

**gastro
central**

A teen's guide
to inflammatory
bowel disease



Start your journey towards
understanding inflammatory bowel disease

janssen
PHARMACEUTICAL COMPANIES OF
johnson & johnson



IMPORTANT NOTICE:

The information in this booklet does not replace any of the information or advice provided by a medical practitioner and other members of your healthcare team. If you have any further questions about inflammatory bowel disease, please contact your doctor.

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INTRODUCTION

You may have just found out that you have inflammatory bowel disease (IBD). You are probably worried, as you may never have heard of this illness before. This booklet is designed to ease your worries and help you learn more about your illness and how you can carry on enjoying your daily life.

It can be difficult to deal with inflammatory bowel disease as a teenager but you are not alone, and with a little help you will be able to carry on with your everyday life. It is important to talk to your doctor and ask any questions you may have about your illness or how it might affect your life.

This booklet has been prepared to help you:

- Learn about your illness
- Understand what treatments are available
- Get some real-life tips for your day-to-day life.

We hope you find this booklet useful. If there is anything you don't understand, please ask your parents or your healthcare team for further help.

Dealing with inflammatory bowel disease as a teenager can be challenging. The good news is that you're not alone.



Here to help

WHAT IS INFLAMMATORY BOWEL DISEASE?

Inflammatory bowel disease is the name given to a group of illnesses including Crohn's disease and ulcerative colitis. These illnesses, the two most common types of inflammatory bowel diseases, affect around 85,000 people in Australia and this number is expected to exceed 100,000 by 2022.¹ In New Zealand, an estimated 20,000 people are living with IBD, with this figure expected to increase by 2026.²

Do not confuse inflammatory bowel disease with irritable bowel syndrome as they are quite different! Inflammatory bowel disease can develop at any age, though most people get this illness during their 20s-30s.³

People with inflammatory bowel disease have some periods, known as 'remission', when the illness seems to disappear (remission can last for months or even years) and other periods, known as 'flare ups', when the illness seems to get worse.

Inflammatory bowel disease affects certain parts of your digestive tract, the system of organs that normally 'digest' or break down the food you eat to extract the nutrients you need to stay healthy. Ulcerative colitis only affects the colon (also called the large intestine) whereas Crohn's disease can affect any part of the digestive tract (from the mouth to the anus).

Around 85,000 people in Australia and 20,000 people in New Zealand have IBD.^{1,2}

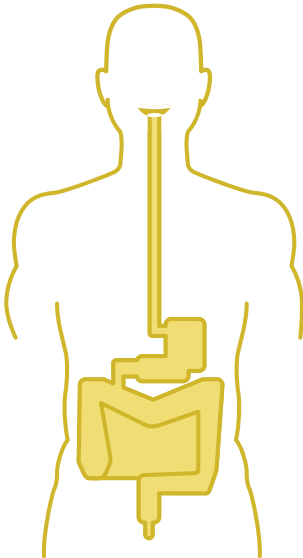
Crohn's disease

In Crohn's disease, the full thickness of the wall of the intestine becomes sore, inflamed and swollen. Crohn's disease can cause abdominal pain, diarrhoea, fever and loss of weight. Some people may even have symptoms that occur outside of the intestinal tract such as pains in the knees, ankles or other joints.

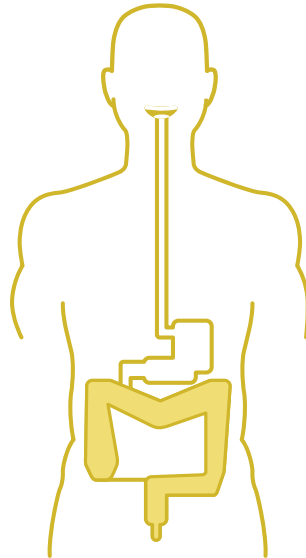
Ulcerative colitis

Patients with ulcerative colitis have sores called ulcers that form in the inner lining of the large intestine. It normally affects the lower large intestine and rectum but sometimes may involve the entire large intestine. People suffering with ulcerative colitis get diarrhoea often mixed with blood, abdominal pain and may occasionally present with other symptoms not related to the gastrointestinal tract such as pain in the joints.

Areas of the gastrointestinal tract affected by inflammatory bowel disease



Crohn's disease



Ulcerative colitis

Symptoms

The symptoms of Crohn's disease and ulcerative colitis can be very similar and vary depending on how severe your illness is. Most people respond well to treatment and never develop more severe complications. However, serious complications can occur over a short period of time and normally require immediate medical attention.

Causes

Inflammatory bowel disease is an autoimmune-related condition, meaning that the immune system, which normally defends the body against disease, attacks the body's own tissues. However, why this happens is not yet known. Some people believe that the immune system may actually be damaging the intestine and causing inflammation (a normal protective biological process in response to harm). Other researchers think that viruses or bacteria may be causing the inflammation.

