POST POLIO MATTERS

Polio Survivors Network Newsletter

JUNE 2020 Volume 10, Issue 2 of 12 [110]

DUE TO THE CURRENT SITUATION

Newsletters will now be less pages and EVERY MONTH

REMINDER FOR POLIO SURVIVORS

Have you reported weakness that has not been corroborated by medical assessments?

Did you realise that Single Action Manual Muscle Testing does what it says?

It tests muscles a **single time** it **does NOT test their endurance level.**
Time constraints for appointments mean that if the first test is good the tester moves on.

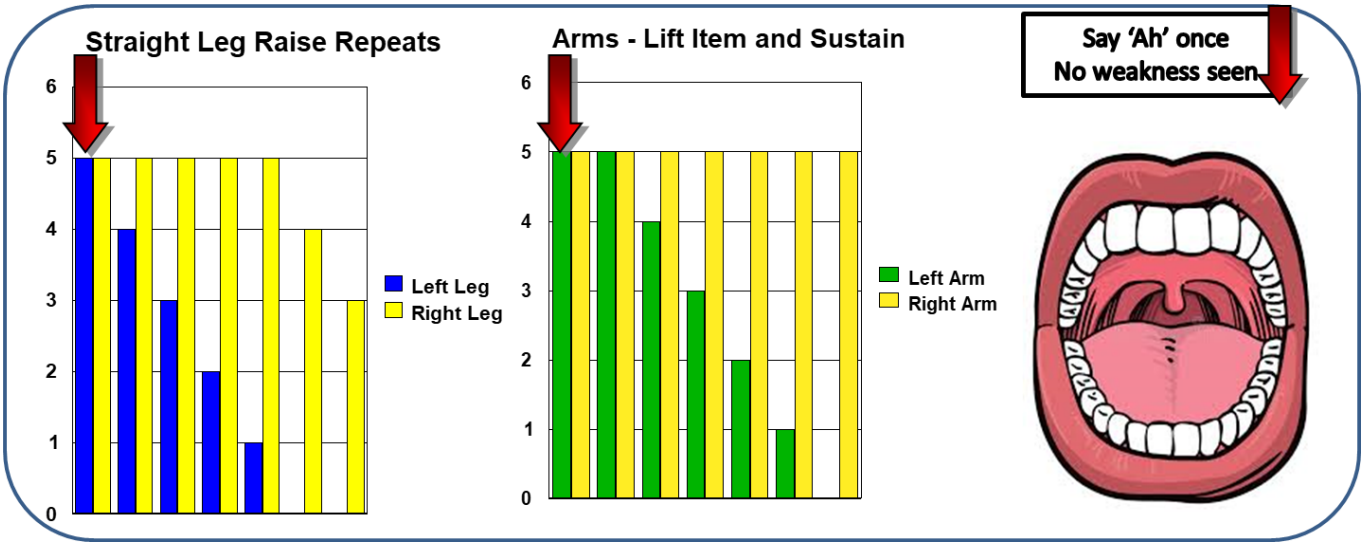
If your weakness, either repeating or sustaining the action
starts after that first test then the weakness can be missed
unless you phrase your problem with more specific information.

"Climb stairs as normal - then right leg first - now have to stop halfway as well"

"I could lift a jug full of water and pour it out with one hand, now I need to use two"

"Swallowing issues - ask for the 'AH' test to be repeated a few times."

We developed **My Polio Life** to help you self-assess how you do all actions of daily living so that you can provide more specific information on your problems.



Continued on page 4. Confirming statements 'there are issues with Single Action Manual Muscle Testing received May 2002 from Dr. L.S. Halstead Director of Post-Polio Program National Rehabilitation Hospital, Washington DC and Dr. F. Maynard, President of the Board of Directors of Post-Polio Health International, St. Louis MO and more on My Polio Life.

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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This issue and the Annual Report enclosed has been printed by Hilary Boone

Editorial by Hilary Boone

From now on a change to monthly newsletters with fewer pages. First some sad news, I took a call from Olivia Branston to say that her husband Barry had passed. They have been long-time Life Members from the Lincolnshire coast for nearly 20 years. Those of you who have attended AGM's will remember them both. We send our condolences and we hope to be feature an article about Barry's interesting life in an upcoming newsletter.

Second some thankyous. My daughter in Canada asked for donations to PSN instead of birthday cards and sent us the magnificent sum of £190.39, for which great thanks. Thank you to Yvonne Webb another long time Life Member for her donation of £100. Thank you to Val Singleton for a cheque for £20 profit from the sale of her photo cards. Thank you to Barbara Taverner for more information for our records. We hope to hear from more of you but know how difficult it is at this time to get out to the post. We have added a stamp and addressed envelope with this issue and hope to hear from you over the next few months. Remember nothing is irrelevant if it means something to you, there will always be someone else who will benefit from reading it, even if it is only a one-liner. You will find bits from Simon, Hilary, Zsuzsi, Verite, Debbie and Toni. Also meet members Eddie, Funmi and Philip Barton on pages 8 and 9, photos back page.

