FACT SHEET

Inflammatory Bowel Disease (IBD)

Crohn's Disease & Ulcerative Colitis

If you have recently been told you have inflammatory bowel disease there are probably many questions running through your mind. We hope this fact sheet will help you understand more about your condition, how you can help yourself, and the treatment you may receive.

What is Inflammatory Bowel Disease or "IBD"?

Inflammatory bowel disease (IBD) is a term used to describe two main diseases: ulcerative colitis and Crohn's disease, which cause inflammation of the bowel. This inflammation is thought to be due to an imbalance of the immune system, and is not due to an infection.

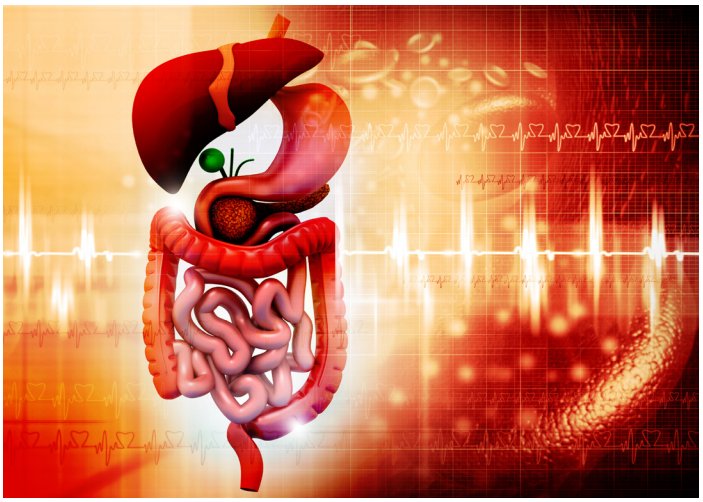
Ulcerative colitis causes inflammation of only the inner lining of the colon (large bowel), and rectum. When only the rectum is involved it is sometimes called ulcerative proctitis or just proctitis. When the entire colon is involved it is sometimes called pan-colitis.

Crohn's disease causes inflammation of the full thickness of the bowel wall and may involve any part of the digestive tract from the mouth to the anus. Most often the ileum, which is the last part of the small bowel, or the colon, or both are involved. These patterns of disease location are referred to as ileitis, colitis and ileo-colitis respectively.

Sometimes people get confused between IBD and Irritable Bowel Syndrome (IBS).

The two conditions are quite different and so are their treatments. IBD involves inflammation or damage to the bowel, whereas IBS is characterized by multiple symptoms related to the bowel including abdominal pain, diarrhoea, constipation, or bloating; but there is no inflammation and blood tests and stool tests are normal as are endoscopy, colonoscopy and imaging. IBS is thought to be due to gut hypersensitivity, hence the use of the word irritable. The two conditions IBD and IBS can, however, occur in the same person. A fact sheet on IBS is available on the GESA website.

Gastrointestinal Tract



What causes ulcerative colitis and Crohn's disease?

Despite a great deal of research, the precise causes of ulcerative colitis and Crohn's disease are unknown. There is evidence, however, that genetic, environmental, immunological and microbiology factors are all involved to a degree, and it may be their interaction in susceptible people that causes IBD to develop. Ulcerative colitis and Crohn's disease are not contagious diseases. Relatives of people with IBD have a slightly greater risk of developing either disease, but even if both parents have IBD a child will still have a greater than 60% chance of NOT having it. Stress and/or diet alone are not thought to cause IBD, although attention to both these factors improves quality of life with IBD. Smoking can increase the chance of developing Crohn's disease and disease activity. Both diseases are more common in the Western world, although their incidence is also rising in developing countries.

Who gets IBD?

It is estimated that about 75,000 Australians have IBD (in 2018). IBD often develops between the ages of 15 and 30 but can start at any age; it is uncommon, but is increasingly being diagnosed.

What are the symptoms of IBD?

People with either ulcerative colitis or Crohn's disease can develop pain in the abdomen, diarrhoea (usually with blood and mucous when you have ulcerative colitis), tiredness and weight loss (especially with Crohn's disease). Some people may also experience fever, mouth ulcers or nausea and vomiting. People with Crohn's disease may also get pain or swelling around the anus, with or without a discharge. A few people have disease affecting other parts of the body and may experience swollen joints, inflamed eyes, skin lumps or rashes.

Symptoms vary from person to person based on where the disease is in the body and how severe the inflammation is. It can flare up or improve over time. When you experience worsening symptoms, you should see a doctor promptly to assess the disease activity. Many people will experience periods of remission when they are completely free of symptoms.

