

Coeliac disease

Information and advice for patients

Nutrition & Dietetics

What is coeliac disease?

Coeliac disease is not an allergy or simple food intolerance. It is an autoimmune disease, which means that the body's immune system attacks its own tissues. In people with coeliac disease this immune reaction is triggered by gluten, a type of protein found in the cereals wheat, rye and barley. A few people with coeliac disease are also sensitive to oats.

In coeliac disease, eating gluten causes the lining of the gut (small bowel) to become damaged and may affect other parts of the body.

What are the symptoms of coeliac disease?

The symptoms of coeliac disease vary from person to person and can range from very mild to severe. Symptoms include:

- bloating
- abdominal (tummy) pain
- feeling sick
- diarrhoea
- excessive wind
- heartburn
- indigestion
- constipation
- weight loss (but not in all cases)
- tiredness
- iron, vitamin B12 or folic acid deficiency
- recurrent mouth ulcers
- hair loss
- headaches
- defective tooth enamel
- osteoporosis
- depression
- infertility or recurrent miscarriages
- joint or bone pain
- nerve problems which cause poor muscle co-ordination or numbness and tingling in the hands and feet

Some of these symptoms may be confused with irritable bowel syndrome (IBS) or wheat intolerance, while others may be put down to stress, or even getting older. Contrary to

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popular belief, you don't need to be underweight or have lost weight to have coeliac disease; most people are of normal weight or even overweight when they are diagnosed.

Symptoms in babies

Babies may start to develop gut symptoms after weaning onto gluten cereals. Other symptoms they may develop include:

- muscle wasting in the arms and legs
- a bloated tummy
- irritability
- not gaining weight, or losing weight after previously growing well

Symptoms in children

Symptoms in older children vary as they do in adults, and can also include:

- poor growth
- short stature
- anaemia
- recurrent mouth ulcers

How is coeliac disease diagnosed?

If you think you or your child has coeliac disease, it is essential to continue eating gluten and speak to your/their GP. This is because taking gluten out of the diet or reducing the amount of gluten eaten before being tested can make it difficult to diagnose coeliac disease.

When you see your GP they will ask you about your symptoms and do a blood test to look for antibodies that the body makes in response to eating gluten. These are:

- Tissue transglutaminase antibody (TTG)
- Endomysial antibody (EMA)

If the blood test shows you are making these antibodies you will then be referred to a gastroenterologist (specialist gut doctor). If the blood test shows you are not making these antibodies, but your symptoms strongly suggest coeliac disease or you have a close relative with coeliac disease then you may still be referred to a gastroenterologist.

Your gastroenterologist will then do a test called a gut biopsy. This involves an endoscope (a thin, flexible tube with a bright light on the end) being passed through your mouth and stomach and into your small intestine (gut). Small samples of the lining of your gut are then taken to be examined under a microscope later, to check for abnormalities that occur in coeliac disease.

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How is coeliac disease treated?

Once you have been diagnosed with coeliac disease the only treatment is a gluten-free diet for life. Your specialist or GP will refer you to a dietitian to help you make the necessary changes to your diet and plan a healthy balance of foods.

The benefit of following a gluten-free diet if you have coeliac disease is that your symptoms will start to improve quite quickly. Your gut will start to repair itself immediately and is usually working as normal in the next 6 months – 2 years.

If you do not follow a gluten-free diet and you have coeliac disease, your symptoms may get worse and gut will become more damaged.

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Following a gluten-free diet

Which foods should I avoid?

The following cereals (grains) contain gluten and should be avoided by people with coeliac disease:

- Wheat
- Rye
- Barley
- Spelt
- Kamut

The most common foods that contain gluten are bread, pasta, pizza bases, cakes and biscuits.

To check whether a food contains gluten you will need to read the ingredients list. If a cereal containing gluten is used as an ingredient it must, by law, be listed on the ingredients list. Some manufacturers will put this information in an allergy box on the food label so that it is easier for you to identify, but this is not compulsory.