Debbie Ison (see back page) has now completed a set of six short videos explaining different therapy techniques that might help you cope with PPS and all that is going on in the world today. Give the different strategies a go and you may find that some of these techniques are more useful than others, but I hope you find one that is successful for you. We have also put links on the scrolling piece of the homepage of our website. We have also sent a donation to Dave Crippen for the use of his cartoons.

If you do not have access to the internet and would like more information then get someone to get in touch with us and we will put our thinking caps on.

***Continued from the Front Page*. Precis of how I realised why my reported weaknesses had not been corroborated by health professionals for over 10 years!**

I had waist down paralytic polio at age 5 but was allowed to go swimming daily. I recovered well although I was always falling. Operations on both feet at age 12/13 and the falling lessened. I got on with my life and competed in any sport that I could manage that did not involve running. I had a very strong upper body and swam for my county. I started lifesaving lessons and was soon passing the qualifications although years later it was realised that I had developed my own sideswipe kick not visible under the towed body. I started judo but because I could not bend my knees far without my legs collapsing I only got as far as orange belt. I became a secretary then passed a medical for the police [did that statement cause you to reread it?] After a few weeks I

was off to training school in Yorkshire. I did not learn until the end of the 3 month course that I nearly got sent home on the second day when I raised the fact that I could not do cross country running on Friday's because I could not run due to polio at age 5. Because of my judo and life-saving qualifications my Chief Constable asked them to reassess me each week. I passed the course and completed the 39 Mile Lyke Wake Walk across the North York Moors in 18 hours.

I married, had two children, passed all my lifesaving qualifications again, passed the Advanced Swimming and Life-Saving Teacher and City and Guilds 730 Further Education Teachers Certificate. I was teaching swimming in a handicapped school, Oct 1988, when I slipped. I spent seven years, including 3 weeks on neck traction in hospital, being physically assessed and given regimes of physiotherapy. I continued to deteriorate no matter how hard I tried to do the physiotherapy. I would explain I was getting worse, I would be examined and told I was not trying hard enough. I thought I had MS and Alzheimer's. I had an MRI scan and the locum told me he was glad I was better. I told him I was not and I had had polio as a child—did that have anything to do with this? My prior polio had NOT been in the equation from Oct 1988 to Nov 1995.
I have not stopped searching for information from that day onwards. I was diagnosed two years later but only after a second opinion request at another hospital. I had a days' full tests with nothing else found - 'confidently diagnose the post-polio syndrome'! Niggling constantly was why did it take so many years? **I suddenly had a eureka moment when I thought 'how did I pass a medical for the police when I could not run?'** There must have be something wrong with the muscle testing used on me.

Time is short for free NHS appointments and if a Grade 5, normal result is found the tester moves on. I decided to test myself as best I could. ***See the charts on front page***. I had been laid on a leather couch in a neurologists office and had to lift my leg against the pressure of his hand. BUT... we are crafty... when we know what they are going to do it is easy to use all the body oomph to show them how good we are. He only tested each leg once. Then he tested my arms, "grip my hand" and boy can I crush fingers, then I am asked to "link fingers and push them over and pull them over", well at six foot tall I could do this easily. Graded 5's, all normal. Those three arm tests are the basic tests for arms. Then why can I no longer lift a jug full of water and pour it out using one hand? I now have to use two hands. I used to go up one flight of stairs normally. Over the last few years I had changed to going right foot first and then stopping half way for a rest. I could not lift the quads exercise bar with my left leg. So how could he record '*On neurological examination of the legs power at the left hip, and knee and ankle was normal'?* I decided that no health professional would write something they did not believe to be correct so assessment by Single Action Manual Muscle Testing must be faulty and unreliable. I wrote to two of the most knowledgeable and experienced Polio Specialists, Lauro Halstead MD a polio survivor himself and Fred Maynard MD. In May 2002 they replied….

"If done only a single time, it can give an erroneous idea of the true muscle strength and endurance" - Lauro S. Halstead MD, Director of Post-Polio Program National Rehabilitation Hospital, Washington DC, USA.

"You have done a brilliant job of describing a real problem for polio survivors and professionals that is, the limitations of the Manual Muscle Testing" - Fred Maynard MD, President Board of Directors, Post-Polio Health International.

We then developed My Polio Life as a self assessment tool to help you look critically at how you are doing each action of daily living. Compare this to how you used to do it and record the difference. Now you have information to ask "what is happening in your body for this to be happening?"

I told the senior physiotherapist I was sent to in 2003 that I had no problem scrambling eggs but now realised that I was using elbow rotation to do this. Providing that extra information meant that specific muscles were now tested and it was found that I had very weak supinators in my wrists. I was also using 'hamstrings and back extensors' to get up from the floor. I have to bend from the waist to pick anything up from the floor. My back is bent forward so I cannot look up and reach up at the same time. A few months later Richard and I started monthly neurofunctional chiropractic

treatment from Dr Darren Barnes-Heath of Newland Chiropractic Clinic. This timely action on any raised issue has meant other health professionals telling us 'you are doing really well considering the length of time you have had symptoms'!

Since Covid-19 and now Day 91 at home and unable to see Darren, we are both having more problems. My back is more bent forward, joints are stiffer and we are in a lot more pain, having to take pain killers every four hours and use Bio Freeze pain spray. Maybe we can get to start again in July?

