

# Crohn's disease

## Why is it called 'Crohn's disease'?

Although Crohn's disease existed for possibly 300 years before it was named, it was only distinguished from other conditions with similar symptoms by a New York physician, Burrill Crohn, in 1932.

## What is Crohn's disease?

Crohn's disease is an inflammatory bowel disease in which the wall of one or more segments of the gastrointestinal tract becomes thickened, inflamed and swollen. The inflammation may involve only a few centimetres of the intestine or may be much longer, over a metre or more. Any part of the gastrointestinal tract from the mouth to the anus can be affected and there may be more than one area of involvement at one time.

The most common sites of involvement are the last part of the small intestine (the terminal ileum) and the colon (the large

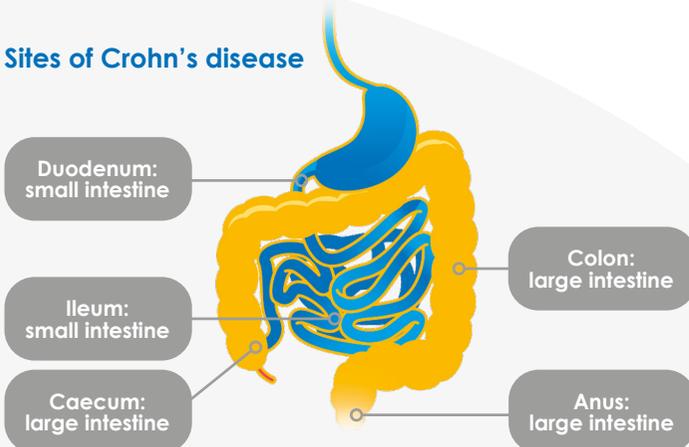
intestine). They can be involved either alone or together. Crohn's disease affects all the layers of the bowel wall from the inside lining to the outside wall.

Inflammation in or around the anus is also common. This may take the form of fissures (cracks) in the skin of the anal canal, fistulae (small openings discharging pus) around the anus, or tags (swollen but often painless lumps) just outside the anus. Crohn's disease is sometimes referred to as an autoimmune disease, a term used where the body's immune system turns on itself by producing inflammation.

## What is meant by Crohn's disease being a 'chronic' disease?

An acute disease is one that runs a short, sharp course; for example, the "flu". A chronic disease, on the other hand, can give trouble over a number of years, although there may be long periods of good health alternating with episodes of symptoms lasting for weeks or months. Crohn's disease frequently runs this type of 'relapsing and remitting' course.

## Sites of Crohn's disease





Crohn's disease can start at any age although it is rare at the extremes of life. It most commonly appears for the first time between the ages of 15 and 40.

Unfortunately, no doctor can predict when a relapse is likely to occur, nor can they guarantee that the future will be trouble-free, even when all visible evidence of Crohn's disease has disappeared following medical or surgical treatment.

### What are the symptoms of Crohn's disease?

Depending on the site of involvement, the intestinal inflammation of Crohn's disease usually produces abdominal pain and often diarrhoea. Sometimes narrowing of the bowel due to scarring or thickening of the bowel wall causes a blockage (obstruction) to the onward passage of bowel contents. Symptoms from this can cause nausea, vomiting, pain and abdominal distension. Blood in bowel motions may accompany diarrhoea in people with disease involving the colon or rectum.

Feelings of tiredness and lethargy are very common symptoms. People may have a loss of appetite, and weight loss can occur. Anaemia (low red blood cell count) can develop, which can contribute to fatigue due to iron and vitamin B12 deficiencies. Disease around the anus (fissures and fistulae) can also cause pain, drainage of fluid and pockets of infection called abscesses. Many treatments, both medical and surgical, can alleviate these problems.

