POST POLIO MATTERS

Polio Survivors Network Newsletter
April 2024 — Volume 11 Issue 5 of 12 [125]

Our 125th edition of Post Polio Matters is a special milestone for us, as we celebrate the resilience and courage of polio survivors

Blooming Resilience
- Celebrating and Honouring Polio Survivors

We hope you find our 125th newsletter enjoyable and informative.
We appreciate your loyal readership and valuable input.
We are honoured to celebrate the resilience and achievements
of polio survivors with you.

Lincolnshire
Post-Polio Library
100+ articles

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

Donations and Charity Incentives Paid

(since last newsletter)

Cheque donation from DC	£50.00
Donation via Making a Difference Cards - from B&S in memory of Patricia Thomas	£60.00
Donation via Making a Difference Cards - from S&V in memory of Pat	£50.00
Donation via PayPal - from RB	£20.00
Donation via PayPal - from CR in memory of Emma's mum	£20.00
Donation via PayPal - from MW	£40.00
Cheque donation from A&S - in memory of Pat Thomas	£500.00
Total	**£740.00**

125

PayPal

PayPal donate link:
https://bit.ly/2KzyAyE

This publication is provided free thanks to your generous donations.

Thank you so much!

Editorial by Hilary Boone

My story starts during WWII when my father served in the Royal Signals and spent some time in the Benghazi, Libya telephone exchange.

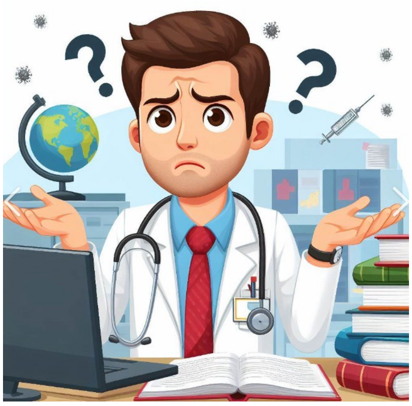
In 1952 the UK General Post Office were looking for someone to go out to Benghazi to organise the rebuilding of the telephone system. My father's interview was late in the afternoon and he was bluntly asked, "why do you want this post?" He told them he was fluent in Arabic and he had set the charges to destroy the equipment during a retreat. He got the job and within a few months along with my mother and younger brother we travelled on the SS Delwara landing in Tobruk where my father met us.

The yellow quarantine flag was flying because my brother and I had caught whooping cough and then a few months later I was paralysed waist down with waist down paralytic polio. I was taken to the Army Hospital in Benghazi and my mother told me that initially they were only allowed to talk to me from the doorway. My mother concerned about occasions I needed the toilet was met with the reply "Oh, I just have to call Orderly and they bring me a bedpan" When out of isolation my parents asked the doctors would swimming help me and it was not long before an Army truck took me to the Mediterranean for a swim each day. My father told me that I quickly learned to swim underwater and he would walk round after me to hold me up whilst I got my breath back. After a few weeks I was allowed home but with the Army truck picking me up daily for hospital physiotherapy. We came back to the UK. I could now walk but fell often. I had to have regular physiotherapy and so remember two of the exercises. The first has caused my feet to twinge. I had to sit on a chair with my foot in a bowl of water and underneath my foot was a metal plate covered in a cotton and I had to pull a lever to give my foot muscles electric shocks. The other was to stand at wall bars in a gym and do knee bending exercises in sets of ten. If I bent my left knee more than four inches my leg would collapse.

I passed to Orange belt in Judo. I was a good swimmer and took and passed life-saving awards to Distinction in the Pool and Open Water. I passed a medical for the Police as fit and went to RAF Dishforth to start my training. The second day we were given the timetable for the week and I was horrified to see Friday was cross country running so I asked to see my Class Sergeant and explained I would not be able to do this. Imagine his response… I told him I could 'run' enough to get round tennis and netball court and I could hit a ball in rounders so far that I could walk round. I had polio as a child and cannot run any distance. I thought my days as a Policewoman would be over before they started. However, I was examined and it was decided that as I already had higher qualifications in Judo and Life-Saving that were required I should be given a weekly chance to complete all the rest of the training. The 39 mile Lyke Wake Walk is across the North York Moors and a list went up for anyone wishing to take part. I put my name up and later saw it had been crossed off. I put it back on the list and again the next day it had been crossed off. I complained to my Sergeant and was told that as I could not run it had been decided that I would not be able to complete this. Now we see an example of where the Pig Headed I can do it don't tell me I can't polio survivor. I asked have the others been asked if they have walked that distance before and the answer was No. I was allowed to do this but my car driven by someone else had to be part of the back up team. They had decided that they would support me for the first nine miles and my car could take me back to Training School. Well my car did take someone back at the first rendezvous point but it was not me. Nearing the end I had to crawl up one hill near Fylingdales on my hands and knees and it took me 18 hours but I did it.

I completed four years as a Policewoman including two years in C.I.D. and marrying a colleague. He wanted to move nearer to his home in Yorkshire and we compromised on Lincolnshire.

We all have different levels of damage, different therapy, jobs and hobbies and can add other medical conditions that need considering. Most health professionals that I have seen have been surprised that my left leg is very weak from hip to knee but right leg knee to toes. I have more weakness on the left side of my body including swallowing muscles and one that moves my eyes side to side.



We are a nightmare for health professionals especially those that have not been taught much about polio by their Colleges of Medicine. Imagine you are one of these health professionals and you see your next patient has had polio for say 60 years. You think back to your training and Polio was a half hour lecture with Leprosy.

I spent seven years at my local hospital each time being given more physiotherapy exercises. I really tried hard but all I did was become less and less able. I found out years later my records are endorsed "malingerer." I was given an MRI and told from the results 'Glad you are better' I replied "I was not better and in fact had continued to deteriorate over the last seven years, I had polio as a child could that have anything to do with this" "Oh," said the locum orthopaedic consultant . "there is something called the Late Effects of Polio but I know nothing about it" I left his office and went directly to the Hospital Library who redirected me to the Health Information Service where I was given copies of the article in the Independent by Patricia Rock and another article by a GP….. both in our PSN Library. I took these articles to my own GP who soon commented I am sorry you have been saying the same thing for some years now. I did not know the condition existed.

It is now over 25 years and getting medical support has been varied but mostly with my providing medical quotes and articles. Although professionals that I see tend to raise a questioning eyebrow when I explain that my left leg is very weak from hip to knee, but my right leg it is knee to toes.

I developed My Polio Life (available on our website or by emailing admin@poliosurvivorsnetwork.org.uk for a copy) to help us list out issues with Actions of Daily Living then we can pick the action or two that most demonstrates our new weakness. There is not enough time to go through them all so pick relevant actions to the health professional you are seeing. A later tool produced is the Preparing for Your Appointment which we hope is helping our members. Again please request a copy to be sent.

I have exercised as much as each daily energy and allowed. The purchase of a Hot Tub for the garden cut out a lot of actions going to and from a swimming pool. Article in our library Julie silver? As a Senior Lifeguard in Pools and at the Coast for safety, it is essential that you have someone with you to help you where needed.

I started using an electric scooter on my 50th birthday which made a huge difference to the amount of places we were able to go and time spent there. In May 2022 I had my third fall where for the third time in the last few months my legs suddenly folded and I badly bruised my ankle. Thankfully it was not broken but our bungalow is small and no room to use a scooter in the house so I used my husbands spare Jazzy electric wheelchair. My GP ordered an electric chair for me 01.08.22 with rise because my legs are not strong enough to stand without using my arms and that is quite a strain on my shoulders. It took a year for the paperwork to be done and the order was placed on 02.08.23. It took many more months and letters copied to Adult Social Care before I was brought a Jazzy Salsa Mini2 with the rise facility. Helped enormously but two more weeks to get a single footplate for use in our small bungalow. The back is still not the correct one and is fitted at the wrong angle yet still I wait…. And my health and wellbeing continue to deteriorate because of these delays restricting what I could manage including trying to help my husband who was confined to his bed for seven weeks. I have been made aware that many others are also suffering due to long delays. I wonder how much money is being wasted on the time it takes for staff to respond each time you contact them plus the often earlier deterioration of the user whilst waiting.

How to overcome problems of getting weaker with Post Polio Syndrome.

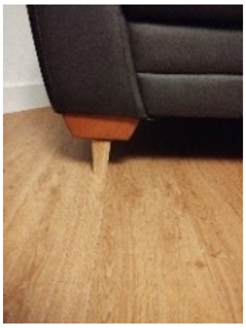
I caught the polio virus in 1949 and was sent home after about 4 weeks in hospital. I was unable to walk at first, so my mother started to rehabilitate me with daily exercises. Later she found a physiotherapist who was trained in the method developed by Sister Kenny, an Australian nurse.

I regained several muscles except for the left leg below the knee where the paralysis started. I was unable to walk for a year, and then I started walking with two crutches, then just one, and finally one stick. My endurance increased gradually, and I was able to attend school, university, and jobs in chemical laboratories. I studied Chemistry at university where I met my husband who was also studying chemistry. After graduating we married, and we had three daughters. I became a science teacher. Teaching was better suited to looking after children and I was able to stand all day, carry heavy books, teaching in science laboratories for 26 years.

Shortly before turning 60, I retired from teaching and trained as a chiropodist. My children had left home, and I was able to visit people in their homes pulling my heavy bag full of instruments and chiropody supplies on wheels which was meant for a suitcase. Luckily, I was also able to have a dedicated surgery in our home and see patients there. Gradually as I became weaker, I stopped visiting and became even busier with patients in the surgery. So much so that I would not even stand up from 9 to 12 and for several hours in the afternoon with patients following one another. I now realise that this was detrimental to my muscles. I also started studying for an Open University degree online which meant many hours sitting at the computer in the evenings. I now know that I should have been doing more activities to preserve my muscles instead of sitting for long hours. Having fallen down our wooden stairs three times I was forced to have a stairlift. The result of that is that now I am hardly able to climb the stairs. To try and remedy this I am now using a small stepping stool in the kitchen and holding onto the work surface with one hand and a sturdy chair with the other I try to step up every morning and evening. I started with just 5 repetitions and gradually increased it to 20. But I can only step up with my right leg. I am not persistent, so I tend to give up easily when I am tired in the evenings.

My balance is getting very bad, I need to hold onto a firm surface. Even when using two sticks I don't like to be far from something to hold onto or lean against. To be able to carry heavy pans, serving dishes, or anything to go in the oven, I have a small stool on castors. This is also useful for getting things out of the fridge, putting clothes in the washing machine, and taking them out, cleaning the floor, vacuuming, and as an extra chair. It is important to be able to stand up from it safely, holding on to a kitchen chair and the table. A few times I have missed standing up, tried to sit back on the stool, and ended up on the floor! A very embarrassing situation.

Both are available on Amazon.



My greatest problem at present is standing up. My husband fixed 4-inch raisers on the settee and on our bed which helps a great deal. I need to pull myself up with one hand while pushing up with the other. I also have to take care not to damage my shoulders when doing this.

The lesson from all this is: keep walking, use the stairs, and do exercises as long as possible to preserve muscles but do not to get overtired because that damages the nerves and muscles.

By Zsuzsanna Snarey

MESSAGE FROM OUR CHAIR

The Long and Winding Road

Firstly, I want to welcome the new clinical pathway from the BPF (*Please* see page 22). I hope we all can get behind this and lobby wherever and whenever possible. We have always needed an holistic and informed polio service and whilst it is still a dream this a step on the way.

