

**AUGUST  
2016**

**Vol 8, Issue 12/12**

**I HAD POLIO  
I RECOVERED  
I ACHIEVED**

If anyone said  
I could not do  
something  
I did my best to  
prove them wrong

**NOW** when I try  
I am in pain, I am  
exhausted some-  
thing is wrong

**Asking is  
not easy but  
I need help**

**Some Comments  
made to members**

Do more exercise  
No you cant have  
wheels you need  
to walk more

Post-Polio never  
heard of it, does  
not exist

**First Medically  
Recorded in  
1875**

See page 17

Home of the  
Lincolnshire  
Post Polio  
Library



Enter 100+ articles

# POST POLIO MATTERS

Polio Survivors Network Newsletter - Volume 8, Issue 12/12  
n.b. Volumes 1 to 6 published under the name LincPIN.

[www.poliosurvivorsnetwork.org.uk](http://www.poliosurvivorsnetwork.org.uk)

**Richard  
1956**



## MEMBERS

Richard Boone Polio 1951  
Jann Hartman Polio 1953

**Recovering from  
Paralytic Polio.**

**ADVISED "USE IT  
OR LOSE IT"** ✓

**Jann  
1955**



## POST-POLIO SYNDROME - Advice changes from



**"CONSERVE TO  
PRESERVE"**

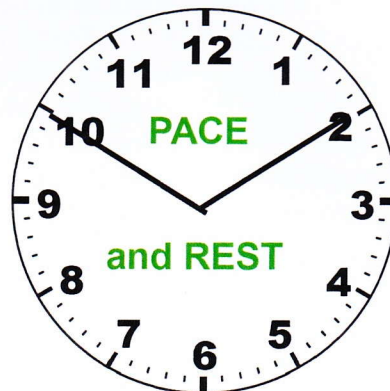
**"USE IT OR  
LOSE IT"** ✗

Which does not mean  
**DO NOT USE IT**  
but stop over-doing and  
fatiguing your muscles

**Pacing and Resting Activities.**

Using any aid that saves energy  
Asking for help with the hard tasks

**Achieving MORE  
with less Pain and Fatigue.**



Polio Survivors Network Newsletter - Volume 8, Issue 12/12  
n.b. Volumes 1 to 6 published under the name LincPIN.

[www.poliosurvivorsnetwork.org.uk](http://www.poliosurvivorsnetwork.org.uk)



## REMEMBER

If you **DO NOT** have access to the Internet and could like a printed copy of anything we refer to then please get in touch.

If you move, change your phone number or email address then please let us know for our records.

We suggest that you let Family and Friends know you are a member of PSN in the event you become ill or go into hospital and might need some Post Polio Information

**Thank you** so much for the donations Without your generosity we could not do the work we do.

## Contents

Page 2	You are reading it ☺
Page 3	Editorial by Hilary Boone.
Page 4	Message from our Chair, Simon Parritt
Page 5	My Polio and Treloar Hospital, Alton by Janet Whitworth.
Page 6	The Continuing Sagas of Dot. By Dot Ives.
Page 7	To supplement or not to supplement.. That is the question. Dot Ives
Page 8	A letter to Medical Colleges and Associations asking for basic polio and post polio information to be disseminated to all members with links to more information if needed.
Page 9	Polio Returns to Haunt GP's <b>1992.</b>
Page 10	Fighting and surviving all over again. Patricia Rock's childhood polio returns in an unexpected way. <b>1993</b>
Page 12	Disability Living Allowance for those born after 9th April 1948. Despite your award being 'indefinite or lifetime' the Government are now inviting you to apply for Personal Independence Payment [PIP] and if you don't your DLA will end.
Page 14	Northern Echo article. Chronically sick and disabled are "collateral damage" to this Government by Julia Breen.
Page 15	Neurological Alliance Latest News and Patient Survey.
Page 16	Aids & Equipment help save energy so you can do more, n.b. More.
Page 17	Two slides from Presentations at PPS Conferences and Meetings.
Page 18	Hints, Tips and Bits is Back.
Page 20	Post-Polio Health International Photo competition Family Life.
Page 21	Post Polio News ppn by Chris Salter. Excerpted items.
Page 22	Important PPS Information.
Page 23	Contact details.
Back Page	Phillip Taylor, The Cordwainer, and Val Scriveners Cards.

## New Members and Donations received.

Polio Survivors Network welcomes New Members

Jenny Woods, Robert Winn, Maureen Chapman, Toni Putnam

### Donations

Donations from Family and Friends of Bridget Langdon £ 456.50  
from the Family and Friends of Leonard Chapman £ 125.00

### Totals for 2016

Donations as above	£ 581.50
Val Scriveners Photo Cards	£ 80.00
Gift Aid paid to us this year	£ 479.50
Donations from members with Subs	£ 877.00
Donations to the Conference & Meeting Fund	£ 995.00
	<b>£ 3,013.00</b>

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

Articles in this publication may be reprinted in full with acknowledgement of this Newsletter name, volume, issue and date. Exceptions are where written by an external author/newsletter when permission must be gained from the original author/s.



## Editorial by Hilary Boone

**August**, already and nearly half way through. This year has already gone so fast... School Uniforms in the shops now and how long before Halloween and then Xmas items?

**Gillian Bryan.** I would like to thank Gill for the years she gave to PSN as Treasurer and Membership Secretary. See Page 23 for update on who is doing what.

**Front page.** I am stunned, and sad, that more than 20 years after I found Post-Polio Syndrome existed that there are still health professionals around the world who have not been taught enough about polio and how it affected us. I spent seven years being told 'Use it or lose it', 'you are not trying' and as a typical polio survivor not to be beaten by anything you can be sure I was doing all asked of me. I just continued to deteriorate. Then I mentioned my prior polio and at last it was in the equation and I went to the Hospital Library and was redirected to Lincoln's Health Information Service and I was given the article in the INDEPENDENT reprinted on the middle pages and Polio Returns to Haunt GP's in the Lincolnshire Post-Polio Library. Time to write another letter to some of the Colleges of Medicine. Page 8 to 11.

**Page 20.** Post-Polio Health International announce their WE'RE STILL HERE photo competition for this year. It would be great to see PSN members submitting photos. We are always pleased to hear from members with articles and photos from their past. See page 5 from Jann in Washington.

**POLIO NOW.** This month we hear, sadly, that polio is not just seen Pakistan and Afghanistan but back in Nigeria with two cases. See Post Polio News page 21

**DLA to PIP!** We have members who were under 65 on 8th April 2013 and expected their 'indefinite or lifetime' award of DLA to mean that. However, the Government decided to change the name of the Benefit to Personal Independence Payment [PIP]. Also considerably reducing the walking distance from 50 metres to 20 metres. Added to that the use of American companies to do the reassessments. This awful procedure with thousands of stories of inaccurate assessments, untrue statements written on the reports, total lack of knowledge and understanding of some of the diseases people are coping with. On top of that some of the centres [A woman arrives in her wheelchair being pushed by her husband who has taken the day off work at the only centre in Croydon. To be told that if you cannot use the stairs to the first floor then you are banned from using the lift under health and safety rules. A new appointment and yet another day off work for her husband to travel a further 14 miles.] Some centres have no parking at all, others no disabled parking spaces, one is even on the sixth floor, buzzers reported hard to reach and traffic too noisy to hear anyone responding. I dread the day Richards letter arrives as I hate this constant completion of forms and seeing again and again how much we CANT do now. See pages 12 to 14 for more information.

**What do you remember about your time in hospital with POLIO.** I was five and remember almost nothing. I have just one picture in my mind from my mother telling me that after a couple of weeks she was allowed to stand at the open door to the ward and asked me 'What do you do if you need the toilet?' and I replied 'I just call out xxxx [the name of the Army orderly, Benghazi] and he brings me a bedpan.' Then we move to when I was 12/13 and had operations on both dropped feet at Heatherwood Hospital in Ascot with surgeon Dr. Macfarlane [Mac the Knife] and I remember being pushed in my bed to 'school' and pushed outside onto the patio to get some sun [Easter both years!] See page 5 for Janet Whitworth story of her time at Treloar.

**IMPORTANCE OF TAKING NOTES** when you attend medical appointments and especially when you are an In-patient. I have just received the first pieces of information from the hospital regarding the complaint I made in March. Way too long a wait and we still have to wait for more information. It will be interesting to see the actual medical file and ask more questions on some of the statements made especially one in this first set that had they looked at more of his notes would have realised is incorrect. We needed the medication information to work out where things went wrong months ago to help us sort out his side effects. It took months longer than needed so we will not let this drop because we have had enough issues over the years and it is time to see changes made so that we and others do not go through what we have been through.



## **MESSAGE FROM OUR CHAIR**

### **Is it all about learning to pace ourselves?**

As yet again this month we see that knowledge and good assessment for PPS, not to mention getting good treatment and support, seems to be such a struggle. I also don't enjoy being told its ALL about learning to accept that nothing can be done, you have to adapt and learn to cope with doing less. Whilst true, this should not be an excuse for health professionals to side line us, or remain ignorant of what they could and can do to keep us well and make it easier for us to live our lives to the full.

Fortunately for us, the Internet now makes medical and therapeutic information from across the world more accessible and no longer the secret domain of those on the inside. Whilst 'google' is often a nightmare journey, and much of it is just wrong or the mad outpourings of the disturbed, angry or just plain quirky, some good and useful information does exist, so long as you adopt a critical and scientific approach. I mention this as we are living in difficult times as the pressures on the NHS, doctors and health professionals are now immense, if not terminal, and so we need to do what we can to maximise our own knowledge and care and fight our corner.

