



INFORMATION SHEET

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 additional challenges and have more concerns and questions. This guide sets out to answer some of those questions, and to give tips and suggestions based on professional advice and the experiences of students with IBD.

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I felt I was being weak asking for help, so I was reluctant to speak to anyone about my Crohn's. But when I met the Disability Service Adviser, they didn't judge me, and the support I did receive made such a difference, so I shouldn't have been worried.

”

Zaineb, age 24
diagnosed with Crohn's Disease in 2010,
studied English

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), 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 them will be on the university or college website. The site may also give information about the types of provision available.

For a student with a chronic medical condition, such as IBD, 'reasonable adjustments' might include, for example, arrangements for extra time in exams or extensions to meet coursework deadlines when fatigue or other symptoms are a problem. It might also include arrangements to allow you to eat or take medication during teaching sessions.

Some universities and colleges offer flexible study options including modular and distance learning courses, giving students more opportunity to learn at their own pace. With such a course structure it might be possible to take a break from studying if you have a flare-up, or to change to working from home for all or part of your course. Speak to the Admissions Team at the university or college for more information on flexible learning.

Some 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 at that particular college/university. Telling Student Disability Services will not affect your chance of being offered a place.

Disability Services can help you to apply for Disabled Students' Allowance (DSA - see **Is there extra financial help?**), if you choose to apply for this benefit. They can also liaise with your teaching department on your behalf. A separate Disabled Students' Allowance may be available to you through the NHS if you are studying a course leading to registration in a healthcare profession. Visit www.nhsbsa.nhs.uk for further details.

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The Disability Services at my university were brilliant. When I talked to them about my Crohn's, they put adjustments into place that really helped me when I was unwell during my degree.

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—
Jake, age 22
diagnosed with Crohn's Disease in 2007,
studied English Literature and Creative
Writing

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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. However, letting your university or college know about your condition will mean you are more likely to receive the help and support that is available.

Many universities and colleges encourage students who feel they may need extra support because of a disability to disclose this at an early stage - for example on their application form. Alternatively, you may prefer to get in contact with Student Disability Services as soon as your place is confirmed. This should make it easier for them to arrange support ready for the start of term. But there is no obligation to disclose your condition if you do not wish to.

If you have any concerns about disclosing your IBD or requesting support, contact the Student Disability Services at your university or college for an informal chat. You may not have to wait until you start your course to speak to a Disability Adviser, as many Student Disability Services can be reached by email, telephone or Skype. Anything you say to a Student Disability Adviser will be kept in confidence and will not be passed on without your permission.

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My accessibility centre even gave me a free taxi account, so if I was too ill to walk to uni or to wait for the bus, I could give the cab firm a call and they would pick me up and drop me back to my door. They also took me to doctor appointments for free.

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—
Jess, age 18
diagnosed with Crohn's Disease in
2008, studying Medicine

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HOW DO I FIND OUT WHAT SUPPORT I MIGHT GET?

If you request support, you will probably be invited to meet a Disability Adviser. You will need to take a supporting letter from your GP or consultant covering the symptoms of your condition and how flare-ups might affect you.

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 Student Support Plan) outlining the support you have requested. This will also cover the information that you have agreed may be passed to other staff or departments. It could be useful to keep a copy of this agreement close to hand, together with the contact details of the staff member responsible for your support, just in case you ever need to request help urgently.

There is a video on the UCAS website (www.ucas.com/connect/videos) which you might find helpful. This features Disability Advisers talking about ways students can disclose a condition and the assistance that can then be put in place.

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I have been lucky enough to receive Disabled Students' Allowance. I found the process quite straightforward and the staff were friendly and supportive with getting my application completed quickly. It was such a help.

”

Kelsea, age 22
diagnosed with Crohn's Disease in 2010,
studying Midwifery

“

My Disabled Students' Allowance has given me the money that I needed to pay the difference for en-suite accommodation. Having my own bathroom has given me peace of mind.

”

Jess, age 18
diagnosed with Crohn's Disease in
2008, studying Medicine

IS THERE EXTRA FINANCIAL HELP?

There is extra financial help in the form of a Disabled Students' Allowance (DSA) which is available for students who meet the definition of disabled under the Equality Act 2010.

