



POST POLIO MATTERS

Polio Survivors Network Newsletter
APRIL 2023 - Volume 11 Issue 1 of 12 [121]

P
O
L
I
O
N
E
N
C
E
P
H
A
L
O
M
Y
E
L
I
T
I
S

L
A
T
E

E
F
F
E
C
T
S

P
O
L
I
O

INFANTILE PARALYSIS POLIO POLIOMYELITIS PARALYTIC POLIO

N
O
N
-
P
A
R
A
L
Y
T
I
C

P
O
L
I
O

S
P
I
N
A
L

B
U
L
B
A
R

P
O
L
I
O

HEALTH PROFESSIONALS - How we can help you?

POLIO SURVIVORS are a **NIGHTMARE**

because the success of the polio vaccine reduced the number of facts taught by your Colleges of Medicine.

The polio virus damage is scattered throughout our body and rarely do two of us have the same level of nerve damage/issues - so no set pattern

We have now developed another condition ending up in your department.

What we respectfully ask is that you take on board that we had damage from the polio virus in our earlier lives and that can have an impact on the way we respond to questions

Change asking "CAN you" to "HOW do you" do an action **and see how we developed our way to achieve that action**

Single Action Manual Muscle Testing

will not show weakness that starts later than the first action

Sedative and muscle relaxant medications and anaesthetics **we need to start on much lower doses and titrate up if needed**

Post-operative recovery times

we need to start slowly and can take much longer to recover

Standard OT equipment **we may need it modifying**

Levels of therapy

we cannot do ten repeats, maybe 3 or 4 at a time.

MANAGEMENT OF POST POLIO IS BY PACING AND RESTING

Continued on [pages 8 to 13](#)

POST-POLIO SYNDROME

POST-POLIO SEQUELAE

[Lincolnshire Post-Polio Library](#)
100+ articles

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

| | |
|------------------------------|---|
| Page 2 | Contents, donations |
| Page 3 - 4 | Editorial by Hilary Boone |
| Page 5 - 6 | From our Chair Simon Parritt |
| Page 7 | Verite Reily-Collins, AgeUK, Channel 4, PSN Annual General Meeting |
| Page 8 | Management of Post-Polio Syndrome. |
| Page 9 | What is Poliomyelitis? |
| Page 10 - 11 | Post-Polio Information for Health Professionals working in other specialities. |
| Page 12 - 13 | How the Polio Virus affects our nerves. Why we need to Pace and Rest Activities and use Aids, Equipment and some human help and the benefits of doing all this. |
| Page 14 - 15 | Explanation of some other issues Polio Survivors are experiencing. |
| Page 16 - 17 | Toni Writes, From our Readers, What You Need to Know About My Condition |
| Page 18 - 19 | Our Advice to Polio Survivors - Getting Ready for an Appointment, Where Should I go? Who Should I see? |
| Page 20 | From Our Archives - Frog Breathing |
| Page 21 | Naidex, Occupational Therapy Equipment |
| Page 22 | Warn & Wise Scheme in Lincolnshire, Easyfundraising, Funnies |
| Page 23 | Management Committee, Donation information, Articles to support PPS |
| Back page | Channel 4, New Book - Making a Difference, Rare Patient Voices |

Donations and Charity Incentives Paid

(since last newsletter)

| | |
|---|----------------|
| Donation (J Dunham) | 15.00 |
| Donations raised at funeral of C Oliver | 80.00 |
| Smile.Amazon | 11.94 |
| Donation (Lincolnshire Neurological Alliance) | 50.00 |
| Gift Aid from donations Apr 22 - Mar 23 | 53.75 |
| Donations raised at funeral of D Taylor | 515.00 |
| Donation (V Scrivener) | 30.00 |
| Donation (D & J Shaw) | 12.50 |
| Total | £768.19 |

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

Thank you so much!



PayPal donate link:

<https://bit.ly/2KzyAvE>

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

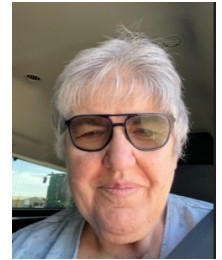
Articles in this publication may be reprinted in full with acknowledgement of this Newsletter name, volume, issue and date. Exceptions are where written by an external author/newsletter when permission must be gained from the original author/s.

Editorial by Hilary Boone

16.3.1947 - Summer 1952 - 1962 - 10.10.1988 - 25.11.1995 - 5.4.2023

Six very important dates for me.

- 16.3.1947 The day I was born.
- May 1952 The day I became paralysed waist down with poliomyelitis.
- 1962 The year after operations on both feet I reached my best recovery level.
- 10.10.1988 The day I fell and started to have new and unexplained issues.
- 25.11.1995 The day I replied that I was not better but had had polio in my earlier life and asked could that be the cause of the **last seven years unexplained problems**.
- 5.4.2023 Today 27.5 years of gradual functional decline, managing well by pacing and resting but the doing time is less and the resting time is more [especially after Covid] and using more aids and equipment and physical help from others.



Far too many polio survivors around the world are reporting being told things like “you don’t look as if you had polio to me”, “Post-polio does not exist and even if it did you would not have it” “oh its post polio live with it”, or “It is just old age it is nothing to do with polio”, etc. I am sure our readers have heard many other responses.

Your committee have been discussing what information we have gleaned that might help our members **and the health professionals that we are being referred to** in other specialities.

This led to the text on the front page and the article continued on pages 8 to 13. If any members or readers of this newsletter from anywhere in the world have any additional information or experiences they would like to share please send them to us. It is only by sharing with other Polio Support Groups around the World that we [and others] can add more information to our databases of issues and ways to manage them.

We are all different - **a nightmare for health professionals** - but rarely does the information not help someone. We would rather have ten copies of the same information than none, so please get in touch.

As I typed this my very early years of researching into Post Polio dropped into my mind and I had to chuckle. I will admit that in the first year I printed off article after article that I found and you could have wallpapered my whole house!

We learned in 1996 that Polio was a half hour lecture along with leprosy for doctors in training . Over the next few years speaking with local members and other polio survivors on our charity telephone line we heard about health professionals throwing the information handed over into the waste paper bin saying it was rubbish. One person having paid for the printing asked a nurse to get it back only to find that it was no longer in the waste paper bin. Others reported being told “you do not look as if you had polio” as the health professional followed from waiting room to consulting room prior to any examination. At a conference a neurologist speaking on Multiple Sclerosis told me “Don’t send me any polio survivors I know nothing about polio”.

Your committee at that time started to discuss all this. We tried play acting as a health professional to see how would we react if we came to see us. We began to see how difficult it would be for a health professional having only been taught a few facts about polio, probably only seeing those medical book photos of the most severely affected, to suddenly find themselves opposite us in a consulting room. Remember most of us have been having problems for some years before we took the plunge to seek help and the last place we want to be is in their office. I know my facial expression would give away what I thought if they said something not quite correct!

We developed My Polio Life which suggested that you self assessed how you did actions of daily living and put them in order of importance. [\[see overleaf\]](#)

Then find out how much time is likely to be allowed for your appointment and practice being you and the health professional to see what you might be able to talk about during the short time allocated. Pick the problem that was affecting you the most so that they could assess the issue and discuss it. If there was time for the next issue on your list then you could continue with that or ask for another appointment.

It is not the fault of a health professional if they have not been taught enough facts about the polio virus and how it affected our bodies. There are many conditions to learn about and that is why many health professionals specialise.

So in 2023 we have tweaked our advice to the following.

What is important is that you are well prepared for every appointment with specific information on the issues you have been experiencing. [See [page 18](#)]

MY POLIO LIFE - we believe is the best starting place to read through and decide how the pages might help you build up a file of information about your Polio Life. This file is for you to record any items that you think will help you pick out relevant facts for each future appointment. Add test results, photographs, anything that corroborates the stages of your polio life.

<https://poliosurvivorsnetwork.org.uk/new/wp-content/uploads/2021/07/My-Polio-Life.pdf>

You could ask the person attending an appointment with you to bring the file with them in case you need to refer to it for a date or test result. We do not recommend having this file on show. A definite no no is bringing a bagful of medical articles with you. Imagine if you were the health professional and knew little about how polio survivors manage their lives, and you saw your next patient dragging a bagful of medical articles behind them!!

