

PARKINSON'S<sup>UK</sup>  
NORTHERN IRELAND

# Parkinson's: Who cares?

Capturing the voices  
of carers.

June 2024



Department of  
**Health**

An Roinn Sláinte

Mánnystrie O Poustie

[www.health-ni.gov.uk](http://www.health-ni.gov.uk)

The *ele*  
Community  
Foundation  
Northern Ireland





## Acknowledgements

**Parkinson's UK Northern Ireland would like to thank all of the carers who took part in this research. They generously gave their time and shared with openness and honesty. It was an honour and a privilege to hear your experiences.**

Thank you to our core steering group of volunteers who have been instrumental in co-designing this work. We look forward to continuing our campaign together for change.

We would also like to thank the Community Foundation Northern Ireland's Carers Support Fund for funding this work.



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# Introduction

## About Parkinson's in Northern Ireland

**Parkinson's is the fastest growing neurological condition in the world<sup>1</sup> and currently, there is no cure. 1 in 37 people alive today in the UK will be diagnosed with Parkinson's in their lifetime. In Northern Ireland, 4,200 people are already living with the condition<sup>2</sup>. While the majority of people develop symptoms after the age of 65, thousands of working-age people are also affected<sup>3</sup>.**

People with long-term neurological conditions are facing huge waiting times for diagnosis. At least 1 in 20 patients have been waiting over 5 years for a first appointment<sup>4</sup>. There are significant delays for consultant reviews, medication changes, mental health support and access to allied health professionals, for example physiotherapists, and speech and language therapists.

People living with Parkinson's have particularly complex and varying needs. They need long-term support to minimise the impact of their symptoms and maximise their independence and quality of life.

Parkinson's does not only affect the person with the diagnosis. Everyone close to them feels the impact too. As Parkinson's progresses, people require high levels of personal care. Much of this care is provided by partners, relatives or close friends - as so called informal or unpaid care. This can include help with getting up, eating, drinking, dressing, washing and toileting as well as support

with communication, changes to behaviour, mental health or cognitive symptoms.

Family and friends often find themselves thrown into a caring role without any training or experience - and with very little support. Carers NI's State of Care Survey 2023 found carers "play a critical role in the survival of the Health and Social Care (HSC) system, with evidence suggesting that, as statutory services in Northern Ireland have deteriorated more and more, unpaid carers are increasingly stepping in to fill the gaps<sup>5</sup>".

The needs of carers as individuals are often overlooked. The aim of the *Parkinson's: Who Cares?* project is to capture this.

## Background

**In January 2024 with funding from the Community Foundation Northern Ireland, we undertook a series of focus groups to identify the needs of carers for people with Parkinson's across Northern Ireland. We held 7 focus groups across Northern Ireland in Armagh, Ballymena, Belfast, Derry/Londonderry, 2 sessions in Lisburn and 1 online.**

Overall, we had 44 people attend, 39 of whom were unpaid carers. Some carers expressed concerns about attending without the person they cared for. Either they didn't feel confident enough to come on their own, or, practically it was just not safe to leave their loved one at home unattended. For this reason, we were flexible in allowing those living with Parkinson's to come along with their carers.



This report summarises the discussions from the focus groups, with quotes from members of the Parkinson's community who took part. It also includes recommendations for Parkinson's UK, government departments and ultimately the Northern Ireland government.

## Who we spoke to<sup>6</sup>

**We asked participants to complete a short survey to provide their gender, name and relationship to the person with Parkinson's as well as additional information about health and wellbeing.**

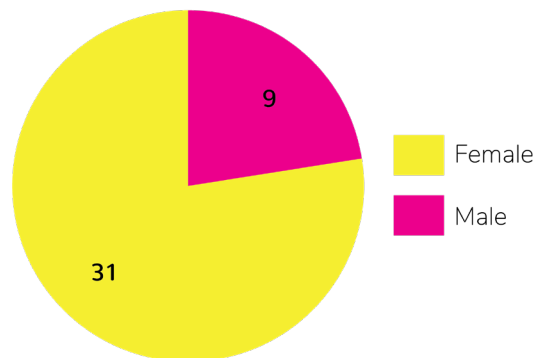
In terms of age, the majority of carers were between 60 and 79 years of age which is reflective of the age profile of Parkinson's in Northern Ireland. However, 10 were under 60 years old. We asked participants to share their relationship with the person with Parkinson's. While the majority were wives, husbands, or partners we also had a sister, daughter and parents.

