



# The LincPIN

The **L**incolnshire **P**ost-Polio **I**nformation **N**ewsletter  
Volume 5 - Issue 8 — March 2005

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



*25th December 2005  
Luke and Grandma Ellen Riddle*

*29th December 2005  
Fiona and Grandma Marcia Falconer*



*February 14th 2006  
Tony & Diane Meladio's  
Wedding Day  
at Montego Bay, Jamaica.*



*21st January 2006  
Mary and Denise  
Celebrate their  
Civil Partnership Ceremony*



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

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### WE WOULD LIKE TO THANK THE FOLLOWING FOR DONATIONS RECEIVED TOWARDS OUR WORK.

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Jim and Jenny Rayner, Judy Barter, Barry and Olivia Branston, Di Brennand,  
Pauline and Robin Butler, Denise Carlyle, Sheila Dunnett, Margaret Edmonds,  
Hilary Hallam, Pat Hollingworth, Mary Kinane, Mary McCreadie, Di Newman, Chris Salter

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

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#### Next LincPIN Newsletter - June 2006

**Articles for publication 4th May by post or - [newsletter@lincolnshirepostpolio.org.uk](mailto:newsletter@lincolnshirepostpolio.org.uk)**

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# Message from the Chair

Dear Readers,

Welcome to the first of our quarterly newsletters. Team members, including some new volunteers on this side of the pond, have been busy writing pieces for this edition. Mary McCreadie has been monitoring some of the issues which come up for discussion and debate on our Members E-mail Forum which is basically a discussion group on e-mail. Some of these discussion topics are printed in this edition for your interest. Thanks to Mary for helping to bring a focus to specific topics relevant to polio survivors both in the UK and beyond. Hilary has also begun a section of congratulations to members who have recently had grandchildren, married or indeed formed civil partnerships (the law changed here in the UK in December), so we hope to continue this trend of publishing members' good news on a fairly regular basis. Thank you Hilary for finding the time and energy, and the copy, to put this newsletter together when Richard has been through so much recently. I also want to acknowledge Robin's regular contribution and wish him well with some surgery on his feet next week—if I get this piece in on time we will have the newsletter printed on time, despite busy schedules. I would encourage members to send stories and viewpoints, to join the e-mail forum, to volunteer some time to help with our upcoming AGM (we are awaiting the Charity Commission's go-ahead to hold the next AGM in June) or just to keep reading the newsletter and sharing the information.

With best wishes. Mary Kinane, Chair.  
mary.kinane@lincolnshirepostpolio.org.uk

P.S. Here is an article from my local neurological alliance, the Lancashire & South Cumbria Neurological Alliance (LASCNA), which was published in the December 2005 - Volume 1, Issue 3 of Neuro News and which I thought might be of interest. What is happening in your area?

The inadequate provision of electronic wheelchairs, across Lancashire & South Cumbria, was brought to our attention by the Regional Care Advisor for the MND Association. LASCNA presented a paper, at the June meeting of the Neurosciences Commissioning Advisory Group, demanding answers as to why waiting times depended very much on postcode.

In response to this paper, PCTs have found additional resources to help resolve this issue. Of the eight PCTs that commission wheelchairs, from the Disability Service Centre in Preston (part of Lancashire Teaching Hospitals Foundation Trust) four have committed additional resources, on a non-recurrent basis, to reduce the numbers on the waiting list and to especially target those that have been waiting an unacceptably long time.

The extra amounts made available are: Blackburn with Darwen £50,000, Blackpool £50,000, Wyre £36,000 and Fylde £12,000. Blackburn with Darwen have also made a further commitment to clear, entirely, their waiting list. The approximate cost of this would be about £45,000.

At least 80 extra patients would be treated with the initial £148,000 and another 23 for the second tranche of Blackburn funding.

Morecambe Bay have stated that there is no extra funding available we are still waiting to hear from Burnley, Pendle & Rossendale, and Hydeburn & Ribble Valley. Preston PCT have given a commitment to clear their relatively small backlog.

## **Response to article on pensions: by Margaret Edmonds.**

Following the article in the last LincPIN about occupational pensions, Dinah Foweraker wrote to me with some ideas. Dinah herself obtained ill-health retirement five years ago and her article about it was published in an earlier issue of LincPIN. She suggests that it may be getting more difficult to get early release of pensions on health grounds and I think in these days of everybody being expected to work longer and longer before getting any pension at all, it's worth being aware of this and being very clear about your own needs and rights – an occupational pension is part of what you've earned over the years.

Dinah makes some very valid points, including:

a) looking carefully at the rules of your own pension scheme; if you are a member of a trade union or staff organisation, get help and advice from them at an early stage. They may be able to act as a 'friend' at any discussions with your employer if you feel you need support.

b) Remember that Occupational Health works for the employer, not for you. But while it's true that the occupational health doctor may not know much about PPS, on the other hand there is a possibility that he or she may have come across it before in an employment situation, as there are lots of us around!

The occupational health doctor can make suggestions to the employer about accommodating your needs within the work place regardless of diagnosis. The Health and Safety people in a large organisation may also be able to make practical suggestions. It's sensible to look at all options before deciding that ill-health retirement is what you want, partly because if you can be seen to have tried to adapt and make changes at work and are still having difficulties, that is 'evidence' of the need for ill-health retirement. The more understanding you gain of the way other people view things, the more clued-up you will become about the best way to present your own point of view. And the clearer you will become about what is best for you.

c) Dinah rightly says it's worthwhile taking the time to get the unequivocal support of a consultant if you can, even if you have to ask your GP for a referral outside your home area. As some neurologists have doubts about PPS, an orthopaedic consultant may have greater practical understanding of your difficulties and the implications. Seeing a consultant privately might be quicker but doesn't necessarily guarantee the results you want.

It's probably true that pension managers will take a letter from a consultant seriously but in my own case, being unable to get written support from anybody relevant (other than verbal support from the occupational health doctor, who couldn't act for me), I got confirmation from the pensions managers that 'medical practitioner' means your GP. In effect, the role of the consultant is to support and enhance what your GP says.

Whether you are seeing your GP or a consultant, make sure they are aware of how your circumstances and health have changed and if necessary provide evidence about how you used to be. No doctor has the right to doubt what you say about yourself, then or now, if you stand by what you are saying.

I would also suggest providing information about PPS for both the doctors and the

pension managers, but make sure the articles are pertinent to your own situation and keep information as brief as possible. Don't be afraid to disagree with the doctors but be ready to give your reasons for disagreeing. Dinah makes the point that it's not necessary to get a diagnosis of PPS to get ill-health retirement, but in the UK PPS has now been recognised by the Department of Health as a genuine long-term condition and this can be pointed out in cases where doctors are still suggesting it may all be a myth.

The permutations of retirement/ ill-health retirement/ part-time work/ less stressful job etc. are different for everybody and different factors also come into play depending on whether you are applying for your pension from your present employer or from a previous employer. Or whether it's a private pension from a financial provider.

