



## **Personal independence payment: second draft assessment criteria and consultation document**

### **Response from the Multiple Sclerosis Trust**

#### **Q1 - What are your views on the latest draft Daily Living activities?**

The MS Trust is pleased that the second draft assessment criteria include the three new activities of Communicating, Engaging Socially and Making Financial Decisions; these three categories recognise the very real cognitive aspects of disability.

For this consultation, we have chosen to respond only in relation to these three new areas within the draft Daily Living activities.

#### **Q2 - What are your views on the weightings and entitlement thresholds for the Daily Living activities?**

##### *Activity 7: communicating*

In its current form, this activity does not appear to make allowance for cognitive problems in processing information that may not be apparent within the other activities of daily living.

For example, in item D 'needs assistance to access written information', we ask for some clarification that this will include problems with understanding written information rather than just reading it. Similar concerns apply to items E 'needs communication support to express or understand complex verbal information' and F 'needs communication support to express or understand basic verbal information'.

Our concerns rest in the fact that some people severely affected by their multiple sclerosis may be able to read or talk with reasonable facility but often lose the ability to process complex information and/or to recognise that this is an area with which they have difficulty. Similar issues must present in other conditions that include cognitive degeneration. So we would like to be sure that the assessor's notes included such cognitive concerns.

### *Activity 8: engaging socially*

Similar concerns arise in relation to activity 8: this descriptor must include difficulties with social engagement caused by cognitive problems, and recognition that communication difficulties may cause problems with social engagement.

### *Activity 9: making financial decisions*

On the whole, we are content with the definitions used and the items within the descriptor.

We are very concerned at the weightings used in this descriptor. In particular, item D 'cannot make any financial decisions at all' attracts only a score of 6, which is not enough to qualify for the entry level of PiP support.

In our view this does not take account of how individuals who are unable to manage any money independently become extremely vulnerable, since this lack of financial understanding removes their ability to live independently in any safe manner.

While we appreciate that such individuals are likely to score additional points elsewhere with other cognitive difficulties, it seems unreasonable that this particular descriptor does not take account of such significant risk. It also looks very odd when compared with similar items of significant vulnerability within the Daily Living descriptors, eg item D within activity 8, 'cannot engage socially at all', which attracts 8 points.

Our preferred weighting might look something like this:

A :can manage complex financial decisions unaided - 0

B: needs prompting to make complex financial decisions - 2

C: needs prompting to make simple financial decisions - 6

D: cannot make financial decisions at all - 8

### **Q3 - What are your views on the latest draft Mobility activities?**

The MS Trust is content with the two proposed categories: activity 10: planning and following a journey, and activity 11:moving around.

**Q4 - What are your views on the weightings and entitlement thresholds for the Mobility activities?**

We are glad that activity 10 has been included in the new draft assessment criteria, and content with the weightings, since these appear to benefit people with MS and similar conditions. It is not unknown for people with MS to become very poor at even familiar journeys as their spatial awareness and cognition starts to fail; and individuals with even quite mild MS may need someone else to plan a journey to an unfamiliar destination. With this kind of support, such individuals may be capable of continuing to drive their own car.

Activity 11 - moving around; we are content with the descriptors and with the sub-items, but slightly puzzled why items F and G are separated, yet score the same:

item F: cannot move up to 50 metres without using a wheelchair propelled by another person or a motorised device - 15 points

item G: cannot either:-

- i. move around at all or
- ii. transfer unaided from one seated position to another adjacent seated position - 15 points

Why not either amalgamate all three descriptions into one item or give them different weightings? Otherwise this seems a pointless distinction.

**Q5 - What are your views on how the regulations work regarding benefit entitlement?**

The regulations appear to be clear on how benefit entitlement will work - the qualifying period of 3 months, plus an anticipated 9 months of disability; they are not obviously ambiguous.

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

The 50% rule approach is consistent with this Government's attempt to be fair while reducing the overall benefit bill.

As we understand it, this approach says that a symptom has to occur more than 50% of the time to count in the assessment. 'Where one single descriptor or activity is not satisfied on more than 50 per cent of days, but a number of different descriptors in that activity together are satisfied on more than 50 per cent of days - for example descriptor B is satisfied on 40 per cent of days and descriptor C on 30 per cent of different days - the descriptor satisfied for the highest proportion of the time should be selected'

The MS Trust is concerned that the chosen approach, to take the disabling symptom that arises most often over other, potentially more disabling symptoms that may arise less of the time, could penalise people who become significantly disabled when serious symptoms crop up. This is particularly true of relapsing/remitting MS, where relapses are unpredictable and can be so seriously disabling that individuals lose all mobility and communication for lengthy periods of time, with no warning. We would like to see recognition of this within the regulations. For example, we would welcome a definition that worked towards suggesting that 'the most disabling descriptor should be selected where this is identified as preventing the individual from living safely and independently for more than 48 hours at the time it arises'. Clearly such descriptors could only be assessed on the basis of a consultation with the individual and/or a medical report.

**Q7 - What are your views on the definitions of 'safely', 'timely', 'repeatedly' and 'in a timely manner'?**

The MS Trust is content with the proposed definitions. We believe they should be included within the Regulations to ensure statutory status. However, it may well be helpful to include them within the detail of activity descriptors, particularly in relation to cognitive activities.

**Q8 - What are your views on the definitions in the Regulations?**

We are content with the draft definitions in the Regulations.

**Q9 - Do you have any other comments on the draft regulations?**

Regulations 5-10 relate to elements of the payments process for PIP, around the requirement to provide information and attend face-to-face consultations; the consequences of failing to meet these requirements and when individuals might have good reason for not meeting these.

We have two main comments on the draft regulations:

1. We would like more detail of how consultations will work for those unable to attend face-to-face consultations. The regulations state that a telephone consultation will be used in these situations, but has it occurred to you how you will deal with severely disabled individuals who may not be able to process complex verbal information and/or leave their homes? For example, it is possible for someone severely affected by MS to be largely or entirely confined to bed, with significant cognitive and communication problems, and still be living at home and therefore entitled to PiP. We would like more clarity about what evidence such individuals will need to provide in their PiP application to ensure that they or their carers are not put under undue pressure to attend a consultation which they are unable to manage. Similar concerns arise with telephone consultation, especially if an individual has significant cognitive problems which mean they are unable to process verbal information correctly: we are concerned that the whole

process may cause significant stress and potentially worsen the health of people who are already ill.

2. Reviews of awards: while we understand the principle behind regularly reviewing awards, we are concerned that where a person is recognised and certified as having a progressive condition that will not improve, and is awarded the highest rate for the daily living and mobility components of PiP, why there is provision within the Act for periodic review of the award? By definition, these individuals will be severely disabled; there is no likelihood of improvement in progressive types of MS; and reassessment for PiP will cause significant stress which is likely to worsen their symptoms and condition. We would like some assurance that in such comparatively small numbers of cases, the system will allow an award for life rather than a long-term award, or that long-term awards are made so long-term that they last until an individual would become eligible for Attendance Allowance (or its successor benefit).