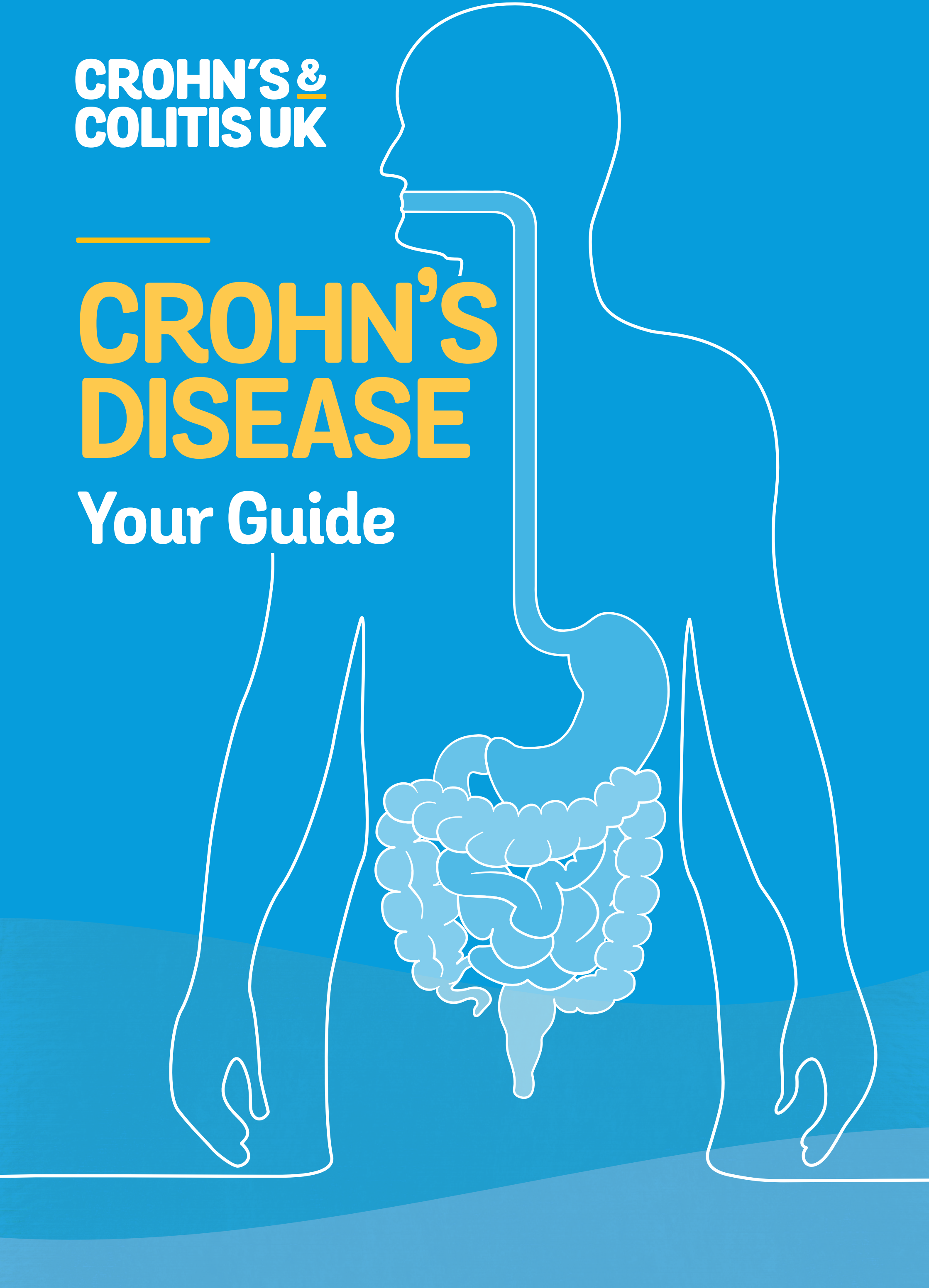
CROHN'S &
COLITIS UK

CROHN'S DISEASE

Your Guide



INTRODUCTION

You may not have heard of Crohn's Disease before, or Crohn's as we'll refer to it. It's a type of Inflammatory Bowel Disease, or IBD, which we'll explain more about later. In Crohn's, parts of the gut become swollen, inflamed, and ulcerated. This can cause pain, diarrhoea, weight loss and fatigue, and you may have other symptoms too.

Being told you have Crohn's can be a shock. You might feel anxious or unsure about what comes next and how your life might change. But you're not alone.

Now that you've put a name to your symptoms, you can start to manage them. And we're here to help, every step of the way.

This information is for anyone who has Crohn's, thinks they might have it or wants to learn more about it. It looks at:

- What Crohn's is
- Symptoms and complications you may experience
- Treatments you might be offered
- Managing daily life with Crohn's

CONTENTS

Key facts about Crohn's

- Crohn's Disease causes ulcers and inflammation that can be anywhere in your gut, from your mouth to your bottom. It is most common in the small bowel and colon.
- Everyone experiences Crohn's differently. Symptoms can include pain, diarrhoea, tiredness and blood in your poo. Other parts of the body can also be affected.
- Most people have times when symptoms are under control, known as remission. They will also experience flare-ups, where symptoms are more active.
- Crohn's is a lifelong condition. Right now, there is no cure for Crohn's. But medicines, surgery, or a combination of both can help to keep you feeling well, help with inflammation in your gut and keep your symptoms under control.
- There is lots of support out there to help you manage and live well with your condition. This includes your IBD team of healthcare professionals, friends and family, and organisations like Crohn's & Colitis UK.

ABOUT CROHN'S & COLITIS UK

Crohn's & Colitis UK is a national charity, leading the fight against Crohn's and Colitis. We're here for everyone affected by these conditions.

Our vision is to see improved lives today and a world free from Crohn's and Colitis tomorrow. We seek to improve diagnosis and treatment, fund research into a cure, raise awareness and give people hope and confidence to live freer, fuller lives.

Our information is available thanks to the generosity of our supporters and members. Find out how you can join the fight against Crohn's and Colitis by calling **01727 734465**. Or you can visit **crohnsandcolitis.org.uk**.

ABOUT CROHN'S DISEASE

ABOUT CROHN'S DISEASE

What you need to know

Crohn's is an Inflammatory Bowel Disease, or IBD. When you have Crohn's, your immune system does not work properly. The body starts attacking itself, causing painful ulcers and inflammation in the gut. Although Crohn's is called an Inflammatory Bowel Disease, any part of the gut can be affected, from your mouth to your bottom. It can also affect other parts of your body.

Crohn's can be diagnosed at any age, most commonly before the age of 30. At least 1 in every 323 people in the UK are living with Crohn's Disease.

Other forms of IBD include **Ulcerative Colitis** and **Microscopic Colitis**. It may not always be possible for doctors to tell the difference between Crohn's and Ulcerative Colitis. If this is the case you may be diagnosed with IBD Unclassified, also known as IBD-U or Indeterminate Colitis.

IBD is not the same as irritable bowel syndrome, or IBS. IBS has some symptoms which are similar to Crohn's, but this is a different condition and treatment for IBS is not the same. Find out more in the section **Crohn's and Irritable Bowel Syndrome (IBS)**.

Crohn's is a lifelong condition. You may have periods of good health known as remission, as well as times when symptoms are more active, known as flare-ups or relapses. This means that sometimes you may feel well and have no or few symptoms, while at other times symptoms may be more difficult to manage.

Remission

- Remission is when you feel better because your Crohn's is well controlled.
- Medical tests, such as blood tests and endoscopy, show your gut is less affected by your condition.
- Your symptoms, such as diarrhoea, an urgent need to use the toilet, fatigue or extreme tiredness, and tummy cramps will improve.
- Some symptoms, like fatigue, may not go away completely.

Flare-up or relapse

- A flare-up, also known as relapse or active disease, is when you feel unwell because your Crohn's is not well controlled.
- Medical tests, such as blood tests and endoscopy, show your gut is sore and inflamed.
- You may have symptoms such as diarrhoea, an urgent need to use the toilet, fatigue or extreme tiredness, and tummy cramps.

Right now, there is no cure for Crohn's. But there are many effective treatments to help you control symptoms and prevent long-term problems. Treatment options may include medicines, surgery, and sometimes a combination of both. Working together, you and your healthcare professionals can find a way to manage the condition that works best for you.

> "The most important thing I needed to know when I was first diagnosed was that I wasn't alone, there's a whole community ready with help and support."
>
> **Ally,** living with Crohn's

Coming to terms with your diagnosis

Coming to terms with having Crohn's can take time. It's common to go through a period of adjustment as you get used to everything, learn more about the condition and find your own ways of living well.

