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THOUGHTS FROM THE CHAIR

Two recent incidents, both happening on a bus, made me think about education. The first involved a girl of about twelve years old who tripped up the top step of the bus and immediately uttered an expletive. She looked up at me as she regained stability and apologised. I was amazed. Why did she feel that an apology was required in such a situation? Where did she acquire such sensitivity? At home? In school? Both?

Not long after the first incident, I was the only adult on a bus full of pale blue blazers. There wasn't much noise coming from within the bus, just a faint sound of pitter-pattering fingertips. The sea of young faces were exercising their thumbs, lost to the world inside their phones. I noticed one boy manage to exit the bus without even looking up as he stepped off onto the platform. It made me wonder: how many of them had the same passion for any of the education that happened in school that day?

What counts as a good education is controversial to say the least. In the 70s, projects came to the fore and it claimed everything necessary in the curriculum could be delivered by spending a term on ancient Egypt. Spelling didn't matter. Freedom of expression was all.

The 80s brought the National Curriculum and Mrs Thatcher's reasonable thought: children needed protection from the idiosyncratic. So the Common Curriculum was born. More controversial was the accompaniment of national testing at 7, 11 and 14. What a child achieved in English and Maths could be compared with national norms. Targets were set. Levels were born. The claim was, schools would know how effective they were and parents could have some objective information about their child's progress and achievement.

But has testing gone too far and, if so, will it lead to a narrowing of educational opportunities? A society that puts too much emphasis on academic success puts in danger allocation in the curriculum for music, art and sport (skills for the whole of life).

It was sad when some councils sold off school playing fields to help balance the books. Happily, in the fight against childhood obesity, the value of exercise for our children is at last being recognised.

Today there is also concern about young people's mental health. Becoming involved in training or following a fitness regime has been shown to help with stress and even depression. It also carries the promise of exercise for other parts of the body besides the thumbs!

And that's a message not just for our youth. Parkinson's UK from the testimony of individuals, including Alison Anderson, our November speaker, have promoted the value of exercise for those with PD. I am well motivated for my daily walk to Waitrose by the promise of coffee and a paper!

I looked out of the window of the same bus that prompted these thoughts about education and saw a school notice board on which is written:

"IT TAKES A WHOLE VILLAGE TO RAISE A CHILD"

More food for thought!



RECENT BRANCH MEETINGS

AUGUST

As usual, at this time of year, we had a social afternoon which included a sing-a-long led by Bob and Jane, a feast of food for afternoon refreshments, and a quiz. The picture round was of 50's celebrities and reminded us of a time when day time television did not exist. There was only one channel and the talking point of the week would be what would make Gilbert Harding lose his temper on the panel game 'What's My Line?'

This was Jane and Bob Thornhill's last meeting before their move to Hereford. We will miss their drive, imagination, and singing, and above all their hard work on behalf of the branch

SEPTEMBER

We welcomed our President, Dr Peter Fletcher, as our speaker who as ever was on good form. He opened with an interesting and often forgotten fact: while we know that the symptoms of PD may be attributed to a loss of dopamine in the brain, we still don't know why this should happen. There might in fact, he suggested, be many causes not just one.

On the drug front, he mentioned tests on using an inhaler to deliver levodopa more efficiently had reached phase 3 in trials in the USA. I think some members were disappointed as, when talking about stem cell research, he said new stem cells introduced to the brain would alleviate symptoms but were not a cure.

He was enthusiastic about current research into the repurposing of drugs, which are already in use for other ailments but are found to have a positive effect on PD symptoms. More about this in research news below.

Here are some of his general advice points:

- You are more likely to fall if you are overweight so aim for a healthy diet. Plenty of fruit and veg helps to alleviate constipation.
- Have regular eye tests. Poor sight can lead to falls. The optician will test for glaucoma.
- Drink plenty of water. Tonic water and vitamin C drinks are also good. Maintaining hydration helps avoid muscle cramp and constipation.
- Take regular exercise: Pilates, yoga, tai chi, dance. These help with balance.
- When travelling use all the help available by booking ahead and asking for support.

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)

On the subject of complementary medicine Dr Fletcher said that, while there was no hard evidence that it worked i.e. major trials had not been carried out on these remedies, some individuals found benefit but sometimes the benefit was short lived.

Dr Fletcher had seen, and very much enjoyed, Paul Mayhew Archer (writer of The Vicar of Dibley) at the Edinburgh Festival doing his stand-up comedy routine on dealing with his own PD.

WALK FOR PARKINSON'S ON CLEEVE HILL

Several members braved the elements on 23 September including James Howell, Didi Jepson, and Pat Edden with her family, including her dog!



OCTOBER

Unfortunately our speaker was unable to attend through illness. Instead Dot Simpson provided a thorough review of Parkinson's UK publications which members were able to browse and take away.

Gloucester Clinical Commissioning group (GCC) is initiating a review of the neurological nursing provision across the county with the aim of identifying existing good practice and opportunities for improvement. In the light of this we spent the rest of the session inviting comments about our experience with Parkinson's nurses.

It is good to report that the feedback was very positive. Both the hospital and community based PD Nurse Specialists were praised as being good listeners who conveyed a genuine, unrushed interest in their patients. The only criticism, from a few members, lay in difficulties of making contact for arranging appointments.

NOVEMBER

We were delighted to welcome back Alison Anderson who, at our last AGM, spoke about her cycle ride across Cambodia and Vietnam.

Alison was diagnosed with PD at the age of 45 and has been determined to use exercise to help maximise mobility and manage her symptoms. As before, she made a strong case for the power of exercise to keep Parkinson's symptoms at bay.

