Coeliac Disease: Recognition, Assessment and Management

1 Recognition of coeliac disease

a. 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)

   Also offer serological testing for coeliac disease to first-degree relatives of people with coeliac disease.

b. 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.

c. 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.

d. 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.

e. 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.

f. 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 (a) or (b) arise or persist.

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

2 Serological testing for coeliac disease

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

b. 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].

c. 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].

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

e. 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.

f. 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).

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

3 Referral of people with suspected coeliac disease

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

b. 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.

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

d Healthcare professionals should have a low threshold for re-testing people identified in recommendations 1 (a) and (b) if they develop any symptoms consistent with coeliac disease.

4 Monitoring in people with coeliac disease

a. 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.

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

c. 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.

d. 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.

5 Non-responsive and refractory coeliac disease

a. 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.

b. 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.

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

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

6 Information and support

a. 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.

b. 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.

c. 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.

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

7 Advice on dietary management

a. 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.

b. 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.

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