



dealing with school or college when you have IBD

IBD and education do not always mix. It can be hard to catch up after being in hospital and you might have a daily battle with fatigue and pain. You might feel left out if you have to miss sports clubs, trips or social activities.

Some young people with IBD are small for their age, which may make them worried about bullying. You may have to take steroids. That can lead to weight gain, a puffy face and acne, and change the way you feel and act.

It can feel like an embarrassing condition to have – and to talk about. Having to go to the toilet a lot, the possibility of accidents and the general feeling of 'being different' are all hard. You might feel low or worried. You might want to hide away and stop doing things you used to like. It can be really tough when you have a flare up and get more ill.

Remember, IBD might have made things harder for you at school/ college, but some of the challenges may have been there anyway. All young people can find it hard, try and pick out what is hard because of IBD and what would have been anyway, even if you didn't have IBD. Sometimes we can blame everything on IBD!

Luckily, there are lots of things you can do to make going to school or college with IBD easier.

"It seemed impossible to start living a normal life, but my parents and siblings helped me build up the confidence and once I went back to school it wasn't as bad as I'd imagined."

Orlaith, 14

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hints and tips

- You might not want to tell anyone about your condition, but **we would recommend telling your class teacher** or head of year and the special educational needs coordinator (SENCO). Between them, they can make sure you have the support you need.
- **Having plans in place**, even if they are never used, is much less stressful than trying to get what you need in the middle of a crisis. Start thinking about what support you might need, such as extra time on exams, early. That way you can be prepared.
- **We are all changing all the time**. What we need, and how, will change too. Work with your parents or carers and school staff to review your healthcare plan at every open evening and after any relapse.
- **If you are going to miss 3 weeks** or more of education, begin discussions with school or college as soon as possible to find out what they can put in place to support your learning at home. This will help you keep up.
- **Remember spending time with your friends is important**. Sometimes, you might want to hide away but that could make you feel worse. Why not try meeting with just one or two close friends for an hour or so?
- **You might not want to tell anyone about your condition, but why not just pick one or two people you trust?** It means you will always have someone on your side.
- Are there any **practical ways to deal with IBD** symptoms in school or college? Could you keep a **second set of textbooks** at home, to avoid carrying them around? Or could you have **extra time between classes for toilet stops?** Ask for a **toilet pass** or a **Can't Wait card** from CICRA, so you can go whenever you need to.
- **Can you distract yourself from pain during classes?** Maybe try a fidget spinner, concentrate on your breathing, or just get up and have a stretch.

"I had a flare in Year 6 that carried on into Years 7 and 8. It wasn't nice to go through the start of secondary school with, but I haven't let it stop me. My friends at school have been very supportive. We are always laughing and whenever I'm not at my best they always keep me up and running."

Harry, 15

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activity one

Express your fatigue

Lots of people with IBD have fatigue. It can make it hard to concentrate or take part in class. It can make you irritable or frustrated – especially when someone says it is 'just' being tired.

It can help to be able to explain fatigue to tutors and friends. Some people say it feels like 'hitting a wall' or 'being completely drained of any energy'. But it is different for everyone.

What does it feel like to you? Why not try writing it down?

Start a fatigue diary

If you understand how different activities make you feel, it might help you manage your fatigue better.

Why not make a note of what you have been up to, and how much energy you have at different points in the day? You could do it on your phone or start a paper diary, like the one below.

Try filling it in once or twice a day.

Day and time	Activity log	Energy level
Monday morning	PE at school	😞
Monday evening	Dinner and TV with the family	😊
Tuesday daytime	Hospital appointment, history lesson	😴
Tuesday evening	After school club	😞

You might find that you have more energy first thing in the morning, or last thing at night. Once you know that, you can plan around it.

Maybe imagine you have a jar of 'energy marbles' and each marble is one 'bit' of energy you have for a day. You might have a certain number of marbles for sport or exercise. Then there is another number for doing stuff you need your brain for, like schoolwork, and some marbles for having fun.

How would you use your marbles? What are the best things to 'spend' your marbles on and when? Remember, it is different for everyone so try different things to see what works for you.



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activity two

Who are you?

IBD is only part of what makes you who you are. Focusing on what you are good at will help you see that.

Why not write a list of the things you like about yourself? Try asking yourself the following questions and, remember, you can always ask your family for a little help.

- 1) **What are you good at?**
- 2) **What do you like best about yourself?**
- 3) **What are you most proud of?**
- 4) **Do you remember a time you did something you didn't think you would be able to?**
- 5) **How did you do it?**
- 6) **What would you do differently if you had to do it again?**

You could even put the list on the fridge or pin it to a notice board in the house.

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more ways to get help or support

- [Watch](#) Dr Kate Blakeley talk about living and coping with IBD
- Speak to others in your situation at a CICRA [Family Day](#)
- Speak to Laura, CICRA's [Family Support Worker](#) or ask her to connect you with others in your situation
- See the emotional wellbeing kit [resources library](#) for lots more ideas and support
- CICRA's [resources for schools](#) include booklets for primary and secondary schools, quick guides for class teachers, information about individual healthcare plans, advice on exams and tests, and examples of letters to exam boards
- Young people share their tips on coping with school in these [videos](#)
- [Bullying UK](#) offers help and support on dealing with bullying

do you need a little more help?

We designed this kit to help you and your family cope with some of the common ways IBD can make you all feel. But sometimes, you might need a little more help – and that is OK.



Lots of people feel that way.

If you spot any of the following signs, it might be a good idea to ask your healthcare team if they can offer any extra psychological support, or at least point you in the right direction of services in your area:

- Feeling like you cannot cope
- Struggling to use the tools in this kit
- The tools in this kit do not seem to be working for you
- A lack of interest in the things you usually enjoy
- A feeling of sadness that does not go away
- Thoughts of harming yourself or others