

## **A guide to the Department of Health consultation on the future of gluten free prescribing in England**

The Department of Health consultation into the future of gluten free prescribing in England asks for feedback from patients and representatives by midday 22 June and we have completed our response [www.coeliac.org.uk/DoHconsultationresponse](http://www.coeliac.org.uk/DoHconsultationresponse)

You can help us try and save an essential service which is under the biggest threat it has ever faced. We want policy makers to consider the needs of all patients, not just those who have the economic and physical means to shop in large supermarkets.

For many people, the constant need to manage the gluten free diet, the difficulty of affording and getting to stores that stock key gluten free products like bread means relying on prescriptions to prevent damaging their health.

We hope this guide will give some context to the consultation and the questions posed, so that if this is an issue that affects you or your household, then you too can send your response. This consultation affects England only but for our members in the rest of the UK we wanted to keep you up to date with our work in this area.

Feel free to use this information to formulate your own personal response to this consultation by **midday 22 June**.

### **The consultation and its questions**

Unfortunately some of the arguments put across in the consultation do not adequately explain the impact of sticking to a gluten free diet for a lifetime and misrepresent the real issues that people with coeliac disease face having to live gluten free. So, we would like to set these out more clearly here so you can understand Coeliac UK's position.

The consultation has three questions that ask for feedback on different scenarios.

**Question 1:** Do you think gluten free foods should be available on prescription in primary care? Yes or no and why.

Answering no to this question would mean completely removing gluten free food from prescribing. We are answering yes because:

- we believe that gluten free food should be available on prescription as a cost effective way to treat coeliac disease, to prevent future costly complications, particularly for the most vulnerable who rely on prescriptions
- it currently costs the NHS approximately £195 a year per patient to support prescriptions which is a low cost and cost effective treatment
- a hip fracture caused by osteoporosis, the most common complication of coeliac disease with 40% of adults at diagnosis having osteoporosis or osteopenia, costs the NHS on average £27,000 – the equivalent of 138 years of prescriptions for one person

- the costs of a gluten free diet are significant. When you look at households with the lowest income in 2015/16, the average food spend was £40 week which was 17% of their total weekly expenditure. With the loss of gluten free prescriptions we have seen this bill increase by £10 a week – meaning a 25% increase in the cost of food for those who can least afford it. Maintaining a gluten free diet is greatly supported by prescriptions, helping with cost and access, particularly for the most vulnerable patients - those on low or fixed incomes, where there is more than one person on a gluten free diet. Helping patients to maintain their gluten free diet helps to avoid other serious health complications, like osteoporosis. Read more on cost. <https://www.coeliac.org.uk/campaigns-and-research/what-is-the-truth-about-cost/>

**Question 2:** Do you think gluten free prescribing should be restricted to certain foods? Yes or no. If yes, which foods should remain on prescription and why?

Answering no here would mean supporting gluten free prescribing in its current model. We are answering yes because:

- only staple gluten free food should be available on the NHS – this has been the case since 2011 [LINK <https://www.coeliac.org.uk/gluten-free-diet-and-lifestyle/prescriptions/national-prescribing-guidelines/>]
- we believe that gluten free prescribing needs to work better within the NHS and provide budget savings whilst maintaining some support for patients with coeliac disease. This will help ensure that the prescribing of gluten free food can be sustained for vulnerable patients into the future or until access to affordable gluten free food is widespread.
- bread, flour and bread flour mixes make up over 75% of all gluten free foods prescribed by the NHS in England. Therefore, as a minimum, we would support the continuation of these products on prescription to help manage the gluten free diet and help meet nutritional requirements. However, we hope that other staple gluten free items will also continue to be available, particularly those more suitable or palatable to children or older people.

**Question 3:** Do you think the range of bread products available on NHS prescription should be limited? Yes or no. If yes, please explain your answer.

Answering no here means that the current system of gluten free prescribing wouldn't change. We are answering yes because:

- there is currently a considerable range of products and pricing for gluten free products from the NHS. We believe that reducing the list of bread items available could be done, but only through a competitive procurement process, to reduce the costs to the NHS and to ensure that patients do not pay the penalty of poor procurement. The criteria for a competitive tender should include nutritional specifications, provision of a reasonable level of patient choice, and pricing which reflect the purchasing power of NHS England.

## Our arguments

- Gluten free substitute staple foods help people stick to their gluten free diet and contribute to nutritional requirements.
- The higher cost of gluten free foods, in particular gluten free bread which is five times the cost (gram for gram) of gluten containing bread, makes the diet unaffordable for some. For those shopping on a limited budget the cheapest gluten free loaf will cost more than 8 times the cheapest conventional equivalent.
- There are issues around availability of gluten free foods for those with limited mobility and those with only access to budget and convenience stores.
- Hindering compliance with the gluten free diet increases the risks of health complications in patients with coeliac disease, and has the potential to cost the NHS much more in the long term.
- The removal of gluten free prescribing would have a disproportionate impact on those on low or fixed incomes, with mobility problems and in families where more than one member is affected.
- The Secretary of State and NHS Board have a duty to reduce health inequalities and withdrawing gluten free food would accelerate inequality.
- We need to safeguard vulnerable patients so that the policy can ensure access to continuing support, in individual cases of need, to prevent complex health problems.

We have also set out our support for alternative models such as pharmacy supply schemes and voucher schemes that have been shown to work elsewhere. And our response details areas of misrepresentation within the consultation and corrects misinformation which we are disappointed to see in the Department of Health Consultation.

### Make your voice heard

You can take part in the consultation <https://www.gov.uk/government/consultations/availability-of-gluten-free-foods-on-nhs-prescription> and ensure your voice is heard. If you know of others who would want to respond then please do encourage them to do so.

You could also consider writing to your Prospective Parliamentary Candidate (PPC) running in the General Election to make your views known.

If you would be adversely affected by any policy change and you'd like to talk to us, then get in touch at [prescriptions@coeliac.org.uk](mailto:prescriptions@coeliac.org.uk)