

Information about

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 leaflet 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 dysfunction of your immune system, and is not due to an infection.

Ulcerative colitis causes inflammation of only the inner lining of the colon and rectum (large bowel). 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 (back passage). Most frequently the ileum, which is the last part of the small bowel, 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 Inflammatory Bowel Disease (IBD) and Irritable Bowel Syndrome (IBS).

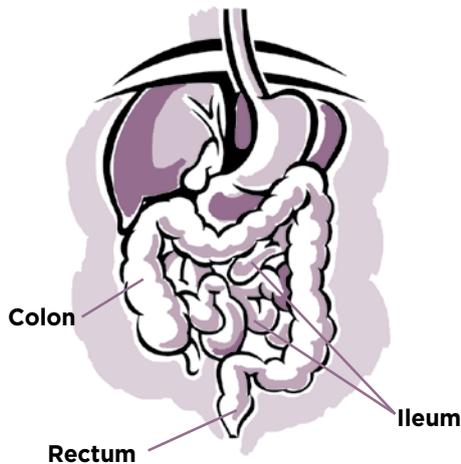
The two conditions are quite different and so are their treatments. **Inflammatory Bowel Disease** is where there is visible inflammation or damage to the bowel, whereas in **Irritable Bowel Syndrome** there are multiple symptoms related to the bowel (abdominal pain, diarrhoea, constipation, bloating), but blood tests are normal and nothing can be seen with endoscopy/colonoscopy or x-rays. It is thought to be due to nerve sensitivity, hence the use of the word *irritable*. The two conditions IBD and IBS can, however, occur in the same person. IBS is discussed in other literature available from the DHF.



An information leaflet for patients and interested members of the general public prepared by the Digestive Health Foundation

SECOND EDITION 2011

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 infectious (bacterial) 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 you 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. Both diseases are more common in the Western world, although their incidence is also rising in developing countries.

Who gets IBD?

IBD often develops between the ages of 15 and 30 but can start at any age; it is uncommon, but becoming increasingly seen, in children. It is slightly more common in women in Australia than in men. It is estimated that about 61,000 Australians have IBD, approximately 28,000 have Crohn's disease and 33,000 have ulcerative colitis.

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, or jaundice (yellow discolouration of the skin).

The symptoms and their severity vary from person to person and usually flare up or improve over time. Many people will experience periods of remission when they are completely free of symptoms. Medical therapy these days aims to prolong these periods of remission, rather than allowing 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 same symptoms can occur with other diseases. When symptoms and signs are severe, the diagnosis is usually made promptly, but in milder cases delays are usual. In general, unless symptoms have been going 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 diagnosed, as IBS is far more common than IBD. Any abnormal test result, however, should guide the diagnosis away from IBS.

Tests which help point towards a diagnosis of IBD include blood tests which may show anaemia, 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.

Most people require an examination of part of the bowel, either by direct inspection via a flexible tube inserted through the back passage (colonoscopy or sigmoidoscopy) or mouth (gastroscopy), or by x-rays, which may include CT or MRI scan and/or barium small bowel series (where dye is swallowed and x-rays are taken). There is no one test that can reliably diagnose all cases of IBD, and many people require several tests, although the diagnosis of IBD is usually strongly suspected from a careful medical history.

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 type of treatment you will be offered depends on whether you have ulcerative colitis or Crohn's disease, which part of your gut is affected and how severe your disease is. There are also some opportunities for you and your doctor to choose between treatments that are similarly effective, but may have different actions and side effect profiles.

Ulcerative colitis

The treatment of ulcerative colitis depends on the amount of the large bowel affected and the severity of the inflammation. If the disease is confined only to the lower part of the bowel, a mild attack may be treated with drugs (such as mesalazine or steroids) given directly into the rectum through the back passage (e.g. by an enema or suppositories).

When more of the bowel is affected, your doctor may suggest you take medicine by mouth. Medicines used to treat IBD include sulphasalazine (Salazopyrin), coated mesalazine (Mesasal, Salofalk granules and tablets, Pentasa tablets and granules), Mezavant tablets, balsalazide sodium (Colazide) or olsalazine sodium (Dipentum). Steroid tablets (usually prednisolone) may be required if the inflammation is more severe or if more extensive amounts of the bowel are involved. Steroids however are only useful for acute treatment of flares and SHOULD NOT be used long-term. Likewise, steroid treatment for flares should not be used repeatedly, and if you require more than one course of steroids in a 12 month period, you should discuss better maintenance therapy options with your specialist. Occasionally anti-diarrhoeal medicines (e.g. loperamide (Imodium) or Lomotil) may be helpful, but these should not be used to control new onset of diarrhoea, which may indicate a flare of disease, without discussion with your doctor.

Most people in remission are advised to take a medicine to reduce the chance of a relapse (a return of the symptoms); this is called maintenance therapy. Mesalazine in one of its forms (as outlined above) is usually effective as maintenance treatment. Maintenance treatment has been shown to reduce the number of flares, keeping you well for more of the time. If you are not on a maintenance therapy, you may wish to discuss this with your doctor.

If your ulcerative colitis is difficult to control, with multiple flares or severe disease, medicines that alter the activity of the body's immune system may sometimes be used both to settle ongoing inflammation and as maintenance treatment. These medicines are referred to as immunomodulator or immunosuppressant drugs. Commonly used immunomodulators in ulcerative colitis include azathioprine (Imuran or Thioprine) or 6-mercaptopurine (6-MP or Puri-Nethol), and methotrexate. For the most severe attacks, treatment

in hospital with steroids given directly into a vein may be required. Sometimes with a severe attack, when intravenous steroids are not helpful, stronger immunosuppressant drugs are used intravenously to prevent the need for surgery to remove the bowel. This is only rarely required.