Everyone is different. There's no right or wrong way of doing things. You may feel more in control if you learn all you can about your condition, or you may find that taking things one step at a time is better for you. If you are finding things difficult, our information at **crohnsandcolitis.org.uk/mentalhealth** can help you find out how to get the help you need.

Your Inflammatory Bowel Disease (IBD) team

> These are the experts who are here to help you through throughout your IBD journey.
>
> **Krupie**, living with Crohn's

Everyone with a diagnosis of Crohn's should be seen by an IBD specialist and cared for by a team of healthcare professionals. Your team will be led by a consultant gastroenterologist. This is a doctor who specialises in the digestive system. All teams are different but are likely to include IBD nurse specialists and surgeons. Some IBD teams may include a gastroenterology dietitian, expert pharmacist and psychologist. They will refer you to any other health professionals you might need to see.

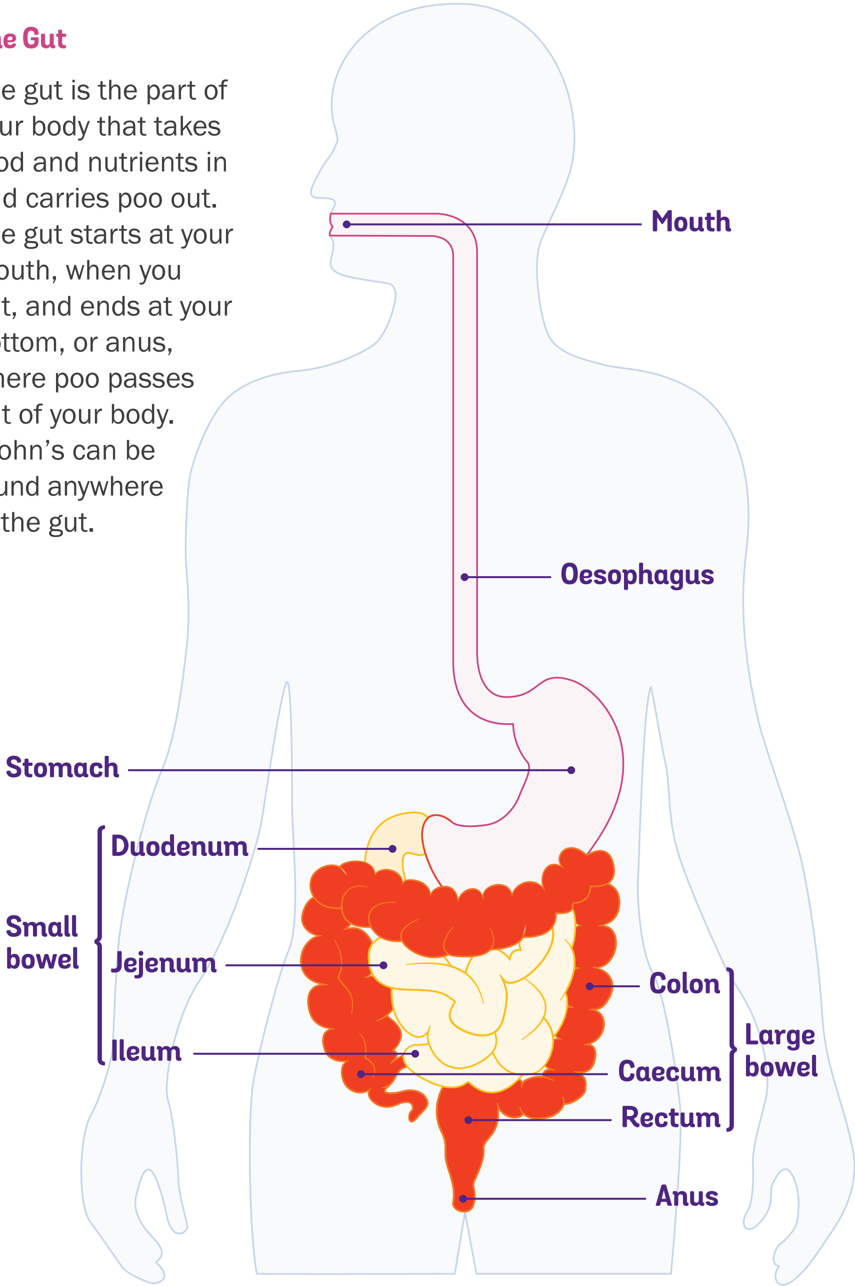
Your specialist team should be able to support you with every aspect of your care. This includes your first assessment and diagnosis, treatment, and rapid care during flare-ups. They can offer nutritional help and support you through surgery if you need this. But remember, although they are experts in Crohn's, you will become the expert in how the condition affects you.

Our appointment guide at **crohnsandcolitis.org.uk/appointmentguide** will help you get the most out of your appointments. It can help you understand what matters most to you about your treatment and care.

> Having a specialist IBD team has helped me immensely, physically, and mentally, to cope with Crohn's. It's reassuring to know there is somebody who understands the condition and how to deal with it promptly and efficiently.
>
> **Melissa**, living with Crohn's

The Gut

The gut is the part of your body that takes food and nutrients in and carries poo out. The gut starts at your mouth, when you eat, and ends at your bottom, or anus, where poo passes out of your body. Crohn's can be found anywhere in the gut.

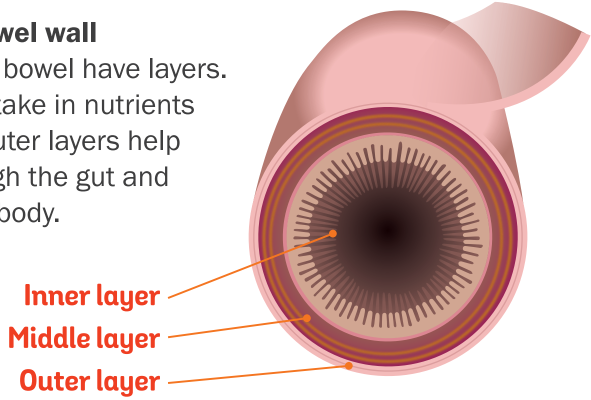


The bowel

The bowel is the largest part of the gut and is made up of two sections. These are the small bowel and the large bowel. The large bowel starts at the beginning of the colon and ends at the anus. It includes the colon and rectum.

Layers of the bowel wall

The walls of your bowel have layers. The inner layers take in nutrients from food. The outer layers help move food through the gut and waste out of the body.

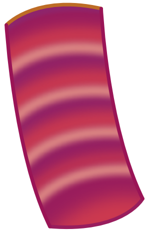


Crohn's can affect all layers of the gut. If this inflammation goes through the middle and outer layers, an abscess or fistula may develop. Find out more in the section on **complications in the gut**.

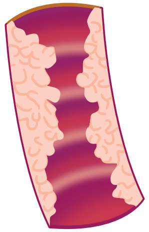
The inflammation in Crohn's affects how your body digests food, absorbs nutrients and gets rid of waste.

While Crohn's can be found at any point in your gut, it will not be everywhere. It is most common in the small bowel and colon. Areas of inflammation are often patchy, with sections of healthy gut in between.

Healthy section of gut



Gut with Crohn's showing ulcers and inflammation



Symptoms

Everyone experiences Crohn's differently. When you're having symptoms, it's known as active disease, a flare-up or relapse. Symptoms may be mild or severe and are likely to change over time.

Your symptoms may also vary depending on where Crohn's is active in your gut. Find out more in the section **types of Crohn's**.

The most common symptoms are:

- Diarrhoea. This is passing looser poo more often than is normal for you. In Crohn's, the poo may sometimes be mixed with mucus, pus or blood.
- Severe pain in the tummy area, known as abdominal pain.
- Needing to reach a toilet quickly, known as urgency.
- Extreme tiredness, also known as fatigue. This can be due to several things, such as anaemia or poor sleep.
- Anaemia. This is when the body does not have enough healthy red blood cells to carry oxygen around the body. This is more likely to happen if you're losing blood in your poo, not getting enough nutrients, or not absorbing nutrients from the food you eat. It can make you feel very tired.
- Generally feeling unwell. This may include having a raised temperature and feeling feverish.
- Loss of appetite and weight loss. Inflammation in the gut may stop your body from absorbing nutrients from the food you eat, leading to weight loss.

Crohn's is a gut condition, but having an overactive immune system and ongoing inflammation can sometimes lead to problems in other parts of your body too. Some people with Crohn's also experience inflammation in the eyes, joints or skin. Find out more in the section **complications outside the gut**.

Flare-ups

A flare-up is when symptoms come back, and you feel unwell. Everyone experiences flare-ups differently.

