



A guide for employers

This information is for people supporting an employee with Crohn's or Colitis.

Crohn's Disease, Ulcerative Colitis and Microscopic Colitis are types of Inflammatory Bowel Disease (IBD). They are lifelong conditions, that can have a big impact on the daily lives of those affected. In this information, 'Colitis' refers to both Ulcerative Colitis and Microscopic Colitis.

This information will help you to:

- Understand what Crohn's and Colitis are and how they can affect people in the workplace
- Recognise how UK employment laws apply to people living with Crohn's or Colitis
- Find out how workplaces can support people living with Crohn's or Colitis

This information might use words you have not heard before. Our page on <u>medical</u> <u>words</u> can help explain more.

This information applies to all four nations of the UK. There are different employment laws in different nations. The Equality Act 2010 applies to England, Scotland and Wales. The Disability Discrimination Act (DDA) 1995 applies to Northern Ireland.





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Key facts for employers

- Crohn's Disease, Ulcerative Colitis and Microscopic Colitis are types of Inflammatory
 Bowel Disease (IBD). They are lifelong conditions of the gut.
- In the UK, 1 in 123 people have Crohn's or Ulcerative Colitis. It is likely that at least one person in a medium sized organisation lives with one of these conditions.
- Around 1 in every 2,000 people in the UK has Microscopic Colitis.
- Most people with Crohn's or Ulcerative Colitis are diagnosed between the ages of 15 and 40. Microscopic Colitis usually starts after the age of 50.
- A supportive employer can help people work well and manage their condition.
- Each person with Crohn's or Colitis is unique, and their needs are different. The best
 way to find out what an employee needs is by asking them. Their needs may change
 over time.
- There are different employment laws in different nations. The Equality Act 2010 applies to England, Scotland and Wales. The Disability Discrimination Act (DDA) 1995 applies to Northern Ireland.
- If UK law classifies an employee as disabled, you have a duty to make reasonable adjustments.
- It is best practice to have organisational policies. This includes policies on sickness absence, disability leave and medical appointments. This can help you and your employee understand their rights and entitlements.

What are Crohn's and Colitis?

Key facts:

- Crohn's and Colitis are lifelong conditions of the gut, with no known cure. They
 happen when the body's immune system goes wrong.
- Crohn's and Colitis do not only affect the gut. They can also affect energy levels,
 mental health, and cause symptoms in other parts of the body.





- Most people have times when symptoms are under control, known as remission.
 They will also experience flare-ups, where symptoms are more active.
- Crohn's and Colitis are not the same as Irritable Bowel Syndrome (IBS). Crohn's and
 Colitis can cause more serious complications.
- For more information, see our resources on <u>Crohn's Disease</u>, <u>Ulcerative Colitis</u> or <u>Microscopic Colitis</u>. The NHS also provides brief information on <u>Crohn's</u> and <u>Ulcerative Colitis</u>.

Crohn's and Colitis can cause lots of different symptoms. Some symptoms can be obvious, while others are invisible. If left untreated, Crohn's and Ulcerative Colitis can lead to other life-threatening conditions.

If you have an employee with Crohn's, Ulcerative Colitis or Microscopic Colitis, they may experience:

- Cramping pains in the tummy
- Frequent and urgent diarrhoea
- Extreme tiredness or fatigue
- Weight loss
- Low levels of healthy red blood cells, known as anaemia
- Bowel incontinence, where you pass poo without meaning to

People with Crohn's or Ulcerative Colitis may also experience:

- Blood in their poo
- Swollen joints
- Mouth ulcers
- Inflamed eyes
- Liver disease





People with Crohn's can also develop tunnels that connect one part of the body to another. These are called **fistulas**.

Myth-busting Crohn's and Colitis

- Crohn's and Colitis are **not** the same as irritable bowel syndrome, known as IBS.
 IBS can also cause tummy pain, bloating, diarrhoea and constipation. But unlike IBD, there is no inflammation or blood in the poo. IBS is a different condition that requires different treatment.
- Crohn's and Colitis are invisible conditions. If someone looks okay from the
 outside, it does not mean that they are well. Many people may look fine even when
 they are struggling with symptoms.
- Crohn's and Colitis are not only about needing the toilet. In 2024, we found that the biggest impact of living with Crohn's or Colitis was managing fatigue.

