

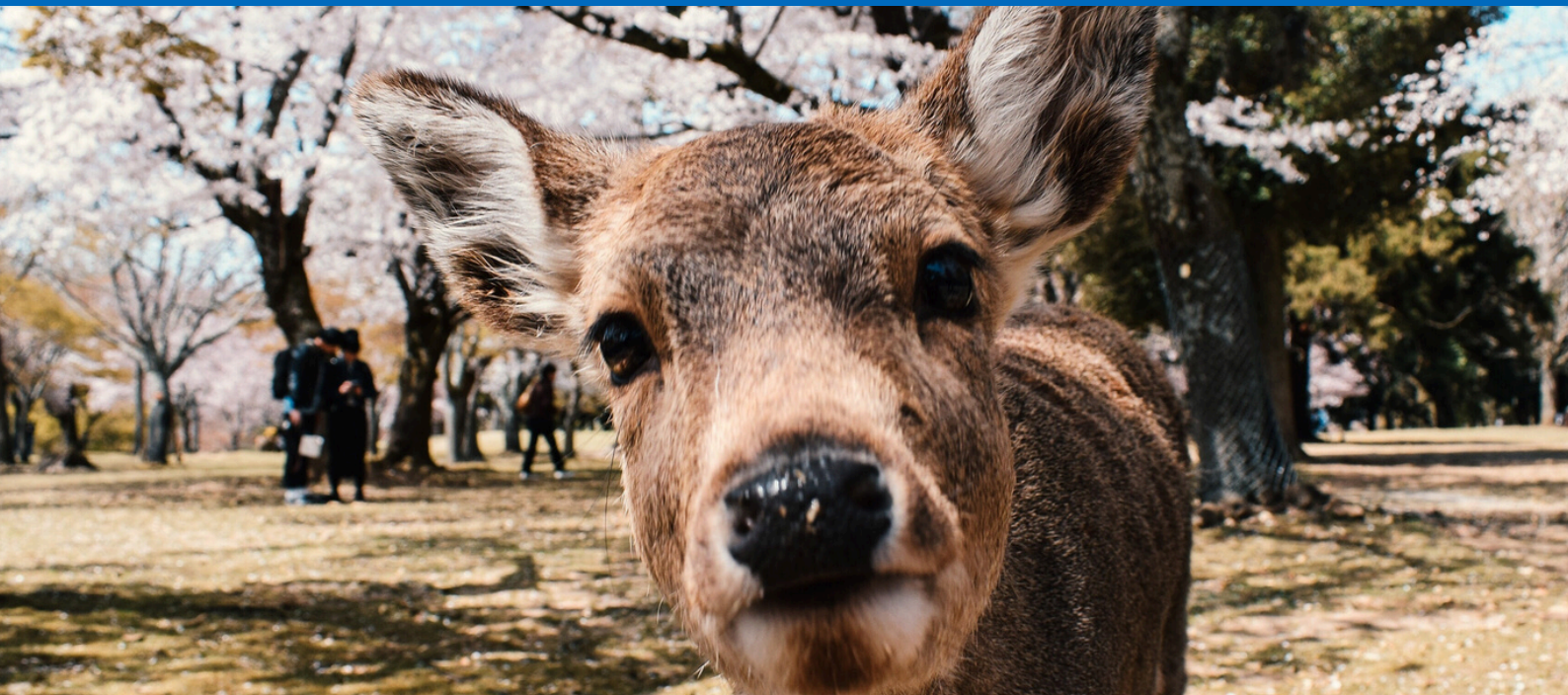


April 2026

www.poliosurvivorsnetwork.org.uk

POST POLIO MATTERS

Polio Survivors Network Newsletter — Volume 11 Issue 12 of 12 [Edition 132]



Living with the late effects of polio can be challenging, but you don't have to navigate it alone.

Our purpose is to offer clear information and give you the tools to make decisions that support your health and day-to-day life.

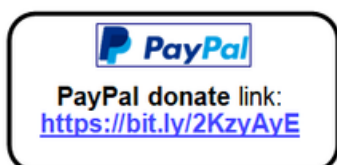
Inside, you'll find practical guidance, lived experience, and resources shaped by survivors for survivors. These resources have been designed to help you understand the late effects of polio and to support you in managing your energy and daily activities.

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Donations, Charity Incentives, Grants, etc Received (since last newsletter)	
PayPal Giving Fund Grant	1.00
PayPal Giving Fund Grant	1.50
Donation via Visufund (anonymous £10 minus fee)	9.26
PayPal Giving Fund Grant	10.50
Bank interest	10.34
Donation VS	30.00
Total	62.60

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We are very grateful!



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JUST A HUG: A Different Way of Thinking About Disability



Opening a Thought

As a community, we share a lot—practical advice, personal stories, and guidance for professionals about post-polio syndrome. All of this matter helps not just us but others we hope. But I'd like, this edition, to gently raise something a little different.

We often talk about access, attitudes, and services. These are very important. But they may not tell the whole story. There is also something more personal, how we experience the world through our bodies, and how that shapes our connection with others.

A Lifetime of Effort

Many of us grew up being told to push ourselves - to be as “normal” as possible, to adapt, and to get on with life. And we did! We worked, had relationships, many of us raised families and built full lives. Also, many polio survivors were an integral part of the early movement towards independent living. But this often came with a hidden cost. We were working harder than we realised - not just physically adapting to the physical non disabled world, but in how we connected with people, emotionally and psychologically.

Small Things That Matter

Take something simple, like a handshake. For most people, it's easy and automatic. For us, it might mean balancing, reaching differently or managing a weaker grip. Over time, this becomes normal to us. But that doesn't mean it was ever easy, or felt or noticed by others, consciously or not.

The Language of Touch

There is also something fundamental about touch. Walking arm in arm, a pat on the back, an arm around the shoulder, a hug—these are small things, but they are part of how people communicate, connect and feel close. For many non-disabled people, this happens without thinking, they are the physical grammar of their lives.

For us, it can take a bit more effort. We adjust. Other people adjust. And over time, we all stop noticing. But something is still different. Without that easy, shared way of touching and connecting, there can be a slight sense of distance. Not always obvious - but it is there nevertheless. We get used to it, even deny its existence. But it will have shaped how we feel about belonging more than we realise.

Not Just Personality

People sometimes describe us as driven, type A personalities, determined, or even, dare I say it, “difficult” patients. But I have always thought this isn't the full story, this may not just be personality. Many of us developed these ways of being because we had to. From a young age, effort, focus and persistence were part of everyday life. Over time, that becomes who we are.

