

# PSG

## PATHWAY SOCIAL GROUP

29th October 2024

### Welcome to Issue 4 of Pathway Newsletter

Welcome to this latest edition of the Pathway Newsletter, aimed at people diagnosed with Parkinson's disease, their friends, family, neighbours, carers and anybody else interested in Parkinson's Disease and, in particular, the Parkinson Centre for Integrated Therapy.

In this edition we cover the next stages in the development of PCIT, further news on the recent introduction of ProDuodopa therapy by the NHS, the importance of sleep and much more.

PCIT is evolving and growing at an incredible rate with new premises, new therapies, new members and new ventures - this is an exciting time for PCIT and a testament to the ambition and hard work of many people.



### Tanglewood



PCIT's footprint on the university campus is set to increase significantly with the addition of buildings at Tanglewood. These buildings are a short walk from Woodlands and will offer a significant increase in space. Plans are still being finalised but there is room for a number of additional treatment rooms, a social space and PCIT's very own neuro gym.

Some building works will be necessary before PCIT can utilise this new space but it is expected to become operational in January 2025. This is entirely additional space, the existing space at Woodlands will continue to be utilised by PCIT.



One of the many spaces at Tanglewood that are to be re-purposed for PCIT use



# Health Services Interaction Survey

Since PCIT first launched, many members have shared their stories, both positive and negative, of their initial diagnosis with Parkinson's and their subsequent interactions with the health services.

Following discussions between several PCIT members, therapists and Management, it was agreed that it would be very useful to collect as much information as possible about members' experiences in order to inform how services could be improved. To facilitate this, each member has been sent a questionnaire asking about their experiences. Paper copies are available in the reception area at Woodlands and Clare Walker will be happy to help you to complete it, if needed.

The survey is, of necessity, quite long (10 - 15 minutes to complete) since it is important that we capture as much information about members' experiences as possible.

To encourage as many members as possible to participate in this survey there will be a prize draw for those who complete the questionnaire with a free therapy session of your choice as prizes for three lucky winners.



PCIT's membership is growing rapidly and we now have more than 260 members. This, together with the publicity we have gained through exposure on local and national television and growing contacts with many influential people and organisations, means that PCIT has a growing amount of influence. It is intended that the findings of this exercise will go into a report to be published in relevant journals and used to pursue changes to how people with Parkinsons' are treated in the future.

This survey has been designed by PCIT members for PCIT members and has the backing of the senior management of PCIT. It is vitally important that we receive as many completed questionnaires as possible and hope that all members will play their part in helping PCIT to pursue change by completing a questionnaire. **A big thank you to all members who have already participated.**

*Thank  
you*

# Sarah Frow's Pilgrims Way Challenge - "Six Marathons in Six Days" - July 2024



Sarah's fantastic fundraising feat of running from Winchester to Canterbury in six days (effectively six marathons), this summer, raised over £42,000 in total.

Despite being diagnosed with Parkinson's in 2021, Sarah Frow, PCIT fitness instructor and all round inspirational figure, breezed into the grounds of Canterbury Cathedral on Saturday the 1st of June as though she had done no more than just run for a bus! Sarah and her running partners were greeted by a crowd of family, friends and many PCIT members who helped her celebrate this magnificent achievement with a glass of bubbly.



Well done Sarah!





# PCIT Members From Further Afield..

## Linda's Story.....

### Liverpool Ladies

Linda and Liz are lifelong friends from Liverpool who made the long journey to PCIT in July and quickly became involved in several activities as well as therapy sessions and met with other members, therapists and staff at PCIT. They plan to return in the Spring for a longer visit. Both were very impressed with the positivity that surrounds PCIT and Linda shares her story here.

My journey began in 2020 when I had been troubled by a problem with my shoulder for some time, and decided it was time to see a doctor. The video consult with the shoulder specialist came to no specific conclusion, and my own suspicion that it was a more complex issue, and possibly Parkinson's, was growing.

I was told at a GP appointment that the waiting list to see a NHS Neurologist was going to be many months away therefore I was encouraged by friends to see a consultant privately; this led a confirmed diagnosis. In fact as soon as I walked down the corridor towards her room I felt she was assessing me as I walked toward her, and that she already knew. Medication was started there and then, although it was several months before I saw Dr Moore, my NHS appointed neurologist.