That said, implementation is everything and something that sits on a shelf does nothing and I have had plenty of experience of that. Realistically we have an NHS in crisis both in terms of demand, personnel, funding, and infrastructure. Change is something that will take a decade or more to fix, and only then if we all agreed how, and start tomorrow. The reality is that achieving this ideal will be, to quote a Beatles song ‘ A long and Winding Road’.

Physical and Emotional Pain

I want to focus on one area. That is pain, not just physical but emotional distress and the psychological. It has often occurred to me, both as a polio survivor for 68 years and as a psychologist for over 35, that this is an area where we often find ourselves met with ignorance and a lack of understanding in the face of our, often unusual history and particular life experiences over decades.

Pain is a huge subject area, both complex and highly individual and subjective. Yet we all experience pain throughout our lives from our first breath to our final breath. Indeed, it is part of everyday life. It’s normal, and its function is to alert us to threat and protect us from harm. But how we experience it varies and that is true whether it is an emotional trauma, physical injury, or illness or of all of them. It is the interaction that makes it so complex. Ultimately it has such an impact our quality of life, our ability to engage and be our true selves and who we want to be in the world.

From my early childhood polio rehab days to now as I age with PPS, like many of you I’m sure, I have had my fair share of pain, both physical and emotional. I’m not sure the physical pain was the most difficult. Pain that is short term, predictable and understandable is unpleasant, even difficult, but perhaps easier to deal with, than ongoing chronic pain and or emotional distress. Pain isn’t just a physical experience, though we may often perceive it to be. But its impact is mediated in the brain by fear, anxiety, memories, social interactions and more. It also differs from person to person; it differs within the same person differently at different times or at different stages of our life and circumstances. The pain when I was having my spinal fusion in the RNOH was often intense, but I was 17, informed and had a long-term relationship and faith in my surgeon. My cognitive view was that this was a gateway to a better future, and indeed less pain. Whether that was objectively true, or my assessment of the risks were over optimistic is by the way, but my psychological approach and belief and sense of control mitigated my fear and experience of the pain. That is a very different situation and situation when having pain at the other end of my life.

The Pain Cocktail

The pain, be it emotional or physical, that most of us meet in our lives is not well served by pharmacological treatments. Most medications or analgesics have unwelcome side effects, whether for mental or physical distress, and on their own often only provide partial help. This is especially true of what’s available for chronic pain. Pain is perhaps a kind of cocktail made up of the biological perception of pain in our bodies and the emotional and psychological distress that we experience living in the world and that is ‘our’ unique and individualised pain cocktail. As disabled people we surely have first-hand experience of what that means.

The Polio Rehab Legacy

My particular interest has always been focussed on how as lifelong disabled people our psychological, emotional and social integration needs are often marginalised, especially as we age. This was no more starkly exposed than during the pandemic and how ironic that is for us as the survivors of the polio pandemic. Part of our ‘cocktail’ is that back in the day, as polio patients we were indoctrinated into a medical model with an almost unswerving faith that doctors, medical professionals and the NHS were always right and if we pushed ourselves to the limit, we could overcome anything and even ‘pass’ as non-disabled and be part of the world ‘as if’ our physical impairments and psychological experiences hadn’t happened or were at least invisible or irrelevant to how were to be perceived and treated in the world.

For many of us it worked for years, if not decades. But now as we age with PPS and the usual other age-related conditions, we experience age-inappropriate loss of function, loss of income, social contact, and even appropriate healthcare. This just at a time when society is in flux and we need better access and holistic health care, not box ticking and generalised care. This is as true, if not more true, for the psychological side of living with PPS which can trigger us going down all possible rabbit holes hoping to find ‘The Answer’ to our physical impairment or pain.

Appropriate Psychological Support

My concern is that the type and availability of appropriately experienced psychologists and therapists trained in the real-life challenges of disabled people is sadly lacking. What is offered is often totally inappropriate for post-polio patients and polio survivors. The social context and real lived experience of those of us with a lifelong knowledge of polio and living in the world as disabled people doesn’t fit well into the simplistic reductionist psychological therapies and approaches on offer. Anyone who has encountered a telephone triage to ‘sign post you to an appropriate therapy service’ will know just how frustrating and often alienating and disheartening the experience can be.

Therapy for disabled and people with chronic conditions requires a broad experience of the medical and psychological world of disabled people. And it also requires a deep under the social context and a commitment to social justice for our clients and patients. When I see in the pathway - psychology - it is hard for me not to worry that the fundamental emotional, medical, and social issues that should be at the core of a psychological service for polio survivors is not appreciated. If we are subjecting PPS patients to the same reductionist and manualised approaches that are widespread, we will fail to meet the needs of PPS patients and others living and ageing with long term and chronic conditions.

Simon Parritt, *C.Psychol, AFBPsS, MSc, BSc (Hon), BA*
Chartered Psychologist. HCPC Registered Counselling Psychologist

Chair Polio Survivors Network
simon.parritt@poliosurvivorsnetwork.org.uk

125

A Cheeky Piece by Verite ...

Statistics tell us 60% of the world is going to have an Election this year.

But how many of us will turn up to vote?

Or are we so disillusioned with politicians we won't bother?

When I think about it, and why I don't want to turn out and vote, I remember the Suffragettes and how hard they worked to get women the vote. Men over a certain age got voting rights long before women in Britain, but courageous women thought this wrong.

After decades of strife and demonstrations, plus the horrors of prison, force-feeding and other measures to punish women who rebelled, finally in 1928 Women in England, Wales and Scotland received the vote on the same terms as men (over the age of 21, without property requirements) as a result of the Representation of the People Act 1928. Mind you, this was a long way after New Zealand, which had given women the vote in 1893.

This year, whom would I vote for?

I can't help remembering Screamin' Lord Sutch! He was a nightclub entertainer, who was clever enough to capitalize on the fact that if he registered as an election candidate, and paid a deposit of £500, becoming a candidate entitled him to the same amount of publicity as every other candidate. All he had to do was turn up in front of the TV cameras in the run-up to any election, and election rules said he was entitled to this.

As a result, although I believe he always lost his deposit as he never polled the minimum percentage of votes, this was an incredibly cheap way of gaining advertising. His popularity soared in nightclubs, and he gained a huge following. Mind you, I don't know if this year one could identify some candidates - many would easily qualify to represent Sutch's Monster Raving Loony Party.

You *could* make a difference

Friends and I have decided we are fed up, but going to do something about it, and have selected two subjects: **NHS and fuel bills.**

Looking carefully through all the election manifestos that will be coming through the letter box, before they go into the recycling bin, we will highlight any that mention either subject, then ask questions - either by email or by turning up at an election meeting.

Election year is the ideal time to highlight important issues - whatever the party!

Verite Reily-Collins
PSN Trustee, Health Journalist and owner of aftercancers.com
veritegreenbee@gmail.com
www.aftercancers.com

Toni Writes …

Well you all continue to amaze me … I sent out a brief email to ask for your help and we are overwhelmed by your response. We have received many replies offering to share your stories, insights, tips, resources, creative pieces and feedback with us and the rest of the polio survivor community. We even had to expand the number of pages we had allocated to member contributions which was a lovely problem to have!

We are truly grateful for your generosity and enthusiasm. Your contributions have made our special 125th edition newsletter more informative, inspiring, and engaging for all our readers. I'm sure you will find the following pages to be a very interesting read.

We are also excited to announce that we are planning to hold our annual general meeting in August this year. This is an important event where we will review our activities, achievements, and challenges of the past year and discuss our plans and opportunities for the future.

Since our members are very spread out in the UK and abroad, we have decided to make the meeting online, so that everyone can join easily and conveniently from their homes. We will use a video conferencing platform that is easy to access and use, and we will provide you with the instructions and support on how to join the meeting. However, we also understand that some of you may prefer to meet in person and socialise with other members. So we are also considering the possibility of organising a local viewing/hosting group in Lincoln, where you can watch the online meeting together and chat with each other. This will depend on the level of interest and availability of a suitable venue. If you are interested in attending the local group, please let us know by post, text message, phone or email as detailed below.

We appreciate that aging with polio can complicate travel and mobility, but we don't want to miss the chance to see you all. We hope that you can join us for this meaningful event and we look forward to seeing you online or in person. Please save the date for the annual general meeting, which will be on Monday, August 19, 2024, from 1:30 pm to 3:30 pm. More details will follow nearer the date.

Thank you once again for your support and participation. You are the reason why we do what we do. You are the heart and soul of the Polio Survivors Network.

Take care

Toni x

Special note: You may have noticed we have received very generous donations recently and we would like to thank the family and friends of our long standing member Mrs Patricia Thomas who sadly passed away for donating in her memory. We send our love at this difficult time.

Email	psnadmin@poliosurvivorsnetwork.org.uk
Post	PO Box 954, Lincoln, LN5 5ER
Website	www.poliosurvivorsnetwork.org.uk
Phone	07480 110334

From our readers:

Thank you for the latest newsletter and especially for the beautiful illustration on the front page (PPM 124). It has such depth and stillness, a real invitation to reflective thinking which I am in need of in these days of PPS bringing me to an almost complete physical halt. I've learned not to dwell on it, but it's always there. Thanks for your time and knowledge, everyone.- Kathy Saunders

Thank you for sending information concerning your work on behalf of polio survivors. This has been of help and interest to me and I hope that the enclosed donation will be useful to you in that work. - Douglas Challons

I just wanted to congratulate you on the last issue. The articles by Verite and Zsuzsanna I particularly enjoyed. Thanks to both of them. - Caroline GW

For this issue:

Di's Polio Story

My polio story is without doubt very similar to many others. I contracted polio just before my fourth birthday in 1952 - I am now 75. I am definitely a half glass full person and I feel I owe that to polio. Some might find that a strange comment, but life has not always been easy and like many polio survivors has made me stronger, more determined, a type A achiever and defiant!

Like many others I had long stays in hospital, operations, callipers, bedtime splints and built up shoes. I was one of the lucky ones and made a good recovery and by eighteen had discarded all assistive aids. I married young, had two children, obtained a degree at 39 and went into teaching. In my late forties I was diagnosed at the Lane Fox Unit with post polio and for the last 27 years have been back in callipers. I was widowed at 58 but in my Motability car can still visit friends and family. Life has become more sedentary, but I can fill my time in with a variety of hobbies, mainly playing bridge, which seems to be keeping the grey cells working. However! It is being reliant on outside agencies where problems occur!

My blue badge blew out of my car six weeks ago, never to be seen again, when I opened my car door in a gale! I immediately went online to order a replacement, paid £10 and am still waiting. My walking is limited so not being able to park on double yellow lines has been a real nuisance. The same week the foot dropped off one of my callipers! That took five weeks to get repaired - luckily I have a spare one. Agencies who are meant to help disabled folk do not seem to understand the urgent necessity of our needs. Delays can cause great anxiety. The post polio clinic which I used to attend at a Liverpool hospital has closed. As polio survivors our physical needs are not understood and this in turn puts a great toll on our mental and emotional health. We are our own ambassadors and facilitators and that takes a lot of our energies and strength. I know I am very grateful to the volunteers who work tirelessly in producing Post Polio Matters and running the Polio Survivors Network. - Di Brennand

125

Update from Barbara…

Pretty ill with multiple things and inflammatory hands ad feet plus Covid. Probably can't do and can't walk on feet. - Barbara Taverner

Congratulations to James and would you like to share your polio survivor experience further?

