

# Coeliac disease: recognition, assessment and management

NICE guideline

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## Your responsibility

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

All problems (adverse events) related to a medicine or medical device used for treatment or in a procedure should be reported to the Medicines and Healthcare products Regulatory Agency using the [Yellow Card Scheme](#).

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should [assess and reduce the environmental impact of implementing NICE recommendations](#) wherever possible.

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This guideline replaces CG86.

This guideline is the basis of QS134.

## Overview

This guideline covers the recognition, assessment and management of coeliac disease in children, young people and adults.

## Who is it for?

- Healthcare staff who care for people with suspected or diagnosed coeliac disease
- Laboratories carrying out testing for coeliac disease
- Commissioners and providers of coeliac services
- People with coeliac disease or suspected coeliac disease, their families and carers

# Key priorities for implementation

The following recommendations have been identified as priorities for implementation. The full list of recommendations is in the [recommendations section](#).

## Recognition of coeliac disease

- Offer serological testing for coeliac disease to:
  - people with any of the following:
    - ◇ persistent unexplained abdominal or gastrointestinal symptoms
    - ◇ faltering growth
    - ◇ prolonged fatigue
    - ◇ unexpected weight loss
    - ◇ severe or persistent mouth ulcers
    - ◇ unexplained iron, vitamin B12 or folate deficiency
    - ◇ type 1 diabetes, at diagnosis
    - ◇ autoimmune thyroid disease, at diagnosis
    - ◇ irritable bowel syndrome (in adults)
  - first-degree relatives of people with coeliac disease.
- For people undergoing investigations for coeliac disease:
  - explain that any test is accurate only if a gluten-containing diet is eaten during the diagnostic process **and**
  - advise the person not to start a gluten-free diet until diagnosis is confirmed by a specialist, even if the results of a serological test are positive.

## Serological testing for coeliac disease

- When healthcare professionals request serological tests to investigate suspected coeliac disease in young people and adults, laboratories should:
  - test for total immunoglobulin A (IgA) and IgA tissue transglutaminase (tTG) as the first choice
  - use IgA endomysial antibodies (EMA) if IgA tTG is weakly positive
  - consider using IgG EMA, IgG deamidated gliadin peptide (DGP) or IgG tTG if IgA is deficient.
- When healthcare professionals request serological tests to investigate suspected coeliac disease in children, laboratories should:
  - test for total IgA and IgA tTG, as the first choice
  - consider using IgG EMA, IgG DGP or IgG tTG if IgA is deficient.

### **Monitoring in people with coeliac disease**

- Offer an annual review to people with coeliac disease. During the review:
  - measure weight and height
  - review symptoms
  - consider the need for assessment of diet and adherence to the gluten-free diet
  - consider the need for specialist dietetic and nutritional advice.

## Non-responsive and refractory coeliac disease

- Consider the following actions in people with coeliac disease who have persistent symptoms despite advice to exclude gluten from their diet:
  - review the certainty of the original diagnosis
  - refer the person to a specialist dietitian to investigate continued exposure to gluten
  - investigate potential complications or coexisting conditions that may be causing persistent symptoms, such as irritable bowel syndrome, lactose intolerance, bacterial overgrowth, microscopic colitis or inflammatory colitis.

## Information and support

- A healthcare professional with a specialist knowledge of coeliac disease should tell people with a confirmed diagnosis of coeliac disease (and their family members or carers, where appropriate) about the importance of a gluten-free diet and give them information to help them follow it. This should include:
  - information on which types of food contain gluten and suitable alternatives, including gluten-free substitutes
  - explanations of food labelling
  - information sources about gluten-free diets, recipe ideas and cookbooks
  - how to manage social situations, eating out and travelling away from home, including travel abroad
  - avoiding cross-contamination in the home and minimising the risk of accidental gluten intake when eating out
  - the role of national and local coeliac support groups.



# Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in [NICE's information on making decisions about your care](#).

[Making decisions using NICE guidelines](#) explains how we use words to show the strength (or certainty) of our recommendations, and has information about prescribing medicines (including off-label use), professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

## 1.1 Recognition of coeliac disease

1.1.1 Offer serological testing for coeliac disease to:

- people with any of the following:
  - persistent unexplained abdominal or gastrointestinal symptoms
  - faltering growth
  - prolonged fatigue
  - unexpected weight loss
  - severe or persistent mouth ulcers
  - unexplained iron, vitamin B12 or folate deficiency
  - type 1 diabetes, at diagnosis
  - autoimmune thyroid disease, at diagnosis
  - irritable bowel syndrome (in adults)
- first-degree relatives of people with coeliac disease.