Like many people, I went down a dark hole. I spent a lot of time on-line researching everything I could about Parkinson's. I joined groups on social networks and tried to gather as much information as possible about the additional non-medical approaches which people were trying, and I became totally overwhelmed.

The local NHS experience was sadly lacking, so with the help of a friend, we explored opportunities for finding centres of excellence where I might be able to register. During that search my friend found PCIT which is 280 miles from my home town, but only 73 miles from hers, and she persuaded me to come down for a visit, incorporating a couple of days in Canterbury for an assessment with a view to spending a longer period of time at a later date.

This was the driving force I needed to pick myself up and start fighting back. For the first time someone listened to me and answered all my questions that had been building up. They gave me support, encouragement and most importantly they gave me back what I was lacking ' hope '. The positivity was with everyone we met and spoke to whilst visiting . It inspired me so much I now have come home and joined a gym, taken up Tai Ci and am helping out at a Foodbank . I also plan to do a fund raising walking event for PCIT.







## The story behind the making of the Parky "I will Survive" song and video

'I will survive' we sang. We did - by the skin of our teeth. Who knew making a pop video could be so enthralling and irritating, so complicated and so all consuming. And finally, such fun. By 'we' I mean the six friends who are the "Movers and Shakers" the team behind the award-winning pub based podcast about living with Parkinson's. And now behind what I hope you find a gloriously silly, catchy, poignant, and ultimately hard hitting campaign tool video and song - if you haven't seen it you can watch it on YouTube [here](#).

It's all the fault of one of my fellow presenters, Gillian Lacey-Solmar, an energetic powerhouse of creativity overflowing from a body ravaged by the condition. She was the original force behind both the Parky Charter and our latest project to promote the cause. Her Parkinson's can be dramatic. A few months ago while we were recording in the pub she nicked a chip from Paxman's plate, which stopped her drugs from working and minutes later she was prone on the pub bench, unable to speak, but clearly in agony. Twenty minutes later she was upright again, chatting away merrily with the rest of us

More recently, terrible cramps made it impossible for her to sit still while we recorded the podcast, so instead she gamely knelt on the floor. We angled the microphone down towards her face and listeners would never know she wasn't seated around the table with the rest of us. She's often 'off' and in a lot of pain. But that doesn't stop her. She has ideas. Lots of them. Often in the middle of the night. Many of us have trouble sleeping and most toss and turn, moan and groan and curse their fate. Not Gillian. Her insomnia is slaved in service to her talents. Once she painted an entire mountain scene in her downstairs loo during a sleepless week. Last year she wrote a whole musical about Lady Hamilton - most of the libretto completed while it was still dark outside. She tosses off poems, from deep to doggerel, in the time the rest of us take to butter our toast. I frequently wake to groggily find the latest product already up for discussing on our WhatsApp group and one morning I was particularly excited to find she had rewritten the lyrics to Gloria Gaynor's 'I will survive' to reflect the plight of us, those living with Parkinson's. I laughed out loud. It was clever and witty, turning a song about defiantly carrying on after a romantic breakup into one about demonstrating the same spirit in the face of our brains and bodies sending us a 'dear John' letter. I gave her a call. "It's brilliant. We should do something with it".

Paul Mayhew Archer, fellow presenter and co author of "The Vicar of Dibley" was equally enthusiastic. We quickly agreed we should try to make some sort of parody pop video. Unwisely, our heads were filled with visions of us prancing around in sequined costumes under glittering mirror balls, a thrashing, flailing, disco disaster, complete with roller skating dancers scooting around us. We knew it would be absurd. We knew we couldn't dance. We knew we would become figures of fun. And giddy with the concept we didn't give a hoot.



Our fellow presenters didn't agree. We thought they were killjoys. They thought we were crazy. They knew none of us could dance and didn't want us or them to be made to look ridiculous. They flatly refused to take part. Rory channelled Meatloaf and told me "I would do anything for this podcast. But not that."

The Judge suggested his family's dignity was at stake. We three were at an impasse so decided to go it alone.. At this stage I foolishly imagined the whole thing could be filmed by a couple of friends with iPhones. Then Paul called an old mate and everything changed. The old mate was Geoff Posner, a renowned, award-winning TV director, whose work includes 'the Vicar of Dibley' and the hilarious Mr. Bean sketch which stole the show at the 2012 British Olympics ceremony. So he thinks big.



