POST POLIO MATTERS

Polio Survivors Network Newsletter
January 2024 — Volume 11 Issue 4 of 12 [Edition 124]

Resilient Reflections: Finding Strength in Stillness for Polio Survivors

Take time to reflect on the year just gone and ponder the year ahead.

Find strength amidst the unique challenges faced by polio survivors.

Enjoy the shared practical insights and experiences from

our amazing polio survivor community.

[Lincolnshire
Post-Polio Library
100+ articles]

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

Donations and Charity Incentives Paid

(since last newsletter)

Donation from J & E P	12.50
Estate of AB	40.30
Donation from AJ	30.00
PayPal Giving Fund	4.38
Donation from JS	30.00
Sale of Photocards MH	12.00
Sale of Photocards HB	26.50
Total	**£155.68**

PayPal

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

This publication is provided free thanks to the generous donations of our lovely members.

Thank you so much!

Editorial Usually by Hilary Boone

Unfortunately Hilary has been unable to provide her full editorial for this edition of Post Polio Matters, we hope she is able to be back to the keyboard for our next newsletter and that you enjoy our shortened version. We send our love to both Hilary and Richard at this time.

A few reflective words from Hilary: I would like to thank my husband Richard for all the support he has given me since we met online on the SJU Polio List in 1997.

I flew to Florida on 20th May 2000 and we travelled in his truck up to the GINI Conference in St. Louis not far from where he was born and had his polio operations.

We have been together ever since. First it was six months in the UK and six months in America. Without meeting him I would not have been able to attend so many PPS conferences in the USA. We married on 25th March 2006 and moved permanently to the UK in 2010. We have attended many Polio Meetings in the UK since then.

Our main hobby was re-enacting pre 1840 American Pioneer Times. We camped out about 30 days a year at three events in Florida, it was great fun sleeping and living in a tent. We also camped in the UK with the British Westerners Association near Holbeach.

<u>MESSAGE FROM OUR CHAIR</u> … it's January 2024 !

These months aren't my favourite, given the weather and short days. I also caught polio in the first week of January 1956 aged 5, with only one term at school under my belt, or is it cap! I didn't return for another two years. So much for polio being 'the summer plague'! We maybe share various experiences as children who succumbed to polio or, as I did the bulbar form, and so being in an iron lung, paralysed, unable to swallow, breathe, or move. We all experienced that schism in the fabric of our lives as well as our parents, siblings and friends to varying degrees.

The child before and the child after polio, rarely talked to one another. I didn't often look back and long to be the adult version of my physically able, bright, risk-taking young self. I even think I may have had an early demise, given my propensity for risk taking, much to my parents' terror. As a small toddler gone missing, I was once found alone, crawling along the top of an 8-foot brick wall and when on my grandparents' farm in Goxhill, North Lincolnshire I enjoyed climbing on the haystacks, a totally forbidden activity, given the dangers of falling between the bales and not being found or heard. Just two of many examples of my reckless, or was it adventurous early self? Perhaps learning to breathe, walk, talk and even eat again in a new way, with a new body for me, was just another adventure. Of course, it involved nearly 2 years of hospitals, away from my parents, my home, my friends and my former life and world. The truth is, as some of you might empathise with, I never did return as that 5-year-old Simon, and whilst everything and everyone was the same, I was not. The buildings, my school and outward surroundings were unchanged, as was my bedroom, but all seen through a different lens and a different Simon.

I was now a 7-year-old with all the experiences of those two years. I had seen, felt, struggled and confronted things that my peers, my teachers and many around me had no concept of. So it wasn't just my paralysis or physical impairments and care needs that were in focus, I felt older, more mature in my head and yet also young and different from my peers. I appeared be just a small disabled, or rather 'crippled' or 'handicapped' child, as they said then. I fitted the 'spastic society (sic)' collection boxes child in callipers outside high street shops. I never liked them and yet was fascinated by them. A small note here, I threw out my callipers when I got home and adjusted to falling - a lot. This wasn't ideal as with paralysed arms, after my knees my head was the next thing to hit the often concrete ground, as the stitches, scars and my poor parents nerves could attest to.

I am now ageing with PPS issues rapidly catching up with me and living with prostate cancer for the last 4 years. I do now indulge in thinking of how I was shaped by fate and a particular form of polio, and how I relate and shares things with that pre-polio 5 year old Simon, who is no doubt still there inside me after all this time.

Thank you for reading and if there are any thoughts of reflections that this has triggered please feel free to share here, or privately to me or for the next newsletter.

