

Parkinson's UK Newport Branch

December 2024 Newsletter

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

A Wonderful Afternoon at the Holiday Inn



The Christmas Lunch saw many of our wonderful members join the festivities at the Holiday Inn. Bettyann did an exceptional job of organising the afternoon, the food, service and company was all exceptional, how wonderful to be able to enjoy a lovely afternoon together and come together to enjoy the event. Keep an eye out for more great events organised by the committee in 2025!

It's been a busy year for us all, with a few ups and sadly downs along the way. One element we must all hold onto is the wonderful and important friendships we all benefit from through our Newport Support Group Parkinson's Community.

On behalf of the Committee, Support Group Members, Friends & Family, our heartfelt thanks for all the support and kindness shown and all that we have achieved in 2024!

[A Super Visit from the Mayor!](#)

The Mayor of Newport, Councillor Raymond Mogford kindly joined our Maesglas Support Group meeting on 25 November, we were also entertained by the awesome Jim Walsh.



[Could you support Parkinson's research?](#)

Research teams across the UK are investigating if ondansetron has a meaningful treatment effect on Parkinson's and Lewy Body Dementia hallucinations. As this is an already licensed low-cost drug, if the research shows significant outcomes, ondansetron could be available for people with Parkinson's who experience hallucinations within the next few years.

We are looking for 306 people diagnosed with Parkinson's or Lewy Body Dementia (LBD) who:

- experience visual hallucinations at least once a week,
- are not taking apomorphine or any anti-psychotic medication,
- and have been taking a stable dose of Parkinson's or LBD medication for 28 days before starting the research

The first activity is a telephone call to discuss the research more fully and complete some questionnaires. This will be followed by a brief face-to-face visit to assess your Parkinson's, take a blood sample, and monitor your heart rhythm.

If you are eligible to take part, you will either receive ondansetron or dummy medication tablets for 12 weeks, which will be shipped to you via a courier. The research team will maintain regular contact throughout to take assessments and let you know how much medication to take. This contact will be through telephone, video call, and face-to-face.

3 face-to-face visits are required, and, for some research sites, home visits may be an option. The research team are based locally in Llandough Hospital, Penarth.

For more information, please read the Participant Information Sheet or contact the TOP HAT team by email at o.zubko@ucl.ac.uk the deadline for taking part in this research is **1 July 2026**.

Maria and Desmond's experience of taking part in the TOP HAT trial

"I'd really encourage anyone thinking about it to take part. It was so easy, just one more pill. And the appointments are just the same as the routine appointments. It was like having extra consultation appointments, we felt like VIPs!" - Maria & Desmond [Click here to read their story](#)

[The Parky Charter](#)

The Parky Charter has been created by the Movers and Shakers and outlines A five-point national plan, that would support people living with Parkinson's.

The Parky Charter and a petition in support of the charter was hand delivered to Downing Street on World Parkinson's Day, 11 April 2024. By the Movers and Shakers, you can find out more here:

[The Parky Charter | Movers and Shakers](#)



The Parky Charter details five important principles:

1. Speedy Specialists

Parkinson's slows many of us down - but that doesn't mean we should be stuck in the NHS slow lane. We hear many complaints about the time it takes to be diagnosed and then the long gap between appointments with the consultant. The NHS (NICE) guidelines are perfectly clear - every person referred by their GP for a possible Parkinson's diagnosis should see a neurologist or geriatrician within 18 weeks. This often doesn't happen - it should be policed and enforced. After diagnosis there should be a maximum of a year between neurological appointments.

2. Instant Information

When first diagnosed every Patient with Parkinson's (PwP) should be given, as of right, a leaflet containing essential information about Parkinson's. At the very least, this should be the Parkinson's UK pamphlet. But the newly diagnosed PwP should also be given information, which is relevant, personal and local. This should include a contact number for their Parkinson's nurse, including a date for a first appointment, and other available help including local support groups.

3. Parkinson's Passport

People with this yet incurable degenerative condition should never be denied benefits because they 'might get better' - instead when diagnosed they should be given a "Parkinson's passport" which would give an automatic right to certain benefits, free prescriptions, a 'blue badge' and other clearly defined services. Any remaining services or entitlements which do require assessment must be undertaken by an assessor trained in an understanding of the complexities of the symptoms of Parkinson's, especially the variable and intermittent nature of some symptoms.

