



# POST POLIO MATTERS

Polio Survivors Network Newsletter  
NOVEMBER 2020 Volume 10, Issue 5 of 12 [113]  
n.b. Volumes 1 to 6 published under the name LincPIN

## A health professional asks you "Can you get up a flight of stairs?"



Polio Survivor  
typical response  
is YES.



But did that answer paint the same picture?



Lincolnshire Post-Polio Library  
100+ articles

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

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*A huge thank you for all the following donations received:*

<b><u>Donations</u></b> (since last newsletter)			
<b><u>September</u></b>		<b><u>October</u></b>	
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		Anonymous (via PayPal Giving)	£13.75
		A Jackson donation	£50.00
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<b>Total</b>	<b>£5.00</b>	<b>Total</b>	<b>£103.75</b>



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## *Editorial by Hilary Boone*

I cannot believe it is already December. What a year this has been for us all both physically and mentally due to Covid 19. I don't know how you have fared with the paperwork coming from the government and your local authority. Ours has been weeks late and pages in government speak and makes me wonder are they really trying to help us? Our latest letter from the local authority informing us what to do from the 5th November was dated the 9th and delivered on the 21st.

For over 25 years of attending meetings I, and colleagues, have asked for the baseline paperwork to be in simple plain English and not government speak. There are other versions that are needed for those with visual, hearing, learning and other language issues. I love the letter that ends if you require a copy in another version please get in touch but how would you know?

I find as we get older with Post Polio issues we modify how we do actions bit by bit as the need arises. Every change becomes our new normal. Richard has Post Polio Syndrome and Parkinsons [6 others local to us have both and we know more across the world] and I regularly update his What You Need To Know About Me sheets and for Carers and any other professionals who need to know provide a regularly updated daily plan of his needs. I had not realised how out of date my information was till I ended up in hospital for a couple of days. I had dull pain over one eye and when I looked at a face I could not see the right side of their face. Thankfully it was not a stroke.

Once home I realised that some of the medical information on my files and that I had provided had not painted the same picture. E.g. My kyphosis [forward bend of my spine] that has got worse was not seen when sat on my scooter or lying on a bed. I have written up what I realised after I left hospital hoping that it will help others [[Page 14](#)].

The most important facts that we need to provide that will help those assessing us and get our muscles graded more specifically are explaining how we do actions now compared with how we used to do them. Ask why have you had to change the way you do the action. In 2004 I asked why I was now scrambling eggs with elbow rotation and it was found that the supinator muscles in my wrists were very weak. This has not been picked up the normal three tests of arms, grip pull and push against me. How many actions can you do once, twice, a few times but then the power drains? How many times have you answered YES you can do an action but not thought to tell the assessor how you do it? Please tell it like it really is.

I would also add that trying any equipment now that you might need in the future so you know how it works and how it feels and what it does can be a great help. Richard practiced transferring with his arm in a sling prior to rotator cuff surgery in 2001 and that made a huge difference post surgery. I have an electric scooter but have borrowed Richards wheelchair a few times. I badly sprained my ankle a few years back and spent a week pushing myself with the other foot round the house in a manual chair. I have now been hoisted so I know how that feels. Have you tried how you would manage with a leg or arm out of action?

We have had requests for information to help restless, itchy and cold legs [[Page 17](#)].

**Carers, Family and Friends of Polio Survivors** - we are happy to speak with you and/or your polio survivor. Personally I have 32 years experience of what it has been like going through new issues. I spent seven years at hospital appointments and my prior polio not even in the equation and because single action manual muscle testing used NO corroboration of my reported weaknesses. Then through years of research with the first few years my giving advice but not doing it myself because 'I was not there yet'. Hard admitting I was. Then years of learning how to manage life by pacing and resting activities, using aids and assistive devices [boy that was hard till I saw how MUCH MORE I got out of life with less pain, to today.

"Bits that have helped me" from conversations on the phone, Instant Messenger and Facebook polio lists [See [page 20](#)].

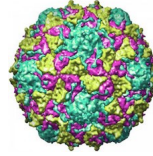
[Page 19](#) Vitamin D3 - we have been taking this for a couple of years now.

*Richard and I wish all our readers a safe and probably video calling Christmas and New Year!*

# Covid-19 & Polio Vaccine



COVID



POLIO

## Politics or Science?

*Simon Parritt* Counselling Psychologist and Polio Survivor

Covid-19 dominates our lives today and its closest parallel is more than 50 years ago when the polio virus came for young people in wave after wave. How did we cope, we had no vaccine to protect us from being paralysed and killed by recurrent epidemics? But what mistakes were made when polio vaccines were eventually developed and then rolled out in the mid 1950s. The story is told as a medical triumph and with mass immunization programmes, as it reduced polio in just the UK from some 45,000 cases and 750 deaths a year to a handful in less than a decade.

### Long Covid and Post Polio Syndrome

Modern medical science has delivered treatments and drugs that have transformed our view and relationship with disease and illness. But there are many subplots and misconceptions hidden within this narrative. Politics, jealousy, national pride and poor organisational planning, which we see so much of now, all played a large part in 1000s of young people, between 1955 and 1957, catching polio when a vaccine was available. Many died and many more survive to this day living with its life-long impact. But polio also had a cruel sting in its tail, even for those who recovered or had minimal or no symptoms. Often decades later they developed what is now called Post Polio Syndrome (PPS) and symptoms including chronic fatigue, pain, unexplained muscle weakness and for some, breathing problems. Is Covid another virus like polio that after the original exposure, infection and recovery has a nasty sting in its tail? And if so, how long is its tail? Whilst hopefully 'Long Covid' is not like PPS, we do not know enough as yet. What might be Covid's impact down the line on younger, mild or even asymptomatic cases. Much like ME, it took decades for PPS to be recognised and less than 20 years ago dismissed as just normal ageing or psychological in origin. Let's hope we don't repeat that error again.

### Asymptomatic Polio and Covid

Much like Covid-19, 70 per cent of polio cases were asymptomatic, but in the other 30 per cent it caused muscle loss, weakness and paralysis that sometimes required ventilation. A minority but significant number of patients died. However, Covid-19 has a higher death rate in older adults, whilst polio's major impact was on children and young people, hence its early name of 'infantile paralysis'. This in itself perhaps challenges our view of how society should manage it. It is a cruel irony that the very generation who survived the polio years, are now at most risk again.

### Public Fear and Panic

Between 1947 and 1957 in the UK, there were rarely less than 5-8,000 recorded cases per year and, bear in mind that maybe 70% were asymptomatic and so went unrecorded. Each summer brought another wave of the virus and as local outbreaks were identified by public health schools, swimming pools and public events were abandoned, restricted or closed. Even in those pre social media days, panic and fear spread amongst parents and the population. With no effective treatments and no vaccine yet, infection control was the only tool available to the authorities to control the outbreaks. Not unlike what we see today with the exception that there was much less controversy over public health actions.

### The American Experience

America perhaps experienced even more panic and fear. Known as the summer plague, unlike other infectious diseases throughout history which largely affected those in poor, overcrowded

and unsanitary conditions polio reached into all corner of society, irrespective of class, ethnicity, culture, wealth or poverty. Perhaps this concentrated the minds of the 'great and good' and those with power, influence and wealth for this was killing and paralysing their own children. So much like Covid-19 today, the push for a vaccine became intense and in the USA as early as the 1930s the National Foundation for Infantile Paralysis, known as the March of Dimes was set up by Franklin Roosevelt who had become a wheelchair user himself due to was thought to be polio in 1921.

