

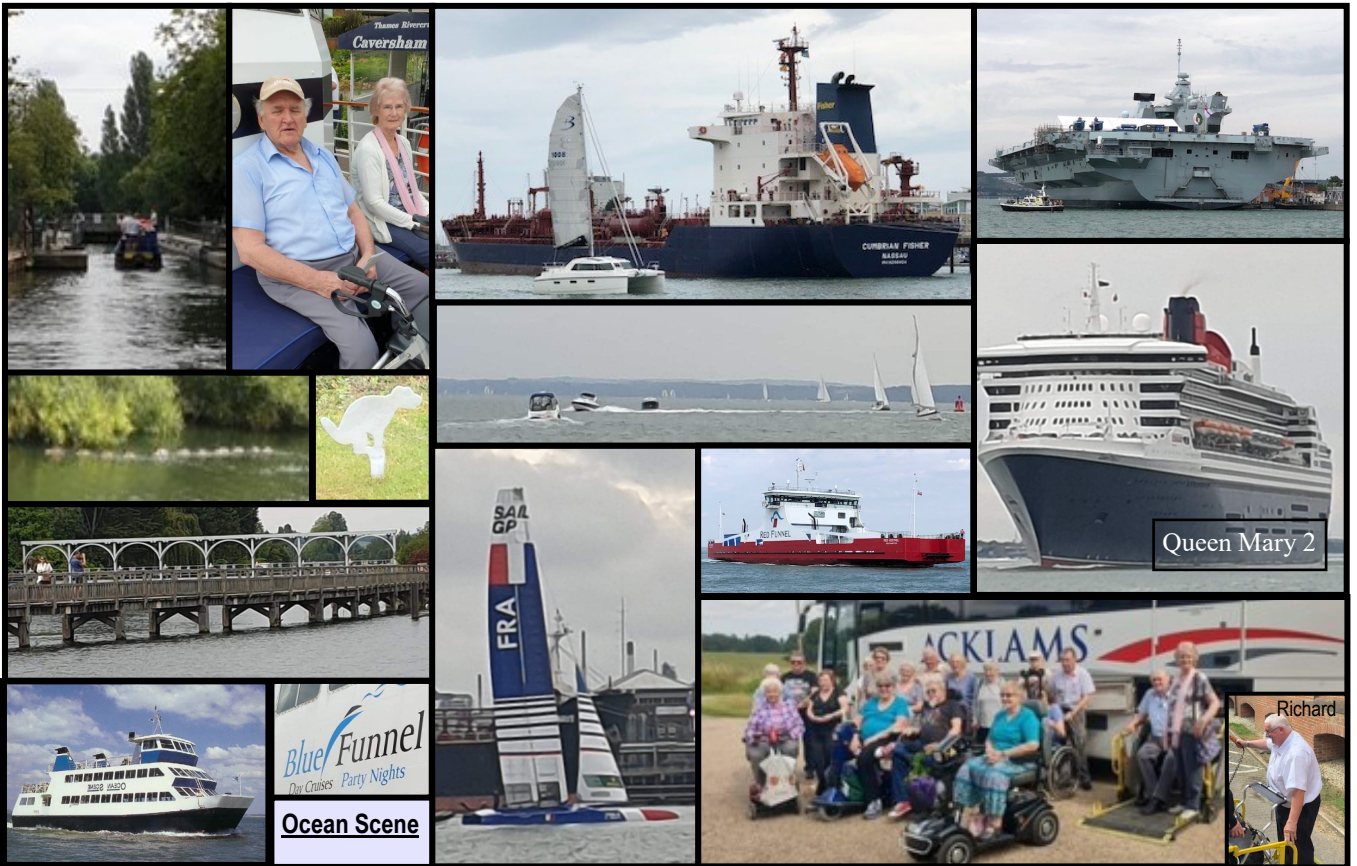


POST POLIO MATTERS

Polio Survivors Network Newsletter
AUGUST 2019 Vol 10 of 12, Issue 106
n.b. Volumes 1 to 6 published under the name LincPIN

BE WISE

POLIO SURVIVORS IS IT TIME
TO TELL IT LIKE IT REALLY IS?



Enter 100+ articles

Some photos from the trip organised by member Mick Harper, also Chair of the BPF Lincolnshire Branch and East Midlands Region.

Photos from the cruise on the River Thames from Reading to Henley-on-Thames and the next day from Southampton Docks to West Cowes on the Isle of Wight, to Portsmouth Docks and back again on the Blue Funnel Ocean Scene.

Polio Survivors Network is the working name of Registered Charity 1064177, The Lincolnshire Post-Polio Network

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QUICK NOTES

- ⇒ The Trustees Annual Report 2018 and Minutes of the Annual General Meeting 2019 are included as separate documents with your newsletter whether by post or by email.
- ⇒ A correction was required for an article appearing in the October 2018 Newsletter. It was entitled 'Therapeutic cannabis and the Post Poliomyelitis Syndrome (PPS)' article by Dr Peter Brauer. This is again enclosed with your newsletter or attached to your email. Our apologies have been passed to Dr. Brauer for this error.
- ⇒ Please also find enclosed (or attached to your email) a very interesting article by Dr Peter Brauer Common Misconceptions Concerning the Post-Polio Syndrome to add to your database of information. See note below regarding all publications in our newsletters. We would be interested to hear your comments.

The Polio Survivors of Australia website is another great resource:

<https://www.poliohealth.org.au/research-categories/>

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.

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Editorial by Hilary Boone

The daily temperatures have been up and down like a yoyo. 38 degrees for a few days in July [nearly the hottest recorded in the UK] and now it is August and around 20 for the week. Thunder storms, flooding and the awful worry the folks in Whalley Bridge had having to move out until the damaged dam was declared safe.

Mick Harper, Chair of Lincoln and East Midlands British Polio Fellowship group [and PSN member] has been chartering a boat from Southampton Docks for a day's cruise to raise money for charities in that area for over 20 years now. Since moving to Lincolnshire he has also arranged a coach to take local folks to the area for a long weekend. Richard and I decided, even though it was a lot to manage in four days, that this year we would join. Along with dual member Caroline Gordon Wilson we were picked up by wheelchair accessible coach in the bus stop layby near our home. Off we set via south Lincoln to pick up John and then via Leicester and Northampton to the Hilton Doubletree Hotel at Reading. Saturday saw us cruising through many locks on the River Thames to Henley-on-Thames and Sunday, Richard our excellent coach driver, drove us to Southampton Docks where we boarded the Ocean Scene for a long trip to West Cowes on the Isle of Wight and then Portsmouth Docks and back. We saw so many different vessels including other ferries, cruise ships, military ships, HMS Warrior, HMS Victory, canoes, power boats, yachts including one that flew and best of all the Queen Mary 2 passed us en route for seven nights in the Fjords with 'hello' sirens passing between our two vessels. Next day home on the coach, totally exhausted but it was fun. Some photos on back page.

However, there were consequences of using up too much of the daily allowance of energy tokens [10 a day, 70 a week] on those four days. The first two days at home were spent snoozing in the riser recliner almost all day except for getting the already prepared meals from the fridge and eaten. The next two days we managed a little more and by the weekend were back to ten tokens a day. For me there was another consequence. When visiting our Neurofunctional Chiropractor, Dr. Darren Barnes-Heath I said I was having "a little problem with my left arm, just biceps area". I then continued without realising to say "and shoulder and elbow and below the first finger of my hand and taking paracetamol and using Bio-Freeze pain gel". Darren said 'So a bit more than just your biceps area then?' He started to assess my arms and upper body and asked 'So tell me how much and what did you overdo from normal on this trip?'

