

# 10,000

# Reasons

Why tackling under-diagnosis  
of coeliac disease in Northern  
Ireland matters

# Executive Summary

Coeliac UK is the national charity for people with coeliac disease and other gluten related conditions; providing independent, trustworthy advice and support, campaigning for change and funding crucial research to better understand the causes and best management of these conditions.

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## Coeliac Disease

Coeliac disease is a serious autoimmune condition, affecting around 1 in every 100 people, yet nearly half of people living with the condition in Northern Ireland have yet to receive a medical diagnosis. This translates to potentially 500,000 people in the UK and more than 10,000 in Northern Ireland, living and suffering avoidable harm due to undiagnosed coeliac disease. Studies show that 80% of children with coeliac disease are currently undiagnosed across the UK.

Symptoms are wide ranging but can include bloating, stomach cramps, vomiting, diarrhoea and tiredness. Extraintestinal symptoms can be very diverse and include anaemia, reduced bone density, skin rashes, loss of balance, numb or tingling hands and feet, cognitive slowing, anxiety and depression.

There is no cure for the condition and the only treatment is a strict gluten free diet for life. Undiagnosed and therefore untreated coeliac disease can lead to development of long term associated conditions such as osteoporosis, neurological dysfunction, fertility problems, and in rare cases lymphoma and small bowel cancer.

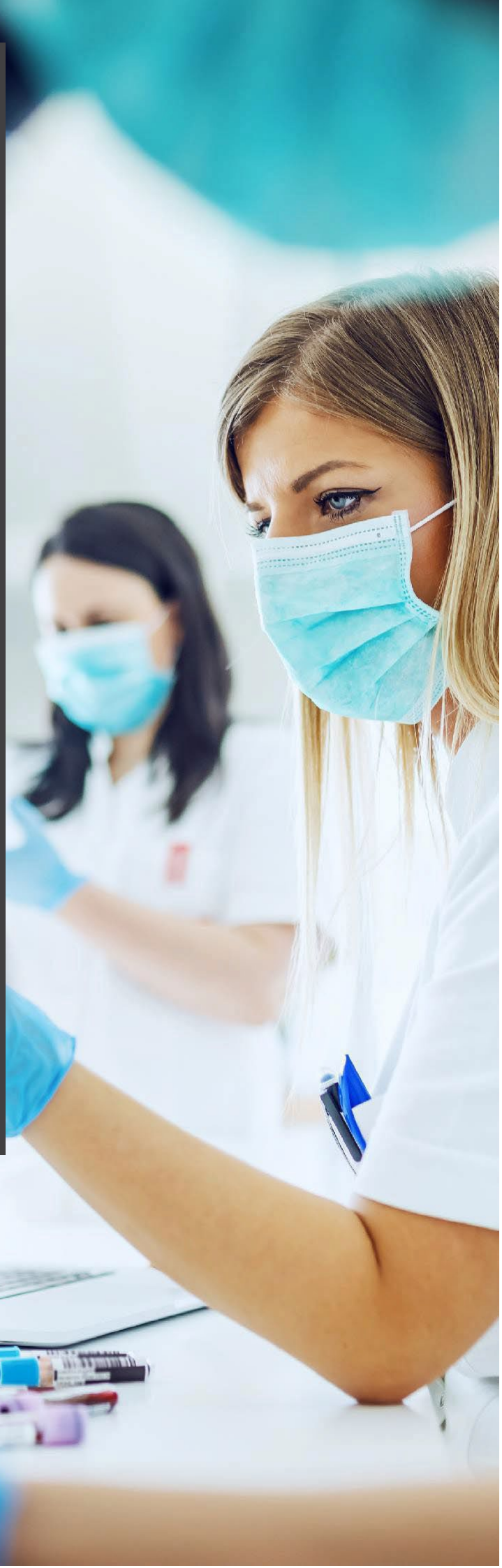
## The Issues

- **Lack of diagnosis** - Approximately half a million people across the UK are as yet undiagnosed.
- **Misdiagnosis** - 1 in 4 people with coeliac disease have previously been misdiagnosed with or treated for Irritable Bowel Syndrome (IBS).
- **Delays to diagnosis** - It takes an average of 13 years from onset of symptoms for an adult with the condition to achieve a diagnosis.
- **Long waiting times for testing** – More than three quarters (77%) of patients are now waiting over 9 weeks, an increase of ~17% compared with the same period in 2019. Meanwhile 62% are waiting over 26 weeks. A majority of people require an endoscopy as part of a successful diagnosis of coeliac disease.

