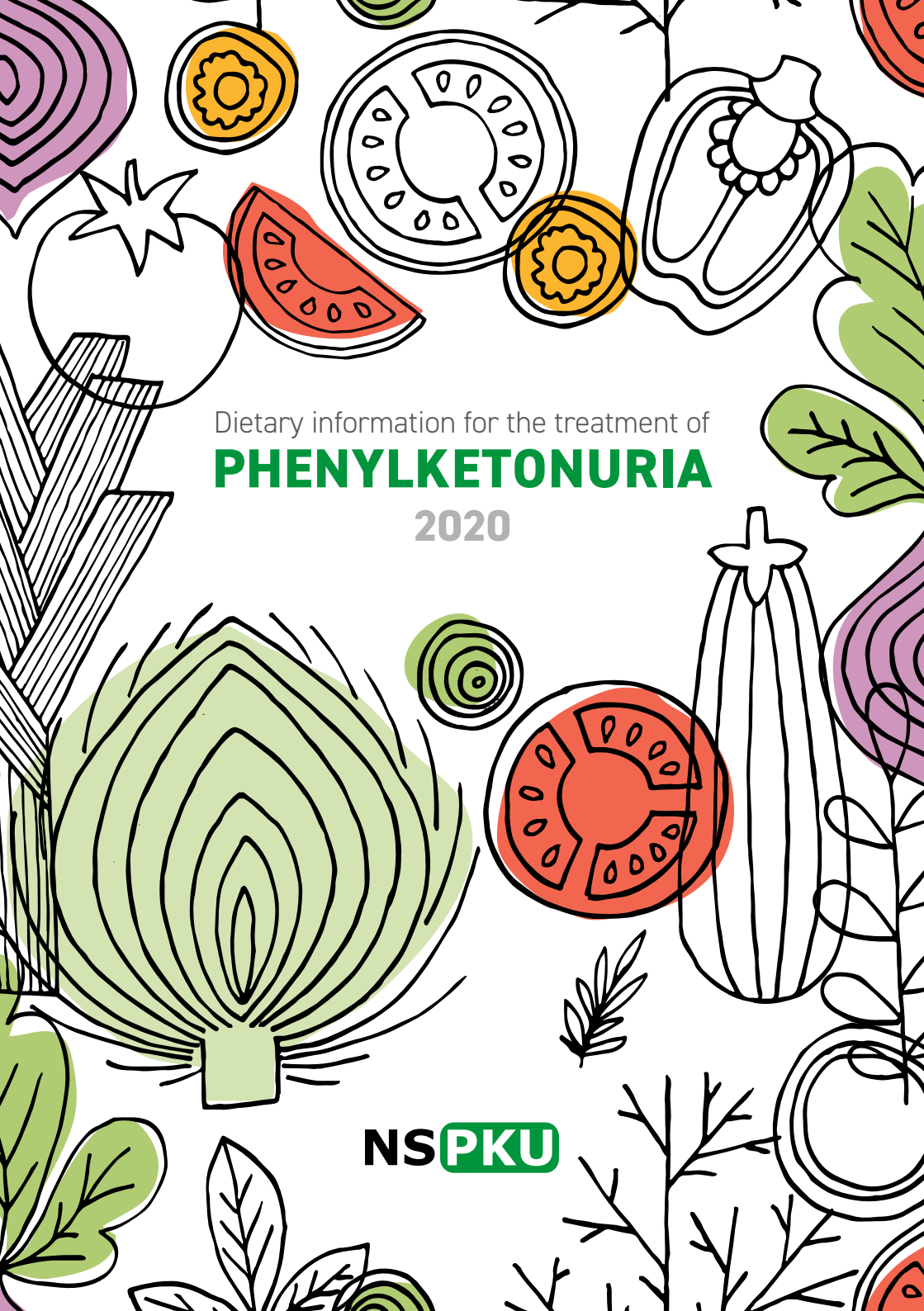


Dietary information for the treatment of

PHENYLKETONURIA

2020

NSPKU

Glossary

Protein is found in most foods. It is made up of 20 amino acids which are the building blocks of protein. It is needed for the structure, function and regulation of the body tissues and organs.

Phenylalanine is one of 20 amino acids found in protein-containing foods. The amount of phenylalanine found in protein-containing foods will vary and is less in fruit and vegetables, but higher in foods such as dairy and cereals. The word phenylalanine is commonly shortened to Phe.

Exchange foods need to be measured in the diet. One exchange is the amount of food that contains 1g of protein or 50mg phenylalanine.

Exchange-free foods are low in protein or phenylalanine. They can be eaten without weighing or measuring.

