



INFORMATION SHEET

STUDENTS WITH IBD: A GUIDE FOR UNIVERSITIES AND COLLEGES

INTRODUCTION

It is very likely that several students in your university or college will suffer from Ulcerative Colitis (UC) or Crohn's Disease, known collectively as Inflammatory Bowel Disease or IBD. IBD affects at least one in 210 people in the UK population, and it is quite common for these illnesses to start in late teens and early adulthood.

IBD can make student life more demanding, and some students with IBD need additional support and encouragement to help them achieve their full potential. This information sheet is intended to help those involved with supporting students to have a better understanding of some of the possible effects of IBD. It also looks at the areas in which help may be most beneficial.

WHAT ARE ULCERATIVE COLITIS AND CROHN'S DISEASE?

Ulcerative Colitis is inflammation of the colon and rectum (large bowel), causing ulceration and bleeding in the lining of the colon.

Crohn's Disease is inflammation of the digestive tract, which can occur anywhere between the mouth and the anus, but most commonly affects the small bowel or the colon. Crohn's can damage all the layers of the lining and wall of the bowel.

These are lifelong illnesses which may have periods of remission when there are few symptoms, but also periods of relapse when the disease is active and the symptoms are much harder to cope with. There is no cure at present.

WHAT THEY ARE NOT...

- They are not the same as Irritable Bowel Syndrome (IBS). This is a different condition that requires different treatment.
- They are not infectious.

WHAT CAUSES UC AND CROHN'S?

Although there has been much research, the cause of IBD is still uncertain. However, over the past few years, there have been major advances, particularly in genetics.

Researchers now believe that IBD is caused by a complex interaction of factors: the genes a person has inherited and an abnormal reaction of the immune system to certain bacteria in the intestines, triggered by something in the environment.

Viruses, bacteria, the use of antibiotics, diet and stress have all been suggested as environmental triggers, but there is no definite evidence that any one of these is the cause of IBD.

WHAT ARE THE SYMPTOMS?

The common symptoms are:

- urgent need to go to the toilet
- diarrhoea (sometimes bloody)
- severe abdominal pain
- extreme tiredness
- nausea
- lack of appetite and weight loss

Some people with IBD also suffer from pains in their joints, eye problems, severe mouth ulcers, and skin rashes.

WHAT CAN BE THE IMPACT OF HAVING IBD?

Delays in development

Inflammation in the gut can affect both appetite and the absorption of nutrients, causing impaired growth. A young person with IBD may look and feel different from their peers - and may find themselves excluded from social activities and treated inappropriately for their age.

Effects of treatment

IBD generally requires life-long treatment, which can have unpleasant side effects. Treatment often includes corticosteroids (steroids) to reduce inflammation, and/or drugs that suppress the immune system.

(These steroids are not the anabolic steroids sometimes used by athletes.)

Unwanted side-effects of steroids, especially at high initial doses, can include:

- significant weight gain
- roundness of the face
- acne
- mood swings, from euphoria to depression

Other unwanted side effects from drugs used to treat IBD may include:

- headaches
- nausea
- flu-like symptoms
- increased susceptibility to infection

While most IBD drugs are taken in tablet form, some treatments involve weekly injections or visits to hospital or clinic for intravenous (IV) drug treatment.

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I had an emergency colectomy operation for Ulcerative Colitis when I was 19. But with support from my family, friends and university, I've achieved a lot in the past few years. I'm now in my second year of university and I lead an active work and social life. I go abroad, spend time volunteering and manage to hold down part time jobs alongside my studies.

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Ellie, age 21
diagnosed with Ulcerative Colitis in 2013, studying English Language and Literature

Some young people may be on dietary treatment. This takes the form of a liquid diet consisting of all the nutrients needed. Usually, nothing other than the diet and water are allowed for weeks or months at a time. If they have difficulty drinking the feed, they may take it via a tube inserted through the nose down into the stomach. Once in place the tube can remain for many weeks. The high concentration of nutrients in the feed can sometimes cause nausea and headaches.

Hospitalisation

There may be times when a student experiencing a severe flare-up of IBD needs treatment in hospital, sometimes lasting several weeks. In very severe cases, badly affected parts of the bowel may need to be removed by surgery. This sometimes involves an ileostomy (surgery to create an opening of the small bowel onto the surface of the abdomen) and wearing a stoma bag to collect waste (faeces). Stomas may be temporary but can be permanent.

