



A deeply dehumanising experience

M.E./CFS journeys through the PIP claim process in Scotland

March 2016



Foreword

The chronic disabling condition M.E./CFS can have a devastating impact.

This in-depth report, based on interviews with people with M.E./CFS in Scotland, demonstrates that one of the measures designed to mitigate this impact is failing.

Personal Independence Payment (PIP) is a welfare benefit designed to support the additional costs that come with being disabled. However, the people with M.E./CFS who shared their experience of applying for this benefit told Action for M.E. that it is adding to, not alleviating, the impact of M.E./CFS.

Findings indicate that key stages of the PIP claim process are not fully accessible to people with M.E./CFS, while the assessment criteria used as part of this process is not only inadequate when it comes to capturing fluctuating conditions such as M.E., but is also not being fairly and consistently applied.

As a result, this report makes 12 recommendations to support improved access to appropriate and timely PIP assessments for people with M.E./CFS.

In light of the forthcoming devolution of Welfare powers to the Scottish Government and the work of the Scottish Parliament Welfare Reform Committee, we trust that this research report will inform much needed changes to the current PIP claims process. Our wider aim is to contribute to shaping a more effective, fairer and supportive welfare system in Scotland, which places people at its heart.

Mary Fee MSP

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Contents

4	Executive summary
5	Key findings
6	Key conclusions and recommendations
7	The policy context and the introduction of PIP
8	What is M.E./CFS?
8	What is PIP?
9	The PIP claim process
10	The UK government case for reforming DLA
11	Reduced support for mobility needs of people with M.E./CFS
11	The implementation and impact of PIP in Scotland
12	Study aims and methods
12	Method
13	Demographics
14	Study findings
14	How PIP can support people with M.E./CFS
15	The claimant journey: forms, phone calls and letters
16	Providing supporting evidence
17	Returning the form on time
17	Missing paperwork or records
18	Case study: Gordon
18	Face to face assessment
18	Home visit requests
19	Length of assessments
19	Conveying information during assessment
20	Interaction with assessors
21	Assessment of fluctuating symptoms in M.E./CFS
23	Case study: Martha
24	An adversarial process
24	Accuracy of information recording
25	Award decisions
25	Reconsideration and appeals
26	Case study: Andy
27	The overriding impact of claiming PIP
28	Impact on physical and mental health
28	Wider impact of claiming PIP
30	Conclusions and recommendations
31	Our recommendations
33	Appendix I: weekly rates and descriptors for PIP
34	Appendix II: interview schedule

Executive summary

This report on the welfare benefit Personal Independence Payment (PIP) is based on in-depth research into the claimant experience for people living with the long-term health condition M.E./CFS in Scotland. Our recommendations are made to ensure that people with M.E./CFS do not continue to be disadvantaged by a system that fails to take into account the fluctuating nature of M.E. and the effect that the application process itself has on claimants' wellbeing.

PIP and its predecessor, Disability Living Allowance (DLA) are one of several disability benefits to be devolved to the Scottish Government following recommendations made by the Smith Commission.¹ Action for M.E. has actively engaged in the Welfare Reform Committee's consultation on the future of social security in Scotland in August 2015.² It is essential that the future Scottish welfare system meets the significant personal care and mobility support needs of people with M.E./CFS to enable them to live independently and participate in society.

PIP is intended to address these very needs, and it represents the largest item of expenditure on disability benefits in Scotland. It is crucial that the design, as well as the implementation, of this benefit is the right one for people with M.E./CFS.

Through a series of qualitative, semi-structured interviews with people with M.E./CFS between April and August 2015, we were able to document the journey through the PIP claim process as well as the overall impact on the lives of people with this condition. Quotations from them appear in green text throughout.

The report's overarching conclusion is that PIP is failing to meet the support needs of people with M.E./CFS. It leaves them isolated, increasingly dependent on family and friends, and in some cases the distress caused by the assessment exacerbates their existing health problems.

The majority of participants found the PIP process overwhelmingly negative rather than supportive in focus. PIP was not felt to be designed with people affected by M.E./CFS in mind. While some successful claimants found the experience positive for the security it gave them once they were awarded PIP, several participants described a "deeply dehumanising experience."

Our research shows that problems with PIP for people with M.E./CFS go far beyond the early operational difficulties with backlogs and lengthy waiting times, already highlighted by initial reviews. We found that at present people with M.E./CFS are being unfairly disadvantaged by the assessment criteria and process. The regular overturning of outcomes at appeal supports this finding.

We are therefore calling for more than an improvement in the delivery of PIP in Scotland. A fundamental overhaul in the design and purpose of PIP and its eligibility criteria is needed if it is to meet its stated aim of reducing disadvantage among people with fluctuating health conditions like M.E./CFS.

¹ The Scottish Government (2015) [Social Security for Scotland](#)

² Action for M.E. (2015) [Written submission to the Welfare Reform Committee](#): Future delivery of social security in Scotland

Key findings

“I’ll sum it up in one word: dehumanising.”

Participants said they used their PIP award (or would use it if their claim were successful) to pay for:

- additional food costs due to restricted diet with M.E./CFS
- additional on-going transport needs, eg. taxis, or one off items such as a car or mobility scooter
- the upkeep of their home, which M.E./CFS prevented them from managing independently
- specialist cleaning equipment due to chemical sensitivities
- additional heating costs due to their illness
- therapies such as yoga to help maintain core strength
- the expense of delivering groceries when housebound.

Participants described the process of claiming PIP as stressful and demoralising from the outset.

- This caused exacerbation of physical symptoms as well as added emotional distress.
- PIP assessment was perceived as adversarial, designed to be as difficult as possible, and failure inevitable.
- The impact was increased stigma and isolation from family and friends as the process left them fearful and feeling judged “like a criminal.” In some cases this placed a strain on family relationships.
- The emphasis on having to prove their disability was disempowering for claimants, and incompatible with the NHS emphasis on self-management.
- Delays and frequent need for appeal tribunals left some in severe financial hardship, with increased debt and dependency.

Those claiming PIP must complete a 35-page form.³ Issues with this were found to be as follows:

- The PIP2 form was felt to be very long and complex, and the guidance accompanying it to be of limited help due to the poor fit of the questions asked with M.E./CFS.
- The timescale for returning the form was felt to be too short. Most participants needed support from an advocate or welfare rights adviser to complete the form, due to its length the complexity of explaining multiple fluctuating M.E./CFS symptoms. Cognitive difficulties related to the condition substantially slowed down the speed at which claimants could accurately complete the form. Some could not travel to an advice centre so experienced great difficulty accessing this support. Others who could, found waiting lists for advisors exceeded the time they had to return the form by one to two weeks.
- Obtaining supporting evidence from a healthcare professional was difficult. Some GPs charged a fee; others refused to do this work citing excessive workload. Some participants had had little (or no) contact with any health professional regarding their condition for several years and did not feel their GP would be able to provide accurate supporting evidence.

