



TALKING TO MY CHILD ABOUT MY IBD

INTRODUCTION

As a parent or carer with Crohn's or Colitis, you may wonder whether to talk to your child about your condition. Some parents with Inflammatory Bowel Disease have found telling their child to be a positive experience that helps them develop a closer relationship. Others may wish to keep their illness to themselves so as not to worry their child, particularly if their condition is mild. This information sheet contains helpful suggestions about how to start telling your child about your IBD.

SHOULD I TELL MY CHILD?

What are the effects of telling my child?

Telling your child that you have IBD could be a positive experience, and it's likely they're able to cope with the truth better than you realise. Telling your child can bring your family closer and relieve tensions – especially if it helps them understand why you sometimes need help when you are feeling unwell. It can help your child to feel included, trusted and valued if they know about your IBD.

Once your child knows about your IBD, you may feel less alone and isolated as you can be more open about what you say. Those around you may also feel more comfortable if they no longer have to keep your IBD a secret – and that might make you feel less anxious too.

Dealing with IBD as a family can be an opportunity for children to learn about the body, treatment and healing. Some parents with IBD have also found their children become more caring and considerate.

What are the effects of not telling my child?

If your IBD is well-controlled, you may feel it isn't necessary to tell your child. It is natural to want to protect your child from worry, particularly if they are young or sensitive.

Be mindful that even young children may sense that something is wrong, particularly if they overhear others talking about your IBD, or see you take medication. Some children can feel hurt if they are not told about what is happening. It can make them feel very anxious, left out and even unwanted.

If your child realises that you are unwell, they may misinterpret the situation. What they imagine may be far worse than the truth. They might start blaming themselves for your illness, especially if you aren't talking to them about it. It is important for children to understand that your IBD is no one's fault.

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I had complications following a bowel resection operation. I had told my children that I was having an operation but not what the outcomes could be or the length of time I could be in hospital. They got very confused when I was in hospital for six weeks. If I had been more open and talked about going into hospital sooner, that could have been avoided.

”

John, age 41, diagnosed with Crohn's Disease in 1995

SHOULD IT BE ME WHO TELLS MY CHILD?

It may reassure your child for their parent to tell them about their IBD. You may wish to do this together with a close relative or friend. Partners, extended family and trusted friends often provide valuable emotional support as well as practical help in caring for your children.

Finding the words to talk about your IBD can be challenging. If you cry, you could explain that it is because you are upset about your illness. While it's best to be wary of revealing extreme distress, seeing you show your emotions in a measured way lets your child know it's okay to share theirs too. Hiding your feelings may make your child feel they have to do the same, making it harder for them to open up about their own worries.

If you're finding it difficult to talk about your IBD without becoming upset, your partner or another close relative could tell your child. You may wish to still be there to reassure them, and it will be helpful to know how much your child has been told and how they reacted.

WHEN AND WHERE SHOULD I TELL MY CHILD?

Having a definite diagnosis of Crohn's or Colitis can make it easier to explain your IBD to your child. Receiving your diagnosis can be overwhelming, so finding an approach that works for both of you is important. You don't have to tell them everything at once, but could gradually explain various aspects as and when they need to know. This will give them time to absorb what you have said and return to the conversation later, when they have thought of more questions to ask – keeping the conversation open and ongoing.

Finding a place where you will not be interrupted and you and your child can talk freely, could make it easier for them to discuss what's on their mind.

Choose a time when you are not in a hurry or feeling pressured. Allow enough time for your child to think about what you are saying and to ask questions. It might help to avoid talking just before bedtime, in case they become worried and find it difficult to sleep. A formal discussion may be intimidating and alarm them. So, if possible, pick a time in your routine which is familiar so they feel relaxed, such as after school or at teatime.

If you have more than one child, it is usually best to tell them together so they don't feel their siblings know more than they do. If you do talk to them separately, try to avoid leaving a long time between telling each one, or the last may wonder why they were left until the end.

