



# PIP and MS: a decade of failure



Our case  
for change

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## About MS

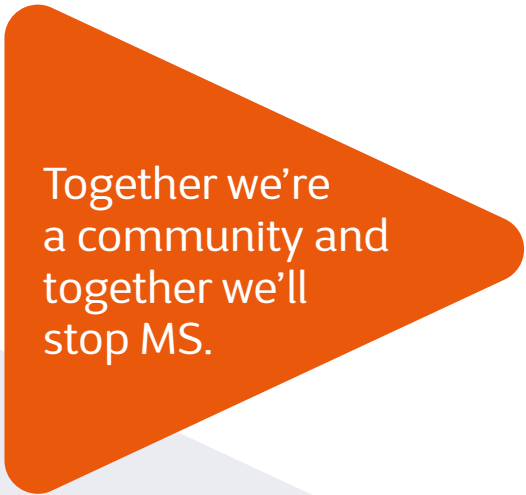
Multiple sclerosis (MS) is a neurological condition that affects more than 130,000 people in the UK. It's unpredictable and different for everyone. It's often painful, exhausting and can cause problems with how people walk, move, see, think and feel.

## About the MS Society

We're the MS Society. We're here for everyone affected by MS. Through the highs, lows and everything in between. Together we fund world-leading research. We provide information and services so that everyone can live well with MS. We make our voices heard and campaign for everyone's rights. And we support one another so no one has to feel alone. Together we're a community and together we'll stop MS.

## Information and advice on disability benefits

We've got [information](#) on our website about claiming disability benefits and other financial support you could get. Our Helpline advisers are also here for you with free and confidential advice. [Find out how to contact them.](#)



Together we're  
a community and  
together we'll  
stop MS.

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## ▶ Executive summary

Personal Independence Payment (PIP) is the main disability benefit people with MS claim in England, Wales and Northern Ireland. It was introduced in 2013 to replace Disability Living Allowance (DLA). It's there to support disabled people with the extra costs they face due to their disability and to help them live independently. PIP is 10 years old this year. But we're not celebrating.



For many people living with MS, PIP provides vital support. Helping them to manage the extra costs of their MS, such as mobility aids and getting taxis to appointments. But many people with MS have been let down by the PIP process over the last 10 years, and too often have missed out on the support they need.

There are problems at every stage of the PIP process. The application form is too long and complex. And it doesn't allow people to accurately explain the impact of their condition. Often people's medical evidence isn't collected by assessors.

The assessment fails to properly consider how people's MS affects them. Like the impact of fluctuating and hidden symptoms. This is because of rigid and arbitrary criteria. Such as the 20-metre rule and 50% rule, which assess mobility and fluctuation.

Informal observations are sometimes used by assessors to assess people's condition. But these only provide a snapshot view. They don't accurately reflect the impact of MS over time.

Sometimes people with MS are shocked when they get their assessment report because it contains factual errors. And it fails to reflect how their MS impacts them.

Issues like these mean many people with MS miss out on the support they need. Often people are only able to get the support they're entitled to after going through a stressful and lengthy appeals process. But many don't have the energy to do this.

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**For this report, we surveyed over 3,500 people living with MS and found that:**

- **Nearly 3 in 5** (58%) said they couldn't accurately explain how their condition affects their daily life on the application form.
- **Over half** (53%) said their assessment report didn't include evidence gathered from their healthcare professionals.
- **Over half** (54%) said their assessor didn't understand the impact of their MS on their ability to move around. Of this group, almost three-quarters (71%) said they felt they didn't get the correct award.
- **Over 3 in 5** (62%) said their assessor didn't consider their hidden symptoms. Of this group, only 5% said they thought their assessment report gave an accurate reflection of their MS.
- **Just under half** (45%) said they didn't have the opportunity in the assessment to explain how their MS affects them on different days or at different points during the day. Of this group, only 4% said they thought their assessment report gave an accurate reflection of their MS.

Going through the PIP process can be incredibly difficult for many people with MS. Including being actively harmful to the health of some.

**Of the people we surveyed, we found that:**

- **Nearly 2 in 3** (65%) said going through the process had a negative or very negative impact on their physical and mental health.
- **Over 7 in 10** (72%) said the assessment made them feel anxious. 7 in 10 (69%) said it made them feel stressed.
- **2 in 5** (40%) said they considered dropping out of the process altogether.

Some of the issues with the PIP process outlined above are ones we've been campaigning on since 2013.<sup>1</sup> This shows the Government has done far too little in the in that time to improve the PIP process for those living with MS.

In its Health and Disability White Paper published in early 2023, the Government set out some welcome proposals for how it might change the PIP process. This includes testing the use of specialist assessors and sharing assessment reports proactively with claimants before they get their decision.<sup>2</sup>

However, the proposed changes don't go far enough. For example, nothing was said about changing the PIP assessment criteria despite the fact they don't work for assessing progressive, fluctuating conditions like MS. There were also no plans set out for how informal observations might be improved or changed.

The most significant change the Government proposed in the White Paper is to scrap the Work Capability Assessment (WCA) for Universal Credit (UC).<sup>3</sup> This change, which won't come in for many years, means the PIP process will become the main way to get extra disability support on UC. These changes now mean it's even more vital the Government makes the PIP process work for those living with MS.

With the Government taking forward its plans for reform, it has an excellent opportunity to make the changes people with MS need. By following the policy recommendations that we set out below, the Government can make sure that the PIP process is made fairer and easier for people with MS. And that they don't continue to miss out on vital support.

In the first section of this report, we set out:

- the key issues with the PIP process affecting people with MS
- what we think the Government should do to improve these

In the second section we talk about the negative impact going through the PIP process can have on people, including on their health and wellbeing.

In the third section, we talk about the positive impact PIP can have on the lives of people with MS, when they do get the right level of support.

In the fourth section, we cover the changes that have happened in Scotland around PIP. The Scottish Government has recently introduced Adult Disability Payment (ADP) to replace PIP.<sup>4</sup> Now it has a real opportunity to avoid the same mistakes made with PIP.

Throughout this report, you'll also find short case study examples of people with MS talking about the process of claiming PIP and the difference receiving it makes to them.

When people do get the right level of support, PIP can make living with MS easier. It can help people to maintain their independence, and to live more fulfilled and positive lives. Like for Patrick who uses his PIP to pay for his car, helping him to get out and about. And Rinah who uses it to go swimming and for coffee with friends.

Their stories show why the Government must fix the unfair PIP process. To make sure that people with MS are no longer denied support that can make such a vital difference to the lives of so many.

## Summary of key recommendations

The Government must review and overhaul the PIP process to make sure it more accurately reflects how people are impacted by living with MS. This should include:



- **Scrapping the 20-metre rule for assessing mobility.**

In the short-term it should be replaced with the previous 50-metre rule used under DLA. The ‘aided’ definition should also be removed. Longer-term, the Government must design a new evidence-based means of assessing people’s needs for mobility support. And they must work closely with disabled people, disability experts and charities to do this.

- **Scrapping all informal observations for people living with fluctuating conditions like MS.**

- **Changing the 50% rule for assessing fluctuating conditions to be more flexible.**

The new approach should consider the frequency, severity and impact of all symptoms over time.

- **Changing how people’s ability to plan and follow journeys is assessed to make it more person-centred.**

The new approach should consider the specific challenges each person with MS can face with planning and following journeys, and the support they may need with this.

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## ► About this report

### What is Personal Independence Payment (PIP)?

Personal Independence Payment (PIP) is a disability benefit provided by the Department for Work and Pensions (DWP), a UK government department.

It aims to support people with their extra living costs if they have a disability or health condition. It's a non-means-tested benefit which means people can claim it even if they're working or have savings.

There are two components to the benefit:

- the mobility component is for help with getting around
- the daily living component is for help with things like getting dressed, eating or making decisions

Each component can be paid at a standard or enhanced rate. People who get the highest rates of the mobility component of PIP can lease an adapted vehicle from the Motability scheme. A share of their benefit is used to pay for this.

PIP was first introduced in 2013 to replace Disability Living Allowance (DLA). Since then, DLA claimants have been moving over to PIP. People are no longer able to make new claims for DLA.

As of April 2023, 58,664 people with MS are receiving PIP across the UK. <sup>5</sup>

### How do people access PIP?

To apply for PIP, people have to send the DWP an application form. After this, they usually have to attend a phone, face-to-face or video assessment carried out by a private assessment provider.

The assessment process also looks at evidence from the claimant. This is usually from medical professionals who know them, or family members. Sometimes, someone can be assessed using their evidence and the information on their form, and they aren't asked to go through an assessment. This is called a 'paper-based' review.<sup>6</sup>

After the assessment process, the assessment provider sends a report to the DWP. This Department then makes a decision on the case. This includes:

- deciding which components the claimant will get
- the award rate
- the length of their award
- when they'll need to be reassessed

If someone isn't happy with the award they get, they can appeal the decision. They do this by submitting a request for a 'mandatory reconsideration.'<sup>7</sup> Then if they are still unhappy with the decision after this, they can appeal through an independent tribunal process.<sup>8</sup> Some people get a revised award after going through these processes.



## Devolved nations

This report makes a number of recommendations for how the UK Government should improve PIP. Unless otherwise specified, all recommendations relating to PIP are relevant to England, Wales and Northern Ireland.

In Scotland, Adult Disability Payment was introduced to replace PIP in August 2022. Like PIP, ADP is non-means-tested and aims to support people with their extra costs if they have a disability or health condition. People living in Scotland can no longer make new claims for PIP. Instead, they have to submit a claim for ADP if they want support with their extra costs. People currently claiming PIP in Scotland are gradually being moved over to ADP.<sup>9</sup>

ADP has a mobility component and daily living component, which are paid at the same rate as the equivalent components for PIP. People who get the highest rates of the mobility component of ADP can lease an adapted vehicle from the Motability scheme. A share of their benefit is used to pay for this.<sup>10</sup>

Social Security Scotland (SSS), a Scottish Government body, determines a person's eligibility for ADP. They use what's been said on their application form and any supporting information they've provided or that SSS has obtained on their behalf. If it's not possible to decide on their application based on that information, SSS might ask them to take part in a consultation. This happens very rarely. In this case, they're assessed by a health or social care professional working for SSS.<sup>11</sup> If they're deemed to be eligible for ADP, SSS will decide:

- which components they'll get
- their award rate and length
- when the award will be reviewed<sup>12</sup>

All recommendations in the report for how the Scottish Government should improve ADP are only relevant to Scotland.

In Northern Ireland, PIP is administered by the Department for Communities, a devolved Northern Ireland government department.<sup>13</sup> But the DWP is responsible for overall PIP policy in England, Wales and Northern Ireland.

## Research methodology

This report presents data from a MS Society online survey of 3,523 people with MS in the UK. The survey ran from 3–31 July 2023 and was promoted by the MS Society via email and social media. It included questions around people's experience of the PIP process and demographic questions.

The MS Society's Evidence Team analysed the survey responses we received. Part of this work included ensuring that no individual could be identified in any use of the data. The analysis was done using specialist software, SPSS, which assisted the team in organising, managing and reporting the findings. The statistics used in this report have been rounded for ease of use.

