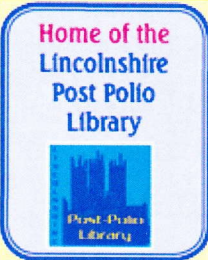


POST POLIO MATTERS

Polio Survivors Network Newsletter - Volume 9, Issue 2/12
n.b. Volumes 1 to 6 published under the name LincPIN.
www.poliosurvivorsnetwork.org.uk

**MARCH
2017**

**MOBILITY
ROADSHOW
2017
1 - 3 JUNE
NAEC
Stoneleigh
Warwickshire
FREE
Admission
& Parking
Fun for
all the Family
mobilityroadshow.co.uk**



Enter 100+ articles

**Polio
2017
5 cases**
Afghanistan 3
Pakistan 2

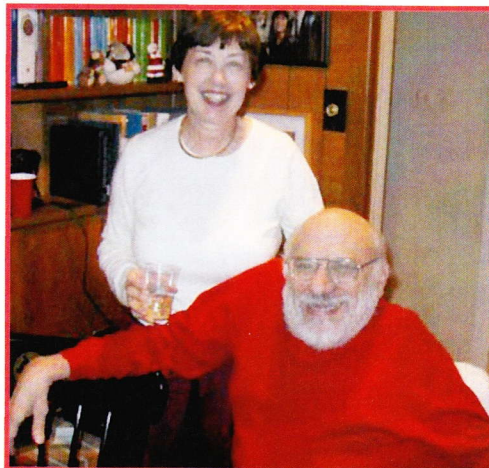
Total for
2016
37 cases



LYNN HOBDAY



MAUREEN ALLISON



Dr. HENRY HOLLAND

CELEBRATING
THE LIVES OF MEMBERS
**LYNN HOBDAY
MAUREEN ALLISON**
and
Dr. HENRY HOLLAND
Pages 5 to 9

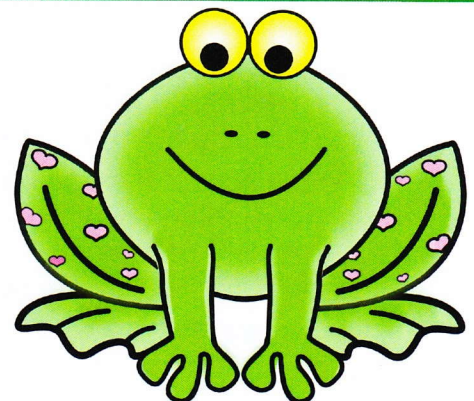
Lincolnshire Post Polio Library
Dr. Henry writes....

[www.poliosurvivorsnetwork.org.uk/
archive/lincolnshire/library/cc_2.html](http://www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/cc_2.html)

Glossopharyngeal breathing
also known as

FROG BREATHING

Article by Simon Parritt,
our Chair, who uses this
form of breathing at times
See page 17



Contents

Front	Photos, Lynn Hobday, Maureen Allison, Dr. Henry Holland and Brenda. Link to Simon Parritt article "Take Back Control !" on page 17
Page 2	You are reading it ☺
Page 3	Editorial by Hilary Boone.
Page 4	Message from our Chair, Simon Parritt [also page 17]
Page 5/6	Lynn Hobday by best friend Barbara Long and Dot Ives.
Page 6/7	Dr. Henry Holland - CVPPSG Dr. Henry Holland In Memoriam and Article "That Hole in My Neck Equals Life by Henry Holland"
Page 8/9	Maureen Allison by daughter Louise Allison.
Page 10	Advice for Polio Survivors and their Families from Louise Allison.
Page 11	The Continuing Sagas of *Decamping Dot!
Page 12	My Polio Life self assessment tool was developed because...
Page 13	Preparing for Medical Appointments.
Page 14/15	University of Washington. RRTC Factsheet - Disability Stigma and Your Patients
Page 16/17	Post Polio News [ppn] by Chris Salter. One item 31st March 2017. The 5 year Forward View News and Comment from Roy Lilley.
Page 17	Take Back Control! By Simon Parritt.
Page 18	Good articles for Polio Survivors to keep with them.
Page 19	Contact Details.
Page 20	Sharing information from PPS Groups World wide. Pennsylvania Polio Survivors Network. Member Val Scrivener Photo Cards Samples.

New Members and Donations received April 2016 to end Feb 2017

PSN Welcomes New Member Douglas Dalwood

Thankyou to the following for your generous donations towards our work.

Olivia and Barry Branston, Rida Nicholson, Clare Colfer, Robert Bass, Rita Unger,
M. Whitley, Maureen Allison, Steve Ives, Gillian Bryan, Stuart Tanfield, Jennifer Paulger,
Victor Gabriel, Yvonne Liggins, Ann Stone, Winifred Hyam, Margaret Embry,
Roland Tomlin, Pearl Norman, John Ward,
Tony Scrase Walters, Susan Freeman, Ian Downing, K.D. Norman, J.D. Fowlds,
Simon Parritt, Margaret Marris, Dot Ives - £685.00
The family and friends of Bridget Langdon - £456.00
The family and friends of Mrs. Chapman - £125.00
The family and friends of Maureen Allison - £500.00
Val Scrivener Photo cards £ 40.00
University of Lincoln [Hilary Boone] for Conference and Meeting Fund - £340.00

TOTAL for 11 months is £ 2,146.00

Please accept our apologies for not providing this information in the last newsletter.

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

Apologies for this issue being a little late due to computer/laptop both replaced under warranty. Back page from Pennsylvania Polio Survivors Network an increasingly used resource worldwide.

In this issue you will find articles celebrating the lives of three of our members. All three have been members since the late 90's. From Lincolnshire Lynn Hobday - a past Trustee and Chair - and Maureen Allison and from Richmond Virginia, USA, Dr. Henry Holland.

Lynn was a more than typical strong willed determined polio survivor. She joined me in numerous meetings with Lincolnshire County Council hoping that our input to discussions would lead to fewer issues and more simplified procedures and paperwork for Direct Payments. Evermore we hoped that the time and energy we gave up from our lives would see considerably less stress, waste of time and council funds trying to reduce unnecessary issues for ourselves, our families and **social services staff**. Numerous delays in implementing improved software and their failure to give us the constantly promised 'trial of new procedures' prior to launches has meant many ongoing year upon year and still in 2017.

On page 5 you will read Lynn's long time friend Barbara Long's article. I so remember Lynn telling her story of her "full assessment" on many occasions as evidence on how poor the NHS Services were/are. That first time she was so angry when we all laughed and then saw that there was a funny side to a health professional thinking that he had provided a full assessment of a polio survivor in less than one minute.

