1st 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 symptoms[14] ranging from gut issues to neurological complications. In addition, the British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN[6]) and the National Institute for Health and Care Excellence (NICE[3]) 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 condition[7].

People with type 1 diabetes are on average six times[3] more likely to have coeliac disease compared with the general population. This increases to 10 times for children[13]. For those with type 1 diabetes the symptoms may not follow those typically associated with coeliac disease[8], 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 times[9] 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 times[11] 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 four, Joshua, 17 from Edinburgh, began experiencing severe stomach problems following a family holiday. Born with Down's syndrome and diagnosed with autoimmune thyroid disease (ATD), Joshua's medical history added layers of complexity to his symptoms.*

Dawn, Joshua's mother, said: "It all started when we came back from a family holiday in Ibiza. Joshua's stomach problems were so bad, I was scared to go from A to B! I took him to the doctors, but they just said that he'd picked up some kind of infection while we were away."

Dawn started to get concerned two to three weeks after returning from their holiday when Joshua's symptoms had not improved.

In the end, it was down to the endocrinology team that Joshua was diagnosed quickly. They helped get Joshua seen early for bloods as part of one of his existing appointments for his thyroid condition.

Dawn continued: "I really want to encourage other people to get tested and raise awareness of the fact that coeliac disease is more common in people who have Down's syndrome. To any parents out there wondering about their child's symptoms, I'd say ask for a coeliac disease blood test and don't stop until you get one."

If a close family member has coeliac disease, the chances of others having the disease increases to 1 in 10, so as a result of Joshua getting diagnosed with coeliac disease, the rest of the family was tested, and Joshua's dad and younger brother, Joe, both tested positive.

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 guidelines[3], 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 guideline[6] 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: *Joe, 16 from Edinburgh, is Joshua's brother. He wasn't exhibiting symptoms of coeliac disease, but he underwent testing following his brother's diagnosis. Joe said: "I was tested for the condition because of my brother, Joshua's diagnosis. If you have a close relative with coeliac disease, including a parent or sibling, your chances of having it too go up to 1 in 10."*

"I'm so glad that I was diagnosed when I was young, I can't imagine having to go through that every day not knowing it was gluten that was making me ill. I was one of the lucky ones to be diagnosed before it got to that.

"I've also got a really good support network around me through family and it feels like Joshua and I are in it together."

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: https://www.dropbox.com/scl/fo/aplps5dj8dy8o3jpwqhq2/AOFoLRAAaLgfDlfiOsyrXvE?rlkey=q6756sohi82jseuxp34248vbq&st=hz4tesjw&dl=0

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

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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
See our fact sheet
Facebook: www.facebook.com/CoeliacUK
X: https://twitter.com/Coeliac_UK
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