

INFORMATION FOR PATIENTS

Coeliac disease – a gluten-free diet

The following information is for people diagnosed with coeliac disease, providing advice for following a gluten-free diet.

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What is coeliac disease?

Coeliac disease (CD) is an autoimmune condition where the body will attack its own tissues in response to eating gluten.

CD is not an allergy or intolerance.

How is it diagnosed?

CD is usually diagnosed via a blood test to check for antibodies present in the blood. Prior to the test, you should have been instructed to include gluten in your diet to promote an accurate result (as the antibodies are produced as a response to consuming gluten). You may have been referred by your gastroenterologist for more blood tests and biopsies for further information.

Where is gluten found?

Gluten is a protein found in wheat, rye and barley. This includes foods within the same families (i.e. spelt, Kamut), or grains blended with the above.

Oats

These do not contain gluten but are usually processed with other grains like wheat, rye and barley, and therefore can become contaminated with gluten. Most people with CD can tolerate gluten free oats, or some people may still be sensitive to this. If you have concerns or symptoms whilst including gluten free oats in your diet, speak to your healthcare professional.

Oats can be contaminated with gluten during processing and therefore only products containing gluten free oats are suitable.

Examples of foods that commonly contain wheat, rye and barley are:

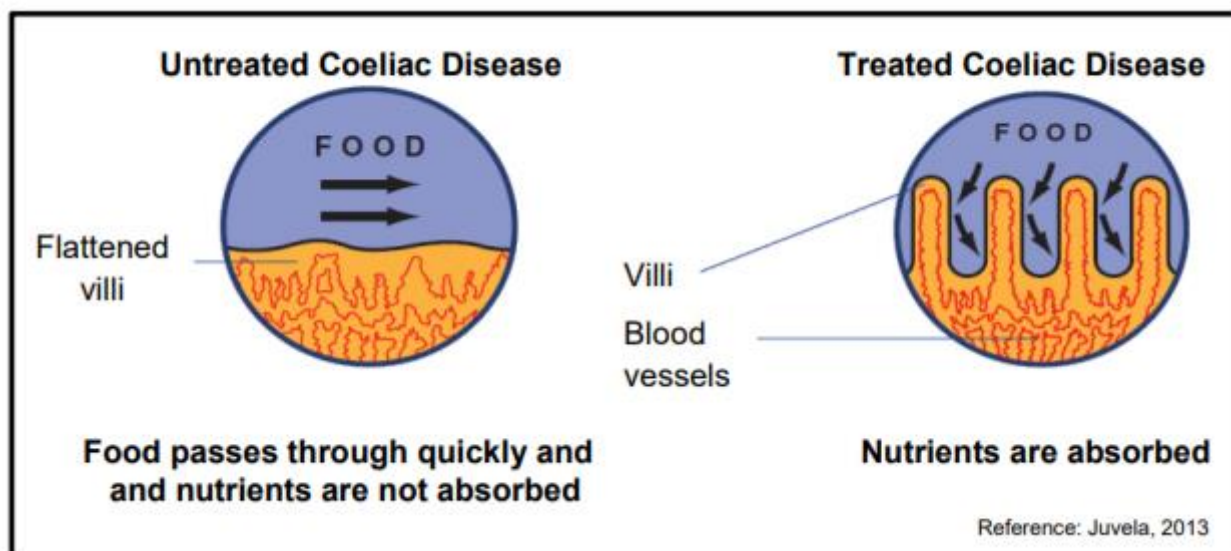
- Bread
- Pastries
- Pasta
- Beer
- Cake
- Biscuits.

What happens when I eat gluten if I have CD?

When gluten is consumed an immune reaction occurs. This damages the lining of the gut and the surface area (known as 'villi') for absorbing nutrients from food is decreased, leading to long-term complications.

The treatment for CD is a **strict gluten free diet for life**.

Below is a diagram of how the villi may look after sustaining long-term damage from gluten ingestion. As the finger-like villi are damaged, they lose their shape, which reduces their surface area, and therefore reduces the amount of nutrients that they can absorb from the food and drinks you consume. It is really important to follow the gluten-free advice to help prevent this damage from occurring.



