

brothers, sisters, IBD and emotional wellbeing



If your brother or sister has inflammatory bowel disease (IBD), you may already realise how it can affect the whole family. It can get in the way of days out, holidays and day-to-day life.

It can be hard to know how you can help your siblings and parents or carers to manage the illness, while keeping up with your own schoolwork, hobbies and friends. At the same time, it can be tough to talk about it.

It is perfectly normal for this to affect the way you feel – even if you don't want it to. Other people who have a sibling with a condition like IBD sometimes feel low, angry, jealous, lonely or guilty.¹

Remember, you are not the only one who feels this way. Many people who have brothers and sisters with IBD go through the same things and have the same emotions.

practical help

The good news is there are lots of things you can do to look after yourself and your feelings.

The CICRA emotional wellbeing kit will help you understand and talk about how you are feeling. You will find information, activities and tips on how to cope from other people in the same situation as you.

Always remember that asking for help is nothing to be ashamed of. It shows you are brave enough to face your feelings and do things to help yourself.

Of course, not everything you go through will be because of your brother or sister's IBD – but some things might. This kit will help you understand when their condition may be affecting how you feel. Because no one's life should be limited by IBD.



“My nine-year-old daughter sometimes gets angry and blames her brother. For example, she will say things like ‘it is his fault for being ill because it is his body’. I know this is said in anger and she probably knows that it isn't true deep down.”

Shirley, mother of a child with IBD..

1. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6408193/>



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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coping with IBD in the family

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.

coping with IBD in the family



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.

coping with IBD in the family



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?



coping with IBD in the family

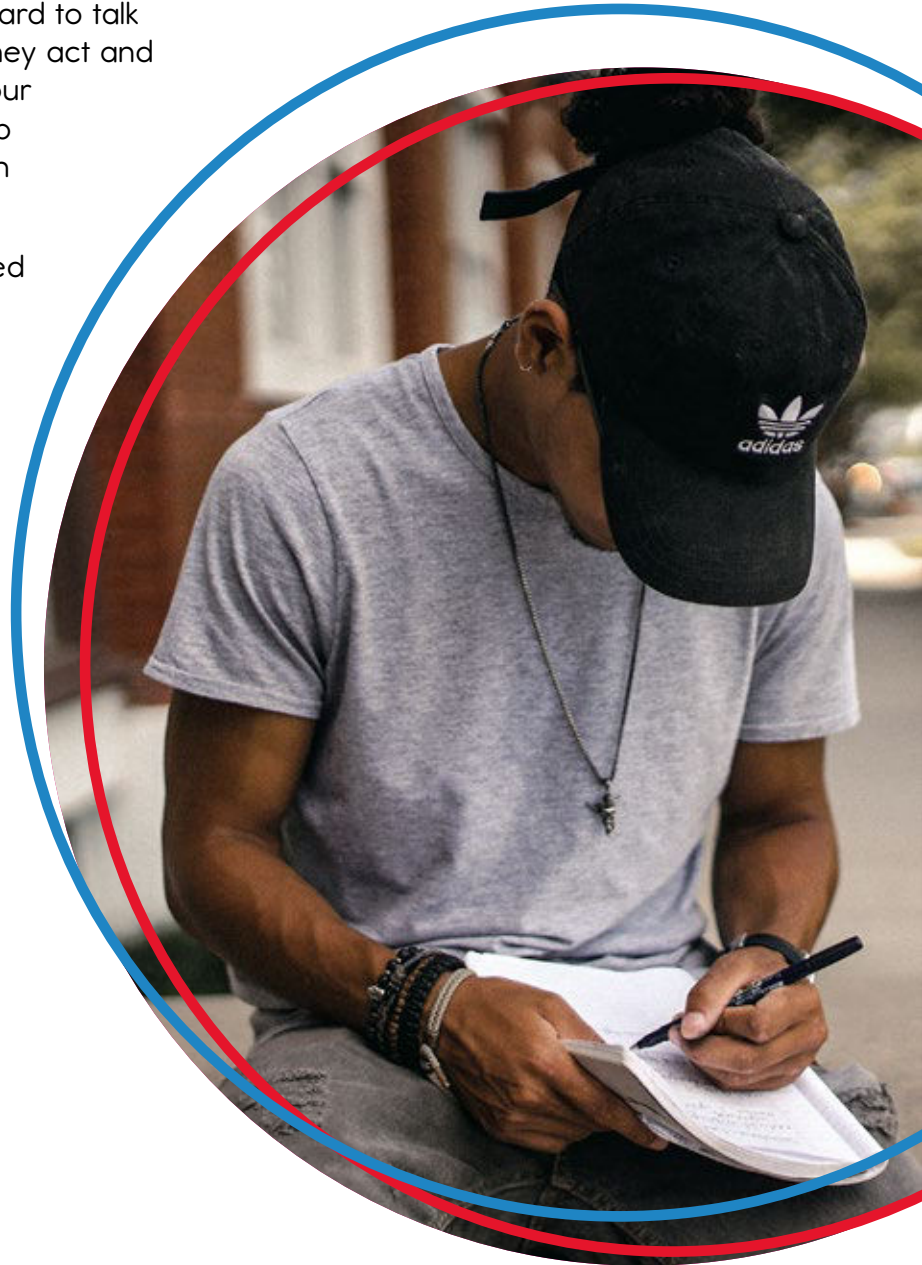


activity three

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.



