



Students with IBD : A guide for universities and colleges

Introduction

It is very likely that at least one student in your University or College will suffer from Ulcerative Colitis or Crohn's Disease, known together as Inflammatory Bowel Disease or IBD. With the increase in adults retraining, it is also possible that they may be a mature student. In the whole population, 1 person in every 400 is likely to be affected and it is quite common for these illnesses to start in late teens and early adulthood. IBD can make student life extra demanding. Some understanding of the physical and psychological effects of IBD will help you to provide the support and encouragement students with IBD often need to achieve their full potential.

What are Ulcerative Colitis and Crohn's Disease?

Ulcerative Colitis is inflammation of the colon (large bowel) which causes 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 causes ulceration and damage to the lining and the wall of the bowel. They are lifelong illnesses with periods of relapse when there is active disease and periods of remission, when there may be few or no symptoms. There is no cure at present.

What they are not...

- They are **not** the same as the more common Irritable Bowel Syndrome (IBS).
- They are **not** infectious.

What causes UC and Crohn's?

The cause or causes are not yet known. Researchers believe IBD may be caused by an abnormal reaction of the immune system to intestinal bacteria, sometimes combined with genetic factors and environmental triggers.

What are the symptoms?

The common symptoms are:

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

Some students may also suffer from:

- pains in their joints, making moving about difficult
- eye problems
- mouth ulcers
- skin rashes

What can be the impact of having IBD?

Delays in development

Inflammatory processes can affect both appetite and the absorption of nutrients, causing impaired growth. The student 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 to reduce inflammation. Unwanted side-effects of this drug, especially at high initial doses, are often:

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

NB These steroids are not the same as anabolic steroids sometimes used by athletes.

Other unwanted side effects from various drugs used for treatment may include:

- headaches
- nausea
- flu-like symptoms

Some people take 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. Very occasionally, if the student has 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 sometimes causes:

- nausea.
- headaches
- a feeling of light-headedness

Hospitalisation

There may be times when a student experiencing a severe acute flare-up of disease 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. Surgery sometimes includes forming an ileostomy (an opening of the small bowel onto the surface of the abdomen), which may create further problems.

Psychological effects

Young people with IBD are at increased risk of depression and anxiety, due to the unpredictability of relapses, feelings of loss of control from the adverse effects of drugs and from the kinds of symptoms they experience. When chronic pain and exhaustion are

ongoing the student may be unable to concentrate, feel depressed and in some cases have suicidal thoughts. Although stress is not a cause of IBD, many doctors have observed that stress is associated with relapses of the condition, often at exam time.

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 lavatory, having an accident, smells and any possible ridicule. Many may feel distressed by being much smaller, thinner and less developed than their friends; or if they are taking high dose steroids for their treatment, putting on weight and becoming fatter, round-faced and spotty. Changes in their perception of body image can lead to low self-esteem.

They may feel even more isolated and out of step with their peers because of missing lectures or being unable to join in activities. Also it is difficult to cope with feeling great one day and utterly drained, pained and exhausted the next. They may not look unwell to others, especially when taking steroids, while in reality they are feeling awful. Having a hidden condition is often even more difficult as others are less likely to be aware of their predicament.

One student's experience whose worsening symptoms forced him to spend three weeks of his first term in hospital ...

"I was experiencing diarrhoea with 20-40 bowel movements a day and felt tired most of the time which caused me to fall asleep during some lectures. I spent 22 days in hospital which meant I missed lectures, social life and coursework deadlines so when I did get round to handing in my work it was capped to a low grade."

How can universities and colleges help?

Being aware of the particular needs and difficulties of students with IBD, you can make a real difference to their lives, making them feel supported, in the following ways:

Respect and understanding

Each individual is unique, and students with IBD are likely to have differing views as to how they wish to be dealt with at university and college. If possible appoint a personal tutor whom the student can go to when they are anxious about anything, from problems with work to difficulties they may have with a particular lecturer not being understanding. Discussion with the student about their individual needs may include the following queries:

- Does the student want their IBD to be kept private, or would they prefer to be completely open about their illness?
- Do they wish to be pushed as hard as all the other students, or are there circumstances when they are likely to need extra consideration?

- If special procedures are implemented, such as extended deadlines, do they need explanation to fellow students etc?
- How should potential teasing and ridicule be dealt with?

Accommodation

Students with IBD usually consider en-suite accommodation a necessity due to the urgent and sudden need to go to the lavatory. If you are unable to offer this type of facility, then it would be very helpful to offer a room nearest to the bathrooms.

Toilet needs during lectures and seminars

Any delay in getting to the lavatory could easily result in an accident and the student may wish to sit close to the exit in order to leave the room quickly. It may be helpful to reassure the student that this is alright.

Using communal toilet areas can be embarrassing for people with IBD, so permission to use staff lavatories could be very helpful. It may also be helpful if the student can have the facility of a locker by a lavatory to keep spare clothes and washing kit in case of accidents, particularly if their accommodation is not nearby.

Lateness

An urgent need for the lavatory (particularly after food) may lead to late arrival at seminars or lectures. Lateness may also result if there is some distance to be covered between rooms. Extreme tiredness or joint pains may slow a student down.

Taking medication

A student may need to take prescribed drugs at certain times of day, for example before meals.

