



POST POLIO MATTERS

Polio Survivors Network Newsletter
JULY 2020 Volume 10, Issue 3 of 12 [111]

© The Green Revolution Starts Here. A Painting by Jane Tomlinson

POLIO SURVIVORS

We are joining
The **GREEN**
Revolution
With
Vicki McKenna
articles [pages 7 - 11](#)
and
HELPFUL TIPS
In Article [13 - 19](#)

JOIN US and SHARE INFORMATION

Your Story
Your Successes
What works for you
might work
for others
Interesting Items
from Magazines
Tasty Recipes
Humour
Meaningful sayings
Photos
Quick Craft items
Etc.



Lincolnshire Post-
Polio Library
100+ articles

Polio Survivors Network is the working name of
registered charity 1064177, The Lincolnshire Post-Polio Network

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Page 23	Contact Information. Post Polio Syndrome Exists (repeated every issue) Polio Survivors Network believes the following two articles are important as they have been well accepted by many NHS Health Professionals: <ul style="list-style-type: none"> • Patient.co.uk article on Post-Polio Syndrome • Polio Patients and Surgery Information for Health Professionals (English version from PTU, Denmark)
Back Page	Post Polio Matters... because "We are Still Here" Link to A Ministry of Health Film 1949. "His Fighting Chance" narrated by Eleanor Roosevelt. Featuring Johnny Green plus a link to this in the book The Health of Nations: The Campaign to end Polio and eradicate epidemic diseases by Karen Bartlett, 2.3.2017. Photos of Yvonne's rabbits and Tom Post who lives in the Philippines. Val Scriveners' Photo Cards for sale to raise funds for Polio Survivors Network.

Thankyou for all the following donations received so far in 2020:

D Brennand	£ 12.50	Alison Whyte and friends instead of a Birthday Card	£ 190.39
M Scarlett	£ 35.00	Val Scrivener Photo Cards	£ 50.00
S & P Tanfield	£ 20.00	John Moore	£150.00
Mr. & Mrs Dunham	£ 15.00	Anonymous by PayPal	£ 10.00
3 members	£ 37.50	Yvonne Webb	£ 100.00
Yvonne	£ 25.00	TOTAL	£ 635.39

Please note £37.50 is from 3 members who did not complete the GDPR information. Some members set up standing orders for membership. A few wrote to say they would keep this as a donation for which we are very grateful and others cancelled theirs. We know that our memory is not what it should be so please check with your bank and ensure that if you set up a standing order you are still happy for it to continue. Thankyou.

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

Wow does time fly. Today is Day 111 [day 120 now] stayed at home and if this fly does not stop landing on me I am going to ... If only I could think of something that worked as he has been doing this for the last 20 minutes. Richard came into the room and I gave him the copper bracelet with magnets in that arrived about an hour ago and he said "Do you have one?" I said "Yes" and showed him. His reply, "Now we can turn green together." Thankfully he has not lost his sense of humour over the 23 years since we met.

Front page. Vicki McKenna sent me an article [page 7 to 9](#) mentioning Jane Tomlinson's picture [thankyou for permission for us to reproduce this] and I thought how this one picture captured what I was thinking we ought to do now our personal funds are less. Use what we have, make and/or mend items, buy second hand and sell what we have not used for years. Share with others, by swapping, lending or borrowing items. Then for those things we have to buy, buy locally. Support our local Farmers and businesses. This had come to the fore when I was searching for PPE for our carers and I started clicking on the name of the firm items and found most were not UK based. I know what my children would have said, 'Oh mum, surely you realised...' but life moves on so fast that we cant keep up with everything happening out there. I have only to think back to visits to my Grandma and remember how we thought the same about her. Read Vicki McKenna article about the formation of the Scottish Post-Polio Network, [pages 10 and 11](#).

About two hours ago when the post arrived there was a letter to PSN using the sae that we had sent out with the posted issues. I read this and was surprised that some of the facts were the same for me... I immediately uploaded Yvonne story see [page 20](#). Yvonne ended with how much she would look forward to monthly newsletters with more stories so she could get to know more of us. She has since sent us some more bits for this and later newsletters.

Then I got an email from Australia asking if we knew of a Polio Survivor called Johnny Green who had featured in a short film when he had polio at the age of 2 and also in a book. See links to the information on the back page. We are so grateful for this - and have shared this already with other polio groups around the world - a chance to see Polio first hand. A real eye opener.

Then an item on a Polio Facebook list triggered comments from polio survivors around the world including me. Concern that whilst exercise is important and you can strengthen polio muscles with higher grades you cannot strengthen weak polio muscles. Why was I so concerned? I spent 7 years [1988 to 1995] being given physiotherapy regimes including using some equipment and all I did was deteriorate year on year. I had no diagnosis and my family, especially my brother who still does, thought that if the health professionals could find nothing wrong then I must be making it up. I ended up at the end of those 7 years struggling mentally and wondering what was wrong because I knew there was definitely something. The health professionals did not grade my muscles correctly, did not take my prior polio into the equation and knew nothing of Post-Polio. Now we are able to have the Newsletter printed properly again I have taken the opportunity to put both the **Pitfalls** and **Helpful Tips** that Polio Survivors need to be aware of so that their muscles are correctly graded, they are diagnosed and advised correctly and preferably by health professionals with experience of working with polio survivors. That the exercise regimes and equipment is correct for each person. [Pages 13 to 19](#).

Then a phone query from another Polio Survivor John Moore who then sent a generous donation towards our work. See other donations on previous page.

Our Chair Simon writes...

One of the few of a few?

I felt it might be of interest to share one aspect of my identity as a disabled person that often makes me feel a bit different from many on the forums and discussions. As someone who caught Bulbar Polio in the winter and with very few others in my area, I realise now I was one of the few of a few, even amongst other polio survivors. Many PPS people, after the initial illness and maximum recovering, went on to lead relatively physically and socially active lives with perhaps some having only minor, or even no obvious residual polio issues before PPS hit them sometimes decades later exposing the original extent of the damage. Of course, this is and has been all the more shocking and confusing for them and equally for the medical profession. However, this was never true for me, I have always been quite severely impaired and well aware of the potential long-term loss of more function. Although I recovered enough to walk independently, as a 5-year-old, I was completely paralysed, put in an iron lung, fed via a nasogastric tube and unable to do anything other than speak. When I did speak, it was only short bursts in time with the rhythm of my iron lung or my spaceship as I called it at the time. Some might of course now say I still have a tendency to talk in bursts, but maybe not so short!

Upside Down Polio

I then became what was called at the time an 'upside down polio' as when I began to recover limited muscle function, it was mostly waist down, unlike many others who lost more of their lower limb function or maybe some isolated muscles groups in one arm or leg. I was however, left as a teenager with very weak chest, arms, torso, hands etc. So even at my best my upper body was always weak, and they now of course suffer the greatest decline of function with PPS. I can still walk and have in the last years begun using a power wheelchair when outside, which for the past few months during Covid-19 doesn't happen and probably won't anytime soon! But it is my upper limbs and functions, such as breathing that has taken the biggest hit and so dressing, washing as well as even using the computer has become more and more challenging but unlike many I am in the fortunate position to have my wife help and support me.

I mention this as so much around disability has been and is focussed around wheelchair access when the issues are so much more complex and diverse. I think this has always been a problem and from driving through to access to public transport the easy options are always around wheelchair access, valuable as that is. For instance, playing on a games machine has never been possible as using a standard games controller requires quite extensive arm and manual dexterity. Years ago, having impaired arm function never qualified me for much, even though using a ticket machine on a station was almost impossible, this was never considered valid for mobility support, unlike being a wheelchair user.

Where is the Innovation and Technology?

Recently I was looking for help or OT advice around adaptations, advice, expertise and quality solutions and adaptations and they were very limited options for upper body impairments even for a kitchen where again the market seems aimed at fit wheelchair users. Given modern technology and robotics this really shouldn't be the situation any longer. Disability access isn't and shouldn't be JUST about wheelchair access. Now that I do use a wheelchair much more I notice so much more on offer, but still the upper body solutions are absent, and it is assumed the only way forward is to use carers and PAs. This really isn't OK for either the carers or for the sense of independence and autonomy for disabled people.

Taxis, Planes and getting older

When ordering an accessible taxi, the fact that I wasn't actually in a wheelchair, meant that help with cases or getting in an out safely wasn't considered or had to be specifically requested. It's an irony really as many colleagues and people I have met who are wheelchair users were actually much stronger and able to navigate the environment better than I could. The same is true for many elderly people. Travelling by plane has been made easier in recent years due to the disability laws that has meant many elderly and those with chronic heart and breathing conditions taking up the assistance travel system on offer. I have benefited from that and of course I am now also officially I guess 'elderly' but I wonder why it takes the non-disabled who are beginning to get age related conditions to produce change.