³ Department for Work and Pensions [PIP2 How your condition affects you](#)

Issues with attending assessments were found to be as follows:

- Assessment centres were often too far away from the participant's home, involving more than one hour's journey, which exhausted some claimants before they started their assessment, impairing their ability to communicate. Difficulty parking close to the centre entrance exacerbated the problem. Home assessments were sometimes difficult to obtain.
- Assessments were sometimes rushed and statements made by claimants were often distorted in the reports to DWP decision makers
- However, the length of the assessment caused flare up of symptoms for some, due to post-exertional malaise, the hallmark of M.E./CFS.
- The style of questioning in assessments often made it difficult to give a holistic picture of how M.E./CFS affects day to day life.
- Participants experienced communication difficulties due to cognitive dysfunction ("brain fog") which got progressively worse during assessments and which affected their self-reporting ability. The energy expense required on the assessment day caused a marked deterioration in participants' condition over several subsequent days.
- Although most felt assessors were courteous, the wording of the questions and format with questions read out and completed on-screen tended to be experienced as disempowering and judgemental, causing emotional distress, and further impacting on claimants' ability to communicate.
- Assessors made statements about the claimant's ability to perform tasks without considering whether they could perform them reliably, ie repeatedly and safely.
- Assessors misreported claimants' capabilities based on irrelevant observations of their personal appearance or manner in the assessment, eg whether female claimants were wearing make-up or could pick-up a handbag.

Key conclusions and recommendations

The evidence gathered in this study suggests that:

- key stages of the PIP claim process are not fully accessible to people with M.E./CFS.
- the PIP assessment criteria are not being fairly and consistently applied as intended.
- the design of PIP eligibility criteria does not adequately capture the functional limitations caused by M.E./CFS.

Based on the experiences of participants, and the conclusions drawn from the evidence they presented, this report makes 12 recommendations with regards to:

- improving access to assessments
- improving decision-making by assessors with up-to-date M.E./CFS training
- taking greater account of the impact of fluctuating conditions such as M.E.

These are set out on page 32 of this report.

The policy context and the introduction of PIP

What is M.E.?

Myalgic Encephalomyelitis (M.E.) is a long-term, chronic, fluctuating illness that causes symptoms affecting many body systems, more commonly the nervous and immune systems.

Defined by the World Health Organisation as a neurological illness, M.E./CFS affects an estimated 21,000 people in Scotland, 250,000 people in the UK and around 17 million people worldwide.

People with M.E./CFS experience severe, persistent fatigue associated with post-exertional malaise, the body's inability to recover after expending even small amounts of energy. Post-exertional malaise is now considered a central key defining feature of M.E./CFS. Additional symptoms include chronic pain, sleep difficulties, cognitive problems and hypersensitivity to light, smell or sound, among other chronically disabling symptoms.

In March 2015, the Institute of Medicine in the United States recommended changing the name to systemic exertion intolerance disease, or SEID.⁴ This has not been universally adopted. In the UK, within the NHS, a diagnosis of Chronic Fatigue Syndrome (CFS) or M.E./CFS is often given.

We have chosen to use the term M.E./CFS throughout this report to include people with both diagnoses.

Research shows that people with M.E./CFS experience high levels of functional impairment across physical and mental domains, scoring lower overall on health-related-quality of life tests than most other chronic conditions (see graphic), including lung disease, depression, heart disease and diabetes.⁵

Researchers have concluded that “quality of life is particularly and uniquely disrupted” in M.E./CFS and that patients are, on the whole, not able to retain their previous capacity to remain active and perform roles in society.⁶

⁴ Institute of Medicine (2015) Beyond M.E./CFS: redefining an illness

⁵ Nacul et al. (2011), The functional status and well-being of people with myalgic encephalomyelitis/chronic fatigue syndrome and their carers. *BMC Public Health* 11:402.

⁶ *ibid*

What is PIP?

PIP is a cash benefit awarded to offset the additional costs of living with a disability or long term health condition. It plays a key role in alleviating poverty among disabled people and their families.

The drivers of poverty among disabled people are twofold:

- reduced earnings capacity from health and labour market barriers to work
- higher costs of living due to the need for specialist transport, assistive equipment and higher costs of food and fuel.

On the standard measure, one in three people in poverty live in a household with a disabled person. However, once higher needs of disabled people taken into account, the poverty measure increases by an extra one million people.⁷

The Scottish Welfare Reform Committee has found that people with health conditions and disabilities in Scotland lose out badly from pre-2015 UK welfare reforms, with reductions in incapacity benefits estimated to average £2,000 per year.⁸

It is important to note that PIP is payable to disabled people both in and out of work, in recognition of their higher costs of living. It is different from the earnings replacement benefit Employment and Support Allowance (ESA) for people with health conditions or disabilities.

The PIP claim process

PIP retains some key features of its predecessor Disability Living Allowance (DLA).

Like DLA, PIP:

- is not means tested, is non-taxable and non-contributory
- is intended to provide financial support for disabled people with the greatest challenges to remaining independent
- is payable both to those in work and out of work
- has two components, Daily Living and Mobility, with different levels of award for each based on the assessed level of need. A claimant may be eligible for one or both of these. Both components have a standard (for those who have limited ability) and enhanced (for those who have severely limited ability) weekly rate.

In contrast to DLA, PIP has:

- a stronger emphasis on assessment of the functional impact of claimants' underlying disabling and medical conditions, rather than the conditions themselves
- a points-based system to assess eligibility for awards

⁷ MacInnes, T (2014) [Disability, long term conditions and poverty](#)

⁸ Welfare Reform Committee (2015) 1st Report 2015 (Session 4) [The Cumulative Impact of Welfare Reform on Households in Scotland](#)

- more regular reviews of eligibility for those receiving awards
- a greater focus on the needs of claimants with mental health conditions.⁹

The process of applying for PIP is as follows:

- Claimants make an initial telephone call to the DWP in which they must provide basic information such as contact details, national insurance number, bank details and doctors' surgery
- A 35-page form is then sent through the post for the claimant to complete.
- For the majority of claimants with M.E./CFS the next step is to attend a face-to-face assessment by an independent healthcare professional. The decision as to whether the claimant is eligible for PIP is made based on this assessment along with supporting evidence provided by the claimant.
- If the claimant is unhappy with the outcome of their claim, they are entitled to a mandatory reconsideration whereby they make a formal request to the DWP for the decision to be reassessed.
- If the claimant is unhappy with the mandatory reconsideration outcome they can then appeal by filling out a six-page form.¹⁰

See Appendix I for more information on weekly rates for PIP and on the activities covered by the Daily Living and Mobility components of the assessment.

The UK government case for reforming DLA

PIP replaces Disability Living Allowance (DLA), the previous extra-costs benefit for disabled people.

PIP was introduced in April 2013 and will be phased in over several years. Atos Healthcare delivers the assessment phase of PIP on behalf of the DWP in Scotland, alongside supply chain partners Salus for central and southern Scotland and Premex for parts of central and northern Scotland.

PIP has similarities to DLA but is a points-based test and people are measured against descriptors to see if they score enough points to qualify for support.

