# Key messages

Benefits are a vital source of financial support for people living with motor neurone disease (MND). Given the nature of the condition, many people will need to reduce or give up primary sources of income and spend more to cope with the impacts of the disease, meaning many will become reliant on the social security system for their financial welfare.

However, for most people affected by MND, the current levels of disability-related benefits falls too far below what is required to placate the stark financial burden of living with the disease. Much-needed and long-awaited reforms to the overall system also risk placing unnecessary pressure on people who require disability benefits.

While reforms to the benefits system are welcome, they must work for people living with MND and not place inappropriate work-related conditionality on those accessing disability benefits. More broadly, the level of entitlement across many disability benefits must be increased to ensure that people do not face financial hardship because of their condition, and the unfairness of different levels of disability-related benefits based on age must be removed.

# Background

People living with MND may be entitled to a range of benefits because of their condition, depending on their financial circumstances and occupation.[[1]](#endnote-2) Personal Independence Payment (PIP), Attendance Allowance and Employment and Support Allowance are common disability-related benefits for people with MND. Carers of people with MND may be entitled to Carer’s Allowance, a benefit for people who provide care for someone with a disability for at least 35 hours a week. If they are on low incomes, they will also be entitled to Universal Credit.

Benefits are integral to people with MND due to the nature of the condition. It is estimated that households affected by MND spend an average of £14,500 a year on the direct costs of living with and managing the condition, with many households spending much more.[[2]](#endnote-3) These additional costs may include the cost of care and support, the cost of equipment and housing adaptations to enable people with MND to live safely at home, increased transportation costs due to reduced mobility, and increased energy costs. In 2017, 82% of people with MND reported experiencing a negative financial impact following diagnosis.[[3]](#endnote-4)

Alongside this, MND is a progressive and incurable condition. This means once people with MND leave the workforce they will never return, resulting in a permanent loss of income. This is also the case for carers, many of whom have to leave employment due to their caring responsibilities.

Therefore, there is a ‘double whammy’ of increased costs and decreased income meaning welfare benefits are the only means to bridge the gap and support people with MND.

# The challenge

## Benefits system reform

In March 2023, the Department for Work and Pensions (DWP) published their White Paper, *‘Transforming Support: The Health and Disability White Paper’.[[4]](#endnote-5)* It proposes to legislate the removal of the existing Work Capability Assessment (WCA), so there is only one health and disability functional assessment – the Personal Independence Payment assessment (PIP). This will involve removing the ‘limited capability for work assessment’ (LCWRA) group and replacing it with a new Universal Credit (UC) ‘health element’.

The MND Association supports changes to the welfare system which allows people with MND to access the support they need more easily.

Specifically, we support changes to simplify the number of assessments needing to be undertaken by people applying for benefits. Far too often people with MND must have to contend with multiple layers of bureaucracy to receive financial assistance. This leads to a poor experience of engaging with DWP and unnecessarily delays timely access to financial support.

However, the space between the WCA and PIP has existed for a reason. The former assesses someone’s ability to work and the latter the impact of a disability on a person. Therefore, using only PIP as a passport to additional disability-related benefits within Universal Credit risks placing work conditionality requirements on those with a disability. Similarly, if there are work-related requirements within PIP, then people may risk being denied PIP because they are judged fit to work.

It is currently unclear and remains for the DWP to define what conditionality looks like for those who will receive the new Universal Credit ‘health element’. However, those with severe, progressive diseases like MND should not be subject to any work-related conditionality within their PIP assessments. If they are, it will put untold strain on a group who will likely recently have had a devastating diagnosis and will be contending with significant financial hardship because of their condition.

The government’s own research found that two-thirds (67%) of people in the Limited Capability for Work and Work Related Activity group on Universal Credit, or who are in the Employment and Support Allowance (ESA) Support Group had ruled out paid work as being a future option for them.[[5]](#endnote-6)

If the aim of these reforms is to simplify the process, then the most effective and fair way to do this is to implement generous conditionality, ensuring all those entitled to the new Universal Credit ‘health element’ are not subject to any work conditionality during PIP assessments. To do otherwise creates extra bureaucracy which undermines the aims of these changes.

Overall, though, these reforms are not a silver bullet. The WCA and PIP have been widely criticised due to their lack of flexibility and understanding of the needs of people with a disability. The removal of the WCA does not change this fact – the poor experience of PIP assessments requires greater reform in consultation with people with disabilities such as MND to ensure they are fit for purpose.

## Adequacy of benefits

The impact of MND on household employment and income means people must rely on the social security system to support them during financial hardship. However, in 2017, of those that received financial support, almost half (45%) of people affected by MND said it was not adequate enough to meet their or their family’s needs.[[6]](#endnote-7)The impact of the recent rising costs due to the crisis only increases the need for an improved social security system. of their condition.

