PARKINSON'S^UK
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

The Park

Magazine of the

Guildford and South Surrey Branch of Parkinson's UK

September 2024

The magazine of the Guildford and South Surrey Branch of Parkinson's UK

* Cover is of **Thorufoss (Þórufoss)** Waterfall, Iceland by Rona Lester. All copyrights are acknowledged

The Committee of The Guildford and South Surrey Branch would like to thank Oakleaf Enterprises for their efforts in printing and distributing this Magazine

TUESDAY AFTERNOON SOCIAL MEETINGS

Venue: Shalford Village Hall, King's Road, Shalford, Guildford, GU4 3JU

All Members (and non members) and their partners, carers, and family members are welcome to attend these monthly social meetings. These meetings are free of charge to attend. They allow you to meet new friends, learn from each other's experiences and often hear a guest speaker while having light refreshments.

2024	Main Presentation
30 January 2024	Quiz
27 February 2024	AGM
26 March 2024	Ruby Ho, Qualified Ba Duan Jin Instructor
30 April 2024	Hilary Reminisces
28 May 2024	Brooke Frances Rose Huxford (Research)
25 June 2024	David Pascoe (Benefits)
20 July 2024	Meeting replaced by Family Friendly Picnic
27 August 2024	No Meeting
24 September 2024	Lindsey Brown—Chair Yoga
29 October 2024	Drum Heads
26 November 2024	Lee Johnson 'The Life of a Personal Protection Officer in the Metropolitan Police'
3 December 2024	Meeting replaced by Christmas Lunch

Foreward from the Chair

Welcome, old and new members, to the September edition of *The Park*. This month's issue is packed with updates, insights, and a bit of reflection on what it means to be part of our amazing community. Our goal is simple: to ensure no one faces Parkinson's alone.

In terms of insights I want to talk about membership demographics. Alongside Keith Black, Membership Secretary, the Committee has worked hard to understand how many members there truly are in the Branch, how many are actively engaged and what the remainder of the membership want.

Before looking into the above, it is Important to define what membership actually is. We have come up with the following:

- Membership is best defined as someone who wishes to stay connected to the Branch and through this connection gain a sense of belonging and support
- The member should have a loose connection to Parkinson's
- Ideally, where the member and his/her family can, they should engage in subsidised activities, social events and fundraising as it increases their social interactions and builds community
- For simplicity and to ensure we can gain meaningful metrics it is helpful if we have a 'single membership record' for the member and his or her extended family group – one person should receive and pass on our communications
- As a Committee our main communication tools with the membership are:
  - *The Park*
  - The Chair's Monthly Newsletter
  - Adhoc communications
- There should be no stigma or view taken, irrespective of whether a member requests a Paper or electronic copy of *The Park*
- We should trust our members to do the right thing both for the Branch's finances and the wider ecology of the planet

Some of you might be thinking, so what? Why are the Chair and Committee so fixated on defining what a member is? The answer is simple, the Committee is made up of a number of unpaid volunteers who get their buzz from helping people, especially those with Parkinson's. We believe in inclusivity and helping all!

Future editions of the Park will contain details of our analysis but the early observation is that there is parity in numbers between those who visibly take part in our activities and those who simply want to keep up with our communications.

Visible Engagement

- Exercise & Therapeutics
- Social Events
- Fundraising, XMAS Parties etc

Non Visible Engagement

- Positive gain from reading about Branch through The Park, Chairs Newsletters etc
- Never likely to take part in any activities

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May 2024

This reinforces our belief in the value of *The Park* and Chair's Newsletters. It also challenges us to ensure we look for improvements in the services we offer this segment of our membership. I expect this will be a big challenge as it's easier to add new services based on current activity models than to innovate a new disruptive approach. Irrespective of complexity we offer our pledge to try our hardest!

Being part of this community is special. Whether you're out there participating in events or just keeping up with our news, you're a valuable member of our Branch. Your involvement, in whatever form it takes, helps make our community strong and connected.

Thanks for being here and being part of something bigger. Here's to staying connected, supported, and always looking out for each other.

David Lowther

Christmas Time again!

Christmas is coming!

Well, not just yet, but please note that our branch subsidised **Christmas Lunch will be on Tuesday 3 December and at Broadwater Pavilion**. It will start at noon, with the meal served at 1.00 p.m.

As in previous years this will be a full three course traditional Roast Turkey meal with all the usual trimmings, with red or white wine, followed by coffee or tea and mince pies. For those who prefer something different or are vegetarian, there are alternate choices to turkey. There will be the usual Christmas crackers and optional wearing of silly paper hats!

