

## **Bedfordshire CCG commissioning position on the provision of Gluten-Free foods on the NHS**

On 24<sup>th</sup> November 2016, Bedfordshire CCG's Governing Body made a decision to discontinue the provision of gluten-free (GF) foods on the NHS, unless there are specific circumstances whereby a dependent patient could be at risk of dietary neglect.

### **1. Why has the CCG taken this decision?**

NHS Bedfordshire Clinical Commissioning Group (BCCG) is the local organisation responsible for planning, organising and buying of NHS funded healthcare functions for the population living in Central Bedfordshire and Bedford Borough. In 2016/17 the CCG was underfunded by 3.1% of its NHS England target. The discontinuation of gluten-free food provision on the NHS was a decision made as part of a multi-service review conducted by the CCG at the time, based on the current funding allocation and financial position. CCGs around the country, in similar financial circumstances, adopted this similar position to restrict or stop GF foods on the NHS.

In March 2017, DHSC published a consultation proposing changes to the availability of GF foods on NHS prescription. The rationale for change was the increased availability of these products in supermarkets and other food outlets at a time when the annual cost to the NHS of prescribing such items was £15.7 million.

In 2018, NHS England issued the following recommendations:

- Advise CCGs to support prescribers to prescribe in line with the revised regulations which allow for no gluten free products to be prescribed at NHS expense, other than gluten-free bread and/or gluten-free mixes.
- Advise CCGs that patients in receipt of NHS prescriptions for gluten-free bread and/or mixes should be those diagnosed by their doctor as suffering from established gluten-sensitive enteropathies, including dermatitis herpetiformis and coeliac disease.

### **2. When will this policy start?**

This policy came into place on 1<sup>st</sup> April 2017. Patients will not be able to routinely access gluten-free foods on the NHS beyond that date.

### **3. Can the GP prescribe on prescription?**

No, clinicians in Bedfordshire are being asked to follow the agreed process to ensure an equitable approach across the BCCG commissioned areas.

### **4. What is the process for a dependent patient who may be at risk of dietary neglect or who is the carer of such a patient?**

Dependent patients will include all children currently receiving gluten-free foods (breads and mixes) on the NHS and may include some adults with mental capacity issues. Being dependent does not mean you are at risk of dietary neglect and are automatically entitled to gluten free foods.

If you are a dependent patient and believe you could be at risk of dietary neglect as a result of this policy change, or are a carer of a dependent relative that you have concerns about, then you can contact the CCG to discuss how we can support you, on:

Enquiries: Tel 01525 624275 or Email – [bedsccg.enquiries@nhs.net](mailto:bedsccg.enquiries@nhs.net)

Dependent patients who may be at risk of dietary neglect need to be referred to their GP or dietician for an assessment of risk and support.

If the GP or dietician believes there are clinical circumstances that warrant consideration of the NHS continuing to fund gluten-free foods (breads and mixes only) then they will complete a prior-approval proforma for consideration by the Individual Funding Request (IFR) team. The proforma can be requested from and submitted upon completion to the medicines management team via email [BEDCCG.bedsmeds@nhs.net](mailto:BEDCCG.bedsmeds@nhs.net)

The IFR team will consider the case and advise the GP or dietician if they have approved or declined the request. If the request is approved a unique reference number will be allocated to the patient. The patient should be given a copy of the letter containing the unique reference number to take to the community pharmacy, they can then remain on the current scheme subject to attending an annual review.

The unique reference number will last until their circumstances change (to be determined at the annual review) or they reach 18 years of age and are no longer classed as dependant.

The GP or dietitian is ultimately responsible for determining the number of Gluten Free Food units a patient requires, depending upon their age and gender, and whether they are pregnant or breastfeeding. The amount of GF food required for adequate nutritional intake need not all be met by items available on prescription. [Coeliac UK have published guidance on this.](#)

If the request is declined, the patient has the right to appeal the decision.

### **Where can I see the relevant CCG policies?**

The BCCG Gluten-Free Foods commissioning position and the CCG IFR policy can be viewed on the Bedfordshire CCG website <https://www.blmkccg.nhs.uk/about-us/our-policies/bedfordshire-ccg/> and on the BLMK medicines optimisation website: <https://medicines.blmkccg.nhs.uk/>

### **5. What other resources are available to patients?**

Helpful resources on following a gluten-free diet and lifestyle can be found on Coeliac UK's website at: <https://www.coeliac.org.uk/gluten-free-diet-and-lifestyle/>

### **6. Will patients still receive an annual review?**

Patients with coeliac disease should be having an annual review with their GP. They will still be entitled to an annual review. It is a very important part of managing the condition over the long-term.

