



The LincPIN

The **Lincolnshire Post-Polio Information Newsletter**
Volume 5 - Issue 6 — October 2005

WebSite - <http://www.lincolnshirepostpolio.org.uk>

MEMO

**Lincolnshire Post Polio Network
Annual General Meeting
Saturday 22nd October 2005**

Hope to see you there!

Art Work by Chris Salter



This publication is provided as a service to those seeking such information. The opinions expressed in this publication are those of the individual authors and do not necessarily constitute endorsement or approval by the Lincolnshire Post-Polio Network. ALWAYS consult your doctor before trying anything recommended in this or any other publication.

Lincolnshire Post-Polio Network - UK Registered Charity No. 1064177

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Lincolnshire Post-Polio Network - UK Registered Charity 1064177
Donations large and small towards our work are always welcome.

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Membership Information

Renewal dates are the first of the Months of Feb, Apr, Jun, Aug, Oct, Dec.

Please make cheques payable to 'Lincolnshire Post-Polio Network'

Post to Membership Sec, 78 Heron Road, Larkfield, Aylesford, Kent ME20 6JZ, UK
UK Membership - Life Member (LM) £150 or £5 x 30 months S.O. - Member £10 a year.
All UK Memberships payable by Standing Order - Forms from Membership Secretary.

Overseas Newsletters by Airmail.

European Membership - LM E300 - Member E25 a year.

USA - LM US\$375, Member US\$25 a year - Canada - LM C\$550, Member C\$40 a year

Other Countries please contact membership@lincolnshirepostpolio.org.uk for details.

Next LincPIN Newsletter - December 2005

Articles for publication 1st November by post or - newsletter@lincolnshirepostpolio.org.uk

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Editorial

This Newsletter is early to save us postage in sending out the Trustees Report and Accounts and the Newsletter in the same post.

I have another apology to make in that the date on the page for nominations was incorrect. It should have been the 15th September 2005. However, as with all AGM's in the past nominations can be taken at any time prior to the voting on the day. So there is still time to post or email your forms.

We are always looking for members/family members to help with our workload. We do appreciate that living with PPS can mean a reduced amount of energy, time, finances, brain power etc. However, you need to be aware that nearly all the committee members/operations team over the last ten years have PPS and have given up time and energy to research and [I am going to be honest here, I cannot think of the word I need, demonstrate is not right, it begins with a d.... And means pass the information on to you. See page 14] After ten years I have to admit that I can't do as much as I could ten years ago.

Last newsletter you saw a picture of the Southport gang. If you would like to meet up with members near to you over coffee then do get in touch and we will write to those locally to you to see who is willing to join in. By the time you read this I will have contacted those near to me in Lincoln for a coffee morning.

We are still looking for folks who regularly receive a copy of a Disability Magazine/Newsletter to do us a short piece for the newsletter/or just send us the information on anything that might be of interest to members.

Members who are connected to the Internet and are not subscribed to our Members Email List and would like to do so, please email me so that we can set this up for you.

. AGM—Day of Speakers

**Saturday October 22nd 2005.
10.00 to 4.30 p.m.**

**North Hykeham Day Centre,
Neale Road,
North Hykeham, Lincoln, LN6 9UA.
[Tel:- 01522 689534]**

AGM commences 10.15 a.m.

Followed by Speaker at approximately
11.30 a.m.

Mr. Mark Rainey, Social Services,
a Carer Services Co-ordinator

Lincolnshire County Council Social Services Directorate is developing a countywide service to provide information, advice and support to carers through a single point of access and a coordinated network of partner providers. Mark is asking for this to be a two way discussion. He will explain what the new service is all about and then would like to hear from members as to any problems that their carers have experienced. An ideal opportunity for us, especially our Carers, to learn more about the new Carers Assessment and bring forward problems that we have experienced.

Buffet Lunch approximately 12.30 p.m.

2.00 p.m. Speaker
**Dr. Darren Barnes-Heath,
BSc, D.C. C.C.E.P.**

A Doctor of Chiropractic specialising in
Neurological conditions in Lincoln.

Chiropractic specialises in mechanical disorders of joints, particularly those of the spine, and their effects on the nervous and muscular system. It is now State Registered and is the third largest primary healthcare profession in the world, after medicine and dentistry. **Darren will explain how he assesses and treats Polio Survivors and looks forward to answering your questions.**

Tea, Raffle, Questions, Chat till 4.30 p.m.

