

Summer Newsletter 2024

Edinburgh Parkinson's Lecture 2024

We are pleased to confirm that booking for the annual lecture is now available. Links to Eventbrite to book tickets are on the Branch website and the dedicated Lecture Page. The lecture programme is also finalised, with times and the various guests who will be contributing.

Please note that there are two options, one is to attend in person (venue is the Royal College of Physicians Edinburgh in Queen Street), and the other is to view live and online. The reception at RCPE starts at 6.15pm with the main proceedings starting at 7.10pm.



GE ATTITUDES.

Our Lecturer is Irish state-registered Dietician, Richelle Flanagan (pictured) who will share with us: How nutrition and diet can help you live better with Parkinson's.

Summer Break: Branch Get-Togethers

We do not have monthly Get-Togethers until 11th September, as we have a break over summer.

(Many of our regular activities do still run over the summer months including the Young Parkinson's Support Group, Pilates and Nordic Walking. Please check with the organisers if you plan to attend for the first time. Details of all activities are on the website).

We have not yet finalised a new venue, though we are looking at a couple of options. We will send out the annual calendar for 2024/25 in August which outlines the agenda for the Get-Togethers.

New Monthly Meeting/Café: Niddrie

As part of our outreach programme, we introduced a new monthly meeting. The first one took place on Monday 24th June 2024 at the Hays Community Hub, 3 Hay Avenue, EH16 4RW.

Louise Day (a speech therapist and voice coach) introduced her work on speech therapy. She took the group through several exercises aimed at strengthening the vocal cords as they get weaker with Parkinson's.

The next meeting is on Monday 22nd July at 2pm, and all are welcome to come along. We are hopeful that if there is enough demand this may become a permanent and long-term activity. For more details please email Stephen: chair@edinburghparkinsons.org.

(Note: our long-standing café at Butterflies Café (Marchmont St Giles) takes place from 10.30 – 12.00 on the second Monday of each month – except August when there is a break).

Parkinson's Nurse Telephone Helpline Changes

As of 1st July 2024, there are new timescales where you can call to request a telephone appointment with a Parkinson's Nurse Specialist:

To book a telephone consultation call: 0131 465 9156, Monday to Friday between 8.30am – 10.30am

Note: It has been brought to our attention that that the secretaries have had an increasing number of calls where individuals have been verbally aggressive/abusive. This is completely unacceptable. The secretaries are receiving the calls on behalf of the nurses and it is very upsetting that they are having to deal with such calls.

Research Opportunity

"The Parkinson's Progression Markers Initiative: How does Parkinson's start and change?" Researchers aim to identify how Parkinson's starts and changes over time. This could help to develop new treatments, better clinical care, and maybe prevent Parkinson's.

50 people who meet the criteria of one of these groups may be eligible to participate:

- Group 1: Aged 60+ who are first-degree family members (parent, child, sibling) of a person with Parkinson's
- Group 2: Aged 60+ who have risk factors for the development of Parkinson's (people who act out their dreams while asleep, or who have a genetic mutation linked to PD, or who experience sustained smell loss)
- Group 3: Aged 56+ who haven't been diagnosed with Parkinson's and there is no known risk

For full details: <u>Take Part Hub</u> (Parkinsons UK).

First Steps Programme

Run by Parkinson's UK, First Steps is an online programme for people recently diagnosed with Parkinson's and family, friends and carers.

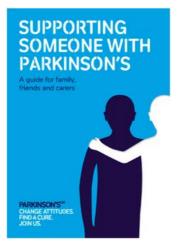
The programme is 3 sessions, where they help you take the first steps in making sense of your diagnosis. They will empower you to start living well with Parkinson's by providing the information and support you need.

If you have any questions, please contact the First Steps team on 020 7963 9381 or email <u>firststeps@parkinsons.org.uk</u>

For more information, please see the <u>First</u> <u>Steps</u> page on the P-UK Website.

Supporting Someone with Parkinson's Booklet

Parkinson's UK have produced a booklet, aimed at those supporting someone with Parkinsons's. They recognise that when supporting or caring for a PwP, it can be difficult to come to terms with changes this brings to your life, as well as the PwP.



This booklet includes information about any benefits you are entitled to, or how changes might affect your relationship with the person you support. It has practical tips and information that can help, along with ways to get emotional support and look after your own health. It also covers carers' needs and rights, how to find more support, including ways to get in touch with other carers.

Please click on the photo to be taken to the webpage to download the booklet.