On pages 8 and 9 you will read Lou Allison's story of her mother Maureen Allison and on page 10 some hints and tips that she hopes might help other family members when a PPSer has to go into hospital. I remember many years back visiting Maureen in her bungalow during her DLA assessment visit. She was asked where her family lived and she pointed to a bungalow a short distance from the back fence of her bungalow. 'Can you walk there?' she was asked. 'Yes' was her reply. I suggested that she explain how and she then added, 'My son has put a garden seat at the back of our garden and I can walk to there with my cane and rest, then walk across part of the field to their back garden where there is another seat and I sit and rest there and then to their bungalow it takes me about 45 minutes but I can do it' [2 minutes for a non polio]

On page 6 and 7 you will read a short memoriam by Central Virginia Post Polio Support Group of their President and our member Dr. Henry Holland. Lynn Singleton [sadly passed] and I were privileged to stay with Dr. Henry and his wife Brenda for a few days in early July 1998 when we travelled to the USA. We landed in New York and hired a car to travel, visiting online friends, to the PPS Conference in Toronto. Dr. Henry tells of how he was looking out the window and saw a saloon car driving very slowly along the road that eventually turned onto his drive. He could see two people in the front seats [Lynn and polio survivor Sheila Tohn who we had picked up en route for the next part of our journey] and a head surrounded by luggage in the back seat, me. [See page 5 for excerpt from newsletter Volume 1, Issue 12 1998]

Dot has just received this email from Rare Disease UK - 29th March 2017

Thanks to your efforts, the Government has finally announced it will develop plans to implement the **UK Strategy for Rare Diseases in England!**

At a Westminster Hall Debate yesterday afternoon, Philip Dunne MP, Minister of State for Health, stated that NHS England will develop an implementation plan for the commitments outlined in the UK Strategy for Rare Diseases that it can influence by the end of the year. For those commitments that are outside of the scope of NHS England, the Department of Health will support its arm's length bodies to coordinate plans for implementation.

This is a fantastic result for patients and families affected by rare, genetic and undiagnosed conditions in England and across the UK, and will provide the rare disease community with an effective tool **to hold the Government to account to improve services and care for patients.**

Read more on their website. <https://www.raredisease.org>. NEWS and EVENTS Button.

YES, POST POLIO SYNDROME is classed as a RARE DISEASE - Less than 5 in 10,000

MESSAGE FROM OUR CHAIR

Spring Arrives

I hope by the time you read this winter is behind us. I, like many of us, find the cold and general virus ridden winter months quite challenging, both on mood as well as energy and health. As we age I think this becomes even more acute, maybe we should seek an NHS prescription for a month in the sun! However, it has been a difficult time for the charity as we have had a number of personal challenges and I must especially mention Hilary, Dot and Margaret for doing a huge amount to keep the charity on track and support members during this time.

Assessments: are they working?

We have been looking at whether there is, or should be, an agreed protocol for post polio assessments. This is a contentious issue as it is often said that everyone is different. However, we are increasingly of the opinion that despite the British Polio Fellowship's recent publication on the management of Post Polio, which raises as many questions as it does solutions, there still seems a lack of agreement on how, or even if, people with past polio, or suspected polio, need an assessment protocol. Indeed despite places offering themselves up as experts in polio and Post Polio assessment and care, it would appear this is based on a generalised medical rehabilitation model. Added to that is the issue of the huge variation in level of service for polio survivors across the country.

Being old is not an illness

Having been fortunate in my career to have spent 5 years in the geriatric department of a medical school in a major teaching hospital, I learnt quite a lot about ageing from both a medical and psychological perspective. What struck me, as a 40 year old with polio, was what I had in common with patients who were often twice my age. Crucially for us now, as we age with polio, it also struck me that many issues appeared on presentation to be the same but were in fact quite different, both in cause and required management. As we now present with multiple conditions, and as most people over 60 have at least 5 chronic conditions, the default can often be to miss the unique polio aspect and fail to assess or treat appropriately. Whilst not everything is PPS the fact that we have polio nerve damage can still impact on our health and treatment options.

Multidisciplinary is not many disciplines

At the heart of good geriatric care is the multidisciplinary team approach, something that is rare today, even if lip service is still paid to it, it seems to be an approach where each discipline refers back and forth with long time intervals and little actual face to face discussion with all disciplines and the patient present.

Aiming for excellence, not average

However, just as we developed protocols to look at falls in the elderly precisely because the complex nature of the many co-existing morbidities, so I suggest we need a similar screening and protocol for Polio patients precisely because in the end it saves times and money as well as benefiting the patient. Short term costs may be an issue in the current state of the NHS but let us not ignore the principle of excellence by pretending we don't need it.

Members, do you think you are getting an adequate level of assessment for the issues you are now reporting?

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

Chartered Psychologist. HCPC Registered Counselling Psychologist,
www.sp-psychology.com - Chair Polio Survivors Network.

Chair Polio Survivors Network. Simon Parritt <simon.parritt@poliosurvivorsnetwork.org.uk>

Editors Note:- I sat here reading this and thought I don't come under geriatric medicine then remembered I just had my 70th birthday and wondered at what age do we transfer from adult to geriatric medicine? Mentally I am still a teenager.

Lynn Hobday - Life Member and Chair in the late 90's. 1932 to 2017

Lynn [Evelynn] was born in Islington London and contracted polio at the age of 4 and spent ___ years in hospital. When she came home World War II had started and the family lost everything. They stayed temporarily with a family in Nottingham and were then rehoused in London in the prison officers accommodation at Pentonville prison as all the prisoners and staff had been evacuated. She went to College and excelled in English and started work as a secretary but within months she became a free lance journalist with an agency and travelled widely for her work.

The man that changed her life was Lt. Colonel Santos Cassini, a much decorated flying ace in World War II and also in the 1920's and 30's a champion dancer for the Tango. Lynn wanted to dance more than anything as in the 1950's young people were in coffee bars enjoying music, including Elvis, and dancing. An article appeared in the London paper about Lt Colonel Cassini and how he had taught his wife to dance in spite of losing a leg in the blitz. She wrote to him and asked him "will you teach me to dance?" An appointment was made and she met him and his wife, he was in his 60's very smart and around 5ft.6" and full of Italian vanity but within six weeks she was dancing and she never looked back, it was such a joy to her.

She met her husband Fred at a dance and they went on to get married and raised two fine sons Ian and Stephen. They moved to Aylesbury Bucks where they enjoyed dancing and going out with friends. They moved to North Hykeham in 1990 when Fred retired, and sadly their youngest son died aged 35 in 1996.

As the polio began to affect her mobility she had to take early retirement as social director for the Blind and Partially Sighted at government level. I met Lynn in 1990 when she came to see me to arrange a demonstration and talk on making and painting ceramics and porcelain dolls, we became firm friends and Lynn started to come to my classes and enjoyed painting many lovely things. After she had a serious fall and she had to use a wheelchair I started to take her shopping and hospital and doctors' appointments because the lifting of the wheelchair in and out of the car was too much for Fred who had had a triple heart valve operation. Being in a wheelchair did not stop Lynn, she was always very active and enjoyed her family and friends, love of dogs, painting and just going out for coffee visiting Garden Centres, rides into the country and the seaside.

She was one of PSN's first members and became a Trustee and Chair for some years. I remember her going for her regular yearly review and the doctor asked her, 'How have you been?' Lynn replied, 'Surely it would be better if you examined me and told me how I am compared to last year?' The doctor, a bit taken aback, agreed and then came round to the other side of the desk and sat knee to knee with her. He put one hand on the outside and then inside of her knee and asked her to push against it. He then did the other leg. He then went and sat back behind the desk and discussed a few more points. He finished by saying 'Is there anything else you want to discuss?' Lynn replied, 'If you do the assessment I might have another question?' The stunned look on her face when he said 'But I already did the assessment see you next year'. For once Lynn was speechless and we left. She was not speechless about it later though...

After Fred died in 1998 I became Lynn's, PA, driver and general helper. I helped her to get an adapted mobility car and electric wheelchair which helped a great deal on journeys out and about and to many meetings. She was eventually awarded a direct payment and I took over the running of it, doing all the paper work and the financial assessments, employing the [names...] their wages and all the bookkeeping that it involved. We both agreed that the procedures she had to continually go through could have been made much simpler.

She moved from their Bungalow in North Hykeham to Minster Court for more support where she made a lot of friends and enjoyed her little bit of garden. Sadly she found she also had cancer which she took in her stride and carried on as best she could and died peacefully on 23 January 2017 at home. She was an inspiration to us all, we shall all miss her.

