

parenting, IBD and emotional wellbeing

Being a parent or carer is difficult at the best of times. But when a child is diagnosed with inflammatory bowel disease (IBD), it can open the door to new worries and concerns. While some cope fine with their IBD, other young people can sometimes struggle.

The physical impact is just one part of IBD. Unfortunately, children and young people with long-term conditions are at greater risk than their peers to experience mental ill health¹.

The pressure of managing the illness, medications and hospital appointments while coping with school, keeping up with hobbies and maintaining friendships can be huge. What's more, the nature of IBD symptoms can make it difficult for children and young people to open up about their illness.

Your child might feel low sometimes. They might have problems at school or at home. They may find it difficult to talk about, or even understand, how they are feeling. This can lead to a range of negative emotions, including anger, anxiety, loneliness and feeling 'out of control'.

It can affect the whole family. Parents and carers can feel as though they are being pulled in all directions. They have to cope with the diagnosis and care for the child and their siblings, all while looking after their own emotional wellbeing.

But you are not alone. Many parents and carers feel this way.

practical help

There are things you can do to look after your and your family's emotional wellbeing.

CICRA's emotional wellbeing kit will arm you with the knowledge and tools you need to support your children and look after yourself. It will also help you recognise when you and your family might need a little more support.

Remember: Asking for help is nothing to be ashamed of. In fact, it shows you are strong enough to take control.

Of course, not all of the issues you and your children face will be related to IBD. As you work through this kit, we will help you to understand when the condition is impacting on your family.

Through practical activities and by sharing the personal stories of others in your position, we hope to help you look after your and your family's emotional wellbeing. Because we believe childhood should not be limited by IBD.



"You will go through many emotions, it's like a grief process. It's ok to cry and be angry. Make sure you have support from friends and family and make time for yourself, it's important to look after yourself so you can take care of your sick child."

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

¹. <https://www.nice.org.uk/sharedlearning/transforming-mental-health-care-for-children-and-young-people-with-long-term-conditions-mental-health-and-psychological-wellbeing-drop-in-centre>



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.



emotional wellbeing when dealing with diagnosis



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.

emotional wellbeing when dealing with diagnosis



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.



emotional wellbeing when dealing with diagnosis



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



emotional wellbeing when dealing with diagnosis



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
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- A feeling of sadness that does not go away
- They express thoughts of harming themselves or others



copling 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.

coping with IBD in the family



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

coping with IBD in the family



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.

coping with IBD in the family



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.

coping with IBD in the family



more ways to get help or support

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- 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

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"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



helping your child cope with school

School can be hard for young people. IBD may add a few extra challenges. Most young people with IBD cope ok, but these are some of the difficulties that may come up.

It might be hard to catch up after a spell in hospital. Dealing with fatigue and pain can sometimes be a daily battle. Young people with IBD might miss out on sports clubs or school trips and struggle to keep up with their peers' social activities.

The nature of the condition can make it embarrassing to have – and to talk about. Frequent trips to the toilet and the general feeling of 'being different' may take a bit of a toll.

Some young people with IBD are small for their age, which may make them worried about bullying. If they take steroids, these can cause distressing side effects: weight gain, a puffy face and acne, mood and behaviour changes.

The risk is these may make them become withdrawn, anxious or feel depressed. Relapses can be difficult to deal with emotionally.

Of course, it is not only children with IBD who have a hard time at school. Growing up is not easy and young people can struggle as they develop their self-identity and their place among their peers.

But, there is lots you can do to support your child through school with IBD.

"Steroids appeared to be the only drug that made any real difference stopping my symptoms. But I fought my way through education, got the best grades I possibly could, and achieved my ultimate goal of getting into medical school."

Karina, 21

helping your child cope with school



hints and tips

- Children might not want to tell anyone about their condition, but **we would recommend telling their class teacher** or head of year and the school's special educational needs coordinator (SENCO). Between them, they can make sure your child's educational and medical needs are met.
- **Having plans in place**, even if they are never used, is much less stressful than trying to get what you need in the middle of a crisis. Start thinking about what support your child might need, such as extra time on exams, early on so you know you are prepared.
- **The only constant is change**. So, discuss and review your child's healthcare plan at every open evening and after any relapse.
- If your child is likely to be **absent from school for 3 weeks or more**, begin discussions with the school as soon as possible to find out what they can put in place to support their learning at home. The local council have a duty to make sure your child gets as normal an education as possible.
- **Remember spending time with others is important**. It is natural to feel protective, but your child wants and needs to do the same things as other children their age.
- Help them **build their resilience** and self-esteem – and to realise that being different is a good thing.
- **Encourage them to tell their closest friends**. This will give them a support network to lean on when you are not there and help them to think about what they might want to say/how they could say this.
- Are there any practical ways to deal with IBD symptoms in school? Could you keep a **second set of textbooks** at home, so they do not have to carry them when fatigued? Could they have **access to a private toilet** and permission to use at any time? Or a **toilet pass**, ask CICRA for a **Can't Wait card**.
- **Help them to develop ways of distracting themselves from pain during the school day**. Could they play with a small toy, such as a fidget spinner, to take their mind off it, for example? They could try carrying a 'grounding object' to focus on when things get too much. That might be a special pebble or coin, or a meaningful wristband or piece of jewellery.

"I had a flare in Year 6 that carried on into Years 7 and 8. It wasn't nice to go through the start of secondary school with, but I haven't let it stop me. Friends at school have been very supportive. We are always laughing and whenever I'm not at my best they always keep me up and running."

