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www.poliosurvivorsnetwork.org.uk

POST POLIO MATTERS

Polio Survivors Network Newsletter — Volume 12 Issue 2 of 12 [Edition 134]



Celebrating 30 years of your newsletter

Thirty years ago, a simple idea took shape: create a publication that truly understood polio survivors. The LincPin became that voice, it was clear, practical and completely grounded in lived experience. As the needs of the community grew, so did our newsletter, transforming into Post Polio Matters, a trusted source for PPS knowledge, research and a voice for our members.

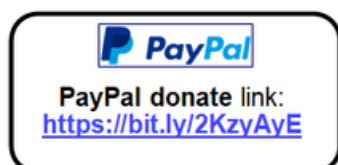
Today, we celebrate a legacy built on resilience. Our past informs our future and this anniversary marks not a new beginning, but a continuation of the steady, essential work of keeping polio survivors informed and connected.

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Donations and Charity Incentives Paid (since last newsletter)	
Donation DM	12.50
Donation from funeral of GH via MuchLoved	216.15
Donation from funeral of GH via funeral director	40.00
Total	£268.65

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We are very grateful!



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Heroes or Zeroes?

It's 30 years since Hilary Boone started the Newsletter, now Post Polio Matters. Originally The Lincolnshire Post Polio Network, as we developed and widened our reach we became known as PSN - The Polio Survivors Network. It's worth remembering that recognition of post-polio syndrome did not mean that survivors consistently felt heard or understood. In my experience, symptoms could be attributed to ageing or to the effects of living with a physical disability since childhood, and explanations could leave us feeling that we were being told 'it's all in your head'.



My Bulbar Polio

I caught bulbar polio in early January 1956 aged five, before the UK vaccine roll out. I was in an iron lung, nasogastric tube fed, totally paralysed and spent nearly two years in hospitals. Eventually I walked unaided, but my arms, upper body and breathing remained severely impaired — what was often termed 'upside-down' polio.

By 25, after four years at art school, I was working as a designer and started having odd symptoms. I saw a neurologist but he could only offer me tricyclic antidepressants, suggesting, my symptoms were vague and it was probable I was having trouble adjusting now that I was 'a handicapped young man' and now working. After my aunt, a pharmacist and ex-nurse, explained what they were, I threw the script away. Life was not easy, but that was and is largely due to the world around me being disablist! Of course, back then neither they nor I knew that word! That was 1975, No equalities Act, no DDA.

I want to be clear: despite the blind spots, and difficult clinicians, I have also had the privilege and luck to be in both camps, both as a patient, and a psychologist with, some exceptionally, humane, and talented medics and health professionals. I mention two such individuals here: Mr. Charles Manning, the pioneering orthopaedic surgeon at the Royal National Orthopaedic Hospital and Dr Geoffrey Spencer, the pioneering consultant anaesthetist instrumental in establishing the Lane Fox Respiratory Unit, Two amongst others over the years.

The Crash Point

Most of us had been told that after recovery, what you had - you would keep. So we went on to live the best active, normal lives we could, stressing muscles and using compensatory muscle groups. We were, it appeared outwardly to be functioning normally — until we weren't - and then the crash happened. I felt like we were back, back where we were if differently presented, but this time older, alone and not understood or often believed.

I actually was never that very able physically, but still overdid it. That was how we were taught to cope, or maybe the term is 'trained' by the then rehabilitation regime. Be as normal as you can, at any cost. Push through. Maybe that contributed to creating a type, sometimes seen as the awkward polio patient! We had expected, the same expert interest, attention and input as we had had as children.

Hilary had been a policewoman, lifeguard and mother — and then the crash. Page 3

Few would listen. There was disagreement about how post-polio syndrome should be defined and distinguished from other late effects of polio. A 1999 newsletter account of a Lane Fox rehabilitation course recorded these differing views, while also describing the unit's work to understand survivors' difficulties. [1] For us, the essential point was that our changing symptoms needed to be taken seriously, whatever terminology was used. Hilary pressed for that recognition. I believe that PSN played a small but significant role in improving understanding: searching for survivors, sources and data, and making contact with other polio survivors and groups in the USA, Europe and across the world. PSN was, and still is I hope, always about communication between survivors. We were and are also about facts, research, challenging services, damaging rehab and misconceptions about polio — and the vital part: sharing our real-life experiences, not only for mutual support, but to educate and inform.

From a child with polio to an adult with PPS

When we were children, when polio was common, everybody was interested in us. We were cute children. Critically Polio was not confined to the poor. No one's children were safe. Parents were scared. So, there was public sympathy, attention, the USA March of Dimes. Medics and researchers were involved and curious. I had medical pictures taken of me for textbooks and was used as a teaching subject. We were 'famous', if that's the right word!

By the 1990s, polio was a historical, forgotten illness. No longer the 'heroes' or those poor children in callipers, we had become an ageing, forgotten cohort, no longer 'famous,' of little research interest or funding. Even during the pandemic, when we had lived experience of epidemics and the damaging effects of vaccine scepticism, what it meant to be isolated as children, we were not asked. What we had to offer was a lost resource even now not recognised.

Many of us are now old — but not all survivors are. The British Polio Fellowship's (BPF) published Optimal Clinical Pathway reports that 16% of patients attending the PPS service at the Lane Fox Unit were under 50.[2] PPS will remain a concern for younger survivors too, as symptoms can emerge decades after the original infection.[3] Yet the lack of expertise is staggering as older clinicians retire or die. We can feel isolated and that is a lonely place. We require individualised, holistic care and assessment. Something hard to find in practice, despite the rhetoric of policy, NHS frameworks and clinical pathways. The original concept of the expert patient needs fighting for, it should not be allowed to be a lost or forgotten cause.

So we now end up in parts, distributed across, and referred to different specialities, different bits in different boxes. We are human beings — complex, biological, psychological and social. We should be mindful always, not to put process before ethics. Clinical pathways are all very well, but they are about structure, not philosophy.

Thirty years on

I believe PSN can quietly celebrate what we have achieved and what Hilary helped start. Much of it is now invisible, owned and absorbed by others. That's success! But there is still much to learn, to challenge and to fight for!

We still need to put reliable information about PPS into the hands of survivors and professionals, challenge misconceptions and keep survivors talking to one another. That knowledge must not disappear as those of us who hold it grow older. As I pointed out in previous editorials, we are actually more relevant today and to the future than is understood. Living well and ageing with a lifelong disability is a skill and not easily understood or learnt. We did it, live it and know how to do it – but we need the right support. PPS isn't just ageing. It can be unpredictable day to day, action to action. It impacts individuals in different ways. We don't fit neatly into a clinical or commissioners' box.

The need for support with PPS will continue internationally. Here in the UK, BPF's clinical pathway describes a growing group of younger, working-age survivors presenting in clinical practice who contracted polio abroad before moving to this country.[3] Despite many of us now being older and fatigued, we can still offer the coming generations our unique insight and advice on how to live well with long-term disabilities and conditions given the support.

It's harder now – we aren't those cute kids or heroes, but older. But let's try not to be zeroes!

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Sources

1. The Lincolnshire Post-Polio Information Newsletter, account of the Lane Fox rehabilitation course, March 1999.
2. British Polio Fellowship, Optimal Clinical Pathway for Polio Survivors, p. 5 (circulated by the Association of British Neurologists in 2024).
3. UK Health Security Agency, Poliomyelitis and post-polio syndrome: migrant health guide, updated 20 February 2026.



Post-Polio Life: A Virtual Celebration of World Polio Day

24 October 2026, 9:00 AM - 1:45 PM

Supporting Global Polio Survivors

This global event, sponsored by the Rotary Club of World Disability Advocacy, is centered on polio survivors and will be a powerful gathering of lived experience, resilience, and long-overdue recognition. It brings together survivors from every region—voices often overlooked in modern health conversations—to share their stories, shape policy, and guide the future of disability-inclusive care.