### **The Kitchen Chemist**

By 1952 the American Jonas Salk had discovered an innovative way of producing a polio vaccine using a live but Inactivated Polio Vaccine, IPV. However, politics, hierarchy and professional rivalry led by Sabin as well as others, were critical, dismissive and sceptical of Salk's vaccine suggesting it was unsafe and needed much more testing. Indeed, Sabin referred to Salk as nothing more than 'a mere kitchen chemist'. In spite of this in 1954, with the backing of the March of Dimes, trials involving 1.8 million schoolchildren known as "polio pioneers" were undertaken. In 1955 Salk and his team announced on TV that it had been a success and was 'safe, effective and potent'. Such was the desire to arrest the virus, that on that very day 12<sup>th</sup> April, 1955, the vaccine was licensed for use and mass immunisation began in the USA.

### **Behind the Curve**

Scepticism and doubt continued in the UK and not for the first time, we were behind the curve. It was not until 1952 that The National Fund for Poliomyelitis Research was not set up in the UK, some 15 years after the March of Dimes. The UK also continued to be critical of the Salk method but also had an agenda to develop its own British vaccine. This British approach begun to run into a succession of problems and in the end failed to meet production needs and the demand.

### **The Cutter Incident**

Those who had political and professionally resisted the import or licence of the Salk vaccine for years were also handed a golden opportunity to delay even further casting even more doubt on its safety when the Cutter Laboratories in the USA, failed to inactivate the polio vaccine properly. The tragically 120,000 children were injected with live poliovirus and 260 caught polio and 10 died.

### **The Coventry Outbreak**

Perhaps national and professional pride, a clumsy system requiring parents to register for a vaccine, combined with financial considerations meant that mass immunisation didn't take off in the UK until there was a public outcry following a severe outbreak in Coventry in the summer of 1957. This was over two years after the USA had identified and resolved all safety issues and other countries had started using the Salk IPV vaccine.

### **The British Reticence**

The British history of delay, politics and risk aversion to new treatments, played major a role in the delay that caused thousands to catch polio between 1955 and 1958. This was not new and in the past the BCG for TB and the diphtheria vaccine were adopted by the UK sometime after many other similarly developed nations were using it. This approach continues to this day when the human papillomavirus (HPV) vaccine was offered to girls in 2008 but not boys until 2018. In Australia it was offered to girls in 2007 and boys in 2013 and is now on track to eradicate cervical cancer in their population.

### **The forgotten Lesson**

Covid-19 is not polio and we have moved on in many ways, but there is a danger again that organisational incompetence, political positioning, economics and national pride again become the enemies of effective and timely prevention, intervention and treatment of people with Covid-19. The untold story of those who caught polio in the UK between 1955-1958 should not be forgotten. Indeed, those of us in this cohort could have had the chance of the vaccine but were

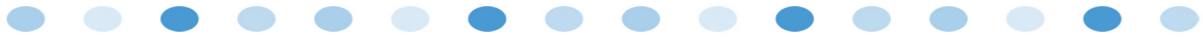
denied it, and have never know that it was not just a bad batch of vaccine that delayed its introduction and use in the UK but health and national politics that was ultimately to blame. Surely we need to learn from history and not repeat it.

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**Simon Parritt**, C.Psychol, AFBPsS, MSc, BSc(Hon), BA, CPsSC, MBACP

Chartered Psychologist. HCPC Registered Counselling Psychologist, [www.sp-psychology.com](http://www.sp-psychology.com)

**Chair Polio Survivors Network** [simon.parritt@poliosurvivorsnetwork.org.uk](mailto:simon.parritt@poliosurvivorsnetwork.org.uk)



*Toni writes...*

I don't know if it is anything to do with turning 40 (where did the time go?!) or whether it is due to the pandemic rumbling on but I have been thinking about the power of kindness.

In these strange times do you find that life can become more and more fixated on some of the smaller things for a while. We can get quite worked up about things which a few months ago we would possibly not have noticed or would have chosen to let slide, realising that in the big scheme of things it really was not important.



A way to combat this that I have found useful is to actively look for extra ways to be kind, to those I already know, and to strangers. It focuses us on the positive and the reactions can make your day too. A few examples:

- \* Giving a genuine compliment to someone
- \* Sending flowers for no reason other than to say I was thinking of you
- \* Holding a door
- \* Sending a card/writing a letter
- \* Giving a book you have enjoyed reading to someone else
- \* Say thank you – especially to those in household/family
- \* Reconnect with an old friend
- \* Like or make a comment on social media feeds
- \* Make someone smile or laugh
- \* Smile – it is contagious!

What kind things do you appreciate? What memories of kind acts do you have? As ever we always enjoy hearing from our members and any little snippets they would like to include in upcoming newsletters. Also, we are always looking out for any articles you have found helpful or books that have inspired you for our library. Please feel free to share them (contact details below).

Take care and keep safe

*Toni x*

<b>Email</b>	<a href="mailto:psnadmin@poliosurvivorsnetwork.org.uk">psnadmin@poliosurvivorsnetwork.org.uk</a>
<b>Post</b>	P.O. Box 954, Lincoln, LN5 5ER
<b>Website</b>	<a href="http://www.poliosurvivorsnetwork.org.uk">www.poliosurvivorsnetwork.org.uk</a>
<b>Phone</b>	01522 888601 - Answerphone if no reply

**PS:** Some of you will no doubt spot at least 3 calls for help from members in this issue, we look forward to hearing from you.

## Might I Have Post Polio Syndrome (PPS)?

Neurologist *Dr. Susan Perlman* is the Director of the Post-Polio Clinic at the University of California, Los Angeles (UCLA) Medical Center.

Most experts require some combination of the following to make a diagnosis of PPS:

- ◆ A confirmed diagnosis of paralytic poliomyelitis in the past [see Editors note]
- ◆ A period of partial or complete functional recovery followed by an interval (at least 15 years) of stable neurological function
- ◆ Gradual or sudden onset of muscle weakness, fatigability, muscle atrophy, or muscle and joint pain
- ◆ Possible problems breathing or swallowing
- ◆ Persistent symptoms for at least a year
- ◆ Exclusion of other neurological, medical, and orthopaedic problems

Not all polio survivors develop PPS, though as they age, they may naturally develop premature tiring and aging of overextended neural muscle units. Furthermore, over half of polio survivors who go to their doctor with new symptoms do not have PPS. Notes one expert: "Sixty percent of polio survivors with new symptoms have a medical or neurological problem that is unrelated to polio, and that problem may be treatable. Half the remaining patients have increasing orthopaedic issues related to their polio residua."

### What Are the Risk Factors?

Though every case is different, the following factors may increase the risk of developing PPS:

- ◆ **Severity of initial polio infection.** Generally speaking, the more severe the initial polio, the higher the risk of PPS
- ◆ **Age at initial onset.** Those who got polio at a younger age are actually less likely to face PPS
- ◆ **Recovery.** Surprisingly, the greater and more complete the initial recovery, the greater the chance of eventually developing PPS
- ◆ **Physical activity.** If a polio survivor has been in the habit of exercising to exhaustion over the years, this may increase the risk of PPS

### Is There a Cure?

Just as there is no confirmed etiology, or cause - and thus no definitive laboratory test - there is really no cure at the present time for post polio syndrome (PPS). There is, however, treatment revolving around a three pronged rehabilitation approach. Says one expert: "More than 80% of patients with PPS will demonstrate benefit with rehabilitation techniques."

#### 1. Life style modifications

- energy conservation
- assistive devices
- non fatiguing exercise
- staying warm

#### 2. Medications and supplements

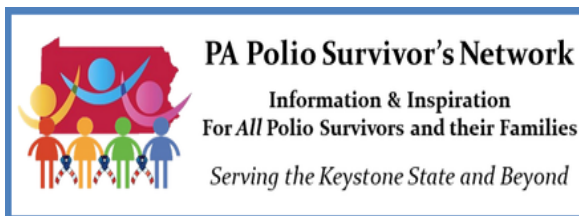
Though many medications, prescription as well as natural supplements, have been tried, none has been proved to help. There are many anecdotal reports of improvement, but further study is needed. Keep in mind that herbs can interact with prescription medicine, so always let your physician know what you are thinking of taking.

