## Scottish Gluten-free Food Service Patient Information Pack

## About this pack

This pack gives you information on accessing gluten-free food in Scotland.

People who have been diagnosed with coeliac disease and/or dermatitis herpetiformis can access the Gluten-free Food Service at their local community pharmacy.

## The Scottish Gluten-free Food Service

The Scottish Gluten-free Food Service is an NHS service that allows you to manage your gluten-free food prescription through your community pharmacy.

When you register for the Gluten-free Food Service you will:-

- visit your community pharmacy to place your monthly gluten-free food order
- manage the amount and type of foods you order each month (up to an agreed amount)
- be expected to have an annual coeliac disease health check with the pharmacist to monitor your health (adults with coeliac disease only)
- be able to use the online Gluten-free Food Service if it is available at your community pharmacy.

This service allows people who need a gluten-free diet to have more control and the flexibility to try different foods each month. This will increase choice and should make the diet easier to manage and more enjoyable.

## Who can use this service

Children and adults with a confirmed diagnosis of coeliac disease or dermatitis herpetiformis who live in Scotland and are registered with a GP practice in Scotland are eligible for the Scottish Gluten-free Food Service.

Care home residents don't have access to this service but continue to be eligible for prescriptions for Gluten-free food from their GP if appropriately diagnosed.

If you're eligible, your GP or dietitian will tell you when you can start using the service and the maximum amount of gluten-free units you're entitled to each month.

## Registration

Once you have a confirmed diagnosis of coeliac disease or dermatitis herpetiformis your GP or dietitian will provide a partially completed and signed (by the GP or dietitian) 'Patient Registration Form'.

The registration form will state how many gluten-free "units" you are entitled to each month. This form must then be taken to a community pharmacy where the pharmacist will register you for the service.

Your community pharmacist will explain in detail how the service works and answer any questions you may have. They will complete the necessary paperwork and give you all the information you will need. This may include this pack, a 'Gluten-free Food List' and a 'Gluten-free Requirement Order Form'. They will also inform you how to access new order forms and the 'Gluten-free Food Lists' in future.

## Placing an order

Using the 'Gluten-free Food List', choose which products you would like to order.
Complete the 'Gluten-free Food Requirement Order Form' with your details and your selected products, making sure you do not to go over the total number of units you have been allowed for the month. You cannot carry units over to the next month.

Give the completed order form to the pharmacist who will contact you when the order is ready to be collected. You may find it helpful to keep a copy of it for your own records. If you are ordering fresh products, you must allow sufficient time for the ordering process and delivery into the pharmacy.

A new food order form has to be completed each month. You can change your order each month if you wish or you can order the same as last month. It's up to you.

## Gluten-free units

There are national recommendations for the number of gluten-free units you are able to order each month. These vary by how old you are and whether you are male or female. They have been calculated to meet some of your gluten-free needs. They have been agreed nationally by Coeliac UK and the British Dietetic Association.

| Age and sex | Number of units/month |
| :--- | :---: |
| Child 1-3 years | 10 |
| Child 4-6 years | 11 |
| Child 7-10 years | 13 |
| Child 11-14 years | 15 |
| Child 15-18 years | 18 |
| Male 19-59 years | 18 |
| Male 60-74 years | 16 |
| Male 75+ years | 14 |
| Female 19-74 years | 14 |
| Female 75+ years | 12 |
| Breastfeeding | Add 4 |
| $3^{\text {rd }}$ trimester pregnancy | Add 1 |

If you feel you need more than the above national recommendations, then your pharmacist or GP (depending on your Health Board arrangements) can refer you to a dietitian who will assess your individual dietary needs.

