







### **GLUTEN-FREE FOOD SCHEME**

### **Information Pack**

The Tayside Gluten-Free Food Scheme is part of the Scottish Gluten-Free Food Service. There are variations from the Scottish Service and more information can be accessed via <a href="http://www.taysidenutrition.scot.nhs.uk">http://www.taysidenutrition.scot.nhs.uk</a>

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### Welcome to the Gluten-Free Food Service in Scotland

People who need prescribable gluten-free food as part of their coeliac disease and/or dermatitis herpetiformis care can access the new Scottish Gluten-Free Food Service. In Tayside this is called the Tayside Gluten-Free Food Scheme.

#### This means:

- You will visit your community pharmacist to place your gluten-free food order
- You do not have to go to your General Practitioner (GP) to order your prescription of gluten-free food
- You will be in charge of the amount and type of foods you order each month (up to an agreed amount)
- You will also be offered an annual coeliac disease health check in line with best practice guidelines to monitor your health (ADULTS with COELAC DISEASE ONLY)

This scheme 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.

#### Quick Guide on how to use the Tayside Gluten-Free Food Scheme

#### Registering

- 1. Your dietitian will give you a 'Patient Registration Form' which you will then take, or get someone else to take, to the community pharmacist you wish to use for your gluten-free prescriptions.
- 2. Your community pharmacist will register you on the Scheme, complete the necessary paperwork and provide information about their service.

### Placing your order

- 3. Look through the Prescribable Gluten-Free Food List (Formulary) and select products up to your maximum unit amount.
- 4. Complete the Gluten-Free Food Requirement Order Form with your selected products. Care must be taken not to go over your monthly units or the units given in Section B.
- 5. Once you have completed the Gluten-Free Food Requirement Order Form, take it to your chosen community pharmacist. You may find it helpful to keep a copy of your order for your own records.
- 6. Your community pharmacist will let you know when your order is ready for collection.
- 7. A new Gluten-Free Food Requirement Order Form must be completed each month. You may wish to change the items you order each month or you can keep them the same as your last order, it is up to you.
- 8. If you choose to use the Gluten-Free Food App, please follow the steps to complete your order.

#### Adult Annual Coeliac Disease Health Check

9. If you are an adult with coeliac disease and are registered on the Scheme, once a year 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 because they are usually in a follow-up system with paediatric and dietetic services (and if there are health concerns, children should be followed up by their GP or with their hospital service).

#### Questions about the Scheme

#### Who is able to join the Tayside Gluten-Free Food Scheme?

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 Tayside Gluten-Free Food Scheme.

### How do I register with the Scheme?

Once you have a confirmed diagnosis of coeliac disease or dermatitis herpetiformis your dietitian will give you with a signed partially completed Patient Registration Form. The Patient Registration Form will state how many gluten-free 'units' you are entitled to each month. The Patient Registration Form must then be taken to a community pharmacy of your choice where the pharmacist will register you on the Scheme. The dietitian will explain the Scheme and provide all the necessary paperwork. The community pharmacist can explain things further if needed.

### Why should I join the Tayside Gluten-Free Food Scheme?

By using the Scheme 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 to help you meet your individual needs.

If you are an adult with coeliac disease you will be invited for an Annual Coeliac Disease Health Check as per national coeliac disease guidelines.

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

No. Your GP can provide gluten-free food prescriptions but they will use the same unit allocation and Prescribable Gluten-Free Food List as the Tayside Gluten-Free Food Scheme. You may not have the flexibility of changing your order as often and you will not be offered a community pharmacy Annual Coeliac Disease Health Check.

Both patients and GPs have found the Tayside Gluten-Free Food Scheme a better way for patients to obtain gluten-free foods compared to GP prescribing. However, you cannot use both systems. If you agree to use the new Scheme then your GP will not provide gluten-free food on prescription.

#### What do I need to do?

1. Register with the pharmacy of your choice.

Take, or get someone to take, the partially completed and signed (by the dietitian) Patient Registration Form to the community pharmacist that you wish to supply your gluten-free order (prescription).

The pharmacist will register you on the Scheme and answer any questions you may have. They will also complete the necessary paperwork. They will inform you how to keep up-to-date and access the Food List and Order Forms in the future. You can also access these documents at <a href="http://www.taysidenutrition.scot.nhs.uk">http://www.taysidenutrition.scot.nhs.uk</a>

#### 2. Place your order

Look through the Prescribable Gluten-Free Food List your dietitian has given you and choose which products you would like to order.

Fill in the Gluten-Free Requirement Order Form with your details and the gluten-free product(s) you have chosen. Add up the units making sure you do not go over your total unit allowance (or over the 3 units in Section B) for the month. Units cannot be carried over to the next month.

Give the completed Gluten-Free Requirement Order Form to the pharmacist. If you are ordering fresh products you must allow sufficient time for processing. If you would like a copy of your order, 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. The pharmacist will also be able to give you further copies of the Gluten-Free Requirement Order Form or you can visit the Tayside Nutrition website where you can download and print off more forms <a href="http://www.taysidenutrition.scot.nhs.uk">http://www.taysidenutrition.scot.nhs.uk</a>

You need to complete a new Order Form each month. You can change the foods if you want to or order the same as last month. If you want to always order the same foods then discuss how you can do this with your community pharmacist. You can also order using the Gluten-Free Food App <a href="http://www.taysideglutenfree.org.uk">http://www.taysideglutenfree.org.uk</a>

#### Are prescription charges still payable?

Scotland has not charged for prescriptions since April 2011 and that applies to prescriptions for items supplied under the Tayside Gluten-Free Food Scheme.

