

Changes to the prescribing of gluten free foods

Evidence to the Surrey Health Scrutiny Committee

19 May 2011

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Summary

The current system of supply of gluten free foods on prescription was established around 40 years ago when gluten free foods were not readily available in supermarkets and shops.

The supply of gluten free products on prescription has been under discussion for some time at both local and regional levels.

The drivers for this discussion include the need to maximise the best and most equitable use of finite NHS resources, ensuring both coeliac and non-coeliac patients are treated fairly.

Discussion has included consideration about whether the prescribing of gluten free products was necessary at all, given that no other food allergy products are available to adults free of charge (for instance to people with diabetes or who are lactose intolerant).

This debate has taken place across the South East Coast (SEC) region which includes Kent, Surrey and Sussex. In recent months it has been co-ordinated by the SEC Primary Care Trust (PCT) Alliance.

The debate has also been informed by the Ethical Framework document that was published by South East Coast Health Policy Support Unit in November 2010. The framework sets out shared principles to lie behind commissioning decisions made by a PCT on behalf of its population.

Regional discussions have been clinically-led and with some involvement of Coeliac UK, the national support group for people with coeliac disease. Following the conclusion of these discussions, the South East Coast PCT Alliance issued recommendations to the region's PCTs about the prescribing of gluten free foods.

In April 2011, NHS Surrey wrote to all Surrey GPs informing them of the decision to implement South East Coast PCT Alliance recommendations about the prescribing of gluten free foods. GPs were asked to write to coeliac patients to inform them of the changes.

This decision ensured the continued supply of gluten free products on prescription but introduced some restrictions to the number and range of products available. It is important that members understand that gluten free foods are not a treatment but support a more varied diet for coeliac patients.

Following implementation of the recommendations, NHS Surrey has received feedback from a number of patients. Many patients have expressed agreement with the decision but have been concerned about the speed of implementation of the decision.

Background

Coeliac disease

Coeliac disease is an auto-immune disorder that involves a heightened immunological response to ingested gluten in genetically susceptible people. Although people with coeliac disease often have gastrointestinal symptoms, other symptoms are increasingly being recognised. Some people have no symptoms at all. Coeliac disease often coexists with other conditions. A gluten-free diet should not be started until diagnosis is confirmed by intestinal diagnosis.

Following diagnosis, patients should receive appropriate dietetic advice and be encouraged to join Coeliac UK. The Coeliac UK food and drink directory is recognised as the best source of information on gluten free food choices and patients should be encouraged to use it.

An extensive variety of gluten-free products can be purchased from community pharmacies and normal food outlets such as supermarkets.

GPs working with coeliac patients should promote a healthy eating message and encourage patients to increase their intake of naturally occurring gluten free options such as rice, potatoes and corn (maize).

Gluten free prescribing

The current system of supply of gluten free foods on prescription was established around 40 years ago when gluten-free foods were not readily available in supermarkets and shops.

A wide range of gluten free foods can be purchased from all major supermarkets, including Asda, Budgens, Marks and Spencer, Morrisons, Sainsbury's, Tesco, and Waitrose. Gluten free foods are currently more expensive. As a general rule they can cost about twice as much as gluten containing foods and so an adult wishing to continue to eat "usual" amounts of bread, pasta, cakes and biscuits would spend about £11 a month more on this food group than someone who was not coeliac.

Members can see that these foods are now widely available in supermarkets, but remain premium-priced. The fact that they remain available on prescription may be stifling competition in this sector and keeping prices artificially high.

Regional picture

Each year the NHS in Surrey, Sussex and Kent spends over £2.3 million on supplying gluten free foods for patients who require a gluten free diet. Included in this figure is the £500k that NHS Surrey spends annually.

A comprehensive review on the supply of gluten free foods to patients by the NHS was undertaken in 2010. It had been previously discussed on a number of occasions at the NHS Surrey Medicines Management Reference Group over the course of 2009/10.

The following is an extract from the notes of the NHS Surrey Medicines Management Reference Group meeting held on 11th November 2009:

“Gluten Free prescribing - the committee were provided with data demonstrating the varying practice spends across Surrey. The prescribing of potentially excessive quantities and specific products such as cakes and biscuits was noted.