Rather than focusing solely on the history of polio, the summit highlights the present: the realities of aging with post-polio syndrome, the gaps in rehabilitation access, and the urgent need for survivor-centered health systems. By elevating personal narratives alongside clinical expertise, the event becomes a platform for dignity, solidarity, and global action, ensuring that polio survivors are not only remembered but actively included in shaping the world's next chapter of disability advocacy.

Register for the event here: <https://rotaryclubwda.org/page/polio-survivors-world-polio-day-celebration>

Is It My PPS, My Age — or My Balance?

Why becoming less steady as we grow older may be more complicated than we think

By Simon Parritt

"I'm not dizzy. I just don't trust my balance anymore."

I suspect quite a few older polio survivors will recognise that feeling. Perhaps you can still walk but increasingly touch the furniture as you pass. Uneven pavements have become more troublesome. Turning suddenly feels less secure. You are fine in daylight but much less confident in the dark. Or perhaps you simply know that if you start to go, you haven't got the same ability to save yourself that you once had. The obvious explanation is often: **"It's my PPS."** It might be. But it might not be — or, more likely, PPS may be only one part of a much more interesting picture.

First - A Disclaimer!

I am not a doctor or a vestibular specialist. I am writing both as a psychologist and as someone who has lived experience of polio and later PPS for most of my life. I have experienced balance difficulties since my twenties and had the dubious pleasure of experiencing both vestibular illness and BPPV.

Earlier in my psychology career I spent five years working in the Geriatric Department at St George's Hospital Medical School. Among my other work, I researched older people and frail elderly, falls and the fear of falling. I learnt a great deal about the fascinating interaction between the physiology and psychology of balance, activity and ageing.

The psychology deserves another article. Fear of falling can make us move less; moving less can make us less well adapted to movement; increased instability creates more fear. Anxiety can make us feel dizzy, while genuine physiological dizziness can make us anxious.

For now, though, I want to concentrate on the balance system itself and why our polio history makes ageing with it particularly interesting.

Dizziness and balance are not the same thing

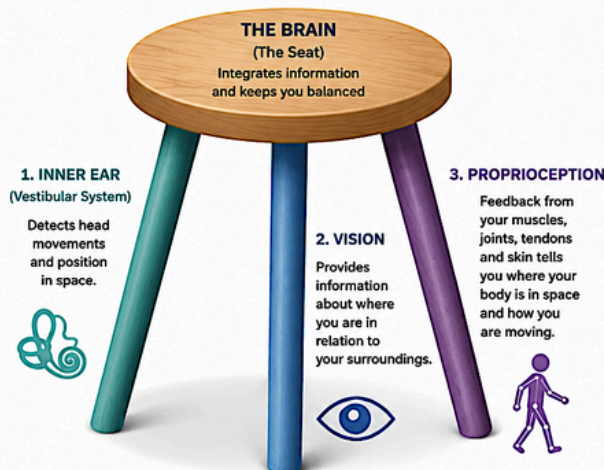
This is worth getting straight from the beginning. Dizziness is something you feel. Balance is something your nervous system and body do. You can have horrible spinning vertigo while lying safely in bed. Equally, you can have very poor balance without feeling remotely dizzy. And you can have both.

A weakened knee may give way. An ankle may no longer make a rapid enough correction. Your trunk may not respond quickly enough when you stumble. You know exactly where you are. The room isn't spinning.

You simply can't make the correction quickly enough. For polio survivors, that distinction can be particularly important. One simple way of understanding balance is to imagine a three-legged stool.

BALANCE: A THREE-LEGGED STOOL

Your ability to stay upright and avoid falls depends on three body systems working together. Your brain is the "seat" that brings them together and makes adjustments every second.



HOW COMPENSATION WORKS

If one leg of the stool becomes weaker, the brain automatically leans more heavily on the other legs.



EXAMPLES OF COMPENSATION

- Poor vestibular (inner ear) function → we rely more on our vision.
- Poor vision (at night or due to age changes) → we rely more on vestibular and proprioception.
- For PPS: muscle loss affects proprioception which becomes less reliable. This may be a greater factor as we age than for someone without a history of polio.



The brain is remarkable. It constantly receives information from all three systems, compares it, and makes tiny adjustments to keep you steady without you even thinking about it.

WHEN A LEG IS WEAKER, YOU MIGHT:

INNER EAR WEAK

- Feel dizzy or unsteady
- Rely more on your eyes
- Do better when you focus on a stable object

Examples: inner ear disorders, infections, BPPV, age-related vestibular changes

VISION WEAK

- Struggle in low light
- Need more time to adjust
- Rely more on inner ear and proprioception

Examples: cataracts, glaucoma, macular changes, poor contrast sensitivity, dark environments

PROPRIOCEPTION WEAK

- Feel less aware of where your feet and body are
- More wobbly on uneven ground or when closing your eyes
- React more slowly

Examples: muscle weakness (such as in PPS), neuropathy, joint problems, fatigue, deconditioning



BALANCE IS DYNAMIC. It changes every moment. The good news? Your brain can adapt, and through safe challenge and activity, you can keep your balance systems as strong as possible.

One leg is **vision**. One is the **vestibular system in our inner ears**, which detects movements of the head and our relationship to gravity. And the third is **proprioception** — the extraordinary stream of information from muscles, joints, tendons, skin and feet that tells us where our body is without having to look at it.

Sitting on top of the stool is our brain, continually comparing all this information. And here's the clever bit ... **If one leg becomes less reliable, the brain can put more reliance on the others.**

If vestibular information becomes poorer, we may depend more upon vision. Turn the lights out and vision becomes less useful, so vestibular and body-position information become more important. This ability to compensate is one reason we can remain remarkably stable despite considerable changes in one system.

Then.... we get older!

Normal ageing gradually changes all three systems. Our eyesight changes. Night vision and contrast may deteriorate. Our vestibular system ages. Proprioceptive and other sensory information may become less precise. Joints become stiffer. Reactions may become slower. Usually the brain adapts - **but now add polio.**

A polio survivor's balance system has a history

Those of us who had polio as children did not grow up learning to move with a neurologically typical set of muscles and then become disabled later. Our developing nervous systems learnt to use whatever remained available after polio. One child learnt to lock a knee. Another used a stronger hip.

Someone learnt to swing a leg, shift their trunk, use momentum, touch something for support or combine several muscle groups to perform a movement another person accomplishes with one. After fifty or sixty years we don't experience these things as clever neurological compensations. They are built into our bodies and brains.

It's simply how we move.

And this matters enormously as we age. Balance isn't just detecting that you're beginning to fall. Once your brain detects it, ***your body needs to do something about it — quickly.*** A knee stiffens. An ankle corrects. A hip shifts. An arm reaches out. A foot takes a rapid step.

The polio survivor may have spent sixty years making that correction using a very particular combination of remaining muscles, very different from the average person and patient.

Then one part of that combination becomes weaker or slower. Perhaps PPS reduces the reserve in a muscle. Perhaps the "good" leg, which has quietly been doing extra work for decades, isn't quite as good as it was. Perhaps arthritis changes a joint. Perhaps vision deteriorates. Perhaps the vestibular system has simply grown older.

None of these changes needs to be enormous. ***Several small losses may finally overwhelm a compensation which has worked brilliantly for sixty years.*** That is a rather different explanation from simply saying: "***Your legs are weak because you had polio.***"

Don't assume everything is PPS

There is another danger. Once we have a diagnosis of PPS, it is very easy for both us and clinicians to put every new problem into the PPS box. But we also get all the ordinary conditions associated with getting older. Changes in vision, arthritis, neuropathy, medications, blood-pressure changes and inner-ear disorders can all affect dizziness or balance.

One particular not uncommon condition is ***BPPV (Benign Paroxysmal Positional Vertigo)***, where tiny calcium crystals associated with the inner-ear balance organs become displaced. It can produce dramatic spinning when rolling over in bed, looking upwards or bending down. ***It is often very treatable.***

Even the standard manoeuvres used to treat it can usually be adapted if a polio survivor cannot lie flat, has spinal fusion, neck weakness, respiratory problems or difficulty changing position. But, it does require expertise that many physiotherapists or clinicians who claim to treat BPPV are not able to adapt to. So as always, treatment need expert adaption for a PPS person again. The lesson is simple:

"I have PPS" should be an early part of the assessment, not the end of it.

