

Students with IBD: a guide for students

Introduction

Planning to go to university or college can be an exciting but daunting time for anyone. If you have Inflammatory Bowel Disease (IBD) – Crohn's Disease or Ulcerative Colitis (UC) – you are likely to face even greater challenges and have more concerns and questions. This guide sets out to answer some of those questions, and to give you some tips and suggestions based on professional advice and also on the experiences of other students with IBD.

What general help and support can universities offer?

One way to find out what help and support is available is to get in touch with the university or college Student Disability Services.

Under the Equality Act (2010), which replaced the Disability Discrimination Act, universities and colleges must not discriminate against applicants or students because of a disability, and have a duty to make 'reasonable adjustments' so that students with a disability are not disadvantaged.

You may not see yourself as having a disability, but having IBD may mean you have needs other students do not, and that you might benefit from some of the support offered in this way. All Higher Education (HE) institutions should have a Student Disability Services department or team, (although the exact name may be slightly different). Details of how to contact this will be on the university or college website. The site may also give quite detailed information about the types of provision the university or college can offer.

For a student with a chronic medical condition, such as IBD, reasonable

adjustments might include, for example, arrangements for extra time in exams or to meet coursework deadlines when fatigue is a problem, or perhaps arrangements to allow you to eat or take medication during class sessions

Disability Services can also help you to apply for DSA (Disabled Students' Allowance) funding (see below) if you wish to apply for this, and can liaise with your department on your behalf.

Do I have to tell them that I have IBD?

You do not have to tell anyone about your IBD if you do not wish to. Many universities and colleges encourage students who feel they may need extra support because of a disability to declare or disclose this at an early stage, for example on their application form. But, there is no obligation to do this. You may feel you would prefer to wait until you have accepted your place at the university or college before you tell them about your IBD. This should not make any difference to the type or level of support you are then offered. You may even decide not to mention your IBD at all. However, if you do not tell your university or college about your condition you may miss out on some of the support that could be available.

Anything you tell the Disability Services team will be kept in confidence, and no information will be passed on without your agreement. If you are undecided whether to disclose your IBD you could have an informal talk with a Disability Adviser first, and discuss your options without committing yourself.

If you do decide to ask for support because of your IBD you will probably be asked to go for an assessment interview and will be expected to provide a

supporting letter from your GP or consultant.

Your Disability Adviser may then work with you to draw up an agreement (which may be called something like a Study Needs Agreement or a Personal Learning Plan) which outlines the support you have requested. This will also cover what information you have agreed may be passed to other staff or departments.

Some former students have found it helpful to talk to or visit Student Disability Services even before they submit their application. This allows them to take into account the sort of support they might be offered when deciding where to apply.

Is there extra financial help?

You may be able to apply for the DSA (Disabled Students' Allowance) to help you meet extra costs or expenses that arise because of your condition, such as extra costs for en-suite accommodation. You might also get, for example, help with buying good quality computing equipment so you can work at home as much as possible, a digital recorder to record lectures in case you feel unwell, or help with travel costs, as shown in the quotes below.

"My uni really helped push my assessment through, and gave me loads of support. The assessment was fine, it took about an hour, and I just had a chat with the assessor. I received payment for my laptop, keyboard, mouse, printer and scanner, ... a £100 printing and copying allowance, and a £158 internet allowance."

"My DSA supplied me with a laptop etc, but they also gave me a travel allowance of £100 to get a taxi if I feel unwell and need to get home quickly."

(Students with IBD who got DSA)

You can apply for a DSA even before you have accepted your place at college or university. For more information see the direct.gov website: www.direct.gov.uk. The university or college Disability Adviser will also be able to advise you about DSAs. SKILL (the National Bureau for Disabled Students) at www.skill.org.uk can be another helpful source of information about disability related support.

You could ask your university or college about help through their Access to Learning fund. Again, see www.direct.gov for more details. These grants are generally means tested, but those with a disability are given priority.

At Crohn's and Colitis UK we offer small Educational and Vocational Grants for young people with IBD between the ages of 15 and 25. Details of these are on the Personal Grants page of our website. We can also help with information about state benefits, including Disability Living Allowance (DLA).

How do I get suitable accommodation?

While some students prefer to continue living at home, for others living independently is an important part of the university experience. You may find you are offered a place in a student hall of residence for the first year, and this can be a good way to get to know people. Alternatively, you could look for private accommodation, which usually means sharing a flat or house, or renting a room as a lodger. University housing services usually have a housing database and provide advice.

Your Disabilities Adviser, if you have one, may be able to help ensure that the accommodation you are offered is suitable for your needs. If you do not have a Study Needs Agreement you will probably find it useful to have supporting evidence, such as a letter from your hospital or GP, when discussing your accommodation requirements.

