

Who is this booklet for?

You & Me

Inflammatory Bowel Disease



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Who is this booklet for?

It's for you, if you have just been told by a doctor that you have *Crohn's disease* or *ulcerative colitis*. If you have started treatment for either of these illnesses and are feeling a bit confused about the whole thing, then it's for you too. This information will give you a better understanding of the disease; it will help you to take as much control as possible over what is happening inside your own body.

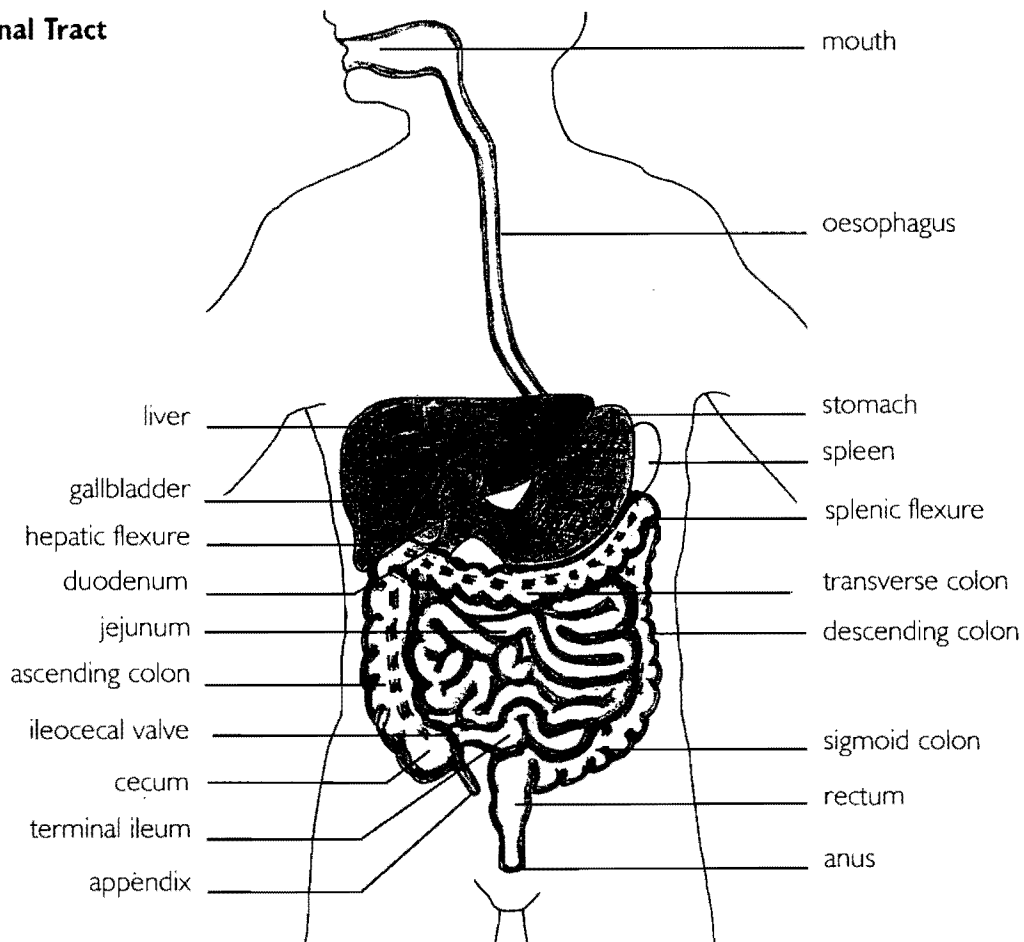
Crohn's disease and *ulcerative colitis* are the two most common Inflammatory Bowel Diseases, so we will begin by describing them and their symptoms. Then we'll explain about the different kinds of treatment. These are the known facts about Inflammatory Bowel Disease, which from now on we'll call IBD. We'll follow them by outlining some of the things you can do to help yourself (there are a lot) and we will discuss how you can deal with the problems that arise from time to time (but by no means all of the time).

Over the years we've helped to treat a lot of young people with IBD, and above all we've talked with them. It's important to remember that everyone who has IBD is different. For example, IBD has a whole range of symptoms, but most people only experience two or three in varying combinations. We think that what young people have told us about how they've dealt with their illness will help you in dealing with yours.

So read away, but remember three things: first look up any words you don't understand in the glossary on page 25; second, you won't be able to take every thing in all at once; you'll need to keep the booklet by you for reference, maybe rereading things at different stages of your treatment; thirdly, and most important, if anything we've written really worries you or if you think of any questions we haven't answered, talk to your doctor or a nurse.



The Gastrointestinal Tract



What exactly is inflammatory bowel disease?