Foods that do not contain gluten, but have come into contact with gluten should also be avoided as they will be contaminated with gluten (see 'Cross-contamination on page 13 for more information).

Most oats that are available in shops are contaminated with gluten so they are not suitable for people with coeliac disease, however most people with coeliac disease can eat uncontaminated oats.

Which foods are safe for me to eat?

Foods that are safe for you to eat on a gluten-free diet are those that naturally do not contain any gluten and gluten-free alternatives to 'normal' foods that have been specially made for people with coeliac disease.

Some products may also be labelled with one of the following and are safe to eat if you have coeliac disease:

- Gluten-free
- Very low gluten
- Suitable for coeliacs
- The crossed grain symbol

There are also some ingredients which are made from a cereal containing gluten where the cereal has been processed in such a way that it is safe for people with coeliac disease to eat.

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These are:

- Glucose syrups made from wheat and barley (including dextrose)
- Wheat-based maltodextrins
- Distilled ingredients made from cereals that contain gluten for example, alcoholic spirits.

Naturally gluten-free foods

There are lots of foods which naturally do not contain any gluten. These are listed below in their food groups.

Meat, poultry, fish and eggs

Meat: lamb, pork, beef, smoked meat, bacon, gammon, ham.

Poultry: chicken, turkey.

Fish: fresh, smoked, canned in brine or oil, shellfish.

Eggs.

Dairy products

Butter, buttermilk, cheese, cream, crème fraiche, milk (liquid and dried), natural yoghurt.

Fats and oils

Butter, margarine, low fat spreads, lard, oil, ghee.

Fruit and vegetables

Fruit: fresh, tinned, dried, frozen.

Vegetables: fresh, tinned, dried, frozen, pickled in vinegar.

Rice, potato and grains

Rice (arborio, basmati, long grain, short grain, brown, wild), potatoes (boiled, mashed, baked), cassava/manioc, polenta, quinoa, tapioca, millet, flax/linseed.

Nuts, seeds and pulses

Lentils, beans, peas, chickpeas, pulses, plain nuts, salted nuts, seeds.

Sauces and seasonings

Garlic puree, tomato puree, herbs, spices, salt, pepper, mint sauces and jellies, vinegars (including barley malt vinegar).

Preserves, spreads and desserts

Marmite, fruit spread, jam, golden syrup, honey, marmalade, treacle, jelly.

Drinks

Water, tea, coffee, squashes (not barley squashes), fruit juice, cider, wine, spirits (including whisky), liqueurs, sherry.

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Suitable and unsuitable cooking and baking ingredients

Suitable ingredients (gluten-free)	Unsuitable ingredients
<ul style="list-style-type: none"> • Agar • Almond • Amaranth • Arrowroot • Bicarbonate of soda • Buckwheat • Carageenan • Chana • Chestnut • Codex wheat starch • Cornflour • Corn starch • Cream of tartar • Dextrin • Dextrose • Flax (linseed) • Food colouring • Gelatine • Glucose syrup • Gram flour (besan) • Guar gum • Hemp • Hops • Icing sugar • Maize (corn), maize starch • Maltitol • Maltodextrin • Millet (bajra) • Modified starch • Molasses • Monosodium glutamate (MSG) • Mustard, mustard flour • Pea starch • Polenta flour • Potato starch • Quinoa • Rice bran, rice flour, rice malt, rice rusk • Sago • Sesame • Sorghum • Soya, soya lecithin 	<ul style="list-style-type: none"> • Barley • Barley flour • Barley malt • Barley wheat • Bulgar wheat • Cous cous • Dinkle • Durum wheat • Einkorn • Emmer • Kamut • Modified wheat starch • Pearl barley • Rusk • Rye, rye flour • Semolina • Spelt • Triticale • Wheat • Wheat flour • Wheatbran • Wheat protein • Wheat rusk • Wheat starch

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Suitable ingredients (gluten-free)	Unsuitable ingredients
<ul style="list-style-type: none"> • Sugar • Sweetner • Tapioca, tapioca starch • Tartaric acid • Teff • Urd/urdi/urad flour • Xanthan gum • Yeast (fresh and dried), yeast extract 	

Gluten-free alternatives to foods that normally contain gluten

There are many gluten-free alternatives to foods that normally contain gluten, such as bread, pasta, pizza bases, biscuits and flour mixes. Most supermarkets now have gluten-free ranges, and some foods are available on prescription.