Hi everyone, my name is James Magnus Carmichael. On the first of July I take over as Rotary Great Britain and Ireland Polio Specialist.

I contracted polio when I was two years old - and as it happens my father contracted polio when he was a boy. Both of us suffered paralysis of the left leg - but of course he contracted polio before there was a National Health Service, and before there were any effective treatments to aid recovery. As a result he suffered the full effects of polio. His left leg was considerably shorter than his right, he could only use the ball of his left foot - his heel was pulled up to the shin, and walking any distance was a considerable effort. By contrast, my leg was fine for many years - until I found that I was suffering from ‘post-polio syndrome’.

In my capacity as incoming Polio Specialist for Britain and Ireland I talk at different occasions and to different groups, and I like to emphasise that polio is not just a medical condition with associated physical problems, it is - and can be - a disease with implications for a person’s career and employment prospects, their social connections, and their mental well-being.

My father was always ‘defined’ by employers on the basis of his physical impairments. I hope these days in Britain we have moved past such prejudices but of course it is still the case in many countries that people who have suffered from polio are excluded from employment opportunities and often socially excluded and subject to prejudice.

At the moment I’m working on a book about polio in Britain and that involves interviewing polio survivors which has been a learning exercise for me. The oldest contributor is in her nineties, the youngest in his thirties. They are all different in important ways, but we do all have some things in common. They are all pretty phlegmatic about their situation, best summed up by one person who, having explained the extreme mobility problems he was experiencing, simply shrugged and said ‘what can you do? You just have to get on with things.’ And that really captured the attitudes of many of the people I’ve talked to.

I have found much to admire in the resilience, strength of character and determination of all those I’ve had the privilege to interview.

The process is ongoing - but I hope later this year to publish ‘Polio Stories’. I hope it will help raise awareness and remind everyone who reads it of the simple fact that there are thousands of people in Britain who are still living with the consequences of a polio infection.

All of the proceeds from sales of the book will go to the End Polio Now campaign. If any member of the Polio Survivors Network would like to contribute to the book - please drop me a line at Jasmagnus@ntlworld.com

Regards

James M. Carmichael
Vice-President Kirkintilloch Rotary
District 1320 South Scotland ENPC.
Rotary GB&I EPN Specialist (nominee).

Editors Comment: It would be wonderful to see the experiences of as many polio survivors as possible collated into a book raising awareness.

Hello from Sylvie in Somerset

I have only had a scooter for just a few months. It enables me to go out for the day and on holidays rather than be a "prisoner" of PPS symptoms which would limit my pleasure in and ability to get out and about. My using the scooter also benefits my husband's health as it means he doesn't miss out on the long walks we can now enjoy together again. So all good and great fun to be out again. Below are three photos of me with my scooter, the last one being in Austria.

* * *

The London Bus Drivers Prayer by Ian Dury who contracted Polio, I think he fronted a band called the Blockheads? It has been around for a while but may still make a few members smile in these hard times.– Mick Harper

The London Bus Driver's Prayer

by Ian Dury

Our Driver
Who art in Hendon
Holloway be Thy name
Thy Kingston come
Thy Wimbledon
In Erith as it is in Hendon
Give us this day our Berkhampstead
And forgive us our Westminsters
As we forgive those who Westminster against us
Lead us not into Temple Station
And deliver us from Ealing
For thine is the Kingston
The Purley and the Crawley
For Iver and Iver
Crouch End

* * *

Thanks from Michael

I would like to thank you for doing your bit to trying to help us in our journey through what can be a very stressful future. Kind regards, Michael H

Pain Relief

My two strategies for pain relief are :

1. Fortnightly visits to my osteopath to realign my spine before it goes too far out of whack;
2. Ease Magnesium spray to relax tight aching muscles which helps me sleep better.

Since last summer I've been following a ketogenic diet which has helped me lose 20lbs weight and has given me so much more energy - that's the most surprising thing because I've not had any post-polio symptoms since then. Before that I'd been having exhaustion on walking even a short distance but now am back to managing about 5,500 steps 3 times a week.

Hope that's of some help to you. - Christine Macklen

125

The Dog Won't Share!

I'm from Illinois. I'm 73. I had a good life, walked with a limp, but did ok.

I do have a suggestion for moving on the mattress, I use a silky kind of fur rug. It has a backing that makes it feel like a real leather I think it's a bath mat. I put it under my hips and it's much easier to move . Except when the dog won't share! - Sue Waters

An Interview with Jeff from West Sussex

⇒ What adaptions have you found most useful?
Wet room shower

⇒ Your life experience
Polio at 4 years, recovered after being in iron lung, at 50 years started signs of post polio, now use wheel and mobility scooter

⇒ How do you cope with the complications of being a polio survivor/post polio syndrome?
My wife helps a lot, especially if I fall, plus she does most of the jobs I used to do, life is much more difficult now compared to 20-40 age range.

⇒ What would you like everyone to know about polio survivors? What lessons can be learned from your life?
I found with care I could lead a normal life and raise a family (until 50) as long as I didn't overdo things physically.

⇒ Photos, drawings, anything that inspires you to stop and enjoy the moment. Videos or books you have found helpful
Polio Survivors network has help, provided data I have used.

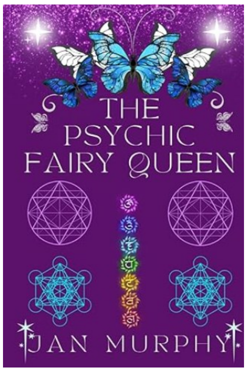
⇒ What works for you when it comes to pain relief?
My main problem is knee joint pain, heat helps, albeit it intensifies with sleep.

⇒ What would you like help/advice on?
Any ideas on limiting damage caused by falls?

The Psychic Fairy Queen

Having polio set the stage for an amazing life for me. I was told that it was unlikely that I would walk again and whilst still in isolation, I met spiritual beings who told me not to give up and that they would help me recover. It took a couple of years before I managed that, and these beings then took a back seat, appearing randomly throughout my life, until post-polio set in and they were back in force! Their message was always "TRUST and let go of fear, you will manage ok. Aged 41 I found myself unwittingly propelled into becoming a medium, then by my mid-fifties, as post-polio was taking hold, I discovered healing. Gradually my problems with walking etc eased as I learnt so much about the power of the mind and how to stay present and not have fear, and eventually trained in various healing modalities, going on to help others till I was 75. Now, aged 77, I have had a book published, with the intent of assisting people in their lives by learning from all I have experienced. It is available on Amazon.

Here is the back cover blurb of The Psychic Fairy Queen, and I sincerely hope other polio sufferers will benefit from reading my story. Very Best Wishes, Jan Murphy



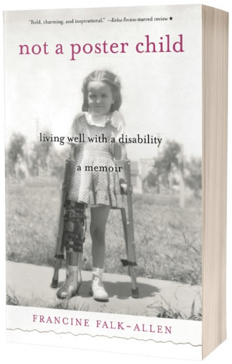
In ‘The Psychic Fairy Queen’, join the extraordinary journey of Jan Murphy as she recounts her remarkable odyssey from fear and torment to fairies and trust, eventually becoming a beacon of hope and healing. At the tender age of ten, a devastating battle with polio left her paralysed, isolated, and seemingly hopeless. But within the confines of her hospital isolation room, she encountered ethereal spirits, setting the stage for a life-changing connection.
These spirits guided Jan through the darkest of times, opening a door to a world beyond the ordinary. As she grew, she realized her calling as a nurse, and later as a healer and Medium. Her path was illuminated by incredible and unbelievable experiences, from encounters with fairies to interactions with extra-terrestrial beings, and the destined meeting with her Twin Flame, her spiritual counterpart.

The Psychic Fairy Queen is a mesmerising true tale of bridging dimensions and helping countless people recover from life’s traumas and illnesses through the power of Trust and healing. Jan imparts the wisdom and skills of manifesting life’s desires while sharing the extraordinary stories of her own and others’ miracles. She felt passionate about writing this book so that others could also benefit from her knowledge and experience that there really is far more to life than we sometimes perceive and that by holding strong intent, absolutely anything is possible if you truly believe it is so. Jan’s motto has always been ‘LOVE CONQUERS ALL’……because it does. This is a book of resilience, transformation, and the boundless potential of the human spirit.

125

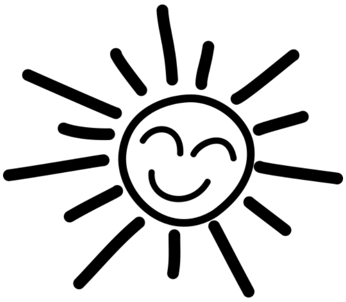
Not a Poster Child … or a Spring Chicken

Two books by Francine Falk-Allen based on her experience:
Not a Poster Child: Living Well with a Disability—A Memoir
and also
No Spring Chicken: Stories and Advice from a Wild Handicapper on Aging, and Disability



https://FrancineFalk-Allen.com

Optimistic Aly



Hi everyone, optimistic Aly here.

After contracting polio when 6 or 7 years old, my post polio journey has not been easy, as I'm sure some readers have also experienced. It's only in recent years the medical profession are learning about the long term affects of Polio.

I'm in my mid 70s now but was one of the 300 children back in the early 1950s who were chosen to trial the, now successful, Salk vaccine used today. The metal and leather callipered boots worn for 18 months were a small price to pay for my life. Anyway, once mastered, they enabled me to inflict substantial damage on anyone who took the Mickey as they had metal side rods, so not all was doom and gloom.

Other children trialling the Sabine and placebo inoculations did not fare so well at all. We lucky survivors will never forget them.

Two years ago, misfortune struck resulting in admission to DORSET COUNTY HOSPITAL and two major bowel surgeries in 10 months. The first nearly costing my life, when the obstruction burst hours before the scheduled operation. My internal muscle power diminished rapidly around this time which left much tiredness and general lethargy.

At a prior consultation, I explained to my wonderful NHS Surgeon my fears that were solely around Anaesthetics. I asked if I could meet the Anaesthetist first. Polio as we all know, affects our already weakening muscles. The heart and lungs are muscles, anaesthetics disable muscles. I wanted to be sure of what these guys knew about my polio beforehand.

I had an amazing hour with the Chief Anaesthetist and came out feeling super confident in my medical team. We also discussed my heart problems, hiatus hernia, aneurysm, scoliosis, diverticulitis, cervical neck bone collapse and arthritis...among other stuff ....and their correlation with polio. I was complimented on the fact I was still alive and in such good spirit. We both learned a lot about how ones mind can overcome a lot of pain and also that occasional feeling sorry for oneself.

After the first operation, hastier there, due to the obstruction bursting, confidence crept in on seeing that handsome anaesthetists face. It does help if they're nice to look at! Feeling relatively I calm I was put out cold in 20 secs flat with my individual "specially prepared" anaesthetic. Trust your anaesthetist everyone. These guys KNOW what they are doing.

Recovery was good I'm told, but I do first recall crinkling sounds on coming round, after which I CLEARLY recall fleetingly looking at the handsome man (anaesthetist number 2) in the recovery room, at bottom of my bed. He was central to a clutch of about 5/6 uniforms calling for more rescue blankets. The crinkly space age silver stuff with warm water pockets all over them. As said above, I have other conditions and my B/P sadly went bit low. Its a family trait. Brilliantly upfront in any crisis, fall apart after.... as I laughed with the anaesthetist earlier. He listened and came prepared for just that in case.

