

# **POST POLIO MATTERS**

The Polio Survivors Network Newsletter - Volume 7, Issue 8 n.b. Volumes 1 to 6 published under the name LincPIN. www.poliosurvivorsnetwork.org.uk



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www.mobility roadshow.co.uk



If you read an article that could interest other members please send it to us. Thank you to the following for donations given towards our work Ivor Hill, H Brown, Nicholas Harvey, Susan Freeman, John De'Ath, Mrs. Peter Norman, Rita Unger and Lynn Hobday

A. Revell, R. Unger, and M Whitley

Thank you to all members who have recently renewed.

A total of £ 255.00 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 type this it is a grey day, not raining, but GREY. At a Parkinsons UK Event in Lincolnshire last weekend I heard a great tip. We were asked to think of something sad and then she told us that we were either looking down or had our eyes shut. Mine were shut. She then asked us to think of something good and as we did we all looked up. She advised us to try looking up on grey days or in grey times and see if it helps. It works for me much to my surprise.

All the changes of the Benefits System, the NHS and Social Services let alone everything else that impacts our lives is mind boggling. PPS is bad enough to cope with but all the future changes in how we will have to claim and be assessed for all this is mind boggling.

Some of our members are under 65 and will have to cope with changes from Incapacity Benefit to Employment Support Allowance [ESA] and Disability Living Allowance [DLA[ to Personal Independence Payments [PIP]. Attendance Allowance is for first claimers over 65.

Disability Rights UK have produced Factsheet 60 on PIP which I think looks really helpful. The direct link is **www.disabilityrightsuk.org/f60.htm** If anyone under 65 would like a copy and does not have access to the internet then give me a ring and I will print one off for you. I found the 11 sections and scoring part very interesting and was able to score both Richard and I and see what level we would get. Richard is only 61 so will be changed over at some stage.

At a recent meeting I attended it was suggested that those of us over 65 and on DLA may also have to be reassessed after 2016 because DLA will no longer be a scheme. We will let you know as soon as we hear anything about this.

#### Personal Budgets.

I am not an expert by any means but have been involved with the previous system of Direct Payments and the new System of Personal Budgets personally and at a variety of meetings for the last few years. We have another member who knows the national and local government documents very well and has experience over 13 years. We work closely together and without her help personally Richard and I would have floundered. The Louth Users Group provide four leaflets for Lincolnshire residents to help folks understand what it is all about. Almost all of the information will be relevant to other counties so I have included the information on pages 6 to 13. You will need to ask your local County Council Adult Social Care department - or go to www. [Countyname].gov.uk to obtain the local documents to you.

**The Crippen Cartoons.** Dave Lupton is the leading disabled cartoonist in the UK and we have used a couple of his cartoons in previous issues. I emailed him to ask if there was any chance of doing some cartoons that reflected comments made by Polio Survivors. The back page cartoon came about when I complained about the mess around Richard and he said 'but this is not a mess, it's an opportunity for a PA'. Richards PA laughed and told him not to worry about making messes. We were only able to send Dave a small contribution towards this cartoon, so if anyone would like to send us a donation to pass on to him for this and the use of more of his cartoons in the future, it would be good. Suggestions for cartoon wording relating to Polio, Post Polio and Disability can be sent to us at any time.

#### AGM responses.

Each posted newsletter AGAIN contains a reply slip. If you have not already sent one then please do or let us know by email or phone. Thank you.

**MOBILITY ROADSHOW, Peterborough** - Richard and I be at this on Friday 22nd June 2012.

#### 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

# Message from the Trustees.

Dear All,

Please will all members who have not let us know if they are able to join us for the AGM.

Dr. Emma Braithwaite FRSM CEng. Will be the speaker from ResMed (UK) Ltd. She is a technician and will be explaining the ventilators and masks. Please would members ring, write or email any questions they would like to be asked on the day. We will include questions and answers in our next issue.

Second speaker on how to improve your body position at night. Do you have new pain and wake often? Are you sleeping on the other side or in a different position than before? A couple of our members have now had visits and advice with reduction in pain. Let us know how things have changed for you and we will include some ideas that you might try in the next issue.

## Responding to our Requests.

We appreciate that living with PPS and all the other problems we might have is not easy. However, we give up a lot of time and effort from our lives to provide you with the information. We would really appreciate more response from our members to requests for items or requests for items for the newsletter. AGM response sheets are added to this issue and if you have not returned one, or let us know by email/phone then please let us know.

We again repeat out request for at least one, preferably two, more committee members to spread the workload. Contact is made mostly by email and Skype every month or two for a couple of hours. Plus if at all possible the AGM and another face to face meeting, but if that is impracticable then you would have to be able to join us via Skype or a telephone Conference call.

Can any member spare a couple of hours a month to take on a small task, research on the internet, reading disability magazines and sending info that other members might benefit from, go to their Library and find copies of newspaper items on polio from the past, all of which will help us provide information for members, and a wider audience via our website.

Give us a ring to chat about how you might help.

Sadly we have to report the passing of Member Peter Norman from South Devon. His wife has offered to write up the story of his life pre, with and post polio and this will be in the next issue for which we thank her.

Looking forward to meeting as many of you as can get to the AGM and to reporting all that happens on the day to those that cannot join us.

Best Wishes to you all.

