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## Department of Gastroenterology

# Coeliac disease

## Information for patients attending Addenbrooke's Coeliac Disease Clinic

### 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 into its constituent components.
- Absorption occurs when the nutrients are carried across the lining of the intestine and into the blood stream.

If the small intestine is damaged then the body may not absorb sufficient nutrients. This can result in weight loss and vitamin deficiencies. Similarly, 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 any 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

Unfortunately, wheat flour is used in many sauces and gravies. It binds and thickens the fluid – this is due to the gluten. Therefore, many prepared and 'ready' meals contain gluten, and it is found in bread, biscuits, batter and beer (and cake), sweets and chocolates.

## 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?

If you have coeliac disease, you are in good company as it is one of the most common conditions in European populations – it is thought to affect as many as 1 in 100 people.

## What symptoms are caused by coeliac disease?

In the majority of cases, coeliac disease is detected coincidentally – for instance by a minor abnormality on a blood test taken for other reasons. It is thought that only about one in every five patients with coeliac disease has symptoms that make them go to the doctor. However, coeliac disease can cause people to be very ill:

- **Weight loss and diarrhoea:** A significant amount of weight can be lost due to the lack of absorption of nutrients. The diarrhoea can be profuse and may be foul smelling, yellow and fail to flush away in the toilet.
- **Shortness of breath and fatigue:** This may be the 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. This results in a feeling of breathlessness. There are three essential ingredients that the body needs for making red blood cells – iron, folic acid and vitamin B12. These fail to be absorbed in sufficient quantities in coeliac disease and anaemia can result.
- **Abdominal pain and bloating:** Food that is not absorbed in the intestine passes 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.

## 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 chemical that the body makes during an immune reaction). This test is not perfect. It is possible to have coeliac disease despite having a negative blood test. Also the blood test can be positive in people without the disease. However, people with very high values on the blood test are most likely to have coeliac disease. A negative blood test does not mean that you will not develop coeliac disease in the future.

- A 'biopsy' is a sample of the body tissues – in this case the intestinal lining. This is the 'gold standard' test for coeliac disease and will confirm the blood test results. 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. This test is performed under local anaesthetic or light sedation as a day-case - it takes only a few minutes. It is not nearly as unpleasant as it may sound and is a safe and entirely routine test. The results of this test can take two or three weeks to be available afterwards.

## What is the cure for coeliac disease?

As gluten causes coeliac disease, simply removing gluten from the diet cures the condition. 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. These can be bought or baked at home using gluten free flour. The dietician will advise you on how to remove gluten from the diet and where you can get gluten free food from.

## How quickly will I get better on a gluten free diet?

It can take some weeks for the intestine to return to normal **when on a very strict gluten free diet**. As most people take some time to learn how to exclude gluten from the diet, we do not check for a response to the diet for several months after you have started it.

## What happens if I accidentally have some gluten?

If you accidentally have some gluten you will come to no serious harm but may experience symptoms.

Unless you are very careful to remove all the gluten from the diet, you will receive no benefit from your gluten free diet as **the effects of even a small amount of gluten can last for a long time**. This can be particularly difficult when out, eating with friends or travelling. 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 find it easier to stick to the diet.

## Why is it important to stick to my gluten free diet?

Even though many 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 complications of coeliac disease that can be life-threatening. However, on a gluten free diet the risk of severe complications of coeliac disease is 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 coeliac disease?

**Weak bones:** One of the vitamins poorly absorbed in coeliac disease is vitamin D, which is required to keep bones healthy. Patients with untreated coeliac disease can have weak bones that fracture easily. However, the condition of the bones can be largely restored by adherence to a strict gluten free diet. Your bone density (strength) will be measured in the coeliac clinic and additional treatment can be started if necessary to strengthen the bones. With proper care, the risk of bone fractures in coeliac disease can be only very slightly higher than in patients without the disease.

**Impaired immunity:** For reasons that are not well understood, patients with 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.

**Cancer:** The most feared complication of 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 reaction with gluten occurring over many years. There are two types of cancer in the intestine of which one – a cancer of the immune cells called a ‘T-cell lymphoma’ – 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 conditions that are associated with coeliac disease?

One of the reasons that you will be invited to attend the coeliac clinic for long term follow up is that there are certain conditions that can be associated with coeliac disease. Fortunately the majority of these can be treated easily. It is important to consider the possibility of these developing if you should experience new symptoms and for the tests to be carried out regularly.