Each prescribable gluten-free food item has been has been given a unit value in the 'Gluten-free Food List'. They have been calculated on the following basis:

| Food item | Units |
| :--- | :---: |
| 400 g bread / rolls / baguette | 1 |
| 500 g flour / bread mix | 2 |
| 200 g biscuits / crackers / crispbreads | 1 |
| 250 g pasta | 1 |
| 2 pizza bases | 1 |
| 300 g breakfast cereal | 1.5 |
| 500 g oats | 1.5 |

Sometimes manufacturers do not make their products in the above unit sizes. For those products, an expert group of dietitians and pharmacists have agreed what the unit allocation is. This may vary from what the manufacturer recommends for their item.

## Online Service

A Gluten-free Food Online Service is available in some areas - your community pharmacist will be able to advise if it is currently being used in your area.

The Online Service can be accessed at: https://www.scotlandglutenfree.org.uk/
Follow the online instructions to create your food order form electronically. You can email the order to some community pharmacies or print and take it along. Your pharmacist will let you know when your order is ready for collection.

## Annual Coeliac Disease health check (adults only)

If you're an adult with coeliac disease and register for the Gluten-free Food Service, you'll be invited to have an annual coeliac disease health check at your pharmacy. It is important that you attend this appointment to ensure your ongoing health and wellbeing.

Children aren't included in the community pharmacy coeliac disease health check. This is because they're usually in a follow-up system with paediatric and dietetic services and if there are health concerns, they should be followed up by their GP or hospital service.

## Frequently asked questions

## Why should I use this service?

By using the service, you can have control and variety in your diet. You can make changes to your order on a monthly basis and, if you wish, this will allow you to try different foods.

You will have regular contact with a community pharmacist who will be able to answer your questions and, if required, refer you to other health care professionals.

The pharmacist will also be able to discuss with you the various gluten-free foods available and help you meet your individual needs.

If you are an adult with coeliac disease, you will be invited for an annual health check in accordance with national coeliac disease guidelines

## Is there any charge?

There is no prescription charge in Scotland and that applies to items supplied under the Gluten-free Food Service.

## Can I go to any pharmacy for gluten-free foods?

Yes. You can choose any pharmacy to register for the service and order your glutenfree foods. Once you have chosen and registered with your pharmacy you must always go to this pharmacy to order your gluten-free food.

## Once registered for the service can I move community pharmacy, for example, if I move house?

Yes. You should tell the pharmacist that you are changing to another pharmacy. You will need to ask your GP or dietitian to provide you with a new registration form to take to the new pharmacy you wish to use, so that you can be registered for the service there.

If you are moving house but are still able to go to the same pharmacy, then simply tell the pharmacist your new address.

If you are moving into a new Health Board area and changing GP then you will need the 'Gluten-free Food List' for that Health Board. You should let your pharmacist know that you have changed GP practice so that they can update their records.

## Orders

## Can I put in more than one order form in any one month?

No, only one order form is allowed per calendar month.

## Can I carry over units from one month to another?

No. If you do not use all of your units, these cannot be saved for a later date.

## What if I don't need any gluten-free foods one month?

You do not need to place an order if you do not need anything. Simply put in an order form the next time you need gluten-free products.

## Can I e-mail my order form to the pharmacy?

Individual community pharmacists may be able to accept e-mailed forms however your pharmacy will advise if this service is available.

## If I don't want to change my order each month can I just put in a repeat order form?

You should check this with the pharmacist.

## What do I do if I lose my order forms or Gluten-free Food List?

If you lose your order forms or food list, you can ask your pharmacist to make you new copies.

If you need a new order form, you can ask your pharmacist or download one from the NHS Inform website - www.nhsinform.scot/publications/gluten-free-food-orderform

## What if I live in one Health Board area but my GP is in another?

You will have to use the 'Gluten-free Food List' from the Health Board your GP is located in. Your pharmacist will advise which food list you can use and how you access this locally.

## Can I order gluten free products from my GP instead?

You can order your gluten-free foods from your GP. They will write a prescription which you take to a community pharmacy to be dispensed.

However, you cannot use both systems and you will still have to use the same gluten-free food list and number of gluten-free units you are entitled too.

