

Crohn's & Colitis UK response to Work Capability Assessment: activities and descriptors

October 2023

1. About this submission

- 1.1. Crohn's and Colitis, the two main forms of Inflammatory Bowel Disease, are lifelong conditions affecting over 500,000 people in the UK. The symptoms can be debilitating, painful and therefore life-changing. There is no known cure. We are the leading charity for people affected by Crohn's and Colitis. Our work with healthcare professionals helps improve diagnosis, treatment and management of the conditions.
- 1.2. Crohn's and Colitis are lifelong immune-mediated diseases of the gut with no cure. They affect young adults during what should be the most productive years of their lives. The symptoms of Crohn's and Colitis include urgent and frequent diarrhoea, rectal bleeding, pain, profound fatigue, anaemia, and inflammation of the joints, skin, liver, and eyes. Three in four people with Crohn's and Colitis experience bowel incontinence - an unpredictable and urgent need to pass stools. The physical and mental impact of living with Crohn's and Colitis can prevent many from fully maintaining their independence and can stop them participating in employment or education.
- 1.3. Crohn's and Colitis follow a relapsing and remitting disease course. Relapses (or 'flare-ups') often occur suddenly and unpredictably throughout a person's lifetime. While there is significant variation in the pattern and complexity of the symptoms both between people and in the individual across life course, we estimate at least a third of people with Crohn's and Colitis have severe form of disease which result in repeat hospitalisation which severely limit their quality of life and likelihood of remaining employment
- 1.4. As a member of the Disability Benefits Consortium (See: <https://disabilitybenefitsconsortium.com/dbc-members>) we have input to their response and fully support the wider points and recommendations raised in their submission.
- 1.5. This particular response focuses on proposed changes to the absence or loss of bowel/bladder descriptor.

2. Summary of Recommendations

- 2.1. We strongly oppose to the changes outlined in this consultation and believe DWP can offer employment support to disabled people without introducing further limitations to the eligibility of benefits or introducing sanctions. Whilst employer attitudes and employee rights to hybrid and flexible working may have changed, evidence suggests that disabled people are least likely to have benefited from this.
- 2.2. Any changes to Work Capability Assessment should be co-developed and coproduced with disabled people. Further, Access to Work, Disability Confident schemes and IPS schemes should be expanded to ensure greater inclusivity for people with invisible conditions.
- 2.3. We would like to highlight that the reduction in disability employment gap masks differences between disabilities and health conditions, and it discounts the fact that more disabled people leave work than enter. Our Helplines and campaigns teams regularly hear from individuals with Crohn's or Colitis who experience multiple barriers in their work place.
- 2.4. Although the modern work environment should make reasonable adjustments for elevated urgency or frequency, such as placing an employee closer to a toilet or allowing them to work from home, this is often not the case. We have heard from multiple individuals whose managers requested them to document every toilet break to make the case for reasonable adjustments, as well as those who have had toilet accidents because they were not offered a suitable toilet facility.
- 2.5. Even when such adjustments are put in place, it is unreasonable to expect an employee to work with episodes of immediate urgency, highly frequent need to use the toilet or unpredictable loss of control, even if working from home.
- 2.6. Bowel and bladder incontinence descriptors require urgent reform, rather than removing or reducing the eligibility. We recommend that the DWP establish a task and finish group to investigate how the descriptors could be improved for toilet needs and incontinence. This working group should include people with continence and incontinence issues and those with experience of the current benefits system. The assessments and descriptors should recognise:
 - 2.6.1. The experience of an urgent and/or frequent need to use the toilet (or manage a collecting device), due to an underlying health condition or the side effects of essential medication
 - 2.6.2. The experience of loss of control where immediate urgent access to a toilet, suitably modified where appropriate, was not possible
 - 2.6.3. The experience of unpredictable or recurrent loss of control
 - 2.6.4. The disruptive impact that bowel or bladder continence has on someone's ability to effectively perform their job role
 - 2.6.5. The disruptive impact that bowel or bladder continence has on someone's ability to commute to work.

3. What are your views on the three Absence or loss of bowel/bladder control (Continence) options?

3.1. Crohn's & Colitis UK strongly oppose the proposed changes to the Absence or loss of bowel/bladder control descriptor and urge the Department for Work and Pensions to reconsider their approach to changing the Work Capability Assessment.