Common symptoms of CD

People can be affected by Coeliac disease in a number of different ways. Some people may notice no symptoms at all. The most commonly reported symptoms are:

- Abdominal or gastrointestinal symptoms such as diarrhoea, constipation, nausea, vomiting, abdominal cramps, pain and bloating.
- Unexplained weight loss.
- Feeling tired.
- Vitamin and mineral deficiencies such as iron deficiency anaemia or B12 deficiency.
- Persistent mouth ulcers.
- Dermatitis herpetiformis (DH) – the skin manifestation of CD, which often causes painful skin blisters.

First steps to following a gluten free diet

Learn which foods are naturally gluten free. All types of potato, rice, corn, meat, fish, eggs, pulses, milk, cheese and fruits and vegetables are gluten free.

Using information on the website Coeliac UK as a resource can help provide you with lots of detailed information to managing your CD (website: www.coeliac.org.uk or telephone 0333 332 2033). They can also help put you in touch with a local group for extra support.

Visit your local supermarkets to identify gluten free ranges. Some supermarkets will produce a list of gluten free products that can help you shop in their store.

Coeliac UK have launched an app called 'Coeliac UK Live Well Gluten Free' (see the www.coeliac.org.uk website for more information), that can be used on Android and IOS mobile phones. This may be a handy tool to have at your fingertips when struggling to find gluten-free foods.

There are also apps available to download to your smart phone that can scan barcodes and tell you if the product is suitable on a gluten free diet.

Food labelling

Checking and understanding food labels is very important when you have CD. Foods labelled **gluten-free** are suitable for people with CD. This term can only be used for foods that contain 20 parts per million or less of gluten.

The 'cross-grain' symbol is an easy way to identify if a product is gluten free. UK labelling laws mean that all allergens must be emphasised in **bold** on the ingredients list.



Food label examples:

As seen below on the baked beans food label, there are no ingredients in **bold**, indicating that there are none of the 14 major food allergens that need to be highlighted under EU law (which the UK still abides by).

Ingredients: Beans (50%), Tomatoes (36%), Water, Sugar, Spirit Vinegar, Modified Cornflour, Salt, Spice Extracts, Herb Extract

Below on the food label for beans and sausages, there are ingredients in **bold**, indicating that some of the 14 major food allergens are present in this food produce.

Ingredients: Beans (38%), Tomatoes (31%), Water, Sausages (15%, Pork (42%), Water, Rusk (**Wheat**), Pork Fat, **Soya** Protein, Starch (**Wheat**), Stabilisers: Diphosphates, Guar Gum, Methyl Cellulose, Sodium Alginate; Salt, Spices, Preservative: Sodium **Metabisulphite**, Antioxidants: Ascorbic Acid, Alpha Tocopherol; Flavourings, Nutmeg Extract, Colour: Carmine), Sugar, Spirit Vinegar, Salt, Modified Cornflour, Natural Flavouring, Spice Extract, Herb Extract.

Sometimes, another message may also be highlighted – this is to further inform the consumer that allergens are present, along with some that may be present due to factors such as proximity in the manufacturing facility with other foods or sharing equipment.

Contains: Soya, Sulphur Dioxide/Sulphites, Wheat.
May contain: Egg.

You may see the following statement on a product's packaging:

- May contain traces of gluten- this means the manufacturer has determined there is a risk that the product may be contaminated with gluten.

There are some products that are 'wheat-derived' (e.g. glucose syrup, maltodextrin) which have been made from wheat products, but have likely been highly processed, meaning that there will be negligible of any gluten content. If you are uncertain, then contact the manufacturer directly for further information on the suitability of the product.

Eating out

All caterers must provide information regarding allergens on all dishes that they serve. If the recipe contains any gluten-containing ingredients, this information must be provided either in writing, verbally, or signposting should be available on where to find it (this may be online via links – some places use QR codes). If you have doubts about the foods you may choose, or about the establishment you are ordering from, please avoid it.

Contacting the premises in advance and speaking with a member of staff about your dietary requirement can help prevent any confusion and unnecessary hassle when you arrive. Talking to staff about how the dish is cooked can also reduce the risk of cross contamination.

Some establishments provide gluten-free menus – feel confident in asking if these are available as some places have accreditations from Coeliac UK. Some may offer a 'non-gluten containing ingredient' (NGCI) menus, that may not contain gluten in the foods, but these are not protected by law due to not claiming to be gluten-free. Please be wary of these menus as cross-contamination of gluten cannot be guaranteed.