### **Where do polio survivors fit in?**

As polio survivors in the developed world get older we are increasingly seen as just old, we are at increasing risk of lower funding, resources, research and expertise. We find ourselves having to fit into services that 'more or less' include some of our symptoms. We are seen within generic services such as pain or respiratory clinics where we are a tiny percentage of patients. This means we are not given optimum treatment or accurate advice. The alternative of a rehabilitation service where the actual condition is not the focus and so, as polio knowledge is very low or non-existent, key elements are ignored or passed over whilst paying lip service to holistic and multidisciplinary mantras. Being told we need to learn coping mechanisms around pacing and adaption is a bit rich in these cases, as many of us have been doing this all our lives! The truth is that whilst this obviously has a part to play, it is only a part and rarely the most important part of what we need, which is good sound expert assessment and information on which we can judge how to make the best of what we have.

### **The problem is not all within the individual**

My anger is that just like many issues around disability, society likes to see the problem as having both its cause and solution within us as individuals, and so this conveniently absolves the medical and social services from playing their full part. The truth is that whilst we all decline and eventually die, after all NO ONE GETS OUT ALIVE! it is really about how we arrive there. Hence preventative care and intervention needs to be at all levels optimum and not just adequate. The difference is between passing and excelling, I expect like many polio people we like to have access to the best in order that we can excel. Cost, expertise, knowledge, training and skills may not be up to the mark but, don't pretend it is, and if it were available it would make our quality of life and health hugely better in ways that pacing and 'accepting reduced ability' cannot do alone.

### **Variability and lack of expertise**

For example, respiratory clinics for polio survivors employ a vast variety of protocols and diverse measures and tests which differ between clinics and clinicians. Some annual check-ups might take less than 15 minutes and not even measure more than BP, SpO2 (finger pulse oximeter) and brief spirometry, usually only sitting up. What is seen as acceptable is often not based upon the best for an individual polio patient, but more to do with a generic standard protocol. The same issues pervade assessments around muscle function where assessments are based upon the old manual muscle testing which still adheres to the belief that single manual muscle testing tells the clinician all they need to know when it misses the polio muscle's particular endurance response.

### **Reliable information is the only basis for effective change.**

It may be adequate and even useful for those new to the disabled community following a traumatic event, illness or new condition to be helped with adjustment, self- management and coping with their new identity and status in society. However, for many polio survivors, we are the experts at coping and management of our 'condition', if anything too good at it! What we need



and rarely get is well researched and expert dialogue with professionals which recognises that there are essential medical differences in polio in particular. Then, we can adjust and use our very well honed and expert patient skills of self-management on the basis of real knowledge. Of course I can and should do less, but it must be with a maximum quality of life and an expertly managed decline. I resent being fobbed off with being advised that I 'just have to come to terms with doing less' apart from anything else, as a psychologist, I find it just unscientific as well as, to quote Basil Fawley, a statement of 'the bleeding obvious'.

On behalf of the Trustees I would like to thank Gillian Bryan for her years as Treasurer and Membership Secretary. Margaret Marris is now Treasurer, Dot is now Secretary & Membership.

**Simon Parritt, C.Psychol, AFBPsS, MSc, BSc(Hon), BA, CPsSC, MBACP**

Chartered Psychologist. HCPC Registered Counselling Psychologist, [www.sp-psychology.com](http://www.sp-psychology.com)  
Chair Polio Survivors Network. Simon Parritt <[simon.parritt@poliosurvivorsnetwork.org.uk](mailto:simon.parritt@poliosurvivorsnetwork.org.uk)>

### **My Polio and Treloar Hospital, Alton by member Janet Whitworth.**

In 1954 I was 7 years old when I got polio. It hit me with a high fever, fast pulse and difficult breathing. The doctor came to see me in the flat above my dad's shop. Polio was suspected but he sent a specialist to confirm the diagnosis. I had never heard of polio. They shipped me off to Alderney Hospital where I was examined and placed in isolation. People asked me what it was like to be in an iron lung well horrible of course not be able to scratch your nose if you had an itch but what I remember the most is the tremendous relief it was that the machine took over my breathing so I could start recovering.

I am not sure how long it was before I could be weaned off the lung but of course it sure was good to get out. They gave me lots of pillows in the bed but I kept slipping down the pillow hill because my left arm was useless. Nurses, or my mother who was a former nurse, would plump up the pillows and haul me back up. Polio mainly affected my left arm, my neck and my diaphragm. After having my mother with me every day at the local hospital I was eventually transferred to Alton for rehabilitation.

Recently my niece in Dorset met a lady who was a former nurse at Alton and I was thrilled to learn that she remembers me. We have exchanged some Emails and I read a book about Alton hospital (The Lord Mayor Treloar Hospital and College by G.S.E. Moynihan) which has given me a whole new appreciation for what that hospital did for me, and many others. My parents were only able to visit once a week on Sundays but I received excellent care with lots of physical therapy. Eventually the day came for me to go home. On the drive back to the house I kept standing up between the two bucket seats to talk to mum and dad. No seat belts in those days and my mother kept telling me to sit down but before long I'd be on my feet again.

My recovery was marvelous and I could almost pass for normal but I was hospitalized for pneumonia several times and penicillin was my wonder drug until sadly I became allergic to it. My mother was always very protective of me and I hated it when she had the talk with new boyfriends. "Janet had polio so she needs to be home by --- - etc." I knew I needed to be careful of course but it was so liberating when I left home and met new friends who never knew about my polio.

Post-polio hit when I was 47 but I am still doing OK and enjoy knowing quite a few other polio survivors through a local support group. It's also good to read polio newsletters and sometimes network with others on line. [Janet moved to Washington State, west coast of USA in 1976]

When I told Hilary about Treloar Hospital she said she knew somebody else who was treated there as a child. Perhaps others might like to share their memory of the hospital. From my new nurse friend I learned that we were served porridge for breakfast and bread and butter with Marmite. I still eat those things. Marmite is not so easy to find in the US but I know a place. I told her how I enjoyed it when the nurses rolled our beds out onto the patio. I liked riding the electric trolley to physical therapy. I remember having my hair washed while I was lying down and Nurse Pither says she was probably one of the nurses that did that for me. She loved working there. [Janhat55@comcast.net](mailto:Janhat55@comcast.net) [See back page for Philip Taylor, the Cordwainer response to Janet]



## The Continuing Sagas of Dot

It is time for a heading title change methinks as I have been deleted and retired no matter how delightedly for just over a year now. The problem is that the 'delightedly deleted' moniker has/had a certain ring to it alliteratively speaking.

Sooo..... what to replace it with? Dippy? Clumsy? Old? Tramadololy? (after my drug of choice)?!..... I am open to suggestions! As they say, answers on a postcard or preferably via email. The 'reward' will be a named mention in despatches! Send to: [dot.ives@poliosurvivorsnetwork.org.uk](mailto:dot.ives@poliosurvivorsnetwork.org.uk)



Well, there wasn't anything remotely interesting or amusing to report for this edition and I was feeling a tad guilty at disappointing my embryonic fan base! I was in rude good health (for me – it is all comparative isn't it)? I had survived the retirement/redundancy treat of the highlights of China without any major mishaps and have become a grandmother again. However, notice the use of 'was' rather than 'is'.....

A couple or so Friday evenings ago, I duly parked and locked my car eagerly looking forward to watching 'Ab Fab the Movie' with a friend when, with my usual flourish of elegance and decorum I tripped up the kerb...said 'friend' blithely oblivious and striding purposefully to the cinema! Unlike two weeks previously when I did the same trick elsewhere, bouncing up as quickly as I could, hoping no-one had noticed resplendent with a bloodied knee and broken toe I immediately knew I was *not* bouncing up quickly at all from these latest war injuries resulting from pavement surfing.

Luckily my friend eventually stopped in her quest for the best seats in the cinema and turned to see what on earth I was up to, with a cry of "oh Dot"! she shimmied back. Just as she was asking if I could get up, the answer being "no, not by myself" a knight on a bike pulled up, together they hoisted me to my feet.

So, I had done my own version of a 'Patsy'. Whilst that Ab Fab sozzled character with a predilection for sliding out of taxis with a bottle of Bolly I kinda knew I had a broken arm. Whilst waiting for Sir Galahad to arrive in the form of Mr Dot, I wanly said apologetically to my friend that perhaps we could still manage to see the film after I had rested for a few minutes!

To cut the story shorter and to cut through to the silver lining... I was seen by a very nice orthopaedic doctor at the fracture clinic the following Monday. (He was nice until he inflicted great pain trying to manipulate my arm)! Anyway, low and behold, upon hearing what had happened and my beginning to explain about PPS he suddenly said that 'explained it' and as I continued with the usual, "I don't suppose you have heard of it" the nice ortho man said yes!!! Furthermore, he said it was one of his specialisms and had an exam in a few days! This is truly astonishing isn't it?

Fast forward an hour or so, the heavy mob are lingering with malcontent near my right arm. (I was trying to get my fill of entinox and be transported to a nice beach somewhere in my delirium)! Nice ortho man was regaling the medics with a 'spot the difference' ... "this is an interesting lady... she has had polio.. see her high arches and how her feet turn?... polio!" He then said I was too lucid (my fault for answering questions). I was told to relax and let the gas and air work! At this I foolishly told them to just get on with it! So they did! I think my screams must have been heard for miles!

