



21 May 2024

Half a million^{1,2} people in the UK unknowingly living with an undiagnosed autoimmune disease

This May (1–31 May) is [Coeliac Awareness Month](#) and the campaign from charity [Coeliac UK](#) aims to highlight the importance of knowing the symptoms and risk factors, encouraging people who recognise the symptoms in themselves or their child to get tested. A simple blood test is the first step, and the earlier a diagnosis can be made, the more likely people are to prevent possible future health complications that could include osteoporosis, recurrent miscarriage and small bowel cancer or intestinal lymphoma.

There's an estimated 500,000 people^{1,2} in the UK who are living with undiagnosed coeliac disease - a serious autoimmune condition affecting 1 in 100 people^{4,5}, yet only 36%¹ of those affected are medically diagnosed. When people with the condition eat gluten - a protein found in wheat, barley and rye - their body attacks its own tissues. If left untreated, it can cause gut damage and serious health complications, however, those who get diagnosed often see a swift improvement in physical and mental wellbeing.

In its campaign, Coeliac UK highlights that coeliac disease can be 'different for everyone' - with symptoms¹⁴ ranging from gut issues to neurological complications. In addition, the British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN⁶) and the National Institute for Health and Care Excellence (NICE³) report that certain groups are more likely than the general population to have coeliac disease. On average, around one in 20 (5%) people in some at risk groups might develop the condition⁷.

People with type 1 diabetes are on average six times³ more likely to have coeliac disease compared with the general population. This increases to 10 times for children¹³. For those with type 1 diabetes the symptoms may not follow those typically associated with coeliac disease⁸, such as stomach pain, diarrhoea, nausea and vomiting - therefore screening is important even if there are no noticeable symptoms.

Those with Down's syndrome are six times⁹ more likely to have coeliac disease compared with the general population, while people with autoimmune thyroid disease (ATD) are up to four times^{3,10} more likely to have coeliac disease and this increases to six times¹¹ more likely for children.

As the symptoms can be so wide ranging, it's possible to attribute them to another cause, or in the case of patients with existing conditions, it can be overlooked.

Case study: *At the age of 10, Sarah, now 34 from Devon, began experiencing painful stomach problems. Her mother frequently took her to the doctor, but the pains would have subsided by the time they arrived, so the issue wasn't taken seriously.*

Sarah said: "A doctor suggested my stomach problems might be due to lactose intolerance, but eliminating lactose from my diet didn't help."

In 2002, at age 12, a blood test revealed coeliac disease-related antibodies, leading to an endoscopy biopsy. The biopsy confirmed coeliac disease, and Sarah had to eliminate gluten from her diet permanently. She said: "It transpired that I had coeliac disease and an overactive thyroid (Grave's Disease). This is not uncommon – many people with coeliac disease also have thyroid issues as autoimmune conditions like this tend to go hand in hand."

"Back then I didn't have the faintest idea what gluten even was. I often think of it as a blessing that I was diagnosed at such a young age. I hadn't yet learnt to cook and was still dependent on my parents, who took the full brunt of the learning curve. It wasn't until I went to university that I think the full reality of being gluten free really hit me. I really struggled with this at first as I felt a lot of pressure to keep up with my friends and not be left out of take-aways or meals out. But thankfully I'd picked up a few basic cooking skills while still at home that I put to good use."

In 2010 she opted for a total thyroidectomy, surgery which involves the removal of some or all of the thyroid gland. Unfortunately, the surgery was only partially successful. She has since had further radioactive iodine treatment, which left her thyroid levels plummeting to extremely underactive.

After a prolonged journey, Sarah, who has since released a gluten free cookbook and runs a blog helping others with coeliac disease, is grateful for her gluten free lifestyle. "Today, it's much easier to navigate the world being gluten free. Supermarkets have dedicated 'free from' aisles and many restaurants offer gluten free menus. For me, having coeliac disease has meant that I have learned to love food again. I'm not sure I'd have discovered my love for cooking without having to switch to a gluten free diet, and now I find it an exciting adventure to try and recreate all the foods I miss. I hope I can try and inspire others to feel the same."

The first step recommended by Coeliac UK for those seeking answers around their unexplained symptoms, is to take its quick and easy self-assessment. This online questionnaire, based on the NICE guidelines³, will confirm whether the individual is recommended to speak with their healthcare professional about getting tested and gives people a letter to take to their GP to help with the process. The BSPGHAN guideline⁶ states that testing should be considered for adults and children without symptoms who have associated conditions, including type 1 diabetes, Down's syndrome, autoimmune thyroid disease, and first degree relatives of people diagnosed with coeliac disease.