Inflammatory bowel disease is not contagious (you can't catch it from someone else) and is not caused by nerves or certain types of food. It is a combination of your genetics, environmental and lifestyle factors that may trigger your illness.

The most common symptoms of inflammatory bowel disease

- Fever, fatigue, low iron
- Mouth ulcers
- Skin rash
- Stomach pain
- Weight loss
- Diarrhoea, blood, mucus

Crohn's disease

- Diarrhoea
- Stomach ache
- Weight loss
- Mouth ulcers
- Swelling of the abdomen
- Perianal lesions

Ulcerative colitis

- Diarrhoea, often with some blood
- Urgency to go to the toilet

Key causes



163 genetic locations have been identified which increase the risk of inflammatory bowel disease.⁴



Smoking makes it at least twice as likely for you to develop Crohn's disease.⁵



Eating too much unsaturated fat may increase the chance of you developing ulcerative colitis.⁶

Medical tests

Your doctor will likely carry out a series of tests to work out exactly what your illness is. These tests may include:



**Physical examination
of your abdomen**



Weight



**A questionnaire about
your health**



Colonoscopy



Imaging



Blood tests



Stool sample



Temperature



After these tests, your doctor may send you to see other medical specialists who will help look after you and your illness. It may take a couple of months until your doctor can confirm what illness you are suffering from. Some tests will be repeated regularly, even when you are taking medication, to check that your illness is improving.

Your healthcare team responsible for looking after your illness and your overall wellbeing may include a:









- Gastroenterologist
- Colorectal surgeon
- General practitioner
- Nurse
- Radiologist
- Dietitian
- Psychologist.

TREATMENT OPTIONS

There are multiple treatments and surgeries available to treat the symptoms of inflammatory bowel disease, but given that this is a chronic illness, you may require lifelong treatment.

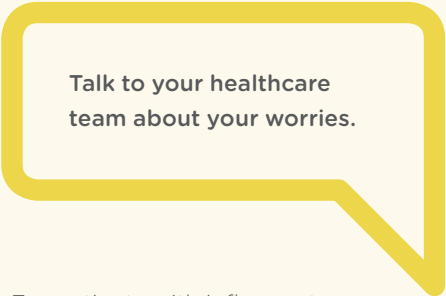
Treating inflammatory bowel disease depends on how severe your illness

is and whether you are in remission or experiencing a disease flare up. Your doctor will tell you about the medications available that are suitable for you. There are many different types of drugs for inflammatory bowel disease that are generally given in several different ways.

Drug class	When used	How given			
		Oral (by mouth)	Intravenous (into your vein)	Subcutaneous (under your skin)	Rectal (into your anus)
Anti-inflammatory drugs (to reduce inflammation)	<ul style="list-style-type: none">• For mild to moderate illness• For relapse				
Corticosteroids (to block inflammation and allergic responses)	<ul style="list-style-type: none">• For moderate to severe illness• To treat flare ups• For short-term use				
Immunosuppressants (to suppress the immune system)	<ul style="list-style-type: none">• For moderate to severe illness• For ongoing treatment				
Biologics (to target proteins involved in inflammation)	<ul style="list-style-type: none">• For patients who do not respond to other drugs				

Medications can sometimes cause unpleasant side effects; your doctor will tell you about these. Always ask if you have any questions or if you don't understand something that your doctor has told you. Always talk to your doctor before taking food supplements and take your medication as your doctor has prescribed to avoid a flare up.

Sometimes, if your illness gets worse, you may need to go into hospital; for example, if you have severe bleeding or severe diarrhoea. Your doctor will manage this and will monitor your illness closely to help you recover.



