Black communities and health inequalities

This information is designed to support Black people affected by Crohn's or Colitis. It focuses on the Black experience, but people from different ethnic backgrounds may also find it useful. This information will help you to:

- Learn about health inequalities and how they can affect Black people with Crohn's or Colitis
- Understand how to access appointments and explain your needs to healthcare professionals
- Speak up and advocate for yourself and your experiences
- Find support services specific to Black people living with Crohn's or Colitis

If this information uses words you have not heard before our page on medical words can help provide an explanation.

This resource covers topics which some people might find upsetting or triggering. This includes racism in healthcare settings. For more on Crohn's & Colitis UK's commitment to anti-racism please see our commitment to anti-racism.

This information was informed by the Caribbean & African Health Network (CAHN), Black people living with Crohn's or Colitis, and Black healthcare professionals. We would like to thank Kohlrabi, CAHN and all our volunteers for their help in producing this resource.

Contents

Key facts

- **Health inequalities are the differences in the health and wellbeing of people. Health inequalities can happen due to unfair and avoidable reasons.**
- **Black people living with Crohn's or Colitis can experience health inequalities.**
- **Understanding your rights and speaking up for yourself is important. It can help you get the care you need and deserve.**
- **Everyone's experience of Crohn's or Colitis is different. Finding a supportive community can help you cope with the challenges of Crohn's or Colitis.**

Health inequalities in Crohn's and Colitis

Health inequalities exist and are common in Crohn's and Colitis.

Health inequalities are differences in the health and wellbeing of people. Health inequalities can happen due to unfair and avoidable reasons. They can be affected by factors like:

- Gender
- Ethnicity
- Disability
- Education levels
- How much money you have
- Where you live

Crohn's and Colitis are lifelong conditions. This means the effect of health inequalities can add up over time.

Ethnicity is not the only factor that might affect your experience with Crohn's or Colitis. You might find some of our other resources helpful:

- LGBTQIA+ health with Crohn's or Colitis
- Growing order with Crohn's or Colitis
- Children and young people

Black communities and Crohn's or Colitis

- **Black people might have similar experiences of Crohn's or Colitis compared to other ethnic backgrounds.**
- **But being Black might affect the care you receive. This can be due to stigma, stereotypes or racism.**
- **It's important to remember everyone's experience of Crohn's or Colitis is different.**

A lot of studies on Crohn's and Colitis do not collect data on ethnicity. This makes it difficult to understand exactly how ethnicity affects Crohn's or Colitis. A lot of the research which does look at ethnicity, comes from the US. It's hard to know if findings from the US would be the same in the UK. This is partly because access to healthcare is so different.

The following section looks at evidence that is relevant to the UK. It looks at what research is currently available. But you may find it does not cover everything you want to know. More UK research is needed before more information can be given.

Getting a diagnosis

Crohn's and Colitis used to be thought of as conditions that mainly affect people of European or Ashkenazi Jewish heritage. But, across the world, more Black people are being diagnosed. This might be to do with:

- Countries becoming industrialised.
- More people having Western European lifestyles.

A 2025 UK study found some people might be more likely to experience a delay in diagnosis. This included:

- Black people
- Women
- People over the age of 70
- People with other illnesses

This is important to recognise as delays in diagnosis increase the risk of having to stay in hospital, or needing surgery.

‘My GP thought I had Irritable Bowel Syndrome (IBS) so they prescribed over the counter medication, and referred me for a colonoscopy and blood tests. The tests returned with low inflammation markers, and images didn't show anything of concern. We did this dance many times over many, many months.’

Natalie's Story

If your symptoms are not taken seriously

It is important to talk about any health concerns you have with your GP. If your healthcare professional is not taking your symptoms seriously, you could try asking these questions:

- What do you think is causing my symptoms? Why do you think that diagnosis is most likely?
- What else could be causing my symptoms? Could it be Crohn’s or Colitis?
- What tests will help you find out what is causing my symptoms? Can I have these tests?
- When should I come back if my symptoms have not improved?