What is accessibility and inclusivity ?

Polio and PPS covers a very broad spectrum of people. I am not sure how many members or others with PPS have had the same experience, but I do think that there has been much less help and consideration for people who have upper limb problems. Even if such services as orthotics and the wheelchair services have been pretty poor it has been focussed on mobility rather than participation. No point in getting somewhere if when you get there you can't access the activity or need a PA or carer to do it for you, when the right technology would make them redundant and me independent. I would prefer were I musician, to be carried up the steps to the concert if there is an instrument and a society that's accessible for me to play amongst, rather than provide wheelchair ramped access to the venue, but then only have the choice to be in the audience or sit on the side lines.

Of course, because the international symbol for disability, pictures a wheelchair user it is so much more important to develop a wider more inclusive concept and view of what disability is. To this end a major barrier to change is that many, even disabled people ourselves, still don't understand the relationship between impairment and disability and how a wider understanding and application of the Social Model of Disability could help us all lead fuller more inclusive and independent lives.

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Some thoughts from Zsuzsanna...

I have been listening to the audio diary of Louise Halling on Radio 4 on Monday morning at 11 called Walks like a Duck. She was diagnosed with muscular dystrophy at the age of 19 and now, 20 years later, works as a counsellor online. Her story has struck a chord with me. I too hate to think of myself as disabled and as far as possible avoid thinking about the fact that I am. Recently we have been watching old videos and some of them show my limping walk. My gait could also be described as "walks like a duck" although I was walking far better than I do these days with two sticks. In those distant days I could walk without a stick even outside in the garden and could carry my one year old daughter on my arm, an unimaginable feat today. I caught polio at the age of 8 and did not walk for a year. I went to university, qualified and worked as a research Chemist, married and brought up three daughters while teaching science for 26 years. I chose to retire early and became a Surgical Chiroprapist which allowed me to work from home until the age of 76 when we moved to be near our families.

Like Louise I too have a love hate relationship with my stair lift. It makes annoying beeping sounds as it slowly ascends or descends and is taking such a long time. I would love to speed it up somehow if that was possible. I resent the time spent sitting on it and try to do something useful like checking my emails while travelling. Of course I cannot do without the stair lift, the thought if it going wrong fills me with dread!

Falling is a regular occurrence with me too and I think that I am very good at falling. I certainly don't worry about falling because I am so used to it. My knee doesn't give way now as it used to because I am wearing callipers to support them. But when I do fall with them on it is almost impossible to get up. If my husband is not around to pick me up I just have to remove them and crawl to the nearest chair to get up.

Getting up from a seated position is also very hard. I have to use a modified A line manoeuvre pushing up with one hand and pulling on something fixed with the other. It is easy to damage the rotator cuff ligaments of the shoulder and I have to take great care to avoid this. But sitting for any length of time is also painful because I have lost most of my 'glutes', the gluteus maximus most people take for granted. Finding the right cushion is not easy.

I am so lucky to have an electric buggy which can be lifted into the boot of the car with a hoist. This makes me independent but of course with the recent lockdown I have only been out for a hospital appointment once. I only walk inside the house, outside I always use the buggy. I enjoy going at full speed with my husband trying to catch me up and pleading with me to slow down. Before coronavirus struck I used to take my 4 year old grandson to nursery sitting between my legs on the buggy. It was such a special time when I could give him a cuddle and he really enjoyed the ride. We used to discuss the flowers and plants along the way and have a lovely time. I really miss him now. After the summer he will be going to school. There are many blessings in life, such as my family, my grandchildren and most of all having a loving supportive husband. I look forward to listening to the next episodes of Louise Halling's Walks like a Duck.

Zsuzsanna Snarey, Trustee zsuzsanna.snarey@poliosurvivorsnetwork.org.uk

Verité writes...

Once lockdown is over, do you want life to carry on as before, or are you concerned with the Government promise to 'Build - Build - Build' without asking people what WE want? Before the Government spends billions more of our dwindling cash, what about

1. Writing to your MP to let them know what you want? You may not get a reply, or one that makes sense, but researchers in an MP's office will be compiling statistics on EVERY letter showing what constituents want.
2. Signing one of the petitions going around from Change.org, 38 Degrees, etc. Once a petition has 100,000 signatures it is considered for debate in Parliament.
3. Or do you have a plan to take advantage of the way of life we have discovered during lockdown.? e.g. Less traffic, less pollution, short commute to work, community spirit, etc.

Revellers worry me - as did Bojo's promise to 'Build Build Build'. It's possible to avoid a pub scrum, but all of us are going to have to pay in some way if the Prime Minister's building boom goes ahead. Do we really need more concrete developments? Especially those ear-marked for Green-belt land? Or is the promise to build just a sop to major party donors from the construction industry?

Will our working lives change? Will we have a 'reverse Industrial Revolution', once people tot up the cost in time, stress and money of commuting? Not forgetting 'designer coffee', take-away lunches, etc.

So tell the Government what YOU want - before Bojo, Richi etc. spend more of our hard-earned taxes. In this posting, I have highlighted what we could petition to be retained

<https://aftercancers.com/will-someone-please-reign-in-bojo/> Verité Reilly-Collins, Trustee.

Toni writes...

I thought I'd share with you some of my random reading and thoughts from this week.

As you've probably already understood I have a bit of an obsession with Italy and all things Italian. It was my wedding anniversary this month (19 years!) and I was treated to a huge bunch of sunflowers. These always put a smile on my face as they remind me of the beautiful fields of sunflowers around Tuscany. Such a beautiful splash of colour on the landscape.



You probably know that immature sunflowers turn according to the position of the sun, chasing the light (heliotropism)? It turns out that they don't just follow the light but, in their stems, they build cell structures during darkness to move their heads to prepare to take in the sunrise. During the sunlight, they build on the opposite side of the stem to move the head toward sunset. They use their internal circadian clock acting on growth hormones to face east at dawn and follow the sun during the day – ingenious! Once the sunflower matures it stops following the sun and is content to just soak up the rays as they fall.

There are many musings and comparisons that can be drawn from sunflowers – feel free to form your own about small beginnings, standing tall, rays of sunshine, goals, inner light etc - for me I just can't help smiling when I see them, it's good to brighten the day for yourself and others.

What natural wonders fill you with awe, bring a smile to your face, help you to just be in the moment you are in? Feel free to share them here.

Wishing you all the very best during these challenging times.

Toni x

Photo competition

We had no entries for our photo competition so we thought we'd try one more time. The competition theme is **"This made me smile"**

Please send us a photo you have taken of something that has made you smile or laugh. Perhaps you have a cat that sleeps in a funny position, a flower in your garden is simply stunning, you baked a cake that tasted delicious, you received a gift from a loved one.

Email	psnadmin@poliosurvivorsnetwork.org.uk
Post	P.O. Box 954, Lincoln, LN5 5ER
Website	www.poliosurvivorsnetwork.org.uk
Phone	01522 888601 (answerphone if no reply)

We hope to print our entries and the winner in the next newsletter. Please send your snaps to me by email (or by post and we will ensure it is safely returned).

Report Suspicious Emails and Scams

If you receive an email that looks suspicious to you or is clearly a phishing email (an email trying to get you to give information especially financial) you can report the address that it came from. Simply forward the email to report@phishing.gov.uk The National Cyber Security Centre act on every email they receive and since 21st April 2020 they have removed 1,387 malicious sites.

Player FM, Inspiring Stories
Money Saving Expert
The Shows Must Go On
What's On Stage
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Classical Music

Free **podcasts** <https://player.fm/podcasts/Inspiring-Stories>
Free **ways to relax and look after yourself** <https://bit.ly/3bzDvLV>
Free **west end shows** <https://bit.ly/2C5gofL>
Free **shows, musicals and operas** <https://bit.ly/2MkEXqw>
Free **concerts and operas** <https://bit.ly/3gQvk03>

CORONAVIRUS: A DAOIST APPROACH by Vicki Mckenna

A Green Revolution

The front cover of this issue with its **Green Revolution painting by Jane Tomlinson** sums up the positive aspects of the Coronavirus pandemic. We have been forced by the pandemic to curb spending, to make do and mend, eating more healthily by cooking from scratch, travelling less and thus lessening pollution levels - all of this is ultimately good for our own health and for the well being of our planet. Nature is the foremost teacher in Daoism, the theory behind the art of acupuncture which I have practised for the past nearly 40 years, and we learn from Nature to waste nothing. Let go of craving new stuff, make do and mend - a life of moderation and simplicity is the way forward and this has become the way for us all during the pandemic.

