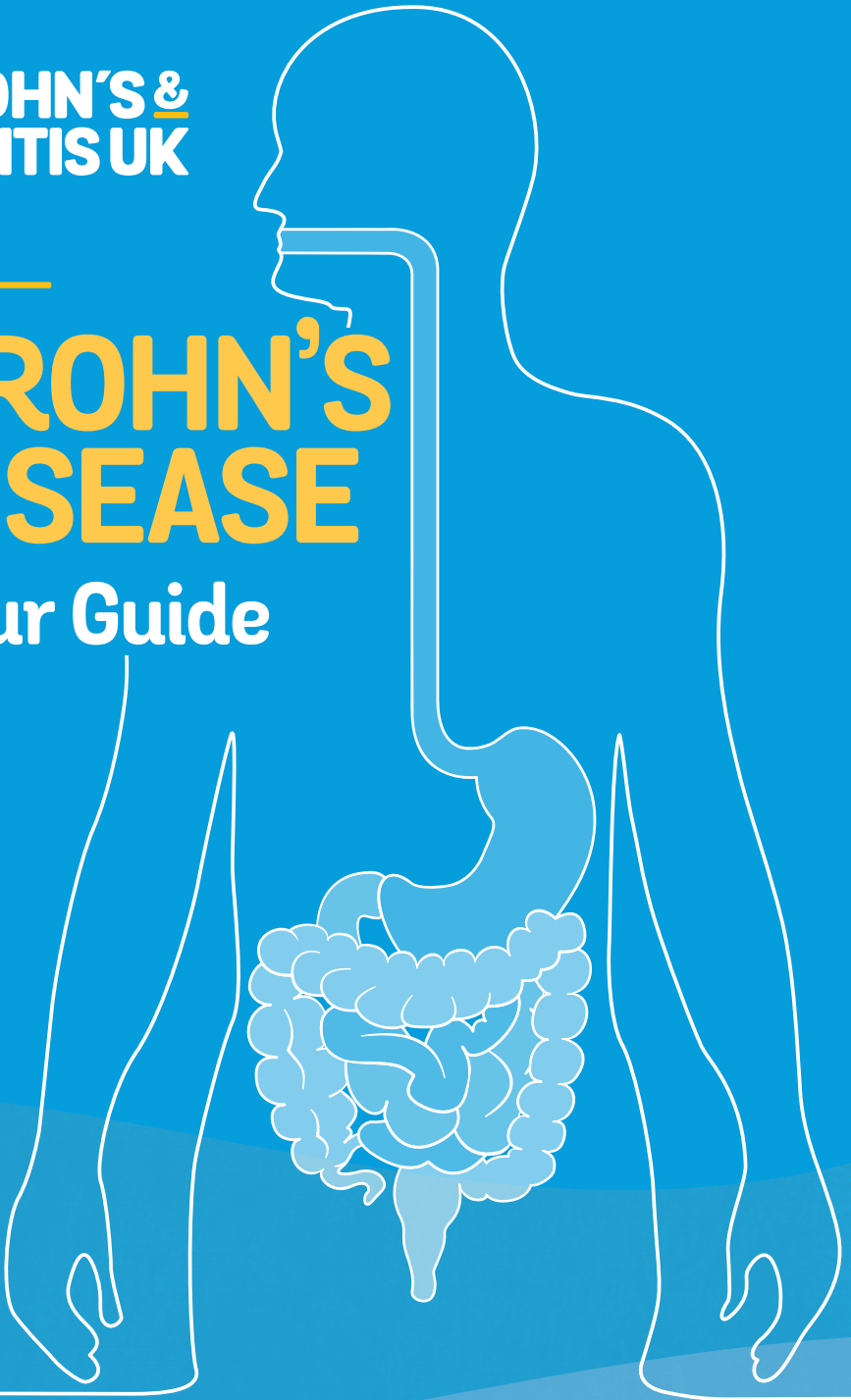


**CROHN'S &
COLITIS UK**

CROHN'S DISEASE

Your Guide



KEY FACTS ABOUT CROHN'S DISEASE

- 1** In Crohn's Disease, your immune system starts attacking your gut. This causes painful ulcers and inflammation that can be anywhere in your gut from your mouth to your bum. It is most common in the small bowel and colon.
- 2** Everyone experiences Crohn's differently. Symptoms can include pain, diarrhoea, tiredness and blood in your poo – but other parts of the body can also be affected.
- 3** Most people have times when symptoms are largely under control known as remission and flare-ups where symptoms are more active.
- 4** Crohn's is a lifelong condition. Medicine, surgery or a combination of both can help keep you feeling well and your symptoms under control.
- 5** There's lots of support out there to help you manage and live well with your condition – including your IBD team of healthcare professionals, your friends and family and organisations like Crohn's & Colitis UK.

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ABOUT CROHN'S & COLITIS UK



We're Crohn's & Colitis UK and we're here for everyone affected by Crohn's and Colitis. To improve diagnosis and treatment, and to fund research into a cure; to raise awareness and to give people hope, comfort and confidence to live freer, fuller lives.

This information is available for free thanks to the generosity of our supporters and members.

There are lots of ways to support our work so we can keep building a better future for people with Crohn's and Colitis: call **01727 734465** or visit **crohnsandcolitis.org.uk**

YOU'VE JUST BEEN DIAGNOSED WITH CROHN'S

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YOU'VE JUST BEEN DIAGNOSED WITH CROHN'S

Coming to terms with your diagnosis

Being told you have Crohn's can be a shock. You might be feeling anxious 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.

You may not have heard of Crohn's before. It's a type of Inflammatory Bowel Disease (IBD), which we'll explain more about later. But in Crohn's, parts of the gut become swollen, inflamed, and ulcerated. This can cause pain, diarrhoea, weight loss and tiredness – and you may have other symptoms too.

Crohn's is a lifelong condition and it can be unpredictable. You're likely to have periods of good health, known as remission, and times when your condition is active, known as flare-ups or relapses. Right now there is no cure for Crohn's, but medicines and sometimes surgery can keep you feeling well for long periods of time.