Simon Parritt, ***C.Psychol, AFBPsS, MSc, BSc (Hon), BA***
Chartered Psychologist. HCPC Registered Counselling Psychologist
Chair Polio Survivors Network
simon.parritt@poliosurvivorsnetwork.org.uk

Do dogs get better health care? by Verite Reily Collins

Fido doesn't have to wait for an appointment

If your dog is sick, how long does it wait to see the Vet? Last time I had a sick dog, I phoned the vet and was told "bring him in this afternoon". I had just come out of hospital, and as the Receptionist fussed over him, I thought how I would have liked a touch of the same TLC. During the consultation, the vet told me " I need to take a blood test" and I groaned.

Whilst in hospital, it had taken 18 hours of painful jabs before nurses managed to get blood out of my shell-shocked veins. I came out looking like a junkie, with bruises up and down my arm. How on earth would the vet manage?

There was a click as he dropped a blood-filled syringe into the dish. "All done", he said, as my dog wagged its tail. "How did you manage that?" I gasped, relating what I had experienced in hospital .

"Ah" said the vet, "you have to remember if we don't do this correctly, our patients bite".

Point taken. So next time …….

If you have a sick dog, would you meekly accept a Receptionist telling you "the first appointment I can offer is in 3 week's time"?

No – if we were told this when we phoned a vet's surgery, we would be up in arms on behalf of our pet, Yet we meekly accept it for ourselves. When Prof. Thomas, a Consultant Surgeon, talks about "fortress surgeries", I know exactly what he means. If I phone the vet for an appointment, one of the girls talks cheerfully, asks how the dogs are, and sounds totally sympathetic when I say one is sick.

Phoning my GP, the Receptionist is totally disinterested, and when offering me a long-distant appointment, this is done with a 'take-it-or-leave-it' attitude. Of course I have to pay up front to see the vet (£25 for a puppy check, £45 for a consultation for my dogs), but we all pay for the NHS – and apparently our GPs are the third-highest paid in in the world (average £100,000 pa) after USA and Germany.

As Prof. Thomas writes, "despite valiant efforts of some GPs … they have been severely criticised for their performance during the pandemic". Come to think of it, one hasn't heard of any vets insisting on telephone appointments – Fido wouldn't stand for that!

Perhaps because we have to pay for Fido to see his vet it makes for better service. If we aren't happy, we can complain to the receptionist. Yet when we go into our GP's surgery, can you imagine complaining to fortress reception, lined up behind the surgery desk, ready to repel boarders? I think not.

When I was a teenager one of my boyfriends had an eminent vet for a father. He looked after the Queen's horses and was often called abroad to examine famous racehorses. When I was not feeling too good, I frequently asked his advice, and remember him once saying "this works for Bovine Mastitis, so it should work for you". I knew I was in good hands as Liverpool General Hospital called him in whenever they had a case of Anthrax amongst farmhands.

So, next time I am told "the doctor can't see you until….." I shall seriously consider if it would be a good idea to speed things up and make an appointment with the local vet.

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

How to manage and survive with Post Polio in the latter years

Strength gradually decreases with advancing years, but this is even more pronounced with people who have PPS. A person who has had polio is already using their muscles at the optimum level and even a small loss of muscle can cause a significant effect. Walking with crutches or braces may tax whatever muscle strength they have, but losing even a small part of that muscle power may be more noticeable and enough to stop them from walking. That can be a drastic change in function.

One of the theories of increasing muscle weakness in PPS is that Polio caused the death of certain nerves and the muscles which have lost their nerve supply are taken over and supplied by surviving nerve cells. These nerve cells are doing extra work and are more vulnerable to overuse. This combined with normal aging has a dramatic effect on strength. It is therefore very important not to overuse polio effected muscles.

Strong muscles are needed to keep bones strong, and lack of muscle is almost always associated with thin fragile bones that can break more easily than normal bone. The terms osteopenia and osteoporosis are used to describe these weakened bones. The bones that can break most often are the vertebrae, the hip and the arm bones. Vertebral fractures are usually discovered when someone complains of back pain. Fractures in arms occur when a person is trying to protect themselves from falling using their hands. Hip fractures are also the result of falls. Preventing osteoporosis is vitally important, because immobilisation can lead to further weakness. There are several treatments available, Calcium tablets with vitamin D (Adcal), weekly Alendronate, or yearly infusions of Zoledronate are just a few. Smoking and drinking alcohol should also be avoided because they speed up bone loss.

PPS symptoms of abnormal fatigue, muscle and joint pain, new muscle weakness are often caused by many years of overuse. It is important to make changes in daily life to ensure preservation and protection of muscles and joints. The help of family members should be involved, as well as assistive devices, like callipers, and using a computer chair or hair dressers' stool to move around in the home, installing a stair lift and using electric scooters outside. It is also important to recognise that with decreased activity the amount of food intake should also decrease otherwise the increased weight will overload muscles and joints, leading to further fatigue, pain and muscle weakness. Exercise for weight reduction is not an option for those with PPS. The only option is reducing the food intake. Daily or weekly weight checks are important and a dietitian's help may be needed in the last resort.