USING Page 10 of [My Polio Life](#) - Actions of daily living. Work through our list and add anything missing. How did you do each action when you were at your best? Believe me we have seen polio survivors that have developed the most amazing ways to complete tasks. However when asked by health professionals can they do the action they have been so proud to say YES, but it never occurred to them that the health professional now had absolutely no idea how they achieved this. Next, when did you start to have new issues? Have these issues increased and at what intervals? How are you doing the action now? **The changes are the most important facts that you need to discuss with your GP and other health professionals.**

Example 1, 2004. I asked the physiotherapist “why am I scrambling eggs with elbow rotation”? Her answer after assessment of the specific muscles that I should have been and were using - “because the muscles in your right wrist are very weak.” There is no way I could keep repeating an action as a Polio Survivor so I had just developed another way to do it.

Example 2, 1990 to 2023. Getting up from the floor. I have gone through seven different ways since 1990 but in 2021 realised I now did not have enough strength in my arms to push myself up onto the low stool. I had to butt shuffle to the bathroom and with the help of a carer be hoisted up by our ceiling track hoist till I could sit on the side of the bath. Take a few minutes to catch my breath and then it was stand and walk with walker but since my 12.7.22 fall [legs just gave way and I dropped to the floor] I must transfer to an electric wheelchair.

It is now 34.5 years since the fall that kicked off my post polio syndrome. It has not been easy seeing my NORMAL change over and over again but with support life is still great. The most important point has been the generosity of other polio survivors sharing stories of their lives.

We hope you find the remainder of this newsletter helpful in your PPS journey.

Your Committee needs help please. We are doing our best to manage our physical health, getting older and dealing with all the paperwork that brings. If you could spare us an hour or two a month to take on a task then get in touch. Our meetings are held on the internet but with the facility of adding someone via their phone. All members/readers are welcome to send us any info on anything that might help us manage/enjoy our lives move fully.

From our Chair ...

The Hospital Experience

For the first time in 25 years I was admitted to hospital for an acute event. I thought that despite my own issues, important lessons can be learned about how we need to be pro-active and prepare, just in case. As we age, we gather more conditions and risks and so the importance of polio as a pre-existing condition becomes vital in getting correct and safe care.



Disabled in hospital

Being a disabled person and a polio survivor in an acute hospital environment is not easy for us or the staff. Being ill is one thing, but being a polio survivor poses problems for both the quality and safety of our care. Being 'ill' is something hospitals are there to deal with, but the complexity of my PPS muscle weakness and breathing issues are largely unknown territory for all nurses, medics (including consultants), physios and radiographers. No one has seen or often even knows what polio is. So they will ignore it unless you, or your advocate, make it absolutely clear what you have and importantly what you need as a polio survivor.

I am lucky but ...

I am extremely lucky having my wife, Alexa, who has had to suffer my slight obsessiveness around everything from my ventilator use to test results and even my preferred medications. Her expert ability and familiarity with everything from washing, dressing and even sometimes eating is invaluable. I am aware that the combination of being disabled, a polio survivor and a psychologist can be challenging for those who care for me. The fact that she is there to inform and be my advocate and carer in this medicalized, disabled, unfriendly environment was critical. I am also lucky to live 20 mins from a major London teaching hospital where I used to work many years ago. I know many of you are far from such services and expertise but all the more reason to 'be prepared'.

Polio is unknown and confusing

It was 24 hours before there was a bed on a ward. In A&E I overheard a discussion that the ward are reluctant to take me as I am 'too dependent' a reference to my disability issues rather than my acute respiratory infection. I was testing negative to both major flu types and Covid-19 and my chest X-rays were confusing to them as a polio survivor with scoliosis, a spinal fusion and what they referred to as 'odd lungs'. A couple of days later a PCR test identified parainfluenza 3 - a respiratory virus usually affecting young children and rarely more than a cold in adults - maybe the pandemic or my other conditions had made me more vulnerable.

Communication and information issues

My wife and I were constantly asking medical teams to contact my polio respiratory consultant team who were only 10 miles away but in a different health Trust and area. Communication between hospitals is problematic and slow at the best of times! My wife chased up with direct calls herself and eventually some exchange seemed to have taken place, though we were not privy to what or with who. However there seemed to be no sharing of x-rays or other medical data. This is another warning, always ask for copies of all your medical tests and assessments as you can never rely on them being available if and when and you need to share them especially in an emergency situation.

Managing Conflicts

Eventually a bed was free on the respiratory ward. I will leave aside some of the more bizarre, if not comical moments, the most amusing being is a tug of war between my wife and a nurse who was intent on taking away my meds as she thinks I did not need them. Long story but the lesson is be assertive - I kept them.

Inaccessible on so many levels

Having worked as a clinician on wards some years ago it's hard not to compare what seems a very different care staffing system and environment with what I experienced now as a patient. The ward is of course not accessible with little space around the bed, though luckily, I was not using my wheelchair, but the fact that I can't use my arms, seemed not to compute. Again, my wife was doing the bulk of care support from helping me drink to helping with on and off with my BiPap. Of course she has to go home at night, and I was left trying to instruct nurses and HCA (Health Care Assistants) how to use my BiPap and explaining I need help doing the basics from using a urine bottle to feeding and drinking. Leaving the call button close on the bed also doesn't help as I can't use my arms if it slips away. I lay there thinking what if I start choking and I can't get hold of the call button. Worse still do they even know what to do with me and I have my BiPap mask so it would be very difficult to call out.

Inpatient care and disability awareness

Two days in I wasn't offered help to wash or change and I had to repeatedly explain with each shift change how to deal with my BiPap as well as my need for assistance toileting, feeding and drinking regularly. I asked 'politely' if there was actually a care plan in place for me. The nurse looked puzzled and said 'I'll get someone.' I was visited by the 'Nurse' in charge and I explained again, and some things did improve. However I am aware that without my wife being there a large part of the day and evening I would have struggled to get the basic care I needed. No one has ever seen or understands polio and how this impacts other conditions as we all can get as we age. So had my condition worsened I wasn't confident they would cope.

The reality is that there wasn't a full assessment process relevant to disabled people. For this reason it is essential that you have YOUR OWN care plan written out clearly by you prior to admission and if possible to have an advocate. We need, not just as PPS people, but all disabled people to educate and inform that we have impairments and care needs that work for and help us function in our home and that needs to be replicated, or at least understood, when we are in an acute hospital situation. The danger is we are not seen any longer as polio survivors but old people and treated, maybe with good intentions, in a totally inappropriate way.

Bottom line take aways

The ultimate take away is BE PREPARED before you need to be. Have a pack ready which includes instructions to give immediately to those who are treating and providing care when you find yourself in hospital for ANY reason. Make sure if you have a smart or iPhone if your medical data or care needs are extensive and that paramedics (or anyone) can access it without a pass code. Make sure it is updated regularly as your care or medical needs change.

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


Chartered Psychologist. HCPC Registered Counselling Psychologist

You are invited to

**Polio Survivors Network
Annual General Meeting 2023**

Our AGM is being held online on
THURSDAY 29 JUNE 2:00 p.m. BST

Please email
info@poliosurvivorsnetwork.org.uk
for further information



Verite Reily-Collins

PSN Trustee, Health Journalist and owner of www.aftercancers.com

Email: veritegreenbee@gmail.com



Dear Readers,

I am a long standing campaigner for Age UK. Recently, I had the amazing opportunity to speak in Parliament about the unaffordable energy bills older people are facing. It's an issue I feel very strongly about, after I was burdened with a colossal energy bill from my supplier.

I spoke at the All Party Parliamentary Group for Ageing and Older People - it is a meeting of MP's and Peers from all political parties and was chaired by Baroness Altmann, a delightful person who made me very welcome and kept a lively discussion!

I shared my experience including how scary it is to have received an estimate for energy consumption this year. For my one-bed property my bill will be £5,500. That is half my pension! As a Cancer and Polio Survivor, it is so important to me to get across that older people need heat to survive. Many have chronic medical conditions. Some stay at home longer and move around less, so easily get colder, - sometimes dangerously quickly. We also need electricity to light homes, run stairlifts, charge mobility scooters, operate alarm systems, etc.

It is absolutely critical we're given bills that we can afford to pay, especially when many of us are on such tight incomes. That is why I was so grateful to have the opportunity through Age UK to tell MP's directly what older people are facing this winter.

