

PARKINSON'S^{UK}



Still nowhere near enough

How the cost of living crisis is
affecting people with Parkinson's

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Parkinson's UK
February 2024

About Parkinson's

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. It gets worse over time and there's no cure. Yet.

Around 153,000 people in the UK are living with Parkinson's.¹ It is the fastest growing neurological condition in the world.² With population growth and ageing, we estimate this will increase by nearly a fifth to 172,000 by 2030. Parkinson's not only affects those with the condition but also has a significant impact on family, friends and carers.

While the majority of people develop symptoms after the age of 65, thousands of working age people are also affected.³

About Parkinson's UK

Parkinson's UK is here for everyone affected by Parkinson's. Funding research into the most promising treatments, taking us closer to a cure every day. Fighting for fair treatment and better services. Making everyone see its real impact.

Executive summary

Following our first cost of living report, *Nowhere Near Enough*, in autumn 2023 we once again asked the Parkinson's community if they were affected by the cost of living crisis and if so, how. This report sets out our findings and what action we believe the UK government must take.

In total, 3,016 people with Parkinson's and their loved ones responded to our survey. A quarter of those respondents are struggling to cover costs. Of that quarter:

- almost 8 in 10 expect they will turn on their heating less frequently during winter (compared to last winter) to save on fuel costs
- a third are having fewer meals to save money
- almost 1 in 4 (24%) had to borrow money to pay for basic necessities such as food or household fuel
- well over two thirds of people with Parkinson's are travelling and socialising less because of their financial situation
- two thirds say they are more isolated than they were at the beginning of 2023
- almost 2 in 5 say that they do not have enough money to cover basic needs
- half say that their symptoms have been made worse by their financial situation.

In January 2023, the Secretary of State for Work and Pensions, Mel Stride, said, "We are sticking by our promise to protect the most vulnerable."⁴ Our findings show that for people with Parkinson's in need, that promise has not been fulfilled.

We call on the UK government to urgently:

- roll out Warm Home Prescriptions to people with Parkinson's in need
- fix Personal Independence Payment (PIP) by scrapping the 50% rule and requiring all welfare benefit health assessors to be trained on how Parkinson's affects a person's day to day living and their ability to get around
- scrap the proposed Work Capability Assessment changes and instead invest in supply side policy interventions to make employment truly flexible, responsive and inclusive
- increase Pension Credit take-up, via funded, targeted local authority campaigns
- review the rate of Carer's Allowance.



The impact of the cost of living crisis on people with Parkinson's

The cost of living crisis began in late 2021. As prices rose, real disposable income fell. At the height of the crisis in autumn 2022, the overall inflation rate was over 11%, a 41-year high.⁵

Whilst inflation has fallen since the high of autumn 2022, this does not mean prices are going down. Quite the opposite.

- The price of gas in October 2023 was around 60% higher than two years previously and the price of electricity was 40% higher.⁶
- Food prices were around 30% higher in October 2023 than in October 2021.⁷

All of these costs will continue to rise, from already extremely high levels, at the rate of

inflation. And some costs will remain higher than others. For example, power prices in Great Britain are not expected to return to pre-2022 levels until the late 2030s.⁸

We wanted to find out how the cost of living crisis was affecting people with Parkinson's. During September and October of 2022, we asked them.

The findings were stark. People with Parkinson's were struggling with the cost of heating, eating less to save money, and becoming more isolated. Many said their symptoms were worse.

A year on, we wanted to find out how people with Parkinson's were faring now that the peak of the crisis had passed. This year's survey was conducted over the same two months in 2023 (see appendix B for more information on our methodology). Our findings show that, as the UK government removes all cost of living support, a significant proportion of people with Parkinson's are still struggling. For these people, the crisis is not over.

The cost of living crisis is not over

At the start of 2023, the Secretary of State for Work and Pensions, Mel Stride, said: "We are sticking by our promise to protect the most vulnerable."⁹ Our findings show that for people with Parkinson's in need, the government has not delivered on that promise.

"No public transport nearby. We share portions of meat and fish. We keep the electric bill down by not switching anything on and staying in bed to keep warm."

Person with Parkinson's, aged 65 to 69, with a weekly income of up to £200, who is claiming benefit

A quarter (24%) of our respondents told us they are struggling to cover costs - a higher proportion than the 20% of the population of Great Britain who say they are struggling. Almost 40% of people with Parkinson's who described themselves as struggling¹⁰ said that they did not have enough money to cover basic needs such as food.

Of respondents to our survey who describe themselves as struggling to cover costs:

- almost 8 in 10 (77%) say they expect to turn on their heating less frequently during winter (compared to last winter) to save on fuel costs
- more than 1 in 10 (11%) say they have fallen into debt with their electricity provider
- 1 in 3 say they are having fewer meals to save money
- a quarter (24%) say they have to borrow money to pay for basic necessities such as food or household fuel
- over two thirds say they are travelling and socialising less because of their financial situation
- 65% say they are more isolated than they were at the beginning of 2023.

