

MANAGING COELIAC DISEASE



What is coeliac disease?

Coeliac disease (pronounced 'see-liac') is a serious illness where the body's immune system attacks its own tissues when gluten is eaten.

Gluten causes damage to the lining of the gut, meaning that you cannot properly absorb nutrients from food. Coeliac disease is not an allergy or food intolerance, it is an autoimmune disease. Symptoms may also affect other parts of the body such as, headaches, brain fog or skin rashes.

What is gluten?

Gluten is a protein found in wheat, barley and rye. Oats can be contaminated with gluten so only oats labelled as gluten free are suitable. Some people with coeliac disease may also be sensitive to gluten free oats, which contain a similar protein to gluten called avenin. See www.coeliac.org.uk/oats for more information.

How many people have coeliac disease?

Around 1 in 100 people has coeliac disease, although many people are not yet diagnosed with the condition. Coeliac disease does run in families but not in a predictable way. There is a 1 in 10 chance that close relatives of people with coeliac disease will have the condition but this means that there is a 90% chance that a family member will not be affected.

What is dermatitis herpetiformis?

Dermatitis herpetiformis (DH) is the skin manifestation of coeliac disease and affects around 1 in 3,300 people. DH commonly appears on the elbows, knees, shoulders, buttocks and face as a rash with red raised patches that burn and sting. It can appear at any age but is not often seen in children and is most common in people in their fifties or sixties. The treatment for DH is a lifelong gluten free diet, however some people also need a medication, commonly Dapsone, to help treat the condition. For more information, see our DH fact sheet or visit www.coeliac.org.uk/dh.

What does coeliac disease do?

When people with coeliac disease eat gluten, the lining of the gut where food and nutrients are absorbed becomes damaged. Tiny, finger like projections called villi which line the gut become inflamed and then flattened, leaving less

surface area to absorb nutrients from food. People with undiagnosed and untreated coeliac disease can have a wide range of symptoms and nutritional deficiencies as a result of the damage to the lining of the gut.

What to do now you're diagnosed

Once coeliac disease is confirmed, it's important to start a gluten free diet. Once gluten has been removed from the diet, the gut will begin to heal and you will usually start to feel better within a few weeks. However, it can take between six months and up to five years (and in some cases longer) for the gut damage caused by eating gluten to fully heal.

After diagnosis, it is recommended to see a dietitian who can provide information about the gluten free diet and advise you on changes that need to be made. You may be asked to fill in a food diary so the dietitian has a good idea of what you normally eat.

Your GP or consultant can arrange a referral to a dietitian for you. Some people with coeliac disease can be deficient in important nutrients so your dietitian will also discuss ways to achieve a healthy balanced diet. After following a gluten free diet for some time, absorption of nutrients from food will improve so supplements may not be necessary in the long term. For advice on this speak to your GP or dietitian.

Managing coeliac disease

The treatment for coeliac disease is a strict, lifelong gluten free diet. You should be offered a check up. If all is going well, you should be reviewed once a year, or sooner if problems arise.

During your review, the following is recommended:

- your weight and height are measured
- your symptoms are reviewed
- the healthcare professional should assess how well you're getting on with the gluten free diet. If you are not being reviewed by a dietitian, the healthcare professional may consider referring you to a dietitian for specialist advice.



for changing their diet as peer pressure, especially among teenagers, can become a real challenge. Whatever your situation, you may find it helpful to seek advice and support from others in the same circumstances.

If any concerns are raised in your annual review, you should be referred to a specialist for further assessment. The specialist will be able to consider the need for specific blood tests, a bone scan to test for osteoporosis and the risk of other conditions or long term complications. For more information visit:

www.coeliac.org.uk/checkups

Are there potential complications of coeliac disease?

Early diagnosis of coeliac disease and following a gluten free diet helps to minimise the risk of long term complications.

Osteoporosis

Due to decreased absorption of calcium, adults with coeliac disease are at a greater risk of low bone density (osteopenia) and osteoporosis. However, for children with coeliac disease following a gluten free diet, long term bone health is likely to be unaffected.

Bone health will usually improve after starting a gluten free diet. It is important to stick to the diet and make sure you get enough calcium to minimise the risk of low bone density and osteoporosis. Tips for getting enough calcium can be found at www.coeliac.org.uk/calcium.

For more information about osteoporosis, please see our fact sheet or visit www.coeliac.org.uk/osteoporosis.

Other autoimmune conditions

Coeliac disease is more common among people with other autoimmune diseases such as Type 1 diabetes and autoimmune thyroid disease.

Cancer

Long term undiagnosed coeliac disease is associated with a small increased risk of developing certain types of cancer. These cancers are very rare and are not associated with childhood. Getting diagnosed and sticking to a gluten free diet reduces the already low risk of developing cancer.

Further help

People react in different ways to changing to a gluten free diet – from relief at finally being able to treat symptoms to worry about what foods to eat. For children, it's important to fully explain the reasons

Coeliac UK has a network of local groups as well as a Member2Member programme offering peer support. For children, our Young Champions pack offers ways to raise awareness of coeliac disease at school. You can find out more about these services by calling our Helpline or by visiting:

www.coeliac.org.uk/localgroups

www.coeliac.org.uk/member2member

www.coeliac.org.uk/youngchampions.

If you are online, we also have very active and friendly social media communities where you can seek advice, read other people's experiences and keep up to date with the latest information. Find us on Facebook, Twitter, Instagram and YouTube.

Visit www.coeliac.org.uk
or call us on **0333 332 2033**
for more information.

Whether you're eating out on the move, in restaurants, or shopping for gluten free food for you and your family, look out for our trusted symbols which mean we're working for you to make things better.



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