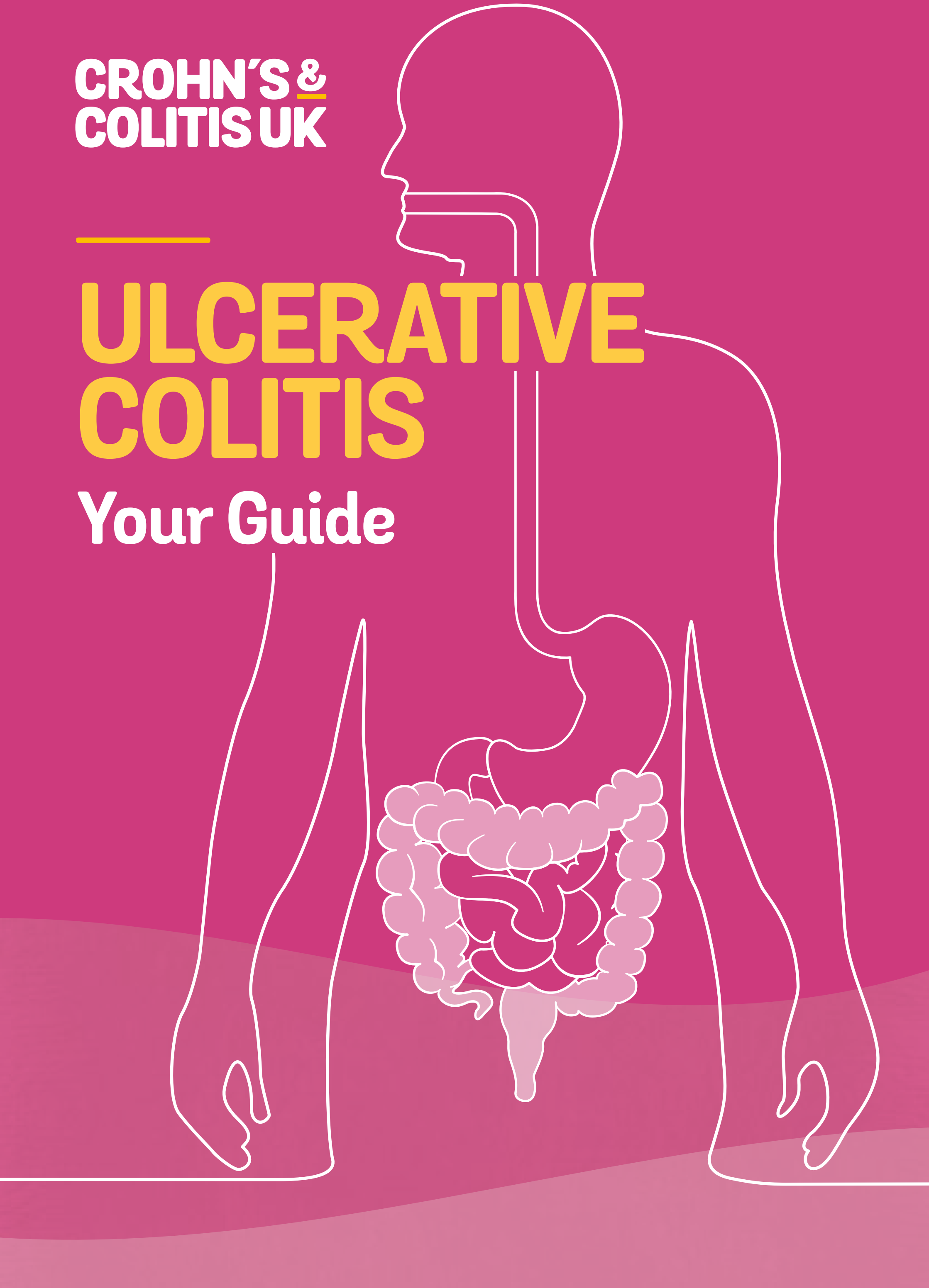
CROHN'S & COLITIS UK

ULCERATIVE COLITIS

Your Guide



KEY FACTS ABOUT ULCERATIVE COLITIS

1 In Ulcerative Colitis, your immune system starts attacking the lining of your gut. This causes inflammation and ulcers in your colon and rectum (the large bowel).

2 Everyone experiences Colitis differently. Symptoms can include diarrhoea, tiredness, an urgent need to poo (sometimes with tummy pain) and blood in your poo.

3 Most people have times when symptoms are largely under control known as remission and flare-ups where symptoms are more active.

4 Ulcerative Colitis is a lifelong condition. Medicines or surgery can help to 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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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 ULCERATIVE COLITIS

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Coming to terms with your diagnosis

Being told you have Colitis 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 Ulcerative Colitis – or Colitis as we’ll refer to it – before. It’s a type of Inflammatory Bowel Disease (IBD), which we’ll explain more about later. In Colitis parts of the gut become swollen, inflamed, and ulcerated. This can cause diarrhoea, blood in your poo, weight loss, tiredness and tummy pain – and you may have other symptoms too.

Colitis 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 Colitis, 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 Colitis 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.

> I try and take each day as it comes. I have learnt that I need to take it easy sometimes, but it hasn't stopped me doing the things I enjoy. I like running, so I get out for a run when I feel up to it.
>
> **Andy,** living with Colitis

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 Colitis.

Support for you

When you live with Colitis 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 Colitis. This will help people understand how it affects you and how they can help.
ittakesguts.org.uk/talk/talking-toolkit

> Colitis isn't a visible illness so it's important to find your own way of describing the nature of your condition. Other people will not know what we need from them unless we tell them!
>
> **Ros,** living with Colitis

Relationships

Having Colitis and some of the treatments for Colitis can affect 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.

In My Shoes: 24 Hours with Crohn's or Colitis App is an immersive experience that allows anyone to find out what it's like to have Colitis.

From low energy levels to managing pain, from rushing to the toilet to juggling work and a social life. The app allows 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**

> Be open about your condition with friends, family, colleagues and even sports coaches. Everyone I've told has been nothing but understanding, accommodating and supportive – and I feel great knowing people are there for me.
>
> **Kate,** living with Colitis

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**

Your Inflammatory Bowel Disease (IBD) team

Everyone with a diagnosis of Colitis should be seen by an IBD specialist and cared for by a team of health professionals. This team will be led by a consultant adult or paediatric gastroenterologist. 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.

