Essex County Council HOSC

Written submission from Coeliac UK

Introduction

The NHS Mid-Essex CCG has recently consulted on a proposed change in policy regarding the prescribing of gluten-free food as the only treatment for coeliac disease. The proposal is to not routinely fund prescriptions for gluten-free foods, effectively ending NHS support in the treatment of this life-long condition.

Coeliac disease is a serious medical condition where the body's immune system attacks its own tissues when gluten is eaten. This causes damage to the lining of the small intestine and means the body cannot properly absorb nutrients from food. It is not an allergy or simple food intolerance. It is an autoimmune disease that occurs in people who have the genes that predispose them to the condition. It is more common among people with other autoimmune diseases, such as Type 1 diabetes and autoimmune thyroid disease.

Serious long term health complications associated with untreated coeliac disease include osteoporosis, infertility, and in rare cases, small bowel cancer. Currently, the only medical treatment for coeliac disease is strict adherence to a gluten-free diet for life.

Submission from Coeliac UK

NHS Mid-Essex CCG has argued that preventing access to gluten-free food on prescription is justified on the basis that gluten-free food is now available to purchase in large supermarkets. The proposal effectively moves the cost of treatment from the CCG to the patient.

While it is accepted that access through large supermarkets has improved significantly, research published as recently as September 2015 in the British Medical Journal has concluded[i]:

> *"There is good availability of GF food in regular and quality supermarkets as well as online, but it remains significantly more expensive. Budget supermarkets which tend to be frequented by patients from lower socioeconomic classes stocked no GF foods. This poor availability and added cost is likely to impact on adherence in deprived groups".*

Coeliac UK believes that the NHS should be both encouraging and supporting dietary adherence in patients with coeliac disease, particularly in deprived groups, to ensure they are meeting statutory requirements to reduce health inequalities and to reduce the risks of long-term health complications. Failure to support these patients is likely to result in poor health outcomes and higher treatment costs for the CCG in the long-term.

The Mid-Essex CCG reduced access to gluten-free staple foods in January 2014 by reducing the number of units available to patients from 16 to 8. It would be helpful if some assessment was made of this 2014 policy change, before the proposal to withdraw the service is considered.

Recently revised NICE Guidance recommends that patients with coeliac disease are offered an annual review to measure weight and height and review symptoms, and to assess adherence to the gluten-free diet and consider the need for referral for specialist dietetic or medical review . As a minimum, this type of patient monitoring should be introduced by the CCG, over a considerable period, to assess the impact of the 2014 policy change and to baseline any future revisions.

NHS England's best practice guidance on planning and delivering service changes states that "at the heart of any major service change or reconfiguration must be that the change will improve the quality of care, and that it is clinically-led and based on a clear clinical evidence base"; the implication being that drivers for change

should not be budget constraint or efficiency alone. Further, in this instance the CCG has not presented evidence to support their case for change, has not provided any data regarding the impact on patient outcomes resulting from the previous service restriction and has not stated how patient outcomes will be monitored.

In fact peer reviewed research has shown that adherence to the gluten-free diet is greatly *improved* through prescriptions for gluten-free staples and regular follow-up and support[ii]. Once treated with the gluten-free diet for three to five years, the risk of developing the cancers associated with coeliac disease reduces to no greater than that of the general population[iii]. The risks associated with osteoporosis are largely dependent on any damage already sustained, due to the inability to absorb calcium.

The NHS is also guided by the principle of commitment to providing the best value for taxpayers' money and the most effective, fair and *sustainable* use of finite resources. This raises the issue of false economy, where small savings in prescription costs could lead to higher treatment costs associated with poor health outcomes and increased health complications. For example, the cost of gluten-free food over a 40-year period is approximately £7,770 (£194.24 per year)[iv] and the cost of treatment for a hip fracture £12,170[v] (increasing by £70,000 per patient if cases become more complex[vi]).

The financial impacts on patient should also be considered. When prescriptions for gluten-free food are withdrawn, the impact on personal finances varies according to the patient's personal circumstances. The variation depends on whether or not, and how, prescription charges are paid. Those who are able access prescriptions free of change in England include older people, children, people on low incomes and those with a condition on the medical exemption list. NICE states that the annual cost per patient of the provision of gluten-free food is £194.24 per patient.

