

Employment and IBD: a guide for employees

Introduction

If you have Crohn's Disease or Ulcerative Colitis – conditions collectively known as Inflammatory Bowel Disease (IBD) – you may be concerned about your employment position. You may be employed or looking for a new job. You may be on benefits and are thinking about returning to work. While IBD is a chronic condition, with appropriate treatment it is often possible to remain well for long periods and many people with IBD are able to work full-time.

This information sheet sets out to answer some questions you may have about your possible options and how you may be protected by law. The quotations that are included are all from people who have IBD who responded to a 2011 Crohn's and Colitis UK survey on IBD and employment.

Who should I tell about my IBD?

If you are applying for a job you may be concerned that you will be at a disadvantage if you declare your IBD during the recruitment process, whether on an application form or at an interview.

The Equality Act 2010 makes it unlawful for employers to ask invasive questions about your health - including previous sickness absence - before making a job offer. This applies to questions that are included on an application form as well as questions asked during an interview. Employers should consider whether or not you can do the job rather than ruling you out early on in the process because of your health condition.

A job offer may be conditional on a medical examination or satisfactory completion of a medical questionnaire after the job offer stage. A conditional offer should only be withdrawn on medical

grounds at this stage if it can be shown that you would not be able to do the job once reasonable adjustments have been made. (See *What are reasonable adjustments?*). If you deliberately withhold information at this stage and it comes out later, you could risk being dismissed.

You may also find it helpful to show any prospective employer our leaflet '*Employment and IBD: a guide for employers*'.

If you are already in a job when you are diagnosed with IBD, or if your condition becomes worse, you may wonder whether to tell your manager about it. There is generally no legal requirement to disclose a medical condition - but it may be required in your own personal contract of employment.

There can be some advantages in telling your manager. Firstly, hiding symptoms can be a strain and it may be a relief to talk about your IBD. Also, if your employer knows about your IBD, they should make reasonable adjustments for you if you fall within the definition of a disabled person in the Equality Act 2010 (See below for *When is IBD a disability?*)

Generally, employers will deal sympathetically with an honest approach, and sometimes a lack of understanding can create more problems, but it has to be your decision.

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

If you want some support when you tell your employer, you could ask someone else to accompany you, such as a colleague, an occupational health worker or a trade union representative.

Even if you tell an employer or prospective employer about your IBD, you may not wish it to become public knowledge. You also need to decide if and what you are going to tell your co-workers and colleagues. Again, there can be advantages in letting others know about your IBD. If fellow staff know that you have a chronic condition and what it means, they are more likely to give you the support and assistance you need, helping to create a better working environment. If they do not know, they may draw the wrong conclusions or believe you are getting preferential treatment if your employer makes adjustments for you. Being more open could also mean that you wouldn't, for example, have to hide taking your medication or that you have painful stomach cramps.

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

"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."

It is common for people to feel embarrassed when talking about bowel movements, so you may find it difficult to explain your symptoms, especially urgency and the frequent need to rush to the toilet. You may find it helpful to give your manager and/or your colleagues some of our information sheets or booklets such as *Understanding Colitis and Crohn's Disease*. Explaining that IBD is not

infectious is often particularly helpful, as this may be a concern. It may also be useful to make it clear that IBD is different from Irritable Bowel Syndrome.

"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."

"I think that sometimes it's very difficult to explain why, for example, you eat differently, or feel a little unwell if you have IBD, as there seems to be generally a great deal of ignorance about this issue, and often co-workers will jump to conclusions without having any idea of the reality of the situation."

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. Most employees said that they felt comfortable about discussing their condition, but two in five respondents said that they worry their colleagues may think that they do not pull their weight at work because of their IBD symptoms. A quarter said that they worry about being discriminated against in the workplace as a result of their IBD.

What are my employment rights?

Nearly all workers have certain legal rights and you may have additional rights in your particular employment contract. You can obtain further information about general employment rights from several sources including the government website: www.direct.gov.uk, ACAS, Citizens Advice (all listed under *Further help*) and trade union representatives.

Having IBD, you may be particularly worried about whether your employer can dismiss you for ill health. The law does give some protection here but the level of protection will depend on whether you are treated as disabled under the Equality Act 2010.

If you have one year's service or more you may have grounds to successfully pursue a claim for unfair dismissal - but there can be reasons why a dismissal can be considered 'fair'. These grounds can include being unable to do your job properly because you have an ongoing illness. However, before deciding to dismiss you, your employer should normally look at any alternatives, such as other duties or different employment.

