

Membership with Coeliac Australia

“For people navigating the challenges of coeliac disease, I always recommend Coeliac Australia membership. The support, benefits and evidence-based information they offer can greatly enhance my patients’ quality of life.”

A/Prof Jason Tye-Din, gastroenterologist and chair Coeliac Australia Medical Advisory Committee

Coeliac Australia membership benefits:

Membership will keep you informed about managing coeliac disease and help you enjoy eating gluten free, with a wealth of information, resources and updates:

- New Membership Resource Kit containing informative materials and gluten free product samples.
- ‘Getting Started’ email series providing essential information for managing coeliac disease and the gluten free diet.
- *The Australian Coeliac* quarterly magazine
- Monthly e-newsletter
- Member Discount Program
- Access to the online Member Area
- Free daily ticket to your nearest Gluten Free Expo
- Ongoing personal support from our dedicated team

For more information or to become a member

Coeliac Australia
1300 458 836
membership@coeliac.org.au
www.coeliac.org.au

Coeliac Australia is not a medical organisation. Persons reading this material should not act solely on it. The advice of a medical practitioner should always be obtained.

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Note: It is recommended that a copy of all coeliac tests including antibody, gene and biopsy results, be kept by those diagnosed with coeliac disease.

Beware of unorthodox diagnosis techniques

There are a number of tests and treatments for allergy, intolerance and coeliac disease that are used in the absence of any scientific rationale. These tests and treatments have been shown to be unreliable when subjected to careful study. Unproven testing methods provide misleading results, delay correct diagnosis and lead to unnecessary and ineffective treatment. The Australasian Society of Clinical Immunology and Allergy (ASCIA) advise against the use of such tests for diagnosis or to guide medical treatment. Such methods may include stool-based tests, Vega testing, iridology, hair analysis or the inappropriate use of tests for food-specific immunoglobulin. For a full list and more information about unorthodox tests and treatments, visit the ASCIA website: www.allergy.org.au.

The benefits of diagnosis

As coeliac disease is a serious medical condition with lifelong implications, a definitive diagnosis is essential. The gluten free diet is not a trivial undertaking and involves lifestyle changes and learning new skills such as reading and interpreting food labels. It should only be undertaken after the diagnosis of coeliac disease has been properly medically established.

- A strict gluten free diet has positive implications for health by reducing the long-term risks associated with coeliac disease. People who have been properly medically diagnosed are more likely to maintain the strictness required to remain healthy.
- By obtaining a proper diagnosis, you can be assured that your symptoms are caused by coeliac disease and not by another more sinister condition.
- As a genetic condition, there could be implications for your family once a diagnosis of coeliac disease is made. Following a diagnosis of coeliac disease, immediate family members should be screened.



- On diagnosis of coeliac disease, screening for complications and associated conditions such as osteoporosis or other autoimmune disease should occur. Being diagnosed appropriately will ensure this important medical assessment takes place.

Once you are diagnosed...

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

Adjusting to the gluten free diet may seem difficult at first but as your knowledge and confidence grows, managing the diet becomes easier. Advice from a specialist dietitian is invaluable and can greatly enhance the enjoyment to be had from a gluten free lifestyle.

Quick recap...

- Symptoms vary considerably
- Do not start a gluten free diet prior to testing
- A definitive diagnosis is important
- Testing is simple
- Support – www.coeliac.org.au

Diagnosing coeliac disease



Coeliac
Australia

Coeliac disease (pronounced seel-ee-ak) is an immune disease caused by gluten, a protein in 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). Untreated, coeliac disease can cause a range of symptoms and health problems. Treatment involves lifelong and strict avoidance of gluten in the diet and leads to healing of the bowel and better health.

The lining of the small bowel is covered with tiny, finger-like projections called villi, which aid the digestion and absorption of nutrients from food. In people with untreated coeliac disease, the villi become inflamed and flattened. This is called “villous atrophy”. Villous atrophy reduces the surface area of the bowel available for nutrient absorption, which can lead to nutrient deficiencies. Inflammation also results in problems that can affect the bones, joints, skin and other organs, such as the liver and brain.



Who gets coeliac disease?

People are born with a genetic predisposition to develop coeliac disease. The most important genes associated with coeliac disease are “HLA DQ2” and “HLA DQ8”. One or both of these genes are present in virtually every person with coeliac disease. Other genes and various environmental factors play an important role in triggering or “unmasking” coeliac disease. It can develop at any stage in life, from infancy to old age.

Symptoms

The symptoms of coeliac disease vary considerably. Common complaints include gastrointestinal upset (such as abdominal pain, bloating, flatulence, nausea, vomiting, diarrhoea, and/or constipation), lethargy, mouth ulcers and weight loss. Some people suffer severe symptoms, while others are symptom free. Further investigation for coeliac disease should occur if one or more high risk features are present. These include:

- Iron deficiency anaemia or other nutrient deficiencies
- Gastrointestinal symptoms
- Osteoporosis (thinning of the bones, which increases fracture risk)
- Autoimmune disease (such as type 1 diabetes or autoimmune thyroid disease)
- Weight loss
- Unexplained infertility or recurrent miscarriage
- A family history of coeliac disease.