The design of PIP was undertaken in a context of fiscal austerity.¹¹ Disabled people argued at the time that the rationale for DLA reform and the consultation process were flawed.¹²

It was argued that the DLA caseload had risen inexplicably by 30% in the eight years to 2010.¹³ HM Treasury predicted that more objective medical assessments and revised eligibility criteria in PIP would reduce the caseload and expenditure on DLA by 20%.¹⁴

⁹ Gray, P. (2014) *An independent review into Personal Independence Payments assessments*. DWP

¹⁰ [SSCS1: Notice of appeal against a decision of the Department for Work and Pensions](#)

¹¹ Gray, P (2014) [An independent review of the Personal Independence Payment assessment](#)

¹² Campbell, S et al (2012) [Responsible reform: a report on the proposed changes to Disability Living Allowance](#)

¹³ Department for Work and Pensions (2010) [Public consultation: Disability Living Allowance reform](#)

¹⁴ HM Treasury (2010) [Budget 2010 policy costings](#)

However, analysis shows that at least half of this caseload rise can be attributed to wider demographic changes. For example, a natural growth in the caseload would be expected as the initial cohort of claimants from 1992 keeps their benefit into retirement age.¹⁵

Moreover, despite the rushed consultation, more than 500 responses were received from disabled people and organisations representing them. More than 90% of them opposed the changes to DLA.¹⁶

Reduced support for mobility needs of people with M.E./CFS

One of the biggest concerns for people with M.E./CFS and other physical health conditions affecting mobility was the introduction of the 20m rule.

This measure, not included in the original consultation, restricts eligibility for the mobility component for people with severe walking difficulties from the previous 50m benchmark used in DLA down to 20m. There was no evidence that people who can walk more than 20m but less than 50m face lower costs for mobility and transport than those who cannot walk 20m.

This aspect of PIP means people with M.E./CFS who would have qualified for the enhanced mobility component under DLA lose £33.25 per week or access to their Motability vehicle.¹⁷

We anticipate that the reformed criteria for enhanced mobility support will leave many people with M.E./CFS transferring from DLA without the financial support to leave their homes, access local services or participate in their communities.

Reports into the implementation of PIP by the National Audit Office,¹⁸ the Work and Pensions Committee¹⁹ and the Public Accounts Committee²⁰ throughout 2014 criticised the severe delays and backlogs in the claims processing system by DWP's contractors Atos and Capita.

¹⁵ Full Fact (2012) [Do Iain Duncan Smith's DLA claims ring true?](#)

¹⁶ Campbell, S et al (2012) [Responsible reform: a report on the proposed changes to Disability Living Allowance](#)

¹⁷ Disability Benefits Consortium (2013) [DBC Briefing: the PIP 20 metre rule.](#)

¹⁸ National Audit Office (2014) Personal Independence Payment: early progress

¹⁹ Work and Pensions Committee (2014) Monitoring the Performance of the Department for Work and Pensions in 2012-13

²⁰ Public Accounts Committee (2014) Personal Independence Payment

By March 2015 waiting times from initial registration to receiving a decision had reduced from a peak of 41 weeks in July 2014 to 15 weeks for new claims and 11 weeks for reassessments.

The first independent review of the PIP assessment by Paul Gray in 2014 focused solely on whether the assessment criteria were being applied as intended, and not on whether the design of PIP criteria was appropriate.²¹

The key findings of his report were:

- the experience of claiming PIP is disjointed
- improvements are required in communications, including decision letters
- there should be a more integrated, digitally enabled claims process
- the way in which further evidence is collected can be clarified and improved
- a rigorous evaluation strategy of fairness and consistency must be implemented with priority given to the effectiveness of the assessment for people with learning difficulties and mental health conditions.

The implementation and impact of PIP in Scotland

The Scottish Government has estimated that out of the existing 190,000 working age DLA claimants in Scotland:

- 55% will see a reduction in their award or receive no award at all
- 30% will see an increase in their award
- 15% will see no change in their award

Of the 105,000 estimated to see a reduction or receive no award, it was estimated they would lose at least £1,120 per year.

In February 2015, the Scottish Government and a number of third sector organisations called for a halt in the roll-out of PIP in Scotland given that the benefit is set to be devolved.²²

²¹ Gray, P (2014) [An independent review of the Personal Independence Payment assessment](#)

²² Welfare Reform Committee (2015) [Agenda 13th Meeting 2015 \(Session 4\)](#)

Study aims and methods

The purpose of this study was to explore in detail the experiences of those with the debilitating condition M.E./CFS at different stages in the process of claiming PIP, with a view to informing welfare policy development in Scotland.

The research was carried out by Action for M.E. staff and volunteers as part of Action for M.E.'s Big Lottery funded project *Hear me, influence M.E.* in the context of:

- ongoing UK-wide welfare reform
- the roll-out of PIP across Scotland
- the forthcoming devolution to the Scottish Government of extensive new powers relating to the delivery of welfare benefits, including PIP.

Initial findings from this research were presented at an M.E./CFS awareness event held in the Scottish Parliament on 13 May 2015. Findings have also informed Action for M.E.'s written and oral evidence given to the Scottish Parliament Welfare Reform Committee during August to September 2015.

The purpose of this report is to set out the full findings of this study, complete with illustrative case studies and our policy recommendations.

Methods

Fourteen semi-structured qualitative interviews were carried out with people living in Scotland who self-identified as having M.E./CFS. This detailed study of 14 people builds upon the findings of larger surveys and feedback from Action for M.E.'s Welfare Advice and Support Service in relation to PIP failing to meet the support needs of people with M.E./CFS.²³

The interviews were carried out April to June 2015, with follow-up during July to August on claims and appeals in progress. Interviewees were offered a choice of carrying out the interview by telephone, Skype call or – where logistically feasible – face-to-face. All of the interviewees were at some stage in the process of claiming PIP. The interview schedule is included (appendix II) for information.

²³ For example, Action for M.E.'s 2014 [M.E. time to deliver in Scotland](#) report (focusing on responses from the 197 people with M.E./CFS in Scotland out of a total of 2,081 UK survey respondents) found that 77% of people with M.E. said they were worried about the impact of welfare benefit reforms. The same report found that 75% of people with M.E./CFS who had applied for PIP were still waiting for their application to be processed. More broadly, [Citizens Advice Scotland](#) has referred to "the massive delays that new claimants are seeing in getting a PIP assessment and then having a decision made. Whilst these delays continue, sick and disabled clients are facing severe hardship, unable to meet the costs of living, and getting into debt."

Each interview took between 30 and 150 minutes, dependent upon the nature of individual interviewee experiences of claiming PIP. Some of the interviews were conducted in several parts with breaks in between to allow recovery from cognitive impairment and other symptoms manifested during the course of an interview.

Interviews were written-up and subsequently analysed thematically.

Demographics

The study group included 11 females and three males. Participants were aged between 24 and 60 years and included a mixture of people living in small towns, cities and rural areas of central, southern and northern Scotland.

The majority had had M.E./CFS for 10 or more years and all of those interviewed had lived with the condition for at least 3 years. Some interviewees had experienced worsening symptoms over several years prior to receiving a formal diagnosis and/or giving up work due to ill-health.

Study findings

How PIP can support people with M.E./CFS

“PIP would give me some dignity.”

We asked participants what they would spend their PIP on if their claim was successful. We also asked others still in the claims process, or whose claim had been refused, what they would spend the benefit on if they received it. Participants described a similar range of expenses.

