

Crohn's disease

Introduction

Crohn's disease is a long-term condition that causes inflammation of the lining of the digestive system.

Inflammation can affect any part of the digestive system, from the mouth to the back passage, but most commonly occurs in the last section of the small intestine (ileum) or the large intestine (colon).

Common symptoms can include:

diarrhoea

abdominal pain

fatigue (extreme tiredness)

unintended weight loss

blood and mucus in your faeces (stools)

People with Crohn's disease sometimes go for long periods without symptoms or with very mild symptoms. This is known as remission. Remission can be followed by periods where symptoms flare up and become particularly troublesome.

Why it happens

The exact cause of Crohn's disease is unknown. However, research suggests that a combination of factors may be responsible. These include:

genetics – genes that you inherit from your parents may increase your risk of developing Crohn's disease

the immune system – the inflammation may be caused by a problem with the immune system (the body's defence against infection and illness) that causes it to attack healthy bacteria in the gut

previous infection – a previous infection may trigger an abnormal response from the immune system

smoking – smokers with Crohn's disease usually have more severe symptoms than non-smokers

environmental factors – Crohn's disease is most common in westernised countries such as the UK, and least common in poorer parts of the world such as Africa, which suggests the environment (particularly sanitation) has a part to play

Treating Crohn's disease

There is currently no cure for Crohn's disease, so the aim of treatment is to stop the inflammatory process, relieve symptoms (induce and maintain remission) and avoid surgery wherever possible.

The first treatment offered to reduce symptoms is usually steroid medication (corticosteroids). If this doesn't help, medication to suppress the immune system (immunosuppressants) and medication to reduce inflammation may be used.

In some cases, surgery may be needed to remove the inflamed section of intestine.

Once your symptoms are under control (in remission), further medication may be needed to help maintain this.

Who is affected?

Crohn's disease is a relatively uncommon condition.

Crohn's disease can affect people of all ages, including children. However, most cases first develop between the ages of 16 and 30.

A large number of cases also develop between the ages of 60 and 80.

It affects slightly more women than men, but in children more boys are affected than girls.

The condition is more common in white people than in black or Asian people. It is most prevalent among Jewish people of European descent.

Complications

Over time, inflammation can damage sections of the digestive system, resulting in additional complications such as narrowing of the intestine (stricture), or a channel developing between the end of the bowel and the skin near the anus or vagina (fistula). These problems usually require surgical treatment.

Symptoms of Crohn's disease

The symptoms of Crohn's vary depending on which part of the digestive system is inflamed.

Common symptoms include:

recurring diarrhoea

abdominal pain and cramping, which is usually worse after eating

extreme tiredness (fatigue)

unintended weight loss

blood and mucus in your faeces (stools)

You may find that you experience all or only one of the above. Some people experience severe symptoms, but others only have mild problems.

There may be long periods that last for weeks or months where you have very mild or no symptoms (known as remission), followed by periods where the symptoms are particularly troublesome (known as flare-ups or relapses).

Less common symptoms include:

a high temperature (fever) of 38°C (100°F) or above

feeling sick (nausea)

being sick (vomiting)

joint pain and swelling (arthritis)

inflammation and irritation of the eyes (uveitis)

areas of painful, red and swollen skin – most often the legs

mouth ulcers

Children with Crohn's disease may grow at a slower rate than expected because the inflammation can prevent the body absorbing nutrients from food.

When to seek medical advice

You should contact your DOCTOR if you have:

persistent diarrhoea

persistent abdominal pain

unexplained weight loss

blood in your faeces (stools)

You should also see your DOCTOR if you are concerned about your child's development.

Causes of Crohn's disease

The exact cause of Crohn's disease is unknown. Most researchers think that it is caused by a combination of factors.

These are thought to be:

genetics

the immune system

smoking

previous infection

environmental factors

There is no evidence to suggest a particular diet can cause Crohn's disease, although changes to your diet can help control certain symptoms and may be recommended by your specialist or dietitian.

Genetics

There is evidence to suggest that genetics plays a role in the development of Crohn's disease.

Researchers have identified more than 200 different genes that are more common in people with Crohn's disease than in the general population.

There is also evidence that Crohn's disease can run in families. About 3 in 20 people with the condition have a close relative (mother, father, sister or brother) who also has Crohn's disease. For example, if you have an identical twin with the condition, you have a 70% chance of also developing it.

The fact that Crohn's disease is more common in some ethnic groups than in others also suggests that genetics plays an important role.

The immune system

The immune system provides protection against harmful bacteria that could potentially find their way into the digestive system.

The digestive system is also home to many different types of so-called "friendly bacteria" that help digest food. The immune system usually recognises these bacteria and lets them do their job without attacking them.

