

**Personal Independence Payment: assessment thresholds and consultation response by the 25% ME Group and Stonebird.**

*1. The government wants to find new and better ways to work out who gets Personal Independence Payment. This will be done through an **assessment**.*

We are concerned that the true intention is primarily to cut costs rather than meet need. We are aware that the stress surrounding the whole reassessment process will put peoples' health and lives at risk, especially those with Severe ME, who are extremely vulnerable and likely to deteriorate, under these circumstances.

The whole message, highlighted by the cartoon on page 5 of the Easy Read Document, is a confusing one for people. The cartoon is too simplistic an interpretation. A lot of people with ME do not necessarily get the amount of help they actually need, like the carer in the picture, because they are so physically hypersensitive and ill and may be unable to access that help.

We would like to pose the questions:- "Will PIP be a genuine assessment of need, or will it be based on a flawed assumption based on what people currently get?", and, "Is PIP going to make the assumption that the applicant doesn't need the care, because they currently haven't got it?"

We would also like to ask what PIP actually considers "*independence*" to be?

*2. Many people and groups got in touch and they had some good ideas to make Personal Independence Payment better.*

We consider this statement to be incorrect; as the last consultation response was ignored.

The need for DLA, as it is, is apparently accurate, given the extremely low fraud rate. We, along with many other groups, asked the Government not to go ahead with these changes and to keep DLA as it is. Also the last consultation was confusing and was likely to result in people answering the questions wrongly, because the questions were so complicated.

To make these changes to the benefit system is to deny peoples' independence because so many claimants will lose money, as a result. PIP, paradoxically, as we spelled out in our last response, will actually result in a loss of independence for many people, who are currently assessed as having a genuine need.

3. *On 14 November 2011 the government sent out a second booklet about the changes it had made as a result of the consultation. The booklet was called "About the Personal Independence Payment Assessment."*

We were not sent a booklet and were unaware of the second consultation process, even though we participated in the first consultation. Who was the booklet actually sent to? Was it sent out only to a certain percentage of respondees, given we did not receive one?

Is this a genuinely inclusive consultation process, where you are reaching everyone who has an interest, or are you simply excluding those who do not agree with your strategy?

4. *There will be 2 rates of Personal Independence Payment – a standard rate and an enhanced rate*

As we stated in our first response, we do not agree that there should be only two rates, as this will automatically exclude all those currently on low rate DLA, presumably. PIP, therefore cannot be about enabling independence, as it claims, as many people will be negatively impacted upon by this loss and their health and safety might be at risk.

This is particularly of concern because people with Severe ME do not always receive the right level of DLA in the first instance and may therefore end up being excluded all together, because of misinterpretation of their need.

5. *Daily Living Activities:*

Without knowledge of what specific questions are going to be asked to assess daily living activities, it is impossible to say whether 8 points is even achievable. Therefore it is unsafe to give to the government the go ahead without knowing in detail how you achieve 8 points.

Not enough detail has been provided here to make a full comment.

The key point is how you frame the questions and whether this will result in the correct information required to safeguard the needs of the ill person. We feel the danger is that the questions may be so confusing, severely ill people will be so confused and therefore not answer them fully or correctly to actually reflect all their needs.

We would hope there would be adequate space to explain needs and not just a simple tick box system, which will not give adequate protection for people with Severe ME by not facilitating their need to fully explain the daily requirements.

*6. Taking medicines, looking after health and doing treatments a health expert says are important .*

It is extremely concerning that this has been included. It sounds as if this could be used to withhold benefit if people do not comply with treatments which either may be impossible for them to do or may actually risk being harmful to the person. With ME there is great potential of harm if people are going to be forced to undergo a Cognitive Behaviour or Exercise programme in order to receive their benefits.

It is completely unacceptable to raise this issue as a benefit need. We feel this needs to be withdrawn to make PIP safe for people.

*7. The change to Personal Independence Payment in 2013 will only affect people aged 16 to 64.*

Why is it not in line with pension age rises, which are going beyond 65?

*8. So, by the end of March 2016, half a million fewer people aged 16 to 64 will be getting Personal Independence Payment than would have been getting Disability Living Allowance.*

How does this equate with the idea of enabling independence, when you are going to cut half a million disabled people off from essential financial support for independent living?

Given the fraud rate is only 0.5%, how can you justify removing half a million people from benefits? This appears to be discriminatory.

*9. To make sure the assessment takes this into account, the government thinks that the assessment should look at how a condition or disability affects a person's daily life or mobility over a 12-month period.*

This is very concerning. We are unsure what the actually means. Does this mean that claimants will be subjected to continual investigations and reassessments? Also, how are you going to ensure that anyone involved in this process understands the physical reality of chronically ill patients?

What is the actual justification for this idea of continual investigation and reassessment if the government has already accepted that unless you can do something constantly you cannot manage it. It seems to us that to continually check on people to see what they can do at any one point, sounds like an harassment of the chronically ill and is likely to cause great harm to people with Severe ME who are at great risk of post

exertional deterioration and physical decline, caused just from the effort of assessment itself. It is also an unnecessary waste of taxpayers money and likely to cause serious deterioration in people's health and life as a consequence.