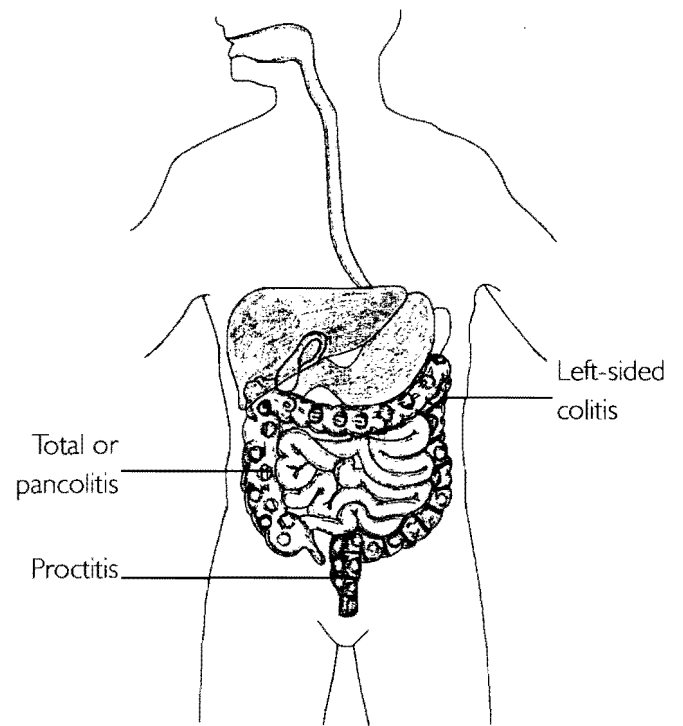
The Alimentary tract

The diagram on page 3 of this booklet shows the gastrointestinal or alimentary tract. It is the sequence of parts of your body through which food goes on its way from being chewed in your mouth to forming a stool and passing out through your anus into the toilet. Maybe you have learned about digestion in school. You may know that the stomach and the small bowel ensure that the right nourishment (called nutrients) from the food gets into your blood to feed the rest of your body and to make you grow. This system also makes sure that the unwanted or waste part of the food finds its way out through your large bowel then your anus.

IBD includes a group of illnesses that cause inflammation (soreness) in parts of the gastrointestinal tract. Crohn's disease and ulcerative colitis are different illnesses although they have quite a lot in common. In fact, in the early stages of treatment it may be difficult to tell them apart. More about that later.

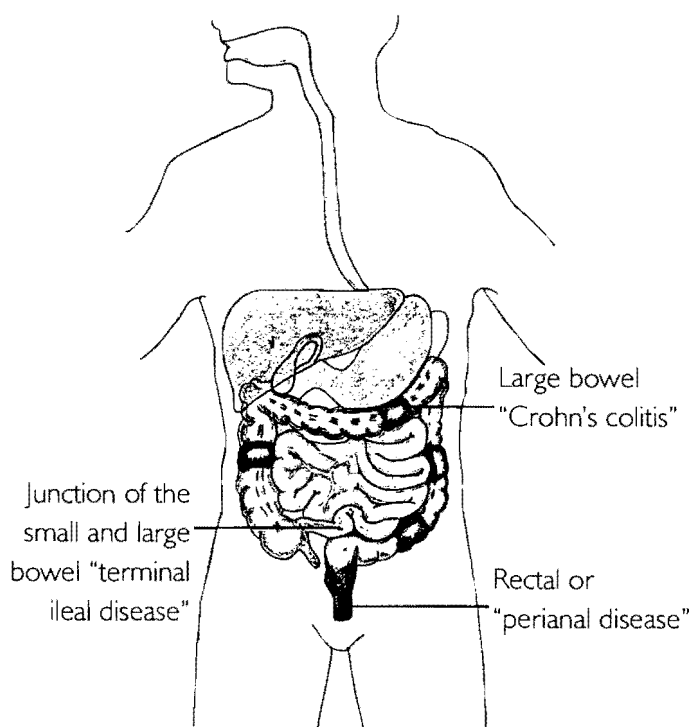


Ulcerative Colitis Sites



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Crohn's Disease sites



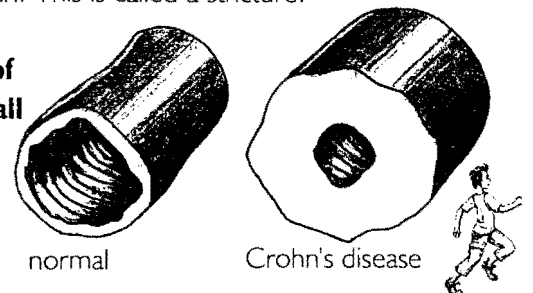
Ulcerative colitis

Ulcerative colitis causes ulcers and / or inflammation in the lining of the large bowel. It may only affect the rectum or it can occur at any point through out the *colon*. When Crohn's type inflammation is found in the colon, it is called Crohn's colitis.

Crohn's disease

Crohn's disease is named after an American doctor called Burrill B Crohn who, with his colleagues, first described it in 1932. It causes inflammation in one or more parts of the gastrointestinal tract, with normal parts in between. It's usually found in the large bowel (called the colon) or in the lower part of the small bowel, but it can occur less often in the mouth, stomach and / or the upper small bowel. The inflammation can lead to scarring, which can cause the bowel walls to thicken. This is called a stricture.

Thickening of intestinal wall



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Who can get IBD?

IBD is not infectious. You haven't caught it from anyone and you definitely can't give it to other people.

Anyone can get it, any age, any race, men and women, boys and girls. It is most common at present in people in their twenties and thirties, but the number of children with IBD is increasing, and sometimes they are as young as five. You are by no means on your own in having this illness, although so far you may not have met anyone else who has it.

Is there a cure?

No, not yet. IBD is a chronic illness. In other words the condition is going to be present for many years (perhaps permanently) but a lot can be done to stop the symptoms. You'll have spells, very often quite long (called remissions), when you'll feel fine. If the symptoms recur (called a flare-up or relapse) they can probably be dealt with fairly quickly. The trouble with IBD is that it's unpredictable, it's hard to tell when you are



likely to have a relapse or how long a remission will last. So it is important that you understand your illness and recognise a relapse if one occurs.

What causes IBD?

What we do and don't know: We don't know, and until we find a cause it's difficult to find a cure. There are a lot of ideas, but so far no one has come up with anything certain. We do know, however, what doesn't cause IBD. It isn't due to your diet, or to the way you've been brought up, or to any worries or distress you may have had. So, it's no one's fault that you have IBD. Is it down to your genes? Well, perhaps a little bit. Sometimes it occurs more than once within a family, but we don't know why this happens. On the other hand, you may be the only member of your family who has IBD. We don't know why this is, either.