Half of carers (20) had been supporting someone with a Parkinson's diagnosis for over 10 years with the longest being 30 years. A quarter of participants were supporting someone diagnosed within the last 2 years. However, many shared that they suspected an issue long before the formal diagnosis.

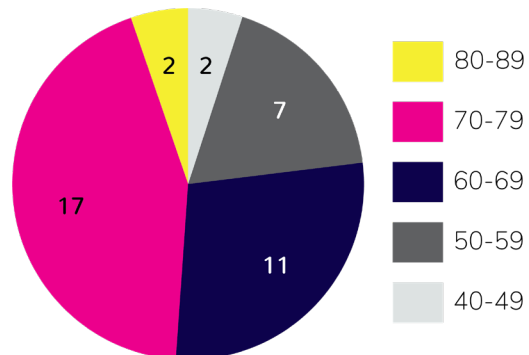
The carers we spoke to were mixed in terms of age and relationship to the person with Parkinson's. This range of experiences added richness to the discussions. Participants were at very different stages in their lives, with working-age households, retired couples living on their own, and some with very young children.

Some were carrying out multiple caring roles, including looking after other siblings, parents and grandchildren. Where their loved one was at in their Parkinson's journey, and their life stage, had an impact on participants' support needs and issues.

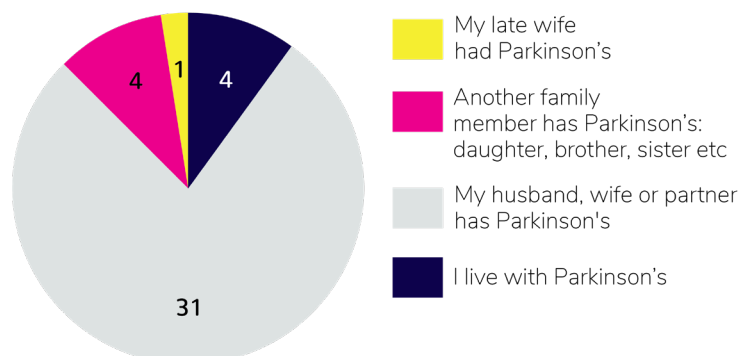
Gender:



Age:



Connection to Parkinson's:



<sup>6</sup> Based on survey responses from 40 participants. Not all questions were completed.



## What we heard

While we prepared questions for the focus group sessions, we let the conversation flow organically. This helped participants feel safe and secure to open up and share. Each discussion was unique. However, several themes emerged and the focus groups discussed the impact of:

- life as a carer
- living with Parkinson's
- a lack of social care support
- relationships
- physical and emotional wellbeing of carers
- finances
- medications
- access to and better understanding of Parkinson's by health professionals.

### Life as a 'carer'

Each focus group discussed language and terminology associated with being an 'unpaid carer'. Many shared that they didn't identify or see themselves as a carer. Instead, many preferred to be referred to as a husband, wife or partner. The term 'carer' often elicited a very emotional, negative response at the initial stage of diagnosis.

**“I don't want to be a carer, it was profoundly difficult to be referred to...there's an expectation, you're the wife, you're the carer.”**

It was hard for the person living with Parkinson's to hear “his wife being called a carer because somebody had put him in a box of - I need to be cared for.”

Carer is “a very cold word for me, caring is the empathy that I would try to have for [PWP], it is very difficult for him not being able to do things.”

There was no agreement across the groups on what term should be used. However, there was a



sense that as Parkinson's symptoms progressed and the support required increased there was a change in the relationship, to very much becoming a 'carer'. This was often when physical needs increased.

**"For the first 10 years of his diagnosis, I refused to be called a carer. I said I'm not a carer, I'm his wife and it's only in the last 3 years since COVID that I felt like a carer because he has deteriorated so much."**

**"It's been quite rapid progression and I don't feel like his wife anymore, I feel like a carer...I need to do something here for me. So that I can be strong to help him."**

There was an expectation that as a wife or partner you have a 'duty' to assume a caring role. It was a natural part of the relationship progression and because of that it was hard to identify with the term 'carer'.

**"You feel a bit of a fraud if you call yourself a carer."**

When we explored their experiences further it was clear that all participants were providing care at multiple levels. But just like living with Parkinson's, the role of being a carer varied significantly and the level of care changed with progression. Some were providing physical care with washing, dressing, feeding, hygiene and toileting. Or for safety reasons they had taken over responsibility for driving and transport.

Across the groups there was a discussion around being responsible for motivating the person living with Parkinson's. Often this was in all aspects of their lives, from taking medication, attending appointments and eating the right food, to using equipment or undertaking 'safe' activities. This at times caused frustration in the caring relationship,

with carers being accused of being 'bossy' or 'nagging'.

