

**REPORT OF THE MEETING OF THE EAST OF SCOTLAND
BRANCH OF ATAXIA UK
LASSWADE HIGH SCHOOL CENTRE,
SATURDAY 20 January 2007
<http://www.ataxia-east-scotland.org.uk>**

Present: Jack & Nancy Blaik, Liz & Pete Dalby, Penny Gardner, Derek Main (Chairman), John Reid, Jim Shepherd, Claire Shepherd & Fabio, Richard, Anne-Marie & Serena Thomson, Frances Wright.

Apologies: Andrea Bothwell, Rhona Brankin, Ronnie Browne, Anne Green, Liz Griffiths, Andy Hogg, John Hunter, Gillian Morrison, Peter Smeaton, Alan Smith and Martin Watson.

1. Welcome and Introduction

Derek Main (our Chairman) has cerebellar ataxia and has just turned 50. Richard Thomson helps with fund raising, mainly sponsored runs. Frances Wright is the Branch Treasurer and has been involved with the Group since it started 12 years ago. Pete Dalby is Liz's husband and principal carer. Anne-Marie Thomson is Richard's wife and also helps the fund raising with her knitted toys and other crafts. Liz Dalby has cerebellar ataxia - she is a Branch committee member and was a former Trustee of Ataxia UK. Penny is the Branch Secretary and runs our website - she has also been with the local group since its inception. Jim Shepherd was diagnosed with CA last March and had travelled from Aberdeen with his daughter Claire and her fiancé Fabio (they are making a weekend of it!). John Reid comes from Hawick and has Friedreich's Ataxia, he has been with group since it was set up and has had FA all his life but it didn't affect him until later. He has lots of hobbies including wheelchair curling and has three horses.

2. Report of 4 November 2006 Meeting

The report of the meeting on 4 November 2006 was approved with one correction: John Reid said that he spent 8 weeks in hospital not 10 days.

3. Talk by Jack Blaik, Senior Social Worker, City of Edinburgh Council

Jack Blaik is a Senior Social Worker at City of Edinburgh Council and came to talk about the Direct Payments Scheme (DP) and the Independent Living Fund (ILF). He planned a 10 minute talk then plenty of time for questions. He has specialised in this area for a number of years, his bottom line task is to try to increase the number of people using DP and the ILF.

Disabled Living Allowance (DLA)

ILF and DP are two different systems to make payments directly to people to provide their care & support. They are not the same as the Disabled Living Allowance (DLA) which is a form of benefit and pays out a maximum of £64 per week with an average of £40 per week. The DLA is centrally

administered through the whole of the UK. The DLA recognises that, as a disabled person, you have some extra costs, but it is not designed to meet all of these costs and makes only modest' small payments. If you receive DLA payments someone else can claim invalid care allowance for looking after you.

History of Independent Living Fund (ILF) and Direct Payments (DP)

DP & ILF come from social work so are different in their origin & purpose and relate to buying care. They are radically different and have an interesting history. In the late 1960s in the USA (at the time of the anti Vietnam movement) young disabled people in California demanded of Federal & State governments that instead of giving money to providers, that it be given direct so they could organise their own care. In USA it is still called 'individualised funding'. With modern technology through the internet in the 1980s communication overcame the barriers of geography and these ideas spread. Jack remembers being in the Thistle Foundation and for the first time seeing someone using email to get in contact with a friend in the USA. The first use of Direct Payments was when 4 or 5 residents in a Leonard Cheshire home set themselves up to receive payments directly from Hampshire Council. In the Lothians, 1985/6 was the first time this happened. The Central UK Government decided to respond to demand and the first system was the ILF, which was established in 1988.

The Independent Living Fund (ILF)

ILF is a central government system of funding, run from a single office in Nottingham. Criteria are tight, but if you meet them you can receive up to 455 per week to buy your own care. ILF still there and available, but large numbers of people who are eligible are not getting it. In Edinburgh 260 people are receiving payments from the ILF but there should be 550 – this means that 300 people are not getting it, not aware it's available maybe.

ILF criteria: You must be between 16 – 65 at time of application - but once you get it, it doesn't matter what age you are, you don't lose it. You must be on the highest rate care component of DLA, (the disability component of DLA is irrelevant) plus you must be receiving at least £200 pw worth of care.

