



## How to get a diagnosis

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Crohn's and Colitis are lifelong conditions that cause inflammation and ulcers in the gut. The symptoms can include:

- Diarrhoea
- Blood in your poo
- Unexplained weight loss
- Extreme tummy pain
- Tiredness

Getting a diagnosis of Crohn's or Colitis is not always easy. You may need several tests, examinations and investigations. For some people, waiting times can be long. And you may be dealing with embarrassing and distressing symptoms and the anxiety they may bring while you wait.

But you're not alone. This information is designed to guide you through the process of getting a diagnosis. We hope our information will make things seem less overwhelming, but if you have any questions, then [our helpline](#) is here to help you.

Below you can find out about:

- How to talk to your GP
- Tests and investigations you might need
- What your results might mean
- What to do if you think you don't have the right diagnosis
- Next steps after you have your results

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## Key facts about how to get a diagnosis

- Everyone experiences Crohn's and Colitis differently. Your symptoms may change over time. Some days may be better than others. You should always contact your GP if you have symptoms that you're concerned about.
- It can sometimes be difficult to get an appointment with a GP but it's important to keep trying. You do not have to manage your symptoms alone.
- Tell your GP about your symptoms, how often you get them or if anything triggers them. It may help to write your symptoms down before your appointment. Don't be afraid to ask questions or tell your GP that you don't understand something.
- There isn't one test that can diagnose Crohn's or Colitis. Your doctor will ask you questions about your symptoms and health. They may also examine your tummy and bottom and test your blood and poo. They might recommend you have further investigations, such as an endoscopy or a scan.
- Once you have your results, your GP or healthcare professional will talk to you about what they mean. You'll then be able to find out about your next steps. You may be offered medicine or may need further investigations.
- If you don't think you have the right diagnosis, talk to your GP or the person who diagnosed you to find out more. It's OK to ask questions. Your doctor should explain why you've been given the diagnosis you have. If you're not happy with your diagnosis, you can ask for a second opinion.

## Do not put off seeking help



Some people may find it embarrassing to talk about their symptoms or may be worried about what the diagnosis may be. But the sooner you find out why you're unwell, the quicker you can start treatment to help you feel better.

Some important things to remember about Crohn's and Colitis:

- There may be times when your symptoms are better and other times when they're worse. Even if you have good and bad days, it's still important to talk to a healthcare professional to find out what's going on.
- Not everyone's symptoms look the same. You might know someone with Crohn's or Colitis whose symptoms are not like yours. Even though your experience is different, you could still have the same condition.
- You don't have to have gut symptoms to have Crohn's or Colitis. Though they're known as Inflammatory Bowel Diseases, many people experience fatigue, joint pain, skin problems, eye issues, weight loss or mouth ulcers. Find out more about the [symptoms of Crohn's or Colitis](#).

Our [symptom checker](#) can help you find out when to talk to your GP and what symptoms to talk to them about. Always talk to your GP if you're concerned about your symptoms.

**I always knew something wasn't right. It's not normal to bleed or feel like that. Initially, I felt scared and didn't want to tell anyone – but being diagnosed helped me come to terms with it and get on with life.**

**Arizona  
Living with Indeterminate Colitis**

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## Talking to your GP

Make an appointment with your GP if you think you may have Crohn's or Colitis. If you need urgent medical advice, call 111 or in an emergency, call 999. You can find out more about [Crohn's Disease](#), [Ulcerative Colitis](#) or [Microscopic colitis](#) on our information pages.

During your GP appointment they will ask you about:

- Your symptoms
- If you have a family history of bowel conditions
- Your overall health
- Your diet



Tell your GP if you're waking up in the night with pain or urgency to poo. Not everyone experiences this, but telling your GP about night symptoms can help them decide which investigations you need.

Some people find it difficult or embarrassing to talk about poo. Try to remember that talking about these symptoms is an everyday part of a GP's job. Their focus is to make sure you get the healthcare you need. You can use our [appointment guide](#) to help you talk about your symptoms.

