

Coeliac Disease

Coeliac disease mainly affects the small intestine (part of the gut). It can occur at any age. Coeliac disease is caused by a reaction of the gut to gluten. Gluten is part of certain foods - mainly foods made from wheat, barley and rye. Various symptoms can develop including abdominal pains, tiredness and weight loss. Symptoms go if you do not eat any foods that contain gluten.

What is coeliac disease?

Coeliac disease is a condition that causes inflammation in the lining of the small intestine (part of the gut).

Coeliac disease is **not** a food allergy or a food intolerance. It is an autoimmune disease. The immune system makes white blood cells (lymphocytes) and antibodies to protect against foreign objects such as bacteria, viruses, and other germs. In an autoimmune disease, the immune system mistakes part or parts of the body as foreign. Other autoimmune diseases include [type 1 diabetes](#), [rheumatoid arthritis](#) and some thyroid disorders.

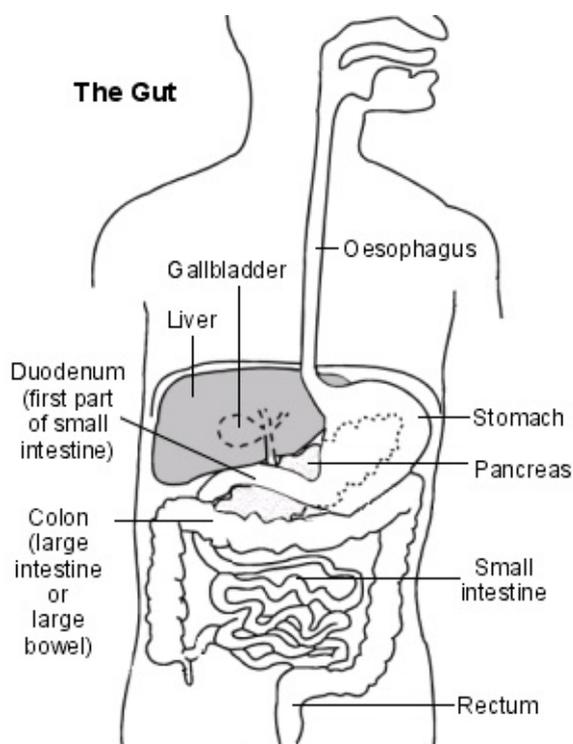
The lining of the small intestine contains millions of tiny tube-shaped structures called villi. These help food and nutrients to be digested more effectively into the body. But, in people with coeliac disease, the villi become flattened as a result of the inflammation. This means that food and nutrients are not so readily digested by the body.

Who does coeliac disease affect?

Coeliac disease affects about 1 in 100 people in the UK. Anyone, at any age, can develop coeliac disease. It is a condition that used to be associated with young children. However, it is now much more commonly diagnosed in adults. It is most commonly diagnosed in people aged between 40 and 50. About 1 in 4 cases are first diagnosed in people aged over 60.

Coeliac disease often runs in families. If you have a close family member who has coeliac disease (a brother, sister, parent or child) then you have a 1 in 10 chance of developing coeliac disease. It is also more common in people who have other autoimmune diseases - for example, some thyroid diseases, rheumatoid arthritis and type 1 diabetes.

What causes coeliac disease?



The cause is a sensitivity to gluten. Gluten occurs in common foods including wheat, barley, and rye, and any foods made from these such as bread, pasta and biscuits. Some people with coeliac disease are also sensitive to oats.

People with coeliac disease make antibodies against gluten. Antibodies are proteins in the immune system that normally attack bacteria, viruses, and other germs. In effect, the gut mistakes gluten to be harmful, and reacts against it as if it were fighting off a germ. These antibodies lead to inflammation developing in the lining of the small intestine.

Coeliac disease can develop in babies. Older children or adults who have not previously had problems may also become gluten-sensitive at some point in their life and develop coeliac disease. It is not known why the immune system of some people becomes sensitised to gluten.

What are the symptoms of coeliac disease?

