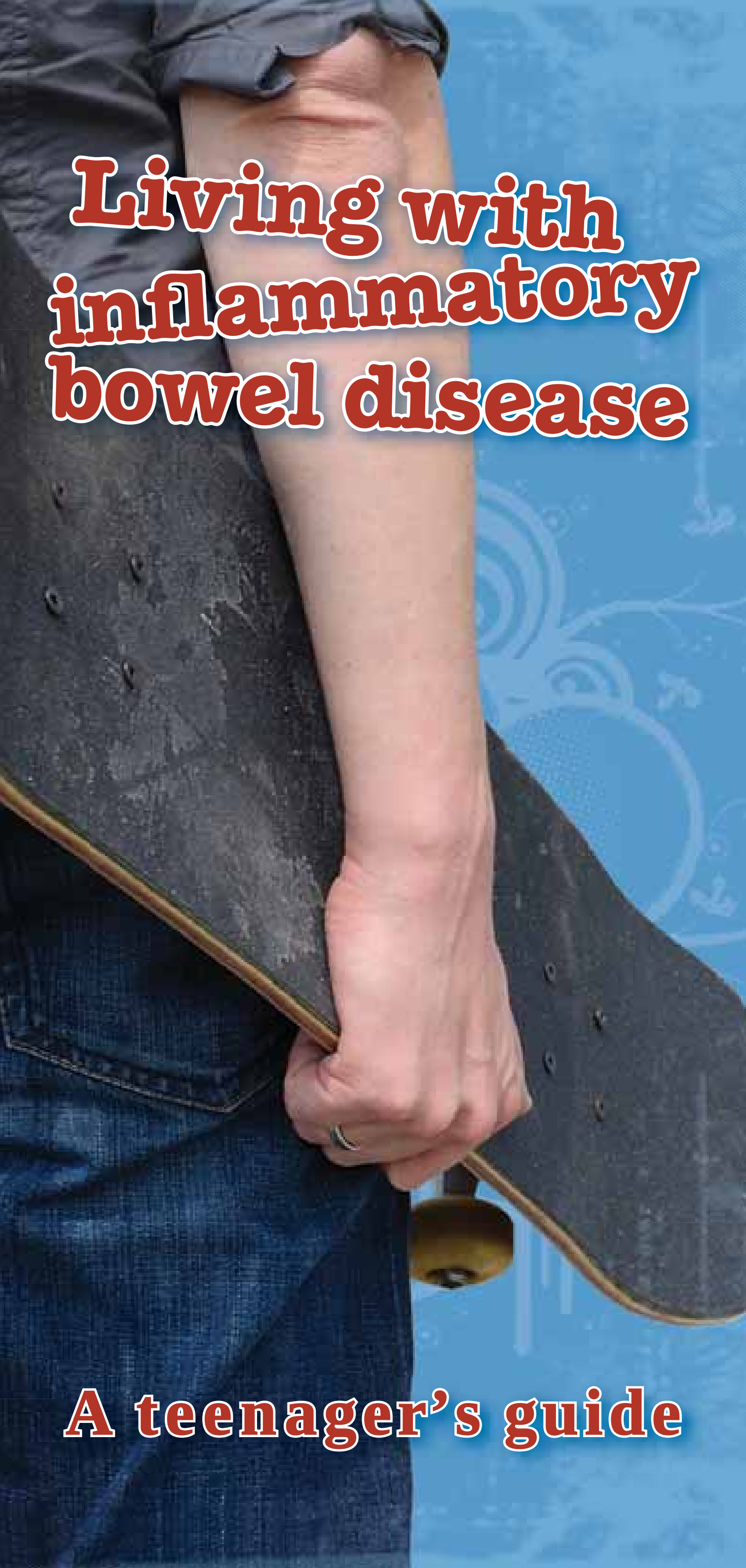
Living with inflammatory bowel disease



A teenager's guide

Photo: Martin Walls

Contents

People depicted in this booklet are models and their images are used for illustrative purposes only.

