

Talking to my child about my IBD

Introduction

If you are a parent with Ulcerative Colitis or Crohn's Disease, together known as Inflammatory Bowel Disease (IBD), you may be concerned about talking to your child about your illness. Some parents with IBD may wish to keep their illness to themselves, feeling it is better for young children not to know about it, particularly if the condition is mild, and that can be the best option for them. For others, an ongoing condition like IBD may have an impact on the family. This sheet looks at why it may be a good idea to talk to your child, when you feel the time is right, and looks at how you might go about it.

Why should my child be told?

IBD can affect the feelings and emotions of the whole family and it is important that your child understands anything that has an impact on the family. Children are very sensitive to tension and stress. Not knowing things can make them feel anxious and leave them feeling isolated and excluded from an issue that affects all the family.

Children have an ability to deal with the truth that adults often underestimate. They can cope better with a parent's illness if they are told what is going on in a way that they are able to understand. Not talking about IBD may suggest to them that it is a subject too terrible to be discussed and they may even believe you will die from IBD. It can give them an exaggerated fear of it or illness later on. Or they may turn to other sources of information, which can sometimes be misleading or frightening. Being open with children about what is happening to you can avoid them misinterpreting the situation. For example: 'I was cross with

Mummy when she told me to pick up my toys. Then she was ill. Maybe I made her ill.' Or 'Grandad died in hospital. Now Dad has to go into hospital. He is going to die too.' . Dealing with IBD in the 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 feelings.

If children know the situation, you won't need to watch what you say all the time or feel secretive and isolated in your own family. That can make you feel more comfortable. Openness can help all of you to feel closer.

Who should tell my child?

As a parent or carer, if you feel able to tell your child, it is usually best for you to do it. You may find it difficult to talk about your illness, but it is all right to get upset or cry. Seeing you cry gives your child permission to cry too. Sharing your feelings in this way means you can give your child more support.

You will know if you can be the one to tell them. If you do not feel able to tell your child, your partner or a close relative, such as a grandparent, could do it. It is important that you know what has been said, and it may be helpful for you to be present when they are told.

When should I tell my child?

You will need to decide when you feel your child has the ability to understand what you want to say to them about your illness. If appropriate, it may be helpful to explain what is wrong soon after being diagnosed with Colitis or Crohn's

Disease. You don't have to tell them everything all at once. You can give a bit of information at a time.

You can explain the treatment you are being given. You can also talk about the side effects, about any changes in treatment, whether things will be different at home or how treatment may affect the way you behave and relate to them. Explaining how your illness affects your feelings and emotions is as important as giving factual information about IBD and treatments. For example, you could say that IBD makes you very tired and easily irritated, but this doesn't mean that you don't love them. You can explain that there will be times when you need to rest more than usual.

Try to keep information relevant to the current situation. It can be best to give them warning when something is about to happen, such as a colonoscopy or an operation, but not too far in advance, just shortly beforehand. Explain to your child why you need it, what is going to happen and how it will affect you afterwards. If you are going into hospital, for instance for surgery, children might need more detailed information about your treatment and things they may see when they visit you. Hospital staff may be able to help you to explain what will happen. Be willing to talk whenever they ask questions or seem concerned about your condition.

Where should I tell my child?

There may be particular places where you feel more able to talk to your child, or they may be more likely to discuss things with you. This may be during bath-time or during a quiet story time. Often, children may talk about things or ask questions when they are in bed and settling down to go to sleep. It is very important to answer any questions that they ask at this time, rather than saying 'we'll talk about it in the morning'. However, this may not be a good time to start a conversation that could be difficult, as they may then have

a long time on their own to think about the situation or may not be able to sleep. If they do ask questions at this time, it is important to spend time with them to make sure that they feel supported before they go to sleep.

How should I tell my child?

The information you give to your child will need to be appropriate to their level of understanding. Young children find it easier to understand if they see pictures, so it may be a good idea to find a children's story about going into hospital, for example.