The key to success seems to be persistence and patience – don't apply for the pension until you are sure you have all the information needed. Be clear not only about the pension scheme rules and how your situation fits the rules, but also as far as possible be clear about your own experience of polio and your past and present experience of its after-effects. Your truth about yourself is inviolable.

***Lincolnshire Post Polio Network, Polio and Post Polio News.  
February 23, 2006 - Welsh drop commitment on disability.***

The Welsh Assembly has dropped its manifesto commitment to provide free personal care for disabled people after admitting that it could not afford its plans. Labour's 2003 Welsh manifesto promised to introduce free care, after estimating the total cost at £50m over three years. But last week health minister Dr Brian Gibbons said new costings had shown that 'we could not put in place our original plans equitably and affordably'. Instead a package costing £76m over the next three years will be created, following consultation. The Welsh Assembly government blamed legal issues over definitions of 'free' and 'disabled', and pointed to evidence from Scotland where demand for free care rose after it was introduced. The minister said funding would be targeted towards disabled people on the lowest incomes who paid for personal care.

Health Service Journal | Welsh drop commitment on disability. 23rd February 2006.

The original of the above article can be found at  
<http://www.hsj.co.uk/nav?page=hsj.news.story&resource=4404983>

<http://mt.lincolnshirepostpolio.org.uk/archives/pandpp-news/001593.html>



**The Post Polio Awareness & Support Society  
of British Columbia, Canada  
is presenting a Post Polio Symposium in the spring of 2006.  
Location: Vancouver, B.C. Canada.  
Dates: March 30th to April 2nd 2006.  
Theme: Maintaining an Independent and Healthy Lifestyle.  
LincsPPN Life Member Marcia Falconer is a speaker  
NEUROINFLAMMATION, STRESS AND PPS SYMPTOMS:  
Marcia Falconer PhD., Virologist from Ottawa  
<http://www.ppass.bc.ca/>**

## **Cherish your arms, by Member Anne Wood**

Accompanying photographs Page 24

Having been on the slippery slope of PPS for at least 15 years, I have amassed many short cuts, tips, etc. I've been jotting things down as I think of them, but so many ways have become second nature to me by now that it takes a bit of head-scratching to think of them all and wonder if everyone does things my way or if I have developed strategic methods peculiar to me.

One of the biggest shocks to my system came when I realised that I had really overdone it after a particularly frenetic Christmas five years ago. My arms and shoulders didn't recover like usual after the last minute shopping and wrapping on Christmas Eve. When The Day dawned I still felt exhausted and my arms were very sore..... just moving them or having them hanging by my sides hurt. I spent much of the day sitting down with my arms supported on pillows. I was getting really worried that the pain would be permanent, as I remembered years ago talking to another polio survivor whose arms ached most of the time.

In the following weeks my GP tried a variety of painkillers, but nothing was effective. I spent days at a time lying flat in bed with a heated pad under my shoulders, crying with despair, my depression deepening as I envisaged the rest of my life in a chair with my arms almost useless. Weeks turned into months with no improvement and my husband had to shoulder most of the housework, cooking and shopping as well as having to work from home, while I was miserably laid up. I could no longer drive, my social life had gone down the tubes, including my singing, and I had resorted to voice recognition in order to continue using my beloved computer. It was a thoroughly miserable time.

Eventually I saw my neurologist who told me there was a drug he used to treat epilepsy but which was also effective with neuropathic pain – Neurontin (gabapentin) – so he started me on a low dose. The pain began to ease as the dose was increased over several weeks, in conjunction with the other painkillers I was on – dihydrocodeine and Dosulepin (dothiepin). I tentatively began using my arms a little more, feeling hopeful, but still I was very careful and in fact it was over a year before I began driving again, after an assessment at a mobility centre to make sure I was safe behind the wheel with my limited strength. They recommended arm rests be fitted to my car, which gave wonderful support when driving. Looking back, I am sure that the deliberate rest I gave my arms for such a long time enabled me now to lead a more fulfilling life, albeit with restricted arm usage and careful pacing.

This long preamble is to show how seriously I took the deterioration in my arms and shoulders.....losing leg strength is one thing, overcome to a reasonable extent by using a wheelchair and other adaptive equipment, but arms are even more precious. A home can be altered fairly straightforwardly to cope with wheels, but there is no device to take the place of arms and life is incredibly difficult when their use is lost. I am conscious of my arms at all times, they are at the forefront of my mind whatever I am doing..... I never over-tax them either with movement or weight. To this end, I have various coping strategies which help my arms and, along with the enforced rest mentioned above, I haven't needed to take the Neurontin for

over 2 years now.

One of the worst stresses arms undergo is lifting and carrying, and I look back ruefully at the years I spent pushing myself up from chairs and beds as my legs began to weaken. Currently I have a perching stool, a manual wheelchair, indoor and outdoor powerchairs, all set at just the right height for me to get up without using my arms, and a rare recliner armchair which raises me vertically without tipping me forward... see <http://www.chessco.net> . They don't mention this chair on their website but it's worth contacting them if you are interested.

I also have a powered cushion-lift [www.mangar.co.uk/products/cushion](http://www.mangar.co.uk/products/cushion) which again raises me straight up and I can take this with me when traveling.

My bed, likewise, raises me the same way, as well as having a reclining mode - email them at [tbs@thebedshop.co.uk](mailto:tbs@thebedshop.co.uk) I don't go *anywhere* if I can't take one of my wheelchairs as I need the armrests and one of my air cushions at my back to accommodate my scoliosis. The air cushions cost a few pounds in a camping shop and I tuck one, half filled, into a cheap cotton tote bag, or other lightweight bag with straps to put over the wheelchair arms. The tote bags are invaluable to carry shopping and I can hook any number on my chair.... I'm sure I must be known as the local bag lady, but I stopped worrying about that when it became necessary for me to take full responsibility for myself after my husband left me.

Also hanging off the arm of my chair is a tubular pencil case with a double zip into which I put my half-litre bottle of water, and I keep a mini umbrella on the back handle. In my capacious wheelchair bag I always keep a pocket urinal [www.woodstockit.com/products/Uribag](http://www.woodstockit.com/products/Uribag) which is a complete unit, or a Whiz [www.whizaway.com](http://www.whizaway.com) used in conjunction with my own one pint plastic screw-top milk bottle with handle.

Thanks to the wonderful Internet I can order bulk groceries from my local superstore, and I ask the driver to put the bags straight on to the kitchen table. I generally arrange for a friend to help me put them away, but if I'm on my own I put the goods on my kitchen trolley to move them nearer the fridge, cupboards, etc, pushing it with my stomach or sideways on with my hips.

Still in the kitchen, I slide heavy pots and pans across the worktops which are in a continuous run along the walls in an L-shape. I rest the edge of saucepans of cooked vegetables on the sink and slide the contents into a colander, rather than draining with the lid. [Editors note: Try using a chip pan basket in the saucepan, or lift larger veg out with a slotted spoon].

