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**THOUGHTS FROM THE CHAIR**

I am writing this on the third day of the Lockdown and as Alice in Wonderland found, the world is getting 'curiouser' and 'curiouser'. An eerie quiet in the streets. Unheard of car parking spaces outside my home. Even the Bath Rd is deserted. 'My Coffee' has rearranged its big letters from OPEN to NOPE!

As though to compensate for the strangeness, the sun is shining some days and spring is very much in the air. As I write this it is a glorious day. Whatever else happens, I feel glad that at least we are not starting winter gloom and darkness as we face all this anxiety-making uncertainty about the future. We now have the possibility of better weather and the certainty of light mornings and longer days to help us cope with our very restricted life.

Donald Trump **was** saying it will all be over by Easter. If our experts are to be believed it is likely to be much longer. Somehow we will have to cope with living in what almost amounts to a life of monastic seclusion. I have newly discovered Skype. It is truly brilliant way to keep in contact. Seeing each other's faces makes a world of difference.

It would be good to hear from you about your own tips for living in this new world of self-isolation and social distancing. For me, the advice to make a routine for each day, seems the best way forward. As I lie in bed each morning I ask myself **what will make this a good, worthwhile day?**

This will help to avoid the scenario I saw in a recent cartoon which had the caption '**knitting a present for her husband**'. **She is clearly working on a noose!**

How already we are very much missing our branch activities!! The coffee mornings, table tennis and branch meetings have been so successful in the past months and for me their absence is very much part of the social loss I feel.

Exercise is so important for those of us with Parkinson's. At the time of writing we can still leave the house for a daily walk. Also you might find it useful to visit Parkinson's UK YouTube Channel where there are short videos of people with Parkinson's showing simple exercises that can be done at home.

Rest assured as soon as our activities can be restored we will let you know! In the meantime more information can be obtained via the contacts listed in the Useful Information on the last page.

Or if you fancy a chat don't hesitate to make contact with me, Harry Mathews, on 07515 857 110 or email me at: parkinsonshjm@gmail.com

**Don't Forget – Be Safe. Stay Indoors.**

PS: From Dot Simpson: -

*'I have extracted my long neglected exercise bike from a pile of clutter in our spare room and I am now doing 5 miles a day, in front of an open window, late afternoon watching TV (sometimes the Doom and Gloom of the daily Coronavirus News Update).*

*To escape this Doom and Gloom for a while daily I have taken a copy of the Cheltenham area from an OS map and then drawn a circle, centred on our house, 2<sup>1/2</sup> miles in radius so I can visualise where I have cycled to and back from each afternoon!*

*One day I go to Seven Springs, another day Crickley Hill (without the gradient) or I imagine cycling through a deserted town centre past Pittville Park to the now quiet Race Course! **Where to today?***

## RECENT BRANCH MEETINGS

### 28 January

At branch meetings and via newsletters, we have regularly advertised the importance of some kind of regular exercise for everyone, not only for those with Parkinson's, so we were glad to welcome to our first meeting of the New Year Toni Vassilouthis who took us through some Tai Chi exercises.

### 25 February

The 36<sup>th</sup> Branch AGM was very well attended. The meeting was chaired by Sarah Wakeman, Parkinson's UK Fund Raiser, West of England, and the following were voted back on to the Committee for a further year: Harry Matthews - Chair, Dot Simpson – Treasurer, James Howell - Minutes Secretary and Didi Jepson, Val Corke and Clive Corke. Ian Jones was welcomed as our new Branch and Membership Secretary and Joy Ingram and James Ingram also joined our committee.

Harry Mathews, Branch Chair, in his annual report for 2019 spoke about the success of our monthly coffee mornings and the Friday afternoon table tennis group.

Dot Simpson, in her Branch Treasurers report for 2019, presented a very healthy set of accounts. These in no small measure were due to a combination of generous donations and fund raising initiatives from a variety of organisations, such as local choirs, who had Parkinson's in mind.

This will enable us to continue, as outlined in the 2020 Branch Budget, to fund the total costs of the neurological exercise group and part of the cost for those who attend conductive education. We are also now able to fund half the transport costs of up to £10 per person to help members attend Branch meetings. In addition some funds will be directed to research.

After the business of the AGM our fascinating speaker was Heather Shute from **Medical Detection Dogs** a charity which trains dogs to use their smell both to either detect early disease or to live with and support those who have a condition for which dogs can warn about deterioration before humans can.

We were delighted that she was accompanied by her very well behaved Ambassador Dog, Edward, who obligingly hunted down a piece of hidden cheese to demonstrate his excellent nasal skills! Here is a summary that Heather gave of the charity's work:

***Medical Detection Dogs is at the forefront of innovative research into dogs' ability to detect the smell of human diseases and save lives.***

*The dog's nose is the best bio-sensor we know. Our 2014 research indicated that our dogs were capable of detecting tiny traces (around one part per trillion – the equivalent of one teaspoon of sugar in two Olympic sized swimming pools) of the odour created by different diseases.*

*Our pioneering work is focused on understanding how dogs could, after training, expand the world of diagnosis by their recognition of trace volatile molecular markers of a disease. As a result of this training, we are confident that dogs will be able to help scientists and medics develop faster and cheaper ways to detect diseases, such as cancers, neurological diseases and bacterial infections much earlier than is currently possible.*

*Neurological diseases affect over 1 billion people worldwide. Our work currently focuses on Parkinson's disease, which affects one in every 500 people in the UK. At present there is no definitive test for Parkinson's. Diagnosis is usually made in response to the individual exhibiting motor*

*symptoms, such as tremor and rigidity and non-motor symptoms such as feeling tired and having sleep problems.*