Coeliac UK provides training to restaurants. If you see the Coeliac UK symbol on the menu, it means the venue is compliant with the Coeliac UK accreditation scheme.

Please see the Coeliac UK website (www.coeliac.org.uk) for accredited venues. Some of these include Bill's, Browns Brasserie & Bar, Brunning & Price pubs, Carluccio's, Pho, Pizza Express and many more.

Takeaways

Make sure to treat takeaway establishments the same way you would with restaurants where you would dine-in. Depending on the cuisine of the establishment, cross-contamination or direct exposure to gluten can be difficult to avoid due to the abundance of gluten in some staple foods for some cultures.

Please be aware of some of the ingredients that contain gluten, but may not be explicitly considered. Please consider the following:

- Soy sauce or tamari (made from the byproducts of making miso). Gluten-free soy sauce is available in supermarkets, but restaurants and takeaways may not have this available for use – check with individual providers.

- Chips – are these fried in the same fryer as gluten-containing foods (such as battered fish or onion rings)?
- What are the cooking methods? Do they have a designated gluten-free fryer?
- Check how sauces are thickened – is flour used?

Cross contamination

Even consuming traces of gluten can cause symptoms and long-term gut damage. Therefore, it is important to ensure that the risk is minimised. The following list gives practical tips to help you keep your food preparation safe:

- Ensure surfaces are clean, and free from debris from previous food preparation.
- Use a separate toaster/grill pans or use toaster bags to avoid cross contamination with .
- Have separate spreads, jams, butter, marmalade, etc.
- Use clean oil or a separate fryer when frying gluten-free foods. If using an air fryer, consider washing this out and changing the liner inside.
- Use separate bread boards and consider keeping gluten-free foods in a separate area to other gluten-containing foods (if you live with others who consume gluten), e.g. breads or crackers.
- Ensure equipment and utensils are thoroughly cleaned after use.
- Consider using separate cooking utensils and dishes than those who eat gluten.

Travelling

Similar to eating out, there is no reason why having CD should prevent you from enjoying your travelling. However, this will require some planning ahead:

- Contact your travel provider/operator to let them know you will require gluten-free meals at the time of booking.
- If you are travelling abroad, make sure you research the local cuisine to see if it is suitable for your needs – be confident in contacting establishments to ensure they are safe to eat with.
- If possible, take some gluten-free staples of your diet (like bread and crackers) for emergencies in case you find it difficult to source gluten-free foods while abroad, or for if there are any cancellations or delays leading to needing to find somewhere and something to eat. Check with your operator that you are allowed to bring gluten-free products into the country you are visiting. **Countries in the EU are covered by the same UK labelling laws.**

Coeliac UK (www.coeliac.org.uk) provides information leaflets on over 50 countries which contain useful translations that can help when eating out abroad.

There are apps specifically designed for travelling with CD and other food allergies. These can be found online. There are also CD translation cards with different languages on, so you can communicate your dietary requirements in a simple way.

If you are travelling abroad, it is important that you ensure your travel insurance provider is aware of your dietary requirements and CD diagnosis, to ensure you are covered if an adverse event occurs related to the condition.

