



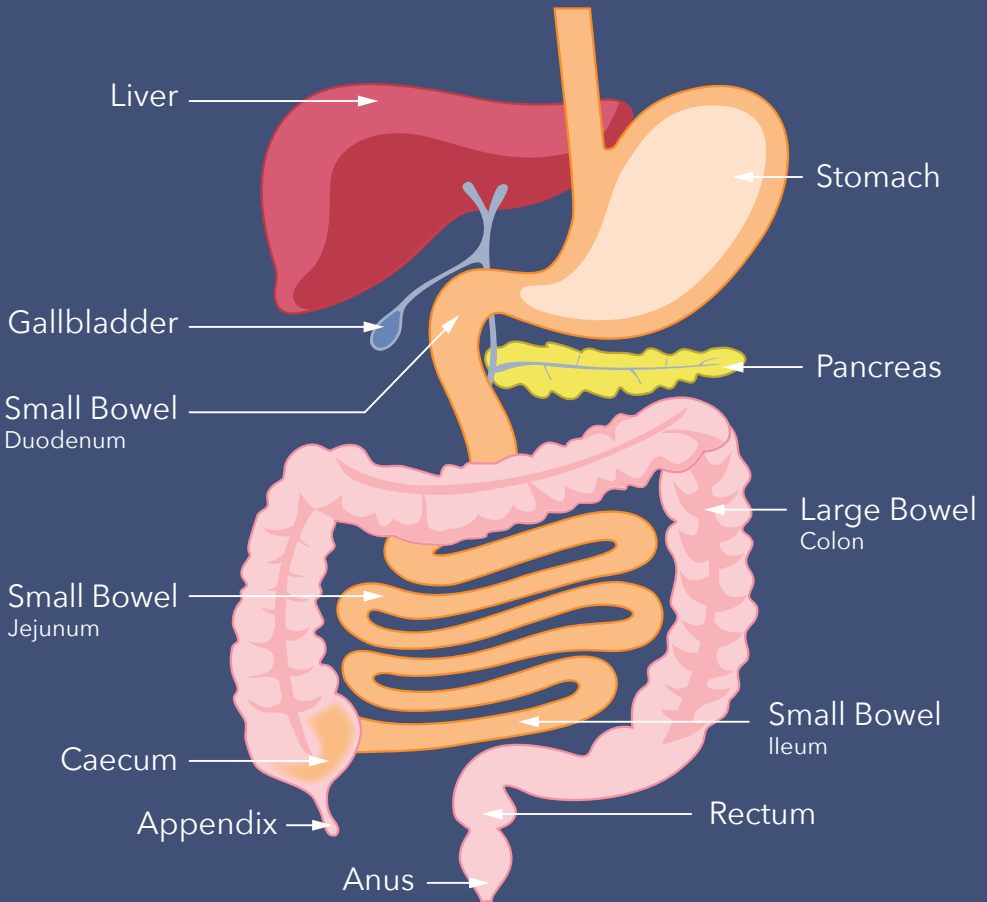
All you need
to know about

COELIAC DISEASE



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.



This leaflet was published by Guts UK charity in 2023 and will be reviewed in 2025. The leaflet was written by Guts UK and reviewed by experts in coeliac disease and has been subject to both lay and professional review. All content in this leaflet is for information only. The information in this leaflet is not a substitute for professional medical care by a qualified doctor or other healthcare professional. We currently use AI translation tools on our website, which may not always provide perfect translations. Please check for further explanation with your doctor if the information is unclear. ALWAYS check with your doctor if you have any concerns about your health, medical condition or treatment. The publishers are not responsible or liable, directly or indirectly, for any form of damages whatsoever resulting from the use (or misuse) of information contained or implied in this leaflet. Please contact Guts UK if you believe any information in this leaflet is in error.



This booklet is about Coeliac Disease

This booklet helps explain about coeliac disease. It describes the causes, symptoms to be aware of and the treatments that are available.

