



CROHN'S & COLITIS UK

MAKING FLEXIBLE WORKING THE DEFAULT

**CROHN'S & COLITIS UK
SUBMISSION
[November 2021]**

Crohn's & Colitis UK submission: Making flexible working the default

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About us

1. Crohn's & Colitis UK welcomes the opportunity to submit evidence to the Department for Business, Energy and Industrial Strategy's (BEIS) consultation on Making flexible working the default.
2. Crohn's & Colitis UK is the leading charity for Crohn's and Colitis in the UK. We work to improve diagnosis, treatment, and care, to fund research into a cure, to raise awareness and to provide information and support.¹
3. Inflammatory Bowel Disease (IBD), the two main forms of which are Crohn's Disease and Ulcerative Colitis, affects over 500,000 children and adults in the UK. They are lifelong, often debilitating conditions, with no cure.² Symptoms include urgent and frequent diarrhoea (often with blood), abdominal pain, fatigue, and weight loss, with associated anxiety and depression. They lead to time off school and work, withdrawal from social relationships and inability to carry out everyday activities, such as shopping and exercise. IBD doesn't just affect the gut. It can affect almost every part of the body and every aspect of life: from digestion, eyes and joints to energy levels and mental health. With many of these symptoms invisible, it can appear that someone looks healthy when they are in fact incredibly unwell. This creates stigma and misunderstanding around IBD, with thousands of people suffering in silence.
4. People can be diagnosed at any age, with most diagnosed between the ages of 15 and 40. IBD requires tight monitoring and management, often over several decades depending on the age of diagnosis. Care is managed across primary and secondary care, often with high-cost medications or surgery, or a combination of both. Delayed diagnosis increases the likelihood of surgery or more expensive treatments and results in a poorer prognosis.³ If left untreated, poorly managed, or in cases of severe disease, Crohn's and Colitis can cause serious complications which require emergency medical and/or surgical intervention. The burden of Crohn's and Colitis on the NHS is increasing year on year and lifetime costs are comparable to cancer and heart disease.⁴ The annual cost of treating a flare (relapse) is up to six times greater than for treating a patient in remission.⁵

Summary of points and recommendations

- We would like to see the introduction of flexible working as default for people with long-term conditions such as Crohn's and Colitis.

¹ www.crohnsandcolitis.org.uk

² [About Inflammatory Bowel Disease | Crohn's & Colitis UK \(crohnsandcolitis.org.uk\)](#)

³ Mozdiak E, O'Malley J, Arasaradnam R (2015). Inflammatory bowel disease. *BMJ*. 351: h4416. [Inflammatory bowel disease | The BMJ](#)

⁴ Luces C, Bodger K (2006). Economic burden of inflammatory bowel disease: A UK perspective. *Expert Review of Pharmacoeconomics & Outcomes Research*. 6: 471-482.

⁵ Ghosh N, Premchand P (2015). A UK cost of care model for inflammatory bowel disease. *Frontline Gastroenterology*. 6: 169-174. doi:10.1136/flgastro-2014-100514.

- Flexible working as default will have benefits for both people with long-term conditions and the economy; helping to better manage sickness absence, address inequalities, promote well-being and boost productivity.
- Given the unpredictable and fluctuating nature of IBD we would like to see a system in place which considers or prioritises flexible working requests from people with long-term conditions more quickly.

Q1. Do you agree that the Right to Request Flexible Working should be available to all employees from their first day of employment?

5. Strongly agree.

Q2. Please give reasons for your answer, including any considerations about costs and benefits that may affect employers and/or employees.

6. We welcome recognition of instances where employees may need *'a little extra flexibility'*, for example when recovering from a *'longer term health condition'* or *'to attend medical treatments.'*⁶ **We would welcome specific proposals to be introduced which would make flexible working the default for people with long-term conditions.** Crohn's and Colitis are lifelong, fluctuating conditions that are unpredictable in nature and characterised by periods of flare (relapse) and remission). Around 50% of people with Crohn's and Colitis experience at least one flare per year. People living with Crohn's and Colitis often require specialist medications and/or surgery, involving hospital admissions, investigations and outpatient appointments. We believe introducing flexible working as default will have benefits for both people with long-term conditions and the economy; helping to better manage sickness absence, address inequalities, promote well-being and boost productivity.
7. Symptoms of IBD include urgent and frequent diarrhoea (often with blood), abdominal pain, fatigue, and weight loss, with associated anxiety and depression. Seventy-eight per cent of young people with IBD who had experience of work said they felt worried about managing their symptoms or flare ups in the workplace.⁷ Of those yet who were yet to enter the labour market:
- 82% expressed concern about managing their symptoms or flare-ups.
 - Two in three respondents (65%) were concerned about their employer not being flexible to their needs.
 - More than half (57%) worried about not being able to find a job that fitted around their condition.⁸
8. Employees with IBD identified accommodations, such as having time off work to attend doctor's or hospital appointments, or for day-case hospital treatments such as infusions or surgeries; having regular toilet breaks at work; and flexible working, as helpful and important to them. A more recent study echoed these survey findings, with people with IBD saying the ability to flex their working hours, reduce travel

