

CHELTENHAM BRANCH NEWSLETTER

SEPTEMBER 2021

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THOUGHTS FROM THE CHAIR

I was delighted recently to meet Virginia Pawlyn who at 82, is going to take part in October's London Marathon. It will be her eighth!

She has already experienced marathon success in New York, Boston, Berlin, Chicago and Tokyo. She will not easily forget the Boston Marathon. It was the year of the bombs!!

The really good news for us is that she will be running to raise money for our branch of Parkinson's UK. We will circulate her Just Giving details when we receive them.

Virginia readily admits that while at school, sport somehow passed her by. But thanks to her encounter with a running club at the age of 70, she is gradually gathering a collection of impressive medals and as she sees it, more importantly, a new zest for life.

Virginia soon felt that her success at sport was about much more than medals. She honestly feels she was born to run. As she put it in a recent interview "Going back many years, decades really, I always felt that I was put on this earth to do something, but I retired and felt that I had achieved nothing extraordinary." But then she was persuaded to join a running club and everything changed! From the outset, it appears she was made for running. At that first meeting, after a very few minutes, a woman she knew called out "Virginia, would you slow down? We can't keep up with you."



Virginia herself also experienced something new "I felt a real runner's high. I had never known anything like it, so I kept going back."

But her biggest discovery was that she could keep up with runners half or even a third of her age. As she put it: "I think that's what I like about running — it doesn't limit you to being with your own age group."



The health benefits were a great bonus, too. The words of a doctor who spoke to her club stuck with her: Regular exercise helps you to spend less time with doctors and waiting in surgeries.

In the meantime, Victoria says she gets pleasure from proving that "being 82 doesn't mean you have to be an old-person couch potato doing very little by way of exercise."

"Only when I started running late in life was I able to demonstrate to much younger runners, who have grandparents of similar age, that old age doesn't have to mean you are condemned to a solitary diet of TV or bingo."

Victoria's story offers a powerful and inspirational attitude to being elderly. As she would put it, we must never use our advanced years as an excuse for limiting our ambition or put it another way seize the day!!

It is now well established that regular exercise gradually improves the mobility of those who have Parkinson's. As we come out of various kinds of isolation thanks to the Pandemic, why not take the opportunity to explore one or two of the exercise groups our branch organises or is linked to and come and join fellow members?

There is table tennis on Fridays at 2pm in St Luke's Church Hall (see details below) and Neuro-led Exercise for Parkinson's and MS (still on Zoom but hopefully back face-to-face in the autumn)

Other local providers run Dance for Parkinson's classes on term-time Wednesdays at 2-00pm at Salem Baptist Church (contact Sarah Hartley on dancebesocial@gmail.com) and Yoga for Parkinson's sessions (again still on Zoom but hopefully back face-to-face in the autumn – contact Ruth on ruth.yogawell@gmail.com)

You will be made very welcome at any of these groups and, after a short time, you might not be ready for a marathon but you will feel the benefit of regular exercise.

Do not hesitate to email me parkinsonshjm@gmail.com or ring me, Harry Matthews, on 07515 857110, with your thoughts and suggestions about resuming face to face exercise activities.

JUST-PUBLISHED RESEARCH POINTS TO LONG-TERM BENEFITS OF DANCE FOR PD

NB: Sarah Hartley recently sent us an interesting link to some Canadian Research published recently in the on the long term benefits of attending Dance for Parkinson's Classes.

A just-published study shows that participation in a weekly class based on the Dance for PD methodology effectively slowed both motor and non-motor Parkinson's symptoms over a period of three years (<https://www.mdpi.com/2076-3425/11/7/895/htm>)

Though a limited, non-controlled pilot study, the research - published in the journal Brain Sciences - suggests that the rapid motor progression that might be expected in people with PD over the same period is not shown with consistent weekly dance training, and motor impairment progression remains much slower in those who participate in dance classes.

"The reasons for our findings," note the authors, "could be due to the additive effects of training, socialization, support and group dynamics that putatively occur within and around the classes."

"Hopefully this data will shed light on additional therapies for this group and be used in the treatment process," said senior author Joseph DeSouza, a neuroscience researcher at York University in Toronto. "There may be changes in the brain that occur with dance with music, but more research is necessary."

We congratulate our Canadian partners - Joe DeSouza and PhD candidate Karolina Bearss and our colleagues at Canada's National Ballet School and Dancing with Parkinson's Canada - for shining light on the long-term positive impact and benefits of dance for people living with Parkinson's.

'THE SHRINKS':

Many of you will remember Alison Anderson speaking so engagingly at branch meetings and, last year, at one of our Virtual Parkinson's Café sessions about her Parkinson's Research Fundraising Cycle Rides.

