

**December 2024**

### **National charity alarmed by prescribing decision in Leicester, Leicestershire, and Rutland**

Coeliac UK has today raised grave concerns about the decision by NHS Leicester, Leicestershire and Rutland Integrated Care Board (ICB) to withdraw gluten free prescriptions for people with a diagnosis of coeliac disease and its potential impact on their health.

The charity highlighted the significant additional cost of gluten free staple substitute products, which poses a real challenge to maintaining the gluten free diet, the only treatment for the condition. 72% of respondents to a recent public consultation disagreed with the ICB's proposal to stop gluten free prescribing yet they have decided to proceed with removal of provision. Coeliac UK is deeply concerned by the potential impact of the decision and believes the ICB has made no effort to meaningfully reduce the impact of this policy change for those on low incomes. This is despite the additional cost of gluten free food being highlighted by 58% of those who disagreed with the proposal [1].

Coeliac disease is a serious autoimmune condition, affecting around 1 in a 100 people. Symptoms are wide ranging but can include bloating, stomach cramps, vomiting, diarrhoea and tiredness. Extra intestinal issues can be very diverse and include anaemia, low bone density, skin rashes, recurrent mouth ulcers, loss of balance, sensory symptoms, anxiety and depression. When a person with coeliac disease eats gluten, even a crumb, it can cause debilitating symptoms and in the long term can lead to development of associated conditions such as osteoporosis, neurological dysfunction, unexplained infertility, recurrent miscarriage and in rare cases even small bowel cancer [2].

The cost of providing gluten free prescriptions accounts for less than 0.07% of prescribing spend in England [3] and is overshadowed by the cost of treating conditions resulting from non-adherence to the diet. For example, the average cost (including medical and social care) to the NHS of an osteoporotic hip fracture is £27,000 – the equivalent to more than a lifetime's supply of gluten free prescribing for the majority of people [4]. There is no cure, and the only treatment is a strict gluten free diet for life, which amidst the cost of living crisis poses an additional challenge for people with coeliac disease.

Following a 2017 Department of Health and Social Care review, gluten free prescriptions for people with coeliac disease in England were restricted to bread and flour mix only, recognising the important role these staples play in supporting adherence to the diet. It was left to local commissioners to decide whether to limit further than this or withdraw it altogether in line with their legal duty to reduce health inequalities. As such prescription policies differ across the country.

A 2024 [Coeliac UK report](#) revealed a weekly gluten free food shop can be as much as 35% more expensive than a standard weekly food shop. A gluten free loaf of bread is on average 4.5 times more expensive than a standard gluten containing loaf gram for gram. There is even more disparity between the cheapest products, with the cheapest gluten

free loaf of bread costing 6.1 times more than the cheapest gluten containing loaf, gram for gram.

The report also surveyed over 1,000 people on availability and cost of gluten free staple substitutes in supermarkets in store and online, finding that 77% of respondents struggled to afford gluten free products and 72% said shopping gluten free adversely affects their quality of life. [5]

Contrary to the ICB's claims, complete replacement of gluten containing staple foods is not easy and gluten free substitute foods are important for both practical reasons and for their nutritional contribution to the diet.

For example, replacing two slices of gluten free bread with a portion of rice containing the same number of calories would reduce the iron content by 96% and the calcium content by 90%. Similarly, replacing gluten free bread with a portion of peeled, boiled potatoes containing the same number of calories would reduce the iron content by 71% and the calcium content by 93%. [6]

Replacing gluten free staples such as bread with rice and potatoes also presents practical challenges for food on the go, packed lunches and there are additional preparation requirements and energy costs for cooking.

Those most affected by the withdrawal of prescriptions will likely be the least able to manage the multiple adaptations required to maintain their nutritional balance while also ensuring their diet remains gluten free. [7]

**Dr Mohamed Shiha, Gastroenterology Registrar at University Hospitals of Leicester said:**

"As a clinician, I have seen firsthand how the increased cost of gluten free foods profoundly impacts patients with coeliac disease. For these people, a strict gluten free diet is not a lifestyle choice but the necessary treatment for a serious autoimmune condition. By not supporting patients to maintain their gluten free diet today, we risk paying a far higher price for treating associated conditions down the line. This is bad news for the NHS and devastating for the individual. It is therefore a real concern that the ICB is taking such a short-sighted and backwards step at the time of a cost of living crisis when patients need the support most".

**Tristan Humphreys, Head of Advocacy, Coeliac UK said:**

"We are extremely disappointed that NHS Leicester, Leicestershire and Rutland ICB has taken this decision. These changes remove a much-needed lifeline for those with coeliac disease at a time when the cost of living crisis is hitting people with coeliac disease particularly hard.

Our own research has shown that those on a budget are paying on average 6 times as much for the cheapest loaf they need to stay healthy. As we explained to the ICB, it is not as simple as switching bread and flour for rice and potatoes. Gluten free substitute foods are important for both practical reasons and for their nutritional contribution to the diet.

Failure to support people with coeliac disease risks them developing serious long-term conditions down the line, the cost of which overshadows that of gluten free prescriptions.

There is a complete lack of mitigation from the ICB for those affected by the additional costs of this decision, and we have grave concerns this decision will have a detrimental impact on the coeliac community across Leicestershire and Rutland, particularly those on low incomes. The ICB plan to phase out gluten free prescribing by the end of January 2025, which allows little time to prepare or adapt to this significant additional financial burden.

This decision flies in the face of the evidence and testimony provided as part of the public consultation process and places an additional financial burden on families and patients at the most challenging of times. We urge the ICB to look again at this policy and do the right thing, based on the evidence.”

-Ends-

#### *References:*

[1] Consultation Report: Gluten Free Products on Prescription Survey – Leicester, Leicestershire and Rutland ICB, JW Research Limited (29th October 2024) available at <https://leicesterleicestershireandrutland.icb.nhs.uk/be-involved/>

[2]. NICE, Coeliac disease, recognition assessment and management. NICE Guideline NG 20, September 2015. Available at: <https://www.nice.org.uk/guidance/ng20>

[3] NHS England Prescriptions Cost Analysis 2023 (published 2024)

[4] NICE, Clinical Guideline CG124: The management of hip fractures in adults. 2011

[5] The Gluten Free Diet: What does it cost and why does it matter?, Coeliac UK (2024). Available at <https://www.coeliac.org.uk/get-involved/campaign-with-us/cost-access-and-availability-of-gluten-free-food/>

[6] McCance and Widdowson (2021) Composition of foods integrated dataset (CoFID); <https://www.gov.uk/government/publications/composition-of-foods-integrated-dataset-cofid>  
Coeliac UK, Coeliac Diet and Nutrition Survey conducted 2018-2019 (unpublished)

[7] Burden, M., et al., (2015) Cost and availability of gluten-free food in the UK: in store and online. Postgraduate Medical Journal, 2015: p. postgradmedj-2015-133395

For more information, please contact the team at McKenna Townsend:

E: [coeliacuk@mckennatownsend.com](mailto:coeliacuk@mckennatownsend.com)

T: 01425 472330

#### **About Coeliac UK:**

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 who have to live 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](http://www.coeliac.org.uk)

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X: @Coeliac\_UK

Instagram: @coeliacuk

Helpline telephone: 0333 332 2033