Should we become more careful — or move more?

Both - and that's the difficult bit. Falling matters. For someone already living with significant disability, the consequences can be considerable. But avoiding movement altogether has consequences too.

As children we constantly challenged our balance systems. We ran, turned, looked up, bent down, spun around and walked over all sorts of surfaces. As we age — particularly after a frightening fall — our movements can become progressively smaller and more cautious. But the brain needs movement in order to keep adapting. This doesn't mean telling a polio survivor simply to "exercise more" or exhaust already vulnerable muscles.

It means finding **safe ways of continuing to challenge the balance system.**

For one person that might mean head movements while securely seated. For another it could be controlled reaching while holding a worktop. For someone else, carefully supervised standing or walking. And for a wheelchair user it might involve trunk movement, reaching, visual tracking and head movement. Sometimes vestibular rehabilitation even deliberately produces a small, controlled amount of dizziness so that the brain can learn to adapt.

The important words are **individual, controlled and safe.**

One question to take to your clinician

If you see a GP, physiotherapist, OT or falls clinic about deteriorating balance, they may know a great deal about ageing and falls but very little about paralytic polio.

There is one question I think is particularly useful: **"Can we work out what has changed from my normal?"**

- Tell them how you have always moved.
- Tell them which muscles were affected.
- Tell them which leg you have relied upon.
- Tell them if fatigue changes things.
- Tell them about old callipers, braces, orthoses or walking aids.
- Tell them if you have respiratory problems or cannot safely lie flat.

And distinguish, if you can, between **dizziness, weakness and loss of balance.**

Your longstanding "abnormal" movement may actually be completely normal for you. The important clue may be the small thing that has recently changed.

We have been adapting all our lives

Becoming less steady doesn't necessarily mean: **"It's PPS and there's nothing I can do."** Nor should we automatically accept: **"You're old and your legs are weak — exercise more."**

The more useful question is: **Which part of this complicated system has changed, and can we treat it, retrain it or compensate for it?**

Sometimes the answer will be treatment. Sometimes rehabilitation. Sometimes a walking aid, wheelchair, orthosis or another adaptation which allows us to continue doing more rather than progressively doing less. And sometimes we will have to accept a new limitation.

But adapting to changing physical circumstances is hardly unfamiliar territory for polio survivors.

We've been doing it most of our lives.

There is much more to this subject than can fit into one newsletter article — including practical balance exercises, vestibular rehabilitation, BPPV and adapted treatments, fear of falling, and how physiotherapists and OTs can assess the very individual compensatory movement patterns of a polio survivor. If there is sufficient interest, the Post Polio Survivors Network could consider producing a more detailed illustrated guide to balance, ageing and the late effects of polio.

Zsuzsi's Thoughts on Polio survivors and Osteoporosis



Bone is a living tissue, which develops and grows most quickly at a young age. The skeleton of a young child is completely renewed in two years, whereas in adults it can take seven to ten years. Exercise, especially weight bearing exercise helps to develop strong, healthy bones supported by a healthy diet with sufficient calcium and vitamin D, which is produced in the skin when exposed to the sun.

I was eight years old when I had polio and was not able to walk for a year and I could never run but many were infected at a much younger age and could not run, jump, dance, or go for brisk walks for some time or not at all and are therefore more at risk of fractures due to osteoporosis. It is important to do what you can. Standing regularly for a few minutes is better than sitting or lying for long periods.

The word 'osteoporosis' means 'porous bone'. Bone tissue is a scaffold of a protein, collagen, made strong by calcium and other minerals. Older bone tissue is broken down by specialist cells called osteoclasts. New bone is then rebuilt by bone-building cells called osteoblasts. Bones have a thick outer shell with a strong structure inside that looks like a honeycomb. With osteoporosis, the holes in the structure get bigger and the bone becomes less dense. Eventually, the inner structure begins to break down. This leads to bones getting weaker and make them more likely to break.

Osteoporosis is usually linked to the natural process of ageing when bone renewal gets out of balance, more bone is broken down than built. Your bones will not look any different from the outside and you won't feel any difference. It means the outer shell becomes thinner and the inner structure becomes more porous. This can lead to bones losing strength and breaking more easily. This bone loss starts sometime before we reach the age of 45, but usually we do not lose enough bone to make a difference to our bone strength until we are older. For women, bone loss starts to increase after the menopause because oestrogen levels decrease. I had a bone scan when I was 60 and on hormone replacement therapy and my bones were good. Oestrogen in HRT helps to keep bones strong. Soon after that, I developed breast cancer, had to stop HRT and started to lose bone as shown by two DEXA scans. Bone density scans, also known as DEXA scans, are effective tools for diagnosing and assessing the risk of osteoporosis. They use low dose X rays to measure bone density which helps to identify the likelihood of fractures. If you have broken a bone, you should have a DEXA scan to check for osteoporosis.

If bones become very weak, spinal fractures (also called 'vertebral fractures') can occur during normal activities. These are different from other fractures because the bones don't snap, but they can squash or compress down on themselves. This can result in you getting shorter and developing a curved spine (often called 'kyphosis'). Some people experience long-term pain, especially if they have had several fractures. Spinal fractures due to

osteoporosis don't cause damage to the spinal cord or paralysis, unlike those caused by a severe injury. In fact, sometimes they are painless. A broken hip is a common consequence of a fall, especially in older people and those with osteoporosis. It can lead to long-term health issues, such as not being able to work and being less able to care for oneself. Until we reach older age, there is usually a balance between the amount of bone that is removed and the bone that is created. This means the total amount of bone tissue stays the same, keeping the skeleton strong and healthy.

Healthy eating will provide your bones with enough calcium and enough vitamin D is produced in your skin by the sun between the start of April to the end of September. You only need to expose your arms for 15-20 minutes a day. Some people take vitamin D supplements if they are housebound, cover up outside or have darker skin. It's never too late to start caring for your bones by making positive lifestyle changes, including eating a healthy diet and starting bone-strengthening exercises. I have been taking Vitamin D (Adcal) tablets daily and weekly Alendronic acid to slow bone loss and I also had yearly infusions of Zoledronate twice, instead of the tablets after a 'holiday' from Alendronic acid.

**For more information contact the Royal Osteoporosis Society by
Freephone helpline 0808 800 0035,
email nurses@theros.org.uk
or write to St. James House, Bath BA2 3BH**



This research project is part of the Advanced Physiotherapy Masters at UCL under the supervision of Dr. Louise Kedroff
Approved by UCL Life and Medical Sciences Research Ethics Committee
Project ID: 3227

Have you attended A&E seeking treatment for a flare up of your persistent pain?

**Would you like to take part in a study exploring
your reasons for and experiences of attending A&E
for help with your persistent pain?**

Who can take part?

- ⇒ Adults aged 18 and over
- ⇒ Anyone living with persistent pain for more than 3 months
- ⇒ Attended A&E in the last 5 years for a flare-up of persistent pain (non-cancer related)

What will you need to do?

Attend one online interview for 30 to 45 minutes and talk about your experience of attending A&E for your persistent pain treatment

Researcher's contact details:

Eshita Shah sejkesh@ucl.ac.uk

Participation in this study is completely **voluntary**. You may withdraw at any time without any consequences.

**For more information
and to take part, scan
the QR code below**



Introducing Our New Trustee Nirja

I am looking forward to the role of Trustee. This is new to me and I hope that I can offer a useful contribution to the Polio Survivors' Network.

At the age of about 12 months, I contracted Polio. I have significant paralysis to my legs. Having been born in India, I was in England by the age of five, learning a new language, adjusting to a new country and becoming aware of my physical disability. I left behind a large loving extended family. This huge loss of relatives became permanent.

