PIP fails: how the PIP process betrays people with MS

Rony Erez
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MS Society

Foreword

Since the introduction of Personal Independence Payment (PIP) in 2013, we have heard countless stories from people with multiple sclerosis (MS) about how difficult it is to get the support they need. 'Humiliating' and 'degrading' are two words that we hear often about the claims process.

There have been a few attempts by the UK Government to improve PIP in recent years. But PIP still continues to fail people with MS. People with MS shouldn't have to keep waiting for PIP to improve – they want to see the changes recommended in this report implemented now.

More than 100,000 people live with MS in the UK. MS can be relentless, painful and exhausting. It's a condition which damages nerves in your body, making it harder to do everyday things like walk, talk, eat and think.

Living with MS is also expensive. It costs, on average, an extra £200 a week to live with a neurological condition like MS[i].

That's why disability benefits, like PIP, are so vital. Having an adapted Motability vehicle, or having the money to pay for things like physio or counselling can make a huge difference to someone's independence and quality of life. In the words of one person with MS that we spoke to, PIP can give people the support they need "to live rather than exist".

However, as you'll see in this report, unnecessary barriers persist throughout every stage of the PIP claiming process, leading to thousands losing or being denied support.

From tackling the complex and lengthy form, to proving yourself to an assessor, to fighting an incorrect decision – people are facing an exhausting and demoralising battle every step of the way. This is while assessors don't always understand MS and too often ignore invisible and unpredictable symptoms.

This lack of knowledge about MS is particularly worrying when assessors frequently use informal observations in their decision making. These are judgements made by what assessors see rather than what they are told.

When these observations are used without being backed up by evidence, they often do not accurately reflect how people are impacted by their MS. We know this because 67% of people with MS who had informal observations included in their assessment report said they did not reflect how their MS affects them.

Shockingly, informal observations are even used to make incorrect assumptions about someone's abilities. Liz told us her assessor wrote in her assessment report that she 'picked up a medium-sized handbag and retrieved a purse', which meant that she could chop vegetables and prepare food. Ben's assessor never saw him walk, yet she decided that because he can drive his Motability car to work, he could walk between 50-200 metres.

The fact that 83% of people with MS who appeal their PIP decision after moving from the previous benefit Disability Living Allowance (DLA) win their case at tribunal shows how inappropriate assessments continue to be for people with MS.

As we demonstrate in this report, there are significant yet simple changes that the UK Government can make immediately to improve the process and build trust.

Decisions should be backed up by evidence not assumptions, and assessors need to have good knowledge of MS.

Having MS is hard enough – it shouldn't be made harder by a welfare system that doesn't make sense. I hope this report goes some way to encourage the UK Government and assessment providers to make much needed changes to PIP, so people with MS can get the support they need and deserve.

Genevieve Edwards
Director of External Affairs, MS Society

About MS

Multiple Sclerosis (MS) is a chronic, neurodegenerative condition for which there is currently no cure. In MS, the body's immune system attacks myelin, the protective cover around nerve fibres. Damage, which can occur anywhere in the central nervous system, interferes with messages travelling from the brain and spinal cord to other parts of the body. Symptoms are many and varied, unique to each person. They can include problems with balance, vision, bladder and bowel function, speech, memory, fatigue and painful muscle spasms, among many other things. MS affects over 100,000 people in the UK, many of whom experience their first symptoms during the peak of their working lives, in their 20s and 30s.

MS is both a fluctuating and progressive condition. While the progression and symptoms of MS vary from individual to individual, primary progressive MS affects around 10 to 15% of people with MS. This type of MS is progressive from the very first symptoms. The remaining 85% of people with MS are initially diagnosed with relapsing forms of MS, where people have distinct attacks of symptoms with the underlying damage building up over time. Many people with MS will go on to develop secondary progressive MS within 15 years of being diagnosed.

The progressive and fluctuating nature of MS presents particular challenges for the assessment of eligibility for Personal Independence Payment (PIP).

About the MS Society

The MS Society is the UK's largest charity for people living with MS. We're here for everyone living with MS – to provide practical help today, and the hope of a cure tomorrow. We play a leading role in research. We fight for better treatment and care. We let people with MS know they're not alone, and offer advice and support to help them manage their symptoms

About this report

The report and recommendations are based on the results of an online survey of people living with (93%) or affected by MS (7%). The survey was conducted in June and July 2019, and received 889 responses.

Further research included 29 telephone interviews with participants who completed the survey, some of which are included in this report as case studies.

An online survey of MS specialist nurses was also conducted in June and July 2019, to understand the views of MS nurses on the effect of PIP on their work. 89 MS nurses responded to the survey, which was promoted via the UK MS Specialist Nurse Association (UKMSSNA) and the MS Society's network of Regional External Relations Officers.

This report continues the efforts of the MS Society to reform PIP so that it makes sense for people with MS. A previous report in 2015 highlighted issues with PIP and how people with MS are assessed for the benefit. Unfortunately this report shows that these issues remain and still require action from the UK Government.

Devolved benefits in Scotland

The Social Security (Scotland) Act 2018 saw the creation of a new agency Social Security Scotland[ii]. The agency oversees the devolution of a range of benefits including PIP.

Several of the recommendations in this report are already policy commitments by the Scottish Government, including:

- The application process for Disability Assistance (the proposed new name for PIP) will be inclusive, accessible, provided in a range of formats, available through a range of routes (online, phone, post and in-person) and transparent.
- A holistic, person centred approach will be taken to decision making - consideration will be given as to how an individual's condition affects them, taking into account all of their circumstances.
- The system will be designed with the intention of significantly reducing the number of individuals required to attend a face-to-face assessment to determine their eligibility for Disability Assistance.
- All Social Security Scotland staff involved in making decisions about eligibility for Disability Assistance will undergo robust training reflective of the Agency's values of dignity, fairness and respect.

The Scottish Government has set out an indicative timetable for the transfer of the devolved benefits with new PIP claimants coming on-stream in 2021 and the full transfer of current PIP claimants by 2024. This means we will simultaneously seek to improve the current reserved PIP regulations whilst influencing the development of the devolved regulations and guidance.

PIP in Northern Ireland

Benefits in Northern Ireland (NI) are the responsibility of the Department for Communities (DfC). While there are some differences, the DfC works to maintain policy parity with the DWP, but is responsible for the delivery of benefits.

Early predictions about the impact of changes to social security, including the introduction of PIP, pointed to Northern Ireland facing particular issues. With a high prevalence of disability and mental health issues in Northern Ireland, the transfer from DLA to PIP posed significant problems. The implementation of welfare reform changes was delayed and a mitigation package was put in place by the NI Executive. This package, funded by the devolved administration for 4 years, was to ensure adequate advice and advocacy services were in place for claimants and that those financially worse off would have this cushioned with a transition period. It could be argued that Northern Ireland is yet to feel the full impact of welfare reform and that there is a significant risk of additional hardship when this package is due to end in March 2020. 'Cliff Edge NI' - a coalition of charities which includes the MS Society, is currently campaigning for the extension of the mitigation package.

The transition from DLA to PIP, which remains ongoing, has been a particular concern for the MS community in Northern Ireland. MS Society NI has worked in coalition with advice and health sector organisations as well as independently in influencing the DfC and assessment provider Capita in the best interests of people living with MS.

As the DfC is responsible for the administration of PIP in Northern Ireland, recommendations in this report aimed at the DWP should be read as recommendations for the DfC in Northern Ireland.

PIP in Wales

As Wales does not have devolved responsibility for benefits, PIP policy and delivery is decided by the UK Government in Westminster. Therefore the recommendations to the DWP and the UK Government in this report also apply to Wales.


WOLFSKIN
JACK WOLFSKIN AT HOME OUTDOORS SINCE 1981

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Executive summary

Since 2013, Personal Independence Payment (PIP) has started to replace Disability Living Allowance (DLA). PIP is a disability benefit designed to help disabled people of working age manage the extra costs associated with their condition. PIP is not means tested and can be claimed regardless of employment status.

There are two components to the benefit – the mobility component is for help with getting around, and 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. The current maximum weekly award is £148.85.

Since its introduction, people with MS have been telling us that the PIP claim process doesn't work for them. Many people with MS do have a good experience but a significant number are still frustrated with the same issues raised in our 2015 MS: Enough report[iii].

MS is a complex neurological condition, and each person is affected differently. Symptoms can fluctuate from day to day or even from hour to hour. Many of the symptoms are hidden, for example pain, fatigue and cognitive issues. The complex and varied nature of the symptoms make it difficult to assess, particularly when the claim process is designed in a way that doesn't enable people with MS to fully explain how the condition impacts their lives on a daily basis. This leads to inaccurate assessments by contracted assessors, which means many people with MS end up with wrong decisions.

This report is based on survey responses of 889 people living with or affected by MS and a separate survey of 89 MS specialist nurses. It breaks down the three main phases of the claim process. In each phase we focus on the main changes that people with MS tell us are necessary in order to make the process make sense for them.

The first section of the report explores the initial application process. Here people with MS tell of their difficulties with filling in the application form. Nearly two-thirds (65%) of respondents to the survey said the form was either hard or very hard to complete. Of those who found the form hard to complete, 61% said this was because the form was too long. Although the form is long, 34% of respondents said they didn't think the form allowed them to explain how their MS affects them. We want the PIP claim form to be redesigned with disabled people so that it works for people with MS and other long-term conditions.

The report also finds continuing problems with evidence collection mechanisms, both for claimants and assessors. 37% of respondents said it was difficult or very difficult to obtain evidence from their healthcare professionals, with half of those saying the reason was that there was not enough time to do that. We want to see an improvement in the way evidence is gathered, and an extension of the deadline for submitting the form and evidence to 8 weeks.

The next section focuses on the face to face assessment. One of the main concerns people with MS have is with assessors' lack of knowledge of the condition. 55% of respondents who had a face to face assessment disagreed or strongly disagreed that the assessor had a good understanding of MS. 55% of respondents also disagreed or strongly disagreed that the assessor understood the impact of their MS. This means that despite guidance around the application of the reliability criteria[iv], it isn't adequately applied in many cases.

