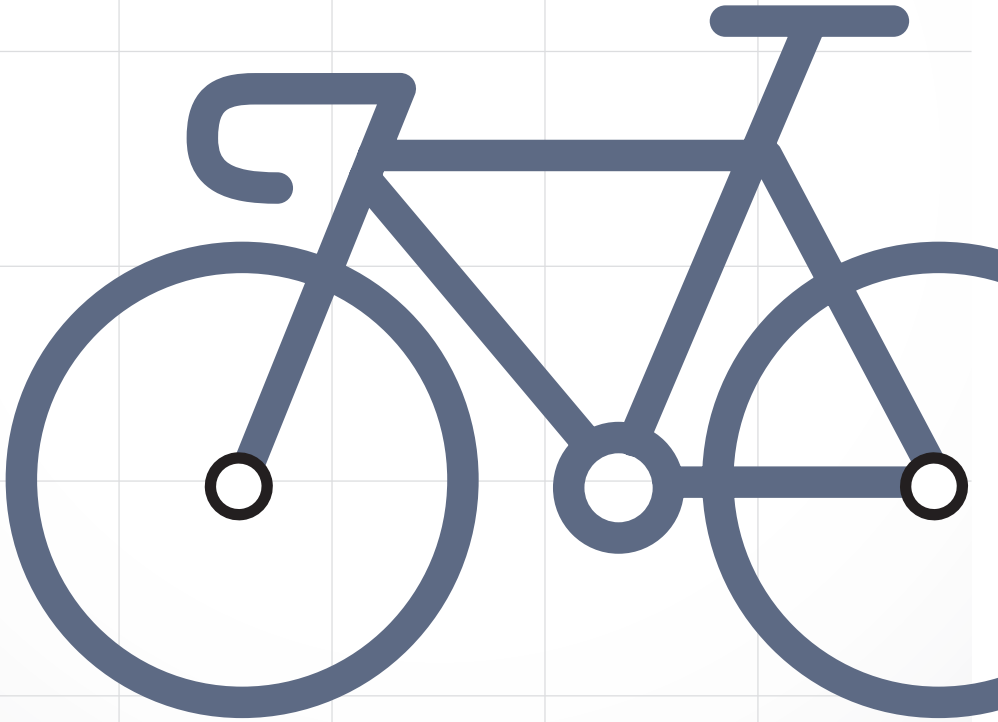


# A PARENT'S GUIDE TO INFLAMMATORY BOWEL DISEASE



START YOUR JOURNEY TOWARD UNDERSTANDING  
INFLAMMATORY BOWEL DISEASE

**GASTRO** CENTRAL

**IMPORTANT NOTICE:**

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

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# INTRODUCTION

You may have just found out that your child has inflammatory bowel disease. 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 child's condition and how you can help him/her enjoy a fulfilling life.

It may be difficult for your child to deal with inflammatory bowel disease but with a little help, he/she should be able to carry on normally with everyday life. It is important to communicate with your child and talk to his/her doctor so you can understand your child's condition and support him/her through their treatment.

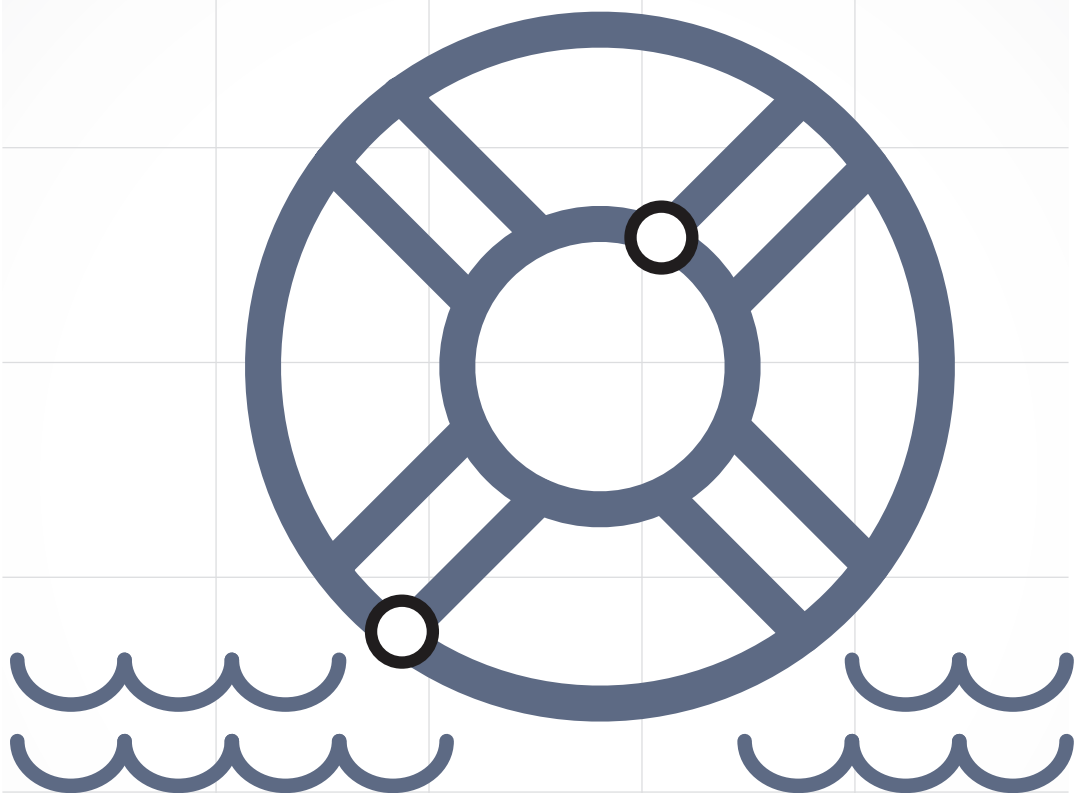
## **DEALING WITH INFLAMMATORY BOWEL DISEASE AS A CHILD OR TEENAGER CAN BE CHALLENGING.**