Later next day on ward it was more comfortable playing with the bed zapper to lie in a Z shape on my back to prevent sliding. Turning gently later in the day, was doable but uncomfortable and slow. More of a slide for first 48hrs, due to 3 of the 7 of illnesses above. Nurses have slide sheets to turn people as well.... much easier as it turned out.

All the above aside, day to day I noticed how the post polio symptoms are getting more debilitating as age encroaches. Good days 200yds upright walking, other days 70 feet if lucky. Aging naturally compounds these existing mobility problems. Occasionally I get out of breath easily and use a stair lift to get up stairs some nights. Exercising any muscle nowadays also causes muscle fatigue quicker than it used to so my GP monitors lung capacity annually. I have crutches if I need them as they are useful to lean on when muscle fatigue hits.

One other thing noticed of late is the occasional kind of excess saliva I can get in my mouth. Regardless of sitting or laying my brain doesn't warn the swallow reflex quick enough. With not much warning it feels like something went down wrong way and coughing occurs. If I rapidly get upright swallowing hard between coughs helps clear it all. ***Does anyone else have problems with their swallowing muscles?***

Anyway lovely to read each of your own stories. It makes us feel less lonely and dismissive of life knowing we share a common bond, I think. *WE ARE ALL SURVIVORS* in our own way. My own mantra is not to make a drama out of a crisis on a day to day basis, do your best for you and *NOBODY* else. Find something you *CAN DO*, rather than feel sorry for yourself and concentrate on what you *CAN'T DO*. We still have a life to *LIVE*, we just need a smidgen of adaptability don't we?!

Love from Aly xx

Editors Comment - If you'd like to respond to Aly please email us and we can include it in the next issue.

125

Andrew's PPS Symptom Advice

Hello from central London, where I live in an alms-house, which takes some of the pressure off life.

What helps? I saw an Australian post-polio video which categorised all the main areas of PPS symptoms. That helped me see which applied to me.

So it's: **1.** Fatigue **2.** Poor sleeping **3.** Limited sleeping positions **4.** Dry throat when lying down (connected with swallowing I believe) **5.** Muscle fatigue (limited to just midriff, from walking) **6.** Hard to get warm when cold

1. Chronic Fatigue is my biggest problem by far. Lots of naps throughout the day help. Writing the day off if you feel tired in the morning, so as not to spend the day worrying about things not done. Avoid deadlines. Gently keep on reminding people about it, so that they understand that it's not just 'getting old'.

Accept that you can only do two to three things in a day, and that a big thing (like going out to dinner) may take 2 to 3 days to recover.

I've found regular visits to a chiropractor, an osteopath (don't tell one about the other) and an acupuncturist brings me back in to 'normal' for a bit every few weeks and stops long term skeletal problems. They're all exceptionally good, which is important. They've given me a long list of supplements to take - which seem to make a difference. The stand-out one is an 8 mushroom blend (from Kiki Health, but there are others) which has wiped out the arthritis in my good joints.

I've also found a few gentle stretches in the morning stops you from feeling stiff later on. Similarly a few different arm waving exercises in bed when you wake up seems to keep limbs working better. Likewise trying to do something difficult with your bad hand - like putting the cutlery back in the cutlery drawer - seems to retrain both brain and hand, making them work better and feel more alive. Finally, a few quiet, Buddhist style breathing exercises in the morning make you breathe better for the rest of the day.

Weight gain seems to have been (finally) countered by a keto diet, which is giving me more energy as a bonus. I'm hoping it will move me away from the danger of diabetes, bring my blood pressure down so I can come off the pills, lower my cholesterol (I avoid taking statins). The number of naps remains the same, but I feel better in between. Red Rice extract (or the actual rice) keeps cholesterol down, apparently, so stops the doctor pressuring you into taking statins.

2. Poor sleeping seems to be helped a bit by reading in bed beforehand and not looking at my phone, a cool room and listening to the radio (on the phone or iPod touch - with a separate Bluetooth speaker - which turns off after an hour). A glass of wine or brandy in the evening helps too, but I'm not sure I should make that a habit.

3. Limited sleeping positions (on either side); seems to be insoluble

4. Dry throat / tickly cough: small bottle of water by bedside and the ever reliable Ricolas.

5. Muscle fatigue is just in my midriff, when I walk too much. No cure.

6. Cold, hard to warm up. A good thick duvet or a warm shower speeds things up a bit. I've got a double bed with two single duvets of different weights. The light one is good for nighttime and the thicker one for naps, when you go back to bed feeling cold.

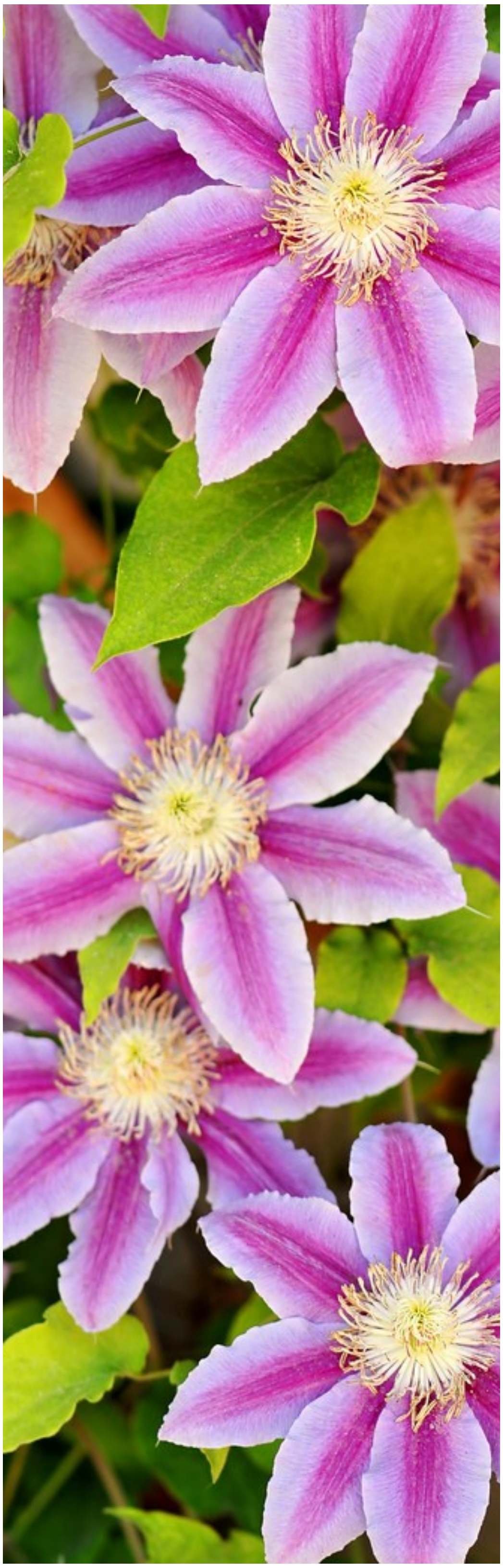
I hope that's of some use. It was actually quite useful for me to write it down. One last thought: I've just today worked out how to categorise my fatigue levels:

A. Full of beans - very rare and usually leads to overdoing it
B. Normal - can get two or three things done in the day
C. Meh! - feel OK but no energy to do anything - worry that I'm not active
D. Tired - nothing gets done - can cook simple meals (reluctantly)
E. Fatigued - feel totally whacked - can't really cope with anything.

As for mattresses, I've come to the conclusion that a foam mattress (mine's a Simba) are a better bet than firm orthopaedic mattresses for side-sleeping. The trade off is between being more comfortable (with a straight spine and less strain on the neck) with the foam vs. being easier to move around and get out of bed with the orthopaedic one. I tried a high quality orthopaedic one for a couple of years, then gave it to my girlfriend, who loves it. She hates my foam mattress!

Best wishes,
Andrew Probert

We are so happy Shonagh shared this very powerful and moving poem expressing their personal polio journey. This survivor faced many challenges and struggles, but also learned and grew from them. It shows the resilience and courage of the poet, who refused to let polio define them and instead found their own identity and voice.



Influencing versus Defining

Do you dream in colour someone once said
I've dreamt of all sorts, in this head.
That organism that robbed me long ago,
of limbs that walk and move and flow,
didn't get my thoughts, imagination.
Didn't dull my hopes and bold ambition.

I'd like to say it enriched me some.
And truth be told, it didn't come
without some additional, alternative blessings.
I learnt from very early on, to look, to listen,
then carry on, with close observance to the fact;
that what was lost, wasn't coming back.

Stoicism is said to be a wonderful thing.
But whilst I could sew a perfect seam
I never would be on the team.
And in my head, though I ran and danced with grace
Reality of my forced debility I viewed full face,
Physical accolades would not be mine.

It took some time, but I morphed and grew.
My brain and tongue got me through.
I used them well but fought emotions,
Rebellion and comparison caused commotions.
Solitary became the preferred existence,
Not wanted was my Mums insistence.

I married and separated, more than once.
I realised late I was far from a dunce.
I worked til exhausted for family and industry
Promoting the social skills; brazenly, aggressively.
My study of people, behaviour, emotions,
Carried me through when my own caused explosions.

It's taken forever but it seems I've attained
A peaceful era; behaviour most times constrained,
That infection I shared with countless others,
didn't make us sisters, didn't make us brothers.
It took me a lifetime to find the key,
It definitely influenced but will never define me.

Shonagh M Terry, June 2018

Michael's Polio Story

I got polio while I was at a Butlins holiday camp (Skegness) in about 1946 (I think from the swimming pool). My parents only hope, so they were told, was a new drug that was being tested at Bart's hospital in London (streptomycin). As the NHS didn't exist then they had to pay for an ambulance to get me to London (maybe they got help from Butlins but I don't know), anyway I ended up surviving but with callipers on both legs. The result was that I missed almost all my early education so my parents paid for me to go to a primary school in Balham. From there I went to a grammar school in Battersea.

I had an interest in motor cars and I got a job at Jack Barclays (the Rolls Royce dealers) from there a friend and I set up our own business repairing Rolls Royce's and Bentley's. Like many partnerships, we parted company, but I continued the business for many years. I sold the business about 12 years ago and in retirement assisted people with problems with their cars until about a year ago when Post Polio Syndrome (PPS) caught up with me.

My GP sent me to our local hospital, St Helier, where I was told that unbeknown to me I'd had 2 mini strokes and was advised to "get a walking stick". I am now in the process of being given advice on how to move forward from the Lane Fox unit at St Thomas' hospital so we wait and see.

The stories I've read about since joining you have made me think that basically you need to do as much as is comfortable with you. I hope my story is of interest to you. - Michael Hall

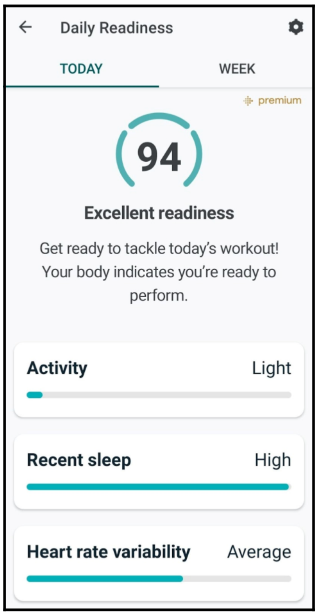
---

Alan's Eleven Years of Post-Polio Personal Management Information and Benchmarking

At the age of seven, I contracted Polio and spent a year in Queen Mary's Children's Hospital, Carshalton, Surrey. Like most children, with a personal experience of polio, it leaves us all with a lot of challenges and limited abilities, which don't improve over time, with wear, use, or age and need to be constantly assessed, monitored and addressed, by ourselves and medical professionals.

