



POST POLIO MATTERS

The Polio Survivors Network Newsletter - Volume 7, Issue 9
n.b. Volumes 1 to 6 published under the name LincPIN.
www.poliosurvivorsnetwork.org.uk

**August
2012**

Vol 7, Issue 9

**WE'RE
STILL
HERE!**

October 7-13, 2012
www.post-polio.org

**POLIO
SURVIVORS
NETWORK
IS A MEMBER
OF**



16th March 2012

Government watchdog finds neuro services are 'well below' standard

22nd March 2012

NICE to publish quality standard for neurological conditions

1st May 2012

Government responds to report on neurological conditions

8th May 2012

We call for an end to the social care crisis

JULY 26TH 2012



Commissioning Board
A special health authority

**Confirms a Strategic Clinical Network to include
neurological conditions**

Immediate Response to Members of the Neurological Alliance from Arlene Wilkie, Chief Executive

"The announcement of a SCN covering neurology is absolutely fantastic news which will ensure that there will be NHS funded and administered networks across England dedicated to enhancing services for all people with neurological conditions. In giving neurology recognition and priority at national level, the SCN represents the single most important development for neurology to date under the new health and social care system and will play a crucial role in the future of neurological care.

"Since clinical networks were confirmed last summer as a core element of the reformed NHS, we have recognised their potential to address the key challenges neurology faces, from delayed diagnosis to lack of service integration, and have championed the need for neurology clinical networks. There can be no doubt whatsoever that it is a credit to the neurological community's tireless work, both through our 'better deal for neurology' campaign and [recent report](#) on the case for a neurology SCN, that we have been allocated one of only four SCNs.

"This achievement is my proudest moment at the Alliance so far. It simply would not have been possible without your input and support; thank you so much. I look forward to working with you all to make sure that our SCN delivers positive and sustained change for the 8 million people we collectively represent."

June 26th 2012

Thinking Ahead: the case for a Strategic Clinical Network for Neurology

Produced in collaboration with Neurological Commissioning Support.
www.neural.org.uk/updates/203-Making-the-case-for-neurology-networks

REMINDER

If you are having problems living with Polio, Post Polio Syndrome, including trying to obtain/retain any type of benefit please let us know to add to our knowledge base

DISABILITY EXHIBITIONS

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NAIDEX SOUTH

17 - 18 Oct 2012

ExCeL London

www.naidexsouth.com

NAIDEX SCOTLAND

18 - 19 Sept 2013

www.naidex.co.uk



If you read an article that could interest other members please send it to us.

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**Member Val Singleton Photo Cards in support of PSN.
Please help us raise funds by ordering a pack or two.**

New Members and Donations received.

Thank you to all members who have recently renewed.

Thank you to the following for donations given towards our work

John De'Ath, Rita Unger, Mrs K Norman, Mrs E Hobday

J Doohan, Diane Lightfoot, Yvonne Liggins

Jennifer Paulger, Clare Colfer, Diane Taylor, Maureen Allison

Plus the members who sent Books of Stamps

A total of **£ 175.50** since last newsletter.

Plus Val Scriveners Card Sales adds another £ 20.00

We have no paid employees.

We would like to recognise and thank the following for so generously donating their time. The Trustees, Chris Salter, and Bob Price

Donations & offers of time towards our work are always welcome.

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.

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Editorial by Hilary Boone

As I start to type this it is a sunny day...., but daily life for polio survivors and others with disabilities is somewhat grey at the moment because of the huge number of changes in the NHS, Social Services and Government Benefits that are going to affect how we manage our lives from here on in. See tip on page 17 for when those dreaded brown envelopes drop on the doormat. Please if you have any ideas/suggestions or know of good user groups/experts in the benefit field who would be prepared to help our members please let us know.

Our Website front page has a changing photo slot and we would like to add some more members photos. What is really good is a three photo collage showing three stages of your polio life. With or at the time you had polio [we know some do not have photos that show polio damage but a photo at about that age would be fine]. Another showing you at your best recovery and one now. This is the fastest way of demonstrating how polio and now post polio syndrome has changed our lives. Also single photos demonstrating achievement or taking part in a sport/hobby or showing good disability equipment/ideas. All photos will be returned.

I thought that regularly adding items in newsletters asking you to send in questions, hints, tips and bits, articles, items that you read in other publications, respond to surveys/requests, purchase Val Scriveners Photo Cards to help us raise funds, and most importantly join the Committee or Operational Team by offering a skill and a few hours a month, etc would be met with a fair level of response. Sadly, response has been none, just a few and rarely over 10%.

I know living with PPS is tough not only physically but emotionally and financially. The dreams and hopes we had for our retirement disappear and the vagaries of living with old age seem to come and meet us head on. We accept that there are members who would find it really difficult to help because of the difficulty with managing their daily lives. However, if every member did just one of the above it would be a huge boost for PSN. [Thanks to those who sent books of stamps]

I ask that you read the Trustees report on the next pages and if you, a partner or family member or friend think you might be able to help us with the future running of PSN then please get in touch to find out more.

Bob Price, CPA, from Jacksonville, Florida, has managed our USA account for many years now, often adding a donation of \$100 when paying in USA \$ checks from American members. Reluctantly due to his and his wife's current health he has asked us to find someone else to take this on board.

I would like to take this opportunity on behalf of all members to thank you Bob for all you have done for us. Congratulations on your 55th Wedding Anniversary on the 15th June 2012. We wish you both all the best for the future.

A good overall article on Post Polio Syndrome on Patient.co.uk.

This PatientPlus article is written for healthcare professionals so the language may be more technical than the condition leaflets. You may find the abbreviations list helpful. .

www.patient.co.uk/doctor/Post-Polio-Syndrome.htm

Members without access to the Internet.

If you would like more information on an item, a copy of any of the articles referred to, or you can think of some way we might help you, then please drop me a line or give me a ring.

Polio Survivors Network - Meeting information

If you have any matters you would like us to discuss at our meetings please get in touch via
info@poliosurvivorsnetwork.org.uk
or Tel: 01522 888601 or write to us at Polio Survivors Network PO Box 954, Lincoln LN5 5ER



SITUATIONS VACANT

TRUSTEES

HELP WITH SECRETARIAL TASKS

and your
stories, hints,
tips and bits.



The Late Effects of ME
- Can They Be
Distinguished From
The Post-Polio
Syndrome?

Author

Dr. E.G. Dowsett
MBChB, Dip Bact.

**A tribute meeting
for the late**

**Dr Betty Dowsett,
who died in June
at the age of 91,
is to be held in
Colchester on**

Sunday, October 28.

**It will take place in
The Samaritans Hall,
Walsingham Road,
Colchester CO2 7BP**

at 2pm

Message from the Trustees.

Dear All,

We would like to thank all who were able to join us for the AGM and for the donations towards the cost.

PSN needs three Trustees to comply with our Constitution and on the day of the AGM we only had two nominations. The meeting agreed to take advice from the Charity Commission. Subsequent to the meeting that advice was that the existing Trustees would need to recruit a further trustee in order to run the charity and make valid decisions. So that we could continue complying with the CC regulations Chris Salter very kindly offered to stand in as our third Trustee whilst further discussions took place as to the future of PSN.

