The Ins and Outs of

Inflammatory Bowel Disease

Third Edition

If you have inflammatory bowel disease (IBD) this booklet will help you to understand your condition and the treatments that are commonly used to manage it. The content is not intended to be a substitute for professional medical advice, diagnosis or treatment. If you have any questions about your IBD or its treatment, make sure you speak to your GP or IBD specialist.

Expert Advisory Group

Associate Professor Miles Sparrow
Inflammatory Bowel Disease Clinic
Department of Gastroenterology
The Alfred, Melbourne VIC

Ms Belinda Headon
IBD Nurse Consultant
Department of Gastroenterology
The Alfred, Melbourne VIC

Ms Sarah Melton
Dietitian
Department Nutrition and Dietetics
The Alfred, Melbourne VIC

Dr George Alex
Consultant Paediatric Gastroenterologist
IBD Lead
Royal Children's Hospital, Parkville VIC

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Dr Falk Pharma Australia P/L
Suite 10.01, 815 Pacific Highway
Chatswood, NSW 2067
ABN 40 631 091 131

Infoline: 1800 DRFALK (373 255)
Email: info@drfalkpharma.com.au
www.drfalkpharma.com.au

Contents

Understanding inflammatory bowel disease

What is IBD? 4
What causes IBD? 4
Symptoms 7
Ulcerative colitis 8
Crohn's disease 9
Investigations and diagnosis 10
Complications of IBD 12
Your IBD team 13
Your general health and IBD 14

Management and treatment of inflammatory bowel disease

Treatment strategies in IBD 15
Medical therapies for IBD 16
Exclusive enteral nutrition (EEN) 18
Drugs used to treat symptoms 19
Surgery 20

Living with inflammatory bowel disease

Nutrition and IBD 21
Smoking and IBD 23
Vaccinations 23
Travel 24

Special situations

Pregnancy and IBD 25
IVF 26
Children and adolescents 26
Mental health and wellbeing 28

Adhering to treatment

Sticking to your treatment program 29
Social media 30

References 30
Support groups 31

What is IBD?

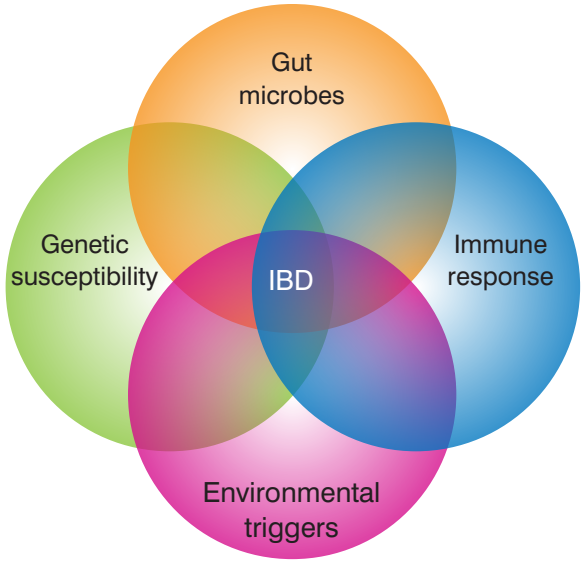
In conditions such as IBD, our own immune system is triggered inappropriately and attacks itself. IBD is classed as an immune-mediated inflammatory disease (also known as an autoimmune disease) affecting the bowel wall. This abnormal inflammatory response can also affect other parts of the body, including joints, skin, eyes and bone, leading to significant disability and poor quality of life in some people.

What causes IBD?

IBD occurs mainly in the developed world such as northern Europe, North America, Australia and New Zealand. Australia has one of the highest rates of IBD in the world,[1] with almost 85 000 having the condition.[2,3]

Despite advances in medical research over the last decade, the exact cause of IBD and other chronic immune-mediated inflammatory conditions has not been established. It seems to be a complex combination of genetic (inherited) and environmental factors.[4] The incidence is increasing in developing countries as they adopt a more westernised lifestyle.[5]

One theory for the cause of IBD is that the innermost layer of the bowel wall (epithelium) is somehow damaged allowing normal gut bacteria to cross it and interact directly with immune cells. The immune cells recognise the bacteria when outside the gut as invaders and this sets off an inflammatory cascade which is uncontrolled, leading to the destruction of the bowel wall over time and the development of IBD.[6] In some people with IBD, inflammatory processes can also occur outside the gut, with the joints, skin and eyes potentially affected.[4,7]



The development of IBD is likely a result of a combination of these factors.

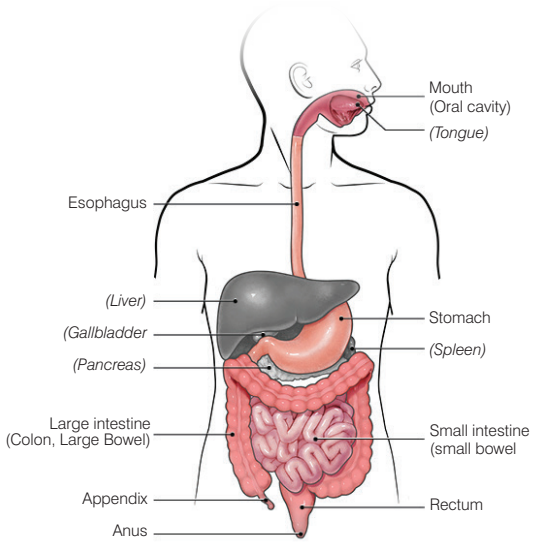
IBD is a lifelong and episodic condition. It is characterised by periods of remission when you have no apparent symptoms, although the inflammatory process in your gut and elsewhere in your body may still be occurring, requiring ongoing treatment. This situation is interspersed with periods of relapse or flares (when your symptoms return),[4] requiring treatment to manage this active phase.

