



## Living with Coeliac Disease

Information & Support is key

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Chairperson Coeliac Society of Ireland

### What is Coeliac Disease?

#### Fact Not Fad



- Auto immune disease - the body produces antibodies that attack its own tissue.
- Children & adults react to gluten a protein found in wheat, barley and rye
- The lining of the small intestine becomes damaged, reducing the ability to absorb nutrients from food
- It is under-diagnosed in Ireland, as in other countries (estimates vary)
- Close to 1% of the population are estimated to be Coeliac (46,000)
- Non coeliac gluten intolerance affects up to 7% of the population / 322,000 people
- It is not solely an Irish disease
- At last 15% of people with "IBS" may be coeliac
- You don't have to be underweight to have coeliac disease

## Living With Coeliac Disease



### My Experience

- Borderline anaemia throughout my childhood
- Bouts of severe abdominal pain, bloating
- Tummy rumbling
- Chronic bouts of diarrhoea
- Weight loss
- Fatigue

Hypothyroidism diagnosed 1988

Diagnosed in 1993 with Coeliac Disease

## Living with Coeliac Disease



### Options?

Joined the Coeliac Society – my lifeline

- Food list – only comprehensive guide of certified GF products
- Newsletter
- Coeliac Handbook

Pestered other coeliacs

Educated my family (Husband + Children) + rest of family



## Coeliac Volunteer



20 + years as active member of Coeliac Society

Assisted with reform of the Cork Branch 1994 – currently  
Chairperson

Currently helping to set up the West Cork Support Group

### National Level – Board of Directors

- Positions of Secretary, Vice Chair and currently Chair

## Volunteer Founded – 45 Years Experience



### Mission

To improve the quality of life for people  
with Coeliacs and others who benefit  
from a gluten free diet for Medical  
reasons

- Information on coeliac disease and dermatitis herpetiformis
- Information on gluten-free food – annually updated GF Food List
- Information on the gluten-free lifestyle
- 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.
- Branches & Support Groups throughout the country are central to the work of the Society
- Society now has seven paid staff, plus CE staff & volunteers

## Associated Conditions & Health Complications



### Associated conditions

- Diabetes (Type 1)
- Thyroid disease
- Lactose intolerance
- Higher risk of coronary artery disease

**Untreated Coeliac Disease** can cause a range of symptoms and future health risks

1. Osteoporosis/porous bones
  - People with undiagnosed or untreated coeliac disease do not absorb sufficient calcium
2. Infertility and frequent miscarriage
3. Cancer
  - On going inflammation and damage to the gut from ingesting gluten increases the need for continuing tissue repair which substantially increases the risk of lymphoma of the small intestine.

## Steps to diagnosis



GP can check bloods for IgA antibodies against tissue transglutaminase (tTG), endomysial antigen (EmA) or deaminated gliadin peptide (DGP).

Referral to a Consultant Gastroenterologist

Biopsy is the

**Gold Standard**

for diagnosis

### Monitoring post diagnosis

- Bone DEXA Scan
- Dietitian
- Monitored post diagnosis by means of Blood tests
- Is there a need for repeat biopsy?

## Treatment of Coeliac Disease



- *Strict Gluten-Free Diet for Life*
- We do not grow out of it – *It is permanent*
- No “*mild*” version though some people are less symptomatic than others
  - extent of immune reaction does not always match nature or severity of symptoms
  - organ damage can occur without symptoms!
- No medication can substitute for the gluten-free diet in treating coeliac disease.
- *There is no pill*

## Gluten Free – not just a problem with wheat



Gluten can be found in anything that's been processed or manufactured

Avoid wheat, barley, oats (unless GF Oats), rye, **spelt**, malt and any derivatives

A little bit will hurt – Cross Contamination issues

Food labelling legislation makes it easier to identify gluten in foods

Manufacturers change processes and ingredients which requires constant checking of labels and use the Society's GF Food List as a guide

Different pack sizes of same product can be produced in different factories with different contamination risks

## Labelling Legislation



### Codex Standard for 'Gluten Free' Labelling 1<sup>st</sup> December 2012

Foods that contain < 20 ppm = labelled gluten free  
Offers better protection for coeliacs

Foods that contain >20 ppm but < 100 ppm = labelled very low gluten

Labelling such as 'does not contain gluten', 'free from gluten', 'may contain gluten' does not comply with legislation and cannot be accepted as suitable for coeliacs.

From December 2014 Allergen labelling information now has to be provided for non-pre-packed foods including those sold in restaurants and cafes.

Definition of ppm = mg  
gluten/kg

## Access to Dietetic Services



**BSG(2014) guidelines outlines that after initial medical consultation, a dietetic consultation is essential**

### Does this happen in Ireland?

- Hospital after diagnosis?
- Follow up visit with Dietician post introduction of GF Diet?
- Non compliance, Difficulties with diet?
- Designated Dietetic Clinics in Hospitals?
  
- 150 (32%) Primary Care Teams do not have access to a 1:1 Dietetic Service
- 226 (49%) PCT's have limited services < ½ or 1 day/week, priority patients seen, resultant waiting list of 2 years.
- Currently 1 Community Dietitian to 54,000 population

### Result

- Many newly diagnosed coeliacs do not receive Dietetic consultation

## Membership Feedback



- Support service available from a health professional for management of disease – 46.5% rated as poor
- Frequency of consulting a health professional: 55.39% annually; 36.24% never
- Dietetic Services: 58.54% saw Dietitian when diagnosed but not since, 30.73% had never seen a Dietitian
- Length of time to gain a positive diagnosis: > 10 years 10.77%, > 5 years 12.31%, > 1 year 15.90%
- Misdiagnosis: 41.62% prior to receiving a confirmed diagnosis
- Hospitalisation of children: 28.21% had been hospitalised, 15.25% more than once
- Financial pressure: 32.85% cited a severe impact in their ability to choose gluten free options

Source: 3.7 % response rate from email membership database of 5,500. No information available from DOH. There is no coeliac disease register available in Ireland.

## Living with Coeliac Disease



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Registered Charity Number: 7484

**Improving Quality of Life for Coeliacs**

## Questions & Answers

