

## **Action for M.E. submission to the Work and Pensions Committee inquiry into Personal Independence Payment**

Action for M.E. is the UK's leading charity for people affected by Myalgic Encephalomyelitis (M.E.) M.E. is a long-term, fluctuating, neurological condition that causes symptoms affecting many body systems, more commonly the nervous and immune systems. M.E. affects an estimated 250,000 people in the UK, as well as impacting on their family members, and professionals and others who support them.

People with M.E. experience severe, persistent fatigue associated with post-exertional malaise, the body's inability to recover after expending even small amounts of energy, leading to a flare-up in symptoms including chronic pain.

The National Institute for Health and Care Excellence (NICE) acknowledges that the physical symptoms of M.E. can be as disabling as multiple sclerosis, systemic lupus erythematosus, rheumatoid arthritis, congestive heart failure and other chronic conditions. Other research shows that people with M.E. score lower overall on health-related quality of life tests than most other chronic conditions.<sup>1</sup>

Around a quarter of people with M.E. are so severely affected that they are unable to do any activity for themselves, or can carry out minimal daily tasks only (such as face washing, cleaning teeth). They have severe cognitive difficulties and depend on a wheelchair for mobility. They are often unable to leave the house, or have a severe and prolonged after-effect if they do so. They may also spend most of their time in bed, and are often extremely sensitive to light and noise.

Our evidence to this inquiry is based on:

- Our 2016 survey on Personal Independence Payment (PIP), which was completed by more than 300 people with M.E.
- A number of people with M.E. who contacted us to share their experience of applying for PIP in detail in order to inform our inquiry response
- The experiences of people affected by M.E. who engage with our information and support services, including our Welfare Advice and Support Service; our ongoing consultations and surveys; our social media platforms; and our peer-support forum, M.E. Friends Online.

### **1. Which aspects of the current assessment process for PIP are and are not conducive to accurate decision-making? What improvements could be made?**

One of the main reasons people with M.E. are frequently inaccurately assessed is due to the failure of the assessment process in capturing how fluctuating and neurological conditions affect a claimant.

Government guidance for the PIP assessment outlines how fluctuating conditions ought to be taken into account,<sup>2</sup> detailing that the assessor ought to consider the functionality of the claimant most of the time. Section 3.3.30 of the guideline states that

*“Consideration should also be given to whether an individual is able to repeat a task on subsequent days[...] an individual may be able to fulfil the ‘Moving around’ criteria*

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<sup>1</sup> Hvidberg et al (2015), *The Health-Related Quality of Life for Patients with Myalgic Encephalomyelitis*, <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0132421>

<sup>2</sup>Department for Work & Pensions, *PIP Assessment Guide*, [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/547146/pip-assessment-guide.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/547146/pip-assessment-guide.pdf)

*one day, but the exertion of doing so means they are unable to do so the following day.”*

However, this is not the experience of people with M.E. who have applied for PIP. One person with M.E. who was claiming for PIP has told us how they described to the assessor getting a coffee with a friend. This person detailed how they were able to go for this coffee, but had subsequently needed to rest for a couple of days following the exertion this simple social activity required. In the assessment report, this description had been used to justify the assessor’s decision to mark the claimant as ‘capable of socialising’, without any reference to how this activity was detrimental to their functionality for the following 48 hours. The structure of the assessment means that each activity is considered in isolation. For people with M.E., the cumulative impact of the exertion of energy over time means that this is not an effective way of assessing capability.

This is indicative of the experience of many people we hear from. The failure to take fluctuation into account is also built in to the observational aspects of the assessment. An assessor uses their own observations on the day to support their conclusion that a claimant is functional to a particular degree. However, this observational method is logically defunct when it comes to assessing a person with a fluctuating condition. Necessarily, their capability fluctuates so how they are seen to behave on one day does not evidence their capability over a period of time. This problem is compounded by the invisible nature of M.E., whereby even the claimant’s ‘healthy’ appearance is not indicative of some of the symptoms they may be experiencing.

The assessment is also poorly suited to neurological conditions such as M.E. that do not fit neatly as either a ‘physical’ or ‘mental health’ condition. For example, one person has said that *“the form criteria does not fit my symptoms and it seems as if any additional information I gave was ignored and at the assessment my answers were adjusted to fit parameters of form.”*<sup>3</sup>

## **2. Do Atos and Capita staff conducting PIP assessments possess sufficient expertise to make accurate decisions on claims involving a wide range of mental and physical health conditions?**

The lack of expertise of Atos and Capita staff has consistently resulted in inaccurate assessment outcomes, and consequently incorrect decisions on PIP. This is because the assessors frequently either disbelieve or misconstrue the way in which the claimant’s condition affects their capability.

