PRODUCED BY THE ALL-PARTY PARLIAMENTARY GROUP ON MOTOR NEURONE DISEASE
WITH ASSISTANCE FROM THE MOTOR NEURONE DISEASE ASSOCIATION

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

EXECUTIVE SUMMARY

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 Demos[1] 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.

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[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.

> *"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."*

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.

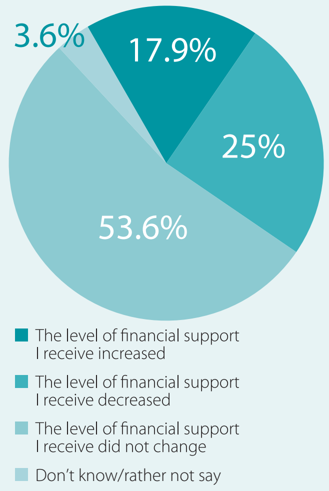
The DWP should update its guidance for assessors to emphasise that staff are not entitled to challenge the validity of a DS1500 form signed by a health professional.

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.

When you moved from DLA to PIP did the level of financial support you receive increase, decrease or stay the same?



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.

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

RECOMMENDATIONS:

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

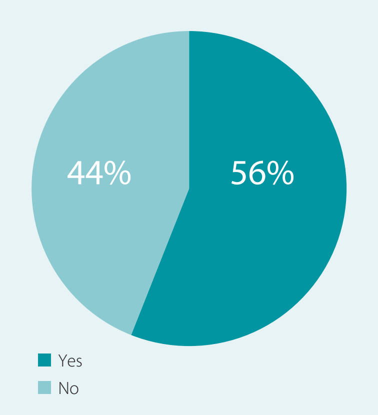
The DWP should review how the DLA to PIP transition process is working for people with progressive conditions and consider changes to meet the needs of this claimant cohort.

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.



Did you receive a face-to-face assessment as part of your PIP application?

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.

> *"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."*

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.

continued overleaf

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.

> *"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."*

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.

RECOMMENDATIONS:

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.

> *"Getting to the assessment centre was difficult - even with friends help."*

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.

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.

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