Needless to say, the manipulation didn't work. Following surgery I am due to have the wires removed in a few weeks. It is a good job I am cack-handed as my dad used to say.

When I return to outpatients I shall be armed (my good one will be at any rate) with past copies of our PSN newsletter. Perhaps nice ortho man may become a member!

Postscript.....still not got to watch Ab Fab the Movie!

Dot Ives

[dot.ives@poliosurvivorsnetwork.org.uk](mailto:dot.ives@poliosurvivorsnetwork.org.uk)



## To supplement or not to supplement?..... that is the question

As with most people of a certain age and with an ever increasing range of medical conditions I take a plentiful amount of prescribed and over the counter medication and an assortment of supplements that would make Bassetts proud! I thought I would share the following 'discoveries' and encourage debate and contemplation.

**VITAMIN D3 10,000 IU** - Following a discussion with my physiotherapist, I have been reading that some American physicians are maintaining that we do not take anywhere near enough vitamin D3 either through sunlight, diet or via supplements. This is especially true of us who live in the northern hemisphere and especially true of us who live in the North East of England! The consequences are that we may suffer from aches and pains, muscle weakness and fatigue. As you know, these sound just like the symptoms of PPS. The recommended daily dosage of vitamin D3 in the UK is currently 10mgms or 400 IU (International Units).

\*Whilst Vitamin D has been in the news recently stating that this may not be enough; the purported recommended dose falls far short of the 10,000 IU daily dose of Vitamin D3 recommended by some of our American counterparts. Protective benefits are said to include those against cognitive decline and lowers the risk of certain cancers and diabetes. See research and information online [[www.vitamindcouncil.org](http://www.vitamindcouncil.org)]

\*\* However, some studies found that adults aged over 70 years are more prone to falls when on increased high dosages of vitamin D3. The article recommends sticking to an overall daily intake of 400 IU.

The scientific debate on both sides of the Atlantic continues. It will be interesting to see what people think. From my non - scientific research amongst friends, some have noticed no difference at all. Another person with severe rheumatoid arthritis and back problems swears by it and says it has transformed her life; resulting in coming off long term strong medication. The jury is out.

\*[www.nhs.uk/news/2016/07July/Pages/The-new-guidelines-on-vitamin-D-what-you-need-to-know.aspx](http://www.nhs.uk/news/2016/07July/Pages/The-new-guidelines-on-vitamin-D-what-you-need-to-know.aspx)

\*\* [www.cbsnews.com/news/high-doses-of-vitamin-d-may-hurt-seniors-instead-of-help/](http://www.cbsnews.com/news/high-doses-of-vitamin-d-may-hurt-seniors-instead-of-help/)

**TURMERIC CURCUMIN 500GM** - Anecdotal evidence and enthusing's of a fellow traveller around China spurred my husband and I to include this supplement in our daily war against aches and pains. We tried the suggested concoction of 1 tsp of turmeric, 1 tsp of cinnamon, and a dash of honey in green tea once daily. After three days we abandoned this in favour of capsules. Research and studies are inconclusive and ongoing. However, after a month of taking this supplement daily my husband is much more mobile and is convinced his decreasing aches and pains are due to the turmeric capsules. This was mentioned to a clinical lead nurse who also finds it beneficial. So much so he is now giving them to his dog!

<http://time.com/3984504/turmeric-supplements-curcumin/> and [www.cancerresearchuk.org/about-cancer/cancers-in-general/cancer-questions/can-turmeric-prevent-bowel-cancer](http://www.cancerresearchuk.org/about-cancer/cancers-in-general/cancer-questions/can-turmeric-prevent-bowel-cancer)

**To Summarise** - I have been taking both products for over a month and do certainly feel better. I ache less and seem to have more energy. I also managed a 5 mile walk yesterday for the first time in years; granted it was on the 'flat' – no hills or bumpy bits and a lunch stop in the middle. Whilst I was aware that my back and sciatica were protesting a little I was not in pain.

I would like to say that this remarkable feat is attributable ONLY to the above supplements but unfortunately that is not the whole story. This coincided with a change of medication and a visit to my GP. Following the usual investigations and review my intake of tramadol has now changed to the slow release variety and an increased dosage. Along with the introduction of statins and amloride for high blood pressure; these and the supplements have rejuvenated me! It is impossible to say which, all or indeed if any are responsible. I guess I will never really know. I would like to think it is the Vitamin D3 and the Turmeric!

Dot Ives.



12th August 2016

To: The Royal College of GP's  
The Association of British Neurologists,  
British Society of Rehabilitation Medicine,  
Primary Care Respiratory Society,  
Association for Respiratory Technology and Physiology.

Polio Survivors are seeking your support to ensure that enough base knowledge of Polio and Post-Polio Syndrome is available to your members with links to further information when polio survivors present. The reason we are asking follows:=-

On 25th November 1995 our Founder seeking help for increasing symptoms of new weakness and fatigue following a fall in 1988 mentioned her prior polio. At last polio was in the equation and instead of 'all in her mind' this could be Post Polio Syndrome. Later that day the Lincoln Health Information Service handed her the two medical articles dated 1992 page 9 and 1993 page 10.

The Lincolnshire Post-Polio Network [now known as Polio Survivors Network] was founded in 1996. Sadly the telephone calls and emails seeking help; medical statements being queried and questions being asked are still the same year on year including last week.

Firstly we accept that nearly all Polio Survivors are strong willed and determined to push themselves to their limit and beyond to continue achieving as they have in the past. We spent decades of being told we would not be able to do x, and we did our best to prove everyone wrong. The last place we want to be is in a doctors office and when we request an appointment is not something we do with ease.

Most often something has occurred to take our ability just below our previous level of managing. Falls or accidents with just a little more nerve damage and muscle ability now below the previous level of achievement. An illness or operation with weeks of inactivity and through lack of knowledge and understanding of polio too high a level of rehabilitation exercises, etc.

We can be our own worst enemy and if asked 'Can you do x?' instead of 'How do you do x?' can proudly tell you 'Yes' leaving a huge difference between the picture in the Health Professionals mind and ours as to how we actually achieve that action.

Secondly we appreciate time constraints for appointment times but single action Manual Muscle Testing far too often, leads to our reported weakness 'not found'. The new weakness we report starts at variable times following a single action. The repetitive and sustaining power of our muscles, our level of endurance, is not being tested. Single action tests of one limb can also mask our ability to perform a pattern of movement with that limb. During our recovery from polio we developed - and are still developing as we encounter new problems - new ways of achieving actions of daily living. Again time constraints often do not allow us to demonstrate how we walk, climb a few stairs, get up and down from a chair or the floor. Polio Survivors across the world report again and again how a variety of health professionals report astonishment at the muscles we are using to perform actions of daily living.

Thirdly we know the NHS is struggling financially. We are certain that with more base knowledge and more appropriate referrals that the huge number of unproductive appointments our members report could be reduced saving the NHS money. Being admitted to hospital to a department where knowledge of polio and post polio is not to the fore can and is causing issues. The delay in our being appropriately diagnosed, advised, levels of treatment, assisted to apply for equipment and benefits etc., has meant so many of our members deteriorating unnecessarily early.

Yours faithfully,

The Chair and Trustees of Polio Survivors Network.



## **Polio returns to haunt G.P.'s - by Thomas Moore**

### **GP - November 1992**

Up to two thirds of people who suffered paralytic polio as children are likely to develop new symptoms similar to motor neurone disease.

They present with muscle weakness, myalgia and respiratory problems roughly 30 years after paralytic polio. GP's will be the patients first port of call, specialists warn.

Specialists think between 22 and 65% of the thousands of people who survived polio could have the condition 'late effects of polio' (LEOP).

St. Thomas's Hospital has already treated 500 patients.

Director of rehabilitation at the Royal National Orthopaedic Hospital at Stanmore Dr. Joseph Cowan believes a considerable number have yet to present.

**"It's GPs who need to be aware** of this problem. LEOP must be included in the differential diagnosis of post-polio patients who present with fatigue. Anaemia and thyroid problems still have to be excluded."

Some experts speculate that patients who lost motor neurones from paralytic polio are vulnerable to further, age-related neuronal loss. Patients' muscles become progressively weaker as they become denervated.

Others believe that following polio infection, surviving motor neurones 'sprout' to take over denervated muscle fibres. These hypertrophied post-paralytic motor neurones are vulnerable to fatigue through overuse. As they die, remaining neurones are left to compensate, increasing fatigue.

Consultant physician in the respiratory support unit at Papworth Hospital Dr. John Shneerson said the theory explained why people who remained physically active after polio seem more vulnerable to LEOP than those confined to wheelchairs.

He said they lose control of their limbs and can drift into respiratory failure. Early referral for orthopaedic and respiratory assessment is crucial, he said.

LEOP should be suspected in patients who had paralytic polio and may present as:

- Fatigue, myalgia and muscle weakness
- Muscle cramps and twitching, sensory changes or loss and sleep disturbances are rarer. A quarter report difficulty in breathing or swallowing.

A slow, steady neuromuscular decline. Others suffer periods of rapid deterioration followed by remission.

### **Post-Polio Syndrome - Pathophysiology and Clinical Management.**

**Anne Carrington Gawne and Lauro S. Halstead.**

**Critical Review in Physical and Rehabilitation Medicine. 7(2);147-188 (1995)**

The first descriptions appeared in 1875 when four case histories were reported in the French literature by Carriere, Raymond, & Cornil and Lepine.