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## Tips for getting a GP appointment

It can sometimes be difficult to get an appointment with your GP. Each GP surgery has its way of managing appointments, but if you're struggling, we have some things you can try:

- If your GP surgery is in England or Wales, you may be able to make a non-urgent appointment using the [NHS App](#) or [NHS Wales App](#).
- GP surgeries often prioritise urgent cases. Let them know if you used our [symptom checker](#) and it suggested you contact your GP within a few days.
- If you're calling at a busy time, such as first thing in the morning, be prepared to wait.
- When calling to make an appointment, find somewhere quiet where you won't be disturbed.
- The receptionist may ask why you need an appointment. This is to make sure you see the right healthcare professional, such as a GP or a nurse. Receptionists are used to talking about symptoms, but you don't have to go into detail about how you're affected. You could tell them you need an appointment because of 'gut symptoms'.
- Sometimes you may be more likely to get a phone appointment. This will still give you the chance to speak to your GP about your symptoms. Your GP can then decide if they need to see you in person for other checks or tests.

If you're employed, you may need to take time off work for a GP appointment. Check if your GP surgery is open at weekends or evenings or try and book an appointment first or last thing in the day. Your employer isn't legally required to give you time off for medical appointments. Check the policy at your workplace. You may need to take holiday, make up the missed time, or take unpaid leave. You don't have to tell your employer why you need to see the GP unless you want to.

If you can't get an appointment with your GP:

- Ask if there's another healthcare professional you could see. This may be a different GP to the one you usually see, a nurse or a paramedic



- Ask the receptionist when the best time is to call to get an appointment
- Keep trying. You may need to keep calling your GP surgery to get an appointment. This can be frustrating, but your health is important. You do not have to try to manage your symptoms alone
- Find out if your employer has a healthcare scheme that could help you

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## Tips on talking to your GP

Once you have a GP appointment, it's important to tell them how your symptoms affect you. But it's not always easy to do this under pressure. Here are some tips to help you:

- Write down your concerns or things you would like your GP to explain to you before you go to your appointment. Mention the most important ones first so that they don't get forgotten.
- Use our [symptom checker](#) to print off a list of your symptoms and take it to your appointment. Our symptom checker also offers a letter you can give to your GP. The letter includes information about Crohn's and Colitis and the resources we offer GPs.
- Bring along any documents and records you think you need. Keeping a diary of things that trigger your symptoms may help your GP understand what's going on.
- Crohn's and Colitis are often linked to problems with teeth, ulcers in the mouth, joint pain, skin conditions and fatigue. Make sure to tell your GP about your general health and any other symptoms you have. It's also a good idea to tell them if your symptoms are affecting your mental health.
- Healthcare appointments can sometimes be confusing or overwhelming. Write down what your GP says, or you can ask them if you can record your conversation. You could also bring along a family member or friend who can help remember what was said.
- Questions to ask your GP:
  - Could anything else cause my symptoms?
  - What tests do I need?
  - When and how will I get my test results?
  - How long will my referral take to come through?
  - What shall I do if my symptoms get worse before I see a specialist?
  - What can I do to help manage my symptoms?
  - If I'm diagnosed with [name of condition your GP thinks it could be] – how is it treated?

Read our [Appointments guide for](#) more tips about talking to your GP or getting the most out of medical appointments.



## Guidelines for GPs

Your GP should recommend you have some investigations if you've been having any of the following symptoms for more than 6 weeks:

- Stomach pain or discomfort
- Bloating
- A change in how you poo

If you have these symptoms, you should speak to a health care professional as soon as possible. Your GP may use the following guidelines to plan which tests you will need and when:

- The [Inflammatory Bowel Disease toolkit for GPs](#), which has guidance for when GPs should test for the conditions.
- The [NICE Quality Standard for Inflammatory Bowel Disease](#). This also provides guidelines on when patients should be tested for Crohn's or Colitis.

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## Looking after your mental health

Taking care of your mental health is just as important as taking care of your physical health. But living with symptoms that you may find embarrassing or distressing 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 some people feel helpless and uncertain. It's natural that you may struggle to cope sometimes. In fact, almost half of all people with Crohn's or Colitis say it's affected their mental health.

