

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 or improve unpredictably. Many people with IBD will have long periods when they have few or no symptoms at all.

IBD affects 1 person in every 250 in the UK population. 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.

This information sheet is intended to help employers and managers understand what it means to have IBD, and how it can be possible, sometimes with minimal changes, for people with Ulcerative Colitis or Crohn's Disease to work successfully and to fulfil their potential. It also considers the legislation that is relevant for managing people with such long-term health conditions.

All the quotations reported here are from respondents to the 2011 Crohn's and Colitis UK survey IBD and Employment.

What are the symptoms of IBD?

The common symptoms are:

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

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

What it is not...

- IBD is **not** the same as the more common Irritable Bowel Syndrome (IBS).
- It is **not** contagious.

"I think they need to understand the unpredictability of it as well. I was asked a lot of questions at interview like, how often do you flare-up? How long do they last? How does it affect you? I just have to say I can't tell you because I don't know..."

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, which may have unpleasant side effects. Treatment can include corticosteroids to reduce inflammation. Unwanted side effects of this drug, especially at high initial doses, are often:

- 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 often used in treatment 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.

Other unwanted side effects from various drugs used for treatment may include:

- headaches
- nausea
- flu-like symptoms

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

Does IBD affect the employee's ability to do their job?

Although their IBD may flare up from time to time, several studies have shown that people with IBD give high priority to maintaining their attendance and performance at work.

Four out of five respondents to the 2011 Crohn's and Colitis UK survey reported sometimes going to work even if they did not feel well enough. More than half reported giving more effort at work to make up for any shortcomings that resulted from their IBD. People who were feeling fine in their current health had a total work productivity score that was better than the general healthy population.

"I feel that as a result of my illness I work harder and generally take fewer sick days than those around me who are of average or good health."

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.

The ability to take time off for doctor or hospital appointments separate from their holiday allowance was important to four out of five respondents to the Crohn's and Colitis UK survey, while three out of five rated flexible working hours as important, and more than one third placed importance on the ability to work from home.

How can employers provide a supportive work environment for people with IBD?

The 2011 Crohn's and Colitis UK survey found that 81% of employees had told their employer or HR department about their IBD, and 77% had told their co-workers. Although most 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.

"I think it is important to explain to your employer about your condition. Being open and up- front has helped in my case, and if they are good employers they will understand."

"I feel that there is a lack of awareness around IBD, and it's challenging talking about the issues which would be private for most people without the condition".

Two in five respondents to the survey said that they worry about their colleagues thinking that they do not pull their weight at work because of their IBD symptoms. A quarter said that they worry about being discriminated in the workplace and one third fear losing their jobs as a result of having IBD.

"I always feel I have more to prove and therefore push myself too hard, leaving me exhausted when I get home. All energy goes to completing a full day and then I crash when I get home."

Hiding symptoms can be a strain on employees, who may find it a relief to talk to you about their IBD. As an employer, once you are aware of an employee's needs you can consider reasonable adjustments to support them. The first step to encourage someone with IBD to disclose their condition is to provide a fair employment policy on illness which covers chronic conditions and to make this known to all employees. It is important too that employees are assured of confidentiality and respect.

Each person is unique and needs may differ from one person to another. It is important to respect the individual's wishes, for example with regards to privacy or general disclosure.

The particular needs of people with IBD are likely to 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 is a 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. Access to a disabled toilet may be an option.

"Employers do not realise how embarrassing IBD can be. Often, going to the loo may be very noisy. I worry that work colleagues may laugh behind my back".

"Employer information from Crohn's and Colitis UK helped me to keep a toilet close to the area I work in and helped my employer understand about my condition."

- **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 then need support from co-workers to offer cover. For example, those working in prisons, schools, or shops.

"I now work in a shop where everybody knows I have IBD and they go out of their way to make it easy for me if I need to leave suddenly to go to the toilet."

- **Flexible working hours**

Flexible working hours, particularly a later start, can help the employee to cope better with their life and in effect may mean they feel less tired. There may also be times during flare-ups of their illness when shorter working hours or, where possible, working from home would be helpful.

"My employer has been good as I work extra hours sometimes to have at least two to three days of 'in lieu' time in case I need to be off, so they have been reasonably flexible."

"Working from home is a god-send and I can manage to work through some flare-ups by taking this option. I am lucky because my hours are very flexible anyway."

Flexible working hours can also help employees with food related needs. Many people with IBD have difficulty eating a normal size meal. This may be because they feel full when very little food has been eaten, or because of pain or needing to go to the toilet during the meal. This means that the employee may need to eat small amounts regularly, and it can really help to be able to take short food breaks whenever necessary.

"I am lucky in that I can plan the day the way I want to plan it. I'm supposed to start at 8am, but it's rare that I do - but I always make it up at the end of the day. They are quite flexible with that. I can also move stuff to the middle of the day if I don't feel up to it in the morning."

An urgent need to use the toilet after meals can also mean that people with IBD need flexible working hours to avoid being late in the morning or after lunch.

- **Travel allowances**

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 and cannot use them. It is therefore important that they are offered alternative provision.

"I work in a hospital with lots of toilet facilities. However, it is the getting to and from work, particularly in the mornings, which proves most difficult."

"Travelling to and from work would be impossible without the use of a car. I wouldn't feel confident enough on public transport, or having to walk long distances, as I am constantly aware that I have to be close to a toilet."

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, it is important to be aware that there are also legal considerations which may apply to people living with IBD, as with any other long-term health condition.

When asked whether or not they consider themselves to have a disability, 51% of respondents to the 2011 Crohn's and Colitis UK survey answered yes.