### Can Crohn's disease affect other parts of the body?

**Yes.** A small proportion of people with Crohn's disease suffer episodes of

inflammation affecting the eyes, skin, the joints, and spine. A few others develop inflammation in the liver, but this is usually recognised by blood tests rather than by symptoms. People with Crohn's disease may also have painful mouth ulcers which can be related to their IBD.

### Is Crohn's disease only a disease of young people?

**No.** Crohn's disease can start at any age although it is rare at the extremes of life. It most commonly appears for the first time between the ages of 15 and 40, a time of life when people normally expect good health to cope with the challenges of studying and starting careers or families. It is equally common in men and women.

### Why do people with Crohn's disease lose weight?

The active phases of Crohn's disease are usually accompanied by a diminished appetite, and people may also be frightened to eat for fear of worsening their pain or diarrhoea. Sometimes weight loss is a result of failure to absorb nutrients because of extensive inflammation of the small intestine.

In addition, severe inflammation causes the body to burn more energy, which can accelerate weight loss. While people often lose weight with Crohn's disease, some people maintain their weight, and some people might even gain weight.



## How is Crohn's disease diagnosed?

Crohn's disease may be suspected in a patient, particularly a young adult, who develops diarrhoea, abdominal pain and weight loss that lasts for weeks or months. Routine blood tests can provide clues that someone might have Crohn's disease. A person may have anaemia (low haemoglobin or red blood cell count) due to loss of blood in the stool or difficulty absorbing iron.

A C-reactive protein (CRP) is a protein in the blood that sometimes increases with inflammation in the body. Some people may have an elevated white cell count. Your doctor may request a stool sample to measure calprotectin, which is a protein found in white blood cells that is often elevated when there is inflammation in the intestines.

A colonoscopy is the single most useful examination to diagnose Crohn's disease. 90% of patients will have abnormalities that are diagnostic of Crohn's disease. A colonoscopy is an examination whereby, after drinking three to four litres of a special

washout fluid to clean out the colon, a flexible tube with a video camera at the tip called a colonoscope is passed through the anus to inspect the entire colon and the end of the small intestine.

This test is usually done under sedation to make it easier and more comfortable. Some patients may also need a gastroscopy (examination of the stomach with a similar flexible tube called a gastroscope). A capsule endoscopy may be performed, whereby a capsule containing a miniature video camera is swallowed and takes a movie of the small intestine as it moves through the intestinal tract.

Other tests that can assist in making diagnosis or treatment decisions are performed in the radiology department. These include CT or CAT scans, MRI scans (which use a powerful magnet instead of X-rays to take pictures), and ultrasound studies. Sometimes the diagnosis of Crohn's disease is made at the time of an urgent exploratory operation.

## Why should a colonoscopy and other examinations need to be repeated?

Specialists looking after Crohn's disease patients will aim to avoid repeated examinations, but from time to time these may be necessary to reassess the changes in the small and large intestine that may occur over time and may result in a change of treatment plan.

## Is Crohn's disease hereditary?

**No**, not in the same sense as colour blindness or a disease such as haemophilia is hereditary. However, there seems to be some inherited contribution to the development of the disease in that some patients have one or more relatives with Crohn's disease. If you have the disorder, there is a 10-25% chance a relative will also have an inflammatory bowel disease. The risk that a child will get Crohn's disease if one of their parents has it is about 5%.

## What causes Crohn's disease?

Despite a great deal of research, the cause of Crohn's disease remains uncertain. It is not an infectious illness that can be passed from people with Crohn's disease to previously healthy individuals. It is thought that individuals with Crohn's have a genetic

predisposition to developing the disease and that some sort of trigger to the immune system, perhaps a bacterium or element in the environment, plays a role in causing Crohn's to develop.

## Is Crohn's disease a psychosomatic illness?

**No**, Crohn's disease is not psychosomatic, although sometimes the disease can flare during times of stress. Remember that stress and depression can also be brought on by having to deal with a chronic illness and it is important to share these feelings with those who are close to you, your doctor, and your nurse.