The risk of relapse or flares is substantially higher in people with IBD who don't take their medication as prescribed by their doctor when they are in remission.

At present there is no cure for IBD.[4] The aim is to normalise the overactive immune system with medication, allowing the bowel to heal, improving symptoms and hopefully achieving and maintaining remission of your disease.

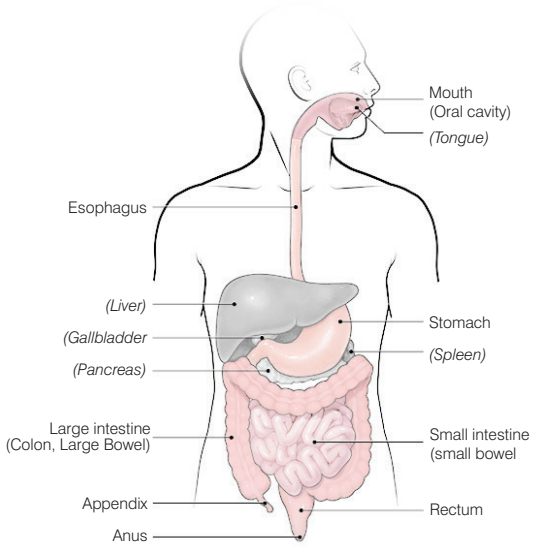
Various factors including either physical stress on the body such as an infection, trauma or pregnancy or every day psychological stress are thought to affect the immune system negatively. Previously, diet and stress were suspected of causing IBD, but it is now known that these factors may worsen but probably don't cause IBD.

The gut or gastrointestinal tract



The gastrointestinal tract runs from the mouth to the anus and includes the oesophagus, the stomach, the small intestine, the large intestine or colon, and the rectum and anus.

Your disease



Used with permission from US Centers for Disease Control and Prevention

Symptoms of IBD

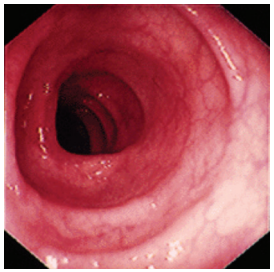
IBD describe two main diseases: ulcerative colitis and Crohn's disease which cause inflammation and ulceration of the bowel.[8] In both conditions during a flare, people can experience a variety of symptoms based on which disease they have, where the disease is located in the body and how severe the inflammation is. Both ulcerative colitis and Crohn's disease can cause tiredness, weight loss and fatigue as well as symptoms outside the gastrointestinal tract.

Symptoms in other parts of the body

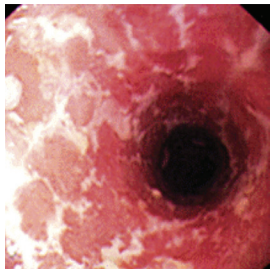
- Red itchy eyes
- Sores in the mouth
- Swollen and painful joints
- Bumps or lesions on the skin (erythema nodosum and pyoderma gangrenosum)
- Thinning of the bones (osteoporosis)
- Kidney stones
- Inflammation in bile ducts and liver

In IBD, symptoms range from mild to severe during relapses, but may decrease or disappear during remissions with effective treatment, even if the inflammation is still ongoing in your gut wall or elsewhere in your body.[4]

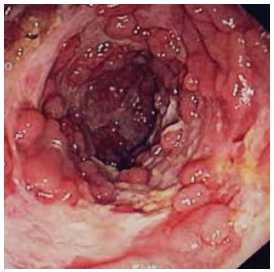
The main difference between these two life-long diseases is the area of the gut wall that they affect and the type of damage caused by the inflammation.



Normal colon



Ulcerative colitis colon



Crohn's disease colon

Ulcerative colitis

The gut is made up of multiple layers. Ulcerative colitis typically affects only the surface layers (mucosa) of the colon (large bowel) and the rectum. It is characterised by inflammation (redness) and ulceration (tiny open sores) primarily of the inner lining of the rectum and descending colon but it can sometimes extend in a continuous manner along a large portion of the colon. Ulcerative colitis does not affect the small bowel.