The overriding issue regarding the future of PSN is whether continuing as a registered charity is a viable option, not only for this accounting year but future years as well. We certainly need more help and we definitely need more Trustees in order to avoid the annual question mark over whether we are able to retain our charitable status for the coming year.

Briefly, our current thinking is we must have a minimum of 6 Trustees. A proportion of these including the Chair will be non-executive posts responsible for oversight and not directly involved in the day to day management which will be carried out by the executive Trustees

All the Trustees, executive and non executive, make up the Management Committee. Trustees do have responsibilities and there are of course financial concerns but we have always had more than £1800 in the kitty at the end of each year.

The Management Team will comprise the executive Trustees and possibly additional helpers and will be in regular contact by email, Skype etc. They will provide a monthly report for the non-executive Trustees who will also be asked to approve any payment over £100 other than the Newsletter printing costs and postage.

During the next few weeks the Trustees will be discussing and planning the detailed tasks needing to be completed in the coming months. These will cover both possibilities, i.e., continuing as a registered charity or relinquishing charitable status. However, a final decision in that respect will be made mid September 2012. The response to this call for more Trustees will obviously be the critical input to that decision.

We fully appreciate that anyone - member/family member/friend - taking this on board will need more information to make a final decision, e.g., to read the C.C. document referred to on the opposite page; to look at the detailed tasks list currently under preparation; to discuss this with us. However we would appreciate hearing from anyone interested by the end of August 2012.

We would also like to hear from anyone who would like to send in items for consideration for the newsletter. Such as questions, hints, tips and

The Essential Trustee

Charity trustees are the people who serve on the governing body of a charity. They come from all walks of life and almost everyone has abilities, knowledge or experience that they can bring to a charity.

Being a trustee should be rewarding and enjoyable, and an opportunity to make a positive difference and serve the community while learning new skills. A strong personal commitment to the charity's aims is important. Most trustees are unpaid volunteers, but trustees are allowed to be reimbursed for reasonable expenses; there is no reason for trustees to be out-of-pocket.

Trustees have duties and responsibilities to their charity, its supporters and beneficiaries. If you have recently become a trustee, or even if you have been a trustee for years, it is important that you are aware of these and we encourage you to read our guidance:

www.charitycommission.gov.uk/Library/guidance/cc3text.pdf

bits, write articles, review medical articles, tell us about your life, work, hobbies, anything you think other readers might like to read.

We would also like some help with secretarial tasks and if you would like to help by taking on a task or have a skill you can offer, can spare a few hours a month and would like more information why not email, write or give us a ring.

Dr. Betty Dowsett, MBChB, Dip Bact.

It was with sadness that we learned of the death of Dr. Dowsett in June 2012. She was an amazing expert and campaigner for ME and similar medical conditions including post polio syndrome. Her support for our work and sharing of information was excellent.

She attended a few AGM's, speaking at a few and gave freely of her time to discuss members issues with them and their families.

There is one memory that always makes me smile. I was waiting for arriving members in the hotel reception. A couple of hours later Dr. Dowsett came from her room, bringing me a drink and seeing I looked tired asked, 'Are you OK, is there anything I can do to help you?' I replied 'You are right I am exhausted in fact I don't know my a**e from my elbow.'

Dr. Betty walked across reception and gently took hold of part of my arm saying, 'Hilary dear, this is your elbow.' Much laughter from myself and the few members sitting with me. A lovely lady, a wonderful sense of humour and we will miss her.

See strip on page 4 for the venue, date and time of a Tribute meeting for her, led by her daughter Mrs. Frances Johnson. If you would like to attend and/or speak please email the organiser, Mrs. Vivienne Mills. vivienne.mills@ntlworld.com

Lincolnshire Post-Polio Library article by Dr. Dowsett.

The Late Effects of ME - Can They Be Distinguished From The Post-Polio Syndrome?

www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/dowsett/lateeffectsmeh.html

We hope you are enjoying the Olympics, have a good summer and we look forward to hearing from you.

Hilary, Gill and Chris.

Postural care and protection of body shape

Basic information sheet <http://www.mencap.org.uk/posturalcare>



Postural care is a gentle form of physical therapy used to protect body shape. People who find it hard to move, at any age and for any reason, are at risk of developing changes in their body shape and these changes lead to secondary complications. People who find it hard to move during the day often spend the majority of the night in one position. Over time this position can become obligatory as their body shape may make it even harder to move or difficult to adopt alternative positions. In June 2009 the NHS/PASA Buyers Guide for night time positioning equipment stated that the following complications are associated with a failure to protect body shape.

- “The musculoskeletal system (contractures, loss of joint integrity, e.g. Hip dislocation, decreased bone density, reduced range of joint motion and deformity, e.g. spinal scoliosis)
- The neurological system (spasticity/muscle tone, primitive reflexes, altered sensation and joint position sense, pain, weakness)
- Respiratory function
- Digestion (including swallowing and choking, both of which are compromised by poor head and neck posture) and kidney/renal function
- Personal hygiene, ease of toileting and changing
- Functional ability
- Environment interaction (sensory perception, body aesthetics, learning, communication)
- Sleep pattern and irritability”

Isn't this happening already?

The provision of therapeutic positioning is patchy. There is very little evidence available for the standard of adult provision. The recent NHS Buyers Guide for night time positioning equipment for children stated that 54% of respondents to a survey of paediatric physiotherapists have a child on their caseload who does not have access to therapeutic positioning equipment. Of these 40% did not have access to funding. One can only assume that the situation for adults is worse as there are no charitable sources of funding for equipment.

The NHS/PASA Buyers Guide describes training for families and PAs as “vital” and that it is available from manufacturers. There are currently no clinical standards for training of company representatives selling night time positioning in the UK. Many therapists in the UK are increasingly frustrated by the lack of funding for equipment, a lack of awareness of their role in this field and are often managed within systems that do not reflect the hard work that is involved in supporting families to provide this fundamental care. Children are often assessed for need using functional assessments – this is not logical as some individuals will never make progress according to these scales, yet their body shape will deteriorate over time. We need to use measurement of body symmetry to assess whether we are effective in protecting body shape.

What are the cost implications of providing postural care?

There are cost implications for training both healthcare professionals and families. Use of therapeutic positioning, particularly at night is dangerous. Thorough safety planning and assessment of competency should be part of a postural care pathway. Families are able to make informed choices only when they are in possession of comprehensive information and supported to weigh up risk and benefit. Sleep systems cost in the region of £400 to £3000. There is a new not for profit organisation supplying sleep system equipment www.simplestuffworks.co.uk

What are the cost implications of failing to protect body shape?

Consideration of the potential secondary complications outlined in The NHS/PASA Buyers Guide indicates considerable cost implications of a failure to protect body shape. Costs would be associated with surgical intervention, complex equipment for mobility as well as moving and handling, pressure care, adaptations to the home should hoists be required, enteral feeding, pain management and an increased need for medications such as Botox or Baclofen. The human cost to the individual and their family of experiencing

avoidable secondary complications must not be forgotten. Ultimately changes in body shape lead to a loss of internal capacity, the contents of the abdomen invade the thorax, leading to premature death.