Treatment for Crohn's and Colitis

Key facts:

- Many people with Crohn's or Colitis will take medicines to control their condition.
 Some people with Crohn's or Ulcerative Colitis may need surgery. It is rare to need surgery for Microscopic Colitis.
- Medicines used for Crohn's and Colitis can have unpleasant side effects. These sideeffects may be noticeable in the workplace.
- Some medicines affect the immune system and can increase the risk of infections.
 This might impact how comfortable your employee feels in certain situations.
- For more detailed information, you might find our information on <u>treatments</u> helpful.
 We also have specific information on <u>steroids</u>, <u>biologics</u>, <u>immunosuppressant</u>
 <u>precautions</u> and <u>surgery</u>.





Crohn's and Ulcerative Colitis generally need lifelong treatment. Effective treatment can reduce the chance of relapses and keep the person in good health. Some people with Microscopic Colitis may take long-term medicines. Others might only take medicines when their symptoms are bad.

Steroids

One type of medicine used to treat Crohn's or Colitis is <u>steroids</u>. Unwanted, noticeable side effects of steroids may include:

- Significant weight gain
- · Roundness of the face
- Acne
- Mood changes such as depression, irritability or extreme highs and lows in mood
- Higher risk of infections, including colds, flu, pneumonia and sepsis

Immunosuppressants

Other medicines used to treat Crohn's and Colitis include immunosuppressants. A person taking immunosuppressants is at higher risk of catching infections. Some people may also have side effects. This can include nausea and flu-like symptoms.

Biologics

<u>Biologics</u> treat Crohn's and Ulcerative Colitis. A person taking these medicines is also at higher risk of catching infections.

Biologics are given by a drip into the arm in a hospital, known as an infusion, or at home by injection. Your employee may need time off to attend their infusion appointments.

Immunosuppression in the workplace

Immunosuppressed people are at a higher risk of catching infections.

For the latest on COVID-19 see <u>COVID-19 (coronavirus) in people with Crohn's or</u>
<u>Colitis</u>





Liquid diet

Sometimes, doctors treat Crohn's flare-ups with a liquid diet. This is also known as enteral or parenteral nutrition. People on a liquid diet need this strict diet and water for weeks or months. Some people may have side effects, like feeling or being sick, diarrhoea, bloating or wind.

The needs of employees with Crohn's or Colitis

Key facts:

- Each person with Crohn's or Colitis is unique and their needs are different. The best way to find out what an employee needs is by asking them.
- Check in and review your employee's needs over time. This is important as their needs may change.
- People with Crohn's or Colitis may need: accessible and adequate toilet facilities, opportunities to take breaks when needed, flexible hours or travel allowances.

"Managing a long-term health condition can be like another job (on top of a full-time job) and employers are not always aware of the full extent. This is especially true if a person is single and does not have a partner to support or assist in certain situations which could alleviate the load."

Emily

Living with Ulcerative Colitis

There can be lots of difficulties for someone managing Crohn's or Colitis at work. Working alongside supportive colleagues and a supportive environment can help.





Accessible and adequate toilet facilities

Many people with Crohn's or Colitis have problems controlling their bowels. There can be a real need to get to a toilet without delay, so access to nearby toilets is important.

People can worry about pooing at work because of smells and sounds. Many workplace toilets do not have proper ventilation. They have limited privacy, with cubicles with spaces below and above partitions. If this applies, it can help to have the use of separate, individual facilities. A toilet for use by disabled people could be a practical option.

Stomas

Some people with Crohn's or Colitis have a <u>stoma</u>. A stoma is an opening on the wall of the tummy that brings the bowel to the outside. For people with a stoma, the contents of their gut does not travel all the way through their bowel to come out of their bottom. Instead, it comes out of the stoma into a bag they wear on their tummy.

Having somewhere appropriate to empty and change stoma bags is important. This could be a bathroom space that is private and has enough room. Disabled toilets often meet these criteria.

Essential facilities for a stoma-friendly accessible toilet include:

- A hook on the door
- Shelf space
- A mirror
- Disposable bin in every cubicle

Frequent toilet breaks

Many people with Crohn's or Colitis worry about the need for frequent toilet breaks. Employees in jobs with fixed breaks may appreciate co-workers offering to cover them. Allowing extra toilet breaks can also be helpful.





