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THOUGHTS FROM THE CHAIR

A number of years ago, Boots ran a New Year campaign which encouraged people to change just **one thing** about themselves in order to improve their quality of life.

I was reminded of this when I read about some recent Parkinson's research. Eight hundred people with Parkinson's at different stages were asked to nominate the symptom they would most like to be rid of.

It was a very useful question to ask. About 295 symptoms have been identified from patients with Parkinson's and by establishing which symptoms are the most troublesome, research for new treatments could in future, be directed to alleviate the real troublemakers.

Those of us with Parkinson's know from conversations with others what a diverse condition we have. It is the case that no two of us have a completely identical set of symptoms. That's why some research papers speak of the emergence of treatments which will be more tailor made to deal with an individual's problems

Anyway, here are the results of the survey. The symptoms are written in order of nuisance factor. The most annoying symptoms on the top. I wonder if these lists match the symptoms which have given you most bother.

THE TOP TEN SYMPTOMS WRITTEN IN ORDER OF NUISANCE VALUE BY PATIENTS AT DIFFERENT STAGES OF PARKINSON'S:

1 to 2 years after diagnosis	11 years+ after diagnosis
Tremor	Balance and Falls
Psychological health	Walking
Dexterity and Coordination	Speech
Stiffness	Movement
Fatigue and energy	Psychological health
Movement	Freezing
Cognitive function	Fatigue and Energy
Slowness	Dyskinesia
Walking	Tremor
Pain and unpleasant sensations	Dexterity and Coordination

Despite the fact that last year Covid19 work interfered with 20 clinical trials of treatments supported by PUK, globally there is an enormous amount of Parkinson's research taking place.

There are 450 clinical trials in progress in three main areas where research progress is focused:

- RELIEF OF SYMPTOMS
- RETARDING THE PROGRESS OF PARKINSON'S
- REPLACING WHAT HAS BEEN LOST

I was intrigued to read recently that one of the key players in finding a vaccine to halt the progress of Parkinson's is the big US drug firm AstraZeneca. That name gives one hope for a start!!

Our January Newsletter publicised the comprehensive website of the Oxford Branch of Parkinson's UK at <https://oxfordparkinsons.org.uk/index> as being worth a visit. I couldn't agree more. You will find in the research section of the Oxford site an excellent well illustrated overview of current research given by Dr Kevin Mc Farthing which he very appropriately calls the Hope List of Drugs.

One of the few identifiable upsides of the Covid19 experience has been the record time in which several vaccines have been produced. I am sure, like me, you felt an enormous sense of relief when notification to receive the vaccine turned up in your message box or through the letterbox.

I had stalked the postman for days in the hope it would be my turn soon!! Then when I was given a date a week away, like a child waiting for Christmas, I found that the days seemed to pass so slowly!

I can't help but hope that all of the excellent collaborative skills which in record time have been so successfully used to produce a Covid19 vaccine, will be transferable for Parkinson's research. It then won't be too long before our nuisance list of top ten symptoms will be wiped out for good and like the virus be consigned to history.

CHANGES TO PARKINSON'S NURSE SPECIALIST SERVICE

From 1st December 2020 the community Parkinson's Disease Service (formerly provided by Gloucestershire Health and Care Services NHS Foundation Trust) became part of the Gloucestershire Hospitals NHS Foundation Trust's Parkinson's Service within the wider Neurology and Care of the Elderly team.

For patients who formerly received care from the community Parkinson's service, they can reach the team on **0300 422 6610**, or by emailing ghn-tr.parkinsonsteam@nhs.net.

Alternatively, you can write to the service at Parkinson's Disease Service, Gloucester Royal Hospital, Great Western Road, Gloucester, GL1 3NN

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>

Parkinson's UK have a booklet with information and support about Parkinson's and coronavirus. You can order a copy of this booklet, free of charge, here.

The following guidance from the Parkinson's UK Website was **up-to-date on 26th February**

What should I do?