How do we know if therapeutic positioning is working?

We can use very simple measures of body symmetry, non-invasive and statistically validated in 1992. These measures can be used by families to monitor progress and to ensure that body shape is being protected. They can also be used to hold service providers to account.

How do I find out more?

You can take a look at our website www.posturalcareskills.com call or email us. We're happy to talk this through with anyone interested in moving this forward in their area. We are here to support therapists and service providers to understand the implications of therapeutic positioning and to improve access for families to person centred, timely provision of therapeutic positioning.

Further reading:

1. Buyers Guide: Night Time Postural Management Equipment for Children. June 2009. NHS Purchasing and Supply Agency; Centre for Evidence Based Purchasing.
2. Whinnett, J. "PAMIS: Supporting People with Profound and Multiple Learning Disabilities and Their Families for a Better Life" Posture and Mobility, vol 27:2, pgs. 16 – 20. 2010
3. Houghton, M. and Royal College of General Practitioners Learning Disabilities Group., A Step by Step Guide for GP Practices: Annual Health Checks for People with a Learning Disability. Page 28.
4. Cobb, J. and Giraud-Saunders, A., Commentary on 'Biomechanics and Prevention of Body Shape Distortion', The Tizard Learning Disability Review, Vol. 15, Issue 2, pgs. 30 - 32 , 2010
5. Hill, S. and Goldsmith, J., 'Biomechanics and Prevention of Body Shape Distortion', The Tizard Learning Disability Review, Vol. 15, Issue 2, pgs. 15 – 29, 2010
6. Goldsmith, L. Golding, R.M. Garstang, R.A. Macrae, A.W., 1992. A technique to measure windswept deformity. Physiotherapy, 78, (4), pp.235-242.
7. Goldsmith, S., 2000. The Mansfield Project: Postural Care at night within a community setting. Physiotherapy, 86, (10), pp.528 – 534.
8. Hill, S. Goldsmith, L., 2008. Posture, Mobility and Comfort. In: Carnaby, S. Pawlyn, J., 2008. Profound Intellectual and Multiple Disabilities: Nursing Complex Needs. Wiley Blackwell Publishing. Ch17.
9. Michael, J. 2008. Healthcare for All. Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities. Available at: <http://www.iahpld.org.uk/>
10. Newlife Foundation, 2007. It's not too much to ask. Available at: <http://tinyurl.com/nzyolq>

Postural Care CIC Company No. 6936947

Simple Stuff Works CIC - Inexpensive, effective therapeutic positioning systems and advice

We are an independent, Community Interest Company dedicated to providing effective, inexpensive postural support equipment. We are constituted as a not-for-profit organisation, meaning that we have no independent shareholders for whom to make profit and all profits made by the company have to be ploughed back into research and development or given to charity.



We are happy to come and do individual assessments, demonstrations and clinics with our fully CE marked products and will travel anywhere in the UK. Just give the office a ring to organise a date for the diary!

Simple Stuff Works, Ground Floor Unit 3, Cavendish Lichfield Road Industrial Estate, Tamworth, B79 7XH
Tel: 01827 307870 Fax: 01827 818313 Mobile: 07813 033 561 Email: anna@simplestuffworks.co.uk

[Editors Note:- John visited Richard and I and assessed how we were resting/lying/sleeping on our beds. He advised changes, e.g. I lie on my left side and had one pillow between my knees but still had pain in my left hip causing me to wake 3 or 4 times a night. I was stunned to learn that whilst the pillow was right it was not high enough and I needed 3 pillows height and it worked, the pain is no more. Fantastic.]

RECENT MEDICAL ARTICLE ABSTRACTS ON POLIO AND POST POLIO

July 22nd 2012

Living with polio and postpolio syndrome in the United Kingdom.

Authors:- Atwal, A, Giles A, Spiliotopoulou G, Plastow N, Wilson L

School of Health Science and Social Care, Brunel University, Uxbridge, Middlesex, London, UK.

Abstract.

Scand J Caring Sci; 2012 Living with polio and postpolio syndrome in the United Kingdom The term Postpolio Syndrome (PPS) is used to describe new and late manifestations of poliomyelitis that occur later in life in polio survivors. Polio had been eradicated in the United Kingdom (UK) and most of Europe, although this is not the case in all countries. Research in this area has tended to focus upon the impact of polio and PPS on health status and functional health rather than its overall effect on people's lives. This study's two main aims were to explore the ways in which polio and PPS in the UK has affected the respondents' lives and to ascertain their views about how the quality of life could be improved. The two questions were as follows: (1) How has the health of people with polio and PPS affected their quality of life? (2) What would people with polio and PPS change to improve their quality of life? Deductive content analysis using existing qualitative data from a cross-sectional survey of 336 returned questionnaires from persons with polio and PPS was carried out. The average age of the participants was 54 years. Our research found that polio survivors valued social occupations and participation in family life. Our research has also shown that healthcare professionals still do not understand polio and PPS and this lack of understanding influences their clients' quality of life. Finances and accessibility of environments also influence participation in chosen occupations. Rehabilitation programmes for people with polio and PPS need to be targeted towards maintaining and improving accessible environments and participation in chosen occupations, and healthcare professionals need to ensure that persons with polio and PPS are referred to persons with specific expertise in this area.

© 2012 The Authors. Scandinavian Journal of Caring Sciences © 2012 Nordic College of Caring Science.

Scand J Caring Sci. 2012 Jul 22. doi: 10.1111/j.1471-6712.2012.01029.x. [Epub ahead of print]

www.ncbi.nlm.nih.gov/pubmed/22816389

9th July 2012

Intravenous immunoglobulin treatment of the post-polio syndrome: sustained effects on quality of life variables and cytokine expression after one year follow up

Authors:- Henrik Gonzalez, Mohsen Khademi, Kristian Borg, and Tomas Olsson

Journal of Neuroinflammation 2012, 9:167 doi:10.1186/1742-2094-9-167

Abstract (provisional) [n.b. Part only]]

Background - Expression of inflammatory cytokines in cerebrospinal fluid (CSF) has led to the hypothesis of intrathecal chronic inflammation to explain the denervation observed in post-polio syndrome (PPS). It has been shown that therapy with intravenous immunoglobulin (IVIg) improves physical performance and dampens down the inflammatory process at 6 months in PPS patients. We here examined the effects of IVIg on cytokine expression and clinical outcome one year after IVIg treatment.

Conclusions - IVIg has effects on relevant QoL variables and inflammatory cytokines up to one year in patients with PPS. This gives a basis for scheduling IVIg in upcoming trials with this therapy.

Complete article available as provisional pdf

www.jneuroinflammation.com/content/pdf/1742-2094-9-167.pdf

Dec 10th 2011

Post-polio syndrome: impact of hope on quality of life.

Authors:- Shiri S, Wexler ID, Feintuch U, Meiner Z, Schwartz I.

Disabil Rehabil. 2012;34(10):824-30. Epub 2011 Dec 10

Abstract

PURPOSE: To determine the effect of future-oriented coping strategies on the quality of life (QOL) of individuals with post-polio syndrome (PPS).

