parenting, IBD and emotional wellbeing

emotional wellbeing for parents

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 health[1].

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.

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[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

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global's Make some NOISE for those who don't get heard

emotional wellbeing for parents

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.

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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

emotional wellbeing for parents

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.

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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
- 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 for parents

coping 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.

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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

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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.

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

- 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
- 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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- They are struggling to use the tools in this kit
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- A feeling of sadness that does not go away
- They express thoughts of harming themselves or others

> *"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

emotional wellbeing for parents

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

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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

emotional wellbeing
for parents

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

- 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
- 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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Lots of people feel that way.

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- They express thoughts of harming themselves or others

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

- 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 feel down or anxious, talk to someone."*
>
> Mansi, 13

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better lives for children with crohns and colitis

emotional wellbeing for parents

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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better lives for children with crohns and colitis

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.

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.

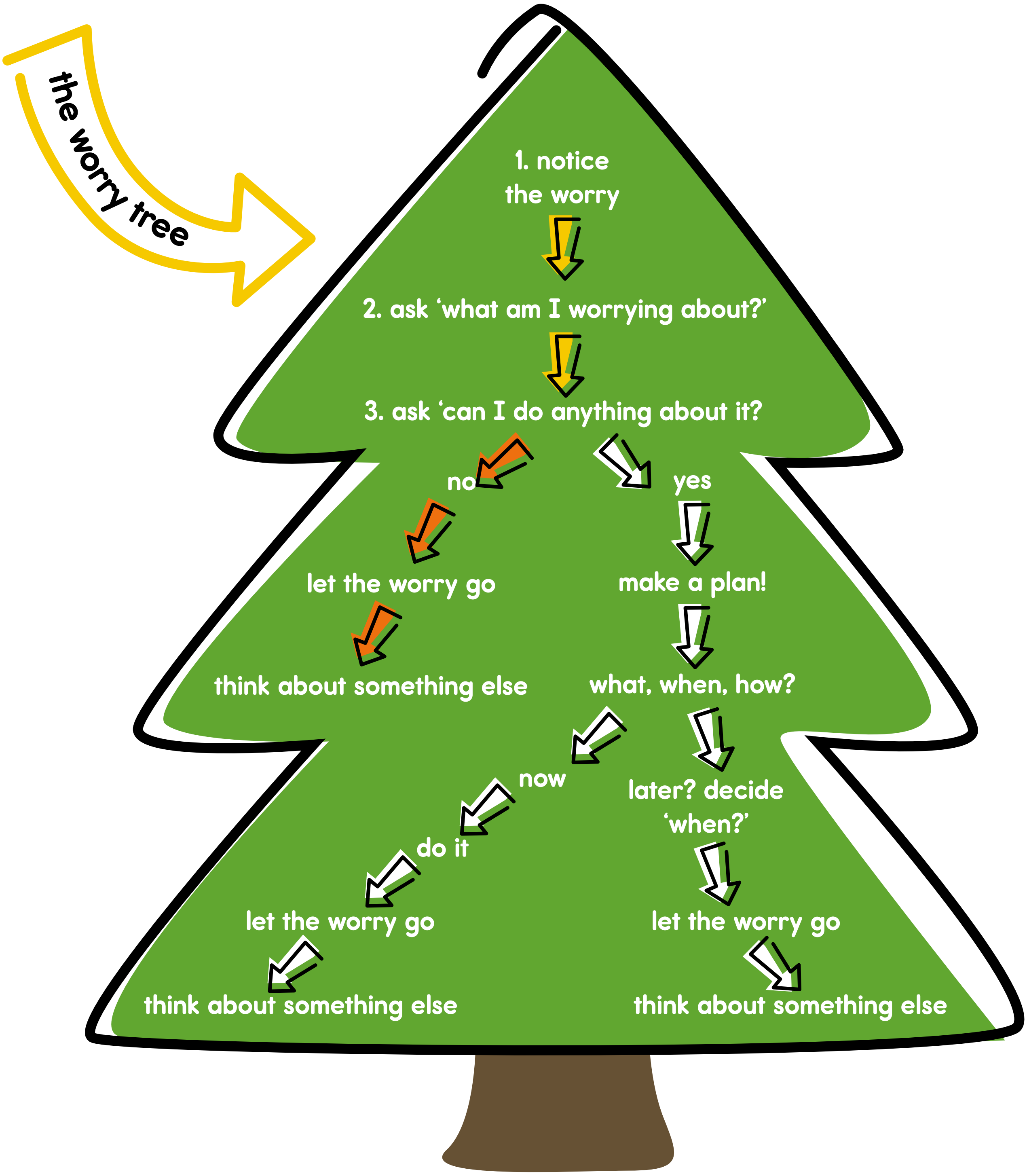
taking control

emotional wellbeing
for parents

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
- let the worry go
- think about something else

yes
- make a plan!
- what, when, how?
  - now
    - do it
    - let the worry go
    - think about something else
  - later? decide 'when?'
    - let the worry go
    - 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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taking control

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

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 charitydedicated to children›s emotional wellbeing

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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

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global's Make some NOISE
for those who don't get heard

CICRA is a registered charity in England & Wales, number 278212 and Scotland, number SC040700.