

# Policy and Campaigns impact report 2024

We know public services are failing people with Parkinson's and we're determined to improve them. This is why influencing and campaigning is at the heart of the work we do.

While change doesn't happen overnight, we're proud to work with the Parkinson's community and health and care professionals to share your experiences with politicians and NHS leaders and demand better.

Here's what we've been doing to influence policy changes and how the Parkinson's community has been involved throughout:

## **Ensuring people get their medication on time in hospital**

The 2022 Parkinson's Audit found that only 42% of people with Parkinson's admitted to hospitals in England always got their medication on time, every time. To tackle this systemic issue, we worked with other national charities and health professional bodies calling on the government to take action.

As a result, NHS England launched a crucial three-year [Medicines Safety Improvement Programme](#) to address this problem following our emergency summit on time critical medication in March 2024.

We managed to secure this very rare opportunity thanks to years of tireless campaigning by the Parkinson's community and the charity. The programme will test and help spread effective interventions across the NHS in England to ensure time critical medication is delivered on time in hospitals.

We are working closely with NHS England so that the programme fulfills this promise.



Our emergency summit on time critical medication brought together patient groups, healthcare professionals and NHS England to take action on this important area.

## **Getting access to new treatments**

New treatments for Parkinson's are rare, so when something is shown to help manage the symptoms of the condition, and is approved for use in the NHS, it is potentially life-changing.

We provided evidence that helped the Scottish Medicines Consortium (SMC) decide to fund Produodopa (also called foslevodopa-foscarbidopa). The SMC decides which medicines are approved and funded in NHS Scotland. This is the first new treatment for Parkinson's that has been approved in years and can be life-changing for some people with severe movement related symptoms that are not managed by other Parkinson's medications.

The All Wales Medicines Strategy Group approved opicapone (also called ongentys) as a first line treatment within NHS Wales. The treatment is a COMT inhibitor that makes levodopa medications work more effectively. This could benefit hundreds of people with Parkinson's in Wales, who will get the right treatment, the first time.

## **National changes on data and research funding**

For the first time, NHS England published data on the rate of Lewy body dementia diagnoses. This is a welcome step - and one which we called for in our [Nobody really knows us](#) report. People living with Parkinson's are six times more likely to develop dementia than those without the condition. We found that the health and social care system is failing to meet their needs, in part because it doesn't know how many people are living with Parkinson's-related dementia. This new data will mean that the NHS can better tailor care to the specific needs of people with dementia with Lewy bodies, and provide training for staff so they can more adequately support people living with Parkinson's-related dementia.

The Department of Health and Social Care commissioned [an important new project](#) on Parkinson's research and funding as a result of our meeting with the then Health Secretary, Victoria Atkins, and the Movers & Shakers. We don't currently have the full picture on how much is spent on Parkinson's research, what topics are being researched, and whether there are any gaps. Securing this project means that we will have the crucial information we need to make sure that future research meets the needs of the Parkinson's community. The findings could even make the case for greater government support of future Parkinson's research.

Plans to update the Adults with Incapacity Act in Scotland include reviewing how adults with incapacity can participate in research. We have been calling for people to be allowed to make their wishes known about taking part in research, should they lose capacity as their condition progresses. Such a change would make it easier for people to take part in research into possible treatments for some of the most challenging aspects of Parkinson's.

## **Influencing the social security system**

People with Parkinson's are 10% more likely to be inaccurately assessed for Personal Independence Payment (PIP) than other claimants. They tell us that the application and assessment process is degrading, and that assessors don't understand rapidly fluctuating conditions like Parkinson's. We are one of a handful of charities who have been invited to sit on a new board that advises the private providers who conduct PIP and Universal Credit assessments on behalf of the government.

The Board brings together representatives from the Department of Work and Pensions, the companies who carry out the health assessments and charities, giving us a vital opportunity to discuss the challenges facing people with Parkinson's with those who provide the service. We hope this will lead to major improvements in the way health assessments are carried out for people with fluctuating and degenerative conditions like Parkinson's.

## **Campaigning to improve services**

We work with local volunteers and groups to campaign for better support in areas with specific issues.

Throughout the year we worked with 24 health bodies, influencing changes in seven of these to increase the Parkinson's workforce and improve training and practices to ensure people get their medication on time in hospital.

Here are some of the campaign successes.

### **Increasing the Parkinson's health and care workforce**

Our campaigners and staff contacted 200 Councillors and all local MPs after discovering that the East Lancashire Parkinson's services were at risk. Thanks to this campaigning, the *Lancashire and South Cumbria Integrated Care System* confirmed that they will continue. They've agreed there will be a change of provider and in developing the services they'll engage with Parkinson's UK and people with the condition to ensure they meet the needs of the community. This work means that over 850 people living with Parkinson's in the area will be able to access the specialist support they need to manage their symptoms and stay well.

*North Cumbria Integrated Care Trust* has now recruited for the vacant Parkinson's Nurse post, after several years of waiting. We hope this new nurse will mean that people living with Parkinson's in the area get the support they've been missing out on for several years.

Sustained pressure from the Parkinson's community through campaign activities and a petition have paid off in the *North West Anglia Trust* as they recruited a new Parkinson's nurse and a physiotherapy post, with initial funding from our grants programme. This

community campaign means the Trust will provide the health care support people with Parkinson's in the area need to stay well and the Trust will also collect data to make the case to retain the service after the initial funding.

Following our involvement, the *Plymouth Home Based Care pathway* that supports over 200 people with Parkinson's will continue, albeit with some changes. This means the service will continue to operate and enable people with the condition to get support to manage their symptoms largely at home.

