Hertfordshire and West Essex Integrated Care System

NHS Hertfordshire and West Essex Integrated Care Board

For use in East and North Hertfordshire

Guidance for the provision of gluten-free food

DOCUMENT CONTROL SHEET

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Change History:

Version	Date	Reviewer(s)	Revision Description
v1.0	19/10/17	Pauline Walton/Stacey Golding	Draft
V2.0	23/11/17	Stacey Golding	Final draft Safeguarding definitions agreed with safeguarding adult and children's leads and learning disability exemption clarified
	27/11/17	Approved by Assistant Director Pharmacy and Medicines Optimisation Team and GP Prescribing Lead	
	28/11/17	Approved by Medical Director	
	7/12/17	Approved by Governing Body	
V 2.0	22nd February 2018	Approved by CCG Governing Body	Following the release of NHS England national guidance

v 2.1	24th January 2019	Approved by CCG Governing Body	Following the addition to the drug tariff blacklist of all GFF products except specified bread and mixes

Implementation Plan:

Development and Consultation	East and North Herts CCG and Herts Valleys CCG conducted a 10-week (6th July – 14th September 2017) public consultation programme called 'Let's talk' which included this issue. Engagement activities included: public meetings in all localities; discussions with local community groups and young people; attendance at community events including Herts Pride and places with high public footfall; promotion via local media; a major social media campaign – primarily via Twitter and Facebook; and sessions in GP practices. In total 2,500 people responded to the survey and thousands more have had access to the consultation information as a whole.
Dissemination	To GP practices through locality prescribing meetings and direct communication. GP practices will be asked to write to patients using a template letter.
Training	CCG Bulletin (internal), direct communication with service providers
Monitoring	Medicines Management Team to monitor using electronic prescribing data.
Review	24th January 2021
Equality, Diversity and Privacy	October 2017 - Equality Impact Assessment October 2017 - Privacy Impact Assessment
Associated Documents	Patient Template letter
References	Full Consultation Joint Committee papers including impact assessments can be found using the below link https://www.healthierfuture.org.uk/publications/2017/october/papers-for-joint-committee-meeting

Document Status:

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1. Introduction

1.1. This document describes the CCG guidance for the supply of gluten-free foods. An assessment was undertaken using the CCG's framework for prioritisation that supports this guidance.

1.2. In 2017/18, East and North Hertfordshire CCG's (ENHCCG) budget was around £722 million (approx. £1,209 per annum per person). From this budget we need to pay for most of the area's health care, everything from medicines and minor treatments to complex surgical procedures and support for long term conditions. As much as we would like to, we cannot afford to pay for everything. Some difficult choices have to be made about what the CCG can or cannot afford to spend.

1.3. Coeliac disease is an autoimmune condition associated with chronic inflammation of the small intestine, which can lead to malabsorption of nutrients. It is a relatively common condition and population screening studies suggest that in the UK, 1 in 100 people are affected. The complications of coeliac disease (which may or may not be present at diagnosis) can include osteoporosis, ulcerative jejunitis, malignancy (intestinal lymphoma), functional hyposplenism, vitamin D deficiency and iron deficiency.

1.4. The main treatment for coeliac disease is a lifelong gluten-free diet. Most people report a rapid clinical improvement after starting a gluten-free diet. Specific education and information, such as advice on alternative foods to maintain a healthy and varied diet, may increase the likelihood of adherence and a positive prognosis.

1.5. Historically, gluten-free products have not always been widely available and receiving them via prescription was often the only way that patients could access them. However awareness of coeliac disease, gluten sensitivity and other similar conditions is on the increase. This, as well as a general trend towards eating less gluten, means that gluten-free food has become more accessible to all. An increasingly varied range of gluten-free foods are now available from shops, supermarkets and online retailers.

1.6. The CCG notes that some gluten-free foods are more expensive than their gluten-containing equivalents. However, the price paid by the NHS for gluten-free foods on prescription is much higher than the prices of similar food products found in supermarkets. In some cases, the NHS has to pay three to four times more than a customer would, to purchase an equivalent gluten-free product. There are often many additional costs to the NHS including pharmacy fees and distributor delivery charges. Appendix 1 provides a breakdown of the CCG spend on gluten-free food.