Barbara Long

Lynn Hobday continued. Dot Ives writes....

I only had the honour to meet Lynn a couple of times but I found her to be like an 'instant friend'. I wish I had known her for longer.

Lynn was already wheelchair bound when I first met her at my first AGM. She wielded the controls with a fierce independence and a definite 'twinkle in her eye'! When negotiating to go to the loo I dared to venture to help her negotiate the doors etc. She looked straight at me and announced that 'brute force' wins!

If I had lived nearer I know we would have become friends. At an AGM, hearing about therapies available including spa-type treats: Lynn said she would only go if I went with her. I had to regrettably decline as I lived in the North East of England and the round trip would have been too much! I wonder if she ever got there?

She always had a smile and didn't complain about her lot in life even though she had a lot to contend with. Her passing is a sad loss and she will be greatly missed at PSN meetings.

Here's to ya Lynn!

Central Virginia Post Polio Support Group - www.cvppsg.org

Dr. Henry Holland In Memoriam

Henry was a polio survivor, a teacher, a mentor and a dear friend. He served our group as president from 1994 to 2000 and as vice-president from 2000 until his passing in early January. As a physician and psychiatrist, Henry was in a unique position to offer both invaluable clinical and psychological support to our members. He contributed articles to our newsletter for years and they are still available on our web site.

We will miss his insight, his expertise, his humor and his friendship greatly.

That Hole in My Neck Equals Life By Henry Holland

<http://www.cvppsg.org/wp-content/uploads/2016/01/ThatHoleinMyNeckEqualsLife.pdf>

As many of you I survived a moderately severe case of polio in 1950 at age eleven. Thereafter I wore a long leg metal brace with leather straps on my right leg. Over the next year my left leg got stronger and I was able to climb steps again. I climbed steps at every school I attended thereafter from elementary school until medical school. There were no hills or steps I could not climb during those days in the sun. During adolescence I developed scoliosis of the spine. I did a rotating internship at Norfolk General Hospital and survived a near fatal case of pneumonia. Following that event I started my residency in psychiatry and was admitted to the hospital several times for respiratory failure. On January 15, 1970 Dr. Robert Brooks performed what became a permanent tracheostomy. At that time I did not think I would even complete my residency. A year later my private health insurance company agreed that money would be saved if I had a ventilator at home rather than having to go to the hospital.

With the hole in my neck and a ventilator at home I was able to sleep on the ventilator every night, plug the trach tube during the day and breathe on my own from morning to night. It was an experience of resurrection. For the next twenty-five years I conducted a full time in-patient and out patient practice of psychiatry in both the public and private sector. I had admitting and consulting privileges at numerous hospitals in the Richmond metropolitan area. In 1991 I began to experience what is now known as Post Polio Syndrome (PPS). I experienced new motor weakness and general fatigue that was progressing over time. I continued to practice in the same manner with the aid of a battery-powered scooter. In 1996, the general fatigue and brain fatigue became overwhelming and I stopped practicing entirely for six months. Gradually I began to practice part time in a home office. In 2002 my pulmonary doctor told me that I needed to use a ventilator 24/7 or I would expire from right heart failure. With the advances in technology I began using a Newport portable ventilator and also got a power wheelchair in 2003. I also was able to purchase a wheelchair accessible van.

During the day I would plug the trach tube and use a mouthpiece to breathe with the ventilator on

my w/c and at night I would use that hole in my neck to hook up to the night-time ventilator. I was able to continue practicing part time in my home office and also volunteered weekly at the CrossOver free medical clinic. My patients did not seem to mind the ventilator or the power w/c and I loved being able to practice with these limitations. For the past three years I still practice part time via telemedicine in attempting to manage and treat patients with dementia or other mental health problems in remote nursing homes in Virginia. This work is a joy in that I feel like I am serving some of the least able among us in our state.

In addition to that hole in my neck that has prolonged my life for forty-six years, there is one significant person who has been a vital and enormous influence on my quality of life. Her name is Brenda. She has been my loving and very strong wife for fifty-one years. She has saved my life on numerous occasions. She has worked when I could not and she has done all of the physical work and much of the emotional work in raising our three kids. She is simply the greatest hero I know and is excellent in all that is good.

Read Dr. Henry writes.... 40 short articles to be found in the Lincolnshire Post Polio Library accessed from the logo top left of our website front page.

http://www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/cc_2.html

Excerpts from LincPIN, Vol 1, Issue 12, August 1998 - **Hils and Lynn's Trip to the States and Canada.**

Lynn Singleton [a member and Polio Survivor from East Sussex, sadly passed] and I met for the first time at the Virgin Atlantic Check in Desk at Heathrow Airport. We landed in New York and the next day hired a car - a Chevrolet Monte Carlo with hand controls - then we stopped in Highstown New Jersey to pick up the electric scooter that I had to hire [my own would not fit in the back of a car]....

We arrived in Richmond Virginia where we were royally looked after by Dr. Henry Holland and his wife Brenda. At a cookout the next day on 3rd July we met many of the Central Virginia Post Polio Support Group [including Linda VanAken who is still on the committee]. The following day we were taken for a tour round Old Richmond - including seeing the hospital that Dr. Henry was in when he had Polio - and that evening to the 4th July celebrations. We were asked if we minded going and were a little perplexed but the comment "Well we did beat you" brought much laughter. The music of the 1812, the bells of the carillon in the War Memorial Tower, the Canon fire and the sky filling massive firework display at Dogwood Dell were thoroughly enjoyed.

Hints, Tips and Bits is Back.

Barbara Twardowski and her husband write about **Accessible Travel**. Here is some useful advice for wheelchair users planning to cruise. www.nextavenue.org/planning-cruise-disability/

The Endocannabinoid System: A Beginner's Guide.

Excerpt.. The endocannabinoid system is a biological system which plays many important roles in the human body. It is also responsible for the physical and psychological effects of cannabis.... The system is a major target of medical research because of its widespread effects and therapeutic potential. While scientists have sorted out the basics of this fascinating system, much more remains to be uncovered...

<http://www.leafscience.com/2017/03/17/the-endocannabinoid-system-a-beginners-guide/>

Fibromyalgia News Today - **Cannabis Science** a company specialized in the development of cannabis-based therapeutics, recently announced the development of two new medications for pain relief in people with fibromyalgia and diabetic neuropathy nerve pain.

<https://fibromyalgianewstoday.com/2016/11/04/cannabis-science-announces-pharmaceutical-development-of-pain-patch-for-patients-with-diabetic-nerve-pain-and-fibromyalgia>

Rotary International in Great Britain and Ireland President Eve Conway recently tested out a replica Iron Lung, an apparatus used to help polio patients survive the disease. It was built by Cumbria-based Rotarian Roger Frank to educate more people about the need for polio vaccination. Read more in the next edition of Rotary magazine or online at <http://ow.ly/BUOo309XyZ2>.

Life Member Jann Hartman has sent the link to a presentation on October 20th 2011 for the Advavnces in Aging Lecture Series on **Polio and Post Polio 2011. Diagnosis, Treatment and Research by Polio Survivor Micki Minner...** [PSN members check out photo of Charlie Minner on the front page series of photos on our website sadly now passed]

<https://www.youtube.com/watch?v=oBFpZdLaCKo>

MAUREEN ALLISSON

Mum was born in Little London, Tetford on 17th July 1934. She was the daughter of Eric and Kathleen Tuplin and had three siblings Barbara, Sheila, and Bill. To her Grandad Tuplin and Uncle Frank cousins etc., she was affectionately known as Mont. The family moved from Little London to Tetford where Grandma opened and ran a fish and chip shop, however when war broke out fish was in very short supply meaning the fish shop had to close and they had to move.