I thought about it and was surprised how much there was to tell about the extra strain on my arms and shoulders from having to push up to get my body over my knees to stand. Getting up from coach seats was not easy, a couple of times impossible so I crawled to the front of the coach to go down the steps sitting on my bottom. I worked a way to do it but not until the last day. Then there were all the disabled toilets with bowls and rails at different heights. Then the chairs in restaurants/cafés where, to start with, I transferred to a chair [too low and no arms] so decided it was best to stay on my scooter seat. Due to the deep tides and ramp angles on the Ocean Scene, Richard had to use his manual chair and I used my new rollator/wheelchair. I ended up having to sit on this as the other seats available were too low by a couple of inches for me.

Darren treated me and gave me some gentle exercises to do in our hot tub and the pain is less. Darren pointed out that I had not thought about the difference in walking/getting up wearing my two new blue Rocker orthoses and shoes compared to my old single AFO and trainers. When I get home my shoes feel like diving boots so I take them off and wear socks with rubber non slip bits as I prefer no shoe weight and being able to feel the floor. There is also an increase in height with my new orthoses and shoes so I am having to push myself a tiny bit further up to get my body over my knees to stand up. Doing this over and over again across four days meant my muscles were constantly used more than usual. I need to think about what other equipment I need to take on trips out to make life less painful. I need a booster seat [LOL] for seats that are too low and for toilets that are too low a toilet raiser. Maybe I can work out how to combine the two and make a zip on padded cover with handle for carrying [I will patent if it works] ☺ Any other ideas gratefully received.

Be Wise. Polio Survivors is it time to tell it like it really is? Read article on page 10. I would love to hear your views/comments to share in our next issue.

MESSAGE FROM OUR CHAIR

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

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Chair Polio Survivors Network

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Another Year Older

As I approach my 'three score years and ten' I am on that rollercoaster of weakening muscles and reduced function that PPS brings on so many of us, over and above what age does to all people. I have always known that this day would arrive, unlike I suspect, many of you who probably bought the myth of 'normal' future life into old age. I recall some 20 years ago travelling to an exhibition at the V&A in London, travelling on my own, no wheelchair, no aids and no freedom pass. I remember thinking at the time, I must enjoy this as it may not last and this could be the last time I am this independent.

This weekend I spent my birthday with my wife, Alexa, staying in London and, amongst other events, again went to the V&A to see the renaissance rooms, which by the way were a delight and a taste of Italy and one of my favourite cities, Florence. It struck me how different it was this time, I am now mostly a wheelchair user, I have to check access, use accessible taxis, indeed even dropping in for a coffee or a meal somewhere I am confronted with endless barriers, both physical and attitudinal. I won't go into the state of the pavements, particularly off the main streets and the poor state of so called dropped curbs the whole experience is bone shaking.

Service with a Smile ... or not?

All the above is of course par for the course as a disabled person, but there is another aspect that is particularly annoying. That is the attitude to my wife, who I rely on for so much of my access to living an inclusive life. I wonder if others meet this problem also. On the rare occasions that I travel alone, at least some people and officials help with cases, or moving me up difficult areas or other physical barriers. However, if I am with my wife, I am left to get on with it, or rather she is. Maybe there is an assumption that she is my paid PA or carer and so no one needs to offer any help to her, or me! It is all her 'JOB'. This extends to taxi drivers booked for disabled access, hotel staff, restaurants, etc. At airports she is often left struggling with the cases and dealing with me, or they offer to push me whilst my diminutive wife is left carrying my breathing equipment and several bags and cases like some pack horse. It does nothing to enable me to feel included and live a good life if my partner is treated as some kind of slave.

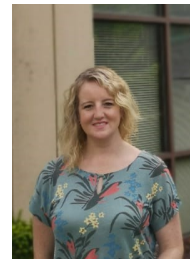
Access versus Attitude

Sadly, this maybe more true of the UK as my experience in Italy and Spain is different in general. In many countries access facilities may not be so good, and there might even be an older charity attitude of 'poor you'. However, it does mean that everyday people are more actively willing to just help. 'There but for the grace of God go I' may have some part of this different culture. I also wonder if this reveals an attitude in the UK of unconscious jealousy or irritation with us. The state gives you all these benefits and access to parking and special help, so we don't have to help on a personal day to day basis.

Have we thrown out the baby with the bath water when we think we can subcontract and professionalise compassion and care, and in doing so abdicate our humanity.

TONI DUNLOP - YOUR NEW ADMINISTRATION OFFICER

As some of you may already know, my name is Toni Dunlop and I have been appointed as an Administrator (part time) for Polio Survivors Network. I have also been appointed as Administrator and Coordinator for the Lincolnshire Neurological Alliance (part time) which certainly meshes well with this role as it is an umbrella organisation for individuals and support groups of people with neurological conditions.



Firstly I would like to thank you very much for having me here. I will be completely honest with you all – I didn't know post polio syndrome existed until earlier this year when I was researching the condition for my interview. I guess I am typical of many (including professionals) that you have no doubt all come in to contact with over the years. I am keen to learn more about the challenges and successes that polio survivors face.

In the short time I have been with Polio Survivors Network I have been constantly amazed at the resilience that polio survivors show day to day. I am also distressed by some of the situations I have heard and seen that some of you face due to lack of support or service from professional organisations – you are already dealing with so much and this unnecessary stress does not help anyone. I've also been heartened by the sense of humour many of you display and the 'not going to let anything stop me' attitude that keeps you fighting another day. I am full of admiration of the resilience you continue to show.

Before working for Polio Survivors Network I worked in the NHS (at United Lincolnshire Hospitals NHS Trust) for around 10 years. Working in complaints was my first NHS role which was both challenging, distressing at times and very rewarding. Building up a rapport with patients and their families was very important to me and I received thank you cards for my efforts even when a satisfying resolution for the patient or family wasn't always possible. This role gave me a real insight into the ripple effects of poor communication, cancelled appointments and poor attitude of staff. Oftentimes patients were desperate just to ensure their experience wasn't repeated, that no one else would go through what they did.

After a while I was asked to move to risk management as the incident officer. This was a role which included the investigation of never events and serious incidents. My people skills and tact were certainly enhanced during this time! I was then promoted to system administrator and later left this role to work at a local university in the digital services team where I enhanced my technological skills - it was great to be working with students too. Prior to working in the NHS I worked in a civilian role for the police force. I was part of the CRB (now DBS) disclosure team. It was a fascinating role and I quickly had to become very familiar with data protection and red tape!

I am a family lady with a huge weak spot for anything Italian! I fell in love with Tuscany when I went on my honeymoon in 2001. La dolce vita! I'm a complete foodie and love to cook, new cuisines and cultures fascinate me.

I certainly hope that I can use my skills and enthusiasm to support you and the Polio Survivors Network in the coming months. I look forward to getting to know you. Please feel free to drop me an email to psnadmin@poliosurvivorsnetwork.org.uk

PLEASE SHARE EXPERIENCES OF YOUR POLIO LIFE

Tell us about the solutions you have found that work for you

Tell us about the issues you have managing your post-polio life

Help us build a larger database of possible solutions to publish in our newsletter

NEXT ISSUE - Deadline October 14th 2019

Osteoporosis and Post Polio Syndrome

By Zsuzsanna Snarey

Most of us who had polio when we were young are now having problems with mobility. As we get older and walk less and less, our bones begin to get weaker and more porous because bones need to be stressed by carrying weight to keep their strength. Those who walk less are more at risk of falling and breaking a bone. This is not a trivial matter. If you break your "good" hip or fracture an arm that you depend on to assist in walking with sticks, crutches, or to propel a wheelchair, or for transferring, it makes a tremendous impact on your lives and your independence. It is important to get persistent spinal pain checked out because it could be a sign of a vertebral fracture and if that is the case, you do want to get the opinion of a professional.

