
ALL YOU NEED TO KNOW ABOUT

COELIAC DISEASE



FUNDING RESEARCH
INTO DISEASES
OF THE GUT, LIVER
& PANCREAS



THIS FACTSHEET IS ABOUT COELIAC DISEASE

Coeliac disease is an autoimmune condition, which occurs in people who become sensitive to a protein called gluten in their diet. Gluten is found in wheat, barley and rye and is normally a nourishing and harmless part of the food we eat. However, if you have coeliac disease, gluten causes damage to the lining of your small intestine. This can cause problems with the absorption of nutrients and vitamins that we eat. Coeliac disease can be diagnosed at any age; from infancy to old age, although most people diagnosed are over 40. The treatment, which is usually very successful, is to remove all sources of gluten from the diet.

Over the past few years, it has become clear that coeliac disease is much more common than we used to think. Recent research has shown that approximately one in 100 people in the UK have this condition. It is known to occur more frequently in Caucasian populations in Europe and also in developing countries where wheat is a staple diet (the west of Ireland has the highest rate of the disease in the world). The incidence of coeliac disease in people with first-degree relatives (parent, child, sibling) who have coeliac disease is 1 in 10 (British Society of Gastroenterology guidelines 'The management of adults with coeliac disease'), and with second degree relatives (aunt, uncle, cousin) who has coeliac is 1 in 394. Some people who have coeliac disease don't actually know they have it but may still have some mild symptoms and it is thought that only 1 in 800 people have been correctly diagnosed with coeliac disease in the UK.

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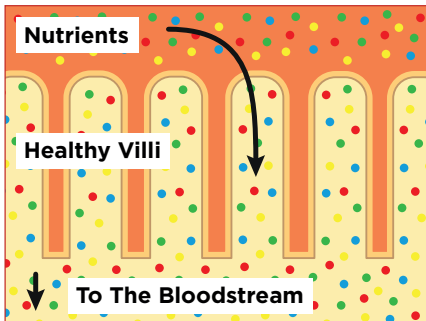
HOW CAN COELIAC DISEASE AFFECT YOU?

Viewing a normal small intestine under the microscope, there will be vast numbers of tiny finger like projections sticking up from the surface. These are villi and their purpose is to increase the absorption of nutrients from our diet. In a person with coeliac disease, the villi have been damaged by inflammation and they will look shorter and stubbier meaning that fewer nutrients pass into the bloodstream.

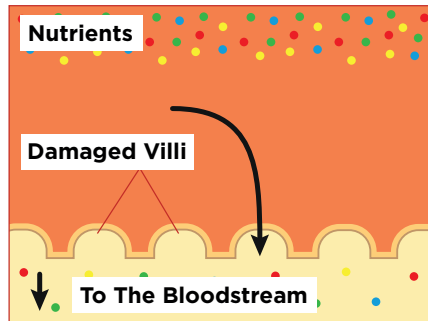
In more severe cases, they can barely be seen at all so the lining of the intestine looks quite flat. Doctors call this villous atrophy. Recognising villous atrophy is the key to making the diagnosis of coeliac disease. If patients with coeliac disease stop eating gluten, the villi can recover.

The main ways that coeliac disease can affect the body is:

- **Physical discomfort:** bloating, abdominal discomfort, diarrhoea, unexplained weight loss.
- **Shortage of essential nutrients:** this can lead to other conditions such as osteoporosis or anaemia.



A. In a healthy person, nutrients get absorbed by villi in the small intestine and go into the bloodstream.



B. In a person with Coeliac Disease, the villi have been damaged by inflammation, so fewer nutrients pass into the bloodstream.

CAUSES OF COELIAC DISEASE

We do not know why people develop this condition but there are many 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.

WHAT ARE THE USUAL SYMPTOMS OF COELIAC DISEASE?

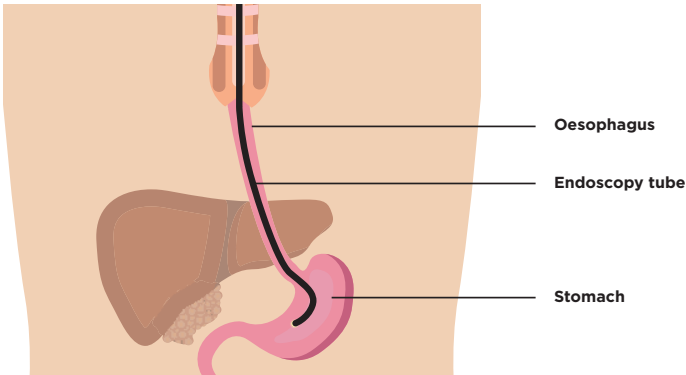
There is a wide variation in the symptoms experienced. In children, there may be diarrhoea, vomiting or a failure to gain weight. In adults, the disease comes to medical attention in a wide variety of ways. A common symptom is diarrhoea with bloating or discomfort in the abdomen. Quite often, patients 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 due to the damaged villi. In other cases, people lose weight for no obvious reason or just feel unwell in a rather vague way. Many patients have only mild symptoms.

