POST POLIO MATTERS

Polio Survivors Network Newsletter

August 2021 — Volume 10 Issue 8 of 12 [116]

n.b. Volumes 1 to 6 published under the name LincPIN

Polio Survivors Network

Lives lived with healthcare lessons for the future

See page 3

NEUROLOGICAL PHYSIOTHERAPIST

Neuromuscular vs Musculoskeletal Disorders

More Information Online WWW.DIFFERENCEBETWEEN.COM

	Neuromuscular Disorders	Musculoskeletal Disorders
DEFINITION	Neuromuscular disorders are diseases that affect neurons controlling the voluntary muscles	Musculoskeletal disorders are diseases that affect muscles, joints, and bones
PARTS AFFECTED	Neurons that control voluntary muscles	Muscles, bones and joints
SYMPTOMS	Muscle weakness, balance problems, droopy eyelids, movement issues, trouble swallowing, double vision and trouble in breathing, etc.	Pain, redness, swelling and muscle weakness, etc.
EXAMPLES	Amyotrophic lateral sclerosis, muscular dystrophy, diabetic neuropathy, toxic neuropathy, myasthenia gravis, small fiber neuropathy and spinal muscular atrophy, etc.	Tendinitis, carpal tunnel syndrome, osteoarthritis, rheumatoid arthritis (RA), fibromyalgia and bone fractures, etc.

MUSCULOSKELETAL PHYSIOTHERAPIST

Lincolnshire Post-Polio Library 100+ articles

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

Page 2	Contents, Donation acknowledgements
Page 3	Editorial - Hilary Boone
Page 4 - 5	Messages From Our Chair, Masks for Covid-19
Page 6	The front page headline in the Daily Telegraph shouted "NHS made pandemic plan to deny elderly care"
Page 7	Toni Writes, From Our Readers
Page 8 - 9	Polio Survivors Sharing Coffee Chat Tips on Problems and How We Overcame Them
Page 10	What does the word fatigue mean to Polio Survivors with Post-Polio Syndrome?
Page 11	We can manage our fatigue and get much more out of life!
Page 12 - 13	Polio Myths and Half Truths by Dr Julie Silver
Page 14 - 17	Post Polio News (PPN) Has the billion dollar crusade to eradicate polio come to an end?
Page 18	Polio Groups - Online Support
Page 19	Management Committee, Useful Polio Articles
Back page	Coffee Catchup, PayPal Donate, Smile.Amazon, Website

Donations and Charity Incentives Paid

(since last newsletter)

Dunham - via PayPal Giving	£70.00
Amazon.Smile	£11.11
CAFBank	£10.00
Anonymous - via PayPal Giving	£1.00
HMRC Gift Aid claim (backdated)	£566.16
Brennand donation	£12.50
Tanfield donation	£20.00
PayPal Giving Fund donation	£17.50
Anonymous - via PayPal Giving	£1.00
Moorhouse donation	£21.00
Mitchell donation	£12.50
Total	**£742.77**

Thank you so much!

This publication is provided as a service to those seeking such information and is not intended as a substitute for professional medical care. The opinions expressed in this publication are those of the individual authors and do not necessarily constitute endorsement or approval by the Polio Survivors Network. ALWAYS consult your doctor before trying anything recommended in this or any other publication.

Articles in this publication may be reprinted in full with acknowledgement of this Newsletter name, volume, issue and date. Exceptions are where written by an external author/newsletter when permission must be gained from the original author/s.

Editorial by Hilary Boone

Where to start? The sun is out, the washing blowing in the breeze, our cat is stretched out fully in a shady spot and Holly Bradshaw just won a bronze medal at the Olympics in the pole vault.

We are both double vaccinated now so able to go out a bit more but restricted by the number of care hours we can spare out of all the other jobs they have to do for us in our home. Regardless of current advice Richard and I have both decided as we are both clinically extremely vulnerable we will always wear a mask inside any venue [except to actually eat a meal in a decently distanced venue]. We also ask any professionals or tradesmen that have to come inside our home for any reason to wear a mask and so far everyone has had one with them in preparation for this. [See page 5 Simon's message re masks]

Along with our carers we get boxes of lateral flow tests sent to us regularly and test twice a week and thankfully all been negative so far. However that did not stop one of our carers and all her family catching Covid which meant our other carer and ourselves had to self isolate for ten days from the date we were notified. It was a real tough time for the two of us without any care support and only the very basics to live were all I could manage. It was a much tougher time for our carer and family but thankfully they got through it. It might seem odd to add this as a benefit but the rest of her family now understand what we [she has Fibromyalgia] mean by fatigue.

I googled the word **fatigue**. First definition was extreme tiredness resulting from mental or physical exertion or illness. I read on and apart from the words chronic fatigue what I was reading was not the sort of fatigue we talk about as survivors of polio virus nerve damage/post polio sequelae. We hear on the news about Covid fatigue so I did some more searching and decided it would be better to move what I learned to page 10. Plus a new contact has just asked me to explain a bit more about pacing and resting and energy tokens, page 11.

Coffee Chats. Despite very few attending we have had some laughs and discussed a wide variety of subjects. See pages 8 and 9. We do understand finding time to do stuff is not easy and if something else comes up we might have to decide to give it a miss or maybe like us sometimes you forget. We can only send reminders if we have an up to date email address for you. Oh boy its nearly 4pm and my brain cannot remember what the letter are for the database rules - polio brain fog! It is not a medical term but it sure makes it easier to accept when it has a name. I googled 'data base rules' and it is GDPR.

At Coffee Chats half the hour will be just a general chat and half we will suggest a subject. Please write and suggest days and times that will be more suitable for you and also subjects that you would like added to our list. You can join and leave at any time during the hour. You can also turn off your camera and microphone and nip to the loo, answer the phone, etc without leaving the chat. Just turn back on again soon as you are ready. There is a typed chat facility on the side that you can use to ask questions whilst someone is talking or let us know you are nipping to the loo, I am more than happy to do a trial run for anyone who is a bit nervous about joining in. I have got four systems that different organisations are using: Skype, Microsoft Teams, Zoom and Webex, For one to one there is Facetime, WhatsApp and Instant Messenger which I use to video chat to my daughter now living on Vancouver Island. Having to learn so many different methods I know how helpful a one to one trial can be. Hoping to hear from more of you as these are great ways to keep in touch with each other and also share much more information.

Launch of Our New Website. Toni's son Jake spent many hours designing options for us to choose from and then produced our chosen design. He is now trading as J Dunlop Design and we wish him success for the future. There are still some more items that we want to add in the near future but, as with all of us, we have to fit this into our available energy tokens.

Chris Salter's Post Polio News [ppn] item I chose is a much longer article than usual but I found it so interesting and hope you do as well. If you want to receive all the items Chris finds go to www.post-polio.org.uk where you can choose a method. Pages 14 to 17.

MESSAGES FROM OUR CHAIR

Reflections on holistic well-being

I have been reflecting on my dealing with the acceleration of my PPS on my mobility, muscle function and breathing over the last 5 or more years. As a Counselling Psychologist for over 25 years and a disabled person for 65, I have been aware both in my work and life that impairment and disability have reached into and impacted all aspects of life. In my case it was never an option to imagine myself or pass as 'normal' and not different, as I was quite obviously physically disabled even as a child. However, the social and economic impact was more subtle and took years to fully sink in, and perhaps more years to accept its full impact.

The medical model

Like many of us, as a child I was indoctrinated into the medical approach. Encouraged to exercise, adapt, push myself, often to the limit, if not beyond, to ignore pain and or discomfort. The rewards were of course that it worked, it helped me achieve the absolute best possible for me. I was praised and rewarded for my efforts and achievements by my 'medical family', all those health professionals I spent so much time with. Of course they were equally rewarded and validated by my success. I was the good patient, if not one of their best patients.