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Overview

Coeliac disease is an autoimmune condition where the body's immune system starts attacking itself. In the case of coeliac disease this attack on self is stimulated by an immune response to eating gluten. In those living with coeliac disease, it causes damage to the lining of the small bowel. This is because the body ends up attacking it's own cells.

Gluten is a protein found in wheat, barley and rye. It is typically a healthy and safe food to eat. But, in those living with coeliac disease, it causes damage to the lining of the small bowel. Gluten can stimulate the immune system in certain people. This can lead to damage in the cells of their small bowel making it hard for the body to absorb nutrients from food. It can cause symptoms and long-term health issues. Coeliac disease is not a food allergy or intolerance. To treat the condition, you must follow a gluten-free diet for life.

Studies show that approximately 1 in 100 people in the UK have coeliac disease. It can affect all ethnicities. The exact cause of coeliac disease involves a complex interaction between genetic and environmental factors. So, around 500,000 people in the UK are unknowingly living with coeliac disease.

What causes the development of coeliac disease?

The exact cause of coeliac disease involves a complex interaction between genes and environmental factors. More females assigned at birth tend to be diagnosed than those assigned male at birth. The average age of diagnosis is between 40 and 60 years old. But people can be diagnosed at any age once gluten is introduced in the diet.

Genetics play an important role in the development of coeliac disease. If a family member has coeliac disease, it increases the chances of others in the family having it too. Examples of those with higher risk are having a parent, sibling or being a child of someone with coeliac disease. Genes carry information that decides traits that are passed on to you. There's a specific gene called HLA-DQ that is linked to coeliac disease. 4 in 10 people have this gene, but not everyone with the gene will get the disease. Many different environmental factors can trigger coeliac disease development in predisposed individuals.

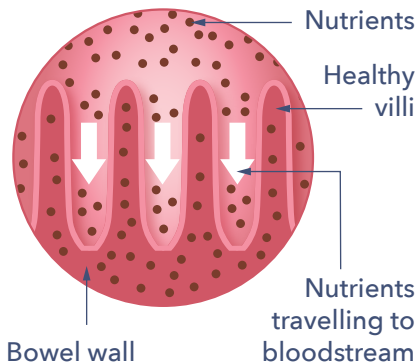
The following conditions can increase the likelihood of developing coeliac disease:

- Down's or Turner syndrome
- Type 1 diabetes
- Thyroid disease

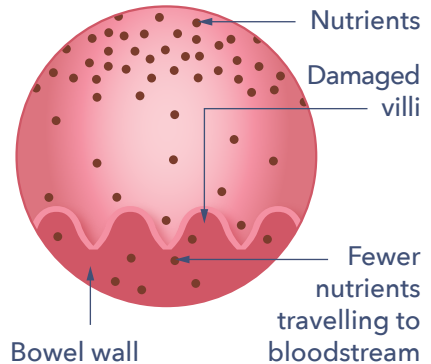
The relationship between these conditions and coeliac disease development is unclear. People with coeliac disease have a higher chance of developing other autoimmune conditions too. Research to learn more about coeliac disease and find out the exact causes of it is ongoing.

What does coeliac disease look like?

Normal small bowel with healthy villi



Coeliac disease with damaged villi



The villi in the small bowel are in charge of nutrient absorption. In a person with coeliac disease, when gluten is eaten, the villi become damaged and inflamed. They will look shorter and stubbier. This means that the small intestine is damaged. When it is damaged, fewer nutrients can pass into the bloodstream.

How can coeliac disease affect the body?

Eating gluten causes damage to the villi, making them much smaller and almost flat. This is called villous atrophy. This reduces the bowel's surface area, and thereby its ability to absorb nutrients. This can lead to nutrient deficiencies in the body. Avoiding gluten allows the villi to recover over time. But, coeliac disease is a lifelong condition. To control it, you must follow a gluten-free diet for life.