Inflammatory Bowel Disease, or "IBD" for short, is a condition that can affect people at any age but most commonly begins between 15 and 40. This booklet is designed to help answer common questions you may have about IBD and provide advice on living with IBD, to help you get the most out of life.

What is IBD?

It is a condition where inflammation occurs in the intestine and it becomes painful, red and irritated like sunburnt skin. We often do not know what causes IBD but in most cases, there is an unidentified outside trigger which sets it off. While it is not a common disease, it is not rare either. In New Zealand about 20-25 children and teenagers are diagnosed with IBD each year. It is possible that these numbers are increasing each year following a worldwide trend.

There are two main types of IBD, Crohn's disease and ulcerative colitis.

Crohn's disease

In Crohn's disease, there can be inflammation in the small intestine and/or the large intestine. The inflammation tends to involve deep layers of the lining of the intestine. Inflammation can also, but less frequently, involve other areas such as your oesophagus, mouth and anus.

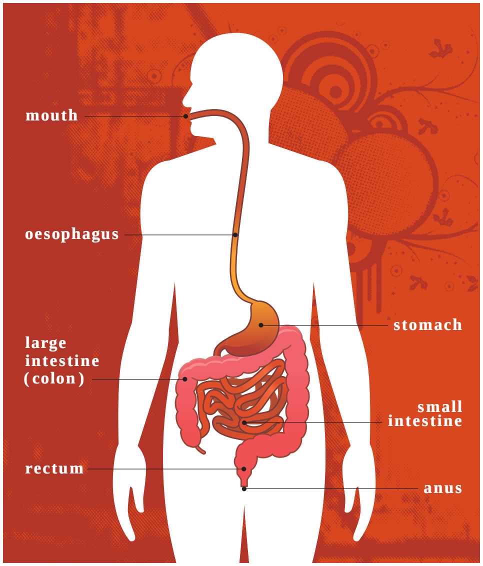
Ulcerative colitis

In ulcerative colitis it is the large intestine that is mainly affected. The inflammation usually involves the surface layers of the lining of the intestine. Ulcers can form in the inflamed areas.

What is the cause of IBD?

IBD often starts in adolescence for reasons we do not yet understand. Many people have wondered about changing hormones or diet causing IBD, but at this time we don't think they play a big role. Sometimes a stomach bug or a viral infection may set things off.

It is possible that certain IBD-associated genes that you carry, interact with bacteria in the intestine causing inflammation through an imbalance in your immune system.



What are the symptoms?

Inflammation in the intestine can cause symptoms such as abdominal pain, diarrhoea, bleeding, poor appetite, weight loss, tiredness, nausea, vomiting and fever.

In Crohn's disease, you tend to have more abdominal pain, weight loss and loose bowel motions. In ulcerative colitis, you tend to get more obvious diarrhoea and blood in the bowel motions. Sometimes you have to hurry to get to the toilet in time.

Other symptoms and signs can occur outside of the intestine such as recurrent mouth ulcers, sore joints and skin rashes. Your eyes may be irritated. Sometimes your bottom becomes tender and inflamed causing little cuts or tears in your anus. This can cause an unpleasant and annoying discharge.

The normal changes that occur with puberty may be delayed. For girls, there may be a delay in starting your periods. For boys, it may take some time before your voice starts to break. You may notice your clothes are looser and that your shoe size has not changed for a while. You may notice that you do not grow as fast as your friends.

At times, you may feel so unwell that you cannot get to school and this may affect your school performance.

Photo: Carlos Butler

How is IBD diagnosed?

To diagnose IBD, blood and stool (bowel motion) tests are done first. These may show signs of anaemia (a lowered concentration of oxygen-carrying haemoglobin in the blood) and indicate that there is inflammation present. You may also be low in iron and some vitamins. If Crohn's disease is suspected, special X-rays called barium contrast studies are needed to also see if there is inflammation in the small intestine. This is where you are asked to drink a special white fluid that enters your stomach and then your small intestine. This fluid shows up on X-ray. It allows the radiologist to look at the structure and inside lining of your intestine to see if there is inflammation.