An assessor's lack of understanding of MS can also mean that informal observations – actions and behaviours observed during the assessment – are used inappropriately. Assumptions are often made about someone's abilities without taking into account the fluctuating nature of their condition. Of respondents who had informal observations included in their assessment report, two thirds

(67%) said the observations did not reflect how MS affects them. We want assessments to be conducted by assessors with good knowledge of MS, and informal observations to be backed up by evidence.

Finally, the report looks at the changes required to improve the decision making process. 45% of respondents who had received a decision on their claim said they don't think they were given enough information with the decision letter to explain how the decision was made. Changing this should start with sending assessment reports with decision letters as standard. We also look at the information people with MS need to be able to challenge wrong decisions. A third (34%) of respondents who had received a decision on their claim didn't think they were provided with clear information about the right to mandatory reconsideration – the first step in challenging a decision. The UK Government must take responsibility for informing people with MS of their right to challenge a decision and provide them with support to do so.

The responsibility for ensuring that assessments and decisions are of good quality rests with the UK Government. The DWP knows that the assessment providers are not achieving what are already low quality benchmarks for PIP assessments, so we are also calling on the UK Government to establish better quality control mechanisms and ensure a better level of service. This can be achieved by creating an independent body to oversee assessments and ensure assessment providers comply with quality indicators.

At least one in four people with MS are losing out on PIP. That's at least 12,886 people with MS who have lost out on support since PIP was introduced, compared to the level of support received under DLA[v]. People with MS have told us that the process of claiming PIP is unclear and unsupported. Nearly two thirds (64%) of respondents disagreed or strongly disagreed that 'the process of claiming is easy to understand', and over half (55%) disagreed or strongly disagreed with the statement 'I received the support I needed throughout the process of claiming'. These views help explain why a staggering 54% of people with MS told us that they disagreed with the initial decision regarding their claim.

Over the years, the UK Government have made small changes to the process, including an end to reassessments for disabled pensioners and some people with severe and progressive conditions, and clarifying communications with claimants. But we have yet to see meaningful changes to the process. Without immediate changes, more people with MS will lose out needlessly on the vital support PIP could provide.

We need a PIP process we can trust. Decisions need to be backed up by evidence not assumptions, and assessments should be carried out by people with good knowledge of MS. For PIP to achieve its stated aim of supporting independent living, the UK Government must act now and work with disabled people and charities to make these much needed changes, so that PIP makes sense for people with MS.

Recommendations

The application process

- The DWP, in consultation with disabled people and charities, should redesign the PIP application form to ensure that it allows people with progressive and fluctuating conditions to fully explain how their condition affects them.

- The DWP should provide clear information with the PIP application form which tells claimants about the right to request an extension to the deadline, and the circumstances under which this should be granted.

- The DWP should extend the deadline to submit the PIP application form to 8 weeks as standard to allow claimants to obtain evidence and the support they need to fill in the form.

- The DWP should provide the criteria and scoring system to all applicants with the PIP application form.

- The UK Government should ensure independent advice services are available to deliver help in filling in PIP application forms. Services should be available to all claimants in the UK free of charge and there should be clear signposting to this service in every communication from the DWP.

- The DWP should reimburse claimants for charges made by healthcare professionals for providing evidence for PIP claims.

- The DWP should provide clear guidance to all claimants on the type of evidence they should provide, including evidence from informal sources such as friends, family and carers.

- The DWP should provide clear guidance to healthcare professionals, including specialists such as MS nurses and neurologists, on what evidence they should provide to support PIP claims.

- The DWP should provide access to support for healthcare professionals who require assistance in filling in reports.

- The DWP should strengthen PIP assessment guidance on evidence collection to ensure that evidence is always requested by assessors when assessing claims by people with MS and other complex neurological conditions. Case Managers should return reports that do not comply with the guidance.

- The DWP should introduce key performance indicators to assessment provider contracts to ensure that evidence is always sought for claims by people with MS. Assessment providers' performance against the indicators should be published regularly.

- The DWP should work with assessment providers and healthcare professionals to achieve a significant increase in evidence return rates. This could include changes to the way the DWP and assessment providers communicate with healthcare professionals, and allowing more time for healthcare professionals to provide the evidence. The DWP should continue working with healthcare bodies on ways to streamline evidence collection mechanisms.

Face to face assessment

- People with MS should only be assessed by assessors who have some professional experience of neurological conditions and have received training developed in conjunction with relevant charities.

- The DWP should amend the PIP assessment descriptors to embed the reliability criteria and its definitions within the wording of each descriptor.

- The DWP should carry out an evaluation of how the PIP assessment criteria consider hidden symptoms including pain, fatigue and cognitive symptoms.

- Assessors' reports must consider the reliability criteria for each descriptor, proactively setting out evidence for why they consider that each activity can be carried out safely, to an acceptable standard, repeatedly and in a reasonable time. Case Managers should return reports that do not comply to the assessment providers, and no decision should be taken without fully considering the reliability criteria.

- All informal observations included in the assessment report must be backed up by evidence. Where this is not the case or where the assessor has chosen to 'overrule' evidence from healthcare professionals and the claimant, the assessor must explain this clearly in the report. Case Managers should return reports that contain unsubstantiated informal observations.

- PIP guidance should be changed to say that the reliability criteria should be applied to informal observations and training and quality assurance should enforce this.

- The DWP should ensure both audio and video recordings of PIP assessments are provided as an option to claimants.

- Assessors should ensure a copy of the audio or video recording is provided to the claimant at the end of the assessment.

Decision making

- The DWP should automatically send the assessment report to every PIP claimant along with their decision letter.

- The DWP should put in place stricter quality assurance measures to ensure that assessment reports are consistently of good quality. Data related to quality of reports should be available publicly on a regular basis.

- The DWP should expand the Claimant Service and Experience Survey to include unsuccessful PIP claimants.

- The DWP should ensure decision letters provide clear sign-posting to mandatory reconsideration and how to go about it.

- The DWP should extend the deadline for mandatory reconsideration to eight weeks, with further extensions considered due to ill health and on a case by case basis.

- DWP Case Managers should contact claimants prior to making a decision on mandatory reconsideration, to discuss the case and obtain further evidence if necessary.

- The UK Government should ensure that independent advice is available at the Mandatory Reconsideration stage as well.

- The DWP should review and establish suitable performance measures and targets for disability benefits, including PIP. These should be published regularly.

- Assessment providers' performance metrics should be monitored by an external, independent body that also has responsibility for direct observations of assessments, with a role analogous to that of the Care Quality Commission for the health and care system.

The application process

Applying for PIP requires filling in a form, and usually a face to face assessment which is conducted by private companies contracted by the DWP. Following the assessment, the assessor provides a report to the DWP which details the evidence used in the assessment and a recommendation on the level and duration of PIP award. Case Managers at the DWP then decide whether a person will get the mobility or daily living component (or both) and the rate and length of the award.

Evidence is essential when assessing the support needs of an individual with a complex and variable condition such as MS. Without further evidence, face to face assessments can only capture a snapshot of someone's life, and never the whole picture. Collecting relevant evidence from people who know that person best, such as friends, family, carers and healthcare professionals, can truly illustrate the impact MS has on someone's life.

The PIP assessment guide stipulates that in cases 'where claimants have progressive or fluctuating conditions', additional evidence from professionals should be sought to help assessors inform their advice to the DWP[vi] . As MS is both a progressive and fluctuating condition, it is appropriate whenever assessing a person with MS to seek further evidence.

Evidence from the individual claiming PIP is also very important. The person with MS knows best how their MS affects their ability to live independently, and the support they need to do this. The PIP application form is the first opportunity for people with MS to tell the DWP how their condition affects them.

However, we know from the experiences of people with MS that the design of the form does not allow them to explain how their fluctuating condition affects them. Confusion remains over who is responsible for gathering evidence from medical professionals, and people with MS still face difficulties obtaining good quality evidence within the allotted time.

The application form

The application form is the first opportunity for claimants to describe how their condition affects them. People with MS should be able to use the form to explain hidden symptoms and fluctuations in their condition, which are often difficult to assess. However, for many people with MS, the PIP application form is the first barrier to obtaining the right level of support.

In our survey of people affected by MS, nearly two thirds (65%) of respondents said completing the form was either hard or very hard. A further 5% reported not being able to complete the form.

A majority (61%) of those who reported the form to be hard or very hard to complete, said it was because the form was too long, and a fifth (21%) said they didn't understand the form. Long and complicated forms can be a barrier to people with MS who often have to deal with fatigue and cognitive issues.

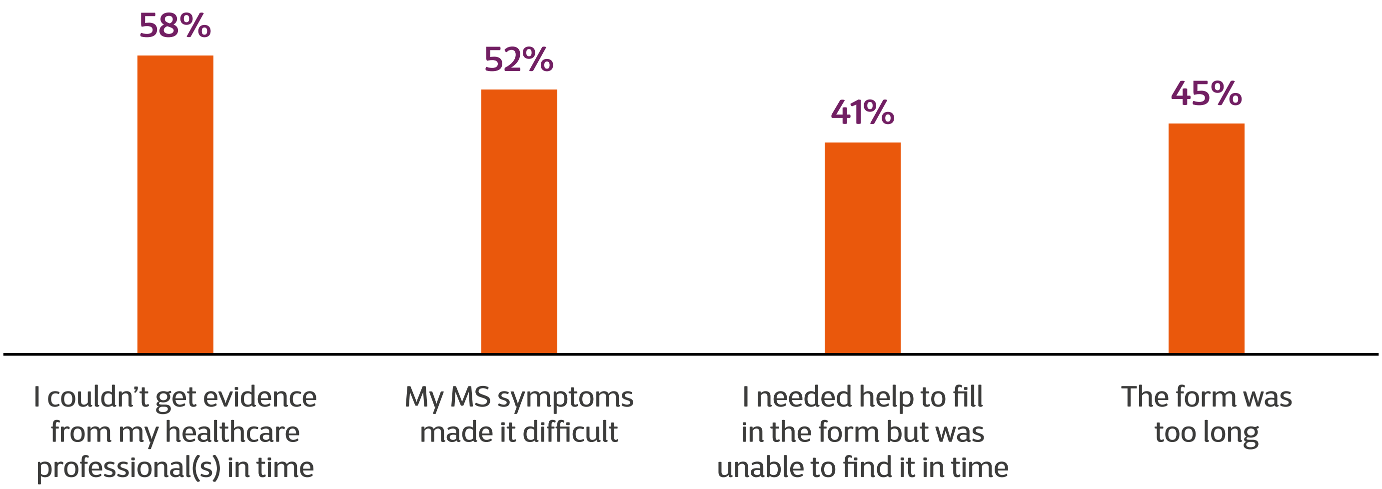
'I found it difficult to fill it out myself because of the tremor in my right hand (I'm right handed). It's also lengthy I find it hard to concentrate on it because of brain fog'

People with MS find that the form isn't designed in a way that enables them to explain how their condition affects them. Only 13% of people with MS said that the form allowed them to fully explain how their condition affects them and only 10% said it allowed them to fully explain how the symptoms of their MS fluctuate[vii].