If you are not happy with the response, you can ask for a second opinion. This includes asking to see a different GP. If you’ve been referred to hospital, it also includes asking to see a different specialist.

The website whatsupwithmygut explains what you should expect if you experience gut symptoms. Crohn's & Colitis UK were involved in the creation of whatsupwithmygut. The website was developed with other charities, people diagnosed with gut problems, and healthcare professionals.

See our information on getting a diagnosis for Crohn's or Colitis, for more support on:

- Getting referred to a gastroenterology team
- If you're not certain about your diagnosis

Medicines

This next section looks at medicines prescribed for confirmed Crohn's or Colitis.

There is a lack of research looking at how medicines for Crohn's or Colitis work in Black people. Many drug trials include lots of White people and very few people from other ethnic backgrounds. This makes it hard to know if different medicines work better for different people. The next section may help you ask questions to find the right medicine for you.

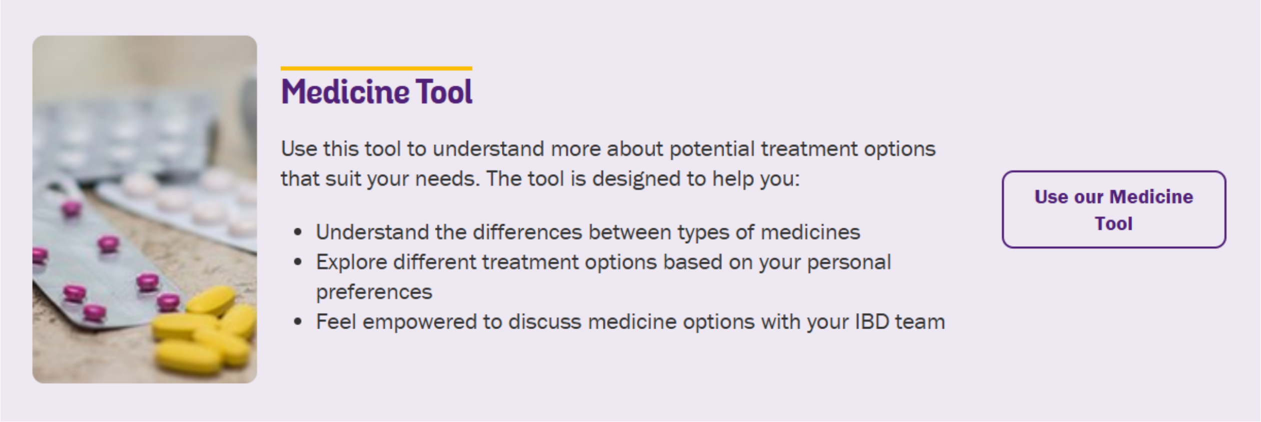
> **'I think it is important to remember that Crohn's and Colitis affect people of all races. Despite this, there is a widespread exclusion of minorities, and in particular the Black community, in research, literature, and publications.'**
>
> **Lori's story**

Finding the right medicine for you

It can take time to find the medicine that works for you. Finding the right medicine and taking it regularly is important. It helps reduce the risk of flare ups, needing to go to hospital, and needing surgery. Your Inflammatory Bowel Disease (IBD) team will help you find the right medicine. When you are talking about medicines it might be helpful to ask the following questions:

- Why have you decided to offer me this medicine?
- What are the benefits and risks of this medicine?
- Are there any different treatment options?
- Is there any research on how well this medicine works in Black people?

For more questions to ask see deciding what you want to talk about in our appointment guide. Our Medicine Tool can also help you understand the options available to you.



Medicine Tool

Use this tool to understand more about potential treatment options that suit your needs. The tool is designed to help you:

- Understand the differences between types of medicines
- Explore different treatment options based on your personal preferences
- Feel empowered to discuss medicine options with your IBD team

Surgery

Surgery for Crohn's Disease

A 2022 study found people of Asian, Black, or mixed heritage backgrounds were more likely to have surgery for Crohn's. People from these ethnic groups were also more likely to have certain complications of surgery. This included complications that needed medicines to treat them , like pneumonia or wound infections.