Geoff is a roly poly chap with a huge moustache and a genial, easy-going manner, under which lurks a steely professionalism and, it turned out, a greater ambition for our little project than we had ever ourselves conceived. He came to the pub where we record the podcast and after watching us shuffle slowly around the place, staggering, dragging our feet and not swinging our arms, he was alarmed. He shared Rory and Nick's fear that any attempt at dancing would make us look ludicrous and pitiful. Fine. No dancing. But what then ?



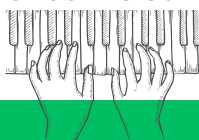
While we pondered the hard question of what to do while singing, we had first to work out whether we would be allowed to repurpose this 1978 disco classic in the first place. What was the situation with copyright? I asked Hattie to find out.

Let me introduce Hattie - she helps me with the website, which is rather like saying Da Vinci helped with redecorating the Vatican. Without Hattie there would be no website and no video. An expert in 17th century Castilian, a documentary producer who happens to have a master's degree in law, currently at home looking after her two small girls, she is fiercely efficient, unfailingly even tempered and pretty good at handling with great care and diplomacy the chaotic, anarchic entity known as the Movers and Shakers. So, from our point of view there was no better person to ask, as a bit of a favour, to go beyond her normal loose and unwritten job description and find out.

She tracked down the right company and found out we'd need a licence and they told her breezily "it should be fairly cheap." Great. Then I asked, rather casually, if she could help Geoff organise some of the stuff. She agreed. That was her only mistake. You know that story about putting a grain of rice on the first square of a chess board, two grains on the second square, four on the next and so on? That double and double again seemed to be the way her workload increased, although she ended up not with warehouses brimming over with rice, but no space in her diary for anything else. Certainly not a life. Or sleep. As Geoff called on his friends and former colleagues to volunteer their services for free, she ended up managing a team of more than 40 people.



We batted back and forth what we could do instead of dancing. One idea was to start with shots of hands playing the piano, and then other instruments. a slow reveal would show all the players to be Jeremy Paxman. Only JP was distinctly frosty about the whole plan, and in keeping with his role as the team's curmudgeon would have nothing to do with it.



We need some movement so what about exercise? Surely the Judge, so proud that he can 'do the plank' the length of a Taylor Swift song, might be up for that. The solution came when Gillian and her husband Mike were giving me a lift through central London and we rang Paul from the car to thrash something out. The breakthrough came as we drove by Marble Arch and Paul hit on a story which gave us a structure – the idea of a Parky making their perilous Parkinson plagued journey to an exercise class. Hallelujah. He is a script writer after all. It was around this time that Rory and Nick came on board. Jeremy was not persuaded (and still isn't).



Hattie then tells us a music company's idea of 'fairly cheap' was a thousand pounds. This was a low blow, but it didn't end when we agreed to cough up the cash. Universal didn't just want to vaguely check the new lyrics didn't do any harm to their product. It seemed on occasions that Hattie had to go back every time a single word changed. They weren't being obstructive, just oh so slow. We weren't the first 'artistes' to find the avaricious bureaucracy of the music biz clashing noisily with the messy creative process but it was another distraction, another few grains of rice on Hattie's chess board. Still, the signals had switched from red to orange – proceed with caution. This positive news means Hattie has wrecked her summer. She just doesn't know it yet.



The first time I was really convinced that our precious, precarious fledgling was really going to fly was when we all five us, plus Geoff, Hattie and a few Parky friends got together in a professional music studio, somewhere in deepest Sussex, an annex built on to the delightful home of James Morgan (himself a Parky) and Juliette Pochin. It was also the one that gave me the biggest thrill. As a huge music fan for decades I've swooned over shots of my favourite artists, behind a glass screen, headphones on, belting out their latest tune into an oversized microphone. Now I was doing the same. Me ! I can't hold a tune and suspect I am tone deaf. I only have to attempt 'Happy Birthday' and I clear the room. But there I was, if not singing, croaking and yelling my solo lines, while James and Juliette calmly gave instructions and advice. In fact I was so excited by the prospect I had dressed up specially: black collarless shirt, tasteful mustard coloured velvet waistcoat and wraparound blue mirror shades. I thought I looked rather cool, just like the ageing rock star I'd like to be rather than the ageing Parky ridden podcaster I in fact am. I was only brought down to earth with a clatter when the group photo was being taken and Hattie quietly but firmly said 'Mark, take those glasses off' in a tone that reminded me she was the mother of two mischievous little girls.