The heavily subsidised price this year will be £27.50 per person for the member and their first guest. Additional guests are welcome, but they will not be subsidised and will need to pay the full meal price of £47.50 per person.

Could those of you who wish to attend either:

- email your name, address, telephone number, and any guest names to our Treasurer, Steve at: sheron@guildfordparkinsons.org.uk

or

- complete the Reply Slip included in the paper copy of The Park and post, including a stamped addressed return envelope (so we can send you a copy of the menu) to:

Mrs Margaret Westwood
Committee Secretary
Guildford and South Surrey Parkinson's Branch
60 Charlock Way
Guildford
GU1 1XZ.

You need to respond by no later than Wednesday 16th October to ensure you are included in this great annual event!

Once we have your response, we will note your interest and numbers of your planned attendees and ensure you get a copy of the menu choices as soon as available, and no later than October .

Understanding and Supporting Those with Voice Challenges

As we all know, Parkinson's disease is a progressive neurological disorder that affects movement, muscle control, and balance. One of the lesser-known symptoms is its impact on the voice. This occurs because Parkinson's disease affects the muscles responsible for speech. Over time, these muscles weaken, leading to a condition called hypophonia, where the voice becomes soft, hoarse, and difficult to hear.

For those living with Parkinson's, the voice often sounds normal to them, as it did in their younger years. However, to others, it may seem quieter, which can create communication barriers. Friends, family, and caregivers might find it challenging to understand them, which can lead to frustration on both sides.

A recent conversation at the Newly Diagnosed (‘ND’) Support Group got me thinking how I interact with those people with hypophonia. I have to hold my head in shame as I often pretend to understand in order to move on from the conversation. It seemed from the adhoc survey of the ND there was sympathy for my approach.

As the ND meeting was only last week I do not have an answer to how I should behave and what the redlines, defining the minimum acceptable behaviour should be. I plan to liaise with Celia Bacon who operates Loud and Clear for guidance. If anyone else has a ‘silver bullet’ approach then feel free to email me on dlowther@GuildfordParkinsons.org.uk with details

I will collate input and report back, either in the January Park or a Chair’s newsletter.

121 %

£1,215

raised of £1,000 target by 36 supporters

Congratulations to Hazel Davies, who In May 2024 trekked solo for 5 days, covering the first 47 miles of the Tamara Coast to Coast Way

The fundraising proceeds are going to be split between Parkinson’s UK and the Guildford Branch.

https://www.justgiving.com/page/hazel-davies-1705346858628

Welcome to our new Local Volunteer Officer
Zoe Sole

Hello there ! My name is Zoe Sole, Local Volunteer Officer (LVO) at Parkinson's UK covering Buckinghamshire, Berkshire, Oxfordshire and Surrey. Starting in March I still consider myself new in post, although unsure when the newbie title expires!? I am new to Parkinson's UK but have worked in charities for over seven years.

I first started working with People with Parkinson's as a Psychology graduate working as a research assistant at Hertfordshire University. At the time I was also a dance teacher and was very fortunate to combine my two passions in life working in a Dance Psychology lab. Here I worked on The Dance for Parkinson's Project with Dr Peter Lovatt and Dr Dawn Rose.

Since then I have mainly worked in mental health charities and although no longer teach dance, attend weekly classes. I am passionate about the wellbeing benefits not only of physical activity and the arts, but more generally in people having hobbies and purpose. Wellbeing is not one size fits all, so services should reflect this. Something I love about Parkinson's UK is the variety of sessions on offer including nordic walking, singing, snooker and mindfulness, there is something for everyone !

In June, I had the wonderful opportunity to participate in a PD Power session in Witley, led by the talented Amado and joined by David. The session left a lasting impression, not only because of the impressive turnout but also due to the diverse array of functional exercises offered. From boxing and chair-based exercises to dancing (a personal favourite of mine!) and cognitive reaction tasks, the session was clearly thoughtfully designed to cater to the unique needs of individuals with Parkinson's. It was evident how each activity was meticulously chosen to assist with various aspects of daily life, such as exiting a car, improving coordination, and enhancing gait.

Following the session, I took the opportunity to stay for tea and coffee while another group began their activities. I've always believed that these social interactions are as crucial as the physical exercise itself, and this occasion was no exception. It was heartwarming to witness the genuine support and friendships that have clearly been cultivated within this community. The experience has further reinforced my belief in the power of both exercise and physical engagement in enhancing the quality of life for people with Parkinson's.

