

RESPONSE TO THE DETAILED DESIGN CONSULTATION FOR PERSONAL INDEPENDENCE PAYMENT

Introduction

- 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 about 5,000 people living with MND in the UK. Half of people with the disease die within 14 months of diagnosis. 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 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.
- iii. We expect people with MND to be broadly eligible for PIP to the same extent as they currently are for DLA. We do have significant concerns, however, about the practical ability of the system to respond to the needs created by MND, which is an extreme disease and poses extreme challenges to all statutory services. Our expectation that PIP will continue to meet the needs of people with MND as DLA has rests on the premise that the system will work effectively; if it does not, it could let people with MND down badly.
- iv. We have two particular concerns: slow reassessment could mean that people with MND die without receiving benefit to which they are entitled; and reassessment of people with MND already on maximum entitlement could take place, which would serve no purpose other than to waste taxpayers' money and cause needless distress to the individual and those around them. We have had no indication that our clear and repeated warnings of these problems are being taken into account, and if either of these wholly avoidable scenarios becomes a feature of PIP in practice we will view it as inexcusable.
- v. We append to this response, as we did to our response on the consultation on eligibility, scenarios illustrating the demands that MND is likely to place on the administration of PIP. The difficulties we outline will be readily apparent from these.

- vi. We would expect few if any DLA claimants with MND to have any trouble being transferred to PIP, as their condition will have deteriorated since their entitlement to DLA was confirmed. Indeed, the transfer programme could be positive for some, as it may alert people to enhanced entitlement which they had not claimed previously. If people with MND get turned down for PIP on reassessment from DLA, that should be taken as an indication that the system is going seriously wrong. Some people with MND will of course die before the reassessment programme reaches them.
- vii. We must also express our disappointment that the consultation is not consulting on as much as first appears; in fact, we respond to relatively few of the specific questions below, and the key points are largely contained in updates not intended for consultation. We recommend that this distinction be made clearer in future documents, to avoid creating the impression that the Department is consulting more widely than is the case.

Question 5

Do you think a requirement that a claimant must have been present in Great Britain for two years out of the previous three years is reasonable in order to demonstrate a long standing affiliation to Great Britain? Would a longer period be more appropriate? And if so what do you think that longer period should be and why?

We do not think that the proposed test is a reasonable way of identifying a “long standing affiliation to Great Britain”. Ex-pats who develop MND can often wish to return to Britain for their final months or years of life, particularly if their family is still here; under this test, they are unlikely to be eligible for PIP, even if their affiliation to Great Britain is indeed long standing.

We recommend that additional tests be introduced, in addition to the proposed one, and that satisfying any one of these should amount to entitlement for PIP. One approach might be that people above a certain age – say, 45 – have spent over half their lives in Britain.

Question 7

Is the period of four weeks temporary absence from Great Britain sufficient? If no - why do you think the absence should be longer? And what do you think that longer period should be (and why?)

We feel that a four week period is ungenerous. People living with MND, mindful of the limited time remaining to them, can wish to undertake final holidays or similar trips while still physically able to do so. Under this proposal they would be obliged to limit the duration of these to four weeks – often this will not be a problem, but there may be circumstances, for instance for people with family abroad, where this will be problematic. Nonetheless we acknowledge the rationale for a limit being in place, but recommend six weeks instead of four.

Question 15

There will be limited appeal rights against the decision to terminate DLA and safeguards will ensure that people who genuinely were not able to claim Personal

Independence Payment within the time limits will be able to re-engage with the claiming process without penalty. Is this a fair and proportionate approach to ensure people engage with the claiming process?

As we understand the proposals, a DLA claimant whose PIP claim is rejected and who appeals that decision will have their DLA stopped while their PIP appeal is being heard, and will have very limited rights to appeal this. This is not acceptable: in this scenario, DLA must continue to be available until all PIP processes have been completed.

Question 18

Our plans include procedures and rules to ensure that everyone invited to claim Personal Independence Payment will be repeatedly reminded before their benefit is first suspended and then terminated. Are there any other matters we should consider to ensure that everyone currently on DLA who may be entitled to claim Personal Independence Payment does so, and within reasonable time limits?

We do not support the proposed two-stage claims process for PIP reassessment. Everyone on DLA should be automatically sent the claims form for PIP – the significance of being ‘invited’ to claim it will be lost on many claimants, and result in them dropping out of the system. Repeated reminders are of course helpful in addressing this, but switching to a single-stage transfer and application process would remove some of the need for so many reminders.