Northern Ireland waiting times statistics – Diagnostic waiting quarter ending December 2021 (pub. Feb 24 2022)  
Available at: <https://www.health-ni.gov.uk/sites/default/files/publications/health/nis-ni-wts-diagnostic-waiting-times-q3-21-22.pdf> [accessed May 2024]

## Recommendations

- For the Northern Ireland executive to **support the development of a training programme** to help primary care physicians and other allied healthcare professionals to better understand the complex nature and diverse manifestations of coeliac disease.
- For the Northern Ireland executive to prioritise **adoption of a single coeliac disease clinical pathway for all Health and Social Care Trusts** in line with its '*Once for Northern Ireland*' approach coupled with long term sustainable funding.
- For the Northern Ireland executive to explore initiatives to better support primary care physicians to:
  - Encourage **earlier diagnosis** for coeliac disease based on low threshold for testing and recognition of the varied symptoms associated with the condition.
  - Encourage the **examination of people living in the community with undiagnosed coeliac disease** that may have been misdiagnosed with or treated for IBS.
- For Health and Social Care Northern Ireland to expand use of a no-biopsy protocols
  - Encourage **local audits of blood tests** against endoscopy and biopsy to standardise testing for coeliac disease.
  - Adopt standardised coeliac disease serology guidance across the service.



# Coeliac disease - a chronic, autoimmune condition

Coeliac disease is a serious autoimmune condition, where the body's immune system attacks its own tissues when gluten is eaten. **It affects around 1 in every 100 people in the UK<sup>1</sup>** and the only treatment is a strict gluten free diet for life.

Coeliac disease can present itself in a **wide variety of complex symptoms**. It is most commonly associated with gastrointestinal symptoms; however, people may also present with neurological, metabolic and/or fertility problems<sup>2</sup>.

**There is no cure for the condition** and the only treatment is a strict gluten free diet for life.

Undiagnosed and therefore untreated coeliac disease can lead to the **development of long term associated conditions** such as osteoporosis, neurological damage, fertility problems and in rare cases lymphoma and small bowel cancer <sup>3,4</sup>.

# Factors causing diagnosis delays

Coeliac disease is a common condition affecting 1% of the UK population, yet nearly half of people living with the condition in Northern Ireland have yet to receive a medical diagnosis. This translates to around potentially 500,000 people in the UK and more than 10,000 in Northern Ireland alone living and suffering avoidable harm due to undiagnosed coeliac disease<sup>1</sup>. Studies show that 80% of children with coeliac disease are currently undiagnosed across the UK<sup>1</sup>.

## Delayed diagnosis

Unfortunately, delays in diagnosis are common and considered a significant barrier to improving patient outcomes. Coeliac UK acknowledges that the average time from onset of symptoms to diagnosis in adults with coeliac disease is 13 years<sup>5</sup> – a frustrating reality for thousands across the country.

## Misdiagnosis

Roughly 1 in 4 people with coeliac disease have previously been misdiagnosed with or treated for irritable bowel syndrome (IBS)<sup>1</sup> despite **National Institute for Health and Care Excellence (NICE) guidance recommending a test for coeliac disease before any diagnosis of IBS is offered**<sup>2</sup>. The median diagnostic delay between an initial IBS diagnosis and coeliac disease is 7.1 years<sup>1</sup>. Many of the symptoms such as bloating, stomach pains or cramps, diarrhoea or constipation and feeling exhausted are the same as the symptoms of coeliac disease and awareness of these circumstances amongst healthcare professionals and the general public remains low. For example, only 3% of UK adults are aware that the symptoms of IBS are also common symptoms of coeliac disease<sup>6</sup>.

## Socioeconomic variations

Socioeconomic background plays a crucial role in determining access to a diagnosis of coeliac disease. For instance, evidence shows rates of diagnosis to be **80% lower amongst children and adults from the most-deprived areas**<sup>7</sup>.

Absence of a diagnosis can have dramatic implications for the health and growth of children. Policymakers must pay close attention to these inequities and make a robust commitment to address them.



# Health complications caused by a lack of diagnosis and treatment

It is vital that those who have coeliac disease do not consume gluten. Without a diagnosis and subsequent advice and treatment, those who continue to consume gluten may face severe health complications. Even small amounts of gluten may trigger symptoms which can develop into greater issues<sup>1</sup>.

## Irreversible neurological damage

Serious consequences of undiagnosed coeliac disease include neurological disorders, the most common being ataxia and peripheral neuropathy. Ataxia is a condition which results in slurred speech, loss of co-ordination when moving hands, arms, and legs and loss of walking balance making it difficult to complete everyday tasks<sup>8</sup>. Peripheral neuropathy can cause decreased or loss of feeling/sensation as well as pain or a tingling sensation in different parts of the body.

