

## **Personal Independence Payment: assessment thresholds and consultation**

### **Introduction**

The British Lung Foundation (BLF) is the only UK charity working for the 8 million people with all lung conditions. We provide support for people affected by lung disease and work in a variety of ways (including funding world-class research) to bring about positive change to improve treatment, care and support for people affected by lung disease in the future.

We support people affected by lung disease in a number of ways, from patient support, nursing, helpline support and information and publications. We have a network of over 250 Breathe Easy Groups in the UK who provide support and information for people living with a lung condition, and for those who look after them.

Many people with lung disease face significant barriers to independent living, and the BLF helpline receives a correspondingly large number of enquiries relating to welfare benefits. This number has risen from 1187 callers in 2009/10 to 1273 in 2010/11 (16% of total calls). The response to the consultation below reflects both the concerns that are most commonly raised and the BLF's own view on the draft PIP criteria, eligibility thresholds and regulations.

Many positive changes and additions have been made to the draft assessment criteria and regulations since the start of the consultation process. The BLF is appreciative of the steps taken by the DWP to seek the views of stakeholders, including holding meetings for stakeholder organisations in which the BLF has participated. Our remaining concerns, many of which were discussed informally at a DWP stakeholder meeting on 23 March 2012, are contained in the response below.

### **Consultation answers**

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

**General.** Activities 1-6 comprise singular activities, each requiring a low level of physical exertion. People with lung disease may be heavily impaired by breathlessness and fatigue, but are less likely to experience problems with manual dexterity and sensorial impairment. This gives rise to two particular concerns in respect of the draft Daily Living activities.

Firstly, the assessment of a series of singular activities disregards the reality of daily living in which tasks are performed sequentially. Considered separately, many people with lung disease will be able to perform the individual activities, but not all together and consecutively as required in everyday life by those living alone. This is of particular concern to those who experience severe breathlessness as a result of conditions such as lung cancer, interstitial lung disease and COPD. In a 2006 BLF survey of people with COPD,

72% said that they required ‘frequent rests’, with the figure rising to 86% amongst those with severe COPD.<sup>i</sup> Similarly, for those who receive long-term oxygen therapy for hypoxaemic symptoms, it is necessary to breathe supplemental oxygen for a minimum of 15 hours per day.<sup>ii</sup> Partial immobilisation for prolonged periods of each day clearly presents a significant barrier to the tasks required for independent everyday living. Yet this will not be taken into account in the draft criteria if it does not preclude the individual activities listed.

Secondly, the daily living component comprises largely static activities requiring a low level of exertion, such as preparing meals, eating and bathing. It omits activities which are equally essential to independent living, and which a lack of aerobic capacity can render preclusively exhausting in people with lung disease. For example, an individual with severe breathlessness may score few or no points in activities 1,2,4 and 6, but may nonetheless be unable to dry themselves after washing, wash up after cooking or perform basic housework. Of the 1300 welfare benefits enquiries received by the BLF helpline each year,<sup>iii</sup> a large number concern the additional costs associated with maintaining a clean and safe home environment through aids, adaptations and hired help.

**Recommendation 1.** The BLF supports the recommendation made by a number of organisations, including RNIB and the Disability Benefits Consortium, to introduce an additional activity for ‘**maintaining a safe and healthy home environment**’, to reflect overall ability to perform the tasks required to maintain an acceptable standard of independent living, irrespective of the specific task or impairment. Descriptors should have regard to the overall, cumulative capacity to maintain hygienic and liveable surroundings without assistance. This should include consideration of condition-specific risk factors such as high levels of dust mite in the home, often found to worsen lung symptoms, such as in sensitised individuals with asthma.<sup>iv</sup> We encourage the DWP to work with a range of representative organisations to develop this activity further.

**Activity 8.** The BLF welcomes the introduction of Activity 8: ‘Engaging socially’, and the acknowledgement it represents of the importance of social inclusion. The present descriptors target the extra costs incurred to employ a trained individual to assist those severely affected by a mental health condition or an intellectual or cognitive impairment. However, we are concerned that this does not reflect the full range of possible barriers to social inclusion. For instance, the same barriers and resultant costs apply to somebody who is too physically impaired to leave the home to engage socially - although assistance in their case is unlikely to come from ‘social support’ as defined in the guidance. The scope of Activity 8 must therefore be amended if it is to meet the DWP’s stated aim of ‘considering the impact of impairments rather than what the impairments are’; inability to leave the house to engage socially can lead to isolation and extra costs, irrespective of the nature of the impairment itself.