If the Department insists on pressing ahead with the two-stage process, we feel that the four-week window to reply to the initial ‘invitation’ is unreasonably short: the notices are likely to cause significant confusion and distress for seriously ill people and their carers, who will simultaneously be dealing with a maelstrom of other issues and problems arising from MND. We recommend six weeks as an absolute minimum, and preferably eight.

We also wish to remind the Department how important it is that all claimants have ample opportunity and space on the claim form to detail their precise needs – with a condition as complex and severe as MND, this can be a challenging task. Adequate design of the form in this respect is essential for minimising needless face to face assessments for people whose situation is sufficiently clear-cut that they can be judged to qualify for PIP on written evidence alone.

Further issues

We note that some of the most important aspects of detailed design, from an MND perspective, are not being consulted on as part of this exercise. We nonetheless offer comment on them here, as we are not currently members of the Implementation and Development Group.

Chapter 4: payability of the benefit

4.17 Generally, when a person is an in-patient of a hospital or similar institution, payment of their DLA care and mobility components stop after 28 days (84 days for children under 16). However, if the in-patient is leasing a vehicle through the Motability Scheme, existing provisions allow for the continued payment of the higher

rate mobility component for the duration of the Motability lease contract which could be up to three years.

4.18 [...]The Government announced in the 2010 Spending Review that it intends to address this anomaly by removing this provision in DLA regulations in 2012. It has now been decided that this change should roll out from 2013 alongside the implementation of Personal Independence Payment. This will ensure that all hospital in-patients are treated in the same way, whether they are a Motability customer or not. We have worked closely with Motability on this matter.

We oppose this change: people with MND who have been forced into an extended period of hospitalisation but who are subsequently able to be discharged could lose vehicles tailored to their specific needs.

The recent National Audit Office and Public Accounts Committee reports on services for people with neurological conditions showed that unplanned admissions to hospital are increasing in respect of neurology at a higher rate than in the NHS as a whole. With people with MND therefore at increased risk of unplanned hospitalisation, the plan to take their Motability vehicles away amounts to penalising them for the failings of the NHS and social care - it is not acceptable to heap double whammies of this sort on seriously ill people.

Chapter 6: award durations and reviews

In the scenarios we have developed to demonstrate the demands that MND will place on the system for administering PIP, all three cases involved quite sudden jumps: from zero entitlement to entitlement to the enhanced rates of both components in three months (scenario A) and seven months (scenario B), from zero entitlement to entitlement to the standard rate daily living component in three months, and from the standard to the higher rate daily living component in five months (scenario C).

In most of these cases, the changes were characterised by a combination of developments in the individual's illness. Isolating precisely when the entitlement kicked in, to within even a week, would be extremely difficult. Reporting each of these changes in their condition could be extremely arduous for a person with MND; they might only just have finished making one notification when they realise a second change has occurred.

Questions therefore arise about how this will be handled within the system for administering PIP. How long will it take for someone who notifies DWP of a change in their condition to secure a reassessment? Will a new reassessment be required for every change? If not, how will DWP determine when to reassess?

We strongly recommend that all awards for people with MND be made for a minimum of five years, and preferably ten. People with MND not on the maximum entitlement will almost universally need to report changes to their condition prior to the expiry of these awards, so this allows reassessment to take place when needed, without imposing an arbitrary timetable that fails to take the needs of the individual into account.

For people with MND on maximum entitlement, awards must be ongoing and not subject to review: there is zero medical possibility of their needs decreasing, so any reassessment of a person with MND in this situation will serve no purpose other than to waste taxpayers' money and cause inexcusable distress to the individual.

We also recommend, as per our previous submissions, that there must be a mechanism for people with MND who are not yet on maximum entitlement to be able to trigger an urgent reassessment of their case when their condition deteriorates. This reassessment must be available within two weeks: as can be seen from the scenarios appended to this response, a wait of substantially longer for reassessment could mean that people die without receiving benefit to which they are entitled in law (for instance Charles lives only five months after meeting the criteria for the enhanced daily living component – any significant delay to his reassessment, combined with the three month qualifying period, could lead to the benefit not being paid in his lifetime).

We have noted in a previous submission that such a mechanism would be at risk of abuse if it were made available to all claimants. Making it available to claimants with specified conditions would, however, cut across the Department's stated policy preference for avoiding condition-specific treatment of any claimant. A similar problem applies in respect of making ongoing awards to people with MND. If PIP is to support the people it is intended to support, the Department must get itself off the horns of this dilemma: we strongly recommend a condition-specific approach be employed in a limited range of circumstances. Without acknowledging the extreme nature of the needs presented by certain claimant groups, the benefit will simply fail. Given the clear warnings we have given on this issue, we do not see how any such failure can be excused. We will be happy to meet with the Department to discuss this point further.

