

Cambridge Branch Newsletter: July-August 2025

Tulip Fun Run 2025



The runners, walkers, volunteers, and Bear from the 2025 Tulip Fun Run!

The sun was shining on Sunday 31st August as over 20 participants took part in this year's Tulip Fun Run/Walk, our branch's biggest fundraising event. We were delighted to be joined once again by our dedicated team of volunteer First Aiders, led by Denise and Anton, who ensured everyone could enjoy the day safely.

Cambridge Branch Newsletter: July-August 2025

The event was officially opened by Mayor Dinah Pounds, who spoke about the importance of local fundraising in supporting the Cambridge Brain Repair Centre and highlighted the wealth of Parkinson's research happening here in our city. She also stressed how vital it is for researchers to stay connected with local charities and the communities their work supports.



Mayor Dinah Pounds with the returning team of (almost volunteer!) First-Aiders lead by Denise and Anton.



Mayor Dinah Pounds, with David Perks, Caroline Bent, Mark Goodridge and Jamie Shonhard.

The Mayor then had the pleasure of presenting the David Johnston Memorial Trophy to David Perks for the second year running, in recognition of his outstanding fundraising efforts. David raised an incredible £2,300 in sponsorship, and was also honoured with a note of thanks from Jane Asher, President of Parkinson's UK, and CEO Caroline Russell.



Mayor Dinah Pounds presents the David Johnston Memorial Trophy to David Perks, who contributed a huge sum in sponsorship for the second year in a row!

Cambridge Branch Newsletter: July-August 2025

With cheers and encouragement from family and friends, the runners and walkers set off along the 4-mile route. The fastest finishers, Tom, Alexa, and Howard, came home in impressive times of 28, 30, and 35 minutes respectively. Others took a more leisurely pace, enjoying the scenery and camaraderie that make this such a special community event.



Tom was the first person to finish the Race!



Other people started to filter in after Tom!

Thanks to the dedication of everyone involved, and with Gift Aid and in-person donations included, this year's Fun Run has so far raised nearly £6,000 for the Cambridge Branch and Parkinson's research, with more than £2,000 coming from David's efforts alone. A huge thank you goes to every runner, walker, donor, and volunteer who helped make the day such a success, especially to the unsung heroes Florence, Mitch, Jack and India who came to help marshall the route to ensure everyone knew where to go!

SAVE THE DATE

The 2026 Tulip Fun Run is proposed for Sunday 12th April, the day after World Parkinson's Day. We hope to see you there!

More Details Coming Soon

Cambridge Branch Newsletter: July-August 2025

A Letter from David Perks

Dear Friends,

Following my contacting you a month or so ago, a number of you made a donation to Parkinson's through my Just Giving page, for which I am very grateful. Many thanks.

Whether you made a donation or not, I thought you would like to know how it went on Sunday. The weather was much kinder than last year. A few spots of rain only and otherwise sunny and not too hot. Some of my fellow Nordic Walkers ran the run - I did not run and, as I said I would, walked it. A very pleasant walk through South Cambridge, which took me about 1 hour 20 minutes, including chats to various people, who stopped to talk to me as I went past, and a slight delay while I waited for a train to go over a level crossing.

If anyone who did not make a donation earlier would like to do so now, my Just Giving page is still open www.justgiving.com/page/david-perks-2

Getting ready for next year? — provisionally 12 April, 2026. Thank you all.

David (Perks)

BRANCH MEETINGS

July Branch Meeting: Wiltshire Farm Foods

Caroline began the meeting by updating members on upcoming branch activities and opportunities to get involved. She thanked Joanna for stepping in to run the information table in place of Gill and for answering questions during the afternoon. Members were also invited to take home donated jars leftover from the Shelford Feast tombola, along with a spare camera tripod kindly offered by Caroline's husband. The meeting started on a cheerful note with everyone joining in to sing *Happy Birthday* to Gabby.