In 2022, people had already reduced their household energy consumption in response to escalating household fuel prices. Our survey shows that, in 2023, people were planning to reduce their consumption even further in winter 2023/24.

"I am really struggling. I have stopped using the oven. I bathe only in shallow lukewarm water. I would be too frightened to put my heating on and I only wash clothes when absolutely necessary. I have no social life as I cannot afford to go out."

Person with Parkinson's, aged 75 to 79, who is claiming benefits



Increased demand for our information and advice

Our specialist adviser team provides information about any aspect of living with Parkinson's. This includes advice and support on accessing welfare benefits and other financial support. Demand for our service has risen significantly in the last year:

- In 2023, for the first time, questions about benefits were the most common type of enquiry our advice service received. And, also for the first time, 2023 saw the number of benefit enquiries a month exceed 1,000.
- In 2023, we gave out over £60,000 in supermarket vouchers to those in need - almost double the amount given out in 2022.
- Orders for our printed materials on welfare benefits increased by over 200% between 2021 and 2023. Visits to our benefit information web pages increased by 59% over the same period.

Our benefits advocacy work in particular can have a transformative impact on the finances of someone with Parkinson's. In 2023, our specialist benefit advisers took 60 of the most challenging PIP cases to appeal and secured £346,410 of previously unawarded entitlement for those clients. And this is just the tip of the iceberg. Across the country, day in and day out, our generalist advisers are also supporting people with their mandatory reconsiderations of PIP. Almost all of the refused or under-awarded PIP claimants we support through our expert advisers succeed in having the refusal overturned or their award increased.

A negative impact on symptoms

Financial struggles have a significant impact on both physical and mental health symptoms of Parkinson's. Having so low an income that it is not possible to heat their homes adequately means people with Parkinson's are dangerously cold. And being cold when living with Parkinson's means physical symptoms such as debilitating periods of immobility and painful muscle rigidity get worse.

Deteriorating physical health negatively impacts mental health. Living in poverty is itself stressful and causes poor mental health.¹¹ Stress also has a negative impact on physical Parkinson's symptoms. All of these factors combined lead to a negative health spiral.

Our survey found that:

- half of those struggling to cover costs say that their symptoms have been made worse by their financial situation
- many people affected report that motor symptoms have been made worse by increased anxiety and stress
- those who experience increased anxiety and stress attribute this to their financial situation.

Physical health

We know that living on a low income is detrimental to health.¹² For people with Parkinson's, the lack of adequate heating and not eating enough nutritious food makes people's motor symptoms worse.

“[My] muscles and joints are stiffer due to cold and not having the heating [on].”

Person with Parkinson's, aged 50 to 54, with a weekly income of £200 to £399, who is claiming benefit

Maintaining an adequate ambient temperature is particularly important to people with Parkinson's.¹³ If people with the condition are unable to maintain a healthy ambient temperature, they may experience pain and difficulty walking and standing.¹⁴ These impacts

would be avoided if those with the condition could afford to heat their home adequately.¹⁵

“Heating costs. Not being able to afford to fill the oil tank so the heating and hot water don't work. We have to boil the kettle to wash up and have not got central heating. Cold affects my tremors.”

Person with Parkinson's, aged 60 to 64, who is not claiming benefit

“[...] Scared to have the heating on as much, so colder and muscles are stiffer.”

Person supporting a person with Parkinson's, aged over state pension age, with a weekly income of £200 to £399, who is claiming benefit

People with Parkinson's have a higher risk of fracturing a bone than the general population, as someone with the condition is at higher risk of developing osteoporosis. This is because the absorption of critical nutrients like calcium is reduced in those with the condition. Consequently, a diet rich in calcium and vitamin D is essential.

Loss of balance and falling also affects many people with Parkinson's. Where bone health is poor, there is a high risk that a fall could lead to a fracture.^{16 17} This risk would be minimised if people with Parkinson's could afford to eat properly.

“To keep our energy bills low we wrap up well indoors. [...] We are both fragile and have to take care not to fall. We have no living blood relatives in the UK. We live very isolated lives. [...] God only knows what will happen if one of us dies.”

Person supporting a person with Parkinson's, aged over 80, with a weekly income of £200 to £399, who is claiming benefit

Mental health

People with Parkinson's tell us that deteriorating motor symptoms have a negative effect on their mental health. And worsening mental health negatively impacts motor symptoms, creating a vicious cycle.¹⁸ This is compounded by the well documented negative impact of poverty on mental health.¹⁹

“The stress caused by worrying if the bills can be paid on time causes anxiety which brings on very bad sessions, for example not sleeping, choking [on] food, hallucinations, not able to speak etc.”

