



The LincPIN

The **L**incolnshire **P**ost-Polio **I**nformation **N**ewsletter
Volume 6 - Issue 3 — November 2007

WebSite - <http://www.lincolnshirepostpolio.org.uk>

SEASON'S Greetings to All



**POLIO SURVIVORS
KAY and LINDA
Mum and Daughter
Pages 16/17**



JAZZ UP
YOUR
CANES
PAGES 18/19



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

Lincolnshire Post-Polio Network - UK Registered Charity No. 1064177

CONTENTS

3. Editorial 4. Message from Your Chair
7. British Polio Fellowship Expert Panel Report
8. Report on British Polio AGM and SW Regional Forum
10. Help, Help, help... Article from Jean Murdoch on Care Assessments, Direct Provision, Direct Payments and more
16. Polio Survivors, Kay and Linda, Mother and Daughter.
17. A few funnies. 18. Decorated Canes.
20. Non Paralytic Polio—Ernest W Johnson MD,
Editor, American Journal of Physical Medicine and Rehabilitation

DONATIONS

We would like to thank the following for their generous donations.

John Hartmann, Frank Knights, Frances Turnbull, Joanne Curtis, Yvonne Grosse, Lynn Hobday, Winifred Hyam, Margaret Lamb, Heather Chadwick, Viv Holland, Stuart Barnett, Jean Simm, Jim & Jenny Rayner, Sylvia Fortune, Post-Polio UK, Bridget Langdon, Ann Stone, Christine Darlington, Elizabeth Tilbury, Margaret Edmonds, Janet Corr, Dianah King, Mrs KF Preece, JD Witheridge, Mrs JE Shaw, Yvonne Webb, Pat Galvin, John De'Ath, PAB Peacey, Angela Johnson, Ivor Hills, John Doohan, Norman Jones, Sandy Yarrow, JM Deans, Lincoln Motorcise, Agnes Walker, Steve Clynch, Pamela Minnit, Cynthia Evans, Mrs AM Carmichael, Kathleen Burrell, Hilary Davies, J&VA Scrivener, Vin Murria, Steve Clynch, Pamela Minnitt, Cynthia Evans, Anne Carmichael, Kathleen Burrell, Hilary Davies, Agnes Walker and donated expenses from the Trustees and Operations Team. USA - Robert Price and Virginia Ottonello.

Lincolnshire Post-Polio Network - UK Registered Charity 1064177
Donations large and small towards our work are always welcome.

Lincolnshire Post-Polio Network,
*** NEW ADDRESS *** P.O. Box 954, Lincoln, Lincolnshire, LN5 5ER, U.K.
Tel: +44 01522 888601 Fax : +44 0870 1600840
[Do not dial first 0 if ringing from outside the UK]

Membership Information

Please make cheques payable to 'Lincolnshire Post-Polio Network'
Post to Membership Sec, UK, 13 Derville Road, Greatstone, New Romney, Kent, TN28 8SX
UK Membership - Life Member (LM) £150 or £5 x 30 months S.O. - Member £12.50 a year.
All UK Memberships payable by Standing Order - Forms from Membership Secretary.
Overseas Newsletters by Airmail.
European Membership - LM E300 - Member E25 a year.
USA - LM US\$375, Member US\$25 a year - Canada - LM C\$550, Member C\$40 a year
Other Countries please contact membership@lincolnshirepostpolio.org.uk for details.

Next LincPIN Newsletter - February 2008

Articles for publication 4th January by post or - newsletter@lincolnshirepostpolio.org.uk

Management Committee [Trustees]

Chair & Email List Facilitator - Mary McCreadie mary.mccreadie@lincolnshirepostpolio.org.uk
Secretary- Hilary Boone - hilary.boone@lincolnshirepostpolio.org.uk
Treasurer - Denise Carlyle - denise.carlyle@lincolnshirepostpolio.org.uk
Committee Members - Mary Kinane - mary.kinane@lincolnshirepostpolio.org.uk
Ruth Bridgens - ruth.bridgens@lincolnshirepostpolio.org.uk
BPF Expert Panel Member - Mary Kinane

Operations Team

Membership Secretary - Robin Butler - robin.butler@lincolnshirepostpolio.org.uk
Phone Team - Di Brennand (Leader), Margaret Edmonds, Judy Barter
Administrative Support - Sheila Dunnett, Pauline Butler, Barry & Olivia Branston
Internet Services Administration - Chris Salter - netadmin@lincolnshirepostpolio.org.uk

Editorial by Hilary Boone.

We pay for our PO Box mail to be redirected so that no-one has to go and collect it. When one member reported that she had not received a response to a letter we checked with Royal Mail to find that on some occasions mail had been put in our Box instead of being redirected and it was still there! So we know we have been having some problems with our Post, but are there more we don't know about or are nearly all of you experiencing Polio Brain Fog! Do you too need to have regular serious talks with the Filing Clerks in your brains about their filing and retrieval methods. I am sure you will agree with me that it is not really fair to us that our 'Filing Clerks' put items in the wrong file or file things away in storage before completed. I have had to resort to adding a white board to my office so that I can list the important 'to do' items and check this person has done their job properly before I rub it off.

If you would like to join others rebutting the **'Survivors of childhood polio do well decades later as they age' [a] 'Polio Survivors faring well' [b] and 'No polio effects' in later life' [c]** Media headlines I reported last year in an article titled 'Polio Survivors throw doubt on Study' [The 15 year Mayo Clinic Study] then we need a photocopy of your completed Self Assessment Questionnaire to send to Dr. Walter Bradley who along with other delegates at the April Miami PPS Conference, Dr. Walter Bradley felt it was important to publish a paper that presents the histories of a group of patients with post polio syndrome as a counterbalance to the papers from the Mayo Clinic and has agreed to take on this task. This is not a scientific survey but will place in the medical literature examples of our experiences. Your copy will be made anonymous before posting to Dr. Bradley.

