

Information for the Media

Medical Information

- Coeliac disease (pronounced see-lee-yak) is a lifelong condition causing people to react to gluten, the protein found in wheat, barley, rye and oats.
- Eating gluten damages the lining of the small intestine reducing the coeliac's ability to absorb nutrients.
- The incidence of Coeliac Disease in Ireland is estimated as approximately 1% of the population, many as yet undiagnosed.
- Most common symptoms are diarrhoea and weight loss but there is a wide range of other symptoms including bloating, anaemia and chronic fatigue.
- Diagnosis requires a blood test followed by biopsy of small intestine while on a gluten containing diet.
- Undiagnosed and untreated coeliacs face increased risk of cancer and osteoporosis. Children face growth retardation.
- The only treatment is a strict gluten-free diet for life.

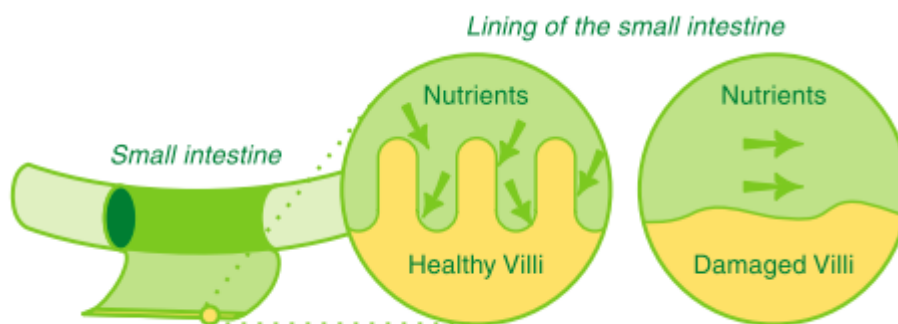
Gluten

Gluten is a general term used for a type of protein called prolamin. Prolamins are found in wheat (gliadin), rye (secalin), barley (hordein) and oats (avenin).

Damage to the Small Intestine

The small intestine is made up of the duodenum, then the jejunum, and then the ileum. In the small intestine there are small finger-like structures called villi. The villi create a large surface area, which absorbs the energy and nutrients from the food.

When the villi are damaged (villous atrophy) the body is unable to absorb energy or nutrients because there is insufficient surface area. This leads to various symptoms caused by the disruption to the digestive system and other symptoms caused by poor absorption.



Symptoms

Symptoms vary from person to person and may be constant or only occur from time to time with varying severity. Coeliacs can experience one or more of these problems:

- diarrhoea
- constipation
- weight loss
- chronic tiredness
- anaemia
- failure to thrive in children
- chronic mouth ulcers
- stomach pain and bloating
- indigestion
- bone pain
- moodiness or depression
- an itchy skin rash called dermatitis herpetiformis

Many coeliacs go undiagnosed because many GPs are unaware of the range of symptoms.

Diagnosis

First step is a blood test for antibodies (IgA tTGA & IgA EMA). If results show raised tTG or positive EMA then patient is referred to a consultant gastroenterologist for a biopsy.

The biopsy procedure is called an upper gastro-intestinal endoscopy or oesophagoduodenoscopy, (OGD). A gastroscope (a small tube) is passed through the mouth and down into the small intestine. A very small piece of tissue is taken from the wall of the intestine. The tissue is examined under a microscope to check for damage to the villi.

Complications

Ongoing inflammation and damage to the gut increases the need for continuing tissue repair, which substantially increases the risk of a cancer called lymphoma of the small intestine. This risk is reduced to normal levels when the Coeliac remains on a gluten-free diet for life.

Calcium is essential for bone maintenance and people with untreated coeliac disease do not absorb enough calcium because of the damage coeliac disease causes to the small intestine. This puts coeliacs at risk of osteoporosis.

Untreated children cannot absorb sufficient nutrients and energy because of the damage coeliac disease causes to the small intestine. This causes growth retardation.

Lifestyle Implications

- Coeliacs must take great care choosing food. They must learn all about ingredients and food labelling. The Coeliac Society of Ireland produces a Food List for members to help them choose food successfully.
- There is a lack of awareness in the food service industry and a risk of cross-contamination when eating out.
- Expense and lack of financial relief.