Low protein prescription foods are low in protein or phenylalanine. They are an essential part of the diet providing energy and variety. They are only available on prescription from the GP.

Contents

This booklet has been produced by the NSPKU Medical Advisory Panel (MAP) dietitians and the information provided is correct at the time of going to print.

If you are unsure about any of the information in this booklet please check with your dietitian.

What is a low phenylalanine diet?

A low phenylalanine diet is the main treatment for phenylketonuria (PKU). People with PKU must restrict phenylalanine which is found in protein. However, phenylalanine cannot be removed completely, so it is given in measured **exchange** amounts each day.

There are 5 parts to a low phenylalanine diet:

1. **Foods high in protein** which should be avoided – **Red list**.
2. **Exchange foods** which need to be weighed before eating – **Amber list**.
3. **Exchange-free foods** which can be eaten freely, without weighing. These include most fruits and some vegetables – **Green list**.
4. **Low protein prescription foods** such as bread or pasta are an important part of the diet. They are listed in a separate downloadable document on the NSPKU website.
5. **Protein substitute** which provides safe protein without phenylalanine. It is taken in three or four doses spread throughout the day. It usually includes vitamins and minerals. Protein substitutes are prescribed on an individual basis, so are not discussed in this booklet.

What is a protein (PKU) exchange?

A measured amount of phenylalanine is called an **exchange** or a **PKU exchange**. One exchange is the amount of food that contains **1g of protein** or **50mg phenylalanine**.

For most foods, the protein content displayed on the nutrition label per 100g of food is used to calculate the amount of food that is equal to one exchange. Fruits and vegetables are an exception. The NSPKU have analysed the phenylalanine content of a wide range of fruits and vegetables in order to calculate their exchange amounts. These are shown on the Amber list (page 10).

Examples of exchange foods

- 14g Kellogg's cornflakes = 1 exchange
- 80g boiled potato = 1 exchange

How is the daily number of phenylalanine exchanges allocated?

Your dietitian will prescribe a measured number of phenylalanine exchanges for you or your child to be taken each day. This will be determined mainly by blood phenylalanine levels. If you have too many exchanges, it will cause high phenylalanine levels. If you do not eat enough exchanges, there may be insufficient protein or phenylalanine for growth, or for repair and maintenance of the body.

The amount of exchanges allocated to each person with PKU is individual.

How to calculate protein exchanges

To work out a 1g protein exchange from a food label, do the following calculation:

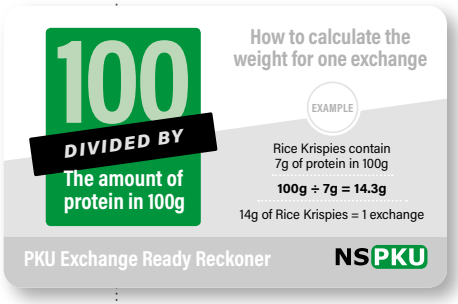
100 ÷ the amount of protein in 100g = 1 exchange

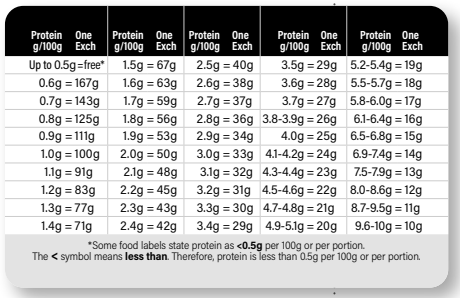
For example:

Rice Krispies contain 7g of protein in 100g

100 ÷ 7 = 14.3

Therefore, 14g of Rice Krispies = 1 exchange





Protein g/100g	One Exch	Protein g/100g	One Exch	Protein g/100g	One Exch	Protein g/100g	One Exch	Protein g/100g	One Exch
Up to 0.5g=free*		1.5g = 67g		2.5g = 40g		3.5g = 29g		5.2-5.4g = 19g	
0.6g = 167g		1.6g = 63g		2.6g = 38g		3.6g = 28g		5.5-5.7g = 18g	
0.7g = 143g		1.7g = 59g		2.7g = 37g		3.7g = 27g		5.8-6.0g = 17g	
0.8g = 125g		1.8g = 56g		2.8g = 36g		3.8-3.9g = 26g		6.1-6.4g = 16g	
0.9g = 111g		1.9g = 53g		2.9g = 34g		4.0g = 25g		6.5-6.8g = 15g	
1.0g = 100g		2.0g = 50g		3.0g = 33g		4.1-4.2g = 24g		6.9-7.4g = 14g	
1.1g = 91g		2.1g = 48g		3.1g = 32g		4.3-4.4g = 23g		7.5-7.9g = 13g	
1.2g = 83g		2.2g = 45g		3.2g = 31g		4.5-4.6g = 22g		8.0-8.6g = 12g	
1.3g = 77g		2.3g = 43g		3.3g = 30g		4.7-4.8g = 21g		8.7-9.5g = 11g	
1.4g = 71g		2.4g = 42g		3.4g = 29g		4.9-5.1g = 20g		9.6-10g = 10g	

*Some food labels state protein as **<0.5g** per 100g or per portion.
The **<** symbol means **less than**. Therefore, protein is less than 0.5g per 100g or per portion.

