

## **Motor Neurone Disease Association Submission to the Work and Pensions Committee enquiry on Benefits Delivery**

### **1. Introduction and summary**

- 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 up to 5,000 people living with MND in the UK. A third of people with the disease die within 14 months of diagnosis, and more than half within two years. 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. The MND Association welcomes the opportunity to contribute evidence on the impact of delays and errors in benefits applications. For people with MND the impact can be severe, particularly in light of the speed of progression of the disease. Delays can mean that a person's physical abilities significantly deteriorate by the time they are awarded the necessary financial support to cope with the extra costs associated. Unnecessary face-to-face assessments, lack of information about MND and problems accessing special rules for terminal illness and the DS1500 forms that act as a passport add to the anxiety and uncertainty that people with MND and their families face. Delays and errors can also cause further delays in accessing passported benefits such as Carer's Allowance.
- iv. To this end, the Association makes the following recommendations:
  - The current DS1500 terminal illness criterion should be changed from six months to 12 months.
  - The Government should work with benefits assessment providers and Department of Work and Pensions (DWP) staff to improve training and information on DS1500s, and stress the importance of taking them into account when processing applications.
  - The Government should work with medical professionals to identify and address any barriers to issuing DS1500s.

- Every effort must be made to reduce delays for people with MND, particularly where they already have sufficient medical evidence of their condition.
  - The Government must ensure that DWP staff and providers follow guidance that states that people with MND should not have to attend face-to-face assessments for PIP providing there is sufficient medical evidence.
  - There should be a full and transparent evaluation of training, information and skills of Health Professionals working for Atos, Capita and Maximus, in order to effectively address any remaining problems.
  - The Government must recognise the valuable economic contribution of carers by reducing delays and removing disincentives to claim, such as taxation and the application of the benefit cap.
- v. We hope that the Work and Pensions Committee consider the evidence submitted of the impact on the lives of people with this terminal illness, and we would welcome the opportunity to work further with the Committee on these issues.

## **2. The impact of errors and delays for people with MND**

- i. People with MND and the people that care for them face a range of problems when claiming key disability benefits. In a survey by the MND Association in November 2014, 70% of people reported that they had encountered issues with a benefits application process. Because of the rapidly progressing and terminal nature of MND, errors and delays can have a severe impact on a person's remaining quality of life.
- ii. People with MND have faced difficulties in accessing benefits according to the special rules for terminal illness, as a result of problems accessing DS1500s. They can face onerous and unnecessary assessments despite having clear medical evidence of their condition. Finally, delays can have a knock on effect, delaying in turn access to passported benefits such as Carer's Allowance.

### **2.1 Special rules for terminal illness**

- i. MND is a terminal condition in all cases. More than half of people will die within two years of diagnosis, and in the mean time many will lose the ability to walk, use their hands and arms, breath unaided, swallow or speak. Special rules for terminal illness can offer an invaluable tool to a person with MND who needs the highest level of support quickly to enable them to manage their time and reduce any potential financial anxiety.
- ii. A recent Freedom of Information Request showed that 56% of people with MND claiming the Personal Independence Payment (PIP) Daily Living Component were doing so under special rules in April 2015. This is extremely encouraging within the limitations of the current system. These limitations specifically relate to the operation of the DS1500 form, which confirms that a person has a terminal illness and can be reasonably expected to die within six months. This six month time frame is inappropriately short, and has the effect of curtailing medical professionals' willingness to provide one, even when confronted with an illness that is known to be terminal. We believe that in all but the slowest progressing

forms a person with MND should be able to access benefits according to special rules. The prevalence rate for these slowest progressing forms is roughly 10% of cases in England, Wales and Northern Ireland. The rate of new diagnoses, and thus the rate of new benefits applications, is likely to be much lower. Reform of the DS1500, along with much-needed work to make sure that professionals involved in benefits understand the purpose and meaning of a DS1500, would help to make sure that people with MND get the support they need, when they need it and according to the right rules.

- iii. We know that people with MND are sometimes unable to obtain a DS1500. This can be as a result of lack of understanding on the part of some medical professionals, and can prevent or delay a person getting the right financial support:

“GP refused to do a DS1500 so didn’t apply at all. Palliative Care Consultant did one in the end... Dad was dead less than 2 months later.”

