# The Dudley Group 

NHS Foundation Trust

# 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.

Symptoms can be mild to severe, and can include bloating, diarrhoea, nausea, wind, constipation, tiredness, mouth ulcers, sudden or unexpected weight loss (but not in all cases), hair loss and anaemia. 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 | - Barley bran |
| - Dextrose | - Barley flour |
| - Glucose syrup | - Oat bran |
| - Isomalt | - Rye flour |
| - Magnesium stearate |  |
| - 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 leat?

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


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


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

Reduced fat and low fat spreads

| Foods allowed | Foods to avoid |
| :---: | :---: |
| Meat and poultry <br> All fresh meats, poultry, game, offal Meat, canned or pre-packed in its own juices or jelly <br> Smoked or cured pure meat such as bacon or ham <br> Sausages that are 100 per cent meat Specially made gluten free sausages | Meat and poultry <br> Meat, poultry or game cooked in batter or breadcrumbs <br> Meat pies and puddings <br> Haggis <br> Ordinary sausages and sausage meat <br> Burgers, faggots and rissoles <br> * Canned meat products <br> * Meat pastes and pates <br> Scotch eggs |
| Fish and shellfish <br> All fresh fish and other seafood Smoked, kippered and dried fish and shellfish <br> Fish, canned in oil or brine Frozen, plain fish and shellfish | Fish and shellfish <br> Fish in batter or breadcrumbs Fish cakes, fish fingers, taramasalata <br> * Fish in sauces <br> * Fish pastes and pates |
| Cheese and eggs <br> All natural plain cheeses, cottage cheese, cream cheese, low fat and diet cheeses Cheese with added fruit, vegetables, nuts and herbs Eggs | Cheese and eggs <br> * Cheese spreads <br> * Processed cheese <br> * Cheese fillers <br> Scotch eggs <br> *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 | * Flavoured crisps and chips |
| Homemade popcorn Specially manufactured gluten free pretzels | Snack products made from wheat, rye, barley and oats, pretzels |
|  | Preserves and spreads |
| Preserves and spreads | * Mincemeat |
| Sugar, glucose molasses, treacle, | * Lemon curd and cheeses |
| jam, conserves, honey, golden syrup, marmalade | * Commercial sweet spreads |
| Peanut and other nut butters | Soups, sauces and seasonings |
| Soups, sauces and seasonings | * Canned and packet soups <br> * Packet sauces and sauce mixes |
| Soups, sauces for gravy made with | * Cook-in sauces |
| gluten free ingredients or thickened | * Bottled sauces and ketchup |
| with gluten free flour | * Stock and stock cubes <br> * Gravy browning and gravy mixes |
| Salt, pepper, ground peppercorns | Soy sauce |
| Tomato and garlic purees | * Mustard powder and curry powder |
| Herbs, spices, garlic | Mixed seasonings and spices which specify flour as filler on the label |
| Malt vinegar and Worcestershire | * Mayonnaise and salad cream |
| sauce are suitable for most people | * Salad dressings |
| with coeliac disease | * Pickles and chutney |
| Wine and cider vinegars, balsamic vinegar | Stuffing mixes |
| Pickled vegetables in vinegar Specially manufactured gluten free stuffing mix | * Gluten free varieties may be available check food labels carefully or check the current Coeliac UK Food and Drink Directory |

## 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

## 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

## 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 lollies
* Custard powders
* Mousses


## 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 | * Baking powder |
| Bicarbonate of soda, cream of tartar | *Quorn <br> Fresh and dried yeast <br> Tofu |
| Foe cream cones and wafers <br> Food courings, essences and <br> flavourings <br> Bovril - meat and vegetable extract <br> Marmite - yeast extract <br> Gluten free communion wafers | *marzipan <br> *Meat, vegetable and yeast extracts <br> Communion wafers |
|  | *Gluten free varieties may be decorations, <br> available - check food labels <br> 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 03003301341
- From pharmacies registered to sell pre-payment certificates
- Online from https://services.nhsbsa.nhs.uk/buy-prescription-prepaymentcertificate/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 $\mathbf{1 0}$ 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 |
| :--- | :--- |
| 400 g bread | One |
| Eight x 400 g loaves of bread | Eight |
| 500 g flour/bread mix | Two |

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
$3{ }^{\text {rd }}$ Floor, Apollo Centre
Desborough Road
High Wycombe
HP11 2QW
Website: www.coeliac.org.uk
Helpline: 03333322033
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

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 01384244017 (8.30am to 4.30pm, Monday to Friday)

Russells Hall Hospital switchboard number: 01384456111
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 08000730510.

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