



A WORD FROM THE AE EDITOR

Welcome to the (larger than usual) 21st edition of (Contaxia) the AE newsletter.

Hope you didn't get flooded, I can't begin to imagine what it would be like to live on living my own and be flooded out, especially being disabled and in a wheelchair.

My sister (Katie) & my stepfather (Roger), both completed the (gruelling) Skegness to Boston sea-bank marathon, raising a considerable sum for *Ataxia East*.

couple from many that were taken on the same sunny day:



In the first part of the afternoon we talked about the setting and planning of meetings, all to make it better for our members to enjoy and socialize better, many ideas were put forward to encourage better participation. All groups seem to suffer from low attendance at meetings.

The meeting was completed by a Consultation with Sue Millman on the way forward for Ataxia UK, in particular the conference and the



Some of those attending

new membership proposals which does away with a subscription but relies on donations from all 'friends'. More will be in the next Ataxian or at our meeting in October.

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### KIRSTIE'S HOLIDAY IN CYPRUS

I have recently returned from a holiday in Cyprus. Although I have been abroad before, this is the first holiday I have been on since I have been confined to a wheelchair and also my first holiday abroad without my parents. As you can imagine because of this I was very nervous but at the same time very excited.



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AE NEWS

As was reported in the last edition of Contaxia, photos of the AE Chairman Dave and his wife Sue (AE Secretary) and AE Editor Simon and family were taken by Ataxia UK's photographer (back in May), for use in future Ataxia UK publications - here are just a



ATAXIA-UK BRANCH COMMITTEE MEETING

As part of the AUK's development of branches, Sue and I attended the meeting at Leicester University on the 14th July. Attended by Sue Millman, the new CEO of Ataxia, and Tina Thatcher, the branch development officer, there were representatives from South Downs, London, East Sussex & Kent and AE. Lasting all day, we discussed the legal requirements of the Data Protection Act, sounds boring but we had a real good time debating the subject among ourselves with the guidance of Bina Cohen and Becky Hickland from Voluntary Action of Leicester.

I flew with British Airways and although I had told them a year previously, and several times in between, that I couldn't walk, they were still very unprepared and had no record of this - not a good start to the holiday! To make matters worse they put me on row 18 so they had to drag me on one of their aisle chairs all the way down the plane.

I decided early on that I would take my own electric wheelchair with me. You can hire them out there but they cost a hundred pound a week, which I thought was expensive considering I had my own. You could also hire out other aids such as electric scooters, commodes, monkey bars etc but obviously you had to let them know before you got there so they could have them ready for arrival.

I stayed in C and A tourist apartments, which is run by a lovely family whose son has FA. We were collected from the airport by the father, Andreas, in an adapted taxi so I didn't even have to get out of my chair.

When we arrived at the apartments we were greeted by my Eva and Chris - mum and son and they gave us a hug as if they already knew us!



Me and my friend had 2 separate apartments which were linked by intertwining doors which was a nice touch - privacy but not totally separate. The bed was at the perfect height, as were all the work surfaces in the kitchen and there were plenty of grab rails for me in the bathroom - it was just as

suitable as back home so I was very impressed.

Leading from my back door was a patio area and a ramp that led to the swimming pool which had a hoist for easy access. I haven't been in a swimming pool for 5 years because of getting in and out so I spent the whole 2 weeks in there!!! They had these great inflatable armchairs that you could sit in - great because the weather was scorching for the whole 2 weeks. They also had raised sun beds for easy access by the side of the pool.

By the pool was also a bar area and this is where Eva cooked her gorgeous breakfasts for her family and guests if you ever tempted!!

In the local area it is well ramped and a lot of the restaurants have raised their tables so wheelchair users can get under. There is also a pub about 2 minutes away from the apartments that has a disabled toilet - bit on the small side but you can manage. The local supermarkets are not disabled friendly - even if you can get in you won't be able to move around because there is stuff everywhere - all over the floors!

The beach is about 15 minutes walk away which also has a ramp so you can literally touch the water - Chris, the son, really has worked hard for his rights and so far so good.



