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PARKINSON'S^{UK}
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The Park

Magazine

SEPTEMBER 2018



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GUILDFORD AREA BRANCH MEETINGS 2018 - 2019

Meetings are held at Shalford Village Hall from 1.45 pm

September 25th 2018	Bowling on the green with Shirley followed by cream tea. All equipment provided, wear flat shoes. Sue Buckland will also introduce Parkinson's Pilates
October 23rd 2018	Quiz and games afternoon. Come along and enjoy a social afternoon with your fellow members, Join in a fun quiz
November 20th 2018	Katherine Crawford, Director PUK and Network Services
December 7th 2018	In the Mood, Christmas Lunch at Broadwater Pavilion, Godalming—home of the Guildford Rugby Club. (see P14 for further details)
January 22nd 2019	Dr Natalie Riddell, a member of the Surrey Healthy Ageing Research Partnership
February 26th 2019	AGM
March 26th 2019	Di Cheeseman of Age UK Surrey
April 23rd 2019	Parkinson's Pilates - Sue Buckland
Cover photograph	RHS Wisley in October—Jo Folkes

Introducing the new Chair.....

A warm “hallo” to all members, family and friends of the Guildford and South Surrey Branch. As some of you know already, I took over as Chair of the Branch on 1 May 2018 and have been made very welcome by the committee and by those of you I have met at Branch meetings and other events.

A bit about my background. I was born and brought up in Surrey and now live “just up the road” in Wimbledon, though am back regularly to visit friends and family. Since taking on my current role, I seem to be constantly up and down the A3! I spent my career working for the Civil Service in central London, retiring from the Department for Transport in 2010. After that, I did various things including some time volunteering with the Citizens Advice Bureau, and serving as a trustee for two different small national charities.

Why Parkinson’s? Sadly, a close family member, my best friend, and my brother-in-law have all been diagnosed with Parkinson’s in recent years, which have made me very aware of the effect of this condition on individuals and their loved ones. When the Chair of this Branch became vacant, I was looking for a new challenge and it seemed like a good opportunity to become more involved with Parkinson’s.

First impressions? Very positive! The programme of activities and events for members is impressive, and the committee and other volunteers untiring in their efforts to give as much support as possible to those who need it. Of course, we have been helped by the wonderful legacy from Florence Pite, which is enabling us to offer such a range of therapies and social opportunities.

My priorities as Chair? Keeping up the good work already in train, but also taking stock of which activities are the most valuable, whether there are any gaps in our programme, and how to plan for the future. The legacy will eventually come to an end and we will need to decide whether to raise money to continue just as we are, or whether it is time to move in a different direction. I am so pleased to have such a knowledgeable and active committee to help me.

What can you do? Don't be backward in coming forward! All feedback on how things operate at present is very valuable, and any suggestions for change very gratefully received. At some point, we will have to ask more formally for your views, but in the meantime please pass them on anyway. If we don't know what you want, we cannot provide it!

I am looking forward to the events planned for the Autumn and Winter, and meeting more of you there. And if anyone would like to get more actively involved in any capacity, no matter how small, then do contact me or anyone on the committee.

With very best wishes

Niki



Niki Tompkinson, Chair, Guildford and South Surrey Branch.

DATA PROTECTION

New data protection regulations came into effect on 25 May 2018 to give all of us greater protection when our personal details are stored by organisations. Charities like Parkinson's UK, and the local Branches, are no exception to this and have to ensure that membership lists and other personal information are stored securely, and that individuals have consented to their data being used for defined purposes,

All Parkinson's Guildford and South Surrey branch members who are not Parkinson's UK members were contacted in June, asking for consent for us to continue to communicate via email or other means.

In line with Parkinson's UK policy, any members who had not renewed their consent by 31 July 2018 were deleted from the membership list and will no longer receive communications from us.

Members wishing to be re-instated on the membership list can do so by completing the form, either online or by post, which is available in the Branch membership section of our website.