These patients, all young men, had paralytic polio in infancy and developed new weakness not only in previously affected muscles but also in muscles believed to be uninvolved.

All had physically demanding jobs and performed repetitive activities.

<http://www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/gawne/>



**Fighting and surviving all over again:  
Patricia Rock's childhood polio returned in an unexpected way,**

**writes Thomas Moore, Tuesday 12th January 1993.**

Had Patricia Rock been properly diagnosed when she tried to stand on her crutches again after a spell in hospital, she might still be walking. Instead she has spent more than 10 years in a wheelchair, battling against immense fatigue, muscle weakness and pain in her back.

Ms Rock is a polio survivor. The virus left her with paralysed legs at the age of two. With the help of callipers and crutches, she enjoyed 30 years of upright activity, but 12 years ago her polio returned in an unexpected way. Ms Rock is one of a number of polio survivors to develop a newly recognised syndrome called 'late effects of polio', which can appear 30 or 40 years after the original attack. Doctors now believe that in about a third of polio survivors, muscles eventually become too weak to support limbs; in some more serious cases, breathing and swallowing can become an effort. Other survivors may experience fatigue only.

Ms Rock had packed her life with activity. She worked full-time as a welfare officer for a disability organisation, went on archaeological digs and excelled at wheelchair basketball. She won a number of Commonwealth paraplegic swimming medals in backstroke.

'I was a go-getter. Polio became less and less of an issue as I grew older and realised I could do most of the things able-bodied people could. I didn't have a progressive disability and, unlike some polio survivors, I didn't have any respiratory difficulties,' she says.

Her life changed when she was forced to come off her crutches when she developed tennis elbow. Because of her reliance on her arms, she was admitted to hospital for intensive physiotherapy and expected to leave after a week with her elbow healed and her crutches back under her arms.

It was not to be. 'Once they had got my arm working, I stood up on my crutches, as usual - and passed out. I had incredible back pain, which I had never had before.' Even now her doctors are unclear as to why the first hospital spell precipitated the weakness of her back muscles. They suspect that the inactivity caused by the unrelated tennis elbow accelerated a process that she would otherwise have experienced gradually.

Two mistakes were made. First, Ms Rock was given a potent analgesic for the back pain, but everyone forgot that she should have received a reduced dose because of her polio, which had left her with poor circulation. As a result she could not clear the drug from her body in the normal way. The overdose sent her chest and back muscles into spasms, she had difficulty breathing and her vision deteriorated.

Ms Rock spent the next three months in hospital. Her back was so weak and painful she could not even sit up. Doctors could find nothing wrong with her, and physiotherapists thought she was malingering.

The second mistake was to make every effort to get Ms Rock back on her feet. Ten years on, the emphasis is on resting the overused and exhausted muscles. 'It is very frightening not being taken seriously by the medical profession. My spine was packing up 40 years early and nobody would listen to me,' she says.

Ms Rock was finally seen by a consultant who specialised in curvature of the spine. He saw from her X-rays that she had a double 'S' bend in her spine. Immediately she was given a corset to support her back that allowed her to sit up - and she was told to stay with her wheelchair. Had she tried to stand much longer, she would have broken her back, the consultant said.

All this pain and difficulty had made Ms Rock suspect that her orthopaedic problems and muscle fatigue might be linked to her childhood polio, but her theories attracted no support from her doctors. Then Ms Rock heard about a conference in St Louis, Missouri, devoted to 'the late effects of polio'. She booked a flight, and it was a decision that changed her life.

During three days she sought advice from dozens of specialists and fellow polio survivors. They confirmed that her back muscles, damaged by the polio virus, had begun to wear out, and without muscular support her back had collapsed, causing the double curves. She was told to



slow down, take plenty of rest and gradually build up her muscles. If she ignored the advice, she risked permanent damage to her back. 'At last I knew what was happening to me and that there were other people experiencing exactly what I was. I couldn't sleep because I was on such a high,' she remembers.

Ms Rock returned to the UK and began to put her life back on the rails. At about this time a handful of British specialists were starting to think that there might be problems, and a rehabilitation unit was set up at the Royal National Orthopaedic Hospital at Stanmore, London. The Stanmore unit has developed a reputation for looking after every aspect of post-polio management. Counsellors and social workers are on hand to help patients to come to terms with their post-polio diagnosis.

Dr Joseph Cowan, director of the unit, estimates that around a third of the 'tens of thousands' of people affected by polio in the post-war epidemics will experience late effects to some degree. Many have yet to approach their GPs.

Doctors have generally been slow to recognise the link between the musculoskeletal symptoms and polio. Many polio survivors who approach their GPs are told their symptoms are simply due to ageing. Dr Cowan says this is rarely the case. If there are no signs of thyroid problems or anaemia, doctors should refer for a full orthopaedic and respiratory assessment. 'GPs need to be aware of this problem. They are patients' first port of call. Post-polio must be included in the diagnosis of patients who present with fatigue.'

Dr John Shneerson, consultant chest physician at Papworth Hospital, Cambridgeshire, agrees. He warns that new musculoskeletal symptoms should never be ignored in polio survivors. 'Not all polio survivors will experience late effects, and in others it will be mild. But if anyone notices any changes, they should seek advice,' he says.

In most cases it seems that the muscles originally affected by polio are those which later begin to weaken. People who were kept alive in iron lungs during the original infection because the virus had weakened their respiratory muscles may have difficulty breathing in later life. They suffer interrupted sleep because of their laboured breathing and are consequently exhausted during the day.

Dr Shneerson says a ventilator can cure the problem. But he adds that people with breathing difficulties must be carefully assessed to find the most suitable device. Mechanical support can also help. The centres with the most experience of assessments are Papworth, and St Thomas's and the Royal Brompton hospitals in London.

Dr Geoffrey Spencer, consultant in charge of the respiratory unit at St Thomas's, has seen around 600 polio survivors at his clinic. He says doctors are beginning to understand what causes the muscular degeneration. During acute polio, the virus attacks and destroys many of the nerves controlling muscle fibres. Without nerves, the fibres cannot work; and without work, they die. Polio survivors have to use their full muscle strength to do the simplest of daily tasks, and the overused muscle fibres begin to wear out.

Dr Spencer says it is crucial to pick up the loss in muscle strength early and then identify the activity that is causing the overuse. Simple lifestyle changes take the pressure off the muscle and after a while light activities become possible once again. Procrastination can lead to chronic strain and cause irreversible loss in muscle function. 'There's no point just saying take it easy, but we can usually find the source of the trouble,' Dr Spencer says.

Ms Rock adopted a lifestyle that was gentler on her muscles, and until she damaged her shoulder in a recent accident, she was nearly back to full strength. She was able to discard the back support corset a year ago and can sit unaided in her chair. She works part-time, is researching a PhD and sits on various disability committees. She has come to terms with the fact that her back muscles will never be strong enough for her to stand. 'I will never walk again, but I don't have the muscle weakness any more. I get episodes of back pain every few years, but that is treatable.

'Fortunately, I had the money to go to another country to find out what was wrong with me. But if we had had post-polio clinics in this country at the time, I might have been diagnosed at an earlier stage and my back might not have collapsed. **I only hope other people take note.'**



**Some of our members were UNDER 64 years of age on 8th APRIL 2013**

And in receipt of a 'lifetime' or 'indefinite'

**DISABILITY LIVING ALLOWANCE [DLA} Award.**

Did you realise that the Government are  
now **'INVITING'** them [you are ok if born on or before 8th April 1948]  
to claim for **PERSONAL INDEPENDENT PAYMENT [PIP]**

If they **DO NOT** claim by the date on the letter their **DLA** will **END**.

**DLA Mobility** eligible for **high rate** if you could not walk more than **50 metres**.

**PIP** the walking distance criteria has been reduced to just **20 metres**

The Department of Work and Pensions consulted on PIP in 2012 but **did not** mention its plans to cut the criteria from 50 to 20 metres until after the consultation closed.

**Reliability Criteria** added in March 2013 DWP introduced an amendment to the Regulations which means that when assessing an individual's ability to undertake the 12 activities in the assessment, consideration must be given to the individual's ability to complete them safely, to an acceptable standard, repeatedly and within a reasonable time period. These criteria are known collectively as the reliability criteria.

Only **TWO levels** now for Care and Mobility and its all about **POINTS**

Qualify for **Standard with 8 points** and **Enhanced with 12 points**.

**Motability Vehicle. [You now need 12 points]** If you have handed your Mobility Allowance over for an adapted vehicle or electric wheelchair and many will have had to pay an additional sum for a larger vehicle and your claim for PIP does not award you 12 points then your Motability Car/Electric Wheelchair will be reclaimed 7 weeks after the decision. You first have to apply for a mandatory review of the decision before you can lodge an appeal and guess what? Yes it takes longer than 7 weeks! You will need to return your car to the dealership in good condition and within the agreed timeframe to qualify for the following transitional support.

Customers who entered into their first lease agreement with the Motability Scheme before January 2013 and therefore could not have been aware of PIP and the associated risks when they joined (the vast majority of customers), we will provide transitional support of £2,000. For many customers this will enable them to continue to have mobility by purchasing a used car. If you entered the Motability Scheme after that date you can still get £1,000.

### **Comments from other disabled people.**

Read the instructions carefully before completing the application.

