



POST POLIO MATTERS

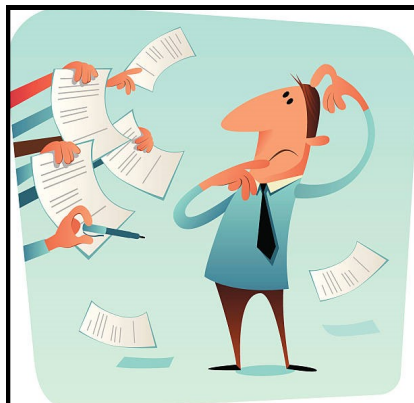
Polio Survivors Network Newsletter
NOVEMBER 2019 Volume 9, Issue 11 of 12 [107]

ELECTION DECEMBER 12th 2019

“Act locally, think nationally”

Watching areas where local campaigners have taken the NHS to task, there have been small, local victories. It seems that if residents get their MP on-side, and mount a targeted campaign, they often win.

What changes are needed where you live?



Turn
FRUSTRATION
Into
HAPPINESS
with
ONE
Nationally Used
Assessment Form



NEURO NUMBERS 2019 - www.neural.org.uk

The importance of data... During the development of the NHS Long Term Plan there was a very clear message from NHS England that if the benefits of a proposal could not be evidenced, it would not be included. It is for all these reasons that The Neurological Alliance has long campaigned for more and better data in neurology, which until recent years, has been virtually non-existent.

Lincolnshire Neuroscience Forum/Lincolnshire Health Authority Survey of GPs 2000

Only **36 of 347 GPs** responded with a **10.4%** figure of **6,633** patients with **34 conditions**

What if all GPs had responded? A possible **64,788**

Lincolnshire HARG Report 2018 6,064 patients with 6 neuro conditions

LINCOLNSHIRE JSNA - Neurological Conditions [New topic Oct 2018]

brings together detailed information on local health and wellbeing needs
and looks ahead at emerging challenges and projected future needs.

NEURO NUMBERS 2019 states ONE in SIX have a neurological condition.

POPULATION LINCOLNSHIRE 2018 - 755,833 divided by 6 is 125,972

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
Page 3	Editorial, Hilary Boone
Page 4	Message from our Chair, Simon Parritt
Page 5	New Features - Toni Dunlop, Administrator
Page 6 - 8	An Interview With <i>*NEW ARTICLE*</i>
Page 8	Introducing Our Member <i>*NEW ARTICLE*</i>
Page 9 - 12	Basher Boris v. Crafty Corbyn start Electioneering slugging it out over NHS 'facts' and The NHS wastes money but ignores 'credit control' on its doorstep! - Verité PSN Trustee and www.aftercancers.com
Page 13 - 14	Why cant we manage Co-Production. Iggy Patel, Halo Able Tec. Added comment from Hilary Boone.
Page 15	I am not LAZY. I have MUSCLE FATIGUE from Polio known as POST-POLIO SYNDROME. - Hilary Boone
Page 16	In 2005 West Berkshire Neurological Alliance raised funds for a General Specialist Neurological Nurse for Six Rare Conditions, Independent Impact Study by the University of Reading .
Page 17	Local adult neurology services for the next decade. Report of a working party - June 2011 Royal College of Physicians. Lincolnshire Neurological Alliance made presentation to Dr. Martin McShane, Director of Commissioning & QIPP NHS Lincolnshire on August 22nd 2011
Page 18 - 19	Continence for Polio Survivors - Zsuzsanna Snarey, Trustee
Page 20 - 21	Post Polio News - Usefulness of electromyography to predict future muscle weakness in clini-
Page 22	Best information found for Polio Survivors repeated every newsletter to give to NHS staff
Page 23	Contact Information
Back Page	New articles, Reset and pause, Val's photocards

QUICK NOTES

Since our last newsletter was published we have had 20 members join. We extend a very warm welcome to you all and hope you enjoy your first newsletter. Please feel free to contact us with a piece to introduce yourselves.

Further Post Polio information:

- ⇒ <http://www.post-polio.org/>
- ⇒ <https://www.polioplace.org/front>
- ⇒ <https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Post-Polio-Syndrome-Fact-Sheet>

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

A big autumn hello to all our members. Where did this summer go? Our summer holiday were just those four days away 'down South' featured in the last newsletter. Thankyou Mick Harper for persuading us to try and see if we could manage. We did, with the fantastic support provided by Richards Carer Helen. Being honest we came home exhausted and in more pain and it took nearly five days doing almost nothing to get back to our norm. Was it worth it? Yes definitely. Lovely memories of people and places to remind us of happy days. We need more.

Why only 4 days holiday? Because I have been so snowed under with paperwork for two years from many different departments [Adult Social Care, Carers First, various NHS departments, the local Clinical Commissioners, the DWP, DLA to PIP, the local Council etc.] taking up energy tokens out of my PPS life. I have had to stay home whilst Helen has taken Richard out to get it done. My social life reduced to almost NIL. We explain PPS and how we manage our lives but because each of them is one department they assume that what they want from us is manageable. Add it all together and it is a mountain - an Everest that this Hilary does not want to keep climbing.

Add to that the help we get from the NHS is minimal and is mostly quick yearly reviews. Social Services think we have lots of appointments and multi disciplinary assessments, and rehabilitation etc... If only. Most I speak to agree it is our own research and that of our support groups that gives us the information to manage our lives.

Brexit is not a subject many of us want to add to the struggles of our daily lives. This newsletter provides you with some information from various view points that I have picked out of a huge number available. The main point that Veritée makes is that for the next few weeks our MPs and councillors are more likely to listen to what we have to raise with them. **Act locally but think nationally.** What problems are there where you live? Can you talk to your local user organisations and other support groups to put forward the problems in your area?

What do we want in Lincolnshire? We want the same thing Lincolnshire Neurological Alliance [formerly named Lincolnshire Neuroscience Forum] have been campaigning for since we started in January 1998. The same services as in larger counties with university hospitals. Lincolnshire as we have told you before is called 'A Black Hole' when you mention neurology.

In 1998 there was just **one visiting neurologist one day a month** at our major County Hospital. Yes just one day a month. That was all the exceedingly low and population extraction figures from nationally published neurological documents Lincolnshire Health Authority thought they needed e.g. 24 patients with Myasthenia Gravis and 112 members in the support group and not everyone joins.

By 2000 we had the results of a joint LNF and LHA survey of GP's asking just one question, how many patients with one of the following 34 conditions? Only a 10.4% response but 6,633 diagnosed with a neurological condition. We had proved their figures were incorrect. More clinics were started, a resident Neurologist appointed, a Neurophysiologist and the MS Nurse moved from Nottingham to Lincolnshire. Sadly whilst things improved for a few years - the Resident Neurologist moved to Shropshire - and whilst others appointed things have started to decline. The reason is exactly the same as before. Without data we cannot prove the need. There is no neuro data available. How can services be planned if the folks at the top have no idea how many patients with neurological conditions there are?

Just look at the block on the front page. If Neuro Numbers 2019 is correct with one in six having a neurological diagnosis then the services in Lincolnshire [and many other counties] are nowhere near enough. Unless the Read Code data from all GP's is accessed we will just have whatever figures each document manages to collate.

Members please tell us about the problems you have with the NHS and Adult Social Care, nothing printed without your permission. The more evidence we have of the issues being faced, the easier it is to campaign for improvements.

Off to the Neurological Alliance AGM next Wednesday so more to report next newsletter.

Wishing you all a very Happy Christmas and the all the best for 2020!

MESSAGE FROM OUR CHAIR

Christmas Promises

This issue is the last of 2019 and the pre Christmas issue but perhaps the most important issue is also the upcoming election and how the outcome will impact us as disabled people and polio survivors. I can only urge you all to vote and to consider how the policies impact upon us as disabled people, and to also think of the many younger disabled people who will be impacted by the outcome of policies that are being promised.

I have spent the best part of my life working as a Psychologist in various settings both privately as well as in a GP surgery through to the geriatric department of a London teaching hospital and also within the voluntary sector where I was also the CEO of a disability charity. In many ways we have made huge progress in technology and medical treatments, but we have slipped back in so far as holistic care has been marginalised. The health and social care reforms have created multiple separate silos of professions, specialties, authorities and budgets. The impact upon disabled people, perhaps like many, but especially PPS and others with complex needs, has been a failure to meet our needs and put an increased burden on us, our family and relatives to become managers of the huge bureaucracy whilst also fighting the ignorance of our needs as polio survivors, patients and human beings.