STOP PRESS
BOOK FOR THE FARM VISIT
ON
SATURDAY SEPTEMBER 15TH
SEE DETAILS ON PAGE 16

Colour your life

A personal experience by Barbara Berks from Somerset

18 months ago I saw a neurologist, who was ‘visiting’ my hospital to help with a backlog of patients. He asked me what I thought was the cause of my right side losing strength and reacting slowly to my requests for movement. I replied that I thought it was Parkinson’s and he agreed with my diagnosis. He arranged for me to have an appointment with the local neurologist who confirmed my suspicion and set up a course of medication.

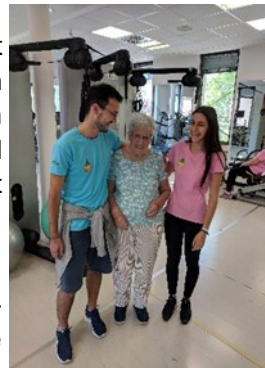
It was then that my daughter found the website for the European **Parkinson Therapy** Centre (EPTC). I followed her link and the quotation at the top of the web page hit me right between the eyes:

“We will see you in twelve months.”

Those were the exact words used by my neurologist at the end of my first 20 minute appointment! I was now a Parkinson’s patient whose life was turned inside out by what seemed a casual diagnosis. I was angry. I had suffered the pain and permanent discomfort of rheumatoid arthritis for the past 30 years, and I was now prescribed another set of pills to try to counteract the inevitable decline brought about by Parkinson’s.

My husband and I read the EPTC website again and again. Our two grown up children became insistent that we book up and go to Boario Terme in northern Italy. (Terme = spa town.) We reserved places in June this year. Just a week, but oh how we enjoyed the visit and how much better it made us feel about the future.

The EPTC literature and website describes itself as a unique specialised international centre for non-hospital treatment of earlier stage Parkinson’s. The Centre was set up 10 years ago by Alexander Reed, an Englishman married to an Italian diagnosed with Parkinson’s at the age of 46, who could not accept that being provided with a prescription and an appointment 12 months later was the only way forward. Alex developed a programme in collaboration with many internationally recognised practitioners from Europe and the USA and the work of the not for profit Centre is monitored by a panel of leading neurologists and researchers including from Parkinson’s UK.



Guests, not patients, from the UK and around the world, many from Italy who return regularly, stay in local, subsidised, quality hotels on full board (the food was delicious!). Dedicated qualified therapists provide one to one sessions daily with each participant undergoing an evaluation to focus the therapy on individual needs. The philosophy of the Centre is simple – make people stronger thanks to a better knowledge of Parkinson's and show, through therapy, how to be better physically and mentally. The friendly, warm welcome received from all who work in the Centre helped to re-inforce this simple message.

Our week took the form of a daily one and a half hour gym session with the allotted physiotherapist, in my case a charming 27 year old male called Pietro, who made it fun as well as hard work. Each day there were further sessions to attend on nutrition, speech, psychological approach, and relaxation techniques including massages. There was time to enjoy the free access to the park

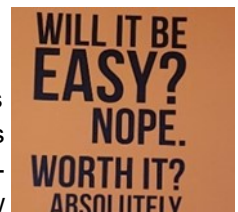


behind the thermal baths or enjoy the spa facilities and to explore the area around Boario.

The Centre's protocol is based upon the 4 Pillars that create a good quality of life

- Lifestyle
- Physical activity
- Medicine
- Psychology

You learn a lot about 'neuroplasticity', the ability of our brains to adapt to new circumstances, and about positive versus negative thoughts. Certainly we left Boario with a very different mindset based upon hope and an acceptance of how things are and could be – we are now on a slower train than before but heigh ho! We can see clearly out of the window and even spot things we never noticed before!! We are planning a return visit.



<http://www.terapiaparkinson.it/en/>

The following poem was written by Peter Taylor, a member of the Working Age Group

DOPE, DOUBLE-DUTCH AND THE DEVIL'S APOTHECARY

An old friend brought dope to spread on New Year's Eve, a levodopa proxy which looked, but did not taste, like butterscotch tart I'd loved at school. Handmade by his high street acupuncturist (who else?), images swirled of a dozen dainty needles quivering in his corpulence, laughing in anticipation of welcoming the New Year in a, shall we say, happy frame of mind. As it happened, the dope was left until the morrow – I have to say, no sorrow in that, though some assumed I'd polished it off, scoffed the lot, when I was found in a dark and quiet room, flat on my back and laid so low, a worn-out doormat silently praying for the pain to go.

