



# The LincPIN

The **Lincolnshire Post-Polio Information Newsletter**  
Volume 3 - Issue 1 - October 2000

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

**This issue is dedicated to the life of  
Denis V. Mardle, C.B.E.**

## **25th September 2000 Department of Health's position on PPS.**

In the current edition of their magazine The Bulletin, the British Polio Fellowship (BPF) clarifies the Department of Health's position on post polio syndrome. In correspondence with the BPF, Yvette Cooper, Parliamentary Under Secretary of State at the Department of Health, writes:

We are aware of the emergence of evidence that post polio syndrome is affecting survivors of epidemics earlier this century.

Polio was previously considered to be a self-limiting disease, once the acute stage was over. The amount of residual damage determined the degree of recovery, which was thought to be stable once optimum function had been achieved. However, it is now well established that polio has a second, slowly progressive degenerative phase, unrelated to normal ageing. This second phase may become apparent many years after the initial infection.

As time passes, an increasing number of previously "stable" persons with a history of polio infection report unexpected new symptoms. The time lag from the initial infection to the second phase varies but is commonly approximately 30 years.

The onset is usually slow and steady. It may occasionally develop suddenly and progress at an irregular pace. Symptoms sometimes commence after a period of physical or emotional strain, or after a period of immobility, e.g. disease or surgery.

Yvette Cooper has given the BPF permission to quote the above text. The Lincolnshire Post-Polio Network are grateful to both the BPF and the Department of Health for their permissions to use the same text for informational purposes.

Remember the opinions expressed are those of the individual writer(s) and do not necessarily constitute an endorsement or approval by the Lincolnshire Post-Polio Network. Although it does not provide an endorsement, it is provided as a service to those seeking such information. ALWAYS consult your doctor before trying anything recommended in this or any other publication. **Lincolnshire Post-Polio Network - UK Registered Charity No. 1064177**

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### EDITORIAL By Hilary Hallam

**Annual General Meeting.** 34 people attended the actual meeting with 18 staying over at the IBIS Hotel. The minutes will be sent with your next newsletter but to bring you up to date here are a few facts from the meeting.

**Precis of Chairman's Report.** Christine Ayre apologised for being unable to do much of the work this year due to ill-health. In the last couple of months a couple of TV programmes have featured PPS which has highlighted the condition. The Healthcheck Watchdog programme resulted in 68 enquiries to which we responded with Information packs and from this we have had 14 new members. Funds are the biggest problem for the Charity. Hilary's daughter Alison was thanked for organising a truck pull which raised over £500. Membership has increased this year and we now have 41 Life Members, 28 Overseas members and 207 ordinary members. A total of 84 are at present due for renewal.

Voting then took place with additional nominations coming in from the floor and the results are:-

Chairman Hilary Hallam  
Vice Chairman/WebSite Administrator - Chris Salter  
Secretary Frank Grimmitt  
Treasurer Wendy Grimmitt  
Members Phil Bilton, Janice Eary, Ted  
Hutchinson and Jennifer McGowan.

As your new Chairman I would like to start by thanking a few people. **Our retiring committee members** - Christine Ayre, Bud Robinson, Myra McManus and Jean Tapper - for their support over the last year. Jean is now on the committee of the Lincolnshire Association of People with Disabilities which means we shall still be in touch on a regular basis. **Our Vice-Chairman and WebSite Administrator** Chris Salter for his work on our growing WebSite which continues to receive high praise from many sources. We have been asked why this post remains with Chris and its simply that he does all the work on a voluntary basis and our organisation would not be what it is without his expertise. **Our co-opted committee members** Wendy and Frank Grimmitt have now taken the posts of Secretary and Treasurer. I am especially grateful to Wendy for taking this post allowing me to put the energy it has taken doing the administration work and preparing and sending out Information packs etc., towards other work. Committee member **Phil Bilton 'our Gopher'** who is always there in the background working hard. A special thankyou to **Marie Lee from Blackpool** who worked almost non stop at the AGM preparing the food for our buffet and making sure the teapot was hot. I have received so many comments on the excellent colourful way the food - bought from ASDA - was presented. I would also like to thank **all those who joined us for the day and weekend** and for the help given. Saturday evening investigating King Edward III's underwear and armour was particularly interesting and my thanks to

**Tony Meladio** - who has been King Edward III for over 20 years as a re-enactor - for bringing his 'full body orthotics' for us to see.

Finally I would like to **welcome our new committee members**, Janice Eary, Ted Hutchinson and Jennifer McGowan and thank them for offering to join our team from the floor of the AGM. We hoped we might get one new member but three surpassed our wildest dreams. There is a new wealth of expertise and a sub-committee will be formed to fund raise and obtain grants to further our work and purchase office equipment for the Charity. Up till now apart from the WebSite computer purchased by three firms in America we have been using our own equipment which is now well used, out of date and warranty. We look forward to telling you next newsletter of our plans for the year. Coffee mornings are a good way to raise some funds and spread the word about PPS, if anyone would like to do this then please get in touch so that we can send you some extra information.

I would like to clarify a query that has come from a non-member who reads the odd newsletter. Attendance at PPS Conference costs have not been paid for by the LincsPPN. Money towards travelling to the States and presenting at the GINI Conference this year was received, as a donation for that purpose only, from members - both in the UK and overseas - from Lincolnshire Health Authority and Lincolnshire County Council and from my family. There was also the generosity of the people that we stayed with en-route without which the trip would have been impossible. Once again my thanks for their support in our quest for more information.

On my return I wrote my story diary style, from notes that I had made, as I had on previous trips, adding some humorous pieces here and there to lighten it up. I have received many compliments on the content, admiration for even attempting a road trip of nearly 3,000 miles - the cheapest way - to meet up with more PPS specialists and PPS Groups, and been asked how did you manage it? PPS is hard to accept, changing from the fast lane of my life to the slow lane is not something I planned for or want. Not being able to just get up and go but having to plan ahead all the time is very tough. It does not mean that you cannot put in times where you know you are going to overdo if its what you want to do and you know it will give you a huge boost from the achievement of doing it. There was no going out at night, there was very little 'tourist time' and being honest not enough resting time and I had to manage on the small amount left once bills are paid as I do in the U.K.

**Meeting - 16th August Neurosciences Forum with Lincolnshire Health Authority.** Unfortunately much of the meeting was taken up by a presentation about the merging of two NHS Trusts. However

more discussion took place on how we can move forward in obtaining better neurological support in Lincolnshire. Andy Rix - the LHA representative - also a qualified nurse and a carer for his wife who has a neurological condition - told us that he was now beginning talks with various people towards our goal.

**Meeting - 4th October in Birmingham.** I attended as the representative for the Lincolnshire Neurosciences Forum an Inaugural meeting of regional neurological support groups. This meeting was very productive with groups detailing how they had started and why. We all gained pieces to add to the jigsaw of our work. A full report is being sent to Deborah Jaines at Lincolnshire Health and more information will be forthcoming following the next meeting on November 16th in our next newsletter.

**Neuroscience Support Group Seminar 7th October at Queens Medical Centre Nottingham.** I manned a stand for the LincsPPN providing information on PPS. Three attendees took information for parents who had had polio. Many therapists took a new 'leaflet for Health Professionals' with many saying they did not know of its existence. Three Occupational Therapists - one who knew of our work - asked for more information, links to their website and a talk to be given to their local OT's. The organisers of this day were particularly helpful and brought various 'Professors and Doctors' to meet me so that I could explain the work we are doing. I look forward to taking up their offers of contacting them again to further the short discussions we had.

Our thanks to the family, friends and work colleagues of **Denis V Mardle CBE** for the generous donation of £800 in memory of his life, and especially to Helen George his daughter for telling us about her father. Starts at page 4. Denis was truly a 'High Achiever'.

**Fund Raising Polo Shirts** with embroidered Logo are now available. Christmas will soon be with us, why not help our funds and promote our charity by buying a Polo Shirt. They are white polyester cotton 65/35%, collar, three button, shirts with a breast pocket located embroidered logo of 13,500 stitches as the front of this newsletter. Sizes available are S 34 - 36, M 37- 39, L 40 - 42, XL 43 - 45, XXL 46 - 48, XXXL 49 - 51 and are priced at £10 with the Logo on, and £13.50 if you wish your Christian Name to appear below this. Please send your orders and cheques, which include postage direct to you, to the LincsP-PN.

**FINALLY** - Information check sheets are enclosed. Please notify us of any errors and if something does not arrive as expected then please give us a ring ASAP.

## **Dennis V. Mardle C.B.E.**

### **Life with Denis - Polio survivor for 55 years by Helen George.**

Denis met my mother through the R.S.P.B. bird watching society in 1979, they were married within six months. We soon learnt a lot about Denis, the difficulties and the achievements. We loved and accepted him into the family, especially because he made our mum happy.

On the Day he contacted polio (aged 15) he had been to a football match (To see his beloved Luton town). On reflection he realises that he must have drunk from a cracked cup, because that evening the middle of his spine felt like it was on fire ! It did affect his lungs and left a permanent weakness, but he did not have to be tied to an iron lung. I think that during his two-year stay in hospital he developed his incredible strength and courage to make the most of life. He must have had such admirable determination to further develop his brainpower as he went on to achieve great levels of academia, and make great contributions in his workplace.

I believe he made full use of what was available for him; he would not let his disability get in the way of going places or doing things. His arms and shoulders were his focused mobility and when his wheelchair would only take him so far, he would use his crutches to get that bit further. He did have to wear a body support, he said that sitting up was not comfortable for him without it, it was made especially to suit his body shape. He also had a calliper on his right leg, which helped him to be stable and walk in a shuffled sort of way.

Around the time that my mum died, 10 Years ago, when Denis was 60, I took on being Denis' carer, I noticed a gradual deterioration in him. At first he would talk of feeling nervous about walking across the room with his crutches. Then he mentioned more frequently that his hands felt clumsy (Age 64) and there didn't seem to be so much strength in his arms. It was around this time that sliding boards were introduced. It wasn't long before he didn't use his crutches at all (Age 65). Doctors took X-rays and said that both of Denis' shoulders were Arthritic and there was nothing that they could do about them periodically dislocating. He would ask for a massage when they used to get really sore, the joints would sometimes twitch and crack, so massage would have been too harsh, sometimes I would just hold his shoulder in-between my hands and hope that the T.L.C. was getting

through.

