

FAQs: Cut the Crap: Check for Crohn's or Colitis

1. Why have you created this campaign?

It is taking too long for people with Crohn's or Colitis to be diagnosed. A quarter wait more than a year for a diagnosis, and nearly a half will end up in A&E at least once before they start treatment. Left unchecked for too long, Crohn's and Colitis can be life threatening. People who experience the longest delays are four times more likely to have serious bowel complications and twice as likely to have surgery. Delays to diagnosis can happen at any point in a patient's journey from patients not seeking medical advice despite their symptoms to delays in primary and secondary care.

We know that too many people are ignoring the most common symptoms of Crohn's and Colitis, putting them down to everyday events such as "a dodgy tummy", "work or relationship anxiety", "too much partying". We also know that people can feel embarrassed, scared or that they don't have the right words to describe their symptoms. Meaning they're likely to look elsewhere to self-diagnose, and unproven remedies found online are giving false hope and delaying seeking professional advice and diagnosis.

So this campaign has been created to remind people of the symptoms of Crohn's and Colitis and encourage them to get their symptoms checked by a medical professional.

2. What is the campaign trying to do?

Ultimately the campaign is trying to reduce the amount of time it takes for people experiencing symptoms of Crohn's and Colitis to be diagnosed. It is focussing on the reasons those with symptoms may delay seeking medical advice in the first instance. Therefore the campaign is looking to raise awareness of the symptoms, encourage people to listen to their bodies and recognise that something is wrong, and provide support to know when and how to talk to a medical professional.

We say "cut the crap" to all the excuses people tell themselves which delays checking their symptoms, and to all the unverified advice. We want to encourage everyone to stop ignoring the symptoms and use our symptom checker to provide guidance on whether they need to see their doctor.

3. Who is the campaign targeting?

Our research shows that young adults (aged 18-34) are the least likely group to get checked for Crohn's or Colitis. This is concerning because, while Crohn's or Colitis can develop at any age, recent epidemiology research commissioned by Crohn's & Colitis UK and conducted by University of Nottingham shows that nearly a third (32.5%) of people living with these conditions would be diagnosed before the age of 34.

A recent survey¹ we commissioned found that:

- Young adults are the group least likely to know about Crohn's or Colitis, and their symptoms

¹ Based on a survey of 10,000 people representative of the UK population. Conducted by Censuswide in June 2022.

- Compared to the general public, young adults are more likely to delay contacting a healthcare professional because they feel embarrassed, scared or because they don't have the right words to describe their symptoms.
- We also found that young adults living with potential symptoms of Crohn's or Colitis (such as frequent diarrhoea, stomach pain, urgent need to go or blood in poo) prefer to "self-diagnose" and follow unproven remedies found online rather than going to a GP.

We want to change that.

4. What do we mean when we say "cut the crap"?

We want people to stop ignoring the key signs of what can be a serious disease, stop making excuses for their symptoms, and get medical advice from reliable healthcare professional like a GP.

There is a misconception that you have to be severely or continuously ill to have Crohn's or Colitis. Many people, especially young adults, ignore symptoms such as diarrhoea, stomach pain, and even blood in poo because they do not have all the symptoms, or not all the time. We want people to stop being in denial about their symptoms, stop making excuses for their symptoms and to see a healthcare professional promptly.

Talking about our toilet habits is still taboo. It is not something we talk about in everyday conversations, and so when people get symptoms like diarrhoea or blood in stools, they are embarrassed to talk about it. Even to a GP. 1 in 6 young adults (aged 18-34) would not go to their GP because they are too embarrassed³. We want to break the taboo on poo.

Unproven remedies found online may be giving false hope to people and delaying them from seeking help. Many young adults self-diagnose medical conditions, assisted by online resources, or by recognising symptoms that a friend previously had. All instead of contacting their GP. In fact, 1 in 7 young adults say they would not speak to a GP, because they do not want to waste a healthcare professional's time.⁴ But self-diagnosis and following remedies promoted online will not help people with Crohn's and Colitis and may be potentially dangerous. The quicker someone is diagnosed the faster they can get treatment and the better their outcome.

