



The LincPIN

The **L**incolnshire **P**ost-Polio **I**nformation **N**ewsletter
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'Friendship is born at that moment when one person says to another,
'What! You too? I thought I was the only one'. © C.S. Lewis

Posted on members email list by member Hazel Coleman

LINCOLNSHIRE POST POLIO NETWORK

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Lincolnshire Post-Polio Network - UK Registered Charity 1064177

Donations large and small towards our work are always welcome.

Lincolnshire Post-Polio Network,

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Next LincPIN Newsletter - May 2007

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Editorial by Hilary Boone.

Please note the NEW ADDRESS for the Lincolnshire Post Polio Network is on the Front Page. Please use this address for all correspondence apart from membership which should continue to be sent to the Membership Secretary address on Page 2.

I am pleased to include a very poignant fictional story based on fact 'Origami Seagull' by Member Robin Brierley a.k.a. 'Hermit' starting on Page 6. The isolation hospital, was originally built in 1893 to cope with the diphtheria epidemic. It was part of the old West Norwich Hospital, which in its turn had started as a workhouse. Apart from the installation of the patient's radio system around the 1940s it had changed very little. Goodness know what germs were lurking in the cobwebs. Please note the warning at the beginning of this story - it is likely to open the box of anyone's memories who was around during those years.

Viola Pahl's story of her move to residential accommodation is something some of us might have to consider in the future. I hope the points raised will help if you get to the stage of looking to see what is available.

Shortly after joining the LincsPPN, member Bridget Langdon agreed to take part in a television program 'A West Country Childhood' made by Testimony Films in Bristol and shown on ITV West. This was video/dvd and if you would like to see it then write or email us. Read the Western Daily Press article starting on page 12.

Viola Pahl, a Canadian PPSer and author has often been a contributor to the LincPIN. Her husband passed away recently and she decided to move to a retirement home. She has written up this 'moving' experience so that anyone considering this might have advance notice of some of the things to look out for.

On the back page we congratulate June Middleton in Australia on her Guinness Book of Records achievement of living in an iron lung for 57 plus years. Thanks to Dennis Lloyd for sending us this story. Two of our UK members are now going to be spending the winters in Australia increasing our contact with this country.

Miami PPS Conference Update. [April 9th to 11th, entitled 'Partnering for a better tomorrow'.] 'My husband and I' [First time I have said that] are pleased to report that Jann Hartman, Mary McCreadie, Paul Stanton, Ros Sinclair and her husband have also registered. We look forward to reporting the latest info in the next issue.

We were very sad to learn of the sudden death of Monica, Sister of California member Jean Hill. In her early career as a nurse she looked after polio patients and was looking forward to writing a story for the newsletter. She attended the AGM and had become a great friend of Lincoln member Lynn Hobday.

The Trustees and Operations Team of the LincsPPN are all volunteers - all but one living with PPS - and give up numerous hours each month to assist in accessing and disseminating information for the rest of the members. To share the workload out a little more two of your Trustees have changed 'chairs'. See next page.

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Message from the Chair

As you will see, Mary McCreadie is the new acting Chair of Lincolnshire Post-Polio Network, as of February 2007. I remain an active Trustee, and continue to concentrate on the collaborative links which we have seen established with the British Polio Fellowship's Chief Executive and Trustees. I am now a panel member of the BPF's Expert (Patient) Panel, which includes a number of medical and allied health professionals and well as administrative staff and a trustee of the BPF; so far we have had two meetings and we are being led by Sir Bert Massie, Chairman of the Disability Rights Commission and who helps guide the Panel in its objectives. The remit of the panel is to help the BPF to bring about overall improvements for their members, who number in the thousands. You might like to look up the BPF website, www.britishpolio.org.uk (see under "New" Expert Panel) as they have decided to post minutes of these meetings as a way of encouraging transparency by the organization for its members. Objectives of the Panel are: to raise the profile of issues related to Polio and its associated effects including Post Polio Syndrome (PPS); to provide direction and advice on matters of strategy, research and policy; to engage effectively with health and allied professionals to promote knowledge sharing and networking across the professions; to ensure publications and other literature produced by the Fellowship are accurate, up to date and easy to understand; and, to underpin and give additional credibility to the work of the Fellowship.

There was a timely need to establish links, beyond the informal ones which, as you know, develop between polio members of different organizations. It is my view that this more formal collaboration (the work of the Expert Panel being a good example) can only serve to strengthen the resolve of those who, like our Founder Hilary Boone, have raised their heads above the parapet and campaigned on behalf of the rights and welfare of polio survivors who experience the late effects of polio and/or PPS (including themselves) for many years. I would also like to thank Hilary for continuing to network and keep people in touch with each other, as well as fostering new alliances with a rights-based focus on disability issues and health. One of our pressing concerns continues to be campaigning for improved access to appropriate orthotics services in the UK. In my attempts to highlight what is a national problem with regard to adequate orthotic provision, I continue to sit as a patient representative on the University Hospitals of Morecambe Bay NHS Trust Orthotics Review Committee. Flagging up service user/patient representative viewpoints allows us to feed into a system which didn't used to consult patients on issues which directly affect them. The issues which are brought up for discussion and/or review have several times included a polio perspective. I believe that this committee forces providers to be more transparent in their decision-making regarding various aspects of orthotics service, and it puts a face to what is often an unrecognised (post-

polio) patient profile. More recently, I have been asked by the review committee to look into reviewing patient opinions about the service – and would indeed welcome feedback from members, especially in the north west of England. We acknowledge that this is not yet a national review process, but think it is a good starting point.

Hilary and Mary McCreadie are attending the Miami Post Polio Conference, entirely at their own expense. I know that Mary McCreadie is full of enthusiasm in her new role, and would love to network more. Our resources remain limited at this time, so we still struggle to make these networking opportunities possible. We hear that there are plans in the pipeline to hold an England-based conference which would gather together our island groups (England, Wales, Scotland & Ireland - both Northern Ireland and the Republic) as well as others in our ever-expanding Europe, but this is in its early stages.

I would like to thank you, the members, for supporting me in my role as Chair for the last 2+ years, and especially to thank the team of dedicated people who continue to keep the operations machine oiled and running, with little reward. Please do let Mary McCreadie know that you support her in her new role, and support us by writing in with your news, views, stories and requests.

Best,
Mary Kinane, B.A. (Hons)
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Dear Members,

Sharing our workload is imperative if we wish to maintain our own health, and following discussion amongst the Committee, I agreed to take on the position of Acting Chair as from 7th February until our AGM in September. I am pleased that Mary will be staying on the Committee as a Trustee, and I would like to thank her for the time, effort and energy she has put into the job of Chair during the past two and half years. I wish her the very best in her work as one of our representatives on the Expert Panel.

As Acting Chair, I will do the very best job I can for the committee and membership of LPPN, and look forward to a busy and productive time.

Mary McCreadie,
mary.mccreadie@lincolnshirepostpolio.org.ukk

Editors Warning. Reading this excellently written and poignant story could evoke unexpected emotional responses for some readers. You may remember nothing, like me. You may have been young and could only understand and remember at the age level of language that you had at that time. You may remember it all. Regardless of age, there can also be words, sounds, smells, and pictures that trigger memories.