This booklet has been designed to help you:

- **Learn about your child's illness**
- **Understand what treatments are available for inflammatory bowel disease**
- **Learn some real-life tips to help your child with their day-to-day life.**

Remember that the information provided in this booklet is general in nature and is not intended to replace professional medical advice.

We hope you find this booklet useful in understanding your child's condition.



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 are the two most common types of inflammatory bowel diseases, and affect around 80,000 people in Australia, and this number is expected to exceed 100,000 by 2022.<sup>1</sup> Do not confuse inflammatory bowel disease with irritable bowel syndrome as they are quite different and need to be treated accordingly. Inflammatory bowel disease can develop at any age, though most people get this illness during their 20s-30s.<sup>2</sup>

## AROUND 80,000 PEOPLE IN AUSTRALIA HAVE INFLAMMATORY BOWEL DISEASE.<sup>1</sup>

Ulcerative colitis only affects the large intestine (also called the colon) whereas Crohn's disease can affect any part of the digestive tract (from the mouth to the anus). People with inflammatory bowel disease experience 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.

The causes of inflammatory bowel disease are not entirely known, however, there are a number of treatment options available. As inflammatory bowel disease is a life-long condition, it is important that you and your child work with the doctor to find the treatment that works best for your child and allows him or her to lead a fulfilling life.

## Crohn's disease

Crohn's disease is a chronic (ongoing) condition that is characterised by inflammation of the digestive tract. The inflammation can affect any part of the digestive tract from the mouth to the rectum but commonly occurs in the lower part of the small intestine (ileum) or the caecum (part of the large intestine).

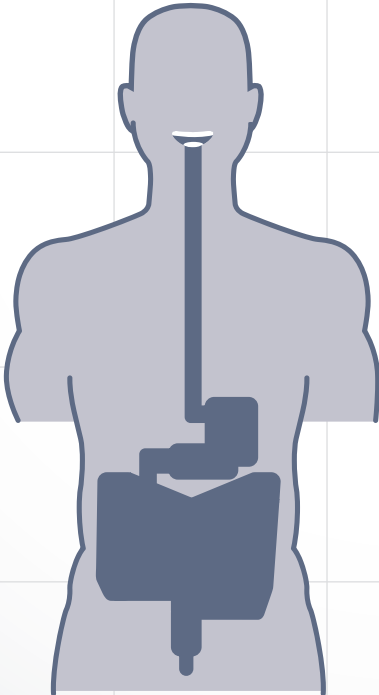
In Crohn's disease, the wall of the intestine becomes sore, inflamed and swollen. Crohn's disease sometimes involves other parts of the digestive tract too, such as the duodenum, the mouth and the anus. Crohn's disease can cause abdominal pain, diarrhoea, fever and loss of weight. Some people even have pains in their knees, ankles and other joints.

## Ulcerative colitis

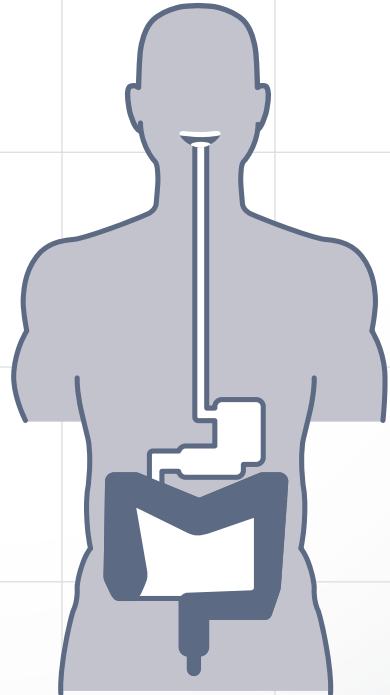
Ulcerative colitis involves inflammation of the superficial layers or lining (called the mucosa) of the large intestine, usually located in the lower large intestine and rectum but sometimes may involve the entire large intestine. It is sometimes referred to as ulcerative proctitis (or just proctitis) if only the rectum is involved. When the entire large intestine is involved it is called pan-colitis.