NICE guidance advises that: "An annual review should be offered to people with coeliac disease so that adherence to a gluten free diet and symptoms can be reviewed, information and advice about the condition and diet can be refreshed, and any further support needs can be identified. Annual reviews for children with coeliac disease also allow any impact on development to be assessed. Annual reviews provide the opportunity to identify people with refractory coeliac disease that does not improve with a gluten-free diet and to monitor any emerging long-term complications of coeliac disease."

An annual review for people with coeliac disease should include:

- measuring weight and height
- review of symptoms
- considering the need for assessment of diet and adherence to the gluten-free diet
- considering the need for specialist dietetic and nutritional advice

- considering the need for referral to a GP or consultant to address any concerns about possible complications or comorbidities.
- The GP or consultant should assess all of the following if concerns are raised in the annual review:
  - the need for a dual-energy X-ray absorptiometry (DEXA) scan (in line with the NICE guideline on osteoporosis: assessing the risk of fragility fracture) or active treatment of bone disease
  - the need for specific blood tests
  - the risk of long-term complications and comorbidities
  - the need for specialist referral.

These are the British Society of Gastroenterology guidelines provide a rationale for blood test request. Coeliac is often a clinically silent disease so there is no robust way of ruling out the listed abnormalities without blood testing. The risk of untreated coeliac disease includes small bowel cancer which is now almost historic as patients are so well managed.

The physician should check on intact small intestinal absorption (full blood count, ferritin, serum folate, vitamin B12, calcium, alkaline phosphatase), associated autoimmune conditions (thyroid-stimulating hormone and thyroid hormone(s), and serum glucose), liver disease (aspartate aminotransferase/alanine aminotransferase) and dietary adherence (anti-TG2 or EMA/DGP), although the sensitivity and specificity of the latter cannot substitute for structured dietary interview.

The GP can decide if it would be helpful for patients to be assessed and supported by an NHS dietician. This support could be ongoing if the ongoing need is identified.

### **7. Will the pharmacy supply scheme remain in place for patients who are eligible to continue to receive gluten-free food on prescription?**

Yes.

### **8. What provision will be in place for people who have had gluten-free foods on the NHS who purchased a pre-payment certificate prior to this policy change?**

If a patient no longer requires a prepayment certificate as a result of the stopping of the supply of gluten free foods the card must be sent to the NHSBSA at the address below, within three months of them no longer requiring a card. A covering letter must be included stating why. The NHSBSA will process the refund for the patient.

NHS Business service authority

PO box 854

Newcastle upon Tyne

NE99 2DE

### **9. If a patient has concerns who should they contact?**

Bedfordshire Clinical Commissioning Group enquires team: Enquiries: Tel 01525 624275 or Email – [bedscg.enquiries@nhs.net](mailto:bedscg.enquiries@nhs.net)

#### **References**

Coeliac disease (NICE guideline NG20) <https://www.nice.org.uk/guidance/ng20>

Diagnosis and management of adult coeliac disease: guidelines from the British Society of Gastroenterology. Jonas F Ludvigsson, Julio C Bai, Federico Biagi, et al. BMJ June 20, 2014

NICE Coeliac disease Quality standard (2016) <https://www.nice.org.uk/guidance/qs134/chapter/Introduction>

NHS England (2018) Prescribing Gluten-Free Foods in Primary Care: Guidance for CCGs <https://www.england.nhs.uk/wp-content/uploads/2018/11/prescribing-gluten-free-foods-primary-care-guidance-for-ccgs.pdf>

Prescribing Gluten-Free foods in Primary Care: Guidance for Clinical Commissioning Groups – frequently asked questions <https://www.england.nhs.uk/medicines-2/medicines-optimisation/prescribing-gluten-free-foods-in-primary-care-guidance-for-ccgs-fags/#what-gf-foods-have-ccgs-prescribed-in-the-past>

NICE CKS (updated 2020) <https://cks.nice.org.uk/topics/coeliac-disease/>