Message from the Chair

"Hello Readers,

It is only just over a month since we issued the last newsletter; so this edition comes out hot on the heels of the previous one with the Annual Report & Accounts for 2005. This newsletter has been reduced to 16 pages as we felt the Report should be a separate document. Team members have worked particularly hard this month to ensure that our Report is with you within the time required by our constitution. In response to our readers' survey, we have raised the annual membership fee from £10 to £12.50 with effect from November. All equivalent currencies are explained in the Report.

It has been a busy month in other respects. 8 other members joined me in attending the BPF's Greater Manchester Conference on PPS, and came back with a number of interesting impressions. Guido D'Isidoro and his team at Manchester worked hard to make it a very welcoming day, and they invited a number of interesting speakers. In particular I was pleased to have established a link with medical professionals in the North West of England. Consultant Neurologist Dr David Shakespeare, from the Preston Royal Hospital (Lancashire Teaching Hospitals NHS Trust) gave an informative talk about the Neuro-Rehabilitation clinic at Preston. It was refreshing to meet and listen to a health professional in the North West Region who is pro-actively involved with PPS patients. Dr Shakespeare gave us permission to recommend his name to polio survivors in the north west area (to request a referral through their GP, if they so wish). This helps us enormously to respond to enquiries which come in both via our website and via the telephone helpline. We seem to have filled our already reduced newsletter this month, so more on Dr Shakespeare's Neuro-Rehabilitation Clinic in the next issue.

It only remains for me to thank a very hard-working team for all their efforts this year, in ensuring that you get your newsletter on a bi-monthly basis, and also safeguarding the activities and assets of the charity. Our AGM promises some interesting speakers – I have heard at least three positive accounts of the benefits of chiropractic for polio survivors this month alone. See the AGM notice for further details. We urge you to continue to support the important work of the charity this coming year. We welcome Mary McCreadie to the Operations Team. She will be introducing topics for discussion on our Members Email List and overseeing the responses to produce short reports for the benefit of all members. We encourage you to help us by sharing the tasks involved in increasing the information we can provide. As usual you will find our contact details on the inside front cover.

Best wishes Mary Kinane, Chair

Two good Consultants in Rehabilitation

Dr. Prasad

Community Rehabilitation Centre, Long Leys Road, Lincoln, LN1 1EF

Dr. Ali Arshad,

Haywood Hospital, High Lane, Burslem, Stoke-on-Trent, ST6 7AG, UK

SCOOTERS AND POWER CHAIRS
Jann and John Hartman, Baltimore, Maryland.
at Post-Polio Health International's
9th International Conference on Post-Polio Health
and Ventilator Assisted Living: Strategies for Living Well,
St Louis, MO, June 2 - 4, 2005.

A gel cell battery is the most popular sealed lead-acid battery used with mobility equipment. It's maintenance free. But, it must be cared for properly.

Lifespan of your battery depends on several factors:

1. how the battery is used.
2. how it is treated
3. how it is charged
4. temperature.

Battery capacity is reduced as the temperature goes down. At 32 degrees F/0 degrees C [freezing] capacity is reduced by 20%. Battery life is affected as the temperature increases. Most manufacturers agree that there is a 50% loss of battery life for every 15 degrees of temperature over 77 degrees F/25 degrees C.

Batteries are designed to be used on a daily basis—inactivity can be harmful. Do not buy new batteries and save them to use later. It is best to buy them when you need them.

Recharge batteries right after using them. When a battery discharges (through use or just setting) sulphate forms on the plates. Recharging takes sulfates off the plates, so they can't harden and shorten the life of the battery.

Batteries should be stored ideally between 32 degrees and 80 degrees F / 0 to 27 degrees C.

When you take your scooter or power chair in for its annual check-up, the batteries will be checked.

All batteries die eventually. For battery replacement, check your durable medical insurance or Medicare. If you need to buy new batteries, shop around for the best price, but consider things like service and freshness of stock. For example, a battery warehouse may have the best price, but they don't provide service.

Internet Resources:

Battery Care [Tutorials]: www.batterystuff.com (shop smart)

Mobility Equipment: www.ibsa.com

How Batteries Work: www.execulink.com/~impact/batteries.htm

Battery Safety [Fact Sheet]

Ohio State University Extension http://ohioline.osu.edu/aex-fact/0596_2.html

[Editors note—Do we have a UK member/family member who could do us a short piece on battery use in the UK that is not covered above?]

**Spinal Bracing & New Technology in Lower Extremity Orthotics
at Post-Polio Health International's
9th International Conference on Post-Polio Health
and Ventilator Assisted Living: Strategies for Living Well,
St Louis, MO, June 2 - 4, 2005.**

by

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Many of us are striving to maintain our ability to independently ambulate. We notice that it takes just a little more effort to get going, maintain our balance and participate in our home and community activities/obligations. Some of us have decided to obtain help from our physicians who in turn refer us to therapists, orthotists, and other health care areas. (Pain management, nutrition clinics). We go, we listen and then we have to make our own decisions on what type of care we are going to accept, participate in.