Some described using it to pay for extra costs related to their illness. Many people with M.E./CFS have food allergies or intolerance and require a specialist diet which they would struggle to pay for on the income replacement benefit ESA alone. Others said they incurred extra costs due to chemical sensitivities they had developed as a part of their illness.

“I have food and chemical sensitivities so would like to buy a small steam cleaner”

Many used their PIP to meet their extra transport costs. Some used taxis while others described using the benefit to enhance mobility with the purchase of a car or mobility scooter. Being able to meet these transport costs was important for access to essential services, to enable participants to maintain a degree of independence and to maintain some social contact outside of their home.

“Having PIP would help me to socialise and have more independence. I could afford a taxi to go and meet friends instead of having to rely on them to pick me up and take me home.”

“It would make it easier to get to the GP, dentist or optician.”

Participants also described meeting extra costs of needing to heat their homes; the upkeep of their homes as they couldn't manage this themselves; and having to have groceries delivered.

Some mentioned costs incurred through long term unemployment such as paying off accumulated debt, and replacing clothing or worn items such as bedding.

“I haven't been able to afford to go to the hairdresser for two years. I'm reliant on family to help with clothing.”

Some participants said they would use PIP for their own health and wellbeing programme. An example was paying for yoga tuition to work on core strength.

One participant described how being able to pay for support from a carer would take the pressure off her family, who currently have “a rota of people coming in” to check up on her and provide support, especially during bad flare-ups of her symptoms when she is unable to prepare food or drinks for herself.

Another participant who had moved in with her parents due to the impact of the illness and lack of income said it would help her to live independently again.

The claimant journey: forms, phone calls and letters

On the whole participants found it hard to get information from DWP about PIP and accessed better information from organisations such as Citizen's Advice and Action for M.E.

The majority of participants were surprised by the amount of information²⁴ needed to be conveyed over the telephone during the initial call to DWP and some questioned whether this was entirely necessary

Participants consistently viewed the information provided by DWP as limited and unclear and the second stage claim form (PIP2) as overly long. Questions at all stages were felt to be a poor fit with M.E./CFS and not appropriate for capturing the lived experiences of those with a fluctuating condition.

The focus of the questions was felt to be very negative, ie. on things they were unable to do. In contrast, interviewees said they would have preferred to describe much more broadly how their condition affects them and the positive things they do (or could do with support) to manage life with their condition.

Many felt that the Information booklet and forms²⁵ were overly complex and need to be improved.

“I was shocked at how thick it was and how intense it was, but also how the questions were phrased. I won't say ambiguous but I would say [...] the way they ask them, there's only particular things they're interested in. Sometimes it does not give you a chance to fully explain or say how it affects you – especially with M.E./CFS and fibromyalgia.”

All of those interviewed required help from a range of sources including advice centres, charitable organisations such as Action for M.E., Citizen's Advice, and internet discussion forums. The majority said that external sources of information were better than DWP sources, because the information received was very detailed and clear and intended to support claims.

Most, but not all, interviewees said that if necessary they would be able to make applications online in future. However, around half expressed a strong preference for written application forms that they could complete in small chunks, read off-screen and more easily discuss with advisors.

One interviewee highlighted disadvantages of written applications:

“There is a lot of money involved in a paper-based application eg. photo-copying at the library – it's essential to keep copies – and sending documents by registered mail. Also the effort of doing these activities.”

²⁴ [PIP1: Personal Independence Payment Claim form](#)

²⁵ [The Personal Independence Payment \(PIP\) toolkit](#)

Providing supporting evidence

Claimants are advised to submit any evidence they already have with their form. The PIP information booklet states:

“It is very important that you provide us with any relevant evidence or information you already have that explains your circumstances. For example, this might include prescription lists, care plans, reports or information from professionals such as a GP, hospital doctor, specialist nurse, community psychiatric nurse, occupational therapist, physiotherapist, social worker, support worker or counsellor, or any other information you think would be helpful for us to see. The supporting evidence you send doesn't need to be recent.”²⁶

Claimants are discouraged from asking for new evidence to support their claim. In theory the assessors are supposed to request additional evidence from health professionals (and pay the fees) where they feel this is required.

In practice, providing supporting evidence was considered to be a minefield for claimants with considerable conflicting advice and confusion. Participants described uncertainty around whether DWP did in fact contact people such as GP, consultants or allied health professionals for evidence (as the form suggests) or whether in reality this was not the case.

As a result, some applicants potentially could (and did) submit reams of evidence including details of appointments with consultants and copies of letters.

The majority of participants described difficulties providing supporting evidence. Three said that they found it difficult due to only being able to provide short or generic medical letters from either their GP or specialist consultant.

Others said that they hadn't been able to provide any supporting evidence: because they had no ongoing contact with their GP about M.E./CFS or because their GP surgery was no longer providing medical letters. Two others who were able to provide a letter from one of the two NHS M.E./CFS clinics in Scotland said that there was no information relating to this letter in the copy of the Atos medical report they received.

Jill²⁷ had to phone her consultant's secretary as well as her GP to try and get supporting letters from them. In the past when she needed a letter for her DLA claim this was never a problem.

Now, in her GP's surgery there are notices up on the wall saying that no more medical evidence letters for benefits claims are being issued, as it wasn't possible to keep up with the high demand. The GPs were happy to have DWP contact them, to ask for a report. Yet Jill has been told by her GP and consultant that no one has contacted them to ask for a report.

²⁶ DWP (2013) [PIP2 How your disability affects you information booklet](#)

²⁷ All participants have been given pseudonyms

Returning the form on time

The time limit for completing an application was felt to be too brief for people needing to get advice or support with their claim. The clock starts to tick from the initial telephone interview until the written form is returned.

All claimants interviewed required help from a range of non-statutory sources including advice centres, charitable organisations such as Action for M.E., Citizen's Advice and from internet discussion forums.

Most participants felt that the timescales for submitting forms was too short because of issues related to either needing help from over-subscribed organisations such as the Advice Shop or Citizen's Advice or due to the severity of their M.E./CFS.

Five participants had requested and received an extension to the deadline by DWP. One described Citizen's Advice Scotland squeezing her in by giving her an appointment over lunchtime when the office was closed so that she could return her form in time.

The application process itself can be very stressful to people with severe illness:

"I needed to see a benefits advisor at short notice. I had to travel to the office as I couldn't get a home visit. I felt like a zombie 30 minutes into the appointment. I couldn't think or concentrate or remember what I'd written in my diary that the advisor got me to use. The appointment lasted two hours and, added to the travel time, I was wiped out for the rest of the week."

"The paperwork took a long time to do. It took the whole month that I had available."

Missing paperwork or records

The administration of PIP appears to be hampered by unacceptable levels of error and incompetence:

- Four participants experienced missing paperwork or records
- Three said that their letters and paperwork were lost by DWP or assessors, one of whom had to have a second medical assessment due to the fact that the first was not saved on the computer.
- Other claimants said they had provided health professional contact details but on follow-up with their GP or consultant, discovered that DWP had never made contact to request supporting evidence.

"My first assessment wasn't saved on the computer so I'm having to attend a second one. This one will be done closer to home instead of having to travel to [a distant town]."