## Is Crohn's disease influenced by diet?

No items of the normal Western diet and no food additives have been found to cause Crohn's disease.

In general, people with Crohn's disease will benefit from the high nutritional content of a varied and ample diet. This should approach, as near as possible, to a normal diet, although individuals may wish to avoid specific foods which they know from personal experience will worsen their symptoms. Please refer to the '**Nutrition and diet**' chapter.



A colonoscopy is the single most useful examination to diagnose Crohn's disease. 90% of patients will have abnormalities that are diagnostic of Crohn's disease.

## Is Crohn's disease worsened by activity or work?

**No**, activity and work do not make Crohn's disease worse. However, at times people may feel too unwell to work or their work will be impacted by a hospitalisation or surgery. People with Crohn's disease should be encouraged to pursue their normal work and leisure activities as much as possible, including sport and remaining fully engaged in family life.

## How will Crohn's disease affect a person's future?

The course of Crohn's disease varies considerably from person to person and can be unpredictable. Some people have very active disease and require intensive medical treatment, and sometimes surgery. However, many people never have more than mild episodic symptoms, have long periods of remission, and are able to live relatively normal lives.

## Can Crohn's disease be cured?

Unfortunately, no known treatment, either medical or surgical, can be guaranteed to completely and permanently eliminate Crohn's disease at this time. However, medical treatment and (sometimes) surgery are frequently very effective in controlling the disease for long periods of time.

## Why is Crohn's disease not always treated by an operation?

Although Crohn's disease may appear to be confined to one or two segments of the intestine, other areas of intestine can become involved in the future. Also, after an operation, the disease often

recurs at the site of the surgery where the two sections of healthy bowel had been reconnected.

Since Crohn's is not cured by surgery and almost always returns, doctors try to reserve surgery for those who have problems with bowel blockages or severe symptoms that cannot be controlled with medications.

Additionally, if someone has several surgeries and more and more of the intestine is removed over time, problems with poor nutrition and diarrhoea can occur – not from the Crohn's disease but from a shortened bowel. Doctors therefore try to achieve a balance between the benefits and risks of surgical treatment.

## When do patients with Crohn's disease need surgery, and what operations are involved?

Troublesome problems around the anus such as abscesses and fistulae may have to be dealt with by local surgical drainage procedures. Other major surgery involves removal of severely inflamed or narrowed segments of the small or large intestine. Please refer to the chapter '**Surgery in IBD**' for more information.

## What special problems do children with Crohn's disease have?

While in adults the reduced intake of food, inflammation and bowel obstructions associated with active Crohn's disease leads to weight loss, in children it may also slow down growth and delay sexual development. Thus, great emphasis is placed on restoring nutritional intake and controlling inflammation.



Nutritional supplements – medicines such as immunomodulators, infliximab or adalimumab, and even surgery – may need to be used more aggressively in children than in adults to optimise growth potential.

Children and young people may also have special challenges due to loss of time from school and feeling isolated and different from their peers. Many benefit from attending CCNZ's Camp Purple Live, a free camp for children and teens with IBD, where they can meet other children and adults who understand their challenges, make friends, and gain a greater understanding of their illness.

Please see the chapter '**IBD in children and adolescents**' for more information.

### **What about pregnancy and Crohn's disease?**

Please see the chapter on '**Sexuality, Fertility, and Pregnancy**'.

### **Is Crohn's disease really a form of bowel cancer?**

**No.** Crohn's disease is not bowel cancer, although the symptoms can be similar.

### **Is any research done on Crohn's disease?**

**Yes.** An enormous amount of research has been and is being done on the causes and treatment of Crohn's disease and other chronic inflammatory disorders of the intestine, such as ulcerative colitis.

Crohn's disease is a disease that frustrates patients and provides a constant challenge to doctors. Nevertheless, little by little, the pieces of the puzzle will be put together so that more effective treatments, and in time a cure, will be found.