Origami Seagull

It was November 1952, tomorrow would be Guy Fawkes Day. The box of fireworks was safely stored in the bottom of the airing-cupboard, away from the damp that pervaded the old house with its coal-fires and draughty door-frames. In the triangle of neglected kitchen-garden behind the back-lane garage, a pyramid of brushwood stood tall, awaiting only a priming of crumpled newspaper and the pyromaniac match.

At the dark end of the afternoon, school had been out for half an hour and most of the children, like Rob, were already home. He should have been excited, rushing around with a torch, making final preparations, finding one more forkful of garden rubbish to thatch the bonfire, collecting long-necked squash bottles to launch the rockets and from somewhere in the attic, unearthing that old camping-stove to kindle the reluctant sparklers. But since returning home from school, the ten-year-old had not been well. His mother took one look at his flushed face, noted his listless collapse onto the old sofa in the alcove at the back of the breakfast-room, worried at the lack of clamouring hunger, then felt his forehead and sent him straight to bed.

At five o'clock she went upstairs to check on him, carrying a tray with milk, biscuits and a saved copy of the Eagle, usually issued several days late as an incentive to be good. Rob wasn't interested, the bedclothes were scrambled, he could hardly speak. The room felt as if a three-bar electric-fire had been left on for hours. She checked his temperature - a hundred and two - then called the doctor.

The doctor got there after evening surgery and examined Rob thoroughly, listening carefully to his complaints of strange flutterings in the stomach and pains in his arms and legs, then dispensed penicillin directly from his black-bag - something they did in those days - and promised to return in the morning.

Eventually the fretful and feverish night was over. The doctor repeated his examination, took samples and went away.

For Rob, the day was a waking nightmare of burning fever, but, towards the end of the afternoon, his temperature dropped a little nearer normal and he rallied enough to show his disappointment at having to miss the fire-works. It is difficult to refuse a poorly child, especially when a little effort makes a satisfactory compromise. His parents decided that a limited Guy Fawkes celebration could be held. The bonfire, so far from the house, was out of the question, but there was space on the terrace outside the French-window, to let-off the

smaller fireworks. Rob was carried downstairs wrapped in an eiderdown, then ensconced on the big old sofa and turned to face the window.

Vesuvius, represented by several different sizes of gunpowdery cardboard cones erupted in unnatural ruby-reds, traffic-light-greens and magnesium-whites. Roman candles produced either one more, or one less, soaring ball of light, than advertised on the packet. Crackerjacks jumped unnervingly at mother's skirts, Catherine's sparkling spirals whirred on the fence-post and impatient rockets tried to whoosh-off father's hat.

Rob forgot his fever and watched the bright-eyed magic, but before the final rocket had flown over the oak-trees, he had fallen asleep. Later, when he awoke, he was back in his room. The doctor was standing by the bed, mother beside him, looking pale and worried. Father again wrapped him in the eiderdown and carried him downstairs to where an ambulance was waiting.

The ride to hospital was strangely dreamlike. The vehicle swayed, Rob's mind seeming to catch up with each movement in time for its dizzying reversal. He didn't know who was with him, but there were comforting voices and a hand in his or on his brow. Then, when they stopped, there was a sudden burst of frosty air, jolting trolley-wheels and a sharp instruction to 'Hold the door.' Bright light beat at his eyelids, turning the world a glowing red. Hands pushed under him and lifted him onto a bed. Then he was alone, the brightness gone, leaving a strange yellow twilight glowing above him. He tried to move but found himself too weak. The effort brought back the fever and his mind floated deliriously free in a maze of lingering, fire-ball after-images.

They didn't let him rest. In the early hours, light blazed again, just one bright white fire-ball, hovering above his bed. He opened his eyes, but couldn't stand the dazzle. His momentary glimpse of white masks and coats would have been terrifying, had he been conscious enough to care. They pulled at him, pushed him from side to side, forced him to sit up and held him there, hit him on the knees and elbows, drew patterns on his stomach with sharp sticks, then did the same to the soles of his feet. They muttered and grunted among themselves, ignored his moans of protest and eventually, like demons of the light-bulb, left him shuddering in the dark.

For four days his only waking moments were when roused, either by the frightening white demons, or by a routine succession of nurses who helped him to drink or encouraged him to urinate. In Rob's mind, a universe of stars, the deeps of the ocean, billowings of sun-stitched clouds and the groaning depths below the mountains of the Earth, held sway. He soared high, tunnelled low, exploded with the galaxies or crushed himself to nothing under seeming tons of bedclothes. Reality was reversed, it was his waking moments that were nightmare.

On the fifth day, as night paled to dawn, he awoke. The bright stars of his delirium had become screaming seagulls wheeling against

the grey sky beyond the window. For the first time he was able to see the detail of the strange room and the alien territories beyond his bed, the erstwhile domain of the light-bulb demons and land of starch encrusted nurses.

He lay, curled-up on his side, facing the glooming sky where bits of it had become trapped between the slender bars of the tall sash. Below the high sill, the space was filled with the massive cream-painted arcades of a cast-iron temple that radiated warmth into the sharpness of the air. Above it, the glazing-bars swam in the rising current, exaggerating the movements of banshee gulls as they skirmished, shrieking past the window, diving out of sight, then reappearing with loaded beaks and rising amidst battles for possession.

To the left of the radiator, a huge rectangular china sink, with curious long-tailed taps, separated it from the door. A heavy, green-painted affair, with panels in the lower third and nine grey-sky-and-seagull-framing panes above. Whatever the birds were fighting over must be just beyond it. Sudden silence heralded its opening; a harsh grey woman, like a fragment of that November sky, hauled down and stuffed into a tight, dark-blue uniform, bustled into the room.

'It's your breakfast, they're eating!' she announced, 'You should have been awake when we offered it to you.'

Rob, to whom these were the first words he had been consciously able to understand since the ambulance man had asked for the door to be held open, was frightened; he burst into tears. The ward-sister called for a nurse to, 'Sort him out!'

The nurse, a wide-faced girl with fair hair and a pale-blue uniform, came in and sat down beside the bed. There was warm tea in a spouted feeder; she applied it with a smile. 'Can you manage to hold the cup?' she asked. Rob thought he could, that is until he tried and suddenly realised something was seriously wrong. His left arm would hardly move and there was no way his head would rise above the pillow. He struggled, trying to pull his right arm out from under him, but seeing his distress, the nurse relented and continued to help him drink. As soon as the routine was over and the nurse had left, Rob wanted to return to the warm, wonderful dreamland of his recent delirium, but his retreat had been cut off by the end of the fever, all he had now was the pain of discovery to fill his head and the sharp cries of the gulls for company.

By mid-morning, after another visit from the nurse, this time with the spout delivering orange squash, the door opened and a tall man strode in and stood by the bed. Rob, fortunately not recognising him as the leader of the light-bulb demons, looked up from the pillow in silence.

'Hello, young fella,' said the demon-in-disguise, the words more friendly than the tone of voice, 'I thought you'd like to know you're suffering from Heine-Maiden Disease, named after the doctors who

discovered it.' - for Rob, this was just another layer of confusion, another flock of feathers falling through the pillow of his mind. Whatever reaction the doctor had expected, Rob failed to give it.

'You might have heard it called "Polio," poliomyelitis, that is.' The man paused - the child still had nothing to say - and continued, 'I expect your parents will explain. Now all you've got to do is rest and recover.' - Rob got that bit, he managed a wan smile.