Ulcers, or tiny open sores, form on the surface of the lining where inflammation has damaged the tissue, and these ulcers may bleed. The inflamed lining also produces mucus, which can sometimes contain pus. People suffering with ulcerative colitis experience diarrhoea, often mixed with blood, abdominal pains and occasionally pain in their 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. While the exact cause of inflammatory bowel disease is currently unknown, it is thought to be caused by a complex interplay between genetic, environmental factors and immune dysregulation. The result is an immune system that promotes inflammation in the digestive tract. In these areas of inflammation, immune cells (lymphocytes) are activated and chemical messengers (called cytokines) are produced.

**Lymphocytes are types of white blood cells that are involved in recognising and responding to infection and inflammation. Cytokines are chemical messengers that are released from lymphocytes and regulate the body's response to disease and infection. Some cytokines reduce inflammation while others interact with the immune system to promote inflammation.**

**Conditions such as psoriasis, rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis, Crohn's disease and ulcerative colitis are associated with an overproduction of lymphocytes and cytokines that promote inflammation and can result in tissue damage.**

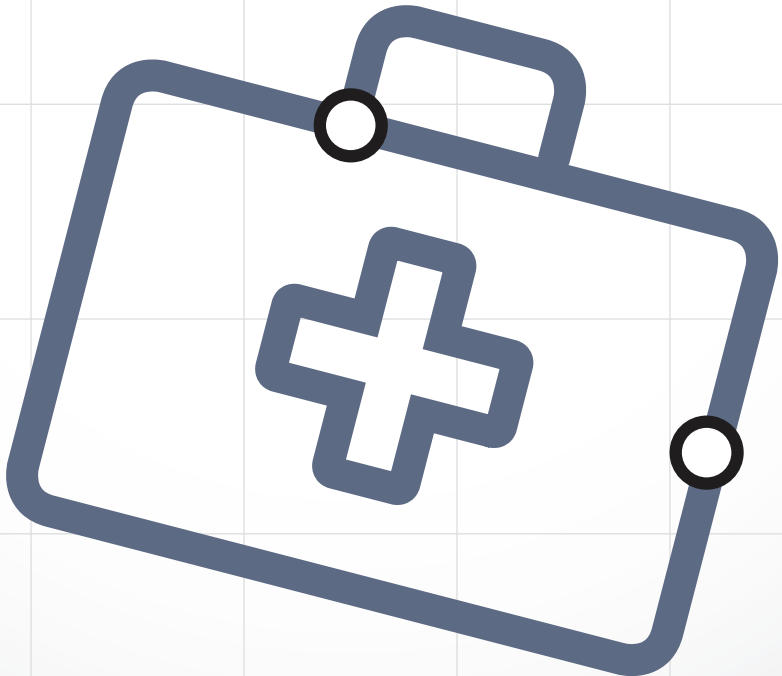
One of these cytokines is a protein called tumour necrosis factor alpha (TNF- $\alpha$ ). TNF- $\alpha$  plays a central role in orchestrating an immune response against infection and tissue damage, which results in inflammation. The immune system is then counterbalanced by other cytokines that normalise the inflammatory response. In conditions such as inflammatory bowel disease, the inflammatory response is magnified due to an over expression of inflammatory proteins such as TNF- $\alpha$ , interleukins 12 and 23 (IL-12 and IL-23), and integrins, and is responsible for increasing inflammation of the tissues lining the intestines. This inflammation results in the symptoms associated with the disease.

Inflammatory bowel disease is not contagious and is not caused by nerves or certain types of food. Some triggers for inflammatory bowel disease may include a genetic tendency, environmental and lifestyle factors, and exposure to certain bacteria or viruses.



