

Scottish Gluten-free Food Service

Patient Information Pack

This pack gives you information on the new way of accessing gluten-free food in Scotland.

People who are diagnosed with **coeliac disease** and/or **dermatitis herpetiformis** and require prescribable gluten-free foods as part of their care will now be able to access the new **Scottish Gluten-free Food Service**.

This means you will:

- no longer go to your GP to order your prescription of glutenfree food
- visit your community pharmacist to place your gluten-free food order
- be in charge of the amount and type of foods you order each month (up to an agreed amount)
- be offered an annual coeliac disease health check in line with best practice guidelines to monitor your health (adults with coeliac disease only).

This service will allow people who need a gluten-free diet, greater control and the flexibility to try different foods each month, which will increase choice. It should make the diet easier to manage and therefore more enjoyable.

How to use the Scottish Gluten-free Food Service

You will be informed by your GP when you can start on the Scottish Glutenfree Food Service and the maximum amount of gluten-free units you are entitled too.

Registration

Your GP will give you a '**Patient Registration Form'**, which you will then take, or get someone else to take, to the community pharmacy you wish to use for your gluten-free prescriptions.

Your community pharmacist will explain the new service, complete the necessary paperwork and provide all the information you should 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 forms and the 'Gluten-free Food Lists' for the future.

Placing an order

Using the 'Gluten-free Food List', you can select products up to your maximum unit amount. Complete the 'Gluten-free Food Requirement Order Form' with your selected products. Care must be taken not to go over your monthly units.

Once you have completed the form, take it to your selected community pharmacy. You may find it helpful to keep a copy for your own records.

Your community pharmacist will let you know when your order is ready for collection.

A new form must be completed each month. You may change your order each month if you wish or you may wish to order the same as last month. It is up to you.

Annual health check (adults only)

If you are an adult with coeliac disease and use this service, you will be invited to the pharmacy for the community pharmacist to complete an annual coeliac disease health check.

Children are not included in the community pharmacy coeliac disease health check. This is because they are 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 with their hospital service.

Questions about this service

Who can use the Scottish Gluten-free Food 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 clients do not have access to this service but will continue to be eligible for prescriptions from their GP in the normal way if appropriately diagnosed.

How do I register?

GP practices will contact those people with confirmed coeliac disease or dermatitis herpetiformis and will provide them with a partially completed and signed (by the GP) '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. The pharmacist will also explain the service and provide all the necessary paperwork.

Some community pharmacies may not offer this service.

Why should I use this service?

By using the service, you can have more 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 as per national coeliac disease guidelines.

Do I have to get my gluten-free products through the pharmacy?

No, you may stay with your GP and carry on obtaining your gluten-free food through this route. However, you cannot use both systems. If you agree to use the new service then your GP will give you up to a month's prescription and this is felt to be sufficient time for you to be registered with the new Scottish Gluten-free Food Service. Your GP will stop your gluten-free food prescriptions from the GP practice once you are set up on the Scottish Gluten-free Food Service.

What do I need to do if I have been identified by my GP as eligible for the Service?

If you have been identified as eligible for the service and wish to register, take the 'Patient Registration Form' that your GP has provided, partially completed and signed to your local pharmacy and register for the service.

Register with the pharmacy of your choice

Take, or get someone to take, the partially completed and signed 'Patient Registration Form' to the community pharmacy that you want to get your gluten-free prescriptions from.

The pharmacist will explain in detail how the service works and answer any questions you may have. They will also complete the necessary paperwork and give you the gluten-free service information which will include your 'Gluten-free Food List' and 'Gluten-free Requirement Order Form'. They will also inform you how to access the forms and 'Gluten-free Food List' for the future.

Place your order

Look through the 'Gluten-free Food List' and choose which products you would like to order. These might be the same as you have had on repeat prescription or something completely different.

Fill in the 'Gluten-free Requirement Order Form' with your details and the gluten-free product(s) you have chosen. Add up your units 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 food order form to the pharmacist. If you are ordering fresh products, you must allow sufficient time for processing. If you would like a copy for your records, then you must either copy it onto a spare form or take a photocopy.

