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THOUGHTS FROM THE CHAIR

It has been a source of humour for some weeks now that being on Zoom provides other members of the group an opportunity to view what's behind you: unfolded laundry, a tray of unwashed dishes, a cluttered table. To avoid this, regular users will know that, if by chance there isn't a glimpse of Country Life Utopia behind you, you can choose a screen background of a tropical beach or rolling hills so that your privacy is maintained.

Most of us don't bother. It's good to have a hint of lived-in space, with untidy book shelves to prove recent browsing. Then a much loved pet can suddenly appear asking for attention. This leaves open a much appreciated element of surprise as when a donkey suddenly appeared with Arnold Schwarzenegger on Zoom when he was demonstrating his indoor work-out!

I have enjoyed reading more than usual. My latest find from the great unread collection on my shelves is the trilogy of George Melly's life. He was well known for his jazz singing and his humour, but I hadn't realised what a good writer he was. The added bonus for me is that he was, like me, born in Liverpool and many of the places he describes I know well.

It would be good to hear from you about good reads these past few weeks. We can't have too many recommendations – we may need a library full before it's all over!

Another aspect of the lockdown has been finding more time for reflection. A New Orleans artist, Candy Chang, covered an old building with blackboards for people to write out what they want to do 'BEFORE I DIE'. The project became an international hit. I am not surprised because being on lockdown carries, for some of us, a feeling that we have been robbed of time. It is not surprising then that Candy's blackboards get filled several times over. For me:

Freedom to be with loved ones

trumps seeing Niagara Falls

on my black board entry!

PARKINSON'S NURSE SERVICE UPDATE:

Our Zoom Parkinson's Café meetings have been very popular in lockdown to help keep members connected with each other and hence feel less isolated. At our Zoom Café on June 11th however it was good to have a chance to meet the new community PD nurse, **Jackie Burnett**, who replaces Sue Watts in our area.

Jackie shared with us something of her very varied background in nursing. She had worked in France as a general nurse then as a district nurse in Stroud. Some time working on a neurology ward aroused in her an interest in Parkinson's. Although she is still in training for our specialty, and is not qualified to write prescriptions, there was no doubting her enthusiasm for her new post as a Parkinson's Nurse.

It remains the case, however, that the Community Parkinson's Nurse Team is still one nurse short which means that there are just two nurses covering the county.

Debbie Thurman is the new Parkinson's Nurse Specialist with the Neurology Department at Gloucester Royal Hospital.

The plan is to merge all the Parkinson's nurse posts into one combined service, based in the hospital but also covering the community with community clinics and home visits. Jackie did not have a date for this happening

Contacting Parkinson's Nurses and Consultants:

At present there are only telephone consultations available from the nurses and consultants locally.

Jackie Burnett, and her colleague, are available on **0300 421 8109** or **Parkinson.Team@ghc.nhs.uk**

Debbi Thurman can be contacted via Denise King, her secretary, who works Wednesdays, Thursdays and Fridays 8am-4pm on **0300 422 6610**

If you need advice sooner don't forget that the Parkinson's UK Helpline is available – ring and ask to speak to a nurse adviser on **0808 800 0303** (phone free).

Please note that the Parkinson's UK website advice on **Coronavirus and Parkinson's** is regularly updated as Government and NHS policies and advice change (See Update Below)

RESEARCH UPDATE:

Repurposing of Existing Drugs:

The good news that an anti-inflammatory drug, which has been on the pharmacist's shelf for decades, is reducing the death rate of those in the most serious stages of Covid19 is a reminder of how exciting the whole business of repurposing existing drugs is.

There are currently about 2000 existing drugs being investigated as possible weapons in our battle with Parkinson's. The aim is to find ones which will either alleviate symptoms, slow down its progression or best of all provide a cure for Parkinson's.

Repurposed drugs offer the great benefit of having already proven that they are safe. One of the front runners in Parkinson' research is Exenatide, currently used in the treatment of type two diabetes. It has been shown to slow down the progress of Parkinson's because it protects neurons. The drug is currently in stage 3 trials and the research team will report back in 2023.