METHODS: A correlative study, in which a cohort of 61 patients was surveyed and a group of 40 healthy, age-matched individuals served as controls. Patients were surveyed as to their QOL, levels of hope and utilization of proactive coping, employment status and degree of functionality.

RESULTS: PPS patients had lower total, physical and mental QOL indices compared to controls. Future-oriented coping strategies associated with hope were positively associated with physical and mental QOL in the PPS group, but not in the controls. In a multivariate analysis, hope and employment status predicted higher QOL among those with PPS.

CONCLUSIONS: Future-oriented coping strategies, particularly hope are distinctively associated with improved QOL benefits in PPS patients. Fostering future-oriented coping related to hope may improve the self-perceived mental and physical status of patients with PPS.

www.ncbi.nlm.nih.gov/pubmed/22149715

[Members are welcome to write reviews or comment on these or any other relevant medical articles, or write articles themselves for consideration for newsletter.]

The Impact of the Salk Vaccine

**Cassandra Howell - Research Writing Student,
Walla Walla Community College, Clarkston, Washington, USA**

Abstract

Polio was a rare disease that the general population didn't think too much about. A cough, headache or sore throat was nothing to be alarmed over. Most would take some aspirin and continue on with their day. This caused the polio epidemic in the late forties to early fifties. After that parents wouldn't even allow their children to play with their friends for fear of contracting the virus. Then Dr. Jonas Salk created a killed polio virus vaccine. In 1954 vaccine trials were done on millions of volunteer children. In 1955 it became a licensed vaccine by the Public Health Service. Only half the polio cases were reported in 1956 compared to the year before.

The Impact of the Salk Vaccine

A child who felt weak, a mother who had a headache, or a father with sore muscles would assume it was a sign of an oncoming cold. Most would move on with their day after popping a few aspirin with no fear of the tragedy that would soon come. This normal reaction to any slight symptom is what caused the polio epidemic. Since no one was concerned or aware of the paralyzing illness, it could easily spread from one person to another (Wilson, 2005).

By the early fifties, there were posters everywhere you looked that deepened the fear of the polio epidemic. They were splashed with, "it may-or may not be polio, call your Doctor promptly if you have the following," followed by a list of signs and symptoms (Wilson, 2005). No longer were achy muscles, upset stomachs and fevers considered evidence of a slight cold or a mild flu. These symptoms sent panic throughout towns. Children did not fill the seats of movie theaters or splash around in public swimming pools for fear of contracting the virus from another. Parents were so terrified they would have gone to extreme lengths to protect their children and family from this virus (Carter, 1966).

In small towns, the polio virus seemed more terrifying than in bigger cities, such as Seattle. Newspapers showed images of children unable to breathe lying in iron lungs and children in leg braces walking with crutches. Robert Howell said he lived in a town of 20,000, and when one case popped up, everything children were involved in stopped: theaters closed, swimming pools closed, school attendance dropped, sports activities stopped. "People always get concerned when they don't understand a disease, its source, how it's transmitted and when it might affect them or their family" (Howell, R, personal communication, April 27, 2012).

The need for parents to protect their families is what helped make the Salk vaccine trials one of the largest of its kind. In 1954, Dr. Jonas Salk was ready for a trial run of the polio vaccine he had worked so hard to create. This trial would be different from others because it was not financially supported by the government, but by volunteers and donations (Dawson, 2004).

Dr. Salk had taken extreme precautions before deciding the vaccine was ready for children's involvement. He handled his work with love and care, knowing that even if he saved one child's life it would be worth it. After discovering there were three strains of polio and only three, Dr. Salk and his team tested their vaccine on monkeys. It worked safely. Then he tested the vaccine on a few children, some victims of the virus and others mentally disabled. These tests showed that the vaccine stimulated the polio antibodies and had no serious side effects. Salk even went as far as to give himself and his family the vaccine. They showed no signs or symptoms of the virus or any unwanted effects from the vaccine itself (Carter, 1966; Dawson, 2004).

There was controversy involving the trial because so many children of grade-school age were needed to have an accurate observation of the vaccine's effects or lack thereof. But society's faith in medicine and desperation to protect communities outweighed any fear that parents may have had in giving their children the vaccine (Dawson, 2004).

Parents had to isolate their children at hospitals and go for weeks with no communication before there was any hope of a vaccine. Medical professionals who had to witness a child's suffering every day could only give sympathy and pray for a better day. A nurse who had worked in a Pittsburgh hospital during the polio epidemic said:

In all my career there has been no experience like Municipal Hospital before the Salk vaccine. One year ambulances literally lined up outside the place... One of our resident physicians never went to bed for nights on end, except for stretching out on a cot in his clothes. We nurses could never get home on time, either. To leave a place you had to pass a certain number of rooms and you'd hear a child crying for someone to read his mail to him or for a drink of water or why can't she move, and you couldn't be cruel enough just to pass by. It was an atmosphere of grief, terror, and helpless rage. It was horrible. I remember a high school boy weeping because he was completely paralyzed and couldn't move a hand to kill himself (Dawson 125, 2004).

Hearing these horror stories only made it easier for parents everywhere to sign waivers releasing their children to the Salk trials. There were over a million children who volunteered (Dawson, 2004; Wilson, 2005).

The NFIP (National Foundation for Infantile Paralysis) wanted the public to be more aware of what the trials would consist of. They sent out videos and leaflets with explanations. Community meetings were held to address any concerns and questions. They wanted to make sure volunteers and others were well-informed on the topic (Dawson, 2004).

There were some arguments and differences of opinion when it came to the design of the killed virus vaccine trial as to whether it should be a trial with injected controls (placebo controls) or observed controls. Salk didn't agree with placebo controls because he believed his earlier trials already proved the effectiveness of the vaccine. Eventually, everyone came to a compromise and it was decided that placebo controls would be used in eleven states and the others would use the observed controls. It was also decided that all laboratories supplying the vaccine would have to pass a safety inspection on each batch (Dawson, 2007).

The trials had started. In 1954, between April 26th and June 15th, children in counties all over were given the killed virus vaccine. There were over 200,000 volunteers helping in every aspect of the trial: teachers, principals, physicians, nurses, and public health officials. Over a thousand hours were put into pre- and post-observations, paper work, blood samples and antibody testing (Dawson, 2004).

The results were ready to be announced on April 12, 1955. Newspaper and radio reporters gathered outside of the University of Michigan to hear the results of Salk's killed virus vaccine. It was safe and effective. The vaccine was 68% effective against type 1, 92% against type 3 and 100% against type 2. Wasting no time, that day the Public Health Service, PHS, licensed the vaccine. On April 26, 1955, the vaccine was released nationwide (Dawson, 2007).

The celebration abruptly ended weeks after when, in Pocatello, Idaho, a little girl, Susan Pierce, came down with polio. She had been vaccinated just days before with the Salk vaccine and shortly after showed signs of the virus. Sadly, Susan was not the only vaccinated child who started to show symptoms. A year-old baby became paralyzed and died soon after. Then six more children were discovered with paralytic polio; each arm that had been vaccinated was now paralyzed (Spencer, 1955).

