mnda
motor neurone disease
association

Response to the Fourth independent review of the Work Capability Assessment

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 of 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.

Q1: What evidence and examples can you provide as to the effectiveness of the Work Capability Assessment (WCA) in differentiating between claimants? In your opinion, what are the strengths and weaknesses of the WCA identification process?

i. Approximately a third of people with MND are of working age, and so the number claiming Employment and Support Allowance (ESA) is relatively low, about 600 or so each year. In the past four months, we have been made aware of two cases where people with MND have been placed into the work-related activity group (WRAG); it is likely that there are further cases where the claimant has been placed in the WRAG and appealed the decision without contacting the MND Association.

ii. 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 function has been lost, it will not return. When a person with MND has been assessed as not fit for work, the nature of the disease means that a return to work will never be possible. We believe placing any person with MND into the WRAG represents a failing of the WCA. Successful appeals against placement in the WRAG highlight the extra cost to the taxpayer from faulty application of the WCA for people with MND.

iii. The WCA identification process as it stands does not take full account of the progressive nature of certain neurological conditions, including MND. We continue to urge that specific guidance is given so that people with an uncontrollable, degenerative and life-threatening disease should automatically be placed in the support group and not expected to undertake any work-related activity.

iv. It is our position that people with MND should be supported to remain in work for as long as they are able and wish to, but beyond that it is unacceptable to require them to seek a new job, retrain, or carry out any other work-related activities.

Q5: There is a perception that the WCA is too heavily weighted towards a medical model. Do you believe this is the case? Do you think that the WCA takes suitable and sufficient account of the psycho-social factors that influence capability for work (this is not about the likelihood of finding work) - if not how do you think this should change?

i. We believe it is important that the WCA takes into account psycho-social and other non-medical factors where appropriate. However, we believe the WCA currently lacks the necessary level of sophistication to apply different weighting to different cases. MND is a highly medical condition, so for the majority of claimants with MND the use of a medical model is suitable. For people with other issues, it might struggle to identify their barriers to work.

ii. In rare cases, the WCA occasionally places people with MND into the WRAG. We believe this is a failing of the WCA in considering medical evidence – due to the nature of the illness – but also in taking account of psycho-social factors, particularly the stress caused to the claimant. For any person with a terminal illness, and particularly a degenerative one such as MND, being directed to participate in any work-related activities will often be a cruel and distressing experience.

iii. 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. The system should recognise this, and prioritise placing them in the support group as soon as possible. We consider it appropriate that there should be guidance to recognise that the medical evidence for certain diagnoses should carry more weight than others, or to instruct decision-makers to place someone with a particular diagnosis in the support group unless there is particularly compelling evidence to do otherwise.

Q6: Changes have already been made to the WCA face-to-face assessment since its introduction. Do you believe that further changes would improve the face-to-face part of the WCA? If so, please detail what changes you would suggest and provide supporting evidence that they would be effective.

i. In general, we do not expect people with MND to get as far as a face-to-face assessment. We welcome Atos's training guidance that emphasises that people should be called in for face-to-face assessments "only in very unusual circumstances". That more people with MND do not report problems with face-to-face assessment almost certainly owes more to the low numbers involved than to the reliability of the process.

ii. We remain concerned at the overall quality of the face-to-face assessment. Although low numbers of people with MND are involved in face-to-face assessments, wider evidence does not leave us confident that the process will work for those who are.

Q7: Assessment processes can be criterion-based, points-based or (as in the case of the WCA) a combination of these. What evidence do you have of the effectiveness of these different approaches in identifying the capability of claimants consistently?

i. We recognise and welcome the positive approach of criterion-based and points-based assessment process in looking at the individual person rather than their diagnosis. However, we remain concerned in practice at the outcomes that both can lead to – particularly in the context of the WCA – where applying the criteria blindly can lead to worse results. 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 could be 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.

ii. Criterion-based, points-based or combination assessment process can consistently and accurately identify the capability of claimants. However we believe this can only be the case for people with MND if the assessment is anticipatory – it cannot simply take a snapshot of how a claimant scores at the time of assessment, but rather it must take into account the rapidly degenerative nature of the disease.

Q9: Please give us any further information and evidence about the effectiveness of the WCA, particularly thinking about the effect on claimants, that you consider to be helpful.

i. We remain concerned 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 do not believe that the overall WCA process is yet of sufficient quality or robustness to ensure that people with devastating terminal diagnoses such as MND are rightfully placed into the support group without exception. We are aware of one recent case 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.

ii. This experience is extremely distressing for the claimant. As detailed previously, the majority of people with MND who are seeking to claim ESA are at the point where they have had to give up work as a result of their illness. Having a requirement placed upon them to carry out work-related activity is liable to cause a great deal of stress. It will also inevitably lead to an appeal, which, given the timescales involved and the often rapid progression of MND, is unduly challenging and distressing for both the claimant and their family and support network.

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August 2013