



PIP AND MND: IS THE BENEFITS SYSTEM FAILING PEOPLE WITH MOTOR NEURONE DISEASE?



CONTENTS

Introduction

About PIP

About MND

About the MND APPG

Executive summary

1. Does the PIP application process work for people living with MND?
2. Transition from DLA
3. How people living with MND experience the PIP assessment process
4. Appeals and reconsideration
5. Reassessment

Section 1. Does the PIP application process work for people living with MND?

- 1.1 About the PIP application process
- 1.2 Information and evidence
- 1.3 Special rules for terminal illness

Section 2. Transitioning from Disability Living Allowance

- 2.1 Awareness of the transition
- 2.2 Changes to rates of support

Section 3. How people living with MND experience the PIP assessment process

- 3.1 Face-to-face assessments
- 3.2 Understanding of MND
- 3.3 Accuracy of results
- 3.4 Overall satisfaction

Section 4. Appeals and reconsideration

- 4.1 Time limits
- 4.2 Tribunals and decisions
- 4.3 Experiences of the appeals process
- 4.4 Engagement with assessment providers

Section 5. Reassessment

- 5.1 Frequency of reassessment
- 5.2 Face-to-face reassessments
- 5.3 Changes to awards
- 5.4 Overall satisfaction

Conclusion

INTRODUCTION

The All-Party Parliamentary Group (APPG) on motor neurone disease (MND) is a cross-party group of MPs and Peers with an interest in MND. We agreed in March 2017 to hold an inquiry on the subject of access to Personal Independence Payment (PIP) for people with MND living in England, Scotland, Wales and Northern Ireland.

For people living with a complex and severe health condition such as MND, PIP is a vital source of support, providing financial payments as well as access to subsidised mobility vehicles for claimants with higher mobility support needs. PIP was introduced to replace Disability Living Allowance (DLA) in 2013, and is due to have replaced it for the majority of claimants by mid-2019. PIP will therefore be the primary benefit for people living with disability and ill-health for the foreseeable future, and it is essential that the system works effectively for people living with MND. Research published by Demos¹ in 2017 found that MND costs individuals an extra £1,000 a month before loss of earnings. Access to benefits like PIP is therefore vital in mitigating the financial impact of the disease.

- The inquiry has sought to determine whether the PIP claims process works well for people living with MND. This includes addressing the following questions:
- Is the PIP application process appropriate and manageable for people living with MND?
- Do people living with MND receive a decision on their PIP support in a timely manner?
- Are the requirements of the PIP application process sufficiently transparent?
- How well does the assessment process meet the needs of people living with MND, and does it produce accurate results?
- What is the impact of the transition from DLA to PIP for people living with MND?
- How often are people living with MND asked to undergo reassessment for PIP, and what is the impact of this?
- Is the appeals process accessible and effective for people living with MND?

A call for evidence was issued in March 2017, inviting people with personal experience of motor neurone disease to complete an online survey in order to better understand their views and experiences of claiming and receiving PIP. In addition, we spoke to health professionals with experience of supporting people living with MND through the PIP application process, and met with PIP assessment provider organisations Independent Assessment Services (IAS, previously known as Atos Healthcare until 2017) and Capita to understand their views on the assessment process. We would like to thank all the people who took part in the survey, especially those living with MND and those who may have died by the time of publication.

¹ MND Costs: Exploring the financial impact of motor neurone disease, Demos 2017 www.demos.co.uk/project/motor-neurone-disease-survey

ABOUT PIP

PIP is a non-means tested benefit for people aged between 16 and 64, which provides financial support to help with the extra costs of long-term illness or disability. PIP replaced the predecessor benefit, DLA from July 2015 onwards, with all DLA claimants expected to have moved over to PIP by mid-2019.

PIP is split into two components, a daily living component and a mobility component, each of which is available at either a standard rate or an enhanced rate. The daily living rate is intended to provide extra help for everyday activities such as washing and dressing, preparing food and communicating. The mobility component is intended to support people who have difficulty getting around, and can include use of a mobility support vehicle.

The weekly rate for the daily living component of PIP is either £55.65 (standard rate) or £83.10 (enhanced rate). The weekly rate for the mobility component of PIP is either £22 (standard rate) or £58 (enhanced rate). In addition, people claiming the enhanced rate mobility component are entitled to lease a mobility vehicle such as a powered wheelchair, scooter, or adapted car. PIP benefits are untaxed, not means-tested and are not subject to the benefits cap. All PIP claimants are required to undergo an assessment of the functional impact of their health condition in order to determine whether they qualify for PIP, and at what rate.

According to the latest caseload figures published by the Department for Work and Pensions, there were 1,294 people living with MND and claiming PIP as of January 2017. In addition, there are currently 1,153 people with MND who still claim DLA according to the latest available statistics from November 2016.

ABOUT MND

MND is a fatal, rapidly progressing disease of the brain and central nervous system, which attacks the nerves that control movement so that muscles no longer work. There is no cure for MND.

While symptoms vary, over the course of their illness most people with MND will be trapped in a failing body, unable to move, talk, swallow, and ultimately breathe. Speech is usually affected, and many people will lose the ability to speak entirely. Some people with MND may also experience changes in thinking and behaviour, and 10-15% will experience a rare form of dementia.

MND kills a third of people within a year and more than half within two years of diagnosis, typically as a result of respiratory failure. A small proportion of people experience slower progression and live with MND for longer, but survival for more than ten years is highly unusual.

A person's lifetime risk of developing MND is up to 1 in 300. It can affect any adult, but is more common in older people: it is most commonly diagnosed between the ages of 50 and 65. There are about 5,000 people living with MND in the UK.

ABOUT THE MND APPG

The All-Party Parliamentary Group on MND is a cross-party group of MPs and Peers with an interest in MND. The purpose of the Group is to increase awareness and understanding of MND amongst parliamentarians and to campaign for better access to high quality services for people affected by MND.

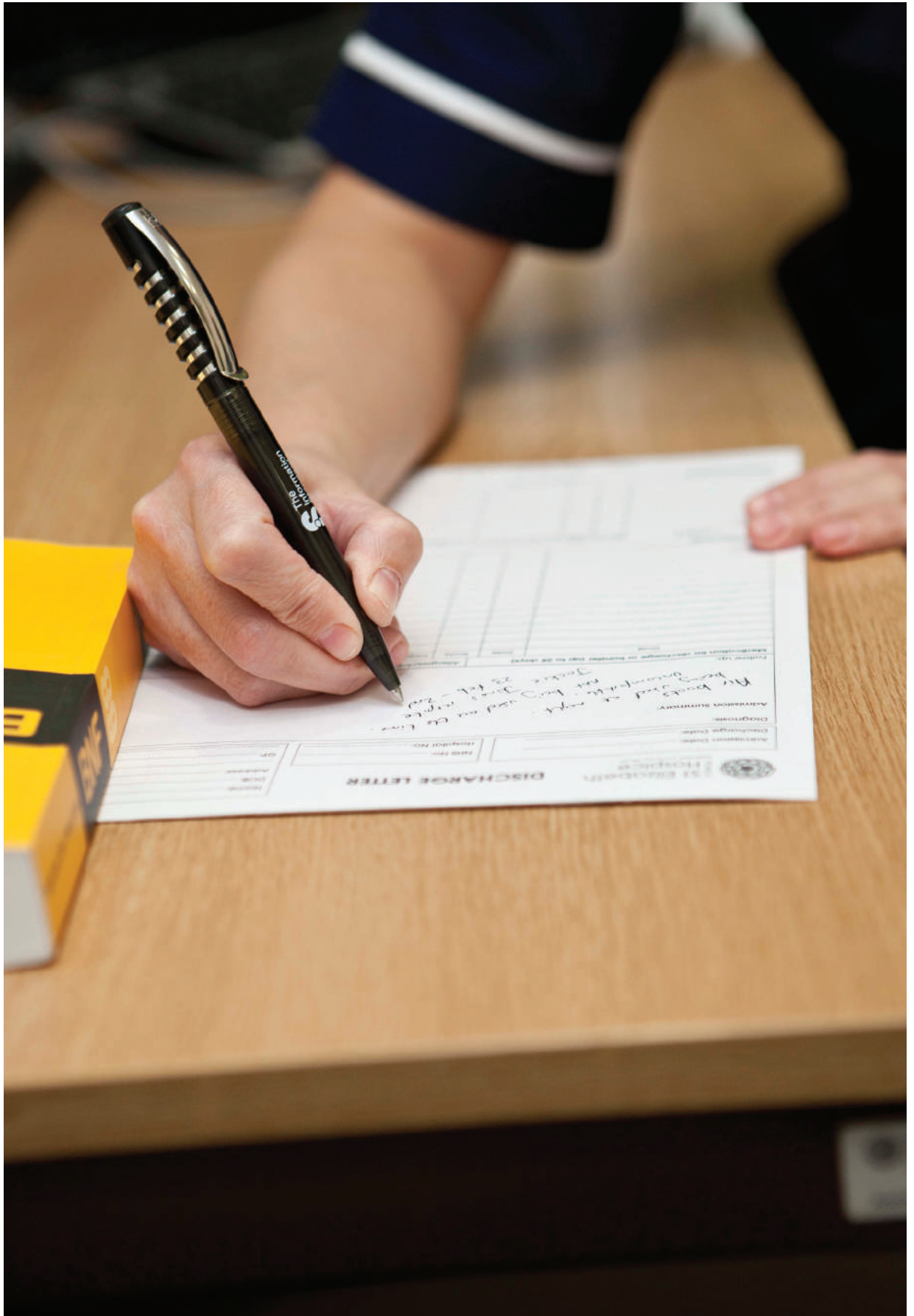
The group was established in 2002 and meets regularly in Parliament. The officers of the group are:

Chair – Madeleine Moon MP (Bridgend)

Vice Chairs – Paul Blomfield MP (Sheffield Central) and Mary Robinson MP (Cheadle)

Secretary – Chris Evans MP (Islwyn)

The MND Association provides the secretariat to the Group.



EXECUTIVE SUMMARY

1. DOES THE PIP APPLICATION PROCESS WORK FOR PEOPLE LIVING WITH MND?

A key requirement of an effective benefits application process is that it should be accessible and comprehensible to prospective claimants. 47% of survey respondents felt that accessing the information needed to apply for PIP was either 'very easy' or 'moderately easy'. However, 31% of respondents found it either 'very difficult' or 'moderately difficult' to find this information.

SUPPORTING EVIDENCE

Alongside their PIP application form, claimants are requested to submit supporting evidence of their disability and its impact. 12% of respondents reported difficulties with this, and it is clear that obtaining the appropriate supporting evidence was a difficult and stressful experience for some. 13 of 22 professionals felt that they had not received sufficient guidance on providing supporting evidence for PIP claims.

Even when they receive the necessary information, claimants may still have difficulty obtaining evidence from health professionals. The majority of health professionals receive no incentives to encourage them to contribute evidence for PIP claims in a timely and supportive manner. In addition, it is essential that assessors do not focus solely on evidence drawn from health and care professionals. The DWP should review its guidance to assessment providers to ensure evidence of carers and family members is given sufficient weight during the assessment process.

SPECIAL RULES FOR TERMINAL ILLNESS

People living with MND can also consider submitting an application under the Special Rules for Terminal Illness (SRTI) provision, which enables applications to be fast-tracked. SRTI claimants need to submit a completed DS1500 form, which must be completed by a GP, consultant, hospital doctor or specialist nurse to confirm that the claimant is living with a terminal condition. MND is a terminal condition in all cases, although the speed of its progression and the life expectancy of people with the condition varies very significantly from case to case.

RECOMMENDATIONS:

The DWP should clarify and improve the information provided to claimants on the provision of further evidence.

The DWP should work with the Department of Health and its counterparts in the devolved administrations to incentivise and support health professionals to engage in providing evidence for PIP claims.

The DWP should review its guidance to assessment providers to ensure evidence of carers and family members is given sufficient weight during the assessment process.

The DWP should review its guidance around the use of DS1500 to reflect the variable nature of terminal conditions and ensure that people living with terminal conditions such as MND are not excluded, with particular reference to the 'reasonable expectation' of death within six months.