Remission is when you feel better because your Crohn's or Colitis is well controlled. Medical tests (like 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 (extreme tiredness) and tummy cramps, will improve. However, some symptoms, like fatigue, may not go away completely.

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

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. Whatever works for you we're here to support you. We have a confidential **Helpline** that can answer your questions and a range of information that explores many aspects of 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** 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. ittakesguts.org.uk/talk/talking-toolkit

“

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

“

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

In My Shoes: 24 Hours with Crohn's or Colitis App

is an immersive experience that allows anyone to find out at first-hand what it's like to have Crohn's.



“
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

From low energy levels to managing pain, from rushing to the toilet to juggling work and a social life, the app will allow friends, family and anyone you want, to see first-hand how the condition can affect every part of your body, and every aspect of your life.

ittakesguts.org.uk/share/in-my-shoes-app

We have information for friends and family, employers, and colleagues. Find all our information online at crohnsandcolitis.org.uk/information.

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. Check our website or call our Helpline to find your nearest Local Network. crohnsandcolitis.org.uk/localnetwork

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 on **Sexual Relationships** includes some suggestions that might help you deal with any difficulties, and shares other sources of help and advice.

Your Inflammatory Bowel Disease (IBD) team

Everyone with a diagnosis of Crohn's should be seen by an IBD specialist and cared for by a team of health professionals, led by a consultant adult or paediatric gastroenterologist. All teams are different but are likely to include an IBD nurse specialist, specialist gastroenterology dietitian, surgeon, psychologist and expert pharmacist in IBD. They will also refer you to any other health professionals you might need to see.

This 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.

My Appointments Journal will help you to get the most out of your appointments and understand what matters most to you about your treatment and care. It will help you work together with your IBD team to find what's right for you.

crohnsandcolitis.org.uk/support/your-guide-to-appointments

“

These are the experts who are here to help you through throughout your IBD journey. ”

Krupie, living with Crohn's

“

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

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ABOUT CROHN'S DISEASE

What you need to know

Crohn's is an Inflammatory Bowel Disease (IBD). When you have Crohn's your immune system doesn't 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 anus. 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 (IBD-U) or Indeterminate Colitis.

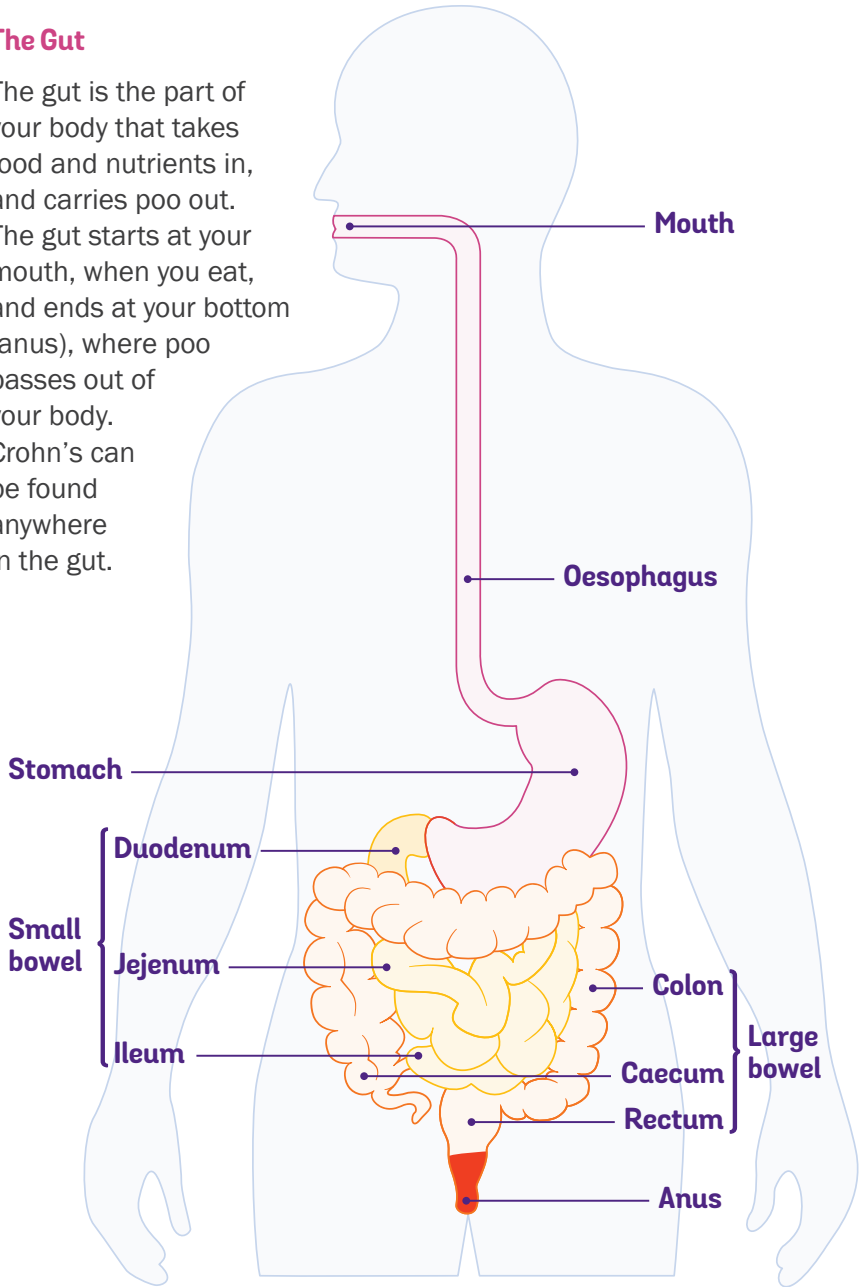
IBD is not the same as IBS (Irritable Bowel Syndrome). IBS has some symptoms which are similar to Crohn's, but this is a different condition and treatment for IBS is not the same. Find out more in the section **Crohn's and IBS**.

