



MICROSCOPIC COLITIS

You may not have heard of Microscopic Colitis before. It's a type of Inflammatory Bowel Disease, or IBD. Microscopic Colitis affects the colon, causing symptoms such as ongoing, watery poo and tummy pain and cramps.

Being told you have Microscopic 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.

This information is for anyone who has Microscopic Colitis, thinks they might have it or wants to learn more about it. It looks at:

- What Microscopic Colitis is
- Symptoms you may experience
- How to get a diagnosis
- Treatments you may be offered
- Where to find more information and support

CONTENTS

Key facts about Microscopic Colitis	3
What is Microscopic Colitis?	4
How does Microscopic Colitis affect the gut?	4
Types of Microscopic Colitis	5
How is Microscopic Colitis different to other forms of Inflammatory Bowel Disease?	6
Symptoms	7



Living with symptoms.....	8
Causes of Microscopic Colitis	9
Microscopic Colitis and other conditions	10
Autoimmune conditions	10
Irritable bowel syndrome (IBS)	11
Crohn's and Ulcerative Colitis.....	11
Bile acid malabsorption (BAM).....	11
Microscopic Colitis and risk of colon cancer	12
Getting a diagnosis.....	12
History of your symptoms	12
Colonoscopy with biopsy.....	13
Other tests you may have.....	14
Delay in getting a diagnosis.....	14
Changes to your lifestyle that can help	15
Stopping medicines that can make Microscopic Colitis symptoms worse.....	16
Changes to your diet and drinking habits	17
Stopping smoking	18
Treatments	18
Loperamide.....	18
Bile acid binders	19
Budesonide	19
Immunosuppressants.....	19
Biologics.....	19
Surgery.....	19



Who to talk to if you are worried	20
Other organisations	20
Help and support from Crohn's & Colitis UK	20
Helpline service	21
Virtual Social Events	21
Crohn's & Colitis UK Forum	22
Help with toilet access when out	22
About Crohn's & Colitis UK	22
About our information	23

KEY FACTS ABOUT MICROSCOPIC COLITIS

- The main symptom of Microscopic Colitis is ongoing watery diarrhoea. Other symptoms include bloating, wind and tummy pain.
- Microscopic Colitis affects your colon, stopping it from absorbing the liquid in your gut. This means that fluid builds up, leading to watery poo.
- It can be difficult to diagnose Microscopic Colitis because it has similar symptoms to other conditions, like irritable bowel syndrome and coeliac disease.
- Healthcare professionals may only be able to diagnose Microscopic Colitis by looking at a tissue sample from your colon under a microscope.
- The cause of Microscopic Colitis is not known. But there are several effective treatment options.



- It is rare to need surgery for Microscopic Colitis. Surgery can help if medicines have not worked.

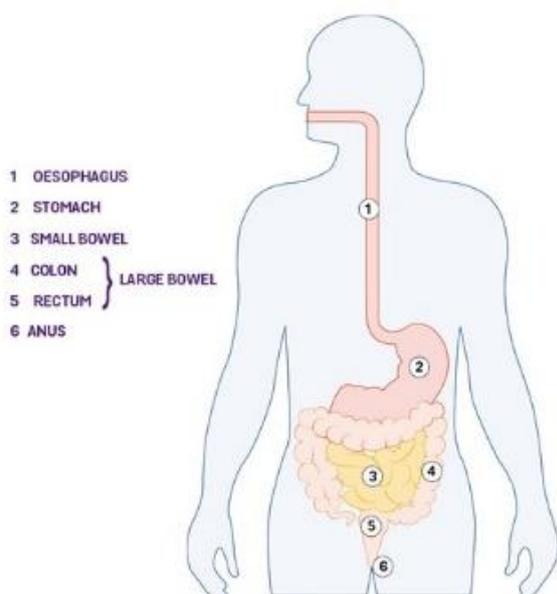
WHAT IS MICROSCOPIC COLITIS?

Microscopic Colitis is a type of Inflammatory Bowel Disease. When you have Microscopic Colitis your immune system does not work properly, causing inflammation. This can lead to frequent, watery diarrhoea that keeps coming back. It can also cause tummy pain, fatigue and bloating.

Microscopic Colitis is a lifelong condition. But the right treatment can make a huge difference to your quality of life. This can help you get your condition under control, and there will be times when you have fewer symptoms or none at all. But you may also experience relapses, when your symptoms return or get worse.