Follow the guidance where you live

You must follow the guidance where you live. You can find out about local restrictions on the relevant government websites:

England. A new national lockdown began on 4 January, and will remain in place until at least mid-February. Everyone must stay at home, leaving only to buy necessities, exercise, provide care, or for other permitted reasons.

<https://www.gov.uk/guidance/national-lockdown-stay-at-home>

NB: The government has published the '[COVID-19 Response - Spring 2021](#)' setting out the roadmap out of the current lockdown for England. This explains how the restrictions included in this guidance will be lifted over time.

England is still in a national lockdown. You must stay at home, leaving only where permitted by law, and follow the rules in this guidance.

From 8 March, some of the rules on what you can and cannot do will be changing including:

- you will be allowed to spend time in outdoor public spaces for recreation on your own, with one other person, or with your household or support bubble. This means you can sit down for a drink or picnic. You must continue to maintain social distance from those outside your household. This is in addition to outdoor exercise, which is already permitted
- the rules on visiting care homes will change to allow regular indoor visits for a single named visitor

No further significant changes will be made on 8 March and restrictions requiring you to stay at home will remain in place. Later changes, including from 29 March, are set out in the [roadmap](#).

Stay at home and limit social contacts as much as possible

Guidance for people who are clinically vulnerable, including people with Parkinson's, says that it's important to stay at home and limit social contacts as much as possible. Follow distancing and hygiene guidelines if you do go out.

If you do need to leave your home, the UK government advises people to think '**Hands. Face. Space**':

- You should wash your hands regularly, for at least 20 seconds.
- You should wear a face covering in enclosed spaces.
- You should give people outside of your household space of at least 2 metres, or 1 metre where other measures are in place.

CORONAVIRUS VACCINE AND PARKINSON'S

This information was updated on 17 February 2021

When you can expect to get the coronavirus (COVID-19) vaccine, and how safe it is for people with Parkinson's.

On 2 December 2020 the UK became the first country in the world to approve a coronavirus (COVID-19) vaccine. The Pfizer/BioNTech vaccine offers up to 95% protection against coronavirus.

On 30 December 2020, the UK medicines regulator approved a second vaccine. The Oxford University/AstraZeneca vaccine offers 62% to 90% protection against coronavirus, and was shown to prevent serious illness in all volunteers taking part in the clinical trial.

The UK approved the Moderna vaccine on 8 January 2021. It's 94% effective and is expected to be rolled out in the spring.

Who is getting the vaccine first?

The roll out of the vaccination for those in the highest priority groups began in December 2020.

Your age, underlying health conditions and any caring responsibilities will determine your priority level.

The Joint Committee for Vaccinations and Immunisations (JCVI) set out the priority levels for people to get the vaccine based on clinical need. You can see the phase 1 priority list on the gov.uk website.

By the middle of February, everyone who is over 70 or extremely clinically vulnerable should have had their first vaccine.

If you're over 70 and live in England but have not yet had your vaccine, or booked an appointment to be vaccinated, please contact the NHS. The easiest way to arrange a vaccination is through the national booking service at www.nhs.uk/covid-vaccination. Or you can call 119 or contact your GP practice.

You can also apply for a new appointment this way if you're over 70 and previously declined your appointment. If you're under 70, or live in Scotland, Northern Ireland or Wales, please wait to be contacted.

The roll out is now moving to groups 5 and 6. This includes people with Parkinson's who have not yet been called, and their carers.

I have Parkinson's and am in group 6. When will I be called?

Group 6 contains over 7 million people, each with their own personal risk factors which increase their chance of serious illness if they were to get coronavirus. Risk factors include conditions like Parkinson's or diabetes, but also your age, ethnicity and weight.

New data from the first wave of coronavirus now allows GPs to predict which patients in this group are at the highest risk, by taking into account all of their personal factors. Some people have multiple risk factors.

In England, people in group 6 will be called according to their personal level of risk, not by age or by condition.

Some people will be told that based on the new evidence, they need to shield until at least 31 March. These people will be prioritised for a vaccination.

This new data has been shared with the medical officers in Scotland, Northern Ireland and Wales. They'll decide if they use a similar approach.

I'm a carer for someone with Parkinson's. When will I be called?

