

Changes to gluten free prescribing in Leicester, Leicestershire and Rutland

Question and Answers

What is coeliac disease?

Coeliac disease is a condition where the immune system attacks the body's own tissues when gluten is eaten. This damages the gut (small intestine) so the body cannot properly take in nutrients.

The [NHS website](#) has lots of information on symptoms, causes, diagnosis and treatment.

The [Coeliac UK website](#) has lots of additional information.

What is Dermatitis Herpetiformis?

Dermatitis herpetiformis is an autoimmune skin condition that can be linked to coeliac disease.

The [NHS Inform website](#) has lots of information on symptoms, causes, diagnosis and treatment.

What is changing for patients receiving gluten-free products on prescription?

The prescribing of gluten-free products for patients diagnosed with coeliac disease and dermatitis herpetiformis is changing.

From 1 February 2025, patients will no longer be able to receive gluten-free food on prescription.

This change is being introduced by the NHS Integrated Care Board (ICB) for Leicester, Leicestershire and Rutland (LLR), the organisation that plans health services locally.

Why is this change being made?

These changes are happening for a few reasons:

- The availability of gluten-free foods used to be limited, therefore foods were made available through a prescription. These products are now more widely available in some supermarkets and online.
- Awareness of Coeliac Disease and Gluten intolerance has improved and there is a general trend towards eating less gluten, so these foods have become more accessible in some supermarkets and online.

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- Better labelling on foods means that people are better able to see whether ordinary foods are free from gluten.
- While gluten-free food is still more expensive than equivalent products containing gluten, the price paid by the NHS for gluten-free foods on prescription is still much higher than the supermarket or online prices.

The local NHS appreciates the impact this may have on patients; however, the health service has had to carefully consider health expenditure on gluten-free products along with support for all conditions, balancing it with the clinical risk and patient needs.

It has been a difficult decision to make but it will save the NHS more than £250,000, at a time of significant financial pressure on the health service.

What was the result of the public consultation?

A public consultation, held in summer 2024, attracted 1,468 responses with the majority of people disagreeing with the proposal to stop providing up to eight units of gluten-free bread or flour on prescription to people diagnosed with these two conditions. Public consultation helps the NHS to understand the experiences of patients and the public and this feedback is then measured against other critical factors when ICBs make a final decision on health services. Such factors include affordability, clinical need and clinical risk, and changes in external circumstances.

What is happening elsewhere in the country?

This move within LLR is in line with other parts of England including Derbyshire, Nottinghamshire and Northamptonshire in the East Midlands who stopped the provision of gluten free products in prescribing some years ago.

Where can people buy gluten-free food?

Most major supermarkets and many other retailers now stock gluten-free foods, as well as other special diet alternatives, both online and in-store. In addition, improved food labelling now means people are better able to see whether ordinary food products are free from gluten. Further information on labelling can be found on the [Gov.uk website](https://www.gov.uk).

What support is available for people with coeliac disease from the local NHS?

For children and young people under the age of 16

Support is provided by the University Hospitals of Leicester (UHL) dietetics department, with consultant gastroenterologist input if there are any concerns. Patients are seen on an individual basis to support with dietary/lifestyle changes. Children are usually discharged back to their GP once they reach 16 years.

Resources provided include:

- Coeliac UK – ‘coeliac disease and me’ booklet

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- Coeliac UK school pack
- UHL coeliac disease in children leaflet
- Information on dietary calcium and iron intake
- Leicester City Council / Leicestershire County Council school meals form (if applicable)
- Leicestershire Coeliac UK group flyer
- Free sample cards for various gluten-free brands and product

For further information on referral, diagnosis and support, please visit the [UHL website](#).

For young people aged 16-18 years

They are occasionally seen on a one-to-one basis by Leicestershire Partnership Trust's (LPT) paediatric dietetic team in the community every six months and then annually once a strict gluten-free diet has been established by the family.

Appointments cover topics such as what coeliac disease is, where gluten is found, and principles of a gluten-free diet.

An information pack is provided on coeliac disease, sample order forms for coeliac products and information on Coeliac UK.

For further information on referral, diagnosis and support, please visit the [LPT website](#).

For adults over the age of 18

The Leicestershire Partnership Trust (LPT) primary care dietetic service offers a virtual group education session for those who are newly diagnosed with coeliac disease. One-to-ones are offered in certain cases. Referral into the sessions is via a GP. Sessions are run monthly, and the waiting time is usually six-to-eight weeks following diagnosis. In the interim, patients are sent advice and a link to an online video.

