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## **Employment: a guide for employers**

Crohn's Disease and Ulcerative Colitis – the two main forms of Inflammatory Bowel Disease (IBD) – are lifelong diseases of the gut. They are painful, debilitating and widely misunderstood. There is no known cure, and the conditions may flare up unpredictably. However, many people with Crohn's or Colitis will have long periods when they have few or no symptoms.

The latest research estimates that over 500,000 people across the UK have Crohn's or Colitis. That is around 1 in every 123 people. It is likely that at least one person in a medium to large organisation lives with one of these conditions.

Most people are diagnosed when they are of working age, between the ages of 15 and 40. For many people living with Crohn's or Colitis, having a supportive employer will help them manage their condition at work and remain in employment.

This information will help employers and managers understand what it means to have Crohn's or Colitis. You may have questions about what you can do to support employees with health conditions. We can help you put plans in place to become a more accepting and accommodating place to work.

**This guide covers the Equality Act 2010, which applies to England, Wales and Scotland. For people in Northern Ireland, this guide should still be helpful but please be aware that the Equality Act does not apply to you. The main anti-discrimination law in Northern Ireland is the Disability Discrimination Act 1995 (DDA). Visit [nidirect](#) for information on the DDA and employment rights in Northern Ireland.**

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## Key facts for employers

- Crohn's Disease and Ulcerative Colitis – the two main forms of Inflammatory Bowel Disease (IBD)– are lifelong diseases of the gut. Crohn's and Colitis can be diagnosed at any age. Some people with Crohn's or Colitis feel well most of the time, other people take longer to find a treatment that's right for them.
- Providing a safe, inclusive and supportive environment can help employees feel that they can talk to you about their condition.
- Each person with Crohn's or Colitis is unique and their needs are very different. The best way to find out what the employee needs to help them at work is by asking them. It is best to continue checking in and reviewing your employee's needs regularly, as their needs may change over time.
- If an employee is considered disabled under the Equality Act, you have a duty to make reasonable adjustments. Where adjustments are more costly, such as installing separate toilet facilities, [Access to Work](#) may help with financial and practical support.
- It is best practice to have organisational policies on sickness absence, disability leave and medical appointments. This can help you and the employee clearly understand their rights and entitlements.

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## What are the symptoms of Crohn's and Colitis?

Crohn's and Colitis don't just affect the gut. They can affect almost every aspect of life: from digestion to energy levels and mental health.

Crohn's and Colitis affect everyone differently. Some people with Crohn's or Colitis feel well most of the time. Other people take longer to find a treatment that's right for them.

Crohn's and Colitis can cause:

- Diarrhoea (sometimes with blood)
- Urgent or frequent need to go to the toilet
- Abdominal pain
- Extreme tiredness
- Nausea
- Lack of appetite and weight loss

Some people with Crohn's or Colitis may also suffer from painful joints, eye problems, mouth ulcers, and skin rashes.

Some symptoms can be obvious to others, and other symptoms are invisible. Most people living with Crohn's or Colitis will have times when symptoms are largely under control, known as remission, and flare-ups where symptoms are more active.

## **Crohn's and Colitis misconceptions**

- Crohn's and Colitis are **not** the same as irritable bowel syndrome (IBS). IBS is a different condition that requires different treatment.
- Crohn's and Colitis are not infectious.

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## **What causes Crohn's and Colitis?**

Crohn's and Colitis happen when the body's immune system doesn't work properly. Usually, the immune system protects the body. In Crohn's and Colitis, the immune system starts attacking the body.

We do not know why the immune system attacks the body. Most researchers believe Crohn's and Colitis are caused by a mix of genes and the environment (like germs, diet, smoking and stress). Right now, there is no known cure for Crohn's or Colitis.

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## Treating Crohn's and Colitis

Crohn's and Colitis generally require lifelong treatment. Many people with the conditions take medication that may have unpleasant side effects. Treatment is designed to control Crohn's or Colitis symptoms when they are active. Effective treatment can reduce the chance of relapses and maintain good health.

One type of medicine used to treat Crohn's or Colitis is corticosteroids (steroids). Steroids reduce inflammation in the gut. Unwanted side effects of steroids can be:

- Significant weight gain
- Roundness of the face
- Acne
- Mood swings, from euphoria to depression.

Steroids can also have the effect of making someone taking them look healthy when they are actually having a flare-up of their illness.

Other medicines used to treat Crohn's and Colitis include immunosuppressant medicines, which affect how the body's immune system works. A person taking these medicines may be at higher risk of catching infections and risk of getting colds and flu. Some people get side effects from taking immunosuppressants. Side effects can include headaches and nausea.

