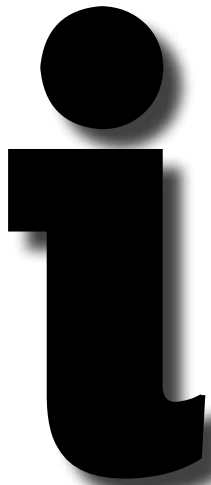


# Coeliac Disease (page 1 of 5)

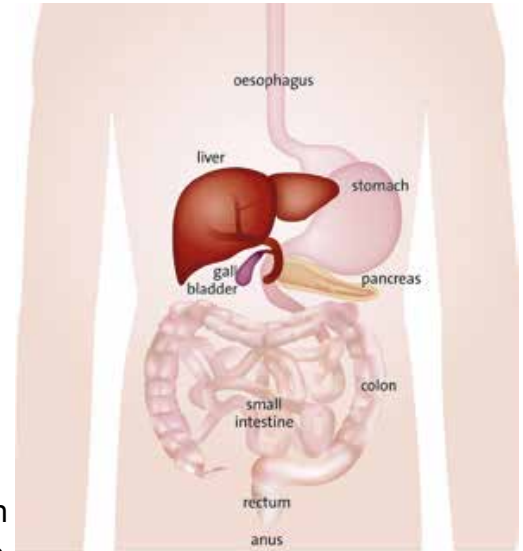


## What is coeliac disease?

Coeliac disease occurs in people who become sensitive to a particular protein in their diet called gluten.

Gluten is found in wheat and other cereals. It is normally a nourishing and quite harmless part of the food we eat.

But with coeliac disease, gluten causes damage to the lining of your small intestine. This can cause problems with absorption - the process of getting the nutrients and vitamins that we have eaten into the body. Coeliac disease can be diagnosed at any age from infancy to old age, but is most commonly recognised in children and young adults. The treatment, which is usually very successful, is to remove all sources of gluten from the diet.



## Why does coeliac disease happen?

We do not know why but there are lots of theories. Most doctors believe that there is a factor in our genes which determines whether our intestines become sensitive to gluten. In other words, whether we get coeliac disease or not is determined before we are born – there's nothing we can do about it. Like many illnesses, coeliac disease can run in families but the specific genes have not been identified. As yet there is no way of testing our genes to see whether you, (or your children), will develop the condition.

## How does gluten damage my intestine?

Although not technically an allergy, it is helpful to think of people who have coeliac disease as being allergic to gluten, in the sense that gluten causes no harm to the body unless you have coeliac disease. If we were to look at normal small intestine under the microscope, we would see vast numbers of tiny finger like projections sticking up from the surface (see diagram on next page). They are called villi and their purpose is to enhance the process of absorption.

In coeliac disease, the finger-like villi are shorter and stubbier. In more severe cases, they can barely be seen at all so the lining of the intestine looks quite flat. Doctors call this villous atrophy.

If you need your information in another language or medium (audio, large print, etc) please contact Customer Care on 0800 374 208 or send an email to: [customer care@salisbury.nhs.uk](mailto:customer care@salisbury.nhs.uk)

You are entitled to a copy of any letter we write about you. Please ask if you want one when you come to the hospital.

If you are unhappy with the advice you have been given by your GP, consultant, or another healthcare professional, you may ask for a second (or further) opinion.

The evidence used in the preparation of this leaflet is available on request. Please email: [patient.information@salisbury.nhs.uk](mailto:patient.information@salisbury.nhs.uk) if you would like a reference list.



We will see later how recognising villous atrophy is the key to making the diagnosis of coeliac disease. If patients with coeliac disease stop eating gluten, their villi grow back again.

## How many people are affected?

It has become clear recently that coeliac disease is much commoner than we thought. Recent research has shown that one in 100 people in the UK have it. It is known to occur more frequently in certain countries and the world's highest incidence is in the west of Ireland. Most people who have coeliac disease don't actually know they have it. Although such individuals will have some degree of intestinal damage, they may have no symptoms at all. Because of this, only 1 in 800 people have been diagnosed with coeliac disease in the UK.