Common symptoms of ulcerative colitis

Symptoms vary from person to person and will range from mild to severe[4,9]

- Frequent, watery diarrhoea often containing blood, mucus and pus
- Sense of urgency to have a bowel movement
- Abdominal discomfort, cramping and pain often intermittent with bowel motion
- Tiredness, fatigue
- Loss of appetite
- Weight loss (in those with more severe disease)

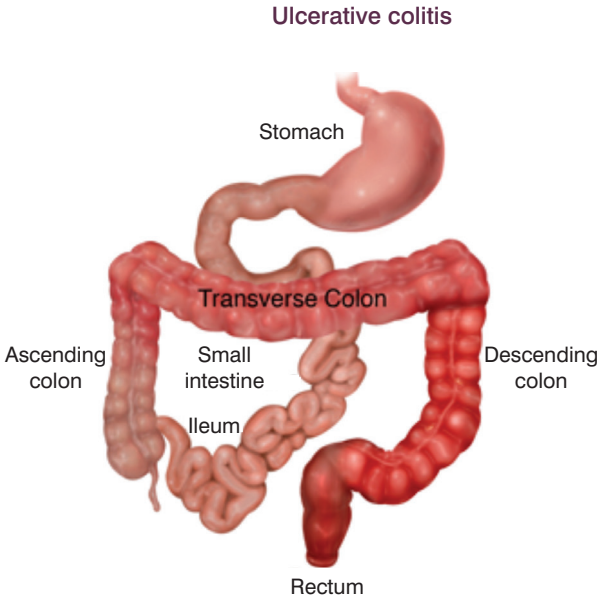


Image courtesy Crohn's & Colitis Australia

Crohn's disease

In Crohn's disease, the inflammation can involve any part of the gut, from the mouth to the anus, although it most commonly affects the small intestine and the colon.[4] The inflammation is often in separate areas (patchy) along the bowel wall, with areas of healthy intestine between areas of diseased intestine. Unlike ulcerative colitis, the inflammation commonly affects all layers of the bowel wall (not just the inner lining).

Crohn's disease is also associated with obstruction or narrowing of the intestinal wall (strictures), the formation of abscesses (pockets of pus) and the formation of abnormal tracts (fistulae) connecting different loops of intestine to itself or to other body organs.

Common symptoms of Crohn's disease

Symptoms often depend on the location affected

- Diarrhoea, with or without bleeding
- Abdominal pain or cramping, often continuous
- Vomiting
- Intestinal obstruction caused by strictures
- Fistulae or abscesses, especially in the perianal region
- Fever during active stages of disease
- Nutritional deficiencies
- Anorexia
- Malabsorption
- Malaise

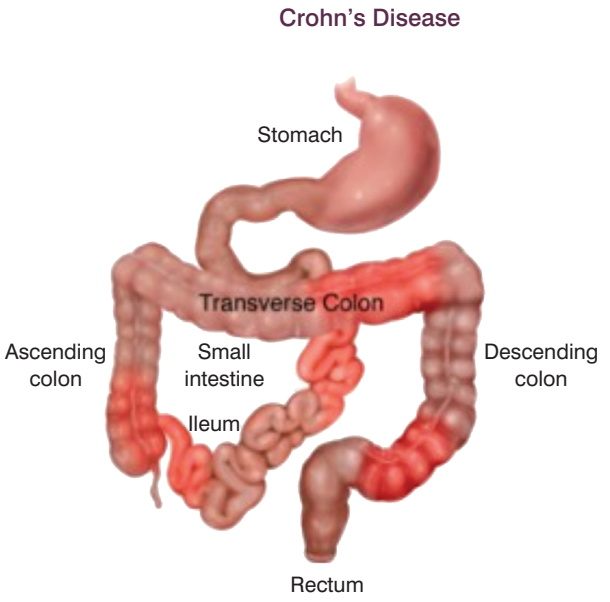


Image courtesy Crohn's & Colitis Australia

Investigation and diagnosis

There is no single test that can be used to diagnose IBD with certainty. Many people require a number of tests before an accurate diagnosis can be made. Obtaining a diagnosis routinely involves excluding other diseases and conditions such as irritable bowel syndrome, coeliac disease or a bowel infection.[4] For others, although the diagnosis of IBD is made, it is not possible to distinguish between ulcerative colitis and Crohn's disease; about 5-15% are diagnosed as having IBD unclassified (IBD-U). This diagnosis may be changed later to ulcerative colitis or Crohn's disease as the disease progresses or after additional investigations are conducted.

Some or all of the following tests may be conducted as part of the diagnostic process

Investigation	Explanation
Stool sample	• To rule out infection: routine faeces samples, often taken by your GP, especially if you have been travelling recently or been around others with infection • To measure inflammation: faeces is tested for a protein (calprotectin) released by inflammatory cells in the gut which helps determine which people with gut symptoms may have IBD and should have a colonoscopy
Blood tests	• To check for anaemia (low blood count) from either bleeding in the bowel or poor iron absorption • To measure the severity of inflammation: inflammatory markers in the blood (CRP or ESR) can be elevated during active disease • To detect vitamin or mineral deficiencies • To assess the severity of your disease: low albumin (a protein) is a marker of inflammation during active disease
Endoscopy: colonoscopy or sigmoidoscopy	• To examine the bowel using a long flexible tube inserted via the anus to assess extent and location of the inflammation • To obtain tissue biopsies to look for microscopic changes seen in the bowel wall in the colon, rectum or lower part of the small intestine (ileum) which may reveal UC or CD
Endoscopy: gastroscopy	• To examine the upper gastrointestinal tract including the upper part of the small intestine (duodenum) using a long flexible tube inserted via the mouth to look for signs of inflammation showing CD • To obtain tissue biopsies to look for microscopic changes in the gut wall of the upper gastrointestinal tract and upper part of small intestine showing CD
Medical imaging	• A non-invasive way to determine disease extent and severity through assessment of structural and functional changes in the gut through scanning technology i.e. magnetic resonance imaging (MRI) and computed tomography (CT) and intestinal ultrasound (IUS) scanning • To avoid the risks of cumulative radiation exposure, MRI or intestinal US, rather than CT scanning, should be used when possible.

