

IBD Concerns for Young People

Introduction

Although you may have Crohn's Disease or Ulcerative Colitis (collectively known as Inflammatory Bowel Disease – IBD) you probably have the same hopes, aspirations and needs as people without the condition. The difference for you is that IBD is part of the equation. This may feel difficult to cope with at times. However, you are not alone. Many other young people with IBD are going through similar problems, and experiencing the same feelings. This information sheet addresses some of the worries and questions that you may have, as well as suggesting some positive things to help you live with IBD.

It is very common to have some strong feelings about IBD, even if it doesn't affect you very much when you are in remission. There is no need for you to feel bad about resenting, or even hating your condition. 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. This is not uncommon - most people with IBD feel like this at some time.

Friends and Family

How shall I tell my friends?

It may be difficult to know whether or not to tell your friends that you have IBD. However, many people feel relieved once they have told them. It may make you feel less alone and it can also make your friends feel closer because you have shared your troubles with them. They should be able to understand you better and appreciate why you cannot do some things. You may find their support really

useful when you are feeling unwell. Once you have told them, you will probably feel a great load off your mind.

You may find that some friends tend to be overprotective and start treating you differently and leaving you out of activities. Or, you may find they start avoiding you. This could be because they feel embarrassed themselves and do not know how to act or what to say. If you can talk to them about your IBD without making a big issue of it, they will probably find it easier to understand and accept your condition.

It may help to plan how you are going to tell other people about your IBD, so you feel comfortable answering questions. You can reassure people that your condition is not contagious, and that they cannot catch it from you.

How can I stop my parents fussing over me?

Relationships with your parents may start getting a little strained. You are probably at the age when you want to be independent and not have them fussing over you. You may get annoyed if they constantly ask you how you are, or tell you to take it easy. Remember, this is probably because they are worried about you. Try talking to them about how you feel. For example, you could say *'I miss out on so much when I am ill that I really want to enjoy myself like everyone else when I feel up to it'*.

One good way to assert your independence in a positive way might be to start showing that you are now able to start taking more responsibility for your health. You could do this by remembering to take your medicines at the right time

without being asked, or starting to find out more information about your IBD. This will also be good preparation for when you go through transition from paediatric (child) care to adult care at hospital (see page 4).

Should I tell my school or college?

You do not have to tell anyone about your IBD if you do not wish to. However, if you do not tell your school or college, you may miss out on some of the support that could be available for you. For example, you may be able to get extensions to help meet course work deadlines or extra time in exams.

For more information, see our information sheets *Children and Young People with IBD: a guide for schools* and *Students with IBD: a guide for students*.

Worries about IBD...

Can IBD affect my growth?

Sometimes having IBD can slow down your body growth and development, especially if the disease is severe or goes undiagnosed for a long time. This may result in puberty being delayed, and your periods (for girls who have started them) may become irregular or stop. However, once the inflammation is controlled and you are getting the correct nutrients, you may catch up with any missed growth.

How might my medications affect me?

There are lots of different medications used to treat IBD. You may be on steroids, 5-ASAs, immunosuppressants, or the new biologics.

Steroids

Many people with IBD who have to take steroids at some stage worry about the side effects they may have. Steroids can have an effect on your appearance, causing you to gain weight, and your face may get rounder. They may also cause an increase in acne, body hair and moodiness. However, these are only temporary effects, and once you have stopped taking the steroids your

appearance should return to normal. Your doctor will keep an eye on your physical development, and your steroid treatment will be reduced or stopped once your IBD is under control. Your GP may also be able to help with treatments for acne. The side effects may be unpleasant while they last, but remember that steroids are generally very effective in calming down the inflammation in your bowels and making you feel better.

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.

5-ASAs

5-ASA drugs (for example mesalazine) work by damping down the inflammation process. They are commonly taken by mouth in tablet form, but can be taken topically (applied directly to the affected area of the body). For example, a suppository or enema can be inserted into the rectum via the anus. This can be very effective when the disease affects that part of the intestines because the drug acts directly on the site of inflammation. Side effects are also reduced because other parts of the body are less affected by the drug.