Fistulas

Some people with Crohn's develop <u>fistulas</u>. A fistula is a tunnel that connects one organ to another part of the body. They can connect one internal organ to another, or to the surface of the skin. People with fistulas may need longer toilet breaks to clean themselves.

Flexible working hours

Many people find their bowels are more active in the morning. Flexible hours, such as a later start, can help with this. During flare-ups, there may also be times when shorter hours or working from home might be helpful.

Extra meal or snack breaks can also be useful. Some symptoms of Crohn's or Colitis make it hard to eat a regular-sized meal. Instead, it can be easier to eat frequent small meals. Breaks may also be helpful if the individual takes medicines at certain times of the day.

Working from home

Many callers to our Helpline tell us that working from home is important to them. Working from home helps with fatigue and worries around infection risk in the office. It also takes away the fear of urgently needing the toilet in public.

Travel allowances

Travel is an important issue for many people with Crohn's or Colitis. Needing the toilet frequently and urgently can make using public transport difficult. Instead, driving can be a better option. Allowances for car travel and a parking space close to the workplace can help to support this.

Having accessible parking spaces may not be enough. This is because people with Crohn's or Colitis often do not meet the criteria for a disabled permit. It is important to offer alternatives.





How employers can help

Key facts:

- Provide a supportive environment.
- Be willing to talk about Crohn's and Colitis. Our <u>employer conversation guide</u> can help support you.
- Maintain trust and treat information your employee tells you as confidential.
- Work together with your employee to arrange reasonable adjustments.
- Let your employee know about mental health support provided through Employee Assistance Programmes (EAPs).
- Think about whether workplace socials are accessible for all employees.
- Pledge your support with our Are You IN? campaign.

Provide a supportive environment

Unlike many other conditions, there is often a stigma attached to Crohn's and Colitis. Some people feel too ashamed to talk about their condition. Almost a half of people living with Crohn's or Colitis experience mental health difficulties.

Some Crohn's and Colitis symptoms may be challenging to talk about. For example, needing to reach a toilet quickly or often. Some people may worry that colleagues think they do not do enough work because of their symptoms.

Having a supportive manager can help improve workplace experiences. This includes providing support with implementing reasonable adjustments.

"Crohn's in the workplace for me was always a difficult one. Once I felt confident opening up to my manager things became much easier. I got the support I needed by having a day off midweek to recharge. This made working life so much easier





physically and mentally. Having a line manager who understands the complexity of Crohn's is so important."

Sonya

Living with Crohn's

Be comfortable talking about Crohn's or Colitis

Knowing how to talk to employees about their Crohn's or Colitis might feel difficult. Our **employer conversation guide** can help you. It contains useful phrases and top tips on how to prepare for a conversation.

"When I was first diagnosed at 25, I kept my symptoms hidden for years and did not seek any help from my employers to make things easier due to some embarrassment and lack of confidence.

However, in my 30s I have been open with my employers when experiencing difficulty and they have been extremely accommodating and supportive. In hindsight I wish I had reached out earlier as the support was always there."

Emily

Living with Ulcerative Colitis

Reasonable adjustments

Take time to understand your employee's needs. Once you do, you can work together to make reasonable adjustments. If you have a Human Resources or Occupational Health team, they may be able to give you advice and support. Otherwise, you may want to refer to <u>Acas</u> or the <u>Equality and Human Rights Commission</u> website.

It's important to respect your employee's privacy and confidentiality. It might help to discuss what they want to tell others about their condition.





Signpost to Employee Assistance Programmes (EAPs)

Many people find that Crohn's or Colitis affects their mental health. Let employees know if your workplace offers an Employee Assistance Programme. This can help employees access extra support like counselling.

There may also be steps you can take to support your employee's mental health. For example, some people might feel anxious about symptoms like toilet urgency and incontinence. This anxiety can show up as nervousness in new places, like client offices. It can be helpful to think about this when asking an employee to go to a new location.

Workplace socials

Some people with Crohn's or Colitis can struggle with workplace social events. This might be due to fatigue, or because they have a diet that makes eating or drinking out difficult. It can be helpful to think about:

- Toilet access. Are disabled toilets available? How many toilets are there compared to people coming?
- Travel. How far do people have to travel to the social? What transport options are available?
- Energy levels. Is the social based on intense exercise? Does the activity work for a range of energy levels?

