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IBD, Crohn's Disease & Ulcerative Colitis
Frequently Asked Questions

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What is Crohn's disease?

Crohn's disease, is an inflammatory condition that can be found in any part of the gastrointestinal tract, from the mouth to the anus, but most commonly it involves the lower end of the small intestine (ileum) and/or the large intestine (colon). Areas of inflammation can appear interspersed with healthy parts of the intestine and may involve the full thickness (all layers) of the intestine.

Sometimes different names are used to describe the part of the intestine that is involved. When Crohn's is confined to the ileum it may be referred to as 'ileitis', whereas for the ileum and colon it is 'ileocolitis', and when only the colon is involved it is called 'Crohn's colitis', or shortened to just 'colitis', which can be confusing. Most people prefer to just call it 'Crohn's'.

What is ulcerative colitis?

Ulcerative colitis, or simply 'colitis', is also an inflammatory condition, but is confined to the inner lining of the large intestine and rectum. It is almost always present in the rectum and tends to be continuous in appearance involving either the lower part only, or extending further along the entire length of the large intestine.
When limited to the rectum, the correct term is 'ulcerative proctitis'. In a few individuals it is not possible to distinguish whether they have Crohn's disease or ulcerative colitis. The condition is then referred to as indeterminate colitis.

How many people in Australia have IBD?

No accurate figures exist as to how many people in Australia have IBD, but it is estimated that there are possibly 30,000 people with Crohn's and a similar or lesser figure for ulcerative colitis.

In recent years there appears to have been a dramatic rise in the number of people with Crohn's disease, whereas ulcerative colitis seems to have levelled out. The most common age groups to be diagnosed with Crohn's disease and ulcerative colitis are those in their teens and twenties, followed by those in their forties and fifties, although people of all ages are diagnosed, including young children and the elderly.

Who is at risk of developing IBD?

IBD can develop in anyone, most often striking people considered to have been healthy. No particular lifestyle factors have been identified to determine who may get IBD, although it is predominantly found in the developed world and Caucasian populations. There is a 10 to 20 percent risk of developing IBD if another family member has already been diagnosed.

What causes IBD?

Research work around the world has revealed some possibilities, including various environmental, bacterial and viral factors, but no one cause (or causes) of IBD has been established. Further work is progressing, including identifying the genes involved in IBD. Studies have shown no evidence to date that diet or emotional stress causes IBD.

What are the symptoms of IBD?

The symptoms of IBD vary depending on the area of involvement; extent and severity of disease, and whether any complications have arisen, but abdominal pain, diarrhoea, the passing of blood and fatigue are commonly experienced. Other signs and symptoms may include nausea and vomiting, constipation, a low-grade fever, weight loss and nutritional deficiencies.

In Crohn's disease, symptoms usually have a gradual onset over many months or years, whereas ulcerative colitis tends to be develop more quickly. Sometimes symptoms occur from several other conditions (some inflammatory) that develop outside of the IBD, although not everyone will have these problems. These affect the skin (mouth ulcers, tender red bumps or blisters on the lower legs), the joints (pain, swelling and stiffness) and the eyes (redness, tenderness and ocular changes).

The liver and bile ducts can also be affected, but symptoms are not usually present until problems have reached an advanced stage.

How is IBD diagnosed?

A physical examination, taking a full history and blood tests may provide useful clues, but looking inside the bowel with the use of an endoscope (colonoscopy) and taking tissue samples for further examination in the laboratory is an important diagnostic tool used to investigate IBD. Barium X-ray may also be needed to detect abnormalities and to investigate those parts of the gastrointestinal tract that cannot be reached by the endoscope. Other tests may also be required.

Despite all these tests being performed, it can sometimes be difficult to diagnose Crohn's disease. There is usually no delay in finding ulcerative colitis.

What complications can occur in IBD?

Commonly in Crohn's disease and rarely in ulcerative colitis, injury to the bowel from the inflammation and ulceration can result in complications.

In Crohn's disease, inflammation and scarring can narrow or obstruct the intestine making it too small for digested food or faeces to pass through. Small breaks in the bowel wall can also occur, resulting in the development of abscesses and fistulas. These are abnormal channels that connect between loops of bowel or to other hollow organs opening out of the body (bladder, vagina), allowing stool to leak through. They can also track through from the bowel to the skin surface.

Abscesses and fistulas are often found in the perianal region. In severe, acute ulcerative colitis, severe bleeding, perforation (open break of the bowel wall) or toxic megacolon (ballooning out of the bowel) can occur. People with ulcerative colitis over many years have a higher risk of developing cancer of the bowel, especially if not treated.

What treatment is available for IBD?

Medical treatment to help reduce the inflammation and other effects currently include the use of oral corticosteroids, various other anti-inflammatory medications from the aminosalicylate group of drugs and rectal preparations. Immunosuppressants (used in organ transplants and some other conditions) are also widely used in IBD, but at much lower doses and help to modulate the immune system and suppress inflammation.