If your IBD is considered a disability, your employer has a legal duty to make 'reasonable adjustments'. Dismissal because of a disability may be unlawful discrimination. You may have grounds for bringing a claim for disability discrimination even if you do not have one year's service.

When is IBD a disability?

When asked whether or not they consider themselves to have a disability, 51% of respondents to the 2011 Crohn's and Colitis survey answered yes. However, many people with IBD do not consider themselves disabled. Anyone with an ongoing illness **may** qualify for protection against discrimination. The fact that your IBD is a variable condition, generally with good days and bad days, does not affect your rights. The main point is that the overall effect is long-term.

The Equalities Act 2010 defines disability as a physical or mental impairment which has an effect on a person's ability to carry out normal day-to-day activities. This includes 'hidden' impairments or disabilities such as incontinence. The effect must be substantial, adverse and long-term. For example, the loss of bowel control is considered substantial and adverse if it is unpredictable and leads to

immediate major soiling, even if it is infrequent. Minor but frequent loss of bowel control may also qualify as substantial and adverse. Long-term is generally taken to mean the effect has lasted, or is likely to last, at least a year. In most cases treatment for a health condition is not considered when deciding if someone is disabled under the law. This means that you may benefit from the protection of the Equalities Act if your symptoms are controlled by medication.

For more information about the Equality Act 2010, contact the Equality and Human Rights Commission or your local Citizens Advice Bureau listed under *Further help*.

What protection do I have under the Equality Act 2010?

The Act applies to all employers, whatever their size, except the armed forces. If you are considered to have a disability you qualify for protection under the Act, which covers all aspects of employment from recruitment to selection, training, promotion, redundancy and dismissal. Discrimination under the Act means either treating a disabled person less favourably than others because of their disability, or failing to make reasonable adjustments to the work place or working arrangements. It is also unlawful to victimise a disabled person if they wish to take or have taken action in relation to their rights under the Act.

What are reasonable adjustments?

If the Equality Act applies to you, you can ask your employer for reasonable adjustments when any aspect of your working arrangements, including the building or place of work or your working hours, puts you at a substantial disadvantage compared to a non-disabled person doing your job. These adjustments are not favours but rights.

“I was informed that I would have to work night duty as part of my role but in the past night duty has given me unnecessary flare ups. My previous manager was very understanding and took me off the night rota. However, my recent employer is unsympathetic, so I sought advice from our occupational health department who sent my manager a letter stating I was not expected to do nights.”

There is no certainty about what is or is not reasonable, but the cost and difficulty in making the adjustment and the size of the employer will be taken into account. Generally, if the adjustment is not too expensive considering the resources of the employer and the type of business, it is more likely to be considered reasonable.

“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. In addition, having a smart phone helps – being able to read emails when I’m away from the office and connected at home really helps to make up for the times that I miss.”

Helpful adjustments that would not generally be too expensive could include:

- Allowing time for medical appointments or treatment
- Changes to your working day such as shorter or different hours
- Unlimited toilet breaks
- Moving your work station close to a toilet
- Providing a car parking space close to the entrance into work
- Allocating some of your duties to someone else
- Offering another place of work
- Providing you with relevant training, for example if some of your duties have been reallocated and you take on new

tasks that are more suitable to your needs.

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.

Where adjustments are expensive, such as installing separate toilet facilities, a scheme called Access to Work may be able to help (see below). Ultimately, if it is not possible for you to agree with your employer about whether an adjustment is reasonable, you could issue a claim in the employment tribunal in respect of your employer's failure to make reasonable adjustments and seek an award of damages. However, before you are able to issue a claim you would need to raise a formal written grievance with your employer. (See *What can I do if I feel I have been discriminated against?*) Contact the Equality and Human Rights Commission for further information (see *Further help*).

What is Access to Work?

Access to Work is a government funded scheme to help people with a disability overcome practical difficulties that may stop them from working. It is available for part-time or full-time workers and for those who are self-employed or unemployed and looking for work.

Besides possible help towards installation of toilet facilities, Access to Work can help in a number of ways such as with the additional costs of travel to work, if you are unable to use public transport. Any help provided is for a maximum period of 3 years, after which there is a review.

More information about Access to Work is available from the government website directgov.com.

You can ask the Disability Employment Adviser at your local Jobcentre Plus office to put you in touch with your closest Access to Work Business Centre.

Travelling to work

Many people with IBD tell us that travelling to work or jobs that require travelling are particularly difficult. You may find it helpful to obtain a key for locked public toilets for disabled people from RADAR (The Royal Association for Disability and Rehabilitation), listed under *Further help*. RADAR runs a National Key Scheme for people to access specially adapted toilets that are kept locked to avoid vandalism. They also provide a location guide to approximately 7,000 toilets throughout the UK. You may also get help with travel costs from Access to Work, as mentioned above.