When i'm not attending various groups and sessions, my role involves looking after our wonderful volunteers, without whom branches such as Guildford simply would not run. Across the area I cover we have around 150 volunteers giving up their time to run 20 branches. It has been a pleasure already to meet such fantastic and dedicated volunteers, and I look forward to getting to know them further. If you, or someone you know is interested in volunteering, you can contact me on zsole@parkinsons.org.uk or give me a call on 07842449295.

Zoe Sole

Ask a Consultant Neurologist

I had the opportunity to ask Dr Jeremy Stern, Neurologist, Frimley Health Trust, the following question and received the response below..

Question: "We know there is a lack of Consultant Neurologists and hence time in 1:1 consultations is precious. If there was one thing patients could do in preparation what would that be?"

Answer: The first aspect of any consultation is to identify the current medication management plan as prescribed by the GP. Accordingly, if the patient could come with a list of medications that would be extremely helpful.

Additionally, if appropriate, it would be helpful if the patient could come with a marked up 'non-motor symptoms questionnaire' (on PD-UK website)

Latest and Greatest support aids and other suggestions

Radar Keys

A Radar key allows disabled people to open locked accessible toilets all across the UK. The official solid brass key has a large head for easy turning for those with limited dexterity. Qualification is by self-certification.
It is available for £8 at shop.parkinsons.org.uk or £5.49 + VAT from the RADAR KEY company. www.radarkeys.org . Note, Disabled people may be entitled to claim Value-Added Tax (VAT) relief on disability goods and services that are designed for individual use.

Brownsea Island

The island has a Seahorse landing craft to provide access for wheelchair users and all-terrain manual wheelchairs for hire. To book Tel: 01202 492164
The Electric Bus Tour has one space for a wheelchair.
Prebooking is recommended tel:01202 707744
Reception, cafe and toilets are all accessible.
The Island, which is owned by the National Trust, is renowned for its Red Squirrels and for the birthplace of the Boy Scouts movement.

Countryside Walking

Trionic Veloped is an off-road Rollator which has big wheels with pneumatic tyres and powerful brakes. There is space for rucksack/bag and a pull-out seat if you need a rest.
Perhaps it is best to use Bridleways to avoid styles.

PALS (Patient Advice and Liaison) team at RSCH.

Some of our members have experienced a considerable decline in their mobility following a stay in hospital from a lack of exercise and others have not received medication on time. If you have any concerns contact the PALS team - https://www.royalsurrey.nhs.uk/patient-advice-and-liaison-service/

Compiled by Myra Newnes-Smith on behalf of the Branch.

2 WEDDINGS in 2 WEEKS on 2 CONTINENTS!

Sometimes things are out of your control – especially the timings of weddings. We received invitations to attend a wedding in Toronto and the NEXT weekend, one in Mallorca! We decided to plan to take on this travel challenge and go for it.

Our trip to attend the nuptials near the Canadian side of Niagara Falls was punctuated by a stopover in Iceland. Never having been there, we rented a minivan with our children and drove for 4 days. (The cover of this edition of The Park was from our recent trip).

I am amazed how accessible Iceland is. It turns out two years ago one of Iceland's riches entrepreneurs, Haraldur Thorleifsson, set up a programme to build 1500 wheelchair ramps by March 11, 2025. This made getting to the beautiful waterfalls much easier.

With the on-going volcanic eruptions near the Blue Lagoon, we were recommended to go to the new Sky Lagoon in Reykjavik. Turns out they built it with Accessibility in mind. They had installed a 'Pool Pod' with a special wheelchair to lower Robin in. Once in he used floating noodles as he can no longer swim. There were so many staff in and out of the water helping Robin, we could ALL enjoy the experience. They had even adapted their '7 step Ritual' for easy access. The sauna, mist, scrub, steam room and shower were wonderful. The thermal water really made Robin feel relaxed and we are now contemplating going back. We would highly recommend Iceland if you were looking for somewhere beautiful to visit. With Its eye on accessibility, Iceland will make your travel enjoyable for everyone.

The two weddings were amazing and I'm glad we made the effort. I just am so pleased countries are really making travelling with a disability easier!

Rona Lester

Saturday 20 July …a perfect day for a PICNIC!

Friends, neighbours, Mums, Dads and children joined members for the Picnic at Great Halfpenny Farm. While many competing activities were available in the vicinity, it was wonderful that over 100 made the effort to attend.

