PARKINSON'S^{UK} CHANGE ATTITUDES. FIND A CURE. JOIN US.



CHELTENHAM BRANCH NEWSLETTER

MARCH 2021

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THOUGHTS FROM THE CHAIR – 'FAKE NEWS'

I am a Tom Hanks fan and enjoyed watching him in a recent Netflix production called *News of the World*. The film is set in the years not long after the American Civil War.

Tom Hanks' character goes from town to town with a selection of national and local newspapers. He reads extracts from these to packed audiences who are eager to know what's going on in the world outside.

He winds up his audience into a passionate opposition as he reads items of local and national political significance. He has them on the edge of their seats as he reads from a features page an account of a daring rescue.

His easily manipulated audiences reminded me of how Donald Trump, with his own spin on current affairs, skilfully manipulated the emotions of his devoted followers. Any reporting that differed from his own version of events he denounced as *Fake News*.

In the days following the Harry and Megan interview with Oprah Winfrey, I heard a radio commentator say that those whose news is solely obtained from Facebook, Twitter, You Tube or Tic Toc etc., will never listen to the whole two hour interview. For them the volume of opinion expressed on their platform of choice will shape what emerges for them as news.

The reluctance of some people to have the vaccine has been put down partly to the prevalence of *Fake News* about it. Here are some of the most frequent *Fake News* statements about the vaccine. Covid-19 vaccines will (it is claimed!):-

- implant microchips into people
- make you infertile
- change your DNA
- not work because the Pandemic was started by 5G technology imported from China

We are very fortunate to live in a democracy which protects the freedom of the press. For the most part our mainline TV and radio stations provide a balanced view of news events. Usually, not only those involved in a story are interviewed, but also independent experts to review the facts. This has been very obvious in the on-going Covid19 reporting where scientists stand alongside politicians to reassure any who have doubts about a vaccine.

As far as trustworthy news is concerned, one of the easily forgotten gifts of our nation to the world, is the BBC's World Service. Based in London, the World Service provides a 24 hour news service to more than 200 countries. I love the true story about President Gorbichov, who at the time of

Perestroika in1991, was for a short time under house arrest. To find out what was really happening in Russia, he tuned into the BBC's Russian branch of the World Service. He knew that any news he heard from the BBC would be infinitely more trustworthy than that of his own media!

A doctor in charge of the enormous vaccine facility at St Helens rugby ground in Lancashire described the almost overwhelming joy and happiness that pervaded her centre on the opening morning as hundreds of people couldn't wait to receive the vaccine.

I heard something of the same about the atmosphere at the Fire Station vaccination centre in Cheltenham. The place was just full of smiles was how one of the recipients described her experience. My own reaction of utter gratitude to so many people, on receiving the vaccine, told me that there was nothing fake about that doctor's news! **It was a truly special moment**.

WHAT A YEAR IT HAS BEEN!

On Wednesday 11th March a group of branch members and friends met at the Norwood for our monthly Parkinson's Café of coffee, cake and lots of enjoyable chat. On Friday 13th our enthusiastic Table Tennis group met for a more active session of table tennis, coffee, biscuits and chat.

Meanwhile up at the racecourse thousands of locals and visitors were enjoying the Cheltenham Festival, admittedly with the novel addition of hand sanitizer stations, culminating in the Gold Cup race on Friday 13th.

It was however that day – Friday 13th - that our branch committee were instructed by Parkinson's UK to halt face to face activities because of the spread of Covid19. Within a week schools closed, we were told to 'Stay at Home' with our first national lockdown starting - although at that stage we had no idea it would be the first of three lockdowns!

We all had to adapt rapidly with major changes to everyday life negotiating online grocery shopping, learning to communicate with family and friends by FaceTime, Skype or Zoom. The branch had also to adapt to keep in touch with our now isolated members.

Within a month members of our Table Tennis group held, and enjoyed, their first tentative zoom chat and so, on April 16th, we held our first Virtual Parkinson's Café on Zoom, assisted by a branch member who already used Zoom for her business. Since then we have enjoyed fortnightly Parkinson's Cafes, alternating with the Table Tennis Groups Quiz and Chat sessions (which were opened up to all members later in the year).

The branch committee also met monthly on Zoom and we increased the frequency of our Branch newsletters from quarterly or monthly, sending them out mainly as e-copies but also paper copies by post to those without the internet.

We have all had to adapt to long periods of lockdown and members have found all sorts of ways to continue with their usual hobbies and activities. We know of members attending on-line versions of their usual exercise classes also dance for Parkinson's, choir practices, country dancing, online quizzes, book groups etc. – ingenuity and adaptability have been very much in evidence!

I mentioned, in one of our early lockdown newsletters, that I had dug out our old exercise bike out of storage, reassembled it at the start of the first lockdown and started to cycle 8k/5m a day. Much to my surprise I have kept it up and, although I have missed the odd day when busy with other things (or just felt lazy) I recently worked out I must have, over this last year, cycled about **1750 miles - the equivalent of from Lands' End to John O'Groats and back!** Dot Simpson

RESEARCH NEWS

A SIMPLE TECHNIQUE BEING TRIALLED FOR EARLY DETECTION OF PARKINSON'S

Results, published on March 11, show it is possible to identify Parkinson's based on compounds found on the surface of skin. The findings offer hope that a pioneering new test could be developed to diagnose Parkinson's through a simple and painless skin swab.

