



## **Personal Independence Payment assessment thresholds**

### **Action for M.E. consultation response**

**30 April 2012**

#### **What is M.E.?**

Myalgic Encephalomyelitis (M.E.) is a chronic, fluctuating illness affecting 250,000 people in the UK. It may be diagnosed as Chronic Fatigue Syndrome (CFS) or Post Viral Fatigue Syndrome (PVFS). For continuity and clarity we will refer to the condition throughout this report as M.E./CFS

The World Health Organisation classifies M.E./CFS as a neurological condition. The National Institute for Health and Clinical Excellence (NICE) emphasises that this is a real illness and that the physical symptoms can be as disabling as multiple sclerosis, systemic lupus erythematosus, rheumatoid arthritis and other chronic conditions.

M.E./CFS involves a complex range of symptoms which includes fatigue, malaise, headaches, sleep disturbance, difficulties with concentration and muscle pain. The pattern and intensity of symptom vary between people, and during the course of each person's illness. People often have symptoms for many years before M.E./CFS is diagnosed. Some patients recover fully and most improve over time. However, a significant minority remains very ill and do not respond to the therapies available.

Up to 25 per cent of patients are so severely affected that they are unable to leave their homes or their beds for prolonged periods which for some can last for years.

#### **Action for M.E.**

Action for M.E. is the UK's leading charity for people with M.E. and their carers.

We provide information and support and have been at the forefront of the campaign for more research, more effective treatments and better services since 1987.

Action for M.E. works in partnership with other organisations in order to transform the lives of people with M.E. for the better and to work towards overcoming M.E. in the longer term.

We do not have any Government funding, but rely totally on donations from supporters.

Find out more about us at our Online M.E. Centre at [www.actionforme.org.uk](http://www.actionforme.org.uk)

## Introduction

The purpose of this document is to respond to the consultation questions in the Government document *Personal Independence Payment (PIP): assessment thresholds and consultation*.

The views represented here are drawn from those of people with M.E. who responded to communications via our Online M.E. Centre, social media, and InterAction magazine.

A key point made was that people with M.E. have grave concerns about the transparency of the process of PIP introduction. A number voiced their support for the Spartacus report (1) which said that the Government's response to the Disability Living Allowance (DLA) consultation presented a highly misleading view of the responses it received. One quote underlines the strength of feeling on this theme: "Sadly, and angrily, I therefore have to say that I have no intention of wasting any more precious energy trawling through yet another DWP whitewash effort, and submitting views that I know damn well they have no intention of taking any account of."

We have also repeatedly made the point that DLA is a highly valued benefit which is relied upon by many people with M.E. The Government's decision to exclude a large proportion of DLA claimants by reducing the tiers of benefit from three to two will cause hardship to many.

We therefore submit that DLA is a fair and equitable system and that the additional time and administration required for the introduction of PIP does not just the costs savings which are claimed, and which, in any case, are targeting the most vulnerable people in society unjustly. The overriding view was that the descriptor weightings are too low, and the entitlement thresholds are too high.

The main points above are evidenced by the notes below which summarise the comments of people with M.E. in response to each of the consultation questions in an attempt to minimize the detriment to disabled people.

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

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

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<sup>1</sup> [http://www.ekklesia.co.uk/files/response\\_to\\_proposed\\_dla\\_reforms.pdf](http://www.ekklesia.co.uk/files/response_to_proposed_dla_reforms.pdf)

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

- The categories are very complex and do not flow from one to the next in a logical clear progression.
- It is not clear what level of incapacity each relates to.

“They seem to jump about. I had to read the activity and descriptor pages several times to even begin to understand them.”