Bones are made mainly of calcium which is found in milk, cheese, and green vegetables, almonds, sesame seeds, sardines, dried fruit, pulses, tofu and fortified foods but in order to be absorbed successfully vitamin D is also needed. This is made in the skin and a sufficient amount of vitamin D can be gained by exposing face and hands to sunlight for just 15 minutes a day. It also can be found in oily fish, like herring, salmon and mackerel and also in eggs. 1000 to 1500 mg of calcium is recommended together with 400 to 800 units of vitamin D. The female hormone oestrogen also protects the bones but it declines after the menopause resulting in loss of bone density. This can show in loss of height and a dowagers hump. Hormone replacement for women (oestrogen with or without progesterone) can slow bone loss, preserve bone strength, and decrease fractures by approximately 50%. Unfortunately, it is not available for women who have had breast or uterine cancer. A new drug, Raloxifene (Evista), can be used for women who have had breast or uterine cancer or for those at high risk for these forms of cancer. Women are more at risk for osteoporosis than men.

It is important to ask your doctor for a Dexa scan to establish the health and strength of your bones. If your bone density is less than it should be you could have osteopenia or if it is more serious osteoporosis. The results indicating a risk of fracture are expressed as a T-score in negative numbers (comparing it to a healthy young person) and a Z-score (comparing it to an average person of the same age). T score of -1 to -2.5 is osteopenia; T score of -2.5 or less represents osteoporosis. Bone strengthening medication should be prescribed together with calcium tablets combined with vitamin D such as AdCal. The most commonly prescribed medication is Alendronic Acid, taken once a week with a large glass of water half an hour before breakfast. It is important to stay upright and not lie down in bed afterwards. An alternative is Zolendronic acid by infusion once a year. There are other newer treatments also available.

You could ask your doctor about a referral to a physiotherapist for **'gait training' and 'fall prevention'**. Every day try and spend a few minutes on balance exercises at home. If you do not fall you are less likely to suffer a fracture, but for many of us falling is a fact of life. It is a good idea to stand up for a few minutes every half hour and not sit for too long in front of the TV or the computer. Tai Chi is excellent for improving balance and bone strength but not an option for the less able. Exercise is definitely an area that should require input from a polio specialist who understands PPS, so you do not overuse or overstress extremities that have already been weakened by polio. Single action manual testing can miss the fact that you can only repeat the action a few times or hold the action for a few seconds before the muscles weaken. Correct assessment is essential so that you do not overuse or overstress muscles already weakened by polio. Exercises can be done to your level of activity by stopping before pain and fatigue sets in and then resting to allow the muscles to recover. However, you may have unaffected or stronger muscles that can be safely used for exercise.

Editors Note: 'gait training' and 'fall prevention'

Referring to the article about how we do our actions of daily living. Please ensure that you tell any therapist advising you how you walk, get up from dining chairs, the floor etc, demonstrating if possible. Many times polio survivors have experienced being told they are not doing the action the proper way, e.g. falls adviser at a major health event and a therapist at a neuro condition meeting demonstrating to me this is the way you should be getting up from the floor.' Finding it difficult to understand when I explained that I have polio damaged muscles that will not allow me to do it that way. I had to demonstrate before I was believed.

Anne Wood (25.02.1945 - 18.04.2019)

Long-time member of the British Polio Fellowship and the Lincolnshire Post-Polio Network [renamed Polio Survivors Network some years ago], Anne Wood, passed away unexpectedly at home at Easter. She was a multi-talented lady, but what follows is mainly taken from an autobiographical account that Anne wrote in 2011 about her burning passion in life – singing.

Anne started singing at school when she learned the descant and tenor recorder and piano and joined the madrigal group, before studying GCE O level music. Music and singing continued to play a large part in her life for the next fifty plus years, including teaching piano and recorder. When she left school, she and a friend produced a couple of variety shows in aid of charity, with acts including dancers, a harmonica player and an accordion band. She also recalled a young ventriloquist named Keith Harris auditioning for one of their shows with Orville the Duck.

Meeting guitarist and singer, Malcolm, at a musical party, they married a year later. They joined Southwick Operatic Society and formed a harmony folk trio, Timbrey Fayre, with a fellow guitarist and singer. Anne added to the musical mix with a small piano accordion, tambourine, maracas, bamboo pipe and recorder. Weekly rehearsals into the small hours were fortified with coffee, beer, laughter and fun. They arranged all their songs in 3 parts and wrote a few numbers of their own.



Timbrey Fayre entered and won the Worthing Talent Contest. Well known band leader, Ken Lyon, offered them a spot on the weekly variety show “Tuesday at the Dome” in Brighton. Anne found it daunting to sing in a 2,000 seat theatre, but enjoyed it nonetheless. Over a number of years they did paid gigs at Masonic dinner dances, clubs, parties and shows. Timbrey Fayre recorded 3 programmes for Radio Brighton, and joined the Radio Brighton team for the Local Radio Station’s Talent Contest in Manchester, judged by comic, Mike Yarwood, and tenor, Bruce Trent, and broadcast on Radios 1 and 2. Radio Brighton also asked them to record a Boxing Day concert with popular singer Jake Thackray and local folk singer Miles Wooto.

Anne was a founder member of Shoreham Light Opera Company, their first production being an opera “Perseus and Andromeda”, written by and starring Patrick Moore, the astronomer. Anne played the soprano lead, Princess Zara, in “Utopia Ltd” by Gilbert and Sullivan, soprano lead, Fiona, in “Brigadoon”, and several other roles. Anne mostly gave up stage work after this, partly because she was looking after her young daughter, but also because she found herself getting too tired to tread the boards. She enjoyed many more years of singing via Shoreham Oratorio Choir, Brighton Consort, and Portslade Community Choir, including trips abroad to perform.

By now, Anne had been diagnosed with Post-Polio Syndrome and was walking with sticks. Sadly, by 2011 PPS finally claimed Anne’s angelic voice and she had to say goodbye to her days as a soloist, moving into the chorus. She was able to enjoy singing holidays in Taunton and Marlborough until she started to need her electric wheelchair. After that she sang with the Shoreham Singers-by-Sea, run by jazz musician, Herbie Flowers, for a few more years before retiring completely.

Anne leaves behind daughter, Becky, and granddaughters, Isobel aged 5 and Grace aged 1. A brave and compassionate lady, she leaves a gaping void within her family.

Editors Note: Anne was a member from the very early years of our Charity. She was also a member of some of the Post Polio Support Groups via Facebook and you only have to look at the sympathy messages to see how many polio survivors across the world she knew. She would keep us all updated with how she and her family were. Would tell us about medical appointments and somehow, even though some of the issues were serious and should not be happening, manage to make us laugh about those ‘not so useful ones’. She was always one of the first to reply with a supporting message to anyone having their own issues. Her family’s favourite picture of Anne is on the back page.

ASPECTS of MUSCLE COMPENSATORY PROCESSES and PHYSICAL ACTIVITY in the Survivors of Polio.

Gunnar Grimby, Professor of Rehabilitation Medicine, Goteborg University, Goteborg, Sweden

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[now known as Post-Polio Health International] St. Louis, Missouri, USA

POLIO NETWORK NEWS - Winter 2000, Vol 16. 1

N.B. Readers please note the date about polio muscles as a lead into pages 11 to 16.

With the increasing understanding of the factors causing new symptoms in polio survivors comes an increasing awareness of the benefits and risks of physical exercise and training. Some training studies have been reported lately in the literature that can be of help in recommending appropriate training regimes. An important aspect is that different muscles in different persons can be very differently affected by polio: some may be atrophied to the point where no exercise or training is possible; some may be moderately weak but in an unstable state showing progressive weakness and a risk for overuse; others may be moderately weak but stable to where some training might be of value; and in some muscles, compensation by re-innervation has resulted in "nearly normal" or "normal" muscle function, but there might be risk for disuse. It is, thus, important to individualize the training advice, not only among individuals but also for different muscle groups of a particular individual.