We were delighted to welcome Steph Baudino, a fitness instructor with more than a decade of experience, who has a strong personal connection to Parkinson's through her father. Steph shared her story of how her dad, who has lived with Parkinson's for 17 years, and her mum as his full-time career, have shaped her understanding of

Cambridge Branch Newsletter: July-August 2025

the challenges and the ups and downs of life with the condition. She spoke about the benefits of gentle movement and music, suggesting short routines at the start of our monthly meetings to help loosen stiff muscles and energise the group.

Members contributed their own helpful tips, from using counting or rhymes to overcome freezing episodes, to voice therapy, arm stretches, and balance exercises. Steph then led a lively demonstration with simple movements including arm shakes, shoulder shrugs, stretches, and breathing exercises, all accompanied by plenty of laughter (helped along by a perfectly timed ringtone from someone's phone!). The taster session was warmly received, and the group agreed that regular short exercise at the beginning of meetings would be a welcome addition.

Our guest speaker for the afternoon was Peter from Wiltshire Farm Foods, who managed to join us despite being delayed by heavy traffic.

He introduced the company's wide range of frozen ready meals, which include everything from everyday essentials to luxury dishes, alongside specialist ranges for people with swallowing difficulties, reduced appetites, or other dietary needs.

Peter emphasised the friendly, reliable service provided by their police-checked drivers, the ability for family members to order on behalf of loved ones, and the company's commitment to sustainability, including recycling millions of trays each year.

He also brought brochures and meal samples for members to see and try. The meals were well received, with one member commenting that they were "some of the best I've ever had." Despite the shortened session, Peter's talk was informative and practical, many members left with useful ideas for meal options at home.



Cambridge Branch Newsletter: July-August 2025

August Branch Meeting: Dr Alistair Mackett

Caroline opened the meeting by welcoming a large group of members, including several new faces. She reminded us about upcoming events for the month sharing notices about upcoming socials, collections, and opportunities to get involved.

We again enjoyed a short warm-up session led by Steph Baudino, who used movement and music to get us energised and smiling at the start of the meeting. This time, Steph led us through a rowing-themed routine, and in true Cambridge style, it finished with a triumphant nod to this year's Boat Race win!



The main part of the afternoon was devoted to an engaging and informative talk by Dr Alistair (Ali) Mackett, Consultant Geriatrician at Addenbrooke's and Regional Clinical Lead for the Parkinson's Excellence Network in the East of England. Ali began by explaining the role of the Excellence Network, which connects neurologists, clinicians, therapists, and researchers across the country to ensure best practices and new treatments are shared. His work focuses on gathering evidence about patients' experiences of care,

identifying where services fall short, such as long waiting times, patchy access to physiotherapy, or shortages of Parkinson's nurses, feeding this back to providers and government. The aim is to ensure that everyone with Parkinson's has access to excellent care, wherever they live.



Ali's talk centred on the non-motor symptoms of Parkinson's, which he emphasised affect nearly every person with the condition, even though they are less visible than tremor or stiffness. Members were surprised to learn that *99.7% of people with Parkinson's experience non-motor symptoms*. These can appear years before diagnosis, with early signs including constipation, fatigue, or vivid dreams. Ali explained current theories that Parkinson's may start in different places in the body, for some, in the brain with motor symptoms; for others, in the gut, with problems like constipation arising long before movement is affected.

He then walked us through some of the most common non-motor symptoms and practical ways to manage them:

Cambridge Branch Newsletter: July-August 2025

- **Constipation:** very common and sometimes present decades before diagnosis; can also affect how well medication works. Strategies include a fibre-rich diet, staying hydrated, probiotics, regular exercise, and medications if needed.
- **Urinary problems:** experienced by around half of people with Parkinson's, ranging from urgency to difficulty passing urine. Management can include bladder retraining, continence services, medication, and in severe cases even Botox treatment.
- **Sleep disorders:** up to 98% of people with Parkinson's have some form of sleep difficulty, whether that is in the form of insomnia, frequent waking, restless legs, or REM sleep behaviour disorder (vivid dreaming and acting out dreams). Solutions range from adjusting Parkinson's medication and improving sleep hygiene, to melatonin or other medication in specific cases.
- **Low blood pressure on standing:** common but important to recognise, as it can lead to falls. Drinking more fluids, reviewing blood pressure medications, or in some cases starting medication can all help.
- **Mood and mental health:** anxiety, depression, and apathy are all under-diagnosed in Parkinson's. Treatment may include talking therapies, antidepressants, or medications like pramipexole which can sometimes also lift mood.
- **Pain:** often overlooked, but can arise from stiffness, arthritis, or nerve pain. Ali stressed that better management of Parkinson's symptoms and pain medication together can make a big difference.
- **Hallucinations and illusions:** more common in advanced stages. These may be treated with medications such as rivastigmine or antipsychotics if distressing.

Ali ended by offering practical tips for living well with Parkinson's:

- **Regular exercise** of any kind helps not only mobility but also sleep, constipation, mood, and even disease progression.
- **A balanced diet rich in fibre**, with careful attention to protein timing (not near medication or bedtime) to avoid interfering with medication.
- **Vitamin D supplements** are recommended for bone and muscle health.
- **Staying hydrated** (1.5–2 litres daily unless advised otherwise) supports blood pressure, digestion, and may help with restless legs.
- **Good sleep hygiene**, consistent routines, cool dark bedrooms, and limiting caffeine is key.

His talk generated plenty of discussion, with members sharing their own strategies and experiences. Some found dietary changes like “breakfast like a king, lunch like a prince, dinner like a pauper” helpful, while others noted the challenges of long waits for services such as speech therapy and access

Cambridge Branch Newsletter: July-August 2025

to Parkinson's nurses. Ali's message was clear: while there is no one-size-fits-all solution, recognising and managing non-motor symptoms early can greatly improve quality of life, and the Parkinson's Excellence Network is working hard to ensure best practices and support are available nationwide.

[Read More About the Parkinson's UK Excellence Network Here](#)

LOCAL NEWS

Rachel Li's Dissertation

If you are one of our members who completed the questionnaire through which Rachel Li (a 6th Former for Hills Road 6th-Form College) gathered the data contained in this very thorough Dissertation, you may be interested to see her conclusions. This link is open until the 13th October 2025.

[A Link To Rachel's Dissertation](#)

Museum Encounters Autumn Term

The popular Museum Encounters program run by Ruth Clarke at the University of Cambridge Museums is back!

The program invites people affected by Parkinson's to take part in a short course led by dance for health artist Filipa Pereira-Stubbs and inspired by objects, artefacts and artworks from the University of Cambridge Museums

[More Details About Museum Encounters Can be Found Here](#)

6 July: Branch volunteers braved rain, thunder and lightning to run a Tombola and information stall at the Shelford Feast



18 July: Nine PwPs took part in the final trial session of Judo-derived Falls control exercises.

This experience will now be assessed in order to establish what, if any, benefits were derived.



Cambridge Branch Newsletter: July-August 2025

29 July: With the help of his colleagues, Andrew Curran, PwP, mounted a cake stall in the lobby of the Bupa Health facility in Histon where he works. The sale raised £450 which will be matched by Bupa!



- **Trusts:** How they can protect your assets
- **Lasting Powers of Attorney:** Understanding their role in planning ahead
- **Sideways Disinheritance:** Issues that can arise from remarriage and how to avoid them.
- **Inheritance Tax:** Breaking it down in simple terms

The session will last around 30–45 minutes, followed by a Q&A. Speakers will also be available afterwards for anyone who would like a private chat.

If you are interested in attending, please contact Deb Liddington (debliddington@btinternet.com).

Active With Parkinson's Cambridge (AwPC) – Free Community Talk – UPCOMING EVENT

Active With Parkinson's Cambridge are pleased to share details of an upcoming free community talk on estate planning, taking place on **Tuesday 28th October, 10.15–11.15am at Shelford Rugby Club**. The session will be led by experienced speakers and is designed to raise awareness, not promote any commercial services.