Some people can go years without feeling unwell. For others, flare-ups may happen more often. A few people have continuous symptoms of active Crohn's.

Over time you'll get to know how to recognise a potential flare-up. You will work together with your IBD team to create a treatment plan for flare-ups. The plan will give guidance on what to do and who to contact. This may be your IBD service, an advice line or your GP.

Signs of a flare-up can include:

- Loose poo, or diarrhoea
- Pain in the tummy area
- Weight loss, when you have not been trying to lose weight
- Generally feeling unwell

If you're worried in any way, contact your IBD team or your GP. You healthcare team can help provide the support and reassurance you need.

PRACTICAL TIPS

Tips for contacting your IBD team

- Find out if your IBD team has a direct phone number or email address. Some hospitals have advice lines run by the IBD Nurse Specialists.
- Ask your IBD team how to best alert them if you become unwell. For example, sending an email with ‘Flare-up’ in the subject line.
- If you leave a message or send an email, include your full name, date of birth and NHS or hospital number, if you know it.
- You could try contacting your consultant’s secretary by calling the hospital switchboard. The switchboard is the main hospital telephone number.
- If you’re still having trouble reaching your IBD team, contact your GP or local out of hours service for medical advice. You could also share the IBD Toolkit for GPs with your GP.

A flare-up can also affect other parts of the body and cause:

- Joint pain and swelling
- Swelling in the eyes
- Mouth ulcers
- Nausea
- Skin rashes
- Fatigue
- Mental health problems

In some cases, your IBD team or GP may use blood tests, poo tests or an endoscopy to check if you’re having a flare-up. The results will help find the best treatment to control your Crohn’s.

Find out more in our information at **crohnsandcolitis.org.uk/tests-and-investigations**.

Flare-ups can be disruptive. Sometimes you may need to cancel plans or take time off work when you feel unwell. It can help to be open about your condition with your family, friends, work colleagues and employers. You can use our talking toolkit at **crohnsandcolitis.org.uk/talkingtoolkit** as a guide.

What you can do to reduce the risk of a flare-up

Taking your medicines as prescribed by your IBD team, even when you feel well, reduces the risk of flare-ups. We do not yet know what causes flare-ups, but possible triggers include:

- Smoking
- Disruptions or changes in medicines
- Ongoing stress
- Taking non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen

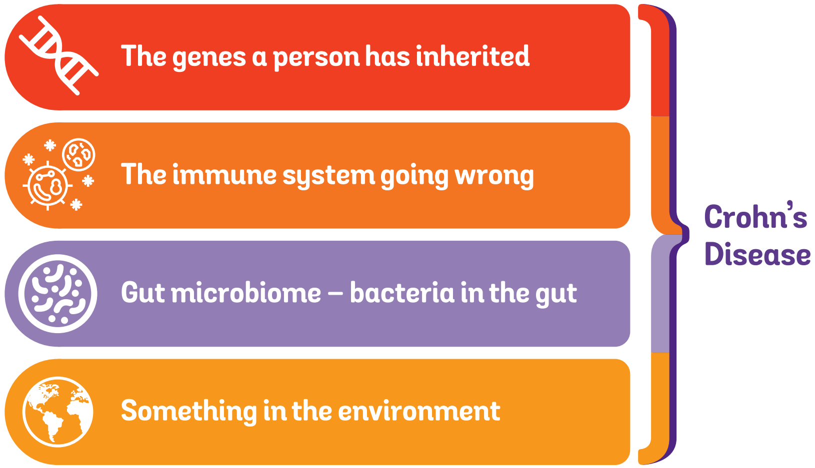
It can help to keep a diary of symptoms to help you notice any triggers. You can find one at **crohnsandcolitis.org.uk/appointmentguide**

Causes of Crohn’s

Crohn’s happens when the body’s immune system goes wrong. Usually, the immune system protects the body against harmful substances and infections. It is thought that in Crohn’s, the immune system starts attacking the gut. When it comes to understanding what causes Crohn’s, there’s still a lot we do not know.

Is Crohn’s an autoimmune condition?

An autoimmune condition is one where the body attacks its own cells. Some sources call Crohn’s an autoimmune condition. But, some researchers think Crohn’s is better described as an immune mediated condition. These researchers think the body is attacking bacteria in the gut, rather than its own cells. Because we do not know exactly what causes Crohn’s, it is difficult to say for sure. Experts believe that a mix of genes, bacteria in the gut and the environment probably cause Crohn’s, but more research is needed to know for certain.



Genes a person has inherited
Researchers have identified more than 200 genetic variations that affect your risk of developing Crohn’s. Many of these changes are in genes that control the immune system. Changes in these genes may alter the immune system’s response to bacteria in the gut. Combined with other genetic and environmental factors, these changes can lead to ongoing inflammation.

Immune response
In Crohn’s, something goes wrong with the immune system. Research suggests that in Crohn’s the protective gut barrier is faulty. The gut barrier allows important nutrients into the gut and keeps harmful substances out. Without this layer of protection, the immune system starts attacking certain bacteria or viruses that live in the gut. This causes inflammation.

Gut microbiome
The gut microbiome, sometimes called the gut microbiota or gut flora, is the natural bacteria, viruses and fungi that live in your gut. It is thought that in people with Crohn’s, there may be an imbalance of good and bad bacteria in the bowel.

Environment
A range of factors in the environment may increase the risk of Crohn’s. These include:

- Smoking
- Viruses
- Taking medicines such as some antibiotics and non-steroidal anti-inflammatory drugs, known as NSAIDs

But there’s no definite evidence that any one of these factors is the cause of Crohn’s.

Types of Crohn's

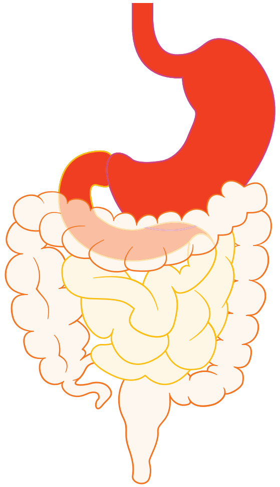
The location of the inflammation in your gut can affect the symptoms you have and the treatment you're offered. You may have just one type or a combination of types.

Upper gastrointestinal

This is Crohn's in the upper part of the gut, including the oesophagus, stomach, or the first part of the small bowel known as the duodenum.

Typical symptoms include:

- Heartburn
- Indigestion-like pain
- Feeling sick, called nausea
- Being sick or vomiting

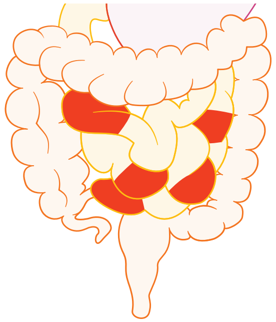


Small bowel

Crohn's that affects the small bowel is known as ileitis or jejunoileitis. This is because it's inflammation of the ileum or jejunum, depending on the part of the small bowel affected.

Typical symptoms include:

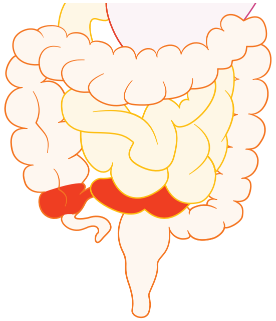
- Pain in the tummy area, also called abdominal pain
- Extreme tiredness, or fatigue
- Bloating
- Tummy cramps when pooing



People with this type of Crohn's may be more likely to have nutrient deficiencies. You may also be more likely to have strictures if Crohn's affects this part of the gut. Find out more in the section **complications in the gut**.

End of the small bowel

Crohn's in the last part of the small bowel, known as the ileum, is called ileal or 'terminal ileal' Crohn's. This is because it is in the end of the ileum, and terminal means end. Terminal may sound worrying but in this context, it does not mean end of life.



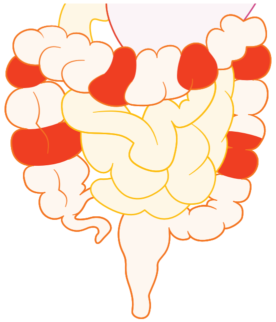
Ileal Crohn's is one of the most common forms of Crohn's Disease. If it also affects the beginning of the large bowel it is known as ileocaecal Crohn's.

Typical symptoms include:

- Extreme tiredness, or fatigue
- Pain in the tummy area, also called abdominal pain
- Tummy cramps when pooing
- Diarrhoea

Colon

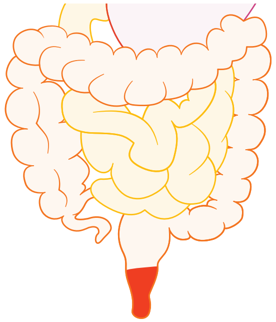
Crohn's Disease where only the large bowel is inflamed is known as 'Crohn's Colitis'. This is because 'colitis' means inflammation of the large bowel. It does not mean you have both Crohn's Disease and Ulcerative Colitis.



