



diagnosis and your feelings

An IBD diagnosis is a lot to deal with. You might feel scared, angry, shocked or anxious. It can be a very tough time for you and your family. But you can get through this.

You may be unsure about what happens next and worried about what it means for your future. Lots of people in your position think 'why me?' Scientists do not know why some people get IBD and others don't – but we do know you have not done anything wrong. It is not your fault.

It may all feel overwhelming at the moment. You are not the only one who feels this way.

It is different for everyone, but remember you are not on your own. Lots of people have been where you are now and have found a way through. We, your family and your friends are all here to help.

"It isn't as scary as it may seem. It took me a while to realise that, but you have to take every day in your stride."

Hannah, 16

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hints and tips

- **Get informed.** Knowledge is power so research your condition – but only as much as you feel comfortable with. Once you understand it, it will not seem as scary.
- **Beware Dr Google.** Be careful what you read because it cannot all be trusted. Stick to trustworthy sources such as CICRA, the NHS and your 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 in your bedroom, or order a [CICRA symptom impact tracker](#). That way, you can take the list to appointments with you.
- **Get involved.** It is natural to want your parents or carers to look after you right now. And they will. But try to get involved in conversations about your treatment and care. It will help you to feel more in control and prepare you for the road ahead.
- **Get support.** Your healthcare team. CICRA and other charities. Support groups, your friends and family. All of these people are here to help you. Getting the support your family needs will help you to feel less alone, feel less scared and get the information you need.
- **Give yourself time.** An IBD diagnosis is a lot to take in. 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.
- **Remember IBD does not define you.** You are still the same person you have always been. It may always be a part of you, but it is not the whole of you.

“There are some tough times, but keeping your mind on all the things you want to do when you feel better really does help to keep you going.”

Luke, 16

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activity one

recognising the curve

When you are told you have IBD, it can feel like you have lost something. Lots of people say it feels like grieving. Grieving is the process people goes through when a loved one dies.

Experts say there are five stages of grieving. These are denial, anger, bargaining, depression and acceptance. Each of them affects how you feel and how you act.

When you are diagnosed, you might go through some or all of them. You might go through them in any order. You might go through some stages more than once. That is all normal. Remember, it is a lot to take in.

In the end, you can come to accept your new normal and get on with the rest of your life. In the meantime, it can help to understand where you are on this 'journey' and how it is affecting your feelings.



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activity two

write your story

Diagnosis throws up lots of different feelings. They can all get mixed up and it can be difficult to see how you will cope with them all.

Sometimes, it can help to put things in order by telling your story. It can help you figure out exactly what is making you feel the way you do. Once you know more about how you feel, you can speak to your parents/carers or healthcare teams about it. They can get you the help you need.

Why not try writing your story now, then doing it again in a month or so to see what has changed? Remember, only do this if you are comfortable with it. You might not be ready yet, and that is fine. You can come back to it at any time.

My life before I was told I had IBD

When I started to feel unwell

activity two continued

How it felt when I was diagnosed

What changed when I was diagnosed

What life is like now

What I would like my life to be like in the future

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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
- Read [more about IBD](#) on CICRA's website
- Ask your healthcare team to direct you to any local support groups or check if they can refer you to a psychological therapist

There may be other times when you feel worried or stressed out after diagnosis, such as during life transitions or during a flare up, and our emotional wellbeing kit covers several areas, so keep it to refer to.

"When I was told about my diagnosis, I felt a whole mix of emotions and had so many questions... Worry filled my mind... I was relieved that I finally had a diagnosis but knew I had a long road ahead of me,"

Amelia, 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