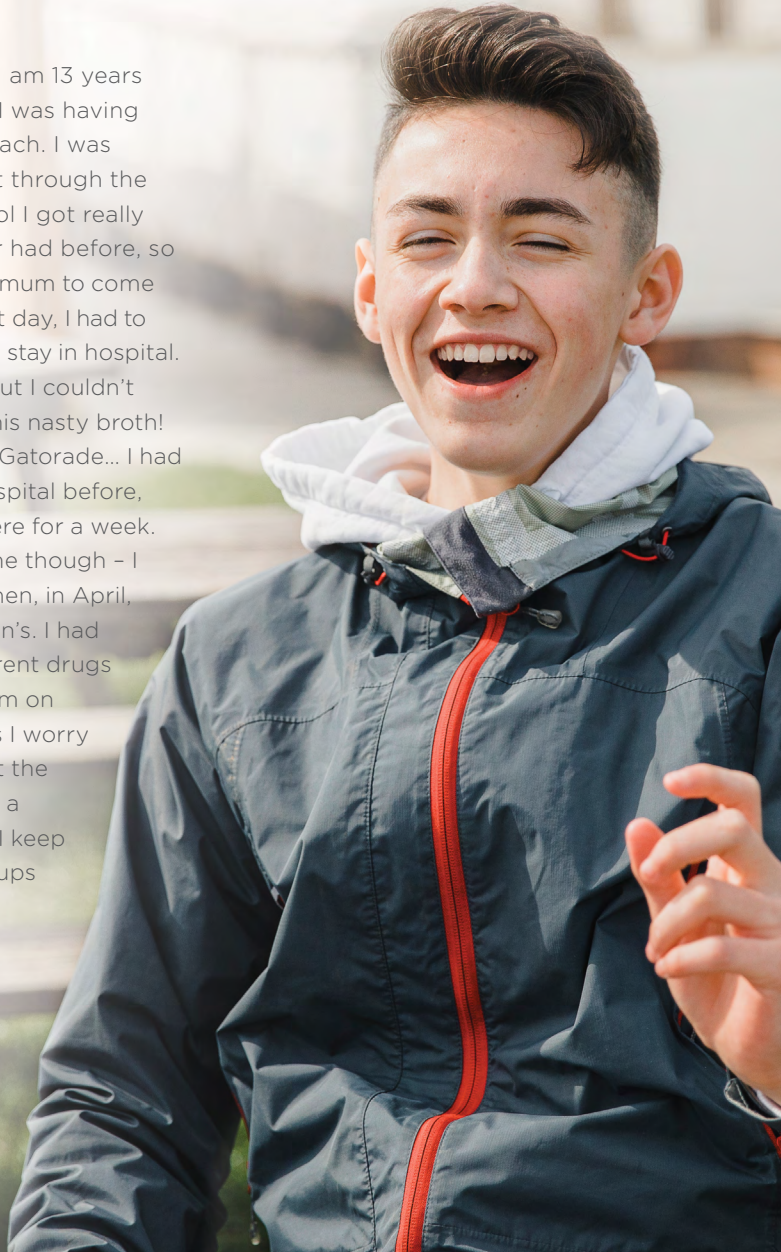
Talk to your healthcare team about your worries.

For patients with inflammatory bowel disease who do not respond well to medication, surgery is sometimes required to remove the diseased digestive area. Your doctor will talk to you about this if surgery is necessary to treat your illness.

TOM'S STORY:

LIVING WITH CROHN'S DISEASE

My name is Tom and I am 13 years old. Last September, I was having bad pains in my stomach. I was always tired and slept through the day. One day at school I got really bad pains that I never had before, so my teacher called my mum to come and get me. Later that day, I had to pack a bag and go and stay in hospital. I had a good doctor but I couldn't eat so I had to have this nasty broth! And drank water and Gatorade... I had been in and out of hospital before, but this time I was there for a week. The hospital helped me though - I had many tests and then, in April, I found out I had Crohn's. I had to have all these different drugs at the start but now I'm on a biologic. Sometimes I worry that I won't be OK but the doctor says I can lead a normal life as long as I keep having regular check ups and treatment.



TIPS FOR AN ACTIVE LIFE

Some things to think about when considering your daily life with inflammatory bowel disease:

Involving your family and friends

It is up to you who you tell about your condition. A lot of people feel embarrassed, but really it is nothing to feel bad about. Decide how best you can tell the people you are close to and don't let your illness take control of you or your life.

Social life

Deciding whether or not to go out when you're feeling sick can be a really tough choice. The truth is that you can't stop diarrhoea or stomach cramps so sometimes you just have to deal with it. You don't have to decide alone – talking to a parent, sibling or friend can really help you to figure out the best choice and prepare you for an outing. Try to do as many things as possible so you don't feel isolated from your friends and your social circle.

Playing sport

Playing sport may not be an option for you right now because of your illness. However, there may be something else you can do to keep you involved with your team and sport; for example, help the coach and keep track of scores and records. One low-impact exercise that does seem to be popular with young people suffering from inflammatory bowel disease is swimming. Swimming is a great all-round activity, but it's also one sport that most people can still do even when they have stomach pain.

Handy hint: Make yourself a rice sock for comfort when your stomach's hurting. Take a long sock, fill with rice and tie the end in a knot. Heat in the microwave for a great heating pad for when you have a stomach ache.

Food and nutrition

When you are first diagnosed, it's normal to feel worried about what you can and can't eat. Keep in mind that learning to eat what is right for you and your illness takes some time. Try to be patient and test out lots of different foods along the way. There may be some foods you shouldn't eat – ask your parents, doctor and dietitian if there are any tasty substitutes for foods you have to go without. Pay attention to how certain foods (e.g. heavy carbohydrates such as pasta, sugary and spicy foods) make you feel. Keeping a diary may help you keep track of foods that make you feel unwell.

