



coping with IBD in the family

IBD can get in the way of life. There are hospital appointments, medications and food choices to think about. Sometimes, you might feel too tired to do your homework, your household chores or even go out with your friends or family.

You may feel your family has changed since you all found out you had IBD. Maybe you don't do the same things, or maybe you treat each other differently. Your parents or carers might be more worried about you going out with your friends than they used to be, for example.

Lots of people find this can make them sad, angry or frustrated. Sometimes, your family can get frustrated too. All this can lead to arguments or disagreements.

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 life sometimes, but it does not always have to.

"I thought having a colostomy would stop me living, going out with friends, even working to my full potential. I also thought relationships would be difficult. But I later told myself that if they cannot accept my past then I have no future with them,"

William, 23

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hints and tips

- **Build your group.** Your friends and family want to help you – but what might you need? And who would be the best people to ask? Will you need someone to talk to when it all gets too much? Or someone to remind you to take your medication?
- **Beware Dr Google.** Not everything you read online is true. Misinformation can make you feel even more anxious and overwhelmed. Look out for trusted sources, like CICRA or the NHS.
- **Share the load.** Your healthcare team are there to help you so make sure you use them! Many people find it helps to talk to people who are going through the same thing. You could go to a CICRA Family Day or join an online support group.
- **Share the care.** As hard as it might be sometimes, it is important to work with your parents or carers to manage your care. It is easier to deal with IBD when you have their support.
- **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, do not beat yourself up. Instead, think about how you could do things differently next time.
- **Not everything that happens will be related to IBD** – try to remember family life is difficult for everyone sometimes.
- **Try making a self-soothe box** and going to it when things get too much. Fill a box with things that make you feel calm and happy – they might be a favourite perfume or scent, pictures of friends and family, inspiring quotes or even song lyrics. It is up to you.

“My family have played a bigger part in my life recently. My mum is always taking me to appointments and cheering me up. My grandparents are always willing... to look after my two siblings while I am in hospital or at appointments. They have all really helped me to cope when my Crohn’s is bad, and they are always there for me no matter what.”

Amelia, 13

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activity one

Building your group

Remember your friends and family want to support you – but sometimes you might need to tell them how.

What sort of support do you think you will need and who do you think will be able to help you? Thinking about this now can make things less stressful later on.

Try completing our group planner. We have added some examples to get you started.

Type of support	What I need	Group member
Emotional support	Someone to talk to when things get too much	
Practical support	Someone to remind me to take my medication	
Educational support	Someone to help me if I get behind on my school/college/university work	

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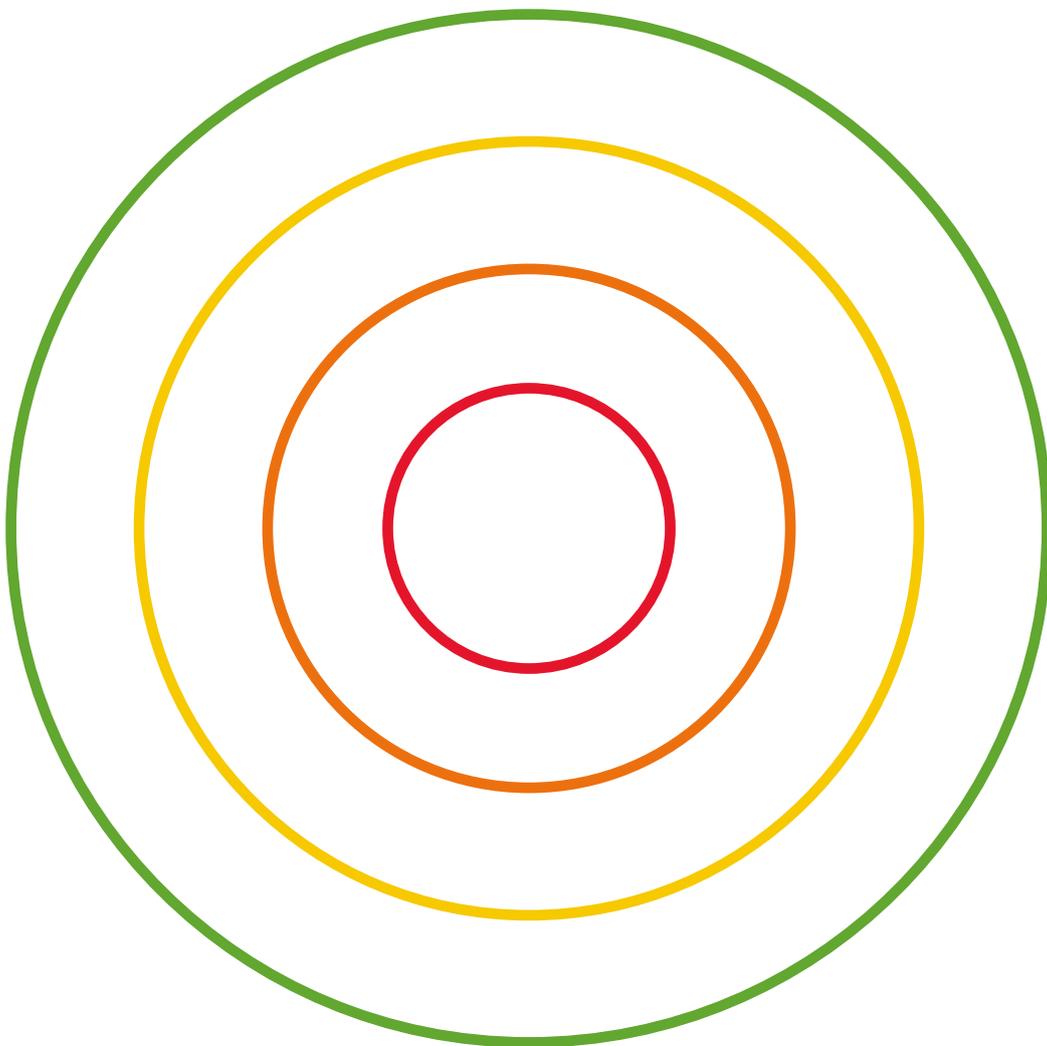


activity two

Circle of support

Dealing with IBD isn't easy – but you are not on your own. You are surrounded by people who love you and care about you.

Fill out our circle of support and see for yourself. Write your name in the middle circle below. Then write names of all the people you feel closest to in the next circle, your next group of 'close people' go in the one after that, continue to do this for all of the outer circles. You may need to add more circles!



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activity three

Take a breath

If you are feeling anxious or overwhelmed, it can help and 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 four

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 a corner. Why not try adding some soft lighting or a Bluetooth speaker so you can listen to calming music.

Or have set times where no-one is allowed to talk about or ask you about IBD, e.g. when you have just got home from school



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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
- 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, 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