My personal comments about how the government has too slowly dealt with Covid-19 leading to people not understanding the seriousness, attending events and protests would burn a hole in this page.

My advice is to self assess and think about the differences in how you do actions now, then think back to how you used to do the actions. Maybe you have changed the way a few times, like when climbing stairs. We tend to not want to think about things like this, so it might be a bit of an eye opener, upsetting and something you really do not want to think about. However, this specific information will be **invaluable to your health professionals**. This should lead them to examine you more specifically to find out why you have had to change the way you do the actions e.g. I changed from wrist action to using elbow rotation to scramble eggs in 2004. I have two different height work surfaces in my kitchen, one nine inches lower than normal. I still use elbow rotation but now have to put the bowl on the lower surface.

Have a look at My Polio Life if you have not already done this. I know many of you have over the years. ***Page 10*** lists many actions of daily living to help you. There is not enough room on this sheet to write all the info you need to so use a separate page and write it out in full and pick a couple of words that will remind you for the form. Remember this is information for you to remind you ahead of an appointment of what information you want to tell the health professional you are seeing.

Can you imagine what you would think if 'you' turned up to see 'you' with a large file of medical articles. If you have a photo or two that shows how fit, or something unexpected you achieved in your earlier life then take that with you.

This might help, imagine you are a doctor training in 1996 and your College of Medicine taught you about polio and leprosy in the same lecture that was half an hour long. Not enough time to do more than provide a few bits of information and photos of polio survivors in iron lungs or with atrophied limbs. You have not had continuing education that has mentioned Post Polio Syndrome and you have not come across a patient that looked like those photos. How do you think you would feel if 'you and your problems' suddenly walked through your consulting room door?

How long is the appointment going to be? How much time will you have to explain your issues? What are the most important facts that you can demonstrate in those few short minutes? You might have to make a second or third appointment to go through all the issues you want to raise.

My Polio Life and a partly filled in copy to give you some idea of how we did it can be found at **https://poliosurvivorsnetwork.org.uk/enter/wp-content/uploads/2018/10/mypoliolife1.pdf**

If you have not got a copy, have no access to the internet or don't know anyone who can print one off for you then please give us a ring.

PLEASE DO NOT TAKE CHANCES especially at the moment, always try any aids or assistive devices that will save you that bit of energy.

If you can get help to do the heavy stuff of an action then take it. Why waste energy on doing something you always used to do and 'will not give up doing it' if there is another way and it leaves you energy to do something that makes you feel better, smile and enjoy life. Anything that you can do to ensure you do not fall or catch Covid-19 and stay out of hospital the better.

Stay safe and contact us if you need any help.

Simon Writes… FEBRUARY WAS THE MONTH OF DENIAL

As we enter the next phase of the covid pandemic, it seems people have begun to fall into different camps when it comes to coping with what to do next at a personal level. Of course, many I spoke to back in February and early March when I was warning that this was a major pandemic didn't really believe it and dismissed it, and me as fear mongering or media hype. To me that was obviously not the case and I shut myself down from around the 20th February. It's hard to get much satisfaction from 'I told you so' but it's hard not to again caution those who seek to diminish the ongoing risk. With largely a disorganised management and inaccurate figures we have to make decisions, as post polio survivors, on what to do at an individual level, often in spite of, rather than because of any official guidance.

MY DUAL ANXIETIES

I feel the issues that confront me fall into two areas, the psychological stress and then my ongoing health monitoring and management of my conditions. There is no doubt that isolation hits some more than others but I have had increased health anxiety around the prevalence of the virus locally, not least as my chances of survival are more or less nil. Even the worrying issue of whether I would be put on a ventilator is not an issue as there would probably be no clinical benefit from being ventilated in ICU.

IS THIS PARANOIA ?

As we creep out of lockdown – too early in my view by about 3-4 weeks, people are getting less careful and I get more concerned. Almost no one is wearing a face covering, let alone a mask. My usual aches, pains and feeling unwell suddenly become more foreground and possible something else in my now hypervigilant mind. However irrational as Covid virus symptoms are so diverse, I am trying to be logical, the virus is unlikely to have floated over the fence from neighbours as they are coughing and sneezing with Bar-B-Q visitors over the weeks of good weather.

POLIO HEALTH CARE EXPERTISE

The second issue is that my respiratory team, consultants and wards have been redeployed to deal with Covid cases. I therefore must rely on local and non-specialists in any crisis, and we all know what that means, basically ignorance around what post polio is and means. The delay in any information around what to do, who to contact was many weeks in coming, as was my shielding letter which I had to chase again and again as polio was never included in the original list, even though I use a ventilator at night. Fortunately, I have a very proactive, professional and responsive GP and Primary Care Practice.

WHEN WILL IT BE SAFER ?

The longer term issues are how and when will we feel safe as vulnerable people to take the risk and return to some engagement in the outside world. I cannot trust what I don't know. Maybe it's the neurotic psychologist in me, but I will be anxious and in fear until I know the level of risk I am taking.

When we get to an R rare nationally under or around 0.5 ***I will feel safer.***

When I can access accurate data on how prevalent the virus is in MY area on a week by week basis***, I will feel safer.***

When everyone is urged to wear masks in ALL public areas, ***I will feel safer***.