Harry, 15

helping your child cope with school



activity one

Take control of fatigue

Fatigue is a very common symptom of IBD. It can make it hard to concentrate in class and take part in activities. It can lead to irritability and frustration. There are a few things families can do to take control of fatigue:

- 1) **Is your child's treatment plan working?** Ask your child's IBD healthcare team to test for active disease. You can also check to see if the fatigue is a side effect of their treatment and ask if there is an alternative.
- 2) **Are they getting enough sleep?** Helping your child to practice good sleep hygiene can improve the quality of their sleep – giving them the best chance of dealing with fatigue. Going to sleep and waking up at the same time every day and having a relaxing bedtime routine should help.
- 3) **Are they moving around enough?** It is hard to get moving when you feel fatigued. But doing too little can be as bad for fatigue as doing too much. Going for a walk, a bike ride or a swim could all help, although don't do too much, it is important to find a balance to avoid boom and bust!

helping your child cope with school



activity two

Take control of bullying

Young people may find it hard to open up about being bullied. If you suspect your child is experiencing bullying, here are a few ways to start talking about it:

- **Use opportunities such as bullying being featured on TV shows.** Try saying something like: 'what do you think of that?' or 'has that ever happened to you?'.
- **Bring up bullying in general terms while making dinner or walking the dog.** Maybe use an example of a friend's child or co-worker to frame the conversation. It could encourage your child to talk about their own experiences – and know they are not alone.
- With younger children, it might help to use **a picture book** to start the conversation. Reading something that tackles the issue together can be a good way to start a conversation.
- **Try asking questions** like 'what would you do if you were being bullied?' and 'what would you want to happen?'.

helping your child cope with school



activity three

Sound asleep

The better your child sleeps, the better chance they have of coping with their fatigue. Here are our top tips for sleeping soundly:

- 1) **Regular rhythm.** Going to bed and getting up at the same time every day – even weekends – will train the body to sleep better.
- 2) **A bed is for sleeping.** To help the body learn the connection between bed and sleep, the bed should only be used for sleeping. That means no TV, eating, reading or computer gaming in bed.
- 3) **Bath time.** A hot bath one or two hours before bedtime can help people feel sleepy and ready for bed.
- 4) **Bedtime.** Bedtime rituals can tell the body that it is time to sleep. Younger children may enjoy a bedtime story, whereas older ones could try calming breathing exercises or reading to themselves.

helping your child cope with school



more ways to get help or support

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- 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
- CICRA's [resources for schools](#) include booklets for primary and secondary schools, quick guides for class teachers, information about individual healthcare plans, advice on exams and tests, and examples of letters to exam boards
- Young people share their tips on coping with school in these [videos](#)
- [Bullying UK](#) offers help and support on dealing with bullying

"It seemed impossible to start living a normal life but my parents and siblings helped me build up the confidence and once I went back to school it wasn't as bad as I'd imagined."

Orlaith, 14

do you need a little more help?

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talking about it

We all know it is good to talk, but often it is easier said than done, especially if the topic may feel embarrassing to talk about like bowels and poo..

Younger children can find it difficult to put their feelings into words. Older children and teenagers can have the same problem, and this can be compounded by a reluctance to open up.

If people do not express their emotions, it can come out in other ways. Feeling angry after diagnosis may be directed at a sibling, for example. And fear of the future can make children and young people withdraw from friends and family.

Of course, parents and carers are not immune to this. You are also going through a tough time as you struggle to adapt to a new reality.

Remember though, you are not the only ones. Many families – even those who are not living with IBD – experience similar problems.

We are here to help. Here, we share some practical ways you can help yourself and your children to express themselves and stay emotionally healthy.



talking about it

hints and tips

- **It is not your fault.** Your family might have different worries to others but opening up is difficult for many young people.
- **Give them a safe space.** Try setting aside a regular hour of one-to-one time for each child. Make it the same time each week and tell them they can talk about anything they want without judgment.
- **Listen.** It sounds obvious, but sometimes it can be tempting to jump in and ask questions. If you try to step back and just listen, you might find your children are more willing to open up.
- **Young people are more likely to open up to you if you have a strong relationship.** Building trust in each other is an essential part of that. Show you trust them by giving them responsibility for something in the household. It could be managing their own medication, looking after a younger sibling, or just popping to the shop for something you have forgotten, for example.
- **Another good way to build trust** is to spend time together doing things you both enjoy. It might be watching films or going to sporting events, for example.
- **Try to control your emotions.** It is easy for tempers to flare when teenagers are rude. But try to stay calm. Remember, they are not as able to cope with their emotions as you are. Try closing your eyes and counting to ten. Or pressing 'pause' on the conversation until you have both calmed down.
- **Use your support network.** You need support too, so remember your friends and family want to help. You could try setting up a regular phone call or visit with a friend or family member. Sometimes it can help to tell them what you want to talk about in advance.



"I had to make sure that Max would never feel the way I had felt. That talking about his condition without shame or embarrassment would be the norm. That he never felt alone. And so, bowels, toilet habits and poo became a celebrated topic of conversation in our house! Max seemed completely comfortable talking about his condition, and so I encouraged this."

Jen, mother to a child with IBD who also had the condition as a child.

talking about it



activity one

Starting conversations

If you can answer a question with a 'yes' or a 'no', it is a closed question. Open questions start with words like 'how', 'why', 'what', and 'where'. Using open questions gives children and young people more of a chance to explain how they feel. It also means you can gather more information about what might be wrong.

Try our open questions quiz to see how you could be reframing your questions and easing conversations.

Which questions do you think would get the most useful reply from your child?

- 1)
 - a. Did you have a good day at school today?
 - b. What happened at school today?
- 2)
 - a. Has your medicine given you any side effects?
 - b. How is your medicine making you feel?
- 3)
 - a. Do you understand what the doctor said?
 - b. What do you think about what the doctor said?
- 4)
 - a. Are you annoyed that you are missing out on the school trip?
 - b. How do you feel about missing the school trip?
- 5)
 - a. Are you angry with your brother/sister?
 - b. What is going on between you and your brother/sister?

talking about it



activity two

Conducting conversations

Starting a conversation is one thing, but how do you keep it going?

