

OUR NEWS

Huntingdonshire Branch

www.huntspds.org.uk

June 2024



Thoughts of Chairman Malcolm

I write this report having been taken completely by surprise that a General Election has been called in July, when all those “in the know” were predicting an October date. Less than a week into the process, I am suffering from acute electionitis. defined by one commentator

as “blinding headaches, palpitations, high blood pressure, shortness of breath and loss of libido”, and there is another 40+ days to go!

And to add to the misery, the Met Office are predicting the wettest summer ever, is there no end to this catalogue of disasters?

I understand that there has been a problem with the exercise group in St Neots, with the lift being out of action again, we will be looking into this and update you with any developments.

Malcolm



Here Comes Summer!

As the year moves on, we have some news on a change of venue and activity for the St Neots Café. This will now be a meet up at Buffalo Restaurant in St Neots, and a slightly earlier time at 1 pm.

Huntingdon Café moved its venue last month to The Cambs Therapy Centre (also known previously as the MS Centre), the first meeting went well and following groups will be the 1st Tuesday of the month at 10.30am.

Please support your local groups, we look forward to seeing you.

We Would Love to Hear from You!

Make this newsletter yours, please send us your stories, tips, poems or photographs to - huntsbranchnews@gmail.com.

This Month and Next

Dates for your Diary...

St Neots Café New Venue
Buffalo Restaurant PE19 1BB
18th June, 16th July

Huntingdon Café
MS Therapy Centre, PE29 1UL
4th June, 2nd July

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Parkinson's UK Activity Dates

(Please check with organiser if any changes)

Face to Face Activities

Date	Activities	Contact
18th June 16th July 1.00 – 3.00 pm Lunch and Chat 3rd Tuesday of the month	St Neots Café New Venue/Time! Buffalo Restaurant 22 Huntingdon Street St Neots PE19 1BB	Malcolm Ryman Tel: 07720 080749 Email: malcolm.ryman1@btinternet.com
4th June 2nd July Coffee and Chat 10.30 am – 12.30 pm 1 st Tuesday of the month	Huntingdon Café Cambs Therapy Centre, Bradbury House, Huntingdon PE29 1UL	Suzanne Ford Tel: 07592 639374 Email: suzanneford346@gmail.com Or Malcolm Ryman as above
June and July 11.00 am – 12.00 pm Every Friday	St Ives Exercise Group with Becky Meets at the Crossways Church	Email beckyadamsrehab@gmail.com
June and July 11am – 12 pm Every Thursday	St Neots Exercise Group with Daniel United Reformed Church, High Street, St Neots, PE19 1BN.	Email danielgodward14@gmail.com
June and July 1.30 – 2.30 pm Every Tuesday (except Third Tuesday 11.30 – 12.30pm) Every Thursday Meets in the coffee bar first	Love to Move Cambs Therapy Centre, Bradbury House, Huntingdon PE29 1UL	Email sj-performing-arts@hotmail.co.uk Mob: 0771 265 8001
June and July Last Saturday in the month Various Venues	Young and Active Parkinson's Group (YAPA)	Julie Wilson Email jmwilson@parkinsons.org.uk Tel: 0300 123 3675

Parkinson's Nurse Information

At our last St Neots Café meeting a few questions were raised about our local Nurse and Consultant Service, and Becky Slimmon our local Parkinson's Nurse kindly answered our questions.

The nurses have long waiting lists as they are still catching up after Covid, they are getting there, but it will take time to get their lists down. They aim to see patients annually 6 months after a Consultant appointment, but at the moment they still have appointments overdue. With extra staff in place this is improving. Their admin team add patients to clinic appointments or home visits, and they will prioritise the longest waiters, although there may be emergency additions as well.

She asked me to confirm that if you do have any concerns or worries about your Parkinson's, please still call 0330 7260077 Monday to Friday, this way they can look into the problem. They have many daily calls, but the nurses will triage them and can allocate an earlier appointment if this is required following a clinical telephone call - this is also the same for home visits.

The Consultants also have waiting lists, but Becky can confirm that Tracey Graves, consultant at Hinchingsbrooke is now back, and has been for 6 months.