"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."

"Because of lack of toilets I have to be careful about my route and avoid stressful situations like tube stoppages. I dread being stuck on the tube. Once I am in work I am generally OK."

What can I do if I feel I have been discriminated against?

If you have had a conditional job offer withdrawn on medical grounds but feel that you would have been able to do the job with reasonable adjustments, you can make a complaint to an Employment Tribunal. The Equality Act places the burden of proof onto the employer to show that you have not been discriminated against.

If you suspect you have been treated unfairly in this way, it may be helpful to

seek advice from the Equality and Human Rights Commission, listed under *Further help*.

You may also face difficulties because of your IBD when you are in work. For example, you may be bullied by colleagues who believe that you just have a stomach upset, or do not understand that your tiredness is due to your IBD. As a first step it is usually a good idea to talk informally to your employer or manager about your concerns of how you are being treated. Often things can be resolved by talking them through, although it can also be useful to keep notes of conversations or meetings just in case you need to take the matter further.

Making a formal complaint

If you find the situation does not improve, you could make a formal complaint through your employer's internal grievance procedure. A written grievance has to be submitted no later than three months after the discrimination happened. Your employer then has to arrange a meeting with you to discuss the problem. You have a legal right to take a colleague or trade union representative with you if you ask your employer beforehand. Alternatively you could ask a family member to accompany you, but in this case your employer does not have to agree to it. If you are not happy with the result of this meeting you can make an appeal to your employer.

If you find it difficult to make a complaint or if, having made it you are still not satisfied with the outcome, you might want to contact the Equality and Human Rights Commission, ACAS or other similar organisations to explore your options (see list under Other Organisations). You may be referred to a caseworker to help you to negotiate adjustments with your employer or, if necessary, to help you make a complaint to an Employment Tribunal.

Returning to work after a long absence

If you have been off work for several weeks or months because of your IBD, you may feel anxious about returning to work. 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. Keeping in touch with an employer can help, and it may be helpful to set up an agreed procedure, if possible in advance, for how your employer will maintain contact with you whenever you are absent. This could specify a timescale, for example, suggest contact once you are absent for more than two weeks and/or specify the method by which you would prefer to be contacted e.g. phone, email or personal visit. You may prefer contact from a co-worker, close colleague or union representative rather than your direct line manager.

It is important not to feel pressured into returning to work too soon before you are well.

You might want to discuss a phased return to work, as you may not be able to work a full day at first. For example you might want to start working only a few hours each day and gradually increase your hours over time. Or perhaps you may want to ask for a reduced work load or lighter duties to begin with. Generally the more open you are about your needs, the more likely it is for your employer to be open and willing to make reasonable adjustments to help you back to work. (See *What are reasonable adjustments?*) If you have to remain away from work until reasonable adjustments are in place (for example, moving your work station close to a toilet), arguably this should not be recorded as 'sick leave'.

"My employer is very supportive and gave me full pay when I returned to work from operations, 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 et., until back up to seven hours a day."

If you are 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 you are not discriminated against if, for example, decisions about promotion or bonuses take other sickness absences into account.

What can I do if my employment is no longer suitable?

You may find that having tried changes to your current employment such as altering your working hours, job-sharing, working part-time, or a change of location closer to home, your condition still makes it difficult to continue despite reasonable adjustments. In this case, it is not unusual to feel angry or upset at the impact of IBD on your working life or career. There are various options you could consider including:

- Self-employment – you may feel daunted at the prospect of setting up your own business or worry that you would miss socialising at work. But some advantages are that you can often work the hours to suit your energy levels and, if you can work from home, reduce the fear or possibility of having an 'accident' in public.

You can get help and advice about self-employment from several organisations including the Citizens Advice Bureau, Leonard Cheshire Disability, the Northern Pinetree Trust (see *Further Help*) and from government schemes such as Access to Work, as mentioned above.

“As I am self-employed, this gives me more flexibility than employment. If I didn't have IBD and its symptoms I might have gone back to employment, but now I consider self-employment more suitable.”

- Re-training – you may find that another kind of job makes it possible for you to work more comfortably. There are a number of organisations that offer training such as the Shaw Trust, Ability Net, Leonard Cheshire Disability, and SHARE Community. For details see *Further Help*.

“I am looking at other ways to develop my business by working from home on individual projects but this is like starting again after I'd spent six months building a business and developing contacts. In the long term I don't think IBD will stop me from developing a business but it has set me back and is making me rethink how to go about it.”

