Newly diagnosed with Crohn's or Colitis

Hearing you have <u>Crohn's Disease</u>, <u>Ulcerative Colitis</u> or <u>Microscopic Colitis</u> can be overwhelming, but there's lots of support out there. Life will change, but it can also improve. And we're here to help, every step of the way. Our practical to-do list will help you get started. As well as the words 'Crohn's' and 'Colitis', you may also hear the term 'IBD' a lot. This stands for Inflammatory Bowel Disease. Crohn's Disease and Ulcerative Colitis are the two main forms of IBD.

If you think you might have Crohn's or Colitis but haven't had this confirmed yet, see our information on <u>How to get a diagnosis</u>.

If you're a child or young person with Crohn's or Colitis, see <u>JJ's tips on coping with</u> <u>Crohn's or Colitis.</u>

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Key facts about being newly diagnosed with Crohn's or Colitis

- It's natural to have lots of questions about how your condition will affect you. We have the information you need to find support, get answers, and take control.
- Go through this list at your own pace and select the things you think would work for you.
- You're not alone. There are lots of ways to connect with people who understand what you're going through.
- Find out if your hospital has IBD nurses and how to contact them. They are there to help if you have questions in between your appointments.
- There's a lot for you to process with a new diagnosis and we're here to help, every step of the way. Once you feel ready, there are plenty of ways you can get involved with the huge and diverse Crohn's and Colitis community.

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 <u>www.crohnsandcolitis.org.uk/supportemails</u>.



1. Look after yourself

- Take your time there's a lot to get your head around. Go through this list at your own pace and select the things you think would work for you.
- Finding out you have a long-term condition can trigger lots of different feelings and emotions. Almost half of people living with Crohn's or Colitis say it has affected their mental health. Our <u>Mental health and wellbeing</u> information can help you understand the ways your condition may affect you emotionally, and has tips on looking after yourself.
- You may find that what you eat affects your symptoms. But it's different for everybody. And there's no evidence that following a particular diet can cure Crohn's or Colitis. See our information on <u>Food</u> for how to eat well with Crohn's or Colitis and make informed choices about your diet.
- If you feel more tired than usual, you are not alone. Fatigue is a common symptom in people living with Crohn's or Colitis. Remember that it's OK to take time for yourself. Watch our video below for top tips on coping with <u>Fatigue</u>.



2. Stay informed

- It's natural to have lots of questions about how your condition will affect you. We have the information you need to find support, get answers, and take control.
- Start with <u>All about Crohn's and Colitis</u> an easy to read introduction to what the conditions are. It's also available in <u>Gujarati</u>, <u>Bengali</u>, <u>Punjabi</u>, <u>Urdu</u>, <u>Welsh</u> and <u>Polish</u>.
- You might also find it helpful to read our more detailed information on your condition: <u>Crohn's Disease</u>, <u>Ulcerative Colitis</u> or <u>Microscopic Colitis</u>.
- Living with Crohn's or Colitis can have its challenges. But you can still get the most out of life. We can help you with information on <u>coping with symptoms</u> and other <u>everyday issues</u>.
- You'll be hearing lots of new words now that you have a Crohn's or Colitis diagnosis. Our <u>A-Z of medical terms</u> will help you understand all the new terminology.
- You can contact our <u>Helpline</u> by <u>email</u>, telephone or you can use our <u>LiveChat</u> service to talk to someone about any aspect of living with your condition.



3. When you're ready, let others know

- It Takes Guts to talk about Crohn's and Colitis, but we've got the words to help you break the ice. Create your own personalised <u>talking toolkit</u> and start your conversation today.
- Our information on <u>Employment</u> has tips on informing your boss and colleagues about how your condition may affect you.
- Your friends and family may find our information on <u>how to support someone with</u> <u>Crohn's or Colitis</u> helpful in understanding what you're going through. They can also take part in our immersive <u>In My Shoes app</u>, which allows anyone to experience 24 hours of what it's like to live with Crohn's or Colitis.



