

The gluten free diet: for people with coeliac disease and

dermatitis herpetiformis

Nutrition and Dietetics

Patient Information Leaflet

Introduction

This leaflet is for people who have coeliac disease and/or dermatitis herpetiformis. It gives information on eating a gluten free diet including how to manage at home and when you are eating out; what foods to eat and what to avoid; and gluten free food prescriptions.

What is coeliac disease?

Coeliac disease is a lifelong autoimmune disease caused by a reaction to gluten, a protein found in wheat, rye and barley. If someone with coeliac disease eats gluten, their immune system reacts by damaging the lining of the small intestine. In some people, coeliac disease may also affect the nervous system and the skin.

Around one in 100 people are likely to have coeliac disease although it is estimated that only one in eight of these has been diagnosed.

<u>Symptoms can be mild to severe</u>, and can include bloating, diarrhoea, nausea, wind, constipation, tiredness, mouth ulcers, sudden or unexpected weight loss (but not in all cases), hair loss and <u>anaemia</u>. Some people can also experience problems with balance (ataxia) and tingling/numbness in fingers and toes (peripheral neuropathy).

Dermatitis herpetiformis (DH) is a skin condition linked to coeliac disease.

How are coeliac disease and dermatitis herpetiformis treated?

The only treatment for coeliac disease and dermatitis herpetiformis is a strict life-long gluten free diet.

This involves avoiding all foods containing wheat, barley and rye. Oats may also need to be avoided – see section on 'Grains and flour manufacturing'.

Gluten free foods are available and, in some areas, your GP may be able to prescribe them. Supermarkets are becoming more aware of coeliac disease and often have their own gluten free variety section.

Coeliac UK is the leading charity working for people with coeliac disease and dermatitis herpetiformis. You may find it helpful to become a member because they produce a lot of useful information including a Food and Drink Directory which contains a list of brand names which are gluten free. However, please note that there is an annual fee for the membership. For further information about Coeliac UK, please see the section 'Can I find out more?'

What are the food-labelling laws for gluten free products?

All ingredients have to be listed on food packaging in the ingredients list.

Any food which contains gluten must be labelled on food packets either in the ingredients list or separately.

If gluten is not present in a product, it does not have to be labelled as gluten free; however, most manufacturers do put this on the label.

If cereal containing gluten is used as an ingredient, it must be listed on the ingredients list, no matter how much is used. Manufacturers will name the specific grain so you will see the following words on the ingredients list if they have been used:

- Wheat
- Rye
- Barley
- Oats
- Spelt
- Kamut
- Or any grain which has been made through breeding these grains together

Please see the section 'What foods can I eat?' for more information.

Labelling legislation for gluten free foods

You may see statements on products that are marketed for people with coeliac disease. When you see the following statements, they indicate that the food is suitable for you:

- Gluten free
- No gluten-containing ingredients
- Suitable for coeliacs
- Crossed grain symbol

These terms are now covered by legislation for the labelling of gluten free foods which was published in January 2009. The legislation states:

 Only foods which contain less than 20ppm (parts per million) of gluten can be labelled 'gluten free'. This will include naturally gluten free foods, specialist substitute products which may contain Codex wheat starch and pure uncontaminated oats.

New legislation on allergen labelling

Under European legislation for allergen (substances which may cause an allergic reaction) labelling, manufacturers are required to emphasise allergens on the ingredients list (for example, by using **bold** or *italic* font). This became mandatory from December 2014.

What should I look for on ingredient lists?

For some ingredients, it is not clear if they contain gluten or not. The following information is to help you choose gluten free ingredients.