Muscle weakness can also be the result of disuse. Too much sitting, being in a plaster cast after a fracture, being in bed with flu, after surgery or an illness causes deconditioning of the muscles. This happens more quickly with people who have PPS and they also recover more slowly than others with normal constitution. A gentle exercise program in a graduated manner can help recovery. The intensity and amount of exercise must be tailored to the individual as polio survivors are all different.

Polio survivors often have difficulty in tolerating cold temperatures especially in the extremities due to lack of muscle contractions leading to bad circulation. Several layers of clothes can help but only in the short term, until the cold air gets through. Massage is useful as it encourages the circulation, but care must be taken with heat sources to avoid burns. There are battery heated insoles that can be placed inside shoes or boots. They keep feet warm for several hours. There are also electrically heated foot warmers that can take booth feet and warm them up while watching the television. Once the feet get very cold the temptation to warm them up quickly by putting them into hot water must be avoided because it will result in nasty, itchy chilblains. I know from personal experience how hard it was to get rid of chilblains over many years. Once I had them, they kept coming back each winter.

By Zsuzsanna Snarey - *Polio Survivors Network Trustee*

Meal Substitute Idea

Next time you can't face the thought of spending time slaving over a hot stove, a Dietician suggested this simple milkshake, using Ovaltine or Horlicks as a meal substitute:

This makes a nutritious alternative to a meal, when you just can't face the thought of cooking. However, to ensure you get all your nutrients, eat some fruit and/or vegetables along with your milkshake . The old stand-by Ovaltine or Horlicks has lots going for it, and if you make the drink with milk, not water, it contains lots of protein. This drink can be made cold in the summer, or with hot milk in winter, and if you whizz it up in a food processor it's lovely and frothy.

Ingredients:

- 2 heaped tablespoons (30g) dried skimmed milk powder
- 5 heaped teaspoons (25g) Ovaltine Original Add Milk powder or 5 heaped teaspoons (25g) Horlicks Malted Food Drink powder
- 1/3 pint (180ml) hot or cold full-fat milk (or used skimmed or semi-skimmed if you prefer)

Directions:

⇒ Mix dry ingredients together in a glass
⇒ Gradually mix in hot or cold milk & stir well

This 220ml milkshake provides 320kcals and 17-19g Protein

Handy feature on Apple iPhone

You may be aware of the Health app on Apple iPhone. It can be very useful for adding an emergency contact and healthcare information. Here is a very brief guide to setting it up on your iPhone. These instructions are for iOS 17 so please see the Apple support website for other versions as some may vary a little.
For additional support see Apple's official guide: https://support.apple.com/en-gb/105072

Setup / Create your Medical ID:

- Open the *Health app*
- Tap *your picture* at the top right, then tap *Medical ID*
- Tap *Get Started* or *Edit*, then enter your information
- Under *Emergency Contacts*, tap *Add Emergency Contact,* then add your contacts. In some countries, after an emergency call ends your iPhone alerts your emergency contacts with a text message and sends your location (if available).
- Tap *Done* to finish

View your Medical ID:

- To view your Medical ID from the Home Screen, touch and hold the *Health app* icon, then choose *Medical ID*.

Don't Do This, Do That

by Millie Malone Lill

You know how we polio survivors are. We have overcome so much in our lives that we think we are invincible. Well, we are. Sort of. We need to know how exactly to play the game to insure that we win. It's not cheating! It's strategy. First we need to define the goal. To beat the Polio Dragon and finish the game as close to intact as possible, that's the goal.

Do Not: Try to downplay your level of disability to avoid making others uncomfortable. **Do:** Simply tell it like it is. “If I go shopping with you today and then out to lunch and maybe a movie after that, I will be in bed for two days. I would love to have lunch with you, though. Maybe we could have a pizza delivered.”

Do Not: Avoid asking for help when you need it. **Do:** If your store offers delivery, take advantage of it. If your neighbor is making a trip to the store and offers to pick up your needs, smile and say Thank You. You can call your order in, perhaps, so your friend doesn't have to do anything more than pick it up and drop it off for you.

Do Not: Get your feelings hurt when others do not understand PPS. I've had PPS for over 40 years and I still don't quite get it. **Do:** Explain in simple terms that you have a neuromuscular disability a little bit similar to MS. If they ask for details, say it is progressive but can be managed if you are careful. That's usually all it takes.