Summer Quiz



1) At 1.34 miles, where is the longest pleasure pier in the UK?

2) What is used as the filling of a summer pudding?

3) The "dog days of summer" are named after the Dog Star; what is the more popular name of this star?

4) In 1936, Billy Butlin set up his first holiday camp in Skegness. Where did he set up his second camp a year later?

5) Which Yorkshire resort set itself up as a spa in the mid-17th century?

6) Which month are most babies born in Britain in summer?

7) In which resort town was the sitcom Fawlty Towers set?

8) The tiny Summer Isles are a few miles Northwest of which Scottish port?

9) Which British seaside attraction is 158 metres tall?

10) What is the birthstone for July?

11) Which US state has the average hottest temperature?

12) Mojitos are a popular summer drink. From which country do they originate?

13) Which band produced the classic summer hit Walking On Sunshine?

14) Which vitamin do you get from sunshine?

15) Which town is the largest holiday resort on the Yorkshire coast?

(Answers at bottom of Page 6)

Summer Salad Recipe

This recipe was shared by Richelle Flanagan (our 2024 Lecturer) on the <u>Parkinson's Europe</u> website. Richelle is a dietician, and a PwP.

Ingredients

1 butternut squash (700g), peeled and diced
1 red onion, peeled and roughly chopped
1 tsp cumin seeds
1/2 tbsp rapeseed or olive oil
1 tin chickpeas or any mix of beans, drained (such as mixed beans, chickpeas, kidney beans, pinto beans – look for BPA (Bisphenol-A) free tins or use dried beans and prepare before using in this dish)
4 handfuls of mixed spinach and rocket salad
1 handful freshly chopped parsley
4 fillets fresh salmon

For the dressing:

- 1 tsp Dijon mustard
- 1 tsp honey
- 1 tbsp cider vinegar
- 2 tbsp olive oil

Method

- Heat the oven to 170°C. Place the chopped squash and onion on a flat baking tray. Toss in the cumin seeds and oil, mix to coat.
- Place in the oven for 15 minutes, turning once halfway through. Make a space for the salmon on the tray and bake for next 15 minutes or until salmon is cooked. The squash and onion should both be soft.
- Place salad leaves into a large serving bowl. Add the beans, parsley, and the cooked squash and onion.
- Make dressing by combining all ingredients in a jar and shake. Pour the dressing over the vegetables and mix to combine. Place salmon fillet on top.

(You can replace the salmon with feta cheese or use kale instead of the spinach and rocket salad).

It's a tasty, light but satisfying dish, full of healthy fats from the dressing and salmon. It contains soluble fibres from the butternut squash, onion, salad and chickpeas to support the digestive system. The protein from the chickpeas and salmon provides the building blocks for keeping muscle mass – which is important for many people with Parkinson's. The salmon also provides B vitamins, in particular vitamin B12, and vitamin D, both of which can be deficient in PwPs.

Senior Smashers! Table Tennis

As you may know, we have a very popular Saturday afternoon <u>Table Tennis</u> session, organised by Gina and Scott from the Young Parkinson's group. The venue for this is North Merchiston Club.

And the club is starting a new Table Tennis session for those who are retired or semi-retired.

As the benefits for PwPs have been expressed to us, we are happy to promote these sessions. They are for anybody who could do with a little more activity in their life, or in need of a new hobby. The Branch has many activities for PwP's, though not so many for family/friends/partners. This could be an ideal opportunity to do an activity together!

- Day/Time: Thursday 13:30-15:00 (weekly from 4 July)
- Cost: £3 per session (enjoy a 25% discount at the Cafe!)
- Venue: North Merchiston Club, 48 Watson Crescent, Edinburgh EH11 1EP

Parkinson's Walks

A reminder that while there is a walk on 29th July (Lauriston Castle), the group take a break in August. Walks resume on September 30th and weather permitting continue over winter. Keep checking the <u>website page</u> for walk details. When the routes are planned, we add the details.



Parkinson's Voice Exercise Group (Online)

Another non-Branch activity we are happy to promote. As we know, many people with Parkinson's suffer from issues in relation to speech. The sessions of the Parkinson's Voice Exercise Group will include elements of music, movement and singing. However, the emphasis is more on exercising and strengthening the voice than on singing.

- When: Weekly on Wednesdays, 10.45am 12pm, on Zoom
- Cost: £3 per session per household

The sessions are tailored for people with Parkinson's – but family members are welcome too. They will use music, movement, breathing, vocalising and singing to help strengthen your body, mind and voice and keep them supple. The sessions will include fun exercises that you can use at home.