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, whilst at other times symptoms may be more difficult to manage.

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

The Gut

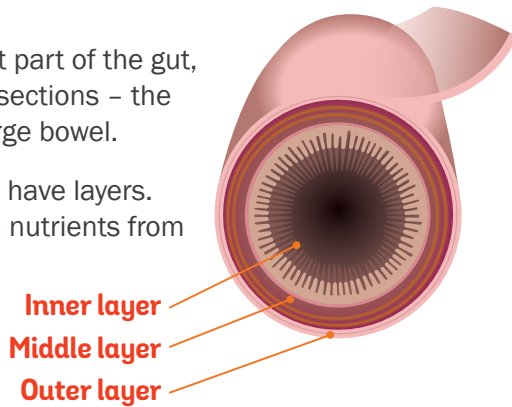
The gut is the part of your body that takes food and nutrients in, and carries poo out. The gut starts at your mouth, when you eat, and ends at your bottom (anus), where poo passes out of your body. Crohn's can be found anywhere in the gut.



The bowel

The bowel is the largest part of the gut, and is made up of two sections – the small bowel and the large bowel.

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

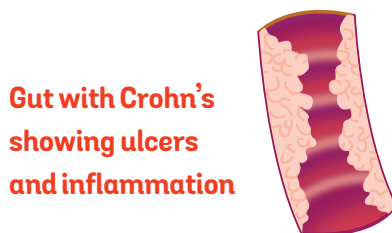


Layers of the bowel wall

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 **Fistulas**.

The inflammation in Crohn's affects how your body digests food, absorbs nutrients and gets rid of waste. This can cause watery poo (diarrhoea), the need to poo more often and reach the toilet quickly (urgency).

While Crohn's can be found at any point in your gut, it won't 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. A patch of inflammation may be small, only a few centimetres across, or extend quite a distance along part of the gut.



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:

- Severe pain in the tummy area (abdominal pain). Where you have the pain may depend on where the Crohn's is affecting your gut. You can find out more in **Types of Crohn's**.
- 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. You may need to reach a toilet quickly – this is known as urgency, or often – this is known as frequency.
- Extreme tiredness – also known as fatigue. This can be due to the condition itself, from the weight loss that can happen with flare-ups or surgery, from lack of iron or a lack of sleep if you keep getting up in the night with pain or diarrhoea.
- 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.
- Anaemia. Lack of iron can lead to anaemia, where there are fewer red blood cells to carry oxygen around the body. This is more likely if you're losing blood, aren't eating much, or your body isn't able to fully absorb nutrients from food. It can make you feel very tired.

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 flares differently. The symptoms may vary over time and will depend where Crohn's is in your gut. They can last anywhere from a few days to several months and you may have different symptoms during flare-up than you had when you were first diagnosed. A flare-up can be a worrying experience.

Flare-ups may not happen very often – people can go years without feeling unwell. For others, flare-ups may happen more often, with two or more a year. A few people have continuous symptoms of active Crohn's.

Over time you'll get to know how to recognise a potential flare-up. Working together with your health professionals you'll create a treatment plan for flare-ups, so you know what to do and who to contact. This may be your IBD service, advice line or your GP.

If you have any of these signs it could be a flare-up:

- Going to the toilet more than five times in 24 hours – or more than is normal for you.
- Loose poo or diarrhoea with any blood or mucus for more than three days.
- Pain in the tummy area.
- Just generally feeling worse, especially if you have a fever.

“

For me, it's important to listen to my body and know when to take it easy and rest, because when I'm stressed and tired, that's when my symptoms flare. It is a bit like being on a rollercoaster, sometimes being well, sometimes being poorly, but you can live your life to the full. ”

Claire, living with Crohn's

If you're worried in any way, contact your IBD team or your GP. Fast access to the healthcare team who know you will provide the support and reassurance you need.



PRACTICAL TIPS

Tips for contacting your IBD team

- Find out if your IBD team has a direct number or email address. Some hospitals have advice lines run by the IBD Nurse Specialists – check our interactive map: **crohnsandcolitis.org.uk/ibd nurse**
- Ask your IBD team how to best to 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 also try contacting the secretary of your consultant. The main hospital switchboard should be able to put you through.
- If you're still having trouble reaching your IBD team, contact your GP or out of hours service for medical advice. You could also share the IBD Toolkit for GPs with your GP: **crohnsandcolitis.org.uk/toolkit**
- Check out **My Appointments Guide** for ideas on how to make the most of time with your IBD team.

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

To confirm that you are having flare-up, your IBD team or GP will use a blood or poo test. The results will help to decide on the best treatment to bring the condition under control. Find out more in **Tests and Treatments**.

Flare-ups can be disruptive. Sometimes you may need to cancel plans or take time off work when you feel unwell. It can help if you feel you can be open about your condition with your family, friends, work colleagues and employers. Our Talking Toolkit can help: ittakesguts.org.uk/talk/talking-toolkit

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

Taking the medicines recommended by your doctor regularly reduces the risk of flare-ups. We don't yet know what causes flare-ups, but possible triggers include:

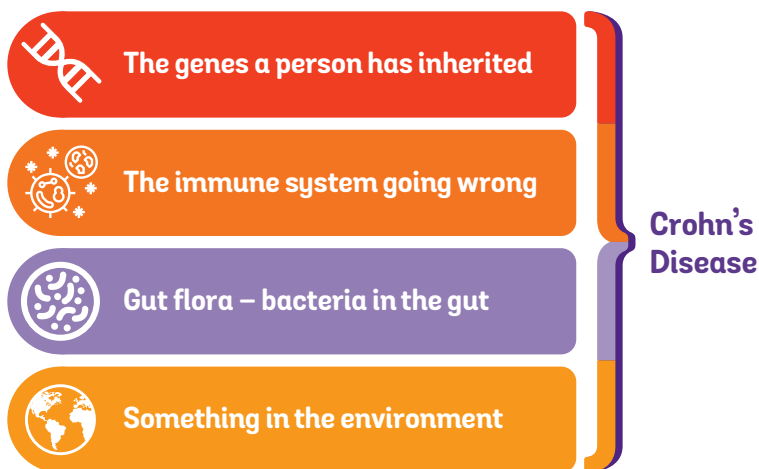
- Smoking
- Disruptions or changes in medicines
- Ongoing stress
- Taking non-steroidal anti-inflammatory medicines (NSAIDs) such as ibuprofen
- Antibiotics

It can help to keep a diary of symptoms to see if you become aware of any triggers for you. You can find one in **My Appointments Journal**.