Face to face assessment

Actually accessing the assessment centre was physically challenging for some of the participants. Assessment centres were often a considerable distance from home, there was difficulty parking close to the entrance to some centres and those taking public transport found the journey particularly difficult and the walking distances involved physically demanding.

The inaccessible nature of some assessment centres for people with severe illness adds greatly to the stress of claiming PIP.

“When I got my PIP appointment I asked my husband to take time off work to drive me. It was more difficult by car as parking was hard to find. It was made more stressful with the added worry of getting a parking ticket. Because I was very stressed, I couldn’t understand the security button system to get into the Assessment Centre. I got into a bit of a state.”

Case study: Gordon

Gordon* phoned ATOS ahead of his assessment to ask about facilities in the centre. He wanted to know about access to the building, parking, floor level access and toilets. He was assured that everything was fine, that the ATOS centre was towards the back of the building and that there was ample parking.

Gordon was given the impression that parking was at the rear of the building and he wouldn’t have to walk far to the main door. As there are no nearby bus stops, a friend gave Gordon a lift.

On arriving, the car park was full. There were no available parking spaces and no designated parking spaces for those coming for PIP assessments.

Home visit requests

Claimants have a right to request a home visit. As a minimum, providers should consider whether a home consultation is necessary where a claimant indicates they are unfit to travel to an assessment.

Four participants had requested a home visit:

- one had their request ignored
- one was initially offered a home visit but the offer subsequently “disappeared” without explanation
- two said they were discouraged by being told it would be a long wait or that they would be unlikely to qualify for one.

* All participants have been given pseudonyms

Length of assessments

Most participants described the length of the assessment as being too long and requiring stamina. Seven participants described difficulties when trying to communicate with assessors due to exhaustion.

“I wasn’t prepared for the interview [...] to go on for so long. It was very, very long and I was exhausted at the end of it.”

“The assessment took around an hour which [...] was too long. Although feeling tired and latterly feeling exhausted towards the end of the assessment I didn’t admit this to the assessor, preferring just to grit my teeth and got on with it.”

“I mentioned that I was having trouble concentrating. I was still bedbound so just going [to the assessment interview] was hard enough. It took a few days to recover. I stated that too.”

Seven participants said their assessment was an hour or longer with a resulting exacerbation of symptoms leading to them becoming extremely fatigued. One said her assessment took more than two and a half hours. Five had assessments that lasted half an hour, and one said hers was 20 minutes. Two said their assessment was too short and that not enough questions were asked whereas another two said the time was adequate as they wouldn’t have been able to manage longer.

Another participant said she felt fatigued, uncomfortable with pain in her back and legs, and unable to mentally process the assessor’s questions. She reports becoming confused about what she could do and when.

Conveying information during assessment

Several participants felt the assessor couldn’t make a fair assessment due to their difficulty in explaining their condition.

Another frequently described frustration relates to the repetition of questions on the form and the questions asked in the assessment. It was unclear why this repetition was necessary. Several participants also questioned the necessity of duplicating information already supplied to DWP in ESA claims.

A consistent description was that the assessment process was associated with considerable stress.

“I started crying. Because the more you bring it to the fore [...] the more you ask me about [the illness] I break down. I broke down completely [...] It’s really difficult emotionally”.

Interaction with assessors

Eleven thought that their individual assessor was pleasant; four described their assessor as “understanding,” “sympathetic” or “empathetic.” This did not correspond with assessors having any apparent knowledge of M.E./CFS.

“She [the assessor] was pleasant – poker face but actually was very sympathetic and asked me lots of questions about things that are not relevant to the actual [condition]. She was really interested”.

However, there were significant problems with the style of questioning, the physical examination, the way evidence about capabilities was elicited and the reporting of this evidence.

“I thought she had got it. She was typing away like mad. You speak to them and they type away [...] so someone must have gone through it and scored it all out”.

“She chatted with me, asked me lots of questions. Bizarrely, she said to me ‘now I’m going to examine you, could you lift your leg like that?’ And I went ‘yes, that’s fine.’ And that was the medical examination!”

“Shouldn’t [assessors] be using their skills to get the full story out of somebody, rather than just letting people who are genuinely ill provide inadequate answers?”

The most frequently criticised aspect of the face-to-face assessment was the disengaged format of the interview. Several participants described their assessor reading questions off a screen and typing responses without looking at them.

“[The assessment was] rushed through. [The assessor] didn’t have access to the IT system and kept saying ‘we will come back to that.’ We didn’t. She didn’t record everything I said and there were things I said that were not in the report.”

Assessment of fluctuating symptoms in M.E./CFS

It is very difficult for a one-size-fits-all assessment of functional status like that used for PIP to capture the nature of impairment in M.E./CFS.²⁸ As with other chronic illnesses, day to day function is limited by pain and fatigue and other symptoms that are cumulative, fluctuate over time, and are invisible in the context of a snapshot assessment.

In recognition of this, the UK government produced additional guidance²⁹ on assessment in 2013 that centred on the key condition of reliability. The addition to the regulations now means that legally individuals should be assessed on what they can do:

- safely
- reliably
- repeatedly and
- in a reasonable time period.

However, our participants' experiences suggest that this guidance is not being applied consistently.

“I scored zero for washing and bathing ‘cause I said that I can wash and bathe [...] but when I’m at my worst, I wouldn’t have a bath unless there’s someone with me, and I’d never have a shower because it’s too knackered [...] Communicating verbally, yes, but just recently I really have been getting confused. I really can express what I want to say, but not all the time.”

Assessors were described as being unwilling to capture the time taken for claimants to carry out actions, the cost in terms of overall capacity/functioning or any coping mechanisms individuals had to employ in order to perform an activity.

Interviewees emphasised how difficult it was to get across how M.E./CFS fluctuates and the cumulative impact of post-exertional malaise to give a full picture of their day to day function.

“The mobility component, I got four for that, you need eight [points] [...] They said, ‘can you move 40 metres?’ [...] That’s what I said I could do, but that’s on a good day. I don’t walk anywhere now. I don’t drive at night now.”

“She [supporting health professional] said to me: ‘All these things you said you can do, can you do them every day? Can you say hand on heart I can walk fifty feet every single day?’ It’s true that one day I could be able to walk the length of four buses but if you’d seen me in September, I could barely walk to the toilet. But they don’t ask you things like that.”

²⁸ Gray, P (2014) [An independent review of the Personal Independence Payment assessment](#)

²⁹ DWP (2013) [PIP assessment guidance to be further strengthened in law](#)

Some questioned the appropriateness of the functional ‘tests’ (ie. the physical examination) while others were aware that assessors also carry out informal assessments based on informal observations of, for example, mood, manner, how a person moves or picks up a bag or coat, or whether they are wearing make-up. It was widely felt that these observations do not provide appropriate evidence of how M.E./CFS limits a person’s activity.

Eight participants said that they had little confidence in their assessors to make a fair assessment because they appeared to have no understanding of the condition and the way the illness fluctuates. One said that because they were having a bad day on the day of the assessment it was more visible to the assessor and they could grasp a better understanding of the condition and thus make a fair assessment.