In practice, this is a great challenge to the physiotherapist, and other professionals who design the training programs, and requires a detailed analysis of the muscle function both with clinical testing and laboratory investigation using dynamometer measurements and electromyography. Our experience is that by having detailed information, the polio survivor has a better opportunity to adopt a daily physical activity pattern that provides the appropriate amount and type of exercise but without overuse and fatigue.

Does too much Daily Physical Activity and Exercise Training cause Acute and/or Persistent Damage of Polio-Affected Muscles.

To answer this question, detailed knowledge about the compensatory processes in the polio-affected muscles is necessary. Compensation occurs through re-innervation by adjacent nerve fibers to muscle fibers (muscle cells), which have lost their innervation by the death of nerve cells in the acute polio phase as well as later on. The polio-affected muscles otherwise would have atrophied. This compensatory mechanism seems to be very powerful: a nerve cell can re-innervate 4-5 times the normal number of muscle fibers and, in extreme cases, even more than 10 times. The other compensatory mechanism is hypertrophy of the muscle fibers, most likely caused by extreme use of the weak muscle that is still strong enough to be used in daily activities. Even to rise from a chair or walk on a flat surface may give a near maximal load and by that be a stimulus for increase in size of muscle fibers, but not in number, just as in very heavy resistance training. Muscle fibers may then reach a size double or three times the normal size. Thus, whereas physical activity does not seem to be a prerequisite for reinnervation, it is for the increase of muscle fiber size.

Is there a Danger in Having Large Motor Units (that is, too many muscle fibers innervated from the same nerve cell) and too Large Muscle Fibers?

Our recent follow-up studies over eight years (Grimby et al, 1998) indicate that very large motor units, more than 20 times normal, with around 10 times the normal number of muscle fibers, may have problems. Either they may lose some of their muscle fibers and thin out due to defective neuromuscular connections, or they may just die easier. We have no systematic information available whether physical activity and overuse could bring about such a loss of muscle fibers or nerve cells. A defective neuromuscular transmission can be identified in some motor units, but we have not found in our studies an indication that this is a major factor for muscle weakness. Whether it can contribute to muscle fatigue is still under debate. The other compensatory mechanism - hypertrophy (increase in size) of muscle fibers - has a positive effect on the maintenance of strength, but it could be a negative for endurance, as capillarization and the aerobic metabolic system of the muscle cell (mitochondria) do not increase in response to the increase in size. Indeed, such large muscle fibers may be less resistant to overuse.

We know, in fact, very little about the risk of overuse causing persistent muscle damage. What we know now is the risk for long-lasting fatigue after too strenuous exercise in polio affected muscles. They need a longer recovery period than "normal" muscles, which must be taken into account when designing training programs and adjusting daily activities. In training studies, we have the experience that with long enough rest periods, which could be days or weeks after a too strenuous bout of exercise (Agre et al, 1998), full

recovery will occur. Thus, there is a risk for overuse but, with proper attention to the fatiguing symptoms, the function will recover after the exertion. The risk occurs when the polio survivor does not rest enough, and his/her muscles remain in a constant condition of overload, with its negative effects on function. Although this is not easy to prove scientifically and experimental studies would be unethical, we must rely on a successive collection of data to understand the balance between the pros and cons of physical activity. My personal view is that an approach of trial and error under professional monitoring will yield in practical terms what is a beneficial level of physical activity and what could be deleterious for a specific individual.

The Literature now Documents a Number of Training Studies.

Of prime importance is separating resistance from endurance training programs. A person with weak muscles may use them close to their maximum only for a short period of time, e.g., climbing stairs. Thus, there will be no time for adaptation to endurance. By reducing the intensity, such as walking slower and taking short breaks for other types of activity, both resistance and endurance training at an appropriate level may be achieved. Another way is to choose a medium where the load can be more individualized between muscle groups as in pool training. In a study with a control group at our polio clinic, increased general endurance and less pain in daily life was demonstrated in the group with pool training compared to the group that received advice about their physical activity. There was no deterioration of function after the pool training (Willen et al, 1999). Other training studies indicate the possibility of improving the general endurance of polio persons by using individual training programs, as on a bicycle ergometer, or group training on the floor with combined endurance and submaximal resistance training with music (Emstoff et al, 1996). In general, it would be of value to encourage endurance types of programs with proper intensity and the possibility of individualizing the load as in pool training, giving proper time for rest between the exercises. The role of resistance training for polio muscles is more controversial. However, short-term resistance training at high or maximal intensity has been demonstrated to give an increase of muscle strength in moderately affected muscles, measuring more than 3 on the manual muscle testing scale (Einarsson, 1991). Such an increase in strength seems to be maintained, probably by adaptation of the physical activity level in daily life, and could be beneficial and allow a broader type of exercises with relatively less effort. Such a program did not result in any negative effects or evidence of muscle damage when properly supervised. Also low intensity strength training can improve muscle performance and reduce the experience of fatigue. There was no change in serum creatine kinase after a 12-week muscle-strengthening program, which would have indicated muscle damage (Agre et al, 1997).

To Learn the Appropriate Level of Physical Activity to Avoid Unnecessary Overload on the One Hand and Disuse on the Other is Important for Maintaining Optimal Physical Function in Polio-Affected Muscles.

As important is to avoid pain, it being both a limiting factor for physical performance and an indication of overload that could be on muscles as well as joints and other tissue structures. The experience of pain is evidently closely related to physical activity. Individuals who spontaneously chose a walking speed close to their maximum speed were more prone to experience pain in their daily life (Willen et al, 1998). The results of that study indicated also that those who were less affected by muscle weakness experienced more pain than individuals with weaker muscles, and they might, thus, have a pattern of daily activity that was too strenuous. Advice and adaptation of the daily physical activity to avoid pain is an important feature in the post polio management.

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How you found staying strong all the time is difficult especially when you are dealing with the many different organisations and departments whilst trying to manage your Post-Polio lives?



The Postman delivers you a letter and you are happy



Then you see that it is yet another form to fill in from yet another department asking many of the same questions....

I have helped many Polio Survivors and their families who have written/rung/emailed over 23 years. Richard and I have been having more and more issues over many months now. It is not easy sharing the following with all readers but I am doing this in the hope that it will help others.

31 years ago I started to have unexplained new symptoms of weakness and functional decline that seven years later turned out to be Post Polio Syndrome. It was not long before I started having to complete forms to obtain benefits etc. Seeing it in black and white was not easy.

Whilst we fully appreciate we have to complete forms. There are so many. Forms for benefits DLA/PIP, ESA, Blue Badges, council tax band reduction for disability, bin collection from where you keep them. Social Services and NHS Assessment forms to see if you qualify for any help. Financial assessment forms, carer's assessment forms, maybe you need changes to your bathroom so more folks visit and Disabled Facility Grant forms, etc., all in 'official speak'

On Friday 26th July 2019 I received an email mentioning that the day before I had not been 'on par' at an event and it triggered me to sit back and think. They were right I had not been my normal self at that meeting. I was embarrassed and felt awful that I let myself down but why? Then it dawned on me... I had reached lower than rock bottom without realising it dealing with all this **** paperwork month after month and this was really a cry for help thankfully answered.

For 24 years now I have attended many meetings with the NHS/Social Services to discuss their new proposals and paperwork to provide the user/carer point of view that the government say must be obtained. It is not easy going from a job with salary and retirement plans to having to live on benefits and cope with disability. Volunteering is our way of saying thank you for our benefits.

