

Prioritising living well with Parkinson's Senedd Election 2021 key asks

About Parkinson's

Parkinson's is the fastest growing neurological condition in the world¹, and currently there is no cure. Parkinson's is what happens when the brain cells that make dopamine start to die. There are over 40 symptoms, from tremor and pain to anxiety. Some are treatable, but the drugs can have serious side effects.

In Wales, around 7,600 people are already living with Parkinson's. This is forecast to rise by around a fifth to approximately 9,000 by 2030.

What matters most to people affected by Parkinson's

The views and needs of people affected by Parkinson's are central to both the work that Parkinson's UK Cymru does, and our ultimate ambition, which is to find a cure and improve life for everyone affected by the condition.

In 2020 we asked people affected by Parkinson's - those living with the condition, their families and carers - what are the most important issues for us to campaign on through our ['What matters most?' survey and our coronavirus poll](#). As the pandemic hit halfway through our survey, causing a great deal of uncertainty, we used the poll to validate the views of our community. More than 2,300 people in the Parkinson's community responded to both surveys across the UK with 5% of responses from Wales.

People affected by Parkinson's in Wales told us they need:

- High quality health and social care
- Access to the right treatments at the right time
- To be able to access financial benefits
- To get their Parkinson's medication on time when in hospital or a care home

¹ Dorsey, E. et al. (2018). Global, regional, and national burden of Parkinson's disease, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. *The Lancet Neurology*, 17

Working in partnership

Parkinson's UK Cymru is an active member of the [Wales Neurological Alliance](#) and we fully support the recommendations of the Cross Party Group on Neurological Conditions [inquiry into the progress of the Neurological Conditions Delivery Plan](#). We are also members of the Wales Carers Alliance, [Age Alliance Wales](#) and the Welsh NHS Confederation Policy Forum and endorse the manifestos we've developed collectively as alliances.

Together with the Parkinson's community in Wales, we urge the next Welsh Government to:

1. Take forward the recommendations of the Cross Party Group on Neurological Conditions including:

- End the 'chronic underfunding' of neurological services.
- Establish a national system for collection, collation and publication of outcomes data on neurological services, working in partnership with the whole neurological conditions community.

2. Ensure people with Parkinson's can access high quality health and social care:

"As a person with Parkinson's my day to day life is affected by the progression of the disease and this is partly controlled by my daily medication. The dosage of medication is decided by my consultant at an appointment, a six month pattern of appointments is recommended. In the last three and half years I have seen my consultant once, this means I have not had my medication rereviewed in the last eighteen months or any support in managing my Parkinson's."

- Commit to and invest in NHS and social care workforce development to ensure sustainability of appropriate numbers of specialist staff across Wales to support the needs of people with Parkinson's and their carers.
- Direct all health boards to implement the [NICE Guidelines](#) and [Quality Standards](#) for Parkinson's and end the inequity in access to and quality of Parkinson's care across Wales.

3. Ensure people with Parkinson's have access to the right treatments at the right time

"For me, having deep brain stimulation (DBS) in a timely manner was very important. I, like many people with Parkinson's, do get anxious at times and having a major operation is quite stressful. There were lots of different assessments that I had to complete but once these were done everything went through as planned. I had the procedure five years ago and I think it has helped me remain active."

Treatments for advanced Parkinson's include apomorphine - an injection or infusion of a dopamine agonist under the skin, levodopa/carbidopa gel inserted into the stomach by a tube and deep brain stimulation surgery (DBS.) Access to these treatments across Wales is inconsistent and wait times for accessing DBS surgery at centres in England are difficult to ascertain, but we have evidence of patients waiting more than 18 months for what is a time sensitive surgical intervention. The next Welsh Government must:

- Assert the need for Welsh Health Specialised Services Committee (WHSSC) to monitor and publish referral to treatment wait times for Welsh patients referred to all centres for Deep Brain Stimulation including monitoring of the whole 'DBS journey', from referral to surgery, to ensure transparency for patients.
- Ensure that the infrastructure and prescribing options are in place for all people deemed suitable for treatments for advanced Parkinson's to be able to access them wherever they live in Wales.

