



Patient information service Bristol Royal Hospital for Children

What are functional gastro-intestinal disorders?



Why have I got this information sheet?

Your doctor believes that some or all of your gut symptoms are functional.

Functional disorders can also be called **disorders of gut-brain interaction**. In these conditions if we took a biopsy and looked at the lining of the gut under a microscope we would not see gut damage.

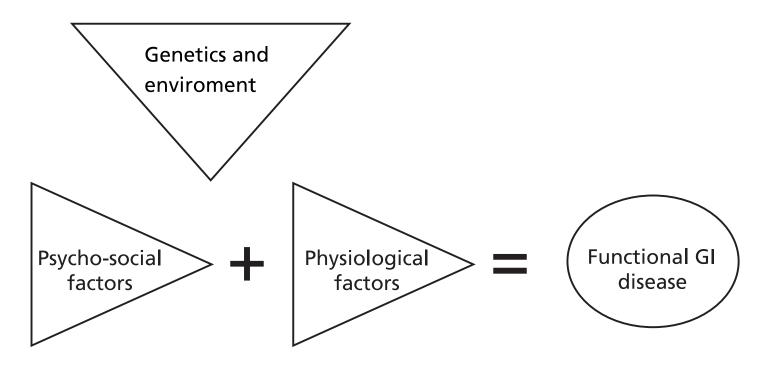
Despite this lack of damage, the nerves lining the gut are sending messages to the brain. When the brain notices these messages you get the symptoms that affect you such as pain, feeling sick, vomiting etc.

The most recent classification of functional gastro-intestinal (GI) disorders included 20 paediatric disorders. This classification is the result of a six year effort of 117 internationally recognized investigators and clinicians from 23 countries.

Why do functional symptoms happen?

There are a variety of factors that need to combine for someone to develop a functional gastro-intestinal disorder (FGID).

It is an area that has not had much research but gradually scientists and clinicians are learning more.



personality type	gut motility	pain
life stress	gut sensation	vomiting
social support	gut microbiota	bloating

For some, but not all, patients there might be a trigger event that is associated with the start of illness, such as an infection or a life event like a death in the family.

Is there a link between gastro-intestinal problems and emotions?

There are some phrases that form part of everyday conversation that link emotions to gastro-intestinal problems:

- "I find that hard to swallow"
- "That gave me butterflies in my tummy"
- "I can't stomach it any longer"

These show that people can link sensations from their gut to situations in life.

For example in a roomful of children taking an exam, nearly half the children might have had a range of gut problems before the exam.

These might include frequent loose stools, feeling sick or vomiting, poor appetite, or tummy pain.

For some children everyday life can be stressful, they might feel different to their peers or might not understand how the world works, many children also have life events to deal with that are very significant to them although may seem trivial to others.

What tests are needed?

There are no tests to make a diagnosis of functional GI disorders.

The disorders are diagnosed on the description you give to the doctors about your problems.

Sometimes blood and poo (fecal) tests are needed to make sure that the symptoms you have are not due to other GI disorders.

Case stories

Alex

Alex had severe abdominal pain, worst around bedtime every evening.

His problems started after he saw something scary on tv in his room. The family had talked about this and didn't think this scary experience was the reason for his pain.

His parents had tried lots of medicines from the GP and done everything to help Alex at bedtime from being really strict to really lenient.

Over time the pain just got worse and worse and his school attendance was decreasing. He came into hospital and had no pain.

He was discharged after his parents had made his room look different with some new paint and moving the furniture around – he had no further pain.

Tom

Tom couldn't stop vomiting, had really bad pain, couldn't sleep at night and was not going to school.

His parents were increasingly angry with doctors who couldn't help. They wanted tests done to find out what was going on.

Tom was admitted to hospital after his tests including endoscopy were normal.

Over two weeks he followed a strict plan of regular mealtimes, bedtimes, waking up times and physical activity.

The symptoms improved with this plan and he was discharged home.

Once home, Tom stuck to the plan they made in hospital and was able to return to school.

Although he still gets some symptoms he understands them and is able to deal with them.

Sarah

Sarah had a chronic kidney problem. She had to take medicines every day.

She started to vomit after every mealtime. To start with she was still able to keep liquids down but over time her problem progressed and she would vomit even sips of liquid.

She was struggling to manage her medicines and was losing weight. Sarah, her family and the kidney doctors were worried.