Gluten free:	Not gluten free:
Aspartame	Wheat flour
Artificial sweetener	Wheat starch
Caramel	Modified wheat starch
Citric acid	Wheat rusk
Corn malt	Wheat bran
Dextrose	Barley malt
Glucose syrup	Barley flour
Isomalt	Oat bran
Magnesium stearate	Rye flour
Maize starch	
Maltitol	
Maltodextrin	
 Modified maize starch 	
 Modified starch 	
Monosodium glutamate	
Rice malt	
Rice rusk	
Sorbitol	
Textured vegetable protein	
Xanthum gum	

Malt extract and barley malt extract

Many people with coeliac disease have questions about barley malt extract.

What is malt extract?

Malt extract is most commonly prepared from barley although it can be produced from other grains. It is widely used in small amounts in the food industry as a flavour enhancer. For example, it is used as an ingredient in most brands of breakfast cereals and many other branded manufactured products.

In line with EU allergen labelling legislation, barley malt extract must be declared in a product ingredients list regardless of the amount used.

Can patients with coeliac disease eat barley malt extract?

The quantity of barley malt extract used in products can vary. Products containing barley malt extract in low levels that meet the Codex standard can be tolerated by most people with coeliac disease.

Food products listed in Coeliac UK's Food and Drink Directory are guaranteed by the manufacturer to comply with the current Codex standard for gluten and can be tolerated by most people with coeliac disease.

Food products high in barley malt, such as malted drinks, are not suitable for people with coeliac disease.

How can I avoid cross contamination?

People with coeliac disease need to avoid contamination of gluten free foods from other foods as even tiny amounts of gluten may cause symptoms in the short term and gut damage in the longer term.

At home

When you are cooking at home, simple steps will help in keeping food preparation safe:

- Wipe down surfaces before you begin.
- Clean pots and pans with detergent (for example, washing up liquid) and water.
- You may want to get separate cutting boards for handling gluten free bread as there are tiny pores in wooden boards where crumbs from 'normal' bread will remain.
- Use separate toasters or toaster bags.
- Use different butter knives and jam spoons to prevent breadcrumbs from getting into condiments (jam, butter etc.).

Grain and flour manufacturing

Although some types of flour are naturally gluten free, they can be milled where wheat flour is also milled. Contamination occurs either because wheat flour is in the atmosphere or traces of it remain in storage containers. It is possible that flour made from pulses, such as gram and urad flour, may be contaminated although they are naturally gluten free.

In the UK, most oats are contaminated with high levels of gluten. Oats or oat products are only suitable if they are labelled as gluten free.

What should I do when I eat out?

There are several things you can do to make eating out a bit easier:

- Call ahead to the restaurant to let the chef know about coeliac disease and gluten free foods.
- Look at the menu to see if breaded items such as chicken or fish are offered. These may be cooked in the same pans as non-breaded dishes.
- Ask the waiting staff or the chef about using separate pans to avoid cross contamination.
- Ask the chef to carefully check the ingredients of soups, dishes with sauces or gravy, stock cubes (if used), coatings on chips and sausages.
- Ultimately, it is your choice to go to certain places or eat certain menu items depending on your own gluten sensitivity and risk consideration.

Bakeries

Cross contamination is likely to occur in bakeries as flour tends to get into the air. We recommend that you do not buy gluten free bread made in the same environment as conventional bread. People with coeliac disease should be aware that individual meringues or macaroons may be made from gluten free ingredients but may be contaminated by products that contain gluten used in the same establishments.

Takeaways

Takeaways can be included as part of a healthy balanced diet. It is important to consider, however, that takeaways can often be a rich source of unhealthy saturated fats, salt and sugar.

Fish and chips

Chips or fish with a gluten free batter cooked in the same oil as gluten containing batter will be cross contaminated. Even if the chips appear to be cooked separately, be aware that the oil is often rotated so the chip oil may have previously been used to cook battered fish. Some shops are now offering designated gluten free days so it is worth asking about this.

Chinese

Rice and rice noodles are naturally gluten free, as are meat, fish and vegetables. However, wheat noodles and soy sauce contain gluten and there may be a risk of cross contamination with food cooked in oil that has been used to cook gluten-containing foods.