There is knowing and knowing

Unlike many polio survivors, when I was 30, I realised 'intellectually' at least, my physical abilities, such as they were, would not last and my muscles would age faster with all that implied around independence and I would likely become a wheelchair user again. In other words, I knew at some level PPS was my future even before PPS was a known thing. But knowing isn't processing and preparing for the psychological and emotional impact when it arrives.

Ageing with a disability

So, I sit here and reflect that having knowledge and information is a help, but it only goes so far. Despite all I have learnt as a Counselling Psychologist for 25 years, I still struggle with the psychological and emotional impact of increasing impairments. The truth is that the skills and abilities offered by a simple medical approach are of limited value or effectiveness on their own especially with long-term conditions such as PPS. The harsh reality is that what's on offer to an 'old disabled person' cannot be compared to when I was 'a disabled child' with polio in the 1950s. Added to that is the fact that polio was then TOP DOG of diseases, especially as children were the main patient group. Now polio is way-down in the hierarchy, an almost forgotten illness and virus, of little interest to medical and health professionals of today. Ironic maybe as we see the world devasted again by a new virus and all the mental and physical long-term impacts that will bring over the coming decades.

The missing half of healthcare

Fixing impairments, making adaptions and using coping strategies only go so far. It doesn't address the years of physical and psychological stress managing long term conditions such as PPS or the toll navigating society takes. We are often in denial ourselves, and so are ill equipped to manage the process of living well with PPS as we age. When I say our 'own denial' I don't just mean polio survivors, though we are probably experts at this. Many disabled people especially those who work at not being seen as disabled people, can be heard colluding with this denial and worse still being admired for phrases like 'I don't think of myself as disabled' or 'my disability hasn't really affected me much' or perhaps 'I have overcome my disability'. The reality is that for so many of us it has affected us every single day but we have learnt to, become conditioned or made ourselves ignore it whenever possible. By doing so we are rewarded by fitting in, up to a point of course, but it can catch up with you.

On both sides of the fence

I have spent my working life on both sides of the fence, as a patient and as a clinician. I realise there is a paucity of psychologically appropriate support. I have tried to lobby for psychologists and psychotherapists to be involved in the well-being of disabled people. It should be there from the day one, when we are born a member of the club or when we become a disabled person at some later stage. Why is it not seen as a priority? Why fix the body only? Surely this is such a myopic reductionist approach to what being healthy human is about and so far from an holistic healthcare system.

Psychology and psychotherapy

Even when support is offered it is almost always short-term and often with a restrictive cognitive model such as CBT (cognitive behavioural therapy) and almost never incorporates the social model or with wider integrative approach. These approaches are delivered with no regard to the emotional complexities and diverse experiences of being a disabled person in a non-disabled world. Psychologists, psychotherapists and counsellors are poorly trained in chronic illness and physical disability and have little clinical experience of working with us. No wonder so few of us want or have good experiences with psychological services even if they are available to us. Maybe we have been indoctrinated into always expecting a medical solution, and yes, even I am sometimes guilty of this.

I tried to think of a medical analogy to convey the central role of an experienced counselling psychologist or psychotherapist being integral in the team and ongoing management. The best I can come up with is that under recognised yet vital person, the anaesthetist. Whilst the consultant surgeon is often the star turn and 'fixes' you with their almost magic skills and sophisticated treatments, it is the anaesthetist who watches, monitors and manages your vital signs, ensures you have the breath of life. The anaesthetist manages your pain and ultimately keeps you alive. Perhaps a well-trained, experienced empathic psychologist or psychotherapist should be as integral and vital to the ongoing well-being of those of us who live life as disabled people, such as polio and PPS, as the anaesthetist.

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

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

Masks for Covid-19

Views around masks are rather muddied by politics rather than relying on research. Equally the messaging about masks was wrong in the early days and also the lack of supply was perhaps the reason government played down their role so as to prioritise the supply to the NHS.

FFP3 Research, which is still in peer review, suggests that the FFP3 masks are the best for both protecting the wearer and also others. These are not generally worn outside medical facilities and are the most expensive. Personally, with my reduced breathing respiratory muscles I find them (the one with valves) more comfortable despite the price, but the danger is that these can protect the wearer more than protecting both the wearer and others. Beware if you buy these that there are a lot of 'dodgy' ones around so thoroughly check before you buy and also the valve filters are the critical.

FFP2 similar to N95 For most people these provide excellent protection for the wearer and others (WHO say it filters about 94-95%). They don't have the same highest-level filter but are close fitting so can be more sweaty and perhaps there is more resistance to the breathing. But for most non respiratory people they are probably the most cost effective and efficient

FFP1 and the ordinary surgical masks These are probably the more basic and offer some protection. They are probably better at protecting others from you than protecting you from others who have Covid.

Home made face coverings/masks These of course vary and to be honest you need to just follow the guidelines around what to use and how to wear them. Its not easy to be define as they are all different but they probably are better than the ordinary surgical mask if made and worn correctly.

For a more detailed description of the various masks try: https://www.pixartprinting.co.uk/blog/kn95-n95-ffp2-masks-guide/

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

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

The front page headline in the Daily Telegraph shouted "NHS made pandemic plan to deny elderly care"

Of course, the NHS denied they meant to throw us oldies on the scrap heap, but there is no gainsaying in the past year over 40,000 residents in care homes died of Covid. The figure confirmed my suspicions; once we reach the age of 60, the NHS regard us as a nuisance and a burden costing the health service money.

Forget about the fact that most of us have been contributing for years without costing the NHS a penny, surely we are entitled to payback? I reminded one receptionist that I hadn't been near the surgery for years, her reply was "but now you are making use of the NHS", as though that wasn't on.

Chillingly, local hospital transport now asks me "do you have a DNR order?" (Do Not Resuscitate). The thought that if I have an 'incident' in an ambulance, the crew will have been told not to bother to resuscitate me is chilling. Getting onto an ambulance I now make absolutely sure I am as nice as I can be - just in case.

I HATE it when outpatients receptionists ask in a loud voice "what's your date of birth?" instead of asking our name, I don't know. But the moment I mention it, I am immediately shoved in the 'over-60' pile. The NHS thinks of us a number, and if we are aged, doesn't expect us to improve as we mature, unlike wine.

I often wonder what happens when The Queen sees a doctor, and defy any medic to place Her Majesty in an elderly slot. HM is walking proof that you don't lose your marbles as you get older, whatever others think.

Sadly, there is now a double burden on the aged; conditions such as cataracts, hip and knee replacements, etc. are suffering massive delays for operations, so many elderly patients are raiding their pension pot to pay for treatment privately to get relief from pain. Just because we are 'over 60'. why should the NHS assume we don't want to enjoy sport (albeit in a gentle form) or be stuck at home inside four walls, because it is too much of an effort to go for a walk when we are waiting for the NHS to repaired our joints?

However, most of us haven't lost our sense of humour, and thanks to Dennis Reed of Silver Voices some of us have recently had a lot of fun at the BBC's expense. That corporation has got far too big for its boots, and when it decided to pay over a £1 million of its licence fee for a potato crisp personality's fee, and then re-introduce charges for the over 75s, Dennis rallied us and gave us legal ways to - as he put it - Gum Up the Works.

Little things gave us a chuckle, like ways we could legitimately challenge the way demands were sent out. This was so successful that currently there is an impasse. The BBC has had to reign in Crapita (sorry - Private Eye's name is so apt for Capita) and its rottweilers are back in their kennels. When I was legitimately entitled to a free licence, Crapita harried me so often that I passed the correspondence on to my MP, Greg Hands, who apparently had a section dealing with this.

So now 3/4 million over 75s have yet to pay their licence fee - but the BBC must be thinking of making cuts as one only has to look at their toned-down coverage of the Olympics. All those staff that used to float in on the massive gravy train have had to stay at home!

