



## coping with IBD in the family

It can be hard if you have a brother or sister with IBD. You may worry about them and your parents a lot of the time. And you might not know the best way to help.

On top of that, it can feel like your life is planned around their hospital visits, medications and what they can eat. It might feel like your parents treat them differently to how they treat you.

You may even think your family has changed since you all found out about your sibling's IBD. Maybe you don't do the same things anymore, or you have had to cancel outings or holidays because they were ill.

Lots of people find this can make them sad, angry or frustrated – even when they don't want to be. Sometimes, your family can get frustrated too. You may sometimes have arguments or disagreements.

**But remember, your family love you and want to be there for you. It can be difficult for them too.**

Luckily, there are things you can do when everything starts to get too much. IBD does get in the way of family life sometimes, but it doesn't always have to.

*“When my brother was very unwell it made me feel very sad. He was in hospital with all the tubes on him and it made me cry. It helped me to think about what I could do to make him feel better. I noticed he had left his favourite teddy bear at home so I kept it with me until we went to visit him so I could make sure he had it for comfort.”*

Lloyd, whose brother has IBD.

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## hints and tips

- **Talk about it.** You might feel like you do not want to stress your parents or carers out more than they might be. But not talking about how you feel can make things worse. Remember, your family love you and want to be there for you.
- **Learn about it.** Some siblings of people with long-term conditions say it helps if they understand more about the illness. You could ask your brother or sister about how it affects them. You can also research IBD on the internet. Be careful where you get your information from though. It might not all be trustworthy. Look out for trusted sources like CICRA or the NHS.
- **Find people who understand.** Sometimes, it helps to talk to people who know what you are going through. You could speak to your parents or carers about attending a CICRA Family Day or join an online support group.
- **Go easy on yourself.** No one is perfect and no one can do all the right things all of the time. If something does not go to plan, don't beat yourself up. Instead, think about how you could do things differently next time.
- One of the worst things to deal with when your family is going through a tough time is not being sure how you can help. **Ask your sibling what you can do to support them** – do they need someone to talk to? Maybe they just want to play a computer game with you for a little while? Or is there more you could be doing around the house?
- **Look on the positive side.** Some experts think that young people who have a sibling with a health condition like IBD are more mature and understanding than other people their age.
- **Not everything that happens will be related to IBD – try to remember family life is difficult for everyone sometimes.**



*“My brother was 10 when he was diagnosed with ulcerative colitis. I was 23 and living away from home so I wasn't there to support my mum. I felt bad about that, but it wasn't intentional... My mum was seriously depressed and cried a lot when he was diagnosed. I tried to be positive.”*

Alex, whose brother has IBD.

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## activity one

### Take a breath

If you are feeling anxious or overwhelmed, it can help to take a moment to concentrate on your breathing. Why not try:

1. Breathe in slowly to the count of four
2. Hold your breath to the count of four
3. Breathe out to the count of four
4. Wait for four seconds
5. Repeat steps one to four until you feel calm

You could also try colour breathing. Think of a nice calm colour then imagine breathing it in. Then choose another colour that means stress and worry, and imagine breathing it out. Keep going until you feel calm.

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## activity two

### No hassle zone

If you are feeling overwhelmed, angry or frustrated, try taking yourself away from it all.

You could create a no hassle zone in your home. Try explaining to your family that when you go into your zone, you would like to be left alone to calm down.

It could be anywhere you feel comfortable – a quiet corner in the garden or your bedroom, or a soft blanket in an alcove or nook. Why not try adding some soft lighting or a Bluetooth speaker so you can listen to calming music?