If you have recently been diagnosed and you have several children, you can talk to them together or individually. It will depend on whether they need to know different things because of differences in their ages or how grown up they are. If you have had the illness for some time older children may already know about it. Taking time to think about what you are going to say beforehand may help you to feel more confident. You may want to practise what you will say and anticipate the questions that will be asked. It is important to talk in a language and at a level that each child understands.

Children can feel very guilty when things go wrong around them – they often feel that in some way, they are to blame for the situation ('If I'd tidied my room up like mum told me, she wouldn't be ill now') Because of that, it is important to be sure that the child understands the situation is not their fault. It can be good to include this in an overall statement such as 'This is just one of those bad things that happen sometimes. It is not anyone's fault – it's just very bad luck.'

It is helpful to create an environment in which your children feel safe and in which they feel able to ask questions, even if they feel upset. Set aside plenty of time, when you know that you will not be interrupted, and let the children know that

you have lots of time to discuss the situation with them.

Some tips:

- Children need to be told information in a way that they can understand.
- Tell them what has happened, such as some details about IBD.
- Ask them what they think IBD is. Explain it as well as you can. Correct any misunderstandings they may have.
- Explain what is happening and what will happen next.
- Leave them feeling that even though you may be ill now, there will be better times.
- Assure them they will still be loved and cared for even when you are ill.
- Keep a plan for when you are unwell or in hospital to reassure them that they will always be looked after.
- Listen to them – it lets you know what they can cope with.
- Answer their questions simply.
- Ask them if they are worried about anything in particular.
- Be honest.

Some suggested ways of saying things

- 'I have an illness. It is called Colitis/Crohn's Disease. The doctor is giving me treatment to help me get well. Sometimes I feel ill or tired and sometimes I feel fine'.
- Simple and straightforward language is the most helpful, for example: "The illness makes my tummy sore and makes me go to the toilet a lot, which can be

awkward. It makes me feel very tired."

- 'Being ill makes me feel upset, but you are a help. You might feel a lot of different things (sad, angry, happy or whatever) and that's all right. Our feelings change but Mummy/Daddy and I will always 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. The doctor thinks that this treatment will help me this time. If you have any questions about Colitis/Crohn's Disease you can ask me.'
- Sometimes it can be helpful to use books about Colitis/Crohn's Disease to help you to describe it.

Some don'ts

- Don't lie.
- Don't trouble them with complicated medical details, money problems (except when it will affect them), or your worries about waiting for the results of tests, etc.
- Don't make promises you may not be able to keep. (Say 'I think I will be able to...' or 'I'll try to...')
- Don't be afraid to say 'I don't know'.
- Don't push children to talk if they do not want to.

Further help

NACC has a range of publications that you might find helpful to draw on when explaining things to your child. For more details contact the **NACC Information Line** on **0845 130 2233** or email: nacc@nacc.org.uk. Information sheets

can also be downloaded from the NACC Website: www.nacc.org.uk.

NACC-in-Contact

☎ 0845 130 3344

**weekday afternoons 1-3.30pm
and evenings 6.30-9pm.**

A supportive listening service run by trained volunteers who have IBD or a relative with IBD.

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We are grateful to Cancerbackup, the UK's leading cancer information charity, for their permission to base this information sheet on their booklet 'Talking to Children about Cancer'. While IBD is not a cancerous condition, the issues about living with an illness and talking to a child about it may be similar.

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We hope that you have found the information helpful and relevant. We welcome any comments from readers, or suggestions for improvements. Please send your comments to Helen Terry at NACC, 4 Beaumont House, St Albans, Herts AL1 5HH – or email: h.terry@nacc.org.uk

The National Association for Colitis and Crohn's Disease (NACC) is a voluntary Association, established in 1979, which has 30,000 members and 70 Groups throughout the United Kingdom.

Membership of the Association costs £12 for the first year and £10 subsequently. Additional donations to help the work of the Association are always welcome.