Typical symptoms include:

- Extreme tiredness or fatigue.
- Diarrhoea, which may include blood or mucus.
- Need to reach a toilet quickly to poo. This is known as urgency.
- Pain in the tummy area, also called abdominal pain.

Perianal
This is Crohn's in the area around the anus, where poo leaves the body. It can happen on its own or at the same time as inflammation in other parts of the gut. Some people notice perianal symptoms before they develop symptoms in other parts of the gut.



Typical symptoms include:

- Fissures. These are small tears in the skin around the bottom, which can cause pain and bleeding when you poo.
- Skin tags. These are small fleshy growths around the bottom that may feel like small bumps or raised areas.
- Abscesses. These are collections of pus that can become swollen and painful. They're often found in the area around the bottom and can cause a fever or lead to a fistula.
- Fistulas. An anal or perianal fistula is a small tunnel that develops between the end of the bowel and the skin near the bottom, where poo comes out. They appear as tiny openings in the skin that leak pus or poo. Fistulas can irritate the skin and are often sore and painful. They do not usually get better on their own, so doctors treat these with medicines or sometimes surgery. Find out more in our information at **crohnsandcolitis.org.uk/fistulas**.

Mouth
Crohn's disease that affects the mouth is called oral Crohn's Disease. It is more likely to affect children. It can cause swollen lips and gums, as well as tears and ulcers inside the lining of the cheeks.

Oral Crohn's can look very similar to another condition, called orofacial granulomatosis.

Other parts of the body
Crohn's can also affect other parts of the body such as the lungs and vulva. Always tell your IBD team if you have new symptoms anywhere in your body so they can be investigated.

Crohn's activity and severity

Assessing how active and severe your Crohn's is will help your IBD team to find the most appropriate treatment for you. Assessments will take into account your symptoms and inflammation in the gut. Your IBD team will also consider how Crohn's impacts your daily life.

Activity
When you have symptoms, your condition may be described as being 'active'. If your Crohn's is very active it may mean you are having a flare-up.

Severity
Crohn's is different for everyone. Your IBD team will assess how severe your Crohn's is to help find the best treatment for you. This will be based on your symptoms, how Crohn's impacts your daily life and your test results.

The following severity groups are only a guide. It is common to be between two severity groups. For example, your IBD team may say you have mild-to-moderate Crohn's or moderate-to-severe Crohn's.

Mild

- Can eat normally
- No signs of dehydration, tenderness in the tummy area or weight loss

Moderate

- No response to treatment for mild disease
- Tummy pain or tenderness
- Anaemia
- Fever
- Weight loss

Severe or severely active

- Continue to have symptoms despite treatment for moderate disease
- Significant weight loss
- Abscesses

Complications in the gut

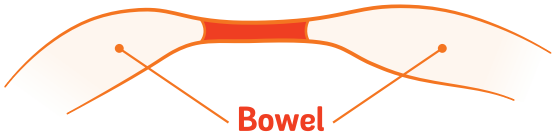
Crohn's can sometimes cause additional problems in the gut.

Fistulas
Around 1 in 3 people with Crohn's develop a fistula. A fistula is when a tunnel develops that connects one organ to another part of your body. In Crohn's, these tunnels can connect the gut to another internal organ, such as the vagina, bladder, another part of the bowel, or skin.

Anal or perianal fistulas are the most common type of fistula. Symptoms include a sore swelling around the bottom. The pain may get worse when you sit down, move around, poo or cough.

Treatment for fistulas involves medicines, surgery, or a combination of both. Your treatment will depend on the type of fistula you have. Find out more in our information at **crohnsandcolitis.org.uk/fistulas**.

NARROWING – STRICTURE



Narrowing of the gut – stricture
Ongoing inflammation or development of scar tissue can create a narrow section of the gut, known as a stricture. A stricture can make it difficult for food to pass through and, if it's very narrow, cause a blockage.

Symptoms of a stricture include:

- Severe cramping and pain in your tummy
- Feeling sick
- Being sick
- Your tummy area being bloated and swollen, known as being distended

Sometimes strictures can be treated by medicines. Other ways to treat strictures include:

- A procedure called balloon enteroscopy to widen the stricture. Find out more at **crohnsandcolitis.org.uk/tests-and-investigations**
- Strictureplasty. A type of surgery where the stricture is cut open and stitched back together. This makes the narrowed section wider.
- Resection. A type of surgery where the narrowed part of the bowel is removed.

Find out more about surgery in our information at **crohnsandcolitis.org.uk/surgery**

Perforations
A perforation is a rupture of the bowel. This creates a hole that contents of the bowel may leak through. They can be caused by:

- Very active inflammation in the bowel wall
- A severe blockage caused by a stricture or bowel cancer

Perforations are very rare, but very serious. Symptoms can include:

- Severe tummy pain that is present all the time
- High fever
- Feeling sick or nauseous
- Being sick or vomiting

Contact NHS 111 straight away if you think you have signs of a perforation.

Complications outside the gut

Crohn's Disease does not just affect the gut. Up to 1 in every 2 people with Crohn's develop problems in other parts of the body. Commonly affected areas include joints, eyes, and skin. These are known as extraintestinal manifestations or EIMs. They usually happen during a flare-up, but can happen without or before any gut symptoms.

For many of the complications, there are things you can do to reduce your risk.

Joints
Joint pain or swelling is a common problem for people with Crohn's. For some, this will get worse during a flare-up, but will usually improve with treatment for Crohn's. Others may have joint problems even when gut symptoms feel better. Find out more at **crohnsandcolitis.org.uk/joints**

Bones
People with Crohn's are more at risk of developing thinner and weaker bones, known as osteoporosis. This can be due to ongoing inflammation, smoking, taking steroids or low levels of physical activity. Calcium is needed for bone formation, and this may be low if your diet does not contain enough dairy. Weight-bearing exercise, calcium and vitamin D supplements, not smoking and avoiding long-term steroid use can help. For some people, medicines can be helpful. Find out more at **crohnsandcolitis.org.uk/bones**

Skin
Crohn's can affect the skin in different parts of the body.

Erythema nodosum affects up to 15 in every 100 people with Crohn's. It causes raised, painful red or violet swellings, usually on the legs. It usually happens during flare-ups and usually improves with treatment for Crohn's.

Pyoderma gangrenosum starts as small tender blisters or pustules, which become painful, deep ulcers. These can happen anywhere on the skin, but most commonly appear on the legs, or near stomas. This condition is sometimes linked to a flare-up. It's often treated with steroids or biologic medicines. In some cases a specialist in skin conditions, called a dermatologist, may treat this with creams or ointments.

Sweet syndrome is where tender red lumps appear on the upper limbs, face, and neck, sometimes with a fever. It is generally associated with active Crohn's. Doctors often use steroids or immunosuppressants to treat Sweet syndrome.

Other skin conditions that may be associated with Crohn's include:

- Psoriasis. This is raised patches of red, flaky skin. It usually appears on your elbows, knees, scalp and lower back.

- Rosacea. A condition causing redness, most commonly on your cheeks or nose.
- Hidradenitis suppurativa. This is where lumps grow on the surface of the skin, usually around the armpits, bottom, groin and genitals. The lumps are often painful and can sometimes leak pus.

Eyes

Episcleritis affects the layer of tissue covering the white outer coating of the eye, called the sclera. Your eyes become red, itchy and sometimes painful. This tends to flare up at the same time as Crohn's symptoms. It often gets better with treatment for Crohn's or with steroid eye drops.

Uveitis is inflammation of the iris and **scleritis** is inflammation of the sclera. These are serious and can lead to loss of vision if they're not treated. Symptoms include pain, changes in vision and sensitivity to light. They're treated with steroid drops, and sometimes immunosuppressants or biologic medicines.

These conditions are not to be confused with conjunctivitis, a common eye condition that is not associated with Crohn's or Colitis. Conjunctivitis causes redness and irritation and produces sticky pus.

If you get any kind of painful eye irritation, redness or inflammation, tell your healthcare professional. They may refer you to an eye specialist.

Mouth

Some people with Crohn's may develop mouth ulcers during flare-ups. These are painful, shallow, round and can be found on the smooth surfaces inside the mouth or under the tongue.

Kidneys

Kidney stones may be caused by:

- Inflammation in the small bowel, which can stop you absorbing enough fat. The fat is then left in the bowel and binds to calcium, forming a molecule called oxalate. This may be absorbed and deposited in the kidneys where it can form stones.
- Dehydration. You may become dehydrated if you lose fluid through diarrhoea and this can lead to kidney stones.