However, in Crohn's disease it seems that something disrupts the immune system, which sends a special protein known as tumour necrosis factor-alpha (TNF-alpha) to kill all bacteria, regardless of whether they are friendly or not. This causes most of the inflammation associated with Crohn's disease.

Previous infection

In certain genetically susceptible individuals, a previous childhood infection may lead to an abnormal immune response, causing the symptoms of Crohn's disease.

One possible source of this infection is a bacterium called *Mycobacterium avium* subspecies *paratuberculosis* (MAP). MAP is commonly found in cows, sheep and goats.

Research has found that people with Crohn's disease are seven times more likely to have traces of MAP in their blood compared with the general population.

MAP has been known to survive the pasteurisation process (where milk is treated with heat to kill bacteria), so it is possible that people have become infected with MAP by drinking milk from contaminated animals.

However, the exact role that MAP may play in the development of Crohn's disease is uncertain and some researchers dispute this theory.

Smoking

Aside from family history and ethnic background, smoking is the most important risk factor for Crohn's disease. Smokers are twice as likely to develop the condition compared with non-smokers.

Furthermore, people with Crohn's disease who smoke usually experience more severe symptoms compared with those who have the condition but do not smoke.

Environmental factors

There are two unusual aspects of Crohn's disease that have led many researchers to believe that environmental factors may play a part. These are explained below:

Crohn's disease is a "disease of the rich". The highest number of cases occurs in developed parts of the world, such as the UK and the US, and the lowest number occur in developing parts of the world, such as Africa and Asia.

Crohn's disease became much more widespread from the 1950s onwards.

This suggests that there is something associated with modern Western lifestyles that increases a person's risk of developing the condition.

One theory to explain this is known as the hygiene hypothesis. It suggests that as children grow up in increasingly germ-free environments, their immune system does not fully develop because of a lack of exposure to childhood infections. However, there is little in the way of hard scientific evidence to support this theory.

An alternative theory is the cold-chain hypothesis, which suggests that the increase in the number of cases of Crohn's disease might be linked to the increased use of refrigerators after the Second World War.

Diagnosing Crohn's disease

A number of different tests may be needed to diagnose Crohn's disease, as it has similar symptoms to several other conditions.

Initial assessment

During your initial assessment, it is likely that your DOCTOR will ask you about the pattern of your symptoms and check whether there may be any contributing causes, such as:

diet

recent travel – for example, you may have developed travellers' diarrhoea while travelling abroad

whether you are taking any medication, including any over-the-counter (OTC) medicines

whether you have a family history of Crohn's disease

Your DOCTOR may also carry out a series of standard tests to assess your general state of health. For example, they may:

check your pulse

check your blood pressure

measure your weight and height

measure your temperature

examine your abdomen (tummy)

Blood tests

Your DOCTOR may then arrange a series of blood tests. These can be used to assess:

the levels of inflammation in your body

whether you have an infection

whether you are anaemic (have low levels of red blood cells), which could suggest you are malnourished

Stool sample

You may be asked to provide a stool sample, which can be checked for blood and mucus. It can also be used to determine whether your symptoms are being caused by a parasitic infection such as roundworm, or other infections.

After you have provided a stool and blood sample, you will probably be referred to a gastroenterologist (a specialist in conditions of the digestive system). They will discuss the results with you and carry out the tests described below if they are necessary.

Colonoscopy

A colonoscopy is a test used to examine the inside of your colon. It involves inserting a long flexible tube called an endoscope into your colon through your back passage (rectum).

The endoscope has a light and a camera on the end. The camera can be used to send images to a television screen. These will show the level and extent of inflammation inside your colon.

The endoscope can also be fitted with surgical tools that can be used to take a number of small tissue samples from different sections of your digestive system. This is known as a biopsy. The procedure may feel uncomfortable, but it is not painful.

These tissue samples will be examined under a microscope for the cell changes known to occur in cases of Crohn's disease.

Wireless capsule endoscopy

A wireless capsule endoscopy is a new type of test that involves swallowing a small capsule (about the size of a large vitamin tablet). The capsule works its way down to your small intestines, where it transmits images to a recording device worn on a belt or in a small shoulder bag.

A few days after the test, the capsule passes out of your body in a stool. The capsule is disposable so you do not have to worry about retrieving it from your stools.

As this is a relatively new test, availability may be limited. In some cases, MRE or CTE scans may be used instead of capsule endoscopy.

MRE and CTE scans

Scans called magnetic resonance enterography/enteroclysis (MRE) or computerised tomography enterography/enteroclysis (CTE) may be used to examine the small intestine in people with suspected Crohn's disease.

Before having these scans you will either need to drink a harmless liquid called contrast agent (enterography), or contrast agent may be placed through a tube in your nose that leads to your small intestine (enteroclysis). These contrast agents allow your small intestine to show up more clearly during the scans.

