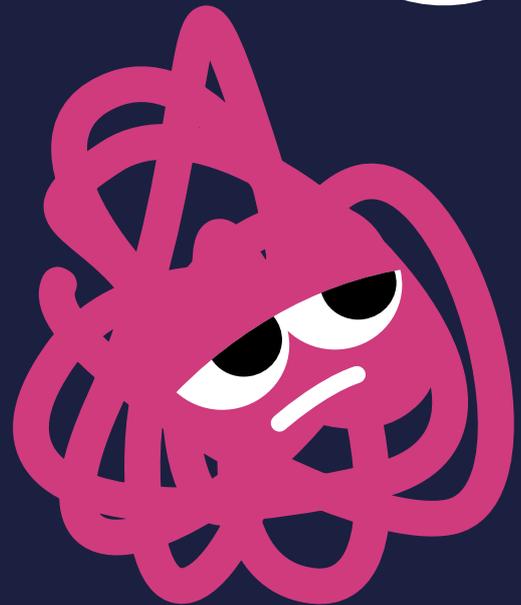


Supporting information for adults

We have created this information to guide and support you alongside your diagnosis journey.



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Understanding your symptoms

If you're having problems with your gut, then you may experience some of the symptoms below:

Changes in how you poo, including:

- How often you go
- How urgently you need to go
- Having accidents
- Straining when pooing
- Changes to the colour or consistency of your poo
- Stomach pain, cramps
- Feeling bloated
- Excessive wind
- Bleeding from your bottom or blood in your poo
- Mucus in your poo or your poo looks greasy
- Weight loss that isn't deliberate

These symptoms may sometimes be accompanied by:

- Not wanting to eat as much
- Feeling sick or being sick
- Feeling worse when eating
- Mouth ulcers
- Feeling extremely tired, also known as fatigue

There may be more symptoms that you experience, see the below sections on 'What could it be?' for symptoms that are more specific to certain conditions.

Talk to your GP if you experience any of the symptoms above. For some conditions, symptoms may go through a cycle of getting better and then worse. It's important not to put off speaking to your GP. Some symptoms may be worse than others, but whatever your symptoms are it's still important to discuss them with your GP.

Is your poo healthy?

It's important to know what healthy poo looks like. If you're not sure if your poo is healthy, you can find out more in our 'useful resources' below.

Symptoms in other parts of your body

Some conditions that affect your gut may also cause symptoms that affect other parts of your body. Tell your GP about any symptoms that you've been experiencing, whether you think they are related or not.

Keep a record

Keep a diary of the food you've eaten, your symptoms and if those symptoms change. This can help you notice if some foods make your symptoms worse and can help track if your symptoms become different. This diary might also help your GP or other healthcare professionals understand what's going on.

Talk to others

Some people might find it awkward or embarrassing to talk about their symptoms, but it's important to tell others what you're going through. This may be a partner, family member, trusted friend or your GP. Talking about your symptoms can help you feel less alone and can reduce stress. Having somebody you can turn to as you go through your diagnosis can be a real help.

Looking after your mental health

Your mental health is just as important as your physical health. Living with embarrassing and distressing symptoms can stir up lots of different feelings and emotions. Not knowing what might happen in the future may make you feel helpless or uncertain. Some people may not be able to go out and can feel isolated.

If you're struggling with your mental health, talk to a partner, friend, family member and your GP. They may be able to give you the support you need.

If you have thoughts of suicide or harming yourself you can:

- Tell someone you trust
- Call the NHS by dialling 111 and selecting the Mental Health Option
- Call the Samaritans - 116 123

If your life is in danger or you feel you're about to harm yourself:

- Call 999
- Go to your nearest A&E
- Ask someone else to call 999 for you or take you to A&E

Your GP appointment

Why book an appointment with your GP?

