

News Release Immediate Issue: 19 March 2019

Is your IBS actually undiagnosed coeliac disease?

- 97%¹ of people don't realise IBS symptoms could be coeliac disease
- 1 in 4 people with coeliac disease were previously misdiagnosed with IBS
- Half a million people in the UK are living with coeliac disease without knowing it
- <u>Coeliac UK Awareness 13 19 May 2019</u>

With only 3%¹ of British adults aware that the symptoms of IBS (irritable bowel syndrome) are also common symptoms of coeliac disease, national charity Coeliac UK, is calling on greater awareness of the similarity of symptoms and urges anyone with IBS to ask their GP for a coeliac disease blood test, if they have not already had one.

As many as 1 in 4 people with coeliac disease were previously misdiagnosed with IBS as many of the symptoms for IBS such as bloating, stomach pains or cramps, diarrhoea or constipation and feeling exhausted are the same as the symptoms of coeliac disease.

Norma McGough Coeliac UK director of policy, research and campaigns said: "It is essential that awareness of the similarity of the symptoms increases and that GPs adhere to the NICE (National Institute for Health and Care Excellence) guideline which states that anyone with IBS symptoms should be tested for coeliac disease before a diagnosis of IBS is made."

Coeliac disease is not an allergy or an intolerance but an autoimmune disease where the body's immune system damages the lining of the small bowel when gluten, a protein (found in wheat, barley and rye) is eaten. There is no cure and no medication; the only treatment is a strict gluten free diet for life.

1 in 100 people in the UK is estimated to have coeliac disease but of these, only 30% are currently diagnosed, meaning there are nearly half a million people in the UK with undiagnosed coeliac disease.

The average time it takes for someone to get a diagnosis is 13 years from the onset of symptoms; by which time, they may already be suffering with added complications caused by the disease. If left untreated, coeliac disease can lead to a number of serious complications, including: anaemia, osteoporosis, unexplained infertility, neurological conditions such as gluten ataxia and neuropathy, and although rare, there is an increased risk of small bowel cancer and intestinal lymphoma.

"The first step to diagnosing coeliac disease is a simple, inexpensive blood test done in primary care, but thousands of people are not getting the necessary testing and are being left undiagnosed including those with IBS symptoms. This not only causes years of unnecessary suffering but also wasted costs to the NHS with repeated appointments and investigations.

We urge anyone who has symptoms such as ongoing bloating, diarrhoea or constipation and has been given a diagnosis of IBS but not been tested for coeliac disease to ask their GP to test them for coeliac disease. However, it is essential to keep eating gluten until all tests are completed as otherwise these tests may give a false negative result," continued Ms McGough.

Coeliac UK's online assessment <u>www.coeliac.org.uk/isitcoeliacdisease</u>, based on the NICE guideline NG20, gives people greater confidence to seek further medical advice from their GP. Upon completion of the assessment, the respondent will receive an email with their results, which will indicate whether their symptoms are potentially linked to coeliac disease.

Coeliac UK Awareness Week 13-19 May 2019 www.coeliac.org.uk/AW19

Ends For more information, please contact Kate Newman <u>kate.newman@coeliac.org.uk</u>

¹ Reference YouGov Survey

When answering the question: 'What do you think are common symptoms of coeliac disease?', only 3% of respondents answered IBS symptoms.

All figures, unless otherwise stated, are from YouGov Plc. Total sample size was 8423 adults. Fieldwork was undertaken between 20th December 2018 - 2nd January 2019. The survey was carried out online. The figures have been weighted and are representative of all GB adults (aged 18+).

Notes to Eds:

- 1. 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.
- 2. Coeliac disease is a serious autoimmune condition where the body's immune system reacts to gluten found in food, making the body attack itself.
- 3. 1 in 100 people in the UK has coeliac disease but half a million people in the UK are undiagnosed.
- 4. Average time to diagnosis is 13 years.
- 5. A wide range of case studies are available on request from Coeliac UK
- 6. Gluten is a protein found in wheat (including spelt), rye and barley. Some people are also sensitive to oats.
- IBS most commonly affects people between the age of 20 30 years and is twice as common in women as men, according to NICE.
- 8. Coeliac UK has a Helpline on 0333 332 2033 and further information can be found at <u>www.coeliac.org.uk</u>