

## Coeliac Disease in Wales

### Briefing for Senedd Election

Why better diagnosis, treatment and service planning is urgently needed

**Summary:** Coeliac disease affects 1 in 100 people, yet over 20,000 remain undiagnosed in Wales, causing avoidable harm and unnecessary pressure on the NHS. Simple, evidence-based changes to testing and follow-up care can deliver faster diagnosis, reduce endoscopy demand, and help people live well.

#### Key facts at a glance

- 1 in 100 people affected
- 20,000+ in Wales currently undiagnosed
- Average 13 years to adult diagnosis
- 300% rise in >8 week waits for gastroscopy (Feb 2020–Jul 2025)
- Diagnosis rates 80% lower amongst most deprived children
- 1 in 4 first misdiagnosed with IBS
- 22% see no dietitian in first year; 60% not offered annual review

---

#### The issue

Coeliac disease is a serious lifelong autoimmune condition. Undiagnosed and late diagnosed coeliac disease leads to osteoporosis, neurological complications, fertility and pregnancy issues, and—in rare cases—cancer. Earlier diagnosis prevents irreversible harm and reduces long term pressure on NHS services.

#### What's going wrong now

- Delayed and missed diagnosis: nearly two thirds of those with the condition remain undiagnosed, and it takes more than a decade to get a diagnosis.
- Low awareness of the symptom overlap between coeliac disease and IBS amongst health care professionals leads to misdiagnosis.
- With the majority of adults requiring an endoscopy and biopsy for diagnosis, significant endoscopy waits delay diagnosis further
- Post-diagnosis support is patchy: Almost a quarter report not seeing a dietitian in the first year of diagnosis and nearly two thirds do not receive annual checks up in line with NICE guidelines.
- Health inequalities: diagnosis rates are significantly lower in the most deprived communities.

## **Solutions we can deliver over the next parliament**

### **Faster, accurate diagnosis**

- Adopt “no-biopsy” diagnosis for eligible adults; expand and standardise serology reporting building on existing best practice.
- Support lower thresholds for testing in primary care; Improve training for healthcare professionals in primary care to support earlier identification and testing for coeliac disease.

### **Workforce and capacity**

- Invest in specialist dietetic capacity and empower dietitians to lead coeliac services.

### **Consistent care across Wales (“Once for Wales”)**

- Drive adoption of a unified coeliac disease clinical pathway by all Welsh Health Boards in line with its 'Once for Wales' approach.
- Appoint a national clinical lead to drive consistency and outcomes.
- Commission a national review of coeliac services against forthcoming BSG guidance to benchmark quality and reduce variation.
- Ensure full adoption of the Gluten Free Subsidy Card across all Welsh health boards

### **Why this matters now**

- Reduces pressure on endoscopy lists and frees clinical time.
- Prevents avoidable complications and costs through earlier diagnosis and consistent follow-up.
- Targets inequalities by standardising access and support across all communities.
- Aligns with value-based healthcare and prudent medicine principles in Wales.

### **What you can do next**

- Meet local patients and clinicians (we can arrange a short roundtable).
- Back the adoption of the coeliac disease clinical pathway by all Health Boards.
- Support training for primary care teams and adoption of no-biopsy protocols.
- Sign the pledge and raise a written question or short debate on improving diagnosis and dietetic support.

---

### **Contact & sign the pledge**

To discuss these proposals or to sign our pledge, please contact:

**Tristan Humphreys (Head of Advocacy & Public Affairs) - [Advocacy@coeliac.org.uk](mailto:Advocacy@coeliac.org.uk).**

**Pledge:** “I pledge to champion faster diagnosis, consistent care, and better long-term support for people with coeliac disease across Wales”

### **About Coeliac UK**

Coeliac UK is the national charity for people with coeliac disease. We work across the NHS, research and industry to improve diagnosis, care and access to safe, affordable gluten free food. We represent patients in Wales and across the UK and would welcome a meeting to discuss these proposals.