

All About Crohn's and Colitis

This information is for people who are new to <u>Crohn's</u> or <u>Colitis</u>. It covers the basics you need to know about the conditions including:

- What Crohn's and Colitis are
- The different types of Crohn's and Colitis
- Symptoms that you may experience
- What causes Crohn's and Colitis
- Some of the tests that you might have
- Some of the treatments that you might be offered
- The role of food and diet in managing your Crohn's or Colitis

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Key facts

- Crohn's Disease and Ulcerative Colitis are Inflammatory Bowel Diseases (IBDs). They
 can cause painful sores (ulcers) and inflammation in your gut.
- In Crohn's Disease the inflammation can be anywhere in the gut, from your mouth to your bottom.
- In Ulcerative Colitis the inflammation and ulcers are only in the large bowel.
- Microscopic Colitis is another type of colitis. In Microscopic Colitis there is inflammation of the large bowel. But Microscopic Colitis does not cause ulcers.
- There will be times when your Crohn's or Colitis makes you feel unwell. We call
 these flare-ups. And there will be times when your Crohn's or Colitis is being
 controlled well. We call this remission.
- There are many different treatments available to help you live well with Crohn's or Colitis. These include medicines, surgery or both. Together with your IBD team, you can decide what treatment is right for you.
- Inflammatory Bowel Disease (IBD) is not the same as Irritable Bowel Syndrome
 (IBS). IBS can cause tummy pain, bloating, diarrhoea and constipation. But unlike
 IBD, there is no inflammation, or blood in the poo.



Crohn's and Colitis

Crohn's Disease and Ulcerative Colitis are Inflammatory Bowel Diseases (IBDs). They can cause painful sores (ulcers) and inflammation (swelling) in your gut.

Crohn's and Colitis are lifelong conditions, which means you will always have the condition. But that does not mean you will always feel unwell. Treatment like medicines and surgery can help you feel a lot better.

There is another type of colitis called Microscopic Colitis. Unlike Ulcerative Colitis, Microscopic Colitis does not cause ulcers, and there is no blood in the poo.

It's something you'll have to learn to adapt to – and you will. Don't let your mind run riot, and know that things will get better if you let them. Everyone goes through their own stuff in life; if you embrace it, everything becomes a lot easier.

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Living with Crohn's

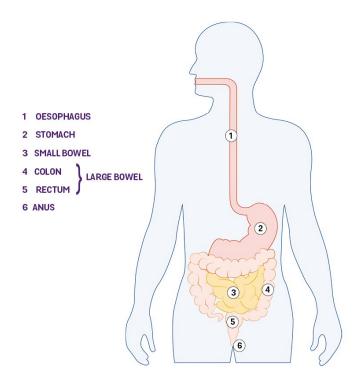


The gut

To understand Crohn's and Colitis, it can help to understand how the gut works.

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 gut is also called the digestive system because it digests (breaks down) food.



The bowel is an important part of the gut. It is a long tube, coiled up inside you, made up of your small bowel, colon, and rectum. The colon and rectum make up the large bowel. At the end of your rectum is your anus, where poo passes out of your body.

The walls of your bowel have layers. The layers take in nutrients from food and help get rid of waste.



Types of Crohn's and Colitis

Crohn's Disease

<u>Crohn's Disease</u> is inflammation anywhere in the gut, from your mouth to your bottom. Although Crohn's Disease is called an Inflammatory Bowel Disease, any part of the gut can be affected, not just your bowel. All layers of the gut can be inflamed.

'Crohn's Colitis' is a type of Crohn's Disease, where only the colon is inflamed. This is because 'colitis' means inflammation of the colon. It does not mean you have both Crohn's Disease and Ulcerative Colitis.

Ulcerative Colitis

<u>Ulcerative Colitis</u> is inflammation and ulcers in the large bowel. It can be anywhere in your colon and your rectum. Only the inner lining of the gut is inflamed.

If only your rectum is inflamed, it's called proctitis.

Microscopic Colitis

Microscopic Colitis is inflammation of the large bowel. Unlike Ulcerative Colitis, Microscopic Colitis does not cause ulcers. There is frequent watery diarrhoea, but there is no blood in the poo. Doctors must use a microscope to see the inflammation.

