

1. The Association welcomes the Committee's inquiry into the wait for UC first payment and is pleased to see that it is considering what the alternatives might be and their potential impacts.
2. We disagree with the concept of the 5-week wait and having a repayable advance as the means of enabling people to get the financial support they need sooner. We are concerned that the built-in delays to receiving the first UC payment and the need to repay advances can have a negative impact on people living with MND and their families. As far as we're aware, even those accessing UC under the Special Rules for Terminal Illness (SRTI) process are required to wait the full 5 weeks before their first payment. The Association recommends that built-in delays to receiving the first payment of UC should be removed.
3. In our brief submission to the committee we will focus on the impact of the 5-week wait and the need for changes to be made regarding Special Rules for Terminal Illness claimants.

Question 1: To what extent have the mitigations the Government has introduced so far (e.g. Advance payments) helped reduce the negative impact of the 5 week wait for UC claimants?

4. Although people can receive an advance payment as a loan, this will result in lower income later while the loan is repaid. Being placed into this kind of debt is counterintuitive for people living with MND, who will only face increasing costs due to the condition. Research undertaken by Demos on behalf of the Association found that people living with MND and their families face extra costs of £12,000 a year on average.¹ This is without taking loss of income into account. Having to repay a UC advance over time is an additional extra cost most people with MND could do without as they struggle to cope with the impacts of the disease in all respects.
5. We would prefer to see a system where a delay is removed entirely and/or where an advance payment is non-repayable, particularly for those who are vulnerable and those living with a terminal illness.

Question 3: Are different mitigating options needed for different groups of claimants?

6. We believe that particular consideration should be given to people who claim UC under the Special Rules for Terminal Illness (SRTI). For most of the benefits that can be applied for via the Special Rules, such as Personal Independence Payment, first benefit payment is often received more quickly than application

¹ DEMOS, MND Costs: Exploring the financial impact of motor neurone disease, (2017). Accessed via: <https://static.mndassociation.org/app/uploads/2017/06/19135031/DEMOS-FULL-report.pdf>

through the standard route. As far as we understand with UC, the 5-week wait still applies.

7. It is essential that people with a terminal illness such as MND, which often progresses rapidly, can get swift access to the financial support they need, including when they apply for Universal Credit. This is so they are able to support themselves and their families financially as their condition worsens.
8. If a blanket removal of the 5-week wait will not be made by the Government, we would suggest that certain groups of claimants, such as those with MND and terminal illnesses, are considered as being in circumstances where a payment should be made quicker and not on the basis of a repayable advance.

About MND

- MND is a fatal, rapidly progressing disease that affects the brain and spinal cord.
- It attacks the nerves that control movement so muscles no longer work. MND does not usually affect the senses such as sight, sound, feeling etc.
- It can leave people locked in a failing body, unable to move, talk and eventually breathe.
- Over 80% of people with MND will have communication difficulties, including for some, a complete loss of voice.
- It affects people from all communities.
- Around 35% of people with MND experience mild cognitive change, in other words, changes in thinking and behaviour. A further 15% of people show signs of frontotemporal dementia which results in more pronounced behavioural change.
- It kills a third of people within a year and more than half within two years of diagnosis.
- A person's lifetime risk of developing MND is around 1 in 300.
- Six people per day are diagnosed with MND in the UK.
- It affects up to 5,000 adults in the UK at any one time.
- It kills six people per day in the UK, this is just under 2,200 per year
- It has no cure.

About the MND Association

The Motor Neurone Disease Association is the only national charity in England, Wales and Northern Ireland focused on improving care, research and campaigning. We have over 9,000 members forming a powerful network that provides information and support for people with MND, their families and carers. We fund and promote research that leads to new understanding and treatments, and brings us closer to a cure. We campaign and raise awareness so the needs of people with MND are recognised and addressed by wider society.

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