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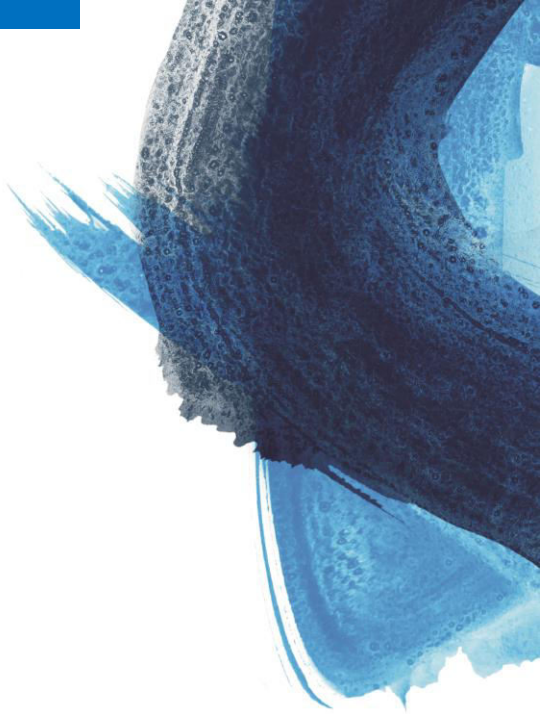

Coeliac Disease

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Coeliac Disease: Introduction

Coeliac Disease is a genetically mediated, chronic autoimmune condition, involving both innate and adaptive immune responses, where the ingestion of gluten, a protein found in wheat, barley and rye, activates an abnormal mucosal immune response within the small bowel, giving rise to malabsorption. Coeliac Disease is a common condition, affecting approximately 1% of the general population. Unfortunately, the condition remains under diagnosed, often referred to as the silent epidemic. The general consensus is that the people diagnosed, estimated to be in the region of 10-15% of all individuals with Coeliac Disease, represent only the tip of the iceberg[1-4].

Coeliac Disease may present at any age[5]. People with a higher risk of having Coeliac Disease include those with other autoimmune conditions such as type 1 diabetes, autoimmune thyroid disease or Downs Syndrome, and first degree relatives of a person with Coeliac Disease[1]. Genetic predisposition plays a key role in the development of Coeliac Disease, notably the specific human leukocyte antigen (HLA), known as HLA DQ2 and HLA DQ8. Approximately 95% of Coeliac patients carry HLA DQ2[6]. While, the cause of Coeliac Disease remains unclear[7], it is thought that a link between genetic and environmental practices, including infant feeding practices, gastrointestinal infections, drugs and surgeries could play a possible stressor role in the expression of this condition[6]. The prevalence of Coeliac Disease has increased in recent years[8]. It has been suggested that increased awareness, increased testing and also changing patterns of early childhood infections, known as the 'hygiene hypothesis', have each played a role[9].

Individuals newly diagnosed with Coeliac Disease can present with a wide variety of intestinal and extra intestinal symptoms, emphasising the need for robust diagnostic testing and appropriate work up[6]. It is recommended that individuals should be tested for Coeliac Disease if they present with the following symptoms: chronic and intermittent diarrhoea, persistent unexplained gastrointestinal symptoms, persistent fatigue, recurrent abdominal pains, cramping and abdominal distension, sudden or unexpected weight loss, unexplained iron deficiency anaemia or other unspecified anaemias, failure to thrive or faltering growth in children[1].

Coeliac Disease can be diagnosed by the presence of specific endomysial antibodies (EMA) and anti tissue transglutaminase (tTG) antibodies. However these antibodies are not confirmatory of a diagnosis of Coeliac Disease and must be followed up a by histopathological duodenal biopsy for the determination of mucosal damage[10]. It is recommended that IgA tTG is checked as first line in anyone suspected of having Coeliac Disease. This result should then be followed up by checking for the presence of IgA EMA antibodies in the event where a tTG result is equivocal. If IgA immunoglobulin deficiency is present, then a false negative result may be obtained. In this incidence, IgG tTG and IgE EMA levels should be checked. Positive serology results should then be followed by duodenal biopsy to

confirm diagnosis of Coeliac Disease from a patient taking a gluten containing diet[1]. HLA diagnosis may aid the diagnostic pathway through its high negative predictive value but is not routinely carried out[6].