HOW IS COELIAC DISEASE DIAGNOSED?

The doctor will carry out an examination and take a medical history. If they suspect coeliac disease, further tests will be carried out:

- **Blood tests:** these will be looking for antibodies indicative of coeliac disease and must be done whilst gluten containing food is still being eaten. However, a positive blood test does not confirm the diagnosis beyond doubt.
- **Endoscopy:** this will be carried out if the result is positive, or in situations where the blood test is negative but there is still a possibility of coeliac disease. Endoscopy involves passing a thin, flexible tube through the mouth and down through your gut to the small intestine where biopsies are taken. Neither passing the tube nor taking biopsies are painful although the procedure may be uncomfortable. The biopsy samples will show whether or not the villi are abnormal and confirm the diagnosis. Sometimes, a second endoscopy and biopsy may be suggested if there was uncertainty about the diagnosis.

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



WHAT TREATMENT IS AVAILABLE FOR COELIAC DISEASE?

The treatment for coeliac disease is to avoid eating any foods, which contains gluten. 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 dietitian as sticking to a gluten-free diet requires knowledge about which foods contain gluten and how to maintain a balanced diet. The dietitian will provide written information and advice.

WHAT IS A GLUTEN FREE DIET?

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 with lots of other foods unexpectedly turning out to contain gluten. For example, flour is used as a thickener in many cooking sauces and barley is used in making all beers and lagers. 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 learning to check the labels on such products to see if they are gluten-free.

There are a wide variety of alternative gluten-free products available for people with coeliac disease. A range of specialist substitute staple gluten-free foods is available on prescription from the doctor to help people with diagnosed coeliac disease adhere to a life-long strict gluten-free diet. The Advisory Committee on Borderline Substances (ACBS), an independent body advising the Department of Health, has approved a list of staple foods that form the basis of a nutritionally balanced diet.

These foods include bread, flour replacement mixes, pasta, crackers and plain breakfast cereals containing no added sugar. Some of these foods are fortified with key nutrients such as calcium and fibre, which can be lacking in gluten-free diets.

Mainstream manufacturers now make gluten-free foods and many of these, including luxury items, are available from supermarkets and health food shops. 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. In addition, food labelling rules may not be as strict in countries outside the UK, so it is important to be careful when travelling.

You should learn to check all foods and be aware of gluten-free sections of the supermarkets.

- Use of food directory/App for guidance on products in supermarkets.
- Maintaining a healthy diet.
- Not relying on processed GF foods too much as they can be high in sugar content.



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 (www.coeliac.org.uk) publishes a list of gluten-free products in a handbook, which is updated every year and a magazine that provides information about new products, recipes, social and educational events and research developments and links to other sources of information. A phone App is also available to help when people are out shopping as a quick reference guide. The Coeliac UK helpline is 0333 332 2033 or visit www.coeliac.org.uk

HOW CAN COELIAC DISEASE AFFECT ME OVER TIME?

This condition does not go away. You are far less likely to develop future problems and stay healthy if you stick to a gluten-free diet. Most people find it easier to follow the diet once they have got used to it.

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.

Having coeliac disease may increase your risk of having certain types of cancer. There is a rare form of tumour called a Lymphoma which can affect the bowel and 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 adhere to the diet, you can expect the same life expectancy as anyone else.

DOES MY COELIAC DISEASE NEED MONITORING?

As 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 annual blood tests 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.

WHAT TO ASK YOUR DOCTOR?

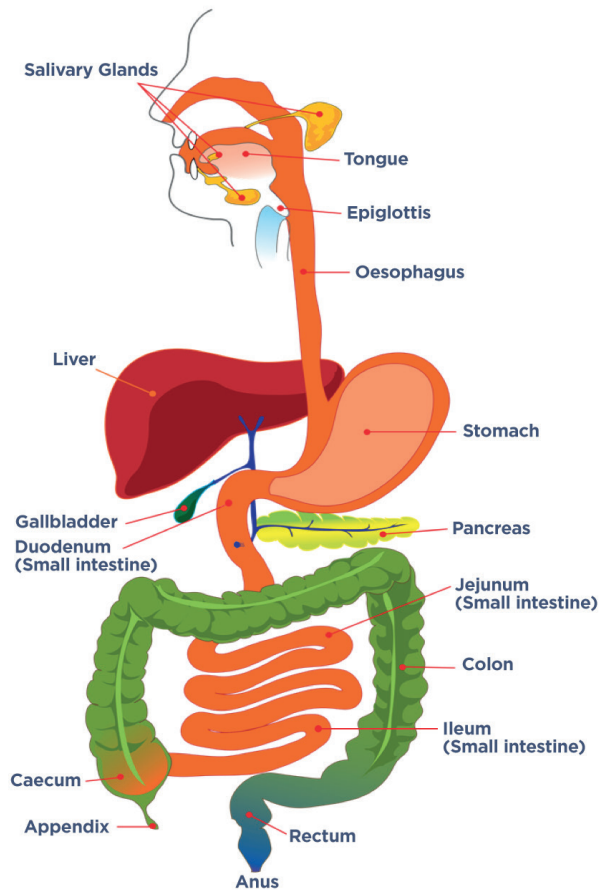
- Where are the best sources of information about living gluten free?
- Are there any support groups for coeliac disease in my area?
- Should my close family be tested for coeliac disease?
- How often will you be monitoring me for anaemia and osteoporosis?
Can I have a bone scan?

