

The Coeliac Society



Coeliac Disease

What is it?



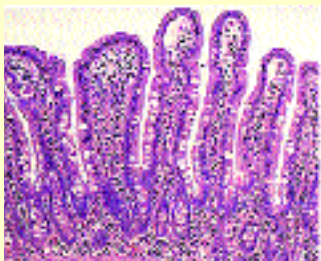
**The Coeliac Society
of Australia Inc**

www.coeliac.org.au

Information about Coeliac Disease

Coeliac disease (pronounced seel-ee-ak) is a medical condition and is a permanent intestinal intolerance to dietary gluten.

In untreated coeliac disease the lining of the small bowel (intestine) is damaged. This causes a flattening of the tiny, finger-like projections, called villi, which line the inside of the bowel. The function of the cells on normal villi is to break down and absorb nutrients in food. In untreated coeliac disease, the lining of the intestine becomes inflamed and gives a characteristic flat appearance (villous atrophy). The surface area, which enables the absorption of nutrients and minerals from food, is seriously depleted. This leads to deficiencies in vitamins, minerals and sometimes calcium, proteins, carbohydrates and fats.



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



Damaged villi of the small intestine. Villi of a person with undiagnosed coeliac disease.

What is the cause?

In people with coeliac disease, the body has an immune (allergic) reaction to gluten (a protein found in wheat, rye, barley, triticale and possibly oats). This causes damage to the lining of the small bowel which results in a reduction in the surface area of the villi or finger-like projections of the bowel. Both genetic and environmental factors play important roles in coeliac disease. It is a genetic condition, but may be triggered by other factors, some as yet not identified.

Is Coeliac Disease familial?

Around 10% of all first degree relatives (parents, brothers, sisters or children) of a person with coeliac disease will also have the disease. With identical twins, if one is affected there is a 70% (approx) chance that the other twin will also be affected (but not necessarily at the same time). This confirms that both genetic and environmental factors influence the development of coeliac disease.

How common is the condition?

Coeliac disease is more common than previously thought. One study indicates that 1 in 250 Australians have the condition whilst another study suggests that the prevalence is 1 in 100. A similar study in Christchurch, New Zealand, found 1 in 84 people affected by coeliac disease. It is now known that coeliac disease affects up to 1% of many communities – over ten times the figure quoted ten years ago. Only 10-20% of individuals with coeliac disease are currently diagnosed despite many of them having symptoms or complications attributable to the condition.

Coeliac disease had been considered to be predominantly a disease of Caucasians, but is known to occur in the population of India and some Middle Eastern countries. It is, however, very uncommon in the Oriental Asian and Australian Aboriginal population.

In the past, it was regarded as only a childhood condition, which produced symptoms in very young children. It is now known that it can affect a person 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 be minor or atypical and can even be clinically silent.

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 be taking place, if gluten is being ingested. However after the removal of gluten from the diet, a reversal of the abnormalities of the lining of the bowel occurs and the problem of deficiencies resolve. Older patients often take longer to recover.

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

How is the condition recognised?

The underlying genetic predisposition is present at birth. Some infants become rapidly and severely ill when gluten is introduced into their diet; other children develop problems slowly over several years. Many people with coeliac disease have few or no apparent problems during childhood, developing symptoms only during adult life. Screening studies have revealed that many people with coeliac disease in the community remain completely undetected.

Symptoms

The symptoms of coeliac disease can vary markedly, ranging from numerous to none which are obvious.

Listed below are some of the symptoms which may occur singularly or in combination:

- Fatigue, weakness and lethargy
- Anaemia - the anaemia will either not respond to treatment or will recur after treatment (iron therapy) until the correct diagnosis is made and a gluten free diet is begun
- Flatulence and abdominal distention
- Diarrhoea - this may begin at any age and is often present for years prior to diagnosis
- Constipation - some are likely to experience constipation rather than diarrhoea although a number of 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 put on weight

Less common in adults

- Easy bruising of the skin
- Ulcerations and/or swelling of mouth and tongue
- Miscarriages and infertility
- Low calcium levels with muscle spasms
- B12, A, D, E and K vitamin deficiency
- Skin rashes such as dermatitis herpetiformis
- Dental defects
- Altered mental alertness
- Bone and joint pains

Common in children

Onset of symptoms can occur at any age after the introduction of gluten.