The family moved to several different villages in the Wolds area during her childhood and early adult years. Tetford, Ashby Peururum, Muckton, Burwell, Authorpe and then to South Reston. Whilst living in Ashby Peururum Maureen spoke fondly of the Italian prisoners of war working on the farm. They spent quite a lot of their spare time with the family. She told that they had made them jewellery from what they could find, They made bracelets and rings from coins. They were fun and played games with them. Some of the soldiers had families of their own back in Italy and were missing their own children.

Mum's fondest memories were when the family lived in Burwell Hall. A lovely Grand house in a super position which has sadly now been demolished. She told of sliding down the huge banisters and sunbathing on parts of the roof which were flat. She remembers the bombers coming low over the house and her Dad pushing them all under the huge kitchen table for protection. Mum could describe the ornate ceilings, chandeliers and mosaic tiled floors. The family lived on the top floor of the house but also had access to the down stairs. She was always very saddened that such a lovely building was eventually demolished for the land it was on to be used for agriculture.

Mum passed the 11 plus and then in 1947 contracted Polio. It was believed that she caught it from Louth's Outdoor Swimming Pool. She was critically ill and was not expected to live. She spent some weeks in an iron lung in Springfield Isolation Hospital, Grimsby. This experience was very traumatic for her and left her with a fear of enclosed spaces. When she recovered enough to be taken out of the Iron Lung she was put into plaster from her neck to waist with her left arm set up level with her shoulder. This was said to have caused her back to be deformed. She was left with a weakness down her left side and paralysed left arm. She learnt to live with the after effects of Polio which continued throughout her life adding post polio syndrome in her later years.

Mum's parents had no transport and it was very difficult for them to visit as regularly as they would have liked. Mum had a special nurse who was very good to her during this time a Sister Smiley. She kept her fighting and was very kind and encouraging. They kept in touch until recent years each Xmas. Sister Smiley would have been in her very late nineties and when the cards stopped coming. Mum assumed she must have sadly passed away.

In her late teens and early twenties Mum lived in Authorpe where Brother Bill had a motorbike. Bill asked Mum to start it up and move it. He didn't explain how to stop it though! Apparently she ran over three bikes, one of them being the vicar's! Mum was never very good with mechanical things. She ended up in a ditch when riding a bicycle and Louise once tried to show her how to drive but very quickly decided it was not a very good idea. She was the leader of the Wolf Cubs in Authorpe (type of scout group for boys) which met in the village hall. We have photos of them camping etc. When she left school she went to work at Lawson & Stockdale Department Store in Louth in the shoe department. At this time she was living at Muckton and would either cycle or walk to and from Authorpe Station to get to work. Mum continued to love her shoes and liked smart, colour co-ordinated if possible, quality clothes.

Mum met Reg who lived locally at the Grange Farm Muckton and they married on 29th July 1961. Their first home was the bungalow 'Heatherdene' South Reston. In June 1964, I was born and Mum stayed at home looking after me. She began to sell eggs from Grandpa's Dad's chickens and also produce she had grown, from the gate. Kaye was born in May 1969 and was only a few months old when they decided they would need to move house. I had reached school age and they needed to be able to get me to and from South Reston Primary School. There were no buses at that time.

Holme Lea, South Reston came up for sale by auction and Reg and Maureen - Mum and Dad - bought it. The house required an awful lot of work and modernisation but Mum loved it. I can remember living in a caravan whilst the house was renovated. A small brick building opposite the house, previously a cobblers shop where they found a wooden leg full of wood worm, she opened as a farm shop. The shop being really busy during the summer months as holiday traffic would flood through the village at weekends. Mum enjoyed meeting people through the shop whether they spent a penny or pounds she just loved it.

The fields at the rear of the house have been a caravan and camping touring site for many years. All the family have met and remained long term friends with many regular campers. Mum would look forward to the summer months seeing these friends again. Holidays were not one of Mum's priorities. She was content with a few days out a year. She enjoyed her shopping trips. She loved the sea and beach, although Dad did not, anything above ankle depth for Dad is more than enough. He would still take us or she would go with her Sister Barbara and family when they visited in the Summer.

Dad had a serious accident at work in November 1989 and spent a long time in hospital. When home he needed a lot of care and was not an easy patient! Anybody who knows Reg well will know what we mean! Mum was patient and caring and got on with whatever needed doing.

Mum was artistic, although had very little leisure time to pursue this. She was good at needlework. Always able to come up with ideas and materials for a fancy dress outfit. She loved all animals wild or tame, but especially horses and black Labradors. My sister and I remember helping Mum rear a clutch of orphaned ducklings. I came home with a hat full of day old partridge chicks which were drowning in a storm puddle which they reared and released. Hatching eggs in the airing cupboard was common place. Sick and ailing chickens and chicks in boxes in the kitchen. Rabbits, hedgehogs anything really. If there was a bit of life she wouldn't give up on them. If she was out of her depth it was round to Elaine Drewery for help and advice. We had bantam chickens that were very tame Mrs. Hen especially. Rosie the pony lived to 36 yrs. old. All due to mum's input and care.

In 2013 Mum had to undergo a serious operation. Due to her having had Polio her recovery from the anaesthetic was traumatic. She was in Intensive Care for some time and because of her memories of being in an iron lung she did not like wearing the respiratory equipment so my sister and I shared staying by her bed to help her cope. She was not expected to make a recovery but her will and determination and our support and against the odds she made it home. Thanks to Dr. Greenstone's dedicated team and the Bi-Pap Machine which Mum found very intrusive but she wanted to live so much and was therefore prepared to put up with this. Her mobility was poor and she hated the walking frame. She soon had it customised with a bike basket to carry her bits and bobs though. Mum was strong willed and liked things done her way. She was still very independent and wanted to do as much as she was able to do herself.

Following a fall she needed help during the day as well and Kaye and I would like to thank Barbara, Sharon, Tracey, Jill and Ruth for helping us look after Mum and Dad. Kaye and I look back now and wonder how Mum managed to have the energy to run a home, look after us, run the shop, care for elderly parents and elderly neighbours. She was so kind, calm, caring and selfless. She was a school Governor for South Reston Primary School. She fought to try and prevent the Church from closing and being demolished and also the school from closing. Mum loved elephants and had a memory like one, she would never forget a kindness likewise she would never forget an injustice either.

Mum would never give in if life became difficult. For a healthy strong person her work load was sometimes hard but for Mum who was very rarely pain free even more of an effort. There was no such word as can't in Mum's eyes. She told us this regularly when we moaned we couldn't do something! She would find a way of achieving what she needed and wanted to do somehow no matter how long it took or how she did it. She loved us all dearly and we all adored her. Her grandchildren have such happy lasting memories of her. She was one in a million and we feel blessed to have had her as a wife, mum, mum in law, nanna, sister and auntie. **LOU ALLISON.**

Advice for Polio Survivors and their Families from Louise Allison.

My Mother had a serious operation in 2013 which resulted in her very nearly losing her life at that time. I really hope these notes will help anyone else should they find themselves in a similar position.

Have a medical Power of Attorney drawn up. It can be quite expensive but you can do it yourself without a Solicitor. This is so important. The medical profession cannot ignore you should your relative be unable to give their consent, instructions etc. Without this they can.