Carers are able to receive their vaccination as part of group 6, regardless of their age. You'll be called when it's your turn for a vaccine.

Unpaid carers are defined as people who:

- receive Carer's Allowance
- have a 'carer flag' on their GP record
- are known to local authorities through a carer's assessment
- are known to local carer organisations
- have self-identified to their local authority.

If you're a carer but there isn't a formal record of your caring responsibilities, a new process will be put in place so that you can be added to the list. We'll share more details of this when they have been confirmed.

How will I get the vaccine?

The NHS will invite you for a vaccination when it is your turn, probably by letter.

You might get the vaccine:

- in your local hospital
- at a nearby vaccination hub

- via your GP or pharmacist
- at your care home.

The injection is not compulsory.

Be alert to fraud. There have been reports of scams asking you to book your vaccine or pay for the vaccine, claiming to be from the NHS. Scams can be via text message, letter, phone call, email or door-to-door.

Is the vaccine safe?

The UK has some of the highest safety standards in the world. All 3 vaccines meet the strict standards of safety, quality and effectiveness set out by the UK's medicines regulator, the Medicines and Healthcare products Regulatory Agency (MHRA).

The MHRA has considered these license applications as quickly as possible without cutting corners, because a vaccine to protect people against coronavirus is a priority.

The Pfizer/BioNTech vaccine is the fastest ever to go from concept to reality. This is partly because companies shared trial data with the MHRA throughout development, which shortened the assessment process.

Is the vaccine safe for people with Parkinson's?

Our Clinical Director, Dr Donald Grosset, advises:

"The vaccine is safe for people with Parkinson's. There is no interaction with Parkinson's medication. Parkinson's is specifically included as one of the conditions that is in a 'clinical risk group' and every adult with Parkinson's should get the vaccine."

If you've had the vaccine

Continue to practice social distancing, wear a mask, and wash your hands frequently. The vaccine reduces your risk of becoming seriously ill with coronavirus, but it isn't 100% effective and it may still be possible for you to pass on the virus to others. It's important to continue following government guidance and restrictions for your area.

If you've had the coronavirus vaccine and are experiencing side effects, please report it on the government's Yellow Card website.

COMMITTEE DECISION ABOUT THE BRANCH AGM 2021

The Branch Committee has been notified of changes to the governance of branches made by PUK's trustees in respect of holding branch AGMs.

Those changes meant that branches would not be required to hold AGMs in person in 2021. Branch committees were empowered to hold 2021 AGMs online or to dispense with an AGM for this year.

Any vacancies arising of Committee members or branch officers can be filled by the Committee and the appointments accepted in retrospect at the next AGM to be held.

Cheltenham Branch had been able to hold its 2020 AGM before lockdown.

The Cheltenham Branch Committee have decided that an AGM should not be held in 2021 since a significant proportion of members would be excluded from participating in an online meeting owing to lack of access to technology.

The Chair's Annual Report for 2020, the Treasurer's Report for 2020 and the Minutes of the AGM held in 2020 are attached to this newsletter, for your information.

USEFUL INFORMATION

BRANCH ON-LINE EVENTS (on Zoom)

Parkinson's Cafe on Zoom 11-00am Thursdays - March 4th & 18th, April 1st, 15th & 29th

Table Tennis 'Chat and Quiz' on Zoom.....2.00pm Fridays - March 12th & 26th, April 9th & 23rd

An invite and zoom link details will be emailed to the branch mailing list before each session

BRANCH MEETINGS & REGULAR EVENTS

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

The Branch Committee are awaiting further guidance from Parkinson's UK, about how, and when, we can restart face to face meetings/events in a Covid secure manner.

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 or email hello@parkinsons.org.uk

Parkinson's Local Advisor Service: contact our helpline on 0808 800 0303 or email hello@parkinsons.org.uk to be put in touch with a local adviser.

Parkinson's Nurse Specialist Service: 0300 422 6610 or ghn-tr.parkinsonsteam@nhs.net

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

Age UK Gloucestershire Website: <https://www.ageuk.org.uk/gloucestershire/>

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

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