



Employment and IBD: a guide for employees

Introduction

If you have Crohn's Disease or Ulcerative Colitis – the two main conditions called Inflammatory Bowel Disease (IBD) – you may be concerned about your employment position, whether you are employed now or whether you are looking for a new job. You may be on benefits and are thinking about a return 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. A recent study by the Institute of Work, Health and Organisations on managing IBD at work found that of particular importance to working successfully was having a positive attitude, not denying the challenge of living with a chronic illness and seeking the support and understanding of other people.

If you are concerned about your employment prospects, the following information sets out to answer some questions you may have about your possible options and how you may be protected by law.

Who should I tell about my IBD?

You may understandably 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. Sometimes it may be best to leave disclosure until a decision has been made, if the application and selection process let you choose when to mention your health. You do not have to tell a potential employer about your IBD unless you are asked directly about having a health condition. If you deliberately withhold the information and it comes out later, you could risk being dismissed.

“...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...”

Disclosing your condition may be helpful if you later need to request 'reasonable adjustments' under the Disability Discrimination Act 1995 (DDA) (See *What are reasonable adjustments?*). If you have not declared your IBD an employer could be justified in failing to make adjustments for you. You may find it helpful to look for employment in organisations that have equal opportunities policies with a certain commitment to employing without prejudice. Jobcentre Plus advertises some jobs with the disability symbol of 'two ticks'. These employers guarantee a job interview to people with a disability if they meet the minimum criteria of the person specification. You could obtain booklets about IBD from the NACC office to help explain the condition to potential 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 contract of employment.

There are some advantages in telling your manager. First, it can be a strain on you hiding your symptoms 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 satisfy the definition of a disabled person in the DDA (See *When is IBD a disability?*) Generally employers will deal sympathetically with an honest approach and a lack of understanding can create more problems, but it has to be your decision.

If you tell an employer or prospective employer about your IBD, you may not wish it to become public knowledge. It might be helpful to talk to them about whether to tell colleagues and, if so, how to tell them. 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 they may believe you are getting preferential treatment, if your employer makes adjustments for you. It would also mean you wouldn't have to hide taking your medication or painful stomach cramps.

“...I think a lot of the problems that people have with IBD is of their own making because they walk around with a blanket over it and if you don't let people know that you've got a problem then they cannot help you...”
“...consequently they will up and double their efforts and workload 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.”

It is common for people generally to feel embarrassed to talk about bowel movements, so you may find it difficult to explain your symptoms, especially urgency and the frequent need to rush to the toilet. It could help to give your manager NACC's booklet *Understanding Colitis and Crohn's Disease*. Explaining that it's not infectious is particularly helpful, as this may be a concern. It's also helpful to explain that it is different from Irritable Bowel Syndrome. If you do not want to tell your manager yourself, you could ask someone else to do it for you, such as a colleague, an occupational health worker, a trade union representative or a disability employment adviser. You can find a disability employment adviser through your local Jobcentre Plus office.

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 are likely to be most concerned about whether your employer can dismiss you for ill health. If you have one year's service you may have grounds to successfully pursue a claim for unfair dismissal, but there can be reasons why a dismissal can be considered 'fair'. This can be for being unable to do your job properly because you have an ongoing illness. Before deciding to dismiss you, your employer should normally look at any alternatives, such as other duties or different employment. It may help to obtain a letter about your condition from your doctor. 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?

Many people with IBD do not consider themselves disabled, but 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 DDA 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, or minor but frequent loss of bowel control. Long-term means 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 DDA if your symptoms are controlled by medication.

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

What protection do I have under the DDA?

The DDA applies to all employers, whatever their size, except the armed forces. If you qualify for protection under the DDA, you are covered in all aspects of employment from recruitment to selection, training, promotion, redundancy and dismissal. Discrimination under the DDA 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 the DDA.

What are reasonable adjustments?

If the DDA applies to you, you can ask for reasonable adjustments from your employer 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. You should make it clear to your employer that these adjustments are not favours but rights.