The public began to panic. Investigation was launched into each of the laboratories producing the vaccine. It was then discovered that Cutter Laboratories had a live virus in its vaccine. It was immediately pulled from circulation. The damage had already been done. One hundred and thirty one of the children who were vaccinated with the Cutter Laboratories supply came down with polio (Spencer, 1955).

The PHS has improved protocols and added new safety procedures to the production of vaccines. Although the Cutter incident concerned the population, PHS did its best to ease the public's mind. The Salk vaccine is a safe and effective vaccination for all polio types 1, 2, and 3 (Spencer, 1955; Dawson, 2004).

The year 1956 was the first one in which there was a noticeable difference in the number of polio cases reported. Thanks to the Salk vaccine, there was a rapid decline and only half as many were reported compared to the years before. Every year following, the numbers got lower and eventually the fear of polio was no more in the minds of parents. Public swimming pools reopened and children were seen playing together again (Carter, 1966).

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- cassandra.nichols@student.wvcc.edu

London 2012: Paralympian warns DLA cuts could 'jeopardise independence'

Disabled people's independence could be jeopardised by the government's planned cuts to disability benefits, according to a leading Paralympian.

David Clarke, who will captain Britain's blind football team at next month's Paralympics in London, said he believed cuts of 20 per cent to spending on disability living allowance (DLA) could put people's independence and equality of opportunity at risk. And he said that the focus on forcing disabled people off incapacity benefits and back to work ignored the barriers in society and workplaces that can prevent them from finding jobs. Asked by [Disability News Service \(DNS\)](http://DisabilityNewsService.com) about the cuts to disability benefits, he said: "It does seem as though disabled people's independence is being jeopardised by the government's proposals and I think what worries me is that it has been done with good intentions in certain areas, but it is so wide of the mark."

Speaking at the official launch of the ParalympicsGB team for London 2012, Clarke said the push towards forcing disabled people off out-of-work disability benefits appeared to be ignoring the "wider debate" about equality and discrimination. He said: "It is about creating opportunities through diversity programmes within businesses, it is about transport, it is about assistance in the workplace." He said the government appeared to have failed to understand the importance of DLA to disabled people's independence. Clarke said: "If a government minister found himself in the middle of a city with no-one to help and needed to get a taxi owing to mobility difficulties, he probably would appreciate his DLA. Or indeed if he needed someone to read his post. "DLA matters. It covers some of those additional costs that we wouldn't necessarily have the money for.

"What DLA does in my opinion is it enables you to afford all the additional support you need in all sorts of guises without impinging on the income you receive. It puts you on a par with other people in society." He added: "Every single penny of that DLA goes back into the economy. It is not like people are clinging onto it and creating a nest egg. "They spend this money on funding their independence, on necessities, on assistance, on transport networks. Whatever it is doing it is going into the economy."

A string of Paralympians have joined him in speaking out about the importance of DLA.

Powerlifter Ali Jawad told DNS: "I just hope when [the cuts] come along that the government have thought this through. "[If they haven't] they are going to have a lot of disabled people who are losing their independence."

Table-tennis star Sue Gilroy said it would be "devastating" if she was to lose her DLA and would make day-to-day life "impossible", as she uses it to help pay for things like support at home, the £20,000-worth of adaptations to her Motability vehicle, and her wheelchair.

Aaron Phipps, a key member of the ParalympicsGB wheelchair rugby team, said: "It is just completely essential. I would be completely lost without it. "A new wheelchair costs perhaps £1,700. I would not be able to live independently without a wheelchair like this."

His team-mate Kylie Grimes added: "DLA is really important. It's been a massive help to me over the years."

And Boccia world number one Nigel Murray, a two-time Paralympic gold-medallist, told DNS: "The benefits that I get are very important to me. They enable me to live and get the support I need."

Dressage medal-hope Natasha Baker said DLA allowed disabled people to be independent. She said: "I love my independence. I hate relying on other people to do everything for me. I drive and I probably wouldn't be able to afford the petrol if I didn't have DLA."

It is not the first time Clarke has spoken out on issues around rights – the historical figure he looks up to more than anyone is Martin Luther-King – such as outdated media attitudes to disabled people, particularly the Sun's "appalling" front page that mocked the speech difficulty of the new England football manager, Roy Hodgson. But he believes some media attitudes are improving, while Channel 4's presentation of Paralympic sport – as the UK's official TV broadcaster for the games – has been "very impressive". He said he was now more likely to be asked sport-related questions about blind football, rather than receiving the "patronising, arm-round-the-shoulder" attitude, but he is keen that the Paralympics further highlight the elite nature of his sport.

Away from sport and disability, he is also keen to speak out in defence of the banking industry. A senior partner with Clydesdale Bank, running a team of corporate and private bankers, he is proud of what he does, despite the scandals and crises that have enveloped the industry. He said: "I know what I do on a day-to-day basis. It is helping people, be it small businesses, corporate businesses, private individuals. "My sole objective is to make them more secure and successful in life, maybe richer, and to protect what they have earned. I build positive relationships with people. "It is a million miles away from the stuff that is going on at the moment, so far removed you can't believe." He added: "Clydesdale have been absolutely amazing to give me as much time as I need to prepare properly, as well as allow me to continue with a full-time career."

Despite his willingness to speak out in defence of disabled people's entitlement to benefits, and his high media profile, he is focused on the competition ahead, and is looking forward most of all to "getting into the tournament and away from all the hype". He said: "Football is about results. There will be a lot of additional attention, but we are here to win a football tournament and fundamentally that has to come first."

Although he hopes the games are a success, he said, the only way he will judge that success personally will be if he comes away with a medal around his neck.

19 July 2012

<http://preview.tinyurl.com/c4ay34v>

Minister wants eight-year delay in new rights for disabled passengers.

The government is seeking to delay major parts of a new European regulation that would have given powerful rights to disabled bus and coach passengers.

The European Union regulation on bus and coach passenger rights is due to come into force on 1 March 2013.

It includes a right to full compensation for lost or damaged wheelchairs, non-discrimination in booking tickets and boarding vehicles, and disability awareness training for all staff who deal with customers.

But EU states have the right to seek lengthy exemptions from other key parts of the regulation, and a consultation document published this week by Liberal Democrat transport minister Norman Baker says the coalition wants to “make use of all available exemptions in order to delay costs to industry and give them more time to prepare”.

These other rights for disabled passengers only apply to journeys over 155 miles, but EU member states can still exempt their regular domestic bus and coach services from these rights for up to eight years.

The rights the UK government wants to delay include the right to compensation if a passenger has a reservation and has explained their need for assistance in advance but is still prevented from boarding the coach or bus.

The government also wants to delay a disabled passenger’s right to free assistance at major coach terminals and on board coaches, if they have notified the provider at least 36 hours before departure; and the right to be accompanied by their own assistant at no extra charge if the transport provider is unable to provide suitable support.

The Department for Transport said the eight-year delay would mean “significant monetised benefits” – of more than £8 million – for bus and coach operators and the bodies that run major coach terminals such as London Victoria and Birmingham.

But it admitted that the delay would cause “costs to passengers, including disabled people and people with reduced mobility” of more than £1 million.