I contacted a few of my peers who have also been giving up hours from their disabled lives for years taking part in these consultations and surveys. We did not want anyone else to go through the problems we had been going through and thought giving up our time would help improve services for all, users, carers and staff. Sadly we agreed that the procedures and forms that have to be completed have get worse and worse. The meaning of some paragraphs, rarely in plain English, are even misunderstood by some staff; take longer and longer to complete; adding unnecessary stress to our lives. A few years ago following one up and coming 'new change' it was agreed we could trial it before release. However, meetings just stopped and eventually we learned that the new system was live. Some of us had to sort out problems in the early days that might not have happened had we been given that promised trial. We reluctantly agreed that we have just been 'Box Tickers' so that the many organisations involved could 'tick the box' to say they had consulted. I now only go to meetings where there is a chance of a positive change.

Agency staff that come into our homes are often restricted in what they can do. To manage our lives well and get the most for the funds we are allocated many of us employ our own staff but have to register as an employer with the Inland Revenue complying with all the Employment, Equality, Health and Safety Laws etc. I am sure many will suggest we could use the CAB or an Agency to help with all this work. Sadly the information still needs providing by us and the final documents produced by staff/assessors etc., all have to be checked for errors. Our experience is that it does not save much time/stress in the long run.

Back to last Friday... I took a huge deep breath because I now realised that I needed to stop the downward spiral and tell 'them' collectively that my husband and I need to live our restricted ability disabled lives more reasonably. My peers agreed with me that assessments and requests for help/equipment/medical help do not have to be as complicated and long drawn out for us and

the staff involved. Changes are needed now and with all sides raising the issues they see and coming up with ways to reduce the stress and costs dealing with things that do not work well. Sadly as I go through this for final check I can report that in the last week another four page document with little more than an hour to respond.

As I see it the major problems for Polio Survivors seeking help are:-

1. **Polio Survivors.** Yes, us. We are such strong willed, determined, do not need any help thank you polio survivors because we have had to be for decades. We have gone to college, university, joined the forces, done all sort of physical jobs, brought up children, decorated, gardened, done all sorts of hobbies, sports, voluntary work. Tell us we could not do something and by heck we would prove to you that we could. When we start to have new difficulties we ignore them hoping they will go away. When we finally seek medical help and it is suggested that we do x, or start using y what do we answer 'Oh, I am not there yet'. This includes me. In my third year of finding PPS I was at a rehabilitation appointment when the doctor asked me 'Who wrote this article about pacing and resting and using equipment in your newsletter?' I proudly told him it was me. He then looked over his glasses and said 'Why are YOU not taking your own advice then?' What could I say!

2. **Colleges of Medicine** gradually reduced the number of facts that they taught their students about polio following the success of the 1955 vaccine with reduction in cases. Twenty years ago as LPPN we were told that for doctors polio was a half hour lecture with leprosy. Is that enough time for health professionals to learn about how the polio virus affected our nerves and muscles, how we recovered, how we used the muscles we were left with to perform actions of daily living? They are also rarely taught about the later stage of Polio following 10 to 50 years of recovery of new pain, fatigue, and functional decline most commonly called Post-Polio Syndrome.

Items, I believe, show this lack of teaching enough information on polio:

- [1996 to me by a Neurologist] "Post-Polio Syndrome does not exist, I just read an article". February 1996 BMJ article 'Study Throws Doubt on Post Polio', the results of the fifth year of the Mayo Clinic Study and....
- [2006] The Mayo Clinic Study went to 15 years in 2005 and my article '**Polio Survivors Throw Doubt on Study**' and '**The Mayo Clinic haunts post polio patients again** by Dr. Ruth Bridgens, '**Mune data review**' by Dr. Mavis Mathieson, '**Examining a Controversial PPS Publication** by Dr. M. Falconer and Prof E. Bollenbach and by Dr. Mary Westbrook '**Inaccurate Mayo Clinic News Release Threatens Polio Survivors' Wellbeing and Healthcare**'; all demonstrated that their results and conclusions were not consistent with the polio population as a whole as stated.
- [2000 Kent member] "Post Polio Syndrome, Oh I have just heard about this new disease" *The facts were first medically recorded in 1875 by Carriere, Raymond, & Cornil and Lepine!*
- [2009 A&E Lincoln] 'Have you come from a 3rd world country, we don't have polio in the UK'.

3. **Lack of understanding of how our polio damaged muscles work.** Most health professionals who do not regularly work with polio survivors often have no idea of the ways we use what muscle power we have to do what we can and what we call it.

3.1 A member was being got up for the first time following a female operation. She asked for her arm crutches to be passed to her and was told "you don't need them we will support you, it says here on your admission sheet that you said you could walk" . She replied " that is because since I recovered from waist down paralytic polio I have 'walked' by using my arm crutches and swinging my paralysed legs through. What else would you call that but walking?

3.2 A physio recently asked a member 'your medical records state you are fully mobile with your calliper & arm crutches if you can't move your legs then how can you walk?'

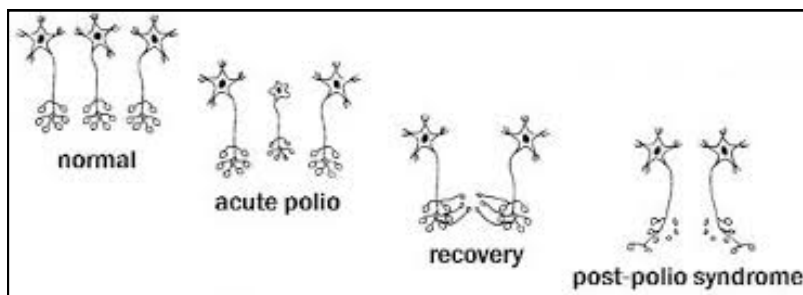
There appears no understanding that to '**walk**' when you are wearing calliper/s, using a cane, arm or elbow crutches that you either raise your shoulder or lean to one side to lift the leg on that side off the ground to swing it through, 'walking' with arms, shoulders and upper back muscles.

Picking something up from the floor whether wearing callipers or not if you cannot bend your legs without collapsing then you have no option but to bend at the waist to reach down and back up again using your upper body. I have had to do this for 67 years. How about you?

Muscles are attached to bones by tendons that help them move. When a muscle contracts [bunches up], it gets shorter and so pulls on the bone it is attached to. When a muscle relaxes, it goes back to its normal size. Muscles can only pull and cannot push. Therefore muscles have to work in pairs to move a joint. One muscle will contract and pull a joint one way and another muscle will contract and pull it the other. When you want to move, electrical impulses come from the brain, down the spinal cord and are transmitted through the **motor nerves to the muscles**.

The Polio Virus if it progresses through to the nervous system kills motor nerves. The greater number of motor nerves killed in a muscle the less ability of that muscle.

The following diagram is taken from a PSN Presentation slide titled Pathophysiology and Diagnosis of Post-Polio Syndrome by Daria A Trojan and Neil R. Cashman, Department of Neurology and Neurosurgery, Montreal Neurological Institute and Hospital, McGill University Montreal, Quebec, Canada.



Normal No damage

Acute Polio You can see the middle nerve is dying off.

Recovery Shows those nerves that did not die were able to grow axonally sprouted roots that took over some of the orphaned muscle fibres. As the nerve supply to the muscle increased then the ability of that muscle increased.

Post-Polio Syndrome Shows one possible explanation of new weakness in that those axonally sprouted roots are dying off thought to be from overuse. Less nerve supply less ability.

HOW DO YOU use your polio damaged muscles to perform actions of daily living?

Polio Survivors are all different. There is no set pattern. We have varied muscle ability from paralysed [no ability] through various stages of weakness to possibly never damaged. If one muscle does not work/work well, we 'ask' another nearby muscle to assist us to do it our way.

