The Association of UK Dietitians

Policy Statement

Gluten Free Food on Prescription

Summary

Coeliac disease is a lifelong autoimmune condition caused by an abnormal immune response to eating gluten. It is one of the most common gastrointestinal conditions requiring dietetic support. If untreated, coeliac disease leads to extensive intestinal villous atrophy resulting in malabsorption of essential nutrients such as calcium, iron and folate. In the long term, untreated coeliac disease can lead to complications such as osteoporosis, small bowel cancer, depression and infertility. A gluten-free (GF) diet is the sole treatment for coeliac disease and many patients find this challenging. The provision of GF staple foods on prescription plays an essential role in supporting people with this condition to adhere to a life-long strict GF diet.

The BDA believes that:

1. Coeliac disease is a condition that warrants the continued availability of staple GF foods on prescription. It is a serious and lifelong autoimmune disease the pathology of which differs from that of food allergies because the ingestion of even small amounts of gluten results in damage to the lining of the small intestine which then results in malabsorption and subsequent nutritional deficiencies as well as increased risk of malignancy.

2. People with medically diagnosed coeliac disease should have access, via prescription, to the monthly number of units of gluten free food recommended by current prescribing guidance in order to
    a. maximise compliance
    b. meet nutritional needs and prevent long term medical consequences of non-adherence to the GF diet
    c. reduce the financial burden of purchasing GF products
    d. ensure equitable access to GF products

    Registered dietitians may make recommendations that deviate from the national prescribing guidance but these will be based on individualised expert assessment, taking into account the individual's clinical condition and overall nutritional requirements.

3. The BDA supports new and innovative models for the provision of GF foods using dietetic or pharmacy-led schemes. These models have been found to be cost effective and convenient for patients and healthcare professionals.

4. The cost to the NHS of supplying prescribed GF foods is complex involving manufacturers, pharmacies and wholesalers. In some cases additional handling charges are placed by wholesalers. The BDA urges Clinical Commissioning Groups and other NHS providers to work with pharmacists and local healthcare professionals in getting the best price for providing gluten-free food on the NHS. It is possible to reduce the overall costs of supplying GF staple foods via new innovative schemes that save GP time and provide better cost control.

5. Where provider organisations are reviewing the provision of GF staple foods on prescription, the BDA recommends that Coeliac UK, local dietitians, gastroenterologists, pharmacy prescribing leads, GPs and patient representatives are fully involved in the review process. Dietetic and patient representation is particularly important when considering rationalisation of the categories and brands of gluten free foods available so as to ensure the needs of the coeliac population in general, and the specific nutritional needs of each individual patient are understood and considered.

Background

A GF diet avoids all food products that contain gluten or gluten-like proteins which means all foods made from wheat, rye and barley. These grains are present in many of the staple foods in the UK diet (e.g. bread, flour, pasta) that provide a large proportion of the energy, fibre and some of the micronutrients needed to sustain life. They may also be present in foods not considered at first appearance to contain gluten.

Patients on a GF diet are also encouraged to consume as many naturally gluten free foods (including rice and potatoes) as possible. However it is not always realistic, convenient or enjoyable to base the diet simply on rice and potatoes This means that GF alternatives to many 'staple foods need to be consumed .The national prescribing guidelines (Coeliac UK 2012)[1] focus on recommending the prescription of reasonable amounts of staple GF foods as a number of units on a monthly basis based on age, sex and average energy requirements. This will:

a) Maximise compliance:

Many patients find it challenging to manage a life-long GF diet. The difficulties in adhering to a strict GF diet and the psychological impact such as anxiety and depression have been highlighted in a number of research papers (Ciacci and Zingone 2015)[2]. A number of factors can affect adherence, including access to GF food on prescription (MacCulloch 2014 and Hall 2013)[3,4]. Patient adherence has been shown to be poor with 42 – 91% of people admitting to lapsing on a gluten-free diet. (Hall 2009)[5.]

b) Meet nutritional needs (in particular energy, fibre, iron and calcium) and prevent long term consequences of non-adherence to the diet at every life stage.

Removal of GF foods from prescription would reduce the nutritional adequacy of the diets of many people with coeliac disease (Kinsey 2008)[6].Long term complications, and their attendant healthcare costs, would increase. Current identified risks of non-compliance include: infertility, anaemia (iron deficiency anaemia and megalobastic anaemia) and other nutritional deficiencies (calcium, fibre, folate deficiencies), osteoporosis, osteopenia, increased risk of fractures, and malignancy (cancer of the gastrointestinal tract). In children long term complications include shorter stature and delayed puberty.

c) Reduce the financial burden of purchasing GF products

The cost of gluten-free products can be a cause of incomplete dietary compliance and research has found limited availability of gluten-free products across different retail outlets (Singh J and Whelan K, 2011, Burden et al 2015)[7, 8]. GF foods on prescription provide a key support for people on low income, those on welfare benefits and the elderly on pensions.

In 2014, £26.8M was spent on prescribed GF products by the NHS. This equates to an annual cost of £180 (i.e. £3.46 per week) per diagnosed patient making it one of the cheapest treatments for a long term condition in the NHS (Coeliac UK, 2015 – letter to Daily Mail)[9].

d) Ensure equitable access to GF products.

Lack of availability of GF products reduces dietary compliance (Singh and Whelan 2011)[7]. Budget supermarkets and corner shops, even the small 'local' supermarket outlets, typically have no GF foods (Singh and Whelan 2011, Burden et al 2015)[7,8]. Patients relying on these types of retail outlets for their food would be disadvantaged should GF foods on prescription be restricted.

