NHS
National Institute for
Health and Clinical Excellence

Quick reference guide

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Coeliac disease

Recognition and assessment of coeliac disease

NICE clinical guideline 86
Developed by the Centre for Clinical Practice at NICE

Further information

Ordering information

You can download the following documents from www.nice.org.uk/CG86

- The NICE guideline – all the recommendations.
- A quick reference guide (this document) – a summary of the recommendations for healthcare professionals.
- 'Understanding NICE guidance' – a summary for patients and carers.
- The full guideline – all the recommendations, details of how they were developed, and reviews of the evidence they were based on.

For printed copies of the quick reference guide or 'Understanding NICE guidance', phone NICE publications on 0845 003 7783 or email publications@nice.org.uk and quote:

- N1859 (quick reference guide)
- N1860 ('Understanding NICE guidance').

Implementation tools

NICE has developed tools to help organisations implement this guidance (see www.nice.org.uk/CG86).

Related NICE guidance

For information about NICE guidance that has been issued or is in development, see www.nice.org.uk

- Irritable bowel syndrome in adults. NICE clinical guideline 61 (2008). Available from: www.nice.org.uk/CG61
- Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy). NICE clinical guideline 53 (2007). Available from: www.nice.org.uk/CG53
- Type 1 diabetes. NICE clinical guideline 15 (2004). Available from: www.nice.org.uk/CG15

Updating the guideline

This guideline will be updated as needed, and information about the progress of any update will be available at www.nice.org.uk/CG86

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This is a quick reference guide that summarises the recommendations NICE has made to the NHS in 'Coeliac disease: recognition and assessment of coeliac disease' (NICE clinical guideline 86).

Introduction

Coeliac disease is an autoimmune disorder that involves a heightened immunological response to ingested gluten in genetically susceptible people. It was believed to be uncommon but population-based studies show that it is much more prevalent than previously thought.

Although people with coeliac disease often have gastrointestinal symptoms, other symptoms are increasingly being recognised and some people have no symptoms at all.

Coeliac disease often coexists with other conditions.

Patient-centred care

Treatment and care, including recognition and diagnosis, should take into account patients' individual needs and preferences. Good communication is essential, supported by evidence-based information, to allow patients to reach informed decisions about their care. Follow Department of Health advice on seeking consent if needed. If the patient agrees, families and carers should have the opportunity to be involved in decisions about treatment and care. If caring for young people in transition between paediatric and adult services refer to 'Transition: getting it right for young people' (available from www.dh.gov.uk).

Key to terms

AGA: anti-gliadin antibodies

EMA: anti-endomysial antibodies

HLA DQ2/DQ8: human leukocyte antigen DQ2/DQ8

IgA: immunoglobulin A

IgG: immunoglobulin G

tTGA: anti tissue transglutaminase antibodies

NICE clinical guidelines are recommendations about the treatment and care of people with specific diseases and conditions in the NHS in England and Wales.

This guidance represents the view of NICE, which was arrived at after careful consideration of the evidence available. Healthcare professionals are expected to take it fully into account when exercising their clinical judgement. However, the guidance does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer, and informed by the summary of product characteristics of any drugs they are considering.

Implementation of this guidance is the responsibility of local commissioners and/or providers. Commissioners and providers are reminded that it is their responsibility to implement the guidance, in their local context, in light of their duties to avoid unlawful discrimination and to have regard to promoting equality of opportunity. Nothing in this guidance should be interpreted in a way that would be inconsistent with compliance with those duties.

Recognition and assessment

Signs, symptoms and conditions associated with coeliac disease

Box A. Offer serological testing to children and adults with any of the following signs, symptoms and conditions

