



## FUNDING RESEARCH TO FIGHT DISEASES OF THE GUT, LIVER & PANCREAS

### THIS FACTSHEET IS ABOUT CROHN'S DISEASE

Crohn's disease is a condition in which inflammation develops in various parts of the gut leading to symptoms such as diarrhoea, abdominal pain and tiredness. In some cases, the inflammation can be very mild whilst in others it may be severe, requiring strong medication or even surgery to remove an affected part of the intestine. Crohn's disease is one of the two conditions known as Inflammatory Bowel Diseases (IBD), with the other being ulcerative colitis.

The disease is most usually diagnosed in young adults but it can also affect teenagers, younger children and older people with the disease spread between men and women equally. About 4 in 1000 people have the condition (most people know one person affected by the condition) and it can run in families – about one-fifth of people with the condition will have another family member who has the disease.

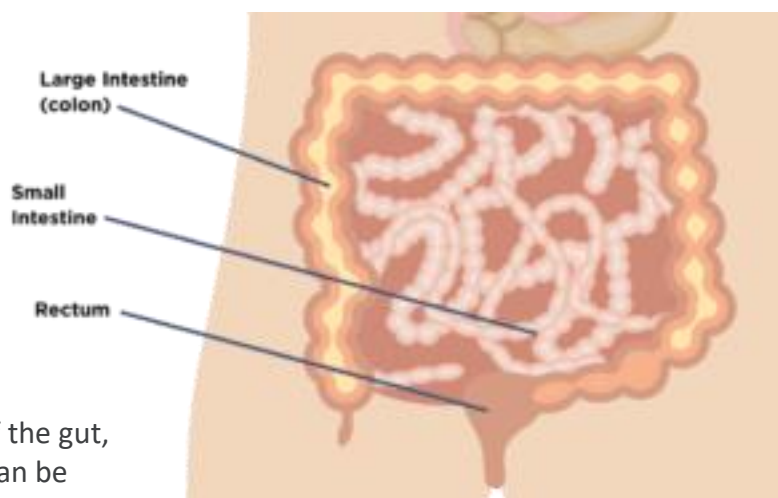
### CAUSES

#### CAUSES OF CROHN'S DISEASE

It is thought that the disease develops because of the immune system in the intestine reacting abnormally to bacteria at the surface of the gut. It is likely to be hereditary, a number of genes which are responsible for how our body handles bacteria in the gut have been identified and it is thought that they may play a part in the development of Crohn's disease. It is still not known if one, a few or many types of bacteria are involved. Other factors affect the chances of getting Crohn's disease with smoking being the most important risk factor. Many patients ask whether there is a dietary cause but there is no firm evidence of this.

#### HOW DOES CROHN'S DISEASE AFFECT THE BODY?

In most people, Crohn's disease results in patches of inflammation in the lining of the intestine with groups of small ulcers, known as aphthous ulcers, which are similar to mouth ulcers. In moderate or severe cases, these ulcers become much larger and deeper with a lot of surrounding inflammation. The inflammation can make the wall of the intestine thicken up, as well as narrow the width of the gut and block the passage of digested food. In some cases, deep ulcers break through the wall of the intestine causing infection outside the bowel (an abscess). Sometimes, if the infection doesn't heal, or if the infection heals but still leaves a channel, a tract (known as a fistula) can open up from the bowel to other areas, most frequently around the anus. In addition, as the inflammation heals, scar tissue may form which can in some cases also lead to a blockage in the intestine.



Any part of the gut, from the mouth to the anus, can be affected. The most common area is the

small intestine (terminal ileum) and the first part of the large intestine (or 'colon'), near the appendix. In some people, only the colon is affected, which is a pattern similar to a disease called ulcerative colitis, and so is known as Crohn's colitis. In others, multiple parts of the gut are affected and, rarely, the mouth, gullet or stomach. In some people, the inflammation in the gut also triggers inflammation outside the intestine leading to arthritis, eye inflammation or skin complaints. These are known as extra intestinal symptoms.

## **SYMPTOMS**

### **WHAT ARE THE USUAL SYMPTOMS OF CROHN'S DISEASE?**

The main symptoms are diarrhoea and abdominal pain, usually shortly after eating as the food and faeces builds up in the narrowed or inflamed areas of the gut. Sometimes, there is a tight blockage in the intestine causing severe, griping abdominal pain after eating, with swelling of the abdomen and vomiting. This is an emergency situation and urgent medical advice should be sought. There may be some blood or mucus in the faeces, especially when the lowest part of the gut is affected. Losing weight is a common symptom and can either be due to pain, avoiding eating or because food is not being absorbed properly. Extreme tiredness, known as fatigue, can also occur for a variety of