This specialist team – your IBD 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 Colitis, you will become the expert in how the condition affects you.

> “I have a good relationship with my local hospital and am fortunate to have an excellent IBD nurse. Knowing that I can contact her when I start to experience a flare-up, and knowing that she will help as much as she can, helps to reduce the stress of the situation and speed up treatment.”
>
> **Andrew,** living with Colitis

My Appointments Journal 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. 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**

ABOUT ULCERATIVE COLITIS

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What you need to know

Ulcerative Colitis is an Inflammatory Bowel Disease (IBD) which causes your immune system to start attacking your gut. This causes swelling and inflammation in your rectum and colon (the two parts that make up the large bowel). Colitis can be diagnosed at any age, most commonly before the age of 30. At least 1 in every 227 people in the UK is diagnosed with Ulcerative Colitis.

Other forms of IBD include **Crohn's Disease** and **Microscopic Colitis**. It may not always be possible for doctors to tell the difference between Ulcerative Colitis and Crohn's Disease if the inflammation only affects your colon. In this case you may be diagnosed with IBD Unclassified (IBD-U) or Indeterminate Colitis.

We'll refer to Ulcerative Colitis as 'Colitis' in this information. The term colitis means inflammation in the colon. As well as Ulcerative Colitis, there are other types of colitis, including:

- **Microscopic Colitis.**
- Crohn's Colitis – this is Crohn's Disease in the colon. See our information on types of **Crohn's Disease.**
- Colitis caused by an infection or an allergy – this is not IBD.

RESEARCH FACT

As many as 1 in 10 people with a diagnosis of Colitis will have their diagnosis changed to Crohn's or IBD-U in the first five years.

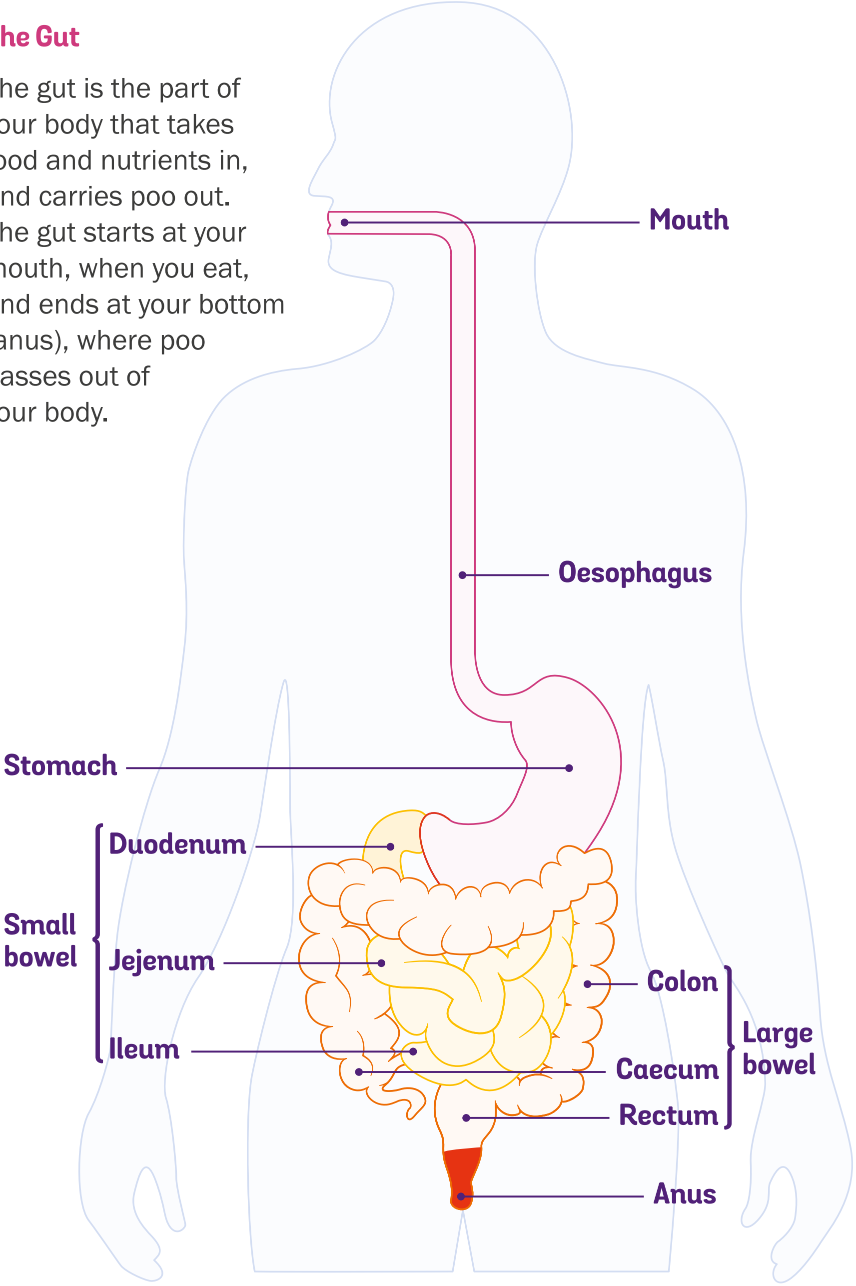
IBD is not the same as IBS (Irritable Bowel Syndrome). IBS has some symptoms which are similar to Colitis, but this is a different condition and treatment for IBS is not the same.

Colitis is lifelong (chronic) and can be hard to predict. 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. At other times symptoms may be more difficult to manage.

There's no cure for Colitis. But there are many effective treatments to help you control 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 a 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.

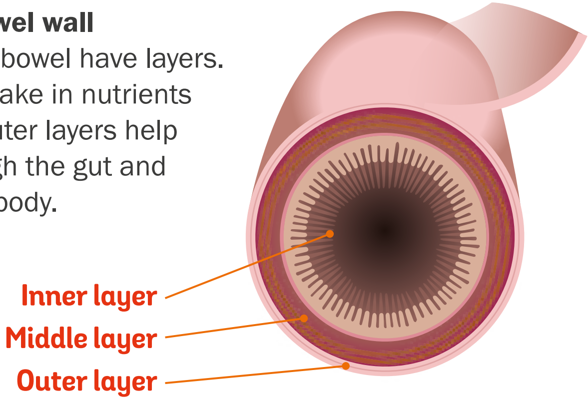


The bowel

The bowel is the largest part of the gut, and is made up of two sections – the small bowel and the large bowel. The colon and rectum make up the large bowel. Colitis usually begins in the rectum and lower colon, but it may involve all of the large bowel. If only your rectum is inflamed, it's called proctitis.