My kettle sits in a tilting stand and I fill it using a plastic jug. I eat in the kitchen and my perching stool is just the right height at the table - I either drag it or "walk" it to the right spot, and I can perch on it to work at the sink with the cupboard underneath open. If a table isn't convenient for a wheelchair or perching stool, try fitting a tray into an open drawer to make a little table for one.

I have a washing "basket" on wheels to carry washing from the laundry bin to the

sink, then to the tumble dryer or washing line, and I have a peg bag on a hanger to hook over the line. If it hurts to bend down I can grasp the washing with a grabber, though this does place more strain on my arm. The grabber is invaluable for picking up dropped items ..... more and more things seem to end up on the floor these days as my grip isn't so good .... and the little magnet on the end is useful. It can also reach up to shelves, though things I use on a regular basis I keep lower down.

I have a long-handled dustpan and brush and a wide cotton mop for quickly running over my parquet flooring which is so easy to keep clean. We ditched some of our carpets which had become stretched and rumpled from the wheelchair, and had the natural wood-flooring restored which is much more suitable.

I rarely iron, but I bought a little travel iron very cheaply and it is extremely lightweight for the odd item needing a press. It can be painful hanging heavy clothes in the wardrobe, but getting them down is easier if you can slip the item off the hanger first then retrieve the hanger on its own, rather than lifting the laden hanger up over the rail.

I am right-handed and because my left shoulder is paralysed I've greatly over-used my right arm, so I try to use my left arm instead when carrying anything small such as a book or hot water bottle. I tuck it right up under my armpit so the dead weight of the arm keeps it there. If it's a little too heavy I grip my waistband or pocket with that hand to take the weight off the straining arm muscles.

I try to avoid my arms hanging loosely at my side because of their weight, so if possible I rest them on something or, again, tuck them into my waistband or pocket. A note of caution here – don't walk with hands in pockets if you are prone to falling as your reaction time may not be quick enough for you to break your fall with your hands: it could be worse to injure your head or face than an arm.

Holding a telephone to my ear is impossible for more than a few seconds and I wouldn't manage without my headset which I keep plugged into the phone. They aren't cheap but are essential for me. The phone is a cordless model and I have two so that one is charging while the other is kept in my pocket or clipped on to my waistband. At night I put the phone on my bedside table.

Also inseparable from me is my Community Alarm button worn round my neck, which I can press for help in the event of a fall. My local council supplies this for a small monthly charge. In the dark evenings I have more than one light on so that when a bulb blows I'm not in total darkness; I have a battery light or torch in most rooms for the odd occasion when there is a power cut.

It took me a long time to work out a comfortable way of using my computer – even the occupational and IT therapists weren't very helpful. I park my indoor wheelchair as near to the desk as the control will allow, then I rest a beanbag tray on the arms of the chair and the desk, put the cordless keyboard on the tray and I use the cordless mouse on the tray in front of the keyboard. I have a lightweight flat screen monitor which is very easy to move around. The beanbag tray is useful for many activities when one might sit at a table, and I also take it to choir practice to rest my

music on.

[Editors note:- another idea is to work from your recliner/electric rise recliner chair. Either with a laptop on your lap, or some PPSers put all their computer gubbins on a wheeled trolley and park this by the recliner chair and use a beanbag on their lap for the keyboard. The trolley can be pushed out of the way or into a bedroom/garden room, allowing computer use at different times/places]

I've just splashed out on having my bathroom turned into a wet-room with a level-access shower and it's bliss to relax on my adjustable bathroom stool, instead of having to clamber into the bath in order to have a not-too-safe shower. My new toilet has a built-up base, [Editors note, I had a much higher toilet base fitted so I did not have to use the booster seat] and with my smaller 4 inch booster seat is just the right height. I opted for a lever action for the flush rather than a button so that I could operate it with my elbow, and in fact my builder ordered a wide paddle especially for that purpose. I wouldn't be without my electric toothbrush as it saves all that back and forth movement which is so tiring.

I am very fortunate to have a south facing, beautiful terrace outside my kitchen with level access through French doors, and raised flower beds which are just the right height for me to work on them. Gardening is wonderful therapy when it's not too arduous and as my terrace is covered I can work or sit out there even when it's raining. I plant up lots of pots which are moved around according to what's currently in flower, courtesy of visiting friends. A good tip to keep your garden in colour or interest throughout the year is to visit a garden centre once a month and buy one or two plants which take your fancy at that particular time of year. My terrace is my pride and joy and I revel in the compliments given me.

My digital camera beautifully captures the changes in my terrace throughout the year and I can recommend a great place to store your digital images..... go to Google, click on More and scroll down to Picasa – a free place to find, edit and store your photos, and it is very easy to use.

All these ideas help make my life a little easier, and I hope some of them will be helpful to you now or in the future.

I am sure others have many more ideas, share them with us, and know that at least one other member will be saying, 'Why didn't I think of that?'

**Anne Wood January 2006**  
**Anne <poglet@BEEB.NET>**

26th January 2006 we learned of the passing of  
Member Raymond M Owen.  
Our condolences to his family and friends.  
His continued support for our organisation was greatly appreciated.

## COMFORT HINTS—Air Cushion and Apron from Viola Pahl

**Air Cushion**—The usual air cushions don't last all that long, so my husband came up with the idea of using the inner tube of a wheelbarrow wheel. I covered it with fake fur, also putting a strip of fur for a small handle so it could be easily carried from place to place. I have not had to put air in the cushion for two years - and it doesn't need air replacement as yet. Earthquakes can have an unexpected effect on air cushions, though! I was sitting on the air cushion when it began to rock and roll like a water bed. After a minute or two, my knick-knacks began to rattle on the glass shelving. The earthquake was east of Seattle - and we are at least 90 miles away. I phoned the seismologist and he said the reason for the agitated air cushion was that the air was trying to escape. So - just hope that if there is an earthquake near you, that you experience nothing more than the shaking of your air cushion.

**Apron** - Here is my idea for keeping things within easy reach when you're in a wheelchair. A good old-fashioned apron, to which I have added pockets of varying sizes, which will take things like your mobile phone, pen and paper, keys, scissors, cutlery etc. As the pockets are going to be supported on one's lap most of the time, it's possible to use something like 'Wundaweb' in order to stick them into position, especially if you're 'sewing challenged' like me!

### Requirements:

1 Apron - Material for making the pockets - Pins  
Wundaweb (or similar) - Iron and damp cloth

Once you have decided on the size and shape of your pockets, cut them out from the material. Fold rough edges inwards and pin on strips of Wundaweb cut to size. Spread apron out flat, place 'wundawebbed' pockets into position. Place a damp cloth over the pocket (I recommend doing one at a time!). Using a hot iron, press pocket until firmly attached. Leave to cool before tackling the next one. Remember to remove pins! If you are more adept, then simply sewing the pockets on does provide a stronger result!