To explain... At 5 years of age I had waist down paralysis, recovered well and learned to walk again. I retained some weakness on my left side from hip to knee and right side from knee to toes. I said 'I had polio' [past tense]. Just couple of examples.

1. **Judo** - if I bent my left knee more than three inches that leg would collapse so I had to do judo with almost straight legs. In a competition my opponent only had to touch the back of my knee and down I went. I managed to pass to the third Orange Belt but no further.
2. **Life-saving** - I had absolutely no propulsion from a life-saving leg kick so developed a strong right leg sidestroke type kick that allowed me to complete the test in the required time. I passed to Distinction Award and became a Pool Lifeguard, Swimming and Life-Saving Advanced Teacher and a Grade 1 Examiner, till 1988 when a fall kicked in PPS.

Richard at age six months also had waist down paralysis but did not recover as well as I did. At school he wore a half leg calliper for a few years and full leg calliper until he was 16 plus the wonderfully styled and coloured orthopaedic shoes.

Walking - His left leg paralysed, right leg weak and both ankles were fused. Age 16 he hated wearing the calliper so he tried walking without. With his left hand in the pocket of his trousers against his thigh he could stop his knee from collapsing. He threw the calliper away and with orthopaedic shoes and cane he walked like this until 1997 when he turned not realising there was a slope and fell. He decided time to go back to wearing a calliper. Sadly a few more falls and further damage to his shoulders meant he had to think seriously that a further fall could prevent

him being able to transfer using his arms. 3 years ago he decided to use his electric wheelchair full time.

My presentations since 2000, and mentioned in quite a few newsletters, are health professionals please DO NOT ask us "Can we do an action?" because we are unlikely to do more than proudly say 'Yes'. Ask us **HOW DO WE DO each action** and now the picture in the mind of the health professional is likely to be the same. Just answering 'Yes' does not tell them how you do it.

Take the question 'Can you get up a flight of stairs?' Write down exactly how you go up and down a flight of stairs with and without carrying anything. How long does it take you and how many times a day do you do this?

Are you going up and down like non disabled folks?, or do you do any of the following:-

Go one leg first each step

Stop once or twice for a short rest,

Use the bannister rail to help pull you up or steady you down,

Only do this once to come down in the morning and go back up again to bed,

Can you now carry anything at the same time up or down, e.g. Are you lifting the items up a few stairs at a time, Throwing the non breakable dirty washing, down the stairs, ...

Do you have to go down facing the stairs.

Does someone help you, or are you using a stair lift.

How many still **go up a flight of stairs backwards step by step sitting on your bottom** but still consider that answering "yes" to the question was correct?

Working in the kitchen. What do you have to do to prepare and cook food, get items out of a below counter fridge, do the washing up, laundry, taking out the rubbish etc.? I am sure you like me do not think about how you do each action you just do it, and that is your 'NORM'. Unless you explain to health, social services, benefits, personnel how they will have no idea. Go into your kitchen [or think about how] and write down some facts about each action. It is not easy seeing in black and white how you cannot do things as easily now; having to use aids and special equipment again or now for the first time etc. It seems like a downward step and for years we do not want to even think about this. The most often heard comment on this subject at PPS Groups is those who come back a few years later and say I wish I had listened when you told me before. I now use an [x] and life is so much easier to manage now.

Some ideas to think about. Do you hold on with either one or the other hand, do you lean against the work surfaces to use both hands. Do you put one hand on your knee to balance to reach down? Do you slide saucepans? Have you moved items to different places so they are more easily used? Have you bought special equipment? Have you had your kitchen adapted?

I have just remembered about fifteen years ago I was helping a lady from the Boston area complete a DLA application. I asked her, 'Do you have any problem preparing vegetables?' She answered 'No'. I was really surprised as she had started our discussions telling me how her arms were not as strong now. I asked her again 'Are you sure you don't have any problems?' She looked up at me and embarrassingly said 'Oh, I don't have a problem because my husband has done the vegetables for the last couple of years, I really will have to think about my answers.'

We have been so strong, so capable, never given in for decades. We know it is hard to accept that changes are taking place, that we now cannot do as much as we did before. It could be down to a combination of post-polio, age, other medical conditions, etc. It is hard to start using aids and equipment again or for the first time. Asking others for help when we have done years of helping others goes so against the grain. It is hard to pace and rest each activity but If we do we can do with less pain and fatigue, it just takes longer to do it. We have ten energy tokens a day and 70 a week [change to £] We have to work out how much each action costs using an average day. Using a diary put in the token amount you need to spend like dressing, getting meals/drinks, then fit in tokens for things you must do, e.g. medical appointments. Now you can see where if you got help and/or equipment there are tokens for doing things you really want to do.

It is time to tell it like it really is. Be wise and get the help and manage life more easily!

NOT WALKING MY TALK! A CAUTIONARY TALE!

By Vicki McKenna, B.A., Lic.Ac. Vickimckenna51@hotmail.co.uk

Author of *A Balanced Way of Living. Practical and Holistic Strategies for Coping with Post Polio Syndrome*,
Available on Random Harvest.

<http://www.postpolioinfo.com/randomharvestabout.php>

Six weeks ago, as I felt a severe and crushing pain in my knee and sensed that my muscles had turned to mush I reminded myself of my own words; "muscles often become weaker when overused by polio survivors and because of all this it makes no sense at all for us to do exercises that result in fatigue and exhaustion". As Dr. Bruno says: 'Feeling the burn means that nerves are burning out.'" At that moment, six weeks ago it was clear that I had stopped walking my talk and instead had been over exercising my muscles and now had to reap the consequences of overuse.

I had developed Post Polio Syndrome (PPS) symptoms in the 1990s and in 1998 I started working on my book --"A BALANCED WAY OF LIVING; Practical and Holistic Strategies for Coping with Post Polio Syndrome". Through the book I was able to share all I had gleaned from my years of treating patients using traditional acupuncture and other Daoist healing techniques. For the next 21 years I followed the strategies outlined in my own book, and in Dr Bruno's marvellous book --"The Polio Paradox". Through the years I have been careful not to overdo, I have kept walking to a minimum by using my scooter out of doors, exercised with gentle swimming and practising Chi Gung and generally have taken good care to ensure my polio damaged neurons stayed as well as they could. I avoided stairs, never walked more than a few yards to my car or my mobility scooter and I have only had one bad fall where I broke my polio leg in 2011 slipping on a blob of one of my favourite food groups --mayonnaise! And all that caution paid off -- I slowed down the rate of PPS and up to this summer (2019) I was still walking with just a calliper (worn since I was a small child) and one elbow crutch for added support.

You know that feeling of freedom when you go away on holiday? Its the anticipation of fun and endless possibilities opening up ahead and as I walked out of my front door and down my front steps, manoeuvred my scooter into the back of my car and took my place behind the steering wheel I was excited and energised to be embarking on a several hundred mile journey to Wales to spend time with family I don't see that often. Little did I know as I took my seat behind the wheel that this would be the last time, for the foreseeable future that I would make such an easy and independent departure from my home.

That sense of freedom -- that unhooking from the normal routine set me free to take what we refer to in Scotland as a "mad turn" and I felt invincible. Stairs -- no problem, on my feet for longer than in years, walking longer distances than I had done in ages -- bring it on! For a week I pushed my limits, reverted to all the polio survivor Type A pathology I had denounced and seemed to get away with it. And then... on the last night of my holiday I knew the staircase I faced was a mistake but staggered up it anyway. My good leg felt wobbly but I was sure that with rest it would recover. How wrong I was!