PARKINSON'S AND CORONAVIRUS - OBTAINING HELP OR ADVICE:

There is support on offer for anyone affected by Parkinson's from the **Parkinson's UK helpline, Website and Parkinson's Local Advisors** (See **Useful Contacts** below).

The Parkinson's UK website advice on **Coronavirus and Parkinson's** is regularly updated as Government and NHS policies and advice change.

<https://www.parkinsons.org.uk/news/understanding-coronavirus-and-parkinsons>

The following guidance from the Parkinson's UK Website was **up-to-date on 19th June**:

What should I do?

Stay at home as much as possible

Following recent briefings from governments in devolved countries, and from the UK government, guidance for people in England, Wales, Scotland and Northern Ireland is to stay at home as much as possible.

The Chief Medical Officers for England, Wales, Scotland, and Northern Ireland have recommended that the alert level be reduced from 4 to 3. They added in a statement that this does not mean the pandemic is over. It means that there has been a steady decrease in all 4 parts of the UK.

Relaxed lockdown guidance for people who are clinically vulnerable, including people with Parkinson's, says that it's very important to stay at home as much as possible. You must strictly follow distancing and hygiene guidelines if you do go out.

Reasons to leave home, and distancing

You should stay at home as much as possible. When you leave the house, for any reason, you should avoid busy spaces and keep a distance of around 2 metres (6 feet) from people you don't live with. You should also continue to follow good hygiene practices, including hand-washing, not sharing crockery and cutlery, wiping down surfaces, and not entering other people's homes.

Reasons you may leave your home include:

- for work, where you cannot work from home
- going to shops that are permitted to be open, staying 2m apart
- to exercise or spend time outdoors, staying 2m apart
- to socialise outdoors, staying 2m apart (with no more than 6 people in England)
- any medical need, including to donate blood, avoid injury or illness, escape risk of harm, or provide care or help to a vulnerable person

If you have to be in an indoor space (like a shop or a bus), it's best to wear a face covering. Face coverings on public transport will become compulsory in England from 15 June.

Can I form a support bubble, or extended household?

If you are shielding (and therefore extremely vulnerable) you should not form a support bubble, or extend your household.

If you live by yourself or are a single parent with dependent children, you can form a support bubble with one other household of any size.

If you meet the criteria and have Parkinson's, the government states you can form a support bubble or extend your household. Support bubbles and extended households are intended to help people who may be lonely and feeling isolated. You should take particular care when deciding whether to form a support bubble, or extending your household, and any implications this may have on your health.

If you are shielding (and therefore extremely vulnerable) you should not form a support bubble.

Forming a support bubble, or extending with another household, means you can meet – indoors or out – and be closer than 2 metres apart. You can also stay overnight as if you lived with that household. Support bubbles or extended households should be exclusive - meaning you should not switch the household you are seeing or connect with more than one household.

Shielding measures for people who are extremely vulnerable

Strict shielding measures for people in the UK classed as extremely vulnerable were introduced in March. Shielding is for people at very high risk of severe illness and hospital admission from coronavirus (COVID-19) because of an underlying health condition. If you need to shield, you will have been contacted by the NHS. Only people who were advised by the NHS had to take this precaution.

Guidance is changing across the UK. And countries are starting to adjust their recommendations for people who've been advised to shield.

People who've been following shielding advice should still stay at home as much as possible. Because disease levels are much lower now than when shielding was first introduced, you can now go outdoors with someone you live with. You may meet someone from another household. If you choose to leave your home, you must stay outdoors, avoid gatherings, take extra care to maintain 2m distance from people you don't live with, and practice good hygiene.

If you are shielding you must not form a support bubble or extend your household at this time.

As Jenny Harries, Deputy Chief Medical Officer for England said at the announcement, "It is not just about what it is possible to do, it's about what it is sensible to do. [...] it's advisory as we keep saying, it is for individuals to choose."

