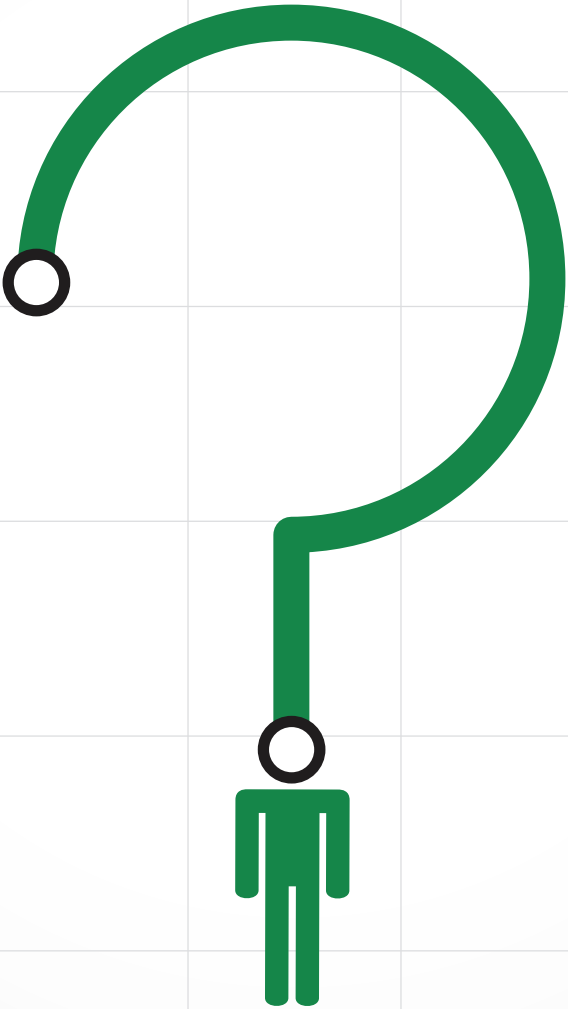
UNDERSTANDING CROHN'S DISEASE



START YOUR JOURNEY TOWARD UNDERSTANDING INFLAMMATORY BOWEL DISEASE

GASTRO CENTRAL

IMPORTANT NOTICE:

The information provided 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 Crohn's disease please contact your doctor.

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INTRODUCTION

Crohn's disease and ulcerative colitis, collectively known as inflammatory bowel disease, affect around 80,000 people in Australia and this number is expected to exceed 100,000 by 2022.[1]

Crohn's disease can affect any part of the digestive tract (from the mouth to the anus), whereas ulcerative colitis only affects the large intestine. In both conditions, people experience periods without symptoms (known as remission) and periods of greater inflammation and discomfort (known as flare ups).