I suggest that when looking at what we should be asking our politicians at this time is about the need to return to a centrally funding and unified NHS health and social care service. Hiding cuts by squeezing local authorities funding and pretending that the internal market has worked cannot be hidden behind just promising more money. It is time to really put patients at the core and take a different and more holistic approach, We should not be hoodwinked by the 'rambo' type solutions and promises of cash that politicians offer at election times.

Yes, it is clearly about funding, but it is NOT all about funding but how and where the funding goes but what we expect from it. Don't fall into the trap of blaming things on administrators, clinicians need administrators, lots of them, and good ones. What they don't need is multiple levels of funding streams and health and care commissioners. We need to return to putting individuals, both patients, doctors and professionals at the heart and not conditions, illnesses and worse, spurious outcome measures. This is about independent living and the social model being at the centre of how we manage our lives. We need to adopt an holistic approach that recognises the multi-disciplinary nature of everyone's life health journey – of whatever ever age.

This is the challenge we need to confront our politicians with. Throwing money at targets and staff numbers around like sweeties is not alone going to make us happier, more included or even ultimately healthier. As a polio survivor when we need an orthotic, or an assessment for respiratory problems, or some other health or support issue be it heart or cancer, home support or therapy, we need to be treated, in one place, by one service and with one holistic assessment shared by all providers We should be treated as independent autonomous individuals with a life and identity that is more than our condition. We must demand by right the support that enables us to be full, contributory and independent members of our community, family and society.

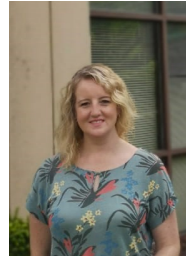
Fixing us isn't what it's all about, even if it that were possible. What is essential is enabling us and supporting us to live independent lives, with choices that deliver, not outcome measures or simplistic friends and family questionnaires, but to have the best possible quality of life.

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

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

New Features

Toni Dunlop, Administrator



A quick hello from me. I want to say what a lovely group of people you are. As I deal with many of you via email or occasionally over the phone I thoroughly enjoy my interactions. Many of you have a great sense of humour, a lovely way with words and a real appreciation for the small but important things in day to day life. This is something that has sadly been brought very close to home for me in recent weeks with a number of bereavements in my family. Every day is precious, make the most of them all.

I wanted to let you know that you will find a couple of new articles in this edition of Post Polio Matters. We hope to turn both into a series with your help.

The first article is "An Interview with". This will take a question and answer format and we hope to have at least one in each newsletter. If any of you have a project, cause, interest or experience that we can turn into a brief interview feel free to contact me (details below). We can do this over the phone by letter or by email, whatever works for you.

The second is "Introducing our Member" which will feature a brief paragraph or two from one of our members, you are all amazing. These will often be new members but we would love to hear from all of our members. I may well be contacting you over the next few weeks to ask for your help. Many have commented that they enjoy reading of other polio survivor experiences as they find it inspiring, comforting or can relate to what is expressed. Any information provided can be published anonymously if preferred and a photo is optional.

We hope that you enjoy these articles and as always please let us know your thoughts.

- Toni Dunlop

Email:

psnadmin@poliosurvivorsnetwork.org.uk

Post:

Polio Survivors Network

PO Box 954

Lincoln

LN5 5ER

PLEASE SHARE EXPERIENCES OF YOUR POLIO LIFE

Tell us about the solutions you have found that work for you

Tell us about the issues you have managing your post-polio life

Help us build a larger database of possible solutions to publish in our newsletter

NEXT ISSUE - Deadline February 2nd 2020

An Interview with Peter Thwaites



Tell us a little about yourself and your polio journey

I caught polio in 1953, aged 4, and to begin with was totally paralysed, not even able to speak. I spent some time in an iron lung and then on an isolation ward.

My early memories are of being in a 'glass dome', with my parents looking at me. All the doctors and nurses were wearing white coats, with full face masks. All very scary for a 4-year-old, which is probably why I am unable to remember much more. Once I had passed the worse, I began to regain the use of most of my muscles and eventually was allowed home. I then had extensive physiotherapy whilst wearing leg braces, and built-up shoes.

I remember having 'rather barbaric' electric shock treatment on my lower legs and feet as they were still very weak. Eventually I was more or less recovered, with a general weakness on my left side. Unfortunately, this weakness, particularly in my chest and back muscles, developed kyphoscoliosis which resulted in me having to have a spinal fusion when I was 14 years old. This was particularly unpleasant with a full body plaster cast from my chin to my hips for 6 months meaning I had to remain horizontal for this entire period, followed by a further 6 months wearing a full Milwaukee straight jacket.

Since then all has been reasonably straight forward, until about 30 years ago when I began to experience post-polio syndrome. This has steadily become worse with extreme fatigue, pains in my lower back and legs, breathing difficulties, and more recently difficulties with my speech and swallowing.

What, in your experience, is one of the larger issues facing polio survivors currently?

The main issues facing polio survivors is the reluctance of the medical profession, and subsequent governments, health authorities, and support agencies, to recognise that post-polio syndrome exists and is a real challenge to a large number of polio survivors around the world.

This means that access to medical support and management of the long-term is very sparse to say the least, with many countries providing no support at all. In fact, many governments actually deny that there are any survivors of polio in their countries, quoting that they have a strict vaccination program.

What is the World-Wide Fellowship of Polio Warriors?

It is a registered charity working to support polio survivors around the world, by acting as a resource by directing sufferers to support groups, medical advice and by any other means that the trustees deem necessary.

We have a members website at www.poliowarriors.org and an information website at www.poliowarriors.info with an accompanying smartphone app, 'Polio Warriors'. These provide mapped listings of support groups, medical practitioners, and polio survivors who have registered with us.

Why was it set up?

A 2001 report by The March of Dimes, a non-profit agency founded by US President Franklin Roosevelt, a polio survivor, noted that up to 20 million polio survivors around the world face the threat of new disabilities 15 to 40 years after their original illness. The World Health Organisation (WHO) in March 2019 estimated there are 20 million people worldwide with some degree of disability caused by poliomyelitis.

For years most of these polio survivors lived active lives, their memory of polio long forgotten, their health status stable. By the late '70s, polio survivors were noting new problems of fatigue, pain, and additional weakness. By the mid-'80s, health professionals and policymakers

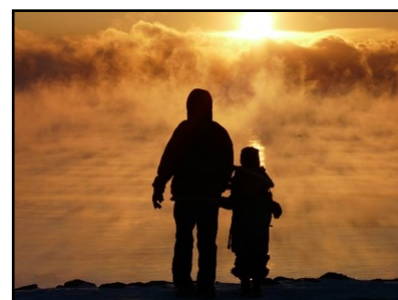
recognised these new problems as being real and not "only in the patients' minds." Studies on this phenomenon called "post-polio syndrome" have been – and are still being – conducted in research institutions and medical centres.

For many polio survivors it is extremely difficult, if not impossible, to locate good medical, welfare, or social support. I decided to develop the smart phone app and websites to provide map-based directories of where some support was available and also where polio survivors were living around the world. After a while I decided that I could no longer do this alone so founded The World-Wide Fellowship of Polio Warriors which is now an England and Wales registered charity.

How can people get involved?

Please register with us and add more names to our world map of polio survivors. Also, we'd love you to consider volunteering with our specialist team research work. If you would like to help us please email peter@poliowarriors.org

An Interview with Verité Reily-Collins



Tell us a little about yourself and your polio journey

My father served in the Royal Navy, and we were all excited when he was appointed for three years to Turkey. Istanbul was a colourful and fascinating place as a teenager, but it came to an abrupt end when I caught polio. In those days the 'Military Covenant' was taken seriously; I was flown home and sent to the Royal National Orthopaedic Hospital at Stanmore (normally it was a six-month wait to get in).

My first day there, I was examined by the Great Man, Prof. Seddon - then one of greatest experts on polio. Gently he told me "you may never walk again". I told him I had no intention of staying in hospital - which annoyed him as it was his pride and joy - and he immediately passed me over to the care of his most junior doctor, J.I.P. James. Mr James and I got on like the proverbial 'house on fire'; saying "it can't hurt", we tried out different ideas, and I walked out of Stanmore.

