

REPORT OF THE MEETING OF THE EAST OF
SCOTLAND BRANCH OF ATAXIA UK
LASSWADE HIGH SCHOOL CENTRE,
SATURDAY 17 MARCH 2007



<http://www.ataxia-east-scotland.org.uk>

Present: Liz & Pete Dalby, Penny Gardner, Andy Hogg, Derek Main (Chairman), Peter Smeaton and Frances Wright.

Apologies: Andrea Bothwell, Rhona Brankin, Anne Green, John Hunter, John Reid, Jim Shepherd, Alan Smith, Richard & Anne-Marie Thomson and Professor Robert Will.

1. Welcome and Introduction

Derek welcomed everyone to the meeting and commented that the usual introductions were not needed as we all knew each other. Although many people cannot attend the meeting they enjoy reading the reports and we are happy to keep sending them. Derek has had two Occupational Therapists on the phone regarding two more possible Branch members: one in Penicuik and one in Clackmannanshire. We hope to hear from them.

2. Report of 20 January 2007 Meeting

The Report of the meeting on 20 January 2007 was approved. The report on Jack Blaik's talk contained a lot of useful information.

3. Talk by Peter Smeaton

PREAMBLE

Narrated by Penny Gardner for the Branch meeting on 17 March 2007.

Keep with **places, people, things** and go easy on the abstract is good advice to speech makers. I cannot respect the last one and to atone for this I have printouts for you - the real heading for today is **TIREDDNESS**.



Peter's Dad

Place - I was born in Station House, Tynehead near Gorebridge quite near here. Dad was the Station Master and had the post office concession too and this was housed in the booking office on the platform. In those days very few people lived more than twelve miles from a station. Throughout his career Dad was responsible for making duty rosters and if someone was not available to work usually another would be: he would post this as Smith **vice** Jones, **vice** meaning one who acts for another.

When in 1969 the Waverley route between Edinburgh and Carlisle closed it

was a case of road **vice** railway. Tiredness for those with CA requires an understanding of cerebrum **vice** cerebellum.

People - Three doctors: two neurologists and one anatomist feature here. The neurologists are Dr. Rajith de Silva and Dr. Paola Giunti; they answered the questions at last year's Ataxia UK Conference. The answers feature in a supplement to the current copy of the Ataxian Magazine.

From page five two quotes from Dr. Giunti, are:

- In general keeping fit is a very good thing.
- I personally do not recommend any specific therapy for fatigue.

Two quotes from Dr de Silva are similar,

- I advise patients to keep active and to exercise.
- Generally speaking, fatigue complaints are quite common in ataxia patients.

To Peter tiredness and fatigue are interchangeable Dr. de Silva also recommends short sharp bursts of exercise, Peter's comment is "do we have the revs?" Also attributed to him is advice of prolonged bed rest for the next 48 hours! Peter wonders if the word **bed** is a mistake. Forty eight hours between for full routine of exercises and/or social events fits with the talk on tiredness.

Dr. Alice Roberts, the third doctor, fronted the recent BBC 2 programme on **organs**. In each episode she did a cameo sketch to highlight a point. When she did the episode on the brain, sleep was limited to four hours for three nights. Communication, concentration, memory and coordination all suffered. If we with CA were deprived of sleep in a similar test the results would be magnified, as well as being grumpier than usual our coping strategies would be compromised and furthermore coordination, which is suspect to start with, would be zero.

Things - are exercises and brain considerations. Recently my Bradford group was addressed by a physiotherapist and I take the liberty of passing on her handout to you. A second handout is a routine of exercises that benefit me.

The brain is largely cerebrum - seven eighths of the three pounds the brain weighs - this is like the cap of a mushroom. The cerebellum is bush like and is at the back and mainly under the cap it is less than one eighth say $\frac{3}{32}$ (three thirty-seconds) the rest is the stalk of the mushroom and is $\frac{1}{32}$ (one thirty-second). The brain uses 20% of all the oxygen the body takes in and it is only 2% of the total body weight so it is very active and tiredness mirrors this.

TIREDNESS

Physically and mentally the Achilles heel of the ataxia sufferer is tiredness. In Friedreich's Ataxia energy levels are low and with Neurological and cardiac issues tiredness must loom large. All SCA's have dominant inheritance and are numbered whereas Friedreich's Ataxia is a recessive condition and does not have a number.