Symptoms of kidney stones include pain, feeling sick, being sick and blood in your pee. Find out more on the NHS website.

Liver

Gallstones. People with Crohn's are more likely to develop gallstones, with up to 1 in 3 people affected. Gallstones are small stones made of cholesterol. These may get trapped in the gallbladder and can be very painful.

Gallstones are more likely if:

- The end of the small bowel has been removed.
- There is severe inflammation in the small bowel.

Primary Sclerosing Cholangitis, known as PSC. This is a rare condition that affects around 1 in 50 people with Inflammatory Bowel Disease. It causes inflammation of the bile ducts and can eventually damage the liver. Symptoms include fatigue, itching, weight loss and jaundice, where your skin and whites of your eyes turn yellow. Talk to your IBD team if you are worried about any of these symptoms.

Circulation

Blood clots. You're more likely to develop blood clots if you have Crohn's. This includes deep vein thrombosis, known as DVT, in the legs and pulmonary embolisms, known as PE, in the lungs.

You're more at risk:

- During a flare-up.
- If you have recently had surgery.
- If you need to stay in bed, for example in hospital.

To lower your risk:

- Do not smoke.
- Stay active. Activities such as walking can help.
- Drink plenty of fluids to avoid dehydration.

These precautions can also be helpful when you travel by plane, car or train for more than three hours, which increases the risk of blood clots for everyone. Find out more at **crohnsandcolitis.org.uk/travel**

If you're staying in hospital because you're unwell with your Crohn's, you should be offered a medicine or injections to prevent blood clots.

Cardiovascular disease

People with active Crohn's may have a slightly increased risk of cardiovascular disease, including heart problems and strokes.

Anaemia. If you're anaemic, you have fewer red blood cells than normal or lower levels of haemoglobin in your blood. Haemoglobin is a protein found in red blood cells that carries oxygen around the body. There are several types of anaemia. People with Crohn's are likely to develop iron deficiency anaemia. It is caused by a lack of iron in your diet, poor absorption of iron from food, or blood loss from the gut.

Anaemia can make you feel very tired. If it's more severe you may also have shortness of breath, headaches, and general weakness.

Treatment depends on the cause of anaemia. You may be prescribed iron supplements that are taken by mouth. Or you may be given iron into your vein by an injection or infusion through a drip. Find out more about iron in our information on **crohnsandcolitis.org.uk/othertreatments**

Hair loss

You might lose more hair if you have Crohn's. This could be due to a condition called alopecia areata or a condition called telogen effluvium. Both are associated with Crohn's and Colitis.

Crohn's and Irritable Bowel Syndrome (IBS)

Although some of the symptoms are similar, IBS is a different condition. Like Crohn's, IBS can cause tummy pain or cramps, but these are often worse after eating and better after a poo. People also have bloating and bouts of diarrhoea or constipation. Unlike Crohn's, IBS does not cause inflammation in the gut and there's no blood in poo.

Some people with Crohn's also develop symptoms like IBS. There may be diarrhoea even when Crohn's is not active. Up to 2 in 10 people in the general population have IBS and this is more common if you have Crohn's.

Risk of cancer

Crohn's can increase the risk of bowel cancer in some people, but this risk is still small. You are more likely to develop bowel cancer than the general population if you have Crohn's that affects the colon, known as Crohn's Colitis.

Having Crohn's that does not affect your colon does not increase the risk of developing bowel cancer.

If you are at increased risk of bowel cancer you will be offered regular colonoscopies to check for early warning signs. Find out more at **crohnsandcolitis.org.uk/cancer**

In very rare circumstances, some medicines for Crohn's can increase the risk of other cancers. The risk is very small and the benefits of taking the medicines will most often outweigh the possible unwanted effects. Check the information leaflet in your medicine pack for precautions you can take to reduce this risk. Talk to your IBD team if you are worried.

Life expectancy

People who have Crohn's can generally expect to live a long life. They might not live quite as long, on average, as people who do not have Crohn's, but the difference is small. It's difficult to be certain because different researchers have found different things, and because other factors like smoking can also affect life expectancy.

Research on life expectancy usually looks back at what has happened to people with Crohn's or Colitis over several decades. Treatment options were much more limited in the past. So we do not know if the data that's available reflects what is happening today, with all the new treatments we now have. We do know that life expectancy is increasing for people with Crohn's or Colitis, but it might not be quite as long as that in people without Crohn's or Colitis.

TESTS AND TREATMENTS

TESTS AND TREATMENTS

Tests to monitor Crohn's

To find out if you have Crohn's, you probably had lots of tests. The same tests help your doctors check your health and find the best treatment for you. How often you need these tests will depend on how severe your Crohn's is, and the medicines you are taking.

Tests for Crohn's include:

History of your symptoms

You know your body better than anyone. Doctors will ask you about the gut symptoms you have been having, how often you have them, and how much they affect you. Doctors may also ask you about any symptoms you have at night, and those involving your mouth, skin, eyes, joints or around your bottom.

You may also be asked about smoking, recent travel, food intolerances, medicines you have taken including antibiotics and non-steroidal anti-inflammatory drugs, and infections.

Physical examination

Your IBD team can examine the outside of your body. This can include your general wellbeing, how fast your heart is beating, blood pressure, temperature, and tenderness or swelling in the tummy area.

Blood and poo tests

Blood tests can show whether you have inflammation somewhere in your body and if you're anaemic. They can also check whether the medicine you take for your Crohn's is causing any side effects.

Your poo can also be tested for signs of bleeding or inflammation, and to check whether an infection is causing the diarrhoea. A faecal calprotectin test can show whether you have inflammation in your gut.

Endoscopy

Doctors will use a long, thin flexible tube called an endoscope with a tiny camera on the end to look closely at the lining of your gut. This helps the doctor to see if your Crohn's is well controlled, or if you still have inflammation.

If the tube goes through your mouth, it's called a gastroscopy or upper gastrointestinal endoscopy. The doctor will look at the mouth, stomach, and small bowel.

If the tube goes through your bottom, it's called a colonoscopy or sigmoidoscopy. In a sigmoidoscopy, the doctor will look at the rectum and beginning of the colon. In a colonoscopy, the doctor looks at the whole large bowel as well as the end of the small bowel.

Biopsy

During an endoscopy, small samples of tissue of your gut may be taken. These are known as biopsies. These are sent to the laboratory and examined under a microscope to check for further inflammation.

MRI and CT scans

Other tests that look at where Crohn's is in your gut include magnetic resonance imaging, known as MRI scans, and computerised tomography, known as CT scans. MRI uses magnets and radio waves, and CT uses X-rays to build up a 3D image of the body. Some hospitals also use ultrasound to locate areas of inflammation.

It's likely that you'll need a few of the tests listed above. You can find more detailed information about these tests at **crohnsandcolitis.org.uk/tests-and-investigations**

Your IBD team should provide you with information about timescales and a point of contact in the IBD team while you're waiting for the results of any tests.

Treatment and care

Everyone with a diagnosis of Crohn's Disease should see an IBD specialist and an adult or paediatric gastroenterologist. They will often be part of a team that includes an IBD nurse specialist, specialist gastroenterology dietitian, surgeon, psychologist, and expert pharmacist in IBD. Find out more in **Your Inflammatory Bowel Disease Team**.

What ideal care looks like is set out in the **IBD Standards**. But every hospital is different, and your team or care may vary from this.

When you've received a diagnosis of Crohn's you should be able to start treatment within 48 hours if you have moderate to severe symptoms, or two weeks if symptoms are mild. However, based on the experiences shared with us, we understand this is not always the case and there may be long waits to start treatment. We are working hard to ensure everyone with Crohn's has access to the right care, support and treatments at the right time. Find out more about what we are doing to improve your healthcare on our website.

The aim of treatment

The aim of treatment is to stop the inflammation in your gut. This will ease or get rid of your symptoms, and make you feel better. It will also reduce the risk of complications or your condition getting worse over time.

> "Treatment will vary over time from the initial treatment to control your symptoms to experimenting to find a longer-term solution."
>
> **Lucy**, living with Crohn's

Treatment for Crohn's may be with medicines, surgery, or a combination of both. For some people, especially children, treatment with a liquid diet may be an option. If your condition is mild, not having any treatment could also be a choice.

Your treatment will depend on how Crohn's affects you, and the choices you make together with your IBD team.

This will include:

- Where the inflammation is in your gut
- How active and severe the inflammation is
- Whether other treatments have helped you feel better
- Complications such as perianal disease or a fistula

It's also important to think about what matters to you about your treatment and care. This will help you and your IBD team make the best decisions together to find the treatment that's right for you. Find out more at **crohnsandcolitis.org.uk/appointmentguide**. Your IBD team should support you to understand all the options available and their benefits, risks and consequences.