Our sincere condolences go to our Phone Team Leader, Di Brennand and her family. Her husband, Stuart died peacefully in his sleep on the 28th July 2007 with Di and their girls at his bedside. Our thanks to Judy and Margaret for standing in for her when needed. Remember if you are not on the Internet and need some help with PPS issues give these gals a call. They do a very important job and are only too pleased to help others as they were helped when they first rang.

Two newsletters ago I published an article 'Pacing our emotional stress' by Sandra Cuadra, a PPSer in Florida who came to our Wedding. In this she stated that she found the stress of attending funerals is to high a price to pay and that she prefers to remember the dead as they were in life. Sadly I have to tell you she passed away on September 15th.

You will notice that I am no longer justifying the paragraphs in Newsetters. I liked them to look neat and tidy but on reading the guidelines from the Blind Society learned that it is easier for partially sighted people to read like this. If you still find this difficult to read then do let me know and I will make a special larger print copy for you.

Copyright of material published in the LincPIN is retained by The Lincolnshire Post-Polio Network and/or the original author(s). Reproduction and redistribution of any material via any media requires permission from The Lincolnshire Post-Polio Network and where applicable, the original author(s). Where permission is given, original material must include a credit to the LincPIN; material from other sources should credit the original publication.

MESSAGE FROM YOUR CHAIR Mary McCreadie

The AGM in September saw a goodly number of members attending, which was very gratifying. For a group such as ours, it is often particularly difficult for members to attend, whether because of health problems, or simply a matter of distance. Our membership is remarkably spread out across the country (and indeed, the World!) and we were delighted that so many people turned up - some of whom had travelled several hundreds of miles to be with us.

The minutes of the AGM will be found attached with this newsletter, but it is important for me to say here that from the nominations received, the following Trustees were nominated, proposed and voted in:

Mary McCreadie	Chair
Hilary Boone	Secretary and Founder
Denise Carlyle	Treasurer
Mary Kinane	Committee member & BPF Expert Panel Member
Ruth Bridgens	Committee member

I'd like to take this opportunity to thank Di Newman for her time as a committee member, and wish her well in her future activities with Cambridgeshire ME Group and Neurological Alliance.

New Trustee - We are delighted to welcome Ruth Bridgens to our committee. Ruth has been a member since 1998, and you may remember her article on post-polio syndrome entitled "We aren't dead yet" was featured on the front page of our June 2005 LincPIN. Ruth has very kindly written the following paragraph to introduce herself to you all:

"After having troubles getting a PPS diagnosis in the 1990s, I saw an ad for a new Open University MSc in Science on understanding controversies in medical research, which sounded like it might be interesting and helpful. Many years previously, I had received a BA in art history and biology from the US, and an art degree in the UK. During the MSc, I carried out a small questionnaire on PPS symptoms, and discovered that most of the participants identified with a symptom, muscle fatigue, which was hardly ever included in medical PPS surveys. From the MSc, I moved on to an ESRC-funded PhD in medical sociology at Cardiff University (2001-5), "Narratives of polio and post-polio syndrome" which combined a larger PPS survey with 31 interviews about people's experiences of living with polio and PPS. Besides people's experiences, I tried to understand the medical attitude to PPS and how the research has tended to look at polio and PPS in a somewhat narrow way, excluding some experiences and symptoms. While writing the PhD, I had a commentary to an article on PPS published in the BMJ (2005) (which I instigated) widening the view of PPS to include people who recovered well and did not necessarily have obvious physical after-effects. Recently I had a letter published in the *Journal of the Peripheral Nervous System* (2007) about flaws in the reporting of the recent Mayo clinic follow-up study. I have given papers at numerous sociology conferences and have had several articles published."

Thank you, Ruth! I am sure that Ruth's experience and expertise will be a great help to us all.

The AGM proved to be quite an experience. It was my first AGM in any official capacity – and as such, did cause a few butterflies to run riot around my insides! Once the business of the AGM was concluded, we were delighted to welcome our first speaker of the day, member Jean Murdoch. Jean is a great lady who has been researching the vagaries of Direct Payments for Care Packages because of her own problems. Her talk was most entertaining and extremely interesting. It is clear that there are a number of differences in how Local Authorities view their responsibilities. Although Jean's work relates mostly to Lincolnshire, she was able to give plenty of information on finding out what your entitlements are under the law, and how to approach your local authority. All the details can be found on pages 10 to 15 of this newsletter.

After her talk, Jean answered various questions from the audience, until it was time for lunch. The food, which was purchased by Hilary Boone, was well up to the usual excellent standard, and I would like to say a huge 'Thank You!' to her as well as to Sheila Dunnett and Francis Turnbull, who did a wonderful job of setting out the buffet, and making sure everyone had plenty to eat. Thank you too, for organising and distributing tea and coffee, and for so cheerfully tackling the mammoth tidy-up when the meal was over. You made light of the work you did, and we are very grateful to you!

You will remember that we had arranged for various health professionals to hold workshops in the afternoon, so that members could discuss the problems they had had in getting their PPS properly assessed; obtaining the correct advice or aids etc. We were really looking forward to the workshops, feeling that a lot would be learnt on both sides, but regrettably, each and every one of the health professionals who had agreed to come, dropped out at the very last minute, leaving us with no opportunity to replace them. But what appeared initially to be something of a disaster turned into a very informative and interesting afternoon discussion amongst members and Trustees, covering a wide range of topics, and allowing a freedom of expression that might otherwise have been a little difficult! We heard several stories of members still being told that PPS 'doesn't exist' and having less than helpful appointments with NHS professionals. Wouldn't it be nice if we could wave a magic wand, and find that the situation changed overnight? All we can do is keep on spreading the word – keep passing information to our doctors, nurses and physiotherapists, until the message begins to sink in. LincsPPN has continuously campaigned for diagnostic tests such as manual muscle testing, lung function, sleep-testing etc., to be reviewed. We know that the tests are basic, and often insufficient to pick up the subtleties of declining function in PPS. Getting the medical profession to accept the truth of what we say and actually do something about it, is an uphill struggle. But we will prevail!