1.7. Given the current challenges facing the NHS, prescribers need to ensure a fair use of resources for all their patients. This guidance addresses the balance between helping patients afford the higher cost of gluten-free diets and ensuring the fair and effective use of NHS resources. It is not equitable that some people are able to receive a significant amount of food on prescription whilst others, who may also have special dietary needs, are not.

1.8. To aid patients in maintaining a healthy and balanced diet, the charity Coeliac UK also publish an annual list of naturally gluten-free foods – rice, potatoes, fruit, vegetables and more – which can be included in a regular grocery shop: https://www.coeliac.org.uk/gluten-free-diet-and-lifestyle/

2. Scope

2.1 This guidance applies to all GPs and non-medical prescribers working in our member practices, whether permanent, temporary or contracted-in (either as an individual or through a third party supplier).

2.2 The guidance applies to all patients including those who are exempt from paying prescription charges and who do not meet the exclusion criteria below.

2.3 The guidance excludes some patients with learning disabilities without a carer to aid in managing a gluten-free diet or where prescribers are aware of safeguarding concerns in at-risk adults or children.

2.4 The guidance does not apply to patients requiring therapeutic dietary treatment for the management of inherited metabolic diseases such as low protein foods.

3. Definitions

3.1. Coeliac disease is an autoimmune disease caused by a reaction to gluten.

3.2. Coeliac UK is an independent charity supporting people with coeliac disease.

3.3. Gluten-free food is food made from products that do not contain the protein gluten which is found in grains such as wheat, barley and rye. A gluten-free diet is primarily used to treat coeliac disease.

3.4. A learning disability is a condition featuring reduced intellectual ability and difficulty with everyday activities; for example household tasks, socialising or managing money, which affects someone for their whole life.

3.5. A carer is a family member or paid helper who regularly looks after a child or a sick, elderly, or disabled person.

3.6. NHS prescription charges are paid by patients for drugs or other treatments prescribed for them by a National Health Service medical practitioner.

3.8 STPs are Sustainability and Transformation Partnerships. The local STP footprint is comprised of three CCGs - East and North Hertfordshire, Herts Valleys and West Essex CCGs.

3.9 Safeguarding means protecting people's health, wellbeing and human rights and enabling them to live free from harm, abuse and neglect[1][2]. Each GP practice has a safeguarding lead.

3.10 'At-risk' can be due to health, social care needs or disabilities to enable people to live free from abuse or neglect.

4. Guidance Statement

ENHCCG does not support the NHS prescribing of gluten-free foods with the following exceptions:

- Exceptions would be made for people with learning disabilities, who could otherwise find it difficult to choose food products which are suitable.
- Patients where clinicians are aware of safeguarding concerns in at-risk adults or children that impact ability to obtain gluten-free foods without a prescription

Where prescribers using professional judgement to consider that a patient meets exclusion criteria, then a limited range of a specified number of units of flour and/or bread can be prescribed.

All patients should be provided with advice about how to eat a balanced gluten-free diet. The charity Coeliac UK can support patients with information about how to achieve a gluten-free diet. Further information is also available on the NHS Choices website:

https://www.nhs.uk/Conditions/Coeliac-disease/Pages/Treatment.aspx

1 http://www.cqc.org.uk/what-we-do/how-we-do-our-job/safeguarding-people

2 http://www.enhertsccg.nhs.uk/safeguarding-adults-and-children

5. Roles and responsibilities

5.1 **CCG Governing Body** is responsible for approving this guidance and the prudent use of NHS resources.

5.2 **CCG Primary Care Medicines Management Group** have discussed and supported the proposal and will work with the Pharmacy and Medicines Optimisation Team to support implementation.

5.3 **CCG Chief Executive – Accountable Officer** has overriding accountability for the prudent use of NHS resources.

5.4 **CCG Medical Director** has professional and strategic accountability for safe and effective use of NHS resources.

5.5 **Assistant Director of Pharmacy and Medicines Optimisation** has professional, operational and strategic accountability for medicines optimisation.

5.6 **Lead Pharmaceutical Adviser (Governance)** is responsible for overseeing the implementation of this guidance.

5.7 **CCG Board Prescribing Lead** is the Chair of the Primary Care Medicines Management Group and is a member of the Governing Body.

5.8 **Locality prescribing lead GPs** are elected as the prescribing leads to represent each of the CCG geographical localities.