Although most respondents who took part in the survey shared their experience of claiming PIP, a small percentage were claiming ADP, which is replacing PIP in Scotland.

Unless stated otherwise, any figures included in this report are drawn from the full sample of people who answered each question, which means they may include data from a small percentage of respondents who were claiming ADP.

Qualitative work was carried out by Humankind Research, an independent research agency commissioned by the MS Society. Potential participants for this research were identified from the survey findings, by taking a small selection of contact details for individuals who had indicated they would be interested in being part of further research.

Humankind conducted in-depth, semi-structured interviews with the participants.

In these sessions, they were asked about their experiences of claiming PIP and how receiving PIP made a difference to their different areas of their lives. Such as their health, employment and social life.

We ran four qualitative focus groups with a small number of people with MS, who were members of the co-production group for the campaign. In these sessions we asked participants questions about how they found the PIP process, including what they thought did and didn't work well. The participants shared what they thought the Government should do to improve how the PIP process works for people with MS.

We also conducted desk-based research. This primarily reviewed reports and papers relating to PIP, including from the government and other charities.

## Quotes

All quotes included in the report are from people affected by MS who took part in our online survey, focus groups or the research carried out by Humankind.





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## ► Why the PIP process doesn't work for people with MS

In this section, we set out the main issues with the PIP process which are causing people with MS to miss out on support. We put forward several policy recommendations for what the Government needs to do to make the PIP process easier and fairer for people with MS.



### The application form

To apply for PIP, people with MS must complete an application form called the PIP2. They use this form to explain how their condition affects them. The form is used with the assessment to decide what level of support someone will get.<sup>14</sup> So, being able to include the right information can make a big difference to the outcome of someone's claim.

Many people with MS tell us the application form is too long, complex and it doesn't allow them to explain how their MS affects them. People with MS often feel there isn't enough information to help them complete the form. So, they may worry that if they provide any information that is inaccurate or incomplete, it could lead to them being awarded the wrong level of support.

Some participants in our research reported dropping out of the PIP process because they found the form too stressful and difficult to complete. Others were put off applying in the first place due to worries about completing the form.

**'[I] found the initial phone calls very hostile and the forms very stressful and not applicable to MS. For my own mental health it wasn't worth continuing.'**

The DWP has set up a new online PIP application form, and this may make applying easier for some who find an online route more accessible.<sup>15</sup> However, the digital application process won't work

for everyone. Our My MS My Needs 2022 survey of 6,500 people with MS found that 2 in 10 (22%) have problems accessing or using digital technology.<sup>16</sup>

There's also a risk the screening questions that currently come before the online application form may lead some people to not go ahead with their application.

### Recommendation

**The DWP must make sure the PIP application form is accessible for everyone.**

A range of methods and channels should be easily available to everyone, so they can choose the one that is most suitable for their needs. These must be maintained and updated in the long-term alongside any digital process. The DWP also needs to provide clarity on the value and purpose of the screening questions that come before the online PIP application form.

**'The questions on the application form are too rigid and do not reflect how MS affects us. The mobility section is completely wrong in the scoring and questions. From memory there was one on mental ability which if you weren't able to plan a route you wouldn't be driving in the first place.'**

#### In our survey, we found:

- **Nearly 3 in 5** (58%) people with MS said they couldn't accurately explain how

their condition affects their daily life while filling in the application form.

- **Nearly 3 in 5** (58%) said they couldn't accurately explain how their condition affects their mobility on the form.

Many respondents said the questions are repetitive, confusing and there isn't enough space to write answers. Some claimants even reported feeling that the form is designed in a way that is trying to 'catch them out' or 'trip them up'. This is concerning and is like many people's perceptions about the assessment. We go into more depth about this in the subsection of this report on assessors.

**'The application form is very difficult to fill in, [the] boxes for info are too small and we ended up adding pages and pages of extra tabs. [It] took weeks to fill in carefully. Some questions are repeated in a different way to try and catch people out.'**

The DWP's Health and Disability White Paper published earlier this year says the Department intends to use its Health Transformation Programme to establish 'new design standards' for forms. Making them more 'accessible' and 'easier' for people to interact with the benefits system.<sup>17</sup>

But information on what this will look like in practice is limited. To date no significant changes have been made to the way the questions in the form are worded.

### **Recommendation**

**The DWP must redesign the PIP2 form to make sure people with progressive and fluctuating conditions like MS can easily and accurately explain the impact of their condition on them.**

**This redesign should be done in close collaboration with disabled people and charities.**

Many people with MS also say they don't get enough clear information with the form to help them fill it in and they aren't sure what's required of them. For example, the PIP criteria and scoring system isn't provided as standard with the form.

Without access to this information, people can struggle to include information which is relevant to the criteria. This is likely to lead to people getting the wrong level of support and being asked to go through unnecessary assessments.

### **Recommendation**

**The DWP must provide the criteria and scoring system with every PIP application form.**

**This would better support people with MS fill in the form in a way which is relevant to the PIP criteria and scoring system. It would also better support people to gather appropriate evidence for their claim.**

**'The forms are too long and overwhelming. I didn't think that the wording explained what was required. When filling in my review form I actually paid for an online course to help decipher each question and what wording and percentage to use to explain my condition. I would never have known without this.'**

People applying for PIP have one month from receiving the PIP2 form to complete and return it to the DWP.<sup>18</sup> However, many people with MS struggle to complete the form within the timeframe, due to its length and complexity. People with MS who have issues with cognition and fatigue can find it especially difficult to meet the existing timeline.

**'The time scale to fill the forms in isn't long enough especially when the stress contributes to making your MS worse.'**

Applicants can ask for an extension to the deadline to return the form.<sup>19</sup> However, some aren't aware they can do this. People must often rely on the support of others, such as welfare rights advisors, to help them complete it. Without this type of support, which can sometimes be hard to access in the time available, some people can find the form too difficult to fill in.

**'The paperwork was overwhelming with no one to help. It took me so long to write everything down and with my fatigue and cog fog. It was exhausting.'**

### **Recommendation**

**The DWP must extend the deadline to submit the application form to eight weeks.**

This would give people enough time to complete it, gather evidence and get support from others if they need it. In the meantime, the DWP should give clear details of the right to request an extension to the deadline with every application form.

People should also be signposted to support they could get with filling in the form. Such as from welfare rights organisations.

## **Supporting evidence**

Anyone claiming PIP can send supporting evidence with their application form.<sup>20</sup> Evidence can often better illustrate the impact MS has on someone's life than the information gathered in an assessment, and so can make a crucial difference to the outcome someone gets.

Evidence can include statements from family, friends and carers, and records, prescriptions and letters from medical professionals. Claimants can also include the details of people who they're happy for the DWP to contact for further evidence.

Our survey showed **10%** of people with MS said they didn't provide evidence with their applications. Either because they didn't know how to or weren't aware they could.

**'For me I didn't really know what other evidence I could give, other than someone saying something...it's not really official is it... like are they going to pay attention if my parents write it... that's why I focused on doctors and nurses.'**

Sometimes people living with MS don't know they can give evidence from family, friends and carers alongside any medical evidence. Or they think that this evidence will be given less weight than medical evidence so don't include it. People may also not know how to go about getting evidence from their medical professionals. This points to the need to continue to improve guidance on how to provide evidence.

### **Recommendation**

**The DWP must improve its guidance to all claimants on the type of evidence they should provide.**

**The Department should work with disabled people and charities to do this. This guidance should be provided in a range of formats, and through different channels.**

## Rina's Story

**Rina has MS and lives with her brother and his wife who care for her. A major symptom of Rina's MS is fatigue. Rina enjoys going swimming, but she can only swim certain strokes and not for long. She also likes walking but only manages short walks now. 'The fatigue is just so bad, I'm always tired, even in the morning. Everything is a challenge. If I do too much, I have to spend the rest of the day, and the next, in bed.'**

Rina has problems with her memory, finding it difficult to remember people's names. She finds simple things, like cooking, a challenge. She says this impacts her ability to move around. 'If I want to go somewhere, I don't know how to get there, even places I go to regularly, like my aunt's.' Rina also has difficulty with her mobility. She loses her balance a lot, outside and inside. 'I have to hold onto walls, and I've banged my head when trying to keep my balance. Sometimes I'm unable to get downstairs and have to have stuff brought up to me.'

When Rina was moved from DLA to PIP, she was awarded a lower rate. She accepted this at first, thinking that maybe her MS wasn't as bad as it had been when she first applied for DLA. But when she and her family heard of people who were challenging their decisions and winning, she decided to do the same. As a result, her award was increased. 'Originally, I thought I should be grateful they'd given me something. After the challenge, they increased my mobility and the length of my award. They'd made a mistake. I felt cheated.'

Now Rina's getting the right level of PIP. She says she can eat better, get help around the house and have a car through the Motability scheme. Rina's unable to work so PIP helps her pay her bills. 'ESA isn't enough. PIP is useful but I still have to go to my brother for help which isn't fair. I've cancelled putting money into my pension. I have to be frugal.' Rina's brother says: 'Some of her PIP goes to bills and things. When she falls short, I help. She also uses her money for swimming and a coffee with friends when she feels well enough. She likes to pay and feel independent. I don't want her to feel we're taking over her life.'

Rina says receiving PIP is a relief, but that it hasn't changed how she feels about the process. She's extremely worried about her reassessment and finds waiting for the result stressful. Rina, and brother don't understand why she has to have a reassessment when she's never going to get better. 'When you have medical evidence, hospital letters, the reports, everything: you're not going to tell lies, are you? Not with MS, and they know MS is forever!'

**'Originally, I thought I should be grateful they'd given me something. After the challenge, they increased my mobility and the length of my award. They'd made a mistake. I felt cheated.'**



Many people include the details of family, friends, carers and medical professionals on their form. These are the people they're happy for the assessment provider to contact for evidence. In 2019, we found that most people with MS (88%) include the name of at least one health professional, and often more than one.<sup>21</sup>

DWP guidance states that assessment providers should seek evidence from those with 'progressive and fluctuating conditions' where they feel 'it would help to inform their advice to DWP'.<sup>22</sup> But it isn't compulsory for assessment providers to do so.

**Over half** (53%) of the people with MS from our survey said their assessment report didn't include evidence gathered from their healthcare professionals.

In its review of the PIP evidence process in Northern Ireland in 2021, the NI Public Services Ombudsman found that assessors only requested evidence from claimants in just over a third of the claims it examined.<sup>23</sup>

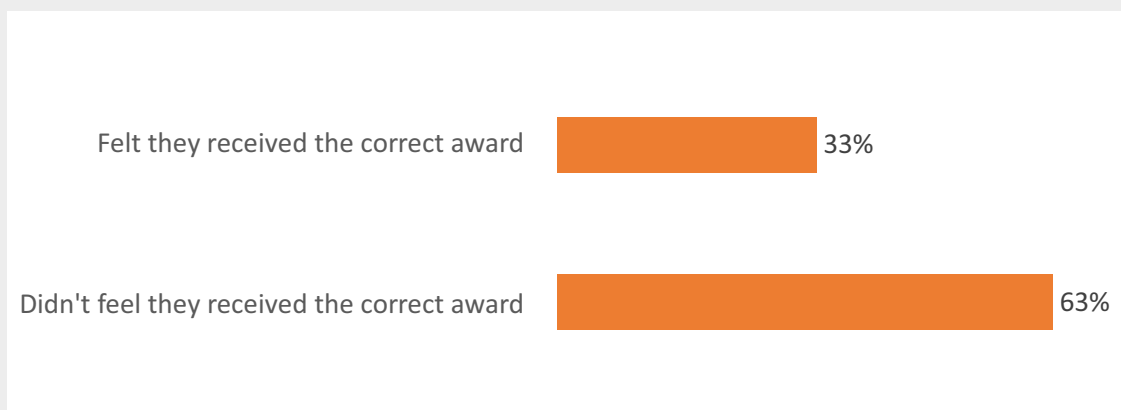
**'None of my evidence had been looked at previously, and definitely not contacted.'**

It's concerning that so many people who may be able to provide important information to help the assessor decide on the claim are not being contacted. Our survey suggests that evidence not being collected is likely contributing to people not getting the right level of support.

