

# Coeliac Disease & the Gluten-free Diet



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## What is coeliac disease?

Coeliac disease (CD) is classed as an autoimmune condition whereby genetically predisposed individuals exhibit a specific histological presentation on ingestion of gluten.<sup>1</sup> The damage caused to the lining of the gut in the small intestines is characterised by duodenal villous atrophy and intraepithelial lymphocytosis, leading to malabsorption of nutrients and both gastrointestinal as well as systemic symptoms.<sup>2</sup> Untreated, it can lead to long-term health issues, including fertility issues, osteoporosis, increased risk of gastrointestinal cancers and non-Hodgkin's lymphoma.<sup>3</sup>

The causes of CD are multifactorial, having both genetic and environmental contributing factors.<sup>4</sup> There is a strong familial component associated with the disease, as with many other autoimmune diseases, and it is thought that occurrence is as high as 1 in 10 for those with a first-degree family member already suffering from the disease.<sup>5,6</sup>

In western countries, the prevalence is around 1%.<sup>7</sup> However, approximately 36% of the population remain undiagnosed.<sup>6</sup> The causes of under diagnosis are numerous but may be contributed in part to absent, minimal or atypical symptoms.<sup>8</sup>

The number of individuals diagnosed with CD has continued to rise in recent years. This may be partially attributed to improved screening and diagnostics.<sup>9</sup>

## Current treatment advice

As the consequences of undiagnosed CD can be highly detrimental and irreversible, timely diagnosis and treatment is imperative. As it stands, currently the only treatment for CD remains a strict life-long gluten-free (GF) diet.<sup>10</sup> Gluten is the protein found in multiple grain products, including wheat, barley, rye, faro, spelt and semolina. In addition to these common foods, gluten may also be present in unexpected items such as seasonings, sauces and stock cubes, and under indistinguishable guises such as 'flavourings' and 'hydrolysed vegetable proteins'. Cross-contamination also presents a problematic source of gluten within the realms of a strict GF diet.

In the past oats were excluded as they were thought to contain gluten however, with improvements in analysis and the availability of pure uncontaminated oats, studies indicate that a volume of 50-70 g of oats per day may be tolerated in adults and 20 g in children with CD.<sup>11</sup> The timing regarding the inclusion of pure oats - e.g. from diagnosis or after symptoms resolve - continues to be debated but for the vast majority of individuals, pure uncontaminated oats (that meet the European standard<sup>12</sup> of <20 ppm) are considered safe. Oats that are not labelled as GF should always be avoided. In individuals in whom symptoms persist, the diet should be thoroughly checked for dietary indiscrepancies and other causes of ongoing symptoms (e.g. changes in fibre intake) should be considered.

Once strict gluten exclusion is established, individuals should, in general, experience an improvement in symptoms (e.g. bowel habit) within 1-2 weeks. Other symptoms, such as fatigue and joint pain, may take longer and be related to sub-clinical deficiencies, e.g. iron and vitamin D, the gradual dampening of the immune response and the recovery of the intestinal mucosa, which can take up to 1-2 years to recover.<sup>13</sup> It has also been observed that mucosal recovery may remain incomplete in adults compared to children, indicating that early diagnosis and commencement onto a GF diet is vital.<sup>14</sup>

Optimal healthcare outcomes necessitate strict adherence to a GF diet. In the past, the threshold for gluten was 200 ppm. Then, in 2012, following several publications and international debates in the coeliac community that asserted the safe thresholds of gluten in a mixed and varied diet<sup>12, 15</sup> might be exceeded if large amounts of food containing up to 200 ppm were consumed, the threshold for classifying a food as 'gluten free' was reduced to 20 ppm. Consuming foods at this level was considered safe for all individuals with CD, regardless of the amount eaten. Over the last decade, changes in food labelling and legislation has also sought to help individuals with CD select foods that are safe to consume. It is now mandated by law that any gluten containing ingredients are listed in bold on labelling, as is the case for all 14 allergens. This has also been accompanied by the 'may contain' labelling, which was introduced to alert consumers to the risk of gluten contamination in foods which should be avoided.