One person with M.E. told us about their experience:

*“They seem to fail to understand the exhaustion that comes with activity. They just look at the fact we can do it so must be ok. The bone crushing concrete feeling that leaves me unable to do anything for the rest of the day, is not understood. I may be able to walk into town but after about 5 minutes my body is aching and telling me to turn around. By the time I get home, I cannot do anything else for the rest of the day.”*<sup>4</sup>

Another person said that the assessor contradicted the symptoms that are typical of M.E.:

*“They found that the cognitive abilities that I reported were inconsistent with a M.E./CFS diagnosis despite the NICE guidelines listing cognitive difficulties as a*

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<sup>3</sup> Action for M.E. (2016), Survey for the Second Independent Review on PIP

<sup>4</sup> Case study submitted to Action for M.E. (2017)

*symptom. When I pointed this out in my letter requesting reconsideration it made no difference.*<sup>5</sup>

People with M.E. frequently find that the assessor displays a lack of understanding that impacts directly on the accuracy of the assessment report.

In order to combat this, assessors ought to be sufficiently briefed on the way in which a claimant's condition affects their capability. Some assessors do not see the information about the claimant until the day of the appointment, with limited time to become better informed on the claimant's condition or to consult the claimant's PIP2 form.

One way to ensure they are better informed would be for an assessor to specialise in a particular group of conditions, and then be matched to claimants with those conditions. Alternatively, there should be a better mechanism for assessors to consult with Disability Advisors on a particular condition. This ought to include, at the very least, assessors having a time period during which they could review the claimant's PIP application, and consult with a DA where necessary, before conducting the assessment.

#### **a. Do staff take enough account of additional evidence supplied by claimants?**

Staff do not take sufficient account of the additional evidence supplied by claimants. The results of the assessment are often prioritised over claimant submissions. This is despite these submissions often being a truer indication of the claimant's capability on a daily basis, such as reports from health professionals, carers, or family and friends, who have prior knowledge of the person's condition, or are in contact with them regularly. One person said "*my GPs evidence was largely ignored and/or replaced with the health professional's observations on the day of assessment.*"<sup>6</sup> This supports what we frequently hear from people with M.E., that the decision is often based on the assessment with insufficient regard given to additional evidence.

This is additionally concerning given that submitted evidence, such as reports from professionals or carers, are explicitly permissible, but the lack of consideration given to them in assessment outcomes suggests a lack of transparency when it comes to how evidence feeds into decision-making processes.

We have also referred to this issue in answer to Question 4a. When benefit decisions are overturned at tribunal, it is often the case that the initial assessment process failed to sufficiently take into account additional evidence (with regard to the degree required by benefit guidance).

One way to give more clarity to claimants, and increase the accountability of benefit outcomes, would be for decision-makers to explicitly state the rationale for prioritising one piece of evidence over another, where evidence is conflicting. This could be included in the notification of the decision that's been made. This would firstly ensure decision-makers have a justification for their decision to disregard a piece of permissible evidence, and secondly give claimants clear grounds on what issues they need to address should they appeal the decision.

### **3. Is the face-to-face assessment appropriate for claimants with a range of different conditions?**

The face-to-face assessment is not appropriate for all claimants, in several ways.

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<sup>5</sup> Action for M.E. (2016), Survey for the Second Independent Review on PIP

<sup>6</sup> Action for M.E. (2016), Survey for the Second Independent Review on PIP

Firstly, the assessment process can be intensive and therefore limit the ability of a person with M.E. to fully participate and convey information accurately. This is because M.E. causes cognitive impairment, particularly when the person has had to expend a lot of energy completing mental or physical tasks. This is particularly exacerbated where the claimant's symptoms are worsened by additional exertion, such as having to travel some distance to attend the assessment.

One person said that *"because of poor cognition I found the whole process very confusing and stressful"*, while another stated *"travelling has a negative impact on my ability to answer questions fully and succinctly."*<sup>7</sup>

Meanwhile, others have told us they have felt lucky to have an assessor who paused between questions allowing them time to pause and give appropriate responses. For some people with M.E. this consideration is sufficient to ensure they take part in the assessment productively. For those who are more severely affected, a different type of assessment altogether may be appropriate.

Secondly, the current assessment process fails to suitably capture the functionality of the claimant for people with fluctuating conditions such as M.E (as discussed under Question 1). One person said:

*"I had my assessment on a good day, and I think that made all the difference, as I looked fairly well. Four days after the assessment I was very unwell and could hardly walk across a room. If I had had my assessment on that day I think I may have been awarded the payment."*<sup>8</sup>

The assessment taking place on a single day does not accurately represent how their condition varies over time. A more effective assessment would be one that better captures the variation in a claimant's functionality without having a detrimental effect on their symptoms.