“Marketing strategies by the manufacturers of GF foods and the Coeliac Society were noted as encouraging the volume and range of products available to patients free of charge on prescription.

“It was considered that the PCT should make recommendations to prescribers on the prescribing of appropriate products and quantities of gluten free products. There was also some discussion as to whether the prescribing of these products was at all necessary since no other food allergy products are available to adults free of charge on FP10.”

Regional review and options

The review of prescribing gluten free foods across the region was led by the SEC PCT Alliance.

The following options were considered by the SEC PCT Alliance:

1. To stop prescribing all Gluten Free foods
2. To only provide Long Life Bread and Flour on prescription
3. To only provide Long Life Bread and Flour on prescription to children
4. To stop prescribing biscuits and cakes – but continue to supply bread, flour, pasta and pizza bases
5. To introduce a payment system – giving patients a six monthly payment to cover the incremental cost of sustaining a GF diet (approx £10- £12 a month).

Option 2 was the preferred option for Kent PCTs, West Sussex PCT and the East Sussex PCTs. Brighton and Hove did not wish to change existing policy. NHS Surrey initially favoured option 5.

Final agreement of option to implement recommendations

The recommendation to restrict the type of gluten free products available on prescription was made by the South East Coast Primary Care Trust Alliance Regional Commission Board on 17th December 2010. NHS Surrey decided to implement this recommendation within Surrey at their December Annual Operating Plan meeting.

There were two main reasons for adopting option 2 as recommended by the South East Coast PCT Alliance: achieving the most cost effective use of NHS resources and ensuring equity in the supply of dietary products across the South East Coast region.

East Sussex Downs and Weald PCT undertook consultation about the recommendations with secondary care clinicians and dieticians as part of the development of their development. Additionally NHS Surrey undertook its own health impact assessment and the 14 Surrey GPs who are part of the Medicine Management Reference Group and the GP Commissioning Consortia leads were consulted about the recommendations. A vast majority of GPs appear to support the changes as it has been rapidly implemented by a number of GP practices within weeks being adopted.

Implications of the recommendations

These recommendations mean that the prescribing of gluten free products on FP10 (i.e. prescribed by a GP) is limited to eight items per month per patient. These eight items can be either long-life bread or flour.

As a wide range of gluten free foods are now available to purchase from all major supermarkets, GPs and clinicians across the south east coast region have re-looked at this issue and recommended that the prescribing of gluten free products should remain limited in future. The decision is supported by the PCT Alliance. Surrey GP consortia leads and GPs who are part of our Medicines Management Reference Group have been involved in these discussions at a local level and they also support this decision. These changes are in line with PCTs across the south east coast region.

Implementation of the SEC PCT Alliance recommendations across the region

Primary Care Trust	Guidance being followed
NHS Eastern and Coastal Kent	Implementing SEC policy
NHS Medway	Not yet implemented SEC policy
NHS Hastings and Rother	Implementing SEC policy
NHS Surrey	Implementing SEC policy
NHS West Kent	Implementing SEC policy
NHS West Sussex	Not implementing SEC policy. Asking GPs to use Coeliac UK guidance
NHS Brighton and Hove	Not yet implemented SEC policy but looking at reducing units and choice
NHS East Sussex Downs and Weald	Implementing SEC policy

Changes to the prescribing of gluten free foods in Surrey

Implementing the changes recommended by the South East Coast PCT Alliance means that the prescribing of gluten free products in Surrey is limited to eight items per month per patient. These eight items can be either long-life bread or flour.

The rationale for not including fresh bread is that it counts as a special order item and subsequently attracts an additional delivery fee of between £10 - £40. NHS Surrey felt there was insufficient justification for the additional spend which requires diverting money from treatments to be spent on delivery charges.