The self-assessment is available at: www.isitcoeliacdisease.org.uk

Coeliac UK is keen to stress that people should not cut gluten out of their diet without first being tested for coeliac disease. This is because gluten must be in the diet for the body to produce antibodies that are measured in the blood test. Removing gluten from the diet risks a potential false negative result and removing gluten from the diet is not considered healthy unless someone has a diagnosed issue with gluten, an intolerance, allergy, or coeliac disease.

Hilary Croft, Coeliac UK CEO, commented: "Coeliac UK is committed to finding the half a million people with coeliac disease that are yet to receive a medical diagnosis. When someone finally gets an answer to the cause, the positive changes can be momentous – for both their physical health and mental wellbeing. It is so important that we raise awareness of coeliac disease so we can improve diagnosis and get those with undiagnosed coeliac disease on the road to recovery."

Coeliac disease is also a genetically linked condition with the risk of having the condition increasing to 1 in 10.¹² While that still means there's a 90% chance of not having coeliac

disease, it's recommended that anyone with a first degree relative with coeliac disease is tested, even if they have no symptoms.

Case study: *42 from Lutterworth, is a highly specialist dietitian with 18 years of experience at the highest clinical level. She has been working at one of the world's leading children's hospitals in London for 15 years and has a passion and dedication for helping infants, children, and adolescents with gastrointestinal and dermatological disorders. This passion stems from her own experience with coeliac disease – having the auto immune condition herself, as well as one of her daughters, Amelie, aged 10.*

Natalie said: "I was diagnosed with coeliac disease in 2010 and suffer from a severe gluten neuropathy. The symptoms are very varied, but I experience numbness in my face and arms and gluten also affects my sensory nerves and balance. My eldest sister was diagnosed when she was a toddler so coeliac disease was always present in our family life growing up. I lived with the symptoms throughout my childhood until aged 28 and one of my three daughters, Amelie, was also diagnosed at 18 months of age which gives me the passion to help others".

"My daughter inherited this condition from me, so I feel it is my duty to help others live symptom free and get the answers they need. I didn't want her life to be limited by coeliac disease, and we do everything we can to make sure that she can enjoy food whilst managing her symptoms."

Case study: *Anne, 77, from Manchester, began experiencing persistent fatigue, heart palpitations, and breathlessness. She said: "When I first started seeing a doctor about my worries, they put the palpitations down to anxiety and suggested that I needed to rest more. Anaemia was my main symptom, though with hindsight there were others as well – including a pain in my stomach after eating."*

Anne finally received a diagnosis of hyperchromic anaemia, leading to the discovery of her underlying condition of coeliac disease. Since diagnosis, Anne encouraged her twin sister to get tested knowing that coeliac disease is genetic, but it took lots of convincing for the doctor to finally do the test. Anne's sister was diagnosed with coeliac disease, and three of her sister's grandchildren have also been diagnosed since.

People with undiagnosed coeliac disease can struggle for years with unexplained symptoms causing a negative effect on physical health whilst also causing anxiety and depression. Once diagnosed, most people with coeliac disease can start on the road to recovery, and often see very swift improvements in their symptoms and a sense of relief leading to improved mental health.

Case study: *Tim, 55 from Aberdeen, began experiencing a host of symptoms, including pins and needles in his hands and feet, pain in his gut, stomach and an unsettling brain fog - all of which led to anxiety and social withdrawal.*

Tim said: "I was willing and ready to accept that this was life, and I reflect now and get upset about it because it was probably about 12-18 months of suffering. The symptoms resulted in me withdrawing from social activities and my friends. I had anxiety about going out and didn't really understand why."

Despite a continuous misdiagnosis, Tim didn't stop fighting for the answers that he needed. Tim took the Coeliac UK online self-assessment that highlighted several symptoms associated with coeliac disease. After moving to a new GP practice, Tim was tested for coeliac disease, revealing his immune reaction was severe. Subsequent testing confirmed the diagnosis. Tim continued: "While I can say I'm in a much better place now, I do still get a bit of brain fog and a few tingles every now and again. I'm still learning and I'm still on a journey."

