



The cost of Parkinson's:

the financial impact of living with the condition

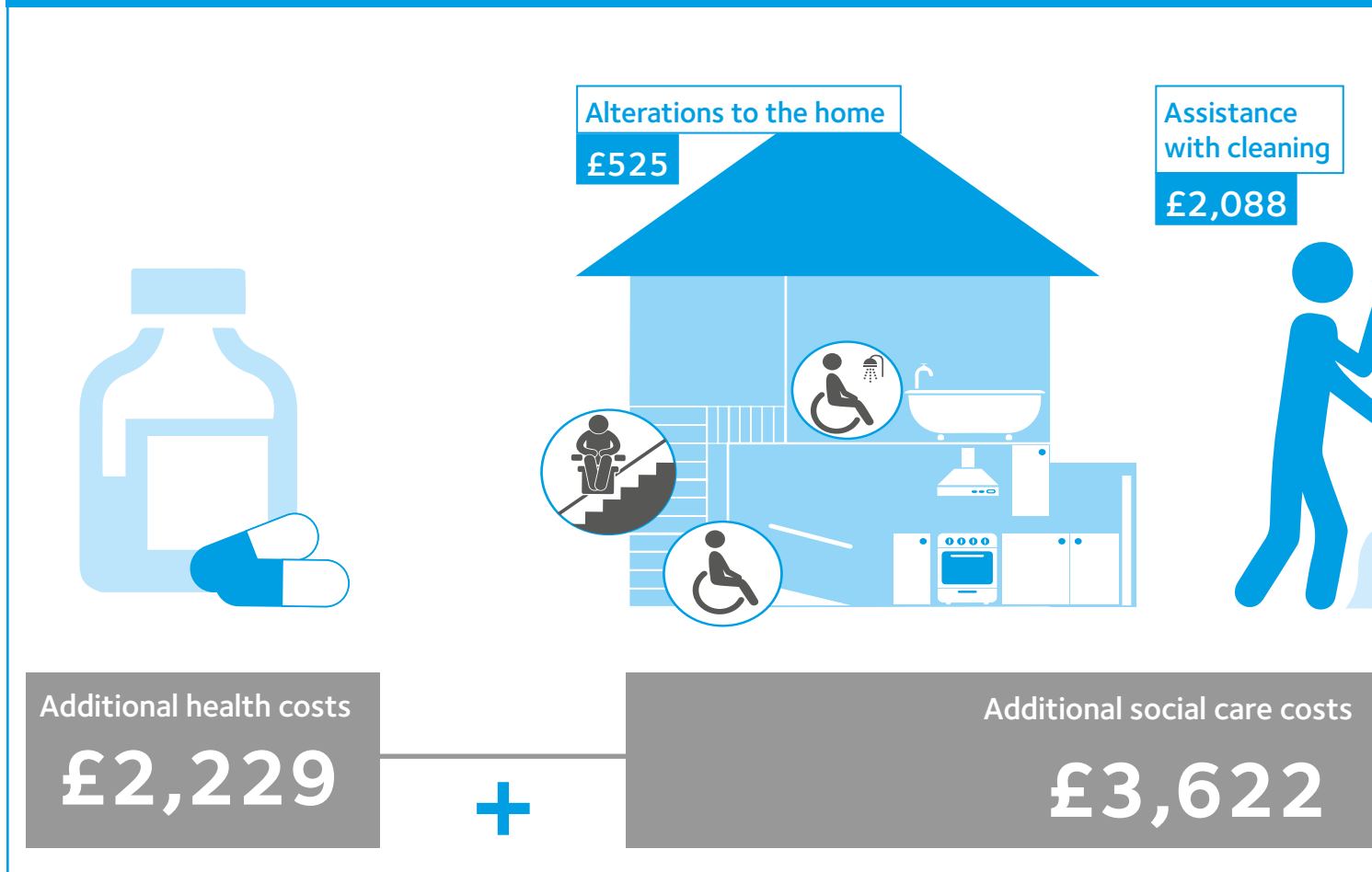
PARKINSON'S^{UK}
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Contents