UC: ulcerative colitis; CD: Crohn's disease; CRP: C-reactive protein;
ESR: erythrocyte sedimentation rate

Complications of IBD

Complications can sometimes occur in people with IBD, with some occurring in the gastrointestinal tract and others occurring outside the gastrointestinal tract (called extra-intestinal manifestations of IBD). Some complications are more serious than others and require medical and sometimes surgical treatment.[4,6]

More common complications of chronic inflammation in the gastrointestinal tract in IBD

- Narrowing (strictures) of the bowel: (Crohn's disease)
- Abnormal connection between the bowel and other body structures, such as the skin or other organs in the abdomen or pelvis (formation of abscess; fistula; Crohn's disease)
- Ulcerated tears or cracks in the lining of the anal canal (fissures): (Crohn's disease)

More serious complications of the gastrointestinal tract caused by IBD

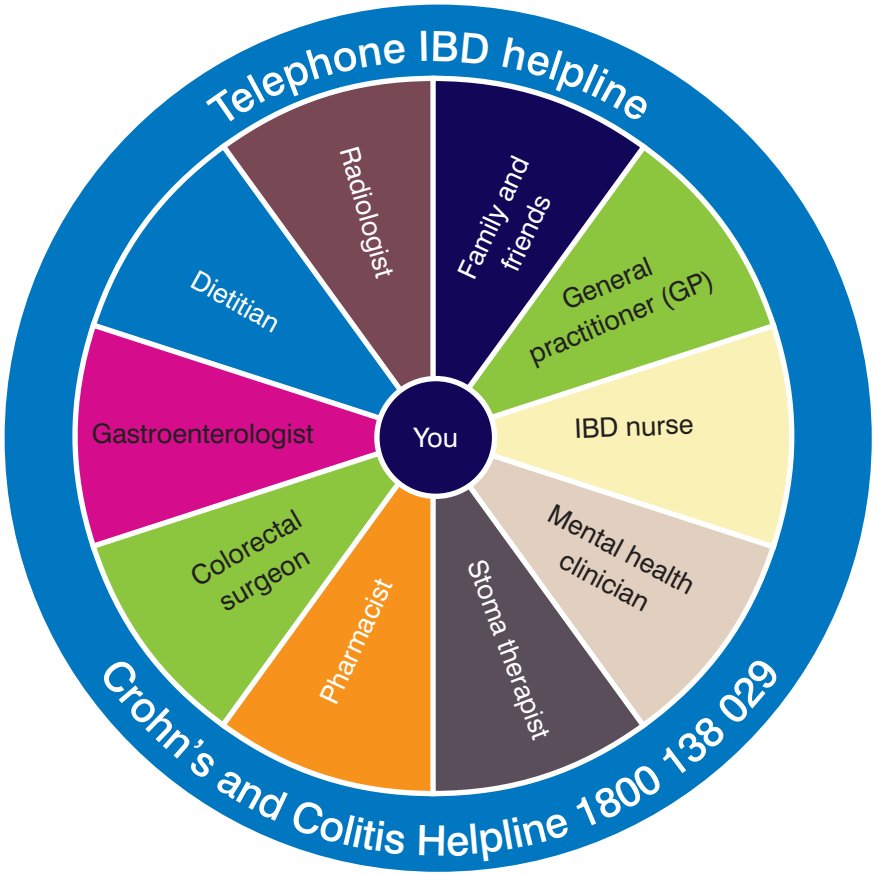
- Profuse bleeding from deep ulcers
- Perforation (rupture) of the bowel wall, potentially with intestinal contents including bacteria spilling into the abdomen causing infection
- Toxic megacolon: (ulcerative colitis) partial or full cessation of normal bowel contractions as a result of severe inflammation. If untreated, this condition can lead to surgery where the bowel is removed
- Colorectal cancer: the risk of developing bowel cancer depends on how long you have IBD and how much of the colon is affected[10]

Complications outside the gastrointestinal tract caused by IBD

- Joint inflammation (swelling and pain)
- Inflammatory skin conditions
- Inflammatory eye conditions (redness, pain and itchiness)
- Bone loss (osteoporosis)
- Liver disease (especially primary sclerosing cholangitis)
- Kidney stones
- Blood clots in veins and arteries

You and your IBD healthcare team

A team-based approach to your IBD management is seen as the best way to achieve optimal treatment outcomes.[4,10,11] Along with your IBD specialists, your GP plays an important part in helping with early diagnosis, referral when it is needed, preventive health care, education and care coordination.[4,12]



Your general health and IBD

IBD is a chronic condition that generally begins in young adulthood and lasts throughout life. People with IBD are understandably concerned about the possible impact of the disease on their general health over their lifetime, and on their ability to lead normal everyday lives.

