

Huntingdonshire Branch Newsletter July – August 2018

Forward Dates

Monday 17th December. Branch Christmas Lunch at Hemingford Abbots Village Hall. Same venue as last year but our original caterers.

Wednesday 6th March 2019. Branch Annual General Meeting

****Have you returned your GDPR form? If you have not returned it by July 31st your details must be deleted. That is the new law. You can of course sign up again later but that is greater hassle.**

News and Views

Swimming

A few people have said they would like to exercise by swimming and having failed to make a suitable arrangement with One Leisure pools, I am in negotiation with Cambridge Branch with a view to sharing their facility. The following is taken from the Cambridge Branch newsletter:

'Exercising in water is one of the best ways to help maintain balance, strength, flexibility and general fitness, whilst also having fun! Chesterton is well equipped to ensure safe exercise and the water buoyancy means there is no risk of falling while exercising. The group runs on Thursday afternoons from 2.30 to 3.30pm at Chesterton Sports Centre in Gilbert Road, Cambridge when the pool is exclusively available to the group. Partners are welcome to join in. Pool access is by ladder or chair hoist, and the group is taken by a chartered physiotherapist with a pool lifeguard also in attendance.

The first half hour is for general swimming of widths or lengths. Flotation aids and assistance are available to those who need them. The second half is spent doing aquarobic balance and co-ordination exercises, and ball games to music. The group also offers the opportunity to make friends and there is a café at the Sports Centre which is good for a chat after the session. The cost is £5.00 per session.'

Costs are currently paid by Cambridge Branch, but if we share the facility we shall expect to pay a share in future years. If more than one car load wish to go, we shall consider contracting a minibus. Please contact David Rudd on 01480 474795 to register an interest.

Exercise and progression in Parkinson's.

Scientists in America at Northwestern Medicine and University of Denver have shown that intense exercise three times a week for people with early stages of Parkinson's decreases the worsening of motor symptoms. This is the first time scientists have measured the effects of intense exercise, which many believed was too physically stressful for pwp. *"The earlier you intervene, the more likely you can prevent progression. We delayed symptoms worsening for six months (the period of the trial). Whether we can do it for longer requires further study. You should exercise three times a week with your heart rate reaching between 80% and 85% maximum. It is that simple"* said Daniel Croker of Northwestern. The study featured 128 participants in the early stages of Parkinson's between 40 and 80 years of age who were not taking medication. All had a score of about 20 at the start. Those in the high intensity exercise group stayed at 20. Those doing moderate exercise got worse by 1.5 points. Those not exercising at all got worse by 3.0 points – a 15% change: clinically important because it makes a difference to people's quality of life. This is believed to be the first study to accurately measure or control the intensity of the exercise..

How does it work?

Scientists at Colorado University, working with mice have shown that exercise can stop the accumulation of the protein alpha-synuclein, clumps of which are believed to be significant agent in the brain cell death associated with Parkinson's. Twelve month old mice showing signs of Parkinson's were given running

wheels, some free and some locked. After 3 months the running animals showed much better movement and cognitive function than the control animals with locked running wheels. They found that exercise increased brain and muscle expression of a protective called DJ-1. The control mice with the locked wheels lacked DJ-1 and had lost much of their ability to run on unlocked wheels. Curt Freed, Professor of Medicine at Colorado said "Our experiments show exercise can get to the heart of the problem in Parkinson's".

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Have you ever seen a Parkinson's helper dog? This charming story comes from USA.

"I call him Tommy most of the time unless I'm calling him in from the yard. Then he's 'Tommy-loohoo', which invariably brings all 145 pounds of him bounding through the door and sitting up beside me.

It's vital that Tommy listens to my voice and comes to me when I call because he is my service dog. It's also essential that he's a big boy because he's a mobility service dog.

That means when my Parkinson's body gives in, I can use his sturdy frame to lean on, tug, hoist, steady and pace myself. It's of no importance that he's undeniably handsome. That's simply a bonus!

Tommy and I met after I'd just passed the decade marker of living with Parkinson's. Meds started to fluctuate and pass into the unpredictable zone. If I wanted to remain upright and moving forward, I needed to add another leg or two. I chose to add four.

In the three years we've been together, I've often introduced him as my 'Furry Four-legged Cane'. His training as a mobility service dog means that he walks beside me to steady my gait, braces when I stumble, stands firm when I wobble, steps me forward when I get stuck. He has moved me out of freezes, off chairs, up from the floor, down grocery aisles, and across airports like no cane could. Or, should I say, like only a canine can. He also has a great deal more personality.

Admittedly, there are quirks mixed in with that personality. There's the puddle incident, for example. I discovered that he doesn't like puddles and leaps over them. I happened to be holding onto his harness at the time. Now, on rainy days, I refer to him as 'Tommy Talulah' – *Talulah* is Native American for 'leaping waters' – and I've learned to go around puddles.

There, too, is charm. How he wags and bows his head each time I strap on the harness that I hold onto while he steadies my step. The way one eye watches me from his bed until I've settled into mine.

Tommy charms wherever he goes, too, which can be an issue. Despite his vest with 'Ignore Me' and 'I'm Working' patches, people stop to ask us about him everywhere we go. When they ask his name, I've been known to make up a few. Ralph. Diggity. Jehoshaphat. L'il Doggie.

If someone starts calling his name, which is what happens when I answer that question, he gets distracted from his job of keeping me upright. He doesn't know a Ralph (nor a Diggity) so his attention stays on his work.

And, no, he's not always working. He gets to romp, sniff and pounce. Still, if I get stuck and need him, all I need to say is: "Tommy: Need You". And he sidles up beside me.