Person with Parkinson's, aged 75 to 79, who is claiming benefit

By far the most commonly identified Parkinson's symptoms affected by respondents' financial circumstances were stress, depression and anxiety. Even without financial worry, 40% of people with Parkinson's have depression and 31% experience anxiety.²⁰ If people with

Parkinson's had enough to live on, the incidence of mental health issues would drop.

“Financial worry affects me both mentally and physically. Worry and anxiety affects my already poor sleep pattern. It also increases physical symptoms such as dyskinesia and dystonia.”

Person with Parkinson's, aged 55 to 59, with a weekly income of up to £200 and no benefits

Many people with Parkinson's aren't just dealing with Parkinson's, but with other health conditions too. Of the respondents who say they are struggling financially, 69% have additional disabilities or long-term health conditions. Diabetes, respiratory, circulatory, and mental health conditions are more common in people with Parkinson's who are struggling financially. Living with additional long-term conditions is less common among those who are not struggling financially.

“Increased anxiety resulting in Parkinson's symptoms worsening [...]. I was also prescribed antidepressants to help me cope with the additional stress.”

Person with Parkinson's, aged 50 to 54, with a weekly income of £200 to £399, who is claiming benefit

It is clear from our findings that avoidable poverty is having a direct, damaging effect on the physical and mental health of people living with Parkinson's.



Financial support and why it doesn't work for people with Parkinson's

Welfare benefits and cost of living support are designed to help people on low incomes or living with a disability to provide for their basic needs. What is available to people with Parkinson's?

Welfare benefits

There are four main benefits that a working age person with Parkinson's on a low income could claim or might be receiving:

- Universal Credit, a means-tested income replacement benefit for working age people on a low income or out of work.
- New Style Employment and Support Allowance, a national insurance contribution based income replacement benefit for disabled people.
- Personal Independence Payment (PIP) in England, Wales and Northern Ireland and Adult Disabled Payment (ADP) in Scotland, a non-means-tested benefits designed to help with the costs of living with a disability.

- Disability Living Allowance (DLA), the predecessor to PIP and ADP which some people still receive (it's no longer possible to make a new claim).

And there are equivalent benefits for those who are state pension age or older:

- Pension Credit, a means-tested benefit for pensioners on low incomes.
- Attendance Allowance, the pensioners' equivalent of PIP and ADP (although, unlike PIP, Attendance Allowance does not allow for the costs of travel).

People caring for someone with Parkinson's are entitled to Carer's Allowance. It's available to people providing at least 35 hours a week care for someone. It's not possible to claim the full amount of both Carer's Allowance and state pension.

Cost of living support

In May 2022 the government introduced the Cost of Living Payment scheme, which, with some variation across the nations, covered the whole of the UK (see appendix A). The scheme, designed to 'help with the cost of living', was targeted on those with the greatest need.²¹

Were someone eligible for all the cost of living support delivered by the UK government in 2022/23, they would have received £1,500. In 2023/24 the figure was £1,350. The UK government has given no indication that the Cost of Living Payments will continue beyond March 2024. Nor have they indicated that it will provide any other form of further cost of living support beyond March 2024.

Support for the cost of living with Parkinson's

Living with a limiting long-term condition like Parkinson's is expensive. In 2023, the extra cost of household energy for people with Parkinson's was £936 on top of already inflated everyday heating costs.²² The total cost of living and caring expenses for people with Parkinson's in 2023 was £4,434.²³

The Cost of Living Payment scheme was designed to help people struggling because of the cost of living crisis. However, even if someone with Parkinson's received the full range of Cost of Living Payments, the amount received would have been nowhere near enough to cover their household fuel bills as well as other essential costs. People in this position may have been entitled to the Household Support Fund. Yet, almost 90% of our respondents in England had not even heard of the Household Support Fund.

Not only were the Cost of Living Payments

inadequate, they were poorly targeted. Eligibility for both the low income and disability Cost of Living Payments were determined by welfare benefit entitlement. People who were not getting the relevant benefit did not get the corresponding Cost of Living Payment.

The UK government does not intend to provide further cost of living support. It has, however, announced a multi billion pound programme for 2025 to 2028 to support energy efficiency measures, such as insulation, heat pumps and boiler upgrades.

When we first highlighted how people with Parkinson's were being affected by the cost of living crisis, we called on the chancellor to identify people with Parkinson's via NHS records and provide those in need with direct household fuel bill support. The UK government did not do this.