**"I have to be the pusher, the manager, the motivator...need to be the boss."**

Carers were often responsible for understanding and administering medication as well as dealing with side effects. They were key in securing, attending and chasing up medical appointments to support the person living with Parkinson's.

**"I do all of his medication. If it was left to him he wouldn't know when to take it. That's been a long time since he's been like that."**

**"I'm now at the stage when I have to give them [medication] to him at the time as he's not remembering to take them."**

Many of the working-age carers had become, or felt in the future that they would become, the main source of income within the family. Others shared they were now responsible for the financial aspect of running their household, such as managing bills, insurance and savings and investments. They also carried the mental load of running a home including cooking, cleaning and laundry, as well as managing family life.

While these roles were undertaken primarily with love and kindness, at times this level of responsibility caused frustration and anger. Carers are constantly on alert and attending to the needs of the person they care for. Often this has become so ingrained that it's a subconscious reaction and second nature. Whether or not they identified as a carer, participants were experts in dealing with Parkinson's and their loved one's care needs.

**"It didn't change in the beginning but it sort of has changed now...it's all those little adjustments, tiny, tiny wee things."**

## Impact of living with Parkinson's

**Carers play a vital role in supporting people with Parkinson's to live well with their diagnosis. Often they're relied on to provide 24-7 unpaid support and are expected to juggle the physical, emotional and financial costs of caring.**

Participants identified a major lack of awareness and understanding surrounding Parkinson's and the variety of symptoms - not just from the general public, friends and family but also from medical professionals.

"People seem to think that Parkinson's is all about sitting and shaking but it's so much more. He doesn't even have a tremor."

"We don't go out anymore because people think he could be drunk when out and about."

Participants felt this lack of understanding in many areas of their lives, from accessing the right support to going out to eat and socialising. They often limited their activities because of misconceptions or lack of appropriate access and equipment.

The sessions highlighted the daily reality of living with Parkinson's and dealing with the complexity of its side effects. These included hoarding, apathy, anxiety, poor diet choices, sexual compulsion, physical deterioration, reduced cognitive ability to plan and remember, softness of speech, tripping, falling and stooping.

"There's a lot of work. I do everything, and I don't mind doing everything but I can't be that person that he probably wants me to be at the minute."

The unexpected life changes and the impact of symptoms that come with living with Parkinson's at times caused carers to feel anger and frustration.

One participant expressed a very raw experience: "I said one day to [PWP] I don't think you realise how selfish you have become and he was shocked. He seemed to be really shocked."

"I shout at him sometimes and get really annoyed. It's because I hate the way it's left him. It's not fair, he shouldn't be like that. He was a great person before and he's not that same person anymore...but it comes to the point when I can't take it anymore."

## Social care support

**When asked about the external support they received, only one person had support from formal paid carers. Another participant shared that her father had admitted himself to a nursing home to be cared for, even though they had made provisions for him in their home.**

Other than limited friends and family support, the majority of carers were doing everything on their own. Very few had a formal Carer's Assessment from their Health and Social Care Trust. Those who had reported they were of little value.

There was a reluctance across all focus groups in terms of accepting or even asking for formal support. Many shared that they could cope currently, but thought that in the future they may need additional help if the physical aspects became too much.





“I can cope at the minute but I just say that if things change, he’ll go further down and not return to where he is at the minute.”

They wanted to be able to look after their loved ones at home and know they were safe and cared for.

“I don’t think there’s an answer to be honest because you don’t want them taken away and put into care, you want them at home and you want to do your absolute best for them.”

However, there was an acceptance that this at times took a big toll on participants. One particular area of concern was sleep. Many shared that they experienced very disturbed and broken sleep at night due to various Parkinson’s symptoms. This left them feeling exhausted.

“He would want to go to bed early and I don’t want to go to bed early because I need my sleep, and if he goes to bed earlier he will be up in the middle of the night and then I won’t get my sleep, so I tried to hold on time going to bed and that creates an awful row.”

“[After] being kicked and throttled in bed, we sleep in separate rooms. You were exhausted and you lost your sleep and yet you were required to be going all day. You have to make a lot of changes.”



## Relationships

Carers play a vital role in supporting someone to live well with their diagnosis. Often they are relied upon to provide 24-7 unpaid support and are expected to juggle the physical, emotional and financial costs of caring.

“It’s not a life that we’ve chosen.”

“Not the same person that I married.”

“We got the diagnosis last year and it was an earth-shattering bolt from the blue.”

