# CROHN'S & COLITIS UK

### All about Crohn's and Colitis



Information

Symptoms



Treatment



Support

Hearing you have Crohn's or Colitis can be a shock. You might feel anxious about what comes next and how life will change.

Because life will change. But it can also improve. And we're here to help, every step of the way.

Crohn's & Colitis UK is here for you whenever you need us. We have information about medicines, food, symptoms, surgery, and more. We also have lots of information about living day-to-day with your condition, such as travelling, schooling and employment. It's all available for free at crohnsandcolitis.org.uk/publications.

Find answers. Access support. Take control.

## **BECOME A MEMBER**

#### As a member of Crohn's & Colitis UK, you'll become part of a powerful community fighting for change.

You'll receive exclusive information and updates, a Can't Wait Card and Radar Key to help with toilet access, and much more.

Join us today: visit crohnsandcolitis.org.uk/membership or call 01727 734465



# **CROHN'S AND COLITIS**

Crohn's Disease and Ulcerative Colitis are Inflammatory Bowel Diseases (IBDs).

# They can cause painful sores (ulcers) and inflammation (swelling) in your gut.

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

There is another type of IBD called Microscopic Colitis, which usually goes away after treatment.

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It's something you'll have to learn to adapt to – and you will. Don't let your mind run riot – things will get better if you let them. Everyone goes through their own stuff in life; if you embrace it, everything becomes a lot easier. 99

Moeed, age 26 living with Crohn's Disease

#### The gut

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

The gut is the part of your body that takes food and nutrients in, and carries poo out. The gut starts at your mouth, when you eat, and ends at your bottom (anus), where poo passes out of your body.

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

Large bowel

- **Oesophagus** 1
- 2 Stomach
- 3 Small bowel
- 4 Colon
- 5 Rectum
- 6 Anus



Healthy intestine Ulcerative Colitis

Crohn's Disease

#### The bowel

1

5

6

2

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

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

AUUUU

Inner layer Middle layers Outer layer

#### **Bowel layers**

#### **TYPES OF CROHN'S AND COLITIS**

#### Crohn's Disease

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

'Crohn's Colitis' is a type of Crohn's Disease, where only the large bowel is inflamed. This is because 'colitis' means inflammation of the large bowel. It doesn't mean you have both Crohn's Disease and Ulcerative Colitis.

#### **Ulcerative Colitis**

Ulcerative Colitis is inflammation and ulcers in the large bowel. It can be anywhere from your colon to your anus. Only the inner lining is inflamed.

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

#### **Microscopic Colitis**

Microscopic Colitis is inflammation of the large bowel. Unlike Ulcerative Colitis, Microscopic Colitis does not cause ulcers, and there is no blood in the poo. Doctors have to use a microscope to see the inflammation.

#### **Uncertain diagnosis**

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

# WHO HAS CROHN'S AND COLITIS?

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



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

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

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# **FEELING UNWELL**

Everyone is different: some people with Crohn's or Colitis feel well most of the time, other people take longer to find a treatment that's right for them.

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



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



#### FLARE-UPS

Times when you feel unwell are called flare-ups.

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

Your doctor (gastroenterologist) and the rest of your IBD Team are there to support you. Ask if the team has an IBD Nurse. You can talk to the nurse in between doctors' appointments if you need help.

#### REMISSION

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

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

If you still feel unwell in your gut, even when your doctor says you're in remission, you may also have a condition called **Irritable Bowel Syndrome (IBS)**.

Inflammatory Bowel Disease (IBD) and IBS are different, but you can have both at the same time. IBS is very common, and can cause tummy pain, bloating, diarrhoea and constipation. But unlike Crohn's and Colitis, there is no inflammation, or blood in the poo.

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

# CAUSES OF CROHN'S AND COLITIS

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

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

We don't know why the immune system attacks the body. It is probably caused by a mix of genes and the environment (like germs, diet, smoking and stress).



The genes a person has inherited



The immune system going wrong



Probably triggered by something in the environment

# TESTS

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

Tests for Crohn's and Colitis include:



#### **Blood tests**

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



#### **Poo tests**

Poo tests check for infections and inflammation.



#### Endoscopy

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

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



#### Ultrasound, CT and MRI scans

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

#### TREATING CROHN'S DISEASE AND ULCERATIVE COLITIS

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

#### Medicines

You will probably have medicines called 5-ASAs (e.g. mesalazine, sulphasalazine) or steroids to reduce the gut inflammation. Steroids work quickly, but you can only take steroids for a short time.

If you still feel unwell, you can take medicine to control your immune system. This stops your immune system attacking your gut.

You can have your medicine in different ways:

- tablet (e.g. 5-ASAs, azathioprine, methotrexate)
- injection (e.g. adalimumab, golimumab)
- drip into your arm (e.g. infliximab, vedolizumab)
- suppository or enema, which goes directly into your anus (e.g. 5-ASAs, steroids)



#### Liquid diet

Sometimes Crohn's flare-ups can be treated with a liquid diet called enteral or parenteral nutrition.



#### Surgery

Medicines help most people feel better, much of the time. But if medicine isn't right for you, or you're very unwell, surgery can also help.

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

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

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My quality of life with a stoma is so much better than when I had a colon. I wish I had surgery before I did, because it has really improved my symptoms. 99

Katryna, age 36 living with Ulcerative Colitis

#### **TREATING MICROSCOPIC COLITIS**

Microscopic Colitis is often caused by medicines such as lansoprazole or NSAID painkillers. So if you stop taking these medicines, you may feel better.

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

People with Microscopic Colitis are also more likely to have Coeliac Disease. Ask your doctor to test if you have this. If you do, avoiding foods with gluten will help you feel better.



#### **Medicines**

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

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Be self-aware and find out everything you can. It's easier if you can simply see it as part of you – and deal with it in a positive way. 99

Helen, age 78 living with Microscopic Colitis



#### DIET

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

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

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

Chronic condition	Lifelong, ongoing disease or illness
Diarrhoea	Going to the toilet a lot, with loose or watery poo
Fatigue	Extreme tiredness
Inflammatory Bowel Disease	Crohn's and Colitis
Relapses, flare-ups, active disease	When you feel unwell
Remission, inactive disease	When you feel better
Ulcerated	To have sore wounds (ulcers)

#### **MEDICAL WORDS YOU MAY HEAR**



#### **HOW WE CAN HELP**

We're the UK's leading charity for Crohn's and Colitis. We want improved lives today, and a world free from Crohn's and Colitis tomorrow.

We work to improve diagnosis and treatment, and to fund research into a cure; to raise awareness and give people hope, comfort and confidence to live freer, fuller lives.

We're here for everyone affected by Crohn's and Colitis.

#### Helpline



Our confidential helpline offers information and support for anyone affected by Crohn's and Colitis.

We can:

- help you learn more about Crohn's and Colitis
- help you access disability benefits
- help you find support from other people living with Crohn's or Colitis

Call us on 0300 222 5700 or email helpline@crohnsandcolitis.org.uk Live Chat: crohnsandcolitis.org.uk/livechat

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