4. Comprehensive Care

Even an assured annual meeting with a neurologist can only help people with this complex, unpredictable, multifaceted condition to a limited degree - every PwP should have a personal plan ensuring regular access to, advice from, and treatment by, a multidisciplinary team including Parkinson's nurses, physiotherapists, nutritionists and speech therapists.

5. Quest for a Cure

Parkinson's is incurable - but it doesn't have to stay that way. Hunting for a cure is a long-term goal but produces many shorter-term benefits. The Government should commit to a major increase in funding for research into Parkinson's from today's modest level (£6.7 million in 2021/22).

During the year there has been a new government which has made significant promises to implement at least part of the Parky Charter. Check out the latest episode with Wes Streeting, the new Health Secretary, [here](#).

There will be a further petition launched in the months ahead, in the meantime please sign up to the mailing list to ensure you are able to pledge your support. The aim is to reach 100,000 signatures in order trigger a debate in Westminster.

In the meantime, take a moment to watch the Parky Peoples very own rendition of [We Will Survive!](#)

[Sign up to Live Loud!](#)

An innovative program of vocal exercises designed to strengthen and maintain the voice for people living with Parkinson's. There are monthly sessions all over Wales and online.

Sessions in person are held in the afternoons on a Monday in Newport & Cardiff and Fridays in Chepstow. Online Zoom sessions are held on Wednesday evening, Thursday afternoon and Friday mornings.

Contact Liz Morgan for further information - lmorgan@parkinsons.org.uk, 0344 225 3767

[Join us for Boccia!](#)

A huge well done to all in the group that have been taking part in our monthly Boccia sessions. It's a fun afternoon to play the team sport and catch up with friends.

If you'd like to join us, please come along next month. We meet on the third Monday of the month at 2pm.

Parking is available onsite at Rodney Parade, please just drive through the main gates.

Please reach out to Ruth if you have any questions.



[Volunteering Opportunity](#)

We occasionally get calls from people with Parkinson's who are nervous about joining a support group, but as we know would likely benefit from joining the group. A particularly effective way to help is to invite them to meet up for a coffee, at a convenient time and place, to chat about what the Support Group has to offer and to assure them there is nothing to fear, whilst also sharing dates for the groups.

If you feel you could do this, please get in touch. This may also be an ideal role for a couple, partners, father and son or mother and daughter or as we know any supportive combination. We can all share experiences of how the group has supported us. It is a wonderful opportunity to share more information and extend that important welcome. Please get in touch via andrea.ovey@gmail.com or call Julie 07446 630229 if you would like to offer your support.

[Community Voices](#)

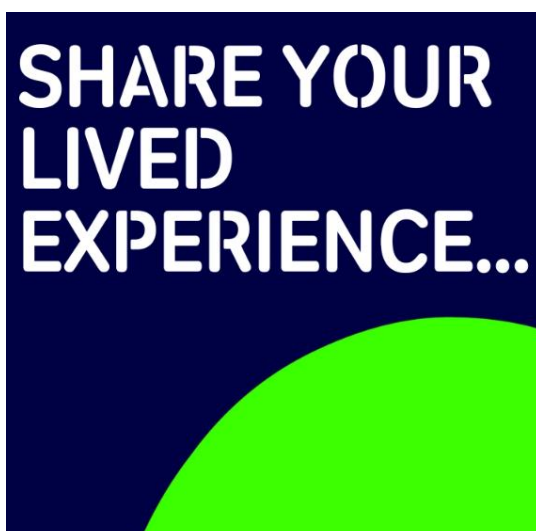
Share your lived experience to improve the communication between healthcare professionals and people living with Parkinson's.

If you live with Parkinson's or care for someone who does, the Parkinson's UK Education team needs your help to develop two new online courses which will educate health and social care professionals about communication challenges.

Lived Experience subject matter experts for Education Courses are available from 10 December 2024 to 31 March 2025.