Our minds want to keep going, but our bodies are telling us that a little less strain would be good for the day. Our joints are aching, our feet are yelping and our backs aren't as strong as they used to be and we find our knees buckling and once in a while we find ourselves on the ground trying to find a decent way to upright ourselves. Thus, we make the decision to obtain help and eventually end up in front of a clinic team trying to figure out why we are having these problems and what to do for them.

Well, we all know why, whether or not we want to believe it. We are wearing out, getting weaker, getting older and getting tired. The clinic team evaluates us and talks their shop language to come up with a solution. Many of the solutions include the new technology that is slowly coming into the orthotics world. What is this new technology? How can it be applied and will I be safe with it? These are the questions that need to be asked and the orthotics plans using the new technology need to be considered very, very carefully.

When applying the new technology, physicians and orthotists alike need to make sure that the patients are not put at any additional risk. This is most difficult when dealing with patients who have weak and or absent quadriceps/knee extensor muscles. The typical way of stabilizing patients with weak quadriceps was always to lock up their knee. Now, modern technology allows the knee to be locked in certain phases of gait and allows the knee to unlock at specific times during the gait cycle. If the knee comes unlocked too early, the knee joint will flex prematurely and the patient is put at risk of the knee collapsing and a severe fall resulting in possible fractures and other damage.

Each and every patient dealing with post polio syndrome is unique, each patient has different muscle strength, skeletal development, and each one has a unique way of substituting for muscle weakness and imbalance and has done so for many years. Thus, understanding the complexities of polio gait, body substitution especially in the lower extremities is a necessity for polio clinic staff, physician and orthotists. Understanding the details of what a new knee joint will do and will not do becomes imperative. Not all new technologies designs are going to work for everybody. Orthotic designs need to be distinctive individual for each and every patient. Careful fitting and involved follow-up programs are extremely important. New ways of walking, new ways of tolerating pressures and making a commitment to stay with and weaning into the new orthotics systems can bring some excellent success. However, catastrophic results can becomes nightmares when this new technology is used in the wrong way/ignorantly.

Polio patients who are seeking help must be their own advocates and make sure they are getting professional medical advice from qualified health care individuals. Patients need to take the time to ask around, call health care professionals and ask them about their qualifications. Many times, the local 'down the street and around the corner type of brace shops' may be alright for arch supports but may not be the ideal place to look for the type of assistance that will be needed to take care of the complex situations and challenges that arise.

Polio patients need to recognize the quality of thorough evaluations and testing that may be necessary in order to understand the 'big picture'. Quality clinical evaluations and orthotics plans performed by qualified and experienced health care professionals can and will help keep patients walking and limit the risk involved.

Remember, you the patient, are the most important member of the team and communication ins the best tool you have in expressing your desires and concerns.

[Editors note:- If you have had any experiences with orthotics/bracing/callipers, good and bad, then why not write and tell us. We especially need more UK information on Orthotists who are doing a good job and are knowledgeable on polio and pps. Personally I am still looking for a good Orthotist who will provide me with a comfortable AFO (Ankle foot orthosis) for my dropped foot that not only works but is comfortable, walking, driving and sitting with my feet elevated.]



MEMORY ARTICLE NEXT ISSUE

Memory failing. Losing words like I did on page 3. You know what letter the word starts with, you can describe the word, but the word itself...?? Some years back I took a call from a member, 'am I getting Alzheimer's or is it PPS to ask your wife to pass you the short pointed thing that you hit with the hammer into the wall to hang the picture'. Forgetting where you are in a conversation. Mostly happens when you are physically or mentally fatigued. Write and tell us your personal experiences with memory issues and a selection will be added as a accompaniment to the article.

Hilary Hallam [Editor]

**Service Dogs for People with Neuromuscular Conditions
and those who use ventilators.
By Joanne Kocourek, RN, DDRC
with Annalies Kocourek and Kristen Kocourek, Worth, Illinois.
at Post-Polio Health International's
9th International Conference on Post-Polio Health
and Ventilator Assisted Living: Strategies for Living Well,
St Louis, MO, June 2 - 4, 2005**

Service Dog Tasks

Service dogs generally receive six months to a year of schooling on tasks, obedience and public access manners. Most dogs placed by non-profits since the 1970's have been trained to assist people who have a wide variety of mobility impairments. Some teams have mastered up to fifty tasks, enjoying the challenge of such an advanced education. The list of tasks in this section are a broad sampling of what has been developed over the past quarter of a century to address daily living needs and safety issues.

