

# Deprescribing of gluten-free foods across the Hampshire, Portsmouth, and Southampton

## Frequently asked questions

### 1. What exactly is proposed to change?

GPs within Hampshire, Portsmouth and Southampton have historically made some gluten-free foods available to patients with established gluten-sensitive enteropathies (including coeliac disease, steatorrhoea due to gluten sensitivity and dermatitis herpetiformis) via local pharmacies. The Hampshire and Isle of Wight Integrated Care Board (ICB), which oversees the provision of healthcare, has changed its position and guidance to GPs on the prescribing of gluten free foods. This means gluten-free foods will no longer be available on prescription.

### 2. When will this change take place?

Work to start the deprescribing of gluten free foods will begin in January 2024.

### 3. Who will be affected by this change?

People who have been diagnosed with coeliac disease or other established gluten-sensitive enteropathies such as steatorrhoea due to gluten sensitivity and dermatitis herpetiformis and who have been receiving gluten-free foods on prescription will be affected by this change.

### 4. How common is coeliac disease?

It is estimated around 1% of the population has coeliac disease, although it is thought that less have actually been tested and formally diagnosed.

### 5. How many people in Hampshire, Portsmouth and Southampton will be affected by this change?

We estimate there are approximately 1600 people currently being prescribed gluten-free foods.

### 6. Why has this change been put into place?

There are four broad reasons for this change:

- Since the formation of the Hampshire and the Isle of Wight into an ICB in April 2023, there has been a 'postcode lottery' in terms of prescribing gluten free products. This decision to stop all gluten free prescribing brings the wider ICB prescribing into alignment across Hampshire and the Isle of Wight. The decision was a difficult one to make, and the ICB considered a range of both clinical and social factors, including the wide availability of gluten free products in supermarkets.
- People with coeliac disease can follow a gluten free diet without needing to have specially formulated gluten free foods.
- Specially formulated gluten-free foods are now widely available in supermarkets, restaurants, and shops. People with coeliac disease can find and buy gluten-free foods themselves and no longer need specially prescribed foods.
- The NHS has a limited prescribing budget and a duty to use its resources wisely. Those working in the local NHS system feel that the money currently being spent on prescribing gluten-free foods is not the best use of the budget. By implementing the proposal to stop service provision, we estimate that we will save over £350,000 per year in prescribing costs across Hampshire and the Isle of Wight.

### 7. How did you make the decision to recommend stopping prescribing gluten-free foods?

The Hampshire and Isle of Wight Integrated Care Board (ICB) executive group at its meeting on 13<sup>th</sup> November 2023, approved a proposal to remove gluten-free food prescribing through the NHS in Hampshire, Portsmouth and Southampton.

The ICB believes its proposal to recommend stopping the prescribing of gluten free foods supports its long term strategy of empowering and activating patients to increase self-care for their long term conditions.

**8. Do you still recommend prescribing foods for any other groups of patients with other conditions?**

We are continuing to prescribe foods for a small number of patients with rare metabolic disorders, such as phenylketonuria (PKU). This is because following a diet for a rare metabolic disorder without access to prescription products is currently considered much harder than following a gluten free diet. These products also tend not to be widely available in supermarkets.

**9. What are the risks associated with stopping the prescribing of gluten-free food?**

We understand that there are always risks associated with any change and that we need to minimise the risks:

- By stopping the provision of the gluten-free products, there is a risk that some patients, particularly people with learning disabilities, dementia or mental health problems, may have difficulty managing their coeliac disease and may experience health problems as a consequence. It is important that carers for such patients understand the importance of following a strict gluten-free diet and are supported to do so.
- Arrangements for people with exceptional medical circumstances are to be put in place through the use of an individual funding request (IFR), where a patient with the support of their GP and a dietitian asks to receive gluten-free foods on prescription because of their particular circumstances, the decision will then be made on a case-by-case basis,
- If an IFR is successful, GPs will take NHS England's prescribing guidelines into account alongside each individual's needs.

**10. Will you be offering extra support and help for people with coeliac disease or other established gluten-sensitive enteropathies who will no longer receive gluten-free foods on prescription?**

- We will continue to support, advise and monitor patients diagnosed with coeliac disease or other established gluten-sensitive enteropathies through our GP practices, community dietetics services and gastroenterology departments.
- We will prepare GPs, dietitians and gastroenterologists for this proposed change so that they are particularly alert to any potential risks to vulnerable patients.
- We encourage patients with coeliac disease who are having difficulty maintaining a gluten-free diet to seek advice and support from Coeliac UK – [www.coeliac.org.uk/home/](http://www.coeliac.org.uk/home/)

**11. Is the ICB following national prescribing guidance?**

We will continue to monitor and advise that patients living with coeliac disease are reviewed in line with the NICE (National Institute for Health and Care Excellence) guidelines, which can be found at [www.nice.org.uk/guidance/ng20?unlid=3818974220162201535](http://www.nice.org.uk/guidance/ng20?unlid=3818974220162201535)