You should always speak to your GP if you have any symptoms that you're concerned about. Your GP will be able to help you find out what's going on. They are key to getting you a diagnosis. Some people may be embarrassed to talk about poo or their bottom. Others may be worried about what their GP might find. But it's important that you speak to your GP about your symptoms so that they can help find out how to make you feel better. Your GP will be used to hearing about these things and will want to know the details so they can help you.

When booking your appointment, talk to the receptionist or try to make it clear on an online booking system if you think your symptoms are urgent.

What will happen at your appointment?

Your GP will ask you questions about your symptoms and your health in general. This can help them understand what's going on and how you feel. They may examine your tummy to see if it's sore or painful. Depending on your symptoms, they may also check your bottom for piles (haemorrhoids).

If it makes you feel more comfortable, you can ask to see a doctor who's the same sex as you. You can also ask for a chaperone. This is someone who will be at your examination and is usually the same sex as you, will maintain confidentiality and does not know you.

How long have you had symptoms?

Your GP will ask how long you've been unwell. If it's been less than two weeks, your GP may think about possible causes, such as:

- Recent travel
- Changes in diet
- How much alcohol you drink
- Medicines you take
- Infections
- Symptoms during your period (if you have them)
- If you have other problems with your bottom

Other questions your GP may ask you

Your GP will need to gather lots of information to find out why you're unwell. They may ask you:

- What are your symptoms?
- Have you felt unwell in any other way?
- How severe are your symptoms?
- Have you noticed anything that makes them better or worse?
- Do your symptoms change?
- Do you have a family history of gut problems?
- Do you have any other health issues?
- What's your diet like?
- What's your general health like?

Questions you might want to ask your GP

- What could be causing my symptoms?
- What are the tests I need?
- How long will it take to get my test results and how will I receive them?
- What can I do to help me feel better?
- If I'm diagnosed with [name of condition your GP thinks it could be] – how is it treated?

If your GP thinks you should be referred for further investigations or to see a specialist, you could ask:

- How long might my referral take to come through?
- Is there anything I shouldn't do before I see a specialist?
- What can I do if I feel worse before I see a specialist?

Researching on the internet

It's natural for us to want quick answers to why we're unwell. Many of us turn to the internet or social media for advice. Sometimes it can be helpful but other times it can be incorrect, worrying or even dangerous. Sometimes, it can lead some people to think they have a certain condition when they may not. This can lead to unnecessary tests and stress.

It's important to try not to self-diagnose. Be wary of misleading information on the internet and social media. If you look for information, make sure that it's:

- From a reliable source (such as the NHS website or one of the links in the 'useful resources' section below)
- Is up-to-date
- Is relevant to you

What could it be?

To help you get a diagnosis, your GP may want to investigate whether you're affected by any of the conditions below. To do this they will need to know the symptoms you have and they may need to carry out some tests or recommend you have further investigations.

Inflammatory bowel disease (IBD)

- **What is it:** IBD is a group of conditions that include Crohn's disease, ulcerative colitis and, more rarely, microscopic colitis. In these conditions, the immune system is overactive, which can damage the gut lining. This causes inflammation and ulcers.
- **Signs:** You may experience some of the symptoms listed in the 'Your symptoms' section above. Everyone is different, but common signs of IBD include:
 - Diarrhoea
 - Stomach pain
 - Bleeding from your bottom
 - Unintentional weight loss
- **Other symptoms you may have:**
 - Needing to poo at night
 - Constipation
 - Fever
 - Problems with your skin
 - Issues in and around your mouth
 - Joint pain
 - Problems with your eyes
 - Issues around your bottom
- **Risk groups:**
 - Signs of IBD can start at any age, but usually begin between 18-35, with a second peak at 65 years or over.
 - A family history of IBD may increase your risk.
 - Having watery diarrhoea if you are over 50 and born a female may be a sign of microscopic colitis.