'The form was not relevant for me and my condition. I found it very hard to make the answers relevant to me and needed help'

Not surprisingly, returning a complicated form within the four week deadline proves to be a challenge for many people with MS. Nearly a third (32%) said four weeks was not enough time to complete the form, with the reasons broken down in the graph below.

Why the four week deadline to submit the PIP form is not long enough



In the chart: main reasons (over 10%) given by respondents to the question 'If you said 4 weeks was not enough time to return the form, please tell us why (tick all that applies)'. 597 responses received.

'Some of the information required was difficult to get within the timescale. Some of the questions were not suitable for the random nature of MS'

It is worrying that of those who said four weeks was not enough time to complete the form, over half (59%) were unaware that it is possible to request a two week extension from the DWP. The majority of those who were unaware said they would have asked for one if they had known. Although the DWP allows for extensions beyond six weeks on a case by case basis, awareness of the possibility of extensions is very low, and therefore this option is underused.

It is clear that too many people with MS find completing the form a challenge, and that some are completely deterred from applying because of this. The form is too long and complex and does not provide sufficient opportunity to effectively illustrate how MS affects the person claiming.

▶ **Recommendation: The DWP, in consultation with disabled people and charities, should redesign the PIP application form, to ensure that it allows people with progressive and fluctuating conditions to fully explain how their condition affects them.**

▶ **Recommendation: The DWP should provide clear information with the PIP application form which tells claimants about the right to request an extension to the deadline, and the circumstances under which this should be granted.**

▶ **Recommendation: The DWP should extend the deadline to submit the PIP application form to eight weeks as standard to allow claimants to obtain evidence and the support they need to fill in the form.**

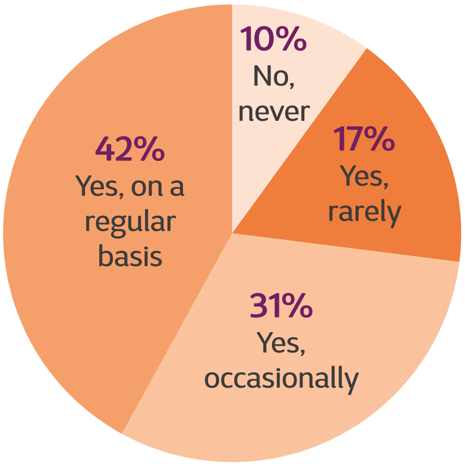
Many people are unaware of the assessment criteria and the way they are scored when completing the application form. While it's possible to find this information online, it is not provided to claimants by the DWP as a matter of course. However, 37% of survey respondents said that while they were not aware of this information, they would have liked to have this information when completing their application. This is a very similar figure to the number of people who were aware of the criteria and did use the available information to fill out the form (36%). This indicates that only half of the people we surveyed who want to know how they are being scored have this information. If all claimants were provided with information that explained the criteria and how they are scored, it would make it easier to fill out the form. It is also likely the information in the form would be better quality. This could lead to assessors being able to make more paper-based decisions, which in turn means fewer face-to-face assessments. It could also mean that recommendations made by assessors are more likely to be correct.

▶ **Recommendation: The DWP should provide the criteria and scoring system to all applicants with the PIP application form.**

Many people with MS seek help to fill in the long and complex PIP application form. Supporting information and practical help in filling out the form can mitigate some of these problems. Such support should be a Government responsibility but advice services have been cut across the country, and are difficult to access in many areas. In many cases charities step in to provide support instead: many respondents to the survey said they received help from sources such as the MS Society and Citizens Advice. But too many people are unable to find the support they need. 16% of respondents who reported finding the form hard or very hard to complete said they needed help to fill in the form but were unable to find any, while 18% said they didn't get enough information with the form to help them complete it.

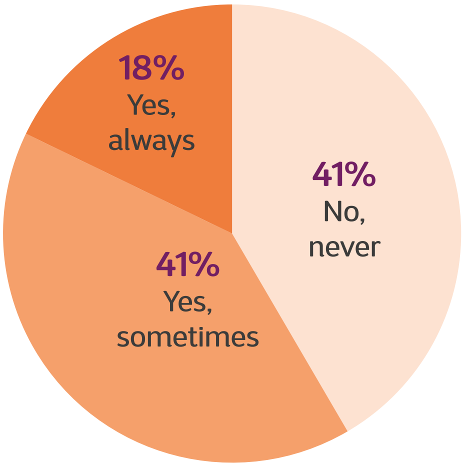
Many people with MS turn to their MS nurse for help in filling in the form. When we asked MS nurses about how they respond to the request, there is a clear contrast between the level of support requested by people with MS from their MS nurses and the level of support nurses are able to provide. This is illustrated in the charts below. This is not surprising, considering that a third of surveyed MS nurses reported this activity increases their workload by 'a lot', with the other two thirds saying it increases their workload 'a little' or 'a moderate amount' respectively. MS nurses are increasingly under strain due to high caseloads,

Do your patients ask you for help with filling in PIP Application Forms?



In the chart: 83 MS nurses responded to the question 'Do your patients ask you for help with filling in PIP application forms?'

If you said your patients ask for help with filling in PIP Application Forms, do you provide this help?



In the chart: MS nurses who said their patients ask them for help with filling in PIP application forms often above what is considered sustainable. The MS Trust estimates 64% of people living with MS in the UK - around 68,000 people – live in areas where there aren't enough MS nurses to provide care and support[viii].

It is clear that many people with MS find filling in the form difficult and stressful, and need help. This help often falls to charitable organisations and clinical staff who are already struggling with workloads. Without this help some people find it impossible to apply for the benefit, leaving them without financial support they are entitled to by law. Help to apply for benefits should be available to all disabled people.

▶ **Recommendation: The UK Government should ensure independent advice services are available to deliver help in filling in PIP application forms. Services should be available to all claimants in the UK free of charge and there should be clear signposting to this service in every communication from the DWP.**

'I feel I have to fit this into my workload as ultimately if you don't provide support for patients they may lose out on benefits they would qualify for. You want your patients not to have to go through the added stress of appealing and having to attend a tribunal. Also possibly losing their mobility component and having to return their cars.' – MS Specialist Nurse

'It was very long and I sourced help from MS society website, my GP, my MS team. Also a good friend helped me.'

'Was struggling so much, I had help from the Citizens Advice Bureau, otherwise I wouldn't have been able to complete, at all.'

'I didn't understand some of the questions so my MS nurse helped me fill out the form.'

Evidence gathering by claimants

The length and complexity of the application form are not the only barriers people with MS face when they apply for PIP. Gathering good quality evidence that demonstrates support needs and the impact that MS can have on their life can also be a challenge. 37% of respondents said obtaining evidence was difficult or very difficult. 51% of those who said it was difficult reported the reason as 'there was not enough time to obtain evidence from healthcare professional(s)'. Health services are often stretched and struggle to offer non-clinical support to patients, making it difficult to provide evidence within the four week deadline.

Of respondents who said that four weeks was not enough time to return the form, 59% said this was because they were unable to get evidence from healthcare professionals within the four weeks. This reason was given more than any other, higher even than the difficulties posed by MS symptoms to return the form on time (52%).

People with MS mainly ask their MS nurse for evidence for their PIP application (59%), followed by their GP (55%) and neurologist (50%). We asked MS nurses in our survey about their experience of providing evidence for PIP assessments.

7 in 10 MS nurses (69%) who responded to the survey said they always provide evidence for PIP applications when requested to do so by a patient. 26% said they sometimes provide evidence and 5% said they never do. This means that some people with MS will not be able to obtain evidence from their MS nurses to support their application[ix].

Of nurses who said that they sometimes or never provide evidence for patients claiming PIP, 37% said this is because they don't have time to do so. 43% said this is because they're unable to meet the deadline given to patients.

'I asked my MS Nurse, but she said they no longer provided evidence as it was too time consuming.'

‘I have increased my hours to be able to have more admin time. Despite this, I often work out of hours to provide evidence.’
– MS Specialist Nurse

MS nurses who do provide evidence agree with people with MS that four weeks to return the form is not long enough. When specifically asked how long it takes nurses to turn around a request for evidence for PIP applications, just over a quarter of nurses (26%) who responded to the survey said it takes three to four weeks. This demonstrates the difficulty for patients to submit their application and evidence within the four week deadline.

While claimants are encouraged to only send evidence they already hold, many people with MS want to send evidence from medical professionals who know them and how their condition affects them. Often people with MS do not have this type of evidence to hand. There is uncertainty about whether assessors will collect evidence from healthcare professionals, which means people with MS often provide it themselves to ensure their claim is backed up with as much evidence as possible.

Being asked to pay for this evidence makes it difficult to obtain it for some people with MS. Of respondents to the survey who said it was difficult or very difficult to obtain evidence, 19% said their GP wanted them to pay for evidence, 6% said their neurologist wanted them to pay for evidence, and 3% said their MS nurse wanted them to pay for evidence. The cost of paying for multiple letters of evidence can place a huge financial strain on disabled people who are in the process of applying for the vital financial support disability benefits provide.

Having the ability to pay should not determine who can and cannot submit evidence to support their claim, therefore all claimants’ expenses on medical evidence should be paid back.

▶ **Recommendation: The DWP should reimburse claimants for charges made by healthcare professionals for providing evidence for PIP claims.**

People with MS who claim PIP are not always aware that they can, in fact, provide evidence, and there is lack of clarity around how to do so for some.