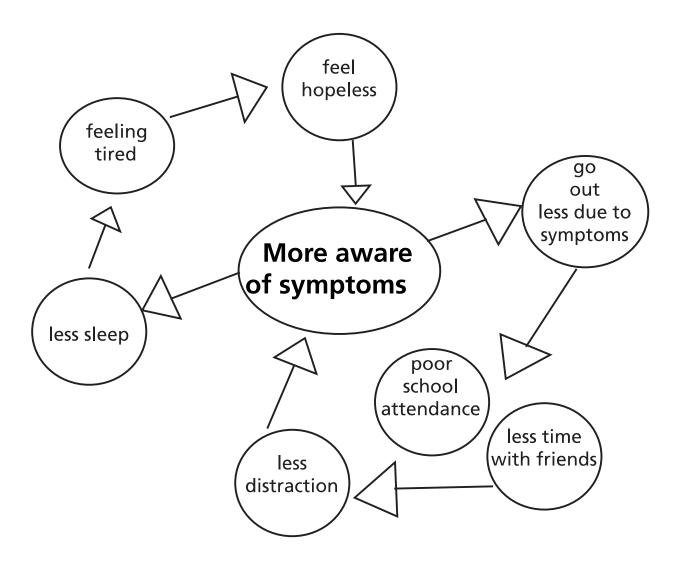
She saw the gastroenterology doctors who diagnosed her with rumination syndrome without any tests.

She started following their advice about controlling her breathing and her vomiting steadily improved and eventually went away completely.

The downward spiral

The symptoms of functional GI disorder can become very severe, we often see young people who become significantly disabled with really low school attendance.

Some children enter a downward spiral where it becomes really difficult to see anything beyond the gut problems.



Are there things I do to help myself get better?

Take back control

As a patient experiencing with functional GI disorder, your life does not have to be run by the symptoms that you have or fear of symptoms happening in embarrassing situations.

Avoid boom and bust

On good days when symptoms are very few, young people want to do everything they can as they are feeling well (we call this the boom).

This can then lead to several days of really bad symptoms, fatigue and exhaustion (we call this bust).

If this is happening then it is better to set a level of activity that is achievable every day and do this regularly before building up a small step up.

Over time this rehabilitative approach allows young people to see progress over time. If you broke your leg you wouldn't expect to run on a good day, you would have to do a gradually increasing amount of walking.

You would expect it to be painful but over time you would see progress and eventually get to the point of being able to run.

Get educated

Hopefully reading this leaflet is a good start, other helpful places to look for information and resources about specific conditions include these websites:

Pain

https://www.paintoolkit.org/persistent-pain/what-is-it

Rumination syndrome

https://www.aboutkidsgi.org/rumination-syndrome.html

Get better sleep

Everyone feels better after a good night's sleep.

There are some things that might help with this. Agree a regular bedtime routine. This might include

- some time spent doing something relaxing (listening to music, reading a book, mindfulness, deep muscle relaxation, exercise, colouring)
- agreed time all screens go off
- bath, hot drink, snuggle with hot water bottle and blanket
- agreed time to be in bed.

Eat regularly

Sometimes not eating produces some relief from symptoms but this can only be a short term plan!

Eating something regularly at breakfast, lunch and dinner with snacks inbetween is an important habit to build up.

To start with you may only manage a few bites of something but set yourself achievable targets to build this up.

Remember it is all about making progress from where you are now.

It may be a slow path to recovery but over time the small steps add up to you getting your symptoms under control.

Tell us your thoughts

Please could you scan the QR code below to complete a few questions about the leaflet you have just read. Alternatively you can access the questions via this weblink https://www.surveymonkey.co.uk/r/5BPLB5J.



It would be useful to know how helpful you have found this leaflet.

Participation is voluntary. The answers that you provide in response to these questions will be anonymous, you will not be identified in anyway and your care will not be affected.

If you have any questions about this survey, please contact the department on 0117 342 9450.

Notes		

As well as providing clinical care, our Trust has an important role in research. This allows us to discover new and improved ways of treating patients.

While under our care, you may be invited to take part in research.

To find out more please visit: www.uhbw.nhs.uk

Help us prevent the spread of infection in hospital. Please make sure your hands are clean. Wash and dry them thoroughly/use the gel provided. If you have been unwell in the last 48 hours please consider whether your visit is essential.

Smoking is the primary cause of preventable illness and premature death. For support in stopping smoking contact

NHS Smokefree on 0300 123 1044.

Drinkline is the national alcohol helpline. If you're worried about your own or someone else's drinking, you can call this free helpline in complete confidence.

Drinkline on 0300 123 1110.

For access all patient leaflets and information please go to the following address:

http://foi.avon.nhs.uk/

Bristol switchboard: 0117 923 0000
Weston switchboard: 01934 636 363
www.uhbw.nhs.uk



For an interpreter or signer please contact the telephone number on your appointment letter.





For this leaflet in large print or PDF format, please email patientleaflets@uhbw.nhs.uk.



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