One participant pointed out how many of the criteria in PIP are designed for assessing different impairments such as learning disabilities, and do not translate to the symptoms and difficulties experienced by people with M.E./CFS.

“Using Facebook even in short spells counts against people. The same goes for bank accounts. It doesn’t matter how much help or time is needed to budget, unless someone deals with your bank account for you then it’s no points. It doesn’t matter how long it takes to do the ‘simple spelling test,’ ie. spell ‘world’ backwards – even writing it on your hand to help, means you’ve passed. They don’t take into consideration how long it takes people to do anything, just whether you can do it, then that’s it. This will have a huge impact on people with M.E./CFS who pace themselves to get anything done.”

Case study: Martha

Martha* felt that she hadn't been listened to during the medical assessment and, having read the report, found that several statements in it were untrue. In particular she felt that her cognitive and communication difficulties had not been correctly assessed.

"Communication causes me frustration. I have to read simple things several times to get the gist and even then I'm not confident in understanding. The same goes for conversation – I find it extremely difficult. Budgeting is another panic point. I don't feel confident at all."

Martha explained how she tried, unsuccessfully, to communicate the difficulty she experiences, and substantial preparatory work, she has to undertake to make any independent journey.

"I explained several times to the assessor that I couldn't 'plan and follow a journey.' I need to prepare by using Google maps, street view and print-outs. My sons need to track my whereabouts. But I got zero points."

Martha requested a Mandatory Reconsideration. She was awarded standard mobility but nothing else.

"With only getting standard mobility [for planning and following a journey], I can't apply for a Blue Badge. I need be on the enhanced rate."

She felt that "as a punishment for daring to question them, instead of being reviewed in 2025 it will now be reviewed in March 2019, no explanation given."

Martha described her experience as: "a very guilt-inducing struggle." She said she never wanted to have to make a benefits claim. "I think the procedure is so difficult and that claimants are having to jump through so many hoops at a time when you don't have the energy to jump at all."

* All participants have been given pseudonyms

An adversarial process

While the majority of participants described the manner of their assessor as “pleasant,” two had difficulty interacting with them. One was described as hostile and the other made them “feel like they were being judged.”

Two participants said that the assessor pressured them into doing exercises beyond what they could comfortably manage.

Some people we heard from said “the process is designed to be difficult” is “designed to fail you.”

“The [assessor] only used the script from the computer screen. She wasn’t asking questions to see if I was eligible for PIP or how severe my M.E./CFS is, she is just going through a process. She didn’t ask for clarification on anything. First thing she asked was ‘How does your condition affect you?’ That’s a very broad question. You can’t go into every little aspect of how your condition affects you [...] I felt like I’d just gone into an exam but unprepared for it [...] I felt I’d sat an oral exam on PIP and just failed it. I felt that they were just taking advantage of me.”

Accuracy of information recording

Six participants said that their assessor’s medical report had recorded inaccurate information. These included recording untrue or distorted statements; or not recording and ignoring what was said in the assessment. Two participants said that their assessors had twisted what they were saying to fit the questions.

“I really didn’t trust him because he seemed to distort things so often. For examples I can’t wash my hair, but since I could put my arms on my head he said therefore I could wash my hair.”

Award decisions

Based on the first assessment, five out of 14 participants received a PIP payment.

Two were happy with their payment (awarded for four years) whereas the other three were not, as they had hoped for a higher award. One of these had a second assessment and subsequently lost their PIP payment altogether. Another appealed but the decision wasn't changed, instead their award time was reduced. This felt like "a punishment for daring to question them."

"I can't imagine what the process is like for people who don't have support."

Nine participants were declined PIP based on their first assessment. Two of these went to appeal. One had a second assessment from which they received a PIP payment. Four participants were still awaiting a decision at the time of research.

Reconsideration and appeals

"I thought, will I appeal? I thought, it's too taxing, too much stress and they're not going to give it to me anyway."

The process of awaiting decisions and appeals had sometimes serious consequences. The length of time waiting for the final decision varied from 5 weeks to 8 months.

- Six participants said that the wait made them stressed and anxious and exacerbated their symptoms
- Two said that the length of time had an impact because of struggling with bills and rent
- Four said that they had become more reliant on their family in this time.
- Four said that the decision made hasn't affected them applying for other benefits
- Three weren't getting any other benefits due to being unsure as to what they're eligible for
- One said they couldn't get a blue badge as they were only getting standard mobility payments (for planning and following a journey) instead of the enhanced rate

The two who were happy with their PIP award said that they felt relieved and more secure.

Case study: Andy

Andy* was previously claiming DLA and managed, with the help of the advice shop, to complete his PIP form on time. His PIP assessment centre was out of town so his wife had to drive him there.

During the assessment Andy felt that his assessor had little or no concept of M.E., or of the limitations it can cause. Despite stating that he had M.E., coeliac disease and Irritable Bowel Syndrome the assessor kept asking about his coeliac disease instead of his M.E./CFS even though he was applying for PIP because of the impact of his M.E./CFS rather than the other conditions.

Andy did not feel confident that he was receiving a fair assessment. He felt that he was judged on how he walked through the door and how he answered the questions rather than the holistic picture of his daily life that he tried to present in the assessment.

Andy said the information he gave during the assessment was recorded inaccurately. For example, when explaining his experience of post-exertional malaise, he mentioned that after his friend picks him up and takes him out for a coffee he has to go to bed because of the exhaustion. From this the assessor wrote that he is capable of socialising but made no mention of the consequences or “payback” of activities, which are the root of his problems.

Andy's¹ claim for PIP was refused for both mobility and personal care. As a result of the PIP decision, his Blue Badge was taken away, as well as his bus pass and mobility car. Andy lost his sense of independence and felt as though he was being punished.

He asked for Mandatory Reconsideration, which was unsuccessful. Then he went to tribunal. The tribunal also found him ineligible for PIP.

Andy found the tribunal process difficult because he was asked only ‘Can you do this?’ rather than ‘What are the consequences of doing this?’ So he couldn't explain how the main feature of M.E., post-exertional malaise, affects him. Andy's overall feeling about claiming PIP was that he felt accused of lying. “They use everything you say against you and they use it in their favour instead of in the favour of the individual.”

* All participants have been given pseudonyms

The overriding impact of claiming PIP

“It was a complete nightmare, a deeply dehumanising experience, a mind-boggling experience. You think it can’t get any worse and it gets worse.”

Participants described the process of claiming PIP as a “stressful and demoralising process from the outset.” The worry associated with it was described as beginning even before the “dreaded brown envelope” arrives.

“The overall experience is sheer terror, it really is. It’s absolutely sheer terror. And it’s ‘Oh my God, do I have to deal with this when I’m tired and when I’m ill.’”

The onset of illness, when it leads to loss of employment, is already a time of worrying financial difficulties:

“I was very, very stressed about what was going to happen. I was praying and hoping that some sort of help would come. I was struggling with the rent. I hadn’t been to work for over a year, I think, when they interviewed me – and my company only paid me the statutory minimum [...] I’ve lost my working tax credit [...] it was very difficult.”

The short timescale for returning the form and the difficulty of obtaining support with the form creates additional anxiety and stress.