The goal of medical therapy is to prolong these periods of remission, and prevent repeated flares of disease activity. With current medical treatment, life expectancy is normal.

What tests are used to confirm the diagnosis of ulcerative colitis or Crohn's disease?

The diagnosis of Crohn's disease or ulcerative colitis is often delayed as the symptoms can be non-specific. When symptoms and signs are severe, the diagnosis is usually made promptly, but in milder cases delays in diagnosis are common.

In general, unless symptoms have been ongoing for more than 8 weeks, it is usually necessary to exclude bowel infections or gastroenteritis (which may occur from contaminated food or after a prolonged course of antibiotics). In mild cases, without rectal bleeding or weight loss, IBS is often first suspected, as it is far more common than IBD. Any abnormal test results, however, should guide the diagnosis away from IBS.

Tests which help point towards a diagnosis of IBD include blood tests which may show a low red blood cell count, raised white cell or platelet count and elevation in CRP or ESR, which are markers of inflammation in the body. Blood tests are also useful to look for complications of IBD, such as iron deficiency or other vitamin or mineral deficiencies. A faecal (bowel motion) specimen may need to be examined to exclude infection and/or to assess the severity of inflammation.

Most people require an examination of part of the bowel, either by direct inspection via a flexible tube inserted through the anus (colonoscopy or sigmoidoscopy) or the mouth (gastroscopy), or by radiology imaging, which may include CT or MRI. There is no one test that can reliably diagnose all cases of IBD, and many people require several tests.

Depending on the severity of your symptoms, it is common for it to take 6-18 months from the first onset of symptoms until a positive diagnosis of IBD is made. In most cases this delay does not lead to any additional problems.

How is IBD treated?

The goals of treatments are to 1) control inflammation 2) ease symptoms and 3) correct nutrition deficiencies, if required, in order to heal the gut. Treatment options involve medications, surgery, nutritional supplements or a combination of therapies depending on the location and severity of the disease.

Medications

Medications are important to achieve and maintain remission (no symptoms and gut healing). The response to each medication may differ between individuals and many need combination of drugs.

- **Aminosalicylates** are a class of medications that help to control mild disease in ulcerative colitis. It includes medications such as sulfasalazine, olsalazine, basalzide, and mesalazine under a variety of brand names.

These medications can be taken orally or delivered directly into the rectum as a suppository or enema.

- **Corticosteroids** help to control moderate to severe inflammation in both ulcerative colitis and Crohn's disease. Medications are available in oral tablets (prednisolone or budesonide), topical therapies (suppositories and enemas) or in intravenous form. These medications help to reduce inflammation quickly but due to the side effects they should not be used long-term. You should not start or stop the medication suddenly without discussing it first with your doctor.
- **Immunomodulator medications** include azathioprine, mercaptopurine and methotrexate. These medications dampen the immune response to treat the inflammation of IBD. These medications can take up to 3 months to start working. It is important to check your blood tests regularly when initially starting immunomodulators to monitor for possible side effects.
- **Biologic treatments** are used in patients with moderate to severe IBD who do not respond to other treatments. These drugs target inflammation potently and specifically to quickly induce healing of the gut. Since these medications are expensive and require intravenous or subcutaneous injection, government subsidy is not available for all patients.

  There are many emerging therapies under research, which will be available in near future.
- **Other medications**

  For pain management, **paracetamol** can be used safely but NSAIDs (e.g. ibuprofen) or opioids (e.g. endone) should be avoided as it can make disease worse.

  For severe diarrhoea, **loperamide** may be helpful but it should only be taken for short periods of time.

  Antibiotics are given to prevent or treat infections from complications of the disease, especially in Crohn's disease.

Importance of taking medications

Medications need to be taken regularly for the long-term to control inflammation. If you don't take medications regularly, even though you may feel well briefly, it can result in significant flares of your symptoms and complications affecting quality of life in the long-term. However, some patients can be weaned off medications, or have their dose reduced, if disease is under good control, the bowel is healed, and after consultation with your treating specialist.

If you feel unwell while taking medications, rather than just stopping the medication, talk to your specialist about ways to reduce side effects.

Most medications are safe to take during pregnancy and breastfeeding, but discuss this with your specialist.

Surgery

Medication helps many patients, but for some it is not enough to relieve symptoms. In Ulcerative colitis, removing the entire large bowel, including rectum, can be curative, but for Crohn's disease it is not a cure, though it can help ease symptoms or treat complications. There are many different types of surgery that are performed depending on your disease location and severity. Some may require having a temporary stoma (bag), but frequently this can be avoided.