My coeliac journey takes me back to Transition year, sitting in class after lunch with excruciating stomach pains and burning acid reflux. This invariably left me sprawled across my desk, adopting some form of position that would help to relieve the pain. There was a history of Coeliac Disease in my family, but with little or no knowledge at that time about the condition I continued on through my leaving cert years putting my ongoing weight loss and gastrointestinal upset down to 'exam stress'. It was towards the end of my first year at college that my GP began to suspect my symptoms could be something more and sent me to have an endoscope exam, where duodenal biopsies confirmed a diagnosis of Coeliac Disease. The treatment: a life-long strict gluten free diet. After receiving my diagnosis on a Friday I decided to have one final blow out of copious amounts of pasta, pizza and freshly baked bread that weekend and to commence the gluten free diet the following Monday. The general opinion from health care professionals that I encountered was that I would be fine – sure I was studying to be a Dietitian so I'd be grand, what more could you ask for!

Coeliac Disease: The Gluten Free Diet

Gluten is ubiquitous in the western diet and cereals containing gluten are used in many foods and manufacturing processes. Gluten is a functional protein component of wheat, rye and barley[11]. The toxic protein fractions of gluten include gliadins and glutenins[12].In Europe, the average consumption of gluten is estimated at 10-20g per day[13].

Adherence to a gluten free diet means that foods such as breads, cakes, biscuits, pastas, semolina, couscous and many processed foods that are either breaded or battered or that contain either wheat, rye or barley derivatives are to be avoided. Many fillers, binders, additives and stabilisers used in the manufacturing process can contain hidden sources of gluten. Despite this, it is important to remember that a lot of foods are available that are naturally gluten free. Suitable foods on a gluten free diet include potato, maize, rice, cornflour, tapioca, arrowroot, buckwheat, all plain meats, fish and poultry, fruits, vegetables, nuts and pulses and the many specially produced gluten free food products that are now commercially available.

The nutritional quality of gluten free foods that replace gluten containing cereal based foods is of pivotal importance for patients with Coeliac Disease. The gluten free diet is complex and individuals require comprehensive nutritional education and support from a registered Dietitian[14]. There is a general assumption made that a food product is healthy if it is gluten free, however there is an overall lack of data analysing the nutritional quality of gluten free foods and their gluten

containing counterparts. Comparative analyses, between cost and nutritional quality of gluten free products and their gluten containing counterparts, found that the gluten free diet offered no additional health benefits from a nutritional perspective and that following such a diet is significantly more costly, thus indicating that a gluten free diet should only be followed where there is a clear medical indication due to gluten intolerance[15,16].

Adherence to the gluten free diet primarily effects consumption of the grain food group. Some questions have been raised about the gluten free diet and its effect on B vitamin, iron and fibre intake[17]. Gluten free foods are frequently made using refined gluten free flours or starches and are not routinely fortified like many gluten containing counterparts. Many gluten free foods therefore do not contain the same levels of certain vitamins and minerals[18,19]. Within a population, grain foods contribute significantly to the intake of B vitamins, iron and fibre[20]. It is therefore recommended that gluten free products consumed should be of a wholegrain or fortified variety where possible[17].

Common nutritional deficiencies at diagnosis of Coeliac Disease include: calorie/protein, iron, fibre, calcium and vitamin D, magnesium, zinc and folate, vitamin B12, niacin and riboflavin. Malabsorption of iron, folate and calcium is common as these nutrients are absorbed in the proximal small bowel. Deficiencies of calcium, phosphate and vitamin D may occur due to malabsorption or decreased consumption of milk and dairy products secondary to lactose avoidance. Lactose avoidance may occur due to possible secondary or transient lactose intolerance that can be found in individuals with newly diagnosed Coeliac Disease[21]. Patients with Coeliac Disease suffering from transient lactose intolerance should be encouraged to consume gluten free/low lactose dairy sources and/or non dairy sources of calcium including calcium fortified juices and soy products[17]. Research has reported certain nutritional deficiencies in individuals established on a long term gluten free diet with low intakes of calcium, iron and fibre [21]. Use of appropriate gluten free nutritional supplements may need to be considered in some individuals[17]. Studies have found that most nutritional deficiencies will disappear following a strict gluten free diet. Once intestinal recovery has occurred adequate amounts of most nutrients can usually be obtained from a well balanced gluten free diet[22]. A large amount of naturally gluten free grains are nutrient dense, such as seeds and pulses, and these can give increased variety, palatability and nutrient quality to the gluten free diet[21].