Indian

Lentils and rice are naturally gluten free. Sauces need to be checked but are often thickened with yoghurt or chickpea flour which is gluten free. Any types of bread will need to be avoided as they will contain gluten unless otherwise stated. Poppadoms are gluten free but may contain gluten if fried in contaminated oil.

Pizza

Conventional pizza bases contain gluten and so must be avoided. However, many well-known chains now offer gluten free pizzas.

What foods can I eat?

The following tables show foods which you can eat for a gluten free diet and the foods you need to avoid:

Foods allowed	Foods to avoid
Cereals and flour Corn or maize, cornmeal Rice (brown and white), wild rice Arrowroot, buckwheat, millet	Cereals and flour Wheat, rye, barley and oats Spelt, triticale, kamut, bulgar wheat, durum wheat
Specially manufactured gluten free flour Specially manufactured gluten free wheat starch Specially manufactured gluten free mixes	Commercial wheat starch, wheat flour Ordinary bread, cake and pastry mixes Semolina, couscous Wheat or oat bran, wheat germ, malt and malted barley
Cornflour or maize flour, polenta Rice flour, ground rice Soya flour, potato flour, potato starch Bean flours, chickpea flour, split pea flour Sago, tapioca, cassava Rice bran Popping corn Breads, cakes and biscuits	 Bread, cakes and biscuits All bread and bread products made using wheat, rye, barley and oats Croissants, brioche, naan bread, pitta bread, ciabatta, chapattis, rye bread, parathas, samosas, poppadoms Ordinary biscuits, crispbread, crackers, matzos, rusks Ordinary cakes and pastries, muffins and
Specially manufactured gluten free bread and rolls Specially manufactured part baked gluten free bread and rolls Specially manufactured gluten free biscuits, cakes, crispbread, crackers and pizza bases Gluten free meringues and macaroons	scones Pizzas, croutons, pancakes, Yorkshire pudding, pastry Slimming breads and biscuits
Rice cakes – not all are gluten free so check the label	

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Foods allowed	Foods to avoid
Fruit, vegetables and nuts	Fruit, vegetables and nuts
All fresh, frozen, canned, dried pure fruits and vegetables including potatoes and pulses (peas, beans and lentils) Oven chips (check the label), microwave and frozen chips	Vegetables and potatoes in batter, breadcrumbs or dusted with flour
	Chips coated with added flour or batter (bought chips should be checked)
Plain and roasted, salted nuts	Chip shop chips/fish due to contaminated oil
Breakfast cereals	Potato products containing flour
Rice cereals – varies according to	Potato croquettes, potato waffles
brand, check the label	* Instant mashed potato
Specially prepared gluten free muesli Buckwheat flakes	* Dry roasted nuts including peanuts
	* Fruit pie fillings and fruit sauces
Pure uncontaminated oats	Fruit in batter, breadcrumbs or dusted with flour
	* Gluten free varieties may be available – check food labels carefully or check the current Coeliac UK Food and Drink Directory
	Breakfast cereals
	Weetabix, Shredded Wheat, Puffed Wheat, All Bran
	Muesli
	Porridge oats and oatmeal, Ready Brek unless they state they are gluten free

Foods allowed	Foods to avoid
Pasta	Pasta
Specially manufactured gluten free pasta	All other fresh, dried or canned wheat pasta including spaghetti, macaroni,
Corn pasta, rice pasta	lasagne, ravioli, pasta shapes, noodles
Rice noodles – may contain gluten so check the label	Milk and milk products
	Milk with added fibre
Milk and milk products	Artificial cream
Fresh, dried condensed and evaporated milk	Oat milk
Skimmed, semi-skimmed and whole milk	Yoghurt and fromage frais containing muesli or cereals
Sterilised and U.H.T milk	Fats and oils
Fresh cream, soured cream, buttermilk, crème fraiche	Shredded suet
Soya milk	* Vegetable suet
Goats' milk	 * Gluten free varieties may be available – check food labels carefully or check
Yoghurts – check the label	the current Coeliac UK Food and Drink Directory
Coffee and tea creamers or whiteners	
Fats and oils	
Butter, margarine, lard and cooking oils	
Pure wheatgerm oil, ghee	

