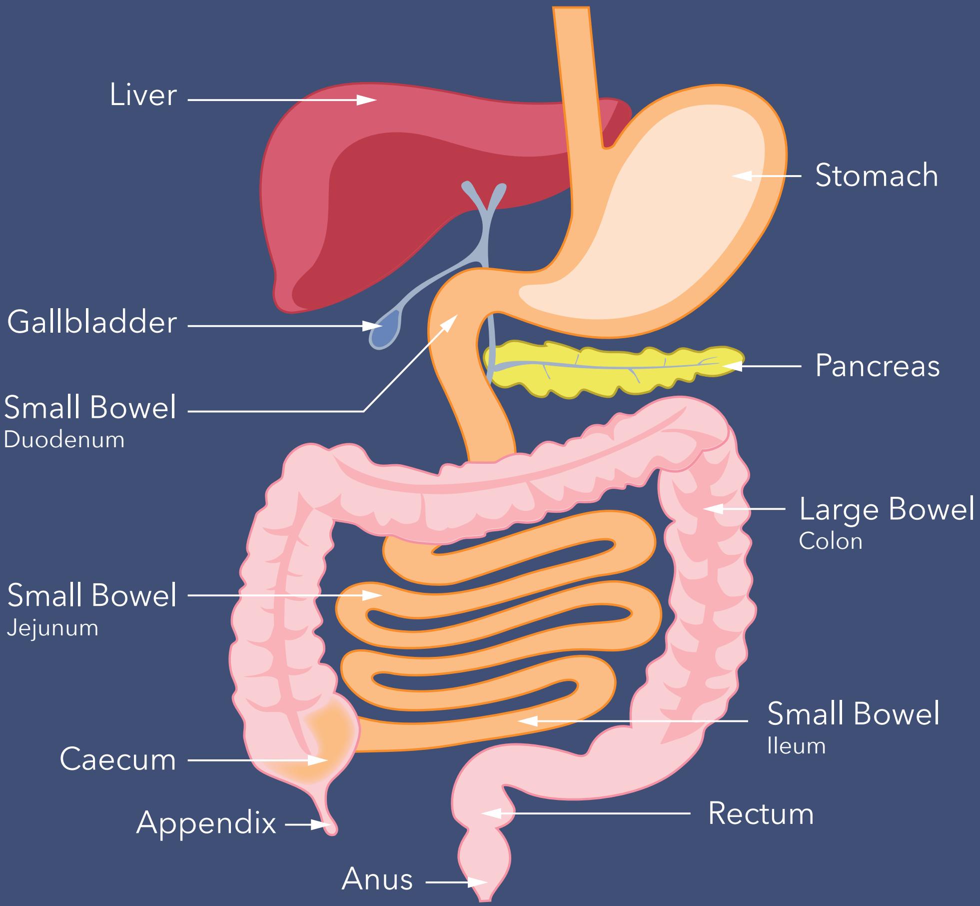
All you need
to know about

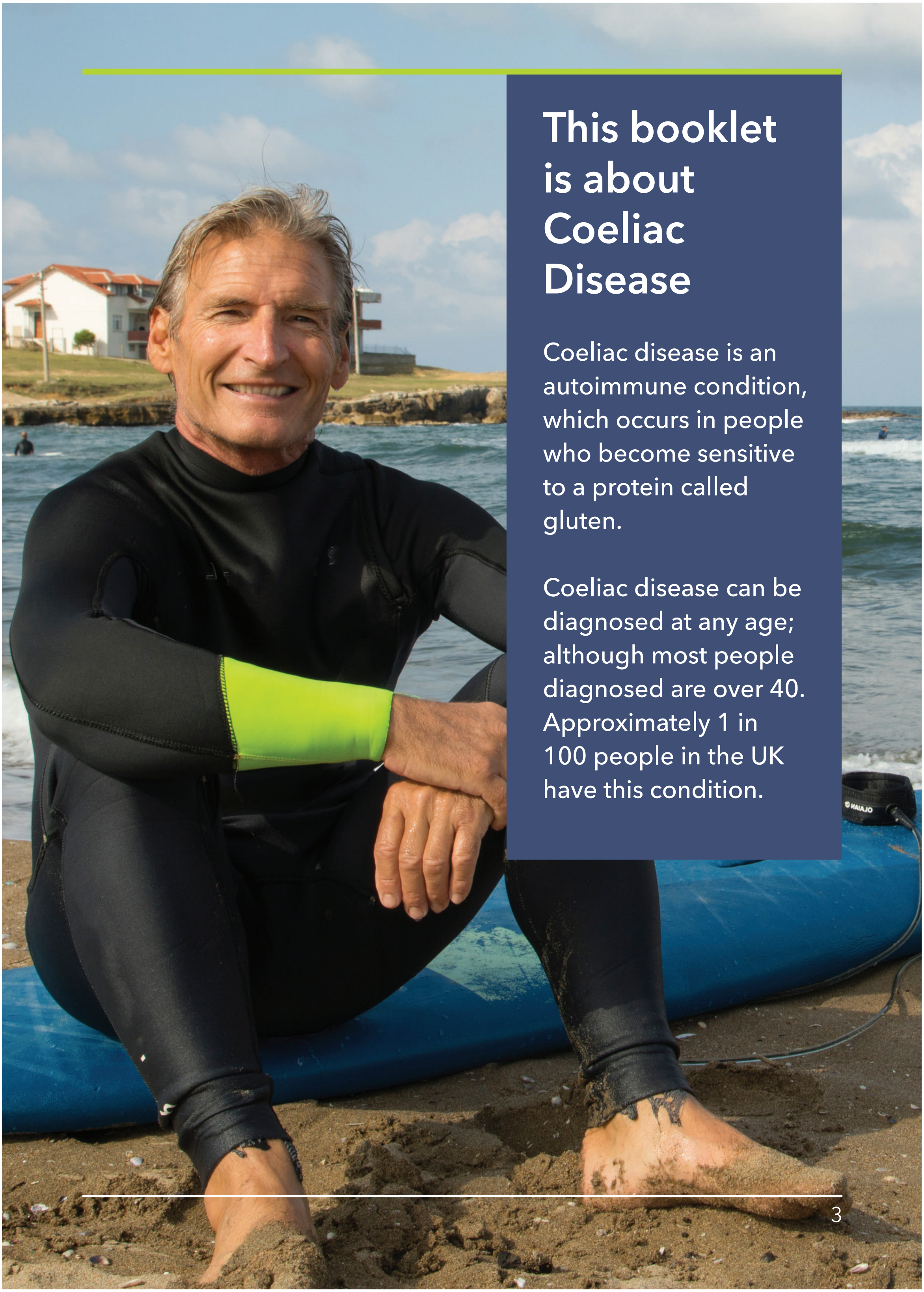
COELIAC DISEASE

BRITISH SOCIETY OF
GASTROENTEROLOGY

Our Digestive System

The Digestive System runs from the mouth to the anus and includes the stomach, the large and small bowels (intestines) and a number of accessory organs. The role of the digestive system is to turn food and liquid into the building blocks that the body needs to function effectively.





This booklet is about Coeliac Disease

Coeliac disease is an autoimmune condition, which occurs in people who become sensitive to a protein called gluten.

Coeliac disease can be diagnosed at any age; although most people diagnosed are over 40. Approximately 1 in 100 people in the UK have this condition.

Overview

Coeliac disease is an autoimmune condition, which occurs in people who become sensitive to a protein called gluten. 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 bowel (intestine). This can cause problems with the absorption of both macronutrients (protein, fats and carbohydrates) and micronutrients (vitamins, minerals and trace elements), from the foods we eat. 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 1 in 100 people in the UK have this condition. Coeliac disease can affect people of all ethnicities.

The incidence of coeliac disease in people with first-degree relatives (parent, child, sibling) who have coeliac disease is 1 in 10.

