

Our latest meeting – held on Sunday 28th April 2013 at Exhall Old School Community Centre



Catherine (CA) and her husband Paul, Kieran's (FA) mum and dad, Neil (FA) and his step-dad Steve, me (FA) and my aunty Monica, Kate (CA), Lorraine (CA) and her daughter Emily.

As Matt (FA) and his PA couldn't make it and he usually picks me up on the way in my powerchair (his PA clamps it down in the back of his wheelchair accessible vehicle), I got on bus from where I live into the city centre and another from the city centre to a bus stop two minutes away from where the meeting is held in Exhall – I took the number 20 and looked out for School Lane. Every day I have somewhere to go by bus; they all have ramps these days so it's all very doable.

Sue was talking about her son Kieran's desire to move out and her apprehension because he falls sometimes when he transfers. No one can take away from the fact that living with ataxia has its risks – it's hard – but at the end of the day you have to find a way to live with those risks and get on with life, otherwise you never achieve anything. My own mum was apprehensive too when I moved out nearly three years ago but it proved to be the best move I ever made.

We talked about personal alarms that are worn around the neck and can be pressed if you run into trouble – when you press it you speak to someone in a call centre via an intercom who helps appropriately. Since moving out I have had to press mine three times: the first time I caught my arm in the kitchen and, it's difficult to explain in brief why, I wasn't able to free it myself. I pressed my alarm and the paramedics were called. The second time my powerchair conked out in the middle of my kitchen; I pressed the button and they called my parents who came to rescue me. The third time, just recently, the fire alarm went off in the middle of the night – I pressed the alarm and they called the fire service for me, and they came but it was just faulty wiring thank goodness! Some said they were advised that these alarms shouldn't be worn at night but after my latest experience I wouldn't be without mine!

Lorraine recommended Switch Sticks (see <http://www.switchsticks.com/>) as they can be folded and stowed easily in overhead lockers on airplanes etc. What's more, if you ask me, they look great!

Our visit to Naidex at the Birmingham NEC on Wednesday 1st May 2013

NAIDEX is a homecare, disability and rehabilitation event held annually at the Birmingham NEC. I would describe it as being a massive showcase for a whole manor of assistive equipment, including bathing and showers, wheelchairs and accessories and lifts and hoists.

Getting to the event was a doddle. My aunty Monica and I took a train from Coventry to Birmingham International, and once we had arrived on the platform we ate the little picnic we brought with us as food is very expensive to buy at the show, found Naidex which was well sign-posted and after a text or two met support group members Neil, Steven, Catherine and Paul.

I met Catherine at the Invacare stand where she was test-driving a powerchair she had seen there and liked. Catherine liked this chair so much that she arranged for a dealer to call her so she could make a purchase – I look forward to hearing what happened next. Catherine also looked at the Motomed stand where she enquired about buying the same type of power-assist exercise bike she uses at physio. Neil bought some Dycem, non-slip matting for use under plates etc, and I bought some too at a special in-show price. I also bought a Trabasac which is an extremely useful multi-purpose lap tray and a couple of reachers/heiping hands for the bargain price of £4 each and a plate with a rim for £2.



Ataxia UK Coventry and Warwickshire Support Group members and something to do with Top Gear at Naidex.

Our next event

I have booked a table for a pub lunch at Mount Pleasant – Hungry Horse, Hinckley Road, Walsgrave, Coventry CV2 2EU on Saturday 22nd June at 2pm.

If you would like to join us you please let me know (contact details below).

Money

We had £71 in the pot after the last meeting. Since the last meeting we've had donations from Marion Abbot, Chris Faulkes and Lorraine Walls – thank you VERY much! We've had no outgoings so we now have a very healthy £104 in the pot.

I'm asking everyone who comes to meetings in future for £1 towards the cost of refreshments.

I'm pretty sure we have enough money to keep the group going for at least another year. Thanks to everyone who's given money in one way or another.

I'd welcome any suggestions of anything specific you'd like to see in future newsletters and meetings – please get in touch! I hope to see as many of you as possible at our pub lunch on 22nd June!

Who I am and how to contact me:

I am Katie Henderson (you can find out more about me at <http://ohbother.co.uk>) and I am the named contact for the group. You can contact me by e-mailing katie@ohbother.co.uk or phoning 07565 247 183. I am also on Facebook and so is the group; search for "Ataxia UK Coventry". For news on group events and to download previous newsletters etc visit <http://ataxiacoventry.co.uk/>.