Reduced fat and low fat spreads	

Foods allowed	Foods to avoid
Meat and poultry	Meat and poultry
All fresh meats, poultry, game, offal Meat, canned or pre-packed in its own juices or jelly Smoked or cured pure meat such as bacon or ham Sausages that are 100 per cent meat Specially made gluten free sausages	Meat, poultry or game cooked in batter or breadcrumbs Meat pies and puddings Haggis Ordinary sausages and sausage meat Burgers, faggots and rissoles * Canned meat products * Meat pastes and pates Scotch eggs
All fresh fish and other seafood Smoked, kippered and dried fish and shellfish Fish, canned in oil or brine Frozen, plain fish and shellfish	Fish and shellfish Fish in batter or breadcrumbs Fish cakes, fish fingers, taramasalata * Fish in sauces * Fish pastes and pates
Cheese and eggs	Cheese and eggs
All natural plain cheeses, cottage cheese, cream cheese, low fat and diet cheeses Cheese with added fruit, vegetables, nuts and herbs Eggs	 * Cheese spreads * Processed cheese * Cheese fillers Scotch eggs *Gluten free varieties may be available – check food labels carefully or check the current Coeliac UK Food and Drink Directory

Foods allowed	Foods to avoid
Savoury snacks	Savoury snacks
Plain potato crisps Homemade popcorn Specially manufactured gluten free pretzels	* Flavoured crisps and chips Snack products made from wheat, rye, barley and oats, pretzels
Preserves and spreads	Preserves and spreads
	* Mincemeat
Sugar, glucose molasses, treacle, jam, conserves, honey, golden	* Lemon curd and cheeses * Commercial sweet spreads
syrup, marmalade Peanut and other nut butters	Commercial sweet spreads
	Soups, sauces and seasonings
Soups, sauces and seasonings Soups, sauces for gravy made with gluten free ingredients or thickened with gluten free flour Salt, pepper, ground peppercorns Tomato and garlic purees	 * Canned and packet soups * Packet sauces and sauce mixes * Cook-in sauces * Bottled sauces and ketchup * Stock and stock cubes * Gravy browning and gravy mixes Soy sauce * Mustard powder and curry powder
Herbs, spices, garlic	Mixed seasonings and spices which specify
Malt vinegar and Worcestershire sauce are suitable for most people with coeliac disease Wine and cider vinegars, balsamic vinegar Pickled vegetables in vinegar Specially manufactured gluten free stuffing mix	flour as filler on the label * Mayonnaise and salad cream * Salad dressings * Pickles and chutney Stuffing mixes * Gluten free varieties may be available – check food labels carefully or check the current Coeliac UK Food and Drink Directory

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Confectionery Homemade and commercially manufactured sweets and chocolates made with gluten free ingredients – check food labels carefully or check the current Coeliac UK Food and Drink Directory Puddings Jelly (gelatine and vegetarian) Milk puddings, made with gluten free ingredients, e.g. egg, cornflour, rice, ground rice, sago and tapioca Homemade puddings using gluten free ingredients	Confectionery Liquorice * All sweets, chocolates, toffees, etc. Boiled sweets and seaside rock rolled in flour * Chewing gum Puddings Puddings containing flour and breadcrumbs Semolina and macaroni milk puddings Trifles Sponge and suet puddings, pastry and crumbles * Instant desserts * Ice cream and Iollies * Custard powders * Mousses
Drinks Tea, coffee Fruit juices and fruit squash Mineral water Clear fizzy drinks Cocoa, milk Complan, Build-Up, Isostar Spirits, wines, liqueurs, cider, sherry and port	Drinks Instant coffee containing barley Barley waters Cloudy fizzy drinks Vending machine chocolate drinks, *chocolate powders and drinks * Milk shakes and mixes Malted milk drinks e.g. Ovaltine and Horlicks * Sports and health drinks *Beer, lager, ale, stout and real ales All home-brewed or low alcohol beers and lager * Gluten free varieties may be available – check food labels carefully or check the current Coeliac UK Food and Drink Directory

