

Social Security Advisory Committee consultation on Universal Credit (draft) (transitional provisions) (managed migration) amendment regulations 2018

Response by the MND Association

1. About MND and the Association

1.1 Few conditions are as devastating as motor neurone disease (MND). It is a fatal, rapidly progressing disease of the brain and central nervous system, which attacks the nerves that control movement so that muscles no longer work. There is no cure for MND.

1.2 While symptoms vary, over the course of their illness most people with MND will be trapped in a failing body, unable to move, talk, swallow, and ultimately breathe. Speech is usually affected, and many people will lose the ability to speak entirely. Some people with MND may also experience changes in thinking and behaviour, and 10-15% will experience a rare form of dementia.

1.3 MND kills a third of people within a year and more than half within two years of diagnosis, typically as a result of respiratory failure. A small proportion of people experience slower progression and live with MND for longer, but survival for more than ten years is highly unusual.

1.4 A person's lifetime risk of developing MND is up to 1 in 300. It can affect any adult, but is more common in older people: it is most commonly diagnosed between the ages of 50 and 65. There are about 5,000 people living with MND in the UK, approximately 250 of them in Wales.

1.5 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

2. Summary of recommendations

2.1 The proposed process for migrating claimants to Universal Credit (by sending a notice of termination of legacy benefits and requiring a new Universal Credit claim) should be revised. Claimants of legacy benefits should be passported onto Universal Credit on the equivalent rate of support.

2.2 The 5-week delay in making a first payment of Universal Credit should be removed.

2.3 Claimants should retain their entitlement to transitional protection in the event of a failed or defective claim for Universal Credit. This issue could best be addressed by automatically passporting claimants onto Universal Credit, avoiding the possibility of defective claims.

2.4 The proposed compensation figures for former Severe Disability Premium recipients who have been "naturally migrated" to Universal Credit (as set out in para. 110 of the Explanatory Memorandum) should be revised to reflect the true difference in the financial support available to them following their migration.

2.5 The Government should clarify transition arrangements for claimants in receipt of the ESA Severe Conditions Exemption, and claimants who accessed legacy benefits via Special Rules for Terminal Illness.

2.6 While it considers and addresses the issues and concerns raised by claimants and their representative organisations, the DWP should halt both “managed” and “natural” migration to Universal Credit.

3. Issues associated with the claim process and ending legacy benefit claims

3.1 We are very concerned that the burden of applying for Universal Credit falls entirely on claimants, who will cease to receive their legacy benefits and are required to submit a new application for Universal Credit (draft reg. 44 & following, re. notice of termination of legacy benefits). This is particularly inappropriate given that Universal Credit replaces benefits designed for those living with disability or long-term health conditions, such as Employment and Support Allowance (ESA). The Department of Work and Pensions (DWP) should not place the burden of managing the transition to Universal Credit on claimants. For those living with a progressive, lifelong and highly disabling condition such as MND, the claim process is lengthy, difficult, and both physically and emotionally draining.

3.2 MND is a progressive and terminal condition in all cases and consequently there is no possibility of improvement in the condition or reduction in the severity of symptoms over time. People living with MND can rapidly lose muscle function, leading to symptoms such as loss of limb movement and loss of the ability to speak. It is consequently extremely difficult or impossible for many people with MND to complete their benefits applications either by phone or online, particularly in the context of a one-month deadline. Although the DWP offers home visits in theory, in practice these are frequently denied on the basis that the person’s carer or support staff should make the application on their behalf instead. Apart from the data protection issues involved with this approach, it ignores that care and support workers or unpaid carers have a hugely demanding job to do to manage the complex needs arising from MND, and simply do not have the time to fill out lengthy forms. There is a strong possibility that people living with MND and other disabling conditions will be unable to complete their applications in time due to the impact of their disability, leading to the loss of essential support on which they rely.

3.3 Furthermore, it is likely that claimants of legacy benefits will undergo significant stress and anxiety when notified that their legacy benefits will stop and that a new claim for Universal Credit is required. Many claimants have previous experience of the DWP’s poor record of assessing claims for disability benefits. DWP assessment decisions are frequently overturned when challenged; figures for the first quarter of 2018 show that 70% of claimants were successful in appealing a decision relating to their ESA claim, while 71% were successful in appealing a decision relating to their PIP claim. A notice of termination of legacy benefits is likely to have a destabilising and stress-inducing effect, particularly for claimants who are already coping with the impact of illness and/or disability.

3.4 As well as the initial application, it is a cause for major concern that people living with MND may be required to take inappropriate actions as part of their Universal Credit claim, such as attending a work-focused interview with a work coach. For a person who has had to give up their career aspirations due to the onset of a highly disabling terminal condition, such an interview is not only an enormous physical burden; it is also utterly insensitive and inappropriate. Although Universal Credit guidance makes provision for exemptions to be made for people who are terminally ill, this refers to the definition of terminal illness used for the Special Rules for Terminal Illness procedure for benefits

applications (“a reasonable expectation of death within six months”). Because MND is a highly variable and unpredictable condition where a precise prognosis is often impossible, the majority (c.60%) of MND claimants of legacy disability benefits did not apply through this route, despite living with a terminal illness. The Association is deeply concerned that the application process for Universal Credit will force people with MND to satisfy completely inappropriate requirements, such as a work coaching interview, even though there is no realistic possibility of them returning to work due to the impact of their condition.