The best news of the day however was how enthusiastic our previously recalcitrant colleagues had become. Nick the Judge has a fine baritone and loves the sound of his own voice so clearly enjoyed himself, even though it wasn't either of his two great loves, Wagner or Taylor Swift. Rory said he was reassured by the professionalism of the whole operation. I don't think he meant my singing.



The demands on Hattie's time were growing as 'project Survive' took on a life of its own. Various demands and instructions were flung out which sound oh so innocuous until someone has to make the word flesh. To take one line in the lyrics 'I can't get on a bus or train' – which immediately conjures up a visual image. A simple, easy, potentially humorous way of illustrating the difficulties of travelling when you've got Parkinson's. Not as tricky it turns out as getting permission from the railway authorities to film on their premises. Let alone arranging for a train to be out of service and still long enough to be part of the repeated shots and angles necessary to the action. Once that plan hit the buffers and Hattie had wasted hours on it, the alternative was obvious; use a bus instead. Not as dramatic as there are no doors to clang shut, but it still works. It turns out that if filming in a station is hard, it is almost as difficult on the street. The Council needs to give permission and of course, a licence. Then there's health and safety to think about. And public liability insurance. So OK, forget the bus.

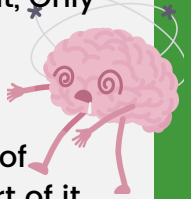




You can make the same point with a lift. Surely loads of buildings in London have lifts, how hard can that be ? Again, quite hard. Once you've located a suitable lift in a suitable building, you have to work out who owns the building and getting their permission and to again quote those lyrics , "...we need it soon – okay, not tomorrow morning, but tomorrow afternoon". As Hattie's summer disappeared into the greedy maw of the Movers and Shakers ambition, she discovered to her cost the price of being super-efficient. Everybody becomes convinced that you can do ten contradictory things at once. And you can. And do. And sleepless nights ensue.

Finding a suitable venue for the main event wasn't easy either. But once a suitable village hall had been located, not too far from London, the fun could really start and it was fun, great fun. We arrived at the hall to find the tiny space already jam packed with camera crews, monitors, clapper boards and the commanding presence of Geoff.

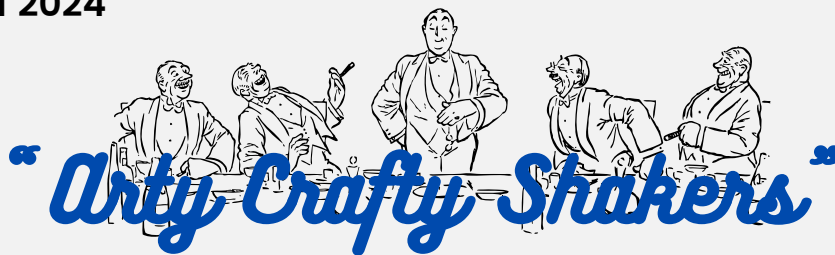
Gillian, Rory and I are veteran TV performers, but on the news, which is very different, Only its not.



Geoff had warned us that it would be a tiring day, with lots of hanging around, lots of repetition and retakes of lines and scenes. In fact we are all pretty used to that part of it and it felt by contrast a liberation. As the main reporter on a TV piece, you are in charge, responsible, constantly looking out fnew lines, new angles and fresh opportunities. Here everything was set in stone before we even set foot in the building -we had our lines.

It didn't stop me thinking 'wouldn't it be better if ..' and "how will that cut with this?" until I realised I didn't have to fret. We could hand all the worry to others. Some of the tension fled from Hattie's face. The huge professionalism of the team and the large safety net called Geoff under us meant we could relax. All that sprang from a sleepless night and a determination to help other Parkys while having a laugh was about to reach fruition. So enjoy and please support our efforts. [Find out how on our website.](#)

## Mark Mardell 2024



*Some of the work produced by our Arts and Craft group "Arty Crafty Shakers" is now displayed in a virtual art gallery on Instagram. If you are interested in viewing some of these works just click on the Arty Crafty button on the [PCIT Instagram page](#).*

*The group is open to everyone, is free to join and meets on Tuesday lunchtimes between 12:30 and 1:30 in the Pavillion. It is as much a social gathering as an Art group with a cup of tea and encouragement and advice from fellow members always available. Materials are provided and most participants are self taught so no expertise or previous experience is necessary.*



# GARDEN TRANSFORMATION

The transformation of the garden at Woodlands has been incredible and much of this is due to the efforts of Speech and Language therapist Laura. While walkways have been cut short to allow ease of access, other areas have been left uncut to encourage wildflowers and wildlife.

