CROHN'S & COLITIS UK

CROHN'S? COLITIS? WE'LL FACE IT TOGETHER.

JOINT PROBLEMS

Many people with Crohn's Disease or Colitis get joint problems. These can include joint pain, swelling and stiff joints. There can be lots of reason for joint pain. Sometimes, joint problems may be caused by a type of arthritis linked to Crohn's and Colitis.

Living with joint problems when you have Crohn's or Colitis can have a big impact on your life. It's important to get the help you need. This information is for anyone who wants to know more about joint problems related to Crohn's or Colitis and how to manage them. Where we use the term Colitis in this information, we mean both Ulcerative Colitis and Microscopic Colitis.

This information is for people in the UK. It should not replace advice from your healthcare team.

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KEY FACTS ABOUT JOINT PROBLEMS

- Joint problems are common in Crohn's and Colitis. They can affect people with Crohn's Disease, Ulcerative Colitis and Microscopic Colitis.
- Having Crohn's or Colitis puts you at greater risk of a type of arthritis. Arthritis is when you have inflammation in your joints. It can affect joints and tendons in your back as well as other parts of your body, such as your hands and feet.
- For some people, joint problems may get worse when their gut symptoms are worse. For others, there is no link to gut symptoms.
- If left untreated, arthritis may sometimes lead to permanent damage. Speak to your GP or IBD team if you have pain, swelling and stiffness in your joints.
- Medicines, exercise and physiotherapy can all be helpful in managing joint problems.

HOW DO CROHN'S AND COLITIS AFFECT YOUR JOINTS?

Crohn's and Colitis do not just cause gut symptoms. Many people also have symptoms that affect other parts of their body. Joint problems, including joint pain and arthritis, are one of the most common symptoms outside of the gut.

Arthritis is when one or more of your joints become inflamed. This causes pain and swelling in the affected joints. There can be a direct link with the gut inflammation that you get in Crohn's or Colitis. This is sometimes known as the gut-joint axis.

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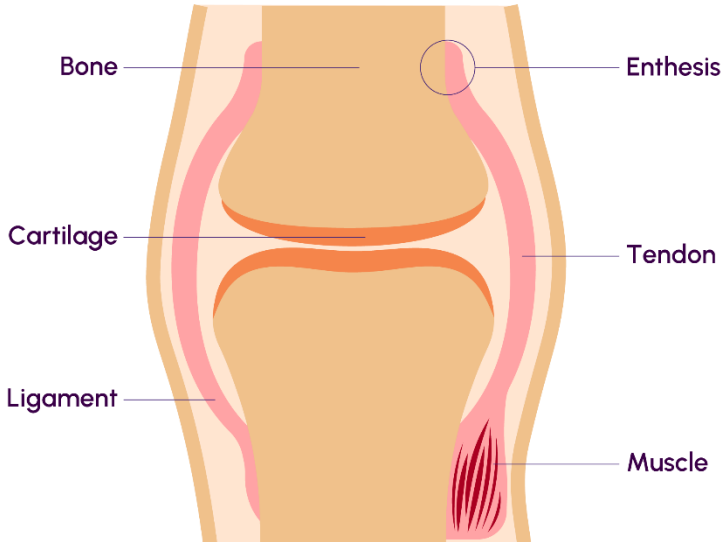
It's difficult to know exactly how many people with Crohn's or Colitis have joint problems. But some studies suggest that nearly half of all people with Crohn's or Colitis may get them.

About joints

A joint is where 2 or more bones meet. These include:

- Large joints, such as your knees, hips and shoulders
- Small joints, like in your hands, wrists and feet

Below, we show a diagram of a typical joint.



A joint is made up of:

- Cartilage. This covers the surfaces of the bones in your joint. It allows the bones to move freely and cushions the joint.
- Muscles. These control the movement of your joint.
- Tendons. These connect your muscles to the bones.
- Ligaments. These connect the bones in a joint together.

- Entheses. These are areas of connective tissue where a tendon or ligament attaches to the bone.