1.1.2 Consider serological testing for coeliac disease in people with any of the

following:

- metabolic bone disorder (reduced bone mineral density or osteomalacia)
- unexplained neurological symptoms (particularly peripheral neuropathy or ataxia)
- unexplained subfertility or recurrent miscarriage
- persistently raised liver enzymes with unknown cause
- dental enamel defects
- Down's syndrome
- Turner syndrome.

1.1.3 For people undergoing investigations for coeliac disease:

- explain that any test is accurate only if a gluten-containing diet is eaten during the diagnostic process **and**
- advise the person not to start a gluten-free diet until diagnosis is confirmed by a specialist, even if the results of a serological test are positive.

1.1.4 Advise people who are following a normal diet (containing gluten) to eat some gluten in more than 1 meal every day for at least 6 weeks before testing.

1.1.5 If people who have restricted their gluten intake or excluded gluten from their diet are reluctant or unable to re-introduce gluten into their diet before testing:

- refer the person to a gastrointestinal specialist **and**
- explain that it may be difficult to confirm their diagnosis by intestinal biopsy.

1.1.6 Advise people who have tested negative for coeliac disease, particularly first-degree relatives and people with type 1 diabetes, that:

- coeliac disease may present with a wide range of symptoms **and**

- they should consult their healthcare professional if any of the symptoms listed in recommendations 1.1.1 or 1.1.2 arise or persist.

1.1.7 Do not offer serological testing for coeliac disease in infants before gluten has been introduced into the diet.

## 1.2 Serological testing for coeliac disease

1.2.1 All serological tests should be undertaken in laboratories with clinical pathology accreditation (CPA) or ISO15189 accreditation.

1.2.2 When healthcare professionals request serological tests to investigate suspected coeliac disease in young people and adults, laboratories should:

- test for total immunoglobulin A (IgA) and IgA tissue transglutaminase (tTG) as the first choice
- use IgA endomysial antibodies (EMA) if IgA tTG is weakly positive
- consider using IgG EMA, IgG deamidated gliadin peptide (DGP) or IgG tTG if IgA is deficient.

1.2.3 When healthcare professionals request serological tests to investigate suspected coeliac disease in children, laboratories should:

- test for total IgA and IgA tTG as the first choice
- consider using IgG EMA, IgG DGP or IgG tTG if IgA is deficient.

1.2.4 When laboratories test for total IgA, a specific assay designed to measure total IgA levels should be used.

1.2.5 Do not use human leukocyte antigen (HLA) DQ2 (DQ2.2 and DQ2.5)/DQ8 testing in the initial diagnosis of coeliac disease in non-specialist settings.

1.2.6 Only consider using HLA DQ2 (DQ2.2 and DQ2.5)/DQ8 testing in the diagnosis of coeliac disease in specialist settings (for example, in children who are not having a biopsy, or in people who already have

limited gluten ingestion and choose not to have a gluten challenge).

- 1.2.7 Laboratories should clearly communicate the interpretation of serological test results and recommended action to healthcare professionals.

## 1.3 Referral of people with suspected coeliac disease

- 1.3.1 Refer young people and adults with positive serological test results to a gastrointestinal specialist for endoscopic intestinal biopsy to confirm or exclude coeliac disease. [In young people and adults, a positive serological test result is defined as unambiguously positive IgA tTG alone, or weakly positive IgA tTG and a positive IgA EMA test result. Note: In people who have IgA deficiency, a serologically positive result can be derived from any one of the IgG antibodies].

- 1.3.2 Refer children with positive serological test results to a paediatric gastroenterologist or paediatrician with a specialist interest in gastroenterology for further investigation for coeliac disease. [Further investigation may include, but is not limited to, one or more of the following: an IgA EMA test to confirm serological positivity, HLA genetic testing, an endoscopic biopsy].

- 1.3.3 Refer people with negative serological test results to a gastrointestinal specialist for further assessment if coeliac disease is still clinically suspected.

- 1.3.4 Healthcare professionals should have a low threshold for re-testing people identified in recommendations 1.1.1 or 1.1.2 if they develop any symptoms consistent with coeliac disease.