Foreword	3
Executive summary	4
Why the research was needed	6
How the research was done	6
Key findings	7
Conclusion	10

The full Sheffield Hallam research report (undertaken by A Gumber, B Ramaswamy, R Ibbotson, M Ismail M, O Thongchundee, D Harrop, P Allmark and A Rauf: **Economic, Social and Financial Cost of Parkinson's on Individuals, Carers and their Families in the UK: Final Report**) can be accessed at <http://bit.ly/2t5dxtT>

The financial impact of living with Parkinson's



Foreword

Being told you have Parkinson's can be a worrying time for people and their families. How will the symptoms affect me? How quickly will the condition progress? Will I have to give up work? How will we manage financially?

As everyone's experience of Parkinson's is different, professionals cannot always give accurate responses to these questions – or the many other questions those living with the condition may ask.

Our new research reveals a household where someone has Parkinson's in the UK is on average **£16,582** per year worse off.

People living with Parkinson's spend more on staying well – buying items like pill-timers and prescriptions (these charges only apply in England), and travelling to their health appointments. They also face higher social care costs from adapting their homes to try to stay mobile, and they can face extra costs paying for assistance with daily tasks like cleaning and shopping.

As the condition progresses, people with Parkinson's who are still working, and their carers, often reduce their hours, or even have to retire, to contend with the condition. They may also lose out on benefits as the welfare system becomes more challenging to navigate.

The current situation isn't good enough.

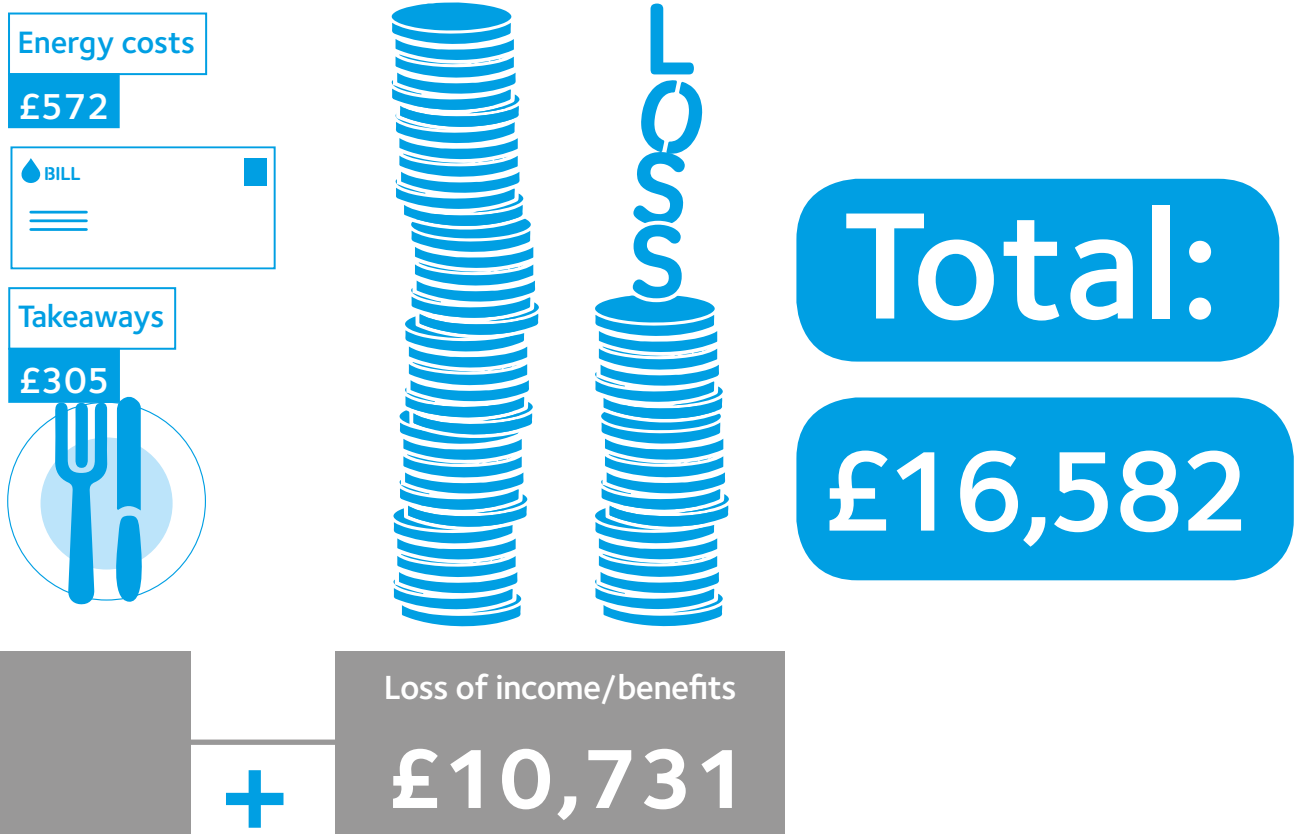
That's why we campaign to make sure people living with Parkinson's are treated fairly and have access to the support they need.