We would therefore recommend that the assessment process is personalised to each claimant. While accessibility needs should always be met, there is also the opportunity to consider what style of assessment can best capture how a person's functionality is impacted by their disability or health condition.

Regarding accessibility, one additional way to improve consideration given to the person's health condition is to create an opportunity for the claimant to state how an assessment could be made accessible. This could be simply asking a question along the lines of: 'What is most important for the assessor to know to make the process as accessible as possible?' Such a question would be inclusive of claimants with a range of conditions or disabilities, and sufficiently recognises that the claimant is the most knowledgeable person regarding their own condition and their own accessibility requirements.

#### **4. What changes are needed to improve the accuracy of decisions made in initial assessments and in mandatory reconsideration, given that the majority of decisions that go to appeal are overturned?**

Throughout this response we have highlighted a number of changes necessary throughout the assessment process to improve the accuracy of decisions, particularly with regard to claimants who have fluctuating, neurological conditions such as M.E.

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<sup>7</sup> Action for M.E. (2016), Survey for the Second Independent Review on PIP

<sup>8</sup> Action for M.E. (2016), Survey for the Second Independent Review on PIP

These include:

1. Increasing personalisation of the assessment process to claimant
2. Enforcement of 'safely, repeatedly, to a reasonable standard, in a reasonable time period', as outlined in regulations of PIP<sup>9</sup>
3. The assessor being sufficiently informed of the impact of the claimant's condition on their capability to be able to produce an accurate assessment report
4. Clear guidance on supporting evidence, including the appropriate weight given to non-assessment evidence of functionality

**a. What are the most common reasons you come across for decisions being overturned on appeal?**

There are two main reasons that we come across for decisions being overturned on appeal. One of these is claimants providing additional medical evidence, and is often because representatives assisting the claimant know what medical evidence is needed and can request it on behalf of clients. This would imply that clearer guidance on what evidence to submit, and moves to tackle barriers that claimant's face when collecting evidence, could reduce the number of decisions that need to go to appeal.

The second reason is that in the tribunal, legal tests are applied correctly. Our Welfare Rights Advisor says:

*"Tribunals consider someone's ability to do things reliably, repeatedly and the majority of the time. They also balance evidence appropriately – a GP letter may be considered just as credible as the health assessment. This may not be how the DWP make their decisions. They appear to rely heavily on the health assessment, even if people have submitted good information from their doctors. Essentially it seems the tribunal look at all evidence fairly and on the balance of probabilities make their decision, whereas the DWP seem to rely heavily on the health assessment."*

We have outlined earlier in this submission how people with fluctuating conditions are often inaccurately assessed because the decision does not take into account whether they can complete activities safely, repeatedly and to a reasonable standard and in a reasonable time period as outlined in Government guidance for PIP assessments.<sup>10</sup>

The additional issue highlighted by our Advisor is that claimants are submitting detailed and supportive medical evidence, but the Mandatory Reconsideration of the benefit decision heavily relies on the health assessment without taking account of this additional evidence.

By ensuring that these standards – regarding both the tests for fluctuation and the types of permissible evidence - are applied correctly in the first instance, there would be a lesser need for cases to progress to tribunal. This has been addressed previously in this submission, and we have highlighted how having assessors conform to benefit guidance correctly and consistently on both of these issues would contribute to more accurate outcomes for people with fluctuating conditions, including those with M.E.

**b. Is the mandatory reconsideration stage functioning properly? How could it be improved, or should it be abolished?**

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<sup>9</sup> *The Social Security (Personal Independence Payment) (Amendment) Regulations 2013*, Regulation 2, accessed at <http://www.legislation.gov.uk/ukxi/2013/455/regulation/2/made>,

<sup>10</sup>Department for Work and Pensions, *Personal Independence Payment handbook*, [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/519119/personal-independence-payment-handbook.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/519119/personal-independence-payment-handbook.pdf)

Evidence suggests that Mandatory Reconsideration is widely failing to overturn inaccurate decision-making. Despite the vast majority (85%) of Mandatory Reconsiderations on PIP upholding the original benefit decision,<sup>11</sup> 63% of Social Security and Child Support tribunal decisions overturn the original judgement in favour of the claimant.<sup>12</sup> Assuming PIP decisions, which are included within the SSCS category, are consistent with the overall pattern, this suggests that MR is widely failing to identify incorrect decisions. This is reflected in the experiences of people with M.E.

