



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 intestines. 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.

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.

Some of the quotations included in this guide are taken from a survey which we conducted in 2011 on IBD and employment. Others are responses provided by employers and people with IBD during the review process of this information sheet. (For more details on our survey, see **Our Survey**).



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
- severe abdominal pain
- extreme 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 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 our Employment Survey, 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.

Key factors that helped their success included: adequate accessible toilet facilities, flexibility in their working arrangements, a knowledgeable and supportive social environment at work, and team working. These factors are, of course, not only specific to IBD, but are also considered best practice management and good ways to attract and retain 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

“

I was treated badly in one of my first jobs because they didn’t understand what my IBD was or my condition. That experience, so early in my career, has made me determined to be the best I can be at my work.

Now I am in another job – my employer has told me that my hard work has not gone unnoticed and I am indispensable to the organisation! ”

—
Linda, employee, age 56
 diagnosed with Crohn’s Disease in 1979

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. It may also be helpful to make all employees aware of your fair employment policy on illness which covers chronic conditions.

In our Employment Survey, 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. However, although most of these employees said that they felt comfortable about discussing their condition, 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.

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.

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 at this stage. Otherwise you may want to refer to the Equality and Human Rights Commission website (see **Other Organisations**).

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

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

Each person is unique and their needs are very different. It cannot be ‘one size fits all’.

Helpful adjustments may include:

- **Accessible and adequate toilet facilities**
 One of the main fears for many people with IBD is 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 therefore extremely important.

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.

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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

• **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 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 could obtain a report from their doctor, either their specialist or GP, to become 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 are under 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 would probably be helpful to consult with the employee about what adjustments they consider would assist them, as they are best placed to make suggestions.

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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

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 employers, whatever their size, except the armed forces. People can be discriminated against in many aspects of employment such as recruitment, selection, training, promotion, dismissal, redundancy and retirement.

For more information about the Equality Act contact the Equality and Human Rights Commission (EHRC). For advice and help in resolving disputes, you can contact the Advisory, Conciliation and Arbitration Service - ACAS (see **Other Organisations**).

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DECIDING ON REASONABLE ADJUSTMENTS

The sort of adjustments which may be considered reasonable will depend on the individual situation. Any assessment, for example by an Employment Tribunal, will look at the facts of each case, while being sensitive to the particular circumstances.

Areas that would be considered could include:

- the effectiveness of the step in lessening the disadvantage,
- the practicability of taking the step,
- the financial and other costs which would be incurred by the employer
- the financial and other resources available to the employer,
- the availability of external financial or other assistance (for example assistance from the Access to Work scheme run by Jobcentre Plus),
- the nature of the employer’s activities and the size of the undertaking,
- the extent to which the step would disrupt any of the organisation’s activities.

More information on the duty to make reasonable adjustments can be found on the EHRC website.

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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 government funded scheme 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. The scheme will also pay all the extra costs of travel to and from work for an employee who is unable to use public transport.

Access to Work is available for individuals on permanent or on temporary contracts and whether they 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. As mentioned previously, bullying 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 liaise in the event of disagreements.

In all such cases, it is always good practice to keep detailed records of meetings. The Advisory, Conciliation and Arbitration Service (ACAS) can help with matters relating to preventing or resolving disputes. See **Other Organisations** below for further information.

MANAGING SICKNESS ABSENCE

There may be times when some people with IBD are off work for longer than average. 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, even after a relatively short time away on sick leave, and keeping in touch with an employee can help with 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. 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

The sickness absence system in Great Britain was reviewed in 2011 as part of a government strategy to examine the broader health and wellbeing of the population. One of the key recommendations to come out of the review was a new 'Health and Work Assessment and Advisory Service'.

Further details about this service can be found on www.gov.uk.

Employees should always 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 want to start by working fewer hours and gradually building up to their usual working pattern. Having a reduced work load to begin with could 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. 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 next page) can provide advice about ending an employment.

HELP AND SUPPORT FROM CROHN'S AND COLITIS UK

All our information sheets and booklets are available to download from our website: www.crohnsandcolitis.org.uk. If you would like a printed copy, please contact our information line – details below.

Crohn's and Colitis UK Information Line: 0300 222 5700. Open Monday to Friday, 9 am to 5 pm, except Thursday open 9 am to 1 pm, and excluding English bank holidays. An answer phone and call back service operates outside these hours. You can also contact the service by email info@crohnsandcolitis.org.uk or letter (addressed to our St Albans office). Trained Information Officers provide callers with clear and balanced information on a wide range of issues relating to IBD.

Crohn's and Colitis Support: 0121 7379 931: Open Monday to Friday, 1 pm to 3.30 pm and 6.30 pm to 9 pm, excluding English bank holidays. This is a confidential, supportive listening service, which is provided by trained volunteers and available to anyone affected by IBD. These volunteers are skilled in providing emotional support to anyone who needs a safe place to talk about living with IBD. Open Monday to Friday, 10 am to 1 pm, excluding English bank holidays. An answer phone and call back service operates outside these hours. You can also contact the service by email info@crohnsandcolitis.org.uk or letter (addressed to our St Albans office). Trained Information Officers provide callers with clear and balanced information on a wide range of issues relating to IBD.

OUR SURVEY

The results from the 2011 Crohn's and Colitis UK survey have been published in a report entitled **Crohn's, Colitis and Employment – From Career Aspirations to Reality**. Another more recent report examining the same data in further detail is called **Inflammatory Bowel Disease in Young People – The Impact on Education and Employment**. Both can be found on the Crohn's and Colitis UK website: www.crohnsandcolitis.org.uk

OTHER ORGANISATIONS

Advisory, Conciliation and Arbitration Service (ACAS)

Offers free, confidential and independent advice on all employment rights issues, and works with employers and employees to solve problems.
Helpline: 0300 123 1100 (Mon-Fri 8am-8pm, Sat 9am-1pm).
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

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

0808 800 0082. (Mon-Fri 9am-8pm, Sat 10am-2pm)

Website: www.equalityadvisoryservice.com



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Employment and IBD: a guide for employers Edition 3

Last review: February 2014

Charity contact details updated: May 2016

Next planned review: 2016



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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 28,000 members and 50 Local groups 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

