

**REPORT OF THE MEETING OF THE EDINBURGH AND LOTHIANS
BRANCH OF THE ATAXIA GROUP
LASSWADE HIGH SCHOOL CENTRE,
SUNDAY 3 SEPTEMBER 2005**

Present: Derek Main (Chairman) Jack & Nancy Blaik (with Nathan the guide dog), Pete & Liz Dalby, Penny Gardner, Faye and Andrew Hogg, Lesley and Andy Pringle, John Reid, Richard, Anne-Marie and Selina Thomson & Frances Wright

Apologies: Sheree, James and Michael Allan, Janice Heath, Anne Mitchell, Jim, Essa, Fraser and Lynn Quin & Alan Smith,

1. Welcome and Minutes of last Meeting

Everyone introduced themselves. The report of the AGM held on 14 May 2005 was approved.

2. Chairman's Introduction:

IAAD International Ataxia Awareness Day, 25 September 2005

This will be running for the 6th year, all across Europe, and aims to:

- Tell more people about ataxia
- Help more people understand the effects of ataxia
- Help raise funds for research into treatments for ataxia.

Ataxia UK Head Office has asked Derek to suggest ideas how our Branch could celebrate this. Ataxia UK's chief executive, Alastair Macdougall, is coming up from London to address the Scottish Executive on 27 September. Our Branch BBQ on Saturday 24 September & the Falkirk Wheel boat trip on 2 October are near enough to be included, so we decided not to do anything on Sunday 25 September as well – unless anyone has ideas? It's also maybe worth contacting the Herald & Post newspaper to see if they can give us any publicity. Janice Heath of the West of Scotland Branch arranged a donation from the Daily Record – it could be worth contacting them again too. The West of Scotland Branch has a fundraiser night on Friday 30 September: 0141 942 3115.

3. Secretary's Report – Branch Website News

The Branch website is finally up and running with 1&1 web hosting; the address is <http://www.ataxia-east-scotland.org.uk> The hosting offers up to 500 email addresses for branch members, so if you would like to be included, please let Penny know: penny@ataxia-east-scotland.org.uk. Your email address will be yourname@ataxia-east-scotland.org.uk. Any emails will be forwarded to your private email address, which will not be published on the website. The web costs will be about £80 p.a. which includes web hosting, some software and the domain name. Katie Henderson of Ataxia UK will be creating a link to our site on the main Ataxia website. If you have ideas for any other useful links on our site, please let Penny know.

4. Treasurer's Report

Frances reported that it has been quiet since the AGM on 14 May. We have joined the SDEF (Scottish Disability Equality Forum) at a cost of £5 pa. John Reid paid in £27.09 from recycling aluminium cans, Derek's brother and friends ran the Edinburgh marathon, splitting the proceeds between our branch and the Sick Kids Hospital: our share is £227 so far, with more to come. £30.75 came from collecting cans (Derek and Penny) plus other monies making £87.82 in all. The Smiths are still making their regular monthly regular donation. Penny had expenses of £120 on the website, postages and photocopying. Although the bank balance was low at the AGM (after making a £2,000 donation to Head Office) it is now £935 and going up. Frances is still looking into CAF (Charities Aid Foundation) Bank but needs to be sure that we can pay cash in eg collecting cans money.

5. Jack Blaik's Talk

Jack is a Senior Social Worker with the City of Edinburgh Council, ILF (**Independent Living Fund**) contact officer and part of the DP (**Direct Payment**) team. He introduced Nancy, his better half and memsahib! and Nathan, Nancy's guide dog. He expected to talk for 30 minutes on Direct Payments, then take questions in the tea break. He brought leaflets on the Social Work Department in Edinburgh, his business cards, and leaflets on DP and the ILF. At the end of the talk he would refer to the ILF, but would be focussing mainly on Direct Payments.

What is the Direct Payments Scheme?

