

Key facts on coeliac disease

- 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 30% of people with the condition are currently clinically diagnosed.
- The average length of time taken for someone to be diagnosed with the disease from the onset of symptoms is a staggering 13 years.
- 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 by food that contains gluten during preparation. 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 and water.
- It is a myth that you can grow out of coeliac disease. Once you are 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 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.
- Dermatitis herpetiformis (DH) is the skin presentation of coeliac disease.
- 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 Clinical Commissioning Groups in England have now reduced or stopped prescribing items.
- For 50 years, Coeliac UK has been the expert on coeliac disease and the gluten free diet. It is an independent charity helping people living without gluten to live happier, healthier lives and has a wealth of information for all those following a gluten free diet including recipes, apps, helpline and a regular magazine. It was established in 1968 and celebrated its 50th Anniversary in 2018 and around 11,000 new members join every year.
- Coeliac UK has two smartphone apps - *Gluten Free Food Checker* and *Gluten free on the Move* helping those with coeliac disease and those choosing to eat gluten free, to manage every element of their diet; whether shopping for food or finding somewhere to eat out. They are available to download in the app store.
- In 2015, the UK's first online assessment for coeliac disease, where people can check their symptoms, was launched to help find the missing 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.
- In 2017 the charity launched the Gluten Freevolution campaign to help encourage the catering industry to offer more gluten free options on their menus. They also launched new guidance on catering gluten free in association with the Food Standards Agency.
- Actress Caroline Quentin is Patron of Coeliac UK. Chef Phil Vickery is the charity's Food Ambassador and Dr Chris Steele, Health Ambassador. The charity also works with a number of chefs including Jane Devonshire, BBC MasterChef winner.
- Coeliac UK's Awareness Week 2019 will take place from 13-19 May and will be focusing on raising awareness to help find the missing half a million people in the UK who are currently undiagnosed.

Website: www.coeliac.org.uk

Facebook: www.facebook.com/CoeliacUK Twitter: [@Coeliac_UK](https://twitter.com/Coeliac_UK) Instagram: [@coeliacuk](https://www.instagram.com/coeliacuk)

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Questions and answers

How many people in the UK have coeliac disease?

Screening studies suggest that 1 in 100 people has coeliac disease; however, only 30% 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.

What exactly is coeliac disease?

Coeliac disease is a lifelong autoimmune disease, 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, eating gluten damages the lining of the gut, which prevents normal digestion and absorption of food. There are serious health problems that can be associated with coeliac disease including osteoporosis, cancer of the small bowel and increased risk of other autoimmune diseases.

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 relative 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. A stressful event may exacerbate the symptoms of coeliac disease. The majority of people are diagnosed from 50 years old.

What are the symptoms we should be looking out for?

Symptoms of coeliac disease range from mild to severe and can vary between individuals. Symptoms can include bloating, diarrhoea, nausea, 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. It affects around 1 in 3,300 people. It can appear at any age but is most common in people aged between 50-69.

Even though people with DH may not have any gut symptoms, they may have the gut damage which is associated with coeliac disease so they should be tested for coeliac disease.

What should people do if they suspect they might have coeliac disease?

The first step is to discuss symptoms with a GP who can take a simple blood test to check for antibodies. Antibodies are produced by the body in response to eating gluten. It is **essential** to continue to eat a diet that contains gluten before and during the testing process, otherwise the test won't work. The National Institute for Health and Care Excellence (NICE) recommend having gluten in more than one meal every day for at least six weeks prior to testing.

If the blood test result is positive, the next step is a GP referral to a hospital specialist (gastroenterologist) for a gut biopsy. This is a simple procedure performed in outpatients, which looks for damage in the gut that is typical in coeliac disease.

The test involves passing a thin flexible tube (an endoscope) through the mouth and down to the upper part of the small intestine where a tiny sample of gut lining is collected. This can be done using a local anaesthetic sprayed to the back of the throat and/or sedation. Although the procedure may not be particularly comfortable, neither passing the tube nor taking biopsies should be painful. For some children, a biopsy may not be needed in all cases. See www.coeliac.org.uk/coeliacdiseaseinchildren for more information.

GLUTEN SHOULD NEVER BE TAKEN OUT OF THE DIET UNTIL ALL TESTS (THE BLOOD TEST AND ENDOSCOPY WITH BIOPSY) ARE COMPLETE OTHERWISE REMOVING GLUTEN IS LIKELY TO CAUSE A FALSE NEGATIVE TEST RESULT.