To join in the fun, go to https://silvervoices.co.uk/

Verité Reily Collins www.aftercancers.com Email: veritegreenbee@gmail.com

Excerpt from About Me. "Probably the naughtiest girl in school, I avoided being expelled by the skin of my teeth, although a wonderful teacher at the English Girls High School in Istanbul, Miss Locke, inspired my love of travel and history. I had ended up there when Daddy was 'lent' to the Turkish Navy by the Royal Navy. Much to the relief of teachers I left when I was 15 to be flown home for treatment for **Polio**, and was lucky enough to be treated when the NHS really was world class.

Toni Writes ...

How are you doing? What have you been keeping busy with? I have been decluttering, I do wonder just how we manage to accumulate so much especially as I am not the sentimental or keep it 'just in case' type of person. I am doing our place in earnest as my mother-in-law needs to downsize in the next few months and she certainly does like to hang on to everything!

As I was decluttering, I came across a few ways to donate of unwanted items. I prefer to give things to charity or to others that are great at upcycling than for them to end up in landfill.

CLOTHES: Send your clothes to **Thrift+** to sell. They send you a prepaid postage bag, you fill it with clothes, send it back and your items are sold. Thrift+ take a third of the money raised, you get a third and a other third is donated to your favourite charity! https://thrift.plus/pages/re-sell

CAR: Donate your car through **Giveacar**. They will collect it from you too. I checked but I didn't find a car to donate at this time. An interesting idea though! https://giveacar.co.uk

ANYTHING AND EVERYTHING: Another way to turn your clutter into funds is to use **eBay for charity**. You can donate 10% or more of each item you sell. https://www.charity.ebay.co.uk/charity/Polio-Survivors-Network/109876

Drop me a line with your tips, or anything on your mind. Take care and keep safe!

Toni x

From our readers

"Really enjoyed the session. Lots of useful information. Thanks." – Virtual Coffee Catchup attendee

"Your fine 115th newsletter one of the best I've seen these last 29 years I have followed your PPSG! Keep up this great work in the UK!"

"Always pleased to receive the newsletter, greatly appreciated."

"I wanted to thank you...for giving me strength to open up about my polio."

Email	psnadmin@poliosurvivorsnetwork.org.uk
Post	PO Box 954, Lincoln, LN5 5ER
Website	www.poliosurvivorsnetwork.org.uk
Phone	01522 888601

Polio Survivors Sharing Coffee Chat Tips on Problems and How We Overcame Them

N.B. Companies and items mentioned are the views of the member regarding an aid/equipment/company that they has helped them manage their Polio Life.

Moving about on a Bed What do you use to get onto and off and turn over a bed?

Whilst at a PPS Conference years ago I was asked to join some of the health professionals to answer questions from the audience. I asked the audience 'How do you roll over in bed?' Answers were slow in coming and many agreed that they would have to go back to the bedroom and do this before they could answer. Then I asked if it was as easy in their hotel room and many said no because there was no bedside table, or handle on the mattress as at home.

Have you gone into hospital and been given a bed with an air mattress and found it made you more disabled because you could not move about on the bed the same way as at home? Both Richard and I ask for a normal mattress and explain why. Sadly the lack of understanding of how varied the ways polio survivors perform their actions of daily living can make this a difficult conversation. Back some years we had to agree for Richard to try one and see how much better it would be. I did enjoy demonstrating the next day that Richard was now unable to move about on the bed or get off it to transfer to the commode.

Turning over in bed has been a problem for over 25 years. Firstly I would hold the handle of the mattress, bounce three times on the bed, grab my nightie and turn. For 7 years now I have had a Snoozle Sheet [www.thesnoozle.com] which is a metre square tube of material shiny on the inside. As you turn one surface slides over the other. I also have an under mattress handle - travel one so that I can move it from bed to bed and take with me when I go away. [Bedside econorail from www.completecareshop.co.uk]

Richard who has Parkinsons as well as PPS has varied movement ability throughout the 24 hours. He has times he can just sit up straight in bed and others where he is stiff like a tree trunk and we have a Vendlet V5S bed turning system fitted to the Profile Bed, www.vendlet.com

Simply a rail either side of the bed that can be raised with a very wide sheet velcroed to each rail. To transfer the rails are at their lowest below the level of the profile bed mattress so that he can transfer from wheelchair to bed and then scoot into position. To turn him, we move the covers so they do not get trapped under him. Raise one rail and using the controls turn him till he is lying on his side. Physically all carer has to do is to make sure arms are comfortable, cover him with the covers he prefers and we unroll the sheet a bit from the other rail so he can get his hand down into the gap to help him turn when he starts to move again.

Bathlifts used in other areas of the home

One of our members told us on the Coffee Chat about a polio survivor who has three bathlifts in his home. One as normal in the bath but another in the bedroom so he can transfer from side of the bed to the floor so that he can get his spinal jacket on the way he has to do it and a third one downstairs.

Another member has put one on a lockable wheeled frame by the side of their hot tub as a second way of getting in and out in an emergency.

Masks

The discussion was mostly on how little information we had received as to which masks would be best for those medically compromised**.** Look on the gov.uk website and there are pages and pages of technically worded information.

The discussion continued as to which we were using. The blue outside white inside masks most often seen and handed out or the more expensive masks the KN95, N95, FFP2 masks which we learned are all the same just different numbers from country of origin.

Simon Parritt, our chair, has added an extra message on masks for Covid to explain more about this. See page 5

Remember you can ask questions at any time to be included in Coffee Chats, Newsletter etc.

Driving into a vehicle in an electric wheelchair using a wheelchair docking system

For people who don't want to hassle of dealing with a 4-point tie down system, a docking device may be the answer. Docking systems are used by many people in wheelchairs who drive their own vehicle from their chair. Wheelchair passengers can also use a docking system. The system is basically a rectangular metal device that is mounted to the floor. It has a spring-loaded electronic hook that grabs on to a metal bolt (or pin) that is mounted to the bottom of the wheelchair. When the bolt is rolled into the docking device, the hook automatically closes around it, keeping the wheelchair in place. Wheelchair seatbelts are then used along with the docking system for additional securement. Docking systems generally include a push button electronic control module mounted on or near the dashboard notifying the driver and passengers when the wheelchair is locked down properly. The control module or quick release button on the docking device is then used to unlock the docking mechanism when reaching your destination.

Motability Vehicles

Member reports that to save time they asked the Motability company allocated to them to bring the vehicle they suggested to their Wheelchair Services so they could borrow the wheelchair that they were going to be supplied with for the assessment. This was agreed and after loading electric wheels a short test drive was provided. All seemed ok so they went ahead. Covid delayed delivery and then the order to Stay Home meant it was only used for Medical Appointments. Once able to get out more they found four issues that they had not anticipated and regret not being assessed at a Motability Centre.

"I know when I was told I would need to have an assessment I thought it would be just like having a driving test but I couldn't have been more wrong. Mobility centres are staffed by occupational therapists (OTs) and approved driving instructors ADI's and their aim is to help disabled people wherever possible to remain mobile."

Members reported good service from:-

Brig-Ayd Controls offering expert supply and installation of wheelchair and scooter hoists, hand controls and left foot accelerators for a wide range of vehicles, plus other disabled driving aids. www.brig-aydcontrols.co.uk

CJ Conversions Motability Registered Installer in Lincoln have given us great service for about ten of the 18 years we had our Kia Sedona and needed a hoist. The hoist had two different lifting bars, one for the electric wheelchair and another for the electric scooter. www.cjconversions.co.uk

Monarch Mobility and the Atlas 4 Folding Mobility Scooter Hoist used by another of our members on the Coffee Chat, www.monarchmobility.com

Medical Information in case of Emergency

A senior lecturer in paramedic science, School of Health and Social Care, University of Lincoln responds that the following is taught to students when checking for medical conditions alerts in emergencies. "There are products available labelled as 'medi alerts' that can be worn like a piece of jewellery. We teach students to look for these. Example www.medicalert.org.uk/products/ Alternatively, in the home there have been local schemes in the past such as "message in a bottle" (e.g. https://www.peoplefirstinfo.org.uk/staying-safe/safety-in-the-home/message-in-a-bottle-scheme/) or where a front door has a sticker and this alerts the clinician to look in the fridge (yes, that's where they would be kept!!) to find the information.