Uncertain diagnosis (IBDU)

If your doctor says you have Indeterminate Colitis or IBDU (Inflammatory Bowel Disease Unclassified) it's not certain whether you have Crohn's or Colitis.

Who has Crohn's or Colitis?

In the UK, 1 in 123 people have Crohn's or Colitis. That's more than 500,000 people.

Crohn's Disease and Ulcerative Colitis can start at any age, but they usually start before you are 30.

Microscopic Colitis is more common in women and usually starts after 50.



Feeling unwell

Everyone is different. Some people with Crohn's or Colitis feel well most of the time.

Others may feel unwell more often or for longer periods of time.

Not everyone feels the same, and how you feel can change over time.

Crohn's and Colitis can cause:

- Cramping pains
- Frequent and urgent diarrhoea, sometimes with blood and thick liquid (mucus)
- Swollen joints
- Mouth ulcers
- Tiredness
- Lack of iron (anaemia)
- Losing weight and not wanting to eat
- Inflamed eyes

If you have Crohn's, you may also get cracks (fissures) in the skin around your bottom. Sometimes your gut can become narrow (strictures). Your IBD team are there to help. Talk to them if you notice anything unusual for you.

Flare-ups

Times when you feel unwell are called flare-ups.

Taking your medicines regularly, even when you feel better, can help stop flare-ups happening.

Your doctor (gastroenterologist) and the rest of your IBD team are there to support you. Ask your hospital if they have an IBD nurse you can speak to if you need help in between appointments. Or search our <u>map</u> to find your local specialist service.

Remission

Remission is when your Crohn's or Colitis is being controlled well. You should continue to take your medicines even when you feel better.



Many people still feel tired even when their Crohn's or Colitis is under control, so it's important to rest when you need to.

If you still feel unwell in your gut, even when your doctor says you're in remission, you may also have a condition called irritable bowel syndrome (IBS). Inflammatory Bowel Disease (IBD) and IBS are different, but you can have both at the same time. IBS is very common, and can cause tummy pain, bloating, diarrhoea, and constipation. But unlike Crohn's and Colitis, there is no inflammation, or blood in the poo.

If you have IBS as well as Crohn's or Colitis, you may need treatment for both.

Causes of Crohn's and Colitis

Crohn's and Colitis happen when the body's immune system goes wrong.

Usually, the immune system protects the body. In Crohn's and Colitis, the immune system starts attacking the body.

We do not know why the immune system attacks the body. It is probably caused by a mix of genes, bacteria in the gut, and the environment (like germs, diet, smoking, and stress).



Inflammatory bowel disease



Tests

To find out if you have Crohn's or Colitis, you probably had lots of tests. The same tests help your doctors check (monitor) your health and find the best treatment for you.

Tests for Crohn's and Colitis include:

Blood tests

Blood tests check for inflammation, signs of infection, and low iron levels. They can also show if you are getting enough nutrients and vitamins.

Poo tests

Poo tests check for infections and inflammation.

Endoscopy

Your doctor looks at your gut with a tiny camera on a long, thin tube (endoscope). The tube goes through your mouth (gastroscopy) or up your bottom (sigmoidoscopy or colonoscopy).

The doctor can take tiny pieces of your gut (biopsy) to check for inflammation.

Ultrasound, CT and MRI scans

Scans help doctors see how much inflammation you have, and where it is in your body.

See our information on **Tests and investigations** for further details



Treating Crohn's and Colitis

There are many different treatments available to help you live well with Crohn's or Colitis. Together with your IBD team, you can decide what treatment is right for you.

Medicines

To start, you will probably have medicines to reduce the gut inflammation. You might be given a medicine called <u>steroids</u>. Steroids work quickly, but you can only take them for a short time. If you have Colitis you might be given a medicine called a <u>5-ASA</u> (such as mesalazine). 5-ASAs do not work so well for Crohn's.

If you still feel unwell, you can take medicine to control your immune system. This might be a medicine called a <u>biologic</u> or another <u>targeted treatment</u>. These medicines stop your immune system attacking your gut.

You can have your medicine in different ways:

- Tablet
- Injection
- Drip into your arm (infusion)
- Suppository or enema, which go directly into your bottom

See our information on <u>Treatments for Crohn's and Colitis</u> for more information.

