

## Patient information

### Introduction to Coeliac Disease and Gluten Free Diet

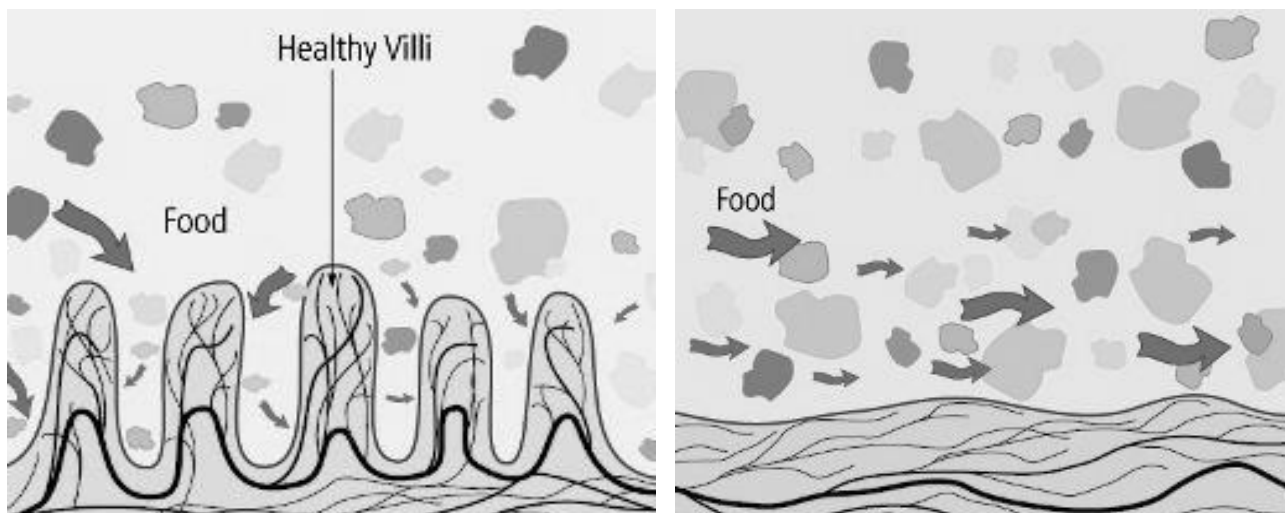
Nutrition and Dietetics - Therapies

#### What is Coeliac disease?

Coeliac disease is an autoimmune disease (your immune system reacts to gluten).

When you eat food, it travels through the stomach and to the small intestine. Nutrients from food are absorbed through the lining of the small intestine. The lining has tiny finger like projections called 'villi' to give greater surface area to absorb maximum nutrients from food as seen on the right.

When people with coeliac disease eat gluten, the lining of the small intestine is inflamed, and the villi flatten as seen below.



#### What are the symptoms?

Your symptoms may have developed gradually or may have appeared suddenly and dramatically. They differ from person to person and may be mild or severe.

### **Possible symptoms may include:**

- diarrhoea, excessive wind, and/or constipation.
- nausea and vomiting.
- recurrent stomach pain, cramping or bloating.
- tiredness and/or headaches.
- weight loss (but not in all cases).
- skin rash (dermatitis herpetiformis).
- joint and/or bone pain.
- neurological (nerve) problems such as ataxia (poor muscle co-ordination) and neuropathy (numbness and tingling in the hands and feet).
- “Irritable bowel syndrome” type symptoms.

Some patients do not have any gastrointestinal problems. If you are one of these people, you may be described as having ‘silent’ disease. Some people may only have an incidental finding of Coeliac disease and may not have any of the symptoms below.

### **‘Silent’ symptoms include:**

- any combination of iron, vitamin B12 or folic acid deficiency.
- osteopenia and osteoporosis (due to calcium deficiency).
- fatigue (tiredness).

**Even with silent disease or without any symptoms, you will need to be treated to prevent further damage.**

### **How common is coeliac disease?**

Around 1 in every 100 people is likely to have coeliac disease. There are many people who remain undiagnosed – around 500,000 in the UK. Coeliac disease can run in families. If a first-degree family member (such as mother, father, sister or brother) has the condition then the chances of having it increase to one in ten. Coeliac disease can occur at any age and the average age is 50 years.

### **Are there health complications?**

In undiagnosed, untreated coeliac disease there is a greater risk of complications including anaemia, osteoporosis, neurological conditions, fertility issues such as miscarriage or stillbirths. Although rare there's an increased risk of small bowel cancer and intestinal lymphoma.