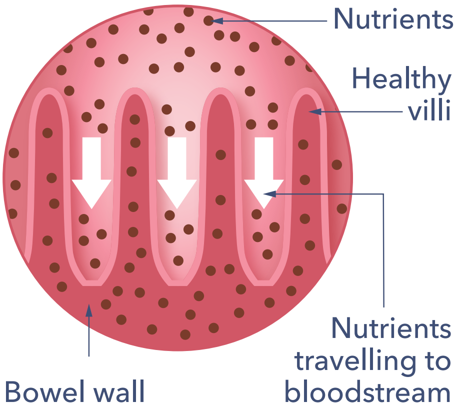
However some people who have coeliac disease don't actually know they have it but may still have some mild symptoms. It is thought that 7 out of 10 people remain undiagnosed. Some people don't have any symptoms and are diagnosed when coeliac disease is suspected during investigation of other problems. Examples are bone fractures, anaemia and thyroid disease.

What causes the development of Coeliac disease?

Why people develop coeliac disease is not fully understood. Most doctors believe both genetic and environmental factors are involved. Research to fully explain the causes for coeliac disease is ongoing.

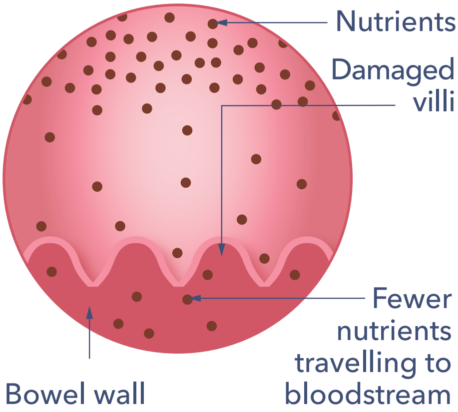
What does Coeliac disease look like?

Normal small bowel with healthy villi



Viewing a normal small bowel 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. If we were able to spread out the small bowel it would be the same area as half a badminton court.

Coeliac disease with damaged villi



In a person with coeliac disease, the villi have been damaged by inflammation and they will look shorter and stubbier. This means that fewer nutrients are able to pass into the bloodstream.

How can Coeliac disease affect the body?

For some people, their coeliac disease can progress so that the villi can barely be seen at all and they look quite flat. Doctors call this villous atrophy. Recognising villous atrophy is the key to making the diagnosis of coeliac disease. Damage from gluten to the bowel in people with coeliac disease can reduce its area when villous atrophy is present. Meaning a much-reduced area to absorb nutrition. If people with coeliac disease stop eating gluten completely, the villi can recover but coeliac disease remains a lifelong condition.

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

Physical discomfort: bloating, abdominal discomfort, unexplained weight loss, a change in bowel habit to diarrhoea or constipation.

Shortage of essential nutrients: this can lead to other conditions such as osteoporosis (causing bone fractures) or anaemia (causing symptoms of lethargy).

Symptoms beyond the gut: occasionally problems with the nerves to the extremities causing numbness and tingling to the hands and feet. This can occasionally affect the balance.

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 performed:

Blood tests

Two antibody tests are carried out and must be done whilst gluten is still being eaten.