The sessions last one-and-a-half hours and cover practical tips on:

- How to avoid food containing gluten and choosing healthy alternatives
- Eating out
- Contact numbers for Coeliac UK, their local network group, and the dietetic team.

For further information on referral, diagnosis and support, please visit the [LPT website](#).

Where can I find further information about Coeliac Disease and my diet?

Further information about Coeliac Disease and how to manage symptoms can be found by visiting - www.nhs.uk/conditions/coeliac-disease/www.nhs.uk/conditions/Coeliac-disease

There is a lot of information on the Coeliac UK website at www.coeliac.org.uk that you can access if you want advice about your diet including:

- Home of Gluten free recipes
- Diet and health workshops
- Food and drink information
- Gluten-free food on a budget

The Association of UK Dietitians also have a range of support and information - www.bda.uk.com/resource/coeliac-disease-and-Gluten-free-diet.html

The BBC Good Food website also contains top 10 tips for a gluten free diet www.bbcgoodfood.com/health/special-diets/top-10-tips-gluten-free-diet

Patient Webinars are also available to view on [Overview of Coeliac Disease - patientwebinars.co.uk](http://patientwebinars.co.uk)

If you require specific advice, please ask your GP if you can be referred to a dietician.

What support is offered if I can't afford to buy gluten-free products?

[There is local advice and support available on the cost of living from local authorities:](#)

- [Leicester City Council - Household support fund](#)
- [Leicestershire County Council - Cost of living support](#)
- [Rutland County Council - Cost of living support](#)

What is the cost difference between NHS gluten-free foods on prescription versus supermarket costs?

It is complex to put together an average difference in cost between supermarkets and prescription costs, however, below are some examples of the variations:

Costs at end of December 2024

From Asda – Asda Free from White or Brown sliced Loaf (535g) = £1.90 (35.5p/100g)

From Asda – Warburtons GF white or seeded sliced loaf (300g) = £2.15 (71.7p/100g)

Asda Sliced Wholemeal Tin Load 400g £1.15 (28.7p/100g)

From Asda- Asda GF plain/ SR flour £1.10/kg

Q&A

Costs at end of December 2024

From Tesco - Warburtons white bread sliced (800g) = £1.40 (17.5p/100g)

From Tesco - Warburtons Gluten free white bread sliced (300g) = £2.20 (73p/100g)

Available on prescription - Warburtons Gluten free white bread sliced (400g) = £3.34 (83.5p /100g)

Costs at end of December 2024

From Tesco – Juvela gluten free fresh fibre loaf sliced (400g) = £3.00 (75p/100g)

Cost at end of Dec 2024

From the Co-oP Free From Brown/ White sliced bread 500g £2.10 (42p per 100g)

Available on prescription - Juvela gluten free fresh fibre loaf sliced (400g) = £3.80 (95p/100g)

There are also hidden costs that the NHS has to pay, which supermarkets don't, such as costs associated with the time it takes a GP practice to generate a prescription and sign it. Also, the cost of the pharmacy ordering the stock and processing the prescriptions and then the pharmacist checking it. All these activities are funded either directly or indirectly by the NHS.

How many people are prescribed bread and/or flour in prescription in Leicester, Leicestershire and Rutland.

Prior to this consultation circa 1,300 people across Leicester, Leicestershire and Rutland diagnosed with coeliac disease and dermatitis herpetiformis receive up to eight units of gluten-free bread or flour on prescription. These figures are broken down below and show data at 26 June 2024.

Place	Patients in receipt of a prescription for GF foods during financial year 2023-24	Patient identified –with Coeliac disease
East Leicestershire and Rutland (includes Rutland Health Primary Care Network)	472	1,947
Leicester City	338	1,344
West Leicestershire	551	2,191
Rutland Health Primary Care Network	49	220

How can patients get in touch with the local NHS?

People can contact the LLR ICB:

- Email: llricb-llr.beinvolved@nhs.net
- Telephone: 0116 295 3405
- Write: Leicester, Leicestershire and Rutland Integrated Care Board, Room G30, Pen Lloyd Building, Leicestershire County Council, Leicester Road, Glenfield, Leicester LE3 8TB

Q&A

How can patients complain about the decision regarding gluten free products?

Please contact the local Integrated Care Board rather than your GP practice should you wish to complain about the decision or the process.

- Email: llricb-llr.beinvolved@nhs.net
- Telephone: 0116 295 3405
- Write: Leicester, Leicestershire and Rutland Integrated Care Board, Room G30, Pen Lloyd Building, Leicestershire County Council, Leicester Road, Glenfield, Leicester LE3 8TB