

What is coeliac disease?



Diagnosis

Currently diagnosis relies upon proving that the small bowel lining shows the typical abnormality (damage) of coeliac disease. This can only be done by carrying out a small bowel biopsy test (through an endoscope), where a special flexible camera tube is passed through the mouth with direct viewing of progress by the doctor, who is able to pass a small biopsy forceps through the instrument to reach the upper small bowel. This allows a tiny piece of bowel lining to be removed for microscopic examination. Since a biopsy test is essential for proper diagnosis, referral to either an adult or child specialist gastroenterologist will be necessary. A specific panel of blood tests that measures antibodies to gluten are available as screening tests to help in the diagnosis of coeliac disease. These tests also give doctors a simple and rapid means to help decide which members of an affected family should have biopsies. These tests may also help to reduce the incidence of delayed diagnosis.

Testing for the common genetic marker may be helpful in deciding whether or not someone is at risk of coeliac disease, but it cannot be used to diagnose coeliac disease itself.

Two approaches to diagnosis are being evaluated internationally, which may mean that a biopsy is not required in all people. At present, however, these approaches are not applicable to the New Zealand situation.

What are the long-term risks of undiagnosed coeliac disease?

Iron deficiency, poor health, osteoporosis due to calcium malabsorption, infertility, miscarriages, depression, dental enamel defects and an increased risk of gastrointestinal and oesophageal carcinoma. 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 the condition will not return. At the start of treatment it may be necessary to correct any vitamin deficiencies (e.g. iron, folic acid and the fat-soluble vitamins A, E and K). Sometimes people require a few weeks of a lactose-free diet, there may be reduced amounts of enzyme that splits or digests the lactose sugar. As the bowel lining recovers, the amount of the lactase enzyme builds back up again. During this recovery period, if ordinary milks cause symptoms, then lactose free milks or soy milks may be required.

A small bowel biopsy may need repeating 6 to 12 months after starting a gluten free diet. This may be particularly important in very young children because other causes of damage of the bowel lining similar to coeliac disease can be present. In some people, where absolute certainty

of the diagnosis is required, a small amount of gluten is returned to the diet for a defined period (this is called a 'gluten challenge'). After a gluten challenge the small bowel biopsy would be repeated to confirm that this leads to return of the damage. Proof of the disease by a 'gluten challenge' biopsy removes all doubts about the absolute necessity of a lifelong gluten free diet.

Notes about the gluten free diet

Gluten – a rubbery and elastic protein – is found in wheat, barley, rye and oats. Gluten is used in cooking and baking as well as many types of prepared and commercial foods. There are many obvious foods which contain gluten but there are also a whole range of ingredients which can be sources of undisclosed gluten. To become 'ingredient aware' and learning to read food labels is essential.

Expert assistance and advice are absolutely essential initially when commencing a gluten free diet. We recommend you seek advice from a registered dietitian with experience in coeliac disease to help you with your gluten free diet (your doctor can give you a referral).

With the information and support available with membership to Coeliac New Zealand, the journey can be much easier. Coeliac New Zealand also promotes and educates and works with gluten free manufacturers, medical professionals and supports research.

Check out our website for more information or to become a member at www.coeliac.org.nz

Health professionals, food manufacturers, restaurants and caterers are also welcome to join as professional members.

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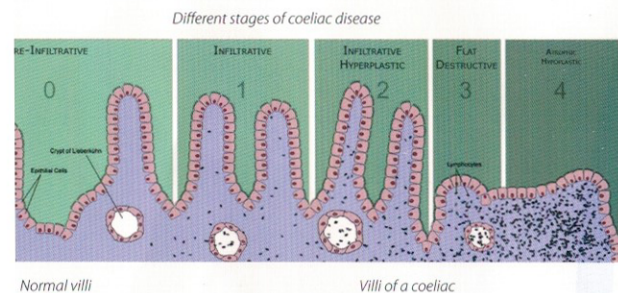
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Coeliac New Zealand Incorporated

Information about coeliac disease

Coeliac disease, (pronounced see-lee-ak) sometimes called coeliac or gluten enteropathy, is a medical condition. This is a permanent intolerance to dietary gluten. In coeliac disease the lining cells of the small bowel (intestine) are damaged and inflamed. This causes a flattening of the tiny, finger like projections, called villi, which line the inner surface of the bowel. The function of the normal villi is to breakdown and absorb nutrients in food. When these villi become flat in coeliac disease, the surface area of the bowel is greatly decreased, which interferes with the absorption of nutrients and minerals from food. This may lead to deficiencies in vitamins, iron, folic acid and calcium. Sugars (such as fructose), proteins and fats are sometimes poorly absorbed as well.