Organising social events that everyone can join helps ensure no one feels left out.

Are You IN?

<u>Are You IN?</u> is part of our Not Every Disability is Visible campaign. Our Are You IN? webpage offers free tools and resources to help organisations better support employees.





The Equality Act 2010 and Disability Discrimination Act 1995

Key facts:

- The Equality Act 2010 applies to England, Wales and Scotland. The Disability
 Discrimination Act (DDA) 1995 applies to Northern Ireland.
- Under these acts, a person has a disability if they have a physical or mental condition that affects their ability to carry out day-to-day activities.
- UK law does not automatically class Crohn's or Colitis as a disability. But if the condition significantly affects daily life over the long-term, it may count.
- If UK law classifies an employee as disabled, you have a duty to make <u>reasonable</u> adjustments.

Not everyone with Crohn's or Colitis may consider themselves to have a disability. But employers should be aware that legal considerations may still apply. This is the same as with any other long-term health condition. By law, nobody has to tell their employer if they're disabled. But if they do, the employer has a legal responsibility to support them. Acas has lots of helpful resources on disability at work.

The Equality Act and DDA are in place to protect people against discrimination at work.

The Equality Act and DDA apply to people who:

- Work for an employer
- · Are self-employed or contracted
- Are applying for a job

The Equality Act and DDA cover conditions that change over time. The employee's rights are not affected because their Crohn's or Colitis symptoms change. Usually, the law does not consider treatment when deciding if someone is disabled. So, employees can still get protection, even if medicines control their symptoms.

With your employee's permission, you might find it helpful to get a report from their doctor. This could be their IBD specialist or GP. The report will inform you about their





condition and whether it is likely to affect them at work. Occupational Health can also provide similar reports.

For more information, see:

- <u>Equality Act 2010: guidance.</u> This information is from GOV.UK and applies to England, Scotland and Wales.
- <u>Disability discrimination law: employment rights</u>. This information is from NI Direct and applies to Northern Ireland only.
- <u>Protection against disability discrimination</u>. This information is from NI Direct and applies to Northern Ireland only.
- <u>Disability at work.</u> This information is from Acas. It applies to England, Scotland and Wales.
- <u>Discrimination and the Equality Act 2010: Discrimination at work.</u> This information is from Acas. It applies to England, Scotland and Wales.
- The law on disability discrimination: Disability discrimination. This information is from Acas. It applies to England, Scotland and Wales.

The Labour Relations Agency has more information that relates to Northern Ireland.

Making reasonable adjustments

Key facts:

- If UK law classifies an employee as disabled, you have a duty to make <u>reasonable</u> adjustments.
- Reasonable adjustments can involve making physical changes to the workplace.
 They could also include changing working arrangements or providing equipment.
- Reasonable adjustments should reduce the disadvantages the employee faces.
- Different employees will need different adjustments. Ask the employee about what adjustments might help them.





Even if you are unsure whether something is a disability, Acas recommend making adjustments.

The sort of adjustments considered reasonable will depend on the employer and employee. When deciding whether an adjustment is reasonable, an employer should consider:

- How effective the change will be in removing or reducing the disadvantage
- Practicality
- Cost
- Impact on the health and safety of other employees

Find more information on the duty to make reasonable adjustments through <u>Acas</u>. For Northern Ireland, you can visit the **Equality Commission for Northern Ireland** website.

"When I had a bad flare up around six years ago, I saw an occupational therapist who recommended a number of workplace adjustments. I went through them with my employer and was amazed at how supportive they were - providing a specialist keyboard and mouse, for example, and even an automatic stapler because the pain in my joints made it very difficult to use a standard one."

Alun

Living with Crohn's

Examples of reasonable adjustments for people with Crohn's or Colitis

Many adjustments have little cost or disruption.

They might include:

- Allowing time off for medical appointments or treatment
- Offering shorter, different or flexible working hours





- Offering breaks when not feeling well
- Moving the workstation close to a toilet
- Providing a car parking space close to the entrance to work
- Allocating some duties 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

Access to Work

Key facts:

- Access to Work is a government programme. It aims to support disabled people to take up or remain in work.
- Access to Work applies to people living in England, Scotland or Wales. Access to Work NI applies to people living in Northern Ireland.
- You cannot use Access to Work to pay for reasonable adjustments.