Do Not: Stress yourself by worrying about what other people will think if they see you using a walker, cane, crutches, wheelchair or whichever tool you need to live your best life. **Do:** Realize that what other people think of you is not your business and also that the chances are they aren't thinking about you in the first place.

Do Not: Beat yourself up by thinking of what you used to be able to do versus what you can do now. **Do:** Try to be grateful that at one time you could do all of that. Even able bodied people find that time and age take away some abilities.

Do Not: Waste time being angry or resentful at your disability. What good does that do? You will still be disabled, but you will also be angry and upset. **Do:** Find things in your life that make you happy. I highly recommend writing a gratitude list every evening. Every day contains something that you are grateful for if you take the time to look for it. I find ending my day with gratitude makes falling asleep much easier.

I'm no guru. I am an elderly woman dealing with PPS the best way I know how. Although having contracted polio 78 years ago, I have managed to have a pretty decent life. I try to find humor wherever possible and I maintain an attitude of gratitude. My Facebook friends have brought me comfort and joy as we share our lives, our sorrows and our triumphs. To me, the secret of beating that Polio Dragon is to thwart his attempts at making me miserable. I find things he can't control and my life is a good one.

Global Polio Eradication Initiative (GPEI) – a brief review of 2023 and full focus on 2024

As the year draws to a close, efforts intensify against the virus in 2024

The Global Polio Eradication Initiative has two goals laid out in its current strategy: to interrupt all remaining transmission of endemic wild poliovirus type 1 (WPV1) and to stop all outbreaks of variant poliovirus type 2 (cVDPV2). 2023 was a critical year for progressing on each of these, and while our urgent and diligent work to end polio must continue into 2024, the GPEI achieved incredible things in the past twelve months.

Continuing work in endemic countries

Despite significant geo-political and environmental challenges in the two remaining WPV1-endemic countries, Pakistan and Afghanistan, the polio programme has continued to reach greater numbers of children with polio vaccines.

WHO Representative in Afghanistan, Dr. Luo Dapeng, vaccinating children against measles in a mobile clinic in Baba Wali Village of Kandahar province. © WHO/Afghanistan

Wild polio transmission was beaten back to just a handful of districts in eastern Afghanistan and the southern area of Khyber Pakhtunkhwa province in Pakistan. In both countries, efforts are increasingly focused on reaching and vaccinating the last remaining 'zero dose' children – children who have received no vaccines of any kind. The number of these missed children continues to dwindle, with the success of improved collaboration with the national immunisation program, new efforts like Pakistan's Nomad Vaccination Initiative and focused vaccination activities at border crossings between the two countries. Just one family of the virus remains endemic in each country, and coupled with this increasing geographic restriction, the situation resembles the end of wild polio eradication efforts in former virus hotspots like India, Nigeria and Egypt.

In addition, after a wild poliovirus outbreak that was confirmed in southeast Africa in early 2022, neither Malawi nor Mozambique has reported a WPV case since August 2022 thanks to a concerted subregional emergency response across five neighbouring countries. We are hopeful that this outbreak will be officially closed in the coming months, affirming that countries have what it takes to protect children from this devastating disease and keep wild polio out of Africa.

Progress on variant polio outbreaks

Thanks to the novel oral polio vaccine type 2 (nOPV2), strong political commitment and community-based efforts to reach more children with the vaccine, the number of cases of variant poliovirus type 2 (cVDPV2) continued to decline in 2023.

Nearly 1 billion doses of nOPV2, a comparably safe, effective, but more genetically stable version of the existing type 2 oral polio vaccine (mOPV2), have now been administered across 35 countries, protecting millions of children from illness and paralysis.

Emergency response to variant polio outbreaks is continuing, notably in the most consequential geographies for the programme—where children are at the highest risk of encountering and spreading poliovirus. In northern Nigeria, for example, variant polio cases have fallen by 90% since a peak in 2021, thanks to concerted commitment from government, unique community programs to improve the reach of vaccines and the extensive rollout of nOPV2. Across these consequential geographies, the programme will continue to focus on increasing access, acceptance and campaign quality, which have helped make incredible progress in Nigeria, and continue to innovate until we end polio for good everywhere.

Finally, In September 2023, after a massive vaccination response in the shadow of ongoing war, Ukraine officially stopped its outbreak of type 2 variant polio that began in 2021. New York, London and Jerusalem, where high-profile outbreaks began in 2022, have not detected the virus in recent months. Still, the emergence of polio in these areas is a reminder that as long as poliovirus exists anywhere, it is a threat to people everywhere.

nOPV2 Vaccination at Guilding Angel School Tunga, Minna, Niger. © WHO/AFRO

A global effort

Most importantly, thanks to the efforts of the GPEI and its partners, health workers vaccinated more than 400 million children in 2023, preventing an estimated 650,000 cases of paralysis from polio and saving the lives of up to 60,000 children. Building full, healthy futures was at the core of Rotary International's mission when it began this fight to end polio for good in 1985, and when the GPEI was launched in 1988—35 years ago.

