



## Press Release

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# **COELIAC UK WELCOMES NEW NICE QUALITY STANDARD ON COELIAC DISEASE – BUT IS IT TOO LATE FOR THOUSANDS ALREADY DIAGNOSED?**

Coeliac UK welcomes the release of a new National Institute of Health and Care Excellence (NICE) [quality standard on coeliac disease](#) announced today, Wednesday 19 October 2016, to drive standards in the diagnosis and care of people with coeliac disease but is concerned that many Clinical Commissioning Groups (CCGs) in England will not reverse blanket bans on gluten-free prescribing in some areas which leave vulnerable people at risk.

The new standard, the first to be published by NICE on coeliac disease, sets out five key areas to drive measurable improvements in diagnosis, support and the health and quality of life for patients with coeliac disease. In addition, NICE identifies areas where health inequality needs to be addressed by healthcare professionals involved in the management of patients with coeliac disease.

The quality standard highlights that attendance of coeliac disease annual reviews for patients in socioeconomically deprived areas needs to be improved and that enabling access to gluten-free food on prescription aids adherence to the gluten-free diet.

Access to gluten-free food has been stopped in 10% of CCGs and a third of CCGs have now introduced restrictions to gluten-free food on prescription for patients with coeliac disease in England. These commissioning decisions have introduced unwarranted variation in the care and support offered by NHS England to patients with coeliac disease and contradicts commitments to reduce health inequalities across the UK.

Sarah Sleet, chief executive of Coeliac UK, the national charity for people with coeliac disease said: “Thousands of people with coeliac disease are missing out on the standard of care recommended by NICE as the ongoing support offered by the NHS varies from one CCG to another. As NICE quality standards are developed in line with clinical evidence and expert consensus, it is clear that the decision by some CCGs to remove vital front-line services, is being based on budget rather than patient need or clinical evidence.”

The Health and Social Care Act 2012 sets out a clear expectation that the care system should consider NICE quality standards in planning and delivering services.

One in 100 people in the UK has coeliac disease, with the prevalence rising to one in ten for close family members. However, currently only 24% of those with the condition are diagnosed, leaving an estimated half a million people in the UK undiagnosed.

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

The potential serious long term health complications of not maintaining a gluten-free diet include osteoporosis, infertility and, in some rare cases, small bowel cancer, conditions that cause considerable suffering and could cost the NHS a lot more in the long run.

"We will shortly be writing to all CCGs in England highlighting the new quality standard on coeliac disease and hope that they will be taking all the suggested prioritised statements on board when caring for those with coeliac disease," continued Ms Sleet.

Ends

**Notes to editor**

- Coeliac disease is a serious illness where the body's immune system reacts to gluten found in food, making the body attack itself.
- 1 in 100 people in the UK has coeliac disease
- A wide range of case studies are available on request from Coeliac UK.
- Average time to diagnosis is 13 years.
- 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](http://www.coeliac.org.uk)