When your disease is well managed, most people with IBD lead relatively normal lives, even though you need to take medication and make some changes to your lifestyle. When your disease is in remission, you feel well and are usually free of symptoms, although the processes causing the inflammation both inside and outside your gut might still be occurring. The majority of people with IBD can live normal lives working, marrying, having children, engaging in sport and recreational activities and travelling.

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With the right treatment, close disease monitoring and regular follow-up with an IBD clinician, people with IBD can expect the same life expectancy as anyone else.[8]

However, even for people who are well managed and in remission, the risk of their symptoms flaring never goes away. It is emotionally worrying to experience unexpected flares that can be painful and inconvenient. Continuing to take your IBD medication your doctor prescribed can significantly reduce this risk.[13] A lifelong condition such as IBD can be difficult for the person living with IBD, their family and friends to understand and accept.

Treatment strategies and IBD

IBD cannot yet be cured but it can be well managed with the use of medications to prevent inflammation and injury to the gut and provide a normal, or near normal, quality of life.[12] With better medical therapies now available, the standard of care for people with IBD is a treat-to-target approach where the target is to control the inflammation in the bowel wall to allow the mucosa to heal, preventing the next flare and reducing the chances that complications may develop.[4]

The consequences of this treatment approach should also be improvement of the associated symptoms for the person with IBD.

In some people with IBD with severe disease in which standard treatment is not successful, surgery may also be an option.

Your treatment strategy should involve an early diagnosis of your disease, appropriate and ongoing medication to lessen gut damage and then regular monitoring by your IBD specialist. Your GP and other IBD clinicians will tailor the management of your IBD including your medication to ensure that the inflammation is controlled long term, even when your symptoms are in remission.

Medical therapies for IBD

IBD can be treated with medical therapies that reduce the inflammation that causes symptoms. IBD treatment aims to induce remission to lessen intestinal damage and then to maintain remission. Your IBD care team will advise you on the best therapy options or combination of therapies for your disease, quality of life and mucosal healing. Available treatment options are summarised in the following table.

Medical therapies most commonly used to manage IBD in Australia[4,12]

Treatment	Medications available	Indication
Mild to moderate disease		
Aminosalicylates	5-aminosalicylic acid (5-ASA)	UC (and some CD): to induce remission (treat active disease) and maintain remission. Available in different preparations including tablets, granules, enemas, foam enemas and suppositories depending on disease location
Corticosteroids	Budesonide, prednisolone	UC and CD: to induce remission in those failing* 5-ASAs. Available in different preparations depending on disease location Not for maintenance
Antibiotics	Ciprofloxacin, metronidazole	CD: to treat complications especially fistulising disease
Moderate to severe disease		
Corticosteroids	Prednisolone	UC and CD: to induce remission Not for maintenance[15]
Exclusive enteral nutrition (EEN)	Liquid nutritional supplements, some of which are dairy free	CD: to induce remission (especially children) as alternative to corticosteroids To provide nutritional support
Immunomodulators	Azathioprine, mercaptopurine (6-MP), methotrexate	UC and CD: to maintain remission in those previously treated for active disease with corticosteroids
Biological agents	**TNF-α inhibitors** Infliximab	UC and CD: to induce and maintain remission in those who failed* treatment with conventional therapy (corticosteroids or immunomodulators)
	Adalimumab	UC and CD: to induce and maintain remission in those who failed* treatment with conventional therapy (corticosteroids or immunomodulators)
	Golimumab	UC: to induce and maintain remission in those who failed* treatment with conventional therapy
	Integrin inhibitor Vedolizumab	UC and CD: to induce and maintain remission in those who failed* treatment with conventional therapy
	IL-12/23 inhibitor Ustekinumab	CD: to induce and maintain remission in those who failed* treatment with conventional therapy

UC: ulcerative colitis; CD: Crohn's disease; TNF: tumour necrosis factor; IL: interleukin

*Failed: not responding, intolerant

See Consumer Medicines Information (CMI) for all medications listed at https://www.tga.gov.au/consumer-medicines-information-cmi

While you are on maintenance medication, it is important to continue medication even though you may be feeling well and not experiencing any symptoms. You are at higher risk of relapsing when you interrupt taking your medicine.[14]

Exclusive enteral nutrition (EEN)

EEN is a treatment option for active Crohn's disease (not ulcerative colitis) to achieve remission or to reduce the inflammation in your gut before surgery. EEN is safe and for some people it may be a good alternative to medications such as corticosteroids, as determined by your IBD specialist. Many children with Crohn's disease are placed on this complete, balanced liquid diet as the initial treatment.[15,16]

The diet involves replacing all food with specialised nutrition drinks to improve your overall nutrition and allow the bowel to rest. These drinks provide all the energy, protein, vitamins and minerals you need and are available in a number of different flavours. You usually follow this program for 6-8 weeks.[16]

Drugs used to treat symptoms of IBD

In addition to controlling inflammation, some medications may help to relieve the symptoms associated with IBD such as diarrhoea and pain. Always talk to your IBD clinician before taking any over-the-counter medications.