Biologic medicines are used to treat Crohn's and Colitis and can also help people in remission keep their symptoms controlled. These medicines are given by a drip into the arm (infusion) in a hospital or given at home by injection.

Sometimes Crohn's flare-ups can be treated with a liquid diet called enteral or parenteral nutrition, where nothing other than the diet and water are allowed for weeks or months. The high concentration of nutrients in the feed sometimes causes nausea, headaches, and a feeling of light-headedness.

Sometimes surgery is needed to treat Crohn's and Colitis.

## Do Crohn's and Colitis affect the employee's ability to do their job?

The effect of Crohn's and Colitis on someone's ability to do their job is dependent on the individual. A range of factors can cause barriers for someone managing their Crohn's or Colitis at work.

Key factors that can help overcome barriers at work for some people with Crohn's or Colitis include:

- Accessible toilet facilities
- Flexibility in working arrangements
- A knowledgeable and inclusive social environment
- Working alongside others in a supportive team

These factors are not specific to Crohn's and Colitis. They are considered workplace 'best practice' and can help you attract and retain committed workers.

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## How can employers help?

The first step is to provide a supportive environment where someone with Crohn's or Colitis feels able to tell you about their condition.

**I decided to tell my employer about my condition after I had to go into hospital. Being up-front and honest was a relief. She was very understanding even though she had never heard of Crohn's or Colitis.**

**I helped her research the illness and we worked together to decide on adjustments that would really help me manage my condition at work.**

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**Sarah**

Living with Crohn's

Crohn's and Colitis can be difficult to talk about and sometimes misunderstood. We have created a campaign called It Takes Guts to help people find the confidence and support they need to talk to other people, including employers and colleagues, about Crohn's and Colitis. You may find it useful to look at the [It Takes Guts](#) website to support your employees.



Unlike many other diseases, there may be a stigma attached to Crohn's and Colitis. Many people feel too ashamed to talk about their condition. A recent study found that almost half of people with Crohn's and Colitis say their conditions have affected their mental health.

An employee telling you about their condition can help develop a positive employment relationship and open communication. The employee may also feel relieved that they don't have to hide their symptoms.

Some Crohn's and Colitis symptoms are challenging to explain, especially needing to reach a toilet quickly (urgency), or often (frequency). Some people with Crohn's or Colitis may also worry that their colleagues think they do not do their fair share of work because of their symptoms.

A recent study showed that when employees with Crohn's or Colitis had a supportive employment relationship with their line manager, the employees said they had a positive experience in the workplace, despite their condition. This positive working relationship included the line manager understanding how Crohn's and Colitis affected the individual. The manager also supported the individual and implemented reasonable adjustments when necessary.

Once you know about the employee's needs, you can work together to make reasonable adjustments to support them. If you work within a larger organisation, your Human Resources (HR) or Occupational Health team may be able to give you advice and support. Otherwise, you may want to refer to [Acas](#) or the [Equality and Human Rights Commission](#) website.

Two-way trust must be developed between employees and employers. Employees should be assured of respect and confidentiality, especially regarding whether and how much they want others to know about their condition.

You may find it helpful to look at our [Not Every Disability is Visible campaign website](#).

Are you IN?, the newest phase of the campaign, provides companies with a range of free tools and resources to help improve support in the workplace for employees living with invisible conditions and disabilities.

We are calling on companies to sign-up to [pledges](#), showing their commitment to making the workplace more inclusive.

Find out more information or sign up by [completing the form](#) on our Are you IN? website.



## What are the needs of people with Crohn's or Colitis?

Each person with Crohn's or Colitis is unique and their needs are very different. The best way to find out what the employee needs to help them at work is by asking them. It is best to continue checking in and reviewing your employee's needs regularly, as their needs may change over time.

Some examples of needs that people with Crohn's or Colitis have are as follows:

### Accessible and adequate toilet facilities

A symptom for many people with Crohn's or Colitis is problems controlling their bowels ([bowel incontinence](#)). The main form of bowel incontinence is urge incontinence, where the person has a very strong need to poo, but does not reach the toilet in time. They may describe this as having an 'accident'. The problem of urgency means there can be a real need to get to a toilet without delay. Having access to toilet facilities close to their place of work is extremely important.



People are also understandably concerned about pooing at work because of smells and sounds, which can be embarrassing. These concerns are often a significant cause of stress.