Since then, Catapult Energy Systems has run a pilot of something called the Warm Home Prescription scheme.²⁴ The scheme is designed to support people with health conditions which are aggravated by the cold with their heating bills.²⁵ Those in need were identified via the health service, offered support to improve the energy efficiency of their household's heating and, crucially, were provided with immediate, direct financial support with heating costs. The evaluation of the Warm Home Prescription pilot found that for every £1 of expenditure, Warm Home Prescription supported £5.10 of wellbeing social value to patients.²⁶

Recommendation

The chancellor must make funding available to roll out Warm Home Prescriptions to people with Parkinson's in need.



Helping working age people meet the cost of living with Parkinson's

Personal Independence Payment (PIP) in England, Wales and Northern Ireland and Adult Disabled Payment (ADP) in Scotland are designed to help with the cost of living with a long-term condition. There are two elements: daily living and mobility, and a number of different rates.

People with Parkinson's tell us again and again about their difficulties with claiming PIP, from the long, arduous claim process, to humiliating and inaccurate assessments and a profoundly stressful appeals procedure.

Chart one shows that just half (53%) of the working age people with Parkinson's we surveyed were receiving PIP or its equivalents.

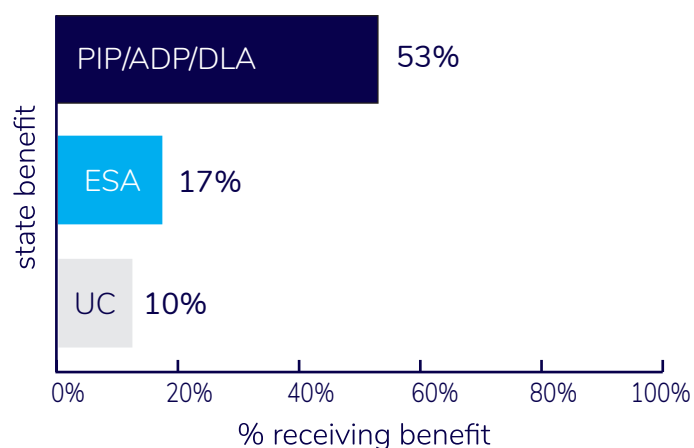


Chart one: Benefits received by all respondents of working age (n=567)

Key: PIP: Personal Independence Payment
 ADP: Adult Disability Payment
 DLA: Disability Living Allowance
 ESA: Employment and Support Allowance
 UC: Universal Credit

Our analysis of Department for Work and Pensions (DWP) statistics²⁷ shows people with Parkinson’s are more likely to be inaccurately assessed for PIP than other claimants. As chart two shows, the rate at which people with Parkinson’s have an initial negative decision on

their PIP overturned at first appeal, known as mandatory reconsideration, is on average, 10% higher than all other mandatory reconsiderations. These figures suggest a greater proportion of people with Parkinson’s are being denied the benefits they’re entitled to.