### Dear Post-polios,

I am an established writer at the start of some major research for a book looking at my parents' life together from the time that my father got polio in 1952 and TB some time later, how it affected our family life together and the realisation, much later, that polio never really is 'got over' but can reappear in the guise of PPS.

My father died in 2003 aged 76, telling us very little of his decade of illness despite having been a wheelchair user for fifty years. My mother is fit and well and has encouraged me to write their story but there are large gaps in her memory. If there is anyone who remembers my father, had experience of the hospitals he was in, knew any of the medical or nursing staff, or has any memories triggered by the names, places and events outlined below, I should be very grateful if you would like to get in touch.

Prockter Pulman (also known as Push, PT or Pete) spent the early part of 1952 training for selection for the Helsinki Olympic Rowing team. He failed selection but he and his partner beat the selected pair later and was expected to be a serious contender for the 1956 Olympics. He took a new job at Muntz Engineering, married Diana Latta in September 1952 and became ill with polio late October where he was taken to the Uxbridge Isolation Hospital (possibly now Hillingdon Hospital). After 8 weeks he was moved to The London Hospital (now the Royal London) in Mile End Road. He was in the orthopaedic section,

Hanbury Ward and the Ward Sister there was Anne Johnson (still a family friend). The physiotherapist was Wendy Hillier. He was there for nearly two years.

Sometime in 1954 he was being measured for callipers and was getting fit enough to try walking (particularly tricky as he was six feet and four inches tall) but he developed TB and was moved to the London Hospital Annexe in Brentwood, Mann Ward. Treatment for TB was the opposite for polio, all the physio sessions had to stop and instead he had to have complete bed rest. He had streptomycin treatment but his legs were too wasted to inject so every injection was in his arms which became very ulcerated. Strep. had 'bad batches' which my father unfortunately experienced but I have no idea what the result of 'bad' strep. was. Has anyone knowledge of polio and TB together?

Eventually, my father went to Stoke Mandeville which was under the direction of Dr Ludvig Guttman, the founder of the para-Olympics. His treatment was heralded as revolutionary in technique and certainly had a good success rate but my father said he and his team were pretty brutal. I'd particularly like to know about this regime. While at Stoke Mandeville he was encouraged to practice archery. He made friends with a fellow wheelchair user called Jim (no surname) who was in the RAF (my father too had been in the RAF and in the Berlin Airlift). Jim was interested in observing how arrows and bowstrings behaved in flight. Together they designed a photographic device to capture these images. I have a letter and photographs of Jim and my father shooting arrows under a score board for 1955. The letter from Jim is written shortly after his release from Stoke Mandeville and he is staying at the Officer's Mess, RAF, Headley Court, Nr. Epsom. I would love to find out who Jim was. He talks about a woman! called 'Coach' at Stoke. Any ideas? Jim was also interested in Aeromodling and had a mutual friend called Dick (also known as Wicky) Higham.

Other facts about my father might help jog some memories. His family home was at Thelveton in Norfolk, he had a scholarship to Cambridge before the war and studied engineering then went up again after the war and did an MA in Business Law. He rowed for London Rowing Club, the RAF and Leander RC before he was ill. He was immensely tall, fair haired, had a black front tooth and was very, very funny, in fact I'm told by Anne Johnson that he had the medical staff in despair because of all the elaborate practical jokes and stunts he would pull. He sounds rather a liability to have on a ward and if you were with him you might remember him because of the chaos he caused!

Finally, if anyone would be prepared to speak to me about what they remember about the first few days of onset of the disease and about the years of rehabilitation, I should be very grateful.

Although my father was almost completely paralysed at one point, he never had to use an iron lung, which was a mercy. He regained his mobility to waist level, minus his thumbs. He had his own successful research and development engineering consultancy, raised me and my brother, provided more than adequately for his family and maintained a strong marriage with my mother until his death. He was a powerfully patriarchal figure with a huge character, very controlling, sometimes very frightening, highly motivated and expected the same from everyone around him. I had a sometimes very prickly relationship with him but I think he would be pleased to know that I was doing this and it is with the complete co-operation of the rest of the family. I miss him like crazy and want to do him proud.

**Please contact me, Sarah Passingham, by email: [sarahpassingham@btinternet.com](mailto:sarahpassingham@btinternet.com)**

Or write via our main address putting Sarah's name on the bottom left hand corner of the envelope and we will pass the letter on to her.

## Hypoventilation? Obstructive Sleep Apnea? Different Tests, Different Treatment.

Judith R Fisher, MSLS, Editor

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People with neuromuscular disorders may be misdiagnosed and mistreated when they encounter breathing and sleep problems. Many general practitioners, and even some pulmonologists, neurologists and sleep physicians, may not fully understand respiratory insufficiency in this group.

Hypoventilation. Generally, in people with neuromuscular disorders who are having breathing problems, the main problem is hypoventilation (underventilation) - not breathing deeply and/or often enough. Muscle weakness, scoliosis and/or chest wall stiffness make it difficult or impossible to fully inflate the lungs.

Hypoventilation results in an imbalance in the carbon dioxide (CO<sub>2</sub>) and oxygen (O<sub>2</sub>) exchange in the blood—too much CO<sub>2</sub> is retained, too little O<sub>2</sub> is taken in. Because hypoventilation usually first occurs during sleep and because several of the **signs and symptoms** overlap, it can be misdiagnosed as obstructive sleep apnea (OSA).

Although any trained health care professional can perform simple pulmonary function tests (PFT's) of breathing ability during an office visit, the tests are most likely to be performed by a pulmonologist, neurologist, nurse or respiratory therapist. The challenge lies in understanding the results of these tests in the context of a person with neuromuscular disease.

Two important measurements of your ability to breathe deeply are the forced vital capacity (FVC) and maximum inspiratory pressure (MIP or PiMax). The SNIP (stiff nasal inspiratory pressure) test has been shown, in some studies, to be a more sensitive test of respiratory muscle weakness, but it is not widely used in the USA.

Forced vital capacity measures the volume of air you can breathe in and then blow out quickly and completely through a device called a spirometer. It should be measured in both the upright and supine (lying face-up) positions, because you can't breathe as efficiently lying down.

Another simple test that measures the strength with which you can breathe in is the MIP. A mouth piece is attached to a negative pressure gauge via a narrow tube. With a nose clip pinching off the nostrils, you exhale and then suck on the mouthpiece as hard as possible; the gauge registers the pressure.

A result of <50% predicted FVC (Forced Vital Capacity) or a MIP (Maximum Inspiratory Pressure) <60cm H<sub>2</sub>O may signal that it's time to get some assistance with breathing.

However, the most important factor in diagnosing hypoventilation is an elevated level of CO<sub>2</sub> (above 45mm Hg). This can be measured invasively with an arterial blood gas (ABG) analysis or noninvasively using exhaled end-tidal CO<sub>2</sub> monitoring or transcutaneous CO<sub>2</sub> monitoring.