The cerebellum is the brain's auto pilot and when it is working the cerebrum (also known as the cerebral hemispheres) which is the 'pilot' has only to initiate, monitor and stop most of the mechanical actions of the body. We with CA do not have a functional cerebellum and fortunately in cerebellar failure the cerebrum takes over.

Now these extra cerebral tasks **vice** the cerebellum are conscious too. With risk assessments the extra cerebral work added to its own work all amount to tiredness. The contrast with normal is a dismal one. The brain when tired needs seven or eight hours sleep to regain full wakefulness and we with CA need quite a lot more. It is prudent to avoid events on consecutive days and in my exercise routine easy and hard days alternate.

A good analogy of the cerebellum and cerebrum is a football team. The cerebellum is the striker who is explosive, agile, strong and tends to act instinctively. To be cerebral usually means studious, brainy with high IQ. In the context of the team the centre halfback anchorman is very clever and can read the game and I choose to call him cerebral, the adjective of cerebrum.

The human cerebrum is big and in evolutionary speak this is called encephalisation. This applies to the brain in general but it really refers to increasing cerebellar size, a response to complexity. As you ascend the animal kingdom, say the section with backbones, it is amphibians, fish, reptiles, birds, mammals, and a bigger brain relative to body size evolves. In creation theory terms only man can look back and forward in time. Stored memory, the present and imagining the future requires a large cerebrum. Anyway, all the spare capacity is most fortunate for CA people enabling us to cope.

Coordination is the orderliness of movement of skeletal muscle. CA's lack coordination and this is exposed by tiredness. There is no short term fix. In the long term physical fitness helps and sleep, strength and suppleness all improve. Ataxia and tiredness make a recipe for depression. The frustrations of ataxia and tiredness are risk factors for bi-polar disorder.

Last verses of Burns' "To a Mouse" and concluding sentences for a person with the Scottish tongue to read. Readings by Frances Wright:.

But Mousie, thou are no thy lane,
In proving foresight may be vain:
The best laid schemes o' mice an' men,
Gang aft agley,
An' lea'e us nought but grief an' pain,
For promis'd joy!

Still thou blest, compar'd wi' me!
The present only toucheth thee:
But och! I backward cast my e'e,
On prospects drear!
An' forward, tho' I canna see,
I guess an' fear!

- The whole thing is vera difficuult.
- Pit a stoot hert tae a steep brae.
- It's a sair fecht if you weaken.

Burns lived roughly 100 years before Darwin, therefore had no origin of Species to refer to; he had no choice but to be a creationist. Also, have we seen the Ataxia conference Q&As? (from the recent Ataxian magazine) - the last Q is Peter's

Depression in long term illness is a common battle & it could be worse for people who are 'half empty' than people who are 'half full'.

Peter also commented that, with tiredness, people like him get a warning when they start to stumble, so stay abstemious - but when in a chair can have a drink & wait for other people to take you home. Do they get a warning before? Can they indulge a bit more? Liz finds a drink helps her to stay steadier. She becomes more relaxed, concentrates on the foot less, looks ahead more. CoQ10 can allay the fear. One chap in Birmingham developed FA as a teenager, pals would take him home. Carrying a stick can indicate to drivers that you are unsteady. We discussed driving, and people thinking you are drunk when you're not.

Peter showed us his shirt which has a zip instead of buttons. The company (Lapidus) don't make them any more, unfortunately.

When they started to fray he turned the collars, now when they wear out he gets the zip changed to a new shirt. The girl next door charges £5 to do it. Here's Peter demonstrating his shirt!



Peter's Shirt

In the cerebrum there are a million million cells (a billion) but in America a billion is 1000 million so they have more than us!

Andy's been having physiotherapy at the Astley Ainsley over the last 2 months, with the OT stretching and moving him, but he has not felt much benefit. Does it make your back stronger? Derek said there may be a limit on the number of sessions allowed (due to costs). Derek's foot is turning in

and he's been referred to the department of clinical sciences. There's a two weeks wait, no referral so far. Liz recommends trying a reflexologist. GP's don't know much about ataxia, there's a general lack of awareness.