When did you first realise you had PPS?

I had a vague idea, so asked Hilary. She told me all about it, gave me enormous help, and I joined up as a member of Polio Survivors Network (PSN)

How did you get a diagnosis?

Theoretically, I've never had a diagnosis from an expert - but then there doesn't seem one around in today's NHS. The NHS website has wiped polio off its pages, and now there is only information about PPS. Anyway, what Hilary has put together is good enough for me.

What, in your experience, is one of the larger issues facing polio survivors currently?

Ignorance. I now call in to play acting techniques learnt at school, and when a doctor or nurse lectures me "why didn't you have the polio vaccine" I burst into crocodile tears, very loudly! I am fed up with such crass comments, and find tears the best way of putting across the fact that we caught polio before Salk produced his vaccine; my mother was so frightened of polio she would have been first in the queue if there had been a vaccine, and breathed a sigh of relief when Dad was appointed to Turkey as in those days it was supposed to be polio-free.

However, ignorance amongst nursing staff is rife, and recently I used my savings to pay for an operation privately; the Pre-Op. Assessment Nurse at Chelsea and Westminster Hospital wouldn't arrange for me to see the Anaesthetist before my op. and I was scared of a repeat of the horrendous problems I had had when an Anaesthetist from The Royal Marsden hadn't

administered the correct dosages, even though I clearly remember telling her twice I had had polio.

I had the operation privately, saw the anaesthetist for a good half hour a week beforehand, and sailed through it all. Worth every penny!

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

Belong to PSN. I find the Polio Matters newsletter always has two or three things I have ringed for action or to follow-up.

What simple change would make the NHS more user-friendly for you?

To follow the same protocols as most European hospitals. In Europe I would phone the consultant for an appointment; here we are supposed to waste our time seeing a GP for a referral - when usually they haven't a clue. In Europe you are assumed to have a brain; in Britain the NHS is surprised we have anything between our ears. I remember the wonderful Professor Guilloff sending me off for an MRI Scan at Charing Cross, then telling me with great satisfaction that the scan showed I definitely had a brain.

You have also had cancer and have a very helpful website aftercancers.com. Why did you write this site?

LIVESTRONG, the American cancer charity, says "We believe in information – not pity". This was exactly what I wanted when I got cancer. I did NOT want "poor you" comments. Neither did I want advice on eating miracle foods, nor alternative treatments. What I *did* want was sensible, down-to-earth medically-approved advice based on clinical trials and scientific evidence – and understanding and help for what my body was going through, especially handling poisons contained in cancer drugs.

Strangely, help was difficult to obtain. All the charity adverts on TV tell us "we are there for you", but cancer charities in Britain tend to follow the NHS line, and this service is one of worst in Europe for dealing with cancer issues. Every major survey of European post-cancer survival rates places UK at bottom of table, but try to find out what is happening in America or Europe, and you come up against a brick wall.

<https://aftercancers.com/why-write-this-site/>

Introducing Our Member - Lynne

Hi there, my name is Lynne Morton I am 53 years old in November. I contracted polio when I was 13 months old, in 1967 I was given the polio vaccine and the very next day I was rushed to hospital put into isolation and diagnosed with polio. I contracted the disease from the vaccine! All of this is in my medical records; apparently it was tested in the lab and was found to be contaminated so basically the thing that was supposed to stop me getting the disease actually gave me it!

I have managed to live a good life; I have 4 children and a beautiful granddaughter who keeps me on my toes and another grandchild on the way.

I've tried to not let the disease stop me too much but recently I am finding it very hard as I feel I am just not taken seriously in regards to my symptoms, and post-polio syndrome seems to be a taboo subject in the health department. I know many other polio survivors are experiencing the same as me, but we will soldier on and hopefully one day make the practitioners see this is something to be taken seriously.



If you would like to be featured in an upcoming newsletter please send your introduction in (short piece) and an accompanying photo if you wish.

Basher Boris v. Crafty Corbyn start Electioneering slugging it out over NHS 'facts'

All politicians will claim that the NHS, first discussed during the 1930s, worked on during the War, and eventually launched in 1948, is 'dear to their hearts'.

Translation – we know it's a vote-winner so watch what we are going to promise! But if you believe politicians' promises – you really do need treatment.

NHS Providers chief **Chris Hopson** said "over dramatising NHS difficulties" or making "disingenuous" funding claims did the service "no favours"

Vote Bait

Health is going to be a political football, kicked around from party to party – so here is a guide (using figures obtained from the BBC) to who is saying what – and what I cynically think might happen.

1. Boris Johnson refers to building 40 new hospitals

Whilst he told the Conservative Party Conference that he "pledged billions of pounds for hospital projects across England". Plans include £2.7bn investment for six hospitals over five years, **BUT a further 34 hospitals will only share an initial £100m in funding to start developing future projects. That will go on 'consultations'; architects' fees, planning, etc. – NOT on actual building.**

And – with a country-wide shortage of staff, how are they going to find enough people to manage these proposed new hospitals?

2. Jeremy Corbyn says waiting times for cancer treatment have risen

He is right. The NHS has become worse at meeting waiting time targets for cancer treatment.

The proportion of patients waiting for more than two weeks to be seen by a specialist, after a GP referral for suspected cancer, has risen from 92% to 95% since 2010. And people who have to wait more than two months from a GP referral until they actually receive treatment has risen from 79% to 86% (relatively small in percentage terms but representing thousands of people waiting longer to be seen).

Wait times are so bad in my area that GPs regularly refer patients 'out of area' where waiting times are less; costs in hospital transport are extra – but this comes out of a different budget!

Boris Johnson said cancer survival rates had increased year on year since 2010

Cancer survival has doubled during the past 40 years right across the World. **Since 2013 the UK lies at the bottom of European cancer survival rates** (according to World Health Organisation, Cancer Research UK, National Audit Office etc)

Mr Corbyn said the NHS was experiencing the longest spending squeeze in its history

Between 2010 and 2018, spending rose by just 1.3% on average. Last year, more money was announced that will bring the annual increase over the next five years to 3.4% – below the long-term average but an increase on most of the past decade.

Mr Johnson said there were 17,000 more NHS doctors and over 17,000 more nurses on wards than in 2010. Mr Corbyn said 43,000 new nurses needed to be recruited to fill vacancies.

The BBC says the prime minister's figures are broadly correct.

According to NHS workforce data, there are now 18,055 more doctors employed directly by the NHS to work in hospitals than there were in May 2010, and 16,989 more general nurses. BBC

Mr Corbyn is also correct to say there are currently about 43,000 nursing vacancies across the NHS.

Why do we need roughly 60,000 more nurses now than we did a decade ago? Because the UK population is ageing and increasing – that's why healthcare is such an important political issue.

Mr Johnson highlighted missed targets in Wales, while Mr Corbyn did the same for England

NHS Wales is run by the Labour-led Welsh Government, while NHS England is under the control of the Conservatives. **Surely, our health is too important to be a political toy?**

There is a list of targets that haven't been met by both health services, including the widely publicised accident and emergency waiting times.

This target aims to ensure at least 95% of patients who attend A&E are dealt with within four hours of arriving. **In the past year I have found this meant waiting 3hrs 55 mins. before being seen by a doctor, who took notes, then disappeared – leaving one waiting even longer.**

It hasn't been met in England since 2015, while in Wales it has not been met in at least a decade.

Is NHS funding worse in Wales?

The Welsh Government allocates budgets for certain departments, such as health and education, but the overall pot is broadly determined by central government. And Mr Corbyn said the problems in Wales stemmed from cuts by Conservative central governments to the Welsh Government budget.

Funding was cut between 2011 and 2017 before it started slowly increasing again. But real-term spending in Wales on public services overall won't return to where it was in 2010 for another three years.

Finally... the effect of Brexit on the NHS

Expect to hear a lot from Labour in this election about a post-Brexit **"Trump trade deal"** and the price the NHS would pay as a result.

Mr Corbyn certainly pushed the point home during PMQs, while the prime minister insisted the NHS would always be protected. In the end, as with so much in Brexit, it depends on what is negotiated.