Responding to requests for information

Last newsletter we sent you out a slip to fill in with your current details. Due to a series of problems beyond our control, the newsletter was sent out very late, and you may have thought we didn't need the information any more. But we

DO need to hear from you - even if none of your details have changed. So far we have received some 20 forms back, and we really need to hear from the rest of you so that we can get our membership list bang up to date. So please - get those forms back to us! If you no longer have the form, please would you drop a note of your full name, address, telephone number and e-mail address to P.O. Box 954, Lincoln, Lincolnshire, LN5 5ER, U.K., or send it in an email to the address at the bottom of this page. Thanks in advance for your help in this.

During the winter months, we shall be attempting to sort out this problem by telephoning everyone on our Membership list, but if in the meantime you would assist by remembering to fill in the form, you would be doing us a great service.

We look forward to another year of hard work, in our efforts to bring information about the diagnosis and management of PPS to our members, Health Professionals, and of course, to the general public.

You can't always judge a book by its cover!

I was rolling back to my car today, with my wheelchair festooned with carrier bags full of shopping, when I saw a group of fairly scruffy youths skateboarding in the car park – a bit too close to my car for peace of mind. I don't know if like me, you feel a touch wary of lads like these, but I found myself mentally gearing up to combat any trouble. But just as I got to the car, three of them zoomed up on their skateboards, smiled broadly and in very refined tones asked if they could help me in any way!

With considerable relief, I smiled back and said no thanks, but how nice it was of them to ask. They hung about and chatted whilst they watched me use the hoist to get the wheelchair back in the car, and as I pulled out of the car park demonstrated some pretty nifty moves on their boards. Thanks lads, you made my day!

Learning to accept help gracefully is probably one of the most difficult things to accomplish. We don't always need it – as demonstrated above – but sometimes we do, and are maybe a bit too proud to admit it. It's taken me a number of years to realise that there's really no percentage in trying to do everything myself all the time. There are occasions when a little bit of assistance is worth its weight in gold as far as pain, anxiety and energy levels are concerned! I got into a situation the other day when I found that (*after* I'd filled up with diesel) I hadn't noticed that there was an enormous step into the garage shop. I didn't have any cash with me and was going to pay by card. But there was absolutely no way I could get into the place. Not knowing quite what to do, I saw a chap coming towards me. 'Problem?' he asked. I explained – and with no more ado, he put a beefy arm right around me, and lifted me bodily right up the step! He waited for me to finish paying, and helped me back out again. He couldn't have been kinder – and when I thanked him, he said it gave him 'a real kick' to be able to help. It seems to me that accepting help can actually be a two-way street, and maybe we do as much for the helper as they do for us.

Mary McCreadie - mary.mccreadie@lincolnshirepostpolio.org.uk

British Polio Fellowship - Expert Panel

In January, The BPF's Expert Panel met for the second time and fine-tuned the key issues needing to be addressed, with detailed discussion papers on a number of issues; Terms of Reference were presented by the BPF so that the Panel would be clear about its remit. It did not take long for the Panel to acknowledge that there is an identifiable and real need amongst polio survivors in the UK to access medical treatment and services for those with long-term conditions which are not currently available to them.

By May 2007, it was agreed that a clear working definition of PPS needed to be agreed before other crucial issues could begin to be addressed with any effectiveness. Some robust discussions have taken place about the nature of PPS, and the panel has, by September 2007, finally agreed its top level definition. This was not an easy process, with varying views being expressed about how we could define the kinds of problems which are all too familiar to our members, i.e. fatigue, including muscle fatigue. I believe that the Panel is in no doubt that it has a clear objective to make recommendations which can improve the lives of those living with PPS in the UK, through improved services, and in order for this to happen three sub-groups were formed early on with the added benefit than anyone on the panel could join in on the discussions of any of the sub-groups. These sub-groups cover the following broad areas: PPS-Definition, Campaigns and Research.

As mentioned above, the panel has now agreed on a top-level, working definition of PPS, which will be recommended for use in a number of settings relating to the dissemination of information about PPS nationally. The next step (currently being taken) is the development of a more narrative piece which supports this top-level definition and which it would be useful for GPs to be able to access when patients come to them initially for help with PPS symptoms, as well as for other clinicians to have ready access to. It is already agreed that while having specialist centres with improved diagnostic services is a good thing, it is necessary at the same time for GPs and specialists within particular NHS trusts to be equipped with better responses for patients, and for a patient pathway to reflect this. Dr Steve Sturman, Consultant in Neurology & Rehabilitation Medicine at Birmingham City Hospital, is an effective champion on PPS issues and will be feeding back to the panel over the next few months on diagnostic issues, along with Dr Ruth Bridgens, PhD, who has had a crucial role on the Panel from its inception.

To date there have been four key meetings held in London, face to face, with much discussion and work also taking place behind the scenes, both via key staff at the BPF's central office, and via a new e-mail list which was set up for panel members to exchange information and views. It was at an early stage that it was decided to refer the crucial area of Orthotics back to the BPF for consideration for action as a separate and important project. It has already been noted that the areas of orthotics and equipment (such as wheelchairs) do not necessarily need to be lumped together, although one of the sub-groups – that of Campaign Issues – could indeed include the issues of adaptations and equipment in any recommendations it eventually makes.

