

Research by the University of Oxford shows that it takes an average of 13.1 years for a person in the UK to be diagnosed with coeliac disease, says Sarah Sleet of Coeliac UK



## DIAGNOSING COELIAC DISEASE

Coeliac disease, an autoimmune disease caused by intolerance to gluten, causes an inflammation in the intestine. Left untreated, the disease can lead to more serious conditions, such as osteoporosis, infertility or bowel cancer.

Many people have to make repeated visits to their GP and some patients report visiting their GP up to 28 times (1), while others often have to insist on being given a simple blood test, which is the first step to diagnosis. The research also demonstrates the disturbingly poor quality of life suffered by patients prior to diagnosis.

Although the symptoms of the disease vary from one person to another, the most common symptoms are abdominal pain or bloating (71%), diarrhoea (70%), anaemia (65%), chronic fatigue (62%) and weight loss (61%). Other symptoms can include vomiting, constipation, breathlessness, depression, weight gain and mouth ulcers. Some people also suffer with neurological problems, migraines and other autoimmune diseases; while children with undiagnosed coeliac disease may exhibit behavioural, learning or concentration problems, irritability, listlessness and failure to thrive.

The only treatment for coeliac disease is sticking to a strict life-long gluten-free diet. Additional research shows that this reduces the number of incidences of cancer within sufferers of coeliac disease.

The Oxford University research showed that before diagnosis, 28.6% of people with coeliac disease experienced extreme pain. This figure falls substantially from to only 5.1% following diagnosis. Similarly, severe anxiety levels fell from 13.2% to 3.2% following diagnosis, with the national average for severe anxiety being 2%.

Sarah Sleet, chief executive of Coeliac UK, says: "Coeliac disease is considered to be the most under-diagnosed common chronic condition in the UK today. One in 100 are believed to be at risk from the condition, but the latest research suggests that only one in eight, or 12.5% of these have been diagnosed. And yet, it is easy to diagnose with inexpensive blood tests available to quickly identify cases in primary care. There is no reason why people should not be diagnosed more quickly, and avoid years of debilitating pain and ill-health."

As part of the awareness campaign, Coeliac UK sought to win support from politicians and organised



a reception at the House of Commons in May at which MPs tried out the Biocard Coeliac Test. The campaign is also being supported by Dr Chris Steele, ITV's 'This Morning's' resident doctor, who is a passionate advocate for greater awareness of coeliac disease amongst healthcare professionals.

Dr Steele says: "I am whole heartedly supporting the campaign for early diagnosis of coeliac disease, it is a disgrace the delay people have to endure from the onset of symptoms to diagnosis — it is totally unacceptable."

• For further information please call the helpline on 0870 444 8804 or visit the website at [www.coeliac.org.uk](http://www.coeliac.org.uk)

Ref 1: Research quoted from the Health Economics Research Centre, University of Oxford survey of Coeliac UK members 2007.

### Genetic risk identified for common chronic disease

Researchers have identified a new genetic risk factor for coeliac disease, an autoimmune disease affecting one in 100 of the population. The findings, made by an international research group investigating the causes of intestinal inflammatory conditions, could pave the way towards improved diagnostics and treatments for the lifelong complaint.

Led by David van Heel, Professor of Gastrointestinal Genetics at Queen Mary, University of London, the study was funded by the charity Coeliac UK, and the Wellcome Trust.

Exploiting technological advances that have enabled comparison of variations across the human genome in large numbers of people, researchers studied more than 4,000 individuals with and without coeliac disease, amongst British, Irish and Dutch populations. Genome data on 1,500 British individuals was made available to the study by the Wellcome Trust Sanger Institute. Researchers found that individuals not susceptible to coeliac disease more often have a protective DNA sequence providing defence against intestinal inflammation compared with individuals who have coeliac disease.

Professor David van Heel, chief investigator in the study, says: "We previously knew that coeliac individuals had a specific tissue type which recognised wheat proteins. We did not know why healthy individuals who had the same tissue type did not develop symptoms or disease. The first findings from our study suggest that interleukin genes that control inflammation are critical. We expect to find more disease risk factors from further in-depth analysis of the genome wide data."

The study shows a protective (against developing coeliac disease) stretch of DNA sequence is more common in healthy people. This stretch of DNA contains the sequence that encodes the interleukin-2 and interleukin-21 genes. Both these genes are critical for inflammation — specifically in controlling the T cells that respond to wheat gluten as "foreign" and trigger an immune response against wheat gluten.

Professor van Heel adds: "Although we now know the genetic risk, we do not yet know the precise details of how this works in coeliac disease. But a good guess would be that coeliac individuals switch on more interleukin-2 and interleukin-21, and this means they are more likely to make an immune response against wheat gluten and so explains in part why they get coeliac disease."

For further information about coeliac disease, expert advice, gluten-free products and recipes along with upcoming national and regional events, go to [www.coeliac.org.uk](http://www.coeliac.org.uk) or call their Helpline on 0870 444 8804. For information on the Biocard Coeliac Test please turn to page 38.



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