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

Problems with diagnosis

Since other conditions can closely mimic coeliac disease, the correct diagnosis can only be made by showing that the bowel lining is definitely damaged. If coeliac disease is suspected, a gluten free diet should not be started, as it will interfere with establishing the correct diagnosis and may delay the diagnosis of another condition with similar symptoms. Trialing of a gluten free diet does not provide a diagnosis of coeliac disease and subsequent investigations whilst on a gluten free diet will render false negatives. This includes both the serological testing (blood tests) and the biopsy test. It is important to discuss the possibility of coeliac disease with a doctor, if anyone has a close relative with the condition or if they have been treated for anaemia on previous occasions.

Diagnosis

Diagnosis relies upon proving that the small bowel lining shows the typical abnormality (damage) of coeliac disease (villous atrophy). This can only be done by carrying out a small bowel biopsy test (endoscopy), where a special optic fibre instrument is passed through the mouth with direct viewing of progress by the doctor, who is able to pass a small biopsy forcep through the instrument when it reaches the small bowel. This allows tiny pieces of bowel lining to be removed for microscopic examination. As a biopsy test is essential for proper diagnosis, referral to either an adult or child specialist gastroenterologist will usually be necessary.

A specific panel of blood tests that measures antibodies to gluten is available as a screening aid in

the diagnosis of coeliac disease. These tests will provide a simple and rapid means to help a doctor decide which family members should have biopsies and may also help reduce the incidence of delayed diagnosis.

The possibility of coeliac disease in other members of the family should be considered. Suspicious symptoms or signs in any close family member warrant a blood screening test. For both children and adults, the diagnosis of coeliac disease should be confirmed by repeating the small bowel biopsy 6 to 12 months after starting the gluten free diet. This is particularly important in young children because other causes of bowel lining damage similar to coeliac disease are possible.

What are the long term risks of undiagnosed Coeliac disease?

Chronic poor health, osteoporosis due to calcium malabsorption, infertility, miscarriages, depression, dental enamel defects and an increased risk of gastrointestinal and oesophageal carcinoma. In fact it has been stated that undiagnosed coeliac disease can affect any organ or system of the body.

In children, undiagnosed coeliac disease can cause lack of proper development, short stature and behavioural 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 all abnormalities, including that of the bowel lining, to recover completely.

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 replace current deficiencies of nutrients (eg. iron, folic acid and the fat-soluble vitamins A, D, E and K). 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. In a few people, a low lactose diet is required for a longer period of time.

Notes about the gluten free diet

Grains containing gluten - a rubbery and elastic protein - are used as ingredients in bread, cakes, pasta etc and many types of prepared and commercial foods. Although the gluten free diet will not be difficult to manage, expert assistance and advice are needed initially. Any person beginning a gluten free diet is strongly advised to do so under the guidance of accredited practising dietitians who can give assistance with advice to suit individual needs. There are many obvious foods which contain gluten, but there are also a whole range of ingredients which can come from a gluten source. To become 'ingredient aware' is essential.

If you are not sure of the gluten content of any food, use the general rule - when in doubt, leave it out. Information about gluten free diets can be obtained from:

- The Coeliac Society of Australia - contact your state society
- Accredited practising dietitians (your doctor can give a referral)

Labelling of gluten free foods

The Australian Foods Standards Code requires that:

- Food labelled as 'gluten free' must not contain any detectable gluten and no oats or malt
- Food labelled as 'low gluten' must contain less than 0.02% gluten
- The gluten content must be added to the nutrition information panel of a food labelled gluten free or low gluten.

The Australian Foods Standards require that ingredients derived from gluten containing grains must always be declared on food labels.

This requirement is part of a food standard relating to Mandatory Labelling of Food Likely to Cause Adverse Reactions (including gluten).

The Coeliac Societies in Australia

Adult coeliacs, parents of coeliac children and those with dermatitis herpetiformis have formed coeliac societies in all Australian states. These societies provide support and information on the disease, the gluten free diet, ingredients, where to buy, cooking and recipes, overseas travel, educational material etc. If you would like to become a member or would like more information, please contact your state society.

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