

CHELTENHAM BRANCH NEWSLETTER

NOVEMBER 2021

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THOUGHTS FROM THE CHAIR

Around 50 years ago when I was working in Liverpool, I visited a hospital ward for severely disabled children. As I approached the Ward Sisters office, I noticed the nurses and the specialist teachers having a glass of sherry.

"Whose Birthday, is it?" I asked.

"It's not a birthday" said one of the teachers. We are celebrating the fact that after months of work with him, Paul has spat his peas out. At last, for the first time, he has shown us that he can discriminate his taste, a real breakthrough in communication"

I marvelled at the existence of such a special brand of teacher who could devise meaningful challenges for that level of handicap.



At the end of September were delighted to be able to hold our first branch meeting since February 2020.

Alison Anderson (a regular and very popular speaker who, each year, shares with us what she has accomplished fundraising on her bicycle) interviewed Neill Russell another Parkinson's athlete.

He is a runner who ran a marathon each day for 36 days as he journeyed from John

O Groats to Lands' End! I really liked his guiding principle for each day:

WHILE I STILL CAN

I can't help but think that is a perfect guiding principle for us as well as we face the prospect of our horizons becoming increasingly limited by Parkinson's.

I remember when my mother-in-law was 89, she moved into sheltered accommodation nearer to where we lived.

As we drove away from her house for the last time, my son Tom who was then 10, said "Nana, I thought you would cry leaving the house you have lived in for so long"

“Cry! Why would I cry? I am so excited about my new home. I can’t wait to move in and carry out carry out my plans. New colours for each room. A new kitchen lay-out. I have so much to look forward to, especially seeing you and your sister more often.”

I do hope that when I am 89 and being moved I will have the Farrow and Ball colour charts on my knee ready to take on the challenge of change and just like Nanna, be filled with excitement and not dread

I was delighted to see such a good attendance at our October branch meeting, given that the media was beginning to publish an alarming rate of daily infections. Thank heavens for the protection of two vaccine injections and a booster to make sure!

After living through a summer of barely giving Covid a second thought, in the week of the October branch meeting we began to feel vulnerable again as the number of local Covid cases had risen rapidly. News of infection of people we know started to come in. The absence of one of our committee added to this evidence as she observed ten days of isolation due to a household member testing positive.

Nevertheless, about 30 members overcame any doubts they may have had and came to hear Dr Fletcher, our Branch President, once again. They clearly trusted our precautions as we followed a detailed COVID protocol of ventilation, masks, social distancing and surface wiping. It was so good to welcome several new members who I am sure will come again.



Before the main business of the afternoon, Virginia Pyne arrived to show us her splendid Marathon medals. They were truly heavy metal, not a hint of plastic!

We described in our September Newsletter how she took up running in her 70’s and became a marathon runner.

I am delighted to say that she completed this year’s London Marathon in 5 hours 11 mins. She raised over £2000, half for Parkinson’s UK.

This was the fastest time for a woman over 80 so she received a second medal for that achievement alongside the finisher’s medal.

Clearly, we are not all at the level of fitness to complete a marathon. But not being able to run a marathon shouldn’t stop us accepting challenges in our own daily round.

Her achievement reminded us that it’s never too late to start serious exercise!

DR PETER FLETCHER, BRANCH PRESIDENT - SOME NOTES ON HIS TALK:

Dr Fletcher’s talk is always well attended. Each year he has the same brief. To explain some Parkinson’s basics and outline any progress that has been made in Research. He never disappoints. He is such a good teacher. I also think he is wonderfully generous with his time as he always stays behind for a long time after his talk, listening to individual members and their personal questions.

He started by reminding us about some terms that we now hear every day which are frequently misused.

ENDEMIC. A virus that is always with us such as the ones that cause Flu. We have been offered flu vaccinations for years because one sort of Flu or another is always around us every winter. Therefore, Flu is endemic in our country.

EPIDEMIC. This term is used to describe a situation when a new Flu virus causes many infections.

PANDEMIC. This term describes the situation where the infection has spread around the world

It is clearly going to be the case that from next year onwards we will have Flu and Covid injections every year as Covid will remain endemic.

The Three Fronts of Our Battle with Parkinson's:

Drugs are currently being developed to:

1. Alleviate the symptoms of Parkinson's and explore ways of controlling the delivery of these drugs across the blood-brain barrier either faster, slower or more efficiently so that a greater proportion of the drug is actually delivered to the brain.
2. Slow down the progression of the disease
3. Protect and replace damaged neurons. Halt the disease completely.