The lockdown from the virus has not been an easy time for any of us. Hard for most of us emotionally as we have found ourselves separated from our family and friends, hard for many of us financially as we have been laid off work with a pittance to live on. For families with small children there has been the strain of keeping kids occupied all day, often whilst parents are working from home. For elderly living alone there is the stress of feeling cut off whilst living in total isolation. We look to the government for advice and find a lack of clarity, we turn to Facebook instead and get inundated with messages that often conflict with each other. We have all experienced anxiety, grief, frustration and confusion. Daoism does not profess to have all the answers but it is a philosophy behind the 5 element acupuncture I have practised for nearly 40 years and it has helped me through challenging times in the past. Certainly I find it helpful today in the current circumstances. Here are some basic building blocks of Daoism - I offer them to you in the spirit of help and support in these troubled times.....

The Way of Wu Wei

The Daoist teacher Lao Tzu taught that the universe is full of constant change - it is composed of cycles that contract and expand - winter for example is a cycle of contraction that expands into spring. So it is that we find ourselves in a cycle where the coronavirus pandemic is expanding and eventually it will contract and move on. All life is change, nothing ever remains static, nothing stays the same. As humans we tend to fear change and we cling to our comfort zones wanting everything to remain as it ever was. To use an analogy - if a thirty foot wave were to come at you its no use asking the universe to rewind and get back to a more comfortable reality - best to go with the flow and either ride the wave or get out of the way. This then is the basic principle of Daoism - the way of Wu Wei - flowing in harmony with life's circumstances .

Although Wu-Wei means to flow in harmony with life's circumstances usually we do the opposite of this - we attempt to force circumstances so that life will, we hope, go the way we want it to. Daoist philosophy proposes that the universe works harmoniously *according to its own ways*. When someone pits his will against the world, against the stressors he faces he disrupts that harmony. Humans need to yield their will and align it in harmony with the natural universe. Faced with a pandemic we will find it is best to yield and accept what we are faced with – trying to maintain the status quo is doomed to failure. So we accept social distancing, not going to work as we used to, washing our hands more frequently than we ever have but deep down we may still object to this new way of living - we yearn, understandably for our old life. This resistance is indeed futile and furthermore it drains our energy as we resist, objecting psychologically to the new circumstances. But what happens if eventually we truly, deeply yield, say “yes” and accept in a positive fashion the very thing we fight against?

Hans Selye the stress researcher talks about “adaptation energy” - a certain type of energy that helps us adjust to stressors. He says; “we have no objective way of measuring adaptability at any given moment: but there appears to be a readily available, replaceable type (of energy), and another more deeply hidden in reserves which can replenish the superficial kind only after some rest or diversion of activity”. Once we truly, deeply accept the circumstances we are in and accept that we feel fearful, angry, worried, then we are yielding in the way of Wu Wei and we are allowing ourselves respite - we let go of clinging to our comfort zone. In this way we can access adaptation energy. This will allow us to adjust to the challenging circumstances we find ourselves in.

One of the best ways to yield to stressful circumstances and draw on this adaptation energy is to

practise Hara Breathing daily where you focus on the Dan Tian (sea of energy) - the energy centre just below the naval. This will have a calming, balancing, energising and spiritually uplifting influence on your energy field. Try it when you feel anxious, sad, frustrated and frazzled for it will help you to connect with and preserve your deep reserves of energy - the source of strength, health and healing in these troubled times.

Hara Breathing

Lie comfortably on your back and focus on the Dan Tien - the energy centre just below the naval to practise lower abdominal breathing also known as "Hara" breathing.

- Sitting or lying comfortable with loose clothing inhale slowly through your nose and gently exhale through your mouth .Do this several times.
- As you inhale feel a movement all the way down to the Dan Tien - the energy centre just below the naval. Allow your abdomen to expand as your diaphragm moves down in a full breath, then let your abdomen relax as you exhale completely. Breathe continuously, with no pauses between the exhalation and the inhalation.
- With closed eyes focus attention fully on the Dan Tien. As thoughts arise simply let them go. You may start to feel a warmth in this area and a deep sense of relaxation. Continue focusing and breathing like this for fifteen minutes or so. Practise twice daily.

The Three Treasures

Daoists understood that there are 3 principles that help us live in harmony with a changing universe. The first is Kindness, the second is Moderation, the third is Humility. When faced with this pandemic Kindness - tender compassion and benevolence is crucial if we are to learn and grow as a result of these challenging times. We are seeing incredible acts of charity and kindness as people open their hearts and purses to help others. And Moderation is without a doubt the order of the day in these troubled times. Nature is the foremost teacher in Daoism and we learn from her to waste nothing. Let go of craving new stuff, make do and mend - a life of moderation and simplicity is the way forward and is in fact the choiceless choice. The third treasure is Humility. Adverse times such as this pandemic are the great leveller - your career, titles, money, power cannot protect you from destructive forces. We are all suddenly in the same vulnerable boat and this is truly a humbling experience.

Now we realise we are not separate beings - we are all part of the process called Life. Daoists were the first organised environmentalist movement and taught that we are all part of the web, the process of life - all in this together. From this place of Humility we can reach out to live lives of Moderation and Kindness - sharing all that we have and letting go of desiring more. This also means that for now we are witnessing a curbing of the ravaging of the natural world –pollution levels are falling as many heavy industries grind to a halt, people are no longer able to fly willy nilly here and there - it seems this might all impact positively on climate change. Hopefully this change in habits is something that will continue even after the virus threat is over.

Health and Longevity

One of the key aspects of Daoism is the focus on looking after one's health. Daoists see that the purpose of life is to feel fully alive and to this end the emphasis is on cultivating longevity. To feel well and live a long life Daoism teaches us how to balance our energy by exercising, by eating in harmony with the seasons, by keeping a sense of humour. Daoists see illness and its signs and symptoms as an opportunity to encourage and restore the flow of Chi energy so that healing takes place and harmony is restored. Interestingly, in Chinese character writing the same symbol is used for the word "crisis" as for "opportunity". Thus whatever creates a disturbance in the flow of life, whatever stressors create crisis, will also serve as an opportunity for fresh growth. Coronavirus, as a threat or a reality can be an opportunity to restore health and balance to your life.

Eat Well

Eat well and in harmony with the seasons...eat foods that are fresh and locally grown. In summer raw foods are best but when winter comes forego salads and, in keeping with the season eat warm, cooked food such as stir fries and stews made with earthy root vegetables. Daoists also realise that if

you are elderly you might be best eating hot cooked foods all year round and forget about salads in the summer. Daoist diet is all about using these ancient principles along with your intuition and common sense to keep your immunity strong and healthy! Omit foods considered to be Damp in the theory of traditional Chinese Medicine - sugar in all its shapes and forms is to be avoided as are dairy foods. As we hunker down and make do and mend this is the time to make meals from scratch - soup costs next to nothing and a pot can be kept on the go and added to daily. Any left overs? Add them to the pot.

Relaxing Exercise

Daoist exercises such as Chi Gung and Tai Chi have been practised for thousands of years and you can easily access you tube videos to learn how to practise these gentle and relaxing movements. Perhaps one of the simplest and yet most incredibly potent forms of Daoist exercise is Standing Meditation. Yang Yang, founder of the Centre For Tai Chi And Chi Gung Studies in the US says "Standing meditation is one of the fundamental training methods of internal Chinese martial arts.... Practitioners hold standing postures to cultivate mental and physical relaxation, tranquillity, awareness and power.... Standing meditation improves core strength, balance, bone density, power, awareness, sleep quality, body alignment, efficiency of movements, and mind-body connection". Yang Yang has conducted research studies into standing meditation at the Kinesiology faculty at the University of Illinois in the US, and found significant improvements in balance, strength, immune function and well being. He says "In one of my research projects, the lower-body strength increased by about 20 per cent after six months of taking part in a one-hour class, which included about 20 minutes of standing, three times per week."

Try practising Standing Meditation on a daily basis and see an improvement in energy and well being. If you cannot stand for any reason then practise this seated.

Standing Like a Tree

If you cannot stand then do this exercise from a seated position. Wear loose comfortable clothing. Gently bend your knees slightly and align the spine vertically so that it is as straight as possible but do not strain to be perfectly straight. Relax your head, neck and shoulders with arms in front of the body but bent gently at the elbows and hands - positioned so that it appears as if you are holding a giant bubble in front of your navel.

Place your tongue on the roof of the mouth just behind the front teeth. Close your eyes relax your breathing and simply watch your thoughts go by rather than clinging to them.