# Hilary, Glenna and Gill.

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Islip Village Hall

**Church Lane** 

**Our AGM** 

23rd June

2012

Islip,

# Oxfordshire OX5 2TA

Doors open 10.30

AGM 11.00

Lunch Break 12.15 to 1.30 Bring your Own lunch Drinks provided

> 1.30 pm Speaker 1 ResMed

2.30 pm Tea Break 2.45 pm Speaker 2

4.00 pm Close

#### NAIDEX - Disability Exhibition BIRMINGHAM NEC May 1st to 3rd 2012

Richard and I visited Naidex for four and a half hours on May 1st. This was not enough time to see more than about a third. It was great to bump into Members Wendy and Frank Grimmitt, and Paul Stanton and quickly catch up before we all wanted to look at more.

We visited **Simple Stuff Works** to ask John a few more questions following his visit to assess how we might improve our body positions in bed to breathe more easily at night.

Then to **Easycare Products Limited** to talk to Owner and Inventor Bob Hestor about our Genie Standing Wheelchair order [See front page]. www.easycareproducts.co.uk. Tel 01952 610300



**Hydrate for Health.** Featured in earlier issues. It was good to meet Mark Moran, Director and Inventor of Hydrate for Health. We have three each, one by bed and one hooked onto side of riser/recliner chair, as the picture on the left, and a spare ready full to change over. Best use for us is at night when all we have to do is to reach out and take hold of the tube, drink and hook the tube back up. We have added OXO All purpose magnetic Bag Clips as they have a hole through that the tube goes through and clip to side of wardrobe/ shelf etc. Clips in pack of 4 we bought in local supermarket.



**The Hydrant** system is a 1 litre water bottle, a unique\*, one piece, cap/handle/ clip, a drinking tube with a bite valve and a small clip to attach the tube to clothing if required. The bottle is hung from the bed, chair or wheelchair and the user simply takes hold of the tube, inserts the bite valve between their lips then bites and sucks. The bite valve opens under pressure and closes when released so there is no leakage. Use for cold and warm but not hot drinks.

- 1. Attach your Hydrant to a bed, wheelchair, or chair using the clip/handle/hanger so it stays as vertical as possible.
- 2. Place the bit valve on the end of the tube in your mouth.
- 3. Gently bite to open the valve (it's worth practicing this with your fingers to see how it works) and suck to bring fluid through the tube.
- 4. If the Hydrant is positioned above head height then once fluid is in the tube it becomes a siphon and no further sucking is needed, simply bite the valve and the drink will gently flow out.
- 5. When you finish drinking simply release the bite valve, it will seal closed and will not drip.

Telephone 0800 292 2382. www.hyrdrateforhealth.co.uk Sold by them and various distributors including Boots, Asda, & Nottingham Rehab Supplies etc

Then to **Easycare Products Limited** to talk to Owner and Inventor Bob Hestor about the Genie Standing Wheelchair we are ordering. [See front page].

# RemZzzs Mask Liners

Robert Rutan CEO and Developer of RemZzzs Liners offers to provide a complimentary 3-day sample pack of RemZzzs® to any person who reads this Newsletter and responds during the month of June. You should email customercare@remzzzs.com with your name and mailing address, mask type and size, and mention you read this in our newsletter. If you do not have internet access then contact us and we will email the information to them.

#### To order from UK visit Intus Healthcare Limited on www.eu-pap.co.uk Tel 0844 504 9999

Our last order arrived in the post 21 hours after ordering!!



# HELP FROM SOCIAL SERVICES, DIRECT PAYMENTS, PERSONAL BUDGETS.

The following information is taken from four leaflets that were prepared for Lincolnshire residents by Louth Service Users Group by a PSN member. All counties work slightly differently but based on Government documents. The information is provided to give you general information. Contact your County Adult Social Care Department for their documents and forms by phone or website www.[county name].gov.uk Remember if you are going to have an assessment then you must be honest with yourself about what you can and cannot manage each day. Remember if asked "Can you do x?" that you need to explain how you do the action now, rather than just answer 'Yes'.

# WHAT IS A PERSONAL BUDGET AND HOW DO YOU GET IT

#### **Frequently asked Questions**

How do I get help, what help is there, who do I ask, what is a Personal Budget? are just some of the many questions. Perhaps this leaflet will give you some answers.

#### The First Person to Contact

Telephone your county Adult Social Care, [Lincolnshire 01522 782155] and ask for an assessment because you can no longer cope and need some help. Everyone is entitled to an assessment. Someone from Adult Social Care (known as the Assessor) will telephone you and arrange a time to come and see you.

#### The Assessment

This is a chat about what things you can manage and those you cannot. It will include your health, how you manage every day, what you can do without help, what help you get from family and friends, and what support you feel you need. It is a good idea to think about these before the person from Adult Social Care comes to see you, talk to family and friends about it and make some notes so you are ready to answer any questions. A friend or member of the family can be with you at the assessment, or you can ask a voluntary organisation [Total Voice 01522 706580) that gives support for you to speak for yourself or to speak for you.

#### What help will I get

The Government has set down levels of needs that affect your independence, these are called Bands. There are four Bands, Low, Moderate, Substantial and Critical. The Assessor will decide from the information you have given in your talk together which is the right band for you. You will need to find out which Band your County funds financially. [Band Information see page 14]

[In Lincolnshire if it is decided you are in the Low or Moderate Bands the Assessor will suggest help that may be available from voluntary organisations and let you know how to get in touch with them. If it is decided you are in the Substantial or Critical bands then you can get financial support from Lincolnshire Adult Social Care.]

