

Coeliac UK & coeliac disease fact sheet

Who is Coeliac UK?

We are the national charity for people who need to live without gluten. For over 50 years, we have been the expert on coeliac disease, gluten related conditions and the gluten free diet. We provide independent, trustworthy advice and support; we strive for better gluten free food in more places; we fund crucial research and aim ultimately, to find a cure.

We have:

- 180,000 followers
- 60,000+ members
- Two food safety schemes: Crossed Grain certification for packaged products and Gluten Free accreditation for venues
- App with a handy barcode scanner for packaged products and a GF venue search function
- A wealth of free-to-access resources for people at any age and any stage of their diagnosis and GF journey

What do we do as an organisation?

We provide evidence-based support and expert advice and resources to our members and the wider community of people with coeliac disease and gluten related health conditions. We work with hospitals, commercial partners and venues to ensure the safe provision of gluten free food to the highest of standards. Our aim is to make gluten free food accessible in every possible environment, so that our community feels confident in maintaining their health wherever they are.

What is coeliac disease?

Coeliac disease is an autoimmune condition, which is triggered by eating gluten, a protein found in wheat, barley and rye. Some people with coeliac disease are also sensitive to oats. For people with coeliac disease, the body's immune system attacks its own tissues when gluten is eaten, which prevents normal digestion and absorption of food.

What are the symptoms?

Symptoms of coeliac disease range from mild to severe and can vary between individuals. Symptoms can include bloating, diarrhoea, nausea, vomiting, wind, constipation, tiredness, anaemia, mouth ulcers, sudden or unexpected weight loss and skin rash (dermatitis herpetiformis). Osteoporosis, small bowel cancer and unexplained infertility are complications of undiagnosed or untreated coeliac disease.

Dermatitis herpetiformis (DH) is the skin manifestation of coeliac disease. It appears as red raised patches often with blisters that itch, sting or burn and can burst with scratching. It commonly occurs on the elbows, forearms, knees and buttocks, although it may occur anywhere on the body.

How many people in the UK have coeliac disease?

It's estimated 1 in 100 people has coeliac disease; however, only 36% of people with the condition are clinically diagnosed. Under diagnosis of coeliac disease is a significant problem and it is estimated around **half a million** people in the UK are currently undiagnosed.



How is coeliac disease diagnosed?

Anyone experiencing symptoms should go to their GP. The next step is a simple blood test to check for antibodies. Antibodies are produced by the body in response to eating gluten. It is essential to continue eating gluten before and during the testing process, otherwise the test won't work. The National Institute for Health and Care Excellence (NICE) recommends having gluten in more than one meal every day for at least six weeks prior to testing.

If the blood test is positive, or there is clinical suspicion of coeliac disease, the GP will then refer the patient to a gut specialist (a gastroenterologist). In adults, a gut biopsy is usually carried out to confirm the diagnosis. However, new guidelines published in June 2020 recommend that for some adults who have very high antibody levels, a further blood test can confirm the diagnosis without the need for a biopsy. **It is important that gluten is not removed from the diet until all tests are complete or until recommended by a gastroenterologist.**

For some children, a biopsy may not be needed. For more information see: www.coeliac.org.uk/coeliacdiseaseinchildren

On our website we have a self-assessment tool that determines whether a person should be tested, and if testing is recommended it provides a letter to show to the GP to confirm that Coeliac UK has provided this recommendation. <https://isitcoeliacdisease.org.uk/>

How is coeliac disease treated?

A strict gluten free diet for life is the only treatment for coeliac disease. Once someone is diagnosed, their gastroenterologist will refer them to a dietitian, who can help them adapt to their new diet.

By switching to a gluten free diet, the gut damage caused by eating gluten will start to heal. The amount of time the gut takes to heal varies between people. For some, the positive effects are immediate. In some cases, it can take up to five years. However, people should start to feel better in the first few weeks after starting the gluten free diet. The health risks associated with coeliac disease are minimised as long as a gluten free diet is adhered to for life.

Is it a genetic condition?

Yes, coeliac disease does run in families, but not in a predictable way. Studies show that if a family member has the condition, there is a 1 in 10 chance of a close relative developing the disease. Anyone who has a close relative (parent, sibling, child) with coeliac disease should discuss getting tested with their GP if they recognise any symptoms. People with coeliac disease are born with genes that predispose them to develop the condition, but the symptoms can be triggered at any age.