1. Before undergoing anaesthetic request up to date respiratory tests are carried out. It would be advisable to have these done before seeing any Consultant and/or Anaesthetist so they have the full up to date picture.
2. Make sure Consultants fully understand that the patient is a Polio Survivor and has a diagnosis of or may have Post Polio Syndrome.
3. Explain carefully any physical weaknesses, paralysis etc. This is important as when the patient is under anaesthetic they will be handled and manoeuvred this could cause injury and pain post operation to the patient and further hinder their recovery.
4. Be prepared to take in extra pillows etc to make your relative more comfortable as they are in limited supply.
5. Request that your relative is taken into ICU post op. They will then be monitored more closely and should complications begin to arise they can be acted on asap.
6. Post op. Insist that a swallow test is carried out before your relative is given fluids. Polio survivors take longer to get the sensation back in their throat after anaesthetic and cannot swallow properly. Aspiration can then occur.
7. My Mother could not tolerate the large Bi Pap mask, due to the fact it brought back the horror of being in an iron lung. ICU said they could not treat her. My Sister and I therefore said we would sit with her round the clock in ICU and did four hour shifts each 24 hrs. a day. She could then tolerate the mask. She held our hand this way she could get attention by squeezing our hand. My Mother had medical lines in one arm and was paralysed in the other. She had a full mask covering her face and therefore could not get medical staff 's attention any other way. ICU do not have bells.
8. If recovery does not go to plan and the patient ends up in ICU with the outlook looking grave. Always insist on a second opinion from a Respiratory Specialist before they withdraw any treatment. This happened to my Mother. ICU Doctors were wanting to withdraw treatment. We resisted but were threatened that they would over rule us. In the end a Respiratory specialist was called. His outlook was the opposite end of the spectrum to the ICU Doctors who do not often treat polio survivors. With that specialist's help my Mother had three more years of life. She was on a Bi Pap machine overnight but had a good quality of life.

Editors Note:- We have our own experience of serious issues in hospital out-patient, in-patient and ICU and can confirm that the lack of knowledge of Polio and PPS is still way too high even in departments where you would not expect this. We have now set up Powers of Attorney. Please will any member that has any information to share with us write, email or ring if you are unable to do either of the other methods easily. The more evidence we have to support our ongoing discussions the better.

I bought some shoes from a drug dealer. I don't know what he laced them with, but I've been tripping all day.

I told my girlfriend she drew her eyebrows too high. She seemed surprised.

My wife told me I had to stop acting like a flamingo. So I had to put my foot down.

How many opticians does it take to change a lightbulb? Is it one or two? One... Or two?

So what if I don't know what Armageddon means? It's not the end of the world.

How do you get two whales in a car? Start in England and drive west.

This is my step ladder. I never knew my real ladder.

What did the pirate say when he turned 80 years old. Aye Matey.

People in Dubai don't like the Flintstones. But people in Abu Dhabi do!

The Continuing Sagas of *Decamping Dot!



You will be pleased to know I am free from injury and haven't fallen or had to attend Casualty (apart from the one on Saturday nights on the BBC). Well..... apart from a path surfing skirmish at my next door neighbour's front door – all was well as I landed on a mattress topper I was carrying at the time! No real injury – apart from sore knees and ego! I was spotted though by our friendly Postman who commented “You were there and then you weren't – just like that Dawn French sketch”! (not sure if he was alluding to the action or my size)!

The main news is that we have moved, relocated to the middle of the country. Couldn't be more extreme really. Here we were living on 'the edge' directly opposite the North Sea apart from a road, pavement, wall, revetment and embryonic sand dune or two and now in the 'Midlands' apparently there is a field about 4 miles away that proclaims to be the furthest point from the sea in any direction!

So we are well and truly landlocked! In our quest for our 'new home' we checked that the pavements were safe to wander (relatively 'trip free'), the area is 'flatish' (no big hills to climb).... nice cake and coffee shops, market day, GP surgery nearby, a theatre, swimming pool and a ukulele group to join! This quest though did not included a recce of the local hospitals (especially A&E) or whether there are teaching hospitals nearby. I wonder if they have heard of PPS? Mmmmm!

Of more note, I have had to trawl my failing and selective memory lately. Just prior to moving, I was contacted by an Occupational Therapy Professor from Teesside University asking me to take part in a survey he was doing as part of his research for a PhD in relation to living with chronic pain. (My details were forwarded to him by the local Neurological Alliance group). Before the 'interview' he expressed an interest in my childhood memories, education, hobbies, lifestyle etc. This I found quite difficult as there are chunks that I cannot remember. He did look a bit disconcerted when I listed my medical and surgical history and we tried to insert them in the correct lifeline box! More of this another time! The main thing he did comment was that I said at least three times that 'things could always be worse'! He did say that there was a 'name' for this attitude but I cannot remember what it was!! Well, as in a reflective mood; once I left primary school (an experience I try not to recall as I don't think it was very happy) I do feel 'lucky' in my life.

My polio was not paralytic, my breast cancer did not require chemotherapy and has not come back (so far), my various fractures ache when it is cold and are painful sometimes but are not drastically life changing or inhibiting.

Given that I wasn't prone to ice-skating, mountaineering, fell running or bungee jumping in the first place! It is difficult to quantify how chronic pain has affected your life when it is your life and part of who you are and who you have always been. As my physio says often – it is 'normal' for me!

We are now registered with a GP Practice and a dentist and know where the local hospital is – although it only has a minor injuries unit. My next task is to find a 'tame' physio, a hairdresser and somewhere for a pedicure.

The major quest will be when I need to see a GP – there seem to be a lot at our new practice – it will be interesting to see how I go. Maybe I need to go armed with some newsletters! Bye for now from sunny (sometimes) but much warmer Lichfield!

*Dot lves Decamping: if you decamp, you go away from somewhere secretly or suddenly. (Collins Dictionary) addendum - not very secret or sudden!

PS! ...we have moved to a bungalow so no stairs – not that I miss them! I wonder how I will stop gaining weight?? (I lost half a stone when I moved into our old three storey house 22 years ago)!

MY POLIO LIFE - self assessment tool was developed because....

Damage and Recovery from Polio was varied with no set pattern, a nightmare for health professionals. Some Polio Survivors have lived their lives in wheelchairs and/or calipers, others have walked well but with obvious upper body weakness, and others recovered so well that they have no or little obvious visual polio residuals.

After years of stable functioning some Polio Survivors are experiencing the start of new and unexpected symptoms of fatigue, pain, weakness and functional decline. Terms used are Post Polio Syndrome [PPS], Post Polio Sequelae, Late Effects of Polio [LEOP], Post-Polio Muscular Atrophy [PPMA]. A variety of terms and definitions. The most commonly used term is Post Polio Syndrome, [Post Polio Sequelae is another term used] [PPS] which refers to the start of new symptoms after years of stable functioning for which there is no other explanation. This can be gradual, or following a traumatic episode, leading to decline in functional ability. Despite a few early medical articles to the contrary there are more stating this **IS** occurring, and at an earlier age than can be accounted for by the normal aging process.

Not everyone experiences this stage or all of the problems outlined in this tool. Currently there are no diagnostic tests. The diagnosis is made from history taking, physical examination and tests to eliminate other causes.

This Self assessment tool was developed because of the huge number of polio survivors reporting that some of their symptoms are not being corroborated yet they are continuing to decline.

Research into this found that some current methods of assessment are not testing the **ENDURANCE OF MUSCLES**. This includes:- Manual Muscle Testing to lesser repeats or sustaining level. Testing [or observing you do] an action that does not go to the point where you state your symptoms start. This is resulting in over-grading of actual physical ability and in many cases due to this lack of corroboration of reported symptoms has led to:-

- incorrect and/or inappropriate diagnosis, advice, and treatment.
- state benefits and aids and equipment being withheld.
- employers, other health professionals and family assuming 'it's all in your mind'
- Increased stress, frustration, anxiety which can lead to depression.