Social isolation resulting from severity of symptoms features prominently both in clinical guidelines for COPD management and in patient surveys.<sup>v</sup> This is of particular concern to those who experience exacerbations - sudden sustained worsening of symptoms, fear of which can severely limit social inclusion. In a survey of people with COPD carried out by the BLF, 83% ‘agreed’ or ‘strongly’ agreed that fear of having an exacerbation often limits social activities. Activities most frequently restricted included seeing family (35%).<sup>vi</sup>

Furthermore, isolation is linked to the development of anxiety and depression in COPD, which in itself can lead to further complications and additional costs. This is noted in the NICE clinical guideline for COPD, which cites the development of anxiety and depression as a possible long-term consequence of disabling and distressing symptoms, which mean that

‘patients often become socially isolated and have to give up activities that they enjoy’. The guideline further considers that ‘a concurrent depressive disorder may bring the patient into a vicious circle: the depressed mood reduces the patient’s ability to cope with the physical symptoms, which become less tolerable. The psychosocial effects of the disease may be enforced by the depressed mood.’<sup>vii</sup> Failure to account for the full range of barriers to social inclusion may therefore undermine the positive preventative effect that DLA often has to allow people to buy small amounts of support to prevent needs from increasing.

**Recommendation 2.** The scope of Activity 8 must be widened to accommodate all types of impairment that are preclusive of social engagement. This should include:

- amending c. to read ‘needs social support to engage socially or severity of impairment results in not being able to leave the house to engage socially without assistance’ (precedent for this measure can be found in the Medical Research Council’s dyspnoea scale, which is used by healthcare professionals to measure breathlessness in a range of conditions, in which the indicator of greatest severity is ‘5: Too breathless to leave the house’<sup>viii</sup>);
- amending d.(i) to read ‘overwhelming psychological distress or preclusive physical discomfort’; and
- amending the definition of “engage socially” in Schedule 1 of the draft regulations to include the physical - as well as mental and cognitive - capacity to interact socially with others.

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

**General.** As indicated above, the BLF considers that singular activities requiring low exertion presently receive a disproportionate weighting. This disadvantages those who are unable to carry out these activities sequentially as is required in everyday living, nor equally important day-to-day activities requiring greater aerobic exertion, such as household cleaning and drying after bathing, as a result of severe breathlessness. We believe that Recommendation 1 above would redress this imbalance by measuring the cumulative safety impact of ability to carry out everyday tasks.

**Activity 6.** Activity 6 accords 4 points to descriptor e. ‘Needs assistance to dress or undress upper body’, and 3 points to descriptor d. ‘Needs assistance to dress or undress lower body’. Many who experience severe breathlessness encounter difficulties in bending over, as this inhibits the expansion of the lungs, and thus in putting on socks and tying shoelaces. The BLF considers that attaching a greater number of points to the inability to dress or undress the upper body than to the lower body would be to the detriment of certain claimants with lung disease, and would therefore risk prejudicing some specific impairments over others. Furthermore, the barriers and costs faced are likely to be similar, irrespective of which part of the body presents difficulties.

**Recommendation 3.** Descriptors d. and e. in Activity 6 should be merged into a single, 4-point descriptor, such that it reads: ‘Needs assistance to dress or undress lower or upper body’. A merged descriptor would recognise that certain specific impairments may inhibit ability to dress either the upper or the lower body, and that the claimant is likely to face similar costs and barriers in either instance.

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

**Activity 11.** The descriptors for Activity 11 posit a narrow definition of the ability to move around, based on the use of wheelchairs and other mobility aids and the ability to walk set distances. More must be done to account for the needs of those with walking difficulties not due directly to motor symptoms or limb movement, and which are not typically mitigated with mobility aids and appliances. This should include those who experience severe breathlessness and fatigue when walking, many of whom face significant barriers to participation and high costs - for example through reliance on taxis or a car to travel short distances.

