

Response to Work and Pensions Select Committee Enquiry into the Employment Support Allowance and Work Capability Assessments.

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. Our evidence focuses on the effectiveness and delivery of the Work Capability Assessment (WCA) for people living with MND.

MND and the Work-Related Activity Group

- iv. Approximately a third of people with MND are of working age, and so the number claiming the Employment Support Allowance (ESA) is relatively low, about 600 or so each year.
- v. Although relatively few people each year claim ESA and undergo the WCA, we are still regularly made aware through our local support structure of instances where, we would consider, an incorrect outcome has been reached or an incorrect process followed.
- vi. Our main concern in this regard is the placement of people with MND into the work-related activity group (WRAG). The WRAG is defined as the group for claimants who the DWP considers will be fit for work at some time in the future. MND is a progressive, degenerative illness. Once a person with MND loses a function, it will not return. Therefore, once a person with MND has

- been assessed as not fit for work, the nature of the disease means that a future return to work will never be possible.
- vii. It is the position of the Association that people with MND should be supported to remain in work for as long as they are able and wish to. However, beyond that, we believe it is unacceptable to require them to seek a new job, retrain or to carry out any other work-related activities.
 - viii. In light of this, we believe that placing any person with MND into the WRAG represents a failing of the WCA.
 - ix. In the past year we have been made aware of a small number of cases where people with MND have been placed into the WRAG, along with one exceptional case where a person with MND was found fit for work. It is likely that there are a number of additional cases each year where the claimant has been placed in the WRAG and subsequently successfully appealed the decision without contacting the MND Association.

The Work Capability Assessment

- x. We remain concerned that the WCA does not sufficiently take into account the progressive nature of certain neurological conditions, including MND.
- xi. Although we recognise the positive approach of a criterion-based assessment as opposed to an assessment based on diagnosis alone, we believe that the current model lacks the necessary sophistication to work in all cases. This is a particular concern with regard to people with MND, because of the rapidly progressive nature of the illness. We believe that a serious diagnosis must be taken into account as part of a holistic assessment of an individual. A result of this not happening is that people with MND can be – and, on occasion, are – assessed against the criteria as suitable for placement in the WRAG, when a return to work is not a possibility, and being required to carry out work-related activities is an unjustifiable burden.
- xii. In looking at alternative models, we believe that criterion-based, points-based or combination assessment processes can all be designed to consistently and accurately identify the capability of claimants. However, we believe that this can only be the case for people with MND if that assessment process is anticipatory. Any assessment that simply takes a snapshot of how a claimant scores at the time of assessment cannot take into account the rapidly degenerative nature of the disease, and is therefore failing to take into account the full extent of the claimant's condition.
- xiii. In most cases, when a person with MND has reached the stage of claiming ESA, it is likely that they have already been forced to give up their job as a result of their illness. As mentioned above, the progressive nature of MND means that any lost functions will not return. We believe that the system must recognise this.

- xiv. It is our view that a mechanism should be established that would prioritise placing claimants with progressive, degenerative illnesses into the support group as soon as possible. This could, for example, take the form of guidance recognising that in the case of certain diagnoses medical evidence should carry greater weight, or, more directly, instructions given to decision-makers to place a claimant with a given diagnosis into the support group unless there is particularly compelling evidence to do otherwise.

Delivery of the WCA

- xv. We welcome Atos's training guidance that emphasises that people with a diagnosis of MND should undergo a face-to-face assessment 'only in very unusual circumstances'. As low numbers of people with MND are involved with the face-to-face assessment process, our understanding of the delivery of the assessment is therefore based on limited evidence.
- xvi. We do, however, remain concerned at the overall quality of the face-to-face assessment. Information sharing with other charities leads us to believe that the fact that we have received relatively few reports of problems with the assessment owes more to the low numbers of people with MND involved, rather than the reliability of the process. We refer to evidence submitted by the Disability Benefits Consortium, of which the MND Association is a member, for more detail.
- xvii. We also have ongoing concerns that, even in the majority of cases for people with MND where there is no face-to-face assessment, mistakes are still liable to be made unacceptably often. We are aware of one case in the past eighteen months where a person with MND being transferred from Incapacity Benefit was placed directly into the WRAG without a face-to-face assessment. It is our position that any claimant with MND should be placed automatically in the support group, but even while that is not the current procedure it is hard to understand how a person with MND can be placed in the WRAG without a face-to-face assessment.

Reconsideration and Appeals

- xviii. The Association has, in the past year, provided a small number of people living with MND assistance with an appeal against a placement in the WRAG. It has been our experience that the appeals process has achieved the correct outcome. However, we are concerned over the impact of the introduction of mandatory reconsiderations for appeals against ESA decisions. Of particular concern is the high associated costs with MND, in terms of carers, transport, equipment and adaptations. With the timescales involved and the often rapid progression of MND, this financial burden is likely to place even more pressure on a process that is unduly challenging and distressing for both the claimant and their family and support network.

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