Although some may not consider themselves to be 'disabled', people with UC or Crohn's disease may well qualify for protection against discrimination.

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.

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.

Also, the fact that an employee's symptoms are controlled by medication does not prevent them from being covered by the Equality Act. If the treatment simply delays or prevents a recurrence, and a recurrence would be likely if the treatment stopped, as is the case with most medication, then the treatment is to be ignored.

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 be wise to consult with the employee with regard to what adjustments they consider would assist them, as they are best placed to make suggestions.

Discrimination occurs 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, or have made, 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, redundancy and dismissal. If an employee successfully wins a case of discrimination, it can be very costly for an employer. So, it is better to try to avoid any issues escalating to this degree by seeking to resolve them internally at an early stage. For more information about the Equality Act contact the Equality and Human Rights Commission. For advice and help in resolving disputes, you can contact the Advisory, Conciliation and

Arbitration Service - ACAS (see *Other Organisations*).

What are reasonable adjustments?

Four out of five respondents to the 2011 Crohn's and Colitis UK survey said that the ability to take time off for doctor or hospital appointments, separate from holiday allowance, was important to them. Nearly three out of five rated flexible working hours as important and more than one third placed importance on the ability to work from home.

Whether or not there is a duty to make a particular adjustment will depend on whether the adjustment is 'reasonable'. Any assessment will look at the facts of each case, while being sensitive to the particular circumstances.

In determining whether the adjustment is reasonable, an Employment Tribunal will take into account the following:

- 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. (It would be reasonable for an employer to spend at least as much on an adjustment to enable the retention of a disabled person, including any training, as might be spent on recruiting and training a replacement.),
- 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.

Many adjustments needed by people with IBD, however, are 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 both part-time and full-time workers. For further information, go to www.direct.gov.uk.

What to do if an employee feels 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. Bullying can also be an issue for people with IBD. For example, colleagues might make comments or jokes about their frequent trips to the loo and may not

understand that their tiredness is due to illness.

Most employees would prefer not to take formal action. Submitting a formal grievance and pursuing a claim in the Employment Tribunal can be stressful experiences. 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.

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 for how you and your employee will 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 could 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

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 to work if they have been off work for a considerable period, as they may not be able to work a full day at first. For example, they may want to start by working a few hours and gradually increasing them.

“My employer is very supportive and gave me full pay when I returned to work, and asked me to return on a phased basis for the good of my health e.g. two hours a day first week back, three hours a day the second week etc., until back up to seven hours a day.”

Having a comparably 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.

When work is no longer suitable

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. You should not take this step however before you have obtained medical evidence, consulted with the employee, considered whether alternative employment can be offered, and warned the employee that you are considering terminating their employment. You could contact ACAS (see below) for advice about the right procedures to follow when ending an employment.

Further help

Crohn's and Colitis UK has a range of information sheets and booklets on various aspects of IBD, including an information sheet for employees. You can call our Information Line for a copy or a list of publications, or download them from our website: www.crohnsandcolitis.org.uk

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. This report can be found on the Crohn's and Colitis UK website.

The Crohn's and Colitis UK Information Line: 0845 130 2233, is open Mondays-Fridays 10am – 1pm (excluding Bank Holidays). There is an answerphone service outside these hours.

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: 08457 474747. (Mon-Fri 8am-8pm, Saturday 9am-1pm).
Website: www.acas.org.uk

Chartered Institute of Personnel and Development (CIPD)

The professional body for those involved in the management and development of

people. Its purpose is to lead in the development and promotion of good practice in the management and development of people.

151 The Broadway, London SW19 1JQ

☎ 020 8612 6200

Website: www.cipd.co.uk

Directgov

Informative UK government website covering a range of issues including all aspects of employment and disability:
www.directgov.uk

Employers' Forum on Disability

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: www.efd.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

EHRC Disability Helpline England:

Freepost RRLG-GHUX-CTR
Arndale House, Arndale Centre
Manchester M4 3EQ
☎ 0845 604 6610 weekdays 8am - 6pm
Email: englandhelpline@equalityhumanrights.com

EHRC Helpline Scotland:

Freepost RRLG-GYLB-UJTA,
The Optima Building
58 Robertson Street, Glasgow G2 8DU.
☎ 0845 604 5510 weekdays 8am – 6pm
Email: scotlandhelpline@equalityhumanrights.com

EHRC Helpline Wales:

Freepost RRLR-UEYB-UYZL

3rd Floor, 3 Callaghan Square

Cardiff CF10 5BT

☎ 0845 604 8810 weekdays 8am – 6pm

Email:

waleshelpline@equalityhumanrights.com**© NACC 2011**

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Crohn's and Colitis UK is the working name for the National Association for Colitis and Crohn's Disease (NACC). NACC is a voluntary Association, established in 1979, which has 30,000 members and 70 Groups throughout the United Kingdom.

Membership of the Association costs £12 a year. New members who are on lower incomes due to their health or employment circumstances may join at a lower rate. Additional donations to help our work are always welcomed.

Crohn's and Colitis UK publications are research based and produced in consultation with patients, medical advisers and other health or associated professionals. They are prepared as general information on a subject with suggestions on how to manage particular situations, but they are not intended to replace specific advice from your own doctor or any other professional. Crohn's and Colitis UK does not endorse or recommend any products mentioned.

We hope that you have found the information helpful and relevant. We welcome any comments from readers, or suggestions for improvements. References or details of the research on which this publication is based, and details of any conflicts of interest, can be obtained from Crohn's and Colitis UK at the address below. Please send your comments to Helen Terry at Crohn's and Colitis UK, 4 Beaumont House, Sutton Road, St Albans, Herts AL1 5HH or email h.terry@crohnsandcolitis.org.uk

