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

Parkinson's East Midlands Research Interest Group
PEMRIG

‘LIVING WELL WITH PARKINSON’S’

A PERSONAL REFLECTION ON PEMRIG’S OCTOBER 2022 FACE TO FACE CONFERENCE

October 8th, the day of PEMRIG’s 2022 Face to Face conference dawned with the sun shining brightly. This raised my spirits in preparation for the drive to The Link Hotel in Loughborough as I was somewhat apprehensive about the long day ahead and whether Face to Face meetings were my thing compared with the zoom research meetings which PEMRIG had organised in 2021 and 2022 and which one can attend from the comfort of one’s own home without the travelling.

In reality this 2022 meeting had been planned for 2020 but the Covid pandemic had put a stop to PEMRIG’s annual October Face to Face meeting that year and also in 2021 so PEMRIG had turned to zoom research meetings to keep interest alive. Now, after over a year of discussion and planning and huge behind the scenes efforts by PEMRIG members especially PEMRIG’S Chair John Turner and Liz Nash, Research Support Network Manager at Parkinson’s UK, the Face to Face approach was back and 85 participants had registered. This free meeting which included lunch and copious tea/coffee was paid for by donations from the Derby and Nottingham local branches. The programme included a mixture of research and support/welfare talks and was aimed at those newly diagnosed with Parkinson’s and those in work with the condition. The inclusion of three Information Stands was a new approach co-ordinated by Katie Smith, Area Development Manager for the East Midlands at Parkinson’s UK. These stands were all geared to how to be more active in the home and community, to getting help about living with Parkinson’s and Living well in Leicester by offering access to a variety of support groups and activities including Nordic Walking which participants could have a go at in the car park.

On arrival I was met by younger members of PEMRIG who complimented me on my colour co-ordination (I didn’t know I had) and guided me to a seat at one of the round tables set with the programme, details of the speakers, a biro, water etc. All very efficient and coffee and tea were already available. I soon got chatting with Lionel, a founding member of PEMRIG who I hadn’t seen for a few years and another couple already at the table. The friendly, informal atmosphere made it easy to start up conversations and within a few minutes John Turner was calling people to order with some housekeeping instructions and opening the meeting.

What did I get out of the day overall? Well, if one word connected virtually all the talks it was ‘positivity’, the need to be positive every day. David Dexter, Associate Director of Research at Parkinsons UK emphasised the need for people with Parkinson’s

(PwP) to be positive about getting involved in some of the many drug trials available at the moment. He was disappointed to record that only 3% of PwP were participating in clinical trials which if they don't recruit enough people are cancelled - a huge waste of money. He emphasised that trials need healthy volunteers as well. Healthy brain tissue is also needed with Parkinson's tissue in the brain bank. David said he was convinced that with all the trials going on disease-modifying drugs to slow Parkinson's progression will soon be available but participation in trials is a must.

Janet Shipton who had been diagnosed with Parkinson's in 2018 at an early age was possibly the most positive person at the meeting. Since diagnosis she explained that she has been on a mission to raise money for research and to boost awareness of Parkinson's. She has been on bike rides, dance and boxing challenges, formed a theatre group (the Parky players) and is now touring the country in a camper van on a one year art road trip funded by Arts Council England stopping off at various places to record her impressions of local people, friends and scenery by painting. She explained how she has had to reinvent herself to cope with Parkinson's.

Lisa Chakrabarti, Professor at the University of Nottingham talked about her enthusiasm for the energy-producing organelles in cells known as mitochondria. She has been fascinated for years by what goes wrong in these organelles in Parkinson's where it is known they produce less energy so that nerve cells can't function properly. This contributes to the loss of dopamine-producing nerve cells in Parkinson's. Lisa described the varied approaches used in her lab to discover what is going wrong in mitochondria in Parkinson's - studies which involve tissue from the Parkinson's brain bank as well as taking her to Antarctica to look at icefish which may hold clues to why mitochondria in Parkinson's fail to produce enough energy to maintain full nerve cell activity.

I didn't visit the marketplace stands during lunch but I could see they were well subscribed and people at my table returned with a Guide to well-being in Leicestershire and I saw others at lunch time testing Nordic Walking. So this new approach had paid off.

Caroline Bartliff, a speech and language therapist from Derbyshire Community Health Services, took on the difficult after-lunch slot giving some really valuable advice on three common problems experienced by PwP - namely Communication, Speech and Swallowing. Caroline described some of the positive ways in which these aspects of Parkinson's can be made easier to cope with. She pointed out what makes it hard for PwP to communicate - soft voice, fast speech and mumbling which can be sometimes made harder if one is talking to a dominant listener. She stressed that singing was a great help in developing a good air supply. She suggested that thicker drinks can facilitate swallowing in Parkinson's and that drooling can be helped by a cue which beeps reminding the wearer to swallow. She concluded on a positive note that attention to the problems she described bring increased confidence. I second that having benefitted personally from Caroline's help.

Would you have thought of golf as the perfect exercise for Parkinson's? Well, that is what Anthony Blackburn, Founder of Golf in Society and David Thornton, an Ambassador for Golf in Society (diagnosed with Parkinson's in 2011) discussed. And they showed a video of several cheerful PwP playing golf getting out into the fresh air and walking the course all helping with a feeling of wellbeing. They stressed the importance of golf as a social occasion and how golf helps muscle control and balance. Apparently, the brain makes 27 decisions during a golf swing (and probably more if one misses the ball and the voice comes into play). They emphasised the positive beneficial effects of golf and belonging to a club - purpose, self-esteem, a sense of belonging and of course playing a round of golf provides exercise as one walks the course. David mentioned that golf has had a very positive effect on his symptoms.

Appropriately the last talk after a refreshment break allowed us a quiet moment to think over what we had heard during the meeting. Lance and Claire Sullen of Mindfulness Leicestershire discussed 'Keeping the body in mind by accepting the gift of the present moment'. Lance stressed that the present moment is all we have - we don't know the future and the past has gone so it is essential to get the best out of each precious present moment and to be positive. They led us in a calming period of silence urging us to let go of any thoughts that arise and changing the way we look at things. They stressed the importance of living for the moment. Lance emphasised the importance of Tai Chi as a way of improving one's mindfulness state and he led us in breathing in and out while raising hands for a calming effect. Lance concluded by reading Spike Milligan's poem 'Smile' which shows how a smile on one person can make other people smile and feel happier.

I felt that was a very appropriate way to end the conference –mindfulness, positivity and smiling. Spike Milligan certainly knew how to have the last word. I had survived the day even though queueing for lunch while feeling wobbly had been a bit traumatic but PEMRIG members were on hand to help out. It had been a friendly and positive meeting and I left for the journey home with a smile on my face. Well done PEMRIG!

MGR

11/10/22