mnda
motor neurone disease
association

POSITION STATEMENT: DISABILITY LIVING ALLOWANCE AND PERSONAL INDEPENDENCE PAYMENT

SUMMARY

- We believe that a non means-tested, tax-free cash benefit should be available to people with motor neurone disease (MND) to help them with extra costs arising from the disabling effects of their illness.

- We call for a mobility component to be added to this benefit for those aged over 65.

- ‘Extra costs’ benefits such as DLA and PIP should not be confused with income replacement benefits; however, for the avoidance of doubt, we believe that people with MND should be supported to remain in work for as long as they wish and are able to, and that they should receive an income replacement benefit unconditionally after they are obliged by their illness to leave work.

- The Special Rules system is currently inadequate for people with MND, even though they are terminally ill: the threshold of life expectancy that counts as ‘terminally ill’ should be increased from six months to twelve.

- It is particularly important that the problems with the Special Rules system are fixed: this will prevent many of the problems outlined below from affecting many people with MND.

- Under the proposed Personal Independence Payment (PIP), some people with MND will never receive the benefit despite their great need. This cannot be right.

- The qualification threshold for PIP and Attendance Allowance (AA) should be aligned at three months, not six as proposed.

- The proposed new medical test for PIP seems likely to repeat the mistakes of the Work Capability Assessment (WCA); it must not be introduced until the problems with this test have been successfully remedied and lessons fully learnt.

- Assessment of people with MND for PIP should be anticipatory, and take into account that their condition is likely to change rapidly; this means that some account must be taken of medical diagnosis, contrary to the Government’s stated intention.

- Claimants of PIP should be able to trigger an urgent review of their entitlement when their condition deteriorates.

- Anyone with a degenerative disease such as MND should be exempted from further assessments once they are receiving the maximum entitlement; any reassessment would be futile, as it is medically impossible for their condition to improve.

- The assessment for PIP must assess the extra costs arising from illness and disability that the claimant will encounter; the proposed approach will not do this and should be dropped.

- Any test for PIP must be carer-blind: people must not be penalised for having carers to support them.

- We do not support the proposal to take aids and adaptations into account: the potential for error and injustice is enormous, and will inevitably be hugely costly for both claimants and the taxpayer.

- We do not support the proposal for penalties for failing to notify DWP of a change in a claimant's condition: it is unworkable.

- We do not accept the Government's arguments for reforming Disability Living Allowance (DLA): it is a well-functioning and well-understood benefit that is in no sense 'out of control'.

- We would support simplification of the process for applying for DLA outside the Special Rules regime.

- We urge the Government to reverse its decision to remove the mobility component of DLA from people in residential care funded by local authorities: none of the justifications presented for it bears scrutiny.

- We regard the consultation process around the proposed reforms as inadequate.

1. PEOPLE WITH MND, BENEFITS AND WORK

1.1. We believe that a cash benefit which is non means-tested and tax-free should be available to people with MND to assist them in meeting the costs arising from the disabling effects of their illness. We are therefore pleased that the Government has agreed to maintain these features of Disability Living Allowance (DLA) in its proposed new benefit, Personal Independence Payment (PIP).

1.2. We remain unsure of the justification of not providing assistance with mobility costs within this benefit for those who claim it aged over 65: cases of MND become more common after this age, and mobility represents a major challenge for these people with MND; the dividing line of 65 serves people with MND particularly badly. We therefore call for a mobility component to be available to claimants aged over 65, whether under the current Attendance Allowance or a new arrangement.

1.3. The benefits in question are not income-replacement benefits, and we are therefore uneasy at the Government's recent rhetoric in which they appear cheek-by-jowl with comments extolling the merits of work for the disabled. For the avoidance of doubt, we advocate that people with MND should be supported to remain in work for as long as they wish and are able to: beyond this point, we do not accept that they should be obliged to re-train, seek work or undertake any other 'work-related activity'. The degenerative and terminal nature of MND makes any such obligation wholly unsupportable, and beyond this point people with MND of working age should be supported by the appropriate income replacement benefit: currently this means they should be in the support group for Employment and Support Allowance. We see this position as in line with the statement made by the parliamentary under-secretary of state for work and pensions, Maria Miller, in her foreword to the proposals to reform DLA, that the Government is, “committed to providing unconditional support to those who are unable to work[.]”

1.4. Finally, we note of the proposed new Personal Independence Payment that its name indicates some of the difficulties we anticipate with its operation: while it is right that the benefits system should support disabled people to live as independently as possible, it must not be overlooked that people with MND will inevitably lose their independence, and subsequently their lives, as a result of their illness. Any benefit that fails to recognise this will fail people with MND.

2. SPECIAL RULES AND MEDICAL DIAGNOSIS

2.1. Although MND is a terminal illness, and the Special Rules system nominally exists for those who are terminally ill, it does not work for people with MND. We argued that the Government should rectify this problem when it legislated in this area in 2006-7, and we urge that the current Government does not miss this opportunity.

