

coeliac disease



Coeliac
Australia



Coeliac disease (pronounced seel-ee-ak) is an immune disease caused by gluten, a component of wheat, rye, barley and oats. When people with coeliac disease eat gluten, an inappropriate immune reaction causes inflammation and damage to the small bowel (intestine). This damage is referred to as “villous atrophy”. The surface area of the bowel available for nutrient absorption is therefore markedly reduced which can lead to nutrient deficiencies.

Many people with coeliac disease have no obvious symptoms at all. However, a number of serious health consequences like chronic poor health, osteoporosis, infertility, miscarriage, depression, liver disease and poor dentition can result if the condition is not diagnosed and treated properly.

There is also a small, but real, increased risk of certain forms of cancer such as lymphoma.

Fortunately, timely diagnosis of coeliac disease and treatment involving lifelong and strict avoidance of gluten in the diet leads to healing of the bowel and better health.



Who gets coeliac disease?

People with coeliac disease are born with an inherited (genetic) predisposition to develop the illness. Over 99% of people affected by coeliac disease possess specific susceptibility genes (HLA DQ2 and/or HLA DQ8). A first-degree relative (parent, brother, sister, child) of someone with coeliac disease has about a 10% chance of also having the disease. Environmental factors also play an important role in the development of coeliac disease although these are poorly understood.

Coeliac disease can also be associated with other autoimmune conditions such as type 1 diabetes, autoimmune thyroid disease (Grave's disease and Hashimoto's thyroiditis), pernicious anaemia, rheumatoid arthritis, Sjogren's syndrome and lupus. The association occurs because of substantial overlap in the genes imparting susceptibility to coeliac disease and these other immune conditions.

Can coeliac disease be cured?

People with coeliac disease remain intolerant to gluten throughout their life, so in this sense they are never cured, and a lifelong gluten free diet is required for optimal health. There is no correlation between presence of symptoms and small bowel damage, so even if people with coeliac disease suffer no symptoms, damage to the small bowel will still occur with gluten ingestion. Fortunately, once gluten is removed from the diet, the small bowel lining steadily repairs and absorption of nutrients returns to normal. The healing of the bowel that occurs with treatment means the risk of long-term health complications from coeliac disease is substantially reduced.

Coeliac disease affects approximately 1 in 100 Australians. However approximately 75% remain undiagnosed. This means that around 160,000 Australians have coeliac disease but aren't aware of it.

How is the condition recognised?

The underlying genetic predisposition to develop coeliac disease is present at birth. Coeliac disease was once considered to be a childhood condition, which only produced symptoms in very young children. It is now recognised that coeliac disease may be diagnosed at any time from infancy to senior years.

Some infants become rapidly and severely ill when foods containing gluten are introduced into their diet; other children develop problems slowly over several years. Many have few or no problems during childhood but develop symptoms only as adults.

In addition, the symptoms of coeliac disease can be quite variable and range from minor to severe and can even be clinically silent. Some symptoms may be confused with irritable bowel syndrome or a food intolerance, while others may be put down to stress, or getting older. As a consequence it may take some time before an accurate diagnosis is sought, or made.

Coeliac disease is not an allergy or an intolerance. These are separate conditions managed differently to coeliac disease, although occasionally they can co-exist.

What are the symptoms

The symptoms of coeliac disease vary considerably. Listed at right are some of the symptoms which may occur singularly or in any combination:



- Fatigue, weakness and lethargy
- Anaemia
- Flatulence and abdominal distention (bloating)
- Diarrhoea – ranging from mild to severe
- Constipation – may be experienced instead of diarrhoea
- Erratic bowel habit ranging between constipation and diarrhoea
- Cramping and abdominal pain
- Nausea and vomiting
- Weight loss
- Recurrent mouth ulcers
- Bone and joint pains
- Miscarriage and infertility
- Vitamin and mineral deficiencies such as low iron levels
- An itchy, blistering skin rash (dermatitis herpetiformis)*
- Dental enamel defects

Common in children

- Abdominal distention, pain and flatulence
- Nausea and vomiting
- Diarrhoea and/or constipation
- Large, bulky, foul stools (steatorrhea)
- Poor weight gain or weight loss
- Delayed growth or delayed puberty
- Tiredness, irritability or feeling “out of sorts”
- Anaemia

*Dermatitis herpetiformis is a chronic, itchy, blistering skin condition associated with coeliac disease. For further information see Coeliac Australia’s brochure “dermatitis herpetiformis”.