You need to have at least one person help you with this and it would be best if one of them was with you at any assessment.

Your application and what you tell your assessor should be the same. If you have forgotten anything on your application then apologise and tell the assessor.

You must keep a copy of all documentation that you submit even though it can be pages and pages. You and the person going to be with you **MUST** read the paperwork again the day before to help you remember exactly what you wrote.

The guides, handbooks will tell you exactly how many points you will get depending on how bad you are at each activity. We know it is not nice remembering how bad things are now, how hard it is to achieve a task and how often we have to rest to complete it, but you need to do this and include the information on your application. [see next page]

The assessor can be typing onto a laptop at the same time you are talking so if you disagree with the assessment check with them what was written so you can clear up any misunderstandings.



It is imperative that **the picture you paint in the mind of any health/social care/benefits assessor of how you do an action is the same as you are actually doing it including resting times.**

It is NOT just a simple I can do it, but this is HOW I have to do it now and if you have to pace and rest in stages then it is important to say this. As we deteriorate the way we perform actions of daily living changes bit by bit but each change becomes our new NORM. Reminder, it is the change in how you are having to perform actions of daily living that is the most important point to discuss with any health professional assessing you. Why and what is causing you to have to change the way you are doing this action? E.g. Using elbow rotation to whisk eggs instead of wrist rotation. The reason was found to be considerable weakness now in the wrist that had not shown up on the normal routine of arm testing. It would not have been found at this time had the question not been asked.

Have you watched yourself in a mirror or seen yourself on video actually getting up from a chair, a couch, off the toilet, out of bed, etc. [Millie, a polio survivor in the States asked her young granddaughter 'Why are you walking like that?' The answer was a surprise 'Copying you Nanna.' Her family then videoed her walking. She had no idea that was how she was walking now] When you are working in the kitchen are you sitting on a chair/stool, are you leaning against the work surfaces and hold on with one hand to use the other. Have you had to purchase already prepared ingredients now? Have you broken down the task into bits? We are pretty good at not thinking about the changes and although seeing all this in black and white can be upsetting it is very important.

**N.B. Aids are devices** that help a performance of a function, for example, walking sticks or magnifying glasses. We add, think of things like pill strips that someone fills for you because you can't open the bottles/packs and you might also set alarms to remind you. A straw because you cannot easily hold/tip a cup up. Maybe you can't help but spill food items on yourself or the floor and need someone to clean up after you. Raised your toilet or use a toilet raiser, any handrails, drawers instead of cupboards so you can see and reach all items. **Appliances are devices** that provide or replace a missing function, for example artificial limbs, collecting devices (stomas) and wheelchairs.

Another important fact for polio survivors to remember is that when being asked about separate activities, e.g. shopping, housework, showering can you do all of them every day? Or do you like most of us now have to spread the activities out across the week. Most people shower at least once a day but can/do we?

Do you rest up the day before a medical appointment so you have more energy tokens for the appointment day? Do you get someone to drive you, load/unload your wheels, pass you your cane/crutches/walker etc., Do you also arrive early so you can find the toilet and rest before you go in? Then there is the return journey and because it took more than a days energy tokens do you have to do almost nothing the day or two after to catch up?

When you get your assessment back and can see how many points you have received you will have a good idea of the outcome of your assessment. If you believe the assessment is incorrect then you have to apply for a mandatory review of the decision before you can appeal.

**DWP - Personal Independence Payment Handbook.**

[www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/519119/personal-independence-payment-handbook.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/519119/personal-independence-payment-handbook.pdf)

**Benefits and Work - [www.benefitsandwork.co.uk](http://www.benefitsandwork.co.uk)** are **the organisation** to join to have access to all the paperwork necessary to help you claim, learn what happens at a medical and how to appeal. Expert step to step guides for all benefits throughout all procedures. Many report success and grateful thanks.

**Anyone still waiting will be "invited" by 30th September 2017**

Please contact us if you have been through this or if like Richard and 2 others still waiting.



## Chronically sick and disabled are "collateral damage" to this Government

Northern Echo - Julia Breen - 21st July 2016.

Disability advocate JO COLE, from Thornaby, says disabled people are being made the scapegoats in a society "thirsty for blame".

The Department for Work and Pensions (DWP) figures show by April 2016, seven in 10 disabled people who were previously claiming DLA are 'eligible' for Personal Independence Payment (PIP). However, social media and websites that highlight disability issues are full of narrative on experiences of undergoing appalling assessment processes for PIP and their claim being refused. Claimants feel 'blamed' for claiming as opposed to feeling enabled to lead independent lives. The emphasis here is whether 'eligible' turns into being awarded PIP and, awarded somehow means deserved. It is this that politicians and the able bodied community seem to resent. The campaign to make anyone on benefits feel a burden was exclusively the ploy of the coalition government after the 2010 election. Margaret Thatcher designed Disability Living Allowance not as a benefit, but as recognition that there was an underlying level of health. Bearing in mind that the UK ratified the UN Convention on Rights of the disabled in 2009, by the 2010 election, the UK had still not developed a structured social policy to protect the vulnerability of the chronically sick and disabled. The Coalition Government developed a set of tactics to undermine the much publicised fraudsters. The chronically sick and disabled became collateral damage.

Frank Gardner, the BBC reporter paralysed by a sniper in the middle east gave the third annual Jack Ashley Memorial Lecture recently and said he would like to see "the sharp edges of difference" between disabled and non-disabled people "sand-papered down so people don't make a big deal about it anymore". He also spoke of his frustration at non-disabled people who use accessible toilets, and the abuse of accessible parking bays by non-disabled drivers. Political criticism of the Motability car scheme has fuelled a sanctimonious attitude and perverse jealousy towards disabled people. Disabled people have no enforceable rights in the UK. Abuse of Blue Badge parking bays is common. Occasionally, someone patrols supermarket car parks to restrict the use of parent and toddler parking bays but no-one cares if the disabled can park or not. The disabled come second to parents with pushchairs on public transport because the bus companies are not sanctioned. The cost of the Blue Badge rose from £2 to £10 because of fraudsters as Borough Councils had to take steps to add mechanisms that could not be copied. Disability hate crime has increased 40% through abuse or theft. Where does the idea come from that somehow the disabled benefit more than others during austerity?

PIP has come about because of the much publicised fraud in DLA applications, largely due to people getting better from short-term injury or ill health but not declaring it. This has led to the idea that everyone can get better.

Austerity has brought a new culture to the UK which has thrown away historical cultural empathy and is now driving chronically sick and disabled people back into the shadows. People are scared. Scared of public ridicule because of their impairment, scared of being seen as a 'scrounger', scared of losing what they have even if they have deteriorated and their needs have changed. Disabled people have been made the scapegoat for a society thirsty for gossip, thirsty to blame. The able bodied feel they have a right to be judgemental. The NHS is in trouble, blame sick people and the disabled for a being a burden on society.

Is this really the way to conduct social policy in the UK? The disastrous PIP assessment process is punishing genuine disabled people. But, it is a self-fulfilling prophecy, designed for a cost-cutting exercise and motivated by greed, a bonus for every Motability car repossessed and stringent time limits regardless of life-long disability. This would not have got through Parliament in the current form had we had a structured social policy and regard for the UN Convention on Rights of the disabled.

So, don't blame chronically sick and disabled people for a highly flawed system. Task the new Government with creating a social policy that softens the sharp edges of indifference toward disabled people.

**Editors Note:** Jo Cole, a long time supporter of the issues polio survivors experience through contact with Polio Survivors Network and Lincolnshire Neurological Alliance through Tees Valley and North Durham Neurological Alliance. Jo had to hand back her Motability Car last Saturday whilst she waits for her appeal to be heard. Watch out for an article coming soon in the Guardian.

**March 2016. BBC.** 650,000 people use the Motability Scheme. To date, Motability has seen around 51,200 people join the scheme using PIP. Of those previously on higher rate DLA, 31,200 people have so far been reassessed for PIP, and of those, 55% - or 17,300 - have kept their car. **But the remaining 45% - 13,900 people - have lost the higher rate and therefore their car as well.**

**August 2016. Independent.** 400 to 500 vehicles reclaimed a week. Estimated 35,000 for this year 2016.



## LATEST NEWS AND PATIENT SURVEY.

15TH AUGUST 2016.



A new report published by the Neurological Alliance has found that GPs in England lack confidence in the primary care pathway for people with neurological conditions. New polling of GPs across the country shows low levels of confidence in the ability of local services and systems to manage neurology patients effectively, and widespread concern over unnecessary delays. It also suggests that GPs feel they would benefit from more support to manage people presenting with suspected neurological symptoms.

The *Neurology and primary care* report, available at <http://bit.ly/2bfLdkh>, presents the results of a survey of 1,001 regionally representative GPs from across the UK (England, n=831) and an expert workshop convened in December 2015. The report focuses primarily on England but additional UK-wide findings are included in the appendix. The report finds that:

- **85% (n=708)** of GPs in England are either 'somewhat concerned' or 'extremely concerned' about the time taken from referral for patients to see a consultant neurologist.
- **59% (n=492)** of GPs believe that the local services and systems in place in their area mean that people with neurological conditions frequently do not receive a timely diagnosis.
- The large majority of GPs in England (**84%, n=701**) feel that they could benefit from further training on identifying and managing people presenting with neurological conditions.
- Fewer than half of GPs (**47%, n=392**) felt confident in their ability to make an initial assessment and referral for people presenting with signs and symptoms of multiple sclerosis.