In today's world of course there are now shared records that can be accessed electronically but, in an emergency, ***you can't beat paper and pen!*** The trick of course is to keep the information up to date! Within the programme a couple of modules touch on the legalities surround DNAR, ADRT forms and all guidance would instruct clinicians, regardless of profession, to follow care plans where they are in place. Where a care plan involves certain medications and the patients meds are available along with prescription advice then it is legal for someone to deliver the medication. They must be both competent with the method of the delivery and it must be within their scope of practice. We see this a lot in end of life care and also for patients who suffer specific repeated events such as seizures.

What does the word fatigue mean to Polio Survivors with Post-Polio Syndrome?

How often have you had difficulty explaining to professionals, family and friends what fatigue means to you?

Fatigue is defined as extreme tiredness resulting from mental or physical exertion or illness. I am smiling as just below this was another definition example, “the nails have become rusted through or fatigued”.

I decided to look further at other examples and am really surprised at the definitions, meanings and examples listed. Apart from the words chronic fatigue what I was reading was not the sort of fatigue we talk about as survivors of polio virus nerve damage with post polio sequelae. We hear on the news about Covid fatigue. I found the following that I thought was worth including in this newsletter.

YOUR COVID RECOVERY - Excerpts

What is Fatigue? We are all familiar with the feeling of fatigue after exercise or a long period of concentration. Sometimes, however, fatigue can be felt in a way that does not seem normal. Despite resting, and a good night’s sleep, fatigue occurs after minimal effort, is prolonged and limits your usual activity. It can leave people feeling dull and finding it difficult to concentrate and recall memories.

Fatigue is very common after viral infections, such as COVID and normally it settles after 2 or 3 weeks. However, in some people it can linger for weeks or months.

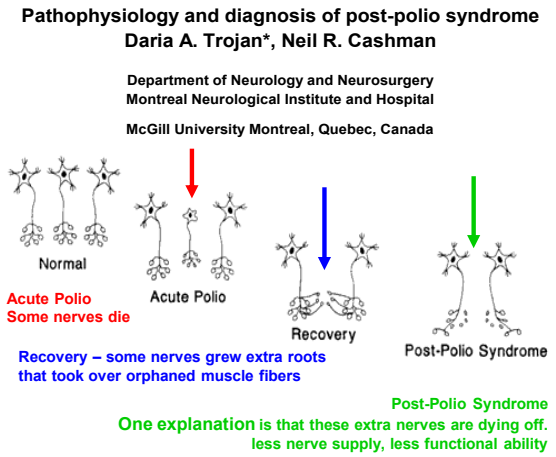
What can I do about Fatigue?

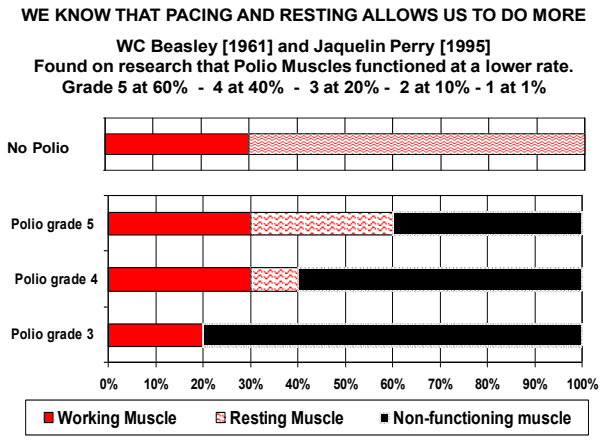
Recognise that the fatigue is real and be kind to yourself. Explain to your family, friends, and colleagues at work the impact the fatigue is having. Because fatigue is invisible, sometimes it is not properly understood. Until it is experienced it can be hard to understand the impact of fatigue and how debilitating it can be.

Plan, Prioritise and Delegate

- **Plan** each day in advance so that you can do what you need, and consider what can be delegated to other people. Build a regular routine, and try to avoid ‘boom and bust’ behaviour, where you are very active on ‘good’ days and then feel exhausted the following day. An activity diary can help with this.
- **Prioritise.** You can also decide which activities that you are doing are most important to you. If this is a task which is very important do it when you have the most energy. If they are not important, but ‘have to be done’ can you delegate them?
- **Delegate.** Think about areas where you can save energy, for example, online shopping rather than a trip to the supermarket, or cooking at the weekend for the week ahead when you are busy. Finally, make sure you are doing some things which are enjoyable, such activities can be energising. www.yourcovidrecovery.nhs.uk/managing-the-effects/effects-on-your-body/fatigue/

Polio Survivors have to take this further due to the fact that the polio virus killed some of our muscles nerves. Our marvellous recovery system where the nerves that did not die growing extra axonal sprouts to take over some of those killed muscles fibres and one explanation that these extra nerves are now dying off through age/overuse. Plus the NHS time constrained examinations where our polio muscles are often only tested a single time and most are not aware of our reduced available resting muscle.





We can manage our fatigue and get much more out of life!

Thousands of us that pace and rest all our activities and use any aid or assistive device plus the help of others for part or all of energy sapping tasks acknowledge this was not easy to read or accept at first. However, the most often made comments to PPS Groups is “I wish I had listened to you earlier because I now have less pain and fatigue and get more out of life.”

You can see from the right hand chart on the bottom of previous page that we do not have as much resting muscle to take over when the part of the muscle being used needs a rest. If we do a bit of an action and then rest we allow the working part of our muscle to rest and recover. **Pace and Rest**.

Aids and Equipment and Accepting Help. In 1996 I had the following conversation with a rehabilitation registrar. “Who wrote this article in the Linc-Pin?” I proudly told him I had written it and his response “then why are you not taking your own advice?” I replied, “Oh, I am not there yet” and he said, “Yes you are and you have been for some years.” March 16th 1997, my 50th Birthday my first electric scooter was delivered and I had to ride it up and down the street to test it out and I felt awful. However, I can tell you that in the last 24 years and thousands of miles my scooters have been to castles, museums, state parks, PPS conferences, antique fairs, local high street, etc. all impossible without electric wheels. Gradually over the years I have added many more energy saving items . For over ten years through direct payments have employed carers for some hours. The first time I saw Richards male carer take my undies out of the dryer I nearly died. It took a year of getting to know him before I told him. He knew us well by then and replied “I have a wife and daughter and know all about knickers mind you yours are twice the size of theirs”. I burst out laughing the best medicine ever and still chuckle to this day when telling this story.

Using Energy Tokens to plan your life. Sadly there is no chart to share because this is individual to each person and it changes as the years go by. The first task is to write down all the activities that you do on an average day at home. This includes turning over in bed, getting in and out of bed, all activities in the bathroom, dressing, preparing food, eating and drinking, cleaning, and some basic exercise etc.

Now you have your list you have £10.00 worth of Energy tokens to share amongst those tasks. It can take a few weeks to tweak it but you soon have a rough idea how many pence you can allow for each task. Now more lists for all the possible extras, GP, Dentist and other medical appointments. Shopping, Family events and anything that you do extra to your average day list. These will also need allocating energy tokens. Unless you have allowed tokens for extra events In your main list then any amount needed over and above the £10.00 MUST come from not doing something the day/days before and doing less the day/ days afterwards.

Look at all the activities, think what aids, assistive devices, other ways of doing the action, getting a bit of help could reduce costs **allowing you to do more of what you enjoy**. We have a bathlift so we can lower it and wash our legs and feet, impossible sitting on a shower stool. We use flannels [wash rags USA] that as little towels to roughly dry hair etc. Next wrap ourselves in a large bath towel and go and sit in the lounge on electric rise/recline chair with a drink and drip dry.

Remember it is either do this or that not both. Overdoing brings more pain and fatigue. Life is more enjoyable if you spend your tokens doing things you really enjoy and want to do. The following chart is just a rough idea how to fit in going to a hospital appointment on Friday and a family event on Sunday.

