

# The Coeliac Society

## Coeliac Disease

### What is it?

The Coeliac Society  
of Australia Inc  
www.coeliacsociety.com.au

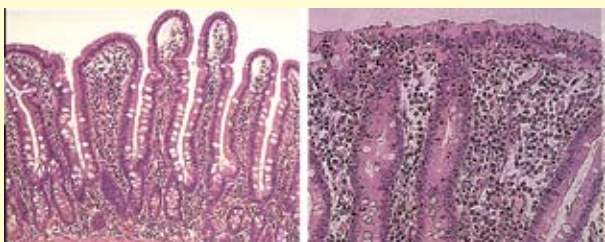


### Information about Coeliac Disease

Coeliac disease (pronounced seel-ee-ak) is a significant medical condition that can result in a number of serious consequences if not diagnosed and treated properly. It is a permanent intestinal intolerance to gluten in food.

Coeliac disease is a condition in which the mucosa (lining) of the small bowel (intestine) is damaged. This results in a flattening of the tiny, finger-like projections, called villi, which line the bowel. The function of the cells on villi is to break down and absorb nutrients in food. Looking through the 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 the small intestine is comparable in size to that of a tennis court.

In untreated coeliac disease, the lining of the intestine becomes inflamed and has a characteristic flat appearance (like a threadbare carpet). This is referred to as villous atrophy. The surface area, which enables the absorption of nutrients and minerals, is seriously reduced (to the size of a table or less) which can lead to nutritional deficiencies.



Healthy normal villi  
of the small intestine  
(as seen under the  
microscope).

Damaged villi  
of a person with  
undiagnosed coeliac  
disease.

### 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.

### 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  $DQ_2$  and  $DQ_8$  being identified as the "coeliac genes". Gene testing is presently available through some pathology laboratories (by blood test or buccal swab test). The gene test can be useful as a test of exclusion for the presence of or susceptibility to coeliac disease. However, the presence of HLA  $DQ_2$  or HLA- $DQ_8$  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.

It is suspected that environmental factors also play a role. In many cases, the condition will not have been diagnosed in other generations, however a first-degree relative (parent, brother, sister, child) has about a 10% chance of also having coeliac disease.

With identical twins, if one has coeliac disease, there is approximately a 70% chance that the other twin will also be affected (but not necessarily diagnosed at the same time). This indicates that both genetic and environmental factors influence 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 certain other autoimmune conditions such as type 1 diabetes (insulin dependent diabetes mellitus), 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 the risk of having another.

### How Common is the Condition?

Blood screening tests have shown that coeliac disease affects approximately 1 in 100 Australians. It is underdiagnosed, probably affecting over 250,000 Australians, with a range of presentations, however it is estimated that only 1 in 5 to 1 in 8 Australians have currently been diagnosed.

## Can Coeliac Disease be Cured?

People with coeliac disease remain sensitive to gluten throughout their life, so in this sense, they are never cured. Even if symptoms disappear, damage to the small bowel can still occur, if gluten is ingested. However, after the removal of gluten, the small intestinal lining steadily returns to normal (or near normal) and so does the absorption of food and nutrients.

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 is present at birth. Some infants become rapidly and severely ill when foods containing gluten are introduced into their diet; other children develop problems slowly over several years.

Coeliac disease was once considered to be a childhood condition, which only produced symptoms in very young children. It is now well recognised that symptoms can appear for the first time at any age from infancy to senior 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 wheat or other 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 severity of symptoms is extremely variable. Listed below are some of the symptoms which may occur singularly or in combination:

- Fatigue, weakness and lethargy
- Anaemia
- Flatulence and abdominal distention
- Diarrhoea - can be quite severe but may not necessarily be obvious
- Constipation - can be experienced rather than 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 and tongue
- Miscarriages and infertility
- Low calcium levels
- Vitamin 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 or constipation
- Large, bulky, foul stools (steatorrhea)
- Poor weight gain
- Weight loss in older children
- Delayed growth or delayed puberty
- Tiredness
- Anaemia
- Irritability

## 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 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 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 should be used for initial screening ("coeliac serology and IgA"). If the results are positive, 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), a procedure that allows tiny samples (biopsies) to be taken from the small bowel which can reveal if gluten is causing damage. 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 about twelve months on a gluten free diet to show that repair of the damage has occurred.