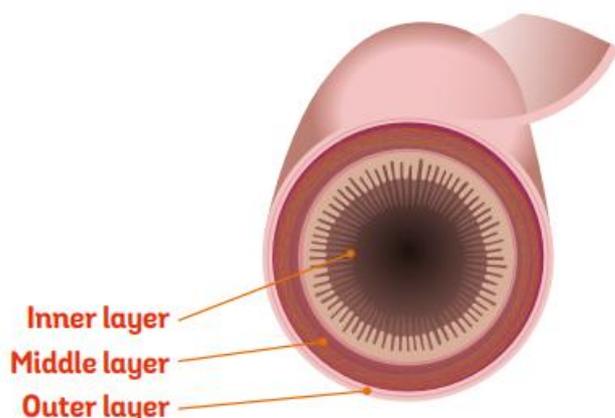
As information about the condition increases, it is becoming better known and understood. More cases are being diagnosed as our understanding develops.

How does Microscopic Colitis affect the gut?





Microscopic Colitis affects the colon, which forms part of the large bowel. Normally, your colon absorbs water from digested food, which helps you pass a solid, soft and well-formed poo. But when the colon is affected by Microscopic Colitis, it cannot absorb as much liquid. This can mean that fluid builds up, producing a large amount of watery diarrhoea.



Types of Microscopic Colitis

There are two main types of Microscopic Colitis:

- Lymphocytic Colitis, or LC – this diagnosis means that your biopsy shows that the inner lining of your colon has a higher number of white blood cells, known as lymphocytes.
- Collagenous Colitis, or CC – this diagnosis means that your biopsy shows that the inner lining of your colon has a thicker layer of collagen than usual. Collagen is a protein that helps in providing structure in the body. In CC, there may also be more white blood cells in the lining than usual.

These two main types of Microscopic Colitis look different under the microscope. But the symptoms and treatment are the same.

Microscopic Colitis incomplete



Sometimes, a biopsy sample may not look healthy but a diagnosis of LC or CC cannot be made. This may be because the number of white blood cells is not high enough and the inner lining may not be thick enough. If this happens, you may be given a diagnosis of Microscopic Colitis incomplete, also known as MCi.

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 at www.crohnsandcolitis.org.uk/supportemails.

HOW IS MICROSCOPIC COLITIS DIFFERENT TO OTHER FORMS OF INFLAMMATORY BOWEL DISEASE?

Microscopic Colitis has not been known about for as long as Crohn's or Ulcerative Colitis.

Crohn's can affect any part of your gut, from your mouth to your bottom. Ulcerative Colitis only affects your large bowel, which includes the colon and rectum.

Microscopic Colitis only affects the colon.

With Ulcerative Colitis, doctors may use a camera on a long flexible tube, called an endoscope, to look at the lining of the large bowel. The doctor will be able to see the inflammation on the lining of the large bowel. But with Microscopic Colitis, your colon will usually look healthy when looked at through a endoscope. The doctor will need



to take samples, called biopsies, of the colon and look at them under a microscope to see the inflammation that Microscopic Colitis causes.

Microscopic Colitis carries less risk of serious complications than Ulcerative Colitis or Crohn's. But it is a serious condition that can have a huge effect on quality of life.

SYMPTOMS

The main symptom of Microscopic Colitis is ongoing watery diarrhoea. Diarrhoea is when you have loose or liquid poo three or more times a day, or more often than is normal for you. For some people with Microscopic Colitis, this can be as many as 15 times during the day and night. It can begin suddenly or gradually, and can get worse over time.

With Microscopic Colitis, the diarrhoea:

- May be sudden – you may not always reach the toilet in time
- May happen frequently, during the day and at night

When you have diarrhoea, your body loses a lot of fluid. It is important to drink plenty of fluids to avoid getting dehydrated. Find out more in our information about [diarrhoea](#) and [dehydration](#).

Other symptoms can include:

- Pain in the tummy area, which may be cramping or dull.
- Fatigue or extreme tiredness. This could be from 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.
- Weight loss.



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

LYN
LIVING WITH MICROSCOPIC COLITIS

Living with symptoms

These symptoms can have a huge impact on everyday life. They can make it difficult to work, go out with friends or plan activities.

You may find our information on [symptoms](#) helpful. It includes information on [diarrhoea](#), [fatigue](#), [bloating and wind](#), and [joint pain](#). Most of the evidence for this information is based on studies of Crohn's and Ulcerative Colitis. This is because there is not as much research available on Microscopic Colitis.

Coping with these symptoms may have an impact on your mental health. Coping with a long-term condition like Microscopic Colitis can be difficult and some people may feel isolated and low. But there is support available. Find out more in our information on [mental health and wellbeing](#).

