

Department of Paediatric Gastroenterology, Hepatology and Nutrition

Coeliac Disease

Information for paediatric patients, parents and guardians

What is coeliac disease?

Coeliac disease is a condition where the lining of the small intestine (the gut) is damaged. The small intestine is the site for digestion of food and absorption of nutrients.

- Digestion is the process of breaking down food.
- Absorption occurs when the nutrients are carried across the lining of the intestine and into the bloodstream.

If the small intestine is damaged then the body may not absorb sufficient nutrients. This can result in weight loss and vitamin deficiencies. Fluid that is not absorbed passes through the intestine and causes diarrhoea.

What causes coeliac disease?

Coeliac disease is caused by the body reacting to a substance called **gluten** that is found in some foods. The gluten itself does not cause real damage. However, people with coeliac disease have an immune system that misrecognises the gluten as being a threat and mounts a defensive response to it. As a result, the lining of the intestine is damaged. The intestinal lining is a little like a battlefield which is damaged by the fighting between the immune system and the gluten.

What is gluten?

Gluten is a mixture of proteins that is found in some cereals such as wheat. It is the component of wheat flour that makes dough sticky and therefore is important in bread-making.

What foods contain gluten?

Gluten is found in certain cereals:

- Wheat
- Barley
- Rye

Why do people get coeliac disease?

All of us are exposed to gluten throughout our lives, but only some people develop coeliac disease. These people have a genetic (inherited) susceptibility to the condition. The genes that lead to coeliac disease have not all been discovered yet.

As coeliac disease can occur at any age, it is quite likely that something acts as a trigger. We do not yet know what this is, but it could, for instance, be an infection in some cases.

How common is coeliac disease?

Coeliac disease is thought to affect as many as 1 in 100 children.

What symptoms are caused by coeliac disease?

Coeliac disease can present with the following symptoms.

- **Weight loss or poor growth:** this can be seen with children of any age as the nutrients are not effectively absorbed. Crossing centiles for weight or height on a child's growth chart or weight loss are causes for concern. Toddlers can present with muscle wasting such as small buttocks and thin legs but with a large tummy (see abdominal pain and bloating).
- **Diarrhoea:** this is caused by the damage to the gut lining. Stools can be foul smelling, yellow and hard to flush.
- **Abdominal pain and bloating:** food that is not absorbed in the intestine is passed into the large bowel ('colon'). Here there are vast numbers of bacteria that happily feast on the nutrients, but in doing so produce large amounts of gas. Gas bloating can result in abdominal discomfort and even pain.
- **Shortness of breath and tiredness all the time:** this may be a result of anaemia – a low red blood cell count. Red blood cells carry the oxygen in the blood to every part of the body. If there are too few red cells, then the body fatigues quickly and the rate of breathing is increased. The three essential ingredients that the body needs for making red blood cells are iron, folic acid and vitamin B12. These fail to be absorbed in sufficient quantities in coeliac disease and anaemia can result.

However, some children have no or very mild symptoms.

How is coeliac disease diagnosed?

There are two main tests for coeliac disease – a blood test and a biopsy.

- The blood test is for an antibody (a protein that the body makes during an immune reaction). This test is not perfect. It is still possible to have coeliac disease despite having a normal blood test. The blood test can occasionally be positive in people without coeliac disease. However, people with very high values on the blood test are highly likely to have coeliac disease in the future.
- A 'biopsy' is a tiny (2-3mm) sample of the lining of the gut. This is the 'gold standard' test for coeliac disease and must be done to confirm a positive blood test. The biopsy is obtained using an 'endoscope' – a flexible tube that is passed down the throat, into the stomach and the upper part of the intestine. The results of this test can take two to three weeks to become available.

What is the treatment for coeliac disease?

As gluten causes coeliac disease, simply removing gluten from the diet effectively cures the symptoms and removes the risks associated with having coeliac disease. Given that gluten is found in so many foods, this is not always very easy. Nowadays however, there are special ways of manufacturing flour that removes the gluten and enables bread, biscuits and cakes to be made that are gluten-free. There are also some naturally occurring gluten-free flours that can be used. These can be bought or baked at home. The dietitian will advise you on how to remove gluten from the diet and where you can get gluten-free food.

How quickly will the gut heal on a gluten free diet?

Even on a very strict gluten-free diet it can take several months for the intestine to return completely back to normal. An improvement in energy levels and reduction in symptoms should be seen within months, although it will take a little longer for growth to catch up.

What happens if my child accidentally eats gluten?

If your child accidentally has gluten they will come to no serious harm, but they may experience symptoms.

Unless you are very careful to remove all the gluten from the diet, they will receive no benefit from the gluten-free diet as the effects of even a small amount can last for a long time. This is because it is not the amount of gluten that is important, but the scale of the body's immune reaction that causes the damage.

Maintaining the diet can be particularly difficult when going out, eating with friends, at parties, while travelling and during adolescence. Some people with coeliac disease find that they have severe symptoms after eating a tiny amount of gluten, such as profuse diarrhoea or vomiting and they of course find it easier to stick to the diet. Having no symptoms does **not** mean you can eat gluten, your gut can still be damaged even if you have no or very mild symptoms.