The DWP should update its guidance for assessors to emphasise that staff are not entitled to challenge the validity of a DS1500 form signed by a health professional.

Although MND is a terminal condition, our survey data reveals that only a small minority of people with MND made a PIP claim under the SRTI provisions. 28% of claimants with MND claimed under SRTI, with over 70% following the standard process.

The DWP's current guidance states that SRTIs should be used where the claimant is suffering from a progressive disease, and their death can be reasonably expected within six months. However, given the highly variable progression of a condition like MND, the prognosis in the early stages of the disease is very difficult to predict. This creates confusion for health professionals who in some cases are reluctant to sign DS1500 forms as a result, leading to distressing delays and unnecessary face-to-face assessments for people with MND. People with MND and their families may also be reluctant to claim under SRTI, as it is an acceptance that death is imminent which is a painful step for claimants and their loved ones.

There are also concerning reports of assessors questioning the validity of submitted DS1500s themselves. However, 13 of 21 HCPs who provided evidence to the inquiry stated that assessors had contacted them to question a submitted DS1500.

2. TRANSITION FROM DLA

Disability Living Allowance (DLA) is a predecessor benefit to PIP, and the majority of DLA claimants will have the opportunity to transfer to PIP if they have not already. The exceptions are DLA claimants who were aged 65 or over on 8th April 2013, and this cohort will continue to claim DLA indefinitely. There are 1,153 people living with MND who currently claim DLA according to the latest DWP figures from November 2016.

When claimants transfer from DLA to PIP, they are not automatically entitled to the same rate of support that they previously received, and are subject to a full assessment for their PIP entitlement. As MND is a progressive condition in all instances, it should never be the case that a claimant with MND experiences a support reduction following their move from DLA to PIP. Where support reductions do occur during the transition from DLA to PIP, they may be linked to a poorly-conducted assessment which fails to accurately assess the needs and circumstances of the individual claimant. A number of respondents to our survey expressed the view that the PIP assessment process that they underwent was entirely inappropriate.

Requiring people living with MND to undergo a new assessment when they transition from DLA to PIP is an unnecessary hurdle which represents an inefficient use of resources, given that there is no possibility that the impact of MND will become less severe over time. It is a source of anxiety and stress to people already struggling with the severest of health conditions, and opens the door to damaging errors during the reassessment process. We recommend that the DWP should agree to 'passport' claimants with a confirmed diagnosis of MND from DLA to PIP at the same rate of support.

RECOMMENDATIONS:

The DWP should transfer claimants from DLA to PIP at the same rate of support, unless the claimant requests a new assessment.

The DWP should review how the DLA to PIP transition process is working for people with progressive conditions and consider changes to meet the needs of this claimant cohort.

3. HOW PEOPLE LIVING WITH MND EXPERIENCE THE PIP ASSESSMENT PROCESS

As MND is a severely disabling and rapidly progressing terminal condition, it is essential the PIP assessment process is delivered swiftly to ensure that people with MND are able to meet their daily living and mobility needs. It is expected that people living with MND will have paper-based reviews in the majority of instances, as set out in DWP guidance. Despite this, the APPG's survey of people living with MND found that as many as 56% had received a face-to-face assessment as part of their PIP application.

UNDERSTANDING OF MND

Given the relative rarity of MND it is important that assessors have access to the information, guidance and training required to be able to understand and provide an appropriate assessment of the functional impact of MND, particularly as it is a progressive condition. A repeated theme throughout survey responses was that assessor knowledge of MND and its functional impacts was poor. 57% of survey respondents thought that their assessor(s) did not show a sufficient understanding of MND.

In addition, concerns were expressed that elements of the assessment were too crude and simplistic to properly measure the functional capabilities of someone living with MND, including the 20 metre walking test which does not prove that an individual retains independent mobility. As a progressive condition, MND can rapidly diminish a person's ability to walk, making the initial assessment obsolete after a short time. Our survey suggests that many claimants have a negative perception of the accuracy of the process, with 53% stating that the results of the assessment did not accurately reflect their needs.

The overall impression the APPG has received from people living with MND is that there is significant dissatisfaction and a lack of trust associated with the PIP assessment process. There is also an underlying feeling that the assessment itself is not fit for purpose in determining functional capability when living with a multifaceted and complex progressive condition such as MND.

RECOMMENDATIONS:

The DWP should collect and publish data on the number of people with MND receiving face-to-face assessments and paper-based reviews for PIP.

The DWP should require assessment providers to demonstrate that they are following guidance and that people with MND are not being called to a face-to-face assessment.

Assessment providers should ensure sufficient information and guidance on MND is provided to assessors prior to an assessment with a claimant living with the condition.

The PIP assessment should be reviewed to ensure it is fit for purpose and takes better account of the complex nature of a condition such as MND.

4. APPEALS AND RECONSIDERATION

TIMELINES

Requests for mandatory reconsideration are required to be submitted within one month of receiving the decision on PIP support, and tribunal appeals must be submitted within one month of receiving the result of the mandatory reconsideration process. The one-month timeframe to appeal decisions can be problematic for claimants in some cases, particularly where the reasoning for the decision is not well communicated. Claimants frequently do not receive clear information explaining the reasoning behind

the decision on their PIP eligibility. Unsuccessful claimants do not usually get a copy of their assessment report along with their decision letter, meaning that they may not understand the basis on which the decision was made. As a result, 50% of respondents believed that they were not given enough time to submit an appeal after receiving their support decision, while 38% believed that they were not given enough information on how to do so.

TRIBUNALS AND DECISIONS

Once an appeal has been submitted, claimants may be asked to attend a tribunal hearing in person. Respondents to our survey did not feel confident that the members of their appeals panel were sufficiently well-informed, with 68% of people stating that the appeal panel did not have a sufficient understanding of their medical condition. Respondents pointed to the rapid progression of MND as an aspect of the condition that was not well understood by panel members

The results of our survey show a mixed picture on waiting times for appeal decisions, which range from less than one month to four months. Although successful appeals will receive backdated payments to the date of the initial award decision, we consider four months to be an excessive wait for a decision of this importance to the individual concerned. It is particularly damaging in the case of people living with MND, who may experience a very significant degree of progression of their condition, or even death, during that length of time.

Both IAS and Capita stated that the appeals process is a stand-alone function, from which they receive little or no feedback and have little involvement with. This suggests that an important opportunity for feedback and learning that may promote improvement in the assessment process is being missed. Both providers suggested they would welcome feedback on how a decision made at the appeals stage relates to the assessment. It was noted that better engagement with the DWP would foster this flow of information.

RECOMMENDATIONS:

The DWP should routinely provide a copy of a claimant's assessment report alongside their decision support letter, to enable an informed understanding of the rationale for the decision and the merits of a potential appeal.

The DWP should clarify the responsibilities of both claimants and assessors in gathering and reviewing supporting evidence and provide this information to claimants once their initial application is received.

The DWP should extend the timeframe in which appeals are allowed after receiving the support decision.

The DWP should review the information and guidance available to appeals tribunals relating to rare and complex medical conditions and their functional impacts.

The Ministry of Justice should reverse its decision to remove the requirement for tribunal panels to include people with relevant medical expertise or experience of a disability.

The DWP should publish updated guidance on PIP appeals including a target time limit by which appeals should be processed and a decision provided. We suggest a target time of three months.

Communication between the DWP and assessment providers on appeals should be formalised, so that providers are routinely notified of the results of appeals and any learnings applicable to the assessment process.

5. REASSESSMENT

All PIP awards are subject to periodic review and the length of an award is decided by a DWP case manager. Upon review, the rate at which PIP is paid to a claimant can be altered, a new component of the benefit can be awarded or taken away and the fixed duration of the award can be extended or reduced. There is currently no exemption from reassessment for people with the most severe conditions such as MND. We believe that people with MND who receive PIP at the highest rates for both components should receive ongoing awards with no review required. In the absence of an exemption policy for reassessment, they should expect to receive an award of maximum possible duration.

However, 27% of people who answered the relevant survey question indicated that since they had started receiving PIP they have had a reassessment. Additionally, in February 2017 the DWP released data showing that 200 reassessments of people living with MND were conducted between April 2015 and October 2016.

The limited availability of data on review periods and reassessments makes it difficult to understand the impact of reassessment requirements on the MND population as a whole. The collection and publication of more detailed data by the DWP on support awards, review periods and reassessment results would enable better scrutiny of the process and support a more informed understanding of its effectiveness for people with MND.

FREQUENCY OF REASSESSMENT

The survey responses indicate that in some instances, people living with MND are asked or request to undergo a reassessment after a very short time. Over half of the responses to the relevant survey question showed that their reassessment had taken place within 12 months of their original award, with 21% happening within 6 months.

If someone living with MND who receives a lower support rate experiences a deterioration so that their current entitlement is no longer adequate, it is essential that this happens quickly so that the benefit can match their immediate support needs. The DWP and assessment providers should aim to achieve demonstrable reduction in the numbers of reassessments happening for people living with MND, particularly those taking place within twelve months.

FACE-TO-FACE REASSESSMENTS

Of those who had been reassessed, the survey found that 67% had face-to-face assessments. As clearly outlined in section 3 of this report, the majority of cases involving MND should be assessed by a paper-based review. Given that there is no prospect of recovery from MND, it is unclear why providers should request face-to-face assessments. Some of the survey responses detailed how condition progression had made it physically harder to attend a face-to-face assessment, the journey to the assessment centre becoming increasingly difficult to cope with even with the support of family and friends.

CHANGES TO AWARDS

Of those who responded to the relevant survey question, 61% said that their award had increased as a result of their reassessment. The remaining 39% reported their award had stayed the same. It is positive that survey responses indicate upon reassessment awards are being increased. However, we are aware anecdotally that this is not always the case. MND is progressive in all cases, so any suggestion that a claimant's support needs have fallen should be treated with great scepticism. The DWP should ensure that any instance of a support reduction on reassessment is fully reviewed and the relevant learnings collected.

Among people living with MND who took part in the APPG's research, 50% indicated that they felt satisfied with the reassessment process overall. However a significant proportion, 42%, said that they were moderately or very dissatisfied with the reassessment process overall. Initial assessment results need to better take into account the rapid progression of MND in order to more accurately reflect its functional impact on claimants. More accurate assessments would reduce the number of reassessments required as well as the number of appeals, increasing the efficiency of the system and ensuring that people living with MND have access to the right rate of benefit as soon as they need it.

As the roll-out of PIP continues, the DWP should closely monitor this important element of the process in order to ensure the system is working properly for people with severe and progressive conditions such as MND.

RECOMMENDATIONS:

The DWP should publish the number and details of ongoing awards and review periods given to claimants with MND.

The DWP should undertake a review of the types of awards and review dates being given to claimants with progressive and severe conditions such as MND.

The DWP should work with provider organisations to end the practice of reassessments for PIP for people living with MND who are already in receipt of the enhanced rate for both components.

The DWP should set a target for a reduction in the number of reassessments for people living with MND within the first 12 months of their award.

The DWP and assessment providers should collect and publish data on the number of people with MND who are asked to attend a face-to-face reassessment.

The DWP should ask assessment providers to demonstrate how they ensure adherence to PIP assessment guidance on face-to-face assessments upon review of a claimant's PIP award.

The DWP should review the reassessment process for people living with rapidly progressing and terminal conditions such as MND, with the aim of ensuring it is fit for purpose and limiting the burden on those with the disease.

Any reassessment outcome for someone with MND that results in a lower award should be reviewed by the DWP and assessment providers, given the progressive nature of the disease in all cases.

Assessors should have access to information on MND prior to conducting a reassessment to ensure there is full understanding of the nature of the disease and its progression.

SECTION ONE



DOES THE PIP APPLICATION PROCESS WORK FOR PEOPLE LIVING WITH MND?

It is essential that the initial application process for PIP is accessible, comprehensible and manageable for people coping with the impact of a severe health condition or disability. The process includes activities that can be challenging for people in this situation, including filling out forms appropriately, conducting telephone applications, providing relevant supporting evidence and accurately capturing the functional impact of the claimant's health condition. It is therefore vital that claimants are provided with the necessary information, guidance and time to fulfil all the requirements of the application process. An unclear or excessively burdensome process will put off people from applying for and accessing the support that they need and are entitled to. It also increases the likelihood of inaccurate judgements and inappropriate decisions on eligibility.

