

In association with:



INFORMATION ABOUT

# Coeliac disease

[www.corecharity.org.uk](http://www.corecharity.org.uk)

**What is coeliac disease?**  
**Why does coeliac disease happen?**  
**How many people are affected?**  
**How is coeliac disease diagnosed?**  
**How is coeliac disease treated?**  
**What exactly is gluten?**  
**What foods contain gluten?**

Juvela have provided sponsorship for the production of this leaflet

# What is coeliac disease?

Coeliac disease is an auto immune condition which occurs in people who become sensitive to a protein called gluten in their diet. Gluten is found in wheat and other cereals. It is normally a nourishing and harmless part of the food we eat.

**But if you have 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?

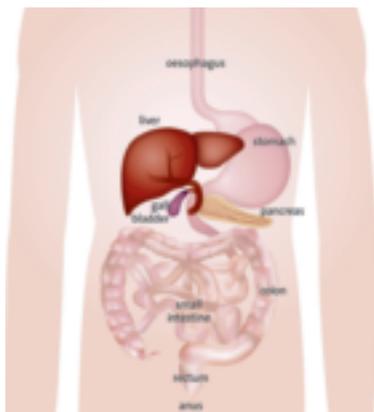
We do not know why people develop coeliac disease but there are lots of theories. Most doctors believe that a factor in our genes determines whether our intestines become sensitive to gluten. Like many illnesses, coeliac disease can run in families and the specific genes are now being identified, although at present 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?

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 page 4). 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. 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?

Over the past few years, it has become clear that coeliac disease is much commoner than we used to think. Recent research has shown that one in 100 people in the UK have this condition. 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 very mild or non-specific symptoms. Because of this, only 1 in 800 people have been diagnosed with coeliac disease in the UK. The implications for health of undiagnosed coeliac disease are unknown.

### ? 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. Quite 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 coeliac disease, you will be asked to have some blood tests which will help to find out if you have the antibodies indicative of coeliac disease. 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 thin, flexible 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 and you will be able to choose the method that suits you best. 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 it is important to appreciate that 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 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 found in wheat, rye and barley. Gluten in flour is milled from these grains and found in many foods, 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 products made from oats may 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.

Coeliac disease under a microscope



Normal

Partial

Severe

## **? 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 magazine which provides information about new products, recipes, social and educational events and research developments.

You can contact Coeliac UK on 01494 437278 or the helpline on 0845 305 2060. 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?**

Current legislation requires food manufacturers to label foods so that all individual ingredients must be clearly stated. Most manufacturers label their products as 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 iron 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 tablet supplements 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?**

Having coeliac disease may increase your risk of having certain types of cancer. 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 may be 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 coeliac disease differ from those who don't have the condition. We also need to know more about how gluten causes damage to the intestine. Gluten-free products have become much better tasting in the last 5 years.

Updated February 2011

This booklet is kindly sponsored by:

**juvela**

# You can help combat gut and liver disease by making a donation.

## Core needs your support

Quality of life may be seriously threatened when things go wrong with our insides.

Diseases of the gut or liver cause pain and distress for many people in the UK and tragically account for around one in eight deaths. Core is here to help.

Core works to prevent, cure or treat gut and liver diseases by funding high quality medical research.

If you have found this leaflet useful, please use the form overleaf to make a donation to help Core's work. Core relies on charitable donations and urgently needs funds both to undertake more research and to continue its information programme.

Send your completed form and donation to:

### Core

**FREPOST LON4268**

**London NW1 0YT**

**tel: 020 7486 0341**

**fax: 020 7224 2012**

**email: [info@corecharity.org.uk](mailto:info@corecharity.org.uk)**

## Your legacy can help cure serious gut disease

Your Will can be an important tool in helping us to find cures and better treatments for serious gut and liver diseases. We need to know the funds are in place so we can continue to pay for the research that will save lives and help people. Mention Core in your Will and be a partner in our fight against gut and liver disease.

For information on including Core in your Will, please contact us on 020 7486 0341, by email at [info@corecharity.org.uk](mailto:info@corecharity.org.uk) or by post to the address above.

All Core's leaflets can be downloaded from the website: [www.corecharity.org.uk](http://www.corecharity.org.uk)

This is published by Core, the digestive diseases charity in association with the British Society of Gastroenterology and the Primary Care Society for Gastroenterology.

This booklet is provided for information only. The information found is not a substitute for professional medical care by a qualified doctor or other health care professional. ALWAYS check with your doctor if you have any concerns about your condition or treatment. The publishers are not responsible or liable, directly or indirectly, for ANY form of damages whatsoever resulting from the use (or misuse) of information contained in or implied by the information in this booklet.

This leaflet has been produced by Core. All Core's patient information is reviewed by two independent experts, one GP and a hospital specialist.

## Core is the charity for research and information on gut and liver disease

YES I want to support the work of Core and enclose my donation of

£250     £100     £50     £20    other £

### NAME AND ADDRESS

Title:     First name:     Surname:

Address:

   Postcode:

Tel:

Email:

Making a regular payment to Core helps us plan our research and patient information programme.

- Please tell me about making a regular donation  
 Please send details of how I can leave a legacy in my Will to Core

### METHOD OF PAYMENT

I enclose a cheque made payable to 'Core'

Please charge my Mastercard / Visa / CAF / Switch Card / AmEx \*    Three digit security code  
\*(delete as appropriate)

Card No        

Issue Number:     Expiry date:  /     Valid from:  /

Amount £     Date  /  /

Signature

*giftaid it*

Do you pay tax? Would you like the Government to give us £2.50 for every £10 you donate – at no extra cost to you?

- YES I wish this donation and all donations I make until further notice to be treated as Gift Aid Donations. Date  /  /   
I understand that I must pay in the tax year an amount of income/capital gains tax at least equal to the tax Core reclaims on my donations.

If you are a higher rate tax payer you can reclaim, on your tax return to the Inland Revenue, the difference between basic rate and higher rate tax which is currently 20%. For example, if you donated £50 you would reclaim £12.50 in tax. Your donation will effectively cost you £37.50 and we would receive £62.50!

Core may contact you occasionally to inform you of its research, fundraising and other activities.

If you do not wish to receive these mailings, please tick this box

Please tick here if you **do not want** a receipt for your donation

Please return your form, together with your donation to:  
Core, FREEPOST LON4268, London NW1 OYT

Core is the charity for research and information on gut and liver disease  
Registered Charity Number 1137029

SUPPORTED & PRINTED BY



T: 01273 420983  
www.cmprint.co.uk  
E: andy.jarred@cmprint.co.uk