⁶ [Making flexible working the default \(publishing.service.gov.uk\)](https://publishing.service.gov.uk) page 3

⁷ Bajorek, Z at al. Working Well: Promoting job and career opportunities for those with IBD. London: Work Foundation, 2016.

⁸ Gay, M.et al. Crohn's, Colitis and Employment - from Career Aspirations to Reality. Hertfordshire: Crohn's and Colitis UK, 2011.

and/or work from home, improved their ability manage and cope better with symptoms such as frequent bowel movements/incontinence, pain and/or fatigue.⁹

9. A 2010 Cochrane Review of the impact of flexible working on people with IBD suggested “that flexible working interventions that increase worker control and choice (such as self-scheduling or gradual/partial retirement) are likely to have a positive effect on health outcomes.” In contrast, interventions that were motivated or dictated by organisational interests, such as fixed-term contracts and involuntary part-time employment, were associated with equivocal or negative health effects.
10. We have also seen this borne out in practice in response to the pandemic. Forty two per cent of people with Crohn’s and Colitis surveyed about their experiences of lockdown said that they felt the pandemic could change the way we work for the better (nearly 8,000 responded to the survey). Over half said that they had more time to rest during the pandemic. As the labour market adapts to ‘living with COVID’ it is important that these gains are not lost.
11. We also ask the government to consider that flexible working, specifically the right to work from home or commute to work during quieter periods, would be a positive option for immunosuppressed or immunocompromised people who currently have less protection from the COVID-19 vaccine. The ability to work from home for this vulnerable group would help to reduce their risk of contracting COVID-19, relieve the anxiety of doing so and decrease pressures on the NHS resulting from higher rates of infections and complications.
12. In implementing their plans, we ask that BEIS review their underlying assumption that conversations between employers and employees can be had easily, and for this reason accept that it would be unreasonable to place all the responsibility on the employee. Only one in four jobs is advertised with flexible working.¹⁰ One in 10 flexible jobseekers will not apply to a job advert that claims the role is ‘open to flexibility’, while a further three in 10 are cautious about applying.¹¹ While the consultation suggests that only 9% of requests are rejected, the research indicates that many people with IBD choose not to disclose their IBD or ask for workplace accommodations. Disclosure and conversations about accommodations can be difficult for many reasons, including embarrassment, the invisible nature of the condition, previous negative experiences of disclosure, stigma, and low employer awareness of IBD. People with IBD often fear that disclosing their condition will hinder their success at a job interview and, if already in post, their prospects within an organisation.
13. Future legislation, guidance and regulations should also make it clearer in job adverts whether flexible working arrangements are available. For those already in post, BEIS should encourage, incentivise, and support employers to invest in line-manager training and HR resources to support high-quality decision making for flexible working requests, especially when it might benefit someone with a long-term condition. Training and resources should aim to support conversations on disclosure and reasonable adjustments, as well as improving understanding and tackling stigmas about living and working with a long-term condition. Crohn’s & Colitis UK have developed a [suite of resources](#) aimed at employers to support discussions about

⁹ Patient Strategies for Managing the Vicious Cycle of Fatigue, Pain and Urgency in Inflammatory Bowel Disease: Impact, Planning and Support. In: Digestive Diseases and Sciences, 08.11.2020.

¹⁰ [Flexible Jobs Index 2021 - Timewise - Flexible Working Research](#)

¹¹ [TWJ-Gaining-an-Edge-in-Fight-for-Talent.pdf \(timewise.co.uk\)](#)

invisible conditions like Crohn's and Colitis. We would welcome the opportunity to meet with BEIS officials to discuss the Are You IN? campaign in more detail and potential opportunities to promote or integrate aspects of our campaign nationally.