Problems with diagnosis

Since the symptoms of coeliac disease can closely mimic other conditions, a correct diagnosis can only be made by confirming the characteristic damage to the bowel lining. Undertaking a "trial" of a gluten free diet is not helpful in making the diagnosis as symptomatic improvement is insufficient to confirm coeliac disease. Moreover, undertaking a gluten free diet prior to appropriate testing can cause falsely negative investigation results and lead to a missed diagnosis. Appropriate testing is important to establish the correct diagnosis and ensure other potentially serious conditions are not overlooked.

If you have symptoms suggestive of coeliac disease or have a close relative with the condition it is important to discuss appropriate testing with your doctor.

Diagnosis

Coeliac blood tests (coeliac serology) are used for initial screening. If the results are positive or your doctor feels further testing is warranted, a referral to a gastroenterologist will be necessary.

It is essential that the diagnosis be confirmed by performing a gastroscopy procedure (a flexible instrument is passed through the mouth into the small bowel) in which several tiny samples (biopsies) from the small bowel are taken. These biopsies are examined under a microscope to confirm the typical small bowel changes of coeliac disease (villous atrophy).

A gastroscopy is a simple day procedure done under light anaesthetic sedation that takes under 10 minutes. Taking small bowel biopsies is an essential part of diagnosing coeliac disease as the blood test alone is not definitive. A repeat biopsy is usually performed 18 - 24 months after commencing treatment with a gluten free diet to confirm small bowel healing.

Coeliac disease is treated by a lifelong gluten free diet. By removing the trigger of the disease, this treatment allows abnormalities, particularly that of the small bowel lining, to recover. As long as the gluten free diet is strictly adhered to, problems arising from coeliac disease should not return.

“At risk” groups, such as first degree relatives and people with type 1 diabetes, should be screened for coeliac disease.

For further information see Coeliac Australia’s brochure ‘diagnosing coeliac disease’.

Notes about the gluten free diet

Gluten is the rubbery and elastic protein found in wheat, rye, barley and oats. Gluten is responsible for the cooking and baking properties of these grains.

There are obvious foods which contain gluten e.g. bread, cakes and pasta, but there are also a whole range of ingredients within prepared and commercial foods which can come from a gluten source. To become “ingredient aware” is essential.

Initially the gluten free diet may seem overwhelming. With the information and support available with membership of Coeliac Australia, it will become much easier.

It is recommended you seek the guidance of an Accredited Practising Dietitian with experience in coeliac disease to help you manage your gluten free diet and ensure your diet is nutritionally balanced.

Once you are diagnosed...

Coeliac Australia is here to help you manage your gluten free diet. Your state organisation provides support and information on the disease, the gluten free diet, ingredients, where to buy, cooking and recipes, overseas travel and education and research material. Specific resources for children requiring a gluten free diet are also available.

For more information or to become a member, call **1300 GLUTEN** (1300 458 836) or visit our website **www.coeliac.org.au**.

NATIONAL OFFICE

Suite 1, 41-45 Pacific Highway Waitara NSW 2077

PO Box 271 Wahroonga NSW 2076

T 1300 990 273 or **T** 02 9487 5088 **F** 02 9487 5177

E info@coeliac.org.au

NEW SOUTH WALES & ACT

Suite 1, 41-45 Pacific Highway Waitara NSW 2077

PO Box 271 Wahroonga NSW 2076

T 02 9487 5088 **F** 02 9487 5177

E nsw@coeliac.org.au

QUEENSLAND

91B Wilston Road Newmarket QLD 4051

PO Box 3455 Newmarket QLD 4051

T 07 3356 4446 **F** 07 3356 4474

E qld@coeliac.org.au

SOUTH AUSTRALIA & NORTHERN TERRITORY

Unit 5-6, 88 Glynburn Road Hectorville SA 5073

T 08 8336 1476 **F** 08 8365 1265

E sant@coeliac.org.au

VICTORIA & TASMANIA

11 Barlyn Road Mt Waverley VIC 3149

PO Box 89 Holmesglen VIC 3148

T 03 9808 5566 **F** 03 9808 9922

E victas@coeliac.org.au

WESTERN AUSTRALIA

Unit 2, 4 Queen Street Bentley WA 6102

PO Box 726 Bentley WA 6982

T 08 9451 9255 **F** 08 9451 9266

E wa@coeliac.org.au



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