These conditions severely impact an individual's quality of life. A gluten free diet can help stop further neurological damage from taking place; however, existing damage is irreversible<sup>9</sup>, and it places greater emphasis on the importance of early diagnosis and adherence to treatment.

## Fertility problems and pregnancy outcomes

NICE recommends testing for coeliac disease should be considered in people with unexplained subfertility and recurrent miscarriage<sup>1</sup>. Some studies have suggested undiagnosed, and therefore untreated, coeliac disease may be an underlying cause of unexplained infertility<sup>10</sup>. In pregnancy, poorly controlled coeliac disease can increase the risk of developing certain complications, for instance, babies born with low birth weights<sup>11</sup>. Research has suggested a possible link between undiagnosed coeliac disease and adverse reproductive outcomes, such as intrauterine growth restriction, stillbirth and preterm birth<sup>4,12</sup>. Some studies call for further research to corroborate these findings<sup>13,14</sup>.

## Life-threatening complications

In rare cases, people with untreated coeliac disease can develop lymphoma, a cancer which affects the lymphatic system, a part of the body that helps fight infection. For people with coeliac disease, a strict gluten free diet reduces the risk of developing cancer<sup>15</sup>, which further reinforces the importance of early diagnosis and treatment.

## Diagnosis - current recommendations according to NICE guidelines

NICE has placed emphasis on the importance of early diagnosis and treatment of coeliac disease. NICE recommends that testing is automatically prescribed to individuals presenting with one or many of the known symptoms, including prolonged fatigue and unexplained persistent abdominal or gastrointestinal problems<sup>2</sup>.

NICE guidelines encourage early diagnosis in people showing symptoms of coeliac disease. However, the clinical community requires additional support to make these recommendations a reality.

## Roles of primary care and secondary care in diagnosis

Primary and secondary care healthcare professionals play a key role in the diagnosis of coeliac disease. GPs, nurses, pharmacists and paramedics are the natural first point of contact for the majority of people experiencing symptoms. Given the varied and complex nature of these symptoms, additional support and incentives should be explored and implemented to help patients and healthcare professionals face these challenges. Secondary care specialists play a key role in confirming a diagnosis of coeliac disease, often through an endoscopy procedure. The increasing demand placed on endoscopy services across the service is a source of strain for these vital services.

A no-biopsy strategy for coeliac disease is an innovative diagnostic approach aimed at expediting and simplifying the process of diagnosing the condition. Traditionally, the diagnosis of coeliac disease has required an invasive procedure known as an endoscopy, which involves taking a biopsy of the small intestine to confirm the presence of characteristic damage caused by gluten consumption. However, the no-biopsy strategy seeks to minimise the necessity for biopsies and their associated challenges.

In a no-biopsy pathway, a patient suspected of having coeliac disease would first undergo blood tests to measure specific markers, such as IgA tTG antibody levels.

### Early diagnosis patient case study



*Nicola explains the story of her daughter, Frankie, who was diagnosed with coeliac disease aged four.*

*“Frankie was constantly vomiting and didn’t want to move from the sofa. We knew it wasn’t right. She missed out on so much because she was so weak and unwell. Most of all she missed out on normal family life. She couldn’t even enjoy a family film.*

*“When we finally found out Frankie had coeliac disease everything completely changed.*

*“Within two days of going gluten free we had our lives back. By simply cutting out gluten we could do all the things we hadn’t been able to do for so long.*

*“She’s now a vibrant, happy and energetic little girl. My advice to parents of children with symptoms like Frankie is to request a test and listen to your instinct.”*



If these blood tests reveal significantly elevated levels, indicating a strong likelihood of coeliac disease, the next step involves consulting a gastroenterologist. This specialist evaluates the patient's clinical history, symptoms, and blood test results to determine whether an endoscopy and biopsy are required for confirmation. While most individuals would still need a biopsy for definitive diagnosis, the no-biopsy approach if applied appropriately can help reduce the pressure on waiting lists.

### Standardised serology guidance for coeliac disease in Wales

Dr Ieuan Davies (Consultant Paediatric Gastroenterologist) and Dr Richard Cousins (Consultant Clinical Immunologist) from Cardiff & Vale University Health Board worked together to develop a simple prompt to support better diagnosis of coeliac disease. By developing a standard message to accompany all paediatric coeliac serology tests, they were able to signpost the requester to the appropriate next steps. This change in reporting will help to avoid common errors in the diagnosis pathway, support other HCPs to meet the NICE quality standards and to limit disruption and harm to children. Discussions are underway to update the reporting for adult coeliac disease blood tests as well.