## 1.4 Monitoring in people with coeliac disease

- 1.4.1 Consider referring people with coeliac disease for endoscopic intestinal biopsy if continued exposure to gluten has been excluded and:

- serological titres are persistently high and show little or no change after 12 months **or**
  - they have persistent symptoms, including diarrhoea, abdominal pain, weight loss, fatigue or unexplained anaemia.
- 1.4.2 Do not use serological testing alone to determine whether gluten has been excluded from the person's diet.
- 1.4.3 Offer an annual review to people with coeliac disease. During the review:
- measure weight and height
  - review symptoms
  - consider the need for assessment of diet and adherence to the gluten-free diet
  - consider the need for specialist dietetic and nutritional advice.
- 1.4.4 Refer the person to a GP or consultant if concerns are raised in the annual review. The GP or consultant should assess all of the following:
- the need for a dual-energy X-ray absorptiometry (DEXA) scan (in line with the [NICE guideline on osteoporosis: assessing the risk of fragility fracture](#)) or active treatment of bone disease
  - the need for specific blood tests
  - the risk of long-term complications and comorbidities
  - the need for specialist referral.

## 1.5 Non-responsive and refractory coeliac disease

- 1.5.1 Consider the following actions in people with coeliac disease who have persistent symptoms despite advice to exclude gluten from their diet:
- review the certainty of the original diagnosis
  - refer the person to a specialist dietitian to investigate continued exposure to gluten

- investigate potential complications or coexisting conditions that may be causing persistent symptoms, such as irritable bowel syndrome, lactose intolerance, bacterial overgrowth, microscopic colitis or inflammatory colitis.
- 1.5.2 Diagnose refractory coeliac disease if the original diagnosis of coeliac disease has been confirmed, and exposure to gluten and any coexisting conditions have been excluded as the cause of continuing symptoms.
- 1.5.3 Refer people with refractory coeliac disease to a specialist centre for further investigation.
- 1.5.4 Consider prednisolone for the initial management of the symptoms of refractory coeliac disease in adults while waiting for specialist advice.

## 1.6 Information and support

- 1.6.1 Explain to people who are thought to be at risk of coeliac disease that a delayed diagnosis, or undiagnosed coeliac disease, can result in continuing ill health and serious long-term complications.
- 1.6.2 Give people with coeliac disease (and their family members or carers, where appropriate) sources of information on the disease, including national and local specialist coeliac groups and dietitians with a specialist knowledge in coeliac disease.
- 1.6.3 A healthcare professional with a specialist knowledge of coeliac disease should tell people with a confirmed diagnosis of coeliac disease (and their family members or carers, where appropriate) about the importance of a gluten-free diet and give them information to help them follow it. This should include:
- information on which types of food contain gluten and suitable alternatives, including gluten-free substitutes
  - explanations of food labelling
  - information sources about gluten-free diets, recipe ideas and cookbooks

- how to manage social situations, eating out and travelling away from home, including travel abroad
- avoiding cross contamination in the home and minimising the risk of accidental gluten intake when eating out
- the role of national and local coeliac support groups.

1.6.4 Be aware that people with coeliac disease may experience anxiety and depression. Diagnose and manage these issues in line with the following NICE guidelines:

- [Depression in adults with a chronic physical health problem](#)
- [Depression in children and young people](#)
- [Generalised anxiety disorder and panic disorder \(with or without agoraphobia\) in adults](#)
- [Social anxiety disorder](#).

1.6.5 Explain to people with coeliac disease and their family members or carers (as appropriate) that the [Department of Health's Green Book](#) recommends immunisation against pneumococcus.

## 1.7 Advice on dietary management

1.7.1 Advise people with coeliac disease (and their family members or carers, where appropriate) to seek advice from a member of their healthcare team if they are thinking about taking over-the-counter vitamin or mineral supplements.

1.7.2 Explain to people with coeliac disease (and their family members or carers, where appropriate) that they may need to take specific supplements such as calcium or vitamin D if their dietary intake is insufficient.

1.7.3 Explain to people with coeliac disease (and their family members or carers, where appropriate) that:

- they can choose to include gluten-free oats in their diet at any stage **and**
- they will be advised whether to continue eating gluten-free oats depending on their immunological, clinical or histological response.

## Terms used in this guideline

### IgA deficiency

IgA deficiency is defined as total IgA less than 0.07 g per litre.



## Context

Coeliac disease is an autoimmune condition associated with chronic inflammation of the small intestine, which can lead to malabsorption of nutrients. Dietary proteins known as glutens, which are present in wheat, barley and rye, activate an abnormal mucosal immune response. Clinical and histological improvements usually follow when gluten is excluded from the diet.

Coeliac disease can present with a wide range of clinical features, both gastrointestinal (such as indigestion, diarrhoea, abdominal pain, bloating, distension or constipation) and non-gastrointestinal (such as fatigue, dermatitis herpetiformis, anaemia, osteoporosis, reproductive problems, neuropathy, ataxia or delayed puberty). Children may also present with features such as faltering growth, static weight or progressive weight loss. Although some people present with typical symptoms, others will initially experience few or no symptoms.