'Is there anything you'd like to ask?' concluded the doctor, hovering a moment before hurrying out.

Ask? Well, no doubt there would have been, had Rob understood what had actually happened to him, there was the problem with his left arm for a start, and why couldn't he sit up. He was an intelligent, technically-minded sort of kid, nobody who had seen his Meccano set in action would dispute that.

What he should have been told, was that polio effects the nervous system; that parts of the body work a bit like model cranes. That the bones are moved about their hinge-points by strings of muscle. If there is nothing to tell the strings to move, then nothing works. Polio attacks the cells that give the muscle-strings instructions; that was what had happened to Rob's arm and much of the nerve-structure down his left-hand side.

Muscles which do no work, fade away and leave bones unsupported, so they become unbalanced and grow awry. Nobody told Rob any of that, in fact, apart from the junk about Heine and Maiden, nobody had told him anything, not even where he was. He thought it was probably a hospital; but the isolation ward looked more like a prison than a hospital.

The room, a cell about twelve feet cube, was divided, on two inner sides, from other similar cells by five-foot of solid partition; the space above filled with glass. The only access was that outside-door, the one besieged by seagulls. Light came in through the tall window or from the single central light with its dazzling white-enamelled shade, or when he was alone, as a distant yellow glow from the glass-walled nurse's room, filtered through the intervening cells.

Apart from occasional items, such as the door and the waste-bin, where the pre-war grass-green paint had been retained, almost everything was painted glossy-cream. Glossy that is, where it had been washed, the lower halves of the two solid walls were clean, but above that they were smutty, cobwebbed and discoloured. The junction between cleanliness and microbe laden squalor was wavy, graded and banded according to the changing stature of subsequent generations of cleaners. Apparently, the hospital's policy had been either to employ smaller and smaller people or supply them with lower and lower chairs to stand on.

With nothing better to do - he was alone and locked to his pillow by the debilitating illness - Rob observed his surroundings. Four walls,

ceiling, red quarry-tiled floor, those portals to an outside world dominated by seagulls, a locker, the radiator, sink, two chairs and his bed, there was nothing else.

Curiously, the bed, despite being closest, was the last thing he examined. It felt large, but that was because he was curled-up small. It was hard; under the mattress his hand discovered a platform of boards, not an inner-sprung divan, like at home. The ends were silver-painted metal tubes, a mixture of builder's scaffold and tiger cage. At each corner were sturdy posts carrying an overhead frame.

Then he noticed something new, almost out of sight, hanging behind the grillwork of the bed-head. It was a set of headphones. He struggled a few inches across the acres of his pillow to get a view between the bars. It was a headset just like the ones in every black'n'white war film he'd ever seen. Beside it, in the centre of a metal plate, was a rotating switch, with 'Off' at the top and four numbered positions. Here, at last, was a worthwhile target for investigation, he began to uncurl, take stock of his position.

Until then, the pillow had been his life-raft, something to cling to, as if he was slowly drowning in a rumpled sea of hospital sheets. The nurse was constantly complaining that whenever she came to tidy him up, all she could find was a heap marooned against the foot of the bed. In fact, it was from that position that Rob began to plan his campaign, and from there too, the bed-head was a far shore indeed.

He scouted the distant coastline through a telescope of hollowed hand. The shore was defended by the breakwater of the bed-frame. Would that be help or hindrance? Behind the defences, a sheer and shiny, gloss-paint cliff loomed high, topped by the rolling landscape of part-washed grey hills supporting a filthy, smut-stained sky. Here, unlike the real sky outside the window, he must imagine the seagulls and the gathering tempest he needed to complete his plan.

The mind-storm broke, calling up the breakers that helped him during the exhausting swim from the foot to the head of the bed. The final effort, pulling himself one-handed as high as he could onto the life-raft pillow, nearly sunk him, but at last, he had a hand against the cliff-wall. He walked his fingers up towards the knob, grasped and hung on, then clicked it one notch to the right. Suddenly his imagined seagulls had gained a scratchy, twittering voice, but they were too high and far away for him to hear the song. He subsided, satisfied and floated with the linen tide, as waves of crumpled sheets washed him back to his haven at the foot of the bed.

When Sister came in with her favourite question about the opening of bowels, she was annoyed that someone had left the earphones switched on; she turned them off, fussed with the loop of trailing flex and centred the headband on its bracket. 'There will be visitors, soon,' she said, following that with her second favourite sentence, 'Sort him out will you Nurse.'

'Visitors?' Who could it be, he had asked for his mother, but had

been told this was an isolation ward and epidemics must be contained. But, wonderfully, it was his mother. She had to stand by the door, not allowed to hug him; so she'd brought cheerful words, pencils, paper, heaps of comics and a jar of peanut-butter.

When, too soon, Sister whisked her away, he read the comics. All his favourites were there: Beano, Dandy, Lion, Eagle, Film-Fun and Practical Mechanics.

The drawing-paper he folded into a seagull, an origami recipe he was delighted to find in the Lion. Now all he needed was some way to fix it in the smutty sky above his bed-head. Nurse, helpfully, stuck it to the overhead frame with shiny pink sticking-plaster; it wasn't what he wanted, but it would have to do.

Later, Sister declared it both a collector of germs and an affront to tidiness, she ripped it down and dumped it in the bin. He was angry and showed it. She took away his comics, refused to switch-on the light and left. The shadowy frame above his bed threatened like prison bars. The gulls had already returned to the sea, leaving only a splatter of sleet and the mournful howl of winter's wind to rattle the sash. He lay there sobbing, his comic lifeline from the outside world torn away. Once more, he was alone, adrift in the frighteningly alien world of the mind.

Outside the sky darkened into night. The distant yellow light came on in the nurse's office Nobody came near him and eventually he fell asleep. Almost at once, the origami seagull stirred and rose, whole and haloed white, from the grave-like hollow of the waste-bin. Rob watched as it circled amid the scarlet whorls of his unforgiving anger, trapped in the shadows of the room. The pale reflection of the gloss-paint cliff attracted it to the bed-head and there it roosted, to await its fellows.

Morning arrived, and with it, nurse and warm tea, bedpan, marmalade and toast - no sign of his peanut-butter. He left the crusts, but Sister caught him before the nurse had time to give them to the birds. She made him eat them, standing there, hip-handed to ensure obedience.

The origami seagull watched from the top of the bed-frame, unseen by all but Rob. When Sister went to leave, it flew, beating strong, wide, wild, white-paper wings, then passed straight through the tall sash-window to rally a feathered squall of gulls from the high grey clouds of dawn.

As the door shut behind Sister, he watched the ravenous seagulls dive past the window, knowing they would be dining well. Soon, screams and cries confirmed it. After that, he felt a little stronger, more able to make the journey to the bed-head, and solve the mystery of the headphones in time for Christmas.

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Hermit <munzly_hermit@BTINTERNET.COM>

A West Country Childhood

On Tuesday 6 February, a program was screened on ITV West which documented the effect of childhood polio on three survivors. One of these brave people was our own member Bridget Langdon. The program was sensitive and poignant, and showed without sentimentality just how courageous polio survivors are – and these three deserve every credit for having the emotional bravery to tell their stories.