Of respondents to the question ‘if you wanted to provide medical evidence for your claim, were you able to do this?’ nearly 1 in 10 (9%) reported that they didn’t know there was an option to do this. Of those who said that providing evidence was difficult, more than a third (35%) said they were unclear on who could provide evidence.

Of course, medical evidence isn’t the only type of evidence that can be submitted with the PIP claim form. Family, friends and carers can also submit evidence and this is an opportunity for those who know the claimants best to tell the DWP how MS affects the claimant on a day to day basis. Regrettably, nearly 3 in 10 (28%) said they didn’t know they were able to send this kind of evidence with their claim.

This lack of awareness of the ability to provide evidence with a PIP claim, as well as who can provide it, shows a clear failure in guidance for claimants and points to an urgent need for simplification and clarification of the process. This will allow people with MS to submit good quality evidence from various sources when they wish to do so.

▶ **Recommendation: The DWP should provide clear guidance to all claimants on the type of evidence they should provide, including evidence from informal sources such as friends, family and carers.**

Considering the strain it puts on healthcare professionals’ time, it is imperative that this time is used to provide evidence that is of high quality and that is relevant to PIP.

The majority of MS nurses report being confident (60%) or very confident (13%) in their understanding of what evidence is required to support a PIP application. Yet even the confident nurses who say they know what evidence they should provide also say they are unsure in some cases. A significant number (25%) say they are not very confident, and that they are unsure of what to include in their report even though they know how their patient's condition affects them.

When reporting difficulty in obtaining medical evidence to support their PIP claim, a quarter of people with MS who responded to our survey (25%) said this was because their healthcare professional(s) did not understand what evidence they needed to provide. That is not to say that healthcare professionals did not provide evidence, but it does suggest that whatever evidence was provided may not have been useful for this particular purpose.

This indicates that a large proportion of people with MS have difficulty obtaining good quality evidence, which can mean they are unable to access the right level of financial support from PIP. Healthcare professionals require clearer guidance on what is good evidence, to improve the quality of evidence they provide.

▶ **Recommendation: The DWP should provide clear guidance to healthcare professionals, including specialists such as MS nurses and neurologists, on what evidence they should provide to support PIP claims.**

▶ **Recommendation: The DWP should provide access to support for healthcare professionals who require assistance in filling in reports.**

Ben, 46

Ben lives in Bristol with his wife and two children. At age 20 Ben was diagnosed with relapsing remitting MS, but 15 years ago his diagnosis changed to secondary progressive MS. Ben uses a wheelchair outdoors, and is affected by poor balance, fatigue and issues with his sight. Because of this Ben needs help with everyday activities like showering.

Ben had a lifetime DLA award for the higher rate of mobility and low rate of care. But following a reassessment to PIP in 2018, Ben was told he's not eligible for mobility payments and had to return his Motability car.

'The assessor didn't have any specialist knowledge of MS. I don't think she understood the severity of my condition or how it affects my everyday life.'

'When I saw the assessment report, it made no reference to the evidence I sent from my GP or neurologist. It said I could cook for myself even though my wife and I told the assessor I can't cook at all'.

'The assessor came to my house. She didn't see me walk at all as I was sitting down and my wife opened the door to let her in. She didn't even see me stand. When she asked if I could walk to the end of the street, I said no."

'Because I could drive and go to work she assumed I could walk 50-200 metres, and decided I didn't qualify for high rate mobility'.

'I asked for a mandatory reconsideration and sent a letter from my neurologist saying he'd seen me struggle to walk 30 metres, but DWP took it to mean I could walk 20-50 metres, completely ignoring their own reliability criteria. They awarded me the standard rate for mobility and daily living'.

'I appealed and was awarded the higher rate for both components. The panel couldn't understand why I was given the lower rate before'.

'I'm so reliant on my car so the stress of losing it was immense and made my MS worse. The PIP process is broken, there's no trust. They don't believe what you tell them and assessments don't reflect reality'.

Evidence gathering by assessors

The PIP application form asks claimants to provide the contact details of the medical professionals charged with their care. The vast majority of survey respondents (88%) reported providing the details of at least one (and for most of those, more than one) healthcare professional.

However, people with MS have told us that they do not think that assessors are requesting evidence from the healthcare professionals whose details they provide. This is despite PIP assessment guidance stating that in cases of progressive or fluctuating conditions this should always be done.

► **Recommendation: The DWP should strengthen PIP assessment guidance on evidence collection to ensure that evidence is always requested by assessors when assessing claims by people with MS and other complex neurological conditions. Case Managers should return reports that do not comply with the guidance.**

When evidence is requested, we have heard from assessment providers that return rates are low. Given what we've been told by nurses, we can assume that this is partly linked to lack of time or lack of understanding of what should be provided. Return rates from specialists are even lower than they are for GPs, so it is essential that DWP and assessment providers work to significantly increase the return rate.

'I was led to believe that PIP would contact all the Health Care professionals that I listed to obtain info. They didn't contact anyone. It was never made clear that I should chase everyone myself and provide written evidence to help them'

The issue of responsibility for collection of evidence has been raised consistently by disabled people, charities and experts since PIP was introduced, but little has been done to improve the mechanism for evidence collection to ensure that it works well for claimants and healthcare professionals. As the DWP repeatedly claims that PIP appeals are won because new evidence is provided at tribunal, it is in the Department's interest to ensure that good quality evidence is obtained as early as possible in the claim process.

► **Recommendation: The DWP should introduce key performance indicators to assessment provider contracts, to ensure that evidence is always sought for claims by people with MS. Assessment providers' performance against the indicators should be published regularly.**

► **Recommendation: The DWP should work with assessment providers and healthcare professionals to achieve a significant increase in evidence return rates, including specialists. This could include changes to the way the DWP and assessment providers communicate with healthcare professionals, and allowing more time for healthcare professionals to provide the evidence. The DWP should continue working with healthcare bodies on ways to streamline evidence collection mechanisms.**

The face to face assessment

The majority of people with MS who are assessed are required to undergo a face to face assessment. This can take place at an assessment centre, or the claimant can request it to take place at home. 44% of people who responded had a face to face assessment at an assessment centre, and 47% had a face to face assessment at their home.

Assessments are conducted by assessors employed through external companies contracted by the DWP for this purpose. During the assessment, assessors should ask questions that help them understand how a person's condition or impairment affects their daily life and their ability to carry out activities. Assessors may also physically assess a claimant, for example by asking them to stand or bend, to assess mobility. The assessor who conducts the face to face assessment also reviews the evidence submitted by medical professionals, friends, family and carers.

Following the assessment, the assessors produce a report for the DWP, which details the claimant's responses to questions, any informal observations made and the medical evidence. It also includes the assessor's recommendation of the level and duration of award the claimant should receive. This report is not shared with claimants automatically, but can be sent to them on request. The final decision lies with Case Managers employed directly by the DWP who inform claimants of the outcome in a decision letter.

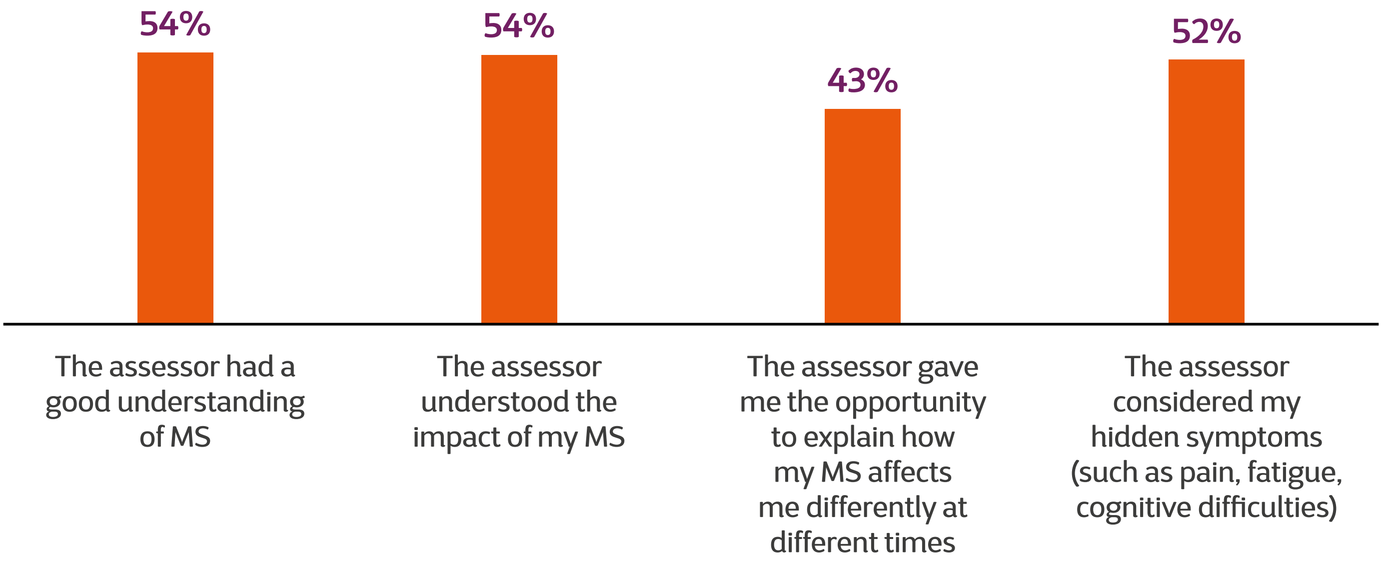
Assessors' knowledge of MS

MS is a complex neurological condition that affects people in different ways. As a fluctuating condition it also affects people differently at different times and symptoms can vary even during the course of one day. For example, a person with MS might be able to walk with the aid of a walking stick to the shop around the corner one day, but the following day won't be able to walk more than a few steps indoors.

Many of the symptoms of MS are hidden, for example fatigue, pain and cognition problems, and can be difficult to detect just by looking at the person. Assessors therefore require a good understanding of the condition in order to be able to accurately assess the impact it has on someone's day to day life.