It was also around this time that Denis had two overhead hoists put in the bungalow, one in the bedroom and one in the bathroom. Up to this point Denis had a procedure for having a bath that he was able to do independently. He adjusted quite well to needing more help for his bath and things in general. He had a carer come every morning to help get him up. The days I spent with Denis were quite slow; this was mainly because we were going at Denis' pace, I could see how vitally important his independence was and besides he loved to chat and reminisce while we were taking our time to doing things anyway.

Denis continued in this vein, although weakness and pain must have been gradually setting in. Denis turned Three Score Years and Ten Last Year. I think he realised that he had done well to live to this age and sometimes would worry that his memory wasn't as good as it used to be.

I would reassure him that, Its not that you get more forgetful ~ Its just 'As you get older you have more things to remember!' And besides ~ I am 42 and Denis knows ten times more information (Or more) than I do, so forgetting what somebody who you met 40 years ago was called, is not a sin. Denis would worry about it and ask me to dig out a book or something so he could make reference to it, until he had remembered.

Around Mid winter he also started to worry about getting himself into bed at night. He had managed quite adequately before, although I believe the whole process would take him a couple of hours. He had a lifeline alarm that he kept around his neck at all times, he had to use it at night on several occasions, this made him realise that he needed even more help.

We made some enquiries about 'live in carers'. It made sense to have some one live in and be there all of the time. At the beginning of this year Denis had to make many adjustments, it was difficult for him at first to get used to a carer and allow them to help him. They would always use the hoist, as this would prevent their backs from harm and Denis from being in too much pain with his shoulders.

Around this time I began to notice that Denis would get quite agitated, he wasn't really himself and would sometimes upset me. I talked with the doctor and after checking him over; he said it was just anxious adjustment? After a short

while he ceased the agitation, and started to be more tired than normal? There were a few incidents when he had visionary experiences, and made some reference to religion (not normally a follower of anything except maths and science). His eyes would sometimes roll and he would either fall asleep in the middle of talking or just not hold a very long conversation.

I wanted Denis to see a doctor, but he insisted it would wait till the end of the week when he had an appointment anyway. The following morning the carer phoned me and we all rushed to hospital. I found myself getting very agitated, because Denis was given an oxygen mask and was left in a queue to see the doctor? After 5 hours I went to get some fresh air and Denis had a Pulmonary Arrest! Suddenly Denis went up the queue of importance and was resuscitated and taken to the intensive care unit. I was given a lot more respect and given explanations.

It was a crucial time and Denis did pull through, although it did result in him having a tracheostomy. It was at this time that I scoured the Internet for information on Post Polio complications late in life. I took in an article about pulmonary dysfunction for Denis to read, He told me later that the doctors were very interested in looking at the article as they admitted to knowing very little about post polio syndrome.

I had told Denis how worried we all were, when he was more 'with it', he wrote down "I am not that weak!" and gave one of his wry smiles. He even told a joke to my sister Lyn when she visited.

When Denis moved from Intensive Care they wanted to do more tests. After exploring many avenues, they discovered that he had a condition called 'Sleep Apnoea'. On his chart it showed that Denis temporarily stopped breathing 179 times in one night. Yet again I scoured the Internet and took more reference for Denis to read. I wanted at this point to encourage him to get in touch with a doctor that was more familiar with polio symptoms. There was mention of St Thomas's in London, the hospital contacted this place and he was referred to Standish Hospital near Stroud for CPAP treatment. Denis was rather confused at times, where he was going or what he was doing, it became more difficult to have detailed lengthy conversations, he would also continue to get agitated at times.

The move to Standish was arranged and the CPAP treatment was explained. I believe Denis had quite lengthy talks with two CPAP Doctors. In Denis's process of thought he decided to refuse the CPAP treatment and said

that: "He would rather die peacefully soon ~ Than be kept alive in his Deteriorated and Dependent state by the treatment"

The hospitals attitude changed and they sent Denis home; it is what he had wanted after being in hospital for six weeks already. I did feel however that they appeared to be washing their hands of him! He was sent home with no medication or recommendation for assistance in his condition. From the words of a nurse came: "We have plenty of sick people who want our help, we haven't time to waste"

Denis had made the choice to go home and die! I think he approved of the treatment but took an opportunity to give up the battle against his other deteriorations. His long-term polio strength had run out! He knew it was going to happen soon. I sent a 'help us' plea to the Lincolnshire Post-polio network who got in touch with Denis and was arranging for someone to visit him.

The first week Denis was home from hospital he was happy, although it was not long before he began to get agitated again. I asked his local doctor if a little oxygen would help him be more comfortable. It was explained that in refusing the treatment, which was oxygen assistance, the doctor could not do anything unless Denis consented. I explained my concern and worry to Denis, he didn't want to talk about it and got agitated and angry with me for bringing it up.

He didn't want to talk about much at all, conversations were short and self focussed. He would frequently fall asleep in the middle of talking. He would keep on saying that there was no time to do the things he used to do! Sometimes his eyes would roll and during the last week of his life he asked if we could see the horse in the garden? Another time when I was elevating his legs on to a cushion he asked if I could see the flames coming out of his feet? I gently held them for a while and did my 'channel healing thing' and said, "Your feet are telling me that they are happily resting now" This was the last 'with it' time I saw Denis.

The Day before he died he spent the afternoon in the garden and talked to the carer a lot about the nature and wildlife that visited his garden, apparently he also said to the carer "God is here you know!".

He was due to go to a six-week follow up appointment with the specialist at the hospital on the very morning that he died. When the carer had tried to wake him, he was delirious, so we all rushed to hospital. Pneumonia had set well in to

one lung, it was a wait and see time. We did not have to wait too long because two hours later he arrested and died. It was peaceful; it was, as he had wanted.

### **AFTER THE LIFE OF DENNIS**

Denis was an avid reader of the Times; he would regularly read the obituary column (lots of people do!) Denis implied once to me that he'd like me to notify them when it was his time. Thanks to the Internet I was able to contact the Times and here is a copy of my article.

**The Times - 15th August 2000.**  
**DENIS MARDLE C.B.E.**  
**A polio victim who became an**  
**extremely talented mathematician**  
**and chess player.**

DENIS MARDLE, died peacefully on July 31st, a week before his 71<sup>st</sup> birthday, he was a talented mathematician who became one of Britain's leading cryptanalysts. A victim of polio from the age of 15, he remained heavily disabled for the rest of his life and could move only slowly with crutches and leg callipers. In spite of these adversities he was by nature cheerful, courteous and sociable.

Denis Victor Mardle was born on August 9<sup>th</sup> 1929 and spent his childhood in Luton. Denis was educated at Denbigh Road Elementary School and Luton Grammar School, where he passed his school certificate exams, just before his fourteenth birthday. In the Science 6<sup>th</sup> form chemistry was his strongest subject, but that changed after his illness. From the autumn of 1944 he spent nearly two years at the Royal National Orthopaedic Hospital, Stanmore. With great help and encouragement from his headmaster, K. B. Webb, he returned to the 6<sup>th</sup> Form, where burly fellow pupils carried him up and down stairs when necessary. He now concentrated on maths with a new determination, and also managed to master School Certificate Latin rapidly in order to gain admission to Cambridge. Entering Christ's College Cambridge to read mathematics in 1948, he obtained his B.A. in 1951 and went on to do a diploma in statistics the next year.

Meanwhile, his abilities as a chess player were developing and he was a regular member of the Bedfordshire and Cambridge University teams. It was at an Oxford v Cambridge match that he was "talent spotted" by C. H. O'D Alexander, then head of the Cryptanalysis Division of G.C.H.Q. Denis joined the Eastcote establishment in 1952; It was in the local chess club, that he met Barbara Lally, who was to become his first wife. He was soon moved with his colleagues to Cheltenham, where he and

Barbara lived for many years. Sadly Barbara died from cancer in 1972, Denis lived alone for seven years.

Denis Mardle was initially appointed to GCHQ as a research mathematician and made a number of contributions that are still held in high regard in both the UK and the US. A steady succession of promotions followed, from Senior Scientific Officer up the ladder to Deputy Chief Scientific Officer. In 1969 he directed the Mathematics Research Group before being promoted to Chief Mathematician in 1973. Denis and his colleague James Ellis made significant contributions to signal processing for radio direction finding at about this time, anticipating the development of the MUSIC algorithm by Schmidt in the USA by several years.

Denis continued his interest in chess for many years, partly by means of correspondence games but also in league matches. He also competed in the British Championship twice, played once for England and often took part in the Hastings tournament. It was here, in about 1960, that he scored a brilliant victory against the Grandmaster Gligoric.

While Denis was living alone his interest in ornithology grew. It was through the R.S.P.B that he met his second wife, Freda Storie, she brought colour and sparkle to his life. They married in November 1979; in 1981 they moved to Teddington near Tewkesbury, they lived here for 10 years. Sadly Freda died of a heart attack in May 1991.

In 1982 he was appointed Head of the Cryptanalysis Division, with considerable responsibilities for planning and staff management. In March 1988 he was awarded a CBE for his overall contributions. He retired officially on his 60<sup>th</sup> birthday in 1989, but continued with administrative tasks. Later, in full retirement, the Internet provided him with a window on the world, including the interpretation of the mysterious Voynich Manuscript.

In the last year or two of his life Denis battled against a deteriorating body with breathing difficulties. Although he lived alone after Freda died, he received much help and support from Freda's children. He had no children of his own. Daughter Helen who lived nearby was able to look after his domestic needs and make his last years comfortable and relatively happy.

Denis Mardle was born in Luton on August 9<sup>th</sup> 1929. He died on July 31st, aged 70. Cont. overleaf. I am spending my days missing Denis and cataloguing all of his books, it is a task and a half I can tell you but I am enjoying it because it is helping me deal with my grief. At one point I felt devastated that all of Denis's knowledge had

gone! I have realised in looking through his books the knowledge is still there and this has comforted me a great deal. I am also beginning to see myself as lucky that I knew Denis and got to spend a lot of time with him. His funny ways would exasperate me sometimes, now they just make me smile.

**Helen George.** <storiefm@btinternet.com>

Editorial Note.

The Lincolnshire Post-Polio Network would like to extend a huge thankyou to the family, work colleagues and friends of Denis Mardle whose donation in memory of his life totalled £800. This will be put towards continuing our efforts to promote the awareness of Polio's late effects and requested provision of specialist PPS multi-disciplinary assessments. The more we all - health professionals, polio survivors, carers, family and friends - understand about polio and PPS and the treatment, advice and equipment that is recommended by PPS Specialist Clinics in other parts of the world the longer and easier we will all be able to manage the remainder of our lives. I am only sorry that I only got to talk to Denis on the phone, he died two days before we were due to meet.