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.



In Colitis, there's inflammation and swelling of the inner layer of the bowel wall. This can cause bleeding. More mucus may be produced by the inner layer of the bowel wall. Ulcers develop on the inner layer as the condition gets worse, but they can also go as the condition gets better.

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

Symptoms

Everyone experiences Colitis 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 vary depending on where Colitis is active in your bowel and how severe it is. Find out more in the section **Types of Colitis**.

The most common symptoms are:

- Diarrhoea – this is passing looser poo more often than is normal for you. There may be mucus or blood in your poo.
- Urgency – you may need to reach a toilet quickly.
- Bleeding from your bottom (anus).
- Cramping pain in your tummy (abdomen) when you need to poo.
- Constipation – this is finding it hard to pass poo regularly or empty your bowels completely. You may need to strain and your poo may be dry or hard. This is common with proctitis.
- Generally feeling unwell. This may include having a raised temperature, feeling feverish or your heart may beat faster.
- Extreme tiredness – also known as fatigue. This can be due to a lack of iron. Or due to a lack of sleep if you keep getting up in the night with diarrhoea or pain. But sometimes you won't know what is causing fatigue.
- Anaemia – a reduced number of red blood cells means that less oxygen is carried around the body. This is more likely if you're losing blood in your poo, aren't eating much, or you're having frequent flares. Anaemia can make you feel very tired.
- Loss of appetite and weight loss. Feeling unwell can impact your appetite. Some people avoid eating when they have diarrhoea.

Colitis is a bowel condition, but having an overactive immune system and ongoing inflammation can sometimes lead to problems in other parts of the body. Some people experience inflammation in their joints, eyes, or skin. See the section on **Complications outside the bowel**.

Flare-ups

A flare-up is when symptoms come back, and you feel unwell. Everyone experiences flare-ups differently. Your symptoms may also change over time. Flare-ups can last anywhere from a few days to several months and you may have different symptoms during a flare-up than you had when you were first diagnosed.

Flare-ups may not happen very often – people can go years without feeling unwell. For others, a flare-up may happen more often, with two or more a year. Around 2 in 3 people have a decrease in symptoms over time – and 1 in 20 people have ongoing symptoms of active Colitis.

Over time you'll get to know how to recognise a potential flare. 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 team, their advice line or your GP.

Signs of flare-up can include:

- Going to the toilet more than five times in 24 hours – or more than is normal for you and this continues for more than a day.
- Loose poo or diarrhoea with any blood and/or mucus for more than three days.
- Urgency – having to rush to the toilet.
- Pain in your tummy, usually when you need to go to the toilet.
- Generally feeling unwell, especially if you have a fever
- Waking up at night to go to the toilet.
- Passing blood or mucus without poo – this is more common with proctitis.

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.

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

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

> "It is important to know the difference between your 5-ASA dosage for maintaining remission, and your dosage for managing a flare-up. This has given me opportunities for early intervention when I feel like I am about to become unwell."
>
> **Andy**, living with Colitis

In some cases, your IBD team or GP may use blood and/or poo tests to check if you're having a flare-up. The results will help to find the best treatment to control your Colitis. See the section **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**

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/ibdnurse**
- 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 Journal** for ideas on how to make the most of time with your IBD team.

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 don’t yet know what causes flare-ups, but possible triggers include:

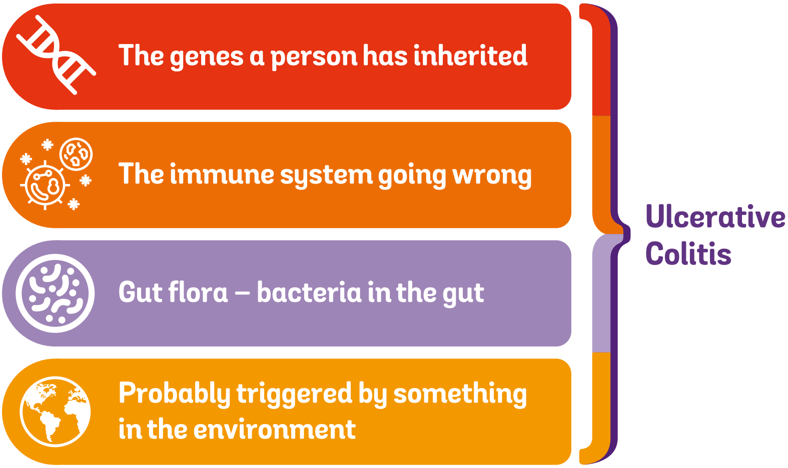
- Disruptions or changes in medicines
- Ongoing stress
- Gut infections
- Taking non-steroidal anti-inflammatory medicines (NSAIDS) such as ibuprofen

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 Colitis

Colitis happens when the body's immune system goes wrong. Usually, the immune system protects the body against harmful substances and infections. In Colitis, the immune system starts attacking the bowel. We don't know why this happens. It's probably caused by a mix of genes, bacteria in the gut and the environment.

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



Genes a person has inherited

Researchers have identified hundreds of genetic changes that affect your risk of developing Crohn's or Colitis. 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. This can lead to ongoing inflammation.

Immune response

In Colitis something goes wrong with the immune system. Research suggests that in Colitis 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 include the bacteria, viruses and fungi that live in your gut. People with Colitis have fewer varieties of helpful bacteria in their gut than people who do not have Colitis. Some bacteria which help the gut are missing.

