



## MICROSCOPIC COLITIS

### INTRODUCTION

Microscopic Colitis is an Inflammatory Bowel Disease (IBD) that affects the large bowel (colon and rectum). It isn't always as well-recognised as Crohn's Disease or Ulcerative Colitis, other forms of IBD.

It can take time to get a diagnosis of Microscopic Colitis. And dealing with watery poo, tummy cramps, and rushing to the toilet can all be hard to manage. But you're not alone; we're here to support you. Many people respond well to treatment and often symptoms go away when you find what's right for you.

If you've just been diagnosed or want to know more about Microscopic Colitis, this information is for you.

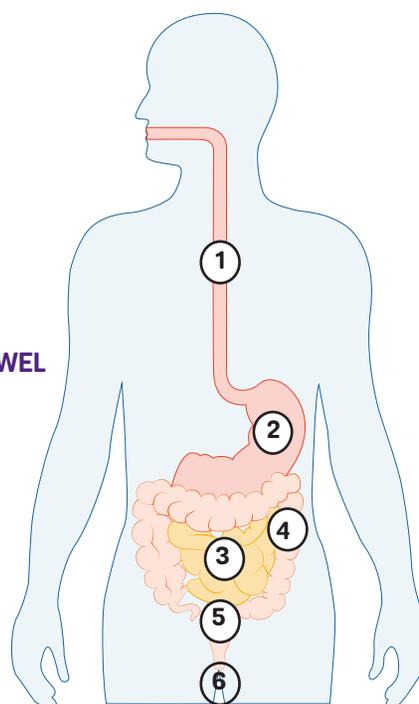
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### WHAT IS MICROSCOPIC COLITIS

Microscopic Colitis affects the part of the gut known as the large bowel – the colon and rectum. The large bowel, or colon's main job is to absorb water from your poo, so you can pass a solid but soft and well-formed poo.

#### THE GUT

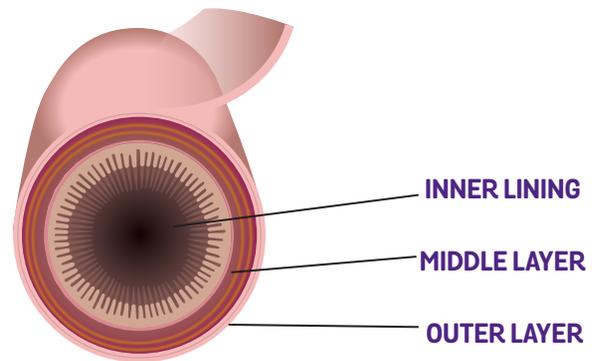
- 1 OESOPHAGUS
- 2 STOMACH
- 3 SMALL BOWEL
- 4 COLON
- 5 RECTUM } LARGE BOWEL
- 6 ANUS



## MICROSCOPIC COLITIS

The walls of your bowel have layers. In Microscopic Colitis the inner lining becomes inflamed. But this change can only be seen when a sample of tissue (biopsy) is taken from your colon and looked at under a microscope.

### BOWEL LAYERS



There are two types of Microscopic Colitis:

- **Lymphocytic Colitis (LC)** – where the inner lining has more white blood cells (lymphocytes) than usual.
- **Collagenous Colitis (CC)** – where the inner lining has a thicker layer of collagen, a protein important in providing structure in the body, than usual. There may also be more white blood cells present.

Microscopic Colitis is the umbrella term for both LC and CC. Although they look different under the microscope, symptoms and treatment are the same. However slightly more people have LC, and women are more likely to have CC. Some people may even have both types of Microscopic Colitis, but at different times.

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## HOW MICROSCOPIC COLITIS AFFECTS THE GUT

Normally, your large bowel absorbs most of the water from the leftover waste of digestion and creates solid poo. But when the colon is affected by Microscopic Colitis, it can't absorb as much liquid from the waste. This can lead to an imbalance of certain chemicals in the gut and mean that even more fluid builds up, producing a large volume of watery poo (diarrhoea).