It was a warm day, but not *too* hot, so while the grown-ups enjoyed relaxing, the children ran around playing games and squealing with delight as they followed the Treasure Hunt trail. Not everyone brought a picnic - but there was an abundance of delicious home-made cakes available to buy with tea and coffee. Or a modestly priced Pimm's - generously crammed with fruit.

As in previous years the Tombola appealed to all ages - the possibility of a "win" pitched against the inevitability of disappointment. (Hope springs eternal.)

The afternoon came to a close with the announcement of the Raffle winners (see overleaf). And the final numbers on the music play-list - masterly compiled to span 50 years of "greats" - sent everyone home, happy!

David Lowther, Chair, when later interviewed reflected:

- Living with Parkinson's impacts the whole family and hence it is great that we can offer a social event for all. In particular it was lovely to see so many members and their grandchildren interacting in a safe environment
- I must personally thank all the people who helped make this a successful event. Particular thanks to Vicky Cooke and Rob Wood for organising and running 'The Pimms Bar', and to Peacocks Delicatessen who kindly donated the fruit!

- Thanks also to Charles Hope who responded to a social media post and provided an excellent and professional music system. He stayed with us all day and is willing to do the same for us next year!
- For those of you that have an electronic copy or a paper copy and the patience to type in a long string of letters/numbers, the following is a wonderful montage of memories from the event—https://hidrive.ionos.com/share/7lhd9mygfq
- In terms of fundraising the event was an enormous success in that over £1600 was banked for the event.

The following is a ditty from David (artificially enhanced by technology)

At Great HalfPenny Farm, on a sunlit day,
We gathered for a picnic, in summer's bright array.
The hills stood tall, the fields so green,
A picture-perfect landscape, a peaceful, lovely scene.

Sheep dotted the meadow, horses stabled nearby,
Beneath a vast expanse of clear, blue sky.
We laid our blanket, spread our feast with care,
Fresh eggs, bread, and jam, a bounty we did share.

With Pimms in hand, and cake to delight,
We savored every moment, from morning to twilight.
The tombola drew a crowd, five hundred eager faces,
Hoping for a win, amid the wide-open spaces.

Music filled the air, lively and grand,
We danced and sang, hand in hand.
Clare and John, our hosts so kind,
Created a haven, with memories intertwined.

As shadows lengthened, and the sun dipped low,
We packed up our treasures, hearts all aglow.
At Great HalfPenny Farm, under the fading light,
We embraced a summer's day, pure and bright.

Guildford and South Surrey Branch of Parkinson's UK
Registered Charity No. 258197
Promoter: Mr S Heron, Branch Treasurer, 11 Merrow Woods, Guildford ,GU1 2LQ

00101

Summer Picnic Raffle

1st Prize - 2 Nights at The Glasshouse, Great Halfpenny Farm, GU4 8PY
2nd Prize - Ride for 1 in Classic 1946 MG car
3rd Prize - Bottle 10 Year Old Bushmills Whisky

To be drawn on Saturday 20th July, at 4.00 p.m.

Registered with Guildford Borough Council
Printed by: Raffle Tickets 4U - www.raffletickets4u.co.uk

Ticket Price £2.00

Raffle Update

Loyal and popular branch members Fran and Colin Dorling were the lucky winners of the main prize of a stay at The Glass House at Great Halfpenny Farm. We hope they enjoy their stay in September. The property is well suited for those with mobililty issues having been designed for 'senior living' and indeed Clare's father, Richard, lived there in his later years living with Parkinson’s Disease.

2nd Prize, the ride in a 1946 MG Car went to Geraldine Earlam

3rd Prize, the 10 year old Bushmills Whisky was won by Rita Sully

Margaret Westwood, Clare Price

Disability and Benefits

On Tuesday 30 July we welcomed Dave Pascoe to our Monthly Afternoon Meeting at Shalford Village Hall. Through years of firsthand experience, Dave has become an expert advocate for disabled people to navigate themselves through the benefits system. While no document can explain all, the next few pages aims to provide a summary.

The Branch Committee would like to thank Dave for his support including allowing us to summarise his briefing documented below. As he himself acknowledges these summaries can only give a flavour and members need refer to the definitive documentation.

Introduction

The benefits system is complex, and the rules often change, so even if you've investigated it before, it might be worth checking again. ***Across the UK, between £12 and £15 billion is unclaimed each year.***

Getting started

- Some benefits are affected by earnings, other types of income and the amount of savings or capital you (and sometimes your partner) have. Others are not!
- As benefits can change, it's worthwhile checking regularly to see if you're claiming everything you're entitled to.
- Some benefits are affected by your circumstances (e.g. change in a claimant's age), so be prepared to regularly recheck your entitlement.