Antibiotic medications may also be needed, in particular for the treatment of abscesses and fistulas. Anti-diarrhoeal and other drugs are less commonly used to help alleviate symptoms. Some of the drug therapies are taken only for the period of time that disease is active (symptoms are present), while others may need to be continued even when disease is inactive. The specialist doctors primarily involved in the medical management of IBD are gastroenterologists.

Surgery can become necessary if the drug treatment is no longer effective or if a complication develops. Up to 75 percent of people with Crohn's disease will have surgery at some time during their lives, however advances in medical management are helping to reduce the need for surgery.

The most common operation is to cut out the affected portion of intestine and rejoin the two ends. This does not result in a cure though, as the disease tends to recur. Sometimes removal of the large intestine (colon) may be required and depending on whether the rectum can be saved, it may result in the need to have the end of the small intestine brought out onto the abdomen permanently. This is called an ileostomy and a special appliance (bag) will need to be worn to collect waste from the small intestine.

Surgery may be required for the drainage of abscesses and for fistula repair. In ulcerative colitis, up to 30 percent of people will go on to have surgery, which does bring about a cure.

The operation of choice nowadays is a pelvic pouch. This involves removing the large intestine and rectum, and fashioning a whole new pouch out of the end part of the small intestine, which is brought down and positioned in the pelvis to connect to the anal opening. Occasionally this operation may not be suitable and a standard ileostomy may be required. When surgery has been recommended, this is arranged with a surgeon who normally does bowel surgery i.e., a colorectal surgeon.

Other treatment approaches include advising smokers with Crohn's disease to stop smoking, as it has been found to make this condition worse. Special liquid nutritional supplements for Crohn's disease can be helpful during flare-ups and newer products that contain anti-inflammatory properties have been used successfully helping to reduce or eliminate the need for steroid medications - an important option for children considering their growth and development needs.

Alternative therapies, including herbal remedies, acupuncture, massage and aromatherapy might be helpful in dealing with some of the effects of the IBD, however they should only be used complementary to conventional medicine. Care also needs to be taken that they do not interfere or react with existing treatments. Therefore it is important to choose a practitioner who has the appropriate credentials recognised by their professional body and is willing to work in with the treating doctor.

What about surgery?

Surgery can become necessary if the drug treatment is no longer effective or if a complication develops. Most people with Crohn's disease require surgery at some stage, most commonly to remove a severely affected portion of the intestine. Unfortunately, surgery in Crohn's disease does not result in a cure. Only a small number of people with ulcerative colitis require surgery, but when performed, the most common procedure involved results in a cure. In both conditions where an operation requires complete removal of the colon and rectum, a permanent stoma (intestinal opening) is brought out on the abdomen. A procedure for an internal pouch is available for people with ulcerative colitis.

Is there a special diet for IBD?

There is no specific diet for people with IBD, but some modification to the diet when the disease is active, such as eliminating foods that may aggravate symptoms, can be helpful.

Some individuals may find that a bland diet is better tolerated. A low fibre diet may be more comfortable for people with Crohn's affecting the small intestine, which when narrowed may result in pain after having eaten.

As IBD can result in malabsorption of nutrients and loss of fluids, attention to diet is still important to ensure there is adequate nutrition for the body's needs. Some of the medications used can also deplete the body of minerals and folic acid. People with IBD may experience nutritional problems as a result of a poor appetite, which can lead to weight loss.

What about children with IBD?

IBD in children and adolescents is managed in much the same way as adults, although greater attention is needed to ensure they are not at risk of poor growth and development as a result of the IBD and steroid medications used.

Are women with IBD able to have children?

Women with IBD are generally able to fall pregnant, carry a baby to term and have a normal birth, no different to most other women, although medication to control the IBD is often required during pregnancy and lactation.

What impact does IBD have on people's lives?

Fortunately, modern medical treatment has helped considerably to improve the quality of life for people with IBD, allowing most individuals to lead a full and normal life. However, when disease is active and symptoms are present, then the daily life of a person with IBD can be altered dramatically.

The effects of the illness, medications and their side effects, the uncertainty of what will happen and other concerns may cause people to feel anxious and have difficulty coping. Therefore, being well educated about IBD (as well as becoming familiar with the particular characteristics of your condition), and having access to information and support, are essential in being able to develop good coping skills and learning to live with IBD.

Where can I get help?

Help is available through various support organisations. The Australian Crohns & Colitis Association (Queensland) Inc. (ACCAQ) is one such organisation.

ACCAQ services include:

- providing information and educational material on IBD to people diagnosed, their families, friends, careers, medical/health professionals and the general public;
- providing support through telephone contact, literature, support group meetings, educational meetings, social events, hospital visits (where possible), library facilities, and contact with other members.

ACCAQ activities include:

- production of education material;
- promotion of awareness of IBD and ACCAQ;
- publication of newsletters quarterly;
- help in establishing support groups
- fundraising;
- support of medical research into IBD;
- exchange of information and contact with other Australian groups.

For more information, please contact the ACCAQ.