#### **Resource Allocation System (RAS)**

The RAS is the way it is decided how much support you will get. You will be asked to fill in a RAS form and you can do this yourself or with the help from family, friend or your Assessor. The form is divided into sections and each section has several answers, all you have to do is tick the answer that best describes your needs. It is a good idea to spend some time thinking about which boxes to tick. It may not be easy to accept the true level of your current ability.

Each answer scores points and the points are added up to see the amount of money you need to maintain you independence.

#### **Financial Assessment**

If Adult Social Care is going to give you some money to help you they will then assess you to see if you should pay something towards the cost of your care. In order to help as many people as possible nearly all

Councils charge those who can afford to pay some of the cost of their care. This assessment is about your income, savings and certain expenditure and is explained in the leaflet "Will you have to pay something towards the cost of your care?" If you do have to pay anything towards your care, this is called your contribution, and is the amount of money you will pay into your Direct Payments account; Adult Social Care will pay the rest to make the money up to the full amount of the RAS total.

#### **Financial Review**

Your income, savings and expenditure is looked at once a year to see if your contribution has changed.

#### Support Plan

When you are told how much money you will get you will need to think about how you will spend it. Think about all the things that are important to you and how the money can be used to help you do those things. The purpose of the Personal Budget is that others are not deciding what is best for you, you decide for yourself. You can decide what will be in your Support Plan on your own, or with the help of family, friends, or Adult Social Care. Your Support Plan should show 'outcomes', they are the things that will happen because of spending the money in the way you have chosen. You can include outcomes that do not cost any money, however your Support Plan should include:

What is important to you

What you want to change

What support you need to do what you want

How you will stay healthy and safe

How you will stay in control of your life

How your support will be managed

What plans you have made if something goes wrong (called contingencies)

What your support will cost.

If you do not want to just write your plan it can include pictures, drawings, a video or audio recording, it is up to you to explain what you want in your Support Plan in any way you wish. When Adult Social Care agrees that your Support Plan will meet your needs you will then be given the money for your support. This is your Personal Budget.

#### Personal Budget

A Personal Budget is the money that you get after you have completed the Resource Allocation System forms and your Support Plan.

You are the best person to know your needs and how you would like them to be met. It gives you choice and flexibility on how your support needs are met. You choose what support you have, who provides that support and when, you choose how best to spend your Personal Budget.

#### Managing the money

You have a choice how the money is managed. Lincolnshire County Council can manage the money for you and pay for the support you have chosen, you can choose someone to manage the money for you or you can manage the money yourself (with help) – that is a Direct Payment.

#### **Direct Payments**

To help you decide if you would like to manage the money yourself read the leaflet "Is Direct Payments Right for You?"

#### Care Review

At any time, if your support needs change, you can ask for your care needs to be looked at again, this is called a review.

Adult Social Care should carry out a routine review once a year. This will look at how well your Support Plan is working and if your support needs have changed. This may involve a new assessment and completion of the RAS forms to see if you needs have changed..

End of leaflet provided by Louth Service Users Group.

#### WILL YOU HAVE TO PAY SOMETHING TOWARDS THE COST OF YOUR CARE?

In order to help as many people as possible, Lincolnshire County Council charge those who can afford to pay for their care. Whether you will be required to pay a charge, and, if so, how much, is calculated on information collected at your Financial Assessment.

The Financial Assessment is very straightforward. Your income from all sources including benefits and pensions is recorded. Any wages you may earn are exempt. DLA Mobility is also exempt. If you receive the night care element of Attendance Allowance or Disability Living Allowance, and Social Services do not provide night care, then the night care element only is exempt.

Savings and investments that amount to less than £14,250 are disregarded. Savings between £14,250 and £23,250 are recorded as a weekly income of £1.00 for every £250, for example saving of £15,250 recorded as £4.00 per week. If you have savings above £23,250 you will be required to pay the maximum charge (if your care funding exceeds it) and you will not be assessed any further. The Council sets the maximum charge every April; for 2011-2012 Lincolnshire it is £250.00 per week. If you do not wish to have a financial assessment, you will then automatically pay the maximum charge.

If your assessment continues there is an Allowance to cover living expenses. The amount is equivalent to Income Support or Pension Credit plus 25%. The Allowance is increased every April, your Social Worker can tell you how much it is for this year. If your income is less than this Allowance you will not have to pay a charge and the assessment is over. However, if your income is greater than the Allowance there are further deductions that can be made. These can be housing costs, such as rent less benefit, or mortgage, council tax less benefit, and building insurance.

**Disability Related Expenditure** is also deducted. These are the expenses you have because you are disabled that you would not have if you were not disabled and will vary with each person as much as disabilities vary. As a guideline they can include:

- Heating and metered water costs above the average (this is in the Council's Fairer Charging Annual Statement)
- Equipment you have bought such as wheelchair, scooter, power bed, stair lift, riser/recliner chair, etc, etc, plus repairs and servicing.
- Staff you employ privately to help you
- Additional laundry costs (5 loads or more a week)
- Community Alarm System.
- Prescription charges to maximum of the NHS Prepayment Prescription Charge
- Travel expenses above DLA mobility
- Dietary needs.
- Excess wear and tear on clothing and footwear.
- Chiropody.
- Extra communication costs.
- Additional wear and tear on furniture and fixtures.
- Any other expenditure that is related to your disability.

After all these deductions from your income, the amount remaining is your Assessed Income, and this is the maximum you can pay for your care. If the funding for your care is less than your Assessed Income you will pay the lesser amount. In Lincolnshire the maximum you pay cannot be more than 90% of the funding provided for your care.