ABOUT THE PIP APPLICATION PROCESS

PIP claims can be initiated by telephone or text phone, or through a paper-based form for those unable to use the telephone. The claimant must provide information about his or her personal details including:

- Claimant's name, age and contact details
- Residency details
- Relevant periods spent in hospital and/or residential care
- Claims under special rules for terminal illness (SRTI)
- Bank account details
- Details of main illnesses or disabilities.²

The initial phone call can be made by someone supporting the claimant, such as a carer, support organisation or family member. They must be with the claimant during the call.

Once the initial claim has been submitted, the claimant will receive a form in the post entitled "How your disability affects you" (also known as a PIP 2 form), along with an information booklet. The form contains questions aimed at assessing the functional impact of the claimant's condition or disability. It also requests the contact details of a health or care professional who can be contacted about the claim.

In addition, the form asks claimants to submit supporting evidence for their application as soon as possible. This refers to evidence of the claimant's disability and its impact, and can include reports or information from family and friends as well as health and care professionals such as GPs, hospital doctors, specialist nurses, occupational therapists, social workers, and support workers.

INFORMATION AND EVIDENCE

A key requirement of an effective benefits application process is that it should be accessible and comprehensible to prospective claimants, including those living with severe disability. Information on how to complete the process should be easily available and there should be clear instructions relating to any requirements for supporting evidence and how to provide it.

We asked survey respondents "how easy or difficult was it to find the information you need about PIP and how to apply?" and their responses showed a mixed picture. 47% of respondents felt that accessing the information needed was either 'very easy' or 'moderately easy'. However, 31% of respondents found it 'very difficult' or 'moderately difficult' to find this information. Although 77% of respondents agreed that they

² Personal Independence Payment: the claimant journey, DWP 2013, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/448596/PIP-advisers-claimant-journey.pdf

were ultimately able to find the information necessary to submit their claim for PIP, it is a cause for concern that 18% stated they were unable to do so.

Alongside their PIP application form, claimants are requested to submit supporting evidence of their disability and its impact. In the majority of cases, claimants are able to acquire this evidence from health or care professionals such as their GP, consultant, social worker or specialist nurse. Positively, 80% of respondents to our survey stated that they were able to obtain and submit this evidence without much difficulty. However, 12% of respondents reported difficulties with this aspect of the application process, and it is clear that obtaining the appropriate supporting evidence was a difficult and stressful experience for a minority of people.

Some survey respondents mentioned the time delay caused by seeking out supporting evidence, which led to a longer wait to receive the support they needed and were entitled to. Others described a slow and frustrating process of having to coordinate and persuade reluctant health professionals to do their part.

“GP reluctant to fill form in. Because it was the doctor who initially delayed a referral leading to diagnosis he gave in. Then there was a delay because I thought they had sent it but wasn't received. Then another GP did one and they didn't tell me, I had to collect it and send myself. I also enrolled help of local Carers association to complete form.”

As part of the inquiry we received comments from health and care professionals with experience of providing supporting evidence for PIP applications. 21 professionals commented on whether they felt their evidence was taken into account appropriately, and views were mixed: 10 agreed that their evidence was properly used most of the time, while seven believed this was sometimes the case and four believed that their evidence was not usually taken into account. One commented that their evidence was listened to “only after I have to write an angry letter on my patient's behalf,” and another that their evidence was frequently questioned. Another commented that the evaluation of evidence by assessors was impeded by their lack of contextual knowledge about the condition, particularly its progressive nature. In addition, over half of the professionals we spoke to felt that they had not received sufficient guidance on providing supporting evidence for PIP claims.

The Second Independent Review of PIP, published by the Department for Work and Pensions in March 2017, noted that there remain “numerous challenges in effectively obtaining Further Evidence, faced both by individuals before they submit a claim and by assessment providers when they receive it.”³ The report cites issues including variable access to health professionals depending on the nature of the claimant's care pathway; lack of understanding about the purpose of the evidence, particularly that it should relate to the functional impact of the condition, rather than simply the medical circumstances of the claimant; and unclear information given to claimants regarding evidence requirements.

PIP's focus on functional impact is influenced by the social model of disability, which views disability as a function of the ways that society restricts the life choices of people living with physical difference or impairment. It primarily aims to remove the barriers that restrict people's ability to participate fully in society. This can include physical solutions such as alterations to the environment and assistive equipment, as well as a focus on changing attitudes within wider society.

This contrasts with the traditional medical model of disability, which focuses narrowly on an individual's physical difference or impairment as the primary cause of disability. This approach has been criticised for detracting focus from an individual's needs and creating a culture of low expectations. It presupposes that the impact of physical difference can be addressed through medical interventions, which is often not the case.

³ The Second Independent Review of PIP, March 2017, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/604097/PIP-assessment-second-independent-review.pdf

SECTION ONE

The DWP should take steps to clarify and improve the information provided to claimants on further evidence. This should include:

- Clearer guidance on the difference between an assessment of functional impact and a medical assessment, with clear examples to show how functional impact can be clearly communicated, evidenced and recorded.
- Clearer information on claimant's responsibilities around the provision of further evidence, emphasising that claimants must take the lead in arranging and providing it.

Even when they receive the necessary information, claimants may still have difficulty obtaining evidence from health professionals. The majority of health professionals receive no incentives to encourage them to contribute evidence for PIP claims in a timely and supportive manner. GPs, as certifying medical practitioners, have a statutory obligation to provide statements of incapacity to patients on their list, and are reimbursed for this activity through the GP contract. However, depending on a person's care needs, a GP will not always be the best source of relevant information.

People living with MND, whose care is most commonly coordinated through specialist MND clinics, often have little contact with their GP post-diagnosis. Where the most appropriate person is not a GP, there is no system in place to ensure that assessors will receive further evidence in a timely manner. We have been made aware through MND Association Care Centres of the difficulties of managing these requests in a setting where there may not be any administrative staff to assist with correspondence. We recommend that the DWP engages with the Department of Health and its counterparts in the devolved administrations to explore options to incentivise and support health professionals to engage in providing evidence for PIP claims.

In their evidence to the inquiry both IAS and Capita, the two PIP assessment provider organisations, stressed the importance of evidence when making a claim. The providers noted that conducting an accurate paper-based assessment of all 12 assessment areas with little evidence is challenging. As part of the investigation, the APPG asked the providers what they thought would be a helpful change that would ensure they had all the required information before an assessment to see a case in a fully rounded way. In response, it was indicated that clear communications with the claimant and people supporting them of the types of information to provide early in the process along with the initial claims pack would be beneficial. Secondly, it was felt a better process for communications between assessment providers and providers of evidence would be beneficial.

A key issue raised by the assessment providers was that not all of the evidence submitted by claimants and health and care professionals relates to functional and day-to-day impacts of a condition, on which the PIP assessment is based. One provider had conducted a trial into gathering evidence and found that of the evidence received by them within the service level agreement time, on average less than 10% related to day-to-day functional capability. This suggests the need for clearer guidance and information on how assessors judge and use the evidence they receive.

In addition, it is essential that assessors do not focus solely on evidence drawn from health and care professionals. Family members, carers, friends and loved ones can provide a real insight into the everyday functional impact of a claimant's disability or health condition. When asked about the types of evidence being considered, both provider organisations stated that all evidence is taken seriously including that of carers, and Capita noted they have developed a training module on health professionals acquiring knowledge from carers during face-to-face assessments. However, the Second Independent Review of PIP found that the evidence of friends and family members is not always given sufficient weight, as evidence from health care professionals is "considered more objective".⁴ The DWP should review its guidance to assessment providers to ensure evidence of carers and family members is given sufficient weight during the assessment process.

RECOMMENDATIONS:

The DWP should take steps to clarify and improve the information provided to claimants on the provision of further evidence.

The DWP should engage with the Department of Health and its counterparts in the devolved administrations to explore options to incentivise and support health professionals to engage in providing evidence for PIP claims.

The DWP should review its guidance to assessment providers to ensure evidence of carers and family members is given sufficient weight during the assessment process.

SPECIAL RULES FOR TERMINAL ILLNESS

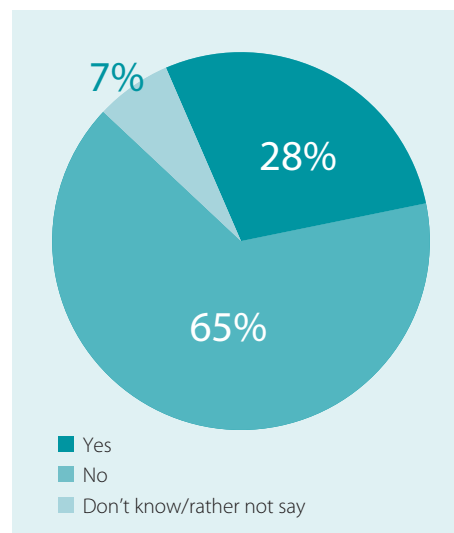
People living with MND can also consider submitting an application under the Special Rules for Terminal Illness (SRTI) provision, which enables applications to be fast-tracked. If an SRTI is approved, the claimant will not have to undergo a face-to-face assessment of the functional impact of their disability, and should receive their first payment much more quickly after application (usually within two weeks). Successful applications under SRTI will receive the highest rate of PIP award.

In order to submit a successful SRTI application, claimants need to send in a completed DS1500 form, which must be completed by a GP, consultant, hospital doctor or specialist nurse to confirm that the claimant is living with a terminal condition.⁵ MND is a terminal condition in all cases, although the speed of its progression and the life expectancy of people with the condition varies very significantly from case to case. 50% of all people diagnosed with MND will die within two years of receiving their diagnosis, while others live for a number of years with the condition. The most common cause of death among people with MND is respiratory failure, often with additional chest infection, as the muscles controlling breathing cease to function properly.

Although MND is a terminal condition, our survey data reveals that only a small minority of people with MND made a PIP claim under the SRTI provisions. 28% of claimants with MND claimed under SRTI, with over 65% following the standard process. The low take-up of SRTI applications for a terminal condition such as MND should be a cause for concern. It unnecessarily delays access to benefits for people who urgently require support, and creates waste in the system as a result of unnecessary assessments for people whose applications should have been fast-tracked.

Evidence suggests that some health professionals are unsure about when it is appropriate to submit an SRTI on behalf of a claimant. The DWP's current guidance states that SRTI applications should be used where the claimant is suffering from a progressive disease, and their death can be 'reasonably expected' within six months.⁶ However, given the highly variable progression of a condition like MND, the prognosis in the early stages of the disease is very difficult to predict. This creates confusion for health professionals who in some cases are reluctant to sign DS1500 forms as a result, leading to distressing delays and in some cases causing people to undergo unnecessary face-to-face assessments.

"GP declined to submit a DS1500 and consulted with a senior G.P who agreed [to sign]. However the DS1500 arrived too late and I had to attend a demoralizing and distressing interview."



Did you make a claim for PIP under the Special Rules for Terminal Illness (SRTI)?

⁵ PIP Assessment Guide, DWP 2015, <http://qna.files.parliament.uk/qna-attachments/437040/original/Annex%20HL%204506.pdf>

⁶ Waiting to Benefit, Macmillan 2014, <http://www.macmillan.org.uk/documents/getinvolved/campaigns/campaigns/welfare-reform/waiting-to-benefit-report.pdf>

It should be noted that this depends to a great extent on the individual professional concerned, and many take a proactive and supportive approach to assisting people with their SRTI applications. In the most positive examples, health professionals are aware of the SRTI system and are able to suggest this approach to patients who meet the criteria.

“My MND specialist nurse offered to fill in the SRTI form once I told him I had been summoned for a face to face interview. I then received a quick decision.”

We asked health and care professionals of their view of the SRTI process, and found mixed opinions. Ten HCPs believed the DS1500 form was fit for purpose, while ten disagreed. Critical comments included the view that the DS1500 is insufficiently flexible for people with progressive conditions, and one HCP commented that “many MND patients die without a DS1500 in place.” There was a degree of uncertainty about the six month requirement, with one HCP describing it as a “hindrance” and another stating that they felt “unsure about the qualifying criteria in terms of MND and unpredictable prognosis”. This suggests a need for clearer guidance in this area.