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## SYMPTOMS OF MICROSCOPIC COLITIS

The main symptom of Microscopic Colitis is ongoing watery diarrhoea. This is where you pass watery or loose poo more than three times a day for longer than four weeks. For some people this can be as many as fifteen times during the day and night. It may begin suddenly or gradually, can happen at any time and may be every time you go to the toilet, or only now and then.

The diarrhoea may:

- be sudden – you may not always reach the toilet in time
- be explosive - this is when your rectum has more watery poo and gas than it can hold and it expels the poo with lots of force, often loudly
- happen several times a day and at night.

There usually isn't any blood in the poo.

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My symptoms include explosive diarrhoea, stomach cramps and tiredness. I've also lost a lot of weight.

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Lyn, age 60  
living with Microscopic Colitis

## MICROSCOPIC COLITIS

“

Nobody told me some of the things I might experience, like fatigue or joint aches.

”

**Helen**, age 63

living with Microscopic Colitis

Other symptoms can include:

- pain in the tummy area – which may be cramping or dull
- fatigue or extreme tiredness, this may be caused by getting up at night to go to the toilet, but many people experience this even if they sleep through the night
- joint pain
- bloating and wind.

### Living with symptoms

These symptoms can have a real impact on life. The fluctuating nature can mean some days aren't good and you can feel that you no longer know your own body. This can make going out with friends, work and planning activities really difficult. Coping with these symptoms may make you feel isolated and low.

Our information on **Fatigue, Joints, Bloating and Wind**, and **Managing Bowel Incontinence** can help you find ways to manage these symptoms.

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## CAUSES OF MICROSCOPIC COLITIS

We don't know yet what causes Microscopic Colitis. It's thought that a combination of factors trigger the body's immune system to attack healthy cells in the lining of the colon.

These include:

- Damage to the lining of the gut – this may be caused by viruses, bacteria or certain medicines.
- Genes a person has inherited.
- Other factors such as smoking, age and gender.

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## WHO GETS MICROSCOPIC COLITIS

You are more likely to get Microscopic Colitis if you:

- **Are over 50 years old.** Most people get Microscopic Colitis when they are aged between 50 and 60. But 1 in 4 are under 25 and children have also been diagnosed with the condition.
- **Are female.**
- **Have an autoimmune condition - see below.**
- **Smoke cigarettes.**
- **Use certain medicines** - see the list in the section **Treatments for Microscopic Colitis**.

At least 1 in 1000 people are thought to have Microscopic Colitis in the UK, but the real number could be a lot higher because it's often underreported and misdiagnosed. It's less well known by both health professionals and the general public which may mean many people with Microscopic Colitis are coping in silence.

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## OTHER CONDITIONS ASSOCIATED WITH MICROSCOPIC COLITIS

### Autoimmune conditions

Around 4 in 10 people with Microscopic Colitis also have a condition caused by the immune system attacking other parts of the body (autoimmune condition).



These include:

- Type 1 diabetes
- thyroid disease
- coeliac disease
- rheumatoid arthritis.

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**Bile acid malabsorption (BAM)**

Around 4 out of 10 people with microscopic colitis also have BAM. Bile salts help you to digest fats. When you eat a meal, especially with fat in it, these bile salts are released from your liver and gall bladder into the upper part of your gut. They help to digest the food as it travels through your small bowel. When the bile salts reach the far end of this, they are mostly absorbed back into your body and return to your liver in the bloodstream.

Bile acid malabsorption happens when the gut can't direct bile acid back to the liver. It's thought that this irritates the lining of the colon and means that your body doesn't absorb water properly. This means you produce large amounts of watery poo. Find out more in **Diarrhoea and Constipation**.