To put it simply, it's a payment instead of receiving a social work service. The public get mixed up with different allowances they receive, paying for care, daily living etc. The DP scheme is very different: it is not connected with the benefits system; there is no relationship between them at all. Payment is made from the Social Work department, instead of the assessed service that you need, for example home care, respite care, transport, laundry. If you are provided with such services by Social Work now, or if Social Work have made a commitment to providing a service ie has assessed you as needing it, then you are entitled to take DP instead and buy your own service. The DP scheme gives you the funding behind the service.

What are the advantages of Direct Payments?

You can choose the services flexibly as & when it suits you. For example, a council run day centre may only be available 9 – 3 or home helps 9 – 11 etc. You cannot choose when or who is providing the service and you may not be happy with it. It's structured to suit the provider. The DP scheme frees you to design your own service, so you could have someone coming

in at 5pm instead of 9am and if you don't like the person employed you can change them.

How do I buy an alternative service with Direct Payments?

There are 3 ways to do this:

1. Buy the service from the local authority. This is VERY rare, only 2 in Scotland that Jack knows of: 1-2% of people. Usually people take DP because they are not happy with the local authority service.
2. Buy from an agency in the private / voluntary sector eg Leonard Cheshire, Capability Scotland (day care), Church of Scotland (respite care) etc. This is more common: about 35% of people.
3. Buy in your own private care / personal assistants. In law you take on responsibilities as employer, and need to set up systems to help with payroll etc. It is like running a very small business, which can be a bit daunting at first. However, there are many organisations which will help you to set it up. People like to use it because it gives almost complete freedom & control. You can employ a non-resident family member, friend etc (not resident family member). It's the most common, dominant model: about 65% of people.

How are Direct Payments received?

The payment comes from the Social Work Department (in Edinburgh 13 weeks in advance, other councils may vary). You have to declare your expenditure at the end of each period. If it was less, then the DP will be reduced next time. If it cost more, there will be no more cash, but if a top up is needed from your own income, you may need to go back to the local authority & look again at the basic design. This makes DP a completely different system: no other form of payment or benefit is monitored in this way (eg DLA, the Disabled Living Allowance).

What problems are there in getting Direct Payments?

It can be difficult to get DP, hurdles may be put in your way. Some local authorities can be more helpful than others. Most local authorities are strapped for cash and have limited resources. The key thing to focus on is the bottom line: if the local authority would provide you with a real service, then you actually have right in law to money instead of the service. The local authority cannot choose, the **MUST** make the payment, it is a positive legal duty. Evidencing that the local authority would otherwise provide the service eg 10 hours home help, 3 days day care = a promissory note to receive payment in lieu of that service. Not complying has left local authorities open to legal action since June 2003: it's no longer optional, now it is compulsory.

What's the History behind Direct Payments?

Where did the idea come from? It originally came from disabled people themselves. At the end of the Great War in the UK, ToCH made payments to men coming back from trenches for equipment and personal care. In late 1960s California, disabled people felt that institutions were not good enough, and demanded that individual payments be made instead; these were radical, young disabled Americans. Modern technology and the internet from the early 1980s meant that these ideas spread. The DP scheme has been road tested in thousands of lives, and used successfully – no one ever wants to go back to being provided with services once they have had the freedom to choose for themselves.

Other Benefits of Direct Payments

Jack then commented that their own son is severely disabled, and they get DP themselves for his needs, they would not want to get back to home care. Nancy said that many of the care assistants provided were awful, many not trained. With DP you can choose your own carers, it's up to you. If an agency is bad, dump it and go to another. Better to have someone you know that's good. Train them yourself or get training for them eg a handling course. Many training organisations eg LCIL (Lothian Centre for Integrated Living) give support.

Their son's carers were used to elderly people, not youngsters and came once a fortnight eg at 10.00 after breakfast was over – no use at all! Another problem is that home helps are not allowed to be in the house on their own, so you can't nip out and leave them to get on with the work. With your DP you can employ your own people and can them to do the tasks you want. You just need to get insurance (it's not expensive).

Are Direct Payments available to everyone, regardless of age?

