

# All you need to know about

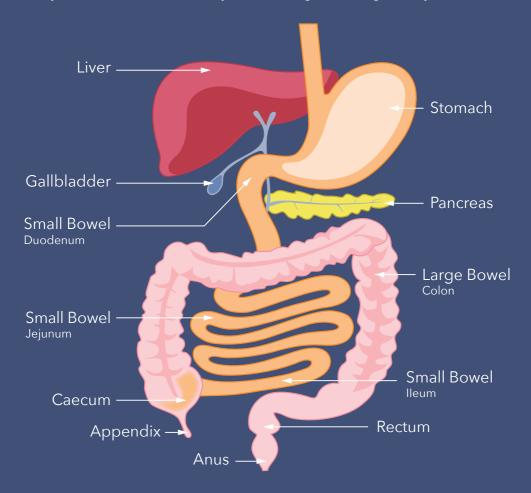


# IRRITABLE BOWEL SYNDROME (IBS)



### **Our Digestive System**

The Digestive System runs from the mouth to the anus and includes the stomach, the large and small bowels (intestines) and a number of accessory organs. The role of the digestive system is to turn food and liquid into the building blocks that the body needs to function effectively. See the image of the digestive system below.



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This booklet helps to explain the symptoms of irritable bowel syndrome (IBS) and what causes it. It will help you to identify when it is a problem needing your doctor to investigate it. The information also highlights what treatments are available to help reduce symptoms.

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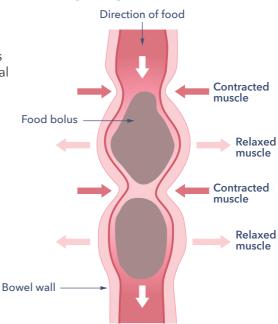
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### **Overview**

IBS is the one of the most common digestive disorders. It's defined by belly pain along with a change in bowel habits. Rates of people living with IBS vary between countries. IBS affects between 4 in 100 to 1 in 10 people of the global population. Twice as many women are diagnosed with IBS than men. A study of pelvic pain in transgender men and gender-diverse adults assigned female at birth found just over a third had IBS. Doctors can diagnose IBS at any stage of life. But the most common age of diagnosis is between 20 and 40 years old.

### How food (food bolus) moves along the gut

This diagram shows how poo is moved through the bowel by contractions of the muscles in the bowel wall. These normal gut contractions can cause pain in the bowel for people with IBS.



### What causes irritable bowel syndrome?

Doctors know IBS as a disorder involving the communication between the gut and the brain. Doctors call this a disorder of the gut brain interaction (DGBI). Nerves supply the gut and enable it to work correctly. In IBS there is a fault with this interaction, and this causes the symptoms. The nerves can be too sensitive to the way the bowel normally moves. This sensitivity causes pain. Doctors call this pain visceral hypersensitivity.

For some people a gut infection or antibiotic use can cause the condition to start. There is a tendency for IBS to run in families, but no gene for IBS has been found. But it's hard to separate genetics and the family environment. Changes in the microbes normally found in the gut have been linked to IBS. These changes may be due to the microbes' environment, for example diet and medicine side effects. A condition called endometriosis is linked to IBS. The nervous system, emotional state, the immune system, and gut microbes seem to interact. There may be groups of people with different causes of their IBS. More research is needed to find out the causes.

