



INFORMATION SHEET

EMPLOYMENT AND IBD: A GUIDE FOR EMPLOYERS

INTRODUCTION

Ulcerative Colitis and Crohn's Disease are similar illnesses and are often referred to together as Inflammatory Bowel Disease (IBD). They cause inflammation, swelling and ulceration in the digestive system. These conditions are life-long and may flare up unpredictably. However, many people with IBD will have long periods when they have few or no symptoms at all.

IBD affects at least one in 210 people in the UK. The majority of people with IBD are of working age when they are diagnosed. This means that they are likely to be concerned about their job and their employment prospects. However, many people with Crohn's Disease or Ulcerative Colitis want to and are able to work successfully and fulfil their potential. Several studies have shown that people with IBD give high priority to maintaining their attendance and performance at work.

This information sheet is intended to help employers and managers understand what it means to have IBD. It also considers the legislation relevant for managing people with such long-term health conditions.

This information sheet also covers the Equality Act 2010 which applies to England, Wales and Scotland. The Act does not apply to Northern Ireland. If you live in Northern Ireland, you may wish to visit [nidirect](http://nidirect.gov.uk) for further information on employment rights: www.nidirect.gov.uk



IBD shouldn't be considered to be any more of a bar to a mutually successful employment relationship than other (perhaps more prevalent and well-known) inflammatory conditions such as eczema or asthma which can flare-up or go into remission...

Not many of us pass through our working lives without some sort of illness or trauma; IBD is just one of the lesser known ones.



Jean, employer, age 56
diagnosed with Crohn's Disease in 1979

WHAT ARE THE SYMPTOMS OF IBD?

The common symptoms are:

- diarrhoea (sometimes with blood)
- urgent and/or frequent need to go to the toilet
- abdominal pain
- tiredness
- nausea
- lack of appetite and weight loss

Some people with IBD may also suffer from painful joints, eye problems, mouth ulcers, and skin rashes.

WHAT IBD IS NOT...

- IBD is not the same as the Irritable Bowel Syndrome (IBS). This is a different condition that requires different treatment.
- IBD is not infectious.

WHAT CAUSES IBD?

The cause or causes are not yet known. Most researchers believe IBD may be caused by an abnormal reaction of the immune system to intestinal bacteria, combined with genetic factors and environmental triggers. There is no cure at present.

WHAT CAN BE THE EFFECTS OF TREATMENT?

IBD generally requires life-long treatment and this can include taking medication, which may have unpleasant side effects. Treatment is designed to control the symptoms of IBD when it is active, reduce the chance of relapses and maintain good health.

Treatment can include corticosteroids (steroids) to reduce inflammation. Unwanted side effects of these drugs, can be:

- significant weight gain
- roundness of the face
- acne
- mood swings, from euphoria to depression

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

Other drugs used in IBD include immunosuppressant drugs which affect the way the body's immune system works. This means that a person taking such medication may be more susceptible to infections and at greater risk of getting colds and flu. Side effects of immunosuppressants can include headaches and nausea.

Biologics, the newest group of drugs used in IBD, are used to treat severe active disease. These drugs may be administered by infusion in a hospital or day clinic or given at home by injection.

Some people take dietary treatment. This takes the form of a liquid diet consisting of all the nutrients needed. Usually, nothing other than the diet and water are allowed for weeks or months at a time. The high concentration of nutrients in the feed sometimes causes nausea, headaches, and a feeling of light-headedness.

Sometimes surgery is needed to treat the symptoms of IBD.

DOES IBD AFFECT THE EMPLOYEE'S ABILITY TO DO THEIR JOB?

This is broadly dependent on the individual with IBD – their condition and the type of job they have.

In a survey we carried out into IBD and employment, it was found that people with IBD who were feeling well had a total work productivity score better than that of the general healthy population. More than half of the respondents reported giving more effort at work to make up for any shortcomings which might result from their IBD. Other research since the survey has shown that people with IBD want to work, and in many cases have the health to work, however a range of factors can cause barriers to managing their IBD at work.

Key factors that helped overcome barriers at work included: accessible toilet facilities, flexibility in working arrangements, a knowledgeable and supportive social environment at work, and team working. These factors are, of course, not

specific to IBD, but are considered management best practice and contribute to attracting and retaining committed workers.