- If your Parkinson's symptoms progress it's worth arranging a benefits check,
- Many benefits overlap, so if you receive one there may be others that you can't get.

It's worth checking how the benefit cap might affect you. It's a limit on the total amount of benefit that most people can get between 16 and State Pension age.

Benefits available if you are still of working age:

1/Personal Independence Payment (PIP)

PIP is designed to support the extra costs of living with a disability. You can spend it on whatever you need, such as paying for support to remain independent during relapses, or to help with extra costs such as heating, transport or help around the house. It is not means tested in any way.

There are two elements to PIP: a daily living part if you need help with everyday tasks, and a mobility part if you need help with getting around. There are two rates for each part - standard or enhanced - depending on the level of your needs.

When you apply for PIP, for the first time, it will take in the region of 3-6 months for a decision to be made, including the assessment. If you are successful, your first payment will be backdated to the time you made initial triage phone call.

PIP is paid 4-weekly in arrears, unless you are receiving a Special Rules PIP for end of life support, which is paid weekly and in advance. So, in effect, you get 13 payments a year.

How long does PIP last?

- If you fit the criteria for a PIP award with no end date, this is called an ‘indefinite award’. If you have an indefinite award the Department of Work and Pensions (DWP) will usually review it every 10 years.
- If you don’t get an indefinite award, you’ll get PIP for a fixed amount of time – your decision

Claiming PIP
(Personal Independence Payment)

letter will tell you for how long. If you're terminally ill the award will be for 3 years.

- If you're awarded PIP for a fixed time of more than 2 years, the DWP will usually review your award before it ends. They'll renew it if they decide you can still get PIP.

Applying for PIP:

Applying for PIP is a well understood and structured process. Call the 'PIP new claims' phone line. You'll then be sent a form that asks about your condition. Complete and return the form. The address is on the form. You might need to have an assessment, if more information is needed.

How you complete the form is very important:

When applying for Personal Independence Payment (PIP), it is crucial to be truthful, honest and open about your condition and the challenges you face in your daily life. Accurate information is essential to ensure that you receive the appropriate level of assistance. Being truthful ensures that the assessment process is fair and that your needs are correctly understood and met. Misrepresenting your condition, whether by exaggeration or understatement, can lead to an inaccurate assessment, potentially resulting in insufficient support or even denial of your claim.

Reporting changes of circumstances:

It's important that you report any changes that could affect your PIP at the earliest opportunity. If you don't report a change, you could find yourself being charged an overpayment. https://www.citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/pip/pip-changes-and-reviews/changes-that-affect-pip/

2/ Disability Living Allowance (DLA)

Disability Living Allowance (DLA) is a benefit for disabled children under 16 and some adults who already claim it. It can help with the extra costs of everyday care and getting around. If you're between 16 and State Pension age and you already get DLA, you'll be reassessed for Personal Independence Payment (PIP) at some stage.

You don't need to do anything until the DWP contacts you, or if your circumstances change and you need to let them know about that.

3/ Unable to work & Statutory Sick Pay (SSP)

SSP is paid by your employer if you're too ill to work. It may be relevant if you have a job but are unable to work because of a relapse. It can be paid for up to 28 weeks.

4/ Employment and Support Allowance (ESA)

You can apply for Employment and Support Allowance (ESA) if a disability or health condition affects how much you can work. You can claim if you're in or out of work. But while you claim there are limits to the wages you can earn and usually, you can only work less than 16 hours a week.

5/ Universal Credit (General Advice)

Universal credit has replaced several benefits, for most people. You might be able to claim this instead of, or as well as, different kinds of ESA.

6/Jobseeker's Allowance (JSA)

You can apply for 'new style' Jobseeker's Allowance (JSA) to help you when you're looking for work.

Benefits available after you have retired:

1/Attendance Allowance (Post-retirement age)

If you’ve reached the State Pension Age and you have care needs, you might be able to claim Attendance Allowance. You don’t have to be getting help already. It’s the help you need that’s important.

If you started getting Disability Living Allowance (DLA) or Personal Independence Payment (PIP) before you reached State Pension age, you won't need to switch to Attendance Allowance.

2/ State Pension

For a full pension, an individual needs to achieve 30 ‘qualifying years’ – the number of years that you have contributed National Insurance payments.

You have until 5 April 2025 to pay voluntary contributions to make up for gaps between April 2006 and April 2016 if you're eligible. After 5 April 2025 you'll only be able to pay for voluntary contributions for the past 6 years.