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

HELEN
LIVING WITH MICROSCOPIC COLITIS



CAUSES OF MICROSCOPIC COLITIS

We do not know what causes Microscopic Colitis. It may be caused by different factors.

These factors include:

- Damage to the lining of the gut – this may be caused by viruses, bacteria or certain medicines.
- Your immune system not working properly and affecting the gut microbiome. The microbiome is the natural bacteria, fungi and viruses that live in your gut.
- Your genes – studies suggest that genes play an important role in Microscopic Colitis.

Microscopic Colitis can affect anyone, from any background, age, ethnicity or sex. But there are some risk factors that may mean you are more likely to get it. These factors include:

- Age. Most people are diagnosed with Microscopic Colitis when they are aged around 60 years. But around 1 in every 4 people (25%) are under 45. Children have also been diagnosed with the condition, although this is rare.
- Sex. The risk of developing Microscopic Colitis is higher in women than men.
- Having an autoimmune disease – see the section on autoimmune conditions.
- Smoking cigarettes.
- Use certain medicines – see the section changes to your lifestyle that can help.

Around 1 in every 2,000 people are thought to have Microscopic Colitis in the UK. But the real number could be a lot higher. This is because the condition may be underreported and misdiagnosed.



MICROSCOPIC COLITIS AND OTHER CONDITIONS

Autoimmune conditions

Microscopic Colitis has been linked to some other autoimmune conditions. An autoimmune condition is caused by the immune system attacking other parts of the body.

Around 4 in 10 people with Microscopic Colitis also have an autoimmune condition.

These may include:

- Type 1 diabetes
- Thyroid disease
- Rheumatoid arthritis.

Having these conditions makes it more likely that you will have Microscopic Colitis as well.

Coeliac disease

Another autoimmune condition closely associated with Microscopic Colitis is coeliac disease. This is a condition that causes your immune system to attack your gut when you eat gluten. Gluten is a type of protein found in wheat, barley and rye.

Both conditions affect the production of white blood cells and have similar symptoms. These can include diarrhoea, bloating and tummy pain. This means Microscopic Colitis can sometimes be misdiagnosed as coeliac disease.

You can have both conditions together. You are more likely to have Microscopic Colitis if you already have coeliac disease. If you do have both, you may still have diarrhoea on a gluten-free diet if your Microscopic Colitis is not treated.



Irritable bowel syndrome (IBS)

IBS is a common, lifelong condition affecting the digestive system. Many of its symptoms are very similar to the symptoms of Microscopic Colitis. These include diarrhoea, tummy pain and bloating. The exact cause of IBS is not known, and there is no cure. But medicines and careful changes to diet can usually help keep the symptoms under control.

Microscopic Colitis is sometimes misdiagnosed as IBS. This is because their symptoms are so similar, and IBS is more well known in comparison. Some people may have both conditions at the same time. Around 1 in 10 people with IBS involving diarrhoea may also have Microscopic Colitis. This can make diagnosis difficult. This means that sometimes people do not receive the correct diagnosis and treatment as quickly as they should.

Crohn's and Ulcerative Colitis

Some evidence suggests that Microscopic Colitis may sometimes develop into Crohn's or Ulcerative Colitis. At the moment, we do not understand how this happens, but the risk of this happening is small.

Bile acid malabsorption (BAM)

Around 4 out of 10 people with Microscopic Colitis also have BAM. This is when bile acids used in digestion cannot be reabsorbed as usual and cause bile acid diarrhoea (BAD).

BAM is treated with bile acid binders. These medicines work by binding to the bile acids in your gut. This stops them from reaching the colon so that they cannot cause diarrhoea. You may be offered bile acid binders if your Microscopic Colitis is related to BAM. You may also be offered bile acid binders if other treatments do not stop your diarrhoea.



If your healthcare professional thinks your Microscopic Colitis is related to BAM, you may be sent for a special test called a SeHCAT scan.

There is more on SeHCAT scans in the section [how is it diagnosed?](#) Find out more about BAM in [other treatments](#). Find out more about diarrhoea, including how to manage it, in our information on [diarrhoea](#).

Microscopic Colitis and risk of colon cancer

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

GETTING A DIAGNOSIS

History of your symptoms

Talk to your GP if you think your symptoms could be caused by Microscopic Colitis. Your GP will need to take a history of all your symptoms. This may help them rule out other conditions.

