

# CONTAXIA.

ATAXIA~EAST Newsletter 'Æ'

#120

Mar 2026

## Dave's 'Dithering's'



Now that Spring is upon us, I hope you are feeling better after our 'dull' winter. I must admit, at times it got to me, my eldest son even provided a Light Pod, which simulates sunshine, and it did work. But now I am looking forward to getting 'out and about' again.



Snowdrops along the B1183 near Boston for approx. half a mile.

**Terry has done some great work in setting up a Facebook group for Æ that I hope you will join in and enjoy this private group. Any 'posts' would be appreciated.**

Dave

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## Meeting Notes 07-02-26 – Zoom

### **Introduction.**

Dave welcomed all 7 that had attended, he then drew to a statement AUK asked to be read out but also empathized that you had to click on the terms of agreement to join the meeting!

### Statement

*safe, comfortable and supported."*

Present:- John Campbell, Nigel Davis, Sheila & Terry Mckenna, Dave Stubley [Co-ordinator], Sue Stubley & Vera Wilday.

Apologies:- Elaine & Phil Sibley, Barbara & Steve Trafford who send their Best Wishes from Isle of Lewis.

### Co-Ordinator Report

Dave reported on an ARSACS Zoom meeting he had attended just before this meeting and how emotional it was for two couples whose young children had been diagnosed and where on a 'learning curve.' There was a professor from Canada attending who gave Power Point presentation on their work and in particular the need to keep exercising regularly, something Dave had found to be true.

Another problem that many encountered was the ability empty your bowels, a delicate subject I know, but it was a 'relief' that I was not the only one with that problem, Nigel agreed.

### Treasury Report

We still have an account which now stands at £ 1378.43.

### Secretarial Report

*"Before we begin, Ataxia UK has asked us to remind everyone that this is not a webinar but a private and confidential support group meeting. Please do not record, screenshot, upload or share any part of today's session. What's discussed here stays within this group so that everyone can feel*

Mrs Vera Wilday from Lutton has joined us via the internet along Alison Harrison who's husband has ataxia joined via internet. There are 56 members and partners and no changes.

### **AOB**

1] Dave reported that he had a loss of taste and smell, which others had claimed on an ataxian web site but no one in the meeting had experienced this. His GP had suggested that he had had a virus or Covid which Dave could not recall?

He then went on to say about his hearing and tinnitus and that new hearing aids from Specsavers, on the NHS, had helped. Their audiologist was wearing hearing aids so probably understood what is hard to describe. Go to the Specsavers web site to hear a verity of tinnitus sounds that can be heard.

2] Nigel told us that his doctor had advised him to look for a suitable wheelchair to use soon as is ability to walk with a rollator diminishes. This was felt advisable, but keep going as long as he can, the frequency of falls/stumbles will dictate. If he fell, people would rush to help but that was not needed, you need time to 'sort yourself out' before getting up, Dave agreed.

3] John let us know about a Gluten Ataxia and Autoimmunity Group on Whatsapp that he has found beneficial.

4] Facebook page - Now that Terry had set up the page, we hope that more will join it. It is a private page so Terry or Dave have control of who can join.

5] Apology to Vera – During the Zoom meeting Dave kept referring to her as Ellenor, sorry, 'I should have gone to Specsavers!'

6] Afternoon Tea at Dobbies, Peterborough in June. A date will be set nearer the time when it can be booked online.

### **Future Meetings**

04 Apr 26 – GAC, 1400hrs. This is Easter Saturday.

?? Jun 26 – Afternoon Tea at Dobbies.

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**KEDGEREE – Serves 4**  
*Beryl Holt, Howarden, Deeside, Clwyd*

6 oz cooked smoked haddock  
6 oz cooked fresh haddock  
3 oz butter  
12 oz cooked long grain rice (about 6 oz raw)  
2 finely chopped hard boiled eggs  
About 4 tablespoons fresh single cream  
Salt and freshly milled pepper to taste.

**GARNISH:** 2 level tablespoons finely chopped parsley

### **Method**

Flake the fish. Melt butter, mix with fish, rice, eggs and cream. Add a little extra cream if the mixture seems dry. Season well with salt and pepper. Transfer to a buttered 1.5-2 pint oven proof dish.

Cover and heat in moderate oven 325f /160c Gas Mk3 for about 30 minutes.  
Garnish with chopped parsley and serve immediately.