When we have a really effective test and trace system working at a local level, ***I will feel safer.***

When I sense that the information being published is about fact and just not politics, ***I will feel safer.***

And of course when there is a vaccine of some kind and its widely in use, whilst not a panacea***, I will feel safer.***

HEALTH FIRST

And then there is the fear is of a second wave in the autumn and winter because we haven't reduced to level enough over this summer. History doesn't always repeat itself exactly but I hope that we are not again victims of the UK's approach as in the 1950s where late decisions, politics and professional rivalry delayed us getting a national polio vaccination program under way until 1957 having been reluctantly forced to import supplies from the USA of the Salk-type vaccine as our vaccine production system had failed.

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Toni writes...

I was thinking about our lovely members and I realise that I know very little about many of you. I understand you all have polio in common but so many have much life experience to share. Some members have gone on to lead very full lives, have exciting careers, raised large families, achieved things people thought weren't possible.

I would love to hear about you or anything that you would like to share with other polio survivors. We run a series of articles introducing our members or an interview with a member – I would like to include as many of you as possible as you all have experiences to share. All of this, in turn, helps us to tailor information to our members' needs and experiences.

Maybe you'd like to share with us your story, your achievements, your tips in a practical matter, your frustrations or even a simple hello from your neck of the woods. Others will have loved travelling or cuisine, send in a recipe perhaps or a memory from your holidays. Our newsletters are about polio survivor support and help but also about our polio survivors as individuals.

If you prefer to be more creative perhaps send in a poem, riddle, a funny cartoon or photo. Don't forget to also check out our photo competition. I look forward to seeing the responses.

My contact details are on the back page and for those of you who have a post only newsletter copy we have included a stamp and address label to make responding as easy as possible.

As always, I send you my fondest regards and hope that you can continue to keep well during these challenging times.

Some recipe ideas follow:

Pea soup

Heat 600g frozen peas with a tablespoon of olive oil and a 400 ml can of coconut milk in a saucepan for 5 minutes or until fully heated through
Pop mixture in a blender to blitz until smooth
Season with salt and pepper to taste (or herbs if you prefer)
Serve in bowls with a splash of natural yoghurt if you have some.

Pesto Pasta (serves 3)

Boil 250g spaghetti in a large pan according to pack instructions
Drain well, then return to the pan
Add a tablespoon of pesto (any type) and 20g of grated parmesan
Mix well. Serve in a bowl with extra parmesan on top.

For inspiration on quick meals try:
https://www.bbcgoodfood.com/recipes/collection/quick
http://allrecipes.co.uk/recipes/slow-cooker-recipes.aspx
https://www.yummly.co.uk/

From aftercancers.com - Verité Reilly-Collins, also a PSN Trustee

Questions the NHS needs to answer - May 25th 2020.

Why was NHS so unprepared to deal with Coronavirus?

The mood in the media is changing. With lockdown easing, British media has turned from eulogising the NHS, to asking questions about NHS administration and its handling of the crisis.

No longer is the NHS regarded as untouchable; editors no longer think 'the NHS is the envy of the world'. They've seen the world's media questioning – loudly – why the virus took such a hold in the UK, and seen the shortage of PPE equipment, etc.

Until May, the media had been after us to "clap for the NHS". Suddenly there was a U-turn, and we were encouraged to clap for NHS Staff – not the Service as a whole. Then the ***Daily Mail***, one of the widest-read papers, got on board with help to provide a solution for the PPE crisis. Its **Mail Force** campaign produced millions of pounds in donations, which the Mail used to buy and distribute PPE to front-line staff. Thereby cutting out the NHS's procurement department (I wonder if they'll ever get refunded for the dud Turkish equipment they landed up with?)

Has clapping passed its 'sell by date'?

Annemarie Plas, a Dutch national living in south London, originated the weekly "clap for carers" event on Thursday evenings. She says next Thursday's event should be the last, concerned the event has become politicised.

She commented : "I think it's good to have the last of the series …. I share some of the opinions that some people have about it becoming politicised". She had been "overwhelmed" by the support for the ritual, but it was better to stop whilst it was at its peak.

Others say clapping doesn't pay the bills, and are worried the Government will tend to 'overlook' any pay rise.

Now it has become the norm to do the unthinkable, and question if the NHS is doing its best to look after the nation's health, with The ***Telegaph, Sunday Times*** and other media asking searching questions about the NHS 's handling of the crisis.

The daily parade of three pompous Minister on TV from Downing Street has viewers questioning what purpose these sessions serve? Plonking their folders full of garbage on the lecterns, they pretend to look interested whilst Journalists ask questions via link-up, but seemed incapable of giving a straight answer.

Contrast their pathetic performance with that of Scotland's First Minister, Nicola Sturgeon. Assured, on top of her brief and honest answers – even if she doesn't know the answer. One big question is bothering me. Is her hair-do a wig? Or is she also a hairdresser?

Statistics coming in from other countries

The fact that Great Britain has had one of the worst outcomes hasn't gone unnoticed in the world's press, from Australia to America. It is shaming to find that we are considered to have been the worst in Europe at handling Coronavirus, along with our appalling record of having the worst cancer care in Europe.