Mary Kinane, B.A. (Hons)
Trustee, Lincolnshire Post Polio Network,
Member of BPF Expert Panel

September 2007

Report on British Polio AGM and SW Regional Forum

At our AGM, member Lynn Hobday suggested that it might be a nice idea to include a few paragraphs in our newsletter about what the British Polio Fellowship is doing these days. As many of us are also members of the BPF, we are happy to oblige.

The BPF held their AGM the week after ours, at the Sheraton Hotel near Heathrow. LincsPPN members – Pat Galvin, Paul Stanton and I - attended. Apparently, I was sitting right behind Pat, and we even had some conversation – but neither of us realised who the other was until a couple of weeks later!

In the morning, instructional sessions were held for those in official positions in their branches. A very nicely presented lunchtime buffet followed, and the AGM began at 2.00p.m. It was fairly volatile initially, as Jackie Ball unveiled their new logo. This has been changed to the words 'british polio' in rather pale shades of green and blue, beside a picture of three circles. It was felt that the word 'fellowship' was not generally understood by the public, and was a bit old fashioned. However, many members objected to 'Fellowship' being left out, as well as the use of lower case lettering for 'british polio'. It was made clear that the BPF will include the word 'fellowship' everywhere else in their literature except on the front pages. It was considered that lower case lettering was more modern and eye-catching.

After Sir Bryan Askew's opening speech, Treasurer Aidan Smith gave his financial report followed by a talk from Leo Redpath about the introduction of a new internet site where members can talk via chat forums, and have access to information on benefits and PPS as well as take part in surveys. Leo Redpath gave a very constructive presentation about how the idea would work, and you can find out all about it at www.forum.britishpolio.org.uk

The members were then asked to vote on changing the BPF's Memorandum and Articles (which was accepted), but another vote to change the structure of the Trustee Board did not succeed.

Next year's AGM will be moved up country to Blackpool, and will be held on 20 September.

South West Regional Forum

On 7 October, the BPF held its South Western Regional Forum at BAWA, in Bristol. The meeting was fairly informal, and offered a great chance to socialise. LincsPPN and BPF members Dinah Foweraker, Ruth Bridgens, Paul Stanton and I attended and it was great to catch up with all the news. After a welcome from Regional Chair Pam Jones, a talk about PPS was given by Dr. Steve Sturman, who also sits on the BPF Expert Panel. I agreed whole heartedly with much of what Dr. Sturman had to say about the diagnosis and management of PPS – which incidentally, reflects everything LincsPPN has been saying for years! - but what disturbed me was his assumption that the rest of the medical profession think the same way. As so many of us know, the current level of understanding makes assessment, correct diagnosis, and treatment of any kind very difficult to achieve. It's all very well telling people to 'get themselves properly assessed', but where and by whom?

Dr. Sturman went on to say that it's a good idea to spend the winter months in a warm climate. This is a nice one to dream about – but practical? For the majority of us, I think not!

His closing words I found most interesting: 'Evidence shows that people with PPS get more out of their muscles and joints than would have been expected. They seem to remain independent in the long term to a degree that is contrary to expectations.'

Could it be that we are so used to being determined to do what we need to do, to manage when there's been no help from health professionals or the Welfare State, and to help ourselves regardless of the difficulties that it extends to our recalcitrant muscles and joints as well? I wonder....

If anyone has any local BPF information that they would like added to these pages please let us know by the date advertised on page 2.

Lord, grant me the serenity to accept
The things I cannot change,
The courage to change
The things I can,
And the wisdom to hide
The bodies of Doctors I shot
When they said,
"You're perfectly healthy,
It's All In Your Head."

Three old guys are out walking.
First one says, "Windy, isn't it?"
Second one says, "No, it's Thursday!"
Third one says, "So am I. Let's go get a beer."

Now that I'm older (but refuse to grow up). Here's what I've discovered:

1. I started out with nothing and I've still got most of it
2. My wild oats have turned into prunes and All-Bran
3. I finally got my head together; now my body is falling apart.
4. All reports are now in; life is officially unfair.
5. If all is not lost, where is it?
6. It is easier to get older than to get wiser
7. It's hard to make a come-back when you haven't been anywhere.
8. The only time the world beats a path to your door is
When you're in the bathroom.
9. If God wanted me to touch my toes,
He would have put them on my knees.
10. When I'm finally holding all the cards,
why does everyone decide to play chess?
11. It's not hard to meet expenses....they're everywhere.
12. The only difference between a rut and a grave is the depth.
13. These days I spend a lot of time thinking about the hereafter
...I go somewhere to get something and then wonder what
I'm here after.

HELP! HELP! HELP! HELP! HELPPPPP.....

Over recent years the Government has found that it is very costly to provide residential care for people who can no longer manage to look after themselves at home, and those who have chronic disability and the elderly place an increasing financial strain on the NHS.

Government has decided that it is much more cost effective to provide appropriate support for people in their own homes and, of course, people prefer it. How much better to use public funds to prevent or slow physical deterioration than having to use precious funds to treat the consequences with the NHS.

The Department of Health sets out the guidelines for both health care, provided by the NHS, and social care, mainly provided through councils by social services. Funding for social care is shared between the Department of Health and Council Tax.

If you use the N.H.S.'s help, the Department of Health would rather you used Social Care to reduce your need for help from the NHS. If I had not asked for and received Direct Payments eight years ago I would have tried to struggle on and failed, be considerable more disabled now, need much greater NHS support and have no quality of life.

What is the support provided by Social Care?

Currently there are two forms of support provided through SOCIAL SERVICES.

1. Direct Provision - where the Council will arrange basic care such as help to get up, washed dressed, fed and put to bed.
2. Direct Payments - where the Council send you the money every month and you employ people to meet your care needs. The money has to be accounted for.
3. A third - Individual Budget - is a scheme being piloted at the moment by 13 councils and is likely to become available to all next year.

<http://individualbudgets.csip.org.uk/index.jsp> [CSIP - See bottom page 13]

How to get Social Care Support?

