Oxfordshire Clinical Commissioning Group

Oxfordshire Clinical Commissioning Group Commissioning Policy Statement

Policy Statement 42g: NHS Prescribing of Gluten Free Foods

Decision making body Oxfordshire Clinical Commissioning Group

Date of issue: **November 2003, revised April 2004, updated August 2012, revised January 2014, November 2017 (no change to policy), June 2018 [1], February 2021 (no change to policy) [2], May 2022[3]**

The Oxfordshire Clinical Commissioning Group (OCCG) has reviewed Policy Statement 42e which addresses the provision of NHS prescriptions for gluten-free foods to adults and children who have been diagnosed with coeliac disease or dermatitis herpetiformis and must adhere to a gluten-free diet.

In considering this issue, the OCCG took account of the views of the public and local clinicians which were provided through an extensive public engagement exercise.

Following discussions at their Board meeting on 7 August 2012, the OCCG RECOMMENDS that NHS prescriptions are provided to adults and children for gluten-free bread, bread mix and flour only. All other gluten-free foods are a low priority for NHS funding.

A follow-up review, undertaken in October 2013, recommends that the number of units available on NHS prescription should be 8 units per patient per month regardless of age or gender.

- Number of units for bread/rolls/baguettes: 400g = 1 unit
- Number of units for flour/bread mix: = 2 units

This is in line with the Department of Health 'Report of Responses Following the Public Consultation on Gluten Free Prescribing in Primary Care' (January 2018).

Definitions:

- Any gluten free bread/flour prescribed must be approved by the Advisory Committee on Borderline Substances (ACBS)
- 'Bread' includes fresh or long life bread, rolls and baguettes but excludes pizza bases
- Flour and bread mixes may be prescribed (but other thickening substitutes; pizza mix, cake mixes; burger mixes and pastry mixes may not be prescribed)

Clinical Exceptionality – Clinicians are asked to note that the Indiv*idual Funding Request* process should be used if they consider their patient's case warrants the provision of NHS prescriptions to a wider range of gluten-free foods or they consider there is a requirement for an increased number of units.

[1] Weblinks updated and addition of reference to DoH "Report of responses following public consultation"
[2] Weblinks updated
[3] Addition of dermatitis herpetiformis

BACKGROUND INFORMATION FOR PRESCRIBERS AND PATIENTS
Part One - EQUALITY IMPACT

The QIPP Disinvestment and Threshold Group (QDTG) made its priority setting recommendations in the context of the *South Central Ethical Framework*. When considering the funding of NHS prescriptions for gluten free foods, the QDTG noted that women are at greater risk from coeliac disease than men, and that children might feel excluded on social occasions, eg, by not being able to share party food.

The QDTG was satisfied that, for the group of people diagnosed with coeliac disease, access to NHS prescriptions for gluten-free food would be equitable under the proposed policy. The most significant impact, however, is likely to be on low income families/individuals who are entitled to free NHS prescriptions. This group is likely to find it more difficult to pay supermarket prices for gluten-free foods. It is not known whether reduced access to gluten-free carbohydrate staples other than bread/flour will affect this group's adherence to a gluten-free diet. Therefore, ongoing feedback from Clinicians will be sought.

Part Two - LOCAL MANAGEMENT OF ADULTS AND CHILDREN WITH COELIAC DISEASE

1. Adult patients

In Oxfordshire, every adult diagnosed with coeliac disease or dermatitis herpetiformis should be reviewed annually by their GP. Guidelines and supporting information for GPs in the management of their adult patients are available on the OCCG intranet: Referral Guidelines Coeliac Disease Adults (June 2022).

Adults with a confirmed diagnosis of coeliac disease should be counselled about their condition and provided with information about a gluten-free diet (Coeliac UK's website: http://www.coeliac.org.uk is an excellent resource and includes recipes for a wide range of breads).

Adults should also be referred to a specialist dietitian. Referral can be made direct to the specialist dietitian at the Oxford University Hospitals:
John Radcliffe Hospital: Specialist Dietitian Phone 01865 221702/3

2. Children

Following diagnosis by a gastroenterologist, children diagnosed with coeliac disease are managed in secondary care.

Part Three - COELIAC DISEASE

Coeliac disease is a common digestive condition - it is "a state of heightened immunological response to ingested gluten in genetically susceptible people"[1]. Exposure to gluten (which is found in wheat, barley and rye) may result in a number of symptoms and adverse effects ranging from mild to very severe[2].

Coeliac disease is believed to be present in up to 1 in 100 of the population although only about 10– 15% of people with the condition are clinically diagnosed[3]. Reported cases of coeliac disease are two to three times higher in women than in men [4].

Coeliac disease may be diagnosed at any age[1]. Approximately 1,000 Oxfordshire residents may have coeliac disease.

The health risks linked to untreated and poorly managed coeliac disease include osteoporosis and increased risk of bone fractures; infertility and adverse outcomes in pregnancy; and some types of cancer[1]. Coeliac disease is managed by excluding foods that contain gluten from the diet. There are no medicines available to treat the condition, and it cannot be cured. Adults and children with confirmed coeliac disease must adhere to a life-long diet that excludes gluten[1].