On a Café Zoom in July we were talking about one how Parkinson's, then Covid, had diminished our worlds. Sadly Covid and Lockdowns, and even worse shielding, have shrunk so many people's lives and many must still be apprehensive about expanding them again.

One of our members mentioned a post on Alison's Blog '**Ramblings of a Cyclopath**' entitled '**the Shrinks**': (<https://theramblingsofacyclopath.com/2021/06/28/the-shrinks/>)

"I remember reading Ronald Dahl's story about The Twits, a hideous couple who catch the 'Dreaded Shrinks' which causes their bodies to gradually shrink until there is nothing left of them except a pile of old clothes and a pair of shoes.

I think I've got the 'Dreaded Shrinks'. Fortunately, I'm 5ft 11" tall, so if I have, there's a lot of shrinking to be done before I become a pile of old clothes and a pair of shoes. Of course, mine would be new clothes and there would definitely be more than one pair of shoes (you can never have too many).

The 'Dreaded Shrinks' started six years ago when I was diagnosed with Parkinson's. It was barely noticeable then but now I can clearly see the impact the 'Shrinks' have on me physically, psychologically and on the world around me.

'The Dreaded Shrinks' I hear those who know me well saying. 'Surely not! She's too confident/outgoing/sociable/energetic/fun/always the last one at the bar.' (Delete as appropriate). But the 'Dreaded Shrinks' grasps hold of each of these attributes and chips away at them, gradually eroding and shrinking them over time.

It's not so easy to be the last one at the bar when you've spent enormous amounts of energy trying to focus on and keep up with the conversation all evening despite the distractions all around.

So the temptation is not to and a little bit of your former self shrinks and a little bit of your world shrinks too.

It's not so easy to throw in a joke or funny quip when you're lagging a few seconds behind everyone else, your voice is quiet, face expressionless and you often forget your words.

So the temptation is not to and a little bit of your former self shrinks and a little bit of your world shrinks too.

It's not so easy being sociable and saying 'yes' to a dinner invitation if you're worried that you might not be able to hold your cutlery properly or cut your food or worse still, not get your food from plate to mouth on first attempt.

So the temptation is not to and a little bit of your former self shrinks and a little bit of your world shrinks too.

It's not so easy to say 'yes' to a night out with friends when you turn into a pumpkin at 8.45pm

So the temptation is not to and a little bit of your former self shrinks and a little bit of your world shrinks too.

It's not easy always being the one who can't quite keep up in the running/cycling/tennis group.

So the temptation is not to and a little bit of your former self shrinks and a little bit of your world shrinks too.

I was pondering recently about how easy it would be to allow Parkinson's to shrink the world around me as well as myself. Then I realised that I needed to give myself a proverbial 'kick up the backside' and admit, it's not Parkinson's that has the potential to shrink my world or to shrink me, it is my attitude towards it.

I like the thought that we might try not to shrink away from our problems but aim to grow bigger than them. So, next time I'm tempted not to do something, I'm going to challenge myself to say 'yes'. I'm not suggesting that it's going to be easy but challenges are not supposed to be easy and I do love a challenge. I'll let you know how it goes.....



Shrinking Me.....

PS Mum, don't worry, I'm still 5ft 11" tall, you know I love a challenge and while I have no intention of succumbing to the 'Shrinks', I'll keep on with the new clothes and shoes just in case!"

STOP PRESS: Alison will be one of our guest speakers at our first face to face Branch Meeting on **Tuesday 28th September.**

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 13th September.**

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 October 7th & November 18th

Table Tennis 'Chat and Quiz' on Zoom 2.00pm Tuesdays October 12th & November 9th

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

NB: Our next coffee mornings will be **Wednesdays October 13th & November 10th**

BRANCH MEETINGS

STOP PRESS: The Branch Committee are delighted to be able to restart face to face branch meetings, in a Covid aware manner, from **Tuesday 28th September**.

We will again meet on the last Tuesday of most months, at 3-00pm, in St. Mark's Methodist Church Hall, Gloucester Road, Cheltenham, GL51 8PX

28 September

Alison Anderson & Neil Russell *'Because we still can' - recent fundraising challenges*

26 October

Dr Peter Fletcher *Latest Research News*

30 November

Mark Cummings *Radio Gloucestershire*

7 December

Christmas Lunch *Venue and details tbc*

NB. It would be helpful for meeting planning and for setting up the hall if you could email or ring us if you hope to be able to attend the branch meeting. Before attending please read the **guidelines for branch meeting attendees** (below)

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.

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.