Time	Thursday	Friday	Saturday	Sunday
7am to 9am	Get up and wash	Get up. Only wash the bit the doctors are going to look at!	Ger up and wash	Late morning
9am to 11am	Items for hosp appt	Rest	Lazy morning	Dressed and rest
11am to 1pm	Lazy day	Be driven to **hosp appt** and use elec wheels at hospital	Local shopping	Driven to event with electric wheels
1pm to 3pm	Lazy day	Have the **hospital tests**	Feet up at home	**Family lunch**
3pm to 5pm	Lazy day	**See consultant** back to car	Prepare for tomorrow	**Rest in chair & chat**
5pm to 7pm	Heat prepared meal	Driven home/stop eat in car	Heat prepared meal	**Family tea**
7pm to 9pm	Bath for hosp tomorrow	Go to bed and watch tv	Shower drip dry	Driven home
9pm to 11pm	Bed and sleep early	Go to sleep early	Watch TV in bed	Watch TV in bed
Token Total	**£ 7.00**	**£ 15.00**	**£ 8.00**	**£ 14.00**

Polio Myths and Half Truths by Dr Julie Silver

Julie K. Silver, MD, Medical Director, International Rehabilitation Center for Polio, Spaulding Rehabilitation Hospital, Framingham, Massachusetts Julie K. Silver, MD, is the medical director of the International Rehabilitation Center for Polio at Spaulding Rehabilitation Hospital in Massachusetts (www.polioclinic.org). She is also an Assistant Professor at Harvard Medical School and has published several books including the book Post-Polio Syndrome: A Guide for Polio Survivors and Their Families (Yale University Press). Dr. Silver's mother, uncle and grandfather all contracted polio in the summer of 1946. During her medical training, she worked with Lauro Halstead, MD, and they have worked together on polio-related projects

Myth #1: Some medications are bad for polio survivors and should be avoided at all costs!

Some medications are bad for polio survivors and should be avoided at all costs. Many polio survivors have read that some medication classes are bad for them – the most common I am asked about is probably the "statins" (e.g., fluvastatin, simvastatin, etc.) These are medications that end in statin and are used to lower cholesterol levels. The fear is that these drugs will cause muscle pain or weakness (a known side effect) and compound the weakness that a polio survivor is already experiencing.

Heart disease is the leading cause of death in men and women as they age. Stroke is a leading cause of further disability. Both conditions are directly linked with high cholesterol levels and "statin" drugs that reduce cholesterol are critical for many people in order to lower their risk of stroke and heart attack. But, why give a drug to a polio survivor that may cause him or her to become weaker? The answer is because it may save a life.

It is important to understand what the actual risk may be of developing musculoskeletal problems if you take a particular medication. For example, the drug Zocor (simvastatin) underwent fairly vigorous testing prior to it being approved by the Federal Drug Administration (FDA). More than 2400 people were tested on the medication.1 No one in the study knew if they were actually taking the drug (it was blinded), and the results showed that more people complained of muscular side effects when taking a sugar pill (1.3%) than when taking the actual medication (1.2%). The point here is that even if you do take simvastatin, there is nearly a 99% chance that you won't develop muscular side effects.

So, my advice always goes like this: talk to your doctor – the one who prescribed the medication in the first place. Ask him or her whether it would be okay for you to stop the medication for a period of time to see whether it is indeed causing you to feel weaker or more pain or whatever you are concerned about. A "drug holiday" is a good way to see whether you are actually experiencing side effects from a medication.

When you go off the medication, pay attention to whether you feel any different. If you do not, that medication is probably fine for you. Keep in mind that every drug has a huge list of potential side effects. This does not mean that you will experience them – it just means that in studies that were done on the drug, some people had these side effects.

At the same time, ask your doctor whether there are other alternatives that you can try – including medications and lifestyle changes. For example, exercise, smoking cessation and weight loss have all been associated with reducing cholesterol levels. Although I used the example of the statin class of medications, this advice applies to any medication that concerns you.

Myth #2: Polio survivors should rest, rest, rest!

This is another myth that has some truth to it, but taken to an extreme is dangerous. All bodies become extremely deconditioned without the constant use of the muscles. Even polio-weakened muscles can become weaker from disuse. Not using muscles results in weakness, and diminished endurance and cardiac fitness. If you are at complete bedrest, your muscles will lose 10- 15% of their strength per week.2 If you stay in bed for a month, you will have lost about half your strength. Muscles need to be contracted regularly in order for them to maintain their size and strength.

On the other hand, it is important to note that the opposite of disuse – overuse – can also cause further weakness in polio survivors. So, the trick is to balance your daily activities with rest and also do an appropriate exercise program.

This sounds easier than it is, and I always recommend that people talk to healthcare professionals who are experienced in prescribing exercise programs for polio survivors. But some simple suggestions are as follows:

▪ Nearly everyone, including polio survivors, should exercise regularly.

▪ Exercise is not what you do in your daily activities, but rather is a set program that has a time limit and a certain number of exercises with a particular amount of weight or resistance that is used.

▪ Doing the same exercises over and over may lead to further weakness. Instead, exercises should be alternated regularly so all of the muscle groups are used and no one muscle group is overused. The concept of cross-training that is widely accepted in sports medicine is what we promote at our center.

▪ Include some strengthening, range-of-motion, and aerobic exercises to be sure you maintain optimal fitness.

▪ If you experience pain or undue fatigue, check with your doctor. This generally means that what you are doing needs to be modified or even stopped altogether roughout her career.

Myth #3: Swimming is good for you.

If you love to swim, do it regularly, and have easy and safe access to a pool, then swimming probably is good for you and you should continue to do it. However, if you do not swim for exercise and you feel guilty about it, then let me relieve you of your guilt – because swimming can be dangerous for your health.

Famous polio survivor, Franklin Delano Roosevelt, loved the buoyancy of water and the freedom it gave him to move his paralyzed body. The fact that much of his swimming was done in the beautiful Warm Springs, Georgia, only added to the benefits he received from this exercise. But swimming is not for everyone and there are some good reasons why you might not want to swim.

First, getting ready to go swimming is a lot of work. For most people swimming involves many or all of the following steps:

- Locate your bathing suit and towel.
- Go from your house to your car.
- Drive to the pool.
- Go from the parking lot to the locker room.
- Change into your bathing suit.
- Go from the locker room to the pool.
- Swim.
- Go from the pool to the locker room.
- Change out of your bathing suit.
- Go from the locker room to your car.
- Drive your car home.
- Go from your car to your house.
- Hang your bathing suit and towel up to dry.

Of the 13 steps I listed, only one of them involves the "exercise" of swimming. But, in order to get that exercise, you must do at least 12 other things that may just serve to wear you out. So, although I am a huge advocate of exercise that promotes cardiovascular fitness for polio survivors (keep in mind that post-polio syndrome is disabling, but cardiovascular disease kills more middle aged and older people than any other condition), swimming is a lot of work.

Second, you may be at risk to fall as you do these 13 steps. In one study, 46% of polio survivors noted that walking outdoors was difficult.3 In another study, 82% of polio survivors reported increasing difficulty with walking.4 Yet another study revealed that 64% of survivors reported falling at least once within the previous year and of this same group, 35% reported they had a history of at least one fracture due to a fall.5 Given these statistics, the number of steps it requires to go swimming (often both literally and figuratively) and the likelihood that there may be some slippery surfaces in the locker room or around the pool, it is easy to see how someone might fall and sustain a serious injury while going swimming.

I think it is really important to not discourage anyone from exercising in a safe manner and swimming can be a great exercise for polio survivors. But, it is not a great exercise for ALL polio survivors. If you love to swim and you can do it safely, then definitely continue. But, if you find yourself overly fatigued after swimming, or if you think you are at risk to fall and have a serious injury then consider other exercise options.