However, once you are diagnosed and are following the gluten free diet, your risk of bowel cancer is reduced to that of the general population.

## **What is the treatment?**

Coeliac disease cannot be cured, and the only treatment plan is a lifelong exclusion of gluten from the diet. Once gluten is removed from the diet, the lining of the intestine (villi) can start to re-grow. At this point the nutrients from the diet can be absorbed. You may notice symptom relief after a few weeks, but it can take upwards of one year. Furthermore, it can take between six months to three years for the intestine to fully heal.

## **The Gluten Free Diet**

### **What is gluten?**

Gluten is a protein found in wheat, rye and barley.

### **What is the gluten free diet?**

A gluten free diet means you must exclude **all** gluten from your diet.

**This means excluding any products that contain wheat, rye and barley and flours made from these products.**

**It is also recommended to avoid any product labelled as “may contain gluten”.**

### **What foods contain gluten?**

#### **The most obvious sources of gluten in the diet are:**

- Bread, pasta, breakfast cereals, flour, pizza bases, pastry, cakes, and biscuits.
- Gluten can also be found in foods such as soups, sauces, ready meals, and processed foods such as sausages, fish fingers, scotch eggs, chicken nuggets and all breaded and battered fish and meat.
- Malted milk drinks, barley water, beer, lager, and stout are all made from barley and must be eliminated from your diet.

### **Which foods are naturally gluten free?**

The good news is that a lot of what you eat is naturally gluten free and therefore safe to eat.

#### **These can include the following:**

- Plain meats, poultry or fish.
- Fruits and vegetables.
- Eggs.
- Cheese, plain yogurt and milk.
- Rice, corn, potato, buckwheat, quinoa, and millet are also gluten free.

## What gluten free alternatives are available?

There are many gluten free alternatives available to replace foods that contain gluten e.g. gluten free breads, pasta, flour, biscuits, cakes, and pizza bases. You can buy these from the supermarkets, by mail order, in health food shops or on the internet.

## Can I eat oats?

Oats are high in soluble fibre and can add variety to the gluten free diet. However, many manufacturers of oats also mill wheat or barley in the same mill which can lead to contamination. Most people with coeliac disease can eat oats as long as they are pure and uncontaminated, so you should switch to varieties labelled as 'Gluten Free'. A list of these products can be found in the Coeliac UK 'Gluten-free Food and Drink Directory'. There may be a small number of patients who are truly sensitive to oats. If you feel you may be sensitive to oats, you can discuss this with your dietitian.

## Can I have gluten sometimes?

**No.** The gluten free diet means eliminating all foods containing gluten. If you eat gluten once a week or even once a month this will cause damage to the villi and they will not heal properly.

However, it is likely that you will sometimes make a mistake especially initially. In some people this may cause symptoms. Mistakes will cause damage to the gut, however once back on the gluten free diet it will repair itself.

## Shopping

Shopping can be difficult when you are first diagnosed and a trip that used to take you an hour can take three hours! The Coeliac UK 'Gluten-free Food and Drink Directory' lists products which you can eat safely. You can also download the 'Gluten Free Food Checker' which has a useful barcode scanner which can support you to identify gluten free foods.

You may find gluten free foods in specialist aisles at supermarkets, but it is also important to realise that most foods will be along the shelves with gluten containing foods. The best way is to check the labelling.

## What do I need to look for on food labels?

Manufacturers have to list all ingredients in food products.

Allergens should now be legally highlighted in bold letters in the ingredients list due to Natasha's Law. If the food item is labelled as 'gluten free' it is safe for you to eat..

## Which ingredients contain gluten?

Wheat starch	Modified wheat starch	Cous Cous	Bulgur wheat
Wheat flour	Wheat rusk	Semolina	
Wheat bran	Barley flour	Spelt	
Barley malt	Rye flour	Oat Bran	

## Which ingredients are gluten-free?

Arrowroot	Artificial sweetener	Aspartame	Buckwheat
Caramel	Citric acid	Corn Malt	Dextrose
Fructose	Glucose syrup	Maize Starch	Monosodium glutamate
Millet	Modified maize starch	Modified Starch	Maltodextrin
Polenta	Rice rusk	Rice malt	Sago
Sorbitol	Sorghum	Soya	Tapioca

## Can I eat malt extract?

Malt extract and malt flavouring are derived from barley. They can be tolerated in small amounts. Most supermarket own breakfast cereal and malt vinegar can be tolerated by most people with coeliac disease, despite being labelled as containing barley. If in doubt, check the Coeliac UK directory.