## Adherence to a GF diet

Coeliac UK estimates that 30% of people with CD will not see a resolution to symptoms despite starting on a GF diet. In the majority this is actually due to not strictly adhering to the diet or avoiding cross-contamination.<sup>16</sup>

Following any restrictive diet can have an impact on many areas of life and trying to adhere to a GF diet is no different. Anxiety about maintaining the diet, cost of food and specialist GF products, impact on social life and limited food choices when eating out, are all contributing factors which influence adherence.<sup>17</sup> In addition to these factors, it has been found that in comparison to the general population, people living with CD experience a poorer quality of life.<sup>18</sup> It has therefore been essential to explore ways in which adherence to a GF diet can be supported. One key area identified is

that receiving prompt advice and support improves a patient's ability to comply with a GF diet, which leads the way to an improved quality of life.<sup>19</sup>

In order to further identify ways to optimally support coeliac patients, Konigova *et al.* carried out a systematic review looking at what interventions could help dietary adherence. They found that a targeted multidisciplinary intervention, which focuses on education and behavioural techniques and utilises multiple platforms for interaction with coeliac patients (e.g. face-to-face, virtual, group and online based) may be beneficial for adherence to the GF diet.<sup>20</sup>

With the cost-of-living crisis and the cost of GF products often up to 3 times more expensive than their non-GF counterparts, financial burden is another aspect that can affect adherence to a GF diet. Across the UK, prescription guidelines differ so that access to GF products on prescription is essentially a postcode lottery. In England, variation is seen across areas; some only receive prescriptions on a case-by-case basis and dependent on circumstances (e.g. pregnancy or age), whilst some are able to obtain prescriptions for bread and flour mixes only. In other areas of Great Britain, flour, pasta and bread are available to all those with a diagnosis of CD. It is also worth noting that in England, patients may also need to pay for their GF prescriptions, further adding to the financial burden of the disease.<sup>21</sup>

Since the withdrawal and reduced access of GF prescriptions across England have come into place, some studies have aimed to look at the impact this has had on the quality of life of individuals living with CD. Peters *et al.* (2020) found that the biggest impact was on dietary burden; however, positively, the majority of people adapted to the change in prescriptions with time. Coincidentally, it was found that patients in areas without the availability of food on prescription often also experienced worse care and follow-up.<sup>22</sup>

## Is a strict GF diet essential for all sufferers?

A small number of patients with CD who remain symptomatic despite strict adherence to the GF diet have a form of CD known as refractory CD. This form of the disease is rare and affects 0.3-4% of the coeliac population. Alongside continuing to maintain a strict GF diet, other therapeutic interventions such as medication may be required for managing the disease.<sup>16</sup>

The threshold of gluten that can be tolerated in the frame of a strict GF diet

“It has also been observed that mucosal recovery may remain incomplete in adults compared to children, indicating that early diagnosis and commencement onto a GF diet is vital.<sup>14</sup>”

continues to be debated in scientific communities. However, for now, the European guidance<sup>12</sup> is that foods containing more than 20 ppm of gluten should be avoided, as should those labelled 'may contain', which may indicate potential contamination.

There is without doubt overriding evidence that continued or higher exposure to gluten can lead to complications, such as increased mortality.<sup>23</sup> The 'British Society of Gastroenterology (BSG) guidelines on the diagnosis and management of adult coeliac disease' provide further discussion on gluten intake and health outcomes.<sup>7</sup> Interestingly, within the guidelines, the BSG reference a 2008 systematic review, which suggests that, although the tolerable amount of gluten varies amongst people with CD, 'a daily gluten intake of <10 mg is unlikely to cause significant histological abnormalities'.<sup>17,24</sup>

Given that follow up can be scant and repeat biopsies are no longer routine in UK, strict adherence to a GF diet should be encouraged in those with a positive diagnosis for CD, even in those who are considered 'asymptomatic', until further robust studies on the short and long-term effects are available that identify the subgroup of patients that may develop gluten tolerance over time, without increasing the risk for CD-related complications.