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 reasonable. Helpful adjustments that would not generally be 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 training

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. 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 Equal Rights Commission for further information (see *Further help*).

"I was given a car parking space at one period, mainly because of my medical condition, you know. They said you can have a car park space because it just made life so much easier".

"...I can plan the day the way I want to...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..."

"...the occupational health people at the place I was working were quite supportive so my office was quite conveniently placed near to toilets and things like that..."

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.

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 which 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 mentioned above.

"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."

"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."

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

If you have the right skills for the job and you feel you have been rejected because of your IBD, you can make a complaint to an Employment Tribunal. In this situation the employer would have to show what their reasons were for rejecting you. If you suspect you have been treated unfairly in this way, it is helpful to seek advice from the Equality and Human Rights Commission, listed under *Further help*.

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

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 making a complaint difficult to do or having done so you are still not satisfied with the outcome, you might want to contact the Equality and Human Rights Commission, ACAS or other organisations with legal help lines, listed at the end, to explore your options. 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 and keeping in touch with an employer can help. It may be helpful to set up a standard procedure for how your employer will maintain contact with you whenever you are absent for more than two weeks. You may prefer contact from a co-worker, close colleague or union representative, who may make you feel more supported than contact from a line manager, which could make you feel you are being checked up on. You could also say what type of contact you would prefer, whether by telephone, email, letter or in person. It is important not to feel pressured into returning to work too soon before you are well.

“...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...”

You might want to discuss a phased return to work, as you may not be able to work a full day at first. You may want to start working a few hours and gradually increase your hours over time. You may want to ask for a reduced work load to begin with. Generally the more open you are about your needs, the more likely it is for your employer 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'.

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 decisions about promotion or bonuses, for instance, take into account sickness absence.

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. 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 work the hours to suit your energy levels and you do not necessarily have to leave home and an accessible loo, removing the fear of an 'accident' in public.

You can get help and advice from several organisations including the Citizen's Advice Bureaux, Leonard Cheshire Disability and the Northern Pinetree Trust listed under *Further help* and from government schemes such as the Access to Work Scheme mentioned above.

"I am self-employed now...so if I am not on top form I can go out to work later, come home at lunch time and then out again in the afternoon instead of doing full days."

- 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, Skill and SHARE Community listed under *Further help*.

"Because engineering is very difficult and very physical...it was inconvenient whereas this office based type employment is much more convenient for a number of reasons...I can work round and work to my own hours and my own organisation."

- Job Introduction Scheme – You may be eligible for this government scheme open to disabled people looking for work, who have concerns about their ability to do a job because of their disability. The scheme helps by paying a weekly grant to the employer which can be used towards wages or extra training. The trial period may be from 6 to 13 weeks. Contact Jobcentre Plus listed under *Further help* for more information.
- Early retirement – If you are closer to retirement age, you may feel this is an option for you. It would be a good idea to check your pension position before deciding. You can get information about pensions from the Department for Work and Pensions and the Pensions Advisory Service listed under *Further help*.
- 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. NACC also has extensive volunteering opportunities around the UK. For further information contact NACC's Group and Volunteer Team on 01727 734475 or email: nacc@nacc.org.uk.

What financial help is available?

As someone with IBD you may be able to claim Disability Living Allowance (DLA), whether you are working or not. NACC provides a *Guide to Claiming DLA*, available on the NACC website or you can contact the NACC Information Line for a copy (see *Further help*).

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 Incapacity Benefit. Some employers may make additional payments through their own sick pay scheme. This will depend on your terms and conditions of employment. See NACC's Guide: *The Personal Capability Assessment of incapacity for work* available from the NACC website or contact the NACC Information Line for a copy.

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 the New Deal scheme. For more information call the New Deal helpline on 0845 606 2626 open every day from 7am to 11pm.

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 the Hospital 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 the NACC's Benefits Guide: *An Overview of Welfare Benefits for people with Ulcerative Colitis and Crohn's Disease* available on the NACC website or contact the NACC Information Line for a copy.