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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 IBD.

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

Sarah, employee, age 30
diagnosed with Crohn's Disease in 2008

HOW CAN EMPLOYERS HELP?

The first step is to provide a supportive environment in which someone with IBD feels able to disclose their condition to you.

In a survey carried out by the Irish Society of Colitis and Crohn's Disease (ISCC) about living with IBD, it was found that over a quarter of employees felt uncomfortable talking about their condition with their employer and co-workers. It is not uncommon for people to feel embarrassed talking about their bowel movements and they can find it difficult to explain their symptoms, especially urgency and the frequent need to rush to the toilet. However, in the survey we carried out, it was found that eight out of 10 employees had told their employer or HR department about their IBD, and nearly as many had told their co-workers. As well as providing a supportive environment, it may also be reassuring for employees to be made aware of employment policy on chronic illnesses.

It was also found in our Employment Survey that many people with IBD worry that their colleagues think that they do not pull their weight at work because of their symptoms. A quarter of respondents said that they are also concerned about being discriminated against in the workplace and one third fear losing their jobs as a result of having IBD.

IBD is associated with higher levels of anxiety and depression, often due to the nature of symptoms. Around eight in 10 people with IBD reported that their IBD affects their confidence and self-esteem. Another study into IBD and employment in 2015 indicated that when there was a good employment relationship with the line manager, employees said that they had a positive experience in the workplace, despite having to manage their IBD. This positive working relationship included understanding how IBD affected the individual, providing the individual with support, and implementing reasonable adjustments when necessary.

An employee disclosing their condition can help to develop a positive employment relationship and open communication. It may be a relief for an employee to talk to you about their IBD because it can be a strain for them to hide their symptoms.

Once you are aware of an employee's needs you can work together to make reasonable adjustments to support them. If you work within a larger organisation, you may wish to consult with your HR and/or Occupational Health team. Otherwise you may want to refer to the Equality and Human Rights Commission website (see **Other Organisations**).

It is important too that two-way trust is developed and employees are assured of respect and confidentiality, especially around, for example, whether and how much they wish others to know about their IBD.

WHAT ARE THE NEEDS OF PEOPLE WITH IBD LIKELY TO BE?

Each person is unique and their needs are very different.

Helpful adjustments may include:

- **Accessible and adequate toilet facilities**

One of the main fears for many people with IBD is having an 'accident'.

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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. ”

Sarah, employee, age 30
diagnosed with Crohn’s Disease in 2008

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 therefore extremely important. The survey carried out by the ISCC showed that nearly six in 10 people with IBD consider the availability of toilets when making plans to attend meetings or events.

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

Many workplace toilets lack sufficient ventilation and have cubicles with spaces below and above partitions, which do not offer sufficient 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 helpful option.

• **Frequent toilet breaks**

Many people with IBD also feel embarrassed about the need for frequent toilet breaks and worry about the consequences if they are not able to go whenever they need to. Those in jobs with fixed breaks may need support from co-workers to offer cover. Allowing additional toilet breaks and establishing cover arrangements can be very helpful.

• **Flexible working hours**

Flexible working hours, particularly a later start, can help the employee if their bowels are more active in the morning, as is often the case. There may also be times during flare-ups of their illness when shorter working hours or, where possible, working from home would be useful.

Additional meal or snack breaks can be of use as many people with IBD have difficulty eating a normal size meal so they may need to eat small amounts more often. Breaks may also be helpful if the individual has to take prescribed medication at certain times of day.

• **Travel**

Travel is a key issue for many people with IBD. Due to frequency and urgency, they may find it difficult to take public transport and prefer to drive to work or to meetings. Allowances for car travel and the provision of a parking space close to the place of work would help in these cases. While many employers provide disabled parking spaces, people with IBD usually do not meet the current criteria for Disabled Permit holders so cannot use them. It is therefore important that they are offered alternative provision.

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IS IBD COVERED BY THE EQUALITY ACT 2010?

Supportive and flexible management will enable most people with IBD to continue to work productively, and most are very highly motivated to do so. However, employers should be aware that there are also legal considerations which may apply to people living with IBD, 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 which has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities.