**TELL YOUR HEALTH PROFESSIONALS  
ABOUT THE FOLLOWING  
ONE DAY COURSE**

**Thursday October 26th 2000**

**Pathophysiology and Management of the  
Post-Polio Syndrome: A Critical Review.**

**Postgraduate Centre, St. Thomas' Hospital,  
London SE1 7EH.**

**ORGANISER - Adrian J. Williams**  
for The Lane-Fox Unit's Post Polio Centre.

**Programme:**

- 9.30 - 10.00 Coffee and Registration.  
1 - Polio Revisited - Robin Howard.  
2 - Post Polio Syndrome - The U.S.  
    Perspective - Anthony Windebank.  
    Break.  
3 - The Post Polio Syndrome - The U.K.  
    Perspective - Adrian J. Williams.  
4 - Post Polio Respiration - A. Craig Davidson.  
5 - Post Polio Sleep - Adrian J. Williams.  
    Lunch.  
6 - The Patient's Perspective - Tony Gould.  
7 - Orthopaedics - Prof. F.W. Heatley.  
8 - Spinal Surgery - John O'Dowd.  
9 - Psychiatry - Andrew Hodgkiss.  
10 - Rehabilitation - A. Craig Davidson.  
Summary and Close - Adrian J. Williams and  
    Robin Howard.

**Course Fee:**

- £50.00 for consultants and GP's.  
£30.00 for allied professionals.

For Registration Form contact Mubina Issaji;  
Tel: 020 7928 9292 Ext 3581  
Fax: 020 7401 8591  
Email: Mubina.issaji@kcl.ac.uk

**South Lincolnshire Healthcare NHS Trust - Specialist Services Department  
present Equipment Awareness Day**

**Wednesday 1st November 2000**

**Spring field House, Springfield Park, Grantham, Lincs.**

See the latest equipment and products available - 24 companies.  
Come to our 'Open House' and meet the staff of the Specialist Services Department  
at Unit 127 Springfield Park. Free transport between here and Springfield House.

**Attend one of our seminars**

- 10.00 to 10.45 - Assistive Technology  
10.55 to 11.30 - Pressure Reduction  
11.40 to 12.10 - Direct Payments/Independent Living  
12.20 to 1.00 - Wheelchair Service - Fitting and General Maintenance  
1.00 to 1.45 - Repeat of Assistive Technology  
1.55 to 2.30 - Continence  
2.40 to 3.15 - Repeat of Direct Payments/Independent Living  
3.25 to 4.00 - Voucher Scheme & Electric Powered Indoor/Outdoor Wheelchairs.  
Program is subject to change.

**Eighth International Post-Polio and  
Independent Living Conference  
St. Louis, Missouri, June 8-10, 2000**

**STRATEGIES FOR MANAGEMENT  
OF ARMS & SHOULDERS**

**Mary Ellen Brown, RPT  
and Nancy L. Caverly, OTR/L**

**POSTURE & ALIGNMENT**

1. Keep your arms in good alignment. This allows improved function, minimizes stress and pain. To have your arms in proper alignment requires good postural alignment of the entire spine and good stabilization of the shoulder girdle muscles. In other words, SIT UP STRAIGHT with chest up and shoulders back and down!

2. To have good posture and a stable position of the spine requires functional trunk strength and/or custom seating to support the back while in a seated position and possibly a custom brace for upright positions instead of just standing.

3. Learn RELAXATION techniques for neck, shoulders, arms, wrists and hands to avoid fatigue from tension and to prevent unnecessary muscle overuse from muscle stress. Explore a variety of relaxation techniques, for the resting body, to find one suitable for you. These may include meditation, listening to music, creative visualization, and/or taking a class on stress management. Deep relaxed breathing is essential. Note: relates to LIFESTYLE, also.

4. Do a daily stretching routine to maintain good mobility of joints and muscles. If you cannot do these exercises yourself, have someone do them with you.

**FINE MOTOR/ HAND TASKS**

1. Make sure your hands are comfortably warm to facilitate improved function and relaxation. Sometimes gloves with the fingertips cut off are helpful.

2. Become more ambidextrous, alternating use of right hand and then left. Don't make the same muscles do everything.

3. Make sure your glasses are adjusted to avoid strain on your neck and shoulders. Remember your postural alignment will shift to enable you to see.

4. When turning pages of a book, use a rubber eraser on a pencil to decrease use of fingertips, or use a mouth wand to eliminate upper extremity

(arms, shoulders) demands altogether.

5. Adapt writing implements and other tools so that your hand is supported and comfortable rather than held in a tight pinched grip or awkward position.

6. When picking up light objects with your hands, mold your hand, using the strength of the palm muscles rather than pinching with the thumb and fingertips.

7. Prevent pressure on the thumb side of your fingers. Using hands incorrectly pushes the fingers away from the thumb into a deforming position. For example, hold purses and bags on the forearm instead of with the fingers.

8. Use scissors to open packaged foods, letters, tightly sealed packages. This reduces hand strain.

9. For drinking, try using a straw with the cup, can or bottle resting on a tabletop to avoid a sustained grasp.

10. Check the ADL section of catalogs such as Sammons Preston or Smith Nephew for self help devices for kitchen, bathroom and other needs. There are wonderfully helpful things to make life easier from one-handed potato peelers to book racks to portable toilet seats to graters on suction cups, etc., etc., etc. Regular stores may have can openers, jar grabbers, etc.; also, JC Penney and Sears have catalogs for "Special Needs".

**LIFESTYLE / STRESS MANAGEMENT**

1. During rest breaks in mid-morning and mid-afternoon, make sure your arms are resting, too. Holding a book to read while relaxing the body doesn't rest the arms.

2. DELEGATE chores that are too demanding such as vacuuming, mopping, scrubbing, chopping, stirring, gripping. "if you have four things to do today, pace yourself to do one in the morning, one in the afternoon, one in the evening, and delegate the fourth. That's one of the reasons we have friends and family."

3. Do deep breathing exercise frequently for relaxation and good oxygen supply to the tissues. Use respiratory assistance if necessary.

4. Eat a healthy well balanced diet low in animal fat and high in vitamins and minerals from fruits, vegetables and grains. Add extra high quality protein for neuromuscular maintenance.



5. Make sure you get plenty of sleep regularly to allow your body to repair itself from any effects of soft tissue micro trauma.

## **MOBILITY**

1. Avoid stairs! Banisters may help legs (lower extremities) but they only strain upper extremities. Use elevators or escalators, if your balance is good enough.

2. Sit in chairs that have sturdy armrests and that are firm. Avoid soft couches as you will really strain your arms getting up and down. One exception to the couch rule -- if you are on the floor, maneuver yourself to the nearest couch, put your arms up on the couch, and then roll yourself onto the couch. This is usually easier than trying to rise from the floor.

3. Avoid falls!! No matter what you might hurt, your upper extremities will pay the price. If you hurt a leg, your arms will be stressed using crutches. If you hurt an arm, you will become more dependent. Some falls are impossible to avoid, but many could be prevented by using the proper bracing, treating medical problems that cause dizziness or balance difficulties. When getting new glasses or trying new medications, be very careful as perceptions and orientation to space may change. Also avoid falls by keeping your environment safe by eliminating clutter, staying off slippery floor surfaces, getting rid of all throw rugs. Stay inside on rainy or snowy days. If you have to go out in inclement weather, always carry a small towel to wipe off the bottom of crutch or cane tips when you go inside.

## **ENERGY CONSERVATION FOR SHOULDERS**

1. When using upper extremities for any activity, take a break at the first sign of fatigue. Do not wait for pain. Take frequent stretch and rest breaks -- at least every 15 minutes with any activity.

2. When lifting anything heavy, use both hands and have object close to Your body to decrease stress on shoulders.

3. When reading a book, support the arms with Pillows or with well-positioned armrests. Prop the book on a slanted reading rack or similar prop on a stand.

4. Use a headset for telephoning to keep neck straight and eliminate need for using arms and hands. Get comfortable in a recliner chair or lying down and enjoy Your chat!

5. Alternatives for heavy Purses or bags are fanny packs (bum bags), backpacks, large jacket pockets. Leave Your Purse (Handbag) in your vehicle when shopping, carrying cash, checkbook or plastic in your pocket.

6. Large Pockets, belt loops are good places to relax arms when standing; rest arm on a fanny pack at your waist or place arms on top of your head for a few minutes. Pillows are essential for arm support when sitting or lying down. Arms are very heavy, so get rid of their weight by supporting them on whatever is available.

7. Avoid unnecessary carrying by putting duplicate supplies in several areas, such as towels, sheets, cleaning supplies in each room where they will be needed.

8. Eliminate ironing from your life by buying permanent press clothing and hanging garments on hangers when still partially damp from the dryer. If clothes must be ironed, rotate iron on and off of the garment without picking it up each time.

9. Use reachers for picking up light objects off floor or other places. Remember the length of the reacher increases the lever arm, so it puts more stress on the shoulder when lifting. Do not try to lift heavy objects.

10. If your legs are getting a little weaker and it is getting harder to get up and down, don't strain your arms to get into an upright position. Use pillows in chairs to raise the height of the chair a little or get a chair with a hinge mechanism to lift you part way up Out of the chair.

11. Raised toilet seats make getting up and down easier; now there are even adapters to lift up the height of the toilet itself.

12. Using a regular toilet in some restrooms is a real challenge, so always wait for the handicapped accessible stall. The toilets are higher and there is more space for maneuvering your body, using grab bars. These stalls are for "walkers" as well as wheelchair users. Note: Alert the facility to any problems with accessibility in the restroom.

13. Get a bathtub seat than can be lowered and raised hydraulically into the tub. Don't try to use arms alone to get in and out of the tub if your legs can't help very much. That is too scary and too much stress on your arms and shoulders! Use a sturdy seat in the shower so you can relax and enjoy the water.

## **CHOOSING ASSISTIVE DEVICES (ASSISTIVE TECHNOLOGY)**

If you are beginning to need assistive devices for walking, think about this very carefully. The use of canes, crutches, walkers and manual wheelchairs will be putting more demands on your upper extremities that already have a full time job.

1. If the need for a cane begins to arise because you need extra security with balance, get a cane with an anatomically correct handle. You can get a right-handed or left-handed cane, also, depending on which side you need support. Collapsible canes are available for those special occasions when you are feeling a little insecure. A cane with a seat allows you to sit when necessary.