Appointment time can be limited so you must make the best use of that time. For instance if the appointment is ten minutes you have to present your problem, be questioned and examined in that time. Reams of paper cannot be read in this time. Typing/Preparing a few short notes will help [sample next page] We recommend that you politely offer a copy for your medical records.

The key to accurate assessment of your functional ability is to present to your health professional that your new symptoms have meant a change in the way you are now doing actions of daily living. This tool and its charts are ideas to help you quickly show this change and point health professionals to where further assessment is necessary.

Demonstration of the actions, photos, short video clips, have been shown to be extremely helpful in showing which muscles are now being used and how.

It is essential that accurate assessment rules out other causes for your symptoms. You can have all other conditions instead of or as well as PPS. However, it is important to add that because you caught one of the three polio viruses your body may react differently to their expected norm.

Health professionals need to be made aware that new problems **ARE** being seen in areas not thought to have been previously affected and that this was first medically recorded in 1875 in three French articles by **Carriere, M. - Raymond, M. - Cornil, V. and Lepine, R. .**

MY POLIO LIFE - <http://poliosurvivorsnetwork.org.uk/mypoliolife.pdf>

PREPARING FOR MEDICAL APPOINTMENTS

From 20 years research we recommend preparing something in writing for each medical appointment or possibility of an emergency medical admission can provide *better outcomes*

First we found we needed some basic information about ourselves, and in case of emergency [ICE] family contacts, GP and other regular medical contacts, our polio and other medical conditions, our allergies and intolerances, our medication inc. name, dose, times per day and any side effects, treatments and medical equipment etc. We started compiling a file of information and MY POLIO LIFE a self assessment tool was developed to help and then a four page WHAT YOU NEED TO KNOW ABOUT MY MEDICAL CONDITION/S form to carry with us.

If you have not already we suggest that you start a ring binder file of information and either add some of the completed pages of My Polio Life or make up some similar pages for yourself. Photos from your past can provide fast information about how you were with and after polio and what you have achieved. Many health professionals have no idea that many of us recovered to high levels and achieved way more than expected, especially if they only see you now.

For medical appointments we suggest that you make up a single sheet [preferably typed and more than single line spaced] for each appointment. We recommend that you make a copy and offer it politely at the start of your appointment "To help me remember I have made some notes and I made a copy for you in case it would be helpful" Be prepared though for this to be refused or left on the table but in our experience often written on and added to your file.

If possible get someone to drive you to the appointment arriving in plenty of time to use the bathroom and collect your thoughts. Plan ahead with that person what you want them to do, just take notes or raise their hand to remind you of something you appear to have forgotten. They could have the file of information with them in a bag to check information if needed. It is NOT a good idea for your or anyone with you to go in carrying armfuls of medical articles and huge files. Think how you would feel if you were the health professional. Remember to answer truthfully and if you are asked a closed question e.g. Can you do x? Do NOT just say "Yes", make sure you add how you do that action. You are not helping being the strong willed determined polio survivor you have been for most of your life if for instance you answer "yes" to I can climb a flight of stairs when you are sitting on your bottom pushing yourself up backwards with your arms and stopping three times for a rest. *You need to paint the actual picture of how you do the action in their mind*

We accept that being at a medical appointment is not somewhere we want to be. It brings back memories and we often leave seeking help for months if not years. A tip that helps if you feel intimidated by a health professional is to imagine them sitting there in their underwear.

Some suggested headings you could use for your sheet/s

Appointment with Date & Time..... ①.....
Name DoB Age M/F.....
Address
Preferred phone number and Email address
Family contact in case of emergency. [ICE] Copy of your Advanced Directive if you have one.
Height, Weight. latest blood pressure or other regular test results
Medication, names dosages and times taken. Vitamins. Any allergies and/or Intolerances.
Regular Therapy and Test Results, e.g. Blood glucose/Lung Function Tests
Names and Contact details of your regular medical professionals.
Medical Equipment that you have at home - need assessing for - need when in hospital, etc.
Reasons for appointment starting with the most important demonstrable point. Find out how long the appointment will be and make further appointments if more time is needed to discuss all.
Result of Appointment - Further Tests, Therapy, Medication, Referral to other department, etc.

* 2nd European Polio Conference presentation by Hilary Boone *

<http://www.informed-scientist.org/presentation/painting-the-same-picture-can-provide-better-clinical-outcomes?symphony=2f5f30a9b64ea6e824c597b649d39f23>

**University of Washington. Healthy Aging and Physical Disability
Rehabilitation Research and Training Centre.
Factsheet - Disability Stigma and Your Patients.**

[Editors Note:- I thought some of the following - suggestive points for the person the other side of the medical appointment desk - could help us plan how we might give our information and later points important to request when we have discussions about improving neurological condition service provision]

For people with disabilities, stigma can be a major barrier to participation. Stigmatizing attitudes about disabilities can also affect relationships between patients and providers. However, health care providers can be allies with their patients and help reduce the impact of stigma.

What Is Disability Stigma? The word stigma comes from the Greek word for “mark.” Generally, stigma is a negative set of beliefs about people with specific characteristics. For example, ethnic or sexual minorities, or people with unusual facial appearance may encounter stigma. People with disabilities have been stigmatized throughout history. In many cultures, disability has been associated with curses, disease, dependence, and helplessness. Disability stigma can play out in a number of ways, including:

- **Social Avoidance** – People with disabilities may be left out of social activities, or they may find that friends become more distant after they develop a disability. People may be hesitant to make eye contact or start a conversation with someone who has a visible disability.
- **Stereotyping** – People with disabilities may be presumed to be helpless, unable to care for themselves, or unable to make their own decisions. People with one disability, such as a speech impairment, may be presumed to have other disabilities they don’t have, such as an intellectual disability.
- **Discrimination** – People with disabilities may be denied jobs, housing, or other opportunities due to false assumptions or stereotypes about disabilities. This still occurs today, despite disability rights laws such as the Americans with Disabilities Act (ADA).
- **Condescension** – People with disabilities may be coddled or overprotected due to perceptions of their helplessness.
- **Blaming** – People may be blamed for their disability, or accused of using their disability to gain unfair benefits.
- **Internalization** – People with disabilities may themselves adopt negative beliefs about their disability and feel ashamed or embarrassed about it.
- **Hate Crimes and Violence** – People with disabilities may be targeted in hate crimes. They are more likely to be victims of physical or sexual violence than people without disabilities.

How Can Disability Stigma Affect Your Relationship with Your Patients?

People with disabilities may manage their condition in ways that guard against being stigmatized. In addition, people with disabilities may be especially sensitive to signs of possible stigmatizing from their providers.

Some issues related to stigma that may arise include:

- **Concealment** – If possible, some people may choose to conceal their disability in public in order to minimize stigma. As a result, they may be reluctant to use assistive devices, such as mobility devices or hearing aids, or to tell others about their diagnosis. They may also forgo some medical services.
- **Disability Pride** – On the other hand, some people express pride and a positive identity around their disability as a way to counteract stigma. These individuals may wish to join groups of people who share their disability, where it is no longer stigmatized. They may also opt against medical treatment intended to “cure” their disability because they have developed a positive identity around the condition.
- **Social Integration** – Stigma is social in nature and may interfere with social integration. In contrast to “concealment,” people may choose to make their disability more evident in order to improve their options for social participation. For example, a person with a mobility impairment may choose to use a wheelchair instead of a walker if the wheelchair would allow him or her to travel to work or family activities without fatigue.
- **Need for Respect** – Your patients may be especially sensitive to your attitude about their disability. Building a collaborative partnership with your patient built on trust and respect communicates your support for the patient as a whole person.