Untreated, coeliac disease can lead to chronic poor health, osteoporosis, infertility, miscarriage, depression, liver disease, poor dentition, and an increased risk of autoimmune disease and some forms of cancer. Importantly, appropriate treatment with a strict gluten free diet leads to small bowel healing, resolution of symptoms, and a reduction in the risk of complications.

Although symptoms can vary considerably, everybody with coeliac disease is at risk of complications if they do not adhere strictly to a gluten free diet. Since bowel damage can occur in coeliac disease even when symptoms are absent, everybody with coeliac disease, regardless of symptom severity, needs to adhere strictly to a gluten free diet.

Coeliac disease affects on average approximately 1 in 70 Australians.

However, around 80% of this number remain undiagnosed.

Diagnosis

As coeliac disease has significant health implications, a definitive diagnosis is paramount.

The tests for coeliac disease are simple – just follow the steps below.

1. Keep eating gluten

Do not commence a gluten free diet prior to being tested for coeliac disease. If a gluten free diet has already been adopted, the tests used to diagnose coeliac disease are unreliable.

If gluten has been removed from the diet, a normal diet must be resumed for at least six weeks prior to testing. During this ‘gluten challenge’, four slices of wheat based bread (or equivalent) should be consumed each day for adults, or two slices (or equivalent) for children under 12. A gluten challenge can be a daunting prospect for some people who experience unpleasant symptoms. While symptoms may be fairly severe for the first few days of the challenge, they often reduce over time. It is important the gluten challenge is carried out properly to ensure reliable testing results.

2. Blood tests are used for screening

Initial testing for coeliac disease involves a blood test that measures certain antibodies (“coeliac serology”).

The test involves the doctor requesting either of the following:

- Transglutaminase-IgA (tTG-IgA) AND deamidated gliadin peptide-IgG (DGP-IgG) antibody tests, or
- Transglutaminase-IgA (tTG-IgA) antibody test AND the total IgA level (to exclude the 2-3% of people with coeliac disease who are IgA deficient).

Positive antibody tests alone are insufficient to diagnose coeliac disease and confirmation of the diagnosis by gastroscopy and small intestinal biopsy is needed; it is possible to have a positive blood test and not actually have coeliac disease.

While a normal coeliac serology result suggests that coeliac disease is unlikely, false negative results can also occur. If symptoms are ongoing (and especially if other risk factors are present) a small bowel biopsy may be warranted irrespective of serology results. Other causes for the symptoms may also need to be investigated.



3. A small bowel biopsy is essential

A diagnosis of coeliac disease can only be made by demonstrating the typical small bowel changes of coeliac disease (villous atrophy). This involves a gastroscopy (or endoscopy) in which several tiny samples (biopsies) of the small bowel are taken. A gastroscopy is a simple day procedure done under light anaesthetic sedation that takes about 10 minutes. In the majority of cases, the bowel damage present in those with untreated coeliac disease is not visible to the naked eye. The biopsies are examined under a microscope to confirm the presence of villous atrophy.

A repeat biopsy should occur approximately 18 – 24 months after commencing treatment with a gluten free diet to confirm small bowel healing. A healthy looking biopsy is good and means the gluten free diet is being followed adequately – but it does not mean coeliac disease has been cured. Relapse will occur if gluten is reintroduced to the diet. Coeliac disease is for life, and a gluten free diet needs to be followed lifelong to maintain health.

Gene testing (HLA genes)

Gene (HLA) testing is a useful test in select cases when the diagnosis of coeliac disease is unclear. This can occur if the blood or small bowel biopsy results are difficult to interpret, or if adequate gluten was not being consumed to make the test reliable. It is performed on a blood test or cheek (buccal) scraping and can be ordered through your local doctor.

A negative gene test for HLA DQ2 and HLA DQ8 effectively rules out a diagnosis of coeliac disease. However, a positive gene test only indicates susceptibility to coeliac disease. Just one in 40 people who possess HLA DQ2 or HLA DQ8 will develop the condition, so most people who are gene positive will never get coeliac disease. Thus the gene test on its own cannot diagnose coeliac disease and a gluten free diet should never be commenced based solely on a positive gene test. A gluten free diet should only be started after confirmation of coeliac disease by small bowel biopsy.

As the gene test is not dependent on gluten intake, it can be used when people have already commenced a gluten free diet. If the gene test is negative for HLA DQ2 and HLA DQ8 then coeliac disease can be excluded. If the gene test is positive, then a gluten challenge followed by small bowel biopsy will be required to test for coeliac disease.