



Royal Surrey
County Hospital
NHS Foundation Trust

Coeliac disease and a gluten-free diet

Nutrition & Dietetics Department

Patient information leaflet

Who is this leaflet for?

The information in this leaflet is for you if you have:

- diagnosed Coeliac disease
- diagnosed Dermatitis Herpetiformis (DH)

What does this leaflet cover?

This leaflet explains Coeliac disease, Dermatitis Herpetiformis (DH) and a gluten-free diet in detail.

What is Coeliac disease?

The word 'Coeliac' is derived from the Greek word *koiliakos* meaning "suffering in the bowels".

Coeliac disease (pronounced or sometimes spelt 'celiac') is often spoken about in terms of food allergies and food intolerances but is in fact an auto-immune disease, like type 1 diabetes.

Coeliac disease is caused by gluten-intolerance. Gluten is a protein found in wheat, rye, barley and possibly oats. With Coeliac disease, eating foods containing gluten has a life-long damaging effect on the body.

What are the symptoms of Coeliac disease?

Coeliac disease can cause symptoms of malnutrition as food and nutrients remain undigested.

The finger-like projections in the small intestine called villi, which aid the absorption of food, are damaged and flattened by the gluten. So although a person may be following a well balanced healthy diet, they may develop symptoms such as weight loss, diarrhoea, fatigue and anaemia as their body fails to absorb enough nutrients from food.

Other signs of Coeliac disease may be infertility, unexplained abdominal pain and generally feeling unwell. These symptoms can

occur together or separately, be mild or severe. Occasionally, the stress of an operation, accident, intestinal infection or pregnancy can trigger the onset of this illness.

Symptoms in childhood normally occur at the weaning stage; children who have been perfectly healthy from birth may fail to thrive at weaning. They may become irritable, have diarrhoea, vomiting, and pass pale stools. Older children may just stop growing and have less obvious symptoms.

How common is Coeliac disease?

Coeliac disease affects both males and females of all ages.

There are thought to be at least 125,000 people diagnosed with Coeliac disease in the UK and the numbers are increasing.

On average over 7,000 people are diagnosed with Coeliac disease in the UK each year. Experts researching the condition believe that the disease may affect as many as 1 person in every 100, with the majority of those currently undiagnosed.

Many people visiting their GP with unexplained symptoms may initially be diagnosed with 'irritable bowel syndrome' (IBS) before further investigations reveal they are suffering from Coeliac disease.

Is Coeliac disease genetic?

Recent research has established that there is a genetic link to Coeliac disease. One in 10 close relatives of a person diagnosed with Coeliac disease may also be affected, so family screening is recommended.

How is Coeliac disease diagnosed?

Coeliac disease can only be confirmed by an endoscopy.

Blood tests are now widely used to help screen for the condition. Self-testing kits are a useful starting point, but are not 100% accurate. Coeliac UK recommends that anyone who thinks they may have Coeliac disease should visit their GP for further investigation.

Your GP will then refer you to a gastroenterologist who will carry out a small intestinal biopsy (by endoscopy), the only official way to confirm that you definitely have Coeliac disease. This procedure normally takes place in an out-patient clinic, under mild sedation. A section of the lining of the bowel is taken and the villi examined under the microscope.

Are there other medical conditions associated with Coeliac disease?

It is now known that Coeliac disease is associated with some other medical conditions. This means that people with certain conditions have a higher risk of developing Coeliac disease. These medical conditions include Type 1 diabetes, Down's syndrome and a range of auto-immune disorder including Thyroid disease, Liver disease, Addison's disease and Sjörger's syndrome.

If you are concerned about any of these related conditions please seek medical advice.

What is Dermatitis Herpetiformis (DH)?

Dermatitis Herpetiformis (DH) is a skin condition which like Coeliac disease is due to gluten sensitivity.

People with DH have a very itchy skin rash which usually occurs on the buttocks, shoulders and knees. A biopsy of their small bowel will show damage to the villi in their small intestine. It is quite a rare condition affecting around 1 in 10,000 people.

The skin rash shows direct improvement when sufferers follow a strict gluten-free diet but this may take up to 2 years so medications are often used to settle the condition at the start. Once the diet 'kicks-in' medication should be stopped but the gluten-free diet must continue.

How do you treat Coeliac disease and DH?

There is no miracle cure for Coeliac disease. The treatment is a gluten-free diet for life.

It is still not exactly clear how gluten damages the small intestine, however experts agree that once a gluten-free diet is followed the villi return to normal. This means the body absorbs nutrients as usual and symptoms disappear. Although the benefits of the diet can often be felt immediately, it can take many months before the intestine completely recovers.

What is a gluten-free diet?

A gluten-free diet is more than just a wheat-free diet. A gluten-free diet requires the exclusion of all sources of gluten in the diet. Gluten is a protein found in wheat, rye and barley.

Which foods are naturally gluten-free?

The good news is that there are many foods that are naturally gluten free including:

- meat, poultry, fish, eggs
- nuts and seeds
- fruit and vegetables
- cows milk products e.g. milk, cheese, plain yoghurt, cream
- soya milk, rice milk
- potatoes, rice, maize (corn)
- buckwheat, millet, quinoa, tapioca
- cooking oils, butter, spreads
- tea, coffee, fruit juices
- wine, cider, spirits

'Obvious' gluten is found in:

- **Wheat products:** bread, crackers, pasta, cakes, biscuits, pizza bases, couscous, batter, breadcrumbs, pastry, breakfast cereals, wheat flour
- **Rye products:** 'Ryvita', rye bread
- **Barley products:** beer, lager, stout, barley water, pearl barley (in soups, casseroles etc), malted milk drinks ('Ovaltine', 'Horlicks')

People often are aware of these obvious sources so it can be relatively simple to avoid these foods. Special gluten-free varieties are sold which can be used instead.