You could:

- 1) Show them you have heard them by repeating their concerns back to them. Try using phrases like 'so what you are saying is...'
- 2) Try to understand their perspective, even though it might be different from yours
- 3) Do not argue, especially if you are the reason they are frustrated
- 4) You do not always need to have a solution. It is really important to validate their feelings, rather than always trying to fix things. You can do this by simply repeating back what you have heard. Something like 'I can hear that you're feeling really sad/angry/upset right now, and that things are really tough for you', usually works well.
- 5) Be interested and, above all, sincere.

Also, be realistic about what your teenager might want to talk to you about. It is normal for them to be more embarrassed and private about some things and to start to feel more comfortable talking to their friends than their family.

talking about it

more ways to get help or support

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- For more advice and resources on effective parenting, check out Australia's [Raising Children Network](#).



"If you feel down or anxious, talk to someone."

Mansi, 13

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taking control

Living with IBD makes life unpredictable. Neither you nor your child know when they will get ill, how bad it will be, or what will happen. It can make them feel as though they are losing control of their life.

This can come out in different ways. Younger children are not usually able to process such emotions, so they may misbehave, act out or even become aggressive. Older children might obsessively check their symptoms. They may refuse to take their medicine or go to clinic appointments.

Of course, everyone reacts differently to living with a condition like IBD. But we sometimes see children and young people develop negative thought patterns as they confront their perceived lack of control.

Some might worry about things all the time. Others might ignore what is going on altogether. But with the help of their family and friends, they can take control of their lives and their feelings.

"It has been a tough couple of years, but a positive outlook has helped us all. We have kept ourselves informed and have researched to help us to understand more about IBD. Talking helps a lot"

Nicola, mother of a child with IBD

taking control

hints and tips

- **Be there, be present.** It sounds obvious, but sometimes just giving children and young people the opportunity to talk can make a world of difference. You could try setting aside an hour one-on-one time each week to ask what is bothering them and how you can help.
- **The siblings of children with IBD can experience similar feelings.** Give them the same opportunities to share their concerns.
- **When you put your troubles down for a minute, they are usually lighter when you pick them back up.** That goes for the whole family. Have you tried mindfulness? It simply means taking a moment to think non-judgmentally about the here and now. Try sitting quietly with your eyes closed for a few minutes. What can you hear? What can you smell? How does your body feel right now?
- **Help them to take a break from IBD** by encouraging them to focus on the things they enjoy, whether it is football, music or the local youth club. After all, life is not all about their health condition.
- **Help them to open up about their condition** and take control of what people know. You could work with your child to prepare a sentence or two that only gives away as much as they are comfortable with sharing. Something like: 'I have a problem with my tummy. It's OK, I take medicine for it and you can't catch it. Anyway, did you see the match/show/ film last night?' You could try role playing the conversation – but remember to keep it fun and light-hearted.
- **Getting them involved in their own medical care** is a great way to help them take control. Try helping them to read up about their condition on the CICRA website and order the symptom impact tracker.
- **Convincing young people to take their medication can be an uphill battle sometimes.** It might be because they want to be the same as their friends or they are worried about the side effects, for example. Why not work with them to build a pros and cons list? Hopefully, this will show them that the best way to stay in control of their condition is to take their medication.
- **Remember – it is normal to be sad, angry or upset sometimes. Not every problem will be related to their IBD.**



"As difficult as it might seem, wherever possible allow your child to make decisions. Our view is that it is Eleanor's 'condition' and she will be managing this for the rest of her life – better that she engages with the process as early and feels in control where at all possible."

Mick, dad of a child with IBD.

taking control

activity one

Who are you?

IBD is only part of what makes your child who they are. Supporting them to build their resilience and self-esteem will help them see that.

You could try working with your child to build a list of the things they like about themselves.

Ask them the following questions but, remember, they might need a little help.

- 1) **What are you good at?**
- 2) **What do you like best about yourself?**
- 3) **What are you most proud of?**
- 4) **Do you remember a time that you did something that you didn't think you would be able to?**
- 5) **How did you do it?**
- 6) **What would you do differently if you had to do it again?**

You could even put the list on the fridge or pin it to a notice board in the house.



