

10 Years of PIP: Briefing for parliamentarians

July 2023

Background

Over 130,000 people in the UK have multiple sclerosis, around 145,000 people live with Parkinson's in the UK and over 500,000 people in the UK live with Crohn's Disease or Ulcerative Colitis. There are many additional costs associated with living with these conditions, such as mobility aids and equipment, treatments, and care. Personal Independence Payment (PIP) is a disability support payment from DWP which is meant to help manage the extra costs of living with a long term condition, enabling recipients to retain their independence, participate in society and stay in work for longer.

MS, Parkinson's and Crohn's and Colitis are fluctuating conditions, meaning that many of the symptoms are different from day to day, or even hour to hour. Many of the symptoms of these conditions – like pain, fatigue, incontinence and cognitive issues - are hidden. At present, the PIP claim process is designed in a way that doesn't enable people with hidden or fluctuating symptoms experienced by people with MS, Parkinson's or Crohn's and Colitis to fully explain how the condition impacts their lives day to day.

In Scotland, people are experiencing delays when being transferred from PIP to Adult Disability Payment (ADP). Compounding these delays, Scottish claimants who report a change in circumstances are having any increase in award that would result in that change of circumstances, put on hold.

It has been ten years since PIP was introduced. Since then, people with these four fluctuating conditions have faced common challenges in accessing PIP, and are frequently let down by the system. This means many people are denied support that they should be getting. This briefing summarises the main problems they are experiencing with PIP, what the Government is doing to address this, and what more can be done.

Summary of recommendations:

Given the UK Government plans to scrap the Work Capability Assessment¹ and make the PIP assessment the sole route to disability/health related financial support, the need to overhaul all PIP descriptors is more urgent than ever.

We call on the UK Government to make changes to the following:

1. **The 20 metre rule** - The 20 metre rule is an arbitrary measure of mobility and should be scrapped. The rule means if you can walk just one step over 20 metres (roughly the length of two double-decker buses) you don't get the highest rate of mobility support.

¹ DWP. Transforming Support: The Health and Disability White Paper. 2023.

2. **Informal observations** - Too often, PIP assessors make inaccurate decisions based on 'informal observations' (the way people look or act during their assessment). 67% of people with MS whose assessment included these said they didn't reflect how MS affects them. When Parkinson's UK 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.
3. **The 50% rule** - This rule says if your symptoms affect you for less than half of the month, you aren't entitled to support for them. For example, using a mobility aid for 14 days of the month would not entitle you to support for this. The nature of fluctuating conditions means that it is impossible to predict when, for how long and how severely symptoms may occur or escalate the 50% rule therefore disadvantages people with these conditions.
4. **Revision of PIP descriptors** - The PIP descriptors should be overhauled to ensure that they accurately reflect the lived reality of those who claim PIP.

PIP and MS

- On average, the extra costs associated with living with MS are around £337 per month. This includes things like heating, transport, treatments and care.²
- 58,643 people with MS are receiving Personal Independence Payment (PIP). 77,163 people with MS have submitted a claim for PIP since it was first introduced in 2013.³
- Despite MS being a progressive condition 48% of those claiming PIP have an award period of less than 5 years.
- Over 1 in 10 people (11%) with MS who have claimed PIP since it was first introduced have submitted a Mandatory Reconsideration (MR) and had their decision changed. In effect, this means over 1 in 10 people with MS aren't getting the correct decision the first time. This figure also doesn't include those who didn't submit a Mandatory Reconsideration (MR) but thought they got the wrong award, so the true number of people getting the wrong decision the first time round is likely to be even higher. 68% of PIP decisions are overturned in favour of the claimant (across all disabilities) after being appealed at tribunal. When moving from DLA to PIP, 29% of people with MS either had their award decreased or disallowed.
- Almost 2 in 10 (18%) people with MS had their award decreased or disallowed after being reassessed due to an award review.

PIP and Parkinson's

- Based on research carried out in 2016⁴ and year on year CPI⁵ and AWE⁶ increases, in 2022 living with Parkinson's cost a household an additional £20,062 per year.
- Since its inception, just over 20,000 people with Parkinson's have applied for and had a decision on their PIP application, 82% of which have been granted an award.
- Over a third (38%) of PIP claims made by people with Parkinson's since the end of June 2015 were initially assessed incorrectly. These cases were revised following

² MS Society – *Reduced to breaking point: The impact of the cost of living crisis on people with MS, 2022*

³ Department for Work and Pensions, Statistics to January 2023 (accessed via Stat-Xplore)

⁴ Gumber A. Economic, Social and Financial Cost of Parkinson's on Individuals, Carers and their Families in the UK: final report. Sheffield Hallam University. 2016.

⁵ Consumer price inflation is the rate at which the prices of the goods and services bought by households rise or fall; it is estimated by using consumer price indices.