coping with IBD in the family



more ways to get help or support

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- [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](#).
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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
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- A feeling of sadness that does not go away
- Thoughts of harming yourself or others



talking about it

Everyone always says it is good to talk. We know it is not always that easy.

It can be hard to put your emotions into words, especially if they do not always make sense to you. You might feel that you do not want to give your parents or carers any more to worry about. Or you might think your friends just will not understand what you are going through.

But not talking about how you feel can make things even worse. It can make you behave in ways you might not want to. If you are angry after your brother or sister's diagnosis, for example, you might take it out on them. Or if you are worried about your family's future, you might lose interest in the things you love doing.

Of course, your sibling's IBD isn't the only thing you have got going on. There's your own school or college work, friends, hobbies, boyfriends and girlfriends to think about, too.

Remember, you are not the only one who feels like this. All young people – even those who do not have IBD in their family – have stuff to deal with.

There are things you can do to make things easier for yourself. And we are here to help.



talking about it

hints and tips

- **You are not alone.** Yes, your family has a lot going on right now. But that does not mean they are too busy for you. They love you and want to know you are OK.
- **All feelings are normal.** Young people whose siblings have IBD experience all kinds of emotions. They can feel scared, worried, angry, jealous, guilty – or all of these at once. Remember, there is nothing wrong with how you feel.
- **Build your squad.** You might not talk to your friends because you think they will not understand what you are going through. Maybe they won't, but they still want to be there for you. Why not try speaking to just one person who you really trust? It could be anyone – a friend, aunt, uncle, grandparent, teacher or even a friend's parent.
- **Give your parents a chance.** Some young people don't feel comfortable speaking to their parents or carers about what is going on in their lives. But remember they were your age once too. Tell them what is bothering you and they might understand more than you thought.
- **Start a journal.** Lots of people say they find it hard to talk about their feelings because they do not really understand them. 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.
- **Do you like music?** You could try putting your feelings into lyrics. You could write your own song, or make up new words for a favourite rap or song. It might make it easier for you to understand and express how you are feeling.
- **How does it feel when other people open up to you?** Are you happy that you are able to help them? Does it help you to feel like you are a good friend who can be trusted? Does it help you to feel closer to them? Remember it can work the other way round too!



“Sometimes all we talk about is my brother’s condition and how we are going to get through things. Sometimes I would like to talk about something positive as when we talk about his condition it makes him upset and down. On the other hand, our family has become closer and we are able to support him together.”

Hannah, 14

talking about it



activity one

Written communications

Sometimes, it can be easier to write about what's happening in your life than it is to talk about it.

Why not try sending your parents or carers an email?

Do you know what you would say?

You could try answering the questions below if you think that would help.

Did something happen? What was it and when did it happen?

How did it make you feel at the time?

Why do you think it made you feel that way?

How do you feel about it now?

Is there anything anyone could do to help?

Another idea is to ask your family to talk to you via an instant messaging app. Remember, they love you and want to support you. They will be happy to communicate in whatever way you feel most comfortable with.

talking about it




activity two

A postcard from the heart

If you are having trouble opening up, you could try sending a postcard to someone you trust, to let them know how you are feeling. Or you could even write the postcard to IBD.

Why not draw a picture on the front that shows how you feel about things – however that might be. On the back, you can write just a few sentences about what made you feel that way.

You might want to send to your parents, sibling, or a friend, or you might not want to send it to anyone. All of these are OK. It's just about giving you a way to open up about how you feel.





talking about it



more ways to get help or support

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taking control

When your brother or sister lives with IBD, life can be unpredictable. You don't know when they might get ill, how bad it will be or what will happen to your family when it does. It can make you feel like you have too many thoughts in your head or that you are not in control.

Feeling that way can make you act differently. Some people might not be able to stop thinking about bad things that might happen. Others might try to ignore it completely. It can make you feel angry, lonely or sad.

It can also make you think differently. Do you worry about things all the time? Do you find yourself not wanting to go out or enjoy time with your family? Well, you are not the only one.

