



TALKING TO MY CHILD ABOUT MY IBD

INTRODUCTION

As a parent with Ulcerative Colitis or Crohn's Disease (collectively known as Inflammatory Bowel Disease or IBD), you may be concerned about whether to talk to your child about your illness. Some parents may wish to keep their illness to themselves, feeling that it is better for their children not to know about it, particularly if the condition is mild. Other parents may decide to tell their children about it, especially if they feel that their illness may be affecting the family. This information sheet looks at talking to your child about your IBD, and suggests ways in which you can go about this.

SHOULD I TELL MY CHILD?

What are the effects of not telling my child?

If your IBD is not severe, or you are in remission, you may feel that it is not necessary to tell your child. You may also decide not to worry your children, particularly if they are young or sensitive.

However, with some children, not telling them can cause problems. Some children are very sensitive to tension and stress. Even young children may sense that something is wrong, particularly if they overhear an adult conversation about your IBD, or perhaps see you take medication for it.

If your child realises that you are unwell, the fact that you aren't telling them anything may make them misinterpret the situation. What they are imagining may be far worse than the truth. The fact that you are not talking about it may suggest to them that it is a subject too terrible to talk about, and they may even believe that you will die from your IBD. Some older children might worry that you have cancer.

Also, some children can feel deeply hurt if they are not told about what is happening. It can make them feel very anxious and left out, even unwanted.

Children often think differently from adults. Many young children have simple cause and effect logic. Some children might start blaming themselves for their parent's illness, especially if their parents aren't talking about it. For example, they may think, 'I was cross with Mummy when she told me to pick up my toys. Then she was ill. Maybe I made her ill.' It is important for children to understand that your IBD is no one's fault.

What are the effects of telling my child?

Telling your child that you have IBD may well help avoid problems such as those mentioned above – and can also have positive benefits. Parents often underestimate their child's ability to cope with the truth. Telling your child can help to build a strong relationship of trust, making them feel included and valued.

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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.

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John, age 41

diagnosed with Crohn’s Disease in 1995

It can also make your family feel closer, and you less stressed, especially if it helps your child to understand why you sometimes cannot do things and may need help when you are feeling unwell. Once you have told your child, you will not have to watch what you are saying so closely or perhaps feel secretive and isolated within your own family. This may also mean that other people are more comfortable that they do not have to keep your IBD a secret from your children any longer. And that might make you feel less anxious too.

Dealing with IBD in a family can also be an opportunity for children to learn about the body, treatment and healing. They can learn about working together to deal with difficult situations.

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SHOULD IT BE ME WHO TELLS MY CHILD?

As a parent or carer, it is usually best if you tell your child, if you feel up to it. It may reassure your child if it is you who tells them, rather than someone else. You may find it difficult to talk about your illness, but it can be helpful to show your feelings and emotions. If you cry, you could explain that it is because you are upset about your illness. Seeing you cry gives your child permission to cry too. Acknowledging and sharing your feelings in this way means you can give your child more support. If you hide your feelings entirely, you might find that your child feels they have to do the same. It could mean that they find it harder to open up about their worries in the longer term. However, try not to reveal acute distress because this may upset and worry your child.

You will know if you can be the one to tell your children. If you do not feel up to it, or feel unable to talk about your IBD without becoming really upset, then it might be a good idea if your partner, or another close relative such as a grandparent, could do it. It may be helpful if you are there as well so that you know how much your child has been told, and how they reacted to the news. Your child will also probably find it less frightening if you are there to reassure them.

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WHEN SHOULD I TELL MY CHILD?

You will need to decide when your child is able to understand what you want to say to them about your illness. If appropriate, you may want to explain what is wrong soon after being diagnosed with IBD. You don’t have to tell them everything at once, you may prefer to give a bit of information at a time. This will give them time to absorb what you have told them, so that you can return to the conversation at a later date when they may have thought of questions they would like to ask.

Try and choose the time you are going to tell your children carefully. If you can, find a place where you will not be interrupted, and tell them at a time when you are not stressed or in a hurry.