"It's about the Journey not the Destination" was the title of her talk. And what a journey it was for her and 19 other cyclists! It took 400 hours of planning and practise rides of up to 300 miles per week to be ready to cycle from Land's End to John O' Groats. Alison highlighted the highs and the lows on the journey and the kindness of strangers.

She is clearly a “What’s Next?” sort of person. So get ready America, Alison and her fellow ‘Cyclopaths’ have both the east and west coasts in view!



RESEARCH NEWS

Developing a new drug from scratch is a long slow and expensive process. That is why at the moment there is a lot of interest in finding out if drugs already being used for one condition might by chance have a beneficial effect on patients with PD.

This is called **REPURPOSING**. One unlikely but powerful example is thalidomide. Sadly famous for the birth defects caused when this drug was prescribed to alleviate the symptoms of morning sickness. However thalidomide is now an important treatment for leprosy and bone cancer.

As far as Parkinson’s is concerned, diabetes drugs are leading the way in being repurposed and the hope is they will slow down the damage done to dopamine producing cells and, therefore, delay the deterioration of symptoms.

Other repurposing drug research:

STATINS – The hope is that these cholesterol reducing drugs will exhibit a range of activities which could help protect brain cells in Parkinson’s.

UDCA – A liver drug which, when tested on skin cells with people with Parkinson’s, had a restorative effect on mitochondria – the tiny energy producing batteries that power our cells. This is very encouraging because research suggests that mitochondrial failure is a key factor in the loss of brain cells in Parkinson’s.

NILOTINIB – A leukaemia drug may protect struggling brain cells and have the potential to slow down Parkinson’s. In 2015 a small phase 1 trial in 12 Patients with PD suggested improvements in memory, movement, and non-motor symptoms.

NEWS FROM CARERS GLOUCESTERSHIRE

Carer’s Gloucestershire now have a website which features a carers’ support group database

<https://www.carersgloucestershire.org.uk/support-groups>

POhWER ADVOCACY (People of Hertfordshire Want Equal Rights)

I attended a morning session on the work of this company who have the Gloucestershire contract for supplying advocates for those who need help in making their voice heard.

For example, when under the Care Act of 2014 someone from the local council comes to assess need, the Act also stipulates that you should have an appropriate person to help you be involved in the needs assessment.

For more information telephone (local rate) 0300 456 2370 or pohwer@pohwer.net

COFFEE DROP-IN

On the **Wednesday 9 January** from 10:30am until 12:00 noon we are beginning our monthly coffee mornings at the **Norwood Arms, Leckhampton Rd, GL53 0AX**. There is disabled access and parking. The modest parking charge is refunded if you spend £3 or more, or if you use a Blue Badge give your details at the bar.

If there is sufficient support for the idea we will meet the second Wednesday of the month. So future dates will be **13 February & 13 March**.



TABLE TENNIS & COFFEE

Are you free Friday afternoons to play table tennis and to socialise over coffee? An opportunity to use a table has been offered at **St. Luke's Church Hall, GL53 7HP (near Cheltenham hospital)**.

The first session will be on **Friday 18 January** from 2:00pm until 4:00pm. There is plenty of car parking and easy access. We need enough interest to meet the hire cost of £20 per week. So please let me know if you are interested. It is such good exercise! parkinsonshjm@gmail.com

NOTICE OF ANNUAL BRANCH MEETING ON 26 FEBRUARY 2019

Please do try to attend our annual branch meeting on **26 February 2019** at 3-00pm, when we will report on the past year, submit the budget for approval, appoint our new committee and talk about future plans.

Please note that additional Committee Members would be welcome. If you are interested in assisting in the running of the branch please contact our Branch Chair, Harry Mathews, on 07515 857110 parkinsonshjm@gmail.com or Jane Henderson, Parkinson's UK Volunteer Co-ordinator - West on 0344 225 3694 jhenderson@parkinsons.org.uk

Particular roles that are vacant are **Branch Secretary, Branch Membership Secretary** and **Fund Raising** but general committee members are also required.

NEW BRANCH WEBSITE

The Branch now has its own website which includes-to-date Cheltenham & Tewkesbury meeting details, committee contacts and the contact details for the Parkinson's Local Advisor and the Parkinson's Nurse Service. The current Newsletter is readable on screen & downloadable. Please make a note of: <http://www.cheltenhamparkinsons.org.uk>

BRANCH PROGRAMME 2019

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

29 January

Ruth Henderson-Cash *Yoga for PD*

26 February

Annual Branch Meeting with Sara Wakeman *Fundraising Tips*

26 March

Gareth Hooper *How Does Clinical Commissioning Work?*

10 April (Wednesday)

Supper & Quiz

7-30pm at Sup and Chow, Bath Road, GL53 7NB

11 April (Thursday) World Parkinson's Day

Gloucestershire Parkinson's Conference

Kingsholm Stadium, Gloucester GL1 3AX

30 April

Sue Watts *Parkinson's Nurse Q&A*

28 May

Discussion Sessions for Those with PD & Carers

25 June

Speaker tbc *Community Police & Crime Prevention*

27 August

Social and Quiz with Bring and Share Afternoon Tea

30 July

Outing *Details tbc*

24 September

Alison Anderson *World Parkinson Congress, Tokyo*

29 October

Tanya Tangye *PD and Mental Health Issues*

26 November

Dr Peter Fletcher *Latest Research News*

10 December

Christmas Lunch *Venue tbc*



BRANCH COMMITTEE CONTACTS

Branch Chair: Harry Matthews, 07515 857110, parkinsonshjm@gmail.com

Branch Secretary: Post currently vacant

Branch Treasurer & Acting Membership Secretary: Dot Simpson, 01242 583894, dsimpson.parkinsons@googlemail.com