#### Your First Financial Assessment.

All income and expenditure is looked at over a year and divided by 52 to get the weekly amount. The only exception is equipment expected to last a number of years, that is divided by 500 to get the weekly cost spread over ten years. Income is recorded for the current year and expenditure is for last year.

To prepare for your first Financial Assessment you will need to gather together the paperwork that confirms your income and expenditure. Some examples are as follows:

Income Documents you are sent every year such as pension and benefits notifications, occupational pension.

Savings Premium Bonds, Post Office savings, stocks and shares, PEPS, TESSA, ISAS, or any other savings or capital, including your current or deposit bank account.

Expenditure Rent and housing benefit notification, or your annual mortgage statement Council Tax and Council Tax benefit Building Insurance Electricity, gas or oil bills for the previous twelve months Metered water bills Receipts for any equipment you have purchased related to your disability Receipts for anything related to your disability, such as listed opposite.

The Council requires proof of purchase, and receipts are the simplest way of providing this. However, as this is your first Financial Assessment, and you did not know that these receipts would be needed, you may not have kept them all. If you paid by cheque perhaps you have the counterfoil, or have a credit card receipt. With heating costs you may have a current bill that an estimate can be made from. For items of Disability Related Expenditure you can show the assessor the items and agree a reasonable cost. There are set allowances for laundry and for any private help you employ, although if your costs are greater than the set allowances you can discuss this with your assessor.

To make sure nothing is forgotten it is helpful to prepare a list of all your income and expenditure and put this with all the paperwork and receipts you can find. Make a list of any items that you do not have a receipt for and find out what the average cost is; you will then have a starting point to agree a reasonable cost with your assessor.

You are now ready for your first Financial Assessment when all the information is re-corded.

#### FINACIAL ASSESSMENT REVIEW

Now you know that you need receipts for all items you want to claim, make sure you keep every one for when you have your next review.

Every April the Council will increase the amount recorded as your income because pensions and benefits go up then and you need to check these figures are correct. It is therefore important that you claim for any increase in your expenditure, such as heating cost, rent or mortgage, any new equipment or purchases you have made related to your disability: ask for a review. If you do not claim, the Council will use the information of your expenses from your last assessment. This could mean you pay more than you need to.

For the review prepare a list so nothing gets forgotten and attach to all the paperwork and receipts to confirm your income and expenditure, just as you did for your first assessment.

If there is a marked change in your income or expenditure at anytime in the year you should notify Social Services and ask for a review.

#### How your Charge is Calculated

	Per Week
Total Income	£
Plus Savings (£1.00 for every £250 over £14,250)	£
Less Total exempt Income	£
Less Allowance	£
Less Total Expenses you have	£
Assessable Income	£

#### Appeal

If you think there is an error on either the information or the calculation of your charge there is an Appeal Procedure.

For further information you can get a copy of the Council's Charging Policy for Non-residential Care and Annual Statement of Charges from the your County's website. [Lincolnshire County Council www.lincolnshire.gov.uk.] End of leaflet provided by Louth Service Users Group.

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# IS DIRECT PAYMENTS RIGHT FOR YOU?

Read the view of someone who has been using Direct Payments for a number of years.

You have probably read the leaflet introducing Direct Payments and are wondering if they are right for you. You may think it might be too difficult, will you be able to cope, who will help you and what happens if it all goes wrong. If you read on I hope I shall cover any concerns you may have, but first let me tell you how Direct Payments has helped me.

The control and flexibility of who I employ, what they do and when, has given me back my independence. Before Direct Payments I had become quite housebound, much was being neglected because it was all a dreadful struggle and I had generally lost interest. Direct Payments has helped me to look after my general wellbeing and enabled me to regain contact with family and friends, and I can now have the support to pursue hobbies I had given up long ago. The flexibility means when I'm feeling all right my Personal Assistants (PAs) can take me out and about and when I'm not so good I can use more support at home. Direct Payments has given me a quality of life I did not think would be possible again.

I have had my care funded by Direct Payments for a number of years and I can tell you how it has worked out for me.

#### **Finding People to Employ**

Living in a rural area, as I do, should be no obstacle to finding suitable PAs. It can be surprising how many people are available for a few hours employment within a quarter of an hour's radius. I believe that employing a number of PA's for a few hours each has definite benefits:

- draws on a wide range of skills.
- shares the care between several people ensuring cover for holidays, sickness, replacing staff and day release for training.
- reduces the risk of getting too dependent when only a couple of PA's provide all the care, which can be very upsetting when one PA leaves.
- easier to find people who only want a few hours work a week.
- people who work for less than the earnings threshold do not have to pay tax and National Insurance. (For the tax year 2012/13 the earnings threshold is £156 a week). As an employer you will have a legal obligation to operate Pay as You Earn (PAYE) on payments you make to anyone who earns more than this – there is help and advice on PAYE if you need it.

Any willing person can be trained to meet your care needs, and you can use your Direct Payments to send employees on Moving and Handling, Hygiene and other courses. The most important factor is that you feel comfortable having the employee in your own home.