Since PIP has been introduced, many people with MS have told us that their assessors do not have a good enough understanding of the condition. Without a good understanding of MS, assessors are unable to ask the right questions to help them understand the fluctuating nature of the condition, or how hidden symptoms affect the individual. The chart below illustrates the proportion of respondents to our survey who had a face to face assessment and disagreed that their assessor understood MS or allowed them to explain fluctuation and hidden symptoms.

The proportion of respondents who had a face to face assessment who **disagreed** with the following statments



The level of dissatisfaction with assessors' knowledge and understanding of the condition is mirrored in the level of dissatisfaction with the PIP decision – 54% of respondents to the survey disagreed with the initial decision on their PIP claim and the level of award they received (if any). This indicates that assessors' lack of knowledge of the condition is linked to incorrect decisions being made for a very large number of people with MS.

▶ **Recommendation: People with MS should only be assessed by assessors who have some professional experience of neurological conditions and have received training developed in conjunction with relevant charities.**

Opportunities to improve – learning from Northern Ireland

MS Society Northern Ireland designed and delivered training sessions for assessors and decision makers. Ten people affected by MS and two medical professionals led workshops on MS treatments, relapses, pain, fatigue, cognition, mobility, depression and anxiety for over 60 assessors and decision makers in Belfast this year. These training sessions were very well received. Assessors reported a better understanding of MS, its impact and symptoms as well as an increased ability in discussing these with people with MS. Importantly, people with MS were central to the development of the sessions themselves.

It is hoped that the training sessions in Northern Ireland will improve outcomes for people with MS, and will lead to further sessions in England and Wales.

The reliability criteria

A lack of understanding of MS means that too often assessors do not know how to obtain a full understanding of the effects of MS on the person they are assessing. This is especially relevant when it comes to assessing fluctuating and hidden symptoms.

According to PIP guidance, an assessor must consider whether claimants are able to carry out each activity safely, to an acceptable standard, repeatedly and in a reasonable time. This is known as the reliability criteria. But too often, people with MS say that assessors overlook the reliability criteria, and only assess the ability of a claimant to do an activity on the day they are assessed. Failing to apply the reliability criteria is one of the main reasons that 54% of people with MS disagree with the initial decisions about their PIP claim as shown below.

We asked people who saw the full report of their assessment whether they think it gave an accurate reflection of how their MS affects them. 61% answered with a resounding 'no' and 25% said it did, to some extent, meaning the report still had some inaccuracies or omissions. Only 12% said the report definitely gave an accurate reflection of how their MS affects them.

The main reasons people gave as to why the report was not an entirely accurate reflection were:

- It didn't take into account the effects of my fatigue (74%)
- It didn't reflect the way in which my MS fluctuates (73%)
- It didn't take into account the effect of my cognitive difficulties (60%)
- It didn't take into account the effects of my pain (57%).

These responses demonstrate that fluctuation and hidden symptoms are not accurately reflected in assessment reports.

The following responses demonstrate that the reliability criteria was not adequately considered in many cases:

- It didn't take into account how long it took me to do what I was observed doing (35%)
- It didn't reflect whether I could do this again (41%)
- It didn't reflect how well I did it (26%)
- It didn't reflect whether it was safe for me to do this in all circumstances (42%).

Although the reliability criteria is meant to apply to all activities, these responses show that the application of the criteria is inconsistent, and this leads to too many inaccurate decisions. It is therefore imperative that the assessors are instructed to consider the criteria for every activity they assess, and that DWP Case Managers only make decisions where this is the case. Any report where the reliability criteria is not applied as guided should be returned to the assessment provider for revision.

▶ **Recommendation: The DWP should amend the PIP assessment descriptors to embed the reliability criteria and its definitions within the wording of each descriptor.**

▶ **Recommendation: The DWP should carry out an evaluation of how the PIP assessment criteria consider hidden symptoms including pain, fatigue and cognitive symptoms.**

▶ **Recommendation: Assessors' reports must consider the reliability criteria for each descriptor, proactively setting out evidence for why they consider that each activity can be carried out safely, to an acceptable standard, repeatedly and in a reasonable time. Case Managers should return reports that do not comply to the assessment providers, and no decision should be taken without fully considering the reliability criteria.**

Paul, 50

Paul lives with his wife and son in Bangor, County Down. He was diagnosed with relapsing remitting MS in 1998. Ten years ago Paul started getting the higher rate DLA for mobility and care. This was around the time he had to stop working due to his MS symptoms that include fatigue, pain, and bladder and bowel problems. Paul is also affected by depression and anxiety.

In 2018 Paul was reassessed to PIP and the initial decision dropped his award to standard rate for mobility and daily living.

‘I found it extremely difficult to fill out the form because the questions weren’t appropriate for me. They didn’t take into consideration how MS symptoms fluctuate.’

‘It was difficult to provide supporting evidence because my GP only printed off my medical history but wasn’t willing to elaborate on it so there was just basic information. My MS nurse and neurologist were too busy to provide letters.’

‘At my home assessment the assessor told me she understood MS because her aunt has it. I explained how it’s not a simple condition and how everyone’s different, but I really don’t think she got it.’

‘The questions she asked didn’t allow me to properly explain how MS affects me. For example, when asked how far I can walk, some days I can walk quite a bit, other days I can’t even get out of bed. So how am I supposed to answer that?’

‘The decision letter said I could cook a meal with some help. But I’d told the assessor my mother in law cooks my meals as I can’t stand long enough to prepare a meal, and numbness in my hands means it’s too risky to use knives or the stove.’

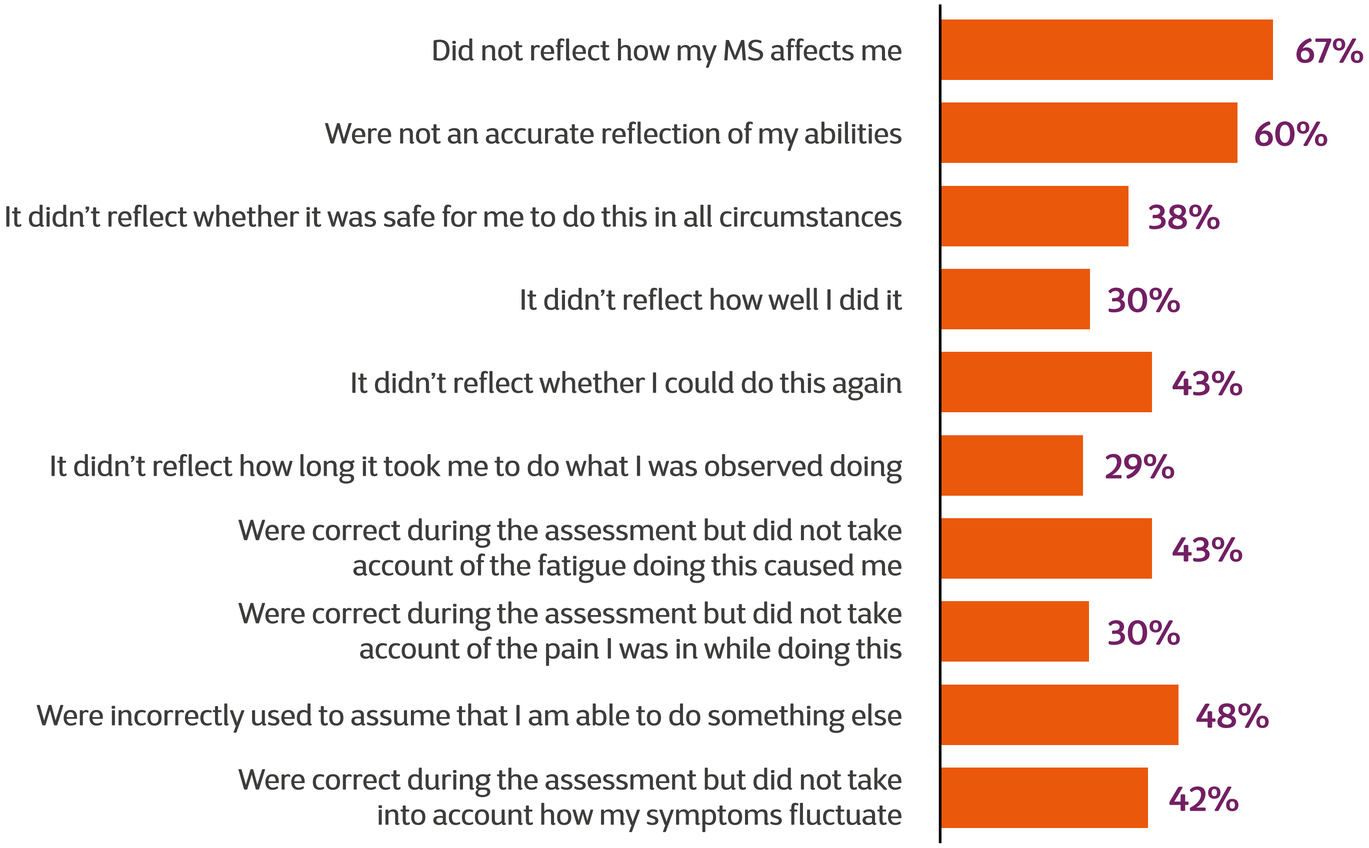
‘I asked for a mandatory reconsideration and submitted a letter outlining everything they got wrong. They then gave me high mobility but didn’t change the care part. Going through this affected me mentally and physically. I was already really struggling with my mental health so I didn’t have it in me to pursue it further.’

Informal observations

One way in which claimants are assessed during a face to face assessment is through informal observations. These are behaviours and actions that the assessor can see during the assessment, rather than answers to questions. Informal observations, by their nature, can only judge how a person does something on the day of the assessment, and while they form part of the assessment, they are not subject to the reliability criteria. Assessors are not required to consider fluctuation or hidden symptoms when informal observations are recorded in reports. The guidance is clear that informal observations should be balanced against evidence. Where there are inconsistencies between what is observed and what is provided as medical evidence, this must be explored by the assessor. People with MS often tell us that this is not their experience. Despite the guidance, the DWP still accepts reports where informal observations are not backed up by evidence.