You will need to have a Social Services assessment. This is not a medical assessment; it is an assessment of your need for support to live independently.

It is essential to prepare for the assessment. It is not likely that the Social Worker will offer you everything you may need. If you are prepared by reading up beforehand the policies and guidance available from the Department of Health together with your own council's policies (available on their websites), you will then know the sort of support to which you are entitled.

Each council has its own form of assessment but it should follow the basic principles as laid down in Fair Access to Care Services.

Preparation

You will be asked for your diagnosis and symptoms; prepare a list of your symptoms so nothing gets forgotten, also a list of your medication. The Social Worker will probably have very little medical knowledge. If you see a consultant,

speech and language therapist, orthotist, physiotherapist or any clinician, either on the NHS or privately ask them to write you a short note stating the symptoms they treat and support you need. Your GP may be willing to do the same. The social worker will automatically accept what clinicians say, but may not accept what you say.

The Social Worker will probably visit you at home and may go into every room of the house to evaluate how you are coping and if you need a visit from the Occupational Therapist who will assess equipment you may need.

Do not get too excited - they do not supply much, but you may be entitled to a Disabled Facilities Grant for alteration to your property for access and use of kitchen and bathroom.

If your house is usually untidy because you cannot manage to keep it tidy, do not tidy it or get someone in to do this. This is not your mother-in-law visiting so you want your home looking as it normally does, it is someone who will decide the level of support you need. If you say you have great difficulty in washing up this is not confirmed if your kitchen is spotless. If you say you have great difficulty in making the bed this is not confirmed if it is a neat as a pin.

This is an assessment of you. If you have support from a partner or family, social services will want to know. Discuss with your family or partner beforehand what support they really want to give and what support could be provided by people you employ. If family is willing to support you, why should Social Services?

Family who are carers have often told me that over the years their relationship with the person they care for, their husband, wife, mother or father has gradually disappeared and changed into carer and cared for. Keep your relationship with your family and partner as just that - do not allow them to turn into *full* time - long term carers.

After you have read Fair Access to Care Services you will realise that risk to independence is at the heart of the assessment, Risks to autonomy, health and safety, ability to manage daily routines and involvement in family and wider community life.

Prepare a list of all the everyday living tasks you cannot do **easily**. Do not forget to add tasks that someone else is now doing for you. Most councils will not provide support for cleaning, but on health grounds they are required to ensure hygiene can be maintained in say the kitchen and the bathroom.

The most important thing is you have to be really honest with yourself. Can you make your bed? If you answer "Yes with difficulty" that answer equals no support. If making your bed means hopping around on crutches and having to rest three times before you finish exhausted an hour later - then the answer should be no.

Do not minimise the amount of pain you experience in doing everyday things. If you say by really struggling you can manage, then you will not get the support to which you are entitled and you health will deteriorate faster than it needs to.

You can only be honest with Social Services if you are first honest with yourself. When I was asked 'do you have good days and bad days', I replied 'No - I have bad days and worse days', something I seldom admit, particularly to myself. When people ask how are you, I usually reply 'I'm fine' - but not to Social Services, I tell

them how I really am.

Preparing for the assessment is very depressing. It brings to the fore of your mind just how much you can no longer do and have had to give up, perhaps how much you rely on others. However if you do not do this preparation it is not likely you will get the help to which you are entitled.

How much will I have to Pay

Many people worry how much they will be asked to contribute towards their care and so do not ask for support. You can work it out for yourself after you have read the government's Fairer Charging Policy and your local council's Fairer Charging Policy which will differ from council to council but must follow the government guidance. Some councils do not charge at all, most do. Those on Income Support or Pension Credit will pay nothing.

Briefly, if you have a partner you are assessed as an individual, not as a couple. Your total income from all sources (except earnings) is added up, and allowance of the equivalent of Income Support or Pension Credit is deducted. House costs such as rent or mortgage, council tax and some heating costs are deducted and then all your Disability Related Expenditure is deducted.

Disability Related Expenditure is anything you purchase because you are disabled that you would not purchase if you were able-bodied. This includes any equipment, large and small, dietary supplements - anything and everything that you would not have to pay for if you were able-bodied. If you really think about it and list everything it will reduce your charge even further, perhaps to nothing, If you do not wish to have a financial assessment you can just pay the maximum your council has laid down.

You are now prepared

You are now ready to contact social services and request an assessment. Councils have a statutory duty to provide an assessment for those who are disabled, but it is polite to ask.

J. H. Murdoch, Member and Direct Payments user. Lincolnshire.

Preparation Leads to Success

[Editors note - Jean has prepared the following notes to help you access the articles that should help you prepare for your Assessment

The LincsPPN fully appreciate that this is not going to be easy or happen overnight [personal experiences]. You WILL need some support to go through all this regardless of how strong you have been in your past life. Whilst it is easy to help someone else deal with all this it is tough doing it for yourself and seeing it all in black and white.

We fully appreciate that not all members are on the Internet but it is likely that you have a family member that is who can help you download the information you need. If you do not have anyone to help you with this then please get in touch either by letter or ring the Phone Team Duty Member and/or contact the British Polio Fellowship on 0800 018 0586

The best Website for Public Services all in one place is
www.direct.gov.uk

There are two allowances that the Government provides:-

1. Disability Living Allowance for those under 65 and
2. Attendance Allowance for those over 65.

1. Disability Living Allowance - sometimes referred to as DLA - is a tax-free benefit for children and adults who need help with personal care or have walking difficulties because they are physically or mentally disabled.

You may get Disability Living Allowance if:

- you have a physical or mental disability, or both
- your disability is severe enough for you to need help caring for yourself or you have walking difficulties, or both
- you are under 65 when you claim

You can get Disability Living Allowance whether or not you work. It isn't usually affected by any savings or income you may have.

http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/DG_10011731

Or ring 0845 7224433 for application forms, have your National Insurance Number to hand.