Continuing research: We certainly haven't given up on trying to find a cause and a cure. Researchers all over the world, as well as in the UK, are working on it all of the time.

If you'd like to know more about current research you can contact the National Association for Colitis and Crohn's Disease (NACC) or the Crohn's in Childhood Research Association (CICRA), two organisations who exist to encourage research into IBD and to help people who have either Colitis or Crohn's. You'll find their addresses on page 24.

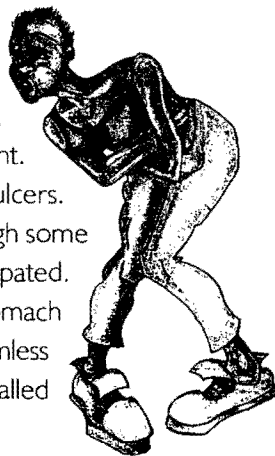
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What are the symptoms?

In other words, what are the first signs of IBD?

Common Symptoms: With ulcerative colitis almost everyone starts with diarrhoea, that is having to rush to the toilet often and pass very loose motions, or stools, often with blood or mucus in them. Most people also have stomach pain, often pretty badly.

With Crohn's disease the first signs are likely to be lack of energy, a poor appetite and loss of weight. Some people may have mouth ulcers. You may have diarrhoea too, although some people with IBD become constipated. Also quite common as well as stomach pain is a sore bottom, often with harmless extra bits of skin around the anus, called skin tags.



With both Crohn's disease and ulcerative colitis some people get pains in their joints and, less often, skin rashes or sore eyes.

Developmental Delay: An important symptom of Crohn's disease in young people is delay in development. Some young people's growth slows down and sexual development can be delayed that is, girls menstruate (having periods) later than other girls do and boys' testicular development slows down. With treatment and time, most people catch up with their friends.

You may have heard that taking steroids can slow your growth down a bit too. This can happen and it's one of the reasons why the doctor keeps a careful check on your physical development. You will be able to catch up with your growth later on.

How can IBD be diagnosed?

You were probably referred by your GP or by a doctor from another hospital to a paediatric gastroenterologist, that is a doctor specialising in gastrointestinal illnesses in children and young people. This doctor will start by giving you a very thorough physical examination, including feeling your stomach and examining your bottom. You'll also be asked a lot of questions.



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You may find some of them embarrassing, but your answers are very important if the doctor is to make an accurate diagnosis and get you going with the right treatment.

Then there will be several tests, which may include:

Blood tests

At your first visit to the hospital you may have a lot of blood tests done to help the doctor decide exactly what is wrong with you.

Some of the tests will continue to be done regularly to monitor your treatment and progress. These tests include looking for changes called inflammatory markers, which indicate whether inflammation is still present. Before you have a blood test, the nurse, or doctor who will be taking your blood can put a special cream (local anaesthetic) on your arm. This will numb the area where they'll do the test and stops the needlepoint from hurting, but the nurse will have to squeeze your arm to help the blood come out.



The cream takes some time to work (45-60 minutes) so if you can manage OK without it tell the nurse or doctor and they will be able to do your blood test more quickly.

A barium meal and follow-through

(This test will take some time, so take a book, magazine or Walkman along with you). Your stomach will have to be empty for this test and so you'll be asked not to eat or drink anything for a few hours beforehand. At the test, you'll be asked to drink some thick white chalky liquid called barium. Its a bit difficult to drink, but as it goes down the radiologist will take several X-ray pictures, so that your doctor will be able to see quite clearly what your bowel looks like and what is happening inside.

You may have to wait for some time between each picture while the barium moves on through your gut. In fact, the whole test can take two to three hours... so you do really need your book.

Colonoscopy and endoscopy

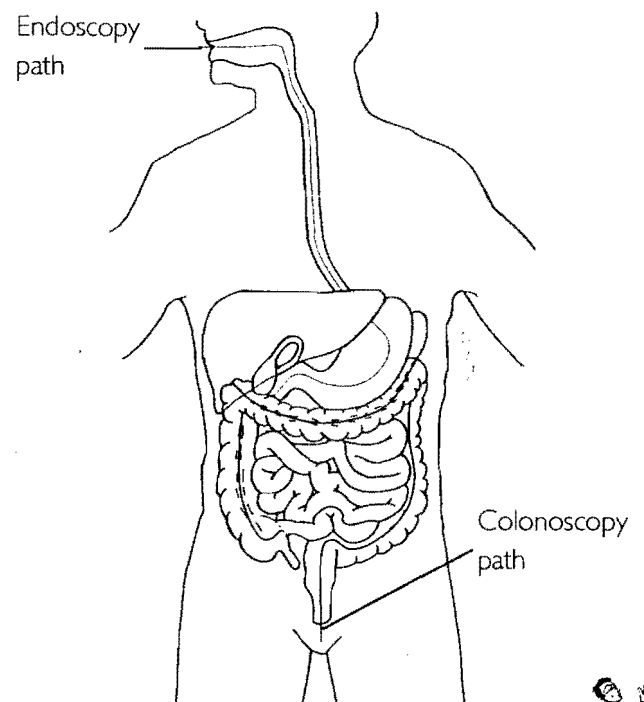
These are ways of seeing right inside your bowel with the aid of a light at the end of a very flexible tube, which goes in either through your anus or your mouth. (Don't worry, different tubes are used!). These instruments can also, without you feeling it, take a biopsy. That is a tiny snippet from the lining of your bowel, which the doctor will examine under a microscope. This sounds rather nasty, but you will be given some medicine called sedation to make you feel very sleepy so that you won't feel too much discomfort. Some people may need to have a light anaesthetic for this test. You can take your parents with you for all of these tests if you want to have them there.