We have lots of honest but reassuring [information for you to read](#), or you can speak to someone from our helpline for support. You can find out more about how others feel and the support that's available to you on our [mental health and wellbeing page](#).

If you have thoughts of suicide or harming yourself, tell someone you trust, or call the NHS on 111. If your life is in danger call 999 or go to your nearest A&E.

If you're feeling emotionally vulnerable, the [Samaritans](#) are available to call 24 hours a day, 7 days a week on 116 123.

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## First investigations

You can't be diagnosed with Crohn's or Colitis from just one test. Your doctor will need to gather lots of information to find out why you're unwell. This can sometimes take time but it's important you get the right diagnosis. The symptoms of Crohn's and Colitis may



be like other conditions, such as irritable bowel syndrome (IBS). To help understand what's going on in your body, your GP will consider all your symptoms, together with some early investigations. These might include an examination of your tummy, as well as tests on your blood and poo. Your GP may also send you to have endoscopies, scans or X-rays. These are all tests to look inside your body.

## Physical examination

Your GP might examine your tummy (abdomen) area to check for any lumps or to see if it's tender. They may also check your bottom for piles, also known as haemorrhoids. You can request a doctor who's the same sex as you, or you can ask for a chaperone for your examination. A chaperone is someone who can go with you to your examination and is usually the same sex as you, is impartial and does not know you.

## Blood tests

Blood tests can show several different things. They can be used to see if you have inflammation in your body. They can also show if you're low in iron, known as anaemia, or if you lack certain vitamins. Anaemia could suggest that you're not absorbing the right nutrients or that you have small amounts of bleeding somewhere in your gut. These are both common in Crohn's and Colitis. Your GP can also order a special blood test to check for signs of Coeliac disease. Coeliac disease is an immune condition that becomes worse when you eat foods that contain gluten. The symptoms of Coeliac disease can be like the symptoms of Crohn's and Colitis. You can take [Coeliac UK's online assessment](#) to see if you should be tested for the condition.

Tell the doctor or nurse before your test if you're worried about needles or seeing blood. They can make sure you're as comfortable as possible and answer any questions you have.

## Stool (poo) tests

Your poo might be tested for signs of bleeding or inflammation. It may also be checked for infections, like a *Clostridium difficile* infection, often known as C.Diff. For these tests, also called stool or faecal tests, you'll need to collect a sample of your poo in a clean, dry screw-top container. Your doctor will give you this container and let you know what to do with it. You can find out more on how to collect and store a poo sample on the [NHS website](#).

The thought of needing to give a sample of poo can be off-putting. But these sorts of test are incredibly useful. They can help with your diagnosis, which means that you get the right sort of treatment for you.

## Faecal calprotectin tests



Your GP may arrange for your poo to be tested for something called faecal calprotectin. Faecal calprotectin tests can show if there's inflammation in your gut. This can be a sign that you may have Crohn's or Colitis. However, a high faecal calprotectin result can also be caused by other issues, such as diarrhoea from an infection, gastroenteritis or certain types of cancerous and non-cancerous tumours.

Usually, levels that are above 100ug/g (micrograms of calprotectin per gram of poo) are considered to be a raised level. Higher levels may suggest that you should have further tests for Crohn's or Colitis. Not all hospitals and clinics use the same cut-off point of 100ug/g.

Lower levels of faecal calprotectin could indicate that you have irritable bowel syndrome or another non-inflammatory condition. However, lower levels can't completely rule out Crohn's or Colitis. You may have a repeat test after 6 weeks if your symptoms carry on.

A faecal calprotectin test may not be helpful for diagnosing [Microscopic Colitis](#). For this condition, faecal calprotectin levels are often quite low.

## **Faecal calprotectin tests in children**

Just like adults, faecal calprotectin tests are sometimes used to help diagnose Crohn's or Colitis in children and young people aged under 18. See above for more information.

A child's calprotectin levels may be assessed by a specialist in a hospital or clinic, rather than a GP.

