



COELIAC DISEASE

WHAT IS IT?

INFORMATION ABOUT COELIAC DISEASE:

Coeliac Disease, sometimes called Coeliac Sprue, is a medical condition and is a permanent intestinal intolerance to dietary gluten.

In Coeliac Disease the cells of the small bowl (intestine) are 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 Coeliac Disease, these cells become flat and inflamed and the surface area, which enables the absorption of nutrients and minerals from food, is seriously depleted. This leads to deficiencies in vitamins, iron, folic acid and calcium, because of poor absorption. Sugars, proteins and fats are often poorly absorbed as well.

WHAT IS THE CAUSE:

Coeliacs are sensitive to gluten (the protein portion of wheat, rye, barley, triticale and oats), which reacts with the small bowel lining. These cause damage and cause loss of effective absorption surface area of the villi or finger like projections. The exact reason for this sensitivity is not known. Some believe Coeliacs are born with an enzyme deficiency (not yet identified), which causes abnormal breakdown of gluten and accumulation of a toxic portion. Others think an abnormal immune body defence reaction to the "foreign" (non human) gluten is responsible.

IS COELIAC DISEASE FAMILIAL?

Around 10% 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 family groups and is probably genetic.

HOW COMMON IS THE CONDITION?

Coeliac Disease is relatively a common condition. There are no firm statistics but it is believed that thousands of Australians have Coeliac Disease, with people of Celtic origin most susceptible to the condition. 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 regarded as only a childhood conditions, which produced symptoms in very young children when gluten was introduced to 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.

CAN COELIAC DISEASE BE CURED?

Coeliacs 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. However, after the removal of gluten from their diet, children and most adults return to being perfectly normal. Older patients often take longer to recover. Coeliacs will remain normal as long as they adhere to the diet.

HOW IS THE CONDITION RECOGNISED?

The underlying abnormality is presumed to be present at birth, but recognisable problems cannot develop until gluten-containing solids are included in the infant's diet. While damage to the bowel lining occurs whenever 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.

SYMPTOMS

There are no specific symptoms of Coeliac Disease. Listed below are some of the symptoms, which may occur singularly or in combination.

Most 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 diet has begun. Weight loss.

Constipation - some are more likely to experience constipation rather than diarrhoea.

Flatulence and abdominal distension.

Cramping and bloating.

Nausea and vomiting

Less Common in Adults -

Easy bruising of the skin.

Ulcerations and/or swelling of the mouth and tongue.

Miscarriages or infertility.

Low blood calcium levels with muscle spasms.

B12, A,D,E and K vitamin deficiency.

Skin rashes such as dermatitis Herpetiformis.

Altered mental alertness.

Bone and joint pains.

Common in Children -

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

Large, bulky, foul stools.

Diarrhoea or constipation.

Poor weight gain.

Weight loss in older children.

Chronic anaemia.

Retarded growth.

Abdominal distension, pain and flatulence.

Nausea and vomiting.

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. Trialing of a gluten free diet does not provide a diagnosis of Coeliac Disease.

The biopsy test should always be performed BEFORE starting a gluten free diet.

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. 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 upper small bowel. Another procedure sometimes used is where a small capsule attached to a thin plastic tube is swallowed and allowed to pass into the upper small bowel (a low intensity x-ray machine checks the correct position). Gentle suction on the tube allows a tiny piece of bowel lining to be removed for testing. Since a biopsy test is essential for proper diagnosis, referral to either adult or child specialist gastroenterologist will usually be necessary.

Blood tests are available as a screening aid 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.

HOW IS THE CONDITION TREATED?

Coeliac Disease is treated by a lifelong gluten free diet. By specially 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 adhered to strictly, problems arising from the condition will 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). An initial few weeks on a gluten free diet which also has a low cow's milk content (to lower the lactose sugar intake) may be warranted. This will allow the bowel lining to recover and replace its normal quantity of the enzyme lactase, which splits or digests lactose sugar prior to absorption. In a small number of Coeliacs the enzyme lactase may slowly recover and the need for low or no cow's milk content in the diet may persist for some time.

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".

The small bowel biopsy will probably need repeating 3 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 more likely. In children, particularly, absolute certainty of the diagnosis requires proof that the recovered small bowel will redevelop damage when gluten is returned to the diet (this is called a "gluten challenge"). 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

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 only under the guidance of a qualified dietitian who can give assistance with advice to suit your individual needs.

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' 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:
Qualified Dietitians (your doctor can give you a referral)
The Coeliac Society of Australia - contact your State Branch.

LABELLING OF GLUTEN FREE FOODS

Changes to the Australian Food Standards Code require that from early 1995:

Foods labelled as 'gluten free' must not contain any detectable gluten.

Foods labelled as 'low gluten' must not contain more than 0.2% gluten (The Coeliac Society does not recommend this category)

A panel providing nutrition information is required if a food is described as being gluten free or low gluten.

THE COELIAC SOCIETY

Adult Coeliacs, parents of Coeliac children and those with Dermatitis Herpetiformis have formed Coeliac Societies in all Australian States. These Societies provide information on the disease, the gluten free diet, ingredients, where to buy, cooking and recipes, overseas travel, medicines which are gluten free, educational material etc. If you would like to become a member or would like more information, please contact your State Society:

more info see <http://www.coeliac.org.au>

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South Australia
106A Hampstead Rd
Broadview 5083
088 266 3899
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Western Australia
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09 310 5371
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TASMANIA
Contact Victoria

Northern Territory
Contact South Aust

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