- The switch from CAN to CANNOT between descriptors C and D is particularly confusing:

C) Can move up to 50 metres unaided but no further

D) Cannot move up to 50 metres without using an aid or appliance, other than a wheelchair or a motorised device

Suggested rewording is:-

D) can move up to 50 m but only by using an aid or appliance (other than a wheelchair or a motorised device)

- The exclusion of physical ability from several parts of the Daily Living Activities (ie. engaging socially, making financial decisions) and the removal of a shopping category mean that these mobility tasks are very important, because presumably the physical restrictions are meant to be covered by this Mobility category. They may not capture an individual’s true restrictions. An individual who cannot move around adequately will be unable to get out of the house to actually carry out any of those Daily Living Activities, such as socialising and buying food, yet they would not be awarded any care costs.
- An example of this would be that the guidance notes say 50 m is considered to give a basic independence by being able to walk from a car park to the supermarket. This does not give any independence. It does not mean the person is also able to actually shop by themselves (which may involve opening heavy doors, reaching, lifting and moving grocery items). At that walking ability they are going to be unable to use public transport, and will have costs associated with transport (car or taxi), acquiring the wheelchair and paying for a carer to push it and lift and move shopping.

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

Key points were:

- Mobility underpins every aspect of life, and if you can only move up to 50 m (regardless of whether that is unaided or with a stick) then you are unable to engage in society or manage daily activities without considerable help and alterations to daily life, all of which incur extra costs which will not be met by the standard mobility component. Examples include having to use taxis instead of public transport, not being able to access shops in pedestrian precincts, having to get shopping delivered. Someone with restricted mobility does not become a wheelchair user overnight, and in the interim, life can be even more restricted, difficult and costly.
- “I am disappointed with the definition for the higher mobility payment which I currently receive under DLA. I am an amputee with fibromyalgia, ME/CFS, bad back (due to posture using a prosthesis). I live alone and value my independence, so I use my car for everything. I drive to shop because I can't manage to walk to the local shops because I regularly fall over and am advised not to walk far. A motorised wheelchair would give me a deal of freedom locally, but if I have to choose between that and a car, I choose a car every time, at the moment.”
- Under the new proposals it seems those who choose to drive rather than use a motorised wheelchair will lose their entitlement to higher mobility. Those who drive a car from the Motability Scheme, in addition to losing the money, would have to find the money to buy a car, insure it, service it and maintain it.
- The new benefit, whilst not denying lack of mobility, is denies any choice in how people get around, potentially restricting them to the immediate vicinity of their homes. By giving up their car and getting a motorised wheelchair, they will still be entitled to the higher rate mobility payment –therefore there is no cost saving here, but the impact on quality of life is significant.

Comments on specific descriptors are summarized as follows:

- Either Higher rate Mobility Component should be achieved at 8 points not 12, or the descriptor weightings for C and D should be increased, so they qualify for Higher rate.
- Descriptor A. If a person ‘can move at least 200m’ descriptor A, then they score zero points. If they can only walk 200m then they do still have mobility needs and costs, for example using public transport, is unlikely to be possible.
- Descriptor B. A person with purely physical problems with walking who matches this descriptor will not in fact be awarded any level of mobility component (as 4 points does not meet the 8point threshold for standard rate). So although a need has been identified by matching this descriptor, it will not be met.
- Descriptor C. If a person ‘can move up to 50 m unaided but no further’ descriptor C, the guidance notes say this is the category for people who then require a wheelchair. Yet this only scores 8 points, the standard mobility component. It should be the Enhanced Rate mobility component, otherwise they will not be eligible for the Motability scheme, or sufficient money to run a car.

- Descriptor D. This person cannot move up to 50 m without using an aid or appliance such as a stick, yet only gets 10 points, therefore the standard rate Mobility component. Again, this is wrong, it should qualify for the Enhanced Rate.
- Both Descriptor C and Descriptor D contradict the stated aim in 3.7 quoted below, that those who need to use a wheelchair will get the enhanced rate. It has in fact only been applied to people who need a wheelchair at LESS THAN than 50 m, but **how else are people who can only walk up to 50 m supposed to get around, if not by wheelchair?** At that level of walking ability, life is very restricted. Where can you go that doesn't require you to move more than 50m? It is therefore virtually impossible to leave the house without a wheelchair, (with all the associated costs of purchase and upkeep and carers) and it is certainly not possible to use public transport.