There are no agreed cut-off levels that reliably show inflammation in children. Sometimes, the same faecal calprotectin cut-off levels as an adult might be used in children over four. But these will be used cautiously.

Children's levels of calprotectin may be naturally higher than an adult's and can vary. This can make it difficult to interpret, particularly in children younger than six.

To help with diagnosis, these tests may be used alongside a list of the child's symptoms. Using both can help give a full picture of what's going on.

## **Faecal immunochemical test (FIT)**

Generally, if you're older than 60, your GP may not use the faecal calprotectin test. This is because they may want to rule out other conditions, such as bowel cancer. Some hospitals and clinics may not use the faecal calprotectin test for some people with certain symptoms under 60 years old.

Your GP might use a FIT or faecal immunochemical test instead. This can check for small amounts of blood in your poo. Blood in the poo does not always mean a person has



cancer. A FIT test may show blood in your poo due to something else, such as Crohn's or Colitis.

**For years I was misdiagnosed with skin conditions and allergies – it only was after finally getting a faecal calprotectin test that I was diagnosed with Colitis. One year later, I'm in remission and getting on with my life.**

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**Megan**  
**Living with Colitis**

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## Getting referred to a gastroenterology team

If your blood and poo tests show inflammation, your GP should refer you to a specialist gastroenterology doctor in an IBD (Inflammatory Bowel Disease) service. They have expert knowledge of gut conditions, like Crohn's and Colitis, and can do specialist tests. If you have been referred through the [NHS e-Referral Service](#), you may be able to choose which hospital you go to.

### Waiting times

It may take some time to get an appointment with your gastroenterology team. The [Inflammatory Bowel Disease Standards](#) state that you should have a specialist assessment within four weeks of being referred, but it may take longer.

In a survey, we found that more than 1 in 4 people living with Crohn's or Colitis waited more than a year to be diagnosed. Waiting a long time for a diagnosis can be difficult, especially as your symptoms may worry you and may impact your daily life. Not knowing how long you will have to wait for an appointment may be frustrating, so it's important you know what to expect and when.

How long you wait may depend on where you live. Your GP should let you know how long you can expect to wait. Contact your GP surgery if you haven't heard from the hospital within that timeframe and they can follow up for you. Your referral letter may also have a telephone number for the department you have been referred to. You could also try contacting the hospital's Patient Advice and Liaison Service (PALS) directly to ask about waiting times.

Tell your GP if your symptoms get worse while you're waiting for an appointment. If you need urgent medical advice, call 111 or in an emergency, call 999. You can use our [appointment guide](#) to help you explain how your symptoms are impacting your quality of life. Your GP may be able to contact the consultant on your behalf to ask if there is any medicine you can take or if you need to be seen sooner.



We have [information on managing many of the common Crohn's and Colitis symptoms](#). While our symptoms information has been written for people with a diagnosis of Crohn's or Colitis, you might still find some of the suggestions helpful.

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## Looking at your gut (endoscopy)

Crohn's and Colitis cause ulcers and swelling in your gut. To look for these signs, a doctor or specialist may insert a small camera into your mouth or bottom. This type of camera is on the end of a long, thin tube and is called an endoscope. The procedure is called an endoscopy.

An endoscopy is not normally painful, but it might be uncomfortable. To help you relax, you might be offered a sedative. Having any sort of procedure can sometimes make you nervous or anxious, especially if you don't know what to expect. Your healthcare professional will be able to answer any questions you have. You may also find it reassuring to look at [our Facebook forum](#) where people share their stories and experiences.

The risks and benefits of an endoscopy should be explained to you before you give consent (permission) to having the procedure. You can find out more about these procedures and any risks on our [tests and investigations page](#).

During an endoscopy, small samples of tissue are often taken from the gut, known as biopsies. These samples can be looked at under a microscope to help understand what's causing your symptoms. These tissues samples are essential for diagnosing [Microscopic Colitis](#). In Microscopic Colitis, an endoscopy may not show any visible signs of inflammation. Instead, changes in the gut can only be seen under a microscope. Microscopic Colitis is a type of Inflammatory Bowel Disease that's different from Crohn's or Ulcerative Colitis.