**12. If I can no longer get gluten-free foods on prescription, how will I manage my condition?**

Following a gluten free diet can be achieved without resorting to specially formulated foods on prescription, by avoiding foods which naturally contain gluten. In addition, gluten-free foods are widely available in supermarkets and shops, so you can continue to buy and eat appropriate food. You

can also seek advice and support from your GP, community pharmacy and dietitian. Check out the information and resources on the Coeliac UK website: [www.coeliac.org.uk/home/](http://www.coeliac.org.uk/home/)

**13. If I struggle to maintain a gluten-free diet without prescribed foods, what should I do?**

If you are having difficulty maintaining a gluten-free diet, please seek advice and support from your GP, community pharmacy and dietitian. Coeliac UK also has a lot of useful resources, information, recipes, and contacts on their website: [www.coeliac.org.uk/home/](http://www.coeliac.org.uk/home/)

**14. I cannot afford to buy gluten-free foods as I am on a low income. Is it proposed that I will be able to receive gluten-free foods on prescription?**

- The recommendation applies to everyone with coeliac disease. Following a gluten free diet can be achieved without resorting to specially formulated foods on prescription, by avoiding foods which naturally contain gluten. You can seek advice from the community dietetics services or your GP practice or look at the resources from Coeliac UK.
- Arrangements for people with exceptional medical circumstances are to be put in place through the use of an individual funding request (IFR), where a patient with the support of their GP and asks to receive gluten-free foods on prescription because of their particular medical circumstances, the decision will then be made on a case-by-case basis,
- If an IFR is successful, GPs will take NHS England's prescribing guidelines into account , alongside each individual's needs.
- You can also find recipes and tips for managing a gluten-free diet on a budget via the Coeliac UK website [www.coeliac.org.uk/home/](http://www.coeliac.org.uk/home/)

**15. Will children with coeliac disease or other established gluten-sensitive enteropathies continue to receive gluten-free foods on prescription?**

- The recommendation applies to children as well as adults. Following a gluten free diet can be achieved without resorting to specially formulated foods on prescription, by avoiding foods which naturally contain gluten. In addition to the resources on their website - [www.coeliac.org.uk/home/](http://www.coeliac.org.uk/home/) - Coeliac UK also offers specific support and advice for parents and families. You can also seek advice from the community dietetics services or your GP practice.
- Arrangements for people with exceptional medical circumstances are to be put in place through the use of an individual funding request (IFR), where a patient with the support of their GP and asks to receive gluten-free foods on prescription because of their particular medical circumstances, the decision will then be made on a case-by-case basis,
- If an IFR is successful, GPs will take NHS England's prescribing guidelines into account , alongside each individual's needs.

**16. My family member has a condition (e.g. learning disability / long term condition / dementia / mental health problem) which will make it difficult for them to maintain a gluten-free diet. Is it recommended that they continue to receive gluten-free foods on prescription?**

- The recommendation to stop prescribing gluten-free foods applies to everyone with coeliac disease. Following a gluten free diet can be achieved without resorting to specially formulated foods on prescription, by avoiding foods which naturally contain gluten. We do recognise that this change may have a disproportionate impact on some vulnerable people, including those with learning disabilities, dementia, a mental health problem or another long-term condition.
- Arrangements for people with exceptional medical circumstances are to be put in place through the use of an individual funding request (IFR), where a patient with the support of their GP and asks to receive gluten-free foods on prescription because of their particular medical circumstances, the decision will then be made on a case-by-case basis,

- If an IFR is successful, GPs will take NHS England's prescribing guidelines into account, alongside each individual's needs.
- You can also find recipes and tips for managing a gluten-free diet on the Coeliac UK website - [www.coeliac.org.uk/home/](http://www.coeliac.org.uk/home/)

**17. How will this proposed change affect people who have coeliac-type symptoms but have not been tested or diagnosed?**

- This proposed change will not directly affect people who have not been diagnosed as the NHS should not be prescribing gluten free foods for patients without a confirmed diagnosis of coeliac disease or other established gluten-sensitive enteropathies. This proposed change will only apply to people who have been diagnosed with coeliac disease or other established gluten-sensitive enteropathies and who are already receiving gluten-free foods on prescription in Hampshire, Portsmouth, and Southampton.
- Patients who are diagnosed as having coeliac disease or other established gluten-sensitive enteropathies in the future will not receive prescriptions for gluten-free foods.

**Useful patient resources:**

Patient webinars: Coeliac Disease -

<https://patientwebinars.co.uk/condition/coeliac-disease/webinars/>

Coeliac UK: Living Gluten Free and Gluten Free Checklist -

<https://www.coeliac.org.uk/information-and-support/living-gluten-free/the-gluten-free-diet/>