# Coeliac diagnosis reveals hidden struggles behind gluten-free living



When I returned from a blissful holiday a couple of months ago, reality crashed in as I received several missed calls from my doctor and an urgent message to contact my surgery. Upon finally reaching my GP, I was blindsided by the news: “We’ve had the results back from your latest blood tests, and it appears you have coeliac disease.” His tone suggested a mix of relief and satisfaction at finally identifying the source of my long-standing fatigue and a catalogue of other troubling symptoms.

Despite having two friends with coeliac disease, I had assumed I was relatively well-informed about the condition. However, the reality of living with coeliac disease quickly became daunting. As noted by Coeliac UK, an estimated one in 100 people in the UK are affected by the disease, yet it is believed that over a third remain undiagnosed. This underdiagnosis echoes the sentiments shared by Olympic swimmer Rebecca Adlington, who recently opened up about her own journey with the illness, highlighting its commonality yet pervasive lack of understanding.

Coeliac disease is an autoimmune disorder wherein the ingestion of gluten—found in wheat, barley, and rye—triggers an immune response that harms the small intestine. The range of symptoms can be extensive, including fatigue, gastrointestinal discomfort, anaemia, and cognitive challenges often described as "brain fog." Without proper management through a strict gluten-free diet, individuals face significant health complications, such as malabsorption, osteoporosis, infertility, and a heightened risk of certain cancers.

A prevalent misconception is that coeliac disease equates to a simple food allergy. In reality, it precipitates lasting damage to the gut which necessitates complete avoidance of gluten, even in minute quantities. This misunderstanding can lead to unhelpful comments from well-meaning friends and acquaintances, such as suggestions to "try just one bite" or disheartening comments about the value of life post-diagnosis. This medical condition is no capricious dietary choice; public awareness surrounding its seriousness remains insufficient, contributing to isolating experiences for many sufferers.

Navigating social situations has become more challenging for me as I reveal my diagnosis of coeliac disease, a process marred by a constant need to scrutinise food options. This extends to restaurant settings where the risk of cross-contamination lurks; for instance, oil shared with gluten-containing items presents a hidden danger. The strain of ensuring safe dining options—especially during important social events—can provoke feelings of self-consciousness and fatigue, compounded by the ever-climbing costs associated with gluten-free alternatives.

My particular situation is any blend of privilege and challenge, as I reside in London—a city renowned for its wider variety of gluten-free offerings. Yet, access to gluten-free bread and flour prescriptions can vary dramatically across regions, reinforcing the so-called postcode lottery in healthcare provision. Research from Coeliac UK highlights that individuals may be paying up to 35% more for gluten-free products, exacerbated by the cost-of-living crisis. The grim irony remains that those least able to afford the necessary dietary changes may endanger their health by consuming gluten-laden foods, which ultimately adds further pressure on an already burdened NHS.

In the recent months since my diagnosis, a petition demanding an end to this prescription postcode lottery has gained traction, amassing 22,000 signatures and landing on the doorstep of Downing Street. As Coeliac Awareness Month unfolds this May, Coeliac UK is urging those experiencing symptoms to partake in an online self-assessment. Increased awareness and diagnosis could foster vital understanding, ensuring that individuals with coeliac disease find appropriate support and feel less isolated in their journeys.

The path ahead will undoubtedly require adjustments, and thankfully, I have an incredible support network of family, friends, and loved ones who have rallied around me. Additionally, the gluten-free product landscape has improved significantly over the past two decades, providing greater access to safe options than ever before. Through online communities, I’ve discovered a wealth of resources, advice, and recipes that have made adapting to this lifestyle more manageable. Yet the overarching sentiment remains clear: the need for increased awareness and education about coeliac disease is paramount, ensuring that fewer people face the battle alone.