This is because:

- 3.1.1. There is no evidence that people experiencing bowel and bladder incontinence, such as people with Crohn's or Colitis have benefited from hybrid and flexible working. In fact, there is substantial evidence suggesting that many might be in insecure or semi-routine occupations which do not lend themselves to remote/hybrid working (See 3.2, 3.3)
- 3.1.2. There continues to be multiple barriers for people with Crohn's or Colitis to enter the job market, and retain their jobs. Although the modern work environment should make reasonable adjustments for elevated urgency or frequency, such as placing an employee closer to a toilet or allowing them to work from home, this does not always happen in practice (See 3.4, 3.5)
- 3.1.3. Even when adjustments are put in place, it is unreasonable to expect an employee to work with episodes of immediate urgency, highly frequent need to use the toilet or unpredictable loss of control, even if working from home. (See 3.6).
- 3.1.4. We do not think it is acceptable to reduce the requirement to experience symptoms 'daily' rather than 'weekly' as it assumes that an employer will make allowances for someone to excuse themselves from meetings or shop/factory floor; promotes harmful coping strategies such as not eating before and at work, or taking high levels of antidiarrheals in order to present at work. This will also deepen the disparity between the criteria applied to WRAG and support group (See 3.7, 3.8)
- 3.1.5. Removing the criteria all together or reducing points eligible does not factor in how incontinence might be physically and mentally tiring it might be for individuals. It does not consider the effect this will have on feelings of self-worth or how this may affect their work, relationships with colleagues and associated stigma. (See 3.9, 3.10)

3.2. Whilst employer attitudes and employee rights to hybrid and flexible working may have changed over the pandemic evidence suggests that disabled people are least likely to have benefited from this shift.

- 3.2.1. Despite the increase in popularity of flexible working since the start of the pandemic, 60% of disabled people had not been offered the chance to try flexible working¹.
- 3.2.2. Across the UK, disabled workers are more likely to be in routine and semi-routine occupations such as cashiers, bricklayers and waiters, and are less likely to be in professional and managerial work relative to non-disabled workers.

3.3. Crohn's and Colitis are life limiting conditions that impact educational attainment and career aspirations.² This means many people might be in insecure

¹ <https://www.scope.org.uk/campaigns/research-policy/employee-retention/>

² In a survey of over 9,000 people living with Crohn's and Colitis 44% said their condition has stopped them from reaching their full potential at work

or routine and semi-routine occupations which do not lend themselves to remote/hybrid working.

3.4. A systematic review of research into IBD (inflammatory bowel disease) and employment identified a significant proportion of respondents reporting that they had some difficulty arranging flexible work or adjustments.³

3.4.1. More than two in five people (43%) with Crohn's or Colitis had to make an adjustment to their working life (for example, home working or flexible hours) because of their condition

3.4.2. A study reported that 90% of people with IBD who had symptoms at some time during their working life required accommodations. However, many found workplace accommodations difficult to arrange or did not ask for these.

3.4.3. Two studies reported that only 34% and 40%, respectively, were able to make work adjustments to avoid taking time off due to their IBD.

3.5. A Crohn's & Colitis UK survey of 5,425 people found people with Crohn's and Colitis experience multiple barriers in workplace:

3.5.1. 2 in 5 disagreed with the statement 'most employers are happy to employ people with IBD'

3.5.2. More than half disagreed with the statement 'most employers do as much as they can to support people with IBD stay in work'

3.5.3. The situation is so dire that 77% of respondents said that work has had a negative impact on their health.

"During the pandemic, I was working from home on my laptop and battling a severe flare of ulcerative colitis.

"I could not bathe myself, feed myself or dress myself during this time, as the amount of blood I was losing on a daily basis through my bottom left me completely catatonic. I spent from morning till night sat on my toilet with a laptop crying in agony as I tried to type while fighting the urge to collapse.

"There was no choice but to keep working through the pain as I was not entitled to any financial help.

"It got to the point I was hospitalised and spent 8 weeks as an inpatient where I had to ask my parents to help pay my bills, as I had no income during that time. Coming out of hospital my mental health was rock bottom, I felt depressed and suicidal. I've had to now drop my hours at work to cope with living with my stoma and my disease as it is exhausting both physically/mentally." (Heather⁴, works in PR)

3.6. Although the modern work environment should make reasonable adjustments for elevated urgency or frequency, such as placing an employee closer to a toilet or allowing them to work from home, this does not always happen in practice.

