

Parents of children with IBD

This information sheet is for parents of children with inflammatory bowel disease (IBD).

Key points

- Learning about IBD can help you better understand what your child is going through, so you can support and advocate for them more effectively.
- Allow your child the time and space to ask you or their healthcare professional questions.
- Your child might only want you to tell people who need to know, such as teachers or other people who look after them. Have a conversation with your child to find out what level of detail you need to include.

How to talk to your child about IBD

Feeling sad, worried or scared are all normal feelings when receiving a diagnosis or living with the uncertainty of IBD and can affect the whole family, not just the person with the condition. Learning about IBD can help you better understand what your child is going through, so you can support and advocate for them more effectively.

Talking about symptoms, tests and procedures

Developing an understanding of the symptoms, tests and treatments prescribed for your child will help you respond to questions your child might have on these topics. Start by talking to your child's gastroenterologist. Make a list of questions you'd like to ask and bring them to your child's next appointment or email the list of questions through to the service.

The information you share with your child about their condition will depend on their age. Allow your child the time and space to ask you or their healthcare professional questions. Refer to trusted sources of information, like Crohn's & Colitis Australia (CCA) or government health websites if you don't have the answers, rather than googling from unknown sources.

Supporting your child

Whether it be letting your child sleep in, preparing nutritious snacks, or celebrating small wins, you may find yourself looking for new ways to support your child since receiving their diagnosis. Supporting your child might be as simple as asking them "what do you need from me today?"

Here are some tips on how you can support your child:

- **Listen to their concerns.** Living with a chronic condition can bring up a lot of difficult emotions. Be honest with them when they ask questions. Let them know you're on their side and ask them what they need from you right now.
- **Reassure your child** that there are options to help them manage their IBD so they can live a great life and that you will get through difficult times together.
- **Communicate with your child's school.** Talk to your child's teacher, school principal or school nurse to make a plan. The school may be able to provide access to a private bathroom, extra time for exams, a plan for catching up on any missed schoolwork or extra emotional support. Students can complete forms for medical special consideration in Year 11 and 12 state exams. Be sure to include your child in decisions.
- **Find opportunities for your child to connect with other children living with IBD.** Peer-to-peer support can help your child to know that they're not alone and provide them with a source of comfort. Keep an eye out for new opportunities for your child to connect with others. Ask your child's healthcare team about peer-support resources and events.
- **Create a support network for your child.** They may not want everyone to know about their condition, but it helps to have a few people in their life that they can turn to for support. Start by asking your child who they want in their support team and have a chat with each person. Direct them to the CCA website if they have more questions on how they can best support your child.
- **Look after yourself.** Reach out for emotional support and connect with others who understand what you're going through.

When you might need to talk about your child's IBD

Whether you're talking to a parent when you drop your child off at a birthday party or sitting down in a meeting with your child's teacher, it's a good idea to identify situations when you will need to share information about your child's health and prepare a script. **You can access a sample script on the CCA website through following the QR code below.**

For help or information

Scan QR code for website:



Use the website search function to find related pages:

- [Crohn's and Colitis Kids](#)
- [Crohn's and Colitis Teens](#)
- [Students with IBD](#)

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