Tips for Respectful, Stigma-free Interactions Establish Respectful Communication

- Do speak directly to your patient, even if he or she has a companion or interpreter in the room. Make eye contact with the patient, not the companion.
- Do use ordinary language. It's OK to say "see you later" to a patient who is blind, or to talk about going for a walk with a patient who is non-ambulatory. Using ordinary expressions signals that you see your patients as full members of their community.
- Do ask patients with speech impairments how they prefer to communicate. Some patients may write or type to communicate if they have impaired speech, for example, or they may have established yes/no signals.
- Do use age appropriate language and tone with adult patients, and assume that a patient with a disability will understand basic instructions unless you have a clear indication otherwise.
- Don't interrupt or rush a patient who communicates slowly because of a speech impairment.
- Don't guess what a patient is saying. If you don't understand the communication, ask for clarification.

Respect Patient Privacy and Autonomy

- Do provide written materials in an electronic format when possible, for patients with visual impairments and those who have difficulty with handwriting or manipulating print materials. A patient can independently fill out an electronic form in advance of an appointment. Provide medical record information, treatment plans, and instructions in a digital format when requested.
- Do ensure that your office building and toilets are accessible to people using mobility aids such as walkers and wheelchairs, so that they can navigate the space independently.
- Do ensure that your office practice is accessible. For example, your patients with disabilities should be able to get weighed, use the exam tables, and access radiological exams.
- Do ask a patient the best way to provide physical assistance if it is needed.
- Don't touch, pull or grab a patient's body without asking for consent. For patients with some physical conditions, inappropriate touch can cause pain or interfere with balance. For others, unwanted touch can cause anxiety. Asking for consent respects the patient's bodily autonomy.
- Don't handle a patient's mobility device without consent.

Respect Disability Identity and Culture

- Do respect a patient's choice to downplay or highlight their disability in particular settings.
- Do introduce your patients to disability support groups. Organizations like the National Multiple Sclerosis Society or the United Spinal Association may have local chapters in your area. Your local independent living center may also have resources.
- Don't use negative words to describe disabilities. Words such as "tragedy" or "suffering" can convey a stigmatizing view of disability to your patients. Patients are not "confined to wheel chairs," but rather use wheelchairs.
- Don't fall into the trap of "golden rule thinking." This is imagining how you would personally feel with a disability as a way to infer how your patients feel. Disability is a complex experience that differs from person to person and changes over time. Listen to your patients to discover how you can be their best ally.

References:

- Eddey, G. E. & Robey, K. L. (2005). Considering the culture of disability in cultural competence education. *Academic Medicine*, 80, 706-712.
- Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity*. New York: Simon and Schuster.
- Morris, M. A., Yorkston, K. & Clayman, M. L. (2014). Improving communication in the primary care setting: Perspectives of patients with speech disabilities. *Patient*, 7, 397-401.
- Olkin, R. (1999). *What Psychotherapists Should Know About Disability*. New York: Guilford Press.

©University of Washington. (2016). Disability Stigma and Your Patients [Factsheet]. Aging Well with a Physical Disability Factsheet Series. Healthy Aging & Physical Disability RRTC, <http://agerrtc.washington.edu>

http://agerrtc.washington.edu/sites/agerrtc/files/files/Aging_Stigma_Final.pdf

nhsMANAGERS.net**The 5 year Forward View | News and Comment from Roy Lilley. [31st March 2017]**

[Roy Lilley is an independent health policy analyst, writer, broadcaster and commentator on health and social issues. He is a former Chair of an NHS Trust.]

To most journalists good news is no news. If we use this as a yardstick Simon Steven's review of the 5YFV, published today, is not news. It's full of good news. Nothing happening here, move along.

You'd be wrong. The review is the most important document you'll read this year. It is a catalogue of achievement and success. Your success. Yes you; coming to work in the daily grind that is the NHS. Working against all odds. Pulling rabbits out of the hat, coals out of the fire, snatching success from the jaws of defeat.

Yes, the headlines will be about a trade-off. Cancer treatments, better access to GPs, a catalogue of improvements, faster A&E triage, including mental health services, balanced against a tacit admission the 18 week waiting list target is parked. With the money available, you can't do everything. Pragmatic, sensible and doable. For the first time, a clear statement; you get what you pay for.

The elective waiting targets have not been met since God wore short trousers. Gps will have to do more to manage waiting patients. Very smart.... when waiting lists for hips and knees go up, so do elector's letters to MPs! Panic on the back benches. If you have been around long enough to remember 'waiting list money', you may just see it come around again... in time for the next election.

Since the publication of the 5year Forward View, demand has gone through the roof and the £8bn asked for, up front, to fuel the changes turned out to be a fiddle. Three and a half billion came from the DH cutting training and other budgets. The upshot, the new money was only £4.5bn.

The report gives us page after page of facts and figures... and yes it's OK to be proud of what you do. I know it doesn't seem like it but there is so much you have achieved.

The report, 70-odd pages, is a must read. The management version of a bodice ripper. I can't do more than say follow the link at the bottom of the page and read it for yourself. Lists of good stuff!

I did it one sitting. If you work in the NHS, social care, the voluntary sector, the private sector, if you have a family and use the NHS, if you are retired, living on a sunlit terrace in Tuscany... read it. Student, time served, junior, senior whoever you are... read it!

Shut the kids in the coal shed, put the dog in the garden and send the other half to the gym, shopping, the pub... it doesn't matter. Make time for yourself to read this document. Take it to the park, sit in the sun. Go to Costa, sit in the corner with a bucket of latte. Lay in the bath with bubbles, sit on the khazi... just read it.

Don't rely on edited versions or news papers to give it their spin. Do not let anyone filter it for you. Read it for yourself.

It paints a picture of a future that is exciting and doable. Not doable and easy. We are moving into the sleeves rolled up period.

I know this is all doable because so many of the initiatives, ideas, innovations and good stuff are already in action. I say that in the certain knowledge that nearly all of them are to be found in the pages of the Academy of Fabulous Stuff.

That is not to boast, idly, about the Academy. It is simply to say that a renewed NHS, ready to face the challenges of no money and unprecedented demand, can deliver because the Vanguardians are doing it, ECIST are doing it, Primary Care Home is doing it, you are doing it. In GP practices, on wards, out in the community, people like you have been finding solutions and sharing them.

Showing us what good looks like and getting on, doing it... better.

The 5YFV review is showing us what good looks like and inviting us to do it, better.

It is fulsome in its praise for your work, sober in recognising the hills still to climb and practical about how

we go about it. The naysayers and the nit-pickers will have their gripes but the question for them is, what would you do.

The review picks a careful path through the debris of the Lansley reforms, reassembling a workable and familiar infrastructure. It invites innovation and asks you to shape the services that are right for where you are.

The original 5YFV took us all by surprise in its approach, fluidity and attitude. The review continues in the same style.

I can't say it enough times; read it. It is important you make up your own mind and have an opinion that is yours. Not mine, not the HSJ, not the two old men at the Confed, Professionals, Providers, Captain Mainwaring, King's Fund, Nuffs, nor anyone else.

It doesn't matter what they think. They will publish press releases with interchangeable words; challenges, resource, effort, risk, blah, blah...