What is the difference between an allergy and intolerance?

Coeliac disease is not a food allergy or an intolerance but an autoimmune disease caused by a reaction to gluten. Eating gluten triggers the production of antibodies, which leads to the body attacking its own cells, resulting in gut damage.

What kinds of foods have gluten in them?

Many everyday foods such as breads, pasta, flours and cereals contain gluten. However, there are plenty of foods that don't contain gluten. Plain meat (including meat fed on gluten containing grains), poultry, fish, eggs, cheese, milk, yogurt, fruits, vegetables, pulses (peas, beans), rice, nuts and seeds, maize (corn) and potatoes are all naturally



gluten free. Gluten free products can also be found in the Free From section of supermarkets, in health food stores and on the internet.

Coeliac UK produces an annual Food and Drink Guide available online and in print, which lists thousands of gluten free foods that are safe for people with coeliac disease.

How we help our gluten free community

We have a wealth of freely available information on our website and our Helpline is open 5 days a week to advise on everything you need to know to get started and maintain a balanced gluten free diet.

We know that coeliac disease touches all aspects of someone's life and alongside our free information we also have a membership scheme that offers a wider service. Anyone can become a member of Coeliac UK and membership starts from just £1.25 a month.

Our membership provides reliable, independent and expert services to make shopping, eating out and travelling gluten free easier. Plus gluten free product news, recipes, travel guides, and exclusive offers and discounts, including 20% off our online Diet and Health Workshops led by our dietitians.

Included within the membership fee is our *Live Well Gluten Free* app, which makes shopping and eating out on the go even easier. It features include a handy barcode scanner to find gluten free products quickly and a listing of around 3,000 venues who have received our Gluten Free Accreditation, meaning they adhere to our strict standards of preparing and serving gluten free food.

To join Coeliac UK, visit www.coeliac.org.uk/join or call 0333 332 2033

Is gluten free food available on prescription?

The Department of Health and Social Care made the decision to retain gluten free bread and flour mixes on prescription in England. However, we are seeing some areas restricting or cutting gluten free prescribing but around 60% of CCGs in England continue to recommend that GPs prescribe gluten free foods. People with coeliac disease in England have to pay for gluten free food on prescription, unless they meet the criteria for exemption (such as age, income etc.). Prescriptions are free of charge in Scotland, Wales and Northern Ireland.

How can you check food labels for gluten?

All packaged food in the UK and the EU is covered by a law on allergen labelling, called the Food Information Regulation: www.coeliac.org.uk/fir This means people can tell from an ingredients list whether a product contains gluten or not. Cereals that contain gluten are one of the 14 listed allergens (www.coeliac.org.uk/14allergens) that must be listed in the ingredients list.

Therefore, if a cereal containing gluten is used as an ingredient, it must be listed in the ingredients list, no matter how little of it is used, and emphasised, usually in bold. Manufacturers will name the specific grain used, so you will see these words on the ingredients list if they are in the product:

- wheat
- rye
- barley
- oats
- spelt
- Khorasan wheat (commercially known as Kamut®)
- or any grain which has been made through breeding these together.



What does it mean when foods are labelled gluten free?

You may see the term 'gluten free' on products. When this term is mentioned the food is okay for people with coeliac disease to eat. Only foods which contain 20 parts per million (ppm) or less of gluten can be labelled gluten free and it is determined that this level of gluten is acceptable for people with coeliac disease. This includes foods that by nature do not contain gluten, specialist substitute products and uncontaminated oat products.

Coeliac UK's Crossed Grain trademark was developed in the 1970s and is now an international symbol of gluten free safety and a quick and easy way to identify gluten free foods. When you see the Crossed Grain symbol on a product, you know that the manufacturer has gone the extra mile to have their processes audited and their product certified. You can find more about this at: www.coeliac.org.uk/crossedgrainsymbol

What about eating out gluten free?

Caterers must be able to provide information on any allergens, including cereals containing gluten, in all the dishes they serve. This means if a recipe uses cereals containing gluten such as wheat, rye, barley or oats in the ingredients, they will need to declare it. Caterers can provide allergen information in written or oral formats.

Coeliac UK runs a GF accreditation scheme to drive improvements and standards in eating out so that people with coeliac disease can find more choice. You can find more about this at www.coeliac.org.uk/accreditation.