Many workplace toilets do not have proper ventilation. They have cubicles with spaces below and above partitions, which do not offer enough privacy. If this applies, it would help to have the use of separate, individual facilities. A toilet for use by disabled people could be a practical option.

### **Frequent toilet breaks**

Many people with Crohn's or Colitis also feel embarrassed about the need for frequent toilet breaks and worry about the consequences if they cannot go whenever they need to. Employees in jobs with fixed breaks may benefit from co-workers offering to cover them, allowing the employee to use the toilet whenever they need to. Allowing additional toilet breaks and having cover arrangements in place can be very helpful.

### **Flexible working hours**

Flexible hours such as a later start can help the employee if their bowels are more active in the morning, as is often the case. During flare-ups of their illness, there may also be times when shorter working hours or working from home would be helpful.

Additional meal or snack breaks can also be useful. Many people with Crohn's or Colitis have difficulty eating a regular-sized meal, so they may need to eat smaller meals more often. Breaks may also be helpful if the individual takes prescribed medication at certain times of the day.

### **Travel**

Travel is a crucial issue for many people with Crohn's or Colitis. Due to needing the toilet frequently and urgently, they may find it difficult to take public transport and prefer to drive to work or meetings. Allowances for car travel and a parking space close to the workplace can be helpful. While many employers provide accessible parking spaces, people with Crohn's or Colitis usually do not meet the current criteria for Disabled Permit

(blue badge) holders, so they cannot use them. It is important that alternatives are offered.

**One adjustment I felt I needed was to be able to take time off for hospital appointments without feeling guilty about missing work. My employer was really helpful. She discussed it with our company lawyer and introduced a 'flexi-time' policy for medical appointments, which she has applied to all employees, rather than just me.**

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**Sarah**

Living with Crohn's

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## **Are Crohn's and Colitis covered by the Equality Act 2010?**

Supportive and flexible management will enable most people with Crohn's or Colitis to continue working productively, and most are highly motivated to do so. However, employers should be aware that legal considerations may apply to people living with Crohn's or Colitis, as with any other long-term health condition.

Under the Equality Act, a person has a disability if they have a physical or mental impairment that has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities.

Not everyone with Crohn's or Colitis may consider themselves to have a disability. But in practice, whether or not they perceive themselves to be 'disabled', people with Crohn's or Colitis may still qualify for protection against discrimination.

The employee's rights will not be affected because their Crohn's or Colitis symptoms fluctuate (change over time). For example, they may have periods when they have few or no symptoms and times when their symptoms are active (such as during a flare-up). The Equality Act covers fluctuating conditions; the main point is that the overall effect is long-term.

In most cases, treatment for a health condition is not considered when deciding if someone is disabled under the law. This means that employees may still benefit from the protection of the Equality Act even if symptoms are controlled by medication.

With your employee's permission, you might find it helpful to obtain a report from their doctor, either their specialist or GP. The report will inform you about their condition and whether it is likely to affect them at work.

The Equality Act is in place to protect people against discrimination at work, even people who may consider themselves not covered by the Act, such as people who are:

- Working on a casual basis
- On zero-hours contracts
- Trainees
- In some situations, self-employed

Discrimination can occur in many aspects of work such as recruitment, pay, training, promotion, dismissal and redundancy.

Discrimination can happen in different forms. It is discrimination when:

- An employee is treated less favourably than a person who is not disabled for a reason related to their disability.
- Reasonable adjustments are not made.
- A person is subjected to harassment for a reason related to their disability.
- A person is treated unfairly because they've complained about discrimination or harassment.

For more information about the Equality Act, see [Citizens Advice](#). For advice and help in resolving disputes, you can contact [Acas](#).

**I know from first-hand experience as an employer in a low margin industry that supporting and respecting our staff has earned us a good reputation with both staff and customers alike. We made reasonable adjustments for a particular employee where it was practical and possible, and in return, we were rewarded with their loyalty and hard work. Small changes can really help to achieve a give-and-take employment relationship.**

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**Jean**

Living with Crohn's

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## **Reasonable adjustments**

If an employee is considered disabled under the Equality Act, you have a duty to make reasonable adjustments. Reasonable adjustments could involve making physical changes to the workplace, changing working arrangements, or providing equipment. Reasonable adjustments must be made to reduce a substantial disadvantage the disabled employee faces, compared to a non-disabled person, when doing their job.

Even if you are unsure whether the employee's condition is considered a disability, it is still a good idea to make reasonable adjustments to support productivity.

Different employees will require different adjustments. Ask the employee about what adjustments might help them, as they will be best placed to make suggestions.