But with the help of your family and friends, you can take control of your life and your feelings.

taking control

hints and tips

- **Take a step back.** Try to focus on the things you enjoy, so you can forget about your worries for a bit. Do you play football or are you a massive music fan? Do you belong to a local club or enjoy spending time with your friends?
- **Have you tried mindfulness?** It means being in the here and now rather than thinking about the past or future. It can help us stop getting lost or tangled up in our thoughts or feelings. Try sitting quietly with your eyes closed for a few minutes. What can you hear? What can you smell? If you like it, there are links to apps you might enjoy at the bottom of this worksheet.
- **Get more involved by asking your sibling what you can do to help.** They might need someone to talk to sometimes, or some help remembering to take their medicine. If they are off school or college, they might ask you to keep the school updated on their condition. It is different for everyone, so just ask the question – it might help you feel more in control.
- **Knowledge is power!** Try going onto the [CICRA website](#) to find out more about your brother or sister's condition.
- **Notice when things are getting too much.** Sometimes, people can't stop worrying about something bad happening. Try to catch yourself if this happens to you. Think: Is this thought useful to me? Try imagining a balloon with your worry inside it – then let it go!



“My daughter was diagnosed at 14, my son was only 8. He has suffered terribly emotionally. He is like a roller coaster. Every time my daughter has a bad day, he is in tears, because he is sad for her.”

Shirley, mother of a child with IBD

taking control

activity one

Are you a disaster forecaster?

If you feel as though you have lost control of your life, it can affect the way you think. Some young people can find themselves thinking that something awful is going to happen. But they probably have very little to back up their ideas.

Next time that happens to you, try asking yourself:

- Am I thinking I can predict the future?
- How likely is it that the thing you are worried about might really happen?
- Is what I am thinking very helpful to me?
- What's most likely to happen?
- What if the thing I am worried about does not happen?



taking control



activity two

Spotting negative thoughts

We all have negative thoughts sometimes. They are automatic, meaning they come out of nowhere. We cannot stop ourselves from getting them, but we can control how we react to them.