With a stretched NHS and social care services and changes to welfare support, it is crucial that the government works with us and people living with Parkinson's to develop solutions and improve the public services we all need.

Together we can bring forward the day when no one fears Parkinson's.

Steve Ford
Chief Executive
Parkinson's UK

Living with Parkinson's in UK



Executive summary

Parkinson's UK is working hard to bring forward the day when no one fears Parkinson's. Currently, we know that people with Parkinson's incur significant additional costs and also lose money as a result of having the condition.

The impact of Parkinson's can be enormous. Parkinson's UK hears from people every day who report challenges with daily activities and feelings of isolation, frustration, depression and fear over their future.

In 2007, we commissioned research to evaluate how much a person's finances are affected by a Parkinson's diagnosis. As this information was produced 10 years ago, circumstances have changed dramatically. In order to ensure we have up to date information, we have worked with researchers at Sheffield Hallam University to calculate the cost of Parkinson's for someone living with the condition in 2015/16.

The researchers surveyed and interviewed people living with Parkinson's and their carers and families across the UK.

The research findings show that living with Parkinson's is expensive and can be broken down into incurred costs of **£5,851** and potential loss of income/benefits of **£10,731**. This means a household in the UK where someone has Parkinson's is **£16,582** per year worse off.

Scope's Extra Costs Commission¹ found that people with neurological conditions spend on average an extra £200 per week due to their condition. However, our research shows that people living with Parkinson's are on average £328.73 per week out of pocket due to living with the condition.

The key findings of the research are that households where someone has Parkinson's experience:

- **higher health costs (£2,229)** as they have to pay for items to help them live on a daily basis such as pill-timers, prescriptions (in England only), mobility aids and travel to health appointments, including parking charges

- **higher social care costs (£3,622)** as they pay towards changes to their homes, for assistance with daily tasks such as cleaning and shopping, and for equipment to help them stay independent
- **loss of income due to early retirement or reduced working hours (£10,731)** because of the progression of the condition
- **a decline in quality of life**

This report provides a summary of the research, the key findings and our recommendations of how governments can improve the support they offer to people with Parkinson's and their families in the UK.

This research clearly demonstrates that governments urgently need to better support people with Parkinson's and their carers through improvements to the welfare, health and care systems.

This new information has enabled us to pinpoint what changes governments could make that would have the biggest impact for people with Parkinson's and their families.

Parkinson's UK will use this research to form a key part of our future campaigns, enabling us to lobby governments to make improvements to the support they offer.

We recognise the current challenging financial situation. It is therefore crucial that governments across the UK work closely with third sector organisations to explore creative solutions to drive these necessary improvements.

