

Coeliac disease

Overview

Coeliac disease is a disorder triggered by gluten, the protein found in wheat, rye and barley. People with coeliac disease often feel tired, bloated, pass a lot of wind and often have diarrhoea or constipation. Some may have abdominal pain and weight loss.

Coeliac disease is an auto-immune condition that affects the lining of the small intestine, reducing its ability to absorb nutrients from food.

In worst-case scenarios, coeliac disease that goes untreated or inadequately treated can lead to a much greater risk of certain cancers. There is about a 20-fold increased risk of throat (oropharyngeal), oesophageal and intestinal cancers, and an 80-fold increased risk of intestinal lymphoma — a cancer that occurs in the middle and lower sections of the intestine.

Coeliac disease occurs in about 1 out of every 100 Australians and is becoming more common. Many of those with the condition are not aware of it. For every one person diagnosed, another four have the disease but do not know it.

Coeliac disease can occur in people of any age and is twice as common in women than men, and significantly more common in Caucasians than other races.

Cause

There is a strong genetic link in coeliac disease — 99.6% of patients have one of two genes that are essential to become coeliac. However, about one-third of the population has either of these genes, but only 1% have the disease, so other environmental factors must also be at play. Researchers are still trying to determine what those might be.

These are some risk factors for developing coeliac disease:

- ▶ A first-degree relative (parents, children or siblings) who has coeliac disease.
- ▶ Type 1 diabetes.
- ▶ Thyroid disease.
- ▶ Other autoimmune diseases.
- ▶ Down syndrome.
- ▶ A second-degree relative (such as aunts, uncles, cousins, grandparents, niece, nephew or half-sibling) with the disease also increases the risk, but not by as much as when an immediate family member has it.

Symptoms

Gastrointestinal symptoms are often associated with coeliac disease, but only about one-third of patients experience them. Another third have no symptoms at all — but may still have extensive damage to their small intestine. Symptoms can include:

- ▶ Bloating.
- ▶ Wind.
- ▶ Abdominal pain.
- ▶ Diarrhoea or constipation or both.
- ▶ Stunted growth (in younger patients).

- ▶ Weight loss (though this is becoming less common).
 - ▶ Fatigue.
 - ▶ Infertility.
 - ▶ Obstetric and gynaecological problems in women (increased rates of miscarriage, amenorrhoea (lack of menstruation).
 - ▶ Decreased potency in men.
 - ▶ Oedema (swelling, often of the ankles).
 - ▶ Bone pain (osteopenia).
 - ▶ Neurological and psychiatric complications, such as migraines, epilepsy, dementia, depression, irritability.
- Some people may not show symptoms of coeliac disease, only to be diagnosed incidentally.

Diagnosis

Blood tests are used to check for higher than normal amounts of antibodies to either a tissue enzyme known as transglutaminase or to gliadin, part of the gluten molecule.

However, these antibody tests are not 100% accurate. A small percentage of patients who test positive for the antibodies are found to have no signs of damage to their small intestine when biopsy is performed. It is often recommended that these patients be retested in 3-5 years. Likewise, a small proportion of patients who have negative antibody test results do, in fact, have coeliac disease, which is why a doctor may still recommend a biopsy.

A biopsy involves taking a small section of the intestine for microscopic analysis. This is done by endoscopy, which involves inserting a small tube with a camera into the intestine.

Genetic testing can be used to rule out coeliac disease, but not to confirm it. This is because the genes are so common in the general population and less than 1 in 20 with the genes has coeliac disease.

The only way to definitively diagnose coeliac disease is with an endoscopy and biopsy. This must be done before any changes to diet have been made, otherwise the intestine will have recovered and it may then not be possible to make the diagnosis without eating gluten again.

Treatment

At present, the only way to treat coeliac disease is with a strict, lifelong gluten-free diet. Even trace amounts — as little as 1/100th of a slice of bread — are enough to create an immune response and cause damage. When people with coeliac disease do avoid gluten they usually make a full recovery. It can take up to two years for the small bowel lining to fully heal, though many people heal more quickly.

For people with coeliac, symptoms usually improve within a few days or weeks once they start a gluten-free diet, while for others it can take months. All adults should have their bone mineral density checked at diagnosis and again after one year on a gluten-free diet.

All those with coeliac disease should also be monitored for other complications, such as

neurological complaints and the development of other autoimmune diseases, especially of the thyroid and liver.

Lifestyle and diet

After being diagnosed with coeliac disease, it is highly recommended you see a dietitian for a comprehensive nutritional assessment and specific advice on following a gluten-free diet. People with coeliac disease should be screened for nutritional deficiencies including iron, folate, calcium and vitamin D.

A gluten-free diet avoids products containing wheat, rye, barley and hybrids of these grains, such as triticale. It also excludes wheat starch and malt — and products that contain them, such as beer and whiskey.

In Australia, oats are often processed with wheat, making cross-contamination a concern. So although tests overseas have not shown an immune response to oat protein, they are generally not recommended for a gluten-free diet in Australia.

Fortunately there is still plenty of room for variety, including rice, corn (maize), soy, potatoes, millet, tapioca, quinoa, sorghum, buckwheat and arrowroot.

Switching to a gluten-free diet generally requires a little more planning, but it is still possible to enjoy meals out, travel and dine at friends' houses without too much inconvenience.

Tips that can help include:

- ▶ Call ahead when going to a restaurant.
- ▶ Give examples of foods that are appropriate and foods that are not.
- ▶ Explain cross-contamination.
- ▶ If there is nothing suitable on the menu, ask if the chef could prepare something that is suitable.
- ▶ Identify foods you can rely on in an emergency when travelling.
- ▶ Several websites for people with coeliac disease have leaflets and cards translated into many different languages that can be used when eating out overseas. For example see www.celiactravel.com/gluten-free-cards

Support and resources

- ▶ www.coeliacsociety.com.au/about
- ▶ www.australiandoctor.com.au/
- ▶ www.uchospitals.edu/pdf/uch_007935.pdf