Many members and staff have commented that the garden is now a pleasant place to sit and relax.



We are also very grateful for pending donation from Shepherd Neame Brewery who are very generously donating some refurbished beer barrels to us to use as planters in our therapy gardens. We can't wait to put them to good use!



Further gardening challenges lie ahead with PCIT's expansion into the Tanglewood buildings and surrounding gardens.

These gardens are somewhat overgrown and are in need of care and attention so plenty of gardening opportunities await us and we look forward to having some of you join us.





# Peter Roger's Duodopa Journey



Pathway champion Peter Roger is a well known figure at PCIT. Peter was diagnosed with Parkinson's in 2007 and had recently suffered from frequent periods of freezing when his medication started to wear off.

Unable to increase his prescribed dosage any further, Peter became the first patient at Kings Hospital (and one of the first in the UK) to receive a new therapy, Produadopa. This involves a small pump, that is worn on the body, and which delivers two drugs (Foslevadopa and Foscarbidopa in liquid form), under the skin. This procedure does not involve invasive surgery and Peter was able to leave King's the same day



As an early adopter of this new therapy, during the first couple of weeks Peter experienced ups and downs as the levels of drugs were adjusted and he was weaned off the tablets he had been taking for many years.

As levels have stabilised and Peter has become used to the new therapy he is reporting genuine signs of improvement in movement and sleep, in particular. As his confidence grows he has started to walk without a stick and he is very pleased with the outcome, so far. Having been absent from PCIT for a number of weeks, Peter is keen to return and get involved again.



# The Importance of Sleep

**“Sleep is the best meditation” - the Dalai Lama**

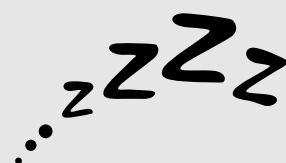
A good night's sleep is widely accepted as important to your wellbeing and scientists have discovered a specific reason why that may be that could be helpful in developing future therapies for neurological disorders

Discovered as recently as 2013, the glymphatic system is responsible for removing waste matter that builds up in the brain. This system uses cerebrospinal fluid to wash away the waste, such as protein tangles, that have been implicated in a number of neurological disorders. This system operates most effectively whilst we are asleep. Research into exactly how this mechanism works is ongoing but it offers another approach to scientists looking for better treatments for neurological disorders.

In recognition of the importance of sleep, PCIT held a well attended Sleep Workshop on the 12th September. The workshop was led by **Professor Gurprit Lall** (who is a Professor of Neuroscience at the University) and assisted by his colleagues. As well as informing those present about sleep related issues, they collected information about attendees' sleep problems in order to prepare for the **Sleep Clinic** that they intend to set up in the New Year in the newly acquired Tanglewood buildings.



**News about our  
forthcoming sleep clinic  
at Tanglewood is coming  
soon**





# PCIT

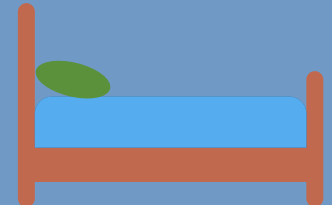
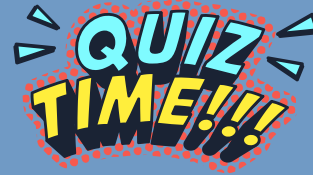
Parkinson's Centre  
for Integrated Therapy

# Fighting Fit Weekend

A Residential Weekend run by PCIT and Parkinson's UK

The weekend of September 6,7 and 8th saw a group of people with Parkinson's – some of them PCIT members, get together for a weekend of education, activities and social events at the University. The weekend was a great success and a number of activities and events were led by PCIT staff, therapists and members.

There are plans to host more such weekends at the University.



## PCIT Promotional Video

This summer has seen PCIT very much in the spotlight with crews from the BBC filming at Woodlands that appeared in both local (South-East) and national programs. This was followed by two further days of filming by a couple of ex-BBC staff, Mike and Poppy, who have moved into the area and have started their own production company, *Outpost Pictures*. Mike and Poppy have produced videos for PCIT that will be invaluable for promotional, educational and fundraising purposes. You can view the promotional video by [clicking on this link](#).