In addition, there is a concern that even where a DS1500 is submitted appropriately, the system has not properly managed the request, either due to administrative errors or a reluctance to accept the judgment of the health professional concerned. In one instance, a practice manager received a call from an assessor requesting further information on a DS1500 submitted by the claimant. The GP who had signed the DS1500 had not yet updated the claimant’s medical records on their system, and so the practice manager informed the assessor that they could see no reason for a DS1500 to have been issued. The DS1500 was then disallowed and the claimant removed from the special rules for terminal illness (SRTI) fast-track.

There are also concerning reports of assessors questioning the validity of submitted DS1500s themselves. We are aware of instances where health professionals have been asked either by an assessor or a case manager whether a person with a DS1500 has less than six months to live. This was corroborated by evidence provided to the inquiry by health care professionals, with over half of HCPs stating that assessors had contacted them to question a submitted DS1500. A number said that assessors contacted them frequently to question forms, and another stated that the willingness of assessors to query completed DS1500s was “entirely inappropriate”.

It is essential that DWP and assessment staff recognise that MND is a terminal and progressive condition in all cases, and do not waste their own time and those of health care professionals by questioning the severity of the condition’s impact. People coping with the severe impacts of MND should not be put in a position where the judgment of health specialists about the impact of their condition is called into question by inexperienced assessment staff. As one health care professional put it:

“All people with MND will deteriorate/progress and die, most likely within 2-3 years of diagnosis, most of that time spent with many physical, psychological and emotional disabilities. It is not right that they have to fight to get a small amount of money to help live day to day.”

RECOMMENDATIONS:

The DWP should review its guidance around the use of DS1500 to reflect the variable nature of terminal conditions and ensure that people living with terminal conditions such as MND are not excluded, with particular reference to the ‘reasonable expectation’ of death within six months.

The DWP should update its guidance for assessors to emphasise that staff are not entitled to challenge the validity of a DS1500 form signed by a health professional.

SECTION TWO



TRANSITIONING FROM DISABILITY LIVING ALLOWANCE

Disability Living Allowance (DLA) is a predecessor benefit to PIP, and the majority of DLA claimants will have the opportunity to transfer to PIP if they have not already. The exceptions are DLA claimants who were aged 65 or over on 8th April 2013, as this cohort will continue to claim DLA indefinitely. For all other claimants, including those with 'lifetime' or 'indefinite' DLA claims, the benefit will end. Former DLA claimants will not automatically begin receiving PIP, but they will receive a letter from the DWP asking them to make a new PIP claim. They will ordinarily then have four weeks to submit a claim for PIP (unless an extension is specifically granted). Those who do not claim within this period will receive neither DLA nor PIP until a claim is made and approved.⁷

The DWP forecasts that all claimants currently receiving DLA who are due to transfer to PIP will do so by mid-2019. There are 1,153 people living with MND who currently claim DLA according to the latest DWP figures from November 2016.⁸

AWARENESS OF THE TRANSITION

The level of awareness among current DLA claimants of their coming transfer to PIP is relatively high, with 71% of current claimants who were under 65 on 8th April 2013 stating that they were aware of the coming change. However, the fact that 29% of DLA claimants were not aware that they would be transferring to PIP should be a cause for concern, as this has the potential to generate uncertainty and confusion, and may lead to people failing to submit their PIP application within the four-week deadline.



CHANGES TO RATES OF SUPPORT

When claimants transfer from DLA to PIP, they are not automatically entitled to the same rate of support that they previously received, but have to go through a new application process to determine their rate of support. When we asked people with MND whether their rate of financial support had changed following the transition to PIP, we found that 54% stated that their rate of support stayed the same, and 18% stated that it had increased. However, it is a cause for concern that 25% of respondents to the question reported that their rate of support fell following the transition. Official DLA to PIP reassessment statistics show that 13% of people with MND received a reduction of award.⁹

As MND is a progressive condition in all instances, it should never be the case that a claimant with MND experiences a support reduction following their move from DLA to PIP. Where this does occur it is a cause of great anxiety, stress and

financial difficulty to people who have come to expect and rely on a certain rate of support. Claimants are understandably shocked to discover that they can experience a financial support reduction despite their circumstances.

"Since my transfer from DLA to PIP I receive £100 per month less. And MND is a degenerative condition!"

7 DLA is Ending, DWP, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/607282/dla-is-ending-leaflet.pdf

8 Statistics accessed via StatExplore, stat-xplore.dwp.gov.uk

9 Accessed via: <https://www.gov.uk/government/statistics/personal-independence-payment-april-2013-to-october-2016>

We also asked respondents whether there had been any change to their eligibility for non-financial support following the transition from DLA to PIP. Non-financial support includes access to leased items to support mobility such as Motability vehicles, powered wheelchairs or mobility scooters, and is available to people awarded the higher rate mobility component of DLA or the enhanced rate mobility component of PIP.

71% of respondents to our question answered that there was no change to their level of non-financial support, but 11% stated that they had experienced a reduction in the non-financial support available to them following their transition. The loss of a crucial element of mobility support, such as a Motability vehicle, can have an enormously damaging impact on a person with MND, effectively confining them to their home and causing a major reduction in their independence and quality of life.

“The care part increased but mobility part decreased meaning I no longer qualified for a Motability vehicle.”

There is evidence that loss of access to a Motability vehicle following transition from DLA to PIP is an emerging trend for people with progressive conditions, with 2016 figures showing that 45% of people receiving higher rate DLA lost the higher rate mobility component of their support, and consequently lost access to their vehicle.¹⁰ A total of 51,000 people have lost access to their mobility vehicle in this way since 2013, of which 3,000 have subsequently had access restored on appeal.¹¹

SANDRA'S STORY

Sandra is aged 60. Having previously claimed DLA and receiving both components at the highest rate, she was reassessed for PIP and found that her entitlement for the mobility component was reduced.

Sandra had been receiving DLA for three years at the highest rate for both living and mobility components before being invited to an assessment to move over to PIP. She had to wait some time to be assessed and had to travel about 15 miles to the assessment centre for a face-to-face assessment where, according to her, they were ‘totally not geared up for anyone on wheels.’ A home assessment was not offered to her.

Sandra had a number of concerns about how she was assessed for PIP. She felt the assessor had a total lack of understanding of MND.

Sandra felt the assessment itself made very little of hand function, and her poor hand function means she cannot hold a walking stick or a frame. She felt the right questions were not asked in this respect and was

unsure of the extent to which assessors would consider hand use as affecting mobility. She also noted that she wasn't asked a single question about the pain she experiences. As she has had spinal problems, back and neck pain, and fibromyalgia for 20 years prior to her diagnosis of MND, pain has been a huge factor affecting her mobility.

Following her assessment, Sandra received a letter from the DWP at the beginning of 2017 detailing her award and that she would now be receiving the standard rate of mobility. As she had been on DLA for three years previously at the highest rates and has a degenerative condition, she could not understand the decision.

Sandra intends to be reassessed and is seeking advice on pursuing this. In the meantime her MND has progressed and she describes her function as ‘dropping off a precipice’. Sandra is no longer able to walk independently.

Names have been changed to protect privacy

CASE STUDY

¹⁰ BBC News, February 2016 <http://www.bbc.co.uk/news/uk-35476904>

¹¹ BBC News, April 2017 <http://www.bbc.co.uk/news/uk-39575293>

Where support reductions do occur during the transition from DLA to PIP, they may be linked to a poorly-conducted assessment which fails to accurately assess the needs and circumstances of the individual claimant. A number of respondents to our survey expressed the view that the PIP assessment process that they underwent was entirely inappropriate and that this resulted in an unjustified reduction in support. We examine the issues affecting the PIP assessment process itself in the next section of this report.

Lower mobility awards also result from strict eligibility criteria for PIP mobility support, including a requirement that an individual must be unable to walk more than 20 metres to qualify for the enhanced rate. This is discussed in more detail in the following section of this report.

Requiring people living with MND to undergo a new assessment when they transition from DLA to PIP is an unnecessary hurdle which represents an inefficient use of resources, given that there is no possibility that the impact of MND will become less severe over time. It is a source of anxiety and stress to people already struggling with the severest of health conditions, and opens the door to damaging errors during the reassessment process which leave people with insufficient support. We therefore recommend that the DWP should agree to 'passport' claimants with a confirmed MND diagnosis from DLA to PIP at the same rate of support. A new assessment should only be conducted at the claimant's request, for example if they believe their rate of support should increase.

Both IAS and Capita were asked about the DLA to PIP transition, and how someone with a progressive and terminal condition could be assessed as having less need. Both providers argued that they are required to assess claims under the current PIP guidelines, which differ from those for DLA, and noted that they will in the majority of instances not know the previous level of award given to someone under DLA. Capita noted that in Northern Ireland, information on additional claims including DLA can be provided via a tick-box exercise. Otherwise, the APPG heard that a claimant would have to make a request to the DWP that their evidence for DLA is considered for PIP, if that evidence is still available. In response to a parliamentary question on this issue, the Government confirmed that,

“Evidence that supports any decision awarding benefit is kept for as long as that award is current and 14 months after it eventually ends. DLA claimants who are invited to claim PIP are asked if they want any medical evidence that supported their award of DLA to be used in considering their claim for PIP.”

Based on the APPG's discussions with the providers on this issue it is apparent that there is a need for a wider policy discussion with the DWP, involving the assessment providers, as to how the transition is working for people with progressive conditions such as MND.

RECOMMENDATIONS:

The DWP should transfer claimants with MND from DLA to PIP at the same rate of support, unless the claimant requests a new assessment.

The DWP should review how well the DLA to PIP transition process is working for people with progressive conditions and consider changes to meet the needs of this claimant cohort.

SECTION THREE



HOW PEOPLE LIVING WITH MND EXPERIENCE THE PIP ASSESSMENT PROCESS

For anyone claiming PIP, the assessment is a key step in their journey towards benefit entitlement. The results of the assessment process determine whether a person can receive support for mobility or for daily living activities, and at what rate. The assessments are carried out on behalf of the DWP by two private-sector providers, IAS and Capita.¹² The assessment is a points-based system that considers the claimant's physical and cognitive functions in relation to a range of daily living and mobility activities (see table below).

Daily living:	Mobility:
Preparing food	Planning and following journeys
Taking nutrition	Moving around
Managing therapy or monitoring a health condition	
Washing and bathing	
Managing toilet needs or incontinence	
Dressing and undressing	
Communicating verbally	
Reading and understanding signs, symbols and words	
Engaging with other people face to face	
Making budgeting decisions	

As MND is a severely disabling and rapidly progressing terminal condition, it is essential the PIP assessment process works to ensure swift access to the support people living with MND require to meet their daily living and mobility needs. Given that people with MND and their families will be coming to terms and living with the realities of the condition, the process should minimise causes of anxiety or distress.

This section of the APPG's report examines how people living with MND experience the PIP assessment process and makes recommendations.

FACE-TO-FACE ASSESSMENTS

The first operational decision that impacts on someone living with MND as part of the PIP assessment process is whether they are required to have a face-to-face or paper-based assessment. Once the PIP assessment provider has received a claimant's application form they will assign it to one of their health professionals for an initial review who, upon considering the information and evidence they have been provided with, will either arrange a face-to-face consultation, sometimes via a home visit, or will conduct a paper-based review.

Given the severe and disabling impact of MND, it is expected that people living with MND will have paper-based reviews in the majority of instances. This expectation is reinforced by the Department for Work and Pensions' (DWP) PIP assessment guidance which states, in section 2.5.10, that cases should "not normally" require a face to face consultation when:

*"The health condition(s) is severe and associated with a high level of functional impairment which is consistently claimed. Examples might include ... Claimants with severe neurological conditions such as motor neurone disease"*¹³

¹² Capita provides the PIP assessment service across Central England, Wales and Northern Ireland and IAS provides the service across the rest of the UK.