> **I used to get such bad stomach aches and then have to go to the toilet heaps of times... then I noticed blood. It got so bad that I was missing heaps of school and time with my friends. Eventually I had to see the doctor. That was when I first heard that I might have "IBD".**

Usually it is necessary to take a look inside your intestine to make the proper diagnosis. This can be done using endoscopic procedures called colonoscopy and often gastroscopy. An endoscope is a special instrument (like a flexible telescope), which allows images of the inside of your intestine to be passed to a TV monitor. It also contains a tiny channel inside it that allows the specialist to pass a wire instrument which can take tiny pieces of tissue (called biopsies) painlessly from the lining of your intestine. Other specialists can then examine the tissue under a microscope for inflammation. It is the biopsies that usually establish the diagnosis of IBD. These procedures are normally done under general anaesthetic and so you are totally asleep while they are being done. For a colonoscopy, you will need to have medicines and a special diet to make sure your intestine is cleaned out beforehand.

How is IBD treated?

Medicines

Medicines are usually prescribed for IBD, though sometimes a diet with a special nutritional liquid formula is used for Crohn's disease. Usually a 5-ASA medicine is taken 2 or 3 times a day and acts to reduce inflammation in the intestine. They are generally safe and relatively free of side effects. If you have moderate-to-severe disease, then often a strong anti-inflammatory medicine called prednisone is given for a few months. Prednisone is usually very effective in reducing inflammation, and getting your symptoms better rapidly. It does have some side effects, including increased weight (sometimes this can be a good thing), difficulty getting off to sleep at night, moodiness, and being really hungry. It can also temporarily have an effect on your growth. Sometimes, if you already have acne, it may make it temporarily worse. Your face may also become rounder. Fortunately, when the prednisone is reduced over time and then stopped, these unpleasant side effects usually disappear. The good thing with the medications is that usually you are able to get back to normal daily activities such as school and sports.

Azathioprine is another medicine that is being increasingly used, especially if the inflammation is severe or extensive. An advantage of this medicine is that it may reduce the need for prednisone later on. Azathioprine's action is delayed, and it may not take full effect until 3 months, so commonly this drug is started early on after diagnosis. Taking this medicine early may be advantageous in better controlling the inflammation later on. Certain side effects can occur with this medicine. They include an effect on the bone marrow, so that your white blood cell production may fall. There is an increased risk of getting infections. Occasionally it may have an effect on your liver. These side effects are monitored by regular blood tests. It is important that if you should become unwell with a fever that you should see the GP early, just to make sure that there is no serious infection. The GP may need to prescribe antibiotics. It is important with this drug, that you keep your skin adequately covered or sunblocked during sunny days. In spite of the side effects, it is uncommon that you will get serious side effects from this medicine.

Nutritional treatment

Sometimes, after discussing things with your specialist, you may choose to have the special liquid diet rather than medicine. What research has shown is that just by having a special liquid drink, you can reduce the inflammation in the intestine. It may be particularly useful if you have lost a lot of weight or you are getting close to puberty as it avoids the temporary slowing of growth caused by prednisone. This type of nutritional treatment is usually continued for 2 months or so. It does mean that you are not able to eat any other food, which can be quite a challenge. Often, this drink is given through a special tube that is passed into your stomach (nasogastric tube). The advantage of this treatment is that you can gain weight without being exposed to possible side effects of prednisone. After 2 months, you can go back to a more normal diet. Sometimes you can continue to take these nutritional drinks on a regular basis as a supplement to try and keep yourself healthy as long as possible.

> **I remember that I was getting really tired. I couldn't do sports which I was pretty keen on and I was sleeping a lot. I also lost a lot of weight because I did not feel like eating. Then I started getting diarrhoea.**

Special Medicines

Infliximab and adalimumab, which also act to reduce inflammation can be very effective in those patients who have not been well controlled with drugs such as prednisone, azathioprine or methotrexate. They act as an antibody (immune system molecule) to bind up one of the tiny chemicals involved in the inflammatory process.

Antibiotics

Sometimes you might need antibiotics, especially if there is inflammation and discharge around the area of your anus. You may need to be on antibiotics for several months to try to get this under control.

What should I eat and drink?

