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**UTTLESFORD SUPPORT GROUP
NEWSLETTER/INFORMATION SHEET
June/July 2024**

Website: www.parkinsonsuttlesford.org.uk

RECENT MEETINGS

In April, Chris Bishop treated us to a very entertaining afternoon of music and songs. Viv Kavanagh, our Parkinson's Nurse, also attended and was able to have some useful one-to-one sessions with some of our members. She is hoping to attend more frequently in future, starting with the Garden Party in June.

In May we had a talk on the subject of Lasting Powers of Attorney. The speaker was good and left information leaflets for his company who are approved by Age UK (these will be available at our next meeting or to anyone on request). His company will visit you at home to discuss, and then can arrange everything for you and with a fixed inclusive price.

He was factual, and covered what seemed like the main points, starting with confirmation that the old EPA is still acceptable, but not so wide reaching.

He warned that registration is currently taking up to 5 months, and emphasised several times, that it is not possible to make a POA without mental capacity - approved by a GP. Furthermore, if you have no POA it will be very costly in time & money to gain a Deputyship, which has to be renewed annually at further cost. Without POA you may be told that Doctors, Banks, etc cannot discuss the person's affairs with you. Accounts will be frozen and you may be in difficulty. Legally there is no such thing as Next of Kin.

Like Martin Lewis (of TV fame), he said it is never too soon to get Power of Attorney. "Death, Divorce and Dementia" affect us all, and Dementia is the worst.

Not a cheerful subject, but I think, very important.

FUTURE MEETINGS

11th June – our annual Garden Tea Party here at Brackendale House, Debden Road, Saffron Walden, CB11 4AB. This runs from 2.30 until 4.30pm. There is parking available for up to about eight cars, with very careful parking, but obviously priority will be given to Blue Badge Holders. If you can share cars, or arrange transport, please do so. Brackendale House is fully wheelchair accessible and has a disabled loo. We look forward to seeing as many of you as possible for which is usually a very enjoyable occasion (& please pray for good weather!)

9th July - Group Outing to Shuttleworth: Shuttleworth is a famous "Collection" of old aircraft & veteran vehicles in 6 huge hangars, a garden, a lake, woodland, parkland and a cafe, with good access to almost all areas. This is near Biggleswade so we will leave at 10 AM, sharing cars for transport. A guided tour is booked for those that want, otherwise the day is yours to enjoy.

Please contact Kate Riley immediately if you are interested in the remaining places, as we are supposed to let them know numbers by 1st June!

IMPORTANT NOTICE

Very sadly, we have been told that we can no longer have the Jubilee Hub, where we normally hold our meetings, on a Tuesday afternoon, with effect from the end of May. We have been offered two alternatives:

1. To change our time and day to a Wednesday morning
2. To move to the Old Council Chamber, at the back of the Town Hall (entrance in Market Row, behind the Tourist Office). This has wheelchair access.

We have decided to try the second option initially – we thought it less disruptive to change the venue rather than the day and time – although, unlike the Jubilee Hub, it is not ideal. So with effect from our next ‘normal’ meeting on Tuesday 13th August at 2pm, that is where we will be.

At this meeting (on Tuesday 13th August), we will have a spokesperson from Charco Neurotech, who will tell us about the CUE1 and CUE1+. For those (like me) who have never come across this device, CUE1 combines the principles of focussed vibrotactile stimulation and cueing, both apparently evidenced by scientific literature to improve motor performance and alleviate freezing of gait for people with Parkinson’s.

Their testing has shown clinically significant improvements in motor symptoms whilst using the CUE1. Their testers have also reported a wide range of benefits including:

- Smoother walking and movement
- Regaining the ability to dance
- Helping fine motor tasks

Whilst we can’t, as an organisation, recommend this device, we think you should be informed about it. It works for some people, but not for others.

The following month, on Tuesday September 10th, Edward Gildea, local adventurer and climate activist, is coming to give us his interesting and entertaining illustrated talk about his travels across seas and up mountains.

FUND RAISING

I am delighted to report that we had a very successful fundraising day on April 13th. We raised the magnificent total of £953.48, and I am convinced that, if we hadn’t had competition from Alzheimer’s UK outside Waitrose for the first half-hour, we would have passed the magic thousand pound mark!

Parkinson’s UK membership If you are not already a member, we do encourage you to join. Please ask for a form. There is currently no fixed fee to join and you do receive an excellent and informative quarterly magazine. We do, however, encourage you to make a donation towards the running of the Uttlesford Support Group. A suggested figure would be £10 p.a.

TRANSPORT: If you wish to attend a meeting but can’t do so because of transport problems – please contact a member of the committee; we will do all we can to find a way to get you there

PARKINSON’S NURSE COVERING UTTLESFORD: Vivienne Kavanagh 01279 621924 Unfortunately Viv is currently unable to offer Clinic sessions, but she is available to give advice over the phone on Tuesdays, Wednesdays and Thursdays. Her email is epunft.westsexneuroteam@nhs.net.

LOCAL ADVISER At present you should contact the national helpline on 0800 8000303

UTTLESFORD COMMITTEE: Interim Chair, Newsletter editor and Joint Outing Coordinator Vivian Falk (01799 513128); Secretary, Judy Millward, 01763 838742; Treasurer (& Donations) Tony Leek, Richmond House, Mount Pleasant, Hundon, CO10 8DW, (01440 786599); Joint Outings Co-ordinator, Mary Woolhouse (01799 530155),

Fundraising Officer, Kate Riley, (01799 530350); Bridget Hardy (01799 550533), David Perks.

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