The government also wants to take advantage of another exemption, delaying compulsory disability awareness training for bus and coach drivers by five years.

The consultation document points out that disabled people in the UK will still have the protection of the Equality Act.

Baker said: “We want people taking coach trips and long-distance bus journeys to get a fair deal. However, we also want to avoid tying operators up in expensive and unnecessary burdens.

“I believe that the approach outlined in this consultation finds the right balance between passenger protection and operator competitiveness and I hope that groups likely to be affected by these changes will agree when they respond to our proposals.”

The consultation closes on 11 October.

19 July 2012

DEPARTMENT OF TRANSPORT

EU Regulation 181/2011 concerning bus and coach passenger rights

Consultation on how this regulation will be applied in Great Britain.

Open 18th July 2012

Closes 11th October 2012

Summary

The EU Regulation on bus and coach passenger rights will apply in all Member States from 1 March 2013, primarily to long-distance regular services 250km or longer. Whilst the EU Regulation is directly applicable, Member States remain responsible for making decisions on several important issues. This public consultation therefore focuses on the use of available exemptions, enforcement arrangements and designating terminals where guaranteed assistance is provided to disabled passengers.

Consultation Document

<http://assets.dft.gov.uk/consultations/dft-2012-19/consultation-document.pdf>

Impact Assessment.

<http://assets.dft.gov.uk/consultations/dft-2012-19/impact-assessment.pdf>

Response Form.

<http://www.dft.gov.uk/consultations/dft-2012-19/>

NB If you are interested and unable to obtain copies please let us know.

WHY NOT TELL US YOUR STORY?

Hints, tips and bits section.

Remember something that helps you might help someone else, drop us a line.

CARERS

Are you a Carer and would like to write and tell us how we might help you understand what you go through.

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

Using the Law to Fight Cuts to Disabled People's Services.

A practical guide for campaigners—disabled people, families, carers and local groups.
(Updated version July 2012)[1]

{Editors Note:- **Introduction and excerpts only** of a 26 page document. Members who would like a copy and do not have anyone who can access a copy from the Internet please ring/write to us and we will provide you with one.}

Introduction.

This paper is intended to help campaigners—including disabled people and those supporting them—understand how the law can be useful to help fight cuts to valued services in their area. The paper is intended to be read by those who do not have a legal background. However, any individual or local group who is considering legal action in relation to actual or proposed cuts to services should not rely only on this paper but should seek specialist advice, including legal advice.

This paper has been written by Steve Broach and Kate Whittaker. Steve is a barrister at Doughty Street Chambers, and Kate is a consultant solicitor at Scott-Moncrieff & Associates, and also provides independent legal consultancy and training. Both Steve and Kate specialise in cases involving disabled adults and children and others who need care and support from public bodies. Before becoming a barrister Steve worked for a number of organisations in the voluntary sector supporting disabled children and adults and their families and was most recently the Campaign Manager of Every Disabled Child Matters campaign. Kate was at Irwin Mitchell from 2001 to 2011, before which she worked at a law centre. She is involved with a number of disabled people's organisations providing advocacy and other services, and is a Fellow of the Centre for Welfare Reform.

This guide is based on another recent paper that was written for the Every Disabled Child Matters campaign and was aimed particularly at parents, carers and local groups concerned about services for disabled children[2], but also considers some of the key issues for disabled children. Many of the principles set out in this guide will also extend to other groups in need of support from the state. It has been written and now updated because of the deep concern felt that many decisions are currently being taken to cut services for disabled people without proper consideration of what the law requires. These include high-level budget-setting decisions which reduce the amount of money available to support, decisions to reduce eligibility or otherwise restrict access to services and decisions taken to reduce individual care packages. All of these decisions must be taken lawfully - and the courts will intervene if public bodies neglect their legal duties when reaching these decisions.

That is why it is so important that everyone concerned with the rights of disabled people and their families to appropriate support understands what the law requires. The following publications go into more detail about the law that relates to disabled people:-

- 1) 'Community Care and the Law (5th edition), by Luke Clements and Pauline Thompson, published by Legal Action Group ('LAG') in 2011, hard copies are available from the LAG website (www.lag.org.uk) priced at £60.
- 2) 'Disabled Children; A Legal Handbook' ('the Handbook'), by Steve Broach, Luke Clements and Janet Read, published by LAG and the Council for Disabled Children ('CDC') in October 2010, hard copies are available from the LAG website priced at £40. Key chapters can be downloaded free of charge from the CDC website (www.ncb.org.uk/CDC)
- 3) 'Carers and their Rights: The law relating to carers' (4th edition), by Luke Clements, published by Carers UK in December 2010, hard copies available from the Carers

UK website. (www.carersuk.org) priced at £15, or can be downloaded free of charge.

- 4) 'Cemented to the Floor by the Law'[3], a paper by Steve Broach which gives more detailed coverage of the legal duties that may be used to fight cuts to disabled children's services, many of which apply equally to services for adults. Available to download free of charge at:- www.councilfordisabledchildren.org.uk/resources/our-partners-resources/cemented-to-the-floor-by-law

Individuals and local groups are welcome to re-use extracts from this paper and are free to copy it and send it round by email. If extracts of the paper are used in other publications please state the content was taken from this paper.

Extracts from the remainder of the document.

3. A right to services to meet their assessed needs. Once an assessment has been completed, the public body must then decide whether it has to take the next step - for instance to provide care services in a person's home.....

In relation to adult social care [31] there will be a right to have a particular need met if that need is determined as 'eligible' through application of eligibility criteria, used by local authorities to target services to those in the greatest need. All local authorities' eligibility criteria must follow a national eligibility framework, according to which an individual's needs are categorised as to the level of risk associated with each need if it is not met [32] The guidance sets out four bands of risk — 'low', 'moderate', 'substantial', or 'critical' - [Ed note, see last newsletter] for full details of criteria] and describes the level of impact on different aspects of independence and well-being that corresponds with each band. For example an individual might be assessed as having a critical need for support to be able them to access work or education, if without that support they would be unable to sustain 'vital involvement' in work or education. Or a person might have a 'moderate' need in relation to personal care or domestic routines, if without support to meet the need they would be unable to carry out several personal care or domestic routines [33]. Each local authority then sets its own threshold for the risk banding at which eligibility is triggered. The majority of local authorities currently set the threshold as 'substantial' so a person will be eligible to have their needs met if they would be at a 'substantial' or 'critical' risk if the need was not met. If their needs are classed as 'low' or 'moderate' then the local authority is not obliged to meet them, although councils are encouraged to do so in order to prevent low-level needs escalating into more serious ones. This approach was recently confirmed as lawful by the Supreme Court in *R (KM) v Cambridgeshire CC* [2012] UKSC 23.....