She confirmed that St Neots is still within the Cambridgeshire nurse service boundary, as long as your GP is registered in Cambridgeshire and not Bedfordshire.

We hope this answers your questions, and she will be back next issue with her Nurse Tip.



New St Neots Café Venue

We are pleased to let you know that we have a new venue for the St Neots Group. The Priory Centre is closing for renovation, and we wanted somewhere locally that we could meet and eat!

Buffalo Mediterranean Restaurant was voted by local members as fitting the bill, as it has a car park close by (Tebbutts Road), is accessible and has tasty food. They have a good menu that also has vegetarian and gluten free options.

We are meeting at an earlier time of 1pm, so that hopefully appetites will still be hearty.

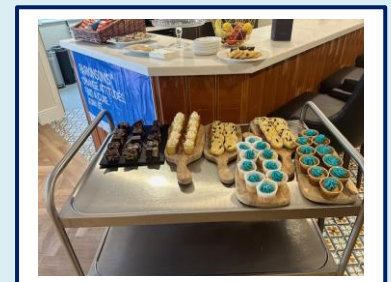
Previous members and new group members will be very welcome. More details on Page 2, we hope to see you there.

Awareness Raising at The Chase



Malcolm our Branch Chair was recently contacted by The Chase Care Home in Huntingdon, as they wanted to raise awareness for us on World Parkinson's Day 11th April.

They were very keen to support us, and Malcolm kindly agreed to attend and represent the Branch.



As you can see from the photographs the banners were out, and there were plenty of cakes to welcome those that attended.

It was an excellent opportunity to meet people face to face who may not know about us, and let them know about the support that we offer as a branch. A big thank you to The Chase and to Malcolm for making this possible.

Getting you on track to a healthier life



A Health Trainer will work with you one to one to help you make healthy changes to your lifestyle, such as improving eating habits or getting more active.

What support will I get?

- 6 x 1:1 sessions spread over a period of time to suit you. You could meet weekly or monthly.
- 60 minute initial assessment
- 30 minute sessions thereafter

It's all FREE!

For more information
text: **HEALTHYU** to **60777** or
call: **0333 005 0093**, or visit
www.healthyyou.org.uk



Young and or Active Group

Another Young and or Active Brunch Meeting has been arranged for June, this time in Cambridge.

The venue is Oakington Garden Centre at the Olive Tree Café on 29th June at 10.30 am until 12.30 pm.

The address of the Garden Centre is Dry Drayton Road, Oakington CB24 3BD, and a link to their website is [here](http://www.healthyyou.org.uk).

Each month the venue is moved around in Cambridgeshire, to give the most people the opportunity to attend. If you haven't been before, give it a try, you will be made most welcome.

If you would like to attend, please contact Julie Wilson, Area Development Manager, so that she can reserve a space for you. Her contact details are email jmwilson@parkinsons.org.uk, or telephone 0300 1233675.

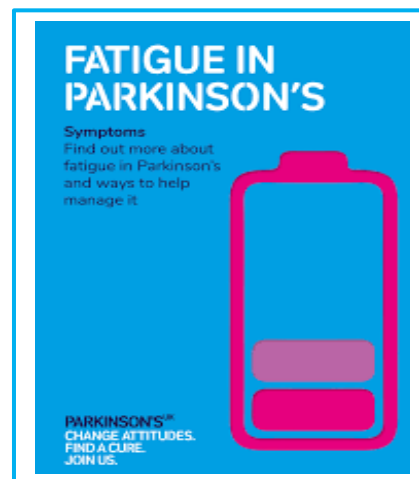


Focus on Fatigue and Parkinson's

Up to half of people diagnosed with Parkinson's will experience fatigue, whether they have had the condition some time or are newly diagnosed. For some, it is the earliest symptom they are aware of. Fatigue is exhaustion without related activity, and does not improve with rest. It is quite different from feeling tired after not sleeping well, it is a feeling of lack of energy, making all tasks, whether they are physical or mental, a strain.

Parkinson's UK have an excellent booklet that covers this symptom and ways to manage it, you can either download from the link [here](#), or ring the Helpline on 0808 800 0303 and request a booklet be sent to you.

In the meantime, here are a couple of articles on fatigue you may find helpful or interesting.



