

Response to Personal Independence Payment assessment: Independent Review call for evidence

Introduction

- i. Few conditions are as devastating as motor neurone disease (MND). It is rapidly progressive in the majority of cases, and is always fatal. People with MND will, in varying sequences and combinations, lose the ability to speak, swallow and use their limbs; the most common cause of death is respiratory failure. Most commonly the individual will remain mentally alert as they become trapped within a failing body, although some experience dementia or cognitive change. There are about 5,000 people living with MND in the UK. Half of people with the disease die within 14 months of diagnosis. There is no cure.
- ii. The MND Association is the only national organisation supporting people affected by MND in England, Wales and Northern Ireland, with approximately 90 volunteer led branches and 3,000 volunteers. The MND Association's vision is of a world free from MND. Until that time we will do everything we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible and to die with dignity.
- iii. We offer comment on selected questions from the call for evidence; where we do not respond, we have no evidence to offer nor suggestions to make for that item.

Q4: Consider how further evidence is used in the PIP process. Please provide information about whether further evidence is being:

a) Requested appropriately by Atos or Capita?

b) Provided on time?

c) Used appropriately and fairly to inform decisions?

- i. We understand from conversations with DWP, Atos and Capita as well as with people affected by MND that obtaining further evidence remains a significant problem within the PIP claims process.
- ii. Although in some cases a claimant's GP will be an appropriate person to contact, for many people with MND that will not be the case. For them, the professional best placed to provide further evidence on how their condition affects them will be a neurologist, specialist nurse or care provider. We currently do not have sufficient evidence to be confident whether the most appropriate person is always contacted.

- iii. We remain concerned over the timeliness of gathering further evidence. As referenced above, a claimant's GP will not always be the best source of relevant information. However, it is only through the GP contract that a mechanism exists to incentivise response to a request for evidence. Where the most appropriate person is not a GP, there is no system in place to ensure that Atos and Capita will receive a response to their request in a timely manner. We have been made aware through MND Association Care Centres of the difficulties simply of handling these requests in a setting where there may not be any administrative staff to assist with correspondence. We believe that the DWP should consider reviewing the best possible way to accelerate the gathering of this evidence.
- iv. Even where a claimant's GP is the most appropriate person to provide further evidence, we have seen cases where the system has not worked successfully. We are aware on one instance, for example, where 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.
- v. Finally, specifically on SRTI, we have received sporadic reports of assessors questioning the validity of DS1500s that have been submitted to support an SRTI claim. We have been repeatedly reassured by the DWP that neither their staff nor the staff of Atos and Capita are permitted to challenge a medical professional's opinion. However we are aware of instances where health professionals have been asked directly – either by an assessor or a case manager – whether a person with a DS1500 has less than six months to live. Not only does this represent a fundamental misunderstanding of the criteria for a DS1500, it is expressly against the remit of assessment staff to question a doctor's professional opinion.

Q5: Where you have evidence of any of the following, please describe how effective the PIP assessment is:

d) For terminally ill people?

- i. As noted above, we remain concerned over any challenge of a medical professional's opinion where an DS1500 has been submitted to support an SRTI claim.
- ii. Our own limited evidence – along with statistics from the DWP – suggest that SRTI claims are being processed in a timely manner. However we do not believe that access to the SRTI process is consistently applied across diagnoses.
- iii. Motor neurone disease is a terminal illness, however it is not always easy to accurately predict any individual's prognosis. Half of people with MND die

within 14 months of diagnosis; in the majority of cases it is rapidly progressive. However because the current definition of 'terminal illness' for benefits purposes includes a mention of a six month timeframe, some medical professionals remain reluctant to sign a DS1500 even for patients whose symptoms are clearly progressing rapidly. This, in turn, can make it difficult for people with MND – a terminal illness – to access the SRTI.

- iv. Due to the nature of MND, and the high costs associated with it, any delay in accessing benefit payments to which a person is entitled have have major consequences. Any delay in accessing PIP also means a delay in access to other passported benefits, most significantly for many people with MND the Carer's Allowance.
- v. We firmly believe that the criteria for accessing the SRTI claims process must be reviewed and revised to make it more accessible for non-cancer diagnoses, fast-progressing terminal illnesses, and terminal illnesses that have high associated costs from their outset.

Q8: What has been your experience of the time it takes from making a claim to getting a decision?

- i. The PIP claims process clearly continues to experience unacceptable delays for non-SRTI claims.
- ii. There are a relatively small number of people with MND who will so far have been through the PIP claims process. However, we have been made aware of many cases where people have had to wait upwards of six to nine months for their claim to be processed. We are aware of cases that have been delayed at every stage of the process. The most common delay we have witnessed is when it comes to arranging a face-to-face consultation.
- iii. At the time of writing, we are still aware of at least one case where the claimant has been waiting in excess of nine months for a decision to be made on their claim.

Q9: What have been the impacts of this?

- i. As mentioned in our answer to question 5, MND is a condition with high associated costs from outset. People with MND will have mobility needs. They may need assistance carrying out everyday activities. They will almost certainly require specialist equipment and adaptations to their home. Most will have complex care needs. Many people with MND will have a partner who needs to give up work to care for them.
- ii. Any delays to accessing PIP can put an enormous strain on people's finances, at what is already a difficult time. PIP is vital to assist people with MND to meet their needs.

- iii. Likewise, the passported benefits associated with PIP are vital to allow a family member to care for the person with MND. They can also allow a person with MND to retain some independence for as long as possible.
- iv. The financial impact of delays to PIP claims have been significant. Both the MND Association, and our local branches and groups have made a number of financial grants to help support people who have experienced delays to their claims. We believe it is simply unacceptable that people living with a terminal condition have been forced to rely on financial assistance from us while waiting for their benefit claims to be processed.

Q10: Consider the whole PIP process. This includes making a claim, going to a face to face consultation, the daily living and mobility criteria used in the PIP assessment and getting a decision. What improvements could be made? Please explain how these improvements would help.

- i. As explained above, we firmly believe that criteria for accessing SRTI must be reviewed.
- ii. For non-SRTI claims, we believe that DWP, Atos and Capita must engage in significant work to reduce the number of claimants who are required to attend a face-to-face assessment.
- iii. For the vast majority of people with MND, there is little additional information of how their condition affects them that can be obtained from a face-to-face assessment that could not more easily be obtained through proper use of further evidence. Attending a face-to-face assessment can be costly and physically difficult for people with MND, and, as mentioned above, is often the largest cause for delays to a claim.
- iv. We believe that there should be a presumption against a face-to-face assessment for people with MND, unless there is a specific reason for one to take place. We believe that creating a more robust mechanism for obtaining further evidence – as well as providing better information to claimants on what supporting evidence they can submit themselves – will dramatically reduce the need for face-to-face consultations, with no risk for lowering the quality of the assessment process.
- v. Finally, we also refer to the submission made by the Disability Benefits Consortium, of which we are a member, and whose recommendations we endorse.

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