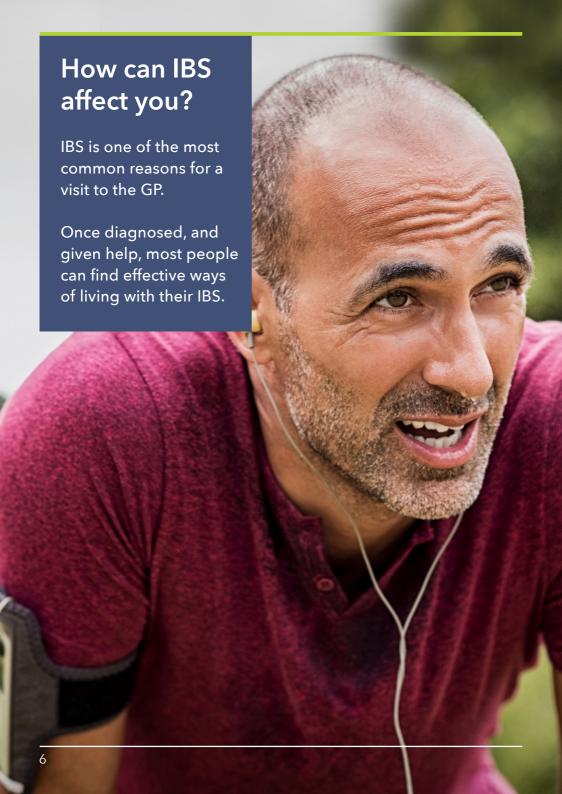
### How is irritable bowel syndrome diagnosed?

If you have symptoms, make an appointment with your doctor. The GP will review your symptoms. They will also do any tests needed to rule out other diseases. Don't be tempted to self-diagnose. Doctors use guidelines to help them to diagnose IBS. The pain happens for an average of one day per week or more for at least three months and is associated with a change in bowel habit. At times, bowel symptoms can be caused by drugs you might take for other conditions. It's worth discussing this with your doctor to see if a medicine switch can be made. Do not stop taking your medicine without talking to your doctor first.

There is no test used within the NHS for IBS diagnosis. The following blood tests might be used to rule out other problems:

- A check for anaemia. This is a low haemoglobin level in the blood, which can be caused by low iron levels. Anaemia is not a symptom of IBS. It could show other diseases.
- A check for how well the liver and kidneys are working.
- A check to see if there is inflammation in the gut. Doctors use a stool test called faecal calprotectin. If results are normal this can help show that the symptoms are not caused by Crohn's disease or ulcerative colitis. These are forms of inflammatory bowel disease.
- A check for coeliac disease. Do not alter your diet before testing, you need to be eating gluten to make sure the test can identify it.

After ruling out other conditions with these few simple tests, doctors can be confident the diagnosis is IBS. This then allows the person to try treatments to reduce the burden of symptoms.



### **Symptoms**

The most common symptoms of IBS include:

- Belly (abdominal) cramps. They can be uncomfortable or painful.
- Abnormal bowel habits. You could have diarrhoea, constipation, or both.
- Wind, bloating and distension (a widening around the middle of the belly).
- Mucus in your poo.

Other symptoms can include feeling tired and sick, backache, and bladder issues.

About 1 in 3 people have IBS-C, causing constipation symptoms. Another third of people have IBS-D, with diarrhoea symptoms. Others don't fall into a specific pattern (IBS-M). IBS-M abbreviation is used for people with both constipation and diarrhoea symptoms. Symptoms can occur daily, or they can come and go over weeks or months. They can alter over time and may not always be present. Bowel movements and stool frequency may vary. Symptoms often ease after a bowel movement. The unpredictability of symptoms can be challenging.

### Symptoms that may need further investigation

These symptoms are not typical of IBS. They may signal other diseases. If you have concerning symptoms, see your doctor as soon as possible. Do this even if you already have been diagnosed with IBS. Symptoms include a persistent change of bowel habit for 4 weeks or longer, especially if you:

- Are over the age of 40.
- Are passing blood from the back passage.
- Have unintentional weight loss of more than 2kg.
- Have diarrhoea waking you from sleep.
- Have a fever.

 Are diagnosed with anaemia (low haemoglobin levels in the blood diagnosed by your GP using a blood test.) Tell your doctor if you have a family history of bowel disease such as cancer, colitis or Crohn's disease.