Coeliac Disease: A Note About Oats

Cereal grains are taxonomically classified. The prolamine fraction of gluten is responsible for its toxicity. It has been suggested that patients with Coeliac Disease may be able to tolerate oats due to their lower prolamine content in comparison to wheat, barley and rye. Oats have a variety of pharmacological activities, including anti-inflammatory and anti-cholesterolaemic effects and

several countries permit the use of oats within a gluten free diet. In vitro studies have demonstrated that the immunogenicity of oats can vary depending on the cultivar used. While the inclusion of oats in the gluten free diet may improve overall nutritional value of the diet, their routine use in gluten free diet for individuals with Coeliac Disease remains controversial as studies have shown contradictory results regarding their toxicity. The source of oats consumed and the cultivar selected needs to be considered as it is suspected that a small minority of individuals with Coeliac Disease, estimated at approximately 5%, will react to pure oats[23,24].

A systematic review assessing the use of oats within a gluten free diet notes that while oats can be symptomatically tolerated by most individuals with Coeliac Disease, the long term effects of consuming oats within the gluten free diet remain unknown. Therefore it is advised that patients including oats within a gluten free diet receive regular follow up, including small bowel biopsy. It has been suggested that oats may exert a latent effect, with histological derangement noted after several years of consumption of oats[25].

The Coeliac Society of Ireland offers the following advice with regards to consuming pure oats within the gluten free diet: a) avoid gluten free and pure oats until antibody titres have returned to normal; b) do not use oats if you have raised tTGs; and, c) do not use oats during episodes of gastroenteritis. It notes that the decision to include oats as part of your gluten free diet should be taken under medical supervision and regular antibody monitoring[26]. Only certified gluten free or pure oats are recommended as part of the gluten free diet in order to reduce possible external toxicity or gluten cross contamination. On a personal level I have chosen to exclude gluten free and pure oats from my diet. While at times I do miss the added variety and palatability that oats certainly offer to the diet, I made this decision due to the lack of long term data on the inclusion of pure oats in the gluten free diet.

Coeliac Disease: Adherence to The Gluten Free Diet

A diagnosis of Coeliac Disease means that total compliance with a gluten free diet is necessary, including strict cross contamination precautions. Eight years on after my own diagnosis and I haven't looked back. Yes, there are days when I get fed up because I have come home from work and I don't have anything in the fridge to make my lunch for the next day or I'm just too tired to go and actually do it. My workplace unfortunately does not cater appropriately for people with Coeliac Disease. Yes, it is frustrating when you are told that your dietary requirement cannot be catered for. But at the end of the day, I have my diagnosis, I understand the importance of it and I feel one hundred times better for having had my diagnosis.

The ability to adhere to a gluten free diet can depend on many individual and environmental factors. Self reported rates of strict adherence to the gluten free diet in adults range from 36-96%[27]. The gluten free diet requires dedication, planning and time. It requires significant dietary and lifestyle changes that can have a significant impact on somebody's quality of life. Gluten free living can be restrictive, particularly if someone does not routinely cook meals from scratch and are reliant on processed foods, ready-made meals, sauces etc., that often contain hidden sources of gluten from manufacturing processes. When living with Coeliac Disease, knowledge of food labels is paramount and can be a real obstacle for some people and a source of anxiety. A lot of anxieties can also exist around food choices, meal times, eating out, food preparation and shopping and can have many social impacts, ultimately impacting a person's quality of life. People can find it hard to or get fed up of having to constantly speak up about their condition and dietary requirement. At the beginning I did find it hard but I now have no difficulty speaking out and I feel I have a responsibility both personally and professionally to champion the cause and to correct inaccuracies and misconceptions that I encounter in day to day life.

It is important to say though that it is not all bad and I do feel the general awareness of Coeliac Disease and dietary requirements is getting better all the time. 'Free from' foods are certainly now the 'niche' and their ever expanding sections within the supermarket aisles is evidence of this. Supermarkets are also jumping on the bandwagon with their own brand, and often considerably cheaper, gluten free products. New catering food laws introduced in 2014 mean that menu choices that contain gluten are required to be labelled accordingly. Personally I have found this to be great, however you must always be cognisant that cross contamination risks remain when eating out. While awareness has certainly improved, I find understanding can still sometimes be lacking. I still, at times, have croutons arrive in my salad, bread served with my soup or the obligatory wafer stuck in my dessert. For individuals with Coeliac Disease, assumptions should never be made about cooking practices when eating out. What may seem like a plain fillet of fish, chicken or steak may actually have been dusted in flour or a flavouring that could contain gluten prior to cooking. Therefore, I always encourage people to advise serving staff of their diagnosis regardless of what is being ordered. I can't tell you the amount of times I have been told some dishes contain 'gluten trace'.

