



Press Release

Issue date: 29 August 2018

COELIAC DISEASE DIAGNOSIS RISES TO 30% - BUT STILL MISSING HALF A MILLION

Coeliac UK, the largest independent charity for people who need to live gluten free, has announced recent research shows diagnosis of the autoimmune disease, coeliac disease, which affects 1 in 100 people, has risen in the UK from 24% ¹ in 2011 to 30% ² in 2015.

The research, commissioned by the charity, from the University of Nottingham, searched UK patient records up to and including 2015 for clinical diagnoses of coeliac disease and dermatitis herpetiformis (the skin manifestation of coeliac disease).

The research showed that although diagnosis rose by a quarter in four years (2011-2015), alarmingly the rate of diagnosis was slowing significantly, resulting in around half a million people in the UK still living with undiagnosed coeliac disease. ²

It also highlighted that 1 in 4 adults over 18 years diagnosed with coeliac disease had a previously been misdiagnosed with Irritable Bowel Syndrome (IBS), the same percentage that had been reported in research from 2013. ³

Sarah Sleet, chief executive of Coeliac UK said: "It's fantastic that the research shows that around 45,000 people were diagnosed between 2011 and 2015. But with half a million people in the UK still without a diagnosis we've got a long way to go. The fact that testing for the condition is slowing and nothing has changed in people being diagnosed with IBS before being tested for coeliac disease, suggests the NHS is failing to address the mountain of underdiagnoses. We know this is even more urgent today as recent research is uncovering some symptoms of coeliac disease, specifically neurological ones that cannot be reversed without an early diagnosis."

It still takes 13 years on average for a person with coeliac disease to be diagnosed.

The NICE guidelines for coeliac disease and IBS recommend that anyone presenting with IBS symptoms should be screened first for coeliac disease.

"It is essential that people with chronic gut conditions - whether that's coeliac disease or IBS - get an accurate diagnosis as quickly as possible. Having the right tests allows healthcare practitioners to put the right treatment in place and patients can learn how to best manage their condition," said Alison Reid CEO The IBS Network.

Coeliac disease is a serious autoimmune condition caused by a reaction to gluten, a protein found in wheat, barley and rye. People diagnosed with coeliac disease must maintain a strict gluten free diet for the rest of their life if they are to avoid very serious complications such as osteoporosis, infertility and although rare, small bowel cancer.

"The blood test for coeliac disease is relatively quick and cheap and we urge anyone that has ongoing symptoms to visit their GP and request to be screened for coeliac disease. Next year we will be launching a campaign targeting the medical profession to encourage them to consider if their patients could be suffering with undiagnosed coeliac disease or have been misdiagnosed with IBS and ensure that they do not to remove gluten from their diet prior to testing as this could lead to a false negative result," continued Ms Sleet.

Although many people present with a range of [symptoms](#) including those that are gut related, other symptoms include mouth ulcers, anaemia, repeated miscarriages and neurological problems.

The charity's online assessment www.coeliac.org.uk/isitcoeliacdisease allows people to quickly check if they should go to the GP and ask for a blood test.

Ends

For more information please contact
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References

- ¹ West et al. (2014) Incidence and Prevalence of Celiac Disease and Dermatitis Herpetiformis in the UK Over Two Decades: Population-Based Study. *Am J Gastroenterol*. May; 109(5): 757-768. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4012300/>
- ² West et al. (2018) Changes in the testing for and incidence of coeliac disease in the UK 2005 – 2015 (Abstract at Coeliac UK Research Conference, 2018). www.coeliac.org.uk/abstracts2018
- ³ Card T et al. (2013) An excess of prior irritable bowel syndrome diagnoses or treatments in Celiac disease: evidence of diagnostic delay. *Scand J Gastroenterol*. Jul; 48(7):801-7. <https://www.ncbi.nlm.nih.gov/pubmed/23697749>

Notes to Editors

- Coeliac UK is the national charity for people who need to live without gluten, whether due to coeliac disease or another medical condition requiring a gluten free diet.
- The charity was launched in 1968 and is celebrating its 50th Anniversary this year
- Coeliac UK has already committed over £2 million to research projects since 2005 including ground breaking discoveries such as identifying genes associated with coeliac disease and other autoimmune conditions related to gluten. And, has also funded research towards a vaccine to restore immune tolerance to eating gluten.

- Coeliac disease is a serious illness where the body's immune system reacts to gluten found in food, making the body attack itself.
- Symptoms include diarrhoea, vomiting, stomach cramps, mouth ulcers, fatigue and anaemia.
- In undiagnosed, untreated coeliac disease there is a greater risk of complications including anaemia, osteoporosis, neurological conditions such as gluten ataxia and neuropathy, and although rare there's an increased risk of small bowel cancer and intestinal lymphoma.
- 1 in 100 people in the UK has coeliac disease
- Average time to diagnosis is 13 years.
- At least 1 in 4 people diagnosed with coeliac disease had previously been diagnosed with IBS.
- Gluten is a protein found in wheat (including spelt), rye and barley. Some people are also sensitive to oats. Obvious sources of gluten include breads, pastas, flours, cereals, cakes and biscuits. It is often used as an ingredient in many favourite foods such as fish fingers, sausages, gravies, sauces and soy sauce.
- Coeliac UK has a Helpline on 0333 332 2033 and further information can be found at www.coeliac.org.uk