The pattern seen on an overnight oximetry tracing may also be helpful for identifying early hypoventilation often seen first during the deepest rapid-eye movement (REM) sleep stage.

Signs and symptoms of nocturnal hypoventilation may include one or more of the following:-

- ◆ Fatigue or exhaustion after normal activity;
- ◆ Excessive daytime sleepiness;
- ◆ Shortness of breath, breathlessness with minimal activity;
- ◆ Claustrophobia or feeling that air in room is somehow bad;
- ◆ Difficulty in speaking for more than a short time;
- ◆ Quiet speech with fewer words per breath;
- ◆ Inability to lie flat while awake due to shortness of breath;
- ◆ Inability to lie flat during sleep/need sitting up (orthopnea);
- ◆ Trouble falling asleep and trouble staying asleep;
- ◆ Anxiety about going to sleep.

Other signs and symptoms, which may also be seen in OSA, (obstructive sleep apnoea) include:-

- ◆ Excessive daytime sleepiness and need to nap during the day;
- ◆ Nightmares, night sweats, bedwetting, or need to urinate frequently;
- ◆ Morning headaches;
- ◆ Restless/fragmented sleep with frequent awakenings;
- ◆ Shallow breathing or cessation of breathing for 10 seconds or more;
- ◆ Awakening from sleep with choking sensation;
- ◆ Worsening mental status, impaired memory, concentration, cognition.

Do not ignore these signs and symptoms hoping they will go away. They are serious. You may need evaluation and treatment immediately!

The treatment for hypoventilation is NOT oxygen but assisted ventilation, generally at night with a bilevel ventilator. Bilevel units that offer the S/T mode (the unit operates in a spontaneous—S—mode, meaning the user can spontaneously initiate each ventilator breath, but switches to a timed—T—mode, referred to as the backup rate, when breaths are not initiated by the individual) are recommended for people with neuromuscular disorders.

Bilevel ventilators provide pressure support ventilation which is achieved by the difference in two set pressures; IPAP (inspiratory positive airway pressure) and EPAP (expiratory positive airway pressure). The IPAP and EPAP pressures settings can be adjusted separately.

People with neuromuscular disorders have more trouble breathing in. They generally need IPAP that is set at least 5-10cm H<sub>2</sub>O higher than EPAP and EPAP that is set at the minimum level. Higher EPAP makes it too difficult for them to exhale. "In my home care company, we start out people new to bilevel with 'training wheels' - a minimum span of 5cm H<sub>2</sub>O. After they become acclimated to the treatment, we increase the span if the individual is more comfortable and/or needs more volume", says Diana Guth, RRT.

For reimbursement of a bilevel unit in the USA by Medicare, the requirements are a diagnosis of a progressive neuromuscular disorder, absence of chronic obstructive pulmonary disease (COPD) or if present it does not significantly contribute to the individual's respiratory limitations, and one of the following test results:-

- FVC <50% of predicted.
- MIP <60cm H<sub>2</sub>O,
- PaCO<sub>2</sub> arterial blood gas >45mm Hg.
- Nocturnal SpO<sub>2</sub> (oxygen saturation)
- <88% for five continuous minutes while asleep.

#### Obstructive Sleep Apnea (OSA)

Apnea is the cessation of airflow for more than 10 seconds. OSA occurs when tissues in the throat collapse, intermittently blocking airflow during sleep. Snoring is often a major indicator of OSA, but not always.

A sleep study (polysomnogram test or PSGT) is primarily used to determine and design treatment for individuals with OSA. A sleep study is not absolutely necessary for the diagnosis in people with neuromuscular disorders but it may be helpful when first introducing bilevel treatment.

The main breathing problem is almost always hypoventilation, although people with neuromuscular disorders early on may also have undiagnosed OSA. Most sleep labs are not equipped to measure CO<sub>2</sub> levels, and therefore cannot diagnose hypoventilation.

The standard treatment for OSA is continuous positive airway pressure (CPAP) to help keep the airway open or a bilevel unit without a backup rate.

Thanks to Josh Benditt, MD, University of Washington, Seattle. benditt@u.washington.edu); Peter Gay MD, Mayo Clinic; Diane Guth, RRT, Home Respiratory Care, Los Angeles (Diane@hresleep.com); E.A. Oppenheimer MD (retired) Los Angeles; and Jesper Qvist, MD Respiratory Centre East, Copenhagen, Denmark (jq@dadlnet.dk) for their assistance.

<http://www.orthoticmobility.com/steppers.html>

### ***It walks with you!***

The Stepper® product line includes both Sure Foot® and Sure Step® canes with attachments and varying sizes available. Each utilizes a skid-resistant sole with a traction surface of 18 square inches -- much larger than the small tip on traditional canes (1 to 2 square inches). The Stepper's sole remains flat on the walking surface regardless of how it is placed, and the patented ankle has a shock absorber to soften the impact on the user's hand and arm.

These revolutionary, user-friendly products are lightweight and able to stand alone. They provide added stability, greater accessibility and convenience not offered in traditional canes. The Sure Foot and Sure Step are the world's only stand-alone canes with an ankle that "walks with you."



#### **MSRP**

Sure Step \$59.95

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Steppers are constructed of aluminum and stainless steel. They are fully adjustable and very lightweight. A 90-day warranty (parts and labor) is included. Typically, using a cane requires a person to be cautious about where the tip is placed, restricting where it can be used, and increasing the chance of a fall and injury. This isn't so with a Stepper! They can be used on most walking surfaces, including stairs, snow, grass and stones. The slid-resistant 3" by 6" base of a Stepper will take you where you need to go. In fact, users often describe the Stepper as an extra leg and foot.

[Sandra Cuadra visited me and showed me her arm crutch. 'Gosh' I said, 'the foot plate looks more disabled than a ferrule' to which we both laughed. I tried hers and was very surprised at how much easier it was for me to walk and stand still. To give a cane/crutch an 'ankle joint and foot' was a great idea, and it is really good on sand and rough ground. I ordered my own and am very pleased with them—Hilary]

## Hydrotherapy by Mary McCreadie.

'I think we'll try some hydrotherapy and an AFO before we go down a surgical route', said my new Orthopaedic Surgeon. Not only has he seen and treated polio victims in the initial stages of the disease, but he actually knows about PPS. He is concerned that the problems with anaesthetics and recovery from surgery with PPS patients, coupled with the danger of actually making things worse, outweigh possible advantages. Finally getting to a doctor who knows about PPS, was rather like winning first prize in the Lottery!

I thought it would be months before I got an appointment for the hydrotherapy – but within a week, I was called to go for a preliminary examination by the Neurological Physiotherapist. I rather came down off my little 'cloud 9' when I met this lady. She was a touch heavy-handed, and her perfunctory examination (which didn't include actually looking at my polio leg) made me somewhat apprehensive. Questions like: 'Well WHY can't you do....' this, that or the other, didn't help either. She admitted that she had never heard of PPS – but told me that having done a little research on the internet, she now knew all about it. Guess which site she looked at? Yes – ours!