2. A better choice, if you are beginning to feel weaker, would be very lightweight forearm crutches. (One supplier is Walk Easy 1-800-441-2904.) These will be less demanding on the upper extremities than trying to take weight off the legs with a cane that is not secure. If you are having increased hip weakness, you definitely need to obtain forearm crutches, as no brace will help the hips. When standing at rest with forearm crutches, rest forearms on cuffs, to relieve stress on hands.

3. Be sure you use any lower extremity bracing that may increase your stability and security, as this will decrease the need to depend so much on crutches and canes which stress the joints and muscles in the arms. This will decrease the chance of failing.

4. Walkers are a good choice for assisting weak legs with your arms. They are usually more stable and you can carry other things in baskets or bags that hang on the walker. Also available are wheeled walkers (4 wheels) with a seat, tray and shelf space that are useful in your home, the mall or craft fairs.

5. For longer distance mobility, you may need wheels! If your arms are really strong, a manual wheelchair may be an option, but again, great demands are placed on your upper extremities. The shoulders, elbows, wrists, and hands are working hard to propel all of you -- plus the wheelchair. If this choice works for you, the wheelchair needs to be very lightweight and the width of the chair needs to be narrow enough to allow your arms to be as close to your body as possible, for better mechanical advantage in propelling the chair. Keep a friend close by to push, in case you get tired.

6. To make life a little easier and decrease the demands on the upper extremities, adding a motor to your wheels makes good sense. There are attachments that can be added to manual wheelchairs to convert them into motorized chairs for short distances. There are many brands of motorized scooters available; choose one according to your need. The scooters put demands on your upper extremities in that you need to be able to steer them but this, in most cases, would be easier than propelling the chair. You need to have fairly good trunk control to stay balanced in the chair/seat.

7. If your upper extremities, trunk and lower extremities are all feeling weaker and fatigued, a motorized wheelchair is certainly the least demanding physically on the upper extremities of any mobility device. Custom seating can be developed to support spine and upper body in a more stable position allowing the upper extremities to be more functional with less fatigue. Sometimes a tendinitis can develop in the thumb and fingers from operating the controls of a motorized wheelchair, so the upper extremities always have some demand unless you get into advanced computer technology.

## **TECHNOLOGY CHALLENGES**

If you have joined the folks in the fast lane and are using a computer, the demands on your upper extremities have just multiplied many times, and could be the subject of a two-day course! The "normal" population in our country is suffering at epidemic proportions from repetitive strain injury (RSI) from many hours at the computer. Over 62% of all workplace injuries are now for upper extremity repetitive strain injuries related to computer work. So, if the "normal" population is having this much trouble with their arms, we, the polio population, need to take our time at the computer very seriously. Because mobility is a problem and the computer can do so much for us, **DON'T SACRIFICE YOUR ARMS** in the process.

1. Get an expert in ergonomics (an occupational therapist, physical therapist or others) to set up your workstation.

2. Make sure your chair supports your spine in neutral, so that your shoulder girdle and upper extremities are in good alignment. Use well positioned armrests to support the weight of your arms. Your feet should be supported, using a footstool if necessary. If you are a wheelchair user, have your workstation designed around your chair.

3. Take a 5-minute stretch break at least every 15 minutes with micro breaks more often. Limit the overall time you spend at the computer to 4 separate hours per day, depending on your strength/weakness.

4. Consult your ergonomic specialist frequently with any problem that gives you pain or causes fatigue.

**A REMINDER** - If you develop any pain, increased weakness, excessive fatigue in the upper extremities, and reasonable amounts of rest do not decrease the symptoms, get a medical evaluation and begin treatment as soon as possible. Many upper extremity problems can be eliminated with proper management, and the sooner the symptoms are addressed, the less risk you face of permanent decrease of upper extremity function. If your doctor does not suggest treatment such as physical therapy and occupational therapy, **INSIST ON IT.** "Normal" people rarely hesitate to seek medical assistance when pain or weakness occurs in their arms and shoulders. Neither should you, who has much more to lose -- your independence.

### **Letter from Sylvia Dymond, Member in Hampshire.**

In August 97 I purchased my second bed which raised me to a sitting position and raised at the foot end to ease my legs. It also had a built in massage unit to ease the pain and other aches due to PPS. I heard that the company were then manufacturing a bed which lowered more - another 6 inches - to enable those who had difficulty getting their legs onto the bed, I omitted to say my first bed from this company raised me to a standing position, my new one does the same. When I expressed my delight over my new bed a spokesman for the company said 'we listen to our customers and try to do our best to help.' I could not live alone without my bed. The company is Bakare Beds, Tel 01752 51222 I have just taken my bed away with me when I went for a fortnights holiday/respite care and cannot cope without it.

### **Sleep Difficulties by Member Philip Dalton.**

I suffer from sleep apnoea and so use a continuous positive airways pressure machine and face-mask, to keep my airways open during sleep.

However, I still had disturbed sleep; frequently waking fully or partially, and recollecting long dream sequences. These disturbances seemed

to coincide with times when I was changing position or trying to. I wondered whether my weakened body was unable to change position during deep - and therefore relaxed - sleep.

I tried the following which enabled me to sleep throughout the night - albeit still with the C-PAP machine. Firstly I removed the thick foam pad I had used on top of my mattress, this seemed to help perhaps because there is less resistance to movement.

Secondly I bought a 'Bed Cradle'. These you will have seen in hospital used to support bed linen over a broken limb etc. It is a plastic coated steel tube, shaped to fit under the mattress and over part of the bed thereby lifting the covers from the body, legs or feet. This cradle serves a dual purpose - not only does it make it easier for me to turn, it also means that my muscles do not have to support my bed linen throughout the night. (I suggest that any such muscular effort expended during sleep is unnecessarily tiring.)

There are a large number of types of cradle available. Mine was from Smith & Nephew, PO Box 5665, Kirkby in Ashfield, Notts, NG17 7QX. Tel No. 0345 023087. They will send an excellent catalogue. The type I ordered was 'Adjustable Bed Cradle' Cat. No. AA3652, Price £28.84. They delivered the following day.

Some words of caution. The above has worked for me and I generally sleep more soundly but it is only my personal theory unsupported by any research or medical advice. Anyone suffering from PPS and disturbed sleep should get in touch with a Sleep Clinic (with PPS knowledge) through their G.P.

**Philip Dalton**

**Correction.** Last newsletters article on page 3 Summary of Anesthesia Issue for Post-Polio Patients - Updated 13th June 2000 by Selma Harrison Calmes. I mentioned this article in my story but did not specifically state that Dr. Calmes presented at the GINI Conference and apologise for this error.

**Nutritional Therapist  
Vivien Holland DNN writes...  
about Constipation**

I am a new member and over the coming months I'm planning to write articles that I hope readers will find helpful regarding health matters, diet etc. obviously we are all so different in needs so I hope you will pick and choose as to what might help you. Do check with your GP if you have any doubts.

Just to let you know a bit about myself, I had polio in 1948 at the age of three. My legs were originally affected but they seemed to recover reasonably well and the only obvious effect was the upper left side, including shoulder arm etc. As a result I managed to lead a fairly normal life. Fully clothed, only very observant people notice anything not quite right.

My biggest problem was always fatigue and general weakness and in my 20's I became very interested in nutrition, trying one supplement after another in an attempt to increase my energy. I think if someone had pointed out to me then that the polio had left its mark in this respect, I wouldn't have berated myself that I couldn't do what others took for granted. I'd have paced myself and not expected so much. Looking back, I realise that, for me personally, anxiety over my fatigue was draining what little energy I had.

When I was 38, enforced rest came upon me when I strained my low back badly, I expected it to get better but it didn't, and seventeen years on the combination of that plus PPS has restricted me considerably.

On the bright side, if I hadn't hurt my back I'd probably still be in my old job, banging away at a typewriter every day. Instead I began to study nutrition seriously, something I've enjoyed immensely, and I'd like to share with you suggestions that have helped me. I soon realised that our optimum health is not about taking the right supplements, although they can help. There is a lot of groundwork to be done to help our bodies function the best they can.

This first article is chiefly about constipation, something that affects so many regardless of whether they've had polio, but for anyone inactive it can be more of a problem. Anyone interested in health matters will have heard of the importance of detoxification. Our bodies are producing waste products all the time, and if our routes of elimination (bowels, kidneys

etc.) aren't working well, it can contribute greatly to fatigue and even aches and pains.

Drinking sufficient water is a must. Eight half-pint glasses a day is not too much. A pint of warm water on rising, half an hour before breakfast is very cleansing and will encourage a bowel movement. A little lemon juice added will stimulate the liver. Then, during the day, more water half an hour before a meal will improve digestion. It's best to drink only small quantities of liquid with a meal. Large amounts will dilute digestive juices and hinder the digestion of the meal.

Having a bowel movement each day will promote a feeling of well being. There's nothing worse than feeling you need to go but can't. One of the jobs of the colon is to extract moisture from the faeces. This is why the longer a bowel movement sits in the back passage, the drier and harder it becomes. Drinking sufficient water during the day will help, as will a diet high in fibre or roughage. A problem I have encountered though is not 'really' constipation but a lack of the urge to go possibly because the muscles in the back passage are sluggish. Something you might like to try are glycerine suppositories (from the chemist). Pushed up the back passage they melt and lubricate the area. I find they also have a stimulating effect on the muscles so that the b ~ 1 movement comes more easily and feels more complete. Try them when you are at home and can reach the bathroom easily.

I've also found that aloe vera juice benefits many people considerably. It has many health benefits, particularly helping bowel problems such as IBS (Irritable bowel syndrome) and constipation.

Clearing up a basic problem like constipation may not directly help polio fatigue but I find that so many things can contribute to our fatigue and make us more tired than we need be. We just want to feel as well as possible, don't we. If you'd like to write to me with your own tips or comments. I'd be pleased to hear from you.