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

Yes. You can choose to register with any Tayside pharmacy to order your gluten-free foods. However, once you have chosen the pharmacy you wish to use, you must always go to this pharmacy to order your gluten-free food.

### Once registered on the Scheme can I move community pharmacy?

Generally you cannot move from the pharmacy you have registered with. However, if you move to a new area then you can change your community pharmacy. The community pharmacist and dietitian will 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. This is determined by your age 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	+4
3 <sup>rd</sup> trimester of pregnancy	+1

If you feel you need more than the above national recommendations, then you can be referred by your community pharmacist 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 given a unit value in the Prescribable 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	11/2

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 on what the unit allocation for that product is. This may vary from what manufactures 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. Your pharmacy will advise if this service is available.

#### Is there a Gluten-Free Food App available to help with ordering?

Yes. NHS Tayside have developed a Tayside Gluten-Free Food App making ordering easy. Discuss setting this up with your community pharmacy and agree how this will work for you both. The App can be downloaded at <a href="http://www.taysideglutenfree.org.uk">http://www.taysideglutenfree.org.uk</a>

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

Generally, no. Only one order form is allowed per calendar month. However, you may want to discuss this with your community pharmacy if this is a problem.

# 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?

You can ask your pharmacist to supply further copies or visit the Tayside Nutrition website where you will find the order forms and the Prescribable Gluten-Free Food List http://www.taysidenutrition.scot.nhs.uk

#### 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 that 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 inform the pharmacist of 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 community pharmacist and dietitian. You would need to let your community pharmacist know and then your dietitian will send a new Patient Registration Form which you can then sign at your new pharmacy.

If you are moving into a new Health Board area and changing GP then you will need to use the Gluten-Free Food List for that Health Board area. You will need to familiarise yourself with their gluten-free food service as it may be different to the one used with the NHS Tayside Gluten-Free Food Scheme.

#### How often will the Gluten-Free Food List be updated?

As new products become available or are deleted, it is hoped that the Prescribable Gluten-Free Food List will be updated as necessary. The community pharmacist will keep you informed when there are changes to the Prescribable Gluten-Free Food List. Regular updates will be available on the website and paper copies may be sent out as necessary. The Gluten-Free Food App will always use the most up-to-date Gluten-Free Food List.

### 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 of the gluten-free foods that are currently available on prescription. This may be because the products are not good value for money, do not support a healthy gluten-free diet or that they have very high delivery and/or handling costs.

#### 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.

# Sometimes it seems a long time from ordering the fresh bread until I get it?

You need to check the Prescribable 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 to allow enough time for them to process your order before the supply company deadline. The pharmacy will telephone 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 Prescribable 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 Prescribable 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 the Tayside Prescribable 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 can help introduce you to your local dietitians.

# 3. <u>Annual Coeliac Disease Health Check</u> (ADULT coeliac disease patients only)

Who should attend the Annual Coeliac Disease Health Check? Only adults with coeliac disease registered on the Scheme need to attend the annual coeliac disease health check at 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 Scheme, you will be asked 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 measure your weight and height.

## What sort of questions will I be asked at the Annual Coeliac Disease Health Check?

If possible you will have your weight and height checked and the pharmacist may 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 do this for you.

### Is it necessary for me to attend for an Annual Coeliac Disease 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.

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

It is very important that you follow a gluten-free diet if you have been diagnosed with coeliac disease or dermatitis herpetiformis. It is also important that you attend your Adult Coeliac Disease Health Check if requested to do so. More information on coeliac disease and/or dermatitis herpetiformis, gluten-free living and self-help measures can be accessed from NHS Inform and Coeliac UK:

NHS Inform Website - http://www.nhsinform.co.uk/coeliacdisease

The NHS Inform helpline can give you further information. To contact the helpline, please phone 0800 224488 (8.00 am to 10.00 pm, 7 days).

Coeliac UK Website – http://www.coeliac.org.uk

Coeliac UK, 3rd Floor, Apollo Centre, Desborough Road, High Wycombe, Buckinghamshire, HP11 2QW Helpline 0845 305 2060

NHS Tayside Nutrition website - http://www.taysidenutrition.scot.nhs.uk

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

If you have any worries or need more help regarding the Tayside Gluten-Free Food Scheme, please visit the NHS Tayside Nutrition website, speak to your community pharmacist or contact Fiona Headridge:

Fiona Headridge, 01307-475228 <a href="mailto:fheadridge@nhs.net">fheadridge@nhs.net</a>, Specialist Dietetic Practitioner for Coeliac Disease (part-time) NHS Tayside

(If I am not in the office please leave a message and contact number and I will get back to you. Please note that my return call will show up on your 'phone as an 0800 number as it diverts via the NHS switchboard)