⁶ Average Weekly Earnings (AWE) is the lead monthly measure of average weekly earnings per employee. It is calculated using information based on the Monthly Wages and Salaries Survey (MWSS), which samples around 9,000 employers in Great Britain.

mandatory reconsideration of the decision and the amount awarded to the claimant was changed.⁷ And, just as for claimants with MS, this figure doesn't include those who didn't submit an MR.

- Despite Parkinson's being a progressive condition, it is only since 2019 that people with Parkinson's have been awarded claims of 5 years or more and even now, less than 50% of those people with Parkinson's claiming PIP have an award period of 5 years or more.⁸
- Even though there has been no cure or radically new treatment for Parkinson's since the creation of PIP, the rate at which people with Parkinson's have been granted an award varied by over 20 percentage points between 2016 and 2023.⁹

PIP and Crohn's and Colitis

- Crohn's and Colitis, the two main forms of Inflammatory Bowel Disease are lifelong, immune-mediated diseases of the gut for which there is currently no known cure.
- The symptoms of these conditions include urgent and frequent diarrhoea, pain, fatigue and inflammation of the joints.
- Flares often occur suddenly and unpredictably throughout a person's lifetime. There is also significant variation in the pattern and complexity of these symptoms both between people and for the individual at different times in their life.
- The physical and mental impact of living with Crohn's and Colitis can prevent many from fully maintaining their independence and participating in employment or education.
- Currently, only 13,700 people with Crohn's or Colitis successfully claim PIP. This figure represents 2.7% of the total population of people living with these conditions. Given what is known about varying degrees of condition severity among the population, Crohn's & Colitis UK estimate that 30% of people will need additional financial support in the form of PIP at some point in their lives.
- In 2022, only 1 in 5 PIP claims for people with Crohn's and Colitis were awarded. Furthermore, 15% of claims made by people with Crohn's and Colitis were initially assessed incorrectly. These cases were revised following mandatory reconsideration of the decision and the amount awarded to the claimant was changed. This figure doesn't include those who didn't submit a MR.

How you can help

- In the autumn, Charlotte Nichols MP will apply for a debate on "10 years of PIP". We ask that if you can, you add your name to the debate application, and that you attend the debate and speak up on behalf of people with fluctuating conditions.
- The MS Society is launching a campaign on PIP and will share more details of how you can support it in due course.

⁷ DWP

⁸ DWP

⁹ DWP

Appendix 1 What are the main problems with PIP and what the Government has said in response

Issue	Explanation	What the Government says ¹⁰	What this means for our communities and what needs to change
20 metre rule	The rule means that if you can walk one step over 20 metres (roughly the length of two double decker buses), you don't get the highest rate of mobility support.	<p>"The enhanced rate of the PIP mobility component is intended to be for people 'unable' or 'virtually unable' to walk. The DWP believes the current assessment criteria, including the 20-metre rule, are the best way of identifying the people whose physical mobility is the most limited."</p> <p>"All health professionals are required to assess individuals in line with the statutory requirements, including whether an individual can complete each of the 12 activities; the manner in which they can do it; and whether they can complete each activity "safely, to an acceptable standard, repeatedly and in a reasonable time period".</p>	<p>How a person functions under clinical testing and in their natural environment can be different. 20 metres represents a snapshot of someone's day.¹¹¹² It does not take into account the impact MS symptoms like fatigue can have for days or weeks after physical exertion. Symptoms can affect people differently from day to day.</p> <p>The Government should scrap the PIP 20 metre rule and work with experts to come up with an appropriate alternative that considers conditions that fluctuate and have hidden symptoms. In the meantime, the 50-metre rules should be reintroduced.</p>

¹⁰ Letter from Tom Pursglove MP to Derek Thomas MP, 11 May 2023, Ref MC2023/34510 (Accessed via <https://www.derekthomas.org/sites/www.derekthomas.org/files/2023-05/Letter%20from%20Tom%20Pursglove%20MP%2011.05.2023.pdf>)

¹¹ Ehling et al, *Ecological validity of walking capacity tests following rehabilitation in people with multiple sclerosis*, 2019

¹² Karle et al, *The Two-Minute Walk Test in Persons with Multiple Sclerosis: Correlations of Cadence with Free-Living Walking Do Not Support Ecological Validity*, 2020

