

## Parkinson's UK policy statement: Disability and age-related benefits

*"Parkinson's has left me less able to cope and is expensive. It has made it difficult for me to continue making a living and provide for a comfortable retirement. However, PIP is there for me and no matter how difficult it is to accept a benefit, it makes a difference. Mobility aids, public transport and taxis, adapted kitchen appliances, and self-referred activities to improve my wellbeing all have to be paid for and PIP is there to help me."*

*John, person with Parkinson's*

### What we believe

Parkinson's UK believes that people with Parkinson's should be able to fairly and equitably access a centrally-provided system of non-means tested extra-cost disability benefits to help meet the costs associated with living with a long-term condition and enable them to fully participate in society, regardless of where they live.

Parkinson's UK also believes that age-related 'universal' benefits, such as winter fuel allowance, free TV licences for over 75s and bus travel concessions, are important in helping older people with Parkinson's maintain their wellbeing and independence. We do not believe that they should be means tested.

### Why we believe this

#### Disability Living Allowance and Personal Independence Payment

The people affected by Parkinson's want a benefit system that is fair to the people with the condition.<sup>1</sup> Parkinson's UK have committed to campaigning for a benefit system that gives people the support they deserve. When people are going through a difficult time in their lives, they should not have to worry about money.

Having a disability or long-term illness can increase the cost of everyday life. For example, accessing transport, services and leisure opportunities can all create extra costs.<sup>2</sup> Scope's Extra Costs Commission<sup>3</sup> found that people with neurological conditions spend on average an extra £200 per week due to their condition. However, when looking specifically at Parkinson's, our own research shows that people living with the condition are on average £328.73 per week out of pocket.<sup>4</sup>

<sup>1</sup> <https://www.parkinsons.org.uk/news/what-matters-most-survey-results>

<sup>2</sup> See facts and figures from the Office for Disability Issues based on the Life Opportunities Survey (2012) <http://odi.dwp.gov.uk/disability-statistics-and-research/disability-facts-and-figures.php>

<sup>3</sup> <https://www.scope.org.uk/Scope/media/Documents/Publication%20Directory/Extra-Costs-Commission-Progress-Review.pdf>

<sup>4</sup> [https://www.parkinsons.org.uk/sites/default/files/2017-07/CS2547%20Cost%20of%20Parkinson%27s%20report%202017%20-%20UK\\_1.pdf](https://www.parkinsons.org.uk/sites/default/files/2017-07/CS2547%20Cost%20of%20Parkinson%27s%20report%202017%20-%20UK_1.pdf)

# PARKINSON'S<sup>UK</sup> CHANGE ATTITUDES. FIND A CURE. JOIN US.

The UK government has changed the law so that people of working-age can no longer receive Disability Living Allowance (DLA). The government moved people away from DLA, even if they were previously offered lifetime awards, by reassessing them for its replacement Personal Independence Payment (PIP).<sup>5</sup> This led to the loss of vital financial support for people of working age and caused great anxiety for people with Parkinson's and their families.

As a charity, we objected to the introduction of PIP and the rationale behind the policy. It was clear that the more stringent PIP criteria have been introduced retrospectively to meet the Treasury's decision in 2010 to reduce the cost of DLA, and therefore the caseload in payment.<sup>6</sup>

At the time, it was also clear that people with degenerative conditions such as Parkinson's were widely expected to bear the greatest burden of these cuts, with 548,000 due to lose the high rate payment in reassessment, as a result of changes to the minimum distance a person must walk to qualify for this support (from 50 metres to 20 metres).<sup>7</sup>

Since reassessments for people with long-term or indefinite DLA awards started in 2015, we have seen a disproportionate impact on people with degenerative conditions such as Parkinson's, with 26% losing access to support altogether, or having it downgraded upon reassessment.<sup>8</sup> We also note that in the most recent quarter, 71% of PIP appeal decisions were overturned.<sup>9</sup>

Changes made in August 2018 now mean that people awarded the highest level of support under PIP, and where their needs are expected to stay the same or increase, will receive an ongoing award with a light touch review every ten years.

In Northern Ireland, the Department for Communities is proactively looking back at cases where claimants would have received the award had the new guidance been in place and is moving them onto the ongoing award.

Previously this was not going to apply to the rest of the UK, but after campaigning by Parkinson's UK the Work and Pensions Secretary has now agreed to ensure this will also be applied to existing claims from November 2018.<sup>10</sup> This will greatly improve the experience for people with Parkinson's and will remove the stress of having to attend a face-to-face medical assessment.

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<sup>5</sup> Disability Living Allowance for working age people (those aged 18 – 64 years old) has been being replaced by a new benefit, Personal Independence Payment since 2013.