### What treatment is available?

Once diagnosed, most people can find effective ways to live with IBS. Treatment may need to be altered according to the symptoms.

Regular exercise should be part of a healthy lifestyle. Aim to include some activity in your daily routine. If you can make some leisure time available, use it for activities that help you relax.

### Healthy eating habits

Some people find that following healthy eating habits helps.

### **IBS** dietary management

Over 8 in 10 people with IBS report food related symptoms. The recommendations may vary depending on whether you have constipation, diarrhoea, or both. If a diet is suspected of causing symptoms, your GP can advise on simple diet changes. These changes are based on the British Dietetic Association and the National Institute of Health and Care Excellence (NICE) guidelines. This includes eating three healthy meals every day. It also means limiting alcohol and caffeine intake. Eating small portions slowly can help with bloating.

Changing your fibre intake is good to try depending on the type of IBS you have. Some people with diarrhoea find reducing dietary fibre improves symptoms. Others with constipation may find a soluble fibre supplement helpful. Also, avoid eating fatty and spicy foods. If initial dietary changes do not help, the GP may refer you to a dietitian.

If you would like an more detailed information sheet on diet and IBs use the link: https://www.bda.uk.com/resource/irritable-bowel-syndrome-diet.html mail to:info@gutscharity.org.uk or call 020 7486 0341.

### Identifying trigger foods

If the simple advice doesn't help, quality standards of care say a trained practitioner should be involved. Only state-registered dietitians are trained to advise on exclusion diets. The dietitian will try to find any foods that cause IBS symptoms. They may remove certain foods from your diet. Then, they add them back slowly. This can identify which foods trigger symptoms.

A particular form of this diet is the low FODMAP diet. This diet excludes short-chain fermentable carbohydrates. These carbohydrates can be a cause of symptoms for some people. It works for about a half to two thirds of people with IBS. There is little evidence that a gluten-free diet may help with IBS symptoms. More research is needed in this area.

Do not try exclusion diets on your own, only do so if a dietitian recommends them. Unsupported use of low FODMAP internet sites and printed low FODMAP diet sheets should be avoided. If you have, or had, an eating disorder, exclusion diets may not be the best treatment for you. There are other treatment options to try instead.

### **Probiotics**

People with IBS can have different gut microbes than people without IBS. A few studies have suggested probiotics can help some people. Trying probiotic supplementation for up to 12 weeks is recommended. If you find no improvement in symptoms, stop using it. If you do have improvement, you should continue to take it. This is because there is little evidence that probiotics repopulate the bowels' own microbes. There is a cost associated with this treatment.

### **Medicines**

Simple lifestyle changes should be the first approach, for example, diet and exercise. If this approach is not effective, then medicines can be tried to improve symptoms. IBS is an individual condition so if one medicine is not helpful another could be tried.

**IBS with constipation** can be treated with laxatives. You can get them prescribed or buy them over the counter. The dose might need to be adjusted depending on their effect. **Guidelines recommend avoiding lactulose as this might make symptoms of wind worse.** Talk to a pharmacist about this if you are struggling to achieve the right dose for you. If laxatives available from your GP don't work, gastroenterologists can prescribe other options such as linaclotide.

For IBS with diarrhoea, loperamide can be used. This medicine increases gut transit times, slowing the passage of poo through the gut. It promotes water reabsorption in the body. Second line medicines are also available for people with IBS with diarrhoea if treatments available from your GP do not work. For example, ondansetron. Another option for people with diarrhoea are intestinal adsorbents. These are available over the counter as 'gels' for treatment of diarrhoea.

For abdominal pain and wind, medications to reduce bowel spasm can be used. These include mebeverine, alverine, and hyoscine butylbromide. Peppermint oil capsules may ease spasm type pain, but they can also worsen reflux in people who have both. Medicine called gut-brain neuromodulators act on the gut and brain. They reduce IBS symptoms in low doses. If simple measures have not helped, your GP might consider using a drug called amitriptyline. This can also help reduce sleep problems in people with IBS. You may know that this medicine can help people with depression in higher doses. But, for IBS, it works differently and is given at much lower doses. In people with IBS, this medicine improves signalling between the brain and the gut to help reduce IBS symptoms.