As if the might of Mirapexin, Madopar and Mirtazapine were worth no more than a row of beans. I call them my three *femmes fatales* (for a laugh, ha-ha!), my three sirens, the last a 15 gram happy tab which my quack insists I shouldn't exceed, however great my need to feel just a little bit happier than we'd agreed. That's not to say there's no good reason – note the double-negative this world seems keen on – to beware gambling addiction or the too-frequent sinking of most things worth drinking. And, thinking of illnesses found to be down to the drugs, not Mr P, the devil's crazy apothecary, it's hard to feel confident, clear-headed, care-free.

And so, for me, Azillect, Amantadine and Entacapone have come, bugged me up and then moved on – like some of our quacks we sack because they cancel, don't turn up or, if they do, pay scant regard to the customer, you. (I should add here that, while some may fear and fret about my guy, my flashy sportscar friend, I find him fine to deal with, if not exactly kind – unlike the staff of The Parrot pub, to whom thanks are ever due.) But let's not get bogged down by relativity between the doctor's science and the landlord's art, we need them both, if ever anything were true, to help us get the real issues out on the table and resolve them as neatly as we are able.

Issue: is there a chance of our seeing the world through before and after eyes – and so being the wiser for it? **Check.**
Issue: is there a chance of meeting people we would not have met – and so join the lucky set? **Check** – just look around.
Issue: is there a chance of our learning humility – and so being heard by people who want to hear us? **Check** – they will find our quiet.
Issue: is there a chance of knowing the glow and full measure of our carers' love? **Check** – again, just look around the room.
Issue: is there a chance of rebuilding our upturned lives? **Check** – there's no better time (I like to think I'm rewriting mine).



Peter started writing poetry in 2012, 5 years after retiring as a City lawyer, despite having intended to start earlier. In those intervening years he walked the Camino trail in Northern Spain, and, in 2011, was diagnosed with Parkinson's. The one event helped him prepare for the challenges of the other, he says, by teaching him about "patience, perseverance and the essential commonality and unity of all human beings." Writing poetry about things he feels passionate about gives him a real sense of achievement. As he puts it: "Parkinson's needs to be salt and peppered regularly with that sense of achievement.....Poetry will become, for many of us, the real/the best/the only medium for our messages – and we Parkies do need to be heard."

PARKINSONS PILATES - A sitting and standing Pilates class that is very different from a normal Pilates class. All the exercises are specifically designed for Parkinson's to improve movement, rigidity, tremors, balance and much more, suitable for all levels

Classes take place at the British Legion Hall, West Clandon (opposite The Onslow Arms) Wednesday's 1.30pm & 2.45pm, plenty of parking outside the hall. If you would like to know more please contact Sue Buckland Tel: 01483 285111 Website: www.pilatesperfection.co.uk email:sue@pilatesperfection.co.uk

Research into “freezing” in Parkinson’s sufferers.

Dr Will Young (Brunel University)

Will began his talk by telling everyone about his background as a Sports Psychologist, from where he had found his way into Parkinson’s research. He explained that he has been looking at issues around posture and gait and particularly the impact of anxiety and freezing in people living with Parkinson’s.

He described the inspiration for his most recent research project which was an experiment conducted in Italy looking at the motor neurone centre of the brain. It had been discovered that viewing someone carrying out an action (in this case a monkey picking up a banana) can trigger a reaction in the corresponding part of the brain in the person that sees it: these are called ‘mirror neurones’.

Will began looking into whether this concept could be applied to Parkinson’s and the prevention of freezing. Early tests showed that listening to the sound of footsteps on gravel gave a 20%-30% improvement in keeping moving without freezing, but this didn’t translate well to the real world. People found it very intrusive and the action of walking is too variable.

With funding from Parkinson’s UK Will then began a project training people to *imagine* the sounds of footsteps: this was still very intrusive and unpopular with participants but did show some evidence of working. Finally, Will decided to focus on the fact that some people can feel freezing about to start 2-3 steps before it happens and asked if it would be more productive to look at ‘getting people going’ and preventing falls, rather than trying to prevent freezing altogether.

