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**UK CHARITY CALLS FOR IMPROVEMENTS TO GUIDELINES
FOLLOWING INQUIRY INTO HOSPITAL DEATH**

A recent inquest into the death of an 80-year-old with coeliac disease¹ and other complex health conditions, who was fed gluten in hospital, has led a national charity to call for an immediate review of hospital guidelines.

The patient fell ill within hours of being fed cereal containing gluten and started to vomit. She died four days later from aspiration pneumonia.

Coeliac UK, the national charity for people with coeliac disease and those who need to live without gluten, is calling for an immediate review of guidelines and increased training for healthcare professionals to improve their management of hospital patients who have this serious autoimmune disease.

For people with coeliac disease the body's immune system reacts to gluten found in food, making the body attack itself. Symptoms vary from bloating, diarrhoea, vomiting and stomach pain, to mouth ulcers, tiredness and anaemia, amongst others.

Coeliac UK is taking a number of steps aimed at improving safety for patients with coeliac disease when in hospital:

- Calling on Government for increased funding to provide education on this serious autoimmune disease to all healthcare professionals
- Direct liaison with hospitals to provide educational materials on providing a gluten free diet for people with coeliac disease
- Support to patients with coeliac disease who are due to attend hospital
- Connecting with allergy organisations on the provision of special dietary needs in hospitals, to ensure a joined-up multidisciplinary approach as recommended in the Hospital Food Review report
- Requesting that the NHS review their information, which currently does not sufficiently identify vomiting as a symptom of coeliac disease

Urgent action needs to be taken to improve education amongst all hospital staff, states Coeliac UK Chair, Maureen Burnside. As someone with coeliac disease herself, she has a personal response also: "This tragic case indicates a broad lack of understanding around this autoimmune disease and demonstrates that additional training on the vital importance of a strict gluten free diet is required amongst healthcare professionals.

"I am personally moved by this case as my own mother, aged 86, has had difficult experiences in hospital due to her own coeliac disease. On one occasion she was offered regular toast, which would have made her very unwell, and on another she was simply told she was 'too late' at 4pm for gluten free food. The hospital clearly regarded a gluten free diet as a specialist request, when it should be standard.

“One in 100 people have coeliac disease and we must keep these people safe in hospitals.

“We have research which shows that people with coeliac disease are not provided adequate gluten free food in hospital but rely on friends and family to bring this in. This is not good enough and can easily lead to food containing gluten being provided to patients if family are not available.

“We are talking to colleagues within the NHS to review their information and to include vomiting as a specific symptom of this disease. There is evidence for this, both in people with undiagnosed coeliac disease, and in those who have been following a strict gluten free diet but are then exposed to gluten.”

Dr Jeremy Woodward, Consultant Gastroenterologist at Addenbrooke’s Hospital in Cambridge, said: “Nausea and vomiting are commonly reported amongst a wide range of other symptoms that are attributable to coeliac disease. In a survey of adults with coeliac disease, carried out by Coeliac UK, nearly one in five respondents noted nausea and vomiting prior to diagnosis.”

Professor David Sanders, Consultant Gastroenterologist, Royal Hallamshire Hospital, Sheffield, agrees that vomiting should be included on medical guidelines. He states: “It is a fact that vomiting is a common symptom pre-diagnosis.

“Also, in adults diagnosed with coeliac disease and then exposed to gluten during a controlled research study, three out of five experienced nausea and two out of five experienced vomiting, most within two and a half hours after eating gluten. These symptoms correlated with increased levels of a marker of immune activation that was measured in blood samples”.

“The gluten free diet is a medically prescribed diet for people with coeliac disease and the only current treatment for their condition. Their gluten free diet should be an integral part of their care plan and in settings such as hospitals must ensure that the mandatory food standards are met, to ensure the safety and wellbeing of patients with coeliac disease.”

As well as contacting the NHS, Coeliac UK is also reaching out to hospitals directly with educational material, guidelines and a training programme.

For patients or family with concerns, the charity is also providing tools and information for people going into hospital for treatment: <https://www.coeliac.org.uk/information-and-support/living-gluten-free/the-gluten-free-diet/hospital-visits/>

-ENDS-

Note to editors

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

Facebook: www.facebook.com/CoeliacUK

Twitter: @Coeliac_UK

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Helpline telephone: 0333 332 2033

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ⁱ What is coeliac disease?

- Coeliac disease is a serious autoimmune condition where the body's immune system reacts to gluten found in food, making the body attack itself.
- Symptoms of coeliac disease range from mild to severe, and can include
 - Bloating
 - Diarrhoea
 - Vomiting
 - Stomach pain
 - Nausea
 - Wind
 - Constipation
 - Tiredness
 - Mouth ulcers
 - Sudden or unexpected weight loss (but not in all cases)
 - Anaemia
 - Slow growth (in children)
 - Unexplained infertility
 - Itchy rash
 - Nerve damage
- 1 in 100 people in the UK has coeliac disease but half a million people in the UK are undiagnosed.
- Average time from onset of symptoms to diagnosis is 13 years.
- 1 in 4 people diagnosed with coeliac disease had previously been misdiagnosed with irritable bowel syndrome
- Gluten is a protein found in wheat (including spelt), rye and barley. Some people are also sensitive to oats.
- Coeliac UK has a Helpline on 0333 332 2033 and further information can be found at www.coeliac.org.uk

ⁱⁱ Daveson AJM et al. Masked bolus gluten challenge low in FODMAPs implicates nausea and vomiting as key symptoms associated with immune activation in treated coeliac disease. *Aliment Pharmacol Ther.* 2020 Jan;51(2):244-252
<https://pubmed.ncbi.nlm.nih.gov/31769533/>