Tissue Transglutaminase (TTg) **(First choice test)**

Endomysial antibody (EMA) **(if TTg weakly positive)**

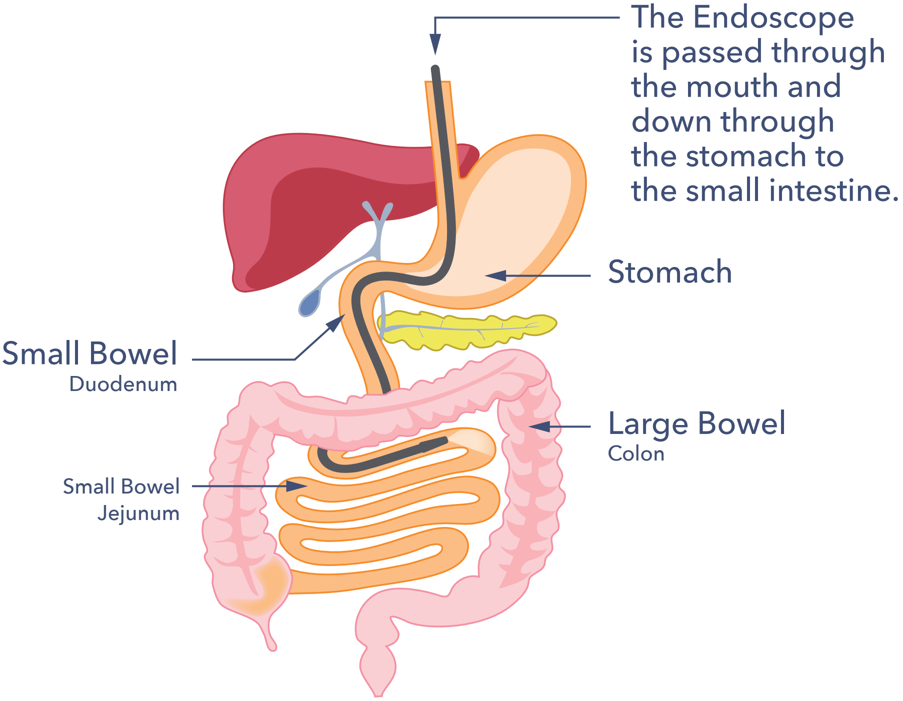
The results of these tests alone may be sufficient to diagnose someone with coeliac disease. A no-biopsy diagnosis can be made for some children and some adults over 55 years or younger who meet certain criteria, in other cases an additional investigation (an endoscopy) is required.

Endoscopy

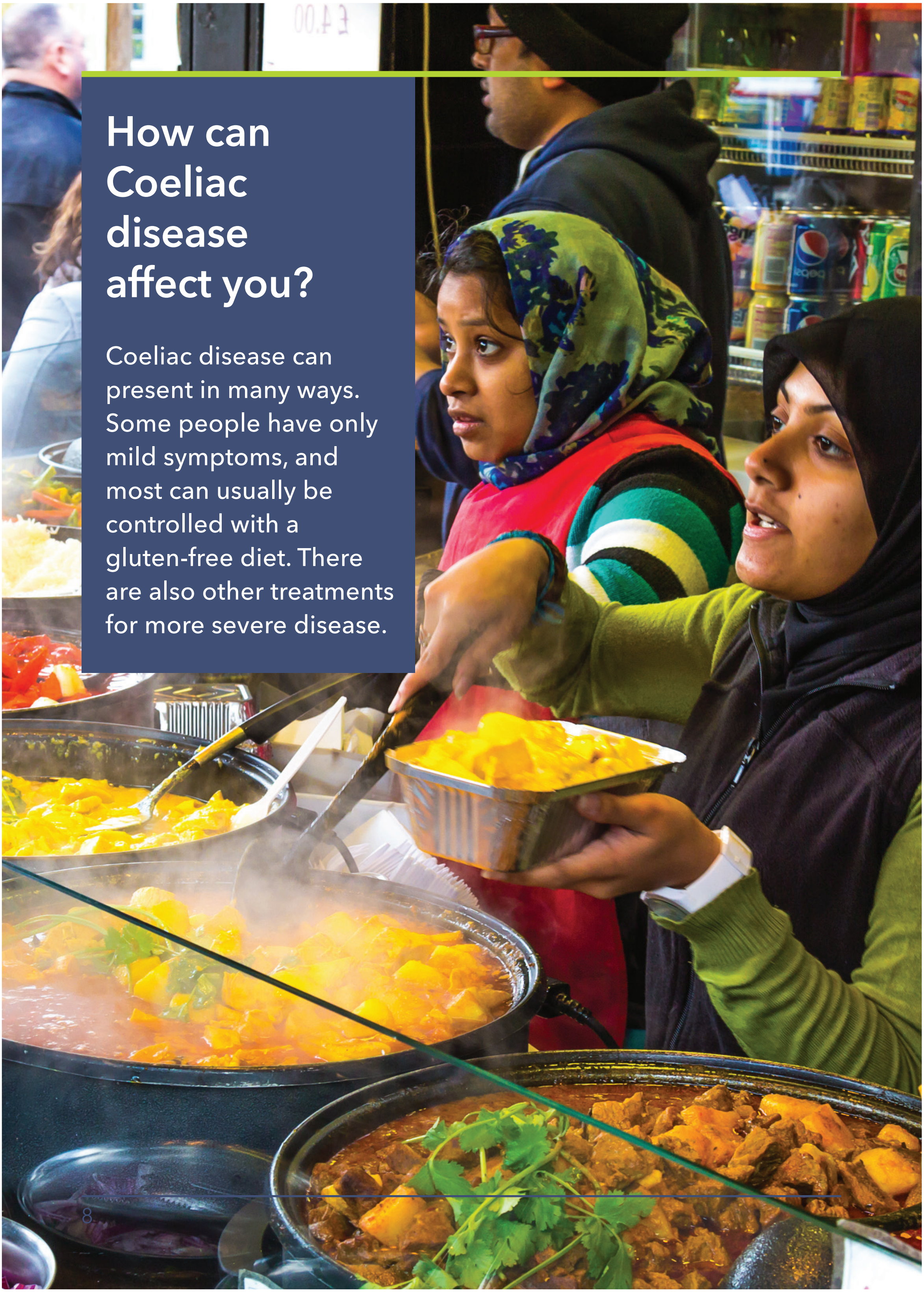
Endoscopy involves passing a thin, flexible tube through the mouth and down through your gut to the small intestine. Biopsies are then taken. Neither passing the tube nor taking biopsies are painful although the procedure may be uncomfortable. The biopsy samples will show whether or not the villi are abnormal and confirm the diagnosis. Sometimes, a second endoscopy and biopsy may be suggested if there was uncertainty about the diagnosis.