In general, you can have a normal diet as long as it is healthy

and balanced. However if you have lost a reasonable amount of weight or have not gained weight that well, a dietician may advise you about certain foods that will especially help including a supplemental drink which has a high concentration of energy.

Sometimes, if you have Crohn's disease and it has caused a narrowing of part of your intestine (called a stricture), the dietician may advise you not to eat certain foods that might get stuck in the stricture. These foods include peanuts, popcorn, and fruits and vegetables with seeds or pips, such as tomatoes. If you have had a lot of diarrhoea, a diet low in fibre may be suggested initially. If there is bad inflammation of your upper small intestine, a low lactose diet (milk free) might be suggested for a month or two until the inflammation is better.

Often, IBD causes you to have low iron levels in your body and so you may need to take iron supplements.
Other minerals, such as zinc, may be low. Sometimes you will also be low in vitamins. This might mean that you may need to take other vitamin and mineral supplements.

Can I expect to stay better?

Medicines will usually get the inflammation under control initially, but the inflammation may flare up again even though you are taking your medicines regularly. This can be really frustrating. When this happens, your specialist may prescribe you a course of prednisone again to get the disease rapidly under control. If in spite of taking the prednisone, your symptoms are still persistent and troublesome, other stronger medicine may need to be considered such as azathioprine or methotrexate. Your specialist will explain to you what these medicines do and also their possible side effects. The main aim for these medicines is to reduce the need to take prednisone frequently and gain better control of the inflammation.

With these medicines, most of you should keep reasonably good health.

Are there complications?

Hopefully, you will not have serious complications, but they can occur.

In Crohn's disease, because the inflammation tends to develop into the deeper layers of the lining of the intestine, complications such as strictures, abscesses and fistulae may occur. A stricture is a narrowed portion of your intestine. An abscess is a collection of infected fluid full of bacteria (called pus). A fistula is a track that has formed through the layers of the lining of the intestine sometimes travelling to other parts of the intestine or coming out to the skin, especially around the anus.

> **I was worried about getting to a toilet in time in case I embarrassed myself. Eventually I just accepted it and got on with things.**

In ulcerative colitis, on very rare occasions, the large intestine may become severely inflamed and dilated (widened). This is a very serious complication and requires immediate hospitalisation for treatment. If you have had ulcerative colitis for more than 8-10 years, there is also a slightly increased risk of getting a tumour in the large intestine. This risk is very small when you are relatively young, increasing when you get older. It means that later on, you will need a colonoscopy done at regular intervals to check for this.

Your bones are rich in calcium. Sometimes because of the inflammation itself or through poor absorption of nutrients, the amount of calcium in your bones is low. Prednisone if taken over a long time can also reduce the amount of calcium in your bones. This in turn increases the chance of getting fractures. This problem can be treated with good nutrition, vitamin and calcium supplements as well as other special medicine.

Can surgery help?

At some stage, you may require an operation to gain better control of your symptoms. If you are unfortunate enough to get a fistula, you may require surgery to heal it. Also, if an abscess should form, this needs to be opened up to allow the pus to drain. Sometimes, if you have a narrowed area of your intestine, and there is no response to medicines, removing that piece of intestine may help. Sometimes the surgeon may try to stretch open the narrowed area of intestine instead.

Occasionally in ulcerative colitis, if you have serious ongoing diarrhoea and medicine does not help or is causing significant side effects, removing the whole of the large intestine may be recommended.

How important is it for me to take my medicine?

It is extremely important that you take the medicine that the doctor prescribes for you. It can be very hard to remember to take the medicine, especially if you are taking several, and also if you have to take it at school. Holidays are another time when it can be difficult to remember. Missing the occasional dose will happen and is probably not going to be a problem. However, if you stop taking medicine altogether, that is serious. Also, if you are on a course of prednisone, it is very important that you do not miss a dose.

You may not be keen on taking medicines because you do not want to be noticed by your friends, or you are annoyed that you have to take medicine every day. Possibly, you think that one of the medicines is giving you side effects.

