



Everyone always says it is good to talk. We know it is not always that easy, especially if the topic may feel embarrassing to talk about like bowels and IBD..

It can be hard to put your emotions into words, especially if they do not always make sense to you. You might think no one will understand how you feel.

But not talking can make things even worse. It can make you behave in ways that you might not want to. If you are anary after your diagnosis, for example, you might take it out on your brother or sister. Or if you are scared about the future you might start giving up your hobbies.

Of course, IBD is not the only thing you have going on. There's school or college work, your friends, your hobbies, boyfriends and girlfriends to think about, too.

Remember, you are not the only one who feels like this. All young people – even those who are not living with IBD – have stuff to deal with.

There are things you can do to make things easier for yourself. And we are here to help.

"My friends know about my condition as I have been very open about it and I believe that this is the right thing to do. It makes playing out and sleepovers a lot easier as I take my tablets with me."

Josh, 12.



hints and tips

- It is not your fault. No one knows what causes IBD, but we do know that you did not do anything wrong.
- You might not want to tell anyone about your IBD. But why not choose one or two people who you really trust? It could be anyone – a friend, aunt, uncle, grandparent or teacher. That way, you have always got someone to talk to when you need them.
- Try to open up about your condition. It can help you to control how people see you. You only need to tell them as much as you are comfortable with. Try something like: 'I have a problem with my tummy. It's OK, I take medicine for it and you can't catch it. Anyway, did you see the match/show/film last night?'
- Give your parents a chance. Some young people do not feel comfortable speaking to their parents or carers about what is going on in their lives. Remember they were your age once too! Tell them what is bothering you and they might understand more than you thought.
- Some people say they find it hard to talk about their feelings because they do not really understand them. One way to start making sense of your emotions is to start a journal. It might help you to figure out how you feel so you can talk about it.
- Do you like music? You could try putting your feelings into lyrics. You could write your own song, or make up new words for a favourite rap or song. It might make it easier for you to understand and express how you are feeling.
- How does it feel when other people open up to you? Are you happy that you are able to help them? Does it help you to feel like you are a good friend who can be trusted? Does it help you to feel closer to them? Remember it can work the other way round too!
- Use your healthcare team. The good thing about talking to your IBD doctor or nurse is they have seen it all before. It means you can talk about whatever you want without ever having to be embarrassed.



"I am lucky to have my family and friends to support me. My school friends always check up on me to make sure I am okay. I have also met some friends while having my infusions at hospital, this is nice because we share our stories and text each other. Friendship and laughter are great medicines."

Katherine. 15.



activity one

Writing versus talking

Sometimes, it can be easier to write about what is happening in your life than it is to talk about it.



Why not try sending your parents, carers or friends an email? Do you know what you would say? You could try answering the questions below if you think that would help

Did something happen? What was it and when did it happen?
How did it make you feel at the time?
Why do you think it made you feel that way?
How do you feel about it now?
Is there anything anyone could do to help?

Another idea is to ask your parents, carers or friends to talk to you via an instant messaging app. Remember, they love you and want to support you. They will be happy to communicate in whatever way you feel most comfortable with.



activity two

A postcard from the heart

If you are having trouble opening up, you could try sending a postcard to someone you trust, to let them know how you are feeling. Or you could even write the postcard to IBD.



Why not draw a picture on the front that shows how you feel about things - however that might be. On the back, you can write just a few sentences about what made you feel that way. You might want to send to your parents, sibling, or a friend, or you might not want to send it to anyone. All of these are OK. It is just about giving you a way to open up about how you feel.

activity three

be prepared

Thinking ahead can be helpful - what questions might your friends ask? Maybe think of some questions (What is IBD? Can I catch it? What medicine do you need to take? etc) and write down how you might want to answer them, so you feel more prepared for when these questions come up.



What do you wish others knew about your IBD?

Once you've written them down, think about showing your parents or carers?



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 <u>Family Support Worker</u> or ask her to connect you with others in your situation
- See the emotional wellbeing kit <u>resources library</u> for lots more ideas and support
- MIND has lots of tips for young people who want to open up to friends and family



"If you feel down or anxious, talk to someone."

Mansi, 13

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