## What symptoms might I expect with coeliac disease?

Interestingly there is a wide variation in the symptoms that people experience.

In children, there may be diarrhoea, vomiting or a failure to gain weight. In adults, the disease comes to medical attention in a wide variety of ways. A common symptom is diarrhoea with bloating or discomfort in the abdomen.

Often patients don't have any symptoms that might relate to their guts, but coeliac disease is suspected if tests show anaemia or they are found to have thin bones (osteoporosis). Such diseases of the blood and bones may occur because patients cannot absorb iron, calcium and several vitamins from their diet. In other cases, people lose weight for no obvious reason or just feel unwell in a rather vague way. Many patients have mild symptoms for months or years before seeing a doctor. Only when they are correctly diagnosed and started on treatment do they realise how long they have been unwell.

## How is coeliac disease diagnosed?

Having both listened to your medical history and examined you, if the doctor suspects you may have it, you will be asked to have some blood tests which will help to find out if you might not be absorbing food properly from your diet. These tests must be done while you are still eating gluten-containing foods. As we have seen, a doctor might consider a diagnosis of coeliac disease in many situations. Fortunately, there is a simple test to look for antibodies in a sample of your blood that can reliably show whether you are likely to have coeliac disease. If the test is negative, it makes it very unlikely that you have coeliac disease. However, a positive blood test does not confirm the diagnosis beyond doubt. So if the result is positive, or in situations where there is still a possibility that you might have coeliac disease, your doctor will advise you to have a further test called an endoscopy.

## What does endoscopy involve?

An appointment for endoscopy will be made either by your GP or your specialist. You will be given information about how to prepare for the test. On the day, a doctor or nurse will explain exactly what is involved. Endoscopy involves passing a tube through the mouth and down to the small intestine where biopsies are taken. Neither passing the tube nor taking biopsies are painful although it is fair to say the procedure is not particularly comfortable. Your doctor will discuss

with you the various ways in which the discomfort can be reduced. The biopsy samples are sent to the laboratory to be examined under a microscope which will show whether or not the villi are abnormal.

## **And if I do not fancy having endoscopy?**

No-one is going to make you undergo any test or investigation. But the only way to be absolutely certain of the diagnosis is by taking a biopsy from your small intestine by endoscopy.

The treatment of coeliac disease requires a special diet for life and it's absolutely crucial to be certain about the diagnosis.

## **How is coeliac disease treated?**

Because the disease is caused by eating gluten, the treatment is to avoid eating any food which contains it. This means following a gluten-free diet for the rest of your life. If you are diagnosed with coeliac disease, the doctor will suggest you should consult a dietician. Sticking to a gluten-free diet requires knowledge about which foods contain gluten and how to maintain a balanced diet without wheat and the other cereals you must avoid. The dietician will provide written information to help you remember.

## **What exactly is gluten?**

Gluten is a protein that is found in flour made from wheat and is also contained in rye and barley. The gluten content of flour is the reason that flour can be formed into dough and then rises during baking. Gluten in flour is contained in many foods but especially bread and pastry.

## **What foods contain gluten?**

Gluten is present in any foods that are made using wheat, rye or barley. Bread, pastry and cakes are all made with flour and contain large amounts of gluten.

Breakfast cereals are often made from wheat, rye and barley. Lots of other foods unexpectedly turn out to contain gluten. For example, flour is used as a thickener in many cooking sauces and barley is used in making all beer and lager. Some foods occasionally get contaminated with small amounts of gluten during production or processing.

Oats are not believed to be harmful to people with coeliac disease, but some cereals made from oats turn out to contain traces of gluten which make them unsafe to eat. It is worth checking the labels on such products to see if they are gluten-free.

## **Where can I find out more about what I can eat safely?**

Coeliac UK (formerly the Coeliac Society) provides a large amount of information for people with coeliac disease. Your doctor will encourage you to become a member if you are diagnosed with coeliac disease. Coeliac UK publishes a list of gluten-free products in a handbook which is updated every year.

The list is also available to members on their website which also has links to other sources of information. They also publish a quarterly magazine which provides information about new products, recipes, social and educational events and research developments.