In 2013, at the age of 60, I retired from full-time work and purchased my first fitness tracker, a Fitbit, with the objective, to proactively monitor and benchmark my own health and activity level.

Since 2013, I've had a number of different Fitbits and have maintained my records, which now show over 46 million steps, and a vast global distance, as well as lots of benchmarking information, that can be drilled down for details. These records include Fitbit's smart automatic functions such as walking, sleep quality and quantity, activity levels and times, flights of stairs climbed, calories burnt, stress levels, swimming, cycling, heart monitoring, alerts and variability, breathing rates, skin temperature, this includes my personal readiness score (suggestions on when to rest and be active). Optional manual functions can be added, such as calories consumed in food, vs calories used, diet nutritional information, water consumed, and weight management.



Daily Readiness

TODAY WEEK

premium

94

Excellent readiness

Get ready to tackle today's workout! Your body indicates you're ready to perform.

Activity Light

Recent sleep High

Heart rate variability Average

Readiness is a Fitbit Premium feature.

On the weight management side, I can manually add my weight or do it automatically. I choose to do it automatically, once a week, using Renpho Bluetooth scales which link into Fitbit. The Renpho scales and app, show, record and monitor 13 different weight management functions such as Body Mass Index (BMI), muscle mass, Basal Metabolic Rate (BMR) and Metabolic Age.

With the Renpho app, and a tape measure, I can also measure and monitor the circumference and length of body parts. I have found this very useful to monitor physical attributes on my appendages to see how they are maintaining and if any specific targeted exercise or change in dietary protein has made any change in size in those areas, such as calf muscles. There are also free mindfulness and workout routines, including gentle yoga, some of which are seated or focused on the upper or lower body.

There is also a Fitbit Premium service, which you can subscribe to. However, before you do, explore the free included ones, as they may be adequate. As a Fitbit premium user, I get Fitbit wellness and monthly health trends reports. I can choose to share this information and any information with people and medical professionals, when I've been concerned about aspects of my health.

I've also set up groups of fellow Fitbit users of family and friends and we can all decide how much information to share or keep private. This is my public Fitbit profile. https://www.fitbit.com/user/25D85C If you have a Fitbit, you can 'friend' me and see a bit more of my real time movement information, which may be a useful benchmark to a fellow, post polio survivor. However, it's important to know we are all different individuals and your level of mobility may be very different from mine. I have also set up an International Post-Polio Syndrome (PPS) Group on Fitbit. This group is ring fenced by invitation only, which I will invite all PPS friends to join.

My Polio- by John Howden-Richards

As I find myself approaching my eightieth birthday (dob 6.6.1944), I continue to be intrigued by my friends and acquaintances who have reached a certain age, whereby they, themselves, are now experiencing some of the symptoms, which, I myself, have encountered during most of my life. I would not say that it is satisfying, in the least, but it does create an element of understanding and empathy towards me, which was often absent, hitherto. Naturally, I, too, am experiencing reduced mobility, arthritis, and pain.

One Wednesday afternoon in June, 1953, my legs ached and I felt quite tired, as I struggled up the steep hill on the return two-mile walk from school. I went straight to bed, and was admitted to Taunton Isolation Hospital by the weekend, when polio was confirmed. All my toys were destroyed, but I was able to keep Ronnie, my mascot, following fumigation - he's still with me! A month later, I was sent to the Bath and Wessex Orthopaedic Hospital, where I received physiotherapy, and learned to walk with the aid of two full-length calipers, aided by two sticks. For my present mobility aids, I use two sticks at home, a frame outside, and a scooter and/or a car to drive around the village, and further afield. After nearly a year in hospital, and two further years away from school (I was fortunate enough to have a private tutor), my parents decided to send me to boarding school, in order to mix with other youngsters, hence my arrival at Wellington School in Somerset. It was the right decision, which I never rued, and for which I am eternally grateful.

Although I was not able to participate in sporting activities, or the CCF, I took advantage of the gymnasium, where there was an enlightened P.E. master. Together with his support, and that of Jeffery Archer (who was a great gymnast and athlete), and the 1st XV rugby team (who allowed me to join in their circuit training, as far as possible), I developed strength in my upper body and an improved balance; this proved instrumental in my ability to deal, thereafter, with both the physical and mental challenges, as they presented themselves. I went on to attend a course at Aberdovey Outward Bound Sea School, a few years later, where I gained the Warden's Award - rarely awarded for an outstanding performance (most of my friends don't know this, but, I consider that it's relevant to this article). Not a day passes, when I do not reflect on the attributes, which I derived from both these institutions.

On leaving School, I became articled to a chartered accountant in Bridgwater, Somerset. Keen to obtain a professional qualification of some sort, this seemed to be the most appropriate for me, in providing job mobility and security. After articles, I went into industry and, then, courtesy of Tube Investments, attended Aston University as a post-graduate, where Lord Plowden (chairman of TI), had established what was to become Aston Business School.

Unilever beckoned, and a move to Gloucester resulted in a couple of years, where I really enjoyed my role as sales accountant at Wall's Ice Cream. However, in 1971, it was clear to me that we would be joining the Common Market (as it was known), which I trusted would provide a necessary stimulus to the UK economy. My decision was to find work on the Continent, before we joined, since I reckoned that this was the likely outcome. We brought forward our marriage, and I left Unilever and joined a British-based company in Düsseldorf, Germany, which was a disaster. Soon after arrival, I discovered, through rather minimal investigation, that the directors were on the fiddle, and that the enterprise was unviable (and, eventually wound up).

On return to London, with no jobs, life took another turn, but with opportunities, too. I had always wanted to work in the City, and was fortunate to help rescue a secondary bank, successfully, for a couple of years, during the 1970's recession. I then found myself on the market, yet again, but the 1974 oil crisis came to my aid, and I joined the DTI and the Arabs in assisting in the establishment of the Arab-British Chamber of Commerce. Five years on, I set up my own practice of chartered accountants & management consultants, with a slant upon managing companies, non-executive directorships, company secretarial roles, and the traditional audit and accountancy - the latter never having been my original aim!

However, my entrepreneurial instincts led me to want to build an organisation, which was not so dependent on my constant input. Together with a business partner, in 1993, I formed a company developing and marketing traffic technology (speed cameras). The product, itself was very successful, gaining Home Office approval, speedily (excuse the pun) but it was the early days for this technology, and securing development finance was not forthcoming during that recession, resulting in the business folding in 1995. At least, I tried to fulfil my ultimate ambition, and don't regret the endeavour. I carried on with my practice, retiring in 2002.

My Christian faith has been my metaphorical anchor, in my ability to cope with, and confront, the many difficulties and frustrations, which have - and continue - to cross my path: it gives me the strength and confidence to cope with the problems of old age, and the infirmities, which accompany one in later life; and it enables me to look forward, enthusiastically, to the future, whatever that has to hold.

My hobbies and other interests range from vintage and classic cars (I had several Bristols et al), antiques, wine (I had a small wine business in the 1970's-80's), interior design, gardening, property refurbishment, classical music, cookery, current affairs. I enjoy good company, and sharing good food and wine; that's what makes me happy!

On reflection, in this momentous year, I consider that I have had my fair share of successes and failures, which must add up, in my view, to a life fulfilled. Without taking risks, you achieve nothing, which life can afford. As Churchill said: "success is moving from failure to failure without loss of enthusiasm".
I subscribe to that!

Tom’s musings …

How many of us, too late in adulthood, have wished they had asked their parents, whilst they were around, to pass on to them the stories in more detail of their early childhood.

In my case about my time in an iron lung at two years old, about their fights with the local authority to get me an education at a "normal" school. The earliest recollection I can envisage is of my mother strapping on two full length callipers in getting me dressed for that school. The traumatic stuff for my parents as passed on to me, is only sketchy however my father being a forward thinking man at the time made a retrospective diary of the onset of my polio.

The onset of my polio hit me on the week before my second birthday. My early childhood memories are of being finally accepted into mainstream education after a week's trial rather than going to a "special school" and of frequent visits to the orthopaedic surgeons to chart my development. And my time, age seven, of being in hospital to have surgery I think to stop me growing up stooped over. Like a right angle. Both my wasted thighs have retained the nine inch scars typical of the surgery of the day ".

On reflection, I've had a very full, almost normal life, despite two full callipers. I don't feel I have Post Polio Syndrome and my trials now are in coping with the normal ageing process. Everyday stuff.

125

We hope that you have enjoyed the extended contributions of our members for this special edition of Post Polio Matters. To all who read this newsletter please know we believe that polio survivors are the epitome of Blooming Resilience (this special edition’s theme). Each day, polio survivors rise, embodying the essence of courage and determination. Their lives are a mosaic of battles fought and won, a series of obstacles transformed into stepping stones. Polio survivors have growth in the soil of hardship. Polio survivor stories are not just tales of survival, but of flourishing against the odds. They are the living proof that resilience is not merely about enduring; it’s about thriving with grace and dignity. Polio survivors teach us that even in the face of life’s harshest winds, the human spirit can bloom with unwavering strength.

Let us not only celebrate and honour the remarkable journey of polio survivors but also draw inspiration from it. They remind us that hope is an unstoppable force, and that true beauty lies in the courage to overcome adversity. Their legacy is one of triumph, a beacon that lights the path of resilience for all to follow.