Aleisha Scott of The Western Daily Press wrote the following piece about the program, and we have very kindly been given permission by the News Editor of the Western Daily Press to copy the text here:

BLIGHTED BUT NOT BEATEN

A polio epidemic after World War II hit the West Country harder than any other part of Britain. Ahead of a new television programme, Aleisha Scott talks to three people whose childhood was blighted by the disease:

Mothers and fathers once lived in fear of a virus that could strike without warning, leaving their children paralysed or at the mercy of the dreaded Iron Lung.

At its peak, polio paralysed and killed half a million people every year, the majority of whom were children.

In the West during the 1950s, three times more children contracted polio than the national average.

Three people who had to rebuild their lives after being struck down by polio are sharing their experiences in the final part of the 'A West Country Childhood' series on ITV 1 tonight.

Being strapped into a frame for most of

his early childhood taught Phillip Whitmarsh, a valuable lesson. In 1945, at the age of four years, Mr Whitmarsh fell over while out playing and couldn't get back up. He spent the next 10 months in Bath Orthopedic Hospital paralysed from the waist down.

"What I found most scary was the doctors in white coats and nurses standing around looking at me," said Mr Whitmarsh, now 66, who lives in Frome.

"I remember undoing the ties on the frame so I could sit up but eventually the nurses tied them in such a way that I couldn't get to them."

After physiotherapy, Mr Whitmarsh was finally sent home but wore callipers on his legs until he was 14.

"One leg was very weak and it never recovered, it was also three inches shorter than the other," he said. "I say now that my good leg is double my age, because it did most of the work for most of my life."

Mr Whitmarsh didn't start school until he was six, was unable to read or write and only attended class in the mornings until he was 10.

"I was put into the dunces' class for a year before going into mainstream classes," he said. "I failed my 11-plus and by the time I was 13, I had only done two full years at school. I managed to catch up thanks to a wonderful maths and sports teacher who turned my life around. He told me I had a brain and I should use it because I wasn't going to earn a living digging holes in the road. That was the first time in my life that someone had told me that I had ability."

After leaving school with a string of G.C.E.s, Mr Whitmarsh worked for Frome Rural District Council. He then worked for an insurance company,

rising to area manager before he and his wife bought a shoe shop. He later started a business as an independent financial advisor. After retiring, he became the Mayor of Frome and is president of Frome Rotary Club.

"They tried to write me off but I wouldn't have it," he said. "When they put those irons around me I wouldn't take it lying down and I've been like that ever since. I was bullied at school but they soon realised they couldn't push me around.

"Polio has been eliminated in this country so no one will have to go through what I went through."

-----*-----

DESPITE being paralysed since he was a boy, Professor Robert Giddings counts himself as lucky. Having completed a doctorate and written 20 books including an autobiography, Prof Giddings, 71, has ensured he takes every opportunity given to him. Struck down by polio at 11, Prof Giddings never recovered the use of his legs.

But he says he was lucky to get such wonderful support from his family, friends as well as doctors and nurses. Prof. Giddings, originally from Bath, was about to start grammar school when he collapsed with a fever while on holiday. After finally being diagnosed with polio, he spent the next two years in hospital.

"I was completely paralysed apart from my left arm," he said. They tried to get me walking with leg irons. I was almost 13 when I returned home. My father knew how important schooling was and he got me into the Lord Mayor Treloar's Cripples College and Hospital, which was a training college where you could learn a trade. But they could never get me mobile enough so they sent me home."

Prof Giddings then had an operation to bend his knees and straighten out his

feet so he could sit up and wear shoes. He secured a place at the commercial college in Bristol where he took his O-levels and A-levels before winning a scholarship to the University of Bristol where he did a BA and MA. He taught in secondary education for many years including 18 years at Bath Technical College. He got a doctorate in Victorian literature from Keele University and then became Professor of Communication and Culture at the University of Bournemouth until his retirement.

"I try to lead as normal a life as I can but I believe that the rights of disabled people have a long way to go and we still face prejudice," he said.

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Decades on and Bridget Langdon is still coming to terms with the full affects of polio. She caught the virus at 18 months old and has now found out she has post-polio syndrome (PPS).

"Polio was known as infantile paralysis in those days and it was not until I was 15 when I was having an operation that the surgeon confirmed I had had polio," she said.

"At two years old, doctors discovered my spine was curving and I had always had some sort of breathing problem. I wore callipers and had a brace around my stomach that went up to my arms and irons to hold my back straight. I even had to sleep in a plaster case. I'm supposed to be 5ft 8in but because of the curvature of my spine I'm 5ft."

Despite being told that she would never be able to have children, Mrs Langdon, who lives near Yeovil, has three children and five grandchildren.

Relatively unknown, PPS affects polio survivors years after recovery from an initial attack. It leads to new weakening in muscles that were previously affected by the polio infection as well as in

muscles that were unaffected.

"Until this week I had not seen an orthopaedic specialist since I was 16," she said.

"For years I had minor things wrong with me, like aches and pains. Last December I read an article about Lord Snowdon who also suffers from PPS.

I looked it up on the internet and went to see my GP. It explains a lot, but no one knew much about it. There must be thousands of people out there who had polio but do not know about PPS."

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As well as coping with tremendous problems resulting from polio, Bridget also suffered when the doctors overseeing her spinal graft made a dreadful error – and gave her 8 and a half pints of Positive blood during the operation. Bridget's blood group was Negative. The error could have killed her, and the knock-on effect meant that the children she had subsequently might have been born with serious disabilities. Each one needed a complete change of blood at birth, and thankfully, they all survived with no damage. Bridget is very proud of her children and grandchildren!

Despite suffering from PPS, Bridget still manages to run a Luncheon Club in her village. She obtained funding for the club through a Lottery grant – which is not as easy as it sounds, and takes a tremendous amount of tenacity. With the £6,500 grant, she set up the club to provide proper home-cooked three-course meals once a week for elderly and disabled folks, and has 8 other ladies to help with the work. She also works hard as a member of her Parish Council.

Bridget found the Lincolnshire Post-Polio Network on the Internet and was soon driving with her husband Derrick to

Lincoln for the 2006 AGM. Bridget was assessed by Helen Kent from Progressive Medical in California - our main speaker - and told that she urgently needed assessment for a night time ventilator. It took some months, nothing unusual in the U.K., for her to get through the assessment procedures but she has just received her night time ventilator and will let us know how she gets on next issue.

The Driving Test

It's a chilly, grey day – the traffic pretty heavy, but I've managed to get where I have to be in plenty of time. My nerves are in reasonable condition, and I'm eager to get the test over and done with. In the little script below, imagine the voices using that sing-song cheery-cheery 'I know I mustn't pat this poor lady on the head...' type of voice..

Press intercom buzzer to announce arrival for 9.30 appointment. 'Please wait, someone will be along to collect you in a moment.'

'So sorry to keep you waiting – please follow me.'

'Let's make sure your vehicle is roadworthy. Hmm. We don't need lights, do we? No. Oh yes, nearly forgot - we do need to reprogram you. Just a moment, I'll ask Richard to come along.'

(Richard arrives with bright smile, electronic pad and pointy thing like screwdriver. Fiddles around with controls on vehicle.) Beep beep be-beep. 'There you are – all reprogrammed, so let's go. NO - WAIT! I've just got to fix this thing on your undercarriage.....' OK, now we really can begin the test.