**Of the respondents to our survey whose report didn't reference any evidence from their healthcare professionals, we found:**

- Almost **two-thirds** (63%) didn't feel they got the correct award.
- Only **one-third** (33%) felt they got the correct award.

### People with MS whose report didn't reference evidence from healthcare professionals



Some people tell us they specifically include significant amounts of evidence with their claim because they're not confident the assessment provider will contact those they've included in their form. We don't think it's unreasonable for the DWP to advise those claiming PIP to provide some evidence of their own. However, gathering evidence often takes people time, can cost them money and cause them stress. People applying for PIP should be able to trust that the names they provide to the DWP for evidence in support of a claim will be contacted.

**'The form is so long and pulling together all the evidence takes so much time. I can't rely on them looking at previous evidence or contacting the health professionals they claim to need contact details for.'**

### **Recommendation**

**The DWP must strengthen PIP assessment guidance on evidence collection.**

**Guidance must set out that assessors should always request evidence when reviewing claims by people with fluctuating and/or progressive conditions. Where this is not provided Case Managers should return assessment reports.**

## **The assessment**

After submitting their application form to apply for PIP, the majority of claimants are asked to attend an assessment. Most

assessments now happen over the phone or by video call.<sup>24</sup> But they may also be done face-to-face at an assessment centre or at the claimant's home.

In the assessment, people are asked questions about how their condition affects their life and their ability to do certain activities. In face-to-face assessments, they may also be physically assessed, for example they may be asked to stand to assess mobility. The assessor is expected to review any evidence submitted by the claimant.

The assessor then sends a report to the DWP giving advice on the level and length of the award they think the claimant should receive. A DWP Case Manager makes the final decision on the award they'll get and informs them of this decision by letter.<sup>25</sup>

Many people's assessments go smoothly, and they get an award they're happy with. However, there are still far too many people with MS who experience poor assessments. This can be hugely stressful and have a negative impact on people's health and wellbeing. They can also lead to people being awarded the wrong level of financial support.

### **Paper-based decisions**

In some cases, there's enough evidence from health professionals and people who know the claimant to be able to make a 'paper-based' decision on the claim. But some people with MS who provide sufficient evidence are still being asked to go through assessments.

These assessments are unnecessary and create stress for people going through them. They can sometimes lead to them missing out on the support they need because they were not assessed accurately.

**'Believe the reports of GPs, consultants, carers, family etc. who know the person and their problems. Assessment from a stranger with an agenda and quotas to meet is absolutely the wrong way to do it.'**

PIP assessment guidance says that people should not normally require an assessment if their form 'indicates a high level of disability, the information is consistent, medically reasonable and there is nothing to suggest over-reporting'.<sup>26</sup> The guidance specifically includes the example of claimants living with 'severe neurological conditions such as multiple sclerosis' as people who would likely meet this guideline.<sup>27</sup>

In the Health and Disability Green Paper published in 2021, the DWP also said it wanted to 'maximise' the use of paper-based assessments.<sup>28</sup>

This guidance, and the Government's aim for more paper-based reviews should mean fewer assessments for people with MS. But our survey shows that **nearly three-quarters** (73%) of people with MS who provided evidence with their application form had an assessment.

Evidence from the DWP shows that over the last seven years the proportion of all PIP assessments which are paper based has barely changed since PIP was introduced.<sup>29</sup> The DWP needs to match its commitment to increasing paper-based reviews by taking action.

### Recommendation

**The DWP must make sure claimants are only asked to go through an assessment where there is a lack of evidence to carry out a paper-based review.**

Assessors should always exhaust all possible avenues to gather reliable evidence to make sure a paper-based review can be done where possible. Assessments should only be done as a last resort, or where a claimant asks for one.

**'The whole system needs to be redesigned. People with long term neurological conditions should be treated differently from those with for example back injuries. Specialist consultants and medical letters from clinics should be sufficient evidence in such cases and not be overridden by unqualified inexperienced assessors who have no understanding of complex often multiple medical conditions.'**

The DWP is currently testing a Severe Disability Group (SDG) for PIP as part of plans set out in the Health and Disability White Paper.<sup>30</sup> The plan for this group is that people with 'severe' disabilities would be referred to it by a medical professional. If they're deemed to meet the criteria of the SDG, they'll be awarded PIP without the need for an assessment.

If the SDG leads to more people with MS being awarded PIP without being asked to go through an assessment, then it'll be a positive step. However, no information has been provided on whether MS would be included as a condition in the criteria. And whether all people with MS, or only those with certain types of MS, could be referred.

### Recommendation

**The DWP must provide clarity on which groups will be included in the Severe Disability Group criteria as soon as possible.**

### Reassessments

People with MS who receive PIP are often asked by the DWP to be reassessed. This type of reassessment is called an 'award review' and, according to the Government, is done to make sure people are getting the right level of financial support over time. People usually know they'll be reassessed, and after how long, when they get their initial PIP award.<sup>31</sup>

Award reviews are done to see if the person's condition has got worse and if they need increased support. But they're also done to see if they should get less support if their condition has improved over time.

For people with MS, being reassessed to see if their condition has improved is unnecessary. There's no cure for MS and it's a progressive, lifelong condition. Someone's MS won't improve significantly, and their need for support won't reduce over time.

**'I strongly feel that as MS is a progressive condition with no hope of getting better, once your condition is proven with medical evidence, you should have an indefinite entitlement to PIP with maybe only a light touch review. This would avoid all the unnecessary stress!'**

Our survey shows that even many people with the most progressive types of MS are getting time-limited awards of under ten years in length. Despite living with a type of MS that will only steadily get worse over time.

#### This includes:

- **Over half** (52%) of those with secondary progressive MS with relapses
- **Just under half** (45%) of those with secondary progressive MS without relapses
- **Over half** (54%) of those with primary progressive MS

They'll be expected to go through an award review reassessment when their award is nearing its end. They could risk losing their support if they're reassessed poorly, even though their condition is likely to have got worse in that time.

Evidence from the DWP shows that, from June 2016 to April 2023, 4,355 people with MS have got a reduced award or lost their support completely following an award review.<sup>32</sup> This is **nearly 1 in 5** (18%) people with MS who've had an award review reassessment.<sup>33</sup> It's not right that so many people living with a progressive condition are losing support as their condition gets worse.

**Recommendation**

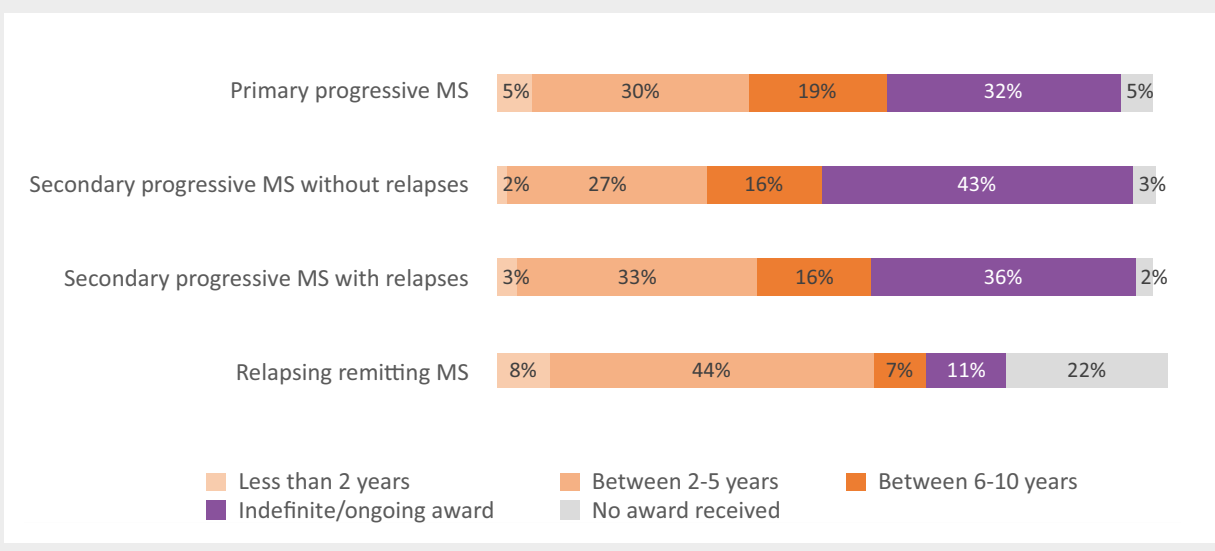
The DWP must make sure no-one living with MS has to go through an unnecessary reassessment and risk losing their PIP. As outlined above, the Department should clarify whether all people with MS or only those with certain types of MS, could be referred to the Severe Disability Group.

In the short-term, the DWP must make sure people with progressive and or lifelong conditions, like MS, are given lifetime PIP awards.

This should include the option of a light-touch review every three years for claimants not on the highest award rates, but only if they wish to be reassessed to receive higher support.

'I now am dreading them wanting to reassess me. I am so worried that they will assess me on a good day or not see the physical effects of my MS.'

**Award lengths received by respondents' MS types**



## Sian's Story

**Sian was diagnosed with MS in 2011. Sian's symptoms include numbness on her right-hand side, neuropathic pain and memory issues. She gets extremely tired and can slur her words. 'The fatigue is overwhelming, it's the worst thing. It affects every aspect, feels like you're walking through mud. Everything is so much effort.'**

Sian's first experience of claiming PIP was positive. She was awarded the standard daily living rate and felt that was correct. Unfortunately, her reassessment two years later wasn't as positive. Sian took a small, light backpack to the assessment and a carrier bag containing a single file with essential, medical details. This was to make sure she provided the assessor with accurate information. 'I wanted to be scrupulously honest. When I read the report after, it made me feel sick and I cried.' The assessor's report said Sian had no problems with her mobility or balance. Saying she was able to carry two large, heavy bags, one full of files. 'These details were so inaccurate and used against me, which was horrible. I was trying to be honest, and the assessor wasn't.'

These weren't the only inaccuracies in Sian's report. 'The assessor asked me about depression and did I ever feel like killing myself. I honestly replied that sometimes I felt low and that there have been times where I've thought I don't want to be here, but never as far as wanting to kill myself. I'd been prescribed the highest dose of an anti-depressant, and my doctor had provided evidence. In the report the assessor simply said that I didn't look depressed. There was so much wrong with what she recorded. I had all

this evidence, and she didn't use any of it.' Sian says it was a huge deal to divulge such personal information which she'd only shared with a few close friends. 'I felt extremely vulnerable, but I understood the need to be honest. For the assessor to dismiss it so easily made me feel worthless and as if I was exaggerating my symptoms which affect me profoundly.'