¹ <http://www.scope.org.uk/Get-Involved/Campaigns/Extra-costs/Extra-costs-commission/Full-Report>



We therefore call on the UK Government to:

- reverse real-terms cuts in rates of essential financial support for people with Parkinson's and protect people with the condition from repeated assessments
- increase investment in social care from central government, and support for carers, to counteract the added stress of caring for someone living with Parkinson's
- front-load investment to the NHS so people have access to a multidisciplinary team of specialists to manage their condition, and stay healthy and independent for as long as possible
- review means-test thresholds for local authority social care funding to ensure they are fair and consistent. Introduce a lifetime cap on the level of social care costs that an individual is expected to pay, set no higher than £35,000 – the threshold originally recommended by the Dilnot Commission
- encourage health and social care professionals to signpost to Parkinson's UK so people living with or supporting someone with the condition are able to access support and information throughout their Parkinson's journey
- ensure employers have better policies and practices in place to support people living with Parkinson's and their carers to stay in work for as long as possible

We call on the Northern Ireland Executive to:

- invest in social care and support for carers, as part of the ongoing health transformation process, to counteract the added stress they have when caring for someone living with Parkinson's
- ensure people living with Parkinson's have access to a multidisciplinary team of specialists to manage their condition and stay healthy and independent for as long as possible
- encourage health and social care professionals to signpost to Parkinson's UK so people living with or supporting someone with the condition are able to access support and information throughout their Parkinson's journey
- make sure welfare support is maintained, so that people affected by Parkinson's are not repeatedly reassessed, are clear about their rights under the mitigation package agreed by the Executive, and are protected from any future welfare cuts

We call on the Scottish Government to:

- use its new social security powers to reverse real-terms cuts in rates of essential financial support for people with Parkinson's and protect people with the condition from unnecessary assessments
- increase investment in social care, including support for carers, to counteract the added stress of caring for someone living with Parkinson's
- introduce Frank's Law and provide free personal care for people with Parkinson's who are aged under 65
- invest in specialist multidisciplinary Parkinson's teams so people can manage their condition, and stay healthy and independent for as long as possible
- encourage health and social care professionals to signpost to Parkinson's UK so people with Parkinson's or those supporting someone with the condition are able to access information and support throughout their Parkinson's journey
- work with energy companies and regulators to ensure that households including people with Parkinson's are identified and placed on the lowest possible energy tariff
- ensure that households including people with Parkinson's are identified as a target group for warm homes initiatives
- use its influence and powers with employers to promote better policies and practices to support people with Parkinson's and unpaid carers to stay in work for as long as possible

We call on the Welsh Government to:

- ensure people living with Parkinson's have access to a multidisciplinary team of specialists to manage their condition and stay healthy and independent for as long as possible
- encourage health and social care professionals to signpost to Parkinson's UK so people living with and supporting someone with the condition are able to access support and information throughout their Parkinson's journey
- invest in social care and support for carers, to counteract the added stress they have when



Why the research was needed

The most recent research about the cost of living with Parkinson's was conducted in 2007, and it didn't include many of the costs associated with living with the condition, for instance social care.

Since then living costs have risen and successive governments have made changes to the support on offer, such as health, welfare and social care.

Therefore Parkinson's UK wanted to understand the true cost of living with the condition now and what the government can do to better support people living with Parkinson's and their families.

How the research was done

In 2015 Parkinson's UK commissioned Sheffield Hallam University to undertake research on the cost of Parkinson's. The aims of the research were to:

- assess the economic cost of Parkinson's in the UK
- assess the financial impact of treatment and care on the households of people with Parkinson's
- examine the impact of Parkinson's on the quality of life and personal wellbeing of people with Parkinson's and their carers
- use this evidence to inform the government and policy makers about areas where they need to focus their efforts to improve care

The research was conducted by survey and in-depth interviews.