After the test

The doctors may not be able to tell you exactly what your illness is immediately after the tests, but they will tell you what they think is likely to be the problem. There can be a definite diagnosis after a few days when the results of the biopsy are known.

As well as the regular blood tests, you'll probably need another colonoscopy later to check on the effect of your treatment.

Colonoscopy and endoscopy



What kind of treatments are there?

There are several kinds such as medicine, diet and surgery, sometimes all at once, sometimes following on from each other. We've already said that IBD behaves differently in each person, so there will probably be a treatment plan designed especially for you.

It can include:

Diet

In Crohn's disease the commonest form of treatment is a special liquid diet – you will hear this called enteral feeding. The diet consists of special milk, which, like baby milk, provides you with all the nutrients you need. It is very important to make sure that you continue to grow properly and this milk diet will help you grow but will also help to heal your gut and make you feel better.

It seems strange to think that you can fill up on milk, but once you start to drink it you will stop feeling hungry. The milk



tastes OK, a bit like slightly sweeter ordinary milk, so most people don't object to it. Occasionally, if you're feeling ill, it may be hard

to drink the amount you need. If so, it can be given down a small tube through your nose. This tube will come out later when you're able to drink the milk yourself.

If the doctors think that you should go on this special diet it will be for a period of 6-8 weeks, during which time you will need to drink just the milk and not eat or drink anything else except water. After this time you will probably need another colonoscopy to see if the treatment is working well. If the doctors are happy with your progress you will be able to start to eat again, just one food at a time to avoid upsetting your gut. The dietician will tell you what to do. It takes a little time, but it is worth it and you will soon be able to eat normally again.

We repeat that IBD isn't caused by anything in your diet, but your loss of appetite means that you may not be getting enough nourishment to keep you growing and developing.

Diet and growth

Sometimes, if your growth is slowing down a lot, your doctor may recommend that you drink the special milk, or another similar one, in addition to your normal diet. This will give you extra calories to help you grow and feel stronger.

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Growth is all-important at your age, so it really helps to eat well and enjoy all kinds of food.

The trouble is that IBD can take away your appetite altogether or can make food taste like cardboard, so a bit of will power is called for. Now is the time when you can ask for all your favourite meals, as long as they are nourishing and you try to eat them. The good news after all the bad news is that pasta and its various sauces are good in food value, and so is ice cream!

Lots of people with IBD find that they can't eat big meals. It's more comfortable to eat small ones more often. You may feel like this especially when you have a poor appetite because it's off-putting to see a big heap of food on a plate. You can ask to have food little and often. It's having the food that is important.

Generally there is no need to limit your diet, but just occasionally certain foods affect people with IBD so that their symptoms return when they eat one particular food.

If you know that a particular food disagrees with you then you may want to avoid it, but be sure to ask the advice of your doctor or dietician before you alter your diet.

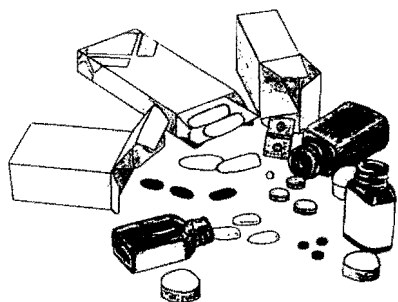


When you are at home people may advise you about your diet. This will be well-meant and could be useful, but if it is different from what you've been told at the clinic, always discuss it with your doctor or the dietician before changing your diet.



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Drugs (Medicines)



Steroids

When you have an attack of IBD or on first diagnosis you may be given steroids. They act quite quickly so that you will soon begin to feel better. You've probably heard that all medicines have some side effects, and different people react in different ways to steroids. It's quite common to put on weight as some people find they get very hungry while they are taking steroids. If this happens to you, you should eat what you feel like eating and not worry about putting on weight as this will soon disappear once the steroids have been stopped. You may get a round face (moon face) or become a bit pimply, and girls sometimes get facial hair. Steroids can make you moody and



restless, too. Some people who have had IBD for a while and have required frequent courses of steroids may develop osteoporosis. Osteoporosis (thinning of the bones), is usually found in older people.

However in patients with IBD who are taking steroids the symptoms may appear at an earlier age. There are ways of minimising this effect – you should talk to your doctor or nurse about this.

It can be tough dealing with these side effects, but you have to weigh the disadvantages against the advantage of feeling much better and being able to get back to normal life. If things get very tough don't hesitate to talk to the doctor or a nurse about how you feel. The doctor will prescribe the lowest possible dose for the shortest possible time, and when you come off the steroids most of the side effects will disappear. By the way, the steroids that you would be given aren't at all like the steroids taken illegally by some athletes.

Other medicines

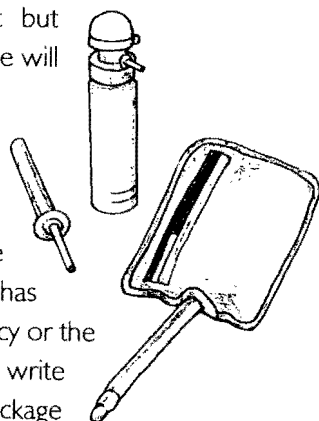
Other medicines will be given to you even after the inflammation has died down in order to discourage relapses. These medicines don't have such conspicuous side effects.