PKU Exchange Ready Reckoner

The NSPKU have produced a handy credit card-size *PKU Exchange Ready Reckoner*. This can be easily carried in a wallet or bag to help calculate exchanges when on the move or at home. These cards are available to members of the NSPKU – please contact the NSPKU using the details shown at the back of this booklet.

Calculating protein exchanges can be confusing. If you are unsure how to do this please speak to your dietitian.

The PKU diet traffic light system

This booklet uses a colour-coded system to differentiate between foods that must be avoided (Red list), foods that must be weighed as exchanges (Amber list) and exchange-free foods that can be eaten freely (Green list).

STOP

Foods that need to be AVOIDED, as they are too high in phenylalanine

GO CAUTIOUSLY

Foods that need to be weighed (exchanges), as they contain some phenylalanine

GO

These foods contain very little phenylalanine and can be eaten without weighing (exchange-free)

STOP

High protein foods

Foods that need to be AVOIDED, as they are too high in protein/phenylalanine

MEAT

All varieties, including beef, lamb, pork, ham, bacon, chicken, turkey, duck and game. Offal e.g. liver, tongue, kidney. Canned meat e.g. corned beef. Meat products e.g. sausages, beef or chicken burgers, meat paste, meat pies.

FISH

All varieties, including shellfish, frozen or tinned fish.

EGGS

All varieties, including liquid pasteurised egg.

CHEESE

All dairy-based cheese, including cheese spreads.

Some vegan or "Free From" cheese is suitable. Check protein on food labelling for protein content.

NUTS & SEEDS

All varieties, including marzipan (almond paste).

FLOUR-BASED FOODS

All varieties of flour (except cassava flour), bread, pasta, cakes and biscuits.

SOYA

Foods made from soya such as texturised vegetable protein (meat substitute).

QUORN

TOFU

GOJI BERRIES

ASPARTAME (E951)

Aspartame is an artificial sweetener, which can be found in some fizzy drinks, squashes, cordials, alcoholic drinks, puddings, jellies, crisps and chewing gums. It can be found in some tabletop sweeteners e.g. **Canderel**, **Flix**, and **granulated sweeteners**. **Aspartame** contains phenylalanine and therefore it should not be taken.

Food and drink containing aspartame will be labelled:

Aspartame or **E951**

The food or drink will also be labelled:

Contains a source of phenylalanine

Aspartame is also used in some drugs. All drugs that contain **aspartame** must declare this ingredient (and all other ingredients) in the patient information sheet, which is dispensed with the drug. If you are unsure check with your pharmacist to ensure the drug is suitable.

Neotame is an artificial sweetener used in non-UK, European countries. The phenylalanine content in **neotame** is not known, so it is best avoided. Please be aware of this when travelling outside the UK.

GO CAUTIOUSLY

Exchange foods

Foods that need to be weighed accurately as they contain some protein/phenylalanine. The weight/volume of each food listed = 1 exchange

Weigh/measure food **after** cooking unless otherwise stated.

POTATOES

Boiled	80g
Canned new potatoes – drained weight	100g
Chips – uncoated	45g
Croquette	40g
Mashed – no milk	80g
Instant mashed potato – dry powder weight	10g
Jacket	80g
Roast	55g

VEGETABLES

Asparagus	60g
Bamboo shoots	60g
Beansprouts	60g
Broad beans	20g
Broccoli	60g
Brussels sprouts	60g
Cauliflower	60g
Chestnuts	40g
Choi sum	35g
Corn on the cob	55g
Kale	35g
Mange tout	60g
Mixed vegetables	30g

VEGETABLES CONTD.

Peas and petit pois	25g
Romanesco	35g
Rocket – raw weight	35g
Spinach	25g
Spring greens	35g
Sugar snap peas	60g
Sweetcorn kernels	35g
Sweet potato fries with coating	50g
Vine leaves	30g
Whole hearts of palm	60g
Yams	60g

FRUITS

Figs	60g
Passion fruit	40g

MISCELLANEOUS

Aquafaba (chickpea water)	100ml

DAIRY

Cow's milk	30ml
Single cream	40ml
Double cream	60ml
Sour cream or crème fraiche	35ml

BE AWARE

Look out for coated vegetables e.g. **chips** or **wedges**. They may be coated with **wheat** or **rice flour** and therefore will contain protein. These foods will need to be calculated as exchange foods.