If your legs begin to ache simply increase or decrease the bend of the knees slightly to allow the muscles to pump blood. If your arms become tired, it is usually because you are trying to hold them up. If need be, simply move them so that your hands are slightly higher or lower than the original position in front of the navel. Begin with five minutes and build by five minutes per day until you can stand for 20 minutes in one session. As you stand feel the chi filling you from above and below and know that you are fully alive, fully and powerfully present! Practise this exercise and Hara breathing daily, eat well and most of all remember that Laughter is the best medicine - stop watching the anxiety provoking rolling news and get onto a comedy channel! Stay well.

ABOUT THE AUTHOR: Vicki McKenna trained at The College of Traditional Chinese Acupuncture in Leamington Spa with Professor Worsley from 1981 gaining her Lic Ac. in 1984 and has been practicing acupuncture in Scotland since then. You can contact her vickimckenna51@hotmail.co.uk Vicki is the author, as acupuncturist and polio survivor of "A Balanced Way of Living; Practical and Holistic strategies for Coping with PPS".

To purchase a copy see www.postpolioinfo.com/balanced_way.php

International Centre for Polio Education - A Balanced Way of Living

A BALANCED WAY OF LIVING, Vicki McKenna's wonderful book is an "inside out" way of thinking about and managing PPS. Her practical strategies and holistic approach encourages even Type A polio survivors to slow down and listen to what their bodies, hearts - and even souls - are telling them. "Do for yourself as you have been doing for others"

www.postpolioinfo.com

THE FOUNDING OF THE SCOTTISH POST POLIO NETWORK (SPPN)

In the late 1990's I began to experience the late effects of polio. I wrote about this time in my book "A Balanced Way of Living; Practical and Holistic strategies for Coping with PPS". This is how I felt then ;

" I had always led a very active life in spite of having had polio as a baby and wearing a calliper as a result of the disease. Even though I managed to achieve a great deal there were always more hurdles to overcome - gaining a degree, travelling, learning different skills including those involved in becoming a mother; all of these experiences were rewarding but there were always, metaphorically speaking, more mountains to climb! When I was 30 I embarked on training to become an acupuncturist and after 3 years gained my license to practise. Working full time with 4 kids under 10 was challenging but did not phase me - I even found time to go swimming every other day and gave time to various committees! Of course I was on a merry go round that got faster and faster until it spun out of control. My poor old body was not prepared to keep up the hectic pace I had set it and with the symptoms of PPS becoming too strident to be ignored, I finally had to let go of pushing on and give myself a break."

At the time of writing those words at the end of the twentieth century, thanks to the techno revolution that had recently given us the internet, I was able to gather much information about PPS but still felt very alone in my search for answers. As I spoke to other polio survivors and recorded their stories to include in my book I began to realise that there were many of us out there and that we needed to get ourselves organised!

Billy was one of the first polio survivors that I interviewed for my book and I wrote ;

"Billy from Glasgow, is also finding a need to fight on behalf of polio survivors and he was in the process of setting up a polio support group when I spoke with him.

He had only recently heard of PPS but had been struggling with his health for years. Finally, due to an article in a local newspaper, he was relieved to discover that the label of PPS could explain the underlying cause of his deterioration. When Billy contracted polio at 3 years old, he was put into an iron lung and when he came out it was to find that he needed to wear callipers on both legs. As he got older he managed to get by with only one calliper and being the fighter that he is, he "went into automatic" as he put it, working hard as a housing manager for the local council and bringing up 5 children. This tendency to get on with life and take on its challenges without a moment of hesitation, is by no means curtailed now that Billy finds himself in a wheelchair in his forties as a result of PPS. He is "angry and annoyed" to find that many health professionals have not heard of PPS and wants to change this for himself and other polio survivors by campaigning for more awareness of PPS."

Meeting with Billy and hearing his story was in fact the start of the SPPN although neither of us realised it at the time!

Thanks to the sterling work of Hilary Ann Boone (Hallam as she was then) and through her organisation the Lincolnshire Post-Polio Network - I connected with another Scottish polio survivor-- Agnes Walker from Edinburgh. Agnes had a wealth of experience when it came to practical organisational skills and it soon became clear that she and I and Billy should all get together and see if we could create a support group of some sort. And that was how 20 years ago the core group that became the SPPN met to share experiences as polio survivors with PPS and also to have a laugh, a blether and light refreshment at a very cosy pub just outside Stirling. A few more local polio survivors members joined us from Glasgow and like Topsy our group grew and grew!

As time went by we formed a committee and thus the SPPN became a registered charity. From those very early days we decided not to be a "moan and groan" group. Although we were there to share our frustrations with regards to living with PPS and also with regards to the lack of support from the medical world we decided at that first meeting that we were not there to have a griping

Subject: Request for help with the circulation of a COVID-19 research survey

Dear Polio Survivors Network,

We are writing to inform you of an online survey investigating the Impact of the COVID-19 Pandemic on Physical Activity and Health-Related Quality of Life in Adults with a Neurologically-Related Mobility Disability.

This study is a collaborative effort between Dr. Tom Nightingale (Lecturer in Exercise Physiology), Dr. Sally Fenton (Lecturer in Lifestyle Behaviour Change), Dr. Jet Veldhuijzen van Zaten (Lecturer in Biological Psychology) and Dr. Nicola Heneghan (Senior Lecturer in Musculoskeletal Rehabilitation Sciences). All investigators are part of the School for Sport, Exercise and Rehabilitation Sciences at the University of Birmingham and have a significant interest in and experience with assessing lifestyle behaviours in different population groups.

Purpose of this study: The purpose of this study is to understand the effect of the COVID-19 pandemic on physical activity levels and health-related quality of life in adults with a physical disability. We plan to capture changes over time as the UK Government alters their procedures to manage this pandemic. We believe the information gathered will help us to better support individuals with physical disabilities, not only during future events involving periods of isolation, but during their everyday lives to engage in health promoting behaviours. This study has been reviewed and approved by the Science, Technology, Mathematics and Engineering (STEM) Ethical Review Committee at the University of Birmingham.

What are we asking from you? We ask that you consider sharing the link for our survey to your mailing lists and promoting on social media so that we can ensure a fair and broad representation from different groups with physical disabilities in the UK. Please take the time to consider this request. Circulating and promoting this link is entirely at your discretion and there is no obligation for you to do so. If you require further information to make an informed decision please contact the study principal investigator Dr. Tom Nightingale T.E.Nightingale@bham.ac.uk

Survey weblink: <https://bit.ly/3iRbTWC>

The participant information sheet and consent form can be found on the first two pages of the above link.

Thank you for your consideration.

Sincerely, Dr. Tom Nightingale

Tom Nightingale, PhD
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Email: tnightingale@icord.org

Simple Things to Spread Happiness:

- Give a sincere compliment. It can mean so much!
- Say thank you for something you may have taken for granted recently.
- Share a joke – good or bad!
- Smile – it is contagious.
- Call someone out of the blue, spontaneous conversations can be the best.
- Listen – if you know someone is having a bad day it can help to have a listening ear for a few minutes.

POST-POLIO SYNDROME - The **Pitfalls** and **Helpful Tips** From a Polio Survivor with 32 years experience of PPS.

A strange title you may think? Sharing with our peers across the world has given PPS groups a huge database of information. All diagrams are from my various PowerPoint presentations.

Let's start with a few definitions.

Infantile Paralysis - Polio - Poliomyelitis

Terms used to describe an infectious viral disease caused by one of three polio viruses. PV-1, PV-2 and PV-3 that are ingested through the mouth, go through the gut and can then go on to affect the nervous system. **Only 5% of the people who ingest the virus are affected from a 'mild flu' through weakness to 1% having temporary or permanent paralysis with some dying.** Confirmation is by throat, stool or spinal fluid sample showing poliovirus.

Interesting Point I found today. The first medical report on **poliomyelitis** was by Jakob Heine, in 1840; he called the disease Lähmungszustände der unteren Extremitäten ("Paralysis of the lower Extremities")

Criteria for a Diagnosis of Post Polio Syndrome:

1. A history of remote paralytic polio or findings on history, physical examination results, and laboratory studies compatible with polio virus damage of the central nervous system in earlier life. [Halstead L, MD, Silver J, MD. Am. J. Phys. Med. & Rehab. Jan/Feb 2000]
2. A period where we recovered.
3. A stable period of functioning, from 10 to 50+ years.
4. New symptoms with no other explanation.

There are NO tests. It is a diagnosis of exclusion of all other conditions.

Now I move on to the **Pitfalls** that I, and many others worldwide, have experienced when seeking answers for unexpected new symptoms after a long period of stable functioning. The purpose of sharing this information is to also give some **Helpful Tips** to hopefully help you manage them.

Helpful Tip 1 My Polio Life was developed to help us and then you self assess and 'see' more of the facts that would help you in your journey. <https://poliosurvivorsnetwork.org.uk/enter/my-polio-life>
There is also a copy with some sample answers from different people to give you an idea.

