

facts about...

CROHN'S DISEASE & ULCERATIVE COLITIS

INFLAMMATORY BOWEL DISEASE (IBD)

If you have recently been told you have inflammatory bowel disease (IBD) 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 large bowel (colon 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 (back passage). Most frequently the ileum, which is the last part of the small bowel, the large bowel (or 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. The two conditions (IBD & IBS) can, however, occur in the same person. IBS is discussed in other literature available from the DHE.

What causes ulcerative colitis and Crohn's diseases?

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. There is no evidence that ulcerative colitis or Crohn's disease is a contagious disease. Relatives of people with IBD have a slightly greater risk of developing either disease. Stress and/or diet alone are not thought to cause IBD, although attention to both these factors is likely to improve your 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 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 disease can develop pain in the abdomen, diarrhoea (loose and/or frequent bowel motions, sometimes with blood and mucous), tiredness and weight loss. Some people may also experience fever, mouth ulcers or nausea and vomiting. People with Crohn's disease of the anus can experience pain (especially while passing a bowel motion) or an itch around the anus. A few people have disease affecting other parts of the body and may



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experience swollen joints, inflamed eyes, skin rashes or jaundice (yellow discolouration of the skin). The symptoms and their severity vary from person to person and may flare up or improve over time. Many people will experience periods of remission when they are completely free of symptoms. 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. It is usually necessary to exclude other diseases such as bowel infections (which may occur from contaminated food or after a prolonged course of antibiotics) or irritable bowel syndrome.

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 through 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.

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 (UC)

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 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 (eg. 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), balsalazide (Colazide) or olsalazine (Dipentum). Steroid tablets (usually prednisolone) may be required if the inflammation is more severe or if more extensive amounts of the bowel are

involved. 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.

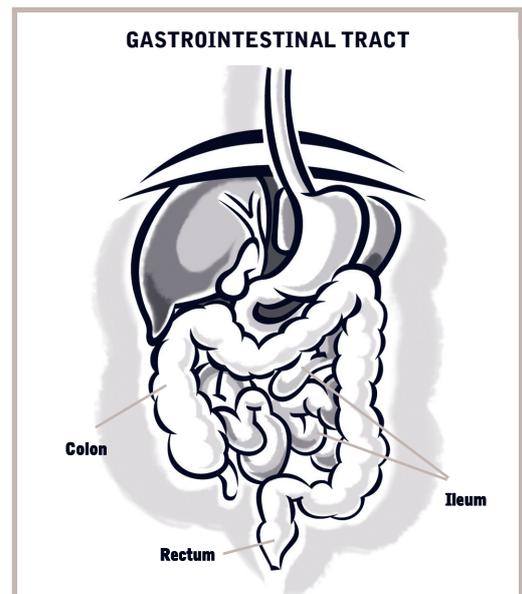
Most people in remission (when the disease has settled down and the bowel movements and other symptoms have returned to normal) are advised to take a medicine to reduce the chance of a relapse (a return of the symptoms); this is called maintenance therapy. Mesalazine in one of its forms (as outlined 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 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 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 rarely required.

If drug treatment is not effective, surgery to remove the large bowel (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 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 too sick to be at home and must stay in hospital). Sometimes, antibiotics are also used, especially if you have 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.

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, some people do require surgery if drug treatment is ineffective, or if Crohn's disease causes a blockage or leak in the bowel. Surgery may also be necessary for people with Crohn's disease of the anus that is not responding to tablets.

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.

You can obtain more detailed information about the medicines used in the treatment of ulcerative colitis and Crohn's disease from the ACCA/DHF publication "Drugs and Inflammatory Bowel Disease", and more information on surgery from the ACCA/DHF publication "Surgery and Inflammatory Bowel Disease". You can also get more information about the medicines used on the GESA website, www.gesa.org.au

How important is diet?

Most people with IBD do not need a special diet 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 foods with a high fibre content (eg. fruits, vegetables, nuts and wholemeal grains), spicy foods or fatty foods.

If so, it is sensible to reduce the amount of these foods in your 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.

For more information on nutrition and diet in IBD, see the GESA leaflet entitled: Dietary Advice for Chronic Gastrointestinal Disease.

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.

This information booklet has been designed by the Digestive Health Foundation as an aid to people who have Ulcerative Colitis or Crohn's Disease or for those who wish to know more about it. This is not meant to replace personal advice from your medical practitioner.

The Digestive Health Foundation (DHF) is an educational body committed to promoting better health for all Australians by promoting education and community health programs related to the digestive system.

The DHF is the educational arm of the Gastroenterological Society of Australia, the professional body representing the Specialty of gastrointestinal and liver disease in Australia. Members of the Society are drawn from physicians, surgeons, scientists and other medical specialties with an interest in GI disorders.

Since its establishment in 1990 the DHF has been involved in the development of programs to improve community awareness and the understanding of digestive diseases.

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.



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This brochure is promoted as a public service by the Digestive Health Foundation. This leaflet cannot be completely comprehensive and is intended as a guide only. The information given here is current at the time of printing, but may change in the future.

If you have further questions you should raise them with your own doctor.

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Digestive Health Foundation,
updated August 2007.