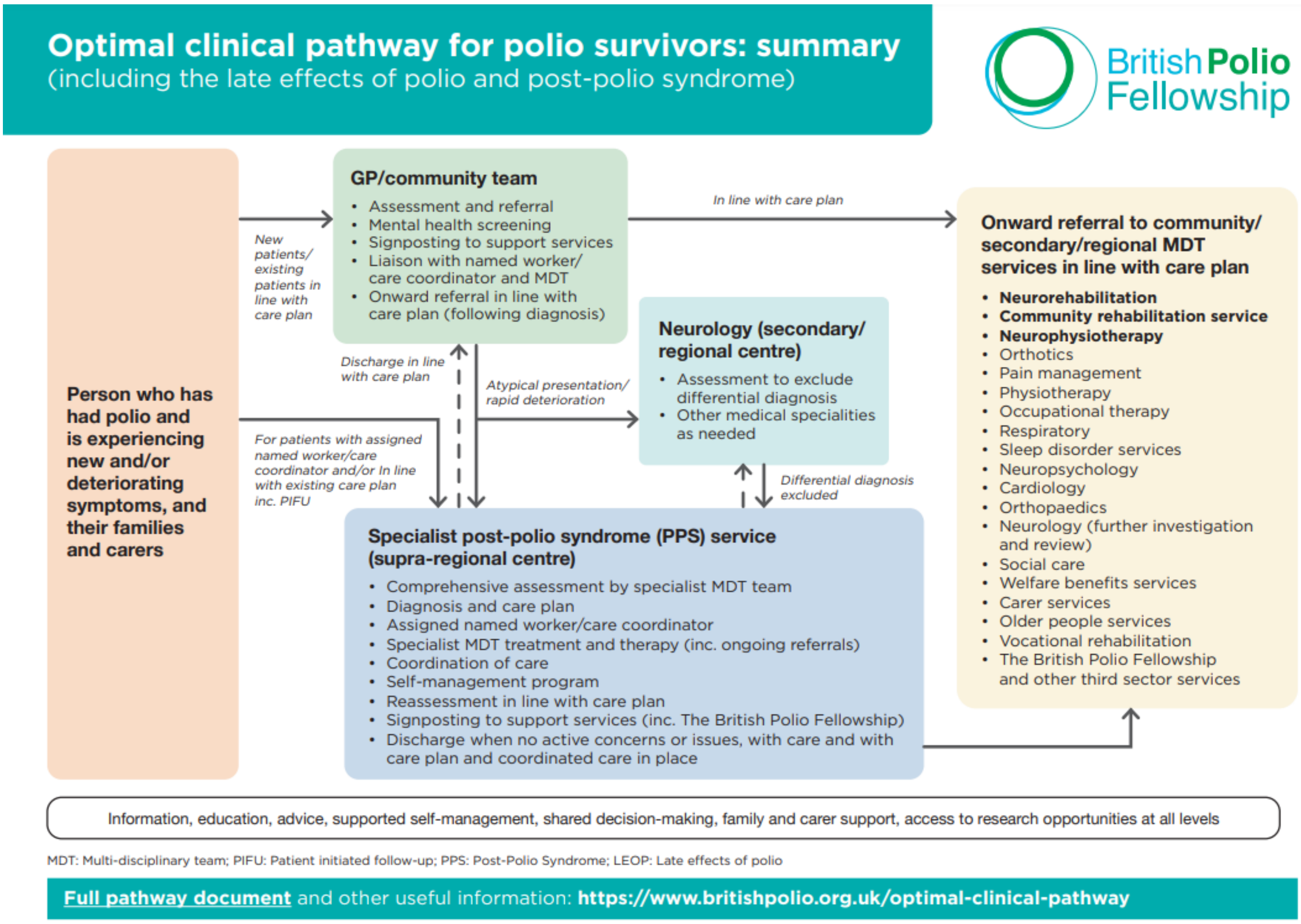
Polio Survivors Network

Optimal Clinical Pathway for Polio Survivors has now been launched by the British Polio Fellowship (BPF)

We are sure that many of you will be aware that the BPF launched its Optimal Clinical pathway for polio survivors on Wednesday 20 March. We are very proud of what they have accomplished with this and wish to extend our support.

Over 100 people joined the presentation and a recording of the event is available here:
https://vimeo.com/925777919/81e3c7c982?share=copy

A copy of the pathway and its associated 2-page summary is available on the BPF website:
https://www.britishpolio.org.uk/optimal-clinical-pathway



Optimal clinical pathway for polio survivors: summary
(including the late effects of polio and post-polio syndrome)

British Polio Fellowship

Person who has had polio and is experiencing new and/or deteriorating symptoms, and their families and carers

GP/community team
- Assessment and referral
- Mental health screening
- Signposting to support services
- Liaison with named worker/ care coordinator and MDT
- Onward referral in line with care plan (following diagnosis)

Neurology (secondary/ regional centre)
- Assessment to exclude differential diagnosis
- Other medical specialities as needed

Specialist post-polio syndrome (PPS) service (supra-regional centre)
- Comprehensive assessment by specialist MDT team
- Diagnosis and care plan
- Assigned named worker/care coordinator
- Specialist MDT treatment and therapy (inc. ongoing referrals)
- Coordination of care
- Self-management program
- Reassessment in line with care plan
- Signposting to support services (inc. The British Polio Fellowship)
- Discharge when no active concerns or issues, with care and with care plan and coordinated care in place

Onward referral to community/ secondary/regional MDT services in line with care plan
- **Neurorehabilitation**
- **Community rehabilitation service**
- **Neurophysiotherapy**
- Orthotics
- Pain management
- Physiotherapy
- Occupational therapy
- Respiratory
- Sleep disorder services
- Neuropsychology
- Cardiology
- Orthopaedics
- Neurology (further investigation and review)
- Social care
- Welfare benefits services
- Carer services
- Older people services
- Vocational rehabilitation
- The British Polio Fellowship and other third sector services

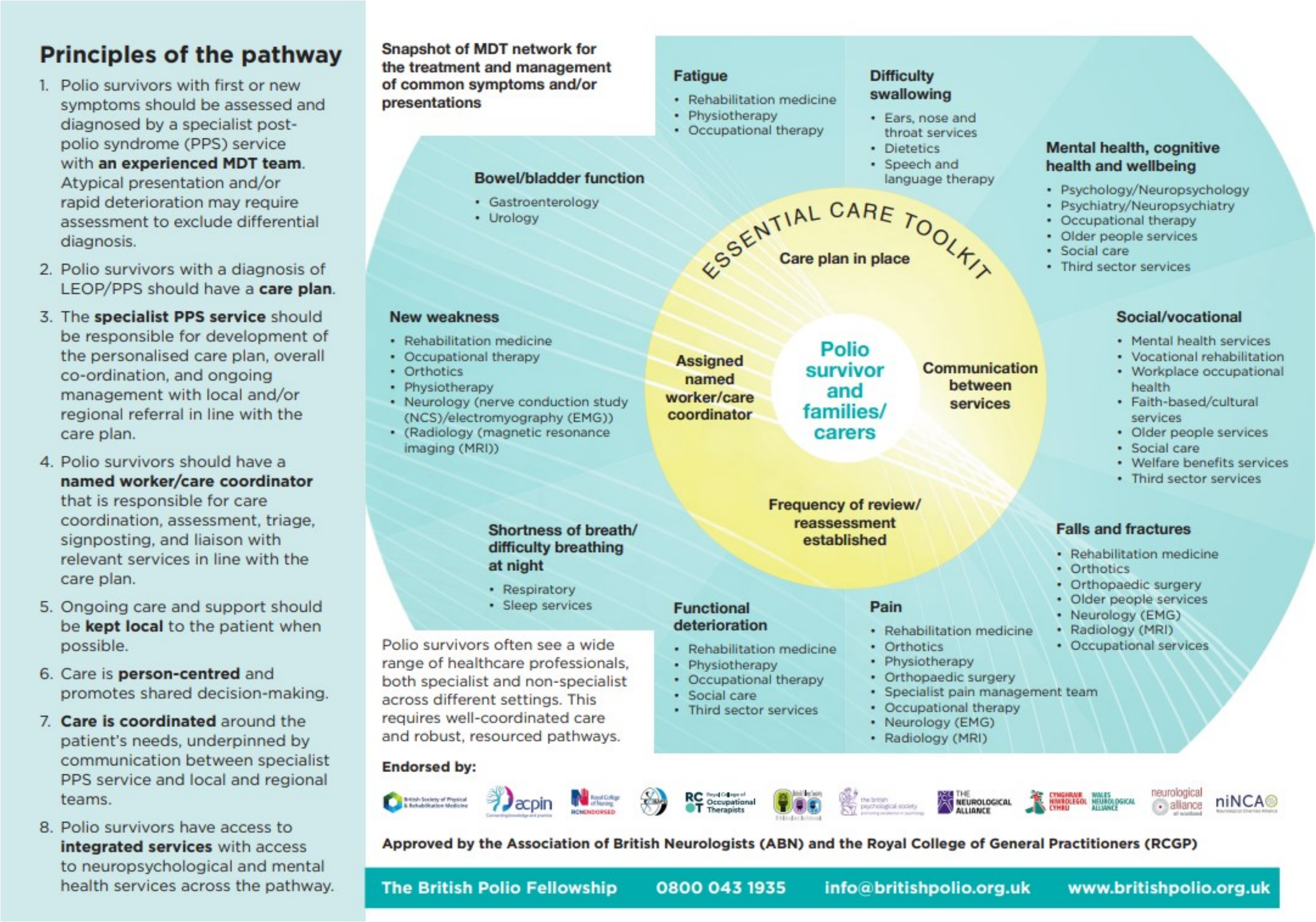
Information, education, advice, supported self-management, shared decision-making, family and carer support, access to research opportunities at all levels

MDT: Multi-disciplinary team; PIFU: Patient initiated follow-up; PPS: Post-Polio Syndrome; LEOP: Late effects of polio

Full pathway document and other useful information: **https://www.britishpolio.org.uk/optimal-clinical-pathway**

What is the pathway?

The BPF, with support from clinicians and polio survivors across all four nations, has developed the clinical pathway to outline what good treatment and care looks like for polio survivors. It maps out a person's journey from first presentation (worsening or new symptoms) through to the GP and on to a specialist service or neurologist, who importantly will ensure nothing else is wrong. The hope is the pathway will make care and treatment for polio survivors much more effective and timelier.



Principles of the pathway

1. Polio survivors with first or new symptoms should be assessed and diagnosed by a specialist post-polio syndrome (PPS) service with **an experienced MDT team**. Atypical presentation and/or rapid deterioration may require assessment to exclude differential diagnosis.
2. Polio survivors with a diagnosis of LEOP/PPS should have a **care plan**.
3. The **specialist PPS service** should be responsible for development of the personalised care plan, overall co-ordination, and ongoing management with local and/or regional referral in line with the care plan.
4. Polio survivors should have a **named worker/care coordinator** that is responsible for care coordination, assessment, triage, signposting, and liaison with relevant services in line with the care plan.
5. Ongoing care and support should be **kept local** to the patient when possible.
6. Care is **person-centred** and promotes shared decision-making.
7. **Care is coordinated** around the patient's needs, underpinned by communication between specialist PPS service and local and regional teams.
8. Polio survivors have access to **integrated services** with access to neuropsychological and mental health services across the pathway.

Snapshot of MDT network for the treatment and management of common symptoms and/or presentations

Fatigue
- Rehabilitation medicine
- Physiotherapy
- Occupational therapy

Difficulty swallowing
- Ears, nose and throat services
- Dietetics
- Speech and language therapy

Bowel/bladder function
- Gastroenterology
- Urology

Mental health, cognitive health and wellbeing
- Psychology/Neuropsychology
- Psychiatry/Neuropsychiatry
- Occupational therapy
- Older people services
- Social care
- Third sector services

ESSENTIAL CARE TOOLKIT

Care plan in place

Assigned named worker/care coordinator

Polio survivor and families/ carers

Communication between services

Frequency of review/ reassessment established

New weakness
- Rehabilitation medicine
- Occupational therapy
- Orthotics
- Physiotherapy
- Neurology (nerve conduction study (NCS)/electromyography (EMG))
- (Radiology (magnetic resonance imaging (MRI))

Social/vocational
- Mental health services
- Vocational rehabilitation
- Workplace occupational health
- Faith-based/cultural services
- Older people services
- Social care
- Welfare benefits services
- Third sector services

Shortness of breath/ difficulty breathing at night
- Respiratory
- Sleep services

Falls and fractures
- Rehabilitation medicine
- Orthotics
- Orthopaedic surgery
- Older people services
- Neurology (EMG)
- Radiology (MRI)
- Occupational services

Functional deterioration
- Rehabilitation medicine
- Physiotherapy
- Occupational therapy
- Social care
- Third sector services

Pain
- Rehabilitation medicine
- Orthotics
- Physiotherapy
- Orthopaedic surgery
- Specialist pain management team
- Occupational therapy
- Neurology (EMG)
- Radiology (MRI)

Polio survivors often see a wide range of healthcare professionals, both specialist and non-specialist across different settings. This requires well-coordinated care and robust, resourced pathways.

Endorsed by:

Approved by the Association of British Neurologists (ABN) and the Royal College of General Practitioners (RCGP)

The British Polio Fellowship **0800 043 1935** **info@britishpolio.org.uk** **www.britishpolio.org.uk**

What can you do?