'Now Mrs. McCreadie up here turn left, turn right and wait at the junction ... that's right. Now we will both be with you, and the test will take about three quarters of an hour..... No hang on, not so fast please or we won't be able to keep up.....Left.. I

mean right....have you checked for traffic? Oh good. Straight over, and up that narrow lane. Yes, you go round the first barrier, and then around the second barrier and continue straight on. Cold isn't it? That's the only problem with these open-top models.. Yes, straight on until you reach the next intersection... Did you check for traffic? Good! Now when we reach the traffic lights up ahead, stop if they are red. Jolly good, you stopped! Keep watching the traffic... Did you press the button? Oh well done.....Now the little green man is showing so we can cross to the next traffic light..... Did you press the button? Well done – yes, there's the little green man. Over we go... Now let's just go into Sainsbury's.'

By now it should be obvious that this was no ordinary driving test! No, it was a test to make sure I could handle my newly-souped up electric wheelchair in both vehicular and pedestrian traffic. If I failed, it would mean that my chair would be programmed back to the 1mph I was so keen to get away from. I'd been waiting months for Wheelchair Services to arrange this test, and didn't really know what to expect. The basic test was simple enough – embarrassingly so – but Health and Safety Regulations demand that anyone having an electric wheelchair from the NHS is required to prove their driving abilities. The fact that I've been using a scooter for years, and have been driving a car for more years than I care to remember has no influence on H and S! The remainder of the test was a different matter. Apparently it is essential to prove that you can also get up and down a 4" kerb. I was taken to the requisite place – on an extremely awkward junction, where, from my somewhat low position, it was almost impossible to see any traffic. I had to start from across the road and travel as fast as I could head-on towards the kerb, and keep going until the w/chair was up on the pavement. Now this can be a bit unnerving – especially as there was a stone wall beyond the pavement. I have to admit it, I

failed the first time. Didn't go fast enough, and ended up sort of side-ways on half way up the kerb. So I tried again and succeeded in mounting the kerb, but the jolt to the wheelchair and my system was not appreciated! Then of course, I was required to go *down* said kerb. This was terrifying. I couldn't see possible traffic and I had to go down backwards into the road before being allowed to turn around. Although I managed it, I did say to my tester that I would never EVER do that in the usual course of events, and that I considered it highly dangerous. We eventually got back to the Wheelchair Services office, where I was given the glad tidings that I had passed the test. So my chair now bombs along at a reasonable 4mph, and I can take it out on the pavements legitimately.

One small thing did escape attention until I pointed it out. The kerb-climber that had been affixed to my undercarriage made it absolutely impossible for me to get out of the chair! I was told to 'just move it into the 'up' position'. Oh yeah? And how do I do that? When you are sitting in the chair, it simply isn't possible for someone with my problems to make any impression on the thing at all! I could no more push the thing into the 'up' position than fly, so Richard (bless his heart, it made him blush as well as me!) leant down, shot a hand right between my lower legs and forced the handle of the kerb-climber out of the way. Even so, the additional bar still makes it more difficult for me to get out of the chair, but I can manage.

So the moral of this story I suppose, is that if you want to pass your test and have the benefit of a wheelchair that goes at a sensible speed: put up with the ever-so slight-patronage with a sweet smile, do whatever they ask you to do as well as you can. Then high-tail it out of there and enjoy the freedom!

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"Handicapped" Suite and "Handicapped Person" are now living together.

I have moved from my magnificent-view condo to an independent seniors complex. In 1981-1985, my husband was chaplain at the Evergreen Baptist Home (EBH) in White Rock (near Vancouver, Canada). White Rock in yester-years used to be a beach resort town. Now it is a very busy city, lots of seniors. Now, it can take from 2-3 years to get into EBH, and because I have so many friends here and there are a lot of church meetings, I wanted to get into the home. I think I was given some preference because of my husband having been part of the staff in earlier years.

There is a section of the Home for intermediate nursing care. Attached to the building is a six-storey condo for independent living. The four corners on each floor are for married couples (one-bedroom suites); the rest of the suites are bachelor suites. However, on the first floor, the four corners are designated as "handicapped" suites where hallways, bathrooms, doorways are wider. So you can see with a two-year waiting list, with only 4 suites for handicapped, I felt I must move in while the place of my choice was available. My husband (now deceased) and I always made changes based on the following: make a change BEFORE you must, and in this way, you have control of the situation and can make choices that you would want. However, I have had polio 58 years and I am 81 years old, so the move was very hard on my muscles, etc. I had help, but when no-one was around, I move this or that, but I suffered the consequences. On my right leg, from the crotch to the knee I got a bruise 9 inches long and 5 inches wide probably a ruptured vein. It has taken weeks for the bruise to travel down my leg into my foot, making it swell and impossible to put on shoes. Things are looking up a little more now.

The EBH was built in the '50's, and no matter how well intentioned the architects were - they allowed some features to be incorporated that are absolutely ridiculous for seniors with disabilities. I maintain that any building enterprise should have a physically handicapped person on the committee, or else ask several able-bodied committee members to spend one or two days in a wheelchair to experience first-hand some of the hazards we encounter. I am, of course, a legally handicapped person. The other seniors in the complex are physically disabled because of age.

The first unit of EBH is for the intermediate care seniors. It is only recently that switches were installed so that the outside doors could open up for wheelchairs. Unfortunately, the entrance here as well as the entrance to the condo complex do not have a "covered" entrance, so if it is pouring rain, you can get quite wet from your car to the entrance door. And if you have a wheelchair, walker, etc. to unload as well, or one's slow pace of walking, this is unfortunate. There are no wheelchair switches on the doorway to the condo. Unless there is someone in the foyer, I cannot open the heavy door and hold it open from a wheelchair position.

The condo and the intermediate care section have between them a dining area, several offices, a chapel, and a huge lounge area. All these features are most desirable BUT - the two major parts of the complex have two formidable slopes - a long rambling slope, plus a shorter extremely sloped runway. I CANNOT get up these slopes by myself because of the stress it places on my shoulders. So - I wait to get "pushed" up the slopes by someone who is more mobile than I am. It is no problem - but my question is: why, why, why are these slopes in buildings which house tottering, shaky seniors? Many of them really have great stress in tackling these slopes.

Down the hall from my suite is a garbage disposal room. I am unable to open the heavy door - so must rely on someone else to take my garbage away. There is a big balcony for general use - but can I get onto the platform? No. Above the concrete walkway is wooden slatted flooring - I guess so people don't have puddles to walk through when it rains. However, I cannot get my wheelchair over the ledge to get outside. "Handicapped" people - or - "handicapped" buildings?

.And now, ladies and gentlemen - the "handicapped" suite! I have a lovely kitchen, big front room (more like an office with all my computer stuff, files, big desk, etc.), and a roomy bedroom. Let's analyze each room. First, the kitchen. The counters are 36 inches high and one cannot reach the taps nor the stove switches from a sitting position. At least I can stand to reach but some handicapped people would not be able to. They did not leave an open space under the sink - an open space would have meant that the wheelchair could go under the sink, thus making it easier to reach the taps. The shelving above the counters was so high that even an able-bodied person had trouble reaching them. They were able to lower the shelving - but still - one has to be able to stand to reach the shelves. In one corner of the kitchen was a small open space - a storage cupboard. I was able to have them remove the doors, and I can put a small deep freeze into the area. I have a small table with folding leaves in the kitchen, so it doesn't take much room, and I can easily push it around

the kitchen, and then into the front room if guests need it for eating. "Handicapped" people - or - "handicapped" kitchen?