Signs and symptoms

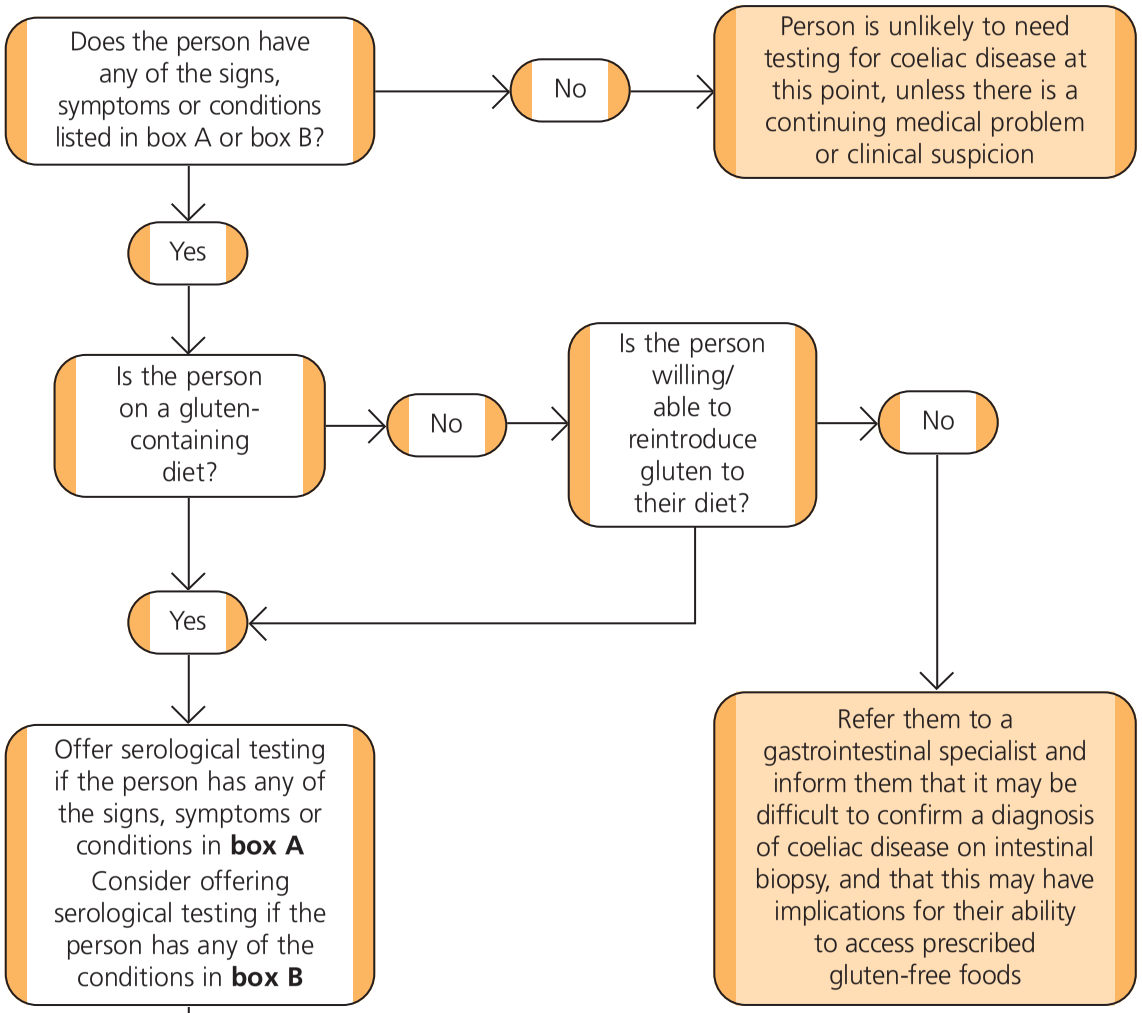
- Chronic or intermittent diarrhoea
- Failure to thrive or faltering growth (in children)
- Persistent or unexplained gastrointestinal symptoms including nausea and vomiting
- Prolonged fatigue ('tired all the time')
- Recurrent abdominal pain, cramping or distension
- Sudden or unexpected weight loss
- Unexplained iron-deficiency anaemia, or other unspecified anaemia

Conditions

- Autoimmune thyroid disease
- Dermatitis herpetiformis
- Irritable bowel syndrome
- Type 1 diabetes
- First-degree relatives (parents, siblings or children) with coeliac disease

Care pathway

Important: Do not use serological testing for coeliac disease in infants before gluten has been introduced to the diet



Box B. Consider offering serological testing to children and adults with any of the following

- Addison's disease
- amenorrhoea
- aphthous stomatitis (mouth ulcers)
- autoimmune liver conditions
- autoimmune myocarditis
- chronic thrombocytopenia purpura
- dental enamel defects
- depression or bipolar disorder
- Down's syndrome
- epilepsy
- low-trauma fracture
- lymphoma
- metabolic bone disease (such as rickets or osteomalacia)
- microscopic colitis
- persistent or unexplained constipation
- persistently raised liver enzymes with unknown cause
- polyneuropathy
- recurrent miscarriage
- reduced bone mineral density
- sarcoidosis
- Sjögren's syndrome
- Turner syndrome
- unexplained alopecia
- unexplained subfertility

Dietary considerations before serological testing

Inform people (and their parents or carers as appropriate) that:

- testing (serology and biopsy if required) is accurate only if they follow a gluten-containing diet
- when following a gluten-containing diet they should eat some gluten in more than one meal every day for at least 6 weeks before testing
- they should not start a gluten-free diet until diagnosis is confirmed by intestinal biopsy (even if a self-test or other serological test is positive)