Poo tests, known as faecal calprotectin tests, are often used to help diagnose Crohn's and Colitis. This test may not be useful for Microscopic Colitis. In Microscopic Colitis, calprotectin levels are often normal or only slightly raised.

If your GP thinks you may have Microscopic Colitis, you will need to be referred for a colonoscopy and a biopsy. You may also need to be tested for other autoimmune conditions, such as coeliac disease. It may take time to diagnose Microscopic Colitis. This is because the condition is not always as well-recognised as other forms of Inflammatory Bowel Disease.

See our [appointment guide](#) for information on getting the most out of your appointments. This includes tips about talking to your healthcare professional.

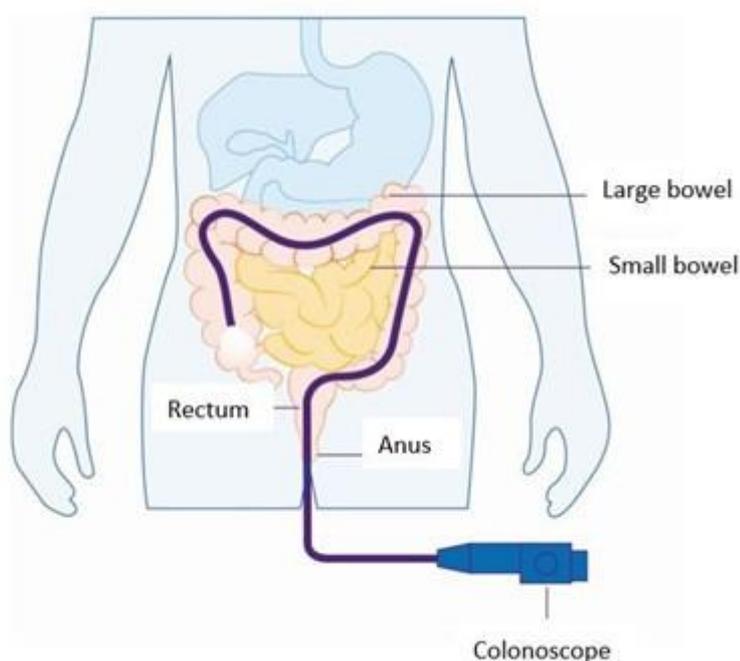


Colonoscopy with biopsy

In Microscopic Colitis, signs of inflammation can only be seen under a microscope. You will need to have a colonoscopy so that a tissue sample, or biopsy, can be taken.

During a colonoscopy, a long flexible tube is inserted through your bottom. The tube is about the thickness of your little finger, with a bright light and camera at its tip. This lets the doctor look at the lining of your colon. During the procedure, a biopsy is taken from your colon. This is then looked at under a microscope.

Most colonoscopies are performed under mild sedation. This is when you are given medicine through a tube in your arm to make you feel relaxed. You may be offered gas and air or painkillers instead, to make you more comfortable.



A colonoscopy

You can find out more in [tests and investigations](#), or [read more about colonoscopies on the NHS website](#).



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

MICHAELA
LIVING WITH MICROSCOPIC COLITIS

Other tests you may have

SeHCAT scan

You will be given a small capsule of synthetic bile salts to swallow. This contains a small amount of harmless radioactive material known as SeHCAT. You will then have a scan, followed by another one a week later. These will measure how the bile salts have been absorbed.

See our information on [tests and investigations](#) for more on SeHCAT scans. And there is more on bile acid malabsorption in our information on [diarrhoea](#).

Delay in getting a diagnosis

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

This may be because:

- A poo test, or faecal calprotectin test is not always helpful in finding Microscopic Colitis
- Your large bowel looks normal at colonoscopy. A biopsy is needed to find Microscopic Colitis. If your GP or specialist thinks you may have Microscopic Colitis, they will arrange for you to have a biopsy.
- Your symptoms may be similar to conditions such as IBS or coeliac disease. You may need to have a blood test to rule out coeliac disease



If it is taking a long time to get diagnosed, you may find our information on [how to get a diagnosis](#) useful.

You may also find it helpful to keep a symptom diary, which you can take to healthcare appointments. When you have a symptom, try recording the date and time with a short description of what happened. Give the symptom a rating from 'mild' to 'very severe'. Try to add any details that might be helpful, such as any food or medication that may have had an impact. These could help your healthcare professional rule out other conditions.

Many people find it uncomfortable to talk about diarrhoea and difficult to share how concerned they are. It can be upsetting to feel like you are not being listened to by your healthcare professional. Being able to self-advocate, or speak up for yourself, can be useful in making sure your voice is heard. You may find the information on self-advocacy in our [appointment guide](#) helpful. It includes tips on communicating your symptoms and talking to your healthcare professional.