taking control

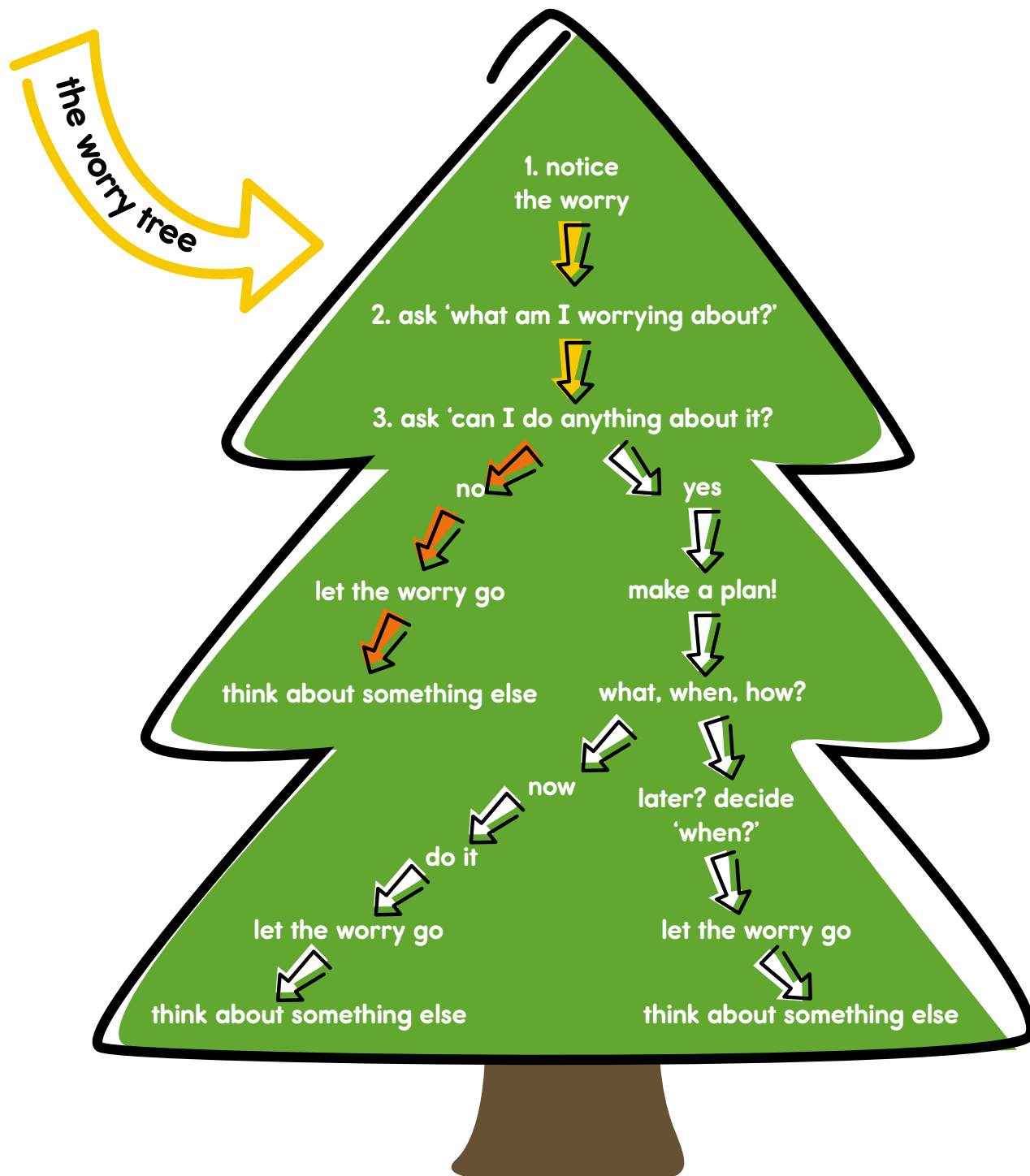


activity two

Climbing down the worry tree

Telling your child not to worry is one thing, but how do they do that?

Helping them to understand how to 'climb down the worry tree' is one way.



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

cicra 
better lives for children with crohns and colitis

taking control



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- See the emotional wellbeing kit [resources library](#) for lots more ideas and support
- For more advice and resources on effective parenting, check out Australia's [Raising Children Network](#).
- If you like mindfulness, check out [Calm](#), [Cosmic Kids](#), [Headspace](#) or [Smiling Mind](#).

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

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



do you need a little more help?

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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- 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



better lives for children with crohns and colitis

growing up, IBD and emotional wellbeing

Being a young adult is not easy for anyone. But inflammatory bowel disease (IBD) can give you an additional set of things to worry about.

We know that IBD affects your mind as well as your body.

Children and young people with conditions like yours are at greater risk than other people their age to experience mental ill health¹.

It can be hard to do everything you need to do to manage your illness while coping with school and keeping up with your hobbies and your friends.

You might feel low sometimes or have problems at school or at home. It can be really tough to talk about how your symptoms and your IBD makes you feel. All this means you might sometimes feel angry, anxious or lonely. You might even feel as though you are losing control sometimes.

But you are not the only one who feels this way. Many young adults 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 IBD – but some things will. This pack will help you understand when your health condition is affecting how you feel.

Because we believe that your life should not be limited by your IBD.



“Crohn’s disease has had a huge impact on my education and social wellbeing. However, I maintain my sense of humour and have even given my stoma a name.”

Natalia, 16

¹ <https://www.nice.org.uk/sharedlearning/transforming-mental-health-care-for-children-and-young-people-with-long-term-conditions-mental-health-and-psychological-wellbeing-drop-in-centre>



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

diagnosis and your feelings



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

diagnosis and your feelings



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.



diagnosis and your feelings



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

diagnosis and your feelings



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?

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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