I'm hopeful that sharing my story might mean politicians, from across the political spectrum, will support our campaign for a discounted energy deal for disabled people, carers and other people who are struggling with bills.

Website www.ageuk.org.uk/campaigns

Twitter [@ageukcampaigns](https://twitter.com/ageukcampaigns)

Age UK Lincoln & South Lincolnshire is a registered charity (1078539) and company limited by guarantee. Registered in England and Wales No: 3777156. Registered Office: 36 Park Street, Lincoln, LN1 1UQ. Age UK Lincoln & South Lincolnshire is an appointed representative of Age UK Enterprises Limited which is authorised and regulated by the Financial Conduct Authority for insurance mediation. Financial Services Register Number 311438.



Verite Reilly-Colins was recently interviewed by Channel 4 news. Watch the short piece here <https://bit.ly/3L8k55e>



Now that Smile.Amazon is no longer available for charity fundraising we have registered with [easyfundraising](https://www.easyfundraising.com), which means you can help us for FREE.

Over 7,000 brands will donate to us when you use easyfundraising to shop with them – at no extra cost to yourself! All you need to do is sign up and remember to use [easyfundraising](https://www.easyfundraising.com) whenever you shop online. It's easy and completely FREE!

Management of Post-Polio Syndrome.

Huge variety of strategies to manage a huge variety of actions.

BUT - how can we meld these into treatment for other conditions?

Your committee and more and more members are experiencing increasing issues when we are being referred to another speciality, visit A&E, admitted to a ward, etc.

Each department/hospital ward has their specialisms, routines, experience of assessments, treatments, etc., but when written they did not appear to allow for the fact that there are many people with other conditions that are unable to fit their regime.

The problem arises when a Polio Survivor with a diagnosis of Post-Polio Syndrome is already managing their condition in a way that provides them with the best outcomes and some of those ways are not easy to slot into the new departments treatment expectations.

A. New Out-patient situation we are being given what is worrying you/symptoms paperwork to complete; exercise regimes we are expected to comply with; told we will provide this equipment for your home etc that this department would normally offer'

1. The **paperwork** covers this condition but does not allow us to add in answers/information relating to the fact that we are already dealing with some of these symptoms/issues.
2. **Exercise regimes** - without the knowledge of how polio survivors manage their symptoms and lives we are constantly being pushed to try harder?
3. **Standard equipment** for the home often does not work for us because we perform actions differently and the equipment could need modifying or might not work at all and staff will have to see what else they can come up with. [This is now in the Masters OT Course]

B. In-patient situation

1. Our medical records state things like 'fully mobile with aids' but health professionals have no idea that we have developed trick ways to manage this and now we have another injury/condition we are struggling to find a new way of managing our normal actions.
2. We are seen to be walking across the ward but it has not been realised that our upper body is very weak and once lying back in bed we can do very little for ourselves.
3. The type of mattress we have been given does not match what we have at home, e.g. An air mattress does not allow us to push ourselves up and move around on it.
4. The bedside table is on the wrong side and does not have the drawer handle that you use to get in and out and turn over in bed, etc.

Your committee have put together some information that we hope will help you and your new health professionals manage situations more easily that you might come up against.

Remember if you are reading this and you have some suggestions/advice/other examples then please get in touch with us. The more we share the more we learn and the better we can help each other.

OTHER MEDICAL CONDITIONS.

We can have these instead of or as well as Post-Polio Syndrome. **Other Specialities** we ask that you please take into account that our prior polio damage can impact on how we react/are able to react to your specialisms paperwork/routines/treatment etc.

[Page 9](#) What is Poliomyelitis. Post-Polio Syndrome Criteria for a Diagnosis & Symptoms.

[Page 10/11](#) Post-Polio Information for Health Professionals working in other specialities.

[Page 12/13](#) How the Polio Virus affects our nerves. Why we need to Pace and Rest Activities and use Aids, Equipment and some human help and the benefits of doing all this.

[Page 14/15](#) Explanation of some other issues Polio Survivors are experiencing.

WHAT IS POLIOMYELITIS?

POLIO is the name given to one of three enteroviruses, Polio 1 [Brunhilde], Polio II [Lancing] and Polio III [Leon]

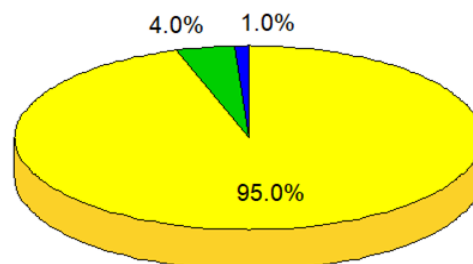
Viruses enter the body through the mouth and go on through the gut and in some cases even further to the central nervous system. There are over 70 enteroviruses and Coxsackie, A9, enterovirus 70, 71a among others can cause 'polio like paralysis'.

The live vaccine is excreted for up to six weeks. Why families are/should be reminded to take extra care during the six weeks after a live vaccination. The figure was 1 in 2 million vaccine recipients of the live polio virus develop paralytic polio but recently this figure has increased. See the latest information at <https://polioeradication.org/>

THE RESULTS OF INGESTING A POLIO VIRUS

95.0% show no clinical symptoms

- 4.0% get ill from mild flu through weakness [non-paralytic polio]
- 1.0% become paralysed [paralytic polio] and with Bulbar Polio need iron lungs and some did not survive.
-



NEW FUNCTIONAL DECLINE first appeared in 1875!

Four Case Histories were reported in the French literature by Carriere, Raymond, & Cornil and Lepine. These patients, all young men, had paralytic polio in infancy and developed new weakness, not only in previously affected muscles **but also in muscles believed to be uninvolved at the time**. All had physically demanding jobs and performed repetitive activities.

[Post-Polio Syndrome : Pathophysiology and Clinical Management, Anne Carrington Gawne and Lauro S. Halstead. Clinical Reviews in Physical and Rehabilitation Medicine, 7(2): 147-188 (1995)]

CRITERIA FOR A DIAGNOSIS OF POST-POLIO SYNDROME

1. A history of remote paralytic polio or 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, Arch Phys. Med. & Rehab. Jan/Feb 2000]
2. A period where we recovered.
3. A stable period of functioning, from 10 to 50+ years.
4. New symptoms for which there is no other explanation

POST-POLIO SYNDROME SYMPTOMS:-

Fatigue often overwhelming both physical and mental

Loss of muscle strength and/or use also in muscles below the line of clinically evident weakness at the time of the original infection.

Pain in muscles and joints

Trouble breathing and swallowing

Problems sleeping.

Intolerance of cold causing muscle weakness and sometimes **burning pain and/or discolouration of limbs.**

POLIO VIRUS NERVE DAMAGE IS SCATTERED THROUGHOUT THE BODY

THERE IS NO SET PATTERN - THERE ARE NO TESTS

IT HAS TO BE A DIAGNOSIS OF EXCLUSION

POST-POLIO INFORMATION for HEALTH PROFESSIONALS

Working in non-polio related departments.

<https://poliosurvivorsnetwork.org.uk/new/i-am-a-health-professional/>

Polio Survivors Network was made aware in the late 1990s that Colleges of Medicine had been reducing the facts taught about polio. This was due to the polio vaccine success (12th April 1955) which reduced the number of people being infected by one of three polio viruses.

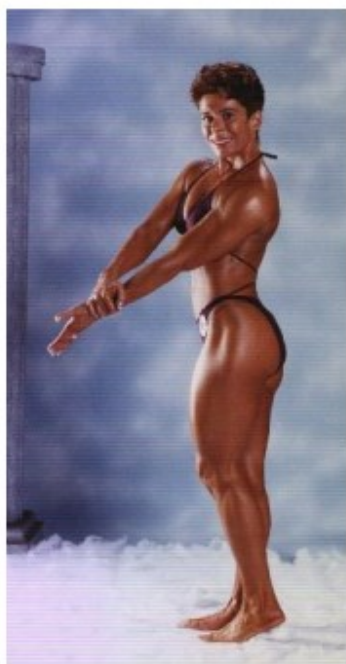
Some health professionals told us that polio was not mentioned during their training, others remember having a half hour lecture with leprosy and seeing photos of withered limbs and patients in iron lungs. Most of us do not match these photographs.

