
Appointment guide

Appointments for Crohn's or Colitis can sometimes feel overwhelming. It doesn't matter whether it's your first appointment, or if you've been attending appointments for years. This information can help you get the most out of your appointments. It will help you think about:

- What you want to get out of each appointment
- What you should ask
- What your doctor or nurse will want to know
- How you can make sure you're being listened to
- What you can do if you're unhappy with the care you've received

This guide is for anyone who wants to make the most of their appointments. We hope that it is helpful for you. This information focuses on hospital appointments. Our information on [how to get a diagnosis](#) can help support you with GP appointments. If you're currently being diagnosed [what's up with my gut](#) may also be useful to you.

This resource brings together experience from people living with Crohn's and Colitis, alongside information from healthcare professionals and our helpline team.

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Key points to make the most of your appointment

Before your appointment

- Find out who your appointment is with.
- Make sure you've had any necessary tests.
- Write a summary of your Crohn's or Colitis journey.
- Write a list of questions or problems that are currently troubling you.
- Think about which words best describe any symptoms you're having.

On the day of your appointment

- Take someone with you, if you think it may be helpful.
- Know what to expect, including whether it's an in person or telephone appointment.
- Familiarise yourself with medical language your healthcare professional might use.
- Communicate confidently and effectively.
- Make sure you know what the plan is, when your next appointment will be, and who to contact in the meantime.

After your appointment

- Arrange a second opinion if you need one.

- **Know how to raise concerns if you're unhappy with the care you received.**

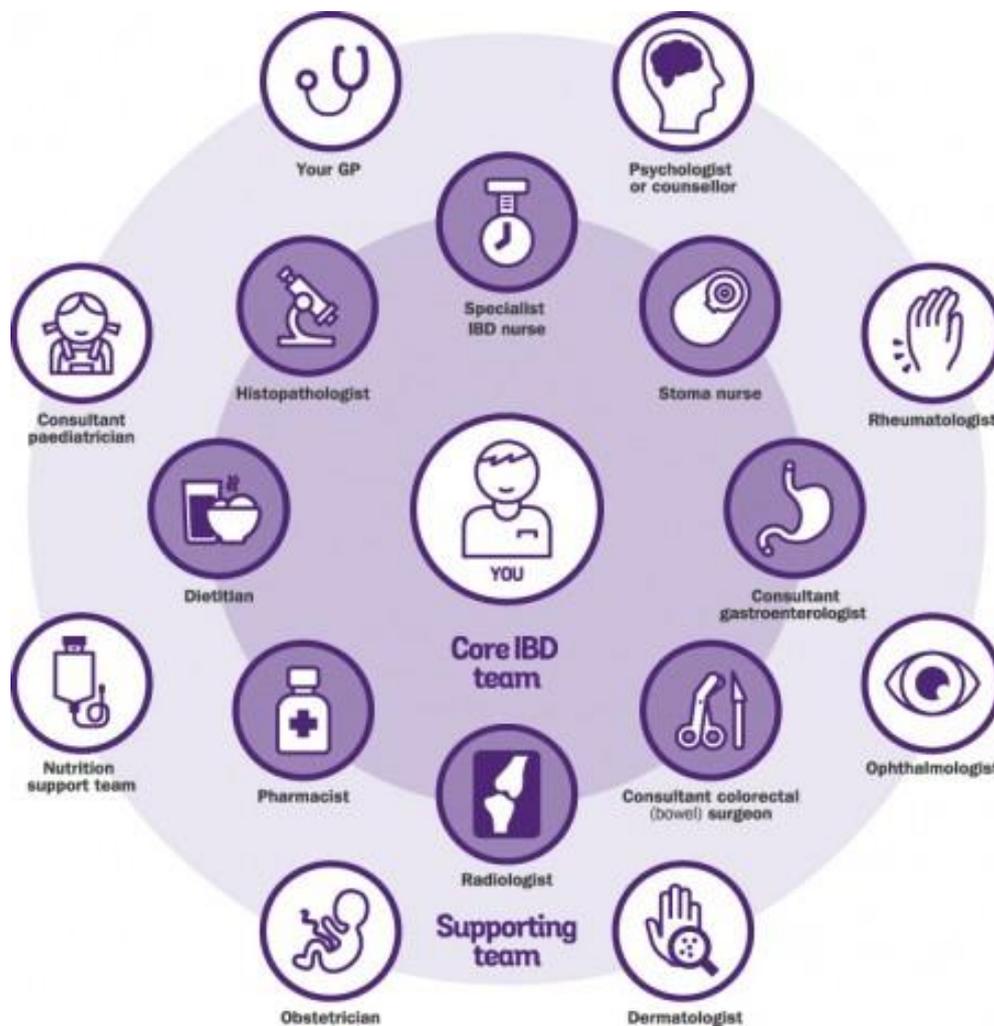
Some groups of people may face extra challenges in their appointments. Our information on [transitioning to adult care](#) has further information.

