Fairness, dignity and respect: How to fix PIP


MS Society
MS Society
Speak up

Contents

MS and PIP

Multiple Sclerosis (MS) is a neurological condition that affects more than 150,000 people in the UK.

Most people with MS begin to experience symptoms between the ages of 20–40. And women are two and a half times more likely to develop MS than men.

MS is unpredictable and different for everyone. It affects people's nervous system and is often painful, exhausting and can cause problems with how you move, see, think, and feel.

Living with MS is expensive. People with MS face unavoidable extra costs as a result of the condition. These can include things like buying mobility aids or paying for treatments not always available on the NHS. Things like specialist mental health support or physiotherapy to manage pain and muscle spasms.

People with MS also find they need to pay more to be able to travel to work and get to appointments. Or to pay for carers to help with day-to-day activities. Personal Independence Payment (PIP) exists to help disabled people, including people living with MS, to meet these extra costs.

John, 55–64, Eastleigh

"PIP is a means of supporting people to live life to the fullest and live as independently as possible. It often helps people to stay in work and make a meaningful impact. But the process is so broken."

"We shouldn't have a system that causes such stress and anxiety for people."

PIP is broken. The application and assessment for PIP doesn't capture the reality of living with MS. It leaves people feeling unseen, unheard and disbelieved — and often ultimately not getting the right level of financial support.

Rigid and arbitrary criteria and informal observations by assessors do not reflect the impact of fluctuating and invisible symptoms on people's daily lives. Even when people do get PIP, the spectre of compulsory reassessments every few years is stressful. They're also unnecessary given the incurable and progressive nature of MS.

Phoebe, 35–44, East Hampshire

"The PIP assessment process was excruciating. It's been the most stressful aspect of my MS journey so far."

Person with MS

"The filling in of the very confusing forms and the assessment were so stressful it bought me into a relapse."

Yolanda, 45–54, Ashford

"The stress of the process makes my symptoms worse."

Right now, too many people with MS have to go without the essentials they need because of a flawed PIP system. This can have knock consequences for people's health — exacerbating MS symptoms and forcing people to compromise on what essentials they can and can't afford. The impact of this can be devastating.

Person with MS

"I can't chop vegetables, so I buy prepared food which is more expensive. PIP means I don't have to think about these extra expenses."

Person with MS

"PIP enabled me to keep my car going so that I could keep my job going, because I needed to drive there.
It did make a big difference to my independence."

Steven, 55–64, Romford

"PIP payments allowed me to purchase a mobility scooter allowing me to socialise with friends and family. The anxiety of simply going to a park with my grandchildren was horrible until I purchased a mobility scooter.
I constantly worried about if there was enough places to rest and sit down. The mobility scooter simply meant my seat could travel with me when I was out and needed it."

The Timms Review

The Timms Review into PIP is an opportunity for fundamental and genuinely co-produced reform. It has potential to finally fix PIP and create a system built on fairness, dignity, and respect.

We’ve been campaigning for reform for more than a decade and have published extensive and comprehensive evidence of the issues people with MS experience with PIP. This includes our 2023 report ‘PIP and MS: a decade of failure’.

Over the last few months we’ve been working with people living with MS to understand what issues they are currently facing. And what they would like to see change as a result of the Timms Review.

Between November 2025 and April 2026, we conducted interviews and workshops with over 40 people with MS. Together, we mapped out the problems at every stage of the PIP journey. And developed new ideas and innovative recommendations for how the process could be improved.

This booklet presents and amplifies those voices. It paints a picture of the issues being felt by the MS community, and presents the solutions to these problems.

Four pillars for reforming PIP

1. Fluctuating and invisible symptoms

The problem

The current PIP application and assessment process is fundamentally flawed in how it assesses fluctuating and invisible symptoms. It fails to capture the wide ranging and often invisible ways that MS can affect people. This means many people with MS aren't given the right award. And as a result they have to either challenge the decision or manage the consequences of coping without support to meet the extra costs they face.

Across the whole PIP journey, people with MS consistently say that their condition is not understood, and its impact underestimated.

There are three main drivers for this disconnect between the reality of people's condition, and how the PIP assessment views it.

