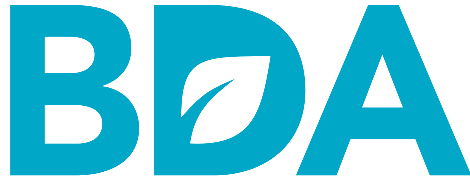

# Policy Statement
## Gluten Free Food on Prescription

---

## 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 that require dietetic support. If untreated, coeliac disease leads to extensive intestinal villous atrophy that causes malabsorption of essential nutrients such as calcium, iron vitamin B12 and folate. In the long term, untreated coeliac disease can lead to complications such as osteoporosis, lymphoma and small bowel cancer, depression and infertility. A gluten-free (GF) diet is the sole treatment for coeliac disease and many patients find this extremely challenging. The provision of GF staple foods on prescription plays an essential role in supporting people with this condition to adhere to a strict, life-long GF diet.

### The BDA states that:

1. Coeliac disease is a condition that warrants the continued availability of staple GF foods on prescription. It is a lifelong autoimmune disease with serious complications associated with non-adherence to a GF diet. The ingestion of even small amounts of gluten causes damage to the lining of the small intestine leading to malabsorption, and therefore subsequent nutritional deficiencies, in addition to an increased risk of osteoporosis, depression, infertility and malignancy.

2. People diagnosed with coeliac disease require access to staple GF foods on prescription. National prescribing guidelines (1) recommend a monthly unit allowance that, ensures equality in treatment for all with the diagnosis of coeliac disease. Gluten free prescriptions:

    a. maximise adherence and facilitate the prevention of long term medical consequences associated with non-adherence to the GF diet
    b. support individuals in meeting raised nutritional requirements, as GF foods on prescription are fortified with calcium and B vitamins.
    c. reduce the financial burden of purchasing GF products
    d. ensure equitable access to GF products

    Dietitians may make recommendations that deviate from the national prescribing guidance (which are currently under review) but these will be based on individualised expert assessment, taking into account the individual's clinical condition and overall nutritional requirements.

3. In line with the NICE Quality Standard for Coeliac Disease (2), all patients diagnosed with Coeliac Disease should receive an annual review, preferably with a dietitian. This will support GF dietary adherence and nutritional adequacy, allow symptoms to be reviewed and further appropriate information, advice and support to be provided.

4. The NHS should take advantage of new and innovative models for the provision of GF foods using dietetic-led (e.g. dietitian prescribing in Rotherham) or pharmacy-led schemes (e.g. Gluten Free Food Service in Scotland). These models have been found to be cost effective and convenient for patients and healthcare professionals.

5. 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 (CCGs) and other NHS providers to work with pharmacists and local healthcare professionals in getting the best price for providing GF food on prescription. 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.

6. 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. In England, the BDA would recommend that providers should, as a minimum, adhere to the outcomes of the national consultation that recommended GF bread, flour and flour mixes remain on prescription. Dietetic and patient representation is particularly important when considering rationalisation of the categories and brands of GF 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. breads, flour, pasta) that provide a large proportion of the energy, fibre and several of the micronutrients needed to sustain life (3). Wheat, rye or barley may also be present in foods not considered at first appearance to contain gluten (for example sausages).

Patients on a GF diet are also encouraged to consume naturally GF foods (including rice and potatoes), however it is not always realistic, nutritionally appropriate, convenient nor enjoyable to base the diet simply on rice and potatoes (for example school packed lunches). This means that GF alternatives to many ‘staple foods’ need to be consumed.

Dietitians have a key role to play in the initial dietary assessment post diagnosis as well as monitoring annually (4) (5) (6). At an annual review, dietitians assess and advise on GF dietary adherence, 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.

## Current provision

- The national prescribing guidelines (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.

- In England, individual CCGs determine whether and what GF foods are provided on prescription. There is considerable variation in provision across CCGs. The UK government consultation for provision of GF food in England (7) resulted in the recommendation of maintaining GF Breads and GF flour mixes on prescription for people with coeliac disease. Prescriptions have a fixed cost unless patients are exempted.