During an MRE scan, magnetic fields and radio waves are used to produce detailed images of your small intestines. During CTE scans, several X-rays are taken and assembled by computer to create a detailed image.

These tests are increasingly used instead of a small bowel enema or small bowel follow-through because they allow more detailed examination of the small intestine. MRE scans also avoid any exposure to X-ray radiation.

Small bowel enema or small bowel follow-through

A small bowel enema (SBE) and small bowel follow-through (SBFT) are two similar tests that have traditionally been used to examine the whole of the inside of the small intestine, usually at the point where it meets the colon. They are

sometimes used because only about the last 20cm of the small intestine is usually seen during colonoscopy.

During an SBE/SBFT, a local anaesthetic spray is used to numb the inside of your nose and throat. A tube is passed down your nose and into your throat before being threaded into your small intestine. This can feel unpleasant at first, but most people find that they get used to the sensation after a few minutes.

A harmless liquid called barium is passed down the tube. The barium coats the lining of your small intestines so that they show up clearly on X-ray. A series of X-ray images will then be taken. The images can often highlight the areas of narrowing and inflammation that are caused by Crohn's disease.

After the test, you will be advised to drink plenty of fluid to help wash the barium out of your body. You may notice that your stools look white for the first few days after having an SBE or SBFT. This is perfectly normal and it is nothing to worry about.

Treating Crohn's disease

There is currently no cure for Crohn's disease, but treatment can help improve the symptoms.

The main aims of treatment are to:

reduce symptoms, known as inducing remission (remission is a period without symptoms)

maintain remission

In children, treatment also aims to promote healthy growth and development.

Your treatment will usually be provided by a range of healthcare professionals, including specialist doctors (such as gastroenterologists or surgeons), DOCTORs and specialist nurses.

Reducing symptoms

If you have Crohn's disease and it's causing moderate or severe symptoms, this is known as "active disease". Treatment for active Crohn's disease usually involves medication, but surgery is sometimes the best option.

Initial treatment

In most cases, the first treatment offered is steroid medication (corticosteroids) to reduce the inflammation. Examples of corticosteroids used for Crohn's disease include prednisolone tablets or hydrocortisone injections.

These medications are often effective in reducing the symptoms of Crohn's disease, but they can have significant side effects, such as:

weight gain

swelling of the face

increased vulnerability to infections

thinning and weakening of the bones (osteopenia and osteoporosis)

Because of these possible side effects, your dose will be gradually reduced when your symptoms start to improve.

If you prefer, you may be able to choose to have a milder steroid called budesonide, or a type of medication called a 5-aminosalicylate (such as mesalazine), as an alternative initial treatment. These medications have fewer side effects, but they are less effective.

In children or young people where there are concerns about growth and development, a special liquid diet may be recommended as an initial treatment. This is known as an elemental or polymeric diet and it can help reduce inflammation by allowing your digestive system to recover while ensuring that you get all the nutrients you need.

Additional treatment

If your symptoms flare up twice or more during 12 months or return when your steroid dose is reduced, further treatment may be necessary.

In these cases, medicines to suppress your immune system (immunosuppressants) may be combined with your initial medication. Medicines called azathioprine or mercaptopurine are most commonly used.

These medicines aren't suitable for everyone, so a blood test should be carried out to check if you can use them. If they are not suitable, an alternative immunosuppressant medication called methotrexate may be used.

Side effects of these immunosuppressants can include:

nausea and vomiting

increased vulnerability to infection

feeling tired, breathless and weak, which is caused by anaemia (a decrease in the number of red blood cells)

liver problems

During the course of medication you will have regular blood tests to check for serious side effects.

The immunosuppressants azathioprine and mercaptopurine are considered safe in pregnancy and breastfeeding. Women can continue to use these drugs when trying to start a family and during pregnancy.

However, methotrexate must not be taken for at least six months before trying for a baby, as this drug is known to cause birth defects. This applies to both men and women. It must also be avoided while you are breastfeeding.

It's important to speak to your doctor if you are planning a pregnancy or if you become pregnant during your course of treatment for Crohn's disease.

Severe Crohn's disease

For people in poor general health with severe symptoms of Crohn's disease, medicines called biological therapies may be used to reduce your symptoms if corticosteroids and immunosuppressants are unsuitable or ineffective.

Biological therapies are a type of powerful immunosuppressant medication created using naturally occurring biological substances, such as antibodies and enzymes.

The two medicines used to treat Crohn's disease in the UK are called infliximab and adalimumab. They work by targeting a protein called tumour necrosis factor-alpha (TNF-alpha), which is believed to be responsible for the inflammation associated with Crohn's disease. Infliximab can be used for

children over six years old and adults, but adalimumab should only be used for adults.

Infliximab is given as a drip into a vein in your arm (known as an infusion) in hospital. Adalimumab is given as an injection, and it may be possible for you, a family member or a friend to be taught how to give it so you don't need to visit hospital for every treatment.