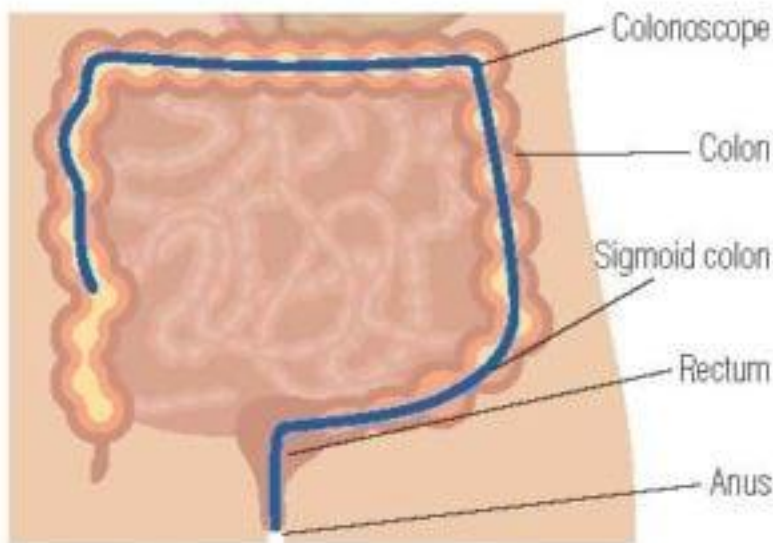
reasons, including anaemia, vitamin and mineral deficiency, medication side effects, poor sleep or low mood. Some people also have a temperature or sweats at night. There may also be sore, red eyes, swollen painful joints and skin rashes. Some patients get perianal Crohn's disease which means that inflammation occurs around the anus and genitals.

## HOW IS CROHN'S DISEASE DIAGNOSED?

There are many causes of diarrhoea in young adults including Irritable Bowel Syndrome (IBS) and infection, for example after travel abroad. So, when someone visits their GP with symptoms of persistent diarrhoea and abdominal pain, the doctor has to decide whether special tests are needed to look for the possibility of Crohn's disease or other conditions. The doctor will listen to the symptoms, ask about any of the related symptoms described above and also whether there is anyone in the family with Crohn's disease or ulcerative colitis. A simple examination will then find out if there are any signs of inflammation (such as tenderness in the abdomen or a lump) and whether there are any general signs of illness such as looking pale or underweight. A blood test might be arranged to see if there are changes in the blood, which suggest inflammation. If the doctor suspects that Crohn's disease is a possibility, he may refer to a specialist or first request a stool sample. If this shows that inflammation is present referral to a specialist will then be made for further diagnostic tests. Further tests may include:

- **Colonoscopy:**

This is the most commonly used test for the diagnosis of Crohn's disease. This is where a tube, linked to a highly magnified video system, is passed, via the anus, into the colon and where possible the end of the small intestine. A colonoscopy gives a very accurate picture of the lining of the intestine and allows the doctor to take samples for examination in the laboratory if needed. Laxative preparation is needed before the examination to clear the bowel and allow good views of the lining of the intestine. In most cases, sedation is given to minimise some feelings of discomfort associated with passage of the tube along the colon. If the colon and last part of the small intestine are seen to be normal, Crohn's disease is very unlikely to be present.



If the entire intestine needs to be examined there are several options including:

- **Magnetic resonance imaging (MRI):** the patient is placed inside a machine that creates detailed pictures of the inside of the body and can be used to check the structure and function of the gut.
- **Capsule endoscopy:** a capsule containing a tiny camera is swallowed and transmits pictures as it passes through the intestine.
- **Barium Follow Through:** liquid barium is swallowed and x-rays are taken as it passes through the intestine.

Scans such as ultrasound or CT scanning may also be needed, especially if an abscess or problems on the outside of the intestine are suspected.

## TREATMENT

### WHAT TREATMENT IS AVAILABLE FOR CROHN'S DISEASE?

The aim of any treatment for Crohn's disease is to heal or reduce the inflammation in the intestine as well as deal with the effects of the disease, such as weight loss. The inflammation is generally treated with medicines but in some cases surgery is required to remove very inflamed or narrowed sections of intestine.

### DIET

Many patients ask whether they should change their diet, but there is no proven specific diet for Crohn's disease. There are, however, diets which can ease certain symptoms. The most frequent dietary change is a reduction in fibre and indigestible foods, which may cause pain when there is a narrowing in the intestine (a 'low fibre diet').

Specialised liquid formula diets ('elemental' or 'polymeric' diets) are also used as treatment in Crohn's disease, especially when it affects the small intestine. These diets rest the bowel, improve nourishment and are used especially in children where maintaining growth and weight is very important.

If you require dietary advice, ask your consultant or IBD team for a referral to a registered gastroenterology dietitian.