Causes of Crohn's

We don't yet fully understand what causes Crohn's, but it happens when the body's immune system goes wrong. Usually, the immune system protects the body against harmful substances and infections. In Crohn's, the immune system starts attacking the gut. We don't know yet why this happens. It's probably caused by a mix of genes, bacteria in the gut and something in the environment.

There's nothing you could have done differently that would have prevented you from developing Crohn's.



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 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 flora

These are the microorganisms that live in your gut and include bacteria, viruses and fungi. People with Crohn's have fewer varieties of helpful bacteria in their gut than people who do not have Crohn's. And some bacteria which help the gut are missing. New evidence suggests that other bacteria in the gut may produce proteins that cause inflammation and lead to the development of Crohn's.

Environment

A range of factors in the environment may increase the risk of Crohn's. These include viruses, bacteria (which can be influenced by diet), smoking, stress, and certain medicines including antibiotics and non-steroidal anti-inflammatory drugs (NSAIDs). But there's no definite evidence that any one of these is the cause of Crohn's.

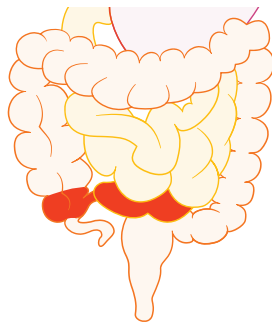
Types of Crohn's

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.

The main types are:

At the end of the small bowel – known as terminal ileal and ileocaecal

Crohn's in the last part of the small bowel, known as the ileum, is also known as ileal or sometimes 'terminal ileal' Crohn's. This is because it is in the end of the small bowel, and terminal means end (it may sound worrying but it doesn't mean end of life). If it also affects the beginning of the large bowel it is known as ileocaecal Crohn's. This is one of the most common forms of Crohn's Disease.

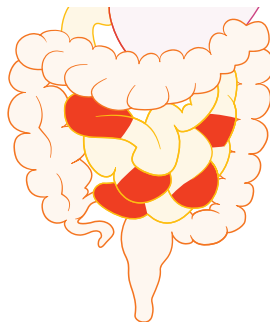


Typical symptoms:

- Pain in the lower right side of the tummy area especially after eating
- Diarrhoea, usually without blood in the poo
- Weight loss
- Anaemia

Small bowel

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



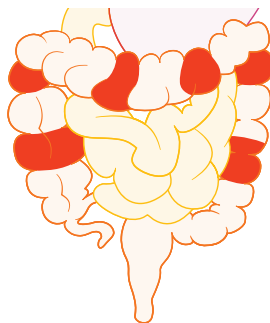
Typical symptoms:

- Pain in the tummy area (abdominal pain)
- Nutrient deficiencies
- Diarrhoea – usually without blood in the poo
- Anaemia
- Weight loss

The small bowel is often affected in children and young people. You may be more likely to have strictures if Crohn's affects this part of the gut. Find out more in the section **strictures**.

Colon (Crohn's Colitis)

'Crohn's Colitis' is a type of Crohn's Disease where only the large bowel is inflamed. This is because 'colitis' means inflammation of the large bowel. It doesn't mean you have both Crohn's Disease and Ulcerative Colitis.



Typical symptoms:

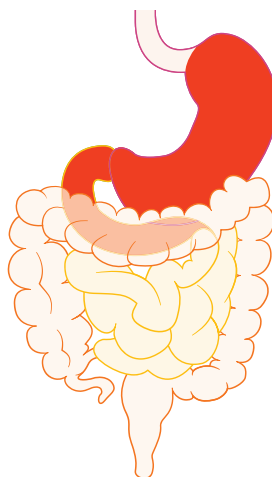
- Diarrhoea, with blood and mucus
- Need to poo very often (frequency) especially if your rectum is inflamed
- Need to reach a toilet quickly to poo (urgency)
- Feel the need to poo even if the rectum is empty (tenesmus)

Gastroduodenal

This is Crohn's in the upper part of the gut – the oesophagus, stomach or the first part of the small bowel known as the duodenum. It may occur on its own or alongside Crohn's in other parts of the gut.

Typical symptoms:

- Indigestion-like pain
- Feeling sick (nausea), sometimes being sick (vomiting)
- Loss of appetite and weight loss
- Anaemia

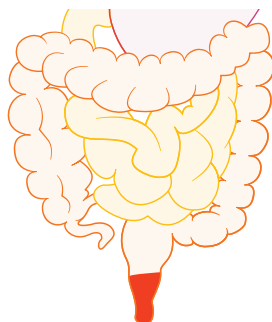


Perianal

Crohn's in the area around the anus, where poo leaves the body. It can occur on its own or at the same time as inflammation in other parts of the gut. Around 1 in 4 people have this type of Crohn's. Some people notice these perianal symptoms before they develop symptoms in other parts of the gut.

Typical symptoms include:

- Fissures – tears or splits in the lining of the anal canal (back passage), which can cause pain and bleeding when you poo.
- Skin tags – small fleshy growths around the anus that may feel like small bumps or raised areas and can be itchy.
- Abscesses – collections of pus that can become swollen and painful. They're often found in the area around the anus and can cause fever or lead to a fistula.



- **Fistula** – An anal or perianal fistula is a small tunnel that develops between the end of the bowel and the skin near the anus, where the poo comes out. They appear as tiny openings in the skin that leak pus or poo. These can irritate the skin and are often sore and painful. They don't usually get better on their own, so doctors treat these with medicines or sometimes surgery. Find out more in our information on **Fistulas**.