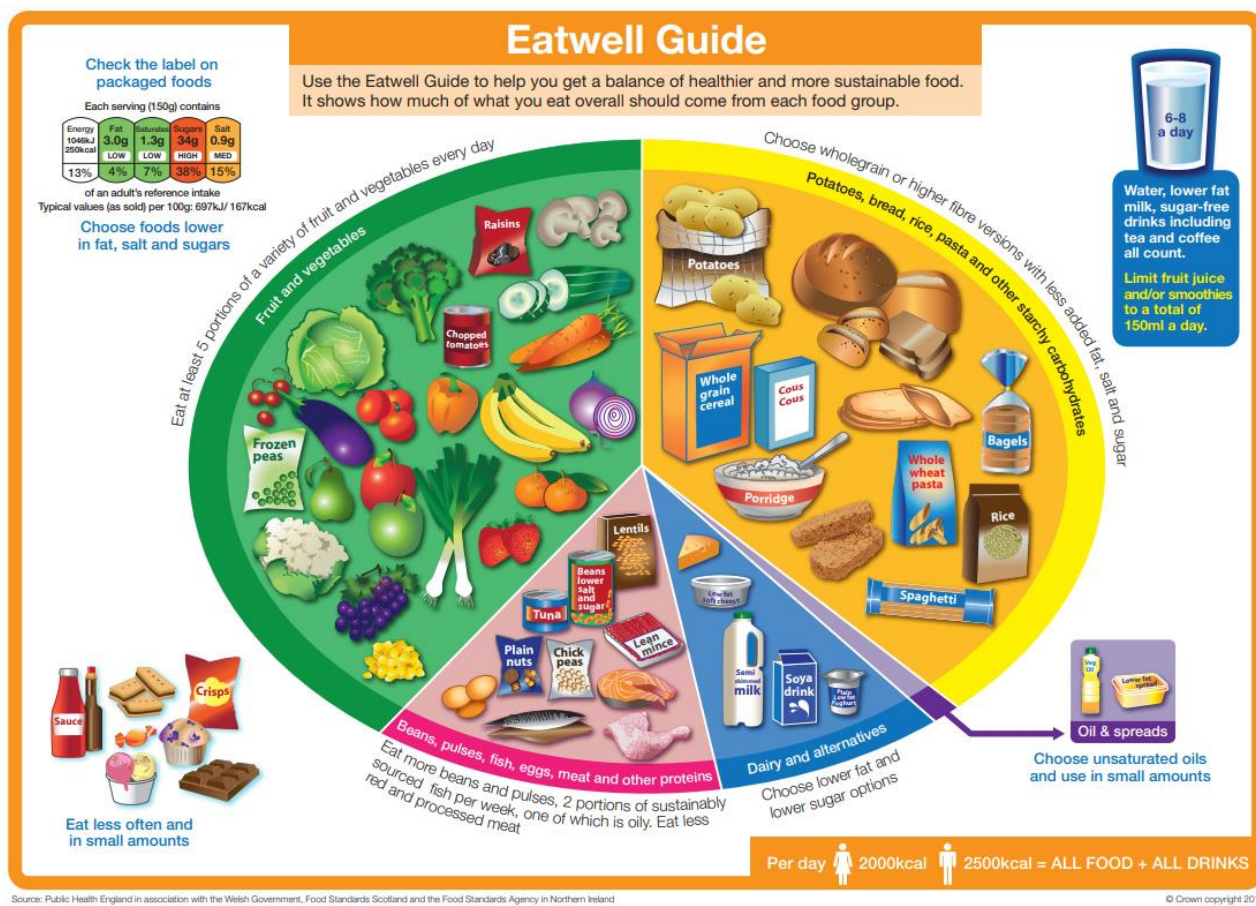
Maintaining a healthy balanced diet

Starchy foods play an important role in maintaining a healthy balanced diet. Therefore, gluten-free starchy foods should NOT be avoided; these should contribute to your daily diet. This is because many gluten-containing foods are also good sources of **fibre, calcium, B-vitamins** as well as energy. It is important to make sure you are getting these nutrients from alternative foods that are gluten-free.

When choosing gluten-free alternatives (such as rice, pasta, and bread), try to choose high-fibre varieties and look for options that are fortified with **iron** or **calcium**.

Healthy eating principles (such as maintaining a healthy weight, aiming for **at least** five fruit and vegetables per day, and limiting high fat/high sugar containing foods) are the same for people with CD as they are for the general population.

The guide below shows an overview of the different food groups and what proportions we should aim for in our diet.



If you lost weight prior to your diagnosis of CD, you should find as your gut heals and your symptoms settle following the elimination of gluten from your diet, your appetite should improve, and you may gain some of the lost weight back to what is normal for you.

Common foods

Below are lists of common foods – please use these tables to help you manage your gluten-free diet.

	Gluten free	Check labels	Avoid
Bread	Gluten free bread and rolls.		All bread, bread rolls, muffins, chapattis (made from wheat), barley flour, rye flour.
Flour	Corn, corn flour, rice, rice flour, arrowroot, buckwheat, soya flour, potato starch, modified starch, polenta, tapioca, gram flour, potato flour, any flours labelled gluten-free.	Flavoured rice products.	Wheat, wheat bran, wheat rusk, wheat durum, wheat starch, wheat flour, Khorasan wheat, rye, barley rye, rye flour, barley, barley malt, barley flour, semolina, couscous.