## What is the difference between wheat free, gluten free, codex wheat starch, and modified starch?

Wheat free does not mean gluten free (it may contain rye or barley).

Normal wheat starch is not gluten-free and should be avoided.

Modified starch must state if it is from a gluten containing cereal e.g., modified wheat starch. If a label states that it contains modified starch and does not refer to a gluten containing cereal (wheat, rye, and barley) then it must be gluten free. For example, modified corn starch/maize starch etc. would be acceptable.

Codex wheat starch is specially washed wheat starch that is low in gluten. It is mainly used in prescribed food items. It is safe for most people with coeliac disease.

## How can I make cooking for the gluten free diet easy?

There are many gluten free cookbooks available however your 'normal' cookbooks can be easily adapted to gluten free. Simply substituting certain ingredients e.g., stock cubes in casseroles and stews can make the dish gluten free.

Foods like lasagne, moussaka, spaghetti bolognese, can be made with gluten free pasta. These are not harmful for the rest of the family. Many people chose to bulk cook and then freeze. These foods should be no more effort to prepare than 'normal' variety.

## Alternative gluten free flours include:

Rice	Corn	Tapioca	Chickpea
Buckwheat	Potato	Soya	Millet

## Cooking tips

- Try different gluten free grains and alternative flours as above.
- Try Xanthan gum in baking - it helps to make gluten free flour to behave more like wheat flour.
- Keep tasting gluten free products – new ones are regularly becoming available.

- Attend cookery demonstrations put on by gluten free companies and local support groups.
- Plan ahead.
- Cook in bulk and freeze.
- Use a variety of naturally gluten free foods.
- Try things more than once.

### **Cross contamination**

If you are following a gluten free diet, it is important to avoid accidental ingestion of gluten by ensuring your gluten free foods are not mixed with foods that contain gluten. Even very small amounts of gluten can cause people with coeliac disease to have symptoms in the short term and gut damage in the long term.

### **How can I avoid cross contamination?**

- Wash down surfaces before preparing food.
- Identifying gluten free foods with stickers or an indelible pen.
- Use clean oil or a separate fryer for frying gluten free foods.
- Cook gluten free and gluten containing foods in separate dishes with separate utensils.
- Use a separate toaster or keep the grill 'gluten free' or use toaster bags.
- Keep gluten crumbs out of your butter, margarine, and jam by either having two separate butters or cut it in half and store separately.

You do not need to buy separate utensils or use a dishwasher. Normal cleaning in hot soapy water will remove the gluten.

### **More about your Gluten Free Diet**

#### **What is a healthy diet?**

The guidelines for a healthy balanced diet are the same for people with coeliac disease as those without.

#### **Starchy carbohydrates**

You should plan your meals around starchy carbohydrates which include gluten free bread, rice or rice noodles, potatoes, gluten free cereals, gluten free pasta and gluten free crackers.

- Choose high fibre varieties where possible e.g. wholegrain gluten free bread, high fibre gluten free pasta and leave skins on your potatoes.
- Aim to include one food from this group at each meal time - these foods should be the main part of meal.

## **Fruit and vegetables**

- Have at least five portions of fruit and vegetables each day. Remember that fresh, frozen, dried, canned and juices all count towards your total.
- Eat a variety of different types and colours of fruit and vegetables.

## **Meat, fish, eggs, and beans**

- Choose moderate amounts of lean meat, fish, eggs, and pulses such as beans and lentils.
- Remove the skin from chicken, excess fat from meat and avoiding frying.
- Try to include two portions of fish each week, one of which should be an oily fish (e.g. mackerel, trout, sardines, kippers, and fresh tuna).

## **Milk and dairy foods**

- Aim for five to six portions of dairy foods per day. A portion is 1/3 pint of milk, a small pot of yogurt or a small (matchbox size) piece of cheese.
- Try to choose reduced fat versions where you can, e.g., semi skimmed, or skimmed milk, “diet” or “light” yogurts, Edam, cottage cheese and half fat Cheddar.

## **Limit your intake of foods containing fat and sugar.**

- Choose low fat or reduced sugar foods where possible.
- When using a spreading fat choose one that is high in monounsaturated fatty acids, e.g., spreads made from olive oil or rapeseed oil.

## **Coeliac Disease and Osteoporosis**

People with coeliac disease are at greater risk of developing osteoporosis because your body may not be able to absorb important vitamins and minerals including calcium which is needed for strong bones.