Why This Matters Now

As we get older, things begin to change. We are told to pace ourselves—to do less, to rest more. But that can be very hard. Because for a lifetime, we have learned to push through. But there is something else. The small adjustments we have always made to physically connect, often without thinking, can become harder or sometimes sadly no longer possible.

When that happens, we may feel a sense of distance or aloneness that is hard to explain, even to ourselves. It's not just ageing. It may be something that was always there but now is becoming more noticeable. Like those muscle motor units that were always overworked and fail, I suggest there is an analogous psychological and emotional effect.

An Invitation

I'm not offering answers here, just a thought. Does this fit with your experience? Or does it not feel relevant to you at all?

I would really welcome hearing what others think.

Simon Parritt, *C.Psychol, AFBPsS, MSc, BSc (Hon), BA*
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When “Normal” isn’t “Normal” for us Ageing with Post-Polio Syndrome and the Limits of Standard Tests

By Simon W. Parritt

I have lived for over 70 years with the lasting effects of extensive muscle loss following polio, and for more than 40 of those years I have worked as a psychologist, and part of my training was in geriatric medicine. Like many others with post-polio syndrome, I have spent a lifetime both inhabiting and observing a body that does not quite fit standard expectations. Now, as I move further into older age, I find that this difference is becoming more relevant in a new way — particularly in how my health is measured and understood.

As polio survivors move into our later years, many of us are encountering a new and sometimes confusing phase of healthcare. We attend GP or hospital appointments, for various health related issues from minor to major and have blood tests and are reassured that results are “normal” or “abnormal” — yet something doesn't always feel quite right.

Part of the difficulty is that our bodies are not typical. We are not simply older adults with a past illness. We are living with a physiology shaped by polio, often from early childhood, and by decades of adaptation that is global not just a weak limb or feeling fatigue.

This matters more than we might think because our baseline was never average. Polio affects more than just strength. Over a lifetime it changes muscle mass, how muscles and nerves work together, energy use, fatigue, and in some cases breathing and oxygen levels. By the time we reach older age, these differences are not minor — they are our normal. But most medical tests are designed for people whose bodies developed in the usual way.

One of the clearest examples is creatinine, a routine blood test used to estimate kidney function. Creatinine is produced by muscle. People with more muscle have higher levels; people with less muscle have lower levels. Many polio survivors, especially those with long-term muscle loss, will therefore have naturally low creatinine. This can make kidney function appear slightly better than it really is.

Laboratories use creatinine to calculate something called eGFR — an estimate of kidney function based on creatinine, age and sex. However, this calculation assumes a typical amount of muscle. In post-polio syndrome, that assumption often does not hold.

The result can be a reassuringly high eGFR that may slightly overestimate true kidney function. This does not mean there is necessarily a problem — but it does mean results need to be interpreted in context.

Some people consider taking creatine supplements to improve muscle or “normalise” their creatinine levels. It is an understandable idea, but it is important to be clear.

Creatine can increase creatinine levels in blood tests, but it does not improve kidney function or restore muscle in post-polio syndrome. It simply changes the number being measured, which can make results harder to interpret.

In post-polio syndrome, the issue is not a lack of fuel, but long-term changes in nerve supply to muscle. Because of this, supplements alone cannot rebuild muscle in the usual way. What actually helps is careful, sustainable management — pacing, appropriate activity, and protecting the function that remains.

Creatinine is just one example. Other tests, such as HbA1c for blood sugar, can also be influenced by underlying physiology and may not always reflect the full picture. The issue is usually not dramatic error, but something more subtle: reassurance based on “normal” results that do not fully reflect our bodies. Many of us are not aware of this. We assume that “normal range” means normal for us.

Most clinicians are working within a system built on population norms. What helps is gentle collaboration:

- Be aware your baseline may differ
- Ask how results apply to you personally
- Focus on trends over time
- Share relevant history such as muscle loss or breathing support

This is not about challenging care, but about improving it.

A final thought

Polio survivors are part of a unique generation. Our bodies have adapted over decades in ways that medicine does not always fully recognise. As we age, understanding this becomes increasingly important.

“Normal” is not a fixed concept — and for us, it never was.

This article reflects personal experience and clinical reflection. It is not a substitute for individual medical advice. Readers should discuss any concerns or treatment decisions with their own healthcare professionals.

The dangers of being sedentary by Zsuzsi Snarey



An inactive lifestyle means long hours of sitting or lying down outside your proper sleeping time. Using the computer, watching television, working at a desk for long periods is going to have an impact on your health. When you don't move enough your metabolism and blood circulation slows down making you feel tired even if you

get 8 hours of sleep at night. Burning fewer calories than you consume means that your body stores the extra energy as fat leading to gradual weight gain especially around your middle.

Sitting too much can also lead to muscle atrophy, loss of muscle mass and function in low back, hips, upper legs. Sitting for long periods can reduce the natural lubrication between joints and weaken muscles. Low levels of physical activity is linked to a variety of chronic diseases such as obesity, heart disease and high blood pressure.

There is a simple way to become less sedentary. Get up and start moving. Look for ways to include small amounts of activity throughout the day to break up periods of sitting. If possible, use a standing desk, and if sitting at your desk remember to stand up at least every 30 minutes. For best results choose an activity you enjoy which involves movement and do it regularly.

It is important to do a mixture of exercises such as stretching, strengthening, which means moving against some resistance, fitness exercises or aerobic exercises which improves strength, balance and the health of your heart and lungs. Balance exercises help to reduce the risk of falling.

Swimming and water-based exercises are very useful because water supports the body and helps with movement. If you are concerned about getting in and out of the pool, ask if there is any help available. Walking is one of the best exercises to improve your lungs and heart. If you can join a fitness class it would help you to keep motivated, make new friends and enjoy doing exercises.

I have noticed that I have been getting gradually weaker, my balance is not so good and when I asked my GP she referred me to an exercise class. There are 14 people who attend on Tuesdays, my husband also takes part to improve his balance, but I cannot do as much as the other people, and I am wondering if I am benefitting from it. I do step ups on a small kitchen stool and exercises on the bed before getting up, but the aerobic exercises in the class are helpful for my heart and lungs.