¹³ DWP, PIP Assessment Guide, September 2016, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/547146/PIP-assessment-guide.pdf

However, despite this guidance, the APPG's survey of people living with MND found that as many as 56% had received a face-to-face assessment as part of their PIP application.

This raises the need to consider whether the DWP's guidance is being consistently followed, if the evidence being supplied with the application is sufficient, and ultimately whether people living with MND are being subject to processes that are not intended nor appropriate for them. The result of having to attend a face-to-face assessment can be burdensome on people living with MND causing unnecessary stress, anxiety and fatigue. Some survey respondents took the time to describe their difficulties in getting to an assessment and the impact it had on them:

"Assessments were difficult to get to, were irrelevant in some points and decision took so long the condition had deteriorated significantly and had to be reassessed."

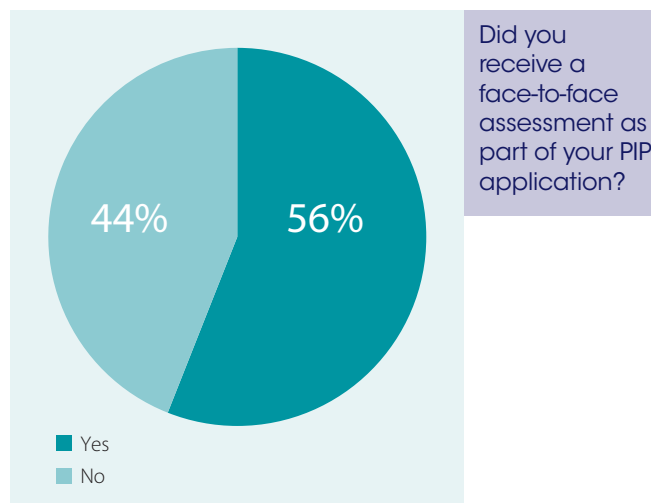
Survey respondents reported both emotional and physical impacts arising from their experience of a face-to-face assessment:

"When you have a progressive illness like MND it should come up as standard that you are living with an incurable, untreatable illness and to have to fill out all the forms and have face to face assessments reminding you of the effects of the illness should not be necessary. A note from the specialist or GP should suffice. It is mentally draining having to deal with the illness without having this extra burden put on you."

"After the assessment I suffered pain and fatigue."

Both IAS and Capita indicated that many applications do not contain strong enough evidence of the functional impact of the condition, and suggested that a face-to-face assessment can provide an opportunity to enhance a claimant's application when the level of functionality reported by the claimant in the PIP2 form does not match the expected severity given their diagnosis of MND. This re-emphasises the need, discussed in section one, for a significant improvement in communication and guidance around evidence requirements for PIP applications in order to avoid unnecessary face-to-face assessments.

Despite the reassurances from the assessment providers, the APPG's findings in relation to face-to-face assessments are concerning, given that DWP guidance recommends that a paper-based assessment should be conducted in the majority of cases. For the situation to improve there needs to be assurance that DWP guidance is being adhered to by providers and that the number of face-to-face assessments for people living with MND is decreasing. In order for this to happen, the relevant assessment data needs to be collected and made publicly available so that improvements can be monitored. Currently, the DWP does not release any statistics relating to the proportion of people required to attend a face-to-face assessment. It should address this gap.



RECOMMENDATIONS:

The DWP should collect and publish data on the number of people with MND receiving face-to-face assessments and paper-based reviews for PIP.

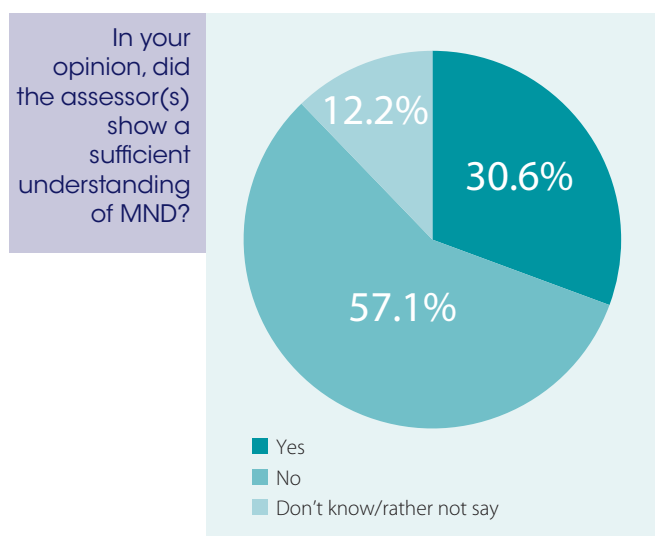
The DWP should require assessment providers to demonstrate that they are following guidance and that people with MND are not being called to a face-to-face assessment.

UNDERSTANDING OF MND

A second element of the process that impacts on people living with MND is the level of understanding of the condition of those responsible for assessing their application. As a relatively rare condition,¹⁴ MND is a disease that even some health and care professionals such as GPs will only come across a few times, if at all, during their career. Given the rarity of the disease it is essential that assessors have access to the information and guidance required to be able to understand and provide an appropriate assessment of the functional impact of MND, particularly as a progressive condition. A repeated theme throughout survey responses was that assessor knowledge of MND and its functional impacts could and should be improved.

This is reflected in the findings of the APPG's research survey, which found that 57% of survey respondents thought that their assessor(s) did not show a sufficient understanding of MND.

The qualitative feedback from the survey suggests a number of reasons as to why this is the case. There is a distrust of assessors and limited confidence in non-specialist health professionals who may not be familiar with MND.



"I had expected a qualified neurologist to assess my application - but it was carried out by non-specialist assessor."

"Not appropriate to send someone with no experience of MND. How could he judge me? I had eight medical professionals on my list they contacted none of them."

"The assessment I evaluate as being carried out by someone not understanding MND. It seems I was only assessed as a generic disabled person. In my opinion only someone who understands and is competent to assess this particular disease and present and future needs should be conducting the assessment. MND should be automatic qualification because you cannot measure the speed of deterioration or disability, and there is no cure."

While assessors cannot be expected to be medical experts on MND, their assessments of functional impact must be guided

by an appropriate understanding of the key aspects of the condition. In the case of MND, for example, assessors must be aware of the potential for an aggressive rate of progression which can cause very rapid escalation in the condition's functional impact. This requires access to reliable sources of guidance and information. Insufficiently informed assessment staff have a negative impact on claimants' trust and perception of the assessment process, as well as the accuracy of award decisions.

"The original assessor did not have any understanding of MND. I had to explain the disease."

"If she didn't understand any aspect of my condition she asked me. I don't understand why she had to visit as my specialist could have provided the information. It seems a waste of public money."

The Second Independent Review of PIP argues that it should be possible for staff without specialist medical training to carry out functional impact assessments to a good standard. However, it does recommend that the right guidance must be in place to address relevant condition-specific knowledge.¹⁵ This is particularly important for rarer conditions such as MND where the functional impact is severe but not widely known. Having access to information on MND was something brought up in a number of survey responses. Some respondents noted that the assessors did not appear to know what condition the claimant had before meeting them for the first time.

¹⁴ The incidence of MND in England, Wales and Northern Ireland is approximately 1 - 2 cases per 100,000 people per year. Due to the rapid progression of MND the prevalence is only about 4 - 5 per 100,000.

¹⁵ *The Second Independent Review of PIP*, March 2017, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/604097/PIP-assessment-second-independent-review.pdf

“It’s all there on the Internet. Pre-interview preparation would have helped.”

“Assessors should be made aware of illness of the person they are going to assess, prior to visit.”

In their evidence to the APPG, both IAS and Capita highlighted the Second Independent Review’s point that an assessor does not need to be a specialist to carry out a functional assessment. However, both acknowledged the value of greater insight into MND and improving awareness among their health professionals of the functional impact of MND. IAS reported that they had considerably expanded their condition insight report into MND, a booklet which is available to all of their health professionals online. Additionally IAS reported sending a series of educational bulletins on MND to their health professionals over a period of a few weeks (as of April 2017). Finally, IAS’s April 2017 continuing professional development topic was on MND. Capita also noted that they are currently developing a continuing professional development module on MND which they would be engaging stakeholders with. Furthermore, at the time of writing IAS are considering the introduction of condition-specific champions among their health professionals. Despite the improvement or initiation of condition insight reports for assessors and the expectation that assessors should use them, there remains no mechanism to measure their impact or use.

In addition to the level of understanding of assessors themselves, claimants expressed concerns that elements of the assessment procedure were too crude and simplistic to properly measure the functional capabilities of someone living with MND.

“The assessment for the most part was too simplistic (possibly purposely) and of no relevance to an individual suffering with MND.”

“The ‘assessment’ was an absolute mockery. It is not possible for muscle power or lack thereof to be accurately assessed without the assessor touching the person being assessed. The assessor did not properly introduce herself, so I have no idea what her qualifications for the job were.”

One such example related to the 20 metre (previously 50 metre) rule, the distance that has been introduced as a means of qualifying for the enhanced mobility component of PIP. Claimants are expected to demonstrate that they are unable to walk further than 20 metres in order to qualify for enhanced mobility support through PIP. Whilst even this short distance will represent a significant struggle for many people with MND, those assessed at an earlier stage of progression may be able to walk further than 20 metres on a particular day. This does not prove they can do so consistently and certainly does not demonstrate that they retain independent mobility. Furthermore, as a progressive condition, MND can rapidly diminish a person’s ability to walk, making the initial assessment obsolete after a short time.

“I got reassessed as my walking has been affected and they determined that I could walk more than 50 metres even though I can’t.”

Across all elements of the assessment, and in particular relating to mobility, the APPG believes more could be done to ensure it is appropriate for claimants with progressive conditions and to strengthen trust among claimants that they are engaging with a robust and accurate process. The Second Independent Review of PIP recommended more should be done to highlight the functional nature of the assessment to claimants,¹⁶ a point reiterated by the assessment provider organisations, which saw it as key to improving the claimant experience. At the same time, it must be recognised that our research findings indicate widespread doubt over the capacity of the assessment process to determine the functional impact of a multifaceted, complex and progressive disease.

Overall, more needs to be done to ensure assessors have a proper understanding of how MND impacts on those living with the condition. This should be reflected in the way that assessors interact with people living with MND during the assessment, their knowledge and understanding of the nature of the

¹⁶ Ibid.

condition, and in the production of an accurate assessment report. We recommend a stronger focus on the provision of relevant information and training for professionals and greater clarity and transparency around how functional ability is being assessed. There is also a need for a wider review of the assessment process itself to assess whether it properly captures the multifaceted and complex impacts caused by MND, particularly around mobility.

RECOMMENDATIONS:

Assessment providers should ensure sufficient information and guidance on MND is provided to assessors prior to an assessment with a claimant living with the condition.

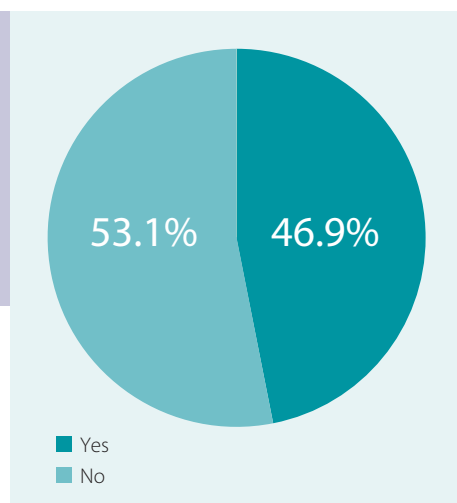
ACCURACY OF RESULTS

As there is clear, indisputable evidence that someone diagnosed with MND has a severe health condition that will only get worse, is terminal in all cases and will in all likelihood progress rapidly, it is reasonable to assume that a claimant with MND should get the highest rate of both PIP components straight away

as a result of the assessment. The only times an award of a lower rate are likely to be appropriate is if a claimant with MND is assessed at a very early stage of progression, or less commonly, in cases when someone has a slow-progressing form of the condition. The accuracy of the initial assessment results is clearly key to the effective running of the PIP system, as well as to claimants' confidence in its ability to handle their claims effectively. Unfortunately, our survey suggests that many claimants have a negative perception of the accuracy of the process, with 53% stating that the results of the assessment did not accurately reflect their needs.