Not everyone with IBD may consider themselves to have a disability. But in practice, whether or not they perceive themselves to be ‘disabled’, people with UC or Crohn’s Disease may well qualify for protection against discrimination.

The fact that the effects of IBD may be sporadic (where, for example, an employee has bad days and better days as their condition fluctuates) does not prevent the condition being considered ‘long-term’. In addition, ‘hidden’ effects like pain, fatigue and incontinence (such as loss of bowel control) are taken into account



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 have been rewarded with their loyalty and hard work. Small changes can really help to achieve a give-and-take employment relationship. ”

Jean, employer, age 56
diagnosed with Crohn’s Disease in 1979

when considering whether the condition 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 the employee may still be covered by the Equality Act even if their 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, to be better informed about their condition and whether it is likely to have any effects on them at work.

If the Equality Act applies to an employee, you have a duty to make reasonable adjustments to any physical feature(s) of your premises or working arrangements that places the employee at a substantial disadvantage compared to a non-disabled person. A ‘substantial disadvantage’ might mean, for example, that they would take much longer to do the same job than someone without a disability. Even if you are unsure about whether the employee’s condition amounts to a disability, it may still be a good idea to make reasonable adjustments in order to maintain the employee’s productivity. Different employees will require different adjustments. It is likely to be helpful to consult the employee about what adjustments might assist them, as they may be best placed to make suggestions.

Discrimination may be said to occur where:

- 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 victimised having made (or intimated that they wish to make) a complaint about non-compliance with the legislation.

The Equality Act applies to all places of employment, whatever their size, except the armed forces. People can be discriminated against in many aspects of employment such as recruitment, selection, pay, training, promotion, dismissal and redundancy.

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 those who are:

- working on a casual basis
- on zero hours contracts
- trainees, or
- in some situations, self-employed.

For more information about the Equality Act, see Citizens Advice and GOV.uk in **Other Organisations**. For advice and help in resolving disputes, you can contact the Advisory, Conciliation and Arbitration Service - Acas (see further details in **Other Organisations**).

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DECIDING ON REASONABLE ADJUSTMENTS

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 you would otherwise experience
- its practicality
- the cost
- their organisation’s resources and size
- the availability of financial support.

More information on the duty to make reasonable adjustments can be found on the EHRC website (see **Other Organisations**).

EXAMPLES OF REASONABLE ADJUSTMENTS FOR PEOPLE WITH IBD

Many adjustments needed by people with IBD are often inexpensive or may not cost anything at all, and/or cause little disruption.

They may include:

- allowing time off for medical appointments or treatment,
- offering shorter, different or flexible working hours,
- unlimited toilet breaks,
- moving the work station close to a toilet,
- providing a car parking space close to the entrance into 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 take into account the effect of sick leave or fatigue.

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

WHAT IS ACCESS TO WORK?

Access to Work is a publicly funded employment support programme to which 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.

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. For further information, go to: **www.gov.uk**.

WHAT TO DO IF AN EMPLOYEE FEELS THAT THEY HAVE BEEN UNFAIRLY TREATED OR DISCRIMINATED AGAINST

An employee might complain if they have received an unfavourable appraisal or performance review when, for example, they have not been able to meet targets due to sick leave or tiredness caused by their IBD. 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 IBD.

Most employees would prefer not to take formal action. Often, the opportunity to talk things through resolves any issues. You should, however, make sure your employees are aware of your grievance procedures. Ideally, they should feel able to discuss any problems with their line manager, HR/Personnel or union representative (if available). Alternatively, there might be another person who can mediate in the event of disagreements. In all such cases, it is good practice to keep detailed records of meetings.

Acas (Advisory, Conciliation and Arbitration Service) can provide help on matters relating to preventing or resolving disputes.

See **Other Organisations** below for further information on Acas.

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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 have 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.

”

Carl, employee, age 35
diagnosed with Crohn's Disease in 2015

MANAGING SICKNESS ABSENCE

There may be times when some people with IBD are off work for longer periods. This may be due to a severe flare-up or occasionally due to surgery for their IBD. It is common for people to lose confidence about being able to return to work, and keeping in touch with an employee can help avoid this.