**Recommendation 4.** Activity 11 must make clear expressly that breathlessness, pain and severe fatigue should be considered, as the descriptors in Activity 10 do for psychological distress. This can be achieved by amending descriptors a., b. and c. to add in 'and without stopping for rest' after each mention of 'unaided'. This would add the clarity required to account fairly for severe breathlessness in a way that the qualifier 'in a timely manner' may not. There is precedent for this type of measurement in the Medical Research Council's dyspnoea scale, used by healthcare professionals to measure breathlessness, in which the indicator of second greatest severity is '4: Stopping for breath after walking about 100 yards or for a few minutes on the level'.<sup>ix</sup>

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

For the reasons above, the BLF is concerned that those with walking difficulties but not using a wheelchair will not receive a number of points proportionate to the barriers and extra costs they face. We believe that Recommendation 4 above would address this.

- **Q5 - What are your views on how the regulations work regarding benefit entitlement?**  
The BLF welcomes the clarity of Regulations 1 to 5 concerning benefit entitlement and, in particular, the inclusion within Regulation 4 of the proposed rules underpinning fluctuating conditions. However, we feel that a significant omission in this section is the direction currently contained within the explanatory note that each descriptor must be carried out 'reliably, repeatedly, safely and in a timely manner'. In view of their considerable importance to claimants' potential entitlements, these qualifiers should be placed on the face of the regulations, in equal statutory footing to the rules governing fluctuating conditions.

**Recommendation 5.** The direction that each descriptor must be carried out 'reliably, repeatedly, safely and in a timely manner' should be included in regulation 4 alongside the rules governing fluctuating symptoms. This would provide the strongest legal basis to ensure that it is consistently and accountably applied.

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

The BLF welcomes the steps that have been taken to address the needs of those with fluctuating conditions since the publication of the first draft assessment criteria and regulations, as set out in Regulation 4(4)(c) of the most recent draft regulations and paragraphs 7.13 to 7.15 of the explanatory note. However, we are concerned that the proposed regulations establish a single, arbitrary cut-off of symptoms being experienced on 50% of days. The effect of this will be to neglect the additional needs and expenses

faced by those who experience severe fluctuations for nonetheless significant periods of time that amount to less than 50% of days.

In many fluctuating conditions, symptoms during periods of sustained worsening are typically acute, matching the higher scoring descriptors in the draft activities for both components. Yet while the scale of severity of symptoms is tapered through the different descriptors for each activity, there is no corresponding tapered scale for how frequently fluctuating symptoms are experienced - despite this being the variable factor.

This is a matter for concern in the assessment of those with lung diseases characterised by periods of exacerbation, such as sarcoidosis, idiopathic pulmonary fibrosis and COPD. It has been estimated that 1 in 3 patients with COPD will be admitted to hospital at some stage as a result of an exacerbation.<sup>x</sup> This can result in a long period of recuperation at home. In a BLF survey of people with COPD, 25% of those who reported having suffered an exacerbation said that this meant being virtually housebound for three months or more.<sup>xi</sup> Yet under the present proposals, debilitating symptoms for 3 months in every 12 would not be accounted for in assigning descriptors, despite the often considerable extra costs incurred. Costs most commonly reported to the BLF helpline in this regard include: additional heating charges for those who are housebound and whose symptoms require them to maintain a high room temperature; a delivery service for food and groceries; and prescription costs for extra inhalers, oral steroids and antibiotics, for those whose prescriptions are not otherwise funded.

We acknowledge that any nuancing of the 50% principle would need to be comprehensible to all parties involved, including claimants, assessors and healthcare professionals - a concern that was expressed by DWP officials during a stakeholder meeting at which this issue was raised by the BLF. However, the BLF considers that the matter should be given specific and detailed examination, on the premise that it may be possible to devise a further division without undue complication. Moreover, the potential difficulties are significantly outweighed by the clear need for accurate and fair assessment of all impairments.

**Recommendation 6.** Further, detailed consideration should be given to nuancing the ‘50% of days’ threshold for fluctuating symptoms. We encourage the DWP to work with a range of representative organisations with a view to reaching a broad consensus on how this issue could be better addressed.

