

Crohn's & Colitis UK written response to the Work and Pensions Committee Call for Evidence on disability employment.

March 2024

Crohn's & Colitis UK welcomes the opportunity to respond to the Work and Pensions Committee [Call for Evidence on disability employment](#).

1. About Crohn's and Colitis

- 1.1 Crohn's Disease and Ulcerative Colitis are the two main forms of Inflammatory Bowel Disease (IBD). They are lifelong immune-mediated conditions, affecting over 500,000 people in the UK. The conditions can be debilitating, painful, and life changing. Symptoms include urgent and frequent diarrhoea, rectal bleeding, pain, profound fatigue, anaemia, weight loss, and inflammation of the joints, skin, liver, and eyes. There is currently no known cure.
- 1.2 Crohn's and Colitis are relapsing-remitting diseases. Relapses (or 'flare-up's) often occur suddenly and unpredictably throughout a person's lifetime. While there is significant variation in the pattern and complexity of the symptoms between people and across the life course, an estimated 1 in 3 people with Crohn's and Colitis have a severe form of the disease which results in repeat hospitalisation. The physical and mental impact of living with Crohn's and Colitis can prevent many from fully maintaining their independence and participating in employment or education.
- 1.3 People living with Crohn's and Colitis often require specialist medications and/or surgery, involving hospital admissions, investigations, and outpatient appointments. Relapses are unpredictable in nature, and around 50% of people with Crohn's and Colitis experience at least one flare-up per year.
- 1.4 More than a quarter of people living with Crohn's and Colitis have had to wait over a year for a diagnosis, with almost half ending up in Accident and Emergency Departments (A&E) during this timeⁱ. Long delays lead not only to worse health outcomes, but they also leave people without a diagnosis, without treatment, and unable to access workplace and Government support.
- 1.5 Crohn's & Colitis UK is the leading charity for IBD in the UK. We work to improve awareness, understanding, diagnosis, treatment, and care of Crohn's and Colitis, and to fund research for a cure. We are also a member of the [Disability Benefits Consortium](#).

"My current biggest worry is being able to work and function whilst my health fluctuates. Because of the uncertainty of my symptoms, and my body's unreliable response to treatment, I find it difficult to commit to plans, certain types of work, and living an enjoyable life in general."

Man living with Crohn's Disease

2. What progress has been made, especially since our 2021 report on the disability employment gap, on supporting disability employment?

2.1 Research commissioned by Crohn's & Colitis UK in 2022 identified that 500,000 people in the UK currently live with Inflammatory Bowel Disease (IBD). This is almost double the previous estimate; meaning the prevalence of Crohn's and Colitis in the UK population is far higher than previously believedⁱⁱ.

2.2 Many people with IBD lead active lives, but this does not mean that their education and employment is unaffected. Employment can be significantly impacted, particularly for those that experience the most severe symptoms, and the unpredictability of the disease can be disruptive to all aspects of life. Flare-ups can lead to frequent and urgent need for the toilet and less visible problems – such as loss of sleep, pain, and fatigue – which can have a profound impact on energy levels, mental health, and quality of life.

2.3 A survey of people living with IBD, run by Demos,ⁱⁱⁱ found that:

- 57% had, at some point, reduced their working hours because of their IBD.
- 46% had left a job because of their IBD.
- 51% had applied for lower-paid work.
- 49% believed they had been made redundant because of their IBD.
- Two-thirds (68%) thought that having IBD had a negative impact on their career.

2.4 While there has been some progress in the provision of flexible working and employment support for people with long-term conditions, Crohn's and Colitis can be difficult to talk about because of stigma and misunderstanding about the conditions. This can leave people too ashamed to talk about their condition or seek the medical treatment and support they need^{iv}.

2.5 More than a quarter of those with Crohn's and Colitis wait over a year before receiving a diagnosis, with almost half ending up in A&E while waiting for diagnosis^v. Delays to diagnosis affect people's ability to continue education and work, limits their treatment options, and increases their risk of being hospitalised or needing emergency surgery.

2.6 We are concerned that healthcare services are not meeting the needs of people with IBD, and we are seeing huge delays in diagnosis and treatment. Limited awareness of IBD means that many people delay presenting in primary care with their symptoms and are misdiagnosed or referred for the wrong tests, because of the lack of a national diagnostic pathway. In secondary care, people with IBD face long waits for appointments with gastroenterology teams, and further waits still for diagnostic tests such as endoscopies^{vi}.