Coeliac disease

- **What is it:** Coeliac disease is an autoimmune condition. When someone with coeliac disease eats gluten, their immune system reacts and damages the gut, causing symptoms and the body can't properly absorb nutrients. Gluten is a type of protein found in wheat, barley and rye. You may find gluten in foods like bread, pasta, cereals, flour, cakes and biscuits.
- **Signs:** Symptoms may not be very specific. You may experience some of the symptoms listed in the 'Your symptoms' section above.

- **Other symptoms you may have:**

- Sometimes people with coeliac disease may have iron, vitamin B12 or folic acid deficiency anaemia. This will be determined by a blood test
- Red, raised patches, severe itching and blisters on the skin (dermatitis herpetiformis)
- Tooth enamel problems
- Weaker bones
- Unexplained fertility issues/repeated miscarriages
- Unexplained problems with coordination and speech
- Numbness or pain in your feet or hands
- Migraines

- **Risk groups:** Coeliac disease may be diagnosed at any age. You may be more likely to have coeliac disease if you have:

- A family history of it
- Down's syndrome
- Turner syndrome
- An autoimmune condition, such as type 1 diabetes or autoimmune thyroid disease.

Irritable bowel syndrome (IBS)

- **What is it:** Irritable bowel syndrome is the term used to describe a variety of gut-related symptoms.

- **Signs:** You may experience some of the symptoms listed in the 'Your symptoms' section above.

- **Other symptoms you may have:**

- Tummy pain or discomfort that feels better after having a poo
- There may be changes in how often you poo or what your poo looks like
- Tiredness
- Feeling sick
- Back pain
- Headache
- Bladder issues, such as needing to wee frequently

- **Risk groups:**

- If you're over 50 it is unusual to develop IBS

Cancer

If your GP wants to rule out cancer, they will follow specific guidelines depending on where you live and the type of cancer they're concerned about. If you would like to understand these guidelines, you can find a link in the 'useful resources' section below.

- Colon cancer - Your GP may ask you to provide a poo sample (stool sample) for testing if they're concerned about colon cancer. This test is not the same as other tests you may have on your poo, which look for signs of other gut problems.
- Ovarian cancer - Your GP may test your blood if they are concerned about ovarian cancer. This test is not the same as other tests you may have on your blood, which look for signs of other gut problems. Your GP may want to check for ovarian cancer if you're over 50 and have IBS-like symptoms. This is because it's unusual to develop IBS if you're over 50 years old.

Other conditions your GP may consider

- Bile acid malabsorption – this is a condition that causes more bile than normal to be released from the gall bladder into the colon. This can cause:
 - Diarrhoea during the day and sometimes at night
 - Bloating
 - Stomach pain
 - Poo may be an unusual colour (green, yellow or orange)
- Diverticulitis – this is an inflammation or infection in parts of your large bowel. This can cause:
 - Lower tummy pain
 - Bloating
 - Diarrhoea or constipation
 - Mucus or blood in your poo
- Small bowel bacterial overgrowth (SIBO) – this is too many bacteria in the small bowel. This can cause:
 - Bloating
 - Diarrhoea
 - Stomach pain
 - Feeling sick
- Problems with your pancreas
- Other bowel conditions

Tests and investigations

The symptoms of several gut conditions can sometimes be similar. To help understand what's going on, your GP will want to do some early investigations. These might include tests on your blood and poo.

Blood tests

Tell the doctor or nurse before your test if you are anxious about needles. They can help you feel as comfortable as possible and will be able to answer any questions.

A blood test may check for:

- How healthy your blood is and how much iron it contains
- Infection
- Inflammation
- Coeliac disease screening (IgA Tissue transglutaminase antibody) – You should carry on eating foods that contain gluten. You should eat some gluten in more than one meal every day for at least six weeks before testing. Cutting it out or reducing it before a test will affect your results
- How well your thyroid, kidneys and liver are working

Poo (stool) tests

For these tests, you'll need to collect a sample of your poo. Your doctor will give you a clean, dry screw-top container to put your sample in. They will let you know what to do with it. Advice on how to collect a poo sample can be found in the 'useful resources' section below.

