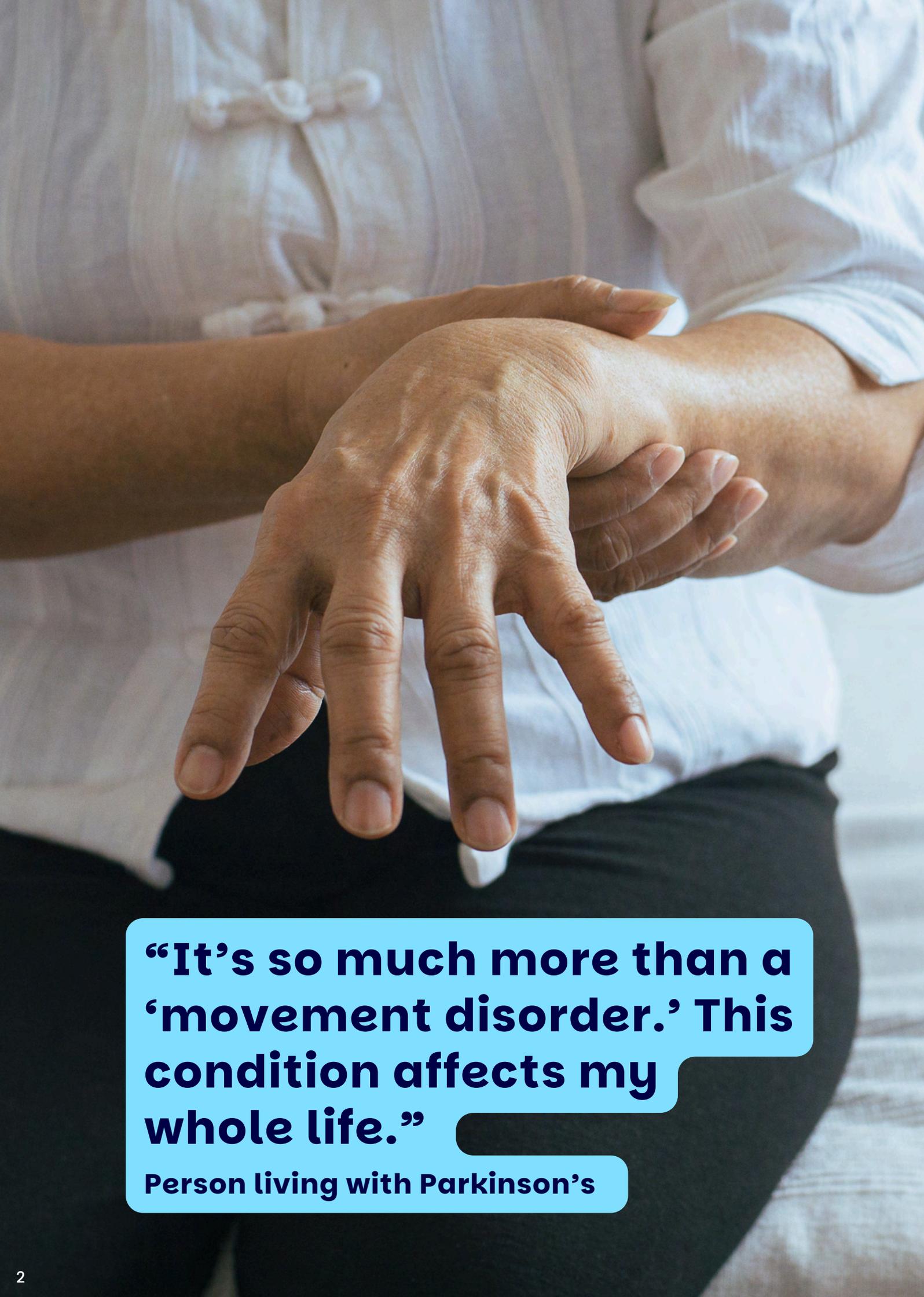


# Your Move

The Parkinson's  
manifesto for the  
Scottish Parliament  
election

**2026**



**“It’s so much more than a ‘movement disorder.’ This condition affects my whole life.”**

**Person living with Parkinson’s**



## **What is Parkinson's?**

Parkinson's is what happens when the brain cells that make dopamine start to die.