I didn't attend primary school regularly as my parents moved around a lot before settling in the East Midlands. They are both graduates, and eventually got a mortgage, so I subsequently went to a 'normal' school at eleven. A bilateral school, it was neither a comprehensive nor a grammar. The authorities paid me little attention except to make sure that I attended school. I got bullied, I got excused from P.E., I didn't really exist, meaning that I was ignored much of the time; it was great. I learned quickly and, after a year, somehow found myself in the top sets. Amongst my peers, the youngest, the wobbliest, the brownest, not academic and with a dysfunctional homelife, I failed spectacularly in everything. According to a consultant at St Thomas', this is quite normal for Polioids. I have had hospital stays, various goes at surgery, callipers and orthotics. I failed numerous driving tests!

By my thirties, I was a graduate, a school teacher, a wife and a mother. An eminent evolutionary biologist recently informed me that these are key markers of success. I don't know about that. I guess I shouldn't grumble, though PPS is pretty tough. Looking back, it's all been rather tough.

I currently live in Hertfordshire with my house rabbit and a couple of humans.

[Editors Note:](#) Some of you met Nirja at our Annual General Meeting, where we were delighted to appoint her as a Trustee. We extend a warm welcome to her in this role and are certain she will bring the tenacity needed to keep the charity moving forward and supporting our members effectively.



Toni Writes ...

How have you been coping with the weather? As we continue through another stretch of unpredictable weather, I wanted to pause and ask how you're doing? Across the UK and many parts of the world, people have been dealing with everything from intense heatwaves to sudden downpours, storms, and sharp changes in temperature.

"THE ANSWER TO AN AGEING SOCIETY IS NOT SIMPLY MORE CARE. IT IS MORE ENABLEMENT SYSTEMS EXIST TO SERVE PEOPLE NOT THE OTHER WAY ROUND."

Simon Parritt, Chair Polio Survivors Network

If you've discovered a helpful tip, a new habit, or even a small moment of joy that made the heat or the weather extremes easier to manage, I'd be delighted to hear about it. Sharing these experiences reminds everyone that they are not facing these challenges alone.

In other news, World Polio Day 2026 will be observed on 24 October 2026, offering a moment to reflect on how far global health efforts have come. It encourages people to look back at the history of polio, to recognise the impact of vaccination, and to acknowledge that completing eradication still matters.

All major polio outbreaks and the global vaccination work happened before I was born and the reduction in polio cases, to 99% worldwide, reflects decades of scientific progress and international cooperation. Millions of children have been protected and many countries now live free from polio. Of course the final phase of eradication is challenging due to things like wars, limited access to healthcare and sadly misinformation. Continued commitment and public support are essential if polio is to become a disease confined to history. I think that World Polio Day provides a reminder of the progress and the need to complete eradication, but it is hearing your experiences that impress on me why finishing this work remains essential.

Take care
Toni x



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From Our Readers

Thanks for another great issue, with some really good articles! BB

I am still reading this excellent newsletter and so far I think the 10 suggestions on how to respond to PPS are the best to share with someone who is trying to help you but needs to know. We can't regain muscle strength that is gone but we do need to keep our bodies moving. Thank you. JW

I just felt compelled to take a minute to let you know how impressed I am with this newsletter, the writing and professional presentations throughout the pages. It felt as if it was something I could share with my doctors and which would be taken seriously. I have struggled in advocating for recognition of this condition and treatment there upon, doctors were much more comfortable in using fibromyalgia as a diagnosis which may be a valid part of PPS but it does not explain many of the symptoms we also deal with on a ongoing basis. I think many of us end up playing along just to get some of the care we require but it costs emotionally by never being validated. The result is often the questioning by our families, co-workers, and general public, they just don't really understand or validate some of the paradoxes that come with it, with many of us doubting our own experience as well. I see your newsletter as a real step forward in bridging that gap. I found it very supporting emotionally as well as the physical. SJ

It's always a good newsletter. JW

I enjoyed the Annual General Meeting - keep up the good work! JH

Just a quick note to say that I enjoyed the AGM yesterday, it was nice to put names to faces. JF

I enjoyed the AGM and members' interesting comments. GC

Wonderful resources, thank you. ME

The above member also kindly suggested interesting articles from earlier this year for all to read about the last woman to die who was in an iron lung. They can be found here:

<https://kfor.com/news/local/oklahoma-woman-the-last-american-in-an-iron-lung-dies-at-78/>

<https://www.bbc.co.uk/news/articles/cwyk4z3e2xlo>



From Our Readers (continued)

Not sure which terminology to use for all those iron lungs in fig 1. "Gruesome or awesome. We only had three iron lungs in our children's hospital The Alexandra Hospital for Children with Hip diseases in LUTON, in 1955, 2 in use and one spare, us nurses all had to have a go in the iron lung to experience what it felt like for the children. We were pre student nurses living in the hospital. BT, S.R.N. S.C.M. Dip, I.H.T.T.

The above member also provided a link to an article: Polio, Still Lurking in the Shadows <https://share.google/AMst3MLkB5ojn8H6L>

March 1971 I caught flu and never recovered from it. Terribly ill and weeks and weeks over eleven plus years in and out of hospitals with six week stretch, four weeks stretch many more hospitals and weeks and tests and muscle biopsy R.N.A 25% in left arm muscle that Dr David Smith M.E Association Medical advisor back then I was under aim was to do two hundred biopsies and he sending the samples to his colleagues in London. And an Orthopaedic surgeon was to do likewise on motor bike accident patients to see if they as healthy individuals apart from smashing their bodies up and months of hospitalisation and operations to save their lives. Dr Smith said mine was the highest result (1986) at 25% from a left arm muscle that I said had never been affected but could he take biopsy from left quad muscle paralysed amongst other muscles. Dr Smith said 'No' as to much fatty tissue and he would struggle to be able to extract a biopsy piece of muscle correctly. That mine was the highest the others were between 14% to 17% and that mine was bad luck he said, but at that time my letter states they didn't know what it meant.

Would it be helpful to print this in your P.S.N magazine and see if it reaches more people who struggle under the umbrella of Myalgic Encephalomyelitis disbelief illness when in actual fact it was a Cocksackie B3 and B4 flu mutation., into a wild strain of Polio.

A Google search: "Does a wild strain of polio with flaccid paralysis from flu mutation Cocksackie B3 and B4 have the same effect on neurons as ordinary polio and post polio syndrome?"

I could write some of my horror story, not a pretty picture what was done to me but time is running out for me now at nearly 88 and only have stamina in mornings and back to bed until the following morning and start a small day again called survival? to write in short articles over a few PSN magazines. Dr David Smith said at the time of many appointments with him in Horndon on the Hill, Essex, we were living in Stourbridge W.Mids at the time he took blood samples from me over nine months, sending to St Mary's Hospital Paddington to a Professor Mowbray who himself had got M.E for eleven years and my bloods showed positive each time on IGM virus positive active circulating in my body continuously.

From Our Readers (continued)

It was Dr Betty Dowsett who told me over many appointments with her eventually 1990 she had moved to St Andrew's Hospital running an M.E clinic, she said it was likely that I had a wild strain of polio. I had fits, dreadful headaches could not lay down to sleep in bed head and neck hurt to much, I went to a chiropractor thinking my neck was out. but couldn't sit down in a seat anywhere day time be it home or friends or family homes without falling into deep sleep, could hear people talking to me but could not wake up to respond, gone blind twice, bed ridden, dreadful diarrhoea and flu symptoms on going, alternating over months affecting work by 1973 and repeatedly having time off from work with three days and back to work before I needed a certificate from G.P, driving mini buses for Devon county. I went from a size 22 clothes down to a size 14 and people said you don't have bags under your eyes Barbara you have suitcases under your eyes. I was only 32 at the time, a sports fanatic, ward sister, youth club leader, professional knitter, I lost it all. I could no longer even knit, couldn't hold my needles nor get my stitches right and no longer follow complicated Aran patterns for the company I was knitting for.