The main ways that coeliac disease can affect the body is:

Physical discomfort. This is caused by the following symptoms:

- Bloating.
- Unexplained weight loss.
- Abdominal discomfort.
- A change in bowel habit to diarrhoea or constipation.

Shortage of essential nutrients. This can cause other problems and conditions like weakened bones (osteoporosis). It can also lead to anaemia, which causes lethargy. This can also affect fertility.

Symptoms beyond the gut. Occasionally there can be problems with the nerves in the extremities. This causes symptoms of numbness and tingling in the hands and feet. Some people may also experience other non-digestive symptoms. Examples are brain fog, balance problems, mouth ulcers and infertility, amongst others.

Dermatitis herpetiformis. This is a skin disease that is associated with coeliac disease. Symptoms consist of skin rashes that can also blister. It is common to see around the elbows, knees, shoulders and face. If this is present, you can get referred to a dermatologist (specialist skin doctor) and have a skin biopsy to diagnose it.

How is coeliac disease diagnosed?

Coeliac disease has similar symptoms to other conditions like Irritable Bowel Syndrome (IBS). This leads to possible misdiagnosis if it is not tested properly. An accurate diagnosis is vital. If you suspect you have coeliac disease, go to your GP. The doctor will carry out an examination and take a medical history. If coeliac disease is suspected the following tests will be performed.

Blood tests

Two antibody tests are carried out. These tests must be done whilst gluten is still being eaten for at least 6 weeks before the test.

Tissue Transglutaminase (TTg)

(First choice test)

Endomysial antibody (EMA)

(if TTg weakly positive)

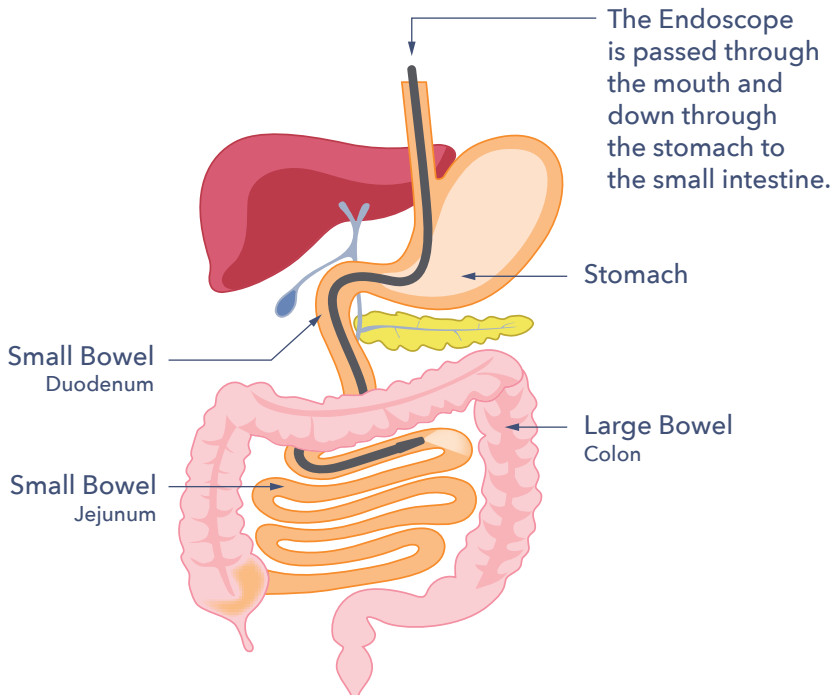
The results of these tests alone may be sufficient to diagnose someone with coeliac disease for some people. This depends on the blood values, the symptoms and the age of the person being investigated. But, in most situations an extra test in the form of an endoscopy is also required to confirm the diagnosis with certainty.

Endoscopy

Endoscopy involves inserting a thin, flexible tube through the mouth and down through your gut to the small intestine. Small tissue samples (biopsies) are taken. Some clinics are also using a new type of endoscopy that passes the thin tube through the nose and into the gut to the small bowel.