As the doctor had suggested trying an AFO (ankle, foot orthosis) for me, the Physio brought me an 'off-the shelf' one to try, shoved it on me and sent me on my merry way. **WARNING!** Don't ever let anyone do this! AFO's must be fitted properly, although I didn't realise this at the time. The idea is fine, but a) my foot is too twisted to accommodate an AFO, b) my boots were too shallow to take my foot and the AFO. c) the part of the AFO which runs up the back of the heel was the wrong size for me and cut in badly, so by the time I got half way back home I was in serious trouble with it. My foot had swelled so much I had great difficulty in getting my boot off, and my knee had swelled to football-like proportions. I did try the AFO again, but with the same result. So that went back, and I now have an appointment for a proper fitting.

My first dip in the water came a few weeks later. I arrived in plenty of time – time enough to start worrying about how I would get from changing cubicle to the water, how I would get in and out of the pool – you name it, I worried about it! But I needn't have done. I was able to drive my scooter to a cubicle 'pool-side', which was big enough to accommodate both the scooter and me, and once I had changed into my swimming costume, was ready for the pool. The attendant pulled back the curtains, and brought a hoist (which looked rather like an enormous sun-bed on a pole) right to me, so that all I had to do was get myself onto it. The attendant helped by lifting my legs up for me, and once settled, the whole thing was wound up and around and then down – very slowly and gently – into the water, where the Physio was waiting for me.

Her attitude towards me changed dramatically when she actually saw my leg. I wonder whether she had secretly thought I was 'making it all up', and had been expecting a perfectly normal leg....

I will never forget the delicious feel of the warm water – first time I've been immersed in water for nearly 10 years! I didn't have to actually do anything. The Physio supported my neck and back with floats, and proceeded to do what she called 'sea-weeding' for about 5 minutes. 'Sea-weeding' involves being held by the shoulders and being wafted from side to side. The idea is to loosen and stretch muscles in one's back, and to get sideways movement at the waist. Initially, not much appeared to happen, other than I became extremely tired. I was then asked to stand holding the rail, and to stretch up to make myself as tall as possible. After a couple of stretches, my time was up and it was back to the hoist to be lifted out and back into the cubicle. After dressing again (which took me ages!), I was given an appointment for the following week, and I got back on the scooter to go and get a well-earned cup of coffee before going home.

Although tired by the hydrotherapy, I was feeling pretty good. But after a 30 mile journey back home I began to feel the effects. The following day I was very, very stiff and uncomfortable – not what I had expected – and it took a couple more days to get over the effort.

The second appointment was far more rigorous. I was in the water for about 20 minutes, did more of the ‘sea-weeding’ and then the Physio started to push and pull me about – albeit fairly gently, with the idea of getting my leg straighter. (I have a flexion contracture of the knee, unstable valgus of the ankle, and my foot is drawn up tight under the arch.)

I did try to get the Physio to understand that I was finding the manipulation of my leg too painful – but she thought it was necessary and ‘a bit of pain’ was only to be expected. I’m not too good at standing up for myself when pushed like this, and didn’t feel able to argue. I wish I had. The consequence was that I spent the next few days in bed through exhaustion and pain, and had to cancel the next appointment. That did not go down very well! However, another appointment was arranged for the following week, and we went back to doing the very gentle work done in the first session. I have a break for three weeks now, as my Physio is away, and then I shall have one or maybe two more sessions.

Results from all this? I have to say that there has been a slight reduction in pain – but more importantly, I am finding that I can sit just a bit straighter in my wheel-chair – which in turn, helps with lessening pain. So all in all, there has been some benefit, but whether it will last, I can’t say. Was it worth all the effort? Bearing in mind that each session cost me at least two days of enforced inactivity to recover, it was expensive in time, but any reduction in pain has to be good.

I think it is important to realise that for PPS patients in particular, going for hydrotherapy is not like a well person simply ‘going for a dip’! We need to consider the effort that will be involved quite apart from the actual therapy. In my case, I had to:

- a) get the scooter ready and in the car the previous day.
- b) drive 30 miles to the hospital.
- c) off-load the scooter, and drive to the Physiotherapy department
- d) get changed ready for the pool.
- e) have the therapy.
- f) get dressed again
- g) drive back to the car and re-load the scooter
- h) drive 30 miles back home.

If you have the chance to go for this treatment, I would still recommend that you take it if you feel you can. Who knows? You might well benefit.

Mary McCreadie

[Editors Note—Back over seven years ago I was offered four weeks hydrotherapy. All ten in the pool had to do the same exercises, regardless of condition. It was do 10, do another 10. Although I knew a bit about PPS by then I did not know enough and assumed that their ‘I know about PPS’ meant that they did. I got a lot of pain/fatigue from the sessions and in fact found out later that two of the exercises were totally contraindicated for the weak muscles in one leg.. Now with my Advanced Swimming Teacher hat on—Warm water and gentle stretching and gentle exercise, that takes into account your Polio body and which muscles can do what and how often, can be very good for you, provided you have the energy from your daily use to do all the getting there and undressing/dressing etc. Listen to your body, write it down and try and get the therapist to work with you to get the most out of the sessions. Therapists are taught to count in 10’s, and many find it hard to be asked to work with other numbers. I am good at 3 sets of 3 repeats with rest in between but push me to five repeats and I am in pain and can do no more.

Good Luck. Hilary Hallam, F.I.S.T.<sup>1</sup>, F.I.S.T.{LS<sup>2</sup>}

<sup>1</sup> Fellow of the Institute of Swimming Teachers.

<sup>2</sup> LifeSaving.

## Back page pictures by Mary McCreadie.

Imagine coming home late on a February afternoon, tired and gasping for a cup of tea – only to find that the Highways Department who have been resurfacing pavements in your area, have knocked off early and left your gateway in this condition! It was known that I was disabled, and we'd had quite a bit of discussion about the problem of access. Not only could I not get over the impossible 'surface', I couldn't even move the bollards!

I was absolutely furious! It took some little time to find one poor little JCB driver who had made the mistake of returning to his vehicle to fetch something he'd forgotten – only to be faced with a very irate me! He came and surveyed the scene, scratched his head and said

'Well.....dunno what we can do 'bout it.....I s'pect foreman's gone 'ome.'

Foreman had indeed gone home, but the driver did manage to find the number of the depot for me. So, I rang and spoke to a chap who immediately organised a gang to come out and try to make it possible for me to get back into my home.

They arrived half an hour later armed with several buckets of quick-setting tar to try and smooth things out for me. NOT very successful! But with great good humour on all sides, two of them lifted me over the mess and I at least got back into my home.

The following morning, everything was put back to rights, and one of the workmen knocked on my door to ask me to come and see how beautifully they had rolled the new pavement – extra smooth, just for me!