### Adequacy of the GF diet

As with many therapeutic diets, adherence and the nutritional adequacy of a GF diet both have a role to play in optimising health outcomes. A literature review by the Food Standards Agency, in 2015, on the nutritional adequacy of a GF diet found, likely due to the limited number of studies and small amount of data, that it was hard to establish information on nutritional adequacy.<sup>25</sup> This, therefore, highlighted an important need for further investigation. A review in 2019 by Melini *et al.* found that the majority of GF products were lower in protein and higher in fat and salt compared to comparable gluten-containing products. However, the review did find that fibre and sugar content of GF foods were improving for the better.<sup>26</sup>

The inadequacies have also been echoed in the findings of a 2023 systematic review by Gessaroli *et al.*, which has demonstrated that coeliac diets have a propensity for high fat foods and can be lower in essential micronutrients.<sup>27</sup>

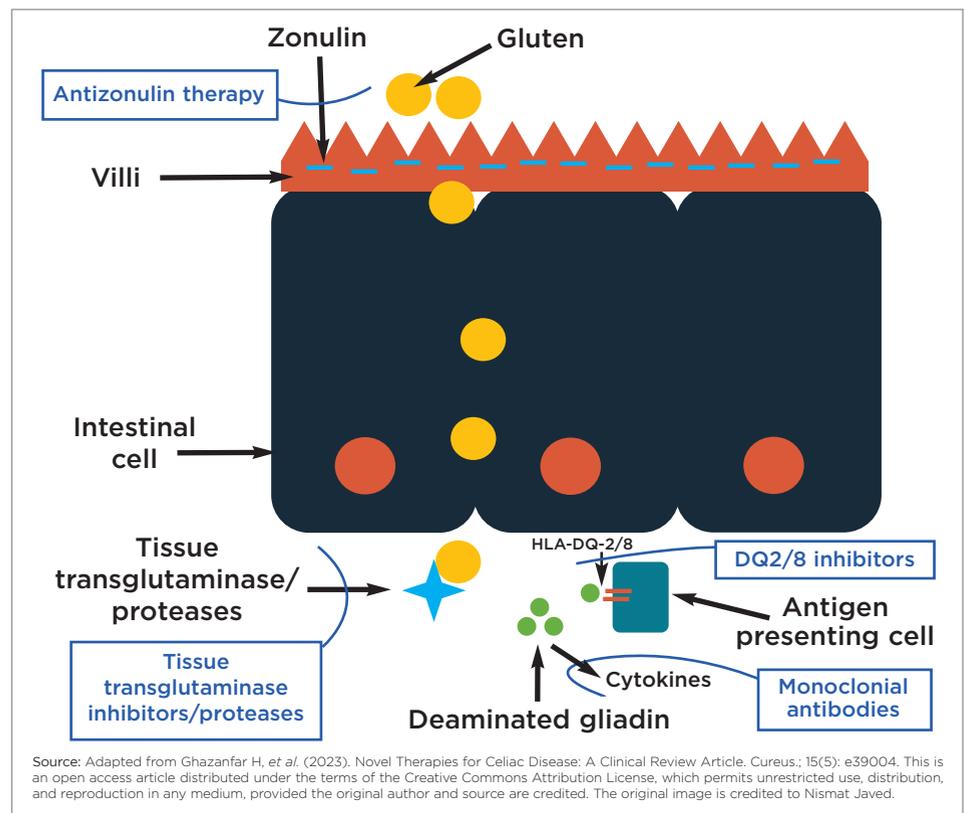
### Future research

As discussed in this article, the GF diet is currently the only available therapy available to those suffering from CD. Although no other therapies are yet approved, there is a growing field of research exploring further therapeutic avenues and an improved understanding of the regulatory pathway involved in CD. Some of the novel treatments being explored are the use of digestive enzymes, anti-inflammatory drugs and anti-cytokine drugs – **Figure 1** shows some of the targets of novel therapies.<sup>28</sup> This provides hope that the future will hold promising alternative treatments to a lifelong GF diet.<sup>29</sup>

### Conclusion

CD remains a highly prevalent autoimmune disease, whereby poor quality of life is associated with under diagnosis and untimely interventional support, particularly in the adult population. Both of these factors can have a significant impact on sufferers' ability to establish and adhere to a GF diet. Despite research into alternative therapies, the only current avenue of treatment remains a strict lifelong exclusion of gluten. In spite of this, some individuals may continue to have symptoms because of exposure to gluten from cross-contamination and, rarely, due to refractory CD. In some subgroups, it is yet to be established whether a tolerance to gluten may occur, which may allow for some gluten to be reintroduced into the diet. Further work is also required to improve the nutritional adequacy and cost of GF products in order to improve quality of life of those with CD.

**Figure 1: The targets for novel therapies in CD<sup>28</sup>**



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