Coeliac disease is a common condition. Population screening studies suggest that in the UK 1 in 100 people are affected. The complications of coeliac disease (which may or may not be present at diagnosis) can include osteoporosis, ulcerative jejunitis, malignancy (intestinal lymphoma), functional hyposplenism, vitamin D deficiency and iron deficiency.

People with conditions such as type 1 diabetes, autoimmune thyroid disease, Down's syndrome and Turner syndrome are at a higher risk than the general population of having coeliac disease. First-degree relatives of a person with coeliac disease also have an increased likelihood of having coeliac disease.

The treatment of coeliac disease is a lifelong gluten-free diet. Specific education and information, such as advice and education on alternative foods in the diet to maintain a healthy and varied intake, may increase the likelihood of adherence and a positive prognosis. These could be provided by a dietitian with experience in coeliac disease. However, access to specialist dietetic support is currently patchy in the UK.

# Recommendations for research

The Guideline Committee has made the following recommendations for research. The Committee's full set of research recommendations is detailed in the [full guideline](#).

## 1 Serological testing in people who have IgA deficiency

What is the sensitivity and specificity of IgG tissue transglutaminase (tTG), IgG endomysial antibodies (EMA) and IgG deamidated gliadin peptide (DGP) tests in detecting coeliac disease in people with IgA deficiency?

### Why this is important

IgA deficiency is significantly more common in people with coeliac disease than in the general population. People with IgA deficiency will have a false negative result when tested for IgA antibody, which may lead to a missed diagnosis of coeliac disease. A missed diagnosis may result in increased use of NHS resources and the person experiencing the risks associated with undiagnosed coeliac disease. IgG antibodies are recommended for use in place of IgA antibodies in people who have IgA deficiency, but there is limited evidence to demonstrate the sensitivity and specificity of tests for IgG antibodies – that is, IgG tTG, IgG EMA and IgG DGP – in people suspected of having coeliac disease with IgA deficiency.

## 2 Serological testing in people who test negative for anti-transglutaminase

What is the sensitivity and specificity of IgA EMA and IgA DGP tests in detecting coeliac disease in people who test negative for IgA tTG?

### Why this is important

In people with suspected coeliac disease, IgA tTG is most commonly used as the first-choice test to detect the presence of coeliac disease antibodies but some people

with coeliac disease will get a false negative result. If this happens, and if there is a strong and ongoing clinical suspicion of coeliac disease, serological testing for IgA EMA or IgA or IgG DGP antibodies should also be requested. However, there is little evidence for the sensitivity and specificity of these antibodies in people who have tested negative for IgA tTG antibodies. A clearer understanding of the sensitivity and specificity of EMA and DGP antibodies in people who have tested negative for IgA tTG will allow clinicians to better interpret test results and make a more informed diagnosis.

### **3 Dietary supplements**

Should people with coeliac disease be offered calcium and vitamin D supplements for a specific time period soon after their initial diagnosis?

#### **Why this is important**

People with coeliac disease are at an increased risk of malabsorption of key nutrients such as calcium and vitamin D. This is because of the role gluten plays in preventing these nutrients from being properly absorbed. It is not known how long the body takes to properly absorb these vitamins and minerals once a gluten-free diet is started. It is also not known whether the majority of people diagnosed with coeliac disease have enough calcium and vitamin D in their diet, or whether some people with coeliac disease are able to get enough of these nutrients from what they eat. Answering this research question will help healthcare professionals to understand whether calcium and vitamin D should be offered to everyone at the time of diagnosis and for how long these vitamin and mineral supplements should be taken.

### **4 Dietitian contribution to patient management**

How can the role of the dietitian contribute most effectively within a coeliac disease team?

#### **Why this is important**

As a gluten-free diet is the primary treatment option for people with coeliac disease, it is important that a dietitian with a specialist interest in coeliac disease should play a significant role in their care and follow-up. Many of the common problems associated with the long-term management of coeliac disease happen because of non-adherence to a gluten-free diet. It is important to explore how to maximise the effectiveness of the

dietitian's role in helping people with coeliac disease to adhere to a gluten-free diet.

## 5 Frequency of monitoring

What is the effectiveness of more frequent monitoring compared with monitoring at 12 months after diagnosis in people with newly diagnosed coeliac disease?

### Why this is important

It is currently not known how often people with coeliac disease should have their condition monitored. No research has adequately investigated the effectiveness of different monitoring frequencies. There is variation across the UK in how often people with coeliac disease have their condition monitored. Further research within this area is important to ensure that people with coeliac disease are having their condition adequately monitored.