I can't control automatic thoughts
but I can control if they stay

recognise them
disagree with them
disprove them
let them go
think positively

taking control

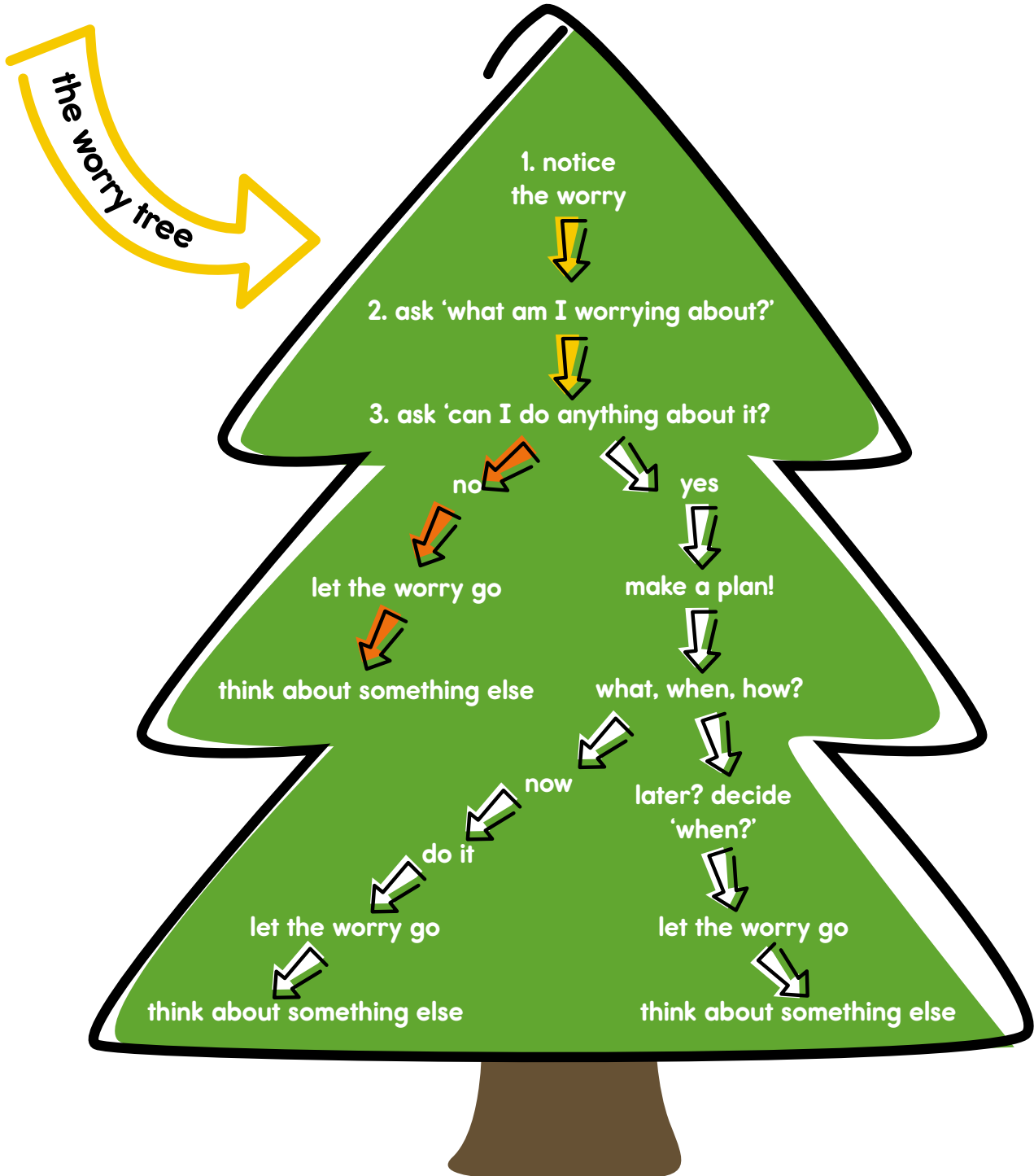
emotional wellbeing



activity three

Climbing down the worry tree

People might say 'don't worry'. But how do you do that?
Try climbing down the worry tree.



If you are still finding it difficult to 'let the worry go',
think about asking for help or talk to CICRA.

Adapted from Butler and Hope 2007

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taking control



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emotional wellbeing kit resource library

signposts and pointers: useful places to find more help

The CICRA Emotional Wellbeing Kit was designed to help you and your family cope with the feelings that come with IBD.

But there is a lot more help out there if you need it. We have listed some of our favourite websites, apps and services here.

Let us know if you have found something you think would help others like you, and we will see if we can add it, email support@cicra.org



Caring for your mental health

- [MIND](#) has lots of tips for young people who want to open up to friends and family
- [Young Minds](#) has lots of help and advice for children and young people struggling with their emotional wellbeing
- [On My Mind](#) aims to help young people make informed choices about their mental health and wellbeing
- [Child and adolescent mental health services \(CAMHS\)](#) CAMHS are the NHS services that work with children and young people who have difficulties with their emotional or behavioural wellbeing. Speak to your healthcare team to find out about services in your area
- [Samaritans](#) provides online and emotional support to anyone in emotional distress, struggling to cope, or at risk of suicide
- [Childline](#) is an online and telephone counselling service for children and young people up to the age of 19.
- [PAPYRUS](#) offers confidential support and advice, as well as trusted information, to young people thinking about suicide
- [BlueIce](#) is an NHS-approved app that helps young people manage their emotions and reduce urges to self-harm. It includes a mood diary, techniques to reduce distress and automatic routing to emergency numbers if needed
- [Ieso](#) is an online course approved by the NHS. It uses instant messaging to put people with mental health problems in touch with cognitive behavioural therapists
- The NHS-approved [MeeTwo](#) app provides a safe and secure place for young people to anonymously discuss any issue with experts or other teenagers going through similar things
- [The Mix](#) offers free information and support for under 25s in the UK about sex, relationships, drugs, mental health, money and jobs
- [Anna Freud NCCF](#) is a charity dedicated to children's emotional wellbeing

emotional wellbeing kit resource library

signposts and pointers: useful places to find more help

Coping with bullying

- [Bullying UK](#) offers help and support on dealing with bullying
- [Childline](#) has lots of tips and information on coping with bullying
- The [Young Minds](#) website covers how bullying can make you feel and what you can do about it

Mindfulness, yoga and meditation

- The [Calm](#) website and app feature lots of different ways to try mindfulness. It is aimed at adults but is useful for older children
- The [Headspace](#) app has guided mindfulness exercises and videos. It is aimed at adults but is useful for older children
- [Cosmic Kids](#): Yoga, mindfulness and relaxation for younger children through interactive adventures
- [Smiling Mind](#) is a web and app-based meditation program developed by psychologists and educators]
- [Feeling Good](#) has a series of audio tracks designed to help you build confidence, energy and a positive mindset

Coping with IBD

- [Crohns and Colitis UK](#) is a national charity offering support for young people and families, as well as supporting adults affected by IBD
- www.whatwhychildreninhospital.org.uk has lots of information and videos to help prepare parents, carers, young people and children hospital visits
- [HospiChill](#) is an app-based relaxation programme that helps children and young people to prepare for hospital visits
- [IBD Relief](#) has a section on IBD and emotional wellbeing
- [Student Health App](#) is aimed at university students, and has more than 900 pages of reliable health information

Support for parents:

- The [Australian Parenting Website](#) has lots of articles, apps and videos offering parenting advice from experts
- [Young Minds](#) has lots of tips and advice for parents of children and young people struggling with their emotional wellbeing



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Sometimes, you might need a little more support in coping with the way IBD makes you feel – and that is OK.

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- Thoughts of harming yourself or others