Direct Payments have no age limits. They can apply to any person of any age, whether receiving DLA or not. For example, if getting a home help costing 13 per hour (real cost), and you have assessed as needing to pay a contribution of £6, you will get paid the difference of £7. Another small advantage is that rather than paying the real home care service bill of £6 per hour, you can stop the physical payment of the council's bill, and instead control how you use your own contribution.

Other questions on Direct Payments

Does the DP scheme apply to **equipment**? You can pick & mix; taking DP for your home care & staying with the local authority for equipment eg bath aid. But if the local authority would provide a basic bath aid for £200, you can take the £200 as a DP and add your own £100 to get better model.

Are the **charges** people have to pay fair? Charging policies are set by politicians. If people need care & have money available, then you must pay. Each local authority has power to set its own charges. Orkney doesn't charge anyone, everything is free.

Direct payments for **respite care** can work a bit differently, as it's a very irregular service. Someone may not use it in the 13 week period, but double in next period to get 4 or 5 weeks. A note can be made on the declaration form to carry the amount forward. Direct Payments are NOT your income or savings. It's the income of the people you employ and should not be taxed twice. Do not declare them for tax.

One member said she has to pay for everything, as Social Work have said her husband should do it all. Jack advised her to apply and say she needs the service. A partner cannot be expected to be available 24 hours a day, especially if working. Then she will get assessed, get it in writing if possible: if the answer is yes then she can ask for DP. A partner's income will affect the charge which would be made for the service, which will deducted from the DP.

Another member asked: If you have been previously assessed for a service and granted it, but not happy with it and turned it down – can you still get DP? Jack said that you can still ask for DP instead of service because you were assessed as needing it. You don't have to prove the service was unsatisfactory, because you are entitled to DP as a legal right. It's an advantage to have been assessed originally as needing it; best of all to have something in writing.

Another member commented that the Social worker can offer to help you, then fight you all the way. Jack said that social workers can be poor, as can agencies. Many local authorities don't wave the flag of DP – but as the money paid is always equal to or less than the cost of the service, some social work managers are clued up and realise that this can mean savings to their budgets. Is fear of job loss a factor? Unison can be a strong opponent of DP, for example day centres may have to close – but are the services any good? Members commented that many are rubbish.

Independent Living Fund (ILF)

The ILF is similar to DP but different. It's from central government and provides a top-up to your DP or services; a bonus extra. The scheme is very generous, with a small target population. If eligible, you can receive up to £420 pw. You must be aged 16 – 65, in receipt of the highest rate care component of the Disabled Living Allowance (DLA) and also receive at least £200 pw of social work services or the DP equivalent. It buys the quality of life stuff. eg swimming, shopping, horse riding, education etc.,

especially important if your condition is progressive. It's not taxed. You don't get charged twice for services, so if you are already paying the local authority for a means tested component, ILF won't charge you. The ILF payments are retained for life, so long as you get in before your 65th birthday.

6. BBQ Sat 24 September 2005 – Almondell Country Park

Pete & James have offered to do the cooking. A small charge will be made: £3 per person, £1 for kids to cover the hire charge, sausages, burgers, soft drinks, rolls, charcoal etc. Bring along anything else you want to cook – we will start at 12.00 and finish at 5pm latest. People who have said they will come are Arthur Davies & his wife. Richard and family (5), Frances (2 or 3), Derek, Pete & Liz, the Allans (5) and the Quins (4). Other possibilities are the McPheats and John & Anna Thomson. Ring Derek on 0131 477 4371.

7. Barge Trip Sunday 2 October 2005

Should we meet in town or there? Does everyone have transport? As it's 2 hours on the boat, bring a packed lunch or there's a coffee shop there. The trip is free but we usually make a donation to the Seagull Trust. Who wants to come? Pete & Liz, the Hoggs (2) and the Quins (4). The maximum number is 12 and we need to know how many wheelchair users will be coming. Ring Frances on 0131 555 5665 or post the form (at the end).

8. Other social events

2005 is the 10th anniversary of the Branch, and the 40th anniversary of Ataxia UK. Derek suggested having a Branch Christmas meal this year- the Braid Hills Hotel is doing a special £17.50 pp. Sunday – Thursday, maybe we could try for the beginning of December? Who is interested? Derek is investigating whether or not we'll get a discount for not needing the disco.

