



ARTHRTIS CARE CONSULTATION RESPONSE:

PERSONAL INDEPENDENCE PAYMENT: ASSESSMENT THRESHOLDS AND CONSULTATION

INTRODUCITON

Arthritis and Arthritis Care

Arthritis is the biggest cause of physical disability in the UK, affecting up to 10 million people, and accounting for one in four of all GP visits. It carries a huge economic as well as human and social cost, estimated at £7 billion annually in terms of lost labour in 2007¹.

Arthritis Care is the UK's leading organisation working with and for people with all forms of arthritis. We are a user-led charity; people with arthritis are at the heart of our work: they form our membership, are involved in all of our activities and direct what we do.

We welcome this opportunity to contribute to this consultation.

CONSULTATION QUESTIONS

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

In the explanatory note we set out revised proposals for the activities relating to entitlement to the Daily Living component (activities 1-9). These include three new activities: Communicating, Engaging socially and Making financial decisions. We would welcome your views on the activities. Are the changes and the new activities an improvement? Do you think we need to make any further changes?

People with arthritis make up the largest group of Disability Living Allowance claimants. For many of them, DLA is a vital form of support which enables them to remain independent, participate fully in society and carry out everyday activities. Reductions to, or withdrawal of, DLA is therefore highly likely to have a devastating impact on many people with arthritis and disabled people in general.

¹ "Fit for Work", The Work Foundation, September 2007

The driver for the reforms to DLA is to make substantial savings to the Treasury in the cost disability benefits. The choice of DLA indicators not to be included in the draft PIP regime makes clear that these savings will fall on those with lower level and less visible ailments. This will in turn undermine the positive preventative role that DLA often plays, of allowing people to buy small amounts of support in order to prevent more substantial needs from increasing.

This aim was made explicit in the 2011 DLA reform consultation which stated that “it is likely that some disabled people with lesser barriers to leading independent lives will receive reduced support, but this has been justified by the policy aim to focus support on those with greatest needs.” (Equality impact assessment in the table 2 in chapter 4).

Perhaps the clearest example of this is claims where under the current regime which are based on the claimant experiencing problems moving around indoors: under the PIP regime, these will be much less likely to succeed under PIP. The current DLA regime includes a section on ‘Moving around indoors’. By contrast, the PIP daily living activities exclude activities related to moving around indoors, e.g.

- problems with using stairs or with moving around generally.
- the definition of ‘toilet needs’ appears to be so tightly drawn that it excludes any consideration of whether a claimant needs help getting to and from the toilet.
- There is no mention of help needed with getting into or out of bed.

There is a particular danger then, that many of the current recipients of lower rates DLA, many of which are people with arthritis, will have no entitlement to PIP. If so, it will have a major deleterious impact on them. In 2011 Arthritis Care surveyed its supporters, to ascertain the role that DLA played in their lives. A common theme of the responses was that people relied on their DLA to meet costs associated with low care needs, but which were nevertheless vital to daily living, e.g. the additional cost of prescriptions, of aids and adaptations, and of regular access to health and fitness facilities recommended to them by medical professionals. These are the sort of expenditures that the proposed PIP regime puts at risk.

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

In the explanatory note we set out proposals for the weightings of descriptors in the activities relating to entitlement to the Daily Living component (activities 1-9). In this document we have set out the entitlement thresholds for the benefit. How well do you think they work to distinguish between differing levels of ability in each activity? How well do you think they work to prioritise individuals on the basis of their overall need? Do you think we need to make any changes to weightings or thresholds?

Re Activity 1A: “If you can cook a meal from fresh ingredients with special equipment, you meet descriptor B. This scores 2 points. This might include a special knife that is easier for you to grip, a food processor.” An applicant may have to rely heavily on such gadgetry to undertake simple food preparation activities, e.g. they may need to use an electric blender simply to slice a tomato, rendering even simple meal preparation as making a sandwich, very labour intensive. To only score 2 points, we feel, is an underweighting of this activity.

Re Activity 1F: “cook a meal...but need someone to physically help you, you meet descriptor F. This scores 4 points. This might mean you need someone to chop vegetables for you, or open a tin for you. This is contrasted with Activity G, i.e. being unable to cook a meal even with assistance. However, for the claimant there is little practical difference between these two scenarios. If someone requires this level of assistance to help them cook a meal then they are reliant on a helper to be present throughout most, if not all, of the cooking process, thus placing them in essentially the same position as that described in 1G, i.e. without the other person to assist them they will not eat a cooked meal. In this context, we submit that 1F is almost an oxymoron, and so should attract 8 points, as per G.

