

**gastro
central**

Understanding
ulcerative colitis



Start your journey towards
understanding inflammatory bowel disease

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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 ulcerative colitis, please contact your doctor.

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

Inflammatory bowel disease can develop at any age, with a peak age of onset in the 20s–30s.³ The causes of inflammatory bowel disease are not entirely known but it is believed to be a combination of genetic, environmental and immunological factors. These factors can trigger the immune system to switch on its normal defence mechanism. It is this prolonged

inflammation that eventually damages the walls of the gastrointestinal tract and causes the symptoms of inflammatory bowel disease.

There are a number of treatment options available. As ulcerative colitis 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 your condition and the different treatments available
- Work with your healthcare team to reduce symptoms
- Identify ways to assist you in managing ulcerative colitis 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.

Estimates suggest 33,000 Australians have ulcerative colitis, with 846 new cases reported every year.⁴



Here to help

WHAT IS 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 bleed. The inflamed lining also produces mucus, which can sometimes contain pus.

Ulcerative colitis is classified as mild, moderate or severe depending on clinical disease activity. People with ulcerative colitis typically experience periods of disease activity (flare ups) and periods of inactivity (remission that can last for months or even years) and cycle through these two states.

People may go into remission following treatment but a relapse of symptoms is common and most patients' symptoms eventually return. Over time, patients may become anaemic and protein and salt depleted if left untreated.

Symptoms of ulcerative colitis

Symptoms depend on the location and extent of intestinal tract involved in the disease and vary from person to person. In ulcerative colitis, colonic inflammation reduces the large intestine's ability to reabsorb fluid from the faeces, causing diarrhoea. Additionally, inflammation in the rectum can lead to a sense of urgency to have a bowel movement. The most common symptom is bloody diarrhoea though other associated symptoms may be present as the disease gets more severe.

Symptoms of ulcerative colitis can include:

- Predominantly bloody diarrhoea
- Frequent small-volume diarrhoea
- Urgency for bowel movement
- Abdominal pain
- The need to pass stools, despite an empty large intestine.

Some people may respond well to treatment and never develop any complications. In more severe cases, where inflammation has penetrated deeper into the wall of the large intestine, serious complications may arise, such as:

- Profuse bleeding from deep ulcers
- Perforation (rupture) of the large intestine
- Partial or full shutdown of normal intestinal contractions (fulminant colitis/toxic megacolon).

These complications can occur over a short period of time and normally require immediate medical attention.

Occasionally, some patients with ulcerative colitis may also suffer with other inflammatory diseases, such as arthritis, inflammation of the eye (iritis), liver disease (sclerosing cholangitis), skin lesions (pyoderma gangrenosum) and osteoporosis, though it is not known why these problems occur outside the large intestine. Scientists suggest these complications may be the result of inflammation triggered by the immune system. Some of these problems go away with treatment. Ulcerative colitis is also a premalignant disease and the incidence of colon cancer increases with disease duration.

WHAT CAUSES ULCERATIVE COLITIS?

Ulcerative colitis is an immune-mediated inflammatory disease and although the exact cause is unknown, it is thought to occur as a result of an abnormal immune response in genetically susceptible individuals. This in turn causes the recurrent 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 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 ulcerative colitis, 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 ulcerative colitis may include a genetic tendency, environmental and lifestyle factors, and exposure to certain bacteria or viruses. Ulcerative colitis is not caused by emotional distress or sensitivity to certain foods or food products, but these factors may also trigger symptoms in some people. The stress of living with ulcerative colitis may also contribute to a worsening of symptoms.



The role of genes and family history

While there is no clear pattern of inheriting ulcerative colitis, 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.

An international study including over 75,000 patients with ulcerative colitis or Crohn's disease identified 163 distinct genetic locations that can determine the risk of either disease.⁵

Genetic links to ulcerative colitis within families have also been studied: Relatives of people with inflammatory bowel disease have a slightly higher risk of developing Crohn's disease or ulcerative colitis.⁶

Environmental factors

A genetic tendency in an individual alone is not sufficient for that person to develop ulcerative colitis. Additional factors, such as environmental factors and infectious (bacterial) factors, may also play a role.

Environmental factor	Link to ulcerative colitis
Diet	High intake of unsaturated fat may enhance the risk of developing ulcerative colitis. Increasing dietary intake of vitamin D helps to reduce risk of ulcerative colitis ⁷
Breastfeeding	Being breastfed as a child may protect against inflammatory bowel disease ⁸
Appendectomy (removal of the appendix)	Having your appendix removed (before 20 years of age) can be a protective factor for ulcerative colitis ⁷

Key statistics



Approximately 11 of every 100,000 Australians and 13 of every 100,000 New Zealanders are thought to have ulcerative colitis.⁹



Your genetic makeup may influence your susceptibility to environmental risk factors for ulcerative colitis.⁶

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.