An O.T told me to only try to knit for a few minutes a day as it was so distressing and gave me a brochure with gadgets, one of which was a gadget to screw onto a table to screw a knitting needle into (like stroke victims using with only one arm to function with)

I couldn't hold my tennis racquet, too heavy and falling to the right and definitely I couldn't no longer run backwards, then my badminton racquet became too heavy I couldn't no longer hold it. And 1st division league netball player and umpire, I could no longer run, I was running two teams from Woodbury Devon, 21 players, and treasurer and couldn't add up any longer. Lost it all still without a diagnosis from 1971 to 1984. Lost my nursing job., then lost my driving job, then sacked from shop assistant in a mewsafent after three weeks as I couldn't add up and I had at the time a honours in City and Guilds Maths, nor remember where the things were.

He sent me to a Dr Betty Dowsett at Basildon Hospital who took nine tubes of blood for various things but saying it was to late to take bloods for many viruses as by the time I got to her from 1971 to 1984 that some viruses stay in the body. BT, S.R.N. S.C.M. Dip, I.H.T.T.



Far Fetched - Vic Baxter

Our member, Vic Baxter has written a series of articles entitled "Far Fetched" on the topic of "Dodgy Wheelchair Transfers" in faraway airports. Please enjoy the first one entitled...



Lufthansa's Strudel Twins Save The Day

Heading back to Riyadh after nine days of R&R at home was hardly a chore in the hands of Team Lufthansa – what could go wrong?

Well, in their wisdom Lufthansa had decided to make Bahrain their Middle East base on account of the Iranian missiles frequenting Saudi Arabia on account of the proxy war ongoing with the Houthis in Yemen.

This resulted in Riyadh being the penultimate stop before overnighting in Bahrain.

So on landing in Riyadh I waited for the plane to empty before heading to the door to hop into a wheelchair. No such thing happened and I heard the door close and the "fasten seatbelts" sign go on while the engines fired up.

Simultaneously the two delightful cabin crew who had spoilt me tween Heathrow and Riyadh, affectionately known as the Strudel Twins in a tribute to their elegantly plaited hair, were also buckling up ready for take off.

So I asked where we were going. "Bahrain" was the answer.

I explained that I had been waiting to be called forward once the plane had emptied but that this had not happened. By now push back was complete and we were headed for the main runway and I was reconciled to a night in Bahrain.

The Cabin Director was called and informed of my plight, upon which she rounded on me like a whirling dervish demanding to know why I had not deplaned in Riyadh.

It transpired that someone had got off who should not have and I had stayed on and should not have – so the headcount for Bahrain tallied. So she was already accountable for one error and here we were with a second one.



The aircraft had ground to a halt at this point and the Captain appeared who as all of six foot six and on buttoning his Cabin Director away for a quiet sit down with an ice pack he apologised profusely for her behaviour and opened the rear door of the aircraft to see if an ambilift was on its way.

After some minutes it arrived but was significantly too low for the large Airbus. I offered to be lowered onto it but he declined and said we'd await the taller one, while engaging in very pleasant small talk meantime.

Finally the larger one arrived and I hopped off in what seemed to be a feeder runway under the stars as it was after midnight.

My faithful driver Shabbir had availed himself of a wee nap meantime and we chatted all the way back to my hotel with the odd chuckle thrown in.

Walk in My Shoes

The Walk In My Shoes campaign shines a light on the experiences of people who rely on NHS-supplied footwear yet often find themselves battling for comfort, function and basic suitability. As polio survivors, many of us know only too well how crucial well-made orthotics are for staying mobile and protecting our long-term health. When services fall short, the consequences are felt every day in our balance, our confidence and our independence.

This campaign urges clinicians, commissioners and suppliers to listen more closely, respond more consistently, and recognise that appropriate footwear is not a luxury but an essential part of living well. By asking decision-makers to quite literally “walk in our shoes,” it calls for a system that understands our needs and acts on them.

Find out more here: <https://www.walkinmyshoescampaign.org/>



The European Polio Union Conference and AGM

held in Malo, Sweden & Copenhagen, Denmark on 13 & 14 June 2026

I attended this year's EPU AGM as a member of PSN and BPF and took the proxy vote on behalf of PSN. I also have a new role as the EPU's Administrator. The following is a taste of this year's conference and AGM. This year's event was jointly hosted by PolioForeningen Denmark and Personskadeförbundet RTP Sweden.

After meeting up with all the delegates and enjoying dinner together on the Thursday evening, we had an early start on Friday morning boarding an arranged coach into Denmark over the stunning Oresund bridge to Copenhagen. Our destination was the SpecialHospital that treats polio survivors and spinal injuries. It is an unimpressive single-storey building on what appears to be an industrial estate! For us, it was a surreal sight to see the word 'polio' signed at the hospital entrance which caused a buzz of interest because no one had ever seen that in any of their countries.

Despite its humble appearance, the hospital houses a treasure of facilities comprising a large hydrotherapy pool, a gym designed with equipment for wheelchair users and patients who are sitting or standing with weakness or muscle loss. There are physiotherapists in attendance both in the pool and the gym to help patients with their exercise programmes. The hospital also has a small film studio where patients make promotional videos about PPS and these are put out on social media platforms. The hospital also has its own full-time orthotist and all walking and other aids and footwear are made locally to the hospital site and he will go to patients' homes for a fitting if they can't get to the hospital. Completing the facilities there is a large dining room and conference room where we spent the rest of the day following the hospital tour having presentations given by senior staff which were very interesting with a lot of information to absorb. The specialities which are on hand at the hospital to treat patients are Physiotherapists, OTs, Orthotist and a Psychologist. They work on the belief of treating the whole patient not just whatever limbs are affected.

Copies of the presentations have been sent out to members including to PSN. The conference opened with a short talk by Gurli Nielsen, chair of Polio Denmark, who organised our visit. Pierre Parrot, EPU's President, also made an opening address and Marina Carlsson from the Swedish organisation closed the proceedings.



Sign outside the entrance to the special hospital with Kripen Dhrona, CEO of the BPF, in the foreground



the smorgasbord lunch we had at the hospital, famous Danish and Swedish open sandwiches, delicious!

On the Saturday morning at the hotel in Malmo, the AGM took place. There were representatives from 12 countries this year which was very good considering everyone is aging and finding travel more difficult or impossible. The meeting was hosted by Pierre Parrot, EPU's new President and Chair with assistance from myself as the new Administrator. It had been a challenging year for the EPU due to the long-term President and Director, David Mitchell, standing down together with Secretary, Stefan Grajcar. The dedication and workload these two Directors managed will be difficult to match. Pierre has taken on the main role and there was also a new Board Director, Conception Garcia-Anton Trassierra from Spain.

After the main business of the meeting and voting took place on the Annual Report, Financial Report and Accounts, there was a general discussion about the future of the EPU and what members wanted to get from the EPU. One point that kept arising was the lack of communication from EPU to the members. This had been due in part to the departure of David and Stefan and Pierre getting settled into the role but it was planned to send out newsletters three times a year and arrange more meetings with members. This was welcomed.

For the future there are a number of ideas under discussion to expand the EPU and raise its profile in Europe. There is a lot to do ahead.

Overall, the meeting was successful with members enjoying the conversations and ideas. Disappointingly, no one volunteered to become a Board Director as more Directors are needed to help with the work ahead.

Caroline Gordon-Wilson
EPU Administrator



**at the conference with yours truly in the foreground
frantically taking notes!**

Travels in Scandinavia

I'm sure some of you will have travelled to Scandinavia as wheelchair users but I thought I would share my experience with you as this was the first time for me. I went to Southern Sweden (Malmo) and Copenhagen when I attended the EPU Conference and AGM.

Firstly, a word about Ryanair who we flew with. No problem until we came out of the 'cherry picker' that took us up to the rear door of the plane when we were asked to get out of our wheelchairs to access the plane!(There was another passenger as well as myself). This was ridiculous because we wouldn't have been in wheelchairs if we could walk! The companion of the wheelchair user in front of me had to lift him out of the chair and somehow drag him into the plane, undignified for both the disabled person and his carer to say the least. I was able to get out and walk with my crutches but I struggled to get over the step into the plane. It took me quite a while and with all the cabin crew trying to help I was scared of falling but eventually managed it with the help of my PA. I was shaking and very stressed when I finally sat down. This unnecessary exercise also resulted in the flight leaving late. I was concerned about the return and, coincidentally, we came back with the same wheelchair user. This time we didn't wait to be stopped from wheeling straight onto the plane which made it much quicker, safer and far less stressful for all of us. (Wheelchair arrived completely undamaged both ways, thank goodness).