'Hidden' gluten may be found in:

- processed meat products e.g. sausages, burgers, ham
- soy sauce
- soups and sauces
- mustards, pickles
- yoghurts, milkshakes
- cola
- confectionary

People often find these sources more difficult to avoid because gluten may be hidden in the ingredients. The labels of these products must therefore be carefully checked. You may find that two different manufacturers produce a food which looks the same but one will contain gluten and one will not.

What about oats?

Recent studies suggest that 'pure' oats can be tolerated by the majority of people with Coeliac disease. However, there are a small number of people who may be sensitive to pure uncontaminated oats. You may wish to discuss with your dietitian whether to include oats in your diet.

What is cross contamination?

It is important that people with Coeliac disease or DH follow a gluten-free diet very strictly. This means that even one crumb of bread could be enough to cause symptoms. Cross contamination is when a gluten-free product has contact with something containing gluten e.g. toasting gluten-free bread in a toaster full of 'normal' breadcrumbs or stirring a pan of gluten-free pasta using the same spoon that was used to stir a pan of 'normal' pasta.

Make sure bread boards, chopping boards, cooking utensils etc are clean and free from any crumbs before using them.

What special gluten free products are available?

There are a number of specially manufactured gluten-free foods available to make a gluten-free diet more varied, less restrictive and easier to comply with. These include bread, rolls, pasta, crackers, biscuits, cakes, cereal bars and pizza bases.

A few of these foods contain an ingredient called Codex Wheat Starch. This is a special wheat starch that has had the gluten removed to a trace level and is safe for the majority of people with Coeliac disease. Using Codex Wheat Starch improves the taste and texture of gluten-free food, making it more closely resemble gluten-containing food.

Staple gluten-free foods are available on prescription for people medically diagnosed with Coeliac disease. The types and quantities of these are currently under review so your dietitian or GP will provide more information on this.

Gluten-free food items are also now readily available from supermarkets, health food shops, via the internet and mail order.

What is Codex?

To protect the health of consumers an international body called Codex Alimentarius has set a level of gluten that is allowed in gluten-free foods and is known to be safe for people with Coeliac disease.

There are two levels within the Codex Standard:

1. Foods containing less than 20ppm will be labelled as 'gluten-free'.
2. Foods containing between 20 and 100ppm will be labelled as 'very low gluten'.

The second term is unlikely to be used in the UK but it may be used in other European countries.

How can I check if a food contains gluten or not?

The introduction of allergen labelling has made it easier to identify from the ingredients list whether or not a product is gluten-free. All food manufacturers legally have to list all ingredients on pre-packed foods and identify any allergens, including gluten and/or wheat, barley, rye. These will be listed either in the ingredients list or in an allergy box.

An allergen advice box is not a compulsory requirement so it is important to always check the ingredients list

It is important to remember to check that the information you refer to is up to-date, as the ingredients for some manufacturers foods change from time-to-time. The Gluten-Free Food and Drink Directory is an annual food list available from Coeliac UK which is updated monthly on their website, on their automated telephone service or on Ceefax.

Always check with your pharmacist that any medication you are prescribed is gluten-free.

So now I have Coeliac Disease/DH what do I do?

A gluten-free diet can be both varied and interesting but it does involve adopting a new attitude to food. Here are just a few suggestions on how to get started:

1. **See a dietitian.** After diagnosis is confirmed by a gastroenterologist, you should be referred to a dietitian who will give you detailed and practical advice on following a gluten-free diet.
2. **Set up a prescription.** Find a pharmacist, as once you have a regular prescription they are ideally placed to support you and answer any questions you may have on a day-to-day basis.
3. **Join Coeliac UK.** Please refer to the 'useful information' section on how to contact Coeliac UK.
4. **Planning ahead.** When eating away from home always check in advance the availability of gluten-free food, or take along a suitable gluten-free meal or snack.
5. **Shopping.** Always remember to take an up-to-date copy of Coeliac UK's Gluten-free Food & Drink Directory with you when you go food shopping. If you are unsure, check the label carefully for guidance.
6. **Eating out.** More and more restaurant chains are considering the needs of people on special diets and now provide or label gluten-free dishes. If unsure, notify the restaurant in advance of your special requirements, and always confirm again when ordering your meal.
7. **Holidays.** If choosing a full-board holiday check to see if the hotel provides gluten-free meals. Many airlines and other transport operators now offer gluten-free meals which must be requested at the time of booking.
8. **Eating well.** Experiment with gluten-free cooking and discover your favourite gluten-free dishes. There are some excellent cook books available. Choose one which is quite new and endorsed by Coeliac UK or the British Dietetic Association, so that you know the information is correct.

Useful information and key reference source used

Coeliac UK is the leading charity working for people with Coeliac disease and DH.

The charity provides a free dietetic and food helpline and support for members via its network of local voluntary groups. For further information on the charity and its resources visit www.coeliac.org.uk or call the helpline on **0845 305 2060**.

Please note that the information in this leaflet was correct at time of writing. The ingredients of manufactured products do change.

Contact details

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PALS and Advocacy contact details

Contact details of independent advocacy services can be provided by our Patient Advice and Liaison Service (PALS) who are located on the right hand side as you enter the main reception area. PALS are also your first point of contact for health related issues, questions or concerns surrounding RSCH patient services.

Telephone: 01483 402757

Email: rsc-tr.pals@nhs.net

Opening hours: 9.00am–3.00pm, Monday to Friday

If you would like information documents in large print, on tape or in another language or form please contact PALS.

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