When people diagnosed with coeliac disease adhere to a strict gluten-free diet most will be restored to full health and will be protected against developing long-term health complications. The law requires that foods labelled 'gluten free' can contain less than 20mg per kg of gluten. For most people with coeliac disease trace amounts of gluten will not cause a health problem. However, there are a minority of people with coeliac disease who are unable to tolerate even trace amounts of gluten[1].

A typical Western daily diet contains an estimated 10-20 grams of gluten, derived from multiple sources; a gluten-free diet therefore necessitates a calculated avoidance of many foods. Many basic foods, such as meat, fish, fruit, vegetables, cheese, milk, butter, potatoes and rice are naturally free from gluten[1], and rice, corn, soy and potato (gluten-free) flours are also available.

Nowadays, many gluten-free products and alternatives to cereal-based foods are widely available in supermarkets and health food shops[1]. However, the substitute products are generally more expensive than carbohydrate staples that contain gluten. Gluten free products provided on prescription through community pharmacists are also available to buy from supermarkets.

Research by the Food Standards Agency to investigate the nutritional adequacy of a "gluten free" diet for people with coeliac disease concluded that currently there is no robust evidence to show that individuals with coeliac disease adhering to a gluten-free diet experience any nutritional deficiency. There was also no firm evidence to show that individuals following a gluten-free diet had an inadequate intake of iron, calcium, and B vitamins.

Limited evidence is available regarding the factors associated with non-adherence to a gluten-free diet. A search of the literature found one systematic review4 which sought to establish the factors that enable people with coeliac disease to adhere to a gluten-free diet. The researchers appraised 10 studies from the international literature (2 studies were conducted in a UK setting) and concluded that the evidence for factors associated with non-adherence to a gluten free diet is of variable quality. More research is needed to characterise those adults most likely to be non-adherent in order that appropriate support can be provided.

Part four: - DERMATITIS HERPETIFORMIS

Dermatitis herpetiformis is the cutaneous manifestation of gluten-sensitive enteropathy and is precipitated by exposure to dietary gluten[6]. It is characterised by herpetiform clusters of intensely itchy urticated papules and small blisters on the elbows, knees, buttocks, and scalp. Age of onset is commonly between 30 and 50 years but may occur at any age after weaning. DH occurs more frequently in men as compared to women, in a ratio of 1.1:1 to 1.9 8 and the disease is lifelong with varying periods of activity potentially linked to dietary adherence.

Less than 10% of patients with dermatitis herpetiformis have signs or symptoms of malabsorption but most have evidence of coeliac disease that responds to a gluten free diet containing uncontaminated oats, and relapses on gluten challenge.

Dermatitis herpetiformis shares with coeliac disease an increased risk of developing lymphomas but these seem to be confined to those with severe gut involvement. The risk declines with time on a strict gluten free diet.

Dapsone is often initiated in dermatitis herpetiformis due to the rash and itch. More than 70% of patients on a strict gluten free diet are able to slowly wean off Dapsone over a 24 month period[7].

At present, the dermatitis herpetiformis-to-coeliac disease prevalence is 1:8 [8]. The incidence of dermatitis herpetiformis is decreasing, whereas that of coeliac disease is increasing, probably because of improved diagnostics.

REFERENCES

1 NICE Coeliac Disease: recognition, assessment and management (2015) https://www.nice.org.uk/guidance/ng20/resources/coeliac-disease-recognition-assessmentand-management-pdf-1837325178565

2 NHS Choices Overview – Coeliac Disease http://www.nhs.uk/conditions/coeliac-disease/Pages/Introduction.aspx

3 NICE Quality Standard QS134 (2016) https://www.nice.org.uk/guidance/qs134/resources/coeliacdisease-pdf-75545419042501

4 Systematic Review: adherence to a gluten-free diet in adult patients with coeliac disease Hall, Rubin and Charnock, 2009. https://onlinelibrary.wiley.com/doi/epdf/10.1111/j.1365-2036.2009.04053.x

5 Department of Health and Social Care Report of Responses Following the Public Consultation on Gluten Free Prescribing January 2018

6 Diagnosis and management of adult coeliac disease: guidelines from the British Society of Gastroenterology Ludvigsson JF, Bai JC, Biagi F, et al. *Gut* June 10th 2014

7 Long term follow-up of dermatitis herpetiformis with and without dietary gluten withdrawal; Fry, L et al. B r J Dermatol1982 Dec;107(6):631-40.

8 Dermatitis Herpetiformis: An Update on Diagnosis and Management Reunala, T et al; AJCD (2021) 22:329-338

9 Bolognia J, Schaffer J, Cerroni L. Dermatology. 4th ed. Elsevier; 2018

NOTES

- Potentially exceptional circumstances may be considered by a patient's CCG where there is evidence of significant health status impairment (e.g. inability to perform activities of daily living) and there is evidence that the intervention sought would improve the individual's health status. http://www.fundingrequests.cscsu.nhs.uk/
- This policy will be reviewed in the light of new evidence or new national guidance, e.g. from NICE.
- Oxfordshire CCG clinical polices can be viewed at http://www.oxfordshireccg.nhs.uk/professional-resources/policies.htm
- **Please check that you are using the most recent version of this policy**