Sometimes, your whole joint can become inflamed. But you can also just have inflammation that affects a tendon or enthesis. This is not always in a joint. An example is the Achilles tendon at the back of your heel.

Impact of joint problems

Having joint problems can have a big impact on your life. It can make it harder to get around, cause pain and **fatigue**, and affect your **mental health**. This can make it difficult to:

- Work
- Exercise
- Look after others
- Do your usual activities

For some people, these symptoms can be just as bad, or even worse, than the gut symptoms associated with Crohn's and Colitis.

> **"Aches and pains and in particular fatigue have been a major issue in my life. My joints are inflamed and painful regardless of what is going on with my gut."**
>
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Without effective treatment, arthritis can cause permanent damage to your joints. But there are lots of treatment options available. Some are the same as medicines

for Crohn's or Colitis. There are also lots of things you can do to help manage your symptoms.

Let your IBD team know about any symptoms affecting your joints. They can help you to get the right treatment as soon as possible. This may make it easier to manage symptoms and prevent permanent damage.

WHAT TYPES OF ARTHRITIS ARE LINKED TO CROHN'S AND COLITIS?

There are many different types of arthritis. Arthritis that is linked to Crohn's and Colitis belongs to a family of arthritis conditions called spondyloarthritis. These types of arthritis are caused by your immune system not working properly. This leads to inflammation in or around your joints, tendons and spine. It's the same process that causes inflammation in your gut in Crohn's or Colitis.

Both people with Crohn's and people with Ulcerative Colitis can get this type of arthritis. But it's more common in people with Crohn's. You may also get it if you have **Microscopic Colitis**, but it's not as common. There are several different types of spondyloarthritis. We describe these below.

Types of spondyloarthritis

- Enteropathic arthritis or IBD-associated arthritis. Spondyloarthritis associated with gut conditions, like Crohn's and Ulcerative Colitis.
- Axial spondyloarthritis. When you mostly have symptoms affecting your back and spine.
- Peripheral spondyloarthritis, When you mostly have symptoms affecting joints and tendons outside of your spine.

- Psoriatic arthritis. A type of spondyloarthritis where you also have a skin condition called psoriasis. See **Crohn's, Colitis and other immune-related conditions** for more information.
- Reactive arthritis. When the arthritis starts after an infection.

You can get any of these types of spondyloarthritis if you have Crohn's or Colitis. The type your doctor diagnoses you with can depend on which most closely fits your main symptoms. But there can be overlap between the different types. You may have features of more than one. Your symptoms and diagnosis may also change over time.

Ankylosing spondylitis is an older term for a more severe form of axial spondyloarthritis. It causes more permanent, structural changes to the joints of your lower back. These changes can be seen on an X-ray.

Most people with Crohn's or Colitis who get arthritis develop symptoms after their diagnosis of Crohn's or Colitis. But for some people, joint problems can happen before a Crohn's or Colitis diagnosis.

WHAT JOINT SYMPTOMS MAY I GET?

If you have arthritis associated with your Crohn's or Colitis, you may get some of the following symptoms.

- Pain and stiffness in your back. This can affect any part of your back. It's due to inflammation in or around the joints of your spine. These are known as your axial joints. Back pain tends to be worse in the morning and gets better with movement. Pain around your lower back and bottom can be due to inflammation in the joints in your pelvis. This is called sacroiliitis.