- In Scotland, gluten free prescribing is managed through a centrally funded, community pharmacy-led supply service called the Gluten Free Food Service. All prescriptions are free (8).

- In Wales, a full range of gluten free products continue to be available on prescription, but there are trials of alternative models of provision, such as the use of debit cards with regular dietetic follow up in West Wales. All prescriptions are free (8).

- In Northern Ireland, the Health and Social Care Board supports the prescription of gluten free staples both in terms of the quantities and range as within the national prescribing guidelines. All prescriptions are free (8).

## Rationale for provision of GF foods on prescription

Receiving GF food staples on prescription will:

a) Maximise adherence:

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 (9) (10) A number of factors can affect adherence, including access to GF food on prescription (11) (12). Adherence to a GF diet has been shown to be poor with 42 – 91% of people with coeliac disease admitting to lapsing on a GF diet (13).

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

Prescribed GF foods contribute substantially to the nutrient intake of people with coeliac disease (14) Commercially formulated GF foods are less likely to be fortified than their prescription only counterparts, only 31% of commercially available GF breads were fortified with iron or calcium, compared to 76% of prescription GF breads (15) Calcium and iron are essential micronutrients, known to be low in the diets of those with coeliac disease. Other micronutrients and minerals such as zinc, magnesium and Vitamins D and B12 have also been found to be lacking in gluten-free diets (16).

Current identified risks of non-adherence to a GF diet 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. In children long term complications include shorter stature and delayed puberty (4)

c) Reduce the financial burden of purchasing GF foods

GF foods have been found to be between two and five times more expensive than gluten containing options (17) (18) The high cost of GF foods can impact upon GF dietary adherence (19). GF foods on prescription provide a key support for people on low income, those on welfare benefits and the elderly on pensions.

It costs approximately £195 a year per patient to support GF prescriptions per diagnosed patient (4). The NICE Quality Standard recognises that "Gluten-free products are more expensive and are usually only available from larger retailers, making access more difficult for people on low incomes or with limited mobility." (2)

d) Ensure equitable access to GF products.

Budget supermarkets and corner shops, even the small 'local' supermarket outlets, typically have no GF foods (17) (18). This problem is exacerbated in more rural and isolated areas where a patient's choice of shops close to home is limited additionally in these areas supermarket online delivery is often limited too. This will have a particular impact on those on a low income, or those more vulnerable patients, who are more likely to shop in small shops close to home and budget supermarkets.

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 GF school meals.

## Alternative models of provision

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 trialed 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. The following innovative services are in operation in the UK:

- Pharmacy-led scheme utilised in Scotland (20) and some parts of England (21), or a voucher/debit card model with dietetic follow-up can improve adherence (by reducing the financial impact on patients) and maintain provision while reducing the impact on GP time and reducing wastage.

- A successful dietetic led service is operating in Rotherham, where Dietitians have full control of the prescribing budget for gluten free and other Nutritional Borderline Substances (NBS), may offer a sound alternative solution to ensuring that products are prescribed efficiently and patients receive the best standard of care and support cost effectively (22).

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 GF dietary adherence. Complications, such as those listed below, will impact 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 increased risk of and the cost of treating the following must be considered:

- Depression
- Infertility
- Anaemia – iron deficiency and megaloblastic anaemias
- Osteoporosis
- Osteopenia
- Fracture
- Cancer – lymphoma and small bowel cancer