<p>Informal observations</p>	<p>Too often, assessors aren't testing whether people can do an activity safely, reliably, repeatedly and in a timely manner – as guidance states they should. Instead, they assess them by making an 'informal observation'. This is when an assessor watches how someone looks or behaves during the assessment. For example, people have told us their mobility has been assessed by being watched walking from their car to the assessment centre. Informal observations such as this fail to consider the fluctuating nature of MS, Parkinson's, Crohn's and Colitis and hidden symptoms such as pain and fatigue.</p> <p>In a 2019 survey of people with MS, 67% who had informal observations included in their assessment report said they did not reflect how their MS affects them.</p>	<p>'Informal observations are part of the suite of evidence used by Case Managers to help them determine entitlement to benefit. Informal observations are of importance to the consultation, as they can reveal abilities and limitations not mentioned in the claimant questionnaire, supporting evidence or during the history taking for the consultation. They may also show discrepancies between the reported need and the actual needs of the claimant.'</p> <p>Government PIP guidance says that assessors should 'balance' the use of informal observations with 'evidence from professionals who may have observed the claimant more regularly'.</p>	<p>Too often we hear from people who say that informal observations are given greater weight than their medical evidence, or their medical evidence is ignored, and this isn't justified in their assessment report. This even happens when evidence may say something completely different about the claimant's abilities compared to what the assessor has informally observed during the assessment.</p> <p>Informal observations must either be backed up by evidence from the claimant or if an informal observation is given more weight than evidence to make an assessment about someone's ability to do a particular activity then the reason for doing this should be fully justified in the assessment report. Where this doesn't happen, the report must be sent back to the assessor.</p>
<p>50% rule</p>	<p>If your symptoms affect your ability to do the activities set out by the PIP criteria for less than 50% of days in a 12-month period, you are not entitled to support for them.</p> <p>There are legal precedents for fluctuating symptoms being treated as constant symptoms which are listed below.</p>	<p>As the 50% rule looks at whether someone's symptoms affect their ability to an activity on more than 50% of days over a 12 month period, the Government claim it enables the assessment to take a 'a view of ability over a longer period of time and helps to iron out fluctuations and presents a more coherent picture of disabling effects'.</p>	<p>Like the 20-metre rule, the 50% rule is a rigid and arbitrary test that doesn't properly consider how fluctuations in someone's condition may affect their day-to-day life.</p> <p>Government should repeal the 50% regulation.</p>

	<p>Harm minimisation In respect to mental capacity, case law has established that, in some instances, fluctuation of the cognitive symptom of diminished capacity, should be treated as a constant symptom, in order to minimise harm.</p> <p>In a 2004 mental capacity case, the court found that, given that withdrawing safeguarding protection would result in a deterioration in the cl’s mental health, the client should be treated as lacking capacity all the time and so be safeguarded, even though in reality their capacity fluctuated. The harm of withdrawing safeguarding in response to the client regaining capacity was so great as to warrant treating the client as lacking capacity all the time.</p> <p>Reflection of severity of harm The guidance which accompanies the Equality Act definition of disability says that:</p> <p>“if an impairment has had a substantial adverse effect on a person’s ability to carry out normal day-to-day activities but that effect ceases, the substantial effect is treated as continuing if it is likely to recur.”</p>		
Repeat assessments	People with progressive conditions which have no cure often go through	The Government has committed to testing the introduction of a Severe	The Government needs to set out clearly which condition groups will be

	unnecessary repeat assessments. Where these assessments are carried out poorly for the reasons outlined above, people can lose the level of award they previously had.	Disability Group for those with the most severe health conditions, so people do not need to complete a detailed application form or go through an assessment.	covered as part of the Severe Disability Group. Progressive conditions which are not going to improve should be included within this.
No option to track PIP application	PIP claimants are left with no idea of when they can expect to learn when their application has been decided. This uncertainty causes claimants entirely avoidable anxiety.	Contracts for the new Functional Assessment Service, which will come into being in 2024, include specific end-to-end clearance targets for PIP. ¹³	Government should place these target times in the public domain.
Revision of PIP descriptors	The current PIP descriptors and their application do not work for people with hidden or fluctuating symptoms. In its recent inquiry report exploring the issues of DWP health assessments, the Work and Pensions Committee asked that, “We request that the Government confirm in response to this Report whether it is still reviewing the descriptors, and if not, what evidence it has found that those currently in use are fit for purpose.”	PIP criteria consider an individual’s ability over a 12-month period, ensuring that fluctuations are taken into account. ¹⁴ Government has not presented the requested evidence demonstrating that the current PIP descriptors are fit for purpose, to the Work and Pensions Committee.	The PIP descriptors should be overhauled to ensure that they accurately reflect the lived reality of those who claim PIP.
The toilet needs and incontinence descriptor	This descriptor is judged on whether someone can get on and off the toilet, evacuate their bladder and/or bowel and clean themselves afterwards. The guidance fails to recognise the differences between types of toilet needs, including		

¹³ Work and Pensions Committee. Health assessments for benefits: Government response to Committee’s Fifth Report of Session 2022–23. House of Commons. 2023.

¹⁴ Work and Pensions Committee. Health assessments for benefits: Government response to Committee’s Fifth Report of Session 2022–23. House of Commons. 2023.

	frequency of bowel movement, urgency, and incontinence.		
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