Coeliac UK's online Venue Guide and Live Well Gluten Free app lists accredited venues and member recommended venues where they've had a good experience. There are over 7,500 venues listed, including 3000 GF accredited making it easier than ever to find a venue that caters gluten free. The charity has launched a range of catering services to support businesses and you can find more information at www.coeliac.org.uk/cateringservices

How can you manage a gluten free diet when travelling?

Coeliac UK produces information leaflets for more than 50 countries, with language translations that can be used when going on holiday. This includes lists of hotels, restaurants, shops and contact details for the local coeliac organisation.

QUICK REFERENCE COELIAC DISEASE KEY FACTS and STATS

- Coeliac is pronounced "see-liac".
- Coeliac disease is not a food allergy or an intolerance but an autoimmune disease caused by a reaction to gluten.
- Damage to the gut lining occurs when someone with coeliac disease eats gluten.
- Coeliac disease affects at least 1 in 100 people in the UK and in Europe; however, only 36% of people with the condition are currently clinically diagnosed.
- The average length of time taken for an adult to be diagnosed with the disease from the onset of symptoms is a staggering 13 years.
- Symptoms range from mild to severe and can vary between individuals. Symptoms can include:
 - Bloating
 - Diarrhoea



- Nausea
 - Vomiting
 - Wind
 - Constipation
 - Tiredness / extreme fatigue
 - Anaemia
 - Mouth ulcers
 - Sudden or unexpected weight loss
 - Dermatitis herpetiformis (DH) is the skin presentation of coeliac disease.
- There is no cure for the condition; the only treatment is a strict gluten free diet for life.
 - If a gluten free diet is not followed, the disease can lead to nutritional deficiencies and other complications such as osteoporosis, a rare type of bowel cancer of the small bowel and unexplained infertility problems.
 - Gluten is a protein found in the grains wheat, rye and barley. Some people with coeliac disease are also sensitive to oats.
 - Obvious sources of gluten include foods that contain traditional flour such as breads, pasta, cereals, cakes and biscuits. Gluten is also found in many favourite foods such as fish fingers, sausages, gravies, sauces, stock cubes, soy sauce and even in some chocolate.
 - If someone with coeliac disease accidentally eats gluten, they are likely to be unwell within a few hours. Symptoms can be varied but include severe diarrhoea and vomiting and can last several days.
 - Gluten free food can be contaminated during preparation by food that contains gluten. Sources of contamination include breadcrumbs in toasters and on bread boards, utensils used for spreading and spooning jam, butter, chutney etc onto bread and from cooking oil in fryers.
 - It is a myth that you can grow out of coeliac disease. Once diagnosed, you have it for life.
 - Coeliac disease is a genetic condition and runs in families. Studies show that if someone in a family has the condition, there is a 1 in 10 chance of a close relative (parent, sibling, child) developing the disease.
 - 1 in 4 people with coeliac disease have previously been misdiagnosed with Irritable Bowel Syndrome (IBS) prior to diagnosis of coeliac disease. NICE (National Institute for Health and Care Excellence) guideline states anyone with IBS symptoms should be tested for coeliac disease before a diagnosis of IBS is made.
 - People with coeliac disease cannot join the armed forces if they are already diagnosed.
 - People medically diagnosed with coeliac disease can access some gluten free staple foods on prescription, but access to these depends on where you live. Some Integrated Care Systems in England have now reduced or stopped prescribing items.
 - In 2015, the UK's first online assessment for coeliac disease, where people can check their symptoms, was launched to help find the missing estimated half a million people in the UK currently undiagnosed with coeliac disease.

Visit www.coeliac.org.uk/isitcoeliacdisease to take the online assessment and find out more.



- Coeliac UK has a smartphone app 'Coeliac UK Live Well Gluten Free' that helps people to manage their gluten free diet by using the barcode scanner while out shopping, or the venue guide when eating out. Available to download in app stores.

We have two food safety schemes:

- Crossed Grain Certification for packaged products
- Gluten Free Accreditation for venues
- BBC MasterChef champion Jane Devonshire and Becky Excell, gluten free cookbook author and blogger, are the charity's Ambassadors.
- Coeliac UK's Awareness Month runs annually in May and will take place from 1-31 May 2024.

Website: www.coeliac.org.uk

Facebook: www.facebook.com/CoeliacUK

Twitter: @Coeliac_UK

Instagram: @coeliacuk

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