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

## What are the Long Term Risks of Undiagnosed Coeliac Disease?

Long term consequences are related to poor nutrition and malabsorption of vitamins, minerals and other nutrients. This can lead to chronic poor health, thinning of the bones (osteoporosis), infertility, miscarriages, 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 behavioural 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 specifically removing the cause of the disease, this treatment allows abnormalities, particularly that of the small bowel lining, to recover. As long as the diet is strictly adhered to, problems arising from coeliac disease should not return.

At the start of treatment it may be necessary to supplement current deficiencies of nutrients. Some people may also have a transient intolerance to lactose (the sugar found in milk) at the time of diagnosis and may be advised by their doctor to temporarily restrict the amount of lactose in their gluten free diet. The normal digestion of lactose should return once the bowel repairs with the gluten free diet. In some people, a low lactose diet is required for a longer period of time.

## Notes about the Gluten Free Diet

Gluten is a rubbery and elastic protein found in wheat, rye, barley, triticale (a cross between wheat and rye) and oats. Gluten is responsible for the cooking and baking properties of these grains.

There are obvious foods which contain gluten ie bread, cakes, pasta etc, 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, however with the information and support available with membership in The Coeliac Society, it will become much easier.

The guidance of an accredited practising dietitian who can give assistance with advice to suit individual needs is recommended.

## Labelling of Gluten Free Food

The Australian Foods 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 gluten (low gluten foods are rarely seen in Australia)
- Ingredients derived from gluten containing grains must always be declared on food labels.

## The Coeliac Societies in Australia

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, education and research material etc. 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 What is it?".

## Contact Details

### The Coeliac Society of Australia

Suite 1, 41-45 Pacific Highway Waitara 2077  
PO Box 271 Wahroonga 2076  
Phone: (02) 9487 5088 Fax: (02) 9487 5177  
Email: [info@coeliacsociety.com.au](mailto:info@coeliacsociety.com.au)  
Website: [coeliacsociety.com.au](http://coeliacsociety.com.au)

### State Societies

If you would like to become a member or would like more information, please contact your state society.

#### New South Wales

Suite 1, 41-45 Pacific Highway Waitara 2077  
PO Box 271 Wahroonga 2076  
Phone: (02) 9487 5088 Fax: (02) 9487 5177  
Email: [nsw@coeliacsociety.com.au](mailto:nsw@coeliacsociety.com.au)  
Website: [nsw.coeliacsociety.com.au](http://nsw.coeliacsociety.com.au)

#### Victoria

PO Box 89 Holmesglen 3148  
11 Barlyn Road Mt Waverley 3149  
Phone: (03) 9808 5566 or 13 ZERO ZERO GLUTEN  
(1300 458 836) if calling from within Victoria  
Fax: (03) 9808 9922  
Email: [vic@coeliacsociety.com.au](mailto:vic@coeliacsociety.com.au)  
Website: [vic.coeliacsociety.com.au](http://vic.coeliacsociety.com.au)

#### Queensland

PO Box 2110 Fortitude Valley BC 4006  
Level 1 Local Government House  
25 Evelyn Street Newstead 4006  
Phone: (07) 3854 0123  
Fax: (07) 3854 0121  
Email: [qld@coeliacsociety.com.au](mailto:qld@coeliacsociety.com.au)  
Website: [qld.coeliacsociety.com.au](http://qld.coeliacsociety.com.au)

#### South Australia

Unit 5-6, 88 Glynburn Road Hectorville 5073  
Phone: (08) 8365 1488 or (08) 8336 1476  
Fax: (08) 8365 1265  
Email: [sa@coeliacsociety.com.au](mailto:sa@coeliacsociety.com.au)  
Website: [sa.coeliacsociety.com.au](http://sa.coeliacsociety.com.au)

#### Western Australia

PO Box 1344 East Victoria Park 6981  
931 Albany Highway East Victoria Park 6101  
Phone: (08) 9470 4122 or 13 ZERO ZERO GLUTEN  
(1300 458 836) if calling from within Western Australia  
Fax: (08) 9470 4166  
Email: [wa@coeliacsociety.com.au](mailto:wa@coeliacsociety.com.au)  
Website: [wa.coeliacsociety.com.au](http://wa.coeliacsociety.com.au)

#### Tasmania

PO Box 159 Launceston 7250  
Phone: (03) 6427 2844 or 13 ZERO ZERO GLUTEN  
(1300 458 836) if calling from within Tasmania  
Fax: (03) 6344 4284  
Email: [tas@coeliacsociety.com.au](mailto:tas@coeliacsociety.com.au)  
Website: [tas.coeliacsociety.com.au](http://tas.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.  
1/07



100% Australian Company

This leaflet is proudly sponsored  
by Orgran Gluten Free Foods