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Examples of these are sulphasalazine, mesalazine or osalazine (pentasa, asacol and dipentum) and you may be asked to take them for a long time, or even permanently. Another long-term medicine, called azathioprine acts rather like steroids and can be used to "take over" from them if you've had steroids for a long time or you haven't got better on them. It can cause changes in the blood of a very few people so, to be on the safe side, regular blood tests are necessary while it's being taken.

Taking the medicines

Some medicines may be given through your anus up into your rectum so as to reduce any inflammation in your bowel. This sounds a bit unpleasant but it isn't difficult to do and the nurse will show you how. Some people even prefer this to taking lots of tablets. Because these medicines are quite powerful, it is very important that you take them exactly as the doctor has prescribed. The hospital pharmacy or the pharmacist at your local shop will write instructions on the bottle or package



and if you don't understand them you should ask there and then for an explanation.

With any medicines, always tell your doctor right away if you find you are getting any unusual symptoms. If you are on steroids or azathioprine you may find that you're more likely to pick up infections, so contact your doctor if you find that you have a temperature or a sore throat. If you'd like to know more about how your medicines work in your body, ask your doctor or nurse.

Surgery

There are three types of surgery in Crohn's disease. The first is necessary if your illness doesn't respond to the prescribed medicines, so that you still have symptoms and you aren't growing as you should. In that case the inflamed part of the bowel can be removed and the two healthy ends are joined together.

The second reason for surgery is when the inflammation has narrowed your bowel (sometimes called a stricture) so much that it could stop food getting through. That would be very unpleasant for you, so the surgeon would perform a surgical technique that



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stretches the narrowed part of the bowel. With this type of operation no bowel is removed. Most young people recover quickly from this operation and feel much better afterwards.

There is a third, less common type of operation which people with Crohn's disease or ulcerative colitis can have. This is advisable for people who have been unwell for a long time and have tried all the available treatments but aren't getting any better. Being unwell for a long time can stop you growing and doing the things that you enjoy, so the doctors may recommend that you have an operation called a *colectomy*. This involves removing the large bowel (*colon*), meaning that you won't be able to pass a stool through your back passage in the normal way, so there has to be another way for it to come out. This problem is solved by what the doctors call an *ileostomy*; that is, the surgeon makes the last part of your small bowel open out onto your stomach like a little spout. The stool from your bowel passes out through the spout into a small bag that you wear under your clothes.



Although this operation sounds a bit scary it makes a lot of people feel so much better that they are glad that they had it done. Looking after an ileostomy soon becomes just a part of everyday life.

Your doctor could probably arrange for you to meet other people who have had this operation to find out how they feel.

It might be possible, at a later date when you've been really well for a while, to have a join-up operation, that is, the small bowel would be rejoined to your back passage. You would need to talk to the doctors and specialist nurses about what this would involve and whether it would be right for you.

None of these operations are that common and would only happen after lots of discussion with you and your parents.

Do I have any say in my treatment?

You certainly do. We all know how easy it is to forget to take medicine and it's up to you to remember. Helpful parents may put it in front of you, but they can't force it down your throat. Building it into your daily routine, like cleaning your teeth or collecting your books for school is a good way to remember.

We've already said how important it is that you eat. Medicine will clear up the inflammation but you also need to eat well to make you grow. Both are needed to keep your symptoms at bay and enable you to live a happy energetic life like your friends.

Finally one very important contribution you can make towards helping yourself to stay well. If you are a smoker and you have Crohn's disease you should STOP SMOKING. If you do not smoke you should not think about starting. We know that smokers with Crohn's disease are more likely to have a worse course of their illness, will have more relapses and will need more medicines to treat their symptoms. This has not been seen in people with ulcerative colitis in fact smoking can sometimes help. But for your health in general this is not a good enough reason for you to start smoking.

You are the patient

You also have a say in decisions about your treatment. The doctor will explain what he or she thinks is the matter with you and what is advisable for treatment and why. But just sometimes, because doctors themselves are adult, they may without thinking talk to the adult who is with you instead of to you. If this happens, chip in politely and ask for a repeat. Sometimes they are very short of time and talk too fast, and then there you are outside the door with a dozen questions you feel you didn't have time to ask. If this happens, don't leave the clinic until you find a nurse who can either answer them or arrange another appointment with the doctor. It may help to write your questions down before you come to the clinic.

Sometimes, especially when you've had time to get to know and trust your doctor or nurse, you may feel you would like to talk to him or her alone. You have a perfect right to ask for this. Perhaps you'll hesitate to ask because you're afraid that your parents will feel hurt and rejected. After all, they've probably done a lot for you and are certain to have been worried and anxious. If you explain your feelings, they should understand that in future you will have to manage your illness yourself, and this



is one way to start. You already live a large part of your life away from your parents at school, although they play an important part helping you through your school life. Perhaps you feel that your hospital life has something in common with this. In any case, it's part of your growing independence and your parents will be proud of you living up to this natural stage of development in spite of your illness.

The doctor should ask your permission, as well as your parents, before any course of treatment if he or she believes that you are old enough to understand what it is all about. In fact, you have a legal right to give consent and if you are old enough to read and understand this booklet, you should be old enough to understand the reasons for your treatment and its procedures. Understanding what is happening to you is the first stage of treatment for you, as well as for the doctor.

What if I need to come into hospital?



You may feel a bit worried if you're asked to come into hospital, but in fact a short stay in hospital will ensure that all the tests you need will be done quickly. This means you will get a

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If you would like one of the nurses or the hospital teachers to talk to your form teacher about your illness or if you think it would help to let the school nurse know then just ask your nurse or teacher. Sometimes it's helpful for the teachers and nurse at your school to know about your illness and any special treatments. This means they'll understand why you have to go to the toilet during lessons or why you have special milk to drink. They'll then be able to support you better and give you any help that you need.