As NHSMangers.net says, "*We know this has been handled badly. World class? Oh yes! In a class of it's own; muddled, slow, confused and way behind the eight-ball*".

In the meantime, Groundswell has produced this video **https://www.youtube.com/watch?v=MO6e_0Dp6-c&t=47s&fbclid=IwAR2AZmzuV5-OlyjVlf-9C-xUOjF5yHasua_GaLLyMl044yNaB46-__RSo0Q**

Future

We like to think of the NHS as 'OUR NHS'. In which case, surely it is up to us to question what went wrong, and ensure that in future we are better prepared.

Will masks be compulsory after we emerge from lockdown?

I have been making facemasks for members of my family and also for many of my neighbours during the lockdown. I used to think it strange seeing people from China and Japan wearing them but the longer we have been told to self isolate the more convinced I became that when we emerge from lockdown the wearing of facemasks will be the solution to the problem of this ever increasing spread of the corona virus.

The use of facemasks is generally accepted in many eastern countries. In Japan which has a population of 126.5 million with a large proportion of elderly there were 16,651 cases of corona virus and 858 deaths even though Japan is a densely populated country. The population of the UK is over 67 million with 267,240 confirmed cases and 37,460 deaths to date [28th May 2020]. In Japan masks are commonplace, handshaking is not the norm and shoes are removed on entering a house.

Masks are also accepted in India where social distancing is difficult. In China, Taiwan or Hong Kong, masks were relatively common even before the corona virus pandemic; people are used to wearing face coverings because of pollution or previous experience with the SARS and H1N1 outbreaks.

On March 18th, the Czech Republic became the first European country to make the wearing of face masks mandatory in supermarkets, pharmacies, and public transport. On April 6th Austria also made masks mandatory in public spaces. On April 9th Cameroon imposed masks for people leaving their homes followed by a dozen more African countries: Angola, Benin, Burkina Faso, Equatorial Guinea, Ethiopia, Gabon, Guinea, Kenya, Liberia, Rwanda, Sierra Leone, and Zambia. Germany, France and Spain also followed later. But in the United Kingdom the government urged the public not to wear masks in order to ensure that there were enough supplies and personal protective equipment (PPE) for healthcare workers. The death rate in this country is 552 per million of the population, the second highest after Spain (580 per million), compared to 7 per million in Japan, 309 per million in the USA and 102 per million in Germany. These figures have not been reported recently at the daily government briefings.

According to the World Health Organization: “Masks are effective only when used in combination with frequent hand-cleaning with alcohol-based hand rub or soap and water. If you wear a mask, then you must know how to use it and dispose of it properly.” Assuming it is a disposable mask.

Analyses show that if 50% of the population were to wear masks, only 50% of the population would be infected by the influenza virus which is similar to SARS-CoV-2 which causes COVID-19. Once 80% of the population wears a mask, the outbreak can be stopped. Face masks are not for self protection, they protect people from the wearer by trapping infectious droplets that are expelled when the wearer is speaking, coughing or sneezing.

Corona virus spreads easily from person to person. Virus carrying droplets dry fast enough to form droplet nuclei and remain airborne, eventually landing on different surfaces. SARS-CoV-2, the virus that causes COVID-19, has been detected in aerosols for up to three hours and on plastic and stainless steel surfaces for up to three days. (N.Engl J.Med. 2020) Masks lower the chances of corona virus entering the respiratory system through droplets still in the air from an infected person. Wearing a protective mask reduces the chances of inhaling the virus but it must be cleaned thoroughly using soap and water and dried in the sun or ironed dry.

https://www.thecompassforsbc.org/sites/default/files/project_examples/FINALMASKMANUAL_pdf_pdf002.pdf Issued by the Office of the Principal Scientific Advisor to the Government of India_ March 30, 2020

A protective mask can be made with simple household materials. Scientists have tested different household materials for homemade masks to measure their effectiveness in stopping viruses. They bombarded 0.02 micron particles (5 times smaller than the corona virus) on to different materials. They found that a double layer of 100% cotton cloth is most effective at capturing small particles, is breathable and this is also easy to use for making a mask at home. Make sure that the mask fits around your mouth and nose and there is no gap between your face and the

mask. When wearing the mask, the side facing you should show pleats facing downwards. You must never reverse the mask for reuse. Always thoroughly wash mask after every use.

IMPORTANT PRECAUTIONS:

1. Thoroughly wash and clean the mask before wearing it.
2. Wash your hands thoroughly before wearing the mask. .
3. Do not touch the front or any other surface of the mask; remove it only with the elastic
4. As soon as the mask becomes damp or humid, switch to another mask and clean the used mask.
5. After removal, immediately clean your hands with 70% alcohol hand sanitizer or with soap and water
6. Never reuse a mask after single use without cleaning it.

https://sarahmaker.com/how-to-make-a-no-sew-face-mask-with-at-home-materials/

One of the simplest and quickest ways to make a no-sew face mask is with a bandana (handkerchief or large cloth napkin) and two hair ties or simple rubber bands

First, lay the handkerchief, bandana, or piece of fabric flat. Fold the top and bottom inward to meet in the middle. Then, fold the bandana in half again. There will be four layers of fabric.