However, back to Sweden. We flew to Malmo rather than Copenhagen where everyone else opted for thinking it would be easier to just take the bus to the hotel. First mistake. The airport was small, very quiet and quite a way from the city centre. We were the only incoming flight and there was a bus outside going into Malmo which wasn't accessible for wheelchairs! Having been told buses were accessible this wasn't a good start. It turned out that none of the buses in Malmo were wheelchair accessible. We ended up taking a very expensive taxi to our hotel. Despite the bad start it was about to greatly improve. The hotel was large, modern and very spacious with easy access to all areas. I had a wheelchair accessible room which was large enough to hold a dance! The bathroom was well appointed and easy to use and the huge bed was blissfully comfortable. My PA was in an adjoining room so she could help me if I needed it.

We wanted to do a bit of sightseeing and before the work started and, as the train station was directly opposite to the hotel, decided to explore the train system. This worked really well, once we worked out where we wanted to go, the tickets were cheap (machines only), lifts down to all platforms (all working). The local trains ran every few minutes and were very easily accessible, just wheel straight on. We went three stops to the town centre and the old town of Malmo is very attractive full of individual shops, all fully accessible, none empty or boarded up, flowers everywhere, lovely traditional architecture of the historic buildings and the harbour area. Everywhere was so clean, no graffiti or litter and traffic free but beware the cobbles! All the streets are cobbled with pathways down either side but at some point, the cobbles have to be negotiated not good



for wheelchairs and difficult for whoever is pushing. Dragging backwards works best so you don't get tipped out.

Buoyed with our success, the following day we tried taking the train to Copenhagen. These trains were different from the local trains and very busy because they serve the airport. They do run every 15 minutes but we had to wait for three to go before we were able to get on, overcrowding isn't allowed. There are two points of entry for bicycles, pushchairs and wheelchairs clearly marked on the outside of two carriages and there is a staff member on the train at these points to put out a ramp and ensure we boarded safely.

When we arrived, we decided to take a bus tour of the city as the best option to see as much as we could. We were able to buy the bus tickets at the station and it was a short walk to the bus stop. The tour buses were all wheelchair accessible but we had a long wait until we were able to get on one. Local people use them as a hop-on hop-off service and they only have one wheelchair space which was always occupied with a baby buggy.

Eventually the official on duty at the bus stop insisted to the next driver that we were allowed on. It was a good tour and went to every important place of interest in the city such as the royal palace and the site of the famous Little Mermaid.

Because of time constraints, we didn't go into any places of interest while in Copenhagen or Malmo so can't comment on how easy that would be. All in all, it was a mixed experience. The lack of accessible buses was a surprise but the ease of rail travel was also a surprise compared to the UK, frequent, efficient and very clean. Ease of getting into shops is good and accommodation caters well for disabled travellers.

Caroline Gordon-Wilson

Do's and Don'ts to keep in mind when going for physical therapy.

DO	trust yourself and the knowledge you have gained over the years about your body.
DO	be willing to alter your lifestyle
DO	avoid fatigue.
DO	get enough rest.
DO	pace your activities rather than discontinuing them
DO	conserve energy. It may make more sense to spread your activities out, allowing for rest periods, rather than eliminating interests and activities
DO	recognise that your body is aging and some physical changes will occur which are not related to post-polio. There IS a normal aging process even though post-polio may be a part of it.
DO	respect your feelings. This may be a difficult adjustment time for you; seeking emotional as well as physical guidance may be a wise thing to consider.
DON'T	follow advice regarding physical exercise if you become fatigued while doing it.
DON'T	become short of breath with exercise
DON'T	do more than your body feels comfortable doing
DON'T	cause pain with activity or exercise.
DON'T	gain weight.
DON'T	reject using aids and assisting devices without giving them serious thought. (They are meant to conserve energy and preserve anatomical structures, i.e. joints, muscles, tendons, cartilage and ligaments.) Most are delighted and surprised by the increased endurance and energy they have with the use of canes, wheelchairs, motorised scooters or the many other easily found assisting devices.

Our newsletter archive holds a remarkable record of Polio Survivors Network's journey, stretching all the way back to the very first edition published in September 1996.

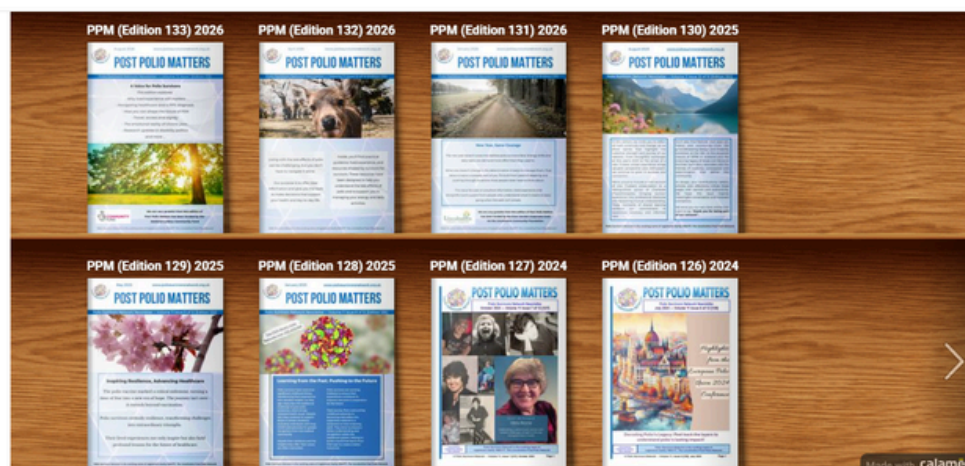
Each issue offers its own mix of experience, reflection and practical knowledge which still resonate today.

Take a little time to explore the back catalogue at www.poliosurvivorsnetwork.org.uk/new/newsletters where you'll find decades of insight waiting to be rediscovered.



Polio Survivors Network
 Lives lived with healthcare lessons for the future

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Tip: To make the text of the newsletter bigger click the + sign in the right hand corner of your screen. Also you can search any word or phrase in each newsletter by using the magnifying glass at top of page.

Recognising How I Cope

When I look back I can see that the ways I learnt to cope influenced how I understood myself, how I related to others, how I approached rehabilitation as an adult. At the time, I didn't realise I was developing a "coping style"; I was simply doing what I needed to get through each day. Only with time did I come to recognise the coping patterns described in polio survivors — Passers, Minimisers, Identifiers — and appreciate how they influenced my behaviour.

Passers often hide their disability so effectively that people around them may not realise anything is amiss. Minimisers acknowledge their disability but tend to downplay its impact, frequently ignoring pain or fatigue. Identifiers weave disability into their identity, openly recognising their limitations while championing independence.

For a long time, I lived as a Minimiser. My disability was visible enough that I couldn't hide it, yet I learnt to diminish it at every opportunity. I told myself it wasn't significant, that others had greater challenges, that I could manage if I simply worked harder. I pushed myself in every direction, determined to prove my capability. Discomfort was brushed aside, fatigue ignored, pain treated as something to be endured.

When the late effects of polio began to appear, that familiar strategy started to crumble. Years of ignoring my body meant I struggled to recognise new symptoms. Asking for help felt uncomfortable. Slowing down felt like letting people down. Admitting that something had changed felt almost impossible. Many Minimisers only recognise late effects when symptoms become overwhelming, which was certainly true for me.

I also recognise parts of the Passer in my younger self. I worked hard to appear "normal", even when it left me exhausted. I avoided explanations or attention that might highlight difference. When new weakness emerged, that instinct made acceptance even harder. I felt exposed, as though I had failed at keeping my disability discreet.

Although I was never an Identifier in the strict sense (I didn't grow up using a wheelchair or respiratory equipment) I understand the fierce independence often associated with them. Identifiers place enormous value on autonomy and independence in daily life.

