



Half a million¹ people in the UK unnecessarily suffering with debilitating symptoms of coeliac disease

Coeliac UK's Awareness Week campaign 'coeliac disease is different for everyone' aims to provide answers to those who are experiencing unexplained and often debilitating symptoms. For the estimated 500,000 people¹ in the UK who are undiagnosed, a simple blood test is the first step that stands between them and getting on the road to recovery. Coeliac Awareness Week runs from 15-21 May.

Coeliac disease is a serious autoimmune condition affecting 1 in 100 people, yet only 36%² 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. The only treatment for coeliac disease is a strict gluten free diet for life.

Although coeliac disease can affect everyone differently, it is most commonly known for 'gut related issues'. The Coeliac Awareness Week campaign looks beyond the typical gut symptoms and highlights the lesser-known symptoms that can help to join the dots to speed up the path to diagnosis. The charity's mission for the campaign is to increase awareness and reduce the time it takes to get diagnosed, which for adults can often be 13 years, whilst they continue to experience persistent health issues, potentially causing lasting damage.

There are a number of lesser-known related symptoms that Coeliac UK is highlighting during this year's Coeliac Awareness Week campaign, including:

- Extreme fatigue
- Persistent mouth ulcers
- Unexplained anaemia
- Neurological symptoms
- Unexplained subfertility (both male and female) and recurrent miscarriage

New research³ highlights the lack of awareness of some of these symptoms, with 93% of UK adults unaware that subfertility or recurrent miscarriage are symptoms of coeliac disease. 88% are unaware of mouth ulcers, while 70% aren't aware of iron, vitamin deficiency or anaemia as a symptom.

For most people, once diagnosed with coeliac disease they can start on the road to recovery, and often see very swift improvements in their health. 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 three minute online questionnaire, based on the NICE guidelines⁴, 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. The self-assessment is available at: www.isitcoeliacdisease.org.uk

However, 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, or the test won't work and could give a false negative result.

Hilary Croft, Coeliac UK CEO, commented: "When someone who has been experiencing coeliac disease symptoms finally gets an answer to the cause, the positive changes can be momentous. We've seen some people struggle with symptoms of coeliac disease for decades, unaware that there is a treatment, a medically prescribed gluten free diet. However, awareness still needs to be increased, with more than a quarter³ (26%) of the UK population reporting to have never heard of coeliac disease. This increases to over 75% for the lesser-known symptoms, despite them being key indicators that something is not quite right and that the person may have undiagnosed coeliac disease.

"There are many more symptoms of coeliac disease than the usual gut related issues, and the condition is different for everyone. Through our Awareness Week campaign, we aim to reach the estimated half a million people living with undiagnosed coeliac disease and help them to get on the road to recovery."

Case Studies

For those who have been diagnosed after years of suffering with symptoms, the change in their quality of life has been dramatic.

Charlene – Recurrent miscarriage

After sadly experiencing 15 miscarriages within four years, Charlene, 30, from Glasgow, Scotland, was desperate for answers. She was diagnosed with anaemia and vitamin B12 deficiency, but the cause was unknown at that stage. Charlene said: "Once I was treated for the B12 deficiency with injections, I got pregnant, and this resulted in a healthy pregnancy."

But after two early miscarriages whilst trying for her second child, Charlene's B12 levels hadn't risen. After a blood test, Charlene was diagnosed with coeliac disease. Charlene continued: "I had blood tests and was shocked when the results came back saying I had the antibodies for coeliac disease, especially as no one else in the family has it. As soon as I cut gluten out of my diet, I fell pregnant within weeks and went on to have my second child with no problems at all."

Kevin – Anaemia

A regular blood donor, Kevin, 68, from Leeds, was surprised to be told that he couldn't carry on donating blood as his iron level wasn't high enough. A subsequent endoscopy revealed coeliac disease. Kevin said: "I was shocked as I didn't know what coeliac disease was, I had never heard of it. The first thing I did was some research and then looked in my pantry and freezer – 80% of the food had gluten in it."