Immunosuppressants

Immunosuppressants suppress the immune system in order to reduce inflammation. Azathioprine, a common immunosuppressant, is usually taken by mouth. It acts slowly over several months, so it may be a while before you see any benefit. You may be more susceptible to infections such as flu or colds while on immunosuppressants, and your doctor may recommend that you have a yearly flu vaccination.

Immunosuppressants can increase your skin's sensitivity to sunlight, so you should use sun block and avoid using sun beds. If you are a young woman with an active

sex life, you may like to consider having a cervical smear test as people on immunosuppressants are at a higher risk of HPV (human papillomavirus).

Biologics

Biologics or 'anti-TNF' drugs, such as infliximab and adalimumab target specific chemicals involved in the body's immune response which are excessive or do not work properly in people with IBD.

Infliximab is given by intravenous infusion (through a drip into a vein) in hospital. It is used to treat severe Crohn's Disease, and occasionally for severe Ulcerative Colitis. The treatment usually takes around 3-6 hours, and you will probably not need to stay the night in hospital. Depending on your needs, you may be on a long or short course of infliximab.

While it may be a hassle having to keep going to hospital, many people find that infliximab works very well to prevent inflammation and relieve the symptoms of IBD. It can also help to maintain remission, and may reduce the need for hospitalisation and surgery. Many people worry about the possible side effects of infliximab, but long term infliximab treatment has been found to have good overall safety.

Adalimumab is given as an injection. It cannot be taken orally because the digestive system would destroy the drug. It is possible to self inject adalimumab after receiving training in injection technique, if you and your doctor decide that this is suitable. Alternatively, a family member or friend may be able to give you the injection, providing they have been properly trained. The injections are usually given once a week at most. Like infliximab, adalimumab increases your chances of remaining in long term remission if you respond well to the drug. It can reduce your need to go into hospital, as well as allow for the withdrawal of steroids, and relieve your symptoms.

For more information about drugs, see our booklet *Drugs used in IBD*.

Will I have to have a different diet?

Some people with IBD can have trouble eating certain foods and this may mean that you are advised to go on a special diet or just avoid particular foods or ingredients. This can make you feel different, and you may perhaps worry that people might think you are strange or attention seeking. However, lots of people without IBD cannot eat certain foods, for example people with allergies, so you probably won't seem that unusual. You may well find that many people are very accommodating and helpful.

If you have Crohn's Disease, your doctor or dietician may suggest that you go on a special liquid diet to help reduce the inflammation in your bowel and give you extra energy and nutrition. There are two types of liquid diets:

- Elemental Fluid Diet
- Polymeric Fluid Diet

These liquid diets are made of very small simple molecules that can be easily absorbed. They both come in different flavours, which you can try to see which tastes best. The liquid diet can last for up to eight weeks and you can then reintroduce a normal diet. In some cases you may be asked to carry on with the special fluids as a supplement to provide you with extra calories and nutrients.

If you cannot take the fluid by mouth you may have to have a temporary tube in your nose that reaches your stomach (a nasogastric tube). This means that the fluid is then slowly given straight into the stomach. These tubes can usually be changed every 4-6 weeks. Having a nasogastric tube should not stop you going to work or school, or enjoying social activities if you feel up to it.

What is transition and how will it affect me?

As a young person you will soon be moving from paediatric (child) hospital care to adult care, if you have not done so already. This is referred to as 'transition' and normally takes place between the ages of 16 and 18, although it can sometimes happen later. Many people worry about this, but the process is usually not as stressful as they may be expecting.

Different hospitals start transition at different times and may do it in different ways. Some hospitals have a dedicated 'Transition Clinic' for young people, with doctors from both the adult and the paediatric teams. Other hospitals may have a joint clinic for just one or two appointments before moving you to the adult clinic. Some hospitals may transfer you in a planned way without the two doctors meeting. Whatever the usual arrangements, you have a right to a managed transition process, and you and your parents should be fully involved along the way.