When I first started on Direct Payments I chatted with a person who had lived in my area all her life and seemed to know everybody. She put me in touch with others until I had built up a team to cover all my care. I was very worried when I had to move house several years ago because I had to start again finding suitable employees. I asked everybody I came into contact with if they knew anyone available for work. I put cards advertising the jobs in the local Post Office, shop, pub and garage, and advertised in the parish magazine and local newspaper. Within quite a short period of time I had built up a new team of PA's. If you do not like the idea of advertising, interviewing and checking references on your own, there are User Groups or Organisations in each county who can help you. [In Lincolnshire Penderels Trust have the Council Contract and Lincolnshire Independent Living is a User Group that can help you, there are others]

If you rely on help to get up, washed and dressed, you may decide to employ a Care Agency for this. However you must make certain you have enough money for the other needs identified on your Care/ Support Plan. If you manage your Direct Payments well you may have some money left over, this can be saved up and used for additional support for anything listed in your Care/Support Plan, a summary of your care needs.





#### Being an employer



Have you ever paid someone to trim the hedge, cut the grass, do a bit of cleaning or pick up some shopping? You have had to find the right person to do the job, negotiate a rate of pay, budget to cover the cost and agree when the work will be done. This is just the same as finding people to help with your care needs. There are rules to follow, but they are not difficult and nothing to worry about. Local Agencies will be able to advise you. You can do it for yourself, with the help of family or friends, or you can use your Direct Payments to pay a Payroll Agency to work out the wages for anyone you employ, including their tax and National Insurance, so that is easy.

#### Paperwork

If you accept Direct Payments the money for your care will be paid into your Direct Payments bank account and you will pay the people who provide your care. You need a separate bank account so your own money does not get muddled up with the Direct Payments money. The Council needs to know that you are receiving help from the people you pay to provide your care and that the care is being delivered as set out in your Care/Support Plan.

This means paperwork. Some people like paperwork, I don't. But the paperwork required is really very simple. You will need to keep a record of the hours worked, the rate paid and the money you have paid each employee and receipts or invoices for every other purchase. At the end of every four weeks you will need to list everyone you have paid and how much you have paid them and any other expenses. The total is what you have spent and should agree with your bank statement for your Direct Payments account.



Again an Agency or someone you choose can help you with this. It is not a requirement of the scheme but I find it useful to use a receipt book and get everyone I pay to sign it. I find this an easy way to keep check on my spending and to do the list at the end of four weeks. So long as the Council's paperwork is completed you can keep whatever records you may find helpful.

#### Asking for Support.



I needed some help when I started, then I managed on my own. Providing you stay in control of your Direct Payments, there is no limit to the help you can receive from family, friends, or an Agency. You can have help with finding and interviewing PA's, help with planning the work they will do, help with paying wages and employment rules, and help completing the paperwork.

There is no need to worry that you can't cope, you do not have to do it alone.

#### What if things go wrong?

An Agency like Lincolnshire's Penderels Trust are there if you get in a bit of a muddle. Over the years some of my PA's have left and I have had to find others. This can be a worry, but my other PA's have covered the work until I've found a replacement. If you are really stuck and rely on help to get up, washed and dressed, remember you can have that part of your care arranged by the Council, that's called Direct Provision, and the rest of your care can be provided by Direct Payments.





Because all our care needs are different, those of us on Direct Payments use the money in different ways. We all look for the best care from the money provided and in that way we gain a quality of life and remain independent. If you choose Direct Payments I'm sure you too will find new and interesting ways to use the money to meet the needs in your Care /Support Plan. If you decide Direct Payments is right for you just tell your care assessor.

End of leaflet provided by Louth Service Users Group.

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# DIRECT PAYMENTS

## How to get the most out of the funds provided.

So you now have your Personal Budget and you have decided to manage it yourself, and the money will be paid into your new Direct Payments account. The next thing to decide is how to spend it. You put in your Support Plan all the things that are important to you so you need to think about how to achieve these. You may have some unpaid help from family or friends, and you will need to pay for support for everything else with the funds provided. Here are a few ideas.

#### Personal Care

If you need two people and a hoist to get you up washed and dressed (and back to bed) then you may decide to employ an agency because you may feel you can depend on them, however they can be quite expensive. Check out the agencies in your area, talk to each of them, and decide if they can meet your needs at a price you can afford. Or you could contact the local school of nursing to see if they have two students in your area who would like to work for you whilst training. Is there a mobile hairdresser in you area as this can be cheaper than paying a PA (Personal Assistant) to take you to the local hair salon or barber?

#### Night Care

If you sometimes need care in the night, you may find someone who you can pay a small amount each week (known as a retainer) who would come at short notice when you need them and you would pay a full wage when they help you.

#### Meals

If you cannot prepare your own main meals think about who can help. You could pay someone to prepare and cook a meal for you every day, but this can be quite costly. Maybe there is a neighbour who cooks for her family and you could pay her to make an extra meal for you and bring it round, or you may be able to arrange to collect your main meal from the local pub or cafe - they may even deliver if you ask them. Or you can employ someone once or twice a week to prepare the meals you like and freeze them for you or your PA to warm up when you want them. Remember if someone else is providing the food you must pay for that out of your own money, Direct Payments can pay for making, cooking and delivery of your meal.

#### **Medical Appointments**

It can be expensive to pay a PA if you need someone with you at medical appointments because you do not know how long you will have to wait. If there is a Voluntary Community Car Service in your area (check with the local council) they only charge mileage plus about £5.00 if it is longer than two hours. This can be the cheaper option if you are able to get in and out of a car. They will also push you in a wheelchair to your appointment, for refreshment or to the toilet, if you need that support, a service you will not get from you local taxi.

Ask if your local Voluntary Community Car Service can also take you hospital visiting, shopping, to meetings, or visit friends.

