



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



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



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?







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

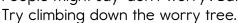




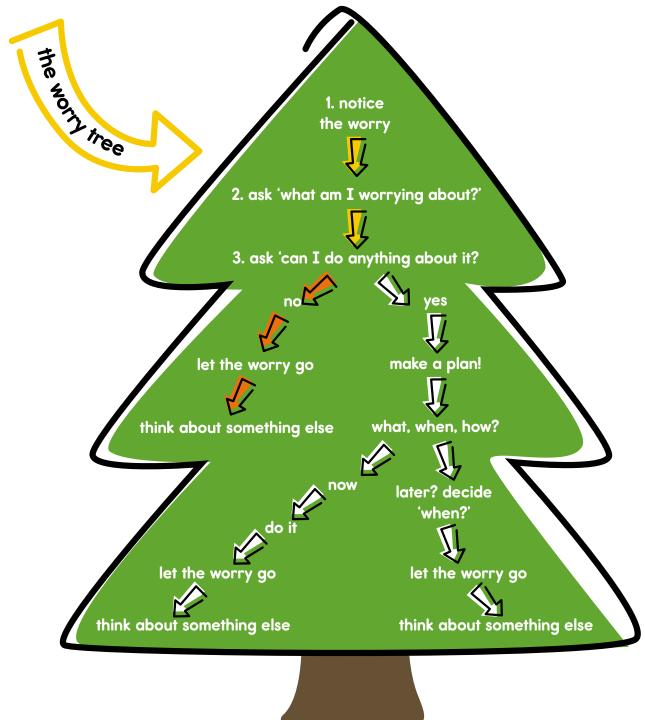
activity three

Climbing down the worry tree

People might say 'don't worry'. But how do we that?







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

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 <u>Family Day</u>
- Speak to Laura, CICRA's <u>Family Support Worker</u> or ask her to connect you with others in your situation
- See the emotional wellbeing kit <u>resources library</u> for lots more ideas and support
- If you like mindfulness, check out Calm, Cosmic Kids, Headspace or Smiling Mind.



"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

do you need a little more help?

We designed this kit to help you and your family cope with some of the common ways IBD can make you all feel. But sometimes, you might need a little more help - and that is OK.



Lots of people feel that way.

If you spot any of the following signs, it might be a good idea to ask your healthcare team if they can offer any extra psychological support, or at least point you in the right direction of services in your area:

- Feeling like you cannot cope
- Struggling to use the tools in this kit
- The tools in this kit do not seem to be working for you
- A lack of interest in the things you usually enjoy
- A feeling of sadness that does not go away
- Thoughts of harming yourself or others