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

The BLF agrees both with the guiding principle of applying ‘safely’, ‘reliably’, ‘repeatedly’ and ‘in a timely manner’ to each descriptor, and with the definitions as provided in the explanatory note.

It is essential that the qualifiers are applied rigorously and consistently to all descriptors in the assessment process. The qualifier ‘in a timely manner’ will be particularly important to those with severe breathlessness and other symptoms associated with lung disease when considering eligibility for each component.

**Recommendation 7.** ‘Reliably, repeatedly, safely and in a timely manner’ must be placed on the face of the regulations to provide the strongest legal basis to ensure that they are consistently applied, and that claimants’ rights are enforceable with regard to their inclusion in the assessment process. The BLF also recommends that the terms should be

restated in the assessment criteria themselves for additional clarity - for example as a note at the start of each component. If this is not possible, the relevant regulation should specify explicitly that each descriptor should be interpreted as if each activity is followed by the words 'repeatedly, reliably, safely and in a timely manner'.

**Recommendation 8.** The importance of the qualifiers should be impressed upon those conducting the assessments. Particular thought should be given to how best to elicit the requisite information through the questions asked of claimants (for example, assessors should be encouraged to ask if claimants with severe breathlessness need to take regular breaks whilst performing specific activities, rather than whether these activities take them twice as long as they might).

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

**Recommendation 9.** Schedule 1. "manage medication or therapy" should include preparing medication before taking it to the extent that this is required by prescribing practice. This would ensure an understanding of medication management that includes, for example, the ability to fill and use a nebuliser, which can be integral to asthma and COPD self-management.

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

No specific comments.

### **Further information**

For further information on any of the above, please contact Malcolm Reid at [Malcolm.Reid@blf-uk.org](mailto:Malcolm.Reid@blf-uk.org) or by phone on 0207 688 5588.

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<sup>i</sup> *Lost in Translation - bridging the communication gap in COPD*. British Lung Foundation, 2006

<sup>ii</sup> R61. *Chronic obstructive pulmonary disease: Management of chronic obstructive pulmonary disease in adults in primary and secondary care*. NICE clinical guideline 101, 2010

<sup>iii</sup> 1276 welfare benefits enquiries in 2010/11 (16% of total calls)

<sup>iv</sup> *British guideline on the management of asthma: a national clinical guideline*. British Thoracic Society; Scottish Intercollegiate Guidelines Network, 2012

<sup>v</sup> E.g. *Chronic obstructive pulmonary disease: Management of chronic obstructive pulmonary disease in adults in primary and secondary care*. NICE clinical guideline 101, 2010; *Breathing fear: the COPD effect*. British Lung Foundation, 2003

<sup>vi</sup> *Breathing fear: the COPD effect*. British Lung Foundation, 2003

<sup>vii</sup> *Chronic obstructive pulmonary disease: Management of chronic obstructive pulmonary disease in adults in primary and secondary care*. NICE clinical guideline 101, 2010

<sup>viii</sup> Accessible at:

[http://www.nice.org.uk/usingguidance/commissioningguides/pulmonaryrehabilitationforserviceforpatientswithcopd/mrc\\_dyspnoea\\_scale.jsp](http://www.nice.org.uk/usingguidance/commissioningguides/pulmonaryrehabilitationforserviceforpatientswithcopd/mrc_dyspnoea_scale.jsp)

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<sup>ix</sup> Accessible at:

[http://www.nice.org.uk/usingguidance/commissioningguides/pulmonaryrehabilitationforserviceforpatientswithcopd/mrc\\_dyspnoea\\_scale.jsp](http://www.nice.org.uk/usingguidance/commissioningguides/pulmonaryrehabilitationforserviceforpatientswithcopd/mrc_dyspnoea_scale.jsp)

<sup>x</sup> Wouters EFM. "The societal impact of COPD in North America and Europe: an economic analysis of the Confronting COPD survey". *Respiratory Medicine* 2003; 97(Suppl C): S3-S14

<sup>xi</sup> *Breathing fear: the COPD effect*. British Lung Foundation, 2003