A person's culture can also play a part in recognising symptoms, getting diagnosed and ultimately learning to live with the condition. While people of different ethnicities are not at a higher risk of having coeliac disease, managing a gluten free diet can be made more challenging due to cultural factors where food plays a central role, such as in South Asian communities. Gluten free alternatives are not always readily available for people to be able to follow a traditional diet, whilst there are also risks of cross contamination, particularly at celebratory events where food is a significant part.

Case study: *Mita, 28, from Wembley with South Asian heritage, has suffered with health problems since she was a teenager, including endometriosis and severe issues with gut health, and spent most of her youth in and out of hospital. Mita said "I thought it could be coeliac disease, but my doctor ignored my concerns and put it down to stress."*

As she turned 18, Mita's symptoms began to completely take over her life, forcing her to take time off school due to her consistent suffering. As she turned 25, despite visiting A&E many times over the years, the on-call doctor Mita saw at one visit took her seriously and listened to her symptoms, eventually leading to a diagnosis of coeliac disease and lactose intolerance.

Lactose intolerance is associated with undiagnosed coeliac disease and is usually temporary. When people are first diagnosed with coeliac disease, the lining of the gut still has the damage caused by eating gluten which can mean that the body does not make enough lactase - the enzyme that breaks down lactose. This can cause uncomfortable gut symptoms. Once you are following a gluten free diet as part of the treatment for coeliac disease, the gut is usually able to heal, and you should be able to digest lactose again. Most people with coeliac disease do not have a problem with lactose intolerance once they have been following the gluten free diet for some time.

Living with coeliac disease can be a huge adjustment. Mita continued: "I went to my cousin's wedding in India earlier this year and the food was absolutely epic, but I was anxious that I wouldn't be able to eat anything due to cross contamination. I took extra suitcases of food with me, but it wasn't the same. The best thing about Indian weddings is the food!"

Further details for the case studies discussed above are available here: [UPDATED LINK](#)
[PENDING IMAGES](#)

For more information about Coeliac Awareness Month, visit:
<https://www.coeliac.org.uk/get-involved/awareness-month-2024/>

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Notes to Editors

References

¹ Office of National Statistics for the UK population

² *Laila Tata, Yvonne Nartey, Colin Crooks, Time Card, Joe West Incidence and Prevalence of coeliac disease across the United Kingdom*; University of Nottingham December 2021 (Coeliac UK internal report, as yet unpublished)

³ NICE guidelines: <https://www.nice.org.uk/guidance/ng20>

⁴ West et al. (2003) Seroprevalence, correlates and characteristics of undetected coeliac disease in England Gut 52; 960-65

⁵ Bingley P J et al. (2004) Undiagnosed coeliac disease at age seven; population based prospective birth cohort. BMJ 325; 322-23, calculation by Coeliac UK, using ONS population estimates for year 2021.

⁶ BSPGHAN guidelines.

⁷ Source data from Coeliac UK website: <https://www.coeliac.org.uk/information-and-support/coeliac-disease/about-coeliac-disease/causes/genetics/>

⁸ <https://academic.oup.com/edrv/article/23/4/464/2433268?login=false#51297347> and <https://pubmed.ncbi.nlm.nih.gov/18250242/>

⁹ Du et al. (2018) Prevalence of celiac disease in patients with Down Syndrome: a meta analysis

¹⁰ Sun et al. (2016) Increased Incidence of Thyroid Disease in Patients with Celiac Disease: A Systematic Review and Meta-Analysis

¹¹ Roy et al. (2016) Prevalence of Celiac Disease in Patients with Autoimmune Thyroid Disease: A Meta-Analysis

¹² Source data from Coeliac UK website: <https://www.coeliac.org.uk/information-and-support/coeliac-disease/about-coeliac-disease/causes/genetics/>

¹³ Lindgren et al. (2024) - Prevalence & predictive factors for CD in children with T1D, whom and when to screen a nationwide longitudinal cohort study of Swedish children.

¹⁴ Symptoms of coeliac disease, source data from Coeliac UK website:

<https://www.coeliac.org.uk/information-and-support/coeliac-disease/about-coeliac-disease/what-are-coeliac-disease-symptoms/>

About Coeliac UK:

For over 50 years, Coeliac UK has been the expert on coeliac disease and the gluten free diet. We are an independent charity helping people living without gluten to live happier, healthier lives. We do this by providing trustworthy advice and support, funding critical research into coeliac disease, working with healthcare professionals to improve diagnosis and fighting for better availability of gluten free food. And we do it all so that one day, no one's life will be limited by gluten.

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