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

- How effective the change will be in avoiding the disadvantage that the employee would otherwise experience
- Practicality
- Cost
- The organisation's resources and size
- The availability of financial support

More information on the duty to make reasonable adjustments can be found at [Acas](#) or the [Equality and Human Rights Commission](#) 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.**

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**Alun**

Living with Crohn's

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

Many adjustments needed by people with Crohn's or Colitis have little or no cost and cause minimal disruption.

They might 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.
- 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.

Where adjustments are more costly, such as installing separate toilet facilities, Access to Work may help you with financial and practical support.

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## **Access to Work**

Access to Work is a publicly funded employment support programme. Disabled people can apply for help to overcome practical difficulties that may stop them from working. The amount of help that may be given will depend on the length of time the person has been employed by you and what support they need. For people who are unemployed and starting a job with you, the grant is up to 100% of the approved costs, subject to a cap.

An example of help that Access to Work may be able to provide is covering the costs of travelling to work in a taxi if the employee is unable to use public transport.

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

You can contact Access to Work to apply. There is the option to apply for an [Access to Work grant online](#).

## Time off work

**At the moment, I have been absent from work for a long period of time due to a flare-up of my condition and surgery. My workplace has been very supportive during this time and they have not put me under any pressure to return to work until I feel 100% better. A few weeks after my operation my manager and HR manager came to visit me to see how I was recuperating and to discuss returning to work and what changes could be put into place to help.**

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### **Carl**

Living with Crohn's

There may be times when the employee will have to take time off work. This absence could be unplanned due to a severe flare-up or fatigue. Or the absence could be planned, such as a hospital appointment to receive treatment. It is best practice to have organisational policies on sickness absence, disability leave and medical appointments. This can help you and the employee clearly understand their rights and entitlements.

It may be helpful to set up an agreed plan about how you and your employee could keep in contact when they are absent. At times, it may be appropriate to appoint a family member as a point of contact. The employee may prefer contact from a co-worker, close colleague, union representative or an occupational health worker. This might make them feel more supported rather than being contacted by their line manager, making them feel they were being checked up on. It is also a good idea to establish what type of contact they would prefer, whether by telephone, email, letter or in person. It is important not to pressure an employee into returning to work too soon before they are well.

If the employee is absent from work because of a disability-related sickness, this should be recorded separately from other sickness absences, such as having a cold. This is to

make sure that the employee is not discriminated against if decisions about promotion or bonuses, for instance, take sickness absence into account.

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## **Return to work after sickness absence**

If the employee is absent for more than a week, they will need to obtain a ['fit note'](#) ('statement of fitness for work') from their doctor. The doctor can suggest any additional support or adjustments the employee would benefit from, such as a phased return to work.

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 may need a phased return if they have been off work for a considerable period and do not feel able to work a full day at first. For example, they may wish to start by working fewer hours and gradually building up to their usual working pattern. To begin with, having a reduced workload might also be helpful.

If the employee has to remain away from work until reasonable adjustments are in place to enable them to return to work (for example, moving their workstation closer to a toilet), this should not be recorded as 'sick leave', and they should receive full pay.

## **Ongoing support and regular reviews**

It is helpful to have regular reviews with your employee. Their situation may change, and they may wish to vary any adjustments to make it easier to continue working.

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## **What to do if an employee feels that they have been treated unfairly or discriminated against**

Employees may feel that they have been discriminated against if they have received an unfavourable appraisal or performance review. An example is if they have not met targets due to sick leave or tiredness caused by Crohn's or Colitis. They might also feel unhappy if there has been a disagreement about 'reasonable' adjustments to their work. Being bullied can also be an issue for people with Crohn's or Colitis.



Most employees would prefer not to take formal action. Often, talking things through resolves any issues. You should, however, make sure your employees are aware of your grievance procedures. Ideally, they will discuss any problems with their line manager, HR team or union representative (if available). Alternatively, 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 or make a claim to an employment tribunal. [Acas](#) can provide help relating to preventing or resolving disputes.

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## **What happens if the employee is finding it difficult to continue working?**

There may be rare occasions when you have made reasonable adjustments, but the employee feels that their condition makes it difficult to continue their job or an alternative job. In these circumstances, you may feel that you have no alternative but to consider ending their employment. Dismissal should be a last resort after you've tried other ways to support the employee and help them get back to work. Certain procedures have to be followed before taking this step. You must ensure you have made all reasonable adjustments with the employee. For example, you will need to consult with the employee, obtain medical evidence and consider whether alternative employment or training has been offered.