Of respondents to our survey who have seen their full assessment report (n=354), 58% said it included informal observations. We asked those respondents how they felt about the informal observations in their report. The answers are shown in the table below. They indicate that a large number of people with MS think the informal observations included in their report do not reflect how their MS affects them, and do not take account of the fluctuating nature of the condition or of hidden symptoms. Responses also indicate that the reliability criteria has not been applied to the informal observations.

informal observations do not reflect the reality of MS



In the chart: responses to the question 'Do you feel informal observations included in the report... (tick all that applies)'.

‘Didn’t take into account time to get dressed and help required to do so when commenting on how I was dressed’

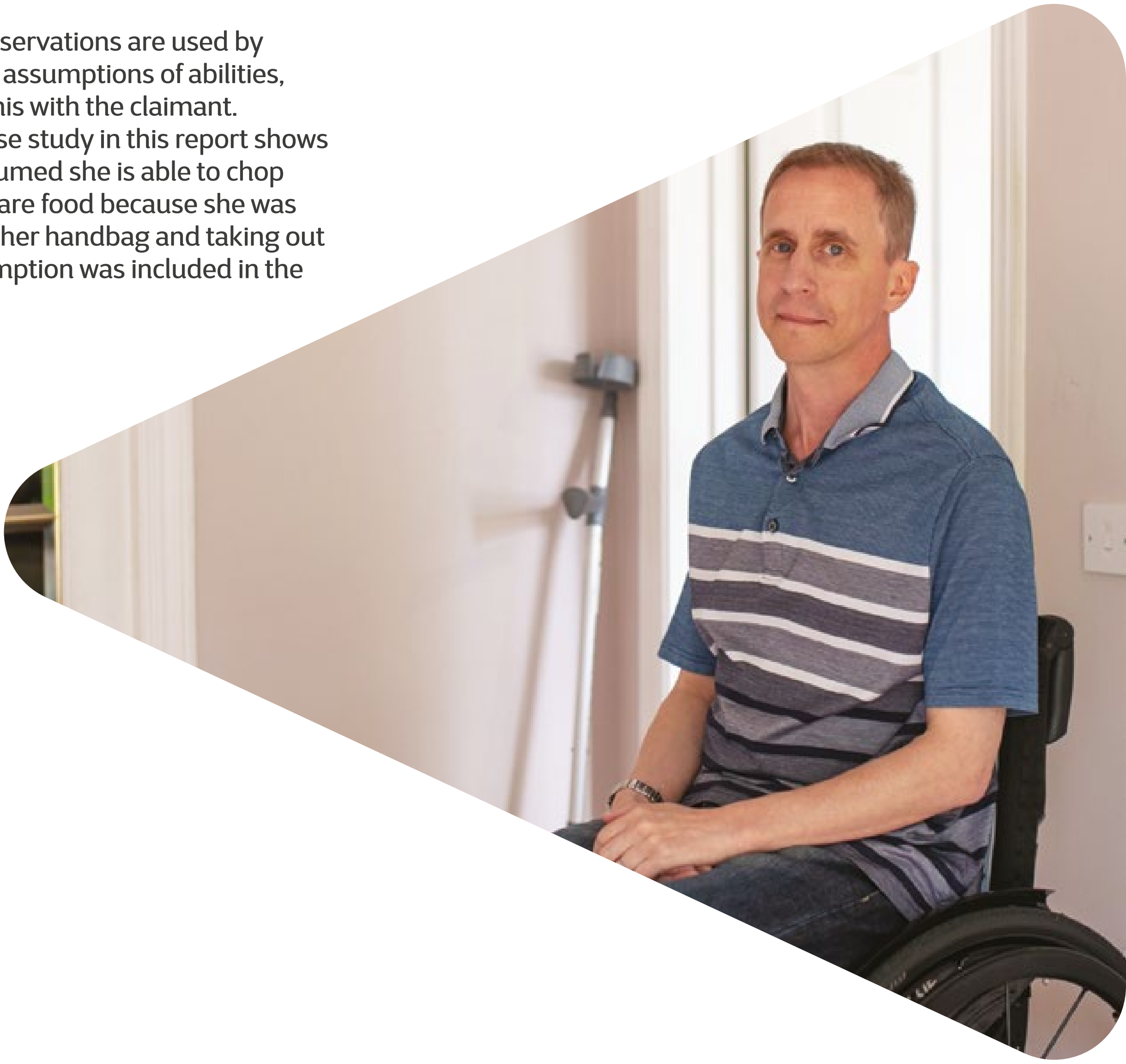
‘I felt so fatigued and in pain even though my appointment was 9am. I told the assessor this but in his report he said I didn’t look tired and looked well it was not how I felt.’

The inclusion of informal observations for people with MS when assessing and deciding their eligibility for PIP doesn’t work. The condition fluctuates and includes many hidden symptoms, which cannot be captured by observations alone. While informal observations can be a useful tool in some cases, they should not be used to make assumptions of abilities over time and against contradicting evidence.

One way informal observations are used by assessors is to make assumptions of abilities, without discussing this with the claimant.
For example, Liz’s case study in this report shows how an assessor assumed she is able to chop vegetables and prepare food because she was observed picking up her handbag and taking out her purse. This assumption was included in the assessment report despite the fact that during the assessment Liz’s husband explained that he does all the cooking, as Liz’s cognition problems mean she either burns the food or harms herself using sharp knives.

▶ Recommendation: All informal observations included in the assessment report must be backed up by evidence. Where this is not the case or when the assessor has chosen to ‘overrule’ evidence from healthcare professionals and the claimant, the assessor must explain this clearly in the report. Case Managers should return reports that contain unsubstantiated informal observations.

▶ Recommendation: Guidance should be changed to say that the reliability criteria should be applied to informal observations, and training and quality assurance should enforce this.



Liz, 65

Liz lives in Staffordshire with her husband. She was diagnosed with relapsing remitting MS in 1998. Fatigue affects everything Liz does, like cleaning, gardening and socialising. Sensory problems also affect Liz's day to day, as she drops things because she loses her grip.

Liz had a lifetime DLA award since being diagnosed, for the higher rate for care and mobility. This allowed her to have a Motability car. In 2015 Liz was reassessed to PIP, and her award for daily living was reduced to standard.

'I found the form very difficult to fill in and it took me weeks. I used to be a welfare officer for the MS Society, helping other people fill in DLA forms so I didn't think it would be that hard. I found it difficult to get my condition to fit into the criteria.'

'I asked the assessor what qualifications he had, and he told me he was a physio. I asked him what he knew about MS, but he just said that he had a friend who was an MS physio. There should be an MS specialist in some way or another. So much is lost because people don't understand the invisible symptoms and have no insight of how MS affects you.'

'In my report the assessor wrote that I "picked up a medium sized handbag and retrieved a purse" which meant I could cut up vegetables and prepare food. I haven't cooked for five years. My husband told him that he did all the cooking because due to my poor cognition I either burnt the food or harmed myself using sharp knives.'

'The assessor wrote that I was well-nourished, well-dressed, clean and of good appearance. Again, what has this got to do with my MS. If I'd been assessed at home I would have been in my comfy clothes. I'm not going to go to an interview in my pyjamas!'

'I didn't ask for a mandatory reconsideration because I was too scared of losing my car. I've had to cut back on things that helped me, my cleaner, and my gardener.'

'Calling it Personal Independence Payment is ridiculous. They're not helping you to be independent. If you go to your assessment showing you're 'independent' it goes against you. But you are only independent because of the support you're receiving and because you've found your way of coping. It makes no sense.'

Assessment recording

Currently the PIP guidance stipulates that PIP assessments can only be audio recorded if the claimant brings their own equipment. The equipment must be a recording device that is able to produce two identical copies of the recording at the end of the assessment, either on audio cassette or CD. Such recording equipment is expensive and readily available to only a handful of claimants.

The DWP has recognised that trust in PIP assessments is very low. One of the ways the Department is trying to build this trust is by looking at ways to record the assessment. The DWP and assessment provider Capita are currently running a pilot to see whether PIP assessments should be recorded by video, with equipment provided by the assessment provider rather than the claimant.

In responding to the survey, a number of people commented that their report contained inaccuracies, including mentions of things they did not say or do. Recording assessments is one way of ensuring that the report reflects the assessment accurately, as long as a copy is provided to the claimant at the end of the assessment.

'The assessor basically lied on certain points. For example my wife is my carer, due to poor memory I was constantly referring to her for answers. The assessor said she was there but took no part!'

'She quoted things my husband said as if I had said them. For example, she asked who walks my dogs and my husband said he did, however the assessment report stated that I said I walk them even though I am unable to.'

'Most of it was made up - Hans Christian Andersen would have been proud of its fantasy aspect!'

'It didn't reflect how poorly I was at the home assessment. In fact I would say there were lies in the assessment, for example she said I stood up to shake her hand but I physically couldn't on that day.'

Although just 1% of respondents to the survey had their PIP assessment recorded so far, 84% would be happy to have their PIP assessments audio recorded in future, and 66% would be happy with video recording.

While some people are unsure of the benefit of recording, or may be intimidated by video recording, the majority of respondents think this will be beneficial to their claim. One stipulation however came up a number of times – that the claimant gets a copy of the recording as well.

More people are comfortable with being audio recorded than video recorded. Notably many people with MS will not want to be recorded at all[x], and therefore recordings must be optional, and those who do not take this up must not be penalised. The MS Society believes that audio recordings are a much simpler solution than video recordings but that both must be available as an option should the DWP proceed with rolling out video recordings following the pilot. In the case where the DWP decides not to roll out video recordings for PIP, the DWP must improve access to audio recordings to all claimants.

▶ **Recommendation: The DWP should ensure both audio and video recordings of PIP assessments are provided as an option to claimants.**

▶ **Recommendation: Assessors should ensure a copy of the audio or video recording is provided to the claimant at the end of the assessment.**

Decision making

Once an assessment has taken place, the assessor sends a report on to the DWP Case Manager. This person reviews the report, the recommendations within it, and the evidence. From this information they decide what level and duration of award the claimant will receive. Unfortunately, over half (54%) of the respondents to the survey who have had a decision on their PIP claim said they disagreed with the initial decision. This points to a widespread failure of assessors and Case Managers in reaching decisions that make sense for people with MS. We know from the previous chapters that problems with evidence collection and the assessment itself are likely to play a significant part in these inaccurate decisions.