It takes guts to speak up for yourself. But being clear about your needs is the best way to get the most out of your appointments.

Understanding your Inflammatory Bowel Disease (IBD) team

Your Inflammatory Bowel Disease (IBD) team may be made up of lots of different people. Everyone's team will look different. It can be useful to keep a note of your team to remind you of who everyone is. Some of the people that may make up your IBD team include:

- **Your GP.** Your GP may be able to provide blood tests, tests on your poo, and prescriptions. They organise your referrals and take a general approach to your health.
- **Your IBD nurse.** Your IBD nurse will help communicate with your wider IBD team. They can support you in your care plan and offer practical and emotional support. IBD nurses can also help manage medicines and some investigations. Not all hospitals will have IBD nurses.
- **Your consultant gastroenterologist.** Gastroenterologists are doctors who specialise in the gut. A named gastroenterologist should lead your care. They are responsible for the overall management of your condition.



Your IBD team may include gastroenterology specialist registrars. Specialist registrars are doctors training in a certain specialty who are not yet consultants. Specialist registrars have been doctors for at least five years, if not a lot longer. Specialist registrars often work alongside consultants to see patients in clinic.

There may be other healthcare professionals who can help you reach a specific goal. This may include help with nutrition or mental health. Ask your IBD team about referrals to other specialists.

Your Crohn's or Colitis journey

When it comes to your Crohn's or Colitis journey, you're the expert. After all, you're the only person who has been there every step of the way. A lot may have happened during your Crohn's or Colitis journey. Particularly if you were diagnosed a long time ago. It can be useful for you to have a summary of the key points in your diagnosis and treatment. You can use this summary at your appointments. This will help healthcare professionals understand everything that has happened. This is particularly useful as you may not see the same doctor at every consultation. It can be useful for your summary to cover:

- Your diagnosis
- When you were diagnosed
- Which parts of your gut your condition affects
- Any other conditions you have
- Any surgeries you've had
- Medicines you're taking now
- Medicines you've tried, including when and why they were stopped
- Allergies to medicines
- Any recent tests you've had

It can also be useful to tell your healthcare professional about:

- The symptoms you experience
- Things that make your symptoms worse
- What helps you in a flare-up
- What is normal for you
- How your condition affects you
- What your goals are

This can make sure they understand more about you and your needs to help work towards the same outcomes.

Deciding what you want to talk about

It can be hard to talk about everything you want to in an appointment. Think about any specific problems you want to address. Make a note of these problems and write them in order of how important they are. This can help you make the most of your appointment. Think about what you're hoping to get out of the appointment and what will help you achieve this. You might want to ask your healthcare professional some of the following questions:

About your condition

- Why do you think this is Crohn's or Colitis?
- Which parts of my gut are affected?
- How does this affect how the condition is treated?
- Are there any reasons why you think I may have a more difficult time in the future?
- What can I do to lower my risk of a flare-up?
- How do I know if I'm in remission? (Remission is a period of good health, free of active disease, with few or no symptoms.)
- How do I know if I'm having a flare-up?
- Who do I contact when I'm having a flare-up?
- How might Crohn's or Colitis affect me in the future?
- Will this affect my ability to have children?
- Might my children also develop the condition?