People with M.E./CFS often have to go to great lengths to have their symptoms investigated properly and to obtain a diagnosis. It is not uncommon to encounter dismissal and disbelief along this journey, which in itself can often take several years.

It appears that claiming PIP triggers the possibility of dismissal and disbelief again and this is partly why people with M.E./CFS find it so harrowing.

“It made me feel a lot less of a person. I’m not used to being ill and to have this kind of judgement hanging over me has made me feel worse.”

Being turned down for PIP is highly distressing experience because it seems to call into question the reality of their illness:

“I just got my PIP decision and they turned me down [...] I just can’t stop crying [...] it just feels like a public denial that this illness stops me from living normally [...] that M.E./CFS is real and can’t reasonably be overcome. I wish I hadn’t started these applications now, as I had no idea when my GP suggested doing it that it would make me feel so utterly depressed and alone and beaten at moments like this.”

Impact on physical and mental health

Participants described the strenuous nature of the face-to-face assessment. They often couldn't communicate effectively by the end of the assessment due to exhaustion and the physical repercussions of this strain lasted over subsequent days.

"I normally deal well with illness. But on the lead-up to assessment there was a huge impact on feeling anxious and depressed and this started to well up again afterwards. I became more agitated, having vivid and unpleasant dreams, waking during the night with a start. It has taken me a step backwards in managing my M.E."

"The whole process seems to be made as difficult as possible [...] All this work and effort; so much pressure. It's just really stressful."

It was noted that the repetition between the ESA and PIP processes exacerbates this stress and adds unnecessary workload.

"It's as though one part of the benefits system does not believe what the other has said – why? I can't understand and I need to know why because PIP is the more in-depth one. But what they put me through in the last three weeks with my ESA claim has been a nightmare."

The focus on inability to perform everyday tasks in PIP claims was considered by those interviewed to be too negative – incompatible with self-management advice some patients were receiving from NHS and third sector sources.

"I felt really silly doing these tests. I kept apologising for the fact that I couldn't do them. They made me feel inadequate."

"I've had this chronic illness for 15 years. It's taken me 10 years to learn to manage it. Don't penalise me for managing it".

Having M.E./CFS often leads to isolation from friends and family members and participants felt this was exacerbated by the application process. They described the general social stigma attached to claiming benefits fuelled by media and political discourse.

"I would love to work. I haven't broken any laws, but I'm imprisoned in this house, scared and frightened and still stay isolated."

Wider impact of claiming PIP

Claiming PIP has impacts beyond the individual. Participants described the impact upon families, carers and friends.

"Claiming PIP has an effect on the family as I'm uptight all the time and not sleeping properly. I've been grinding my teeth in the night so that has caused severe headaches."

Laura's husband thought that the interview had gone quite well but Laura³⁰ found it damaging to their relationship.

"I wished afterwards that he hadn't been there as the whole thing was quite humiliating. I don't want to be seen as a very dependent person per se although in some ways I am. I don't want it to be part of our relationship and felt uncomfortable being spoken to in that manner in the interview."

One participant noted that it is charities and local councils that are picking up the bill for the provision of independent advice required by claimants and that advisors are under substantial pressure from clients to provide support within DWP timeframe for submitting forms.

"You have to flip your normally positive thinking on its head and think about and talk about and explain the negatives of your life. Those things that we never talk about or face because we simply can't live life that way [...] I am both relieved that I got something and upset that they either didn't believe me completely or I hadn't represented myself and my illness well enough."

³⁰ All participants have been given pseudonyms

Conclusions and recommendations

The evidence gathered in this study, building upon earlier Action for M.E. surveys and feedback from our Welfare Advice and Support Service, suggests the following:

Key stages of the PIP claim process are not fully accessible to people with M.E./CFS.

- The form is too lengthy and complex to complete without a significant amount of support which is often difficult to access due to pressures on local welfare advice services.
- People with M.E./CFS often experience great difficulty obtaining supporting medical evidence, particularly in Scotland where most have no access to specialists and often have little or no follow-up monitoring of their condition by GPs.
- Assessment centres are sometimes inaccessible and this is exacerbated by limited or distant (from the entrance) parking provision.
- The face to face assessment format is too strenuous for people who lack the physical and mental stamina to represent themselves due to the cognitive difficulties present with M.E./CFS.

The PIP assessment criteria are not being fairly and consistently applied as intended.

- Few participants felt their assessor had enough knowledge and understanding of M.E./CFS to be able to apply the descriptors accurately and fairly.
- In particular, the lack of awareness of post exertional malaise in M.E./CFS, combined with the snapshot nature of the assessment means PIP assessment too often fail to establish the capacity to undertake activities repeatedly, reliably and safely and in a reasonable time period.
- Trade-offs that claimants make every day in order to maintain enough functionality to complete basic activities of daily living such as showering, preparing food or washing dishes are not being taken into account.
- Current assessments are not identifying that when claimants with M.E./CFS say they are able to complete specific activities this may only be true when they are able to isolate and space out those activities with adequate rest periods over the course of a day or week.

The design of PIP eligibility criteria does not adequately capture the functional limitations caused by M.E./CFS.

- Many of the questions around activities are not relevant to M.E./CFS and many of the debilitating symptoms of M.E./CFS are not captured by the questions.
- In particular, the questions are not capturing people with M.E.'s ability to sustain activity over time or to repeat the activities on subsequent days.
- The questions designed to assess mental and intellectual function seem to be adapted to difficulties faced by people with mental health conditions or learning difficulties but do not translate to the difficulties caused by fluctuating, post exertional cognitive impairment in M.E./CFS. These typically manifest as problems with short term memory, concentration, finding words, processing information, decision-making, spatial navigation and functioning in busy or noisy environments. As a result, people with M.E./CFS are not accessing

support with difficulties such as form-filling, managing appointments and finding their way around.

- The current 'Moving Around' descriptors are not capturing the difficulties people with M.E./CFS have with using public transport and accessing local services. As a result, people who can mobilise more than 20/50 metres but less than 200m are losing their mobility vehicles and/or Blue Badge awards and becoming less independent.
- Although PIP is supposed to be a benefit for people in as well as out of work, under the current system, it would be exceptional for someone with M.E./CFS who has capacity to work, to qualify for PIP.

“I think that it could be simplified. I think the whole problem is the actual illness of M.E., it's not applicable, it needs to be rethought. I know it's a standard form. It needs to say: 'communicating verbally, when you've had a good day; you can manage the toilet, when you've had a good day.' Most of the stuff is not applicable, it's too black and white.”

Our recommendations

Based on the experiences of participants, and the conclusions drawn from the evidence they presented, this report makes 12 recommendations with regards to:

- improving access to assessments
- improving decision-making
- taking greater account of the impact of fluctuating conditions such as M.E.

Our first eight recommendations concern quick-gain improvements to the current system. The remaining four consider longer-term development goals.