Mouth

Some people with Crohn's may develop mouth ulcers during flare-ups. But true oral Crohn's is also known as orofacial granulomatosis and is more likely to affect children. It can cause swollen lips and red, swollen patches in the corners of the mouth where your lips meet and make an angle.

Other parts of the body

Crohn's disease can also affect other parts of the body such as lungs, vulva and inside the passages of the nose. These are very rare, but always tell you IBD team if you have new symptoms anywhere in your body and they'll investigate these.

Crohn's activity and severity

Assessing how active and severe Crohn's Disease is will help your IBD team to find the most appropriate treatment for you. This is based on measures which 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 Crohn's 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

Your IBD team will assess how severe your Crohn's is to help find the best treatment for you. This is based on your symptoms and test results. The following severity groups are only a guide. Crohn's is different for everyone – you know your body best and which symptoms may mean you're having a flare-up. 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 – Need to poo often, with or without tummy pain, but you can eat normally. There are no signs of dehydration, tenderness in the tummy area or weight loss.

Moderate – Need to poo often, have tummy pain or tenderness in this area with fever and possible weight loss.

Severe or severely active – Very poor general health and one or more symptoms such as weight loss, fever, severe pain in the tummy area and usually 3 to 4 or more loose poos (diarrhoea) a day.

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 an organ to another part of your body. In Crohn's, these tunnels can connect the bowel to another internal organ, such as the vagina or bladder, or to the skin.

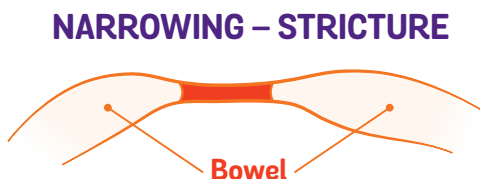
On the skin, a fistula looks like an open boil and often occurs around the anus. Biologic medicines such as infliximab or adalimumab or an operation are treatment options. What's best for you will depend on the position of the fistula, and if one or more channels has developed. Find out more in our information on

Fistulas.

Narrowing of the gut – stricture

Ongoing inflammation and then healing in the bowel may cause scar tissue to form. This can create a narrow section of the bowel known as a stricture. Strictures can also be caused by severe inflammation alone.

A stricture can make it difficult for food to pass through and, if it's very narrow, cause a blockage.



Symptoms include:

- Severe cramping and pain in the tummy area, feeling sick (nausea), being sick (vomiting) and constipation.
- Tummy area may become bloated and swollen (distended).
- Gut may make loud noises.

For some people it may be possible to widen the stricture with a

type of endoscopy or an operation known as a strictureplasty. In other cases the part of the bowel may need to be removed with surgery. Inflammation alone can also cause narrowing of the gut and if this is the case biologic medicines such as adalimumab can be helpful to reduce this. Find out more in **Surgery for Crohn's**.

Perforations

Inflammation deep in the gut wall or a severe blockage caused by narrowing may lead to a perforation or rupture of the bowel, making a hole in the bowel wall. The contents of the bowel can then leak through. This only occurs in around 2 in 100 people with Crohn's, but symptoms include:

- Severe pain in the tummy area
- Fever
- Feeling sick (nausea) and being sick (vomiting)

In some cases, the leak may form an abscess. **This is a medical emergency, and you need to see your doctor.**

Complications outside the gut

Crohn's Disease doesn't just affect the gut – around 1 in 2 people develop problems in other parts of the body. Most affected are joints, eyes, or skin. These are also known as extra-intestinal manifestations or EIMs because they're outside the gut. They often occur when you're having a flare-up but can develop before any signs of bowel problems and even when you're not having any gut symptoms.

These complications can also happen in people who do not have Crohn's. For many of the complications, there are things you can do to reduce your risk.

Joints

You may have pain or swelling in your joints. Around 1 in 3 people with Crohn's or Colitis experience joint problems. For some these problems affect joints of arms and legs, and usually improve with treatment for your Crohn's. Some people develop swelling and pain in the smaller joints of the hands or feet, and these may go on even when gut symptoms feel better. Find out more in **Joints**.

Bones

People with Crohn's are more at risk of developing thinner and weaker bones or osteoporosis. This can be due to the inflammation caused by Crohn's, poor absorption of calcium needed for bone formation, or low calcium levels if your diet doesn't contain enough dairy foods. Smoking, lower levels of physical activity or taking steroids can all increase the risk. Things that can reduce your risk include engaging in weight-bearing exercise, taking calcium and vitamin D supplements, not smoking, and avoiding use of steroids over the long term. For some people, medicines can be helpful. Find out more in our information on **Bones**.

Skin

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

Erythema nodosum affects about 1 in 7 people with Crohn's and is more likely in women than men. It causes raised, tender red or violet swellings around 1.5cm long, usually on the legs. This tends to occur during a flare-up and often improves with treatment for Crohn's.

Pyoderma gangrenosum. This starts as small tender blisters or pustules, which become painful, deep ulcers. It's most common on the shins or near stomas but can occur anywhere. This condition is sometimes, but not always, linked to a flare-up. A dermatologist, a specialist in skin conditions, will often treat this with creams or ointments. You may also need to take steroids, immunosuppressants or a biologic medicine.

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

Eyes

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

Episcleritis affects the layer of tissue covering the white outer coating of the eye, the sclera, making it red, sore, and inflamed. This tends to flare up at the same time as gut symptoms and often gets better on its own.

Scleritis (inflammation of the sclera) and **Uveitis** (inflammation of the iris). **These are serious and can lead to loss of vision if they're not treated.** They're usually treated with steroid drops, and sometimes immunosuppressants or biologic medicines.

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 pee. Find out more [nhs.uk/conditions/kidney-stones](https://www.nhs.uk/conditions/kidney-stones)

Liver

Gall stones – Around 1 in 3 people with Crohn's develop gallstones. These 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 (PSC) – This is a rare condition that affects around 1 in 50 people with Crohn's. 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.