Following this assessment, Sian was denied PIP, and her daily living allowance was removed which she says, 'hurt like hell'. 'She made me feel like a liar. This person decided I was better, from an illness that can't be cured, that's progressive! It is a cruel, dehumanising, insensitive, horrible system.'

Sian appealed the decision, which led to many sleepless, anxiety-ridden nights. But her award has been reinstated. Sian says receiving PIP makes a difference to her financial situation. '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 do out 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. It means you don't have to worry so much about the pennies.'

**'It is a cruel, dehumanising, insensitive, horrible system.'**

## How fluctuating and hidden symptoms are assessed

Everyone's experience of MS is unique, and people's symptoms can vary in different ways across time.<sup>34</sup> Hidden symptoms can include fatigue, cognitive issues and bladder and bowel difficulties. These can all have a significant impact on people's ability to carry out certain activities.

PIP assessment guidance does require assessors to look at fluctuation and hidden symptoms in relation to the criteria they use during the assessment.<sup>35</sup> However, too often people with MS tell us this doesn't happen for them. This is leading to assessment reports being produced that don't accurately reflect how their MS affects them. Causing them to get the wrong level of support.

### In our survey, we found:

- **Just under half** (45%) of respondents said they either disagreed or strongly disagreed that they had the opportunity in the assessment to explain how their MS affects them on different days or at different points during the day.

- Of this group, **only 4%** said they thought their report accurately reflected of their MS.

### The survey also showed:

- **Over 6 in 10** (62%) people with MS said they either disagreed or strongly disagreed that their assessor considered their hidden symptoms.
- Of this group, **nearly 9 in 10** (86%) thought their assessment report didn't give an accurate reflection of their MS. While **only 5%** said it did give an accurate reflection.

The DWP has recognised there needs to be improvements in how fluctuating conditions are assessed. As part of this, the Department is testing of the use of a 'Health Impact Record' (HIR) as part of the PIP assessment process.<sup>36</sup> This would likely involve claimants filling in a record over a period of time to show how their condition changes. This would be included alongside other forms of evidence in a claim.

### People with MS who didn't feel their assessor considered their hidden symptoms

Didn't feel their report gave an accurate reflection of their MS

86%

Felt their report gave an accurate reflection of their MS

5%

DWP has provided little detail on how the HIR will work in practice. But we're concerned it could place an extra burden on claimants as they'll be asked to fill in even more paperwork. It's also not clear whether someone would have a choice to complete a HIR. And what the impact of choosing not to would be.

There's a risk that whatever a claimant includes on their Health Impact Record could be ignored by an assessor. In the same way that evidence is often currently not considered in people's claims.

The DWP needs to work closely with disabled people, including those with MS, and disability charities as it tests the Health Impact Record.

### Informal observations

Assessors can make 'informal observations' as part of assessments. This is when they assess a claimant's ability to do a certain activity based on how the claimant looks or behaves during the assessment. Assessors are supposed to 'balance' their informal observations with evidence from medical professionals, and to consider hidden symptoms when making them.<sup>37</sup>

We've heard from many people with MS who read their assessment report and realise they were awarded no points for certain activities because their assessor said they informally observed them doing them in the assessment. Informal observations are often used to make assumptions that a person can do a particular activity and contradict medical evidence showing their limitations.

In its review of the PIP evidence process in Northern Ireland in 2021, the NI Public Services Ombudsman found that assessors regularly 'did not explain or record why more reliance was placed on their observations' in assessments than 'other available evidence from claimants, carers and professionals.'<sup>38</sup>

Informal observations don't properly consider fluctuation or the hidden symptoms someone may experience. For example, an assessor may say a person can walk 20-metres because they saw them walking down the corridor. Yet this doesn't consider the pain they're experiencing while doing it or whether they could walk this distance the next day.

**'Informal observations are inaccurate as MS is a fluctuating condition and can be different from one day to the next.'**

### In our survey, we found:

- **Nearly 4 in 10 (37%)** people with MS said they didn't think informal observations were useful in helping the assessor understand how their condition affects them. While only **18%** thought they were useful.
- Of those who didn't think they were useful, **89%** said they didn't think their report gave an accurate reflection of their MS. And only **4%** thought it did give an accurate reflection.

The DWP's PIP assessment guidance says 'a 'snapshot' view of the claimant's condition on a particular day at a particular



time is not an adequate assessment.<sup>39</sup> But by its nature, an informal observation is a snapshot view of someone's ability to do something at a particular time. It doesn't look at whether they can or can't do that activity the next day, or the week after. It doesn't consider whether someone may experience pain or other symptoms for a time after performing the activity. And it's physically impossible for an assessor to observe hidden symptoms.

**'I think the informal observations were inflated by the assessor especially over the telephone. She said I was able to recall information such as meds and symptoms, yet she didn't see the 6 pages of A4 paper with notes written down that I was referring to. That's just one example, there were plenty more.'**

People with MS are being consistently denied the support they need because informal observations are being used to assess their ability to do certain things. They're not a suitable approach for assessing the abilities of people living with a condition that can vary across days, weeks or months. And which often includes many invisible symptoms.

### **Key Recommendation** **The DWP must scrap all informal observations for people living with fluctuating conditions like MS.**

**In the meantime, assessment providers must always tell claimants they could be subject to informal observations. And PIP guidance should be changed to say that the 'reliability criteria' should be applied to them. This could be through follow-up questions if someone is observed to be doing something which is inconsistent with the evidence provided.**

**Where informal observations have been recorded in assessments, claimants should have the opportunity to comment on them. These comments should be included in the final report. You can read more about how we think the reliability criteria should be improved later in this section.**

**All informal observations should be included in the assessment report and be backed up by further evidence. If the assessor contradicts evidence from healthcare professionals and the claimant by making an informal observation, then they must explain clearly why they did this in the report. Case Managers should return reports that do not comply with this.**

### The 50% rule

Under PIP, if someone's MS affects their ability to carry out an activity more than half of the year, then it must be considered as affecting them all the time. Equally, if a condition or disability doesn't affect their ability to do an activity half the year, then it can be ignored. This is called the 50% rule.<sup>40</sup>

The 50% rule doesn't work for assessing the impact of a fluctuating condition like MS. It's a rigid and arbitrary measure where if someone struggles to or can't complete an activity for slightly less than half their life, then they receive no support with it.

For example, someone who is entirely unable to walk for five months in a year, but able to walk over 20-metres for the rest of the year wouldn't be eligible for any mobility support according to the 50% rule. Under the rule this person would be treated as if they can walk 20-metres for the whole year. No consideration would be made of how severely their symptoms may be affecting them in the five months where they can't walk. Or for the support they may need with walking.

**'[They had] no understanding of fluctuation of symptoms, how different temperatures affect [you]. They just wanted black and white answers [to] 'well is that 2 of 3 days a week?'**

People with MS can often still face high costs for support with daily living and mobility activities, even if they're able to do them for more than half the year. A person who cannot walk for five months of the year may need to use a mobility scooter but would not receive any financial support. This is despite their costs for buying and maintaining that aid being similar to someone who uses it for slightly more than half the year.

**'I just feel that they don't understand the condition at all. Yes I may be able to walk 50 metres on a Monday but the rest of the week I might not have the energy to get out of bed. Also they don't understand that you adapt your way of life to how you are feeling on that particular day, even that particular hour.'**

The 50% rule is causing people with MS to miss out on vital support. Even when their symptoms severely affect their abilities for a sizeable part of the year. People with MS need a fairer and more graded system, which has no cliff-edge like the current criteria. The new approach should be more holistic, person-centred and assess the frequency and impact of all symptoms and how they interact.

### Key Recommendation

**The DWP must change the 50% rule for assessing fluctuating conditions. It should be more flexible, considering the frequency, severity and impact of all symptoms over time.**

**The Scottish Government should also follow this recommendation to improve how fluctuating conditions are assessed for ADP.**

#### The reliability criteria

An assessor is expected to consider whether a claimant can carry out each activity safely, to an acceptable standard, repeatedly and in a reasonable time. This is known as the reliability criteria.<sup>41</sup> But too often, people with MS say that assessors don't consider these criteria, and only assess their ability to do an activity on the day they're assessed. Again, this fails to consider fluctuating and hidden symptoms and the impact they may have. And it's leading to people getting the wrong level of support.

**'I now am dreading them wanting to reassess me. I am so worried that they will assess me on a good day or not see the physical effects of my MS. The hidden symptoms that mean I cannot reliably, safely and repeatedly do normal tasks and movements will not be obvious to them.'**

#### In our survey, we found:

- **Nearly 2 in 5 (37%)** respondents disagreed or strongly disagreed that their assessor applied the reliability criteria when assessing them. Of this group, only a quarter (24%) said they felt they got the correct award.
- **Over two-thirds (67%)** of those who agreed or strongly agreed their assessor did apply the reliability criteria said they felt they got the correct award.

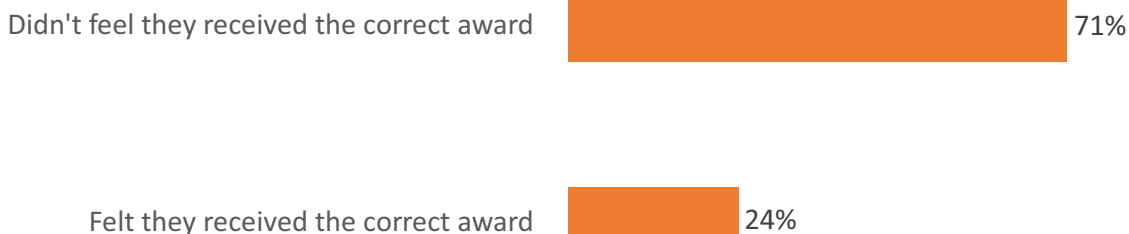
The application of the reliability criteria is audited as part of the DWP's monitoring of the quality of assessments.<sup>42</sup> However, this doesn't go far enough. Guidance needs to be strengthened to make it clear that the reliability criteria must be considered for every descriptor.

#### Recommendation

**The DWP must change the PIP assessment descriptors to include the reliability criteria, and their definitions, within the wording of each descriptor.**

**Assessors should always give evidence in their reports for why they think each activity in the criteria can be carried out safely, to an acceptable standard, repeatedly and in a reasonable time. Case Managers should return reports that don't do this back to the assessment provider. And no decision should be taken without fully considering the reliability criteria. Reports must meet this standard to be considered acceptable in quality audits.**

### People with MS who didn't feel the assessor understood the impact of MS on their mobility



#### How mobility is assessed

MS can affect many people's ability to get around.<sup>43</sup> Many MS symptoms can impact mobility, including fatigue, spasticity, dizziness and pain. And as these symptoms often fluctuate, people's ability to move around can also change over time.

Many people with MS say the impact their MS has on their mobility was assessed poorly, and this led to them missing out on the right level of support.