- Antidiarrhoeal medication: may relieve diarrhoea
- Bile salt binders: may relieve diarrhoea due to bile salt accumulation in your colon
- Analgesics (pain relievers): paracetamol is sometimes used for mild pain during an acute flare-up. Other analgesics such as non-steroidal anti-inflammatory drugs (NSAIDs) should be avoided as they can induce or worsen flares of IBD. The use of opiates such as codeine and morphine should be minimised as chronic use may be associated with numerous side-effects, especially constipation and physical dependence
- Iron infusion: chronic intestinal bleeding may result in iron deficiency anaemia. Intravenous iron is recommended as oral iron supplementation can aggravate intestinal inflammation and worsen symptoms in the gut.[4]

Surgery in IBD

While surgery may not be appropriate for everyone, it is an important part of the management of severe IBD when medication, diet and lifestyle changes are no longer effective or not tolerated. Surgery in severe IBD is used to remove damaged parts of the bowel if serious complications occur such as strictures, abscesses or bleeding. Advances in treatment with medications mean that surgery is less common for IBD than it was a few decades ago.

Since Crohn's disease and ulcerative colitis affect different parts of the gut, the surgical procedures are different for the two conditions. In Crohn's disease, removing part of the inflamed intestine may improve symptoms but it is not curative. The disease usually returns after surgery, but recurrence can be prevented or delayed by post-operative medications. For people with severe ulcerative colitis, surgery to remove the colon and rectum can cure the disease but patients will have to cope with both the physical and psychological consequences of surgery such as an ileo-anal pouch (an internal pouch made from the end of your small intestine and attached directly to your anus) or more rarely a permanent stoma (an external opening in your abdomen to an attached bag which collects waste).

Nutrition and IBD

Most people with IBD do not need dietary restrictions and should eat a healthy balanced diet, unless advised otherwise by their dietitian or IBD clinician. As for all Australians, it is important for people with IBD to follow a healthy, balanced diet to maintain a healthy weight and to prevent nutritional deficiencies.[12,15] This advice is particularly important for children with IBD to ensure normal growth and development. Following a healthy, balanced diet means including foods from each of the five food groups every day to make sure you get enough nutrients.[17]

- Plenty of vegetables, including different types and colours, and legumes/beans
- Fruit
- Grain (cereal) foods, mostly wholegrain and high cereal fibre varieties (with advice for your doctor)
- Lean meats and poultry, fish, eggs, tofu, nuts and seeds, and legumes/beans
- Milk, yoghurt, cheese and their alternatives, mostly reduced fat
- Drink plenty of water.

Making dietary changes can help people maintain adequate nutrition. It is most likely that you will have periods when you go through a flare of your IBD. During flares it is common to experience weight loss as a result of reduced appetite and increased nutrition needs especially in Crohn's disease and in severe ulcerative colitis.

Iron

People with IBD are more prone to iron deficiency due to increased losses in the gut, reduced absorption or reduced food intake.[4,18] It is important to eat enough iron-rich foods as it is better to get iron from your diet than from taking supplements. Good sources of dietary iron include green leafy vegetables, legumes (including lentils, nuts, tofu), fortified breakfast cereals and red meat. Iron from plant-based sources is not as well absorbed as iron from animal sources, but it is absorbed better when eaten with foods high in vitamin C.[19] Your doctor will monitor your iron levels to ensure that you are getting enough through your diet, or if you need supplements.[4]

Calcium

Another important mineral is calcium for bone health. Calcium is also important for heart, nerve and muscle functions.[20] It is found in dairy products, tinned fish containing bones, green leafy vegetables, tofu, nuts, seeds and calcium-fortified products. There is no need to restrict dairy in your diet unless you are lactose intolerant. If you suspect you may be lactose intolerant (symptoms include diarrhoea, abdominal cramping or bloating after consuming dairy products), you should talk to your doctor or dietitian, with the option of switching to low or non-lactose containing products a possible consideration. If you are restricting dairy in your diet it is important that you replace it with other calcium-rich foods. If using milk alternatives such as soy, almond or rice milk, check that they are fortified with calcium.

Fibre intake

It is not advised to follow a low fibre diet in the long term unless advised to do so by your doctor or dietitian. They may recommend you reduce the fibre in your diet when you have:[15]

- a stricture (narrowing) in the bowel (foods that are high in fibre can cause a blockage)
- a flare of your IBD, even without a narrowing in the bowel as it may help to reduce symptoms, especially abdominal pain (foods that are higher in fibre are thought to also worsen diarrhoea during a flare of IBD).

The low FODMAP diet

FODMAP stands for a group of carbohydrates (fermentable oligo-saccharides, di-saccharides, mono-saccharides, and polyols) that are poorly absorbed in the intestine, which can lead to symptoms, especially in people with irritable bowel syndrome (IBS). The symptoms of IBS are lower abdominal pain, discomfort, bloating, wind, distension and altered bowel habit. These symptoms are not caused by inflammation or other disorders. IBS can also occur in people with IBD, and can be a cause for symptoms when your IBD is in remission. The low FODMAP diet can be helpful as a treatment option for IBS and it is important you seek advice from a dietitian to start this diet as it is restrictive and is not designed to be followed long term.[15] It is also important that inflammation or blockage of the bowel is excluded as a cause for your symptoms before trialling the low FODMAP diet.[21]

Smoking and IBD

In Crohn's disease cigarette smoking is associated with greater disease activity and more flares. Quitting smoking is a highly effective way to reduce the risk of flares in people with Crohn's disease who are in remission,[4,12] although this shouldn't be a substitute for good adherence to medication prescribed by your doctor. Smoking appears to be a protective factor in the development of ulcerative colitis or to improve outcome in patients with active ulcerative colitis. However, the many potential harmful health effects of smoking such as cancer and heart disease generally outweigh any benefits for people with ulcerative colitis.[9] Adherence to medication prescribed by your doctor is the best way to prevent flares in ulcerative colitis.