## The most common symptoms of inflammatory bowel disease

CROHN'S DISEASE	ULCERATIVE COLITIS
<p>DIARRHOEA</p> <p>STOMACH ACHE</p> <p>WEIGHT LOSS</p> <p>INFLAMMATION IN THE MOUTH</p> <p>SWELLING OF THE ABDOMEN</p> <p>PERIANAL LESIONS</p>	<p>DIARRHOEA, OFTEN WITH SOME BLOOD</p> <p>URGENCY FOR THE TOILET</p>

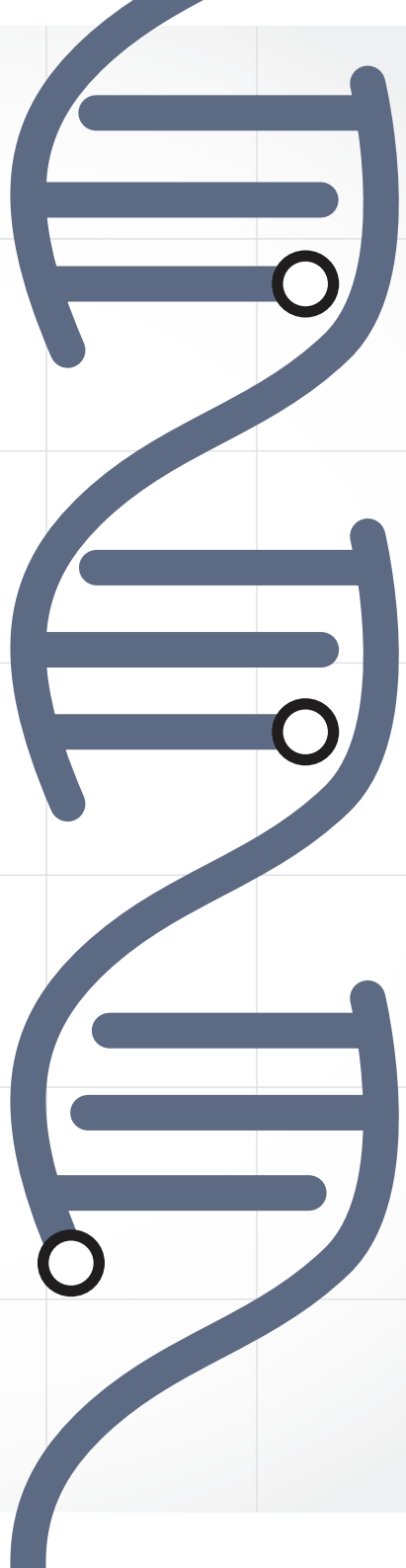


## The role of genes and family history

While there is no clear pattern of inheriting inflammatory bowel disease, gene markers appear to be an important contributor in some people who develop the disease. In people with inflammatory bowel disease mutations have been found in some genes that play a role in controlling the levels of inflammation in the digestive tract.

An international study including over 75,000 patients with ulcerative colitis or Crohn's disease identified 163 distinct genetic locations that influence the risk of either disease.<sup>3</sup> Genetic links to inflammatory bowel disease within families have been studied.

The results from a study of identical twins showed that if one twin has Crohn's disease, there is a 36% chance that the other twin will have Crohn's disease too.<sup>4</sup> There is also a chance of another family member being diagnosed with Crohn's disease.<sup>5</sup>



## Environmental factors

A genetic tendency in an individual alone is not sufficient for that person to develop inflammatory bowel disease. Additional factors, including environmental factors, may also play a role.

ENVIRONMENTAL FACTOR	LINK TO CROHN'S DISEASE
<b>SMOKING</b>	Smoking is associated with an increased risk of developing Crohn's disease <sup>6</sup>
<b>DIET</b>	In some studies, a high sugar diet has been associated with an increased risk of developing inflammatory bowel disease, particularly Crohn's disease. There is a possible link between high levels of fat and the development of Crohn's disease <sup>7</sup>
<b>BREASTFEEDING</b>	Being breastfed as a child may protect against inflammatory bowel disease <sup>8</sup>
<b>CHILDHOOD INFECTIONS</b>	An absence of infections during childhood may also increase the possibility of developing inflammatory bowel disease <sup>8</sup>
<b>APPENDECTOMY (removal of appendix)</b>	Removing the appendix increases the risk of developing Crohn's disease <sup>9</sup>