A service dog requires more work than a cane. Canes don't poop or need to go to the vet. But with all that Parkinson's takes from us, I've discovered that adding a service dog has given me more than just a canine.

In the words of Naomi Shihab Nye in her poem about loss, she could have been referring to another name for Tommy: ". . . only kindness . . . raises its head from the crowd of the world to say ... it is you I have been looking for, and then goes with you everywhere like a shadow or a friend."

## Stop press

Sniffer dogs can detect Parkinson's with over 90% accuracy before symptoms appear.

Tears with 5 times the normal alpha-synuclein seem to be a marker for Parkinson's years and maybe decades before symptoms appear. Earlier diagnosis will mean better control of the condition. .

## Your Branch Committee March 2018 to 6<sup>th</sup> March 2019

|               |                |              |              |                                                                                  |
|---------------|----------------|--------------|--------------|----------------------------------------------------------------------------------|
| Chairman      | Malcolm Ryman  | Brampton     | 07720 080749 | <a href="mailto:malcolm.ryman1@btinternet.com">malcolm.ryman1@btinternet.com</a> |
| Vice Chairman | David Rudd     | St Neots     | 01480 474795 | <a href="mailto:dirudd@talktalk.co.uk">dirudd@talktalk.co.uk</a>                 |
| Treasurer     | Ildiko Drexler | Hartford     | 07413 130161 | <a href="mailto:drexlerildiko@gmail.com">drexlerildiko@gmail.com</a>             |
| Minuting sec. | Sally Beaman   | Needingworth | 01480 462379 | <a href="mailto:rsde.beaman@btinternet.com">rsde.beaman@btinternet.com</a>       |
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|               | Elaine Bottom  | Hartford     | 07548817627  | <a href="mailto:elaine@oscars.plus.com">elaine@oscars.plus.com</a>               |
|               | Ian Mackintosh | Buckden      | 01480 810533 |                                                                                  |
|               | Ivan Ward      | St Ives      | 01480 380804 | <a href="mailto:ivancath3@ntlworld.com">ivancath3@ntlworld.com</a>               |
|               | Cath Ward      | St Ives      | 07941680023  |                                                                                  |

## Parkinson's Nurses.

I have frequently been asked who the nurses are now after the changes of the Spring, so here is a complete list.

### Peterborough and Fenland area

|                  |                                     |
|------------------|-------------------------------------|
| Carolyn Noble    | Neuro Conditions Clinical Manager   |
| Danielle Duffill | Senior Parkinson's Specialist Nurse |
| Karen Aird       | Senior Parkinson's Specialist Nurse |
| Kirsty Richards  | Parkinson's Nurse                   |

### Cambridge and Huntingdon area

|               |                                     |
|---------------|-------------------------------------|
| Amanda Eady   | Parkinson's Nurse Specialist        |
| Lorna Woor    | Parkinson's Support Nurse           |
| Becky Slimmon | Senior Parkinson's Specialist Nurse |
| Claire Snee   | Parkinson's Nurse                   |

## Exercise and Therapy

| WHAT                                    | WHERE                                          | WHEN                                                                                                           |
|-----------------------------------------|------------------------------------------------|----------------------------------------------------------------------------------------------------------------|
| <i>Reflexology</i> by Vanessa           | At your home                                   | By appointment (01489 435718)                                                                                  |
| <i>Chair-based exercise</i> with Gareth | Pilgrim Hall, United Reformed Church, St Neots | Tuesdays, at 11.00                                                                                             |
| <i>Parkinson's Dance</i> with Kim       | StageWorks, Buckden Towers                     | July 12 <sup>th</sup> , 26 <sup>th</sup> , August 9 <sup>th</sup> , 23 <sup>rd</sup> , at 3.00                 |
| <i>Music Therapy</i> with Alison        | MS Centre, Mayfield Road, Huntingdon           | July 5 <sup>th</sup> , 19 <sup>th</sup> , August 2 <sup>nd</sup> , 16 <sup>th</sup> , 30 <sup>th</sup> at 2.00 |
| <i>Love to Move</i> with Kim            | StageWorks, Buckden Towers                     | July 12 <sup>th</sup> , 26 <sup>th</sup> , August 9 <sup>th</sup> , 23 <sup>rd</sup> at 1.30                   |
| <i>Love to Move</i> with Kim            | Ms Centre, Mayfield Road, Huntingdon           | July 5 <sup>th</sup> , 19 <sup>th</sup> , August 2 <sup>nd</sup> , 16 <sup>th</sup> , 30 <sup>th</sup> at 1.00 |
| <i>Chair-based exercise</i> with Becky  | Crossways, St Ives                             | Fridays at 11.00                                                                                               |

## Demise

The St Neots Carers' Hub at Marbrooke Centre, Eaton Socon has been discontinued. The last meeting was in May. This facility was seriously underused, and did not justify the use of staff time.

## Social and Support Meetings

St Neots meeting 2.00 pm at Old Market Court 16<sup>th</sup> July– Assistive Technology.

August 20<sup>th</sup> –'St Neots Pubs': talk by Chris Jones

St Ives meeting 2.00 at Dolphin Hotel July 4<sup>th</sup> July tba

August 1<sup>st</sup> 'My Life in Make Up with the BBC': talk by Marcia Paterson

Ramsey meeting 2.00 at Rainbow Surgery, July 11<sup>th</sup> and August 8<sup>th</sup>.

CHAIRMAN Malcolm Ryman 07720 080749: VICE CHAIRMAN David Rudd 01480 474795:TREASURER Ildiko Drexler 07413 130161  
COMMITTEE SECRETARY Sally Beaman 01480 462379 FUND-RAISING Elaine Bottom 07541 377391:  
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