Transition should not affect your current care, or your choices about treatment. It should mean you can start taking more responsibility for your care, voicing your own opinions and making your own decisions. You can begin this process by taking charge of your own medication and finding out what helps keep you in remission. If you start to feel anxious about your treatment in an adult clinic, talk to your doctor or nurse about it.

Emotions ...

Is it wrong for me to hate having IBD?

You may sometimes feel:

- Angry that it is you who has been landed with IBD, and not someone else
- Frustrated because you cannot do some of the things that your friends or family can do
- Fed up with people asking you questions, or thinking they know what

you are going through when they have no idea what it is like

- Smothered by people who treat you differently just because you are ill
- Humiliated by people who make unkind jokes about your condition
- Annoyed at having to take medications, or have a special diet
- Self-conscious about taking medicines in front of people
- Embarrassed about leaving unpleasant smells or having to rush off to the toilet
- Helpless because you feel out of control
- Frightened about medication, having more tests, going into hospital or having to have an operation
- Anxious about the future.

Many people with IBD have these feelings from time to time. You may find that it is easier to talk to a stranger than friends or family. You can phone **Crohn's and Colitis Support** (see *Further Information*) to talk to a trained volunteer with experience of IBD. Your school, college or GP surgery may have a counselling service, or you may also find it helpful to read our leaflet *Counselling for IBD*.

It may also help to talk to other young people who have IBD and may be going through similar situations to you. One way of doing this is through the Crohn's and Colitis UK **IBD and Me** discussion board for young people between the ages of 16 and 29 at:

www.ibdandme.crohnsandcolitis.org.uk.

On The Positive Side.....

There are also things that you can do to feel more in control with your IBD and your body. You can help yourself by:

- ❖ **Taking your prescribed drugs.** You might hate taking drugs every day with no end in sight. It may be tempting to wish your illness away and you might not take your tablets because that helps you forget your IBD. However,

this may just make flare-ups worse and more frequent, and prolong your need for treatment.

- ❖ **Eating a balanced and healthy diet.** If you think that certain foods are causing you problems, seek advice from your doctor or dietitian.
- ❖ **Getting as much rest as possible** when your IBD is active, and if you can, cut down on stress. A strong support network can help with this.
- ❖ **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 carry spare underclothes or pads and wipes to clean themselves with. Others map out their routes according to where the toilets are.
- ❖ **Asking others to respect your dignity.** Many people find hospital examinations embarrassing. If you don't want to have medical students watching, then you have the right to ask for them to leave the room. (Try telling the nurse before they come in).
- ❖ **Believing in yourself.** Negative feelings about yourself may send out negative signals which can influence the way people see you. If you believe in yourself for what you are – kind, cool, understanding, clever, sporty or talented – others are more likely to see you that way.
- ❖ **Giving yourself credit for your successes,** however small. Sometimes even getting out of bed or travelling on a bus can be a triumph if you are feeling really unwell.

Final Things to Remember...

- Nothing you did or ate gave you IBD. You didn't catch it and it is not your fault. Don't blame yourself for how you feel.
- IBD doesn't mean that you can't live a long, fulfilling life. Many people with IBD go to school and university and then go on to have a career, marry and have a family.
- IBD is a chronic (long term) condition, but this does not mean that you will feel unwell every day. You may have flare ups, but you will probably have periods of remission, and may well feel healthy more often than you feel ill.
- You are facing challenges that many teenagers do not have to face. This may broaden your perspective on life and make you a stronger and more compassionate person.
- Your IBD does not define who you are as a person. It is helpful to accept it, but try not to let it take over your life.

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 experience of IBD.

Crohn's and Colitis UK produces a wide range of information sheets and booklets. You can get a copy of any these from our Information Line. They are also downloadable from our website: www.crohnsandcolitis.org.uk

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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. 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.