2.7 Without timely access to diagnosis and treatment, people with Crohn's and Colitis are less able to participate in the workforce and are unable to engage with programmes designed to support disabled people in work. To ensure that progress is made in supporting people with IBD to enter and remain in work, it is vital that they can access diagnosis and treatment without delay.

3. What should be the priority actions to enable further progress with supporting disability employment for: i) employers; and ii) the Government?

Employers

3.1 It is vital that employers create an environment where people with IBD feel able to disclose their condition. With a supportive line manager, people with Crohn's and Colitis report a positive experience in the workplace and can better receive support and reasonable adjustments when needed. Employers should consider how they can improve their own awareness of disabilities and long-term conditions and ensure employees are supported to disclose their needs.

Campaigns such as '[Are You IN?](#)' from Crohn's & Colitis UK can help with this.

“Although the adjustments have improved my working experience, I have to say that it is the caring and understanding nature of my line manager and colleagues that has meant the most to me.”

Woman living with Crohn's Disease

3.2 Examples of reasonable adjustments for people with Crohn's or Colitis can include:

- Allowing time off for medical appointments or treatment.
- Offering shorter, different, or flexible working hours.
- Unlimited toilet breaks.
- Moving the workstation close to a toilet.
- Providing a car parking space close to the entrance to work.
- Considering whether some duties could be allocated to another member of staff.
- Offering another place of work or the option of working from home.
- Adjusting performance targets to consider the effect of sick leave or fatigue.

3.3 Reasonable adjustments cannot be “one size fits all”. Employers should be educated about the nature of fluctuation conditions and develop plans to support employees at all stages of their disease.

3.4 Employers should ensure that flexible working is made available from day one, so that people with long-term health conditions are to participate in the workforce and manage their health and symptoms. Where roles can be flexible, we urge employers to make this explicit in job adverts so applicants will know from the outset what level of flexibility will be available to them. Employees should also be made aware that it is possible to make time-limited requests to work flexibly.

3.5 We encourage employers to share best practices around flexible working, particularly where they have supported staff with fluctuating health conditions. This not only makes employers more desirable for people with long-term conditions, but also shows other organisations how they can better support staff with health conditions.

“First of all, we’re doing it because it’s the right thing to do. But it also means you can attract a wider pool of talent, and it’s great for your reputation as you’re seen as a forward-thinking employer. We’ve had some very good feedback from clients, and it means we’re a business they want to do business with.

The rewards far outweigh the costs in terms of time and effort. I’d 100% recommend [Are you IN?] to other organisations”.

Managing Director of an organisation signed up to ‘Are you IN?’

Government

3.6 We would welcome specific proposals to make flexible working the default for people with long-term conditions. We believe introducing flexible working as default will have benefits for people with long-term conditions and for the economy; helping to better manage sickness absence, address inequalities, promote well-being and boost productivity. People living with Crohn’s and Colitis have told us that flexible working practices - including flexible working hours, reduced travel, and/or working from home - improved their ability manage and cope better with symptoms.

3.7 We ask that the Government consider steps 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 reduce their hours permanently. In all circumstances, when flexible working is discussed, employees should be made aware of the time-limited request option.

3.8 We would like the UK Government to follow the example of the Scottish Government and launch a national campaign to raise awareness of Crohn’s and Colitis. An awareness campaign will raise awareness of symptoms, support more people to access a diagnosis, and help tackle the stigma and misunderstanding of IBD.