## Implementation: getting started

This section highlights 2 areas of the coeliac disease guideline that could have a big impact on practice and be challenging to implement, along with the reasons why change is happening in these areas (given in the box at the start of each area). We identified these with the help of stakeholders and Guideline Committee members.

### **The challenge: making sure laboratories offer testing for tissue transglutaminase and endomysial antibodies**

See [recommendations 1.2.2, 1.2.3 and 1.2.7](#)

The benefit of implementing IgA tissue transglutaminase (IgA tTG) as the first-choice test will result in optimal sensitivity and specificity in serological testing. However, there is no clear guidance on how to interpret weakly positive IgA tTG results. Conducting an endomysial antibody test to follow up people with weakly positive IgA tTG test results will provide the opportunity for a secondary serological screen to inform the decision to biopsy in people with suspected coeliac disease.

### **Offering both tTG and endomysial antibodies tests**

Many laboratories currently offer only one of these tests, usually only tTG. This may be because of a lack of demand, lack of equipment, or a lack of expertise to conduct the endomysial antibodies (EMA) test. Some laboratory staff may not be trained or may not have experience in carrying out EMA tests.

## What can laboratories do to help?

- Work with commissioners and local pathology networks to make a business case. If demand is sufficient they may wish to include offering EMA tests in-house (this may include purchasing new equipment such as immunofluorescence microscopes and slide staining equipment, and training staff to carry out EMA testing). Or if demand is low, look at alternative options to providing EMA testing in-house, such as sending samples for testing to other laboratories in their network.

## Ensuring that anti-tTG assays have been appropriately validated in each laboratory before use

There are several different testing kits and methods available to laboratories to detect tTG. However, in the absence of international standards for IgA (and IgG) anti-tTG, there is wide variability in sensitivity and specificity between these assays and currently no method to ensure comparability between tests.

## What can laboratories do to help?

- Internally validate their serological testing assays and develop an appropriate threshold for their local screening population to ensure optimal diagnosis, and re-audit this threshold at regular time intervals.

## Interpreting the results of the tTG and EMA tests

Often laboratories report the results of the assays to the requesting GP as numbers, with no other indication about whether coeliac disease is serologically suspected or not. Without help or explanation of the appropriate threshold, it is possible that the requesting GP could wrongly interpret the result.

## What can laboratories do to help?

- Change the way the results of serological assays are reported to clearly state if coeliac disease is suspected so that the results are not open to incorrect interpretation by the requesting GP.

## The challenge: making sure people have access to a

## healthcare professional trained to give specialist dietetic advice in relation to coeliac disease

See [recommendation 1.4.3](#) and [recommendation 1.5.1](#)

The only treatment for coeliac disease is for the person to follow a gluten-free diet. The advice and support of a healthcare professional with specialist knowledge of the dietary requirements of coeliac disease is one approach to help ensure lifelong adherence to a gluten-free diet.

### Providing access to a healthcare professional trained to give specialist dietetic advice in both primary and secondary care settings

There is a lack of dietitians in the NHS nationally, and specifically a lack of dietitians who have a specialist interest in coeliac disease or gastroenterology. This leads to variation in the provision of specialist dietetic advice.

### What can commissioners and providers of services for people with coeliac disease do to help?

- Work together to develop a local service model for follow-up care for people with coeliac disease. This model could include having access to specialist dietitians, group clinics or pharmacy-based support. It could also cover developing the skills and knowledge of existing dietitians or other healthcare professionals in coeliac disease using training. For example, dietitians could attend the [British Dietetic Association's course Coeliac disease: an overview of management](#), and community pharmacists could work through the learning in the coeliac disease section of the [Centre for Pharmacy Postgraduate Education's The Learning Pharmacy](#). Both these resources have been developed in conjunction with Coeliac UK.
- Visit the [NICE local practice collection](#) to see examples on, or to share, innovative models of care.

## Finding more information and committee details

To find NICE guidance on related topics, including guidance in development, see the [NICE webpages on blood and immune system conditions](#) and [digestive tract conditions](#).

For full details of the evidence and the guideline committee's discussions, see the [full guideline](#). You can also find information about [how the guideline was developed](#), including details of the committee.

NICE has produced [tools and resources to help you put this guideline into practice](#). For general help and advice on putting our guidelines into practice, see [resources to help you put NICE guidance into practice](#).



# Update information

## Minor changes since publication

**January 2020:** Recommendation 1.6.5 was added to link to the Department of Health's advice on vaccination against pneumococcus for people with coeliac disease.

**February 2016:** Units in terms used section for IgA deficiency corrected.

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# Accreditation