# Telephone Befriending



Work is already underway to develop

a PCIT telephone befriending service. This service will be primarily targeted at members who, for one reason or another, face challenges in accessing the Centre as much as they would like, but wish to maintain contact with PCIT. The service will be provided by trained volunteers who are also members and will therefore be most able to relate to others with Parkinsons'. It is planned for this service to be introduced in the coming months.



## *Singing App*

For those who have enjoyed our recent singing sessions and even those who missed them there is now an App available, specifically aimed at people with Parkinson's. This App allows users to join in sessions of vocal exercises as well as group singing remotely. This App has been developed In partnership with Arts Council England, Britten Pears Arts, Trinity Laban and Sing to Beat and can be downloaded on to your phone or tablet, If you are interested, [click on this link.](#)





# PCIT TIMETABLE

## MONDAY

- **Neuro-physiotherapy** with Helen, 9.30am-4:30pm - Woodlands CT2 7LR

## TUESDAY

- **Speech and Language Therapy 1-1** appointments with Laura, 9.30am-4.30pm - Woodlands CT2 7LR
- **Exercise class** with Sarah (higher impact), 11am - Pavilion CT2 7SR
- **"Arty Crafty Shakers"** (free of charge, no booking required), 12.30pm-1.30pm - Pavilion CT2 7SR
- **Seated Neuro Circuit Class** with Sarah, 2pm - Pavilion CT2 7SR

## WEDNESDAY

- **Acupuncture** with Paul, 9.30am-3.30pm - Woodlands CT2 7LR
- **Seated Dance Class** with Melanie, 10.30am - Woodlands CT2 7LR
- **Relaxation Class** with Melanie, 11.30am - Woodlands CT2 7LR
- **QiGong/Tai Chi Class** with Paul, 4pm - Woodlands CT2 7LR

## THURSDAY

- **Reflexology/Indian Head Massage** with Kathryn (1st and 3rd Thursdays of the month only), 9.30am-4.30pm - Woodlands CT2 7LR
- **Thursday Fitness Class** with Sarah, 10am - Woodlands CT2 7LR
- **1-1 Personal Training** with Sarah (1h slots), 10.30am-4.30pm - Woodlands CT2 7LR
- **Enjoyment of Movement** with Melanie, 3.30pm - The Dance Studio CT2 7NL
- **Therapeutic Horticulture** (by arrangement with Laura) - Woodlands CT2 7LR

## FRIDAY

- **Relaxing Massage** with Jo, AM only (additional slots available, please check Facebook and email as and when available) - Woodlands CT2 7LR
- **Initial Assessments** slots
- **Counselling** (available to PCIT members and partners - separately), Tuesday to Friday as per appointment made by Counsellor

## BOOK NOW!

Call us at 01227 824775 available from 9 a.m. to 5 p.m. Monday through Friday, or email us at [parkinsons@kent.ac.uk](mailto:parkinsons@kent.ac.uk)

Your PCIT Champions are:



Peter Roger: email  
[peterroger@btinternet.com](mailto:peterroger@btinternet.com)

PSG  
PATHWAY SOCIAL GROUP



Francis Ball: email  
[francisball09@gmail.com](mailto:francisball09@gmail.com)



<https://www.kent.ac.uk/parkinsons>



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# Christmas is coming!

Calling all PCIT members - if you have not done so already, please RSVP to your email about our Christmas Celebration - we hope to see as many of you as possible



**Raffle**

**PCIT** Parkinson's Centre  
for Integrated Therapy

INVITES YOU TO A

# Christmas Celebration

CHRISTMAS QUIZ  
WITH PRIZES

ON FRIDAY 13TH DECEMBER  
11.30 - 3.30 AT TANGLEWOOD,  
UNIVERSITY OF KENT CAMPUS, CT2 7LX

Live Christmas  
Singalong with  
 THE SMILING  
SESSIONS

'BRING AND SHARE'  
BUFFET

RSVP to [parkinsons@kent.ac.uk](mailto:parkinsons@kent.ac.uk)



 THE SMILING  
SESSIONS  
are coming to visit!

**FRIDAY 13th DECEMBER**  
**at 2pm at Tanglewood**

Please come and join The Smiling Sessions  
for a fun Christmas Singalong.  
Sing all your favourite songs & share a cup of tea & mince pie!  
Songbooks will be provided, so everyone can join in.



Address: Tanglewood, Canterbury Campus, Giles Lane Canterbury Kent CT2 7LX

     Parkinson's Centre  
for Integrated Therapy  SHAPESHIFTER