Space for parents

It's usually possible for a parent to stay with you while you are in hospital. It's a good idea to talk to the nurse on the ward before you are admitted and let them know that someone will be staying with you. You may feel that you don't need your parent there all the time. You may need to tell them it's OK to leave you on your own for a while if they feel that they should stay with you all the time. You'll probably both need some time apart. After all, parents will need to go to the shops or take a break for a coffee from time to time.

diagnosis and can start your treatment as soon as possible – and begin to feel better. We've already said it's hard to predict who will have a relapse, or when it's likely to occur, but it's possible that if you had a relapse you might have to come into hospital again. It's also hard for doctors to be able to tell how long you're likely to be there. Being in hospital can be very boring – you'll find that you are often waiting around for blood tests, X-rays etc so you will need to bring with you lots of things to keep you amused. You will be able to watch television and often there is a video you can use but it's best to bring favourite videos with you, as the ones the hospital have may be for younger children.

Keep up with school work

It's a good idea to bring schoolwork with you. This gives you something to do and also makes sure that you don't fall behind at school. Maybe your teacher could send some work to you in hospital or if they live nearby friends can bring work in when they come to see you. It may also be possible to attend the hospital school. If this opportunity is available, take it up! It will get you away from the ward, give you a chance to meet other young people in a similar situation to you and you will be able to get help from the teacher with your school work.

Help from hospital staff

The doctors and nurses are there to help you. So if you don't understand what they tell you about your condition or treatment, or you don't understand what is involved in a particular test make sure you ask someone to explain again. If you want to talk to a nurse or doctor on your own you can ask to do so as IBD is your disease and nobody else can know quite how it feels, you will probably want to be a little bit independent about looking after yourself and taking your treatments.

How will I cope with IBD at home?

What you can do

No one can deny that IBD can be a pretty miserable illness when it's active. But although the possibility of a relapse is always there, it's very likely that in time all the symptoms will disappear for months or even years at a time, in a remission. Remember, and remind everyone else, that during remission you are not an invalid, even though you may be taking medicine as a precaution against a relapse. Go out and enjoy yourself with your friends and family. There's nothing to stop you going on holiday, although it's best to avoid places renowned for stomach



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upsets as these can sometimes trigger relapses. Often antibiotics can be taken to prevent a relapse in these sorts of places. Make sure that you discuss this with your doctor BEFORE you go away.

As long as you're feeling fine, are eating well and don't get too tired, you're just like anyone else of your age. You will want to catch up on what you've missed, in fun as well as in schoolwork.

Your parents point of view

You may find that your parents continue to worry even when you're feeling well and you'll begin to resent their continuous "how are you feeling today", "don't over do it" and so on and on, and on. After all, your illness, through no fault of yours, has caused them a lot of anxiety and they aren't inside your body, so it's understandable that they can't be as sure as you are that you are now well again. Reassure them that you really are feeling different and that you will let them know if any of the symptoms recur. You could ask your doctor or nurse to explain that a remission almost always means that you can enjoy a normal life.



But there will be some problems, won't there?

Yes, probably there will be. You may be back at school or at work before you are fully recovered from an attack and that's when problems may arise. You'll need to take some precautions.

What makes people with IBD most fed up is having to go to the toilet so often and the embarrassing things that happen there. It's a good idea to check out the quickest route to the toilet when you visit anywhere new. Some people carry sheets of toilet paper and a spare pair of pants when they go out. They say this gives them confidence, even when they don't use them. A good tip for blocking out sound effects is to flush the toilet just before you use it.

You may feel frustrated at having to take pills every day when you're feeling much better. Most people have been tempted to "forget" them now and then and actually be like other people as well as feeling like them. It'll need a bit of willpower to fight this temptation, but you'd be furious with yourself if you then had a relapse.

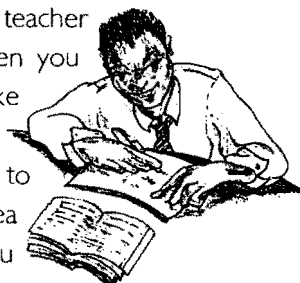
What about school?

Explaining IBD to school staff

Both NACC and CICRA (see page 24) publish leaflets for teachers explaining about IBD and the kind of needs you will have. They suggest, for example, that you should be allowed to leave class quickly whenever you need to, that you should be able to use the staff toilet if it's nearer and have your own key to the toilets if they're kept locked during lesson time.

They also explain that your illness may come and go from day to day: at times you may feel tired, and being allowed to lie down somewhere for one class period will probably be enough to restore your energy. That's much better than going home and missing two or three periods.

If your school doesn't have any of these leaflets you can take one yourself and talk to your teacher about it. It will support you when you explain about having to take medicine at certain times and about needing to get permission to eat between meals. It's a good idea to ask if there is one teacher you



can go to if you need help in coping with your IBD at school. Maybe you hate being singled out at school like this, but it will pay off and avoid more singling out later.

Catching up with work

You may have missed a lot of schoolwork through being in hospital or attending clinics. Talk to your teacher about how best you can catch up. If you have to stay at home during a mild relapse, ask if someone can bring you homework. That way you'll not only keep up in class, you'll keep up on school gossip too, so you won't feel so out of it when you go back.

