# CONTAXIA.

ATAXIA~EAST Newsletter 'Æ'

# 96

August 2021

### Dave's 'Dithering's'

Some interesting little articles for you to peruse this time? I hope you find something to interest you.

I only picked up on the change in petrol from a brief radio news item.

Here's hoping for fine weather when we go for our first face to face out door meeting in early August, bring you brolly 'just in case'!

Those that remember Alison Crosby will be disappointed to hear she has been lost! By that I mean the usual Contaxia's I send her, the last one came back marked 'not known at this address' and 'addressee gone away'. On telephoning the care home they denied any knowledge of Alison. Very frustrating, even Auk could not help due to the data protection act. Some things are set not to help a 'vunerable person'.

Who found the hot and sunny weather near the end of July 'a little overpowering'? Being 'a lover of the sun' I found it too much and had to give-in and take to the shade. I seemed to ache all over, my legs and feet really swell up and I even went off food? Not like me, I hope it was not too bad for you?

Dave

*ЕЕЕЕЕЕЕЕ* 

### 'Virtual' AGM meeting 12-06-21

Able to attend this meeting was Terry & Sheila, Lesley, David, Elaine & Phil, Fran, Dave & Sue and the meeting was hosted by Anastasia of Auk.

Steve & Barbara sent their regards as they enjoyed the delights of Cornwall. [To near the G7 restrictions for me!]

Anastasia gave a presentation listing the updates that are going on with Auk.

One thing that Auk was asking was that Friends and their families complete the survey asking how they would like to see Auk priorities and develop plans over the next three years.

Surveys have been sent out via the magazine, but you can also complete online through the link provided:-

https://www.ataxia.org.uk/ataxia -uk-news/help-shape-ourstrategy

There had also been a good response to the virtual Chair Pilates with many extra sessions added.

Many other items were included in the presentation which had been circulated to Æ members. The InContol team can always be

### volunteering@ataxia.org.uk

contacted on

The meeting then continued with various conversations. David was happy to tell us about his experiences of going to a gym with a Neurological section included within it!

The return of face-to-face meetings was discussed with the hope of arranging something for the October meeting though the August picnic would be a start.

Lesley told us that there had been no change in the accounts since the last time, due to nothing happening!

ÆÆÆÆÆÆÆÆÆ

### **HealthWorkz**

## Some hopeful information from Æ member David Martin

Neurologist could recommend physiotherapy and I was lucky to find a local physio who had expertise appropriate to people with Neurological conditions. Physio is available free on the NHS but is limited in Suffolk to a few sessions for each referral. I attend Otago classes (fitness and balance in later life) but still felt the need, even in my early 70's, for some upper body strength work and light cardio exercise. Accordingly, I joined a gym but the pandemic put paid to that and while I considered if, when and how to return to the gym I saw a link to a new facility in Colchester. Alan Pearson is an exercise coach who used to work for the MS Society and has a unique (in my experience) grasp of the special fitness needs and constraints of people with Neurological conditions. He has set up his own business to make his services available to people with a wider range of conditions.

I drove to Colchester to meet him, expecting to say that he was too far away for me to become a regular client. However, it was so good to speak to a fitness coach with his specialised expertise, knowledge and equipment, that I am going again soon for proper assessment of my capability and needs. I shall report back later on that visit.

### David Martin Long Melford

P.S. At that first meeting, during his assessment process, Alan asked if I had had any falls. I replied "not for a couple of years". Blow me down, that same afternoon, I fell over in the garden, half in and half out of the garden shed. Beware - he may be a jinx?

See his advert at: <a href="https://www.healthworkz4u.co.uk/">https://www.healthworkz4u.co.uk/</a>

### A follow up from David

I have now been to Colchester twice since my initial assessment visit. It has been very rewarding, discussing my fitness needs and constraints with a trainer who has experience of customers who have a neurological condition. Indeed, that is Alan Pearson's job and he has set up his own deliver business to Healthworkz occupies a dedicated studio in a large facility (the Energyze gym and fitness studio) surrounded by a conventional gym, a martial arts dojo, a "Ninja" course and other associated activities. Alan has a variety of specialised equipment, including

a vibration plate, leg and arm exercisers, electrical muscle stimulators and others that I have yet to have explained. The difference with the conventional gym equipment is quite noticeable. I set goals which were

- Raise my heart rate
- Improve "sit to stand" performance
- Strengthen arms and upper body

In these first 2 visits I have only used a specialised "recumbent bike". However, I am pleased with the results as I found I could cycle 30 minutes under load, and the machine told me that one leg was weaker than the other. Then the cycle ran a game that required me to use more effort on the weaker leg. Cycling only with the arms then revealed my limitations in upper body strength. To test my gait and balance, Alan took away my rollator, took my hands and had me walk the length of the main gym, Then, to my horror, he said "that was OK; don't turn around, now let's do it backwards"!

I have signed a monthly membership. Oh, and after today's session, I treated myself to a lovely omelette with salad and a cup of tea in the onsite cafe

ÆÆÆÆÆÆÆÆÆ

### For Motorists!



# The Introduction of E10 Petrol

Posted in Disabled Motoring *General News* on Monday, June 21st, 2021

This summer the standard grade of

petrol will change from E5 to the greener E10 fuel, so called because it contains 10% bioethanol. Most petrol-powered vehicles manufactured after 2011 and modern motorcycles are E10 compatible. However, approximately 5% of petrol vehicles will need to continue to run on E5 petrol which will soon be available as a super grade option at the pumps. Using E10 fuel in a vehicle which is not compatible with it will not cause immediate harm. However, if it is continued to be used then it could cause damage to the engine.