References

1. Physicians' Desk Reference. (2002). (pp. 2222-2223). Montvale, NJ: Medical Economics Company, Inc.
2. 2. Rehabilitation Medicine Principles and Practice. (1993). DeLisa, J., & Gans, B. (Eds.) (p. 689). Philadelphia, PA: J.B. Lippincott Company.
3. 3. Nollet, F., Beelen, A., Prins, M.H., et al. (1999). Disability and functional assessment in former polio patients with and without post-polio syndrome. Archives of Physical Medicine & Rehabilitation 80, 136-143.
4. 4. Halstead, L.S., & Rossi, C.D. (1985). New problems in old polio patients: Result of survey of 539 polio survivors. Orthopedics 8, 845-850.
5. 5. Silver, J.K., & Aiello, D.D. (2000). Abstract: Risk of falls in survivors of poliomyelitis. Archives of Physical Medicine & Rehabilitation 81, 1272

Has the billion dollar crusade to eradicate polio come to an end? | The BMJ.

BMJ 2021; 374 doi: https://doi.org/10.1136/bmj.n1818 (Published 29 July 2021)

The polio juggernaut, which has skidded past eradication deadline after deadline, seems to have finally run out of fuel, reports **Robert Fortner.**

As Covid-19 overran the world, the extensive surveillance and response capacities of the polio eradication programme pivoted towards this new threat. Now, in a surprise move by the World Health Organization, the reorientation looks permanent—perhaps ending a decades long, multibillion dollar crusade engineered by some of the most powerful actors in global health. WHO's reordering of priorities may also point to a reassertion of its primacy in setting and administering global public health policy.

Since the effort began in 1988 the Global Polio Eradication Initiative (Box 1) has pushed polio to near annihilation, pushing down cases by 99.99%. Perhaps tens of millions of people walking today can thank the GPEI. 1Two of the three serotypes of wild poliovirus have been declared eradicated worldwide, leaving only type 1, which has been cornered in just two countries, Afghanistan and Pakistan, which had a total of 140 cases last year.

Box 1 What is the GPEI?

The Global Polio Eradication Initiative (https://polioeradication.org) was created after the World Health Assembly's 1988 resolution to eradicate the disease. Its goal is to complete the eradication and containment of all wild and vaccine related polioviruses. It has six core partner organisations: WHO, Unicef, Bill & Melinda Gates Foundation, Rotary International, US Centers for Disease Control and Prevention, Gavi vaccine alliance.

However, the live oral vaccine used to accomplish these feats is double edged: the attenuated vaccine strains can revert to virulence, circulate, and paralyse. Afghanistan and Pakistan now report more cases of paralysis from vaccine derived polio than from the wild virus, and a massive outbreak of vaccine derived infections engulfs much of Africa, with more than 1000 children paralysed last year.2

The polio juggernaut skidded past its eradication deadline of 2000, the first in a series of such cycles. The GPEI has been perched, exhaustingly and expensively, at the cusp of success for years. In 2017, for example, Bill Gates predicted that "humanity will see its last case of polio this year."3 Instead, cases surged.

WHO's decision. With eradication forestalled yet again, and ubiquitous covid pressing hard, WHO decided in December last year to accelerate the transition of the polio programme's infrastructure. Instead of shuttering the GPEU and passing its staff and assets along to other programmes after eradication, WGO scheduled transition to occur before eradication, starting in January 2022.

At that point the "global" eradication initiative would operate fully only in Afghanistan and Pakistan. Other functions and responsibilities would be spun out into existing programmes such as routine immunisation, some landing within WHO, others absorbed and managed by member countries. The decision, reportedly originating from WHO deputy director general Zsuzsanna Jakab, effectively ended the GPEI as a monolithic entity possessed of all the means necessary to achieve eradication. (WHO did not respond to *The BMJ*'s request to interview Jakab.)

The breath-taking pronouncement drew relatively little notice, until WHO's regional office for Africa (AFRO) acted on it by firing some 500 polio programme staff. WHO must provide a contractually required nine months' notice to staff for termination. On schedule, beginning in March, nine months before the January 2022 transition, WHO AFRO's director general, Matshidiso Moeti, brought the axe down on polio programme staff, surprising GPEI's partner groups and donor nations.

In a statement a spokesperson for Canada's government said it was aware of the need to accelerate WHO's transition plan but that "we were not aware of all steps being taken in advance of implementation, including the termination of GPEI staff in the AFRO region." Canada, in the critical December 2020 timeframe, called for integration, increased accountability for the GPEI, and expanded donor representation.4 Canada was joined by Germany and Australia, the UK's Foreign, Commonwealth & Development Office, and the US Agency for International Development (USAID).

The Bill & Melinda Gates Foundation, topmost funder of polio initiatives and behind only the US government as the largest funder of WHO, reportedly had no idea that the firings were coming and quickly undertook damage control measures, dispatching an envoy to WHO AFRO's offices in Brazzaville, capital of the Republic of the Congo. The foundation did not respond to *The BMJ*'s request for an interview. WHO AFRO declined a request to interview Moeti.

"I think Dr Moeti's point is that primary care is the thing of the future or should be the thing of the present, with routine immunisation and other services all integrated into primary care," comments Liam Donaldson, chair of the independent board that monitors progress towards a polio-free world.5

"The direction of travel is very clear," says Aidan O'Leary, who started work as the new director of the GPEI after the December transition decision had been taken. "What we are looking at is really making sure that [polio] is part of integrated public health systems.. Building on that momentum is essentially what AFRO has done."

The momentum grew with the June release of a new strategic plan that heavily emphasises the integration of polio efforts into routine immunisation and primary healthcare.6 O'Leary says the polio programme is becoming "part of the more mainstream immunisation space," but this represents a massive turnaround, the programme embracing what had for decades been considered anathema. And integration, once seen as an existential threat, now promises to be the very means for achieving eradication. The world would have "gotten rid of this bugger a long time ago," says Zulfiqar Bhutta, a paediatrician at Aga Khan University in Karachi, Pakistan. But to succeed "you have to strengthen everything else," says Bhutta, and, until now, "none in the program wanted to do that."

The GPEI explicitly separated polio from routine immunisation because eradication requires very high coverage rates: 90% or more. Nigeria, for example, has extremely weak routine immunisation, with coverage of (maybe) 60%, far below the levels reached by the polio only campaigns that have successfully rid the country of the wild virus.7

A costly effort

However, as money is lavished on polio, millions of children, not just in Nigeria, have been left vulnerable to a slew of often deadly, vaccine preventable diseases. This unintentional harm was a "lesson learnt in the early 2000's" says Oliver Razum, an epidemiologist at the University of Bielefeld, Germany. Razum points back to India, where the "sheer number of [polio] doses that had to be distributed," twice a year, literally left no space in refrigerators for other vaccines against diseases such as measles. Razum wonders: "Would there have been other ways to spend that money which would have saved even more children from really nasty diseases?"

Polio funds from abroad also led to local brain drains—into eradication and away from local and locally funded health priorities. "Let's be very honest," says O'Leary, "member states have been demanding [an integrated approach] for quite some time."

Some eradication advocates privately voice a second, blatantly neo-colonial justification for the polio programme going its own way: foreign nationals, like many of those fired by Moeti, are critical to the successful operation of the polio only programmes, while countries and local staff are an impediment. O'Leary says that "functional reviews" might see some of the released staff in Africa landing new roles. But the power has shifted. "Whether it's going to be exactly the same people in all cases, that's going to be up to the regional and country teams," says O'Leary.

Eradication hawks are concerned or even incensed by accelerated transition and the new strategic plan. The calls for integration, primary healthcare, and a gender equity lens are, in the eyes of some, at best distractions from achieving eradication.