About available support

- What support is there in my local area?
- Are there any patient education sessions?

Crohn's & Colitis UK provides lots of support. Check out our [Local Networks](#) and [Virtual Social Events](#) for more.

About your lifestyle

- Would it help my condition if I made some changes to my lifestyle, such as giving up smoking or changing my diet?
- Will I be able to work full-time?
- Will I still be able to exercise?

About medicines

- Why have you decided to offer me this medicine?
- What are the benefits and risks of this medicine?
- How will it help me?
- How long will it take to have an effect?
- What will happen if I do not take this medicine?
- How will I take this medicine?
- Are there any other options if I have a needle phobia?
- What effect will this medicine have on my symptoms and everyday life?
- Are there any different treatment options?
- Is it safe to get pregnant on this medicine?
- Is it safe to breastfeed on this medicine?
- Are there any long-term effects of having this medicine?
- Do I need regular blood tests when taking this medicine and why?
- Do I need any other medicines or supplements while taking this medicine?
- How might steroids affect my bones?
- Do I need any vaccinations?

About medicine side effects

- Are there any potential side effects with this medicine?
- What should I do if I get any side effects?
- Who should I contact if I get any side effects?
- What monitoring do I need to look for side effects?

Our information on [Treatments](#) has more on medicines used for Crohn's and Colitis.

About surgery

- How will having surgery help me?
- What would happen if I chose not to have surgery?
- What are the risks associated with this surgery?
- What will the surgery involve?
- What improvements can I expect?
- Could I have more information about living with a stoma?
- How long will I need to stay in hospital after the surgery?
- Could I talk to someone who has had the surgery?
- Is there any information on the surgeon who will be doing the operation?
- How long will it be before I can get back to my usual activities?
- Will this surgery affect my daily life?
- Will this affect my sex life?
- Will surgery affect future fertility or how a baby might be delivered?

See [surgery for Crohn's](#) and [surgery for Colitis](#) for more information on surgery.

You might want to go one step further and guess what the answers to your questions may be. This might help you think about further questions you may want to ask in response to these answers.

“Make a list of questions, make a list of symptoms and frequency and take pictures if needed!”

Tom
Living with Crohn's

Arranging tests

Sometimes your IBD team might ask for you to have tests before your appointment. These could include blood tests or tests on your poo. Tests on your poo might include faecal calprotectin tests or stool cultures. Make sure to arrange these in good time so your IBD team can see the results before your appointment. Sometimes you will need to arrange these tests with your GP. Other times these tests will be done by a monitoring clinic at your hospital. What happens will depend on where you live, so make sure to check with your IBD team if you're unsure.

Sometimes different computer systems are used in hospitals compared to GP surgeries. This can mean that if you've had tests organised by your GP, your hospital team may be unable to see the results. If possible, it can help to come to your appointment with a copy of any recent tests that your GP has done. It can also be useful to know when your GP has prescribed you medicines, like steroids.

Take someone with you

Even with lots of preparation, going to appointments can sometimes be overwhelming. It can be difficult to remember what was said or what actions were going to be taken. To help with this, you might want to take someone along with you. This person can provide support, as well as help you remember what was said. You might want to ask them to take notes for you. This can help you focus on talking to your healthcare professional.

Thinking of questions to ask while trying to understand something you've been told can be hard. Having someone else who can help ask questions can be useful, but some

people may not like this. It's important to set boundaries with the person who is coming to your appointment. Let them know what you'd like help with and if there's anything you are uncomfortable with.