Choosing Food

The society produces a Food List to help coeliacs choose food. It is a comprehensive list of suitable manufactured products on sale in Ireland and many members refer to it as their 'Coeliac Bible'. Monthly updates are provided to accommodate changes to the Food List.

Coeliacs must learn all about ingredients:

- Gluten is in bread, biscuits, cakes, pasta, beer, pizza and communion hosts.
- Many manufactured foods may contain gluten such as sausages, burgers, soups, sauces, salad dressings, crisps, chocolate, sweets and ready meals.
- Gluten is in beer and other drinks that are brewed.
- There are categories of food that are naturally gluten-free such as fresh meat, fresh fish, fresh fruit and vegetables and rice.

And labelling:

- The EU Allergen Directive stipulates that all deliberate ingredients containing allergens (including gluten) must be declared on the label. This does not take into account the gluten cross-contamination that can happen on production lines. All the products in the Food List have been investigated with respect to cross-contamination to be considered gluten-free for inclusion.
- The Codex Standard stipulates that a product must have less than 20mg of gluten per Kg to be labelled 'gluten-free' that can be tolerated by all coeliacs and between 20 and up to 100mg gluten/kg to be labelled 'very low gluten' which can be tolerated by most coeliacs.

Eating Out

Some restaurants feature gluten-free items on their menu, however cross-contamination is always a concern for coeliacs. The society is working with the Food Safety Authority of Ireland on raising awareness on providing safe food for coeliacs. The society advises the food service industry on the preparation, storage and labelling of gluten-free food to encourage more establishments to cater for coeliacs. The society produces a Gluten-Free Catering Booklet, which lists suitable ingredients and products available in catering sizes. It is available free of charge to the food industry.

The society keeps a list of places where members have enjoyed their experience called the Coeliac Friendly Restaurant List, which is available to members. The Coeliac Society has not vetted the restaurants listed and no responsibility can be assumed by the society for dishes incorrectly served as gluten-free.

Expense and Relief

Gluten-free bread is about five* times the price of normal bread, weight for weight. Gluten-free pasta, cakes and biscuits are also more expensive. Coeliacs can claim Tax Relief on their gluten-free products as medical expenses.

Some products can be prescribed by a doctor and coeliacs can take advantage of the Drug Payment Scheme where anything spent on prescribed goods over €120 per month is free, or use their Medical Card if they are eligible. These products come from the General Medical Services scheme (GMS List) and members have reported difficulties in getting what they are entitled to, either from reluctance on the GP's part to prescribe many items, or because the pharmacy is unable or unwilling to order in the foods.

There is also a payment called the Diet Supplementary Allowance, which is available to those on social welfare who may have difficulty affording the diet. This is means tested.

In Italy the government allows €200 a month for women and €100 for men who have diagnosed coeliac disease for the purchase of gluten-free food items. Many other European countries have similar allowances in recognition of the difficulties and expenses faced by coeliacs.

*Genius Gluten-Free bread at €4.49 for 400g compared with Brennans Wholemeal loaf at €1.78 for 800g

The Coeliac Society of Ireland

- Established in 1970.
- Our mission is to improve the quality of life for Coeliacs and those who benefit from a gluten-free diet.
- Managed nationally by voluntary Management Committee with local support provided by voluntary branches and support groups.
- Funded mostly by membership and with grants from the HSE.
- Annual membership to the society costs €25.

We aim to improve the quality of life for Coeliacs and those who benefit from a gluten-free diet by providing:

- Information on coeliac disease and dermatitis herpetiformis, gluten-free food and the gluten-free lifestyle useful to:
 - the general public.
 - health professionals.
 - manufacturers, caterers and retailers.
- Opportunities for members to meet and to share experiences.
- A campaigning voice for coeliacs to the government, health professionals, the food and hospitality industry and the general public.



The society delivers various products: 'Coeliac Ireland' (twice yearly magazine), CN Online (monthly email bulletin), The Coeliac Friendly Restaurant List, Eating Out Cards (credit card sized cards in different languages to explain needs to restaurants), The Coeliac Handbook, Information booklets, Cookbook, The Food List (suitable manufactured products) and the Gluten-Free Catering List (suitable manufactured products in catering sizes) and website which includes an active forum.

A national event is held every year at varying locations around the country. Branches organize meetings and events such as Christmas lunches and cookery demonstrations.