## Gluten-free Food Products <br> How often will the Gluten-free Food List be updated?

As new products become available or are deleted, the list will be updated as necessary by the local Health Board. The community pharmacist will keep you updated when there are changes to the 'Gluten-free Food List'.

## What items are available on the Gluten-free Food List?

Each Health Board publishes their local formulary listing the gluten-free food items available.

## Why are some prescription foods not included on my Gluten-free Food List?

All Health Boards have their own 'Gluten-free Food List', known as their formulary, It is up to each Board to decide which products are available in their area, based on demand, variety and value for money.

## What if I have additional food intolerances/allergies?

The pharmacist should be able to discuss this with your GP or Dietitian who will be able to give guidance.

## Why is it sometimes a long time from ordering the fresh bread until I get it?

You need to check the 'Gluten-free Food List' for exact details of when to place your order. If you miss the deadline it can be up to ten days before the next batch is delivered. It is important that order forms are put into the pharmacy in enough time for them to process your order before the supply company deadline. The pharmacy will contact you when your order is ready for collection.

Fresh bread should have a 'use by' date of approximately five days so you can enjoy some of it before freezing. If the dates are consistently less than this then you need to let your pharmacist know.

How long can fresh bread or rolls be frozen for?

The products have all been tested for one month in the freezer. Manufacturers suggest that their products should not be frozen for longer than six weeks just like gluten containing bread. You should follow the manufacturer's instructions on how to store their products.

## If there's a problem with one of my products, what should I do?

The products should be taken back to the pharmacy and they will arrange for them to be returned to the supplier. The manufacturer(s) should also be informed - they are grateful for feedback on their products (a list of manufacturers is available at the back of the 'Gluten-free Food List') - the pharmacist may also contact the manufacturer on your behalf if required.

## What is the best way of trying different products?

Many manufacturers will send out samples of their products if they are contacted (a list of manufacturers is available at the back of the 'Gluten-free Food List'). Please make sure that any prescribable gluten-free food that you order is on your Health Board's 'Gluten-free Food List'.

Coeliac UK (www.coeliac.org.uk) will often have details of new products.

## Annual pharmacy health check

## Why do I need an annual health check?

People with coeliac disease should have an annual health check to establish if you are having any issues with your gluten-free diet or wider issues. This brief check will give you the chance to discuss any concerns and the pharmacist can then make sure that you are put in touch with the correct healthcare professional to help if required.

## Who should attend the Coeliac Disease annual health check?

Adults with coeliac disease registered on the service need to attend the annual coeliac disease health check when invited by their pharmacy. Community pharmacists are required to carry this out as part of your registration for the Glutenfree Food Service. You will be asked to attend the pharmacy at a time that suits you.

## What will happen at the annual coeliac disease health check?

The pharmacists may ask or take your weight and height, ask you questions relating to coeliac disease and your gluten-free diet. They might identify that seeing another healthcare professional, for example a dietitian or GP, would be useful as part of your ongoing coeliac disease care.

The pharmacist will also check and see if you are still entitled to the same number of units as before. If there is a change then they will let you and your GP know about the change.

## Help and Support

## How do I contact a Dietitian if I need one?

Dietitians are available to offer additional support and advice. Your pharmacist or GP can help you to get in touch with your local dietitians.

## Further information

More information on coeliac disease and/or dermatitis herpetiformis, gluten-free living and self-help measures can be accessed through:

- NHS inform website

Coeliac Disease information - www.nhsinform.scot/illnesses-and-conditions/stomach-liver-and-gastrointestinal-tract/coeliac-disease

Dermatitis Herpetiformis information - www.nhsinform.scot/illnesses-and-conditions/skin-hair-and-nails/dermatitis-herpetiformis

- NHS inform Helpline can be contacted on 0800224488 (calls from a landline are free).
- Coeliac UK website (www.coeliac.org.uk)

Community pharmacists will always be happy to answer any questions you may have on your condition and on the Gluten-free Food Service.