Polio Survivors Network research has picked up three possibly missed issues:

1. The high level of recovery many polio survivors reached
2. How questions are asked by health professionals and how polio survivors answer
3. Often a single action manual muscle test is used

Many members who have been in the armed forces, police, professional sportsmen and women, and had other physical occupations report being told 'you must have had a mild case' when in fact they had paralysis in at least one limb and some spent some weeks in iron lungs. The following slide is taken from the PowerPoint Presentation – Information from a Polio Survivors Perspective – and used by the author for over 20 years.

Problem 3 - Which lady is the Polio Survivor?



The one on the left
or the one on the right?

The picture on the left
was taken in 1995

The picture on the right
was taken in 2003

They are the same person.

**You need to find out more
about the level of
achievement your
Polio Survivor patient
reached before the start of
their new symptoms**



Gwen - Thank you for permission to use your photos

Polio Survivors Network October 2018

33

This slide is taken from a variety of PowerPoint presentations by our Founder, Hilary Boone. People who had polio and are experiencing **new** symptoms, after years of stable functioning, need to be assessed by medical professionals who are knowledgeable and experienced in the effects of the original polio infection, level of recovery, and post-polio. Unfortunately for health professionals, there are no tests to confirm post-polio, tests can only rule out other conditions, it is a diagnosis of exclusion.

Assessing a polio survivor, especially one who has not long learned about this later stage to having had polio, is not easy. Polio survivors are reported to be strong-willed, determined, and even pig-headed people who have got on with their lives achieving as highly as they can despite their level of polio damage. The last place a polio survivor with new medical problems wants to be is in a doctor's office. Nearly all polio survivors I have met, fit this category including me. Many have blocked or suppressed memories and emotional responses to sights, smells and sounds from the past. One member only a year ago asked why the nurses in the UK did not wear black. Further questioning elicited the fact that he had been in a catholic hospital when he was having his surgeries aged 5 to 8 and the nurses were nuns first. Not once in 60 years had he made the connection.

It is therefore important to note that to be in your office polio survivors are likely to have been experiencing symptoms over a long time – months and even years – and they/we are reluctant to admit that actions of daily living are becoming harder. As actions of daily living become more difficult they adapt how they do an action and it becomes their new norm. Often they do not notice or don't want to accept that this is happening. It is very hard to change from our childhood 'Use it or lose it' mentality. So many of us will respond to advice to pace and rest or start using aids and assistive devices with 'But I am not there yet'.

You can ask five polio survivors 'Can you get up a flight of stairs? All will answer 'Yes' and be proud that they can do this action. However, if you had asked 'How do you get up a flight of stairs? The responses would be, [a] walks up, [b] walks up right leg first, [c] does the same but stops half way to rest, [d] also has to use the banister rail to pull themselves up and [e] sits on the stairs and goes up backwards one step at a time pushing up with their arms. Help us tell it like it really is by asking us 'How do we do x, y or z?'

TAKE THIS PATIENT FOR EXAMPLE



He was born in 1946 and grew up and went to school in New York.

He made the Gymnastics Team at College.

At the University of Tucson in Arizona, he gained a Bachelor's Degree in English Literature, a Masters Degree in Special Education and a Bachelors in Nursing. He worked as a private school teacher in English and Science then as a Critical Care Registered Nurse in Cardiac Surgery.

MEET CHARLIE

On the left, he is 10 years of age.

On the right, he is 53 years of age.

The photo above was when he was 19 in his college gymnastic team.

<https://www.ssa.org/charlie-lite-minner/>

Member of POLIO EPIC Inc -
www.polioepic.org

LIST OF POLIO SURVIVORS -
<https://bit.ly/41hnzb5>



HOW MANY WOULD YOU HAVE REALISED HAD POLIO IN THEIR EARLIER LIVES?

CHART 1 - HOW THE POLIO VIRUS AFFECTS NERVES

CHART 2 - WHY PACING and RESTING ALLOWS US TO DO MORE?

The Polio Virus damages nerves

Acute Polio As more nerves die the muscle became weaker through to paralysis.

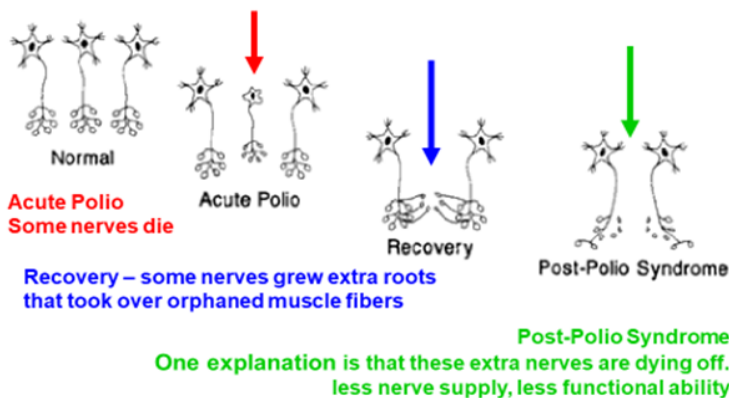
Recovery Nerves that did not die grew axonal sprouted roots that took over some of the orphaned muscle fibres, ? The muscle became stronger. Polio Survivors renowned strong willed and determined pushed ourselves to the limit and beyond to achieve. Anyone said we could not do something then we would do all we could to prove them wrong.

Post-Polio Syndrome is a label given to many NEW symptoms. It is thought that one of the explanations of new weakness is that the axonal sprouts are dying off. Less nerve supply to the muscle and it becomes weaker.

Pathophysiology and diagnosis of post-polio syndrome

Daria A. Trojan*, Neil R. Cashman

Department of Neurology and Neurosurgery
Montreal Neurological Institute and Hospital
McGill University Montreal, Quebec, Canada



It can take Polio Survivors months and often years before they seek medical help. The last place any Polio Survivor wants to be is in a doctors office. When we get that far, we have probably needed help for many months, sometimes even years. We do not like admitting actions are getting harder.

Polio affected muscles. When they start to weaken we are advised to pace and rest our activities. The chart to the right explains why Polio Survivors need to do this because there are less nerves in a polio affected muscle resting to take over when the working part of the muscles needs to rest and another part of the muscle takes over.

No Polio. On average 30% of muscle is used to perform an action and there is 70% resting to take over. Normal muscle power is graded 5.

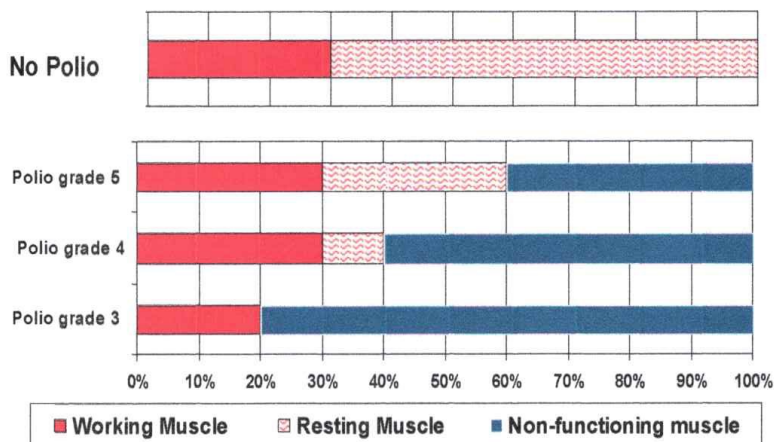
Polio Grades. When grading Polio Muscles there is likely to be far less nerve supply to that muscle. A Polio Muscle graded as 5 is likely to only have 60% nerve supply. 30% working and 30% resting. Polio Grade 3 only 20% working muscle, no resting.

WE KNOW THAT PACING AND RESTING ALLOWS US TO DO MORE

WC Beasley [1961] and Jaquelin Perry [1995]

Found on research that Polio Muscles functioned at a lower rate.

Grade 5 at 60% - 4 at 40% - 3 at 20% - 2 at 10% - 1 at 1%



Nearly all Polio Survivors... achieved highly and way more than was expected of us from the level of nerve damage from our initial polio. A few remained in Iron Lungs, some progressed to a variety of other ventilation equipment, traches and oxygen. Some visibly lived with atrophied limbs, wore braces used canes, arm crutches, manual and electric wheelchairs. Many raised children and worked full time despite all the equipment they had to use. Others recovered that well [even from iron lungs and paralysis] that externally we do not look like the photographs in the medical books. Many went into office jobs but also Teaching and Medical Careers. Others physical professions like the Armed Forces, Police [author initially waist down paralysis], Fire Service, Professional Sportspeople, working on the land etc.