Working with another Sports Psychologist (and former cage fighter!) from Exeter, Will has been looking at techniques to use cues to get people to shift their weight onto the moving foot. He gave examples of imagining you are balancing on scales, or ‘Wobbling like a Weeble’, swaying like a tree etc. and used these with participants to develop new techniques. Participants in the experiments tried out a range of techniques while wearing Virtual Reality Headsets and attached to climbing ropes.

The results from the study were just in and are showing it has been very successful and that it can be translated into real-life situations. Will was keen to find out from the group what next steps the project should take and the best way to disseminate the information via Parkinson's UK. Options included developing information flyers, producing a range of videos and tutorials on the cueing strategies which could be made available online or even taking the training out 'on the road' to different groups and venues.

The way forward is now being considered by Parkinson's UK. Watch this space!

PARKINSON'S UK MEMBERS' DAY and AGM

Saturday 20 October 11 am – 3.45 pm

Conference Aston, Birmingham B4 7ET

For further details, please visit parkinsons.org.uk/agm

or email agm@parkinsons.org.uk

‘What is Crossroads’?

June Members Meeting reported by Myra Newnes-Smith

At our monthly Shalford meeting in June we were a smaller group than usual, which was probably due to the hot weather and holidays. However those members in attendance were treated to a very informative talk by Jenni Pringle on Crossroads Care which was followed up by a very useful open question and answer session and then there was finally a chance for individual chats with Jenni.

The service is named after the soap opera ‘Crossroads’ as the programme makers donated money to set up the pilot scheme in 1973 in Rugby. Crossroads has been providing vital respite breaks in Surrey for over 36 years.

The core service provision after an assessment of needs is as follows-

A regular Carers break of 3.5 hours funded through Crossroads by SCC on a weekly or fortnightly basis on the same day, at the same time and with the same Support Worker. Additional hours can be provided at a competitive rate.

Self-funded packages are available of 10, 24 and 48 hours, the latter to allow for a weekend break. A recent introduction is for Assisted Holiday Breaks where a Support Worker accompanies the client and carer on a UK based holiday and takes over the caring role for 9 hours in any 24

Support Workers are not volunteers and many have worked for Crossroads for a number of years. They are highly committed to their work and trained for many caring tasks.

Activities undertaken include –

- Personal care such as washing, dressing and toileting
- Health care procedures such as continence management and administration of prescribed medication if appropriate
- Meal and drink preparation
- If preferred just chatting, playing games or a visit out to a tearoom

For further information

Tel: 01372 869970 or enquiries@crossroadscaresurrey.org.uk

If in future you are interested in the additional 3 hours per month, mentioned in the last edition of the Park, (on offer for 10 people per year and funded by the legacy money) please do not go direct to Crossroads. Please contact Jackie Wingrave (Parkinson's Local Advisor) for a referral on Tel:0344 225 3669

Walk for Parkinson's - Richmond Park 2018

Why not join a Walk for Parkinson's around the beautiful Richmond Park.

Event start date and time: 21 October 2018 - 10:00 AM

Signup fee: £10 for adults and £5 for under 16s

Sponsorship: £50 suggested.

Every year millions of people visit Richmond Park, the largest of the capital's eight Royal Parks and the biggest enclosed space in London. The park is home to the beautiful Isabella Plantation, Pembroke Lodge and herds of red and fallow deer. With a choice of two routes – 2 or 5 miles – there really is something for everyone.

For further information see: <https://www.parkinsons.org.uk/events/walk-parkinsons-richmond-park>

Report on the Cream Tea on July 17th by Angela Campling:

A delicious afternoon cream tea was enjoyed by 64 members, their friends and families, at Guildford Golf Club, on a beautiful sunny June afternoon, with the glorious outlook over the North Downs. It was a pleasure to have 12 member of the 'Working Age Group" join us and a big welcome to the members who have not attended any of our events before (please do come again)

We were joyfully entertained by Emily, Choirmaster of our 'Parkinson Songsters Choir' and 6 members of her other choir. They gave us a wonderful selection of songs including one Emily had written herself especially for our choir, a very talented lady and a big thank you to her and her friends.



This took place while we enjoyed a selection of finger sandwiches, delightful little cakes and cream scones, together with copious amounts of tea & coffee.

