

Parkinson's UK policy statement: Working age income replacement benefits

"I have found the whole ESA procedure totally inadequate for people like me with progressive neurological diseases like Parkinson's. They currently deem me unfit for work now but say I could return to work within the next six months ... do they know of some miracle cure for [people with] Parkinson's!"

Person with Parkinson's

What we believe

Parkinson's UK believes that people with Parkinson's of working age, who are unable to work because of their condition, should receive an income replacement benefit paid at a level that enables independence and social participation.

This should be reflected through:

A system that's fair to those unable to work

- Returning to employment is not an option for lots of disabled people including many people with Parkinson's. Those unable to work should receive an income replacement benefit that ensures a meaningful income.
- Respect for those who cannot work must underpin the benefit system.
- The system should not repeatedly reassess people with progressive conditions or presume that everyone is available to work unless proven otherwise.

A system that helps those who need additional support to return to work

- Tailored support should be offered to people with Parkinson's who may be able to return to work with additional help
- Opportunities to retrain should be made available to those who are unable to continue in their chosen career because of the condition but could make a return to work.
- The benefits system must accommodate people only able to work intermittently because of the fluctuating nature of their condition.
- There should be no requirement to undertake back-to-work activity as a condition of receiving the benefit. This is particularly the case for people with Parkinson's, given the side effects of medication and fluctuations in the condition.

An accessible benefits system

- Forms and claims processes should be easy to access and complete, and additional support should be made available to those who struggle with the application forms.
- Paper copies should be available for all benefit applications, in parallel with online claims processes.
- Good quality information about benefits should be available to all.
- There should be a clearly signposted and straightforward appeals process.

Decisions on ability to work must take into account the complexities of the condition

- Assessments must be holistic and take account of the degenerative and fluctuating nature of conditions such as Parkinson's.

- Assessments must take into account all aspects of the condition, including both physical and mental health symptoms and the side effects of any medication.
- Assessments must allow sufficient time for all symptoms to be properly assessed and considered.
- Staff making benefit-related decisions about claimants with Parkinson's must have a strong understanding of the condition and access to relevant up-to-date guidance and information.
- Any decision relating to a person with Parkinson's must take into account their medical history and the judgement of Parkinson's consultants and other experts who know the person well.
- The process for handling overpayments must avoid unnecessary stress and hardship.

Why we believe this

There is a poor understanding of the condition amongst welfare advisors and assessors

The fluctuating nature of Parkinson's is poorly understood. There is a danger of someone having a 'good day' at interview for benefits or medical assessments and the interviewer not understanding that this is not typical of the person's condition.

This problem is reinforced by poor understanding of the non-motor symptoms of Parkinson's, including mental health problems, which can be difficult to diagnose and manage. A third of respondents to a training needs analysis of healthcare professionals identified that they were not confident in identifying the mental health symptoms of Parkinson's. There was also uncertainty about the side effects of both mental health and Parkinson's drugs.¹

There are various issues that any assessor needs to be aware of in dealing with a claimant with Parkinson's. People with Parkinson's may be misinterpreted as being uncooperative if the advisor has not had training about the condition. These issues include fluctuations in functionality where a person can change from reasonable mobility to absolute immobility in the space of a few minutes, and limited facial expression due to muscle rigidity, which can make people appear anxious, hostile or bored. People's ability to write can often be affected by Parkinson's so completing forms can be very difficult. Parkinson's can also have an impact on people's ability to communicate verbally.

Poorly designed assessment criteria

We have serious, ongoing concerns about the quality and design of the Work Capability assessment criteria, which ask whether a person can undertake a series of simple tasks, such as standing and sitting, picking up and moving a 500ml container of liquid or lifting a £1 coin.

It is clear that whether a person can lift a pound coin or raise their hands above their head are not useful measures of whether a person with Parkinson's is well enough to work.

What's the evidence?

¹ Parkinson's UK (unpublished) results of training needs analysis

There are a number of different benefits available to support people of working age with Parkinson's. The working age income replacement benefit is Employment and Support Allowance (ESA). ESA is a benefit paid if your ability to work is limited by ill health or disability. An 'assessment phase' normally involves undergoing a Work Capability Assessment which involves a face-to-face discussion of a person's functional ability. In the long-term there is an aim to move people from ESA into a 'limited capability for work' element of Universal Credit (UC).

In 2014, a Freedom of Information request conducted by Parkinson's UK found that almost 8,000 people with progressive and incurable conditions such as Parkinson's, MS, Spinal Muscular Atrophy, Cystic Fibrosis and Rheumatoid Arthritis have been put in the Work-Related Activity Group². We continue to hear examples of people not getting access to the support they urgently require.

We also note the increasing proportion of successful ESA appeals. **Between June-September 2018, successful appeals rates stood at 68%**³. This indicates the continued failure of assessors and the assessment criteria themselves, to correctly identify the impact of a complex, degenerative condition like Parkinson's.

In April 2017 the government withdrew the Work-Related Activity Group (WRAG) component from ESA payments, for new claimants. This was an additional £30 per week top up that people in this group received to help them with the additional costs of their illness. In 2015 the Disability Benefit Consortium (DBC) published a report based on a survey of people with disabilities who had claimed ESA.⁴ When asked what the likely impact would be if their ESA were to be cut by £30 per week, the survey found that:

- 69% think their health would get worse.
- 69% would struggle to pay their bills.
- 70% would struggle to maintain their independence

Over half of the people surveyed said that the amount of ESA they currently received was not enough to live on. As a consequence:

- Almost a third (28%) couldn't afford to eat.
- Over a third (36%) have been trapped in their house as they couldn't afford a taxi.
- Over a third (38%) have been unable to heat their home (38%).
- 52% have struggled to stay healthy.

In 2017 Sheffield Hallam University, working with Parkinson's UK, published a study that looked into the cost of living with Parkinson's.⁵ Key findings were that:

- A high proportion of people of working-age, with Parkinson's, rely on benefits for their income, or part of their income.

² <http://www.independent.co.uk/news/uk/politics/thousands-with-degenerative-conditions-classified-as-fit-to-work-in-future--despite-no-possibility-of-improvement-9811910.html>

³ <https://www.gov.uk/government/statistics/tribunals-and-gender-recognition-certificate-statistics-quarterly-april-to-june-2018>

⁴ <https://disabilitybenefitsconsortium.wordpress.com/2015/10/27/almost-70-of-disabled-people-say-cuts-to-esa-will-cause-their-health-to-suffer-and-half-may-return-to-work-later/>

⁵ <https://www.shu.ac.uk/research/specialisms/health-and-social-care-research/reports/economic-social-and-financial-cost-of-parkinsons-on-individuals-carers-and-their-families>

- Of the working age people who provided details of their income, 64% reported that they were in receipt of benefits.
- When looking at all age groups, 83% of people with Parkinson's reported that they were in receipt of benefit income.
- Of those that reported their income, just 13% received income from employment.

The Cost of Parkinson's report (2017), found that in the UK, people with Parkinson's and their families, were on average £16,582 worse off each year. This was due to higher health and social care costs, loss of income due to retiring early or reducing their hours, and loss of state benefits.⁶

With the loss of the WRAG component, people with Parkinson's now find it harder to pay for the cost of their condition. The £30 they would have received with this component could have paid for around 25% of that additional cost.

What Parkinson's UK is doing

We are working to ensure that people are aware of their rights to working age income replacement 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 advisors. We work with other charities as part of coalitions and 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

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⁶ https://www.parkinsons.org.uk/sites/default/files/2017-07/CS2547%20Cost%20of%20Parkinson%27s%20report%202017%20-%20UK_1.pdf