What to expect on the day

When you arrive at the hospital, you'll have to make your way to the department where your appointment is. Once you arrive, you'll need to check in and take a seat in the waiting room. You might find that you must wait longer than you thought. Take something along to keep you busy while you wait. Hospital WiFi can sometimes be unreliable, so take something that does not need a WiFi connection.

Hopefully, you will know who you're seeing before you attend your appointment. This information should be in your appointment letter. But sometimes there might be last-minute changes. You might be expecting to see your consultant but instead, see a specialist registrar. See Understanding your IBD team for more information on who they are.

Appointment times vary from hospital to hospital. But, depending on what your appointment is about, it will probably be 15 to 30 minutes long. First appointments tend to be longer than follow-up appointments.

Each appointment you have is different. But there might be a similar structure. Areas often covered include:

- Background information, such as talking about symptoms and previous medicines
- Current situation, such as how you're feeling at the moment and what, if anything, is working
- Creating a plan going forwards

Telephone and video appointments

Your appointment may be in person, or it may be a telephone or video appointment. Some people prefer telephone or video appointments. These appointments can be easier to fit in around other commitments, like work, and you do not need to travel. Other people may find telephone or video appointments frustrating. This is because they want to be seen in person or know that their issue needs a face-to-face review.

“You never quite know when the phone is going to ring, and you might be in the middle of doing something else when it does, so you need to be able to focus and get in the right mindset quickly.”

Richard
Living with Colitis

Here are some top tips on how to make the most of telephone appointments:

- Ensure your phone is on and nearby to accept the call.
- Make sure you're in a place with good mobile phone reception.
- Try to be in a quiet place. If in an office or other area where you need time to get to a private location, answer the call and explain this.
- Have a list of your current medicines. This includes medicines for Crohn's or Colitis, anything else you've been prescribed, and any over-the-counter or recreational drugs.
- Have a list of questions ready beforehand.
- Write down any issues you've had since your last appointment.

“You might also need to be a bit more assertive, as the healthcare professional won't be able to see your body language so will be relying entirely on what you say to understand how you are and what you need.”

Richard
Living with Colitis

Describing your symptoms

It can be hard to explain how you're feeling to someone else. You might find it difficult to find the right words or struggle to be open and honest. Describing your symptoms is important. It helps your healthcare professional understand what you're going through. This section looks at words and scales to help you talk about poo, pain, and fatigue. Our [Talking toolkit](#) can also help you find the words to explain how you're feeling, whoever you're talking to.

Talking about poo

The Bristol Stool Chart can be a useful way to talk about poo. It can help you describe the shape and texture of your poo.

 **Poo chart** – Bristol Stool Chart, your health professionals will be familiar with this.

	Type 1	Separate hard lumps	Severe constipation
	Type 2	Lumpy and sausage like	Mild constipation
	Type 3	A sausage shape with cracks in the surface	Normal
	Type 4	Like a smooth, soft sausage or snake	Normal
	Type 5	Soft blobs with clear-cut edges	Lacking Fibre
	Type 6	Mushy consistency with ragged edges	Mild diarrhoea
	Type 7	Liquid consistency with no solid pieces	Severe diarrhoea

It can also be useful to tell your healthcare professional about:

- How often you go to the toilet
- How urgently you need to go to the toilet
- Mucus in the poo
- Blood in the poo

Talking about pain

Everyone feels pain differently. Pain scales can help your healthcare professional understand how bad your pain is.