"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 conditions."

LYN
LIVING WITH MICROSCOPIC COLITIS.

CHANGES TO YOUR LIFESTYLE THAT CAN HELP

There are several changes to your lifestyle that may improve your symptoms. Your healthcare professional may suggest:

- Stopping taking certain specific medicines for other conditions and switching to another
- Making changes to your diet



- Stopping smoking, if you currently smoke

Stopping medicines that can make Microscopic Colitis symptoms worse

Before offering any treatment for Microscopic Colitis, your doctor will check if you take any medicines for other conditions.

Medicines that may make your Microscopic Colitis symptoms worse include:

- Non-steroidal anti-inflammatory drugs, known as NSAIDs. These include aspirin, ibuprofen or diclofenac.
- Certain medicines used to reduce stomach acid, known as proton pump inhibitors, or PPIs. These include omeprazole and lansoprazole.
- Certain medicines to reduce indigestion and heartburn, such as histamine-2 antagonists. This includes famotidine.
- Certain medicines used to treat depression, such as selective serotonin reuptake inhibitors (SSRIs). These include citalopram, fluoxetine, sertraline,
- Aspirin.
- Acarbose, for type 2 diabetes.
- Ticlopidine, for blood conditions.
- Statins, for cholesterol control, such as simvastatin or atorvastatin.

Many of these medicines can also cause diarrhoea as a side effect. You can read more about some of these medicines in our information on [other treatments](#).

Always talk to your doctor before stopping or changing any medicines you are taking.



Changes to your diet and drinking habits

Making changes to your lifestyle may help to reduce your symptoms.

- Try cutting down on caffeine. Drink decaffeinated tea, decaffeinated coffee and non-caffeinated soft drinks. Try reducing the amount of chocolate you eat - chocolate contains caffeine.
- Cut down on alcohol. Drinking less has been shown to help symptoms. National guidelines recommend drinking no more than 14 units of alcohol per week, spread over at least three days. See the [NHS website](#) for more information.
- There is no evidence to suggest that specific foods affect people with Microscopic Colitis. But you may find that certain foods are a trigger for you. Everyone is different, but keeping a food diary can help you understand what foods make you more unwell. A dietitian can help you find a healthy diet that works for you. Try using the food diary in [food](#).

Many people ask:

- Should I avoid gluten? People with Microscopic Colitis are more likely to have coeliac disease than the general population. Having coeliac disease means you are not able to digest a type of protein called gluten, which is found in wheat, barley and rye. Talk to your GP if you think you may have coeliac disease. They can do a blood test to check. If this is positive, you may also need an endoscopy. This can help confirm your diagnosis. 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. Lactose is a type of sugar found mainly in milk, cheese and other dairy products. Keeping a food diary and recording your symptoms can help you find out if this is the case for you. Sometimes, a simple breath test is used to find out if you are lactose intolerant. Speak to your GP if you think you may be lactose intolerant.



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

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

LYN

Living with Microscopic Colitis

Stopping smoking

If you smoke, stopping can help. Smoking increases the risk of Microscopic Colitis. People who smoke have symptoms that are worse and less likely to get better with treatment. Your GP practice can offer support with stopping smoking.

TREATMENTS

There may be several options for treatment depending on the severity of your symptoms. These include:

Loperamide

If you have mild Microscopic Colitis, medicines to stop diarrhoea, such as loperamide, can help. These make food move through the gut more slowly and allows more water to be absorbed. Poo becomes firmer and you may need to go to the toilet less urgently. They can also help to control symptoms while other medicines take time to work. Find out more in our information on [diarrhoea](#).



Bile acid binders

Bile acid binders, such as colestyramine or colesevelam, attach to the bile acids in your gut. You may be offered this medicine if your Microscopic Colitis is related to bile acid malabsorption (BAM). It may also be offered if you continue to have diarrhoea despite other treatment. Find out more in our information on [other treatments](#).

Budesonide

Budesonide is used to reduce inflammation to control symptoms of Microscopic Colitis. This steroid has been found to help some people who have moderate to severe Microscopic Colitis. As with all steroids this is not usually a long-term option. Find out more in our information on [steroids](#).

Immunosuppressants

Azathioprine and mercaptopurine may help some people if budesonide has not worked. Find out more in [azathioprine and mercaptopurine](#).