#### In our survey, we found:

- **Over half** (54%) of people with MS said they disagreed or strongly disagreed their assessor understood the impact of their MS on their ability to move around. Of this group, **almost three-quarters** (71%) said they felt they didn't get the correct award.

#### The 20-metre rule

One of the changes to the disability benefits system that has affected people with MS most negatively has been the introduction of the 20-metre rule to assess mobility for PIP. This rule says that those who can 'reliably' walk over 20-metres, with or without an aid, such as a walking frame, are not eligible to receive the highest rate of mobility support on PIP.<sup>44</sup> Previously under DLA, the threshold for receiving the higher rate was 50-metres.

The 20-metre rule has led to thousands of people losing their higher rate mobility support when they've been reassessed moving from DLA to PIP. The latest DWP evidence shows that **9,468 people** with MS who had the higher rate of mobility award on DLA got it reduced or lost it entirely when they were reassessed when they moved over to PIP.<sup>45</sup> This amounts to **almost a quarter** of all people (24%) with MS who've been reassessed when moving from DLA to PIP.<sup>46</sup> This figure also doesn't include those who've missed out on the higher rate of mobility support when applying for PIP as new claimants.

## Shereena's Story

**Shereena is in her early 30s and was diagnosed with MS in 2009. In 2017 her mobility began to get worse. 'I was tripping up, I was walking into walls at work, veering off into things. I couldn't wear certain things anymore and was getting drop foot. My spasticity got worse, I had some terrible flare-ups and it's only got worse.'**

Shereena applied for PIP and was awarded the standard rate for daily living. She'd been told it was difficult to get and was surprised to get anything. So, rather than challenge it and risk losing it, she left it. However, in 2020, her mobility continued to get worse. She started using a rollator and a mobility scooter to get around. Shereena decided to submit a change of circumstances, because she now needed more support from PIP. 'It felt like I needed them to change what I was awarded because now I require something different. I need better equipment - not just a rollator bought on Ebay through the Access to Work scheme. The only way I can do that is getting money from PIP to help.'

Unfortunately, Shereena's claim was denied. When things got worse again, she submitted another change of circumstances and was denied again. 'I wish I'd been assessed in person not just on my form. It didn't make any sense. I can't stand up for more than seven minutes. I can't walk without an aid. I use my scooter most of the time. How can I not get enough points for mobility?' Shereena found being denied even more frustrating when she thinks about how hard it was to complete the forms. 'I'd lost function in my right hand at that time so



was typing one letter at a time. I filled in pages and pages showing how my MS had progressed. Being denied after making all that effort was very frustrating.'

PIP does make a difference to Shereena. But there are things she needs which she can't afford. However, she doesn't want to risk trying to claim more again. 'It's too risky for me to go through it again. They might take away what little I currently get. So, I just thought I'll deal with daily living on what I get, even though I know I should get more for my mobility.'

Shereena uses most of her PIP to pay bills. 'I don't have the luxury to do the things I want, or I need to do. If I did get the higher level of PIP, I could make sure I'm warm in the winter and still have the money for vitamins and supplements. I got crutches, but my mum bought them. If I had more PIP, I could have bought them myself, I wouldn't have to rely on others.' Shereena's bladder specialist suggested physiotherapy could help her. But attending wasn't possible because of the cost of getting to the appointments. 'When you don't have the money for something that might help, you have to weigh everything up and decide what stays and what goes. It could be worth it, but you just don't know.'

Thousands of people living with a progressive condition that doesn't get better, like MS, shouldn't be losing support with their mobility as their condition worsens. Losing the higher rate of mobility support means a reduction of people's income. It also means they no longer have access to getting an adapted vehicle on the Motability scheme. This can have a devastating impact on people's ability to live independently.

**'Prior to being moved to PIP I had a lifetime DLA award and mobility vehicle. Since being moved to PIP my award has changed to every 2 years, it has removed all mobility so I lost my mobility car. I then lost my independence for some time. I have been more stressed, anxious and depressed since moving to PIP and constantly feel it will all be taken away or I will be told I am not believed and be asked to pay all the money back due to what they believe is fraud. I feel like I am worthless and that they would prefer me dead.'**

The DWP has provided no evidence to show the 20-metre rule effectively assesses the mobility needs of people with MS. In a letter to the MS Society in September 2018, the Minister for Disabled People said 'there is no evidence for one particular distance being used'. And that 20-metres was introduced to distinguish those who are 'unable' or

'virtually unable' to walk. (Please see annex for more information).

The 20-metre rule is an arbitrary and rigid measure that simply looks at someone's ability to walk a set distance reliably. It doesn't assess the true impact MS can have on people's ability to move around in real-world surroundings. When people leave their homes, they move from a controlled environment into one where their ability to move around can be challenged in unpredictable ways by many symptoms. Visible symptoms like problems with balance and dizziness can make it difficult to move around but are not considered by the 20-metre rule.

Cognitive issues can make it difficult to multi-task while walking, such as walk and talk. These are important functions for most people but are not considered under the current assessment. Walking can worsen symptoms of fatigue for people with MS days, hours or even weeks after exertion. However, these factors are not included in the criteria.

**'From a mobility point they don't consider that one day you may be 'fine' and can walk 1 mile but don't consider the fact it will take 3 days to recover from doing it or that you don't have a choice (e.g. school run) so you do it every day but spend the day resting to be able to do it the next day.'**

PIP assessment guidance for how the 20-metre rule should be applied also doesn't consider the variety of walking surfaces and environments people encounter in everyday life. The rule is only looked at in relation to whether someone can walk the distance on a 'surface normally expected out of doors' such as flat pavements and includes 'the consideration of kerbs.'<sup>47</sup>

The guidance doesn't consider stairs and slopes, and different terrain such as grass and gravel. Or the fact that walking often involves moving through crowds or around obstacles.

**'The assessor did not understand MS and lack of balance, trying to walk on concrete or crowds, not being able [to] avoid oncoming people.'**

People with MS who can walk over 20-metres but under 50-metres are likely to face similar extra costs as those who can walk just under 20-metres. For example, if one person can only walk 15-metres, and the other can walk 25-metres, they both face severe limitations to their mobility. It's unlikely either of them would be able to reach their local bus stop or train station. It's likely that both need to use a wheelchair, mobility vehicle or similar aids to get around.

It doesn't make sense that only the person who can walk just under 20-metres would get the right level of support to help them with these extra costs and maintain their independence.

**'I can't walk to the bus stop without being pushed in a wheelchair - I can't drive anymore because of my variable vision and I don't think they took any of that into consideration. I am now using my savings to get taxis to the hospital - luckily Access to Work have given me funding to get a taxi to the office once a week. Without that and my savings for hospital visits I wouldn't leave the house.'**

People aren't eligible for the highest rate of PIP mobility support if they can walk 20-metres 'aided', for example, by using a walking frame.<sup>48</sup> But using aids shouldn't make the level of support needed lower. An aid might help someone to be more independent, but having to rely on it also shows they face severe barriers with their mobility.

**'They always say can you walk a certain distance with or without aids. Well I think this question is ridiculous. I can walk further with my rollator of course I can, it stops my falling over, tripping, when my leg gives way I can hold on so I don't fall!'**

### Key Recommendation

**The DWP must scrap the 20-metre rule. In the short-term it should be replaced with the 50-metre rule previously used under DLA. The 'aided' definition should also be removed.**

**However, the 50-metre rule is still a flawed, arbitrary measure of mobility needs. So, the DWP must design a new evidence-based means of assessing people's needs for mobility support. It should work closely with disabled people, disability experts and charities as it develops this.**

**This approach should move away from rigid and arbitrary measures for assessing mobility. It should look at the challenges each person with MS faces with moving around in real-world environments and consider the specific types of support they may need.**

**The Scottish Government should also follow these recommendations to improve how people's ability to move around is assessed for ADP.**

### Planning and following journeys

People's ability to 'plan' and 'follow' a journey is assessed as part of the mobility assessment. PIP assessment guidance says this part of the assessment looks at limitations on mobility 'deriving from mental health, cognitive and sensory impairments'.<sup>49</sup>

There is a lack of consideration of the impact physical symptoms can have on people's ability to plan and follow journeys. Including in interaction with cognitive issues. The support people with MS may need is also not properly considered. For example, support from family members and friends to take public transport.

Many people with MS face bladder and bowel problems.<sup>50</sup> For them, planning and following a journey can be complex. The same is true for those who have problems with balance and dizziness who may be worried about falling over. Many people in these situations won't leave their house without knowing where the nearest toilets will be, or where there could be a risk of falling. People may even choose to stay at home when they're not confident about easy access to toilets or that their route is safe for them.

**'They dismissed my mental health and cognitive issues, ignored the fact I'm not fit to work with my condition, ignored that I was scared to go outside alone in case I fell or pee or pooed myself, ignored my diagnosis of MS, lied and said I like to see friends when I said I haven't seen them or been out the house for 3 months.'**

Physical and cognitive difficulties can often interact for people with MS.<sup>51</sup> For example, many people with MS experience fatigue as one of their symptoms. This can sometimes have an impact on their



cognitive function. Fatigue can make concentration and memory issues worse. This could mean that someone who has been able to plan and complete their journey to the shops, may then be unable to plan their journey home as their cognition has been affected by their fatigue.

**'Personally my hidden symptoms weren't taken into account. The fatigue and impact of bladder and bowel issues were ignored. No account was taken in the huge impact they have on me being able to leave the house.'**

### **Key Recommendation**

**The DWP must change how people's ability to plan and follow journeys is assessed to make it more person-centred.**

**The new approach should consider the specific challenges each person with MS can face with planning and following journeys, and the support they may need with this. The descriptors should be extended to include challenges such as:**

- **Planning journeys around access to toilets due to incontinence.**
- **The interaction of fatigue with cognition, and the impact this can have on making journeys.**

**The Scottish Government should also follow these recommendations to improve how people's ability to plan and follow journeys is assessed for ADP.**

### **Assessors**

Many of the problems experienced by people with MS going through PIP assessments are due to many assessors having no expertise in neurological conditions. Despite this, assessors have a greater deciding role in assessments than a healthcare professional involved in a claimant's care. The assessment report and the advice included in it by the assessor is the main tool DWP Case Managers use to make their decision on people's awards.<sup>52</sup>

## David's Story

**David receives PIP after being reassessed from a lifetime award of DLA. David's MS symptoms include fatigue, poor mobility, problems with his memory and bowel issues. It took him a long time to get a diagnosis, which was frustrating and unsettling. Since his diagnosis he's found that his mobility's got worse - with more pain in his legs and arms. He also experiences dizziness, which causes problems with his balance.**

David's MS means he needs to sleep a lot during the day and spends most of his time at home. But he likes to try and keep busy. He volunteers and sees friends for coffee on his good days. However, David feels that, overall, his quality of life is poor. 'It's sort of a black hole really. You need to try and get going. I do have good days, but then the day after is bad and you feel fed up.'

David had a face-to-face assessment and was awarded 0 points for mobility and the standard rate for daily living. Even though his support was reduced, and his award was for two years rather than a lifetime, he didn't complain. After two years, David applied again. This time he had a phone assessment which lasted two hours. '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?'