N.B. I don't *really* have the wheelchair sign on my gate at the time – it's just a bit of computer flap-doodle for fun! But, I will put one up in the future if I know this is likely to happen again.

### TOILET CLEANING INSTRUCTIONS.

1. Put both lids of the toilet up and add 1/8th cut of pet shampoo to the water in the bowl.
2. Pick up the cat and soothe him while you carry him towards the bathroom.
3. In one smooth movement, put the cat in the toilet and close both lids. You may need to stand on the lid.
4. The cat will self agitate and make ample suds. Never mind the noises that come from the toilet, the cat is actually enjoying this.
5. Flush the toilet three or four times. This provides a "power-wash" and "rinse".
6. Have someone open the front door of your home. Be sure that there are NO people between the bathroom and the front door.
7. Stand behind the toilet as far as you can, and quickly lift both lids.
8. The cat will rocket out of the toilet, streak through the bathroom, and run outside where he will dry himself off.
9. Both the toilet bowl and the cat will be sparkling clean.

Yours Sincerely,  
THE DOG.

## No Nursing Home for Me—Author Unknown

About 2 years ago my wife and I were on a cruise through the western Mediterranean aboard a Princess liner. At dinner we noticed an elderly lady sitting alone along the rail of the grand stairway in the main dining room. I also noticed that all the staff, ships officers, waiters, busboys, etc., all seemed very familiar with this lady. I asked our waiter who the lady was, expecting to be told that she owned the line, but he said he only knew that she had been on board for the last four cruises, back to back.

As we left the dining room one evening I caught her eye and stopped to say hello. We chatted and I said, "I understand you've been on this ship for the last four cruises". She replied, "Yes, that's true." I stated, "I don't understand" and she replied, without a pause, "It's cheaper than a nursing home".

So, there will be no nursing home in my future. When I get old and feeble, I am going to get on a Princess Cruise Ship. The average cost for a nursing home is \$200 per day. I have checked on reservations at Princess and I can get a long term discount and senior discount price of \$135 per day. That leaves \$65 a day for:

1. Gratuities which will only be \$10 per day.
2. I will have as many as 10 meals a day if I can waddle to the restaurant, or I can have room service! (which means breakfast in bed every day of the week).
3. Princess has as many as three swimming pools, a workout room, free washers and dryers, and shows every night.
4. They have free toothpaste and razors, and free soap and shampoo.
5. They will even treat you like a customer, not a patient. An extra \$5 worth of tips will have the entire staff scrambling to help you.
6. I will get to meet new people every 7 or 14 days.
7. T.V. broken? Light bulb need changing? Need to have the mattress replaced? No Problem! They will fix everything and apologize for your inconvenience.
8. Clean sheets and towels every day, and you don't even have to ask for them.
9. If you fall in the nursing home and break a hip you are on Medicare; if you fall and break a hip on the Princess ship they will upgrade you to a suite for the rest of your life.

Now hold on for the best! Do you want to see South America, the Panama Canal, Tahiti, Australia, New Zealand, Asia, or name where you want to go? Princess will have a ship ready to go. So don't look for me in a nursing home, just call shore to ship.

PS - And don't forget, when you die, they just dump you over the side at no charge.

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Fifteen days ago, I read that smoking can kill you; the next day I stopped smoking. Twelve days ago, I read that too much red meat can kill you; the next day I stopped eating red meat. Eight days ago, I read that drinking can kill you; the next day I stopped drinking. Yesterday, I read that having sex can kill you; this morning I stopped reading.

## Members E-mail Forum by Mary McCreadie

The last couple of months have seen a really big increase in the number of postings to the e-mail forum, which is very gratifying! Welcome to LincsPPN, member James Pullin – great to have you aboard!

Subjects discussed since the last Newsletter have again been diverse and interesting, as well as being very helpful. Remember if you do not have access to the Internet you can always write and ask me the question and I will put it on the list for you. Write to the Lincolnshire Post Polio Network address on page 2 and put “For Mary McCreadie” on the bottom left hand corner of the envelope.

So here’s a brief look at some of the questions that raised the most responses:

### **Q - Anybody know of a good neurologist/doctor/health professional?**

“**I finally** got to see an orthopaedic surgeon, after waiting nearly two years. I had been absolutely dreading going to see him, as previous experience with neurologists has been so horrible. I took some pps literature with me just in case he was one of those doctors who would argue about the diagnosis. This man was a delight, and knew not only polio but was well aware of pps and all the ramifications.”

“**I am** mostly a person looking at the positive, but it makes me angry that we have to sit and worry in advance about consultants and their moods. (The consultant) was rude in his manner with me and I just had enough of it all and I lashed back at him. Told him I do not work for him and IF they are afraid of him it is their problem. I heard the collective breath being sucked in and he stared at me and then cracked a smile, from there on we became good buddies until he retired. I prefer peace and quiet. Upsets make me feel off for days afterwards so I avoid them like the plague where I can.”

“**It is** difficult recommending any health professional unless you have had experience with them yourself and have had help, although that in itself is not enough as you might have totally different problems from other folks.”

**Note: We are considering the possibility of compiling a list of neurologists, surgeons etc. who have proved helpful to our members. However, we know from past experience that there are a number of significant issues that have to be addressed first. In the meantime, if you have had a positive experience, do please continue to share that with other members on the list.**

### **Q - What are your experiences of being out and about on a scooter/wheelchair?**

“...**at first** the electric wheelchair seemed very daunting to accept. NOW? I will not change it for anything.”

“**I’m glad** that I’m not on my own in feeling angry and resentful when pushed in a manual. Another thing I’ve remembered is that the pusher seems to have no idea of where in space our feet and the footplates end and I keep having to keep an eye on other people’s legs, and steering myself away from obstacles - which we can avoid perfectly well when in control of a power chair.”

“**I hated** my first time being pushed in a Manual Chair, all those bus exhausts and wheels the same height as you, and cars that seemed to be coming at 90 miles an hour.. and kerbs and the clunk as you came off the kerb.”

“**Did you** know that you can get electric controls that also go on the handle of the electric chair so that someone can push and steer you if you are in a crowd where you can't see enough.. or if you get tired.... YOU control when you want to and let someone else take over when necessary.”

“**I find** that when I am on my portable electric scooter people are very pleasant, holding doors open, letting me through and even admiring the scooter and wanting to ask about it!..... When you are on a scooter it is obvious that you are OK apart from your legs, whereas when you are in a wheelchair there could be anything wrong with you - does he take sugar syndrome!”