### Reference Map

* Paragraph 1: [[1]](https://www.independent.co.uk/voices/coeliac-disease-awareness-month-symptoms-b2749241.html)
* Paragraph 2: [[1]](https://www.independent.co.uk/voices/coeliac-disease-awareness-month-symptoms-b2749241.html), [[4]](https://www.easterneye.biz/coeliac-disease-rebecca-adlington/)
* Paragraph 3: [[1]](https://www.independent.co.uk/voices/coeliac-disease-awareness-month-symptoms-b2749241.html), [[2]](https://www.mayoclinic.org/diseases-conditions/celiac-disease/symptoms-causes/syc-20352220), [[3]](https://www.niddk.nih.gov/health-information/digestive-diseases/celiac-disease/definition-facts)
* Paragraph 4: [[1]](https://www.independent.co.uk/voices/coeliac-disease-awareness-month-symptoms-b2749241.html), [[4]](https://www.easterneye.biz/coeliac-disease-rebecca-adlington/)
* Paragraph 5: [[1]](https://www.independent.co.uk/voices/coeliac-disease-awareness-month-symptoms-b2749241.html), [[2]](https://www.mayoclinic.org/diseases-conditions/celiac-disease/symptoms-causes/syc-20352220)
* Paragraph 6: [[1]](https://www.independent.co.uk/voices/coeliac-disease-awareness-month-symptoms-b2749241.html), [[3]](https://www.niddk.nih.gov/health-information/digestive-diseases/celiac-disease/definition-facts)
* Paragraph 7: [[1]](https://www.independent.co.uk/voices/coeliac-disease-awareness-month-symptoms-b2749241.html)
* Paragraph 8: [[1]](https://www.independent.co.uk/voices/coeliac-disease-awareness-month-symptoms-b2749241.html), [[3]](https://www.niddk.nih.gov/health-information/digestive-diseases/celiac-disease/definition-facts)
* Paragraph 9: [[1]](https://www.independent.co.uk/voices/coeliac-disease-awareness-month-symptoms-b2749241.html), [[4]](https://www.easterneye.biz/coeliac-disease-rebecca-adlington/)
* Paragraph 10: [[1]](https://www.independent.co.uk/voices/coeliac-disease-awareness-month-symptoms-b2749241.html), [[4]](https://www.easterneye.biz/coeliac-disease-rebecca-adlington/)

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## Bibliography

1. <https://www.independent.co.uk/voices/coeliac-disease-awareness-month-symptoms-b2749241.html> - Please view link - unable to able to access data
2. <https://www.mayoclinic.org/diseases-conditions/celiac-disease/symptoms-causes/syc-20352220> - The Mayo Clinic provides comprehensive information on celiac disease, detailing its causes, risk factors, complications, and treatment options. It explains that celiac disease is an autoimmune disorder where the ingestion of gluten leads to damage in the small intestine. The article also discusses the prevalence of the disease, noting that it affects about 1% of the population worldwide, and highlights the importance of a strict gluten-free diet for management.
3. <https://www.niddk.nih.gov/health-information/digestive-diseases/celiac-disease/definition-facts> - The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) offers a detailed overview of celiac disease, including its definition, prevalence, and associated health problems. It emphasizes that celiac disease is a chronic digestive and immune disorder triggered by eating foods containing gluten. The article also notes that many people with celiac disease remain undiagnosed, and it discusses the importance of a gluten-free diet in managing the condition.
4. <https://www.easterneye.biz/coeliac-disease-rebecca-adlington/> - This article discusses the prevalence of celiac disease, noting that only around 36% of people living with the condition have been officially diagnosed. It provides an overview of the disease, its symptoms, and the challenges individuals face in managing it. The piece also highlights the importance of awareness and understanding of celiac disease to improve diagnosis rates and support for those affected.
5. <https://www.mayoclinic.org/diseases-conditions/celiac-disease/symptoms-causes/syc-20352220> - The Mayo Clinic provides comprehensive information on celiac disease, detailing its causes, risk factors, complications, and treatment options. It explains that celiac disease is an autoimmune disorder where the ingestion of gluten leads to damage in the small intestine. The article also discusses the prevalence of the disease, noting that it affects about 1% of the population worldwide, and highlights the importance of a strict gluten-free diet for management.
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