Anything Worth Doing is Worth Doing Badly

One of my college professors used to say "anything worth doing is worth doing poorly". I didn't understand that for years, because I didn't do anything poorly, I couldn't do anything poorly, I had to Do Everything Perfectly.

But brushing your teeth for 30 seconds is better than not brushing them at all when that 2 minutes seems exhausting. Doing ten minutes of yoga is better than 10 minutes of sitting when 30 minutes of cardio sounds impossible.

Changing my clothes is good when a whole shower is impossible. Standing on the porch for a few minutes is worth it after being in the house for three straight days because I don't have the energy to go anywhere.

Anything worth doing is worth doing poorly.... because doing it poorly is better than not doing it.

Source:banonbinary

Spoon Theory



How do you manage or describe to others the impact of fatigue?

In 2003, a US writer and blogger Christine Miserandino coined the phrase Spoon Theory, and using spoons as a metaphor she was able to show - in a simple measurable way - how fatigue affects someone who has this symptom.

She herself had Lupus, an autoimmune condition, but the theory works for anyone experiencing chronic illnesses, and can help you understand and manage fluctuating energy levels.

Christine was eating dinner with a friend, who asked what it felt like to live with her condition. Christine took all the spoons she could find and explained how things impacted on her. She advised every spoon was equal to a unit of energy. Without a health problem, you can wake up with unlimited energy, do everything you want to do – get ready, work, exercise, socialise – all without planning.

But with chronic health conditions, you may only have a certain amount of energy – or spoons. And this can vary daily. If you have the equivalent of 12 spoons energy, these can easily be used by the tasks of just waking up, brushing teeth, washing your face, dressing, eating breakfast, going to the doctors, coming home, making dinner and getting ready for bed. Each activity task may use 1 spoon or up to 6 spoons - like when going to the doctors. This leaves only 5 spoons for everything else, and you will be short. You can borrow spoons from the next day, but then you will have less to manage on that day. It's easy to get trapped into a cycle of overdoing it, so the key is managing your "spoons" – your energy levels. This can mean modifying, postponing, breaking down, prioritising or delegating activities.

Spoon theory is being used to raise awareness that we cannot take other peoples energy levels for granted, and with this insight into others situations, we can then support one another better.

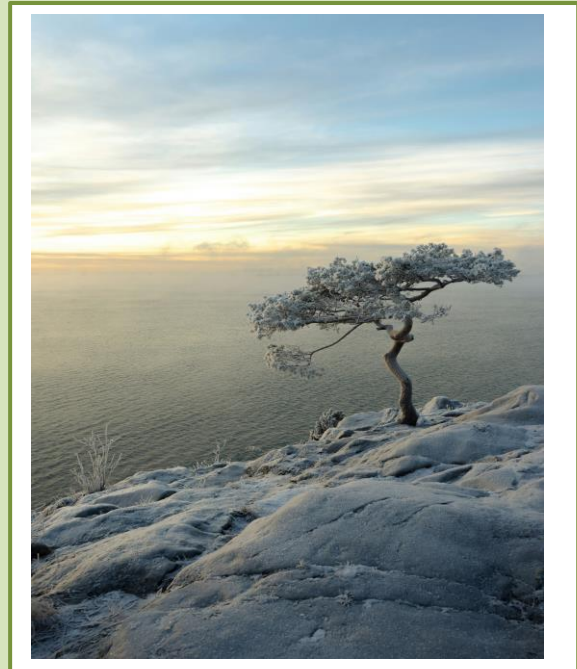
Resilience by Echo

In the quiet of morning light
A journey starts anew each day
With tremors that may mark the path
Yet courage never fades away

Through every moment, steps unsure
Represent a fight embraced
For every challenge met with grace
Are testaments to strength's true face

Though moments pass with shadows cast
A spirit shines beyond the fray
In laughter shared and love received
Resilience will light the way

So, walk with pride and hold on tight
Nurture dreams and let them grow
For in the battle you will find
A deeper strength than you could know



TV Crime Fighters Quiz

Can you work out the titles of the crime series from these clues?