Further help

If you have any further questions you may wish to telephone the **NACC Information Line: 0845 130 2233**. Or you might like to speak with a volunteer on our supportive listening service line: **NACC-in-Contact: 0845 130 3344**.

Other organisations

Ability Net

Advice helpline: 0800 269545

Website: www.abilitynet.org.uk

Provides free help and training on the use of computers for people with disabilities or health conditions.

Advisory, Conciliation and Arbitration Service (ACAS)

☎ Helpline: 08457 47 47 47. Monday-Friday 8am-6pm. Website: www.acas.org.uk.

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

Citizens Advice Bureaux (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 – 6.30pm.

Website: www.clsdirect.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.slab.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 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

Confidential advice and information for people with disabilities, their carers and representatives, about benefits and how to claim them.

Department for Transport

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

☎ 020 7944 8300 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 (Closed 1-2pm). Website: www.dls.org.uk

The DLS offers free advice and representation for disabled people, their families and carers. One of the specialist areas is the Disability Discrimination Act.

Employment Opportunities

53 New Broad Street, London EC2M 1SL

☎ 020 7448 5420 to find your nearest centre. Website: www.opportunities.org.uk.

Offers a free service to employers and people with disabilities and medical conditions looking for work. It aims, through training and guidance, to help secure and maintain employment for people with disabilities, and offers advice to employers on financial assistance and other services available.

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

Third Floor, 293-299 Kentish Town Road, London NW5 2TJ

☎ 020 7428 4400 Website: www.lawcentres.org.uk.

For information about Law Centres and where your nearest Law Centre is.

Leonard Cheshire Disability

30 Millbank, London SW1P 4QD

☎ 020 7802 8200 Website: www.leonard-cheshire.org

Provides training, career advice and help for disabled people to start their own business.

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 long term illnesses to start their own business.

Pensions Advisory Service

11 Belgrave Road, London SW1V 1RB

☎ Helpline: 0845 601 2923 Weekdays 9am-5pm.

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) or 0800 085 1001 for help to find and stay in employment. Website: www.shaw-trust.org.uk

Provides training and work opportunities for people with disabilities or ill health.

Skill: National Bureau for Students with Disabilities

Chapter House, 18-20 Crucifix Lane, London SE1 3JW

☎ Information Service: 0800 328 5050. Website: www.skill.org.uk Links to Skill Northern Ireland, Scotland and Wales. Helps young people and adults with any kind of disability in post-16 education, training and employment.

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 Development Agency

129 Ormeau Road, Belfast, Northern Ireland BT7 1SH

☎ 028 9023 6100. Website: www.volunteering-ni.org.

To find current opportunities in your area visit www.volunteernow.co.uk.

Volunteer Development Scotland

Stirling Enterprise Park, Stirling, Scotland FK7 7RP

☎ 01786 479593. Website: www.vds.org.uk

Volunteering England

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

☎ Information Service: 0800 028 3304. 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

All quotations in this sheet are from people with IBD who participated in a research project on 'Working with IBD: Managing Inflammatory Bowel Disease at Work' carried out by the Institute of Work, Health & Organisations, University of Nottingham and funded by NACC. We are grateful for their permission to use these quotes.

Disclaimer

This Information Sheet is intended for guidance only and NACC cannot accept responsibility as advisers in this field. If you have any particular employment difficulties you should get individual advice about any legal matter.

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. The Association also provides a supportive listening service called NACC-in-Contact which is available to anyone affected by Inflammatory Bowel Disease.

Membership of the Association costs £12 for the first year and £10 subsequently. Additional donations to help the work of the Association are always welcomed.

NACC Registered office: 4 Beaumont House, Sutton Road, St Albans, Herts AL1 5HH
Information Line: 0845 130 2233. NACC-in-Contact: 0845 130 3344.
Administration Line: 01727-830038. Fax: 01727-862550
Website: www.nacc.org.uk Email: nacc@nacc.org.uk

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A company limited by guarantee in England: company number 5973370.