HOW SHOULD I TELL MY CHILD?

Be clear

Use simple and straightforward language. You could ask your child what they think IBD is, whether they know what happens to the food we eat, or, for older children, how much they know about the digestive system.

Depending on how much your child is able to understand, you may want to discuss particular aspects of your IBD. This could include the treatment you are being given, how it makes you feel, and possible side effects. You could then talk about why there may be times when you need to rest more than usual.

Be honest

Maintaining regular commitments when you have Crohn's or Colitis can be tricky. It's not uncommon to feel exhausted by holidays and social events, or need to limit how much you go out with your child for fear of having an accident. Explaining that IBD is a fluctuating condition that may be 'up and down', could help them understand that your condition will not always affect you in the same way, and that you will have good days and bad days. Be honest and try not to make promises that you may not be able to keep. You could say, 'I will try to...' or 'I think I will be able to...'

Reassure them

It may be a good idea to talk about your feelings and emotions with your child. You could explain that your IBD makes you more tired and easily irritated, but this doesn't mean that you don't love them and you'll still care for them. They may blame themselves, so make it clear that it isn't their fault. Make the most of spending time with your child when your energy is up, doing the things you enjoy together. When you're feeling less well, think about ways in which you can still encourage fun either together at home, or by encouraging your child to take part in physical or social activities outside the home.

Encourage openness

Asking your child questions can help them feel part of a discussion, for example, if they are worried about anything in particular, or if there is anything they want to know about IBD. Don't be afraid to say if you don't know the answers to all of their questions. Crohn's and Colitis are very individual conditions and people's experiences vary widely.

You might find it helpful to use jokes to diffuse the tension when talking about potentially embarrassing topics, like passing wind. One parent with IBD expressed the positive effect this had on their relationship with their child, saying 'if they could talk about bowels, they could talk about anything.'

“Openness is super important. I think because we have not been embarrassed by it, our children are not embarrassed by it, so they don't hide it away. They say to kids at school 'that's my mum, she's ace'.”

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—
Timm, husband of Sam, age 36,
diagnosed with Ulcerative Colitis in 2013

WHAT SHOULD I TELL MY CHILD?

How much your child understands will depend on their age. Listening to them and looking out for non-verbal clues will help you know how much they are taking in and can cope with. It may be worth practising what you want to say beforehand. Think about what questions your child may ask and how you could respond. If you can, try to balance the news by ending with a positive so that you leave them feeling that even though you may be unwell now, there will be better times. All children are different, but they may show typical reactions depending on their age:

Toddlers:

Very young children will not be able to understand much, but older toddlers may start to ask questions.

A simple statement should be enough:

- 'Mummy/Daddy is feeling poorly.'

3-5 years:

Pre-school children are more aware of things happening around them and will need simple explanations. You may find it helpful to do this using visual tools such as books, pictures or drawings. Young children may be anxious about separation from their parents, or a disruption to their daily routine, if, for example, there is talk of you going into hospital. Try to let them know in advance of any changes to their routine and when they will be able to see or speak to you. At this age, they may start to worry about 'catching' IBD from you, so help them understand that IBD is not contagious. It may also be helpful to remind your child not to touch your medication.

You could try the following phrases:

- 'Mummy/Daddy has to go to the hospital to get some medicine to make her/his tummy better.'
- 'Eating some foods makes Mummy's/Daddy's tummy sore.'
- 'Mummy/Daddy is feeling sad because her/his tummy is sore.'

6-11 years:

Primary school children will be able to understand more about IBD and the effect it can have on the body. They may ask questions about dying, so reassure them IBD is not a terminal illness, and this isn't something they need to worry about at all. Explain how your IBD may impact your family's routine, for example, if you sometimes feel too tired to take them to school. They may also want to feel involved and know how they can help you.