776 people, either with the condition or family members of those with Parkinson's, completed a survey about costs attributed to the household due to the condition, in the past 12 months. From these surveys a random selection of five respondents

were asked to participate in an in-depth interview. The purpose was to provide a better understanding of how these additional costs impact an individual and a household on a daily basis, so we could suggest where future government changes could have the biggest impact.

Those participating in the research were largely white, married (with mainly female spouses in the role of carer), and with qualifications beyond GCSE. Most of the people who responded were 65 and over. However, the age profile of respondents was younger than previous studies, and included people in the earlier stages of Parkinson's.

Only 5% of respondents in total were from ethnic minorities.

Out of the respondents across the UK:

- 80% were from England
- 11% were from Scotland
- 6% were from Wales
- 1% were from Northern Ireland

Demographic information of interviewees

Identifier	AL	MA	CC	AC	LA
Gender	Male	Male	Male	Male	Female
Role	Living with Parkinson's and wife joined the conversation too	Living with Parkinson's	Living with Parkinson's	Carer for someone living with Parkinson's	Living with Parkinson's
Age at diagnosis	68	52	65	Spouse aged 51 at diagnosis	52
Years living with Parkinson's	Into his fifth year	Into his ninth year	Into his third year	Spouse into her 11th year	Into her fifth year
First symptom	Wife noticed tremor in right hand and AL noted slowness of movement	Slowness and tremor	Slowness and tremor	Stiffness and slowness	Stiffness and slowness
Country	England	Wales	Northern Ireland	Scotland	Scotland

Key findings

Higher health costs

People with Parkinson's use a variety of NHS services to stay well, including GPs, Parkinson's specialist nurses, consultants, physiotherapists, speech and language therapists, occupational therapists and dietitians.

However, people with Parkinson's also frequently pay for private consultations when the waiting times on the NHS are long or no NHS service exists – for example podiatrists/chiropractors, optometrists or physiotherapists.

The research found that people living with the condition also pay for other items to help them

live on a daily basis, such as pill-timers, travel to health appointments and parking charges, and prescription charges that apply in England only.

For example, one of the interviewees (MA) pays for regular private chiropractor visits because podiatry in the local hospital is only available every four to six weeks, and he requires management at least monthly. He stated: "... and even in between them I'm suffering."

The cost for people with Parkinson's to attend these private appointments and purchase equipment is on average **£2,229**.

Higher social care costs

The research found that many households that have a person with Parkinson's have to pay towards changes that are needed to their home so that the person with the condition can move around it easily and stay independent.

Alterations to the home

About half of the households that responded have made alterations to their home since the diagnosis of Parkinson's.

The changes were not easy, with some even moving house to limit pain and reduce the need to use stairs, or making alterations in anticipation of the condition progressing. One of our interviewees (MA) felt forced into moving house and shared his thoughts on the move:

“ I'm now in a bungalow because I couldn't manage the stairs where I was before. So I've moved into sheltered housing ... But it was a case of I had no choice. It's something I had to do because I couldn't have continued where I was. ”

Some of this support is provided by the respondents' local authority. However, many people in need of these changes pay for them individually. The average annual expense contributed per household for equipment and adaptations to the home is **£525**.

Equipment

People with Parkinson's often need to purchase equipment to improve mobility around the house, as well as improve balance and reduce falls outside the house. The research found that the most common items purchased are walking sticks, walkers, reclining chairs, raised toilet seats, wheelchairs, mobility scooters, specialist cutlery, stair lifts, grab rails and adjustable beds.

For example (AL) spent £500 on new specialist glasses so he could stay active and continue to play table tennis. He didn't realise his decline in eyesight could be due to his Parkinson's.

His wife also talked about some other things they have bought:

“ We have bought a new sofa which is more comfortable We also got a new bed which is easier to get out of, because he finds it difficult to work his way to the edge of the bed. ”

Daily living assistance

As Parkinson's is progressive and fluctuating it means that many people living with the condition find how it affects them can change from day to day, and even from hour to hour. Therefore they often need assistance with daily tasks around the home to enable them to stay healthy and well.