It is important to continue eating gluten whilst testing for coeliac disease is being completed. This includes both the blood test and an endoscopy if one is advised. Both tests are looking for a reaction. If you're not eating enough gluten, no reaction will be noticed. Eat a source of wheat, barley or rye (some breakfast cereals, bread and pasta) for more than one meal every day. Guidelines advise for at least 6 weeks before testing[3]

If this gives you symptoms discuss with your doctor to see if you can take medicines to reduce their impact. It may be possible to undertake a shorter period of eating gluten prior to any tests however this must be discussed with the gastroenterologist.



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



How can Coeliac disease affect you?

Coeliac disease can present in many ways. Some people have only mild symptoms, and most can usually be controlled with a gluten-free diet. There are also other treatments for more severe disease.

Symptoms

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, people 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 people with coeliac disease cannot absorb iron, calcium, and 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. Other symptoms may include persistent lethargy, loss of sensation of fingers and toes, skin rashes (called dermatitis herpetiformis). Whilst diarrhoea is a common symptom, it is also possible for people to have a change in bowel function to constipation symptoms too. As coeliac disease can present in so many ways it is important that people with associated conditions such as IBS, Type 1 Diabetes and other autoimmune diseases are also tested.

Will 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. 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, as with most people, symptoms usually resolve once a gluten-free diet has started. The small bowel can take some time to recover fully and can take from 2 to 5 years depending on the amount of initial damage present.

If diarrhoea is not resolving initially when following a gluten-free diet, it could be due to lactose intolerance. Lactose (a sugar found in milk) is digested when lactase (an enzyme) is produced at the end of the villi, this production is less effective when damage from gluten has occured. Ask your dietitian for advice if you think this has happened to you. Lactose intolerance usually recovers when the villi recover from following a gluten-free diet. Others who may have neurological symptoms may need a referral to a neurology specialist.

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. Lymphoma 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 similar life expectancy as anyone else.

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 strict gluten-free diet for the rest of your life. If you are diagnosed with coeliac disease, your doctor will refer you to see a dietitian. 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 gluten?

Gluten is a protein found in wheat, barley and rye and products made using these grains.

What foods contain gluten?