We recommend that you start a Box, Folder or File to contain all the information you collect - photos, old letters, school and medical reports/test results/anything that will help you provide more pertinent information. The form only has room for short comments to help you remember important points so you will need to write/type these up in full. From this prepare **One or two pages double spaced with information specifically for each appointment, plus a photo or two and a coloured chart.**

Going into a health professionals office dragging a bag full of medical articles etc is **not advisable**. Think how you would feel if you were the health professional?

Pitfall No. 1 - How many Survivors of Polio look like the photos in medical literature?

At my first PPS Conference in the USA we were told 'observe well what we are going to do next'.

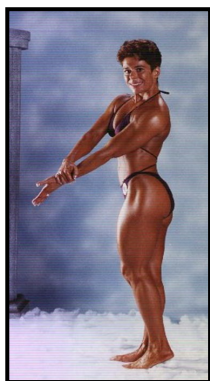
'Would all Polio Survivors that can please stand'. Apart from those visibly in wheelchairs and on scooters nearly everyone had stood up. Wow! I had never seen so many polio survivors.

Then came 'If your polio damage is easily visible please sit down.' A few sat down but not as many as I had expected. About half attending were still standing.

Then "if you are not a health professional please sit down". More folks sat down but there was still an unexpected number standing.

Health professionals that were also Polio Survivors themselves. A few then told us that it was their prior polio that had led them to their current careers.

If you do not look like the pictures in medical literature have you been told you must have had a mild case? Lots have and seen the surprise when we tell them we were paralysed waist down.



Which lady is the Polio Survivor?
The one on the left or the one on the right?

The photo on the left was taken in 1995
Gwen competing in a body building competition.
She was a Head Nurse of a 50 bed ward.

The picture on the right was taken in 2003 and showing
the photo on the left at medical appointments
demonstrated the changes.



Helpful Tip 2 Photographs from your earlier life.

Pitfall No. 2 - The number of facts taught to medical students about Polio.

The greatest number catching polio in the world in the 1950's was in 1952, the year I caught it in Benghazi, Libya. Thankfully the success of the vaccine from 1955 reduced the numbers of people catching polio decade on decade. In the 1980's the world figure was about 350,000 a year in 125 different countries. As a response the "Global Polio Eradication Initiative" (GPEI) was founded in 1988 to fight the virus's spread and disease burden with a global vaccination campaign. Since then the world has made rapid progress against the disease and until 2016 the number of paralytic cases was reduced by 99.99% with 42 cases in that year worldwide.

[www.ourworldindata.org/polio] WPV is wild polio virus. cVDPV is circulating vaccine derived poliovirus.

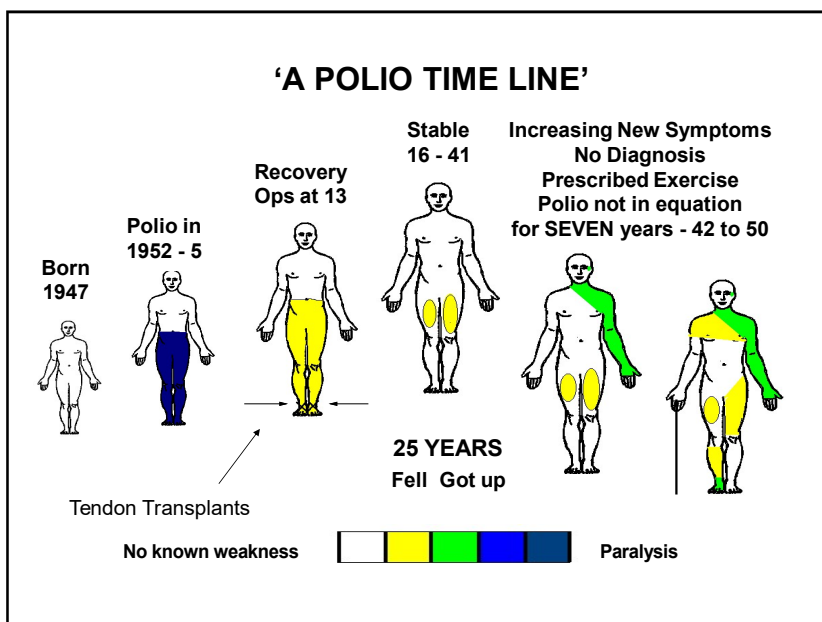
January 1st to July 10th 2020 is **81 WPV** and **194 cVDPV**

January 1st to July 10th 2019 was **60 WPV** and **62 cVDPV**

Covid 19 is having an effect on the continuation of the eradication plan. Since the start of the COVID-19 pandemic, polio workers around the world have had to adapt their work to provide support and information within their societies.

[<http://polioeradication.org/polio-today/polio-now/this-week/>]

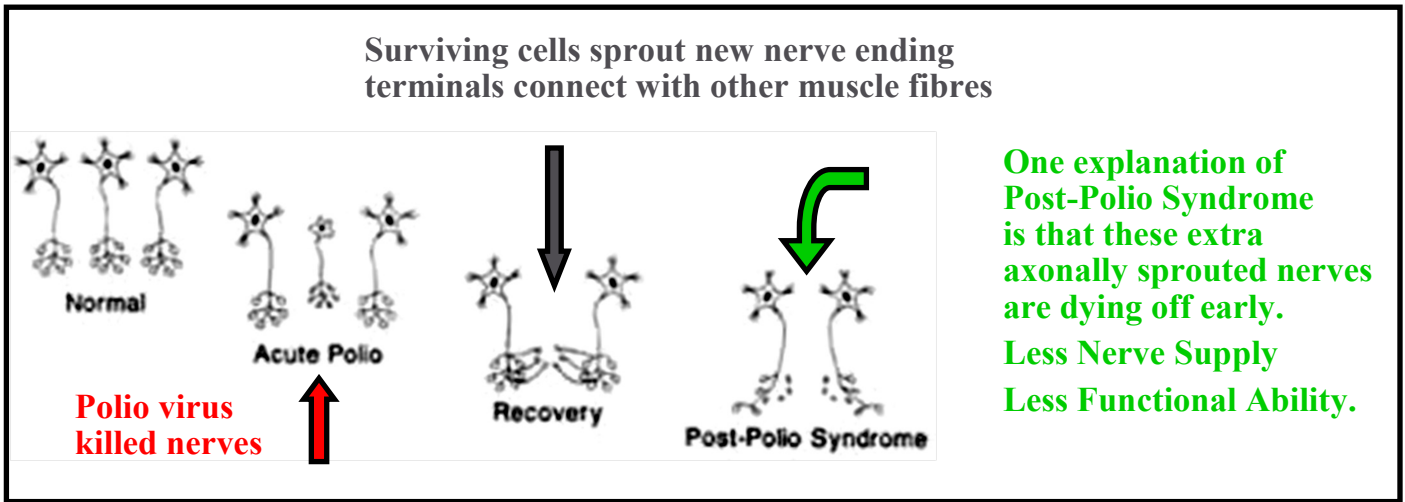
The reduction in numbers catching polio led Colleges of Medicine to reduce the number of facts they taught to their students about polio. The Lincolnshire Post-Polio Network was founded in 1996 and at the end of that year we learned that for doctors polio was a half hour lecture combined with leprosy. If you are the health professional and all you were shown was some medical literature and photos of the worst affected would you have any idea how many of us recovered that we are not easily visible as Polio Survivor's.



The lower the number of facts taught the harder it is for a medical professional in the UK today to suddenly find themselves with 'you with your experience of polio and all your pps symptoms and issues in front of them.' How would you feel if you were this health professional meeting you and all your problems?

Helpful Tip 3 Visual items are a quick way to show the changes. Colour in a body chart from My Polio Life. **Enclosed with newsletter is a body chart for you to use to show pre polio, with polio, stable years and changes, use a second sheet for more changes.**

Helpful Tip 4 - Polio Survivors wonderful recovery system.



Pitfall No.3 - Single Action Manual Muscle Testing was developed over 100 years ago and used widely across the world.