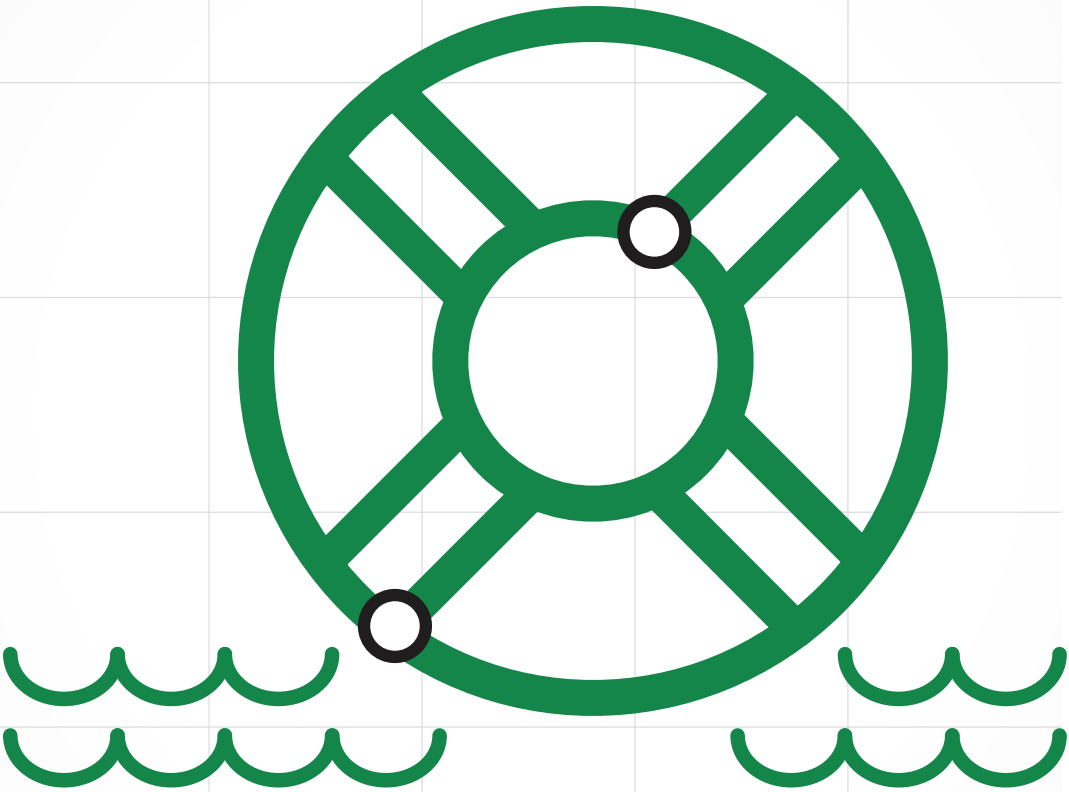
The causes of inflammatory bowel disease are not entirely known, but there are a number of treatment options available. With life-long conditions like Crohn's disease, it is important that you work with your doctor to find the treatment that works best for you.

This booklet has been prepared to help you:

- **Understand your condition and the different treatments available**
- **Work with your healthcare team to reduce symptoms**
- **Identify ways to assist you in managing your Crohn's disease and living a full and balanced 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 your journey with Crohn's disease.



HERE TO HELP

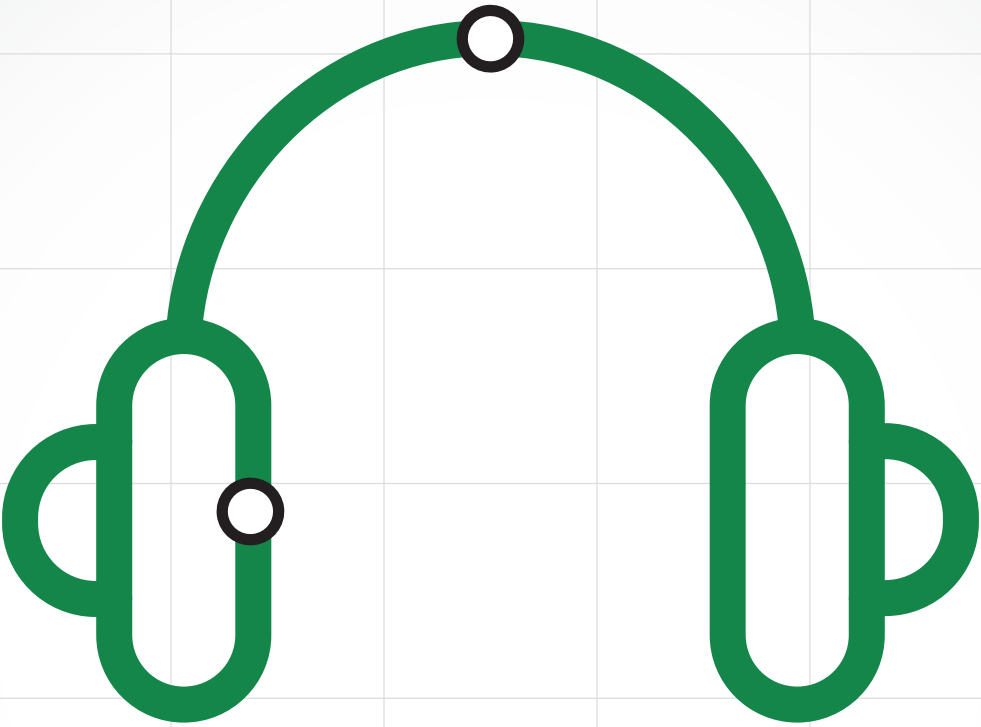
WHAT IS CROHN'S DISEASE?