November 2014

- v. We also know that in a minority of cases a DS1500 has been challenged inappropriately or ignored. In one recent case, a person’s DS1500 was challenged on the grounds that a person could still breathe and swallow, which are not appropriate indicators of terminal illness. The case below had a positive resolution as a result of the intervention of a third party, but caused entirely unnecessary stress and loss of income in the intervening period:

When Mr P was diagnosed with MND in January 2013, it quickly became obvious that he would not be able to continue working as a carpet fitter. While his upper body strength remained strong, weakness in his legs meant that working was not an option. Reluctantly, he started to claim Employment and Support Allowance (ESA) and was examined by Atos in March. It was ruled that Mr P was fit to work as he had upper body strength and could work while using a wheelchair.

Mr P said, "No-one seemed to realise that MND is a degenerative disease and one which is terminal. I can understand that the Government want to make it difficult for the wrong people to claim benefits, but this is entirely different. I couldn't believe I was being treated this way."

Mr P took the case forward with help from the local Citizens Advice Bureau (CAB), which wrote directly to the tribunal asking for an urgent hearing.

The CAB adviser said: "Once I had found the DS1500 and found someone who knew what they were doing, it took just three hours for the original decision to be overturned."

March 2014

While this example is from the previous ESA contract it is a useful example of how a person with MND can be made to feel when assessments aren’t carried out appropriately, and without the right knowledge. This example demonstrates

the difference a DS1500 can make, but also the problems that can occur when professionals are not aware of what they are and what they mean.

- vi. Because of the problems and delays caused when a person with MND either cannot access a DS1500 or has one challenged inappropriately, we recommend that:
- The current DS1500 terminal illness criterion should be changed from six months to 12 months. This will benefit people with MND – and other conditions – that have a terminal but less confidently defined prognosis. It will increase confidence amongst GPs and other medical professionals in providing a DS1500 and allow people with MND to access the benefits they need in good time.
  - The Government should work with benefits assessment providers and DWP staff to improve training and information on DS1500s, and stress the importance of taking them into account when processing applications.
  - The Government should work with medical professionals to identify and address any barriers to issuing DS1500s.

## 2.2 Assessments and waiting times

- i. Delays in assessing benefits for people with MND can be extreme, as the quotes below demonstrate:

“It took the DWP nine months to sort my benefits out, I had to rely on family and friends while I got what I was entitled to.”

“Waited 6 months for benefits to be sorted. Initially a family of 5 living off £80 a week.”

“My husband’s benefit started two weeks after he died.”

November 2014

“I am still waiting... It is now 25 weeks.”

September 2015

- ii. Delays can put considerable financial strain on people with MND and their families. In the case below, a lack of information also added a sense of uncertainty and anxiety.

Mr D was diagnosed in May 2013. He applied for PIP and was offered an assessment on 6<sup>th</sup> September by Capita. He heard nothing about the outcome of the assessment afterwards, despite phoning the DWP twice weekly. The DWP reported that Capita had not forwarded the paperwork.

Since the assessment, Mr D’s MND had progressed and he needed adaptations to his home such as additional stair rails, the installation of a shower as he could not get into the bath. On occasions when he had to attend clinic there was a financial strain as his wife has to take unpaid leave to accompany him. PIP would allow Mr D to automatically claim a Blue Badge which would allow him to continue in his employment for a little longer.

- iii. Again, this example is from early on in the PIP process, but it demonstrates well the rapidly progressing nature of MND and the physical impact it has. A person can quickly develop severe mobility restrictions, as well as difficulties speaking, swallowing and breathing unassisted. Delays in benefits processes mean that a person has to live through this deterioration without the financial support necessary to deal with the associated extra costs.
- iv. The impact of this can be compounded by problems with assessments. According to DWP guidance, people with MND should not have to attend face-to-face assessments providing there is sufficient medical evidence supplied with their claim. This means that PIP applications are able to be processed without unnecessary anxiety or physical strain, and at a lower cost both to people affected by MND and to providers. However, as demonstrated by the cases throughout this document, people with MND are often required to attend assessments. In one recent case a gentleman was told by an Atos adviser that he would have to have a face-to-face assessment because he was moving from Disability Living Allowance (DLA) to PIP, and medical evidence from his GP or neurologist would not be sufficient for a paper-based assessment. This is clearly contrary to DWP guidance.
- v. As well as the unnecessary physical strain put on someone with MND, the financial cost to a household to attend an assessment and the cost to the provider of conducting one, there is the issue of lack of understanding of MND.