The change in dynamic was particularly evident in the more advanced stage of Parkinson’s, often when more physical care was required. Numerous people shared that at this stage they felt they had become a ‘carer’.

There were discussions around anticipatory grief and feelings of anger over the life that had been planned but would now not happen. At the same time people expressed feelings of sadness and worry for the person they love and acknowledged how hard it is to be living with Parkinson’s.

“Part of what I really went through and what I felt really strongly was I’m going to lose him mentally, physically, emotionally...So I have



been living with that anticipation and mostly terribly sad that he has all of this to go through...he’s going to be chipped away from me and that made me feel really really terrible.

“It is also the frustration at the whole situation as well the disappearance of the person in front of you.” There was also an acknowledgement that their lives had become centred around Parkinson’s. “It feels like our lives are consumed a lot by Parkinson’s.”

Some shared that the diagnosis had brought them closer together as a couple and that they now spent more time doing things with each other instead of individual hobbies.

“It’s not a life that we’ve chosen but yet the men in our lives didn’t choose it either.”



## Physical and emotional wellbeing of carers

### Caring can have a significant mental and emotional toll on carers.

“From my own personal point of view, there are times when I’ve felt at my wits’ end, completely alone, and it’s caused me to have a lot of dark thoughts. I’ve never been like that in my life before but this, it’s tough.”

Due to the degenerative nature of Parkinson’s, some carers talked about how their world had become smaller, as their loved one’s condition had progressed. They would limit social activities and stop going out to eat, or to events, as it had become too complicated and hard. This social isolation often leads to loneliness.

“There is no conversation in my house at all. I would say things...and most of the time he’s not there, he’s not listening and if he does he doesn’t answer me. And I would find that very lonely. It’s very lonely.”

“I haven’t been anywhere at Christmas. I didn’t get to buy a present, as I didn’t get out.”

“I don’t have anybody else in my life that has Parkinson’s in their life and I’ve never been to groups or branches.”

Their own care needs often come last as their primary focus is on the person living with Parkinson’s. Even when at times this makes them very sick so it’s harder to carry out their caring role.

“I have a problem at the minute, in that I need surgery but how do I have surgery? I’ve told

the neurosurgeon that I can’t have surgery because what am I supposed to do with [PWP]. I’ve no support. I’ve never had a Carer’s Assessment.”

Some shared that they’re concerned about how any changes to support them would interrupt the daily routine and potentially negatively impact their partner’s condition.

“I think he would need to go into respite. First, he wouldn’t even hear of it. He’s kind of come around [to] it but I can also say that a change in his daily routine would set him back further.”

“We try not to talk about being a Parkinson’s person, try not to define him as Parkinson’s. But watching other people I’m aware that things could get a lot worse and that scares me a wee bit too. I am not in a great place [got upset] due to the change of dynamics. There’s a lot worse he could have.”

There was recognition of the need for carers to take time to do things for themselves to keep well so they’re able to look after others. Going for a walk, having lunch with friends, getting their nails done or having a massage were mentioned. Sadly for many, these were very limited, as there was no one to support the person they cared for if they took time out.

## Financial impact

**The groups identified a ‘hidden cost’ of living with a long-term condition. For example, having to pay for private medical appointments and therapies to stay well.**

“Everything seems to have a cost. We are not well-off or we are not by any means struggling financially but there is a financial impact to having Parkinson’s, and it’s unseen.”

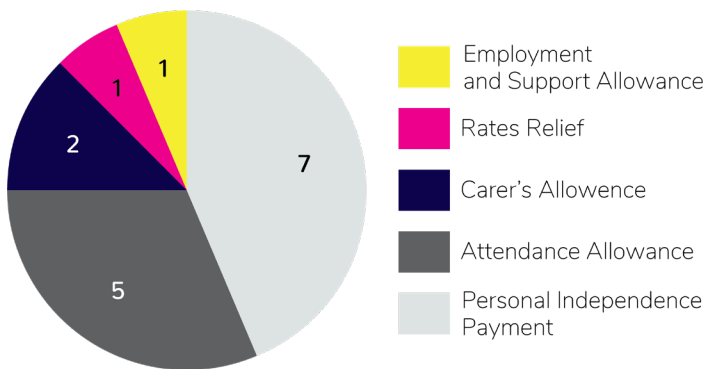
Heating the home and doing laundry also has a financial impact.

“My husband is very very cold all the time. I have to have my heating on all the time...plus all the washing.”

Participants gave numerous examples of significant financial changes they had undertaken to support someone living with Parkinson’s including undertaking home improvements, and downsizing or moving house to more suitable accommodation.

## Benefits

We asked those who attended if their household received any financial assistance.