#### Practical needs around the house

If you do not need a lot of support to get up washed and dressed then the PA you employ to help you with that could also make the bed, keep the house clean and prepare a light lunch or warm up a meal already prepared. If you need help with laundry check out the cost at your local laundry for the larger items such as sheets as you may find this cheaper than your PA washing, drying and ironing these at home. Do you want your windows cleaned – find out the cost of the local window cleaner, it may be cheaper than paying your PA to do it? See if there is a local handyman who can come for a couple of hours to carry out minor repairs, check the tyres and batteries on your scooter or wheelchair, or keep the paths clear.

There are many different ways to meet your care needs. These are just some ideas for the everyday things, and if you can keep your costs as low as possible on these then you will have more money to spend on the more enjoyable things you may like to do.

#### Accessing the Community

You can employ a PA to take you to disabled horse riding, disabled swimming, disabled sailing, disabled ramblers, so find out what is available in your area. Maybe you may like to employ a PA to take you

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fishing, to the pub, community centre, theatre, cinema, garden centre, attend adult education classes, go to the library, to your place of worship or meet up with friends and family. You could put your money together with others who also get Direct Payments to employ a couple of PAs to support you all and hire a minibus for a trip out together, or for something else you may like to do together. You can use your Direct Payments to pay for your PA's costs such as refreshments or admission (although some places offer free admission to carers), however you cannot use Direct Payments to pay for your own admission and refreshments. These are just some ideas, everyone has different things they enjoy doing, it is up to you to choose.

#### The Cost of Employing PAs

You must pay at least the minimum wage that is reviewed every October. However do not pay your PAs too much or you will not have enough money to do all the things that are important to you. You can always increase wages if the PA turns out to be very good, but you cannot cut wages. When interviewing, try asking what wage the PA expects – you may be pleasantly surprised. If you employ several PAs you do not have to pay them all the same, wages are usually based on skills, experience, and responsibilities that can be different for each PA.

If a self-employed person works for you expect to pay at least £1.00 more per hour because you do not have all the employer's costs such as paid holidays or sick pay, however make sure they fit the self-employed status for the work they will do for you as set out by HM Revenue & Customs; the support agency, Penderels Trust, can help you with this.

#### What you CANNOT use your Direct Payments For

Direct Payments is to support your care needs so you can lead a life as independent as possible therefore you **CANNOT** use your Direct Payments:-

- to pay for everyday costs that you would have if you were able-bodied.
- as a "piggy bank" to dip into or borrow from when you want extra money to supplement your own income
- to pay for electricity, gas, oil or telephone.
- to pay for food for yourself, cigarettes and alcohol.
- for services that would normally be provided by the NHS
- for accommodation costs.
- for gambling
- for anything unlawful

If in any doubt always check with your Social Worker before you use the money.

If you use your Direct Payments for anything other than supporting your independence, as set out in you Support Plan, you are likely to be asked to repay the money and your funding by Direct Payments will be stopped.

End of leaflet provided by Louth Service Users Group.

#### [Editors Note:-

I have been raising issues locally through Physical and Sensory Impairment Partnership Board, Adult Social Care Reference Group and Lincolnshire LINk meetings for a number of years. In Lincolnshire we have raised issues with initial contact, assessments of needs and finances and the paperwork provided and the yearly financial reviews.

Devon County Council has an excellent website with all documents and forms available and easy to find. If you already have help from your County Social Services then I would like to know what you think of their paperwork and services. Whilst we cannot specifically help anyone out of Lincolnshire if you are having difficulties then I would appreciate learning what they are and hopefully help you find a local User Group who can help you.

# Prioritising need in the context of *Putting People First*: A whole system approach to eligibility for social care

Guidance on Eligibility Criteria for Adult Social Care, England 2010

Page 21

#### The eligibility framework is graded into four bands, Critical, Substantial, Moderate and Low.

The eligibility framework is graded into four bands, which describe the seriousness of the risk to independence and well-being or other consequences if needs are not addressed. The four bands are as follows:

#### **Critical - when**

- life is, or will be, threatened; and/or
- significant health problems have developed or will develop; and/or
- there is, or will be, little or no choice and control over vital aspects of the immediate environment; and/or
- · serious abuse or neglect has occurred or will occur; and/or
- there is, or will be, an inability to carry out vital personal care or domestic routines; and/or
- vital involvement in work, education or learning cannot or will not be sustained; and/or
- vital social support systems and relationships cannot or will not be sustained; and/or
- vital family and other social roles and responsibilities cannot or will not be undertaken.

## Substantial – when

- there is, or will be, only partial choice and control over the immediate environment; and/or
- abuse or neglect has occurred or will occur; and/or
- there is, or will be, an inability to carry out the majority of personal care or domestic routines; and/or
- involvement in many aspects of work, education or learning cannot or will not be sustained; and/or
- the majority of social support systems and relationships cannot or will not be sustained; and/or
- the majority of family and other social roles and responsibilities cannot or will not be undertaken.

## Moderate – when

- there is, or will be, an inability to carry out several personal care or domestic routines; and/or
- involvement in several aspects of work, education or learning cannot or will not be sustained; and/or
- several social support systems and relationships cannot or will not be sustained; and/or
- several family and other social roles and responsibilities cannot or will not be undertaken.

## Low - when

- there is, or will be, an inability to carry out one or two personal care or domestic routines; and/ or
- involvement in one or two aspects of work, education or learning cannot or will not be sustained; and/or
- one or two social support systems and relationships cannot or will not sustained; and/or
- one or two family and other social roles and responsibilities cannot or will not be undertaken.