*Symptoms typically only start when more than half of the relevant neuro transmitters in the brain have already been lost Being able to diagnose the condition earlier would lead to treatments starting sooner and might greatly increase the chances of developing drugs which slow progression of the disease.*

*Alert Dogs: Again using their amazing sense of smell, dogs can be trained to identify minute odour changes emitted from a sufferer prior to a debilitating episode and so alert the person to take preventative action.*

## **PARKINSON'S & CORONAVIRUS**

Parkinson's UK has an excellent website which is a mine of information about all aspects of Parkinson's. If you haven't already done so it is certainly worth visiting, especially their section on **Understanding Parkinson's and Coronavirus** which is being updated regularly:

**[www.parkinsons.org.uk/news/understanding-coronavirus-and-parkinsons](http://www.parkinsons.org.uk/news/understanding-coronavirus-and-parkinsons)**

*The advice for people with Parkinson's is to **stay at home**.*

***Some groups of people have an increased risk of severe illness if they get coronavirus. These groups include everyone over 70, people who are pregnant, and people with certain conditions. The conditions include Parkinson's. However, people with Parkinson's don't have a greater risk of catching coronavirus than anyone else.***

*Coronavirus (COVID-19) is a new illness. As a result, we don't yet have accurate information about it and Parkinson's. But we do know that people with Parkinson's are more prone to pneumonia and infections.*

*Parkinson's can cause respiratory issues for some people. If you have advanced Parkinson's or have lived with the condition for a long time, you're more likely to have breathing and respiratory difficulties. Coronavirus affects your lungs and airways. **This is why people with Parkinson's are described as being at greater risk of severe illness if they get coronavirus.***

Be alert for the following symptoms:

- A high temperature – over 37.8 degrees. If you don't have a thermometer, check if you feel hot to touch on your chest or back.
- A new, continuous cough – this means coughing repeatedly for a long period.

If you, or someone you live with, experiences these symptoms follow NHS guidance on Coronavirus, including on how long you should stay at home and self-isolate, on:

**[www.nhs.uk/conditions/coronavirus-covid-19/](http://www.nhs.uk/conditions/coronavirus-covid-19/)**

Obviously **self-isolation** (and especially **shielding**, if your other health conditions require it) can be stressful. The charity, Mind, have put together some helpful guidance on wellbeing and coronavirus:

**[www.mind.org.uk/information-support/coronavirus/coronavirus-and-your-wellbeing/](http://www.mind.org.uk/information-support/coronavirus/coronavirus-and-your-wellbeing/)**

## **PARKINSON'S NURSE PROVISION UPDATE**

During the past twelve months there have been worrying changes in the availability of Parkinson's Nurses. Claire Pollock, the hospital based nurse, left last summer and Sue Watts who had reduced her work to two days a week will finish as team leader of the community nurse team at the end of March. Both these Parkinson's nurses were very experienced with excellent reputations and we have all been anxious about how soon they can be replaced.

It is good to report that Claire Pollock's position has been filled by Deborah Thurman who is now seeing patients. Deborah can be contacted via her secretary Denise King on **0300 422 6610**.

Deborah is seeing patients in Beacon House (Gloucester Royal Hospital). Although she is not yet prescribing herself yet, she can liaise with your Consultant if a change of prescription is warranted.

Currently there have not been any applicants for Sue's position. Mark Greening was however appointed in January 2020 as the community nurse team administrator. For those who were cared for by Sue Watts, the team can be contacted about the availability of Parkinson's Community Nurses at [mark.greening@ghc.nhs.uk](mailto:mark.greening@ghc.nhs.uk) or **0300 421 8109**

It is hoped that, in keeping with the recommendations of the recent appraisal of neurological nurse provision in the county, all the Parkinson's Nurse Services will operate from Gloucester Royal Hospital by the end of the year.

**STOP PRESS:** Outpatient and clinic appointments are currently cancelled as the hospital trusts concentrate on the Coronavirus response but telephone advice may still be available via the above numbers or **Parkinson's UK Helpline:** (phone free) 0808 800 0303

## USEFUL INFORMATION

### BRANCH MEETINGS & REGULAR EVENTS

All cancelled until further notice

### BRANCH CONTACTS

**Branch Chair:** Harry Matthews 07515 857110 or [parkinsonshjm@gmail.com](mailto:parkinsonshjm@gmail.com)

**Branch and Membership Secretary:** Ian Jones 07903 850597 or [ianjones.parkinsons@gmail.com](mailto:ianjones.parkinsons@gmail.com)

**Branch Treasurer:** Dot Simpson 01242 583894 or [dsimpson.parkinsons@googlemail.com](mailto:dsimpson.parkinsons@googlemail.com)

**Committee Members:** Didi Jepson, James Howell, Val & Clive Corke, Joy & James Ingram

**Branch Website:** <http://www.cheltenhamparkinsons.org.uk/>

### USEFUL CONTACTS

**Parkinson's UK Website:** <http://www.parkinsons.org.uk>

**Parkinson's UK Helpline:** (phone free) 0808 800 0303

**Parkinson's Local Advisor:** 0344 225 9821 or [adviser10.west@parkinsons.org.uk](mailto:adviser10.west@parkinsons.org.uk)

**Parkinson's Nurse Specialist Service:** 0300 421 8109 or [Parkinsons.team@glos-care.nhs.uk](mailto:Parkinsons.team@glos-care.nhs.uk)

**Age UK Help Team:** Monday – Friday 9am – 4pm 01452 422660

**Age UK Out of Hospital Team:** Monday – Friday 9am – 4pm 01452 420937 or 420928

**Mind:** Infoline: 0300 123 3393 or [www.mind.org.uk/information-support](http://www.mind.org.uk/information-support)

**Samaritans:** call free any time, from any phone, on 116 123.