Learn more about this opportunity and apply on our [website](#) :

[Click Here](#)



Useful Information



Hynt is a national access scheme that works with theatres and arts centres in Wales to make sure there is a consistent offer available for visitors with an impairment or specific access requirement, and their Carers or Personal Assistants. If you need support or assistance to attend a performance at a theatre or arts centre, then you may be eligible to join hynt. [Find out more about Hynt!](#)

National Exercise Referral Scheme

The National Exercise Referral Scheme, more commonly known as NERS, is designed to provide help and guidance for people living with conditions to improve their health and wellbeing. To be referred onto the Exercise Referral Scheme speak to your Health Professional or GP. For more information about The National Exercise Referral Scheme call 01633 238510. The National Exercise Referral Scheme in Newport is run in partnership with [Aneurin Bevan University Health Board](#), [Newport Live](#) and [Newport City Council](#).

Newport Citizens Advice Warmer Wales Project



Representatives from Newport Citizens Advice kindly attended the Newport Support Group Café recently. If you would like to reach out for any guidance and support, please do so via 01633 222622.

Are you over the State Pension Age?

With changes being introduced to who will be eligible for the Winter Fuel Payment this year, it's now time to check what support is available for you. Visit gov.wales/heretohelp for further details or visit our website to read more about pension credit www.parkinsons.org.uk/information-and-support/pension-credit

The Riverfront Theatre & Arts Centre

Your guide to an exciting lineup of shows, workshops, and performances scheduled from February 2025 to April 2025 at The Riverfront Theatre.

The season promises a vibrant array of entertainment, featuring spectacular theatrical productions, engaging workshops for all ages, and mesmerizing performances. Whether you're a fan of drama, music, or dance, there is something for everyone to enjoy this Spring.

Don't miss out on the fantastic experiences awaiting you, read the brochure or listen to an [Audio Brochure online](#) : [Click Here!](#)



Important Dates for your Diary

Group Support Meeting

Maesglas Community Centre,
Bideford Road, Newport NP20 3XT
Last Monday each month 2.30pm – 4.30pm
except May, August & December

Parkinson's Café

Maindee Library
79 Chepstow Road, Newport NP19 8BY
Second Friday each month
2.15pm - 4.15pm

27 January 2025

British Red Cross

24 February 2025

U3A Choir

31 March 2025

Cllr Dimitri Batrouni - Newport City Council Leader

28 April 2025

Lorna Pearson Comic Verse

10 January 2025

14 February 2025

14 March 2025

11 April 2025

Curry Club

Godfrey Morgan Wetherspools, Maindee, Newport. NP19 8EG
Monthly - Third Thursday each month at 1pm
Contact Ruth 07966 754366 to confirm attendance to ensure we can confirm the table numbers

19 December – 16 January – 20 February – 30 March – 17 April

Boccia

Dragons RFC, Rodney Parade, Newport. NP19 0UU
Third Monday each month at 2pm
Contact Ruth 07966 754366 for more information

16 December – 20 January – 17 February – 17 March – 21 April

Additional Dates for your diary!

The below sessions are not organised by the Newport Support Group but are held locally and may be of interest to you.

Live Loud Newport

Christchurch Centre, B T Compound, Malpas Rd, Newport NP20 5PP
First Monday each month at 2pm – 4pm (unless Bank Holiday)
Contact Liz Morgan at lmorgan@parkinsons.org.uk
6 January – 3 February – 3 March – 7 April

Please share your thoughts and feedback.

Our Group Meetings, Café and Curry Lunches and other events are an important opportunity to meet as a group and support each other across the Parkinson's Newport Network. We would love to hear your suggestions and recommendations for

Parkinson's UK Helpline 0808 800 0303

Help can be found here on many topics, including medical. You can also contact your local adviser, Karen Miles, and Helen Dobson via the helpline number.

We are the Newport Branch of Parkinson's UK Wales. Any views and contributions are welcome (the right to edit reserved). Please send by the first Wednesday of the month to Andrea's email shown below. For further information, or to unsubscribe from this Newsletter and/or any other contact from the Newport Branch, please contact the Editor, Andrea Ovey on 07970 364779 or email andrea.ovey@gmail.com. The UK website is parkinsons.org.uk