

coeliac disease

THE COELIAC SOCIETY

Australian Society

PO Box 271 Wahroonga NSW 2076
Telephone: 02 9487 5088 • Facsimile: 02 9487 5177
Email: info@coeliacsociety.com.au

New South Wales & ACT

PO Box 271 Wahroonga NSW 2076
Suite 1, 41-45 Pacific Highway Waitara NSW 2077
Telephone: 02 9487 5088 • Facsimile: 02 9487 5177
Email: nsw@coeliacsociety.com.au

Queensland

PO Box 2110 Fortitude Valley BC QLD 4006
10 Love Street Spring Hill QLD 4000
Telephone: 07 3839 5404 • Facsimile: 07 3839 4588
Email: qld@coeliacsociety.com.au

South Australia & Northern Territory

Unit 5-6, 88 Glynburn Road Hectorville SA 5073
Telephone: 08 8336 1476 • Facsimile: 08 8365 1265
Email: sa@coeliacsociety.com.au

Tasmania

C/- PO Box 89 Holmesglen VIC 3148
Facsimile: 03 9808 9922
Email: tas@coeliacsociety.com.au

Victoria

PO Box 89 Holmesglen VIC 3148
11 Barlyn Road Mt Waverley VIC 3149
Telephone: 03 9808 5566 • Facsimile: 03 9808 9922
Email: vic@coeliacsociety.com.au

Western Australia

PO Box 726 Bentley WA 6982
9B/4 Queen Street Bentley WA 6102
Telephone: 08 9451 9255 • Facsimile: 08 9451 9266
Email: waf@coeliacsociety.com.au

The Coeliac Society of Australia Inc 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.

If you would like to become a member or would like more information, contact your state society on 13 ZERO ZERO GLUTEN (1300 458 836).

www.coeliacsociety.com.au



What is Coeliac Disease?

Proudly sponsored by:



TheCoeliacSociety

Information about Coeliac Disease

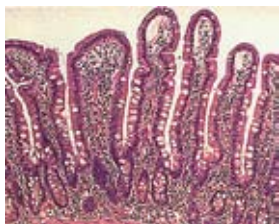
Coeliac disease (pronounced seel-ee-ak) is an auto-immune disease. Auto-immune means the body mistakenly produces antibodies that damage its own tissues. It is a permanent intestinal intolerance to dietary gluten. A number of serious health consequences can result if the condition is not diagnosed and treated properly.

In those with untreated coeliac disease the mucosa (lining) of the small bowel (intestine) is damaged: The tiny, finger-like projections which line the bowel (villi) become inflamed and flattened. The function of the cells on villi is to break down and absorb nutrients in food. Through a microscope, the lining of the small bowel normally looks rather like shag-pile carpet, the villi making up the "pile". The entire surface area of a healthy small bowel is comparable in size to that of a tennis court.

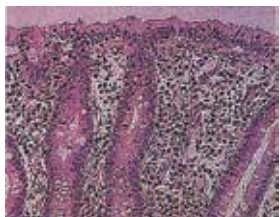
In those with untreated coeliac disease, the villi become inflamed and the bowel has a characteristic flat appearance (like a threadbare carpet). This is referred to as villous atrophy. The surface area of the bowel available for nutrient absorption is markedly reduced (to the size of a table or less) which can lead to nutrient deficiencies.

What is the Cause?

In people with coeliac disease the immune system reacts abnormally to gluten, causing small bowel inflammation and damage. Gluten is a protein found in wheat, rye, barley and oats.



Normal healthy villi of the small intestine (as seen under the microscope)



Damaged villi of a person with undiagnosed coeliac disease.

Who gets Coeliac Disease?

People are born with a genetic predisposition to develop coeliac disease. They inherit a particular genetic make-up (HLA type) with the genes DQ2 and DQ8 being identified as the "coeliac genes". Gene testing is presently available through pathology laboratories (by blood test or buccal swab). The gene test is useful for excluding coeliac disease. The presence of HLA DQ2 and HLA DQ8 is not helpful as a positive predictor of coeliac disease, as only 1 in 30 people (approximately) with these genes will have coeliac disease. The gene test cannot diagnose coeliac disease – only exclude it.

Environmental factors also play an important role in the development of coeliac disease.

A first-degree relative (parent, brother, sister, child) of someone with coeliac disease has about a 10% chance of also having the disease. If one identical twin has coeliac disease, there is an approximate 70% chance that the other twin will also be affected (but not necessarily diagnosed at the same time). This highlights the role of both genetic and environmental factors in the development of coeliac disease.

Coeliac disease affects Caucasians and west Asians. It is uncommon in the Oriental Asian and full-blood Australian Aboriginal populations.

Coeliac disease can also be associated with other autoimmune conditions such as type 1 diabetes, autoimmune thyroid disease, pernicious anaemia, rheumatoid arthritis, inflammatory bowel disease and lupus. It has not been shown that there is a causative link, but having one genetic autoimmune disease increases your risk of having another.

How Common is the Condition?

Coeliac disease affects approximately 1 in 100 Australians. However 80% currently remain undiagnosed. This means that approximately 200,000 Australians have coeliac disease but don't yet know it.