Write to:  
Vivien Holland  
32 Green Lane  
St. Albans  
Herts AL3 6EZ

**PPS and Nutrition**  
**Report on talk given by USA Nutritionist**  
**and Life Member Jann Hartman at our AGM**

Dr. Bruno does not recommend a "high protein diet" but a dietary plan that includes plenty of protein, especially at breakfast. (See LincPIN Vol 2, Issue 7, The Post-Polio Institute "Protein Power" Diet back page). It seems many of us have been skipping breakfast, and that is not good; and many times when we do eat, it is less than adequate for our PPS bodies, as we all need more nourishment to "break the fast" after sleeping. He has been saying that we need to get at least 16 grams of protein at breakfast to get a good start on our protein needs for the day. But, along with animal protein there is often a type of unhealthy fat (whole milk, sausage, even hash brown potatoes, and other fried breakfast foods) so you need to choose well. Bacon is practically all fat, and should be used very, very sparingly, if at all. You can also use the imitation bacon bits (made from naturally low fat soy) in things like sauces, omelets, quiches, etc instead of real bacon. To cut back on fat but keep high quality protein, you can use the "egg substitutes" or egg whites (the fat is in the yolk). If you have a problem with cholesterol the elimination of the egg yolks is the most important. But, otherwise you can certainly have a couple of egg yolks a week, and as many whites as you want!

High protein diets are unsafe for most people because the amount of protein is usually so high that it can be hard on your kidneys. A normal diet consists of 50% to 60% carbohydrates (whole grains, and other complex carbohydrates with much less sugar and other simple carbs). But, when you increase protein and fats to try to replace the carbs, you are not taking in the complex carbs your body needs to function. Fats have been shown in many reputable studies to contribute to cardiovascular problems. Some people do lose weight by mistreating their bodies with these "all you want to eat protein/fat diets," but I also hear many stories of people who end up in the hospital from these poorly constructed diets, too. Not something \*I\* care to risk.

Keep to a sensible diet of complex carbohydrates, proper fats, and enough good quality protein (both plant and animal). Lean meats are best for those who need to increase iron, for others, plant protein is often a good substitute for at least some of the animal protein.

Soybeans (granules, tofu, etc.) are the only complete protein in the plants, but other beans, legumes, and vegetables offer various amounts of protein, too. It is best to try to get all the nutrients you need by eating as large a variety of

foods as possible, and not to eliminate any one food or food group. The less you eat the harder it is to get all you need from your food, and then a supplement may be needed.

I would suggest to all who are able to take a college level class on Nutrition, especially as it applies to eating well. If you are over 55, many of the college classes (at community colleges and others) are free or at reduced rates. Call around to find out. It is very helpful to know all the facts as there is much nutritional misinformation out there.

Beans are very good for you and you can even make Bean Fudge and Bean Pecan Pie!

Jann Hartman JKH <jann@home.com>  
<<http://www.geocities.com/arojann.geo>>

Jann and John are now continuing their holiday travelling through Europe. They flew from Baltimore, Maryland in the States to the UK via Iceland. They arrived at Heathrow and travelled by train to Lincoln and spent three days with us. We visited some of Lincoln's sites on the Sunday and took them to Newark Station on Monday. From Newark they travelled overnight by train to Paris and then again overnight to Rome. From there they visit their son in Sicily. John is a radio ham and has his equipment with him and will be attending a 'meet' whilst there. They then travel back through Switzerland, Germany, Scandinavia and back to Brussels and the UK for a few days and then fly home on October 24th.

Jann is travelling with a very small scooter that easily comes to pieces and can be lifted by John. Other than this Jann uses crutches but only for short distances. The scooter is a flat base with a pole up the front with handlebars and another at the back for the bucket type seat. Underneath this is a standard size car battery that John has adapted to go on and off quickly. John straps one bag to the back of the chair - the one that contains his radio ham equipment! Another small bag goes behind Jann's legs. John has a rucksack on his back and pulls a large suitcase. They have developed many ideas that others could find useful and on their return will be writing them up for us.

Jann will send us the recipes for Bean Fudge and Bean Pecan Pie (I am sure you like me have a queried expression on your face) for the next newsletter on her return. The proof will be in the eating! More from Jann next newsletter.

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### DRUGS TO WATCH OUT FOR WITH POST POLIO

1. Beta Blockers - e.g. Inderal, Propandolol, etc.
2. Benzodiazapams - e.g. Valium, Diazepam
3. Opiates (central nervous system depressants) -e.g. Darvon, Demerol, Morphine, Tylenol 3
4. Steroids - e.g., Prednisone, Cortisone, etc.
5. Muscle Relaxants - e.g., Norgesic, Norflex, (includes also Benzodiazapams – Valium)

We live in a time when most patients want an instant fix for their ailments, an antibiotic for an illness or a pill or shot for pain. Our doctors are conditioned to respond to these expectations. As we age it is not unusual for patients to go to a different doctor for each problem. This can be especially dangerous as one doctor may be unaware of what other doctors have prescribed or the interactions and contra indications for other conditions. One doctor simply can't be current on everything. Insurance companies and HMO's rely on the primary care physician to keep everything straight, but that doctor may not be as well trained as the other doctors or specialists.

This leaves us with a potentially serious problem. We, as patients, may innocently take a medication that may cause further problems or even give us a new ailment completely. As we age we can't remember everything and many doctors do not care or have the time to listen carefully to what we have to tell them.

Dr. Paul D. Stolley, M.D. (Professor of Medicine, University of Pennsylvania School of Medicine) wrote the preface for the book "Worst Pills Best Pills". In it he states, "For older Americans, nothing less than the closest attention to their health problems is adequate. Although many older adults can benefit from drugs which lower blood pressure, reduce the pain, and discomfort of angina or arthritis, or treat other common ailments, they are extraordinarily sensitive to adverse effects of medicines, such as drug induced Parkinsonism, confusion, decreased co-ordination, falls and hip

fractures, and mental deterioration. Thus the best medicine may be no medicine.

But if a drug is needed, the choice could be made by the active and informed participation with a sympathetic and unhurried physician. Furthermore, the continual monitoring of the patient is necessary after drug treatment is initiated: is the desired therapeutic effect occurring? Are there adverse effects? When should the drug be stopped? Is there the possibility of an undesirable drug interaction because of the other drugs the patient is taking?" (Ed. Note. I recommend you read this book and refer to it or one like it when new prescriptions come your way.)

Many doctors do not realize that post polio carries with it drug inter-actions and consequences that the normal population does not have to deal with and, therefore, not many doctors are familiar with them. They may linger in affect long after their stated duration.

**1. Beta Blockers -- A class of drugs** used to treat high blood pressure, angina, irregular heart rhythms, and migraine headaches. A beta blocker works by blocking the beta nerve cells. In a simplified way let's just say that beta cells make the muscles contract. It is not for use in any way where breathing is compromised by asthma, allergies, emphysema, or chronic lung problems such as post polio. Breathing problems aside. Post polios by definition have their nerve pathways damaged by the polio. Anything that interferes with the function of the remaining nerves is not a good thing. (Ed. Note – I was once given a beta blocker and luckily I was sitting up when it took affect. I was unable to move and had great breathing distress until it was out of my system. I was home alone I could not even call for help.) These include, Inderal, Corgard, Inderide, Lopressor, Tenormin, etc.

**2. Benzodiazapams -- A class of Addictive-drugs** used to treat nervousness and sleeping problems, to relax muscles and to treat seizures. Their adverse reactions include confusion, mental depression, drowsiness, hallucinations and difficulty co-ordinating muscle use resulting in increased incidence of falls, etc. Due to the problems with the reticulating activating system resulting from the polio infection this type of sedative is not a good idea even if you have sleep problems.

We have enough problems with co-ordinating the muscles that are functioning.

We should not be taking something that

interferes with what co-ordination we have left. These include, Valium and Diazepam.

**3. Opiates** -- A highly addictive central nervous system depressants and pain killer. Medical texts state that opiates such as codeine works best with a non-steroidal anti-inflammatory such as aspirin. All members of this class of drugs depress breathing, the ability to cough, and the function of the intestines and bladder. In the case of Darvon, studies have shown that it's level of effectiveness is close to that of aspirin alone. All members of this class cause ataxia or loss of the ability to coordinate muscle use. It has been found that when the drug is given locally with a pump inserted into the spine that it acts with less central side affects. These include codeine, Darvon, Demerol, Morphine, and Tylenol 3.

**4. Steroids** -- This class of drugs is used for allergic reactions and to reduce inflammation. The use of steroids has been shown to make polio symptoms worse. It also suppresses the immune functions, increases osteoporosis, and raises blood pressure. It is commonly used to treat asthma. Make sure you do not have the post polio lung changes that are often misdiagnosed as asthma and/or sleep apnea. These include – Prednisone, Cortisone, etc.

**5. Muscle Relaxants** -- This class of drugs works within the brain and nervous system to block the ability of the nerves to function therefore causing release of muscle spasm and pain. Again, our nerves are not functioning at 100% to begin with anything that works to interfere with function must be avoided if possible. These include Norgesic, Norflex, Soma and, in addition, includes the class of Benzodiazapams.

I have made this information as condensed as I can. I know you have much better things to do than read a long dry technical text. It is intended to help you and your doctor make a more informed choice of treatment. If you have any questions, please feel free to get in touch with me.

#### Bibliography

1. "The Merck Manual" 14th Edition, Merck & Co., Inc.

2. "Worst Pills Best Pills" 1988 Ed/ Author Sidney M. Wolfe, M.D., Lisa Fugate, Elizabeth P. Hulstrand, Laurie E. Kamimoto and the

Public Citizen Health Research Group

3. "Physicians Desk Reference" 1998 Ed. Medical Economics Co.

**Editor's Note:-** This article was written by J. Ann Singleton, Information Officer of the Orlando Post-Polio Group. She can be reached at 407-260-9238, FAX 407-260-6837, or at her e-mail:- <jsinglehsd2@earthlink.net>

**LincPIN Editors note** - We are all different. We have had polio, have PPS and can have any other condition as well as PPS. Drug names across countries are not the same. This article has been included as an additional article to the drugs leaflet we issue for your information. It is imperative that any health professional that prescribes you any drugs or anaesthetic is aware that you are a polio survivor and that you may tolerate what he gives you differently from what he expects. Weaker polio muscles that do not look atrophied or test as weak on single manual muscle testing have a larger uptake of drug than expected.

An example this week is a GP prescribing a member Amitryptaline at 100mg and it zonked her out. We have another member who slept all day on 2.5mg. I take 5mg and am asleep within ten minutes.

Another member had a Gynae operation eight years ago with difficulty coming round, longer time recovering in hospital, and longer recovery at home than expected. This past year the same operation and 'just enough anaesthetic to keep you under' (anaesthetists words) meant she was awake drinking tea mid afternoon.

The best advice is to work with the person prescribing the drug/anaesthetic. Discuss this with your GP/Consultant ahead of time so that this is in your records. If possible and if there is time start at a very low dose.