CHART 3 - HOW PACING/RESTING, USING ASSISTIVE DEVICES WORKS.

CHART 4 - HOW TO USE ENERGY TOKENS TO PLAN THE WEEK

Polio Survivors through Recovery and Stable Period of Function

pushed themselves to the limit and beyond, often working full time jobs plus hours as volunteers, bringing up family, etc.

Once muscles start to weaken

continuing to push hard to finish a task causes a lot of pain and exhausting fatigue. When you stop there is no energy for any other tasks. Less is achieved overall.

Stopping 20% before completing an action and resting allows that muscle to recover and do the action again.

Pace and Rest each activity and use any aid/assistive device/human help so that you do not waste energy allows more to be achieved overall with less pain and less fatigue. As much as 240% more has been medically recorded.

USE ENERGY TOKENS, £10.00 A DAY AND £70 PER WEEK.

There can be no set energy token chart as we all manage our lives differently. Write down your full days average activities and share out your £10.00.

Now complete a chart something like the one on the right. *Where will you use your tokens?*

Remember washing, dressing, food preparation, eating etc must come first.

Medical appointments/therapy next. **Tip, bathe the day before. Only wash the bit they are going to look at on day.**

Now shopping and social events adding rest time as you go.

If you need 14 tokens one day then this chart allows 7 for the days either side.

Using electric wheels means you can do more shops. Have a riser recliner taken to the Reception and stay longer meeting more folks. What aids/help can you use so that you don't waste energy and **do more of what you want to do.**

Changing the habits of a polio lifetime of pushing yourself to the limit 'because I can' is not easy but

PACING AND RESTING WORKS!

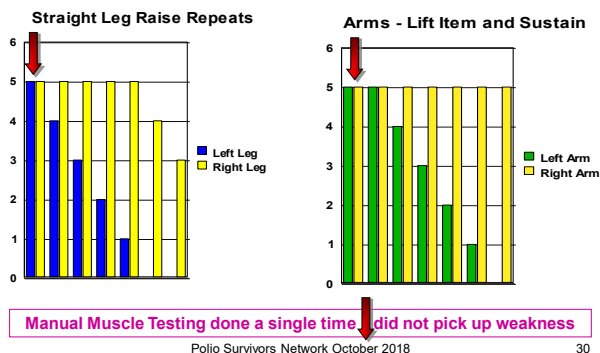
| ACTIVITY BEFORE AND AFTER CHANGE | Time of day | Mins Doing | Mins Resting | Pain Level | Fatigue Level |
|---|----------------------|---------------|----------------|------------|---------------|
| Getting up, showering, dressing | 8.00 | 30 | 90 | 3 | 5 |
| Change to showering Put on underwear and callipers Now add top clothes | 8.00 8.25 8.40 | 15 10 5 | 10 10 10 | | |
| <u>30 mins resting instead of 90</u> <u>LESS PAIN and LESS FATIGUE</u> | | 30 | 30 | <u>2</u> | <u>3</u> |
| Walking round one store picking up items and pushing trolley. | 11.00 | 15 | 180 | 4 | 7 |
| Use electric wheels and you are now able to visit many more shops | 11.00 | 180 | 120 | | |
| <u>165 mins more doing time.</u> <u>120 mins resting instead of 180</u> <u>LESS PAIN and FATIGUE.</u> | | <u>165</u> | <u>60</u> | <u>2</u> | <u>4</u> |

| | MON | TUE | WED | THU | FRI | SAT | SUN |
|-------|--------|---------|--------|----------|--------|-----------|--------|
| NIGHT | | | | | | | |
| 07.00 | Wash | Wash | Wash | Bed | Bed | Wash | Bed |
| 08.00 | B'fast | B'fast | B'fast | B'fast | B'fast | B'fast | B'fast |
| 09.00 | Dress | Dress | Dress | Rest | Rest | Rest | Wash |
| 10.00 | Rest | Driven | Rest | Wash | Wash | Dress | Rest |
| 11.00 | P'work | Therapy | Shop | Dress | Rest | Driven | PJ day |
| 12.00 | Rest | Driven | Shop | Lunch | Rest | Wedding | PJ day |
| 13.00 | Lunch | Rest | Lunch | Driven | Lunch | Wedding | PJ day |
| 14.00 | Rest | Lunch | Shop | Hosp | Rest | Rest | Lunch |
| 15.00 | P'work | Rest | Driven | Hosp | Rest | Reception | PJ day |
| 16.00 | Rest | Rest | Rest | Driven | Rest | Reception | PJ day |
| 17.00 | Meal | Rest | Rest | Rest | Meal | Reception | PJ day |
| 18.00 | Rest | Meal | Meal | Rest | Rest | Reception | Meal |
| 19.00 | Rest | Rest | Bathe | Snack | Bath | Driven | PJ day |
| 20.00 | Bath | Rest | Bed | Bed | Hair | Bed | Bed |
| 21.00 | Rest | Bed | | | Bed | | |
| 22.00 | Bed | | | | | | |
| Event | P'work | Therapy | Shop | Hospital | Hair | Wedding | PJ day |
| | 8 | 12 | 7 | 14 | 7 | 17 | 6 |

SINGLE ACTION MANUAL MUSCLE TESTING.

Assessment time during appointments can be short and Single Action Manual Muscle Testing used. This can be **unreliable where weakness in muscles is not evident until a few repeats or some seconds later than the time available for testing.** There can also be issues where the pattern of movement is not tested, e.g. Arm tests of grip my fingers, pull then push against me.

I self tested Straight Leg Raise Repeats - no pressure against action and Lift Item with Arms and sustain at 3 second intervals



“I spent seven years following a fall with new weakness and pain in my left arm with no corroboration of the reported symptoms.

From 1988 to 1975 normal results for Single Action Manual Muscle Testing had been recorded on all my medical reports.

In 2004 I asked my new rehabilitation consultant for a baseline physical assessment which was undertaken by a senior physiotherapist.

She started the appointment wanting to explain a new condition called Post-Polio Syndrome. I explained who I was and we started discussing assessments and why I believed they failed as the diagram above. We then concentrated on issues I was having.

Getting up from the floor now - I was using hamstrings and back extensors.

I asked, “Why am I now scrambling eggs with elbow rotation?”

Specific examination now found that I had very weak supinator's in my right wrist.

Of possible interest is that in 1989 when receiving the results of my nerve conduction studies I was told they would operate on the ‘carpal tunnel syndrome’ in my right wrist. I refused as all the pain and weakness was in my left arm. The Doctor honestly suggested that I had mixed up my left and right sides. Could that ‘carpal tunnel syndrome’ have been polio nerve damage?