Surgery for Ulcerative Colitis

The same 2022 study found no link between ethnicity and surgery for Ulcerative Colitis.

If you need surgery

Having surgery can be a big step. It can help to talk to your IBD team about why surgery is being recommended. You could ask questions like:

- 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 would be different for me after surgery?

For more questions to ask see deciding what you want to talk about in our appointment guide.

It takes time to recover after surgery. If you're worried about anything you experience during your recovery, talk to your IBD team. This includes if you are in pain, or worried about any new symptoms.

Our information on surgery has more on what to expect before, during and after surgery.

Communicating with healthcare professionals

Some Black people might not have English as their first language. This can make it difficult to talk to and understand healthcare professionals. This difficulty in communication can lead to worse health outcomes.

Translation services

If you find it difficult to understand English, you have the right to ask for a translator. You can also ask if patient information is available in your first language.

If you need a translator for a GP appointment. Ask for a translator when you book your appointment.

If you need a translator for a hospital appointment. After you receive your appointment letter, contact the hospital to ask for a translator to be booked.

If you need a translator for NHS 111. If you live in England, Scotland or Wales, translation services are also available for NHS 111. For more information on how to access this, see:

- NHS 111 (England only)
- Using language translation services (Wales only)
- Access to 111 in other languages (Scotland only)

Accessing healthcare

- **Crohn's and Colitis are lifelong conditions which need specialised care.**
- **You might be able to get help with transport to your appointment.**
- **Everyone deserves high quality care, and the NHS does not stand for racism. If you experience unacceptable care, make sure to report it. Citizen's Advice has information on how to report discrimination.**

Getting the care you deserve

Crohn's and Colitis are lifelong conditions that need specialised care. The IBD Standards give guidance on the quality of care you should expect to receive. These Standards were created to make sure care is similar throughout the UK. They help healthcare services identify strengths and areas for improvement. Visit IBD UK to find out more.

If you are not familiar with the UK health system, Doctors of the World provide translated information on how the NHS works.

Transport to appointments

Sometimes, the hospital where you get treated for your Crohn's or Colitis can be far away. This can make getting to and from your appointment difficult. Family, friends or people from your community might be able to help you get to appointments.

Voluntary organisations

Age UK and the Royal Voluntary Service might also be able to help with transport. Go to Age UK or the Royal Voluntary Service to find out if there is support in your area and if they can help you.

Patient Transport Services

Some people might be able to get free transport organised by their hospital. This free transport is called Patient Transport Services (PTS). PTS is only for people who:

- Need additional medical support during their journey
- Find it difficult to walk
- Are parents or guardians of children who need to go to hospital

To find out if you can get PTS, talk to your GP or the person who referred you to hospital.

Claiming for hospital transport costs

You might be able to claim the cost of your transport through the Healthcare Travel Costs Scheme (HTCS). Click on the links to find out more about this service:

- England – NHS website
- Northern Ireland – NI Direct
- Wales – GOV.WALES
- Scotland – NHS Inform

Our information on finances has more on handling extra costs for people with Crohn's or Colitis.

Reporting racism and discrimination

Nobody should have to experience racism or other forms of discrimination. The NHS and other healthcare professional bodies have guidance on treating people fairly.

Sometimes though, you may receive unacceptable care. It's important to report this, if you feel able to.

Citizens Advice provide a step-by-step guide to reporting discrimination. This includes information on:

- Checking if what you experienced was discrimination
- Finding information to support your complaint
- Making a complaint
- Finding a mediator
- Taking legal action

Go to Citizens Advice for more information.

Making a complaint

If what you experienced was not discrimination, you can still make a complaint.

Making a complaint about your GP surgery

All NHS services must have a complaints procedure. You may be able to find this on your GP website. You could also speak to a receptionist about how to make a complaint.

Making a complaint about a hospital

If you want to raise an issue, it may help to contact the Patient Advice and Liaison Service (PALS). PALS can give free, confidential advice. They are there to help with concerns or problems you have when using NHS hospitals in England. They can help raise issues with the service to a senior level. Similar organisations exist in Wales, Scotland, and Northern Ireland.