Sport

Maybe you're keen on sport and are a member of a school team and you've missed some matches. If you're feeling fit there should be nothing to stop you playing again. Think of the months professionals have to take off for injuries and they bounce back again. One famous sportsman actually has IBD and it doesn't stop him winning medals. Some people with IBD have run the London marathon! Your team captain and PE teacher may be afraid of overtaxing your strength. You'll need to talk to them and explain that your illness is in remission and that it's perfectly in order to carry on as normal.



What can I tell my friends

A lot of young people have told us that their friends have been really good and a great help about IBD. But if your friends are going to be able to help they'll need to know something about what you're going through. Otherwise, they won't understand how come you are as fit as they are one week and the next week you're having to rest, or why you have to go to the toilet often and take medicine regularly. Most people genuinely like to help – usually it's not knowing how to help that holds people back.



Some of your friends, as well as your teachers, may show their concern for you by being over-protective and they may start telling you what to do and what not to do. You'll have to explain that your IBD can make you feel different from day to day. When you are at school you are the best person to know what you are capable of doing at any particular time.



So how will I actually feel about all this?

Of course you won't feel like getting your friends together and holding forth about IBD on your first day back at school. You'll have your own way of telling them. You may prefer to tell just one or two of your friends and get them to help tell the others. There will always be people who snigger about luo jokes and so on, but if you have the support of friends with sound knowledge, they'll probably handle that problem for you.

Get some allies

Everyone finds IBD embarrassing – we've mentioned this already – and some people avoid things like parties and discos in case they have an emergency. But these are activities that will cheer you up and make you feel really one of your group of friends. If you miss out, you may feel very lonely. It helps if you have one or two people with you who know about your situation and can help you cope if you do hit a bad patch.

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Why me?

With an illness like IBD it's very easy to feel lonely. People feel they're different from everyone else and sometimes they find themselves saying "Why me?", "Why do I have this miserable illness and not my brothers and sisters or friends?" They feel angry at the world in general, and they may begin to feel that there's something wrong with them as people. Some people feel guilty thinking they've landed their family with such a problem. Well, they haven't. IBD is a stroke of bad luck that hits some people rather early in life. It's not your fault or anyone else's.



Some people feel so angry about IBD that they try to deny that they have it. It's easy to do this during a remission, especially when there are early signs of a relapse. When you're feeling cool and rational you can see clearly that stopping your medicine will only make matters worse, but you don't see so clearly when you're feeling angry or depressed. It's always helpful to talk to someone when you're feeling low. At times you probably need a hug and to be told that you're great. And you are, you're standing up to and coping with a really nasty illness.

Being too thin or too fat (because of steroids) or not growing as fast as other people are big worries. Medicine never seems to act quickly enough. With time, you'll probably change your course of treatment and will revert back to your normal weight.

What about my IBD when I'm older?

Partners

Lots of young people worry about how their boy or girl friend will feel about their illness. But people a bit older have told us that in spite of their acute fears it made no difference in really close relationships. There are a lot of young people with IBD walking round hand-in-hand with partners, and many of them will one day be pushing baby buggies.

Leading a normal life, enjoying all sports, going on holiday, taking exams, going to college, having a career, having a family: it's all possible with IBD.

Your doctor will probably want to keep an eye on you even when you're having a long period of remission. The time will come when you'll stop attending the paediatric clinic and start in with the adults.



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Your doctor will suggest this to you when he or she thinks it's the right time for you.

If you come to this conclusion before the doctor does, mention it at your next session. There may be good reasons for a delay, like finishing off a course of treatment, but often the transfer is easily made. On the other hand, you may want to stay with the familiar surroundings a bit longer. This may be fine with your doctor for a while, but you'll have to make the change-over eventually.

Attending the adult clinic will mean sitting around waiting with a lot of people older than you are, some of them really old, and you may feel out of place or irritated by this at first. It's a good idea to talk with someone about the significance of this change, and a nurse will often be the person who can make the time and has the knowledge for this.

Nurses will be around in the adult clinic to ease you in on your first appointment. They can also help you to take over the full management of your illness gradually, so that you no longer need the close support from your parents that you probably had up till now. It's very natural too, for parents to feel a bit worried



at this stage, at the same time welcoming your growing independence. The nurse will help them to cope with their feelings, as well as you with yours.

How can I remember all this?

We know only too well how difficult it is to remember a lot of information all at once. So here's a summary of what we think are the most important things about living with IBD:

- IBD can attack out of the blue – we don't know why. It's no-one's fault and it's certainly not yours.
- It's not infectious.
- Although there's no permanent cure yet, IBD comes and goes. You'll have periods of remission, when you can live a perfectly normal life and should not be treated as an invalid.
- Information is important. Get as much as you can from doctors and nurses and keep this booklet handy for reference.

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- Taking care of yourself by getting enough rest, doing the things you like to do, eating the things you like to eat and taking your medicines will all help to make you feel better.
- Explain about IBD to people you can trust so that they can help you when you need support.
- Remember that your doctor and the specialist nurses are there for you.
- Work hard when you're feeling well, but don't forget to enjoy yourself.

More questions?

This booklet has been written under headings, which are questions we think you might want to ask. Now you may have other questions. If so, go ahead and ask them, using either the clinic staff or NACC and CICRA, the associations whose address we've listed on page 24. Talking with other young people with IBD may help you to deal with the worries of every day life better than talking to adults. You could find out about various groups of young people in various parts of the country from NACC and CICRA, too.

Available from NACC is a video called "Talk about Crohn's", where three young people in their twenties talk about the difficulties they've dealt with and how they've worked out interesting and stimulating lives for themselves. What they say applies as much to ulcerative colitis as it does to Crohn's disease.

Good luck!