The global nature of COVID19 **provided for research a huge potential data base** upon which new Vaccines and drugs could be tested quickly. *Dexamethasone*, an anti-inflammatory drug, has a wide range of uses. When given to patients seriously ill with a Covid infection it immediately made a big impact on lung function. It reduced the death total of patients in intensive care. This huge data base may eventually yield useful information about the prevalence of all sorts of illness, not least the conditions in which they thrive. It would be good if valuable information about Parkinson's was harvested eventually from this database.

Bad Proteins

One thing that Parkinson's has in common with Alzheimer's is that in both diseases, neurons in the brain become clogged up with invasive proteins which once inside a cell misfold. The proteins are different for each of these diseases. However, there are similarities in approach when it comes to preventing the neurons being killed off by this gradual misfolding of rogue proteins.

In the case of Parkinson's, the name of the rogue protein is Alpha-Synuclein. There is an enormous amount of current research going into a variety of possible ways of defeating this invader.

A drug called Prazinezumab targets Alpha-Synuclein and early signs are promising. It has been shown to reduce the decline in motor function of those with Parkinson's by 35%!

Repurposing

This is possibly the most exciting news for heralding early delivery of something new and useful in making a difference for us with Parkinson's. The immense increase in computer power has enabled thousands of drugs to be investigated at once to test their efficacy in treating diseases other than the one for which the drug was originally produced.

The huge advantage of using these drugs is that they are already on the pharmacy shelf. We are aware of any side effects already. This means they can be safely used in Parkinson's trials. The front runner now is EXENATIDE which is currently used for treating type -2 diabetes

GDNF BBC2

In March 2019 many of us viewed with excitement and fascination the two- part BBC2 coverage of the GDNF trial. This is a protein which hopefully will protect enough neurons from Parkinson's damage to be worthwhile developing.

The Parkinson's research team at Bristol invented an amazing system by which GDNF was delivered right to the spot inside the brain where the GDNF protein would have the biggest impact.

Unfortunately, this trial did not achieve a 60% success rate. This was the target set by the drug company before it would commit itself to investing millions in the production of GDNF. The really sad aspect of this trial was that we could clearly see the benefits in movement for most of the participants and so could they. Once the trial was abandoned so was the drug and these patients soon lost the benefits they had clearly gained. They had glimpsed the Promised Land!

One positive outcome was that the team had invented an instrument to deliver a drug directly into the brain.

But the good news is that Parkinson's UK have committed £800,000 to plan a new GDNF trial.

Adolf Hitler and Parkinson's

A number of genetic factors have been shown to increase a person's risk of developing Parkinson's. Although exactly what makes one person more susceptible is not clear. Sometimes movements of a large number of people, e.g. an army crossing to new lands, present conditions for the emergence of a variety of ailments including Parkinson's.

Adolf Hitler was gassed when he was a soldier in WW1 and it is thought that one of the effects of the gas was neuron damage. This was revealed in transient symptoms of Parkinson's in 1924.

His type of Parkinson's (post encephalitic not the more common type, idiopathic) may have been a contributing factor to his asocial behaviour, his obsessions and compulsions, his cruelty and rages.

Exercise and Parkinson's

Vertical exercise at least twice a week such that your heart rate is increased will slow down the progression of Parkinson's and furthermore by increasing the density of bone and muscle will reverse the decline of resilience, which decreases with ageing. These improvements will also reduce the damage caused by a fall.

Useful Medication Advice to Even Out the Effect of Your Sinemet

A branch member in question time spoke about the dramatic way her medication can sometimes wear off and leave her almost immobile. Dr Fletcher suggested taking a soluble Madopar tablet about half an hour before your medication is due to avoid running on empty.

Things to Do

- Have an eye test annually. This should help to prevent falls
- A personal trainer will build up your exercise regime gradually
- There is no special diet for Parkinson's other than the usual balanced diet that has been well publicised for healthy living
- Deal with constipation by a good intake of fruit and fibre with a plenty of water throughout the day supplemented by a laxative if necessary

- Always carry with you a list of your medications in case you are taken to hospital unconscious. It is essential that your Parkinson's medication is maintained.

BBC BREAKFAST SHOW FEATURES PARKINSON'S ON OCTOBER 13th



Mike Tyndall's father has Parkinson's and on the day that Mike organised a fund raising golf tournament to raise money for PUK, The BBC added to their coverage of the event by having Mike interviewing four people with Parkinson's.