The bedroom. I was able to put my sewing machine and table ironing board along the window wall. Nice light, and everything fits great. Instead of doors on the closet, there is a lovely lace curtain. What is that monstrous thing covered with a gold velvet cloth? Well, friends, here I must make a confession. I have purchased a battery-operated wheelchair so I can get up and down those miserable ramps in the building, but so far I haven't had the time or strength to practise with it. But my two wheelchairs are okay in the bedroom - not much floor space is left, but who walks around the bedroom anyhow.

And finally, the front room. To get the wheelchair from one doorway to another requires back-up, adjust wheels an inch or so - WATCH OUT - you're getting your fingers caught in the doorway - OUCH! The builders left just a quarter of an inch on each side for clearance. Ridiculous. One wall is the patio door area, and the doorway has to be kept clear because of fire regulations. The suites open up to a wrap-around walkway, and I am at the beginning of this walkway. On my doorway I have a sign saying "Welcome to Viola's cosy corner of Brilliant, Beautiful, Butterflies." Yes, butterflies have been acquired by me over the years, so I have made "butterflies" my theme: some are from Brazil, Australia, and a peacock made of butterfly feathers from Africa. One side of the room has TV, two bookcases which I use for artifacts and not books, a long glass topped coffee table with 4 fibre optic lamps on it to bring a rosy glow to the room. Against the other wall, my desk and computer equipment, plus 3 two-drawer filing cabinets and 3 sets of plastic drawers, all covered with cloth from Thailand to hide the "ugliness" of filing cabinets. There are two chairs for guests. My recliner is in a corner, and the whole room is interesting and "cute." "Handicapped" people - or - "handicapped" living quarters?

My daughter does my shopping, takes me to medical appointments if necessary, etc. I am very blessed to be so fortunate. At the Home, I can go to the chapel to join up with the orchestra (I play Hawaiian steel guitar). I take one Sunday evening program a month. I know many people - even a gal who was in my church's youth group in the 1940s. I miss my dear husband so much, but all things considered, I am blessed to be so well looked after in my old age. If you have any questions, don't hesitate to write me privately.

The lovely chapel was built when my husband was chaplain. Unfortunately, because it is a link between the two buildings, it is built on a slope, and I have seen newcomers nearly take a tumble on the sloping floor. The first time I went into the new chapel, I sat on one of the padded pews. My face fell with dismay - the pews are some of the most uncomfortable I have ever sat upon. I need an air cushion to sit on when I am playing my instrument. The pews are not wide enough for our tender "seats". My husband put a foot board across some of them so people could brace their feet on the pew ahead of them for a little more balance. There are two HIGH steps to the platform - and it took them years to put in a handrail. The handrails are terrible - the railing ends on the first step, so when you come off the last step to the auditorium floor, there is no railing support for the last step down. The chaplain stands at the bottom of the steps to provide his arm for the additional support for choir members when they come off the platform. I could go on and on - but you get the idea - able-bodied designers just didn't get it.

Now I ask you: Are the hallways, suites, chapel "handicapped" or am I "handicapped"? Well, in spite of the builders' endeavors, I would say that the suite definitely is "handicapped" and I hope that builders nowadays will have a little more sense when it comes to building a "handicapped" suite. And it goes without saying, I am handicapped and will continue to be thus for the rest of my life. Let's get the word out: build wisely for handicapped people - some of the changes needed would require no extra money, just better planning and with lots of input from handicapped people things could be much more convenient.

Conclusion. Hear ye, hear ye: "Handicapped" Suite and "Handicapped" Person are now living together - for better or worse - in sickness and in health - until death do us part. As always, polios are survivors, so I think I shall survive this situation in grand style - but not without protest!

Viola Pahl, Viola Pahl <viola@PAHL.CA>

Whilst I have a computer I know many of your readers do not. If anyone would like to correspond then please write to me at the Evergreen Baptist Care Home, 1550 Oxford Street, White Rock BC V4B 3R5, Canada.

E-Mail Forum

Once again, the e-mail forum has been buzzing, and I am very pleased to report that I've received a number of private e-mails telling me how much the forum is appreciated. Being able to discuss problems, offer experience and advice to others, share a giggle or simply off-load one's feelings in a safe environment, can only be beneficial. The couple of months before Christmas were particularly busy – although January has been a little quiet! I'm looking forward to hearing much more from you all very soon. Anyway, here's the usual sample of what we've been talking about:

1. I went to see our local chest consultant a couple of weeks ago with a view to getting help with the cough I have especially when I have back pain and on exerting myself. His answer was that unless the cough became primary or I became suicidal (his words) then he wouldn't refer me. I wonder what happened to caring for the people like this government said.

“One minute the government is saying we have choice and can go to other countries to get operations (oh, but that helps waiting lists) but we can't even see a doctor in another county. Where is the choice?”

“If you already have a respiratory specialist that you see I don't see why you should have to pay for tests privately. Surely if you saw a specialist outside your county any tests could still be done locally. Also many doctors will see someone privately and then arrange for tests on the NHS.... For that matter, with a bit of pushing you can probably see someone outside your county on the NHS if you can just show that there is no expertise in the county.”

“Seeing a specialist privately is no guarantee of success: all it does guarantee is that you will see the specialist much quicker.... I think the golden rule here is - always try to obtain a personal recommendation from someone who has seen the specialist already, although that does not always work because different people can form very different opinions about a specialist - it may even come down to how s/he was feeling on that particular day and how s/he reacted to that particular patient.”

2. I'm still at the stage of wondering whether early retirement through ill health is definitely the way I want to go.

“... if you leave it too long then you may find the decision of when to go is taken from you, and you may be in a less fit state when you do finally retire. I do think that anyone with PPS who is able to give up work should do in order to conserve what they still have and to be able to enjoy other things in life. It is a difficult decision and only you know what is right for you. I wish you all the best in your decision making.”

“The decision to retire is a huge one, personally it took me 2 years of ifing and butting, until finally I reached the point when it wasn't just me to consider. After I'd bitten the bullet, it all came together....for the first time in ages I was able to think about what I could do especially with my husband who had been doing all the housework etc to enable me to work! I thought I wouldn't be worth as much as a person if I gave up my profession, how stupid that sounds now.”

“I can echo many of the things that have been said... I felt it was time to pack up when colleagues were 'carrying' me and taking work off my in-tray, and I was making too many mistakes, and dropping off to sleep at 3 pm. If you're on top of the job - fantastic. If the job's on top of you - disaster.”

The retirement issue then developed into a discussion about problems with Incapacity Benefit:

3. It took me 10 years to retire, then I screwed up on IB and have to appeal. Should I take someone knowledgeable with me to the tribunal, if so who? I didn't apply on time and was given bad advice.

"We had a talk from John Gill at Lincoln CAB and I am sure he would have the answer for you on this from the excellent talk he gave us. He prepares and attends many appeals. He spoke at a Lincolnshire Neurological Alliance meeting this year."

"I think it's best to have someone with you. These tribunals can be very unpleasant, and you need support. Try your CAB - they should be able to send a rep to come with you, and if you give them permission, will speak on your behalf. You need to do your homework first and be properly prepared, because the questions you will be asked can be very skewed."