Your GP can give you a prescription for some gluten-free foods which you then take to your local pharmacy. The pharmacy may need to order-in your items so be aware this could take a couple of days. Unless you qualify for free prescriptions you will have to pay the NHS prescription charge for each type of food you have been prescribed.

You can order a repeat prescription from your GP for the items. If you want to change your prescription you should make an appointment with your GP.

For more information about the gluten-free foods available on prescription and the process involved you can speak to your GP, dietitian, practice nurse or pharmacist.

For more information about NHS prescription charges, who qualifies for free prescriptions and purchasing pre-payment certificates visit www.nhsbsa.nhs.uk.

How can I find out which foods are gluten-free?

Coeliac UK gluten-free lists

Coeliac UK produce a gluten-free checklist that tells you which types of foods are gluten-free, which are not gluten-free and which ones you need to look out for. This is available on their website.

Coeliac UK also produce an annual Food and Drink Directory which is published every January and lists over 11,000 gluten-free products that are safe for people with coeliac disease to eat. Monthly updates for the directory are available online, by phone or post. It is important to keep your directory up-to-date because manufacturer's often change the ingredients of foods, which means that some may become unsuitable for those on a gluten-free diet, and others may become suitable.

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Members of Coeliac UK receive the directory free of charge every year and non-members can purchase it via their website.

As well as the main annual Food and Drink Directory, Coeliac UK also publishes seasonal lists such as a special Christmas list and an Easter list.

Supermarket 'free-from' lists

The following supermarkets produce their own lists detailing which of their foods are 'free-from' gluten. Please speak to someone at Customer Services in store or visit their website for more information.

Tips for gluten-free baking and cooking

Gluten and wheat free cakes can be really successful. Bread and pastry is trickier so start with cakes to gain confidence.

- Be extremely accurate with weights and measures – always use scales and measuring spoons.
- If you are using gluten-free mixes follow the manufacturer's instructions.
- Many of the 'free from' foods can be high in fat and salt so try using some of those alongside making your own, and keep this in mind when aiming for a balanced diet.
- Gluten-free pastry works best with rice and soya flour or potato and polenta flour. The rice or potato flour will make the pastry fine and very absorbent, so it holds the liquid and is less crumbly. Gluten-free pastry can be frozen or chilled.
- Use cling film to cover gluten free pastry when rolling it out to prevent it from sticking to the rolling pin.
- Xanthan gum is a useful ingredient to add to gluten free baking to improve texture.
- Potato flour is a good alternative to wheat flour/cornflour for thickening sauces.
- Quinoa is a gluten-free and extremely nutritious grain which is high in protein – it also contains essential fats omega 3, 6, and 9. Rinse it well as it has 'stones' in it. Red quinoa is the wholemeal version so needs to cook for longer.
- Brown gluten-free pasta is chewier but doesn't break up or disintegrate as easily as white gluten-free pasta does if it is overcooked.

(Written by Tanya Wright of the British Dietetic Association May 2010)

Cross-contamination

If a gluten-free food comes into contact with gluten it will be contaminated with gluten, and this is called cross-contamination. Even tiny amounts of gluten may cause damage to the gut so it is important to make sure this doesn't happen.

