Information about Coeliac Disease



The Crossed Grain symbol, created by Coeliac UK, is a registered Trademark promoted by coeliac organisations worldwide. It is a food labelling symbol used on product packaging, which indicates that a product is gluten-free (less than 20ppm gluten).

Coeliac disease is a common digestive condition where a person has an adverse reaction to gluten

Eating foods containing gluten can trigger a range of symptoms, such as:

- diarrhoea – which may be particularly unpleasant smelling
- bloating and flatulence (passing wind)
- abdominal pain
- weight loss
- feeling tired all the time – as a result of malnutrition (not getting enough nutrients from food)
- children not growing at the expected rate.

Symptoms can range from mild to severe or non at all.

Who is affected

Coeliac disease is a common condition that affects approximately 1 in every 100 people in the UK. However, some experts think this may be an underestimate as milder cases may go undiagnosed or misdiagnosed as other digestive conditions, such as irritable bowel syndrome (IBS).

What causes coeliac disease?

Coeliac disease is what is known as an autoimmune condition. This is where the immune system – the body's defence against infection – mistakenly attacks healthy tissue.

Coeliac disease isn't an allergy or an intolerance to gluten.

In cases of coeliac disease, the immune system mistakes substances found inside gluten as a threat to the body and attacks them.

This damages the surface of the small bowel (intestines), disrupting the body's ability to absorb nutrients from food.

Exactly what causes the immune system to act in this way is still not entirely clear, although a combination of a person's genetic make-up and the environment appear to play a part.

Gluten

Gluten is a protein found in three types of cereal:

- wheat
- barley
- rye

Gluten is found in any food that contains the above cereals, including:

- pasta
- cakes
- breakfast cereals
- most types of bread
- certain types of sauces
- some types of ready meals

In addition, most beers are made from barley.

Coeliac disease is usually treated by simply excluding foods that contain gluten from your diet

This prevents damage to the lining of your intestines (gut) that is caused by gluten, and the associated symptoms, such as diarrhoea and stomach pain.

If you have coeliac disease, you must give up all sources of gluten for life because eating foods that contain it will cause your symptoms to return and cause long term damage to your health. This may sound daunting, but your GP can give you help and advice about ways to manage your diet.

Your symptoms should improve considerably within weeks of starting a gluten-free diet. However, it may take up to two years for your digestive system to heal completely. You will also need to return to your GP for regular check-ups.

A gluten-free diet

When you are first diagnosed with coeliac disease, you will be referred to a dietitian to help you adjust to your new diet without gluten. They can also ensure that your diet is balanced and contains all the nutrients you need.

If you have coeliac disease, you will no longer be able to eat foods that contain wheat (farina, graham flour, semolina, durum cous cous and spelt), barley or rye.

Even if you only consume a small amount of gluten, such as a spoonful of pasta, you may have very unpleasant intestinal symptoms. If you keep consuming gluten regularly, you will also be at greater risk of osteoporosis and cancer in later life.

Oats

Oats do not contain gluten, but many people with coeliac disease avoid eating them because they can become contaminated with other cereals that do contain gluten.

If, after discussing this with your health professional, you want to include oats in your diet, check that the oats are pure and that there is no possibility that contamination could have occurred.

It is recommended that you should avoid eating oats until your gluten-free diet has taken full effect and your symptoms have been resolved. Once you are symptom free, gradually reintroduce oats into your diet. If you develop symptoms again, stop eating oats.

Advice on feeding your baby

Do not introduce gluten into your baby's diet before it is six months old. Breast milk is naturally gluten free and all infant milk formulas are too. If you have coeliac disease, Coeliac UK recommends that gluten-containing foods be introduced gradually when a child is six months old, and the situation carefully monitored.

Other treatments

As well as eliminating foods that contain gluten from your diet, a number of other treatments are available for coeliac disease. These are described below.

Vaccinations

In some people, coeliac disease can cause the spleen (a small an organ behind the stomach) to work less effectively, making you more vulnerable to infection from certain germs.

Therefore, you may need to have extra vaccinations, including:

- flu (influenza) jab
- HIB/MenC vaccine, which protects against sepsis (blood poisoning), pneumonia and meningitis (an infection of the lining of the brain)
- pneumococcal vaccine, which protects against infections caused by the Streptococcus pneumoniae bacterium

However, if your spleen is unaffected by coeliac disease, these vaccinations are not usually necessary.

Please see your G.P for these injections.

Dermatitis herpetiformis

If you have dermatitis herpetiformis, also known as DH, (an itchy rash that can be caused by gluten intolerance), cutting gluten out of your diet should clear it up. However, sometimes it can take longer for a gluten-free diet to clear the rash than it does to control your other symptoms, such as diarrhoea and stomach pain.

If this is the case, you may be prescribed medication to speed up the healing time of the rash. It is likely that this will be a medicine called Dapsone, which is usually taken orally (in tablet form) twice a day. Dapsone can cause side effects, such as headaches and depression, so you will always be prescribed the lowest effective dose.

You may need to take medication for up to two years to control your dermatitis herpetiformis. After this time, you should have been following a gluten-free diet long enough for the rash to be controlled without the need for medication.