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 but commonly occurs in the lower part of the small intestine (ileum) or the caecum (part of the large intestine).

Sometimes, the intestinal inflammation can be accompanied by a skin rash or inflammation of the eye, joints or tendons.

Symptoms of Crohn's disease

People with Crohn's disease typically experience periods of disease activity (flare ups) and periods of inactivity (remission) and cycle through these two states. People may go into remission following treatment but a relapse of symptoms is common.[2] Symptoms during a flare up can include diarrhoea, abdominal pain or discomfort, fever, nausea, vomiting, fatigue and weight loss. In more severe cases, Crohn's disease can cause extensive damage to the intestines, ulceration of the intestinal wall and other serious complications, such as the formation of fistulae (tunnels that form between sections of the intestines or between the intestines and other organs such as the skin) and the need for surgery.



20% TO 30% OF PEOPLE DIAGNOSED WITH INFLAMMATORY BOWEL DISEASE ARE UNDER THE AGE OF 20.[3]

Crohn's disease is thought to occur similarly between men and women and is commonly diagnosed in people under the age of 30.[4,5] Some studies suggest that Crohn's disease is more likely in Caucasian people,[6] but the differences between ethnic or racial groups are thought to arise from lifestyle and environmental differences rather than genetic differences.

WHAT CAUSES CROHN'S DISEASE?

Crohn's disease is an autoimmune-related condition, meaning that the immune system attacks its own body tissues. While the exact cause of Crohn's 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 in the body released from lymphocytes that 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.

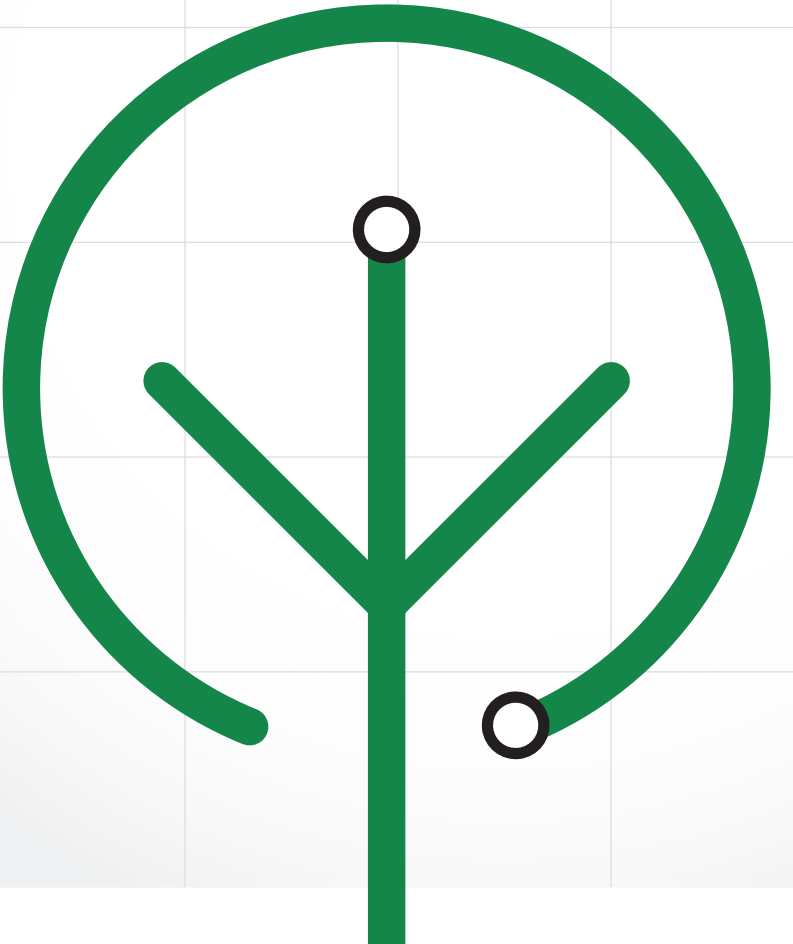
One of these cytokines is a protein called tumour necrosis factor alpha (TNF-α). TNF-α plays a central role in orchestrating an immune response against infection and tissue damage, which results in inflammation. The immune system is then counter-balanced by other cytokines that normalise the inflammatory response. In conditions such as Crohn's disease, the inflammatory response is magnified due to an overexpression of inflammatory proteins such as TNF-α, 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.