This year, the Independent Monitoring Board (IMB) conducted a rigorous mid-term review of the GPEI's progress towards its strategic goals. This welcome counsel is already helping inform and guide the GPEI's own ongoing analysis and strengthening of its strategic approaches to achieve a polio-free world, as the programme published its initial response to the mid-term review, under the guidance of the Polio Oversight Board (POB).

Achieving and sustaining a polio-free world has proven harder – and taken longer – than anyone could have imagined. But making history is never easy, and we are confident that together we can eradicate a second human disease from this earth, and build stronger, more resilient health systems along the way.

2023 has firmly set the stage for success. With the complexities of the world today, this programme still inspires to bring about the very best in our humanity.

Thank you to all who have contributed to this effort so far and continue to do so. Let us double down and make the dream of a polio-free world a reality

https://polioeradication.org/news-post/gpei-a-brief-review-of-2023-and-full-focus-on-2024/

What Does a Person Experiencing Post-Polio Look Like?

A great resource listed by Polio Australia Inc and hosted on YouTube (*copyright Polio Australia Inc 2023)* This is the fourth video in a series of ten videos discussing post-polio conditions, this video presents:

- What features do and do not suggest a person has been affected by polio
- Visible and invisible signs and symptoms of post-polio
- Polio affected individuals may or may not identify as polio survivors
- Some individuals with a history of polio may not wish to share their experiences

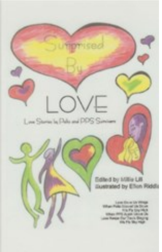
To watch go to: http://tinyurl.com/2ve8sbm3

Toni Writes …

How are you? I hope the start to 2024 has been ok for you. First of all, I want to say a huge thank you for all your kind donations and ongoing support. Having just completed the end of year financial report, it really it is clear to see that it really does make a difference to Polio Survivors Network. Thank you so much.

Talking of end of year reports, the 2024 Polio Survivors Network Annual Trustees Report (covering January to December 2023) is now available. Please contact me (details below) to request a copy. This report will also be discussed at the 2024 Annual General Meeting to be held in the summer.

As you will have seen we have included with this edition of Post Polio Matters, a tool which we hope will be useful for when you are attending appointments. We know how important it is to get the most out of every appointment. We would love to hear any feedback you may have.



In our last newsletter we featured a book entitled 'Surprised by Love: Love Stories by Polio and PPS Survivors' edited by Millie Lill and illustrated by Ellen Riddle. We have a copy available for our members and are also happy to post overseas (as we know our USA members may not have been able to order via the Amazon link in the last newsletter). Please contact me with your name and address if you would like this copy.

Please remember too that we have photocards available to purchase which will help raise money for Polio Survivors Network. We currently have two beautiful designs (Polio Survivors Network collaborated with a local photographer) available and will hopefully add more as sales grow. A6 size blank photocards £1.75 each or £6.00 for 5 (inc P&P). Please contact me to purchase or click this link for more information https://poliosurvivorsnetwork.org.uk/new/greeting-cards/

As part of our 'lives lived with healthcare lessons for the future' project we would like to ask our readers what legacy would you like polio survivors to leave? What would you like to let people know so they can learn from polio for the future? We hope we can include your comments in an upcoming newsletter.

Take care

Toni x

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

From our readers:

I hope this will be of interest to your readers. Hello, my name is Stuart Barnett. I was born in December 1946, I contracted Polio (then known as Infantile Paralysis) when I was 9 months old. I was living with my parents in a village called Navenby, near Lincoln.

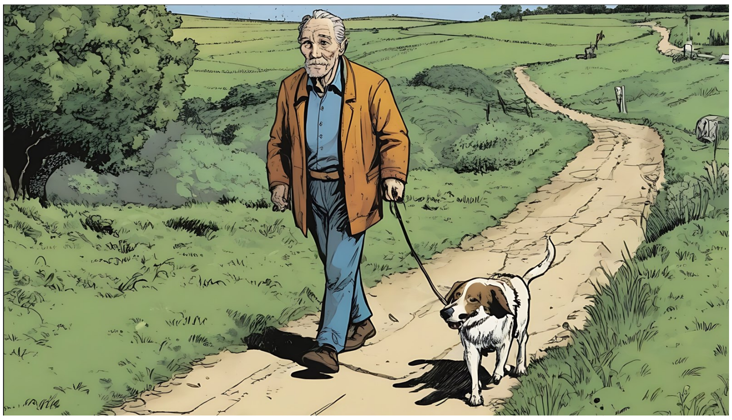
Polio left me with my left leg thinner and shorter than my right leg. My parents were told that I would never be able to walk, but after wearing callipers I eventually learned to walk although I had to wear a built-up shoe on my left foot, for all of my school life.