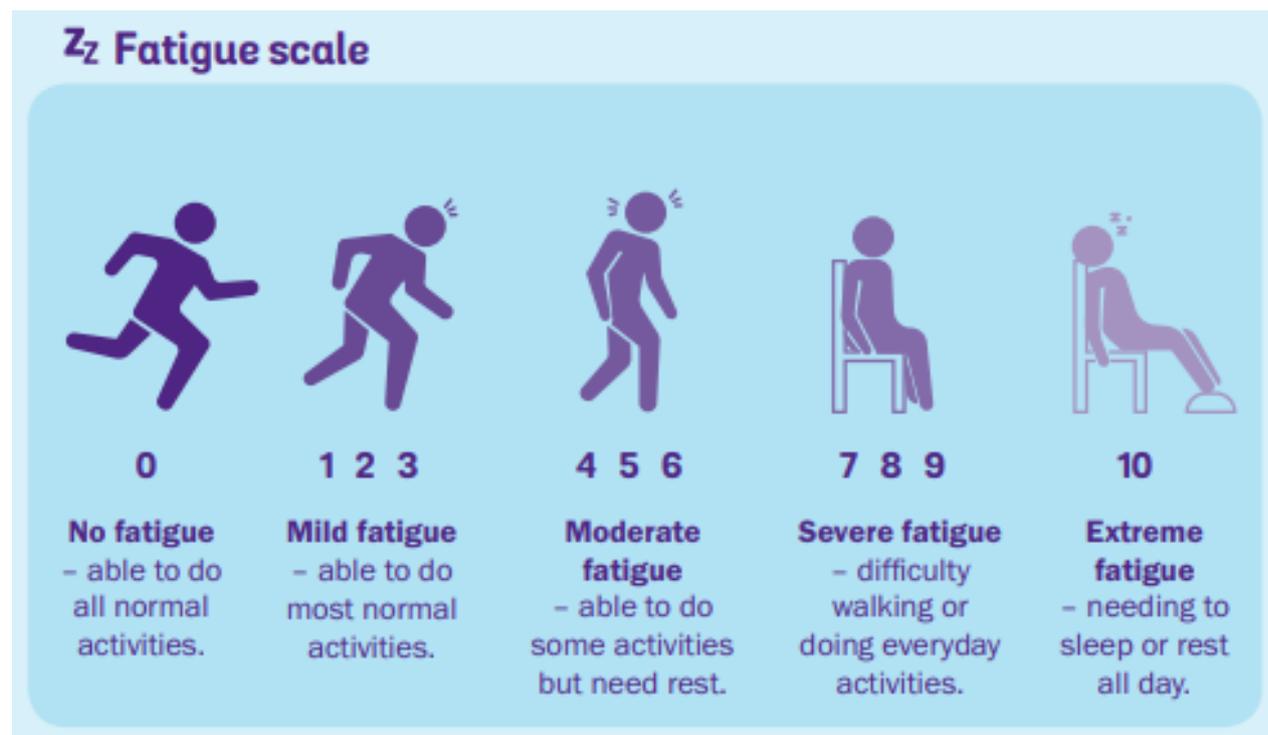


Pain can be very difficult to describe. Some of these words might be useful to help describe your pain:

- Aching
- Biting
- Blunt
- Burning
- Sharp
- Stabbing

Talking about fatigue

Like pain, fatigue can be difficult to describe. It can help to think about how fatigue affects your everyday activities.



You might find it helpful to describe fatigue as:

- Brain fog
- A big black hole
- Being woozy
- Heaviness
- Feeling shattered
- Extreme exhaustion

Talking about mental health

Living with Crohn's or Colitis can trigger lots of different feelings and emotions. It's important to tell your IBD team how you're doing mentally, as well as physically. Speak to

your GP or IBD team if you're finding things hard and feel you need help with your mental health.

Read our information on [Mental health and wellbeing](#) for more.

Understanding medical language

There are lots of complex words that can be used when talking about Crohn's and Colitis. Your healthcare professional should try and explain things clearly. But you might find they use words that you're unsure of. Here are some words your healthcare professional might say and what they mean. If you hear a word you do not understand, make sure you ask what it is. Our page on [Medical Terms](#) has more information.