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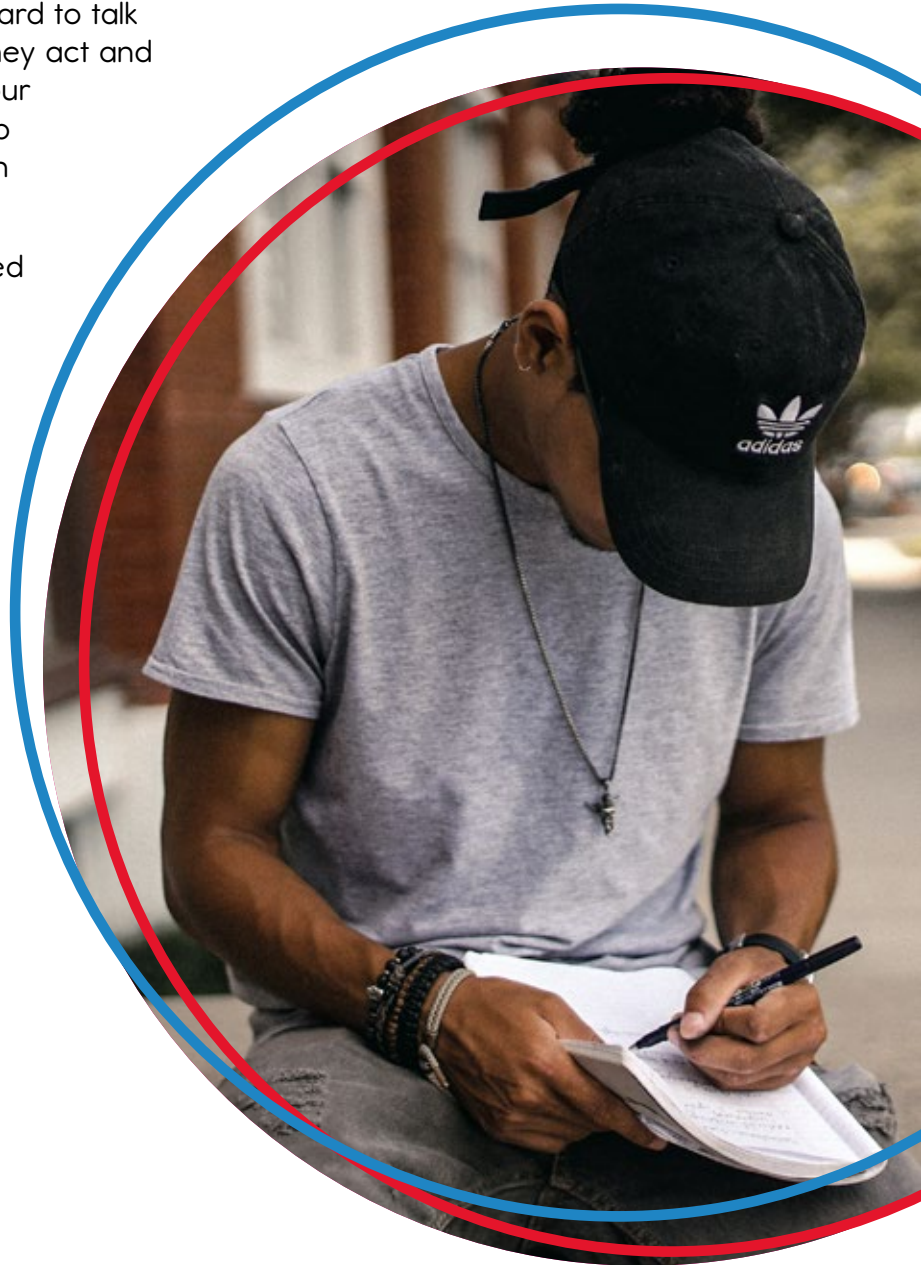


## activity three

### Start a journal

Some people say that when they find it hard to talk about their feelings, it can change how they act and feel. 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 with your family.

You could try writing down what happened each day and how it made you feel. You don't have to share it with anyone, it is just about giving you a way to open up about how you feel.



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## more ways to get help or support

- Read [more about IBD](#) on CICRA's website
- Speak to other siblings in your situation at a CICRA [Family Day](#)
- Speak to Laura, CICRA's [Family Support Worker](#)
- [Watch](#) Dr Kate Blakeley talk about living and coping with IBD
- [MIND](#) has lots of tips for young people who want to open up to friends and family
- If you like mindfulness, check out [Calm](#), [Cosmic Kids](#), [Headspace](#) or [Smiling Mind](#).
- See the emotional wellbeing kit [resources library](#) for lots more ideas and support

## 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 brother or sister's 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