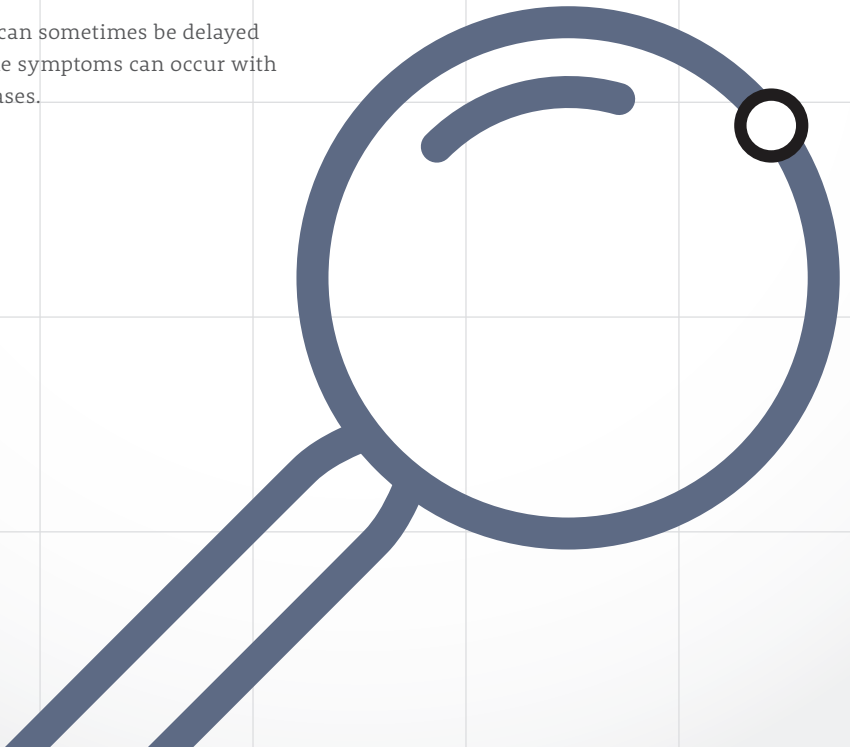
## Diagnosis

Diagnosis of inflammatory bowel disease, as well as disease extent and severity, can be confirmed based on a physical examination, patient history and a variety of clinical tests such as blood tests, stool examination, endoscopy, biopsies and imaging studies.

Your child's doctor plays an important role in recognising the signs of inflammatory bowel disease and facilitating an early diagnosis. They may perform several tests before referral to an appropriate specialist. It is common for 5–9 months to elapse from the first onset of symptoms until a positive diagnosis of Crohn's disease is made.<sup>10</sup>

Diagnosis can sometimes be delayed as the same symptoms can occur with other diseases.

As inflammatory bowel disease is a chronic condition, it requires management by a multidisciplinary healthcare team including gastroenterologists, colorectal surgeons, general practitioners, nurses, radiologists, dieticians and psychologists.



## Key statistics



7 in every 2,000 Australians have inflammatory bowel disease.<sup>11</sup>



Up to 14% of individuals with Crohn's disease also have a family history of the disease.<sup>5</sup>



Smoking is associated with an increased risk of developing Crohn's disease.<sup>6</sup>

# TREATMENT OPTIONS

Inflammatory bowel disease is a chronic illness but treatments are available to help people live a fulfilling life. Your child can expect to take medications for the rest of his or her life. Management of inflammatory bowel disease depends on the extent of the intestines affected and the severity of the inflammation. Your child's doctor will work closely with you and your child to decide which treatments are most suitable.

## Medication

The goal of medication is to induce and maintain remission and to improve quality of life. Several drug types for single or combination therapy are available for the treatment of inflammatory bowel disease. Other drug classes may also be given to help relieve pain, diarrhoea or infection. Depending on the severity of your child's condition, their doctor may recommend a single or combination medication.

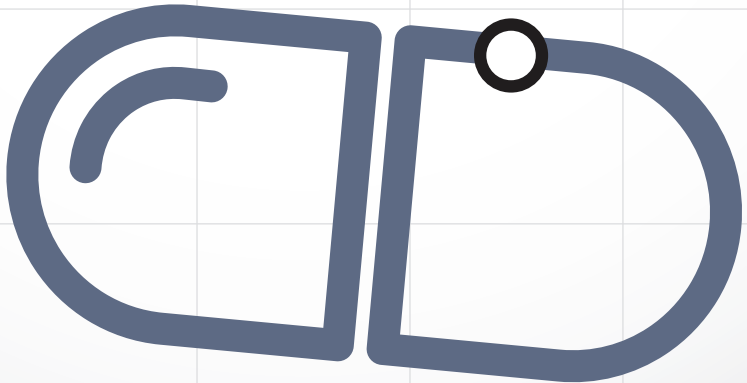
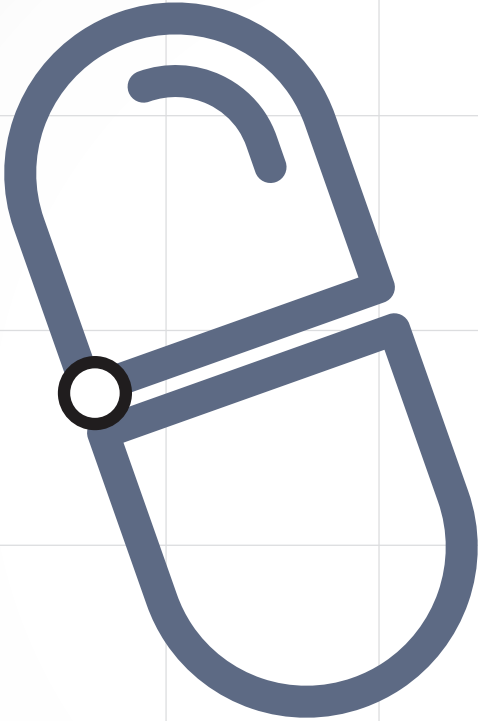
All medications can have side effects and it is important to discuss the risks and benefits of any treatment with a doctor. Always encourage your child to talk with their doctor about any concerns they have about the medications they are prescribed, or if they experience any side effects. Additionally, consult their doctor before using dietary supplements as part of a treatment, and always make sure your child takes medications as prescribed, as suddenly stopping treatment may cause a flare up.