3/ Free bus pass

Surrey County Council, the qualifying age is currently 66, unless you are in receipt of disability benefits or similar, in which case it can be issued independent of age.

Benefits irrespective whether you are still working or retired

1/ Council Tax Reductions

Council Tax reductions in England provide financial relief to eligible residents, including low-income households, individuals and those with disabilities

2/ Payments towards heating costs

Var

ious payments are available depending on the type of benefit

3/ Registering your vehicle as a disabled vehicle

If you are awarded PIP and specifically the enhanced level of the mobility component, you're entitled to register your vehicle as being driven by a disabled person. That brings with it certain benefits, one of which is an exemption from paying road fund license.

Other information:

1/Government Gateway – Benefits of having this type of account:

The Government Gateway is an IT system launched in 2001 and developed to allow applicants to register for online services provided by the UK government. The online system is available to those individuals and organisations and can prove incredibly useful. Services offered include obtaining or changing the address of a driving license, pension projections, and HMRC self-assessments, as well as many others.

2/Debt Charities & Debt Advice

Get free, confidential, and independent advice on dealing with debt problems is available from Money Helper the National Debtline and numerous alternative organisations and charities.

3/Support For Carers

Carers UK (Link below) – A great website packed full of information, advice and guidance.

4/Access Card (https://www.accesscard.online/apply-or-renew/)

The Access Card costs **£15 for 3 Years.** It is designed to streamline the process of communicating your disability access needs, the Access Card translates your disability or impairment into easy-to-understand symbols. It summarises how you can use the card to convey your access requirements to venues and service providers, ensuring a more accessible and enjoyable experience wherever you go.

Parkinson Specific Booklets from Parkinson’s UK

Parkinson’s UK have developed a suite of booklets that describe each of the main benefits. These are available for free from the Parkinson Shop (https://shop.parkinsons.org.uk/collections/benefits) and on free download from the Parkinson-UK website

Local Help

While the Branch do not recommend any specific individuals or organisations for paid consultancy on filling in benefit forms, we are aware of a number of individuals with experience of completing forms. This experience may have come from previous employment with organisation such as Citizens Advice. If you contact a member of the Committee we can provide details of such individuals WITHOUT RECOMMENDATION OR ANY LIABILITY WHATSOEVER!

Attendance Allowance
£0.00

Carer's allowance
£0.00

Employment and Support Allowance
£0.00

General information about benefits
£0.00

Help with Council Tax
£0.00

Help with getting around
£0.00

Pension Credit
£0.00

Personal Independence Payment
£0.00

Universal Credit
£0.00

TWO LEAVES

We will bud green together,
a fresh, bright green,
and we will be washed together
by the same water cleaned.

We will be fed together
by the same moist earth and light
and a deeper green we'll turn together
as the days deny the nights.

Yes we will turn our backs together
when the South-west wind blows strong
and we will dance entwined together
as it softens into song.

And we will hide the sun together,
grant travellers cool shade;
and we will help them rest together
with every journey made.

It may be we will fall together
if lightning sears the branch,
the branch which we adorn together
will keep us close perchance.

And when we see greens turn together
to reds and browns and golds,
we'll play our glory days together
then watch ourselves grow old.

But we can't choose to fall together
if we reach deep autumn's end;
you may take your leave on a different breeze
and lose your love, your friend.

So let us watch and wait together,
until the wind blows true,
then, letting go our grip together,
I'll fly away with you.

Peter Taylor

Interview with Peter Clutterbuck by
David Lowther

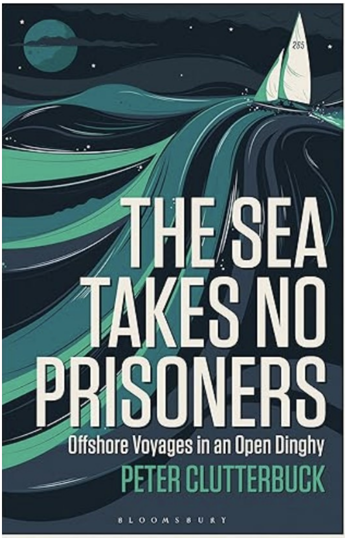
David. How did this article come about?. I met Peter at the 9:30 Monday Whitley Exercise class. As you will know the purpose of such a class is to improve (or more accurately degrade more slowly) and as such individuals measure their performance against their own targets rather than each other. That said, it was obvious that Peter had serious symptoms. We might have continued with this cursory relationship was it not for the fact that a pipe burst at the Chichester Hall and we had to decamp to Milford Golf Club. While the actual room was smaller and less suitable there was the advantage that the Golf Club had a bar. That enabled me and my fellow exercise buddies to partake in coffee in reward for the exertion of the class. Up to this point I had never talked to Peter. What a mistake that was as Peter is such an amazing chap as you are about to find out…

David. Tell me about your childhood?