The report also sets out eight recommendations aimed at improving the primary care pathway for people with neurological conditions, including a call for the development of a pan-neurological 'watch list' of the ten signs and symptoms GPs should be aware of during patient interactions in primary care settings.

Arlene Wilkie, CEO of the Neurological Alliance, said: "It is essential that NHS England and the Department of Health respond to these findings and engage with the concerns of GPs and people living with neurological conditions. Without an effective pathway through primary care, patients will continue to suffer the consequences of undue delays to referral, diagnosis and treatment, and outcomes will continue to suffer."

### 30th June 2016 - PATIENT SURVEY LAUNCH 2016

The Neurological Alliance has launched its second neurological patient experience survey. The **ONLY ONLINE survey** is now open for responses and is available at

[www.neural.org.uk/campaigning/making-the-case-for-stronger-services/patient-survey-and-commissioning-audit-2016](http://www.neural.org.uk/campaigning/making-the-case-for-stronger-services/patient-survey-and-commissioning-audit-2016)

The survey aims to collect vital information about the experiences of people affected by neurological conditions, including the quality of the treatment, care and support that they receive. It will help us to understand how much progress has been made in improving neurological services, and which areas to focus on for improvement.

The survey opened on June 30th and will remain open until September 30th and we welcome responses from anyone with a neurological condition living in England.

Read the last report at [www.neural.org.uk/store/assets/files/495/original/Invisible\\_patients\\_-\\_revealing\\_the\\_state\\_of\\_neurology\\_services\\_final\\_14\\_January\\_2015\\_.pdf](http://www.neural.org.uk/store/assets/files/495/original/Invisible_patients_-_revealing_the_state_of_neurology_services_final_14_January_2015_.pdf)

Post-Polio Syndrome entries for this report were **106** only 1.5% of the total responses.

**MEMBERS Please help us see a larger number of polio survivors responses.**

**PAPER COPY AVAILABLE FROM PSN and we will enter your responses.**



## AIDS AND EQUIPMENT HELP SAVE ENERGY SO YOU CAN DO MORE, n.b. MORE.

I find it very hard, and have done for over eighteen years now, to attend events that Polio Survivors attend and see people struggling to get from a to b when there is an alternative. Now I fully understand that it takes years to accept that actions of daily living are getting harder and change needs to happen. That is because I have been there and I am still there occasionally. Richard telling me to please take a break.. "Where is your rollator, use your scooter, when I am walking those extra few steps with a walking stick.

I had a fall in 1988 and ended up with neck and left arm pain. After five months of pain pills, physio, neck traction, nerve conduction studies and EMG's, I was told. 'Ulnar median in both arms but the right arm also showed carpal tunnel syndrome and we will operate'. I refused because there was no pain in my right arm at all. You won't be surprised to learn that they said I had got the sides of my body mixed up.

I was an Advanced Swimming and Life-Saving teacher, a senior pool Lifeguard and it was suggested that I go back to training to help me recover. I could no longer swim as fast failing the basic time for the two length swim and two length tow in 3 minutes. Before, with weak legs from polio which I disguised so no-one knew, I could do it in 2 minutes 50 seconds. Then - and this would have been a very sensible fact to tell the health professionals examining me - I could no longer pull myself out of the deep end of the pool let alone hold onto my 'towed body's hands' and then pull them out of the water. My Pool Bronze medallion needed renewing for insurance purposes so that career and salary went out of the window.

I was lucky to get some relief work at the Day Centre and this led to full time work. Then I was offered the post of an Occupational Therapist Aide to run the Disabled Craft Classes in West Lindsey. This involved travelling to a different venue each day. None of the groups had the funds for equipment to do all they really wanted so I got myself one of everything and carried it in boxes in and out of each venue.

Sometimes I fell doing this but had not tripped and I could not understand why. Years after finding PPS existed I realised I was asking my weakening back muscles to help me walk, to carry a large box and to breathe. So something had to go and my brain said 'Breathing important, better not drop what you are carrying in case you break it, so sorry legs no more help' and I had just sank to the ground.'

I would come home from work and fall asleep in the chair every day. The household tasks got harder and harder to manage. I had no time or energy for baking bread, cakes and making meals from scratch. I bought a dryer so I did not have to hang washing on the line and took it out soon as finished so I did not need to iron it. I belonged to a group but had to stop going on walks because I could no longer keep up.

Then I found PPS existed. My polio was in the equation at last. I started 'meeting' other polio survivors online and learning about pacing and resting, using aids and **doing more**. I did not want to change but I heard how much more they did and I wanted to do more. Was what they were saying really true?

On 16th March 1997 I took delivery of my charity purchased electric scooter. I was devastated when the driver asked me to ride it round the street. A few days later a friend insisted that I go on the walk this weekend and take my scooter. Horror to find that despite being told it came to pieces to transport it did not. He managed to get it into the back of his car by lifting it and I 'wheeled seven miles'! So I was torn between hating riding on it and joining in again. One day I rode into town and went to M & S and I passed an old lady on a scooter and turned round to say hello. Shock! It was me in a mirror! I have had to shut my mind off to what I look like on my scooter.

**So to the people that ask me.** Would I rather not use one? "Yes". Would I give it up? NO, definitely not. I have gone miles and miles on three different scooters. Across the Atlantic by plane, right across USA by train and bus from Florida to California. 12 PPS Conferences would have been impossible without one. Museums, Castles, Flea Markets, Antique Fairs, Re-enactment four day events and Americana International. Shopping. Being part of the University of Lincoln User and Carer Panel, attending NHS and Social Service and other meetings. Last November I rode 3 miles from our hotel near Tower Bridge to the Neurological Alliance AGM in North London. Took me 55 minutes but saved me £20 taxi fare.

Would I be managing what I can still manage now if I had not done this. I can definitely say NO because in the nine years from the 1988 fall to starting to accept PPS and the advice in 1997 I continued to deteriorate at a fair old rate. Since starting to pace and rest and use aids and assistive devices, ask folks for help with things I cannot really do now and accepting a PA needs to drive us there and back if I want to do and enjoy doing whilst there, I have slowed the level of deterioration considerably. Polio Survivors have a look at how far wheelchairs and scooters can go each day. The larger the wheels the rougher the ground they will go over. The larger the AmpH of the batteries the further they will go. Some more than 20 miles. Go where no-one knows you, try different ones. Try renting for a week or two. Make sure you can sit comfortably for a few hours. See how much energy it saves and do more stuff you want to do. PPS Groups Worldwide repeatedly report members saying 'If only I had listened earlier because now I have got my scooter/electric chair/riser recliner etc **I can do so much more each day with less pain and fatigue.**



Two slides from presentations given at PPS Conferences and Meetings.

#### PACING AND RESTING & USING AIDS AND ASSISTIVE DEVICES WORKS

ACTIVITY BEFORE AND AFTER CHANGE	Time of Day	Time Doing	Time Resting	Pain Level	Fatigue Level
Getting up, showering and dressing	8.00 10.00	30 mins	90 mins	3	5
Changed to showering Underwear and callipers Top Clothes  SAVED TIME RESTING LESS PAIN AND LESS FATIGUE	8.00 9.00	15 10 5 30 mins	10 10 10 30 60 MINS	1	2
Walking round one shop pushing trolley then sit in cafe	11.00 2.15	15 mins	180 mins	4	7
Doing the Town Centre using electric scooter, walking in shop where necessary, no bag carrying.  GAINED TIME DOING SAVED TIME RESTING LESS PAIN AND LESS FATIGUE	11.00 4.00	180  165 mins	120  60 mins	2	4

### The first descriptions appeared in 1875

4 case histories were reported in the French literature  
by Carriere, Raymond, & Cornil and Lepine.

These patients, all young men, had paralytic polio in  
infancy and

developed new weakness

- not only in previously affected muscles
- but also in muscles believed to be uninvolved.
- All had physically demanding jobs and
- performed repetitive activities

Post-Polio Syndrome : Pathophysiology and Clinical Management,  
Anne Carrington Gawne and Lauro S. Halstead.  
Critical Reviews in Physical and Rehabilitation Medicine,  
7(2): 147-188 (1995)

Full text in Online Library

<http://www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/gawne/ppspandcm.html>



## HINTS, TIPS AND BITS IS BACK.

### NEW UK CIVIL AVIATION AUTHORITY report: DisabledGo Blog, August 8th 2016.

The quality of assistance airports provide to disabled people and those with reduced mobility is the focus of a new performance report by the UK Civil Aviation Authority.

Under European regulations, airports and airlines must provide help and support to disabled passengers and those with reduced mobility, to better enable this group of people to travel by air.

During 2015/2016 the CAA established a new performance framework and worked with 30 of the busiest UK airports to assess each of them against a number of key measures.

<https://www.caa.co.uk/News/New-CAA-report-rates-airports-on-quality-of-assistance-for-passengers-with-a-disability-or-reduced-mobility/>

### AUSTRALIAN PPS CONFERENCE.

Sadly we don't have anyone with the oomph or funds to go to this Conference but Australian PSN Member Robyn Aulmann, Secretary of the Hume PPS Group will be taking notes for us.

Australia has the **Australian Polio Register** established by Polio Australia in 2010 to gather information on the survivors living in Australia today. There are currently 2854 entries on the Register. [www.australianpolioregister.org.au/](http://www.australianpolioregister.org.au/)

## 43 Naidex

### NAIDEX AT THE NEC, BIRMINGHAM dates are 28th - 30th March 2017. [www.naidex.co.uk](http://www.naidex.co.uk)

PRYSM Group, the UK's fastest growing independent exhibition organiser, are "absolutely ecstatic" to have completed their acquisition of Naidex.

