mnda
motor neurone disease
association

RESPONSE TO THE CONSULTATION ON UNIVERSAL CREDIT AND RELATED REGULATIONS

1. Introduction

1.1. 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.

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. While we have seen no reason in principle why the new benefits Universal Credit and Personal Independence Payment should not support people with MND effectively, we have become more concerned that they might fail to do so as more detail on them has become available. More alarmingly still, our repeated warnings of design and implementation problems with PIP in particular have been consistently ignored.

2. Losers under the new system

2.1. The underlying policy rationale of Universal Credit – to encourage people back to work – does not apply in respect of MND: once someone with MND has reached the point of having to leave work, no return will be possible. Nonetheless it has become clear that some of the details of UC will affect some people with MND negatively, relative to the current system.

2.2. The abolition of the Severe Disability Premium will have a serious negative impact on people with MND who do not live with any other adult. The proposed boost to benefit for those in the support group will not balance out this loss for a person who is not part of a couple. We urge that the premium be reinstated: a person with MND who has had to leave work will not be able to return, so penalising them in this way is wholly unjustified.

2.3. A person with MND whose partner is also disabled will find that overall the couple are penalised by about £100 a week, also due to the loss of the SDP.

2.4. A couple in which one partner is a pensioner and the other develops MND will also be badly hit by the changes. This is quite a common scenario: MND is more common in older people and the risk increases when someone is in their sixties. Because the new system requires the couple to claim the less generous universal credit rather than pension credit, as at present, they will be worse off under the new system.

3. The benefits cap

3.1. The supporting documentation relating to the benefits cap variously states that households where an individual is in receipt of DLA or PIP will be excluded from it. These exemptions appear to be missing from the regulations: we urge that this be corrected, and the exclusion extended to both benefits.

4. PIP

4.1. We note that the regulations do not address our longstanding warnings about failures being built into the design of PIP. In particular, there is no provision to the effect that individuals with degenerative illnesses who have reached the maximum entitlement will not be subjected to reassessment. The rationale for this provision is beyond dispute: when it is a medical impossibility for a person's need to have reduced, subjecting them to a new assessment serves no purpose other than to waste taxpayers' money and cause unforgivable and needless distress to a seriously ill individual.

4.2. The regulations also lack detail on how the system can be sure to respond with appropriate speed to someone whose condition changes rapidly, as can often be the case in respect of MND. The obvious danger is that a person's entitlement will not be established by the system until the person has died: as things stand, a failure of this type is bound to happen. A provision is required under which such an individual can trigger an urgent reassessment of their case. It should be noted that these individuals will probably not be within the special rules regime: although it is intended to assist people with terminal illnesses, the special rules system is the mechanism by which only a minority of people with MND access DLA (or, when appropriate, AA).

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July 2012