Retrieve based tasks.

1. Bring portable phone to any room in house.
2. Bring in groceries—up to ten canvas bags. Fetch a beverage or food bowl
3. Pick up dropped items like coins, keys etc. in any location.
4. Bring clothes, shoes, or slippers laid out to assist with dressing.
5. Unload towel, other items from dryer.
6. Retrieve purse from hall, desk, dresser of back of van.
7. Fetch basket with medication and/or beverage from cupboard.
8. Use target stick to retrieve an indicated item off shelves in stores
9. Retrieve one pair of shoes from the closet
10. Drag Cane from its customary location to another room or pick up and return cane if it falls.
11. Drag walker back to partner.

Carrying based tasks (non retrieval)

1. Move bucket from one location to another. Lug a basket of items around the house.
2. Transport items downstairs or upstairs to a specific location.
3. Send the dog to obtain food or other item from a care giver and return with it.
4. Pay for purchases at high counters.
5. Transfer merchandise in bag from a clerk to a wheelchair user's lap.
6. Carry mail or newspaper into the house.

Deposit based tasks.

1. Put trash, junk mail, plastic into a wastebasket or garbage can or recycling bin
2. Assist partner to load clothing into top loading washing machine
3. Put silverware, non-breakable dishes, plastic glasses, dirty food bowls in sink
4. Deliver items to 'closet'. Deposit dog toys into designated container.
5. Put prescription bag, mail, other items on counter top.

Tug based tasks

1. Open refrigerator, cupboard doors or drawers with attached strap. Open interior doors via a strap.
2. Answer doorbell and open front door with strap attached to lever handle.
3. Shut restroom door that opens outwards via a leash tied to doorknob. Shut interior home, office doors.
4. Assist to remove shoes, slippers, sandals, socks, sweater, coat
5. Drag laundry basket through house with a strap. Drag bedding to the washing machine.
6. Pull a drapery cord to open or close drapes.

Nose nudge based tasks.

1. Cupboard door or drawers—nudge shut, dryer door—hard nudge, stove door - push it shut.
2. Dishwasher door—put muzzle under open door, flip to shut.

3. Refrigerator and freezer door—close with nudge.
4. Call 911 [999] on K-9 rescue phone—push the button.
5. Operate button or push plate on electric commercial doors. Turn on light switches.
6. Turn on metal based lamps with touch lamp device installed—nudge base.
7. Assist wheelchair user to regain sitting position if slumped over.
8. Help put paralyzed arm back onto the armrest of a wheelchair.
9. Return paralyzed foot to the foot board of a wheelchair if it is dislodged.

Pawing based tasks (some dogs prefer it to nose nudge)

1. Cupboard door, dryer door—shut it with one paw.
2. Refrigerator and freezer door—one forepaw or both.
3. Call 911 on K-9 rescue phone—hit button with one paw.
4. Operate light switches on wall—jump up, paw the switch.
5. Depress floor pedal devices to turn on appliances.
6. Jump up to paw elevator button or operate push plate on electric commercial doors.
7. Close heavy front door, other doors—jump up, use both forepaws.

Bracing based tasks (no harness)

1. Transfer assistance from wheelchair to bed, toilet, bathtub or van seat—hold, stand, stay position then brace on command, enabling partner to keep their balance during transfer.
2. Assist to walk step by step, brace between each step, from wheelchair to nearby seat.
3. Position self and brace to help partner catch balance. Prevent fall by bracing on command if the partner needs help recovering balance.
4. Steady partner getting in or out of bathtub.
5. Assist partner to turn over in bed; have appropriate back up plan.
6. Pull up partner with a strap [tug of war style] from floor to feet on command.

Harness based tasks—Mobility assistance.

1. Assist moving wheelchair on flat [partner holds onto harness pull strap] avoiding obstacles.
2. Work cooperatively with partner to get the wheelchair up a curb cut or mild incline.
3. Haul open heavy door, holding it ajar using six-foot lead attached to back of harness.
4. Tow ambulatory partner up inclines [harness with rigid handle or pull strap may be used]
5. Brace on command to prevent ambulatory partner from stumbling [rigid handle]
6. Help ambulatory partner to climb stairs, pulling then bracing on each step.
7. Pull partner out of aisle seat on plane, then brace until partner catches balance.
8. Transport text books, business supplies or other in a wagon or collapsible cart.
9. Backpacking— customary weight limit is 15% of the dogs total weight.

