



Coeliac disease: the patient perspective

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Introduction

- About Coeliac UK
- What is coeliac disease?
- What is gluten?
- Reaction to eating gluten
- The treatment – the gluten-free diet
- Issues faced by people with coeliac disease



About Coeliac UK

- National charity for people with coeliac disease in the UK
- Part of AO ECS – Association of European Coeliac Societies – 29 countries
- Provide information via newsletters, website, magazines, Local Voluntary Support Groups, support for parents
- 65,000+ Membership
- Aims are:
 - Support
 - Campaigns
 - Research



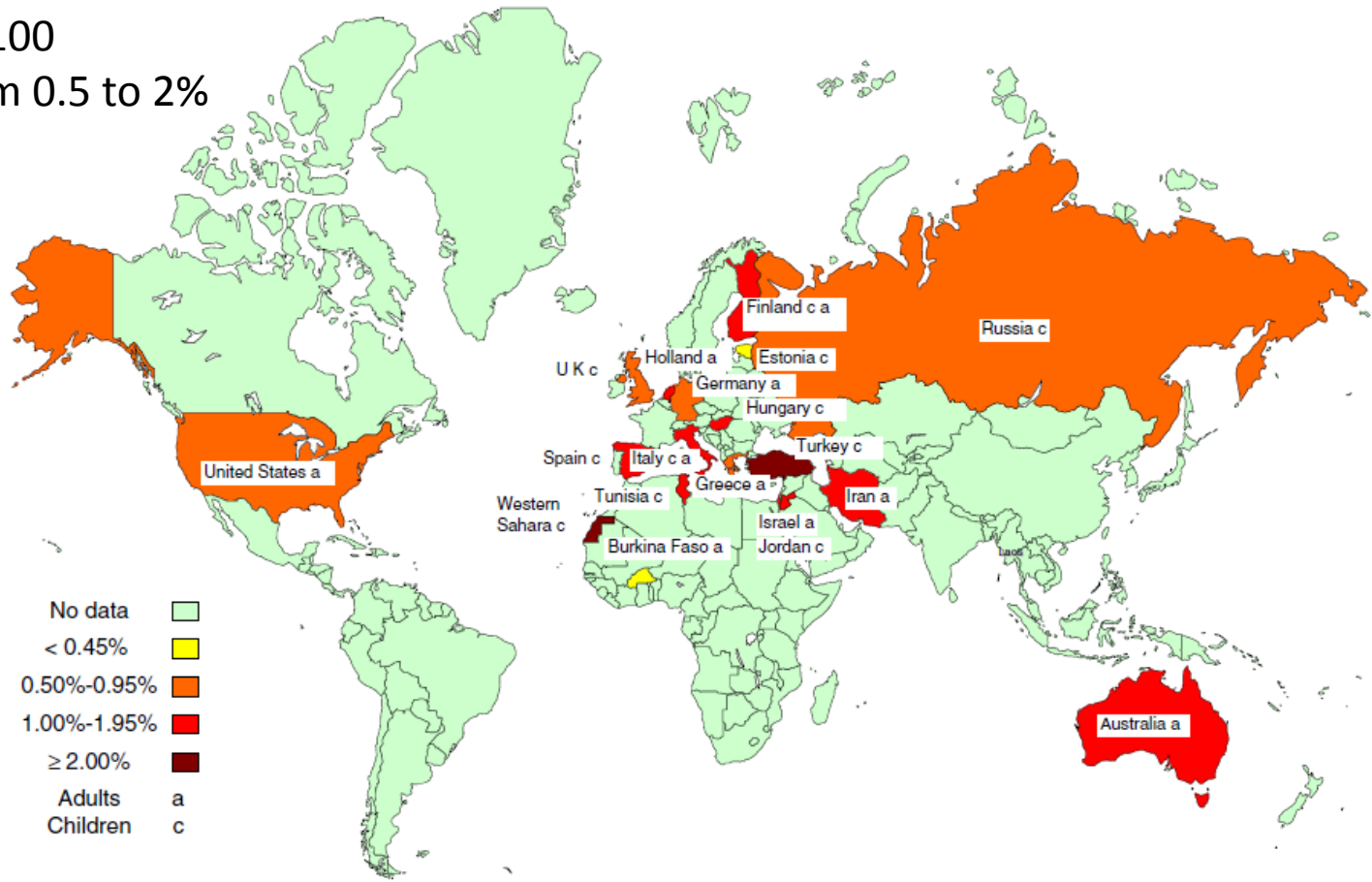
Coeliac disease

- Autoimmune disease, triggered by eating gluten in genetically predisposed individuals
- Symptoms vary, common ones include diarrhoea, constipation, mouth ulcers, anaemia, tiredness, abdominal pain, bloating
- Affects 1 in 100
- More common in 1st degree relatives
- Diagnosis rates low but improving