Hitting NHS nails on the head

Patients Over Politics – take action in the Patients Association election campaign – contact them on their website, www.patients-association.org.uk

Dr. Jennifer Dixon, CEO of the Health Foundation, comments *"despite the promised spending, there are structural questions of funding left unaddressed, such as the real lack of detail on funding social care properly – an issue which is currently crippling the NHS"*

You might watch

www.999CallfortheNHS (independent) "Summer 2019 We're determined to continue fighting with other campaigners to stop USA Accountable Care moving into our NHS - now called "Integrated Care" and **Health Campaigns Together** (backed by Unions).
www.healthcampaignstogether.com

They each hold regular meetings bringing a variety of local campaigns together, they advise campaigns on their websites and blogs, and are run by "hands on" campaigners who are willing and able to give individual campaign advice.

"Act locally, think nationally"

Watching areas where local campaigners have taken the NHS to task, there have been small, local victories. It seems that if residents get their MP on-side, and mount a targeted campaign, they often win. It's the mass rallies with catchphrases that look good on banners, but don't say anything definite, that lose out.

An effective campaigner told me *The key "awareness-raising" which needs to be done by all campaigners is of local councillors. They should be opposing the proposals of the CCGs (dictated by Govt). Instead, they are rolling over without asking any questions and swallowing the cost-*

cutting “newspeak” of patently untrue claims from NHS managers. Most Health and Adult Social Care councillors are simply not doing their job of holding NHS managers to account and scrutinising all the details. If they were they would retaliate in the only language which NHS managers understand: legal threats.

She is right – because of polio I need my neck supported when lying down on an A&E trolley. As a cost-cutting measure pillows are being removed; I find murmuring “Injurylawyers4U” produces pillows p.d.q. [pretty darn quick]

What you can do

What’s needed locally? Think small and focus on a project that is do-able. Save our NHS is a lovey catch-phrase but – save what?

When someone wearing a massive party rosette and a false smile comes knocking on your door

ASK what is happening about then bring in your local health issue.

NOW is the time to hit hard – when politicians will promise anything to get YOUR Vote. You are probably face-to-face with a local Councillor, or someone who is active behind the scenes, so now is your chance.

I can’t wait!

(with thanks to Cartoon Stock for their royalty-free image)



The NHS wastes money but ignores ‘credit control’ on its doorstep!

‘If you watched TV in the 80s, you might remember **Sir John Harvey Jones** fronting the ‘Troubleshooter’ series. He had personal reasons to be grateful to the NHS as his daughter had polio but got the best treatment she could have received. That was in the 50s and the NHS still in its infancy, Matrons were hands-on, not today’s CEOs who are unknown in their own hospital. No MDTs – instead there was a ward round with everyone treating you, from your surgeon to physios and nurses, clustered around your bed. They discussed your treatment with you there rather than in a far-off room with no-one able to say “that’s not me”.

My favourite shot in ‘Troubleshooter’ showed Jones’s utter astonishment, visiting an NHS hospital on a Friday afternoon, and finding it closed down. Then explaining that if you wanted to run a business successfully, you didn’t leave expensive equipment idling when it could be working.

Today, nothing much has changed. One wonders what Jones would think about the continuing saga of the NHS. As he once said, ‘the NHS has the same problems now as it did when I looked at it: vastly over-managed, over-administered, its people under-trusted. There is just far too much micro-management”.

Money pumped in [to the NHS] seems to have gone on increased rewards, paying a vast administrative organisation that can’t even do the accounts properly. It’s mind-blowing!

Things have got to change, and along comes **David Gilbert** with his book ‘**The Patient Revolution**’, asking “**Could the solution to NHS problems be in the hands of the patients themselves?**”. His book comes up with numerous reasons why patients might have answers - not the patients who slavishly repeat the mantra ‘NHS is the envy of the world’ when patently it isn’t. But those Patients who think through medical problems, then want to suggest ways of improving their care.

The NHS must learn to listen to us. Especially for non-medical problems. It doesn’t take rocket science to work out if the motor opening hospital entrance doors breaks down, and you can’t buy a new one off the shelf; get a company to make a one-off replacement.

But instead, last winter the John Radcliffe hospital in Oxford bought in a massive industrial

heating unit belching out warm air 24 hours a day. Costing a fortune to run. And the doors stayed open because no-one fixed the motor. Surely a patient's company might have supplied the motor unit for free? Matron would have known just whom to ask.

Patients are an untapped resource!

Any hospital cares for a cross-section of people as patients. Perhaps instead of asking all those Politically Correct questions on forms about race etc., someone might ask us what is/was our job? and next time a ward needs – say – a cupboard to house equipment, a glance at data from recent patients would surely throw up some who had been joiners or carpenters who would be happy to give something back?

Patients are often physically immobile, but many of us find our brain is still very active. Faced with health problems, we go on a hunt for ways to improve this., and often turn to the Internet. From our experience, we can filter out quacks and charlatans, and come up with ideas to improve our health and wellbeing.

I remember discovering via the Internet that I had Peripheral Neuropathy. The trouble I had to convince my doctors that this was a cancer drug side effect! It was only after I showed the hospital info from top official US websites that I was able to arrange suitable treatment.

We can all help

Doctors can't know it all - but by telling each other what we discover in Newsletters like this, by exchanging accurate information, etc. Patients can gradually change treatment for the better.

When an Election is called it's surprising what you can achieve if you put your mind to it!

The trick is to get your MP onside and make sure they ask for a share of Government funds for your particular interests.

Polio and the PSN are going to have to compete with vested interests demanding funding for **their** project. Therefore, unless there is a particularly strong campaign locally for one thing e.g. closure of A&E, etc. it's best to ask for overall funding for NHS in the manifesto and fight over the spoils once they are allocated.

NHS is going to have to compete for funding this winter with potholes, education and a host of other services wanting a share of the government pot, so the more emails on 'funding for the NHS' the better.

When you send an email to your MP, it is highly unlikely they will have time to read it, particularly in the run-up to an election. What happens is, one of the PAs/secretaries/party workers will be given the task of counting up how many emails/letters/etc received under each topic, then reporting to party HQ, who tots up the returns across the country and decides which has the most demand.

So don't spend hours over your email - just make sure **Subject** says what it's about in **LARGE** letters.

If applicable, get the Unions on your side: Unite and/or Unison are the two biggies.

Charities such as Age UK, Patients' Association, etc. will all be lobbying. If you belong to any you can add your plea for extra funding to their efforts. But again, keep it short.

Get other patients involved. This can be difficult, and don't be surprised if they shy away and say "I don't want to be involved". There is a mindset that believes if it complains they will be marked – and there is nothing you can do about this except move on to the next person. Eventually you will find a like-minded patient and the two of you will be formidable.

And if you want inspiration, no French doctor would have dared tell a Frenchwoman, as I was told, that her skin problems "are due to your age", neither would an American woman have taken it lying down if US healthcare tried to operate a post-code lottery!

We just have to forget the stiff upper lip and go for it – and have some fun!

Verité Reily Collins - veritegreenbee@gmail.com

WHY CAN'T WE MANAGE CO PRODUCTION? 2.10.2019

by Iggy Patel [Halo Able Tec - iggy@haloabletec.co.uk]

You would think after all most 30 years of talking about co production, we'd have nailed it by now. You'd presume as everyone seems to think it's a good idea co production would be a concept so firmly embedded into our culture that nothing would happen without it being co-produced. It's so natural that it doesn't even need to be mentioned it just happens. So why doesn't it?

Who doesn't think people should actually be getting involved in local democracy, helping to shape what is needed, working together to improve matters. Isn't that co-production? So why aren't people invited to have their say at council meetings? Or to work on policies and processes? To remind those that are there, that these things actually matter and affects people on a daily basis? Why must reports come only from officers who are paid to produce such? Can they truly be Independent?

Unfortunately as our politics seem to show, trying to get anything done is a nightmare. What sort of democracy is this? Whether in Government, NHS or Local Authority, those in power seem to want to hold on to it and stand and tell people you will do as you're told. I make the decisions. Isn't it time to stop that bossy, top down attitude, and to try and work towards a true democracy.

You wonder why then we can't get co production done or even started. Still every day I see snippets all over social media which says it's time to talk, we must meet and discuss, even this last week the NHS where promoting at quite an expense and with countless people attending personalisation. Which in essence is all about independence, choice and control, something you can't really do without co-production. How do you know what my needs for independence, choice and control even are without talking to me?