Bathroom dash

Everyone has to dash to the bathroom sometimes! Be prepared as much as possible and also realise that, now and again, you may have an accident if you don't make it to the toilet in time.

Handy hint: Pack a change of clothes to carry with you in case of a bathroom emergency.

School life

Talk to the teachers so they understand what your illness is and how it might affect your needs at school. Carry a letter from your doctor that explains the drugs you take (dose and time that they should be given and potential side effects) and work with school staff to set up a system for taking your medication that easily fits into your school day.

Handy hint: Carry your doctor's and healthcare team's contact information with you at all times!

Feeling sad?

Your doctor and healthcare team care about your complete wellbeing and not just what goes on with you physically. If you're feeling stressed, depressed, having trouble at school with your friends, or even your parents, talk to your healthcare team. Your team can help you deal with the emotions your illness may cause as well as looking after your physical health.

If you need to talk to someone immediately,

**call Lifeline on 13 11 14 in Australia
or 0800 543 354 in New Zealand.**



OLIVIA'S STORY:

LIVING WITH ULCERATIVE COLITIS

I'm Olivia and I'm 16 years old. I was diagnosed with ulcerative colitis when I was 7. Back then, I worried and cried a lot, as I was ashamed that I had really runny diarrhoea. One day, my mum noticed that my stool had blood in it and took me to the doctor. I had also lost weight and needed the toilet a lot even if I couldn't go. I went to the hospital and drank one of those horrible drinks before they did several tests to work out what was wrong with me. It took a while and my mum was really worried as she also had some bowel problems a while ago. The doctor said it was ulcerative colitis – I didn't even know what that was! I was scared to go to school and tell my teachers but the tablets they gave me helped a lot.

Now I'm used to taking my medication every day and I do all the things my friends do. I was worried that having ulcerative colitis might affect me at school and time with my friends but I only have to think a bit more about my diet now and again.



RESOURCES

GastroCentral Australia and New Zealand

GastroCentral.com.au | **GastroCentral.co.nz**

This website is an informative portal, created by Janssen, about inflammatory bowel disease for patients and healthcare professionals. The patient portal provides information and videos to help you understand your condition and treatment journey. Shared patient experiences, the latest news in the field and other useful links and resources are also available.



Use the QR code to access
GastroCentral Australia



Use the QR code to access
GastroCentral New Zealand

Crohn's and Colitis Australia*

crohnsandcolitis.com.au 🇦🇺

Provides information on Crohn's disease and ulcerative colitis and support programs that provide education, advocacy, counselling, awareness and fundraising for research.

IBD Support Australia*

ibdsupport.org.au 🇦🇺

Resources include an online forum where you can share your experiences and learn from others who are also living with inflammatory bowel disease.

Beyond Blue*

beyondblue.org.au 🇦🇺

Provides information about depression and its symptoms.

Crohn's and Colitis New Zealand*

crohnsandcolitis.org.nz 🇳🇿

Crohn's and Colitis New Zealand is a charitable trust which aims to provide support, advice, resources and information about Crohn's disease and ulcerative colitis.

Living Beyond IBD

livingbeyondibd.co.nz 🇳🇿

Provides you with easy to understand information on IBD, its impacts and practical tips on how to manage it in everyday life. The website also includes videos of people sharing their experiences of living with IBD.

*The websites above are provided for information only. The websites may contain content that the sponsor of this booklet does not endorse. The sponsor is not responsible for the validity of the information on these sites. The websites may contain or link to information that is not consistent with the way medicines are used in Australia or New Zealand. Always discuss any issues relating to your treatment with your doctor or a member of your healthcare team.

NOTES

Use this space to write down the name of your doctor and nurses or write down any questions or concerns you may have about your condition.

References: **1.** Crohn's and Colitis Australia. About Crohn's & Colitis. Available at: www.crohnsandcolitis.com.au/about-crohns-colitis (accessed June 2021). **2.** Crohn's and Colitis New Zealand. Reducing the growing burden of inflammatory bowel disease in New Zealand. Available at: <https://static1.squarespace.com/static/59c9a99bf14aa1faebdc9469/t/5b5a399103ce6423d9189069/1532639643871/CCNZ+Burden+of+Disease+Report.pdf> (accessed June 2021). **3.** Duricova D *et al.* *J Crohns Colitis* 2014;8:1351–61. **4.** Jostins L *et al.* *Nature* 2012;491:119–24. **5.** Lakatos P *et al.* *World J Gastroenterol* 2007;13:6134–39. **6.** Ananthakrishnan A. *Dig Dis Sci* 2015;60:290–98.