These feelings are understandable. But not taking medicine could mean that you will get sick again. This might mean that you miss school or even end up in hospital. It is important that you talk with your parents or caregivers, and your doctor about your concerns, rather than stopping medicines without letting them know. Sometimes you may be tempted to stop medicine because you are feeling better, but taking these medicines may be the very reason you are keeping good health.

How can I cope with IBD?

It is natural to be frustrated and perhaps feel "down" about having IBD. Embarrassment, anxiety about going out or doing activities such as sport are common feelings.

Travelling may be an anxious time. You may be forced to suddenly cancel planned events or occasions. It can affect your confidence and self esteem. It is important to share these concerns with your parents or caregivers, so that they are able to support you as much as possible. At school, you may be worried about having to go to the toilet frequently and others noticing that you are taking medicine. You may ask yourself how you will manage exams, especially if you have had to miss school because of ill health. IBD may make you tired or stomach aches may make it difficult to concentrate on school work and get through a school day.

It is important to discuss your disease with your teacher so that leaving class can be done discreetly and without fuss. The teacher will understand if you have not managed to keep up with school work or that for short periods, you are not able to do sports or P.E. It is also a good idea to talk to your close friends about your disease. Giving them simple explanations helps to reduce embarrassment, gives them some understanding of how you might feel, and also makes them more comfortable when they are with you, going out or playing sport. Friends are an important support for you, so it is important to keep in contact with them. Also, try to keep yourself occupied – listening to music, reading a book or some physical exercise are helpful things to do.

It is important to remember that while you might have a chronic illness, most of the time you will be able to do most of the things that normal teenagers do. But there will be times when the disease may get worse (you may have flare ups), and this is something that you will learn to live and cope with. Remember that you are not alone with your disease. Talk about your feelings with your parents or caregivers, and close friends.

What about my family?

Understandably your family will be worried about you. It is not unusual for the families of individuals with chronic illnesses to become overly anxious about their loved ones and it may take them time to come to terms with their emotions towards your illness.

Remember that there was nothing you or they have done that brought this about, nor was there anything that you or they could have done to avoid you getting IBD. Make sure that you talk freely with your family about your feelings.

While your family will want to take care of you, there will come a time when you will need to take responsibility for yourself. It is natural to want to be self independent. It will be up to you to take your medication regularly, be familiar with the doses, make sure you do not run out of medicine, and attend regular visits to your specialist or doctor. You will need to learn to take note of how your body functions normally and know when your IBD is getting worse, so that changes in treatment can be made to get you better without too much delay.

Is there ongoing research into IBD?

There is a lot of research going on in the field of IBD. Scientists are actively studying the genetic profile of patients with Crohn's disease to see if they can predict how the disease behaves, and to possibly select the most appropriate medicine. Medicine trials are conducted frequently to work out which medicine or medicine combinations and what dose works best in certain situations. Newer and better medicines are constantly being researched and developed, hopefully with less side effects, so that IBD can be better controlled.

What about the future?

Generally, you will be able to have a reasonably normal life. There will be challenges in the beginning adjusting to IBD, but with time and the advice and support of your doctor, family and friends, you should be able to do all the things that teenagers do. There will be ups and downs, as with most chronic illnesses, but you will learn to live with your IBD. It is important to make the most out of life and be positive about it.

How do I access support and information?

Your doctor, IBD nurse and the Crohn's and Colitis Support Group can provide support and information on resources available such as useful books, websites and health services.

CCNZ

Crohn's and Colitis New Zealand is a charitable trust whose aims are to provide support, advice and information to interested individuals and people who have Crohn's disease or ulcerative colitis and their families and caregivers, and educational material to medical professionals and organisations within New Zealand.

CCSG

There are a number of Crohn's and Colitis Support Groups (CCSG's) around the country. See the back cover for contact details.

Acknowledgements

Thank you to Dr Simon Chin, Paediatric Gastroenterologist and the Department of Paediatric Gastroenterology, Starship Children's Health, Auckland, for writing this booklet.

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Crohn's & Colitis Support Groups

To find your local support group details and to access the Crohn's & Colitis NZ Facebook please refer to;

www.crohnsandcolitis.org.nz

Toilet Map

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September 2010