## **You can reduce your risk of developing osteoporosis by**

- Following a strict gluten-free diet to make sure you absorb all the nutrients from the food you eat.
- Taking regular weight-bearing exercise such as walking, jogging or gardening.
- Stopping smoking.
- Not drinking too much alcohol.
- Eating a calcium-rich gluten-free diet.

Calcium is an important nutrient that is essential for strong bones. People with coeliac disease need more calcium than people without the condition, so it is important to include enough in your diet. It is recommended that adults with coeliac disease have between 1000 milligrams (mg) and 1500mg (five -seven portions) of calcium each day. You may need to consider a calcium supplement if you do not like calcium rich foods.

## Which foods are high in calcium?

Dairy foods are high in calcium. Below is a list of good sources.

You need six portions of calcium rich foods a day if you are diagnosed with coeliac disease.

Food	Calcium (mg)	Number of Portions
<b>A third of a pint milk</b>	225-236	One
<b>Matchbox size cheddar cheese</b>	216	One
<b>Low-fat plain yoghurt</b>	243mg	One
<b>Low-fat fruit yoghurt</b>	222mg	Three quarters
<b>Small can rice pudding</b>	198	Three quarters
<b>Individual pot custard</b>	150	Three quarters
<b>Small can baked beans</b>	109	Half
<b>One large orange</b>	99	Half
<b>Average serving spinach</b>	144	Half
<b>Average serving broccoli/ cabbage</b>	34/ 71	Half
<b>100g tinned sardines with bones</b>	550	Two and a half
<b>100g tinned salmon with bones</b>	93	Half
<b>Small can pilchards</b>	645	Two and three quarters
<b>Standard bar chocolate</b>	119	Half
<b>Six almonds</b>	31	Half

## Coeliac disease and anaemia

Iron has a many important roles in the body. For example, it helps make red blood cells, which carry oxygen around the body.

When the villi in your bowel are flattened it is difficult for your body to absorb iron from your foods. If your bloods show you are iron deficient (anaemic), you may have been started on iron tablets. Eating a diet rich in iron may also help and will keep your diet balanced.

## **Foods high in iron include:**

- Meat – especially red meat, liver, kidney, and corned beef. Try and eat red meat two three times per week.
- Canned fish e.g., sardines, pilchards.
- Eggs.
- Dark green vegetables e.g., spring cabbage, spinach, broccoli, watercress.
- Beans and pulses.
- Dried fruit (e.g., apricots).
- Nuts.
- Brown rice.

Eating food containing lots of vitamin C at the same time as you eat food containing iron from non-meat sources might help the body absorb the iron. An example could be having fruit juice or fruit with your fortified breakfast.

Vitamin C is found in:

- Citrus fruits.
- Peppers.
- Broccoli.
- Brussels sprouts.
- Potatoes (with skins) and sweet potatoes.
- Kiwi fruit.

Tea and coffee also contain a substance that can bind with iron making it harder for the body to absorb it. Try drinking these separately from your meals, approximately 30 minutes to one hour later.

## **Coeliac disease and fibre**

Many gluten free products are highly refined and can have lower fibre content than the gluten containing foods. Fibre is important to keep you bowels regular.

- Eat at least five portions of fruit and vegetables a day.
- Many companies now provide high fibre options of bread, pasta, and crackers.
- Eat more peas, beans, and lentils.
- Include oats where possible (discuss with your Dietitian).

When increasing the fibre content of your diet you need to make sure you drink enough fluid or else you may become constipated. Aim for at least eight ten glasses of fluid each day, especially water. It is important that you increase you fibre gradually.

## **Vitamin D**

Vitamin D works with calcium and phosphorus for healthy bones, muscles and teeth. Your body makes the most vitamin D under your skin when you are outside in the sunshine in the summer months. Even if you have a calcium-rich diet, without enough vitamin D you cannot absorb the calcium into your bones and cells where it is needed. You can help your body get more vitamin D by eating plenty of vitamin D rich foods, including:

- oily fish such as salmon, sardines, pilchards, trout, herring, kippers and eel contain reasonable amounts of vitamin D.
- cod liver oil contains a lot of vitamin D (don't take this if you are pregnant).
- egg yolk, meat, offal and milk contain small amounts, but this varies during the seasons.
- margarine, some breakfast cereals and some yoghurts have added or are 'fortified' with vitamin D.

Over the winter months you may wish to consider taking a vitamin D supplement containing ten micrograms of Vitamin D to ensure your stores stay optimal.