Biologics

Biologics are a high-cost treatment which IBD teams must apply for funding for. Funding for biologic use in microscopic colitis is not generally given. But in rare circumstances some people may be offered a biologic. There is some evidence from small studies to support this so far. But there have not yet been any well controlled clinical trials.

Surgery

It's rare to need surgery if you have Microscopic Colitis. Your healthcare professional may suggest surgery if other treatments have not worked. You can find out more about possible operations in [surgery for Ulcerative Colitis](#).



WHO TO TALK TO IF YOU ARE WORRIED

Our Helpline takes many calls from people with Microscopic Colitis, so you are not alone. We cannot 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 and daily life with Microscopic Colitis, and help you to live well with IBD. But NHS support services vary – unfortunately some hospital IBD teams do not treat Microscopic Colitis. And some areas still do not have an IBD nurse, while 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](#).

Our Helpline team can provide information and support to anyone affected by Inflammatory Bowel Disease. You can find more information, including contact details, below and on the [Helpline](#) webpage.

OTHER ORGANISATIONS

Guts UK – the charity for the digestive system

gutscharity.org.uk

020 7486 0341

HELP AND SUPPORT FROM CROHN'S & COLITIS UK

We're here for you. Our information covers a wide range of topics. From treatment options to symptoms, relationship concerns to employment issues, our information can help you manage your condition. We'll help you find answers, access support and take control.



All information is available on our [website](#).

Helpline service

Our helpline team provides up-to-date, evidence-based information. You can find out more on our [helpline web page](#). Our team can support you to live well with Crohn's or Colitis.

Our Helpline team can provide support by:

- Providing information about Crohn's and Colitis
- Listening and talking through your situation
- Helping you to find support from others in the Crohn's and Colitis community
- Providing details of other specialist organisations

You can call the Helpline on **0300 222 5700**. Or visit our [LiveChat service](#). You can read our information on [when the Helpline](#) is open for more details..

You can email helpline@crohnsandcolitis.org.uk at any time. The Helpline will aim to respond to your email within three working days.

Our helpline also offers a language interpretation service, which allows us to speak to callers in their preferred language.

Virtual Social Events

We offer people affected by Crohn's or Colitis the chance to join a virtual social event with others across the UK. The events will be a chance to chat, share experiences and potentially learn from others. Each event may have a specific topic but the overall discussion will be driven by what those attending wish to talk about.

Family, friends and colleagues are more than welcome to attend.

Visit our [Virtual Social Events](#) page to find out what is available.



Crohn's & Colitis UK Forum

This closed-group Facebook community is for anyone affected by Crohn's or Colitis. You can share your experiences and receive support from others. Find out more about the [Crohn's & Colitis UK Forum](#).

Help with toilet access when out

There are many benefits to becoming a member of Crohn's & Colitis UK. One of these is a free RADAR key to unlock accessible toilets. Another is a Can't Wait Card. This card shows that you have a medical condition. It will help when you are out and need urgent access to the toilet. See [our membership webpage](#) for more information. Or you can call the Membership Team on **01727 734465**.

ABOUT CROHN'S & COLITIS UK

We're Crohn's & Colitis UK and we're changing what it means to live with these lifelong gut conditions. 1 in 123 people in the UK have Crohn's Disease or Ulcerative Colitis. These are unpredictable conditions that could flare up at any time.

No one should face that alone. That's where we can help.

We provide trusted information and support cutting-edge research. We also lead bold campaigns to get more people talking about Crohn's and Colitis. We help people understand these conditions, give them the attention they deserve and bring people together to create change.

This year, 25,000 people will be told they have Crohn's or Colitis. Once diagnosed, the obstacles continue. Today, there is no cure. People simply don't understand these conditions. So, we have listened. It's time for change & we're leading the way.



Our information is available thanks to the generosity of our supporters and members. Find out how you can join the fight against Crohn's and Colitis by calling **01727 734465**. Or you can visit [our website](#).

About our information

We follow strict processes to make sure our information is based on up-to-date evidence and is easy to understand. We produce it with patients, medical advisers and other professionals. It is not intended to replace advice from your own healthcare professional.

You can find out more on [our website](#).

We hope that you've found this information helpful. Please email us at evidence@crohnsandcolitis.org.uk if:

- You have any comments or suggestions for improvements
- You would like more information about the evidence we use
- 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 you can contact us through the **Helpline** on **0300 222 5700**.

We do not endorse any products mentioned in our information.

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Microscopic Colitis, edition 6d

Last amended: March 2026

Last review: October 2024

Next review: October 2027