Points you might like to think about and check could include the following:

- Is the accommodation ensuite? Many students with IBD feel this is essential. If you are expected to share, would this be acceptable to you? With shared bathrooms you might want to check how close the facilities are to your room, and how many other students would be using them.
- Does the hall or block have its own laundry facilities, or if not, is there a launderette nearby?
- How far is the accommodation from campus and how easy will it be to travel in to lectures and other student facilities?
- Is it catered or self-catered accommodation? You may find it easier to have meals cooked for you, or, on the other hand, if you have to be careful about what you eat, you may prefer to do your own cooking. Some catered halls also have cooking facilities – would this be helpful?

For further information on accommodation see *The Disabled Students' Guide to University* listed at the end of this leaflet.

There are also several useful search websites such as

www.accommodationforstudents.com

and www.homesforstudents.co.uk

What about getting medical help?

If you're studying away from home you will probably have to register with the University Health Service or a local GP, which will mean a change of doctor. You can search for a new GP on the NHS website at www.nhs.uk or by phoning NHS Direct on 0845 4647. The University Health service may also have a list of local GPs. You should still be able to see your old GP while back home on vacation.

It may be helpful to discuss your move with your home hospital IBD team before you leave for university – and to check with them who might be a good contact should you need access to specialist services once away from home. It could

also be useful to sort out with them, or with your home GP, a plan of action to follow if you do have a flare up. Also, ensure you have a good supply of your medication, especially when you first leave home. Once you get to university or college it can be a good idea to register as soon as possible, so that you can get a new prescription before you start to run out.

Your new doctor will be sent your existing medical records so they should be aware of your condition. However, you may still feel it is worth making an appointment, even while you are well, to make sure they know what having IBD means for you. Building a good relationship with your new doctor can make it easier to get you the support you need if you do have a flare up.

Should I tell my department?

If you have a Study Needs Agreement or something similar, this will cover who may be given information about your needs, including academic staff.

However, you may still find it helpful to talk to your personal tutor if you have one, or to your head of department, about your IBD and the impact this might have. Many students with IBD recommend doing this as soon as possible. You may feel embarrassed about this, but once you have established an understanding with the appropriate people, you will probably feel less stressed about the idea of needing support. Also, the more honest you can be, the more help you stand to gain. It might help to give your department a copy of our leaflet *Students with IBD: a guide for universities and colleges*, which includes basic information on IBD and some suggested ideas for support.

Students with IBD have found the following points useful to raise:

- **Toilet needs during lectures and seminars.** You might like to sit close to the exit in order to leave the room

quickly. If locker facilities exist, you could request the use of a locker for spare clothes and washing kit in case of accidents, and/or permission to use staff toilets if these are available.

- **Lateness.** You may arrive late because of urgent toilet needs or because tiredness and/or painful joints have made it difficult walk quickly.
- **Taking medication.** You may need to take medication during lectures, seminars or classes.
- **Eating between breaks** You may need to eat during lectures/seminars if you have to eat small amounts regularly.
- **Feeling unwell.** There may be times when you are feeling exhausted and in pain and need to take a brief rest, or even return to your accommodation.
- **Missing sessions.** At times, you may need to miss classes because of medical and hospital appointments, hospital admissions or being ill at home.
- **Field trips.** Given the unpredictability of IBD it may be difficult for you to commit to going on a trip much in advance of the day itself. You may also be concerned about toilet facilities on the journey and at the field trip accommodation. You could ask for the facilities to be checked with your needs in mind, and also whether and for how long you might be able to delay your decision before committing yourself financially.
- **Privacy** – you may want your condition kept private or you may prefer others to know about your illness.

What about course work deadlines?

One of your main concerns is likely to be about getting work in on time, especially when you are having a flare-up or if you have to go into hospital. Being able to request a coursework extension should you have a flare up is likely to be in your Study Needs Agreement if you have one. You may also be given an automatic extension if you are in hospital. If you do

find yourself having to negotiate a coursework extension, try to be realistic about how much time you need to recover and how much work you can do when you're still not feeling completely well.

Can I get help to cope with exams?

The intense pressure of exams affects most people, and having IBD you may find the stress triggers a flare-up. Try to pace yourself and find ways that help you to relax, such as taking regular exercise, deep breathing exercises, or yoga.

If you have a Study Needs Agreement or you have talked to your tutor about your condition, and are able to provide a medical certificate from your doctor, you may be able to make advance arrangements for exams. These might include, for example, sitting close to the exit nearest the toilets, having someone ready to accompany you if necessary, and being able to request extra time if needed.