Treatment will usually last at least 12 months, unless these drugs stop being effective sooner than this. After this time, your condition will be assessed to determine if further treatment is necessary.

There is a risk of these medicines causing an allergic reaction, which can cause symptoms such as:

itchy skin

a high temperature

joint and muscle pain

swelling of the hands or lips

problems swallowing

You should seek immediate medical assistance if you experience these symptoms. Reactions can occur immediately after treatment, although they have been known to occur months later, even after treatment stops.

Surgery

Surgery may be recommended to reduce your symptoms if your healthcare team feel the benefits outweigh the risks.

In many cases, a type of surgery called a resection is used. This involves removing the inflamed area of the intestine and stitching the healthy sections together.

In some cases, your doctor may recommend a procedure called an ileostomy to temporarily divert digestive waste away from the inflamed colon (large intestine) to give it a chance to heal.

During this operation, the end of the small intestine (the ileum) is disconnected from the colon and re-routed through a hole made in the abdomen, which is

known as a stoma. An external bag is attached to the opening to collect waste products.

Once the colon has sufficiently recovered – usually after several months – a second operation will be needed to close the stoma and re-attach the small intestine to the colon.

Maintaining remission

Remission is a period when you don't have any symptoms or your symptoms are mild. During these periods, you can choose whether or not to use medication to help maintain this.

If you decide not to have further treatment, you should be advised about attending regular follow-up appointments and which symptoms to look out for. These symptoms include unintended weight loss, abdominal pain and diarrhoea.

If you choose treatment, this will usually involve immunosuppressants. Corticosteroids are not recommended for maintaining remission.

Complications

If you develop complications of Crohn's disease, such as fistulas (channels that develop between two sections of the digestive system) or intestinal narrowing (stricture), these will also need to be treated. Surgery will be necessary in most of these cases.

See complications of Crohn's disease for more information about this.

Complications of Crohn's disease

People with Crohn's disease are at risk of developing a number of complications.

The two most common problems associated with Crohn's disease are discussed in more detail below.

Intestinal stricture

The inflammation of the bowel (intestines) in Crohn's disease can cause scar tissue to form, leading to the affected areas becoming narrowed. This is known as stricture.

If this happens, there is a risk of digestive waste causing an obstruction. This means you will not be able to pass any stools or you will only be able to pass watery stools.

Other symptoms of bowel obstruction include:

abdominal pain and cramping

being sick (vomiting)

bloating

an uncomfortable feeling of fullness in your abdomen

Left untreated, there is a risk that the bowel could split (rupture). This creates a hole that the contents of the bowel can leak from. You should contact your DOCTOR as soon as possible if you suspect that your bowel is obstructed.

Intestinal stricture is usually treated with surgery to widen the affected section of intestine. In some cases this may be achieved using a procedure called balloon dilation, which is performed during colonoscopy.

During balloon dilation, a colonoscope is passed up your back passage (rectum) and a balloon is inserted through the colonoscope. This is then inflated to open up the affected area.

Read [diagnosing Crohn's disease](#) for more information about colonoscopy.

If this doesn't work or is unsuitable, a surgical procedure known as a stricturoplasty may be needed to widen the affected area. During this operation, the surgeon widens the narrowed part of the intestine by opening it, reshaping it and sewing it back together.

Fistulas

If your digestive system becomes scarred as a result of excessive inflammation, ulcers can develop.

Over time the ulcers develop into tunnels that run from one part of your digestive system to another or, in some cases, to the bladder, vagina, anus or skin. These passageways are known as fistulas.

Small fistulas do not usually cause symptoms. However, larger fistulas can become infected and cause symptoms such as:

a constant, throbbing pain

a high temperature (fever) of 38°C (100°F) or above

blood or pus in your faeces (stools)

leakage of stools or mucus into your underwear

If a fistula develops on your skin (usually on or near the anus) it may release a foul-smelling discharge.

Biological medication is usually used to treat fistulas. Surgery is usually required if these are not effective.

Read more about treating a fistula.

Other complications

People with Crohn's disease are also at an increased risk of other complications, such as:

osteoporosis – weakening of the bones caused by the intestines not absorbing nutrients and the use of steroid medication to treat Crohn's disease

iron deficiency anaemia – a condition that can occur in people with Crohn's disease because of bleeding in the digestive tract; common symptoms include tiredness, shortness of breath and a pale complexion

vitamin B12 or folate deficiency anaemia – a condition caused by a lack of vitamin B12 or folate being absorbed by the body; common symptoms include tiredness and lack of energy

pyoderma gangrenosum – a rare skin reaction that causes painful skin ulcers

Children with Crohn's disease may also experience problems with their growth and development because their bodies are not absorbing enough nutrients.