Many of those who attended the focus groups did not know that they might have an entitlement to benefits. There was a lack of knowledge about Personal Independence Payment (PIP), Employment and Support Allowance, Attendance Allowance, Carer’s Allowance, Pension Credit and Rates Relief.

Pension Credit wasn’t discussed at any of the sessions. Some who received financial support had been helped to apply by independent advice agencies.

“Advice NI were on the call, which supported him to apply for PIP.”

There were discussions around the inadequacies of the financial assistance and support available from benefits, particularly after state pension age when many receive their Parkinson’s diagnosis.

Limited financial support is available for care. For example, unless a carer is already in receipt of PIP pre-state pension age the only support available to supplement care needs is Attendance Allowance. Unlike PIP it doesn’t have a mobility component and isn’t a passporting benefit for a Blue Badge. The upper age limit to claim Carer’s Allowance is also state pension age.

“Why is it assumed that generally when you’re retired that you don’t need these things? Surely to goodness, there’s more need once you retire.”

“Financial impact: you have lost your wage. I don’t get anything from anywhere.”

There was frustration at being penalised for having savings and being above the income requirements and therefore not being eligible for a Disabled Facilities Grant. Carers highlighted that ultimately, by helping keep the person at home, they’re saving money for the health and social care system.

“Never thought they’d have to navigate the financial system and be penalised for having savings after working your whole life.”



## Employment

**The financial impact of being a carer was highlighted, caused by losing both the carer and person they care for's income and earnings.**

"We have lost 2 wages."

"We have gone from 2 full-time jobs to half a job."

Experience varied across the focus groups. Some carers had to give up work or reduce their hours to balance their work life and home caring role. In positive situations, they found their employers were flexible and supportive. But sadly in some situations they were left with no choice but to leave the workforce.

"I'm used to being in control and being efficient in work but all of a sudden I've had to give that up because I couldn't get my sleep at night, so I couldn't function during the day and I need to be on point."

"I've taken a career break from my job because it's gotten to that stage that somebody needs to be with him all the time, so it's just the start of my journey."

Some employers offered carer's leave. However, in most cases carers were expected to take annual leave or unpaid leave to attend medical appointments and cover their caring role. While they were happy to have this flexibility, carers were left with very little annual leave or had to work extra to make up the time.

"Extra leave would be helpful because you lose your leave very quickly. There's no issue about having to go to appointments but you have to make that time back and use your leave."

"I have 5 days carer's leave over a year [used up] between mum and [partner] for appointments. I took 19 days of annual leave last year for the [PWP] DBS service."

## Medication

**People with Parkinson's rely not only on taking their medication, but taking it on time. A delay of as little as 30 minutes can mean the difference between functioning well and being unable to move, walk, talk or swallow. Delays can cause stress, anxiety, immobility, severe tremors, and in extreme cases, death.**

Significant numbers of carers shared they had witnessed side effects from medication such as delusions and hallucinations. They expressed that they had difficulty in accessing medical professionals to have the person living with Parkinson's symptoms reviewed and/or medication changed.

"We spent the best part of the day dealing with hallucinations and delusions, all drug-related. I had a great deal of difficulty getting anybody to take responsibility for changing the medication."

"When the medicine stops working effectively, definitely his cognition goes down, and his memory."

Carers shared that their lives are planned and dictated around medication and 'on' and 'off' periods. They plan appointments, trips and social occasions to coincide with when medication is effective.

"Your whole day is geared around tablets."



“Once the Madopar kicks in we have a window, but after that window, it’s just a different world.”

There were also examples of the negative impact when medication wasn’t administered on time in a hospital setting, and a general lack of understanding from medical professionals surrounding Parkinson’s symptoms.

While medication is essential, some carers shared that neither they nor the person they support had been given information on how and when to take it, and in some cases even why it was being prescribed.



# Access to and better understanding of Parkinson's by health professionals

**Carers shared that while they're not living with Parkinson's themselves, they're very much dealing with the impact and managing the condition on behalf of their loved one.**

Very quickly they have to become experts in their loved one's care, observing every move and action, assessing the impact of their medication and mitigating against side effects as well as dealing with changes in movement, speech and mood; and navigating cognitive changes all while worrying if it's related to Parkinson's, other underlying conditions, or something else. They're balancing all this alongside maintaining their relationship with the person they care for.

While levels of support and advocacy varied depending on the stage of progression, all carers carried a huge weight of responsibility to ensure that the person they supported was living as well as possible. This undoubtedly has a major impact on them.