For more information about research in this area please contact Guts UK.

gutscharity.org.uk | 020 7486 0341 | info@gutscharity.org.uk



OUR DIGESTIVE SYSTEM



MY NOTES

Can you support Guts UK charity?
Whatever you do already, do it for
Guts UK charity. The more we all
know about our digestive system,
the better we can look after it.



Fancy making us a knitted guts
set for education purposes?
Contact us for a pattern



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PLEASE SHARE IT WITH OTHERS**



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About Guts UK

Guts UK's vision is of a world where digestive disorders are better understood, better treated and everyone who lives with one gets the support they need.

Our mission as Guts UK is to provide expert information, raise public awareness of digestive health and transform the landscape for research into our digestive system to help people affected by diseases of the gut, liver and pancreas.

WE ARE PASSIONATE ABOUT OUR GUTS. COME ON BOARD AND JOIN US.

This charity was set up to change something – to increase the levels of research into diseases of the gut, liver and pancreas so no one suffers in silence or alone. Since 1971 we have funded almost 300 projects and invested £14 million into medical research that leads to better diagnoses and treatments for the millions of people who are affected by digestive diseases and conditions.

But we still have much more to do.

Will you support Guts UK?

Give a donation today and play your part in the next vital research that will change things for future generations of people affected by the frustration and misery of digestive disease.

Together we can make more important change happen. Vital answers, new treatments and hope.



FIND OUT MORE
visit gutscharity.org.uk

gUTS UK!

FUNDING RESEARCH INTO DISEASES
OF THE GUT, LIVER AND PANCREAS

TURN OVER FOR
DONATION FORM



DONATION FORM

You can donate by filling in the form below and sending it to **Freepost RTJK-YYUL-XXSZ, Guts UK, London NW1 4LB**, online at **gutscharity.org.uk**, by calling us on **020 7486 0341** or by texting **GUTS18** and your donation amount to **70070**

DONATING IS EASY

- 1** Choose whether you want to make a one-off donation, or make regular donations.
- 2** Enter your details in the form below.
- 3** Send this form, via Freepost to us or call us to take payment.

YOUR DETAILS

Name	<input type="text"/>		
Address	<input type="text"/>		
	<input type="text"/>	Postcode	<input type="text"/>
Tel	<input type="text"/>	Email	<input type="text"/>

MAKE A ONE-OFF DONATION

Card no	<input type="text"/>	Expiry	<input type="text"/> / <input type="text"/>	Sec code	<input type="text"/>
Address (if different from above)	<input type="text"/>				
	<input type="text"/>				
Please call me on	<input type="text"/>	to take my details	<input type="checkbox"/>		

I would like to support GUTS UK with a donation of

£5 ☐ £10 ☐ £25 ☐ £50 ☐ £100 ☐ £500 ☐ Other

SUPPORT BY REGULAR GIVING

Instruct your Bank or Building Society to pay by Direct Debit. Please fill in the form in ballpoint pen and send to: **Freepost RTJK-YYUL-XXSZ, Guts UK, London NW1 4LB**



Name(s) of Account Holder(s) <input type="text"/>	Guts UK reference <input type="text" value="0009 /"/>
Bank/Building Society Accu No. <input type="text"/>	Sort code <input type="text"/>
Name and address of your Bank or Building society Branch name: <input type="text"/>	Instruction to your Bank or Building Society Please pay Guts UK Direct Debits from the account detailed in this instruction subject to the safeguards assured by the Direct Debit Guarantee. I understand that this instruction may remain with GUTS UK and, if so, details will be passed electronically to my Bank/Building Society.
Address: <input type="text"/>	Signature(s) <input type="text"/>
Postcode: <input type="text"/>	Date <input type="text"/>
Contact number <input type="text"/>	Payment date (not 31st) <input type="text"/>
	Amount <input type="text"/>

Note:
Banks and Building Societies may not accept Direct Debit instructions for some types of accounts.

giftaid it **Please turn every £10 you donate into £12.50 - at no extra cost to you!**
I am happy for all gifts of money that I have made to Guts UK charity (Core) in the last four years and all future gifts of money that I make to be Gift Aid donations. I am a UK taxpayer and understand that if I pay less Tax & Capital Gains Tax in that tax year than the amount of Gift Aid claimed on all my donations across all charities, it is my responsibility to pay any difference. Guts UK charity claims 25p for every £1 you donate from the tax you pay for the current tax year. *If your circumstances, name or address change, please do let us know.*

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