PIP mandatory reconsiderations resulting in a change of amount of benefit

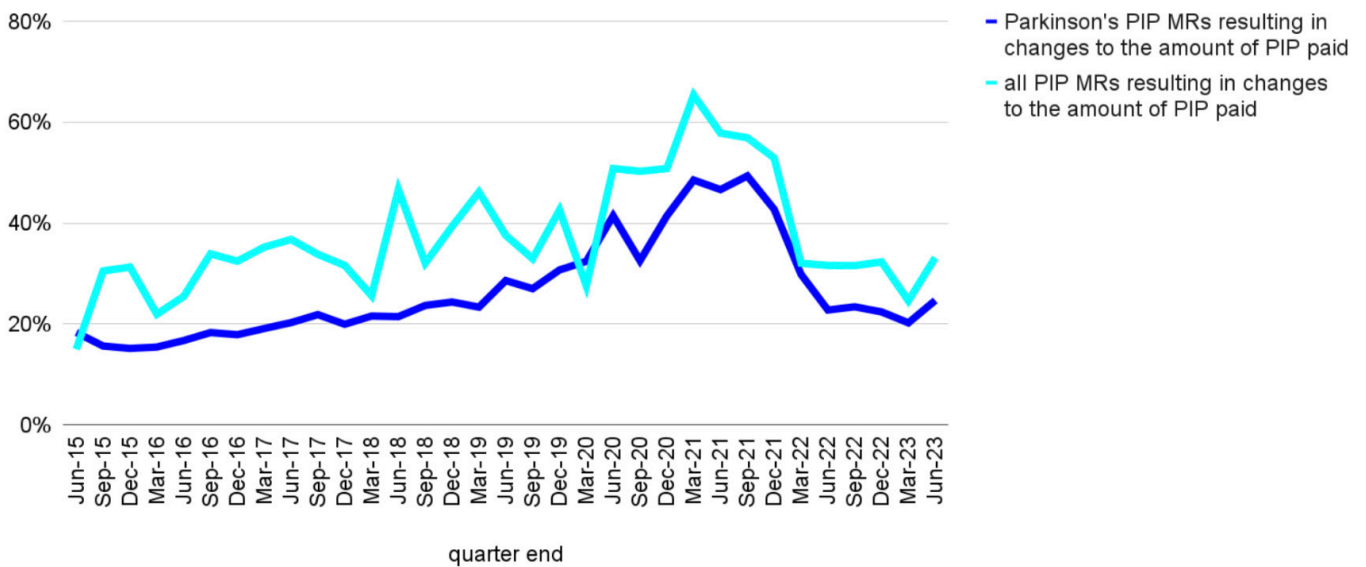


Chart two: Rate at which initial negative PIP decisions are overturned at mandatory reconsideration

In a recent case, a person with Parkinson’s called our advice team after her claim for PIP had been turned down. Our advice team supported her to challenge the outcome via a mandatory reconsideration. Following our intervention, she was awarded higher rate daily living part and lower rate mobility part, increasing her weekly income by £126.65.

Challenging a benefits decision is stressful, even with support. People with Parkinson’s should not have to go through a distressing process, just to receive their entitlement.

When we spoke to people with Parkinson’s in 2021, half (50%) of those who had experience of benefits and employment support said the person assessing how Parkinson’s affects their daily living didn’t have a good knowledge of the condition. This is particularly worrying given that,

without sufficient knowledge of Parkinson’s and how symptoms impact daily living, it is simply not possible for assessors to assess the eligibility for PIP of someone with the condition.

Phil Bungay, a 56-year old man with Parkinson's, was told by the DWP that his PIP payments had been stopped. Appealing the decision, Phil said "I had never been made to feel like a criminal before." Phil was left without the financial support he needed to pay for his medication and believes he may not have survived without the support of his friends and family.

We know there are many people with Parkinson's who are incorrectly assessed and simply accept the DWP's decision because they are not aware of expert help on offer through organisations like Parkinson's UK. If those who do not challenge initial PIP claims are factored in, the proportion of people with Parkinson's who do not get the benefit they are entitled to first time would exceed 30% of applicants by a substantial margin.²⁸

When we asked our survey respondents with a Parkinson's diagnosis, 58% said they lived with other long-term conditions. In contrast, 72% of people who support someone with Parkinson's said the person they cared for lived with additional long-term conditions. This suggests that those with the diagnosis are underestimating the severity of their health issues. Illness denial, particularly among people living with multiple long-term conditions, is a recognised phenomenon.²⁹ This makes it all the more important for PIP assessors to understand Parkinson's, as well as other common long-term conditions.

These issues are not unique to PIP. They also affect people with Parkinson's who apply for Universal Credit and New Style Employment and Support Allowance. In the case of Universal Credit and New Style Employment and Support Allowance, the health assessment is known as the Work Capability Assessment. Reports

from our clients are that the assessments for the new Adult Disability Payment (ADP), which replaces PIP in Scotland, are better. However, it is too early to say whether this reflects a long-term positive difference in assessment and decision-making quality.

Enabling people with Parkinson's to work

While the majority of people develop Parkinson's symptoms after the age of 65, thousands of working age people are also affected.³⁰ Many people with Parkinson's are able to continue working well beyond their diagnosis.

But many people with Parkinson's who want to work are prevented from doing so. When we asked people with Parkinson's, they told us that they often encounter a lack of understanding and outright discrimination from prospective employers, employers and colleagues. Discrimination occurs both when applying for jobs and once they have secured a job. Research has found that over two thirds (67%) of those who had become unemployed or who had retired as a result of Parkinson's believed that adjustments such as changes in work schedule, type of work, or having a longer time to complete tasks, could have helped them to stay employed longer.³¹

Helping those unable to work

The only option open to people with Parkinson's of working age who cannot work and are on a low income is to claim Universal Credit or New Style Employment and Support Allowance (ESA). Neither of these benefits is generous. Universal Credit standard rate amounts to £368.74 a month for single people aged over 25. For ESA, it's £367.47 a month. Both of these figures exclude support for housing costs.



People with health issues who apply for Universal Credit or ESA may be granted a higher rate of benefit if they are found to have limited capability for work and work-related activity, for example, looking for a job. To qualify for this higher rate, a claimant must meet the Work Capability Assessment criteria. Those who qualify receive an additional £390 a month in the case of Universal Credit and £193.70 a month in the case of ESA. Claimants who are found to have limited capability for work and work-related activity are also protected from having to engage in specified activity to receive their full benefit entitlement.

“Some days I feel like giving up altogether, it’s so bad.”

Person with Parkinson’s, aged 55 to 59, with a weekly income of £200 to £399, who is claiming benefit

The UK government plans to change the Work Capability Assessment to make it more difficult for people to be categorised as having limited capability for work and work-related activity. If these proposed changes go ahead, the assessment criteria will be tightened, meaning more people with Parkinson’s will miss out on financial support.