For those paying single prescription changes, the monthly cost in charges for 2015/16 is £8.20 per item, if a patient limits themselves to three items (e.g. bread, pasta, flour) per month this equates to £24.60 per month or £295.20 a year towards the cost of their prescribed gluten-free food costs. Those using a pre-pay certificate (PPC) will pay £104.00 per year toward their prescription costs.

The CCG should be cautious of introducing means testing or prescribing for those only able to access free prescriptions, as this will likely both reduce cost recovery and put dietary adherence at risk.

Prescription charging also means that if gluten-free prescribing is removed altogether, then the most significant impact is on those who do not currently pay for their prescription. This vulnerable group will need to pay the full cost, while those who previously paid for prescriptions will have at least already been paying something towards their gluten-free food. Far from reducing health inequalities, the proposal would exacerbate them.

Gluten-free foods such as gluten-free bread can cost around three to four times as much as their gluten containing equivalent. For example, gluten-free bread costs up to four times that of standard bread[vii]. Therefore, the withdrawal of treatment impacts most significantly on those with the low or fixed incomes or those who currently receive prescriptions free of charge.

The CCG has also argued that food is not provided to other patient groups, such as people with diabetes or those with food intolerances. While leaving to one side the issue of playing patient groups against one another, the important issues to note are that food intolerance cannot be objectively diagnosed, coeliac disease is not a food intolerance but an autoimmune condition, the total avoidance of gluten is the only treatment for coeliac disease, there are no specialist food requirements in diabetes and that the NHS does provide food to patients such as those with PKU (Phenylketonuria), a condition that requires management by low protein diet in conjunction with additional essential amino-acids.

The other main argument raised by the CCG is the difference in prices paid for gluten-free products when compared with retail prices. While the CCGs has not always compared like for like products when making their assessment there are circumstances when the NHS does pay a higher price than the retail product equivalent. What is surprising about this argument is that prescription services seem to be now at risk because the NHS has been unable to secure prices comparable to those paid by supermarkets. The total UK market value of gluten-free foods in 2014 in England was £211m[viii], making the NHS England annual spend of circa £27m on gluten-free food around 13% of the total gluten-free food market. It would be reasonable to expect that such a significant market share provides sufficient purchasing power to negotiate prices equal to those paid by commercial retailers.

Coeliac UK has been in touch with BSNA (British Specialist Nutrition Association Ltd.), the representative body for specialist nutrition product manufacturers, to better understand why there are cost differentials. One important point made by BSNA was that GP prescribing and pharmacy dispensing provides a universal service. On 20 November 2015, BSNA stated:

> *"Availability and access to a reasonable supply of staple gluten-free foods is essential to the successful management of coeliac disease which is a lifelong condition. BSNA members ensure guaranteed supply to every pharmacy in the UK without additional handling or delivery charges incurred. Regardless of whether the patient is in the highlands of Scotland or near to a city, the cost to the NHS remains the same. This ensures every coeliac patient is able to receive a foundation of nutritional support regardless of locality or socio-economic status."*

The use of community pharmacies ensures that all patients, regardless of where they live can access staple food when needed, including those who rely on home deliveries due to mobility issues; 89% of the population in England has access to a community pharmacy within a 20 minute walk[ix].

Cutting and reducing service provision is not the only way to find efficiencies in the NHS. Service innovation, improved procurement (as stated earlier) and national collaboration also have the potential to deliver efficiencies, as well as improvements in patient experience.

Some CCGs have attempted to improve or innovate support services for patients with coeliac disease, while also looking for savings. The NHS Five Year Plan outlines use of pharmacy services to extend existing primary care resource. One way that this can be achieved is through pharmacy-led prescribing schemes, and Coeliac UK has long advocated and supported healthcare professionals wanting to establish such services. A centralised pharmacy-led scheme has recently been piloted for 18 months in Scotland and is now established as a permanent service.

Technology has also moved on to the point that web based ordering with pharmacy or retail store collection is possible (i.e. electronic voucher or smart card scheme), and suitable for a large number of patients. Setting up such a scheme would require IT system development and the establishment of partnerships with retailers or pharmacy groups.

There are several options that could be explored by the CCG, which have the potential to offer savings while ensuring continued treatment and support for patients with coeliac disease, before NHS treatment is removed.

About Coeliac UK

Coeliac UK is the national charity for people with coeliac disease and dermatitis herpetiformis (DH), the skin manifestation of coeliac disease, giving support for health and the gluten-free diet. We campaign, research and offer support and advice to people with these conditions and those supporting them.

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