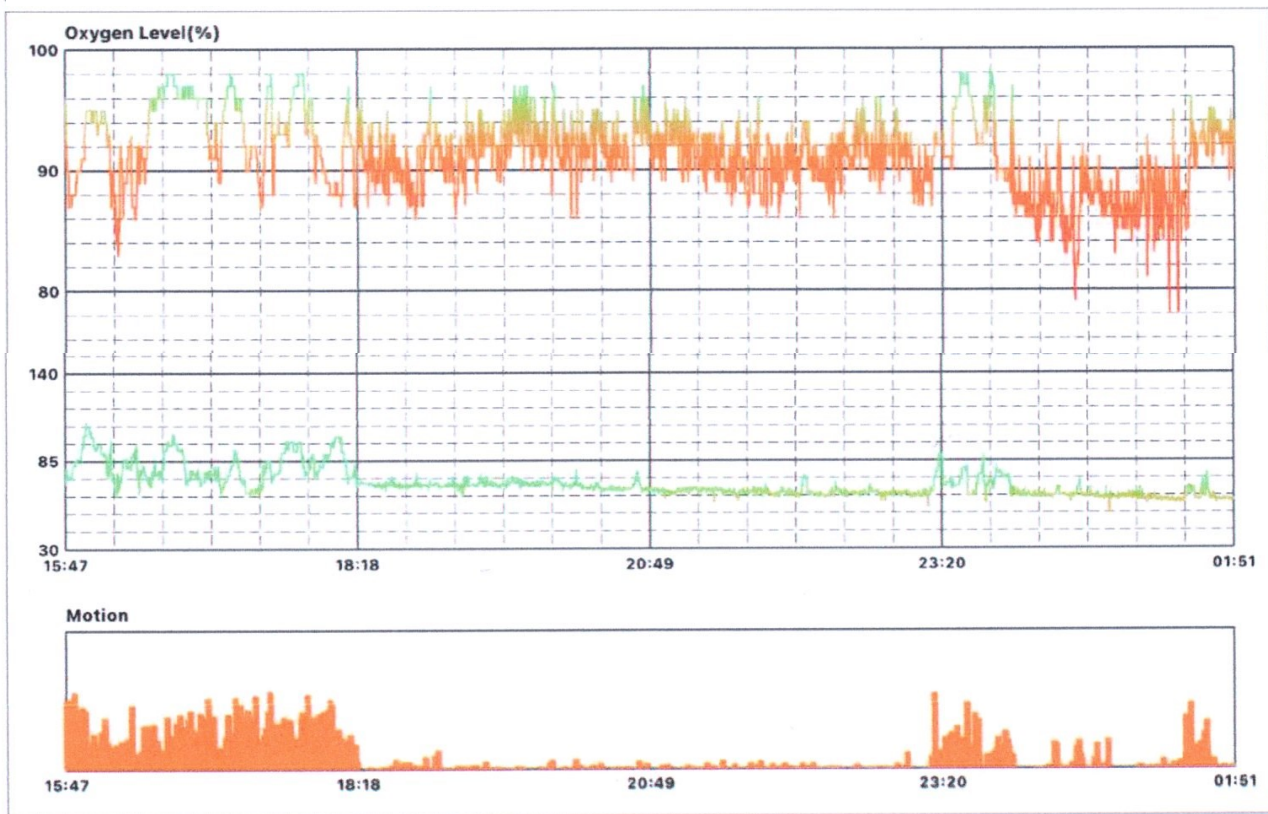
*We therefore advise our members that
the most important facts to give health professionals are relating
the changes in the ways they are now having to do actions of daily living
ask why this has happened?*

To assist polio survivors to ‘see’ the changes in black and white (although this is often a difficult experience for them) we suggest that they make up a file of information on their lives. To assist them with this we have formulated a **Self Assessment Tool called ‘My Polio Life’** Link to the tool is here <https://tinyurl.com/mrrvzwj6>

Completing page 10 has been eye opener for many. Up to then little changes became the normal way of doing the action. **Provided they could still say “Yes” they could do the action polio survivors ‘did not want to address the fact that changes were taking place’.**

| Action | At Best | New Issues |
|-----------------------------|---|---|
| Lifting Saucepan | Lift large pan full of potatoes and drain. | Then sliding pans across hob and work surfaces and tipping pan of veg on edge of sink into a colander. |
| Climbing a flight of stairs | Two at a time – one flight only at Senior School Normally. | First change to right foot first every step. Using banister rail and stopping for rests. Sitting on the stairs and going up backwards pushing themselves up a few steps at a time. |

POLIO SURVIVORS PULSE OX RESPIRATORY CHART



A good result as the chart above has been reported on, even by a Consultant with knowledge of polio survivors, as FINE. No need for any ventilator support.

Patient diagnosed Severe Mixed Sleep Apnoea resulted in an average of 7 hours a night on a bi-level ventilator.

7 years later following a heart attack stents were fitted resulting in better circulation but also a new symptom of excessive sticky saliva that now needed managing. Also has another neuro condition causing varying ability levels that can change anytime. Mix the two conditions together and the patient struggling to swallow the saliva choked and unable to move enough to remove the mask panicked thinking they were going to die.

Panic attacks increased over the next five years and bi-level usage reduced. Referral was requested to another hospital and within 15 minutes it was explained that when second swallowing the Bi-level thought the patient was asking to breathe in and triggered the [IPAP] IN pressure of 15 causing the patient to choke. Hospital advice that someone stays in the room to remove the mask when choking occurs enabled the patient to resume usage of a bi-level ventilator.

The need for usage is to enable the Polio Survivor to pace and rest the usage of their secondary accessory muscles of respiration. Charting has shown that at least 60 minutes is needed for best daily function. This is currently done in two sessions. Resting in the afternoon and after medication for his other condition at 6.30 a.m.

Send out the perfect feel good, do good Thank You Card!
 Make someone smile with a personalised card that supports a good cause. Available at the online charity card shop

cards £2.50 + donation + p&p
 e-cards £2.00 send to 25 people

making a difference



Send ecards that support Polio Survivors Network even when you don't know the recipients email address - take a look here for more information

<https://tinyurl.com/4n2uhmxe>

Toni Writes ...

I hope this newsletter finds you doing ok. I just had to include the photo of this beautiful big cat! Those eyes!!

I was feeling quite reflective last week and was thinking how life can certainly twist and turn so quickly. I wonder if you have ever questioned your decision making. I watched a piece on the internet about making wise decisions. It explained that our actions are usually the result of decisions we have made. Some decisions are made after a lot of serious thought, but others are made very quickly. No matter how much thought goes into deciding wise decisions bring positive rewards.

We all want to make wise decisions, but it is important that from time to time we review decisions we have made. We may find that we need to make a few adjustments. It can often be wise to consider the future when making decisions e.g. will we need a larger/smaller space in a few years' time, will I need to go from a walking stick to a more substantial aid and will this require a larger boot space in my vehicle, etc. Thinking like this can help avoid expense and upheaval later. It is not easy to do though, accepting a circumstance and then planning with it in mind.

I also wanted to take this opportunity to thank you so much for the generous donations we have been receiving recently - it really is much appreciated. I have also thoroughly enjoyed the emails we have received; you are a really very inspiring bunch (or whatever the correct collective noun for polio survivors should be - host, crew, gaggle? - why not send me your suggestions)!

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 enjoyed reading the latest newsletter.

I had bulbar polio when I was just 2 years old. I am now 71 and have 2 grown up children and 3 grandchildren. I lost the use of the left side of my face and had several operations in Great Ormand Street hospital to put muscle from my thigh into my cheek! Still going strong!! I would just like to wish everyone who has had polio a good life!!

Can you help?

I am interested in the diversity of the folk with PPS and particularly how they manage pain and short sharp rapid deterioration of muscle in limbs, grip etc some may experience. I am also keen to map the vast range of medications that GP's use for PPS.

Experience from one of our new members:

I had polio in 1956 and spent 3 months in hospital, in isolation for a few weeks then out on the children's ward. My left foot and lower leg were affected. Obviously I had to learn to walk again. Strange to say but I enjoyed being on the ward because I wasn't having any awful treatment, and as a result have never feared hospitals and worked in one as a medical secretary for several years. Also, whenever I'm ill now I prefer to isolate myself as it seems to have programmed me to believe that's the best way to get well. I hate people fussing over me - just leave me be for a few days!! Consequently, the covid lockdowns didn't faze me as much as for some people. I'm happy being indoors. Weird eh?

I've been more fortunate than many people in that I'm still able to walk, though much shorter distances these days. In my 40's I used to swim 4 or 5 times a week, 50 metres at a time, head down, goggles on, front crawl, in the fast lane. I even did a few Swimathons. Now though (at age 70) I find it hard to get in and out of the pool safely and 20 lengths is about my maximum, once in a blue moon!

For pain relief I have a two-pronged attack. First and foremost I usually visit my osteopath once a fortnight to keep my spine in better alignment. I've been going to him for over 10 years and in the beginning he helped straighten out my polio-affected foot enough to improve my walking so that now I can feel my outer toes more on the ground and there is less over-pronation. Now he treats my neck and upper back mostly, and sometimes my pelvis. It's expensive yes, (£60 a session) but I get so much benefit that it's really worth the cost.

At night I use a magnesium spray on my neck, my good side hip and down that leg and foot to ease the daily discomfort so that I can have a good sleep. It takes effect within about 10 minutes, absorbed through the skin, so it doesn't upset the digestion. Again, it's quite costly because it comes from abroad and the delivery charge is high, working out at about £90 in total for 3 large bottles. That lasts me about 6 months. I prefer not to take ibuprofen or paracetamol.

My biggest problem when younger was buying shoes in 2 different sizes but these days, I just wear lace ups or boots so I get only the big size. I get them from Hotter and choose the ones with extra stability. An advantage of getting older (I'm 71 now) so I don't care too much about fancy footwear!