Medical Assistance Tasks (Sample)

1. Bark for help on command
2. Find the caregiver on command, lead back to location or disabled partner.
3. Put forepaws in lap of wheelchair user, hold that upright position so wheelchair user can access medication or cell phone or other items in the backpack.
4. Wake up partner if smoke alarm goes off, assist to nearest exit
5. Operate push button device to call 911 [999]; let emergency personnel into home and lead to partner's location.
6. Fetch insulin kit, respiratory assist device or medication from customary place during a medical crisis.
7. Lie down on partners chest to produce a cough, enabling patient to breathe, when suction machine and/or care giver unavailable.

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**Two Snippets from the Handouts of Presentations
at Post-Polio Health International's
9th International Conference on Post-Polio Health
and Ventilator Assisted Living: Strategies for Living Well,
St Louis, MO, June 2 - 4, 2005.**

Eating better for better health with your family and friends.

John and Jann Hartman, Baltimore, Maryland.

John and Jann Hartman enjoy sharing the cooking and clean-up in their kitchen. They are devoted to eating well despite the constraints of lack of energy and time. Sharing the tasks and planning ahead can make it easier than ever to make your own nutritious foods.

Eating well means that the foods we choose are going to be good for our body. Maintaining a healthy weight (or as near as possible) is a good goal as well as staying as active as possible. Eat heart healthy foods, and serve small portions. WE need to eat well and to eat foods that are nutritious and delicious. [Jann has written us a longer article on this subject for our next LincPIN.]

Planning ahead to stay in your home when getting older:

Stephanie Malench, MSW, LCSW, Saint Louis, Missouri.

Shopping with the Five Senses—Here are some general guidelines when shopping for any type of new residence.

Eye scan

During your tour of the potential living environment, notice if the building or unit is clean, uncluttered, and in good repair.

Is it wheelchair accessible (if needed)?

Is staffing visible?

Smell

Are there any strong urine, disinfectant, or deodorizer smells?

How does the building smell during meal times (if meals are provide)?

Sound

How frequently do the call buttons go off?

How does the staff talk to each other?

Is the intercom used frequently?

Taste

If a complementary meal is provided within the tour, did it taste homemade, or commercially mass produced?

Touch

Are there positive interactions between staff and residents, between staff, and between residents (hugs, pats on the back)?

[Editors note: We would welcome articles, comments good and bad, problems encountered and ways you dealt with this, hints or tips from any member/family member who has experience of living or visiting polio survivors in hospitals, sheltered accommodation, residential or nursing homes, respite care, etc.]

Hurricane Katrina

What would you have done if you lived in this area and had to evacuate?

One of our members lives near New Orleans and has had to leave her home and go and stay with her parents in Denver, Colorado. Her home has a little damage but mostly OK, but it could be months before the electric is back on and she can return home. En route in Houston her scooter threw a puncture and a local firm supplied and fitted two wheels FREE of CHARGE. Our thanks to that firm and to the Churches along evacuation routes who stepped in and supplied free meals at motels, etc. Our wishes go to her and her family for a speedy return home.

The area affected was the size of England! This has certainly made us think. What would/could we take from our homes if we had to evacuate? Household equipment specially for you? Do you have enough medication? If you need refills whilst you away do you have the paperwork to get this done. What if your health practitioners offices are damaged, do you have copies of your records/prescriptions etc?

Are you in an area that could flood? Just looking round this room I can see Video, DVD player, CD's, DVD's computer tower, scanner/printer, photo albums on lowest widest shelf.... All would be damaged with just a 10" of water.

Another PPSer on an email list wrote and said she would be stuck if the power went off as her adapted Van is in a garage with an electrically operated door. This prompted responses on back up equipment that you can have fitted.

What would you do about electrical equipment in your home if there is a Power Outage? Richard got stuck once in his electric rise recliner chair in Florida when the power went off—which it does far more often than in the UK. We had fun trying to work out how to get him off that chair but have you thought, what would you do? Last winter we had a power outage within days of returning and the torch battery had run out. Our neighbours laughed when we arrived with an old candle lantern [from our Re-enactment pre 1840 equipment] asking for a light. If you live alone, do you carry a mobile phone/cordless phone around with you as you go round the house/garden in case you need to call for help?