Last September I booked a coach holiday to Italy making sure that I could have disabled rooms. I had to be able to get on the coach and take my small Luggie in the hold. The coach was going to pick us up locally and take us to Lake Garda after stopping for one night in Belgium. They were day excursions to Verona and Venice. I have always wanted to see the beautiful building and canals of Venice, but I knew that there were many bridges with steps. My friend went there on a cruise and told me that the bridges now have ramps, and I would be able to use them. This was the reason I booked the holiday.

Sadly, when I checked again after paying the balance, it turned out that the holiday company could not guarantee disabled rooms downstairs and if the lift was broken, I would have to be able to use the stairs, so I had to cancel the holiday. I am still carrying on learning Italian and leading a U3A Italian class. Maybe the best way to get to Venice is on a cruise, although we are not too fond of that way to travel because you don't stay long in a place and don't have a chance to see it properly.

Can you write in with suggestions or your experiences for holidays that are possible for the disabled?



Review: Rachel Charlton-Dailey, *Ramping Up Rights. An Unfinished History of British Disability Activism*. London: Hurst & Company, 2025

Apart from a couple of years when I was chair of the Southwark UNISON disabled workers' self-organised group, I've never been what could be called a disability activist. Having joined PSN as a trustee last year, I bought this book, thinking it was high time I got up to speed with both the historical background and current thinking and practice.

This book is an excellent guide to exactly what it says in the subtitle. I finished the book feeling rather ashamed of my prior ignorance, but now fully

conscious of the hard work so many people have put in over the years, to fight for the rights of disabled people in Britain, a struggle which is far from won. Although I've been very conscious of the demonisation of disabled people by successive governments, and especially in the media, I hadn't at all picked up on the fact that the Equality Act 2010 was actually a step back from the 1995 Disability Discrimination Act. So much for progress!

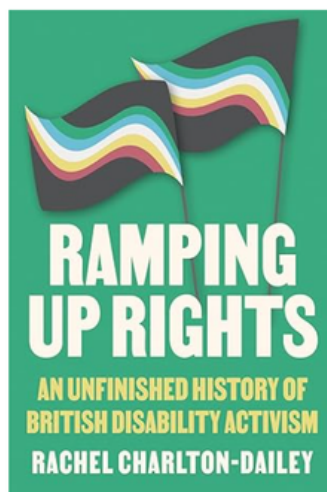
I was also woefully unaware that the social model of disability was developed so long ago. I'm afraid I thought it probably came in in the early years of the present century, but it turns out it dates from as far back as the 1970s. It's extraordinary, considering this, that it's so little understood among non-disabled people: possibly not as fully appreciated as it deserves to be even among the disabled.

This history prior to the 1950s is a bit sketchy, but perhaps it doesn't need much more than this, in the present context. But from the 90s onward it's much fuller, and the author's own role as an insider and activist comes into its own. Part Two of the Book, 'Today and Tomorrow', brings us right up to publication date, though the woeful record of the Starmer government on welfare cuts is too recent to be included, as is the defeat of the Assisted Dying bill.

The style is fresh and colloquial, so it's an easy read. The conclusion is particularly good, with two final pages providing a bulleted list of the key battlegrounds, going forward.

Recommended.

Ben Beck



Toni Writes ...

I want to start by saying thank you. Over the past months, so many of you have shared your thoughts, worries, ideas, and experiences with me and I'm genuinely grateful. I'm not a polio survivor myself, but I see the lasting effects polio has had and I'm constantly reminded of the strength shown. Your feedback helps me understand what matters most and how we can better support you.

Life feels heavy for many right now. The world seems to be in a constant state of chaos on top of the day-to-day challenges that come with post-polio syndrome and other health issues. Please remember you're not alone, many understand just how much energy it takes to get through an ordinary week.

As the polio survivors community gets older and health needs become more complicated, running the charity is becoming harder for the small group of people who've kept things going for so long. Most are dealing with their own health struggles and it's tougher to stay involved in the way they once did. This is why I'm reaching out for your help. If you've ever thought about getting more involved, even in a small way, now would be a really good time.

One of the roles we especially need support with is as a trustee. You don't need special qualifications, just a bit of time and a genuine interest in helping the charity continue. A trustee can live anywhere in the UK and we meet on Zoom roughly once every three months. If you think this might be something you could do, I'd love to talk with you.

We're also keen to hear more of your personal stories. We've welcomed many new members recently, especially from Scotland, and we'd really like to understand your experiences. How does NHS Scotland support post-polio syndrome? Is it similar to NHS England, or quite different? What has helped you manage day-to-day life? What tips or small adjustments have made things easier for you? Member stories help others feel understood and we all learn from one another. Importantly they help us make sure the charity is doing the right things for the right reasons.

Take care
Toni



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**IT IS A SORRY STATE OF AFFAIRS
WHEN POLIO SURVIVORS AROUND
THE WORLD MUST GIVE UP HOURS
OF THEIR TIME TO RESEARCH
THEIR MEDICAL CONDITION**

Hilary Boone

From Our Readers

Just to say thanks for the newsletter. It's lovely to see snow, from the comfort of being indoors! Good content too, All the best to everyone, KS

I loved this issue. Well done. Hilary's quote is right on the money. I looked up "jumper" and loved discovering that it's a wool sweater. It's always fun sharing information with/from our friends in the UK and Australia. CF

Thank you for your informative newsletter especially the article on cold intolerance. I live on Skye and it is a big problem for me being cold in winter and heating costs in Scotland are much higher than England. I think there should be some allowances to help us keep warmer. It is difficult to get orthotic services here and most GP's are not knowledgeable about our problems with PPS so I am very isolated and don't know if there are other people like me in my area as I have never met any. Anyway your organisation looks good and I look forward to getting information from your newsletter in future. Thank you, CM

Member JF sent in a link to this interesting article that was in the The Telegraph on 28 January 2026. It is an in-depth piece examining why the global effort to eradicate polio, despite extraordinary progress, is facing a complicated final chapter.

The article explains how the oral polio vaccine — the same tool that helped drive cases down by more than 99% — can, in rare situations, lead to vaccine-derived outbreaks in communities with low immunisation coverage. It also outlines why the vaccine is still essential in many parts of the world, and how a newer, more stable version is being used to reduce these risks.

The catch-22 in the global battle to eradicate polio by Maeve Cullinan, Global Health Security Reporter.