If drug treatment is not effective, surgery to remove the rectum and colon may be recommended. If this is done the disease is cured and cannot return. Your doctor will fully discuss the surgical options available to you and there will be time to talk with a specialist nurse or another person who has already undergone an operation for ulcerative colitis.

Crohn's disease

The medicines used to treat Crohn's disease are mostly the same as those used for ulcerative colitis, however there are some differences. Medicines like mesalazine are of less benefit in Crohn's disease. Therefore, as long-term steroid therapy is not advisable because of the risk of side-effects, immunomodulators (azathioprine, 6-mercaptopurine or methotrexate) are used both more commonly and earlier in Crohn's disease compared to ulcerative colitis. These drugs are used both acutely to help control the inflammation and as maintenance therapy. These immunomodulators generally take some weeks to exert their full effect however, and because of this, active Crohn's disease is generally initially treated with steroids (prednisolone) either as tablets (if you are well enough to be at home) or intravenously through a drip (if you are sick enough to be in hospital). Sometimes, antibiotics are also used, especially if there are complications of your disease.

Where standard drug treatment is ineffective, other, new generation therapies may be used. These generally target the inflammation of IBD more powerfully. These newer drugs are licensed for use in Australia but are expensive, and government subsidy is not available for all patients. Your doctor can discuss this with you in more detail if it is thought to be required. These agents are given into a vein in hospital every eight weeks (Infliximab - Remicade) or administered by injection into the skin fortnightly at home (Adalimumab - Humira). They require screening for certain infections before starting therapy, and you need to take additional precautions regarding vaccinations, infections and travel while on these agents. If you need more information on these therapies, ask your specialist or hospital IBD nurse.

In contrast to ulcerative colitis, it is not possible to remove the entire bowel that may be affected by Crohn's disease, so the disease cannot be cured by surgery. However, surgery is great for treating complications of the disease such as a blockage, leak or abscess in the bowel, and also to remove the worst affected areas if drug treatment is ineffective. Surgery may also be necessary for people with Crohn's disease

of the anus, especially to drain abscesses so that medical therapy can work more effectively.

In Crohn's disease, when surgery is performed, a conservative approach is generally adopted, to keep as much of the gut intact as possible.

After an operation your doctor may recommend that you take maintenance therapy, as this is shown to reduce the chance of the disease returning in the future. You should discuss this with your gastroenterologist. It is not recommended to stay off therapy after an operation for Crohn's disease unless you are having regular reviews to ensure any recurrent disease is promptly attended to.

How important is diet?

Most people with IBD do not need special food and can eat a healthy balanced diet. It is particularly important to eat enough to prevent weight loss. Some people are advised to take nutritional supplements to maintain their weight. If you find that you can eat a normal mixed balanced diet without any ill effects, then continue to do so.

There is no evidence that ulcerative colitis or Crohn's disease are due to food allergies. You may find that some foods seem to make your diarrhoea worse, particularly spicy or fatty foods, and foods with a high fibre content (e.g. some fruits, vegetables, nuts and wholemeal grains). If so, it is sensible to reduce the amount of these foods in your diet. Some people with Crohn's disease who may have a narrowed area in their bowel, may be advised to consume a low fibre diet to avoid blockages. This is usually only a short-term solution while your doctor tries to treat the narrowing with drugs. If this is unsuccessful an operation to remove (or open up) the narrowing should allow you to return to a normal diet.

A few people with Crohn's disease are unable to absorb particular nutrients. These individuals may need to take vitamin or mineral tablets. Some require an injection of vitamin B12 every 3 months. Nutritional deficiency is uncommon in people with ulcerative colitis, although blood loss can lead to anaemia (a low blood count), which may require iron tablets. However, there is little evidence to suggest that extra vitamins or special food supplements are necessary or helpful for most people with Crohn's disease or ulcerative colitis.

Inflammatory bowel disease in children

IBD is uncommon in children but does occur. Children with IBD develop the same symptoms as adults. However, untreated IBD can lead to delayed or impaired growth and it is important to keep inflammation under control to prevent this. The treatment of children with ulcerative colitis or Crohn's disease is very similar to that of adults with IBD.

Can people with IBD lead a normal life?

The vast majority of people with IBD lead useful and productive 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 marry, engage in sexual activity and have children. They hold down jobs, care for families and enjoy sport and recreational activities.

Even though there is no cure for IBD, current medical therapy has improved the health and quality of life of most people with ulcerative colitis and Crohn's disease. There is good reason to believe that research underway today will lead to further improvements in medical and surgical treatment of inflammatory bowel disease.

Digestive Health Foundation

The Digestive Health Foundation (DHF) is committed to promoting better health for all Australians through education and community health programs related to the digestive system. The DHF is the educational arm of the Gastroenterological Society of Australia (GESA). GESA is the professional body representing the specialty of gastrointestinal and liver disease. Members of the Society are drawn from physicians, surgeons, scientists and other medical specialties with an interest in gastrointestinal disorders. GI disorders are the most common health related problems affecting the community.

Research and education into gastrointestinal disease are essential to contain the effects of these disorders on all Australians.

Further information on a wide variety of gastrointestinal conditions is available on our website.

dhf

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