Their experience of support and engagement from healthcare professionals varied significantly. There were numerous stories of medical professionals lacking an understanding of Parkinson's and its symptoms. Some GPs failed to consider a diagnosis as there was no tremor or the person was 'too young'.

Some received excellent support and had frequent appointments and access to various allied health professionals. They spoke very highly of the support received from Parkinson's specialists in the movement disorder clinic

in Belfast and from Parkinson's nurses.

There was widespread agreement that it was helpful to speak to someone with specialist Parkinson's knowledge.

Sadly others reported that they had not seen a consultant in years and had no access to a Parkinson's nurse. There was no consistency across Northern Ireland.

**"We were lucky. We had private health care through a work package and we got a diagnosis in only 2 months and for over 10 years he had his appointment every 4 months. Then the consultant said he wanted him to leave private because you're not able to access a lot of services [including Parkinson's specialist nurses]. So he's gone into the NHS and hasn't seen anybody for over 8 months."**

**"I can't get physio for him, still waiting for physio. We've been waiting 2 years."**

Due to the pressures on the health system in Northern Ireland and chronic waiting lists, many have been forced to pay for a private diagnosis and subsequent support.

**"Initially we had gone private because it was taking so long."**

Evident across all sessions was the strain and frustration of having to understand and navigate a complex healthcare system as well as having to continually fight for access to basic services such as GP appointments, physiotherapy and consultant reviews.

**“I feel like we’re fighting the system. I’m fighting for him and you’re mentally tired and physically tired.”**

**“Fighting against the tide all the time. Why is it such a fight? Why can’t things just go simply? Every aspect there’s a barrier. When does the barrier come away? And it gets easy? Does it?”**

Carers also shared that they try to attend appointments alongside the person with Parkinson’s as these can be overwhelming, with a lot of information shared quickly and often at a very complex level.

They added that when they don’t attend appointments, things are often missed or overlooked. Sometimes the person living with Parkinson’s downplays the daily impact of their symptoms or doesn’t even notice them. Due to cognitive decline in some people living with Parkinson’s, details of discussions and actions may also be forgotten or not understood.

**“He doesn’t even tell the consultant how bad he is and won’t admit to himself how bad he is.”**

Carers’ experience of being included by medical professionals varied significantly. There were experiences when healthcare professionals spoke directly to carers instead of the person living with Parkinson’s. Others shared that they weren’t allowed to be a part of the appointment, particularly with telephone appointments.

**“The thing I found is, they keep addressing the carer and dehumanising the person.”**

**“I can’t even remember the man’s name. We were at the Ulster Hospital and he wouldn’t even let me in the room. He said ‘Would you mind waiting in the corridor?’ and he put me out.”**

In contrast, others described being actively engaged and listened to as experts in their partners’ care, with staff appropriately considering their concerns and views.

**“I need to hear this from your side, from the care side. I’ve heard from him, but you tell me. You’re his wife. And she gave me that weight and I appreciate that.”**

Some carers shared there were issues they wanted to discuss with medical professionals, but didn’t feel comfortable raising it in front of them. These included sensitive issues such as sexual compulsion or cognitive decline. They noted that they struggled to find a way to communicate these concerns.



# What carers need

We asked carers to share what would help them in their caring role.

## Parkinson's-specific information and support

Carers highlighted a need for additional information on what support is available and how it can be accessed; particularly about living with Parkinson's. They were clear this would be helpful from diagnosis, as part of discussions on progression and expectations.

"Going back to the very beginning, at diagnosis. Some sort of your husband has Parkinson's, this is going to impact you. Now there's a whole lot of information. This is what you can expect, it can be different for everyone. The whole process."

"Parkinson's UK website was our go-to. It was there that we found, try and take somebody with you to every appointment, so much information."

The discussions identified a need for Northern Ireland-specific benefits support related to Parkinson's.

## Recommendations

- Parkinson's UK NI to undertake an awareness-raising campaign highlighting the support offered through the local adviser team, including signposting to services and the Parkinson's UK First Steps programme.
- Parkinson's UK NI to review how it provides benefits advice.
- The Department of Health should ensure that people newly diagnosed with Parkinson's and their care partners are made aware of sources of support and information including from Parkinson's UK NI.

## Access to a break from their caring role

**Opportunities to have a break and respite from the caring role were highlighted as a major priority. The majority of carers had no formal support. They wanted to be able to leave the person they cared for and know they were safe. Support at night time was a priority to ensure carers could sleep and be well rested to manage their daily caring activities.**

“I normally don’t leave him longer than 1 hour 30 minutes.”

“You feel very guilty [leaving them alone] but you have to have your own outlet.”