Some triggers for Crohn's disease may include a genetic tendency, environmental and lifestyle factors, and exposure to certain bacteria or viruses.

The role of genes and family history

While there is no clear pattern of inheriting Crohn's disease, gene markers appear to be an important contributor to 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.

Genetic links to Crohn's 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.[7] There is also a chance of another family member being diagnosed with Crohn's disease.[8]



Environmental factors

A genetic tendency in an individual alone is not sufficient for that person to develop Crohn's disease. Some environmental and additional factors and their link to Crohn's disease are listed below.

ENVIRONMENTAL FACTOR	LINK TO CROHN'S DISEASE
SMOKING	Smoking is associated with an increased risk of developing Crohn's disease[9]
DIET	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[10]
BREASTFEEDING	Being breastfed as a child may protect against inflammatory bowel disease[11]
CHILDHOOD INFECTIONS	An absence of infections during childhood may also increase the possibility of developing inflammatory bowel disease[11]
APPENDECTOMY (removal of appendix)	Having had your appendix removed may increase the risk of developing Crohn's disease[11]

Key statistics

4 in every 2,000 Australians have Crohn's disease.[12]

Up to 14% of individuals with Crohn's disease also have a family history of the disease.[8]

Smoking increases the risk of developing Crohn's disease by at least 2 times.[9]

Assessing your condition

The severity of Crohn's disease varies between people. To treat your Crohn's disease in the best possible way, your doctor will need to determine how severe your symptoms are. Your doctor will also use an assessment tool such as the Crohn's Disease Activity Index (CDAI) to monitor how well you are progressing on your treatment. It is important to remain in contact with your doctor throughout treatment as this will allow them to modify your treatment as needed and manage any complications. Always consult your doctor before using dietary supplements as part of your treatment.

CROHN'S DISEASE ACTIVITY INDEX (CDAI)

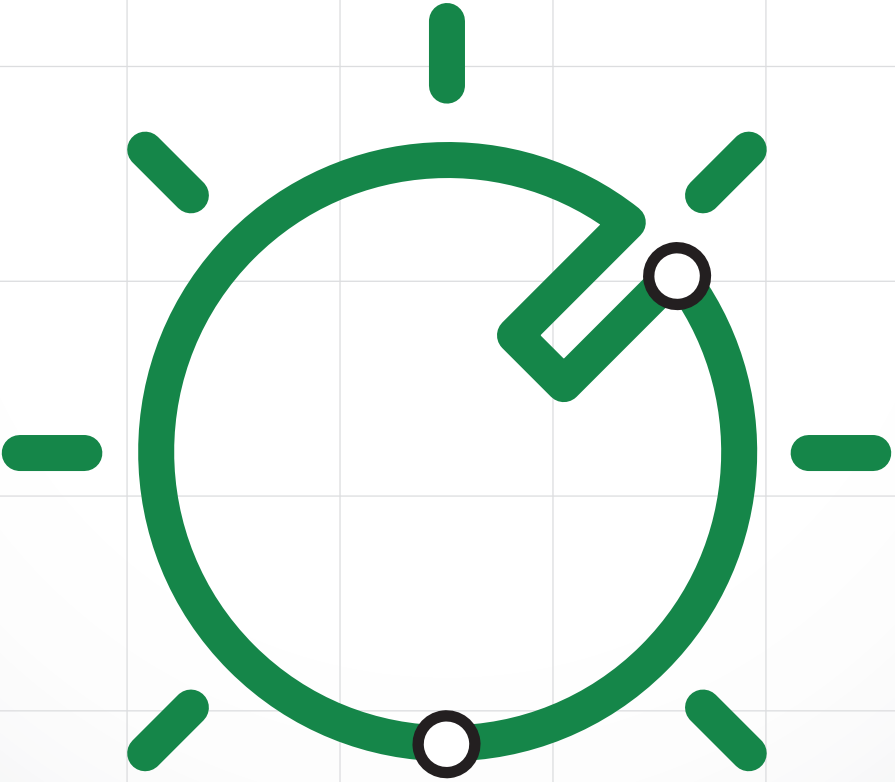
The CDAI is a set of eight questions which records the activity of your Crohn's disease. The questions address wellbeing, bowel movements, use of medication, cramping or pain, stress levels and body temperature.