Standard breads, pastas, breakfast cereals, cakes, biscuits are generally made with wheat flour and contain large amounts of gluten. However, many other packaged foods can also contain gluten. For example, flour is used as a thickener in many cooking sauces and barley is used in making all beers and lagers. Additionally, some foods occasionally get contaminated with small amounts of gluten during production or prossessing.

Due to farming and processing methods most oats are cross-contaminated with gluten - only gluten-free varieties of oats should be used by people with coeliac disease. It is worth learning to check the labels on such products to make sure that if you do eat oats it is clearly stated on the label that they are gluten-free. A small number of people do react to avenin, a protein found in oats that is like gluten (even ‘gluten- free’ versions). If you continue to have symptoms despite following a gluten-free diet oat avenin may be suspected as a cause. For most people with coeliac disease gluten-free oats are suitable and a great source of soluble fibre.

Grain suitability

Some flours are made from naturally gluten free grains and may be contaminated with gluten in the place of manufacture - always read the label. Flours labelled gluten free will be free from contamination.

Not gluten free	Barley, pearl barley, bulgar wheat, couscous, einkorn, durum wheat, khorasan (kamut), emmer (faro), freekah, rye, semolina, spelt, tricale, wheat.
Check food label	Oats/barley, malt extract and ‘flavourings’.
Gluten free	Almond, amaranth, buckwheat, cassava, chestnut, corn, flax/linseed, gram (besan or chickpea) flour, hemp, maize, millet, mustard, polenta, potato, pulses, quinoa, rice, sago, sesame, sorgum, soya, tapioca, teff, urd.

Food labelling

Current legislation requires food manufacturers to label foods so that all food allergens (including in the gluten containing grains) must be clearly stated on the ingredients list in bold text. Accordingly, it is important to check labels for **Wheat, Barley, Rye** and **Oats**.

Some products are not made with wheat, barley, rye or oats but have additional advisory labelling such as **'May contain gluten'** or **'Made in a factory handling wheat'**. This labelling should only be used when there is a significant risk of the product becoming cross contaminated with gluten. If you are unsure of a product it's best not to eat it. Coeliac UK (the UK charity for people diagnosed with coeliac disease) can help with clarifying the risk of specific products.

Food labelling rules may not be as strict in countries outside the UK, so it is important to be careful when travelling, although most European countries have strict standards in place. Even travelling further afield can be done safely with research and careful preparation.

What foods are suitable for a gluten-free diet?

A wide variety of foods and products are suitable for people with coeliac disease. You should learn to check all foods and be aware of gluten-free sections of the supermarkets. Although naturally gluten free foods that are not made specifically for people with coeliac disease are found throughout the store. These might prove to be cheaper options. The Crossed Grain symbol (see right) is an easy way of identifying foods you can eat.

Labelled gluten-free foods

These foods are usually identified as suitable for people with coeliac disease on the packaging and meet a specific legal standard of less than 20 parts per million gluten (sometimes written as '<20 ppm').

Mainstream manufacturers and supermarkets make a wide variety of labelled gluten-free foods. It's helpful to experiment with labelled gluten-free foods by trying a wide range of different varieties to see which you most enjoy.

In Wales and Northern Ireland a range of substitute gluten-free staple foods are available on prescription from your doctor, or in Scotland from your pharmacist. In Scotland, Wales and Northern Ireland ranges may include bread, flour mixes, pasta, crackers and breakfast cereals.

However in England local Clinical Commissioning Groups (CCGs) (management for GP surgeries) decide their own prescribing policy. This may mean that they further restrict or suspend the availability of gluten free products on prescription in some areas. Where available, these foods include bread and flour mixes in England. You can check with your pharmacist to find out if prescription gluten free products are available in your area.

Foods made without gluten containing ingredients

Many supermarket and mainstream brand foods are made without gluten containing ingredients and with controls in place to minimise the risk of cross contamination. These foods can be identified by reading labels: check no wheat, barley, rye or oats have been used in their manufacture and there is no indication of cross contamination risk. If you are unsure, Coeliac UK resources such as **'The Eat Well, Live Well' food and drink directory** and **'GF Food Checker'** digital application can help to identify these products.