Please contact us if you have any queries on this.

**N.B. Some articles included in our Newsletter contain technical information that we know some members do not fully understand. However, Health Professionals treating you will more readily accept information in this format.**

- 0 -

**Polio Biology XI - The Biology of Fatigue  
Eddie Bollenbach  
A Lincolnshire Post-Polio Library Publication  
6th August 2000**

William Shakespeare, Sonnet XXVII:  
'Weary with toil, I haste me to my bed.'

Everyone has experienced fatigue, even Shakespeare. It is a reaction the body has evolved to maintain a healthy steady-state. It is a countermeasure to overuse and acts to avoid damage to muscles and nerves. If our bodies, sculpted through millions of years of evolution, had no way to tell us that it is time to shut down, we wouldn't have gotten this far. So my first point in this essay is to emphasize that fatigue is not just the province of people living with post-polio syndrome. Everyone in the human family has experienced fatigue.

One area of the biomedical literature which has examined fatigue, and its components, is the discipline of sports medicine. The 2000 Sydney Olympics is on the docket and you can be sure that trainers and sport's physicians are studying every aspect of fatigue that can affect their athletes. Why? Fatigue degrades performance. An understanding of all of its manifestations allows athletes to take steps to avoid and minimize the likelihood of a poor performance.

Of course we with post-polio syndrome live with fatigue. It is a much more common state for us and does not abate easily and normally as it does for an athlete. We have to be especially careful about it and also knowledgeable about it if we are to improve our lives.

Elite athletes know about fatigue to win medals, we must know about fatigue to improve our lives. Who knows more about the biology of fatigue, the elite athlete or the post-polio survivor? I hope this essay can help improve our general knowledge, from the biological perspective, and allow us to intelligently use this information to improve our lives.

Biology of Fatigue.

Throughout this series we have mentioned the motor unit. This is the nerve/voluntary muscle unit of contraction. The nerve depolarizes (that means the charge on the outside of the cell membrane (+) rushes

inside (-) resulting in the charge on either side cancelling). This depolarization moves along the nerve away from the Central Nervous System eventually to a voluntary muscle. When an activity requiring muscle contraction begins (running is a good example) the rate of depolarization and re-polarization (which requires energy) is rapid in the motor unit. The nerve cell depolarization triggers depolarization in the muscle cell membrane. The muscle cell depolarizes and the muscle fiber contracts (shortens) due to the activity of proteins inside the muscle fiber. The muscle and nerve quickly recover and re-polarize. This uses nutrient energy. Then they fire again. If this rapid firing is not interrupted, either by other motor units taking over (which we lack- see Polio Biology X), or because of maximum intensity exercise over a long period, the nerve, nerve/muscle junction, and/or the muscle fiber itself will fatigue.

Inside the nerve the energy used to re-polarize the membrane is derived from specialized molecules, nutrients, and enzymes. As they become depleted waste products accumulate. If the waste products interfere with normal energy production and utilization we have metabolic fatigue inside the cell. The same can happen in the muscle fiber where chemicals like lactic acid, ammonia, and creatine build up faster than they can be excreted. All of this biochemistry, which may manifest as a feeling of burning inside a muscle, cramping, weakness, pain, or creepy crawly feelings are the result of fatigue, specifically localized fatigue. Any fatigue in the nerve, muscle fiber, or entire motor unit (muscle and nerve) constitutes localized fatigue.

If fatigue occurs in any nerves above the motor unit it is called Central Fatigue. It too is a common protective mechanism for the muscles and nerves below it and athletes experience it mostly as a consequence of over training. I get the sense that many polio survivors think that Central Fatigue is reserved for them and is a unique and disturbing symptom not known to others. This is not so.

There is a way to measure the magnitude of subtypes of Central fatigue. If you use a small electric shock to stimulate a muscle and measure the maximum force of contraction you can use this as a baseline of strength of contraction. If you then prompt a person to contract the same muscle as vigorously as possible you can measure the difference between tetanic contraction (of the unit with the electric pulse) and the maximum voluntary force possible. This is one measure of one subtype of Central Fatigue. We don't know a lot about Central Fatigue at the molecular level but it manifests itself, often, as a loss of drive or motivation to perform. Again, one can appreciate the role of Central Fatigue in protecting the nerves and muscles by inhibiting their over work at the level of the Central Nervous System.



There is a part of the human brain you may have heard about: The Reticular Formation. Nerve cell firing there keeps us awake. Some say, or have said, that polio damage has affected the reticular formation and that this is why some of us sleep so much and cannot easily rouse. I think this would be a very difficult idea to prove because of the complexity of the arousal system and the role of Central Fatigue in overwork, blood gases, and other factors. If you experience a blow to the head the neurons of the Reticular Formation can all depolarize and you will be rendered unconscious. If re-polarization occurs (hopefully in a short while) you will awaken. Anyway, this depolarization and re-polarization is how all neurons work.

Let's get back to Central Fatigue. Any negative effect on muscular performance, which is generated above the motor unit, is Central Fatigue. This includes inhibitory processes arising in the brain. We know less about this but we do know that it occurs in athletes as well as in polio survivors. The Central Nervous System is involved to a large extent in the regulation of muscular activity. (Bompa 1990)[1]. Elements within the Central Nervous System result in a number of psychological factors, and emotions, which can degrade muscle performance and result in a loss of drive due to Central Fatigue. (McComas 1996)[3].

During prolonged exercise in an athlete, or during any activity which exceeds the fatigue point for a polio survivor, the blood chemistry changes. Amino acids, which make up proteins, change with respect to their relative abundances. Those amino acids with branched chains decrease and fatty acids increase. Examples of branched chain amino acids are leucine, isoleucine, and valine. Tryptophan is an amino acid but is not a branched chain amino acid. The ratio of Tryptophan/BCAA rises during fatigue, which results in a biochemical alteration of tryptophan to 5-hydroxytryptamine (5-HT) in the brain. You may know (5-HT) by its more commonly used name of serotonin.

To make a very complicated story short serotonin can act on serotonin receptors in the brain to cause sleep and also increase the mental effort (motivation) needed to maintain muscular activity. It's all rather complicated chemically, and this is but one theoretical biochemical pathway of many that helps explain Central Fatigue.

We've also heard of dysfunction of the hypothalamus and pituitary to explain Central Fatigue in post-polio syndrome. As is to be expected, these areas are implicated in Central Fatigue for elite athletes too. Possible indicators of Central Fatigue, cited by Lehman et.al. (1993)[2] include an impaired

neurotransmitter metabolism, with increased cerebral 5-hydroxytryptamine (5-HT) concentration, partial hypothalamic and pituitary dysfunction, with resultant dysfunction of the neuro-endocrine axes.

It has been observed that over-training in athletes (which happens often for our normal activities) results in faulty prolactin metabolism as well as adrenocortical insufficiency. Well, enough of the biochemistry.

Suffice it to say that fatigue is a complicated phenomenon which involves motor units and the CNS and regulates the body by preventing overuse on many levels. There is not much difference in the CNS aspects of fatigue comparing elite athletes and polio survivors in my opinion. We just must do more with less and get to fatigue sooner.

I've never heard of anyone trying Branched Chain Amino Acids to help with Central Fatigue but I believe they are available at health food stores. To do any good (and they may not) you probably need 10 to 20 grams. Ask a physician before you try this. The fatigue is there for a purpose. If you reduce it without addressing the root of it you could hurt yourself.

#### References.

1. Bompa TO (1990): Theory and methodology of training: The key to athletic performance. (2nd ed.) Dubuque: Kendall/Hunt Publishing Company.
2. Lehmann, M., C. Foster, and J. Keul. Overtraining in Endurance Athletes: A Brief Review. *Medicine and Science in Sports and Exercise*. 25 (7):854-862, 1993.
3. McComas AJ, Stuart DG, Thomas CK and Pierce PA (Eds) (1996): *Fatigue: Neural and muscular mechanisms*. New York: Plenum Press, pp. 457-469.

#### **Linda Wheeler Donahue Polio Survivor and Professor Emeritus of Humanities writes Don't overdo Physical Activity.**

For those who have had polio, the mantra is: "Conserve to Preserve." The more motor neurons you preserve, the more capacity you will have in the future. Each day, focus on pacing activity with rest breaks, recline and restore. Take frequent rest periods during the day with your feet elevated as high as possible. Don't overdo physical activity.

There is no cure for Post-Polio Syndrome. . . no magic bullet to restore our vitality. The only measure available to slow down the progress of PPS, albeit undramatic, drudging, and boring, is 'conserve to preserve.'

**More from Linda Donahue next newsletter.**

## Illusions by Judy Sander

How many of you ignore that you have a disability? Be honest. We ignore our disabilities because the word "disabled" was and is a stigma to be avoided at all cost. It was especially a stigma when we were recovering from polio. We were taught during and after polio that the only reason we might not conquer the aftermath of this horrid disease would be that we were weak, lazy, and did not try hard enough. So, many of us have created illusions that we are not disabled or we may accept only a portion of our disabilities within our illusion. We pretend that if we wear certain clothing, stay home, smile in spite of our pain or lack of breath, no one will notice. By doing this, we are not only hurting ourselves but also those who care for us.

Of course, there are different degrees of disabilities but alas, many of us try to ignore those that we should not. Have you created an illusion concerning your disability? This may be the time in your life to face reality, the complete reality of your abilities and disabilities.

I had polio when I was six. I was paralyzed and very ill for eighteen months and at the age of seven, I weighed a mere twenty-seven pounds. After six surgeries, years of therapy and more, I had conquered polio. At least the illusion was that I had conquered polio.

I am not sure when the illusion, that I was not disabled began. Possibly, it began during the illness itself. Or during therapy? Could it possibly have been that my family considered it an illusion and the thought penetrated my very being. Or is it because I was taught by therapists, doctors, nurses, Mom, Dad, and other relatives, through out my illness and recovery, that I could not show weakness, refuse a task, and to never ever give up? If I did, it would prove that I lacked initiative. However, if I tried my very best, never complained, believed I could do anything, everyone would love me and accept me.

After the age of 13, I pushed into things I never had done before. I played softball. I ran. (Well, I thought it was running.) I even became a band majorette, limping as I marched and dropping the baton every so often. I somehow had convinced the band director that I could twirl the baton and march.

At the Cheyenne Frontier Days parade, my illusion was broken when a large bone dropped through the muscles in my right foot. A cast for six weeks seemed to correct this problem but my

majorette dream, became a bad memory.