Rob, 45–54, St Helens

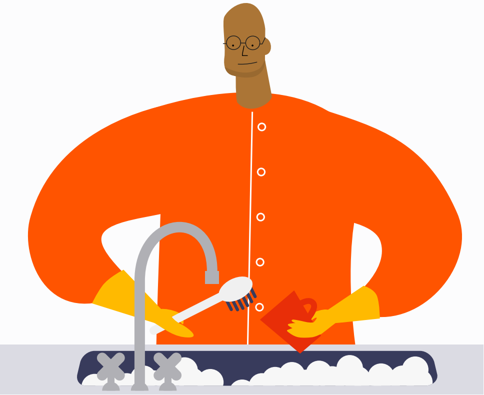
"With MS, my symptoms fluctuate a lot. I might be able to do something one day, but then fatigue will kick in and the next day I can't. But the form only gives you yes or no questions. It's impossible to fit a fluctuating condition like MS into the boxes they provide."

Megan, 25–34, Bridgend

"Oh, you said you've got animals. So who walks them?' 'Well, primarily me.' 'Ah, so you can walk then.' 'Yes, but on a good day.' I could be two entirely different people. You wouldn't recognise me."

The 50% rule is too rigid.

If someone has an impairment for less than half of the time, its impact is ignored when assessing someone for PIP. It is a rigid, arbitrary way to judge fluctuation that does not capture how MS affects people. Often, MS can affect people less than 50% of the time, but the impact can still be very severe in that time.



Reliability criteria are inconsistently applied.

PIP assessors are supposed to assess whether someone can do an activity reliably (as well as safely and repeatedly).

This criteria should help capture how much a fluctuation in someone's condition could affect them. But the reliability criteria are not applied consistently. The criteria are also not expansive enough to consider the cumulative risk of doing activities, symptom exacerbation, and whether people can do them consistently and in real-world conditions.

Too often people with MS are not being assessed with this in mind, leading to many people losing support they are entitled to.

Informal observations are often given more weight than evidence provided by applicants.

Strong, comprehensive evidence is often given less consideration than informal observations made during the PIP assessment. Observations made by assessors during assessments often bias the outcome based on inaccurate, snapshot assumptions about someone's condition and physical ability. Observations are often made without due consideration of clinical and other reliable evidence provided by the person being assessed.

Right now, the PIP system is not set up to capture some of the things that affect the day to day lives of people with MS the most. There must be a shift across the whole PIP application and assessment process to rectify this.

Rachael, 55–64,
Beverley and Holderness

"MS doesn't run on a percentage — some days you're fine, some days you're not."

Rob, 45–54,
St Helens

"When I got the report back, it was full of subjective observations about how I navigated the assessment centre and my cognitive ability. The observations about these, and other symptoms, didn't reflect my experience of the assessment. Nor those of my advocate, who was present throughout."

The solution

The DWP should change how they assess fluctuation and invisible symptoms.

They should introduce a more flexible person centred approach to capture the reality of living with MS, and stop using inaccurate informal observations.

Moving away from the use of the rigid 50% rule.

The DWP should pilot a new approach that considers whether activities can be carried out sustainably over time, in line with all reliability criteria.

Person with MS

“The assessment doesn’t take into account the daily battles we’re in — or the impact of doing something that can leave you unwell for days afterwards.”

Expanding the reliability criteria and ensuring it’s consistently applied.

In particular, ensuring it assesses if people can carry out activities:

- without cumulative risk
- without disproportionate recovery time
- consistently over time
- in real-world conditions.

To ensure the reliability criteria are always applied, we would also like to see them embedded within the activities, rather than assessors asking yes/no questions and making decisions based on snapshot observations.

Ending the use of informal observations.

The DWP should phase out the weight informal observations carry in the assessment process. Guidance and training should be updated and monitoring and quality assurance (QA) improved. Any use of informal observations should be strongly backed up by other evidence collected in the PIP assessment.

Person with MS

"If you admit to being able to do anything it felt like she just jumped down your throat at it. You know, 'oh, so you can do this, this and this and this and this.' […] it's like this kind of, you give an inch and they take a mile, you know."

2. Assessing mobility

The problem

How PIP assesses mobility is a major issue for people with MS. The ‘20 metre rule’ is particularly hard to justify. It shuts people out of mobility support, even when their mobility is severely compromised and requires extra cost to manage.

We’ve been clear ever since the rule was introduced that 20 metres is not an acceptable measure for enhanced mobility support. Setting a punitive cliff edge for mobility support on such a short distance doesn’t reflect the real-world challenges — or extra costs — that people with MS face.

The 20 metre rule also fails to capture both how people’s mobility plays out in practice, and the impact of being able to get around.

We consistently hear from people with MS about issues stemming from the reliability criteria not being applied to the assessment of their mobility.

It’s clear the mobility assessment process, in particular the 20m rule, is failing people with MS. There must be a fundamental rethink of how mobility is assessed for PIP.