2.2. The definition of 'terminally ill' as meaning a prognosis of six months or less is particularly awkward for people with MND: half of people with MND die within 14 months of diagnosis, so while only a modest proportion survive for fewer than six months after diagnosis, many more die shortly after this period. Unsurprisingly therefore, fewer than half of people with MND report being able to access the Special Rules scheme despite all being terminally ill.

2.3. We believe that the Special Rules system was intended to extend protection and support to people with devastating, terminal diagnoses such as motor neurone disease, and urge that it be amended to meet their needs and correct a long-standing failing.

2.4. This might be achieved in several ways. Changing the threshold from a prognosis of six months to twelve months would be the simplest, and would open up Special Rules to people with MND except those with the slowest-progressing forms. This extra period could be made available only for certain diagnoses, although we acknowledge this cuts across the Government's desire to avoid any automatic entitlement based on diagnosis.

2.5. It is particularly important that the problems with Special Rules be addressed at this juncture, as the effect of some of the other proposed changes could result in some people with MND being denied PIP altogether if they are forced to claim via the normal route, as will be explored below. Solving the problems with Special Rules will, to a large extent, prevent these further difficulties from arising.

3. SOME PEOPLE WITH MND WILL NEVER GET PIP

3.1. Under the Personal Independence Payment, it is proposed that the benefit may not be paid until the claimant has had their impairment or disability for six months: this is the same as under Attendance Allowance, but much less generous than DLA, where the claimant must have had an impairment for only three months.

3.2. We recommend that this threshold be aligned for both PIP and AA at three months. Under the proposed change to six months, combined with the proposed new medical test (see below), a person with MND may not develop sufficient disability to qualify for the benefit at all until some time after their diagnosis.

3.3. Let us take the case of a person with MND whom a neurologist declines to support for Special Rules, in the expectation that they might live another twelve months or so. The individual goes on to develop a level of disability judged to qualify for PIP three months after diagnosis and subsequently dies within the next six months, their condition having deteriorated more rapidly than their neurologist had anticipated. This would be among the poorer outcomes of an

MND diagnosis, but is by no means unheard-of. This person will have been denied support either entirely, or until very shortly before their death.

3.4. If the Special Rules threshold is increased to 12 months as we recommend, this scenario will not arise: the same person who becomes eligible for PIP outside the Special Rules Regime three months after diagnosis and dies six months later, receiving no PIP at all, would instead receive PIP for the whole nine months. The amended Special Rules regime would remove the problem of a neurologist predicting survival for 12 months and therefore delaying the person's access to PIP. Under the current proposals, however, if a neurologist expects the person to live for twelve months and declines to sign a DS1500, but this prognosis later proves optimistic, that person could well be denied any PIP at all.

4. MEDICAL TEST

4.1. We have two concerns about the proposed medical test to assess claimants' entitlement to PIP. Firstly, it seems likely to repeat the mistakes and duplicate the problems of the Work Capability Assessment (WCA) for ESA. Secondly, we believe that such assessments will often be wholly inappropriate for people with MND.

4.2. Firstly, the WCA has been shown to work far less effectively than the current arrangements for DLA: while the Harrington review found high levels of successful appeals against WCA decisions, the DWP's own figures show a fraud rate of 0.5% for DLA under current arrangements, which strongly suggests they are effective. Given that the medical test model has proved so problematic for the current income replacement benefit, we urge that it should not be used for the new extra costs benefit until its many difficulties have unambiguously been remedied.

4.3. Secondly, the rapidly degenerative nature of MND makes regular reassessments problematic in two respects. MND often progresses so rapidly that unless the reassessments are very regular indeed, they will fail to keep up with changes in the individual's condition. There are several possible solutions to this: one would be to set a review interval of no greater than two months, although this would be very expensive for the Government; our preferred option would be to ensure that assessment in cases of MND is anticipatory, takes into account the inevitable decline in the individual's condition and awards PIP accordingly. Again, revising the Special Rules regime in line with our recommendations will also prevent this problem from arising for most people with MND.

4.4. We also recommend that claimants should be able to trigger an urgent review, so that a deterioration in their condition can be quickly taken into account and their entitlement revised accordingly.

4.5. Once a person with MND is receiving the highest rates of PIP, there is no point reassessing them: MND is degenerative and there is no medical possibility that their condition will improve. Once a person with MND is receiving maximum entitlement, they should be exempted from reassessment: any such reassessment will serve no purpose other than to waste taxpayers' money.

5. ASSESSMENT OF NEED

5.1. We are not convinced that the proposed new assessments will adequately identify the needs of claimants. Disability and illness both decrease people's earnings and increase their costs, and simple assessments of ability to perform certain tasks do not identify these complex phenomena.[1] The proposals for PIP do not state that any attempt will be made to assess the extra costs that the benefit will meet: clearly, this is the wrong approach and such an assessment must be made.

5.2. Extra costs incurred by people with MND are many and varied. Heating bills are higher because people with MND cannot move around to keep warm (winter fuel allowance will of course be unavailable to most DLA / PIP claimants as they are of working age); powered wheelchairs and other equipments require extra electricity (and are often paid for using DLA anyway); there is no end to the number of small practical items that might be required, for instance special sheets to make it easier for the person to turn in bed; adapted cars are currently a major use of DLA. The new test does not appear to be framed to assess any of these things, and is therefore not fit for purpose.