"I always get the CAB to help me with forms and things. I find they are very good and very helpful in many ways."

4. The only thing I loathe is having to wear horrid lace up shoes and trousers all the time, but this is just pure vanity! The first thing I always look at in magazines are SHOES!

"I do so agree about the shoes. It's worst on those rare dressy occasions - what wouldn't I give to slip my toes into some delicate strappy beauties? I keep saying that if/when I start using a wheelchair all the time, my first purchase is going to be the most alluring pair of killer heels I can find!"

"At the San Francisco Conference there were about eight of us PPS support group gals all standing talking.. well some of us were leaning against the tables.. and we were all dressed to the nines. Someone suddenly laughed and said.. look down at our feet. All of us had white sports shoes on....

"Shoes! I had to wear lace up shoes, brown" Kilties", my right shoe had to be built up one and three quarter inches until I had my graft ,when I was 14. I could have no slippers, sandals. or daps. Once I could wear "proper" shoes I for years spent every penny on shoes--,I still have some of them. 4 inch heels black, green, red, you name it I had them. Just as well really because now I'm in Jesus sandals my feet and ankles do get puffy."

5. How different would our lives have been without polio? Better or worse? Judging by the way we all seem to be so positive (most of the time!) and so determined, and to prove we can do everything just that little bit better, it occurs to me that the very fact of having polio has changed the characters that we might have been otherwise.

"I have come to realise and life has shown me that polio was the best thing that happened to me. It allowed me to be my own person and a very strong individual. I also agree that many things do not get past polio people and to prove a point on Sunday my husband (who has MS) and myself did ice skating in our wheelchairs in an outdoor ice rink outside Windsor Castle. It was magical and there were so many spectators that wanted to see us get on (along with many other able bodied peeps), we had comments like "I would not be so brave to get on the ice", and that I should get special ice tires for my wheelchair! It was the first time that anyone had asked

the organisers if wheelchairs could be taken onto the ice and after a little confusion we got on!!!! So there is always a way if you are willing to take the risk and enjoy life to the full!

“At least it has been and interesting and certainly not a boring life and I have met a lot of interesting people.”

“I think having had polio has contributed to my character in countless ways. Throughout my life, reports on me have usually included words such as 'tenacity', 'determined', 'won't be beaten', etc., and I'm sure the same has been said of most of the folk who post messages here. I think polio has had another effect too. I think I've become quite accepting of the small annoyances in life that seem to wind other people up (traffic jams, waiting for hours for an appointment, etc.). Somehow, having to live life so slowly seems to put so many niggles in context. I'm usually quite happy to listen to the car radio or read magazines while waiting. Fretting and agonizing won't change a thing, and will only make the fretter feel more het up, so I try to just 'live in the moment' and make the best of it.”

Quite apart from the above, we have covered many other subjects including VAT, Public Transport and holidays, as well as commiserating with each other about the weather. I'm very pleased to welcome those members who have recently joined the ranks – it is great to have you with us!

If you would like to join the e-mail list, please send an e-mail to

join-pnl@lincolnshirepostpolio.org.uk (please include your full name in the e-mail).

Those of you who are not on the internet can write to our main address with your questions, stories, memories or concerns. Alternatively, you could call the Polio Survivor on duty (details are on 01522 888601). The more we share experience, the more we learn!

WHEEL USERS - SAFETY TIP

If you are going anywhere with your wheels where you might be alone or go off the beaten track ensure that you not only have a well charged batteried mobile phone with you but something that makes a loud noise so you can attract attention of others. Plus tell someone before you go where you are going and how long you think you are going to be away.

Whilst at the Singing River Rendezvous Richard [without brace on] was killing time waiting for the moccasin traders to open up. In his wheelchair he went along the nature park tracks and all was fine until he hit a small bump and veered off into some sandy ground. Although he could hear people in camp and was only 40 yards from folks they could not hear the beep on his wheelchair. He tried banging SOS in Morse code on a tree only to be answered by a woodpecker! He got off the chair onto the ground and pushed himself backwards towards the main track into camp. The 70 foot journey took him an hour and a half. We have been given a police whistle but are also looking for a noise making machine that you can push a button in case we don't have enough breath to blow the whistle. Any ideas? We do have walkie talkies and a mobile phone but as we were living pre 1840 we did not take them with us. There were seven sets of wheels at this Rendezvous and it has now been decided that provided usage is kept to a minimum mobiles and walkie talkies for 'wheelies' will be allowed. Mary McCreadie reminds me that when its cold batteries can run out early and the three of us have all been stuck like this and had to be 'free-wheeled' back to base, and me more than once!

How many of these did you know?

A sealed envelope - Put in the freezer for a few hours, then slide a Knife under the flap. The envelope can then be resealed.

Use Empty toilet paper roll to store appliance cords. It keeps them neat and you can write on the outside of the roll.

To remove old wax from a glass candle holder, put it in the freezer for a few hours. Then take the candle holder out and turn it upside down. The wax will fall out.

Candles will last a lot longer if placed in the freezer for at least 3 hours prior to burning.

Blood stains on clothes? Not to worry! Just pour a little hydrogen peroxide on a cloth and proceed to wipe off every drop of blood. Works every time!(Now, where to put the body?)

Use vertical strokes when washing windows outside and horizontal for inside windows. This way you can tell which side has the streaks. Straight vinegar will get outside windows really clean. Don't wash windows on a sunny day. They will dry too quickly and will probably streak.

To clean artificial flowers, pour some salt into a paper bag and add the flowers. Shake vigorously as the salt will absorb all the dust and dirt and leave your artificial flowers looking like new! Works like a charm!

Spray your TUPPERWARE with nonstick cooking spray before pouring in tomato based sauces and there won't be any stains.

Wrap celery in aluminum foil when putting in the refrigerator and it will keep for weeks.

To get rid of itch from mosquito bites, try applying soap on the area and you will experience instant relief.

[Editors note - This really does work]

Use air-freshener to clean mirrors. It does a good job and better still, leaves a lovely smell to the shine.

When you get a splinter, reach for the scotch tape before resorting to tweezers or a needle. Simply put the scotch tape over the splinter, and then pull it off. Scotch tape removes most splinters painlessly and easily.

Now look what you can do with Alka Seltzer.....

Clean a toilet. Drop in two Alka Seltzer tablets, wait twenty minutes, brush and flush. The citric acid and effervescent action clean vitreous China.

Clean a glass vase. To remove a stain fill with water and drop in two Alka Seltzer tablets.

Polish jewelry. Drop two Alka Seltzer tablets into a glass of water and immerse the jewelry for two minutes.

Clean a thermos bottle. Fill the bottle with water, drop in four Alka Seltzer tablets, and let soak for an hour (or longer, if necessary)

Unclog a drain. Clear the sink drain by dropping three Alka Seltzer tablets down the drain followed by a cup of Heinz White Vinegar. Wait a few minutes, and then run the hot water.



Helping you with your Polio and PPS related Problems.

Apart from finding and disseminating information about Polio and PPS, LincsPPN is dedicated to helping with any problems or concerns that members come across. If we do not know the answer then we usually know someone or another organisation that might be able to help. We have listed some of the organisations that we use on the facing page. However, we do need **YOU** to ring or write to us and tell us what you are concerned about! I heard recently of someone who had a problem, failed to tell us what it was and then was unhappy that we had not been able to solve it. With the best will in the world, we are not telepathic and nine times out of ten you won't be the only member with this problem.

