DIAGNOSIS AND MANAGEMENT OF COELIAC DISEASE

Currently only 36% of individuals with coeliac disease have been diagnosed in the UK. Undiagnosed and untreated coeliac disease can lead to haematinic deficiencies, reduced quality of life, reduced bone mineral density with increased fracture risk, refractory coeliac disease and in rare cases small bowel lymphoma.

GLUTEN MUST BE KEPT IN THE DIET BEFORE TESTING AND THROUGHOUT

The tests for coeliac disease are only accurate if a gluten containing diet is eaten. 3-6g of gluten e.g., 1.5 - 2 slices of bread and/or 90g cooked pasta, should be included daily for at least 6 weeks before testing and until the diagnosis process has been completed.

FIRST STEP PRIMARY CARE

1ST CHOICE TEST
IgA tTG and total IgA
(to test for IgA deficiency)

If IgA deficient (<0.07 mg per litre) test with any of:
- IgG tTG
- IgG EMA
- IgG DGP

POSITIVE SEROLOGY

NEGATIVE SEROLOGY → Have a low threshold for re-testing as coeliac disease can develop at any age

NEXT STEP SECONDARY CARE

REFERRAL

ADULTS
Refer to gastroenterology / coeliac service

CHILDREN
Refer to a paediatric gastroenterologist or paediatrician with a special interest in gastroenterology

Further investigations to confirm the diagnosis may include (ensure gluten is in the diet) :
- Endoscopic intestinal biopsy; including assessing for potential and ultra short coeliac disease
- No biopsy pathway tTGA 10x ULN
- Repeat serology

Endoscopy should be completed within 6 weeks of referral

For the no biopsy pathway external quality assurance for tTG assay or local audit to confirm accuracy

Negative serology but coeliac disease is still clinically suspected

Repeat serology
Ensure gluten is in the diet

Negative but ongoing clinical suspicion

Seronegative coeliac disease if:
- Villous atrophy
- Other causes of villous atrophy ruled out
- HLA DQ2/8 positive
- Improvement on a gluten free diet

DIAGNOSIS CONFIRMED

GLUTEN FREE DIET EDUCATION

Refer to a Specialist Dietitian and Coeliac UK for further advice and support, including local support groups

INDICATORS FOR TESTING

TEST RECOMMENDED

- Persistent unexplained abdominal/ gastrointestinal symptoms
- Faltering growth
- Prolonged fatigue
- Unexpected weight loss
- Severe/persistent mouth ulcers
- Unexplained iron, vitamin B12 or folate deficiency
- Type 1 diabetes (at diagnosis)
- Autoimmune thyroid disease (at diagnosis)
- Irritable bowel syndrome
- First degree relatives of people with coeliac disease

TEST TO BE CONSIDERED

- Metabolic bone disorder
- Unexplained neurological
- Unexplained subfertility or recurrent miscarriage
- Dental enamel defects
- Persistently raised liver enzymes with unknown cause
- Down syndrome
- Turner syndrome

MANAGEMENT IN ADULTS

Regular follow up for up to 2 years after diagnosis:
- Duodenal biopsy should be considered
- Symptoms assessment
- Monitor iron, folate, vit B12, vit D and calcium
- Assess LFT and TSH
- Adherence to the gluten free diet
- Physical and psychological wellbeing
- Vaccination status for more information visit coeliac.org.uk/vaccinations
- DEXA scan after first year
- Assess if long term follow up is needed

Longer term care or patient initiated follow up (PIFU) for people responding well to a gluten free diet, should be discussed and agreed between the patient and clinician.

If PIFU is appropriate, provide contact details and instructions on how to request an appointment should things change.

Patients who should be considered for longer term follow up, may include those with:
- Poor adherence to the gluten free diet
- An increased risk of poor adherence to the gluten free diet
- Lack of response to the gluten free diet
- Developed complications or related problems

The information in this summary is based on NICE and BSG Guidance and has been adapted for use by Coeliac UK.

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For more information scan the QR code, or:
Email: advocacy@coeliac.org.uk
Call our Helpline on 0333 332 2033 or visit **coeliac.org.uk/hcp**