If you'd like to read the full article, you can find it online here:

<https://www.telegraph.co.uk/global-health/science-and-disease/the-catch-22-in-the-global-battle-to-eradicate-polio/>



From Our Readers (continued)

RE: your article in PSN on how you truthfully perceive the dreadful state of our NHS

My PSN magazine has just plopped on my floor from a postal delivery failure system of 14 plus days before some of my letters are delivered in a biggish pile, including birthday cards in December taking fourteen days, completely missing my birthday, nil cards once a year special occasion.

I am laying flat on my back in bed in pain resisting appalling Hospital admission yet again and 100% not getting things right and can't feed me with a lactose free diet, yeast free diet, Histamine intolerance diet, told fat free, at which I I whinged saying soon I will only have fresh air pie and paper bag soup to eat, so they up it to three grams. Now my G.P practice has written a letter saying I am borderline diabetic blah blah dated 20th December post mark 24/12/25 second class stamps, received 14/01/26 that's taken 25 days from start to finish to tell me Septembers blood test has just come to their attention that I am borderline diabetic! Having been under my G.P practice dietician for well over a year and it's gone nowhere.

Hospital told me awhile back to bring my own food in. Then another time when it was all dairy menu, cauliflower cheese or lasagna, bread and butter pudding with custard or cheese and biscuits for supper etc, so I asked could I have cornflakes and bottled water please. Staff said no problem we keep cereal on the ward, when evening came and I asked for it, staff came back saying the cereal is locked in a cupboard and we haven't a key! B----r me when you are hungry self-control can sometimes go out of the window.

Following day menu sheet came to fill in the day before the actual day and was Sunday roast, and apple pie with custard, an ignorant cleaning lady collecting menus up said get your family to bring a meal in. I got sarcastic saying, I have one son who works for BT in Hong Kong training staff and another son who is a missionary working in Russia and Poland, and summer camps in Tanganyika Africa, (2015) which son would you like me to call to bring in a roast dinner!!! ? Do you think it may be cold! Too much to bear I run away in my scooter home never mind I'd just had a Pulmonary Embolism from my shoulder surgery.

Another time along comes menus, for some reason staff seem to think in their untrained ignorance that Lactose free is gluten so they bring me a gluten free menu. Then a vegan menu then ask is it like coeliac.

I grit my teeth whilst inner anger mounts after all I was a nurse from the 1950's for 34 plus years and part of our training in P.T.S three months, was a weekly course in invalid cookery in Tante Marie cookery school, I came first with 99%! For very special diets we had to lay a tray with a little pretty embroidered tray cloth, serviette and cutlery and a little egg cup size posy of flowers, when meals were cooked freshly by the hospital premises and each wards receiving a big metal plated heated container on wheels that had to be immediately plugged in on its arrival, being pulled by mechanical means of a porters on a type of tractor, thirteen wards in all, and ward sister always stood in the ward and served out the most delicious non chemical, non GM, type food to each patient. No choice everybody that wasn't on a special diet received the same and wolfed it all down.

Just recently another four days in hospital completely wrong diagnosis admitted by emergency 999 severe reaction to the Lidocaine infusion in my wrist that morning in The Pain clinic theatre and too my horror going down the same old, same old, route of wait three days for a scan for gall stones, can't find any, and on discharge I say to the woman associate doctor who came to discharge me from the third ward I'd been in in the four days, so I'd never seen her before called GUTTI and gabbled away so fast I couldn't understand her, so I interrupted saying, 'I am in here because I've just had a severe reaction to Lidocaine infusion, Who told you, she abruptly said. I replied, I've just had an I.V of Lidocaine into my wrist in Pain clinic Theatre and reacted to it. She turns to another person saying, 'How did I miss that.' Page 12

I wanted to scream out at her saying if you ALL kept your noses OUT of those dam computers and mobile phones and gave eye contact to your patients and dare I say, speak to them, even if you can only say 'Good morning, how are you today', then you might learn something from your patients that the computer can't tell you and if I haven't been asked why am I here, but nothing, trolley comes in with a computer on the top into a six bedded ward that's only three beds each side, wheeled in by a robot human being, has to be robot, because she does not speak. She walks in the centre of the LONG route of three beds in pushing her computer trolley, turns around and walks the LONG route of three beds, not even glancing up to speak to anybody. I bet if like Pauline Collins in the film Mrs Cabbage patch or something it's called, makes me chuckle, I bet if all six of us were missing she wouldn't notice the empty beds!!!

I tried another day same admission time to order a cottage pie, a very bolshy nurse who had a mini iPad in her hand going along the other side and I heard her saying she had to do the menus as staff shortage and that she didn't know what she was doing. When she got to me and I asked for the cottage pie, before I could finish, she jumped down my throat saying put that's got milk in it. Yes, I reply, but I take the potato top off and please order me a jacket potato and in capital letters put No butter, No cheese because that's what they had done to my previous jacket order. I don't think I can do that she says jacket potato is not on today's menu... a bit of negotiating she disappears to ask, comes back saying that's alright.

I am laying flat in bed and really looking forward to my meal, when it arrives minus jacket, I query please where is my jacket potato?, bearing in mind I can't have desserts as always smothered in custard. Off goes the staff in search, she comes back saying, a new patient has just come in and they've given her the jacket potato. I burst into tears and stop short of demanding in hunger, please can a nurse take me in a wheelchair up to the Oasis, Hospital Restaurant that cook the most delicious meals and let me purchase something from their huge selection of meals cooked on the Hospital premises please.

A nurse does just that and fetches a wheelchair, I chose a sausage roll and some vegetables with gravy, the meal costs £8.99 but the server says I can't charge you for that so just charges me £2.99 for the sausage roll. Back to the ward in the wheel chair looking forward to my meal, off comes the lid and I try for three quarters of an hour to eat this meal now gone cold because three different staff come to me one after the other when since breakfast of corn flakes and water I've laid flat in bed drifting in and out of sleep and not a dicky bird had spoken to me but smell the food and in they come, one for blood pressure, one to take bloods and other man to discuss in depth my pharmacy and what I can or can't have. The lid has been of this lovely meal now cold for three quarters of an hour. I could have cried but let inner anger and disappointment stop me from crying. Then staff came in wanting my tray saying the trolley with the ward dishes was just leaving.