The answer to each question is given a score, which are tallied to give an overall score. The lowest score is 0 and the highest total score is 600. These scores are used as a guide to monitor the activity and severity of Crohn's disease.

CDAI SCORE	ACTIVITY GUIDE
<150	Clinical remission
150–219	Mildly active disease
220–450	Moderately active disease
>450	Severe disease

You can assist your doctor by answering these questions to monitor your health between visits. If you do, take your results with you to your next visit to discuss your progress with your doctor.

AT PRESENT, MOST TREATMENTS FOR CROHN'S DISEASE ATTEMPT TO CONTROL INFLAMMATION, RELIEVE SYMPTOMS AND PREVENT NUTRITIONAL DEFICIENCIES. ADEQUATE TREATMENT CAN HELP CONTROL THE DISEASE, BUT THERE IS NO CURE.



TREATMENT OPTIONS

Crohn's disease is a chronic disease, which cannot be cured. In more severe cases the inflammation leads to ulceration (mucosal damage) of the full thickness of the lining of the intestine. If this damage progresses, serious complications such as bleeding, infections, fistulae (tunnels that form between different sections of the intestines or between the intestines and the skin) may occur, leading to the need for surgery. Treatments exist that may relieve symptoms, reduce inflammation, heal the intestinal lining (mucosal healing) and thus reduce the need for hospitalisation and surgery. Your doctor will work with you to decide which treatments are most suitable for you.

Medication

Depending on the severity of your Crohn's disease, your doctor may recommend a single or combination medication treatment option. All medications can have side effects and it is important to discuss the risks and benefits of any treatment with your doctor.

Always speak with your doctor about any concerns you have about the medications you are prescribed, or if you experience any side effects. Always consult your doctor before using dietary supplements as part of your treatment.

ANTI-INFLAMMATORY DRUGS

When treating mild to moderate inflammation, doctors often prescribe the class of drugs known as aminosalicylates. These drugs can help to ease symptoms, induce and maintain remission and prevent flare ups.

CORTICOSTEROIDS

Corticosteroids are also used to treat flare ups and to relieve abdominal pain and tenderness. They may also improve appetite and a general sense of wellbeing.

Steroids are naturally produced by the body to be used in many normal body processes. Chemical corticosteroids are potent anti-inflammatory agents that block the production of substances (such as prostaglandins) that promote inflammation or trigger allergic responses. Common corticosteroids

TALK TO YOUR DOCTOR ABOUT ANY CONCERNS YOU HAVE ABOUT THE MEDICATIONS YOU ARE PRESCRIBED OR IF YOU EXPERIENCE ANY SIDE EFFECTS.

include intravenous, oral and rectal forms. Possible side effects with longer term use may include weight gain, brittle bones and osteoporosis, glaucoma, cataract, increased risk of infection, high blood pressure, fragile skin and onset or worsening of type 2 diabetes. For this reason, corticosteroids are usually prescribed for a short period of time.

IMMUNOSUPPRESSANTS

Immunosuppressants are generally prescribed when anti-inflammatory drugs have failed and a person demonstrates signs of moderate to severe Crohn's disease.

Some immunosuppressants work by blocking the immune reaction that causes inflammation. It can take up to 6 months for immunosuppressants to have an effect.[13]

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 Crohn's 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-α, 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.

Surgery

For some people with chronic, severe inflammation, surgery may be necessary. Surgery is only considered after consultation with a doctor and a surgeon. Opinions are often sought from other healthcare professionals also.