The pharmacist will contact you when the order is ready to be collected.

A new food order form is required to be completed each month and the foods ordered can be changed each month if required. If you want to order the same as last month, then simply tell the pharmacist.

If you need a new order form, you can ask your pharmacist or download one from the NHS Inform website - www.nhsinform.co.uk/GFFSeligibility

Are prescription charges payable?

Scotland has not charged for prescriptions since April 2011 and that applies to prescriptions for 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 and get your gluten-free foods from. 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 you move community pharmacy?

You generally cannot move pharmacy for the first year of this service except if you move to a new area. You can then move community pharmacy but you will need your GP to set this up for you.

How many gluten-free units will I be allowed?

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.

Age and Sex	Units per Month
1-3 years	10
4-6 years	11
7-10 years	13
11-14 years	15
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	+1
3 rd trimester of pregnancy	+4

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

How much is one gluten-free unit?

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

Sometimes manufactures do not make their products in the above unit sizes. Where this has been found, an expert group of dietitians and pharmacists have agreed what the unit allocation for that product is. This may vary from what manufacturers' recommend for their item.

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 in their practice.

Is there a gluten-free App available to help with ordering?

Your community pharmacy will advise if this is available in your area.

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

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

If I don't want to change what I am ordering each month can I just put in a repeat order form?

You will need to ask your individual pharmacist if this service is available.

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.

New order forms are also available to download from the NHS inform website – www.nhsinform.co.uk/GFFSeligibility

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 uses. Your pharmacist will advise which food list you can use and how you access this locally.

I am moving house, what do I need to do?

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 further away, you will need to register with a new pharmacy but this needs to be organised by your GP. You would need to let your GP know and then your GP will send a new registration form which can then be taken to a new pharmacy.

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.

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 will publish a local formulary listing the gluten-free food items available. The items available will be in line with the **Advisory Committee on Borderline Substances (ACBS)** advice.

There are foods that are available on prescription but they are not on the Gluten-free Food List, Why is this?

All health boards will have their own 'Gluten-free Food List', These lists may not include all the gluten-free foods that are currently available on prescription. This may be because the products are not good value for money or do not support a healthy gluten-free diet.

What if I have additional food intolerances/allergies?

The pharmacist should be able to discuss this with the 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 will need to follow the manufacturer's instructions on how to store their products.

If there is a problem with the quality of one of the products ordered, 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').

Coeliac UK's 'Crossed Grain Magazine' will often have details of new products.

Please make sure that any prescribable gluten-free food that you order is on your health board's 'Gluten-free Food List'.

What if I have never seen a Dietitian - what do I need to do if I need to have contact with one?

Dietitians are available to offer additional support and advice and your pharmacist or GP can help introduce you to your local dietitians.

Where can I get more information about coeliac disease and/or dermatitis herpetiformis?

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

- NHS inform www.nhsinform.co.uk/coeliacdisease
 www.nhsinform.co.uk/dermatitisherpetiformis
- Coeliac UK www.coeliac.org.uk

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

Questions about the annual coeliac disease health check

Who should attend the annual health check?

Only adults with coeliac disease registered on the service need to attend the annual coeliac disease health check when invited by their pharmacy.

If you have been asked to attend the pharmacy for an annual coeliac disease health check, what can you expect?

If you are an adult with coeliac disease and registered for the service, you will be invited by your pharmacist to attend an annual coeliac disease health check. You will be asked to attend the pharmacy at a time that suits you. Your pharmacist will discuss your health in relation to coeliac disease and may ask or measure your weight and height.

What sort of questions will I be asked 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.

Is it necessary for me to attend for an annual coeliac health check?

Ideally, people with coeliac disease should have a yearly health check but often this does not happen. 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. **NHS Scotland** gratefully acknowledges the assistance of all those involved with the **Tayside Gluten-free Food Service** and those that have helped to produce this information pack.

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