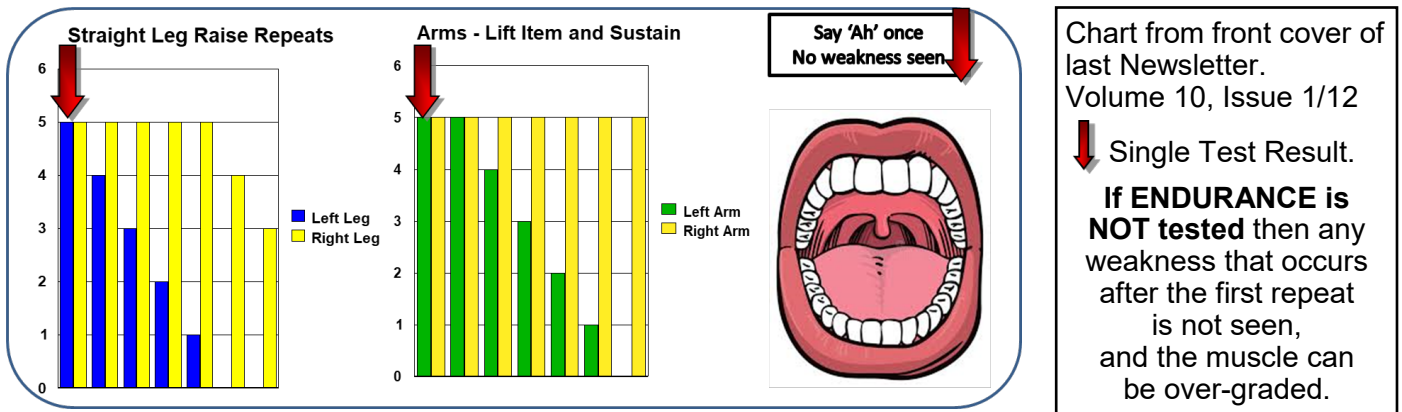
Testing a single time does not test the endurance of our polio muscles. It does not test our repetitive or sustaining power or the ability of the muscle to perform as a pattern of movement. In early 2002 I wrote and asked Dr. Halstead and Dr. Maynard about this issue.

Lauro S. Halstead MD - May 2002 - Director of Post-Polio Program NRH Washington DC

If done only a single time, it can give an erroneous idea of the true muscle strength and endurance.

Fred Maynard, M.D. - May 2002 - President Board of Directors, Post Polio Health International.

"You have done a brilliant job of describing a real problem for polio survivors and professionals that is, the limitations of the Manual Muscle Testing"



© Physiopedia - A UK charity providing info for Physiotherapists.

<https://www.physio-pedia.com/Muscle Function: Effects of Aging>

The age-related loss of muscle function is known as **Sarcopenia**, derived from the Greek words for flesh (sarcos) and loss (penia) and its definition includes loss of muscle strength and power, as well as reduced function. It occurs with increasing age, and is a major component in the development of frailty.

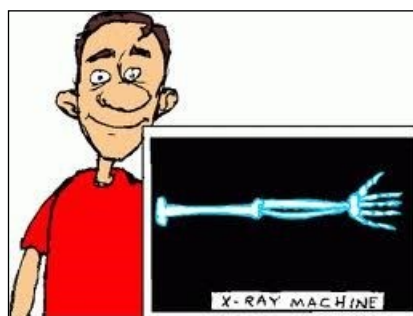
The loss of muscle mass during the aging process is important clinically as it reduces strength and exercise capacity, both which are needed to perform activities of daily living.

Polio Survivors have already loss muscle mass when they caught Polio. They then recover to varying levels but most often not as high as they thought. These nerves are dying off early and we say things like 'I am 50 but some of my muscles feel 85 now'

Helpful Tip 5 - “Tell it like it really is”

Medical appointments with our free National Health Service are often restricted to a certain number of minutes. You need to make every word you say count.

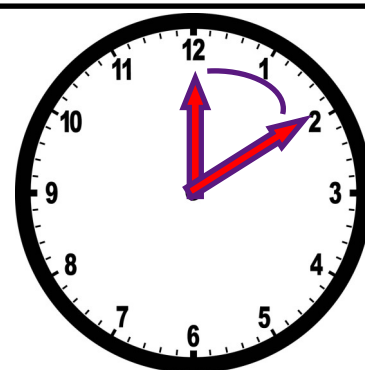
From my presentation 'Painting the Same Picture Can Improve Clinical Outcomes' at the Second European Polio Conference in Amsterdam in 2014.



Doctor takes your History then examines you, arranges others tests and then discusses results.

SOMETIMES IN AS LITTLE AS TEN MINUTES

Doctor, I used to walk upstairs normally but now I have to go up right leg first one step at a time and stop halfway. Please can you tell me what is causing this change?



Can you get up a flight of stairs?



I am a Polio Survivor. I have never admitted defeat and I am not going to start now.

Yes



I go one step at a time, right foot first, pull myself up with the rail, Oh! and stop half way for a rest.



How many times have you been asked a closed question? Can you do x?

How many times have you proudly said “Yes”

Did you paint the same picture in the health professionals mind as yours of HOW you actually did the action asked about?

If not, then you did not do yourself or the health professional any favours and were wasting valuable time.

How many Polio Survivors reading this have said “Yes” when they have got up a flight of stairs by sitting on their bottoms and lifting themselves step by step and resting every few steps but got to the top?

Look at my Polio Life page 10. It provides a list of actions of daily living. The important points to share with your health professionals are the difference between how you did the action at best recovery and the changes since.

My experience. All assessments for 7 years after my fall in 1988 did **NOT** find any of the weakness I was reporting. I was given physio exercises at the hospital including standing and sitting repeatedly from a chair and at home to go up and down stairs twice every time to strengthen my muscles. I tried I got worse. I was told I was not trying hard enough. **My prior polio was NOT in the equation.**

If only I had known to say, “Prior to my fall I was a Swimming Teacher and Lifeguard with very strong arms because my legs are weaker from Polio. I passed the RLSS Bronze Medallion every 3 years. Now after 6 months training I still cannot pass this test and have lost all my jobs. I cannot swim as fast, I cannot lift myself and the body towed out at the deep end of the pool. What is wrong?”

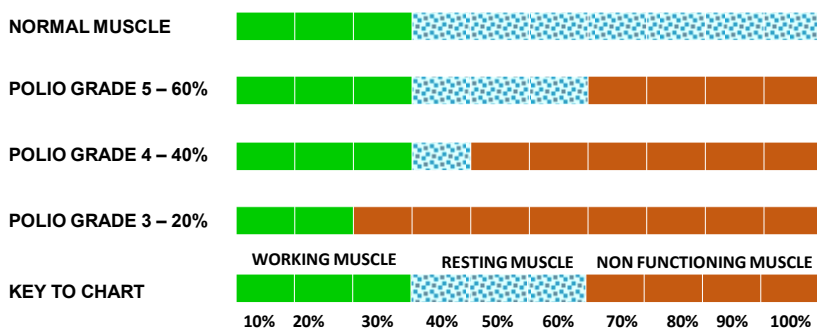
Helpful Tip 6 - Less nerve supply to muscles means less functional ability.

Below is a chart that shows working muscle, resting muscle and for polio survivors non functioning muscle. The top line is non-polio folks who have an average of 30% of muscle working and therefore 70% resting. 30% can take over and there is still 40% resting to take over after that.

However, W.C. Beasley and J. Perry found that when normal muscle grades were given to polio muscles they were actually functioning at a lower level. They had less or no resting muscle to take over. It does not take a medical degree to see that if you do not have enough resting muscle to take over and you continue to push actions then you will have problems. Overuse will likely cause you more pain; your having to stop and rest for some time and could cause those precious axonally sprouted nerves to fail earlier than necessary.

W.C. Beasley [1961] and Jaquelin Perry MD [1995] found that when normal muscle grades when given to polio muscles that they were functioning at a lower rate.

Grade 5 at 60%, Grade 4 at 40%, Grade 3 at 20%.



Helpful Tip 7

Muscles that do not have enough resting muscle to take over will fatigue quickly.

The endurance of your muscles must be taken into account when grading them.

Exercise can now be planned to your physical level.

Helpful Tip 8 - Pace and Rest all activities to your level.

This means do a bit of an action and stop 20% before pain or fatigue. Rest and allow that muscle to recover and it should do the same action again. The Resting Times most likely will get longer and the Doing Times shorter. The most important and wonderful statement is that overall you will be able to do MORE of that action with LESS pain and LESS fatigue.

Helpful Tip 9 - Use Energy Tokens to Plan the Week Ahead.

One token is £10.00 and you can have ten tokens a day and that makes £70.00 per week. Unfortunately we cannot say how much each token will allow you to do because we all have different levels of ability and stamina.

First you have to list the basic actions of daily living that you have to do, like washing, dressing and undressing, preparing meals, cooking or reheating, eating, Washing up, turning over in bed, etc. Once you have a basic days action listed then decide how much of the £10 is needed to do each action. Remember you have to save some energy tokens for when you go to a medical appointment, go out for a haircut, have a meal out, visit relatives, the theatre etc.

Plan the week ahead. Remember £70.00 is the maximum for the week. Any day that needs more tokens means that the day/s before or afterwards will need to use less. Some of your normal actions will have to go, e.g. have a pyjama day. Is there any equipment that would save you energy or could you ask someone to do the heavy part or all of a task for you? It does take a bit of practice to get it right but hopefully you will find you can do more of what you want to do.