Ask your GP for a referral to a gastroenterologist if symptoms continue. New drugs are also being developed.

### **Gut-specific behavioural treatments**

If symptoms continue after 12 months of treatment, then a more holistic, rehabilitative approach with gut-specific behavioural therapies (otherwise known as brain-gut behavioural therapies) can be considered. These treatments are amongst the only treatments that have been shown to work when a person's symptoms have not responded to medical treatments. Unfortunately, these services can be difficult to access with long waiting times. Your GP can advise.

Gut-directed hypnotherapy has evidence that it can be helpful to treat IBS. The aim is to induce a deep relaxation to teach the person skills for self-management of IBS. You can get gut-directed hypnotherapy treatment from approved therapists. Therapists should be members of the British Association of Clinical and Academic Hypnotherapists or the National Council for Hypnotherapy. There may be a cost associated with this treatment.

Experts have also suggested using IBS-specific cognitive behavioural therapy (CBT) to treat IBS. It is a psychological based therapy based around a five-systems model. It proposes that thoughts, actions, and emotions all interact. This includes thoughts, behaviours, and bodily functions. CBT can reduce IBS symptoms. It does this by teaching the individual to relax the body and reduce symptoms. Your doctor can prescribe CBT.

Online platforms, and group interventions have been shown to be effective for both gut-specific CBT and gut-directed hypnotherapy. There are now also several emerging mobile applications (apps) which deliver self-directed CBT and gut-directed hypnotherapy skills training for IBS. There may be a cost associated with this treatment. Mobile brain-gut behavioural treatments such as these apps

may be effective for some people with IBS. If you are considering an app, please ask the organisation for their research evidence that it has been shown effective for people with IBS.

Those with more complicated IBS with severe symptoms may require a more personalised approach to treatment delivered by a therapist.





# How can I self-manage my irritable bowel syndrome?

Building a good doctor-patient relationship is key to managing IBS. Your doctor can help you with how to manage the condition and reduce symptoms. This partnership can help improve your quality of life. IBS is very individual, and you're the best person to know what may work for you. Try different treatments. They may not all work, but there are several to try. Sometimes, it might take a combination of them to work. According to NICE's quality standards, you can request a review. This enables newer treatments to be considered. A review is not provided automatically. You should ask your doctor (usually your GP).

For information and support:

Call our freephone Helpline on **0300 102 4887** (Monday to Friday, 10am to 2pm, excluding bank holidays).

Use our online form at www.gutscharity.org.uk/helpline https://gutscharity.org.uk/helpline/

Email us at helpline@gutscharity.org.uk.

If you would like a printed copy of this leaflet or wish to request a Can't Wait Card, which may help you to access toilet facilities, please email <a href="mailto:info@gutscharity.org.uk">info@gutscharity.org.uk</a> including your address or ring 020 7486 0341.

You could also purchase a RADAR key to access some locked toilets. These can be purchased for a small fee from several organisations.

### What to ask your doctor

These are some useful questions you can ask your doctor:

- Have I been fully checked for other bowel conditions?
- Are there any medications that would be useful for me to take?
- May I be referred to a dietitian?
- Can I have my IBS reviewed regularly?



### Research

### Guts UK's priority setting partnership (PSP) into IBS

PSPs aim to identify and prioritise the unanswered questions for certain medical conditions or areas of health.