David had to wait nearly two years, due to Covid and PIP delays. He was finally awarded the enhanced rate for daily living and mobility for five years. And he received a backdated payment. Getting PIP has made a difference to David's life. He says being given a lump sum has given

him some security as he's been able to put some into savings. He was able to install a ramp at home, rather than having to wait to get a grant from his local authority. He's also been able to pay for some treatments privately. However, the two year delay in being awarded PIP meant he had to go without things he needed during that period. For example, taxis, a cleaner, and a blue badge.

David says having monthly PIP payments helps him pay for regular counselling and physiotherapy sessions. Which he finds important for his emotional wellbeing and improves his quality of life. He's able to employ a cleaner and doesn't have to worry about getting a taxi to hospital. 'A lot of people rely on some kind of support. I use a frame, an item I need to go about my daily life, and PIP should help people pay for that. Small things can make a big difference. For example, something as simple as equipment to help me hold my toothbrush, or an aid for the bathroom or to help me get into the car. Those are things PIP helps me buy.' But David also says that he worries about a reassessment. 'I'm glad to have it [PIP] otherwise I'd be stuffed.'

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

Assessors do receive training in different conditions.<sup>53</sup> But many people with MS tell us they didn't think their assessor understood their MS. This is a key reason why assessments don't work for them. Without a good understanding of MS, assessors are often unable to ask the right questions to help them understand how someone's MS affects them. This leads to inaccurate assessment reports being produced, and people getting awarded the wrong level of support.

**In our survey, we found:**

- **Almost 3 in 5** (59%) people with MS didn't think their assessor had a good understanding of MS.
- Of those who didn't think their assessor had a good understanding of MS, **almost two-thirds** (65%) said they didn't feel they got the correct award.

**'The process of claiming PIP or ADP is full of pitfalls especially if you have an illness that most assessors have no idea how it affects people, they can't see past their own inadequacies of what they think MS is as a whole. Assessors aren't adequately trained, have no actual knowledge of the specifics of MS.'**

In its Health and Disability White Paper, the DWP committed to 'begin testing matching people's primary health condition to a specialist assessor.'<sup>54</sup> We welcome this

commitment and we've been engaging with the DWP as they begin this testing. But we're concerned their current plans seem to be for assessors to receive better training in different conditions. This wouldn't go far enough.

**Recommendation**

**The DWP must make sure people with MS are only assessed by assessors who have some professional experience of neurological conditions.**

While many people with MS are treated with dignity and respect by their assessor, a significant minority have told us this didn't happen for them. **More than 1 in 5** (22%) respondents to our survey said they disagreed or strongly disagreed their assessor treated them with dignity and respect.

Many people told us they were made to feel like they were lying about their condition by how the assessor spoke to them and the types of questions they asked. Some said it felt like their assessor was trying to catch them out and spot inconsistencies in what they were telling them.

**'It feels like what I'd imagine it's like to be questioned and judged by police for a serious crime. The stressful degrading process affected the MS BIG TIME. Us that know MS, know what stress does to MS.'**

DWP guidance for assessors doesn't place a strong emphasis on dignity for claimants and making sure they feel heard and believed. The approach to assessing people seems to be for individuals to prove to the DWP that they need support. Rather than assessing what support they may need.

It's no surprise that many disabled people's trust in the disability benefits system is low. They're too often made to feel like liars in their interactions with the DWP and their assessors. Unsurprisingly, being treated in this way is one of the aspects of the PIP process which can have the most negative impact on people's health and wellbeing.

**'They need to ensure the assessors are qualified and knowledgeable about the illness they are assessing. They also need to stop tarring everyone as scroungers and look at each case on an individual basis. Cutting and pasting of reports need to stop. And assessor training needs to be positive and relevant about each individual case.'**

**Recommendation:** The DWP must overhaul its training and guidance for assessors. The Department should work closely with disabled people, including people with MS, and disability charities to do this.

Training and guidance should make clear to assessors they should always treat claimants with empathy, dignity and respect before, during and after their assessment. Assessors should approach the assessment on the premise that the claimant knows best about how their condition affects them. And that what they're telling the assessor is an accurate account of this. The aim of an assessment should be to find out what support the claimant needs. Not for the claimant to prove they need support.

### Assessment reports

After an assessment, the assessor sends a report to a DWP Case Manager. This sets out:

- What was said at the assessment
- What the assessor observed
- Details of any evidence used

In the report the assessor recommends what level of award and duration they think the claimant should get. The DWP Case Manager then uses the report to help them make the final decision on the claimant's award.<sup>55</sup> So, it's vital reports should be as accurate as possible to make sure people get the right level of support.

However, many people with MS don't even see their assessment report to be able to know whether it's accurate or not in the first place. **Nearly 2 in 5** (37%) respondents to our survey said they didn't see their report but would have liked to.

If someone doesn't see their assessment report, it may be difficult for them to decide whether the decision is correct, and whether, or how, they should challenge it.

We welcome the Government's commitment in the Health and Disability White Paper to share assessment reports with 'people making a claim before a decision is made, offering them the opportunity to clarify evidence so that we can make the right decision as early as possible'.<sup>56</sup> This should be rolled out immediately.

Of the people who do see their report under the current system, far too many tell us it didn't accurately reflect what happened in the assessment. And it didn't consider important pieces of evidence they provided. Sometimes people think their assessment went well, and then are shocked to see how inaccurate the report is.

**'The assessment was over the phone and [I] thought it went well. Got the report and it was utter, utter garbage as if it was someone else's.'**

Far too many poor-quality reports are being produced. Which means Case Managers often don't have accurate information on how people's conditions affect them. This can lead to them getting the wrong level of support.

### In our survey, we found:

- **Over 3 in 5** (61%) people with MS said their report didn't give an accurate reflection of their MS.
- **Only a quarter** (26%) said their report did give an accurate reflection of their MS.

**'Previous assessment report had so many inaccuracies. It was shameful how the assessor reported absolute lies. No nice way of putting it.'**

Many people with MS tell us their assessment report contained factual errors. For example, it might include information that doesn't match what the claimant said in the assessment.

Often supporting evidence isn't included in reports, or it's contradicted by inaccurate information included by the assessor. Evidence from health professionals, family and carers is one of the main ways a claimant can show how their condition affects them. But if it isn't being properly considered in reports then it makes it more likely the report won't be accurate.

**'I'm now blind in one eye and it won't come back. She asked me "well what can you see" and I said, well nothing, went through not being able to drive etc. But when I got the report back none of this was mentioned, when it played such a huge part in the diagnosis itself and the part it's played in my life since. I couldn't believe it wasn't even alluded to.'**

Assessment providers are audited by the DWP to ensure the quality of assessment reports. The latest evidence from the DWP shows most reports (97%) are deemed to be 'acceptable'.<sup>57</sup> But the evidence from our survey of people with MS tells a different story:

- **Half** (50%) of respondents said their assessment report contained factual errors.
- **Over half** (53%) said their report didn't reference any evidence gathered from their healthcare professionals.

The reason for the difference in our figures and the DWP evidence could be explained by the fact that what the Department considers to be acceptable allows for errors and omissions in reports.

'Acceptable' reports to the DWP can include ones that have incomplete use of evidence and that contain more serious errors. But not serious enough that they're deemed to affect the decision.

The only 'unacceptable' reports are those which are such poor quality, a Case Manager wouldn't be able to use them to make a decision due to the risk of making the wrong decision.<sup>58</sup>

### **Recommendation**

**The DWP must put in place stricter quality assurance measures to make sure assessment reports are consistently good quality and accurate.**

**Reports that contain any serious error and/or incomplete use of evidence should be considered unacceptable. Case Managers should send unacceptable reports back to assessment providers.**

## ► The impact of going through the PIP process

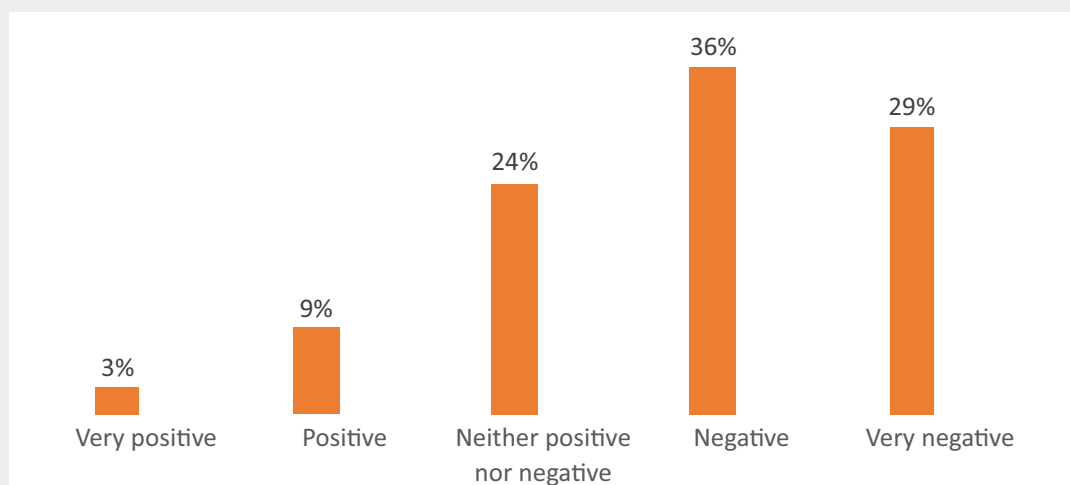
PIP is designed to support people with MS with their extra costs of their condition and to help them live independently. But too often the process of getting it is incredibly stressful for people with MS. And it can be actively harmful to their health and make them less independent as a result.

‘The 18 months was awful. It exacerbated every single symptom that I had. It had a massive knock-on effect along with anxiety and mental health issues.’

### In our survey, we found:

- **2 in 3** (65%) respondents said going through the process had a negative or very negative impact on their physical and mental health.
- **Over 7 in 10** (72%) said the assessment made them feel anxious.
- **Nearly 7 in 10** (69%) said the assessment made them feel stressed.

### Impact of the process on people’s overall health (physical and mental)



**‘I feel totally humiliated by the process, having to recall information that I struggle to do, find words that I struggle with when I am unable to work because of this condition and they make me feel totally useless and invalid as a human being, I wish I had enough money so that I didn’t have to be put through this horrendous and humiliating experience. I dread it every time.’**

For many living with MS, applying for PIP is such a negative experience for them they consider dropping out of the process before completion. Our survey found that **1 in 5** (40%) respondents considered dropping out during their applications.

**‘The stress after filling in the huge amount of forms can only be described as a totally degrading and humiliating experience with someone who obviously knew nothing about MS and then having to wait again to see if you had been awarded anything.’**

Certain problems with the PIP process have a particularly negative impact on people.

**For example, in our survey we found:**

- **92%** of those who didn’t think the assessor believed what they told them about their condition said the process had a negative or very negative impact on their physical and mental health.
- **93%** of those who said their assessor didn’t treat them with dignity and respect said the process had a negative or very negative impact on their physical and mental health.