For it to really happen we need a change of thinking, we need those in power whether in National Government or Local to remember they are there to serve the people and not for their own financial or personal interests. We need to change our way of thinking away from I'm in it for myself, what's best for me, to we are all in it together, what's best for all of us.

One of the first steps to co production as to be involve people at the start. Don't develop plans and reams of paper which is all technical and needs a dictionary to understand. Remember at the end a service user needs to understand it. Bring in people at the idea stage, take the people along the journey. Don't just send a postcard at the end. Too often we are brought polices, within which the detail or practical considerations are missing. I have literally just read a report with wonderful diagrams and jargon filled where it shows the communication with the client happening three quarters of the way in the process, all the decisions and planning already being made. This Policy is supposed to be a new way of working locally.

People say no one's going to do it for free, well I along with a number of colleagues have gladly attended meetings 10 years for free. It's my life, as a disabled person with physical and learning disabilities in order to have the benefit of living independently, with choice and control for me it's not about money. It is literally my life my basic rights, that I fight for. The sticking point is always we talk and nothing ever happens. I and my colleagues have drawers, boxes full of files, from meetings, which never get anywhere, only to be reinvented a few years later. When asked why it is the same crowd faces all the time. The answer is pretty obvious, if you can't be bothered to listen to us, we are not going to go out and tell people to get involved you'll be heard. The word of mouth is a powerful tool that can work for you or against you. It's free and easy, it's up to you whether you want it to work or not.

For years I worked in the system, trying to get things done as a local authority worker in effect co-producing and partnership working without even actually calling it those things. No words, no fancy titles, just doing it, and time and time again I was faced with egos and power struggles. As an example often I would ask people in departments to pass me a process or report or document and in some occasions it could take up to a year before I finally got to see it. Now I work out of the system, if I want a document I'll ask, if it's not forthcoming I will use the powers available to me via Freedom of Information or Data Protection and get the same reports in weeks. Surely that's just

ridiculous isn't it! The point is here if you can't talk to each other properly within, how can you go outside and ask for people to help you?

Sure I and my fellow disabled friends and colleagues will work with any organisation and give you our time because it's important to us. However if it has, it usually becomes just another talk, discussion, meeting without any succinct manageable plans with achievable targets, you'll soon notice we'll stop attending. If you can't make it happen stop doing it and give it to someone who can get it done.

I guess at the end of the day, everyone tries to fight for what is truly important to them, not just a pay packet, but knowing that you make a difference, you've achieved or done something for society or someone that will make it better. Or will it be more of the same I've done my 8 1/2 hours, give me my money and good night?

Whether its democracy or co production you want you only get what you truly put in. If it's something you are passionate about, regardless of the financial benefit you will move forward. Somethings, some freedoms are worth fighting for whatever the cost.

Hilary Boone adds... along with Iggy and many friends and support group workers have also attended many meetings for up to 30+ years. We have been giving up valuable time from our disabled User/Carer of a disabled user lives to positively raise issues that we experience hoping that changes can be made so others do not struggle to get through the same problem.

Sadly after all these years we have realised that every time there is a change in boundary, trust name, Government Act, change of political party in power nationally or locally, everyone starts again, archiving all the previous information. How many times have we heard 'Forget the past, this is a new way of working'.

Just one example of an issue that costs the LCC money.

To receive a direct payment to help manage our lives we are assessed by a [RAS] questionnaire. Our answers to the questions award points, totalled then multiplied by a figure for the year.

Then a Financial Assessment to see if we have enough money to pay towards this amount. The form lists funds coming in and then amounts we can deduct. Disability Related Expenditure Special items we have to purchase because of our disability can be deducted. The larger items, like a wheelchair, are divided by 500 [10 years] smaller items over 1 year. If the final figure is a positive amount then that amount is deducted from the yearly figure. We have to pay that money into a separate bank account and Social Services pay in the remainder by instalments.

Every late March we are sent a **Financial Assessment Charge Explanation for next year.**

"If the amounts of money we have used to work out how much you should pay is wrong, please tell us in writing by May You can do this by crossing out the information that is wrong and putting the right amount next to it" Example border added for this publication.

Fc Buildings Insurance	- £ 4.00
Fc Council Tax	- £ 9.45
Fc Other outgoings	- £ 2.42
Fc Miscellaneous	- £ 1.40

On 12th March 2012 - 5 of us who attended a Lincolnshire County Council paid for Partners in Policymaking Course were asked to repeat our presentation to a huge meeting of County Staff.

We asked for lines from words to figures. We asked for a column to put the new figure in. We asked for increased information on what 'other outgoings' and 'miscellaneous' referred to.

March 2019. There is still no change to the form. Users, Carers and Staff spend more time and stress trying to deal with this and that costs the Council money.

So are they really listening? Are we more than box tickers to say they have consulted?

I am not **LAZY**. I have **MUSCLE FATIGUE** from Polio known as **POST-POLIO SYNDROME**.
PLEASE will each of the many departments/organisations I have to deal with
understand that in total this has to be fitted into managing my disabled life.

Slide 1. Our muscles were affected by the Polio virus and some nerves were killed.

Those that were not killed grew axonally sprouted roots that took over some of the orphaned muscles fibres. This was our recovery system.

We do not know how many orphaned muscle fibres were reactivated in each area. Many thought parts of our body recovered fully.

Slide 2. Simply shows that when the working part of the muscle wants a rest it asks resting muscle to take over. No polio and there is about 70% resting and when this takes over there is still about 40% still resting.

Many of us thought that many of our muscles recovered to normal. However, a muscle graded 5 normal that was affected by the polio virus might only have 60% usable. 30% working and 30% resting to take over. Now many of think back we remember that whilst we could achieve highly we did not have the stamina of our non polio peers.

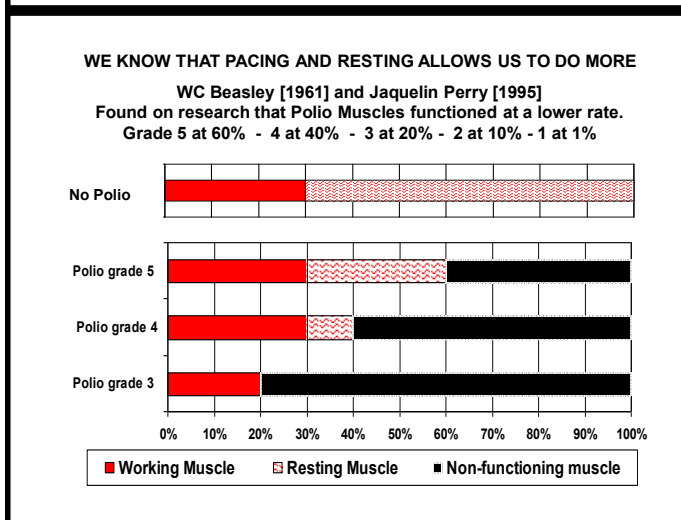
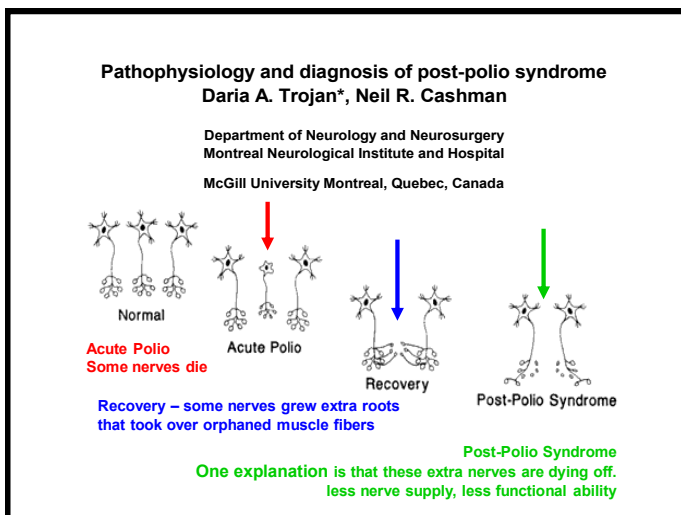
Polio affected muscles graded 4 do not have enough resting muscle to take over. We can use this muscle but are advised to stop 20% before we have used up the muscles energy and rest and allow the muscle to recover so that it can do it again.

To manage our lives we advise our members to use Energy Tokens. £10 a day and £70 a week.