- Early retirement – if you are closer to retirement age, you may feel this is an option for you. You can check your pension position and get information about pensions from the Department for Work and Pensions and the Pensions Advisory Service listed under *Further Help*. It may be helpful to get financial advice, including information on how your pension could affect entitlement to other benefits should you need to claim them.

“My employer has allowed me to take progressive retirement and reduce my hours to three days a week for 18 months then two days. I am building a paid pension in addition to my earnings.”

- Volunteering – if income is not crucial, you might consider voluntary work, which could provide a challenge while allowing you to give something to others. You can contact national volunteering organisations listed at the end for ideas and opportunities. They each provide an online database of volunteer jobs. Crohn's and Colitis UK also has volunteering opportunities around the UK. For further information contact our Member Involvement and Volunteering Team on 01727 734475 or email: enquiries@crohnsandcolitis.org.uk.

What financial help is available?

If you have care or mobility needs arising from your IBD you may be eligible for Disability Living Allowance (DLA), whether you are working or not. We provide a *Guide to Claiming DLA*, available on our website, or you can contact our Information Line for a copy.

If you are in employment, your employer should pay Statutory Sick Pay if you are too ill to work. This starts after you have been off sick for 4 days and can be paid for up to 28 weeks. If you are not well enough to return to work after this time, or if your employment is terminated, you may qualify for Employment and Support Allowance (ESA). Some employers may make additional payments through their own sick pay scheme. This will depend on your terms and conditions of employment.

If you are well enough to look for work you may be eligible for Jobseeker's Allowance. You may also get help and support through schemes available to help people get back into work. For more information contact Jobcentre Plus or see the directgov website.

If you have been on benefits and are going to start a job, you may be able to obtain a job grant. This is a one-off tax-free payment.

If you are on a low income or on certain benefits you may be entitled to claim help with fares to hospital through the Health Care Travel Costs Scheme. The scheme allows travel by public transport or private car.

You can get more information about these and other benefits and details of helpful organisations from our guide: *An Overview of Welfare Benefits for people with Ulcerative Colitis and Crohn's Disease*, available on the website and from our Information Line.

Further help

Crohn's and Colitis UK

Information Line: 0845 130 2233, open Monday to Friday, 10am-1pm. There is an answer phone service outside these hours or you may email us on info@crohnsandcolitis.org.uk.

Information staff will help with any IBD related queries.

We also have a supportive listening service line, staffed by trained volunteers:

**Crohn's and Colitis Support:
0845 130 3344.**

Other organisations

Ability Net

Advice helpline: 0800 269545

Email enquiries@abilitynet.org.uk

Website: www.abilitynet.org.uk

A national charity helping disabled adults and children use computers and the internet by adapting and adjusting their technology.

Advisory, Conciliation and Arbitration Service (ACAS)

☎ Helpline: 08457 47 47 47. Monday-Friday 8am-8pm. Saturday 9am-1pm

Website: www.acas.org.uk.

Free, impartial, confidential advice about any kind of dispute or query about relationship issues within the workplace.

Citizens Advice Bureau (CAB)

There are over 750 bureaux in mainland Britain. Look under Citizens Advice Bureau in your phone book for

details of your nearest one. You can also find details of your nearest bureau at: www.citizensadvice.org.uk.

More information about employment rights is available on their Advice Guide website:

www.adviceguide.org.uk.

Citizens Advice Scotland

To find your nearest bureau, look under Citizens Advice Bureau in your phone book or visit the CAS website at: www.cas.org.uk

Community Legal Service Direct

☎ Helpline: 0845 345 4 345. Monday to Friday 9am–8pm, Saturday 9am-12.30pm. Website:

www.communitylegaladvice.org.uk

Offers free legal information if you qualify for Legal Aid and live in England and Wales. You can search for a local legal adviser or solicitor.

For information about services in Scotland contact:

Scottish Legal Aid Board

☎ Helpline: 0845 122 8686. Daily

7am-11pm. Website: www.slabb.org.uk

For information about services in Northern Ireland contact:

Northern Ireland Legal Services Commission

☎ 028 9040 8888 Monday-Friday 9.15am-5.15pm.