Peter was thanked for his interesting talk. Questions were raised as we went though.

4. Meeting with West of Scotland Branch 28 April

We are repeating the successful event of last year and the Inverness support group are joining us too. Meeting at the Alona Hotel, Strathclyde Country Park for a get together with sandwiches, 1.30 – 5pm. It will be good to go and meet people from other branches again. Please email Anne Green directly if you'd like to attend: westscotland@ataxia.org.uk or ring Derek on 0131 477 4371.

5. Treasurer's Report

Frances reported on the income and expenditure since January:

Income: Total income is £370.

This morning Frances received a sad letter from Susan Campbell and a cheque for £200 in memory of her Mum Isobel Haddow who died on 2nd March – there was a collection at her funeral. Susan asked for it to be used by the Branch or passed on to the research programme. We send our sympathies to Susan and family.

Standing orders: Claire Shepherd has started a monthly £10 & Mr & Mrs Smith are generously continuing their standing order of £10 per month. Other income was mostly subs. Andrea Bothwell sent a cheque for £75, a mix of subscriptions & general fund raising. Other subs from all members totalled £75. 3 collecting cans brought by Derek to the meeting have not yet been counted: 2 from Lasswade and 1 from the Braid Hills Hotel.

Expenditure: Total expenditure was £111.28. £81.28 stationery & website costs. Teas & haggis meal at January meeting was £30.

At 26 Feb the balance was £1,652.24. Frances & Penny will be getting together to do the accounts for 2006/07 in the next couple of weeks. These are due at Head Office in early April. Also, Frances has received a letter from our bank, the CAF Bank, saying that they now have over 20,000 charity accounts.

6. Secretary's Report – Branch Website News

The Branch website (<http://www.ataxia-east-scotland.org.uk>) has now had over 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 to 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!

7. AOCB

We were shown an article from the Sunday Post on March 4 2007 about Brian McNeill, from Argyll, who has a family history of Ataxia.

Elizabeth Cassidy is carrying out a research study at Brunel University on physiotherapy. Fliers are coming in the post, will be posted out with report. Derek is keen to participate – they will pay travel costs but it's a long way to go for a 1 hour interview. If enough people are willing to be involved they may travel here to carry out the interviews. They are looking for people with CA to participate in a discussion group to talk about living with ataxia, strategies to maintain activity levels and physiotherapy treatment. Please phone 01895 268736 or email elizabeth.cassidy@brunel.ac.uk for details.

We discussed another mailshot to GP's (notice to display in waiting room).

The Seagull Trust are running new cruises in 2007, taking bookings now from April to late October eg Falkirk wheel. Frances is willing to organise it.

Leaflet on fire safety for people with sight, hearing or mobility difficulties.

Pete had phone call from Kate working from Head Office following up the feedback on Tina Thatcher's post. Head Office are putting in a bid for more money to keep her. Pete said that it's great that so much information is coming out voluntarily. Tina's been great at keeping us informed.

We discussed any other social activities and fund raising. Suggestions included the Bo'ness railway, Scottish Parliament. Regarding the latter, Derek offered to contact Rhona Brankin about the possibility / dates etc.

Is it time we asked for one or two more issues of the Ataxian magazine a year? Maybe five plus a conference one? After all, the Editor is always saying she has too much stuff to fit it in. We all like it and read it from cover to cover. The Branch committee is strongly in favour of this and will put the suggestion to Head Office.







Penny (the Branch Secretary) informed members that Derek has agreed sharing the Branch website hosting with her for her personal use – this will halve the costs to the Branch. We are only using a very small part of the space available (20MB out of 1500MB) and Penny will be using about 20MB more. The websites will be completely separate.

Derek asked about an article from the newspaper that Frances brought along to the last meeting about disabled people getting computers, but she doesn't have any more information on this.

8. Dates of Next Meetings

The next Branch meeting (the AGM) will be held at Lasswade on Saturday 12 May 2007 from 1.30pm to 4pm. We have also arranged meetings for Saturday 22 September and Saturday 17 November. We're hoping to go for a 'Christmas' meal at the Laird and Dog in Lasswade after the November meeting.

YOUR BRANCH 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 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
		

ADDRESS FOR MAILING:

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Penny Gardner, Branch Secretary
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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