It's not just the decisions themselves that are a problem. The way they are communicated to claimants means that many people do not fully understand how a decision has been made. Without this knowledge, many people with MS cannot effectively challenge decisions they believe to be wrong.

The assessment report and decision letter

Once a decision has been made about whether to award PIP and at which level, the claimant is sent the outcome in a decision letter. This breaks down the number of points awarded for each activity and how the assessor decided this. But the decision letter doesn't specify what happened at the assessment, or the evidence that was used to come to the decision. Informal observations made at the assessment are also not included in this letter.

In fact, 45% of respondents who had received a PIP decision said they do not think they were given enough information with the decision letter to explain how the decision was made. Of respondents who said they disagreed with their initial decision, only 25% said they received enough information in the decision letter to understand this outcome.

In stark contrast to our findings, the DWP's Claimant Service and Experience Survey for 2017/18 indicates that 91% of PIP claimants reported that the decision about their benefit was clearly explained[xi]. One possible explanation for this difference is that the DWP survey only measures the satisfaction of PIP claimants, and not those who have been unsuccessful in their claim.

To understand more about how the decision was made, claimants can request to see a copy of their assessment report. This is the report prepared by the assessor, and is designed to provide all the information to the DWP Case Manager in order for them to make a decision. The report details what was said at the assessment, what the assessor observed and what they think this means, and details of any evidence used. In the report, the assessor also makes recommendations to the Case Manager as to the support needs and corresponding level and length of award they think the claimant should get.

Although the decision letter mentions that it is possible to ask the DWP for more information around the decision, it is not entirely clear what the process is around this. While 46% of respondents have seen a copy of their report, 39% said they had not but would liked to have seen it. This indicates that 4 in 10 people are either unaware they can request it, are unclear about how to, or what the benefit of seeing their report might be.
Without full sight of the report it may be difficult for people with MS to decide whether the decision they receive is correct, and whether or how they should challenge the decision. Sending a copy of the report to all claimants following the assessment will increase transparency in the process and will give people with MS more tools to understand the decision they get.

It is important to note that by the DWP's own assessment quality indicators, too many assessment reports do not reach the required quality agreed by contract. The DWP stipulates in agreement with IAS and Capita (the two companies contracted to carry out assessments in the UK) that no more than 3% of reports they submit to the Department should be deemed unacceptable. According to information shared in 2018 by the then Minister for Disabled People Sarah Newton with the Work and Pensions Committee, neither company has met this target to that date[xii].

Even what is deemed acceptable by the DWP allows for errors and omissions in reports. As stated by the Work and Pensions Committee, the Department's quality standards for PIP set a low bar for what is considered an acceptable standard[xiii]. Acceptable reports to the DWP include reports that are flawed, with incomplete use of evidence and where it's clear the assessor requires learning, as well as reports that need amendments as they contain more serious errors but not ones that are deemed to affect the decision. The only unacceptable reports are those where a Case Manager would not be able to use to make a decision or it will cause them to make the wrong decision.

It is clear that too many assessment reports are of insufficient quality. While they are written by employees of the assessment providers, the responsibility for ensuring that assessments reports are of an acceptable standard lies with the DWP. It is imperative that Case Managers at the DWP, and the claimants, receive accurate reports that allow for correct decision making.

▶ Recommendation: The DWP should automatically send the assessment report to every PIP claimant along with their decision letter.

▶ Recommendation: The DWP should put in place stricter quality assurance measures to ensure that assessment reports are consistently of good quality. Data related to quality of reports should be available publicly on a regular basis.

▶ Recommendation: The DWP should expand the Claimant Service and Experience Survey to include unsuccessful PIP claimants.

Deborah, 54

Deborah lives in Nottingham with her husband, and has twin boys aged 21. She was diagnosed with relapsing remitting MS in 2002, and with secondary progressive MS in 2016. Deborah's symptoms fluctuate, and include fatigue, pins and needles and numbness. She uses a walking stick and wheelchair, and her husband helps with dressing and cooking.

Around 12 years ago, Deborah started getting the high rate mobility and standard rate care on DLA. She was reassessed for PIP in 2018 and lost her mobility award.

'Filling out the form was depressing and exhausting. I don't think it allowed me to express how my MS affects me. I wasn't able to say whether I can always do something. It's far too black and white and MS isn't.'

'My assessor was a nurse, not an MS specialist. I didn't think she completely understood MS. She might not see many people with MS, and they'll all have different symptoms.'

'I counted at least 10 discrepancies in the decision letter. For example, saying I do all the food shopping and cooking, which I don't. Saying that I can bathe myself, when I can't.'

'I disagreed with the decision so I asked for a copy of the report. Again, it was inaccurate. I went in my wheelchair to the assessment, yet she wrote that I walked fine. She also said that I retrieved documents from a plastic wallet, which meant I didn't have problems with my grip. How does this one action show my grip is OK? I drop things all the time, my husband has to cut up my food for me.'

'I asked for a mandatory reconsideration. I sent two letters in addition to the eleven I sent initially. After four months I was given the higher rate of both mobility and daily living until retirement age'

'It's an awful, terrible system. The crazy thing is that you're doing this because you're not well and it just makes you feel worse.'

Signposting to mandatory reconsideration

Although 54% of respondents did not agree with the decision they received on their PIP claim, only 63% of those who disagreed requested a mandatory reconsideration of the decision. One in 10 of those who disagreed with the decision were unaware that they are able to request a mandatory reconsideration, and a further 25% reported that they did not ask for a mandatory reconsideration.

The reasons people with MS do not request a mandatory reconsideration are varied. Lack of information around the process seems to be a substantial contributor to the relatively low levels of people asking for a review of the decision. When we asked all those who had received a decision on their PIP claim if they think they were provided with clear information about the right to a mandatory reconsideration and how to go about it, only 42% answered positively, 34% answered no, and 24% were unsure.

Anecdotal evidence suggests that the stress of the process, which can negatively impact MS, as well as fear of receiving an even lower award can contribute to the low levels of requests for mandatory reconsideration. Lack of trust in the assessment process has also been mentioned by some people with MS as a reason not to challenge the decision.

'I was on high rate mobility on DLA, I now get standard for PIP, therefore lost my car. I didn't ask for reconsideration as scared I may lose what I had and also the process made me relapse with the stress'

'The process is immensely stressful and made my MS symptoms worse and caused me tremendous depression and anxiety, affecting my days and making me unable to sleep. Assessment contained many inaccuracies. To keep going through this time and again and applying for reconsideration and appeals is stressful and costing far more than granting the correct help in the first place'

The deadline to request a mandatory reconsideration is within a month of receiving the decision letter. For people with MS this deadline may be too restrictive, especially if going through a relapse at the time. Symptoms such as pain, fatigue and cognitive difficulties can also make it difficult to challenge the decision within this timeframe.

▶ **Recommendation: The DWP should ensure decision letters provide clear sign-posting to mandatory reconsideration and how to go about it.**

▶ **Recommendation: The DWP should extend the deadline for mandatory reconsideration to eight weeks, with further extensions considered due to ill health and on a case by case basis.**

The process of mandatory reconsideration

The process of mandatory reconsideration is stressful and difficult for many people with MS. A lack of information about the process means many people are unaware of how to effectively challenge the decision through this mechanism.

Of respondents to the survey who requested a mandatory reconsideration (n=239), 49% said it resulted in no change and 30% said they received a higher award[xiv]. However, even when a reconsideration is successful, it does not always result in a correct award. 40% of respondents who requested a reconsideration and subsequently received a higher award still went on to challenge the decision at an independent tribunal and either won their case in court or had their award increased again by the DWP prior to their hearing.

As mentioned above, a third of respondents did not think they were given enough information about how to request a mandatory reconsideration. Challenging a decision is also difficult for those claimants who have not seen a copy of their assessment report. The information in the report indicates why the Case Manager came to the conclusion they did. Without this, the claimant is unable to highlight issues with the assessment to request a mandatory reconsideration.

‘I had to pay a company to fill in all my forms and do mandatory reconsideration for me. If it had not been for them I would not have been awarded anything. They made sure I knew what and how they were going to do for me’

All people with MS should be given the opportunity to discuss their decision with their Case Manager when requesting a reconsideration. This gives the claimant the opportunity to provide the relevant information relating to the activities they believe have been scored on incorrectly. It also means Case Managers are able to ask claimants to expand on answers given during the assessment. As the DWP claims that decisions are overturned at tribunal due to new evidence, this is a chance for the DWP to ensure that all relevant evidence is collected and considered before going to court. Following a recent pilot, this process is being rolled out to all PIP mandatory reconsiderations. It is important that the lessons learnt from the pilot are applied during the roll out, and outcomes are monitored to ensure that the process works for people with MS.

▶ **Recommendation: DWP Case Managers should contact claimants prior to making a decision on mandatory reconsideration, to discuss the case and obtain further evidence if necessary.**

▶ **Recommendation: The UK Government should ensure that independent advice is available at the Mandatory Reconsideration stage as well.**

Signposting to appeals

A mandatory reconsideration is the first step in appealing a decision. People with MS who believe the reconsideration decision is still incorrect can ask to have their case heard at an independent tribunal. PIP tribunals are generally made up of a three person panel – a judge, a doctor and a disability expert.

Unlike the low levels of successful mandatory reconsiderations[xv], people with MS see high levels of successful appeals. Of respondents who have had a mandatory reconsideration decision (n=203), 53% have appealed and 7% plan to appeal.

Of those who have appealed and had a decision (n=87), 50% received a higher award at tribunal and 10% have had their award changed by the DWP before their tribunal date. 19% are still waiting for an appeal or the appeal decision. Only 15% of respondents who appealed have said following their appeal their award was unchanged and 7% said their award was reduced.

Data obtained from the DWP points to even higher levels of successful appeals for people with MS than is indicated from our survey. Analysis by the MS Society in 2018 revealed that 83% of people with MS who appeal their PIP decision after moving from the old benefit DLA go on to win their case at tribunal[xvi]. At the time the data was released, this meant a success rate 12% higher than the general overturn rate for PIP[xvii].

