

Talking to my child about my IBD

Introduction

If you are 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 their illness is affecting the family. This information sheet looks at why it may or may not be a good idea to talk to your child, 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. Many children are very sensitive to tension and stress, and even young children may sense that something is wrong.

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 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. If they feel that

you have deceived them, they may be more distrustful of you in the future.

Some children might start blaming themselves for their parent's illness, especially if their parents aren't talking about it. Children often think differently from adults. Many young children have simple cause and effect logic. 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 should 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. It can also make your family feel closer, and you less stressed, especially as your children will be able to understand why you sometimes cannot do things, and help you when you are feeling unwell. Once you have told your child, you will not have to watch what you are saying all the time, or perhaps feel secretive and isolated within your own family. This can make you feel more happy and comfortable.

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 how strong people can be during hard times, and how to deal with difficult things.

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 is fine to show your feelings and emotions. If you cry, you could explain that it is part of your illness. Seeing you cry gives your child permission to cry too. Sharing your feelings in this way means you can give your child more support. 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 your partner or another close relative such as a grandparent, could do it. It is important that you know how much your child has been told, so it may be helpful if you are there as well. Your child will also probably find it less frightening if you are there to reassure them.

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 wish to give a bit of information at a time.

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 in a hurry or stressed. A formal discussion may be intimidating and alarm your child. If possible, talk to your child when they are relaxed. If you have more than one child, you can tell them together or separately. If you do tell 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. This may be during

bath time, or during quiet story time. Try to avoid telling your child before they go to school in the morning, because they will not have time to ask questions. If you do choose to talk to your child at bed time, try and allow time for 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 should 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. 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 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 off 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. It may help 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 worries too much, especially things they can do little or nothing about, such as money problems.

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.

You may want to explain the treatment that you are being given. You could talk about any side effects you may have. You could explain that there are times when you need to rest more than usual.

Explaining to your children about your feelings and emotions can be as important as giving them factual information. It may be helpful to explain that IBD makes you more tired and easily irritated, but this does not mean that you don't love them.

If you have to go into hospital for surgery, you may wish to prepare your child. You may also want to let your child know 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 will 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 may be able to help you explain what will happen. You may find it helpful to look at our leaflets *Surgery for Crohn's Disease* or *Surgery for Ulcerative Colitis*.

Some final points:

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. 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...'

Try and leave them feeling that even though you may be ill now, there will be better times

Some suggested ways of saying things to young children:

- 'I have an illness. It is called Ulcerative Colitis/Crohn's Disease. The doctor is giving me 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.'

We have a range of publications that you may find helpful to look at when you are explaining things to your child. For more information, contact the Crohn's and Colitis UK Office or see our website www.crohnsandcolitis.org.uk. All our information sheets and booklets can be downloaded from this site

Further Information

Crohn's and Colitis UK Information Line: 0845 130 2233, open Monday to Friday 10am - 1pm (excluding bank holidays). There is an answerphone service outside these hours, or you may email info@crohnsandcolitis.org.uk.

Information staff will help with any IBD related queries.

Crohn's and Colitis Support:

0845 130 3344, open Monday to Friday 1pm - 3.30pm and 6.30pm - 9pm(excluding bank holidays). This is a supportive listening service staffed by trained volunteers with personal experience of IBD.

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