Polio Survivors are known world wide to be the most stubborn, determined, strong willed folks and 'Cannot' is not in our vocabulary. I have spent 24 years talking to a huge number of polio survivors. Often a few years later they contact me again and say 'I wish I had listened to what you told me earlier because pacing and resting and using aids and equipment and help from others means that I am no longer crashing out exhausted every day.'

Pitfall No 5 Exercise is recommended for a healthy lifestyle but...

For Polio Survivors - and others with similar neuromuscular conditions - there are a **few Pitfalls** that it is best not to fall into. There are different ways to exercise, different equipment - a variety of exercise machines, dumbbells, weights, resistance bands etc - and a variety of different professionals that will advocate their ways. We are all different and have different areas of polio nerve damage and different levels which does not make it easy for our health professionals.

As a qualified Advanced Swimming and Life-saving Teacher who has worked in and on the Poolside with a huge variety of disabilities I know how much benefit being in the water can be. Warm water is lovely because it helps relax tight muscles and we can do exercises in water that are not possible on land.

Stretching exercises are so much easier in the pool. Gently move your neck side to side and front to back. Stretch your arms and legs. Remember start low and increase at your level. It is not a race, be like the hare, slow and steady. To get any benefit from the time in the water you need to ask others to drive you there and back, load and unload wheels if you need to use them. Put your swim stuff on and a track suit over the top. Anything that will help you reduce the number of energy tokens to the minimum so you get the benefits of being in the water. We manage this by having a hot tub at home where we can do all the exercises we need. We are managing about five times a week at the moment and only go in when there is a Carer here to help for safety.

Do you breathe shallowly at times? Have you tried a few deeper breaths now and then to stretch your intercostal muscles [between your ribs]? It is much easier to do with chest under water.

The Pitfalls Together are where the health professional/therapist are NOT AWARE:-

- A) that polio muscles function at a lower level and
- B) that we do not have as much resting muscle and therefore are unlikely to be able to do the normal sets of ten repeats.
- C) that if single action manual muscle testing has been used to grade our muscles they could have been over graded.
- D) that only the higher graded polio muscles can be strengthened and only to a level where you do not experience muscle fatigue,
- E) and that if Points A to D are not taken into consideration that the use of any extra equipment like exercise machines, dumbbells, weights, and resistance bands **could** cause more harm than good. The word could has been used because there will be times when with the correct knowledge and understanding of points A to D some of these may become part of the prescribed therapy.

The Benefits to Health

Taking all these facts into consideration and with the agreement of your G.P and/or your polio and post polio knowledgeable health professional plus accurate grading of your muscles a decision can then be made as to which therapies are right for you, where and with what equipment you need to go to do them. Don't forget as with swimming you have to factor in the going and coming back from a venue into your Energy Token Plan.

An explanation of each exercise, what it does and why it is beneficial for you to do this really helps. Whatever is eventually decided upon it should be a partnership between you and each therapist.

What is very important is that you both take on board that basic Actions of Daily Living have to come first before the base level is set. The next problem is that there are days where you have to do something extra - like attend a medical appointment - and there is no spare energy that day and sometimes the day after. Fit what you can into your weekly energy token plan.

Start low, start slowly and move forwards at your pace. Whatever you achieve overall will be of benefit to your overall health.

Helpful Tip 10 Remember if it hurts or makes you exhausted then stop doing it and think..

I have a few different options....

1. I can Pace and Rest and not push myself till I drop.
2. I can try out some aids and assistive devices and see how much less pain and fatigue I have using them.
3. I can halve the time I spent doing the action and see what difference that makes. Halve again till you reach an optimum number of repeats and time you can spend on each action of daily living or exercise.
4. I could try all three.

We know its tough doing this the first time because all of us that are doing this have been there and experienced this. I remember in our early charity years when a member rang me and said she had been delivered ten items by the OT to use and she was mad, I don't need this stuff, I can manage. I suggested that she try them all first and see if any were of any help. She said "OK" put the phone down. Two days later she rung me and said, "Ok you win, I am keeping two of them".

STOP PRESS. Advice for those staying at home during the Covid-19 times. "Evaluate how active you are now compared to before you started physical distancing. If you are less active, then set a goal to get back to your previous activity level (**your baseline**)" Dr. Julie K. Silver. Author of **Post-Polio Syndrome: A guide for Polio Survivors and their families.**

Excerpted from AARP website. Dr. Julie K. Silver is an associate professor and association chair in the Department of Physical Medicine and Rehabilitation at Harvard Medical school and a medical staff member at Massachusetts General, Brigham and Women's and Spaulding Rehabilitation Hospitals. <https://www.aarp.org/health/conditions-treatments/info-2020/prehab-during-coronavirus.html> - note full article is not specific advice for polio survivors.

Pitfall No. 6 - Neurological Services need more funding. The lack of accurate statistics how many people have each neurological condition has been a stumbling block for years.

I am also a founder member of the Lincolnshire Neurological Alliance - January 1998. The first most surprising fact was in 2000 when the results of our questionnaire to all groups what are your members ten top problems gave 13 responses. **9 were almost identical issues** and the remaining 4 specific to condition. The support groups and NHS and LCC staff in attendance were all surprised. Sadly we add to that the second reason for the lack of adequate neurological services in many counties is the lack of accurate numbers for each neurological condition. As single conditions we could be told there are not enough of you to warrant funding but TOGETHER a whole different picture. Despite the LNA campaigning year on year - providing the same information to yet another newly named group every few years - 'THEY' have still not collated the statistics of how many people in each GP surgery are diagnosed with each condition. We need these facts to fight for the improvement to services needed in Lincolnshire.

The March 2018 Independent Report by the University of Lincoln HARG A Health Needs Assessment For People Living With Neurological Conditions In Lincolnshire.

<http://eprints.lincoln.ac.uk/id/eprint/32510/> did support our work but with only 84 responding does not appear to be enough to speed up the process of promised joint discussions.

Pitfall No 7 - Health professionals who have little experience of seeing polio survivors with late effects of polio and post-polio syndrome issues. Where do you go? This is hard for us as a Charity to answer because we hear good and bad things about the few different places and professionals there are in the UK.

Covid 19 has had an impact on this because staff and resources have been moved in many hospitals to help Covid patients. In Lincolnshire we have been told they will be back in touch once things settle. In the last few months we have Covid 19 and the polio virus gets mentioned. Now we hear that a number of people have described debilitating symptoms for weeks or even months after developing Covid-19. Scientists want to establish if "post-Covid syndrome" should be recognised as an illness in its own right. This is all very worrying but maybe Post-Polio Syndrome and our issues will become more recognised now?

Hilary Boone, Polio Survivor of 1952. Founder of Polio Survivors Network.

"Introducing our member... Yvonne"

I'm Yvonne from Derbyshire and joined this very informative network quite a few years ago.

At the age of 10 months I contracted Polio when we were living in Army Married Quarters in Aldershot where my dad was an army nurse. My parents were incredibly supportive and encouraging and therefore I grew up believing I could achieve anything. They moved to Harlow New Town in 1955 when Dad came out of the Army and here I had an idyllic childhood alongside the very many children and families who had moved from London, ecstatic to move into a new house and countryside everywhere. A lovely community grew in our area and I can honestly say although I wore a knee length calliper until I was 11, I never ever suffered any micky taking or teasing.

An ankle fuse and tendon transplant together with knee stapling by Mr. Fisk at both Epping and Harlow hospitals completely changed my walking abilities and by the time I was 16 I felt incredibly lucky to have had the full force of the NHS working together to help me.

Passing my driving test at 17 was the single most liberating and exciting achievement, all down to my wonderful Dad who when I was around 12 would take me over to a disused wartime American airfield on Sunday mornings and taught me to drive in the family car.

I worked as a telephonist receptionist, then moved onto stock record clerk/parts collection driver until I met my husband and moved up here to beautiful Derbyshire.

We have a daughter, a son and daughter-in-law and two gorgeous granddaughters who live locally, and are a joy.

For a few years while the children were growing up I stayed at home, making a friend Daphne who fifty years later is still my loyal friend. A domestic science teacher/needlework teacher she tried her to pass on some of her skills. Needlework/dressmaking fabulous cooking... I had no interest in whatsoever!, still don't!

Returning to the workplace found me as a special educational needs teaching assistant for 25 years, a job I adored. However, I was beginning to wonder why I was getting so tired and walking was becoming harder, making life in school exhausting. So it was with interest I heard Peter Jay from the British Polio Fellowship speak on the radio about PPS and everything fell into place. My GP did some research and found a Consultant Dr. Whiteley at Queens Medical Centre in Nottingham who made his own knowledgeable conclusion of PPS.