I saw a neurologist Princess Royal Hospital, and Kings London who was very helpful getting a diagnosis of PPS but that was several years ago. She explained that I needed to pace myself to help manage the symptoms which really helped. But now I'm older, looking after grandchildren all day really exhausts me so I'm afraid I'm going to have to stop that soon. A shame, because I love their company, but I need to "conserve to preserve".

I count my blessings every day and am doing my best to stay optimistic about the future. As long as I can still afford my osteopath I will be okay. He'd better not retire any time soon!!

Editors comment: to the piece about your grandchildren; I do not know how old they are and I do understand the need to pace and rest and maybe not do this anymore. However, I can say from my own and other polio survivors experiences that children can be extremely helpful if you explain your difficulties to them. Most of them love being helpful and it is very rewarding knowing this is going to help them in their future lives.

What You Need To Know About My Condition

Polio Survivors Network with the help of The Neurological Alliance has provided an aid for Polio Survivors who are going into hospital. It is a document which can be filled in to provide medical staff with an overview of your situation and needs.

An electronic version which can be typed into and then printed is available to download from our website (see News). For those of you who have a printed newsletter a form version has been included with your newsletter these can also be requested by email or downloaded from our website.

For download options please go to <https://bit.ly/3oldoUt>

The most important thing to do is ensure that the form is up to date and to hand if you are admitted to hospital, pop it in your 'go bag' just in case. We hope you find it useful and would appreciate any feedback.

OUR ADVICE TO POLIO SURVIVORS - Getting ready for an appointment.

Firstly, we understand how excited you are when you start researching and find article after article. Did you print them each one as you found it? I could have wallpapered my house with those I printed off the first few months of 1996. Please do not drag a bag behind you containing all these articles because there is absolutely no time to read any of them and how would you feel if you were the health professional?

Secondly, We advise that you take someone with you to every appointment that can take notes about what is discussed, remind you of anything important that you have forgotten to say, and have your My Polio Life file in their bag in case you need to refer to a date or test result. We do not advise placing the file on the desk at the start of the appointment.

Step 1 Who are you going to see and why and do you know how long the appointment is planned for and if any tests are going to be carried out?

The reason we suggest that you do this for each appointment is that if the appointment time allotted is only ten minutes then there will be questions to you and the answers and most probably a short examination followed by some statements from the doctor. This means that you may get about two minutes to get across what you want to say and ensure that the picture you paint in the health professionals mind is the same as yours.

Step 2 Write down the most important facts that have triggered this appointment. Work out ahead of time how to word this or maybe you could try asking to demonstrate the action or use pictures/photos or charts.

Step 3 The appointment. Ensure you know where you are going and where the car park is and how far you might have to walk/ride/be pushed to the clinic. Preferably get someone to drive you there and arrive early enough to have a few minutes to recover from the journey.

Arrange with that person to take notes and with your permission remind you of anything you have forgotten to say.

Step 4 Make up an Appointment Sheet. Two copies and plenty of room to add comments because some health professionals have added notes to this sheet and added it to your medical file, others have not wanted the sheet.

Here are some ideas of facts you might need to record:

- Name and contact details
- Date of appointment and with whom including all their contact details
- Polio — The date, age and where you caught polio and the diagnosis and any equipment you used at the time, e.g. Iron lung, callipers
- Recovery — The level to which you recovered and your highest achievement(s)
- Other diagnoses
- Current medication
- Allergies
- Other relevant test results for this appointment
- Current issues starting with the most important or most demonstrable depending on who you are seeing
- A couple of examples of visual ways that quickly demonstrate your new issues
- Part of a medical article with a relevant part to your issues highlighted.

Remember the time allotted for the appointment is important. Only raise issues that this health professional can deal with. You could list the other issues for their information.

Before you leave ensure you have raised all you wanted to and if you have run out of time ask for a second appointment. Ensure the person with you has recorded what has been said and if you require any further tests etc. Oh and don't forget to thank the health professional.

Where Should I Go and Who Should I see?

This will depend on which of your symptoms are causing you the most problems, where you live, the cost of travelling and possibly hotel accommodation, if you have someone to go with you, your level of disability and if you have enough energy to manage the appointment, etc

Once you have looked at all these facts you should first approach your GP for their advice and the choices available to you. Sadly we have to report that finding health professionals with the adequate knowledge and experience that you need, especially in the UK, is not easy.

There were two issues that we came across in our early years. **Firstly** some hospitals were providing names and we learned 8 of them to their knowledge had never examined a polio survivor. **Secondly** some polio survivors with minimal knowledge of PPS and grateful for the amount of help they got were naming the professional as an expert. However, others with more post-polio knowledge obtained appointments on this recommendation but realised that the 'expert' did not have the level of expertise needed.

Our advice is to contact your local/nearest Polio Support Group for advice.

If Polio Survivors Network is unable to help please try:

- International Ventilator Users Network
www.ventnews.org
- Disabled Motoring UK
www.drukdiscounts.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.nepolio.org.ipage.com
- Polio Australia
www.poliohealth.org.au
- World-Wide Fellowship of Polio Warriors
www.poliowarriors.org
- British Polio Fellowship (BPF)
www.britishpolio.org.uk
- Polio Survivors Ireland
www.polio.ie
- Scottish Post Polio Network
www.sppn.org.uk
- Cancer & Polio Survivor
www.aftercancer.com

From the Archives ...

One of our members sent in this interesting older article. To see a video of the glossopharyngeal breathing (frog breathing) technique go to <http://www.polioplace.org/resources/frog-breathing>

Frog Breathing: Still Useful, Still Lifesaving by Judith R. Fischer

Frog breathing, the common term for glossopharyngeal breathing (GPB) because of the frog-like gulping technique, has been used for centuries by deep sea divers in order to fill their lungs with reserve air just before diving. During the polio epidemics of the 1950s, respiratory polio survivors accidentally taught themselves to use GPB, and Rancho Los Amigos Hospital under Clarence W. Dail, MD, in Downey, California, became the leading respiratory center for GPB use. GPB enabled a person to produce adequate ventilation without the use of equipment. Many polio survivors still use it during equipment emergencies, and as a way to stretch the chest and aid coughing. GPB can also be taught to individuals with spinal cord injury.

Basically, the mechanism of GPB is the same as that of a pump: the tongue and the throat act as a piston, and the mouth, soft palate, and larynx act as valves, resulting in an expansion of the lungs as air is pumped into them. Canadian polio survivor Gary McPherson describes the technique thus: "Frog breathing involves the use of the throat and posterior tongue muscles to hold the breath once you have taken it. A vital capacity three to four times the tidal volume can be achieved with frog breathing.

"You take a breath through your nose or your mouth, then hold your breath and add to it with gulps of air. I start by taking a neck breath with my accessory muscles. I get about 150 cc of air in my lungs and then I hold it. Next I open my mouth and draw my tongue and throat muscles down to allow air to enter my throat. Then I close my mouth and force the air down my throat with my tongue and throat muscles while I hold my breath. I call this inspiration of air a stroke, and I get about 50-75 cc of air into my lungs with each stroke. Since my average breath is about 800 cc and I started with 150 cc from the neck breath, I need about ten strokes per breath. Sitting and talking I need about eighty breaths per minute... Only when I have taken several strokes do I release my breath. It takes a lot of practice, and your throat and tongue muscles need to be active... "Frog breathing through the nasopharyngeal airway is very similar except you draw air in through your nose instead of your mouth. However, the stroke volume is somewhat reduced. The advantages of frog breathing through the nose are that it provides natural humidification, it eliminates the dryness of the mouth, and aesthetically it is less obvious to the people around you. The muscles used in frog breathing need to be exercised regularly to gain strength and efficiency."

Augusta Alba, MD, who has helped many people learn frog breathing at Goldwater Memorial Hospital in New York, suggests one start by saying, "gup." The "g" puts the ball of the tongue in the proper position to push a bolus of air into the pharynx. Then the "p" closes the lips while the tongue relaxes in the floor of the mouth. "gup" should be said repeatedly about 100 times per minute with a pause every 15 seconds to exhale. If there is enough air in the lungs, the air expired at the end of a series should last 15 seconds. Dr. Alba's frog breathing studies show that effective use of the technique permits a more effective cough, improves lung compliance, allows more normal speech, decreases lung infections, and, of course, reduces dependence on mechanical assistance.