Our members on the Internet and subscribed to our Members Email List will already know that Mary McCreadie has agreed to collect and collate all information on any hints, tips and bits that you have worked out as answers to problems. Photos and patterns would be really helpful as well for some of the ideas. For instance, Pat Galvin has an ironing board fitted into a top drawer and a wheelchair user friends is in a middle drawer. She has also had all her low level cupboard shelves removed and replaced with sliding chrome baskets and a carousel under the sink area. Di Brennand sits on her perching stool in the kitchen but opens the cupboard so that she can put her feet on the shelf. When I have to sit on a settee where there is only one arm to get up with I put my arms out at shoulder height and overlap my fingers on each hand and can use my right elbow as a lever on the arm of the chair to get up turning as I go. Now you will know why we are asking for photos as a description like this is not enough to really understand. Photos can be copied and returned. We already have some great ideas coming from Viola Pahl in Canada including patterns for her Kangaroo Aprons.

Write to Mary McCreadie via the main address or email her on mirarah2@TISCALI.CO.UK

THE TEN COMMANDMENTS OF PPS

**Dr. Richard L. Bruno [PhD] and his wife
Dr. Nancy M. Frick, [M.Div, Lh.D.]**

**[First printed in LincPIN Vol 2,
Issue 6, August 1999]**

After 15 years of searching, archaeologists from The Post-Polio Institute have unearthed the commandments for treating Post-Polio Sequelae (PPS).

1) Listen to Yourself!

Polio survivors often turned themselves off from the neck down after they got polio. The first step in treating PPS is to listen to yourself: to what you feel, physically and emotionally, when you feel it and why. Our most powerful tool in treating PPS is the daily logs our patients keep that relate activities to their symptoms. However, polio survivors sometimes listen too much: to vitamin salesmen saying some herb or spice will "cure" PPS, to other polio survivors who warn that you will eventually have every possible PPS symptom, and to friends and family members (and the voices in you own head) saying you're lazy and that you must "use it or lose it." Polio survivors need to listen to their own bodies, not to busybodies.

2) Activity is Not Exercise!

Polio survivors believe that if they walk around the block five times a day, spend an hour on the exercise bike and take extra trips up and down stairs, their muscle weakness will go away. The opposite is true: the more you overuse your muscles the more strength you lose. Muscles affected by polio lost at least 60% of their motor neurons; even limbs you thought were not affected by polio lost about 40%. Most disturbing is that polio survivors with new muscle weakness lose on average 7% of their motor neurons per year, while survivors with severe weakness can lose up to 50% per year! You need to substitute a "conserve it to preserve it" lifestyle for the "use it or lose it" philosophy. Stretching may help pain and non-fatiguing exercise for specific muscles can prevent you from losing the strength you have after you get a brace. But polio survivors need to work smarter, not harder.

3) Brake, Don't Break.

The follow-up study of our patients showed that taking two 15 minutes rest breaks per day - that's doing absolutely nothing for 15 minutes - was the single most effective treatment for PPS symptoms. Another study showed that polio survivors who paced

activity -- that is worked and then rested for an equal amount of time -- could do 240 percent more work than if they pushed straight through. Our patients who took rest breaks, paced activities and conserved energy had up to 22% less pain, weakness and fatigue. But polio survivors who quit or refused therapy had 21 percent more fatigue and 76% more weakness. For polio survivors, slow and steady wins the race.

4) A Crutch is Not a Crutch...

...and a brace is not a sign of failure or of "giving up." You use three times less energy (and look better walking) using a short leg brace on a weakened leg. Overworked muscles and joints hurt and nerves die after decades of doing too much work with too few motor neurons. So why not use a brace, cane, crutches (dare we say a wheelchair or a scooter) if they decrease your symptoms and make it possible to finally take that trip to Disney World? We know, you'll slow down and take care of yourself "when you're ready." And you'll use a wheelchair "when there's no other choice." Well, you don't drive your car until it's out of gas. Why drive your body until it's out of neurons?

5) Just Say "No" to drugs, unless...

Five studies have failed to find that any drugs that treat PPS. And there have been no studies showing that herbal remedies or magnets reduce symptoms. Polio survivors shouldn't think that they can run themselves ragged, apply a magnet or pop a pill, and their PPS will disappear. Pain, weakness and fatigue are not-so-subtle messages from your body telling you that damage is being done! Masking symptoms -- with magnets or morphine -- will not cure PPS. However, two studies have shown that polio survivors are twice as sensitive to pain as everyone else and usually need more pain medication for a longer time after surgery or an injury (see number 10).

6) Sleep Right All Night.

The majority of polio survivors have disturbed sleep due to pain, anxiety or sleep disorders, such as sleep apnea (not breathing) or muscles twitching and jumping all over your body during the night. However, polio survivors are usually not aware that they stop breathing or twitch! You need a sleep study if you awaken at night with your heart pounding, anxiety, shortness of breath, choking, twitching, or awaken in the morning with a headache or not feeling rested. "Post-polio fatigue" may be due to a treatable sleep disorder.

7) Some Polio Survivors Like it Hot.