Before the diagnosis in 2010, Kevin's undiscovered anaemia left him feeling weak and exhausted. He continued: "I felt much more tired back then than I do now and was always tired much earlier than other people – I was falling asleep constantly. When I think back, even as a teenager I often felt really tired! I'd lost a lot of weight as well, which I've now put back on."

Ben – Extreme fatigue

At the age of 16, Ben, now 30, from Ipswich, started feeling extreme fatigue and put it down to his busy life as a student athlete. However, as an adult, Ben noticed some of the more recognised symptoms of coeliac disease. He said, "I had stomach cramps and pains after every meal and the symptoms just got stronger. I realised it was nearly 10 years I'd been feeling this way and I wanted to get it investigated."

He got his diagnosis in 2022, having not even heard of the disease beforehand. Since diagnosis, Ben has been strictly gluten free, and his symptoms have improved significantly. Ben continued: "I feel 100 times better. The tiredness and fatigue have pretty much gone now. People often ask me what I'm eating at work and that gives me the opportunity to talk to them about my experience - I've grown to want people to ask me because I didn't put two and two together. When they hear the statistics about how many people are undiagnosed, it really gets them thinking."

Karen – Persistent mouth ulcers

Karen, 64, from Chelmsford, Essex, had suffered with constant mouth ulcers for as long as she could remember. She said: "My mouth was literally covered in ulcers, all around my lips and my gums and I could barely eat a thing."

She was misdiagnosed with irritable bowel syndrome (IBS) but she was only alerted to the possibility of coeliac disease 15 years later. Karen continued: "My mum gave me an article from a newspaper about coeliac disease and I could've written it! I told my GP I thought I had it and he said, 'Yes I think you're right.'"

After diagnosis, and following a strict gluten free diet, Karen says the change in her health was 'a miracle.' She said: "I like to remind people of the potential severities of the condition if you don't go gluten free. Any problems with your gut or bowels, or if you have symptoms like mouth ulcers, you must get it checked out."

Laura – Neurological symptoms

Originally diagnosed with long covid due to 'brain fog', Laura, 39, from Strabane, Northern Ireland, struggled with neurological symptoms that had a detrimental effect on her family's routine. She was forgetting simple admin tasks that are usually second nature to her. She said: "I had terrible brain fog – it was the worst! My family were used to me being on top of everything and then my kids would say: 'Mummy, you sent me to school today wearing my PE kit and I was meant to be in school uniform.' I didn't know the days of the week – I was really struggling."

After suffering with muscle pain, bowel issues, and persistent pins and needles, Laura's GP performed 'every test under the sun' and was told she had tested positive for coeliac disease. Laura continued: "The doctor asked me if it was a surprise and I realised it wasn't because it ran in my family, but I was never asked about it and it didn't occur to me that it could be that condition."

Laura now wants to raise awareness of how debilitating the symptoms can be. She said: "I don't think people understand the impact of coeliac disease. People talk about their invisible illnesses, and this was the same; I didn't look sick so I couldn't get others to understand how unwell I felt. It was very strange, and I felt lonely."

For more information about Coeliac Awareness Week, visit:

<https://www.coeliac.org.uk/awareness-week-2023/>

-Ends-

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Notes to Editors

References

¹ Source data from *West et al. (2003) Seroprevalence, correlates and characteristics of undetected coeliac disease in England Gut 52; 960-65* and *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.

² Source data from *Nartey Y, Crooks CJ, Card TR et al. Incidence and prevalence of coeliac disease across the United Kingdom*; University of Nottingham December 2021 (Coeliac UK internal report, as yet unpublished)

³ All figures, unless otherwise stated, are from YouGov Plc. Total sample size was 4,461 adults. Fieldwork was undertaken between 13th - 17th April 2023. The survey was carried out online. The figures have been weighted and are representative of all UK adults (aged 18+).

⁴ NICE guidelines: <https://www.nice.org.uk/guidance/ng20>

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.

For more information visit: www.coeliac.org.uk

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