“My complete Universal Credit pays the rent only. I pay all the bills but have fallen a month behind with gas and electric. Gas and electricity credits would help loads.”

Person with Parkinson’s, aged 55 to 59, with a weekly income of £200 to 399, who is claiming benefit

From late 2024, the UK government's Back to Work Plan³², will begin to come into effect. This will mean that, in England, Scotland and Wales, Universal Credit claimants who only receive the standard allowance will have their entire benefit claim stopped if they are sanctioned or do not engage with Jobcentre Plus support for over six months. In England, where a Universal Credit claim stops, in most cases, so does access to free prescriptions.

Also, from late 2024, Universal Credit claimants in England and Wales who have completed the Restart employment support scheme, yet remain unemployed after 18 months, may be asked to engage in more intense work search activities. This may include mandatory work placements. If claimants do not agree with what is asked of them, their benefit claim will be stopped.

At the same time, the UK government has said that it will not mandate employers to provide occupational health support to their staff. Instead, it plans to develop a voluntary occupational framework. And, while the government provides businesses with tax incentives to encourage them to invest in machinery, it does not intend to provide any employer tax incentives to promote the employment of people with long-term conditions, like Parkinson's.

Recommendation

The UK government must:

- **fix PIP by ensuring that assessors get regular thorough training on Parkinson's and revising the PIP criteria so they are fit for purpose**
- **scrap its planned changes to the Work Capability Assessment and instead improve the employment prospects of people with Parkinson's by changing workplace culture.**



Helping pensioners on low incomes

Pension Credit is designed to protect people of state pension age and over from poverty. The credit is means tested, but people with sources of income other than their state pension, own their own home or have savings, may still be eligible for Pension Credit. Couples which include one person younger than pension age are called mixed age couples and cannot claim Pension Credit.

As chart three shows, just 6% of respondents to our survey who are aged over 64, with a partner, but not in a mixed age couple, and a weekly income of less than £200 are receiving Pension Credit.³³ For those with an income of less than £400, it's just 4%.³⁴ This is an extremely low Pension Credit take up rate and is particularly concerning given that Pension Credit is a passporting benefit, providing access to a variety of discounts and rebates.³⁵

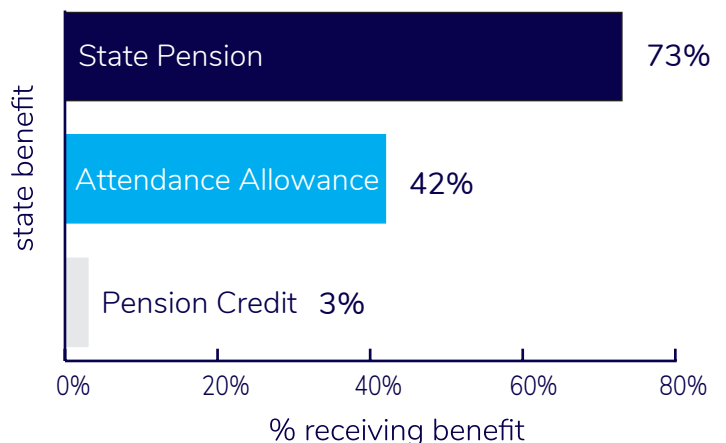


Chart three: Benefits received by all respondents of state pension age and over (n=2,323)

We know from other research that the main reason eligible people do not claim Pension Credit is their assumption they are not (or no longer) eligible. For example, Independent Age found that 65% of eligible non-claimants felt they had too much money to qualify.³⁶ Other barriers include perceived stigma from claiming, with almost two thirds (62%) of eligible non-recipients agreeing that they ‘do not like asking for benefits’.³⁷

There is a clear, proven mechanism for significantly increasing take-up of Pension Credit. The Policy in Practice Low Income Family Tracker (LIFT) allows local authorities to identify the most vulnerable households and target support to them, including maximising income by ensuring that people are receiving all the benefits they are entitled to.³⁸ Some councils, such as Croydon Council, Leeds City Council and Oxford City Council, are already using LIFT. However, the LIFT tool costs. With councils in England, for example, facing a funding gap of £4 billion over the next two years, local authority budgets will remain extremely tight.³⁹

Recommendation

The chancellor must make funding available for local authorities to use LIFT to maximise benefit take-up.

Inadequate help for those who support people with Parkinson’s

Carer’s Allowance is designed to provide a contribution towards the cost of caring. Claimants must be caring for another for at least 35 hours a week. Currently, Carer’s Allowance is paid at a weekly rate of £76.75. This equates to an hourly rate of pay of £2.19, well below the £10.42 an hour of the national minimum wage (for people aged over 23).