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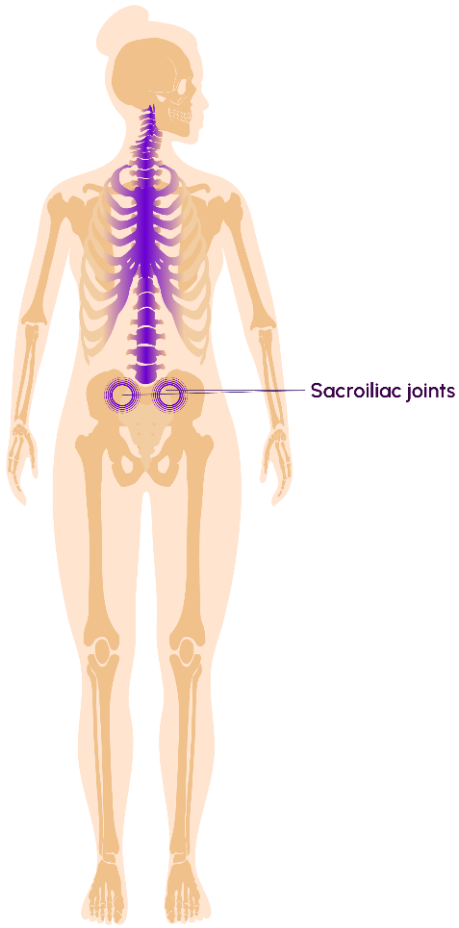
- Painful, swollen joints in other parts of your body, such as your:
    - Knees
    - Ankles
    - Shoulders
    - Elbows
    - Wrists
    - Fingers

  These are known as your peripheral joints. You might find the pain and swelling comes and goes, or switches between different joints.
- Inflammation of the entheses. This causes pain and tenderness in areas where tendons or ligaments attach to the bone. The medical term for this is enthesitis. The areas most commonly affected include:
    - The back of your heel, known as Achilles tendinitis
    - Underneath your heel, known as plantar fasciitis
- Swollen and painful fingers and toes. They are sometimes described as looking "sausage-like". The medical term for this is dactylitis.

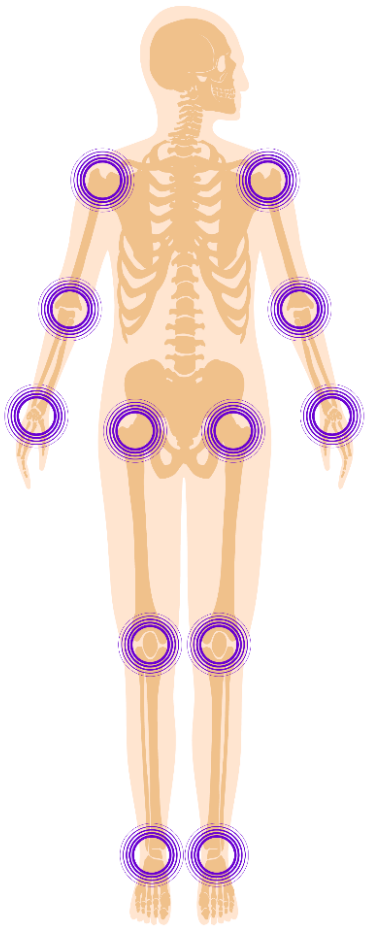
These diagrams show the location of the axial and peripheral joints, and the entheses around your heel.

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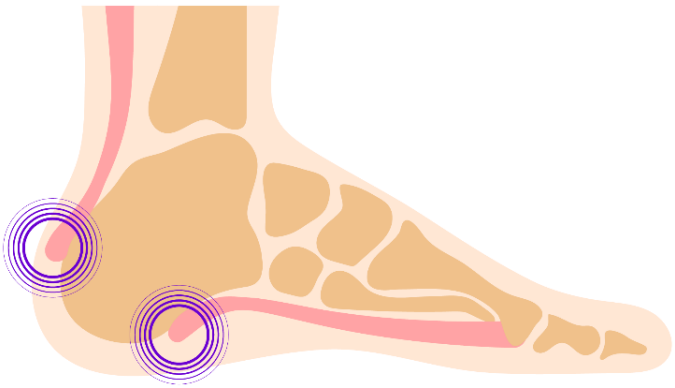
Joints affected by axial spondyloarthritis



Joints affected by peripheral spondyloarthritis



Location of enthesitis pain and swelling



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If your peripheral joints are affected, there can be different patterns to your symptoms:

- You may have a small number of large joints affected, such as your knees or hips. These might flare up at the same time as gut symptoms, and then get better within a few weeks.
- Or you may have several joints affected at once, on both sides of your body. This will often be the small joints in your hands. This can last for months or years, and might not be related to your gut symptoms.

This pattern can change over time.