PSPs bring together people with lived experience, carers, doctors, nurses, researchers, and other health professionals. They all have an equal voice. Together, they have decided the top ten research priorities for a health condition. These are listed below for IBS:

- Are all forms of IBS the same condition, or are there different types of IBS with different causes and needing different treatments?
- What causes bowel urgency (a sudden urgent need to go to the toilet) in people with IBS? How is this best treated and managed?
- What causes pain and/or gut hypersensitivity in people with IBS, including spasms and cramps? Are there better ways to treat and manage these?
- Could a better understanding of the gut-brain connection in IBS lead to the development of new treatments?
- Do hormonal changes during the menstrual cycle, pregnancy and menopause affect IBS symptoms? If yes, could this understanding lead to new treatments?
- How does mental health, particularly anxiety and depression, affect IBS?
- Do treatments for anxiety/depression reduce or stop IBS symptoms?
- Are there ways for people with IBS to improve sensitivity in the bowel and/or improve control of their bowels e.g. through training with biofeedback?
- How can a fast and accurate diagnostic test be developed for IBS? How can different types of IBS be diagnosed more reliably?
- What changes in diet benefit people with IBS? Which diet is best for the long-term?
- Are treatments which balance the gut bacteria effective for people with IBS, including faecal transplants? Which prebiotics and probiotics are most effective?

Research on IBS is carried out globally. A new registry called ContactME-IBS allows users to find out about IBS research and will also give users the opportunity to be matched to relevant IBS studies when they become available.

Register at www.contactme-ibs.co.uk for further information, call 0191 333 2812 or email info@contactme-ibs.co.uk.

## **Guts UK**

### The national charity for the digestive system

Our three main areas of work are

- information and support
- raising awareness and public education
- research with patient and public involvement and engagement (PPIE)

### It's time the UK got to grips with guts.

Guts UK provides information and support to people affected by digestive conditions and symptoms. We raise vital awareness about our guts and fund life-changing research into the digestive system. Our mission is a world where digestive conditions are better understood, better treated and everyone who lives with one gets the support they need.





### Get in touch

If you need information and support for digestive conditions or symptoms, please call our freephone Helpline on 0300 102 4887 (Monday to Friday, 10am to 2pm), use our online webform at www.gutscharity.org.uk/helpline or email helpline@gutscharity.org.uk.

For anything else, please call us on 0207 486 0341 or email info@gutscharity.org.uk.

For more information about Guts UK. visit our website www.gutscharity.org.uk.

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# 25FT ISA LOT OF GUTS: TO UNDERSTAND

Far too many of us ignore or shrug off what our gut is telling us. 58% of people are embarrassed to talk about their digestive condition or symptoms.

Guts UK exists to change that. We empower people to seek help.

# IT'S TIME THE UK GOT TO GRIPS WITH GUTS

**Support Guts UK today** 



www.gutscharity.org.uk

### **Donation Form**

I would like to make a donation to Guts UK and fund life-changing research. Title First name Surname Address Postcode Tel Email Guts UK Reference: 005 If you wish, please share with us your motivation for giving today. This will help us tailor our thank you: I would like to support Guts UK with a donation of £25 £50 £100 £500 Other £ £5 £10 OR Please debit my credit/debit card I enclose a cheque payable to Guts UK Charity Card no CVC / Security code Expiry Address (if different from above) OR Please call me on to take my details Signature(s) Date Add Gift Aid Please turn every £10 I donate into £12.50 at no extra cost to me, by adding gift aid to my donation. I am a UK taxpayer, please treat all donation I make or have made to Guts UK in the past 4 years as Gift Aid donations until further notice. For more information on Gift Aid please see below. Signature(s) Date I am happy for all gifts of money that I have made to Guts UK charity (Core) in the last four years and all future gifts of money that I make Aid claimed on all my donations across all charities, it is my responsibility to pay any difference. Guts UK charity claims 25p for every £1 you donate from the tax you pay for the current tax year. If your circumstances, name or address change, please do let us know. Stay in touch with Guts UK If you'd like to stay in touch and hear more about our work, including information, By email awareness, research and more, please tell us how you would like to hear from us: By post By telephone Please return this donation form

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