After leaving school I worked with horses and learned to ride. I then started a job as a Painter and Decorator and eventually started my own business. This I did for 37 years and finally retired at 67 years old and have been retired for 10 years.

I met my wife Susan and got married when I was 23 years old. We then had 2 children and now have 5 grandchildren.

I consider myself very fortunate as during all my working life I had no signs of Post Polio Syndrome. I led a very active life, both in my working life climbing ladders etc, and in my hobbies which included Fell walking in the Lake District, where I was able to climb many of the higher Lakeland Fells and also enjoyed playing tennis. I am now 77 years old and have no sign of Post Polio Syndrome. I am able to lead a very full life and still walk with my working Cocker Spaniels.

I consider I am very fortunate to have been able to lead such a normal life and enjoyed doing a physical working job and enjoy my physical hobbies. I sincerely hope not to be affected by Post Polio Syndrome in the future and to carry on with my Fell Walking and Dog Walking.



Wild poliovirus cases have decreased by over 99% since 1988,
from an estimated 350 000 cases in more than 125 endemic countries then,
to just two endemic countries, Pakistan and Afghanistan
(as of October 2023)
- World Health Organisation (WHO)

A couple of films worth watching …

Lives Well Lived

An inspirational documentary by Post Polio Victoria Inc. Australia featuring three polio survivors. It is listed by Focus on Ability Film Festival and hosted on YouTube. https://www.youtube.com/watch?v=aToqAEdzuYs

Hidden Figures in Polio History

We want to share with you a link to a film by a disability commentator and activist (listed by Rotary and hosted on YouTube). It explores the history of a hospital created for the black American community and we think you'll be interested to learn how advocacy played a key role in bringing it into existence. https://www.youtube.com/watch?v=GHH1CuyCHGY

If only it was as easy to create a medication to treat all of the symptoms of Post Polio Syndrome …

… as it was to generate these Artificial Intelligent (AI) realistic photos!

Managing Pain: Insights from the Polio Survivors Network Community

Being a survivor of polio can pose unique challenges and managing pain can become an important aspect of maintaining quality of life. Polio survivors, like anyone else, may experience pain for various reasons, but the likelihood of pain as a consequence of surviving polio is higher. Even if you've been diagnosed with post-polio syndrome (PPS), it doesn't always mean that the syndrome is the direct cause of the pain. There could be other reasons for the pain, and it's essential to explore and understand those factors to effectively manage and address it. An accurate medical assessment is needed - we know that this can be a challenge.

Members of Polio Survivors Network have shared their experiences on what has worked for them in managing their pain. Many agree that finding a careful balance between physical exertion, mental stress reduction, and using pacing and resting techniques when it comes to daily activities has been very beneficial.

Understanding the multifaceted nature of pain in polio survivors, here is a list of some of the practical tips reported by members which they have found to work for them:

- Moist Heat & Light Massage - Application of moist heat and light massage to alleviate
- tension in affected muscles.
- Cold Therapy - Use of ice packs on painful areas to reduce inflammation and numb localised pain.
- Chiropractor – For neck, back, or joint adjustments for improved musculoskeletal alignment.
- Acupuncture - Traditional acupuncture and electro-acupuncture (some have found just on the ear lobe has worked) for pain relief.
- Herbal Dietary Supplements – Members state use of ginger, pycnogenol (extracted from pine bark) and/or cayenne pepper. *As with any supplement, individuals should consult with their healthcare provider before using any supplement, especially if they have existing health conditions or are taking medications.*
- Addressing Sleep and Breathing Difficulties – ensuring enough sleep in the various stages required and ensuring proper oxygen intake.
- Assistive and Adaptive Aids – Using various aids to minimise stress and strain on muscles and joints.
- Anti-Inflammatory Drugs and Medications - Use of non-steroidal anti-inflammatory drugs (e.g. ibuprofen, aspirin) and prescription drugs for inflammation. Anti-depressant medications for nerve pain and sleep disturbances. Occasional and careful use of muscle relaxants (*these may increase fatigue and decrease muscle strength)*. HRT especially for individuals with low hormone levels post-menopause or hysterectomy. *Even if you're using pain relief medication, it's important to manage the pace of your activities to prevent excessive strain on your muscles and joints.*
- TENS (Transcutaneous Electrical Nerve Stimulation) machine.
- Referral by General Practitioner (GP) to a Pain Clinic

As ever, ensure that you always seek professional medical advice before initiating any changes to your healthcare routine. Every individual's health is unique and what works for one person may not be suitable for another. Your GP or healthcare provider can provide personalised guidance based on your specific health needs. They can assess you for any potential medication interactions or how any of your existing health conditions should influence your choice of pain management strategies.