Symptoms of Crohn's and Colitis can come and go. Your symptoms might get better while you are waiting for your appointment. It is still worth having your endoscopy. Your doctor might find signs of inflammation even when you do not have symptoms.

## Types of endoscopy

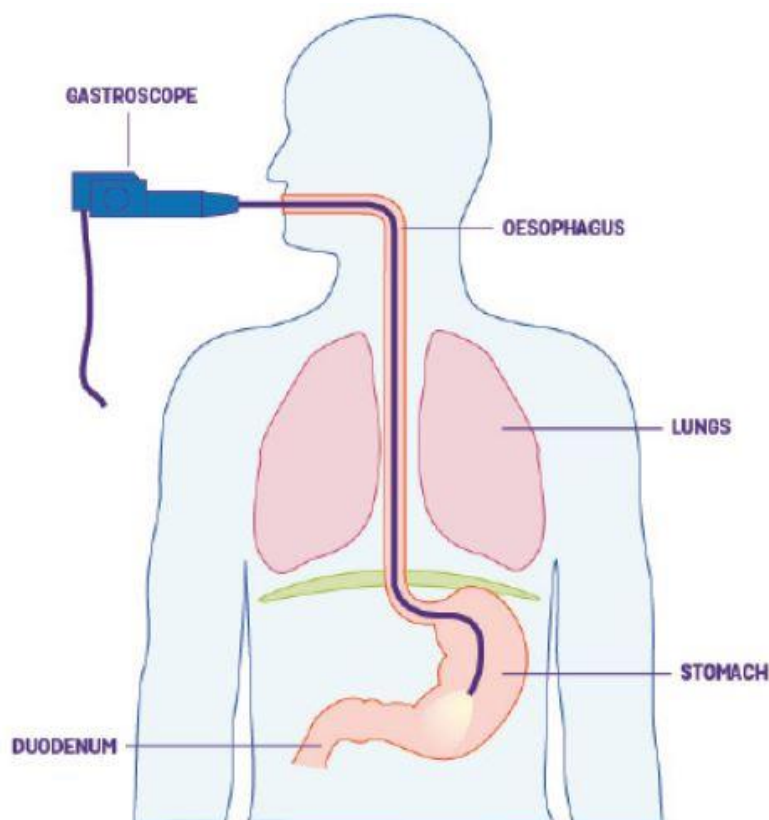
There are several types of endoscopy. The type of endoscopy you have will depend on the part of your gut that needs to be looked at. The main types are:

### **Gastroscopy, also known as upper gastrointestinal (GI) endoscopy**

An endoscope is passed into your mouth to look at the upper part of your digestive system. This includes your throat, stomach and small bowel, also known as the