Next, use two hair ties to create ear loops. Slip one hair tie over each of the ends. Slide the hair ties a few inches toward the middle of the folded bandana.

Then, fold the ends of the bandana in to meet in the middle. You want the ends to overlap slightly, so you can tuck one end into the other. This will help keep the ends secure.

Wear the mask with the smooth side out and the ends against your face.

If the mask feels too tight around your ears, then you can adjust the position of the hair ties to make it wider. Remember to wash the bandana after each use, or if it becomes moist during use.

https://sarahmaker.com/how-to-sew-a-surgical-face-mask-for-hospitals-free-pattern/

To make **a DIY "surgical" mask** using a sewing machine you need 100% cotton fabric (with a tight weave), 1/8″ flat elastic for ear loops, scissors, ruler, pins or clips.

For an adult size mask:

Cut 1 fabric rectangle 16″ long and 8.5″ wide and 2 pieces of elastic, each 7″ long (or up to 8″ for a larger adult size)

For a small child-size mask:

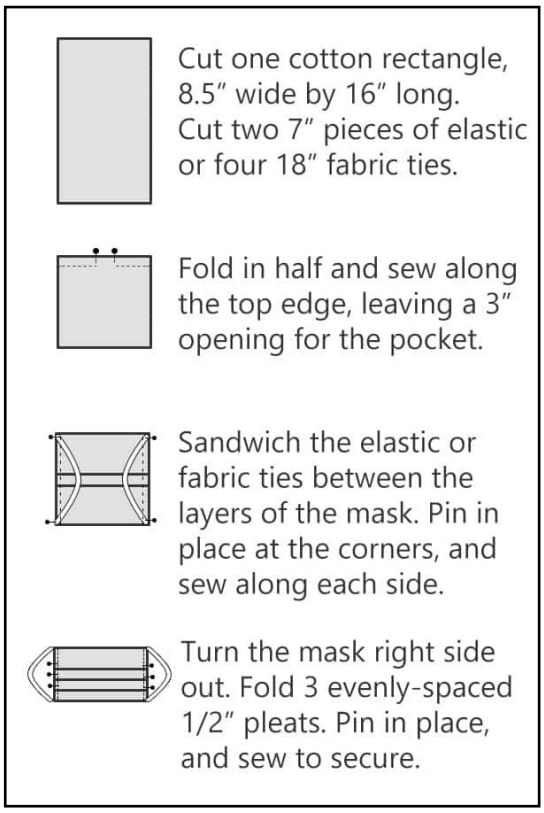
Cut 1 fabric rectangle 14″ long and 6.5″ wide and 2 pieces of elastic, each 6″ long

For a large child-size mask:

Cut 1 fabric rectangle 15″ long and 7.5″ wide Cut 2 pieces of elastic, each 6.5″ long

This pattern has 2 layers of fabric, and an optional internal pocket in which you can add additional layers of disposable filtration material if desired. The opening in the centre shown in the third diagram is where the mask is turned inside out.

There are instructions on the following link **https://www.youtube.com/watch?v=6gcLp0y-Mfg**



NB ADVICE CHANGES - check for latest. Stay safe.

Zsuzsanna Snarey BSc Chem. MBChA MSSCh MA (Hons)
PSN Trustee

"Introducing our member… Phillip"

Hello. I am Philip Barton and contracted polio when I was seven months old. Here is a photo of me with a physiotherapist at Bristol Children's Hospital taken in 1951 [***see back page***].

I never let my disabilities get the better of me and in my teens became a Queen Scout and earned my Duke of Edinburgh's Gold Award. My late mother told me that her proudest day was when I drove her into Buckingham Palace to collect my award from Prince Philip.

One of my few frustrations was when I started grammar school and suffered somewhat by being 'different' as the only boy not wearing regulation black shoes; at that time, Remploy made surgical boots only in brown. After a triple arthrodesis at Winford Orthopaedic Hospital (memorable for the fact that all the boys had to drink a bottle of Mackeson each evening) I was able to return to school as a teenager wearing my first pair of black slip-on shoes.

After qualifying as a Chartered Management Accountant, I joined a part of Midland Bank which led to me spending most of my career in the plastic card industry (credit cards, ID cards, etc), ending-up running the European subsidiary of a North American company manufacturing card personalisation equipment. Having been diagnosed with prostate cancer (now cured), I took early retirement eight years ago. We then moved to Buxton on the edge of the beautiful Derbyshire Peak District to be closer to our two children and now five grandchildren.

Since retiring I have remained busy and have had many overseas holidays; we returned from South America just before the lockdown. I am treasurer of two local community interest companies, a director of a local business group, and sat on a Home Office working party developing new legislation to help prevent ID card fraud. I am also a trustee of two opera-based charities.

Over the past three months I have at last found the time to start working through some of my retirement projects and have even managed to sit down during the day to read a book.

Unfortunately, we were unable to celebrate my 70th birthday as the party which had been planned for over a year, with visits from friends and relatives from all over the UK and USA, had to be cancelled and replaced by a Zoom call.

Having been diagnosed a couple of years ago with post-polio syndrome, which has started to affect my previously "good" right hand side, maybe now is the time to start to think about slowing down?