I don't think that any of these coping styles are wrong as each was shaped by necessity, childhood experience, social expectations, the world we grew up in.

These coping styles probably helped us to succeed. Yet when new post-polio challenges arise, these styles can begin to hold us back. Maybe we need a mix of all of them.

Recognising my coping style was a turning point. It helped me understand why I resist certain changes, why asking for help feels uncomfortable, why I sometimes push beyond what my body can reasonably sustain. It has shown me that adapting now is not a failure; it is simply another stage in a lifelong process of adjustment.

Passers can begin to release the pressure to hide. Minimisers can learn to listen to their bodies with greater compassion. Identifiers can embrace new forms of support without losing their independence. I am still learning to cope in ways that work for me now, not just ways that helped in the past.



Editors Note: The terms Passers, Minimisers and Identifiers come from rehabilitation psychology and still help describe coping styles familiar to many polio survivors. Today, disability communities often use more modern language. Passing is now commonly called masking or covering. Identifying aligns with disability pride and disability identity.

Our Message to Healthcare Professionals

Polio survivors often carry coping styles shaped in childhood, developed at a time when strength, silence or independence were essential for getting through each day. These patterns have supported many people for decades. Rehabilitation today is most effective when it builds on these long-standing strategies rather than trying to remove them.

Some survivors learnt to pass as non-disabled, doing everything possible to avoid drawing attention to their differences. When working with individuals who cope in this way, gentle encouragement and a sense of safety can help them feel able to share their experiences more openly.

Others became Minimisers, pushing through pain, ignoring fatigue, and convincing themselves they could manage if they simply tried harder. These

individuals often respond well when their determination is acknowledged. With sensitive guidance, they can begin to recognise symptoms they have spent years downplaying.

There are also survivors who identify strongly with their disability. For them, independence is deeply valued. Respecting that autonomy while offering new ways to maintain control as circumstances change helps preserve confidence and dignity.

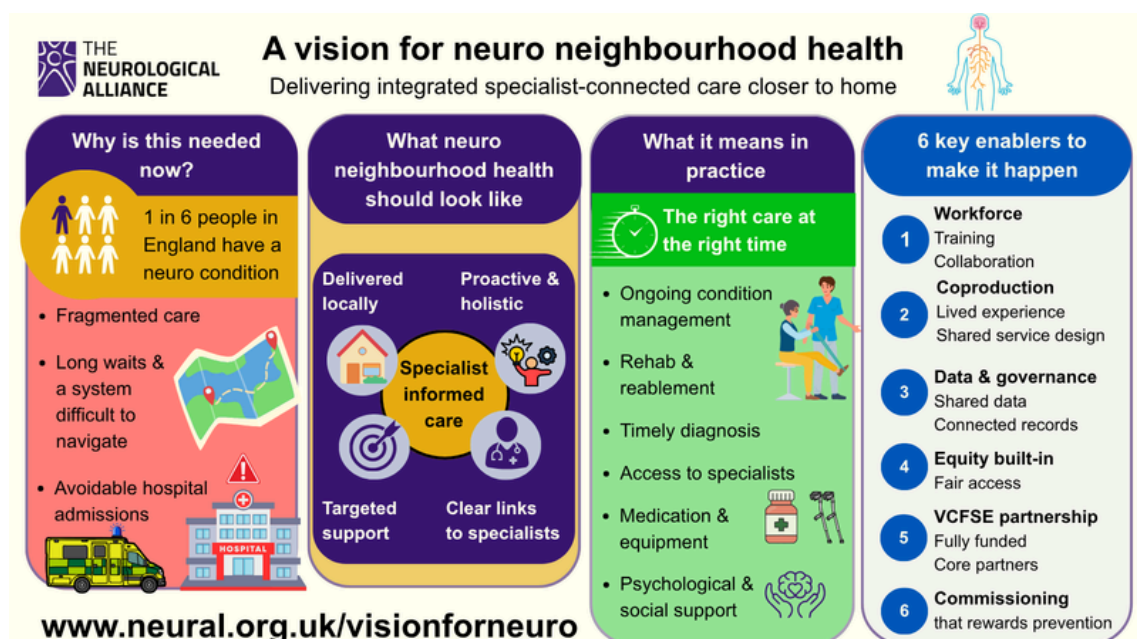
Every polio survivor brings a distinct history and a personal way of coping shaped by early experiences of illness and recovery. Recognising these patterns enables healthcare professionals to meet each person where they are, offering support that feels respectful, collaborative and grounded in trust.

Polio Survivors Network encourages all clinicians to consider these coping styles when working with survivors. Understanding them can make rehabilitation more effective, communication more open, and the journey ahead more manageable for those living with the late effects of polio.

We're backing The Neurological Alliance's Vision For Neuro Neighbourhood Health.

This report sets out why neurological conditions must explicitly be included in the government's neighbourhood health programme and an achievable model of coordinated specialist care closer to home for people affected by neurological conditions.

Now we're calling for action from government to make that happen. Learn more here: www.neural.org.uk/visionforneuro



For our 30th Anniversary edition we just had to include a couple of pieces from Verite and Hilary who we still miss dearly. We think these may resonate with you...

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Lessons have been learned - or have they?



When Nurses or Doctors asked me "why didn't you get the polio vaccine?" I would politely explain that this wasn't developed until after I had caught polio. Until I realised they didn't listen. Now, I just burst in to crocodile tears. These flow until I reckon the point is taken that this is an insensitive question.

I am a cynic, and not convinced everyone looking after my health has learned lessons they should. I tip-toe around a 'new' doctor, until I can work out if they know what's what. Like all of us, 'I get on with it' if there is a problem, otherwise we'd never get anything done.

I remember telling the Anaesthetist from The Royal Marsden, twice, that I had had polio. Went off for my op - and when I woke up alone in the recovery room, lying on a theatre trolley, thought "they haven't operated". Hooking my legs under the trolley mattress, I attempted to sit up and find out what was going on. The trolley shot across the room, banging into a tsunami of other trolleys that shot off in every direction. The noise bought people running to see what was going on.

Were they concerned about me? I should cocoa. Sister bore down saying "you weren't supposed to be awake", and was obviously furious - with me. With polio you have different reactions to anaesthetics, but - of course - it was my fault that things had gone wrong!

I just hope rivalries twixt NHS and Military are sorted out today! Many years ago, a Military Ambulance transferred me from Millbank Military Hospital in London to the Royal National Orthopaedic Hospital at Stanmore to start my polio treatment. Nurses had wrapped me in sheets, as it was too painful to dress me in a nightdress or PJs.

On my journey I had a full Military escort; nothing to do with me, but you were 'nursed' according to rank (or in my case my father's), so two smart male orderlies in full khaki uniform, and two female Queen Alexandra nurses in their elegant red capes, accompanied me.

Marching me smartly on my trolley into the ward, out of the corner of my eye I saw a Sister shoot out of her office, calling up her 'troops' as she swept down to repel this invasion. Elbowing the nurses aside, she proceeded to whip the sheets off my trolley - leaving me fully exposed and stark naked. No doubt this made a lively tale when everyone returned to quarters, I'll always remember receiving a lovely 'care parcel' from the Military team, of delicious Meltis New Berry fruits, as a kind memento.

It was a different problem with French student doctors. In hospital, every Friday my surgeon would carry out his Ward round, trailing a group of doctors from abroad who had come to learn from the great man.

I enjoyed meeting these doctors, until one day I heard sniggering amongst the young, male group. I spoke French, and could hear my legs being discussed at length (they were long even though I was only 16). With idiomatic French (learned from dubious sources), I told them to F-off.

My surgeon suddenly found his audience were cowering in the centre of the ward, looking at me transfixed. Astonished anyone in Britain spoke French - and such words! - but my surgeon had a quiet smile on his face.

MRI Scans can cause me problems because there is no way I am able to lie on the flat metal bed without lots of padding. I explained this to the doctor in charge, several times. Eventually, I thought she had grasped that I needed strong pain relief, and she produced some tablets for me to take. But, ten minutes into the procedure, I could feel red-hot pokers starting to dance up my spine, and had to call a halt.

