

RESPONSE TO THE CONSULTATION ON PERSONAL INDEPENDENCE PAYMENT ASSESSMENT AND THRESHOLDS

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. 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. There are about 5,000 people living with MND in the UK, of whom approximately a third are of working age at the time of their diagnosis. 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. This response considers how the proposed assessment and thresholds for Personal Independence Payment (PIP) are likely to work for people with MND who claim the benefit (only a minority of people with MND will access PIP via special rules, despite the terminal nature of the illness; this ongoing problem is not addressed further in this response). Overall, we feel there is some way to go before the benefit is truly workable for people with MND.
- iv. Some of the outstanding issues pertain to the detailed design and implementation of the benefit, although these are sometimes closely intertwined with the thresholds; these will be flagged briefly here for completeness, and addressed more thoroughly in our response to the consultation on the final design of PIP.
- v. We have charted three plausible scenarios of MND progression: fast progression, with the limbs affected first; slower progression; and bulbar onset MND, which is typically rapid and affects speech, swallowing and breathing most quickly. These scenarios are not directly based on specific individuals, but have been derived from our experiences of people with MND, to give a representative spread of the demands that the new benefit will face from this group of recipients.
- vi. It should be noted that all cases of MND, barring those involving sudden deaths due to co-morbidities or other external factors, involve levels of physical impairment that will inevitably lead to the individual qualifying for PIP (or Attendance Allowance, for older claimants); it is a question of when and how someone qualifies, not whether they will or not – the nature of the illness is such that entitlement to an 'additional costs' benefit is essentially guaranteed.

- vii. This response answers the consultation questions (where we have not answered a question, we offer no comment on that issue), sometimes with reference to the three scenarios. The scenarios are appended in full to the response, and can be summarised as follows:
- Scenario A, Andrew (fast progression, limbs affected first) – qualifies for both components at enhanced rates in month nine of his illness, so receives them from month 12 onwards; we feel this is somewhat late;
 - Scenario B, Beth (slower progression, limbs affected first) – starts receiving standard rate mobility component in month 12 of her illness (again, somewhat late we feel), misses out on daily living component at month 13, and qualifies for both at the enhanced rate by month 20; determining exactly when Beth’s entitlement should commence is a considerable challenge;
 - Scenario C, Charles (bulbar onset, rapid progression) – 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; gets the enhanced daily living component at month 18, qualifies for the enhanced rate mobility component in month 18 but dies during the qualifying period without receiving it.
- viii. Key conclusions from this exercise include:
- Sudden jumps from zero entitlement to one or both enhanced rates will be possible, and probably common, among people with MND, and only those whose illness progresses relatively slowly will spend prolonged periods receiving PIP at the standard rates; the system must be able to respond quickly to these demands;
 - Some people with MND will die without receiving the PIP to which they are entitled; if the system is slow to respond to the often rapid degeneration of MND, this number will be substantial;
 - The three month qualifying period has a significant proportional effect on people with MND; without it, some people with MND would receive PIP for a third as long again, or more;
 - Inaccurate assessment or a system that is slow to respond will have a significant detrimental effect on how beneficial PIP is for people with MND; we will explore this point in more depth in our response to the consultation on design.

Q1 – What are your views on the latest draft Daily Living activities?

- i. The criteria for PIP as a whole remain in large part an assessment of the individual’s physical abilities, and strongly resembling a medical model of disability. MND is a condition whose demands are highly medical, so of itself this is not overly problematic from an MND perspective, although we sympathise with those patient bodies for whom a more social model would have been appropriate.
- ii. Overall, the daily living component is the more complex of the two for people with MND: they will often ‘bump along the bottom’ in the earlier stages of their illness, earning zero or low numbers of points; small changes in their condition may, however, see them qualify for the benefit quite quickly. This will require vigilance on the part of both DWP and people with MND, to notice when such a change has occurred and respond quickly to it. In our Scenario A, Andrew goes within three months from accruing points under activity 2 alone to scoring under activities 1, 2, 4, 5 and 6 and qualifying for the enhanced rate.
- iii. One major problem in respect of daily living is the restricted definition of aids and appliance: people with MND often make use of small items such as velcro fastening,