You may wish to use some of the following phrases:

- 'I have an illness called Ulcerative Colitis/Crohn's Disease. My tummy is red and sore inside. I'm taking medicine to help me get well.'
- 'Sometimes I feel very ill or tired, but other times I feel fine.'
- 'The illness can make me go to the toilet a lot, which might seem embarrassing but is just a normal part of my condition.'
- 'Being ill makes me feel upset. I may seem tired and cross sometimes, but it's not your fault and I still love you.'
- 'You'll still be able to go to (the park/football/gymnastics/the cinema), but I won't be able to go this time.'
- 'Some foods make my tummy sore, so sometimes my dinner might be different from yours.'

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I told my three year old daughter about my Crohn's after I got the diagnosis. It was hard, but I tried to be brave, and I felt by telling her that we could face the future together as a family.

”

Glenda, age 34, diagnosed with Crohn's Disease in 2012

12+ years:

Secondary school children are starting to become more independent, and may need encouragement to talk about their worries.

They might start to want more complex explanations, and worry they will get the same illness as you. Reassure them that the risk is small. For every 100 people with Ulcerative Colitis having a child, about 2 of the children may be expected to develop IBD. For every 100 people with Crohn's having a child, 5 to 10 of the children may be expected to develop IBD.

Older children may also worry more about you. While you should try not to worry them with concerns they can do little about, such as money, identifying things they could help with may help them feel involved.

Teenagers can find information empowering, so you could suggest looking up IBD together as a way of explaining it. You should focus your search on websites that have reliable information, such as the Crohn's and Colitis UK website (crohnsandcolitis.org.uk) or NHS Choices (nhs.uk). You may find it helpful to read our booklet **Understanding IBD** together. Our mobile-friendly Crohn's and Colitis Companion website (companion.crohnsandcolitis.org.uk) might be a less intimidating and overwhelming way to learn new information about IBD together.

Some of the following phrases may be useful:

- 'I have a condition called Ulcerative Colitis/Crohn's Disease. It causes my small intestine/large intestine/bowel/digestive system to become red, swollen and painful. This can mean that I need to use the toilet a lot/get stomach aches/get tired easily.'
- 'Some foods give me a stomach ache, so sometimes my meals might be different from yours.'
- 'Crohn's Disease/Ulcerative Colitis is an invisible illness. This means that you can't always see the symptoms. Sometimes I might look OK, but inside I might be feeling unwell/have a stomach ache/feel very tired.'
- 'Crohn's Disease/Ulcerative Colitis is a chronic illness. This means it's long-term and I will always have it, but I have treatment to help me feel better.'
- 'Sometimes I might not be able to do as much with/for you, and I may need you to help me.'
- 'If I'm unwell it can make me feel upset or cross – but this isn't your fault and I still love you.'
- 'It is an illness that can get better for some time and then get worse again – I will have good and bad days. If you have any questions about it, you can ask me.'
- 'Crohn's Disease/Ulcerative Colitis can run in families, but the chance that you'll get it is very small.'

Older children might be asked questions by their friends, so agree with them what information is OK to share. If you are worried about your child at school, ask them about what is going on. Picking the right time and place can help them open up to you. See **When and where should I tell my child** for tips.



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When I was in hospital, I had a chat with one of the nurses about explaining things to the children. My eldest son, who was 10, was very anxious about me being in hospital. But when he came into visit, the nurse met him at the door and explained what he might see and what the equipment was for. It really helped having someone ‘official’ speak to him, rather than a member of the family.

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Claire, age 44, diagnosed with Ulcerative Colitis in 1981

GOING INTO HOSPITAL

If you have to go into hospital, you may wish to reassure your child beforehand. You could start by letting them know who will look after them, then explain why you need to go, how long for, what is going to happen, and how it will affect you afterwards. You could also talk about what they might see in hospital if they come to visit you, for example drips or oxygen, so they aren't worried or overwhelmed when they visit. Hospital staff may help you to explain these sorts of details. Being able to show your child pictures can be particularly useful if you'll be having a stoma. You may wish to look at our leaflets **Surgery for Crohn's Disease**, **Surgery for Ulcerative Colitis** or **Living with a Stoma**.

