

Ulcerative Colitis and Crohn's Disease: 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. Their effects vary considerably from one person to another, but they 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 400 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. A recent study of working people with IBD by the Institute of Work, Health & Organisations at the University of Nottingham found that they are usually successful, generally do not want 'special' treatment at work, and that they appreciated employers who were understanding. The majority of participants felt that their condition had not substantially impacted on their ability to perform well at work.

This information sheet is intended to help employers and managers understand what it means to have this condition and how it is usually possible, sometimes with minimal changes, for people with IBD 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 people with IBD interviewed for the Nottingham study.

What are the symptoms?

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
- ◆ skin rashes

What it is not...

- ◆ It 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. Researchers believe IBD may be caused by an abnormal reaction of the immune system to intestinal bacteria, sometimes 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 can have unpleasant side effects. Treatment often includes 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.

As well as steroids, other immunosuppressant drugs often used in treatment affect the way the body's immune system works. This means that a person taking such medication may be 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

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
- ◆ 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 performance at work. Their attendance may, in fact, be better than that of many of their colleagues, as they are often keen to show that their illness does not adversely affect their work performance.

However, key factors that help their success include adequate accessible toilet facilities,

flexibility in their working arrangements, a knowledgeable and supportive social environment at work and team working. It is important to point out that these factors are not only specific to IBD: they are considered best practice management and attract and retain committed workers.

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

People with IBD often feel reluctant to tell their employer about their illness. They may fear discrimination, having their condition become public knowledge or even losing their job. It is common for people generally to feel embarrassed talking about their bowel movements and they are likely to find it difficult to explain their symptoms, especially urgency and the frequent need to rush to the toilet.

As an employer you can only respond to employees' needs when they are known. 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. It is important too that employees are assured of confidentiality and respect.

Remember that each person is unique and needs may differ from one person to another. It is important to respect the individual's wishes.

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 lavatory without delay. Having access to a lavatory 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.

Often workplace lavatories lack sufficient ventilation and have cubicles with spaces

below and above partitions, which do not offer sufficient privacy. Where possible it would help to have the use of separate, individual facilities. Offering the use of a disabled toilet may be an option.

“...the only thing I find really horrible is having to share toilets, you know, where it’s all open. It’s extremely embarrassing and if there was a cubicle which was extremely well ventilated that if someone went in 2 minutes later you wouldn’t get gassed...it really is an issue because you dread it, you dread going in to the toilet, you really do...”

◆ Frequent toilet breaks

Many 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.

“...there are times in the classroom yes...but there are always colleagues that I could say look I need to just go and sit on the loo would you sort this out for me and they’re fine.

◆ Flexible working hours

People with IBD generally need regular check-ups and may require regular tests and ongoing hospital treatment. They may be concerned about taking time out from work for medical appointments and would welcome the availability of flexible working hours.

Feeling exhausted is a common symptom for people with IBD. The Nottingham study found that one of the main concerns of those who experienced problems at work was the effect of tiredness and exhaustion. This affected their ability to arrive at work on time

in the morning and their performance, especially early in the day. The study has shown that those who actively cope with their condition, by reducing stress for example, are less exhausted and have a better quality of life. Flexible working hours, particularly a later start, can help the employee to cope better with their lives and in effect may mean they feel less tired. There may be times during flare-ups of their illness when shorter working hours or working from home, where possible, would be helpful.

“...if I’m going to be ill, it’s usually in the morning and it’s all over and done with by the time I go to work...”

“...it’s just though fear of not being able to get up in the morning to get to work, you know, and that’s playing on your mind because when the tiredness and exhaustion does hit you, it really does knock you off your feet...”

Flexible working hours may also help those who are affected by food. They may 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 lavatory during the meal. This means that the employee may need to eat small amounts regularly. It would help them to have the flexibility to take such 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 lavatory after meals means that people with IBD may also need more flexible working hours to avoid being late in the morning or after lunch.

◆ **Social support**

Having social support helps people to cope with their condition and to continue to work successfully. It might be helpful to talk to your employer about whether and how to tell colleagues of their situation. If other workers are aware of their illness and what it means, they are more likely to be supportive and to help, especially in team working.

“...consequently they will up and double their efforts and workloads to accommodate me for shortfalls. So, when I'm feeling ok I do more than my share and when I'm not ok I do less than my share.”

Some people with IBD may not wish their condition to be known and respecting their desire for privacy is essential. Others may wish someone else to speak on their behalf: a friend, a colleague, an occupational health worker, a trade union representative or a disability employment adviser, available through the local Jobcentre Plus office (see *Other organisations*).

◆ **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 have used rail and air but I prefer to be in control ... so I choose to drive ... I can stop and do what I need to do.”