How is coeliac disease treated?

A gluten free diet for life is the only treatment for coeliac disease. Once someone is diagnosed, their GP should refer them to a dietitian to help guide them through the initial steps of changing their diet. It may take a while to learn how to live gluten free but it is a learning process and people do get there.

Coeliac UK has a wealth of information on its website www.coeliac.org.uk and for as little as £2 a month, people can access comprehensive resources to adapt to a gluten free diet and receive support to manage their condition.

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; and can take between six months and 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.

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. It is important to distinguish between food allergy and food intolerance as these two terms can sometimes be confused.

Food allergies are generated by the immune system and usually occur within seconds or minutes of eating the food in question. Tiny amounts can cause potentially life threatening allergic reactions, which is why it is vital to know about the ingredients and preparation of foodstuffs.

Food intolerance is not triggered by the immune system and is generally not life threatening. It may affect the digestion and common symptoms include digestive discomfort, diarrhoea and bloating.

Coeliac disease is an autoimmune disease which is triggered by eating gluten in the cereals wheat, barley and rye. Some people with coeliac disease are also sensitive to gluten free oats. Eating gluten triggers the production of antibodies which leads to the body attacking its own cells, resulting in gut damage. Coeliac disease requires ongoing review and management. There are serious problems associated with coeliac disease including osteoporosis, cancer of the small bowel and increased risk of other autoimmune diseases.

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 can be eaten on a gluten free diet. Plain meat (including meat fed on gluten-containing grains), poultry, fish, eggs, cheese, milk, yoghurt, fruits, vegetables, pulses (peas, beans and lentils), rice, nuts and seeds, maize (corn) and potatoes are naturally gluten free.

Coeliac UK produces an annual Food and Drink Guide which is available online or hard copy which lists thousands of foods from tins of soup to ready meals that are safe to eat. By using the Food and Drink Guide, a knowledge of which foods contain gluten, and those which can be included on a gluten free diet can be built up. Gluten free products are available in the Free From section of supermarkets, in health food stores and on the internet.

Can anyone get hold of the Food and Drink Directory?

Membership of Coeliac UK is available to anyone with an interest in coeliac disease and the gluten free diet. Members receive the charity's Food and Drink Guide, access to its apps, venue guide which contains thousands of venues with accreditation to the charity, Coeliac UK's *Live Well Gluten Free* magazine and many more services.

Included in the membership package are the charity smartphone apps, *Gluten Free Food Checker* with access to the Coeliac UK Food and Drink Guide, allowing items to be scanned whilst out shopping to see if they are suitable, and *Gluten free on the Move* which helps you find places to eat out gluten free.

Membership costs £2 a month (concessionary rates available). Around 11,000 new members join Coeliac UK every year. To join Coeliac UK, call 0333 332 2033 or visit www.coeliac.org.uk/join.

Can you get gluten free food on prescription?

The Department of Health and Social Care has 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.

Can't you just read the list of ingredients on the label?

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.

Are there some foods that are labelled gluten free?

Yes, you may see the term gluten free on products. When this term is mentioned the food is OK for people with coeliac disease to eat. The term gluten free is covered by legislation on the labelling of gluten free foods which came into force on 1 January 2012.

Only foods which contain 20 parts per million (ppm) or less of gluten can be labelled gluten free. This includes naturally gluten free foods, specialist substitute products and uncontaminated oat products. This legislation is based on the revised Codex standard published in July 2008.

What about eating out – it must be difficult?

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. Where the information is not provided written and upfront, there must be clear signposting to where the information can be found. Businesses choosing to provide information orally must ensure that there is a written notice, menu, ticket or label that is clearly visible, at the point food is chosen, to indicate that allergen information is available from a member of staff.

Coeliac UK runs an 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 lists accredited venues and member recommended venues where they've had a good experience. There are over 7,000 venues listed so that more and more people can find somewhere to eat that caters for their gluten free diet. The charity has launched a range of catering services to support this and you can find more information at www.coeliac.org.uk/cateringservices.

What about going on holiday or even going abroad?

Coeliac UK produces information leaflets for more than 50 countries, with language translations that can be used when going on holiday. These are available on our website. The leaflets include translations and contact details for their destinations local coeliac organisation if they have one. The local organisation can sometimes provide lists of hotels, restaurants and shops which supply gluten free foods, as well as their gluten free food list.

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