Unfortunately each individual polio survivor has to work out how much each action will cost you. Some examples on chart opposite, note the change if you have help.

If your day is going to take more than £10 of tokens then you have to do less the day before and after. Things like do not get dressed, don't have a shower just flannel wash. Eat already prepared meals. Get someone else to drive.

Paperwork should be as minimal as needed to comply with rules and regulations. It should not take us hours and hours to read, provide the information and check it when complete to make sure there have not been any misunderstandings. Why does every department formulate their own assessment forms?



Get self washed and basic dressed for home	50p
Add putting on one brace and shoes.	£1
Add getting out and putting on coat, hat and gloves	50p
Get shower on bath seat wash hair without help	£1
Get shower on bath seat wash hair with help	75p
Get simple breakfast	50p
Get simple snack lunch or reheat already prepared meal.	50p
Prepare and cook a dinner	£2
Eat meal pacing and resting swallowing	50p
Washing up and putting items away.	75p
Add Paperwork for NHS ASC per hour, resting regularly.	25p
Drive about 10 miles in Lincoln easy traffic	50p
Drive about 10 miles in Lincoln in heavy traffic	£2
Load or unload both sets of electric wheels by hoist	50p
Hospital medical appointment on own.	£4
Hospital medical appointment with driver who loads and unloads wheelchair assist with undressing/dressing.	£2

ONE NATIONAL FORM WOULD SAVE £THOUSANDS!

In 2005 West Berkshire Neurological Alliance raised funds for a General Specialist Neurological Nurse for Six Rare Conditions,

MND, Huntington's, Myasthenia Gravis,

Ataxia, Late Onset Polio, PSP Multiple System Atrophy.

This post won a **Leadership for Improvement Award** and an **Independent Impact Study** by the University of Reading



EVALUATION SUMMARY

This specialist nursing post was funded by 4 Berkshire charities, the West Berkshire Neurological Alliance, the Motor Neurone Disease Association [Reading and West Berkshire], British Polio Fellowship [Berkshire Branch] and Huntington's Disease Association [Reading Branch]

It established a clinical nurse specialist [CNS] for neurodisabilities, based within the Royal Berkshire hospital NHS Foundation trust, to work with patients across the Berkshire West area who have rare, complex neurological conditions.

A multimethod evaluation of the post was undertaken by staff from the University of Reading.

The post was highly cost effective. Cost savings from the reduction in bed stay more than covered the cost of the post. **Savings in 2006** [the year following appointment of the CNS] **were of the order of twice the cost of the post - ranging from 165% to 274% of the post costs, depending on the method of calculation.**

This is likely to be an **underestimate of the cost benefit**, since it does not include any additional income to the hospital trust from freed capacity to increase the number of hospital admissions.

Patients and Carers valued the post highly. The majority believed there was little improvement to be made to the service, beyond ensuring it was continued, in the words of Carer asked to choose something to improve the service

"She [CNS] is wonderful. She gave me so much support, without which I don't think I could cope. My wife [of over 50 years] only wish is to stay at home, and [CNS] gets us all the help we need. Her job is vital, she cannot be done without. FOR HER: more money, more help with her workload."

FINDINGS.

1. The evaluation found that the post met the outcomes desired by the funders.
2. It provided rapid and timely access to specialist knowledge and services.
3. Patients and Carers reported greater satisfaction with health services
4. Patients' length of stay in hospital was reduced.
5. Patients and Carers were extremely positive about the post, indicating that the CNS helped meet national and local policy objectives, providing
6. A patient centered service, with patients offered information about their condition
7. Rehabilitation, advice and support to meet continuing and changing needs.
8. Support for Family and Carers.
9. Care during admission to hospital or other health and social care settings ensuring patients neurological needs are met when they are having care for any other reason
10. Appropriate speed and flexibility of service delivery, within and across professional and agency boundaries.

This post was then funded by the NHS.

Local adult neurology services for the next decade.

Report of a working party - June 2011



Royal College
of Physicians



ASSOCIATION OF BRITISH NEUROLOGISTS

EXCERPTED

Neurological disorders are very common

- Accounting for about **one in 10 GP consultations**
- Around **10% of emergency medical admissions** [including stroke] and
- **Disability for one in 50 of the UK population.**

They include many different conditions of varying severity, some very common **and** others exceeding rare, from migraine to motor neuron disease.

This new report makes three proposals:

1. An expansion and improvement of local services with a shift in emphasis from scheduled to emergency care
2. Better organised care for patients with long-term neurological conditions, managed in part through an enhanced role for **specialist nurses and general practitioners** with a special interest in neurology.
3. Better local planning of services with increased clinical involvement within a commissioner/provider forum, creating a neurological network to improve clinical and financial outcomes.

Lincolnshire Neurological Alliance made presentation to Dr. Martin McShane, Director of Commissioning & QIPP NHS Lincolnshire on August 22nd 2011

January 1998 at the Lincolnshire Neuroscience Forum first meeting we learned that Lincolnshire County Hospital held ONE NEUROLOGICAL CLINIC ONE DAY A MONTH.

In 1999 Lincolnshire Health Authority showed us the Specification for Neurology Top 16 Neuro conditions. **At Number 16 was Myasthenia Gravis with 24 patients.** The MG rep stood and said we have 112 members and not everyone joins. HB stated there are 5 support groups here not listed all with all more than 24 members. Lincolnshire Health Authority admitted their figures came from extrapolating a population figure from the 16 nationally published figures. Sadly we then learned for years the national figures had come from adding up the local health authorities figures.

In 2000. The LNF asked and LHA agreed to survey their 347 GP's with just one question. "How many patients do you have with a diagnosis of the listed 32 neurological conditions?"

Only 36 [10.4%] of the 347 replied with 6,633 patients - Population of Lincolnshire **634,300.**

How many would there have been if all GP's had responded?

Lincolnshire Neurological Alliance have had to campaign hard over the last few years to get neurological conditions added to the Joint Strategic Needs Assessment.

From research-lincs.org.uk [The Joint Strategic Needs Assessment (JSNA) for Lincolnshire reports on the Health and Wellbeing needs of the people of Lincolnshire. It brings together **detailed information on local health and wellbeing needs** and looks ahead **at emerging challenges and projected future needs.**

How big is the problem and how do we compare?

What services & activities are in place and how well are they performing?

What inequalities exist? What are the unmet needs and gaps?

What are people telling us? What are the risks of not doing something?

Nineteen years later in 2019 - despite many requests from LNA and promises from a variety of Public Health/NHS departments - Lincolnshire are still unable to provide accurate DATA for how many patients have neurological conditions.

"How can you plan neurological services if you do not know how many patients?"

Continence for Polio Survivors by Zsuzsanna Snarey

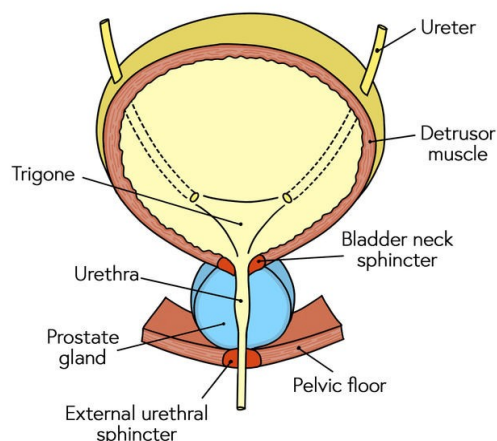
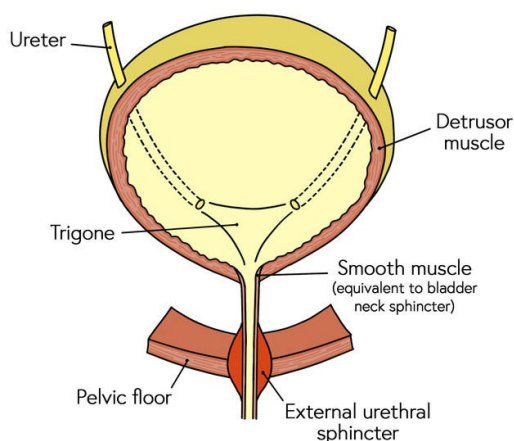
It is hard to talk about continence as it is an embarrassing subject. Many people do not seek advice from their GP because they believe it is a normal part of ageing or because they are too embarrassed. Many people are not aware that there are successful treatments available and don't like to bother their GP. But given that the polio virus affected the whole body it is probable that bladders and bowels were also affected. It is a very common problem of polio survivors. Even in the general population, approximately 10% of all adult women suffer from urinary incontinence¹. It affects 11% men and 20% women over the age of 60. That means 1 in every 5 older women and 1 in every 10 older men have problems with continence. Older women experience more incontinence than breast cancer, heart disease or diabetes. The number of affected men also increases with age. Men aged over 75 are likely to experience bladder problems because of an enlarged prostate. This can be treated with drugs from the GP.

