

SUBMISSION FROM CROHN'S AND COLITIS UK (NACC)

Inflammatory Bowel Disease

Approximately 240,000 people in the UK have Crohn's Disease or Ulcerative Colitis, collectively known as Inflammatory Bowel Disease (IBD). Prevalence is higher in Scotland than in other parts of the UK, with latest research suggesting that one in every two hundred people in Scotland live with one of these lifelong conditions. IBD most commonly first presents in the teens and early twenties (mean age a diagnosis is 29.5 years). In IBD the intestines become swollen, ulcerated and inflamed. Symptoms include acute abdominal pain, weight loss, diarrhoea (sometimes with blood and mucus), tenesmus (constant urge to have a bowel movement), and severe fatigue. Symptoms vary in severity from person to person and from time to time and relapses often occur suddenly and unpredictably. Between 50% and 70% of patients with Crohn's Disease will undergo surgery within five years of diagnosis. In Ulcerative Colitis, lifetime surgery rates are approximately 20-30%

Crohn's and Colitis UK

Crohn's and Colitis UK is the leading charity offering information and support to anyone affected by these conditions. Established in 1979 as a partnership between patients, their families and the health professionals caring for them, the charity's services include four helplines, a website, a wide range of accredited information sheets and booklets and a nationwide network of locally-based Groups. The charity raises awareness of these little understood or known conditions, campaigns for improved care for patients, funds vital research and seeks to influence policy to ensure that it reflects and meets the needs of people living with IBD.

Personal Independence Payments

Crohn's and Colitis UK are calling for a fairer assessment which includes a wider range of activities. This is needed to make the system more sensitive to the complex needs of people living with long-term conditions and to ensure the system is able to adequately recognise and measure the additional costs encountered by people with little understood conditions such as IBD.

We are disappointed that draft regulations published by the UK Government appear to include a much narrower range of activities than DLA, which PIP seeks to replace, and are concerned that these focus only on those activities required for the bare essentials of existing.

Range of activities

For people with IBD, participation in social activities can be important in reducing the sense of social isolation, which is known to be a serious problem for some, and help needed to support people to engage in such activities should be recognised in the assessment. Failing to account for activities of particular importance to the individual, beyond those currently included in the draft descriptors proposed by the UK Government, will lead to a system that is less sensitive to the complex needs of people living with the myriad of disabilities and medical conditions that PIP aims to

support. Consequently, the assessment will fail to adequately recognise or measure the additional disability costs and barriers to participation encountered by people with little understood conditions such as IBD.

We know from members of Crohn's and Colitis UK that the fluctuating nature of their condition makes it more difficult for them to establish their entitlement to DLA. The criteria for PIP should recognise the difficulties of people whose abilities may fluctuate within each day, but also others whose abilities may fluctuate over a longer period of time. 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. We remain concerned that the proposed 12 month rule may have a disproportionate effect on people with conditions such as IBD who may have periods within this time when their symptoms are reduced.

Crohn's and Colitis UK welcome the inclusion of a descriptor which specifically assesses the impact of managing toilet needs or incontinence. However, we believe that this descriptor should account for the impact of the frequency and urgency experienced twenty four hours a day by people living with conditions such as IBD, and that it will be limited in its application if it fails to take into account the difficulties experienced in getting to a toilet (inside or outside the home) and cleaning up after using the toilet or an episode of incontinence. Help with cleaning the toilet or surrounding area is a specific need arising from a medical condition which goes beyond the cleaning that is required in relation to general household duties. We believe that the need for assistance with changing bedding following an episode of incontinence or leakage from a stoma appliance should also be addressed in the assessment.

Mobility Activities

Planning and following a journey:

For people with IBD, what determines whether a journey is achievable or not is often the proximity and availability of publically accessible toilets.

Crohn's and Colitis UK believe that the descriptor which assesses mobility activities should account for the full range of disability-related costs in getting around, including the need to use taxis or the additional fuel and wear and tear on a personal car for those who have rely on these modes of transport because their toilet needs, continence problems and lack of public toilet facilities prohibit the use of public transport.

Moving around:

Crohn's and Colitis UK would like to draw attention to CDLA/217/2009 which considered "the physical and muscular effort involved in trying to control [her] bowels" and "the very real effects of an episode of faecal incontinence" on the appellants mobility.

We believe these factors should be recognised and taken into account in the PIP assessment of this descriptor.

Measuring additional IBD-related costs

Planning and buying food and drink:

People with IBD may experience additional costs associated with buying food and drink. For example, they may need to buy more costly food to increase their intake of certain nutrients to address deficiencies, or modify their diet to avoid certain foods or food additives which exacerbate their symptoms. The need for frequent and urgent access to toilet facilities and the fatigue associated with IBD may necessitate the use of taxis to and from the shops or the use of online shopping facilities. Crohn's and Colitis UK ask that these additional costs of buying food and drink are recognised in the assessment..

Dressing and undressing:

Laundry or high utility costs may be incurred by people with IBD who have to wash their clothes more frequently due to soiling. The need to replace clothes more frequently because of excessive wear and tear arising from frequent washing, or extreme fluctuations in weight due to the condition or the drugs prescribed to treat it, also attracts additional expenditure. Crohn's and Colitis UK believe these extra costs should be recognised in the assessment, in addition to the needs arising from the physical ability to dress.

Other factors

Crohn's and Colitis UK believe that consideration should be given to the additional cost of utilities for people living with disabilities or long-term medical conditions. In particular, we know from calls to our Helplines that people with IBD worry about water bills arising from increased laundry costs and the need flush the toilet more frequently. Higher heating costs also apply to people whose condition means that they spend more time in the house.

Blue Badge

Ineligibility for the blue badge means that, for a substantial number of people with IBD, participation in daily life is a difficult challenge. The sudden and uncontrollable need to use a toilet is a genuine and recognised symptom of IBD, and experiencing an episode on incontinence is each individual's worst nightmare. Such an episode often results in a devastating impact on the individual's ability to engage in activities beyond the home and can lead to social exclusion and poorer health. Many people with IBD apply for the blue badge, hoping that it will allow them to quickly access parking facilities and find a nearby toilet should they experience a flare in their condition away from the home.

In linking eligibility for a Blue Badge to the receipt of the Mobility Component of PIP, an application made by a person with IBD is likely to be identified as ineligible within the confines of restrictive criteria which continues to ignore how the condition can impact on mobility.

Crohn's and Colitis UK believe the underlying problem to be a fundamental lack of knowledge and understanding of IBD and the impact the condition can have on the mobility of an individual, such as the pain and discomfort experienced by those experiencing a flare when attempting to walk. Any assessment should measure the impact IBD has on the individual's mobility during a flare; more specifically, it must account for the affect that severe diarrhoea, abdominal pains and the urgent and uncontrollable need to access a toilet can have on the individual's capacity to walk (move around). Crohn's and Colitis UK would like to draw attention to CDLA/217/2009 which recognises "the physical and muscular effort involved in trying to control [her] bowels" and "the very real effects of an episode of faecal incontinence" on the appellants mobility.

In conclusion

Crohn's and Colitis UK are concerned that the range of activities covered in regulations which will determine entitlement to PIP is too narrow. This, we suggest, could render it ineffective in its stated aims of supporting participation and contributing to the extra costs associated with living with a disabling condition such as Crohn's or Ulcerative Colitis.

We would be happy to discuss any of the comments or suggestions made in this paper, and look forward to the opportunity to engage further with the Scottish Government in relation to the Welfare Reform agenda in Scotland.

CROHN'S AND COLITIS UK (NACC)
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