These tests may check for:

- Infections
- Inflammation (called a faecal calprotectin test)
- Blood in your poo (called a faecal immunochemical test or FIT)

Being referred

Depending on the results of these tests you may be referred to a specialist doctor or nurse at a hospital or specialist clinic. They have expert knowledge of gut conditions and can perform specialist investigations, such as endoscopies (a doctor or specialist may insert a small camera through your mouth or bottom to look at your gut), scans or X-rays. If you have been referred through the NHS e-Referral Service, you may be able to choose which hospital you go to.

Referral waiting times

For some people, waiting times can be long. This may depend on where you live. Waiting a long time for a referral can be difficult, especially as some of your symptoms might worry you and impact your everyday life. It can be frustrating to not know how long you'll need to wait. Ask your GP how long it may be for you to get a referral. You may find average waiting times in your area in our 'useful resources' section. Contact your GP surgery if you have not heard from the hospital in this time. They may be able to follow up for you. Alternatively, your referral letter may have a telephone number on it that you could try. You could also try calling your hospital's Patient Advice and Liaison Service (PALS) directly to ask about waiting times.

Tell your GP if your symptoms get worse while you're waiting for an appointment. If you need urgent medical advice, call 111 or in an emergency, call 999.

Your diagnosis

It can sometimes take time to find the correct diagnosis. You may receive a diagnosis from your GP or a specialist you've seen. Once you've received your diagnosis, you will be advised about any medicines you need to take or changes in lifestyle or diet that can help you.

Sometimes, to get a diagnosis, your GP may need to:

- Consider if you have more than one gut problem at the same time
- Redo some of your tests to check the results are correct
- Consider other conditions, such as gynaecological, liver or kidney issues

Inflammatory bowel disease (IBD)

Your GP won't be able to give you a diagnosis on the tests that they can carry out. They will look for signs of inflammation and blood in your poo. If your results show that you have inflammation in your bowel or if you have blood in your poo, you will be referred to a specialist who can carry out further investigations. These investigations can help you get a diagnosis. You may need to have a non-urgent endoscopy at a hospital. This involves a small camera being inserted into your mouth or your bottom while you are sedated. This helps healthcare professionals to look at your gut. During an endoscopy, they may take a small tissue sample.

Coeliac disease

If your coeliac screening results are positive, or your GP thinks you may have coeliac disease, they will refer you to a gut specialist, known as a gastroenterologist, to confirm the diagnosis. To do this the specialist may need to take a small tissue sample called a biopsy. To take a biopsy, a small camera called an endoscope is passed through the mouth and into the small intestine. For adults, this will be done using either a numbing throat spray or while you are sedated. A sample of the gut lining is collected and checked to see if it shows damage to the gut lining, which is common in people with coeliac disease. In some cases, adults can be diagnosed based on a second blood test carried out by a specialist, without the need for a biopsy. You should continue eating gluten until all tests are complete and you receive a diagnosis.

Irritable bowel syndrome (IBS)

Your symptoms may be characteristic of IBS. Your GP may give you advice on changes to your lifestyle or diet and may refer you to a dietitian. Other tests may help rule out other causes, such as IBD or coeliac disease. If you are diagnosed with IBS, speak to your GP if your symptoms carry on or get worse despite treatment.

Being referred after your diagnosis

Even once you have a diagnosis, your GP may refer you if:

- Your tests are negative and your symptoms carry on despite treatment
- They're concerned about your symptoms. In some cases, you may be referred urgently
- They think you may have other health issues
- You have IBS and your symptoms are severe

If you disagree with your diagnosis

It's important to raise your concerns with your healthcare professional if you think your diagnosis is incorrect. They should be able to explain why you've been given your diagnosis and how your treatment was chosen. Your healthcare professional will tell you about the next steps.

It's okay to tell them you disagree with a diagnosis. It's important to trust your instincts but you should be able to explain why you don't think your diagnosis is correct.

Keep a record of your symptoms. This can help your healthcare professional understand why you think your diagnosis isn't right.