If you are unsure about the compatibility of your vehicle then you can use the online E10 compatibility vehicle checker f or more information. You can access the vehicle checker by visiting <a href="https://www.gov.uk/check-vehicle-e10-petrol">www.gov.uk/check-vehicle-e10-petrol</a>.

### ÆÆÆÆÆÆÆÆ

### NHS Digital Database – Your choice!

Extracted from Healthwatch Lincolnshire email – But it applies all over!

Healthwatch Lincolnshire is aware of recent media interest raising concerns about patient data being shared by GP Surgeries into national database, unfortunately many of the media articles contain facts that are just not true. NHS Digital is the organisation behind this work, which is intending to share vital trends in data to help health research and development to find better treatment and new cures for many of our diseases and long term conditions. If you want to

know more about what is and is not true about national opt-out then you might find this link useful <a href="https://digital.nhs.uk/services/national-data-opt-out/mythbusting-social-media-posts">https://digital.nhs.uk/services/national-data-opt-out/mythbusting-social-media-posts</a>

Everyone is entitled to opt-out as the national data opt-out was introduced on 25 May 2018, enabling patients to opt out from the use of their data for research or planning purposes, in line with the recommendations of the National Data Guardian in her Review of Data Security, Consent and Opt-Outs.

Patients can view or change their national data opt-out choice at any time by using the online service at <a href="https://www.nhs.uk/your-nhs-data-matters">www.nhs.uk/your-nhs-data-matters</a> or by calling 0300 3035678.

By 30 September 2021 all health and care organisations are required to be compliant with the national data opt-out policy.

Healthwatch Lincolnshire will regularly be liaising with Healthwatch England, the Lincolnshire Medical Committee and NHS England with regards to this issue of sharing of patients data and will report back when we know more.

It has been announced they are moving the deadline for the optout from 23 June to 1 Sep. You can read more here - <a href="https://digital.nhs.uk/.../collection-of-gp-data-for...">https://digital.nhs.uk/.../collection-of-gp-data-for...</a>

ÆÆÆÆÆÆÆÆ

### Good news from Kirstie.

We are getting married on the 9th August which also happens to be Deacon's birthday! Only a tiny do with the kids, and mum and Terry present - then a nice meal at the Fitzwilliam Arms
- nice and quiet which is perfect
for us xx

We wish them All the Best for their future.

slams the door and returns to bed.

"Who was that?" asked his wife.

"Just some drunk guy asking for a push," he answers.

"Did you help him?" she asks.



Kirstie & Aaron with Megan and Deacon - photo Thanks to Terry

ÆÆÆÆÆÆÆÆ

#### **Time to Relax**



A man and his wife are awakened at 3:00 am by a loud pounding on the door. The man gets up and goes to the door where a drunken stranger, standing in the pouring rain, is asking for a push.

"Not a chance," says the husband, "it is 3:00 in the morning!" He

"No, I did not, it's 3 am in the morning and it's pouring out there!"

"Well, you have a short memory," says his wife. "Can't you remember about three months ago when we broke down, and those two guys helped us? I think you should help him."

The man does as he is told, gets dressed, and goes out into the pounding rain. He calls out into the dark, "Hello, are you still there?"

"Yes," comes back the answer.

"Do you still need a push?" calls out the husband.

"Yes, please!" comes the reply from the dark.

"Where are you?" asks the husband.

"Over here on the swing," replies the drunk .....



### The Afterlife!

A couple made a deal that whoever died first would come back and inform the other if there was sex after death.

After a long life together, the husband was the first to die so the wife went to a medium to make contact...and after the usual Routine the husband came through.....

H: "Darling... Darling...can you hear me?"

W: "Is that you Baby?"

H: "Yes, I've come back like we agreed"

W: "That's wonderful!!! What is it like in the afterlife? Is there sex?"

H: "Well, as soon as I get up in the morning, I have sex. After sex and breakfast it's off to the golf course. Thereafter I bathe in the warm sun and have sex a couple of more times. Then I have lunch .....you'd be proud of me.... I'm eating lots of greens. After lunch, it's back to the golf course again. Then it's more sex until late at night.

I catch some much-needed sleep and then the next day it starts all over again."

W: "Oh Baby...it sounds wonderful for you.... are an Angel in Heaven?"

H: "No, I'm a rabbit on a golf course in Milton Keynes..



ÆÆÆÆÆÆÆÆÆ

### **CONTACTS**

Æ Chairman
Dave Stubley
33, Grosvenor Road,
Frampton,
BOSTON,
Lincolnshire,
PE20 1DB.
Tel: 01205 722771
e-mail:

djstubley@aol.com

Æ Treasurer:
Lesley Gordon,
lesley.gordon@live.co.uk

Æ Secretary
Sue Stubley
stubleysue@aol.com

Æ Committee Member:
Alison Gilby
alisongilby@gmail.com

Ataxia UK Helpline

<u>help@ataxia.org.uk</u> <u>0800 995 6037</u>.

Opening hours are **10.30-2.30**, **Monday to Thursday**. The helpline is closed on Fridays.

**ÆÆÆÆÆÆÆ** 

### **Dates for your Diary**

THESE ARE STILL UNDER CONSIDERATION DUE TO THE CURRENT SITUATION!

7<sup>th</sup> August – 2pm – Social Picnic at Ferry Meadows Country Park, Peterborough PE2 5UU. Near to the café. Bring your own picnic!

October – Stanground CC will be contacted to see if is open and available.
All subject to Government Covid guidelines at present times.

ÆÆÆÆÆÆÆÆÆ