WHAT ELSE CAN CAUSE JOINT PROBLEMS IN CROHN'S AND COLITIS?

There can be lots of other reasons for joint problems in Crohn's and Colitis. Some of these may be related to your Crohn's or Colitis, and some not. They can include injury, infection, side effects of medicines, and other types of arthritis.

Joint pain without arthritis

You may get joint pain without any signs of arthritis or inflammation in your joint. This is known as arthralgia. Anyone can get arthralgia. But it is more common in people with Crohn's or Colitis. For some people with Crohn's or Colitis, having joint pain may mean you're more likely to go on to develop arthritis. But this is not the same for everyone. Tell your doctor or IBD team if you regularly have joint pain.

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Medicines

Some medicines may occasionally cause joint pain as a side effect. You can find out about side effects from your medicine in the patient information leaflet that comes in the box. Many medicines for Crohn's and Colitis help with joint pain.

Stopping steroids too quickly can also cause joint pain. This is part of a serious condition that people may get when stopping steroids, called adrenal insufficiency. It's important to lower the amount of steroids you take gradually. You can find out more in our steroids information. High doses of steroids can also sometimes be associated with a rare complication called osteonecrosis. This causes damage to your joints and joint pain, usually in your hip.

Talk to your doctor, IBD team or pharmacist if you have any concerns about medicines you are taking.

Other types of arthritis

You may get other types of arthritis if you have Crohn's or Colitis. They include:

- Osteoarthritis. This is the most common type of arthritis in the UK. It usually starts in people aged 45 or older. It's caused by damage to your joint over time. It most commonly affects the knees, hips, hands and back. Find out more about osteoarthritis from Arthritis UK.
- Rheumatoid arthritis. This is a form of arthritis caused by your immune system attacking your joints. It often starts in the joints of the hands and feet first, and gets worse over time. There is some evidence that people with Crohn's or Colitis may be more likely to have rheumatoid arthritis. But scientists are not sure why yet. Find out more about rheumatoid arthritis from Arthritis UK.
- Gout. This causes sudden, severe joint pain and swelling, often in the big toe. You might get it in other joints in your body too. It's caused by too much of a chemical called urate in your body. It's more common in men, women after

menopause and people with kidney disease. Find out more about gout from Arthritis UK.

Infection

Inflammation of a joint can be caused by bacterial infection. This is known as septic arthritis. It is rare but is a medical emergency.

Germs can enter a wound on your body and travel through your bloodstream to infect a joint. Your joint can also get infected directly, through an injury or during surgery.

You are at greater risk of infections if your joints are already damaged or you are taking immunosuppressant medicine to treat your Crohn's or Colitis. We have more information about **immunosuppressant precautions**.

Usually, a single joint is affected. Symptoms may include:

- Sudden pain
- The joint swelling or changing colour
- A high temperature

Get medical help immediately if you think you might have septic arthritis.

Find out more about septic arthritis from Arthritis UK.

HOW CAN I GET HELP FOR JOINT PROBLEMS?

Your IBD team may not always ask about joint problems. But it's important to tell them if you are experiencing pain or swelling in any of your joints, or any back pain. Getting a diagnosis of arthritis when you have Crohn's or Colitis can often take a very long time. This means that effective treatment may be delayed.

Some medicines for your Crohn's or Colitis may be better at treating joint symptoms than others. Letting your IBD team know early on about joint symptoms can help you to get the right diagnosis and treatment as soon as possible. This may help to prevent damage to your joints.

If you find it hard to get in contact with your IBD team, you can also book an appointment with your GP. Ask your GP or IBD team if they can refer you to a rheumatologist. A rheumatologist is a doctor who can diagnose and treat arthritis and related conditions.

Tests and checks for joint problems

When investigating joint problems, your doctor may:

- Ask about your symptoms, including which joint or joints are affected, and how bad any pain and stiffness are
- Ask about any other conditions that affect you or your immediate family
- Look at your joints to check for swelling, and to see how well you can move them
- Carry out blood tests to rule out other conditions and look for signs of inflammation
- Ask you to have a blood test for a gene called HLA-B27, which can be linked with spondyloarthritis
- Refer you for an X-ray, MRI or ultrasound scan on the affected joint

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WHAT TREATMENT CAN HELP WITH JOINT PROBLEMS IN CROHN'S AND COLITIS?