**‘It was a completely humiliating process. I was made to feel like a liar as the assessor clearly had no idea about MS and how it affects daily living. I was in recovery from a relapse that involves learning how to walk again and intensive physiotherapy- the assessor recorded that I could walk unaided for 25m. A blatant lie as during the assessment I needed support to stand up.’**



The impact of going through the process can be particularly negative for those who end up getting the wrong level of support. Our survey showed:

- **98%** of respondents who said they didn't feel like they got the correct award said the process made them feel anxious, stressed, let down or embarrassed, or a combination of these.
- **82%** who said they didn't feel like they got the correct award said the process had a negative impact on their physical and mental health.

Even **around half** (49%) of respondents to our survey who felt they got the correct award told us going through the process had a negative or very negative impact on their physical and mental health.

**'I was awarded PIP the first time round, but the filling in of the very confusing forms and the assessment were so stressful it bought me into a relapse. I have to renew in 2025 and I worry about it even now with going through the process again and the fear of being declined as without it I couldn't survive as I now can't work full time.'**

We also heard from a significant minority of people with MS who had considered applying but were put off even starting an application. Of this group, **almost 1 in 5** (37%) said they hadn't done so because they were worried about going through the process.

Some people with MS are missing out on potentially getting vital support because they're so worried about the impact the PIP process may have on them.

**'Scared and embarrassed I would be made to feel silly or not deserving. I have heard of it being very stressful and stress gives me worse symptoms and relapses.'**

### Recommendation

**The DWP must commit to commissioning regular independent reviews of the health impacts (mental and physical) of going through the PIP process.**

The results of these should be publicly shared on an ongoing basis and should be used by the DWP to help inform improvements in the PIP process. To enable researchers to carry out the reviews, the Department should make sure they have access to good quality, anonymised claimant data.

As part of their contract with the DWP, assessment providers carry out Claimant Satisfaction Surveys to find out how people found the assessment process. In 2018, the DWP said that assessment providers are 'consistently exceeding their customer satisfaction targets' of 90% satisfaction for those claiming PIP.<sup>59</sup> However, this figure doesn't tell the whole story.

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## The impact of going through the PIP process

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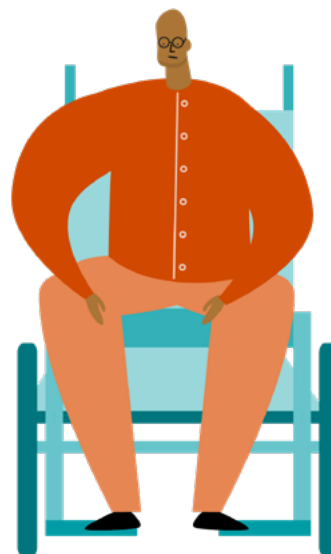
Evidence from a Freedom of Information Request in 2019 showed that only **around 1%** of all PIP claimants are surveyed.<sup>60</sup> People are only surveyed after they've had their assessment, but not after they've got their decision and seen their assessment report. This means people's experiences of the whole PIP process aren't being accurately reflected in those survey findings.

Many people's feelings on the PIP process are strongly influenced by the decision they get and what they think of their assessment report. Yet people won't be able to express these views in any survey run by assessment providers.

### **Recommendation**

**The DWP must make sure assessment providers offer all PIP claimants the opportunity to fill in a claimant satisfaction survey.**

**The survey should include people who've had their decision and seen their assessment report. Survey findings should be made publicly available on an ongoing basis and used by the DWP to help inform improvements to the PIP process.**



## ▶ The impact of receiving PIP

When people do get the right level of support, PIP can be a benefit that makes living with MS easier. It can help many people to maintain their independence and live more fulfilled lives. In this section, we outline different ways PIP can have a positive impact on people with MS. For example, people may use their PIP to help them stay in work. Or to cover the costs of adaptations that help them move around safely at home.

The positive difference that PIP can make to people's lives shows why it's so vital the Government fixes the unfair PIP process.

### Employment

Many people with MS face extra costs to be able to work. For example, someone may need to use an adapted vehicle to travel to their office. PIP can play a vital role in helping meet these needs. And therefore, help people to stay in work longer.

**'From the first time I received it, it made a difference. At the time, it 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.'**

PIP can also give people the opportunity to reduce the amount they work, when this is the right decision for helping them to manage their condition. People in our research told us that getting PIP gave them the peace of mind to know they'll have a source of income even when they're working less.

**'It has enabled me to be able to work less because it pays for the bills [...] I can have less hours at work, but if it comes out that they're going to take it off me, then I'm going to have to up my hours at work and I don't know how I'm going to cope.'**

## Case Study

# Jo's Story

**Over time things changed and she noticed her MS was beginning to have an impact on her everyday life. 'My balance had gone a little. My back goes into spasms on uneven ground or if I walk too far. I'm very much of the 'if you don't use it, you lose it' spirit. But that probably means my mobility has got worse.'**

Jo says what she really misses is the ability to be spontaneous. 'I always have to plan. How am I going to get there? Will I be able to park? Will it be close enough? Will the facilities be good enough? Before I would just turn up! Now, I resent the fact that I must think about these things.'

Jo was awarded a life-time award of DLA and had no reason to doubt this would change, since her condition wouldn't get better. However, when PIP was introduced, she had to be reassessed. 'It was a stressful few years. You fill in the form, which is daunting, then have an assessment. But because it means so much to you, it adds a whole layer of 'I've got to get this right.'

In 2019, Jo was given the standard rate of daily living and the enhanced rate for mobility for three years. In May 2022 her award was reviewed again. 'This time they awarded it for six years. But the worry of reassessment is always in the back of your head. They know it isn't going to get any better. I would be delighted if tomorrow they announced they'd found a way to reverse my MS. Why put us through the agony of making us apply again?'

PIP means Jo has a Motability car which has been adapted with a hoist and has hand controls fitted. It gives her independence to go out and do things.

She uses PIP to help pay for a cleaner and support with cooking. Jo says the support she gets makes a big difference. 'PIP gives me the ability to do things and not think twice about having to spend additional money. It's silly things, for example, 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.'

Because Jo works part-time, she can pay bills and use PIP for the things she needs to help her live independently. 'PIP is a real buffer for me, and I know that I can still do all the things I need to. Without this buffer, it will be difficult for someone to live independently. The person who doesn't get it will be worrying about all sorts of things, always. It helps me not to have to make a choice between two things that will be good for me. I'm lucky I can have both.'

As time goes on, Jo finds that you can forget how much of a positive impact getting PIP can have. 'It's only when you reapply and you realise you might lose it, that you realise how big a difference it makes. It gives you peace of mind. If I lost it, I'd have to think about getting rid of my car, my cleaner, changing the food I buy and replacing my scooter and walker. Because PIP helps me pay for all those things.'

**'This time they awarded it for six years. But the worry of reassessment is always in the back of your head. They know it isn't going to get any better.'**

## Financial planning and security

Research participants told us they liked the flexibility of PIP, because they could spend it how they chose. This meant they could use it in a way that best suited their condition and broader life. It's also a consistent payment that's provided every month. Research participants found this to be helpful, as they could factor it into their financial planning.

Some people were able to use their PIP payments to cover extra costs to help them live more independently. People in this group tended to be on higher incomes than those using PIP to pay for essentials or bills. People who were able to use PIP in this way described it as giving them 'wiggle room'. As it gave them the ability to save small amounts or carry out activities that helped their wellbeing, such as socialising.

Those whose finances were more stretched told us they had no choice but to use their PIP to pay for essentials because they had very little or no other income. Some research participants mentioned they'd been struggling more with high essential costs because of the cost-of-living crisis. This shows how people living with MS continue to be affected by the financial pressures outlined in our Reduced to Breaking Point report published in autumn 2022.<sup>61</sup>

**'Again, shopping wise, I don't buy as much, like I used to in the olden days. Which is why the pension had to go, so that way I've got a little bit more. Not a lot but, you have to be frugal, to see what money's coming in and how it's going out.'**

## Health and adaptations

Many people with MS face extra healthcare-related costs due to their condition. This can include private treatment or drugs they may struggle to access on the NHS, which they need to use to manage their symptoms and stay well. Therapies such as massages and physio can be important for managing physical symptoms. People may also access therapies and counselling to support their mental health.

Receiving PIP can allow people with MS to access these vital treatments and therapies. And because people are free to spend their PIP in the way they choose, they have the flexibility to meet their specific health needs.

**'I get these massages, because my legs are so solid that if they don't get some manipulation, they're like concrete. And they only get worse if I don't do anything for them.'**

Getting PIP can allow people to buy aids and make adaptations to their home, to make it safer to get around and do daily activities. This can include installing ramps or purchasing mobility scooters for getting around.

Some people with MS may be able to get grants to help with home adaptations. But often this can take a very long time and the application process can be tricky. In our research, people told us they liked that they could use their PIP to get adaptations done sooner.

**‘I went to this place in [town] which is a special shop that is full of everything, scooters, all that stuff. I mentioned to him about the stairs, and he came and put [in] this ramp. Someone told me you can get a grant for adapting your home, but I’m thinking that’s another form and another 2 year wait. If you have the money just do it now. I’ve been back since to get a couple of other items for the kitchen, it’s really good. I do like things that make life easier.’**

## Daily activities

Living with MS can make many aspects of daily life more challenging. Such as getting around and preparing food. PIP can help meet the extra costs of things which make these activities easier.

People in our research told us they use PIP to pay for taxis to attend appointments or get to work. Some people with MS pay for their own adapted vehicle using their PIP, such as leasing a Motability vehicle, so they’re able to maintain independence and get around.

Getting PIP can make it easier for people to meet their food and cooking-related extra costs. People may use it to buy pre-cut vegetables – which are usually more expensive – when they find cutting too difficult due to their symptoms. Some people also buy high-quality microwaveable meals because using the stove has become a hazard due to symptoms such as memory impairment.

**‘I think what it does is give me the ability to do things. Not think twice about spending that additional money. It’s silly things but, for example, I can’t cut or chop vegetables. So I buy a lot of prepared stuff which is a bit more expensive. It’s silly but it just means I don’t have to think about it.’**

## Caring

PIP can let people take some of the burden off their family and friends who often care for them. People may use PIP to pay for outside help with tasks to give family members and friends a break from doing them. For example, getting a taxi rather than a lift from a friend.

Participants in our research described how having PIP to help cover chores or take pressure off their other finances meant they had more energy to focus on personal relationships. Some told us they liked that PIP could help them to be less reliant on others, which can have a positive impact on people’s emotional wellbeing. It can contribute to creating more of an equal footing in households, enabling the person receiving PIP to also provide for their family.

**‘I get out of the house a couple times a week. I go for a walk with my friends, I use my scooter. It’s helped my life in a big way to be able to get out and about.’**

**‘If I didn’t have PIP to help me with my bills, it would be a lot harder on my husband and on me. The stress would be a lot on him. Because he takes on a lot already, having to take time off and help me with this stuff, and I would feel more of a burden because I couldn’t contribute anything. At least I can contribute something. I still feel like this is us, we’re in this. Otherwise, I would feel like, you’re taking care of me, you’re literally a caregiver and that’s it.’**

## **Social life and leisure**

People with MS are more likely to experience poor mental health than the general population. The uncertainty and unpredictability of MS can cause anxiety and distress and make people feel isolated. Loved ones of those living with MS may also experience poor mental health. For example, due to struggling to adapt to the new dynamics of their relationship.