#### 3. Quality of life

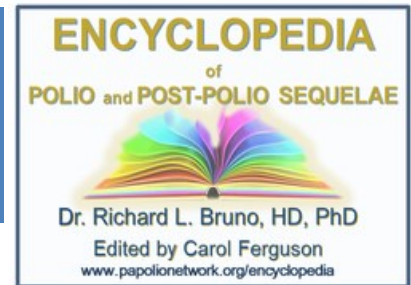
"The strongest medicine that a practitioner can provide to a patient with PPS is education and encouragement. . . . Patients who were better able to make lifestyle modifications (those with better problem solving skills, more accessible environments, more access to information and support, and a readiness to compensate with assistive devices) adapted better in their daily occupations."—Dr. Susan Perlman.

**Editors Note:-** The diagnostic criteria PSN uses adds findings on history, physical examination results, and laboratory studies compatible with polio virus damage of the central nervous system in earlier life [Halstead L, MD - Silver J, MD Am. J. Phys. Med. & Rehab. Jan/Feb 2000].

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### **A Message from Dr. Richard L. Bruno:**

During the past 36 years I've written three books and more than 600 articles, book chapters, monographs and commentaries about polio and the cause and treatment of Post-Polio Sequelae. This work was done for the medical community and, more importantly, for polio survivors. Most of the medical journal articles, chapters and monographs have been uploaded into the Post-Polio Library on the International Centre for Polio Education website at [postpolioinfo.com](http://postpolioinfo.com).

More than 500 commentaries (often answers to questions from our Post-Polio Coffee House members on Facebook) have been expanded, edited and uploaded to the Pennsylvania Polio Survivor's Network "Bruno Bytes" page by their volunteer team. But about one-third of my articles, with important information for polio survivors and their families, have been sitting on my computer, just gathering electrons. That ends here.

The International Centre for Polio Education and Pennsylvania Polio Survivor's Network have partnered to update, edit, then index and upload for easy retrieval and reading, everything I've written on polio and PPS to this new Internet based ENCYCLOPEDIA of POLIO and POST-POLIO SEQUELAE.

This will be updated with new articles and commentaries on a regular basis to make sure that the post-polio community has the latest information about the cause and treatment of PPS.

I can never adequately thank Carol Ferguson and the Pennsylvania Polio Survivor's Network for taking the lead in providing information for the world's polio survivors, for tirelessly editing and indexing my writings and providing a home for the ENCYCLOPEDIA.

So, to the world's estimated 15 million-plus polio survivors: Read on!

[www.papolionetwork.org/encyclopedia.html](http://www.papolionetwork.org/encyclopedia.html)

### **The Effects of Cold on Polio Survivors - Dr. Richard L. Bruno, HD, PhD**

**Link:** <https://bit.ly/3mW6DCZ>

Polio survivors are extremely sensitive to changes in temperature. At merely cool temperatures, most polio survivors report that their feet have always been cold to the touch, their skin a purplish color. However, as polio survivors have aged, 50% report "intolerance to cold" and that their limbs have become more sensitive to pain as the temperature decreases (Owen, 1985). Cold was reported to cause muscle weakness in 62% of polio survivors, muscle pain in 60% and fatigue in 39% (Bruno & Frick, 1987). When polio survivors were cooled in our laboratory from 86°F to 68°F, motor nerves functioned as if they were at 50°F and polio survivors lost 75% of their hand muscle strength (Bruno, et al., 1985a). Although during the same study polio survivors were found to be *twice* as sensitive to pain as those without polio, no increase in pain sensitivity was seen at lower temperatures (Bruno, et al., 1985b).

The reason polio survivors have such trouble with cold is that the parts of the central nervous system that should control body temperature were damaged by the poliovirus. In the brain the hypothalamus (the "automatic computer" that controls the body's internal environment) was damaged by the poliovirus, including the body's "thermostat" and the brain area that tells your blood vessels to constrict (Bodian, 1949). In the spinal cord, the nerves that carry the message from the brain that tells the capillaries in the skin to contract when it's cold were also killed by the poliovirus (Bodian, 1949).



Thus, polio survivors are unable to stop warm blood from flowing to the surface of the skin as the outside temperature drops. This allows loss of heat from the blood near the surface of the skin and causes the limbs to cool. When the limbs cool, arteries carrying blood to the skin and veins that should carry blood out of the skin narrow, passively, as they get cold, trapping blue venous blood in the capillaries and causing the feet to look blue and to become even colder. The cold skin chills the motor nerves, causing them to conduct more slowly and to be less efficient in making muscles contract. The cold also chills tendons and ligaments (imagine putting a rubber band in the freezer) making movement of weak muscles more difficult. As polio survivors know, it takes hours under an electric blanket or a long, hot bath to warm cold legs and regain strength. contract.

However, when polio survivors take a hot bath, blood vessels do exactly the opposite of what they do in the cold. Polio feet and legs become bright red as arteries and veins relax and blood rushes to the skin. Then, when polio survivors stand to get out of the tub, they can feel dizzy or even faint as blood pools in their legs and causes their blood pressure to drop (see Bruno, 1997). The pooling of blood in the feet also explains why polio survivors' feet swell in the heat, swelling that increases as they get older. And polio survivors' easily losing body heat explains why they have an increase in symptoms, especially cold-induced muscle pain, as the seasons change, especially from summer to winter.

Polio survivors need to dress as if it were 20°F colder than the outside temperature. They need to dress in layers and wear heat-retaining socks or undergarments made of polypropylene (marketed as Gortex or Thinsulate) that should be put on immediately after showering when the skin is warm and dry. Polio survivors need to remind doctors that EMGs or nerve conduction tests must be performed in a room that is at least 75°F to prevent false abnormal readings and that a heated blanket is necessary in the recovery room after polio survivors have surgery (Bruno, 1996).

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## Cold and Purple “Polio Feet”

A Bruno Byte from. Richard L Bruno, HD PhD

[www.papolionetwork.org/uploads/9/9/7/0/99704804/polio\\_feet.pdf](http://www.papolionetwork.org/uploads/9/9/7/0/99704804/polio_feet.pdf)

**Question** : Why are my feet and lower legs always ice cold and purple, especially in winter? My doctor checked my blood flow and says it sounds "clear." I've tried heavy socks and leg warmers. What's going on? What can I do to stay warm?

**Dr. Bruno's Response** : You have "polio feet", and legs that are always cold and purplish. Your blood flow sounds "clear" because your arteries are open. It's your veins that are the problem because they are too "open."

Polio survivors have trouble with cold because the neurons in the brain and spinal cord that cause the veins to contract were killed by the poliovirus. You are unable to stop warm blood from pooling in the veins near the surface of the skin, causing the feet to look purple or even blue. As the outside temperature drops, pooling allows the loss of heat from warm blood near the surface of the skin and causes your tissues to cool. Motor nerves and muscles - lying just below the surface of the skin - cool. Cold motor nerves conduct more slowly and may be less able to make cold muscles contract quickly and forcefully. Tendons and ligaments also get cold and become less elastic (like putting a rubber band in the freezer) making movement of weak muscles more difficult. Cold causes muscle weakness in 62% of polio survivors, muscle pain in 60%, and fatigue in 39%. It takes hours under an electric blanket or in a long, hot bath to warm cold legs and regain strength.