Nutritional therapy and diet

Nutritional therapy such as exclusive enteral nutrition (EEN) for active Crohn's disease or supplemental enteral nutrition in general is important to maintain remission and provide nutritional support. These consist of liquid nutritional supplements, some of which are dairy-free.

Most people with IBD do not need dietary restrictions and can eat a healthy balanced diet. Good nutrition is very important. Some foods can trigger symptoms for different people so certain changes in diet may help improve symptoms. For example spicy or fatty foods, and foods with a high fibre content (e.g. some fruits, vegetables, nuts and wholemeal grains) can make your symptoms worse. Speak to your specialist or dietician about what nutrition step would be best for you.

When you have active disease, sometimes it is hard for particular nutrients to be absorbed by the inflamed gut. After blood tests, some people may need to take vitamin tablets or require vitamin B12 injections or an iron infusion.

Emotional management

As with other illnesses, stress may make symptoms worse, so stress management and emotional support is helpful in combination with medical treatment. Speak to your doctor, psychologist or psychiatrist about what management would be best for you. Also joining IBD support groups locally or through a website may be helpful.

Can people with IBD lead a normal life?

The vast majority of people with IBD lead normal lives, even though they need to take medications. When their disease is in remission, they feel well and are usually free of symptoms.

People with IBD can marry, engage in sexual activity and have children. They can hold down jobs, care for families and enjoy sport and recreational activities.

Special considerations

Pregnancy

IBD has no direct effect on fertility in either males or females. The single most important thing to have a successful pregnancy and delivery is to have your IBD under control before you attempt to become pregnant and during pregnancy. Bad outcome usually results from active disease NOT from medications. Therefore, it is important to discuss with your specialist BEFORE you attempt pregnancy, and to continue your IBD medications unless a decision is made with your doctor to cease them.

Travelling

Whether you are going on a short or long trip, travelling with IBD can present special challenges such as risk of flare, infections and travelling with certain medications. Sometimes your medications can suppress your immune system so caution is required when travelling to places with high infection risks. Make sure you talk to your doctors and plan ahead.

Vaccination

People with IBD may be at increased risk of infection because of the use of immune suppressive medications. Some of these infections are preventable with timely and diligent use of vaccination, such as flu. However, live vaccination should be avoided. Talk to your doctor about it if you are not already up to date with your vaccination schedule.

Screening for cancer

It is more important to be diligent with cancer screening compared with the general population. Make sure you are up to date with skin checks and Pap smears.

Smoking

Smoking can make your symptoms worse especially in Crohn's disease. Giving up smoking is as good as taking a medicine and reduces the risk of flare by up to 65%.

Others

When you are starting new medications or undergoing any invasive procedures/surgery unrelated to your IBD, it is important to let your doctor know.

When to seek urgent medical attention?

- Severe abdominal pain
- Persistent vomiting, accompanied by constipation
- Significant or new rectal bleeding
- Drastic changes in bowel movements
- High temperature
- Severe fatigue, tiredness
- Weight loss
- Red itchy eyes, sores in the mouth, swollen and painful joints, bumps or lesions on the skin

Further information:

Mental health:

- www.beyondblue.org.au
- www.lifeline.org.au

National Bowel Cancer Screening Program:

- https://www.health.gov.au/our-work/national-bowel-cancer-screening-program

National Cervical Cancer Screening Program:

- https://www.health.gov.au/our-work/national-cervical-screening-program

Patient Support Groups:

- Crohn's and Colitis Australia: https://crohnsandcolitis.org.au/

Diet in IBD:

- GESA Diet in IBD patient information fact sheet: https://www.gesa.org.au/public/13/files/Education%20%26%20Resources/Patient%20Resources/IBD/GESA%20IBD%20and%20Diet.pdf
- Dietitians Association of Australia: https://dietitiansaustralia.org.au/

Requests and enquiries concerning reproduction and rights should be addressed to: The Gastroenterological Society of Australia (GESA) Level 3 517 Flinders Lane Melbourne VIC 3000 | Phone: 1300 766 176 | E-mail: gesa@gesa.org.au | Website: http://www.gesa.org.au

This document has been prepared by the Gastroenterological Society of Australia and every care has been taken in its development. The Gastroenterological Society of Australia and other compilers of this document do not accept any liability for any injury, loss or damage incurred by use of or reliance on the information. This work is copyright. You may download, display, print and reproduce this material in unaltered form only (retaining this notice) for your personal, non-commercial use, or use within your organisation. Apart from any use as permitted under the ***Copyright Act 1968,*** all other rights are reserved. © 2018 Gastroenterological Society of Australia ABN 44 001 171 115.