Editors Note: Welcome to all and please remember pacing and resting activities and using aids and assistive devices and someone to do the heavy work is **not giving in, it is not a downward step**. It is the best way to reduce fatigue and pain and actually **do MORE of what you want to do**. Yes, I did say **MORE**. If you do a bit and then rest a bit you allow your muscles to recover and do it again. If you push them till you crash out then they need at least a weeks holiday to recover.

OK I will admit that even after 32 years since my PPS kicked in I don't always take my own advice. I will answer that I was just testing to see how far I could push myself. Who am I kidding? Other long time PPSers from around the world will admit they do the same thing now and then and it does give one a bit of a boost at the time.. See I can still do x… but you really have to think hard if it was worth the extra pain and crashed out doing nothing for some days.

ENERGY TOKENS - £10.00 a day, £70.00 a Week. Only you can work out how you spend yours. Take an average day and list the activities you have to do and decide how much you are going to spend for how long. Then how much for medical appointments, times with family etc. If a day is going to take more than £10 then you have to spend less the day before and after. An idea for me for £1 would do 3 hours automatic driving on a motorway with easy traffic but only 15 minutes on a winding Devon road with all the extra arm movements, braking etc. [Gosh I just realised that that was about fifteen years ago. Now, although I love driving, I only drive in and around Lincoln now as I need to use my tokens for other daily living actions] Electric scooter user for 23 years now, it carries my bags, drinks etc and I have been to hundreds of places that I could not have managed without it. Museums, Castles, Conferences. Watch envious faces in Museums when they see you looking at items sitting down and with your coat and bags on your scooter or wheelchair.

"Introducing our member… Eddie"

Hi everyone I'm Eddie. I was 7 years old when polio put me into isolation in hospital and after being paralysed for 6 weeks plus, I slowly over time managed to have a near normal life until my late 50s when I started feeling changes. Not knowing and still now at 70 not sure after see my doctor who referred to a very young neurologist, nerve and muscle test I fight on, pacing myself in life, doing a bit, leaving a bit.

It wasn't until I read the outcome of PPS that the jigsaw came together for me, my symptoms to a tee. I always have plan B now when I do anything and this helps a great deal. Keeping a positive attitude, building bridges, not brick walls in life allows me to grow my life style and adjust to daily tasks.

Editors Note: 'Building bridges, not brick walls' - a good phrase for us all to use.

"Introducing our member… Funmi" [photo on back page]

The shortened form of my name is Funmi. I am 62 years young. I had polio at 18 months of age. The infection left me with weakness on my left foot.

I have lived a full life. I was a nurse by profession. I raised 3 beautiful daughters and I am currently helping out with my grandson.

I became very unwell in my late 40s and it just got progressively worse. I also noticed a more significant weakening in my left foot, lower back pain, extreme tiredness, recurrent chest infections. I had tests upon tests with the doctors in hospitals but nobody seemed to know what was wrong with me. The Rheumatologist gave me a diagnosis of Fibromyalgia and Chronic Fatigue.

I am not sure how I heard about the Polio Survivors Network; it was a real "God lead" knowledge. I began to research and read about all my symptoms in the library of the Lincolnshire Post-Polio Network. This was where I first read of post-polio syndrome.

At this point I had so many medical issues from prolapse of the posterior vaginal wall, to problem with constipation getting worse, sleeplessness and constant tiredness pain all over my body and weakness and pain on my affected limp. At some point l spoke to Hilary Boone who gave me so much encouragement about dealing with my issues one by one.

I decided to take early ill-health retirement at the age of 53. I had to fight for it because my doctors felt they did not want me to give up working yet. I felt differently - I knew I had to look after myself without the stress of working. To date I believe this was the best decision I made.

In 2015 I had an operation to fuse and stabilise my left ankle. This has given me a new lease of life. Last year (2019) I visited Israel thereby fulfilling a lifelong desire. The picture on back page was taken last year on my trip to Israel on mount Carmel. My hobbies are music, reading, crafting, and travelling. I am a retired nurse practitioner and a spiritual and general wellness coach.

ppn

POST POLIO NEWS [PPN] www.post-polio.org.uk

An online news cutting service from Chris Salter that specialises in news relating to polio, post polio, disability and other health related issues.

Twitter, Newspaper, RSS feed, Facebook, LinkedIn, Daily digest emails.

Chris Salter's researched and provision of excellent information service is followed by many important and influential organisations and people worldwide. We have included some items every newsletter for years. However, conscious of the fact that many of us are elderly, some live alone, a few in residential or care homes and all self-isolating we have decided to leave it up to you. If you would like to read the items in this excellent resource we recommend that you subscribe to one of the services referred to above. Go to www.post-polio.org.uk and chose the method you prefer. We will repeat this item every issue.