The country's most established event for the independent living industry, Naidex is held at NEC Birmingham and attracts over 9,000 trade visitors, consumers, and health professionals across three days.

And following July's acquisition, the event will now be celebrating its 43rd birthday under the guidance of the Bristol-based company, home to such shows as Farm Business Innovation, winner of the Best Trade Show award at this year's Exhibition News Awards.

## Slō® Drinks

### Stress Free Drinks for Dysphagia. [difficulty or discomfort swallowing]

We test each drink someone could need or want with various thickener formulations; analysing how its temperature, sugar, fat and pH levels affects each thickeners' ability to thicken safely. When we've identified the best formulation, we run more tests to calculate the precise amount required to change the drink into a specific consistency and then put enough for one drink in a sachet.

You simply add the contents into a drink to change it into a Slō Drink. They can be drinks needed for nutrition and medication, favourite drinks that can be used for hydration or drinks people want to relax with to help them cope with their dysphagia like a glass of wine or a beer. They will all look like an ordinary drinks and taste like them – they just flow slowly and can be drunk without worry.

Jackie from Slo Drinks offers PSN Readers that they are more than happy to send out samples to any reader who would like to try them. Please contact her directly referring to this offer.

[support@slodrinks.com](mailto:support@slodrinks.com)



## **Pennsylvania Polio Survivors [Sharing information worldwide]**

**What is the difference between POST-POLIO SEQUELAE and POST-POLIO SYNDROME?**

**[N.B. in the UK Post Polio Sequelae is not heard very often but we have USA members and we thought this of interest to all. LEOP, Late Effects of Polio usually refers to problems that you were left with after recovery and any new problems as Post Polio Syndrome]**

### **A Bruno Byte "Tidbit" by Dr. Richard L. Bruno, PhD.**

"Post-Polio Sequelae" was coined by the always insightful Dr. David Bodian, at the First Warm Springs Conference on PPS in 1984. It means "the sequel" to having had polio and refers to all of the things that could possibly happen to a person as a result of their having had polio (not just fatigue, muscle weakness and pain) but also brain stem damage causing slowing of their guts, heightened sensitivity to pain and to anesthesia.

"Post-Polio Syndrome" has many definitions but only refers to muscle weakness and, depending on who's suggesting the definition it could also cause fatigue and pain. Post-Polio Syndrome is a subset of Post-Polio Sequelae.

It is important to note that Post-Polio Sequelae is the diagnosis used by the US Social Security Administration to determine sedentary work disability.

Check out "Bruno Bytes" on our website. These Q&A's from the Post-Polio Coffee House are updated monthly, and are available in PDF format for sharing.

<http://www.papolionetwork.org/bruno-bytes.html>

### **DAVID WASSER - POLIO REVISITED. 47 minutes video. <https://vimeo.com/66577988>**

Polio revisited examines the highly infectious viral disease that, before the advent of a vaccine, caused paralysis and in some cases death, for thousands of people, nationally and internationally. The show profiles survivors and victims of the disease, the vaccines and their creators, and the genuine risk that polio presents today for American children who aren't immunised and the challenge of Post-Polio Syndrome. The program won a National Capital Emmy Award for historical documentary and the Association of Health Care Journalists has honored the documentary as well; it was the first-place winner in the television category. Polio Revisited originally aired on Retirement Living TV {RLTV} as a TV Special Project in the Healthline series.

### **JOURNAL OF LANCASTER GENERAL HEALTH - Poliomyelitis in Lancaster County by Ellen Hendrix '16, Franklin and Marshall College.**

A very interesting read for those seeking more information of polio during the outbreaks.

<http://www.jlgh.org/Past-Issues/Volume-10---Issue-2/Poliomyelitis-in-Lancaster-County.aspx>

### **MEMBER JANN HARTMAN - Have Scooter, will Travel.**

[Havescooterwilltravel.blogspot.co.uk](http://Havescooterwilltravel.blogspot.co.uk) 2000 European Tour. Excerpt.

We spent three wonderful days in England, which isn't nearly enough time. And, I mistakenly assumed that Lincoln [where we were to attend a meeting] (PSN AGM) was just a short ride from London. But it turns out Lincoln in Lincolnshire was 130 miles north of Heathrow Airport! It was embarrassing to find out how little I knew of Europe, and especially England. I had sent an email to my friend in Lincoln, thinking we could maybe just take a taxi from the airport to the hotel in Lincoln! She must have wondered how this crazy woman and her husband would ever get to Lincoln, but we did. [Hilary writes... I did chuckle but then when we flew back and forwards to Florida each year I realised that the picture in my mind of the size of the country we would be flying into would grow as we got nearer and where we had left get smaller to atlas size.] .. Tour of Lincoln Cathedral and Lincoln Castle... but I couldn't have seen nearly as much of it without my little Amigo scooter. Jann and John flew from the States to UK via Iceland, and after visiting us travelled via train then to France, Italy, Switzerland, Germany, Denmark, Norway, Sweden, Holland, England and back to Baltimore USA. A very interesting read.



**WE'RE STILL HERE! 2016 Photo Contest Family Life!**

What activities do you enjoy with your family? What activities do you enjoy with your "disability" family? Send us a photo that illustrates polio survivors are active participants in family life. Have you taken your grandkids on a trip? Have you participated in their school activities? Do you contribute to your family life day-to-day in ways that may "surprise" others who do not have a disability? Send us your photos of families in action and help us tell the world that WE'RE STILL HERE!

*Help us document that people who had polio are still here, active and involved in family life.*

Post-Polio Health International will select a grand prizewinner (\$150 USD) and four runners up (free PHI Membership for two years).

The runners-up will be announced October 10-13 with the announcement for grand prize to follow on October 14th.

Contest rules:

- Print or digital (JPEG with a minimum of 300 dpi) photographs will be accepted. Print photographs will not be returned.
- Color or black and white photographs will be accepted.
- Identify the location and date of the photograph and include a short statement about how polio survivors impact family life. Submitting a caption is optional.
- Each person is limited to submitting two photographs.

**NOTE:** By submitting the photograph to PHI you are confirming that the photograph is your property/work. You are agreeing to its limited use by PHI. PHI will state with the winning photos the following: Photo by (Name). Permission to use must be obtained through PHI. Decision of the judges is final.

**Deadline to submit a photograph to [info@post-polio.org](mailto:info@post-polio.org) is 12:00 pm CST on October 3, 2016**

**Paraprosdokians** are figures of speech in which the latter part of a sentence or phrase is surprising or unexpected; frequently humorous. Winston Churchill loved them.

1. Where there 's a will, I want to be in it.
2. The last thing I want to do is hurt you. But it 's still on my list.
3. Since light travels faster than sound, some people appear bright until you hear them speak.
4. If I agreed with you, we 'd both be wrong.
5. We never really grow up, we only learn how to act in public.
6. War does not determine who is right - only who is left.
7. Knowledge is knowing a tomato is a fruit.. Wisdom is not putting it in a fruit salad.
8. To steal ideas from one person is plagiarism. To steal from many is research.
9. In filling out an application, where it says, 'In case of emergency, Notify: ' I put 'DOCTOR '.
10. Women will never be equal to men until they can walk down the street with a bald head and a beer gut, and still think they are sexy.
11. You do not need a parachute to skydive. You only need a parachute to skydive twice.
12. I used to be indecisive. Now I'm not so sure..
13. I 'm supposed to respect my elders, but it's getting harder and harder for me to find one now.

**Department of Work and Pensions. Open consultation**

Personal Independence Payment (PIP) assessment: second independent review call for evidence Summary We are seeking evidence about how the Personal Independent Payment [PIP] assessment process is working.

Consultation closes 5.00pm 16th September 2016 - 17 page document.

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/536899/pip-second-independent-review-call-for-evidence.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/536899/pip-second-independent-review-call-for-evidence.pdf)

**WE'RE  
STILL  
HERE!**

**October 9-15, 2016**  
**[www.post-polio.org](http://www.post-polio.org)**



**15th August 2016.****West and Central Africa: Weekly Regional Humanitarian Snapshot (9 to 15 August 2016) | UN Office for the Coordination of Humanitarian Affairs via ReliefWeb.****BURKINA FASO** - 26,000 Affected by Floods.**CENTRAL AFRICAN REPUBLIC** - 15 killed in Cholera Outbreak.**NIGER** - Floods kill 14 and leave 46,000 homeless.**NIGERIA - FIRST POLIO CASES REPORTED.**

Since 2014: On 10 August, two cases of polio were confirmed in Gwoza, Borno State, and a third case was reported in the Muna Garage IDP settlement. The cases involve IDP children who lived in Boko Haram-controlled areas for more than three years without access to polio vaccination campaigns. Genetic sequencing of the viruses suggests that the new cases are closely linked to a wild poliovirus strain last detected in Borno in 2011. Partners have deployed medical teams in both locations, and called for a massive vaccination campaign at strategic entry points to Maidugan to prevent further spread of the disease. The Government is planning to roll out emergency polio vaccinations starting late August, including in neighbouring countries with a focus on the Lake Chad region and northern Cameroon.