A number of survey respondents commented that the scores they received from assessors did not seem to be in line with their experience of the assessment:

In your opinion, did the results of the assessment accurately reflect your support needs?



"...when I first applied I was given standard rate for mobility even though I had fallen a lot."

"I am in the middle of the appeal process due to only being given standard rate mobility but also because I felt the scoring for both parts were unfair."

The qualitative evidence provided through the APPG's survey also suggests this creates distrust in the assessment process and contributes to anxiety and emotional distress. Respondents pointed out that explaining and discussing their symptoms and experiences with a stranger can be a traumatic process in itself, and this is compounded when it results in an inadequate award.

"The results did not reflect what I had said in any of the forms or interview. We did not receive a copy of what was said about me either. Very annoyed with the outcome as it is very distressing and traumatic having to explain again all your symptoms."

Given the levels of frustration demonstrated towards the lack of understanding shown of MND, the APPG endorses the recommendation of the Second Independent Review of PIP to allow claimants to have routine access to assessment reports,¹⁷ so that they can better understand how the impact of their condition was recorded. When questioned about the perception that assessment results often do not

reflect need, IAS and Capita noted that decisions are ultimately made by the DWP. In relation to the assessments specifically they suggested that improved understanding of, preparation for and interaction with the assessment as one based on function, in tandem with new continuing professional development resources on MND, should lead to improvements.

The following case provided by a family member of a person living with MND further demonstrates the lack of accuracy and consistency in assessment outcomes, particularly given the progressive nature of the disease, and how this can have a detrimental impact on the claimant.

“I am completing this [survey] on behalf of my sister who has recently passed away. She had MND. When we applied for her PIP she had to undergo a gruelling face to face interview where she had to describe MND in lots of detail to the interviewer who had no understanding of the rapidly deteriorating nature of the terminal disease. This was one of the most traumatic events of her whole journey. At the time she would still walk with crutches so she was assessed as being eligible for the lower rate of payments. She never had the emotional strength or desire to contest this as it was so traumatic. As expected she rapidly lost the ability to walk & deserved higher payments.”

There appears to be a disconnect between what claimants with MND are experiencing as a result of their condition, how the PIP assessment captures this, and how this informs a DWP decision entitling them to the highest rates of PIP. As the above case demonstrates, the result of this can have a significant impact on claimants with MND. Ultimately it should be a shared aim of all those involved with the PIP assessment process that a negative impact of the assessment itself to someone living with MND should be avoided at all costs.

“I got depressed by the whole process and felt like I was being judged by people who were not appropriately qualified or experienced to make a decision. PIP made me ill.”

Improvements to the assessment need to be made to ensure the impacts of MND as a progressive condition are taken into account, and to reduce the amount of assessment reports and decisions that are subsequently and rightly challenged. We explore the appeals procedure in section four of this report.

RECOMMENDATIONS:

The PIP assessment procedure should be reviewed to ensure it is fit for purpose and takes better account of the complex nature of a condition such as MND.

OVERALL SATISFACTION

It is worth noting that through the APPG’s research there have been examples of positive experiences of the assessment process from people living with MND, as exemplified in the following survey responses,

“At the time I hadn’t been diagnosed with MND only 80% certain I had it. When I applied I sent all my neurologist reports with PIP paperwork which my assessor had in front of them. It was straight forward and had no issues.”

“All was smooth and simple.”

However, the overall impression the APPG has received from people living with MND is that there is significant dissatisfaction and a lack of trust associated with the PIP assessment process. This is demonstrated by people living with MND being required to attend face-to-face assessments, a lack of knowledge of the impact of MND demonstrated by assessors, which is in turn leading to assessment

outcomes that do not reflect people's need. There is also an underlying feeling that the assessment itself is not fit for purpose in determining functional capability when living with a multifaceted and complex progressive condition such as MND.

While the APPG recognises the purpose of the PIP assessment is to investigate the impact of a disability on an individual's life rather than make judgements on the basis of that disability, these research findings suggest there is a need for greater recognition within the assessment system that the impact of a medical condition such as MND on someone's life is well documented. MND is always progressive and always terminal and although it will progress in different ways it will always have a profoundly disabling and permanent effect on a person's life. This needs to be reflected in both the way people with MND are assessed, which should be on paper in the vast majority of cases, and in how functional impact is assessed, particularly for progressive conditions.

IAS and Capita welcomed the feedback provided via the inquiry regarding the assessment process and a number of actions had been taken prior to them giving evidence, mainly in relation to continued professional development resources on MND for their assessors. In addition some actions were taken forward as a result of the evidence session including a commitment from Capita to monitor some of the referrals they receive involving MND and quality control the assessments, especially for those transitioning from DLA to PIP.

Given the importance of PIP for people living with MND and the stress, anxiety and burden the assessment process has the potential to cause, the APPG believes there is significant scope to make the assessment process work better for this claimant group and hopes the DWP, the assessment providers and other involved stakeholders take steps to review and implement these recommendations.

SECTION FOUR



APPEALS AND RECONSIDERATION

For people who are dissatisfied with the results of their PIP assessment, there is a route to register a challenge to the decision. Claimants wishing to make a challenge are required to request a mandatory reconsideration of their decision within one month of receiving a decision on their rate of support. This can be done by contacting the DWP by telephone or in writing, and triggers a review of the case by the DWP itself.¹⁸

If the mandatory reconsideration process does not lead to a change in the decision, there is an option to submit an appeal to an independent tribunal. The mandatory reconsideration process must have been attempted prior to starting a full appeal. It is significantly more common for a decision to be altered through the appeals process than through mandatory reconsideration.

The Second Independent Review of PIP notes that there is scepticism about the mandatory reconsideration process among both claimants and appeals tribunal judges, who view it as a “rubber stamp” exercise which does not thoroughly examine the original decision and creates an “additional administrative barrier” for claimants wishing to appeal.¹⁹ The statistics demonstrate that large numbers of decisions are unchanged after mandatory reconsideration but then go on to be overturned on appeal. The most recent available figures, covering April-June 2016, show that 63% of PIP appeals heard in that period were successful, up from 53% in the previous year.²⁰

The majority of respondents to our survey did not need to submit an appeal of their PIP award as they were happy with the decision that was made. However, 31% of respondents considered an appeal after receiving their support decision. Of those who considered making an appeal, just over half (52%) ultimately did so.

TIME LIMITS

Both mandatory reconsideration and appeals processes for PIP are subject to a time limit. Requests for mandatory reconsideration are required to be submitted within one month of receiving the decision on PIP support, and tribunal appeals must be submitted within one month of receiving the result of the mandatory reconsideration process. If the deadline is missed, applicants can request an extension of up to 12 months, but this is at the discretion of either the DWP (for mandatory reconsiderations) or the independent appeals panel.

The one-month timeframe to appeal decisions can be problematic for claimants in some cases, particularly where the reasoning for the decision is not well communicated. Claimants frequently do not receive clear information explaining the reasoning behind the decision on their PIP eligibility. Unsuccessful claimants do not usually get a copy of their assessment report along with their decision letter, meaning that they may not understand the basis on which the decision was made, or their prospects for a successful reconsideration or appeal.²¹

In order for claimants to make an informed decision on whether they should appeal their PIP award, they must understand the reasoning behind the decision that was made. This must include consideration of any issues with the evidence provided by them in support of their application. The Second Independent Review of PIP notes that it is often not clear to claimants what evidence has been considered to determine their entitlement to support, and moreover that because the information provided to claimants about the provision of evidence is unclear, many wrongly believe that the DWP will request evidence on their behalf. The appeals process could provide an opportunity to rectify a lack of supplied evidence, but only if claimants are clearly advised that this issue affected the success of their application.

¹⁸ <https://www.gov.uk/social-security-child-support-tribunal>

¹⁹ *The Second Independent Review of PIP*, March 2017 https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/604097/pip-assessment-second-independent-review.pdf

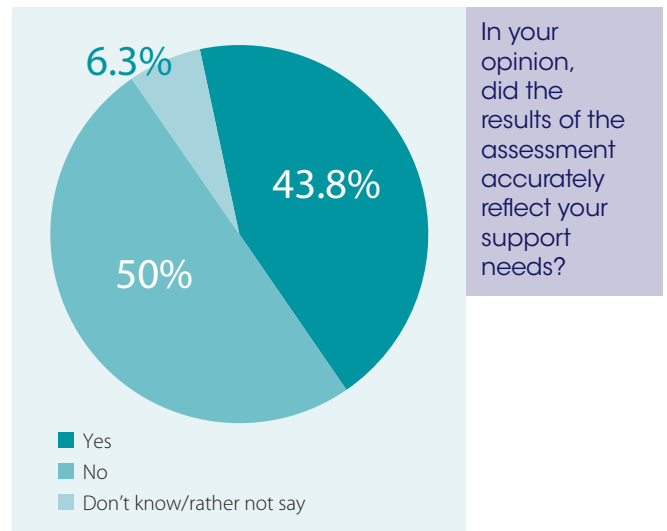
²⁰ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/426612/pip-ad-hoc-statistics-to-Mar-2015.pdf

²¹ *The Second Independent Review of PIP*, March 2017, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/604097/pip-assessment-second-independent-review.pdf

It is therefore essential that unsuccessful claimants are given enough information to understand the reasoning behind the decision and make an informed decision on whether to appeal. In addition, they must have enough time to process and understand this information and to take steps to redress any identified issues, such as seeking out further evidence from additional sources. Unfortunately, responses to our survey suggest that this is often not the case. 50% of respondents believed that they were not given enough time to submit an appeal after receiving their support decision, while 38% believed that they were not given enough information on how to do so.

“I got help to fill in the forms by my MND volunteer who knew how to fill the form in. If I hadn’t her help I would not have filled in the form correctly and would have appeared less ill than I am.”

It should also be remembered that people living with MND will be coming to terms and coping with the realities of a severely disabling condition that will affect all aspects of their lives. The time limits attached to mandatory reconsideration and tribunals are incredibly short given the other arrangements and priorities that will be occurring in their lives. The DWP should review its policies around time limits for appeals. A three-month limit would significantly reduce the pressure on claimants and give them more opportunity to gather any further evidence required to support their appeal.



RECOMMENDATIONS:

The DWP should routinely provide a copy of a claimant’s assessment report alongside their decision support letter, to enable an informed understanding of the rationale for the decision and the merits of a potential appeal.

The DWP should clarify the responsibilities of both claimants and assessors in gathering and reviewing supporting evidence and provide this information to claimants once their initial application is received.

The DWP should extend the timeframe in which appeals are allowed after receiving the support decision.

TRIBUNALS AND DECISIONS

Once an appeal has been submitted, claimants may be asked to attend a tribunal hearing in person. An in-person hearing can be requested as an option on the appeal form. The evidence suggests that an oral hearing increases the chances of a successful appeal, with tribunal judges citing “coherent oral evidence from the claimant at the hearing” as their most common reason for overturning decisions.²² This again emphasises the importance of better communication around evidence requirements at all stages of the application process, particularly as 65% of appeal hearings overturn the initial decision. Much of this activity could be reduced by more effective processes at an earlier stage.

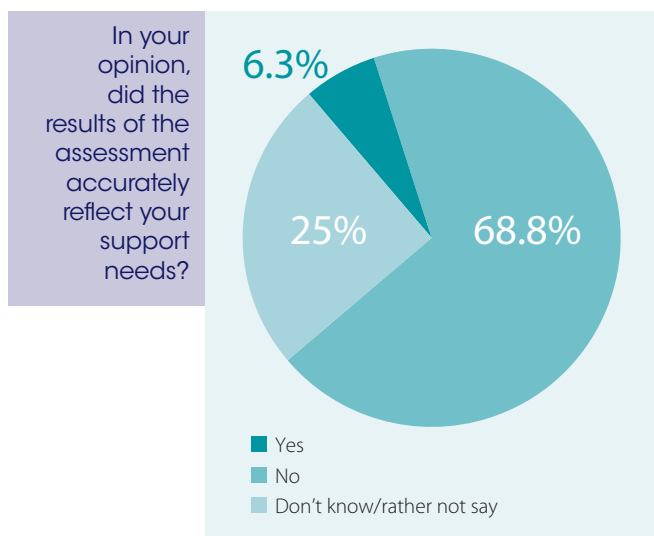
Respondents to our survey did not feel confident that the members of their appeals panel were sufficiently well-informed, with 68% of people stating that the appeal panel did not have a sufficient

²² Ibid.

understanding of their medical condition. Respondents pointed to the rapid progression of MND as an aspect of the condition that was not well understood by panel members.

