



## Response to the draft Welfare Reform and Work Bill 2015

### 1. Introduction and summary

- i. 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 up to 5,000 people living with MND in the UK. A third of people with the disease die within 12 months of diagnosis, and more than half within two years. There is no cure.
- ii. 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.
- iii. This submission covers elements of the Welfare Reform and Work Bill 2015 that will affect people with MND and their carers. In particular, we are concerned that the benefit rate freeze will mean that people with a terminal illness will be subject to benefits cuts despite the Government's assurances of protections for the most 'vulnerable' people. We do not support the inclusion of ESA as a whole in the benefits freeze; but as a minimum, people receiving people receiving ESA in the support group must have their full ESA entitlement, including the basic allowance, up-rated in line with inflation.
- iv. The reduction in the benefit cap will adversely affect full-time unpaid carers who do not live in the same household as the adult that they care for, and we believe that the continued inclusion of Carer's Allowance and Bereavement Allowance is both principally wrong and impractical, given the level of support that these people need in the face of significant disruption to their lives. Both benefits should be removed from the scope of the benefit cap, and protection must be extended to carers who do not fall under the same household as the adult that they care for.
- v. There has not been sufficient evidence-based consideration of how changes to support for mortgage interest (SMI) benefits will affect people with disabilities, and in particular people with a terminal illness such as MND. The Committee must maintain the current system of support for mortgage interest (SMI) payments as a

benefit, rather than a loan and ensure that there is provision for people with a terminal illness such as MND so that they do not have to wait for 39 weeks to qualify for SMI support.

- vi. We also believe that there is an important opportunity in this bill to address levels of disability poverty. We recommend that the Bill should create an annual reporting obligation on levels of disability poverty, a realistic target for year-on-year reductions and ensure that further legislation is compliant with this target.
- vii. We welcome the opportunity to contribute to the formation of this Bill, and hope that the Bill Committee will consider seriously the evidence and suggestions laid before it.

## **2. Measuring disability poverty**

- i. We believe that this Bill presents an opportunity to further consider how we monitor the extent to which people with disabilities are living in poverty.
- ii. Recent statistics from the Department of Work and Pensions (DWP) reveal that the percentage of people living in households where at least one member was disabled who were in absolute poverty rose from 27 per cent in 2012-13 to 30 per cent in 2013-14. The number of people in these households living in absolute poverty rose by 300,000 in that single year.<sup>1</sup> This is an issue that needs realistic action. The Government must commit to an annual reporting obligation on the number of disabled households living in poverty, if it is to work seriously to reduce that number. It must also set targets for achieving the necessary reductions. Making this commitment will help the Government to achieve its ambitions both to support more disabled people into work and to protect people who cannot work as a result of their disability or health condition.
- iii. We recommend that:
  - a. An additional clause is inserted to create an annual reporting obligation on levels of disability poverty, measured as households with at least one member with a disability with income below 60% of median household income, in line with current methodology.
  - b. The Government should create a realistic target for year-on-year reductions in disability poverty and ensure that further legislation is compliant with this target.

## **3. Clause 7 and 8: changes to the benefit cap**

---

<sup>1</sup> Department of Work and Pensions and the Office for National Statistics, *Households below average income* (2015), <http://bit.ly/1dhKERZ>

- i. People who provide unpaid care to people with MND, but do not live in the same household, may be affected by the benefit cap. This might include adults with caring responsibilities for both their children and their parents.
- ii. We do not believe that the Impact Assessment for the benefit cap provides adequate justification for reducing the cap. The Department of Work and Pensions (DWP) has previously been criticised by the UK Statistics Authority for implying a causal link without robust evidence between the application of the benefit cap and people moving into work. What is more, even if there were a causal relationship between capping benefits and people moving into work, it would not work exponentially; there is no robust evidence that simply lowering the cap will cause more people to find jobs. It will, however, force more people who provide full-time unpaid care into financial hardship.
- iii. In addition, the Impact Assessment does not provide a justifiable rationale for reducing the cap. While we remain opposed to the benefits cap overall, the existing level of the cap has an identifiable rationale, set at average household earnings. The reduced cap does not. Furthermore, clause 8 enables the Secretary of State to review and change the level of the cap at any time without any adequate protection; matters that the Secretary of State consider relevant under clause 8 section 3(b) is a dangerously vague specification. If the link is maintained with household earnings, then changes in this rate, taking inflation into account, should be the only relevant consideration.
- iv. Finally, the continued inclusion of Carer's Allowance, along with Bereavement Allowance, under the cap is unfair and penalises those who are far from the job market. This Government has noted the importance of unpaid carers and the vital support they provide to people with MND and other illnesses and disabilities. The Conservative Party manifesto committed to increasing support for full-time unpaid carers,<sup>2</sup> and the Party has since declared its intention to create a new Carers Strategy to look at how it supports carers.<sup>3</sup> Policies such as the benefit cap are inconsistent with this objective. People who care full-time for people with MND are extremely unlikely to be able to move into the job market, and yet face financial disincentives through the cap. Carers and others who have recently lost a husband, wife or civil partner and claim Bereavement Allowance may also be subject to the cap, which is grossly unfair at a time when they may need to cope with significant changes to their lives.
- v. In response to these concerns and inconsistencies, we call on the Committee to:
  - a. Remove Clause 7 section 2 reducing the level of the benefit cap, in order to maintain its current level and relationship with average earnings