More information on pain, medication and Polio Survivors:

- British Polio Fellowship
https://www.britishpolio.org.uk/_files/ugd/149bdd_044f059c9c5b4f29a7bd1ae8916b4d7c.pdf

- NHS Advice https://www.nhs.uk/conditions/post-polio-syndrome/

- Mayo Clinic
www.mayoclinic.org/diseases-conditions/post-polio-syndrome/diagnosis-treatment/drc-20355674

Once I Could Run

Polio Survivor Charles Mobley tells his story of resilience.

Embark on the captivating journey of 'Once I Could Run,' where you'll immerse in Charles's carefree childhood adventures in a quaint Mississippi town, sharing the impactful moments of his polio diagnosis and treatment in Warm Springs, Georgia. Witness his unwavering determination to conquer physical challenges, while applauding his notable business accomplishments, and join in celebrating his heartfelt personal milestones.

Once I Could Run is a remarkable evolution from marriage and parenthood to Charles's esteemed role as an engineering professor at UNC Charlotte.

Available to purchase on Amazon:

https://www.amazon.co.uk/Once-Could-Run-Charles-Mobley/dp/B0CL6NMRYL

Did you know? Squirrels are one of the most important animals for helping the spread of oak trees. They store acorns in the ground but only recover around 70 per cent of them, allowing the forgotten acorns to grow into healthy trees. The biggest species of squirrel is the Indian giant squirrel which grows up to 36 inches (1m) long. The smallest is the African pygmy squirrel which is a only 2.8-5 inches (7-13cm).

Useful Resources

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

Management Committee [Trustees]

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

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

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

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

Donate by **cheque** to Polio Survivors Network
by **PayPal** to treasurer@poliosurvivorsnetwork.org.uk
By **PayPal donate** link: https://bit.ly/2KzyAyE

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

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

PatientPlus article POST-POLIO SYNDROME
Written by U.K. Doctors for Doctors
http://patient.info/doctor/post-polio-syndrome
NB Respiratory and Sleep Problems Section very informative.

GOOD ANAESTHETIC ARTICLE - English version used by many PPS Groups

POLIO PATIENTS AND SURGERY - Information for health staff.
Lise Kay, MD, Surgeon PTU – Danish Society of Polio and Accident Victims
http://www.europeanpolio.eu/documents/13642_Polio_operation_eng_TRYK.pdf
Printed copies on our headed paper with permission are available.

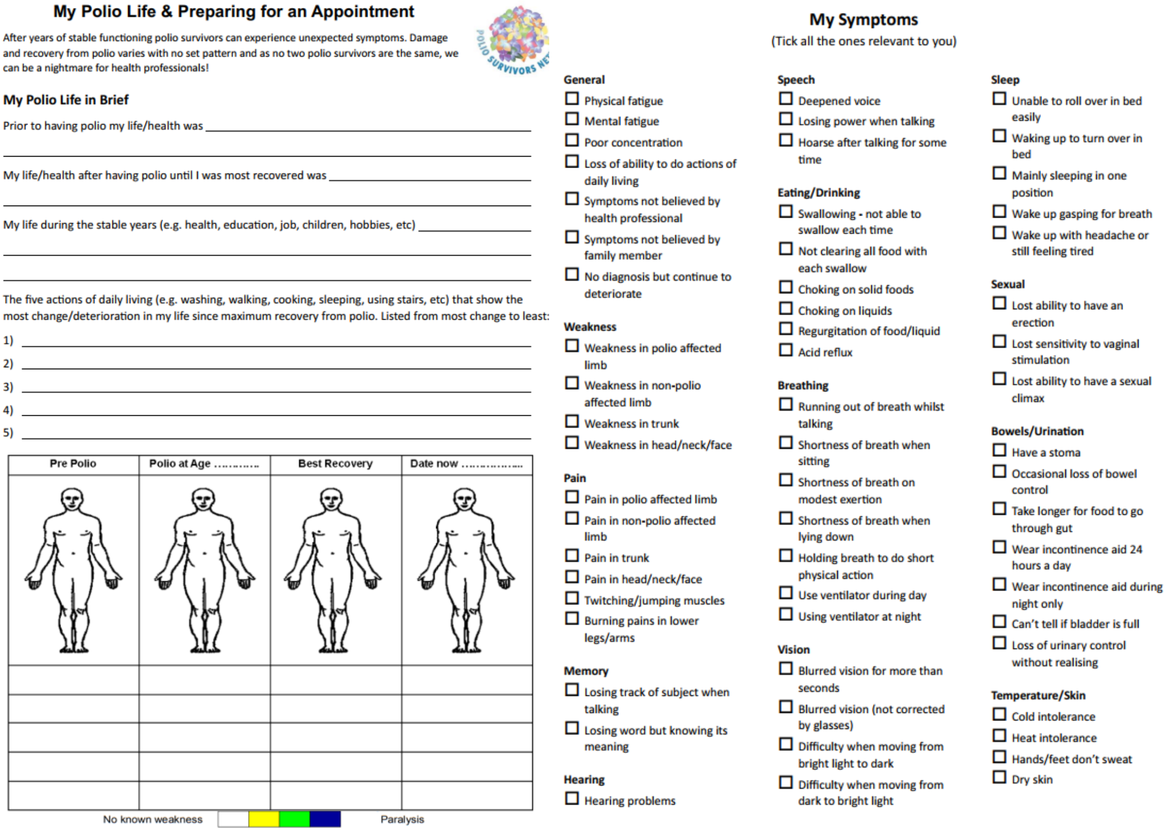
Editors Note: Articles from Polio Survivors and Health Professionals welcomed