Psychological effects

Young people with IBD are often at increased risk of depression and anxiety because of the unpredictability of their condition, the feelings of loss of control their symptoms can cause, and the adverse effects of IBD drugs. When chronic pain and exhaustion are ongoing, the student may be unable to concentrate, may feel depressed, and perhaps, in extreme cases, have suicidal thoughts. Although stress is not a cause of IBD, a number of studies have shown that stress is often associated with relapses of the condition. Exams can be particularly stressful and have been linked with flare-ups of IBD.

It can be hard for young adults with IBD to have to cope with the embarrassment of their disease. They may dread having to rush for the toilet, having an 'accident', smells and ridicule. They may feel distressed about being much smaller, thinner or less developed than their friends. Or, if they are taking high dose steroids for their treatment, they may become depressed about putting on weight and becoming fatter and round-faced. Changes in their perception of body image can lead to low self-esteem.

Students with IBD may also feel isolated and out of step with their peers due to missing lectures or being unable to join in activities. It can be particularly difficult to cope with the unpredictability of IBD, which might mean feeling perfectly well one day, and utterly drained and exhausted the next. IBD is also an unseen condition, which can again be hard to manage. Someone with UC or Crohn's may not look that unwell to others, especially if they are taking steroids, when they are, in fact, feeling awful.

HOW CAN UNIVERSITIES AND COLLEGES HELP?

By being aware of the difficulties and needs of students with IBD, and offering support where needed, staff at universities and colleges can make a real difference to the lives of students with these conditions.

Some of the main areas where support might be required are listed below.

Respect and understanding

Each individual is unique, and students with IBD are likely to have differing views about how they wish to deal with their condition while at university or college. Some students may wish to keep their IBD entirely private and avoid disclosing their illness, whereas others may want to be completely open. It is very important that whatever their view, the student feels supported and knows that his or her position will be respected.

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I started to have a lot of absences, so I confided in my head of year. He referred me to the Disability Services as he realised I needed help. They were so helpful. When I was struggling with extreme fatigue, they arranged for me to have access to a working laptop so I could work from home, and help with taxi costs to get home from university. Both made a real difference.

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

Access to Disability Services

Students with IBD may or may not consider that they have a disability.

However, if they have UC or Crohn's, they may have needs which mean they might benefit from the support offered by Student Disability Services. For example, Disability Advisers can often:

- help with suitable accommodation
- advise students about applying for Disabled Students' Allowance
- at some universities and colleges, draw up a general agreement outlining the student's extra support needs
- agree with the student what information about their condition may be shared with other university staff, and what will be kept completely confidential
- liaise with the student's department on their behalf

If it seems the student may be unaware of this, it may be helpful to flag up the kind of help and assistance that Disability Services can offer.

Accommodation

Many students with IBD consider en suite accommodation a necessity. If this is not available then it helps if the student can have a room very close to a toilet and bathroom/shower. However, this is less satisfactory as without en suite facilities there can still be the possibility of embarrassing accidents.

Other accommodation needs may include:

- living on or close to campus to help minimise travel needs
- convenient laundry facilities
- catering on site, or, alternatively,
- cooking facilities, which may make it easier for some students with IBD to meet their dietary requirements
- access to a fridge for medications

Departmental support

Many students with IBD find it helpful to have someone within their academic department whom they can talk to about their IBD and some of the difficulties it might cause. This can apply even if the student has a Study Needs Agreement or something similar. If no personal tutor is available, please consider appointing another member of staff as a contact for the student.

Common IBD-related support needs

Students with IBD often have particular needs or difficulties such as the following:

- **Contenance or urgency problems.** Many people with IBD worry that a delay in getting to the toilet might result in an 'accident', so often prefer to sit close to the exit or at the end of a row in a teaching room or lecture theatre. Students may also appreciate the use of a locker for spare clothes and washing kit, and/or permission to use staff toilets if these are available.
- **Lateness.** An urgent need for the toilet (particularly after food) may also lead to late arrival at seminars or lectures. Or, a student may arrive late because general fatigue or joint pains have made walking quickly difficult.
- **Medication and extra snack breaks.** Some students with IBD may need to take prescribed drugs at certain times of day. This may, on occasion, mean taking medication during lectures or seminars. Some will also need to eat at regular intervals, so may need extra meal breaks.
- **Feeling unwell.** Frequent pain and exhaustion affect concentration, so a student with these symptoms may need to return to their accommodation during the day. At other times they may be able to take a brief period of rest or a prescribed painkiller, and carry on.
- **Missing sessions.** A student may miss teaching sessions because of medical and hospital appointments, hospital admissions or being ill at home. If they are resting at home there may be times when they are still able to cope with most academic work. At other times, for instance during a relapse or when in hospital, they may not be able to manage as much.