In the case of rarer conditions such as MND, it is important that appeals panel members have access to accurate guidance on the nature of the condition and its progression. Although PIP assessments and appeals aim to assess the functional impact of the condition or disability, rather than focusing on the details of a claimant's medical history and prognosis, a certain level of understanding of the condition is essential to provide appropriate context to this assessment.

Following proposals put forward in February 2017 by the Ministry of Justice (MoJ), which is responsible for tribunal procedures, PIP panels will no longer have to include a judge and medical/disability expert, but can be varied at the discretion of the Senior President of the Tribunal.²³ This would open the door to a further reduction in the level of relevant expertise on the panels and would exacerbate the lack of understanding identified by survey respondents. Given the complex nature of the cases heard by these panels, the Ministry of Justice should reconsider its proposals and ensure that clinicians, medical experts and staff with personal experience of disability are included on tribunal panels examining disability benefit decisions.



RECOMMENDATIONS:

The DWP should review the information and guidance available to appeals tribunals relating to rare and complex medical conditions and their functional impacts.

The MoJ should reverse its decision to remove the requirement for tribunal panels to include people with relevant medical expertise or experience of a disability.

EXPERIENCES OF THE APPEALS PROCESS

The wait for the results of a PIP appeal is a stressful and anxious time for any claimant. For someone with MND, who may be experiencing rapid progression of symptoms and a corresponding increase in their need for support, an extended wait can have a major negative impact on their quality of life, independence and wellbeing, and that of their family. The results of our survey show a mixed picture on waiting times, which range from less than one month to four months.

Although successful appeals will receive backdated payments to the date of the initial award decision, we consider four months to be an excessive wait for a decision of this importance to the individual concerned. It is particularly damaging in the case of people living with MND, who may experience a very significant degree of progression of their condition, or even death, during that length of time. The DWP does not currently publish a specific target time by which appeals should be processed. It should consider doing so in order to incentivise tribunal panels to process decisions in a sufficiently timely manner.

"I submitted my appeal late December last year and have not yet had a decision [as of March 2017]. I feel the people at DWP who deal with the claim do not have an understanding of MND and how it progresses."

²³ Transforming our justice system: assisted digital strategy, automatic online conviction and statutory standard penalty, and panel composition in tribunals: Government response, February 2017 https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/590391/transforming-our-justice-system-government-response.pdf

“As of now I have not received any feedback from my appeal. It has been approximately 7 weeks. I am particularly angry that I never had an assessment.”

Of respondents to our survey who submitted an appeal, 42% received a higher award as a result. However, overall satisfaction with claimants’ experience of the process was poor, with 67% of respondents describing themselves as ‘very dissatisfied’ with their overall experience of the process. The additional stress and anxiety caused by extended waiting times is a clear contributor to this dissatisfaction and the DWP should prioritise this as an area for improvement.

RECOMMENDATIONS:

The DWP should publish updated guidance on PIP appeals including a target time limit by which appeals should be processed and a decision provided. We suggest a target time of three months.

ENGAGEMENT WITH ASSESSMENT PROVIDERS

Both PIP assessment provider organisations, IAS and Capita, stated that the appeals process is a stand-alone function, from which they receive little or no feedback and have little involvement with. It became apparent during discussions that should the appeal be granted on any basis related to the assessment, the providers would be unaware of this. This indicates that a vital opportunity for feedback and learning that may promote improvement in the assessment process is being missed. Both providers suggested they would welcome feedback on how a decision made at the appeals stage relates to the assessment. It was noted that better engagement with the DWP would foster this flow of information.

In response to a parliamentary question on this issue, the Government responded with the following:

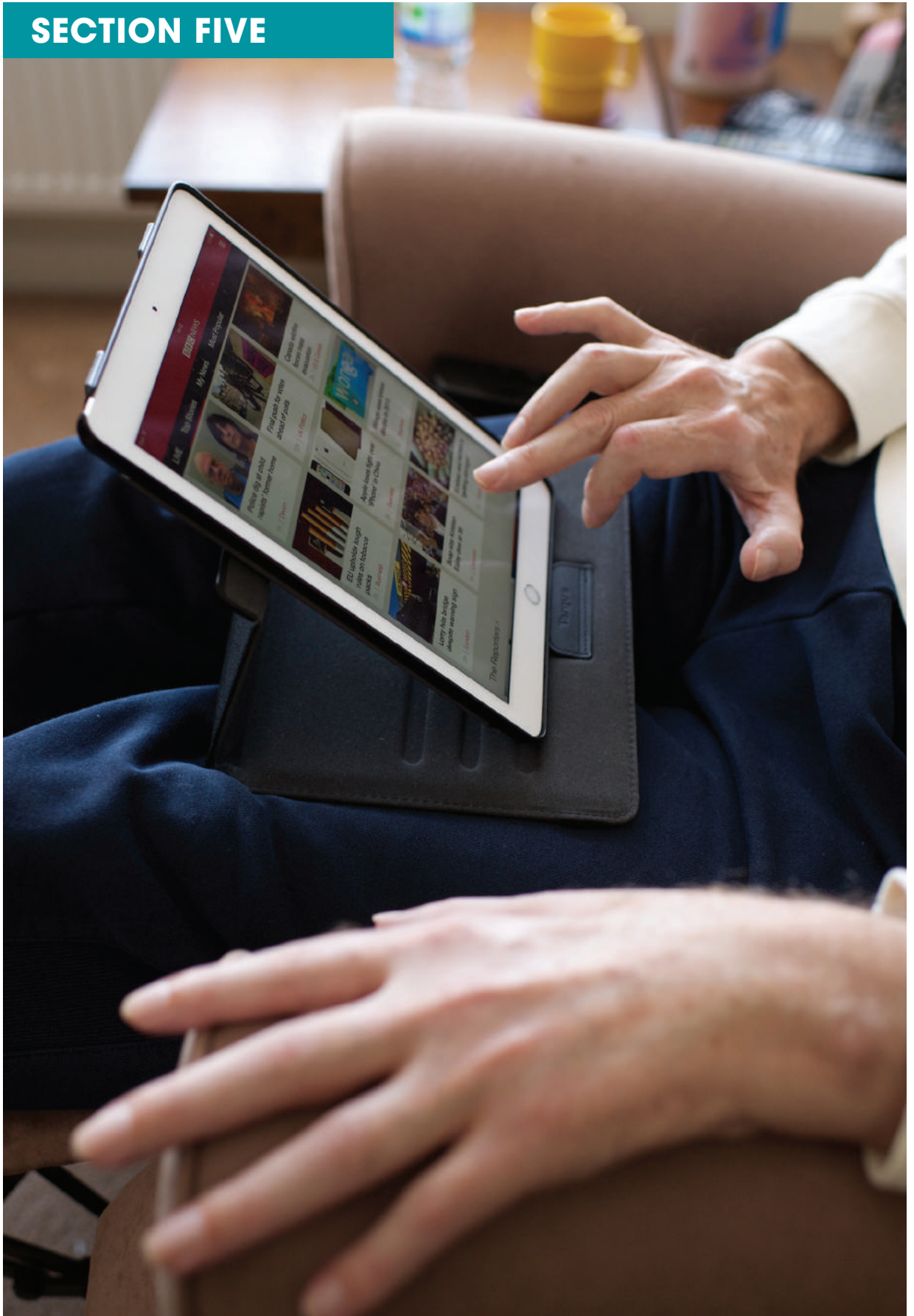
“The Department [DWP] is working with the Tribunals Service to establish how it can get more detailed and regular feedback on tribunal decisions. A recent initiative to use more Presenting Officers will help in this regard. The Presenting Officer will note any of the tribunal’s comments regarding the assessment, in particular anything adverse, and, where it is appropriate, feed this back to the provider.”²⁴

RECOMMENDATIONS:

Communication between the DWP and assessment providers on appeals should be formalised, so that providers are routinely notified of the results of appeals and any learnings applicable to the assessment process.

²⁴ Accessed 27.04.2017 via Parliament.uk: <http://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Commons/2017-04-24/71691/>

SECTION FIVE



REASSESSMENT

All PIP awards are subject to periodic review and the length of an award is decided by a DWP case manager. Upon review, the rate at which PIP is paid to a claimant can be altered, a new component of the benefit can be awarded or taken away and the fixed duration of the award can be extended or reduced. There is currently no exemption from reassessment for people with the most severe conditions such as MND. However, if a claimant's restricted daily living or mobility functions are not likely to change it is possible for a DWP Case Manager to give them an ongoing award, which has an intervention date for review of up to ten years, dependent on the circumstances of a particular case.

Advice given on prognosis by a health professional will help inform the DWP Case Manager's decision on the claimant's support requirements, and advice from a health professional on the progress of the claimant's functional impairment will also help form a case manager's decision on when a review should take place. Crucially in the context of MND, the PIP Assessment Guide states a health professional can select a 'no review required' option:

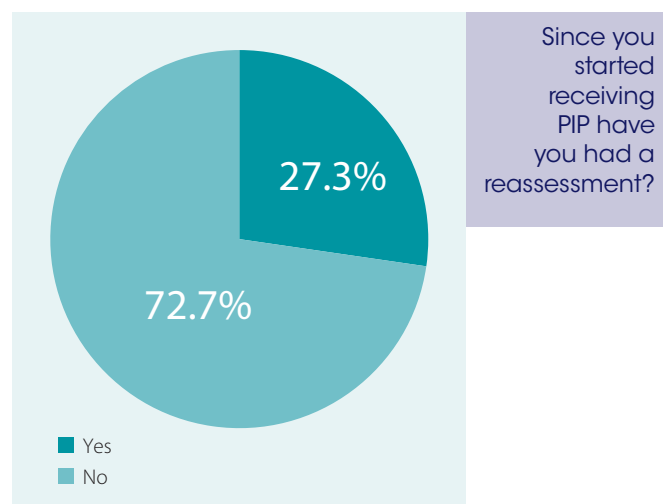
"Where the claimant has high levels of functional impairment which are only likely to increase, such as with progressive conditions – in such cases claimants are likely to receive an enhanced award of benefit and so a review of the level of award would be unlikely to change the award amount."²⁵

Based on the PIP Assessment guide and the fact that MND has a severe impact and is progressive in all cases, we believe that people with MND who receive PIP at the highest rates for both components should receive ongoing awards with no review required. In the absence of an exemption policy for reassessment, they should expect to receive an award of maximum duration.

However, 27% of people who answered the relevant survey question indicated that since they had started receiving PIP they have had a reassessment.²⁶ This should be seen as an indicative figure only due to the relatively low numbers involved. Additionally, in February 2017 the DWP released data showing that 200 reassessments of people living with MND were conducted between April 2015 and October 2016.²⁷

Although the research survey did not ask about the circumstances of a reassessment, for claimants with MND who have been awarded only one PIP component or a payment of a lower rate (assuming these awards were appropriate and not subject to mandatory reconsideration or appeal), the likelihood is that a reassessment will be needed at some stage due to an inevitable worsening of their condition. Of those who detailed which rate of PIP they were receiving for each component in the APPG's survey, 18% reported receiving the standard rate of the daily living component and 16% the standard rate of mobility.

For those who have experienced the reassessment process the APPG's research has found that there are key issues for people living with MND, namely the speed at which a reassessment is required after an original award and unnecessary requirements for face-to-face reassessments. The limited availability of data on review periods and reassessments makes it difficult to understand the impact of reassessment requirements on the MND population as a whole. The collection and publication of more detailed data by the DWP on support awards, review periods and reassessment results would enable better scrutiny of the process and support a more informed understanding of its effectiveness for people with MND.