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### **Dave & Sue's 50th**

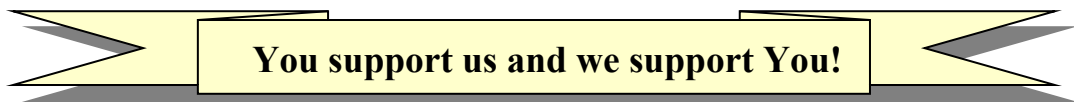


I am pleased to announce that Sue & I have been able to celebrate our 50<sup>th</sup> Wedding anniversary on 21<sup>st</sup> Feb 26 at the Lincolnshire Aviation Heritage Centre, East Kirkby [my 2<sup>nd</sup> home] with a few family members & close friends.

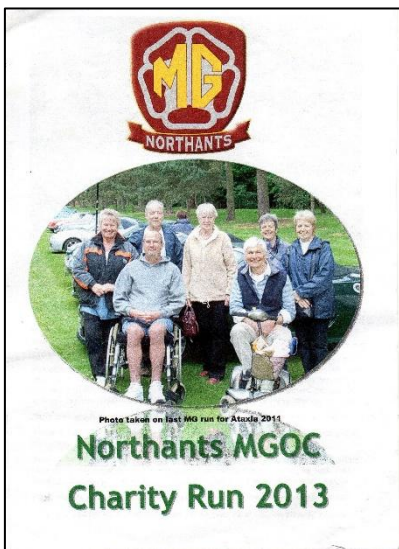
We didn't want 'big do' just a relaxing get together and friendly natter, just like Æ meetings really, with an afternoon tea to enjoy.

Thanks for all the acknowledgements we received, from them that knew about it.

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## A Blast from the Past



After some contact with Barbara and Steve on the Isle of Lewis they told me that whilst 'clearing out' ready for some building work they found this –

It was done for us, Æ, and provided some nice funding for our Christmas lunches at the time. L- R, Barbara, Terry, a thinner me, Jan, Bob, Sue and Sheila.

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## Naidex 2026

NEC Birmingham – 25/26 March

## Welcome to Naidex

**Learn. Connect. Celebrate.**  
**Experience the UK's largest inclusive event space this March.**

Running for over 50 years, Naidex is the most established platform for the disability community. It brings together a powerful community of innovators, care professionals, and people with lived experience to connect, share knowledge, and explore products and services.

More than just an event, Naidex is a platform for change. This collaborative and passionate community is what sets Naidex apart.

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## Gov Press Release 17-02-26

### **Will This Help You?**

### **£400 cash boost for disabled adults to tackle cost of living**

150,000 disabled adults to keep £400 more cash each year to help with cost of living, and £700 million to support tens of thousands of home adaptations.

- More money in people's pockets as 150,000 working-age adults who receive social care to keep at least £400 more each year
- Biggest above-inflation uplift to the minimum income guarantee for working-age adults in over a decade
- £723 million investment into home adaptations to help tens of thousands live independently

Over 150,000 people will get at least £400 back in their pockets to help with the cost of living, thanks to government action to support adults with disabilities.

Government is increasing the amount that working-age adults who receive social care must be able to keep after paying for home care (known as the minimum income guarantee) by 7% from April 2026 - strengthening this safety net to ensure that people have enough

for daily expenses and helping to ease financial pressures.

This is the largest above-inflation uplift in more than a decade and means working-age adults receiving care in the community will have more money left over for everyday essentials such as food, heating and bills. Those eligible for the disability premium, an additional amount for people with greater disability needs, will keep up to £510 more per year.

The government has also confirmed £723 million for the Disabled Facilities Grant (DFG) next year to help older and disabled people adapt their homes so they can live safely and independently.

The DFG supported around 60,000 people last year and it helps keep people out of hospital and living comfortably in their own homes.

The changes form part of the government's action to support those that need it most with the cost of living, while reforming adult social care and improving independence.

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## Time to Relax

A man walks into the doctors. He has a cucumber up his nose, a carrot in his left ear and a banana in his right ear. 'What's the matter with me?' he asked the doctor. The doctor replies 'you're not eating properly.'

I met a girl who runs a battery kiosk in the local park

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So basically, she sells C cells by the seesaw

'I told the doctor: "Every time I bend down, I see Micky Mouse, yet every time I stand up, I see Donald Duck."

So, he said: "How long have you been having these Disney spells?"

A sweater I bought was picking up static electricity, so I returned it to the store.

They gave me another one free of charge.

Patient: 'Doctor, I keep getting these uncontrollable urges to steal things.'

Doctor: 'Take two of these tablets every day. If they don't work, can you get me a TV?'

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?? Jun 26 – Dobbies,  
PE7 8NY

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## CONTACTS

Æ Co-Ordinator  
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## Dates for your Diary

04 Apr 26 – GAC 1400 hrs  
PE2 8QS

**You support us and we support You!**