Sometimes the protein content is given on the label as the final prepared weight, assuming that the product is made with an added ingredient such as **milk** or **egg** e.g. **custard**. If you are unsure about this ask your dietitian.

See pages 18 – 23 for more guidance on reading food labels.

IMPORTANT INFORMATION

Use the protein value per 100g on the food label to calculate the exchange amount for foods such as **breakfast cereals**, **yogurt**, **ice cream**, **coconut products** and **rice**.

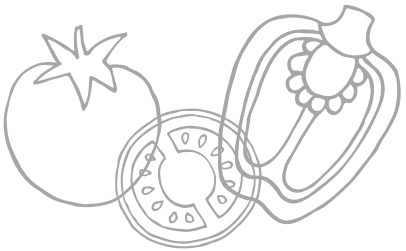
Exchange foods should be weighed unless it is already packaged as a pre-measured food portion e.g. **crisps** or **popcorn**.

If fruit or vegetable dishes contain exchange ingredients such as **rice** or **milk** they should be counted as exchange foods. Use the protein content on the food label to determine the exchange amount.

GO

Exchange-free foods

These foods contain very little protein/ phenylalanine and can be eaten without weighing



FRUIT

Fresh, frozen, tinned, raw, puréed, cooked in sugar and dried except where stated.

- Apples
- Apricots
- Avocado
- Bananas
- Banana chips
- Bilberries
- Blackberries
- Blueberries
- Candied angelica
- Candied peel
- Cherries
- Clementines
- Cranberries
- Currants – black, red, white
- Custard apples
- Damsons
- Dates
- Dragon fruit
- Fruit crisps – apple, pineapple
- Fruit pie filling
- Fruit mincemeat
- Fruit salad
- Glacé cherries
- Gooseberries
- Grapes
- Grapefruit
- Greengages
- Guavas
- Jackfruit
- Kiwi fruit
- Kumquats
- Lemons
- Limes
- Loganberries
- Lychees
- Mandarins
- Mango
- Medlars
- Melon – all varieties
- Nectarines
- Olives
- Oranges
- Papaya (Paw paw)
- Peaches
- Pears
- Physalis
- Pineapple
- Plums
- Pomegranate
- Prickly pear
- Prunes
- Quince
- Raisins
- Raspberries
- Rhubarb
- Satsumas
- Sharon fruit
- Star fruit
- Strawberries
- Sultanas
- Tamarillo
- Tangerines
- Watermelon

VEGETABLES

Fresh, frozen, tinned, raw and puréed except where stated.

- Artichoke – globe, Jerusalem
- Aubergine
- Baby corn
- Beetroot
- Cabbage
- Capers
- Caperberries
- Carrots
- Cassava
- Celeriac
- Celery
- Chayote
- Chicory
- Courgette
- Cucumber
- Dudhi
- Eddoes
- Endive
- Fennel
- Garlic
- Gherkin
- Ginger
- Green beans – dwarf, French, runner
- Karela
- Kohl rabi
- Leeks
- Lettuce
- Marrow
- Mooli
- Mushrooms
- Okra (Ladies' fingers)
- Onion
- Pak choi
- Parsnips
- Peppers – all colours
- Pickled vegetables – eg: onion, gherkins, red cabbage
- Plantain
- Pumpkin
- Radish
- Salad cress
- Samphire
- Squash – butternut squash, acorn squash, spaghetti squash
- Swede
- Sweet potato
- Tomato
- Turnip
- Watercress
- Water chestnuts

SUGAR

- Brown
- Cane
- Caster
- Demerara
- Fruit sugar
- Glucose
- Granulated
- Icing
- Molasses
- Muscovado
- White

GO Exchange-free foods – continued

ARTIFICIAL SWEETENERS

- Acesulfame K – E950
- Cyclamate – E952
- Fructose
- Isomalt
- Lactitol
- Maltodextrin
- Mannitol saccharin – E954
- Sorbitol
- Stevia or steviol glycosides
- Sucralose – E955
- Xylitol

BAKING INGREDIENTS

- Arrowroot
- Baking powder
- Bicarbonate of soda
- Cassava flour
- Cornflour/Maize starch
- Cream of tartar

FATS

- Butter
- Margarine
- Oil sprays
- Vegetable fats and oils
  – liquid, solid

FIBRES & GUMS

- Psyllium fibre
- Psyllium husks
- Xanthan gum

FOOD ESSENCES & COLOURINGS

- Almond essence
- Cochineal
- Food colourings
  – gels, liquids, pastes
- Peppermint
- Vanilla