Polio survivors have cold and purple polio feet because the nerves that control the size of blood vessels were killed by the poliovirus. Actually, polio

survivors nerves and muscles function as if it's 20 degrees colder than the actual outside temperature! Cold is the second most commonly reported cause of muscle weakness and is the easiest to treat. Dress in layers and wear socks made of the silk-like plastic fiber polypropylene (sold as CORTEX or THINSULATE) that holds in your body heat.

8) Breakfast Is the Most Important Meal of the Day.

For once Mom was right. Many polio survivors eat a Type A diet: no breakfast, coffee for lunch and cold pizza for dinner. A recent study shows that the less protein polio survivors have at breakfast the more severe their fatigue and muscle weakness during the day. When our patients follow a hypoglycaemia diet (have 16 grams of low-fat protein at breakfast and small, non-carbohydrate snacks throughout the day) they have a remarkable reduction in fatigue. Protein in the morning does stop your mid-day yawning.

9) Do Unto Yourself as You Have Been Doing For Others.

Many polio survivors were verbally abused, slapped or even beaten by therapists or family members when they had polio to "motivate" them to get up and walk. So polio survivors took control, becoming Type A super-achievers, "the best and the brightest," doing everything for everyone except themselves. Many polio survivors do for others and don't ask for help because they are afraid of being abused again. Isn't it time that you got something back for all you've done for others? Accepting assistance is not the same as being dependent. Accepting assistance can keep you independent. But appearing "disabled," by not doing for others, asking for help or using a scooter, will be frightening. Remember: If you don't feel guilty or anxious you are not taking care of yourself and managing your PPS.

10) Make Doctors Co-operate Before They Operate.

Polio survivors are easily anesthetized because the part of the brain that keeps them awake was damaged by the poliovirus. Polio survivors also stay anesthetized longer and can have breathing trouble with anesthesia. Even nerve blocks using local anesthetics can cause problems. All polio survivors should have lung function tests before having a general anesthetic. Your complete polio history and any new problems with breathing, sleeping and swallowing should be brought to the attention of your surgeon or dentist - and especially your anesthesiologist - long before you go under the knife.

Polio survivors should NEVER have same-day surgery or outpatient tests (like an endoscopy) that require an anesthetic.

The Golden Rule for Polio Survivors: If anything causes fatigue, weakness, or pain,

**Don't Do It! (or do a lot less of it.)
..and...**

The Golden Rule for Polio Survivors' Friends & Family: See no evil, hear no evil and help only when asked.

Polio survivors have spent their lives trying to look and act "normal." Using a brace they discarded 30 years ago and reducing their super-active daily schedule is both frightening and difficult for them to do. So, friends and family need to be supportive of life-style changes and accept survivors' physical limitations and new assistive devices. Most important, friends and family need to be willing to do the physical tasks a polio survivor should not do, but only when the polio survivor asks. Friends and family need to know everything about PPS but say nothing: neither gentle reminders nor well-meaning nagging will force survivors to use a new brace, sit while preparing dinner or rest between activities.

Polio survivors must take responsibility for taking care of themselves and ask for help when they need it.

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Hints Tips and Bits

From Ann Post in Missouri postann59@YAHOO.COM

I feel like my body has gotten totally out of shape since the arthritis got worse, so my doctor suggested I join a fitness club and start exercising ... I decided to take a stretching class for people with arthritis. I bent, twisted, gyrated, jumped up and down, and perspired for an hour. But, by the time I got my leotards on, the class was over.

From Pat Galvin in Southern England— patgalvin@WAITROSE.COM

I got a life line with help from REMAP. They are a UK wide organisation of mainly retired engineers etc. who, invent or adapt equipment to our individual needs. They do not charge but appreciate a donation. Your local CAB should have your nearest contact - each county have their own reps.
www.remap.org.uk

From Mary Guild from Scotland mary.guild@shell.com

Holiday accommodation - The attached websites might be of interest to you if holidaying in the UK and I've also attached two in France which are owned by disabled people so therefore accessible.
www.radarsearch.org

www.montcuq.com/tourisme/tourism_sites/calvet/calvet.htm

This one is a superbly adapted (including a lift!) 14th century building with magnificent views in the Lot - owned by a French wheelchair user who lived in England

www.jcgites.freeuk.com/index.html

This one is in Burgundy and owned by an English wheelchair user and his physiotherapist wife who live in Maidstone.

It looks really excellent but is quite large and expensive so would have to be shared with other people to make it economical.

Sign Language

How do mathematicians communicate?
Sine language..

How do biblical prophets communicate?
Heavenly Sign language.

