

## Our Manifesto

Coeliac UK has developed a manifesto outlining our key asks for the UK Government. These are challenging times for our community. Almost half a million people across the country are living with the consequences of undiagnosed coeliac disease, potentially struggling with debilitating symptoms and at risk of serious health complications. For those with a diagnosis, the increased cost of a gluten free diet – the only treatment for their condition – has turned a cost of living crisis into a health crisis for many. This is not only hurting those with the condition but poses serious challenges to the NHS that must pick up the tab for treating any associated ill health. As a result, it denies too many the opportunity to maximise their skills and talent, to the detriment of our communities and our country.

Policy makers have consistently failed to recognise the seriousness of coeliac disease. That must change. We believe our Election Manifesto offers an opportunity for the next Government to help better utilise NHS resource, further develop our world leading food regulations and improve the lives of the nearly 700,000 people with coeliac disease across the UK.

### **Saving NHS resources by finding the half a million living with undiagnosed coeliac disease**

Around two thirds of those with coeliac disease are undiagnosed. It takes on average 13 years from onset of symptoms for an adult to receive a medical diagnosis. As a result, half a million people are potentially feeling unwell, being put at risk of long term health conditions. These include osteoporosis, neurological dysfunction, unexplained infertility and in rare cases small bowel cancer. Moreover, people are going through unpleasant, and crucially, unnecessary investigations for other conditions. This is damaging for the individual, the health service and society as a whole. Early diagnosis and treatment of coeliac disease is life changing for patients and promises to free up resource for a health service under enormous strain.

#### **Our Asks:**

- **Commit to adoption of a unified diagnostic pathway for lower GI symptoms in primary care**
- **Support the development of a coeliac disease training programme for primary care physicians and other Allied Health Professionals (AHPs) so that they can better understand the complex nature and diverse manifestations of coeliac disease**
- **Develop a public health campaign to raise awareness of coeliac disease and its symptoms.**

### **Supporting world leading research to unlock our understanding of autoimmune diseases**

We know that people with coeliac disease may have ongoing symptoms despite following a gluten free diet and 6 out of 10 are not offered any follow up care. The genetics and antigen involved in coeliac disease have been determined and we know that other autoimmune conditions share a genetic link so enhancing our understanding of coeliac disease could also help us to understand and treat or cure other autoimmune conditions too. Research suggests that up to 40% of the population may carry the genes for coeliac disease, yet only 1% develop the condition, with research to show the prevalence is potentially increasing, so it's vital that we fund research into understanding the disease so that we can prevent or cure the condition.

### **Our Asks:**

- **Commit annual funding to sustain research related to coeliac disease with the potential to make a breakthrough towards prevention and/or a cure.**
- **Establish a scheme to encourage early career researchers to embark on a career in coeliac disease research**
- **Create a coeliac disease patient registry linked to NHS health records to provide for health analytics and improve patient care.**
- **Trial and test a screening programme to achieve earlier diagnosis.**

### **Stopping the cost of living crisis from becoming a health crisis**

Increased costs and the limited availability of gluten free staple substitute products pose a significant barrier to adherence to the diet and risk development of serious health conditions. Recent data shows that the average gluten free loaf of bread is more than 4 times as expensive gram for gram compared to its gluten containing equivalent whilst the cheapest loaf is more than 6 times as expensive gram for gram. This disproportionately impacts those least able to afford it. Nearly 8 in 10 respondents to a recent survey, reported struggling to afford gluten free food. This comes as NHS support to gluten free staple substitute products on prescription is being withdrawn in many parts of England, leaving people with coeliac disease cut adrift. It is critical that support is available for those who need it most to avoid the cost of living crisis becoming a health crisis.

### **Our Asks:**

- **Work with Coeliac UK and healthcare experts to develop and share best practice models for protecting access to gluten free prescriptions for those who need it**
- **Review the decision making processes from ICBs who have removed provision since 2022, monitoring their impact and report back to the Minister.**
- **Publish updated guidance for Integrated Care Boards in England that re-iterates the critical role of the gluten free diet, highlights in the ICB's legal duties to reduce inequalities and meaningfully engage patients in decision making; and emphasises the vital importance of maintaining access to gluten free bread and flour for those who need it.**

### **Helping people to make safe food decisions**

Currently, a lifelong gluten free diet is the only treatment for people with coeliac disease. Ingesting even small amounts of gluten can cause significant gut damage and trigger symptoms that last several days. It is therefore crucial for people with coeliac disease to be able to access food suitable for a gluten free diet, whether grocery shopping or eating out, that this is clearly and accurately labelled. Two key pieces of assimilated law help people with coeliac disease make informed and safe choices daily – one defines *the absence of gluten* (i.e. 'gluten free'; Ref. Reg. (EU) 828/2014)), the other requires the *presence of allergens* to always be provided (Ref.: Reg. (EU) 1169/2011).

### **Our asks:**

- **To recognise the distinct position that "gluten free" holds under the law and the need to address the coeliac community separately from other food hypersensitive consumers.**

- **To review and improve the labelling provisions to ensure consistent information for coeliac consumers and food providers.**