Rob, 45–54,
St Helens

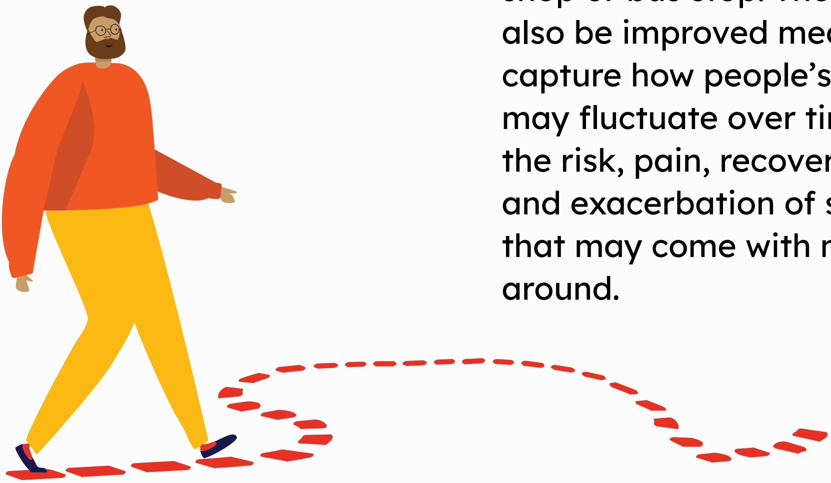
“What does it prove if on one day I can walk 20 metres unaided or with a stick but, at the end, I’m exhausted and collapse? It takes no account of the pain involved — pain that for me is the baseline for walking.”

Rachael, 55–64,
Beverley and Holderness

“The 20-metre rule doesn’t work. It’s arbitrary — it doesn’t capture what support is actually needed.”

Yolanda, 45–54,
Ashford

“You might be able to walk it, but the brain power it takes to do even a very short distance is enormous — and then there are the after-effects.”



The solution

The DWP should change how mobility is assessed for PIP.

They should scrap the arbitrary and punitive 20 metre rule. New criteria should assess if people have a level of mobility necessary to complete essential daily tasks and live independently.

In practice, this means shifting the criteria for moving around away from fixed distances (like 20m, or even 50m). Instead measures should look at doing essential daily tasks such as walking to the local shop or bus stop. There must also be improved measures to capture how people’s mobility may fluctuate over time. And the risk, pain, recovery time, and exacerbation of symptoms that may come with moving around.

3. Reassessments

The problem

Compulsory reassessments (otherwise known as Award Reviews) for people with MS are inefficient for DWP and deeply distressing for people living with the condition.

MS has no cure and does not get better with time. Not everyone with MS is eligible for treatment with Disease Modifying Therapies (DMTs). And even people on highly effective treatments will still have to manage acute and often fluctuating symptoms. And many still experience increasing levels of impairment over time.

Reassessing people with MS is therefore inappropriate, unnecessary, and risks people unfairly losing the support they need.

Robert, 35–44, Twickenham

"I was reassessed via telephone call. And based on that reassessment, they said that I was no longer entitled to the higher rate mobility component. So they had to take my car. That was quite a traumatic experience for me because It sort of left me high and dry […]. It did derail my studies. I didn't think I would be able to carry on because I tried, but it just wasn't possible, commuting by public transport."

Person with MS

“The worry of reassessment is always in the back of your head. They know it isn’t going to get any better. Why put us through the agony of making us apply again?”

Person with MS

“I think for MS reassessments just seems really crazy… for conditions that you know you won’t get better then it just seems it’s just adding stress.”

It does not make sense to reassess people with MS who are on the highest rates for both the mobility and daily living components of PIP.

This issue can be resolved quickly and definitively, with clear benefits for both people with MS and for the DWP. Improving how people feel about PIP process and the support it provides them. And saving time and money for the DWP.

The solution

The DWP must end unjustified, unnecessary and costly compulsory reassessments.

Instead, they should offer lifetime awards which cannot be reduced over time for people with long term, incurable, progressive conditions like MS. Replacing compulsory reassessments with 'light-touch' check-ins to see if people's needs have increased. Those on the highest awards with conditions like MS should never have to face reassessment.

We would also like people with severe neurological conditions like MS not be put through assessments unless absolutely necessary. This model is already in practice in Scotland for ADP claimants. Here, eligibility is primarily assessed through a paper-based approach that makes decisions based on improved evidence collection methods.

Person with MS

"Support should be linear and the only time it changes is if your condition gets worse."

Person with MS

"You think of all the money that then has been spent... if they'd agreed for the award in the first place, it wouldn't cost half as much."

4. Making PIP person centred

The problem

People with MS have consistently told us that applying for PIP is actively harmful to their health and wellbeing.