Typically, no-biopsy is considered for adult patients under the age of 55, whose symptoms and blood test results strongly suggest coeliac disease. This approach aims to minimise unnecessary invasive procedures, reduce patient discomfort, and expedite the diagnostic process.

The no-biopsy strategy represents a significant advancement in coeliac disease diagnosis, offering a more streamlined and patient-friendly approach that relies on a combination of clinical evaluation, serology (blood tests), and the expertise of HCPs to make accurate diagnostic decisions. Already in place for children, this approach has the potential to improve the efficiency of adult diagnosis while maintaining the accuracy and reliability necessary for appropriate patient care and reducing pressure on overburdened endoscopy waiting lists.

## Developing a coeliac pathway

The diagnostic pathway for coeliac disease and the rate of diagnosis<sup>17</sup> varies across the country and its efficacy is closely tied to local clinical engagement and leadership. The clinical pathways should be whole system focused and patient centred, with a focus on seeing the right healthcare professional at the right time. It should be dietetic led with gastroenterologists seeing only those with the most complex needs, making use of digital tools to support self-care<sup>17</sup>.

### Characteristic of an effective clinical pathway for coeliac disease:

- Focuses on whole system working to increase awareness, ensure early detection and support, and provide care which supports self-management and lifelong living well.
- Shifts care into the community with dietetic-led, patient-centred and self-management focused care with lifelong community pharmacy support.
- Gastroenterology consultants only see people with the most complex coeliac disease, e.g., when the gluten free diet has not improved symptoms and wellbeing.
- Makes use of digital platforms to better support people to manage their long term condition at home.

One such example can be seen in the Scottish coeliac pathway developed by the Scottish Government. Whilst not yet in place in all parts of Scotland, it has been successfully implemented in NHS Lothian.

### The role of dietitians

One key element of this pathway is the crucial role played by dietitians. In a standard pathway for diagnosis a patient receives a referral to a dietitian following a positive diagnosis, who helps provide advice and support around the management of a gluten free diet. They are recognised as being the experts in the field and key to the successful treatment of coeliac disease.



A survey on patients with coeliac disease found that 65% of patients' first choice would be to see a dietitian, with 80% of those requesting a specialist dietitian<sup>18</sup>. The use of dietitians is cost effective, as it means patients experience fewer complications and will become less dependent on healthcare services. Dietetic-led clinics whereby the dietitian replaces the gastroenterologist and nurse-led coeliac clinics, have proven to be particularly effective. A recent study found that dietetic-led coeliac clinics helped to identify involuntary gluten ingestion, avoid repeat endoscopy and was associated with significantly improved adherence to the gluten free diet<sup>20</sup>.

To set up a dietetic-led service requires local clinicians to champion the condition and understand the long term value gains of running a service in this way. However, there is a shortage of dietitians in the HCS, which is exacerbated by a lack of dietitians with an expertise in coeliac disease. To address this, dietitians need to be better incentivised to become experts in the diagnosis and management of coeliac disease and educated on the long term implications of poor adherence to the gluten free diet.

Approaching diagnosis in this manner aims to ensure the patient has a better understanding of their condition and the necessary tools with which to manage their condition throughout the rest of their lives. This is reflected in the Western Health and Social Care Trust's (WHSC) approach where qualified dietitians play a central role in the diagnosis of the condition, as well as its ongoing management. However this requires not just buy-in from gastroenterology colleagues and Trust leadership but also long term sustainable funding that allows for forward planning for services. Too often exemplar coeliac services in Northern Ireland have been undermined by short term funding and the need to dismantle established dietetic led clinics. A unified clinical pathway coupled with appropriate sustainable funding can deliver better, patient centred care whilst securing efficiencies for the wider HSC service. The establishment of Integrated Care System Northern Ireland offers the perfect opportunity to deliver on this promise and ensure improved health outcomes for the more than 19,000 people with coeliac disease across Northern Ireland.

## Contact

For more information and to find out how you can support our work,  
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## Recommendations

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- For the Northern Ireland executive to explore initiatives to better support primary care physicians to:
  - Encourage **earlier diagnosis** for coeliac disease based on low threshold for testing and recognition of the varied symptoms associated with the condition.
  - Encourage the **examination of people living in the community with undiagnosed coeliac disease** that may have been misdiagnosed with or treated for IBS
- For the Health and Social Care Northern Ireland to expand use of a no-biopsy protocols:
  - Encourage **local audits of blood tests** against endoscopy and biopsy to standardise testing for coeliac disease.
  - Adopt standardised coeliac disease serology guidance to adults

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## Patient case study

Scan the QR code below to listen to Gill explain how she was diagnosed with coeliac disease after she was admitted to hospital for stroke-like symptoms.



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