Towards the end of the afternoon the numbers were drawn for the lucky winners of our large and varied raffle prizes. We hope all that came along had a wonderful time and thanks for your help in raising £172



Partners Lunch Dates

September 11th, October 9th, November 13th, December 11. 2018

The lunches are held at The Refectory, Milford between 12 - 2pm as a drop in to suit whatever time you can spare. However I do need to know if you are planning to come so that I can book an appropriate table. New faces are always very welcome.

The number of partners attending the lunches has fallen and I am aware that the second Tuesday clashes with the Losely lunch. Please could you let me know if you would like to attend but are prevented from doing so because the lunches are held on the second Tuesday of the month.

Myra@newnes-smith.com or Tel: 01483-422440

FARM VISIT - SEPTEMBER 15TH

Darren Dunkley, one of our Working Age group members has invited us to visit the farm where he cares for and milks 500 cows.

We can meet at **12 noon** at **The Milk Churn Cafe**
The Brickworks,
4, Lynwick Road.
Rudgewick
Horsham
Sussex. RH12 3DH

See www.brookhams.com , click on Milk Churn to see the delicious food available

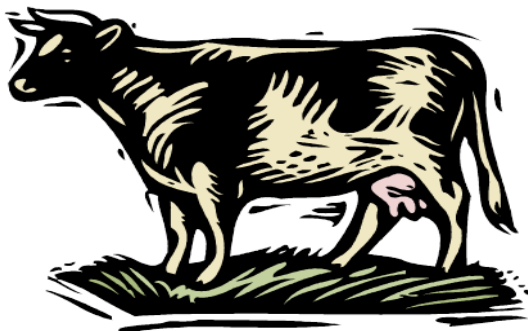
At 2pm we are due on the farm with our wellington boots to see the calves etc

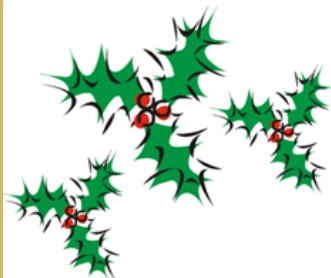
Some of Group went last year and thoroughly enjoyed it.

See last January's Park magazine page 7

Darren was the member who abseiled from the Cathedral tower and so we should like to support him.

He milks the cows twice a day 4.30am "ugh" and again at 4 in the afternoon





Make a date in your diary for the

Parkinson's Christmas Lunch

Friday 7 December 2018

at

Broadwater Pavilion

Home of Guildford Rugby Club

Guildford Road Godalming GU7 3DH

£15 including wine

Please return the enclosed reply slip to Mrs Margaret Westwood by **FRIDAY 19 OCTOBER 2018**.

You will then receive a menu as acknowledgement which you should return with your choices together with a cheque made out to The Parkinson's Disease Society Guildford

NO LATER THAN 7 NOVEMBER 2018



Walking and Tramping in Derbyshire and Devon

By Myra Newnes-Smith.

As mentioned before, in last September's edition of the Park, my husband Roger owns a Trampler - an off-road mobility scooter. For a couple who planned to spend their retirement years walking and cycling the Trampler has been a great success especially as we live on a common with access to several neighbouring commons. However, despite the ability to visit several pubs for lunch and involving walks up to 10 miles, we wanted to venture further afield.

Armed with research on the internet and help from our supplier of the Trampler we had a list of places throughout the country where the vehicles could be hired. What we were looking for was sites where we could do long walks and Derbyshire fitted our criteria. Derbyshire County Council (DCC) run a scheme 'Access for All' and have Trampers for hire at six sites including on the Tissington and High Peak Trails which run along old railway tracks. A truly wonderful way to see the Peak District if your mobility is restricted.

Off we went in May and took full advantage of the scheme which was so much easier than trailing our own Trampler to Derbyshire. In addition to the DCC scheme there are many other options to visit. We particularly enjoyed Carsington and Derwent Reservoirs both owned by Severn Trent Water. (The latter not to be confused with the North East one of the same name or Derwentwater in the Lake District!), During the Second World War the reservoir was used by pilots for practising the low level flights needed for 'The Dam Busters' raids due to its similarity to the German dams.