Diarrhoea	Going to the toilet a lot, with loose or watery poo
Chronic condition	Lifelong, ongoing condition
Fatigue	Extreme tiredness
Relapse, flare-up, active disease	When you feel unwell
Remission, inactive disease	When you feel better
Ulcerated	To have sore wounds called ulcers
Opening bowels	Poo, bowel movement, stool, faeces
Personalised care	You have choice and control over the way your care is planned and delivered

What to do if you feel you're not being listened to

Sometimes you might feel like your healthcare professional is not listening to you. This can be upsetting and frustrating. It's important to remember that while they are an expert, you're also an expert. You're the expert when it comes to your experience of Crohn's or Colitis.

Being able to speak up for yourself can be useful in making sure your voice is heard. This requires knowledge, communication skills, and being able to assert yourself.

Knowledge

We have lots of information to help you find out more about Crohn's and Colitis. If you know what you want to talk about it can help to read up on that area. See [All information about Crohn's and Colitis](#) for more.

Communication skills

Communication is key to a successful appointment. But some people may find this difficult, especially when under pressure.

You could try using phrases like:

- “Can you help me understand...”
- “So, you mean...” and repeat back what you've understood

Communication is not just about talking. Sometimes pictures can help you and your healthcare professional understand each other. See if your healthcare professional can draw a diagram to help show things like:

- Where your Crohn's or Colitis is most active
- What will happen in a surgical procedure
- How and when to take your medicines, such as the best way to insert an enema

If you need a translator to help you communicate, let your IBD team know. They should be able to arrange for a translator to be present in the appointment.

“Don't be afraid to say how you are feeling, it's important to us if it's important to you. We need to

hear what your main concerns are so we can address these.”

Bridgette
IBD nurse

Being assertive

Be assertive if you feel like you're not being listened to. Being assertive means saying what you want in a respectful way. If you find it difficult to be assertive, try and imagine someone you know who is assertive and what they would say. You might find that taking someone along to your appointment also helps.

It takes guts to speak up for yourself. But being clear about your needs is the best way to get the most out of your appointments. Do not be afraid to ask questions about what matters to you. Your feelings and symptoms are valid and can have a huge impact on your life. It's important to not let what you're going through be dismissed.

The care you should receive

Crohn's and Colitis are long-term conditions that need specialised care. It's important that the healthcare professionals who look after you provide a certain level of care. The IBD standards give guidance on the quality of care you should expect to receive. These standards were created to ensure care is the same throughout the UK. They help healthcare services identify strengths and areas for improvement. The IBD standards have been created by IBD UK. IBD UK is a group of organisations who work together for everyone affected by Inflammatory Bowel Disease. Crohn's & Colitis UK is part of IBD UK. Visit [IBD UK](#) to find out more.

Arranging follow up

Before you leave your appointment, check that you know what will happen next. You might find it useful to ask the following questions:

- What should I do if I have a flare-up?
- What should I do if I have an urgent problem?
- How long will it take for a new medicine to start working and what side effects should I look out for?
- When will I get my test results?
- How long will it take for my referral to come through?
- Where can I find out more information?
- Who can I contact for help? What are their full contact details?
- Is my next appointment in person, or a telephone appointment?

At your appointment, your healthcare professional might suggest a new medicine. Sometimes this medicine can only be provided and monitored by your hospital team. Other times this may be monitored by your GP. Make sure you know who to follow up with for any monitoring or questions.

We've created a [template](#) that you can print off to write down your follow-up plan. You can also ask your IBD team to send you a copy of your clinic letter. This can act as a reminder of what was discussed and what the next steps are.

When you receive a date for your next appointment, try setting a reminder on your phone a week before. This will help give you time to prepare any questions in advance.

Some people might not have frequent appointments with their IBD team. Instead, they may be placed on Patient Initiated Follow-Up, known as PIFU. When someone is placed on PIFU, they can arrange an appointment as and when they need to. Being placed on PIFU does not mean you have been discharged. It means you oversee arranging your next appointment.