This can be uncomfortable, but it should not be painful. Any abnormalities that indicate coeliac disease will be shown on the biopsy samples once they are processed. This confirms the diagnosis with certainty.

It is important to continue eating gluten for 6 weeks before the blood tests or endoscopy tests are done to ensure accurate results. An abnormal reaction won't be found if you're not eating enough gluten. Discuss things with your GP if this is a problem.



The treatment of coeliac disease requires a special diet for life, so it's absolutely crucial to be certain about the diagnosis.

How can Coeliac disease affect you?

Coeliac disease can present in many ways. Some people have only mild symptoms, and most can usually be controlled with a gluten-free diet. There are also other treatments for more severe disease.



Symptoms

Coeliac disease symptoms can vary between people. In children, symptoms include diarrhoea, vomiting or a failure to gain weight. Adults often experience a combination of symptoms. A typical symptom is diarrhoea with bloating or discomfort in the abdomen.

People don't always have symptoms that appear to relate to their gut. Coeliac disease can manifest in a variety of ways. It is important that people with associated conditions like autoimmune thyroid disease and type 1 diabetes be tested.

Some other symptoms may include:

- Persistent lethargy (tired all the time).
- Loss of sensation of fingers and toes.
- Headaches and migraines.
- Skin rashes (called dermatitis herpetiformis).
- Whilst diarrhoea is common, constipation can also occur.
- Unexplained weight loss.
- Feeling generally unwell.
- Persistent mouth ulcers.
- Weakened bones and bone fractures.
- Unexplained infertility or repeated miscarriage.
- Lack of absorption of vitamins and minerals like iron, B12 and folate.

Will coeliac disease affect me over time?

Coeliac disease is a lifelong condition. Sticking to a gluten-free diet is the only treatment that restores the gut and keeps it healthy long-term. If the gluten-free diet is not followed there can be reduced nutrient absorption. This might lead to issues such as anaemia (low iron levels) or osteoporosis (weakened bones). There is also a slightly increased risk of certain cancers in individuals who continue to consume gluten. This risk is a lot smaller if gluten is avoided for life. Coeliac disease may also cause infertility in those designated female at birth, if they remain undiagnosed. This is usually resolved with a gluten-free diet. It is worth noting that the small bowel can take from 2 to 5 years to fully recover after gluten is stopped, depending on the amount of initial damage present.

The gut is linked to the brain, and so coeliac disease can cause neurological symptoms like headaches and 'brain fog'. Nearly 4 in 10 adults will have neurological symptoms when diagnosed with coeliac disease. These often improve with a gluten-free diet. If they do not, you may need a referral to a neurology specialist. If you have coeliac disease and exclude gluten from the diet, your life expectancy shouldn't be affected.

What treatment is available for coeliac disease?

The treatment for coeliac disease is to follow a lifelong gluten-free diet. If you are diagnosed with coeliac disease, your doctor will refer you to see a dietitian. They can provide you with information on how to avoid gluten. It is important to know how to maintain a balanced gluten-free diet. Sticking to a gluten-free diet requires knowledge about which foods contain gluten and how to maintain a balanced diet. The dietitian will provide written information and advice.

What is gluten?

Gluten is a protein found in wheat, barley and rye and products made using these grains. You may find it useful to remember the acronym BROW. This stands for the main grains that should be identified and avoided. These are barley, rye, oats and wheat. But, it is important to bear in mind that most people living with coeliac disease can eat oats if they are gluten-free. It is explained who may not be able to eat them below.

What foods contain gluten?

Breads, pastas, breakfast cereals, cakes, biscuits are generally contain gluten. For example, flour is used as a thickener in many cooking sauces and barley is used



in making most lagers. Foods can also get contaminated with small amounts of gluten during production or processing. It can happen if gluten comes into contact with gluten-free food. This is why it is important to always avoid gluten in ingredients and from a cross-contact point of view. We know that very small amounts of gluten can cause problems for people with coeliac disease.