In relation to carers, eligibility criteria are applied to the needs identified from the carer's assessment, according to a similar banding of risk as with disabled adults' assessments. In this case the risks being considered are to 'the degree to which a carer's ability to sustain {the caring role} is compromised or threatened either in the present or in the foreseeable future by the absence of appropriate support' [40]. However, unlike with the determination of eligibility as to the needs of a disabled person themselves, when a carer's needs are categories as 'critical' (say) the local authority still has discretion whether or not to meet them, as there is only power, rather than a duty, to provide services [41]

In relation to health, although the law is less clear than for social services there will almost certainly be a duty for health bodies to ensure that assessed health needs of disabled people are met unless these needs are minor or trivial. Health bodies must in particular comply with the National Framework for NHS funded Nursing Care in England [42], which requires them to take a decision as to whether a disabled person has a 'primary' health needs, in which case the NHS will be responsible for meeting all their health and care needs [43]

- 4) **a right not to have services taken away.** Generally, and as noted above, the only way in which a public body can lawfully stop providing a service to a disabled person is if a re-assessment is carried out which shows that the person's needs have lessened or gone away. The only other way in which a public may be able to withdraw services to an individual lawfully is if it has raised the eligibility criteria so the individual is no longer eligible [44] - but even then there should be a re-assessment and a range of other legal issues will need to be taken into account before services can lawfully be withdrawn [45]

End of excerpts. There is information on consultations that is interesting.

References.

- 1 In this update the authors have sought to amend any outdated references and have considered some important recent judgements, including the Supreme Court judgements in McDonald and KM. The authors would be grateful if any errors or omissions could be brought to their attention by email at s.broach@doughtystreet.co.uk or kate.whittaker2@googlemail.com. Kate can also be contacted at Scott-Moncrieff & Associates, email kwhittaker@scomo.com
- 2 Available for free download from Every Disabled Child Matters campaign website, at www.ncb.org.uk/edcm/Using_the_Law_to_Fight_Cuts.pdf
- 3 'Cemented to the Floor by the Law' draws heavily from an earlier paper entitled 'Defending services for disabled children: using the law to fight the cuts', produced for the Community Care Law Reports Seminar in November 2010 and published at (2010) 13 CCLR 565. Some of the material in the current paper also comes from the Defending services for disabled children;. The authors are grateful to the Legal Action Group for permission to re-produce extracts from this paper.
- 31 See Clements and Thompson, Community Care and the Law (5th ed) for detailed coverage of all the adult social care powers and duties.
- 32 The national eligibility framework for England is set out in the FACS Guidance (Prioritising need in the context of Putting People First (2010—formerly known as the Fair Access to Care Services (FACS) Guidance; the key guidance for Wales is the UFSAMC Guidance.
- 33 Some of the risks to independence and well being classed as critical involve life-threatening circumstances or serious safeguarding concerns, but other than these there is no hierarchy of needs, so needs relating to social inclusion and participation, family roles and responsibilities, work and education should be seen as just as important as needs relating to personal care. Councils should make decisions in the context of a human rights approach, considering people's needs not just in terms of physical functionality but in terms of a universal right to dignity and respect. See here R (JM) v Isle of Wight Council [2011] EWHC 2911 (Admin); 15 CCLR 167, where a local authority's decision to only meet 'substantial' needs relating to the person's safety and ability to remain in their home was held to be unlawful.
- 40 Prioritising Need... (2010) para 99, and Practice Guidance to the Carers and Disabled Children Act (CDCA) 2000.
- 41 CDCA 2000 created a power (s 2) for local authorities to provide support services to carers, and to make these services available by way of direct payments and 'vouchers'. Guidance to the Carers Acts suggests that examples of services could be a short holiday for a carer to have time to themselves, driving lessons, taxi fares to maximise a carer's time, training, laundry or help with housework.
- 42 In Wales the equivalent guidance is set out in Welsh Assembly Circular 018/2010
- 43 See Clements and Thompson, Community Care and the Law (5th ed), Chapter 14 for more on health care duties.
- 44 In adult care this would mean the authority raising its criteria from (for example) 'moderate' to 'substantial', so that only individuals with more serious needs are eligible. These bands come from the 'Prioritising Need'/FACS guidance for adult services as set out above (the UFSAMC guidance in Wales). There is no equivalent to this guidance for children's services—but it is likely that children's services would be allowed by the courts to take a similar approach.

I tried to do a few Kiegels [Pelvic Floor Exercises] and found that after 3, I was using chest and shoulder muscles instead of pelvic floor muscles. Have to laugh when I think of doing Kiegels to improve sex life with all of my shoulder action!

PPSers comment to make you laugh but demonstrates how we use other muscles to help actions

Respiratory Item [see item under polio.today.org page 18]

Directed towards ladies but the topic is for all members. A discussion after the AGM between Sandy Yarrow and Hilary Boone revealed they were both taking off their bra early evening because it felt really tight by this time of day. When Sandy added, 'but it does not seem to make much difference' Hilary added, 'oh, wow, no you are right I have thought this but never said it out loud.' An email on our members email discussion list brought forward a few more responses that had also experienced this. One reply which made us smile was from one of our male members 'Does this mean I now have to wear a bra?'



We think that whilst our intercostals [between ribs] muscles have the ability to move our ribs a fair distance when we take a deeper breath, if we try and repeat this a few times our chest expansion measurement can decrease. By late afternoon we think what we feel is weakness in these muscles to expand and a lessening of our ability to breathe in as well as earlier in the day. Another comment is 'when I have a cough I can only cough very lightly and even then it really hurts'. Others raising issues on **breathing in** today on our members list.

We have requested comments from some professionals who have acknowledged receipt but mentioned due to holidays it might take longer than normal for a response. More next issue.

Brown envelopes that contain forms that need completing.

Something we all dread are those brown envelopes complete with forms of many pages that drop through our letter boxes. It is hard enough coping with daily life without the added stress that these cause. The changes to benefits will mean more forms will be coming our way.

Many years ago my daughter came in and saw I had been crying. I tried to make light of it, that I was fine. She looked round the room, saw the form sticking out slightly from behind the chair where I had thrown it, half read. She picked this up and without looking at me said 'Social Services have told me I am your official carer [news to me] so I am going to fill this in for you. Just answer the questions without comment.' [eek.. I am the Mum and I am being told what to do by my daughter, a role change!, but seeing the anger on her face I dare not comment]

She asked me basic contact details flipping through the huge document and after my response of age 50 she said 'and 60 by the time I get to the end of this form.' [I had to smile]

She turned the page, 'Is this a benefice of an ecclesiastical estate...., what on earth is that?' I explained it related to churches and she replied voice rising 'and how many folks live in a church!!!!'. A few pages later she asked 'Do you have an in-valid carriage!!!?' I pronounced the word correctly as invalid and her voice rising even higher said 'How many decades old is this form, if they mean mobility or electric wheelchair why not say so!'

Why I am telling you all this is because I saw her STRESS rise as she went through the form just like mine had, but her comments were making me smile and it took some of the stress away. Maybe trying to do this all myself had not been the best way of doing this. I needed to swallow my pride and ask others for help. Talking with other Users & Carers at meetings I attend in Lincolnshire we agree the following. It is less stressful if you and at least one other family member/friend/support group worker read and understand all forms and any guidance that comes with them, including the national and local government documents on the process. We know from personal experience how difficult this is but ... if you understand all the nitty gritty bits to each question then you can discuss your response with others to ensure it is phrased well. Yesterday a DWP employee visited to review my care component. I was able to give him info which he then worded for me to approve which was less stressful. Hopefully you wont have to appeal decisions but if you do then you will be able to discuss this fully with the support agencies that you contact to help with your appeal. We are very proud folks but asking and accepting help does not mean we are not capable and/or not coping, it means that we are managing our lives the best way we can without adding extra stress detrimental to our overall health..



