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central**

Understanding
fistulising
Crohn's disease



Start your journey towards
understanding inflammatory bowel disease

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INTRODUCTION

Crohn's disease and ulcerative colitis, the two most common types of inflammatory bowel diseases (IBD), 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 Inflammatory bowel disease is not to be confused with irritable bowel syndrome as the two conditions are quite different and need to be treated accordingly.

Fistulae develop in up to one third of patients with Crohn's disease.³

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 (colon). Fistulae (abnormal tunnels between the intestines and other structures) develop in up to one third of patients with Crohn's disease, hence the name fistulising Crohn's disease.³

Inflammatory bowel disease can develop at any age, with a peak age of onset in the 20s-30s,⁴ however, the causes of inflammatory bowel disease are not entirely known. In both conditions, people experience periods without

symptoms (known as remission) and periods of greater inflammation and discomfort (known as flare ups).

The therapeutic goals of management of fistulising Crohn's disease are to close fistulae, maintain their closure, reduce infection and limit the need for surgical intervention. As fistulising Crohn's disease is a lifelong condition, it is important that you work with your doctor to find the treatment that works best for you and allows you to lead a fulfilling life.

This booklet has been designed to help you:

- Understand fistulising Crohn's disease
- Understand the different treatments available to treat fistulising Crohn's disease
- Work with your healthcare team to reduce symptoms
- Identify ways to assist you in managing fistulising Crohn's disease and leading 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 understanding your condition.



Here to help

WHAT IS FISTULISING 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 anus 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.

Crohn's disease may be complicated by the formation of fistulae (abnormal tunnels between the bowel and other structures), which may develop between two segments of bowel (enteroenteric fistulae), between the bowel and the vagina (rectovaginal), between the bowel and the bladder (enterovesicular) or between the bowel and the skin (enterocutaneous).

Perianal fistulae (affecting the areas around the anus) are the most common type.

Fistulae are more common in Crohn's disease than in ulcerative colitis. It is estimated that up to a third of individuals with Crohn's disease will develop fistulae at some point.³

Symptoms of fistulising Crohn's disease

People with fistulising 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.

Symptoms during a flare up of Crohn's disease can include diarrhoea, abdominal pain or discomfort, fever, nausea, vomiting, fatigue and weight loss. The fistulae may also drain pus or a foul-smelling discharge.

The symptoms of fistulising Crohn's disease vary based on the severity and location of the fistulae but they can be very distressing and impair quality of life:

- Passage of gas or stool
- Painful sexual intercourse
- Perineal pain
- Tenderness
- Faecal incontinence.

Crohn's disease is thought to occur similarly in men and women.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 FISTULISING 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 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- 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 counterbalanced 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 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. 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 fistulising Crohn's disease. Additional factors, such as environmental factors, may also play a role.

Environmental factor	Link to Crohn's disease
Smoking	Smoking is associated with an increased risk of developing Crohn's disease ⁹
Diet	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 the appendix)	Having had your appendix removed may increase the risk of developing Crohn's disease ¹¹

Key statistics



Approximately 17 of every 100,000 Australians and 26 of every 100,000 New Zealanders are thought to 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



Fistulae affect up to a third of patients with Crohn's disease.³

Assessing your condition

The severity of fistulising Crohn's disease varies between individuals. To treat your Crohn's disease in the best possible way, your doctor will need to determine how severe your symptoms are. Diagnosis of fistulising Crohn's disease, as well as the disease's extent and severity, can be confirmed by a combination of medical history-taking, physical examination in addition to laboratory tests, imaging studies and surgical procedures. Careful assessment of the fistula location, extent, and any potential complications is required. 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.¹³

Your doctor will also use an assessment tool such as the Crohn's Disease Activity Index (CDAI), which comprises a series of questions about wellbeing, pain and use of medication, 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 your treatment to be modified as needed and any complications to be managed. Always consult your doctor before using dietary supplements as part of your treatment.

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



TREATMENT OPTIONS

The therapeutic goals of management of fistulising Crohn's disease are to close fistulae, maintain their closure, reduce infection and limit the need for surgery.

Medication

Several drug types for single or combination therapy are available for the treatment of fistulising Crohn's disease. Other drugs may also be given to help you relax or to relieve pain, diarrhoea or infection. Your doctor will fully assess your condition before deciding on your individual treatment course.

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 Crohn's 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. Possible side effects with longer-term use may include weight gain, brittle bones and osteoporosis, glaucoma, cataracts, increased risk of infection, high blood pressure, fragile skin and onset or worsening of type 2 diabetes. They are therefore not recommended for long-term use, though are considered very effective when prescribed for short-term use.

Immunosuppressants

Immunosuppressants (or immunomodulators) are generally prescribed when 5-ASAs or corticosteroids have failed, and for 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.¹⁴ Your doctor will closely manage your condition over this time.

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- 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 other medications.

Surgery

For some people with fistulising Crohn's disease, surgery may be necessary in combination with medication. Surgery is only considered after consultation with your gastroenterologist and a surgeon. Opinions are often sought from other healthcare professionals also. Although surgery may not be a cure, it can relieve or correct complications that may occur with your condition.



Talk to your healthcare team about any concerns you have about the medications you are prescribed or if you experience any side effects.

LIVING WITH FISTULISING CROHN'S DISEASE

The effects of fistulising Crohn's disease are more than just physical and can have a significant impact on quality of life. Living with fistulising Crohn's disease can affect your life socially, psychologically and even financially. That said, people with inflammatory bowel disease can lead productive lives even though they take medication. They can play sport, care for families, hold down good jobs, marry and have children. In short, they can lead fulfilling lives.

Psychological wellbeing

Everyone responds differently to challenges. If you experience emotions such as anger, frustration, helplessness or anxiety in relation to your fistulising 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, as there are ways to help you manage the emotional challenges of your condition.

To find out more about depression and its symptoms, visit Beyond Blue: www.beyondblue.org.au

Living well with fistulising Crohn's disease

Living with any long-term health condition is a challenge for anyone. Taking medication may help relieve the symptoms of fistulising Crohn's disease but you also need to take care of yourself physically and emotionally. There are many things that you can do on a day-to-day basis that could help you manage your condition positively.

If you need to talk to someone immediately,
**call Lifeline on 13 11 14 in Australia
or 0800 543 354 in New Zealand.**



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.**
As well as physical benefits, physical activity is also great for relieving stress and enhancing your mental health.
- **Eat a healthy, well-balanced diet.**
What you eat 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. Lack of adequate nutrition worsens fatigue and eventually leads to weight loss, so make sure you eat appropriately to avoid these symptoms.
- **When Crohn's disease is active, softer, more bland foods may be easier to tolerate.** Some people find that certain foods aggravate their symptoms like diarrhoea. 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.^{9,15} Quitting smoking can be challenging but is an important step to help you manage 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

People living with fistulising Crohn's disease can lead fulfilling lives.

- **Educate your friends and family** about fistulising Crohn's disease. This way they can better understand what you are going through and provide you with the necessary support.
- **Consider talking to your employer** about your condition and your needs whilst at work as this can ease any concerns you may have.
- **Get in touch.** Feeling connected with others who are going through similar experiences to you can make a huge difference to how you feel. Consider joining a support group; see 'Resources' in this booklet for further information.

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.org.au 🇺🇸

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

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.

*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.

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