by Lauro Halstead, MD

April 1998 - 9.4.98 Scientific American U.K. £3.20

*Decades after recovering much of their muscular strength, survivors of paralytic polio are reporting unexpected fatigue, pain and weakness. The cause appears to be degeneration of motor neurones.*

Lauro S. Halstead is director of the spinal-cord injury and post-polio programs at the National Rehabilitation Hospital in Washington D.C., and clinical professor of medicine at the Georgetown School of Medicine. He received his M.D. from the University of Rochester in 1963 and a master of public health degree from Harvard University in 1970. Halstead taught rehabilitation medicine and epidemiology at Rochester and Baylor College of Medicine for more than 20 years. His research interests include the late effects of polio, metabolic and endocrine changes in persons with spinal-cord injury, enhancing fertility in men with spinal-cord injuries and developing outcome measures for rehabilitation patients.

**STOP PRESS!** We applied for and received permission from Scientific American to reproduce the article in Lincolnshire Post-Polio Library. You can [read it now!](#)

See also the Lincolnshire Post-Polio Library catalogue entry for [Halstead, Lauro S., MD](#)



## **Hypertension in PPS**

Thyagarajan Subramanian, MD

Assistant Professor of Neurology Emory University, USA.

[<tsubram@emory.edu>](mailto:tsubram@emory.edu)

Sleep Apnea is an important cause for hypertension and you may not even know that you have sleep apnea. This condition is very common in polio survivors and in patients with PPS. Check with your spouse/companion whether you have periods of apnea (no breathing) when you are in deep sleep. If you don't have anyone who can do this or if you have one who refuses to check on you, put a tape recorder or VCR attached to a microphone close to your bed and tape your sleep sounds. If you have noisy breathing/snoring, the periods of apnea will be readily apparent from the tape. If you don't have noisy breathing you have to carefully listen to find your breathing pattern and then figure out if you have periods of apnea. Remember to run the tape at EP mode (Long Play). This is a cheap screen for sleep apnea. Confirmatory testing involves getting a formal sleep study in a sleep lab.



## **POLIO SURVIVORS JAZZ UP YOUR CANES, SCOOTERS, AND WHEELCHAIRS**

Polio Survivors believe that using aids and assistive devices make them look more disabled, and therefore fight against using them. Education on disability is sorely lacking and should be started in

infant school when children accept life much more easily. The general public do not know what to say to someone who is using a cane, riding a scooter or in a wheelchair. They look away, they talk to the people with you. This is why we fight so hard against these aids. However there is an answer and it works.

Dress brightly yourself and jazz up your cane, scooter, or wheelchair. Make a statement to the world. 'I am here, this is me, take me as I am. I might be using a cane or wheels but they are no different to shoes, they are just an aid to moving from one place to another.' Suggestions are to decorate your cane to match your outfit (sleeves of material to match can be slipped over it and fixed so they don't slip off) have it sprayed fluorescent colours, add stickers or walking stick badges, or have a suitable handle added to a carved wooden one. For our scooters and wheelchairs, make or buy a multi-coloured rucksack/bag for the back, jazz up that basket on the front, add badges and stickers, transfers, holograms, in fact anything you can think of that will make you more noticeable. Allow folks to talk to you, to start a conversation, give them something that they have to comment on.

Gwen Hunn, RN, BS in California [celticwings@EARTHLINK.NET](mailto:celticwings@EARTHLINK.NET). I sewed a Harley Davidson "WINGS" patch on the back on my Quickie wheelchair...the biker bros loved it!!

David G. Henson, Salt Lake [dhenson@englab.slcc.edu](mailto:dhenson@englab.slcc.edu) says I have a "hand-me-down" cane made of Texas cedar. It is not only beautiful wood, but it is also unique in character. I get comments on the cane, not on my limp nor why I am in need of its (cane's) use. This "deflection" of perspective may give rise to further questions about my disability without embarrassment to either party.

Elizabeth Lounsbury, Chairperson [Ontario March of Dimes](http://Ontario March of Dimes) [loonie@ican.net](mailto:loonie@ican.net). I'll never forget the first time I went outside in my suburban home in my wheel chair. The first person I saw said "ah come on E, who do you think you're fooling?". It had already been over a month since I had bought it and that was the first time I had used it. Wouldn't have used it then, but my husband said, "I have taken it out and we are going for a walk. If you won't come on your own you'll come with force." I've come a long way since that day. Yes Hils jazzing things up does help. I shocked everyone when I ordered a purple electric chair. Was at a meeting in Toronto last week. I wore a mauve suit had forgotten that my chair was purple. The first comment I received was 'boy do you ever look striking'. I would never have thought to colour coordinate my clothes with my chair. The thing that had been noticed was the colour not the fact that I was in a new chair. I love my purple chair. My husband thought I was nuts but said it's going to be part off you, if that's what you want go for it. We have a company in Canada that makes all kinds of decorative canes. One friend has a red chair & several different canes to go with different outfits.



**LINCOLNSHIRE POST-POLIO NETWORK**  
**Registered Charity No. 1064177**

**Articles for publication by May 18th please - Publication date May 24th 1998**

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

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

**Facsimile: +44 (0)870 1600840**

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

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Document preparation: Chris Salter, [Original Think-tank](#), Cornwall, United Kingdom.

Document Reference: <URL:<http://www.zynet.co.uk/ott/polio/lincolnshire/linkpin/linkpin9810.html>>

Last modification: 21st February 2010.