HERBS, SPICES & CONDIMENTS

- All herbs and spices – fresh and dried
- Mint jelly
- Mint sauce
- Salt and pepper
- Vinegar

PLANTS & CEREALS

- Custard powder
  – traditional
- Konnyaku
  – sometimes used to make noodles and rice
- Sago
- Tapioca and tapioca starch
  – NOT ready to serve milk puddings including sago and tapioca

JAMS, SYRUPS & SWEETS

- Agave syrup
- Barley sugar sweets
- Boiled sweets
- Candy floss
- Candy sherbet
- Fruit sorbets
- Fruit syrup
- Golden syrup
- Honey
- Jam
- Maple syrup
- Marmalade
- Rock
- Treacle
- Vegetarian jellies
  – without gelatine and check the label for aspartame

BE AWARE

Vegetables coated with **wheat** or **rice flour**, e.g. **chips** or **wedges** adds extra protein. These will need to be counted as exchange foods.

Vegetable crisps (including homemade) are NOT exchange-free. Once the vegetables are prepared as crisps they contain phenylalanine in concentrated amounts. They should be counted as exchange foods.

Custard comes in many varieties e.g. **traditional custard powder** (consisting of cornflour/maize flour, colouring and flavouring only), **instant custard mix** (containing milk) and **ready-to-pour custard**. Traditional custard powder, if made up with with a suitable low protein milk, is exchange-free. For the other custard varieties, please check the protein content on the label to calculate the protein exchange amount.

Do NOT use **Silver Spoon Half Spoon** granulated sugar as it contains **aspartame**.

IMPORTANT INFORMATION

Curry powders, **mustard powder** and **spices** are all high in protein but because small amounts are used they are considered exchange-free.

Curry paste is NOT exchange-free.

Corn starch and **cornflour** are usually referring to the same thing and are low in protein. They are not the same as cornmeal, which is much higher in protein.

Baby corn (exchange-free) is NOT the same as **sweetcorn kernels** and **corn on the cob** which are both exchange foods – see Amber list on pages 10 & 11.

GO

Low protein prescription foods

There is a wide range of low protein foods available on prescription

- Low protein pasta
- Low protein rice
- Low protein bread
- Low protein rolls
- Low protein baguettes
- Low protein pizza bases
- Low protein burger and sausage mixes
- Low protein cheese sauce
- Low protein milk
- Low protein crackers
- Low protein biscuits and cakes
- Low protein flour
- Low protein cake mix
- Low protein dessert mixes/custard mixes
- Low protein egg replacer
- Low protein chocolate

- Low protein foods are usually ordered monthly. The GP is responsible for writing the prescriptions. A chemist or home delivery company will then supply these food items.
- There are guidelines on the quantity of low protein food items that are given out on prescription each month. The amount increases with age and in pregnancy. Your dietitian will advise.
- A list of all the low protein foods available on prescription is on the NSPKU website.
- Ensure you keep adequate stocks of low protein products, as new orders take up to four weeks to be supplied.
- Check the foods on your repeat prescription list with your surgery on a regular basis to remove any items that are not used.
- If you experience any problems with your prescriptions, please contact your dietitian.

Useful guidance when handling low protein prescription foods

Check expiry dates – some foods have a short shelf life. Remember to rotate your stock to minimise any wastage.

Fresh low protein bread has a short shelf life – it is a good idea to freeze fresh bread supplies immediately after delivery. Keep frozen bread no longer than three months.

