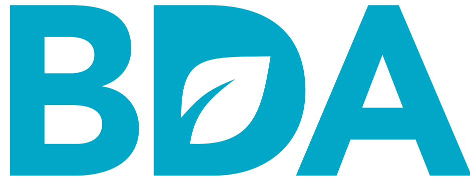

The Association
of UK Dietitians

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 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 B_{12} and folate. In the long term, gluten consumption in 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 facilitate adherence to their treatment; a strict, life-long GF diet. Excluding gluten from the diet requires removal of many staple food items such as breads and pasta, additionally gluten is found in many processed foods, requires people to develop skills and knowledge to navigate the numerous sources of gluten in and out of the home environment.

The BDA states that:

- Coeliac disease is a condition that warrants the continued availability of staple GF foods on prescription (such as breads, flour mixes and pasta). 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 inflammation and malabsorption, and therefore subsequent nutritional deficiencies, in addition to an increased risk of osteoporosis, depression, infertility and malignancy.

- 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:

    - help ensure equitable access to staple GF foods.
    - maximise adherence and facilitate the prevention of long-term medical consequences associated with gluten consumption.
    - support individuals in meeting raised nutritional requirements, as many GF foods on prescription are fortified with calcium and B vitamins.
    - reduce the financial burden of purchasing staple GF foods.
    - Dietitians may make recommendations that deviate from the national prescribing guidance; these will be based on expert assessment, taking into

account the individual's clinical condition, overall nutritional requirements, and external influencers of, the only treatment, GF dietary adherence.

- 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 with expertise in coeliac disease. This will support GF dietary adherence and nutritional adequacy, allow symptoms to be reviewed and further appropriate information, advice and support to be provided.

- 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), in Wales Hywel Dda University Health Board has successfully trialed a card payments scheme. These models have been found to be cost effective and convenient for patients and healthcare professionals.

- 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) in England 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.

- Where provider organisations are reviewing the provision of GF staple foods on prescription, the BDA strongly advises that Coeliac UK, local dietitians, gastroenterologists, pharmacy prescribing leads, GPs and patient representatives are fully involved in the review process and monitoring any impact of changes. In England, the BDA would recommend that providers should, as a minimum, adhere to the outcomes of the national consultation that recommended GF bread and GF multipurpose 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 gluten free (GF) diet avoids all food products that contain gluten, this requires excluding all foods made from wheat, rye and barley and oats (not certified as GF). These grains are present in many of the staple foods in the UK diet (e.g., breads, flour, cereals, 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 encouraged to consume naturally GF foods (including rice and potatoes). However often it is not 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' are regularly 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 GF as well as use

prescribed GF foods effectively in order to optimise dietary adherence and 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.

- The UK government consultation for provision of GF food in England (7) resulted in the recommendation and subsequent legislation that, in England, only GF Breads and GF multipurpose mixes are available on prescription for all people with coeliac disease. In England, individual CCGs decide on what level of provision is available, there remains considerable variation in provision across CCGs. Prescriptions have a fixed cost unless patients are exempted.

- In Scotland, GF 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 GF products continue to be available on prescription. Hywel Dda University Health Board has successfully trialled a card payments scheme, which is being rolled out on a voluntary basis throughout the board area. Welsh government are considering the outcomes of the trial. All prescriptions in Wales are free (8).

- In Northern Ireland, the Health and Social Care Board supports the prescription of GF 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. Adherence to a GF diet has been shown to be poor with 42 – 91% of people with coeliac disease adhering to a GF diet (9). 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 (10) (11) A number of factors can affect adherence, including access to GF food on prescription (12) (13).

Current identified risks of non-adherence to a GF diet include: infertility, anaemia (iron deficiency anaemia and megaloblastic 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 (14) (15) (16) (17).

b) Meet nutritional needs (in particular 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 (18). Commercially available GF foods are less likely to be fortified than their prescription only counterparts, only 16% of commercially available GF white breads were fortified with calcium, compared to 53% of prescription GF white breads (19). Calcium is an essential micronutrient, 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 (20).

c) Reduce the financial burden of purchasing GF foods

GF foods are up to five times more expensive than gluten containing options (21) (22). The high cost of GF foods can impact upon GF dietary adherence (23). GF foods on prescription provide a key support for people on low income, those on welfare benefits and the elderly on pensions.

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 convenience stores, even the small 'local' supermarket outlets, typically have no GF foods (21) (22). 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, with required minimum spends. 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 (24) and some parts of England (25), 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 (26).

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

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