

# PCSG

## Primary Care Society for Gastroenterology

### Follow-up care of adult coeliac disease

The purpose of this document is to assist those healthcare professionals with responsibility for the follow-up care of patients with established coeliac disease.

#### **Key facts about coeliac disease**

- The prevalence of coeliac disease is about 1 in 300, more than two thirds of whom are undiagnosed.
- The main treatment is a strict life-long gluten-free diet.
- Long-term risks of poor dietary compliance include osteoporosis, gastrointestinal malignancy and nutritional deficiency.

#### **Diagnosis of coeliac disease in primary care**

Coeliac disease is often undiagnosed or misdiagnosed in general practice unless the condition is actively considered. Coeliac disease should be considered in patients who have malabsorption symptoms or diarrhoea, anaemia, or are tired all the time, especially if there is a family history of the disease.

#### **Why follow-up patients with coeliac disease?**

- Patient compliance with a gluten-free diet is poor, ranging from 45-87%.
- The long-term health risks for patients who comply poorly with a gluten-free diet include increased risk of malignancy, nutritional deficiency and reduced bone mineral density.
- Coeliac disease is associated with an increased risk of gastrointestinal malignancy, notably lymphoma of the small intestine, although the absolute risk appears small. A strict gluten-free diet for 5 years or more protects against these malignancies.
- About a quarter of patients with coeliac disease have osteoporosis of the lumbar spine compared to 5% of matched controls. Bone mineral density improves significantly with a gluten-free diet.
- Dietary compliance positively correlates with regular follow-up and knowledge of the condition.
- Half of all coeliac patients have an inadequate energy intake, and 10% have inadequate intake of calcium and vitamin B6. 80% of elderly patients have inadequate intake of vitamin D.
- GPs are responsible for the appropriate prescription of gluten-free products.
- Regular follow-up is an opportunity to provide patient centred care that is sensitive to the individual's life circumstances.

### **How often should patients be reviewed?**

- Patients should be followed up throughout their lifetime (D).
- After diagnosis, the patient should be reviewed at the gastroenterology clinic after 3 months and 6 months to ensure they are making satisfactory progress and managing the diet (D).
- If well, they should be reviewed annually or sooner if problems arise (D).
- Follow-up assessments are currently being carried out by dietitians, nurses, general practitioners and gastroenterologists in primary and secondary care.

### **What should be done at annual assessments?**

#### *Disease status:*

- Weight, Height, Body mass index (D).
- Symptom assessment - bowel function (stool frequency, stool consistency, blood in stool) abdominal pain (D).
- Investigations: haemoglobin, red cell folate, serum ferritin, serum albumin, alkaline phosphatase. Patients with coeliac disease who adhere to a gluten-free diet often eat inadequate intakes of folic acid and iron. (B) Low haemoglobin, red cell folate, and serum ferritin may suggest persisting malabsorption warranting further assessment.
- Gliadin and endomysial antibodies to monitor significant dietary gluten ingestion (C).

#### *Disease prevention:*

##### *Osteoporosis risk assessment and management*

- DEXA at menopause for women, at 55 years for men, at any age following fragility fracture.
- Advise regular physical activity (A), reduce smoking and alcohol consumption (B).
- Calcium supplement - if poor dietary intake (A).
- Vitamin D supplements - if housebound (A).
- HRT and biphosphonates - if osteoporotic (A).

*Some degree of splenic atrophy is present in most patients with coeliac disease, and is sufficiently severe to cause peripheral blood changes in about a quarter. Patients should be considered for:*

- Vaccination against pneumococcus and haemophilus influenzae type b (D).
- Vaccination against influenza (D).
- Guidance about the increased risks attached to tropical infections e.g. malaria (D).
- Life long prophylactic antibiotics are not recommended (C).

*Medical care:*

- Management of associated medical problems.
- Discussion of familial risk if required. First-degree relatives of people with coeliac disease have a 1 in 10 chance of developing the disease, and should be assessed if they develop suggestive symptoms.
- Review prescription items.

*Self care:*

- Discuss gluten-free diet compliance and advice.
- Discuss membership of Coeliac-UK.
- Discuss use of the Coeliac-UK's Gluten-Free Food & Drink Directory.
- Dietary advice on weight, macronutrients, calcium, vitamin D, iron and fibre intake as required.

**When should the patient be under specialist care?**

*You should consider specialist referral if there is:*

- Poor response to gluten-free diet.
- Weight loss on gluten-free diet.
- Blood in stools.
- Onset of unexplained abdominal pain.
- Other clinical concerns.

**How should we organise the service?**

- Create a database of coeliac patients to facilitate recall and audit. This may be organised at practice, district or primary care organisation level.
- Use a template to record clinical data in a standardised way, in order to facilitate audit and research.
- Have a named person who will have clinical and administrative responsibility for the service.
- The service should be audited annually: audit standards may include number of patients who have recorded evidence of:
  - [1] Compliance with gluten-free diet (GFD).
  - [2] Body mass index.
  - [3] Osteoporosis assessment.

**Useful sources of information on coeliac disease**

- Primary Care Society for Gastroenterology: Decision points in the management of adult coeliac disease in primary care **[www.pcs.org.uk](http://www.pcs.org.uk)**
- British Society of Gastroenterology: Guidelines for the management of patients with coeliac disease **[www.bsg.org.uk](http://www.bsg.org.uk)**
- Coeliac-UK **[www.coeliac.co.uk](http://www.coeliac.co.uk)** provide a Gluten-Free Food & Drink Directory and patient information leaflets.

*The strength of the recommendations is based on the quality of supporting evidence:*

*[A] Evidence from randomised controlled trials.*

*[B] Evidence from other controlled or quasi-experimental studies.*

*[C] Evidence from descriptive studies.*

*[D] Expert opinion and clinical experience.*

**Report of a Primary Care Society for Gastroenterology Working Group  
August 2001**

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Printed and distributed with an educational grant from SHS International and Nutricia Dietary Care

**PCSG**  
**Primary Care Society for Gastroenterology**

**Background**

The Primary Care Society for Gastroenterology (PCSG) was founded in 1985 to provide a network for general practitioners and others interested in all clinical, research and educational aspects of gastroenterological disorders and in particular their management in primary care.

The Society has established links with the British Society of Gastroenterology and a number of other bodies. The PCSG aims to provide a general practice voice and perspective to policy makers and expert bodies.

**Promoting research in general practice**

The Society holds an annual scientific meeting and also a session at the annual British Society of Gastroenterology meeting where original papers are presented and issues concerning gastroenterology in primary care are discussed and debated.

Since the bulk of patients with gastroenterological disorders are managed in primary care the Society is keen to promote research in a general practice setting. A small number of research grants are awarded for suitable projects.

Further information and details about membership can be obtained from:

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*Revised 26<sup>th</sup> October 2001*