---

<sup>2</sup> The Conservative Party Manifesto 2015 (2015), p. 39 <http://bit.ly/1FPYN2z>

<sup>3</sup> Jeremy Hunt, *Personal Responsibility: speech to Local Government Association conference* (2015), <https://www.gov.uk/government/speeches/personal-responsibility>

- b. Insert an additional sub-section stating that those in receipt of Carer's Allowance must be exempt from the benefit cap in all circumstances, including when they do not fall under the same household as the adult that they care for
- c. Remove clause 7 section 4(a) and section 4(b) in order to remove Carer's Allowance and Bereavement Allowance from the scope of the benefit cap
- d. Remove clause 8 section 2 and section 3(b) in order to safeguard against inappropriate reviews and any reductions on grounds other than the national economic situation.

#### 4. Clause 9: Freeze on certain social security benefits for four tax years

- i. The Bill as drafted proposes a real terms benefit cut for terminally ill people. In the Summer Budget, the Chancellor stated that "the welfare system should always support the elderly, the vulnerable and disabled people."<sup>4</sup> But under the proposed reforms the system will fall short. We see no justification for subjecting the most vulnerable group imaginable to these cuts, and we oppose the proposals. We agree that benefits for the most vulnerable, including carers' benefits, pensioners' premiums and PIP, should be exempted from the four year benefit rate freeze. However, the Government's current proposals do not extend this exemption to the full value of ESA for people who are terminally ill or are unable to engage in work-related activity for other reasons.
- ii. The benefit freeze will affect people with MND in two ways. Firstly, people with MND who claim housing benefit, child tax credit and a range of other benefits will feel the cumulative impact of these benefits being reduced, while their daily cost of living and the cost of managing their disability rise.
- iii. Secondly, even if they are placed in the support group for ESA they will see a real-terms reduction in their benefit. Only the support group component of ESA remains unfrozen; the basic component will stay at its 2015/16 cash level. Assuming that without the freeze the basic rate would continue to rise at the 1% rate set during the last parliament, people in the support group in 2016/17 will be almost £40 worse off that year. By 2019/20 they will be over £150 worse off.

Table 1: Impact of benefits rate freeze on people in the support group for ESA

Year	CPI applied to support group component (OBR projection)	Basic rate up-rated by 1% per annum (weekly rates)			Benefit rate freeze applied to basic rate (weekly rates)			Annual difference
		Basic rate	Support group component	Total	Basic rate	Support group component	Total	
2015/16	0.0	73.10	36.20	109.30	73.10	36.20	109.30	n/a
2016/17	1.2	73.83	36.63	110.46	73.10	36.63	109.73	<b>£37.96</b>
2017/18	1.7	74.56	37.25	111.81	73.10	37.25	110.35	<b>£75.92</b>

<sup>4</sup> George Osborne, Summer Budget 2015 Speech (2015), <http://bit.ly/1Tl8ZXb>

2018/19	1.8	75.31	37.92	113.23	73.10	37.92	111.02	<b>£114.92</b>
2019/20	1.9	76.06	38.64	114.70	73.10	38.64	111.74	<b>£153.92</b>

- iv. The impact of the benefits freeze for people furthest away from the jobs market is even clearer when compared to what the total entitlement to ESA would be if it rose directly in line with prices, as Table 2 below shows. By 2019/20, people with MND in the support group will be £257.40 worse off in real terms.

Table 2: Impact of up-rating ESA in line with inflation for people in the support group

Year	CPI (OBR projection)	Up-rating according to CPI (weekly rates)			Benefit rate freeze applied (weekly rates)			Annual difference
		Basic rate	Support group component	Total	Basic rate	Support group component	Total	
2015/16	0.0	73.10	36.20	109.30	73.10	36.20	109.30	n/a
2016/17	1.2	73.98	36.63	110.61	73.10	36.63	109.73	<b>£45.76</b>
2017/18	1.7	75.24	37.25	112.49	73.10	37.25	110.35	<b>£111.28</b>
2018/19	1.8	76.59	37.92	114.51	73.10	37.92	111.02	<b>£181.48</b>
2019/20	1.9	78.05	38.64	116.69	73.10	38.64	111.74	<b>£257.40</b>