In some circumstances, if you are completely unable to sit an exam, you may be able to defer sitting it until you are better, without a cap on your grade.

What about telling other students?

Meeting new people usually means wondering if and when to tell them about your IBD - and everyone has their own way of dealing with this. Some students with IBD find it easier not to mention it at first until they get to know people better. Others feel they want to be open from the beginning and if people can't deal with the truth, then they aren't likely to become good friends anyway.

If you do feel unwell during the first few weeks you could just say you have a 'tummy bug', or if you want to avoid concerns about infection, just limit your explanation to the fact that you have a gut condition which means you have to rush to the loo frequently. You can then give more details if and when you are ready.

Whichever approach you take, as you make friends you will get to know who is

most likely to be understanding and who you can trust to talk to about your IBD. Many students have found that it does help to tell a few friends at least, as having a supportive network of people who understand your condition and can offer support when it is really needed can make all the difference.

Having IBD, you may be more mindful about what you eat and drink. This may make you feel different, particularly if you avoid alcohol during 'freshers' week when there tend to be a lot of activities around the bar. But remember that many people don't drink alcohol, for a variety of reasons, and this is usually respected. You could think ahead about how you would respond to any comments on your staying off alcohol.

If you are sharing accommodation you may choose to cook your own food. Having good nutrition is particularly important with IBD to help the body strengthen its resistance to illness. (For further information on diet see our booklet, *Food and IBD*)

It can be tempting to throw yourself into college life, but it may help not to go beyond your limits just to fit in. Pushing your body too far may make you feel ill for longer, so that you end up missing out more in the long run than if you paced yourself in the beginning. Feeling ill is also likely to affect your ability to do coursework.

When you do have good days, try to do as much as you reasonably can in terms of being sociable and doing your work, as you don't know when a bad day will come along, which could restrict what you are able to do. Just try to take each day as it comes and see how you feel.

What other support is there?

Sometimes the pressure of exams, coursework, being away from home, feeling isolated when ill – any or all of these – may become too much to deal with on your own, even if you have the

support of friends and family. If you do find you are feeling anxious, stressed, or depressed, you can turn to the counselling service at your university or college in complete confidence. You may find that as well as face to face counselling services, there are also phone-based helplines, accessible from the privacy of your room.

Counselling can help with all kinds of issues, health related or more general, such as dealing with dilemmas or making difficult decisions, relationship difficulties, sexual problems, or identity issues.

At Crohn's and Colitis UK we have a web-based discussion board for people aged 16-29 living with IBD. This can be found at www.ibdandme.nacc.org.uk.

There are also Crohn's and Colitis UK groups around the UK, some with sub-groups for young people, and you might find it helpful to contact the group nearest your university or college. Check our website or contact our office for locations.

We also operate a supportive listening service, Crohn's and Colitis Support, and a general Information Line. (See below for contact details)

And finally...

Take time to plan, talk to the relevant people and develop a supportive network – don't wait until you are feeling unwell and having a flare-up before you seek help.

There may be setbacks along the way, such as having to take time out. If this means taking an extra year, it might seem like a lot of time, but try to keep in mind that, in the long run, it will probably not make a lot of difference.

"One thing I would say is don't let having IBD stop you from achieving anything. I refuse to let my disease get the better of me."

(Student with IBD)

Further information

Skill

National Bureau for Students with Disabilities, Chapter House, 18-20 Crucifix Lane, London, SE1 3JW.
Information Service : **0800 328 5050**.
E-mail: info@skill.org.uk
Website: www.skill.org.uk

Disabled Students' Guide to University 2005 3rd Edition. Ed. Emma Caprez.
Trotman Publishing.

Information on academic and cultural provisions at each institution, as well as summaries of each institution's disability statement, contact details for disability advisers/co-ordinators, and information on access and facilities for disabled students.

Crohn's and Colitis UK Information line: 0845 130 2233. Open Monday to Friday 10am - 1pm. There is an answerphone service outside these hours, or you may email info@crohnsandcolitis.org.uk. Information staff will help with any IBD related queries.

Crohn's and Colitis Support; 0845 130 3344. Open Monday to Friday 1pm - 3.30pm and 6.30pm - 9pm. This is a supportive listening service staffed by trained volunteers with personal experience of IBD.

We produce a wide range of information sheets and booklets. You can get a copy of any these from our Information Line. Most are also downloadable from our website: www.crohnsandcolitis.org.uk

© **NACC 2011**

Students with IBD: a guide for students.
Edition 2

Last review February 2011; Next review 2013

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 conflict 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

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. Additional donations to help our work are always welcomed.