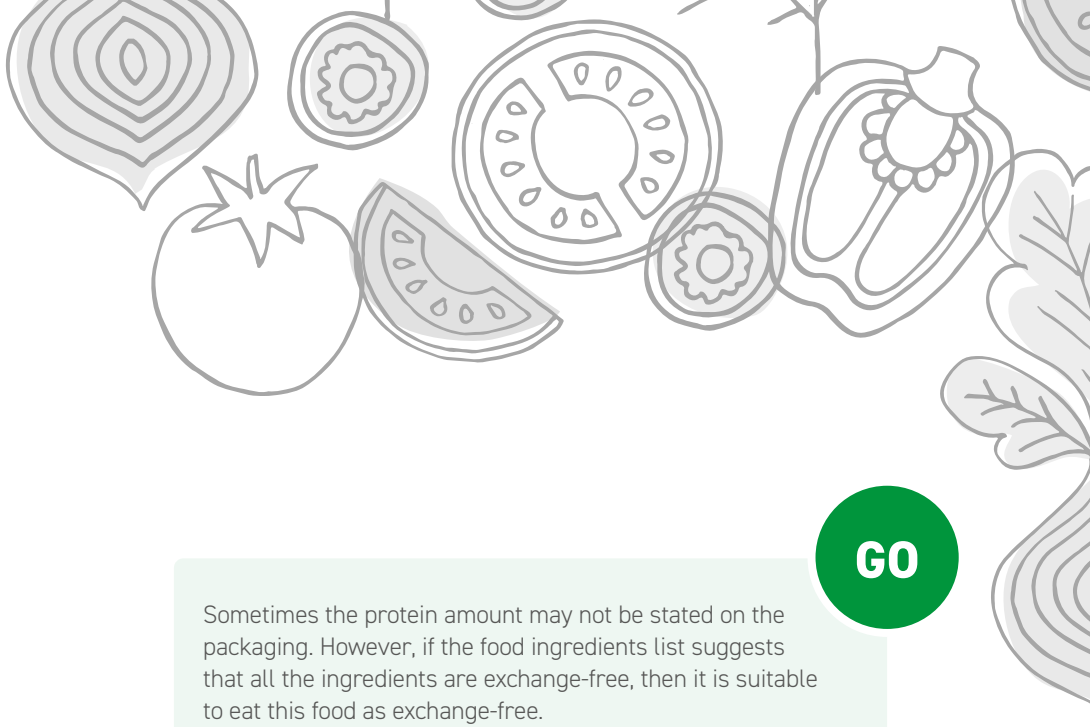
Follow instructions on how to cook the food carefully – they do not always cook in the same way as regular pasta, rice and flour. Sometimes it is necessary to practise when cooking low protein foods – it takes time to perfect low protein cooking skills.

There are useful low protein recipes using prescription foods available online.

Reading food labels: exchange or exchange-free?

Almost all processed foods contain some protein. Most food labels/packaging display a **nutrition table** and a **list of ingredients**. The protein content shown on the nutrition table and the list of ingredients help determine if a food should be weighed as an exchange or if it is exchange-free food. Please use the following guidance to help you interpret food labels.

Always read the ingredients AND the protein content.



GO

If all the ingredients are clearly exchange-free e.g. tomato sauce, vegetable sauces, fruit bars, then it is appropriate to eat this food as an exchange-free food even if the protein amount on the nutrition table suggests it should be counted as an exchange. In this case it is the ingredients rather than protein content that determine if a food item is suitable.

One exception is vegetable crisps (Page 15).

Example label information: Tomato sauce for lasagne

Ingredients
Tomatoes (76%), Tomato Paste (15%), Modified Maize Starch, Onion, Sugar, Salt, Basil (0.4%), Garlic, Acidity Regulator (Citric Acid), Herb, Parsley, Spices

Nutritional Information per 100g	
Energy	194kJ/46Kcal
Fat	<0.5g
Saturates	<0.1g
Carbohydrate	9.0g
Sugar	5.9g
Protein	**1.4g**
Fibre	1.4g
Salt	0.76g

GO

Sometimes the protein amount may not be stated on the packaging. However, if the food ingredients list suggests that all the ingredients are exchange-free, then it is suitable to eat this food as exchange-free.

Example label information: Blackcurrant flavour chewy sweets

Ingredients
Sugar, Glucose Syrup, Fully Hydrogenated Coconut Oil, Blackcurrant Juice from Concentrate (3%), Citric Acid, Starch, Concentrates (Black Carrot, Hibiscus), Flavouring, Maltodextrin, Thickeners (Gellan Gum, Cellulose Gum, Gum Arabic), Emulsifier

No protein value given on label

BE AWARE

If there is no nutritional analysis on the food product but it contains ingredients that are calculated/measured as exchange foods, then it is not appropriate to use this food until the food protein analysis is known.

Protein 'cut-off' points

If a food product contains exchange ingredients such as milk or rice flour, then it is the amount of protein it contains that is used to decide if it is an exchange food. Foods have a protein 'cut-off' point. These identify if a food product should be exchanges or exchange-free. These 'cut-off' points have been calculated based on normal portion/serving sizes. PLEASE NOTE: 0.5g protein or less per 100g is NOT the same as a protein content of 0.5g per bag or item.

0.5g per 100g

The following foods are exchange-free if the protein content is **0.5g per 100g or less** or **0.5g per 100 ml or less**. If they contain more protein than 0.5g per 100g or 0.5g per 100ml, they need to be counted as exchange foods.