A formal discussion may be intimidating and alarm your child – so if possible, talk to your child at a time in your routine which is familiar and secure so that they feel relaxed (see below for some ideas).

If you have more than one child, you can tell them together or separately. If you do talk to them separately, try to avoid leaving a long time interval between telling each one, or the last one may wonder why they were left until the end.

WHERE SHOULD I TELL MY CHILD?

There may be particular places where you feel more able to talk freely with your child and they might find it easier to talk about what's on their mind, maybe after school or teatime. Try to avoid starting a conversation about your IBD when you feel pressured for time and there is not an opportunity to ask questions. This may be just before they have to go to school in the morning, or it might be at bedtime.

If it seems best to tell your child at bedtime, then make sure you allow them to think about what you are saying, and to ask questions about any aspect that is worrying them. Spending time with them before they fall asleep may make them feel supported.

WHAT SHOULD I TELL MY CHILD?

What you tell your child should be appropriate to their level of understanding, and how much your child will be able to understand tends to relate to their age. There will be no 'perfect' way to tell your child. But, to make you feel prepared, it may be worth practising what to say beforehand, and perhaps thinking about how you may respond to questions they could ask. See the section 'How to tell your child' later in this information sheet, which may help you with this. All children are different, but they may show typical reactions depending on their age:

- **Babies and toddlers:**

Very young children will not be able to understand any sort of explanation, but older toddlers may start to ask questions. A simple statement, such as 'Mummy is feeling poorly' should be enough.

- **3-5 years:**

Pre-school children are more aware of things happening around them. They need simple explanations to explain changes. You may find it helpful to do this with visual tools such as pictures and drawings. Young children may blame themselves for their parent's illness, so need reassurance that it is not their fault. They may also be scared of separation from their parents if, for example, there is talk of you going into hospital, so they will need reassurance about this too. At this age, they may start to worry about "catching" IBD from you, so you may need to help them understand that IBD is not contagious.

- **6-11 years:**

Primary school children are able to understand more complex explanations. They may start asking questions about death. It might help to reassure them that this is highly unlikely. They may also want to feel involved, and want to know how they can help you. You may wish to inform your child's school teacher if you have told your child about your IBD.

- **12+**

Secondary school children are starting to become more independent, and may need encouragement to talk about their worries. They may start to want more complex explanations, and to worry more about you. However, try not to overburden them with your own concerns, especially things they can do little or nothing about, such as money problems. If you know they use the internet, you may wish to bring this up in the conversation and suggest you look up IBD together as a way of explaining it. You could talk about only using websites which have reliable information, such as the Crohn's and Colitis UK website (www.crohnsandcolitis.org.uk). NHS Choices could be another good starting point.

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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.

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Glenda, age 34

diagnosed with Crohn's Disease in 2012

HOW MUCH INFORMATION SHOULD I GIVE?

According to your child's age and ability to understand, you may want to talk about particular aspects of your IBD.

For example, you may want to tell them about the treatment that you are being given, how this makes you feel, and perhaps any side effects it may have. You could then talk about why there may be times when you need to rest more than usual.

Explaining to your children about your feelings and emotions can also be very important. For example, it may be helpful to explain that your IBD makes you more tired and easily irritated, but this does not mean that you don't love them.

You may wish to tell your child that IBD is a fluctuating condition and it may be 'up and down'. If they do not understand this, they may make assumptions based on how you are now, not realising this may change. It may be worth talking about this with your child so that they understand that your IBD will not always affect you in the same way, and that you will have good days and bad days.

If you have to go into hospital for surgery, you may wish to reassure your child by talking through what might happen. You could start by discussing who will look after them while you are in hospital. Explain why you need to go, 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 are prepared for what they may see. Hospital staff and hospital information sheets may be able to help you explain these sorts of details. You may find it helpful to look at our leaflets **Surgery for Crohn's Disease** or **Surgery for Ulcerative Colitis**.