Complications

Complications of coeliac disease only tend to affect people who continue to eat gluten, or who have yet to be diagnosed with the condition (which can be a common problem in milder cases.)

Potential long-term complications include:

- osteoporosis (weakening of the bones)
- anaemia – lack of red blood cells which can cause breathlessness, tiredness and lack of energy.

Less common and more serious complications include those affecting pregnancy, such as low birth weight, and some types of cancers, such as bowel cancer.

Osteoporosis

Osteoporosis causes your bones to become brittle and weak. Your bones need a wide variety of vitamins and minerals to stay dense and strong.

If you have coeliac disease, you have an increased risk of developing osteoporosis due to the effect on your digestion. The damage gluten causes to your intestines (gut) prevents enough nutrients being absorbed into your bones from the food that you eat.

Osteoporosis usually causes no obvious symptoms until a person has an accidental fall or similar and ends up breaking a weakened bone.

Osteoporosis can be treated with supplements that strengthen the bones, such as vitamin D and calcium. More severe cases of osteoporosis may require medication.

Malnutrition

As coeliac disease causes your digestive system to work less effectively, severe cases can sometimes lead to a critical lack of nutrients in your body. This is known as malnutrition, and can mean your body is unable to function normally or recover from wounds and infections.

If you have severe malnutrition, you may become fatigued, dizzy and confused. Your muscles may begin to waste away, and you may find it difficult to keep warm. In children, malnutrition can cause stunted growth and delayed development.

Treatment for malnutrition usually involves increasing the number of calories in your diet and taking supplements.

Lactose intolerance

If you have coeliac disease, you are more likely to also develop lactose intolerance, whereby your body lacks the enzyme to digest milk sugar (lactose) found in dairy products. Lactose intolerance causes symptoms such as bloating, diarrhoea and abdominal discomfort.

Unlike gluten in coeliac disease, lactose in lactose intolerance does not damage your body. Rather, you may get some gastrointestinal symptoms when you take foods containing lactose, as you can't digest it properly. Lactose intolerance can be effectively treated by not eating and drinking dairy products that contain lactose. You may also need to take calcium supplements because, as dairy products are an important source of calcium, you will need to compensate for not eating them.

Refractory Coeliac Disease

A rarer type of coeliac disease is refractory coeliac disease. In this form of the condition, for reasons that are still unclear, the symptoms continue to persist even when a person has switched to a gluten-free diet.

It is estimated that around 1 in every 140 people with coeliac disease will develop the refractory form of the condition.

If you do develop suspected refractory coeliac disease it is likely that you will be referred for a series of tests to make sure that your symptoms are not being caused by some other rare condition.

If no other cause can be found and the diagnosis is confirmed you will likely be referred to a specialist.

Treatment options include steroid medication (corticosteroids) which can help block the harmful effects of the immune system.

Cancer

Some research has suggested that having coeliac disease can increase your risk of developing certain types of cancer, including:

- bowel cancer
- lymphoma (cancer of the lymphatic system, which is part of the immune system)

The same research found people with coeliac disease have a lower risk of developing lung and breast cancer, although the reasons for this are unclear.

It is estimated that people with coeliac disease are twice as likely to develop bowel cancer as the general population. However, this is still a very small increase in risk: only 1 in every 200 people with coeliac disease will develop bowel cancer in the first 10 years after diagnosis. As age is an independent risk factor for bowel cancer, your risk of developing bowel cancer increases as you get older, in line with the general population.

The risk of developing cancer is thought to be highest during the first year after diagnosis, before dropping to normal as your gluten-free diet starts to take effect.

Whether or not you have coeliac disease, it is important to be aware of the symptoms of bowel cancer, which include:

- blood in stools (faeces)
- unexplained weight loss
- changes in your normal bowel habit lasting more than four weeks

See your GP if you develop these symptoms.

Coeliac UK

The UK's leading charity for people affected by coeliac disease is Coeliac UK.

Their website contains a range of useful resources, including information on gluten-free diets, specific products and information on local groups, volunteering and ongoing campaigns.

The charity also has a telephone helpline on 084 305 2060
Monday, Tuesday, Thursday and Friday from 10am - 4pm
Wednesday from 11am - 4pm.

Local groups

Many people feel overwhelmed when first diagnosed with coeliac disease. Switching to a gluten-free diet can be confusing, particularly if you have been eating foods that contain gluten not free for many years.

In the first few months after being diagnosed, many people accidentally eat foods that contain gluten, which may trigger a return of their symptoms.

You can learn more about coeliac disease and receive practical advice about switching to a gluten-free diet, by contacting your local coeliac disease support group.

Groups support people with coeliac disease, including those recently diagnosed, and those who have been living with the condition for years.

The Coeliac UK website provides further information and advice, and details of support groups in year area.

Notes

If you have any comments about this leaflet or the service you have received you can contact :

Sister
Medical Outpatient Department
Huddersfield Royal Infirmary
Telephone No: 01484 343262

www.cht.nhs.uk

If you would like this information in another format or language contact the above.

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