²⁵ PIP Assessment Guide, DWP 2015, <http://qna.files.parliament.uk/qna-attachments/437040/original/Annex%20HL%204506.pdf>

²⁶ For clarity this is a PIP-only reassessment i.e. where a claimant has already received PIP and is being reassessed, not a DLA to PIP reassessment.

²⁷ Access 13.04.2017 via: <http://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Commons/2017-01-31/62586/>

RECOMMENDATIONS:

The DWP should publish the number and details of ongoing awards and review periods given to claimants with MND.

The DWP should undertake a review of the types of awards and review dates being given to claimants with progressive and severe conditions such as MND.

FREQUENCY OF REASSESSMENT

The survey responses indicate that in some instances, people living with MND undergo a reassessment after a very short time. Over half of the responses to the relevant survey question showed that their reassessment had taken place within 12 months of their original award, with 21% happening within six months.

As one respondent who was reassessed within 7-12 months of their original award and had their amount increased noted,

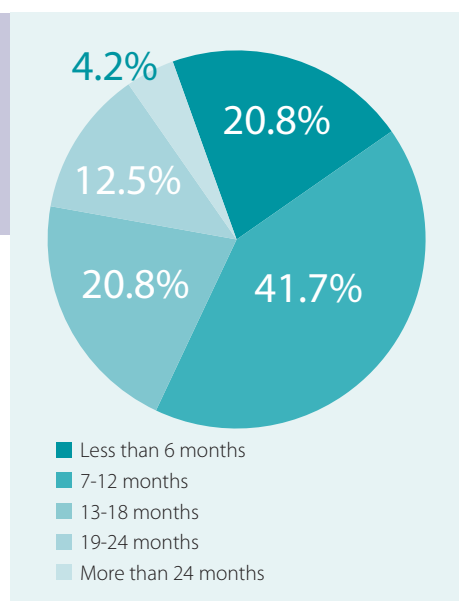
“My mobility had deteriorated to the point where I needed a wheelchair and crutches to remain safe.”

This relatively short amount of time before a reassessment calls into question whether the current assessment and original award is taking into account disease progression to a large enough extent, leading to unnecessary distress for claimants and wasted resource. The qualitative evidence provided by survey respondents suggests frustration as to why the enhanced rate is not awarded in the first place:

“I just could not understand why MND would not automatically receive the higher level PIP to start with. My GP did not really give me much help! So I got reassessed again and had a good outcome.”

“After a devastating diagnosis I then had to explain to a stranger why I am struggling to get around. With a diagnosis of MND you should automatically be entitled to both enhanced rates.”

How long had you been claiming PIP for before you were reassessed?



If someone living with MND who receives a lower support rate experiences a deterioration so that their current entitlement is no longer adequate, it is essential that this happens quickly so that the benefit can match their immediate support needs. The DWP and assessment providers should aim to achieve demonstrable reduction in the numbers of reassessments happening for people living with MND,

RECOMMENDATIONS:

The DWP should work with provider organisations to end the practice of reassessments for PIP for people living with MND who are already in receipt of the enhanced rate for both components.

The DWP should set a target for a reduction in the number of reassessments for people living with MND within the first 12 months of their award.

particularly those taking place within twelve months. This would indicate the right decision is more often being taken the first time around and would serve as a strong proxy indicator of the quality of the assessment experience for people living with MND.

FACE-TO-FACE REASSESSMENTS

Of those who had been reassessed, the survey found that 67% had face-to-face assessments. As clearly outlined, the majority of cases involving MND should be assessed by a paper-based review. Given the progressive and incurable nature of the condition it should be assumed that the need for reassessment is based on the fact that the condition has got worse rather than better and the claimant's daily living and mobility functions have deteriorated. Given that there is no prospect of recovery or sustained reduction in the impact of MND, it is unclear why providers should request face-to-face assessments. As discussed in previous sections, it suggests that assessors have insufficient understanding of the nature of MND as a progressive and terminal condition.

The requirement to attend a further face-to-face assessment is burdensome and adds stress and anxiety to claimants living with a condition that will only get worse. Some of the survey responses detailed how their condition progression had made it physically harder to attend a face-to-face assessment, the journey to the assessment centre becoming increasingly difficult to cope with even with the support of family and friends.

“Getting to the assessment centre was difficult - even with friends help.”

More needs to be done to ensure people living with MND who are in need of a review are not required to endure difficult and unnecessary travel to attend a face-to-face assessment. Better profiling of the disease and its progression should inform decisions by providers to conduct paper-based reviews wherever possible, relying on medical evidence that details the nature and progression of MND.

Where face-to-face assessments have taken place, a number of respondents noted similar issues to those experienced with the original assessment, including a lack of understanding of MND leading to assessment reports that people with MND felt did not accurately reflect their circumstances.

“The “nurse” did not really know about MND. We gave her information to take away.”

“Came to my house and after I got the reassessment report they didn't report what I told them.”

“My claim for mobility was assessed as low. Clearly not the case.”

“Very slow to get a result. The hospital in London even chased it up as I required the enhanced rate due to deterioration.”

A repeat of these experiences will only instil a lack of trust and confidence in the system for people living with MND.

RECOMMENDATIONS:

The DWP and assessment providers should collect and publish data on the number of people with MND who are asked to have a face-to-face reassessment.

The DWP should ask assessment providers to demonstrate how they ensure adherence to PIP assessment guidance on face-to-face assessments upon review of a claimant's PIP award.

The DWP should review the reassessment process for people living with rapidly progressing and terminal conditions such as MND, with the aim of ensuring it is fit for purpose and limiting the burden on those with the disease.

CASE
STUDY

JOHN'S STORY

John was diagnosed with MND in September 2014 and had to give up his work in the construction industry. He applied for PIP and had a face-to-face assessment at home in early 2015. At that point he was awarded the enhanced rate of the daily living component and the standard rate of mobility, which at the time he believed to be the rate of support he needed. By March 2016, a year later, his function and mobility had deteriorated and a face-to-face reassessment was carried out at his home. Following the assessment he received a copy of the assessors report to find that his point score was less than the previous year. As a result his award was reduced to the standard rate of both components.

John felt that the assessment was perfunctory and that the assessors did not have the skills or understanding needed to understand the impact of the condition. His consultant and the MND Association's PIP adviser advised him to appeal as his condition had deteriorated. He appealed and a few months later received a reply from the DWP saying they were standing by their decision to reduce payment.

At the end of 2016 he received a 100 page document from the DWP on why he should be refused, which had compiled the previous assessments, reports, appeal documents and evidence of their decision.

In early 2017 John received a notification that he was going to have another face-to-face assessment. A few days later he got the assessment report back, which showed that he had scored even less than the previous reassessment, despite no longer being able to dress himself or walk 20 metres.

A week after his third assessment John phoned the appeals service to see when his court hearing was due as they had initially told him his case was going to court in December 2016 and by the middle of March 2017 he still hadn't had a date. A week after this he was informed his case would be in court at the beginning of April 2017. At the hearing, against the 100 page DWP statement the tribunal panel had a two page letter from John's local NHS team explaining the current situation. The panel placed particular reliance on this evidence. The day after the hearing John received a letter from the court saying the appeal had been upheld and he would be awarded the enhanced living and mobility components, backdated to March 2016.

John said: "At that point you just think, why has the government and in turn the DWP been doing this for over a year, when it's a known condition that gets worse? You don't get better."

Names have been changed to protect privacy.

CHANGES TO AWARDS

Of those who responded to the relevant survey question, 61% said that their award had increased as a result of their reassessment. The remaining 39% reported their award had stayed the same. It is positive that upon reassessment awards are being increased. However, given some time-frames between the original award are short and the progression of MND can be rapid, there should be greater consideration as to whether this process is best suited to properly assessing and meeting the needs of these claimants.

Whilst no respondents indicated that they had their award reduced following a reassessment, John's case study above shows there have been instances where this has happened.

MND is progressive in all cases, so any suggestion that a claimant's support needs have fallen should be treated with great scepticism. The DWP should ensure that any instance of a support reduction on reassessment is fully reviewed and the relevant learnings collected.

OVERALL SATISFACTION

Among people living with MND who took part in the APPG's research, 50% indicated that they felt satisfied with the reassessment process overall. However a significant proportion, 42%, said that they were moderately or very dissatisfied with the reassessment process overall.

The evidence provided to this inquiry suggests a mixed picture of how people living with MND experience the reassessment process, and points to certain key issues that should be addressed as a priority. Firstly, initial assessment results need to better take into account the rapid progression of MND in order to more accurately reflect its functional impact on claimants. More accurate assessments would reduce the number of reassessments required as well as the number of appeals, increasing the efficiency of the system and ensuring that people living with MND have access to the right rate of benefit as soon as they need it.

We recognise that in certain situations it will be necessary for a person with MND to go through the reassessment process. The majority of these should be conducted as paper-based reviews in order to minimise the stress placed on people living with a severely disabling disease. Given the progressive nature of MND, there should be an expectation that reassessments will result in either a higher award or the same award if the claimant is already receiving the higher rates. As people living with MND do not experience improvements in their functional capability and mobility, any reassessment that results in a lower award should trigger a prompt review.

As the roll-out of PIP continues, the DWP should closely monitor this important element of the process in order to ensure the system is working properly for people with severe and progressive conditions such as MND.

RECOMMENDATIONS:

Any reassessment outcome for someone with MND that results in a lower award should be reviewed by the DWP and assessment providers, given the progressive nature of the disease in all cases.

Assessors should have access to information on MND prior to conducting a reassessment to ensure there is full understanding of the nature of the disease and its progression.

CONCLUSION

People diagnosed with motor neurone disease have to cope with one of the most severe and rapidly progressive health conditions that anyone can experience. During this hugely difficult time, it is essential that people living with MND are given the support they need to maintain the highest possible wellbeing and quality of life, retain their mobility and independence for as long as possible, and carry out the everyday tasks that most of us take for granted.

For many people living with MND, as well as their carers, families and loved ones, Personal Independence Payment is a key source of this support. It provides a vital source of income at a time when many people are forced to give up or reduce their work due to the impact of their condition. On average MND costs individuals and families an extra £1,000 a month even before loss of earnings. Access to benefits like PIP is therefore vital in mitigating the financial impact of the disease.

PIP also provides access to mobility support vehicles that can make the crucial difference between retaining independent mobility and being trapped at home. Consequently it is essential that the PIP system works well for everyone living with MND, including those transferring from DLA as well as new and existing PIP claimants.

This inquiry listened to the views of a wide range of stakeholders in the PIP process, including assessment provider organisations, health and care professionals with experience of supporting applications, and most importantly people living with MND, their carers and their families. The results suggest that real improvement is needed across all stages of the application, assessment and review process to achieve a system that delivers effectively and consistently for all those who rely on it.

There is potential to increase the efficiency and accuracy of the initial application process by improving communication and information around the requirements of this stage, particularly in relation to the provision of relevant and reliable supporting evidence, both for standard claims and for those made under Special Rules for Terminal Illness. Assessors must have access to relevant guidance and information about MND to improve their understanding of its functional impact. An automatic passport system for DLA transfers would improve the efficiency of the process and remove a major source of stress and concern for DLA claimants.

Claimants must be able to have confidence in the ability of the assessment process to accurately assess their support needs. The use of crude measures such as the 20 metre walking test should be reviewed with the aim of better capturing the multifaceted and complex impacts of MND, particularly around mobility. Providers should also take steps to reduce their use of face-to-face reassessments, particularly those that take place within a year or two of the initial award, creating unnecessary anxiety among claimants who have no prospect of any improvement in their condition or disability. A faster, more accurate and more responsive appeals process would also go a long way to improving the experience and outcomes of claimants with MND.

It is positive that assessment provider organisations have indicated that they recognise a number of the concerns raised throughout this inquiry, and have begun to engage with them. However, we call on the DWP to work closely with provider organisations as well as claimants and their representative organisations to address the issues raised in this review. It is time for all stakeholders to work together to deliver a benefits support system that meets the needs of everyone living with MND.

For further information please contact:

Alison Railton

Secretariat to the APPG on Motor Neurone Disease

Email: alison.railton@mndassociation.org

Telephone: 01327 844911

Mobile: 07760 788611