“1 year to receive full PIP, assessor questionable on any knowledge on MND”

September 2015

The MND Association has been working with Atos, Capita and Maximus to provide information and improve training on MND for Health Professionals. However, a transparent evaluation of training, learning materials and delivery of assessments would help to identify remaining problems and find solutions for them so that the assessment process for people with MND works as well as possible in the future.

- vi. It is disappointing that people with MND are still reporting delays in accessing benefits. Alongside the delays, problems with unnecessary assessments and wrong decisions cause considerable financial hardship and anxiety at a time when a person with MND is trying to manage a rapidly progressing and terminal illness. For these reasons, we recommend that:
  - Every effort is made to reduce delays for people with MND, particularly where they already have sufficient medical evidence of their condition.
  - There should be a full and transparent evaluation of training, information and skills of Health Professionals working for Atos, Capita and Maximus, in order to effectively address any remaining problems. This will reduce instances of

errors and help to make assessments more positive experiences for people with MND.

- The Government must ensure that DWP staff and providers follow guidance that states that people with MND should not have to attend face-to-face assessments for PIP providing there is sufficient medical evidence.

### 2.3 Passported benefits

- i. Delays and errors in processing disability benefits can also have a significant impact on people who care for people with MND. Eligibility for Carer's Allowance is dependent on, amongst other things, the person receiving care also being in receipt of PIP or Attendance Allowance. The examples below demonstrate the financial anxiety caused by a delay in processing a PIP claim, and the knock-on effect on other benefits:

Mr A has MND and is becoming increasingly dependent on his wife for care.

His wife is working and feels that she needs to consider giving up work or reducing her hours to help her husband, but cannot currently afford to do this. He has applied for PIP and has been told that it could take 26 weeks.

Until he knows whether he has been awarded PIP, his wife cannot apply for Carer's Allowance. This means that she cannot consider leaving work to provide full-time unpaid care without considerable financial strain.

2014

Mr and Mrs C were advised that because Mr C doesn't have less than 6 months to live that his PIP is not urgent and is in a pile, therefore he will have to wait for assessment. He has not been told when this will be. They are unable to access any other benefits while waiting for PIP.

His partner has had to reduce her hours and is unable to access Carer's Allowance as this is linked to PIP. They are desperate and feel that they are coming up against a brick wall.

2014

- ii. Unpaid carers deliver considerable savings to the UK economy, and yet the benefits system prevents them receiving adequate financial support. In addition, for people who live in a separate household to the person they care for, Carer's Allowance is subject to the Benefit Cap, limiting the amount of support a carer can receive. It is also subject to taxation, affecting a person's income particularly if they are looking to return to work. These limitations go against the Government's ongoing commitment to supporting and encouraging friends and family members to provide unpaid care.
- iii. In light of these problems, we recommend that:
  - Any delays to PIP or Attendance Allowance are minimised, in line with the recommendations earlier in this document, to prevent knock-on delays to passported benefits.

- The Government must recognise the valuable economic contribution of carers by removing disincentives to claim, such as taxation and the application of the benefit cap.

### **3. Conclusion**

- vii. The MND Association welcomes the opportunity to contribute evidence from people with MND on the impact of delays and errors in benefits applications. As highlighted above, the impact can be severe, particularly in light of the speed of progression of MND. Delays can mean that a person's physical abilities significantly deteriorate by the time they are awarded the necessary financial support to cope with the extra costs associated.
- viii. We hope that the Work and Pensions Committee consider the evidence submitted of the impact on the lives of people with this terminal illness, and we would welcome the opportunity to work further with the Committee. Simple changes to the existing system could do much to improve support for people with MND and their carers.

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04 September 2015