**DR CONGO** - 42 Killed in Beni in the east (attack by armed group of Ugandan origin)<http://reliefweb.int/report/burkina-faso/west-and-central-africa-weekly-regional-humanitarian-snapshot-9-15-august-2016>**Published online August 16 2016 - pay to view full text.****The effects of a home-based ergometry exercise programme on physical fitness, fatigue and activity in Polio Survivors: A randomised controlled trial | Clinical Rehabilitation****Abstract****Objective:** To investigate the effect of an eight-week home-based ergometry aerobic exercise program on physical fitness, fatigue, activity and quality of life in Polio Survivors.**Design:** An assessor blinded randomised controlled trial. Setting: home-based exercise.**Subjects:** Fifty-five Polio survivors randomised to exercise or control groups.**Intervention:** Home-based arm ergometry at an intensity of 50% - 70% maximum heart rate, compared with usual physiotherapy care.**Main measures:** The Six-minute Arm Test, Fatigue Severity Scale, Physical Activity Scale for individuals with Physical Disabilities and SF=36. Assessments were completed at baseline and at eight weeks.**Results:** There was no significant difference in the primary outcome, exercising heart rate during the Six-Minute Arm Test, between the groups at follow-up [97.6 (SD10.1) compared to 102.4 (SD13.7) beats per minute ( $P=0.20$ )]. Blood pressure was significantly lower in the intervention group at follow-up (systolic blood pressure 132(18.6) mmHg compared to 144.1(14.6)mmHg ( $P=0.002$ )). There were no between group differences in the Fatigue Severity scale ( $P=0.25$ ) or Physical Activity Scale for individuals with Physical Disabilities ( $P=0.49$ ), with a small difference in SF36 physical component score ( $P=0.04$ )**Conclusions:** This home-based arm ergometry programme successfully facilitated aerobic exercise in Polio Survivors, but did not result in a significant change in physical fitness, measured by the Six-minute Arm Test.Contact: Deirdre Murray, Physiotherapy Department, Beaumont Hospital, Beaumont, Dublin 9, Ireland.  
Email: [deirdremurray@beaumont.ie](mailto:deirdremurray@beaumont.ie)<http://cre.sagepub.com/content/early/2016/08/12/0269215516661225.abstract?rss=1>



## **POST POLIO SYNDROME EXISTS**

**Colleges of Medicine** please add more facts to your lectures on the Polio Virus and the effects that it could have had on our bodies. Ensure health professionals understand how varied our nerve damage, our recovery and stable years have been. The majority of us recovered that well that externally we do not look like those photos in the old medical books. That there is a massive overlap of symptoms with other neuromuscular conditions. Tell them about **Post Polio Syndrome** and give them links to where they can find more information. Thankyou.

**The most accepted articles we have found by NHS professionals are:-**

### **PatientPlus article POST-POLIO SYNDROME**

**Written by U.K. Doctors for Doctors**

**<http://patient.info/doctor/post-polio-syndrome>**

**And in case you need an anaesthetic  
an excellent leaflet translated into English  
now used by many PPS Groups around the world.**

### **POLIO PATIENTS AND SURGERY.**

**Information for health staff.**

**Lise Kay, MD, Surgeon PTU – Danish Society of Polio and Accident Victims**

**[http://www.ptu.dk/fileadmin/FILER/PDF/ISSUU\\_PDF/BROCHURER/  
Polio\\_operation\\_ENG.pdf](http://www.ptu.dk/fileadmin/FILER/PDF/ISSUU_PDF/BROCHURER/Polio_operation_ENG.pdf)**

**Text copies of both have been sent to members and are available on our Website link on front page**

## **REMINDER FOR MEMBERS**

**Have you changed your home, email address or phone number recently?  
Did you let us know?**

**Your Newsletter needs your stories, hints, tips and bits**

**A way of doing something, or aid, that helps you might help someone else. Tell us.**

**How about a recipe that tastes great on the lips but not on the hips.**

**CARERS - Are you a Carer and would like to write and tell us how we might help  
Carers understand what you go through helping us manage our lives.**

**Articles and items for Post Polio Matters**

**are always welcome, by post, by email and by phone if writing is not easy for you.**

**Deadline date for next issue is 1st October 2016**

## **Editors Note:-**

**Articles from Polio Survivors and Health Professionals  
Welcome for future issues**



# Management Committee [Trustees] and Operations Team

## Management Committee [Trustees]

Chair - Simon Parritt - [simon.parritt@poliosurvivorsnetwork.org.uk](mailto:simon.parritt@poliosurvivorsnetwork.org.uk)

Secretary, Membership & Email enquiries - Dorothy [Dot] Ives - [dot.ives@poliosurvivorsnetwork.org.uk](mailto:dot.ives@poliosurvivorsnetwork.org.uk)

Treasurer - Margaret Marris - [margaret.marris@poliosurvivorsnetwork.org.uk](mailto:margaret.marris@poliosurvivorsnetwork.org.uk)

Newsletter Editor - Hilary Boone - [hilary.boone@poliosurvivorsnetwork.org.uk](mailto:hilary.boone@poliosurvivorsnetwork.org.uk)

## Operations Team

Phone Enquiries - Hilary Boone - [info@poliosurvivorsnetwork.org.uk](mailto:info@poliosurvivorsnetwork.org.uk)

Printing and Website - Elpeeko Ltd, Lincoln.

➡ Please contact us if you would like to help with our work ⬅

## Membership

**Full membership** includes voting rights and is available to polio survivors, their partners, families and friends.

**Associate membership**, no voting rights, is available to patient organisations, health and social care professionals working in the interests of polio survivors £10.00 per year

### Membership Fees

UK Individual - £ 12.50 per year

Associate Membership - £ 10.00 per year

Yearly fees can be paid by Standing Order.

Life membership - £ 150.00 or pay by Standing Order £ 5.00 x 30 mo.

We welcome members living in other countries and details will be sent upon request.

Please note the majority of information will be sent via the Internet.

Email:- [membership@poliosurvivorsnetwork.org.uk](mailto:membership@poliosurvivorsnetwork.org.uk)



All Forms are available on our Website,  
by phoning our helpline or writing to us.  
<http://www.poliosurvivorsnetwork.org.uk/>

*giftaid it*

## Donations

Donations, small or large, towards our work will always be gratefully received.

**SEE BACK PAGE - Val Scrivener is making and selling brilliant photo greetings cards**

- Some members send us a few postage stamps
- Some members take their newsletter via the internet saving us printing and posting costs.
  - Others add a donation amount to their yearly cheque, or Standing Order amount.
- Some members send us a donation with some specifying, e.g. for AGM, for Conference. Fund
  - UK Taxpayers can Gift Aid their subscription and donated amounts.

### NEW CONFERENCE & MEETING FUND

To support attendance at National Meetings and PPS Conferences

**The Gift Aid scheme.** Charities can reclaim an extra 25% in tax on every eligible donation by a UK taxpayer. This 'transitional relief' does not affect your personal tax position. You must pay tax at least equal to the amount reclaimed on your donations in the current tax year.

If you pay tax at the higher rate, you can reclaim tax relief on your gross donation at 20% (i.e. the difference between the higher rate of tax at 40% and the basic rate at 20%).

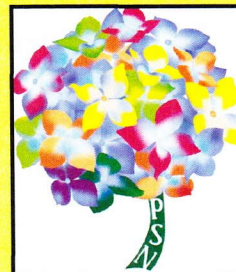


# Polio Survivors Network

Lincolnshire Post Polio Network - Registered Charity No. 1064177

Website - [www.poliosurvivorsnetwork.org.uk](http://www.poliosurvivorsnetwork.org.uk)

Email - [info@poliosurvivorsnetwork.org.uk](mailto:info@poliosurvivorsnetwork.org.uk)



**POST POLIO MATTERS** because **WE'RE STILL HERE!**  
[www.post-polio.org](http://www.post-polio.org)

**See page 5. Philip Taylor - The Cordwainer** - Responded to Janet - I was at Treloars on and off for around 10 years from 1956 onwards. I lived in Alton then so it was quite handy. I hope you have managed OK since. To be honest I have little recollection of it other than being lonely, but it did get me up and mobile so in that way I am grateful for all they helped me with including training me to be a shoemaker. I made shoes for Hilary and her husband around 10 years ago.

## **The Cordwainer. Bespoke and Orthopaedic Shoemaker.**

The Cordwainer manufactures specialist boots and shoes for people with complex foot problems, and we work with both private and NHS Clients. I have been a member of the British Polio Fellowship's Orthotics Expert Panel since 2008 as well as organised the 2005 and 2010 Independent Shoemakers Conferences. I also worked with Leeds University to organise a Patient Led Initiative conference in 2011 to look at the provision of footwear within the National Health Service. I am now an active member of the Orthotics Campaign which hopes to work with the NHS to improve the provision of orthotics for all us

Unit 8 Brough Business Centre, Bradwell, Derbyshire, S33 9HG. Tel: 01433 621623  
[thecordwainer@hotmail.co.uk](mailto:thecordwainer@hotmail.co.uk)

Gallery - photos of some of his work. <http://thecordwainer.co.uk/gallery-2/>



## © PHOTO CARDS by MEMBER VAL SCRIVENER

Sold in aid of **POLIO SURVIVORS NETWORK**

**Pack of 5 - £3.95 inc. P & P.**

Order by writing to PSN [Samples on every newsletter]

Emailing [johnval.scrivener412@btinternet.com](mailto:johnval.scrivener412@btinternet.com)

Or ring Val Direct on 01234 346 397

