

IBD Concerns for Young People

Introduction

Having Crohn's Disease or Ulcerative Colitis (collectively known as Inflammatory Bowel Disease - IBD) may be difficult to handle at times. You can have times when you feel okay, but sometimes having IBD can make you feel poorly, confused and miserable. Most young people with IBD experience at least some of these feelings.

Body worries

Having IBD can sometimes slow down your body growth, particularly if the disease is severe or goes undiagnosed for a long time. Puberty may be delayed and your periods (for girls who have started them) may become irregular or even stop. However, once the inflammation in your bowel is under control and you are getting the correct energy and nutrients from your diet, your IBD can be managed and any growth you have missed will be caught up.

Liquid diets

It is important to make sure that the inflammation in your bowel is reduced and that your diet gives you all the energy it needs to repair, grow and develop. Your doctor may suggest a special liquid diet as the first treatment, especially if you have Crohn's.

There are two types of liquid diets:

- Polymeric Fluid Diet
- Elemental Fluid Diet.

They both come in different flavours – ask to try them to see which you prefer. For the first 4-6 weeks, only the special fluid and water is given to help the inflammation in the bowel come under control. After this time you can return to a normal diet, but you may be asked to carry on with the special fluids to supplement calories and nutrients.

If you can't take the fluid by mouth you may need to have a temporary tube put into your nose that reaches the stomach (a naso-gastric tube). These tubes can usually be changed every 4-6 weeks. The fluid is then slowly given straight to the stomach. Having a naso-gastric tube should not stop you from going to school or work, or enjoying a night out with friends, if you feel well enough.

You may need a more permanent feeding tube to be fitted in hospital (a gastroscopy) if you are very small or thin, to encourage growth. All that is seen by others is a thin tube on the outside of your tummy that can easily be hidden under your clothes when not being used.

Side effects from drugs

Steroids - the drugs sometimes used to treat IBD - can be very effective at calming down the inflammation in your bowels, but unfortunately they can also slow down your growth. You may also be worried about the effects that steroid treatment can have on your appearance. At high doses they can cause weight gain, rounding of the face, possibly worsening of acne, increased body hair and moodiness. But remember that these side effects are only temporary, and will disappear once you stop taking the steroids.

Your doctor will keep a close eye on your physical development, and will reduce or stop steroid treatment once your IBD is under control. Normal growth and development can then get going again and the steroid side effects reverse. If you are worried about taking steroids, you, your family and your doctor or IBD nurse should discuss whether the good effects of steroids outweigh the side effects for you

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I hate IBD because...

...of the way it makes me feel.

It is common to have some strong feelings about IBD, even if it doesn't affect you that much. Feeling different, watching others grow and mature faster than you, perhaps feeling embarrassed about scars if you have had surgery, or unattractive if steroids are affecting your appearance, can be very difficult to handle. You are not alone as other people with IBD are likely to be feeling the same.

You may **sometimes** feel:-

- **angry** that it's you who has been landed with it
- **guilty** for worrying those who love you
- **embarrassed** about leaving unpleasant smells, or having to keep rushing off to the toilet
- **scared** to leave the house in case you have an accident
- **worried** about keeping up with your work, especially if you have had a lot of time off
- **frustrated** with people who think they understand what you are going through
- **annoyed** at people who treat you differently because you are ill
- **self-conscious** about having a special diet or needing to take medication in front of others
- **humiliated** when others laugh or make jokes about 'farting' and 'shitting'
- **frightened** about having more tests, going into hospital or having to have an operation
- **anxious** about your future.

...of the way others react to me.

People are often extremely understanding and supportive, but sometimes they are not. Perhaps if you don't look ill from the outside, they don't realise how much you are hurting inside.

Some friends may be overprotective, and start treating you differently or leaving you out of certain activities. They may find it hard to imagine feeling too tired to stay up late and have fun, and you may resent that they find it all so easy. You may feel that others are avoiding you. This could be because they feel embarrassed themselves and do not know how to act or what to say.

Relationships with parents can also be fraught. Of course they worry about you, but it might drive you mad if they are constantly asking how you are, or trying to make you take it easy when you do feel full of energy. You may feel fierce love/hate feelings, because you like being cared for and comforted when you are ill, but don't want to be fussed over when you feel well.

Try telling them how this makes you feel – something like *'I miss out on so much when I'm ill that I really want the chance to enjoy myself like everyone else whenever I'm well'* or *'I feel like a freak if I'm asked how I am all the time'*, may work better than *'You are always trying to stop me doing things'* or *'You are always fussing over me'*.