People with MS describe the PIP assessments as “sceptical rather than supportive”. They feel the process is designed to challenge their accounts of living with MS, rather than understand the impact it has on their daily lives. They also report that the assessment is conducted from a place or mistrust, or like the assessor was trying to “catch them out”.

We also consistently hear frustrations from people with MS who feel the process is not set up to show understanding and empathy. Instead, it makes them feel targeted, humiliated and disrespected.

Person with MS

> “It was a completely humiliating process. I was made to feel like a liar.”

Person with MS

> “It just makes you feel diminished. It makes you feel like a liar.”

Rob, 45–54, St Helens

> “At the assessment, it felt like I was on trial. It felt like they were trying to catch me out.”

These perceptions create anxiety. For many people with MS, it makes the assessment feel intimidating rather than a process intended to understand the support they may need.

Most people we interviewed also experienced distress during the process. Participants described feeling exhaustion, anger, and fear as a direct result of the PIP process and called it distressing and degrading.

Additionally, the stress of the PIP process can have a negative impact on MS. Many people we spoke to described how the PIP assessment compounded their MS, causing relapses and driving a downturn in their mental health and wellbeing.

Person with MS

"When I left the assessment, I felt awful. I felt like I was a burden on society."

Person with MS

"It's a stressful process. The assessment was terrible. It's an interrogation, like being interviewed by the police. Why is it done this way?"

Person with MS

"I feel totally humiliated by the process."

This demands a more comprehensive overhaul of PIP — not just in how it practically functions and assesses — but how it is conducted and how it feels for people going through the process.

The solution

The DWP should redesign the PIP process so it is underpinned by similar principles to those used in the ADP system and it treats people with fairness, dignity and respect.

They should embed the principles of fairness, dignity, respect, consistency and transparency across the PIP system. Ensuring all staff adhere to these when interacting with claimants and carrying out their roles.

Only this cultural change will genuinely change the success of the process, and the experience for people going through it. And only this will mean PIP can deliver on its original intended purpose — to support disabled people to live more independent lives.

Rachael, 55–64, Beverley and Holderness

“It’s got to start off with dignity and respect — we shouldn’t feel interrogated and communication should be respectful and accessible.”

Some examples of how these principles could be displayed in practice include:

- greater investment in assessor capacity — so they are best supported to conduct timely, supportive and respectful conversations
- stronger auditing and QA of assessor conduct
- recording all PIP assessments on an opt-out basis
- open access to all notes and reports throughout the process.

The opportunity to create a fairer PIP assessment

The Timms Review into PIP was commissioned in 2025 to "ensure the assessment is fair and fit for the future rather than to generate proposals for further savings".

This is a clear opportunity to fix the long-standing issues with the benefit. Make it fit for purpose for people with fluctuating, progressive, and incurable conditions such as MS. But this opportunity can only be truly grasped if the UK Government upholds the Review's intent.

The Timms Review can be a significant and consequential chance to change the broken assessment system, and ensure people are getting the right award. That opportunity — to finally make PIP work for disabled people — is what is within our grasp. And we must take it.

Kate, 55–64, Manchester Withington

"They're driven by the form and not by the person in front of them. I would like it to be a conversation"

Now is the time to not just make small incremental changes, but to improve PIP wholesale. It is time for a bold approach, and to build a culturally different disability benefits system with fairness, dignity and respect throughout the process. One that listens to people and supports them to live independently and participate fully in society.

Supportive not sceptical. Understanding not judging. A conversation, not an investigation. A system set up to support people, and one that saves time and money in the process.

Person with MS

“The money does help. It gives me more freedom to do things. Disability takes away so many of the freedoms you take for granted. And adjustments to get those freedoms back can cost more.

For example, if I’m somewhere and I need to get home but fatigue hits, I’ll have to get a taxi rather than the bus. PIP makes it easier to get out of the house.

It means I can go out: as simple as going for a coffee with my daughter. We’re not talking about huge amounts of money here, but it’s enough to make a difference.”

Living with MS is not a choice. And dealing with the symptoms and effects of MS is enough, without the added burden of an antagonistic social security process.

But the UK Government does have a choice before them. And at this critical juncture we implore them to choose positive change, and to support more fulfilling, more independent lives for people with MS.

How to fix PIP

1. The DWP should change how they assess fluctuation and invisible symptoms.
2. The DWP should change how mobility is assessed.
3. The DWP should end unjustified and unnecessary compulsory reassessments.
4. The DWP should redesign the PIP process so it is underpinned by similar principles to those used in the ADP system.

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