People in our research told us that getting PIP was vital for helping them do activities that brought variety and positivity into their lives. For example, some people spend their PIP on going to visit friends and family, attending exercise classes or going out for meals. These activities can be hugely beneficial to the mental health of those living with MS, and their loved ones, and make them feel less isolated.

## Patrick's Story

**Patrick lives in Belfast and has been diagnosed with progressive MS. Patrick's symptoms means he's unable to walk. He needs aids to get around, and he's had to stop doing some things he used to enjoy, like swimming. He uses a mobility scooter which he says has been a big help in his life, enabling him to get out and about. 'I like to get out a couple of times a week to go for a walk with my friends. It means so much to get out and my friends are very important to me.'**

Patrick says the biggest impact of his MS is on his mental health. This also impacts his family. 'I try not to focus on the things I can't do, but on the things I can. I try to think - I might not have control of the MS, but I do have control of me.'

Patrick was reassessed from DLA to PIP when it was introduced. His award was reduced from high to standard. 'They were saying that I didn't need the help I was telling them I needed. You feel like you're a beggar, and that they don't believe you.' Patrick appealed and his award was changed back to the enhanced rate. 'I was elated. Elated because they believed me.'

Patrick is unable to work and says without the financial support PIP offers, things would be a real struggle. PIP enables him to get out of the house, which is how he copes with his MS and the impact it's had on his mental health. He says without PIP he'd be housebound. 'I wouldn't be able to go out, because I wouldn't have a car or be able to afford to keep a car. Not having it would have a massive impact. It would be bad, very bad.' Learning to live with MS and changing his mindset over the last couple

of years means Patrick feels: 'more up than down now, and PIP has helped with that. If it was taken away, I'd be sitting here doing nothing.'

Patrick believes that people with a physical disability are more likely to get PIP. 'For those of us who don't, there's the impression there's nothing wrong with us, so we don't need the money. But I know I'm 100% entitled to PIP. People who are eligible don't apply because of how stressful and difficult the process is. It will help so much with their mental health, they must get it, they must.'





## ▶ Adult Disability Payment

The Scotland Act 2016 transferred new social security powers to the Scottish Parliament. It gave the Scottish Government control over aspects of social security that were previously managed by the UK Government.<sup>62</sup> After this, the Social Security (Scotland) Act 2018 enabled the Scottish Government to set up Social Security Scotland (SSS), an executive agency of the Scottish Government.<sup>63</sup> This agency manages devolved benefits in Scotland. One of these benefits is ADP, which was introduced to replace PIP from August 2022 onwards.<sup>64</sup>

During the process of setting up SSS and developing ADP, the Scottish Government stated their commitment to work in partnership with disabled people. In order to make changes to the way that benefits in Scotland are delivered. This includes a commitment that disabled people receive the support they're entitled to. And that their vision for disability assistance is to create a 'compassionate, person-centred approach'. These aims are included in the Social Security Scotland Charter which sets out the agency's aim of 'delivering social security with dignity, fairness and respect.'<sup>65</sup>

### Differences with PIP

The differences with PIP mainly focus on the application and decision-making processes. These changes include:

- Strengthening the reliability criteria to stress that clients must be able to carry out specified activities safely, repeatedly,

in an acceptable manner and in a reasonable time.

- Only one piece of formal supporting information to support the general care and mobility needs described on an application will be required. Evidence from 'informal support network' sources will be given 'equal weight'.<sup>66</sup>
- It will be Social Security Scotland's responsibility to collect supporting information.
- They say they will apply eligibility criteria more 'fairly and consistently' than PIP and say their processes and guidance will be better.<sup>67</sup>
- There will be no functional examinations as part of a consultation and consultations can take place over the phone. These will only be used as a method of last resort to gather information when all other avenues have been exhausted.
- People can apply online, over the phone or by a paper application form. Social Security Scotland will have local delivery teams which are able to support clients to complete the application process.
- SSS has reintroduced indefinite awards for some people in receipt of the enhanced rate of both components of ADP whose needs are highly unlikely to change.
- SSS has worked with disabled people to design the application form.

## Similarities with PIP

While ADP has several key differences to PIP, there are also some similarities. ADP has the same eligibility criteria as those currently used in PIP. These criteria are what people are assessed against to decide whether they qualify for the benefit, or what level of benefit they will receive. The criteria the Scottish Government have chosen to adopt include:

- The 20-metre rule to assess mobility needs
- The 50% rule to assess fluctuating conditions
- The existing criteria for planning and following a journey

The Scottish Government has told us it adopted these criteria as it needed to develop a 'like for like' benefit to make sure people who qualified for additional support because of receiving PIP/ADP, would still qualify for this. For example, top-up premiums to benefits like Pension Credit. The Scottish Government said it was also reluctant to develop a two-tier system with different eligibility criteria so it could manage the complex transition of Scottish clients from the DWP to SSS.

## Next steps for ADP

We're pleased about some of the differences with ADP compared to PIP, such as there being no functional assessments and more people being given indefinite awards.

However, we're disappointed ADP uses the same criteria as PIP. To date, relatively few people with MS have claimed ADP. So, we

have limited evidence on how well it works in practice for them. But it's likely the criteria will cause the same issues for people as they do with those who go through the PIP process and could lead to people missing out on support.

When ADP was brought in, the Scottish Government committed to carrying out a full independent review of ADP. As part of this, they've already run a consultation on the Mobility Component of ADP.<sup>68</sup> We responded to this consultation earlier this year.<sup>69</sup> We called for the criteria to be changed so they better consider how the fluctuating nature of MS and hidden symptoms impact people's mobility. This included calling for the 20-metre rule to be scrapped.

In the first section of this report, we outlined our recommendations for the changes we would like the UK Government to make to:

- The 20-metre rule
- The 'planning and following a journey' descriptors
- The 50% rule

These recommendations are also relevant for ADP. They should also be adopted by the Scottish Government.



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## ► Conclusion

PIP is 10 years old this year. It's a benefit that can support disabled people with their extra costs, and can be a lifeline to an independent life for many people with MS. The case studies set out in this report show the positive difference PIP can make. Like for David who uses his PIP to pay for counselling and physio sessions, helping to improve his health and wellbeing. And for Sian who uses it to pay for taxis, helping her to get out and about.

However, too many people with MS are denied the support they need because the process for applying for PIP is unfair and filled with problems at every stage. Application forms are too complex, long and don't enable people to explain how their condition affects them. Evidence from people's health professionals often isn't considered, or even collected.

The criteria used for assessing how people's MS affects their ability to undertake daily living and mobility activities don't consider the impact that fluctuating and hidden symptoms can have.

Informal observations are sometimes used to assess people but only provide a snapshot view of someone's life. They don't reflect how their MS affects them over time.

Some people are shocked when they see their assessment report as it includes factual errors. Reports often fail to reflect what happened in the assessment or how someone's condition affects them.

Many say they find the whole process to be unempathetic, and that their assessor made them feel like they were lying. Applying for PIP can be hugely stressful, anxiety-inducing, and can make people's physical and mental health deteriorate. Too often, the PIP process is making people ill and denying them their independence.

We've been campaigning to improve how PIP works for people with MS for a decade. In that time, we've achieved some wins, such as the Government committing to testing the use of specialist assessors. However, the evidence from people with MS shown in this report shows far more needs to be done. The Government is now rolling

out its plans for changes to the disability benefits system following the White Paper, and has the opportunity to finally make the PIP process work for those living with MS.

The whole PIP process needs to be overhauled to make sure it more accurately reflects the impact of living with MS.

As part of this, the 20-metre rule for assessing mobility should be scrapped. It should be replaced with a new evidence-based approach that properly considers people's needs for mobility support.

Informal observations should no longer be used to assess those living with fluctuating conditions like MS. The 50% rule for assessing fluctuating conditions also needs to be made far more flexible to consider the frequency, severity and impact of all symptoms over time.

There are unfair barriers at every step of the PIP process, meaning too many people with MS miss out on the right level of support. But by following the recommendations in this report, the Government can make sure people with MS are no longer failed by a damaging PIP process. And are no longer denied the support that can make a vital difference to the lives of so many.



## Annex

### Letter from the Minister for Disabled People to the MS Society regarding the 20-metre rule - 18 September 2018

Thank you for your letter of 10 August 2018 in which you requested for me to provide the rationale for the introduction of 20 metres in the mobility component of the Personal Independence Payment (PIP) Assessment Criteria. I understand you have since discussed this in more detail with my officials on the 6th September and a further meeting is being arranged with our Assessment Providers to discuss the implementation of the policy.

I recognise the queries and concerns you have regarding the high rate mobility component of PIP and its potential effect on individuals with Multiple Sclerosis. This letter provides further clarification around the purpose and application of the policy.

The enhanced rate of the PIP mobility component was always intended to be for those 'unable' or 'virtually unable' to walk.

We consulted extensively and on multiple occasions while developing the mobility component of the assessment: the first formal consultation on PIP was launched on the 6th December 2011 and a subsequent specific consultation exercise was launched on 23rd June 2013, following feedback that the 'moving around' activity was difficult to understand. We carefully considered all the consultation responses, including the suggestions for alternative approaches and the Government's official response was published on 21 October 2013.

The consultation responses confirmed that there was no consensus across the health and social care community of the perfect measure of mobility, but distance is often used as it is clear and easy to understand and apply. Equally there is no evidence for one particular distance; the 20 metres distance

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was therefore introduced to distinguish those whose mobility is significantly more limited than others and as such are 'unable' or 'virtually unable' to walk. We believe this criteria is the best way of identifying those whose physical mobility is most limited and hence those individuals who have the highest needs.

It must be remembered that the 20 metres distance is not the only factor considered when applying a descriptor for the moving around activity: the impact of taking reliability into account is another factor when considering the operation of the mobility criteria. Specific legislation recognises that determining the distance an individual can stand and then move is rarely cut and dry and that individuals are unlikely to only be able to walk a certain distance every time. The reliability criteria ensure that decisions are based on what individuals can actually achieve on a regular and reliable basis, not on what they can do when at their best but are not able to repeat. This means that the enhanced rate of the mobility component will be awarded to those people who cannot walk beyond 20 metres and those who can walk beyond 20 metres but cannot do so reliably, i.e. safely, repeatedly, to an acceptable standard and within a reasonable time period.

In addition, we do recognise that people who are unable to reliably walk more than 50 metres also have restricted mobility and independence to a level which requires support from the Government. This is achieved through the assessment criteria as set out in Regulations which award the standard rate of the mobility component to those who cannot reliably walk between 20 and 50 metres.

Whilst other Government policies use different measurements of mobility, it does not mean that one or another measure is right or wrong. Given the policy intent of PIP is to target support on those with the greatest needs, we believe this criteria is the best way of identifying those whose physical mobility is most limited and hence those individuals who have the highest needs.

Full information on the introduction of PIP mobility criteria can be found in the Government Response to the consultation on mobility activity 'moving around' and associated DLA Reform impact equality assessment, both of which are published on GOV.UK. I have attached a copy for your information.

I hope this provides some helpful background to the introduction of the policy. Please don't hesitate to get in contact with my office or directly with the PIP policy officials if you have any further questions.

Yours sincerely,

**Sarah Newton MP**

**Minister for Disabled People, Health & Work**

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