For details, contact Chloe on 0300 123 3679 or email: cmacmillan@parkinsons.org.uk

Edinburgh Fringe and Festival Shows of Interest

Dance Base Festival 2024

Dance Base in partnership with Assembly Festival have announced their 2024 Edinburgh Festival Fringe Programme. Jim Hollington, current Chief Executive of Dance Base tells us:

DANCE BASE FESTIVAL 2024 IN Partnership with assembly



"Delivered in a unique partnership with Assembly Festival, the 2024 programme is back to full strength, presenting 274 performances of 29 shows from 33 companies in the home of dance at the Edinburgh Festival Fringe. As well as providing a platform for incredible dance artists based in Scotland, this year we feature work from countries that include Australia, Taiwan, South Korea, Hong Kong, Belgium, Denmark, and Germany."

Here are links to see the <u>full programme</u>, and <u>book tickets</u>

(Dance Base host Dance for Parkinson's. The summer term ends soon, with the autumn term starting again in September. Please see our dedicated page for <u>Dance for Parkinson's</u>)

Parky Players

The Parky Players are making a return visit to the Fringe this August. They are the Parkinson's-led theatre company that first performed in Edinburgh two years ago, with the memorable, very funny and moving show 'Shake It Up', which a number of the Edinburgh Branch members attended.

Their new show is 'Shaken, Not Stirred' – "a fiercely funny, no-holds barred variety sketch show about the modern-day challenges of living with Parkinson's. A cocktail of fast-moving, irreverent comedy and music, with a sprinkling of Bond on top (just where he likes it). You'll laugh, you'll cry; you might even learn something. 00 agents, film enthusiasts and blue-badge holders welcome. We'll be expecting you!"

- When: Monday 12th to Friday 17th August at 11.45 am
- Where: The Space on The Mile, 80 High Street

For more details and to buy tickets please use this link: EdFringe

(The Parky Players was formed by Janet Shipton and fellow PwPs. During the pandemic they got together and wrote and recorded an online pantomime. This was developed further with Arts Council England funding which led to creation of their first show 'Shake It Up')

Khalid's Fundraising Run

Khalid Al-Ani is a student from Napier University who conducted a research study: "Effects of Mindfulness Meditation and Exercise Prescription on Self-efficacy for Physical Activity and functional outcomes in People with Parkinson's Disease: A Case Series Experimental Design"

Khalid gave a talk to the Edinburgh Research Interest Group (ERIG) and was able to recruit some participants as a result of this. In his own words:

"Whilst completing my project I was awestruck at the overwhelming enthusiasm, and dedication of those with and without the disease to support one another, help fund research and donate their time and effort to people like myself who were researching Parkinson's. I was always welcomed with open arms and a smile at every support group, charity event and research session I attended.

I wanted to go some way to repaying the countless amount of time all those involved in my study gave me. Specifically, the participants in the study, the wonderful volunteers of Parkinson's UK and all those involved in the Edinburgh Research Interest Group (ERIG) for Parkinson's".

Khalid is running in the Scottish Half Marathon on 18 August 2024. He has started a <u>Just Giving</u> page, with all the money he raises going to Parkinson's UK. Please do consider donating.

Singing 4 Fun Birthday

On 25th June 2009, our <u>Singing4Fun</u> sessions began. Congratulations to all those involved. Fifteen years have flown by!

We don't have a picture of this year's celebration but Lou Ogilvy shared on our Facebook page a lovely picture of Cathie Quinn who started the activity and her great friend Heather (and a key member of Edinburgh Parkinson's for many years), cutting into a previous birthday cake. (Sadly, Heather died in 2019).



Side By Side Course: Autumn Delivery

Cathie is a busy lady and also organises the <u>Side-by-Side</u> course. She has confirmed there are plans to run the course in the autumn. We highly recommend this course for anyone who knows/lives/works with someone with Parkinson's and wants to learn more about the professional help, drugs, benefits and support available. If interested, you may want to contact Cathie to check for a wait-list.

Quiz Answers

3) Southend; 2) Soft fruit (such as raspberries or blackcurrants); 3) Sirius;
4) Clacton; 5) Scarborough; 6) September; 7) Torquay; 8) Ullapool
9) Blackpool tower; 10) Ruby; 11) Florida; 12) Cuba; 13) Katrina and the Waves
9) Blackpool tower; 10) Ruby; 11) Florida; 12) Cuba; 13) Katrina and the Waves