Travelling is still sometimes tricky, depending on your chosen destination. Airlines have certainly improved too, with some airlines now offering a gluten free snack box that can make for a very pleasant alternative to squashed tinfoil packed sandwiches.

Coeliac Disease: Support

The Coeliac Society of Ireland is an excellent resource for anyone with Coeliac Disease, particularly in those first few years after diagnosis. With a modest annual subscription fee it really is an excellent aid for keeping yourself up to date, offering regular email updates and an annual gluten free food directory. The provision of ongoing support for patients with Coeliac Disease in following a gluten free, healthy, balanced diet cannot be underestimated. There is a lot of inaccurate information out there that is easily accessible to all. Often, well meaning friends and family members can also offer inaccurate advice too. This can result in individuals following diets that are not in fact gluten free or are very restrictive and therefore not nutritionally balanced. People can also experience a lot of anxiety around food and often self-diagnose varying food intolerances resulting in the consumption of diets that are nutritionally unbalanced. It is important that people are getting reliable information from reputable resources.

A gluten free diet can be an expensive diet to follow and unfortunately, due to recent economic conditions, government cutbacks were made that had a direct impact on anyone with Coeliac Disease seeking assistance with the cost of the gluten free diet. In 2012, the government decided that costs associated with Coeliac Disease would no longer be covered under state schemes such as the medical card, the drugs payment scheme and the long term illness scheme. This was a great shame, especially given that a specialised diet is the sole treatment of Coeliac Disease. PAYE tax payers can claim medical expenses by submitting a MED1 claims form. Tax back can be claimed at the standard rate once you have not already received a repayment from a medical insurer or health board. It is important to note that tax relief cannot be claimed on foods that are naturally gluten free and any receipts must be kept for a period of 6 years. Some supermarkets do not denote food items as gluten free on their receipts so a helpful tip is to highlight any gluten free items on the receipt when you get home and store them away somewhere safe where they can be found again at the end of the tax year. Some supermarkets will now provide an annual certificate of expenditure when customers buy gluten free products using their loyalty cards.

Non- coeliac Gluten Sensitivity

It is now becoming increasingly recognised that reactions to gluten are not confined solely to a diagnosis of Coeliac Disease. It is now recognised that there exists a spectrum of what has been termed as ‘gluten related disorders’. Non-coeliac gluten sensitivity falls under this umbrella term of ‘gluten related disorders’, a term proposed by an expert panel in 2011 to describe all conditions related to gluten[2].

With this gluten sensitive disorder, individuals experience symptoms upon gluten ingestion and show improvement on a gluten free diet. Non-coeliac gluten

sensitivity has a symptomatic presentation that is similar to that of Coeliac Disease however the clinical picture is not. This condition shows signs of an innate immune response, however there is no enteropathy, elevation of coeliac specific serology or increase in mucosal permeability[28]. Interestingly, it has be noted that the HLA DQ2/8 genes, while seen in nearly 95% of Coeliac Disease cases, can be present in up to 50% of those with gluten sensitivity thus higher than that of the general population[29].

There is no standard diagnostic approach for non-coeliac gluten sensitivity. The diagnosis is based on systematic evaluation and exclusion of Coeliac Disease and other inflammatory disorders including Wheat Allergy and also on an elimination diet. It has been suggested that this should then be followed by an open challenge, however this approach lacks specificity and is at risk of the placebo effect [2,28].

The natural history of this condition remains unclear and further research is warranted to clarify disease duration, gluten threshold and long term complications[28]. Avoidance diets are difficult and restrictive and present many socio-economic challenges to some people trying to adhere to them. It is therefore important that a rational approach to the prescription of a gluten free diet is taken and an appropriate diagnosis through exclusion is found. It is suggested that ultimate confirmation of gluten sensitivity would require re-challenge but often patients can decline this[30].

This article was written by Alison Murray (M.I.N.D.I) as requested by FreseniusKabi in April, 2017

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