## MEDICINES

These are mainly directed at the immune system in the intestine and include:

- **Antibiotics:** (e.g. metronidazole) these can be helpful, either by reducing the bacteria, which 'drive' the inflammation, or to treat abscesses. They are not used for long-term treatment.
- **Aminosalicylates:** these are a relative of aspirin and used to treat milder inflammation or reduce the chances of recurrence (for example, after an operation). Not all patients are helped by these drugs.
- **Steroids:** these are much stronger drugs used to suppress inflammation when the symptoms are more severe. Steroids are very effective (about eight out of ten patients have a good response) but some steroids can have side effects such as weight gain, insomnia, infection and acne. Prolonged use can result in thinning of the bones, although a steroid called budesonide has far fewer side effects than the standard steroids such as prednisolone. Steroids are therefore only used as a short-term measure to get Crohn's disease under control.
- **Immunosuppressive drugs:** these are often used to reduce inflammation over a longer period and allow steroids to be stopped. Azathioprine and 6-mercaptopurine are the most frequently prescribed and around two-thirds of patients have a successful response. Most patients tolerate the drugs well and they are currently the most commonly used medicine for keeping Crohn's disease under control. Methotrexate is another immunosuppressive drug, commonly used for treating rheumatoid arthritis. This is usually the next choice if azathioprine or 6-mercaptopurine have failed.
- **Biologics:** over the last few years the use of these drugs has become more common as evidence increases about their benefits and safety, with newer, improved forms of these medications becoming available each year. The best-known biological therapies target a substance called tumour necrosis factor (TNF) and are given by a regular intravenous drip or an injection under the skin. These include infliximab, adalimumab and golimumab. Other similar treatments, which target different inflammatory mediators are now available, including vedolizumab and ustekinumab. These treatments are very effective but can also have side effects, especially increased rates of infection and allergic reactions, so they are usually reserved for people with moderate to severe Crohn's disease, or when other medicines have not worked. They need to be used under care of hospital specialists and it is important that you discuss any concerns or questions with your healthcare team.

## SURGERY

Surgical operations can be a very important part of the treatment of Crohn's disease. The main reason for needing surgery is to remove thickened blocked segments of the intestine which medicines are usually unable to tackle. The surgical removal of the affected intestine usually works very well, results in few problems post-operatively and restores full health quickly. Surgery is also usually carried out when badly affected parts of the intestine have caused an abscess or fistula in the abdomen or in the perianal area. An operation can sometimes also be the best option when severe Crohn's disease is not responding to drug treatment. Occasionally, colonoscopy with special dilating balloons can be used to open up narrowed sections.

- **Stoma surgery:** many people presume that surgery for Crohn's disease means having a permanent stoma bag. In fact, stomas (ileostomy or colostomy) if used, will often be temporary. After a section of affected intestine has been removed, a very delicate join (or 'anastomosis') is made between the unaffected ends of the intestine. In order to protect this join while it heals, the surgeon will then create a temporary stoma, which is then taken away at a second, smaller operation a few months later. This happens particularly when someone is underweight or taking steroids which reduce the ability of body tissues to heal.

## SUPPORT

### HOW CAN CROHN'S DISEASE AFFECT ME OVER TIME?

As there is no cure for this condition it can return, often in the section of intestine just above a surgical join. However, despite this, most people have no problems for many years after their operation. There is a reduced chance of recurrence in people who only had Crohn's disease in the terminal ileum at the time of surgery. Recurrence is two times more likely in smokers compared to those who do not smoke. Medications including antibiotics and immunosuppressants may help to reduce the chance of recurrence and doctors will make a decision based on the individual risks of a particular patient.

Overall, Crohn's disease does not have a significant effect on the chances of becoming pregnant or carrying a baby. Risks include inflammation or infection in the pelvis or surgery to this area which can affect the ovaries, fallopian tubes or uterus reducing fertility but this is rare. The commonly used drugs in Crohn's disease are safe during pregnancy, however methotrexate must not be taken when considering a pregnancy because it carries a known risk to a forming foetus. Other medications such as sulfasalazine are known to reduce male fertility, but this is reversible when the medication is no longer taken. It is always best to talk to your specialist if you have Crohn's disease and are planning a pregnancy or are already pregnant.

In most cases, the condition does not have much impact on daily life, the ability to work or to enjoy an active social life but does take some getting used to. When it is at an active stage, symptoms such as diarrhoea and abdominal pain often require time away from work, college etc and can make it difficult to cope going out or even being at home.

However, treatment usually makes the symptoms better within days or weeks so normal quality of life is restored quite quickly. Crohn's disease does not increase your risk of dying.

## WHAT TO ASK YOUR DOCTOR?

- Is my Crohn's disease well controlled?
- What monitoring do I need?
- Is my steroid intake being kept to the minimum?

## WHAT OTHER RESOURCES AND ORGANISATIONS CAN HELP?

There are many forums and support groups around for those who suffer from Crohn's disease to join and get help. You can find more information from:

### **Crohn's and Colitis UK (CCUK)**

CCUK are the UK leading charity working on Crohn's disease and other inflammatory bowel diseases (e.g. ulcerative colitis).

<https://www.crohnsandcolitis.org.uk>

### **forCrohns**

forCrohns mission is to fund research that helps those with the condition today and contributes to finding a cure for Crohn's disease in the future whilst making more people in the UK aware of the disease and its symptoms.

<http://forcrohns.org>

**[For further information, visit gutscharity.org.uk](https://gutscharity.org.uk)**