Medicines to treat Crohn's

Medicines can be very effective in treating your symptoms. They can help to prevent your condition from getting worse or causing complications.

First, medicines are used to get your Crohn's under control. This is called induction. Once your Crohn's is under control, you might take medicine to keep it under control. This is called remission.

Medicines sometimes cause side effects, but your IBD team will monitor these carefully. Medicines do not work the same way for everyone. It is not always possible for your IBD team to predict which treatment will suit you best. It is important to make sure you find a medicine that works for you. But it may take some time to find the right medicine for you.

Our medicine tool can help you understand more about potential treatment options that suit your needs.

You may take one medicine or a combination of medicines. When your condition is well controlled you may need to take your medicines on an ongoing basis, sometimes for many years. Or you may need to take them for only a short time.

The main types of medicines are:

Steroids
Examples include: beclomethasone dipropionate, budesonide, hydrocortisone, methylprednisolone, prednisolone.

Steroids are often the first medicine your IBD team will try to get your Crohn's under control. When you're in a flare-up, steroids can quickly reduce the inflammation in your gut to help you feel better. But steroids cannot be used to control Crohn's long-term. You'll only take steroids for a set amount of time. Your doctor may then suggest a different medicine that can help to keep you well.

Some types of steroids have a different risk of side effects. For example, steroids that work directly on the bowel have a lower risk of side effects. Find out more in our information at **crohnsandcolitis.org.uk/steroids**

Immunosuppressants
Examples include: azathioprine, mercaptopurine, methotrexate.

These medicines are tablets that dampen down the immune response. This reduces inflammation in the gut and helps to prevent flare-ups and reduce symptoms.

Immunosuppressants can be used to both get your Crohn's under control, and keep it under control. If you've had two or more flare-ups in 12 months that needed treatment with steroids, you might be offered these medicines. They may help you reduce or stop taking steroids without having another flare-up. Find out more at **crohnsandcolitis.org.uk/azathioprine-and-mercaptopurine** and **crohnsandcolitis.org.uk/methotrexate**.

Biologics and other targeted medicines
Examples of biologics include: adalimumab, infliximab, risankizumab, ustekinumab, vedolizumab.

Examples of other targeted medicines include: upadacitinib.

Biologics and other targeted medicines are treatments that block particular proteins or chemical pathways involved in inflammation. This reduces inflammation and helps get your Crohn's under control and keep it under control. They also alter your immune system, so you might not fight off infections as well as other people.

These may be an option when other medicines such as immunosuppressants or steroids have not worked, have stopped working or where unwanted side effects are hard to manage. Biologics and targeted medicines can be used to both get your Crohn's under control, and keep it under control. Find out more at **crohnsandcolitis.org.uk/biologics** and **crohnsandcolitis.org.uk/treatments**

Medicines to help you manage symptoms

Some medicines can be helpful at times to ease symptoms, but these do not reduce the inflammation or treat the underlying condition.

Talk to your doctor or IBD team before you take these or other medicines you can buy yourself. They may make your symptoms worse, can cause blockages or could interact with other medicines you're taking.

Diarrhoea

- Anti-diarrhoeal medicines such as loperamide and diphenoxylate. These work by slowing down the muscle movements in the gut, so food moves more slowly. Do not use these if you're having a flare-up. Always check with your IBD team before you take these medicines.
- Bile salt binders such as cholestyramine. If you have inflammation in the ileum or you've had it removed by surgery, bile salts can enter the colon and cause diarrhoea. Bile salt binders combine with the bile salts to stop this.

Constipation

- Laxatives such as macrogol. Macrogol might be known as the brand name Movicol, Laxido, CosmoCol or Molaxole. These help to relieve constipation by increasing the amount of water in the large bowel. This makes poo softer and easier to pass.
- Bulking agents such as Fybogel are made from plant fibre and make poo easier to pass. Avoid these if you have narrowing of the gut or a stricture.

Pain

- Painkillers such as paracetamol. Do not take non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen, unless these are prescribed by your doctor. This is because they may trigger a flare-up.
- Antispasmodics such as hyoscine butylbromide and mebeverine. These can reduce painful cramps and spasms by relaxing muscles in the gut. Antispasmodic medicines can be useful in people with IBS-like symptoms.

Find out more about these medicines in our information at **crohnsandcolitis.org.uk/othertreatments**

Liquid only diet

We do not yet know exactly how a liquid diet works. But we know it can help with inflammation, which may encourage the gut lining to heal. Special liquid diets provide you with all the nutrients you need and are usually prescribed for six to eight weeks. A liquid diet is also known as exclusive enteral nutrition or EEN.

Children with Crohn's will usually be treated with an exclusive liquid diet. These products are easily digested and provide all the nutrients children need to grow properly. Although not used as often in adults, this can be an option for treating flare-ups where someone wants to avoid steroids. Liquid only diets should only be undertaken on medical advice. A dietitian will usually supervise this treatment.

Find out more in our information at **crohnsandcolitis.org.uk/food** and **crohnsandcolitis.org.uk/supporting-your-child**

Surgery

If medicines are not helping and flare-ups keep happening, then surgery to remove the affected part of the gut may be an option.

Your doctor may recommend an operation if you have:

- Severe Crohn's that is not getting better with medicines
- Fistulas
- Strictures
- Cancer or pre-cancerous changes in the bowel

> “I've found life much easier since I had surgery – I was very lucky because it completely changed my life for the better. I still have issues with my joints and eyes sometimes, but my weight has been stable for years now, I'm no longer housebound, and I'm very grateful that I rarely have pain anymore.”
>
> **Kate**, living with Crohn's

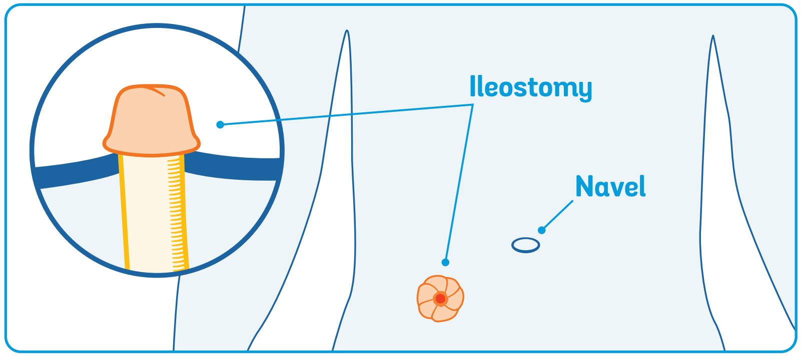
You'll see a surgeon who will explain what will happen and give you the chance to ask any questions you have.

Find out more about surgery at **crohnsandcolitis.org.uk/surgery**

Stoma

If you have a large part of the gut removed, you may need a stoma. A stoma is an opening on the wall of your tummy that brings your bowel to the outside. If you have a stoma, the contents of your gut do not travel all the way through your bowel to come out of your bottom. Instead, they come out of the stoma into a bag you wear on your tummy.

- If the stoma is made from an opening at the end of the small bowel, known as the ileum, it's called an ileostomy.
- If the stoma is made from an opening in the colon, it's called a colostomy.



Both types of opening are called a stoma and the bag is known as a stoma bag. A stoma may be temporary, or permanent.

Many hospitals have a specialist stoma team to support you during and after the surgery. You can find out more in our information at **crohnsandcolitis.org.uk/living-with-a-stoma**. There are lots of personal experiences of people living with a stoma on our website and Facebook Forum.

Emergency problems

Very occasionally, some people need an urgent operation.

This may be if there is:

- A hole or tear in the wall of the bowel, known as perforation
- Severe bleeding from the bowel
- Acute severe colitis
- A bowel obstruction

Find out more about these operations in our information at **crohnsandcolitis.org.uk/surgery**

Smoking

If you smoke, your IBD team will support you to stop before you have any surgery. This is because smoking increases the risk that you may need further operations.

NOTES

LIVING WITH CROHN’S

LIVING WITH CROHN'S

Support for you

When you live with Crohn's it can help to have the understanding and support of those around you. But it takes guts to start the conversation.

Our talking toolkit at **crohnsandcolitis.org.uk/talkingtoolkit** can help. From opening up about mental health, speaking with your boss or talking to children, there are lots of important conversations that will help others understand what it's like to live with Crohn's. This will help people understand how it affects you and how they can help.

We have information for friends and family, employers, and colleagues. Find all our information online.