HINTS, TIPS AND BITS

Mary Read from the Lincolnshire Neurological Alliance shares the following for those seeking more technical neurological Covid information.

https://blogs.bmj.com/jnnp/2020/05/01/the-neurology-and-neuropsychiatry-of-covid-19/

https://www.thelancet.com/journals/laneur/article/PIIS1474-4422(20)30142-3/fulltext

https://www.medrxiv.org/content/medrxiv/early/2020/02/25/2020.02.22.20026500.full.pdf

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7170017/

https://www.cureus.com/articles/30897-covid-19-pandemic-a-neurological-perspective

Tom House [Thomas House-Arno] shares the following:

Just a note to let you know that a German poem for polio survivors that I translated for my Friend Peter Brauer MD has been posted to the WHO website – see link to the WHO Polio Global Eradication Initiative: http://polioeradication.org/news-post/not-without-a-trace/

Caroline Gordon-Wilson also Secretary Lincolnshire and East Midlands BPF shares:
When you think of riding the subway, laughter and joy aren't the first words that spring to mind. It's a cramped place full of grumpy people either coming home from a bad day at work or are just generally upset. Many are glued to their cell phones or "wired up" and have no time for anyone else. Yet if you're lucky enough, sometimes you can find happiness in a subway train. One such moment was captured when a Belgian advertising agency working for Coca-Cola hired an actor to randomly start laughing on the train. Just watch and try to keep a straight face. Click Below....turn up the volume https://www.youtube.com/embed/1veWbLpGa78

Toni's Reminders ...

If you shop at **Amazon** 0.5% of your purchase price is donated to PSN by Amazon if you sign up to www.smile.amazon.co.uk It costs you nothing.
If you would like to donate to PSN by **PayPa**l then this is the link https://bit.ly/2KzyAyE
West End Shows - a new one each week. https://www.youtube.com/theshowsmustgoon
Shows, musicals and operas online for free https://bit.ly/2MkEXqw
Concerts and operas http://www.classical-music.com/concertlivestreams

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This is the first year I'm not going to Fiji due to Covid 19.
I usually don't go because I'm poor— Brenda S Butler

Let's turn the shit of 2020 into fertile compost
and grow a beautiful new world — Hannah Fraser Moore

What if 2020 is not cancelled?
What if 2020 is the year we have been wating for?
A year so uncomfortable, so painful, so scary, so raw that it finally forces us to grow.
A year that screams so loud, finally awakening us from our ignorant slumber.
A year we finally accept the need for change.
Declare change. Work for change. Become the change.
A year we finally band together, instead of pushing each other further apart,
2020 is not cancelled, but rather the most important year of them all— Leslie Dwight

In Control and Disability Rights UK have set up a register to record experiences of getting health, social care and treatment for Covid-19 during the time of the pandemic. They want to hear the experiences of disabled people, those people with long-term health conditions, carers and family members, both good and bad experiences in getting support so that they can help out and learn for the future. They will not record your name or personal details unless you want them to. Go to this webpage to give them your feedback: https://puttingpeoplefirst.limeask.com/949771?lang=en
Further info here https://be-human.org.uk/register-of-covid-19-experience/

Management Committee [Trustees]

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

Trustee/s - Vacancies please contact Toni for more information

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

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

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

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

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

Donate by **cheque** to Polio Survivors Network

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

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

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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

POST POLIO MATTERS because WE'RE STILL HERE!

Meet Our Members Photos

Pages 10/11

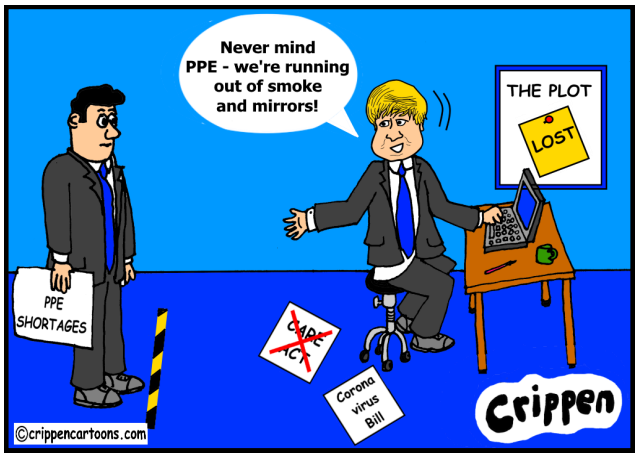
Funmi on left

Phillip Barton

On right.

Photo competition: Will be printed in fuure newsletters.
The **theme** is "***This made me smile***". Please send us a photo you have taken of something that has made you smile or laugh. Perhaps you have a cat that sleeps in a funny position, a flower in your garden is simply stunning, you baked a cake that tasted delicious, you received a gift from a loved one. We hope to print our winner in the next newsletter and other entries in subsequent ones. Please send your snaps by post [returned] or by email.

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



A wheelchair should not be a symbol of disability.
A wheelchair is a vehicle to liberation and freedom,
a chariot for independence — Rick Hansen

Six Short Videos from Debbie Ison

Examples of therapeutic interventions you can try which might help with the day to day challenges of this ongoing situation. Links can be found on our website homepage and Facebook page

(https://www.facebook.com/PolioSurvivorsNetwork)

Debbieison34@hotmail.com

1. Emotional Freedom Technique
2. Changing a feeling or physical situation
3. Changing a visual memory
4. Changing an auditory memory or inner voice
5. Energy spinning and a mindfulness activity
6. Grounding

Tranquil Awakenings

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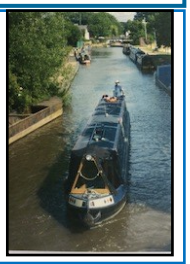
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