The following information only applies to people living in England, Scotland or Wales. See NI Direct for more information on Access to Work NI.

Disabled people can apply for Access to Work. This can help them overcome practical issues that may stop them from working. For example, paying for taxi rides to work if an employee cannot use public transport. The amount of help received depends on their length of employment and what support they need. For unemployed people about to start a job, the grant is up to 100% of the approved costs, subject to a cap.

Access to Work is available for individuals on permanent or temporary contracts. It is available to people who are working part or full-time.

Employees can contact Access to Work to apply. There is the option to apply for an Access to Work grant online.





Supporting time off work

Key facts:

- Employers should have an absence policy. This should include what to do if someone needs time off for reasons related to their disability.
- As a reasonable adjustment, you could record disability absence separately from sickness absence.
- Organisational policies can help both you and your employee understand your rights.

There may be times when the employee needs time off work. This could be unplanned due to a severe flare-up or fatigue. Or the absence could be planned, for reasons such as:

- Colonoscopies. These procedures need bowel preparation and sedation. You can find out more about colonoscopies in <u>tests and investigations</u>.
- Regular blood tests.
- Infusion of medicines in hospital. Some medicines, like <u>biologics</u>, need infusions every month or two months.
- Appointments with their medical team. These might be face-to-face or telephone appointments.
- Collection of medicines within office hours. This could include needing to be at home to accept a homecare delivery of medicines.

If the absence is unplanned, an employee might not know how long they will be off for. It may be helpful to set up an agreed plan about how you and your employee could keep in contact when they are absent. It's helpful to ask how they prefer to be contacted, whether by phone, email, letter, or in person. It is important not to pressure an employee into returning to work too soon before they are well.





Supporting return to work after sickness absence

Key facts:

- If an employee is unwell and cannot work for over a week, they should get a fit note.
- When the employee is feeling better, try and involve them in planning their return to work.
- Provide ongoing support and regular reviews for your employee.

If the employee is absent for over a week, they will need to get a 'statement of fitness for work' or 'fit note'. Lots of different healthcare professionals can provide a fit note.

If possible, involve the employee in planning their return to work. This allows them to voice any concerns they may have or to request adjustments. They might need to return back to work gradually. They could start with shorter hours and slowly increase to their regular schedule. To begin with, having a reduced workload might also be helpful.

If an employee feels they have been treated unfairly

Key facts:

- Talk to your employee if they feel they have been treated unfairly. You may be able to resolve things informally.
- Make your employee aware of your grievance procedures.
- Acas or the <u>Labour Relations Agency</u> can help with preventing and resolving disputes. They can be helpful when issues cannot be solved informally.

Some employees may feel that they have been discriminated against. For example, if their performance review does not take their condition into account. They might also feel unhappy if there has been a disagreement about reasonable adjustments.





Often, talking things through can resolve any issues. But, you should make sure your employees are aware of your grievance procedures. Ideally, they will discuss any problems with a relevant person. For example, their line manager, HR team or union representative, if they have one. Or, there might be another person who can mediate in the event of disagreements. It is good practice to keep detailed records of meetings in all cases.

If the issue is not solved informally, the employee may raise a formal grievance. They could also make a claim to an employment tribunal.

Acas or the Labour Relations Agency can help with preventing and resolving disputes.

If an employee finds it difficult to continue working

Key facts:

- There may be rare occasions when an employee cannot do their job.
- Dismissal should be a last resort. You should first try other ways to support the employee and help them get back to work.
- Acas or the or the <u>Labour Relations Agency</u> can provide advice on ending employment.

There may be rare occasions where you have made adjustments, but the employee cannot do their job. In these circumstances, you may feel your only option is to end employment. But you should follow certain procedures before taking this step. You must ensure you have made all reasonable adjustments with the employee. And show that you have looked for alternative solutions to the problem.

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Other organisations

Acas (Advisory, Conciliation and Arbitration Service)

Provides free, impartial, confidential advice about any kind of dispute or query about issues at work. For England, Scotland and Wales.

www.acas.org.uk.

