

# Coeliac UK Strategy

## “No life limited by coeliac disease”

### Our Strategy 2025+

Our strategy centres around three themes: **Diagnosis & Equality, Support & Access, and Research & Advocacy**. Through these, Coeliac UK aims to increase diagnosis, extend support, improve the accessibility of gluten free food, and contribute to life-changing research.

Under these themes we have five strategic pillars, and for each one a stated overarching ambition as shown below:

	Diagnosis & Equality	Support & Access	Research & Advocacy
Strategic Pillars	<p>Help more people to get an accurate diagnosis quickly, regardless of who they are.</p>	<p>Provide support and connection for people affected by coeliac disease when and where needed</p> <p>Improve access to gluten free food for anyone who needs it, wherever they are.</p>	<p>Drive research aimed at improving the lives of people with coeliac disease, and ultimately find a cure</p> <p>Influence decision makers to choose the best options for people with coeliac disease.</p>
Ambition	<p>All people with coeliac disease are diagnosed within 2 years of their first symptom.</p>	<p>Everyone understands what they need to do to help people affected by coeliac disease, stay well</p> <p>100% availability of safe gluten free food everywhere.</p>	<p>A new treatment for coeliac disease is available in the UK by 2035, and a cure by 2050</p> <p>New legislation and corporate best practice, improves outcomes for people with coeliac disease.</p>

For each theme we have then developed key goals that will support the ambition that we have set.

## Diagnosis & Equality

Strategic Pillar	Ambition	Goal
Help more people to get an accurate diagnosis quickly, regardless of who they are.	All people with coeliac disease are diagnosed within 2 years of their first symptom.	<ul style="list-style-type: none"> <li>• 100% awareness of coeliac disease in the UK adult population.</li> <li>• 80% awareness of the symptoms of potential coeliac disease in the UK adult population.</li> <li>• Minimum of 100k self-assessments completed per annum.</li> <li>• A clinical champion for coeliac disease in every primary care or secondary care organisation in the UK.</li> <li>• A non-invasive, non-gluten diagnosis method available for all.</li> <li>• Regular coeliac disease population screening available in the UK.</li> </ul>

We will achieve our strategy for diagnosis in the following ways:

### ***Raising awareness***

We will continue to educate the public about the symptoms and impact of untreated coeliac disease. This includes national campaigns, including our month long “Coeliac Disease Awareness Month” campaign in May (linked to International Coeliac Disease Awareness day) which target’s groups who may not realise they’re at risk, such as those with a family history of coeliac disease, people with autoimmune conditions, and communities less informed about the disease. By increasing public understanding, we hope to encourage more people to seek testing to get a diagnosis.

### ***Collaborating to improve diagnostic methods***

Currently, diagnosis involves a blood test, often followed by a biopsy, but many people avoid getting a diagnosis because of the invasiveness of biopsy or difficulty of eating gluten in order to demonstrate a reaction in the blood and gut. We are funding and collaborating on research into new diagnostic pathways to develop less invasive, more accessible, diagnostic approaches to boost diagnosis rates.

### ***Advocating for routine screening***

One of the most effective strategies will be advocating for routine screening, starting with high-risk groups. For instance, people with Type 1 diabetes, autoimmune thyroid disease, and close relatives of those diagnosed with coeliac disease are all at an increased risk. Coeliac UK plans to collaborate with researchers, healthcare providers and the NHS to at least ensure that screening becomes a standard practice in these cases, thereby catching cases that might otherwise go unnoticed.

### ***Creating a national network of healthcare champions***

Another key area of focus is improving access to coeliac disease healthcare specialists. We know that in areas where they already exist, diagnosis rates are at least 50% higher than that of areas

without specialists. By identifying, training, and supporting a wider network of specialists we will help to increase diagnosis and improve the care of people with coeliac disease across the UK.

### ***Investing in digital tools***

We will continue to invest in our new website (launching in 2025) our app and other digital channels which will make it easier for individuals to assess their risk via our “Is it coeliac disease” symptom checker and learn about the next steps for diagnosis. This approach allows individuals to take the first step in the diagnostic process with privacy and convenience, increasing accessibility across age groups and regions.