**DIAGNOSIS**

**History of your symptoms**

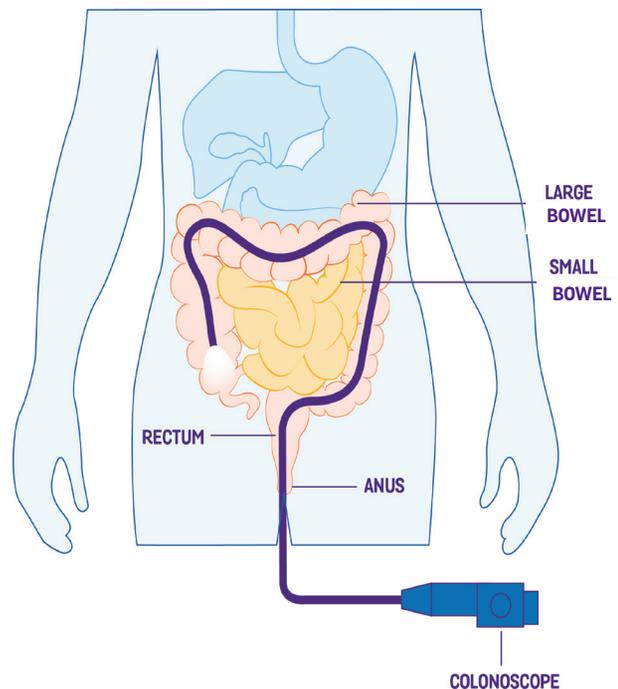
Your doctor will take a careful history of all your symptoms as some can be similar to other conditions such as Irritable Bowel Syndrome (IBS).

**Colonoscopy with biopsy**

In Microscopic Colitis, changes in the gut can only be seen under the microscope. So, to diagnose the condition a small tissue sample (biopsy) is taken from the colon when you have a colonoscopy. This is then looked at under a microscope.

In a colonoscopy, a long flexible tube (about the thickness of your little finger) with a bright light and camera at its tip is inserted through your anus. This allows the doctor to have a look at the lining of your colon and painlessly remove small pieces of tissue to look at under a microscope. A few samples are usually taken from different parts of the colon.

**A COLONOSCOPY**



The doctor won't be able to see any visible signs of inflammation when they look at your colon and rectum. This is different from Crohn's or Ulcerative Colitis when inflammation or ulcers can be seen. Find out more in **Tests and Investigations**.

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I was diagnosed by a biopsy taken during a colonoscopy. This followed 6 months of unexplained weight loss, persistent frequent diarrhoea and abdominal pain.

**Michaela**, age 54  
living with Microscopic Colitis

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It's been hard to get a diagnosis and treatment. Even after that Microscopic Colitis is still not considered to be as serious as other conditons.

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Lyn, age 60

living with Microscopic Colitis

### Other tests you may have

You may have a test for bile acid malabsorption. This is usually carried out in the Nuclear Medicine outpatient department of the hospital. You'll be given a small capsule of a synthetic bile salts to swallow which contains a small amount of harmless radioactive material known as SeHCAT. You'll then have a scan and another one a week later. These will measure the absorption of the radioactive bile salts. Find out more about bile acid diarrhoea in our information on **Diarrhoea and Constipation**.

### Delay in getting a diagnosis

It may take some time to get a diagnosis of Microscopic Colitis, and this can be frustrating.

This may be because:

- A poo test (faecal calprotectin) isn't usually helpful – this finds evidence of inflammation in the gut, but with Microscopic Colitis levels are often quite low.
- Your colon and rectum will look normal at colonoscopy - it is vital to take biopsies to find Microscopic Colitis.
- Symptoms may be similar other conditions such as Irritable Bowel Syndrome (IBS) or coeliac disease which doctors may be more familiar with,

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## TREATMENTS FOR MICROSCOPIC COLITIS

Before you're offered any treatment for Microscopic Colitis your doctor will review the medicines you already take for other conditions.