We say "cut the crap" to all the excuses people make to delay checking their symptoms, and to all the unverified advice. Use our symptom checker to find out if you should see your GP.

5. What is the Symptom Checker?

The campaign features an online symptom checker, which was developed in partnership with GPs and clinicians. In less than 30 seconds, it can help you decide if you should speak to your GP about your symptoms.

In just six questions you can find out if the symptoms you're worried about are something you should contact your GP about. You'll know within 30 seconds what to do and what symptoms to discuss with your GP. You can receive a letter personalised with your symptoms to give to your GP - to help start the conversation.

³ Censuswide

⁴ Censuswide.

The symptom checker has been tested with people who have Crohn's and Colitis symptoms but who do not yet have a diagnosis, and with people who have a diagnosis of Crohn's or Colitis. It is based on clinical guidelines by the British Society for Gastroenterology and the National Institute for Health and Care Excellence (NICE).

Over 120,000 people have already used the symptom checker to see if they have symptoms of Crohn's or Colitis and should visit their GP.

6. How does the symptom checker use my data?

We will collect anonymous data from this symptom checker to monitor our earlier diagnosis campaign and help us make improvements, including data on symptoms, ages and ethnicity. If you give us your contact details, we will anonymise your data for monitoring purposes. More information on this will be provided before you give us any contact details. We will not use your contact details for marketing, unless you later opt in to this or have already opted in to this. Read our privacy policy [here](#). You can unsubscribe/opt-out of marketing at any time by emailing [HYPERLINK "mailto:supporters@crohnsandcolitis.org.uk"](mailto:supporters@crohnsandcolitis.org.uk)

7. I have opted in to receive an email, but I didn't receive it. What do I do?

Firstly, check your spam/junk folders. If you don't find the email there, try using the symptom checker again to resend the email. We don't store emails sent by the symptom checker, so we're unable to resend them.

If you still don't receive the email, it may be that your email provider is blocking the emails from the symptom checker. You could try using a different email address, if you have access to one.

Alternatively, you could make a copy of your results screen, which has your symptoms listed.

For desktop users - print the webpage. Or you could copy and paste the text into a Word document.

For mobile users - print the webpage. Or you could take a screenshot of your symptoms by pressing the power and volume down buttons at the same time. Or for an iPhone, press the power and volume up button at the same time. If this doesn't work, check the manufacturer instructions for your phone.

8. What else are you doing to address delays to diagnosis?

Delays to diagnosis can happen at any point in a patient's journey from patients not contacting their GP despite their symptoms, to delays in primary and secondary care.

We are working on a multi-year Early Diagnosis and Better Care programme to address challenges people face from first experiencing symptoms to the point they receive their diagnosis and treatment.

Our **policy campaign on Early diagnosis** aims to influence decision makers to reduce the burden of delayed diagnosis of Crohn's and Colitis on the patients and the NHS. The campaign's audience is politicians (across the four nations), and health leaders. The policy campaign will raise awareness of all the delays which occur as part of a person's diagnostic journey from first experiencing symptoms until they receive their diagnosis and treatment.

We ask politicians to take three actions:

- ✓ Back our public campaign and help people take control of their health.
- ✓ Support our call for a national diagnostic pathway for people with lower gastrointestinal symptoms.
- ✓ Prioritise endoscopies by patient need, to get people diagnosed and on a treatment plan, rather than on an operating table.

Find out more here: www.crohnsandcolitis.org.uk/earlydiagnosis

We are also working with healthcare professionals and health leaders to ensure that people with suspected Crohn's and Colitis are appropriately prioritised for diagnosis and receive the best possible treatment. Find out more here.

<https://crohnsandcolitis.org.uk/our-work/healthcare-professionals>