Peter. I come from a military family, which involved having 21 homes in 20 years. One of the more memorable postings was Malaya. Our family went there by troopship when I was six, in 1956. We were struck by a North Atlantic winter storm, which seriously damaged the ship. This gave me a fascination with the sea and the oceans.

David. While researching to prepare these questions I found out you are an author – can you tell more about this and your interest in dinghy sailing ?

Peter. I wrote a book called “The sea takes no prisoners”, published by Bloomsbury. I was a teenager in the 1960s, looking for adventure. Two of us sailed a 16 foot open dinghy to the Mediterranean then the North Sea and the Baltic, surviving gales, capsizes, big waves, fog, dismasting, and nine rudder breakages.



David. I see you studied Engineering at Cambridge. What was the most significant thing you learned?

Peter. To tackle problems by going back to first principles.

David. Can you give some background to your working life?

Peter. I was an operations manager for BP in Abu Dhabi, the North Sea, and Alaska, then CEO of some listed energy companies, operating mainly in Colombia, Arctic Russia, Gabon, Tanzania and Poland. These were mostly in very remote and hostile areas in deserts, offshore in deep water, and jungles.

David. You've told many stories of dealings with the Middle East, can you elucidate ?

Peter. I enjoyed travelling with the Bedouin Arabs in the very hot and remote Rub' al-Khali, the Empty Quarter of Arabia.

David. You seem to have travelled the world with your various companies. What would you say were the most rewarding?

Peter. Working with Russians to rebuild a broken and collapsed system at the end of the USSR; and developing a gas to electric power system which lifted millions of Africans out of poverty.

David. You clearly progressed to significant management positions in various companies. What did it teach you?

Peter. To believe in your principles, to deliver what people want, and to enjoy time with your team.

David. I hear you were a mountaineer and Antarctic adventurer, can you provide more background.

Peter. I climbed in various places in Alaska, Patagonia, and the Himalayas; and had the good fortune to climb unclimbed peaks in unexplored mountain ranges of Greenland and Antarctica. I raised some money for the Macmillan Cancer charity as part of the Antarctic expedition.

David. You were obviously by anyone's measure a high flyer and James Bond like character.

Peter. I never thought of myself as a 007 type, but I did envy some of the lifestyle.

David. How do you see your action packed life through the filters of having Parkinson's?

Peter. The best bit about having Parkinson's is meeting so many wonderful people: motivated, kind hearted, focussed, positive, and selfless.

Health Qigong Ba Duan Jin classes for people living with Parkinson’s

The thought of attending my first Health Qigong class was quite daunting. I didn’t know what I was in for: would I be able to learn the routines? Would I feel silly?

All my fears were soon allayed. Ruby Ho, a retired Occupational Therapist and qualified Health Qigong Ba Duan Jin (BDJ) instructor, talked us through every stage of the gentle routines, explaining to us the philosophy behind Qigong and demonstrating very clearly how we should stand. Which, by the way, is mainly ‘as if we are sitting on a high bar stool’. We also learned when to breathe during the moves, how we should move and where to look.

Ruby used visual stories that enabled us to remember routines, such as holding up luggage in an airplane‘s overhead luggage compartment or ‘shooting with a bow and arrow’. She also followed up each class with diagrams and written explanations so there was no reason for us not to understand and practice the steps. On Zoom, Ruby could see us and let us know (very kindly and gently) if we needed to adjust our hands or lower our shoulders for example. While Ruby could see us and we could see her, we couldn’t see the other participants, so there was no need to worry about making mistakes.

I embarked on Ruby’s course with my husband Paul in the hope that a) it might help alleviate his Parkinson’s symptoms and b) it was something new for both of us and we could enjoy learning it together. I found that I had no trouble in learning the routine, although placing my arms or legs in the right place is going to take a lot more practice. I really enjoyed our Wednesday Zoom class with Ruby and felt quite disappointed when we had to miss a class because we were away on holiday.

BDJ is a traditional Chinese exercise, well known for its gentle, slow movements and associated health benefits. From Ruby’s experience as a BDJ instructor, she believes that BDJ can help to reduce some of the problems faced by people living with Parkinson’s. Qi means energy and the philosophy behind BDJ is that it aims to ‘excite the internal good qi for internal health promotion and balance’ as well as helping to unblock obstructed energy pathways or meridians. Whether or not you initially fully understand or embrace the philosophy, this gentle exercise is good for both body and mind. So why not give it a go.