Prevalence of coeliac disease

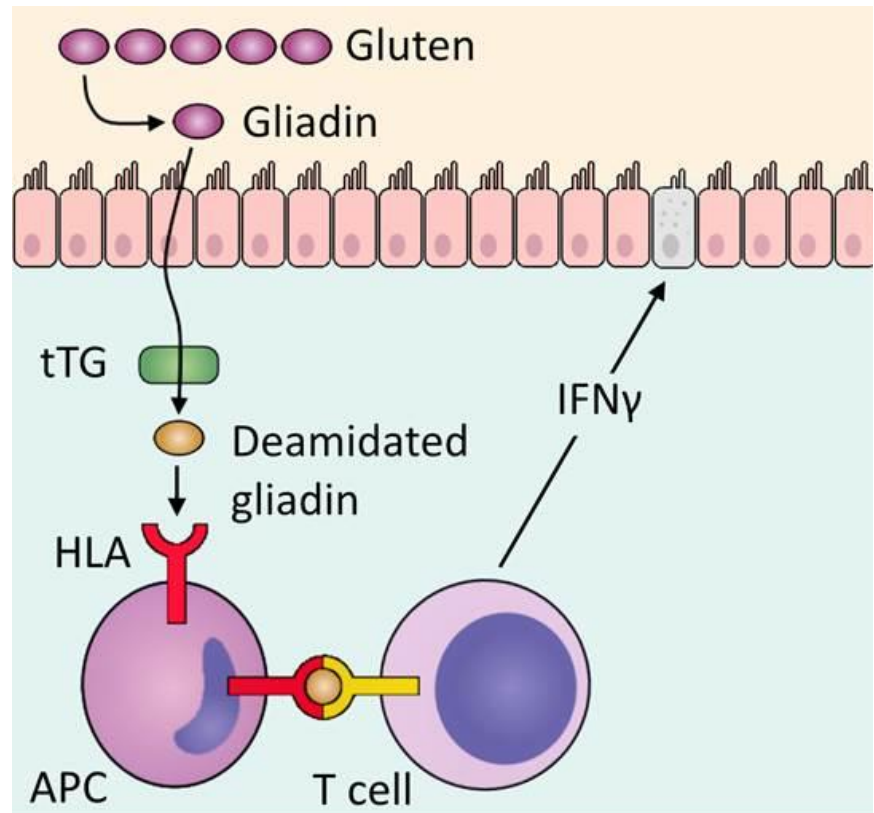
- UK – 1 in 100
- Varies from 0.5 to 2% in Europe



Kang et al. 2013

What happens in coeliac disease?

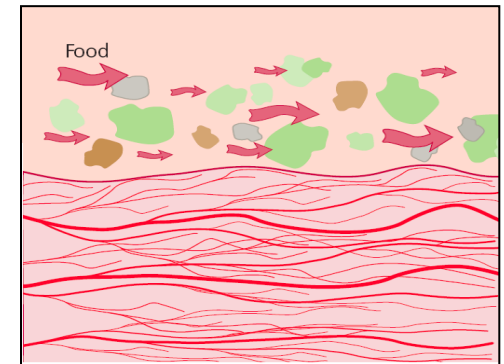
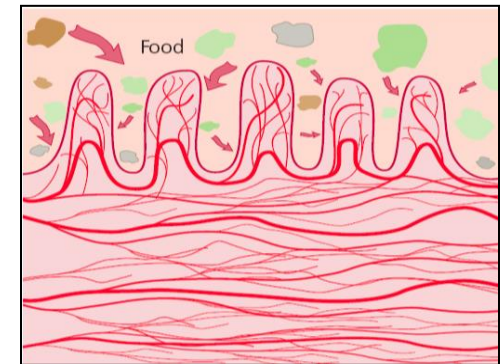
- Eating gluten damages the gut in genetically susceptible people
- Triggers immune system leading to gut damage



Ref: University College Dublin

Damaged gut lining

- Villous atrophy, loss of surface area for absorption, leads to malabsorption
- If untreated, can lead to a range of nutritional deficiencies (eg anaemia)
- And more serious complications like osteoporosis and small bowel cancer
- In untreated CD up to 70% have evidence of reduced bone mineral density (BMD)



Treatment

- Gluten-free diet is the complete treatment for coeliac disease
- Improves symptoms, quality of life
- Helps to treat complications and nutritional deficiencies
- Minimises the risk of complications including osteoporosis and malignancy – after 5 years on gluten-free diet
- Provision of a balanced nutritional intake



Gluten

- Storage protein found in wheat, rye and barley – made up of glutenin and gliadin
- Similar protein in oats, avenin
- Common foods that contain gluten include bread, pasta, pastry, biscuits, crackers, cakes
- Also found in not such obvious places – sausages, cooking sauces, soya sauce, ready meals



The gluten-free diet

- Naturally gluten-free foods – fruit, veg, meat, poultry, fish, pulses, rice, eggs, milk, cheese
- ‘Mainstream’ foods made from no gluten-containing ingredients
- Gluten-free staples – pasta, bread, crackers, biscuits, cakes
- Commonly made from:
 - Corn, rice, potato, soya
 - Also buckwheat, millet, sorghum, quinoa