Can Coeliac Disease be cured?

People with coeliac disease remain sensitive to gluten throughout their life, so in this sense they are never cured. There is no correlation between symptoms and bowel

damage, so even if asymptomatic (you have no symptoms), damage to the small bowel can still occur if gluten is ingested. Once gluten is removed from the diet, the small bowel lining steadily repairs and the absorption of nutrients from food returns to normal.

People with coeliac disease should remain otherwise healthy as long as they adhere to a diet free of gluten. Relapse occurs if gluten is reintroduced.

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 triggered 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 range from severe to minor or atypical 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.

What are the Symptoms

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

- Fatigue, weakness and lethargy
- Anaemia
- Flatulence and abdominal distention
- Diarrhoea – can be quite severe but may not necessarily be obvious
- Constipation – may be experienced instead of diarrhoea, although many people do not experience either and some experience both
- Cramping and bloating
- Nausea and vomiting
- Weight loss – although many do not lose weight and some can even gain weight

Less Common in Adults

- Easy bruising of the skin
- Recurrent mouth ulcers and/or swelling of mouth or tongue
- Miscarriage and infertility
- Low calcium levels
- Vitamin and mineral deficiencies
- Skin rashes such as dermatitis herpetiformis
- Dental defects
- Altered mental alertness
- Bone and joint pains

Common in Children

- Abdominal distention, pain and flatulence
- Nausea and vomiting
- Diarrhoea and/or constipation
- Large, bulky, foul stools (steatorrhea)
- Poor weight gain
- Weight loss in older children
- Delayed growth or delayed puberty
- Tiredness
- Anaemia
- Irritability

Many people with coeliac disease are 'asymptomatic', that is they have no obvious symptoms at all.

Problems with Diagnosis

Since the symptoms of other conditions can closely mimic coeliac disease, correct diagnosis can only be made by showing that the bowel lining is damaged. Trialling a gluten free diet does not provide a diagnosis of coeliac disease. Subsequent investigations whilst on a gluten free diet will render false negative results (this includes both the serological testing [blood tests] and histological testing [biopsy]) and may delay the diagnosis of another condition with similar symptoms. If gluten has been excluded prior to testing, it will be necessary to reintroduce it to the diet at least six weeks prior to having the blood test and biopsy (the equivalent amount of gluten from four slices of standard bread daily for adults). If you think you may have coeliac disease, have a close relative with the condition, or have been treated for anaemia on previous occasions, it is important to discuss it with your doctor.

Diagnosis

Coeliac blood tests are used for initial screening ("coeliac serology and IgA"). If the results are positive or your doctor feels further testing is warranted, a referral to a gastroenterologist will be necessary. The diagnosis must be confirmed by performing a gastroscopy (an endoscope is passed through the mouth into the small bowel) to collect tiny samples (biopsies) from the small bowel. These biopsies are studied under a microscope to determine if coeliac disease is present. A gastroscopy is done in a hospital or day-procedure centre while the patient is sedated (most people find it very straight forward). Taking small bowel biopsies is an essential part of diagnosing coeliac disease as the blood test alone is not definitive. A second biopsy is usually performed after twelve months on a gluten free diet to show that bowel repair has occurred.

"At risk" groups, such as first degree relatives and people with type 1 diabetes or other autoimmune conditions, should be screened for coeliac disease.

What are the Long Term Risks of Undiagnosed Coeliac Disease?

The long term consequences of coeliac disease are related to poor nutrition and malabsorption of nutrients. Untreated coeliac disease can lead to chronic poor health, osteoporosis, infertility, miscarriage, depression and dental enamel defects. There is also a small, but real, increased risk of certain forms of cancer such as lymphoma of the small bowel. In children, undiagnosed coeliac disease can cause lack of proper development, short stature and behavioral problems.

Fortunately, timely diagnosis of coeliac disease and treatment with a gluten free diet can prevent or reverse many of these problems.

How is the Condition Treated?

Coeliac disease is treated by a lifelong gluten free diet. By removing the cause 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.

Once diagnosed, your doctor or dietitian may initially recommend the use of supplements to correct any deficiencies caused by coeliac disease. Some people may also have a transient intolerance to lactose (the sugar found in milk) at the time of diagnosis. In most cases this will resolve

once the bowel has repaired with the gluten free diet. Speak to your doctor if you suspect you may be lactose intolerant. A dietitian will be able to guide you regarding suitable foods.

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 The Coeliac Society, it will be 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.

Labelling of Gluten Free Food

The Australian Food Standards Code requires that:

- Foods labelled as gluten free must contain no detectable gluten and no oats or malted gluten-containing cereals or their products
- Foods labelled as low gluten must contain less than 200 parts per million of gluten (low gluten foods are rarely seen in Australia and are not recommended for those on a gluten free diet)
- Ingredients derived from gluten containing grains must always be declared on food labels.

The Coeliac Society

Adult coeliacs, parents of coeliac children and those with dermatitis herpetiformis* have formed a Coeliac Society in each Australian state. These Societies provide 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.

*Dermatitis herpetiformis is a chronic, itchy, blistering skin condition associated with coeliac disease. The Coeliac Society has a separate pamphlet "Dermatitis Herpetiformis"