hooks or loops on clothing, an electric toothbrush and so on that an able-bodied person might use – these are discounted from the current definition even though someone with MND would rely on these in a way that a person in full health would not. This accounts in large part for the sudden jump from low or zero scores on many activities to very high ones. We recommend that this definition be broadened; this would have the effect of allowing some people with MND to spend some time on the standard rate, rather than having no PIP and then jumping straight to the enhanced rate. The definition currently proposed would lead to people with MND receiving PIP later in their illness than should really be the case, by which time it will already have started generating noticeable additional costs to them. This is particularly noticeable in our scenarios A and B, and in the case of slower-progressing cases of MND will delay access to PIP quite substantially.

- iv. A serious omission from the revised daily living activities from an MND perspective is the concept of supervision in relation to nutrition: MND affects swallowing, and choking episodes are quite common in MND (although, for the avoidance of doubt, they are very seldom fatal – this is a common misconception). We would suggest this should carry at least four points, in line with ‘prompting’. This would lead to Charles, in our scenario C, being awarded the enhanced rate of the daily living component at an earlier stage.

Q3 – What are your views on the latest draft Mobility activities?

- i. With one caveat, we generally are satisfied with these activities from an MND perspective, providing our understanding of them as set out in the scenarios below tallies with the intended implementation by DWP (for instance, a person with little use of their hands, in addition to their weak legs, requires an electric wheelchair).
- ii. The caveat is that a person who needs a wheelchair to move around safely and reliably must be treated as though they use one, whether they have one or not. In some areas wheelchair provision for people with MND is notoriously slow, and wheelchairs often have to be taken away to be modified as the individual’s disease progresses. Some people with MND will therefore be assessed for PIP at times when they need a wheelchair, but do not have one (or at least, not a suitable one).

Q6 – What are your views on how we are dealing with fluctuating conditions?

- i. For the avoidance of doubt, MND is not to be regarded as a fluctuating condition: while it is true that individuals with MND may speak of having ‘good days and bad days’ the overall MND journey is one of degeneration. Once a function has been lost, it is medically impossible for it to return; this is not true of fluctuating conditions such as some types of multiple sclerosis, where the individual may be incapable of something at one time, but able to do it at a later time – with MND, function does not return in this way.

Q7 – What are your views on the definitions of ‘safely’, ‘timely’, ‘repeatedly’ and ‘in a timely’ manner?

- i. These stipulations are extremely important to the accurate assessment of people with MND, particularly in cases where the person’s hands, for instance, have become weak and completion of a task may be possible with effort but it cannot be done reliably or repeatedly. When assessing mobility, the risk of falls is of course key: many people with MND will be able to walk some distance some of the time, but will be liable to falls and therefore unable to walk that distance safely, reliably, repeatedly or in a timely fashion.

- ii. We therefore strongly recommend that these conditions are included in the regulations, and that they are placed both in a general description at the start and in the detail of each descriptor. This will not make for elegant regulations, but we know from the experience of the Work Capability Assessment (WCA) that the intention behind individual provisions can easily be forgotten, lost or distorted in the day-to-day implementation of an assessment process, or that items intended to be applied with common sense instead get applied with unyielding and unthinking rigidity. These stipulations should therefore be spelled out clearly, repeatedly and 'in crayon'.
- iii. The same approach must also be applied to whatever software is developed or purchased to deliver the new assessment: assessors must never be able to forget or overlook these stipulations. Experience of the WCA makes it impossible to have confidence in any other approach.

Q8 – What are your views on the definitions in the regulations?

- i. We feel that aids and adaptations are too narrowly defined, as per Q1.

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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.