Heart and circulation

Blood clots

You're more likely to develop blood clots if you have Crohn's including DVT (deep vein thrombosis) in the legs, and pulmonary embolisms in the lungs. You may be most at risk during a flare-up or if you need to stay in bed, for example in hospital.

Symptoms include:

- Pain, swelling and tenderness in your leg, or chest.
- Pains and shortness of breath.

Contact your doctor urgently if you experience any of these symptoms.

To reduce your risk:

- Don't smoke.
- Keep as mobile as possible.
- Drink plenty of fluids.
- Wear support stockings.

These precautions can also be helpful when you travel by air, which increases the risk of blood clots for everyone. Find out more in **Travel**.

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 and/or lower levels of haemoglobin in your blood. Haemoglobin is a protein found in red blood cells that carries oxygen around the body. Anaemia can make you feel very tired and if it's more severe you might also develop shortness of breath, headaches, and general weakness. It may be due to:

- **Iron deficiency** – A lack of iron in your diet, poor absorption of iron from food, or blood loss from the gut. Try to eat foods that contain iron, and you may be prescribed iron supplements tablets. Find out more in **Food**.
- **Vitamin deficiency** – This is caused by a low intake or poor absorption of some vitamins, such as vitamin B12 or folic acid. This may affect you if you've had sections of the small bowel removed. You can take extra B12 or folic acid, as tablets or by injection.

Hair loss

Losing more hair than usual is common if you have Crohn's. This type of hair loss called telogen effluvium. Many things can trigger this including severe flares, poor nutrition, iron and zinc deficiency, some medicines and surgery. Hair loss often happens months after the trigger so it may not be obvious what's caused it. It can seem worrying at the time, but hair will usually grow back completely.

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 it doesn't cause inflammation in the gut and there's no blood in poo.

Some people with Crohn's also develop IBS-like symptoms. There may be diarrhoea even when Crohn's isn't active. Between 1 and 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. The risk increases if you've had Crohn's affecting most of the large bowel for more than 8-10 years or have strictures in the gut. If you are at increased risk of bowel cancer you will be offered regular colonoscopies to check for early warning signs. Find out more in **Bowel cancer risk**.

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.

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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 (monitor) 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 (pulse rate), 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 part of the large bowel (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 MRI (Magnetic Resonance Imaging) and CT (Computerised Tomography) 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 the tests in our information on **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 **My IBD 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.

The aim of treatment

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

Treatment for Crohn's may be with medicines, surgery, or a combination of both. For some people, especially children, therapy 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 (see the section on Types of Crohn's).
- 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 in **My Appointments Journal**. Your IBD team should support you to understand all the options available and their benefits, risks and consequences.

“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

Medicines to treat Crohn's

The medicines used to treat Crohn's aim to:

- Stop inflammation in the gut and reduce symptoms such as diarrhoea and pain.
- Control flare-ups and get you into remission.
- Keep you in remission and prevent a flare-up.

Medicines sometimes cause side effects, but your IBD team will monitor these carefully. Not everyone responds to treatment in the same way, and it may take some time to find the treatment that's right for you. This can seem frustrating but remember your health care team are trying to do their best for you.

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** such as prednisolone and budesonide. When you're in a flare-up and feel unwell, steroids can help to quickly reduce the inflammation in your gut to help you feel better. But they have a higher risk of side effects and

can't control Crohn's long-term. You can take steroids by mouth as tablets, capsules or granules. If the inflammation is in the lower part of the colon or rectum, steroids can be delivered directly to the affected area in your gut as enemas or suppositories which are inserted into your bottom. If you have a severe flare-up, steroids may be given through a drip into a vein in your arm by intravenous (IV) infusion to help you feel better more quickly. Find out more in **Steroids**.

- Immunosuppressants such as azathioprine or mercaptopurine. These dampen down the immune response and reduce inflammation in the gut. They may help you reduce or stop taking steroids without having another flare-up. If you've had two or more flare-ups in 12 months that needed treatment with steroids, these medicines could help. They are tablets and can take between 8 and 16 weeks to start working. Find out more in **Azathioprine and mercaptopurine** and **Methotrexate**.
- Biologic medicines such as **infliximab**, **adalimumab**, **ustekinumab** and **vedolizumab** are available for people with moderate to severely active Crohn's. These medicines work in different ways to block parts of the immune system and reduce inflammation. They may also be known as immunosuppressants because they dampen the immune response. Some are taken by injection under your skin, and some by intravenous (IV) infusion (through a drip into a vein in your arm).

These may be an option when other medicines such as immunosuppressants or steroids haven't worked, have stopped working or where unwanted side effects are hard to manage.

Find out more in **Biologic medicines** and **individual medicine information**.

The treatment you're offered may also depend on where Crohn's is active in your gut. See **Types of Crohn's**.

WHERE CROHN'S IS ACTIVE	POSSIBLE TREATMENT OPTIONS
<p>At the end of the small bowel and the caecum – terminal ileal and ileocaecal</p>	<p>Mild – oral budesonide.</p> <p>Moderate– budesonide or other steroids. If steroids haven't worked for you in the past or side effects are difficult to manage you may be offered an immunosuppressant.</p> <p>Severely active – If you flare after you stop steroid treatment, biologic medicines such as infliximab or adalimumab are likely to be offered. Vedolizumab or ustekinumab can be an alternative if these are not an option.</p>
<p>Small bowel</p>	<p>You'll usually be offered steroids first, but immunosuppressants or biologic medicines may be suggested early in treatment.</p> <p>You should be assessed to make sure you're absorbing enough nutrients and will be offered nutritional support if you need this.</p>
<p>Stomach and duodenum – gastroduodenal</p>	<p>Mild – Proton-pump inhibitor such as omeprazole or lansoprazole.</p> <p>Moderate – Severely active – If this treatment doesn't work or the condition is more severe, steroids or biologic medicines.</p>
<p>Colon – Crohn's Colitis</p>	<p>Mild – steroids such as prednisolone can bring about remission.</p> <p>Moderate – Severely active – if you flare after steroid treatment then immunosuppressants or biologic medicines such as infliximab or adalimumab may be offered. Vedolizumab or ustekinumab can be an alternative if these are not an option.</p>
<p>Perianal</p>	<p>Abscess – antibiotics and draining the pus.</p> <p>Fistula – medicines or surgery. Find out more in Fistulas.</p>
<p>Mouth</p>	<p>Steroid cream or mouth wash or ointment containing tacrolimus. There is some evidence that a diet free from cinnamon and benzoates may help oral Crohn's.</p>

Medicines to help you manage symptoms

Some medicines can be helpful at times to ease symptoms, but these don't 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 drugs** such as loperamide and diphenoxylate. These work by slowing down the muscle movements in the gut, so food moves more slowly. But don't use these if you're having a flare-up, particularly if you have inflammation in colon or a stricture. 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 these to stop this.