Choose only gluten-free varieties of oats, as they can be at risk of gluten cross-contact during processing. These are a great source of soluble fibre. Check the labels to ensure they are gluten-free. A small number of people react to avenin, a protein found in oats that is like gluten (even 'gluten-free' versions). If you continue to have symptoms despite following a gluten-free diet, this may be why. You should discuss this with your dietitian or doctor.

Grain suitability

Some flours made from naturally gluten-free grains may have cross-contact risks, so always read the label. Flours labelled gluten-free will be free from gluten cross-contact.

Not gluten-free	Barley, pearl barley, bulgar wheat, couscous, einkorn, durum wheat, khorasan (kamut), emmer (farro), freekah, rye, semolina, spelt, tricale and wheat.
Check food label	Oats/barley, malt extract and 'flavourings'.
Gluten-free	Almond, amaranth, buckwheat, cassava, chestnut, corn, flax/linseed, gram (besan or chickpea) flour, hemp, maize, millet, mustard, polenta, potato, pulses, quinoa, rice, sago, sesame, sorgum, soya, tapioca, teff and urd.

Food labelling

Food manufacturers are required to label allergens, including gluten, on ingredients lists in bold. Check labels for **Barley, Rye, Oats** and **Wheat (BROW)**. Some products without these grains have advisory labelling such as 'May contain gluten' or 'Made in a factory handling wheat'. **This shows a risk of cross-contact with gluten.**

If you are unsure of a product it's usually best to avoid it. Coeliac UK can help with the suitability of specific products.

Be cautious when travelling abroad as food labelling rules may not be as strict in countries outside the UK. Most European countries have similar regulations in place. Travelling further can be safe with research and planning.

What foods are suitable for a gluten-free diet?

Many foods are suitable for people with coeliac disease. Learn to check foods and find gluten-free sections of the supermarkets. Naturally gluten-free foods can be found throughout shops too. The Crossed Grain symbol (see right) is an easy way of identifying foods you can eat. It also ensures there is an additional layer of testing to guarantee safety.



Labelled gluten-free foods

These foods can be consumed by people with coeliac disease. They meet a specific legal standard of being tested to have no more than 20 parts per million gluten (sometimes written as '<20 ppm'). This will be labelled on the packaging of food products. Manufacturers and supermarkets make a wide variety of gluten-free foods. Try a variety of these to see which you most enjoy.

In Wales and Northern Ireland a range of substitute gluten-free staple foods are available on prescription from your doctor. Some places in Wales use a top-up card scheme to get these products. In Scotland, gluten-free foods are available on prescription through your pharmacist. These ranges may include bread, flour mixes, pasta, crackers and breakfast cereals

Integrated Care Boards (ICBs) manage GP surgeries in England. These organisations decide their own prescribing policy. These vary according to where you live. The ICBs can restrict or suspend the availability of gluten-free products on prescription in some areas. **You can ask your pharmacist if prescription gluten-free products are available in your area.**

Foods made without gluten containing ingredients

Many foods are made without gluten containing ingredients. There are measures in place to minimise the risk of cross-contact. These foods can be identified by reading labels. If you are unsure, Coeliac UK resources such as **'The Eat Well, Live Well' food and drink directory** and **'GF Food Checker'** digital application can help to identify these products.

**Naturally
gluten-free
foods**

Fruits and vegetables (fresh, most dried fruit, frozen, canned).
Meat fish and poultry.
Pulses and plain nuts.
Eggs and dairy.
Naturally gluten-free starchy foods: rice, corn, potatoes and other root vegetables.

Eating out

Restaurants are increasingly trying to help by labelling dishes containing gluten. Caterers are required to provide you with information about gluten in all their dishes. If the information is not easily seen it must be clear where it can be found. Coeliac UK (see page 13) has an accreditation scheme for restaurants and a symbol that can be used on a menu. The symbol that tells you that the dish is gluten-free according to the law. This standard covers all aspects of gluten-free preparation and ensures training is in place to reduce the risk of gluten cross-contact.