Then Simon, your article arrives today of your hospital experience which is like you were/are writing my hospital experiences briefly!!! Much more of my stories would make your hair curl I haven't even began on medical reasons and lack of care and no knowledge whatsoever from nurses saying, what's wrong with you and I say, I have M.E from flu mutation Coxsackie virus mutation into a wild strain of Polio with flaccid paralysis March 1971 that I never recovered from. They haven't a clue saying they've never heard of it, until exasperated I say it's similar to M.S. oh, now I understand, so I shoot another bolt further saying, I am surprised you have never heard of it because you have just had a young patient in here in The RD&E Hospital on National T.V news with M.E who was too ill to feed herself, so she was given a diagnosis of anorexia sent home and she died and it's been on the news three weeks ago.

So much like I was in the 1980's and when my husband was trying feed me he said he didn't like seeing me so ill. I had always loved my food and been a size 22 down to a size 14 when first so ill. When will medical staff stop fighting over illnesses of M.E and Post Polio and other illnesses basically calling patients liars. And get their heads together to help us instead of binning literature. So distressing.

Government after government closed down so many hospitals and convalescing places and much else to save money without putting any form of replacements in place. Now people are greatly suffering and nowhere to go.

Another time when I had a foot injury how I discharged myself on my scooter with a friend beside me on Christmas Eve through a group of 22 staff congregating around the staff station I was told was a meeting. Nobody had been in the six bedded ward for well over an hour and we literally went through the middle of them turning to look at us, but not a word was uttered and we left, having a giggle outside of the ward at how easy it was to escape and we felt like naughty St Trinians school girls and that nobody stopped us. Probably didn't recognise me fully dressed as staff never look nor speak to you except for Obs.

Here I rest my case for the time being.
Barbara Taverner (Mrs)
S.R.N: S.C.M: dip; I.I.H.T,T

Feel free to print in PSN and ***see if others have hospital food issues on top of what you have printed.*** I know Richard and Hilary did.



2026 Polio Survivors Network Annual General Meeting

We are holding our 2026 Polio Survivors Network Annual General Meeting on

Monday 03 August 2026

online using Zoom

1:00 - 2:30 pm

(British Summer Time)

Join Us Virtually!

Send your name and email address to us at
psnadmin@poliosurvivorsnetwork.org.uk
and we'll make sure you get all the details to log in
and participate in shaping our future.

Your Voice Matters!

If you're unable to join us, your vote still counts. Please complete this
[Voting Form](#) by **Wednesday 29 July** to ensure your voice is heard.

Received your newsletter by post?

You'll find a printed voting form included for your convenience.

We look forward to seeing you there

PSN Management Committee

Please save the date.

We are also calling on you to consider if you could contribute as a trustee? These roles are vital in guiding our future and ensuring we achieve our goals. Whether you are passionate about polio survivor advocacy, fundraising or bring valuable personal experience, your voice could make a meaningful impact.



The Hidden Legacy of Polio: Why Late Effects Still Matter Today

Many people assume polio is a disease of the past, but for millions of survivors worldwide, its impact continues long after the original infection. The late effects of polio — including Post-Polio Syndrome (PPS) — are often misunderstood, frequently overlooked, and too easily dismissed. As Dr Peter Brauer notes, “over 99% of physicians do not possess the knowledge required to treat polio survivors”, a gap that leaves many patients struggling for recognition and appropriate care.

Although only a small percentage of polio infections caused visible paralysis, up to 99% produced subtle neurological damage that often went unnoticed. These survivors lived for decades believing they had fully recovered, only to experience new symptoms later in life. Fatigue, muscle weakness, pain, swallowing difficulties, sleep problems and respiratory issues can emerge gradually or suddenly, sometimes triggered by illness, surgery, trauma or inactivity. Spinal Life Australia highlights that the rate of motor neuron loss in PPS is roughly twice that of normal ageing, reflecting the long-term strain placed on surviving nerve cells.

A major misconception is that PPS only affects those who had paralytic polio. In reality, most infections were mild or silent, yet still capable of causing central nervous system injury. As Brauer emphasises, “visible sequelae such as muscle paralysis and muscle atrophy need not exist” for PPS to develop. This misunderstanding contributes to frequent misdiagnosis, with symptoms often attributed to ageing, depression or deconditioning.

Diagnosis relies heavily on clinical history rather than laboratory tests. Symptoms do not need to persist for a year before being recognised, and the presence of other conditions does not exclude PPS. A thorough history of the original infection, even if undocumented, and a clear understanding of symptom progression are essential. As Brauer warns, “No diagnosis in the case of a suspected Post-polio syndrome is already a misdiagnosis.”

Management focuses on improving quality of life through a multidisciplinary approach. Energy conservation, pacing and the use of aids or orthotics help reduce overuse of weakened muscles. Specialist physiotherapy supports safe, non-fatiguing exercise, while respiratory and swallowing assessments are vital for those with breathing or bulbar symptoms. Psychological support also plays an important role, as new symptoms can revive memories of past trauma or hospitalisation. Regular monitoring ensures that changes are identified early and treatment plans adjusted accordingly.

The late effects of polio are not rare, not imaginary and not simply a part of ageing. They are a recognised neurological condition rooted in the original infection, even when that infection went unnoticed.

*Thoughts about article **Common Misconceptions Concerning the Post-Polio Syndrome** by Peter Brauer MD (see PSN library)*

Post-Polio Research Update

Frederick M. Maynard, MD

Two new clinical research studies (references below) were recently published by a group of Italian investigators led by Dr. Antonio Toniolo, who has previously received funding from PHI's Research Fund. Taken together, they offer hope for how to better identify those individuals with post-polio syndrome (PPS) who may benefit from treatments thought to improve the immune system's ability to fight chronic viral infection.

STUDY 1: Low-grade persistent poliovirus infection in long-term polio survivors diagnosed with post-polio syndrome: diagnostic and clinical implications

Methods: *White blood cells (WBCs)* were isolated from blood samples taken from 96 subjects diagnosed with PPS according to the European Federation of Neurological Societies' criteria, as well as from 26 stable paralytic polio survivors, 57 family members and 72 non-polio control group participants. The WBC samples then underwent an innovative procedure for identifying low-grade viral infection. The procedure includes culturing the WBCs with poliovirus (PV)-susceptible human cell lines and then extracting ribonucleic acid (RNA, a genetic material) samples that are next subjected to Reverse Transcriptase-PCR (Polymere Chain Reaction) in order to obtain sufficient RNA amounts for identification and analysis.

Results: PV genomes and proteins were found in 87% of subjects diagnosed with PPS compared to only 12% of 26 stable paralytic polio survivors, 3.5% of family member controls, and 0% of 72 other non-polio control groups. It also found high concordance of positive findings between results using WBCs or using CSF (cerebrospinal fluid), muscle tissue, or colon tissue samples from some PPS subjects for human cell line culturing and processing.