Constipation

- **Laxatives** such as macrogol (Movicol). 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. Don't take non-steroidal anti-inflammatory medicines such as ibuprofen (NSAIDs), unless these are prescribed by your doctor, 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. They are often used by people with IBS but are occasionally helpful if you have Crohn's.

Find out more about these medicines in our information on **Other treatments**.

Liquid only diet

Having a break from eating food can help some people feel better by giving the gut a chance to rest and heal. Special liquid diets provide you with all the nutrients you need and are usually prescribed for 6-8 weeks. It's also known as exclusive enteral nutrition (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 on **Food** and **Supporting your child with Crohn's or Colitis**.

Surgery

If medicines aren't 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 isn't getting better with medicines.
- Complications that don't get better with medicines, such

as a narrowing in part of the gut (stricture) or a pus-filled area in the wall of the bowel (abscess).

- A perforated bowel.
- High risk of cancer in the bowel.
- Cancer in the bowel.

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

The most common operations are to:

- Remove the damaged part of the gut – this is a resection.
- Widen a narrowed part of the gut known as a stricture – this is a strictureplasty.

Find out more about these and other operations in our information on

Surgery for Crohn's.

Stoma

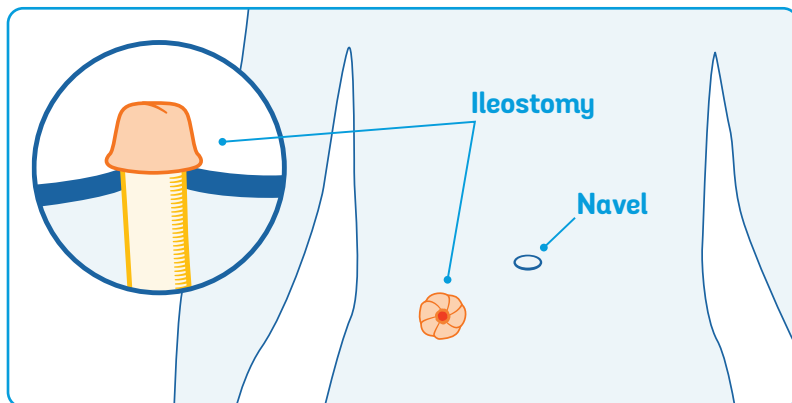
If you have a large part of the gut removed, you may need a stoma. A stoma is an opening through the tummy wall (abdominal wall), made during surgery. The end of the bowel is brought outside the body through this opening, onto the surface of the tummy. Poo then passes out of this opening, and into a disposable bag that is worn over the stoma.

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

“

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



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 on **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:

- Severe bleeding from the bowel.
- A hole or tear in the wall of the bowel – perforation.
- Toxic megacolon – very severe disease of the colon
- A bowel obstruction.

Find out more about these operations in our information on **Surgery for Crohn's**.

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.

LIVING WITH CROHN'S

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LIVING WITH CROHN'S

Diet

There isn't any clear evidence that specific foods cause or cure Crohn's. The most important thing is to try to eat a nutritious and balanced diet so that you maintain your weight and strength, 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 in the information on **Food** and in **My Appointments Journal**.

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 you need to take a vitamin supplement. The most common deficiencies are:

- **Iron** – this 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 can cause calcium loss which may lead to osteoporosis. Calcium supplements with vitamin D may help prevent this. Find out more in **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 your immune system and 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 on **Food**.

Your mental wellbeing

Taking care of your mental health is just as important as taking care of your physical health. Almost half of people with Crohn's say their condition has affected their mental health.

It's important to remember that these feelings aren't irrational or a sign of weakness.

You're more likely to be at risk of experiencing mental health problems at certain times, such as:

- When you're first told you have Crohn's.
- When you have a flare-up and symptoms come back after you'd been feeling better.

“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

- After you've had surgery – especially if it leaves scarring or you have a stoma.
- Experiencing side effects of your treatment for Crohn's. If you take steroids, you may experience extreme highs and lows in your mood. Find out more in **Steroids**.
- If your condition stops responding to the medicines you're taking.
- Living with ongoing invisible symptoms such as fatigue or pain.

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

Living with Crohn's can trigger lots of different feelings and emotions. You may feel anxious, frustrated, scared, or angry. Not knowing what might happen in the future may make you feel helpless and uncertain, and you may even have feelings of guilt or shame.

These feelings are completely normal. Long-term health conditions are a lot to deal with, and it's natural that you might struggle to cope sometimes. Give yourself space to accept your feelings and understand that they won't last forever.

For some people, these negative feelings can become overwhelming and stop you from living your life to the full. You may experience stress, anxiety, low mood, or depression. Struggling with your mental health can make it more difficult to manage Crohn's. Share how you feel with your IBD team, they can refer you to psychological support. Learn more in our information on **Mental health and wellbeing**.

If you start to feel like your life isn't worth living, or that you want to harm yourself, get help immediately. You could see your GP or call NHS 111. You can also call Samaritans on 116 123 for 24-hour confidential, non-judgemental emotional support.