We found in our very first study of PPS that polio survivors lose 75% of their strength when the temperature drops from 85 to about 65 degrees. We also found that polio survivors' motor nerves function as if it's 20 degrees colder than the actual temperature. So, polio survivors should dress as if it's 20 degrees colder than it actually is. The trick is to stay warm from the get-go. You should dress right after showering when your skin is warm and red. Try heat-retaining sock liners or even long-johns made of the woven, breathable plastic fiber polypropylene (marketed as Gortex or Thinsulate). Then put on warm socks or try battery-powered socks or ski-boot insoles. Also, keep your feet elevated as much as possible during the day.

Remember that changes in season are also difficult, since your body can't figure out whether it's warm or cool. Polio survivors report more muscle pain, especially headaches, during seasonal changes. Regardless of the season, whether you're being chilled by a Northeast wind in November or by excessive air conditioning in August, dress in layers to control your body temperature, because your body can't. Try not to wear skirts, dresses or shorts between Labor Day and Memorial Day [Labor Day was September 7th 2020 and Memorial Day May 31st 2021].

The Encyclopedia of Polio and Post-Polio Sequelae contains all of Dr. Richard Bruno's articles, monographs, commentaries and "Bruno Bytes"

<https://www.papolionetwork.org/encyclopedia.html>

**Polio Survivors Network thanks Carol Ferguson and PA Polio Survivors Network for providing this information on their Website for the benefit of polio survivors in the Keystone State [Pennsylvania] and Beyond [the rest of the World.]**



**Restless, itchy legs?**

Any experiences or tips to share with our member?

Please see [page 13](#)

## 12 November 2020: People with rare neurological conditions need a much better deal



A new report by the Neurological Alliance is calling for better treatment and care for the 150,000 children and adults living with a rare neurological condition in England.

The hard-hitting report, '[Out of the Shadows: what needs to change for people with rare neurological conditions](#)' includes extensive input from member charities of the Alliance, in addition to expert clinicians.

The report points out that while the number of people living with rare neurological conditions equals the number who have other conditions such as some types of cancer, people with rare neurological conditions are all too often left behind when it comes to accessing the care and treatment they need.

In addition, more than 200,000 people with neurological conditions are expected to be waiting for specialist appointments by the end of the year. People with rare neurological conditions risk experiencing further delays and gaps in their support due to overstretched services and waiting lists exacerbated by COVID-19.

Specifically, we are calling for:

- **Changed perceptions around rare neurological condition:** just because they are complex does not mean they cannot be managed well, says the report. People with rare neurological conditions are entitled to equal access to care and treatment.
- **Speedier access to specialists and a diagnosis:** 4 in 10 charities surveyed recently for the report said diagnosis of the people they represent takes, on average, 3-5 years. The report points out that there needs to be greater awareness of rare neurological conditions in primary care, so people are more quickly referred on for a specialist assessment when they have neurological symptoms – and they can benefit more quickly from available treatments and support.
- **Faster access to new treatments:** the UK often lags behind other countries in Europe when it comes to approving and funding new treatments for rare neurological conditions. For example, the Batten Disease Family Association told the Alliance in our recent survey: "*The NICE process takes literally years of upset and our families don't have years; two children died waiting to access Brineura.*" Spinal Muscular Atrophy UK also told the Alliance "*The paediatric roll out of Spinraza has been quite good, but the treatment roll out for adults hasn't progressed at all well.*"
- **Improved mental health support:** less than a third of people with rare neurological conditions feel they are getting the mental health care they need according to the [Alliance's 2019 Patient Experience Survey](#). Again, in our more recent survey of September 2020, all 10 charities who responded reported that the mental health needs of those they represent, were either 'not being very well met' or were 'not being met at all'.
- **As a matter of course, information should be provided to people with rare neurological conditions and/or their families on diagnosis:** again, the Alliance's Patient Experience Survey 2019 found that just a third of people (or families) with rare neurological conditions are provided with written information about their condition at the time of diagnosis to help them understand more about their condition and care choices.
- **High quality social care and home adaptations are not just 'add on extras' for those that need them:** the report points to recent research by the Motor Neurone Disease Association (MNDA) which found that some people with motor neurone disease do not always receive the home adaptations they need before they pass away, due to lengthy delays in service provision and the cost. People with rare neurological conditions, and their families, need proper well-funded support in the community.

**Georgina Carr, Chief Executive of the Neurological Alliance, said:**

*“Taken together, rare conditions are not that rare at all – 1 in 17 people will be affected by a rare condition at some point in their lives, and it has been estimated that nearly a third of genetic rare conditions are neurological or have neurological symptoms. [See Editors Note] Yet, poor public awareness and a lack of investment in services for rare conditions has meant that, for too long, people with rare neurological conditions have experienced long waits for a diagnosis, poor care coordination and insufficient information provision.”*

*“We hope that this report will bring about a sea change in how rare neurological conditions are viewed, both in the medical profession and in wider society. It’s time that rare neurological conditions came out of the shadows.”*

The report includes the experiences of a number of people with neurological conditions. Livvy, aged 19, has a rare, undiagnosed neurological condition that leaves her in a wheelchair, needing a feeding tube, and having multiple seizures every day. Bradley’s dad, John, died with progressive supranuclear palsy (PSP) at the age of 62, before we was even diagnosed, despite his mobility deteriorating quickly over just a few years – clinicians were not able to agree on what condition he had. Sam, aged 54, has Huntington’s, another progressive neurological disorder; he also has related mental health problems which have not been successfully addressed and he has been in and out of psychiatric wards. Now, tragically, Sam has terminal cancer.

**Amanda Mortensen, mother of Livvy and Chief Executive of the Batten Disease Family Association (BFDA), said:**

*“We first had that gut-wrenching sense that she wasn’t developing like her peers when she was around 9 months.” Livvy is now aged 19: “Livvy has been tested for a myriad of conditions that cause her relentless epilepsy, but we still don’t have an answer as to why.”*

**Amanda added:** *“We hope the findings of this report will give people with rare neurological conditions a voice, influencing decision-makers as we shape the services of the future post Covid. We represent a multitude of unique conditions, yet our journey has shared challenges and we speak together on the need to improve the diagnostic odyssey, access to treatments, awareness and information.”*

**Dr Wendy Edwards, PSPA said:**

*“The launch of the ‘Out of the Shadows’ report has given us a great opportunity to come together as a collective with the Neurological Alliance, to shine a brighter light on the challenges people living with rare neurological conditions such as Progressive Supranuclear Palsy and Cortico-basal Disorder (CBD) face, and the crucial role charities play in providing support and lobbying for more rapid diagnosis and access to co-ordinated care.”*

**Link:** <https://bit.ly/37ATjgz>

*Editors Note - Yes Post Polio Syndrome is classed as a Rare Disease.*

**Rare Disease UK**

The European Union defines a disease or condition as rare if it affects fewer than 1 in 2,000 (1) people within the general population. Currently, there are over 6,000 (2) known rare diseases and new conditions are being described through medical literature on a regular basis, [www.raredisease.org.uk](http://www.raredisease.org.uk)

*Editors Note: There is a link to Polio Survivors Network on this website:*

**National Organisation for Rare Diseases**      **Link:** <https://bit.ly/3ge9MLu>

## An Interview With ... Marion Carlisle

**Q: Tell us a little about yourself and your polio journey**

My mother is very sure I had polio when I was 2 (1960). She said it was the worst week of her life, though I was not hospitalised. I recovered with slight walking impediment for a year. Then apparently nothing until I was 39 when symptoms started: unexplained temperature rises, progressive fatigue.

**Q: When did you first realise you had PPS?**

I self-diagnosed P.P.S in 2003 (age 45) after reading Dr. Bruno's *'The Polio Paradox'*. So much in his book rang bells. There was the gradual onset of unexplained symptoms in my late '30s. The fact that all blood tests fell into the 'normal' range and yet I could hardly function at all sometimes.