Following the success of this trip we then headed to Devon at the beginning of July. In the South West there is a charity 'Countryside Mobility' which runs a similar scheme covering Cornwall, Devon, Dorset and Somerset. The highlight of our Devon visit was the Granite Trail. Again this is on an old railway track which runs from Okehampton to Lydford

and crosses the spectacular Meldon Viaduct with its wonderful views of Meldon Dam and Dartmoor beyond.

Since these trips we have visited Sheffield Park (NT) in East Sussex and they have a two seater mobility scooter which enables a carer to drive the scooter if necessary. The water lilies were amazing and we plan to return for the autumn colours which are apparently spectacular.



Finally we have discovered a website for Disabled Ramblers so maybe the next issue of The Park.....!

Derbyshire County Council : Access for All

Carsington Water Visitor Centre: Tel: 03306780701

Derwent Reservoir Tramper hire:Tel: 01433 651261

Countryside Mobility: www.countrysidemobility.org

Sheffield Park NT:Tel:01825790231

PD Movers and Shakers

Those members who attend exercise classes regularly recently celebrated our second birthday.

It is a tribute to Melanie and Sam's enthusiasm and skill that we have grown from one class to six. Very few have fallen by the wayside as most find it enjoyable and very helpful and there is plenty of evidence to confirm the value of exercise in PD –see www.parkinsons.org.uk/information-and-support/parkinsons-exercise-framework for suitable exercises for people with Parkinson's,



Our Chair has received information about a programme for younger people of working age recently diagnosed with Parkinson's Disease from Peter Miller.

Peter writes: *My wife was diagnosed 4 years ago at 57 - she works a part time teacher.*

*Together with friends, and supported by Parkinson's UK, we have launched **Fighting Fit**, a residential weekend programme for younger and working-age people with Parkinson's.*

This activity is not-for-profit and is being run by healthcare professionals and people with Parkinson's on a voluntary basis.

If you want to find out more, please go to our website <https://fighting-fit.org.uk/home/> where you can either [contact us](#), or sign up to our [newsletter](#).

**New weekend residential course for younger and
working-age people with Parkinson's**
14:00 Friday 9th until 15:00 Sunday 11th November, 2018
Holiday Inn, Weston Turville, HP22 5QT

For people who have come to terms with their diagnosis (and partners if desired) wanting to take control and improve their wellbeing and working life.

Aims:

- To inspire healthy lifestyle choices to help maintain physical and psychological wellbeing.
- To build knowledge about how to take control of Parkinson's.
- To share concerns and anxieties in a 'safe' environment.
- To involve partners (if desired), to stimulate and have fun.

Outcomes:

- Make new connections and friendships.
- Develop fresh approaches and new skills for working life
- Get information and signposting specific to working-age people
- Encourage exercise and reinforce its importance as medication.
- Develop a personal life plan for ongoing review.

Be inspired, motivated and empowered by experts and other people living with the condition. Try out new forms of exercise and activities. Become more informed and join in discussions about the key issues affecting working-age people.

The pilot will cost £250 for a couple and £150 for a single.

**The availability of places for the pilot is limited,
so please don't delay in responding.**

Useful Information

Parkinson's Local Advisers

Runnymede, Surrey Heath, Waverley and Woking

Jackie Wingrave 0344 225 3669

Reigate, North Tandridge and East Surrey

Nicky Lawrence-Gravestock 0334 225 3743

Mole Valley, Dorking, Kingston, Spelthorne, Elmbridge, Epsom
and Ewell

Emma Southwell 0334 225 3772

Mid Sussex, Tandridge, Horsham, Crawley and

East Grinstead

Carol Coupe 0334 2253686

Parkinson's Nurse Specialists (NHS)

South West Surrey, Milford Hospital

Amanda Dodson 01483 782750

North Surrey. Farnham Hospital Outpatients

Rose McKinley 01483 738903

Parkinson UK Helpline Service 0808 800 0303

Lines open: Monday to Friday 9.00 am–8.00 pm

National Website

www.parkinsons.org.uk

Local website

www.guildfordparkinsons.org.uk

Don't forget to stay informed of classes, events, meetings and much more on our own Guildford website..