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How to avoid eating contaminated food:

- Keep surfaces clean when preparing food.
- Always clean pots, pans and cutlery with soapy, warm water.
- Do not prepare or cook gluten-free food with the same utensils and pans used to prepare food that contains gluten, unless it has been washed properly in between use.
- Use a separate bread board for gluten-containing foods and gluten-free foods, as crumbs can get trapped in the tiny holes on the board.
- Use a separate toaster for gluten-free and gluten-containing breads, or use toaster bags if you do use the same toaster.
- Do not eat jam, margarine or other condiments that have been contaminated with crumbs from normal bread.
- Do not eat gluten free bread or cakes that have been made in the same environment as gluten-containing bread and cakes, as the flour from these products can get into the air and contaminate the gluten-free ones.
- Do not eat gluten-free food that has been cooked in oil previously used to cook gluten-containing food. For example, fish with a gluten-free batter and chips which have been fried in oil previously used to fry normal fish and chips will be contaminated with gluten.

Takeaways and eating out

When you go out to eat or order a takeaway talk to the chef before you order. If you are planning on going out to eat it is useful to call ahead in advance. Explain that you have coeliac disease and the types of foods that are suitable and not suitable for you to eat. Make sure they are aware that your food cannot be cooked in the same oils or pans as other foods that contain gluten because this will contaminate your food.

They may then be able to suggest some suitable items from the menu, or can arrange to cook something else if nothing is suitable. Many restaurant chefs are happy to do this once they know the reason.

Fish and chips: Avoid chips that are fried in the same oil as battered fish as they will be contaminated with gluten. Removing batter from fish does not make it safe to eat as it will be contaminated with gluten.

Chinese: Avoid wheat noodles and soy sauce in Chinese food. If your food is cooked in the same pan as dishes that contain gluten, your food will become contaminated.

Pizza: Pizza bases contain gluten so are not suitable to eat, however some restaurants and takeaways now do gluten-free bases or can cook your gluten-free base if you supply them

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with one. However you still need to be aware of your food being contaminated with gluten in the kitchen.

Your local Coeliac UK group may be able to recommend good places to eat out where other members have had positive experiences. You can find your local group by visiting the Coeliac UK website or calling their helpline.

A note about calcium

Calcium is important for healthy bones and teeth. Adults with coeliac disease need more calcium in their diet than other adults and should have 1000 – 1500mg of calcium per day. Children with coeliac disease need the same amount of calcium in their diet as children who do not have coeliac disease.

Dairy products such as milk, cheese, yoghurt and other milky foods are good sources of calcium. Your dietitian can give you advice on getting enough calcium in your diet.

Further information

The following organisations can provide you with further information on coeliac disease and gluten-free products:

Coeliac UK

www.coeliac.org.uk

Helpline: 0845 305 2060

Gluten Free Foods Ltd

www.glutenfree-foods.co.uk

0208 953 4444

Glutafin

www.glutafin.co.uk

0800 988 2470

Juvela

www.juvela.co.uk

0800 783 1992

Dietary Specials

www.dietaryspecials.co.uk

0800 954 1981

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Contact details

If you have any questions or concerns about following a gluten-free diet please contact your dietitian:

Dietitian: _____

Tel: 0121 507 4085 (Monday – Friday, 9am – 5pm)

Sources used for the information in this leaflet

- Coeliac UK website, www.coeliac.org.uk, accessed March 2013
- Nutrition and Diet Resources UK, 'A Guide to Gluten Free Living', September 2010
- British Society of Gastroenterology, 'The management of adults with coeliac disease', 2010
- Shaw and Lawson, 'Clinical Paediatric Dietetics' (3rd edition), part 3 chapter 7: 'Gastroenterology', 2007
- Thomas and Bishop, 'Manual of Dietetic Practice' (4th edition), section 4.8: 'Coeliac disease', 2007
- 'Guidelines for the Diagnosis and Treatment of Celiac Disease in Children: Recommendations of North American Society for Pediatric Gastroenterology, Hepatology and Nutrition', January 2005

If you would like to suggest any amendments or improvements to this leaflet please contact the communications department on 0121 507 5420 or email: swb-tr.swbh-gm-patient-information@nhs.net



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