Having never met or spoken to anyone else with polio during my life, which I know sounds unbelievable, I started to look for information. I found Hilary and the Linc-Pin - I still call it that, sorry Hilary, in my head it is the Link-pin which joins us all together. Speaking to her, I found her friendly and ultra-informative.

Like Hilary, my darling husband has Parkinsons, which makes life very interesting?!!

I love the fact that Hilary is doing a monthly newsletter, giving us something to look forward to, especially 'our' stories. We have a chance here to get to know each other through the pages of 'our' newsletter and I hope many of you will put pen to paper/email as I have done..

Love Yvonne.

P.S. I've always been a crafty person for as long as I can remember, and it was during a stay in Epping Hospital for several weeks following an ankle fuse aged around ten years that I was delighted when a lady used to come to the ward a couple of times a week. She was probably the most patient lady I have ever encountered. She spoke like the Queen and smelt heavenly... She tried me with knitting.. Nope and even today I 'can' knit but it is not my favourite. Sewing I quickly mastered and still love. We made 3 figures among other things, made from wool, felt and pipe cleaners. Those days that felt like years in hospital flew by when she came on the ward. I still have them. They go on our Christmas Tree every year. My children and granddaughters, always mimic 'I made these when I was ten'

My latest interest is rabbits, felt rabbits and as rabbits do they are multiplying. See photo on back page. I found a Book by Sarah Peele - Making Luna Lapin. Sew and dress Luna, a quiet and kind rabbit with impeccable taste. My daughter Kerenza and I were completely hooked. We sent for 2 kits and made from wood felt and liberty fabric they are gorgeous and cry out for dressing.

Its rather worrying that my daughter who served her apprenticeship as a joiner has had to make her rabbit a wardrobe to house all its clothes.

To make matters worse, my lovely friend Pauline, who is a master knitter found the book 'Knitted Animal Friends' by Louise Crowther, and got completely carried away knitting clothes for our rabbits. Cardigans, shoes, trainers, duffle coat, and even a rucksack which I filled with a tiny plastic bottle of champagne, a picnic rug and a map. It continues....

I am sure there must be many of your out there making things, spending pleasurable hours creating. My friends husband does the most wonderful cross stitch pictures. So if there are any fellow crafters out there it would be lovely to hear from you and share stories and pictures. With Hilary kindly giving us a monthly newsletter during this awful pandemic, we could help her fill some of the pages.

I have been a member for some years and I would love to hear from other members too in the newsletter. To be honest the world is our oyster as far as subjects go. Technology is not my forte but I will endeavour to send Hilary some rabbit photos so you can see what I have been up to [tech success!—see [back page](#)].

To finish off, I had a chat to a lady walking her dog past our house and we got talking about what we were doing to keep occupied during lockdown. She told me that she had got her 'Redicut' rug down from the loft... she had had it 35 years and now had nearly finished it. I complimented her on her achievement and asked where in her house it would go when finished? Back in the loft, she said, it doesn't go with my colour scheme.

Editors note: There is more for the next newsletter.

Seen on Facebook, shared by Helen Spencer:

Just seen a news report about the stresses and strains of self isolation. It reported that people are going crazy from being in lock down! It was strange, actually, because I had just been talking about this with the microwave and toaster and all of us agreed that things are getting bad. I didn't mention anything to the washing machine as she always has to put a different spin on everything, and certainly not to the fridge as he is acting cold and distant. In the end the iron calmed me down. She said everything will be fine, which surprised me because she's usually the first one to apply unnecessary pressure and get steamed up over nothing!!!

Simple Sweet Treats:

Frozen Berry Yoghurt (serves 4)

- Blend 250g frozen mixed berries
- 250g Greek yogurt
- 1 tablespoon honey (or agave syrup) in a blender for 20 seconds, until it comes together to a smooth ice-cream texture
- Scoop into bowls and serve. Enjoy!

Chocolate Mousse (serves 3)

- Snip 75g marshmallows in half and drop into a saucepan
- add 25g butter
- add 125g dark choc pieces (70% cocoa minimum)
- add 30 ml hot water from recently boiled kettle
- Heat, stirring occasionally until everything is smooth and melted, remove from the heat
- In a large bowl whip 150ml of double cream with 1 tsp vanilla extract until thick
- Pour chocolate mixture into cream and fold until combined
- Pour into small dishes/ramekins and cover with cling film. Place in fridge to set, at least 3 hours. Enjoy!



SunStar Zamboange July 8th 2020

CITY Health Office (CHO) personnel step up preparations for the third round of Sabayang Patak Kontra Polio in Zamboanga City.

The CHO said in a statement Wednesday, July 8, 2020, that the third round of anti-polio immunization drive is set from July 10 to August 2 for children below 10 years old.

It said that a series of orientation for health workers covering all health districts in this city is ongoing with emphasis on the minimum health setting standards as well as infection control protocols, as the world shifts to a new normal.

The World Health Organization provides technical assistance while the Department of Health provides logistics for the anti-polio campaign.

The conduct of the anti-polio campaign was slated from March 23 to April 4 but it has been suspended when this city was placed under enhanced community quarantine on March 20 due to the Covid-19 pandemic.

Corazon Pagotaisidro, City Health Office's Immunization Program coordinator, said that Bivalent Oral Polio Vaccine will be given to children from zero to 10 years old.

Pagotaisidro said the City Health Office is targeting to vaccinate 205,780 children in this city.

Original article:- <https://www.sunstar.com.ph/article/1862894/Zamboanga/Local-News/Zamboanga-City-health-office-readies-for-anti-polio-campaign>

PPM Editors Note: Zamboange is a City in the Philippines. It is the sixth most populous and third largest in land area and in 2015 it was recorded as having a population of 861,799

Picked above item then thought, Tom Post, who I met in 2000 in Branson lives in Philippines.

My name is Tom Post and I live in Oroquieta City, Philippines on the island of Mindanao. I have been here since January, 2016. We are supporting a high school initiative for students that cannot afford to pay to attend high school. It is a Christian program called HISchool. My foster son, Conmar, came up with the concept and our church in Santo, Texas is sponsoring 45 students at a cost \$300 per year per student. This has been ongoing for 6 years.

I used to use a Scrollsaw and make items but the dust started bothering me and I am limited to the amount I can lift because of my colostomy. I needed to find something I can do without overtaxing myself. So, Conmar suggested I paint cans or pots. I started with cans that food came in, but quickly progressed to pots. In the past 5 months, I have painted about 60 pots. Some I have sold, but most are used by Conmar in the garden. It keeps me sane, out of trouble (sort of) and off the streets. I have always enjoyed doing art and crafts. This is fun and useful. See photo of me and my pots on the [back page](#).

Do you shop at Amazon?

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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 email/post you one. Thankyou.

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

PatientPlus article POST-POLIO SYNDROME

Written by U.K. Doctors for Doctors

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

NB Respiratory and Sleep Problems Section very informative.

GOOD ANAESTHETIC ARTICLE - English version used by many PPS Groups

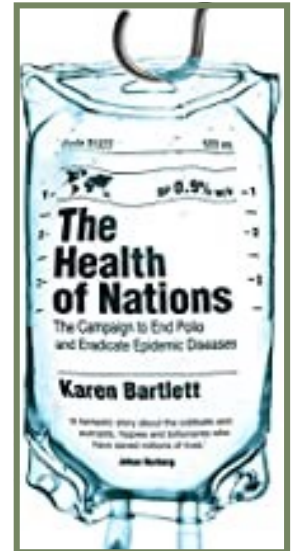
POLIO PATIENTS AND SURGERY - Information for health staff.

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

http://www.europeanpolio.eu/documents/13642_Polio_operation_eng_TRYK.pdf

Printed copies on our headed paper with permission are available.

Editors Note: Articles from Polio Survivors and Health Professionals welcomed



A Ministry of Health Film
narrated by Eleanor Roosevelt
1949 Polio Awareness Film
"His Fighting Chance"

The Health of Nations:
The campaign to end Polio
and eradicate epidemic diseases
by Karen Bartlett - 2nd March 2017

Excerpt from Chapter 2. The Crippler:

While Americans feared polio second only to a nuclear attack, Britain, by contrast responded to outbreaks with calls to keep calm and remain optimistic. **A UK Ministry of Health film**, released in response to a 1947 epidemic that paralysed 7,800 and killed 700, featured the two-year old Johnny Green, who started benignly into the camera, unable to raise his hands or head off the mattress. **"Go ahead Johnny and win through"** urged a stirring voice-over from Eleanor Roosevelt.

Watch here: https://www.youtube.com/watch?v=Zrli_MUai1s



Yvonne's Rabbit's
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Tom Post and his Pots - see [page 22](#)



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