 $www.dh.gov.uk/en/Publications and statistics/Publications/PublicationsPolicyAndGuidance/DH\_113154$ 

#### 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.

Polio Place looks at the past - not only the history of the disease, but also the stories of its survivors. It examines the present from the perspective of people around the world who are living with polio and post-polio syndrome today.

Post-Polio Health International (PHI) developed Polio Place with the generous support of the Roosevelt Warm Springs Foundation.

PHI is committed to reaching out to polio survivors and their families, health professionals and policymakers, particularly in countries where living independently and successfully as a polio survivor is not a priority.

PHI invites survivors and health professionals worldwide to explore this storehouse of information and let us know your needs, concerns and successes.

Here's how to participate:

Polio survivors - Have you devised a unique way of doing something to increase your independence? Have you created a simple device to assist you?

Can you write an essay on Living with Polio? Contact us.

Do you have a photograph, letter, newspaper article, etc., that tells your polio story? Please visit the Artefacts area of the website, and submit it.

Health Professionals and Researchers - Are there Medical Articles you would recommend or articles you judge to be classic, seminal, excellent overviews or longitudinal studies? Click on Contact and let us know.

Historians and Authors - Do you have suggestions for additional Collections of historical material or recommendations for additions to the People section? Have you written a book that should be included? Contact us.

Polio Place is a new additional website and an extension of our mission to enhance the lives and independence of polio survivors through education, advocacy, research and networking. Our other trusted sources of online post-polio.org and ventusers.org will continue.

#### http://polioplace.org

#### Editors Note: Share your story with PSN.

#### Post-polio.org.uk

#### **Post-Polio News Service**

RSS and Twitter feeds

Twice daily 'Newspaper'

Daily Digest via Email

http://www.post-polio.org.uk/

Overview by Author 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 our Website front page.

#### - 0 -

#### 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. Dr. Jonas Salk, who developed the first safe and effective polio vaccine, founded the Salk Institute in 1960.

Watch the 3 Breathing Symposium presentations under Videos. Excellent information.

http://poliotoday.org

- 0 -

#### Patient.co.uk article on Post Polio Syndrome

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.

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

#### My Story By Sandy Yarrow.

I was born in 1946 near Nottingham and as a child all I wanted to do was dance. I did ballet, tap, modern and Greek but my favourite was acrobatic dance, as I was very flexible. So agile that many people would ask my mother if I was made of rubber.

From the age of 9 years old, in two consecutive years, I was fortunate enough to dance in West End shows and was promised a solo part the following year but that was not to be. In the January of that year I contracted Polio which affected me from the waist upwards and left me with limitations in the use of my left arm and albeit that I didn't fully appreciate it at the time breathing problems. Although I knew that my chances of realising my lifetime ambition of being a professional dancer were all but over I carried on with my dancing as much as I was managed able and still parts in two Derby professional pantomimes at the Hippodrome. However, not being able to lift my left arm fully and getting out of breath guicker than those around me, eventually, forced me to accept that from now on dancing would have to remain a hobby.

On leaving school I did office work doing payrolls but a little later in my working career I was fortunate enough to secure what was a dream job for me in a Sports Centre. This enabled me to be close to sport another of my great loves.

I met my husband Eric in the sixties when he was in the Royal Air Force and attending a training course at RAF Newton near Nottingham, we were married less than two years later and I became a military wife.

We have two daughters and when the youngest was 3 years old we decided that it was time for Eric to leave the RAF to enable the family to have a more stable way of life not the endless moving from place to place that military life demands. Fortune took us to a beautiful village in Surrey called Cranleigh where we enjoyed 10 wonderful years but Eric's career prospects forced a move to where



we presently live near Henley on Thames, still not a bad place to be.

After living here for 5 years and now in my 40's my problems began. It started with a virus a bit like meningitis and I was taken into hospital for a few days. I was later told that I had an overactive thyroid gland and given lots of medication.

I just didn't recover even though my thyroid had gone back to normal levels. It also left me with low white blood cells and they remain so to this day.

Following this I was sent to London to see a viral illness specialist and she diagnosed me with M.E. albeit this was an incorrect diagnosis it did lead me to join the ME Association and this is where I learnt about PPS. At this point I gathered as much information as I could about PPS and took it along to my GP who proved to be very supportive but trying to get a specialist to confirm it was a nightmare.

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#### 9 YEARS LATER

With my left arm and shoulder becoming ever weaker and my breathing an increasing challenge I was sent to see a Neurologist who carried out various tests. I now think that his prime objective was to prove that there was nothing wrong with me, not a very pleasant experience. In my final consultation with the Neurologist he stared into my eyes and said "I haven't sent you to see a psychiatrist yet have I?" I was so angry that I returned the stare and said "you have made a big mistake."

In the event, accepting that my breathing was an issue and that I was experiencing some muscle loss the Neurologist sent me to see an eminent respiratory specialist in Oxford.

This proved to be a major turning point in my diagnosis. This specialist was extremely sympathetic to my situation and following a thorough one and half hour head to toe examination including checking my breathing he confirmed that I did have PPS and that I only had 40% lung function. It was also a great boost to my morale when he apologised for the way I had been treated by some of his colleagues.

To provide a second opinion of his diagnosis this specialist sent me to see Dr Robin Howard at St Thomas's who also confirmed PPS.

