

## **Personal Independence Payment: second draft of assessment regulations**

### **Response submitted by Crohn's and Colitis UK – April 2012**

#### **1. Crohn's and Colitis UK**

Crohn's and Colitis UK is the major UK charity offering information and support to anyone in the UK affected by these conditions, collectively known as IBD. Established in 1979 as a partnership between patients, their families and the health professionals caring for them, the charity's services include four information and support services, a website, a wide range of accredited information sheets and booklets and a nationwide network of locally-based Groups. The charity also raises awareness of these little-known conditions, campaigns for improved health and social provision for patients, and funds vital research. Crohn's and Colitis UK is the working name of the National Association for Colitis and Crohn's Disease and currently has nearly 31,000 members UK-wide.

#### **2. Inflammatory Bowel Disease (IBD)**

About 240,000 people in the UK have Crohn's Disease or Ulcerative Colitis. These are lifelong conditions that most commonly first present in the teens and early twenties (mean age at diagnosis is 29.5 years). In IBD, the intestines become swollen, inflamed and ulcerated. Symptoms include abdominal pain, weight loss, tenesmus (constant urge to have a bowel movement), diarrhoea (sometimes with blood or mucus) and profound tiredness. The sudden and uncontrollable need to use a toilet is a genuine and recognised symptom of IBD. The constant anxiety about suddenly needing a toilet and having very little time to find one, can have a devastating impact on an individual's ability to engage in day to day activities..

Symptoms vary in severity from person to person and flare up or improve unpredictably.

#### **3. General comments**

Crohn's and Colitis UK welcome the attention given to the responses from individuals and organisations such as ours to the initial draft regulations, and the subsequent assessment testing of the revised descriptors to analyse their impact across a range of conditions. We do, however, remain concerned that the level of understanding of the impact of bowel conditions such as IBD, is poor amongst regulators, medical advisers, and decision makers, and that this is still reflected in the second draft of assessment criteria.

Of the fifteen case studies included in the consultation document, two include examples of 2 points being awarded on the need for a raised toilet seat and a third on the persons need for prompting to use the toilet. No example is given of needs arising from a bowel condition such as IBD, nor do the explanatory notes clarify how the proposed activity/descriptor would recognise such needs.

#### **4. Bathing and grooming**

This descriptor, as it stands, excludes any help needed with cleaning of the perineum, as this is considered to be more appropriately covered by the activity relating to toilet needs. However, neither of these descriptors capture the need to clean the perineum as a consequence, for example, of a discharge from a rectal fistula or the mucus discharge or 'wet wind' often experienced by people with Inflammatory Bowel Disease.

#### **5. Managing toilet needs or incontinence**

We suggest that this descriptor may still be too limited in its application, by failing to take into account the difficulties experienced in getting to a toilet in time (inside or outside the home) and cleaning up after using the toilet or an episode of incontinence.

We suggest that further thought and/or clarification be given to the wording of this activity and its application, in particular descriptors 5 D, 5E and 5G. For example, someone may need assistance to manage incontinence if their need for assistance with toilet needs is not met. Would someone who experiences episodes of incontinence which happen regardless of assistance satisfy 5G and achieve 8 points?

The descriptor also fails to work to prioritise individuals on the basis of their overall need by ignoring the impact of the frequency and urgency experienced twenty four hours a day by people living with conditions such as IBD.

We believe that the proposed weighting for this descriptor under-accounts for the profound and disabling impact of urgency, frequency and incontinence on a persons' day to day living.

#### **6. Fluctuating conditions**

We note the clarity given to threshold for recognizing an individual's ability for the 'majority of the time' by amending the assessment to consider the impact experienced on the 'majority of days'.

However, we regret that this falls short of our recommendation to include situations in which a persons' ability to perform an activity may fluctuate within each day as well as those whose abilities may fluctuate over a longer period of time, nor does it recognize the impact of living with an unpredictable condition. The cumulative impact of the range of different barriers that may be experienced by someone with a condition such as IBD is not adequately addressed by the current scoring.

*Example 1:*

*"Sort of go to work, barely get through the day and then coming home and then just crashing out and I couldn't do anything in the evening because I didn't have the energy."*

*Example 2:*

*"My Ulcerative Colitis is so unpredictable. Some days I am fine.... Other days I spend half my time on the toilet. I find it so hard waking up in the morning expecting one symptom when something totally different comes on. Wish I had a disease that every day I had the same symptoms..."*

The nature of IBD means that a person may experience periods of reduced symptoms if their disease is in remission, but the unpredictability of the condition means that they never know when it may flare-up again.

## **7. Mobility**

The emphasis on mental distress in activity 10 excludes the wider range of needs that impact on a persons' ability to plan and follow a journey – for example, the very real and debilitating anxiety that is experienced by people who need urgent and frequent access to toilet facilities (getting to a toilet also excluded from the activity of managing toilet needs). We therefore propose an assessment which considers the impact of impairments equally, regardless of their nature.

We would be happy to discuss any of the comments or suggestions made in this response.

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