The Direct Payments Scheme (DP)

DP has nothing in common with ILF, apart from paying into same person's bank account. DP comes from Local Government and has fairly open criteria. In theory, any person in need (regardless of age etc), if they are getting a care service can ask for a payment instead of that service and buy their own care.

The two together (ILF and DP) could give up to £600/700 pw towards buying care services. In theory there is no limit to the number who could get DP. A total of 6,000 people in Edinburgh are receiving some form of care service eg 1-2 hours home help, 5 hrs pw in a day centre. Currently only 200 out of the 6000 are claiming Direct Payments. DP is a substitute for the care you are getting; it doesn't give you any more care but gives you flexibility, choice & control.

It's important to remember that neither of these schemes is going to make you richer, they just provide funds for your essential care and to give 'quality of life'. They mean that you are in control of when, how and from whom you receive the services you need. You have to show that the cash you have received has been spent on care services by making a periodic report, otherwise it can be returnable.

People entitled who are not receiving ILF and / or DP

ILF is a pure top-up, an add-on in addition to what you get from the Local Authority and your benefits. So the 300 people who are not getting ILF payments concern Jack more than the 5,800 not getting DPs (as they are still getting their care, in a different way (provided by the LA or other care organisations)).

Jack then invited questions, especially from anyone having problems with getting LIF and/or DP. Felt most useful to have plenty of time for questions and to be able to answer queries on individual cases, if people didn't mind sharing personal information. NB In the interests of confidentiality, the identity of questioners has not been reported.

Questions

Does DLA / SDA go past retirement age? DLA does – but it changes to attendance allowance, which is effectively the same thing. You keep ILF for life, and it doesn't affect your pension or any other payment. The purpose of ILF is, for example, to go swimming, shopping, cinema etc. - giving you the same quality of life as anyone else.

Eligibility for ILF: Assuming someone meets the criteria ie is between 16 and 65 and is on the highest rate care component of DLA, the third determinant is that the Local Authority has to be providing £200 worth of care services per week. This is £200 cost to the local authority so could be as little as 15 hours a week of home care, as it's not calculated as the hourly wage of the worker, there are additional costs of tax, national insurance etc and the cost of administering the scheme. It also doesn't matter if you are paying part of the cost yourself, the total is what counts.

Being assessed for your care needs

If you are having an assessment made, it's a good idea, before the Social Worker arrives, to write your own statement of what you need, eg 2 hours help in the morning, 1 hour at lunchtime, 2 at tea time. The assessment should then state what YOU need, eg if the rest of your family were in hospital for 6 months, what needs would you have? This puts you in a position of power, rather than leaving it to the Social Worker to tell you what they think you need.

What if you have already been assessed before?

One member reported that Social Work did offer a home help (they didn't say how many hours would be offered) but said it would cost £14 per hour which the member couldn't afford. Jack said that unless your household is receiving a high income or you have over £18,000 savings, you should not be paying the full amount. It is worth contacting the social work office again, saying that you need care / your needs have changed or there has been a crisis. Say you want to be assessed and that you wish to make an application to the ILF and also to receive DPs. Once your care needs have been assessed and you are receiving Direct Payments, you can buy a service from a relative so long as they don't live with you. However, if employing someone directly this might involve employer duties such as tax, national insurance contributions etc. So, for the member who asked, it needs someone to say you are entitled to 14 to 15 hours home care as a minimum, this could include any requirements for respite care.

Why are all the different systems so complicated?

In the UK, there are so many government offices delivering & making payments that it's confusing – which payment comes from where? In Australia and NZ one payment covers everything which is much clearer.

Other Matters

A member commented on the differences between the Borders & Edinburgh. Payments are lower in the Borders - but then maybe care services are cheaper too (wage rates may be lower).

Carers are needed not just to look after you in the house; they could also take you to the cinema, swimming etc. - your 'quality of life' needs.

Derek has ILF and DP funding and he is responsible for the care he receives, with some help from his brother and Jack. As you get older you do need a bit more care. The Lothian Centre for Independent Living (LCIL) will help you with all the tax. NI etc. if you need it. If you employ an agency is simpler, you are then not an employer, but you have slightly less control over the services you receive.