**Q: How did you get a diagnosis?**

I've been living in West Wales since 2002 and haven't had any official diagnosis or seen any expert in the field. My local GP accepted my self-diagnosis but apart from prescribing Q10 on the NHS, I've had no medical help.

**Q: What has helped you to cope?**

I've been following protocol for M.E. / C.F.S patients, ie pacing, supplements and a low carb / high protein diet for many years. Accepting limitation rather than fighting it has been a key. Although I don't need physical aids and can walk OK, new arm weakness means I don't lift heavy things - including a half-full kettle. A background in meditation, being in the 'here and now' as much as possible helps me to accept what I can't change. Perhaps mental fatigue is the most challenging - not able to read or engage socially when I'm very exhausted. Then re-charging the batteries, alone and doing nothing is the only help.

**Q: Is there anything that our members can help you with currently?**

Yes, I wonder if any other members have experienced constant tingling sensations, like pins and needles. This tingling started just in the soles of my feet, then progressively moved up my body. This used to disappear with prolonged rest. Now the tingling never goes away and is my whole body, including my head. I also experience a strong pulse in my adrenal area, especially in the night and on waking. There seems to be no medical reason for this.

**Q: What one piece of advice would you give to other polio survivors?**

I know I'm not facing challenges like many polio survivors. I can walk and have been working part-time musically for the last 10 years, finding more strength by sticking to the diet and supplements protocol. So advice? Not really. I'll just say that feeling empowered - in whatever way that means for a person - is vital. Celebrating one's talents, however small. Enjoying the world around - the elements, the natural world and being able to receive and give to others. Also spiritual gifts are so important. Through undergoing limitation (not something I'd wish on anyone), I'm more receptive to the essentials in life. There is a silver lining in having to let go ambition!

**Editors Note:-** I am not medically qualified but have 24 years of talking with other Polio Survivors and many health professionals. A neurological physiotherapist in the late 1990's told me that if we had restless, jiffly, aching legs then we should get our feet up every time we can. This helps the blood flow back up our legs and gets the waste products back out of our body instead of pooling in our feet. I got an electric rise leg raise chair and it made a huge difference. When unable to get feet up at meetings or pps conferences, long flights, etc then back it comes. I touchtype and use my laptop on my lap on my chair and have the following additions. To support neck have a pillow to fill the kyphosis curve of neck forwards, my elbows rest on the arms of the chair, left hand rests on the front of a 17" laptop keyboard and right arm swivels from the elbow. If I forget to raise my legs then its not long before my shoulders and left arm really ache.

**Question: Did you always tell it like it really was?**

**Answer: “No, but since I learned about Post-Polio Syndrome and how to use Pacing and Resting activities to better manage my life, I do now”**

**Question: Has it crossed your mind to self-assess again and update any information that you have prepared to take with you to medical appointments, into hospital?**

***I ask because I had not done this!?***

I have updated my husbands regularly but not mine because I did not think much had changed.. That was until I started looking at the changes over the last few years. PSN have found over the years that when sharing our stories there is always someone else that picks up some information to help them. Here is what I learned.

I got a pressure pain round my left eye and lost patches of vision. GP sent me to A&E and after a negative Covid test they admitted me for 36 hours. Once home and talking about my time with daughter and carers there were a few points that occurred to me that I could have done/said that might have made things easier for myself and the staff.

I will start by saying that for the most part I was exceptionally well treated, assessed thoroughly and as soon as possible for which I am very grateful. I also saw and heard first hand how hard a job it is for the staff having to work hours on end wearing a mask. They deserve more than just our thanks.

**The reasons we have decided that it did not occur to me were because:-**

1. I had not thought about updating my What You Need To Know About Me sheets for some years as I had not stopped and thought [maybe I did not want to see the changes] am I doing anything a different way? Soon as I thought about it I knew I was, duh!
2. I had not realised - my daughter told me this - that they would consider me an old lady at 73 and not someone with a huge amount of knowledge about post polio and my condition.
3. My medical file is a few inches thick and it did not occur to me that there might not be an overall sheet of which departments I have been seen in. [Four years at eye clinics after the fall but **before my prior polio** was added to the diagnostic equation]
4. Those couple of days all I was thinking about was my current symptoms, the scan, the three and a half hours in the eye clinic and the MRI.
5. Plus wondering how long am I going to be here and who would look after Richard if I had to stay here much longer. A huge thankyou to our Carers who managed him those 36 hours?

After a few hours of gaps in my vision I rang our GP surgery and was given an appointment to see a GP. I had not met the doctor before but was sent straight to A&E for testing. I can only say how impressed I was at the way patients were treated, ensure all had masks on, kept 2 metres apart, dealt with quickly, assessments, tests and reviewed. Chatting with others nearby we agreed it helped reduce some of the worry about being in a hospital during Covid.

I was triaged then seen by Doctor and was sent for a scan of my brain [yes there is some there] but then told that I needed an MRI and to see an ophthalmologist and would need to be admitted to speed up the appointments.

I was given a Covid test which made me look like a large rabbit for a few minutes because my nose would not stop twitching. The result was negative so I was taken up to a ward. I never saw the name so had no idea what ward. Thankfully room for my scooter by my bed and I was given a lovely pink nightie and was soon in bed about 9pm.. I had been drinking all day about 2 litres of the three that is my norm when I was told that I was now 'Nil by Mouth' and put on a drip.

## **Issues that I wished I had realised I needed to make the doctors aware.....**

A. **I was mostly lying on the bed so hardly anyone saw how bent forward I am when standing.** [I raise my legs every time I sit down at home but their armchair did not have that facility so I laid on the bed.] Therefore hardly anyone got to see me standing and my kyphosis - bent forward posture. Covid and less treatments this year has caused the forward curvature of my spine to have more body leaning over my legs so use a walker all the time to prevent falling. When I lie on my back on a treatment couch I have to have a pillow to support my head. [I now have photos on my phone/iPad.]

B. **I went down to the Eye Clinic seated on my electric scooter.** I found that I could no longer get my chin on the rest and my forehead up to the different eye testing machines on the ones they have at the hospital. They did not seem to understand that this was a physical issue and the best I could do was hold my forehead against the right bit of the machine and keep my chin still. All I did was transfer a few feet from scooter to chair.

C. **Getting up from swivel chair.** My legs are weak so I have to push up with my arms to stand from a chair. The eye clinic chairs - and I have raised the issue in earlier years - are swivel without arms and on wheels. The offices rarely have anything that I could use to help me stand. Two years ago I tried five different places in the room to try and get off their darn swivel chair and ended up just getting down on the floor [can you imagine her face?] asking her to open the door so I could crawl out and get up using my scooter that had to be parked outside the room. She was horrified and was saying I will call for security to help you and a couple of nurses ran towards me grabbing my arms thinking they were helping. I called out in a loud voice 'Let go, and then sang 'I do it my way' much to the amusement of the waiting room that burst out with applause. I cant sing but I did it to cover my embarrassment, This time I just scooted the chair from the room next to my scooter and transferred across. I had developed a way of getting up onto my 3 wheel scooter [need to put my long legs each side of the tiller] after falling off one day turning on a slope.

D. **After the fall in 1988 that triggered my PPS I had had some visual issues and spent four years being tested at two hospitals without a definite diagnosis.** Now 2020 and after three and a half hours of test after test, drops, and scans and all sorts [cannot fault the number they did or the way they got through them] I was told there was nothing significant. So what was causing this? I suddenly remembered the issues years before and I had eventually found out through 3 others on a polio list and an Australian Optician that the issues could be weaker muscles from polio that move the eyes sideways. I took the information to my Optician and he examined me then read the information examined me again and confirmed this was my problem, if I moved my head no distorted vision. If I moved my eyes left and right and repeated it then the left eye moves slower and causes some distorted vision. The doctor tested this and confirmed it to another man training but only asking me to do it a couple of times he told me 'it is not much, don't worry about it'. I did not think to tell them that this gets worse as the day progresses if I don't rest my eyes. At the time I had not remembered that the opticians letter that explained all this is only on my GP records. I need to get a copy and keep it in my information file.