In my late teens and early twenties, it was wonderful to wear high heels. No more brown built up shoes for me. In fact, **never** would I wear a brown shoe again. Short skirts with shaded hose, added to my wonderful illusion of perfect legs and a perfect gait plus no one would see the scars.

Three pregnancies with four children certainly underlined my illusion of not being disabled. Or did it? Home movies show me limping. Home movies of my children's birthday parties show that although I am smiling, I recall the pain and fatigue. A movie of mountain camping with four children only brings memories of the pain. The pain of carrying twin babies while pulling a six-year-old away from a riverbank is unforgettable. Pain pills were a main stay. Falls were a common occurrence. Even my children, limped when they walked besides me, bobbing together. Cortisone shots to the hip joint were a monthly event. Almost all of my memories of these good old days include the pain of overused, weak limbs.

In my 40's, my illusion began to fade. A cane became necessary for walking any distance. Then a fall at a sports event fractured several vertebrae because I wanted to look stylish, impress my husband with high-heeled boots and of course, the cane was in the car. No one would ever think that I had a problem, that I was disabled. Of course, they saw me limp and they saw me fall. They knew. I had the blinders on.

Still in my 40's, it was common that when my mother visited and we went shopping, she found me a place to sit down and rest at each store. Fairs, antique shows, walks on the beach, sport events and more, became impossible. My husband and my family did less together as time went by.

When I travelled to Europe in 1989, the 70 and 80-year-old fellow travellers went where I could not. They climbed the steps at St. Michael's in France; they walked the length of every cathedral. I stayed behind. Sometimes with a man in a wheelchair, but often he could go where I could not.

Two years ago I helped start our local Post Polio Support group. This was a big step in accepting my limitations. After watching, listening, and talking with many of our group members I slowly began to let go of my elusive illusion.

I watched how many walked with more grace and smoothness than I did, yet they were

wearing braces on both legs. Even those with crutches and braces moved quicker and were more stable than I. I noticed that those in scooters and wheelchairs were not limping, grasping for falling canes, or grimacing from pain. A light bulb began to glow in my mind. Perhaps, just maybe, I am disabled. Perhaps my doctors are correct, maybe I do need a brace and just maybe, a portable wheelchair in the trunk of my car.

Right before Thanksgiving in 1999, I was fitted for an AFO for my right leg. Of course, the prescription said to go for a full leg brace, but the illusion, although becoming dim, is still there. "No, I will get by with the AFO", I told my Orthotist.

What a wonderful Thanksgiving and Christmas holiday. What wonder to have one leg stable. The fatigue was less at the end of the day. The pain in that leg was less. I was even able to process down the church aisle for the choir concert in December, the first time in years. My husband, who was in the audience, could not find me as we processed. Why? He was looking for the blonde-haired woman that limped.

Why did I not get a brace when a concerned Doctor recommended it, in my 40's? If I had needed glasses, I would have not hesitated. Of course we know the answer; the illusion was stronger than the reality.

I am still working to face the complete reality of my disability. No, not to make it more or less, just to accept it for what it is. We must face the reality that we are only fooling ourselves with our illusions. By obtaining proper bracing, a scooter or whatever it takes, will not only improve our lives but will lessen our chances of creating even a worse disability. Consider a fractured hip, arm, or pelvic. We must have the courage to accept reality and to ignore the illusions we have created about our disabilities.

I hope that as you read this you will stop, look, and examine your abilities and your disabilities. Look at yourself objectively. You very well could walk straighter, limp less, have less fatigue and pain, by stepping forward in obtaining braces or (horrors) by using a wheelchair or scooter. You could possibly do more things and embrace life with increased vigour. Your family and friends will enjoy you more. You will enjoy them more. Relax, smile, face reality and throw your particular illusion out the door. Life is waiting for you.

**Judy Sander, 3/2000**

## **Network Spinal Analysis**

Hilary and I were asked by Vic and Joan to visit with them and experience some treatment that they had been having in Australia and were now having here in the UK. Hilary had not seen Vic for nearly a year and could see a definite improvement in his walking. We enjoyed the treatment. It was relaxing, soothing, gave you a sense of wellbeing and following the first two treatments the pain left my shoulders and arms. Unfortunately for the third treatment and to use the toilet I had to negotiate three flights of stairs where I had to pull myself up with my right arm and some pain returned. The pain is now bad in my shoulders and arms but I think that is because I am now having problems steering my scooter. Hilary said she felt 'taller' her spine straighter and generally her joints less stiff. This was only a short session but if a therapist was nearby and money available then we both felt that we would try a longer series of treatments. As with many alternative therapies, the time being spent on you personally really can make a difference.

**Richard L Boone. <l2smith@aol.com>**

## **Raffaello Sciffo, D.C. explains NSA.**

Several months ago I was approached by Mr Victor Oliver, who mentioned that he had had Network Spinal Analysis (NSA) care in Australia, with relatively good results. We decided to embark on an intensive course of visits and achieved once again, good changes in his health and overall wellbeing.

Most significant of these were that he no longer needed to use a cane, he could walk longer distance without tiring and muscle mass from his thigh and buttock area that had atrophied, had come back considerably.

Due to these great results and Mr Oliver and his partners enthusiasm, we decided to try a short experiment with two other Polio people. You notice I use the word 'People' not victims, patients or sufferers. The reason for this is that the terms all signify a *separation*. A victim and a patient are all acted on by an outside (or internal) force, which is *separate* from your Self. This is an important concept to keep in mind.

Due to the positive results those two people experienced I was asked to write a brief

explanation of what it is that I do. Normally what NSA tries to do is make your body more *consciously aware* of the tensions it is holding. Once these tensions are let go of, the nervous system is freed up to work on other tasks. The freer the nervous system is to focus on other tasks, the more efficient it is, and the less intense are the symptoms it is manifesting due to 'exhaustion'.

**What is Network Spinal Analysis?:**

Network Spinal Analysis (NSA) is a Chiropractic method that was developed by a Chiropractor Dr. Donald Epstein in America, initially in the early eighties.

It is so different from traditional Chiropractic that it has recently been officially separated from it, although only Chiropractors so far, are able to achieve training and certification in it.

**What does NSA actually do?**

It focuses on making your nervous system work more efficiently. What people find most amazing is that the largest ever study of NSA with over 3,800 people over 3 years, showed that there was no plateau in their improvement!

This shows the body seems to have no limit in optimising its healing potential.

The study was not limited to physical symptoms. The six areas monitored in the study done by Sociologists at the University of California, Irvine were:

- 1) Physical Improvement (symptoms) 64% Improved
- 2) Less Stress 66% Improved
- 3) Emotional and Psychological Well Being 64% Improved
- 4) Life Enjoyment 69% Improved
- 5) Positive Lifestyle Changes 76% Improved
- 6) Overall Quality of life improvement 59% Improved

**How, technically speaking, does NSA work**

NSA is a gentle technique that involves, unlike most other health care methods, *training* the nervous system to function more effectively. It is based on the four tenets of Chiropractic that are:

- a) That the nervous system is the master

controller and co-ordinates all the actions of the body from making new blood cells to producing insulin.

- b) That the housing of this system (spine and skull) is capable of being distorted which can affect the nerve systems functioning.
- c) That these distortions causing nerve message irritation lead to inappropriate messages being transmitted, and thus wrong actions taken by the body.
- d) Those consistent inappropriate body responses can lead to ill health,

How NSA is so different from most other types of care, including even to some extent Chiropractic, are its concepts of healing.

**Concept 1 *Healing versus Curing:***

In *Curing* you are concerned with the symptoms and getting them under control. The goal is to get you back to where you were before you developed those symptoms, or what is considered normal or average for the population.

*Healing* on the other hand sees symptoms as a way the body is trying to communicate to you and let you know what it needs, or what you are not doing optimally e.g. the feeling you get after one too many drinks. Its goal is to *teach* you about yourself so that after the 'crisis' you function at a higher level, you become greater than what you were.

It must be noted that curing may be an essential part of the healing process.

**Concept 2 *Myths and misconceptions about Healing:***

Many misconceptions are held by western society in regards to healing science that are 'too advanced for the lay person to understand,'

Two examples include;

1) *The more serious your illness, the longer the recovery will take. Also, if the conditions is more serious, the treatment needs to be more expensive, more dangerous and more invasive. E.g. Cancer versus the common cold.*

The body does not work in a linear fashion, invasive methods may have little effect and a brief comment by someone may change your life (and thus health) forever.

2) *The body works like a machine, with different bits having different life spans, so at a certain age, it is expected that a certain body part 'wears out'.*

**The body works more along the principles of quantum physics than mechanics. It is constantly repairing itself.**

**Your body replaces  
your stomach lining every 5 days  
and your skin every 4 weeks.**

**Your body makes  
a new liver every 6 weeks  
and a new skeleton every 12 weeks.**

If this is the case, why is an injury from 10 years ago, still bothering you?

The basis of all the concepts of NSA is *SEPARATION*.

As you are part of the population of a city or country, or perhaps a team or an assembly line, so are your cells part of you. A community of 75 trillion individuals working together, with a personality of its own.

If all members of a team are communicating well, not only do they work well, but (a) they will constantly improve on their efficiency; and (b) they will have FUN.

The moment communication starts to break down, small groups form and they take on their own identity. If you focus on them as the problem, persecute them, attack them, ignore them or otherwise focus on your differences and *separation*, you give them power and autonomy. This is the whole principle of medicine and in fact of much of our society, as we know it.

The other option is to focus on the similarities, and try to tighten up the bonds between the parties. To create more unity and wholeness.

Symptoms are the bodies way of letting us know all is not well, that communications have broken down and that attention to our lives is now more vital than ever.

Too many of us want to quieten the messenger that brings us this information, with painkillers, anti-histamines, anti-depressants, anti-inflammatories, and anti anything else we can come up with that we do not want to *feel*.

Others take to *learning from the experience* and listening to what it has to teach us regarding ourselves. They turn to yoga, meditation, Tai Chi and other more internally guided types of healing.

Neither is better or worse, only appropriate for

the individual. With NSA we do however focus on the latter. We want to get people more in touch with their essence, their true selves, and to maximise their experience of life.

The study shows just how effective we are in these areas with people spontaneously changing habits and lifestyles. Sixty nine percent had a greater life enjoyment. and a full seventy six percent did undertake some positive lifestyle changes.

**But what are the real nuts and bolts of how it works?**

The Chiropractor lightly touches the spine with a pressure ranging from that of a feather, to a decent prod, placing the brains awareness on that area. The brain then processes the information and if it finds the tension located there to be no longer vital to the body, it just lets it go.