A useful new resource

We know that getting the most from your health appointments is very important so we hope that our new tool will assist you.

A copy is enclosed.

If you would like further printed copies please get in touch - *see page 15*



My Polio Life & Preparing for an Appointment

After years of stable functioning polio survivors can experience unexpected symptoms. Damage and recovery from polio varies with no set pattern and as no two polio survivors are the same, we can be a nightmare for health professionals!

My Polio Life in Brief

Prior to having polio my life/health was ____________________

My life/health after having polio until I was most recovered was ____________________

My life during the stable years (e.g. health, education, job, children, hobbies, etc) ____________________

The five actions of daily living (e.g. washing, walking, cooking, sleeping, using stairs, etc) that show the most change/deterioration in my life since maximum recovery from polio. Listed from most change to least:

1) ____________________
2) ____________________
3) ____________________
4) ____________________
5) ____________________

Pre Polio	Polio at Age …………	Best Recovery	Date now ………………

No known weakness ⬜ 🟨 🟩 🟦 Paralysis

My Symptoms

(Tick all the ones relevant to you)

General
☐ Physical fatigue
☐ Mental fatigue
☐ Poor concentration
☐ Loss of ability to do actions of daily living
☐ Symptoms not believed by health professional
☐ Symptoms not believed by family member
☐ No diagnosis but continue to deteriorate

Weakness
☐ Weakness in polio affected limb
☐ Weakness in non-polio affected limb
☐ Weakness in trunk
☐ Weakness in head/neck/face

Pain
☐ Pain in polio affected limb
☐ Pain in non-polio affected limb
☐ Pain in trunk
☐ Pain in head/neck/face
☐ Twitching/jumping muscles
☐ Burning pains in lower legs/arms

Memory
☐ Losing track of subject when talking
☐ Losing word but knowing its meaning

Hearing
☐ Hearing problems

Speech
☐ Deepened voice
☐ Losing power when talking
☐ Hoarse after talking for some time

Eating/Drinking
☐ Swallowing - not able to swallow each time
☐ Not clearing all food with each swallow
☐ Choking on solid foods
☐ Choking on liquids
☐ Regurgitation of food/liquid
☐ Acid reflux

Breathing
☐ Running out of breath whilst talking
☐ Shortness of breath when sitting
☐ Shortness of breath on modest exertion
☐ Shortness of breath when lying down
☐ Holding breath to do short physical action
☐ Use ventilator during day
☐ Using ventilator at night

Vision
☐ Blurred vision for more than seconds
☐ Blurred vision (not corrected by glasses)
☐ Difficulty when moving from bright light to dark
☐ Difficulty when moving from dark to bright light

Sleep
☐ Unable to roll over in bed easily
☐ Waking up to turn over in bed
☐ Mainly sleeping in one position
☐ Wake up gasping for breath
☐ Wake up with headache or still feeling tired

Sexual
☐ Lost ability to have an erection
☐ Lost sensitivity to vaginal stimulation
☐ Lost ability to have a sexual climax

Bowels/Urination
☐ Have a stoma
☐ Occasional loss of bowel control
☐ Take longer for food to go through gut
☐ Wear incontinence aid 24 hours a day
☐ Wear incontinence aid during night only
☐ Can't tell if bladder is full
☐ Loss of urinary control without realising

Temperature/Skin
☐ Cold intolerance
☐ Heat intolerance
☐ Hands/feet don't sweat
☐ Dry skin

Help PSN raise funds

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