You can find out more about how to make a complaint below:

- Making a complaint in England
- Making a complaint in Wales

- Making a complaint in Scotland
- Making a complaint in Northern Ireland

Our information on how to get a diagnosis contains more details on making a complaint.

Speaking up and self-advocacy

- Self-advocacy is speaking up for yourself, and the things important to you. It's about saying what you think and asking for what you want or need.
- Being able to speak up for yourself is important. But Black people with Crohn's or Colitis may face extra challenges. This means it's even more important their voices are heard.
- There are lots of situations where you might need to speak up for yourself. For example, during appointments, at work, or with friends and family.
- When you advocate for yourself, other people can better understand your needs. And when other people understand your needs, they can better support you.
- Speaking up for yourself is not always easy. Our Talking Toolkit can help you find the right words.

Speaking up and self-advocacy during appointments

Appointments for Crohn's or Colitis can sometimes feel overwhelming. But it is important to speak up and advocate for yourself. Here are some top tips on how to do this during appointments.

- **Come prepared.** Before you go to your appointment, make a note of what you want to talk about. Keep a diary of your symptoms. It can also help to have a summary of your Crohn's or Colitis journey, including any medicines you're taking.
- **Think about bringing someone with you.** Seeing a healthcare professional can be overwhelming. If you can, it might help to take someone along with you to your appointment.

- **Listen to your body.** Crohn's or Colitis are different for everyone, and you are the expert of your experience. Know what your personal triggers are and be ready to explain those to your IBD team.
- **Communicate clearly.** Say what you are worried about or need in a clear way. Our appointment guide has a section called 'deciding what you want to talk about'. This contains a list of key questions you might want to ask.
- **Let your IBD team know if you are in pain.** Racist stereotypes can mean the pain of Black people is not taken seriously. Let your IBD team know if you are in pain and ask what they can offer you.
- **Ask questions.** If something does not make sense, ask for it to be explained. You can also ask why your healthcare professional is recommending a certain plan.
- **Do not be afraid to ask for a second opinion.** If you are not happy with what you've been told, ask for a second opinion.
- **Stay informed.** We have lots of information to help you stay informed about symptoms, treatments and more.

Our appointment guide has more on how to speak up for yourself and make the most of your appointments.

Talking about Crohn's or Colitis with family and friends

'Being open about my condition tells others that I'm not ashamed of living with Crohn's and helps them feel comfortable enough to ask questions, which can reduce stigma and correct assumptions that surround Crohn's and Colitis.'

Hakeem's story

What is stigma?

Stigma is when people think badly about someone because of something they cannot control, like an illness or a difference.

Managing stigma

Research suggests some Black communities are not familiar with Crohn's or Colitis. Some people have told us that this makes it difficult to be able to talk about their condition. Talking about things can also be difficult due to the stigma associated with Crohn's and Colitis.

Finding the right words is not always easy. And sharing how you feel can be scary. But talking about your condition can help the people around you better support you.

Femi was diagnosed with Crohn's Disease when he was a teenager. In this video he talks about how he's managed to be more open about living with the condition with his friends.

Finding the right words: Meet Femi, living with Crohn's Disease

Talking about Crohn's or Colitis at work

Talking about Crohn's or Colitis at work can be uncomfortable. You do not have to tell your employer about your diagnosis. But some people find that telling their employer helps them feel better supported. If your employer knows about your Crohn's or Colitis, they can make changes to help you do your job. These changes as known as reasonable adjustments.

For more on reasonable adjustments and your legal rights, see our guide for employees.

> ‘Management needs to understand what’s going on so they can support you better, but you have to be comfortable before you start sharing it with others.’
>
> **Akua's story**

Talking about Crohn’s or Colitis at school

Crohn’s and Colitis can affect people of any age, including children. If you are looking for information on how to support a child, you might find our children, young adults and students information useful.