The pathway maps (page 7 – 9) need to be used locally, regionally, and nationally. To achieve this, they need them to reach clinicians and commissioners in Health Boards and Integrated Care Boards (ICBs), as well as general practitioners (GPs), clinical specialists, and therapists working locally and in neurological rehabilitation centres and specialist centres.

You can help by sharing the pathway with these individuals and bodies, or even better, if you have If you have contacts within Health Boards or Integrated Care Boards, introduce them to the BPF who is ready to take the lead from there.

Email the BPF info@britishpolio.org.uk
Call the BPF 0800 043 1935
Visit the BPF website www.britishpolio.org.uk

Editor's Comments: Looking at the pathway it is clear that in many of our member's local areas this not what is happening but we agree that it is what ***SHOULD*** happen for polio survivors.

Please can we encourage you to share this pathway with your local Health and Integrated Care boards or contact the BPF as advised above for assistance in reaching out to them. Please consider helping spread this message far and wide by remembering that your voice is powerful and can make a real difference in the lives of polio survivors. By reaching out to your local health officials, you can help ensure that this pathway has the best chance of being implemented effectively to improve care. As stated this pathway is designed to guide clinicians, commissioners and therapists, but they need to be in the right hands to have an impact.

Your initiative could be the catalyst for change, ensuring that polio survivors receive the care and support they deserve. Share the pathway, make connections, and be a part of this vital advocacy effort.

If you would like to share this pathway directly with your local healthcare professionals please consider using the following text:

Hello

I would like to draw your attention to the British Polio Fellowship's (BPF) Optimal clinical pathway. Currently in our area ***(INSERT NAME OF YOUR AREA)*** it is not what is happening but I believe it is what SHOULD happen.

Please see the following link for a copy of the Optimal Clinical Pathway for Polio Survivors, along with its associated 2-page summary on the BPF website: https://www.britishpolio.org.uk/optimal-clinical-pathway

Link to presentation of the pathway: https://vimeo.com/925777919/81e3c7c982?share=copy

I am proud to support this initiative from the British Polio Foundation. Please note the following information they have provided:

What is the pathway?
The BPF, with support from clinicians and polio survivors across all four nations, has developed the clinical pathway to outline what good treatment and care looks like for polio survivors. It maps out a person's journey from first presentation (worsening or new symptoms) through to the GP and on to a specialist service or neurologist, who importantly will ensure nothing else is wrong. The hope is the pathway will make care and treatment for polio survivors much more effective and timelier.

The pathway needs to be used locally, regionally, and nationally. To achieve this, it needs to reach clinicians and commissioners in Health Boards and Integrated Care Boards (ICBs), as well as general practitioners (GPs), clinical specialists, and therapists working locally and in neurological rehabilitation centres and specialist centres.

Thank you for taking the time to consider this necessary improvement for the lives of those affected by the late effects of polio.

Kind regards
(INSERT NAME)
(INSERT CONTACT INFORMATION)

LIVING WELL WITH POST-POLIO AS WE AGE

Nikki Wingerson, MSW, Ph.D., October 26, 2023

I. Introduction

At the Ohio Polio Network 30th Anniversary and 2023 Conference, I was asked, as a mental health professional and member of the OPN Advisory Board, to write an article for OPN. I am an aging 77-year-old who has lived 38 years with Post-Polio Syndrome, so I decided to selectively explore evidence-based literature on both polio and aging to ultimately address living well with Post-Polio as we age. This article provides what I hope is relevant information for any reader about polio and its impacts; physiological changes that come with normal aging; challenges of aging with Post-Polio; suggested adaptations to aging and Post-Polio; and a few reflections derived from this exploration.

II. Poliomyelitis

Poliomyelitis is the virus that causes the disease called polio. The virus is capable of attacking nerves in the spinal cord or brain stem, paralyzing muscles related to breathing, speaking, swallowing, and moving one's limbs. The virus attacks nerves with a shotgun scatter effect, such that the resulting physical symptoms manifest unevenly: One leg might be capable of climbing stairs, the other not. Vaccination against polio since 1955 has eradicated the disease in the United States and in virtually much of the world.

III. Late Effects of Polio and Post-Polio Syndrome: Definitions, Causation, Diagnosis

The Late Effects of Polio (LEoP) is the term for symptoms related to a person having had polio. These symptoms include fatigue; decreased muscle strength and endurance; pain; breathing or swallowing or speech problems; sleep problems; and physical symptoms, such as joint problems and scoliosis. [1]

The LEoP are not associated with re-infection by the polio virus, but rather, with a greater loss of motor neurons than is typical in the normal aging process. Loss of motor neurons leads to increased muscle weakness. Reduced muscle tissue leads to muscle fatigue and pain. Weakened limbs can lead to reduced weight-bearing activity and reduced bone density. Postural abnormalities resulting from polio can lead to pain, and/or sleep or breathing problems. Increased stress on joints can lead to arthritis and pain. [**1**]

Post-Polio Syndrome (PPS) is a sub-category of LEoP and is a diagnosable neurological condition for those who have had polio, with or without paralysis. PPS is diagnosed 1) when new pain and/or weakness occurs following recovery from the acute illness and 10+ years without new symptoms; 2) when these new symptoms continue for at least one year; and 3) when there is no other clinical explanation for the new symptoms. [1] Nerve Conduction Studies and EMG tests, which measure muscle electrical activity, are sometimes useful in identifying the bases for new symptoms. [6]

The symptoms of Post-Polio Syndrome typically appear 15 to 30 years after recovery from the acute illness. [9] PPS symptoms have been "associated with the degree of residual weakness immediately following [patient] polio infections." [11] However, PPS symptoms usually are not as severe as those experienced following the acute illness. [6] Along with the symptoms of LEoP noted above, other reported symptoms of PPS include cold intolerance and restless leg syndrome. [9]

The prevalence of PPS among polio survivors is estimated to be 25% - 40%, according to the CDC. [2] Risk factors for PPS include female sex, permanent disability caused by motor neuron damage, respiratory symptoms, muscle overuse and underuse, aging, and "immunologic mechanisms." [9] The severity of, and degree of recovery from, symptoms caused by the acute illness determine the risk of developing PPS. [9] "As deficits at the end of the disease increase, the probability of experiencing post-polio symptoms increases." [11]

There are three major theories for the cause of PPS. [8] The prevailing theory for the origin of PPS is based on the fact that recovery from polio involves the body creating new connections between surviving nerve cells and muscles, this to compensate for nerves damaged by the virus. [6] Over time, these compensatory nerve cells or extra nerve branches breakdown due to inflammation, injury, illness, one's immune system, periods of inactivity, and normal aging. [6] This breakdown can occur anytime [11]

A second theory for the existence of PPS is the persistence of polio infection in the brain and spinal cord. [6] Several studies have shown the existence of polio virus genome fragments in the cerebrospinal fluid of PPS patients. [8]

A third theory for the cause of PPS is delayed immune response to the polio virus, leading to chronic inflammation and, thus, persistent symptoms of polio. [8] One study explicitly states that PPS symptoms were attributed to neuronal loss over time with inflammatory mechanisms, but "without any convincing evidence of viral reactivation." [9]

IV. Normal Physiological Changes with Aging

With the increased experience of increased age comes wisdom. At the same time, normal aging also poses physiologic limitations apart from those experienced due to PPS. [5]

The Washington Post on October 15, 2023 included an online article by Judith Graham, "What's normal for the body and brain as we age? An expert weighs in." The information Graham provides is based on an evidence-based new book by Rosanne Leipzig, "Honest Aging: An Insider's Guide to the Second Half of Life." Leipzig is a physician and vice chair for education at the Brookdale Department of Geriatrics and Palliative Medicine at the Ichan School of Medicine at Mount Sinai in New York. Graham describes Leipzig's book as "the most comprehensive examination of what to expect in later life I've come across in a dozen years covering aging." [3]

In her article, Graham notes that explaining how we change with aging is difficult, because the aging process is gradual, decades-long, and influenced by one's behaviors, as well as one's economic and social circumstances, and the like. There are common and predictable physiological changes, but the sequence and timing of these changes vary from one person to the next. [3]

Graham delineates some of the age-related issues that Leipzig describes in her book. Importantly, she includes why these changes occur, not covered here due to space constraints. Older people often present with different symptoms than do younger people when they have the same illness, and they often react differently to the same medication. Indeed, due to physiologic changes with aging, older people often require lower doses of medications which they have taken for years. Older people more frequently experience cognitive changes related to medications and illness than do younger people. These cognitive changes are normal and not a sign of dementia. Also, due to physiologic changes with aging, older people experience less musculoskeletal flexibility; weakened tendons and ligaments; reduced joint range-of-motion; reduced height; decreased muscle mass, strength, and energy; and reduced sense of hunger, thirst, taste, smell, and appetite. Older people require more energy for daily tasks and more protein for maintaining and building muscle. [3]

With aging, balance is compromised due to changes in the inner ear, the brain, and the vestibular system. Compromised balance, along with reduced bone density, leads to more frequent falls and fractures among the aging. Older people require more light to read, and more time to adjust to changes in available light. They experience difficulty in hearing, especially higher-frequency sounds and rapid speech. They find it more difficult to fall or stay asleep. Finally, people's information-processing and reaction times slow with aging, while new learning, multitasking, and word-finding become more difficult. [3]

V. Aging with Post-Polio

In general, conditions which impact the aging population, including age-related chronic diseases, such as high blood pressure, diabetes, heart disease, COPD, and osteoporosis, may occur "more frequently, and at younger ages" among those who are physically disabled. [10] This is because health issues and barriers to maintaining health are often increased in the physically disabled population. Thus, those who are aging as well as physically disabled "need preventive services and at younger ages." [10]

New symptoms in aging polio survivors might include pain at rest; cold intolerance; issues related to standing, walking, and climbing stairs, which increase both fall risk and accessibility issues. [4] PPS patients lament the lack of accessible public spaces, new lack of accessibility to friends' homes, and the cost of purchasing assistive technology and services. [2] In one study, research participants were surprised at the nature of their fatigue, as it seemed unrelated to their physical effort. Some expressed surprise that they could no longer rely on parts of their body which they had previously relied upon. [4] All of these new symptoms and issues can lead to greater social isolation.