Environment

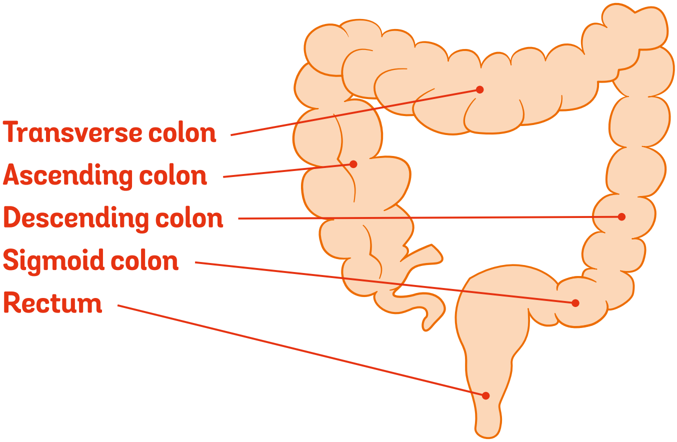
A range of factors in the environment may increase the risk of Colitis. These include viruses, bacteria (which can be influenced by diet), stress, and taking NSAIDs (like ibuprofen) long-term. Colitis is more common in non-smokers and for some people stopping smoking may trigger Colitis. Smoking carries many other health risks – see our information on **Smoking**. There's still no definite evidence that any one of these factors is the cause of Colitis.

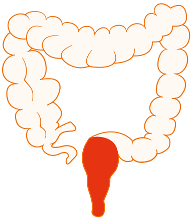
Types of Colitis

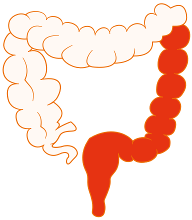
The types of Colitis are based on how much of your large bowel is affected. This can affect the symptoms you experience and the treatment you're offered. You may not know which type of Colitis you have when you are diagnosed. This may depend on whether you have had a colonoscopy (to look at the whole colon) or a sigmoidoscopy (to look at part of the colon). See the section on **Tests to monitor Colitis**.

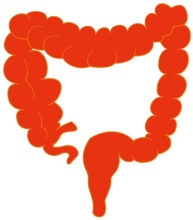
The main types are:

- Proctitis
- Left-sided Colitis (also called distal Colitis)
- Total Colitis (also called pancolitis) or extensive Colitis




Proctitis


Left-sided Colitis


Total Colitis

Proctitis

In proctitis, only the rectum (the lowest part of the large bowel) is inflamed. The rest of the colon is unaffected and can still function normally.

Typical symptoms:

- Blood or mucus in your poo, or passing blood or mucus without poo
- Diarrhoea or constipation
- An urgent need to use the toilet
- Tenesmus

Tenesmus is an urge to poo, but not passing anything as the bowel is empty.

Some people may also have inflammation in the sigmoid colon. This type of Colitis is called proctosigmoiditis. Symptoms are similar to those of left-sided Colitis (see below).

Up to half of people with proctitis or proctosigmoiditis will develop Colitis that affects more of the colon. 1 in 10 people with proctitis will later develop Colitis that affects most of their colon.

Left-sided (or distal) Colitis

Inflammation is in the distal colon. This includes the rectum and the left side of the colon (also called the descending colon).

Typical symptoms:

- Diarrhoea with blood and mucus
- Pain on the left side of your tummy when you need to use the toilet
- An urgent need to use the toilet
- Tenesmus

Total Colitis (or pancolitis)
Colitis that affects the whole colon is known as total Colitis or pancolitis. If the inflammation affects most of the colon, but not all, it is known as extensive Colitis.

Typical symptoms:

- Very frequent diarrhoea with blood and/or mucus
- Tummy cramps and pain
- Tenesmus
- Fever
- Weight loss

In milder flare-ups, the main symptom may be diarrhoea or looser stools without blood.

For some people with total or extensive Colitis, inflammation may reduce over time – so Colitis affects less of the colon.

Colitis activity and severity

Activity
When you have Colitis symptoms your condition may be described as being ‘active’. If your Colitis is very active it may mean you are having a flare-up.

Severity
Your IBD team will assess how severe your Colitis 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. Colitis is different for everyone – you know your body best and which symptoms may mean you’re having a flare-up. For example, some people may experience severe constipation instead of more frequent poos. Your IBD team will also consider any other symptoms you have and how Colitis impacts your

daily life. It is common to be between two severity groups. For example, your IBD team may say you have mild-to-moderate Colitis or moderate-to-severe Colitis.

Mild

- Fewer than 4 poos each day.
- Small amounts of blood in poo less than half of the time.
- No fever or anaemia, and a normal heart rate.
- Blood and poo tests may not show inflammation.

Moderate

- Between four to six poos each day.
- Some blood in poo – half of the time or more.
- No fever or anaemia, and a normal heart rate.
- Blood and poo tests may show some signs of inflammation.

Severe

- Six or more poos each day.
- Visible blood in poo or passing blood without poo.
- Blood and/or poo tests show inflammation.

Acute Severe Ulcerative Colitis (ASUC)

ASUC is a serious medical emergency that requires a stay in hospital for treatment and monitoring. Symptoms include all those for ‘severe’ Colitis, as well as signs of infection, such as a fever or increased heart rate.

Complications in the bowel

In very rare cases, Colitis can cause other problems in the bowel. These complications include:

Toxic megacolon

When inflammation is extensive and severe, the bowel wall thins and the colon becomes bloated with gas. This is known as toxic megacolon. Symptoms include a high fever with pain and tenderness in the tummy. It's essential to get treatment quickly. There is a large risk of perforation (see below) and sepsis (a life-threatening over-reaction of your immune system). Emergency surgery may be needed.

Perforations

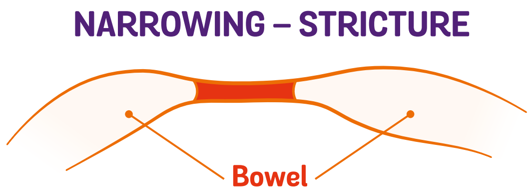
A perforation is a rupture of the bowel. This creates a hole that contents of the bowel may leak through. They can be caused by:

- Very active inflammation in the bowel wall, such as toxic megacolon.
- A severe blockage caused by a stricture (narrowing of the bowel) 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 (nausea) and being sick (vomiting).

Get medical help immediately if you think you may have a perforation.



Narrowing of the bowel – stricture
Ongoing inflammation can create a narrow section of the bowel known as a stricture. A stricture can make it difficult for poo to pass through. If it's very narrow it can cause a blockage.

Strictures are rare in Colitis, but they can sometimes be a sign of bowel cancer (see section on **Risk of cancer**). Even though most strictures are benign (not cancer), they may still need surgery.

