



The Spire Dunedin Hospital
16 Bath Road
Reading
RG1 6NS

Tel Appointments: 0118 952 1313
(Monday to Friday 9am to 1pm)

Dr Jude D'Cruz (Endoscopist)
Annette Panting (Manager)

Information Leaflet - Coeliac Disease

What is coeliac disease?

Coeliac disease is a condition of the small intestine (the gut). It can occur at any age. The small intestine is where food is absorbed. Coeliac disease is caused by a reaction of the gut to gluten. Gluten is part of certain foods - mainly foods made from wheat, barley and rye. The reaction to gluten causes inflammation in the lining of the gut. This stops the gut from working properly and absorbing foods properly. Various symptoms can develop including abdominal pains, tiredness and weight loss. Symptoms go if you do not eat any foods that contain gluten. **Treatment is for life. That is, you should not eat any foods that contain gluten for the rest of your life.**

Who does it affect?

It affects about 1 in 100 people in the UK. Anyone, at any age, can develop coeliac disease. It is a condition that used to be associated with young children. However, it is now much more common in adults than children. The average age of diagnosis is about 45 years old. About 1 in 4 cases are now first diagnosed in people over the age of 60. There is often a family history. About 1 in 10 close relatives of someone with coeliac disease will also develop it. That is - brother, sister, parent, or child.

What causes coeliac disease?

The cause is a sensitivity to gluten. Gluten occurs in common foods including wheat, barley, and rye, and any foods made from these such as bread, pasta and biscuits. People with coeliac disease make antibodies against gluten. Antibodies are proteins in the immune system that normally attack bacteria, viruses, and other 'germs'. In effect, the gut 'mistakes' gluten to be harmful, and reacts against it as if it were fighting off a germ.

Because of the antibody 'attack' against gluten, inflammation develops in the lining of the gut. This stops the lining of the gut working properly. The cells that normally absorb food into the bloodstream do not work so well.

Coeliac disease can develop in babies. Older children or adults who have not previously had problems may also become 'gluten sensitive' at some point in their life and develop coeliac disease. It is not known why the immune system of some people becomes sensitised to gluten.

What are the symptoms of coeliac disease?

The inflammation in the lining of the gut stops food from being properly absorbed. You then do not absorb nutrients very well into your body. A variety of symptoms may then develop.

Babies - Symptoms first develop soon after weaning when the baby starts eating solid foods containing gluten. The baby may fail to gain weight and become miserable. As food is not being absorbed properly, the faeces (stools) may be pale and bulky. Smelly diarrhoea may occur. The abdomen (tummy) may become swollen. The baby may have repeated vomiting.

Older children - Poor absorption of food may cause deficiencies of vitamins, iron, and other nutrients. This may cause anaemia and other problems. As the fat part of the diet is poorly absorbed, the faeces may be pale, smelly, and difficult to flush away. Diarrhoea may develop. However, the

symptoms may not be very typical or obvious. If the gut and bowel symptoms are only mild then the first thing that may be noticed is poor growth.

Adults - Poor absorption of food may cause deficiencies of vitamins, iron, and other nutrients. Anaemia due to poor absorption of iron is common. Other common symptoms include: abdominal pains which tend to 'come and go', excess wind, bloating, diarrhoea, and tiredness or weakness. Mouth ulcers may occur. You may lose weight due to poor absorption of food. An itchy skin condition called dermatitis herpetiformis occurs in some people with coeliac disease. If the common symptoms described above develop, the diagnosis may be made quickly. However, common or typical symptoms do not always develop. Particularly in adults, the areas affected in the gut may be patchy. Symptoms may then be mild, or not typical, and it may be a while before the diagnosis is made.

How is the diagnosis confirmed?

If coeliac disease is suspected, a blood test to detect a certain antibody that occurs in coeliac disease may be advised by your doctor. If it is present the diagnosis of coeliac disease is likely. To confirm the diagnosis, a biopsy (small sample) is taken from the inside lining of the gut. This is looked at with a microscope to see if the typical changes of coeliac disease are present. The biopsy is usually taken by a flexible tube (endoscope) which is passed into the small intestine.

Other tests may be done to find out how much the poor absorption of food and other nutrients has affected you. For example, checks may be made for anaemia and for the levels of vitamins, iron, protein, etc, in the blood. You may be advised to have a special bone scan (a DEXA scan) to see if your bones have become affected due to poor absorption of calcium and vitamin D.

Note: if you suspect that you may have coeliac disease from your symptoms, then see a doctor. Do not treat yourself by going on a gluten free diet (described below) without a firm confirmed diagnosis. If you do go on a gluten free diet before the diagnosis is confirmed, then any tests done at a later time may not be conclusive and may even give negative results. So, get it checked out first - and then treat it if it is confirmed.

