

# Coeliac disease: recognition, assessment and management

Information for the public

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[nice.org.uk](http://nice.org.uk)

## About this information

NICE guidelines provide advice on the care and support that should be offered to people who use health and care services.

This information explains the advice about coeliac disease that is set out in NICE guideline NG20.

This replaces advice on coeliac disease that NICE produced in 2009.

## *Does this information apply to me?*

Yes, if you have:

- symptoms that suggest you might have coeliac disease
- been diagnosed with coeliac disease
- a condition that means you would be more likely to develop coeliac disease (for example, type 1 diabetes or a thyroid condition)
- a close relative (parent, child, brother or sister) who has coeliac disease.

It does not cover other conditions affecting the stomach or intestine (the tube between the stomach and anus [the opening to the outside of the body at the end of the digestive system]).

## Coeliac disease

When someone has coeliac disease, their small intestine (the part of the intestine where food is absorbed) becomes inflamed if they eat food containing gluten. This reaction to gluten makes it difficult for them to digest food and nutrients. Gluten is found in foods that contain wheat, barley and rye (such as bread, pasta, cakes and some breakfast cereals).

Symptoms of coeliac disease may be similar to those of other conditions such as irritable bowel syndrome. Common symptoms include indigestion, constipation, diarrhoea, bloating or stomach pain. People can also develop anaemia (a condition in which a person doesn't have enough red cells in their blood to carry oxygen around the body); lose weight; or have ongoing tiredness, thinning bones, reproductive problems, or problems that affect growth or puberty. Some people might have several of these symptoms, but others might have very few or no symptoms. Some people may have had symptoms for a long time.

When people eat gluten and their small intestine becomes inflamed, their bodies produce antibodies, which can show up on a blood test. Once coeliac disease has been diagnosed, the main treatment is to avoid eating foods that contain gluten for the rest of their lives (a lifelong gluten-free diet).

## Your care team

A range of professionals who specialise in different areas of treatment or support may be involved in your care. These could include doctors (including gastroenterologists, who specialise in problems with the stomach and intestines), dietitians, nurses, GPs and pharmacists. All of these professionals will be trained and experienced in providing particular treatments or support.

## *Working with you*

Your care team should talk with you about coeliac disease. They should explain any tests, treatments or support you should be offered so that you can decide together what is best for you. Your family or carer can be involved in helping to make decisions, but only if you agree. If you are a child or young person your parent or carer may be involved in helping to make decisions depending on your age. There are questions throughout this document that you can use to help you talk with your care team.

You may also like to read NICE's information for the public on [patient experience in adult NHS services](#). This sets out what adults should be able to expect when they use the NHS. We also have more information on the NICE website about [using health and social care services](#).

Some treatments or care described here may not be suitable for you. If you think that your treatment does not match this advice, talk to your healthcare team.

## When you should be tested for coeliac disease

Your doctor should discuss with you having a blood test for coeliac disease if you have any of the following:

- problems related to your stomach or intestines (such as diarrhoea, abdominal pain, vomiting or nausea) that are long-lasting and can't be explained by anything else
- ongoing tiredness
- unexpected weight loss (for example, you are losing weight but you are not on a diet)
- mouth ulcers that are severe or long-lasting
- anaemia, or a deficiency in vitamin B12 or folate (also known as vitamin B9 or folic acid) that can't be explained by anything else
- irritable bowel syndrome (if you are an adult)
- type 1 diabetes
- autoimmune thyroid disease (when a person's immune system attacks and damages their thyroid gland; the gland in the neck that produces hormones controlling metabolism, growth and development).

You should also be offered a blood test for coeliac disease if one of your close relatives (such as your parent, child, brother or sister) has coeliac disease. Children who are not growing as fast as expected should also be offered a test. But babies shouldn't be tested before they have started eating foods containing gluten.

You might also be offered a blood test if you have any of the following:

- reduced bone density or soft bones
- abnormal liver test results
- unexplained problems with your nervous system (for example, problems with your balance or coordination, or numbness or tingling in your hands or feet)
- problems getting pregnant, or recurrent miscarriage (3 or more miscarriages in a row)
- damage to the enamel on your teeth (the hard outer layer of the tooth) – for example, grooves in your teeth
- Down's syndrome or Turner syndrome.

If you are thought to be at risk of coeliac disease your doctor should explain to you that there are risks to your long-term health if you have coeliac disease and it's not diagnosed or there is a delay in getting the diagnosis.

### *What to eat while waiting to have a blood test*

If you are having blood tests for coeliac disease, you will need to eat some gluten so that the tests can pick up the antibodies. If you take the tests without eating gluten, the results may not be accurate. You should eat some gluten in more than one meal every day for 6 weeks before you have the blood tests. You should carry on eating foods containing gluten until you have had coeliac disease confirmed by a specialist.

If you have already stopped eating gluten or have cut down, and you don't want to eat it again or you can't, the blood tests won't be appropriate for you. You should be referred to see a doctor who specialises in treating people with stomach and intestine problems (called a gastrointestinal specialist). They may want to perform a biopsy to find out more information. During a biopsy, your specialist will look inside your intestine for any inflammation or damage by passing a long thin tube with a camera attached down your throat and into your intestine. They will also take some tissue samples for testing. But your doctor should explain to you that it may not be possible to confirm a diagnosis of coeliac disease by having a biopsy.

#### Questions about finding out what is wrong (diagnosis)

- Please give me more details about the tests I should have.

- What do these tests involve?
- Why might a biopsy not be able to confirm the diagnosis?
- How long will it take to get the results?
- Can you give me any help or information about what I should and should not eat?

## What do the blood test results mean?

If you are aged 16 years or over and your blood test is abnormal (suggesting that you probably have coeliac disease) you should be referred to a specialist in stomach and intestine problems. You will need to have a biopsy to confirm whether or not you have coeliac disease.