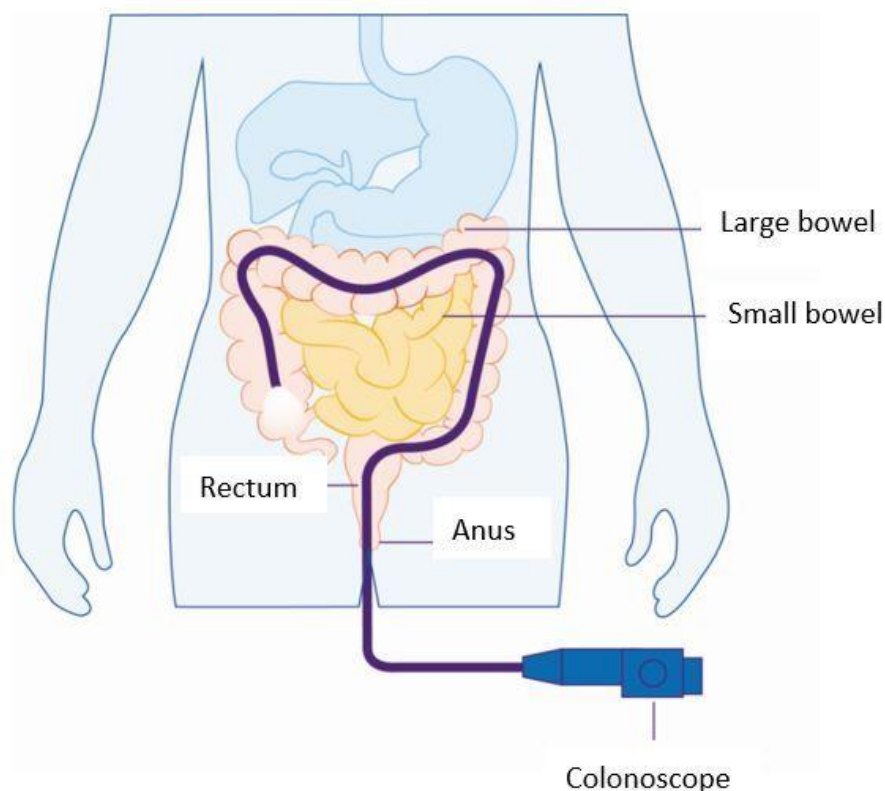


duodenum. You may have this type of endoscopy if you have indigestion or vomiting. It's not usually used if Colitis is suspected.



## Colonoscopy

An endoscope is inserted into your bottom to look at your large bowel, including your rectum and colon. For a colonoscopy, your colon must be empty of poo. You will need to fast and be given a strong laxative to take around 24 hours before.



## A colonoscopy

### **Sigmoidoscopy (or proctosigmoidoscopy)**

This is like a colonoscopy but only examines the rectum and lower part of the colon. Usually, a flexible endoscope is used, which is bendy and helps the specialist see further up the bowel. You will not need to fast for this procedure. A gentle laxative will be used before the procedure.

### **Other type of investigations and preparing for an endoscopy?**

Please visit our [tests and investigations](#) page to find out about other types of investigations you may have, how to prepare for an endoscopy and if there are any risks.

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## **Understanding your results**

After your endoscopy, you should receive a report within three weeks. Contact your GP if you haven't heard back. In some cases, you may be given your report right away, and an endoscopy nurse may explain the results to you. You may be referred for an appointment with a gastroenterologist to talk about your results in more detail.



Some people may feel anxious while waiting for their results. Some people find it helpful to find out more information while they wait, while others prefer the distraction of their normal life. There is no right way to feel, but if you need to talk then [contact our helpline](#) for support.

You might need to have another endoscopy in case something was missed the first time. This can happen if the bowel preparation did not fully clear out your bowel before the procedure.

## Different forms of Crohn's and Colitis

The results on your endoscopy report might not specifically say 'Crohn's Disease' or 'Ulcerative Colitis'. There are different forms of Crohn's and Colitis, and their different names suggest where you're most affected.

Forms of Ulcerative Colitis include:

- **Proctitis or E1 colitis** - In proctitis, only the rectum (the lowest part of the large bowel) is inflamed. The rest of the colon is unaffected and can still work normally.
- **Proctosigmoiditis or E1 colitis** - 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.
- **Left-sided Colitis (also called distal Colitis) or E2 colitis** - Inflammation is in the distal colon. This includes the rectum and the left side of the colon (also called the descending colon).
- **Total Colitis, also called pancolitis or extensive Colitis or E3 colitis** - 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.

Forms of Crohn's Disease include:

- **Ileal or terminal ileal Crohn's** - 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.
- **Ileitis** - 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.
- **Gastroduodenal Crohn's** - 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.



- **Crohn's Colitis** – this means that only the large bowel is inflamed. This is because 'colitis' means inflammation of the large bowel. It does not mean you have both Crohn's Disease and Ulcerative Colitis.
- **Perianal Crohn's** - 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. Some people notice these perianal symptoms before they develop symptoms in other parts of the gut.
- **Oral Crohn's** - 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.

Find out more about the forms of [Crohn's](#) and [Ulcerative colitis](#), including information and images of where in the gut you may be affected.

## Microscopic Colitis

Microscopic Colitis is an Inflammatory Bowel Disease that affects the large bowel (colon and rectum). There are two main forms of Microscopic Colitis – Lymphocytic Colitis and Collagenous Colitis. These are very similar conditions and are commonly referred to under the single name 'Microscopic Colitis'.