Discussion: These findings suggest persistent low-grade infection can persist for 50 years or more after Acute Paralytic Polio and that CSF, muscle, and/or intestinal tissue are the likely reservoirs for PV. Low detection rates among family members suggests minimal transferability of the PV genomes, many of which appeared to be mutated variants of either wild or vaccine-associated strains of PV. Viral genome replication rates were also shown to be very low.

The study's results also suggest that a test for the presence of PV genomes in blood samples could become a feasible and useful diagnostic tool for prediction of which polio survivors were at greatest risk of PPS. Results also strongly support ongoing efforts to find effective anti-viral treatments, such as immunotherapies to slow or stop progressive PPS symptoms.

STUDY 2: Post-Polio Syndrome: Impact of Humoral Immune Deficiencies, Poliovirus Neutralizing Antibodies, Vitamin D Deficiency²

Based on blood sample analyses, 80 PPS subjects, as well as 40 family members, were shown to have significantly reduced levels of IgG (Immunoglobulin G), IgA, and IgG subclasses compared to non-polio controls. Mean serum Vitamin D levels were also found to be significantly reduced in PPS subjects compared to non-polio controls, while the mean Vitamin D levels of the PPS family member group was intermediate between the PPS group and control group.

Conclusions

These studies' overall findings suggest genetic, immunological, and nutritional factors may all increase susceptibility to the pathogenic effects of PV. Findings additionally highlight the complex relationships between immune status and long-term health of aging polio survivors.

Courtesy Post-Polio Health International (PHI), St. Louis, Missouri, USA.

References

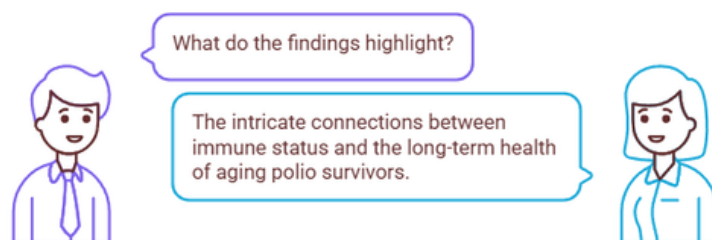
- Toniolo A, Genoni A, Maccari G, Chumakov K, Basolo F, Bono G, Mauri M, Molteni F, Arrondini L, Bertolasi L, Monaco S. Low-grade persistent poliovirus infection in long-term polio survivors diagnosed with post-polio syndrome: diagnostic and clinical implications. J Neurol. 2025 Sep 6;272(9):617.
- Toniolo A, Chumakov K, Federico G, Maccari G, Genoni A, Saba A, Nauti A, Bono G, Molteni F, Monaco S. Post-Polio Syndrome: Impact of Humoral Immune Deficiencies, Poliovirus Neutralizing Antibodies, Vitamin D Deficiency. Vaccines (Basel). 2025 Sep 2;13(9):939.

Watch the video - [CLICK HERE](#)



or go to

<https://tinyurl.com/4u2ncpb2>

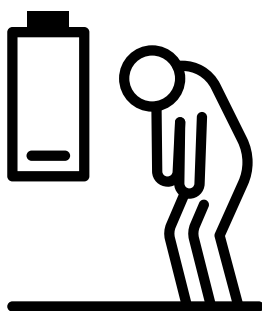


Living With Post-Polio Fatigue: What I Wish People Understood

I've lived with post polio syndrome long enough to know that fatigue is not a side issue, it's one of main challenges for me. I don't mean the kind of tiredness that a good night's sleep would fix. Post-polio fatigue is deeper and far more complex. It affects my body, my thinking, mood and even my decision making ability. Some days it feels as if my brain and body have run out of power, even when I have hardly done anything.

What I've learned, especially from my own research and explanations shared by fellow survivors, is that this fatigue isn't imagined and it isn't weakness. It's neurological. The motor neurons that survived the original infection have been overworking for decades, and the brain itself is doing extra work to compensate for lost pathways. This extra effort has a cost so when I hit my limit it shows up in ways that are hard to explain: losing my train of thought mid-sentence, struggling to make decisions, or feeling mentally "foggy" after something as simple as a conversation. This "brain fatigue" can be just as disabling as the physical kind.

I used to think I just needed to push harder or stay active to keep my strength up but post-polio fatigue doesn't follow the usual rules. I can do the same activity on two different days and feel completely different. Sometimes a short walk is fine; other times I am done for the rest of the day. I've had to learn that overactivity and under-recovery can trigger a crash that affects me for days, not hours. I found Hilary's explanation of using energy tokens helpful. Every activity has a cost and it is easy to overspend, I had to reconsider using aids and asking for help. That has been very challenging and still a work in progress if I am completely honest. What helps me most is understanding what's actually happening inside my body. Rest is now part of my routine and I plan my days more honestly.



Editor: Hilary Boone published articles in this newsletter about Energy Tokens and using energy wisely using pacing and resting. She suggested imagining that each of us has 10 energy tokens a day, 70 a week and viewing it like having £70 to spend. Every activity has a cost: some are 10p, some 50p, some £1. Work out our own prices for the activities we do each day.



The British Polio Fellowship has introduced a practical resource designed to make healthcare conversations clearer and less repetitive for polio survivors, the **BPF Care Plan** and its companion help guide. The care plan offers a structured way to record your polio history, daily challenges, symptoms and support needs, with the guide providing prompts to help you capture the details that matter most.

This new tool sits alongside other helpful options such from Polio Survivors Network such as My Polio Life, Preparing for Your Appointment, and What You Need to Know About My Condition all designed to help you share the details of your situation. Simply choose the ones that work best for you. By gathering your information in one place, you only need to tell your story once, allowing it to travel with you to every appointment and helping clinicians offer more personalised care.