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A glossary of IBD terms

ALIMENTARY TRACT:

otherwise called the "digestive tract" or (GI) "gastrointestinal tract"- this describes the part of your body involved with swallowing, digesting food and eliminating waste. That is your oesophagus, small bowel and large bowel.

ANASTOMOSIS:

joining up of the bowel after resection.

ANUS:

the opening of the back passage through which stools are passed.

AZATHIOPRINE:

a drug used in ulcerative colitis and Crohn's disease to help reduce the inflammation and the amount of steroids needed to keep the disease under control.

BARIUM:

a chalky liquid which when drunk can show up in the stomach and bowel on X-ray.

BARIUM MEAL AND FOLLOW THROUGH:

a test where you are asked to drink some barium which is then "followed through" your bowel by taking several X-ray pictures. This test helps to show up any problems in the bowel such as strictures.

BIOPSY:

a small piece of tissue removed from the body to be examined under a microscope. Biopsies are taken from the bowel to help diagnose Crohn's disease and ulcerative colitis. They are taken during colonoscopy and endoscopy and do not hurt.

COLECTOMY:

an operation to remove the colon.

COLITIS:

inflammation of the colon.

COLON:

otherwise called the "large bowel" or "large intestine". This is the lower part of your bowel where stools are formed and made solid.

COLONOSCOPY:

a test where a small tube with a camera on the end is inserted into the back passage. This allows the doctors to see into the large bowel and the terminal ileum.

ENDOSCOPY:

a general term for a test using a narrow tube with a camera on for seeing into the body. Often used to describe the test where the tube is inserted through the mouth to look at the upper gastrointestinal tract (the oesophagus and stomach).

ENEMA:

a liquid medicine inserted into the back passage which can be absorbed by the gut lining – used to deliver medicines to treat a specific area of the large bowel or sometimes to clear the lower bowel (occasionally needed prior to sigmoidoscopy).

ENTERAL FEEDING:

special feeding of a milk type drink, given by mouth or by tube. Often used in Inflammatory Bowel Disease as the main form of treatment or to help give extra calories to maintain growth and development.

FISSURE:

a small crack in the skin sometimes found around the anus in people with IBD.

FISTULA:

a small, sore opening sometimes found around the anus in people with IBD.

GASTROINTESTINAL TRACT:

the alimentary tract or digestive tract.

GUT:

another word for bowel or intestine.

HEMICOLECTOMY:

an operation to remove a part of the colon if it is diseased.

IBD:

inflammatory bowel disease – a general term for ulcerative colitis and Crohn's disease.

ILEOSTOMY:

a spout formed from the small bowel that opens out onto the stomach to allow stool to pass into a special bag worn over it. This is needed when a colectomy is formed and the colon has been removed.

ILEUM:

part of the intestines sometimes called the small bowel or small intestine.

INFLAMMATION:

irritation or soreness

INFLAMMATORY MARKERS:

special blood tests that show if you have any inflammation and can be used to monitor your progress and effects of treatment.

INTESTINE:

another word for bowel or gut.

LARGE BOWEL:

the lower part of the bowel – otherwise called the large intestine. Sometimes used to mean the colon although there are other parts to the large bowel as well as the colon.

MESALAZINE:

a drug used in ulcerative colitis and Crohn's disease to help reduce the inflammation and to keep the disease in remission.

MUCUS:

a white and slimy substance sometimes produced with stool in IBD.

NASOGASTRIC TUBE:

a fine tube inserted through the nose into the stomach which can be used for giving special feeds if they cannot be taken by mouth or for keeping the stomach empty after an operation.

NUTRIENTS:

the "good bits" that the body absorbs from the food we eat and that makes us grow and develop.

OLSALAZINE:

a drug used in ulcerative colitis and sometimes Crohn's disease to help reduce the inflammation and to keep the disease in remission.

PAEDIATRIC GASTROENTEROLOGIST:

a doctor who is a specialist in looking after children with problems with their stomach or bowels.

PERIANAL:

the area around the anus.

RADIOLOGIST:

a doctor who is a specialist in taking and interpreting X-ray pictures.

RECTUM:

the very last part of the large bowel or the part of the bowel just inside the anus.

RELAPSE:

a "flare up" when your disease makes you feel unwell again after a period when you have been well – when the disease is "active" again.

REMISSION:

when you feel well and your disease is not really causing any problems – when disease is "inactive".

RESECTION:

an operation to remove a diseased part of the bowel or a stricture.

SEDATION:

the medicine given by mouth or into a vein which makes you sleepy.

SIGMOIDOSCOPY:

a test where a small tube is inserted into the lower part of the large bowel.

SIGMOID COLON:

the bottom part of the colon.

SKIN TAGS:

small bits or tags of extra skin that are sometimes found around the anus of people with Crohn's disease.

SMALL BOWEL:

the upper part of the bowel – otherwise called the small intestine. Sometimes used to mean the ileum although there are other parts to the small bowel as well as the ileum.

STEROIDS:

a special type of medicine used to reduce inflammation – they are not like anabolic steroids that athletes take. They do have some effects like mood swing and getting a round face or putting on weight. These go away when steroids are stopped.

STOMA:

a general term for a special opening like an ileostomy but can be formed from other parts of the bowel.

STRICTURE:

a narrowing of the bowel.

SULPHASALAZINE:

a drug used in ulcerative colitis (and sometimes Crohn's disease) to help reduce inflammation and to keep the disease in remission.

SUPPOSITORY:

a solid medicine inserted into the back passage which then melts and is absorbed through the gut lining – used if medicine cannot be taken by mouth.

TERMINAL ILEUM:

the last part of the small bowel.



You & Me

Who is this booklet for?