2. Attendance Allowance

You may get Attendance Allowance if:

- you have a physical or mental disability, or both
- your disability is severe enough for you to need help caring for yourself
- you are aged 65 or over when you claim

Attendance Allowance is not usually affected by any savings or income you may have.

http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/DG_10012425

Independent Living Fund.

Another fund that has been established to help disabled people is the Independent Living Fund.

Set up as a national resource dedicated to the financial support of disabled people to enable them to choose to live in the community rather than in residential care. You need to be under 66 years of age to apply.

<http://www.ilf.org.uk>

Government legislation - Guidance for Councils.

To read the guidance for Councils provided by Government Legislation you will need to go the Department of Health Website.

<http://www.dh.gov.uk>

N.B. When you read any of these documents when the Department of Health says 'should' it means the Council must do as it says, and when it says 'could or may' means the council has a choice.

Direct Payments

Direct Payments are cash payments made in lieu of social service provisions, to individuals who have been assessed as needing services.

<http://www.dh.gov.uk/en/Policyandguidance/Organisationpolicy/financeandplanning/Directpayments/index.htm>

Essential Reading

Direct Payments Guidance Community Care, Services for Carers and Children's Services (Direct Payments) Guidance England 2003

[This is 68 pages and not available in hard copy.]

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4096246

Useful Reading

A Guide to receiving Direct Payments from your local council: a route to independent living (August 2007) [84 pages]

Available as hard copy Product Number 282882

from DH Publications Orderline, PO Box 777, London SE1 6XH

Telephone: 0870 155 54 55 (8 am to 6 pm Monday to Friday)

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_078092

Other useful reading under Social Care:

1. National Service Framework for Long-term Conditions
http://www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/Longtermconditions/Long-termNeurologicalConditionsNSF/DH_4128647
2. National Service Framework for Older People (if over 65)
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4003066
3. Independence, choice and risk: a guide to best practice in supported decision making
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_074773

The Assessment Process and how the Charge for your care is calculated. Department of Health Website www.dh.gov.uk

Type in FACS - Select Fair Access to Care Services Guidance 1st January 2003 and read guidance on eligibility criteria for adult social care, also read the Practice Guidance - Questions and answers.

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009653

Type in Fairer Charging - Select and read Fairer Charging Policies for Home Care and other non-residential Social Services August 2002 [43 pages]

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4005701

and September 2003 [41 pages]

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4117930

For Local Social Services Information Leaflets and Policies

Most are online. Search for the name of your County.

E.g. Lincolnshire County Council - <http://www.lincolnshire.gov.uk/>

Leaflets and Publications. These are available in print copy.

<http://www.lincolnshire.gov.uk/section.asp?catId=2559>

Select Direct Payments Policy

<http://www.lincolnshire.gov.uk/section.asp?catId=2453>

Select Fair Access to Care

<http://www.lincolnshire.gov.uk/section.asp?catId=2443>

NEW DOH Organisation

Care Services Improvement Partnership - CSIP www.csip.org.uk

We are part of the care services directorate at the Department of Health. Most of our staff and services are based in eight regional development centres spread all over the country. These regional bases, hosted in local NHS organisations, mean that we can respond more flexibly to people locally, regionally and nationally.

We work with the statutory, voluntary and private sectors to make the best use of the full range of resources and expertise available to improve services.

We aim to:

- provide high-quality support to help services improve
- help services to put national policies into practice and provide them with a link into government
- involve people who use services and their carers in all improvement work
- share positive practice and learning about what works and what doesn't
- pass on research findings to organisations to help them improve services, and
- encourage organisations to work in partnership across all sectors.

Polio Survivors, Kay and Linda, Mother and Daughter.

My daughter and I had a lovely visit from Mary McCreddie recently and spent a few happy hours together. During her visit, Mary suggested I might like to write an article for the magazine, about my experience of Polio and I do hope you will find the following of interest.

Linda, my daughter, was about 5 in the autumn of 1953 when she contracted Polio, we believe, at a children's dancing display in Bristol. At the time, the disease was prevalent in the area. In those days one could just pop around the corner to visit the family doctor, without an appointment, and find just a handful of people in the waiting room!

When I spoke to the doctor I said I had left Linda in bed, because I thought she had a touch of flu, whereupon he started asking me a lot of different questions. He explained that a year before, one of his patients (a young mother with a very young baby) had been crippled for life by the disease, due to the lack of a swift diagnosis - he wasn't about to let that happen ever again. Doctor said he would be round to the house in half an hour - and he was.

After examination he said *"I am very sorry to tell you Linda has Polio and I must send her to Ham Green Isolation Hospital, immediately"*. My instant reaction was concern for my 18 month old son, Alan, and whether he too might have been exposed to the infection. (We later realised that he had been protected by the drug Streptomycin, which had recently been given to him as a protection against measles. We understood that the same drug had been prescribed for the Queen, when she visited Australia, to protect her from the Polio virus.) [Editors note - this might have been thought at the time but there is only one protection against the polio virus and that is polio vaccine.]

That was on a Thursday and by Tuesday I had to be admitted to the same hospital with pains which indicated I, too, had contracted Polio. I was not allowed to see Linda - she was in the children's ward, whereas I was placed in a cubicle designed for TB patients, with one other lady.

Here Linda and I remained for three months over the Christmas period. It was bitter cold in my little cubicle and we were allowed no heating. One side of it was completely open to the four winds, although a veranda with a roof protected us from the snow and rain. My only warmth came from a mountain of blankets piled onto me!