4. How can people with disabilities and health conditions be better supported to start and stay in work?

- 4.1 GP surgeries and IBD services should provide all newly diagnosed IBD patients with a pack, detailing information on IBD and employment. Department for Work and Pensions (DWP) and NHS staff should be trained to signpost to patient organisations that can support people with IBD with up-to-date information around employment and living with their condition.
- 4.2 The DWP should provide regularly updated information and resources on IBD for work coaches that are co-produced by the voluntary sector, clinicians, and people with IBD. They should also commit to increasing and protecting the number of Disability Employment Advisers and ensure they receive continuous training to help them effectively support work coaches.
- 4.3 Access to Work and Disability Confident need to do more to acknowledge and improve work opportunities for people living with invisible disabilities and/or conditions. We believe that both Access to Work and Disability Confident would benefit from using language and descriptions of disability that are more inclusive and that embrace those that are non-visible and fluctuating like IBD.
- 4.4 The Government should work with the voluntary sector to help improve awareness of the Access to Work programme amongst employers and employees. It is important that the benefits of the scheme are properly communicated to people with long-term health conditions, particularly those leaving education and entering the workforce.
- 4.5 Due to the unpredictable and fluctuating nature of IBD, we would like to see a system in place which prioritises flexible working requests from people with long-term conditions and responds to them more quickly. This would minimise the impact on both employees and employers.
- 4.6 The Government should explore other ways of supporting people with fluctuating conditions. For example, some Scandinavian countries have adopted the concept of 'partial sick leave', whereby state benefits are paid to disabled people and people with long-term conditions to help them remain in employment. Trials in Finland demonstrated that people on such a scheme had 20% fewer additional 'sickness' days than people on the standard scheme and were able to remain in employment^{vii}. This could allow people with IBD to return to work on a part-time basis rather than being fully on sick leave.
- 4.7 When people with IBD are experiencing a flare, they may be unable to work for some time and may therefore receive sick pay. They may also face additional costs during this time; for example, needing to pay for multiple new prescriptions. Currently, those eligible for Statutory Sick Pay receive £109.40 a week, for up to 28 weeks. It is essential that Statutory Sick Pay is fit for purpose and allows people the time and resources to focus on their recovery. Stress can exacerbate symptoms of Crohn's and Colitis, and financial uncertainty can exacerbate stress.
- 4.8 Some people with Crohn's and Colitis need to try multiple medications before finding one that is suitable, which can mean paying for multiple prescriptions. Our research has found that the cost of prescriptions is leading people with chronic conditions to skip medication, resulting in worse health outcomes and a longer period away from work. At a time when people should be able to focus on getting better, it is essential that they have the financial support to do so.

4.9 The dynamic nature of IBD needs to be captured in workplace research, to assess the extent to which workers with IBD experience changing needs. Both workers and employers would benefit from resources that assist them with identifying aspects of jobs that may become difficult and provide suggestions for accommodations that can help to reduce these barriers.

5. What are the barriers to employers hiring disabled people and ensuring those people stay in work?

5.1 IBD has a significant impact on the working lives of people with the condition and can affect people from the start of their career until the end – impacting aspirations and career choices.

5.2 Some people with Crohn's and Colitis may be unsure about disclosing their condition to their employer, because of stigma and misunderstanding about the disease, and concerns about how their employer will respond. It is vital that employers create a supportive environment where people with IBD can discuss their condition and what reasonable adjustments may help them. Guidance for employers can help to address concerns, misunderstandings, and provide useful tools and tips^{viii}.

5.3 People living with Crohn's and Colitis tell us how important 'reasonable adjustments' are for them to remain in employment. As the impact of IBD is different for different people, and can change throughout an individual's life, reasonable adjustments should be tailored to individual needs. Examples of adjustments that can benefit someone with IBD include remote working, flexible working hours, good quality toilet facilities and access, time off for medical appointments, and accessible parking.

5.4 Employers should be educated about the adjustments they are required to provide for employees and made aware of how the Access to Work scheme can help facilitate more accessible workplaces and practices. Employers should be educated on the nature of fluctuating symptoms and have plans to support employees at all stages of disease.

5.5 Opportunities to develop and progress within an organisation should be available to employees with long-term conditions. Organisations should consider whether their appraisal and performance metrics disadvantage staff with health conditions and promote presenteeism over effective work.

6. How can employers be better incentivised and supported to employ disabled people and to adapt jobs and workplaces to better accommodate their needs?

- 6.1 We would like to see tailored communications activity that increases employers' understanding of fluctuating and invisible conditions to improve work opportunities for all disabled people and people with long-term conditions.
- 6.2 We would encourage the Government and employers to work with expert third sector organisations, such as Crohn's & Colitis UK, to improve their understanding of long-term health conditions and how to better support people living with these conditions. For example, the Crohn's & Colitis UK '[Are You IN?](#)' campaign helps employers understand invisible disabilities and supports them to talk about long-term health conditions like Crohn's and Colitis.
- 6.3 Looking after employee wellbeing can benefit employees, their company, and wider society. Employers that recognise the needs of people with invisible conditions can improve workforce productivity, lower staff turnover, and drive better employee well-being and satisfaction.
- 6.4 We believe that employers should be required to show that they have considered alternative working arrangements when rejecting a statutory request for flexible working. Employees should be signposted to further guidance and advice on their rights if they are unhappy with their employer's decision.
- 6.5 Employers should be educated about what adjustments they are required to provide for employees and made aware of how the Access to Work scheme can help facilitate the adjustments. They should also be made aware that reasonable adjustments are not necessarily high-cost interventions, and that straightforward adjustments – like toilet access and leave for medical appointments – can make a real difference.
- 6.6 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.

7. Does self-employment provide a valuable route for disabled people to find and stay in work? How could support for self-employed disabled people be improved?