## References


1. **Coeliac UK.** *Gluten Free Foods: A revised prescribing guide.* s.l. : Coeliac UK, 2012.
2. **National Institute for Health and Care Excellen.** *Coeliac Disease Quality Standard [QS134].* 2016. pp. 25-27.
3. **Public Health England.** *National Diet and Nutrition Survey (NDNS): Results from year 7 and 8.* London : Public Health England, 2018.
4. **National Institute for Health and Care Excellent (NICE).** *Coeliac disease: recognition, assessment and management [NG20].* 2015.
5. *Diagnosis and management of aduolt coeliac disease: Guidelines from the British Society of Gastroenterology.* **Ludvigsson JF, Bai JC, Biagi F et al.** s.l. : BSG/BMJ, 2014, Gut, Vol. 63.
6. *Joint BSPGHAN and Coeliac UK guidelines for the diagnosis and management of coeliac disease in children.* **Murch S, Jenkins H, Auth M.** s.l. : RCPCH/BMJ, 2013, Archive of Disease in Childhood , Vol. 98, pp. 806-811.
7. **Department of Health and Social Care (DHSC):.** *Report of Responses Following the Public Consultation on Fluten Free Prescribing.* London : s.n., 2018.
8. **Coeliac UK.** Prescription Policies. *Coeliac UK website* . [Online] 2018. [Cited: May 9, 2018.] https://www.coeliac.org.uk/gluten-free-diet-and-lifestyle/prescriptions/prescription-policies/.
9. *The relationship between gluten free diet adherence and depressive symptons in adults with coeliac disease: A systematic review with meta-analysis.* **Sainsbury, K and Marques, M M.** s.l. : Elsevier, 2018, Appetite, Vol. 120, pp. 578-588.
10. *The perceived social burden of celiac disease.* **Ciacci, C and Zingone, F.** 2015, Diseases, Vol. 3, pp. 102-110.
11. *Adherence to a gluten free diet is associated with receiving gluten free foods on prescription and understanding food labelling.* **Muhammad H, Reeves S, Ishaq S, Mayberry J and Jeanes Y.** July 2017, Nutrients, Vol. 9, p. 705.
12. *Intentional and inadvertent non-adherence in adult coeliac disease: A cross sectional survey.* **Hall, N.** 2013, Appetite, Vol. 68, pp. 56-62.
13. *Systemnatic review: adherence to a fluten free diet in adult patients with coeliac disease.* **Hall N, Rubin G, and Charnock, A.** 2009, Ailmentary Pharmacology and Theraputics , Vol. 30, pp. 315-330.
14. *A dietary survey to determie if patients with coeliac disease are meeting current healthy eating guidelines and how their diet compares to that of the British general population.* **Kinsey L, Burden ST, Bannerman E.** 2008, European Journal of Clinical Nutrition, Vol. 62, pp. 1333-1342.
15. *A comparison of the nutritional content of a range of commercial and prescription gluten free bread products.* **Barne, Powell and.** 2017. Coeliac UK research conference.
16. *Gluten Free diet and nutrient deficiencies: a review.* **Vici G, Belli L, Biondi M, Polzonetti V.** 6, 2016, Clinical Nutrition, Vol. 35, pp. 1236-1241.
17. *Cost, availability and nutritional composition comparison between gluten free and cluten containing food stapes provided by food outlets and internet food delivery service.* **Hanzi O, Jeanes Y.** 2018. BSPGHAN AGM Abstracts. p. 31.
18. *Cost and availability of gluten-free food in the UK: in store and online.* **Burden, M, Mooney PD et al.** 2015, Postgraduate Medical Journal.

19. *Factos governing long-term adherence to a gluten-free diet in adult patients with coeliac disease.* **al., Villafuerte-Galvez J et.** 6, September 2015, Ailment Pharmacol Ther, Vol. 42, pp. 753-60.
20. **Community Pharmacy Scotland.** Gluten Free Food Service. *Community Pharmacy Scotland website.* [Online] 2017. [Cited: May 9, 2018.] www.communitypharmacyscotland.org.uk/nhs-care-services/services/glute-free-foods/.
21. **H, Fraser-Mayall.** The future of Gluten-Free Prescriptions: A dietitian's reflections on the pharmacy-led gluten free prescribing scheme in Cumbria. *Complete Nutrition.* 12, 2012, 1, pp. 41-43.
22. **Ward J, Lakin, S.** The Rotherham Nutrition Prescribing Project. *CN Focus.* June 2012, Vol. 4, 2, pp. 47-49.

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

First Published: September 2015
Reviewed: July 2018
Next Review: July 2021

©2015 The British Dietetic Association
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

Commercial copying, hiring or lending without the written permission of the BDA is prohibited.