In a nearby harbour town called Latchi, there is a glass bottom boat that has ramp access. They even have a hoist on the side which allows us to go and swim in the sea. I went on that trip twice and I

thoroughly enjoyed it and would definitely go again.

The thing that makes this holiday stand out is the family who run the apartments. They really welcome you into their family and straight away everyone is so relaxed. You really bond with the other guests too and you end up going out in the evenings together. I met some amazing people and we have all kept in touch and we are all going back next year on the same date which is fantastic!

It's just a shame I had to come back to all this rain!!!! www.ca-touristapts.com

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## ATAXIA~EAST MEETING NOTES ~ 30-JUNE- 2007

### Introduction

Dave Stublely welcomed everyone and introduced Jenny Bell a Clinical Exercise Physiologist who was to give us a talk/demonstration on exercises that we could do to help us keep mobile with our ataxia.

### Present

Alison Crosby, Jenny Bell, Sue Howard, Gerry Howard, Sheila Jones [Fundraising], Terry McKenna [vice Chair], Maureen McKenna, Dave Stublely [Chair], Sue Stublely [Secretary], Arnold Turland and Doreen Taylor

### Apologies

Lesley Gordon [Treasurer], John Hackett & Margaret, Kirstie Jones [Fundraising] Shaza Jaffer, Jean Pearson, Bob Robson, Mona & Keith Taylor

Jenny Bell gave us an excellent and interesting talk on exercising with ataxia, demonstrating various exercises that could even be done in a wheelchair. Everyone benefited as Jenny tried to help everyone do variety of movements. A Clinical Exercise Physiologist is a study of the way the body works, it can prevent any oncoming diseases and ca

with everyday life. Individuals need different exercises depending on their circumstances. Flexibility of movement in joints and muscles helps you keep moving and improves strength in the legs which is essential

Jenny has produced a simple 'explanation' to the exercises, which has been produced separately so that you can use them to help when you do your exercises?



**Jenny putting Arnold through a few exercises.**

After that exhaustive exercise we all enjoyed the mandatory cup of tea with cakes and biscuits. It put a bit of energy back or fat on!



**Maureen presents Dave with a cheque from the Rotary Club of Peterborough**

The next part of the meeting we heard from Mrs. Maureen McKenna from the Rotary Club of Peterborough and Terry's sister. Maureen was here to explain the fundraising side of Rotary and to present Æ with a cheque for £750. Money had been raised through the Fireworks Fiesta at Ferry Meadows and goes to local charities. Æ had been selected through Kirstie Jones's activities; she had been on a Calvert Trust Adventure holiday sponsored by

the Rotary Group. Kirstie had then returned to the group and given a talk about her experiences on the holiday. So Thanks must go to the Rotary Group of Peterborough and Kirstie for her efforts in promoting our cause.

### Updates

#### **Membership**

When having to do the returns for the annual report to AUK they had informed me that several members of Æ where not 'Friends' of AUK, it is hoped that these Æ members can be persuaded to contribute towards AUK. A note would be added to their copy of Contaxia when next produced.

#### **Focus Group**

Can anyone help in the AUK Focus Group at Æ by getting together and discussing their experiences and problems in getting a diagnosis or help from the specialists. 6 people have offered so far. The date is to be Tuesday 14<sup>th</sup> August and run by Laura Stewart [Research Officer] for AUK. Lunch will be provided and travel expenses paid to those that need it.

#### **AUK Staff Changes**

Some have been reported in the latest Ataxian, but many will not know that Rebecca Orr [Marketing & Fundraising] and Rachel Parker [Assistant] have moved on to new challenges.

Rebecca is being replaced by Sinead Devlin.

Julie Greenfield [Research Manager] has been on maternity leave for a while has now given birth to a baby boy, Luca. More details no doubt will be in the next Ataxian.