Carers in Northern Ireland have the right to have their needs assessed through a Carer’s Assessment, and the right to a support plan identifying what the Health and Social Care Trust can do to support them in their caring role.

It is evident from all these discussions that **this is not happening**. There is an urgent need to increase understanding and awareness around the Carer’s Assessment and support offered by Health and Social Care, Care Coordinator teams.

It’s also essential that Health and Social Care Trusts have adequate funding to provide support to help carers. This includes for the provision of short breaks, and for regular, occasional or emergency time-limited carer breaks. Stretched budgets and long waiting lists mean that this isn’t currently happening.

Across the focus groups, there was limited knowledge and understanding of the different types of social care support available in Northern Ireland, for example Self Directed Support and Direct Payments. For those eligible, these can provide choice, control and flexibility over the support they receive.

## Recommendations

- **Health and Social Care Trusts must fulfil their legal duty to carry out Carer’s Assessments and ensure adequate funding is available to provide support to carers, most urgently in terms of short break services.**
- **Parkinson’s UK NI to raise awareness within the Parkinson’s community of the different types of social care support available, including Self Directed Support and Direct Payments.**

## Support from other Parkinson's carers

**Feelings of loneliness and social isolation were identified across the discussions. Carers identified a need for more social interaction and support, particularly from those with lived experience as Parkinson's is so different to other conditions.**

"You talk to your friends and all but they don't appreciate it. You have to live it to know it."

"Hard to talk to friends because they're sympathetic but you don't want them to be sympathetic. You just want them to let you moan and you don't need a solution because they can't give you a solution, but you don't want them to feel sorry for you."

They identified that they would like an opportunity to meet up with others who are caring for someone living with Parkinson's. They felt this would be of benefit in a number of ways, including to have a safe space to be able to discuss their experience, but also to socialise, build friendships, and be themselves as individuals.

## Recommendations

- Parkinson's UK to review the support offered to carers and embed the findings from this report and the recent *Minds Matter* project in our future practice/services.



## Financial support

**The carers we spoke with were clear they were happy to carry out their role and did so with great love and affection. They didn't want to receive payment for their unpaid caring role. However, it was apparent that other financial support would help make it easier for them.**

Living well with Parkinson's comes with financial costs. These range from paying for private appointments and treatments, to travel costs for medical appointments, and increased heating and household costs that stem from living with a long-term condition. These costs can be significant.

Using rates of inflation up to 2022<sup>7</sup>, we estimate that each household in Northern Ireland that includes someone with Parkinson's has an additional £18,182 of annual costs. This figure includes both expenses incurred by the person with Parkinson's and their household due to the condition itself and the associated loss of income.

Focus group participants reported they received very little financial support from the government to cover their additional care costs. Those over state pension age in particular have very limited financial support. Carer's Allowance is available to people providing at least 35 hours a week of care for someone. However it's not possible to claim the full amount of both Carer's Allowance and state pension.

People who care for someone with Parkinson's may be able to claim Attendance Allowance, the pensioners' equivalent of PIP. This does cover travel costs but not mobility needs.

The discussions also highlighted a need for access to capital financial support particularly for home adaptations. Making changes such as widening driveways, adding wet rooms and/or stair lifts may be essential to make homes safe and suitable, so carers can take care of their loved one at home for as long as possible.

## Recommendations

- The Department for Communities in Northern Ireland should urgently review Carer's Allowance rates and entitlements.
- The Northern Ireland Housing Executive should review Disabled Facilities Grants rates and entitlements.
- The Department for Communities should implement the Carer's Allowance Recognition Payment as set out in the recommendations of the *Independent Review of Welfare Mitigations* report<sup>8</sup>.
- Parkinson's UK NI to raise awareness of the existing financial support available to carers and those living with Parkinson's.

## Support from employers

**Carers often want to remain in the workforce for as long as possible, to provide a more financially secure future and also for their sense of self, identity and independence.**

Our carers shared that they wanted all employers to recognise the needs of carers and offer flexibility and support. Examples given were flexible working options including working from home. They would also welcome paid carer's leave similar to maternity/paternity pay.

## Recognition as expert partners

**The support of carers is critical in helping people to live well with Parkinson's. The health and social care system is reliant on their unpaid support.**

However, our discussions highlight that they are often overlooked. Carers need to be part of shared decision-making and their role as expert partners<sup>13</sup> must be recognised.