You may choose to remain at home if you do not feel comfortable with contact with others. Though time outside in the fresh air, when it's very quiet, is likely to make you feel better in yourself. Parkinson's is different for everyone and we know that it's a challenge to balance your mental health, physical health and social wellbeing. If you're unsure or need to talk to someone, we're here. Call our advisers on 0808 800 0303.

Parkinson's and coronavirus (COVID-19)

I have Parkinson's - am I more at risk of coronavirus and what precautions should I take?

Some groups of people have an increased risk of severe illness if they get coronavirus. These people are described as clinically vulnerable and include everyone over 70, people who are pregnant, and people with certain conditions. These conditions include Parkinson's.

Although people experience Parkinson's differently, government guidance for people with Parkinson's, wherever you are in the UK, is to stay at home as much as possible. As you may be at increased risk of complications, you must keep 2 metres apart from people you don't live with when you go out. You must also maintain good hygiene.

Why do people with Parkinson's have an increased risk of severe illness from coronavirus?

We consulted our clinical director to try and understand this better. Coronavirus (COVID-19) is a new illness. So 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.

What are the symptoms?

Coronavirus (COVID-19) affects your lungs and airways. Normally, it starts with a fever and dry cough which can lead to a shortness of breath.

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.
- sudden loss of smell or taste – while loss of smell can be an early symptom of Parkinson's, it's important to rule out coronavirus (COVID-19) before exploring other diagnoses.

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

How might coronavirus affect Parkinson's medication?

If you do become unwell with a virus of any kind, it's important to keep taking the medication prescribed to you for Parkinson's.

Our Clinical Director, Dr Donald Grosset, advises: "You should not suddenly stop taking your prescribed medication for Parkinson's, as that can cause additional problems. However, missing a small number of doses – because of vomiting, for example – will not cause you harm.

"Follow the advice given to you by your health professional who might adjust your tablets or dose, depending on your condition."

Coronavirus testing and contact tracing - what do I do?

Each country in the UK has announced systems for coronavirus testing and contact tracing to control the spread of the virus. The system in Northern Ireland is already running. In England and Scotland it started on 28 May, and in Wales the system is due to start on 1 June.

Testing and tracing means that, if you have symptoms, you can arrange a test. If your test comes back positive, you will be asked about who you've been in close contact with in the 2 days before, and 7 days after, developing symptoms. Close contact means:

- people you've spent 15 minutes or more with at a distance of less than 2 metres.
- people you've had direct contact with - such as sexual partners, household members or people with whom you've had face-to-face conversations at a distance of less than 1 metre.

Those people will be notified by phone, email, or text that they should isolate for 14 days. They won't be told who they were in contact with who had the virus.

If you are notified that you may have been in contact with the virus, you must self-isolate for 14 days even if you do not have symptoms.

How will I know if a notification is genuine?

If you've been advised by one of the country testing and tracing services to isolate, please do so. Trace callers will never ask you for details that could put your privacy or finances at risk.

The BBC have shared [advice on how to avoid scams here.](#)

USEFUL INFORMATION

BRANCH ON-LINE EVENTS (on Zoom)

Parkinson's Cafe on Zoom **11.00am Thursdays July 9th and 23rd.**

An invite and meeting link details will be emailed to the branch mailing list before each Parkinson's Café.

Table Tennis Zoom Meeting **2.00pm Fridays July 3rd, 17th and 31st.**

An invite and meeting link details will be emailed to the group members before each meeting.

BRANCH MEETINGS & REGULAR EVENTS

NB: All face to face meetings/events are cancelled until further notice.

BRANCH CONTACTS

Branch Chair: Harry Matthews 07515 857110 or parkinsonshjm@gmail.com

Branch and Membership Secretary: Ian Jones 07903 850597 or ianjones.parkinsons@gmail.com

Branch Treasurer: Dot Simpson 01242 583894 or dsimpson.parkinsons@googlemail.com

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

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

Parkinson's Nurse Specialist Service: 0300 421 8109 or Parkinson.Team@ghc.nhs.uk

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

Mind: Infoline: 0300 123 3393 or www.mind.org.uk/information-support

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