Symptoms include:

- Severe cramping and pain in your tummy
- Feeling sick (nausea)
- Being sick (vomiting)
- Not passing poo or wind
- Tummy area may become bloated and swollen (distended)
- Gut may make loud noises

Complications outside the bowel

Colitis doesn't just affect the bowel. As many as 1 in 5 people with Colitis develop problems in other parts of the body. Most affected are joints, eyes or skin. These are known as extraintestinal manifestations (EIMs). They usually happen during a flare-up, but can occur without or before any bowel symptoms.

These complications can often happen to people who don't have Colitis too. For many of the complications, there are things you can do to reduce your risk.

Joints

You may have pain and/or swelling in your joints. Around 1 in 6 people with Colitis experiences joint problems. For some, this will get worse during a flare, but will usually improve with treatment for Colitis. Others may have joint problems even when bowel symptoms feel better. Find out more in our information on **Joints**.

Eyes

Episcleritis affects the layer of tissue covering the white outer coating of the eye, the sclera, making it red, itchy and painful. This tends to flare up at the same time as bowel symptoms. It often gets better with treatment for Colitis 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, (usually more than in episcleritis), changes in vision and sensitivity to light. They're treated with steroid drops, and sometimes immunosuppressants or biologic medicines.

These 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, but not pain. If you get any kind of painful eye irritation, redness or inflammation, tell your health professional. They may refer you to an eye specialist.

Skin

Colitis can affect the skin in different parts of the body.

Erythema nodosum affects fewer than 1 in 20 people with Colitis. It causes raised, painful red or violet swellings, usually on the legs. It tends to occur during flare-ups and usually improves with treatment for Colitis.

Pyoderma gangrenosum is a rarer skin condition in people with Colitis. This starts as small tender blisters, which become painful, deep ulcers. These can occur anywhere on the skin, but most commonly appear on the shins or near stomas. This condition is sometimes, but not always, linked to a flare-up. It's often treated with steroids or biologic medicines, such as infliximab. In some cases a dermatologist, a specialist in skin conditions, may treat this with creams or ointments.

Anaemia

Around 1 in 5 people with Colitis develops anaemia. There are several types of anaemia. People with Colitis 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. Your body needs iron to help make red blood cells which carry oxygen around your body.

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 intravenously (into your vein) by an injection or infusion through a drip. Find out more about iron in our information on **Other treatments**.

Bones

People with Colitis are more at risk of developing thinner and weaker bones or 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 doesn't contain enough dairy. Weight-bearing exercise, calcium and vitamin D supplements, not smoking and avoiding long-term steroid use can help. Some people may also take bisphosphonate medicines. Find out more in our information on **Bones**.

Liver

Primary Sclerosing Cholangitis (PSC) affects around 1 in 20 people with Colitis. PSC causes inflammation of the bile ducts and can eventually damage the liver. Symptoms can include pain in the top right of the tummy, itching, fatigue, weight loss and jaundice (yellow skin and whites of your eyes). Some people do not get any symptoms and it is only picked up on blood tests.

Some medicines used to treat Colitis, such as azathioprine, can affect the liver. Changing your treatment may help to reduce this type of liver complication.

Mouth

About 1 in 25 people with Colitis get sores or ulcers in their mouth, usually when their condition is active. These sores can be minor and disappear within a few weeks, but can occasionally last longer and may need topical steroid treatment.

Hair

Losing more hair than usual is common with Colitis. Many things can trigger this, including severe flares, poor nutrition, iron and zinc deficiency and surgery. This type of hair loss is called a telogen effluvium. Rapid hair loss may occur 4-8 weeks after a Colitis flare. Less often, hair loss may be a side effect of medicines. You shouldn’t stop taking a medicine unless your doctor has told you to. Losing your hair can be distressing, but it’ll usually grow back as you get better. Speak to your IBD team to check what might be causing your hair loss.

Heart and circulation

Contact your doctor immediately if you experience chest pain, shortness of breath, or a feeling of numbness, weakness or tenderness in your arms and legs.

Blood clots

You're more likely to develop blood clots if you have Colitis. This includes DVT (Deep Vein Thrombosis) in the legs and PE (pulmonary embolism) in the lungs. You're more at risk during a flare-up or if you need to stay in bed, for example in hospital.

To reduce your risk:

- Don't smoke.
- Stay active – walking can help.
- Drink plenty of fluids to avoid dehydration.

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

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

Cardiovascular disease

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

Irritable Bowel Syndrome (IBS)

Although some symptoms are similar, IBS is a different condition to IBD. IBS can cause tummy pain or cramps, but these are often worse after eating and better after a poo. IBS also causes bloating, diarrhoea and constipation. IBS is more common than IBD. Colitis causes inflammation in the bowel and blood in poo – but IBS does not.

Some people with Colitis also develop IBS symptoms – and have pain and diarrhoea even when Colitis isn't active. Doctors can use a poo test called faecal calprotectin to check if you're having a Colitis flare (inflammation) or if your symptoms could be IBS. Find out more in our information on **Tests and**

Investigations for IBD. IBS treatment can include changes to diet and lifestyle and medicines to ease symptoms.

Risk of cancer

Colitis can increase the risk of bowel cancer (also known as colorectal cancer) in some people. Bowel cancer is cancer in the colon or rectum. However, the number of people with Colitis who develop bowel cancer is still small.

The risk of bowel cancer increases about 8-10 years after the start of your Colitis symptoms. This may not be when you were diagnosed, as your symptoms could have started some time before diagnosis.

The risk of cancer is highest if all, or most, of your colon is affected by Colitis (extensive, total or pancolitis). If only the left side of your colon is affected by Colitis (distal Colitis), there is less risk. If you have proctitis (Colitis in your rectum), your risk is little or no greater than for the general population.

Having Primary Sclerosing Cholangitis (PSC) also increases your risk of bowel cancer.

If you are at increased risk of bowel cancer you will be offered regular colonoscopies to check for early warning signs. Cancers can be more successfully treated when found early. The risk of bowel cancer is related to ongoing inflammation in the bowel, so keeping your Colitis under control will reduce your future risk. Find out more in our information on **Bowel cancer risk**.

In very rare circumstances, some medicines for Colitis 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 leaflet that comes with your medicine for precautions you can take to reduce this risk. Talk to your IBD team if you are worried.