Donaldson observes that "it was always said that the transition cart would come after the polio horse," transition following, not preceding, eradication. Significantly, Donaldson also chairs the GPEI's Transition Independent Monitoring Board, which cautioned WHO over aspects of accelerated transition in its latest report.8 Although the pandemic is being invoked to justify transition now, Donaldson says, "The WHO emergency team is dominated by covid and wouldn't have time to deal with polio outbreaks. And the essential immunisation team, apart from all its other vaccines, is delivering covid vaccine. So it hasn't got space to do this either." The pandemic put polio efforts on hiatus for several months in 2020. More than 31 000 polio workers in more than 30 countries turned their focus to covid.9

The GPEI seems to be going ahead. "If you look at Sir Liam [Donaldson]'s report, he did call for bold decision making by WHO in terms of how to progress this particular agenda," says O'Leary, who argues that covid has created a transition opportunity.

Insiders suggest a stark division among the six core GPEI partners (Box 1) with WHO and Unicef driving accelerated transition. Holger Knaack, president of another partner, Rotary International, speaking before he left office last month, said the most important lesson from covid is that "we cannot indefinitely sustain the effort

to eradicate polio—we have been on the 'final stretch' for several years now." Rotary, the partner that arguably launched the eradication crusade, did not respond to *The BMJ*'s request to interview Knaack. The US Centers for Disease Control declined an interview request. A spokesperson for the Gavi vaccine alliance, the newest GPEI partner, said staff vacations prevented a response to emailed questions.

O'Leary describes GPEI partners' commitment to eradication as "pretty unequivocal." But the once indomitable tone now seems muted, with O'Leary adding a further caveat: "It's not just polio eradication. It's the broader commitment to what I would call global health initiatives."

Money problems alone are enough to sink eradication. As Gates said at the launch of the new strategic plan, "To be blunt, we are also closer than ever to losing the gains we have fought so hard for [if] GPEI doesn't identify substantial new resources soon." The UK has slashed its £100m pledge by 95%. Historically, the UK is the third largest financial backer of polio initiatives, making the blow demoralising as well as financially debilitating. The funding cut leaves a hole of at least 15% in the GPEI's budget. So far, no big donor has answered Gates's call.

Neither do countries have money to pay for transitioned pieces of the polio programme. "Basically, there is really no country equipped to take over funding in the transition sense," says Donaldson. "Africa, which is where most polio resources and staff are, was not nearly in a position to be able to do that." In what O'Leary describes as a "risk adjusted" approach, transition might be less radical than originally envisaged, with 10 high risk countries in Africa staying under GPEI's aegis and funding.

The two remaining endemic countries, Afghanistan and Pakistan, have large question marks next to them. NATO's withdrawal from Afghanistan further heightens unpredictability. The Taliban made large swathes of the population inaccessible to vaccinators but say they are not antivaccination. Their ban on house-to-house polio campaigns arose from concerns about how record keeping on inhabitants and vaccinators leaving suspicious looking chalk marks on buildings might have been contributing to deadly drone strikes. Expanded Taliban control could increase the reach of polio campaigns. Donor nations, however, may be more likely to impose sanctions than to fund projects that advance health in a Taliban controlled Afghanistan.

Pakistan: perplexities

Pakistan presents different difficulties. Absent from the global eradication effort, polio wouldn't rate as a priority. "Why would it be?" asks Bhutta. "You've got a country with an infant mortality rate that is among the highest in the region, a maternal mortality rate that's among the highest in the region."

Pakistan, where polio is not seen as a priority, is widely criticised for not being committed to eradication. Says Donaldson: "There is this magic thing called ownership. Everybody says you won't get eradication until the country owns the problem." But Pakistan is not a political monolith. Gates spoke to the prime minister, Imran Khan, about polio in late June, a kind of annual check in. Khan might be fully committed to polio eradication, but, notes Donaldson, "of the four [polio] affected provinces now, two are run by Imran Khan's party and two aren't."

Part of the animus behind transition is to apply pressure to Pakistan. According to Donaldson the country received $1.6bn (£1.2bn; €1.4bn) between 2016 and 2020, "and it bought more polio, not less . . . And that's back to the country ownership again. Pakistan can't just sit there accepting the money and then not perform." Polio insiders cite numerous shortcomings, such as falsified coverage data and inconstant progress in which hard fought gains later slip away.

Pakistan has in fact mounted wave after wave of polio vaccination campaigns but with the result that communities became tired of it. "They weren't just rejecting the vaccine," says Donaldson, "but were completely hostile to it because it was seen as the only thing that the government was trying to give them."

Expansion and integration of health services beyond cheap polio vaccines costs money and takes time. And GPEI has neither. The Gates Foundation, which has a larger footprint in Pakistan than WHO, according to Bhutta, is also growing "increasingly frustrated by the lack of progress." They are tightening the financial screws. "Their model is very much shifting from direct grant support to just making money available," through debt financed by development banks.

Eradication but not as we knew it

Even if we bravely assume adequate funding, would integrated health service delivery also deliver eradication? If efforts broaden to encompass vaccinating against more diseases and, sometimes, to health services beyond vaccination, will eradication get lost? Integrated delivery has "not ever really been tested for an eradication programme," says Nicholas Grassly, an epidemiologist at Imperial College London and an independent adviser to GPEI. The only successful effort to eradicate a human disease came against smallpox (box 2). "Smallpox eradication was very much a vertical programme," Grassly notes, while O'Leary, perhaps forgetting his endorsement of integration, still says that to achieve eradication "you have to remain focused, ruthlessly focused."

SHORT HISTORY OF ERADICATION.

1909: Hookworm. The Rockefeller effort to eradicate hookworm focused on treatment rather than conditions of rural poverty, such as lack of shoes and open defecation, that enabled transmission. Hookworm Is still found in the UK. 10 The Gates Foundation has funded research into a vaccine.

1915: Yellow fever. The Rockefeller Foundation next turned to yellow fever, breaking new ground by funding research into a vaccine. Eradication efforts focused on eliminating the breeding grounds of the mosquito vector and dramatically drove down yellow fever in the Americas.11 In 1932 came discovery of an animal reservoir, monkeys, effectively ending eradication.12

1952: Yaws. WHO and Unicef pursued eradication of yaws between 1952 and 1964, achieving a 95% reduction in caases. 13 The yaws project was integrated into primary healthcare as a way to get to zero

1967: Smallpox. Smallpox is the only human infectious disease to have been eradication. The effort officially began in 1967, and the last case was isolated in 1977.

1955: Malaria. WHO's attempt to eradicate malaria, mainly relying on DDT to kill mosquitoes, was beset by problems, notably the evolution of resistance to DDT. The effort sputtered, ending in1970. 14 Malaria resurged in many countries where people no longer had any immunity, resulting in severe illness and death, a still remembered instance of how eradication failure did public health harm.

1980: Guinea worm. Guinea worm eradication, like polio, has reduced cases by 99/99%. But in 2012 animal reserves began to be discovered. Efforts continue, but in 2020, besides 27 human cases in six countries, Chad reported 1507 infected dogs and cats and Ethiopia four infected baboons.

2007: Malaria revisited. In 2007 The Gates Foundation unilaterally shifted malaria policy away from control to eradication at the same time it jumped behind polio eradication with a $700m commitment.

Amid the great flux a paper entitled "Polio eradication at the crossroads" appeared at about the same time as the GPEI's new plan. The authors, including long-time polio researcher Konstantin Chumakov, suggest that eradication of all poliovirus from the planet has never actually been possible.15 The reasons include the likelihood of containment breaches of the virus kept in scientific facilities and the ability to synthesise polio.

The problems aren't new, but the authors use them as the basis for a new policy direction: "The objective of our efforts should be to eliminate the disease, not the virus." We can still "eradicate polio" because in lay terms both the disease and the virus go by the same name. The means proposed, much as envisaged in the new polio strategic plan, are "global immunisation programmes."

Bhutta says that GPEI "may need to call the new reality the new eradication."

Footnotes Competing interests: I have read and understood BMJ's policy on declaration of interests and have no conflicts of interests to declare. Commissioning and peer review: Commissioned; not externally peer reviewed.

