

CONTAXIA.

ATAXIA~EAST Newsletter 'Æ'

#122

July 2026

Dave's 'Dithering's'



Now that summers here, what a damp squid! Good job I made the best of it in April/May. On the positive side not getting too hot does help the body. Though at the moment as I finish the dithering we are getting over another heatwave!!!!

This year we've decided not to have summer holiday, instead opting for nice days out, to pack everything you need, plus the kitchen sink, according to Sue, is not worth it. Also, leaving her lovely, precious garden for a week only to come back and find it all 'wilted' is soul destroying, so we may as well sit in the garden and enjoy it with the odd drink or two. No risk of being breathalyzed in your electric wheelchair in your own back yard. 🤔

We have had another afternoon tea at Dobbies where we were able to sit and chat over enjoyable food. The only unfortunate thing was that we were on a long table, it would have been better on a round table to make talking easier but it did not 'subtract' too much. The picture shows plenty of food all round for the nine of us and we all took a 'doggybag' home.

A big Thank You to Angie Trafford for very comprehensive report on visiting her mum and dad in the Highlands and Islands



of Scotland, it proves what can be done – more in the next Contaxia.

Dave

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Auditory Processing Disorder [APD]

During a recent Facebook 'exchange' with Kirstie Cooper from our group, Æ, we realised we had similar hearing problems that are not always diagnosed. I had had a telephone conversation over a recent repeat prescription and I had to terminate the call stating I would call back when my wife was present.

To quote Kirstie –

Anyone that knows me personally knows how much I struggle with my APD, and that if you have an accent in particular I have no chance of understanding you 🤔

I really struggle on the phone as I obviously can't lip read so I now tell the person straight away to avoid any awkwardness.

Just had a phone consultation with a diabetic nurse. When I explained to her I had auditory processing disorder and that I was really struggling to understand her accent she apologised to me.

I felt awful - as if someone should ever apologise for their accent.

I don't have a proper diagnosis as apparently there are not many places that test and diagnose officially - and my referral was never completed as it was just after COVID. I did say to Aaron a few weeks back actually that I don't know if it's worth asking for a new referral or not as nothing will change.

I went for a normal hearing test at the hospital - before I had it done, I told the lady that I think it was pointless me being there as I know it will come back that my hearing is normal, as listening to noises through headphones isn't an issue - but that if she played music through them at the same time, then that's where my problems would be. She asked me a few questions and then I had the test. They did this really weird thing which I didn't realise was part of the test - I could hear her

tapping on the keyboard but through the headphones and it's all I could hear and as I said, didn't hear any of the bleeps.

Afterwards she gave me feedback and told me there and then I had auditory processing disorder but would need specialist tests which they don't do at Peterborough hospital.

When I read into it, it makes so much sense - the background noise part but also not having a clue what direction a noise is coming from either.

I am much the same and hearing aids do not help that much, though you can turn them up they lack 'clarity', words/noise seems 'muffled'. It's frustrating, isn't it? The next time I see Prof Marious at the Sheffield Ataxia Clinic I will seek his advice.

To add to all of this the 'high whistle' from tinnitus does not help which many ataxian's complain about on ataxian web sites.

We wonder how many more suffer with this problem???

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### **Group Leaders Meeting**

Near the beginning of June I attended a Zoom meeting for group leaders within AUK where we had chance to discuss any issues we had [if any] and get any updates from AUK.

Interesting Points –

- An update on research can be found on AUK web site.
- The Helpline now operates from Mon – Fri 0800-995-6037
- IAAD will coincide with the virtual conference over the week 21 – 25 Sept, thus avoiding a long day sitting at your screen.
- ID cards are available [with or without a photo of yourself]
- Speech therapy and voice banking is widely used
- Many meetings have a low attendance
- It is better to meet in a quiet venue to avoid distractions and help those with hearing difficulties. [something AE has experienced]

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MY WEE SCOTTISH HOLIDAY

Part 1

Peterborough to Inverness & Northwest Scotland

My parents, Steve and Barbara arranged for me to take a 'wee holiday' to see where they now live – the Isle of Lewis in the Outer Hebrides. It took a lot of organisation, but finally I made the long journey on the Easter weekend Sunday 5th April, accompanied by 2 of my carers, Ian and Yvonne Large.

My mum had planned the entire journey like a meticulous plan, which all came together very well.

So, we set off from my house to Peterborough railway station, where our train departed at 12.50, a direct journey to Inverness, which stopped at many stations on the way. So left my car at the railway and no test where parking is reasonably charged at £10 a day.

Assistance was also pre-arranged and as so much she on as we found our man at Peterborough, he took control in ensuring we got onto the train without any hiccups. The train was very comfortable, and we settled in for what was a long journey, 7-hours, but we could all relax and watch the different areas, towns and views along the way. We had



packed some snacks to keep us going and got some hot chocolate on the train, which was delicious.

As we got into Scotland, and into the highlands (as name suggests,



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very high altitude) we looked out at the snow-covered fields and snow-capped mountains. The snow remained visible throughout our journey to Inverness, where we disembarked from the train at 8:10 pm. Upon arrival, we were once again greeted by rail staff who provided exceptional assistance. My dad was waiting for us at the station. He had travelled from the Isle of Lewis a couple of days earlier to collect the hire vehicle access van from Glasgow (as they were closed during the Easter weekend) and drove it to Inverness.



From there Dad drove us to the Premier Inn where a hoist had already been delivered and in place for my arrival. This was organised via the OT in Northamptonshire together with the OT in Inverness – but only after my mum had contacted her local MSP (Member of the Scottish Parliament) and he rattled a few cages to make it happened – why nothing can be easy and straightforward is anyone's guess.

The next morning was a (understandably) a lazy start. Having had a late breakfast, my dad took us to the shopping centre in Inverness, as mum had suggested we take a look at the clock, which at 12.00 noon goes through an automated programme to music. It lasts 5-



minutes and lots of people stop to watch it. My carers and I enjoyed watching that. Then we visited a very large garden centre, before dad decided to start our road journey to Ullapool Ferry terminal a little earlier than he would normally have done because of the snow. From Inverness to Ullapool is 55 miles and normally takes one-hour, but just after going over the high bridge over the River Ness, dad pulled into a viewing area, and I got out to have a look at Inverness from this elevated area. We then drove to Ullapool through a remote, mountainous region with impressive snow-capped peaks.

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## **CAMEL ROLL**

*Mrs V Howells, Wrexham, Clwyd*

½ lb shortcrust pastry (using 8oz flour etc)  
2 oz soft breadcrumbs  
12 oz golden syrup  
2 oz currants  
½ pint milk

## **METHOD**

Roll pastry to a rectangle. [as for a roly poly]  
Spread with syrup and sprinkle crumbs and currants evenly over.  
Roll up and place in a deep oval dish  
Pour milk round and bake for 1.5 hours at 360F or Gas Mk 4

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Time to Relax

Very disappointed that the daffodils I planted last year turned out to be Marigolds 😞



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Patient: 'I believe I'm a moth.'
Doctor: 'Well, that's a psychiatric problem. I'm a GP. Why did you come here?'
Patient: 'Your light was on.'

Dates for your Diary

01 Aug 26 – Ramsey Show
PE26 2XD

05 Sep 26 – GAC 1400hrs.

'Isn't it unnerving that doctors call what they do "practice"?'

Someone asked me to spell
BNAG....I thought that was bang
out of order.

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**I read that WD40 keeps mice out
of the garden. I tried it. Didn't
work. But they have stopped
squeaking.**

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AUK Helpline
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