Due to the nature of the work, in changing a bodies habit, the visits are frequent and short. Usually the Chiropractor will see the person three times a week for several weeks before cutting down to a less frequent schedule,

**Why Group Adjusting?**

We adjust people in a group room because it has been shown to reduce tension and enhance a family atmosphere in the practice. In NSA it has been shown to significantly enhance the healing process.

**How much time does it take?:**

Initial consultation takes 1 hour. Follow-up visit., generally take about 15 minutes, unless you are acute in an emergency situation.

So, that's NSA in a nutshell. For further information or to look for a Chiropractor near you, go to the website [www.networkchiropractic.co.uk](http://www.networkchiropractic.co.uk) or call 01865 377877.

## **Helpers Simply Helping Simply**

by Art Coburn

My Nancy is *vertically challenged*, in today's newsspeak, and today, as happens nearly every time she goes shopping, she had to ask another customer to please get her something that was on a shelf way too high for her to reach. This happens quite often but she's ***had the problem all her life***. Sound familiar?

What I'm getting at is simply this: At various

times in the lives of most people, disabled or no, we simply have to ask for help. And you can't ask for much simpler help than, "Please, sir, would you get that can of beans for me? I can't reach it. Thank you."

Where do you and I, PPS-ers all, find this simple help?

May I be so bold as to suggest the local church? In the Christian New Testament, James wrote this in the 27th verse of the first chapter:

"Religion that God our Father accepts as pure and faultless is this: to look after orphans and widows in their distress and to keep oneself from being polluted by the world." (James 1:27NIV)

The rational and logical understanding of this verse includes all who need help, not just the orphans and widows. Period. Does that include you and me? Definitely, my polio friend, definitely. Actually, the man who helped Nancy get the can of beans was simply putting this instruction into action, whether or no he was in the Church.

Many of us belong to a PPS Support Group, but there we find that most of our friends are in the same shape we are or they may be even worse off, so when we need a bit of physical help with some household chore that we simply cannot accomplish, our Support Group cannot provide much support, can it? But if your church around the corner is also a support group for you, then you will have another means to defeat that old polio dragon, won't you?

So if we say that the local church is a support group to help us in our daily lives, then let's define a Support Group as a **tool**, defining a **tool** as some **thing** we use to help us get along in life. Just as a carpenter cannot drive a nail without a hammer or cut a board without a saw, we cannot go to the mailbox without a wheelchair, callipers/braces, a cane or crutches, or an electric scooter. **A tool is a tool is a tool**, whether it is inanimate or animate. Now let's use a syllogism to illustrate what I mean about using the **Church as a tool**:

- A. A Support Group is a **tool** for you and me to use.
- B. A Church is a Support Group (at least for its members).
- C. Therefore, a Church should be a **tool** for you and me to use.

We had a very large branch fall into our yard the

other day, but it didn't do much damage. The branch was about 22 meters (75 feet) long and about 3/4 of a meter (about 30 inches) through at the end where it broke from the pecan tree. Obviously much too big a job for Nancy and me to take care of, so I called my friend and neighbor who lives about a mile away to come look it over. He's also a deacon in our church who really lives up to his office. When he came over he said he'd show up the next morning and I figured I could help him then (mornings are best for me), but he and his grandson came after supper, so my granddaughter and I went out to help with the clean up, and a good time was had by all, really. It didn't hurt that the grandson and the granddaughter were near the same age, either.

If my friend and neighbor had been unavailable - it is haying season for him, there are other men in the church I know that I could call. But on occasion I have called the church office and simply said, "I need a bit of help," and got it.

The problem is, **We Simply Hate To Call For Help!** I know I do. If there is some possible way that I can get something done, then I'm just stubborn enough, *and stupid enough*, to go ahead and do it. Then, like you, I pay for it later. Dumb. Dumb. Dumb.

**"When push comes to shove, your POV will change."** In the last few years, push has come to shove, and my *point-of-view* has changed markedly. The unfortunate thing is that my friends that I call for help are all getting older. My friend and neighbor who cleaned up the tree branch for me is 73, but can easily work me under the table anytime. So when I need younger help, I may simply have to call the church office and say to the secretary, "I need some help, please." The help may not be instantaneous, but what help is in this life? Even when you pay for it!

Do we have a misplaced sense of loyalty? Or perhaps a sense of confusion as to what the mission of the church around the corner really is? Perhaps you are afraid that they will want you to "tithe," or pray, or some other ritual that you may not be familiar with. So what? Be honest with them and explore your doubts that they can really help you. Or even that they really will help you. For free, too.

Obviously I am writing this from a Christian perspective, but to the best of my knowledge all religions usually have some sort of service policy for the poor at least. Our church has a walk-in closet full of canned and dry foods to give to those unfortunates who come to the church door

saying they have no food in the house, and it happens more often than we, the laity, know. By extension, as I said above, the local church's consciousness regarding those who need a bit of physical help now and then, can be and should be raised, whatever the religion or denomination of the particular church, assembly, synod, synagogue or temple.

It isn't just us PPS-ers, you know. Nancy and I live in Florida, USA, and this is a "retirement" state. Our church membership is heavy with those over 60, so our pastor and some of the deacons spend a lot of time in the city at each of the hospitals with the folks getting kidney transplants, heart transplants, x-rays, MRI's, and on and on. A religious fellowship of whatever kind, to be worth its salt, must support its members whether in the birthing room, the funeral parlour or the ICU. It is a **tool** to be used by its fellowship. You and I, my polio friend, are under that same umbrella, and when you get there, under that umbrella that fits you, then you will find life to be just a bit less stressful, knowing and being comforted by the simple promise of help when you call. Do try and develop your friendship with your local church. I think you will be surprised and pleased, and I also believe that you may find a new usefulness in yourself within that fellowship.

You may email Art Coburn at: [artinfla@afgn.org](mailto:artinfla@afgn.org)  
To view pictures of the Coburns go to  
<http://www.photopoint.com>  
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### Articles added to the Lincolnshire Post-Polio Library

sourced on our WebSite  
since last newsletter

**Reminder** - All the medical articles printed or referenced in this section of the LincPIN's are sourced in full in the Lincolnshire Post-Polio Library on our WebSite. For those of you without access to the Internet who would like copies of any article they are available from us for the price of photocopying. Members post free.

#### **Title: Dr. Henry writes about the Virginia Polio Epidemic of 1950**

Author(s): Henry Holland MD

Original Publication: Central VA PPS Support Group (PPSG)'s newsletter, The Deja View, in August/September 2000.

**Abstract/Extract:** I contracted polio on Sunday, September 17, 1950, entered the polio isolation ward on the ninth floor, south wing of the Medical College of Virginia Hospital on Saturday, September 23 and was discharged almost three months later on Monday, December 18. In addition to the isolation ward, I spent time on nine west during post isolation, and the majority of my hospitalization on five south and five west in convalescence and rehabilitation. The event of polio changed my life thereafter. Until recently, I had little interest in the polio events of that year. With help from the Virginia Health Department, Division of Immunization, and newspaper records from Richmond Newspapers, I have learned that 1950 was a record year for polio in Virginia and that Virginia ranked second in the nation in the incidence of polio per capita in 1950.

#### **Title: Polio Biology XI - The Biology of Fatigue**

**Author:** Eddie Bollenbach B.A., M.A.

**Abstract:** Elite athletes know about fatigue to win medals, we must know about fatigue to improve our lives. Who knows more about the biology of fatigue, the elite athlete or the post-polio survivor? I hope this essay can help improve our general knowledge, from the biological perspective, and allow us to intelligently use this information to improve our lives. (Included in this newsletter - page 16)

### Medical Articles continued from previous page

#### **Title: Poliomyelitis and the Post-Polio Syndrome**

**Author(s):** Burk Jubelt and Judy Drucker.

**Original Publication:** Chapter 34. Reprinted from Motor Disorders edited by David S. Younger. Lippincott Williams & Wilkins, Philadelphia © 1999

**Abstract/Extract:** In the first half of the this century, epidemics of poliomyelitis (polio) ravaged the world. In the epidemic of 1952, over 20,000 Americans developed paralytic polio. With the introduction of the Salk inactivated polio vaccine (IPV) in 1954 and the Sabin oral polio vaccine (OPV) in 1961, the number of paralytic cases decreased to a handful per year. Polio had vanished and no longer was on the

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consciousness of Americans. The elimination of polio was a tremendous achievement for science and American medicine. However, in the late 1970s, survivors of paralytic polio began to notice new health problems that included fatigue, pain, and new weakness, thought not to be "real" by the medical establishment. The term "post-polio syndrome" (PPS) was coined by these patients to emphasize their new health problems. This chapter reviews acute poliomyelitis and the related PPS.

manifestations of PPS. Subsequent studies in the 1990s have found the occurrence of PPS among patients with previous poliomyelitis to range from 28.5% to 64%. The average time in various reports from the acute poliomyelitis until the onset of PPS is about 35 years, with a range from 8 to 71 years. However, it is unclear if the occurrence of PPS increases with aging, which may be the case based on the most accepted etiologic hypothesis. The large number of PPS cases presently being seen is probably due to the poliomyelitis epidemics of the 1940s and 1950s.

**Offsite Article by  
Burk Jubelt & James Agre**

**Linking Evidence and Experience:  
Characteristics and Management of  
Postpolio Syndrome**

<http://jama.ama-assn.org/issues/v284n4/full/jct00011.html>

**Author(s):** Burk Jubelt, MD; James C. Agre, MD.  
**Published:** JAMA Vol. 284 No. 4, July 26, 2000.

Introduction: Postpolio syndrome (PPS) refers to new, late manifestations occurring many years after acute poliomyelitis infection. Over the last 25 years, PPS has become a relatively common problem encountered by primary care physicians. A 1987 National Health Interview Survey estimated that about half of the 640,000 survivors of paralytic poliomyelitis in the United States had new late

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**Founder & Chairperson** - Hilary Hallam <linpolio@legend.co.uk>

**Honorary Secretary** - Wendy Grimmitt - <CWGrimmitt@aol.com>

**Vice Chairman/WebSite Administration**, Chris Salter - <linpolioweb@loncps.demon.co.uk>

**UK Treasurer**, Frank Grimmitt - <CWGrimmitt@aol.com>

**Committee Members** - Phil Bilton, Janice Eary, Ted Hutchinson, Jennifer McGowan.