Jack said he is happy to take more questions, or his care team has an advice line: 0131 652 3229. They can do something for you if you live in Edinburgh but if you don't they can still give you general advice. Alternatively, you can contact Jack through Derek 0131 477 4371. It is VERY important that you get on with your ILF application before you are 65, it comes very quickly. Once you are past 65 you can't get the extra help. Also remember that if you are receiving a service, DP etc your needs should be reviewed on a regular basis.

Derek then thanked Jack for coming along and giving us such an interesting and informative talk.

4. Treasurer's Report

Since our November meeting:

Income

Richard collected £210 sponsorship for Branch funds by running a 10k marathon and Anne-Marie's knitting brought in another £23.

Mark White from Dundee, who came by train to our Falkirk wheel outing, passed away suddenly a few weeks later aged 37 which Frances said she had enjoyed chatting to him so it was a bit of a shock. We sent his Dad a card on behalf of the Branch and he replied with a nice letter and £200 donation for Branch funds.

Other income includes the regular standing order from Mr & Mrs Smith, Richard and Anne-Marie's friends, two collecting cans of £16.90 and £10 from John Reid's can in his house, £1 from the sale of the book of Susan's stories and a donation of £20 from John Hunter. Total income was £535 including the money just brought in by Richard & Anne-Marie today

Expenditure:

£79 for Secretary's costs of stamps, stationery and photocopying. £40 teas, coffees and refreshments at November and January meetings. Total expenditure since our last meeting £216.60.

The bank balance was £1,304.24 at the end of December 2006 and we are now getting a better rate of interest. Frances also has details on someone to contact if anyone wants to know how to get a computer. Finally, thanks to everyone for their fund raising efforts throughout the year.

5. Secretary's Report – Branch Website News

The Branch website (<http://www.ataxia-east-scotland.org.uk>) has now had nearly 1000 visitors. If you have ideas for any other content pages or useful links on our site, please let Penny know: info@ataxia-east-scotland.org.uk. There is a ClustrMap on the home page of the site which shows where in

the world our users live – so far it includes people from North America, South America, Iceland, Turkey, South America, Australia and Fiji!

Due to the volume of spam being generated, all automatic mail links have been removed, apart from the two that link to the secretary: penny@ataxia-east-scotland.org.uk and info@ataxia-east-scotland.org.uk. This means that people making genuine enquiries can still contact us, but the other links are disguised eg DerekATataxia-east-scotland.org.uk so if you type this in replacing AT with the @symbol, it will work.

6. AOCB

We are sorry to report that Arthur Davies passed away on 5 January, unexpectedly but peacefully. Penny sent a card to Lorraine and family on behalf of the Branch and our thoughts are with them all.

7. Dates of Next Meetings

The next Branch meeting will be held at Lasswade on Saturday 17 March 2007 from 1.30pm to 4pm and the AGM will be held on Saturday 12 May 2007. We have also provisionally arranged Branch meetings for Saturday 22 Sept and Saturday 17 November. We may go for a 'Christmas' meal to the Laird & Dog pub in Lasswade after the November meeting.

YOUR COMMITTEE

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USEFUL WEB LINKS

If there are any suggested additions to this list please let us know

www.ataxia-east-scotland.org.uk: our Branch website

www.ataxia.org.uk the Ataxia UK website, it has many good links.

www.ohbother.co.uk: by an Ataxian and full of very useful information.

www.bbc.co.uk/ouch for an inside view on disability news.

www.evoc.org.uk: for local disability information in Edinburgh.

www.digg.org.uk: Glasgow's online resource for disability information.

www.gig.org.uk Genetic Interest Group

www.matchinghouses.com: re: accessible holiday house swaps.

www.skill.org.uk information & advice for disabled students

E MAILED REPORTS

If you would prefer an e mail instead of a hard copy, please let us know your e mail address:

Name _____ Telephone No. (optional) _____

E Mail address _____

Please post to the Secretary, Penny Gardner, at 3 Craigleith Gardens, Edinburgh EH4 3JW or e mail penny@ataxia-east-scotland.org.uk

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MEMBERS VOLUNTARY SUBSCRIPTIONS.

Please send a contribution if you can - £5 per household is suggested,

Please send a cheque, payable to East of Scotland Branch of Ataxia UK to: Frances Wright, Flat 8, 25 Queen Charlotte Street, Edinburgh EH6 6AX