There are more than 40 symptoms which impact on all aspects of daily living including walking, speaking and eating, mood and thinking.

Parkinson's gets worse over time and no existing treatment can slow down, stop or reverse its progress.

## **Parkinson's UK Scotland**

We're here to support every Parkinson's journey, every step of the way.

We don't wait for change, we make it happen. Campaigning for better health and care. Funding research into groundbreaking new treatments. Running life-changing support services.

# Parkinson's priorities for 2026 and beyond

About 14,000 people in Scotland have Parkinson's. Every day, about 7 new people are told they have Parkinson's,<sup>1</sup> changing their lives and the lives of those close to them.

Here's what people with Parkinson's and their care partners need in Scotland:

1. Access to specialist, multidisciplinary Parkinson's care.
2. Faster roll-out of innovative treatments, so new drugs reach the people who need them.
3. Protection for Adult Disability Payment so that people with Parkinson's can live with dignity.
4. The right to self-administer Parkinson's medications safely in all Scottish hospitals.
5. Clinical research opportunities across Scotland.
6. Local physical activity provision.
7. Closure of the evidence gap on Parkinson's-related dementia.
8. Short breaks for people with complex conditions and those who support them.
9. Condition-specific support and a "Diagnosis Connect" model for Scotland.

These actions could be life changing for people with Parkinson's. The next Scottish government can make it happen. Your move.

# 1. Specialist, multidisciplinary Parkinson's care

When we asked people with Parkinson's and their care partners whether specialist healthcare was important, 99% said yes.<sup>2</sup>

But workforce pressures are putting people with Parkinson's at risk. There are shortages of consultants and Parkinson's nurses. And that means long delays for diagnosis, and problems with ongoing care. Overstretched NHS services have left up to 21,000 people with Parkinson's undiagnosed across the UK.<sup>3</sup> Up to 2,800 of them are in Scotland. They remain unaware and unsupported.

Parkinson's has more than 40 recognised symptoms that get worse over time. That's why people with Parkinson's need input from a team of multidisciplinary health professionals working together, including physiotherapy, occupational therapy, speech and language therapy, and mental health support.

Moves towards preventative, population-wide healthcare must not come at the expense of people with complex conditions like Parkinson's. Without accessible and responsive specialist care, more people risk serious harm, including emergency hospital and care home admissions. Specialist Parkinson's care must be planned and funded to meet local needs.

## 2. Faster roll-out of innovative treatments, so new drugs reach the people who need them

No current treatment can slow Parkinson's down, stop, or reverse it. And advanced and complex Parkinson's can be particularly hard to live with. But treatments, including surgery and new medicines, can be life-changing. They help people to manage advanced Parkinson's symptoms, regaining independence and improving their quality of life.

Bureaucracy, budget, and workforce pressures mean that NHS boards are effectively denying access to clinically and cost effective treatments that have already been approved for use in NHS Scotland.

The next Scottish government must streamline the process of making new treatments available locally. Scottish Medicines Consortium decisions must apply once for Scotland. And Parkinson's teams must have the capacity and skills to deliver new and potentially life-changing treatments.



### **3. Protection for Adult Disability Payment so that people with Parkinson's can live with dignity**

Social Security is a lifeline for people with Parkinson's. In Scotland, we estimate that when someone has Parkinson's, it costs their household over £18,000 per year, including lost income.<sup>4</sup> People with Parkinson's and their families need disability benefits to help meet those costs.

Adult Disability Payment (ADP) is much better for people with Parkinson's than Personal Independence Payment (PIP).

When claiming PIP, people with Parkinson's often spoke of being made to feel like a "scrounger" during intimidating and degrading face-to-face assessments. With ADP, people provide evidence of how Parkinson's impacts them, and feel believed. People with Parkinson's are more likely to get the right ADP decision first time, reducing the stress and bureaucracy associated with appeals.

But disability benefits are under review in the rest of the UK. The UK government may still try to make multi-million pound savings, which will impact Scotland's block grant and make the budget gap worse. The new Scottish government must protect the principles behind ADP, as an investment in the people of Scotland that supports disabled people to meet some of the additional costs they face. The Independent Review of ADP recommendations should be implemented. Above all, if damaging cost-cutting measures are adopted elsewhere in the UK, they must not be mirrored in Scotland.