I thought he was really good at drawing out from those he interviewed what it is like to live with Parkinson's.

One of those interviewed was Alison Anderson (see above)). Like Mike, Alison is a Parkinson's Ambassador, and she is invited to give talks on Parkinson's to widen the understanding of those who know very little about it. She is second from the right in the photograph

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 4th November**.

WHAT SHOULD I DO?

Restrictions and social distancing for people with Parkinson's

Some restrictions and social distancing guidelines are beginning to lift in all 4 UK nations.

If you have Parkinson's, or are a friend, family member or carer for someone with Parkinson's, you should continue to follow the guidance and timetable where you live: England:

<https://www.gov.uk/guidance/covid-19-coronavirus-restrictions-what-you-can-and-cannot-do>

Our Clinical Leadership team does not recommend any additional measures for people with Parkinson's.

However, you should continue to take measures that feel suitable and right for you. For example:

- Be aware of where you are most at risk from catching coronavirus (indoors, and crowded places with close proximity to others).
- Increase the amount of close contact you have with people from outside your household gradually. You may want to continue to meet outdoors.
- Consider avoiding busy places at peak times and continue to practice good hand hygiene.
- If it's not already required by your country's guidance, consider continuing to wear a face covering and keeping a social distance.
- Ask others to wear a face covering and maintain a distance when coming into your home.

Alongside your government's guidance, it will be up to you to decide how you want to work, travel and socialise safely.

USEFUL INFORMATION

BRANCH ON-LINE EVENTS (on Zoom)

Parkinson's Cafe on Zoom -- 11-00am Thursdays November 18th, December 16th & January 20th 2022

Table Tennis 'Chat and Quiz' - 2.00pm Tuesdays November 9th, December 14th & January 11th 2022

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

REGULAR EVENTS

Table Tennis Club every Friday 2-4pm in St Luke's Church Hall, St Luke's Place GL53 7HP.

Cost £4 pp, £5 couples. All abilities welcome. There is disabled access and parking.

Drop-In Coffee Morning on the second Wednesday each month at the Norwood Arms,

Leckhampton, GL53 0AX from 11-00am to 12-30pm. There is disabled access and parking. NB: the

Norwood pay and display car park has a £3 per day charge which will be refunded to customers.

NB: Our next coffee mornings will be **Wednesdays November 10th & January 12th 2022**

(THERE WILL BE NO DROP-IN COFFEE MORNING IN DECEMBER)

BRANCH MEETINGS

We meet on the last Tuesday of most months (except December) at 3-00pm, in St. Mark's Methodist Church Hall, Gloucester Road, Cheltenham, GL51 8PX. Before attending please read the guidelines for branch meeting attendees (below)

30 November - Mark Cummings, Radio Gloucestershire

25 January 2022 – Kate Cole, Community Link Officer - Telecare and Assistive Technology

22 February 2022 – **Branch AGM** followed by Sarah Wakeman, Parkinson's UK Regional Fundraiser

BRANCH CHRISTMAS LUNCH: To be held at 12-00pm on 7th December at Clock Tower, Cirencester Road, Charlton Kings, GL53 8EG. **NB.** Please contact us ASAP to book one of the few remaining places.

GUIDELINES FOR BRANCH MEETING ATTENDEES

(Taken from the risk assessment for branch meetings at St Mark's Church Hall)

1. Hand sanitizer will be available for your use at the welcome table
2. Masks should be worn when moving around the hall. They may be taken off once you are seated.
3. There must only be four members at each table.
4. Members are discouraged from visiting other tables.
5. At present it is good practice to just have one toilet in use. This will be the disabled toilet cubicle which will have sanitizer wipes to use to clean touch points – toilet flush, taps & door handles - as you leave the cubicle.
6. Members should be made aware of the fire exit, which must never be blocked by chair stacks, and also where the fire extinguishers are.
7. Only the two refreshment volunteers are permitted in the kitchen. One will make the tea/ coffee and the other will serve the members at each table so there will be no need for a queue to form.
8. Any spillages must be wiped up immediately.
9. If a visiting speaker uses audio visual aids care must be taken to avoid wires trailing across the floor unless taped down.
10. At the end of the afternoon when chairs are moved only one is to be carried and then not stacked more than four high.

Parkinson's UK is the operating name of the Parkinson's Disease Society of the United Kingdom.

A charity registered in England and Wales (258197) and in Scotland (SC037554)

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, Caroline Priest

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.