Medicines that may trigger Microscopic Colitis include:

- non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen, diclofenac
- some proton pump inhibitors (PPIs) such as omeprazole and lansoprazole used to reduce stomach acid
- selective serotonin reuptake inhibitors (SSRIs) used to treat depression
- aspirin
- acarbose for diabetes,
- ranitidine for indigestion and heart burn
- ticlopidine for blood conditions
- statins for cholesterol control.

Many of these medicines can also cause diarrhoea as a side effect. But if you are taking any of these do not stop taking them until you've talked to your doctor.

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Food triggers often change. I can eat something perfectly well one month and not the next.

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Michaela, age 54

living with Microscopic Colitis

### Lifestyle changes

Cutting down alcohol and caffeine can be helpful in reducing diarrhoea. It's often useful to keep a record of when you stop or cut down and how your symptoms change, such as in the food diary in **Food**.

- **Try cutting down on caffeine** – drink decaffeinated tea, coffee, soft drinks or water and reduce the amount of chocolate you eat.
- **Cut down alcohol** – drinking less has been shown to help symptoms.
- **Stop smoking** - smoking increases the risk of Microscopic Colitis, and people who smoke have symptoms which are worse and less likely to get better with treatment. Your GP practice can offer support with stopping smoking.

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Don't give up. Find out about Microscopic Colitis yourself. Your GP is unlikely to know the answer to all your questions so you can go with the information and ask for what you'd like help with.

”

Jaqui, age 35

living with Microscopic Colitis

### Medicines

There may be several options for treatment depending the severity of the symptoms you have.

- **Loperamide**

If you have mild Microscopic Colitis, medicines to stop diarrhoea, such as loperamide, can be effective. These slow down muscle contractions of the gut which makes food move through more slowly and allows more water to be absorbed. Poo becomes firmer and less urgent. They can also help to control symptoms whilst other medications take time to work. Find out more in our information on **Diarrhoea and Constipation**.

- **Bile acid sequestrants**

These include colestyramine, colestipol or colesevelam. If Microscopic Colitis is related to bile acid malabsorption (BAM), or you continue to have diarrhoea despite other treatment, you may be offered this type of medicine. These bind to the bile acids in your gut and help to improve symptoms of diarrhoea. It has been suggested that this may be effective even where BAM isn't present.

- **Budesonide**

This steroid has been found to be an effective treatment if you have moderate to severe Microscopic Colitis. Around 8 out of 10 people have been shown to improve when taking this medicine and there are usually few side effects.

The normal dose is 9mg of budesonide a day for 6 to 8 weeks. You may also be offered loperamide to control the diarrhoea whilst the budesonide gets your condition under control. Your symptoms may start to get better within one or two days but for some people it can take around three and six weeks.

Over half of people on budesonide find their symptoms come back when the treatment stops. If this happens to you a lower dose may be tried, and this could be continued for up to a year. As with all steroids this isn't usually a long-term option.

Most people get better with these approaches but if they don't work for you other treatments may be tried

- **Biologic Medicines.**

Infliximab and adalimumab have been shown in small studies to improve symptoms for some people where budesonide hasn't been effective. Small studies also suggest that vedolizumab could be helpful. These medicines are taken by infusion or injection and you can find out more in our information on **Biologic Medicines**.

- **Immunosuppressants.**

Azathioprine and mercaptopurine have been shown to be effective for some people where budesonide hasn't worked. Find out more in **Azathioprine and Mercaptopurine**.

### Surgery

Surgery is very rarely needed, but for the few people where other approaches haven't been successful this can be an option. You can find out more about possible operations in **Surgery for Ulcerative Colitis**.

## MICROSCOPIC COLITIS AND RISK OF COLON CANCER

Microscopic Colitis does NOT make you any more likely to get colon cancer than the general population.