Six out of 10 respondents need assistance to clean their house on a daily or weekly basis, with this rising to three quarters of people if they are over 75. Almost half of respondents need assistance with ironing, decorating or gardening.

Around half of respondents need daily or weekly help with their shopping and around half of respondents need help attending their medical appointments.

Regarding things he and his wife need help for, CC noted:

“ We've suddenly realised that the garden is too big for the pair of us to look after it, but we just have to adapt it so that we can manage as best we can before we have to actually hire somebody to do it. Some of the things in the garden that I ”



would have done years ago, like hedge trimming and stuff like that, the heavy work, we get somebody to do it for us now.

A family member, usually a spouse, undertakes most of these activities. Those living alone receive help from their children or grandchildren. Despite this, figures continuously show that a significant amount of money is spent on accessing support from private care agencies, particularly for those in the more advanced stages of the condition.

Assistance for daily living, including things such as personal care, transport to appointments or shopping, house cleaning and gardening were also included in this category and total **£2,088**.

The results also show that about half of respondents need assistance preparing meals due to being unable to hold saucepans or safely cut up ingredients. This means that one third of people with Parkinson's spend **£305** on takeaways and convenience food every year.

Over half of respondents stated they have additional utility costs (mainly energy) due to needing electric blankets or heaters to keep warm or air conditioners or cooling fans. On average households with a person living with Parkinson's in the UK spend **£572** extra per year on energy costs due to their condition.

Eight out of 10 respondents have access to a car, with almost a quarter of these vehicles being a mobility vehicle. Almost 90% of respondents have had to meet the expense of these cars being modified out of their own pocket. In the UK people with Parkinson's spend on average **£132** for these modifications.

Therefore living with Parkinson's can result in incurred costs of **£5,851**.

Loss of income due to early retirement or reduced working hours

The research found that Parkinson's directly impacts on employment and working hours.

Half of those diagnosed, and one third of family members, have either reduced their working hours, looked for more flexible roles or given up work entirely.

On average across the UK a working age person with Parkinson's loses 62.1 work days per year as a consequence of having the condition, and carers lose on average 18.9 work days a year.

People with Parkinson's who are still able to work reduce their hours on average by 12.4 hours per working week and carers by 10.7 hours per working week. This means there is an average loss of income to the household of **£1,981** in the UK.

In the UK, one in three people with Parkinson's have been forced to take early retirement or are unable to work due to their condition. This results in an annual average loss of **£6,013** per household in the UK.

Many of the carers who responded to this survey are not receiving Carer's Allowance and are therefore providing unpaid care. This results in an annual average loss of **£1,235** per household in the UK.

Finally, many of the respondents have been unsuccessful in retaining their state benefits (Personal Independence Payments and Employment and Support Allowance) due to government changes to eligibility criteria. This results in a further average loss of **£1,502** per household in the UK.

Therefore the average overall loss of income due to living with Parkinson's, from being unable to work or not getting the support they should receive, is **£10,731** per household in the UK.

The interviews provided a greater insight into the impact of Parkinson's symptoms, even prior to diagnosis. For example, one interviewee (MA) was self-employed and installed and serviced hands-free kits in cars for mobile phones or radio systems. He stated:

“I noticed when I was doing installations that I was having problems sort of feeding cables through small gaps. Whereas previously I would've done it say in a matter of a few seconds, it would take me several minutes to do the same thing. Because I didn't seem to be able to, I didn't have the dexterity in my hands. Using tools was becoming more difficult ... I would have to give

myself longer on the job which isn't always a good thing ... You've got a limited amount of time to do it so it increased the pressure on me as well.

“As a result the business was starting to suffer. I ended up having to sell my house because I couldn't afford the mortgage ... I eventually had to give up self-employment and I then went to work for my local authority.”