The Equality 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. The Disability Rights UK website has information for disabled students about the Equality Act (see **Other Organisations** for further details).

A DSA may also be available to you if you are undertaking a distance learning course or studying part-time. If you are studying part-time, how much allowance you receive might be affected by your course intensity (how long your course takes to complete compared to an equivalent full-time course).

The support you get from a DSA will depend on your individual needs and not on income. Your Student Disability Service will be able to provide more information about this.

You can apply for a DSA before you begin your course. It is usually possible to apply for the allowance at the same time as your tuition fees loan. The university or college Disability Adviser will also be able to advise you about DSAs.

You could ask your university or college about help through their Access to Learning fund. Those with a disability are among those given priority. Students are individually assessed and may receive the grant from the Access to Learning fund, particularly when the DSAs are unable to meet specific costs. These grants are generally means tested. Speak to your Student Disability Adviser for more information on the Access to Learning fund, and how to apply for it.

At Crohn's and Colitis UK we can help with information about state benefits, including Personal Independence Payment (PIP).

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 can 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. Some accommodation offices are able to prioritise requests for en suite facilities based on medical conditions.

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My IBD team is amazing and so flexible for students arranging appointments. Even at my GP surgery, there is a member of the pharmacy staff who is very knowledgeable about IBD. I feel better knowing I can go to her to ask questions about my medication, when I can't get to see my GP.

”

Isobel, age 22
diagnosed with Crohn's Disease in 2012,
studying Fashion and Costume

“

Don't be ashamed to speak out about how your condition affects you. I found the adviser I spoke to in Student Disability Services so helpful in suggesting ways to make things easier for me. I was offered solutions to things I had never even considered were options! I would highly recommend speaking to them as soon as you can.

”

Zaineb, age 24
diagnosed with Crohn's Disease in 2010,
studied English

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

- Is the accommodation en suite? 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?
- Is there access to a fridge? If you have medications that have to be stored at a certain temperature, you could ask whether you would have easy access to a communal fridge, or could perhaps be provided with a smaller fridge in your room.

There are useful search websites that may be helpful such as www.accommodationforstudents.com

WHAT ABOUT GETTING MEDICAL HELP?

If you are living away from home you will need to register with the University Health Service or a local GP, which would mean a change of doctor. You can search for a new GP on the NHS website. You should still be able to see your old GP during vacations if you complete a temporary registration form when you go back home.

Your new doctor will be sent your existing medical records so they should be aware of your condition. 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 the support you need if you do have a flare-up.

It may be helpful to discuss your move with your 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. You could sort out with them, or with your home GP, a summary of your condition and a written plan of action to follow if you have a flare up.

Make sure you have a good supply of your medication with you, when you first leave home. If you are changing doctors, register with a new GP as soon as possible, so you can get a new prescription before your medication runs out.

SHOULD I TELL MY UNIVERSITY / COLLEGE DEPARTMENT?

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

However, even if you have agreed that details of your condition should be passed on, you may still find it helpful to talk to your head of department or your personal tutor (if you have one) about your IBD and the impact this could have on your studies. Many students with IBD recommend doing this as soon as possible.

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I was daunted by the idea of telling my lecturer about my IBD. But speaking to them was the best decision I made. They were really understanding. I found it reassuring, to know that I had someone to go to who could help with making adjustments for me if I had a flare-up and couldn't keep up with my studies.

”

Nicholas, age 22
diagnosed with Ulcerative Colitis in in 2006, studied Sport Science

You may feel embarrassed about talking about your IBD, but once you have established an understanding you will probably feel less uncomfortable about asking for support when needed. Also, the more open you can be, the more help you are likely to be able to access. If staff are aware of your condition, they may be able to be more flexible around your studies. It may 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.

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WHAT SHOULD I SAY?

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 or at the end of a row in order to leave the room quickly. If there are locker facilities, 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 or painful joints have made it difficult to walk quickly.
- **Medication and nutritional needs.** You may need to take medication or perhaps eat a snack during lectures, seminars or classes.
- **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 GP or hospital appointments, hospital admissions or because you are unwell.
- **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.

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WHAT ABOUT COURSE WORK DEADLINES?

One of your main concerns may be about getting work in on time, especially when you are having a flare-up or if you have to go into hospital.