On the positive side

There are things you can do to help you feel more in control of your IBD and your own body.

You can help yourself by...

...taking your prescribed drugs, even if you hate the thought of having to take drugs every day, with no end in sight. It

may be tempting to wish your illness away - thinking that if you don't take your treatment it will feel as if you haven't got the disease. Sadly, that may just make the flare-ups more frequent and worse and the need for treatment more prolonged.

...watching what you eat. Enjoy as balanced and healthy diet as possible, avoiding only those foods that you know will cause problems.

...drinking bottled water if you are anywhere abroad where hygiene is doubtful.

...getting as much rest as you need when your IBD is active.

...getting help with side effects of medication. Ask your GP about treatments for acne, or salons can suggest hair removal products.

...finding ways to talk about IBD that you feel comfortable with when others need or want to know. Make it clear that the condition is not infectious, so people don't worry about catching it.

... being confident in your daily life. Depending on your personality, this might mean just getting on with it, or it might mean taking precautions to avoid embarrassment. Some people say they carry spare underclothes, or pads and wipes to clean up with when they go out; some map out their routes according to where the toilets are. Sound effects can be minimised when using the toilet by putting some sheets of loo roll in the bowl before using it.

...asking others to respect your dignity. Most people find the anal examinations in hospital embarrassing, and if you don't want to have medical students watching, you have the right to ask for them to leave the room. (Try telling the nurse before they come in.)

...giving yourself credit for your successes, however small. If you have been feeling really ill, travelling on a bus or even getting out of bed can be a triumph.

...believing in yourself. Negative feelings about yourself can send out negative signals that influence the way others see you. But if you can believe in yourself for whatever you are – warm, kind, cool, quiet, funny, understanding, clever, sporty, thoughtful or talented – that is how others are likely to see you and accept you.

...talking about your feelings. Sometimes it is easier to talk to a stranger than a friend or member of your family. There are several different ways in which you could talk about your situation and not feel isolated. You could share your feelings and experiences with others on the IBD and Me discussion board on our website or at a local Crohn's and Colitis UK Group meeting. Or you could use our supportive listening service, Crohn's and Colitis Support, or, if you are a Crohn's and Colitis UK member, make new friends through the Pen Friends page of the newsletter.

Where to go for more help

The Crohn's and Colitis UK Information Line: 0845 130 2233, is open Monday to Friday 10am - 1pm. 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. This is a supportive listening service staffed by trained volunteers with personal experience of IBD.

We also produce a wide range of information sheets and booklets. You can get a copy of any these from our Information Line. Most are also downloadable from our website: www.crohnsandcolitis.org.uk

IBD and Me is a discussion board for young people between the ages of 16 and

29 available via the our website at <http://www.ibdandme.nacc.org.uk>

Some **Crohn's and Colitis UK (NACC) groups** have young adult sub groups or arrange social activities for young adults between 16 and 29. Phone the Information Line or visit our website for contact details of your nearest group.

Smilie's Network is a special Group within Crohn's and Colitis UK that offers support to children and young IBD sufferers, their families and friends. Email: SmiliesNetwork@groups.nacc.org.uk or visit our website.

CICRA – children with Crohn's and colitis - has a website with two separate sections: one for parents and a 'cool zone' for children and young people: www.cicra.org

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This leaflet has been produced with the help of Crohn's and Colitis UK members and young people, and includes feelings and concerns expressed by them from their own experience of living with IBD.

Crohn's and Colitis UK publications are research based and produced in consultation with patients, medical advisers and other health or associated professionals. They are prepared as general information on a subject with suggestions on how to manage particular situations, but they are not intended to replace specific advice from your own doctor or any other professional. Crohn's and Colitis UK does not endorse or recommend any products mentioned.

We hope that you have found the information helpful and relevant. We welcome any comments from readers, or suggestions for improvements. References or details of the research on which this publication is based, and details

of any conflicts of interest, can be obtained from Crohn's and Colitis UK at the address below. Please send your comments to Helen Terry at Crohn's and Colitis UK, 4 Beaumont House, Sutton Road, St Albans, Herts AL1 5HH or email h.terry@crohnsandcolitis.org.uk

Crohn's and Colitis UK is the working name for the National Association for Colitis and Crohn's Disease (NACC). 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 a year. New members who are on lower incomes due to their health or employment circumstances may join at a lower rate. Additional donations to help our work are always welcomed.