Liquid diet

Sometimes Crohn's flare-ups can be treated with a <u>liquid diet</u>. This is called enteral or parenteral nutrition.



Surgery

Medicines are important for managing Crohn's and Colitis, but surgery can also be an effective treatment. Some people may have both medicines and surgery. Whether your IBD team suggests surgery as an option and what type of surgery you have will depend on:

- Whether you have Crohn's or Colitis, and the part of your gut affected
- How bad your symptoms are
- How well medicines are working and if you have any side effects
- Any problems you might have

Surgery can remove the part of the bowel that's making you feel unwell. If a lot of bowel is removed, you may need a stoma bag. This is when your bowel is brought outside your tummy, and your poo goes straight into the stoma bag.

Having bowel surgery can be daunting, but many people find having a stoma is easier than feeling unwell with Crohn's or Colitis.

We have more information on <u>Surgery for Crohn's Disease</u> and <u>Surgery for Ulcerative</u> <u>Colitis</u>.



Treating Microscopic Colitis

Some medicines can trigger Microscopic Colitis. Common medicines that can trigger Microscopic Colitis include acid-lowering medicines, such as omeprazole or lansoprazole, and NSAID painkillers, such as ibuprofen. So if you stop taking these medicines, you may feel better.

Making changes to your diet and lifestyle may help. Common triggers are smoking, caffeine, and alcohol.

People with Microscopic Colitis are also more likely to have coeliac disease. Ask your doctor to test if you have this. You should include gluten in your diet when you have the blood test. This is because avoiding it could lead to a wrong result. If you do have coeliac disease, avoiding foods with gluten will help you feel better.

Medicines

Your doctor might give you tablets to stop your diarrhoea, or a **steroid** called budesonide.

If you have very severe Microscopic Colitis that does not respond to steroids, your doctor might offer you a medicine called an <u>anti-TNF medicine</u>.

Be self-aware and find out everything you can. It's easier if you can simply see it as part of you – and deal with it in a positive way.

Helen

Living with Microscopic Colitis



Diet

There's no single diet that helps Crohn's or Colitis. Keeping a food diary can help you find what works for you. Spicy and high fibre foods (like vegetables, nuts and wholegrains) make a lot of people feel worse when they're in a flare-up. But everyone is different.

The right diet also depends on how your Crohn's or Colitis affects you. For example, if you have a narrowing in the gut (stricture) that makes it harder to digest food.

It's important to eat a balanced diet. Talk to your doctor or a qualified dietitian before making any big changes.

See our information on Food for further details.	



Help and support from 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

Our Helpline is a confidential service providing information and support to anyone affected by Crohn's or Colitis.

Our team can:

- Help you understand more about Crohn's and Colitis, diagnosis and treatment options
- Provide information to help you live well with your condition
- Help you understand and access disability benefits
- Be there to listen if you need someone to talk to
- Help you to find support from others living with the condition

Call us on 0300 222 5700 or email helpline@crohnsandcolitis.org.uk.

See our website for LiveChat: crohnsandcolitis.org.uk/livechat.

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.

Crohn's & Colitis UK information is research-based and produced with patients, medical advisers and other professionals. They are prepared as general information and are not intended to replace advice from your own doctor or other professional. We do not endorse any products mentioned.

About Crohn's & Colitis UK

We are Crohn's & Colitis UK, a national charity fighting for improved lives today – and a world free from Crohn's and Colitis tomorrow. 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. We're here for everyone affected by Crohn's and Colitis.

This information is available for free thanks to the generosity of our supporters and members. Find out how you can join the fight against Crohn's and Colitis: call **01727 734465** or visit <u>crohnsandcolitis.org.uk</u>.

About our information

Crohn's & Colitis UK information is research-based and produced with patients, medical advisers and other professionals. They are prepared as general information and are not intended to replace advice from your own doctor or other professional. We do not endorse any products mentioned.

We hope that you've found this information helpful. You can email the Knowledge and Information Team at evidence@crohnsandcolitis.org.uk if:

- You have any comments or suggestions for improvements
- You would like more information about the research on which the information is based
- You would like details of any conflicts of interest



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

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Patient Information Forum