



emotional wellbeing when dealing with diagnosis

No one is prepared for the range of emotions they go through when their child is diagnosed with IBD. It is an extremely challenging time for the whole family. But you can get through this.

Fear, anxiety, disbelief and shock are some of the most common reactions to the diagnosis. You may be uncertain about what happens next, worried about what the future holds for your child or wonder why this has happened to your family.

There is a lot to take in as you and your family come to terms with your child's health condition – and the realisation that it is not going away. You are not alone in having these feelings.

Many people say that dealing with an IBD diagnosis is a little like grieving. You and your family may go through some or all of the classic phases of grief: denial, anger, bargaining, depression and acceptance.

It is different for everyone, but remember you are not alone. Lots of people have been where you are now, and we are here to help.

“It hit home hours later that we had very little idea what Crohn’s was and what it meant for our daughter’s future. We went to pieces.”

parent of a child with IBD, CICRA’s Dealing with Diagnosis survey, 2019.



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hints and tips

- **Get informed.** Knowledge is power so research your child's condition. Once you understand it, it won't seem as scary.
- **Beware Dr Google.** There's lots of misinformation out there, so be careful what you read. Stick to trusted sources such as CICRA, the NHS and your child's healthcare team.
- **Write down your questions.** We can all go blank in the doctor's office. Try making a note of your questions on your phone or on a pad on the fridge as they occur to you. That way, you can take the list into appointments.
- **Involve your child.** It's natural to want to wrap your child up in cotton wool right now. But it is really important to involve them in discussions and decisions. It will give them some control over their situation and start to prepare them for the road ahead.
- **Get support.** Your child's healthcare team. CICRA and other charities. Parent support groups and your friends and family. All these people are here to help you. Getting the support your family needs will help you to feel less alone, deal with your fears and get the information you need.
- **Give yourself time to adjust.** A diagnosis of IBD is a lot to take in and everyone will deal with it differently. Take it one step at a time. You will adjust to this 'new normal' in your own time.
- **Never blame yourself.** We do not know what causes IBD. But we do know it is nothing that you or your family have done.
- **Look after yourself.** You have to look after yourself in order to look after your child. Take care of your own mental health. Give yourself time to rest and rejuvenate, and always ask for help if you need it.

"IBD is not a life sentence, but does require acceptance and commitment to the meds."

Parent of a child with IBD, CICRA's Dealing with Diagnosis survey, 2019.

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activity one

recognising the curve

Dealing with a diagnosis of IBD has been likened to grieving – for the parents and the young person themselves.

There are five classic phases of grieving and people might go through any of them, in no particular order, when faced with an IBD diagnosis.

In the end, hopefully, they will come to accept their new normal. But it can help to recognise where you or your child are on this “journey” and how this is affecting your family’s emotional wellbeing.



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activity two

Build your support network

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. Think about the kind of support you might need and the family members, friends or colleagues you could trust to call upon. Do you need someone to talk to? Or more practical support like help getting the children to school or picking up prescriptions?

Try completing our support network planner.

People you can talk to when you are sad, angry or upset



People who can help out with the practical stuff



People you can have a good time with



People who can help you achieve your goals



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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
- Read [more about IBD](#) on CICRA's website

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