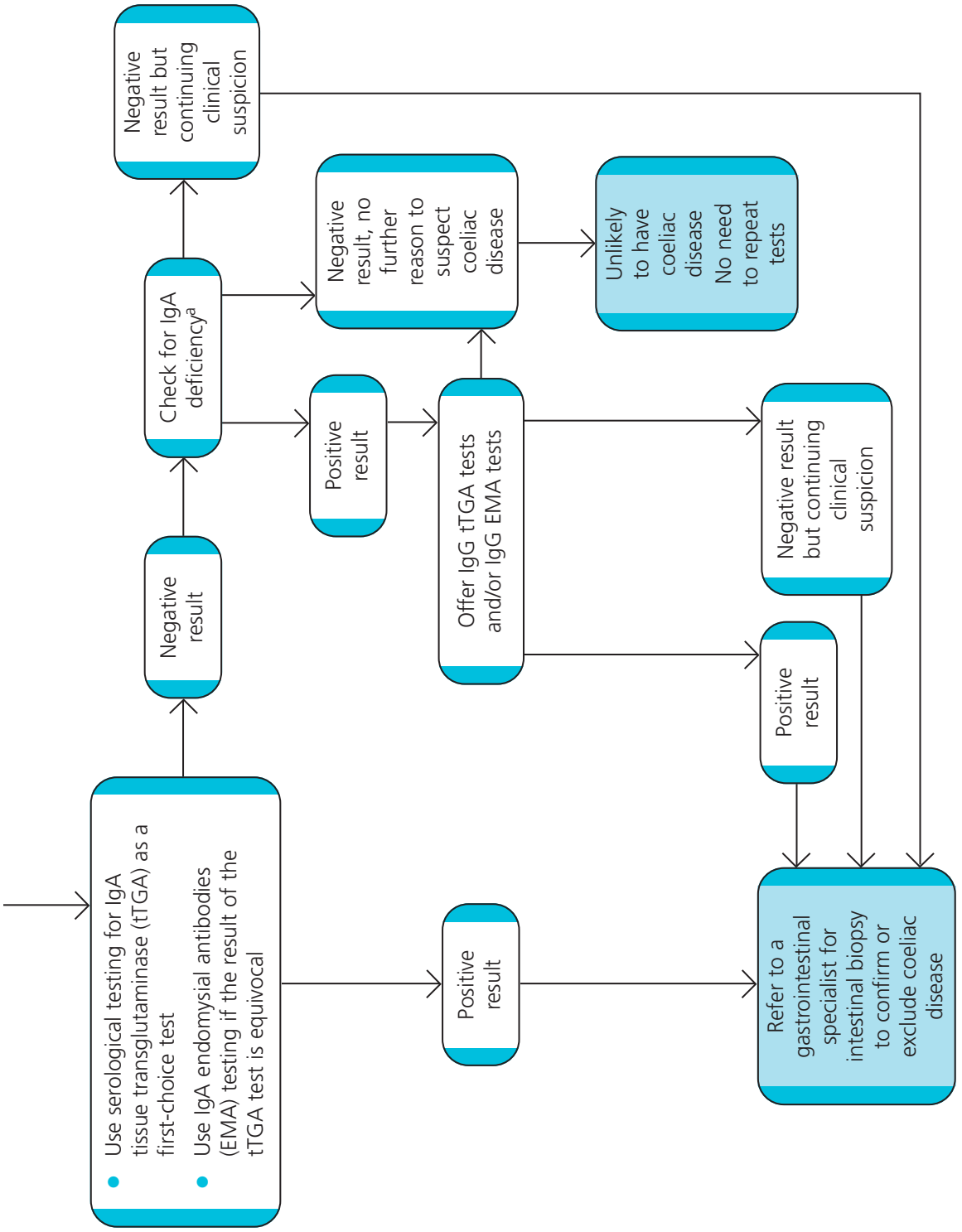
Other information before serological testing

- Inform people who are considering, or who have undertaken, self-testing for coeliac disease that any result from self-testing needs to be discussed with a healthcare professional and confirmed by laboratory-based tests
- Before seeking consent to take blood for serological tests, explain:
  - what coeliac disease is
  - that serological tests do not diagnose coeliac disease, but indicate whether further testing is needed
  - the implications of a positive test (including referral for intestinal biopsy and implications for other family members)
  - the implications of a negative test (that coeliac disease is unlikely but it could be present or arise in the future)
- Inform people (and their parents or carers as appropriate) that a delayed diagnosis of coeliac disease, or undiagnosed coeliac disease, can result in:
  - continuing ill health
  - long-term complications, including osteoporosis and increased fracture risk, unfavourable pregnancy outcomes and a modest increased risk of intestinal malignancy
  - growth failure, delayed puberty and dental problems (in children)

Important:

- All tests should be undertaken in laboratories with clinical pathology accreditation (CPA)
- Do not use IgA or IgG anti-gliadin antibody (AGA) tests in the diagnosis of coeliac disease
- Do not use HLA DQ2/DQ8 testing in the initial diagnosis of coeliac disease (However, its high negative predictive value may be of use to gastrointestinal specialists in specific clinical situations)
- Do not use self-tests and/or point of care tests for coeliac disease as a substitute for laboratory-based testing

Serology testing and after



[a] Investigation for IgA deficiency should be done if the laboratory detects a low or very low optical density on IgA tTGA test or low background on IgA EMA test.