The outcome of adopting the recommendations:

- Providing these essential food items ensures equity for all coeliac patients across Surrey. (One proposal considered ceasing the prescribing of gluten free food).
- It ensures we are treating coeliac and non-coeliac patients equally. Previously coeliac patients received all gluten free foods, whilst non coeliac patients paid for their essential products in their entirety. The new policy means coeliac patients are provided with some gluten free food on the NHS at a level that covers the increased cost of maintaining a gluten free diet. If patients choose to purchase further items the increased cost of these items could be set against their saving from receiving some items free of charge on prescription.
- By adopting these changes we are providing products in line with other PCTs across the south east coast region, therefore ensuring equity across the wider health community.
- We expect these changes to deliver savings in the region of £290k and given the challenging financial situation we face in Surrey this must be taken into account. This money is being re-invested into services and treatments.

Implementation

To ensure that patients are aware of the changes and their entitlement to gluten free products, NHS Surrey asked all practices to identify coeliac patients who are routinely receiving gluten-free food on prescription and to write an explanatory letter to them. The template letter supplied by NHS Surrey included a list of approved suppliers. The list of approved suppliers was collated based on the availability of these items at the major wholesalers.

Acceptance by patients in Surrey

There have been over 160 calls from patients to NHS Surrey's Medicines Management Team. Patients have also been supported by NHS Surrey's Patient Advice and Liaison Service (PALS). In addition, NHS Surrey has received correspondence from patients.

Ethical framework

An Ethical Framework document was published by South East Coast Health Policy Support Unit (SEC HPSU) in November 2010 and agreed at the NHS Surrey Quality Assurance Sub-Committee in February 2011. The latest version of the ethical framework was developed following a number of events with all PCTs in the region held by the SEC HPSU.

The ethical framework sets out the six key shared principles that underpin how each South East Coast PCT makes commissioning decisions on behalf its population.

The first principle states that decision making should be *rational* and based on a consideration of the relevant factors and evidence, including those relating to costs and the likely benefit to patients.

The second principle asserts that policy should be *inclusive* and not discriminate on characteristics which are irrelevant to health conditions and the efficacy of treatment.

The third principle states that decision making should be *clear and open to scrutiny*, with the process for arriving at a policy being transparent and easily understood.

The fourth principle stresses that decision making should take into account *finite resources* and how investment in one area of health care will divert resources away from other areas of potential investment.

The fifth principle considers the importance of *allocating health care resources according to health needs* and the requirement to balance the needs of the individual with the needs of the wider community.

Finally, the sixth principle is that of considering *a wide range of factors* in decision making and being open to new ways of working and thinking.

The Ethical Framework is available within the papers that went to the March meeting of the Board of NHS Surrey:

<http://www.surreyhealth.nhs.uk/AboutUs/Board%20Meeting%20Papers/March%202011%20Board%20Paper.pdf>

Conclusion

The recommendations being adopted across Surrey, Kent and Sussex mean that the prescribing of gluten free food products is limited to a maximum of eight items of either bread or flour, per patient, per month.

Given the challenges facing the NHS, it is necessary to re-look at every area of health spend and whether it can be justified. These recommendations, being introduced across the south east coast PCTs, including Surrey, are fairer and more equitable than the previous arrangements.

Gluten free products cost more and the recommendations acknowledge this. They mean that coeliac patients continue to be eligible for some products on prescription. However, the NHS will not simply cover the total cost of all these gluten free products, as it has done in the past. This is unfair to those who eat bread and other foods containing gluten, who pay for these foods in their entirety as part of their weekly shop.

Following discussions with clinicians in the south east coast region, it has been decided that it would be fairer to provide some, but not all, gluten free foods on prescription as a contribution towards the cost of maintaining a gluten free diet. People can choose to purchase additional items if they wish.

Although the quantity of gluten free items available on prescription is being limited, the NHS is continuing to subsidise these products. Whilst these changes may be disappointing to those affected by them, it has to be recognised that some people with other special dietary requirements – for example those who need dairy free diets – are not entitled to products on prescription, even though they too are buying more expensive replacement foods.

NHS Surrey is continuing to work with Coeliac UK, discussing how best to support people with coeliac disease. Coeliac UK understand the need to ensure the most effective use of finite resources. Coeliac UK has indicated its willingness to continue further discussions aimed at meeting the needs of coeliac patients, while achieving the best and most equitable use of NHS resources in Surrey.