[BPF Care Plan](https://britishpolio.org.uk/new-care-plan-for-polio-survivors/) <https://britishpolio.org.uk/new-care-plan-for-polio-survivors/>
[BPF Care Plan Help Guide](#)

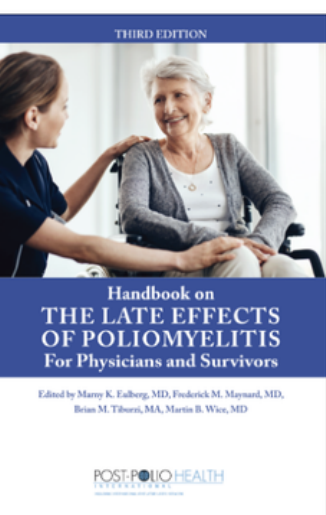
[My Polio Life](https://poliosurvivorsnetwork.org.uk/new/my-polio-life/) <https://poliosurvivorsnetwork.org.uk/new/my-polio-life/>
[Preparing for Your Appointment](#)
[What You Need to Know About my Condition](#)



POST-POLIO HEALTH INTERNATIONAL

Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors PHI has released a new edition of the **Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors**. It is a concise, 120-page reference covering more than 90 key topics. Drawing on the expertise of over 50 contributors and presented in an easy-to-use dictionary format, it's a valuable resource for both polio survivors and clinicians. The handbook is available to read online [HERE](#)

Edited by Marny K. Eulberg, MD, Frederick M. Maynard, MD, Brian Tiburzi, MA, and Martin Wice, MD. Copyright 2026.



The Brain & Spine Foundation provide creative groups and activities for those with neurological conditions. Their aim is to create a safe and supportive space for people to try a creative activity, share ideas and gain inspiration.

Click this link for more information <https://www.brainandspine.org.uk/support-for-you/peer-support-groups/creative-groups/>

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 fifth one entitled...



Loss of a Pair Of Levis on the Runway at Embakasi

It had been a magnificent week in Nairobi attending the AfriCities Conference on behalf of Shell. As well as certain other funnies that week between myself and my client, a rumbustious Nigerian I had known for a number of years, I was accosted on the runway, in my wheelchair, between the terminal and a distant Boeing 757, to explain some hardware in my suitcase which had been noticed when screening the bags after having checked them in.

Lying my Samsonite horizontally on the runway, in a high wind, beyond my reach, the walky talky carrying guys prized the bag open only to have a pair of Levis and miscellaneous socks and underwear take of in a very high breeze, to expose my prosthetic spare leg as the offending hardware.



Rotary GB&I statement on UK government funding for polio eradication



Source <https://www.rotarygbi.org/statement-uk-government-polio-funding/>

Rotary in Great Britain and Ireland has issued the following statement following the UK government's decision to withdraw financial support to the Global Polio Eradication Initiative:

It is with deep concern we have heard that the UK government has decided to withdraw its financial support for the Global Polio Eradication Initiative (GPEI). The GPEI depends on financial support that enables the World Health Organization (WHO) and UNICEF to maintain their actions on the ground around the world. Even prior to the UK's announced budget reduction, the GPEI was forced to reduce its 2026 budget by almost 30% compared to 2025 as a result of reduced global health funding from major donors. The decision by the United Kingdom to stop providing funds to the GPEI after 2026 puts at risk the great efforts that have been made over the last 40 years to improve the health and wellbeing of children across the world.

We are at a critical stage in the campaign to eradicate polio, infection numbers in Pakistan and Afghanistan are very low, but this is a result of great efforts on the ground in these last two endemic countries. Pakistan has 400,000 people working in vaccination teams, in Afghanistan teams are working street by street in cities, towns and villages to ensure that every child is reached. Vaccination teams operate in very dangerous regions along the border between the two countries where they are constantly at risk of attacks and violence. Conflict between the two countries has put them at further risk but still the effort to vaccinate goes on, a recent drive in Pakistan inoculated 45 million children.

These challenges extend beyond the two endemic countries of Pakistan and Afghanistan. Today, outbreaks of variant polio persist in the world's most fragile settings. Humanitarian crises, conflicts, and disasters complicate efforts to vaccinate every child against polio, while logistical challenges and resource constraints make it hard to respond quickly to every outbreak. As immunisation rates remain low globally, the risk of international spread is high, even to places long polio-free.

Last year traces of the polio virus were found across Europe. In January this year, traces were found in wastewater in London. Failure to eliminate the polio virus in Pakistan and Afghanistan would open the door to new outbreaks in countries where the virus was eliminated. We cannot afford to be complacent. Loss of financial support for the eradication campaign could have dire consequences. We face the last mile of this journey and it would be tragic if all the efforts of the last four decades to eliminate polio were to fail at this final step. Failure now would have direct implications for every country, every community, every family around the world. Rotary International pioneered the campaign to eradicate polio. Our members have given huge amounts of financial, volunteering and advocacy support to this endeavour, and we remain fully committed to the task of eradicating polio as our organisation's number one

humanitarian goal. Alongside our partners and in collaboration with national governments including the UK, we have helped immunise more than 3 billion children against polio in 122 countries, prevented over 20 million cases of paralysis and reduced the number of polio cases by 99.9%.

We intend to fulfil the promise made 40 years ago, to safeguard the health of children by eradicating polio. We sincerely hope that the UK government will consider future support for this goal which is anticipated to save US\$33 billion in health-related costs by the year 2100 compared to the ongoing costs of outbreak control and treatment.

Now, more than ever we need every Rotarian and supporter to do everything possible to back our campaign. We need to redouble our efforts to ensure that we succeed, that we achieve our goal, that this, our most important humanitarian cause is realised, we must End Polio Now.

James Carmichael, Rotary GB&I End Polio Now Coordinator, **Amanda Watkin**, Rotary GB&I Chief Executive Officer, **Heather Stuart**, Rotary GB&I Chair of the Board



GPEI statement on UK announcement to end funding for GPEI

20 March 2026

We regret yesterday's announcement that the United Kingdom of Great Britain and Northern Ireland (UK) is planning to end its funding for the Global Polio Eradication Initiative (GPEI). For nearly four decades, the UK has been a crucial partner in our efforts to eradicate polio—providing technical expertise, political leadership, and over US\$ 1.75 billion in flexible funding. This support has helped protect more than 3 billion children from polio, prevent over 20 million cases of paralysis, and bring the world to the brink of ending polio for good. In 2025, the GPEI vaccinated 440 million children against polio, many of them in fragile and conflict-affected areas.

We note the UK will continue to support WHO and Gavi and look forward to engaging closely to ensure those investments support the goal of a polio-free world. However, reductions in earmarked funding for GPEI carry significant risks and will have a real impact on the health of some of the most vulnerable children in the world. Due to reduced support from major donors, the GPEI has already been forced to cut its 2026 budget by 30%, causing the program to scale back operations, especially around surveillance and outbreak response.

