



## coping with IBD in the family

Sometimes it can feel like IBD is another member of the family – albeit an unwanted one.

Events must be planned around hospital appointments, medication schedules and food diaries. Fatigue and flare-ups mean days out and holidays can be postponed or cancelled at the last minute. Even the daily logistics of checking on homework, setting chores and arranging after-school activities may seem to come second place to managing IBD.

Relationships, both within and outside of the family, can change. Priorities change. All this can place stress on the whole family. Children and young people with IBD may have feelings of shock, anger or fear of the unknown. Their siblings can feel scared and confused, or even jealous and guilty.

With so much going on, it can be really tough to keep up. Parents and carers may feel overwhelmed. That is normal. But there are things you can do to better cope with having IBD in the family.

*“Little things, like having friends round for tea, after school clubs or even getting his brothers to school on time, became impossible.”*

Ruth, mother of a child with IBD.

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## hints and tips

- **Externalising: sometimes it is helpful to refer to IBD as if it is a object or person** so when we are talking about it we can say that IBD is making me feel this way or making me angry. Sometimes this is enough to unite the family against IBD rather than fight amongst themselves.
- **Have dedicated family time where you don't talk about IBD.** Let your child know there is more to them than their IBD. Make sure IBD is not the first thing your child hears as you greet them after school or after a trip.  
  
Have dedicated time to talk about their day/ problems/ IBD etc so that your child knows if they have a problem they know who to talk to and when. Make sure you also provide time to talk to siblings so they don't feel let out.
- **Get siblings involved** – let them ask questions to the health care team as they may have worries themselves.
- **Beware Dr Google.** Not all health information is created equal. Misinformation can make you feel more anxious and overwhelmed. Look out for trusted sources, such as CICRA or the NHS.
- **Share the load.** Your healthcare team is there to help you. Use them! Many people find it helps to talk to people who are experiencing similar things. You could attend a CICRA Family Day or join an online support group.
- **Share the care.** As hard as it might be sometimes, it is important to include young people in their own care decisions. It will help give them some control, take some pressure off you, and start to prepare them for the future.
- **Take time for yourself.** You cannot look after your children if you are not looking after yourself. Try to keep an hour a week for a bubble bath, or plan a regular film night with your partner, for example.
- **Not everything that happens will be related to IBD – try to remember family life is difficult for everyone sometimes.**

*“I remember standing in my dressing gown, crushing the prednisolone tablets to mix with a little squash, feeling utterly bewildered by what our life had become. Drew and I both feel somewhat detached from other parents and families at times, and the worry can be overwhelming and all-consuming.”*

Sarah, mother of a child with IBD

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## activity two

### 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 three

### Rest nest

When children feel anxious or overwhelmed, it can help to take them away from the source of their worries.

Why not try building a rest nest or den with them? It can become a refuge from the outside world. A place to go, close their eyes, and just feel safe when things get too much.

It can be anywhere they feel comfortable – a few pillows on the front room floor, or a soft blanket in an alcove or ‘nook’ in the house. It might include some soft lighting or a Bluetooth speaker so they can listen to soothing music.

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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](#)
- See the emotional wellbeing kit [resources library](#) for lots more ideas and support
- Ask your child's healthcare team to direct you to any local support groups

### 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



*“My advice to other parents is talk about it! Keep positive and know that there are people out there going through the same thing.”*

Nicola, mother of two children with IBD