

SUBMISSION TO THE EVIDENCE-GATHERING EXERCISE ON THE PATHWAYS TO WORK PROGRAMME

1. INTRODUCTION

- 1.1. Few conditions are as devastating as motor neurone disease (MND). It is rapidly progressive in the majority of cases, it is always fatal and it kills five people every day in the UK. It can leave people locked into a failing body, unable to move, speak or eat normally. The intellect and senses usually remain unaffected. There are around 5,000 people living with MND in the UK. Half of people with the disease die within 14 months of diagnosis. There is no effective curative treatment.
- 1.2. 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.
- 1.3. We have one specific area of concern in relation to the Pathways to Work programme, which is that some people with MND are reportedly being obliged to undergo Work Capability Assessments. We have been alerted to this problem by our regional staff and are observing it via our monthly monitoring survey of services available to people with MND. The instances we are currently aware of originate in the Midlands, but it has historically been a sporadic problem.

2. MND AND WORK CAPABILITY ASSESSMENTS

- 2.1. We note the statement in the explanatory document that it is DWP's intention to move to, "a simpler, stronger, more personalised model of support where customers are given support based on need, not what benefit they are on." We commend this ambition, and also note the analysis that more people in the "EAS customer group" will be actively seeking work in future.
- 2.2. Within this context it is clear that the needs of people with MND, if properly taken into account as envisaged, will see them placed in the group of EAS customers who are not expected to undertake any further work activity. MND is not only a rapidly terminal illness, but also a progressive and unstable one: just because an individual has certain capabilities at one point in time does not mean that they will retain all those capabilities even a few weeks later. It is wholly inappropriate for anyone with MND to be obliged to remain in, or re-

enter, the workforce, and therefore wholly inappropriate for them to be required to undergo a Work Capability Assessment.

- 2.3. We understand that at present the key criterion for automatically excluding individuals from Work Capability Assessments, in cases of progressive illness, is that they are likely to die within six months. We have serious concerns about the use of this criterion, on two grounds. Firstly, it is a criterion which people with MND cannot reliably be said to meet: the progression of the illness is extremely varied and unpredictable, and most people with MND survive for longer than six months after diagnosis (assuming any initial WCA is scheduled to take place shortly after this point). Yet people with MND cannot sensibly be assessed for a return to work: they are terminally ill and, if not already significantly disabled, likely to become so very quickly.
- 2.4. Moreover, we do not believe that the application of such a six-month criterion complies with the section of the Employment and Support Allowance Regulations 2008 regarding exceptional circumstances. This states:

29.—(1) A claimant who does not have limited capability for work as determined in accordance with the limited capability for work assessment is to be treated as having limited capability for work if paragraph (2) applies to the claimant.

(2) This paragraph applies if—

*(a) **the claimant is suffering from a life threatening disease** in relation to which—*

*(i) there is medical evidence that **the disease is uncontrollable**, or uncontrolled, by a recognised therapeutic procedure; and*

(ii) in the case of a disease that is uncontrolled, there is a reasonable cause for it not to be controlled by a recognised therapeutic procedure [emphasis added]

- 2.5. MND is a life-threatening disease, and is uncontrollable in the sense of this regulation. This regulation does not allow the application of a time period by which the capacity for work of an individual may be judged. According to this regulation, anyone with MND should be treated as having limited capability for work.
- 2.6. A more appropriate filter therefore needs to be applied to WCAs, to prevent people with MND being pressured to submit to them inappropriately. Firstly, any guidance that allows a time-based criterion to be applied to any assessment of capacity for work must be revised in line with the Regulations. Secondly, a recognition of the particular nature of MND should be included within the relevant procedures. Our preference would be for MND to be specified within Pathways to Work procedures such that anyone who has received a diagnosis of it is exempted from WCAs. This would be the simplest approach.

- 2.7. However, we understand that a condition-specific exemption may not be DWP's preference. A set of criteria that considers whether a condition is degenerative or unstable, as well as terminal, may therefore be appropriate. Under such a regime, an individual whose condition is terminal and whose physical condition is liable to deteriorate in the short to medium term should be exempted from undergoing a WCA. This could be achieved by amending Schedules 2 and 3 to the Regulations, which currently make no reference to the stability of a person's condition.
- 2.8. For such a system to be effective, clear guidance and training to staff would be essential, so that they recognise MND as a degenerative condition and do not pressure people with MND into inappropriate WCAs. This option is likely to be less reliable in achieving the desired effect, and more costly, than a straightforward exemption by condition, as it will require more sophisticated and intensive staff training in order to succeed.
- 2.9. We hope that the forthcoming review will take this matter seriously. In instances where it happens, it is highly distressing for a person with MND to be threatened with losing their financial support and being obliged to re-enter the workforce at a time when they are living with a terminal diagnosis and are suffering from often significant deterioration in their physical condition. Inflicting suffering and distress of this sort on people with MND and their carers is unforgivable and we look forward to a time when it is not allowed to happen.

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