

50%
diagnosed
by 2025

**Improving diagnosis
rates for those living
with coeliac disease**

Executive Summary

Coeliac UK is the national charity for people with coeliac disease and other 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.

Coeliac Disease

Coeliac disease is a serious autoimmune condition, affecting around 1 in every 100 people, yet nearly two thirds of people living with the condition have yet to receive a medical diagnosis. This translates to potentially 500,000 people in the UK and more than 30,000 in Scotland, 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, low bone density, skin rashes, loss of balance, sensory symptoms, 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** - The number of people waiting more than the minimum 6-week target for an endoscopy in Scotland has increased by almost a third (31%) since the same period in 2019. A majority of people require an endoscopy as part of a successful diagnosis of coeliac disease.

NHS Scotland waiting times diagnostics (December 2022). Published February 2023.
Available at : <https://publichealthscotland.scot/publications/nhs-waiting-times-diagnostics/diagnostic-waiting-times-waits-for-key-diagnostic-tests-28-february-2023> [Accessed February 2023]

Recommendations

- For the Government 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 Government to prioritise **adoption of the coeliac disease clinical pathway by all Scottish Health Boards** in line with its *'Once for Scotland'* approach.
- For the Government to explore initiatives to better support primary care physicians to:
 - Encourage **earlier diagnostics** for coeliac disease to be prescribed; including the adoption of 'no biopsy' diagnosis protocols where applicable.
 - Encourage the **examination of people living in the community with undiagnosed coeliac disease** that may have been misdiagnosed with or treated for IBS.
 - Encourage **local audits of blood tests** against endoscopy and biopsy to standardise testing for coeliac disease.



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 UK¹** 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 problems².

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 damage, fertility problems and in rare cases lymphoma and small bowel cancer^{3,4}.

Factors causing diagnosis delays

Coeliac disease is a fairly common condition affecting 1% of the UK population, yet two thirds of people living with the condition have yet to receive a medical diagnosis. This translates to around potentially 500,000 people in the UK and more than 30,000 in Scotland alone living and suffering avoidable harm due to undiagnosed coeliac disease¹. Studies show that 80% of children with coeliac disease are currently undiagnosed across the UK¹.

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 years⁵ – 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)¹ despite **NICE guidance recommending a test for coeliac disease before any diagnosis of IBS is offered**². The median diagnostic delay between an initial IBS diagnosis and coeliac disease is 7.1 years¹. 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 British adults are aware that the symptoms of IBS are also common symptoms of coeliac disease⁶.

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**⁷.

Absence of a diagnosis can have dramatic implications to the health and growth of children. Government officials 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 issues¹.

Irreversible neurological damage

Serious consequences of undiagnosed coeliac disease include neurological disorders, the most common being ataxia and 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 every-day tasks⁸. Neuropathy can cause decreased or loss of feeling/sensation as well as pain 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 irreversible⁹, 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 miscarriage¹. Some studies have suggested undiagnosed, and therefore untreated, coeliac disease may be an underlying cause of unexplained infertility¹⁰. In pregnancy, poorly controlled coeliac disease can

increase the risk of developing certain complications, for instance, babies born with low birth weights¹¹. Research has suggested a possible link between undiagnosed coeliac disease and adverse reproductive outcomes, such as intrauterine growth restriction, stillbirth and preterm birth^{4,12}. Some studies call for further research to corroborate these findings^{13,14}.

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 cancer¹⁵, which further reinforces the importance of early diagnosis and treatment.

Scotland and the coeliac disease pathway

In 2018, a new national evidence-based **pathway for coeliac disease** was launched across four health boards (NHS Lothian, NHS Lanarkshire, NHS Greater Glasgow and Clyde and NHS Tayside). It was funded by the Scottish Government's Modernising Patient Pathways Programme, and co-produced in partnership with key stakeholders including Coeliac UK, people living with coeliac disease and clinicians. The dietetic led pathway delivers early diagnosis, early intervention and support, so people can self manage their condition with monitoring via community pharmacy¹⁶.

The pathway was seen as a success however to date adoption by health boards has been patchy and inconsistent. The charity believes implementation of the pathway on a *once for Scotland* basis should be a priority for the Scottish Government.

Diagnosis - current recommendations according to NICE guidelines

The National Institute for Health and Care Excellence (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 problems².

NICE guidelines encourage early diagnosis in people showing symptoms of coeliac disease. However, the clinical community requires additional support to face this challenge.

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 all domains of care is a source of strain for these vital services.

Serology testing has grown more sophisticated in recent years and can play a greater role in helping improve diagnosis rates. It can also help mitigate demand to endoscopy services by avoiding the need of a biopsy.

However, adoption of a no biopsy diagnosis, where applicable, has been limited in some areas. Additional support is required to ensure we tap into this potential through local audits of blood tests versus endoscopy to determine locally applicable thresholds for implementation.

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.”



Recommendations

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- For the Government to explore initiatives to better support primary care physicians to:
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 - Encourage **local audits of blood tests** against endoscopy and biopsy to standardise testing for coeliac disease.

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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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