³ [Accommodations and Adaptations to Overcome Workplace Disability in Inflammatory Bowel Disease Patients: A Systematic Review - FullText - Inflammatory Intestinal Diseases 2018, Vol. 3, No. 3 - Karger Publishers](#)

⁴ Name changed.

3.6.1. We have heard from multiple individuals whose managers requested them to document every toilet break to make the case for reasonable adjustments, as well as those who have had toilet accidents because they were not offered a suitable toilet facility.

3.7. Even when such adjustments are put in place, it is unreasonable to expect an employee to work with episodes of immediate urgency, highly frequent need to use the toilet or unpredictable loss of control, even if working from home.

“The reality of living with incontinence and urgency problems can be debilitating at the best of times never mind at work.

“[When I was offered a home-based job] I didn't realise how much incontinence was going to affect my work. I could be on the phone to someone and get the urge and sometimes not even have the time to say 'sorry I need to put you on hold'. Even an extra few seconds make all the difference between making it to the toilet or soiling myself.”

“If I soil myself, I need to shower and get changed. I can't just go straight back on the phone. You feel humiliated, you need to compose yourself, you need to get back in the zone but the pain and discomfort doesn't let you just quickly recover.

*“I even resorted to using my laptop on the toilet but when you're having a flare or are in a lot of pain how can you concentrate on work? It's definitely a category that needs to stay in health assessments as this condition is still totally debilitating and uncontrollable and painful and you just can't work when you are suffering so much.”
(Drew⁵, recently left his role in a Customer Helpline)*

3.8. We strongly refute the suggestion to amend the LCWRA criteria from “weekly” to “daily” is rationalised. Currently the criteria assumes that the person can get to a suitable place to change their nappy, that they can shower or clean themselves, and that there is a suitable place to dispose of the nappy hygienically and discretely - which usually, especially for men, there is not. It assumes that an employer will make allowances for someone to excuse themselves from meetings, or from the shop floor of a business or a conveyor belt of a factory, to do this at any time of a shift, without planning or warning, and possibly multiple times over the day, on a repeated basis. In the absence of such flexibility, people would be putting in place harmful coping strategies, such as not eating before and at work or taking high levels of antidiarrheals in order to present at work.

3.9. Further, the DWP handbook issued to assessors implementing the support group criteria states, in reference to the continence descriptor, that a person must experience extensive evacuation of the bowel “at least once a week”, in comparison to “once a month” for the work-related activity group (WRAG). The DWP previously acknowledged that, “unlike other [support group] categories, the disability described is at a higher level than the highest [WRAG] continence descriptor”.⁶ Therefore, we struggle to understand why DWP would increase this disparity given that WRAG and support group criteria is not applied to other symptoms. We are concerned that this inconsistency is likely to disproportionately

⁵ Name changed.

⁶ Centre for Health and Disability Assessments, ‘Revised WCA Handbook’, 30.

impact on people with Crohn's and Colitis who often rely on this descriptor to pick up most of their points.

- 3.10. Removing the criteria all together or reducing points eligible does not factor in how incontinence might be physically and mentally tiring it might be for individuals. Experiencing an episode of incontinence can be profoundly embarrassing for people. The fear of incontinence or of being unable to locate a toilet can have a significant impact on mental wellbeing and lead to social isolation through people choosing not to risk leaving their home.

“The only way I can avoid diarrhoea and bleeding in public [at work] has been to lie down in front of the toilets then, when they have been vacated by someone (highly likely to not have a disability) to dash in when the urge to push has momentarily eased. Even then, I've ended up walking round my offices with faeces and blood in my knickers and with diarrhoea running down my legs.” (Rachel⁷)

- 3.11. Using a nappy can be embarrassing and distressing for some. For people with IBD, the poo may also have blood and mucus and it may smell due to inflammation or infection. It does not factor in how physically and mentally tiring it might be to go through this process multiple times a day. It does not consider the effect this will have on feelings of self-worth or how this may affect relationships with colleagues and associated stigma.

⁷ Name changed.