5.3. We recommend that any such test should also be carer-blind: that is, the person being assessed should not be found able to do something, for instance making a journey, if they can only do it with the assistance of a carer. The PIP proposals are silent on whether assistance from carers will be taken into account or not.

5.4. The proposed tests are particularly likely to fail people with bulbar onset MND: this is a particularly rapid form of the disease, but tends to affect the ability to speak and swallow before the ability to move the limbs, so that the person can appear deceptively able despite being extremely ill and likely to die quickly. Such a person should be within the Special Rules regime, but this is not guaranteed: again, solving the problems of Special Rules would avoid the problems with the medical tests affecting people with bulbar onset MND.

5.5. We do not support the proposal to take aids and adaptations into account. Wheelchairs and other aids are often provided inappropriately slowly to people with MND, and also require modification over the course of the person's illness: they do not solve all mobility problems, and even the help they do provide can be temporary, as the person's condition deteriorates further. Adaptations to people's homes are also extremely unreliable and slow: it is not uncommon for someone with MND to obtain a wheelchair but be unable to use it because the necessary adaptation to their home has not been made. Taking aids and adaptations into account would introduce such massive potential for error into

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[1] 'Counting the Cost', Demos, November 2010

the assessments that it would inevitably lead to many unjust decisions, and many more appeals – the costs of these errors would be enormous, both to the claimants affected and the taxpayer.

6. PENALTIES

6.1. We do not support the proposal for penalties for failing to notify DWP of a change in an individual's condition. Particularly when combined with the problems associated with including aids and adaptations in assessments, the consequences for people with MND could be terrible.

6.2. Changing circumstances could, for instance, include obtaining a new wheelchair or having one modified to cope with a new need – as has been outlined above, these things can take a long time to arrive, and so such 'changes' could occur long after a PIP assessment.

6.3. As with many of our concerns, effective reform of the Special Rules system would stop these problems arising for a great number of people with MND.

7. ARGUMENTS FOR REFORM OF DLA

7.1. We do not accept the Government's arguments for reforming DLA.

7.2. The benefit is not confusing and complex: among people with MND, 93% say that they feel they understand it, the highest figure for any benefit.

7.3. The benefit is not 'out of control': increased uptake is a sign of a successful benefit that is well understood among the people who are entitled to it. The Government should make a clear statement that it intends to maximise uptake of all benefits, so that people who need them do not miss out.

7.4. We do not see that there is any supportable policy rationale for pegging DLA expenditure back to 2009-10 levels as the Government proposes; such a decision is purely arbitrary.

7.5. We would, however, welcome simplification of the form and process by which applications are made, as many people with MND find this difficult. Reforming Special Rules to reduce the number of people who need to go through this process is also vital.

8. DLA MOBILITY FOR PEOPLE IN RESIDENTIAL CARE

8.1. We urge the Government to reverse its decision to deny the mobility component of DLA to people living in residential care funded by local authorities.

8.2. The Government has put forward many justifications for this decision; none bears scrutiny.

8.3. For instance, it is not appropriate to suggest that withdrawing the mobility component from people in residential care is justified because it aligns their position with that of people in hospital or in a nursing home and receiving NHS Continuing Healthcare. In both of the latter scenarios, the claimant is receiving medical treatment: centres for medical treatment are not residences. The appropriate comparison is between people in residential homes and their own homes: there is no justification for the mobility component being available in one situation but not the other.

8.4. The Government has also attempted to justify this on the grounds that local authorities fund mobility needs and therefore there is a duplication of funding. This has been shown to be untrue.[2] Contracts between local authorities and care homes will include an obligation to cover the individual's assessed needs, as defined by their social care assessment, but general mobility needs are not covered by these assessments.

9. PROCESS OF REFORM

9.1. The reform process around DLA and the introduction of PIP has been extremely disappointing, and leaves the Government open to charges that its consultation exercises are a sham.

9.2. The official consultation period for the PIP proposals was only nine weeks, which included the Christmas and New Year holiday period: this was wholly inadequate and well short of the best-practice minimum period of 12 weeks recommended by the Cabinet Office.

9.3. Moreover, we received intelligence that an unofficial deadline of 17 January 2011 existed for submissions, after which DWP officials would begin drafting the Welfare Reform Bill. This represents an unacceptably short timeframe for interested parties to gather and submit views, doubly so in light of the high volume of reform processes currently being undertaken by the Government to which many of those parties wish to contribute.

9.4. The fact that this unofficial deadline was not widely publicised compounds the matter further: with the Welfare Reform Bill due for publication the day before the consultation officially closes, it is hard to escape the conclusion that there was never any intention of allowing the consultation to have any meaningful influences over the Government's decision-making.

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[2] 'Don't Limit Mobility', Mencap et al. November 2010

ABOUT MND

Few conditions are as devastating as motor neurone disease (MND). It is rapidly progressive in the majority of cases, and is always fatal. Patients 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 suffer from dementia or cognitive change.

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.

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