Psychological features might include reliving original polio trauma; recognition that former coping behaviors, such as "blending in," no longer work; shame; lack of motivation; and fear of injury. [4] Fatigue due to PPS must be distinguished from fatigue due depression. Risk factors for depression include one's previous illness experience, attitude towards disability, previous coping style, nature of physical changes, and degree of increased impairment, as well as the quality of one's support. [12]

Interestingly, one study of aging post-polios found "modest increased weakness which may be commensurate with normal age." These researchers found a discrepancy between patient experience with growing weakness and actual measurements of strength and neuronal loss, the measurements indicating "modest declines." This discrepancy was considered likely due to "increased sensitivity due to their disease experiences… they lost so much strength at the time of their illness that any change is very noticeable to them." [11]

VI. Adaptations to Aging and Post-Polio Syndrome

According to Graham, Rosanne Leipzig, in her evidence-based new book, recommends the following for adapting to age-related changes: Seek medical attention for sudden changes in functioning. Regularly ask your physician what each of your medications is for, and whether or not continued usage and dosages are currently appropriate. Engage in physical activity and in balance and resistance exercises. Stay well-hydrated – "Drink liquids even when you aren't thirsty" - and eat sufficient protein. Have your eyes checked annually. Use hearing aids, if you find keeping up with conversation difficult. Two to 3 hours before bedtime, avoid exercise, alcohol, and heavy meals. Reduce multitasking and pace yourself. [3]

Post-Polio Syndrome management includes energy conservation; pacing of physical activities to avoid overuse; frequent rest periods; avoidance of stress; avoidance of cold temperatures; avoidance of pain with exercise; use of assistive devices; surgeries for joint repair; respiratory, occupational, and/or speech therapies; exercise physiology; podiatric care; dietetic consultation for weight management; use of mental health specialists and support groups to meet emotional needs; and planning ahead for one's every move. [1] [2] [4]

The theory of PPS causation as an immune response to the polio virus leading to chronic inflammation proposes "treatment with immune modulators as means of combating the chronic inflammation." [8] Management might include immunoglobulin to reduce "proinflammatory cytokines present in the cerebrospinal fluid of the spinal cord." [9]

Aging is "often seen through the lens of the biomedical model of health, which focuses on preventing and curing medical problems causing disability." Disability is often seen through the lens of the "social model of health, which focuses on building inclusive environments and eliminating systemic barriers." [2] Both lenses are needed for clear vision towards patient quality of life. Living well with Post-Polio as we age requires an individualized, goal-oriented, comprehensive, interdisciplinary approach, with focus on empowerment and positive self-evaluation. [4]

VII. A Few Reflections

Undoubtedly, there is overlap in symptoms of PPS and aging. Either may aggravate the other. Both PPS and aging populations may experience an increased sense of vulnerability and difficulty accepting help. We aging Post-Polios must trust and honor what our bodies tell us about our need to make adaptations, regardless of how others perceive or judge our capabilities, or what tests might indicate about our strength.

Likewise, there is overlap in adaptations to PPS and aging. The good news is that those with PPS likely have already devised ways to adapt to changes in their physical function prior to experiencing the effects of advanced aging. In fact, they might consider themselves expert at adaptation.

As a polio survivor, I used to be able to conceal my left arm paralysis, the only polio residual I had for years. I was encouraged to find ways to do physically most everything that my peers could do. I was fortunate, for the most part, to be able to "blend in." Then, at the age of 39, about 35 years after I had polio, I began having trouble climbing stairs. An orthopedic specialist described my legs as "misaligned," in that polio had impacted muscular function in each leg differently. I had not known my legs were impacted at all.

I was informed that I had Post-Polio Syndrome. I gradually made adjustments. While I had to make adaptations that my non-polio peers did not have to make, I was exceedingly fortunate in having much remaining physical ability, adequate supports, and the financial means to hire help or buy equipment as needed.

Now I use a railing and climb stairs one at a time, since only one particular leg can lift me up each stair. I use a sling to support my limp arm. I've had to ask for assistance like never before. The difference for me now is that as I look around, I see that I have company among my aging non-polio friends in the use of assistive devices and asking for assistance. I "blend in," but in a different way now. Aging has become a common leveler.

If age makes common bedfellows of us all, then I am in good company. Perhaps I can let go of past capacities with a bit more grace, if I view my increasing limitations from that perspective.

Living well with Post-Polio as we age requires that each of us find our own unique way to capitalize on our strengths and move forward, just as we always have. We need to take seriously suggested adaptations to PPS and aging, such as those noted above. That said, I rest my case and will adjourn for my regularly scheduled nap.

VIII. References

1 Better Health Channel, 2021, Victoria State Government Dept. of Health. Polio Australia. Retrieved October, 2023. https://www.betterhealth.vic.gov.au/health/conditionsandtreatments|polio-and-post-polio|syndrome

2 Duncan, Andrea and Batliwalla, Zinnia, "Growing old0er with post-polio syndrome: Social and quality-of-life implications," NIH National Library of Medicine, National Center for Biotechnology Information. Retrieved October, 2023. Sage Open Med. 2018; 6: 2050312118793563 . Published online Sep 3.2018. doi: 10.1177/2050312118793563 PMCID: PMC6122244 | PMID: 30202523

3 Graham, Judith, "What's normal for the body and brain as we age? An expert weighs in," *The Washington Post.* Published online October 15, 2023. Retrieved October 15, 2023.

4 Hammarlund, Catherina Sjodahl, Lexell, Jan, and Brogardh, Christina, "Perceived consequences of aging with late effects of polio and strategies for managing daily life: a qualitative study," *BMC Geriatrics.* 17, Article No. 179, 2017. Retrieved October, 2023. https://doi.org/10.1186/s12877-017-0563-8

5 Jensen, Mark P., Ph.D., Department of Rehabilitation Medicine, Hughes M. and Katherine G. Blake Endowed Professor in Health Psychology, University of Washington, Seattle, Washington, "Aging Well with Post-Polio Syndrome," *Post-Polio Health*. Vol. 25, No. 1, Winter, 2009. Retrieved October, 2023.

6 LeWine, Howard E., MD, Reviewer as Chief Medical Editor, Harvard Health Publishing, "Post-Polio Syndrome," *Harvard Health*. March 24, 2023. Retrieved October, 2023.

7 Li Hi Shing, Stacey, Chipika, R.H., Finegan, Eoin, Murray, Deirdre, Hardiman, Orla, and Bede, Peter, Computational Neuroimaging Group, Academic Unit of Neurology, Biomedical Sciences Institute, Trinity College Dublin, Dublin, Ireland, "Post-polio Syndrome: More Than Just a Lower Motor Neuron Disease," *Frontiers Neurol*. 16 July 2019, Sec. Neurodegeneration Vol. 10, 2019. Retrieved October, 2023. 10:773. doi: 10.3389/fneur.2019.0073. PMID: 31379723; PMCID: PMC6646725

8 Morolake, Amole and Khouzam-Skelton, Nadine, with Lobmann, Raif, Academic Editor, "Diagnosing Post-Polio Syndrome in the Elderly, a Case Report," *Geriatrics* (Basel). Jun; 2 (2): 14, 2017. Published online 2017 Apr. 30. Retrieved October, 2023. doi:10.3390/geriatrics 20 200 14 PMCID: PMC 637 1137\PMID: 310 11024 https://doi.org/10.3390/geriatrics2020014.

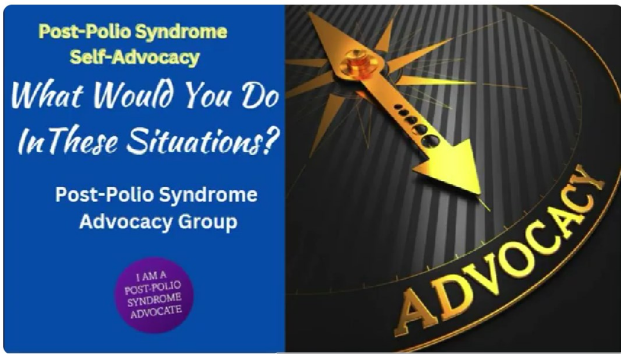
9 Oiuwasanmi, Oiuwaseyi Jacob, McKenzie, Devaunna Adrene, Adewale, Idowu Oluwasegun, Aluka Christian O, Iyasse, James, Olunu, Esther, and Fakoya, Adegbenro Omotuyi, "Postpolio Syndrome: A Review of Lived Experiences of Patients," *Int J Appl Basic Med Res.* 2019 July-Sep; 9 (3): 129-134. Retrieved October, 2023. doi 10.4103/ijabmr.lJABMR 333 18 PMCID: PMC665 2271 | PMID: 31392174

125

An interesting discussion ...

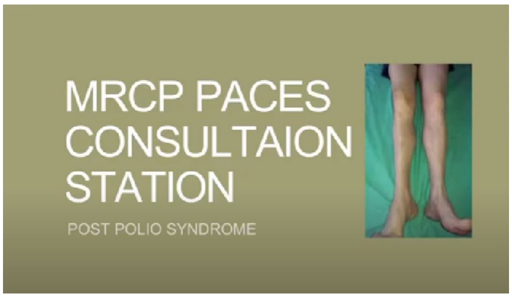
'Championing For The Medical Rights Of People With Post-Polio Syndrome' by Post Polio Syndrome Advocacy Group.

It is listed by Ken Masson on behalf of the Post Polio Syndrome Advocacy Group and is hosted on YouTube



https://youtu.be/47Wb0Vl9kvE?feature=shared

Worth a watch …



We want to share with you a link to a training video for a Doctor meeting with a post-polio syndrome patient. It is listed by MRCP Paces Haider Internal Medicine and hosted on YouTube https://www.youtube.com/watch?v=Cpg5tf3ok2s

Here is a link to the 8th video in a series of ten videos discussing post-polio conditions, this video covers the health risks people face who have been exposed to polio, provides an overview of the four risks areas and presents ways to manage risks for those with history of polio exposure. It is listed by Polio Australia Inc who own the copyright and is hosted on YouTube https://www.youtube.com/watch?v=LKDfrCq6--E

Useful Resources

- International Ventilator Users Network
  www.ventnews.org
- Disabled Motoring UK
  www.dmukdiscounts.co.uk
- Pain UK
  www.painuk.org
- National Voices
  www.nationalvoices.org.uk
- Neurological Alliance
  www.neural.org.uk
- Rare Disease UK
  www.raredisease.org.uk
- End Polio Now – Rotary International
  www.endpolio.org
- European Polio Union
  www.europeanpolio.eu
- Post-Polio Health International
  www.post-polio.org
- PA Polio Survivors Network
  www.papolionetwork.org
- Polio Quebec
  www.polioquebec.org/eng/
- Polio Survivors of Marin
  www.facebook.com/groups/163909760771171
- Atlanta Post-Polio Association
  www.atlantapostpolio.com
- Nebraska Polio Survivors Association
  www.nepolioorg.ipage.com
- Polio Australia
  www.poliohealth.org.au
- Word-Wide Fellowship of Polio Warriors
  www.poliowarriors.org

Management Committee [Trustees]

With grateful thanks to the generous legacy from Ms A Brown, we are able to make
membership **FREE** whilst our funds remain above £10,000.00

Website www.poliosurvivorsnetwork.org.uk
Write to us at PO Box 954, Lincoln, LN5 5ER, UK
Email psnadmin@poliosurvivorsnetwork.org.uk
Phone us on 07480 110334 and we will ring you back when we collect our messages

UK Members - receive newsletter by post and/or email (overseas members newsletters by email only)

All donations, small or large, towards our work are gratefully received
Donate by **cheque** to Polio Survivors Network
by **PayPal** to treasurer@poliosurvivorsnetwork.org.uk
By **PayPal donate** link: https://bit.ly/2KzyAyE

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

We hope this special edition captures the diversity and uniqueness of each polio survivor, we all may well have different experiences and perspectives. We have all been affected and influenced by polio, but it does not define who we are.

Is your polio survivor story ...

a symbol of resilience and journey. This artwork depicts a tree with half of its leaves transforming into flying birds. The dark, dense part of the tree represents the challenges and hardships faced because of polio. The birds, formed from the leaves, represent overcoming obstacles and moving towards recovery, freedom and possibilities.

... or more like ....

a cat tangled in the lines of a notebook, symbolising the challenges and obstacles constantly faced. The cat's calm expression represents a kind of acceptance but with the ongoing effort to work things out. It is also a metaphor for the creative and adaptive ways that we polio survivors cope with our condition and find our own solutions.

Help PSN raise funds

Our beautiful A6 blank photocards are £1.75 each or £6.00 for 5 (inc P&P)