REFERENCES

1. Centers for Disease Control and Prevention. *Polio.* https://www.cdc.gov/globalhealth/newsroom/topics/polio/index.html
2. Global Polio Eradication Initiative. Vaccine-derived polioviruses. https://polioeradication.org/polio-today/polio-prevention/the-virus/vaccine-derived-polio-viruses.
3. Sipherd R. Bill Gates: For polio the endgame is near. CNBC. 2017. https://www.cnbc.com/2017/10/24/bill-gates-humanity-will-see-its-last-case-of-polio-this-year.html.
4. Global Polio Eradication Initiative. Meeting of the Polio Oversight Board. 2020. https://polioeradication.org/wp-content/uploads/2021/02/POB-minutes-20201218.pdf.
5. Global Polio Eradication Initiative. Independent Monitoring Board. https://polioeradication.org/who-we-are/governance-and-structure/independent-monitoring-board.
6. Global Polio Eradication Initiative. GPEI strategy 2022-2026. https://polioeradication.org/gpei-strategy-2022-2026.
7. Gavi. Nigeria. https://www.gavi.org/programmes-impact/country-hub/africa/nigeria.
8. Polio Transition Independent Monitoring Board. Navigating complexity: adapting to new challenges on the journey to a polio-free world. Jan 2021. https://polioeradication.org/wp-content/uploads/2021/02/4th-TIMB-Report-Navigating-Complexity-20210131.pdf.
9. A multibillion-dollar plan to end polio, and soon. *New York Times*. Jun 2021. https://www.nytimes.com/2021/06/09/health/polio-eradication-plan.html.
10. Whitehead N. The US thought it was rid of hookworm. Wrong. National Public Radio. https://www.npr.org/sections/goatsandsoda/2017/09/12/550387650/the-u-s-thought-it-was-rid-of-hookworm-wrong?t=1626446377115.
11. Henderson DA. *A history of eradication—successes, failures, and controversies. Lancet2012;379:884-5doi:10.1016/S0140-6736(12)60381-X.*
12. Fenner F. *Candidate viral diseases for elimination or eradication. MMWR1999;48(SU01):86-90.*
13. Asiedu K, Amouzou B, Dhariwal A, et al. *Yaws eradication: past efforts and future perspectives. Bull World Health Organ 2008;86:499-499A. doi:10.2471/BLT.08.055608. pmid:18670655*
14. Slutsker L. Malaria: past, present, and future. https://www.cdc.gov/grand-rounds/pp/2010/20101118-presentation-malaria-eradication-H.pdf.
15. Chumakov K, Ehrenfeld E, Agol VI, Wimmer E *Polio eradication at the crossroads. Lancet Glob Health2021;9:e1172-5. doi:10.1016/S2214-109X(21)00205-9. pmid:34118192*

POLIO GROUPS - ONLINE SUPPORT

During the pandemic polio support groups from around the world have been turning to offering digital/virtual support. PA Polio Survivors Network have compiled a very useful webpage. We've converted the times for your information (information taken from https://www.papolionetwork.org/support-group-zoom.html). Not all meetings are each week so please check with the group contact.

The UK times are approximate – **please check times and how to access details with the organiser** also a handy time zone converter is here https://www.thetimezoneconverter.com/

This list is not exhaustive, other groups may exist in your local areas too.

DAY	GROUP	UK TIME	GROUP DETAILS
Sun	Nebraska Polio Survivors	8.00 pm	npsa.org@hotmail.com www.nepolioorg.ipage.com/
Mon	Polio Quebec - adapted Yoga	8.00 pm	monaarsenault@gmail.com association@polioquebec.org www.polioquebec.org/eng/
Tues	Polio Quebec	12.00 midnight	monaarsenault@gmail.com association@polioquebec.org www.polioquebec.org/eng/
Wed	March of Dimes Canada	7.00 pm	bstupar@marchofdimes.ca www.marchofdimes/ca/enca/programs/postpolio
	Marin County Polio Survivors	9.30 pm	FrancineAllen@comcast.net
Thurs	Boca Area Post-Polio Support	6.00 pm	bappg@aol.com www.postpolio.wordpress.com/
	Marin County Polio Survivors	9.30 pm	FrancineAllen@comcast.net
Fri	Polio Survivors Network	Varies	info@poliosurvivorsnetwork.org.uk
Sat	Atlanta Post-Polio Association	7.00 pm	nicolsw@locinc.com appaemail@gmail.com
	Land of the Sky Post-Polio Support	5.00 pm	emcanallen@gmail.com
	Polio Support Group San Gabriel Valley	6.30 pm	hopemle@juno.com www.facebook.com/1ppssgvwie/
	World-Wide Fellowship of Polio Warriors	11.00 am 5.00 pm	peter@poliowarriors.org www.poliowarriors.org/

Polio Australia (steph@polioaustralia.org.au) please contact for information of events

Polio Survivors Ireland provide a telephone conference (fsw@ppsg.ie)

Post-Polio Health provide ideas for support group discussions (info@post-polio.org)

Microsoft Teams

zoom

Management Committee [Trustees]

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

Trustee - Vacancies please contact Toni for more information

Operations Team
Phone Enquiries - Hilary Boone **- 01522 888601**
PSN Admin, Enquiries and Website - Toni Dunlop - psnadmin@poliosurvivorsnetwork.org.uk
Printing - Imprint Colour Printers, Lincoln

With grateful thanks to the generous legacy from Ms A Brown, we are able to make

membership **FREE** whilst our funds remain above £10,000.00

Website www.poliosurvivorsnetwork.org.uk
Write to us at PO Box 954, Lincoln, LN5 5ER, U.K.
Email psnadmin@poliosurvivorsnetwork.org.uk
Phone us on 01522 888601 - will ring you back when we access our messages

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

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

Donate by **cheque** to Polio Survivors Network

by **PayPal** to treasurer@poliosurvivorsnetwork.org.uk

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

giftaid it

The Gift Aid scheme. Charities can reclaim an extra 25% in tax on every eligible donation by a UK taxpayer. This 'transitional relief' does not affect your personal tax position. You must pay tax at least equal to the amount reclaimed on your donations in the current tax year. If you pay tax at the higher rate, you can reclaim tax relief on your gross donation at 20% (i.e. the difference between the higher rate of tax at 40% and the basic rate at 20%).If you have not filled in a current Gift aid form please contact us and we will email/post you one. Thankyou.

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

PatientPlus article POST-POLIO SYNDROME

Written by U.K. Doctors for Doctors

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

NB Respiratory and Sleep Problems Section very informative.

GOOD ANAESTHETIC ARTICLE - English version used by many PPS Groups

POLIO PATIENTS AND SURGERY - Information for health staff.

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

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

Printed copies on our headed paper with permission are available.

Editors Note: Articles from Polio Survivors and Health Professionals welcomed

August Virtual Coffee and Catchup

30 mins chat followed by 30 mins on a theme.

Friday 13th August 5:00 p.m. BST
The importance of keeping your weight down

Friday 27th August 11:00 a.m. BST
How to cope with disability

If you would like access details please email
info@poliosurvivorsnetwork.org.uk

POLIO SURVIVORS NETWORK

Support us with amazonsmile
You shop. Amazon gives.

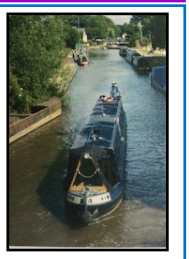
PayPal

Donate to PSN by using the **PayPal donate** link:
https://bit.ly/2KzyAyE

Polio Survivors Network are pleased to let you know about our new website. We hope you love it as much as we do.

We plan to add more content over the coming months and would love to hear your views as to what we should think about including.

Do let us know, please visit

www.poliosurvivorsnetwork.org.uk

© PHOTO CARDS by MEMBER VAL SCRIVENER
Sold in aid of **POLIO SURVIVORS NETWORK**
Pack of 5 cards **£3.95** including P&P
Order by **email** to vala.scrivener412@btinternet.com
Or **ring** Val on 01234 346 397