The e-mail forum recently flagged up something that I had not previously considered. Not all of us have cars, or if we do, may not always want to use them and would prefer to use the bus. But just how easy is it to access public transport? The following post made me think:

“We have just received our first disabled bus in this area and one of our ladies at the day centre was asked by Radio Cumbria what she thought of it. She went off and tried the bus. Her experience was to say the least terrifying. To start with it was a ramp that the driver had to put out for her friend to push her onto the bus. Then the allotted space for the wheelchair was very tight and hard to manoeuvre in. So with difficulty her friend managed to get her into the space. On the journey she had to hang on for dear life as there was no way of clamping the wheels down. Every time the bus stopped or set off the wheelchair tipped, and when the bus went down hill it slid forward. Needless to say she has given her report to Radio Cumbria and also wrote to Stagecoach. The lady in question is my friend who has PPS and she like the rest of us likes to make her point very strongly.”

Getting your wheelchair into a cramped space, and then finding yourself sliding around at the whim of the bus movement does not sound healthy to me! I decided to look into the situation myself. After speaking with the Disability Rights Commission and looking at several web-sites on the matter, I spoke with the Operations Director of Stagecoach (West) and told him of my concerns. He was extremely interested and helpful, and has offered me and my wheelchair the opportunity of a test-run in one of their buses - which I will definitely take up. Assuming I remain in one piece, I'll report back! He told me that the law requires that wheelchairs are restrained in mini-buses and the like, when the passenger is facing forwards. In larger buses, the arrangement is that the person in a wheelchair faces to the rear of the vehicle, and the w/chair is backed up to a special board. Thus the chair cannot go shooting forward if the driver has to brake suddenly. Interestingly, nobody seems to have thought that when standing on a smooth or carpeted floor, a w/chair with the brakes full on will still slide. Restraints are not considered an option because a) they are deemed unnecessary, b) it would take too long for the driver to apply them, c) the passenger needs to be able to do things by him/herself in the interests of equality and d) they don't want the driver getting out of his seat as that might mean that his ticket money and the bus are 'at risk. I now have a copy of Stagecoach's leaflet on their responsibilities to disabled people, and their progress towards getting the whole fleet up to Disability Equality Duty standards. I will comment further once I've seen the information and tried the bus for myself. Wish me luck!

Mary McCreadie - mary.mccreadie@lincolnshirepostpolio.org.uk

[Editors Note - We stay overnight at the Gatwick Airport Travelodge and use the Hoppa Bus. They fold the ramp out and Richard goes in first in his electric chair and there is room for him to turn by the wheelchair space—get in the space, but getting out is another matter. I walk by my scooter and take it in backwards having to hootch it round a bit physically and stay in the aisle. I doubt together we could ever travel on a bus. Riding the Greyhound in the USA was an experience facing forward and hanging on to the seat in front]

OTHER ORGANISATIONS THAT MAY ALSO HELP YOU

BRITISH COUNCIL OF DISABLED PEOPLE

UK's national organisation of the worldwide DPA, setup by Disabled people to promote equality in UK society.

Phone: 01332 295551

Web: www.bcodp.org.uk

BRITISH POLIO FELLOWSHIP

We provide a wide range of information and advice on your rights, housing issues, equipment, Self-Management courses, the late effects of polio/post polio syndrome etc. The list is extensive and you will find a great deal of information here on the website. If you can't find the information you're looking for, please contact our helpful office team

Eagle Office Centre, The Runway, South Ruislip, Middlesex. HA4 6SE

Freephone: 0800 0180586

Web: www.britishpolio.org.uk

E-Mail: info@britishpolio.org.uk

DIAL UK

DIAL groups give advice on all aspects of disability and are run and staffed by people with direct experience of disability.

Phone: 01302 310 123

Web: www.dialuk.org.uk

DISABILITY ALLIANCE RIGHTS ADVICE LINE

Telephone advice on benefits for people with disabilities. Publish Disability Rights Handbook among other titles.

Phone: 020 7247 8763

Web: www.disabilityalliance.org

DISABILITY LAW SERVICE

Provides free confidential legal advice to disabled people, their families, carers and enablers. Service is made up of solicitors, advisors, trained volunteers providing informed legal advice.

Phone: 020 7791 9800

DISABLED LIVING FOUNDATION

Leading source of information on disability equipment, day-to-day household gadgets, new technologies and training techniques.

Phone: 0845 130 9177

Web: www.dlf.org.uk

DISABILITY RIGHTS COMMISSION HELPLINE

Provides information and advice to disabled people and employers and service providers about their rights.

Phone: 08457 622 633

Textphone: 08457 622 644

Web: www.drc-gb.org

HOLIDAY CARE

Providing holiday and travel information for disabled people and their carers; funding, accessible hotels and respite care.

Phone: 0845 124 9971

Web: www.holidaycare.org.uk

MAKING CONTACT.ORG

A service of Contact a Family, Making Contact.org is a place where families of disabled children or adults, their friends or disabled adults themselves can find and contact others affected by similar disabilities or other local disabled people.

Web: www.makingcontact.org

MAVIS (MOBILITY ADVICE AND VEHICLE INFORMATION SERVICE)

Driving ability assessment including advice on car adaptations and the opportunity to test drive a range of vehicles.

Free information service.

Phone: 01344 66100

Web: www.dft.gov.uk

This is just a small selection of phone numbers and web-sites that just might be helpful to some people. If anyone has found a particularly useful/helpful organisation that you think might benefit other members, do please let us know.

Congratulations

June's Iron Lung Guinness World Record

Following an application by the Polio Advisory Committee of Polio Network Victoria, Mr. Peter Turner, CEO of ParaQuad Victoria today joined with team members of AFL's Carlton Football Club to present a very proud June Middleton her Guinness World Record certificate. The wording on the Certificate reads:

“June Middleton of Melbourne, Victoria, Australia, has relied on an iron lung to keep her alive since contracting polio in April 1949.

Ms June Middleton, (b.4 May 1926) spends approximately 16 hours each day on the negative pressure respirator and has done so to date for over 57 years.”



Mr. Peter Turner, CEO of ParaQuad Victoria and Mary-ann Liethof [Polio Community Officer] photographed with June Middleton.



June Middleton in 1949/1950 and in 2007 in her iron lung at the Austin Hospital's Bowen Centre



Also present at the Ceremony were Carlton Football Club members. Captain, Anthony Koutoufides, assisted in the presentation of the Certificate and said ‘June has been a wonderful supporter of Carlton Football Club for a long time; she has built some very strong friendships.’ In fact, June keeps a poster of the team on the inside lid of her iron lung stating that she “sleeps with the whole Carlton Football Club team every night.”

Ms. Middleton, 80, contracted polio in 1949 at the age of 23, and now spends 16 hours a day at Austin Hospital's Bowen Centre inside the machine which helps her breathe. “I suppose it is amazing when you consider the doctors told my parents I wouldn't last 24 hours, and I'm still here 57 years later,” Ms. Middleton said.

<http://www.polionetworkvic.asn.au/news-events/items/2007/02/136192-upload-00001.pdf>

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