Audrey King, polio survivor and frog breather, says, "Those who have reduced capacities may find it a little harder to learn glossopharyngeal breathing because they guard the air they have and don't relax their chests to allow air in. Also, if you say "gup" you need air coming out of the lungs to voice the word, and that's the opposite of what you're trying to do, so it gets a little confusing... It takes about eight or so successful "gups" before you can feel your chest expanding and know that you're doing the right thing, but once you get this feedback, you really are on to it.

"I think the best way to teach somebody is by having that person imitate the cluck sound that you make in the back of your throat. Then once you're copying the cluck sound, if you form the word "gup," but don't actually voice it so that you have the lip and mouth movement, you can feel the air going in fairly quickly. Frog breathing can be done anywhere, anytime. It is great for fatigue, for coughing, and for getting a deep breath."

Randy Haims, C-2 quad, learned frog breathing from a polio survivor while he was in a rehabilitation hospital following his accident. He did not use it consciously until about eight months later when he suddenly found himself doing it automatically. Haims asked his attendant to plug his trach, and frog breathed for about 25 minutes. He eventually worked his way up to almost two hours of frog breathing time. For Haims, the disadvantages are dry mouth and fatigue; he prefers to neck breathe.

Frog breathing is not easy to learn for some people; perhaps the best way is to watch another person "frogging." John R. Bach, MD, of the University of Medicine and Dentistry of New Jersey, who also helps people learn to frog breathe, advises, "Frog breathing should be monitored by regular measuring of the volume of air per gulp and the number of gulps per breath. Many people are successful at it, but do not realize it."

Once learned, frog breathing can provide valuable minutes of air during ventilator breakdowns or other emergencies. Gary McPherson states, "a person can rest comfortably knowing that he is ultimately dependent on himself, not on a machine."

Reprinted from Ventilator-Assisted Living (formerly called IVUN News) with permission of International Ventilator Users Network (www.ventusers.org). Any further reproduction must have permission from copyright holder.



Using aids, assistive devices and help from others

It is not easy changing the habits of a lifetime from being able to do a task to having to ask for help or return to or start using an aid or assistive devices.

However, I can report that whenever polio survivors get together and discuss this issue over and over again we say 'once I tried this I found it so much easier and wish I had tried it much earlier'.

It is much easier if you can find someone else who has similar needs to go together and look and try

what is out there. It is imperative that you try before you buy if at all possible because items can be expensive and many of us have been advised to purchase items and have later found that another version would have been much better.

Local or national exhibitions are great places to go. Try [Naidex](#), [Mobility Roadshows](#) or look for your nearest [Disability Living Centre](#) or contact your local disability organisations.

Occupational Therapy Equipment

Looking back at the front page of the last newsletter there are many items of equipment that can save you time and energy. Some everyone uses so that is easy. Others far too many of us have fought against because we think it will make us look disabled and regardless of the level of our polio damage most of us have not thought of ourselves as disabled.

NAIDEX or MOTABILITY ROADSHOWS are great to go to because there are so many people with different disabilities attending that we have noticed the able bodied can be in the minority.

Stores selling equipment for the disabled are also a place to try but we have noticed if you are on your own then the staff tend to follow you around which can be a bit off putting when you really want to try a piece of equipment.

Ladies do you remember going with friends to a certain store and trying the hats on? Not easy to do on your own but with others it was easy, so much fun with lots of giggles. The same works now, do not go alone, get two or more others to join you and it is much easier to try all sorts of items just to see how they work.

How many of you have told an Occupational Therapist or other Health professional that you have a problem and been told we can provide you with an x. You receive the x and it does not work for you.

An article in a very early newsletter demonstrates that out of ten of the items the OT provided only two helped.

- ◇ Support is available through home visits or by telephone
- ◇ Advice on how to reduce your energy use and bills.
- ◇ Fit free energy saving devices, such as draught excluders, timers and LED light bulbs.
- ◇ Priority Service Registration.
- ◇ Maximise your income through grant and benefit checks.
- ◇ Provide energy saving tips, information and signposting.



warmandwise@aguklsl.org.uk 03455 564 144 [ext 1240]



Now that Smile.Amazon is no longer available for charity fundraising we have registered with easyfundraising, which means you can help us for FREE.

Over 7,000 brands will donate to us when you use [easyfundraising](https://www.easyfundraising.org.uk) to shop with them – at no extra cost to yourself! All you need to do is sign up and remember to use easyfundraising whenever you shop online. It's easy and completely FREE!

Interesting headlines

Grandmother of eight makes a hole in one.
 Two convicts evade noose, jury hung.
 Queen Mary having bottom scraped.
 Panda mating fails - vet takes over.
 Eye drops off shelf.
 Squad helps dog bite victim.
 Enraged cow injures farmer with axe.
 Lawmen from Mexico barbecue guests.
 Two sisters reunite after eighteen years at checkout counter.
 Something went wrong in jet crash, experts say.

Life

Sometimes you're the hammer, sometimes you're the nail!
 Sometimes you're the bug and sometimes you're the windscreen!
 Sometimes you're the pigeon and sometimes you're the statue!

Adverts

Dog for sale: eats anything and is fond of children.
 Mixing bowl set designed to please a cook
 with round bottom for efficient beating.
 For sale: antique desk suitable for lady with thick legs and large drawers.
 We do not tear your clothing with machinery...
 We do it carefully by hand.

Management Committee [Trustees]

Chair - Simon Parritt simon.parritt@poliosurvivorsnetwork.org.uk

Trustee - Zsuzsanna Snarey zsuzsanna.snarey@poliosurvivorsnetwork.org.uk

Treasurer, Newsletter Editor - Hilary Boone hilary.boone@poliosurvivorsnetwork.org.uk

Trustee - Verité Reily-Collins verite.reilycollins@poliosurvivorsnetwork.org.uk

Trustee/s - Vacancies please contact Toni for more information

Operations Team

PSN Admin, Enquiries and Website - Toni Dunlop 07480 110334 psnadmin@poliosurvivorsnetwork.org.uk

Printing - Imprint Colour Printers, Lincoln

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

Website www.poliosurvivorsnetwork.org.uk

Write to us at PO Box 954, Lincoln, LN5 5ER, 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>

giftaid it

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

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

PatientPlus article POST-POLIO SYNDROME

Written by U.K. Doctors for Doctors

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

NB Respiratory and Sleep Problems Section very informative.

GOOD ANAESTHETIC ARTICLE - English version used by many PPS Groups

POLIO PATIENTS AND SURGERY - Information for health staff.

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

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

Printed copies on our headed paper with permission are available.

Editors Note: Articles from Polio Survivors and Health Professionals welcomed



Our very own trustee Verite Reily-Collins was recently interviewed by Channel 4 news – watch the short piece here <https://bit.ly/41Rf6LN>

Integrated Ongoing
NEUROLOGICAL SUPPORT
in the Community
MAKING A DIFFERENCE



How to improve function and quality of life
for Neurological Conditions such as Stroke, Head Injury,
Parkinson's, Multiple Sclerosis, and support for Carers

MAKING A DIFFERENCE: Integrated Ongoing Neurological Support in the Community

The book is about the work of Integrated Neurological Services, a medical charity operating in the London boroughs of Hounslow and Richmond upon Thames www.ins.org.uk

The book is independently published on Amazon by the editors and authors. <https://amzn.to/3KEMNsV>

Nearly three million people in the UK have a neurological condition; Stroke, Traumatic Brain Injury, Parkinson's disease, Multiple Sclerosis (MS), Brain Tumour, Motor Neurone disease, and many more, all affecting the person for the rest of their life.

The NHS provides treatment at the onset of a condition but after that there is a huge need for ongoing support. Research shows that those who are supported and know more about their condition are less likely to have to call on further in-hospital and GP care and there is enormous scope for improving the quality of life for those with neurological conditions. The right support, therapeutic and social, makes all the difference.

The book shows how those with neurological conditions benefit from integrated ongoing support provided in the local community and self-help, and how lives can be improved. It explains good practice and encouraging methods in the support and treatment of those with life changing conditions.

All the proceeds from the sales of this book are donated to the medical charity Integrated Neurological Services (INS).



Make your voice heard by participating in paid surveys, interviews, and online communities! Sign up and start talking to the right people. Panelists will be invited to participate in *paid* interviews, surveys or online communities where your insights can help researchers develop products and services related to your condition(s).

For more information see <https://www.rarepatientvoice.com/rp/PolioSurvivorsNetwork>