coping with IBD in the family

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

coping with IBD in the family



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	

coping with IBD in the family

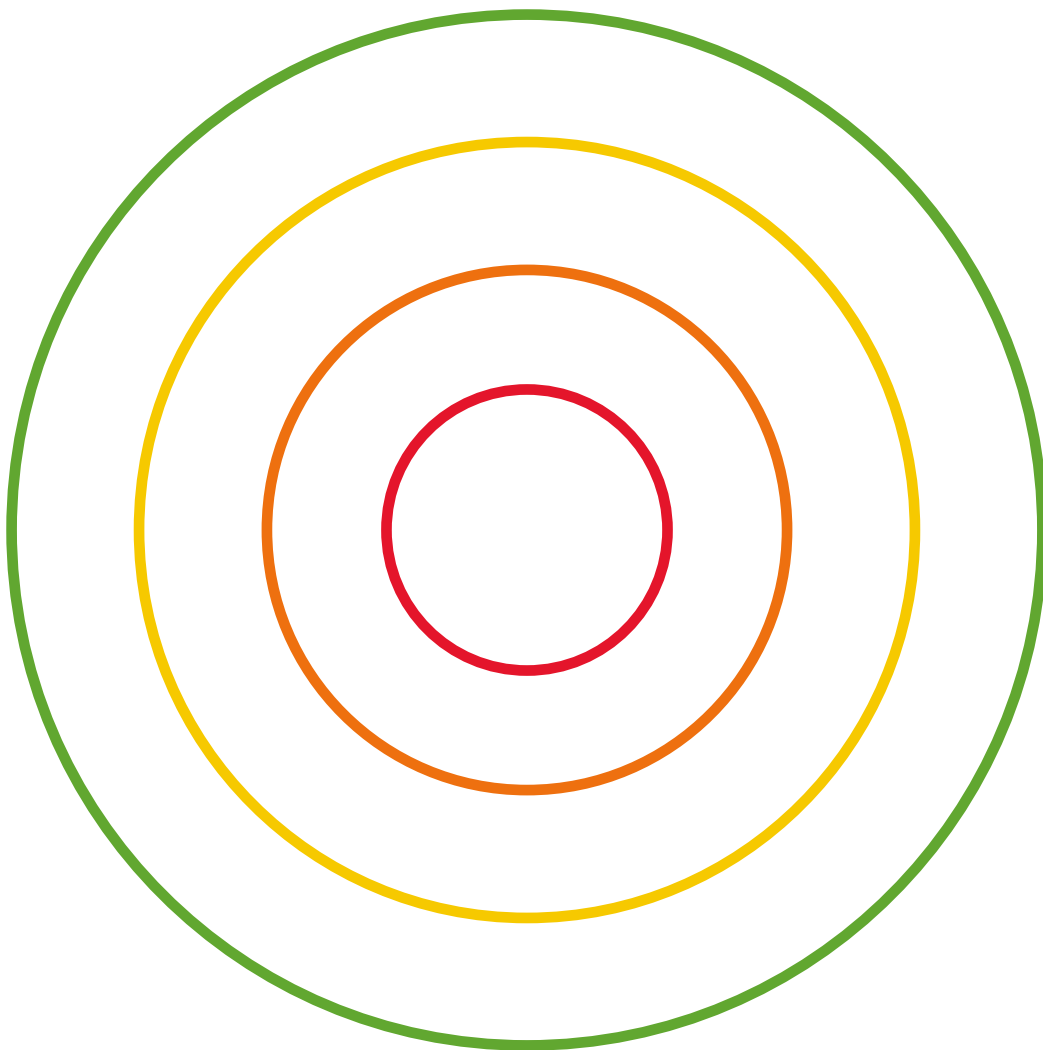


activity two

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!



coping with IBD in the family



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.

coping with IBD in the family



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



coping with IBD in the family



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?

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dealing with school or college when you have IBD

IBD and education do not always mix. It can be hard to catch up after being in hospital and you might have a daily battle with fatigue and pain. You might feel left out if you have to miss sports clubs, trips or social activities.

Some young people with IBD are small for their age, which may make them worried about bullying. You may have to take steroids. That can lead to weight gain, a puffy face and acne, and change the way you feel and act.

It can feel like an embarrassing condition to have – and to talk about. Having to go to the toilet a lot, the possibility of accidents and the general feeling of 'being different' are all hard. You might feel low or worried. You might want to hide away and stop doing things you used to like. It can be really tough when you have a flare up and get more ill.

Remember, IBD might have made things harder for you at school/ college, but some of the challenges may have been there anyway. All young people can find it hard, try and pick out what is hard because of IBD and what would have been anyway, even if you didn't have IBD. Sometimes we can blame everything on IBD!

Luckily, there are lots of things you can do to make going to school or college with IBD easier.

"It seemed impossible to start living a normal life, but my parents and siblings helped me build up the confidence and once I went back to school it wasn't as bad as I'd imagined."

Orlaith, 14

dealing with school or college when you have IBD



hints and tips

- You might not want to tell anyone about your condition, but **we would recommend telling your class teacher** or head of year and the special educational needs coordinator (SENCO). Between them, they can make sure you have the support you need.
- **Having plans in place**, even if they are never used, is much less stressful than trying to get what you need in the middle of a crisis. Start thinking about what support you might need, such as extra time on exams, early. That way you can be prepared.
- **We are all changing all the time**. What we need, and how, will change too. Work with your parents or carers and school staff to review your healthcare plan at every open evening and after any relapse.
- **If you are going to miss 3 weeks** or more of education, begin discussions with school or college as soon as possible to find out what they can put in place to support your learning at home. This will help you keep up.
- **Remember spending time with your friends is important**. Sometimes, you might want to hide away but that could make you feel worse. Why not try meeting with just one or two close friends for an hour or so?
- **You might not want to tell anyone about your condition, but why not just pick one or two people you trust?** It means you will always have someone on your side.
- Are there any **practical ways to deal with IBD** symptoms in school or college? Could you keep a **second set of textbooks** at home, to avoid carrying them around? Or could you have **extra time between classes for toilet stops?** Ask for a **toilet pass** or a **Can't Wait card** from CICRA, so you can go whenever you need to.
- **Can you distract yourself from pain during classes?** Maybe try a fidget spinner, concentrate on your breathing, or just get up and have a stretch.

"I had a flare in Year 6 that carried on into Years 7 and 8. It wasn't nice to go through the start of secondary school with, but I haven't let it stop me. My friends at school have been very supportive. We are always laughing and whenever I'm not at my best they always keep me up and running."

Harry, 15

dealing with school or college when you have IBD



activity one

Express your fatigue

Lots of people with IBD have fatigue. It can make it hard to concentrate or take part in class. It can make you irritable or frustrated – especially when someone says it is 'just' being tired.

It can help to be able to explain fatigue to tutors and friends. Some people say it feels like 'hitting a wall' or 'being completely drained of any energy'. But it is different for everyone.

What does it feel like to you? Why not try writing it down?

Start a fatigue diary

If you understand how different activities make you feel, it might help you manage your fatigue better.

Why not make a note of what you have been up to, and how much energy you have at different points in the day? You could do it on your phone or start a paper diary, like the one below.

Try filling it in once or twice a day.

Day and time	Activity log	Energy level
Monday morning	PE at school	😓
Monday evening	Dinner and TV with the family	😊
Tuesday daytime	Hospital appointment, history lesson	😓💤
Tuesday evening	After school club	😓

You might find that you have more energy first thing in the morning, or last thing at night. Once you know that, you can plan around it.

Maybe imagine you have a jar of 'energy marbles' and each marble is one 'bit' of energy you have for a day. You might have a certain number of marbles for sport or exercise. Then there is another number for doing stuff you need your brain for, like schoolwork, and some marbles for having fun.

How would you use your marbles? What are the best things to 'spend' your marbles on and when? Remember, it is different for everyone so try different things to see what works for you.

dealing with school or college when you have IBD



activity two

Who are you?

IBD is only part of what makes you who you are. Focusing on what you are good at will help you see that.

Why not write a list of the things you like about yourself? Try asking yourself the following questions and, remember, you can always ask your family for a little help.