The talk, *Tax, Care and The New Guy*, will cover important topics in a clear and accessible way, including:

- **Wills:** Why they can protect your assets

SCIENCE AND RESEARCH

Get Involved in Research - Clinical Trial Information

I have had conversations with a few members recently regarding finding out what clinical trials are recruiting locally, so have decided to compile a list of websites that you can access to find out about upcoming and ongoing clinical trials and their criteria. The information below is sourced from the Cambridge Clinical Trials Unit, Prof. Roger Barker's Team & Parkinson's UK.

Cambridge Branch Newsletter: July-August 2025

Clinical Trial Websites:

[Parkinson's UK Take Part In Research!](#)

[Cure Parkinson's Currently Recruiting Research Studies](#)

[Cambridge Clinical Trials Unit \(All Neuroscience Trials, DAPA-PD is the upcoming PD Trial\)](#)

[NIHR Be Part of Research Parkinson's Trials in Cambridgeshire](#)

[ISRCTN UK Parkinson's Disease Trials](#)

BeechBand Feedback

We have recently purchased BeechBands for members who wanted to give them a try. If you have received one, we encourage you to use it for a little while before sharing your thoughts (whether positive or negative!) on how it has (or hasn't) helped with your Parkinson's symptoms. Your feedback will then be passed on to Parkinson's UK, who are keen to learn more about the effectiveness of the device.

Please email feedback to:

pukcambridge@gmail.com

UPCOMING BRANCH EVENTS

2025 Dates

7 September: from 2pm, Cream Teas in the lovely garden of The Dovecote, 29 High Street, Haslingfield, CB23 1JW; in aid of Parkinson's and the Little Owls playgroup. Entrance £5 (and worth every penny!).

12 September: 10:30, Carers Zoom:

<https://us02web.zoom.us/j/85471586856?pwd=Blfp9m0n8rFKFlIEkduOLVGGGx0Z9y.1>

Meeting ID: 854 7158 6856 Passcode: 232571

17 September: 2:30, Launch of a new Parkinson's Café meeting in the Cherry Hinton Care Home, 369 Cherry Hinton Road, CB1 8DB. Tea and Tai Chi! Tel 01223 210070. Just turn up or Contact: bdm@cherryhintoncarehome.co.uk

18 September: 11:00 -- 12:00, in the Jubilee Pavilion in Stapleford, voice coaching with Linda Bance. If you don't know where the Pavilion is, consult satnav: CB22 5BQ.

26 September: 10:30-12:30, Branch Meeting, Speaker Clotilde Tournier, PhD student: "*The AD/PD 2025 International Conference on Alzheimer's and Parkinson's Diseases and related neurological disorders in Vienna*"

3 October: Museum Encounters Autumn Term begins, Dance for people living with or affected by Parkinson's. Inspired by stories from the University of Cambridge Museums and Botanic Garden. FREE, Friday 3rd October 10.30-12:00. Cambridge Junction, Clifton Way, Cambridge CB1 7GX.

17 October: Museum Encounters Autumn Term, session 2. See 3 October above.

24 October: Branch meeting; Parkinson's nurses Preethi Biju, Claire, and Rachel, and Local Advisor, Becky Linnell, will be present.

25 October: 10:30 – 3:30, Young Active with Parkinson's, and Family Carers meeting; contact Julie Wilson for details: jmwilson@parkinsons.org.uk or book [Booking for YAPA and family carer/supporter session](#)

Cambridge Branch Newsletter: July-August 2025

28 October: 10:15 – 11:15 at the Shelford Rugby Club, a talk promoted by Active with Parkinson's Cambridge, entitled "Tax, care, and the New Guy"

7 November: Museum Encounters Autumn Term, session 3. See 3 October above.

21 November: Museum Encounters Autumn Term, session 4. See 3 October above.

28 November: **Branch Christmas Party** - Raffle, quiz and the return of Tom Gamble to play his guitar for us.

5 December: Museum Encounters Autumn Term, See 3rd October Entry for Details

12 December: **Branch Christmas Lunch** - At the David Rayner Building, Friday 12 December, 12:30 for 13:00. Tickets: Branch members £10; guests £15. Order your ticket(s) from Caroline at carolinebent@me.com or in person.