“I'd often get to the bus stop and I'd have to return and go back home again. And then, even when I got off the bus in town and I'd got to then walk to the office, you know, frequently I'd have to just dart in somewhere to be able to get to work.”

“It makes me more conscious of the distances I am travelling ... I suppose the only thing I have done is made a conscious decision to travel on motorways because I know there are service stations where there are toilet facilities.”

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 legal considerations which may apply to people living with IBD or with any other long-term health condition. Although they may not consider themselves to be 'disabled', they may well qualify for protection against discrimination.

Is IBD covered by the Disability Discrimination Act (DDA)?

Under the DDA 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 good days and bad 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.

The fact that an employee's symptoms are controlled by medication, does not prevent that from being covered by the DDA. 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 DDA applies to an employee, you are under a duty to make reasonable adjustments to any physical feature(s) of your premises or working arrangement 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 doubt whether the 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 DDA.

If an employer dismisses an employee because of their disability, this will be direct discrimination.

The DDA 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; 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 DDA 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?

Whether or not there is a duty to make a particular adjustment will depend on whether the adjustment was one that was '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, however, the 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 extent to which the step would disrupt any of its activities;
- ◆ 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.

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 expensive, 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 which disabled people can apply for to help them overcome practical difficulties that may stop them from working. If your employee is eligible, the scheme can provide a grant of up to 80% of approved costs between £300 and £10,000. Grants may be up to 100% of the approved costs above £10,000. For people who are starting a job with you, the grant is up to 100% of the approved costs. The scheme will 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 part-time or full-time workers. For further information contact the Disability Employment Adviser at your local Jobcentre Plus office, who can put you in touch with the closest Access to Work Business Centre.

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 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.

It may be helpful to set up a standard procedure for how your employee will maintain contact with you whenever 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 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, it is important that this is 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 into account sickness absence.

I was so ill last year and then coming back to work, I was ill when I was back at work...I think I went back too quickly actually..."

“...they [occupational health] would have pulled together a structured time plan for me coming back to work...that for me would have been absolutely brilliant and because they are saying these are the rules then I'd have felt better about it but because we didn't know about that...I sort of jumped straight back in...”

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. They may want to start by working a few hours and gradually increasing them. Having a comparably reduced work load to begin with may also be helpful. If the employee has to remain away from work until reasonable adjustments are in place (for example, moving their work station close to a toilet), which would enable them to return to work, 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 or Business Link (see below) for advice about

the right procedures to follow when ending an employment.

Further help

NACC has a range of information sheets and booklets on various aspects of IBD, including an information sheet for employees. You can call the NACC Information Line or email: nacc@nacc.org.uk for a copy or a list of publications or download them from the NACC website: www.nacc.org.uk.

If you have any further questions about IBD you could telephone the **NACC Information Line: 0845 130 2233**.

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 47 47 47.
Monday-Friday 8am-6pm.
Website: www.acas.org.uk.

Business Link

UK wide government support for businesses providing information on various aspects of employing people. To find your local centre:

☎ 0845 600 9 006 or visit:
Website: www.businesslink.gov.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

Department for Work and Pensions (DWP)

Provides information on the Disability Discrimination Act, employment, pensions and benefits.

☎ Benefits Enquiry Line: 0800 882 200
Website: www.dwp.gov.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-CTRX

Arndale House, Arndale Centre
Manchester M4 3EQ

☎ 0845 604 6610 weekdays 9am-5pm
except Wednesdays 9am-8pm.

EHRC Helpline Scotland:

Freepost RRLG-GYLB-UJTA,
The Optima Building
58 Robertson Street, Glasgow G2 8DU.

☎ 0845 604 5510
weekdays 9am – 5pm.
except Wednesdays 9am-8pm

EHRC Helpline Wales:

Freepost RRLG-UEYB-UYZL
3rd Floor, 3 Callaghan Square
Cardiff CF10 5BT

☎ 0845 604 8810 weekdays 9am – 5pm
except Wednesdays 9am-8pm

Jobcentre Plus

A government agency which is part of the DWP set up to help more people into work and manages the Access to Work scheme. To find your local office look in your phone directory or visit the website:

www.jobcentreplus.gov.uk

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NACC publications are research based and produced in consultation with patients, NACC medical advisers and other health or associated professionals.

This Information Sheet is intended for guidance only and NACC cannot accept responsibility as advisers in this field.

We hope that you have found the information helpful and relevant. We welcome any comments from readers, or suggestions for improvements. Please send your comments to Helen Terry at NACC, 4 Beaumont House, St Albans, Herts AL1 5HH – or email: h.terry@nacc.org.uk

The National Association for Colitis and Crohn's Disease (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 for the first year and £10 subsequently. Additional donations to help the work of the Association are always welcome.