Website: www.nilsc.org.uk

Department for Transport

Great Minster House, 76 Marsham Street, London SW1P 4DR

☎ 0300 330 3000 8.30am-5.30pm

Monday-Friday. Website: www.dft.gov.uk

Directgov

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

www.directgov.uk

Disability Law Service

39-45 Cavell Street, London E1 2BP

☎ 020 7791 9800 weekdays 10 am-5pm

Website: www.dls.org.uk

The DLS offers free advice and representation for disabled people, their families and carers, on specific areas of law, including disability discrimination, employment and welfare benefits. You may need to leave your name and phone number on an answering machine, and someone will call back within 24 hours. An answer-phone is also available for out of hours calls.

Equality and Human Rights Commission (EHRC)

Website: www.equalityhumanrights.com
Help for people who have been discriminated against because of their disability.

EHRC Disability Helpline England:

Freepost MID02164,
Stratford upon Avon CV37 9BR
☎ 08457 622 633 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.

EHRC Helpline Wales: Freepost RRLR-UEYB-UYZL, 1st Floor, 3 Callaghan Square, Cardiff CF10 5BT
☎ 0845 604 8810 weekdays 9am – 5pm.

Jobcentre Plus

A government agency which is part of the DWP, set up to help more people into work and to give people of working age the help and support they are entitled to if they cannot work. To find your local office, look in your phone directory or visit the website: www.jobcentreplus.gov.uk

Law Centres Federation

22 Tudor Street, London EC4Y 0AY
☎ 020 7428 4400
Email: info@lawcentres.org.uk
Website: www.lawcentres.org.uk
Law Centres are not-for-profit legal practices providing free legal advice and representation to disadvantaged people

Leonard Cheshire Disability

66 South Lambeth Road, London, SW8 1RL

☎ 020 7802 8200

Website: www.lcdisability.org

Provides training, career advice and help for disabled people to start their own business. Also Scotland, Wales and N. Ireland.

Northern Pinetree Trust

Pinetree Centre, Durham Road, Birtley DH3 2TD

☎ 0191 492 8215 Website:

www.northernpinetreetrust.co.uk

Provides help for people in the North East with a disability or a long term illness to start their own business.

Pensions Advisory Service

11 Belgrave Road, London SW1V 1RB

☎ Pensions Helpline: 0845 601 2923

Weekdays 9am-5pm.

☎ Helpline for women: 0845 600 0806

☎ Helpline for self-employed:

0845 602 7021. Email:

enquiries@pensionsadvisoryservice.org.uk

Website:

www.pensionsadvisoryservice.org.uk.

An independent non-profit organisation providing free information and advice on pensions including State, company, personal and stakeholder schemes.

RADAR – The Royal Association for Disability and Rehabilitation

National Key Scheme, 12 City Forum, 250 City Road, London EC1V 8AF

☎ 020 7250 3222

Website: www.radar.org.uk

RADAR can provide a key for NKS toilets for £3.50 (including UK delivery) on declaration of disability, and a location guide to these toilets for £10.25 (including UK delivery).

SHARE community

64 Altenburg Gardens, London SW11 1JL

☎ 020 7924 2949

Website: www.sharecommunity.org.uk.

Provides training for people with disabilities or long-term health problems in London and the surrounding area.

Shaw Trust

Fox Talbot House, Greenways Business Park, Bellinger Close, Chippenham Wilts SN15 1BN

☎ 01225 716300 (General enquiries)

Website: www.shaw-trust.org.uk

Supports disabled and disadvantaged people to prepare for work, find jobs and live more independently

Trade unions

An employee has the right to join a trade union and should not be refused a job, dismissed, harassed or selected for redundancy because they are a member of or wish to join a trade union. For further information contact the Trades Union Congress (TUC):

England and Wales: ☎ 020 7636 4030

Website: www.tuc.org.uk.

Scotland: ☎ 0141 337 8100

Website: www.stuc.org.uk.

Northern Ireland: ☎ 028 9024 7940

Website: www.ictuni.org.

Volunteer Now

129 Ormeau Road, Belfast, Northern Ireland BT7 1SH

☎ 028 9023 6100.

E-mail: info@volunteernow.co.uk

Website: www.volunteering-now.co.uk

A regional to local organisation that will work to promote, enhance and support volunteering across Northern Ireland.

Volunteer Development Scotland

Jubilee House, Forthside Way, Stirling, FK8 1QZ

☎ 01786 479593.

E-mail: vds@vds.org.uk

Website: www.vds.org.uk

Volunteering England

Regents Wharf, 8 All Saints Street, London N1 9RL

☎ General Enquiries: 0207 520 8900.

E-mail: volunteering@volunteering.org.uk

Website: www.volunteering.org.uk

Volunteering Wales

Website: www.volunteering-wales.net

For information about volunteering opportunities throughout the UK visit: www.do-it.org.uk

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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@crohnandcolitis.org.uk

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