Medicines, exercise and physiotherapy can all help with joint problems.

If your joint problems are related to flare-ups in your gut , taking your usual medicines for Crohn's or Colitis should help. This is important even when you feel well. We have tips for remembering to take medicines in our information on **understanding** medicines for Crohn's and Colitis.

Any other treatment your doctor recommends will depend on several things, including:

- Which joint or joints are affected
- If there is inflammation in your joint and how severe it is, based on your symptoms and any tests or scans
- Whether or not your Crohn's or Colitis is under control
- If you also have symptoms affecting other parts of your body, such as your eyes or skin

Medicines they may suggest include the following.

- Non-Steroidal Anti-Inflammatory Drugs (NSAIDs), such as ibuprofen or naproxen. See our information about NSAIDs below.
- **Steroid** tablets, or if a single joint is affected, a steroid injection into the joint.
- If peripheral joints are affected, **methotrexate** or sulfasalazine. Sulfasalazine is a type of **5-ASA**.
- Anti-TNF medicines, including **adalimumab**, **golimumab** and **infliximab**.
- Sometimes, if other treatments have not helped, other **biologic or targeted medicines**.

You may need to try several different treatments until you find one that works for you.

Your IBD team should work together with a rheumatologist and any other healthcare professionals involved in your care. You may also be referred to a specialist physiotherapist. They can design a structured exercise programme to help with your symptoms.

If your treatment is not helping, speak to your IBD team about other things you could try.

> "I found a course on Pain Management at my local hospital extremely effective in helping me be kinder to myself and to understand the way I have to live in order to minimise my aches and pains."
>
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Non-Steroidal Anti-Inflammatory Drugs (NSAIDs) in Crohn's and Colitis

NSAIDs include ibuprofen, diclofenac and naproxen. Some evidence suggests NSAIDs can make Crohn's or Colitis symptoms worse. This could be more likely if your condition is active, or you take NSAIDs for a long time. But it's difficult to know for sure. Because of this, your doctor may only recommend taking NSAIDs if your gut symptoms are under control. They are likely to advise only taking a low dose for a short time.

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NSAID gels and creams have a much lower risk of causing side effects in your gut than NSAID tablets or capsules. This is because only a very small amount is absorbed into your blood. If you try NSAID gels and creams for joint pain, you should still use the lowest dose you can. This should never be more than the maximum dose stated on the packet. This will help to keep the risk of side effects as low as possible.

If you need any advice about taking NSAIDs when you have Crohn's or Colitis, talk to your GP, pharmacist or IBD team.

You can find out more about painkillers for Crohn's and Colitis in our information on **other treatments.**

WHAT ELSE CAN I DO TO MANAGE MY JOINT PROBLEMS?

Living with joint problems when you have Crohn's or Colitis can be really difficult. But sometimes, small changes can help to make things more manageable. Here, we list things you can try that might help with symptoms or daily life.

Keeping active

Doing any form of movement or exercise might feel impossible when you're dealing with joint pain and stiffness. But doing what you can, when you can, may make a difference. Staying as active as you can may help with your joint symptoms in the long term. It may also help to boost your energy and mood.

If possible, try to build more activity into your daily life. For example, you might walk to the shops rather than drive. Other types of gentle exercise you could try include:

- Swimming

- Cycling
- Tai chi, Pilates and yoga
- Walking or jogging
- Gym-based exercises, like using exercise bikes or treadmills

It may take some time to find a type of exercise that works for you. Read more about exercising with arthritis from **Arthritis UK**. We also have more information on **being active with Crohn's or Colitis**.