19 December: Museum Encounters Autumn Term, See 3rd October Entry for Details.

21 December: **CHRISTMAS CONCERT IN TRINITY COLLEGE CHAPEL** (by kind permission of the Master and Fellows of the College) **SAVE THE DATE**

2026 Dates

6 February: Museum Encounters Winter Term begins, details later.

11 April: WORLD PARKINSON'S DAY

12 April: The **Tulip Fun Run** returns to its preferred Springtime slot – Date and Route TBC, but save the day and plan to join in in 2026.

NETWORK NEWS FROM PARKINSON'S UK HQ

Learn more about Parkinson's UK's research - new video and podcast

We've got a new short video all about our role as the leading European funder of Parkinson's research - finding out why people get Parkinson's, unlocking new tests, and developing new treatments. Take a look at: [The Video Here](#)

We are delighted that a recent episode of the '2 Parkies in a Pod' podcast spotlights our Brain Bank - the world's only brain bank solely dedicated to Parkinson's research.

Based at Imperial College London, the Parkinson's UK Brain Bank collects tissue from people with and without Parkinson's who pledge to donate for research. We're incredibly grateful to donors and their families for these generous contributions. To listen to the full episode visit: [This Link](#)

Thanks to your support and driven by your needs, we're involved in every part of Parkinson's research - from cause to a cure.

Upcoming name change

At the AGM in October, we'll be holding a vote to allow us next year to update our official registered name from 'Parkinson's Disease Society of the United Kingdom' to a closer variation of the 'Parkinson's UK' name we use every day. You'll receive more information about this in September if you are registered as a member of Parkinson's UK (as well as your local group). If you're not sure whether you are a member of Parkinson's UK please

Cambridge Branch Newsletter: July-August 2025

email membership@parkinsons.org.uk or call 0800 138 6593 to ask.

Nominate your hero for the 2025 Community Awards

What are the Community Awards? The Community Awards exist to recognise these incredible unsung heroes. There's no single 'winner' - every nominee gets recognised for the difference they've made with a Community Awards certificate. We're also hosting a drinks reception at the year's Par-Con to celebrate nominees on Friday 24 October, for those joining us in person.

Nominate your hero - We've already received over 180 nominations this year. We can't wait to celebrate all of the amazing individuals, but we want more!

Anyone can make a nomination online [here](#) and they can nominate anyone in the Parkinson's community, from people living with Parkinson's and their families, to volunteers, for any reason, big or small. Please ask your staff contact for help if you are unable to nominate using our online page. Nominations will close at 12pm on Friday 31 October.

Charging for Continuing Healthcare (CHC) information and advice

NHS Continuing Healthcare is a package of care arranged and funded by the NHS (England and Wales) for adults with on-going, complex health needs. It's not dependent on a specific condition like Parkinson's, but rather on the level and type of care required due to those needs. Our Helpline has heard from a number of people who are understandably upset because they've paid significant

amounts to organisations for advice on CHC (Continuing Healthcare) applications, only to be turned down.

We would always advise people to reach out to free information services first, before making a decision to pay for support with a CHC application. If they ring the Helpline instead we would offer the following-

- Referral to the Care team: As a care team we can advise people how best to prepare for a CHC assessment, what to expect and where to find support should they need it. As well as information on how to appeal a decision. We also have links with CHC regional leads where people are having particular difficulties accessing an assessment.
- Beacon (England only) : [Beacon](#) offers free information and advice around the CHC process and up to 90 minutes free advice for more in depth case work to prepare for an assessment or to launch an appeal. They also have detailed information in their navigational toolkit which can be downloaded from their website.