Many Activities that require someone to physically help the claimant, or special equipment, to be carried, that are essential daily tasks, attract only a feeble 4 or even 2 point - score, e.g.:

- Activity 4D: someone to help with grooming such as brushing or washing hair, 2 points.
- Activity 4G: someone to physically help you bathe, 4 points.
- Activity 5D: help going to the toilet, 4 points.
- Activity 6D: you need someone to physically help you to dress or undress below the waist, 3 points.

Someone with quite substantial physical impairments, who in turn incurs significant additional cost in order to carryout essential daily functions, could easily find themselves ineligible under such entitlement thresholds, or barely scrape into the standard rate (8 points), when their actual need is much greater.

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

In the explanatory note we set out revised proposals for the activities relating to entitlement to the Mobility component (activities 10-11). Are the changes an improvement? Do you think we need to make any further changes?

Re Activity 11: this Activity is restricted to considering claimants' ability to mobilise 'on the flat' in relation to outdoor surfaces. Whilst we note that that kerbs are specifically mentioned, there is no consideration of individuals' ability to move around inside the home or workplace, e.g. navigating steps, or to deal with uneven surfaces such as cobbles, countryside or hills. These obstacles can be particularly problematic for people with balance problems, such as experienced by many people with arthritis. We submit that it will be the exception rather than the rule that applicants will not regularly encounter uneven surfaces when going about their normal lives. It follows that the parameters of the "moving around" are simply unrealistic, and need to be re-drawn to more accurately reflect real – world scenarios.

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

No comment.

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

No comment.

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

Regulation 4(4)(c) of the draft regulations and paragraphs 7.13 to 7.15 of the explanatory note set out how we are proposing to assign descriptors to people who have fluctuating conditions. These are that:

Scoring descriptors will apply to individuals where their impairment(s) affects their ability to complete an activity on more than 50 per cent of days in a 12 month period.

If one descriptor in an activity applies on more than 50 per cent of the days in the period – i.e. the activity cannot be completed in the way described on more than 50 per cent of days – then that descriptor should be chosen.

If more than one descriptor in an activity applies on more than 50 per cent of the days in the period, then the descriptor chosen should be the one which applies for the greatest proportion of the time.

Where one single descriptor in an 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.

What are your views on this approach and how this is set out in the regulations?

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Applicants may need to spend extra money, for example on ready - made food or help in the kitchen, for a wheelchair or taxis or from friends and family, even if they only need help in performing these activities for marginally less than half the time. Such help can and does incur significant financial burdens. A lower percentage threshold should be considered.

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

In the assessment an individual must be able to complete an activity descriptor reliably, repeatedly, safely and in a timely manner. Otherwise they should be considered unable to complete the activity described at that level. In paragraph 7.4 of the explanatory note we set out draft definitions for these as follows:

Reliably means to a reasonable standard.

In a timely fashion means in less than twice the time it would take for an individual without any impairment.

Repeatedly means completed as often during the day as the individual activity requires. Consideration needs to be given to the cumulative effects of symptoms such as pain and fatigue – i.e. whether completing the activity adversely affects the individual's ability to subsequently complete other activities.

Safely means in a fashion that is unlikely to cause harm to the individual, either directly or through vulnerability to the actions of others; or to another person.

What are your views on these? Some organisations have suggested that these terms should be included within the regulations. Do you agree? If so, do you have views on how we should do so – for example, as a general provision or referring to them in the detail of activity descriptors?

At the moment, these definitions are not included in the legally-binding rules proposed for PIP. We firmly believe they should be.

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

The draft regulations contain a number of definitions in Regulation 1 (Interpretation) and Schedule 1. Do we need to make changes to any of these?

“Bathe” is given the following description: “means clean one’s torso, face, hands and underarms” We fail to understand why capacity to wash the lower half of the body is not deemed to be an essential a daily living task, when bathing the top half is. Some people with disabilities report that they find it harder to wash the lower half of the body, as it requires a lot more support and balance to do so. As a matter of basic human dignity, we urge that the definition is amended to include the whole body.

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

Regulations 5 to 10 of the draft regulations relate to elements of the assessment process for Personal Independence Payment, 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. Do you have any comments on these regulations?

It needs to be recognised that any cuts will also have an impact on passporting for other benefits and services currently linked to DLA. Such impacts should be risk – assessed and their impacts costed.

The Government plans for the majority of claimants to go through a face-to-face assessment with an independent healthcare professional. We believe more emphasis should be placed on gathering evidence from relevant professionals who know the claimant best, and that face-to-face assessments should only be carried out where such evidence, alongside the claim form, is not sufficient to demonstrate an entitlement to PIP.

Finally, we draw to the Government's attention that the DLA regime was the result of an acceptance by government, after hard fought legal battles, that disabled people have a right to enjoy an ordinary life, which includes social and leisure activities, in the same way as people who are not disabled. In the PIP scoring system, there is no mention whatsoever of help needed with social and leisure activities.