What are the treatments for coeliac disease?

The main treatment is not to eat any food that contains gluten. The symptoms then usually go within a few weeks. The main foods to stop are any that contain wheat, barley, or rye. Many common foods contain these ingredients such as breads, pasta, cakes, pastries and some cereals. Foods made from oats are usually safe to eat. However, many people with coeliac disease have symptoms if they eat oats. This is probably because of contamination of commercially available oats with other grains. Potatoes, rice, maize, corn, fruit, dairy products and soya-based foods are fine.

You should get advice from a dietician. Coeliac UK also provides advice about which foods are suitable (see address below). You can buy special gluten-free flour, pasta, bread, etc. These are also available on prescription. There are many diet sheets with food alternatives and recipes. Unfortunately, many processed foods, ready-made meals, and 'fast-foods' contain gluten. Food labels will often say whether the food contains gluten or not.

Avoiding gluten is for life. If you eat gluten again, symptoms will return. Even small amounts of gluten can sensitise the gut again. To avoid symptoms and complications (see below), you must be strict about avoiding **all** foods with gluten. You may have to accept some restriction on lifestyle. However, the many foods that are allowed are varied and interesting.

Other treatments

In addition to avoiding gluten:

- You may be advised to take some vitamin, calcium and iron supplements at least for the first six months following diagnosis. This is to replace any deficiencies, and to make sure you get enough of these whilst the gut lining is returning to normal.
- You may be advised to have certain Immunisations. This is because some people with coeliac disease also have a poorly functioning spleen. This makes you more prone to infection from certain germs. The immunisations likely to be advised are to protect against:
 - The pneumococcus bacterium.
 - Haemophilus influenzae type b (the HIB vaccine)

- The influenza virus (the annual 'flu jab').

Are there any complications?

Untreated coeliac disease - Apart from the symptoms listed above, people with coeliac disease have an increased risk of the following:

- Developing osteoporosis ('thinning of the bones') due to the nutritional deficiencies which occur with coeliac disease.
- Developing cancer of the gut in later life. However, there is conflicting research on this subject. Some research studies have failed to show any increased risk, whilst other studies have shown a small increased risk of developing a gut cancer. If you notice bloody or black faeces (stools), lose weight, or develop abdominal pains or persistent diarrhoea, tell your doctor.
- Developing an ulcer of the small intestine which may bleed (but this is rare).
- Developing other immune related diseases (autoimmune diseases) such as Type 1 diabetes, an underactive thyroid, Sjöögren's syndrome and primary biliary cirrhosis.
- Having a baby with low birth weight and with spina bifida if you become pregnant.

A common mistake is to eat small amounts of food which contain gluten. This may be unintentional. However, some people wrongly think that 'a small amount won't matter'. It does. A well known example is thinking that the small amount of bread in a communion wafer will not matter. Even this small amount of gluten is sufficient to cause symptoms, and maintain the increased risks associated with coeliac disease detailed above.

Some people with coeliac disease may not realise they are taking small amounts of gluten. They may feel well, or ignore mild symptoms such as bloating or mild diarrhoea. Again, the increased risks (osteoporosis, etc) still remain if any gluten is eaten.

So, in short, it is vital to *completely* avoid gluten to remain symptom free, and to eliminate the increased risk of developing other serious problems.

Treated coeliac disease (eating no gluten at all) - If you have coeliac disease but do not eat any gluten, you can expect to be free of symptoms and to have a normal healthy life span. The increased risk of developing other autoimmune disorders reduces. After 1-5 years of gluten free diet, there is probably no increased risk of gut cancer and your life expectancy is the same as the general population.

Follow up - Once you have been diagnosed with coeliac disease, you should have regular follow up appointments. This may be after three and six months to ensure that you are making satisfactory progress and managing your gluten-free diet. Thereafter, an annual review (often by your GP) is common, and sooner if problems arise.

There are various reasons why an annual review is useful. For example, to review your diet as some people find it difficult to maintain a fully gluten free diet. Some people do not realise that they may be eating small amounts of gluten (say, for example, processed foods that are contaminated with small traces of gluten containing products). So, for example, an annual blood test can assess if you still have any antibodies against gluten. Also, a blood test to check for anaemia and other indicators of poor food absorption is useful. A review of symptoms is also useful to check if you have developed any associated diseases or complications. Depending on your age and other factors, you may be monitored to see if you have developed osteoporosis.

So, in summary. You can expect to live a life free of the symptoms of coeliac disease if you totally avoid gluten. But, an annual review with a doctor is useful to monitor your progress and health.

Further help and information

Coeliac UK

Suites A - D, Octagon Court, High Wycombe, Buckinghamshire, HP11 2HS

Helpline: 0870 444 8804 Web: www.coeliac.org.uk

This leaflet has been reproduced from information provided by Patient UK