

Understanding NICE guidance

Information for people who use NHS services

Coeliac disease: recognition and assessment of coeliac disease

NICE 'clinical guidelines' advise the NHS on caring for people with specific conditions or diseases and the treatments they should receive.

This booklet is about the signs and symptoms that should make your doctor consider whether you might have coeliac disease, and the steps to follow when making the diagnosis in the NHS in England and Wales. It explains guidance (advice) from NICE (the National Institute for Health and Clinical Excellence). It is written for people who may have coeliac disease but it may also be useful for their families or carers or for anyone with an interest in the condition.

The booklet is to help you understand how coeliac disease should be diagnosed in the NHS. It does not describe coeliac disease or the tests or treatments for it in detail. Your GP should discuss these with you. There are examples of questions you could ask throughout this booklet to help you with this. You can get more information from the organisation on page 8.

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The advice in the NICE guideline covers:

- People with symptoms and/or signs that suggest coeliac disease.
- People with conditions that sometimes also affect people with coeliac disease such as type 1 diabetes, Down's syndrome, or thyroid conditions.
- People with close relatives (parents, children, brothers and sisters) who have coeliac disease.

It does not specifically look at:

- People with other disorders affecting the digestive system.

Your care

Your treatment and care should take into account your personal needs and preferences, and you have the right to be fully informed and to make decisions in partnership with your healthcare team. To help with this, your healthcare team should give you information you can understand and that is relevant to your circumstances. All healthcare professionals should treat you with respect, sensitivity and understanding and explain simply and clearly how coeliac disease is recognised and diagnosed.

The information you get from your healthcare team should include details of the possible benefits and risks of particular tests and treatments. You can ask any questions you want to and can always change your mind as your treatment progresses or your condition or circumstances change. If you agree, your family and carers should have the chance to be involved in decisions about your care. Your own preference is important and your healthcare team should support your choices wherever possible, but this does depend on your age. If you are over 16, or under 16 and fully understand the plan for your care, you may be able to give your own agreement. If you are too young, your parents or carers may need to agree the plan on your behalf.

Family members and carers also have the right to the information and support they need in their roles as carers.

Your treatment and care, and the information you are given about it, should take account of any religious, ethnic or cultural needs you may have. It should also take into account any additional factors, such as physical or learning disabilities, sight or hearing problems, or difficulties with reading or speaking English. Your healthcare team should be able to arrange an interpreter or an advocate (someone who supports you in putting across your views) if needed.

If people are unable to understand a particular issue or are not able to make decisions for themselves, healthcare professionals should follow the advice that the Department of Health has produced about this. You can find this by going to the Department of Health website (www.dh.gov.uk/consent). Your healthcare professional should also follow the code of practice for the Mental Capacity Act. For more information about this, visit www.publicguardian.gov.uk

Some tests may not be suitable for you, depending on your exact circumstances. If you have questions about specific tests covered in this booklet, please talk to a member of your healthcare team.

Coeliac disease

Coeliac disease is a condition in which the immune system in a person's intestine (gut) reacts to a protein called gluten. Gluten naturally occurs in wheat, barley and rye. The immune reaction makes part of the gut inflamed, which can make it difficult for the person to absorb nutrients from their food. Coeliac disease can cause a wide range of symptoms in the digestive system (such as indigestion, diarrhoea, or constipation) and in the rest of the body (such as tiredness, weight loss, bone thinning, reproductive problems or delayed puberty). Symptoms may be similar to those in other conditions, such as irritable bowel syndrome. Some people with coeliac disease have no symptoms. Most people with coeliac disease have antibodies that show on a blood test. Once the diagnosis of coeliac disease is made, the treatment is a gluten-free diet.

Questions you might like to ask your healthcare team

- Please tell me more about coeliac disease.
- Are there any support organisations in my local area?
- Can you provide any information for my family/carers?

Recognition and assessment

Your doctor should offer a blood test:

- if you have:
 - type 1 diabetes
 - autoimmune thyroid disease
 - a skin disorder called dermatitis herpetiformis
 - irritable bowel syndrome
 - anaemia without an obvious cause
 - certain symptoms related to your digestive system (such as frequent diarrhoea, abdominal pain or vomiting, nausea or sudden weight loss)
 - close relatives (parents, children, or brothers or sisters) with coeliac disease
- if you are tired all the time
- for a child who is not growing as fast as expected.