Business Disability Forum

Provides a framework for UK employers to develop best practices in the employment of disabled people.

www.businessdisabilityforum.org.uk

Chartered Institute of Personnel and Development (CIPD)

The professional body for those involved in HR and the management and development of people at work.

www.cipd.co.uk

Citizens Advice

www.citizensadvice.org.uk.

Disability Rights UK

www.disabilityrightsuk.org

Equality Advisory Support Service (EASS)

Offers information, advice and support on discrimination in the workplace.

www.equalityadvisoryservice.com

Equality and Human Rights Commission (EHRC)

Provides information on the main areas in which discrimination in employment can arise. Also, explains who it applies to, and what employers can do to prevent it. Applies to England, Scotland and Wales.

www.equalityhumanrights.com





Equality Commission for Northern Ireland

Provides information on the main areas in which discrimination in employment can arise. Also explains who it applies to, and what employers can do to prevent it. Applies to Northern Ireland.

GOV.UK

www.gov.uk

Labour Relations Agency

Free, impartial, confidential advice about any kind of work dispute or query. For Northern Ireland.

www.lra.org.uk/

NI direct

www.nidirect.gov.uk/

Help and support from Crohn's & Colitis UK

We're here for you whenever you need us. Our information covers a wide range of topics. From treatment options to symptoms, relationship concerns to employment issues, our information can help you manage your condition. We'll help you find answers, access support and take control.

All information is available on our website.

Helpline service

Our helpline team provides up-to-date, evidence-based information. You can find out more on our <u>helpline web page.</u> Our team can support you to live well with Crohn's or Colitis.

Our Helpline team can help by:

Providing information about Crohn's and Colitis





- Listening and talking through your situation
- Helping you to find support from others in the Crohn's and Colitis community
- Providing details of other specialist organisations

You can call the Helpline on **0300 222 5700**. You can also visit our <u>livechat service</u>. Lines are open 9am to 5pm, Monday to Friday, except English bank holidays.

You can email helpline@crohnsandcolitis.org.uk at any time. The Helpline will aim to respond to your email within three working days.

Our helpline also offers a language interpretation service, which allows us to speak to callers in their preferred language.

Social events and Local Networks

You can find support from others in the Crohn's and Colitis community through our virtual social events. There may also be a Local Network in your area offering in-person social events. Visit our <u>Crohn's and Colitis UK in your area webpage</u> to find out what is available.

Crohn's & Colitis UK Forum

This closed-group Facebook community is for anyone affected by Crohn's or Colitis. You can share your experiences and receive support from others. Find out more about the Crohn's & Colitis UK Forum.

Help with toilet access when out

There are many benefits to becoming a member of Crohn's & Colitis UK. One of these is a free RADAR key to unlock accessible toilets. Another is a Can't Wait Card. This card shows that you have a medical condition. It will help when you are out and need urgent access to the toilet. See <u>our membership webpage</u> for more information. Or you can call the Membership Team on **01727 734465**.

About Crohn's & Colitis UK





Crohn's & Colitis UK is a national charity, leading the fight against Crohn's and Colitis. We're here for everyone affected by these conditions.

Our vision is to see improved lives today and a world free from Crohn's and Colitis tomorrow. We seek to improve diagnosis and treatment, fund research into a cure, raise awareness and give people hope and confidence to live freer, fuller lives.

Our information is available thanks to the generosity of our supporters and members. Find out how you can join the fight against Crohn's and Colitis by calling **01727 734465**. Or you can visit <u>our website</u>.

About our information

We follow strict processes to make sure our information is based on up-to-date evidence and is easy to understand. We produce it with patients, medical advisers and other professionals. It is not intended to replace advice from your own healthcare professional.

You can find out more on our website.

We hope that you've found this information helpful. Please email us at evidence@crohnsandcolitis.org.uk if:

- You have any comments or suggestions for improvements
- You would like more information about the evidence we use
- You would like details of any conflicts of interest

You can also write to us at Crohn's & Colitis UK, 1 Bishops Square, Hatfield, Herts, AL10 9NE. Or you can contact us through the Helpline on 0300 222 5700.

We do not endorse any products mentioned in our information.

CROHN'S & COLITIS UK

INVISIBLE DISABILITY

CROHN'S & COLITIS UK

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A guide for employers, edition 6

Last review: June 2025

Next review: June 2028