Debbie Gaskell

Our '100 Club'

The 100 Club has been running for 3 years now and we have almost 200 numbers in play each month. As well as providing the opportunity for those participating to win a cash prize, It raises funds for the Branch and in 2023 this amounted to £759.

Anyone wanting to join this Club should contact Nick Hetherington (NHetherington@GuildfordParkinsons.org.uk) or our
Treasurer (Sheron@GuildfordParkinsons.org.uk).

Recent winners are:

2024	1st Prize £60		2nd Prize £20		3rd Prize £10	
May	Joan Peacock	189	Ian Robinson	49	Peter Taylor	9
June	Tony Chapman	144	Gaber Burnick	130	Laura O'Connor	56
July	Barry Butcher	70	Valerie Box	201	Steve Heron	35

The back from the Chair

Well what do you expect? I write a forward so naturally I should write at the back as well. My choice of topic is people who inspire. No one has ever asked this question but as co-editor I get to decide what goes in so here goes..

The first person that comes to mind is Niki Oldroyd. Niki is married to the ex-Headmaster of Barrow Hills School. She inspires me in multiple directions but her practicality won me over. She fell multiple times a day, so she wore kneepads. She learned to fall safely and with grace. What a star!

The next person is Rona, my co-editor, and all those who share a common belief that travel expands the mind. She demonstrates in her article that travel is still possible. So if it's a short stay at Clare's Surrey retreat, or to the Paris Olympics (Paul & Debbie), or to the Antarctic (Peter) or even to the MIR space station (Richard Clifford) have a go…

David Lowther

Clare would like members to know that if they are interested in a short break at anytime, she can offer a stay from Monday to Thursday at a discounted rate. email : cprice@GuildfordParkinsons.org.uk

Branch Activities

Activity	Where	When	Comments	Contact
Carer's Group	Inn on the Lake	2nd Monday of Month	Share with others Carers	Carers@GuildfordParkinsons.org.uk
Committee Meeting	Church House	6 weekly 10:00 - 12:00	volunteers always welcome	Chair@GuildfordParkinsons.org.uk
Friendship Group Meeting	White Hart, Godalimning	3rd Wednesday of Month @19:00	All welcome Option to eat or not	Membership@GuildfordParkinsons.org.uk
Loud and Clear Speech Therapy	Online	1st Monday and Wednesday	Improve your speech in fun format	Treasurer@GuildfordParkinsons.org.uk
Newly Diagnosed Social Meeting	**Grantley Arms Wonersh**	2nd Tuesday of Month @ **19:00**	All welcome Option to eat or not	Secretary@GuildfordParkinsons.org.uk
Tuesday Social Meeting	Shalford Village Hall	Last Tuesday of Month @14:00	Guest Speaker, Refreshments and Camaraderie	Secretary@GuildfordParkinsons.org.uk
Dance for Parkinsons	Godalmin United Church, Godalming	Weekly on Wednesday		Treasurer@GuildfordParkinsons.org.uk
Parkinsong Voice Classes	Busbridge Village Hall (and Online)	Tuesdays 11.45 - 12.45	Work on breathing	Treasurer@GuildfordParkinsons.org.uk
PD Warrior type Exercise Class	Whitley	Weekly	Multiple sessions on different days	Foundation Physio
PD Warrior type Exercise Class	West Clandon	Weekly	Multiple sessions on different days	Foundation Physio
PD Warrior type Exercise Class	Cranleigh Youth Centre, Snoxall	Weekly	Multiple sessions on different days	Surrey Hills Rehab
Pilates	West Clandon	Weekly on Wednesday		Treasurer@GuildfordParkinsons.org.uk

Key Email Addresses for Branch

Chair	David Lowther Chair@GuildfordParkinsons.org.uk
Treasurer	Steve Heron Treasurer@GuildfordParkinsons.org.uk
Communications Manager	Deborah Gaskell Comms@GuildfordParkinsons.org.uk
Membership Secretary	Keith Black Membership@GuildfordParkinsons.org.uk
Carers Support	Myra Newnes-Smith Carers@GuildfordParkinsons.org.uk
Support Groups	Sharyn Grenville SupportGroups@GuildfordParkinsons.org.uk

National Website www.parkinsons.org.uk

Local website www.guildfordparkinsons.org.uk

Parkinson’s Nurse Specialists (NHS)

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