- Gravy and stock cubes (when made up as directed by the manufacturer)
- Vegetable soups
- Free from and vegan cheeses
- Flours and starches
- Fibres and gums
- Fruit bars
- Sweet sauces/toppings
- Sweets (even if they contain gelatine)
- Ice lollies, sorbets
- Milkshake powders, syrups and straws
- Icings and frostings

Examples of two different vegan cheese nutrition tables

(For illustration purposes only)

Nutritional Information per 100g	
Energy	1269kJ/305Kcal
Fat	24.6g
Saturates	20.9g
Carbohydrate	19.4g
Sugar	0.2g
Protein	**0.2g**
Fibre	–
Salt	1.8g

This is very low in protein, therefore it is exchange-free.

Nutritional Information per 100g	
Energy	1269kJ/305Kcal
Fat	24.6g
Saturates	20.9g
Carbohydrate	19.4g
Sugar	0.2g
Protein	**0.8g**
Fibre	–
Salt	1.8g

This is above the upper cut-off point for an exchange-free cheese, therefore it should be weighed as an exchange food.

1g per 100g

The following foods are *exchange-free* if the protein content is **1g per 100g or less** OR **1g per 100 ml or less**. If they contain more protein than 1g per 100g OR 1g per 100 ml, they need to be weighed as *exchange* foods.

- Cake decorations/sprinkles
- Cook-in, pour-over or liquid sauces
- Mayonnaise, salad cream, oil-based dressings
- Savoury sauces, brown sauce, ketchup, pickles and spreads

0.1g per 100g

Plant milks should usually be measured as *exchange* foods. They are only *exchange-free* if their protein content is **0.1g per 100g or less** OR **0.1g 100 per ml or less**. In practice, this means that only a small number of coconut milks or rice milks are *exchange-free*.

1.5g per 100g

Soya sauces are *exchange-free* if the protein content is **1.5g per 100g or less** OR **1.5g per 100 ml or less**.

BE AWARE

Occasionally a product may show incorrect information about the protein content. It may suggest a product is very low in protein when it contains high protein ingredients. If the protein content appears incorrect, please discuss this with your dietitian.

Additional guidance and ideas

Alternative 'milk' and 'cream'

Coffee whiteners and non-dairy creams can be useful store cupboard items. Check protein content as they vary from product to product. Also look out for plant milk alternatives to cream and milk – any milk product (plant or animal) containing protein more than 0.1g per 100 ml must be measured as an exchange food.

Branded exchange-free foods

A list of common low protein exchange-free foods is available to download from the NSPKU website. It is not inclusive of all suitable branded foods, but it does include a number of useful products. This list is updated regularly.

Crisps and snacks

Check the amount of protein for each packet. There are many which contain 1 exchange per bag, and some are only 0.5 exchange per bag, but others which are much higher.

Crisps made from tapioca or cassava are lower in protein. These do not need to be weighed as an exchange if all the ingredients are exchange-free. Ask your dietitian to check for you. Check that aspartame is not added to crisps or snacks.

Cereal bars

There are several useful cereal bars which are 1, 1.5 or 2 exchanges per bar. Some of these bars may contain gelatine, but are suitable provided they are counted as exchange foods.

Cup a Soups

Many vegetable Cup a Soups contain between 1 to 1.5 exchanges per sachet. Please check the label.

Food without protein labelling

If all the ingredients on a food label are clearly exchange-free, then it is appropriate to use as an exchange-free food even if the protein analysis is unavailable on the label.

Gelatine

Gelatine is best avoided as it is high in protein. However, if it is added to sweets and the protein content is 0.5g per100g or less, then the food is exchange-free as the amount of gelatine added will be small.

Jellies thickened with gelatine have a protein content more than 0.5g per 100g – these are best avoided.

Some jellies use vegetarian setting agents instead of gelatine e.g. gellan, carrageenan, locust, carob, and xanthan bean gum. They are low in protein and exchange-free. Avoid jellies containing aspartame.

Plant-based meal options

Aubergine, jackfruit and mushrooms are useful exchange-free 'meat replacements' in dishes like stews, casseroles and curries.

Butternut squash, eddoes, parsnips and sweet potatoes are useful exchange-free potato replacements.

Ready-made puddings/desserts

Calculate the protein content for each dessert e.g. meringue or brandy snap basket. They are useful to serve with fruit, sorbet, coconut ice cream, fruit syrups, exchange-free jelly. Strawberry and raspberry sauces are useful as a topping on fruit, ice cream or low protein dessert pudding or sponge.

Rice

Rice has a variable protein content depending on whether it is raw, or precooked.

Traditional uncooked rice (e.g. basmati, long grain, paella, brown): 14g = 1 exchange.

Traditional cooked, boiled weight: 40g = 1 exchange.