Scientists at The University of Manchester have developed a technique that works by analysing compounds found in sebum - the oily substance that coats and protects the skin — and identifying changes in people with Parkinson's. Sebum is one of the lesser-studied biological fluids in the diagnosis of the condition. People with Parkinson's may produce more sebum than normal.

The research has been funded by charities Parkinson's UK and the Michael J. Fox Foundation as well as The University of Manchester Innovation Factory.

IT'S NEVER TOO LATE TO PUT ON A VIRTUAL REALITY HEAD SET!



One of the common symptoms of Parkinson's is gait impairments that reduce the ability to walk safely. These impairments are characterized, in part, by a compromised ability to turn and negotiate both predictable and unpredictable environments.

This research tracks the development and usability of virtual reality training. The software *Wordplay VR*, allows those with Parkinson's to practice skills such as turning, obstacle avoidance, and problem-solving during over-ground walking in a game-based setting.

Preliminary results suggest that the application and task design yielded an experience that was motivating and user-friendly. Lastly, with repeated practice over multiple sessions, therapists were able to reduce the time required to help their patients don the headset and sensors and begin the training experience. Whatever else it sounds fun!

LINKS BETWEEN THE APPENDIX AND PARKINSON'S

Throughout the history of medicine the appendix has been an unresolved puzzle. So when it becomes infected it is removed without a second though. Recent research results have suggested that the appendix may be a reservoir of good bacteria which waits to replace invading bacteria that our immune system has disposed of.

During this fresh interest in what might turn out to be an underappreciated worm-like projection from the colon, the question was asked does having an appendix affect you chance of developing Parkinson's? Having lost my appendix at 14, I was relieved to read that there was no significant difference in the emergence of Parkinson's between those with or without an appendix.

GOOD OLD RE-PURPOSING

I am always glad to read about well-established treatment for one ailment being investigated as a possible medication for Parkinson's. Researchers have found that Terazosin, a drug used to treat enlarged prostate glands and high blood pressure, has, under lab conditions been found to reduce the progression of Parkinson's. It really helps that Terazosin has been around for some time (1975). Given so many years of safe usage, it is not surprising that clinical trials are underway to verify its use for Parkinson's treatment.

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 29th March**.

WHAT SHOULD I DO?

Follow the guidance where you live

Restrictions and social distancing guidelines remain in place across the UK. Check your relevant government website:

<u>England</u>. Some restrictions, including on social contact and outdoor exercise, have eased as of 29 March.

https://www.gov.uk/government/publications/covid-19-response-spring-2021/covid-19response-spring-2021-summary

Social contact

The evidence shows that it is safer for people to meet outdoors rather than indoors. And this is why from 29 March, when most schools start to break up for the Easter holidays, outdoor gatherings (including in private gardens) of either 6 people (the Rule of 6) or 2 households will also be allowed, making it easier for friends and families to meet outside.

Business and activities

Outdoor sports facilities such as tennis and basketball courts, and open-air swimming pools, will also be allowed to reopen, and people will be able to take part in formally organised outdoor sports.

Travel

The 'stay at home' rule will end on 29 March but many restrictions will remain in place. People should continue to work from home where they can and minimise the number of journeys they make where possible, avoiding travel at the busiest times and routes. Travel abroad will continue to be prohibited, other than for a small number of permitted reasons. Holidays abroad will not be allowed, given it will remain important to manage the risk of imported variants and protect the vaccination programme. The government has launched a new taskforce to review global travel which will report on 12 April.

Later changes, including from 12th April are set out in the <u>roadmap</u>.

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.

Look after your wellbeing and mental health

During this pandemic, it's especially important to take extra care of your wellbeing and mental health. We've compiled some resources to help you feel your best self:

• <u>How to cope if you're feeling isolated</u>.

www.parkinsons.org.uk/information-and-support/your-magazine/experts/managingyour-mental-health-during-pandemic-when-you

- Mind's <u>helpful guidance on coronavirus and your wellbeing</u>.
 www.mind.org.uk/information-support/coronavirus/coronavirus-and-your-wellbeing/
- The British Red Cross's online resources and tools to help you tackle loneliness.

www.redcross.org.uk/loneliness-resources#

• Public Health England's wellbeing resource, Your Mind Plan.

www.nhs.uk/oneyou/every-mind-matters/your-mind-plan-quiz/

• And if you're experiencing symptoms of anxiety, depression or other worries, you may be able to access <u>NHS talking therapies</u>.

www.nhs.uk/mental-health/talking-therapies-medicine-treatments/talking-therapiesand-counselling/nhs-talking-therapies/

USEFUL INFORMATION

BRANCH ON-LINE EVENTS (on Zoom)

Parkinson's Cafe on Zoom 11-00am Thursdays - April 1st, 15th & 29th, May 13th & 27th.

Table Tennis 'Chat and Quiz' on Zoom2.00pm Fridays - April 9th & 23rd, May 7th & 21st.

An invite and zoom link details will we 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.