Complementary and alternative approaches

Around 1 in 2 people with Crohn's or Colitis try complementary or alternative medicine (CAM) at some time, although there isn't always evidence that they're effective. If you decide to try any of these approaches you may want to consider:

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

Find out if your complementary therapist is qualified if possible, although many practitioners aren't regulated as other health professionals are.

Speak to your doctor first, especially if you're thinking of taking any herbal medicines as these may interact with some prescription medicines.

Some commonly tried CAMs include:

Omega-3 fatty acids – These are found in foods such as oily fish, like sardines, salmon and mackerel, and nuts and seeds including chia, flax, and walnuts. Some studies suggest these may have some benefit in maintaining remission, and they're an important part of a healthy diet.

Prebiotics and probiotics – There's no evidence as yet that they can help treat Crohn's. But there is great research interest in this area and Crohn's & Colitis UK have funded some of these projects.

Meditation, mindfulness and relaxation – These may improve mental wellbeing and symptoms in people with Crohn's. Crohn's & Colitis UK are funding research into whether mindfulness can improve mental wellbeing, sleep, pain and fatigue in young people with Crohn's and Colitis.

Yoga – A small study has shown that yoga may reduce symptoms and improve how you feel.

Exercise can have benefits for your overall health, physical well-being, stress and how you feel. Research shows that you may benefit from low intensity walking, moderate intensity continual exercise, and High Intensity Interval Training (HIIT) if you have Crohn's. Regular exercise may also help with fatigue.

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, ensuring your Crohn's is controlled and consider your pre-conception general health. They'll also review your medicines to ensure you have the safest possible combination for pregnancy.

Fertility

Crohn's is unlikely to affect fertility if your condition is well-controlled and you're feeling well. However, if you're a woman and have active Crohn's, it may be more difficult to get pregnant, particularly if you are underweight or not eating well.

Pregnancy and beyond

If Crohn's is under control, most women can expect to have a typical pregnancy and a healthy baby. For most women, having a baby won't make the condition worse. Some women find that Crohn's symptoms improve during pregnancy.

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 – and, with a few exceptions, you can continue most treatments while you're pregnant.

If you have a flare when you're pregnant, you'll receive the treatment you usually do for a flare. Unless there are reasons such as perianal Crohn's, you can expect a typical delivery of your baby. You can take medicines that are safe for use in pregnancy when breastfeeding your baby.

If you have any worries, talk to your team and find out more in our information on **Reproductive Health** and **Pregnancy**.

Crohn's in the family

There's not always a family connection, but your risk of developing Crohn's is higher if you have a family member with Crohn's or Colitis. It's hard to put a number on this risk, but research has shown:

- The risk is highest when you are young, and reduces as you age.
- You could develop either Crohn's or Colitis, but you're more likely to develop the same condition as your family member.
- The risk is higher if you have two or more close relatives with Crohn's or Colitis.
- A family history is more common in some ethnic groups, for example, in Europeans compared to South Asians. And in specific groups such as people of Ashkenazi Jewish descent.

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. As with adults, some children's condition rarely bothers them, whereas others need lifelong medication or surgery. Crohn's may affect growth and delay puberty.

In children, treatment often begins with a liquid diet instead of normal food for 6 - 8 weeks. This easily digested food provides all the nutrients needed for them to grow properly whilst 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 won't be able to go on to further education, training, or employment. Find out more in **Supporting your child with Crohn's or Colitis**.

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.

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 anus. 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

More than 1 in 3 people with Crohn's or Colitis identify as disabled.

The Equality Act 2010 defines disability as a physical or mental condition that has a substantial and long-term adverse effect on your ability to carry out normal day-to-day activities. Although Crohn's Disease isn't specifically named in the Act, you may be protected depending on how Crohn's affects you.

The Act is likely to cover you if:

- You sometimes can't reach a toilet in time and have an accident where you lose control of your bowels and soil yourself.
- You have bowel accidents that happen often but may be more minor.

If this is the case, you're protected from discrimination because of your condition. You can ask for reasonable adjustments at work or use the government's Access to Work scheme. Some people may also be eligible for **Benefits** such as Personal Independence Payments (PIP) or Blue Badge parking.

not every
DISABILITY
is **VISIBLE**



USEFUL INFORMATION

Other useful organisations

- Colostomy UK
colostomyuk.org – 0800 328 4257
- Guts UK
gutscharity.org.uk
- CICRA (better lives for children with Crohn's and Colitis)
cicra.org

Crohn's & Colitis UK Forum

This closed-group community on Facebook is for everyone 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

Members of Crohn's & Colitis UK get benefits including a Can't Wait Card and a RADAR key to unlock accessible toilets. This card shows that you have a medical condition, and will help when you need urgent access to the toilet when you are out. See crohnsandcolitis.org.uk/membership for more information, or call the Membership Team on **01727 734465**.

ABOUT THIS BOOKLET

We write our information together with people affected by Crohn's and Colitis, health professionals and other experts. The content is based on up-to-date, unbiased, evidence-based research. We don't recommend any particular products, and this information isn't meant to replace medical advice. Please speak to your GP or IBD team before making any changes.

If you'd like more information about how we've written this, the evidence we've used, or if you have any comments or suggestions for improvements, please email the Knowledge and Information Team at: **evidence@crohnsandcolitis.org.uk**.

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**.

CROHN'S & COLITIS UK



We're here for you whenever you need us. Our award-winning information on Crohn's Disease, Ulcerative Colitis, and other forms of Inflammatory Bowel Disease have the information you need to help you manage your condition.

We have information on a wide range of topics, from individual medicines to coping with symptoms and concerns about relationships and employment. We'll help you find answers, access support and take control.

All information is available on our website:
crohnsandcolitis.org.uk/publications

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Helpline

Our confidential helpline offers information and support for anyone affected by Crohn's and Colitis.

We can help you:

- Learn more about Crohn's and Colitis treatment, symptoms, tests, diet and more.
- Find support.
- Access disability benefits.

Call us on **0300 222 5700**

Email us at helpline@crohnsandcolitis.org.uk

Speak to us on Live Chat at

crohnsandcolitis.org.uk/livechat

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