6. Process and procedures

- Information will be available for health care venues that patients may access.
- Prescribing messages will be available on clinical systems (such as Scriptswitch and Ardens) and for receptionists and prescription clerks.
- The CCG will work with the Local Medical and Pharmaceutical Committees.
- The CCG will monitor the impact of the guidance through changes in prescribing data at practice level to identify successes and challenges.
- The CCG will record and monitor patient comments and complaints.

Implementation Process

6.1. Existing patients

Practices will be supported to undertake clinical system searches to identify patients receiving repeat prescriptions for gluten-free food. Once identified, patient lists will be reviewed to assess if patients meet exclusion criteria.

Patients not meeting exclusion criteria, will receive a letter from their GP (appendix 2) explaining the new guidance. They will be provided with advice on the importance of maintaining a gluten-free diet, either through naturally gluten-free foods or buying gluten-free food from pharmacies, supermarkets etc.

6.2. Newly diagnosed patients

GPs will support all patients with newly diagnosed coeliac disease including stressing the importance of a gluten-free diet and referring them to resources such as the Coeliac UK website[3]. Patients will be counselled to make them aware of how to achieve a gluten-free diet, either through naturally gluten-free foods and/or buying gluten-free food from pharmacies, supermarkets etc. Patients also have the option of a dietician referral.

[3] https://www.coeliac.org.uk/gluten-free-diet-and-lifestyle/

Appendices

Appendix 1 - Spend by gluten-free food group (ePACT April 2016 to March 2017)

Annual prescriptions costs for gluten-free food was **£22.8m** in England over the last 12 months and **£284,000** in East and North Hertfordshire CCG.

Gluten-free food group	Total annual spend in England	Total annual spend in East and North Herts CCG
Bread	£11,600,273	£150,296
Flour and bread mix	£3,496,892	£44,953
Pasta	£1,977,618	£36,307
Pizza base	£961,962	£16,825
Cereals or grains	£809,905	£15,574
Crackers	£438,795	£7,834
Biscuits	£327,272	£3,740
Other	£3,211,394	£8,215

Appendix 2 – Template letter to send to patients affected by guidance change

Dear Patient

Changes to the local NHS guidance on prescribing gluten-free food

We are writing to let you know about changes which are coming soon and will affect everyone in our area who receives gluten-free food on prescription.

NHS East and North Hertfordshire Clinical Commissioning Group (CCG) – the local NHS organisation which plans and pays for healthcare in this area, has made a decision that gluten-free foods **will no longer be routinely available on prescription**. This decision follows a 10-week public consultation during the summer to gain the views of local people, clinicians and interested groups. You might be interested to know that 77% of the public who took part in the consultation agreed with this proposal. 67% of people who considered themselves to be directly affected by this guidance supported these proposals during the consultation.

This means that from 15th January 2018, gluten-free foods will no longer be prescribed on the NHS for the majority of patients in Hertfordshire, with the exception of those with a learning disability who could otherwise find it difficult to choose food products which are suitable for their condition.

In the past, specialist gluten-free products were not widely available, and receiving them on prescription was often the only way to get them. However, awareness of coeliac disease, gluten-sensitivity and other similar conditions is on the increase and a varied range of gluten-free foods is now available from shops, supermarkets and online. Changes to the law mean food labelling has improved, making it easier to see which foods contain gluten.

There is also lots of good information available about eating a healthy and balanced diet which is naturally free from gluten. For example, by eating wheat-free carbohydrates such as rice and potatoes and using flour alternatives such as millet and cornflour.
Coeliac UK has produced lots of information about how to eat a gluten-free diet which you may find useful. You can find this on the charity's website: www.coeliac.org.uk or by calling their helpline on 0333 332 2033 (local call rates apply).

If you are concerned about your health, it is very important that you make an appointment to talk to your GP or drop in to see a community pharmacist.

You can read more about how the CCG reached this decision by visiting: www.healthierfuture.org.uk/nhsletstalk

If you would like to raise your concerns regarding this or the consultation process you can contact the CCG's Patient Experience Team using the following details:

- Telephone – 01707 685356
- Email – enhccg.quality@nhs.net
- In writing – Quality Team, East and North Hertfordshire CCG, Charter House, Parkway, Welwyn Garden City, Hertfordshire, AL8 6JL

Yours sincerely

On Behalf of the GPs at xxxxxxxxx Surgery