Staple foods such as bread and pasta are particularly important for children – as they provide sufficient energy for growth and development. For school age children these staples are very important and are used to make up packed lunches when there is limited availability of gluten-free school meals.

The types of GF foods made available on prescription should not be limited without due consideration of the typical food intakes and preferences of different people in the community e.g. younger people eat more pizza and pasta than older people. Should limits be placed on one particular staple and not another then it could unfairly disadvantage vulnerable groups such as the young and the elderly.

Dietitians have a key role to play in the initial dietary assessment post diagnosis as well as monitoring annually (PCSG 2006, BSG 2014 and NICE 2015)[10,11,12]. At an annual review dietitians assess and advise on dietary compliance including the best ways to use foods naturally low in gluten as well as use prescribed GF foods effectively in order to optimise overall nutritional status.

The budgetary pressures on the NHS are significant. It is important that providers consider the instigation of innovative approaches to GF prescription so as to improve accessibility and limit cost increases. In the last few years a number of approaches have been trialled and adopted. Outcomes have been very positive in terms of acceptability to the patient and healthcare professionals. These innovative models (led by or involving dietitians) can be effective in controlling and reducing the cost of GF prescriptions while ensuring equitable and straightforward access to prescription items for patients (Fraser-Mayall 2012)[13]. The following innovative services are in operation in the UK:

1. Services supplying GF foods via pharmacy led schemes include those in Cumbria, Northamptonshire and Bedfordshire
2. A successful dietetic led service is operating in Rotherham
3. In Jersey a voucher scheme (allowing patients obtain GF foods from supermarkets free of charge) is running successfully

The cost to the NHS of prescribing many GF products is complex. It comprises the cost of the item from the manufacturer as well as additional handling costs that are charged by pharmacists and wholesalers. It is this that makes the cost to the NHS more than the cost of purchasing a similar item from the supermarket. The BDA urge NHS providers to seek to reduce the costs charged by pharmacies and wholesalers instead of restricting access to GF foods for coeliac patients. This may be achieved by rationalising the ordering and supply system. The new models referred to above have successfully reduced the cost to the NHS whilst maintaining access to GF foods on prescription for patients – rather than relying on GF product restrictions.

When considering the costs of prescribing GF foods it is important to be mindful of the cost of the long term health consequences of poor compliance. Complications, such as those listed below, will affect the frequency of visits to GPs and even secondary and tertiary health care facilities - with associated financial implications for the NHS. When calculating the consequences of non-adherence to a GF diet the following must be considered:

The increased risk of and the cost of treating:

- Depression
- Infertility
- Anaemia – iron deficiency and megaloblastic anaemias
- Osteoporosis
- Osteopenia
- Fracture
- Cancer – lymphoproliferative and gastrointestinal

Further Information and References

1. Coeliac UK, BDA, PCSG, BSPGHAN (2011) Gluten Free Foods: a revised prescribing guide https://www.coeliac.org.uk/document-library/378-gluten-free-foods-a-revised-prescribing-guide/?return=/gluten-free-diet-and-lifestyle/prescriptions/national-prescribing-guidelines/ (Last accessed 19/08/2015)
2. Ciacci,C., Zingone,F.(2015) The perceived social burden of celiac disease. Disease 2015,3,102-110;doi:10.3390/diseases3020102
3. MacColloch,K. and Rashid, M.(2014) Factors affecting adherence to the gluten free diet in children with coeliac disease. Paediatric Child Health, 19(6): 304-305.
4. Hall,N. (2013) Intentional and inadvertent non adherence in adult coeliac disease. A cross sectional survey. Appetite 68,56-62.
5. Hall,N., Rubin,G. and Charnock,A.(2009) Systematic review: adherence to a gluten free diet in adult patients with coeliac disease. Alimentary Pharmacology and Therapeutics,30, 315-330.
6. Kinsey,L et al (2008) A dietary survey to determine if patients with coeliac disease are meeting current healthy eating guidelines and how their diet compares to that of the British general population. EJCN,62:1333-1342.
7. Singh, J. & Whelan, K. (2011). Limited availability and higher cost of gluten free foods .Journal of Human Nutrition & Dietetics 24:479 – 86.
8. Burden M, Mooney PD et al (2015). Cost and availability of gluten-free food in the UK: in store and online. Postgrad Med J. 2015 Aug 26. [Epub ahead of print]
9. Coeliac UK (2015) Letter to Daily Mail. Available at https://www.coeliac.org.uk/about-us/news/coeliac-uk-letter-to-the-daily-mail-and-others-on-gluten-free/ (Last accessed at 24/8/15)

10. PCSG (2006) the management of adults with coeliac disease in primary care. Available at www.pcgs.org.uk.
11. BSG (2014) Diagnosis and management of adult coeliac disease: guidelines from the British Society of Gastroenterology Gut 2014;0:1–20. Available at: http://www.bsg.org.uk/images/stories/docs/clinical/guidelines/sbn/bsg_coeliac_14.pdf (Last accessed 19.8.2015)
12. National Institute for Health and Care Excellence (NICE)(2015) Guideline 86 Available at www.nice.org.uk.
13. Fraser-Mayall, Helen. (2012) The Future for Gluten-free Food Prescriptions. A dietitian's reflections on the 23. pharmacy-lead gluten-free prescribing scheme in Cumbria. Complete Nutrition 12 no 1: 41-43

This document has been prepared by a BDA working group including members of the BDA Gastroenterology Specialist group.

Published: September 2015
Review Date: August 2018

5th Floor, Charles House, 148/9 Great Charles Street Queensway, Birmingham B3 3HT

Tel: 0121 200 8080 Fax: 0121 200 8081 email: info@bda.uk.com