14. The Flexible Working Taskforce should also explore how to promote flexible hours, part-time and remote working as positive career choices. The consultation recognises flexible working can be associated with reduced career prospects and lower pay. Most part-time jobs pay under £20,000, limiting well-paid and high-quality options for people with long-term conditions.¹² Conversely, home working and flexible hours are associated with higher salary levels and rarely available for low paid jobs. The taskforce should examine how opportunities for flexible working can be strengthened across the board, where possible.

Q3. Do you agree that employers should be required to show that they have considered alternative working arrangements when rejecting a statutory request for flexible working?

15. Strongly agree.

Q4. Please give reasons for your answer.

16. It is good practice to be able to demonstrate transparently that full and reasonable consideration has been given to a statutory request and helps to ensure that this takes place.

17. Reasonable adjustment that an employees could consider may include, but not be limited to:

- allowing time for medical appointments or treatment
- flexible working arrangements, such as shorter or different hours
- unlimited toilet breaks
- phased return to work following operations
- moving your workstation close to a toilet
- providing a car parking space close to the entrance into work.

18. Employers should demonstrate that they have considered adjustments through the Access to Work programme. Employees unhappy with an employer's decision should be clearly signposted to further guidance and advice on their rights and organisations such as the Equality Advisory and Support Service (EASS) or ACAS.

Q5. Would introducing a requirement on employers to set out a single alternative flexible working arrangement and the business ground for rejecting it place burdens on employers when refusing requests?

19. No.

Q6. If yes, would this requirement have an effect on the time taken by employers to handle a request?

¹² [Flexible Jobs Index 2021 - Timewise - Flexible Working Research](#)

20. Any potential future requests should be considered and factored in by employers as part of role planning to reduce time taken by employers to handle said requests for flexible working.

Q7. Do you think that the current statutory framework needs to change in relation to how often an employee can submit a request to work flexibly?

21. Yes.

Q8. Please give reasons for your answer.

22. Crohn's and Colitis are incurable, fluctuating, and unpredictable conditions, which can cause people to experience flares when symptoms are active and are associated with extra-intestinal manifestations, including joint and eye problems. The statutory framework should not restrict people with long-term conditions from making multiple applications, for example, if their condition worsens and/or causes complications.

Q9. Do you think that the current statutory framework needs to change in relation to how quickly an employer must respond to a flexible working request?

23. Yes.

Q10. Please give reasons for your answer.

24. Given the unpredictable and fluctuating nature of IBD, we would like to see a system in place which quickly considers or prioritises requests from people with long-term conditions. Three months is currently too long. For someone with Crohn's or Colitis, their symptoms may have significantly worsened during this time, impacting not only on their physical and mental health but also their ability to work efficiently.

25. We would ask that the time for consideration is reduced. Employers and employees could be encouraged to develop plans in advance, so these can be executed promptly when conditions flare. This would minimise impact on both the employee and employer.

26. When drafting the legislation, we would ask that the government consider steps to prevent employees from being forced to permanently alter their working conditions in order to benefit from a shorter period of flexibility that will accommodate their long-term condition or disability. Steps should be taken to ensure that employers are not able to use the introduction of flexibility to gradually manage someone with a long-term condition out of their job or to reduce their hours permanently, so their employment is no longer financially viable. In all circumstances, when flexible working is discussed, employees should be made aware of the time-limited request option.

Q11. If the Right to Request flexible working were to be amended to allow multiple requests, how many requests should an employee be allowed to make per year.

27. There should not be a limit on the number of requests an individual should make.

Q13. Please give reasons for your answer, including any consideration about costs, benefits, and practicalities.

28. Requests should reflect the fluctuating nature of certain long-term conditions.
- Q14. If the Right to Request flexible working were amended to reduce the time period within which employers must respond to a request, how long should employers have to respond?**
29. Less than two weeks.
- Q15. Are you aware that it is possible under the legislation to make a time-limited request to work flexibly?**
30. We are fully supportive of time-limited requests to work flexibly. We believe this option could be more clearly promoted to employees. We would encourage BEIS to talk with the Department of Health about how clinicians, in both primary and secondary care, can improve awareness of this option in discussions with patients and as part of the Fit to Work/Rehabilitation process and discussions around supported self-management.
- Q16. What would encourage employees to make time-limited requests to work flexibly? Please provide examples. Please share your suggestions for the issues that the call for evidence on ad hoc and informal flexible working might consider.**
31. Time-limited requests are a positive option for people with Crohn's who may be experiencing a flare and may want to reduce/change their hours to manage their condition while they start a new medication or to manage fatigue or recovery from surgery/surgical intervention.

Contact

For further information, please contact policy@crohnsandcolitis.org.uk