After 3.5 hours at the eye clinic still no food and drink now 21 hours I was back on the ward and just about to be attached to the drip again when a Porter arrived to take me for an MRI.

E. **On arrival at MRI** I did explain that because of kyphosis I cannot lie flat and would need a pillow under my head and my legs up as I had fused lumbar vertebrae. I also explained that I had a trapped nerve in my cervical vertebrae that would be triggered again doing this. I was told not to worry they had dealt with many different folks. What I did not like was the fact that I had to wait for half an hour listening to the man in front of me being G, G, Gd.

Then it was my turn. I did not look at the machine I just transferred to the conveyor belt and laid back but my head is still three inches above the bed. Even with their little pillow I was still inches off and I put my knees up to help but they wanted my legs over a rolled piece that meant that I could not push up on my heels to help get my head lower. I did not see what they did I kept my eyes shut. Earphones were put on my head and they went to back me into the machine.

My trapped nerve had kicked off with pain all down my left arm, my shoulders were crunched up [also have damaged acromion joint on left shoulder]. I explained I was in a lot of pain and asked how long. I was told that the first most important scan is 2 minutes [20 minutes all together] so I agreed and in I went still with eyes shut. I said nursery rhymes over and over again to keep my brain occupied and suddenly remembered I had done the same thirty years ago. That finished and a voice said can you do another two minutes it is also important., OK although tears were falling down my face from pain. That ended and “can you manage just a bit more” but I said sorry I cant do anymore because of the pain. I was pulled out.

Next day on the ward doctors rounds I apologised that I could only manage that much time in the MRI because of the pain as I could not lie flat. They had my records - which I see from the discharge sheet states chronic neck pain - but there are so many pages in there they may not have realised that I have an abnormal spine, T11 and 12 are one bone as are L2,3,4. The trapped nerve at C7. I never thought to stand and demonstrate. Had I done this earlier I am sure it would have been easier to plan what was needed to get the MRI completed.

F. **Another issue raised by my daughter.** I had come home and the next day felt as if I had just got over flu, about a third of the energy I had earlier that week. Her immediate reaction was “you sound if you are low on electrolytes, how many bags of saline did you get through?” I replied, “Only one a day and sometimes like when I was at the eye clinic and then MRI it was over five hours without.” “Mum!” you know the tone of voice... “Why didn't you tell them how much fluid you drink each day.” I had mentioned to at least two of the nurses that I drank 3 litres a day but why would they during their shift think of anything other than does the bag need changing. To lose weight I have had sessions of fasting drinking only water with electrolytes and some plain and can fast with no hunger, fainting or anything but feeling great for five days. I did as she told me and immediately went and got some electrolytes into me and started to feel better but it took a few days to get back to my normal energy levels, just from 36 hours!

G. **The next issue is being seen by an Occupational Therapist.** I am 73 and got asked the memory questions. I did ok except I could only remember three of the five words. Then she said “**I will take you into the kitchen and see if you can make a cup of tea etc.**” Luckily I thought I have photos on my iPad of my kitchen and bathroom so I can show how we have adapted our place so that I/We can do what we need to do. She happily told me not to worry she could alter the heights of the units for me. I explained that Polio Survivors have their own way of doing actions and they are all different because our polio nerve damaged muscles are all different. That I have to use short arm levers and to work in the kitchen hold on with one hand or the other and if I need to use both hands I lean against the work surface. I have to rest every few minutes. My kitchen is small but set out so that I have what I need where I need it. She still wanted to assess me in their kitchen again reaffirming that she could alter their unit heights. Sadly I was discharged the next day before I got the chance to see how hospital based assessments are carried out. When it becomes possible again I will contact the department and ask for a look round and demonstration of how they assess and if there any points that I can raise to explain how Polio Survivors and others with neuromuscular issues might have difficulties I will.

For years I have found it hard to explain that there might be a better way of doing an action but not if our body does not work that way. This was the main reason I was so keen to be part of the User/carer team at the University of Lincoln working on the new Masters Occupational Therapy Course right through to validation. The main point that I had raised was that many polio survivors were reporting difficulties with assessments. This is the piece of equipment for that problem' when for some of us it wont help us at all and other solutions need to be looked at. I used to work for Social Services many years back so I do understand the need to provide the most cost effective solution for the problem. However, it is not cost effective to provide equipment that will not help and it just get put in the garage. I suggest that you have some photos taken of your home and your adaptations. If possible get someone to make short video clips of you doing different actions so that you can show the what's and why's.

H. **Pharmacy rounds.** I am only on one medication now but the Pharmacist that came round had picked up from my GP records that it still showed I was taking medication that I have not



taken for some years. It may be useful for you to check your prescription sheet to see if you have any items on yours that you no longer take. A good idea that we do is to have dosette boxes for a couple of days in our going out bags. It is a good idea to carry your latest prescription sheet with you as well that will show when you last received each item.

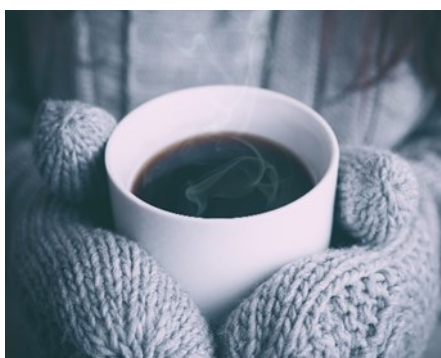
I. **Cannulas.** I had had one fitted some years ago in a position that meant that I could not do actions of daily living that I needed to do the way I need to do them because of where it had been inserted.

This time I was able to show how I needed to move about on the bed and get up and down from it and ask that it be inserted where it would not cause me any problems. 'No problem, would here be ok?' It was ok.

However, I missed the fact that most of the time I kept my left arm in one position and I ended up with pain in my biceps. Then remembered back to early 2010 when I had the same pain so knew what to do and it worked.

In 2010 I raised the issue of pain in my left biceps to our Chiropractor Dr. Barnes-Heath. He asked 'How long have you had the pain?' I replied about six weeks. He asked 'what did you start doing six weeks ago?' I thought and simulating the action said 'Oh I am making a cross stitch picture for Alison's Wedding but it is my right arm that moves... Oh, but it is my left hand that holds the material in one position.' Darren laughed at my self diagnosis and said 'I know you are not going to stop cross stitching what you need to do is change the way you hold the material every few minutes.' It worked!

*It would be really helpful if you let us know if my sharing all this has triggered something for you. Please tell us your stories of attending appointments etc so we can increase our database of information that could help other polio survivors and others with neurological conditions.*



### Can You Help?

A new member has reached out to ask how you cope with the cold temperatures please. A suggestion has been made to the polio survivor that they take pain medication to help with the cold but they are not keen to do this. Any tips you can share about keeping warm?

Thank you in advance.

Please email [info@poliosurvivorsnetwork.org.uk](mailto:info@poliosurvivorsnetwork.org.uk) or post to PO Box 954, Lincoln, LN3 4RA

**Editors Comment:** In my early post polio years and in the winter I would still pop out in the garden to have a quick word with neighbour wearing just a T shirt. I had swum in the North Sea for eleven years May to September as a lifeguard the cold does not bother me.

Then I got an electric scooter March 1997 and after a couple of months was persuaded to use it more and found I was able to spend hours at an Antique Fair, shopping mall, museum, State parks, etc. Doing more for less energy, it carried my bags, brilliant, my quality of life had increased a thousand fold. Being honest, I still try not to think about what I look like on it.