#### **Boston Street Collection.**

Expecting to get a little wet given



what the weather had been through most of June, we were lucky to have a moderately fine day on the 23<sup>rd</sup>, only one cloudburst lasting about 15 min occurred and a lot of the time it was sunny. All this made for a better day for those taking part and a total of £160 was collected for AUK.

#### **Group Newsletters**

For those on the internet will have received copies of the various groups newsletters, paper copies were available at the meeting for everyone to browse over tea.

#### **Raffle Collection - £19.**

As a follow up from the meeting a pupil, of Deacon's school, Peterborough, you may recall supported us a short while back, has again had his long hair cut off and donated the proceeds to Æ, we Thank Mostafa Pirpashteh for raising £40.50 for our group.

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A LITTLE LIGHT-HEARTEDNESS

DADDY'S GONNA EAT YOUR FINGERS ...

This one is for everyone who...

- A) Had kids
- B) Has kids
- C) Is going to have kids
- D) Knows a kid
- E) Was a kid

I was packing for my business trip and my three year old daughter was having a wonderful time playing on the bed.

At one point she said, "Daddy, look at this," and stuck out two of her fingers.

Trying to keep her entertained, I reached out and stuck her tiny fingers in my mouth and said,

"Daddy's gonna eat your fingers," pretending to eat them.

I went back to packing, looked up again and my daughter was standing on the bed staring at her fingers with a devastated look on her face.

I said, "What's wrong, honey?"

She replied, "What happened to my bogie?"

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### Do not cheat - go with the first dessert you picked.

If all of the desserts listed below were sitting in front of you, which would you choose (sorry, you can only pick one!). Pick your dessert, and then look to see what psychiatrists think about you.

Here are your 8 choices:

1. Angel Cake
2. Brownies
3. Lemon Meringue
4. Vanilla Cake with Chocolate Icing
5. Strawberry Short Cake
6. Chocolate on Chocolate
7. Ice Cream
8. Carrot Cake

No, you can't change your mind once you look down, so think carefully about your choice.

OK - Now that you've made your choice this is what the research says about you:

### LOOK DOWN --- No Cheating

**1. ANGEL CAKE** -- Sweet, loving, cuddly. You love all warm and fuzzy items. A little nutty at times. Sometimes you need an ice cream cone at the end of the day. Others perceive you as being childlike and immature at times.

**2. BROWNIES** -- You are adventurous, love new ideas, and are a champion of underdogs and a slayer of dragons. When tempers flare up You whip out your sabre. You are always the oddball with a unique sense of humour and direction. You tend to be very loyal.

**3. LEMON MERINGUE** -- Smooth, sexy, & articulate with your hands, you are an excellent after-dinner speaker and a good teacher. But don't try to walk and chew gum at the same time. A bit of a diva at times, but you have many friends.

**4. VANILLA CAKE WITH CHOCOLATE ICING** -- Fun-loving, sassy humorous, not very grounded in life; very indecisive and lack motivation. Everyone enjoys being around you, but you are a practical joker. Others should be cautious in making you mad. However, you are a friend for life.

**5. STRAWBERRY SHORTCAKE** - - Romantic, warm, loving. You care about other people, can be counted on in a pinch and expect the same in return. Intuitively keen. Can be very emotional.

**6. CHOCOLATE ON CHOCOLATE** -- Sexy; always ready to give and receive. Very creative, adventurous, ambitious, and passionate. You can appear to have a cold exterior but are warm on the inside. Not afraid to take chances. Won't settle for anything average in life. Love to laugh.

**7. ICE CREAM** -- You like sports, whether it be baseball, football, basketball, or soccer. If you could, you would like to participate, but you enjoy watching sports. You don't like to give up the remote control. You tend to be self-centred and high maintenance.

**8. CARROT CAKE** -- You are a very fun loving person, who likes to

laugh. You are fun to be with. People like to hang out with you. You are a very warm hearted person and a little quirky at times. You have many loyal friends.

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DATES FOR YOUR DIARY

NEXT MEETING

This will be at Stanground on Saturday 6th October at 2.00pm.

A speaker from the British Red Cross will give a talk on the many services they provide to aid the disabled.

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