If you are under 16 and your blood test is abnormal, you should be referred to a paediatric gastroenterologist (a children's doctor who also has training and expertise in diseases of the stomach and intestine), for more tests (for example, blood tests for genetic testing).

If your blood test is normal (suggesting you don't have coeliac disease) it doesn't necessarily mean that you will never have coeliac disease. Your body might not start producing antibodies straight away in response to the inflammation in your gut, and symptoms may appear later on. So you should be advised to contact your doctor if any of the symptoms listed in [when you should be tested for coeliac disease](#) persist, or if you get any of these symptoms. This is particularly important if you have type 1 diabetes or you have a close relative with coeliac disease.

If your blood test is normal but your doctor thinks that you might have coeliac disease you should still be referred to a specialist for more tests.

## Information and support

If you have been diagnosed with coeliac disease your healthcare professional should explain to you (and members of your family or your carers, if appropriate) that eating a gluten-free diet is the medical treatment for coeliac disease. They should also give you information to help you with this, including information on:

- where to find out about coeliac disease and the gluten-free diet, including national and local coeliac support groups and specialist dietitians

- which types of food contain gluten and suitable alternatives that you'll be able to eat without getting a reaction
- understanding labels on food, such as whether something contains gluten
- recipe ideas and cookbooks for gluten-free meals
- advice when eating out, travelling away from home, and travelling abroad
- how to avoid cross-contamination at home by keeping foods containing gluten away from other foods, and how to reduce the risk of eating gluten accidentally when eating out.

## Diet

If you have been diagnosed with coeliac disease you will be advised to follow a gluten-free diet for the rest of your life. Many naturally occurring foods, such as vegetables, don't normally contain gluten. Some man-made foods that contain gluten, such as pasta, have gluten-free alternatives that are available to buy. Most people with coeliac disease can eat gluten-free oats. However, a small number of people may still be sensitive to oats because they contain a protein that is similar to gluten. Your doctor or specialist dietitian may advise you to stop eating gluten-free oats depending on your symptoms and blood test results (see [checking your condition](#)).

People with coeliac disease sometimes don't absorb enough nutrients from their diet because the gluten has damaged their gut. But once someone has been on a gluten-free diet for a while this shouldn't be a problem. This is because removing gluten from your diet can help to heal your gut. If you are thinking about taking vitamin or mineral supplements you should talk to a member of your healthcare team for specific advice on your needs. Your doctor may advise you to take specific supplements such as vitamin D or calcium to help keep your bones strong if you are not getting enough of these nutrients from your diet.

### Questions about coeliac disease

- Can you tell me more about coeliac disease?
- Are there any support organisations in my local area?
- Can you provide any information for my family/carers?
- Should I make changes to my diet?

- What will happen if I choose not to change my diet?

## Checking your condition

If you have coeliac disease it is important that you have regular check-ups. You should be offered an appointment once a year to check how things are going. During this annual review your healthcare professional should measure your weight and height and check your symptoms. They may ask you about your diet and whether you are eating any gluten, and think about whether you would benefit from specialist advice on diet and nutrition.

If there are any concerns from your annual review, you should be referred for further assessment. During the assessment the doctor will check whether you need to have a bone scan or treatment for bone disease, or whether you need to have any blood tests. They should also assess whether you're likely to have any problems caused by the disease in the future and whether you need to be referred to a specialist. If you are assessed for bone disease you may want to read our guidance on assessing the risk of osteoporosis-related fractures (see [other NICE guidance](#)).

If you have ongoing symptoms such as diarrhoea, stomach pain, weight loss, tiredness or unexplained anaemia, or your blood test results don't show any change after a year, you might be referred to have a biopsy of your intestine (see [what do the blood test results mean?](#)).

Some people with coeliac disease may experience anxiety and depression. Doctors should follow NICE guidance for diagnosing and managing these conditions (see [other NICE guidance](#)).

## Questions about following up on your gluten-free diet

- When should I start to feel better and what should I do if I don't start to feel better by then?
- What should I do if I still have symptoms?
- Are there different treatments that I could try?

## If you still have symptoms

If you have been advised not to eat gluten but are still having symptoms, your doctor may check that your diagnosis is correct and that you really do have coeliac disease. They might also check to see if anything else might be causing the symptoms, such as irritable bowel syndrome, colitis (inflammation of the colon), intolerance to lactose (a sugar found in milk) or an abnormally high level of bacteria in the intestine. They might refer you to a specialist dietitian to check whether you still might be eating food with gluten in it (for example, you might be eating it without realising).

If the original diagnosis is confirmed, and the symptoms are not caused by other conditions or by any gluten remaining in your diet, it is likely that you have what is known as 'refractory' coeliac disease. Refractory coeliac disease is when a person's condition doesn't respond to a gluten-free diet, or it does respond at first but then the symptoms return. You should be referred to a specialist for more tests, and you may be offered a steroid called prednisolone to help with your symptoms until you see the specialist.

## Sources of advice and support

- Coeliac UK, 0333 332 2033  
[www.coeliac.org.uk](http://www.coeliac.org.uk)

You can also go to [NHS Choices](#) for more information.

NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

## Other NICE guidance

- [Social anxiety disorder](#) (2013) NICE guideline CG159
- [Osteoporosis: assessing the risk of fragility fracture](#) (2012) NICE guideline CG146
- [Generalised anxiety disorder and panic disorder \(with or without agoraphobia\) in adults](#) (2011) NICE guideline CG113
- [Depression in adults with a chronic physical health problem](#) (2009) NICE guideline CG91
- [Depression in children and young people](#) (2005) NICE guideline CG28

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## Accreditation