**All hospitals should have a self-administration of medication policy so people who can manage their own Parkinson's medicines are empowered to do so.**



## **4. The right to self-administer Parkinson's medications safely in all Scottish hospitals**

Parkinson's medication is time critical. Every minute counts. If someone with Parkinson's misses a dose, or medication is delayed by as little as 30 minutes, it can be very serious. People can become unable to move, speak or swallow and experience severe anxiety, pain or hallucinations.

Despite these risks, fewer than half of people with Parkinson's in Scotland receive their medication on time, every time, when they are in hospital.<sup>5</sup> It is a serious patient safety issue, and can lengthen hospital stays. When people become more unwell in hospital, it increases pressure on ward staff, rehabilitation, and social care services.

Many people who routinely manage their Parkinson's medicines at home have them taken away when they go into hospital, putting them at risk of harm.

All hospitals should have a self-administration of medication policy so that people who can manage their own Parkinson's medicines are empowered to do so. The right to self-administer time critical medication should be incorporated into the Charter of Patient Rights.

This needs to be part of a wider bundle of measures, including electronic prescribing and education, so that everyone with Parkinson's receives their time critical medicines on time, every time, as outlined in our recent [Time Critical Medicines Summit Report](#).

## 5. Clinical research opportunities across Scotland

People with Parkinson's want to take part in clinical research but are often unable to do so. As the leading European funder of Parkinson's research, we've invested over £100 million in vital research delivering groundbreaking discoveries, new medications and better care.

The new Scottish government must support clinical research and life sciences in Scotland. It must grow the infrastructure to conduct vital Parkinson's research, so that a wider range of people can take part, wherever they live in Scotland.

This includes taking action on NHS pressures that threaten the ability of NHS clinicians to engage in research alongside direct patient care.<sup>6</sup> It also involves working with researchers, clinicians, universities, third sector and commercial organisations to maximise opportunities to conduct and take part in research here.



**I see research as the only chance there is to advance knowledge about Parkinson's and move towards a cure or better treatments. If people do not take part, how can there be any progress?**

**David, who lives with Parkinson's**



## 6. Local physical activity provision

Regular physical activity supports people with Parkinson's to live as well as possible. Physical activity is good for everyone, and especially for people with Parkinson's. Many people find it essential to manage their Parkinson's symptoms, with improvements in muscle and bone strength, flexibility, balance, mental health and more.

People with Parkinson's face additional barriers to physical activity, so it is vital for exercise providers to know about the condition so that activities are safe, accessible and beneficial. People with Parkinson's say that Parkinson's-specific exercise classes and support groups are more helpful than general options.<sup>7</sup>

We work in partnership with local leisure trusts, sports organisations and NHS professionals to develop exercise classes specifically for people with Parkinson's. The new Scottish government must explore this partnership model to widen access to condition-specific exercise options in local communities. Embedding condition-specific knowledge in health and leisure settings must be part of a commitment to protect funding for grassroots physical activity.

More than 2 in 5 disabled people in Scotland fear that taking part in physical activity will mean their benefits will be taken away.<sup>8</sup> People with Parkinson's must not be financially penalised for taking part in therapeutic physical activity.

## 7. Closure of the evidence gap on Parkinson's-related dementia

About 3 in 10 (30%) of people with Parkinson's have dementia.<sup>9</sup> But Parkinson's dementia is often poorly understood by healthcare professionals, carers and patients. Many people remain undiagnosed with dementia, reducing their access to support.

Data on dementia in Scotland is limited. NHS Scotland does not currently collect data on subtypes, including Parkinson's dementia and dementia with Lewy bodies. This makes it impossible to identify whether there are gaps in diagnosis for different types of dementia, and to plan services that meet everyone's needs.

The new Scottish government must now meet the commitment to finding out how many people are living with dementia in Scotland, including the type or types of dementia that they have.<sup>10</sup>



**People assume all dementias are like Alzheimer's, but Parkinson's-related dementia is quite different. It's a treble whammy of physical, cognitive and mental symptoms, and general dementia resources and support are not always helpful. We need more interest, compassion and understanding about dementia and Parkinson's, and more action.**

**Claire, whose husband has Parkinson's and dementia**



## 8. Short breaks for people with complex conditions and those who support them

Parkinson's is complex. It affects every aspect of daily living. As it progresses, people need more care and support from partners, family members and friends.