If you decide to consult your GP he will probably ask you about your symptoms and medical history, whether urinary incontinence occurs when you cough or laugh. This is called stress incontinence. If you need to go to the toilet frequently during the day or night, you might have an oversensitive bladder. The GP will ask if you have any difficulty passing urine when you go to the toilet and if you are currently taking any medication, also how much fluid, alcohol or coffee and tea you drink. Caffeine has an irritating effect on the bladder. You might try and see if giving up tea and coffee has any beneficial effect. You may also have some tests and examinations to rule out things that may be causing incontinence.

We also need to think about the 'almost' leaks and the people who get to the toilet 'just in time', because providing advice and treatment at this stage may prevent incontinence from developing later. Lower urinary tract symptoms and incontinence is never normal and should always be investigated and treated. A significant, painless urinary infection can cause a general sense of being unwell, fatigue, weakness and confusion. A painless urinary infection can cause incontinence and frequency of urination during the day and the night. If undetected and untreated, it is responsible for a great deal of problems.

The normal bladder functions as a reservoir to store between 350–500ml of urine. The bladder has two phases – filling and emptying. The kidneys constantly filter urine into the bladder, gradually filling it. During filling, the bladder, which is made of muscle, should remain relaxed and slowly expand to a point where you become aware of a sensation of fullness. It is normal to be able to put off urinating until a convenient time and place is found. When ready to pass urine, the bladder should squeeze to empty itself completely. Then the filling begins all over again.

In females there is only one actual bladder neck sphincter, the external sphincter, comprising striated/skeletal muscle under the voluntary control of the somatic nervous system. This muscle can be exercised and will strengthen with pelvic floor exercises. Compared to males, females are more at risk of problems with their urinary continence, as they have a short urethra and only one bladder neck sphincter. They are also more at risk of infections because the anus is fairly close to the urethra.



Males have two sphincters:

1. Bladder internal/neck sphincter, smooth muscle is continuous with the detrusor muscle and is under involuntary control or autonomic control; the function of this sphincter is to keep the bladder closed at the time of ejaculation.
2. External bladder neck sphincter, striated/skeletal muscle at the base of the prostate and is under voluntary control of the somatic nervous system. This muscle can be exercised and will strengthen with pelvic floor exercises.

The pelvic floor muscles are made up of slow and fast twitch fibers. It requires the combination of both slow and fast twitch fibers for the pelvic floor to work. It is also important to also understand the interrelationship between pelvic floor and abdominal muscles. When abdominal muscles are contracted **strongly** the entire pelvic floor contracts in response. This is known as *co-contraction*. It may be advisable to be instructed by a qualified nurse about the correct way of doing pelvic floor strengthening exercises.

Urgency and accompanying urinary leakage may be due to an over reactive or irritable bladder which may want to empty even when not very full. You may feel as though you are busting but when you get to the toilet there may not be much urine to pass. There are many reasons why a bladder may become irritable such as infection, poor bladder habits, poor fluid intake, constipation. Sometimes we just don't know the reason why. Bladder training involves learning techniques to help you to calm the bladder down.

The aim is that your bladder will, eventually, squeeze to empty only when you are quite ready for it to happen and will hold larger volumes of urine. This may take time, patience and determination. You should expect good and bad days for a while. Learning pelvic floor muscle control is essential to success.

Other ways to help yourself are

- Drinking 2 liters of water a day and cutting down on tea and coffee
- Not drinking 2–3 hours before going out where there is no toilet access
- Not drinking 3–4 hours before going to bed
- Not suppressing a desire to void
- Visiting the toilet so that voiding volume generally is 200–300 cc
- Taking time for toilet visits
- Going to the toilet before going out where there is no toilet access
- Going to the toilet just before going to bed.
- Make access to the toilet as easy as possible
- If having trouble getting pants off quickly, consider elasticated waistlines.
- Increase ability to fully empty the bladder by leaning forward slightly when sitting on the toilet – rest elbows on knees to give urine a “straighter” path.

Swollen legs which cause more voiding at night may be relieved by elevating legs as much as possible when sitting, exercising such as walking to stimulate the venous pump in the legs, and using compression stockings. Swollen legs can be caused by diseases other than weak muscles. If you have swollen legs you should discuss it with your doctor. Contact your GP if these symptoms have arisen within 1–2 years or if the above advice is of no help.

Many health conditions are a result of being overweight or obese. Weight gain is a result of eating too much fatty, sweet or high-calorie foods, coupled with too little exercise. Many of today's common health conditions are called “lifestyle diseases” as they're caused by our poor choices of (more) food and (less) activity over time. If you're overweight, you're in a high-risk group for poor bladder or bowel control.

Editors Note: Foods move slowly through our guts and more water is excreted and stools become harder. Further reading 'Slow Guts & Polio Survivors' <http://postpolioinfo.com/library/SlowGuts.pdf>

Usefulness of electromyography to predict future muscle weakness in clinically unaffected muscles of polio survivors | PM&R.

[Manuscript received: 12 April 2019; Manuscript accepted: 24 October 2019; Accepted manuscript online: 08 November 2019] **Abstract only.**

Background - Post-polio syndrome-induced muscle weakness may develop in limbs that have had normal muscle strength and been considered unaffected by polio.

Objective - To investigate the utility of electromyography (EMG) for predicting future muscle weakness in clinically unaffected limb muscles of polio survivors.

Design - Retrospective Study

Setting - Academic polio clinic.

Participants - Polio survivors (N = 77) who underwent EMG between April 2008 and March 2010 and were followed for at least 2 years.

Materials and Methods - Chart reviews were conducted to extract baseline EMG and manual muscle strength test (MMT) results to investigate the relationship between baseline EMG abnormalities and change in muscle strength over 2 years for various upper and lower limb muscles that control movement in the limb joints.

Main outcome measures - Sensitivity, specificity, positive predictive value (PPV), and negative predictive value (NPV) of EMG findings for prediction of subsequent muscle weakness.

Results - EMG data were available for 44 deltoid, 59 biceps brachii, 60 triceps brachii, 59 vastus lateralis, 59 tibialis anterior, and 55 gastrocnemius (medial head) muscles. The percentage of muscles with an initial MMT of grade 5 that developed weakness over 2 years of follow up was approximately 15% for most muscle types. Sensitivity of EMG to predict subsequent weakness was higher in the lower limbs (0.67-1.00). Specificity was higher in the biceps brachii (0.83). PPV was higher in the biceps brachii (0.50). NPV was higher in the lower limbs (0.89-1.00) but lower in the deltoid (0.75).

Conclusion - EMG abnormalities were detected in some clinically normal muscles of polio survivors. EMG abnormalities predicted muscle weakness 2 years later, although the strength of this relationship varied depending on the muscle.

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

Polio Vaccine May Stall The End Of Polio | npr Goats and Soda

[November 15, 2019: 5:04 PM ET] Jason Beaubien writes: As the global effort to eradicate polio gets tantalizing close to its goal, the program is running in to new challenges.

One of the biggest obstacles this year is the proliferation of so-called "vaccine-derived" polio outbreaks.

Conventional polio caused by the traditional form of the disease is now only occurring in two countries in the world — Afghanistan and Pakistan. The World Health Organization calls this form "wild" polio and there've been roughly 100 cases so far this year. This is a tiny number compared to the 350,000 cases that occurred globally before the Global Polio Eradication Initiative was launched in 1988.

But what's troubling now is that there are currently more kids being paralyzed by cases of vaccine-derived polio than by the original "wild" variety.

"We have seen a lot more countries impacted this year than last year," says Dr. John Vertefeuille, the head of polio eradication at the U.S. Centers for Disease Control and Prevention. There've been outbreaks this year in the Philippines, China, Myanmar, Pakistan and a half a dozen African countries.