We have around 50 Local Networks across the UK that bring local people affected by Crohn's and Colitis together. They are run by volunteers and host a range of events, from educational talks to socials. We also offer virtual social events. The events are a chance to chat and share experiences with others across the UK. Check our website or call our helpline to find your nearest Local Network or the next virtual social event.

> "Being diagnosed with Crohn's hit me pretty hard and took a long while to mentally and physically adjust to. Since then I've had good days and bad days, but I've tried not to let it stop me living my life. If anything, it has given me that extra motivation to say yes more and go after my dreams."
>
> **Tom,** living with Crohn's

Relationships

Having Crohn's and its treatments can also have emotional effects on your personal and sexual relationships. Your body image may change, you may feel embarrassed by some of your symptoms, or you may not feel up to having sex. This can have an impact on your relationship, or you may feel discouraged from starting a new relationship. Our information at **crohnsandcolitis.org.uk/sex-and-relationships** includes some suggestions that might help you deal with any difficulties, and shares other sources of help and advice.

> "Carry on living your life, Crohn's is a part of you but don't let it define you and try and be positive."
>
> **Ally,** living with Crohn's

Diet

There is not any clear evidence that specific foods cause or cure Crohn's. The most important thing is to try to eat a healthy, balanced diet, and drink enough fluids to stop you getting dehydrated.

Some people find that making small changes to their diet, for example avoiding spicy or high-fibre food, helps them cope with their symptoms. If cutting out a food makes no difference to your symptoms, make sure you start eating it again to avoid missing out on important nutrients.

A food diary can be a handy tool to help you when you speak to your IBD team or dietitian about your diet. It may help show whether you're getting enough nutrients or if any foods may be triggering symptoms. You can find one at **crohnsandcolitis.org.uk/food**.

If you have a stricture you may need to consider limiting dietary fibre and fibrous foods such as fruit and vegetable skins, nuts, and seeds. Some people find it helpful to supplement with liquid food to make sure you're getting all the energy and nutrients you need. Your IBD team or dietitian will help you with this.

Vitamin supplements
If you have trouble absorbing nutrients due to inflammation in the small bowel, you could be at risk of vitamin deficiencies. Your doctor, dietitian or IBD nurse will tell you if this is the case and if you need to take a vitamin supplement. The most common deficiencies are:

- **Iron**. Low iron levels can lead to anaemia, where there is less haemoglobin or fewer red blood cells to carry oxygen around the body. You may be given iron supplements as tablets by mouth, or as a drip into a vein in your arm.
- **Calcium**. Steroids make it harder for your body to absorb calcium, which can cause weaker bones. Calcium supplements with vitamin D may help prevent this. Find out more at **crohnsandcolitis.org.uk/bones**
- **Vitamin B12**. People who have had the last part of the small bowel removed, or who have inflammation in that area, may not absorb this vitamin. This can lead to a form of anaemia, which is treated by vitamin B12 injections.
- **Vitamin D** is important for healthy bones. Your body makes vitamin D when your skin is exposed to sunlight. You can also get it from eating oily fish, egg yolks and foods with added vitamin D, like margarine and breakfast cereals. People with Crohn's are more likely to have low levels of vitamin D. Some recent research suggests that having low vitamin D levels may increase the risk of Crohn's flare-ups, but it's not clear whether low vitamin D levels can cause flare-ups or whether it is the result of flare-ups.

Find out more in our information at **crohnsandcolitis.org.uk/food**

Complementary and alternative approaches

Many people with Crohn's try complementary or alternative therapies to help manage their condition.

There is some limited evidence that some of these therapies may help manage Crohn's symptoms. But there is not enough to recommend them as treatments. These include:

- Aloe vera
- Curcumin, an extract from turmeric
- Fish oils, such as omega 3 fatty acid
- Wormwood plant

Other therapies include homeopathy, herbal medicines, acupuncture and other traditional Chinese medicines. There has been little or no scientific evidence that these types of therapies work.

If you decide to try any of these approaches you may want to consider:

- How helpful it might be in managing your symptoms
- The cost of the therapy
- Possible unwanted side effects

Find out what qualifications your complementary therapist has. Many complementary therapists are not regulated as other health professionals are.

Do not forget to talk to your doctor first, especially if you're thinking of taking any herbal medicines. There may be interactions with some prescription medicines.

Find out more about complementary and alternative therapies at **crohnsandcolitis.org.uk/food** and **crohnsandcolitis.org.uk/othertreatments**.

Your mental wellbeing

> “You don’t have to put on a mask to cover up how you are truly feeling, it’s ok not to be ok!”
>
> **Rebecca,**
> living with Crohn’s

Taking care of your mental health is just as important as taking care of your physical health. Protecting your mental health is a major part of living with Crohn’s. Research suggests that people living with Crohn’s or Colitis may be twice as likely to experience mental health problems, like anxiety and depression, as the general population. And around half of all people with Crohn’s or Colitis say it has affected their mental health in some way.

You are more likely to experience poorer mental health at certain times, such as:

- When you’re first diagnosed with Crohn’s
- During a flare-up of your symptoms
- Needing to go into hospital for treatment or surgery, especially if you may need a stoma
- Starting a different treatment for your Crohn’s
- Taking steroids, as these can cause extreme highs and lows in your mood
- Living with ongoing invisible symptoms, such as fatigue or pain

It can help to be aware of the times when you may be at greater risk of changes in your mental health. You can then get the help and support you need.

Living with a long-term condition like Crohn’s can trigger lots of different feelings and emotions. You might feel shocked or a sense of disbelief when you are first diagnosed and find it hard to adjust. You may feel anxious, frustrated, sad, scared, or angry about having the condition and dealing with distressing symptoms. Not knowing what might happen in the future may make you feel helpless and uncertain. You may feel very isolated or even ashamed about your condition.

These feelings are completely normal, and many people with Crohn’s experience them from time to time. It’s not a sign of weakness. Long-term health conditions are a lot to deal with, and it’s natural that you might struggle to cope sometimes. Give yourself time and space to accept your feelings. For some people, these negative feelings can become overwhelming. This can lead to stress and mental health problems like anxiety and depression.

It can be helpful to understand more about your mental health, recognise your feelings and know what you can do. Getting support in place and developing coping strategies can make a difference. You’re not alone. We’re here to help.

A mood diary or mood tracker app can help you keep a record of how you’re feeling. You can also share this with your IBD team. **crohnsandcolitis.org.uk/mentalhealth** has information on things you can do to improve your mental health and getting the help you need.

If you have thoughts of suicide or harming yourself, tell someone you trust, call the NHS on 111 or go to your nearest A&E.

If you need someone to talk to, you can call the **Samaritans** 24 hours a day, 7 days a week on 116 123.

Exercise and Crohn's

We understand that it is not always easy to be physically active if you're living with Crohn's. But being active is important for physical and mental health. It is safe to be physically active or to exercise with Crohn's. Current research suggests it does not cause flare-ups.

You might find it difficult to be active if your Crohn's is severe. Symptoms like tummy or joint pain, fatigue, or urgently needing to poo can get in the way. Most people with Crohn's say exercising makes them feel better. Some said they have more energy, better sleep and fewer gut symptoms.

If you're not very active or your symptoms are making it difficult, try to build up your activity levels slowly. Walk to the shops instead of taking the car, use the stairs instead of the lift. Even sitting down less during the day can help. But be kind to yourself. If you're not feeling up to it, do not put pressure on yourself.

Being active can improve mental wellbeing and quality of life, as well as reducing fatigue. Being active may also have positive effects on your condition, such as reducing the risk of a flare-up. Scientists believe regular exercise could help reduce inflammation in Crohn's. This has been seen in other long-term illnesses, but more research is needed to know for sure.

Find out more at **crohnsandcolitis.org.uk/exercise**

Having a child

It's a good idea to talk to your IBD team when you're planning a pregnancy. They will talk through the importance of keeping well and making sure your Crohn's is controlled. They'll also consider your general health. They'll review your medicines to check you have the safest possible combination for pregnancy.

Fertility

If your Crohn's is well-controlled, you are likely to have similar fertility levels as someone without Crohn's. However, if you have active Crohn's, it may be more difficult to get pregnant.

Pregnancy and beyond

If you are pregnant and your Crohn's is under control, you are most likely to have a typical pregnancy and a healthy baby. In most cases, having a baby will not make the condition worse.

If you do get pregnant during a flare-up, you may be more likely to give birth early or have a baby with a low birth weight. However, your doctor should be able to help you to control your symptoms as much as possible. Many medicines are considered safe to take during pregnancy. If you have a flare-up when you're pregnant, you'll the receive the treatment you usually do for a flare-up.

Most pregnant people with Crohn's can give birth vaginally, but some might be advised to have a caesarean section. You can find out more in our information on **crohnsandcolitis.org.uk/pregnancy-and-breastfeeding**.