## **Support & Access**

Strategic Pillar	Ambition	Goal
Provide support and connection for people affected by coeliac disease when and where they need it.	Everyone understands what they need to do to help people affected by coeliac disease stay well.	<ul style="list-style-type: none"> <li>• Increase Coeliac UK engaged “membership” to 700k.</li> <li>• At least 500k followers on social media.</li> <li>• At least 2 million unique visitors to our website p.a.</li> <li>• 100% of newly diagnosed contact Coeliac UK within 3 months.</li> <li>• Every “member” of Coeliac UK has the chance to connect with another “member” at least 4 times a year.</li> <li>• HCP training in coeliac disease compulsory for all.</li> </ul>
Improve access to gluten free food for anyone who needs it, wherever they are.	100% availability of gluten free food everywhere.	<ul style="list-style-type: none"> <li>• At least 50% of pre-packaged gluten free food certified with the crossed grain trademark in the UK.</li> <li>• Increase share of UK venues trained in gluten free food handling – public sector 100%; private sector 50%.</li> <li>• Gluten free food cost subsidy/prescribing available for 100% of those who need it in the UK.</li> <li>• Unified global legislation and standards for gluten free.</li> </ul>

We will achieve our strategy for support and access in the following ways:-

### ***Improve and expand membership***

In addition to continual enhancement and improvement to our membership services to ensure they are relevant and high quality; we will offer a new tiered membership model to increase accessibility for all. This will include a basic free tier with more limited access, and one or more premium tiers with additional benefits. This improved flexibility will help people of all backgrounds and requirements to join us for the support they need, and we hope many more will want to contribute to our work once they see the value of what we do.

### ***Virtual support and community engagement***

Coeliac UK will improve its digital resources, including its website, app, social media and online events and forums. These platforms serve as hubs for information, community interaction, and real-time updates on gluten free food availability and regulations. By leveraging digital technology,

Coeliac UK will create a strong virtual community network, where individuals can share experiences, access resources, and find support.

#### ***In person support and community events***

Through in person community events, and local meetings, we will work with our volunteers to extend the national support network. These increased opportunities to meet physically, offer some individuals the most effective way to access the emotional and practical support they need to navigate life with coeliac disease. By meeting others with the condition, it will help make coeliac disease feel less isolating and living with it easier to navigate.

#### ***Education programmes for healthcare and foodservice professionals***

To ensure understanding and appropriate support for people with coeliac disease, Coeliac UK plans to deliver enhanced education programmes for healthcare providers, and food industry professionals. We will work with medical and training institutions to integrate coeliac disease training into standardised courses, developing online training modules and certification for healthcare professionals and foodservice employees. In addition, we will advocate with the appropriate governing bodies until coeliac disease/gluten free training becomes mandatory. Part of the healthcare training will signpost patients to Coeliac UK and encourage them to join us to continue to get ongoing information and support for their condition.

#### ***Expanding accessibility to gluten free food***

We are committed to making gluten free food more widely available. By partnering with major food producers, retailers, and the foodservice industry, and expanding our food safety training and certification programmes, Coeliac UK will enable more gluten free product lines and meals, in more locations. Additionally, we will continue to develop and improve our app and digital content to help people identify safe products, and places to eat out.

#### ***Making gluten free affordable for all***

As gluten free food is the only current treatment for coeliac disease and is approximately 4 times more expensive to buy than gluten containing equivalents, we will continue to lobby and advocate for gluten free prescribing and subsidies to be accessible in all regions, especially for underserved areas and low-income individuals and families who find the gluten free diet prohibitively expensive. We will continue to work with the food and retail industry to encourage ways to bring the cost down for core gluten free products.

#### ***Gluten free advocacy and policy support***

Working alongside government bodies and health organisations nationally and internationally, Coeliac UK will continue to push for policies that support people with coeliac disease, including enhanced labelling regulations, nutritional standards, and gluten free food safety standards.

## Research & Advocacy

Strategic Pillar	Ambition	Goal
Drive research aimed at improving the lives of people with coeliac disease and ultimately find a cure.	A new treatment for coeliac disease is available in the UK by 2035, and a cure by 2050.	<ul style="list-style-type: none"> <li>50% of people with coeliac disease in the UK available on a patient registry, available for research.</li> <li>Regular clinical trials for coeliac disease established in the UK.</li> <li>Increase annual funding for coeliac disease research supported by Coeliac UK to at least £2m/annum.</li> </ul>
Influence decision makers to choose the best options for people with coeliac disease.	New legislation and corporate best practice, improves outcomes for people with coeliac disease.	<ul style="list-style-type: none"> <li>Coeliac disease recognised by the UK Government as a public health issue.</li> <li>New legislation launched to protect and improve outcomes for people with coeliac disease.</li> <li>Coeliac UK are the source of information that influencers and decision makers use to understand the needs of people with coeliac disease.</li> </ul>

We will achieve our strategy for research and advocacy in the following ways:

### ***Increased investment and focus***

Coeliac UK will increase funding for research focused on new therapeutic approaches, including immunotherapy, pharmacological interventions, and gut health. By prioritising high-potential studies, Coeliac UK aims to uncover treatments that reduce gluten sensitivity or alleviate symptoms without the need for a strict gluten free diet. We will re-invigorate the “journey to a cure” funding initiative dedicated to the search for a cure. Coeliac UK will seek donations, grants, and philanthropic support from individuals and organisations passionate about finding a cure.