It may be helpful to set up an agreed procedure about how you and your employee could maintain 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, which could make 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. If in person is considered the best option, and if the employee is too unwell to attend a meeting on company premises, an Employee Wellbeing Meeting might be arranged at either the employee's home or at an alternative venue. This meeting is to maintain contact. It is also to provide support, with the aim of achieving a successful return to work that is appropriate for both employer and employee. All Employee Wellbeing Meetings must be agreed with the employee. 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.

RETURN TO WORK AFTER SICKNESS ABSENCE

In England or Wales, if your employee has been off sick from work for four weeks or more, you can refer them for a voluntary occupational health assessment. GPs can also refer employees for this assessment. This is a government funded initiative called Fit for Work. It is designed to support people in work with health conditions and help with sickness absence. For more information, visit: fitforwork.org

If you live in Scotland or Northern Ireland, the rules may be different. For Scotland, visit: fitforworkscotland.scot

For Northern Ireland, visit nidirect: www.nidirect.gov.uk

Employees should be involved in planning their return to work. This gives them the opportunity 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. Having a reduced workload to begin with might also be helpful.

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

ONGOING SUPPORT AND REGULAR REVIEWS

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

WHAT HAPPENS IF SUFFICIENT REASONABLE ADJUSTMENTS CANNOT BE MADE?

There may be some rare occasions when you have made reasonable adjustments, but your employee feels that their condition makes it difficult to continue their job or an alternative job. In these circumstances you may have no alternative but to consider terminating their employment on grounds of incapability. There are certain procedures you need to follow before taking this step and you will need to 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 (see below) can provide advice about ending an employment.

HELP AND SUPPORT FROM CROHN'S AND COLITIS UK

We produce over 40 information sheets, booklet and guides about all aspects of IBD which are available to download for free on our website:

www.crohnsandcolitis.org.uk

We run a confidential helpline which is staffed by a team of trained Information Officers providing information and support to anyone affected by Inflammatory Bowel Disease.

Our team can:

- help you understand more about IBD, diagnosis and treatment options
- provide information to help you to live well with your condition
- help you understand and access disability benefits
- be there to listen if you need someone to talk to
- put you in touch with a trained support volunteer who has personal experience of IBD

Call us on **0300 222 5700** or email **info@crohnsandcolitis.org.uk**

See our website for WebChat (Live Online): **www.crohnsandcolitis.org.uk**

OTHER ORGANISATIONS

ACAS (Advisory, Conciliation and Arbitration Service)

Offers free, confidential and independent advice on all employment rights issues, and works with employers and employees to solve problems.

Helpline: 0300 123 1100

Website: **www.acas.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.

151 The Broadway, London SW19 1JQ

020 8612 6200

Website: www.cipd.co.uk

GOV.uk

Informative UK Government website covering a range of issues including all aspects of employment and disability:

Website: www.gov.uk

Business Disability Forum

Provides framework for employers for developing best practice in the employment of disabled people.

Nutmeg House, 60 Gainsford Street

London SE1 2NY

020 7403 3020

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

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

Equality Advisory Support Service (EASS)

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

Freepost Equality Advisory Support Service FPN4431

Telephone: 0808 800 0082

Website: www.equalityadvisoryservice.com

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We hope that you have found this leaflet helpful and relevant. If you would like more information about the sources of evidence on which it is based, or details of any conflicts of interest, or if you have any comments or suggestions for improvements, please email the Publications Team at publications@crohnsandcolitis.org.uk. You can also write to us at Crohn's and Colitis UK, 45 Grosvenor Road, St Albans, AL1 3AW or contact us through the **Information Line: 0300 222 5700**.

ABOUT CROHN'S & COLITIS UK

We are a **national** charity established in 1979. Our aim is to improve life for anyone affected by Inflammatory Bowel Diseases. We have over 33,000 members and 50 Local Networks throughout the UK. Membership costs start from £15 per year with concessionary rates for anyone experiencing financial hardship or on a low income.

This publication is available free of charge, but we would not be able to do this without our supporters or members. Please consider making a donation or becoming a member of Crohn's and Colitis UK. To find out how call **01727 734465** or visit www.crohnsandcolitis.org.uk