TESTS AND TREATMENTS

TESTS AND TREATMENTS

Tests to monitor Colitis

To find out if you have Colitis, you probably had lots of tests. The same tests help your doctors check (monitor) your health and find the best treatment for you. Your Colitis should be checked regularly. How often you need these tests will depend on how severe your Colitis is, and the medicines you are taking. Tests for Colitis 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. You may also be asked about symptoms involving other parts of your body, such as your skin, eyes and joints.

Your doctor may also ask you about smoking, recent travel, food intolerances, recent medicines you have taken (including antibiotics and NSAIDs), 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 your tummy.

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 Colitis is causing any side effects.

Poo tests are also used to see whether you have an infection. Your poo can also be tested for signs of inflammation. A faecal calprotectin test can show whether you have inflammation in your bowel.

Endoscopy

A doctor will look at the lining of your gut with a tiny camera on a long thin flexible tube. This is called an endoscope. Endoscopy is the best way to look at the large bowel. It helps your doctor see if your Colitis is well-controlled, or if you still have inflammation.

- **Colonoscopy or sigmoidoscopy** – the tube goes through your bottom. In a sigmoidoscopy, the doctor will look at part of the large bowel (rectum and left side of the colon). In a colonoscopy, the doctor looks at all of the large bowel as well as the end of the small bowel. Your colon has to be completely clean (empty of poo) for a colonoscopy. You'll be asked to take a laxative around 24 hours before. For a sigmoidoscopy, you may given an enema (a liquid that goes directly into your anus) just before the test to clean your rectum and the left side of your colon.
- **Gastroscopy or upper gastrointestinal endoscopy** – the tube goes through your mouth. The doctor will look at your mouth, stomach, and small bowel. This is used to rule out Crohn's if you have symptoms in the upper parts of your gut – it's not usually used if Colitis is suspected.

Biopsy

The doctor may take very small samples of bowel tissue during an endoscopy. These are called biopsies. There is usually no pain when biopsies are taken. These are sent to the laboratory and examined under a microscope to check for inflammation.

MRI and CT scans

Other tests that look at where inflammation is in your gut include MRI (Magnetic Resonance Imaging) and CT (Computerised Tomography) scans. MRI and CT are usually used to look at the small bowel to rule out Crohn's, but can also be used to check for complications of Colitis. MRI uses magnets and radio waves, and

CT uses X-rays to build a 3D image of the body. Some hospitals also use ultrasound scans to look at areas of inflammation.

You may need a few of the tests listed above. You can find out more 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 Colitis should see an adult or paediatric gastroenterologist. They will often be part of a team that could include an IBD Nurse Specialist, dietitian, surgeon, psychologist, and expert pharmacist in IBD. Find out more in the section on **My IBD team**.

The **IBD Standards** set out what ideal care should look like. But every hospital is different, and your team or care may vary.

You should be able to start treatment within 48 hours of being diagnosed with Colitis if you have moderate to severe symptoms. If your symptoms are mild you should be able to start treatment within 2 weeks.

The aim of treatment

Treatment aims to stop the inflammation so your bowel can heal and your symptoms reduce (remission). This will help you to feel better. It can also reduce the risk of complications or your Colitis getting worse. Treatment is often needed long-term to help keep you in remission.

Treatment for Colitis may be with medicines, surgery, or a combination of both.

You should work with your IBD team to decide on a treatment together. Your treatment will depend on how Colitis affects you. This will include:

- Where the inflammation is in your bowel (see the section **Types of Colitis**).
- How active and severe the inflammation is.
- Whether you have any complications.
- Whether other treatments have helped you feel better in the past.

It's important to think about what matters most to you about your treatment and care. This will help you and your IBD team find the treatment that's right for you. Find out more in **My Appointments Journal**. Your IBD team should help you understand all the treatment options available and their benefits, risks and consequences.

If your condition is mild and your gut looks healthy, you may consider stopping treatment. You should first discuss the risks and benefits of this with your IBD team.

Medicines to treat Colitis

The medicines used to treat Colitis aim to:

- Stop inflammation and reduce symptoms.
- 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 IBD 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. Or you may need to take them for only a short time.

You may take one medicine or a combination of medicines. The main types of medicines are:

- **Aminosalicylates (5-ASAs)** such as mesalazine, olsalazine, sulphasalazine and balsalazide. 5-ASAs reduce inflammation in the lining of the bowel and help to keep you in remission. 5-ASAs are often the first treatment option for mild to moderate Colitis. They can be taken by mouth as a tablet, capsule or granules. You can also take 5-ASAs as enemas or suppositories (topically) which are inserted into your bottom. This treats inflammation that's in the lower part of your colon or rectum. See our information on **5-ASAs**.

- **Steroids** such as prednisolone, budesonide and beclometasone dipropionate. When you're in a flare-up, steroids can quickly reduce the inflammation in your gut to help you feel better. You can take steroids by mouth as tablets, capsules or granules. You can also take steroids as enemas (liquid or foam) or suppositories (which look like a large tablet). These are inserted into your bottom. This treats inflammation that's in the lower part of your colon or rectum. In severe flare-ups steroids may be given by intravenous (IV) infusion (through a drip into a vein in your arm) to help you feel better more quickly. Some types of steroids have a higher risk of side effects. Steroids can help you feel better but can't be used to control Colitis 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 (in remission). See our information on **Steroids**.

- **Immunosuppressants** such as azathioprine, mercaptopurine (6-MP), ciclosporin and tacrolimus. These dampen down the immune response, which reduces inflammation in the gut. Some are taken by mouth as a tablet and others as an injection. They may be an option if you've had two or more flare-ups in 12 months that needed steroids. They may help you reduce or stop taking steroids without having another flare-up. They may also help if the inflammation hasn't been controlled by 5-ASAs. See our information on **Azathioprine and mercaptopurine**.

> "You can live a full and happy life with Ulcerative Colitis – it hasn't stopped me doing anything! Medicines have kept me well for most of the 30+ years since my diagnosis."
>
> **Paul**, living with Ulcerative Colitis

- **Biologic medicines** such as adalimumab, golimumab, infliximab, vedolizumab and ustekinumab. These medicines work in different ways to block parts of the immune system, which reduces inflammation. They're also 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). You may take a biologic medicine in combination with an immunosuppressant. Find out more in **Biologic medicines** and in our **individual medicine information**.
- **Janus kinase (JAK) inhibitor.** Tofacitinib is a medicine that blocks JAKs. JAKs are proteins that are involved in activating the body's immune response, which causes the gut inflammation in Colitis. Tofacitinib is taken by mouth as a tablet. It's available for people with moderate to severely active Colitis. See our information on **Tofacitinib**.