The inflammation in the lining of the small intestine stops food from being properly absorbed. You then do not absorb nutrients very well into your body. A variety of symptoms may then develop.

Babies

Symptoms first develop soon after weaning when the baby starts eating solid foods containing gluten. The baby may fail to grow or to gain weight. As food is not being absorbed properly, the faeces (stools) may be pale and bulky. Smelly diarrhoea may occur. The abdomen (tummy) may become swollen. The baby may have repeated vomiting.

Older children

The symptoms of coeliac disease in older children may be similar to those in babies. Poor absorption of food may cause deficiencies of vitamins, iron, and other nutrients. This may cause anaemia and other problems. As the fat part of the diet is poorly absorbed, the faeces may be pale, smelly and difficult to flush away. Diarrhoea may develop. However, the symptoms may not be very typical or obvious. If the gut and bowel symptoms are only mild then the first thing that may be noticed is poor growth.

Adults

Poor absorption of food may cause deficiencies of vitamins, iron, and other nutrients. Anaemia due to poor absorption of iron is common. Other common symptoms include: abdominal pains which tend to come and go, excess wind, bloating, diarrhoea, and tiredness or weakness. Mouth ulcers may occur. You may lose weight due to poor absorption of food. However, most adults with coeliac disease do not lose weight and are not underweight.

Occasionally, an itchy skin condition called dermatitis herpetiformis can occur in some people with coeliac disease.

If the common symptoms described above develop, the diagnosis may be made quickly. However, common or typical symptoms do not always develop. Particularly in adults, the areas affected in the gut may be patchy. Symptoms may then be mild, or not typical, and it may be a while before the diagnosis is made.

How is the diagnosis confirmed?

If coeliac disease is suspected, a blood test to detect a certain antibody that occurs in coeliac disease may be advised by your doctor. It is important that you are eating a diet containing gluten for at least six weeks before the blood test is performed.

If the blood test is positive, then you may be referred to a specialist who may arrange for a **biopsy** to be taken. The biopsy is small sample of tissue that is taken from the inside lining of the small intestine. This is looked at with a microscope to see if the typical changes of coeliac disease are present. The biopsy is usually taken by a thin flexible tube (endoscope) which is passed down the gullet (oesophagus), through the stomach and into the small intestine.

Other tests may be done to find out how much the poor absorption of food and nutrients has affected you. For example, blood tests for anaemia and for the levels of vitamins, iron, protein, etc. You may be advised to have a special bone scan (a **DEXA scan**) to see if your bones have become affected due to poor absorption of calcium and vitamin D.

Note: if you suspect that you may have coeliac disease from your symptoms, then see a doctor. Do not treat yourself by going on a gluten-free diet (described below) without a confirmed diagnosis. If you do go on a gluten-free diet before the diagnosis is confirmed, then any tests done at a later time may not be conclusive and may even give negative results. So, get it checked out first - and then treat it if it is confirmed.

Are there screening tests for coeliac disease?

Coeliac disease tends to be under-diagnosed. There are certain groups of people who are much more likely to have coeliac disease than others. They should have a test for coeliac disease even if they have no or few symptoms. This includes people with:

- Type 1 diabetes: if available, children should be tested for the most common gene types that are associated with coeliac disease. These are HLA-DQ2 or HLA-DQ8. If they do not have these types, they are extremely unlikely to develop coeliac disease. If this test is not available they should have the blood test for the specific antibody, every three years.
- Close relatives (parent of, child of, brother/sister of) of a patient with coeliac disease.
- Down's syndrome
- Autoimmune conditions such as thyroiditis, Sjögren's syndrome or arthritis.

What are the treatments for coeliac disease?

Gluten-free diet

The main treatment for coeliac disease is not to eat any food that contains gluten for the rest of your life. The symptoms then usually go within a few weeks. The main foods to stop are any that contain wheat, barley, or rye. Many common foods contain these ingredients, such as breads, pasta, cakes, pastries and some cereals. Foods made from oats are usually safe to eat. However, some people with coeliac disease have symptoms if they eat oats. Potatoes, rice, maize, corn, fruit, dairy products and soya-based foods are fine.