What is the cause?

Coeliac disease is triggered by gluten, the protein portion of a number of grains (e.g. wheat, rye, barley, triticale, and oats). In people with the right combination of genes, the initial response to the undigestible part of the gluten proteins leads to a series of reactions in the surface of the bowel. The immune response is driven by various immune cells: the products of this response then lead on damage to the lining of the small bowel, which changes to the number and shape of the villi. As a result, there is a decrease in the surface area available to absorb nutrients from foods. Genetic factors are very important in the development of coeliac disease. Almost everyone with coeliac disease has a particular genetic marker present called HLA-DQ2/8. Environmental factors, such as intercurrent infections, may also be important in the onset of coeliac disease: these lead to the bowel wall being more leaky thereby increasing the chance of the cereal proteins getting into the bowel.

Is coeliac disease familial?

Approximately 10 per cent of all first degree relatives (parents, brothers, sisters or children) of known coeliacs also have the disease. If one identical twin is affected, the other twin is virtually certain to be affected also (not necessarily at the same time). So coeliac disease certainly occurs in families and has a large genetic component.

How common is the condition?

Coeliac disease is a relatively common condition with around 1 in every 100 people in NZ having coeliac disease. There are no firm statistics but it is likely that thousands of New Zealanders have coeliac disease. Because of increasing recognition of new clinical patterns of presentation, the true prevalence is probably much higher than supposed. In the past, coeliac disease was sometimes regarded as only a childhood condition which produced symptoms in very young children when gluten was introduced into their diet. At present, a large proportion of newly diagnosed coeliacs are diagnosed as adults. Many have few or no problems during childhood but develop symptoms only when adults. In addition the symptoms of coeliac disease can be minor or atypical and can even be completely silent.

Can coeliac disease be cured?

Coeliacs remain intolerant 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 still being ingested. However, after removal of gluten from their diet, children and most adults return to normal health. Older patients may take longer to recover. Coeliacs will remain healthy as long as they adhere to a gluten free diet.

How is the condition recognised?

Some people inherit a predisposition at birth and may develop coeliac disease at a later stage in life. It is possible to have a normal bowel biopsy and then to later develop the typical abnormal biopsy. While damage to the bowel lining occurs when gluten is eaten, the effect on different coeliacs varies markedly making diagnosis very difficult. Some infants become rapidly and severely ill. Other children develop problems slowly over several years. Many coeliacs have few or no apparent problems during childhood, developing symptoms only during adult life. Family studies suggest many coeliacs in the community remain completely undetected.

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. 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 thorough check-up.

Symptoms

There are no specific symptoms of coeliac disease. Listed below are some of the symptoms which may occur alone or in combination.

Common in Adults:

- Diarrhoea – This may begin at any age and is often present for

years prior to diagnosis. It may first appear after other illnesses (eg gastroenteritis) or abdominal operations.

- Fatigue, weakness and lethargy
- Anaemia – iron or folic acid deficiency are the most common. The anaemia will either not respond to treatment or will recur after treatment until the correct diagnosis is made and a gluten free diet is begun.
- Weight loss
- Constipation – some people are more likely to experience constipation rather than diarrhoea
- Flatulence and abdominal distension
- Cramping and bloating
- Nausea and vomiting

Common in Children:

Symptoms do not occur until gluten is introduced into an infant diet – later onset is also possible.

- Large, bulky, foul stools
- Diarrhoea or constipation
- Poor weight gain
- Weight loss in older children
- Chronic anaemia
- Poor height gains
- Abdominal distension, pain and flatulence
- Nausea and vomiting
- Irritability

Less Common in Adults:

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

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. Trialling of a gluten free diet does not provide a diagnosis of coeliac disease: this will make subsequent investigations much harder to interpret, as the results may be falsely negative. Therefore, the biopsy test should always be performed before starting a gluten free diet.