Gluten-free labelling


■ Codex standard 200 ppm

- Discussed since 1980s
- 200 ppm not safe for all
- Revised in 2008
- New limits set at 20 ppm, suitable for all
- Greater safety for people with CD

■ Gluten-free – EC41/2009 introduced in Jan 2009

- 20 ppm
- Suitable for all with coeliac disease
- Unlimited amounts



21.12.2009  Official Journal of the European Union

COMMISSION REGULATION (EC) No 41/2009
of 20 January 2009
concerning the composition and labelling of foodstuffs suitable for people intolerant to gluten
(Text with EEA relevance)

THE COMMISSION OF THE EUROPEAN COMMUNITIES,

Having regard to the Treaty establishing the European Community,

Having regard to Council Directive 89/393/EEC of 3 May 1989 on the approximation of the laws of the Member States relating to foodstuffs intended for particular nutritional uses⁽¹⁾, and in particular Article 2(4) and Article 4 thereof,

Whereas

(1) Directive 89/393/EEC concerns foodstuffs intended for particular nutritional uses which owing to their special composition or manufacturing process are intended to satisfy the particular nutritional requirements of specific categories of the population. People with coeliac disease are such a specific group of the population suffering from a permanent intolerance to gluten.

(2) The food industry has developed a range of products presented as 'gluten-free' or similar equivalent terms. Differences between national provisions concerning the conditions for the use of such product descriptions may impede the free movement of the concerned products and may fail to ensure the same high level of protection for consumers. In the case of dairy and in order to avoid confusing consumers with different types of product descriptions at national level, the conditions for the use of the terms related to the absence of gluten should be laid down at Community level.

(3) Wheat, rice, all Triticum species, such as durum wheat, spelt, and kamut, rye and barley, have been identified as grains that are scientifically reported to contain gluten. The gluten present in these grains can cause adverse health effects to persons intolerant to gluten and therefore should be avoided by them.

(4) The removal of gluten from gluten-containing grain products constitutes technical difficulties and economic constraints and therefore, the manufacture of totally gluten-free food is difficult. Consequently, many foodstuffs for this particular nutritional use on the market may contain low residual amounts of gluten.

(5) Most but not all people with intolerance to gluten can tolerate only a limited amount of gluten in their diet without adverse effects on their health. This is an issue of ongoing study and investigation by the scientific community. However, a major concern is the combination of oats with wheat, rye or barley that can occur during grain harvesting, transport, storage and processing. Therefore, the risk of gluten contamination in products containing oats should be taken into consideration with regard to labelling of these products.

(6) Different people with intolerance to gluten may tolerate variable small amounts of gluten within a restricted range. In order to enable individuals to feed on the market a variety of foodstuffs appropriate for their needs and for their level of sensitivity, a choice of products should be possible, with different low levels of gluten within such a restricted range. It is important, however, that the different products should be properly labelled in order to ensure the correct use of these products by people intolerant to gluten with the support of information campaigns fostered in the Member States.

(7) Foodstuffs for particular nutritional uses which have been specially formulated, processed or prepared to meet the dietary needs of people intolerant to gluten and marketed as such should be labelled either as 'very low gluten' or 'gluten-free' in accordance with the provisions laid down in this Regulation. These provisions can be selected by the use of foodstuffs which have been specially processed to reduce the gluten content of one or more gluten containing ingredients and/or foodstuffs where the gluten containing ingredients have been substituted by other ingredients naturally free of gluten.

(8) Article 2(4) of Directive 89/393/EEC provides for the possibility for foodstuffs for normal consumption which are suitable for a particular nutritional use to indicate such suitability. Therefore, it should be possible for a normal food which is suitable as part of a gluten-free diet because it does not contain ingredients derived from gluten containing grains or oats to bear terms indicating the absence of gluten. Directive 2004/39/EC of the European Parliament and of the Council of 20 March 2004 on the approximation of the laws of the Member

(1) OJ L 186, 30.6.1989, p. 27.

Allergen labelling legislation

- 2003/89/EC allergen labelling legislation
 - People could find out what was in a packaged food
 - Prior to this people with CD relied solely on the Coeliac UK Food and Drink Directory to choose foods
- 1169/2011 (EU FIC) Food Information for Consumers
 - Changes to allergen information, and in catering



Issues affecting people with coeliac disease

- Adherence to the GF diet varies:
 - 20-80% of people admitted to occasional or prolonged lapses
 - 42-91% range for strict adherence
- Factors affecting adherence to the diet:
 - Knowledge of the GF diet
 - Cost, access, and availability
 - Taste and texture of GF foods
 - Eating out of the home



Summary

- Coeliac disease is common, 1 in 100 people affected
- The GF diet is a complete treatment
- EU labelling laws have made it easier for people looking for GF foods
- People cope differently with the transition to a GF diet
- Many people are not yet diagnosed – current estimates in the UK show 24% diagnosed



Thank you or listening

Any questions?