Why is it important to stick to the gluten free diet?

Even though some people claim to have no symptoms at all when first diagnosed, the majority do actually feel better on a gluten-free diet.

People who do not stick to a very strict gluten-free diet are at risk of the complications of untreated coeliac disease. However, on a gluten-free diet the risk of the more severe complications of coeliac disease is very low. The average life expectancy of coeliac patients on a gluten-free diet is exactly the same as for people without coeliac disease.

What are the complications of untreated coeliac disease?

Poor growth: children who present with coeliac disease will often have poor weight gain and/or poor growth. Without removing all gluten from their diet, it is highly unlikely that these children will reach their maximum height potential.

Weak bones: one of the vitamins poorly absorbed in untreated coeliac disease is vitamin D, which is required to keep bones healthy. Patients with coeliac disease can have weak bones that fracture easily. However, the condition / strength of the bones can be largely restored in children and young adults by adherence to a gluten-free diet.

Impaired immunity: for reasons that are not well understood, patients with untreated coeliac disease can be susceptible to certain bacterial infections such

as pneumonia and meningitis. This risk is rapidly reduced to normal levels by adherence to a gluten-free diet.

Dermatitis herpetiformis (or DH): this is a very rare condition where the skin is also damaged by eating gluten (it is not due to exposure of the skin to gluten). It causes an intensely itchy blistering rash, often on the elbows, buttocks and or knees. While this will get better with a gluten-free diet, this takes some time to respond.

Cancer: the most worrying complication of undiagnosed / untreated coeliac disease is the development of cancer in the small intestine. This is almost certainly the result of longstanding inflammation and damage in the intestine due to the immune reaction against gluten over many years. This is usually a cancer of the immune cells (called a 'T-cell lymphoma'), which is almost unique to coeliac disease. However, this cancer is **extremely rare** and the risk of this condition is almost completely removed by adherence to a gluten-free diet.

Are there any other conditions associated with coeliac disease?

One of the reasons that your child will be invited to attend yearly clinics for follow up is that there are certain conditions that are more common in patients with diagnosed coeliac disease, even if gluten has been completely removed from the diet. Fortunately, the majority of these can be treated easily. It is important to consider the possibility of these developing if your child experiences any unexplained new symptoms.

- **Autoimmune conditions** patients with coeliac disease actually have a very well developed immune system. It's so powerful that it attacks things that it should not, such as gluten! Certain organs can also be damaged by the immune system and cause other so-called 'auto-immune' (or 'self-immune') conditions. However, the sooner gluten is completely removed from the diet, the lower the risk of developing other immune conditions later in life. These conditions include:
 - **Thyroid disease:** the thyroid gland can become either over or under active. This is easy to detect with blood tests and easily treated if necessary with tablets.
 - **Pernicious anaemia:** this is due to damage to the lining of the stomach and results in a loss of vitamin B12 that is essential for making blood. This can be easily detected in blood tests and treated.
 - **Diabetes:** there is an increased risk of diabetes in patients with coeliac disease but only the type of diabetes that requires insulin treatment and

begins in early life. About 1 in 10 diabetic patients may develop coeliac disease in their lifetime.

- **Addison's disease:** this is caused by damage to the gland that produces the body's own steroids and can be detected by a simple test, and treated with tablets to replace the body's steroid production.
- **Rheumatoid disease:** this can be caused by an immune reaction against the joints and requires medications to control the arthritis in the majority of cases.
- **Primary biliary cirrhosis:** this is a reaction against the tubes that drain bile from the liver and can result in itching or yellow discoloration of the skin (jaundice).

Can other members of the family also have coeliac disease?

Yes. The risk of a first degree family member (such as a parent or brother/sister) having coeliac disease is about 1 in 10. This is inherited through the genes and **cannot** be 'caught' like an infection.

We advise first degree relatives are tested even if they have no symptoms, and members of the extended family are tested if they have medical conditions or unexplained symptoms of any sort. As coeliac disease can present at any age, a single test does **not** mean that the individual will never develop coeliac disease. Therefore it may be necessary to repeat the test at a later date if new / different symptoms occur.

When should a child with a family history of coeliac disease be weaned?

The advice is to avoid gluten containing products until six months of age. However, there is no advantage in delaying introduction any longer than six months. Breastfeeding is protective against coeliac disease and can delay the onset of symptoms. Formula milk and breast milk are gluten-free. If you have any concerns or your child is showing signs of coeliac disease then contact your GP.

How do I find out more about coeliac disease?

Coeliac UK- the patient support group is an excellent resource. As well as publishing a booklet of all gluten-free food manufacturers and produce, they produce a quarterly magazine – 'Crossed Grain' and advertise local groups that meet regularly. There is also a very informative website for those with internet access. This can be found at www.coeliacuk.co.uk. The helpline number is 01494 444 8804.



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