## Indeterminate Colitis/IBD Unclassified

It can be hard to tell whether a person has Crohn's or Colitis, especially in children. If this happens, you may be given a diagnosis of Inflammatory Bowel Disease Unclassified (IBDU) or 'Indeterminate Colitis'. Your health care professional will help you find a treatment that works best for you.

## Other conditions that aren't Crohn's Disease or Ulcerative Colitis

The term 'colitis' by itself is a general term that means inflammation in the colon. If your endoscopy finds inflammation but no ulcers, your inflamed colon may be caused by something other than Ulcerative Colitis. You may see terms like 'nonspecific colitis' or 'ischemic colitis' on your endoscopy report. These are not types of Inflammatory Bowel Diseases and are different to Ulcerative Colitis. Your healthcare professional will help you understand more about these conditions and will be able to support you further with these conditions.

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## If you're told you have Crohn's or Colitis

After diagnosis, the [Inflammatory Bowel Disease Standards](#) state that you should:



- Be seen by a Crohn's or Colitis specialist. They will work with you to find the treatment options that suit you best.
- Have a personalised care plan with a full assessment of your condition, nutritional status, bone health and mental health.
- Be supported by a health care professional to make decisions about your treatment and care. These decisions should explore your options and consider your treatment goals. This should include any preferences that might influence your options, such as a needle phobia.
- Be able to start a treatment plan within two weeks of diagnosis, or within two days if your symptoms are severe.

Your GP should be informed of your new diagnosis and the care plan that has been agreed within 48 hours.

## Finding out more

Finding out you have Crohn's or Colitis can be a shock. But now that you can put a name to your symptoms, you can start to manage them. And we're here to help, every step of the way. We've helped thousands of people access the information they need to find answers. We can help you get support and take control.

Read our [newly diagnosed](#) information to find out more about:

- How to tell friends, family or your work
- What to expect from your care
- Learn about your treatment options
- Getting connected with your local Crohn's and Colitis community
- Financial support
- How to look after yourself

You can also find out more about [Crohn's and Colitis](#), including possible symptoms, treatments and living with these conditions.

**Don't get too overwhelmed. When I was diagnosed, I panicked. It felt like my world was falling apart. So, I'd tell myself not to spend time worrying about what may or may not happen. Instead, listen to the doctors, read up on it yourself, and know that you will find a point where it all feels normal. It'll become so day-to-day that you won't even think about it.**

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**James**



## Living with Colitis

### Sign up to our support emails

Have you recently been diagnosed with Crohn's Disease, Ulcerative Colitis or Microscopic Colitis?

Our eight, bite-sized, weekly emails can help you:

- Understand more about life with your condition
- Read other people's stories
- Find out about the support that's available to you

[Sign up to our new series of emails](#) to help you navigate life after diagnosis.

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### If your endoscopy doesn't find Crohn's or Colitis

If your endoscopy didn't find anything, you could still have Crohn's or Colitis. You may need more tests and investigations, such as an X-ray, ultrasound or MRI scan to check for inflammation. Find out more in our [Tests and investigations](#) information.

Microscopic Colitis, a type of Inflammatory Bowel Disease, can sometimes be difficult to diagnose. If you have Microscopic Colitis, then your colon and rectum may look normal on a colonoscopy. During a colonoscopy, a tissue sample, known as a biopsy, may be taken from your gut. This biopsy will be looked at under a microscope for signs of Microscopic Colitis, which is the only way to diagnose it. You may have to wait a few weeks after your endoscopy to get the results of the biopsy back.

If further tests still can't explain your symptoms, you might have another condition. Your healthcare professional will tell you about the next steps.

We know it can be frustrating not to have a clear answer to what's making you feel unwell. It can sometimes take a bit of time to reach the correct diagnosis. You may find it helpful to keep a record of the symptoms you experience so you can show your doctor.

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### If you're not certain about your diagnosis

It's important to raise your concerns with your healthcare professional if you think your diagnosis is incorrect.