The medicines you take will depend on how severe your Colitis is.

COLITIS SEVERITY	POSSIBLE TREATMENT OPTIONS
Mild to moderate Colitis	You'll first be offered 5-ASAs (aminosalicylates). These may be topical (enemas or suppositories that are inserted in your bottom) or oral (tablets, capsules or granules that you take by mouth) or both. 5-ASAs may be taken long-term to keep your condition under control. If 5-ASAs don't work or aren't right for you, you'll be offered topical steroids. Some people will also take an oral steroid (such as prednisolone). Other people may be offered oral steroids that work specifically in the bowel (such as Budesonide MMX or beclomethasone dipropionate). Steroids can't be taken long-term, so you may be offered azathioprine or mercaptopurine to keep your Colitis under control.
Moderate to severe Colitis	You'll first be offered oral steroids (such as prednisolone). If you're very unwell you'll be given steroids by an infusion in hospital. Steroids can't be taken long-term, so you may be offered azathioprine or mercaptopurine to keep your condition under control. Some people may be offered 5-ASAs instead. If these medicines don't work or aren't right for you, you may be offered a biologic medicine (such as adalimumab, golimumab, infliximab, vedolizumab or ustekinumab) or a JAK inhibitor (tofacitinib). You can take these medicines long-term to keep your condition under control. Some people may take azathioprine or mercaptopurine in combination with their biologic medicine.
Acute Severe Ulcerative Colitis (ASUC)	You'll stay in hospital and be treated with a high dose of steroids by infusion. After three days, if steroids haven't worked you'll be given an infusion of infliximab or ciclosporin. After seven days, if infliximab or ciclosporin haven't worked, surgery may be necessary.

Medicines to help you manage symptoms

Some medicines can help to ease symptoms, but don't reduce inflammation or treat the underlying Colitis.

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 (Imodium, Arret) and diphenoxylate (Lomotil). 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. They increase the risk of toxic megacolon. You should only take these medicines if your IBD team has said it's ok to do so.

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. These medicines may help people with proctitis who have constipation.
- **Bulking agents**, such as Fybogel, make poo easier to pass. Do not take these if you have a stricture.

Pain

- **Painkillers** such as paracetamol. Do not take non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen unless told to do so by your IBD team. NSAIDs may trigger a flare-up.
- **Antispasmodics** such as hyoscine butylbromide (Buscopan) 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 Colitis.

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

Surgery

If medicines aren't helping and flare-ups keep happening, then surgery may be an option. You may choose surgery over other Colitis treatments if your condition is difficult to control and it's affecting your quality of life.

Most people with Colitis who need surgery will have planned surgery, so you'll have time to discuss all of your options and prepare. You'll see a surgeon who will explain what will happen and give you the chance to ask any questions you have.

More rarely, people with very severe Colitis or severe complications may need urgent surgery (within a few days) or emergency surgery (within a few hours).

You may consider surgery if you have:

- Severe Colitis that isn't getting better with medicines.
- Severe complications such as perforations or toxic megacolon.
- Bowel cancer or a high risk of bowel cancer.

RESEARCH FACT

1 in 10 people with Colitis will need major surgery to remove their colon 10 years after diagnosis. But, fewer people are needing surgery than they did 20 years ago.

The need for surgery also depends on how severe the disease is and which parts of the bowel are affected. People with extensive or total Colitis are more likely to need surgery than those with proctitis.

10 years after diagnosis:

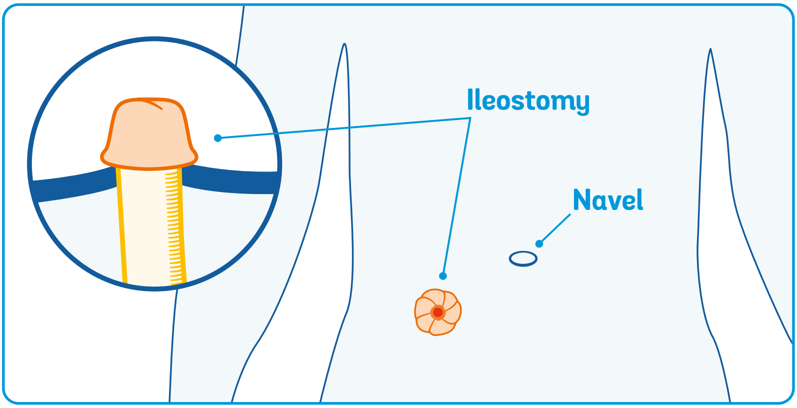
- 19 in 100 people with extensive Colitis may need a colectomy.
- 8 in 100 people with left-sided Colitis may need a colectomy.
- 5 in 100 people with proctitis may need a colectomy.

A colectomy is surgery to remove all or part of the bowel. The most common operations for Colitis will remove part or all of the large bowel. Find out more (including diagrams) in our information on **Surgery for Colitis**.

Stoma

If you have a large part of the bowel removed, you may need a stoma. A stoma is an opening through the tummy (abdomen 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.**
- If you have Colitis, the stoma will usually be an ileostomy.



Both types of opening are called a stoma and the bag is known as a stoma bag. A stoma may be temporary or permanent. You can find out more in our information on **Living with a Stoma**.

> I am amazed how many people are surprised to hear I have a bag. Obviously it's not 'obvious'!
>
> **Annie**, living with Ulcerative Colitis

Coming to terms with surgery

Having a major part of the bowel removed may be a frightening thought. You may also be concerned about using a stoma bag. However, there have been big improvements in the design of stoma products. They are now very discreet and comfortable.

Many hospitals have a specialist stoma team to support you during and after the surgery. There are lots of personal experiences from people living with a stoma on our **website** and **Facebook Forum**. There are also other organisations that can give practical advice and support – see their contact details at the end of this guide.

LIVING WITH COLITIS

LIVING WITH COLITIS

Diet

There isn't any clear evidence that specific foods cause, cure or treat the inflammation in Colitis. The most important thing is to try to eat a nutritious and balanced diet so that you maintain your weight and strength. It's also important to drink enough fluids to stop you getting dehydrated.