It is still important to check with staff and let them know your requirements.

Initially eating outside the home can feel daunting. It is important to not let a gluten-free diet become socially restrictive. Over time you will learn how to navigate social situations and ask the right questions about how your meal is prepared. If you have concerns please discuss this with your dietitian.



Does my coeliac disease need monitoring?

As you might develop problems in the future, it is important to check your health long-term. It is recommended that you have an annual check up, including blood tests to check for anaemia or nutrient deficiencies. If symptoms persist or new ones arise, ask for another specialist referral. This can be to the gastroenterologist and dietitian if you are not already under their care.

Your doctor may arrange for you to have a bone scan (a DEXA scan). This will look for any sign of bone thinning so this can be treated early. Some people can have weaker bones. This is due to not absorbing enough calcium and vitamin D. People with coeliac disease may have impaired spleen function. The spleen is important in immune function, so vaccinations against flu and pneumonial infections may be advised.

What to ask your doctor

- *Where are the best sources of information about living gluten-free?*
- *Can you refer me to a dietitian?*
- *Are there any support groups for coeliac disease in my area?*
- *Should my close family be tested for coeliac disease?*
- *Are gluten-free prescriptions available in my area?*
- *How often will you be monitoring me to ensure coeliac disease is well controlled??*
- *Should I have a bone scan?*

Support

Coeliac UK

Coeliac UK is the leading UK charity supporting people diagnosed with coeliac disease. The Coeliac UK helpline is **0333 332 2033** or visit www.coeliac.org.uk.

Coeliac UK membership services include:

- Helpline supported by expert dietitians and advisers.
- Access to the latest gluten-free products and food and drink information. The printed version is updated monthly. Use the online version for most up to date information.
- Recipes, information and advice on gluten-free cooking and baking.

- Over 50 Travel guides with information on where to eat out and shop, alongside useful translations.
- Venue guides on over 3,000 accredited venues as well as others' recommendations on where to eat out.
- Award winning digital application.
- Coeliac UK app (scan barcodes, identify suitable foods and help identify suitable places to eat when you're away from home)
- Local groups and peer support through Member2Member scheme.
- Live Well Gluten-Free magazine.
- Useful educational videos and dietetic workshops.

The National Institute of Health and Care Excellence (NICE)

NICE develop guidelines of treatment that should be expected with a diagnosis of coeliac disease.

www.nice.org.uk/guidance/ng20

Patient Webinars

These have been developed by NHS doctors and dietitians.

www.patientwebinars.co.uk/condition/coeliac-disease/webinars/

What research is needed?

A Priority Setting Partnership (PSP) has been completed which identifies the top ten research priorities for coeliac disease. You can find out what those are from Coeliac UK.

References available on request.

Guts UK

The charity for the digestive system



Our guts have been underfunded, undervalued and underrepresented for decades.

"I chose to fundraise for Guts UK because when I was in hospital, I was amongst others with various digestive diseases. It was there that I realised there needs to be so much more awareness for these invisible illness. We must raise much needed funds for this important research!"

Abi, Guts UK fundraiser.



Join our community

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

With new knowledge, we will end the pain and suffering for the millions affected by digestive diseases. Guts UK's research leads to earlier diagnoses, kinder treatments and ultimately a cure.

Let's get to grips with our guts, and save lives.

Discover more about our fascinating digestive system at gutscharity.org.uk

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 info@gutscharity.org.uk

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At Guts UK we only want to send you information you want to receive, the way you want to receive it. We take great care of your personal data and never sell or swap data. Our privacy policy is online at www.gutscharity.org.uk and you can always change your preferences by contacting us at info@gutscharity.org.uk or calling 0207 486 0341.



Our research shows that 51% of people delay seeking advice for their symptoms for over 6 months. Guts UK exists to change that. We empower people to seek help. Together, we will join forces and bring about important change in this misunderstood area of health.

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

Support Guts UK today

www.gutscharity.org.uk



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Please call me on to take my details

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