Linda says she vividly remembers hearing carol singers somewhere outside their window, but they were not allowed anywhere near these isolated children and she couldn't see them. She also recalls her father waving to her from behind a large glass panel; she dearly wanted a cuddle and cried when she was told he couldn't come in

As time went on and Linda was allowed outside the ward, she was given a small fairy cycle for exercise. She would come past our cubicle and I was so thrilled to see her waving to me and notice that she seemed to have no lasting damage to her limbs.

After Linda was discharged I remained in the hospital for another month, as I had two small children at home and my husband was unable to look after all three of us.

I eventually came home wearing a calliper on my left leg. As we then lived in a maisonette, I remember the difficulty I had in negotiating the two flights of stairs, which I did mostly on hands and knees!

I was treated by the Chief Orthopaedic surgeon in Bristol for the next three years and, mercifully, met up with a local osteopath who was my saving grace as he was able to get me walking again and relieve the dreadful back pain I had been suffering.

I have never recovered the 'spring' in my step and was unable to dance or pursue my sporting activities again, although, after many years, I did learn to swim and thoroughly enjoyed the sense of freedom and accomplishment.

Now in my 89th year, I am grateful that I have been able to live a reasonably normal life due, in no small part, to the prompt diagnosis by my family doctor all those years ago. I owe him so much.

Kay Preece, Somerset, U.K.

An elderly couple had dinner at another couple's house, and after eating, the wives left the table and went into the kitchen. The two gentlemen were talking, and one said, "Last night we went out to a new restaurant and it was really great. I would recommend it very highly.

The other man said, "What is the name of the restaurant?"

The first man thought and thought and finally said, "What is the name of that flower you give to someone you love? You know... the one that's red and has thorns."

"Do you mean a rose?"

"Yes, that's the one," replied the man. He then turned towards the kitchen and yelled, "Rose, what's the name of that restaurant we went to last night?"

Morris, an 82 year-old man, went to the doctor to get a physical. A few days later, the doctor saw Morris walking down the street with a gorgeous young woman on his arm.

A couple of days later, the doctor spoke to Morris and said, "You're really doing great, aren't you?"

Morris replied, "Just doing what you said, Doc: 'Get a hot mamma and be cheerful.'"

The doctor said, "I didn't say that. I said, 'You've got a heart murmur; be careful.'"

A psychologist returned from a conference in Aspen lodge, where all the psychologists were permitted to ski for free. Her husband asked her, "How did it go?"

She replied, "Fine, but I've never seen so many Freudians slip."

Q. Where does Santa stay when he's on holidays?

A. At a Ho-ho-tel!

Q. What does Mrs. Claus sing to Santa on his birthday?

A. "Freeze a jolly good fellow."

Q. What did Santa say to Ms. Claus when he looked out the window?

A. Looks like "rain", "Dear"!

Q. What goes oh, oh, oh?

A. Santa Claus walking backwards!

Q. What do you call someone who doesn't believe in Father Christmas?

A. A rebel without a Claus!

DECORATED CANES

I turned to making my own sticks for three reasons. Firstly, I need a staff more than a stick, like a hiker does, to put more effort from my arms into walking and take some effort from my legs. This works well for me but I need a fairly thick handle too as gripping a thin handle soon becomes painful. The combinations is not easy to get off the shelf so I started to make one and thought.. 'Why not make my own stick a bit more interesting while I'm at it? This would make it something I'm actually pleased to use, rather than just have to use.

I have learnt a lot in the process and tried more materials (I have sticks with antler handles, regular height sticks) and met lots of people too. It is amazing just how many people open conversations about the stick I'm using. I plan to carry on experimenting with new styles and materials, (so far I have not made two sticks even remotely the same) and meeting new people.

If anyone out there wants to talk sticks (I would be fascinated to hear of anyone else's sticks, tricks and styles) then they can reach me at s.gray374@btinternet.com or ring or write to the LPPN and they will pass the message on to me.

Stuart Gray - s.gray374@btinternet.com

I had to take my dog to the Vet the other day, and when I got there, found that they were having a Macmillan Coffee Morning. So naturally, I stayed, joined in the fun and chatted with everyone. Another disabled lady happened to be there, who delightedly showed me her new and very pretty walking sticks, which were those paisley patterned ones you can now get. I (with a grin!) complained that it wasn't fair – you can only get the type of elbow crutch I have to use in grey, grey and more grey!

The Veterinary Nurse heard me, and promptly whisked my elbow crutch away and disappeared with it. Some minutes later she returned – and it was transformed! Pale lilac with navy blue paw prints – cool, or what? She'd simply wrapped it up with a fancy type of animal bandage called Vet wrap, which sticks to itself to make a very firm bandage for a wriggling, injured quadruped. (I'm quite sure the colours and patterns are to please owners rather than the animals!) Of course, it caused a great deal of amusement with everyone, and I went home more than happy. But there's a knock-on effect I hadn't expected – and that is, that it's much easier to hang on to the darn thing now. The bandage stops it sliding through my hands, and it's far more inclined to stay where I put it, when I hang it on my wheelchair. The bandage finally got a bit dirty, so on my next visit, I asked the Vet. Nurse to replace it with a new one – and this time I got Shocking Pink with purple paw prints as you can see in the picture on the front page. I think I'll have to get all my spare elbow-crutches done in different colours, so I can match outfits!

Repeat article from March 1998.

POLIO SURVIVORS - JAZZ UP YOUR CANES, SCOOTERS AND WHEELCHAIRS

Polio Survivors believe that using aids and assistive devices make them look more disabled, and therefore fight against using them. Education on disability is sorely lacking and should be started in infant school when children accept life much more easily. The general public do not know what to say to someone who is using a cane, riding a scooter or in a wheelchair. They look away.. They talk to the people with you... This is why we fight so hard against these aids. However, there is an answer and it works.

Dress brightly yourself and jazz up your cane, scooter, or wheelchair. Make a statement to the world. 'I am here, this is me, take me as I am. I might be using a cane or wheels but these are no different to shoes. They are just an aid to moving from one place to another.'