You can take medicines that are safe for use in pregnancy when breastfeeding your baby.

If you have any worries, talk to your team or find out more at **crohnsandcolitis.org.uk/reproductivehealth** and **crohnsandcolitis.org.uk/pregnancy-and-breastfeeding**.

Crohn’s in the family

Most people who have Crohn’s or Colitis in their family will not develop either condition. But your risk is higher if a close family member is affected. Research has shown:

- A family history of Crohn’s is more common in specific groups, such as people of Ashkenazi Jewish descent.
- The risk of developing Crohn’s or Colitis is higher if you have two or more relatives or a sibling with either condition.
- 5 in every 100 children might develop Crohn’s or Colitis if one parent has Crohn’s.
- Up to 30 in every 100 children might develop Crohn’s or Colitis if both parents have Crohn’s or Colitis.

Children and young people

Crohn’s can occur at any age. Nearly 1 in 5 people report that they were diagnosed with Crohn’s before the age of 18. It’s less common in very young children and babies. Crohn’s may affect growth and delay puberty.

In children, treatment often begins with a liquid diet instead of normal food for six to eight weeks. This easily digested food provides all the nutrients needed for them to grow properly while allowing the gut to heal.

Medicines used for adults may also be used in children and doses are adjusted accordingly. Surgery may also be an option for children with more severe disease, strictures or fissures.

Most children and young people continue to go to school and take part in sports and other interests. There’s no reason why they will not be able to go on to further education, training, or employment. Find out more at **crohnsandcolitis.org.uk/supporting-your-child**

Older people

Nearly 1 in 16 people with Crohn’s or Colitis are diagnosed after the age of 60.

Older people are more likely to have inflammation in the colon and perianal fistulas than younger people. Find out more about fistulas in the section **complications in the gut**.

Medicines and surgery are treatment options for Crohn’s in older people, just as they are in younger adults. However, there are some extra things your IBD team will consider when recommending treatment options to you.

Many older people have other health conditions, such as high blood pressure or diabetes, and may be taking other medicines. Your body also changes as you age. Your organ function may differ to younger people and you’re more at risk of infections and of developing cancer. If you’re less mobile, it may also be difficult to take medicines that go directly into your bottom. Your IBD team will look at potential side effects and interactions with other medicines when thinking about the best treatments to offer you.

Crohn’s as a disability

There is no single definition of disability in use in the UK. Disability Rights UK explain the different definitions. Currently, there is no national register of people who are classed as disabled. But you may be able to register with your local council if you meet their criteria.

A survey we conducted in 2019 found that more than 1 in every 3 people with Crohn’s or Colitis considered themselves to be disabled. If your condition affects your daily life, you may be entitled to help with your finances and protection at work. Some people with Crohn's might be able to get a Blue Badge if they get certain benefits or find it hard to walk from their car to where they're going. Find out more about Blue Badge parking in our information at **crohnsandcolitis.org.uk/travel**

The Equality Act 2010 defines when someone is considered disabled and is protected from being treated unfairly. Although Crohn's is not automatically classed as a disability under the Equality Act, it is a condition which might be classed as a disability depending on the effect on your daily life. You may not personally see yourself as being 'disabled' but be considered disabled under the legal definition in the Equality Act.

If your employer knows about your Crohn's, they can make changes to your workplace to help you do your job. These are called reasonable adjustments. Find out more at **crohnsandcolitis.org.uk/employment-a-guide-for-employees** and **crohnsandcolitis.org.uk/employment-a-guide-for-employers**

Living with a long-term health condition like Crohn's can have an impact on your financial situation. **crohnsandcolitis.org.uk/finances** outlines the help and support that may be available.

You could also be entitled to benefits to help you support yourself and your family. Which disability benefit you can apply for will depend on your age and where you live. Find out more at **crohnsandcolitis.org.uk/disabilitybenefitsquickguide**

USEFUL INFORMATION

Crohn's and Colitis UK information

- Understanding Crohn's and Colitis
  crohnsandcolitis.org.uk/understandingibd
- Treatments
  crohnsandcolitis.org.uk/treatments
- Surgery and complications
  crohnsandcolitis.org.uk/surgery
- Managing symptoms
  crohnsandcolitis.org.uk/managing-symptoms
- Employment and education
  crohnsandcolitis.org.uk/employment-education
- Benefits and finances
  crohnsandcolitis.org.uk/benefits-and-finances
- Healthcare
  crohnsandcolitis.org.uk/healthcare
- Supporting someone with Crohn's or Colitis
  crohnsandcolitis.org.uk/supportingsomeone
- Appointment guide
  crohnsandcolitis.org.uk/appointmentguide
- Talking toolkit
  crohnsandcolitis.org.uk/talkingtoolkit
- Campaigns
  crohnsandcolitis.org.uk/our-work/campaigns

Other useful information

- IBD toolkit for GPs
  https://elearning.rcgp.org.uk/course/view.php?id=537
- IBD standards
  ibduk.org/ibd-standards
- Samaritans – 24-hour emotional support service
  samaritans.org
- Disability Rights UK
  disabilityrightsuk.org
- Colostomy UK
  colostomyuk.org – 0800 328 4257
- Guts UK
  gutscharity.org.uk
- CICRA (Crohn's in Childhood Research Association)
  cicra.org
- IA – The Ileostomy and Internal Pouch Support Group
  iasupport.org – 0800 018 4724

Crohn's & Colitis UK Forum

This closed-group Facebook community is for anyone affected by Crohn's or Colitis. You can share your experiences and receive support from others at **facebook.com/groups/CCUKforum**.

Help with toilet access when out

There are many benefits to becoming a member of Crohn's & Colitis UK. One of these is a free RADAR key to unlock accessible toilets. Another is a Can't Wait Card. This card shows that you have a medical condition. It will help when you are out and need urgent access to the toilet. See **crohnsandcolitis.org.uk/membership** for more information. Or you can call the Membership Team on **01727 734465**.

Social events and Local Networks

You can find support from others in the Crohn's and Colitis community through our virtual social events. There may also be a Local Network in your area offering in-person social events. Visit our webpage **crohnsandcolitis.org.uk/our-work/crohns-colitis-uk-in-your-area** webpage to find out what is available.

Crohn's & Colitis UK Medicine Tool

Our Medicine Tool is a simple way to compare different medicines for Crohn's or Colitis. You can see how medicines are taken, how well they work, and what ongoing checks you need. You can find out more at **crohnsandcolitis.org.uk/medicinetool**.

The Medicine Tool can help you:

- Understand the differences between types of medicines
- Explore different treatment options
- Feel empowered to discuss medicine options with your IBD team

Always talk to your IBD team before stopping or changing medicines.

ABOUT THIS BOOKLET

We follow strict processes to make sure our information is based on up-to-date evidence and is easy to understand. We produce it with patients, medical advisers and other professionals. It is not intended to replace advice from your own healthcare professional.

You can find out more on **our website**.

We hope that you've found this information helpful. Please email us at **evidence@crohnsandcolitis.org.uk** if:

- You have any comments or suggestions for improvements
- You would like more information about the evidence we use
- You would like details of any conflicts of interest

You can also write to us at
Crohn's & Colitis UK,
1 Bishops Square, Hatfield,
Herts, AL10 9NE
or contact us through the **Helpline:**
0300 222 5700.

We do not endorse any products mentioned in our information.

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NOTES

CROHN'S &
COLITIS UK

We're here for you whenever you need us. Our information covers a wide range of topics. From treatment options to symptoms, relationship concerns to employment issues, our information can help you manage your condition. We'll help you find answers, access support and take control.

All information is available on our website at **crohnsandcolitis.org.uk/information**.

Follow us

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Helpline service

Our helpline team provides up-to-date, evidence-based information. You can find out more at **crohnsandcolitis.org.uk/helpline**. Our team can support you to live well with Crohn's or Colitis.

We can help by:

- Providing information about Crohn's and Colitis
- Listening and talking through your situation
- Helping you to find support from others in the Crohn's and Colitis community
- Providing details of other specialist organisations.

You can call the helpline on **0300 222 5700**. You can also visit our live chat service at **crohnsandcolitis.org.uk/livechat**. Lines are open 9am to 5pm, Monday to Friday, except English bank holidays.

You can email **helpline@crohnsandcolitis.org.uk** at any time. The helpline will aim to respond to your email within three working days.

Our helpline also offers a language interpretation service, which allows us to speak to callers in their preferred language.

Crohn's and Colitis UK. Charity registered in England and Wales Number 1117148, Scotland Number SC038632.
A company limited by guarantee in England: Company number 5973370. General enquiries 01727 830 038.