Moreover, a couple receiving a higher rate of PIP and Carer’s Allowance are eligible to receive £12,974 a year. This leaves more than a 10% shortfall in covering the average direct cost of living with and managing MND - £14,500 a year, although many people spend much more – which lays bare the inadequacy of benefits for disabled people.[[7]](#endnote-8)

The shortfall is considerably higher when other costs outside the direct costs of having a disability, such as food, energy and rent, are considered. Analysis has found that when these are taken into account an even more stark picture can be painted.[[8]](#endnote-9) For example:

* If you are under 65 on a higher income with MND, less than 35% of the cost of essentials and MND will be covered by your benefits.
* For people with MND who are in a couple, over 65 and on low incomes, their welfare benefits only cover around 60% of the basic essentials to live and the costs of living with MND.
* If you are single, under 65 and not entitled to Universal Credit, at most, only 31% of your costs of essentials and MND will be covered by your welfare payments.
* Single people with MND over the age of 65 who, will only receive welfare payments which cover 73% of their basic living costs and the costs of their condition.
* For single people, under 65 years old with MND who are entitled to the lower rate of PIP, 75% of the cost of MND and their basic costs of living are covered.

Given this, it is integral that the level of financial support provided through benefits should be enough to at least cover life’s essentials. This should begin with a review of the adequacy of benefit benefits available to disabled people to ensure that those who leave the workforce indefinitely because of their condition do not face significant financial hardship.

## Inequality of entitlement

As well as adequacy of benefits being insufficient, strict eligibility criteria governs access for some benefits. In particular, there is an inequality of entitlement for people living with MND based on their age. For example, people under 65 are eligible for PIP, which contains a mobility assessment and additional entitlement on top of the standard benefit rate. However, those living with MND over 65 are not entitled to PIP but are entitled to Attendance Allowance, which does not include a mobility element. This not only means older people receive less in total benefits but are also denied access to welfare schemes that could help support their independence such as the Motability scheme.[[9]](#endnote-10)

Overall, per year a person receiving the higher rate of PIP with the added mobility element will receive £8,983 per year, this is nearly 70% more than received by those with Attendance Allowance (£5,291). The same applies for lower rate claimants.[[10]](#endnote-11)

Given this, there needs to be a shift away from the inequality of entitlement between Personal Independence Payments and Attendance Allowance, ensuring that older disabled people are not discriminated against in their level of disability entitlement.

# What changes do we want to see?

**From Government:**

* Ensure that those entitled to the new Universal Credit ‘health element’ are not subject to any work conditionality during PIP assessments.
* Review the adequacy of benefit benefits available to disabled people to ensure that those who leave the workforce indefinitely because of their condition do not face significant financial hardship.
* Address the inequality of entitlement between Personal Independence Payments and Attendance Allowance, ensuring that older disabled people are not discriminated against in their level of disability entitlement.

# What MND Association is doing

* Running our Benefits Advice Service, which is available for anyone living with MND or a carer, who needs guidance about benefits. The team of qualified advisers can provide support by phone and email in England, Wales, and Northern Ireland. The service can help people identify available benefits and the best way of claiming them. They also provide help for complex benefits issues and appeals. They also offer home visits to help with the completion of forms, depending on your circumstances and where you live.
* Engaging with local councillors and other local decision makers, in partnership with our Campaign Volunteers, to raise awareness of people with MND and their experiences of the welfare system.
* Influencing national policy through consultations, campaigns, and meetings, either directly or through coalitions, on the the issues around welfare and benefits for people with MND
* Lobbying MPs and other parliamentary stakeholders and groups ensuring that the experience of people with MND and their interactions with the welfare system remains high on government agendas.

# **References**

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2. MND Association. (2023). 2023 Spring Budget Statement. Available: https://www. mndassociation.org/2023-spring-budget-statement/ [↑](#endnote-ref-3)
3. Demos. (2017). The financial impact of motor neurone disease. Available: https:// demos.co.uk/research/motor-neurone-disease-survey/ [↑](#endnote-ref-4)
4. Department for Work & Pensions (2023). Transforming Support: The Health and Disability White Paper. Available: [Transforming Support: The Health and Disability White Paper - GOV.UK (www.gov.uk)](https://www.gov.uk/government/publications/transforming-support-the-health-and-disability-white-paper/transforming-support-the-health-and-disability-white-paper) [↑](#endnote-ref-5)
5. Department for Work & Pensions (2020). Summary: The work aspirations and support needs of claimants in the ESA Support Group and Universal Credit equivalent. Available: <https://www.gov.uk/government/publications/work-aspirations-and-support-needs-of-claimants-in-the-esa-support-group-and-universal-credit-equivalent/summary-the-work-aspirations-and-support-needs-of-claimants-in-the-esa-support-group-and-universal-credit-equivalent> [↑](#endnote-ref-6)
6. Demos. (2017). The financial impact of motor neurone disease. Available: https:// demos.co.uk/research/motor-neurone-disease-survey/ [↑](#endnote-ref-7)
7. Personal Independence Payment paid at a higher weekly rate for both daily living and mobility parts represents a yearly payment of £8,983. In addition, a yearly Carer’s Allowance represents a cost of £3,991. [↑](#endnote-ref-8)
8. Data available upon request [↑](#endnote-ref-9)
9. MND Association. (2022). 10a Benefits and Entitlements. Available: <https://www.mndassociation.org/sites/default/files/2022-12/10A-Benefits-and-entitlements.pdf> [↑](#endnote-ref-10)
10. Calculated using DWP stats [↑](#endnote-ref-11)