Lifestyle changes

Making small, healthy lifestyle changes when you can may have a positive effect on your joint problems. As well as keeping active, this may include:

- Eating a healthy, balanced diet. There is no specific diet for arthritis. The most important thing is to aim for a balanced diet. We have more information on food for people with Crohn's or Colitis.
- Aiming to keep to a healthy weight. This will ease any strain on your joints. It may help to ease inflammation too. The NHS have more information about healthy weight.
- Stopping smoking, if you smoke. Smoking may worsen symptoms of axial spondyloarthritis and lead to more damage to your joints. We have more information about **smoking** and Crohn's and Colitis, including getting help to stop.

Managing fatigue

Fatigue is very common in Crohn's and Colitis. But it can also be an effect of joint problems, especially spondyloarthritis. Fatigue is very different from being tired. You may feel extreme mental and physical exhaustion that does not go away after rest or sleep. It can affect people differently.

There are several things you can do to manage fatigue. Find out more in:

- Our information on **fatigue**
- **Managing fatigue**, from Arthritis UK

Taking care of your mental health

Coping with a long-term condition like Crohn's or Colitis can have a big impact on your mental health. Joint problems can add to this, especially if they are causing you pain and limiting what you can do.

Taking some small steps to look after your mental health can make all the difference. It's also important to know when, and how, to get help. You can find out more on this in:

- Our information on **mental health and wellbeing**
- **Mental health and arthritis**, from Arthritis UK

Support and benefits

You may be able to claim certain benefits if joint problems are having an impact on:

- Your everyday tasks
- Your ability to get around
- Your ability to work

Other Crohn's or Colitis symptoms may also mean you can claim benefits. But joint problems can often be a major factor in this.

Certain disability benefits may also make you eligible for a **Blue Badge**. This allows people with severe problems in getting around to park closer to their destinations.

We have lots of helpful information on getting benefits and support, including:

- **Disability and sickness benefits**
- **Claiming Personal Independence Payment (PIP)**
- Getting a blue badge in our information on **travelling with Crohn's or Colitis**

Getting the help you need at work

Living with joint problems, as well as other Crohn's or Colitis symptoms, may mean you need more support at work. For some people, it can mean being unable to work at all. Under UK law, employers have a duty to make reasonable adjustments for employees that are considered to have a disability. Depending on exactly how they affect you, joint problems may count as a disability.

Examples of reasonable adjustments may include:

- Starting later in the day if your joint problems are worse in the morning
- Supports or aids that may make desk-based work more comfortable, such as a back rest, wrist rest or foot support
- Specialist equipment to support with tasks
- Working from home when possible, if travel is difficult

Find out more in our guides for **employees** and **employers**.

RESOURCES WE TRUST

- Arthritis UK
  The UK's leading arthritis charity, providing support for people with arthritis.
  Helpline: 0800 5200 520
  arthritis-uk.org
- National Axial Spondyloarthritis Society
  UK charity providing support, advice and information for people with axial

spondyloarthritis.
Helpline: 020 8741 1515
nass.co.uk

- NHS – arthritis
  Information from the NHS website for England on different types of arthritis.
  nhs.uk/conditions/arthritis

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

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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**.

HOW TO HELP OTHERS LIVING WITH CROHN'S OR COLITIS

We want to make a difference to people affected by Crohn's or Colitis. But we can't do that without help.

If you want to support others in our community, here are some ways you can get involved:

- Volunteering: If you'd like to volunteer, we have a range of ways you can get involved. Find out more about our **volunteering roles**.
- Campaigning: None of our award-winning campaigns would be possible without our amazing community of dedicated campaigners. Your voice really does matter. Find out more about **joining our Campaigner Network**.
- Fundraising: Every pound you give helps power our life-changing work. Together we'll create bold campaigns, fund pioneering research, and give vital support when people need it most. Find out about ways to **fundraise**.
- Research: Research aims to improve the lives of people living with Crohn's or Colitis. One day, it may even find a cure. But good quality research can only happen when people with Crohn's or Colitis are involved. Find out about ways **you can be involved in future research**.
- Share your story. We hear from people every day who rely on the Crohn's and Colitis community for help and support. Why not **share your story** to help others feel seen or inspired?

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 do not 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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