[3.5 Figures given in response to a Parliamentary Question](#) reveal that 29% of Universal Credit full service claims were closed and not paid as of November 2017, including 10% for failure to attend an initial interview and 4% for failure to attend a subsequent interview. Given the additional barriers faced by people with MND and other conditions, these percentages are likely to be higher for those groups. The risk is unacceptably high that people living with MND will be unable to satisfy the Universal Credit claim requirements within the Government’s deadlines, and consequently will be left without the vital support on which they rely.

3.6 We therefore believe that the DWP should not place the onus on disabled people to make a new Universal Credit claim. It should instead passport claimants of legacy benefits onto Universal Credit at the equivalent rate of support that they received through the legacy system.

3.7 We would also like to highlight specific issues around two particular groups of claimants:

3.8 Special rules for terminal illness (SRTI): Claimants who were awarded legacy benefits through the SRTI process did not need to make a standard application. Instead they provided a DS1500 form signed by a relevant health professional. Because of the unpredictable nature of MND and the requirement of a “reasonable expectation of death within six months”, many people living with the condition find it difficult to get their application approved by their doctor or GP. Those who have already provided this form as part of their legacy benefits application through SRTI should not be put through the difficulty of doing so a second time. The Government should clarify how it will ensure that terminally ill claimants who claimed through SRTI are able to access support through Universal Credit without going through the process again.

3.9 Employment and Support Allowance (ESA) Severe Conditions Exemption: In September 2017 the DWP introduced a Severe Conditions Exemption for people with terminal health conditions who receive Support Group ESA, meaning that they would not need to undergo reassessment in future. This reflected the fact that this cohort has no prospect of recovery or improvement in their condition, and therefore their support needs will not reduce in future. We are concerned that this group, who were assured that they could now count on receiving their benefits for as long as required, will now be made to undergo a new claims process for Universal Credit which could result in the loss of their benefits if completed incorrectly or too late. The DWP must set out how it will ensure that the commitment made to this group will be upheld, and how it will ensure that they do not need to undergo stressful and wasteful application and assessment processes in order to continue accessing their support. This could best be achieved by passporting claimants onto the new system at the same rate of support as they received through legacy benefits.

4. Delay in making payments

4.1 Even if the claim process is navigated successfully, claimants migrating to Universal Credit will have a minimum 5-week wait for their first payment. Although interim payments are available, they are in effect loans that will reduce claimants’ incomes to very low levels as they are repaid. This is a major cause for concern. A progressive and highly disabling disease such as MND carries a major

financial burden, above and beyond the impact of having to give up work. A research report produced by Demos on behalf of the MND Association found that people living with MND spend an average of £1,000 per month on additional costs of coping with the condition, such as purchasing equipment, making homes accessible, and meeting the costs of care and support ([Demos, MND Costs, 2017](#)).

4.2 People with MND simply cannot wait five weeks to access the financial support they require. Nor can they endure a period of little or no income while an interim loan is repaid. The Government must ensure that claimants are able to access the support they need as soon as possible by removing the built-in five-week wait for the first Universal Credit payments. Instead, those claiming legacy disability benefits should be immediately passported onto the equivalent rate of support through Universal Credit.

5. Transitional protection

5.1 As we argue above, there is a high probability that a proportion of claimants living with disability will struggle to meet the demands of the Universal Credit claim process, resulting in “defective claims” which could lead to the loss of their transitional protection under draft reg. 48(2). This must be amended so that claimants cannot lose transitional protection because of a “defective claim,” including where there has been a delay in providing evidence or information. As recommended above, the most effective way to address this issue would be to passport claimants automatically to Universal Credit from legacy benefits, avoiding the possibility of defective claims.

5.2 The Government has now determined that people in receipt of the Severe Disability Premium should not be “naturally migrated”, so as not to lose transitional protection, and has agreed to compensate those who were already migrated. However, the compensation amounts given at para. 110 of the Explanatory Memorandum are too low. For those claimants in the UC Limited Capability for Work-Related Activity Group, the compensation level is reduced to reflect the fact that the UC LCWRA element is higher than the equivalent ESA Support Group addition. However, the difference in monthly value between the Severe Disability Premium + ESA Support Group addition and the UC LCWRA element is £114.35- significantly higher than the £80 proposed as compensation. This discrepancy must be addressed to ensure that this group is not unfairly disadvantaged by virtue of having been migrated before the Government changed its policy.

6. Overall migration timetable

6.1 We are concerned that the strain on capacity caused by the migration of claimants to Universal Credit in a short period of time will lead to errors that negatively effect claimants. The DWP has not adequately explained how front-line services will access the capacity required to manage both initial claims and ongoing cases effectively. For example, the Government has stated that each Work Coach is responsible for a caseload of around 100 and conducts 10 to 20 claimant interviews per day (<https://publications.parliament.uk/pa/cm201516/cmselect/cmworpen/549/54907.htm>). The migration of c.3 million new claimants to Universal Credit will inevitably raise already high caseloads even further. This is of particular concern in relation to claimants living with conditions such as MND, who are at risk of being subjected to inappropriate and unnecessary work-related requirements through Universal Credit. It is essential that these claimants are supported by staff who have sufficient understanding of their condition and situation to ensure that this does not happen. It is hard to see how this will be achieved without a major increase in capacity on the ground.

6.2 We recommend that the Government halt managed and natural migration to Universal Credit in order to consider how it will address this issue as well as the other issues detailed above.

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