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

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

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

The inclusion of these terms was welcomed. It was felt that it is essential that these terms be included in the Regulations to give them the full weight of law, not just relegated to the notes. It would also prove the government’s commitment to them. Without these terms the threshold for entitlement is moved to such a high level it alters the entire benefit, and far fewer people would qualify for it. As the terms form such a fundamental part of setting the threshold they must be part of the Regulations.

It was also stated that the phrases must be printed on the claim form, and are asked of the claimant at an examination, so that they cannot be overlooked by either the claimant or the assessor.

Unless these phrases form an integral part of the assessment, then the results of the assessment will not be an accurate reflection of the abilities of the claimant. For example the question ‘Can you move unaided up to 50 meters?’ (Activity 11, descriptor C), the claimant may well tick ‘Yes’. But closer questioning could well reveal that they can only do this on some days, or only once a day, or it may prevent them from being able to prepare a meal afterwards, or may mean they need extra pain relief and to lie down later in the day, etc. All of this would mean that the true answer was No.

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

Bathe - should mean just that, either bath or shower. Everyone should have a right to that as a basic human dignity. By using the word ‘clean’ they are leaving open the possibility that just having a wash is sufficient, it is not. It also seems that feet have been omitted from the definition

Prepare Food is defined as make ready for eating, there is nothing about clearing up and maintaining basic hygiene in the kitchen, such as disposing of rubbish and cleaning of utensils and work surfaces, which is essential if you are to be able to make food safely.

The definition of cook is to heat food at or above waist height. The definition is too narrow. Food and clean utensils do not just happen to be laid out at waist height like a cookery show, unless someone other than the claimant has been able to put them there in the first place. This means a reliance on others and (if you live alone) a cost for carers, which has to be met by the claimant, yet the need for it is ignored by this definition.

The definition of social support seems to imply that friends or relatives do not count, though many people will have a lot of essential social support provided by these categories of people.

Simple financial activities is defined far too simply. It also implies that the person is physically present, such as in a shop. The claimant may be unable to access goods and services to be able to conduct these simple financial activities unless mobility costs/limitations are addressed too.

The definition of communication does not address the problem of being unable to communicate at all due to severe exhaustion or illness. People with M.E. can experience times when they can no longer talk to anyone or think or answer the phone or be in company. That is a restriction on ability to be independent, and they may need others to do things or take messages for them. However, no amount of support is going to allow them to be involved at that particular moment in time.

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

- Respondents said that it was vital that there was an option of completing a paper claim form, as it would be impossible for many people to provide that amount of information and to concentrate for long enough to do a telephone interview.
- It was stated that there must be exempt categories from the requirement for face to face assessments for those who are too ill to attend. It was also asked who would make the decision as to whether a face to face assessment is required? How does a severely ill claimant gather the necessary evidence that they are not able to attend? Will a letter from your GP be accepted? This needs to be made clear to avoid unnecessary stress to the claimant and a worsening of health due to trying to attend the assessment.
- Regulation 9 concerning redetermination of the claim does not specify a minimum period before the claimant can be reassessed. There should be a minimum period, or it will become a continual and stressful process for the claimant, with an adverse effect on health.
- The Required Period Condition definitions are too stringent and will be impossible to prove for anyone with an uncertain diagnosis or prognosis. A considerable concern was the requirement to prove that you will have the same needs for the next 6 months. What happens if an individual claims after 6 months, is turned down, but 6 months later is still as much in need? At this point, would they still have to prove that you will be ill for a further 6 months? If so the condition will be impossible to meet, a constantly moving goal. It was suggested that in a case such as this the claimant should be awarded their claim backdated to the original claim date.