Then winter came and I was at an antique fair with no gloves on [I am hardy I don't need gloves] when I went to get off to use the disabled porta loo and found my hands were so cold they were fixed round the tiller arms. It suddenly dawned on me that I was not 'feeling the cold' not realising that my hands were getting cold. Until I warmed them up they would not move. Time to look at the 'old ladies shops' for socks, gloves, long johns, vests [no not liberty bodices] etc. Wear layers of clothing so its easy to change to my temperature needs. Plus by a woollen hat [I think I look awful in hats but now I don't care what I look like so long as I am warm].

I look forward to hearing others ideas.

To All Our Lovely Members

Thank you for your support over the year. You are all really such an example of resilience. Support has been given in so many ways – donations, card making and purchases, submissions for our newsletter, sharing your life stories, using **smile.amazon** when purchasing online – all very much appreciated.

We would also like to know how we can help you – what can we do to support you. We'd love to include any articles, comments, stories, poems, tips, 'Hello From ...', well wishes to other polio survivors, photos, experiences etc from our members in our next newsletter.

If you would like to submit something please contact us. Any late submissions can be put into the following newsletter.



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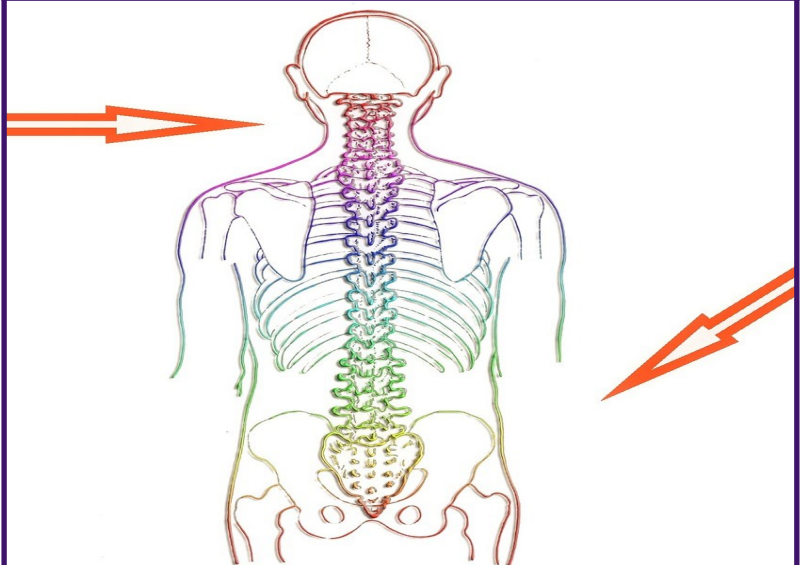
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We were thrilled to hear that Amazon has donated **£11.31** to PSN as a result of member activity between

1 July  
and  
30 September 2020

**A member is very interested to find out how polio has affected the spines of survivors as the years have gone by.**

Please send your experiences to [info@poliosurvivorsnetwork.org.uk](mailto:info@poliosurvivorsnetwork.org.uk) or post to PO Box 954, Lincoln, LN5 5ER



## Items of Interest

### BRITISH POLIO FELLOWSHIP

#### Coronavirus Survey

Our Expert Panel are currently conducting a survey to better understand how the current Covid-19 pandemic has effected Polio survivors. If you would like to take part please download the survey on our website [www.britishpolio.org.uk/coronavirus-survey](http://www.britishpolio.org.uk/coronavirus-survey) and either send to central office by post or email to [joanna@britishpolio.org.uk](mailto:joanna@britishpolio.org.uk)

#### Pain Guide

The Expert Panel has also just released a new extensive guide on pain management. It can be accessed on our website on the factsheets page [www.britishpolio.org.uk/factsheets](http://www.britishpolio.org.uk/factsheets)

### THE BRITISH MEDICAL JOURNAL

Improving our resilience to microbes could be an important non-drug intervention in the fight against Covid19, in addition to ways of preventing transmission, and I agree all public health advice should be evidence based.

One non-drug intervention might be a vitamin D supplementation program to rectify the widespread vitamin D deficiency in the UK which is largely due to a lack of outdoor-living. By now it is well established knowledge that optimal vitamin D is needed for optimal immune function and best defence against microbes, evolution designed humans like that (1). Recently existing evidence was reviewed comprehensively by Linda Benskin (2) showing a causal link between lower than 75 nmol/l blood levels and incidence and severity of Covid19. For comparison, the average D-blood level in England is 45 nmol/l, in Scotland 37 nmol/l (3,4). Several other studies have since also found correlations between vitamin D levels and severe outcomes in Covid19, including in 4.6 million Israelis (5-7). Now, a randomised controlled trial from Spain showed a significant benefit to those receiving vitamin D during hospital admission for Covid19 with more than 90% reduction in ICU admissions and 100% reduction of mortality (8). Although the study had only 76 participants and the authors called for a larger study, there cannot be any doubt, that there is now sufficient evidence for public health departments to engage in implementing a vitamin D repletion program before the next winter rise in severe Covid19 cases.

Unfortunately Public Health advice for all to take a small D-supplement of 10 mcg (400 IU) is insufficient for adults to elevate blood levels to the required optimum, as well as being poorly taken up by some of the Covid19 high risk groups in areas of deprivation.

First, do no harm!

But harm is presently done by tolerating an unacceptably high degree of Vitamin D-deficiency in the UK thereby risking poor outcomes of Covid19.

1. National Library of Medicine <https://bit.ly/2lccDrR>
2. Research Gate <https://bit.ly/3ooH6Cv>
3. NICE <https://bit.ly/3oujJYp>
4. Food Standards <https://bit.ly/2JT7hSI>
5. National Library of Medicine <https://bit.ly/2VLGk6v>
6. The FEBS Journal <https://bit.ly/2le8yDH>
7. MedRxiv <https://bit.ly/33LLQua>
8. Science Direct <https://bit.ly/3gakP8y>

**Editors Note:** On advice we have been taking Vit D 3 for over two years now.

## **Bits that have helped**

*N.B. These are members and other Polio Survivors comments from discussions about issues we are dealing with and are provided to give you a larger database of information that you can share with your health professionals, family and friends. We must advise you that you need to discuss this with the health professionals that you are seeing to ensure there is no contraindication that means that you should not do any of the items mentioned here.*

### **Guts**

"Asteroids" is what my husband answered to the nurse when asked about the constipation he suffers from low gut motility from polio [slow movement through the gut means more water taken out] plus the medications he takes for Parkinsons.

Vitamin C is a natural antihistamine, which means it can lower histamine levels and mitigate allergic reactions and symptoms. Consume plenty of Vitamin C rich foods, like tropical fruits, citrus fruits, broccoli and cauliflower, and berries. Once your body has had what it needs [more if you have a cold, hay fever etc] then it is eliminated from the body and it speeds up the process of food through our guts. We started having Vit C tablets a few years ago but for the last year have changed to taking ascorbic acid powder - nothing else added - and have been taking two of the tiny spoons provided in a bottle of water or diluted fruit juice. We usually have one dose a day but if that does not have the desired effect then we add it to a second drink.

### **Restless, jiffly, aching swollen legs**

A neurological physiotherapist in the late 1990's told me that if we had restless, jiffly, aching legs then we should **get our feet up every time we can**. This helps the blood flow back up our legs and gets the waste products back out of our body instead of pooling in our feet. I got an electric rise leg raise chair and it made a huge difference.

When unable to get feet up at meetings or pps conferences, long flights, etc then back it comes.

I touchtype and use my laptop on my lap on my chair and have the following additions. To support neck have a pillow to fill the kyphosis curve of neck forwards, my elbows rest on the arms of the chair, left hand rests on the front of a 17" laptop keyboard and right arm swivels from the elbow. If I forget to raise my legs then its not long before my shoulders and left arm really ache.

