WHAT'S UP WITH MY Gut?

Supporting information for parents

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



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Understanding your child's symptoms

If your child is having problems with their gut, they may experience some of the symptoms below:

Changes in how they poo, including:

- How often they go
- How urgently they need to go
- Having accidents
- Straining when pooing
- Changes to the colour or consistency of their poo
- Stomach pain, cramps
- Feeling bloated
- Excessive wind
- Mucus in their poo or their poo looks greasy
- Weight loss, growth issues or delayed puberty

These symptoms may sometimes be accompanied by:

- Bleeding from their bottom or blood in their poo
- Not wanting to eat as much
- Feeling sick or being sick
- Feeling worse when eating or after eating
- Mouth ulcers
- Feeling extremely tired, also known as fatigue

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

Talk to your child's GP if your child experiences 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 the GP. Some symptoms may be worse than others, but whatever your child's symptoms are it's still important to discuss them with the GP.

Is your child's poo healthy?

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

Symptoms in other parts of your body

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

Keep a record

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

Talking to others

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

Mental health and emotional wellbeing

Mental health is just as important as physical health. Living with symptoms that can be distressing or embarrassing to talk about can stir up lots of different feelings and emotions.

If your child is struggling with their mental health, try to encourage them to talk to you, a friend, other family members or their GP, who may be able to give your child the support they need.

If you are concerned about your child's mental health, you can talk to the GP. If you need more urgent help, you can:

- Call the NHS by dialing 111 and selecting the Mental Health Option
- Call the Samaritans – 116 123

Your child's GP appointment

Why book an appointment with your GP?

You should always speak to the GP if your child has any symptoms that you're concerned about. The GP will be able to help you find out what's going on. They are key to getting your child a diagnosis. Some children 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 the GP about your child's symptoms so that they can help find out how to make them feel better.

When booking your appointment, if you think your child's symptoms are urgent, talk to the receptionist or try to make it clear on the online booking system that your child may need to be seen quickly.

What will happen at your appointment?

Your GP will ask your child questions about their symptoms and their health in general. This can help the GP understand what's going on and how your child feels. They may examine your child's tummy to see if it's sore or painful. Depending on your symptoms, they may also check your child's bottom.

How long have you had symptoms?

The GP will ask how long your child has been unwell. If it's been less than two weeks, the GP may think about possible causes, such as:

- Recent travel
- Changes in diet
- Medicines your child may take
- Infections
- Symptoms during your period (if you have them)

Other questions your GP may ask about your child

The GP will need to gather lots of information to find out why your child is unwell. They may ask:

- What are their symptoms?
- Have they felt unwell in any other way?
- How severe are their symptoms?
- If you or your child have noticed if anything makes symptoms better or worse?
- Do the symptoms change?
- Is there a family history of gut problems?
- Are there any other health issues?
- What's your child's diet like?
- What's your child's general health like?

Questions you might want to ask your GP

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

If your GP thinks your child 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 your child shouldn't do before they see a specialist?
- What can my child do if they feel worse before they see a specialist?

Researching on the internet

It's natural to want quick answers to why our children are 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 their children 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 our 'Useful resources' below)
- Is up-to-date
- Is relevant to your child and their age

What could it be?

To help your child get a diagnosis, the GP may want to investigate whether your child is affected by any of the conditions below. To do this they will need to know the symptoms your child has, and they may need to carry out some tests or recommend your child has 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:** Your child may experience some of the symptoms listed in the 'Understanding your child's symptoms' section above. Everyone is different, but common signs of IBD include:
  - Diarrhoea
  - Stomach pain
  - Bleeding from your bottom
  - Weight loss
- **Other symptoms your child may have:**
  - Looking pale
  - Pain or problems around their bottom
  - Needing to poo at night
  - Fever
  - Problems with their skin
  - Joint pain
  - Problems with their eyes
- **Risk groups:**
  - Uncommon in preschoolers
  - A family history of IBD may increase your child's risk.

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. Your child may experience some of the symptoms listed in the 'Understanding your child's symptoms' section above.

- **Other symptoms you may have:**
  - Looking pale
  - Tooth enamel problems
  - Issues with coordination
  - Numbness or pain in your feet or hands
- **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.