“Carer’s Allowance needs to be looked at. £76 a week is a joke. Nobody told us we were eligible so missed out on 3 years or more.”

Person with Parkinson’s, aged 65 to 69, with a weekly income of up to £200 to £399, who is claiming benefit

“Pay carers more. If it’s a family member, they often give up their own way of living to fit in with the ‘patient’. My son has very little time of his own, has lost friends and can’t get other part time jobs to supplement what is, after all, a quite meagre Carer’s Allowance (£70 a week). He can’t holiday on his own or with friends and leave me alone.”

Person with Parkinson’s, aged 50 to 54, with a weekly income of £400 to £599, who is claiming benefit

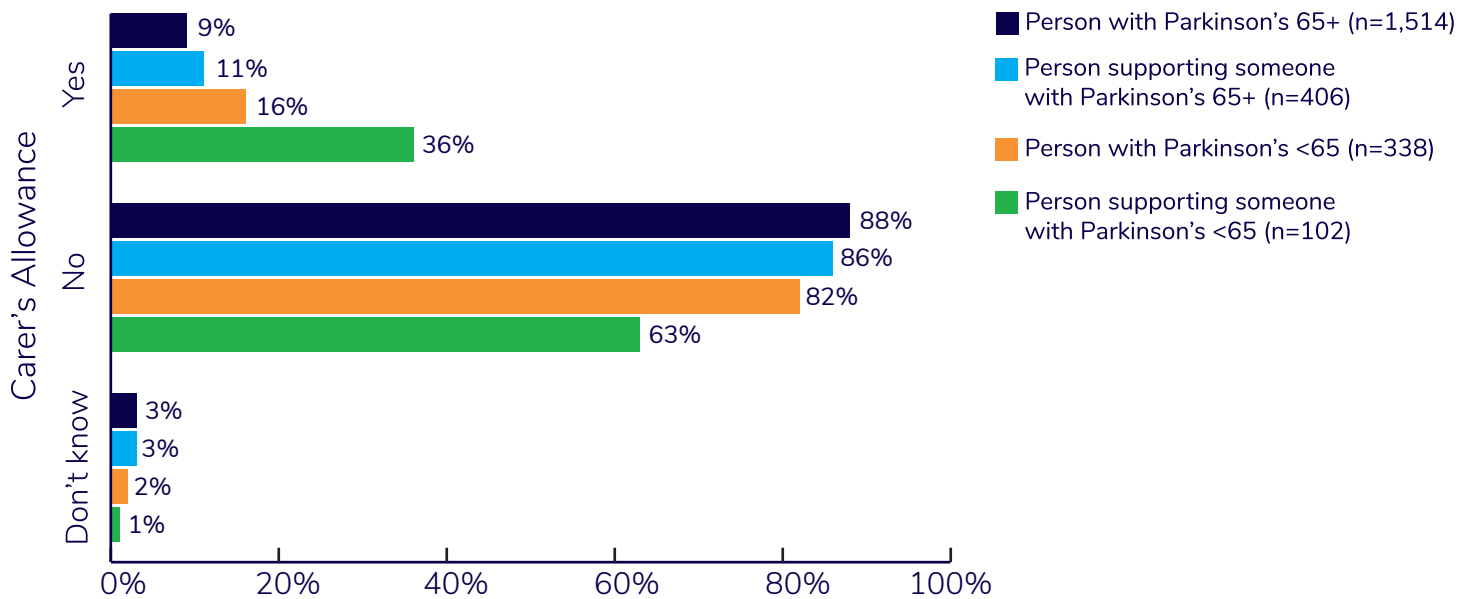


Chart four: Proportion of those providing support to someone with Parkinson's who received Carer's Allowance

As chart four shows, over two thirds (68%) of working age respondents to our survey and three quarters (74%) of respondents aged state pension age or older said they have someone who supports them. Yet the vast majority of those providing support do not receive Carer's Allowance.

Recommendation

The Department for Work and Pensions must urgently review the rate of Carer's Allowance.

“No support to carers! We need support for the pitance we receive. Carers do not get enough and we are penalised by not receiving any form of cost of living payment.”

Person supporting a person with Parkinson's, aged 45 to 49, with a weekly income of £200 to £399, who is claiming benefit

The UK and devolved governments must act now

We are worried that the UK and devolved governments have lost their focus on the cost of living crisis. With no plans to provide any further cost of living support beyond March 2024, the UK government is abandoning those people with Parkinson's who are struggling to survive.

The benefit system is failing people with Parkinson's.

People with Parkinson's are living in cold homes, with not enough food to eat, unable to get out with their health deteriorating. We are concerned about how people living with Parkinson's will cope financially in 2024 and beyond.