	Gluten free	Check labels	Avoid
Cereal	All products labelled gluten free. For gluten free oats follow guidance from your dietitian.	Cereals containing barley malt extract, corn, buckwheat, rice based cereals.	Oats not labelled gluten free, wheat based breakfast cereals, muesli.
Pasta and noodles	Anything labelled gluten-free e.g. corn pasta, rice noodles/pasta etc.		Pasta or noodles containing wheat.
Pizza	Gluten free pizza bases.		Pizza bases made with wheat, barley or rye flour.
Potatoes	All potatoes that are baked, boiled or mashed and are plain.	Pre-made potato products such as instant mash, chips and potato waffles.	Products in batter or breadcrumbs or that contain flour.

	Gluten free	Check labels	Avoid
Meat and fish	All fresh meat, poultry or fish, all smoked/dried/cured meat or fish, canned fish (in oil, brine or water) and shellfish.	Meat or fish in sauce, pâtés, sausages, burgers.	Meat, poultry or fish cooked in batter or breadcrumbs, fish cakes/rissoles, fish fingers, breaded ham, faggots, haggis and taramasalata.
Eggs	All plain eggs.		Scotch eggs.
Pulses and nuts	All beans, peas and lentils, all plain and salted nuts.	Pulses in a sauce, e.g. baked beans, dry roasted nuts.	
Vegetarian protein sources	Tofu – plain.	Marinated tofu, Quorn, soya mince, vegetarian burgers and sausages.	

	Gluten free	Check labels	Avoid
Fruit	All fresh, canned, frozen, dried and juiced fruits.	Fillings, e.g. fruit pie	Pies/sponge cake/crumbles with fruit, any fruit in batter.
Vegetables	All fresh, canned, frozen, dried, pickled and juiced vegetables, All mushy, processed or marrow fat peas.	Pre-packed vegetables e.g. coleslaw, vegetables in a sauce.	Vegetables in batter, breadcrumbs or dusted with flour, e.g. tempura vegetables or onion rings.

	Gluten free	Check labels	Avoid
Milk, yoghurt, cream	Plain cows, sheep, goats and soya milk, all cream including double, clotted, whipped, crème fraîche etc., buttermilk, plain yoghurt or fromage frais.	Flavoured yoghurt or fromage frais, rice milk, coffee and tea whiteners.	Milk with added fibre, yoghurt/ <u>fromage frais</u> containing cereals/ biscuits/muesli.
Cheese	Most cheeses.	Speciality varieties, e.g. Caboc.	

	Gluten free	Check labels	Avoid
Savoury snacks	Popcorn (home-made), rice cakes/crackers	Crisps	Any snack made with wheat, barley or rye.
Cakes and biscuits	Gluten free cakes and biscuits.	Macaroons, meringues.	All cakes, biscuits, pastries and scones made with wheat, barley or rye.
Puddings and desserts	Jelly, gluten free ice cream cones.	Ice cream, sorbet, mousse, custard, pannacotta, pavlova, rice pudding.	Any pudding made with wheat or semolina, e.g. sponge, pie, pasty, trifle etc., ice cream cones and wafers.



	Gluten free	Check labels	Avoid
Soups, sauces, gravies, seasoning	Tomato and garlic puree, herbs and spices, pepper, mint sauce, vinegar, Worcestershire sauce.	Gravy granules, stock cubes, canned/packet soups, Japanese/Indian soy sauce, mustard products, mayonnaise, salad cream, blended seasoning, curry powder, pickles and chutney.	Soups/broth mixes containing barley, noodles or croutons, Chinese soy sauce, stuffing mix.
Home baking	Artificial sweeteners, glucose syrup, icing sugar, gelatine, bicarbonate of soda, yeast (fresh, dried, extract), beef or chicken extract.	Baking powder, ready to use cake icing, decorations and marzipan.	Flour containing wheat, barley or rye, ready-made batter mixes, breadcrumbs.

	Gluten free	Check labels	Avoid
Fats and oils	Cooking oil, butter/margarine, lard, ghee, reduced fat spreads.	Suet.	
Sugars, sweets and preserves	Sugar, jam, honey, preserves, marmalade, molasses, golden syrup, treacle, liquorice root, rock.	Mincemeat, peanut/other nut butters, chocolate, lemon curd, liquorice sweets.	