Some universities and colleges will include requesting coursework extensions in a Study Needs Agreement, if you have one. Others may ask that you submit work when you can, and if it is late, you can then apply for mitigating or extenuating circumstances. You may need to submit a doctor's note as evidence for this. If your request is successful, the penalty for late submission may be waived or you may be given the opportunity to do the coursework again.

Rules are different from one university or college to another, and it is worth checking in advance what the policy is.

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. If you have IBD, you may find the stress can trigger a flare-up. Try to pace yourself and find ways to 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 ask for special arrangements in exams. These might include, for example, sitting close to the exit nearest the toilets, taking the exam in a separate room away from the main cohort of students or requesting extra time. 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.

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At the beginning it felt like I had to fit in with going out and socialising a lot. But once I had told people about my Crohn's, they were understanding if I needed a 'night off' to rest.

—
Jess, age 18
diagnosed with Crohn's Disease in 2008, studying Medicine

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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 this, then they aren't likely to become good friends anyway.

If you do feel unwell during the first few weeks but don't want to go into details, you could just say you have a 'tummy bug'. Or just limit your explanation to the fact that you have a gut condition that means you have to rush to the loo frequently. You can then give more details if and when you are ready.

One way to give people more information about IBD could be to suggest that they visit the Crohn's and Colitis UK website at: www.crohnsandcolitis.org.uk.

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 at least a few friends, and they are able to build up the same support in their new environment as they had around them at home. Having a supportive network of people who understand your condition and can offer support when it is really needed can make all the difference. For example, you may wish to give a close friend or flat mate a contact number of a family member in case you are unwell, or tell them where you keep your treatment card if you have one.

As someone with IBD, you may need to be careful about what you eat and drink. This might make you feel different from other students, particularly if you avoid alcohol during freshers' week when there tends to be a lot of activities around going to bars. 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 not drinking 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**.)

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Sometimes IBD and a social life can feel like they don't go together. But I felt it was important to tell people who I trusted about my Crohn's. I'm glad I did because they have been really supportive.

—
Chris, age 25
diagnosed with Crohn's Disease in 2013, studying Medicine

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I have found telling tutors and friends has been really helpful. On days when I feel ill or tired, they are supportive and usually try and find a way to lift my spirits.

”

Isobel, age 22
diagnosed with Crohn’s Disease in 2012,
studying Fashion and Costume

Most people want to throw themselves fully into university or college life, and enjoy the new experiences on offer, but it may help to recognise your limits. Pushing your body too far might make you feel unwell, so that you end up missing out on more activities than if you had paced yourself from the beginning. In such a new and exciting environment, it can be difficult to keep the same routine, which is likely to be very different from when at home. You may, for example, find it harder to remember to take your medication on time without parents around to help you remember. You might find it useful to plan ahead and set yourself reminders, particularly in the early days, when you are you getting used to new surroundings. There are many medicine reminder apps for mobile phones which could help with this. Or, you might want to put a note on the back of the front door as a prompt when you are going out. (See our leaflet: **Staying Well with IBD**, for further suggestions.)

When you 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.

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WHAT ABOUT SEX AND RELATIONSHIPS?

A common concern, although people don’t like to talk about it, is the potential impact of IBD on sex and relationships. See our leaflet: **Sexual Relationships and IBD** for further information.

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I FEEL ANXIOUS AND STRESSED. IS THERE SOMEWHERE I CAN GO FOR SUPPORT?

All students experience anxiety when they start university. Sometimes the pressure of exams, coursework, being away from home, or feeling isolated when ill may become too much to deal with, even if you have the support of friends and family. If you do find you are becoming anxious, stressed, or depressed, you can access the counselling service at your university or college in complete confidence. You may find as well as face to face counselling that some counselling organisations offer support by telephone or webchat.

Counselling can help with not just health-related issues but also in dealing with dilemmas or difficult decisions, relationship difficulties, sexual problems, or identity issues. See our leaflet: **Counselling and IBD**, for more information.

Some students with IBD have found it helpful to talk about their condition with others through online forums and social media sites such as Facebook. Crohn’s and Colitis UK run a Facebook Forum in which young people can share experiences and get support from others. See **Help and Support from Crohn’s and Colitis UK** for details.

Membership of Crohn’s and Colitis UK is free for students.