Here are some things you can do if you have doubts about your diagnosis.



- Both Crohn's and Colitis affect people in different ways. Many of the symptoms are seen in other conditions. Ask your doctor to explain why you've been given your diagnosis and how they chose your treatment.
- Have an open conversation with your doctor. Tell them that you don't think your diagnosis is correct and why. Some people find it difficult to disagree with a healthcare professional, but it's important to trust your own instincts.
- If you don't think your diagnosis fits, continue to keep a record of your symptoms. Tell your doctor why you don't think your symptoms match your diagnosis. Make sure you record how often they affect you, when you're affected, how severe they are and whether they change over time. Keep a note of anything that you think may make them worse or better. Bring this record to future appointments.
- Information on the internet and social media can sometimes be misleading. It's important to try not to self-diagnose. If you want to look for information, make sure that it's evidence-based, up-to-date and regularly reviewed. You can also look for the [PIF Tick](#), a UK-wide quality mark for health information, enabling NHS organisations, health charities and companies to demonstrate that the health information they create and publish meets certain criteria We are a member – [find out more about how we produce our health information](#).
- Tell your healthcare professional if you're becoming more unwell, are not improving in the expected timeframe or your medicines aren't helping. This might suggest that you need different medicine or need further investigations.

## Asking for a second opinion

If you've asked for a second opinion, your GP may be able to make a recommendation of who to see. Some people may want to do their own research to find a particular hospital or specialist to be referred to. Due to funding restrictions, your GP may not be able to refer you to your chosen specialist. Your GP does not have to refer you if they think you do not need a specialist assessment or specialist treatment. You can find how your local hospital is performing compared to the IBD standards on the [IBDUK website](#).

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## Making a complaint

Each of us has the right to good healthcare. We also have the right to complain if we don't think we've received this. You may want to make a complaint if:

- You're unhappy with the service you've received
- There's been an unreasonable delay in treatments or investigations
- There's been a misdiagnosis
- A healthcare professional has made a serious error
- A healthcare professional has acted inappropriately



## First steps – talk about it

If appropriate, you might be able to deal with the issue straight away by raising your concerns informally. You could talk to your healthcare professional directly and let them know what's wrong. If you're not comfortable doing this, you could speak to someone who isn't directly involved.

## Making a formal complaint

This should be within 12 months of the incident or you becoming aware of it. You can make a complaint in writing, by email or verbally. If you've made a verbal complaint, make sure you write down everything you've discussed. You should also be provided with a written copy of what was said by your NHS service.

When making any complaint, keep a record of any communication that takes place.

If you're complaining on behalf of someone else, make sure you provide their written consent. If that person can't give their consent, for example, if they're a child, lack mental capacity or have died, you may be able to make a complaint on their behalf.

## What to include

When making a complaint, include:

- Details of what happened and when
- Who or what you're complaining about
- What you'd like to be done
- How you have been affected
- Your contact details

## Making a complaint about your GP surgery

All NHS services are required to have a complaints procedure. You may be able to find this on your GP website or you could speak to a receptionist about how to make a complaint. You should make your complaint as soon as possible.

## Making a complaint about a hospital

If you want to raise an issue about something within a hospital, you could speak to the hospital [Patient Advice and Liaison Service \(PALS\)](#). This is a service that most hospitals have and is free, confidential and independent.

## Further information

You can find out more about to make a complaint below:



- [Making a complaint in England](#)
- [Making a complaint in Scotland](#)
- [Making a complaint in Northern Ireland](#)
- [Making a complaint in Wales](#)

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## About this information

We follow [strict processes](#) to make sure our information is based on up-to-date evidence and easy to understand.

Please email us at [evidence@crohnsandcolitis.org.uk](mailto:evidence@crohnsandcolitis.org.uk) if:

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

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

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## 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](https://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](mailto:helpline@crohnsandcolitis.org.uk).



See our website for LiveChat: [crohnsandcolitis.org.uk/livechat](https://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](https://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](https://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.

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## **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 [crohnsandcolitis.org.uk](https://crohnsandcolitis.org.uk).

## **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](mailto: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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