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UTTLESFORD SUPPORT GROUP
NEWSLETTER/INFORMATION SHEET, October–November 2020
www.parkinsonsuttlesford.org.uk

PARKINSON'S UK LOCALLY

The Uttlesford Support Group committee wishes we could tell our members that we will soon be up and running again! However, in common with other Parkinson's UK local groups we are not currently able to run any events, owing to the continuing problems caused by Covid-19. We very much hope to get back to normal before too many more months have passed.

In the meantime, the group's committee wants to stay in touch with members, so please let us know how you are getting on. Contact details are at the end of this newsletter.

Members will be very sorry to learn that Susan Smith has died. Susan and her husband Gordon were members of the group for many years until they moved away to Suffolk. Susan (like Gordon) was also an important figure in local choral music. She taught 'Voice for Life' classes and Royal School of Church Music 'ribbon' courses, and she acted as music librarian for the choir of St Mary's parish church, Saffron Walden. Funeral donations were made for the Uttlesford Support Group.

CORONAVIRUS AND PARKINSON'S DISEASE

Information on what the pandemic means for people with Parkinson's disease is available on the Parkinson's UK website [here](#).

RESEARCH: RECOMMENDED READING

- A leading Parkinson's journal has published an important supplement, which is freely available for anyone to read online [here](#). (Unlike most published medical research, you don't have to pay a hefty fee before you can access it!) The *Journal of Parkinson's Disease* takes a positive view of the future for people with the condition providing: 1) that they receive the treatments already available tailored to their own individual needs; 2) that research aimed at finding a cure continues. The first article in the supplement says that the priority is to ask people with Parkinson's themselves what they need! Topics dealt within other articles include reviews of current thinking on: sleep problems, pain management, problems with vision, exercise and frailty. These scientific articles are a demanding read but worth the effort. (There's also a very brief summary [here](#).)
- Also some recommended viewing! A recent Parkinson's 'research webinar' – *A Good Night's Sleep: Parkinson's and your Pillow* was recorded and can be seen on YouTube [here](#). Two experts discuss current research into sleep and what this means for people with Parkinson's and their partners. (In places the sound is not brilliant but you can click on the subtitles button in the lower right-hand side of YouTube.)
- One interesting new study concerns the potential use of slow-release pills. Researchers in Singapore have managed to combine three Parkinson's treatment drugs into a single pill, which is taken daily and releases the drugs gradually over 24 hours. Further studies are needed but this could result in better management of the condition and also be a lot easier to take. Summary [here](#).
- Everyone knows that there is a lot of variation in how Parkinson's affects those who have the condition. Could there in fact be two types of the disease? The possibility is raised by Danish researchers based on brain scans they have conducted on 37 people with Parkinson's. They suggest that some people have 'Body-first Parkinson's' and others 'Brain-first Parkinson's'.

The former seems to start in the gut and the latter in the brain. It is just a theory but an interesting one! More information [here](#).

- Worryingly, however, medical research itself is under threat. Across the world, Coronavirus research is attracting astonishing levels of funding but specialists in most other conditions are finding it difficult to continue their work and face a shortage of funding in the future. An article in the *Guardian* has [more information](#). These are troubling times and the work of Parkinson's UK in supporting research is more important than ever.

AND HOW ARE YOU?

Here are some of the things that members of our committee have done lately, *despite* the pandemic! But how are other members getting on? [Please let us know](#). Maybe you would like to contribute to the next issue of the newsletter?

Judy: 'Cambridge without the hordes of tourists was a delight to visit ... We made the most of the government subsidised meal deals ... I am catching up on maintaining my neglected house ... My bridge, book club and yoga sessions have been relegated to Zoom, which I have dropped out of as, living alone, it is human company I crave, not conversing via a screen ... I have enjoyed croquet, my writing group meeting in gardens and lots of walking, often with friends ... I'm not looking forward to winter!'

Simon: 'A couple of months ago the Office for National Statistics contacted us asking us to take part in a Covid survey. For this we have been tested on a weekly basis for five weeks, and from now on a monthly basis for the next eleven months. The test is a throat and nasal swab that we do ourselves with the kit left on our doorstep, then taken immediately after. So far we are negative.'

Kate: 'I loved and was grateful for the good weather in summer. I really enjoyed the peace and quiet at first ... I've tried to be more observant and learn some names of wild flowers and butterflies ... I've met more 'birders' and there was a general thrill when a cuckoo and then turtle doves were seen and heard ... I have a small allotment and it has been pretty successful, so I am now picking tomatoes, too many courgettes, salad and spring onions, potatoes, beetroot and cucumbers - much more variety than ever before. The freezer is now full of soup and frozen berries! ...

'...A friend had suspected Covid-19. She was unable to get a test, but had most of the symptoms. She is much better and none of us have been affected thankfully, but it certainly reminded me what it is like to self-isolate. My heart goes out to those who have had to do so for much of the year.'

Mary: 'Walking in the countryside ... We have seen a variety of wildlife and taken more notice of flowers; I have been amazed by the wild orchids in the Wellcome Trust wetlands ... Open-air events in the churchyard, village barbecue with cake and veg competition, take-away fish and chips ... It was a treat to get my hair cut once we were allowed!'

Parkinson's UK membership: if you are not already a member, we do encourage you to join. Please ask for a form. The fee to join is £4 a year, with an extra £6 a year to join the Uttlesford Support Group.

PARKINSON'S NURSE COVERING UTTLESFORD: Vivienne Kavanagh 01279 621924 or 07778 934669. Viv does not offer clinic sessions, but she is available to give advice over the phone.

LOCAL ADVISER: Angela Nullmeyers 0344 225 3707. If you are not successful in attempting to reach Carol, then please contact the national helpline on 0808 8000303

UTTLESFORD COMMITTEE: Chair, Simon Russell (01799 524638); Secretary, Judy Millward (01763 838742); Treasurer (**Donations**), Tony Leek, Richmond House, Mount Pleasant, Hundon, CO10 8DW (01440 786599); Joint Outings Coordinators, Sheila Bricknell (01799 219078) and Mary Woolhouse (01799 530155); Representing Dunmow members, Val McGregor (01371 870296); Membership & Welfare Officer, Janet Crofts (01223 893619); Fundraising Officer, Kate Riley (01799 530350); Speaker organiser: Pat Lodge (01799 500255); Newsletter Editor, Paul Chinnock (01799 522570).

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