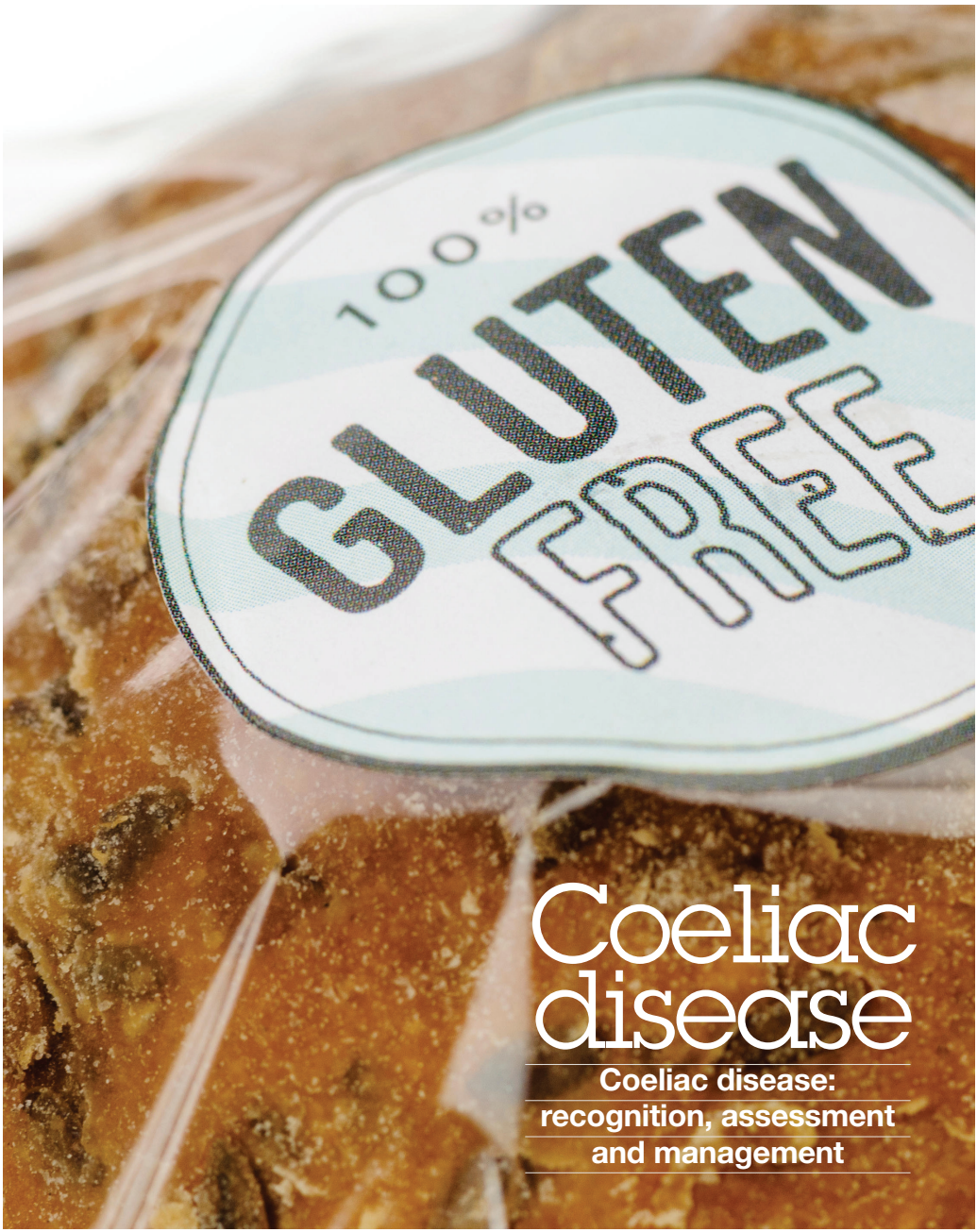

Coeliac disease

Coeliac disease: recognition, assessment and management

PULSE Nursing IN PRACTICE

Welcome

This is a summary of guidance on the recognition, assessment and management of coeliac disease in children, young people and adults. It updates and replaces NICE guideline CG86.

The full version of this guidance is available at www.nice.org.uk/guidance/ng20

Clinical guideline

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. Complications of coeliac disease (that 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

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.

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.

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.

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.

If people who have restricted their gluten intake or excluded gluten from their diet are reluctant or unable to reintroduce 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.

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 above arise or persist.

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

SEROLOGICAL TESTING FOR COELIAC DISEASE

All serological tests should be undertaken in laboratories with clinical pathology accreditation (CPA) or ISO 15189 accreditation.

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*.

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

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.

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).

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

REFERRAL OF PEOPLE WITH SUSPECTED COELIAC DISEASE

Refer young people and adults with positive serological test results* to a gastrointestinal specialist for endoscopic intestinal biopsy to confirm or exclude coeliac disease.

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

Healthcare professionals should have a low threshold for retesting people with symptoms mentioned above if they develop any symptoms consistent with coeliac disease.

MONITORING IN PEOPLE WITH COELIAC DISEASE

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.

Do not use serological testing alone to determine whether gluten has been excluded from the person's diet.

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.

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.

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.

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.

Refer people with refractory coeliac disease to a specialist centre for further investigation.

Consider prednisolone for the initial management of the symptoms of refractory coeliac disease in adults while waiting for specialist advice.

INFORMATION AND SUPPORT

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.

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.

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.

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.

ADVICE ON DIETARY MANAGEMENT

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.

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.

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.

*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.

*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.

RESOURCE

The full, updated NICE guideline on Coeliac disease: recognition, assessment and management is available to view on the NICE website at: www.nice.org.uk/guidance/ng17.

*See full guidance for footnote details.

Visit
GastroEducation.co.uk

THINK GASTRO
From confusion to clarity: raising awareness of GI conditions

TEST GASTRO
From symptoms to diagnosis: who, when and how to test

TREAT GASTRO
From diagnosis to treatment: your guide to current management recommendations

CPD
Build your CPD: A range of activities including CPD modules

EXPERT OPINIONS
Learn from the experts: Short presentations from key experts in GI disease

RESOURCES
Your clinical toolkit: Resources to aid the identification and management of GI conditions

ELIA_AD_1501
Date of preparation: October 2015

ThermoFisher SCIENTIFIC