Our care adviser team provides support to all 4 nations around any CHC or social care enquiries they may have. More information is available on our [Website](#)

Join our Black, Asian, Arab and Mixed Heritage support group

At Parkinson's UK, we run an online information and support group **for people affected by Parkinson's from Black, Asian,**

Cambridge Branch Newsletter: July-August 2025

Arab or mixed heritage backgrounds. The group helps to connect people, and inform about support and opportunities available to live well with Parkinson's and to get involved in Parkinson's research and other activities.

Please use [this form](#) to register your interest. If you have any questions, please contact us by email on zbibi@parkinsons.org.uk or by phone on 07964037154.

In-person tickets for Par-Con are now sold out!

We're pleased to share that in-person tickets for Par-Con are now sold out, with over 300 attendees set to join us for two days in Birmingham this October. The response to this year's event has been fantastic—thank you to everyone who has helped spread the word so far!

There's still space to join Par-Con 2025 online! All key sessions will be livestreamed for the online audience, and also recorded and made available on demand after the event. Attendees will be able to chat and connect with others online through our streaming site, and ask questions to the speakers. Attendees can register for an online ticket on [our registration page](#).

Questions

If you have any questions, please contact [Emma Williams](#), Research Events and Engagement Manager.

Newly Diagnosed webinars

We have 2 Newly Diagnosed webinars coming up! Please find out more below.

Wednesday 10 September - Devices and tech for Parkinson's Are you newly diagnosed with Parkinson's? Have you wondered what devices and apps are available to support you? Join our webinar to hear our panel talk about what tech is tried and tested in supporting Parkinson's, how it can help, and what to look out for when finding what's right for you.

Wednesday 8 October - Mental health and Parkinson's Are you newly diagnosed with Parkinson's? Join our webinar to hear our panel talk about mental health. They will explore navigating mental health after a Parkinson's diagnosis, ways to manage it with Parkinson's, and the different treatment options available.

You can find out more about both webinars and book your place on our [Newly Diagnosed webinars page](#)

Please get in touch with us at newlydiagnosed@parkinsons.org.uk if you have any difficulties booking.

The annual volunteer survey is open!

What do you think about volunteering with Parkinson's UK? Now is your time to tell us. The volunteer survey is now open!

Please take some time to share your feedback about your experience of volunteering. From today until Sunday 28 September, you can share what you love about volunteering and what you find challenging.

[Complete the survey here](#)

Cambridge Branch Newsletter: July-August 2025

Your feedback has directly shaped work across the organisation. Based on the 2024 volunteer survey, we have been focusing on:

- Providing more opportunities to connect with other volunteers and colleagues in person and virtually
- Making processes to be easier and for there to be less bureaucracy involved in your volunteering
- Making systems, like Assemble and Create, to be more user friendly and easier to navigate
- Improving the recruitment process to find more volunteers to be recruited to ensure that we can continue to provide vital support to people with Parkinson's, families and friends, especially in local groups (including cafes)
- Reviewing the volunteer induction to be more proportionate and relevant to your role

Please take the time to complete the volunteer survey. Tell us about your volunteering experience and shape our work for the year ahead.

Feedback

Your feedback is really important to us. It helps us shape this newsletter into something that is useful and interesting to you. Please share your thoughts by emailing the [Local Networks inbox](#).

All Branch Enquiries: pukcambridge@gmail.com

CAMBRIDGE BRANCH COMMITTEE MEMBERS

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USEFUL CONTACTS

Branch Website: <https://www.parkinsonscambridge.org>
Parkinson's UK: www.parkinsons.org.uk 020-7931-8080
enquiries@parkinsons.org.uk

Helpline: A free, confidential helpline is available from
Mon-Fri: 9am-7pm and Saturday 10am-2pm. Call 0808-
800-0303, or email hello@parkinsons.org.uk

Facebook: www.facebook.com/parkinsonsukcambridge/

Parkinson's Nurses locally; for help and information:

- Parkinson's Nurse Team 0330-726-0077

- Addenbrooke's Hospital Parkinson's Nurses 01223-
349814

Parkinson's UK is the operating name of the Parkinson's Disease Society of the United Kingdom. A company limited by guarantee. Registered in England and Wales (258197) and in Scotland (SC037554).