Other conditions your GP may consider

- Constipation with or without overflow diarrhoea
- Food intolerances or allergies
- Infections
- Functional symptoms including irritable bowel syndrom, also known as IBS or functional abdominal pain
- Other uncommon gut issues

Tests and investigations

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

Blood tests

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

A blood test may check for:

- How healthy your child's blood is and how much iron it contains
- Infection
- Inflammation
- Coeliac disease screening (IgA Tissue transglutaminase antibody) – Your child should carry on eating foods that contain gluten. They 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 their results
- How well their thyroid, kidneys and liver are working

Poo (stool) tests

For these tests, a sample of your child's poo will need to be collected. The doctor will give your child a clean, dry screw-top container to put the sample in. They will let you and your child 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)

Being referred

Depending on the results of these tests, your child 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 child's mouth or bottom to look at their gut), scans or X-rays. If your child has been referred through the NHS e-Referral Service, you or your child 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 symptoms might worry you and your child and impact their everyday life. It can be frustrating to not know how long your child will need to wait. Ask the GP how long it may take to get a referral. You may find average waiting times in your area in our 'useful resources' section.

Contact the GP surgery if your child has not heard from the hospital in this time. The GP may be able to follow up for you. Alternatively, your child's referral letter may have a telephone number on it that you could try. You could also try calling the hospital's Patient Advice and Liaison Service (PALS) directly to ask about waiting times.

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

Your child's diagnosis

It can sometimes take time to find the correct diagnosis. Your child may receive a diagnosis from the GP or a specialist your child has seen. Once your child has a diagnosis, they will be advised about any medicines they need to take or changes in lifestyle or diet that can help them.

Sometimes, to get a diagnosis, the GP may need to redo some tests to check the results are correct.

Inflammatory bowel disease (IBD)

The GP won't be able to confirm a diagnosis using the tests they can carry out themselves. The GP will look for signs of inflammation and blood in the poo. If your child's results show they have inflammation in their bowel or if they have blood in their poo, your child will be referred to a specialist who can carry out further investigations.

These investigations can help your child get a diagnosis. They may need to have an endoscopy at a hospital. This involves a small camera being inserted into their mouth or bottom while they are sedated or under general anaesthesia. This helps healthcare professionals to look at your child's gut. During an endoscopy, your child may have small tissue samples taken.

Coeliac disease

If coeliac screening results are positive, or the GP thinks your child may have coeliac disease, they will be referred to a specialist to confirm the diagnosis. This may involve a second blood test, or the specialist may need to take small tissue samples called biopsies. To take a biopsy, a small camera called an endoscope is passed through the mouth and into the small intestine while they are sedated or under general anaesthesia. This will be done in hospital. A sample of the gut lining is collected and checked to see if it shows damage, which is common in people with coeliac disease. Your child should continue eating gluten until all tests are complete and they receive a diagnosis.

The GP may investigate other conditions

If Coeliac disease and IBD have been considered, the GP may think about whether it could be another common gut condition.

Being referred after your diagnosis

Even once your child has a diagnosis, the GP may refer your child if:

- Tests are negative and symptoms carry on despite treatment
- They're concerned about the symptoms. In some cases, your child may be referred urgently
- They think your child may have other health issues

If you disagree with your diagnosis

It's important to raise your concerns with a healthcare professional if you think your child's diagnosis is incorrect. The healthcare professional should be able to explain why your child has been given their diagnosis and how their treatment was chosen. The 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 do not think your child's diagnosis is correct.

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

These records could include:

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

Bring this record to future appointments.

- Tell your healthcare professional:
- If your child becomes more unwell
- If your child is not improving in the expected timeframe
- If medicines or treatments aren't helping

Getting a second opinion

Most people don't need a second opinion, but if you're unhappy with your child's care then it allows you to speak to another GP or different specialist.

You may want to ask for a second opinion if:

- You don't think your child is being offered the investigations or treatments you think they need
- You don't think you or your child's concerns are being taken as seriously as you'd like

The 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. The GP may not be able to refer your child 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 the complaint procedure at the GP practice. 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)

Inflammatory bowel disease (IBD)

- Crohn's disease (Crohn's & Colitis UK)
- Ulcerative colitis (Crohn's & Colitis UK)
- Microscopic colitis (Crohn's & Colitis UK)
- Supporting a child with Crohn's or Colitis
- Crohn's & Colitis UK symptom checker
- Information if you're newly diagnosed with Crohn's or Colitis (Crohn's & Colitis UK)
- CICRA

Coeliac disease

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

Hypothyroidism

- Underactive thyroid hypothyroidism
- Overactive thyroid hypothyroidism

Other conditions

- Irritable bowel syndrome (Guts UK)
- Bile acid malabsorption (Guts UK)
- Functional Abdominal Pain (Evelina Hospital)
- Problems with your pancreas (Guts UK)

General resources

- Understanding what is healthy poo? Poo-Torial (Guts UK)
- NHS mental health support - dial 111 and select the Mental Health Option
- 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