Tips for looking after yourself

- **Try and find a community who understand what you're going through. See the list of other organisations for support groups for Black people.**
- **Crohn's and Colitis can have a big impact on mental health. Mind has a list of organisations which can provide mental health support specific to Black communities.**
- **The Crohn's & Colitis UK Helpline can also help provide support and information, in the language of your choice.**

Top tips from our Crohn's & Colitis UK IBD nurses

Make sure you have regular check-ups, even when you have no symptoms. (Aldea, IBD nurse)

Try and talk about your diagnosis with people you feel comfortable with and trust. (Aldea, IBD nurse)

Think about traditional foods and whether they trigger your symptoms. You can continue to enjoy traditional foods, but it might be helpful to get support from a dietician to make some changes. (Aldea, IBD nurse)

Take your medicine every day, even when you are feeling well. This will ensure you remain well and avoid flares. (Bridgette, IBD nurse)

Remember the impact Crohn's or Colitis can have on mental health. Try and find out what support is available to you. (Aldea, IBD nurse)

Mental health and wellbeing

Looking after your mental health is a big part of living with Crohn's or Colitis. Around half of all people with Crohn's or Colitis say it has affected their mental health in some way.

Mental health difficulties can be viewed differently by different cultures. Some Black people find that physical illness is accepted more than mental health problems in their community.

Mind has a list of organisations which can provide mental health support specific to Black communities.

Our information on mental health and wellbeing has more on how to look after your mental health. It includes top tips for wellbeing and how to find support.

Finding support

Having a community who understand what you're going through is helpful for many people with Crohn's or Colitis. This support can come from lots of different places, including churches or mosques.

You might find the list of other organisations at the end of this information helpful.

Support from Crohn's & Colitis UK

Crohn's & Colitis UK have local networks of volunteers across the country. You can also connect with people online through our Facebook Forum or virtual social events.

Crohn's & Colitis UK Helpline

Our Helpline team provides up-to-date, evidence-based information. They can support you to live well with Crohn's or Colitis.

If you prefer to speak to our Helpline team in another language, interpreters are available. When you call the Helpline you'll hear a short recorded message. When the call is answered by our team say, in English, the language you would like to use.

Other organisations

Caribbean and African Health Network

https://www.cahn.org.uk/

Color of Gastrointestinal Illnesses (COGI) (A US organisation aiming to improve quality of life for global majority people affected by IBD)

https://colorofgi.org/

Mind – Racism and mental health (a list of organisations who can provide mental health support, with some offering tailored services to Black communities)

https://www.mind.org.uk/information-support/tips-for-everyday-living/racism-and-mental-health/useful-contacts/

Doctors of the World (provision of translated health information)

https://www.doctorsoftheworld.org.uk/translated-health-information/

Help and support from Crohn's & Colitis UK

We're here for you whenever you need us. Our award-winning 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 at crohnsandcolitis.org.uk/information.

Helpline service

Our Helpline team provides up-to-date, evidence-based information. They can support you to live well with Crohn's or Colitis.

Our Helpline team can help 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**. You can also visit crohnsandcolitis.org.uk/livechat for our LiveChat service. Lines are open 9am to 5pm, Monday to Friday, except English bank holidays.

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

Social events and Local Networks

You can find support from others in the Crohn's and Colitis community through our virtual social events. There may also be a Local Network in your area offering in-person social events. Visit crohnsandcolitis.org.uk/our-work/crohns-colitis-uk-in-your-area 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 at facebook.com/groups/CCUKforum.

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 crohnsandcolitis.org.uk/membership for more information. Or you can call the Membership Team on **01727 734465.**

About Crohn's & Colitis UK

Crohn's & Colitis UK is a national charity, leading the fight against Crohn's and Colitis. We're here for everyone affected by these conditions.

Our vision is to see improved lives today and a world free from Crohn's and Colitis tomorrow. We seek to improve diagnosis and treatment, fund research into a cure, raise awareness and give people hope and confidence to live freer, fuller lives.

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 crohnsandcolitis.org.uk.

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.

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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