- 7.1 Self-employment can offer a level of flexibility that traditional employment does not, for some people living with Crohn's and Colitis. With ongoing stress recognised as a potential trigger of flare-ups, some people find that self-employment offers greater control over their workload and their stress levels.
- 7.2 However, with fluctuating conditions like Crohn's and Colitis, it can be difficult for self-employed people to predict what their workload and income will be. Unexpected flare-ups or long periods of ill health will have a significant impact on self-employed people with IBD, particularly as they will be unable to access Statutory Sick Pay. People with pre-existing conditions may face high premiums or be ineligible for income protection insurance.

Soon after university I got my first full time job, where I had to travel to and from an office. I was there for 9 months, and during this period I was in and out of hospital multiple times. Some stays were up to a week because no medicine worked for me. The company decided to let me go.

After this, I was at home with no plans for my future because I didn't know if I would be able to fulfil my role and commit to it with Colitis.

I realised that the only thing I could do is work for myself, meaning I can give myself the flexibility I need for appointments and medications. I started a company with the help of my father and uncle who gave me the stepping stone, help, and motivation to get to where I am now.

I still struggle every day of my life. I am now 28 years old, run my own business, and engaged to a beautiful girl. But all this comes with the fear that anything can happen at any time, and I could end up in hospital, which will impact my future life."

Man living with Colitis

7.3 It is vital than people living with long-term health conditions do not feel pressured into self-employment, because of inaccessible and unaccommodating workplaces. While self-employment can provide valuable employment for some disabled people, it should be one of many employment options available to people with long-term conditions.

7.4 Access to Work is available for self-employed people, however work is needed to improve awareness of the scheme. Additionally, people living with Crohn's and Colitis often find it difficult to talk about and articulate their condition in face-to-face assessments. It is important that Access to Work assessors have a good understanding of invisible and fluctuating conditions.

8. How successful have policies, such as Access to Work and the Disability Confident Scheme, been at increasing employment rates among disabled people and ensuring disabled people stay in work? How could they be improved?

8.1 Access to Work and Disability Confident need to do more to acknowledge and improve work opportunities for people living with invisible disabilities and conditions. We believe that these programmes would benefit from using language and descriptions of disability that are more inclusive and recognise conditions that are non-visible and fluctuating.

8.2 Access to Work is currently very focused on aids and equipment in the workplace. We believe it should extend the approach it takes in mental health, in terms of developing a support plan, to disabilities/long-term health conditions. We believe that this group of workers would also benefit from flexible working patterns, regular catch ups to discuss their concerns, phased work returns and additional time to complete certain tasks.

8.3 We also believe that support planning would promote a more proactive, preventative approach to managing absence and presenteeism in long-term conditions/disabilities that flare. We believe it would encourage employers and employees to co-produce work strategies to enable employees to work well in the long-term and address periods of ill health, mitigating against avoidable periods of absence or changes to working conditions.

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

ⁱ Crohn's & Colitis UK, *Weeks Not Years*, April 2023.

[crohns-colitis-uk_weeks-not-years-briefing.pdf \(crohnsandcolitis.org.uk\)](#)

ⁱⁱ University of Nottingham, *Rates of Crohn's and Colitis have been vastly underestimated for decades, says new study*, March 2022. [News - Rates of Crohn's and Colitis have been vastly underestimated for decades, says new study - University of Nottingham](#)

ⁱⁱⁱ Demos, *The Economic Cost of Inflammatory Bowel Disease in the UK*, November 2021. [Economic-Cost-of-IBD-Report.pdf \(demos.co.uk\)](#)

^{iv} Crohn's & Colitis UK, *Break the silence: It takes guts*, Accessed Online 26.03.2024. [Break the silence. Let's talk about Crohn's and Colitis \(crohnsandcolitis.org.uk\)](#)

^v Crohn's & Colitis UK, *Campaigning for early diagnosis*, Access Online 26.03.2024 [Campaigning for early diagnosis \(crohnsandcolitis.org.uk\)](#)

^{vi} Crohn's & Colitis UK, *Weeks Not Years*, April 2023. [crohns-colitis-uk_weeks-not-years-briefing.pdf \(crohnsandcolitis.org.uk\)](#)

^{vii} Nordic Social Statistical Committee, *Sickness Absence in the Nordic Countries*, 2015. [FULLTEXT06.pdf \(diva-portal.org\)](#)

^{viii} Crohn's & Colitis UK, *Employment: a guide for employers*, 2022. [employers-ed5.pdf \(crohnsandcolitis.org.uk\)](#)