## Recommendations

- Support Carers NI's campaign to extend the Carer's Leave Act to Northern Ireland to provide a new legal right to unpaid carer's leave from work and support the inclusion of paid carer's leave as part of the pending Employment Rights Bill, to ensure that carers can take the time away from work they need.
- Health and care professionals should treat carers and family members as 'expert partners', including them fully in decisions wherever this is possible and in the best interests of the person with Parkinson's.

## Improved healthcare system

### The focus group sessions highlighted that helping those living with Parkinson's to stay well ultimately helps reduce the pressure carers face.

Neurology has one of the longest waiting times of all healthcare specialities in Northern Ireland. As of September 2023, 19,536 people were waiting for a neurology outpatient appointment. At least 1 in 20 patients (5%) have been waiting over 5 years with the median wait time being 1 year and 19 weeks<sup>9</sup>.

This is due to significant shortages of staff and resources available to see people with Parkinson's. This is reflected in the Regional Review of Neurology Services<sup>10</sup>, which has been tasked with identifying the optimal service configuration for neurology services through to 2035. Northern Ireland currently has 21 consultant neurologists, 3 of whom work on a part-time basis. This is less than half of the recommended 45 full-time neurologists<sup>11</sup> for the Northern Ireland population.

The Department of Health budget for 2023/24 was around £470m short<sup>12</sup> of estimated funding requirements, with no budget yet agreed for 2024/25.

The Parkinson's community are feeling the impact of these overstretched and underfunded resources. Not being able to access GPs, specialist consultants, Parkinson's nurses and allied health professionals promptly is having a significant impact. Long waiting times for assessment, treatment and medication alongside a lack of social care support is making it harder to live well with Parkinson's.

Taken together, this has a compounding effect on carers, making their role much harder. The message from the focus groups in this research is clear: having to continually 'fight' the system for access and support is draining.

## Recommendations

- The Department of Health should ensure the Regional Review of Neurology is completed and set out a commissioned delivery plan to support the implementation of its recommendations, alongside the financial commitment required to do so.
- As a matter of urgency the Department of Health should address workforce shortages and issues with consultants, specialist nurses, allied health professionals, and multidisciplinary teams.
- The Department of Health should publish a Parkinson's specific pathway to ensure consistency in service provision across Northern Ireland. This should enable those living with Parkinson's and their carers to understand their clinical journey and what they should expect.
- The Department of Health should ensure that new and review outpatient waiting times in neurology services are prioritised in waiting list initiatives.



## Next steps

**Carers must be supported to look after their loved ones well, while recognising that they are individuals with needs of their own. This research has been the start of our conversations to identify what these needs are.**

Parkinson's UK will review these findings and identify how the charity can incorporate the learning into our community activities and use these areas for improvement to drive our policy and campaign work across Northern Ireland.



## References

1. Bloem, Bastiaan et al. 2021. 'Parkinson's disease' The Lancet vol 397, issue 10291, p.2,284-2,303, June 2021 [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(21\)00218-X/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(21)00218-X/fulltext), accessed 30 April 2024
2. Parkinson's UK. 2018. 'The incidence and prevalence of Parkinson's in the UK' <https://bit.ly/3ntTYJK>, accessed 14 January 2024
3. Pringsheim, Tamara et al. 2014. 'The prevalence of Parkinson's disease' Movement Disorders 29.13: 1,583-1,590
4. NISRA. 2023. 'Northern Ireland Outpatient Waiting Time Statistics' <https://bit.ly/3QgYvxi>, accessed May 2024
5. Carers NI. November 2023. 'State of Caring 2023, The impact of caring on health in Northern Ireland', accessed May 2024
6. Based on survey responses from 40 participants. Not all questions were completed
7. Parkinson's UK. 2017. 'The cost of Parkinson's. The financial impact of living with the condition' [bit.ly/3WfQyMG](https://bit.ly/3WfQyMG), accessed May 2024
8. Department for Communities NI. 2022. 'Welfare Reform Mitigations. Independent Advisory Panel Report 2022' [bit.ly/4b9upUI](https://bit.ly/4b9upUI), accessed May 2024
9. NISRA. 2023. 'Northern Ireland Outpatient Waiting Time Statistics' <https://bit.ly/3QgYvxi>, accessed May 2024
10. Department of Health NI. 2018. 'Review of Neurology Services', [bit.ly/44hf1Dw](https://bit.ly/44hf1Dw), accessed May 2024
11. Ibid
12. Department of Health NI. 2023. Press release 'Department details 2023/24 Budget measures' [bit.ly/4d5dbJT](https://bit.ly/4d5dbJT), accessed May 2024
13. NICE guideline [NG197]., 202.1 'Shared decision making guidelines', <https://bit.ly/4b3ZybO>, accessed May 2024





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