Vaccinations

Immunisation for people with IBD follows the standard Australian guidelines except for those taking immunosuppressive medication.[4,22]

People with IBD receiving immunosuppressive medication are at a greater risk of infection. Soon after you are diagnosed with IBD, and before you start immunosuppressive treatment, your IBD clinician will recommend vaccinations to prevent infection. These include hepatitis A and B, tetanus, diphtheria, pertussis, human papillomavirus, the influenza ('flu) vaccine every year and the pneumococcal vaccine every 5 years. Make sure you keep your vaccinations up to date.

If you are receiving immunosuppressant medication (corticosteroids, immuno-modulators and biologics), get advice about the need to avoid live vaccines.[23] Live vaccines can be safely used only if you are receiving a 5-ASA.[4,12]

All standard vaccinations should be given to a newborn baby with the exception of babies born to a mother receiving biologics. Your IBD specialist will advise you that babies should avoid live vaccines (measles, mumps and rubella [MMR] and the rotavirus vaccine) that may be given subsequently when your baby is over 12 months old.[22,24]

Travel

Most people with IBD can travel but you should plan your trip well. The preparation you and your IBD team do before your trip is an important part of your travel. It is better to travel when you are in remission. Always ensure you have adequate travel insurance and obtain a letter from your GP or IBD specialist outlining your medical history and all medications you are currently taking. Consider your travel destination to be sure that you are comfortable with all the necessary amenities and have had all necessary vaccinations.

Ensure you take an adequate supply of medication. Keep your medications in their original packaging in case you need to show them at customs.

Your IBD team can also advise you about dietary precautions when travelling, managing your medication and dealing with diarrhoea. People with IBD are no more at risk of traveller's diarrhoea than other people. You should pay close attention to precautions regarding food and water during your travel. You should not stop your prescribed medication for IBD during a disease flare or possible gastrointestinal infection.

Check with your airline before you fly whether you can carry your medications in your hand luggage, especially if you need to take syringes.

Pregnancy, fertility and IBD

During the reproductive years, many men and women with IBD are concerned about the effect of the disease on fertility, how the changes of pregnancy will affect a woman's disease and if IBD treatments will harm their baby. With appropriate therapy and care, most women can have a normal pregnancy and deliver a healthy baby. Medical research has shown fertility rates for people with IBD are similar to the general population, although fertility might decrease if the woman has had surgery resulting in scarring and adhesions or has active disease.[4]

Ideally when planning a family, both men and women should discuss their intentions with their IBD specialist well before a pregnancy. For a woman, your IBD specialist can work out the best time to conceive when your condition is in remission. Regular medical care and adhering to your treatment plan will give you the best chance of a successful pregnancy.

Breastfeeding is generally encouraged in babies born to mothers with IBD, and may be protective.[4] Low levels of IBD medications may be found in breast milk but it is not thought to have any effect on the baby.[25]

Medications

Most medications are considered safe during pregnancy and breastfeeding although information on some medications is limited. Methotrexate cannot be taken during pregnancy. Your IBD specialist and nurse will advise you of an appropriate treatment plan.

It is important to understand the risk to the pregnancy of stopping medications and having a flare. Active disease is usually more risky than taking some medications for your IBD.[4]

Vaccinations

All standard vaccinations should be given to a newborn baby of mothers with IBD with the exception of babies born to a mother receiving immunosuppressive medication. Your IBD specialist will advise you that these babies should avoid live vaccines (measles, mumps and rubella [MMR] and the rotavirus vaccine) which may be given subsequently when your baby is over 12 months old.[22,24]

IVF

In the general population up to 15% of women have problems with infertility[26] and many seek professional advice to assist such as in vitro fertilisation (IVF). The success of IVF in all woman is influenced by many factors such as age, weight and smoking history. Currently it is not known whether IBD influences the success of IVF but there have been plenty of successful pregnancies for women with IBD who have undergone IVF treatment.[27] If you are having difficulty getting pregnant and are planning on IVF treatment, it is important to discuss your situation with your IBD specialist to consider strategies that will give you the best chance of a successful outcome.

Children and adolescents

Around 25% of people with IBD are diagnosed before the age of 20 years,[4,28] while the most common age for diagnosis is between 15 and 29 years.[29] More recently, the number of paediatric patients being diagnosed with IBD has increased, for reasons which are currently unclear. For children and young people, the disease, complications and treatment of IBD are generally similar to that of adults for both ulcerative colitis and Crohn's disease. However, for some children, the disease can be more extensive and aggressive when compared to adults. It can sometimes be difficult initially to differentiate between ulcerative colitis or Crohn's disease with the term IBD unclassified (IBD-U) given to these children's condition.