### **Peter's story**

"It's more important than ever for the government and MPs as well as local NHS Trusts to hear from people with Parkinson's about challenges they are having with accessing care and financial support.

My wife, Laurel (who has been living with Parkinson's for nearly 11 years) and I with Sarah Champion, our local Lib Dem MP and her team. We shared our concerns about Parkinson's services in Buckinghamshire and asked her to take action.

"We were delighted that Sarah tabled four written questions in Parliament and also wrote to the Chief Executive of Bucks Healthcare NHS Trust.

"We've thanked her for asking questions and suggested she join the All-Party Parliamentary Group on Parkinson's. I'd encourage any groups or volunteers to reach out to their MP, and get in touch with the Campaigns Team if you need help."

### **Improving Blue Badge processes**

After several meetings with *Norfolk County Council*, they consulted with the Parkinson's community about their communications around Blue Badges and have used their feedback to change all of their communications (letters and information to applicants) to ensure they are now easily understood.

The Council have also added Parkinson's awareness information to their staff intranet, following a successful awareness session with a representative from the local group. We hope these changes will improve the process and experience, make it easier and quicker to apply for a Blue Badge in the area, and that ultimately more people with Parkinson's are successful.

In *York* our campaigning with members of the community meant that the City Council committed to making improvements about how they process Blue Badge applications, which will benefit people with Parkinson's by making it easier and quicker to obtain one, enabling more people to get out and about.

And similar improvements to Blue Badge processes have also been made in *Trafford* following ongoing pressure from volunteers and local staff in the area.

### **Helping hospitals ensure people get their medication on time in hospital**

An NHS nurse, who also lives with Parkinson's, has successfully made the case in the hospital where she works to deliver 10 staff training sessions on time critical medication at the *Queen Elizabeth hospital trust in Kings Lynn*.

#### **Campaigner Tincy hosting a stall on World Parkinson's Day**



Following several incidents that campaigners raised with staff at *Basildon* hospital, the trust have agreed to train staff around patient safety, Parkinson's and the importance of time critical medication to keep people with the condition well.

And *Colchester Hospital* have agreed to use Parkinson's UK resources across their wards and are embarking on a quality improvement project around time critical medication. We hope this will enable staff to better understand the condition, the importance of medication timing in Parkinson's and that this will improve care for those with the condition who attend these hospitals.

### **Putting Parkinson's on the election agenda**

When the general election was called in May, we shared information with our local groups and volunteers to encourage them to contact their election candidates and put Parkinson's on the agenda. Our supporters connected directly with 48 candidates during the election, receiving responses from 12 of them.

- Volunteers in Yeovil, Selby, Whitehaven & Workington, Southend West and Leigh, North Bedfordshire, Bolton North East, Bury St Edmunds, East Grinstead and Crawley spoke to or contacted candidates.
- All 37 candidates standing in Sheffield constituencies were contacted and as a result she has made links with local councillors to raise issues about Blue Badges.
- Out of all the candidates contacted, four were elected. Parkinson's UK has followed up with them, asking them to meet us at their autumn party conference and to join the All-Party Parliamentary Group on Parkinson's.

## Asking for my vote?



Then let's talk about Parkinson's care and support

**PARKINSON'S<sup>UK</sup>**

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### Nicky's story

"I worked with Kim, our local campaigns officer, to get the Parkinson's UK election posters out across Sheffield.

"Members of the Sheffield Support Group of Parkinson's UK group also wrote to every election candidate across the various constituencies - we focused on Blue Badges as it's a real issue in our area.

"We've been really pleased that some of the candidates responded and suggested they'd meet with us after the election, if they're successful."

As you can see, campaign volunteers were really busy working with us and the wider Parkinson's community to improve health, care and transport services throughout the year. In total, they shared their concerns and suggested solutions to MPs, health bodies and local councils 135 times throughout 2024.

And campaigners supported our work by taking 28,443 online actions during the year, which included signatories to the Movers and Shakers 'Parky Charter', which was handed in to Downing Street on World Parkinson's Day.

**The Movers and Shakers, with Parkinson's UK CEO Caroline Russell at Downing Street**



Matt Crossick/PA Media Assignments

**Juliet Tizzard, Director of External Relations commented:** "We've achieved some amazing things over the last year in our campaigning to improve health, care and transport services across the UK. We've made a real difference in some areas, but we know there's more to do as everyday we hear from people with Parkinson's who are really struggling. That's why, alongside our campaigning, we fund NHS posts and offer learning opportunities to health and care staff so they understand Parkinson's better.

“We can’t do this campaigning work alone. We need more people affected by Parkinson’s to speak out on what’s not working and to work with us to push for change. It’s only by working together that we’ll create the noise needed to shift the NHS and government. And we know you can’t wait for better services that meet your needs!”

## Work with us to improve services

The success of both our policy and campaigning work depends, as ever, on members of the Parkinson’s community sharing their experiences with us and volunteering to make a noise with decision makers. We’re always keen to involve more people in our work.

Why don’t you:

- [share your story](#)
- [find out more about becoming a campaign volunteer](#) to make a change in your local area.

Find out [other ways you can get involved](#) and support Parkinson’s UK.



### Mark’s story

“I’d recommend attending one of the party conferences with Parkinson’s UK.

“The lived experience is integral to helping people in power understand what it’s really like for carers and the cared for, and why our ‘asks’ are so important.

“It can be a bit nerve-wracking if you haven’t spoken to MPs before, but the staff team are really good at supporting volunteers to get their points across, and the MPs are willing to listen and help where they can.”

**Carer Mark Worrall meeting with Justin Madders MP at the 2024 Labour Party conference**