- v. We believe that this is wrong in principle. People with MND will face reductions in financial support both directly and indirectly as a result of this bill, increasing an already considerable financial challenge in managing the extra costs of their condition. As such, we recommend the following amendments to the draft Bill:
- a. Under clause 9, insert a further sub-section exempting ESA as a whole from the freeze of social security benefits in order to fulfil the commitment to protect disability benefits.
  - b. Ensure that people receiving ESA in the support group have their full ESA entitlement, including the basic allowance, up-rated in line with inflation

**5. Clause 13 and 14: removal of the Employment and Support Allowance Work-Related Activity Component and Universal Credit Limited Capability for Work Element for new claims**

- i. Most people with MND should be placed in the Support Group when assessed for ESA. However, a very small minority with the slowest progressing form of MND may be in the Work-Related Activity Group (WRAG). In addition, we know that people with MND are occasionally mistakenly put in WRAG and are not necessarily aware of either the distinction or their right to appeal the decision. Universal Credit does not yet affect people with MND, but is likely to in the lifetime of this parliament.
- ii. People of working age who are diagnosed with MND will typically endeavour to remain in work for as long as it is possible for them to do so. For a person with MND, being forced to leave work is often a highly unwelcome milestone in the progression of their illness, which they will often strive to delay as much as possible. People with MND who claim ESA do not do so because they do not want to work.

They do so because the profoundly disabling effects of their illness make it impossible to work. They will rely on ESA to ensure that they are still able to meet their basic costs of living. Reducing ESA reduces their ability to meet these costs. Clearly more needs to be done to support people with disabilities, including people in the early stages of MND, to be able to work but this must not include penalising them when they lose that ability. ESA was designed to recognise that some people may not be able to work as a result of ill health and that they would need extra support to be able to access the job market, avoiding the false dichotomy of 'fit-for-work' or 'unfit' that Incapacity Benefit created. Reducing financial support for those in the WRAG is a clear step backward.

- iii. As such, we recommend the following amendments to the Bill:
  - a. Remove Clause 13 in order to maintain the work-related activity component of ESA
  - b. Remove clause 14 in order to maintain the limited capability for work component of Universal Credit.

## **6. Clause 16: loans for mortgage interest**

- i. We are concerned that the conversion of the support for mortgage interest (SMI) benefit to a recoverable, interest-bearing loan will put people who are unable to meet the cost of their mortgage as a result of a sudden MND diagnosis, and the resulting costs, at serious risk of foreclosure. This will be true both of people who do not have life insurance, and of people who have difficulty securing a speedy payout from life insurance. While a loan will still be available to people with MND this reform relies on the assumption that fewer people will be prepared to take up a loan. People with MND will be no different; once their disease progresses to the point that they are unable to work and earn, they will not be able to return to work, and so will lack the ability to manage the required interest payments and administrative charges proposed by the Bill.
- ii. In addition we are extremely concerned that a person with MND or any other terminal illness will be required to serve a 39 week qualifying period before being entitled to support. For some people with MND, this will be longer than the period between their diagnosis and death. The Committee should either remove the qualifying period entirely, or introduce a fast-track mechanism for those with terminal and rapidly progressive conditions, for whom any qualifying period is entirely inappropriate.
- iii. People with MND who have life insurance will usually find that this ultimately covers their mortgage costs; however, securing a payout can sometimes be problematic, as insurance companies sometimes quibble, in error, over whether the diagnosis meets the term of the policy. In this situation, urgent assistance to meet costs in the short term is vital, and eliminating the 39 week qualifying period all the more important.

- iv. The impact assessment accompanying this reform bases its forecasts on assumptions that people have substantial levels of asset wealth, and that they are able to rely on families and friends for alternative financial support. There is little evidence in the impact assessment to back these assumptions up. There is also no consideration of the impact of the long qualifying period for people in emergency situations and no substantial consideration of the impact of this policy on people with disabilities and health conditions.
- v. We recommend that:
  - a. The current system of SMI as a benefit, rather than a loan, is maintained
  - b. Provision is made for people with a terminal illness such as MND so that they do not have to wait for 39 weeks to qualify for support.

## **7. Conclusion**

- i. We welcome the opportunity to contribute to the formation of this Bill, and hope that the Bill Committee will consider seriously the evidence and suggestions laid before it. In particular, we hope that the Committee will recognise the difficulties posed by the benefit rate freeze and changes to the benefit cap, ESA and SMI for people with MND and their carers.
- ii. We also hope that the Government will take this opportunity to consider how it will measure the rate of disability poverty and how it will work to reduce this rate. We would welcome further conversations on this subject in the future.

### **For further information contact:**

Ellie Munro  
Policy Officer  
MND Association  
David Niven House  
10-15 Notre Dame Mews  
Northampton  
NN1 2BG

Tel: 020 72508449

[ellie.munro@mndassociation.org](mailto:ellie.munro@mndassociation.org)

11 September 2015