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## MAKING CHANGES TO YOUR DIET

Diet with Microscopic Colitis is different for everyone. There isn't evidence that specific foods affect some people with Microscopic Colitis but you may find that some foods are a trigger for you. Fatty, spicy and high fibre foods make some people feel worse, but everyone is different, Many people ask:

- **Should I avoid gluten?** - People with Microscopic Colitis are more than 50 times more likely than the general population to have coeliac disease. This means you're not able to digest a type of protein called gluten, which is found in wheat, barley and rye. To find out if you need to avoid gluten, your doctor will do a blood test to check for this. If your blood test is positive, you may also have an upper Gastrointestinal endoscopy to confirm. Find out more in **Food and Tests and Investigations**.

- **Should I avoid dairy products?** – If your diarrhoea is worse after eating dairy, you may have trouble digesting lactose - the type of sugar found mainly in milk, cheese and other dairy products. Keeping a food diary to see how you feel can help you to find out if this is the case for you – try the one in **Food**. Sometimes a simple breath test is used to find out if you're lactose intolerant.

Talk to your doctor or dietitian before making any major changes to your diet. They can help you plan how to avoid dairy products or gluten while still getting the nutrients you need.

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## WHO TO TALK TO IF YOU'RE WORRIED

Our Helpline takes many calls from people with Microscopic Colitis so you're not alone. We can't advise but it may help to talk through your worries. Your doctor will support you and you should ask for support from an IBD nurse-led service.

An IBD nurse can offer support and advice about treatment options, daily life with Microscopic Colitis and help you to live well with IBD. But NHS support services vary - some areas still don't have an IBD nurse, whilst others have limited resources and may not be able to support you if you have Microscopic Colitis.

**Find out if your hospital has an IBD nurse at** [crohnsandcolitis.org.uk/ibd nurse](http://crohnsandcolitis.org.uk/ibd nurse)

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After many years of experimenting, I've found dairy products seem to trigger my symptoms, so I've replaced milk with soya or almond milk instead.

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**Lyn**, age 60  
living with Microscopic Colitis

## HELP AND SUPPORT FROM CROHN'S & COLITIS UK

We're here for you whenever you need us. Our award-winning publications on Crohn's and Colitis 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, school and employment. We'll help you find answers, access support and take control.

All publications are available to download from our website **[crohnsandcolitis.org.uk/publications](http://crohnsandcolitis.org.uk/publications)**

The It Takes Guts Talking Toolkit is an interactive tool with all the information, talking tips and resources you'll need to feel confident to start your conversation about Microscopic Colitis. There are lots of personalised options based on who you want to talk to and what your main worries are **[www.ittakesguts.org.uk/talking-toolkit](http://www.ittakesguts.org.uk/talking-toolkit)**.

### Helpline

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

Our team can:

- help you understand more about Crohn's and Colitis diagnosis and treatment options
- provide information to help you to live well with your condition
- help you understand and access disability benefits
- put you in touch with a trained support volunteer who has personal experience of Crohn's or Colitis.

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](http://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)**

### Crohn's & Colitis UK Local Networks

Our Local Networks of volunteers across the UK organise events and provide opportunities to get to know other people in an informal setting, as well as to get involved with educational, awareness-raising and fundraising activities. Visit **[crohnsandcolitis.org.uk/local-network](http://crohnsandcolitis.org.uk/local-network)** to find your nearest network.

### Help with toilet access

If you become a member of Crohn's & Colitis UK, you will get benefits including a Can't Wait Card and a RADAR key. This card shows that you have a medical condition, and combined with the RADAR key will help when you need urgent access to the toilet when you are out and about. See our website for further information: **[crohnsandcolitis.org.uk/membership](http://crohnsandcolitis.org.uk/membership)** or call the membership team on **01727 734465**.

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## OTHER ORGANISATIONS

Coeliac UK  
**[coeliac.org.uk](http://coeliac.org.uk)**  
**0333 332 2033**

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[crohnsandcolitis.org.uk](https://crohnsandcolitis.org.uk) and the Information Standard website: [www.england.nhs.uk/tis](https://www.england.nhs.uk/tis).

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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 publication 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).

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