Foods allowed	Foods to avoid
Miscellaneous	Miscellaneous
Gelatine Bicarbonate of soda, cream of tartar Fresh and dried yeast Tofu Food colourings, essences and flavourings Bovril – meat and vegetable extract Marmite – yeast extract Gluten free communion wafers	 * Baking powder * Quorn Ice cream cones and wafers * Cake coverings, *cake decorations, *marzipan * Meat, vegetable and yeast extracts Communion wafers * Gluten free varieties may be available – check food labels carefully or check the current Coeliac UK Food and Drink Directory

Prescriptions

If you have been medically diagnosed with either coeliac disease or dermatitis herpetiformis, you may be entitled to receive a limited number of gluten free foods, such as bread and flour on prescription. This depends on your GP and the prescribing policy in your area.

It is best to try gluten free foods from different companies and to choose the most suitable brand before asking your GP for a repeat prescription. Most companies are happy to send out free starter packs for those who have just been diagnosed with coeliac disease.

People with coeliac disease do not receive prescriptions free of charge unless they are exempt for another reason.

Therefore, it is advisable to purchase a pre-payment certificate (FP95), which can be obtained by:

- Ringing the Department of Health on 0300 330 1341
- From pharmacies registered to sell pre-payment certificates

Online from https://services.nhsbsa.nhs.uk/buy-prescription-prepayment-certificate/start

Gluten free products available on prescription from GP practices within the Dudley area:

In England, from December 2018, gluten free bread and flour mixes are the only foods available on prescription. In addition local clinical commissioning groups (CCGs) in England can introduce further restrictions.

Within the Dudley area, the following number of gluten free products (units) are available on prescription:

- Adults 19 years of age and over may obtain **10 gluten free units each** calendar month on NHS prescription.
- For information on the number of gluten free units available on prescription for people aged 18 and under, please speak to your dietitian.

Some examples are shown in the following table of some food items and how many gluten free units they contain:

Prescribable food item	Number of units
400g bread	One
Eight x 400g loaves of bread	Eight
500g flour/bread mix	Тwo

Please be aware that fresh loaves can only be ordered in multiples of eight loaves, which equals eight units.

Unfortunately, due to the current economic climate, items considered nonessential such as crackers, biscuits, crispbreads, breakfast cereals and oats are not available on prescription, but they can be purchased from many supermarkets.

Can I find out more?

You can find out more from the following:

Coeliac UK

3rd Floor, Apollo Centre Desborough Road High Wycombe HP11 2QW **Website:** <u>www.coeliac.org.uk</u> **Helpline:** 0333 3322033

You can get gluten free recipes, information on coeliac disease and the gluten free diet, and a directory of gluten free restaurants from the website. A downloadable app is also available through this site with a barcode reader to check if products are gluten free, as well as a restaurant search function (if you are a member).

There is a Coeliac UK Stourbridge and District support group which can be contacted on:

Email: stourbridge@coeliac.org.uk

Page 19 If you have any questions, or if there is anything you do not understand about this leaflet, please contact:

The dietitians at Russells Hall Hospital on 01384 244017 (8.30am to 4.30pm, Monday to Friday)

Russells Hall Hospital switchboard number: 01384 456111

This leaflet can be downloaded or printed from:

http://dgft.nhs.uk/services-and-wards/nutrition/

If you have any feedback on this patient information leaflet, please email dgft.patient.information@nhs.net

This leaflet can be made available in large print, audio version and in other languages, please call 0800 073 0510.

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