- 1) **What are you good at?**
- 2) **What do you like best about yourself?**
- 3) **What are you most proud of?**
- 4) **Do you remember a time you did something you didn't think you would be able to?**
- 5) **How did you do it?**
- 6) **What would you do differently if you had to do it again?**

You could even put the list on the fridge or pin it to a notice board in the house.

dealing with school or college when you have IBD



more ways to get help or support

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- 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
- CICRA's [resources for schools](#) include booklets for primary and secondary schools, quick guides for class teachers, information about individual healthcare plans, advice on exams and tests, and examples of letters to exam boards
- Young people share their tips on coping with school in these [videos](#)
- [Bullying UK](#) offers help and support on dealing with bullying

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talking about it

Everyone always says it is good to talk. We know it is not always that easy, especially if the topic may feel embarrassing to talk about like bowels and IBD..

It can be hard to put your emotions into words, especially if they do not always make sense to you. You might think no one will understand how you feel.

But not talking can make things even worse. It can make you behave in ways that you might not want to. If you are angry after your diagnosis, for example, you might take it out on your brother or sister. Or if you are scared about the future you might start giving up your hobbies.

Of course, IBD is not the only thing you have going on. There's school or college work, your friends, your 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 are not living with IBD – have stuff to deal with.

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

“My friends know about my condition as I have been very open about it and I believe that this is the right thing to do. It makes playing out and sleepovers a lot easier as I take my tablets with me.”

Josh, 12.

talking about it

hints and tips

- **It is not your fault.** No one knows what causes IBD, but we do know that you did not do anything wrong.
- **You might not want to tell anyone about your IBD. But why not choose one or two people who you really trust?** It could be anyone – a friend, aunt, uncle, grandparent or teacher. That way, you have always got someone to talk to when you need them.
- **Try to open up about your condition.** It can help you to control how people see you. You only need to tell them as much as you are comfortable with. Try something like: 'I have a problem with my tummy. It's OK, I take medicine for it and you can't catch it. Anyway, did you see the match/show/film last night?'
- **Give your parents a chance.** Some young people do not feel comfortable speaking to their parents or carers about what is going on in their lives. Remember they were your age once too! Tell them what is bothering you and they might understand more than you thought.
- Some 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!
- **Use your healthcare team.** The good thing about talking to your IBD doctor or nurse is they have seen it all before. It means you can talk about whatever you want without ever having to be embarrassed.



"I am lucky to have my family and friends to support me. My school friends always check up on me to make sure I am okay. I have also met some friends while having my infusions at hospital, this is nice because we share our stories and text each other. Friendship and laughter are great medicines."

Katherine, 15.

talking about it



activity one

Writing versus talking

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

Why not try sending your parents, carers or friends 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 parents, carers or friends 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

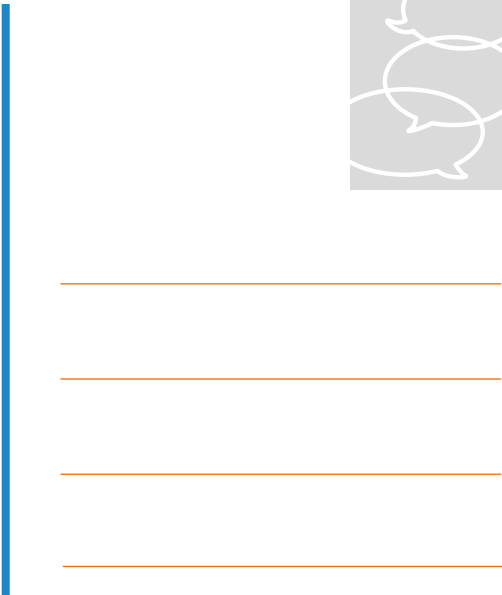



activity two

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 is just about giving you a way to open up about how you feel.



talking about it

activity three

be prepared

Thinking ahead can be helpful - what questions might your friends ask? Maybe think of some questions (What is IBD? Can I catch it? What medicine do you need to take? etc) and write down how you might want to answer them, so you feel more prepared for when these questions come up.



What do you wish others knew about your IBD?

Once you've written them down, think about showing your parents or carers?

talking about it

more ways to get help or support

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- [MIND](#) has lots of tips for young people who want to open up to friends and family



"If you feel down or anxious, talk to someone."

Mansi, 13

do you need a little more help?

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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



taking control

When you live with IBD, life can be unpredictable. You don't know when you will get ill, how bad it will be or what will happen. 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 their IBD. 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 take your medicine? 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.

"I wouldn't change me having this illness... I believe that I am the person I am because of it. I feel that I have come out stronger on the other side. Don't forget to be proud of yourself and who you are."

Abbi, 16

taking control

hints and tips

- Remember, IBD is only part of what makes you who you are. **You are not a patient, you are a person.** Try making a list of all the things you like about yourself. What things are you good at? What do you think is important in life? These are the things that make you who you are, not IBD
- **Take a step back.** Try to focus on the things you enjoy, so you can forget about your IBD 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?
- It's easy to focus on how we are different from our peers which can make us feel worse. Try to **list all the ways you are still similar** to your friends.
- **Have you tried mindfulness?** It means paying attention to everything that is happening in the here and now, noticing it without making a judgement about it. 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 check out [Calm](#), [Cosmic Kids](#), [Headspace](#) or [Smiling Mind](#).
- Getting involved in your own medical care is a great way to take control of things. **Try reading up about your condition** on the [CICRA website](#) and letting your parents/carers see how much you have learned.
- **Keep taking your medicine** – it's the best way for you to stay in control of your IBD. Why not make a list of all the good and bad things about your medication?
- **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!



"I learned NOT to let the illness control me...I control the illness."