How do astrologers communicate?
Star Sign language.

How do naval cadets communicate?
Ensign language.

How do couturiers communicate?
Design language.

How do lighthouse keepers communicate?
Shine language.

How do real estate closers communicate?
Sign here and Sign here and Sign here language.

How does everyone communicate on December 31st?
Old Lang- syne -uage.

How did Gertrude communicate at the Bavarian Oktoberfest?
She used Stein language.

How do lovers communicate?
Sighin' language.

How do tech writers talk?
Manually.

*To Use or Not to Use
{ with apologies to William Shakespeare }*

*To use, or not to use: that is the question:
Whether 'tis nobler in the mind to suffer
The going to the shop for one item and out again,
Or straining the shoulder joints by using crutches.
Not listening to doctors, 'I am not there yet'
'I did not give in then, I will not now;
Use wheels, change my lifelong goals?
The answer is NO, I will not change,
I am not listening, don't take me there.
To change, perhaps improve, must be a joke,
For if I change 'disabled' labels will I get.
I am a Polio Survivor. I do not give in.
Must pace and rest, listen to advice,
Goes against the goals of my whole life.
She can't do that, we can't go there,
I can, I will, I did and on I'll go,
On foot with canes, the steps to climb.
Tell me retire from work, No way!
Work, Sleep, No social life, that's me.
I'll stay here and read my book, you go,
With grandkids off to run and play,
I'll be ok, I have my book.
I tell no truth, with them I want to be,
Electric wheels, with them I could have gone,
Why is making change so hard to start
To take that plunge it strains my heart,
Five miles instead of twenty yards.
Why do I continue with my 'not yet',
My doc's advice of electric wheels,
Fills me with dread, a downward step.
Meet others like me and watch their joy,
Comfy seats, simple controls to hand,
Would I like to try? To do the same as you,
I try, what joy, less pain, less weary,
Why have I been so stubborn?*

*By Hilary Hallam -
(who still needs to take her own advice at times]*

**Polio and Post-Polio related news items
from news sources around the world.**

From the Lincolnshire Post-Polio Network Website.

September 7th 2005.

Non-invasive assessment of respiratory muscle strength in patients with previous poliomyelitis.

**Soliman MG, Higgins SE, El-Kabir DR, Davidson AC, Williams AJ, Howard RS.
Guy's, King's and St. Thomas' School of Medicine, St. Thomas Hospital,
Lane-Fox Unit, Lambeth Palace Road, London SE1 7EH, UK.
Respir Med. 2005 Oct;99(10):1217-1222. Epub 2005 Apr 12.**

In patients with poliomyelitis, respiratory failure requiring ventilatory support may occur during the acute illness. Some patients continue to require long-term nocturnal ventilatory support; others are weaned but subsequently require support because of a late deterioration in ventilatory function.

OBJECTIVES: To assess the sensitivity of sniff nasal inspiratory pressure (SNIP) to post-poliomyelitis respiratory muscle weakness and to assess the relationship between the respiratory muscle strength and the need for ventilatory support in patients with previous poliomyelitis (post-polio patients).

METHODS: Respiratory muscle strength was measured in 50 post-polio patients. Tests included forced vital capacity (FVC), maximum inspiratory and expiratory pressures (MIP and MEP), and SNIP.

RESULTS: Twenty-one patients used non-invasive nocturnal ventilatory support (NIV group) compared to 29 on no support (non-NIV group). The percentage predicted FVC was significantly lower in the NIV group compared to the non-NIV group ($P=0.01$). Similarly, the percentage predicted MIP was significantly lower in NIV group ($P=0.007$). Low SNIP values (both absolute value and percentage predicted) were associated with the need for ventilatory support ($P<0.001$). Of the patients requiring no support, those who had been ventilated during the acute episode of poliomyelitis had a significantly lower SNIP than those who had never been ventilated ($P=0.04$).

CONCLUSIONS: Post-polio patients who are currently on nocturnal ventilation have significantly lower FVC, MIP and SNIP compared to currently non-ventilated patients. Non-ventilated patients who were ventilated during the acute episode of poliomyelitis have significantly weaker respiratory muscle strength than patients who were never ventilated. This study indicates that SNIP is more sensitive to post-polio respiratory muscle weakness than other non-invasive tests. Thus measurement of SNIP is a valuable tool for monitoring the progression of respiratory muscle weakness due to previous poliomyelitis and this can be applied to other neuromuscular disorders.

Respiratory Medicine, Vol. 99, Issue 10 October 2005, Pages 1217-1222

<http://mt.lincolnshirepostpolio.org.uk/archives/pandpp-news/001187.html>