Childhood and adolescence represents a very important time for your development into adulthood. Having a long-term disease like IBD in childhood can affect developmental milestones such as growth (achieving one's final height), puberty and bone health. If IBD is diagnosed early, the IBD team will be able to advise the best treatment to achieve and maintain remission while limiting the negative outcomes of IBD on your development.

Eating well is an important part of the management of young people with IBD, as it is for adults. Good nutrition supports normal physical activity and growth, and helps prevent caloric, nutritional and vitamin deficiencies. Many children with Crohn's disease are placed on EEN as their initial treatment as an alternative to corticosteroids.[4,15]

Changing from the care of the paediatric gastroenterology team to an adult IBD team is often very stressful for young people with IBD and for their families. The IBD team with a multidisciplinary approach can support young adults to become active participants in their own healthcare management and make this change a smooth and successful transition.

Mental health and wellbeing

While stress does not cause IBD, it may be a trigger for flare-ups in some people. For people with IBD, the chronic and unpredictable nature of the disease can cause a range of psychological effects associated with fear of losing bowel control, poor body image and social isolation.

As is the case with most chronic illnesses, people with IBD are more likely to suffer from anxiety and depression than the general population.[30] These psychological symptoms tend to be more severe during flare-ups. There is some evidence that coexisting depression can make managing active disease more challenging.

There are special concerns during adolescence, a time of challenges with physical development, puberty, school completion, changing social networks and the desire to experiment with risky behaviours. Young people with IBD may experience low self-esteem that can lead to problems with schooling, work and relationships, potentially leading to social isolation.

People with IBD and their family and friends should watch out for mood changes or anxiety. It is important to talk to the IBD team and seek professional help from a psychologist or psychiatrist if needed. Treating IBD is not always as simple as just treating the disease in the gut. Management requires a multidisciplinary approach with a variety of health professionals working together with the person living with IBD and their family to achieve the best possible outcome. Mental health counselling and support groups may be helpful in dealing with the psychological impact of IBD.

Seek professional help

- Talk to your IBD care team
- Crohn's and Colitis Australia Helpline: 1800 138 029
- BeyondBlue: 1300 224 636
- LifeLine: 13 11 14
- Headspace: 1800 650 890

Sticking to your treatment program

Good management of IBD is aimed at two aspects of treatment: induction of remission and maintenance of remission.[4,12] As there is no medical cure for IBD, it is important to manage the condition throughout both flares and periods of remission. This approach depends on long-term medication. Stick to the treatment regimen you and your doctor agreed on during periods of remission even if you feel well, as the underlying disease is still present and can become active (flare-up). The consequences of non-adherence include increased risk of flares with associated symptoms and complications affecting your quality of life over the long term.[4]

Talk to your IBD care team as soon as possible if you have any side-effects from your treatment.

Three reasons to stay on your medication

- If you are sick, you have to get better
- Once you are better, you have to stay well
- Think about the long-term outcomes of your disease

It can sometimes be difficult to stay on the treatment your doctor has recommended. Some people feel uncomfortable about the idea of taking medication long term. It is important to understand exactly why you are taking the prescribed medication, and to discuss any concerns that you may have regarding your treatment plan and the condition itself with your care team.

People's lifestyles can also make adherence to the prescribed treatment difficult. If you have a busy social or working life, it can be hard to remember to have your medication with you especially when you are away from home. And it is not always convenient to take drugs that must be administered rectally such as enemas. These issues should be raised with your doctor or IBD nurse so that together you can work out strategies and a treatment plan that best fit your lifestyle. Your IBD team can balance your needs with the approach most likely to achieve the best treatment outcome for you.

Social media

Social media is an essential part of life today. It can be an effective medium for people with IBD and clinicians to communicate to improve the understanding and overall management of IBD.

The information on these websites should never be a substitute for that provided by your doctor or your IBD team. Every person with IBD is different and the management of your IBD will be specifically tailored to your needs.

Your IBD care team can suggest accredited sites for you to explore online, including those listed at the end of this guide.

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Further information

Crohn's and Colitis Australia (CCA)
www.crohnsandcolitis.com.au
IBD Telephone Helpline and Nurseline free call 1800 138 029

The Gastroenterological Society of Australia (GESA)
www.gesa.org.au/resources/inflammatory-bowel-disease-ibd/

The Australian Council of Stoma Associations Inc (ACSA)
www.australianstoma.com.au

Crohn's & Colitis Foundation of America (CCFA)
www.ccfa.org

Crohn's & Colitis UK
www.crohnsandcolitis.org.uk

The J-Pouch Group
www.j-pouch.org

The Gut Foundation
www.gutfoundation.com.au

Mind Over Gut
www.mindovergut.com

The IBD Passport
Comprehensive information about travel with IBD
www.ibdpassport.com

Australian Government
Travel advice to check specific country requirements
www.smartraveller.gov.au

The TGA Health Safety Regulation
For travellers with medicines or medical devices entering or leaving Australia
www.tga.gov.au/travellers-visitors

This booklet is available online at: **www.insandoutsibd.com.au**
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