We have the tools and expertise to end polio, but without sustained commitment, we risk a global resurgence of this devastating disease—at a cost far exceeding what continued eradication efforts require.

Eradicating polio is also a strategic investment in the UK's own health security. Recent detections of poliovirus in countries that have long been polio-free, including earlier this year in the UK, underscore that as long as polio exists anywhere, it remains a threat everywhere. The GPEI remains committed to working with the UK and hopes that direct funding will be restored in the future. Together, our goal must be to finish the job and secure a lasting polio-free future for generations to come.



Could you write to your MP? *This appeared in guardian.letters@theguardian.com on 09/04/2026, from GR of Winchester.*

It is extremely disheartening to read that after 2026, the UK government is to end its contribution to the Global Polio Eradication Initiative (GPEI) putting at risk the great efforts that have been made over the last 40 years to improve the health and wellbeing of children across the world (Polio virus found in London days before cuts to global vaccination plan, 28th March [Link here](#)) The eradication of polio is a cornerstone of humanitarian work of Rotary International (a GPEI partner).

I am one of the many Rotary members who have taken part in vaccination days in India and seen at first hand the dedication of local health workers in ensuring that all children are vaccinated.

We are at a critical stage in the campaign to eradicate polio. Infection numbers in Pakistan and Afghanistan are very low, but this is a result of great efforts on the ground in these last two endemic countries. A recent drive in Pakistan inoculated 45 million children.

I caught polio in 1954 at 18 months old- the year before the vaccine was introduced in the UK. As a result, I have no use in my left arm, and I underwent surgery on my left leg several times in childhood- and I am one of the lucky ones. This dreadful disease, which mainly affects young children and has lifelong consequences, must be eliminated- and the work to achieve that must be adequately funded.

Polio Survivors Network is part of the **Octopus People Power** programme, a simple way for us to raise funds just by helping our community get cheaper, greener energy.



How it works:

- Use our unique link to get a quote and sign up to Octopus Energy.
- You'll receive £50 free credit on your new energy account after your first direct debit is taken.
- Polio Survivors Network also receives £50 as a boost for our work

Octopus Energy is the UK's most awarded energy supplier, offering 100% zero-carbon electricity and outrageously good customer service. Switching is simple and usually takes just a few days with no disruption to your supply.

Ready to make the switch and make a difference?

Sign up via our link today: <https://poliosurvivorsnetwork.octopus.energy>



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retailers donate**

Sign up to easyfundraising
and see your favourite
retailers donate to

Polio Survivors Network

whenever you shop with them

Sign up and get started

Please remember to use easyfundraising every time you shop online. Over 8,000 retailers will donate to us. This means you can raise FREE donations for us no matter what you're buying.

If you haven't signed up to support us yet, it's easy and completely FREE.

You can find our easyfundraising page here:

<https://www.easyfundraising.org.uk/causes/polio-survivors-network>

Ask the Doctor

Have a medical question? PHI has experts on hand to help answer your pressing questions.

ASK THE DOCTOR

POST-POLIO
HEALTH
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Ask the Psychologist

New! Have a question related to the psychological, emotional, or social effects of living with polio? Let us help.

ASK THE PSYCHOLOGIST

Have a medical question about the late effects of polio?
Have a question about the psychological, emotional, or social effects of living with polio?

Polio Health International's Medical Advisory Committee can assist.

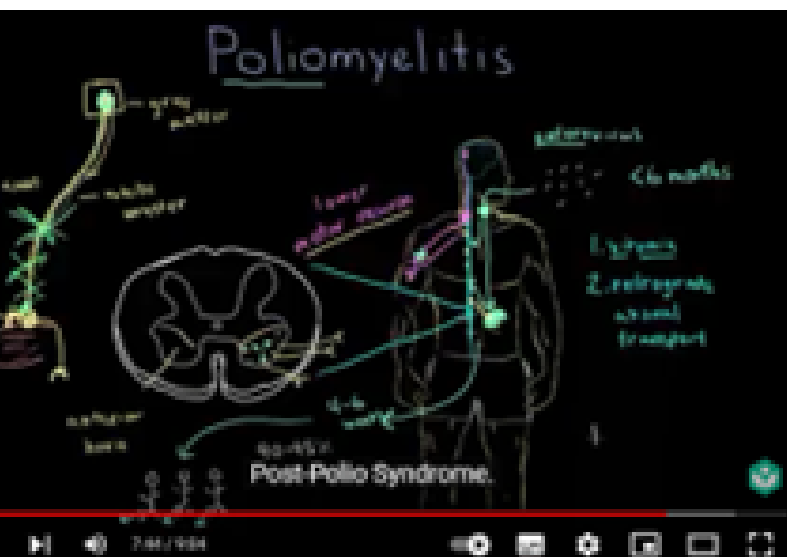
<https://post-polio.org/>



Want a clear explanation of Polio and Post Polio Syndrome to share with others?

Try this video from the Khan Academy Medicine
(created by Ian Mannarino and hosted on YouTube)

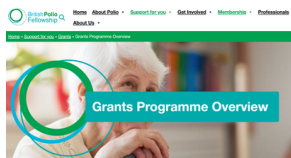
<https://www.youtube.com/watch?v=aBBTiPsYUVA>



These videos do not provide medical advice and are for informational purposes only. The videos are not intended to be a substitute for professional medical advice, diagnosis or treatment. Always seek the advice of a qualified health provider with any questions you may have regarding a medical condition. Never disregard professional medical advice or delay in seeking it because of something you have read or seen in any Khan Academy video.

Grants and Funding Options for Polio Survivors

Polio survivors have access to two targeted sources of financial support that address different kinds of needs. The **British Polio Fellowship Grants Programme** offers small grants to UK polio survivors for things like holidays, home adaptations (e.g. ramps or handrails), mobility aids and equipment or help with high energy bills.



<https://britishpolio.org.uk/support-for-you/grants/grants-programme-overview/>

The **Joyce & Arthur Siegfried Memorial Fund** from **Post-Polio Health International** provides funding (up to a set limit every two years) specifically for personal items such as braces and custom-made shoes, with payments made directly to the supplier. Polio survivors from any country can apply.

<https://post-polio.org/siegfried-fund/>

POST-POLIO HEALTH
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About Resources

The Joyce & Arthur Siegfried Memorial Fund

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>

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Account name: **Polio Survivors Network**

Bank: **CAF Bank**

Account: **00014980**

Sort Code **40-52-40**

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