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Appendix: Scenarios of MND

Notes on the scenarios

These three scenarios offer plausible and representative examples of the types of demand that people with MND will place on the new system for delivering PIP, and which it must be able to meet. They are not based on specific individuals, but are derived from our understanding of the demands of MND.

It must be emphasised that the course of MND is unpredictable: no two cases are the same, and for the sake of usefulness these scenarios are somewhat more 'neat' than most real-life cases of MND. We feel, however, that they offer a fair idea of how MND can progress in its varying forms.

All three scenarios were devised without specific reference to the proposals for PIP; initially they were developed with the intention of giving an overview of the needs of people with MND. The proposed PIP assessment was applied to them subsequently; accordingly, they contain some detail that is not directly assessed under PIP, and their chronology continues after the individual has achieved their maximum entitlement under PIP.

All three scenarios involve people of working age. Fronto-temporal dementia is a symptom of some cases of MND, but our understanding of its place in MND is still developing, and it is not covered here.

All of our scenarios assume that changes in a person's condition are promptly reported and accurately assessed; if people with MND cannot trigger urgent reassessments of their entitlement, and assessments are not accurate, there is a significant risk that substantial numbers of people with MND will die without receiving the PIP to which they are entitled.

Scenario A – Andrew: fast progression

Summary

- does not qualify for PIP at all in month six of his illness
- meets the criteria for the enhanced rates of both the daily living and mobility components in month nine of his illness, but has to wait until month 12 to receive it
- dies after being in receipt of PIP for 14 months.

Full chronology

- Andrew notices difficulty using his hands, which he has investigated by his doctor
- in **month six**, MND is diagnosed; Andrew can now use a pen, knife and fork or other implements only with difficulty and is using small aids for minor tasks (often non-medical ones, for instance velcro fasteners rather than buttons, for ease)
 - 2bii (daily living) applies (**2 points**)
 - The restrictive definition of 'aid or appliance' to exclude items that a person without a physical impairment might use, will mean Andrew does not receive PIP at this stage; a more practical definition of 'aid or appliance' would also see him pick up points under 1b (2 points), 4b (1 point), 5b (2

- points), 6b (2 points), totalling 9 points and qualifying for the standard rate daily living component
- by **month nine**, Andrew has lost use of his hands, and his arms are becoming weak; he has also become slightly prone to falls and had started using a stick before he lost use of his hands
 - in respect of daily living, 1g (8 points), 2f (10 points), 4g (4 points), 5d (4 points), 6f (8 points) all apply: total **34 points** – Andrew qualifies for the enhanced rate of the daily living component
 - However, he has had this level of impairment for less than three months; he will need to wait until month 12 before receiving any benefit
 - In respect of mobility, 2f (**15 points**) applies: Andrew can still walk modest distances, but his tendency to fall means that he needs an aid to do so reliably and safely; as he cannot use his hands and his arms are weak, a stick, frame or manual wheelchair are out of the question; Andrew qualifies for the enhanced rate of the mobility component
- by **month 12** Andrew has given up attempting to move any distance without a powered wheelchair; his employers have been supportive but he has concluded that he has to give up work
- by **month 14**, Andrew's speech is slurred; he requires a hoist to get in and out of bed or the shower; he uses a computer-based speech aid with eye-gaze technology for most communication
- by **month 19** Andrew's speech has become so slurred that only close relatives can understand him; his breathing is noticeably weak
- in **month 26** Andrew dies in hospital, a week after a respiratory crisis and emergency admission.

Scenario B – Beth: slower progression

Summary

- meets the criteria for the standard rate mobility component in month nine of her illness, but has to wait until month 12 to receive it
- narrowly misses out on the standard rate daily living component in month 13
- qualifies for both enhanced rates in month 20; identifying when the transitions to meeting each set of criteria take place is, however, extremely challenging; depending on the implementation of PIP, Beth may or may not have to wait until month 23 to access the benefit
- dies after being in receipt of PIP for 37 months.