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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

HOW TO TELL YOUR CHILD

Simple and straightforward language is the most helpful for children. Ask them what they think IBD is, and correct any misunderstandings they may have.

Listen to them – it lets you know what they can cope with. Ask them if they are worried about anything in particular. Try and answer their questions simply. Don't be afraid to say that you don't know the answer to all of their questions. Doctors may also find it difficult to answer questions as IBD is an 'individual' condition and people's experiences vary so widely. Be honest and try not to make promises that you may not be able to keep, say 'I will try to...' or 'I think I will be able to...'

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 ill now, there will be better times.

Sometimes the child may find it too difficult to talk about your IBD with you, and may feel that they cannot speak to a family member either. Or you might have noticed a change in their behaviour since you told them about your IBD. If you feel it would help your child, you could suggest counselling to them as a way of talking through their worries or anxieties. Counselling sessions for children are tailored to be age appropriate, and if they are younger they may be encouraged to express themselves in non-verbal ways, for example through artwork or play. Your IBD Team or GP may be able to tell you about a counsellor with experience of helping people with ongoing illnesses. More information about different types of therapy can be obtained from organisations such as the British Association for Counselling and Psychotherapy (BACP) (See **Other organisations**). Or you may wish to look at our information sheet **Counselling and IBD** for more details.

SOME SUGGESTED WAYS OF SAYING THINGS TO CHILDREN:

- ‘I have an illness called Ulcerative Colitis/Crohn’s Disease. I’m taking medicine to help me get well. Sometimes I feel ill or tired and sometimes I feel fine.’
- ‘The illness makes my tummy sore and makes me go to the toilet a lot, which can be awkward.’
- ‘Being ill makes me feel upset. I may seem tired and cross sometimes, but it is not your fault and I still love you.’
- ‘My tummy is red and sore inside. The tablets I am taking are helping to make it better. It is an illness that can get better for some time, and then get worse again, but it probably won’t go away altogether. If you have any questions about it, you can ask me.’

YOUR CHILD’S REACTION

You might find that your child does not respond to the news that you have IBD in the way you anticipate. They might not ask questions and may appear quite uninterested. But this does not mean that they do not care. They may need time to absorb the information. You may find that their emotions come out later and they express themselves in actions rather than words. So their behaviour could be an indicator of how they are feeling. For example, your child may behave unusually – they may become withdrawn or ‘act up’ in some way by being naughty, which could be their way of showing how upset they are. If your child is at school, and you are happy for the school to know about your condition, it could be a good idea to speak to your child’s teacher so that they are aware of the conversation you have had at home. The teacher can keep in touch with you should there be any change in behaviour.

HELP AND SUPPORT FROM CROHN’S AND COLITIS UK

All our information sheets and booklets are available to download from our website: www.crohnsandcolitis.org.uk. If you would like a printed copy, please contact our information line – details below.

Crohn’s and Colitis UK Information Line: 0300 222 5700: Open Monday to Friday, 9 am to 5 pm except Thursday open 9 am to 1 pm, and excluding bank holidays. An answer phone and call back service operates outside these hours. You can also contact the service by email info@crohnsandcolitis.org.uk or letter (addressed to our St Albans office). Trained Information Officers provide callers with clear and balanced information on a wide range of issues relating to IBD.

Crohn’s and Colitis Support: 0121 7379 931: Open Monday to Friday, 1 pm to 3.30 pm and 6.30 pm to 9 pm, excluding English bank holidays. This is a confidential, supportive listening service, which is provided by trained volunteers and available to anyone affected by IBD. These volunteers are skilled in providing emotional support to anyone who needs a safe place to talk about living with IBD.

OTHER ORGANISATIONS

BACP

British Association for Counselling and Psychotherapy: www.bacp.co.uk
01455 883300

Professional body representing counselling and psychotherapy. They provide a directory of member therapists which you can search on their website.

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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 28,000 members and 50 Local groups throughout the UK. Membership costs start from £15 per year with concessionary rates for anyone experiencing financial hardship or on a low income.

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