	Gluten free	Check labels	Avoid
Soft drinks	Water, fruit juice/squash, tea, coffee, cocoa.	Drinking chocolate, fizzy drinks, takeaway hot chocolate.	Malted milk drinks, barley water/squash.
Alcohol	Wine, spirits, cider, sherry, port, gluten free beer, liqueurs.		Beer, lagers, ales, stouts.

What happens if I don't follow a gluten-free diet?

A gluten-free diet is the only treatment for CD and dermatitis herpetiformis. There is an increased risk of developing a number of conditions if a strict gluten-free diet is not followed. These conditions may include osteoporosis, lymphoma, small bowel cancer, and fertility problems (some of these will be explored in a little more detail in the following sections).

Vegetarian and vegan diets

If you need a gluten-free diet and you are also following a vegetarian or vegan diet and lifestyle, you are at a higher risk of being deficient in calcium, Vitamin B, Iron, and folic acid (Vitamin B9).

A blood test can confirm if you are having enough of these nutrients in your diet. If you are not getting enough, your dietitian can help you adapt your diet to meet your increased needs. It is important to ensure you have adequate protein as these are building blocks for the tissues in your body (especially muscle). Good vegetarian sources are dairy foods, eggs, nuts, seeds, beans, pulses, and tofu.

Pregnancy

The dietary advice when you are pregnant remains the same as before conception. However, it is worth getting your levels of folic acid checked.

The recommendation for the general population is 400 mcg folic acid, but the Coeliac UK's Health Advisory Council recommends a higher level of 5 mg folic acid per day for women with CD as a precaution in case of ongoing malabsorption. If your levels are low, you may require a higher dose. Your GP can advise on this.

Osteoporosis

Osteoporosis (OP) is where the bones can become weaker and thinner, resulting in an increased risk of them breaking (known as fractures). People with CD are at an increased risk of developing OP. Your age at diagnosis or delayed diagnosis, compliance with a gluten-free diet, and gender will impact on your risk of OP.

Following diagnosis, you may be offered a DEXA scan (or bone scan). This is a simple procedure to identify OP or osteopenia (thinning of the bones before developing OP, which is more advanced). Half of adults diagnosed with CD may have a low bone mineral density at diagnosis.

In children who are diagnosed, strict adherence to a gluten-free diet results in normal bone health in adulthood.

To optimise bone health, you are advised to follow a gluten-free diet. This will allow the gut to heal and improve the absorption of calcium, as well as meeting helping to meet your calcium requirements.

Calcium requirements:

Age group (years)	Daily requirement (mg)
1-3	350
4-6	450
7-10	550
11-18	800
Adults with CD [without CD]	1000 [700]
Breastfeeding/menopausal/men (over 55)	1000-1500

Dietary sources of calcium:

Food	Portion	Calcium (mg)
Dairy		
Milk (all types)	200ml	240
Cheese	30g (matchbox size)	220
Cheese triangle	15g (1 triangle)	60
Yoghurt	120g	200
Fromage frais	92g (2 small pots)	140
Rice pudding	200g (1/2 large tin)	176
Non-dairy sources		
Sardines (with bones)	60g (1/2 tin)	258
Pilchards (with bones)	60g	150
Tinned salmon (with bones)	52g (1/2 tin)	47
Whitebait	50g	430
Fish paste	60g	170
Broccoli	100g	40
Spinach	60g	100
Orange	1	70
Dried figs	30g	75
Sesame seeds	12g (1 tablespoon)	80
Almonds	30g	70
Kidney beans	35g (1 tablespoon)	25
Non-dairy sources – calcium fortified products		
Soya or almond milk with calcium	200ml	180
Calcium fortified soya yoghurt	125g pot	126
Gluten free bread	1 slice	32-140

Vitamin D

Vitamin D is important in maintaining good bone health as it helps your body to absorb calcium. It is found in some foods such as eggs, oily fish, and wild edible mushrooms. However, our body does not absorb Vitamin D well in this form. Most vitamin D is absorbed from sunlight (our body converts it from its original form into the right form of vitamin D to be used within the body). This may be difficult in the winter months as the sunlight is limited during this period in the UK (this is also prevalent in many countries across the Northern Hemisphere).

The recommendations within England and Scotland are that all adults should consider taking a daily supplement of 10 mcg of Vitamin D daily over the winter months – this remains the same if you have CD.