4. Know what to expect from your care

- Find out if your hospital has IBD nurses and how to contact them. They are there if you have questions in between your appointments. Use <u>our map</u> to search for your local specialist IBD service and see how to contact their advice line.
- Make sure you tell your GP about your diagnosis, and where you'll be receiving your IBD care.
- Our <u>Appointment guide</u> can help you get the most out of your time with health professionals, and focus on what matters to you.
- You'll have had different medical tests to help doctors diagnose your condition.
 The same tests help your IBD team check (monitor) your health and find the best treatment for you. Find out more in our information on <u>Tests and investigations</u>.
- You deserve the best quality of care. We've set out what good Crohn's and Colitis care should look like in the <u>IBD Standards</u>, which has a section for the <u>newly</u> <u>diagnosis</u>.

5. Know your treatment options

- There are many different medicines used to treat Crohn's and Colitis, and it may take some time to find the one that works for you. We have detailed information on <u>common medicines used to treat Crohn's and Colitis</u>.
- Making decisions on your treatments can be hard. Our information on <u>Taking</u> medicines looks at things to consider when choosing which medicine to take.
- Although it may sound scary, surgery is an important treatment option for some people. See our information on <u>Surgery for Ulcerative Colitis</u> and <u>Surgery for</u> <u>Crohn's Disease</u> – including videos on the common types of surgery used to treat these conditions.

It is really important to not lose hope when medicines are not working. There will be a plan and the IBD team will keep trying options.

Anonymous Living with Colitis

6. Get connected with the Crohn's and Colitis community

You're not alone. There are lots of ways to connect with people who understand what you're going through.

- Follow us on <u>Facebook</u>, <u>Twitter</u>, <u>Instagram</u>, <u>YouTube</u>, <u>LinkedIn</u> and <u>TikTok</u>- we share personal stories of other people living with Crohn's and Colitis. We also have a <u>closed-group community on Facebook</u> for everyone affected by Crohn's or Colitis to share experiences.
- <u>Become a member</u>. Join our community of almost 50,000 people affected by Crohn's and Colitis. As a member you'll receive a <u>Can't Wait Card</u> and <u>Radar Key</u> to help with toilet access, as well as member-exclusive updates.



- Join a <u>virtual social event</u> with others affected by Crohn's or Colitis across the UK. The events are a chance to chat, share experiences and potentially learn from others.
- Connect with people in your area who are affected by Crohn's and Colitis. We have 47 <u>Local Networks</u> across the UK bringing local people together and raising awareness. <u>Find your Local Network</u>.
- Sign up to the <u>Crohn's & Colitis UK newsletter</u> to hear about the amazing things we're achieving together.
- Share your story we're always looking for people who are willing to share experiences which help us provide support and representation to everyone affected by Crohn's and Colitis.
- Hear from ordinary people with Crohn's and Colitis who have overcome extraordinary challenges in <u>Unstoppable: stories of living with Crohn's and</u> <u>Colitis</u>.



7. Find out about financial support

- If you normally pay for your prescriptions, it may work out cheaper to purchase a **prescription prepayment certificate** now you have Crohn's or Colitis. This will cover all your NHS prescriptions, no matter how many items you need.
- Some people can get money off their water bill. And other people may be eligible for grants. Find out about these and other sources of financial support in our <u>Finances</u> information.
- You may be eligible for welfare benefits, such as <u>PIP (Personal Independence</u> <u>Payment).</u> See our information on <u>welfare benefits</u> to find out about the disability benefits that are available in your nation.

8. Look to the future

There's a lot for you to process with a new diagnosis – and we're here to help, every step of the way. Once you feel ready, there are plenty of ways you can get involved with the huge and diverse Crohn's and Colitis community. You could give your voice to our <u>campaigns</u>, participate in ground-breaking <u>research opportunities</u>, <u>volunteer</u> your time, <u>improve your health services</u> and <u>help us raise vital funds</u>.

Together, we give each other comfort, confidence and strength. Together, we are unstoppable.

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; this is just what you've gone through, and if you embrace it, everything becomes a lot easier.

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Living with Crohn's

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: <u>facebook.com/groups/CCUKforum.</u>

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 <u>crohnsandcolitis.org.uk/membership</u> 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 <u>crohnsandcolitis.org.uk</u>.

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