Your doctor may also offer you a blood test if you have other symptoms or conditions that sometimes occur in people with coeliac disease, such as mouth ulcers, particular types of problems with your bones or liver, Down's syndrome or persistent constipation.

Blood tests for coeliac disease are not recommended for infants who have not started to eat foods containing gluten.

If your blood test shows that you might have coeliac disease your doctor will refer you for another test (called an intestinal biopsy) in hospital or at a health centre.

Diet

Once coeliac disease has been diagnosed, the treatment is a strict gluten-free diet. However, a blood test and intestinal biopsy will show coeliac disease only if the person being tested is eating gluten regularly. It is important that you eat some gluten (for example, bread, chapattis, pasta, biscuits, or cakes) in more than one meal every day for at least 6 weeks before a blood test for coeliac disease. You should not start a gluten-free diet until intestinal biopsy confirms that you have coeliac disease. If you are already on a gluten-free diet and find it hard to reintroduce gluten, your doctor should refer you to a specialist and should explain that you may not be able to get gluten-free foods on prescription if you don't have your coeliac disease confirmed by biopsy.

If you think that your care does not match what is described in this booklet, please talk to a member of your healthcare team in the first instance.

It is important that you eat some gluten every day until your diagnosis has been confirmed by a biopsy.

Information before testing

You might have used a test for coeliac disease that you bought over the counter at a chemist. There is not yet enough evidence that over-the-counter tests are reliable. If you have used one, it is important that you talk to your doctor about the result, and you will still need to have some blood taken for another test to confirm the result.

Before you decide whether to have the blood test, your healthcare professional should explain:

- what coeliac disease is
- what it means if the test is negative
- what it means if the test is positive, and what will happen next
- the risks to your health if you have coeliac disease that has not been diagnosed.

Questions about finding out what is wrong (diagnosis)

- Please give me more details about the tests I should have.
- What do these tests involve?
- What are you testing for?
- How long will it take to get the results?
- Can you provide me with any help or information about what I should and should not eat?

After having blood tests

After your blood test, your doctor should offer to refer you to a specialist if:

- the result is positive, or
- the result is negative but your doctor still thinks that you might have coeliac disease.

You should carry on eating foods containing gluten until you have had coeliac disease confirmed by intestinal biopsy.

Questions if the blood test is positive

- Please give me more details about the tests I should have next.
- Should I make changes to my diet?
- What will happen if I choose not to change my diet?

For family members, friends or carers

- What can I/we do to help and support the person with coeliac disease?
- Is there any other support that I/we as carer(s) might find helpful or are entitled to?

More information

The organisation below can provide more information and support for people with coeliac disease. NICE is not responsible for the quality or accuracy of any information or advice provided by this organisation.

- Coeliac UK, 0870 444 8804
www.coeliac.org.uk

NHS Choices (www.nhs.uk) may be a good place to find out more. Your local patient advice and liaison service (usually known as 'PALS') may be able to give you more information and support. You should also contact PALS if you are unhappy with the treatment you are offered, but you should talk about your care with a member of your healthcare team first. If your local PALS is not able to help you, they should refer you to your local independent complaints advocacy service. If you live in Wales you should speak to NHS Direct Wales for more information on who to contact.

About NICE

NICE produces guidance (advice) for the NHS about preventing, diagnosing and treating medical conditions. The guidance is written by independent experts including healthcare professionals and people representing patients and carers. They consider the evidence on the disease and treatments, the views of patients and carers and the experiences of doctors, nurses and other healthcare professionals. Staff working in the NHS are expected to follow this guidance.

To find out more about NICE, its work and how it reaches decisions, see www.nice.org.uk/aboutguidance

This booklet and other versions of the guideline aimed at healthcare professionals are available at www.nice.org.uk/CG86. The versions for healthcare professionals contain more detailed information on the tests you should be offered.

*You can order printed copies of this booklet from NICE publications (phone 0845 003 7783 or email publications@nice.org.uk and quote reference N1860). The NICE website has a screen reader service called *Browsealoud*, which allows you to listen to our guidance. Click on the *Browsealoud* logo on the NICE website to use this service.*

We encourage NHS and voluntary organisations to use text from this booklet in their own information about coeliac disease.