Crawling out, I was met by a furious doctor, arms akimbo: "I gave you tablets for claustrophobia" she almost screamed. And wasn't too interested when I tried to tell her I didn't suffer from fear of being enclosed, but she was past listening.

Recently, it took me four months to find someone in the vast NHS network who could check if it was safe to have the Covid-19 vaccine. Previously my reactions to drugs had included losing the sight of my right eye, to a 7-hour heart operation; so I didn't want a repeat.

Finally, everything comes to he (or she) who waits! And a friend-of-a-friend introduced me to a charming Nobel medicine prize-winner (how lucky can you get) - who in a no-nonsense way talked me through what I should and shouldn't do.

Reading through the literature handed out after the vaccination, I saw the words 'chimpanzee' and 'ethanol'. Now, it's not rocket science: these words could be worrying - yet those ladling out the vaccines don't seem to have cottoned on.

Perhaps those moaning about 'anti-vaxxers' should learn some lessons, and be prepared to answer questions that concern us. Or will it take the Army yet again to step in and sort things out do we get listened to?

Verite Reily Collins

Hilary was editor at the time and responded:

Editors note: Apart from chuckling a lot whilst I typed this up it reminded me of similar issues Richard and I had had. Please tell us your stories. These are important points and we need to find a better way of telling health professionals about our issues.

Waking up early in the Recovery Room. I had the same coming round early experience in the Recovery Room after a small gynae op. I woke up, I could not see any staff so I lifted my blanket to see if I had been operated on. I had. I called out and Staff came running, they were mystified and said we will send you back to the ward but you are going two ahead of what we expected. They sent the anaesthetist to see me later that day. He told me that he had researched and found I needed less anaesthetic as our polio weakened muscles cannot clear the normal dose as easily. He added that maybe he should have given me just a little bit more as I had given the Recovery Staff quite a shock.

MRI last year. I too cant lie flat I explained. They said they would sort it and laid on my back with my knees up [they were lowered over a cushion] I had my head pushed into a plastic cage and I started my journey in with my eyes tightly closed. I was in massive pain in my back due to the curvature of my spine and told them. Two minutes really important, so saying Nursery Rhymes constantly I manage the two minutes. Then it was two minutes more and with tears rolling down my face from the pain I continued saying my nursery rhymes as

the machine made its g,g,g,g,g sounds. That was over and would you believe they said just another ten minutes but I had to say please get me out of here and out I came my face wet with tears and my back killing me.

Richards story is that I had had an accident and he had come with me in the ambulance. He did not have any food at the right time and he fainted so they put him in the next bed to me. I had broken my ankle and it was wrapped up in cotton wool and my plastic Ankle Foot Orthosis put on and I was sent home at 3.00 am in a Taxi. Richard however was low on potassium so they kept him in. Next morning a Consultant arrived on the ward with a gaggle of students. The Consultant started to ask him questions about his conditions and the medication he was taking. He asked "What are you taking this Mirapex for". Richard replied "Parkinsons" The Consultant responded "I have never heard of it being prescribed for Parkinsons". Richard then asked him "Are you a Neurologist?" He tutted, spat feathers and stormed out of the room saying "Discharge this man". Richard said the students were having a hard time keeping straight faces.

"Polio Survivors – a strong-willed, determined, highly motivated, hard-working group of people – want to live for as long as possible, doing as much as possible.

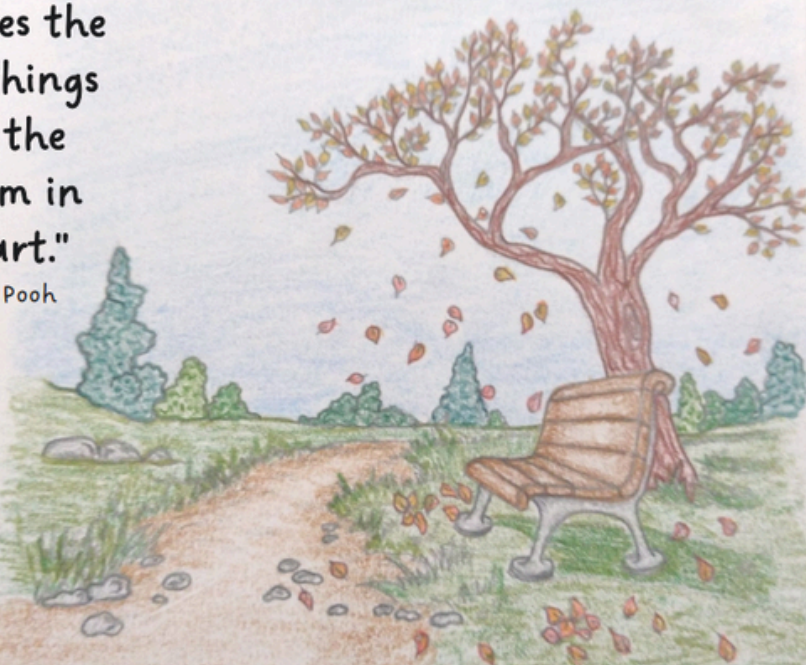
We need a full and accurate baseline assessment that takes into account the endurance of our weakening muscles.

We need advice, and the understanding that it takes time to accept that we have to change our lifestyle.

We need treatment where it is available, appropriate aids and equipment, and benefits so that we can financially cope in this world where anything 'disabled' has a high price label."

— Hilary Boone

"Sometimes the
smallest things
take up the
most room in
your heart."
- Winne the Pooh



OVERVIEW: Why Diagnosis is Hard

► Limited Medical Education

Medical training often includes little or no teaching on Polio or Post Polio Syndrome (PPS). Many clinicians don't know PPS exists, so they don't look for it. Polio-affected muscles may not appear atrophied, adding to the confusion.

► Recovery Masks Earlier Polio

Most survivors recovered externally, so earlier Polio is not obvious until new symptoms appear. Do not assume current mobility aids were always needed.

► Lack of Referral Pathways

GPs have historically had no clear routes for PPS assessment. Pathways are only now being developed.

► Manual Muscle Testing Limitations

Single-action muscle testing rarely reflects the severity of symptoms. Patients are often told "nothing is wrong," leading to repeated referrals and at times, dismissal of symptoms as psychological.

► No Definitive Test for PPS

PPS is a diagnosis of exclusion. EMGs and muscle biopsies can show old polio damage but should only be used when essential, as they can be painful or risky for survivors.

► Inadequate Initial Assessments

Consultations often lack the time and space needed for thorough history taking and functional assessment, making it harder to confirm decline.

► Problems With Questioning

"How do you walk?" provides far more accurate information than "Can you walk?" Clearer questions lead to clearer answers.

► How Symptoms Are Presented

Survivors are often determined, independent, and may deny new symptoms for years. Advice on pacing, resting, or using aids is frequently resisted.

► Use of Outdated Research

Older studies may not represent the full range of Polio survivors. Using them without context can lead to inaccurate assumptions.





WORLD POLIO DAY IS 24 OCTOBER



One Day, One Focus, Ending Polio

World Polio Day is a chance for Rotary members, public health advocates, and others who care about ending polio to come together, acknowledge the progress so far, and focus on the ongoing actions required to reduce polio's presence worldwide.

<https://endpolio.org/world-polio-day>



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

British Polio Fellowship

<https://britishpolio.org.uk>

Post-Polio Health International

www.post-polio.org

PA Polio Survivors Network

<https://polionetwork.org>

Polio Quebec

www.polioquebec.org/eng/

Polio Survivors of Marin

www.facebook.com/groups/163909760771171

Atlanta Post-Polio Association

www.atlantapostpolio.com

Ohio Polio Network

www.ohiopolonetwork.org

Polio Australia

www.poliohealth.org.au

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

We currently offer FREE membership while our funds allow.

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 **PayPal** to treasurer@poliosurvivorsnetwork.org.uk
or use **PayPal donate** or **bank transfer** as below



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

Bank Transfer

Account name: **Polio Survivors Network**

Bank: **CAF Bank**

Account: **00014980**

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