If I sat on a computer chair at a desk then I would be in pain and have to stop working in about fifteen minutes.

### **Swallowing**

Some Polio Survivors have problems with swallowing. We need to take care that we do not aspirate food or drink.

Richard and I both have polio weakened palatal muscles - the ones you can see at the back of your mouth when you say 'Ah'. They work for a few times and then weaken, so when we were only tested once this weakness was not corroborated.

We pace and rest eating and drinking. We have found that when drinking with a straw that we need to take care that we don't suck too hard where the fluid can hit the back of the throat and make us cough. So our recommendation is that you only suck the fluid into the front of your mouth and then swallow it.



## Expert comment - UK approval of Pfizer/BioNTech COVID-19 vaccine London School of Hygiene & Tropical Medicine

2 December 2020

The Medicines and Healthcare products Regulatory Authority (MHRA) has announced that it has approved the Pfizer/BioNTech COVID-19 vaccine for mass national roll out.

**“Today is a good news day, but there are challenges ahead”**

**Professor Stephen Evans - Professor of Pharmacoepidemiology**

The UK is the first country to approve the vaccine for mass vaccination. Professors Stephen Evans and Liam Smeeth react to the news.

**Prof Stephen Evans, Professor of Pharmacoepidemiology, London School of Hygiene & Tropical Medicine, said:**

Today is a good news day. However, we do have to acknowledge several key things that are not being said by everyone

1) We will not be able to change distancing, mask wearing etc for quite some time - months at least, and we don't yet know when or whether that will stop.

2) Making vaccination available is not enough; people need to be convinced so that they do accept being vaccinated

3) We do not yet know about effects of vaccines that are extremely rare, and before we do there will be scares about adverse effects that are coincidental in fact, but perceived by some as being caused by the vaccine. As soon as we vaccinate very large numbers of people there will be coincidental deaths and strokes that occur in elderly people soon after receiving a vaccine. The MHRA and other groups are poised to study these things and to ensure that they are not in fact CAUSED by vaccination, but such events we know will happen, but jumping to conclusions will be unwise

4) Although we are, physically, an Island, viruses do not respect borders. “No country is an island entire of itself; every country is a piece of the world, a part of the world” (adapted from John Donne 1624). We need to ensure low and middle income countries must also get access to effective vaccination. Selfishness will rebound.”

**Prof Liam Smeeth, GP, Professor of Clinical Epidemiology, and Dean of the Faculty of Epidemiology and Population Health, London School of Hygiene & Tropical Medicine, said:**

“The continued progress on vaccines is fantastic news. A route towards a much better situation in the UK is becoming clear. A further circuit breaker in January or possibly February is likely to be needed. But, it is realistic to hope that by March or April the vast majority of older people, care home residents, and those with severe conditions will have been immunised. We can then work towards wider immunisation – with ideally much of the population covered in time for next winter. Life won't ever be the same as it was before COVID-19, but it will feel a whole lot better than now.

“For the foreseeable future – and maybe forever – we are very unlikely to reach the situation we are in with smallpox (gone), polio (almost gone), or measles (controlled in populations with high enough vaccine coverage). Instead, we are going to need to find ways to fairly happily live alongside this virus.

“Maintaining public confidence in the vaccine will be key. Complete, timely data on who has been vaccinated, where, and when will be of enormous importance as we continue to monitor not just coverage, but also safety and effectiveness. Ensuring this data is entered into peoples' NHS general practice records is crucial. General practice has proven ability to rapidly vaccinate large sections of the population, and with adequate support, is ideally placed to lead the COVID-19 vaccination programme.

“Ensuring equitable global distribution remains a major challenge. And equity is the key. Many low-income countries with little resilience in their health systems and wider infrastructures face unimaginable challenges from COVID-19, and distribution of vaccines according to need will require affirmative action from richer countries, working with the World Health Organisation and other key players.”

Original Source Article: <https://bit.ly/2JFf7jI>

## Rita Sandford, of Taunton, who caught polio in 1955 - Somerset County Gazette

[1st December 2020]

*Rita Sandford, who has written a book about her life, with local councillor Simon Nicholls.*

Phil Hill writes:

### **A TAUNTON woman has told how her life was turned upside down by a virus that ravaged lives in the 1950s.**

Rita Sandford caught the polio virus before a vaccine was found as a five-year-old in 1955.

There was no lockdown and people had to carry on their everyday lives not knowing who would be the next person to catch the deadly disease.

Rita was completely paralysed and was admitted to the Cheddon Road Isolation Hospital, where she was put into an iron lung, along with her mother, who sadly died, her brother, who was slightly affected, and father, who remained healthy.

Their home was fumigated and the council marked a large white cross on the door and barricaded the road.

Rita said: "Everyone was frightened."

"I had to spend a long time in hospital while the physiotherapist worked on my arms and legs to see if I could improve.

"Polio attacks the central nervous system killing the nerves which my brain would tell my arms and legs to move.

"Without these nerves working, my body would not respond.

"Not all the nerves were affected and I slowly gained the use of my arms, but not my legs."

Rita was transferred to hospital in Bath, where she was put in solitary confinement if she cried and was locked in the gym one night for not eating her supper.

She said: "It was a hard lesson for a five year old to learn, having just lost my mother, while my father, who did not drive, lived so far away.

"Most disabled people in those times were locked away out of sight. The aim was to get me up and walking so that I would be accepted back into society.

"I gradually walked using heavy full-length leg irons and a spinal support which I struggled to do. I did mainly use a wheelchair for distance."

Rita was allowed home after 15 months and spent many months back in hospital every year. From the age of seven, she received an hour's home tuition every day. She said: "Despite this, I was determined to live an ordinary life. I worked for 30 years, living independently, driving a van from my wheelchair, and went on many exciting holidays with friends."

Rita has written her life story entitled *To Paddle My Feet*, which is available from Brendon Books, Rumwell Farm Shop, Amazon and Amazon Kindle, with all profits going to charity.

Original Source Article: <https://bit.ly/2VEayYR>

# Management Committee [Trustees]

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

Trustee/s - 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](mailto: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](http://www.poliosurvivorsnetwork.org.uk)

Write to us at PO Box 954, Lincoln, LN5 5ER, U.K.

Email [psnadmin@poliosurvivorsnetwork.org.uk](mailto: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

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

*giftaid it*

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*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

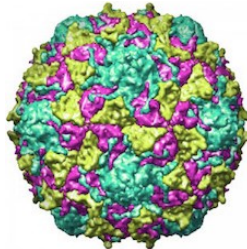
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Printed copies on our headed paper with permission are available.

***Editors Note:*** Articles from Polio Survivors and Health Professionals welcomed



**COVID**



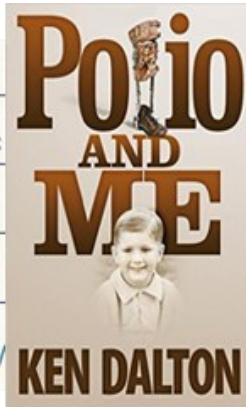
**POLIO**

## Covid-19 & Polio Vaccine - Politics or Science?

**Simon Parritt**  
Counselling Psychologist  
and Polio Survivor

[See page 4](#)

DATE	MATERIAL
First Dose APR 26 1955	SALK VACCINE
Second Dose AUG 9 1955	SALK VACCINE
Third Dose Oct. 19, 1956	
REMARKS	
#2 - July 17, 1956	



## Post Polio Health International:

Explore the past, the present, and help build a promising future for the world's polio survivors at

[polioplac.org](http://polioplac.org)

*There are my braces,  
They set me free  
But, these are my braces  
They are not me.*



**Can you help some of our members?**

[See pages 10, 17 & 18](#)



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