### ***Global collaboration and partnerships***

Curing coeliac disease will require a global effort, and Coeliac UK will play a leading role by joining international coalitions focused on eradicating the disease. We will actively pursue partnerships with leading universities, research institutions, biotech companies, and pharmaceutical firms in the UK and internationally.

### ***Patient recruitment and research***

We actively encourage individuals with coeliac disease to join an approved patient registry. We will promote the registry as a vital resource for understanding coeliac disease. By ideally integrating the registry with NHS systems, Coeliac UK can make enrolment straightforward and accessible, increasing participation rates. We will work with research partners to encourage clinical trials focused on coeliac disease. By highlighting the UK’s established healthcare system and its growing patient registry, we will position the UK as an ideal location for clinical studies. Coeliac UK will provide information about clinical trial opportunities to individuals in the registry and through our network. By educating patients on the importance of clinical trials in developing new

treatments and finding a cure, we will encourage participation and build a community that's engaged in advancing coeliac research.

### ***Amplifying advocacy***

We will collaborate closely with policymakers and public health officials to communicate the significant impact coeliac disease has on individuals, healthcare costs, and society. By presenting evidence-based data on prevalence, diagnosis gaps, and health risks associated with untreated coeliac disease, we will emphasise the need for government recognition and action. Coeliac UK will foster partnerships with other health organisations, charities, and advocacy groups to build a coalition that emphasises coeliac disease as a critical public health issue. By working together, Coeliac UK and its partners can amplify their reach and effectiveness in gaining government recognition.

### ***Policy development and lobbying***

We will draft and submit comprehensive policy recommendations that outline necessary legislative changes to ensure safety, support, and equality for people with coeliac disease. This will include recommendations around food labelling, access to gluten free food options, and support for medical and dietary needs. Working with MPs, public health officials, and stakeholders, Coeliac UK will actively lobby for legislation that enhances the rights and protections for people with coeliac disease. This will involve engaging directly with government representatives, holding briefing sessions, and sharing expert insights to build legislative momentum. Coeliac UK will present research and case studies to demonstrate how new legislation can positively impact individuals' quality of life and reduce healthcare costs by preventing complications of undiagnosed coeliac disease. This data-driven approach will help secure legislative backing for new measures and investment.

### ***Expanded knowledge hub and outreach***

Coeliac UK will continue to maintain a central repository of up-to-date, evidence-based information on coeliac disease accessible via our channels. This will provide policymakers, influencers, and healthcare professionals with easy access to resources, including research, diagnostic guidelines, and dietary information. By hosting regular events, webinars, and roundtable discussions, we will ensure decision-makers and influencers are kept informed of the latest findings and developments in coeliac disease research and patient needs. These engagements will foster relationships and position Coeliac UK as the go-to expert.

### ***Digital outreach***

Coeliac UK will leverage media channels and social media to reach influencers and the broader public, sharing stories, infographics, and impactful statistics that convey the challenges people with coeliac disease face. These efforts will help keep the issue prominent in public and political discourse.

## Vision, mission, and values

### Our Vision: A world without coeliac disease

Ultimately, we don't want anyone to suffer from coeliac disease, or Coeliac UK to be needed anymore. Then we will have done our job.

### Our Mission: No life limited by coeliac disease

In the meantime, we want to do everything we can to make life seamless for people affected by coeliac disease. We want them to live, at least, as good a life as those not affected by the condition.

We also want to articulate values that our stakeholders recognise in the way that we work and behave towards others. Our employees have helped shape and validate these new values, known internally as our "T's" and "C's":

### Our Values:

- **Trustworthy**  
We are reliable and do what we say. We are the experts. We seek knowledge, check the facts, and give the best advice and support possible.
- **Caring**  
We care about people and our impact. We want to help everyone feel good.
- **Tenacious**  
We don't give up. We relentlessly pursue our vision. Every set back is an opportunity to learn and do better.
- **Collaborative**  
We work positively with others to achieve our mission. We are helpful. We respect differences, encourage participation, and actively listen.

These essential foundational elements have provided an up to date and relevant basis for the building blocks for our new strategy.

## Summary

Coeliac UK is committed to evolving and expanding our efforts. We will strengthen partnerships, enhance our advocacy, and foster global collaboration, ensuring that we remain an essential, evolving support system until we are no longer required. Our vision, **A world without coeliac disease**, guides us as we work tirelessly toward a future where no one's life is limited by this condition. This comprehensive strategy will enable us to meet the current needs of those affected by coeliac disease while paving the way for a future where Coeliac UK has ultimately fulfilled its vision.