<sup>6</sup> See Reassessments and Impacts report (December 2012) Table 6 shows of those who will be reassessed. 510,000 on DLA will receive a lower award under PIP, and 450,000 on DLA will receive no award under PIP. <http://www.dwp.gov.uk/docs/PIP-reassessments-and-impacts.pdf>. £2 billion is expected to be saved by the exchequer. Department of Work and Pensions. Disability Living Allowance Reform Impact Assessment (May 2012) <http://www.dwp.gov.uk/docs/dla-reform-wr2011-ia.pdf>

<sup>7</sup> See the Government's response to the PIP moving around activity consultation – October 2013. Table 4 and paragraph 6.10 [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/251631/PIP-mobility-consultation-government-response.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/251631/PIP-mobility-consultation-government-response.pdf)

<sup>8</sup> DLA to PIP reassessment outcomes October 2017: <https://www.gov.uk/government/statistics/personal-independence-payment-april-2013-to-october-2017>

<sup>9</sup> <https://www.gov.uk/government/statistics/tribunals-and-gender-recognition-certificate-statistics-quarterly-april-to-june-2018>

<sup>10</sup> DWP Announcement: <https://www.parliament.uk/business/publications/written-questions-answers-statements/written-statement/Commons/2018-12-20/HCWS1224>

PIP is also vital in passporting people with Parkinson's to other sources of support that help maintain or increase their mobility, such as the Blue Badge disabled parking scheme, or the opportunity to lease a vehicle through the Motability scheme. Changes to eligibility criteria and rates of payment can therefore have a significant wider impact on people with Parkinson's, if they are denied access to this support.

We believe that PIP has lost the confidence of people with Parkinson's, who regularly have to undergo appeals to receive the appropriate level of support for their needs. Parkinson's UK concludes that PIP is a failure and a replacement extra-costs benefit is now urgently required, in order to correct systemic failures and inequalities inherent in the design of the current system.

## Attendance Allowance and the localisation of financial support for disabled people

Attendance Allowance (AA) is a source of financial support valued by over 36,000 older people with Parkinson's, 75% of these people (27,000) receive the higher rate.<sup>11</sup> People with Parkinson's use it to pay for energy bills and transport to and from medical appointments.

*'[Having Attendance Allowance] means that I can pay for help around the house, as I live alone, and pay for somebody to keep the garden tidy. As my Parkinson's is beginning to deteriorate I can't always walk very far so I can now afford to pay for taxis to get to the shops, doctors etc.'*

Working-age carers of people with Parkinson's in receipt of Attendance Allowance can also make a claim for Carers Allowance.

Governments have in the past proposed devolving responsibility for funding and administering Attendance Allowance to local authorities, instead of providing it from central government. Parkinson's UK strongly opposes any localisation of financial support for disabled people, for a number of reasons:

- If people with Parkinson's lose access to Attendance Allowance, or other extra-cost disability benefits they are likely to be unable to reach hospital appointments. This would significantly reduce their independence, to the detriment of their physical and mental wellbeing.
- Devolving responsibility for the delivery of disability benefits to local authorities would introduce a postcode lottery of provision. Each council is likely to introduce their own eligibility criteria in order to ration access to essential financial support, particularly if they face significant demand. This would also make it extremely difficult to hold local authorities to account for their decision-making or ensure equality of access for people with Parkinson's.

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<sup>11</sup> [http://tabulation-tool.dwp.gov.uk/100pc/aa/disabled/ccaaawd/a\\_carate\\_r\\_disabled\\_c\\_ccaaawd\\_feb16.html](http://tabulation-tool.dwp.gov.uk/100pc/aa/disabled/ccaaawd/a_carate_r_disabled_c_ccaaawd_feb16.html)

- Difficulties claiming the benefit may be compounded if assessors have a poor knowledge and understanding of Parkinson's, its symptoms and the impact it has on a person's daily life.
- If the funding allocated for Attendance Allowance or other disability benefits can be spent on other areas, we believe local authorities would absorb the additional funds into other services that have faced budget cuts, such as social care, or even other areas of local authority spending, and may not provide this critical support at all. This would have a significant impact on people with Parkinson's.

We believe no one with Parkinson's should lose their financial support due to these potential benefit reforms. Instead, all governments should be looking to improve uptake and experience of the disability benefits system for those with Parkinson's, by:

- Retaining a centrally provided system of disability benefits.
- Ensuring that older disabled people are supported to maintain and improve their physical mobility, through the addition of a mobility component to Attendance Allowance. This would mirror the mobility component of PIP/DLA.
- Making sure the rates of disability benefits give a realistic representation of costs when living with a long-term condition and reflect annual increases in the true cost of living, providing equality of support, regardless of age.
- Making sure those who make changes to the benefit system have a good understanding of Parkinson's and that assessors take into account the impact Parkinson's has, including the fluctuating and progressive nature of the condition.
- Asking decision makers to make full use of evidence from health and social care professionals who know the person best. Decisions on disability benefits should never be solely based on 'snapshot' interviews with assessors.
- Making sure there is less bureaucracy and paperwork, to avoid repeated questions, form filling and the need for 'face-to-face' assessments wherever possible. It is wasteful to repeatedly assess people with Parkinson's for benefits when the condition only progresses, or where they already get the highest award.
- Making sure the criteria for disability benefits are clear and applied consistently, with decisions and appeal processes made within reasonable times. It is unacceptable that long wait times for tribunals means people can wait many months to get their disability benefit.
- Researching the way these benefits work with other important services for disabled people, as well as the economic impact they have – for example if someone uses their PIP to be able to work, or their Attendance Allowance to keep active.