Although surgery is not a cure, it can relieve or correct complications that may occur, such as:

- **Strictures – narrowing of the intestines, making it difficult for food/faeces to pass.**
- **Obstructions – blockages of the intestines, making it difficult or impossible for food/faeces to pass.**
- **Abscesses – an infection in the intestinal wall resulting in accumulation of pus, which requires clearing.**
- **Perforations – formation of a hole in the wall of the intestine, which may have come about through presence of a blockage or a stricture.**
- **Fistulae – tunnels that form between sections of the intestines or between the intestines and other organs such as the skin.**

LIVING WITH CROHN'S DISEASE

The effects of Crohn's disease are more than just physical. Living with Crohn's disease can have an impact on your life socially, psychologically and even financially.

Psychological effects

Everyone responds differently to challenges. If you experience emotional reactions such as anger, frustration, helplessness or anxiety in relation to your Crohn's disease, you are far from being alone. If you do feel depressed, it is important to talk to someone you trust, such as a family member, close friend or a healthcare professional. There are ways to help you manage the emotional challenges of living with Crohn's disease. To find out more about depression and its symptoms, visit Beyond Blue: **www.beyondblue.org.au**

Living better with Crohn's disease

Living with any long-term health condition is difficult. Taking medication helps your disease but you need to take care of yourself too. There are things that you can do to help you cope more positively, beyond taking your medications as prescribed.

If you need to talk to someone immediately,
call Lifeline on 13 11 14.

Things you can do for yourself

- Learn about your condition and take an active role in its management. A good place to start is by talking to your doctor and visiting the websites provided in the resources section of this booklet.
- Make time for physical activity – it has great mental health benefits such as relieving stress.
- Eating a healthy, well-balanced diet. While what you eat does not cause Crohn's disease, it may affect the way you feel. A good diet helps the body deal with the common deficiencies that result from Crohn's disease: loss of appetite, increase in caloric needs during flare ups and, possibly, the poor absorption of dietary protein, fat, carbohydrates and water. A healthy diet should contain foods from all food groups.
- However, when Crohn's disease is active, softer, more bland foods may be easier to tolerate. Some people find that certain foods aggravate their symptoms. If you limit the intake of these foods, especially during flare ups, you may reduce the severity of your symptoms. Some people also find it easier to eat a low fibre diet without spicy foods. Your doctor or a dietitian may be able to help you with individual dietary advice to suit your needs.
- Don't smoke – cigarette smoking is associated with Crohn's disease severity.[9,14] Quitting smoking can be challenging but an important step to help your Crohn's disease. If you would like advice on how to quit smoking, you can talk to your doctor or other healthcare team members, call the Quitline on 13 18 48 or visit www.icanquit.com.au
- Educate your friends and family about Crohn's disease. This way they can better understand what you are going through and provide you with support if needed.
- If you are comfortable, talk to your employer about your Crohn's disease and discuss your abilities and note any constraints or concerns you may have.
- Get in touch. Feeling connected with others who are going through the same thing as you can make a huge difference. Consider joining a support group – a good place to start is by contacting Crohn's and Colitis Australia – www.crohnsandcolitis.com.au

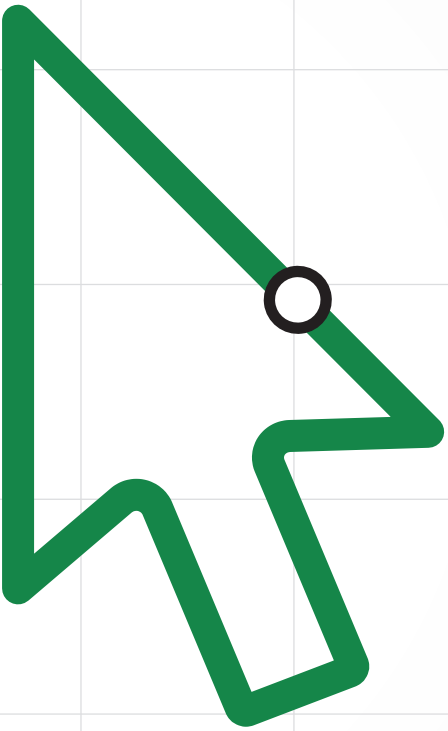
RESOURCES

Crohn's and Colitis Australia*
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
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
Provides information about depression and its symptoms.

Gastro Central
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 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.

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