1. Overall delays to the PIP claims process must continue to reduce. However, the timescale for returning the “How your condition affects you” form should be extended³¹ to take account of the difficulties in completing this form and the need for support from external organisations for many people with M.E./CFS.
2. Assessment centres should have adequate parking facilities close to the entrance and claimants should not have to travel more than 45 minutes to reach their assessment centre to limit the impact of travel on claimants' functional capacity. Home visits should be more readily and consistently available.
3. Ensure all assessors and decision-makers are fully trained in M.E./CFS to understand the key feature of post-exertional malaise and its impact on daily living and mobility. Assessments should only be undertaken by assessors who have had up-to-date specialist training.

³¹ On the basis of the evidence we have from this study and from organisational experience of delivering welfare advice, we suggest that a four week extension (ie. eight weeks in total) would be an appropriate timeframe. However, we would recommend further specific research or consultation on this matter.

4. There must be greater consistency in applying the current guidance on reliability. The assessor should always seek evidence on whether the claimant can perform each activity safely, repeatedly, reliably and in a timely fashion. Claimants who are unable to move around or carry out essential activities without experiencing excessive pain, breathlessness, physical exhaustion, debilitating cognitive impairment or a deterioration in health brought about by the exertion required should qualify for PIP support.
5. Due to the characteristic fluctuating nature of this illness, greater weight should be given to self-reporting and supporting evidence than to physical examination or informal observations during the face to face assessment which give only snapshot evidence and false picture of capability.
6. Decision-makers should routinely request supporting evidence for all cases directly from the claimant's chosen healthcare professional or support worker, without disadvantaging people with M.E./CFS who do not have access to an NHS health professional with sufficient knowledge of their condition to provide reliable supporting evidence.
7. Revert to 50m rule (i.e. that applied under DLA) for eligibility to enhanced support for mobility.
8. Cut down on the need for appeals. A high appeal success rate is indicative of poor initial decision-making. Welfare advisors are currently telling people with M.E./CFS they have a strong case but should expect to have to go through the appeals process to access their benefit. This places a huge emotional and physical burden on claimants and is costly to taxpayers.
9. Change questions to specifically capture the impact of pain and fatigue on activities (both mental and physical); ability to sustain activity; and ability to repeat activity over subsequent days. Explicitly consider the impact of exertion-induced (fluctuating) cognitive dysfunction.
10. Take into consideration difficulties with maintaining a clean and safe home environment, including essential tasks such as shopping for food and basic necessities, managing laundry and maintaining a healthy diet.
11. Assessment style should be more discursive and supportive and less tied to rigid descriptors; inviting claimants to give a holistic picture of how their condition affects them and their needs. There should be a much more positive focus on what claimants can achieve with appropriate support and less on proving their disability.
12. Better support is needed to ensure those engaged in claiming are aware of what is required and feel able to participate in a meaningful and engaged way. The Scottish Government should support the provision of independent advocacy for people with long term health conditions across the whole of Scotland. We recommend establishing a statutory right to independent advocacy support for people with physical disabilities in line with that already established for people with mental health disorders.

Appendix I: weekly rates and descriptors for PIP

The standard weekly rate for the daily living component is currently £55.10, whereas the enhanced weekly rate is currently £82.30. The standard weekly rate for the mobility component is currently £21.80, whereas the enhanced weekly rate is currently £57.45.

Claimants score points by demonstrating their lack of ability to perform the specific activities listed under

- the daily living component
- the mobility component.

The points scoring system is underpinned by prescriptive criteria purporting to measure capacity. Scores are allocated on the basis of information provided in the claim form and, in the majority of cases for people with M.E./CFS, information gathered (including through assessor observations) during the face-to-face assessment.

The daily living component covers the ability to complete the following activities:

- prepare food
- take nutrition
- manage therapy or monitor health condition
- wash and bathe
- manage toilet needs
- dress and undress
- communicate verbally
- read and understand signs, symbols and words
- engage with other people face to face
- make budgeting decisions.

The mobility component covers the ability to:

- plan and follow a journey
- move around.

Each activity has a set of 'descriptors' and points are awarded according to the descriptor that a claimant satisfies. Points for each activity in each of the components are added-up.

If a claimant scores eight points for either component, they will receive the standard rate of PIP for that component. If a claimant scores 12 points for a given component, they will receive the enhanced rate of PIP for that component.

Appendix II: interview schedule

Beginning the claims process

1. Was the initial claims procedure straightforward or did you need help?
 - a) Were you aware of all of the information you needed to provide when you made the initial claim by telephone or online? Yes, no, partially – if so what not known at the time?
 - b) Were you aware of any organisations (or guidance) that could assist you? Who, if anybody, did you receive help from? (eg. family, friends, online, DWP, voluntary sector organisations)
 - c) Was there a difference between info/support received from DWP vs other sources? If so, what difference/s did you notice?
 - d) Was there any source of information that was better than the rest? Why? (eg. easier to understand, enough detail, more relevant, timely?)
 - e) Did you encounter any problems with the timescale for submitting forms etc.? What problems, why, outcome?

Assessments

2. Face to face interviews

a) Assessment Centre

How accessible was it (travel time, transport links, parking, walking distance, steps etc)?

Comfortable?

Did you request a home visit? If so, was it declined? On what grounds?

b) Home visit

How well did it meet your needs?

Did you request a home visit or was it offered to you?

If requested, was it difficult to obtain?

c) Confidence in assessors

- How satisfied are you with the way your assessor interacted with you?

- How long was your assessment? Did this seem adequate? Too long?

- How much confidence did you have in your assessors' knowledge and ability to make a fair assessment? Why?

Decision

3. How long did it take from making the claim until payment (or final decision) received and what has been the *impact* of any delays in receiving payment/a decision?

a) On you as an individual

b) On family members

c) Any knock-on effects – access to other benefits (e.g. passported benefits - housing, blue badge or linked benefits eg. ESA)?

4. Are you satisfied that a fair decision was made in the end? Why?
If not, have you appealed or do you have plans to appeal?
How long was your award made for & does this seem reasonable?
How do you feel about your situation now?

Overview

5. Did you experience any difficulties with the following aspects of your claim – if so, what were the causes and to what extent were any problems resolved?

- a) Completing the forms (online or paper)?
- b) Explaining your situation to advisors or assessors over the telephone or face-to-face?
- c) Providing supporting evidence?
- d) Missing paperwork or records?
- e) Finding out about the outcome of your application?
- f) Inaccurate information recorded?
- g) Reconsideration & appeals process?
- h) Termination, suspension of payments or sanctions?

6. Online applications – capacity and preferences

- a) Would you be able to make a future application online?
- b) What is your preferred application medium (i.e. online, written form or telephone?)

7. What is your overall experience of claiming PIP?

- a) Negatives?
- b) Positives?
- c) How well informed did you feel about how the system works:
For welfare benefit claims overall?
For PIP specifically?
- d) How would you sum up the overall process in a few words?

8. Is there anything you know now that you wish you'd known about when you first made your claim? (eg. how to make an effective claim, save time etc)

9. How could the PIP claims process be improved?

- a) Generally for all PIP claims?
- b) For people with M.E. specifically?

10. For those who have received PIP – how are you spending the benefit and what difference has this made to you?

For those who are still in the process of applying/appealing – what difference do you hope PIP will make to you? How would you spend the benefit?

For those whose claim has been rejected – what difference would the benefit have made to you? How would you have spent it?



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