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

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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.

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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.

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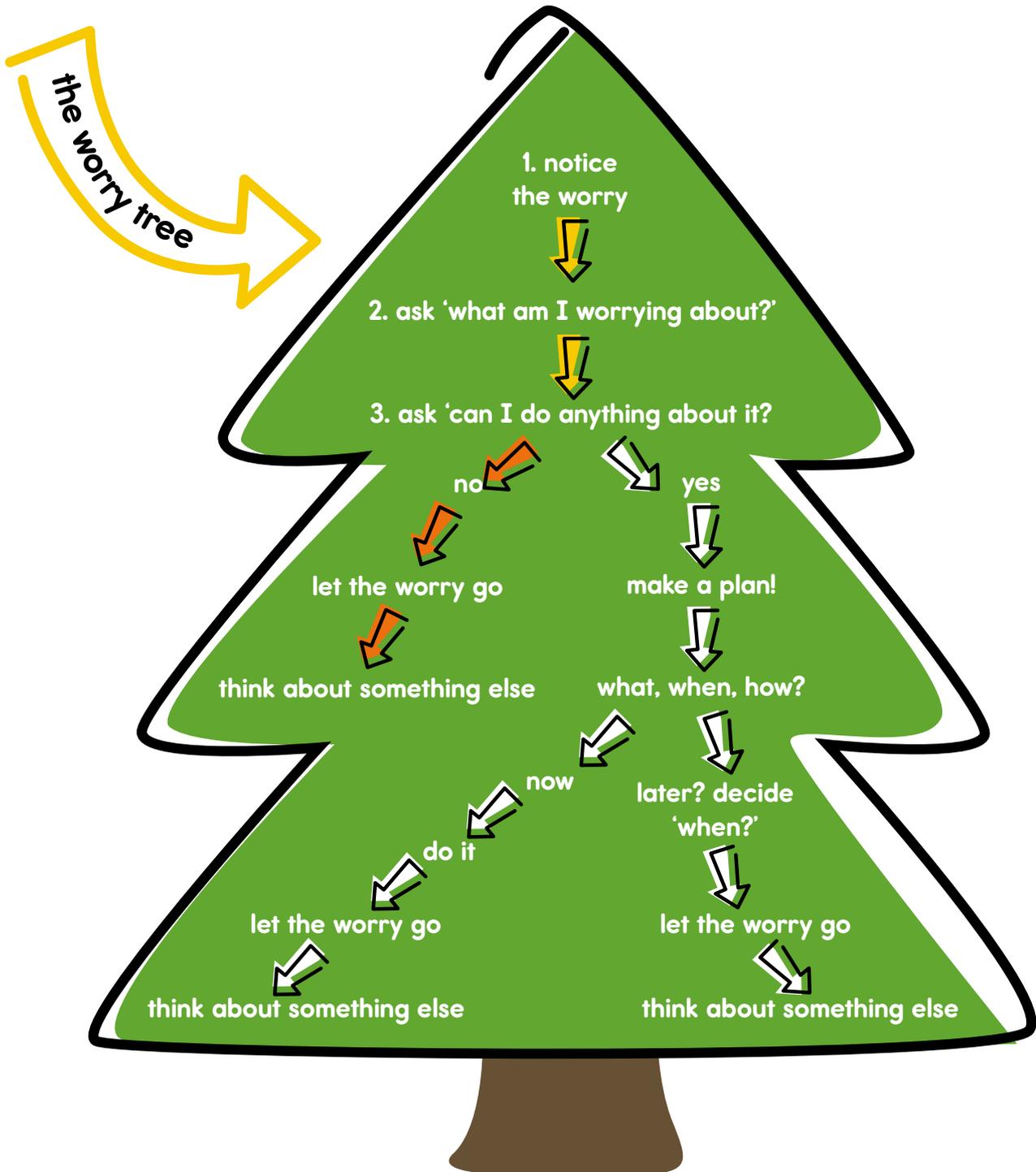better lives for children with crohns and colitis

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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.

the worry tree

1. notice the worry

2. ask 'what am I worrying about?'

3. ask 'can I do anything about it?

no   yes

let the worry go   make a plan!

think about something else   what, when, how?

now   later? decide 'when?'

do it   let the worry go

let the worry go   think about something else

think about something else

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

Adapted from Butler and Hope 2007

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emotional wellbeing
for parents

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

- 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

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