TREATMENTS ARE  
AVAILABLE TO  
HELP PEOPLE LIVE  
A FULFILLING LIFE.



## ANTI-INFLAMMATORY DRUGS

When treating mild to moderate inflammation, doctors often prescribe the class of drugs known as aminosalicylates, which contain 5-aminosalicylic acid (5-ASA). 5-ASAs are given orally or rectally depending on the location of the inflammation in the large intestine. Most people with mild or moderate inflammatory bowel disease are treated with these drugs first. This class of drugs is also used in cases of relapse. These drugs can help ease symptoms, induce and maintain remission, and prevent flare ups.





## CORTICOSTEROIDS

Corticosteroids, also known as steroids, may be used to treat moderate to severe inflammatory bowel disease or to treat patients who do not respond to 5-ASA drugs.

Steroids are naturally produced in the body and are important for normal bodily function. Chemical corticosteroids are potent anti-inflammatory agents that block the production of substances (such as cytokines) that promote inflammation or trigger allergic responses. They are used to treat flare ups and to relieve abdominal pain and tenderness, and can also improve appetite and your sense of wellbeing. Corticosteroids can be given orally, intravenously or rectally depending on the location of the inflammation. These drugs can cause side effects such as weight gain, acne, facial hair, high blood pressure, diabetes, mood swings, bone mass loss and an increased risk of infection. For this reason, they are not recommended for long-term use.

## IMMUNOSUPPRESSANTS

Immunosuppressants (or immunomodulators) are generally prescribed when 5-ASAs or corticosteroids have failed, and for more moderate to severe disease states. They are also used to prevent or reduce corticosteroid dependence in inflammatory bowel disease. Immunosuppressants control inflammation by blocking the immune reaction and therefore maintain disease remission. They are administered orally. As immunosuppressants are slow acting, they are not useful for inducing remission – it may take up to 6 months for immunosuppressants to have an effect.<sup>12</sup>

## ANTIBIOTICS

Antibiotics are generally used to treat active flare ups and to prevent and fight infections. Some broad-spectrum antibiotics such as metronidazole and ciprofloxacin are used to treat any underlying infection. For some people, a bacterium is involved in the development and persistence of inflammation in inflammatory bowel disease. To target this bacterium, doctors will prescribe specific antibiotics.

## **BIOLOGICS**

Biologic response modifiers (biologics) work by blocking the immune system's production of proteins that intensify inflammation such as TNF- $\alpha$ , IL-12 and IL-23, and integrins. Biologics can only be prescribed by a gastroenterologist, are administered intravenously or subcutaneously and are generally only offered once a patient has failed to improve on standard therapy.