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If I could give one piece to students with IBD, it is that you should never be afraid to ask for help. It can make all the difference.

”

Jake, age 22
diagnosed with Crohn’s Disease in 2007, studied English Literature and Creative Writing

“

One thing I would say is don’t be embarrassed to have IBD, speak up, and don’t let it stand in the way of things you want to do!

”

Helen, age 18
diagnosed with Ulcerative Colitis in 2010, studying Biochemistry

WHAT OTHER SUPPORT IS THERE AT COLLEGE OR UNIVERSITY?

Careers Service

If you are worried about starting work, and whether to speak to your employer about your IBD, you may wish to speak to the Careers Service at your university or college. The Careers Service can support you in finding employment, during your course, and most can help even after you have graduated. If you are unsure about whether to tell an employer about your condition, a Careers Adviser will be able to talk through the options with you. If you decide to tell an employer, a Careers Adviser will also be able to guide you about how to approach this. It is likely to be worthwhile visiting your Careers Service on campus to see how they can help. Careers services and their contact details can also usually be found on the university or college website.

We produce two information sheets on employment and IBD – one for employees, and one for employers. See our website in **Help and Support from Crohn’s and Colitis UK** for further details.

Students’ Union

You may also find a Students’ Union on your campus. As well as offering clubs and societies for students to join, the Students’ Union can also provide advice relating to a range of areas including finance, accommodation and welfare. Details of the Students’ Union can usually be found on the university or college website.

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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 from study. But, even if this means taking an extra year, although this might seem like a long time, it is unlikely to disadvantage your future career, and might enable you to complete your studies more successfully.
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HELP AND SUPPORT FROM CROHN'S AND COLITIS UK

You can download all our information sheets and booklets from our website: www.crohnsandcolitis.org.uk. You can also request them free of charge from our office – call or email the Information Service.

Crohn's and Colitis UK Information Service: Our helpline is a confidential service providing information and support to anyone affected by Crohn's Disease, Ulcerative Colitis and other forms of Inflammatory Bowel Disease (IBD).

Our team can:

- help you understand more about IBD, diagnosis and treatment options
- provide information to help you to live well with your condition
- help you understand and access disability benefits
- be there to listen if you need someone to talk to
- put you in touch with a trained support volunteer who has personal experience of IBD

Call us on **0300 222 5700*** or email info@crohnsandcolitis.org.uk

Monday, Tuesday, Wednesday and Friday – 9 am to 5 pm
Thursday – 9 am to 1 pm

*Calls to this number are charged at a standard landline rate or may be free if you have an inclusive minutes' package. Calls may be recorded for monitoring and evaluation purposes.

Crohn's and Colitis UK Forum

This closed-group community on Facebook is for everyone affected by IBD. You can share your experiences and receive support from others at:

www.facebook.com/groups/CCUKforum

OTHER ORGANISATIONS

Disability Rights UK

12 City Forum, 250 City Road, London, EC1V 8AF.

Students' Helpline: 0800 328 5050

Email: students@disabilityrightsuk.org

Website: www.disabilityrights.org.uk

Here you can find a link to the Disability Rights UK 'Into Higher Education' guide with information you may find helpful on visiting universities and choosing your course, funding and disability support services.

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Students with IBD: a guide for students - Edition 4

Last review: November 2016

Next planned review: 2019

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We hope that you have found this leaflet helpful and relevant. If you would like more information about the sources of evidence on which it is based, or details of any conflicts of interest, or if you have any comments or suggestions for improvements, please email the Publications Team at publications@crohnsandcolitis.org.uk. You can also write to us at Crohn's and Colitis UK, 45 Grosvenor Road, St Albans, AL1 3AW or contact us through the **Information Line: 0300 222 5700**.

ABOUT CROHN'S & COLITIS UK

We are a **national** charity established in 1979. Our aim is to improve life for anyone affected by Inflammatory Bowel Diseases. We have over 28,000 members and 50 local groups throughout the UK. Membership costs start from £15 per year with concessionary rates for anyone experiencing financial hardship or on a low income.

This publication is available free of charge, but we would not be able to do this without our supporters and members. Please consider making a donation or becoming a member of Crohn's and Colitis UK. To find out how call **01727 734465** or visit www.crohnsandcolitis.org.uk