However, many people with Colitis notice that specific foods may cause gut symptoms. This can be during a flare-up or when they are in remission. The effect that food can have on symptoms can sometimes lead to a difficult relationship with food. Restricting what you eat may cause weight loss or malnourishment. Find out more about disordered eating in our information on **Mental health and wellbeing**.

Some people find that making small changes to their diet, for example avoiding spicy food, dairy or raw vegetables, 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.

You may find that eating too much fibre can increase the urge to go to the toilet. It may be helpful to reduce the amount of fibre you eat if you're having a flare-up. Fibre is important, so once the flare-up is over, you should try to increase your intake again.

It's important to get advice from your IBD team or dietitian before you make any major changes to your diet. A food diary can be a handy tool to help you when you speak to your health professional about your diet. It may help to show whether you're getting enough nutrients or if any foods may be triggering symptoms. You can find one in our information on **Food** and in **My Appointments Journal**.

Your healthcare professional may recommend a liquid food supplement. This can help make sure you're getting all the energy and nutrients you need.

Vitamin supplements

You may need to take supplements to replace low levels of vitamins and minerals (deficiencies). This can happen when you have a poor appetite, do not eat enough, or when you have ongoing diarrhoea. Your doctor, dietitian or IBD nurse will tell you if this is the case. The most common vitamin and mineral deficiencies are:

- **Iron.** Your body needs iron to help make red blood cells which carry oxygen around your body. Low iron can lead to anaemia. You may be given iron supplements as tablets by mouth, by injection or as a drip (infusion) into a vein.
- **Calcium.** Steroids can cause calcium loss which may lead to osteoporosis. Calcium supplements with vitamin D may help prevent this. Find out more in our information on **Bones**.
- **Vitamin D** is important for keeping your bones and your immune system healthy. Low levels of vitamin D have also been linked to fatigue. More than half of people with Colitis have low levels of vitamin D. 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.

> “I have to be careful now that I have an ileostomy, as certain foods don’t digest well, and can cause blockages, which are not only painful, but can be very dangerous.”
>
> **Katryna**, living with Colitis

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 and Colitis say their mental health is affected. 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 Colitis.
- When you have a flare-up and symptoms come back after you'd been feeling better.
- After you've had surgery – especially if it leaves scarring or you have a stoma.
- Experiencing side effects of your treatment for Colitis. If you take steroids you may experience extreme highs and lows in your mood. Find out more in our information on **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.

> "There are lots of positive things you can do for yourself to influence the course of your Colitis – but acknowledge that you do not need to deal with this alone."
>
> **Ros**, living with Colitis

Living with Colitis 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 Colitis. Share how you feel with your IBD team – they can refer you for psychological support. Find out 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. Contact 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 and Colitis try complementary or alternative medicine (CAM), 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
- The cost of the therapy
- Possible unwanted side effects

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

Speak to your doctor first, especially if you're thinking of taking any herbal medicines. There may be interactions with some prescription medicines.

Some commonly tried CAMs include:

Probiotics – 'gut-friendly' bacteria. They can be added to drinks or yoghurts, or taken in capsule form. Probiotics may help to get Colitis into remission – but more research is needed to prove this.

Curcumin – a natural anti-inflammatory found in the spice turmeric. There's some evidence that curcumin may help to get and keep Colitis in remission when taken alongside 5-ASAs. More studies are needed before curcumin can be recommended as a treatment option.

Exercise – can have benefits for your overall health, physical wellbeing, stress and how you feel. There's some evidence that people with higher exercise levels may be less likely to have a Colitis flare-up – although more research is needed. Regular exercise may also help with fatigue.

Yoga – a small study has shown that yoga positively affected the lives of people with Colitis.

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

> “Being in the present moment is my key... you can't change the past or control your future. Being in the present moment and taking it day by day really helps me to reduce anxiety.”
>
> **Sharon**, living with Colitis

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 Colitis 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

Colitis is unlikely to affect fertility if your condition is controlled and you're feeling well.

Older studies suggest that fertility in women may be reduced if you have had pouch surgery. However, there may be less risk with newer surgical techniques, such as keyhole surgery (laparoscopy). Having a colectomy with an ileostomy does not appear to affect fertility.

The 5-ASA drug sulphasalazine can lead to a temporary loss of fertility in men. You can ask your IBD team about trying a different 5-ASA.

Find out more in our information on **Reproductive Health**.

Pregnancy

Speak to your IBD team if you're planning to get pregnant or find out you're pregnant. You shouldn't stop taking your medicines unless your IBD team say it's ok to do so.

If your Colitis is well controlled when you become pregnant, you can expect a typical pregnancy and a healthy baby.

A flare-up in pregnancy increases the risk of giving birth early or having a baby with a low birth weight. Your IBD team should be able to help you to control your condition – and, with very few exceptions, you can continue most treatments while you're pregnant.

Most women with Colitis should be able to have a vaginal birth rather than a caesarean section. Talk to your IBD consultant and your obstetrician (specialist doctor in pregnancy and childbirth) about your options. A caesarean section may be recommended if you have had pouch surgery.

Find out more in our information on **Pregnancy and Breastfeeding**.

Colitis in the family

There's not always a family connection, but your risk of developing Colitis 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

Colitis can occur at any age. Nearly 1 in 5 people report that they were diagnosed with Crohn's or Colitis before the age of 18.

Symptoms are similar to those in adults and many of the medicines used for adults can also be used to treat children. Some children's condition rarely bothers them, whereas others need lifelong medication or surgery. Colitis is often more severe when diagnosed in childhood.

Most children and young people with Colitis 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.

For more, read our information on **Supporting your child with Crohn's or Colitis**. You can also check out our other **information, videos and other support for young people and families** affected by 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 left-sided or extensive Colitis, but may have less severe symptoms than younger people.

Medicines and surgery are treatment options for Colitis 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 doctor will consider any other illnesses you have when thinking about the best option for you. If you're less mobile, you may also find it difficult to take medicines that go directly into your anus (such as suppositories or enemas). Your doctor will look at potential side effects and interactions with other medicines you take. Talk to your IBD team about the risks and benefits of each treatment and decide together which is the best option for you.

Colitis 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 Ulcerative Colitis isn't specifically named in the Act, you may be protected from discrimination depending on how Colitis 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.

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
- IA – (Ileostomy and Internal Pouch Support Association)
  iasupport.org – 0800 018 4724

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.

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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/information

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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