You might find your health or symptoms change between appointments. IBD nurse advice lines can be useful for accessing help between appointments.

IBD nurse advice lines are not an emergency service. Most advice lines do not run outside of office hours.

You may also be able to contact your consultant via their secretary, should you need to. You could try contacting your consultant's secretary by calling the hospital switchboard. Switchboard is the main hospital telephone number. Other contact details might be on clinic letters or in clinic information booklets.

Getting a second opinion

Following an appointment, you may want to get a second opinion. You have no legal right to request a second opinion. But the General Medical Council (GMC) states doctors must respect a patient's right to ask for a second opinion. The GMC is the independent regulator of doctors. They focus on making sure doctors provide good and safe patient care. Most healthcare professionals will consider your request for a second opinion.

In England and Wales, your GP will need to make a new referral if you would like a second opinion from a different IBD service. In Scotland, you should ask your consultant to arrange a second opinion. If they do not agree your GP may be able to help.

Getting a second opinion can take a long time. It will depend on how long the waiting list for the hospital is.

Our [interactive map](#) can help you find other IBD services who could provide a second opinion. Not all IBD services are listed on this map. Your GP can also provide advice on the location of other nearby services.

Making a complaint

Sometimes you might be unhappy with the care or treatment you receive. In these situations, it's important to report this, so things can change. Where possible, try and discuss your concerns directly with the team involved. Sometimes this is not possible, or you may feel uncomfortable doing so. In these situations, Patient Advice and Liaison Services (PALS) can help. Our information on [How to get a diagnosis](#) has more information on how to make a complaint. [Citizens Advice](#) has advice on what to do if you've been discriminated against.

Other organisations

IBD Standards

<https://ibduk.org/ibd-standards>

Citizens Advice

<https://www.citizensadvice.org.uk/>

Help and support from Crohn's & Colitis UK

We're here for you whenever you need us. Our award-winning information on Crohn's Disease, Ulcerative Colitis, and other forms of Inflammatory Bowel Disease have the information you need to help you manage your condition.

We have information on a wide range of topics, from individual medicines to coping with symptoms and concerns about relationships and employment. We'll help you find answers, access support and take control.

All information is available on our website: crohnsandcolitis.org.uk/information

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

Our team can:

- Help you understand more about Crohn's and Colitis, diagnosis and treatment options
- Provide information to help you live well with your condition
- Help you understand and access disability benefits
- Be there to listen if you need someone to talk to
- Help you to find support from others living with the condition

Call us on 0300 222 5700 or email helpline@crohnsandcolitis.org.uk.

See our website for LiveChat: 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.

Help with toilet access when out

Members of Crohn's & Colitis UK get benefits including a Can't Wait Card and a RADAR key to unlock accessible toilets. This card shows that you have a medical condition and will help when you need urgent access to the toilet when you are out. See crohnsandcolitis.org.uk/membership for more information or call the Membership Team on 01727 734465.

Crohn's & Colitis UK information is research-based and produced with patients, medical advisers and other professionals. They are prepared as general information and are not intended to replace advice from your own doctor or other professional. We do not endorse any products mentioned.

About Crohn's & Colitis UK

We are Crohn's & Colitis UK, a national charity fighting for improved lives today – and a world free from Crohn's and Colitis tomorrow. To improve diagnosis and treatment, and to fund research into a cure; to raise awareness and to give people hope, comfort and

confidence to live freer, fuller lives. We're here for everyone affected by Crohn's and Colitis.

This information is available for free thanks to the generosity of our supporters and members. Find out how you can join the fight against Crohn's and Colitis: call **01727 734465** or visit crohnsandcolitis.org.uk.

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We hope that you've found this information helpful. You can email the Knowledge and Information Team at evidence@crohnsandcolitis.org.uk if:

- You have any comments or suggestions for improvements
- You would like more information about the research on which the information is based
- You would like details of any conflicts of interest

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

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Patient Information Forum