Iron deficiency anaemia

The damage caused to your gut by eating gluten can also affect how iron is absorbed. This can lead to a diagnosis of iron deficiency anaemia, (where the amount of iron in your blood is low, leading to low levels of red blood cells – the cells that carry oxygen around the body in the blood).

Once gluten is excluded and the gut has healed, the absorption of iron should improve. If supplementation is required, your doctor can advise you on this. If supplementation is not required, people with CD require the same amount of iron as the general population.

Recommended iron intake:

Men over 19 years: 8.7 mg/day	Women 19-49 years: 14.8 mg/day	Women over 50 years: 8.7 mg/day
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Foods below are good sources of iron in the diet:

- Offal (animal organs) - liver is high in Vitamin A so that is not appropriate during pregnancy.
- Red meat.
- Leafy green vegetables.
- Nuts, seeds, dried fruit, chickpeas, pulses, lentils.
- Fortified gluten-free breakfast cereal.

Dermatitis herpetiformis and gluten neuropathy

Dermatitis herpetiformis (DH), sometimes referred to as Dühring's disease, is a long-term (chronic) condition that causes itchy bumps and blisters on your skin due to gluten sensitivity. Most people who experience DH are also diagnosed with CD can be asymptomatic (without showing symptoms) with DH, sometimes leading to it being called the 'skin manifestation of coeliac disease'. You can have these conditions separately without being diagnosed with both. As with CD, the symptoms of DH are triggered by consumption of gluten, and a strict gluten-free diet is very important for preventing flare-ups.

Gluten neuropathy is defined as damage to peripheral nerves occurring outside of the brain and spinal cord (for example, in your arms and legs). There are different descriptions, such as polyneuropathy (affecting multiple areas of the body), sensory neuropathy (nerves that drive your sense of touch are affected), motor neuropathy (nerves that drive movement are affected). This can exhibit as symptoms of decreased feeling in arms, legs, hands, and numbness, tingling or burning pain in any area of your body. The most common type in people with CD involves both the motor (movement) and sensory (touch) nerves.

Other neurological (nervous system) conditions include gluten ataxia (impaired coordination, balance and speech), and gluten encephalopathy (brain problems).

Medications

The majority of medicines that are prescribed by your GP, or available to buy without a prescription are gluten-free. However, it is worth checking with your pharmacist when starting new medications to confirm that they are gluten-free. If they aren't then an alternative should be available.

Recipes

There are lots of gluten free recipes available online and in recipe books. Coeliac UK also have more than 1000 recipes on their website. More recipes can be found on some of the product websites listed below:

- www.glutenfreegoddess.blogspot.co.uk
- www.glutenfreecupatea.co.uk
- www.intolerantgourmand.com
- www.freefromfairy.com
- www.foodsmatter.com/freefrom_recipes
- www.bbcgoodfood.com
- www.wheat-free.org

Product websites:

- www.amyskitchen.co.uk Wheat and gluten free meals and soups
- www.bfreefoods.com Wheat and gluten free products and recipes
- www.bakelshomebaking.com Bread mixes
- www.dovesfarm.co.uk Gluten-free products and recipes
- www.ds glutenfree.com Gluten-free products and recipes
- www.geniusglutenfree.com Gluten-free products and recipes
- www.glutenfree-foods.co.uk Gluten-free products
- www.justglutenfree.co.uk Gluten-free breads
- www.kirstys.co.uk Free-from ready meals.
- www.nairns-oatcakes.com A range of gluten-free oat products
- www.newburnbakehouse.com A range of gluten-free products
- www.organglutenfree.co.uk Gluten-free products
- www.pureglutenfree.co.uk Gluten-free flours and other baking ingredients

Further sources of information

NHS Choices: www.nhs.uk/conditions

Our website: www.sfh-tr.nhs.uk

Patient Experience Team (PET)

PET is available to help with any of your compliments, concerns or complaints, and will ensure a prompt and efficient service.

King's Mill Hospital: 01623 672222

Newark Hospital: 01636 685692

Email: sfh-tr.PET@nhs.net

If you would like this information in an alternative format, for example large print or easy read, or if you need help with communicating with us, for example because you use British Sign Language, please let us know. You can call the Patient Experience Team on 01623 672222 or email sfh-tr.PET@nhs.net.

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