Full chronology

- Beth notices her foot is dragging slightly when she walks, but thinks nothing of it
- by **month two**, the problem has not gone away and she goes to her GP
- by **month four**, the prescribed physiotherapy has done no good, and her foot is dragging conspicuously
- in **month six** she is referred to a neurologist
- by **month nine** her neurologist suspects MND; Beth's legs are now slightly weak and she is somewhat prone to falls; she insists on walking without a stick
 - 2d (mobility) applies (**10 points**); Beth qualifies for the standard rate of the mobility component, but has to wait until month 12 to receive it

- by **month 13** Beth has been diagnosed with MND and has been forced to walk with a stick; she is very prone to falls and is struggling to pick up small objects with her left hand
 - As with Andrew, Beth may be using a range of non-medical aids at this point to compensate for her weakening left hand; the narrow definition of aids and adaptations precludes these being taken into account, and could delay her access to the daily living component
- by **month 20** Beth is using an electric wheelchair for all outdoor and most indoor movement; she has a frame but is using it less and less; she can do small amounts of typing but needs assistance with anything more challenging, including eating; she has an adapted computer; she needs a hoist to get in and out of bed, and the shower; her heating bills have gone up during the hard winter, as she cannot move around to keep warm; she has mostly stopped her freelance work, though can occasionally do some smaller pieces
 - in respect of mobility, 2f (**15 points**) and 2gii (**15 points**) could both apply
 - in respect of daily living, 1f (**4 points**), 2f (**10 points**), 4g (**4 points**), 5d (**4 points**) and 6e (**4 points**) apply
 - Beth qualifies for the enhanced rates of both components; while her entitlement under the mobility component is clear-cut, her entitlement under the daily living component arises from the accumulation of points under multiple descriptors. Isolating the exact time at which each change developed since month 13 will be a challenge. If Beth were to be reassessed in month 20, demonstrating that she met the descriptors over the previous three months would also be a challenge. She may not be able to access the benefit until month 23.
- by **month 25** Beth is using a speech aid for communication, and has had her wheelchairs adapted several times, going without them for several weeks on each occasion; she is now unable to work on a freelance basis as she is prone to tiredness and so cannot be sure of completing work to deadlines
- by **month 38** Beth is using non-invasive ventilation (NIV) at night for her breathing
- by **month 46** Beth is using NIV regularly during the day
- in **month 49** Beth is totally reliant on NIV in order to breathe; she asks for it to be withdrawn and dies at her hospice.

Scenario 3 – Charles: bulbar onset, rapid progression

Summary

- Meets the criteria for the standard rate daily living component at month 10 of his illness, but needs to wait until month 13 to receive it
- Qualifies for the enhanced rate of the daily living component at month 15, accesses it at month 18
- Meets the criteria for the enhanced rate mobility component at month 18
- Dies having been in receipt of PIP daily living component at varying rate for seven months, but without receiving the mobility component at all.

Full chronology

- Charles has it pointed out by a friend that he is occasionally slurring his words slightly; he hadn't noticed, but becomes increasingly concerned
- in **month two**, the problem seems worse and Charles visits his GP

- by **month six**, Charles's speech is becoming difficult to understand and he is told it may be MND
- in **month seven**, Charles is diagnosed with MND; at the same time, he is given a lightwriter for communication; his mobility remains unaffected
 - 7c applies (**2 points**)
- by **month 10** Charles has difficulty being understood by anyone other than close family; he also has trouble swallowing and has suffered a couple of choking incidents
 - 7f applies (**8 points**)
 - Charles qualifies for the standard rate of the daily living component; however, he has not had this level of impairment for more than three months, and may need to wait until month 13 before he receives any benefit
 - The lack of a concept of supervision in the nutrition descriptor serves Charles badly: he has no problem conveying food to his mouth as his arms and hands remain unaffected, but his swallowing difficulties mean that he needs supervision to eat safely.
- by **month 15** Charles is unable to form words, and has noticed a slight weakness in his hands and arms; he is also suffering from breathlessness; he has been fitted with a percutaneous endoscopic gastrostomy (PEG) for nutrition, and no longer takes food by mouth
 - 7f (**8 points**) and 2e (**6 points**) apply
 - Charles qualifies for the enhanced rate of the daily living component, but may need to wait until month 18 to access the enhanced rate
 - As with Andrew and Beth, Charles may be using minor non-medical adaptations to compensate for his weakening hands; the narrow definition of 'aid or appliance' means that these will not be taken into account, although in Charles's case this does not debar him from receiving the daily living component of PIP
- by **month 18** Charles needs NIV for his breathing, and can walk only short distances; his hands and arms are now notably weak
 - 2f (**15 points**) applies, as Charles cannot walk any distance safely and reliably, and cannot use a manual wheelchair
 - Charles meets the criteria for the enhanced rate mobility component, but will have to wait until month 21 to start receiving it
- in **month 20** Charles dies of respiratory failure
 - Charles dies without receiving the mobility component.