## **Hospitalisation**

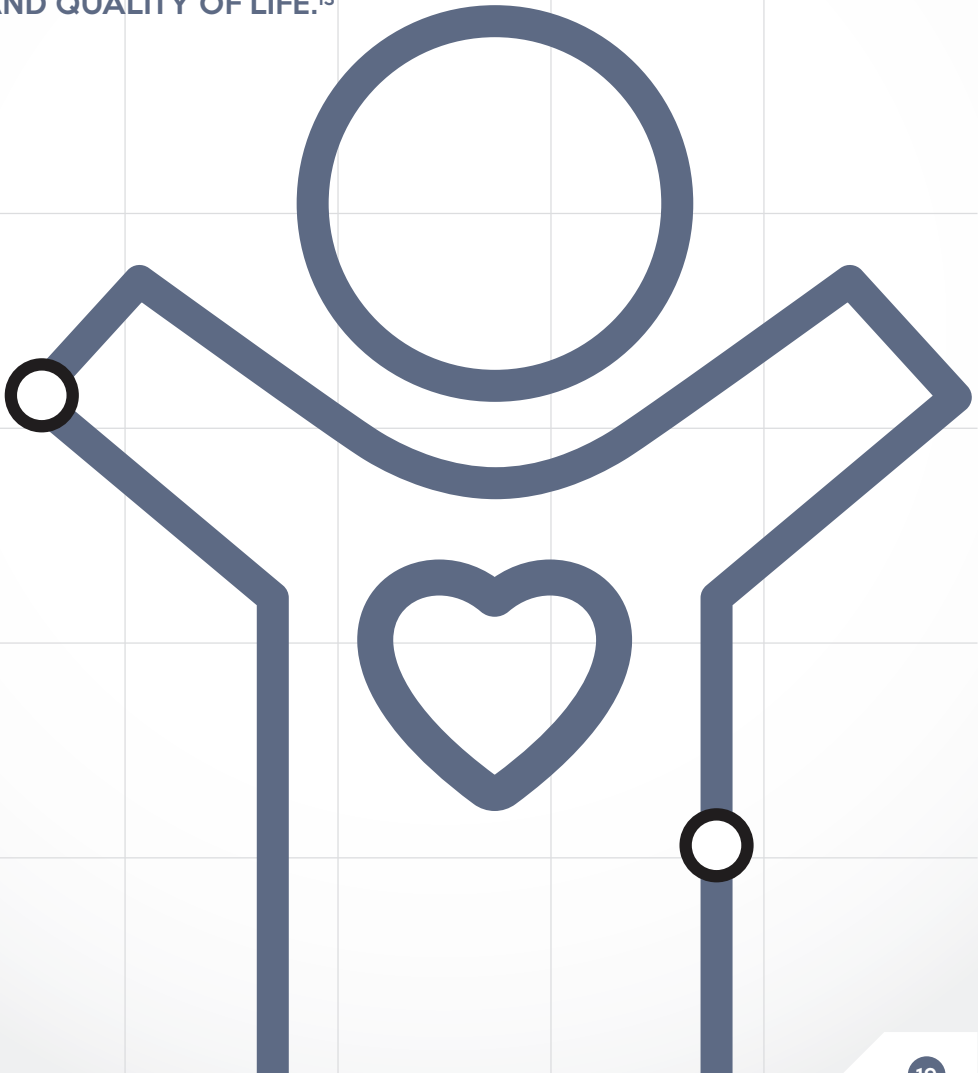
Occasionally, symptoms may be severe enough that hospitalisation is required, for example, if a person has severe bleeding or severe diarrhoea that causes dehydration. Your doctor will manage these complications which may include a special diet, nutrients supplemented through a vein, medications or surgery.

## **Surgery**

For some people with chronic severe inflammation, surgery may be necessary. Surgery is only considered after consultation with a gastroenterologist and a surgeon. Opinions are often sought from other healthcare professionals also. Although surgery is not a cure for Crohn's disease, it can relieve or correct complications that may occur. Technically, surgery cures ulcerative colitis; however, this treatment option is reserved for patients who do not respond to medical treatments as it may create additional problems.

**TALK TO YOUR CHILD'S HEALTHCARE TEAM ABOUT ANY CONCERNS YOU HAVE REGARDING MEDICATIONS OR IF YOUR CHILD EXPERIENCES ANY SIDE EFFECTS.**

**ACHIEVING EARLY REMISSION  
HAS A POSITIVE IMPACT ON  
NORMAL CHILD GROWTH  
AND DEVELOPMENT,  
LONG-TERM REMISSION  
AND QUALITY OF LIFE.<sup>13</sup>**



# TIPS FOR AN ACTIVE LIFE

Some tips and suggestions to consider when helping your child manage his/her inflammatory bowel disease on a daily basis:

## Involving family and friends

A lot of people feel embarrassed about having inflammatory bowel disease but you should help your child to understand that it is a medical condition and nothing to feel bad about. Decide how best you or your child can tell the people they are close to. Informing family and friends can help them to understand what your child is going through and provide necessary support.

## Social life

When your child is in remission or feeling well, it's important to encourage them to maintain a social life so that they don't feel isolated from their friends and social circle.

## Playing sport

Playing sport may not be an option for your child right now because of his/her illness. However, there may be other ways for him/her to stay involved with sport; for example, perhaps your child could help the coach and keep track of scores and records.

Encourage exercise as much as possible as it is great for relieving stress and enhancing mental health. 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 your child a rice sock for comfort when his/her tummy's hurting.**

**Take a long sock, fill with rice, tie the end in a knot and then heat in the microwave. It is a great heating pad for when your child has a stomach ache.**

## Food and nutrition

When first diagnosed, it's normal for your child to worry about what he/she can and can't eat. Eating a healthy, well-balanced diet from all food groups should be encouraged, as good nutrition is essential to the healing process. When the disease is active, many people lose their appetite or try to avoid eating in order to prevent further symptoms. Lack of adequate nutrition worsens the fatigue and eventually leads to weight loss – make sure your child eats appropriately to avoid these symptoms. Learning what is right for your child to eat may take some time. Some people find that certain foods aggravate their symptoms, such as diarrhoea. Some people also find it easier to eat a low-fibre diet without spicy foods. Your child's doctor or a dietician may be able to help with individual dietary advice.