You should get advice from a dietician. Coeliac UK also provides advice about which foods are suitable (see address below). You can buy special gluten-free flour, pasta, bread and other foods. These are also available on prescription, from health food shops, by mail order and via the internet. There are many diet sheets with food alternatives and recipes. Unfortunately, many processed foods, ready-made meals, and fast foods contain gluten. Food labels will often say whether the food contains gluten or not.

Avoiding gluten is for life. If you eat gluten again, symptoms will return. Even small amounts of gluten can sensitise the gut again. To avoid symptoms and complications (see below), you must be strict about avoiding **all** foods that contain gluten.

You may have to accept some restriction on lifestyle. However, the many foods that are allowed are varied and interesting.

Other treatments

In addition to avoiding gluten, you may be advised to take some vitamin, calcium and iron supplements, at least for the first six months following diagnosis. This is to replace any deficiencies and also to make sure you get enough of these whilst the gut lining is returning to normal.

Having coeliac disease can cause your spleen to work less effectively, making you more vulnerable to infection from certain germs. If your spleen is working less effectively, you may need to have several immunisations including:

- The **flu** (influenza) jab.
- The **Hib vaccine** - which protects against blood poisoning, pneumonia, and Hib meningitis.
- The **pneumococcal vaccine** - which protects against infections caused by the bacterium *Streptococcus pneumoniae*.

Are there any complications?

Although there is no once and for all cure for coeliac disease, the symptoms can be kept away by having a diet free from gluten. Also, having a gluten-free diet reduces the risk of developing complications in the future.

Apart from the symptoms listed above, people with coeliac disease have an increased risk of the following:

- Developing **osteoporosis** (thinning of the bones) due to the nutritional deficiencies which occur with coeliac disease.
- Developing lymphoma (a type of cancer) of the gut in later life. This is rare.
- Developing other immune-related diseases (autoimmune diseases) such as type 1 diabetes, an **underactive thyroid**, Sjögren's syndrome and **primary biliary cirrhosis**.
- Having a baby that has a low birth weight or is born prematurely if you become pregnant.

A common mistake is to eat small amounts of food which contain gluten. This may be unintentional. However, some people wrongly think that a small amount won't matter. It does. A well-known example is thinking that the small amount of bread in a communion wafer will not matter. Even this small amount of gluten is sufficient to cause symptoms, and to maintain the increased risks associated with coeliac disease detailed above.

Some people with coeliac disease may not realise they are taking small amounts of gluten. They may feel well, or ignore mild symptoms such as bloating or mild diarrhoea. Again, the increased risks (osteoporosis, etc) still remain if any gluten is eaten.

If you do not eat any gluten, you can expect to be free of symptoms and to have a normal healthy lifespan. The increased risk of developing other autoimmune disorders reduces. Eating a gluten-free diet also reduces the risk of developing lymphoma.

Follow-up

Once you have been diagnosed with coeliac disease, you are likely to have regular follow-up appointments. This may initially be after three and six months to ensure that you are making satisfactory progress and managing your gluten-free diet. Depending on your age and other factors, you may be monitored to see if you have developed osteoporosis.

You can expect to live a life free of the symptoms of coeliac disease if you totally avoid gluten.

Further help and information

Coeliac UK

3rd Floor, Apollo Centre, Desborough Road, High Wycombe, Buckinghamshire HP11 2QW
Helpline: 0845 305 2060 Web: www.coeliac.org.uk

Further reading & references

- **Coeliac disease**; NICE Clinical Guideline (May 2009)
- **The Management of Adults with Coeliac Disease**; British Society of Gastroenterology (2010)

- [Guideline for the diagnosis and management of coeliac disease in children](#), British Society of Paediatric Gastroenterology, Hepatology and Nutrition with Coeliac UK (Sept 2013)
- [Coeliac Disease](#); NICE CKS, May 2010
- [Prescribable Product List](#), Coeliac UK

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