



## helping your child cope with school

School can be hard for young people. IBD may add a few extra challenges. Most young people with IBD cope ok, but these are some of the difficulties that may come up.

It might be hard to catch up after a spell in hospital. Dealing with fatigue and pain can sometimes be a daily battle. Young people with IBD might miss out on sports clubs or school trips and struggle to keep up with their peers' social activities.

The nature of the condition can make it embarrassing to have – and to talk about. Frequent trips to the toilet and the general feeling of 'being different' may take a bit of a toll.

Some young people with IBD are small for their age, which may make them worried about bullying. If they take steroids, these can cause distressing side effects: weight gain, a puffy face and acne, mood and behaviour changes.

The risk is these may make them become withdrawn, anxious or feel depressed. Relapses can be difficult to deal with emotionally.

Of course, it is not only children with IBD who have a hard time at school. Growing up is not easy and young people can struggle as they develop their self-identity and their place among their peers.

But, there is lots you can do to support your child through school with IBD.

*“Steroids appeared to be the only drug that made any real difference stopping my symptoms. But I fought my way through education, got the best grades I possibly could, and achieved my ultimate goal of getting into medical school.”*

Karina, 21

# helping your child cope with school



## hints and tips

- Children might not want to tell anyone about their condition, but **we would recommend telling their class teacher** or head of year and the school's special educational needs coordinator (SENCO). Between them, they can make sure your child's educational and medical needs are met.
- **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 your child might need, such as extra time on exams, early on so you know you are prepared.
- **The only constant is change**. So, discuss and review your child's healthcare plan at every open evening and after any relapse.
- If your child is likely to be **absent from school for 3 weeks or more**, begin discussions with the school as soon as possible to find out what they can put in place to support their learning at home. The local council have a duty to make sure your child gets as normal an education as possible.
- **Remember spending time with others is important**. It is natural to feel protective, but your child wants and needs to do the same things as other children their age.
- Help them **build their resilience** and self-esteem – and to realise that being different is a good thing.
- **Encourage them to tell their closest friends**. This will give them a support network to lean on when you are not there and help them to think about what they might want to say/how they could say this.
- Are there any practical ways to deal with IBD symptoms in school? Could you keep a **second set of textbooks** at home, so they do not have to carry them when fatigued? Could they have **access to a private toilet** and permission to use at any time? Or a **toilet pass**, ask CICRA for a **Can't Wait card**.
- **Help them to develop ways of distracting themselves from pain during the school day**. Could they play with a small toy, such as a fidget spinner, to take their mind off it, for example? They could try carrying a 'grounding object' to focus on when things get too much. That might be a special pebble or coin, or a meaningful wristband or piece of jewellery.

*"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. 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

# helping your child cope with school



## activity one

### Take control of fatigue

Fatigue is a very common symptom of IBD. It can make it hard to concentrate in class and take part in activities. It can lead to irritability and frustration. There are a few things families can do to take control of fatigue:

- 1) **Is your child's treatment plan working?** Ask your child's IBD healthcare team to test for active disease. You can also check to see if the fatigue is a side effect of their treatment and ask if there is an alternative.
- 2) **Are they getting enough sleep?** Helping your child to practice good sleep hygiene can improve the quality of their sleep – giving them the best chance of dealing with fatigue. Going to sleep and waking up at the same time every day and having a relaxing bedtime routine should help.
- 3) **Are they moving around enough?** It is hard to get moving when you feel fatigued. But doing too little can be as bad for fatigue as doing too much. Going for a walk, a bike ride or a swim could all help, although don't do too much, it is important to find a balance to avoid boom and bust!

# helping your child cope with school



## activity two

### Take control of bullying

Young people may find it hard to open up about being bullied. If you suspect your child is experiencing bullying, here are a few ways to start talking about it:

- **Use opportunities such as bullying being featured on TV shows.** Try saying something like: 'what do you think of that?' or 'has that ever happened to you?'
- **Bring up bullying in general terms while making dinner or walking the dog.** Maybe use an example of a friend's child or co-worker to frame the conversation. It could encourage your child to talk about their own experiences – and know they are not alone.
- With younger children, it might help to use **a picture book** to start the conversation. Reading something that tackles the issue together can be a good way to start a conversation.
- **Try asking questions** like 'what would you do if you were being bullied?' and 'what would you want to happen?'

# helping your child cope with school



## activity three

### Sound asleep

The better your child sleeps, the better chance they have of coping with their fatigue. Here are our top tips for sleeping soundly:

- 1) **Regular rhythm.** Going to bed and getting up at the same time every day – even weekends – will train the body to sleep better.
- 2) **A bed is for sleeping.** To help the body learn the connection between bed and sleep, the bed should only be used for sleeping. That means no TV, eating, reading or computer gaming in bed.
- 3) **Bath time.** A hot bath one or two hours before bedtime can help people feel sleepy and ready for bed.
- 4) **Bedtime.** Bedtime rituals can tell the body that it is time to sleep. Younger children may enjoy a bedtime story, whereas older ones could try calming breathing exercises or reading to themselves.

# helping your child cope with school



## 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](#)
- 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

*"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

## 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, your child 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 their healthcare team if they can offer any extra psychological support, or at least point you in the right direction of services in your area:

- They say they feel as though they cannot cope
- They are struggling to use the tools in this kit
- The tools in this kit do not seem to be working for them
- A lack of interest in the things they usually enjoy
- A feeling of sadness that does not go away
- They express thoughts of harming themselves or others