You can contact Coeliac UK at:  
PO Box 220, High Wycombe, Bucks,  
HP11 2HY or phone: 01494 437278.

Website: [www.coeliac.co.uk](http://www.coeliac.co.uk)

## **What can I eat instead?**

Many food manufacturers make alternative products for people with coeliac disease. These products replace staple constituents of the diet such as bread, biscuits, pizza bases and flour but are carefully made without gluten and are therefore safe to eat. These products can be purchased from supermarkets and health shops. It is currently possible to obtain a supply of these foods on prescription from your doctor. Many other foods are naturally gluten-free and therefore safe to eat.

## **Can I rely on food labelling?**

The current legislation requires food manufacturers to label foods with the basic constituents but this is to change soon so that all individual ingredients must be clearly stated. Most manufacturers label their products separately as gluten-containing or gluten-free, but generally gluten should be listed as an ingredient where present.

Restaurants are increasingly trying to help by indicating the use of gluten in dishes. However many restaurants currently do not label their meals and you may have to ask.

## **What happens if I eat gluten by accident?**

This depends on how sensitive you are to gluten. If you only had mild symptoms in the first place then you will probably not feel ill if you consume some gluten by accident. This does not mean that you should not try to stick to your gluten-free diet as any amount of gluten can potentially cause inflammation in your intestine. Some patients are very sensitive to gluten and develop symptoms if they accidentally eat even a tiny amount of gluten. It is even more important that they follow a strict gluten-free diet.

## **Why do I have to follow a gluten-free diet?**

You are far less likely to have any symptoms if you follow a gluten-free diet. Most people who follow the diet say they feel healthier and more energetic. Following the diet will also reduce the risk of you developing future problems.

## **Will I need to stick to the gluten-free diet forever?**

Yes. Coeliac disease does not go away although you will feel healthier if you are following the diet properly. You are far less likely to develop future problems if you stick to the diet. Most people find it easier to follow the diet once they have got used to it.

## **What future problems might I have with coeliac disease?**

Most people with coeliac disease stay well provided they follow a gluten free diet. There is a risk of developing problems such as a low blood count (anaemia) or thinning of the bones (osteoporosis) but these are far less likely if you eat the correct foods.

If you do develop these problems, your doctor may put you on tablets. Before starting the diet, women with coeliac disease can have fertility problems but these usually resolve once the gluten-free diet has started.

## Does coeliac disease increase your risk of cancer?

Some research a few years ago showed that coeliac patients might be more likely to develop certain types of cancer. In fact, more recent studies have shown that this is incorrect. There is a rare form of tumour affecting the bowel which does occur in a very small number of people with coeliac disease after many years, especially if they continue to eat gluten.

If you have coeliac disease and stick to the diet, you can expect the same life expectancy as anyone else.

## Does my doctor need to check me regularly?

Because you might develop problems in the future, it is worth keeping an eye on your health. It is recommended that you have a check-up once a year to ensure all is well. It is a good idea to have blood tests once a year to ensure you are not anaemic or have become short of vitamins and other nutrients.

Your doctor may also arrange for you to have a simple scan of your bones from time to time to look for any sign that the bones have become thin so this can be treated early.

People with coeliac disease are less able to produce antibodies to infections, so that vaccinations against flu and pneumococcal infections are recommended.

## Are any of my family likely to be affected?

Coeliac disease can run in families. If you have the condition, your parents, children and brothers and sisters have a one in 10 chance of also being affected.

As the condition is easy to treat, there is emphatically no reason to worry about deciding to have children – unless you plan a very large family, the chance is that your children will be unaffected.

However, you may wish to let your brother or sister know that they might have coeliac disease so they can have a check-up. Other more distant relatives, such as uncles, aunts and cousins are not more likely to be affected.

## What research is needed?

We need to know more about why people develop coeliac disease. This will involve more research on how the genes of people with it differ from those who don't have the condition. We also need to know more about how gluten causes damage to the intestine. There is much to be done to develop gluten-free products as tasty alternatives for patients to eat.

With acknowledgements to Core – the Digestive Disorders Foundation in association with the British Society of Gastroenterology and the Primary Care Society for Gastroenterology

## CORE

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