Survey responses indicate that similarly to mandatory reconsideration, the vast majority of people with MS are aware of the option to appeal. However, 49% of respondents who disagreed with their decision said they did not think they were provided with clear information about the right to appeal and how to go about it. This suggests there is a shortage of information relating to the appeal process.

Relatively low rates of appeal cited by the DWP[xviii] may be explained in part by the lack of readily available information from the DWP about the appeals process. The DWP should signpost all mandatory reconsideration decisions to information about appealing a PIP decision, as well as national and local advice services that can help with the process. This would help ensure that every person with MS has access to an independent tribunal and the right level of award.

Information is essential, but people with MS also tell us that the stress of the process and the fear of losing their award deters some of them from appealing. With expert advice and support, more people with MS may be able to challenge their PIP decision in court.

▶ **Recommendation: The DWP should ensure clearer information about the appeals process is proactively offered to claimants when providing the outcome of a mandatory review.**

Accountability and transparency of PIP

The DWP uses a number of ways to assess how well it is doing and what claimants can expect when engaging with the Department. The Department's Customer Charter[xix] provides a standard against which customer service delivery can be measured. The DWP say that the Charter provides an effective framework to drive improvements to engagement, interaction and satisfaction for both claimants and staff.

The Claimant Service and Experience Survey (CSES) is designed to monitor claimant satisfaction across ten benefits including PIP. It uses the four areas of the Customer Charter to frame the survey.

The DWP also have a 'Single Departmental Plan' which contains a list of objectives and how it aims to achieve them. However it does not contain any targets, timeframes or specific commitments.

However, a number of public bodies argue that the Department's measures for ensuring transparency and accountability are insufficient and must be improved.

In the Equality and Human Rights Commission's evidence to the Work and Pensions Select Committee inquiry on the welfare safety net, it concluded that the Department's existing methods of monitoring and standards are inadequate and not fit for purpose[xx]. This includes the Single Departmental Plan, the Customer Charter and the Claimant Service and Experience Survey.

In a recent report, the Work and Pensions select committee recommended that the Department work with stakeholders and delivery partners, including Citizens Advice, to establish suitable performance measures for delivery of working-age benefits. The measures should be published and accompanied by clear targets, and monitored initially by an internal review body and external advisory board. The committee also recommended that alongside this, the Department scopes whether there is a case for establishing an independent regulator for working age benefits and services. These recommendations are echoed by the National Audit Office and the Social Security Advisory Committee[xxi].

As our report shows, many people with MS do not receive the level of service they can expect from the DWP and its PIP contractors. The quality bar set by the DWP in relation to PIP assessments is very low, allowing for low quality reports in the decision making process. Changes to the levels of quality and the way it is measured are essential if the DWP is to increase trust in its functions and improve the quality of PIP assessments for people with MS.

▶ **Recommendation: The DWP should review and establish suitable performance measures and targets for disability benefits, including PIP. These should be published regularly.**

Recent recommendations from the National Audit Office, the Social Security Advisory Committee and the Work and Pensions Select Committee amongst others have all repeatedly called for measurable standards of service and to define what good is, so the DWP know if they are delivering a good service. They see no reason why the DWP can't maintain flexibility within 'targets' in the same way other public services are measured and monitored.

▶ **Recommendation: Assessment providers' performance metrics should be monitored by an external independent body that also has responsibility for direct observations of assessments, with a role analogous to that of the Care Quality Commission for the health and care system.**

Ashley, 28

Ashley lives in Leeds with her partner and two dogs. She was diagnosed in 2016 with relapsing remitting MS, just as she was training to become a veterinary nurse.

Ashley has reduced sensation and pain in her left leg. She is also affected by fatigue, vision problems and numbness in her left arm. This affects how much she can do at home, and she has had to reduce her working hours. In 2017, Ashley was awarded the standard daily living rate and nothing for mobility. She was reassessed for PIP again in 2019.

‘The form was difficult and so long. You don’t really get any guidelines or advice on how to fill it in.’

‘I got quite confused, flustered and stressed at the assessment. When I got the report it was full of contradictions.’

‘Because the assessment was up a flight of stairs, I was asked if I needed to use the lift. I said no, but I was holding on to the rail. My report said that I was observed walking with no difficulties and a normal gait. But the assessor walked in front of me and didn’t observe me walking. And I definitely don’t have a normal gait.’

‘When I was talking about one day being able to walk the dogs far, but today for example I couldn’t, the report only mentioned the times I could. It was the same with cooking, some days it would be dangerous for me to cook. Nothing was mentioned about fluctuations in the report.’

‘I got the same award as I did in 2017, but I thought I should have got more as my mobility got worse. I thought about appealing but I was afraid of losing the award altogether. I felt stressed about having to go through it all again and justifying my illness, when I just don’t feel supported by the system at all.’
‘To have someone judging you for a chronic illness is terrible. You don’t want to prove you have MS but you have to prove how badly it affects you, it is not easy.’

Conclusion

Since the introduction of PIP in 2013, people with MS have been telling us how difficult they find the process of applying for PIP, from start to finish. Not much has changed for people with MS since we published our MS: Enough report in 2015.

PIP provides vital support to people with MS, and helps pay for things such as adapted cars and help around the home, or for therapies that help manage the condition and symptoms. But too many people with MS are denied the right level of support, because of an application and assessment process that does not work for people with a fluctuating condition such as MS.

The first hurdle is the PIP application form, which is too long and still doesn't allow people with MS to explain how their condition affects them. Additionally, there is confusion around evidence and who should obtain it. For those who want to get evidence themselves, a tight deadline can make it difficult or impossible. Healthcare professionals who want to support their patients sometimes have to work out of hours to provide evidence, or even to help out with filling in the complicated form. No wonder 65% of respondents to our survey found it difficult or very difficult to complete the form, and 5% said they couldn't complete it at all.

For those who manage to send the form in, the next stage of the process is usually a face to face assessment. Assessor's lack of knowledge of the condition mean that they are too often not able to get the necessary information during the assessment. 55% of respondents who had a face to face assessment said they didn't think their assessor had a good understanding of MS. If assessors don't understand the condition, they are unlikely to be able to apply the reliability criteria appropriately or accurately assess hidden symptoms.

Too often, PIP assessors make inaccurate decisions based on 'informal observations' – the way people look or act during their assessment. 67% of people with MS whose assessment included these said they didn't reflect how MS affects them.

All this leads to too many incorrect decisions. People with MS are going through exhausting, demoralising and unnecessary appeals – where 83% of those moving from DLA to PIP win their appeal.

It's important that correct decisions are made the first time around, but when this isn't the case, it is vital that people with MS have clear information on how a decision was made. Without clear information, they may not be able to decide whether to appeal and how to go about it. It should be up to the DWP to ensure that people have enough information and support to understand their decisions, and how to challenge them through mandatory reconsideration and in the courts. At the moment this is not the case for too many people with MS.

We have been telling the UK Government that PIP doesn't work for too many people with MS since it was introduced. It is time for the UK Government to take action to ensure that PIP makes sense for people with MS.

References

[i] Extra Costs Commission – Driving down the extra costs disabled people face: final report, June 2015

[ii] For more information on Social Security Scotland visit https://www.socialsecurity.gov.scot/

[iii] MS Society – MS Enough: Make welfare make sense, 2015

[iv] According to PIP guidance, an assessor must consider whether claimants are able to carry out each activity safely, to an acceptable standard, repeatedly and in a reasonable time

[v] DWP data on DLA to PIP reassessment outcomes indicates that 23% of people with MS who were reassessed from DLA to PIP have seen their award reduced, with a further 9% who lost their award altogether prior to having an assessment. See: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/766240/pip-dla-to-pip-reassessment-outcomes-october-2018.xls. We calculated the rate of loss for new claims by comparing the rate of different awards for new claims under DLA (before PIP roll-out began) to the rates for new claims under PIP. Overall, this analysis shows that 24.3% of people with MS have lost out either via reassessment or a less generous award for a new claim. This is likely to be a significant underestimate as it does not include people who were entirely unsuccessful in a new PIP claim (as there are no public statistics regarding the comparable rate under DLA). Hence we use "at least one in four" as our overall assessment.

[vi] Department for Work and Pensions – PIP Assessment Guide Part One – The Assessment Process, 2019, pp.14

[vii] Of those who responded more positively to this question, 34% of respondents said they do not think the form allowed them to explain how their MS affects them, and 53% said it allowed it 'to some extent'. Nearly two thirds (64%) said they do not think the form allowed them to explain how the symptoms of their MS fluctuate, and a quarter (26%) said the form allowed this 'to some extent'.

[viii] https://www.mstrust.org.uk/a-z/ms-specialist-nurses

[ix] In our survey of people with MS 13% of respondents who wanted to get evidence said they were not able to obtain it

[x] 9% of respondents said they would not be happy to have their PIP assessments audio recorded in future, and 25% said they would not be happy with video recording.

[xi] Department for Work and Pensions – Claimant Service and Experience Survey, 2019

[xii] Department for Work and Pensions – written evidence to the Work and Pensions Select Committee, PEA0449, 2018

[xiii] Work and Pensions Committee – Welfare safety net: twenty-eighth report of session 2017-19, July 2019

[xiv] Only 5% of respondents who requested a mandatory reconsideration said it resulted in a lower award, and 15% are still waiting for the outcome.

[xv] According to DWP official PIP statistics, 20% of mandatory reconsiderations result in a change of award.

[xvi] Upon request from the MS Society, the DWP provided the Society with more recent data on appeals. This data is not used in this report as it showed significant discrepancies with data provided previously relating to the same time period, so clarification was needed with the DWP.

[xvii] MS Society – People with MS win 83% of PIP appeals – as UK Government wastes almost £1 million trying to stop them, December 2018 (online)

[xviii] Response to Parliamentary Question 180081 in October 2018 indicates that between 2013 and 2017, 8.5% of PIP decisions for people with MS were appealed. This is similar to the general PIP appeal rate of around 9%.

[xix] DWP – Customer Charter, 2014

[xx] Work and Pensions Committee – Welfare safety net: Twenty-eighth report of session 2017-2019

[xxxi] Ibid.

We're the MS Society.

Our community is here for you through
the highs, lows and everything in between.
We understand what life's like with MS.
Together, we are strong enough to stop MS.

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