Naturally gluten-free foods	Fruits and vegetables (fresh, most dried fruit, frozen, canned). Meat fish and poultry. Pulses and plain nuts. Eggs and dairy. Naturally gluten-free starchy foods: rice, corn, potatoes and other root vegetables.

Eating out

Restaurants are increasingly trying to help by indicating the use of gluten in dishes. Caterers by law should be able to provide you with information about gluten in all the dishes they serve, verbally or written. If the information is not easily seen it must be clear where the information can be found. Coeliac UK (see below) has an accreditation scheme for restaurants and a symbol that can be used on a menu. The label that tells you that the dish is gluten-free according to the law and that the caterer meets all requirements of the Gluten-free standard. This standard covers all aspects of gluten-free preparation and ensures training is in place. It is still important to check with staff and let them know your requirements.

When initially going gluten-free eating outside the home at restaurants or with family and friends can appear daunting. However, it is important that following a gluten-free diet does not become socially restrictive. Over time you will learn how to navigate social situations. But if you have concerns about how to manage such situations please discuss this with your dietitian.

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. During your review, certain blood tests might be carried out to ensure you are not anaemic or have become short of vitamins and other nutrients. If your symptoms are not responding or you have developed new symptoms, ask for another referral to the gastroenterologist and dietitian.

Your doctor may also arrange for you to have a simple scan of your bones (a DEXA scan), if there are concerns at the follow up appointment, to look for any sign that the bones have become thin so this can be treated early. People with coeliac disease may have reduce spleen function and the spleen is important in immune function, so 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?*
- *Are gluten free prescriptions available in my area?*
- *How often will you be monitoring me for anaemia and osteoporosis?*
- *Can I have a bone scan?*

Support

Coeliac UK

Coeliac UK is the leading UK charity supporting people diagnosed with coeliac disease. The Coeliac UK helpline is **0333 332 2033**
or visit **www.coeliac.org.uk.**

The National Institute of Health and Care Excellence (NICE)

NICE develop guidelines of treatment that should be expected with a diagnosis of coeliac disease.
https://www.nice.org.uk/guidance/ng20

Patient Webinars

These have been developed by NHS doctors and dietitians.
https://patientwebinars.co.uk/condition/coeliac-disease/webinars/

What research is needed?

A Priority Setting Partnership (PSP) has been completed which identifies the top ten research priorities for coeliac disease. You can find out what those are from Coeliac UK

1 Singh P, Arora S, Lal S, Strand TA, Makharia GK. Risk of Celiac Disease in the First- and Second-Degree Relatives of Patients With Celiac Disease: A Systematic Review and Meta-Analysis. Am J Gastroenterol. 2015 Nov;110(11):1539-48. doi: 10.1038/ajg.2015.296. Epub 2015 Sep 29. PMID: 26416192.

2. McAllister BP, Williams E, Clarke K. A Comprehensive Review of Celiac Disease/Gluten-Sensitive Enteropathies. Clin Rev Allergy Immunol. 2019 Oct;57(2):226-243. doi: 10.1007/s12016-018-8691-2. PMID: 29858750.

3. **https://www.nice.org.uk/guidance/ng20**

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The charity for the digestive system

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> *"I chose to fundraise for Guts UK because when I was in hospital, I was amongst others with various digestive diseases. It was there that I realised there needs to be so much more awareness for these invisible illness. We must raise much needed funds for this important research!"*
>
> *Abi, Guts UK fundraiser.*

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It's time the UK got to grips with guts.

With new knowledge, we will end the pain and suffering for the millions affected by digestive diseases. Guts UK's research leads to earlier diagnoses, kinder treatments and ultimately a cure.

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Our research shows that 51% of people delay seeking advice for their symptoms for over 6 months. Guts UK exists to change that. We empower people to seek help. Together, we will join forces and bring about important change in this misunderstood area of health.

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I enclose a cheque payable to Guts UK ☐ **OR Please debit my credit/debit card** ☐

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