[Acas](#) can provide advice about ending employment.

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## **Other organisations**

**Acas (Advisory, Conciliation and Arbitration Service)** (Free, impartial, confidential advice about any kind of dispute or query about issues at work.)

Telephone: **0300 123 1100**

Website: [www.acas.org.uk](http://www.acas.org.uk).

**Business Disability Forum** (Provides a framework for employers to develop best practices in the employment of disabled people.)

Telephone: 020 7403 3020

Website: [businessdisabilityforum.org.uk](https://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. Its purpose is to progress and promote good practice in these areas.)

Telephone: 020 8612 6200

Website: [www.cipd.co.uk](https://www.cipd.co.uk)

### **Citizens Advice**

Citizens Advice deliver advice services from over 2,900 community locations in England and Wales. You can find details of your nearest office at: [www.citizensadvice.org.uk](https://www.citizensadvice.org.uk).

There is also specific information on the website for people living in Scotland, Wales or Northern Ireland.

**Equality Advisory Support Service (EASS)** (Offers information, advice and support on discrimination in the workplace.)

Telephone: 0808 800 0082

Website: [www.equalityadvisoryservice.com](https://www.equalityadvisoryservice.com)

**Equality and Human Rights Commission (EHRC)** (Provides information on the main areas in which discrimination in employment can arise, who it applies to, and what employers can do to prevent it.)

Website: [www.equalityhumanrights.com](https://www.equalityhumanrights.com)

**GOV.UK** (The UK Government website covers a range of issues, including all aspects of employment and disability.)

Website: [www.gov.uk](https://www.gov.uk)

## Help and support from Crohn's & Colitis UK

We're here for you whenever you need us. Our award-winning information on Crohn's Disease, Ulcerative Colitis, and other forms of Inflammatory Bowel Disease have the information you need to help you manage your condition.

We have information on a wide range of topics, from individual medicines to coping with symptoms and concerns about relationships and employment. We'll help you find answers, access support and take control.

All our information is available on our website: [crohnsandcolitis.org.uk/information](https://crohnsandcolitis.org.uk/information).

Our Helpline is a confidential service providing information and support to anyone affected by Crohn's or Colitis.

Our team can:

- Help you understand more about Crohn's and Colitis, diagnosis, and treatment options.
- Provide information to help you live well with your condition.
- Help you understand and access disability benefits.
- Be there to listen if you need someone to talk to.
- Help you to find support from others living with the condition.

Call us on **0300 222 5700** or email [helpline@crohnsandcolitis.org.uk](mailto:helpline@crohnsandcolitis.org.uk).

See our website for LiveChat: [crohnsandcolitis.org.uk/livechat](https://crohnsandcolitis.org.uk/livechat).

### Crohn's & Colitis UK Forum

This closed-group community on Facebook is for everyone affected by Crohn's or Colitis.

You can share your experiences and receive support from others at:

[facebook.com/groups/CCUKforum](https://facebook.com/groups/CCUKforum).

### Help with toilet access when out

Members of Crohn's & Colitis UK get benefits including a Can't Wait Card and a RADAR key to unlock accessible toilets. This card shows that you have a medical condition, and

will help when you need urgent access to the toilet when you are out. See [crohnsandcolitis.org.uk/membership](https://crohnsandcolitis.org.uk/membership) for more information, or call the Membership Team on 01727 734465.

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## About Crohn's & Colitis UK

We are Crohn's & Colitis UK, a national charity fighting for improved lives today – and a world free from Crohn's and Colitis tomorrow. To improve diagnosis and treatment, and to fund research into a cure; to raise awareness and to give people hope, comfort and confidence to live freer, fuller lives. We're here for everyone affected by Crohn's and Colitis.

This information is available for free thanks to the generosity of our supporters and members. Find out how you can join the fight against Crohn's and Colitis: call 01727 734465 or visit [crohnsandcolitis.org.uk](https://crohnsandcolitis.org.uk).

## About our information

Crohn's & Colitis UK information is research-based and produced with patients, medical advisers and other professionals. It is prepared as general information and is not intended to replace advice from your own doctor or other professional. We do not endorse any products mentioned.

We hope that you've found this information helpful. You can email the Knowledge and Information Team at [evidence@crohnsandcolitis.org.uk](mailto:evidence@crohnsandcolitis.org.uk) if:

- You have any comments or suggestions for improvements.
- You would like more information about the research on which the information is based.
- 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 contact us through the **Helpline: 0300 222 5700**.

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