Your records could include:

- How often your symptoms affect you
- When you're affected the most
- How severe your symptoms are
- Whether they change over time
- A food diary. This can help you and your healthcare professional see if certain foods trigger your symptoms
- If anything makes your symptoms better or worse

Bring this record to future appointments.

Tell your healthcare professional if you become more unwell, are not improving in the expected timeframe or your medicines or treatments aren't helping.

Getting a second opinion

You could ask for a second opinion from a different GP or a different specialist if:

- You don't think that you're being offered any new investigations or treatments
- You don't think your concerns are being taken as seriously as you'd like

Your GP may be able to make a recommendation of who to see. If you want to, you can do your own research to find a particular hospital or specialist to be referred to. Your GP may not be able to refer you to your chosen specialist due to funding restrictions.

Making a complaint about your GP

If appropriate, you could talk to your healthcare professional and let them know about your problem or concern. If you're not comfortable doing this, you could speak to someone who isn't directly involved.

If you would like to make a more formal complaint, you should follow your GP practice's complaint procedure. You may be able to find this on their website or you could speak to a receptionist about how to make a complaint. You should make your complaint as soon as possible.

Useful resources

More about your symptoms

- [Diarrhoea \(NHS\)](#)
- [Constipation \(NHS\)](#)
- [Bloating and distension \(NHS\)](#)
- [Wind \(farting/flatulence\) \(NHS\)](#)
- [Fatigue \(NHS\)](#)
- [Bowel incontinence \(NHS\)](#)
- [Dermatitis herpetiformis \(Coeliac UK\)](#)
- [Polycystic ovary syndrome \(NHS\)](#)
- [Endometriosis \(NHS\)](#)
- [Menopause and perimenopause \(NHS\)](#)

Inflammatory bowel disease (IBD)

- [Crohn's disease \(Crohn's & Colitis UK\)](#)
- [Ulcerative colitis \(Crohn's & Colitis UK\)](#)
- [Microscopic colitis \(Crohn's & Colitis UK\)](#)
- [Crohn's & Colitis UK symptom checker](#)
- [Information if you're newly diagnosed with Crohn's or Colitis \(Crohn's & Colitis UK\)](#)

Coeliac disease

- [Coeliac disease \(Coeliac UK\)](#)
- [Coeliac UK's self-assessment \(Coeliac UK\)](#)
- [Support after a diagnosis of coeliac disease \(Coeliac UK\)](#)

Irritable bowel syndrome (IBS)

- [Irritable bowel syndrome \(Guts UK\)](#)
- [Changes to your diet if you live with IBS \(BDA\)](#)

Colorectal cancer

- [Bowel \(colon\) cancer \(Bowel Cancer UK\)](#)

Diagnostic pathways your GP may follow, depending on where you live:

- [England](#)
- [Scotland](#)
- [Wales](#)
- [Northern Ireland](#)

Ovarian cancer

- [Ovarian cancer \(Target Ovarian Cancer\)](#)

Diagnostic pathways your GP may follow, depending on where you live:

- [England](#)
- [Scotland](#)
- [Wales](#)
- [Northern Ireland](#)

Hypothyroidism

- [Underactive thyroid hypothyroidism](#)
- [Overactive thyroid hypothyroidism](#)

Other conditions

- [Bile acid malabsorption \(Guts UK\)](#)
- [Diverticular disease & diverticulitis \(Guts UK\)](#)
- [Problems with your pancreas \(Guts UK\)](#)

General resources

- Understanding what is healthy poo? [Poo-Torial \(Guts UK\)](#)
- [The Samaritans](#) (call 116 123)
- NHS information on hospital waiting times
 - [England](#)
 - [Wales](#)
 - [Scotland](#)
 - [Northern Ireland](#)
- [How to collect a stool sample \(NHS\)](#)

[whatsupwithmygut.org.uk](https://www.whatsupwithmygut.org.uk)

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