


# **CONSULTATION ON GLUTEN-FREE PRESCRIPTIONS**

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A blue ribbon graphic with a white border, containing the date '20 September 2017'.

20 September 2017

A large decorative graphic on the left side of the page, composed of overlapping curved shapes in various shades of blue and purple.

Patient focused,  
providing quality,  
improving outcomes

## **1. Introduction**

- 1.1. This paper builds on a report submitted to the Kent County Council (KCC) Health overview and Scrutiny Committee in March 2017 following the results of a public consultation.
- 1.2. At the March meeting the HOSC asked NHS West Kent Clinical Commissioning Group (CCG) to:
  - (a) take into account the views expressed by Committee Members when forming recommendations for the Governing Body;
  - (b) submit a report to the Committee when a final decision has been made by the Governing Body.
- 1.3. Following consideration of feedback from HOSC members and the consultation report, the Governing Body decided at its 25 July meeting that from 1 September 2017, gluten-free food will no longer be routinely prescribed for people with coeliac disease in west Kent.
- 1.4. The CCG will continue NHS funding for gluten-free products only for people with Phenylketonuria (PKU) who need specific low protein food.

## **2. Background**

- 2.1. For the past 30 years, the NHS has been prescribing gluten-free products to patients who have been diagnosed with coeliac disease. NHS West Kent CCG spends over £130,000 a year on these prescriptions. Prescriptions started when gluten-free foods were not as readily available as they are today and food and diets were not so widely understood and documented.
- 2.2. Even with much greater availability of gluten-free products in shops and online, NHS West Kent CCG has to date continued giving prescriptions for a limited number of standard gluten-free items per month for patients with coeliac disease. These standard products include: fresh and long-life bread, flour mix, plain savoury crackers, pasta and pure oats breakfast cereal. Depending on age, a patient can receive up to 18 items per month, with extra items allowed for breastfeeding women and women in the third trimester of pregnancy.
- 2.3. The NHS faces a very challenging financial situation. With a limited budget and an increasing demand for services, NHS West Kent CCG is evaluating every service it

pays for and making decisions about the best value for all its patients. In that context it has proposed stopping prescriptions of gluten-free products. The CCG undertook a consultation to understand if West Kent residents agree with the proposals, if there are any groups who would be particularly impacted by the change and, if so, how that impact could be reduced.

### 3. Consultation

3.1. The CCG Governing Body launched consultation at its meeting of 29 November. A two month consultation was undertaken from 29 November 2016 to 29 January 2017. The consultation comprised a survey, a public meeting, attendance at two local Coeliac UK coffee mornings and stands at five public roadshows in shopping centres across the west Kent area. It was broadly promoted through a press release, which led to coverage on BBC Radio Kent, and emails to West Kent Health Network members, Healthwatch Kent, children's centres, care homes, children's clubs, community centres, councillors, education contacts, faith groups, churches, Gypsy and Traveller sites, leisure centres, libraries, MPs, opticians, parish councils, community pharmacies and patient participant group (PPG) chairs. A poster promoting the consultation was sent to local government gateways, GP practices and hospital waiting rooms.

3.2. During the consultation process, NHS West Kent CCG received 505 responses through the online or paper survey. Another 41 people were engaged with at a public meeting and local Coeliac UK coffee mornings. Three letters and emails were received from the public and three from organisations.

The consultation document outlined the proposed changes and the rationale for the change. It asked a series of questions about the level of support for the proposal and if any exemptions should be made if the proposal is accepted by West Kent CCG. It also explored whether those respondents with coeliac disease or caring for those with coeliac disease would have problems affording and accessing gluten-free products if prescriptions were to cease.

3.3. Of the 505 people who responded to the survey, 43 per cent had coeliac disease, eight per cent were the parent or carer for a child with coeliac disease, two per cent the parent or carer for an adult with coeliac disease and six per cent were responding on behalf of someone with coeliac disease. Forty one per cent neither had coeliac disease nor were carers for someone with the condition. Overall, the survey was answered by more people with/caring for someone with coeliac disease than people without.

3.4. Overall, 55 per cent agreed at least in part with the CCG's proposal to stop the routine provision of gluten-free products on prescription: 29 per cent of respondents agreed routine prescriptions should be stopped completely; 26 per cent thought there should be some exemptions if the proposal is accepted by the CCG. Just under half of respondents (46 per cent) did not agree with the proposal.

#### **4. Governing Body decision**

4.1. Following consideration of feedback from HOSC members and the consultation report, the Governing Body decided at its 25 July meeting that from 1 September 2017, gluten-free food will no longer be routinely prescribed for people with coeliac disease in west Kent.

4.2. The CCG will continue NHS funding for gluten-free products only for people with Phenylketonuria (PKU) who need specific low protein food.