The next morning I woke up and swung my good leg out of bed and as my foot went down onto the floor my knee straight away felt weird. For some years I have felt a slight obstruction in that knee -- perhaps some loose meniscus but it never turned into a problem so I ignored it. Now it felt as if my knee was jammed and also very very weak. To my horror I realised it had swollen like a balloon and once I tried walking the pain was excruciating. A nine hour drive home to Scotland followed, we scrapped our plan to stop half way overnight and pressed on - I just wanted to get home! The next day with my knee now three times its normal size and massively in pain we visited the Accident and Emergency at our local hospital here in Glasgow. To cut this long story short it seems I had pushed my good leg too far -- I had overused it and now fatigued, exhausted

and weakened it had become all too easy to sprain it. Rest, ice, compression and elevation followed but unable to straighten it or put weight on it I had to take to wheels full time indoors and outside. Not that I go out much but more of that later!

As ever Doctors have been slightly mystified – they tell me its no big deal – 6 to 8 weeks and all will be well -- meanwhile “crack on” as one orthopaedic specialist said. With no real experience of polio and its long term effects this generation of medics don't really get it -- there is an expectation that I should be able to walk using my other leg. I then explain I can't as its paralysed from polio. They shrug and try to look sympathetic....I get the feeling they also fail to understand that the polio affected muscles of my overused “good” leg wont spring back into action in the way a “normal” leg might after a sprain.

Six weeks on and I am finally able to get out of my chair and put some weight on my “good” leg - walking with 2 elbow crutches and weight bearing also on my calliper leg – the latter no doubt stunned to find itself with a degree of responsibility previously unknown to it! The things I miss the most these days are – walking (obviously), swimming and getting out of my home easily - I now rely on my kindly husband to push my chair into the lift (elevator), then he sets up the ramps to manoeuvre me down the steps of the apartment block to the car park. I then get pushed up the ramp of my van to sit in the back like the Queen of Sheba and get carted off and later brought home. I haven't yet practised my new walking mode out of doors – no risk taking for me! Getting out is such a hassle (and all the pushing is affecting my husband's back) that I now rarely bother to venture forth. And I am not after your sympathy here! I am just telling you this tale to share and to warn other polio survivors – many of whom doubtless don't need a warning as they have already experienced this situation of overuse causing the loss of function in a previously fairly OK limb.

One week was all it took to change my life around. I have grieved for the loss of my leg, for the loss of a great slice of independence, I have felt angry at myself for being so careless with my one precious limb but ultimately I have dusted myself down as we polio survivors do and got on with adapting. Most polio survivors contracted polio as children and therefore have grown up adapting from an early age to disability. It is harder to adapt at my age of 67 than when I was a young energetic child, but adapt I will.

And as we all know there are blessings! So much support from my marvellous husband, my wonderful daughters, son in laws and grandchildren, extended family, my dear friends and of course my lovely polio community (especially as ever Dr Dick Bruno!) who have given tons of advice and good wishes and a big thanks to Helene for the loan of her power chair!

Acupuncture, aromatherapy oils, visualisation, Chinese linaments, – all these things are helping to heal my poor old worn out knee and leg. And I am still childminding my gorgeous grandkids and seeing my patients to give them acupuncture. It is clear that for me caring for others nourishes my spirit - it gives me a sense of purpose. Also I have discovered that, although challenging, my transition to a wheel based life is suiting my body rather than pushing myself to walk as I previously did. I now feel much more rested using wheels indoors. I realise how much I have resisted using them – it felt like giving in, giving up. Turns out giving in is actually an acceptance and a surrendering to the reality of what is and cultivating that attitude has been a real turning point. And I feel so much better wheeling most of the day rather than pushing to keep walking. If I can just walk enough to get into my beloved car I will be very content!

Editors Note: Vicki's story appeared on a Facebook Group list as I was preparing this Newsletter. I often wonder if readers think that maybe the problems that Richard and I have that I write about in our Newsletters, they are not going to experience. What PPS Group leaders call the 'I am not there yet' replies. Therefore I asked Vicki permission to add this to this newsletter, as in fact did other newsletter editors around the world. We know how hard it is to make changes that to you look and feel like you are giving in. We will tell you that as we have made changes to using equipment and making changes to our home and settled into a new routine, we can report less pain and fatigue and in fact doing more of what we really enjoy.

Member Caroline Gordon-Wilson would like members to read and comment on the letter she wrote to The Rt Hon Frank Field MP, Chair, Motability Select Committee, House of Commons, London SW1A 0AA - 25th January 2019

Having followed the investigation into Motability Operations first reported in *The Daily Mail*, I watched the recent Select Committee meeting with great interest. I feel I need to write to you from the opposite side of the coin as a Motability customer because there are some comments I would like to make.

I have been disabled since the age of six and have worked all my life until circumstances meant I could no longer buy my own car and get it adapted at which time I gratefully turned to the Motability scheme in order to maintain my independence and there is no doubt that it is a wonderful scheme. However, I was horrified to read of the obscene salaries being paid to the senior management and the size of the company's reserves. It appeared to me that none of the reasons given at the meeting regarding these issues have been addressed by the Motability management. I heard a lot of waffle, prevarication and avoidance of the direct questions the management was being asked but no clear answers from them. It seems to me they have been amassing money at disabled people's expense and would still be doing so if this had not been exposed by investigative journalism. Among the self-congratulations it was mentioned that customers now did not have to pay for certain adaptations and a lot less for the more expensive adaptations. This is true but despite this they are still awash with money.

I now live on a low income and would very much like to receive some of my DLA but it all goes to Motability. We as individuals sign a contract with Motability for our DLA to be paid to them in return for a car but the DLA goes up each year during the life of that contract but they still take all of it - it should be a sum set at the start and any increases year on year should come back to us especially as it was stated that the cost of vehicles to Motability have decreased. I was pleased to hear that customers whose cars are returned in good condition will now receive £500 instead of £250 but this will only offset whatever the customer pays for the next one.

Catherine McKinnell MP twice suggested that we were being charged too much of our allowance in the first place. This was ignored. Would it not be a gesture of goodwill to its customers if Motability gave us some of our allowance back as a lump sum payment? I understand this is government money in the beginning but once it has been awarded to us it becomes our money to use as necessary.

Although I respect Lord Sterling for instigating the scheme I felt his remark that individuals do not have to have a car they can "go to the cinema or something" rather condescending. We do not get DLA or PIP to go to the cinema (if we could get there and access it anyway) we are awarded this payment to help us get around however we choose to do that. Just because some of us choose to have a car does not give them the automatic right to take all our allowance. It is true that there is a small range of cars where not all the allowance is taken but these are not suitable for everyone who have special needs when choosing a car such as how difficult it is getting in and out of, is there space for a wheelchair, is it automatic (these can cost more), etc.

I am Secretary of the local branch of a disabled charity and without the car I could not do my job of going to meetings and enjoying outings as well as taking others who either do not drive or have given up and who rely on me to participate in branch activities.

While these executives are sitting in their smart apartments overlooking the Thames I wonder if they ever give a thought to those disabled adults and children who are funding their lifestyle. I think not.

Thank you for taking up the reins and looking into this matter and asking for further information from the management and perhaps some clear answers as to how this situation has arisen in the first instance. I will await the results with interest and, hopefully, some positive changes that will help their customers.

Yours sincerely, Caroline Gordon-Wilson. Member of PSN and Secretary Lincoln and East Midlands Branch of the British Polio Fellowship. Email: carolinegordonwilson@gmail.com

PS: Customers are getting £500 back if they return the car in good condition and customers are being offered a manual wheelchair when they lease a Motability car. This is little compensation for the £millions amassed by Motability Operations. The CEO has resigned (but not until next year, no doubt with a huge pay-off, but to date the DWP has still not laid out a new set of rules under which Motability needs to operate in the future.