Since then my respiratory specialist in Oxford has taken care of me. He organised a consultation with a Cardiologist to diagnose a long term fainting problem that I had (probably PPS related) that resulted in the fitting of a pacemaker, problem resolved. When I developed severe swallowing problems leading to dramatic weight loss and diagnosis that the muscles in my throat had all but stopped working he immediately admitted me to his hospital ward, got me on a drip and arranged for me to have a PEG fitted which I have had ever since. I have been unable to eat food for 7 years all my nourishment now comes through the PEG via an Enteral Feeding Pump. Whilst I try not to take advantage of my relationship with this wonderful specialist he is always at the end of the phone for me if needed.

Eric, my husband, is also my hero, whenever something else goes wrong with me, we only get down for a day then he says come on its just another challenge in our lives and we get on with things, he is such a great support.

Each night he connects me up to my Enteral Feeding Pump and takes me off 6 hours later. The next morning he sterilises all the equipment as well as giving me any medication that needs to go through the PEG.

He does the cleaning, the shopping, the gardening, helps friends and neighbours and still finds time for some charity work as well as helping to maintain the grounds at our local church. He's a gem.

Although, like most PPS sufferers, I have many more ailments than I have discussed in this brief story I do have the love of my life as my carer, he is always there for me when I need him. I also have a very good GP and health centre not to mention my extremely supportive Professor in Oxford. I consider myself the luckiest lady in the world and yet friends can't understand why I smile and stay positive when things keep going wrong. I am sure that most of you are positive thinkers but if you do find it difficult from time to time try talking to someone with a positive outlook. I feel that we all need to make the most of every day we have on this earth.

# 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.

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

# The following is taken from a Polio Email List after the reporting of a long standing members passing. This is with permission from the authors who both live in the USA.

I do not know her personally, other than through a few posts, but each loss to our little community seems huge to me.

#### A response was as follows:-

As it does to me, too. The only hope I have is that we can, as a civilization, rid the planet of polio. At this point it's something we can do.

I know that polio has shaped each of us. We are probably different than we would have been, had it not been for polio.

I'd like to think we are "better" for having had the experience. (Though I know of some examples of people who had polio, that could stand a "do over"!  $\odot$  )

I've met some very nice people; people I'm happy to call "friend" because I had polio. I'm glad for those friendships.

Too much of what and who we are, may be as a result of the way polio shaped our destiny. Since I like who I am, and "where" I am, I wouldn't want to change the fact that I had polio. But I don't believe that "polio" is necessary to make a person I'd like to know.

Incidences of polio peaked at a time when medical science and our culture were prepared to use the opportunity to do some things that have benefitted many, even those who didn't have polio.

Can you imagine a polio epidemic today, with even "minor" illnesses bankrupting families and our nation? The idea that you might need a year or two of inpatient treatment and rehab, or possibly an even longer term need for respiratory support is beyond anything our society is willing to contemplate.

The idea that everyone would send in their dimes [March of Dimes], and that this would care for those in need, and provide protection for others just isn't in our national ethos right now.

This change in our focus from a collective good, to one of "personal good" is not, in my opinion, our finest hour.

Because I see no "merit" in any one else having polio, I wish to see it eradicated. Because we have the means to do so, and by doing so, we can prevent all the bad consequences of having had polio, it would be a great shame on our civilization, should we falter in this effort.

I do hope that, should a tear be shed, at the passing of the "last" polio survivor, that it be a mixture of sadness at the passing of a good person, and joy at the end of era where polio and the trappings that go along with polio will never be known again.

There are plenty of other mountains to climb. Can you imagine a "vaccine" against hate or bigotry? A "seed" of a plant that will feed everyone, for a price they can afford, that promotes health and well being? Heck, if you are "wishing" you can wish that it tastes good, too!

Let us find another way to "make good people".

# Quiz for 'Bright People' - ANSWERS

#### 1. BOXING

- 2. 2. NIAGARA FALLS. The rim is worn down about two and a half feet each year because of the millions of gallons of water that rush over it every minute.
- 3. ASPARAGUS AND RHUBARB
- 4. STRAWBERRY
- 5. IT GREW INSIDE THE BOTTLE. The bottles are placed over pear buds when they are small, and wired in place on the tree. The bottle is left in place for the entire growing season. When the pears

are ripe they are snipped off at the stems.

- 6. DWARF, DWELL and DWINDLE
- PERIOD. COMMA, COLON: SEMICOLON; DASH — HYPHEN -APOSTROPHE ' QUESTION MARK ? EXCLAMATION POINT! QUOTATION MARK "" BRACKETS [ ] PARANTHESIS ( ) BRACES { } AND ELLIPSES....
- 8. LETTUCE
- 9. SHOES, SOCKS, SANDALS, SNEAKERS, SLIPPERS, SKIS, SKATES, SNOWSHOES, STOCKINGS, STILTS

# 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

Glenna Tomlin - Glenna.tomlin@poliosurvivorsnetwork.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

**Friend/Supporter**. If you would like to support the Polio Survivors Network you can do so by making a yearly donation of your choice.

You will receive a yearly update of our activities and be invited to our AGM.

#### Membership Fees

Individual - £ 12.50 per year Life membership - £ 150.00 or pay by Standing Order £ 5.00 x 30 mo. Associate Membership - £ 10.00 per year

Yearly fees can be paid by Standing Order.

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.



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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.

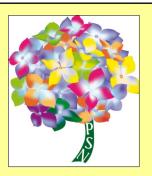
If you pay tax at the higher rate, you can reclaim tax relief on your gross donation at 20% (i.e. the difference between the higher rate of tax at 40% and the basic rate at 20%).

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# **Polío Survívors Network**

Registered Charity No. 1064177

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