Scott, 16

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

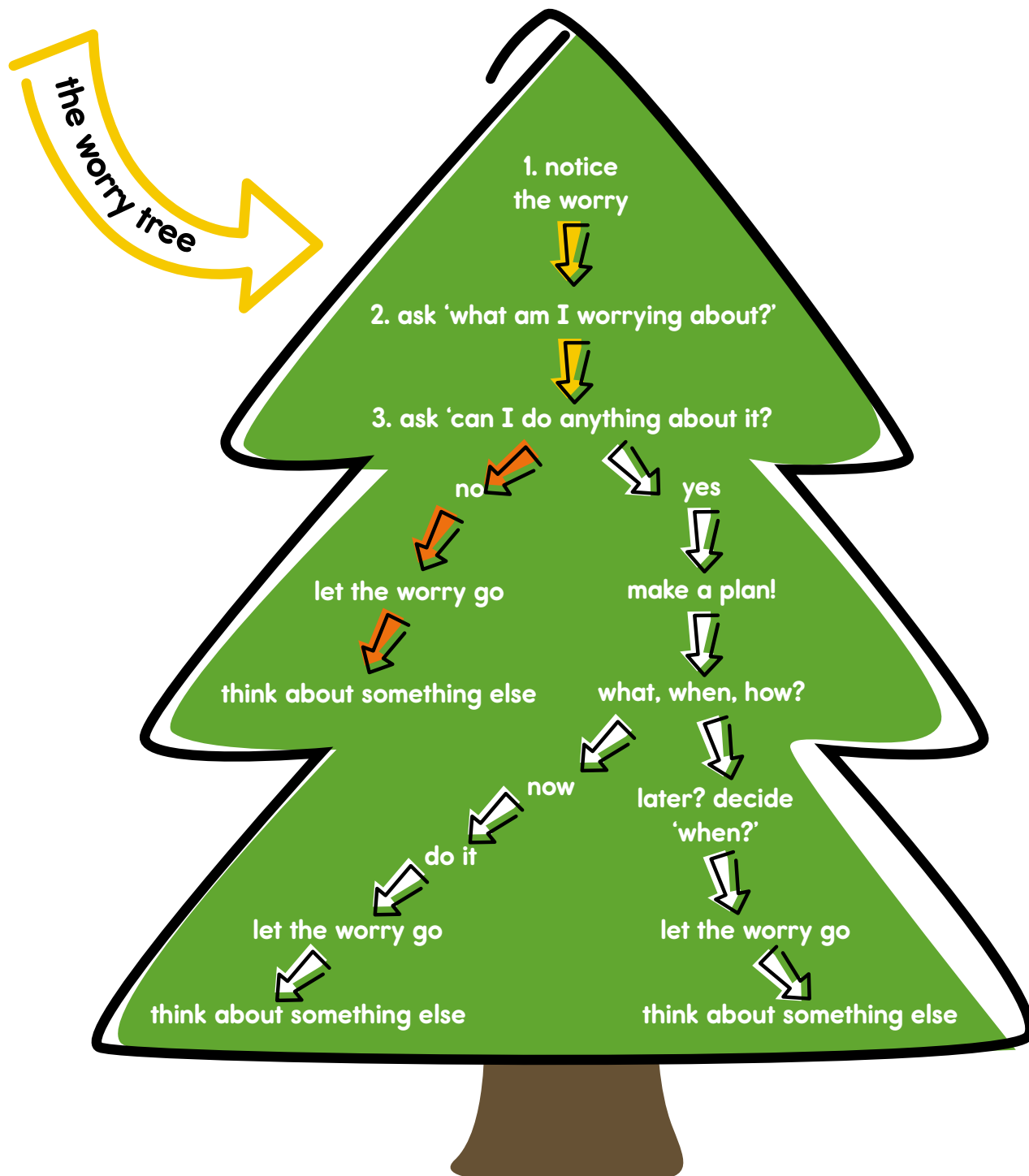
taking control



activity three

Climbing down the worry tree

People might say 'don't worry'. But how do we 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 from the psychologist in your IBD team or talk to CICRA.

Adapted from Butler and Hope 2007

cicra 
better lives for children with crohns and colitis

taking control

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"Having a chronic illness is terrifying and unpredictable. I never knew when a flare up would come to haunt me and I was left living in fear,"

Karina, 21

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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.

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- [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



do you need a little more help?

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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better lives for children with crohns and colitis

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.