## Means testing

Currently these benefits are not means tested and are tax free, and a disabled person will only be eligible once they are assessed as having a certain level of functionality. Disability benefits help people where daily living causes challenges and extra costs, including people with Parkinson's. Parkinson's UK believes they should be available regardless of means and should stay tax free.

Separately there are tax-free and non-means tested benefits that older people can get, which include winter fuel allowance, free TV licences for over 75s and bus or train travel discounts. These are often called 'universal' because everyone of a certain age can claim them. This is different to disability benefits, where a person will only get the benefit once they show a high level of disability.

Their universal nature 'captures' the 1.5 million pensioners who are in poverty today,<sup>12</sup> and they will be among the 2.38 million households in fuel poverty.<sup>13</sup> Parkinson's can make it more difficult to leave the house or drive a car, so these benefits can be invaluable – especially as costs of living and fuel continue to rise.

There is an ongoing debate on whether 'wealthier' pensioners should also be eligible in times of austerity, and whether benefits could be better targeted towards those on low incomes by means testing. For example, Attendance Allowance recipients are notably less well off than the rest of the retired population which suggests that although the benefit is not means tested, it operates as though it were.<sup>14</sup> Research also shows that people who receive Attendance Allowance tend to have levels of wealth that would mean they would be eligible for means-tested local authority social care support in future.<sup>15</sup>

Parkinson's UK believes that means testing these universal benefits would not necessarily mean they are better targeted. Means testing can stop people who genuinely need the benefit from claiming for a variety of reasons, such as confusion over the rules. It can also cost the state large amounts of money in administration.

For these reasons Parkinson's UK would not support means testing of these benefits. There are other ways in which system reform might better target, while not undermining, the universal nature of benefits. Some have suggested making them taxable benefits or looking at the age of eligibility. However, as with any reform, there should be consideration over the impact of doing so, and the evidence for it.

## Scotland

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<sup>12</sup> *Households Below Average Income 2014/15*, Department of Work and Pensions, 2016. Poverty is defined as income of less than 60% median income (adjusted for family size) after housing costs. <http://research.dwp.gov.uk/asd/index.php?page=hbai>

<sup>13</sup> *Annual report on fuel poverty statistics 2016*. National Statistics publication with Department of Energy and Climate Change (2016). Fuel poverty is currently defined as if a household needs to spend more than 10% of its income on fuel to maintain a satisfactory heating regime. <https://www.gov.uk/government/organisations/department-of-energy-climate-change/series/fuel-poverty-statistics>

<sup>14</sup> Using data from the English Longitudinal Study of Ageing: <http://www.elsa-project.ac.uk/publicationDetails/id/9354>

<sup>15</sup> <http://strategicsociety.org.uk/wp-content/uploads/2016/07/Attendance-Allowance-and-Local-Government-Examining-the-evidence-and-the-options.pdf>



Following the Scotland Act 2016, responsibility for DLA, PIP and Attendance Allowance will be devolved to the Scottish government. They are in the process of consulting on the changes they are going to make and will likely put legislation into place from 2020. Once the details are in known, Parkinson's UK will develop a policy position.

## Special rules

In Scotland, the 6-month limit has been abolished so claimants who are terminally ill can rapidly access PIP and Attendance Allowance. The decision will now be based upon the judgement of a clinician that they have a progressive illness which can reasonably be expected to cause the individual's death. Whilst this may not affect many people with Parkinson's it is a much more progressive approach that we support. This could benefit people with advanced Parkinson's who have not previously accessed the benefits system and those who have a diagnosis of rapidly-progressing Parkinsonism's like Multiple System Atrophy and Progressive Supranuclear Palsy.

## Northern Ireland

Most welfare policy is devolved to Northern Ireland. The Northern Ireland Assembly, during the 2011-16 term, negotiated and agreed a series of "mitigations" before welfare reform legislation was applied to Northern Ireland (three years later than in the rest of the UK).

However, although many of the mitigations were welcome to people with Parkinson's, they do not specifically cover the issues raised in this document.

## What Parkinson's UK is doing

We are working to ensure that people are aware of their rights to disability and age-related benefits through our information resources, advisory services and regional teams. We also train professionals working with people with Parkinson's, so they are better educated about the condition, including benefits assessors. We campaign hard for improvements to the welfare system where these are needed.

## Acknowledgement

We are grateful for the advice and guidance of our Policy Panel in shaping this position paper on working age income replacement benefits. The Policy Panel consists of people with experience of Parkinson's who meet on a regular basis to help guide the charity's position on a range of policy issues.

## Further information

Please contact the Policy and Campaigns team. Tel: 020 7963 9307 or email: [campaigns@parkinsons.org.uk](mailto:campaigns@parkinsons.org.uk)