One person with M.E. told us:

*“I wrote a several page rebuttal of the report pointing out the lies, inconsistencies and issues with her claims and assertions... Within days of that being sent – almost quick enough that I’m not even sure they opened and read it and didn’t just sent an automatic letter without waiting for me to ask for mandatory reconsideration – the MR reply landed saying I still had 0 points.”<sup>13</sup>*

For anyone who goes through MR and has their benefit outcome amended, that person is prevented from the stress and exertion of appealing at tribunal, which can itself have detrimental effects on a person’s health. Were MR succeeding in overturning incorrect benefit decision, this would make it a positive addition to benefit design. However, the evidence outlined demonstrates that the policy intent is not being reflected in its practice.

One person who had to take their benefit decision to a tribunal stated, *“Although the whole process made me very ill, I found the chance to speak with the judge and the other panel members at appeal court very helpful... wonderful to be heard and have no assumptions made about how my illness affects me.”*

While not all experiences of tribunal are as positive, this does demonstrate the strength of the tribunal compared to MR. MR does not offer the opportunity of looking at the assessment and subsequent benefit decision in greater depth as it merely reinforces the decision-making processes of the initial assessment.

Our Welfare Rights Advisor said:

*“MR stage statistics compared to appeals statistics show a failure of second checks within the system. People who are ill may expend a lot of energy at this stage only to find they cannot go on to appeal. This puts them at an unfair disadvantage as they will be more likely to win at appeal.”*

On that basis, we would recommend the MR stage is abolished. While in theory it is of benefit to claimants, its performance would need to substantially improve in order to justify its inclusion prior to a tribunal. From our experience it frequently re-produces the initial assessment outcome, and this re-production is frequently overturned at appeal. As it can prevent people from M.E. from going to appeal, its continuation is likely to result in greater numbers of people being denied the benefit amount that, accurately assessed, they would be entitled to.

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<sup>11</sup>Department for Work and pensions (2017), *Personal Independence Payment: Official Statistics*, [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/598755/pip-statistics-to-january-2017.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/598755/pip-statistics-to-january-2017.pdf)

<sup>12</sup>Ministry of Justice (2017), *Tribunals and Gender Recognition Statistics Quarterly, October to December 2016 (provisional)*, [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/597905/tribunal-grc-statistics-q3-2016-2017.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/597905/tribunal-grc-statistics-q3-2016-2017.pdf)

<sup>13</sup> Action for M.E. (2016), Survey for the Second Independent Review on PIP

## 5. What is the impact on claimants of delays in getting an accurate decision on their claim, and how could this be reduced or better managed?

In our 2016 survey of over 300 people with M.E., the length of the initial claim process (ie. not counting any appeal) for 17% of respondents was less than 2 months, 40% two-four months, 25% four-six months, and 18% more than six months.<sup>14</sup>

The direct effect of these delays include financial insecurity and anxiety, which is particularly acute for claimants who are either more severely affected or who do not have alternative sources of support. One of the hallmarks of M.E. is that exertion, including stress and anxiety, can cause symptoms to worsen which can lead to a long-term deterioration in the health of the person in question.

A number of comments from people with M.E. demonstrate these effects:

*"It affected my mental health terribly... all my symptoms got worse. Much more physical pain and the depression took its toll on me."<sup>15</sup>*

*"Affected me financially emotionally and physically and made my M.E. worse and harder to deal with. I could not afford my treatment."<sup>16</sup>*

*"Huge financial worries, no income no food... felt like I was treated like a scrounger, who was lying to get on benefits. Totally inhumane. Got very depressed and angry."<sup>17</sup>*

*"Waiting 3 months sounds ok but was agony affecting my sleep and therefore health negatively."<sup>18</sup>*

As outlined previously in this submission, the worsening of symptoms often causes claimants not to pursue the correct benefit decision, because to do so would be detrimental to their health. Therefore, as well as the above impact in the short-term issues, the impact on claimants of delays may be that they are deterred over the long-term from pursuing the appropriate benefit amount.

One way to reduce these experiences would be to increase the length of the award once someone has successfully claimed PIP. The Government intended PIP to have more frequent review periods than its predecessor Disability Living Allowance, but with the additional built-in time for the new assessment to take place claimants are left with a very short period during which they can rely on these financial payments. One person said "*The second time they reviewed my award only after about 8 months*". Such short awards are not only distressing to claimants, but are unrealistic when compared to the length of time a person is likely to be affected by a long-term condition. By achieving a better balance when scheduling periodic re-assessments, PIP could operate a system whereby claim decisions are regularly reviewed but claimants are allowed to have more significant periods of financial stability.

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<sup>14</sup> Action for M.E. (2016), Survey for the Second Independent Review on PIP

<sup>15</sup> Case study submitted to Action for M.E. (2017)

<sup>16</sup> Action for M.E. (2015), Survey on benefit delivery

<sup>17</sup> Action for M.E. (2015), Survey on benefit delivery

<sup>18</sup> Action for M.E. (2016), Survey for the Second Independent Review on PIP