Visiting you in hospital gives your child a chance to see how you are getting on, and to tell you how they feel. However, they may not want to stay very long, and young children in particular may feel awkward or bored. You could ask whoever brings them to pack a book, game or toy for something fun to do together, or to keep them occupied if you need rest.

YOUR CHILD'S REACTION

You might find that your child reacts unexpectedly when they find out about your IBD. They might not ask questions and may appear uninterested. This doesn't mean that they don't care – they may just need time to absorb the information. Try regularly asking your child how they are feeling and give them the opportunity to ask you questions.

You may find their emotions come out later and they express themselves in actions rather than words. Their behaviour could be an indicator of how they are feeling. For example, your child may become withdrawn or 'act up' in some way by being naughty, or becoming more clingy. This could be their way of showing how upset they are.

If you have noticed a change in your child's behaviour, or if they find it too difficult to talk to you about your IBD, you could suggest counselling as a way of talking through their worries or anxieties. Counselling sessions for children are tailored to their age, and younger children may be encouraged to express themselves in non-verbal ways, for example through artwork or play. Your child's GP, and in some cases your IBD team, may be able to help you find an experienced counsellor. You can read more information about the different types of counselling and how to find a counsellor in our information sheet **Counselling and IBD**.

TELLING YOUR CHILD'S SCHOOL

If you are happy for your child's school to know about your condition, it might be a good idea to speak to their teacher. The teacher can let you know if there are any changes in your child's behaviour. If you tell your child's school, they may be able to offer you extra support, such as ensuring you have access to toilets at the school and being understanding if your child is sometimes late.

LOOKING AFTER YOURSELF

There may be times when the responsibilities of parenthood feel overwhelming. Looking after yourself, slowing down when you need to and maintaining good relationships with other family members and friends will have a positive impact on both you and your child. Our **Living With IBD** booklet contains helpful suggestions on how to make sure you're looking after yourself.

HELP AND SUPPORT FROM CROHN'S AND COLITIS UK

We offer more than 45 publications on many aspects of Crohn's Disease and Ulcerative Colitis. You may be interested in our comprehensive booklets on each disease, as well as the following publications:

- Understanding IBD
- Living With IBD
- Fatigue and IBD
- Claiming Personal Independence Payments (PIP)

All publications are available to download from:
crohnsandcolitis.org.uk/quick-list

Health professionals can order booklets in bulk by using our online ordering system, available from the webpage above.

If you would like a printed copy of a booklet or information sheet, please contact our Helpline - a confidential service providing information and support to anyone affected by Inflammatory Bowel Disease.

Our team can:

- help you understand more about IBD, diagnosis and treatment options
- provide information to help you to live well with your condition
- help you understand and access disability benefits
- be there to listen if you need someone to talk to
- put you in touch with a trained support volunteer who has a personal experience of IBD

Call us on **0300 222 5700** or email info@crohnsandcolitis.org.uk

See our website for **LiveChat**: www.crohnsandcolitis.org.uk/livechat

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Talking to my child – Edition 4
Last review: March 2018
Next planned review: 2021



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ABOUT CROHN'S & COLITIS UK

We are a national charity established in 1979. Our aim is to improve life for anyone affected by Inflammatory Bowel Diseases. We have over 35,000 members and 50 local networks throughout the UK. Membership costs start from £15 per year with concessionary rates for anyone experiencing financial hardship or on a low income.

This publication is available free of charge, but we would not be able to do this without our supporters and members. Please consider making a donation or becoming a member of Crohn's and Colitis UK. To find out how call **01727 734465** or visit crohnsandcolitis.org.uk



Crohn's and Colitis UK has received funding from Shire Pharmaceuticals. Shire was not involved in developing the content for this information sheet.

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