Diagnosis of ulcerative colitis can be delayed as the same symptoms can occur with other diseases. Your doctor plays an important role in recognising the signs of inflammatory bowel disease and facilitating an early diagnosis. Your doctor may perform several tests before referral to an appropriate specialist. 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

Management of ulcerative colitis depends on the extent of the large intestine affected and the severity of the inflammation. Unfortunately, there is no known cure for ulcerative colitis other than surgical removal of the large intestine, though surgery is only indicated when medication can no longer control the symptoms that prevent a person from leading a fulfilling life. However, treatments do exist that can 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.

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, or if you experience any side effects during treatment. Additionally, consult your doctor before using dietary supplements as part of your treatment and always take medications as prescribed as suddenly stopping your treatment may cause a flare up of your ulcerative colitis.

Initial therapy and agents for disease flare ups

For people with ulcerative colitis, the goals of medication are 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 ulcerative colitis. Other drug classes may also be given to help you relax or to relieve pain, diarrhoea or infection.

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 ulcerative colitis 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, facial hair, hypertension, diabetes, mood swings, increased risk of infection, bone mass loss or acne. They are not recommended for long-term use, though are considered very effective when prescribed for short-term use.

Maintenance therapy

For patients with extensive disease who are in disease remission or who suffer from more than one relapse per year, lifelong therapy is recommended to reduce the chance of relapse (a return of the disease symptoms).

Immunosuppressants

Immunosuppressants (or immunomodulators) are generally prescribed when 5-ASAs or corticosteroids have failed and for patients with more moderate to severe disease. 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 a full effect.¹⁰ Your doctor will closely manage your condition over this time.

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.



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

Hospitalisation

Occasionally, symptoms may be severe enough that a person requires hospitalisation. For example, if a person has severe bleeding or severe diarrhoea that causes dehydration. In such cases, the doctor will try to stop the diarrhoea and loss of blood, fluids and mineral salts. In this instance, the patient may need a special diet, parenteral nutrition (a sterile liquid containing nutrients infused into the bloodstream), medication or sometimes surgery.

Surgery

In people with severe ulcerative colitis that is not responding adequately to medication or in those who are at higher risk of colon cancer, surgical removal of the large intestine and rectum, known as proctocolectomy, may be the most appropriate long-term solution. Surgical removal of the large intestine is generally followed by one of the following:¹¹

Ileostomy

The surgeon creates a small opening (called a stoma) in the abdomen and attaches it to the end of the small intestine (called the ileum). Waste exits the body through the stoma and a pouch is worn over the stoma to collect waste. The patient empties the pouch as needed.

Ileoanal anastomosis

The surgeon removes the large intestine and the inside of the rectum, leaving the outer muscles of the rectum, which allows the patient to have normal bowel movements as it preserves part of the anus. The surgeon then attaches the ileum to the inside of the rectum and the anus, creating a pouch. Waste is stored in the pouch and passes through the anus in the usual manner. Bowel movements may be more frequent and watery than before the procedure.

Technically, surgery cures ulcerative colitis; however, this treatment option is reserved for patients who do not respond to medical treatments as it may often lead to a different set of problems. Surgery does eliminate symptoms and the need for ongoing medication to control inflammation, which can greatly enhance patients' quality of life.



People living with
ulcerative colitis can
lead fulfilling lives.

LIVING WITH ULCERATIVE COLITIS

The effects of ulcerative colitis are more than just physical and can have a significant impact on quality of life. Living with ulcerative colitis 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 ulcerative colitis, 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 ulcerative colitis

Living with any long-term health condition is a challenge for anyone. Taking medication may help relieve the symptoms of ulcerative colitis 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.** A healthy diet should contain foods from all food groups, 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, so make sure you eat appropriately to avoid these symptoms.
- Some people find that certain foods aggravate their symptoms such as 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.
- There is no evidence to suggest that vitamins or food supplements are necessary for most people with ulcerative colitis, although blood loss can lead to anaemia (a low blood count), which may require iron tablets. Again, your doctor or a dietitian will be able to help should you have any concerns.
- **Educate your friends and family about ulcerative colitis.** 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. Consider joining a support group; see 'Resources' in this booklet for further information.

Get in touch. Feeling connected with others who are going through the same thing as you can make a huge difference to how you feel.

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.

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