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

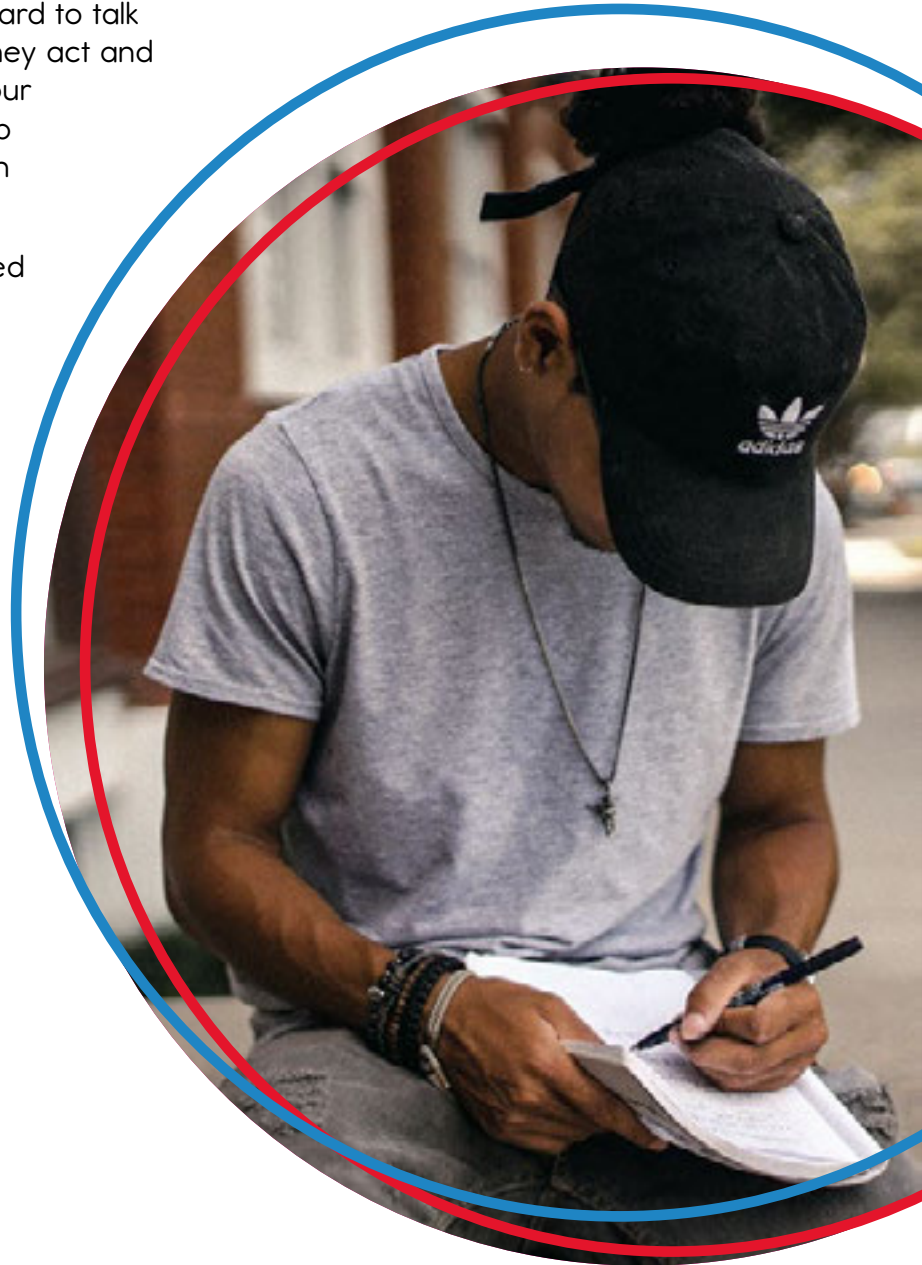


activity three

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



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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



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- **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

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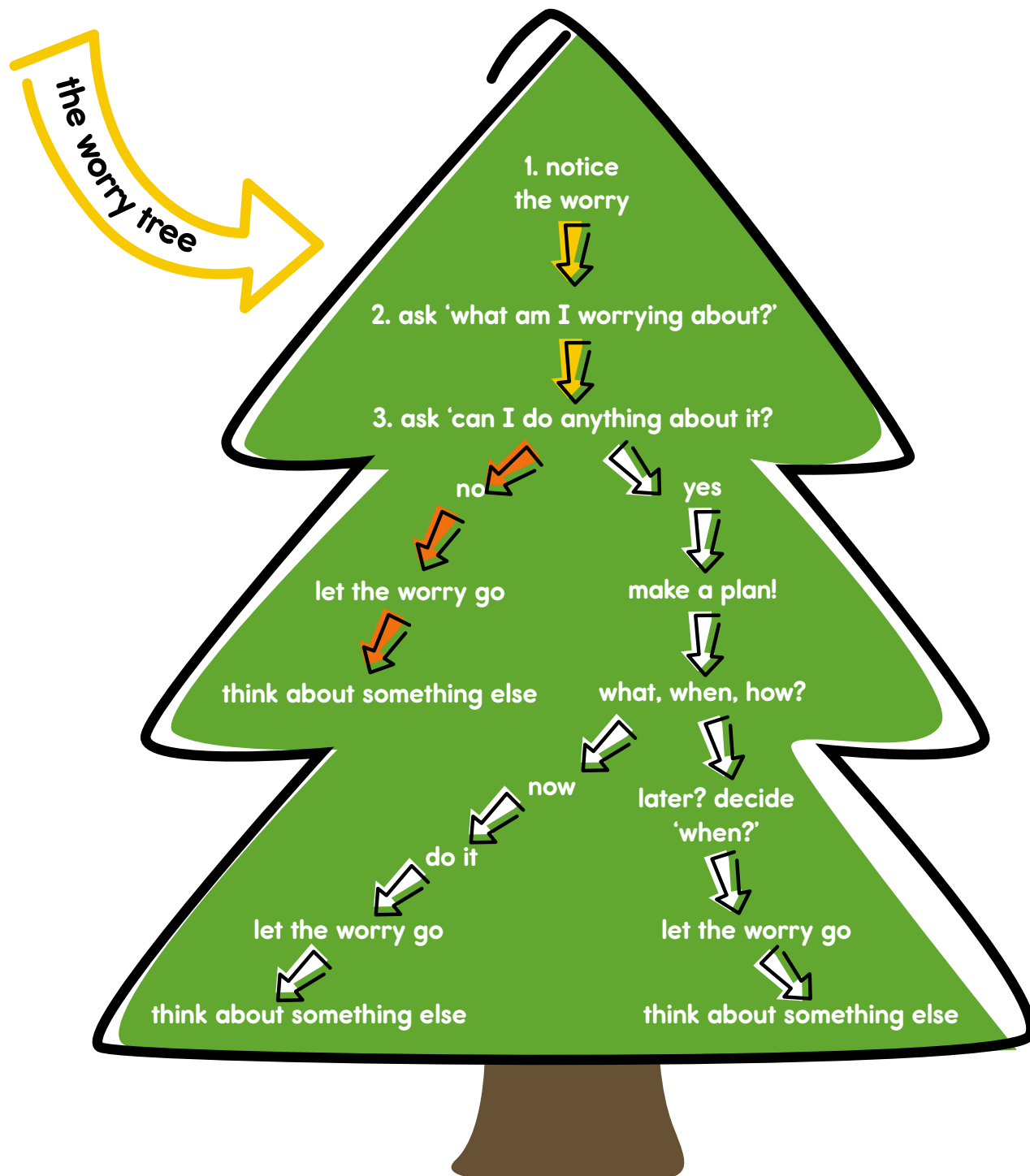
taking control



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',
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Adapted from Butler and Hope 2007

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- [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



do you need a little more help?

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

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
- 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