"Because of the rising number of individual outbreaks," Vertefeuille says. "The CDC has taken a decision to do a surge staffing effort focusing on Africa."

He says the CDC is in the midst of sending up to 100 additional personnel to Africa to help track, manage and wipeout vaccine-derived polio outbreaks over a six-month period.

Currently around the world, all children are supposed to get vaccinated against polio. In the U.S. and other wealthy nations, kids get 4 injections of inactivated polio vaccine spread out over their first 7 years of life. This injectable vaccine does not contain live virus, so it does not and cannot cause vaccine-derived polio. In lower income countries with weaker health systems, an oral vaccine containing a live but weakened version of

the polio virus is used. It's cheap and easy to administer through a few drops in a child's mouth.

In the early days of polio eradication, this live oral vaccine also had the added benefit that it could circulate in a community just like the real, wild virus. In places with poor sanitation, wild polio and the virus in the oral vaccine can spread from sewage to drinking water. At first this was great. Kids who hadn't been vaccinated by health workers ended up getting exposed to the oral vaccine and protected against wild polio because of their lousy drinking water supplies. But over time the virus from the oral vaccine starts to regain strength and if it's allowed to circulate long enough, it reverts back to the point that it can cause paralysis just like the original virus.

"We actually do genetic analysis so that we can understand the closest relative of each (virus) detection that we see globally," says Vertefeuille at the CDC. And in these vaccine-derived outbreaks, they can see that the virus that's paralyzing kids is directly linked to the vaccine that was distributed earlier.

Andrew Noymer, an associate professor of public health at the University of California Irvine says the global polio eradication effort has made incredible progress over the last three decades but now it's reached a difficult moment. He compares the current efforts to vaccinate every child against polio to being stuck on a treadmill. "You have to keep vaccinating all the children so you won't have any paralyzed children," Noymer says, "But the more you vaccinate, the more live virus continues to circulate. And the minute you step off the treadmill, you get some paralyzed kids."

One way to get off that treadmill would be to get rid of the live oral vaccine and switch to the not-live, injectable vaccine used in the United States. The Global Polio Eradication Initiative has tried to move in that direction but there are several challenges. First there just isn't enough supply globally of the injectable vaccine to cover the hundreds of millions of kids in low income countries. Training vaccinators to give injections is much harder than training them to give two drops in to a child's mouth.

Also the vaccines work slightly differently — with the oral version doing a better job of breaking chains of transmission and stopping outbreaks.

The Switch

A few years ago the world looked like it had a chance to get off the virus/vaccine treadmill at least partially. There are three distinct strains of polio and each strain requires a different vaccine to prevent against it.

In 2015, the WHO declared Type-2 wild polio eradicated. But the problem was that the oral polio vaccine still contained live weakened Type-2 virus and while the wild Type-2 was gone, occasionally there continued to be outbreaks of vaccine-derived Type-2 polio.

So the Global Polio Eradication Initiative orchestrated a manoeuvre that insiders call the "switch". In April 2016, everywhere around the world the old oral polio vaccine that contained all three strains of the virus were to be pulled out of circulation and replaced with a new vaccine. The new oral vaccine would only contain virus to protect against types 1 and 3. Health officials expected that some rogue Type-2 viruses would pop up and they had plans to quickly attack any Type-2 outbreaks that might occur. But they also expected that Type-2 vaccine-derived polio would die out relatively quickly.

"It was it was a bold move," says Noymer, who studies the history of outbreaks. "It was a sign of incredible progress. But it was a gamble and it didn't pay off." Now, three years after Type-2 polio was declared eradicated, the most problematic form of polio is vaccine derived Type-2.

That's because in order to respond to those predicted vaccine-derived Type-2 outbreaks, health officials inoculate kids near the outbreak with a specially stockpiled vaccine that protects only against Type-2. But there can be spill over from these mop-up campaigns, which gives the virus another chance to get into the environment, circulate and regain strength in communities. People who were never immunized end up getting exposed, sparking another outbreak.

Since the switch in April 2016, health officials have distributed roughly 300 million doses of this emergency vaccine to combat outbreaks. By doing so they've put hundreds of millions of viruses in to the environment that kids are no longer routinely being vaccinated against.

The switch seemed like a good idea at the time, but it turned out to be a blunder, says Noymer. Public health drives and particularly eradication campaigns can be hard to sustain. In the mid-20th century there was a lot of talk about "donor fatigue" and whether efforts to wipe out malaria and other tropical diseases would get the funding needed to finish the job. But he says the situation with polio now is different.

"The danger in the 21st century, in the age of social media and the age of anti-vaxxers is not that the donors will lose interest and be fatigued because they've shown to be very patient," Noymer says. "But rather that populations will start saying, you know, we're sick of this." He says the real threat could be that parents no longer see any reason to get their kids repeatedly vaccinated against a disease that they don't see anywhere around them. "And then, of course, you get more people who are susceptible to polio if that were to come to pass."

Original Source Article <https://n.pr/33YfFWy>

POST POLIO SYNDROME EXISTS

Colleges of Medicine please add more facts to your lectures on the Polio Virus and the effects that it could have had on our bodies. Ensure health professionals understand how varied our nerve damage, our recovery and stable years have been. The majority of us recovered so well that externally we do not look like the photos found in old medical books. There is a massive overlap of symptoms with other neuromuscular conditions. Tell new professionals about **Post Polio Syndrome** and direct them to our website so they can find more information. Thankyou.

The most accepted article we have found by NHS professionals is:

PatientPlus article POST-POLIO SYNDROME

Written by U.K. Doctors for Doctors

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

And in case you need an anaesthetic
an excellent leaflet translated into English
now used by many PPS Groups around the world is:

POLIO PATIENTS AND SURGERY

Information for health staff

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

http://www.ptu.dk/fileadmin/FILER/PDF/ISSUU_PDF/BROCHURER/Polio_operation_ENG.pdf

Text copies of both have been sent to members and are available on our headed paper with permission

REMINDER FOR MEMBERS

Have you changed your home, email address or phone number recently?
Did you let us know?

Your newsletter needs your stories, hints and tips

A way of doing something, or an aid that helps you might help someone else. Tell us.

How about a recipe that tastes great on the lips but not on the hips.

Articles and items for Post Polio Matters are always welcome,
by post, by email and by phone if writing is not easy for you.

CARERS - We'd love to hear from you too. Help us understand what you go through in helping us to manage our lives.

Deadline date for next issue is 14th January 2020

Editors Note:-

Articles from Polio Survivors and Health Professionals very welcome for future issues

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 Rely-Collins - verite.reilycollins@poliosurvivorsnetwork.org.uk

Trustee - Vacancies please apply for more information.

Operations Team

Phone Enquiries - Hilary Boone - info@poliosurvivorsnetwork.org.uk

PSN Administrator, Email Enquiries and Website - Toni Dunlop - psnadmin@poliosurvivorsnetwork.org.uk

Printing - Imprint Colour Printers, Lincoln

Membership

With grateful thanks to the generous legacy from Ms A Brown,

Membership will now be **FREE** whilst our funds remain above £10,000.00

UK Members can choose to get their newsletter by post or email or both.

Overseas Members will get their newsletter by email

Contact us via our **website** Contact Us page

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

Email psnadmin@poliosurvivorsnetwork.org.uk

Phone us on 01522 888601

(please be prepared to leave a message, your name and phone number
we will ring you back as soon as we access our messages)

Donate by cheque or 

Cheque payable to **Polio Survivors Network**

PayPal send funds to treasurer@poliosurvivorsnetwork.org.uk

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

Towards our GENERAL FUNDS (including printing and posting of newsletters)

Or our CONFERENCE AND MEETING FUND (supporting attendance at national meetings/conferences)

We are always grateful for postage stamps, 1st and 2nd class both normal and large size.

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 post you one.

Thankyou.

giftaid it

new article - Introducing our members

See page 8



new article - Interviews with members, supporters and sympathetic causes

See page 6



Take time whenever possible to pause and reset. Spend time in natural settings, reflect on the beauty around you. It is good for the soul.

Each season has its beauty.



© **PHOTO CARDS** by MEMBER **VAL SCRIVENER**

Sold in aid of **POLIO SURVIVORS NETWORK**

Pack of 5 - £3.95 including P&P

Order by Email to vala.scrivener412@btinternet.com

Or ring Val on 01234 346 397