If their promise to protect the most vulnerable is to include people with Parkinson's, the UK government must take immediate action.

Introduce Warm Home Prescriptions

The UK government and devolved administrations must fund Warm Home Prescriptions for people with Parkinson's identified by healthcare professionals as needing support.

Fix PIP

The Department for Work and Pensions must ensure that those carrying out PIP health assessments undertake thorough, regular training in Parkinson's and its effects on day to day living. This training must include a particular focus on the effect of symptom fluctuation.

The Department for Work and Pensions must scrap the rule that says symptoms must affect someone with a long term condition for 50%

of the time if they are to be taken into account for PIP. The nature and degree of fluctuation of Parkinson's symptoms mean that it is impossible to predict when, for how long, and how severely they may manifest, and so whether or not the 50% threshold will be met or exceeded.

Scrap the proposed Work Capability Assessment changes

The Department for Work and Pensions has presented no evidenced rationale for the proposed changes to the Work Capability Assessment. The UK government should scrap these proposals and instead make work better for people with long term conditions like Parkinson's. We set out how the UK government can do this in our employment policy statement.

Increase Pension Credit take-up

The UK government and devolved administrations must fund local authorities to deliver local, targeted take-up campaigns to increase the uptake of Pension Credit, using the proven Low Income Family Tracker (LIFT) platform.

Urgently review Carer's Allowance

The Department for Work and Pensions must urgently review the rate of Carer's Allowance.

Appendix A: Cost of Living Payment scheme

	Energy Bills Support Scheme	Low Income Cost of Living Payment	Disability Cost of Living Payment	Pensioner Cost of Living Payment	Council Tax rebate	Total *
Eligibility criteria	none	Be receiving means-tested benefit	Be receiving disability benefit	Be of state pension age or above	Be in council tax band A-D	
2022/23	£400	£650	£150	£150 or £300, depending on age	£150	£1,500
2023/24	£0	£900	£150	£150 or £300, depending on age	£0	£1,350

Table one: UK government Cost of Living Payments

* assuming higher Pensioner Cost of Living Payment

Additional payments

Scotland 2022-23

Until the end of 2022, a person under 19 who was receiving enhanced rate of the daily living component of ADP or PIP, or the higher rate of the care component of DLA, was entitled to Child Winter Heating Assistance Payment of £214.10.

In February 2023, people receiving Universal Credit, Pension Credit, Income Support, Jobseeker's Allowance, Employment and Support Allowance or support for mortgage interest in the week beginning 7 November 2022 received a £50 winter heating payment.

2023-2024

Child Winter Heating Payment of £235.70.

Wales

From September 2022 onwards, people in Wales could apply for a £200 Wales Fuel Support Scheme payment from their local authority, if they were or are receiving Universal Credit, Tax Credit, Pension Credit, means-tested Employment and Support Allowance or Jobseeker's Allowance, Income Support, Personal Independence Allowance, Disability Living Allowance, Carer's Allowance, AFIP, Attendance Allowance, war pension mobility supplement or lives with someone who received Personal Independence Allowance, Disability Living Allowance, AFIP, Attendance Allowance or war pension mobility supplement, during the period 1 September 2022 and 30 January 2023.

Appendix B: Survey methodology

We ran the 2023 survey via an online and a paper questionnaire between August and October 2023. In total, there were 3,016 survey respondents. The vast majority (89%) of respondents completed and returned paper questionnaires. Of those, the vast majority (98%) received their questionnaire in their copy of *The Parkinson*, our magazine for members of the charity.

The online questionnaire was shared with our online campaigners by email, through a news story on the Parkinson's UK website, Facebook, X, LinkedIn, the Parkinson's UK email footer, and online communications to Parkinson's UK groups and branches. A small number of respondents contacted Parkinson's UK and completed their questionnaires over the phone.

Change in methodology from 2022

This was our second cost of living survey. Our first survey was conducted online only. In 2023, in order to get a better response, we decided to use both online and offline methods to collect data.

This resulted in a higher proportion of older respondents than in 2022. Broadly speaking, this means there is a higher probability that the 2023 sample includes people who have had greater opportunity to accrue savings and other assets. For example, in 2022, a third (34%) of respondents said they had paid off their mortgage in full. In 2023, the figure was 53%.

Given the differences in methodology and samples, caution should be exercised when drawing conclusions by comparing the 2022 and 2023 survey results.

Appendix C: UK geographical breakdown

Country	2022 survey (n=441)	2023 survey (online responses) (n=335)	2023 survey (all responses) (n=3,016)
England	79%	77%	87%
Scotland	12%	13%	7%
Wales	5%	5%	5%
Northern Ireland	4%	5%	2%
Other (please tell us where)	<1%	0%	0%

Table two: geographical distribution of respondents across the UK

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