Post-Polio News Service

RSS and Twitter feeds
Three times daily 'Newspaper'
Daily Digest via Email
www.post-polio.org.uk/

Overview by Post Polio News Editor Chris Salter.

Post-Polio News (ppn) an online news cutting service that specialises in news relating to polio and post-polio issues. Disability and other health related issues are also covered. News sources are many and varied including newspapers, magazines, medical journals and support group notices to name but a few.

As editor of this independent service I have total freedom over what news I choose to output. Post-Polio News therefore inevitably reflects a personal bias. Nevertheless, I try to report with an even hand and views expressed by the authors of the news items I include in Post-Polio News do not necessarily reflect those of my own.

Direct link from PSN Website front page.

Examples of entry below & pages 8, 12 and 13.

From Diary of a Benefit Scrounger

<http://diaryofabenefitscrounger.blogspot.co.uk/>

Links to 'Panorama' & 'Dispatches'
Just in case you missed last night's [30.7.2012] Dispatches and Panorama - both investigating the real stories behind the government's Work Capability Assessments - used to determine if a sick or disabled person is capable of working or not—here are the links to the shows.

Panorama :www.bbc.co.uk/programmes/b006t14n
Dispatches www.channel4.com/programmes/dispatches/4od#3388055

From Disabled People Against Cuts {DPAC}

ILF consultation dates

www.dpac.uk.net/2012/07/ilf-consultation-dates/

Dates are mostly full but you can also respond to the consultation through the DWP website www.dwp.gov.uk/future-of-ilf, you can also email your response to ilf.consultation@dwp.gsi.gov.uk

Or respond in writing to ILF Consultation Team, Ground Floor, Caxton House, Tothill St, London, SW1A, 9NA

Poliotoday.org

is published by the Salk Institute for Biological Studies. The website is designed to raise awareness of post-polio syndrome and to be a resource for polio survivors.

Breathing Symposium III, 2011, Dr. Joshua Benditt video presentation a MUST to watch for all members, specially those raising issues now. http://poliotoday.org/?page_id=877 [



Polioplace.org

An internet repository for medical and practical information, historical records and artefacts, launched on January 30, the 129th anniversary of Franklin D. Roosevelt's birth. A service from Post-Polio Health International. www.post-polio.org

[PSN are members of PHI]

See back page for info on new entry from PSN of our self assessment tool, My Polio Life.

Post-Polio Health International would like to thank Diane Young, daughter of polio survivor Grace Young, for granting permission to display her writings in this section. Grace, an occupational therapist, shared her professional knowledge tempered by her personal experience with the post-polio community from the late '80s until her death in 2009. <http://polioplace.org/> [followed by.....]

- [living-with-polio/living-polio](#)
- [living-with-polio/breath-control](#)
- [living-with-polio/carrying](#)
- [living-with-polio/joints](#)
- [living-with-polio/lifting-techniques](#)
- [living-with-polio/pacing](#)
- [/living-with-polio/posture](#)
- [living-with-polio/seating](#)
- [living-with-polio/kitchen](#)
- [living-with-polio/preventing-falls](#)
- [living-with-polio/house-remodeling](#)
- [living-with-polio/braces](#)
- [living-with-polio/canes](#)
- [living-with-polio/crutches](#)
- [living-with-polio/scooters-and-wheelchairs](#)
- [living-with-polio/essays#Grace%20Young](#)
- [/living-with-polio/gardening](#)
- [living-with-polio/readinghttp://polioplace.org/](#)
- [living-with-polio/cruising](#)
- [living-with-polio/mobility-aids](#)
- [living-with-polio/computer-comfort](#)

Management Committee [Trustees] and Operations Team

Management Committee [Trustees]

Chair - Position Vacant

Secretary - Hilary Boone - hilary.boone@poliosurvivorsnetwork.org.uk

Treasurer - Gillian Bryan - gillian.bryan@poliosurvivorsnetwork.org.uk

Trustee - Chris Salter - chris.salter@post-polio.org.uk

Operations Team

Membership Secretary - Gillian Bryan - membership@poliosurvivorsnetwork.org.uk

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

Administrative Support - Gillian Bryan - gillian.bryan@poliosurvivorsnetwork.org.uk

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

Membership Fees

UK Individual - £ 12.50 per year

Yearly fees can be paid by Standing Order.

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

Associate Membership - £ 10.00 per year

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.

Donations

giftaid it

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.
 - UK Taxpayers can Gift Aid their subscription and donated amounts.

The Gift Aid scheme. Charities can reclaim an extra 25% in tax on every eligible donation by a UK taxpayer. Between 6 April 2008 and 5 April 2011, the government will also give UK charities an extra 3% of all eligible donations. 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%).

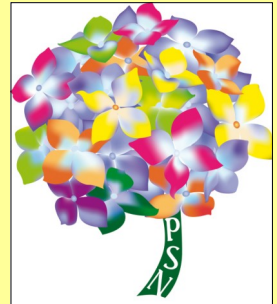
Polio Survivors Network

Registered Charity No. 1064177

Website - www.poliosurvivorsnetwork.org.uk

Email - info@poliosurvivorsnetwork.org.uk

P.O. Box 954, Lincoln, LN5 5ER, U.K.



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POST POLIO MATTERS because **WE'RE STILL HERE!**

Welcome to Polio Place

Explore the past, the present and help build a promising future for the world's polio survivors.
www.polioplace.org [a service from Post-Polio Health International]

The following was added in June 2012.

Self-assessment.

Post-polio advocates noticed that polio survivors experienced very frustrating visits to physicians when reporting new post-polio problems. Barriers included the limited amount of time a physician had for an appointment and the lack of experience of physicians in the early days. They weren't as skilled at asking the right questions.

Additionally, polio survivors knew they didn't feel well, but hadn't spent much time thinking about details. In fact, many survivors spent years pushing polio and its effects out of their every day thoughts. "[My Polio Life](#)" developed by the United Kingdom based [Polio Survivors Network](#) is designed to help survivors understand their polio and post-polio experience or "life." The authors provide an excellent introduction followed by a questionnaire that provides details which then provides insights to a polio survivor.

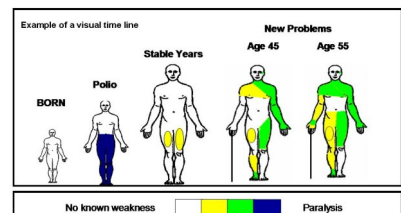
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PRESENT

'MY POLIO LIFE'

A Self Assessment Patient Questionnaire to assist you with collating information on your Life as a Polio Survivor



My Polio Life - A Self Assessment Tool

Created in May 2007 - Updated August 2011

POLIO SURVIVORS NETWORK

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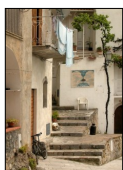
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