- **Field trips.** Given the unpredictability of IBD it can be difficult for students with this condition to commit to going on a trip much in advance of the day itself. They may also be concerned about toilet facilities on the journey and at the field trip accommodation.

Being aware of these sorts of needs, if a student with IBD decides to disclose their condition, will enable members of academic staff to respond in a positive manner, for example:

- allowing students to leave and rejoin class sessions without comment
- not commenting on or penalising late arrival at lectures or seminars
- giving permission for the student to take a short break to take medication or to eat in class when necessary
- ensuring that the student is able to access assignments and lecture notes electronically if they are, for example, well enough to work from home but not to attend on campus lectures or seminars
- appreciating that IBD may mean that the student has to miss sessions and understanding that they may not always be able to get a doctor's appointment as evidence of their absence
- being flexible with arrangements for them to catch up, for example, practical or lab classes
- ensuring that suitable arrangements have been made if a student is expected to go on a field trip.

Coursework extensions

At times when a student's IBD is causing particular trouble, they may be too tired to complete coursework on time. In such circumstances an extended deadline can be very useful. Not all universities and colleges allow this and the policy may be to suggest that students submit as much as they can. If they then feel their IBD has affected their ability to meet a deadline, they may be able to request mitigating or extenuating circumstances. This might mean that if their request is successful, the penalty for late submission is waived or they are given the opportunity to do the coursework again. It can be helpful if staff are aware of the policies in place and encourage students to feel they can discuss possible difficulties with deadlines at an early stage.

Exams

The stress of exams has been linked to flare-ups of IBD. Studying for exams may also be very difficult and the student may need extra guidance and emotional support.

The fact that exams have to take place at fixed times puts additional pressure on students with a fluctuating and unpredictable illness like IBD. They may also have particular problems with morning exams if their bowels are most active then, as is often the case.

You can be mindful of the student's needs by, for example, planning seating arrangements so they can sit close to the door nearest the toilets and by organising in advance who will escort them to the toilets if they need to go urgently. Students with IBD may also need extra time to complete papers if they have had to take several breaks or if they suffer from severe fatigue. Providing a separate exam room for such students can be a good way of meeting these needs without disrupting other students, provided the student with IBD is happy with this.

Occasionally a student with IBD may be completely unable to sit an exam. It is helpful if the university or college can then offer the opportunity to defer the exam, if possible with no cap on grades.

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In my exams, I had extra time and one-to-one invigilation so I could take extra toilet breaks. It meant I didn't get so worried about running out of time to finish the exams, because I had extra time and could go to the toilet.

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

Extra-curricular activities

Some students with IBD may feel they are less able than other students to join in clubs and activities, however interested they may be, because they are unsure about committing themselves. Any special encouragement, consideration or adjustment that can be given will help their full involvement in college/university life.



ADDITIONAL SUPPORT

Support for HE students may be available through Disabled Students' Allowance (DSA) funding. For more information contact the university or college Student Disability Services.

If students are worried about getting into work and whether to speak to an employer about their condition, it is worth referring the student to the university or college Careers Service. A Careers Adviser will be able to talk through the different options with the student. We produce two information sheets on employment and IBD – one for employees, and one for employers. See our website below for further details.

Disability Rights UK is another useful source of information about disability related support. See www.disabilityrightsuk.org

At Crohn's and Colitis UK, we offer personal grants for people with IBD under our Educational and Vocational Support programme. Further information is available on our website: www.crohnsandcolitis.org.uk, and via the Crohn's and Colitis UK Information Service (see details of this in **Help and Support from Crohn's and Colitis UK** on the next page).

Young people with IBD may find it useful to share their experience and get support from others by joining a web forum, such as the Crohn's and Colitis UK Forum (see **Help and support from Crohn's and Colitis UK** on the next page for further details).



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

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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 or 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