One question which brought a flood of replies (if you will pardon the pun!) was about portable loos! Anyone disabled is going to have a problem at some time or another, so this question was really helpful:

**Q - Help! My daughter's house has 24 stairs - in stages - to the bathroom, so I am in need of a Porte Jane. Please could someone give me a website?”**

“**I got two** kinds, courtesy of my GP so didn't have to pay for them. One is called the Whiz [www.whizaway.com](http://www.whizaway.com) and is a funnel type which you direct into, in my case, a 1 pint plastic milk bottle with a screw top lid! You have the option of asking someone to empty it down the loo, or taking it home with you The other is the Uribag [www.woodstockit.com/products/Uribag](http://www.woodstockit.com/products/Uribag) which contains granules. They turn solid when the urine hits them and it will hold quite a lot. You dump the bag when full. I also bought another one called a Traveljohn on the internet from ‘[www.betterlifehealthcare.com](http://www.betterlifehealthcare.com)’”

“**I believe Tesco** sells the Traveljohn - ring a few supermarkets to find out. Alternatively, your chemist might even have one or other of the above, in these more enlightened times.”

“**How about** a commode that you take with you?”

“Just type **Toilet Frames + Portable** into an internet search engine and go look at what's available. I did not have the time to look today at more than a couple but what I would like is something that can be folded and put in the car..”

“**UK Benefits Now Shop** have 'Folding Commodes' the most expensive of which appears to be height adjustable (see <http://www.benefitsnowshop.co.uk/>). While it appears the site offers quite a range of disability aids, although some items look good value, a lot of items seem quite expensive to me.”

This was just a small selection of the questions and replies  
and it's great to see our e-mail forum fairly buzzing!

We are looking forward to many more of our members joining in the discussions,  
so please - if you would like to join the list and are a paid-up member of the LincsPPN,  
send an e-mail to

**[join-pnl@lincolnshirepostpolio.org.uk](mailto:join-pnl@lincolnshirepostpolio.org.uk)**  
(please include your full name in the email).

Mary McCreadie, List Facilitator. [mary.mccreadie@lincolnshirepostpolio.org.uk](mailto:mary.mccreadie@lincolnshirepostpolio.org.uk)

## A Caregivers Bill of Rights - Author Unknown

I have the right....

1. To take care of myself. This is not an act of selfishness. It will give me the capability of taking better care of my loved one.
2. To seek help from others even though my relative may object. I recognize the limits of my own endurance and strength.
3. To maintain facets of my own life that do not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person and I have the right to do some things just for myself.
4. To get angry, be depressed and express other difficult feelings occasionally.
5. To reject any attempts by my loved one {either conscious or unconscious} to manipulate me through guilt and/or depression.
6. To receive consideration, affection, forgiveness and acceptance for what I do from my loved one for as long as I offer these qualities in return.
7. To take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my loved one.
8. To protect my individuality and my right to make a life for myself that will sustain me in the time when my loved one no longer needs my full-time help.
9. To expect and demand that as new strides are made in finding resources to aid physically and mentally impaired persons in our country, similar strides will be made towards aiding and supporting caregivers .
10. To be myself.

### Caregivers Tips.

1. Be good to yourself. Love, honour and value yourself. You are doing a very hard job and deserve some quality of time just for you.
2. When people offer to help, accept the offer and suggest specific things that they can do to help.
3. Seek support from other caregivers. There is great strength in knowing that you are not alone.

#### **THREE TIPS TO HELP IDENTIFY IF SOMEONE HAS HAD A STROKE**

Sometimes symptoms of a stroke are difficult to identify. Unfortunately, the lack of awareness spells disaster. The stroke victim may suffer brain damage when people nearby fail to recognize the symptoms of a stroke. Now doctors say a bystander can recognize a stroke by asking three simple questions:

1. \*Ask the individual to SMILE.
2. \*Ask him or her to RAISE BOTH ARMS.
3. \*Ask the person to SPEAK A SIMPLE SENTENCE (Coherently) (i.e. . . It is sunny out today) If he or she has trouble with any of these tasks, call 9-1-1 [999] immediately and describe the symptoms to the dispatcher.

After discovering that a group of non-medical volunteers could identify facial weakness, arm weakness and speech problems, researchers urged the general public to learn the three questions. They presented their conclusions at the American Stroke Association's annual meeting last February. Widespread use of this test could result in prompt diagnosis and treatment of the stroke and prevent brain damage.

## A Message to our Caregivers... by Hilary Hallam

We know we are stubborn, determined and often pigheaded. We know there are aids and assistive devices out there that might make our lives easier. We know that you, other family members and friends would be only too pleased to help us with tasks that are now more than we can manage.

We know all these things **BUT** we do not want to own or accept them. This is why we won't discuss them or even consider them. As we recovered from our polio we were told, 'no pain, no gain', 'use it or lose it', and we had to push ourselves constantly to prove that we could do all the things that we were being told 'would be too much for you'. To make a change seems to us like a backward step, seems to us as if we are giving in, that we are becoming old or that dreaded word 'disabled'. Health professionals and you, our caregivers, can tell us till you are blue in the face that it will make our life easier, but we have to do this when we are ready and we need you to understand this.

Those of us who have progressed through the first stages of accepting PPS have been surprised that whilst it was hard to use, *and be seen to use and go on being seen to use*, those aids and assistive devices, the energy they saved allowed us to do so much more. What seemed like a backward step in our lives was actually a forward step to managing life and getting more out of it. Hard to admit, but it is true.

We still don't like using the aids and equipment but we do so enjoy the improvement to our daily lives. [If many of us are honest we will admit that we tried canes, crutches and wheelchairs for the first time when we were away from home, far from where anyone knew us]

Only yesterday at a meeting a Physical Therapist said, 'If I become disabled I will use a cane, a walker, and a wheelchair, because I have seen how much help they can give you.' It was easy for her to make that statement. She had empathy and understanding but she had not experienced reality... I know, I have been there and thought the same thing, after all I knew all about disability, I had had polio... **BUT** when my time came I sobbed my heart out when asking my GP for a wheelchair.

[A polio survivor who has gardened successfully for over thirty years has gone outside to start digging over the vegetable patch ready for winter. The non polio partner watches him/her dig and rest, dig for less time and rest, dig for even less time and rest for longer. They don their 'welly boots' and out into the garden they go... 'I have come to help you'... they are stunned to be told vociferously, 'I have not needed any help for thirty years and I don't need any help now.' They go inside, deflated. Next day, unlike previous years, half the patch still needs digging, and out goes the gardening PPSer, who digs and rests and digs and rests and then storms inside and says... 'I don't suppose it would occur to you to come out and give me a hand'!!! - Anyone recognise this or a similar story?]

**Caregivers to Polio Survivors**—we need to learn how you feel about the things that are happening to us. Write to us with any hints, tips, suggestions, funny stories, that would help us all work together to improve the quality of all our lives. Let these two pages be your pages. Is there a Caregiver out there that would like to join our Operations Team and co-ordinate the information that comes in for these pages?

**MORE PICTURES FROM OUR MEMBERS.**



**Above and Left See page 18**



**Above and Left see article starting on page 6.  
Anne's wheelchair complete with bags.**

**Below—Picture on card is Anne's Garden**



*To  
Caregiver  
John Hartman,  
  
We send you  
Our good wishes  
And  
Prayers  
For a  
Speedy Recovery  
  
The LincPIN*