- **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 and there is a drug called ‘Dapsone’ that can be used to speed up the improvement. However, this drug does not help heal the intestine.
- **‘Autoimmune conditions’:** Patients with coeliac disease actually have a very well developed immune system – so powerful that it unfortunately attacks things that it should not, such as gluten! Certain organs can also be targeted by the body’s own defenses and cause ‘auto-immune’ (or ‘self-immune’) conditions such as:
  - **Thyroid disease:** The thyroid gland can be either over or underactive. 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 with blood tests and treated by an injection every three months.
- **Diabetes:** There is an association of diabetes with coeliac disease – but only the type of diabetes that requires insulin treatment and begins in early life. Adults that develop coeliac disease rarely go on to develop this type of diabetes, whereas about 1 in 10 diabetic patients may become coeliac.
- **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 to 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 I pass coeliac disease on to my children?

Yes. The risk of a close family member (such as children or parents) having coeliac disease is about 1 in 10. This is inherited by the genes as it cannot be 'caught' like an infection. As coeliac disease can present at any age, it is not uncommon for parents to be tested positive for the disease after one of their children has become coeliac. Adults should be tested every two years with blood tests and if they develop symptoms at any stage.

Children should be tested if they have symptoms or at the age of 16 years if they are entirely well with no symptoms at all.

### How can I find out more information 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 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](http://www.coeliacuk.co.uk). The helpline number is 01494 444 8804.

## The Addenbrooke's Coeliac Disease Clinic

The Coeliac clinic at Addenbrooke's Hospital is held every Tuesday afternoon.

- Dieticians are present every week
- Doctors are present on alternate weeks, when newly diagnosed patients will be seen.
- All the staff that you will see (dieticians and doctors) are specialists in coeliac disease.
- Companies that manufacture gluten free foods will be present – or have produce on display.
- Representatives for 'Coeliac UK' - the patient support group will be available on certain weeks.
- Information regarding coeliac disease and gluten free food will be available in the waiting area.
- We hope to provide a book of local expertise in which you can contribute your experiences and knowledge – for instance with eating out and travelling.

## What happens in the coeliac clinic?

### Information for patients of the Addenbrooke's Coeliac Disease Clinic

This information is intended for people who have been recently diagnosed with coeliac disease.

#### At your first visit:

- If you have a positive blood test or biopsy for coeliac disease, you will be attending the coeliac clinic for the first time.
- Firstly, we need to confirm that you have coeliac disease. In the majority of cases this is clear already, but some people may need to have additional tests organised.
- A doctor will discuss the diagnosis with you and make sure that you have received all the necessary information.
- You will have further blood tests if necessary and be offered immunisations against bacteria that cause pneumonia and meningitis.
- A dietician will discuss the dietary treatment with you.
- You will receive complementary trials of gluten free products and a membership pack for Coeliac UK – the patient support group.
- You will be provided with a prescription for supplements that you may need. This might include calcium and vitamin D tablets and any vitamins in which you are found to be deficient.
- You will be given an appointment date for two months later (your second clinic visit).

**At your second visit:**

- A doctor will be available if you have any medical concerns.
- A dietician will see you and discuss any problems that you are having with the diet.
- Some further blood tests may be taken, especially if you were known to be deficient in any particular vitamins previously.

**After your second visit:**

- If all is well, you will not need to return to the clinic until after further tests – but if you wish to come back to the clinic beforehand, you may make an appointment or discuss a problem with the dietitians over the telephone.
- You will be sent an appointment for a further **endoscopy** which will take place approximately nine months after starting the gluten free diet. This is to make sure that you are responding to the gluten free diet.
- You will be sent an appointment for a **bone density scan** which will also take place approximately nine months after starting the gluten free diet.
- You will be sent an appointment for a follow up visit approximately one year after your first visit.

**At your third clinic visit:**

- A doctor will discuss the results of your tests with you.
- Routine blood tests will be taken.
- A dietitian will discuss any problems you are experiencing with the diet.
- Further follow up visits will depend on whether you or the medical staff has any concerns. In most cases, you will be invited to visit the clinic in one year.

**After your third clinic visit:**

- We will initially invite you to attend the clinic on an annual basis. Routine blood tests will be taken and any problems with health or diet can be addressed.
- If all is well and you feel that the annual visits are no longer necessary, then we can discuss annual review with your General Practitioner.

**If you have any questions or wish to receive further information about the Addenbrooke's Coeliac Disease Clinic, please contact Kate Nancekivell, telephone number 01223 216655.**

For further information please feel free to contact Dr Jeremy Woodward, Consultant Gastroenterologist at Addenbrooke's Hospital on 01223 596231



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**Help with this leaflet:**



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**Document history**

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