There is such misinterpretation and misunderstanding of the severity of illness in ME that people with ME will at great risk of misinterpretation and misrepresentation. If someone has a variable condition they should be respected as disabled without constant monitoring, worry and stress.

*10. If the person's health condition or disability affects them enough to get assessment points for*

- at least half the year (183 days or more), the points should be taken into account in the assessment for the full year.*
- less than half the year (182 days or less), the points should not be taken into account in the assessment at all.*

If a person's health condition or disability affects them enough to get points during any part of the day, the assessment should treat those part days as full days.

How is the government going to determine a variable condition in the first place? Are they going to choose certain illnesses and treat everyone within that category the same way? This could certainly result in unnecessary stress and potentially a decline in health, as a direct result of the repeated assessment procedure.

How is the government practically going to do this without making people more ill and wasting taxpayers money?

If you have a disease, you have it; you do not have it some days and not others, even if you can manage some days better than others. It is wrong to put this additional reassessment burden on people.

On what basis has the government decided that 182 days is the cut-off? How are you going to determine on the 183rd day the person is still eligible for benefits? It should be respected they have the illness all the time.

We feel this is just making people's lives harder, not enabling independence.

*11. The government thinks that the person doing the assessment should always think about whether a person can do an activity 'safely, reliably, repeatedly and in a timely fashion'.*

- **Safely** means that, when doing the activity, the person is unlikely to hurt themselves or other people.
- **Reliably** means that the person can do the activity in an acceptable way.
- **Repeatedly** means the person can do the activity as many times as needed during the day.
- **In a timely fashion** means the person can do the activity in less than twice the time it would take a person without a condition or disability.

Is the government going to publish the precise times they are talking about or will it be up to the assessor to make an arbitrary decision? Anything less than "normal" ability is going to be potentially dangerous to health and safety.

Who is being judged as fit and able, who is being used as a benchmark?

An arbitrary judgement of how long is ridiculous. If, for example, you need to get to the toilet, have an overheating chip pan, break or need to apply the break while driving, an immediate response is required for safety. Anything less than full ability should count towards points. It would potentially endanger people's lives to make these judgements.

### **Some Key Points about Specific Questions in the Consultation**

#### ***Question 1 – What do you think of the government's latest ideas about the daily living activities?***

Endangering, sinister, punitive, neglectful, arbitrary and prejudiced.

#### ***Question 2 – What do you think of the government's ideas about the points allowed for daily living activities and the points you need to get this component?***

Not enough detailed information to make a fair judgement.

Potential to misrepresent real need.

#### ***Question 3 – What do you think of the government's latest ideas about the mobility activities?***

Not enough information on how it is going to be assessed, what questions are going to be asked and what information will be required.

***Question 4 – What do you think of the government's ideas about the points allowed for mobility activities and the points you need to get this component?***

Not enough information to tell.

***Question 5 – What do you think of what the regulations say about deciding who can get the payment?***

The fact the government's intention is to take half a million disabled people off DLA rather than honour their need, is unacceptable. There is a discrepancy between what the government says it wants to do and what it is actually doing. There is also no clarification whether the proposed high rate will be the same as high rate DLA.

***Question 6 – What do you think of the government's ideas for dealing with health conditions that are sometimes a little better and sometimes a little worse?***

Unnecessary, discriminatory and irrelevant. If you need help some of the time it should be equated with needing help all the time, there is no need for this harassment of disabled people. The underlying motive is suspicious.

***Question 7 – What do you think of the government's ideas about the meanings of the following words – safely, reliably, repeatedly and in a timely fashion?***

"Timely fashion" is ambiguous, it appears to be completely arbitrary, vague and not respectful enough of the individual problems and issues people experience.

***Question 8 – What do you think about the way the regulations show the meanings of words?***

Not enough words have been explained. There is not enough detail about how people will be assessed and how the points will be allocated to particular abilities, within a section, on which to base comments generally.

Given that the Personal Independence Payment: second draft of assessment criteria 2.10 states : "As with the technical note we published in May, this document does not consider the delivery of Personal Independence Payment assessments as work on the claims and assessment processes of the new benefit is still ongoing." People should not be asked, at this stage to make blanket comments validating the process.

***Question 9 – Do you want to say anything else about the draft regulations?***

We are greatly concerned that people with Severe ME may be subjected, wrongly, to additional assessments and hope that people who are severely affected will not have to

face the added burden of a yearly assessment which appears to be discriminatory rather than supportive.

It is unacceptable to have any health provider recommendation associated with gaining benefits whatsoever and needs to be withdrawn to ensure people's safety in obtaining support.

It is essential that people with Severe ME, whose health would be endangered by face to face contact, are not exposed to face to face assessments; their health is in great jeopardy and must be protected at all costs.