India: KTR helps polio-stricken boy stand on his feet | Telangana Today. [14th Aug 2019 11:40 pm]

In January this year, TRS working president takes up case with officials of Chief Minister's Office to mobilise funds from Chief Minister's Relief Fund. Assures nine-year-old Sairam and his family of complete support for his recovery.

Hyderabad: A small gesture by TRS working president KT Rama Rao helped a nine-year-old boy from Godavarikhani to stand on his legs, literally.

Sairam is not only able to walk on his own, but is also looking forward to play with his friends. Unable to walk due to polio, Sairam, who comes from a poor family and a class IV student, depended on his family for his daily chores.

But, in January this year, Ramagundam MLA Korukanti Chander took Sairam to Rama Rao in Hyderabad and sought the latter's help to perform a surgery.

The TRS working president responded promptly and took up the case with officials of the Chief Minister's Office to mobilise funds from the Chief Minister's Relief Fund (CMRF). He entrusted party leader K Srinivas Yadav to provide all necessary support to get the surgeries done for full recovery of the boy.

About eight months later, on Wednesday, Sairam along with his parents, Rajamallu and Laxmi, and Ramagundam MLA Chander returned to meet Rama Rao. He thanked the TRS working president for his support. Rama Rao enquired about the boy's health, and assured all support for his full recovery.

"He returned with his surgeries done and was able to walk normally, thanks to CMRF. These are the memories that will stay with you, when you call it a day," said Rama Rao, sharing his experience on Twitter.

Original source article <https://telanganatoday.com/ktr-helps-polio-stricken-boy-stand-on-his-feet>

Stiffness modification of two ankle-foot orthosis types to optimize gait in individuals with non-spastic calf muscle weakness – a proof-of-concept study | Journal of Foot and Ankle Research.

[Open Access] [Received 23 April 2019; Accepted 02 July 2019; Published 07 August 2019] **Abstract.**

Background. To reduce gait problems in individuals with non-spastic calf muscle weakness, spring-like ankle-foot orthoses (AFOs) are often applied, but they are not individually optimized to treatment outcome. The aim of this proof-of-concept study was to evaluate the effects of modifying the stiffness for two spring-like AFO types with shoes-only as reference on gait outcomes in three individuals with calf muscle weakness due to polio.

Methods. We assessed 3D gait biomechanics, walking speed and walking energy cost for shoes-only and five stiffness conditions of a dorsal-leaf-spring AFO and a spring-hinged AFO. Outcomes were compared between stiffness conditions in the two AFOs and three subjects.

Results. Maximum ankle dorsiflexion angle decreased with increasing stiffness in both AFOs (up to 6–8°) and all subjects. Maximum knee extension angle changed little between stiffness conditions, however different responses between the AFOs and subjects were observed compared to shoes-only. Walking speed remained unchanged across conditions. For walking energy cost, we found fairly large differences across stiffness conditions with both AFOs and between subjects (range 3–15%).

Conclusions. Modifying AFO stiffness in individuals with non-spastic calf muscle weakness resulted in substantial differences in ankle biomechanics and walking energy cost with no effect on speed. Our results provide proof-of-concept that individually optimizing AFO stiffness can clinically beneficially improve gait performance.

Original source article <https://jfootankleres.biomedcentral.com/articles/10.1186/s13047-019-0348-8>

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 so well that externally we do not look like the photos found in old medical books. There is a massive overlap of symptoms with other neuromuscular conditions. Tell new professionals about **Post Polio Syndrome** and direct them to our website so they can find more information. Thankyou.

The most accepted article we have found by NHS professionals is:

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 is:**

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 headed paper with permission

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 and tips

A way of doing something, or an 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.

Articles and items for Post Polio Matters are always welcome,

by post, by email and by phone if writing is not easy for you.

CARERS - We'd love to hear from you too. Help us understand what you go through in helping us to manage our lives.

Deadline date for next issue is 14th October 2019

Editors Note:-

Articles from Polio Survivors and Health Professionals very welcome for future issues

Management Committee [Trustees]

Chair - Simon Parritt - simon.parritt@poliosurvivorsnetwork.org.uk
Secretary, Zsuzsanna Snarey - zsuzsanna.snarey@poliosurvivorsnetwork.org.uk
Treasurer, Newsletter Editor - Hilary Boone - hilary.boone@poliosurvivorsnetwork.org.uk
Trustee - Verité Reilly-Collins - verite.reillycollins@poliosurvivorsnetwork.org.uk

Trustee/s - Vacancies please apply for more information.

Operations Team

Phone Enquiries - Hilary Boone - info@poliosurvivorsnetwork.org.uk
PSN Admin, Email Enquiries and Website - Toni Dunlop - psnadmin@poliosurvivorsnetwork.org.uk
Printing - Imprint Colour Printers, Lincoln

Membership

With grateful thanks to the generous legacy from Ms A Brown,
Membership will now be **FREE** whilst our funds remain above £10,000.00
UK Members can choose to get their newsletter by post or email or both.
Overseas Members will get their newsletter by email

Contact us via our **website** Contact Us page

Write to us at PO Box 954, Lincoln, LN5 5ER

Email psnadmin@poliosurvivorsnetwork.org.uk

Phone us on 01522 888601

(please be prepared to leave a message, your name and phone number
we will ring you back as soon as we access our messages)

Donate by cheque or 

Cheque payable to **Polio Survivors Network**

PayPal send funds to treasurer@poliosurvivorsnetwork.org.uk

All donations, small or large, towards our work are gratefully received

Towards our GENERAL FUNDS (including printing and posting of newsletters)

Or our CONFERENCE AND MEETING FUND (supporting attendance at national meetings/conferences)

We are always grateful for postage stamps, 1st and 2nd class both normal and large size.

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%).

If you have not filled in a current Gift aid form please contact us and we will post you one.

Thankyou.

giftaid it

Wiktionary

HANDICAPABLE

Coined as a more positive-sounding term.

<https://en.wiktionary.org/wiki/handicapable>

Polio Survivors 'What works for me'

2 in 1 Rollator and Transit wheelchair.

Flip down foot rests if you need to be pushed.

Height adjustable.

Under seat bag



**PSN Member
Anne Wood
25.2.1945
to
18.4.2019
Her family's
favourite photo**



Toni Dunlop stopped outside Post-Polio Health International Offices in St. Louis for a quick photo

WHAT is WOW?

The WOW petition campaign began at the end of 2012 when several disabled people decided to do something about austerity cuts the Tories & LibDems in the coalition government were making and targeting, they believed, disabled people. They set up a petition on the government's e-petition website (43154) calling for a Cumulative Impact Assessment of Welfare Reform and a new deal for sick & disabled people based on their needs, abilities and ambitions.

wowvoices.uk/send-us-your-voices

If you are a disabled person, carer or a health professional you can send your experience of how the cuts to services, the NHS and welfare reform have affected you personally and the people you know.

You can send a written account, a recording or a video. You can send your file or a link to where you have uploaded it by email to info@wowvoices.uk or via the website <https://wowvoices.uk/send-us-your-voices/>

You can also choose if you would like your experience to be published on the Send Us Your Voices website (remember it will also be shared on social media) or not. If you prefer you do not need to use your real name.

WOW Voices state that they won't disclose your identity or give your email address to anyone without your consent.

WOW Voices state that some of the facts the 'voices uploaded' you may not believe could possibly have happened. If you have not personally or know someone who has had to apply for a change from Disability Living Allowance to Personal Independence Payment then it is probable that you will not believe some of the facts reported. Some examples are assessors not taking into account/totally ignoring the facts given by highly qualified health professionals. [Some people who had high level DLA have received letters awarding them NO points at all!](#)



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Or ring Val on 01234 346 397