1. Evening all! (DODG)
2. His name is also a type of code (IM)
3. Jessica is always writing (MSW)
4. Always a nip in the air when he is about (F)
5. Crimefighter in a raincoat (C)
6. A Belgian detective (HP)
7. He wore a deerstalker (SH)
8. Only half this team was visible! (RAH)
9. A crimefighter who hangs upside down and has a feathered friend (BAR)
10. "You take care out there" said the desk sergeant (HSB)
11. Another village, another killing.... (MM)
12. An American Medical Examiner – a sharp fruit (Q)
13. Not such a cheerful place to be (HV)
14. Jed Mercurio's AC12 series (LOD)
15. He solved crime with a lollipop (K)

Answers on Page 6

Carers Update from Caring Together

Huntingdon Carers Hub

11th June, 9th July, 10.30am – 12.30pm
Coneygear Centre, Huntingdon PE29 1PE
2nd Tuesday of the month



Meet with other carers, have a chat, and get support from one of the Caring Together Advisors, join in relaxing activities or learn from local speakers. Please contact Caring Together on details below if you would like to join them, and you can find out more about the Carers Hubs [here](#).

If you would like more details on carer support locally or their activities, please contact one of Caring Together's care advisers for help and advice, by emailing them at hello@caringtogether.org, or by phone on 0345 241 0954.

Update on GDNF

Parkinson's UK were the major funders in a trial using a custom-built device to deliver GDNF, a brain protein, as a potential treatment to protect dopamine producing brain cells and to help them regrow. The challenge was administering the GDNF deep inside the brain, and unfortunately, the results were inconclusive. However, some of the 41 participants over the 9-month trial felt they experienced some benefit from it, and some brain scans appeared to show dopamine producing cells were regenerating.



Since 2021, the charity has been working with experts and people with Parkinson's to try to arrange a further trial of GDNF. Unfortunately, they have not been able to identify a partner to make this possible. Earlier this year, Parkinson's UK announced they will no longer be actively looking to further this research, and will instead be looking at other projects that may be more fruitful.

Though this particular device delivered GDNF project is not going forward, there are other new ways and approaches for administering GDNF led by other companies who may be able to develop and build on the previous research.

The projects include using a modified inactive virus as a carrier for the genetic instructions for making GDNF that is injected into the brain as a one-off procedure. This way the brain cells will be triggered to make their own GDNF.

It appears so far in early trials that this approach is safe, and that it can stimulate production of GDNF. There are now plans underway for a major international trial to test the safety and effectiveness of this treatment on a larger group of people. We will update you as soon as we hear more.

Medication Shortages

There have been some reports of shortages of medication, that is varying area to area. The medications in question are Carbidopa/entacapone/levodopa 50 mg/200mg/200mg tablets x 30 and 100, also Ropinirole 0.25 mg and 2.0 mg tabs – both likely to face supply problems until late 2024.

Teva Pharmaceuticals will no longer be supplying Amantadine hydrochloride, but they will still be available through different distributors.

The British Medical Journal (BMJ) suggests that factors affecting this are global chain and post pandemic issues, post Brexit costs and an NHS spending cap.

If you have any issues, please discuss with your GP or pharmacist, as other alternatives may be available.

TV Crime Fighters Quiz Answers

1. Dixon of Dock Green 2. Inspector Morse 3. Murder She Wrote 4. Frost 5. Columbo 6. Hercule Poirot 7. Sherlock Holmes 8. Randall and Hopkirk 9. Batman and Robin 10. Hill Street Blues 11. Midsomer Murders 12. Quincy 13. Happy Valley 14. Line of Duty 15. Kojak

Useful Contact Numbers

BRANCH CHAIR

Malcolm Ryman

07720 080749

VICE CHAIR

Vacant

PARKINSON'S UK CONFIDENTIAL HELPLINE

0808 800 0303

(Also access to Parkinson's Local Adviser)

Email: enquiries@parkinsons.org.uk

PARKINSON'S DISEASE SPECIALIST NURSES

0330 726 0077

BRANCH MOBILE

07724 400527

FACEBOOK PAGE

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PARKINSON'S UK WEBSITE

www.parkinsons.org.uk

This Newsletter is compiled to the best of our knowledge from information available at the time of publication.