The effect of Parkinson's on another interviewee (LA) caused her to be signed off work. She has since attempted two returns to work, and considered part-time working, but ended up having to work irregular hours over a seven-day period, so this was untenable. She stated:

“So I tried to work away but a lot of my work is outdoors because it's working in gardens and stuff ... I have digestive problems as a result of the Parkinson's and some of the medication I'm on, so work was becoming difficult and I was becoming very, very self-conscious to the point where I got quite anxious about it and ended up being signed off by the doctor with anxiety and depression.”

“I have had to, in recent months, not accept but absorb the fact that I've got Parkinson's and the impact that's having on my life as it progressed and the potential impact it has on my life. So I decided to approach my boss ... I just asked them to consider ill health retirement.”

Decline in quality of life with less focus on wellbeing as the condition progresses

The majority of respondents with Parkinson's noted a decline in their health, compared with around half of carers.

Only a third of people with Parkinson's reported their health was good or very good, with up to two thirds reporting a need for help with activities within and outside the house.

The researchers used globally recognised scales to rate people with Parkinson's and their carers against the general population of the same age. They found they were generally less well and less satisfied with their lives. This feeling increased the

longer that someone had been diagnosed. People who had lost their independence (eg the ability to drive or not being able to travel abroad) discussed how altering their life choices also came with extra stress (like trying to find hotels that have appropriate accessible facilities) and reduced their ability to be socially active. This could in turn reduce their feelings of positivity and satisfaction with their life.

Where markers of independence are lost, one interviewee (AL) noted:

“Last week the DVLA took my licence away on medical grounds ... so where we'll be taking buses and taxis and the like, there will be expenditures on that.”

Conclusion

Living with Parkinson's is expensive. This research found that people with Parkinson's and their families in the UK are on average **£16,582** worse off per year as they have higher health and social care costs, lose income due to retiring early or reducing their hours, and lose out on state benefits. There is also a reduction in the quality of life of those living with Parkinson's and their carers.

The 2015 Extra Costs Commission² found that people and families with neurological conditions in England and Wales spend on average an extra **£200** per week. This is almost **£119** per week less than the findings of this research.

Parkinson's UK will use this research as a key part of our future campaigns to lobby governments to make improvements to the support they offer.

This research clearly demonstrates that governments urgently need to better support people with Parkinson's and their carers through improvements to the welfare, health and care systems.

² Scope, June 2015: <http://www.scope.org.uk/Get-Involved/Campaigns/Extra-costs/Extra-costs-commission/Full-Report>

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- make sure welfare support is maintained, so that people affected by Parkinson's are not repeatedly reassessed, are clear about their rights under the mitigation package agreed by the Executive, and are protected from any future welfare cuts

We call on the Scottish Government to:

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- work with energy companies and regulators to ensure that households including people with Parkinson's are identified and placed on the lowest possible energy tariff
- ensure that households including people with Parkinson's are identified as a target group for warm homes initiatives
- use its influence and powers with employers to promote better policies and practices to support people with Parkinson's and unpaid carers to stay in work for as long as possible

We call on the Welsh Government to:

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- invest in social care and support for carers, to counteract the added stress they have when

Every hour, someone in the UK is told they have Parkinson's – a brain condition that turns lives upside down, leaving a future full of uncertainty.

Parkinson's UK is here to make sure people have whatever they need to take back control – from information to inspiration.

We want everyone to get the best health and social care. So we bring professionals together to drive improvements that enable people to live life to the full.

Ultimately, we want to end Parkinson's. That's why we inspire and support the international research community to develop life-changing treatments, faster. And we won't stop until we find a cure.

**Together we can bring forward the day
when no one fears Parkinson's.**

Parkinson's UK
215 Vauxhall Bridge Road
London SW1V 1EJ

Free confidential helpline **0808 800 0303**
(Monday to Friday 9am–7pm,
Saturday 10am–2pm). Interpreting available.
Text Relay **18001 0808 800 0303**
(for textphone users only)

hello@parkinsons.org.uk
parkinsons.org.uk