Suggestions are to decorate your cane to match your outfit. Put sleeves of material over the cane which can be slipped over it and fixed so they do not slip off. Another is have it sprayed fluorescent colours or add stickers or walking stick badges. You can have a suitable handle added to a carved wooden one.

For our scooters and wheelchairs, make or buy a multi-coloured rucksack/bag for the back. Jazz up the basket on the front, add badges, stickers, transfers, holograms, in fact anything you can think of that will make you more noticeable. Give folks that see you something to open a conversation, something to comment on.

Gwen Hunt in California 'I sewed a Harley Davidson 'WINGS' patch on the back of my Quickie Wheelchair.. The biker bros loved it!!

David G Henson, Salt Lake.. Says I have a 'hand-me-down' cane made of Texas cedar. It is not only beautiful wood, but it is also unique in character. I get comments on the cane, not on my limp nor why I am in need of its (cane) use. This 'deflection' of perspective may give rise to further questions about my disability without embarrassment to either party.

Elizabeth Lounsbury [now Chair of Polio Canada]. I'll never forget the first time I went outside in my suburban home in my wheelchair. The first person I saw said 'Ah, come on E, who do you think you are fooling?' It had been over a month since I had bought it and that was the first time I had used it. Wouldn't have used it then but my husband said... 'I have taken it out and we are going for a walk. If you won't come on your own you'll have to come with force'. I've come a long way since that day.

'Yes, Hils, jazzing things up does help. I shocked everyone when I ordered a purple electric chair. I was at a meeting in Toronto last week and wore a Mauve Suit, forgetting my chair was purple. The first comment I received was 'boy do you ever look striking'. I would never have thought to colour coordinate my clothes with my chair. The thing that had been noticed was the colour not the fact that I was in a new chair. I love my purple chair. My husband thought I was nuts but said 'It's going to be part of you, if that is what you want go for it.'

Editors note - there are now many more companies making fancy canes. Remember that you must ensure that it is the right height for you and that the handle is suitable. The arthritic grip shaped handle is especially good for preventing carpal tunnel syndrome.

The post just arrived and included Polio Messenger from The Polio Outreach of Connecticut. Page 3.. The Beautiful Cane by Linda Wheeler Donahue.. The first paragraph is.. The adjective 'beautiful' combined with the noun 'cane' may seem like an oxymoron. However, as part of disability enlightenment beauty can be an integral part of our canes, crutches and ambulation supports. Let's explore some companies that clearly believe in The Beautiful Cane www.lemonaidcrutches.com, www.fettermancrutches.com, www.stylestick.com/specs.htm, www.annarowan.com, www.hardwoodcanes.com, www.canemart.com/index.html, www.fashionablecanes.com

Not fancy but I found the following. www.access-ability.co.uk, www.youareableshop.co.uk/, Must Get It in Glastonbury, <http://www.mustgetit.com>. I know my local pharmacy has a few paisley and other pattern sticks. However whilst searching I did find Nancy Thorgaard, owner of Creative Canes, www.creativecanes.com who has personal knowledge of disability and who has replied that she can put palm handles on her canes.



A Clarification of Non-Paralytic Polio

By Ernest W. Johnson MD, Editor,
American Journal of Physical Medicine
and Rehabilitation.

For many years, most physicians have understood that non-paralytic is a loose clinical term implying that neither the patient nor the clinical examiner reported functional weakness. This determination was often made without the understanding that 50% of the motor units can be lost before a manual muscle grade of four occurs. This means that many patients with acute polio were labeled non-paralytic incorrectly, but certainly in a well-meaning way.

When the polio virus is in the gastrointestinal tract of an individual and causes symptoms, the term abortive polio has been used. This is the condition that confers the immunity of the individual and also prevents the carrier state. This is why the Sabin (attenuated, live poliovirus) vaccine prevents the invasion of the poliovirus into the central nervous systems, but not the poliovirus from living in the gastrointestinal tract.

In these individuals, whose immune systems, for whatever reason, permit invasion of the central nervous system by the poliovirus, a population of anterior horn cells will die. The number of these cells that die will determine whether the clinician will be able to identify paralysis.

In the late 1950's, our electromyography studies suggested that in all patients who experienced the invasion of the central nervous systems by the virus, pain, meningismus, and positive spinal fluid findings revealed abnormal (fibrillation and positive waves) in many muscles that were clinically 'normal'.

It should be absolutely understood that patients who were told that they had non-paralytic polio did, in reality, have polio, which affected their anterior horn cells. Now, 30 to 40 years later, these patients are potentially subjected to all the vagaries and insults to the body that affect other persons with post-polio syndrome.

Reprinted from San Francisco Bay Area Polio Survivors Newsletter, September 2007, originally from Polio Canada Spring 2004.

Editors Note - From LincsPPN Presentation Slide

The first descriptions appeared in 1875: four case histories were reported in the French literature by Carriere,[3] Raymond,[4] and Cornil and Lepine.[5]

These patients, all young men, had paralytic polio in infancy and developed new weakness – **not only in previously affected muscles but also in muscles believed to be uninvolved.**

They all had physically demanding jobs and performed repetitive activities.

Post-Polio Syndrome : Pathophysiology and Clinical Management,
Anne Carrington Gawne and Lauro S. Halstead.

Critical Reviews in Physical and Rehabilitation Medicine, 7(2):147-188 (1995)

<http://www.ott.zynet.co.uk/polio/lincolnshire/library/gawne/ppspandcm.html>

See also. Non-Paralytic Polio and PPS by Marcia Falconer, Ph.D. cell biology and Eddie Bollenbach, M.A. biology. A Lincolnshire Post-Polio Library Publication - January 1999

<http://www.ott.zynet.co.uk/polio/lincolnshire/library/falconer/nonparalytic.html>