Precooked rice (e.g. microwave or boil in the bag): the protein content on the product label (cooked or uncooked) should be used to determine the exchange weight.

Sauce mixes

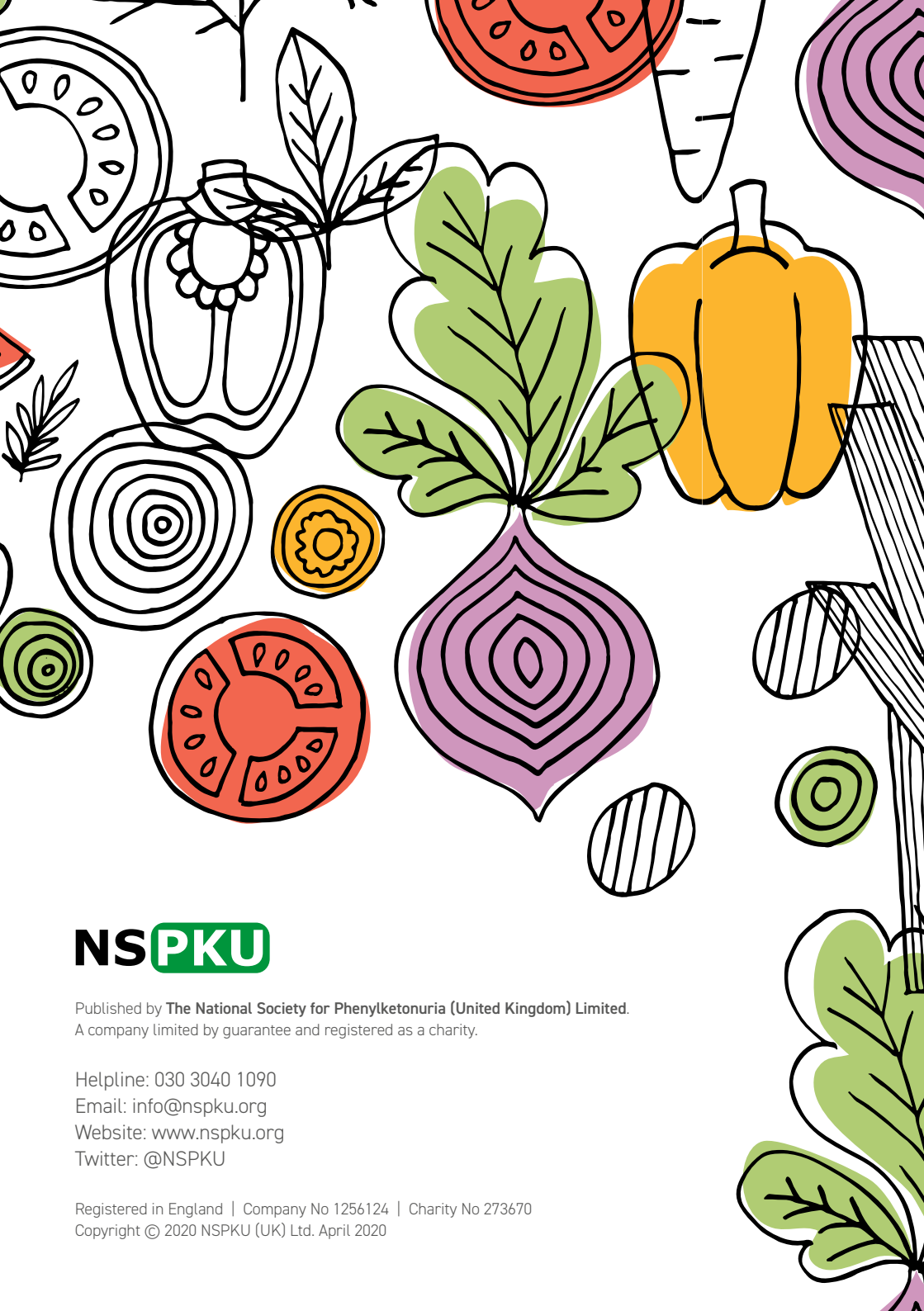
Look for easy to prepare hot sauces needing water only e.g. Bisto Curry Sauce (50ml as prepared = 0.5 exchange).

Savoury paté

Vegetable patés and spreads e.g. mushroom, aubergine, roasted peppers are likely to contain exchange containing ingredients so should be weighed as exchange foods unless all the ingredients are exchange-free.

Table sauces

Tomato ketchup and brown sauce are usually exchange-free. However, if they contain wheat, rye or rice flour and also contain more protein than 1g per 100g they should be weighed as exchange foods.



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Helpline: 030 3040 1090
Email: info@nspku.org
Website: www.nspku.org
Twitter: @NSPKU

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