However, you should not take a vitamin D supplement if you are already on a combined calcium and vitamin D supplements (e.g. Adcal D3, calcichew-D3), if you take cod liver oil, or are having vitamin D injections.

You should not exceed the daily recommended dosage of 10 micrograms per day as this can become toxic. Always check with your doctor or dietitian if you have questions or concerns.

## **Eating out with coeliac disease**

Eating out is a pleasurable experience and following the gluten free diet should not change that. However, it can be difficult to ensure your meal is gluten free.

While many places now have a gluten free menu, the following tips may help you:

- Use the internet or Coeliac UK to find local restaurants.
- Call ahead to discuss your needs before you arrive.
- Speak to the manager or waiter.
- Ask for the sauce on the side.
- Do not hesitate to send food back if you think it contains gluten..

## **Asking the following questions may help you to make your meal is gluten free:**

- Is there flour in the sauce?
- Are there croutons on the salad?
- What's in the BBQ sauce/ salad dressing/ marinade?
- Are the foods deep fried?

- Does it contain soy sauce?
- Is there a batter/ a breaded coating?
- Are the noodles wheat based?
- Is the pan dusted with flour?
- Go for fresh fruit, fruit salad, sorbet, and cheese for puddings.

Some restaurants already cater for the gluten free diet, and some have menus with notes to highlight safe options. If you are a member of Coeliac UK, there is a section on the website with updated reviews and recommended gluten free restaurants.

### **Social gatherings**

Social gatherings can be difficult and increase the risk of cross contamination. You can still thoroughly enjoy social events without allowing gluten containing foods to come into contact with your meal.

#### **Useful tips include:**

- Making your host aware of your gluten-free requirements, preferably before they begin to plan the menu.
- If possible, provide some of your own gluten free dishes to share to ensure there are guaranteed gluten free foods at the event.
- Ask the host if you can serve yourself first to avoid potentially already contaminated foods

### **What about takeaways and fast food?**

This can be difficult as cross contamination is always a risk. Coeliac UK has a useful 'venue guide' which can identify certified gluten free food establishments in your area.

#### **Fish and chips:**

- If the chips are cooked in the same oil as battered fish, they will be contaminated.
- It isn't safe to eat the fish after the batter has been removed as the fish will be contaminated.
- Some fish and chip shops will make gluten free batter.
- Some will cook in separate oil or have a 'gluten free day'.

#### **Chinese:**

- Plain rice is usually gluten free.
- Soy sauce contains gluten therefore avoid dishes that may contain this.
- Avoid egg noodles.
- Contamination is a risk as many foods are stir fried in a wok where soy sauce has been used.

- Some gluten free soy sauces are available.

#### **Indian:**

- Avoid all breads.
- Poppadums are made with chickpea flour and are gluten free.
- Most Indian dishes are made from chickpea flour however you will need to check.
- Deep-fried food may be cooked in oil that has cooked other gluten containing foods.

#### **Italian:**

- Normal pizza is unsuitable.
- Some restaurants will allow you to take in your gluten free pizza base.
- Some restaurants make gluten free pasta or allow you to take in your gluten free pasta.

#### **How can I make travelling easier?**

This will require some planning ahead, especially if you are travelling abroad.

#### **Some tips which may help you to plan your holiday:**

- Take gluten free snacks in the event that flights are delayed.
- Some airlines will provide a gluten free meal which may need to be requested in advance.
- Coeliac UK can provide a list of useful phrases in foreign languages to help you to explain what you need.
- The allergen labelling legislation is EU wide therefore, gluten cereals should be listed in the ingredients.
- Consider taking gluten free products with you – your GP can write a letter stating it is for special medical purpose.
- Coeliac UK can provide a list of holidays that cater for the gluten free diet.
- Contact your hotels or travel companies to discuss your needs in advance.

#### **Feedback:**

Your feedback is important to us and helps us influence care in the future.

Following your discharge from hospital or attendance at your outpatient appointment you will receive a text asking if you would recommend our service to others. Please take the time to text back, you will not be charged for the text and can opt out at any point. Your co-operation is greatly appreciated.

## **Further information**

### **Dietitians**

**Aintree Hospital**

**Tel: 0151 529 3473**

**Royal Liverpool Hospital**

**Tel: 0151 706 2120**

### **Coeliac UK**

**Tel: 08704448804**

**Email: [helpline@coeliac.co.uk](mailto:helpline@coeliac.co.uk)**

**Web: [www.coeliac.org.uk](http://www.coeliac.org.uk)**

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