Care partners often provide constant supervision and support with daily tasks and medication all day and overnight. Many do so without any other support.

Care partners who support people with Parkinson's need a break to maintain caring. The Care Reform (Scotland) Act established a right to short breaks. But those who support people with the most complex care needs are struggling to find placements that provide appropriate and safe care. There are delays in social work assessments, and settings that are willing or able to provide care to someone with advanced Parkinson's are limited.

We must make sure that unpaid carers who need a break the most can get them. The availability of short break placements for people with complex care needs must match local needs.



**My husband had his name down for day care, but places at centres that could cope with his disabilities were few so he did not access it.**

**Person caring for someone with Parkinson's**



## 9. Condition-specific support and a ‘Diagnosis Connect’ model for Scotland

Nobody should face a Parkinson’s diagnosis alone. Yet 40% of people with Parkinson’s and their care partners did not think that they received enough information when they were diagnosed.<sup>11</sup>

[Parkinson’s Connect](#) is our pioneering programme to connect with people with Parkinson’s, and their families, right at the point of diagnosis. It allows healthcare professionals to refer people automatically to Parkinson’s UK, connecting people to the support and resources available to them as early as possible. Already on offer in NHS Greater Glasgow and Clyde, we want to roll this out more widely across Scotland.

We think the new Scottish government should accelerate the implementation of projects like Parkinson’s Connect. Our experience could be transferred to a model similar to ‘Diagnosis Connect’ in NHS England.<sup>12</sup> Introducing something similar would allow NHS Scotland clinicians to refer people with long-term health conditions to specialist charities that can support them, reducing the burden on the NHS.



# References

- <sup>1</sup> Gandhi S.E., Grosset, K.A., Iruthayaraj, P.A., Gravesande R., Lee, L., Doyle, C., Yoav Ben-Shlomo, Y.B. and Grosset D.G (2025) "Comparative Analysis of the Incidence, Prevalence, and Survival of 8 Types of Parkinsonism in a Population-Based Study with 367 Million Person Years of Observation over 21 Years" Movement Disorders Clinical Practice.
- <sup>2</sup> Survey of 248 people with Parkinson's and unpaid carers (July 2025).
- <sup>3</sup> Gandhi S.E., Grosset, K.A., Iruthayaraj, P.A., Gravesande R., Lee, L., Doyle, C., Yoav Ben-Shlomo, Y.B. and Grosset D.G (2025) "Comparative Analysis of the Incidence, Prevalence, and Survival of 8 Types of Parkinsonism in a Population-Based Study with 367 Million Person Years of Observation over 21 Years" Movement Disorders Clinical Practice.
- <sup>4</sup> Parkinson's UK (2017) Cost of Parkinson's Report. We have adjusted the data on expenses using ONS Consumer Price Index inflation and income data using ONS Average Weekly Earnings (AWE) growth data.
- <sup>5</sup> Parkinson's UK (2023) [UK Parkinson's Audit 2022](#).
- <sup>6</sup> [Universities Scotland press release \(2025\)](#).
- <sup>7</sup> Survey of 248 people with Parkinson's and unpaid carers (July 2025).
- <sup>8</sup> Scottish Disability Sport, [Report Findings](#) (September 2025).
- <sup>9</sup> Aarsland D, Kurz MW. The epidemiology of dementia associated with Parkinson disease. *Neurol Sci.* 2010 Feb 15;289 (1-2) : 18-22.
- <sup>10</sup> [Scottish Government Dementia Strategy - Everyone's Story](#) (2023).
- <sup>11</sup> Parkinson's UK (2023) [UK Parkinson's Audit 2022](#).
- <sup>12</sup> [UK Government press release 17 June 2025](#).

**We're Parkinson's UK,  
the charity that's  
here to support every  
Parkinson's journey.  
Every step of the way.**

**Free confidential helpline 0808 800 0303  
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Saturday 10am to 1pm (interpreting available)  
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