10. Ataxia Conference and AGM 7 – 9 Oct in Birmingham.

This is the Ruby anniversary of Ataxia UK (40 years). Lesley & Andy Pringle are going. After the first hotel messed up the booking (having no rooms for Ataxia attendees), they now have a better hotel at good rate: £99 per room B&B. Derek is going too, from Friday – Sunday.

11. AOCB – Fund Raising

Pete reported that a company called Blaze looking for people to walk over hot coals to raise funds. Strangely, there were no volunteers for this.

Rebecca Orr from Head Office has asked if we have anyone wanting to run in Ed marathon next year, as she can book places on behalf of the group. People must raise a minimum of £500 each to qualify for a place. Is there anyone wanting a place in the marathon & able to raise £500? Please let Penny know as soon as possible on 0131 332 518. We don't know if

spaces in the Edinburgh marathon are at a premium – if not, there seems little point in Ataxia UK paying to reserve them!

Derek has investigated and the Assembly Rooms hypermarket is not running this year. It was very expensive to book a stall and not enough people attended. Finding enough volunteers to staff it can be a problem too. Nancy Blaik reported that EVOG used to run it, but the last time only one hall was used and they could hardly sell anything. She suggested a tombola as the best way to raise money, you get money for nothing and there's nothing left at the end to take home! You can ask shops eg John Lewis to donate goods. Another good stall is to have wine bottles in carriers with covers over them, people have to guess which is the full one, if correct they win one bottle of wine. They made £200 from at the fair on Leith links last June.

Anne-Marie Thomson has been knitting toys and making gift tags. She needs donations of wool and old foam pillows for stuffing. As the Hypermarket is not running this year we need to find an alternative venue and/or sell goods on the website. Penny will set up an email address for Anne-Marie and a web page with photos.

12. Vote of Thanks

Derek thanked Jack on behalf of the Branch for his interesting and informative talk. It was good to see so many people at the meeting and we hope for an even better turn out in November. The November speaker has not been decided, but we will let you know.

13. Date of Next Meetings

The next Branch meeting, will be held on Saturday 12 November 2005 at Lasswade. Then 21 January 2006 (Burns supper), 11 March (provisional), 6 May (AGM - provisional).

YOUR COMMITTEE

Chairman	Derek Main	0131 477 4371 derek@ataxia-east-scotland.org.uk
Secretary and Vice-Chair	Penny Gardner	0131 332 5218 penny@ataxia-east-scotland.org.uk
Treasurer	Frances Wright	0131 555 5665 (to be set up soon) frances@ataxia-east-scotland.org.uk
Committee Member	John Reid	johnreid@ataxia-east-scotland.org.uk
Committee Member	Liz Dalby	
Email committee Member	Susan McPheat	

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

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

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

BARGE TRIP

These trips are free, but we usually make a donation to the Seagull Trust so a small contribution would be appreciated on the day. If more than 12 people apply we may arrange a repeat visit another time. Bring a packed lunch.

If you would like to come on the boat trip to the Falkirk wheel on **SUNDAY 2 OCTOBER 2005**, please complete the form below and send to:

Frances Wright, Flat 8, 25 Queen Charlotte Street, Edinburgh EH6 6AX

I would like to come on the boat trip to the Falkirk Wheel:

Name(s) _____ Telephone No. _____

Address _____

Number of People _____ including number of wheelchairs _____

BRANCH BARBECUE

We will be making a small charge to cover the cost of hiring the site and food costs: £3 per adult, £1 per child under 10.

If you would like to attend the Branch barbecue on **SATURDAY 24 SEPTEMBER 2005**, please complete the form below and send to:

Frances Wright, Flat 8, 25 Queen Charlotte Street, Edinburgh EH6 6AX

I would like to come to the Branch Barbecue:

Name _____ Telephone No. _____

Address _____

Number of Adults _____ @ £3 per person

Number of Children _____ @ £1 per person (babies free)