## Bathroom dash

Everyone has to dash to the bathroom sometimes! Help your child be prepared for these occasions as much as possible, and also realise that now and again, he/she may have an accident if they don't make it to the toilet in time.

**HANDY HINT: Help your child pack a change of clothes to carry with them in case of a bathroom emergency.**

## School life

Talk to the teachers at your child's school so they understand your child's illness and how it might affect their needs at school. Make sure your child carries a letter from the doctor that explains the drugs they take and work with school staff to help your child set up a routine for taking their medication (dose and time it should be given, and potential side effects) that easily fits into his/her school day.

## Emotional wellbeing

Your child's doctor and healthcare team care about your child's complete wellbeing and not just the physical symptoms. If your child is feeling stressed, depressed or having trouble at school, encourage him/her to talk about it with you or with their doctor or other members of his/her healthcare team. The healthcare team are trained to help your child deal with the emotional aspects of inflammatory bowel disease, as well as looking after your child's physical health.

**ENCOURAGE YOUR CHILD TO GET IN TOUCH WITH OTHERS WHO HAVE INFLAMMATORY BOWEL DISEASE. FEELING CONNECTED WITH OTHERS WHO ARE GOING THROUGH THE SAME THING MAY MAKE A HUGE DIFFERENCE TO HOW YOUR CHILD FEELS.**



# RESOURCES

You may like to look at these websites for more information about inflammatory bowel disease. Ask your parent to read the information with you if you are not sure or write down some questions for your doctor.

## **Crohn's and Colitis Australia\*** **[www.crohnsandcolitis.com.au](http://www.crohnsandcolitis.com.au)**

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

## **IBD Support Australia\*** **[www.ibdsupport.org.au](http://www.ibdsupport.org.au)**

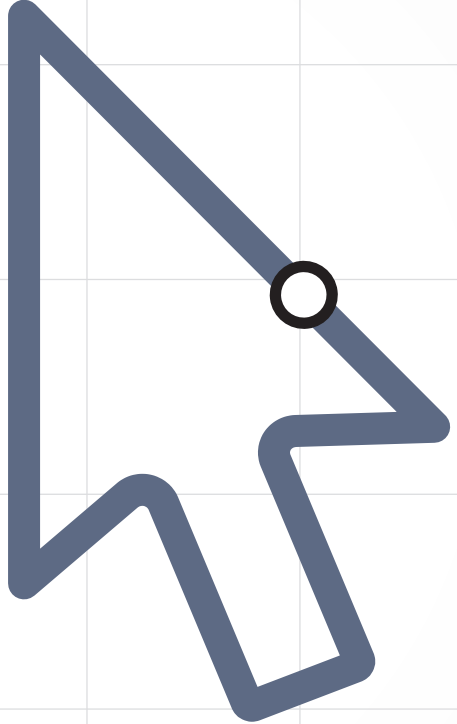
Resources include an online forum where you can share your own experiences and learn from others who are also living with inflammatory bowel disease.

## **Beyond Blue\*** **[www.beyondblue.org.au](http://www.beyondblue.org.au)**

Provides information about depression and its symptoms.

## **Gastro Central** **[www.gastrocentral.com.au](http://www.gastrocentral.com.au)**

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.



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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. Always discuss any issues relating to your treatment with your doctor or a member of your healthcare team.

**References:** 1. Crohn's and Colitis Australia. About Crohn's & Colitis. Available at [www.crohnsandcolitis.com.au/about-crohns-colitis](http://www.crohnsandcolitis.com.au/about-crohns-colitis) (accessed 20 March 2020). 2. Duricova D et al. *J Crohns Colitis* 2014; 8: 1351–1361. 3. Jostins L et al. *Nature* 2012; 491: 119–124. 4. Henderson P and Satsangi J. *Clinical Medicine* 2011; 11: 8–10. 5. Halme L et al. *World J Gastroenterol* 2006; 12: 3668–3672. 6. Lakatos P, Szamosi T and Lakatos L. *World J Gastroenterol* 2007; 13: 6134–6139. 7. Owczarek D et al. *World J Gastroenterol* 2016; 22: 895–905. 8. Molodecky N et al. *Gastroenterol Hepatol* 2010; 6: 339–346. 9. Segal A. *F1000Research* 2016, 5: 2510. 10. Fiorino G and Danese S. *Dig Dis Sci* 2016; 61: 3097–3098. 11. Studd C et al. *Gastroenterology* 2016; 31: 81–86. 12. Wilhelm S and Love B. *Clinical Pharmacist* 2016; 9: doi: 10.1211/CP.2017.20202316. 13. Guariso G and Gasparetto M. *World J Gastroenterol* 2017; 23: 5469–5485.