In April and May 2020 (in conjunction with Lancaster University) we conducted a survey about the impact of Covid restrictions on people affected by Parkinson's². More than 2000 people responded to the survey, 6.6% of these from Wales. The survey included questions on access to speech and language, physiotherapy and occupational therapy during the pandemic. Wales fared worse than all of the UK nations and the UK as a whole in terms of appointments cancelled and an alternative not being offered:

Across the UK 70.9% of people were not offered an alternative means of having their appointment (telephone or video.) In Wales the figure was 87.2% not offered an alternative. 20.4% across the UK were offered an alternative. Only 8.5% in Wales were offered an alternative.

- Ensure that, as we recover from the impact of the Covid-19 pandemic on our health and care services, people with long term conditions such as Parkinson's are not forgotten and are able to access the speech and language, physiotherapy and occupational therapy they need to retain their independence.
- Pledge to support Parkinson's UK Cymru in achieving the aims of the 'Right to Rehab' campaign led by the Royal College of Occupational Therapists and Chartered Society of Physiotherapy.

4. To be able to access to financial benefits

People with Parkinson's rely on financial support to stay independent and in control. Our 2017 'Cost of Parkinson's in Wales' report³ found that households in Wales where someone has Parkinson's are £17,136 out of pocket each year. This was broken down into higher health costs (£1,861), higher social care costs (£3,249), loss of income due to early retirement or reduced

² <https://www.parkinsons.org.uk/news/how-have-coronavirus-covid-19-restrictions-impacted-people-affected-parkinsons>

³ <https://www.parkinsons.org.uk/news/whats-cost-living-parkinsons>

working hours (£12,026.) While this research was conducted pre Covid-19, we know from The Joseph Rowntree Foundation that the impact of Covid-19 has led to even more precarious financial circumstances for disabled people including rising costs and reduction in incomes.⁴ The next Welsh Government must:

- Pledge to hold the UK Government to account on the welfare system so as to make disability benefits fairer and ensure people with Parkinson's are not left behind.

5. Ensure people with Parkinson's get their Parkinson's medication on time in hospital or a care home, every time

"I was left with the impression that I was thought to be an over anxious pensioner who could be ignored. Overall I felt that some of the staff refused to realise the importance of me having my Parkinson's medication on time"

NICE Quality Statement 4⁵ says that people who are in hospital or a care home take levodopa within 30 minutes of their individually prescribed administration time. Serious complications can develop if Parkinson's levodopa medication is not taken on time.

Of those in Wales going into hospital with Parkinson's 73% told us they didn't get their medication on time. (source Parkinson's UK Your Life, Your Services survey of people affected by Parkinson's 2018.) The next Welsh Government must:

- Direct all health boards to implement specific procedures relating to the prescribing, supply and administration of Parkinson's medications in the hospital setting which mean that Parkinson's medication can always be administered on time.
- Direct all care homes to implement specific procedures relating to the prescribing, supply and administration of Parkinson's medications in the care home setting which mean that Parkinson's medication can always be administered on time.

6. Commit to ending the digital exclusion of older and disabled people

"The virus has also highlighted how important internet access and basic technology skills are for people with Parkinson's." (response to [Parkinson's UK survey on impact of lockdown restrictions on people with Parkinson's](#))

The Covid-19 pandemic has sharpened the focus on digital exclusion of older people in Wales.

- It is essential that the next Welsh Government move at pace to invest in digital inclusion support and removing barriers to digital inclusion.

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⁴ <https://www.jrf.org.uk/report/financial-impact-covid-19-disabled-people-and-carers>

⁵ <https://www.nice.org.uk/guidance/qs164/chapter/Quality-statement-4-Levodopa-in-hospital-or-a-care-home>