It's what you think that counts. You've got us this far and you will get us to the next stage. No one else.

If you can't manage the whole thing read the bits that affect you directly. There is an excellent index.

If it doesn't make you feel proud, if it doesn't make you say 'yup, that's right' and if it doesn't make you say 'we should give this a try'... you're in the wrong business!

Five Year Forward View - <https://www.dropbox.com/s/r33miu2ia4wjzi4/EMBARGOED-NEXT%20STEPS%20ON%20THE%20NHS%20FIVE%20YEAR%20FORWARD%20VIEW.pdf?dl=0>

Academy of Fabulous Stuff - <http://fabnhsstuff.net/>

Original source article - <http://myemail.constantcontact.com/The-five-year-forward-view-review.html?soid=1102665899193&aid=6FDA7kzmNOE>

Take Back Control !

Don't panic, this is about frog breathing, not BREXIT!

When I was 6 and in the iron lung, or my spaceship as I called it, I was taught a technique which some of you might also recall. It was a way of using my mouth to breath without using any breathing muscles at all. It was originally to help wean me off the iron lung 24 hours a day. Glossopharyngeal Breathing (GPB), or frog breathing, was taught to all respiratory polio patients back then. It is a way of supplementing breathing capacity with positive pressure using your mouth and tongue without any machines by 'swallowing' air into your lungs, note into your lungs NOT stomach! For some very expert patients, they could survive with this for hours with minimum or no lung or diaphragm muscles. Whilst this is unusual even for those less able it has huge benefits as an exercise or to supplement coughing.

Though I never lost this technique, I rarely used it until a few years ago when my lung capacity seemed to be dropping. I began using it to improve my ability to cough and having researched it further, I now also try to use it 2 or 3 times a day as an exercise to expand my lungs. This has had the effect of improving my overall vital capacity by around 10% and my cough by about 30%.

As we age everyone suffers from atelectasis, or stiffening lungs, to some extent and for those on ventilators, particularly pressure controlled, the lungs are not stretched enough to fill them to their capacity. As the purpose and standard measures for night ventilation is to achieve adequate blood gasses such as carbon dioxide and oxygen levels, not lung capacity. By using regular frog breathing you can help improve your cough and general breathing, potentially counteracting, to some extent, the impact of your lungs losing their elasticity.

Sometimes the low tech old ways are best. Few modern physios are skilled at teaching this and medics often know little about it, apart from maybe as an historical skill of old polio patients. Today it can be useful for many neuromuscular patients, but for us polios, it remains what I think should be a an important part of an exercise programme.

By Simon Parritt. Chair Polio Survivors Network.

Associated Chartered Physiotherapists in Respiratory Care article link.

http://www.acprc.org.uk/Data/Publication_Downloads/GL-07-v04.pdf



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 that well that externally we do not look like those photos in the old medical books. That there is a massive overlap of symptoms with other neuromuscular conditions. Tell them about **Post Polio Syndrome** and give them links to where they can find more information. Thankyou.

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

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.

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](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 Website link on front page

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, tips and bits

A way of doing something, or 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.

CARERS - Are you a Carer and would like to write and tell us how we might help Carers understand what you go through helping us manage our lives.

Articles and items for Post Polio Matters

are always welcome, by post, by email and by phone if writing is not easy for you.

Deadline date for next issue is 1st June 2017

Editors Note:-

Articles from Polio Survivors, family and friends and Health Professionals
Welcome for future issues

Management Committee [Trustees] and Operations Team

Management Committee [Trustees]

Chair - **Simon Parritt** - simon.parritt@poliosurvivorsnetwork.org.uk
Secretary, Membership & Email enquiries - **Dorothy [Dot] Ives** - dot.ives@poliosurvivorsnetwork.org.uk
Treasurer - **Margaret Marris** - margaret.marris@poliosurvivorsnetwork.org.uk
Newsletter Editor - **Hilary Boone** - hilary.boone@poliosurvivorsnetwork.org.uk

Operations Team

Phone Enquiries - 01522 888601 [Hilary Boone]
Email general enquiries - info@poliosurvivorsnetwork.org.uk [Dot Ives]
Printing and Website - Elpeeko Ltd, Lincoln.

➔ Please contact us if you would like to help with our work ➔

Membership

Full membership includes voting rights and is available to polio survivors, their partners, families and friends.

Associate membership, no voting rights, is available to patient organisations, health and social care professionals working in the interests of polio survivors £10.00 per year

Membership Fees

UK Individual - £ 12.50 per year

Associate Membership - £ 10.00 per year

Yearly fees can be paid by Standing Order.

Life membership - £ 150.00 or pay by Standing Order £ 5.00 x 30 mo.

We welcome members living in other countries and details will be sent upon request.

Please note the majority of information will be sent via the Internet.

Email:- membership@poliosurvivorsnetwork.org.uk



All Forms are available on our Website,
by phoning our helpline or writing to us.
<http://www.poliosurvivorsnetwork.org.uk/>

giftaid it

Donations

Donations, small or large, towards our work will always be gratefully received.

SEE BACK PAGE - Val Scrivener is making and selling brilliant photo greetings cards

- Some members send us a few postage stamps
- Some members take their newsletter via the internet saving us printing and posting costs.
 - Others add a donation amount to their yearly cheque, or Standing Order amount.
- Some members send us a donation with some specifying, e.g. for AGM, for Conference Fund
 - UK Taxpayers can Gift Aid their subscription and donated amounts.

NEW CONFERENCE & MEETING FUND

To support attendance at National Meetings and PPS Conferences

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.

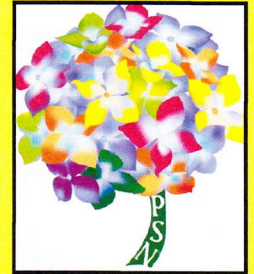
If you pay tax at the higher rate, you can reclaim tax relief on your gross donation at 20% (i.e. the difference between the higher rate of tax at 40% and the basic rate at 20%).

Polio Survivors Network

Lincolnshire Post Polio Network - Registered Charity No. 1064177

Website - www.poliosurvivorsnetwork.org.uk

Email - info@poliosurvivorsnetwork.org.uk



POST POLIO MATTERS because **WE'RE STILL HERE!**
www.post-polio.org

SHARING INFORMATION from PPS Groups WORLDWIDE

On April 22nd 2015, the Pennsylvania House of Representatives passed a unanimous Resolution naming April as Polio Awareness Month.

POLIO AWARENESS MONTH HAS A DUAL PURPOSE

1. To draw attention to the estimated 1.1 million Polio Survivors in the USA [15+ million polio survivors worldwide] and to recognise the disabling affects of Post-Polio Syndrome.
2. To recognize the importance of being immunized against this crippling disease.

We Can ENDPOLIONOW
Please Vaccinate Your Children

© Pennsylvania Polio Survivor's Network
www.papolionetwork.org

Don't let **your** children become Polio Survivors.

Please have them Vaccinated.



The Pain and Disability from Polio Lasts a Lifetime.



© Pennsylvania Polio Survivor's Network
www.papolionetwork.org



© PHOTO CARDS by MEMBER VAL SCRIVENER

Sold in aid of **POLIO SURVIVORS NETWORK**

Pack of 5 - £3.95 inc. P & P.

[Samples on every newsletter]

Order by writing to PSN

Emailing johnval.scrivener412@btinternet.com

Or ring Val Direct on 01234 346 397



STOP PRESS - ANNUAL GENERAL MEETING DATE 20.5.2017
INFORMATION IN SEPARATE SHEET WITH YOUR NEWSLETTER/EMAIL COPY.