Food and eating between breaks

Very often the student will have difficulty in eating a normal size meal. This may be because they feel full when very little food has been eaten, or because of pain or needing to go to the lavatory during the meal. This means that the student may need to eat small amounts regularly, sometimes supplemented by special liquid feeds, to make sure that they eat enough to meet their needs.

Feeling unwell at college

Frequent pain and exhaustion affect concentration, so a student with these symptoms may need to return to their accommodation. At other times they may be able to take a brief period of rest or a prescribed painkiller to help them carry on.

Coursework

On days when the disease is causing particular trouble, a student may be too tired to complete course work on time. In such circumstances, an extended deadline would be most helpful. Studying for exams may also be very difficult and the student may need extra guidance and emotional support.

Missed college

A student may miss college because of medical and hospital appointments, hospital admissions or being ill at home. If a patient is resting at home they may be able to cope with most college work. At other times, when in hospital for instance, they may not be able to manage as much, but will benefit from contact and reassurance about catching up.

Exams

The fact that exams have to take place at fixed times puts pressure on students who have a fluctuating and unpredictable illness. They may also have particular problems with morning exams if their bowels are most active then, as is often the case. It is helpful to seat the student close to the door nearest the lavatories and to arrange in advance who will escort them to the lavatory if they need to go urgently. Providing extra time would also be helpful. Sometimes it may be helpful to provide a separate room for such students but this should only be done with the student's agreement.

In exceptional circumstances when a student is unable to leave home, it would be helpful to provide an invigilator to enable the student to sit an examination at home.

Visits and field trips

These can be a major worry if there are no toilet facilities on a coach or none readily available during the trip. Due to the fluctuating nature of the illness, it would be helpful, where possible, if they could delay a decision about being able to go until the day or close to the day and don't have to commit themselves financially beforehand.

Extra-curricular activities

A student may not feel able to join in clubs and other activities, however interested they may be, because they are unsure about committing themselves. They may also be unsure about whether intermittent attendance is acceptable. Any special encouragement or consideration that can be given will help to support their full involvement in college life.

Additional support

A Summary sheet is attached. It would be helpful to circulate copies of this to all your departments, including your medical centre, to raise the awareness of the possible effects of IBD on students with the condition. Communication between learning support staff, college counsellors and other specialist providers will enable those with IBD to make the best use of their opportunities.

Your Disability Officer may be able to help the student access support, particularly the Disabled Students Allowance, which could help, for instance, to pay for en-suite accommodation.

NACC offers Educational and Vocational Grants for young people with IBD between the ages of 15 and 25. Further information is available from the NACC office.

The National Association for Colitis and Crohn's Disease (NACC) operates a supportive listening service called **NACC-in-Contact** on **0845 130 3344** run by trained volunteers with personal experience of IBD.

NACC has produced a video/DVD called **Talk About Crohn's** of three young people talking about their experience of growing up with Crohn's Disease. A similar video/DVD

for Ulcerative Colitis has one young person and two older people talking about living with this condition. Copies are available for £20 from the NACC website: www.nacc.org.uk.

Further information

For further information on any aspect of IBD and for full details about all NACC's publications and services please contact our **Information Line: 0845 130 2233**.

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This document has been prepared by NACC as general information on the subject and is not intended to replace specific advice from a health professional.

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
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For lecturers who teach someone with Ulcerative Colitis or Crohn's Disease ...

A summary of how you can help

Ulcerative Colitis and Crohn's Disease are inflammatory bowel conditions which can cause severe stomach pain, an urgent need to use the lavatory, diarrhoea, nausea, loss of appetite or extreme tiredness. Sometimes there are joint pains that can make moving about painful as well. Symptoms fluctuate: one day a student may be fine, the next day in pain and exhausted.

The disease can delay growth and cause extreme thinness. However, treatment with steroids can cause excessive weight gain, a moon-face, spottiness and mood swings, particularly weepiness. These conditions are very embarrassing and very painful, both physically and psychologically.

Actions that can help:

- Let the student leave and return to the lecture room freely whenever they need to use the toilet.
- Let them use the staff toilet for privacy or if other toilets are some distance away.
- Appreciate that they may arrive late at college or for lectures because of urgency to use a toilet or joint pains that have slowed them down.
- Let them judge for themselves how much they can join in; but don't stop them trying whatever they want to try.
- Respect their embarrassment about this condition and their need for privacy; they should decide how much anyone in the class is told.
- Try to check arrangements for them on group trips (eg: using a coach that has a toilet).
- Try to be alert to ridicule from others.
- Leave the student to decide whether they need to go and rest at their accommodation, or can keep studying after a break.
- If they have to have time off, either at home or in hospital, don't automatically wait for them to return before offering coursework. Sometimes they need to rest, but would be able to do some work.
- At other times, when they are more ill, they still need contact and reassurance about catching up.
- Arrange a liaison person for the student or other lecturers to talk to.
- If further information would be helpful, contact the student's specialist nurse or doctor, or the National Association for Colitis and Crohn's Disease Information Line: **0845 130 2233**.
- The occasion might arise when a tutor might wish to speak to the student's doctor. This should only be done with the agreement of the student concerned except when it is a matter of urgency or when great concern is felt for the welfare of the student.