



The PKU diet at school

A practical guide for schools
catering for a child with
phenylketonuria (PKU)

NS **PKU**

All children regardless of their ethnicity, religion or medical condition are entitled to a school meal. To ensure social inclusion, the school's catering service should work with the parent/carer and medical professionals to ensure that the child with PKU is provided with a safe and suitable school meal.





The UK Government (Supporting pupils with medical conditions at school), Scottish Government (Supporting children and young people with healthcare needs in schools), Welsh Government (Supporting learners with healthcare needs) and Education Authority Northern Ireland (School meals dietary requirements) have published guidelines for assisting children with medical conditions at school and advise that all school staff have a responsibility for supporting the health needs and wellbeing of the child.



Phenylketonuria (PKU) is a rare inherited metabolic disorder managed by a complex diet. When starting school, a parent/carer will hand over some of the responsibility for managing the diet to other people and this can be an anxious time for all.

It is important for children with PKU to be able to have school meals if they request this, they need to feel included and be able to have the same choices as their friends. By supporting the family in providing suitable school meals, catering staff become part of the team helping to manage the diet and will give the child and the family confidence that having this condition is not going to make them different from others or permit anyone to discriminate against them.

Children with PKU will have regular contact with a hospital dietitian trained in managing PKU. They will be a contact for you to provide help and support.

The dietitian should be able to help in adapting the usual school menu to make it suitable for the PKU diet. The parent/carer will provide guidance on the child's food preferences.

What is PKU and how is it diagnosed



PKU is a rare, inherited metabolic disorder in which a part of protein called phenylalanine cannot be used properly by the body.

Phenylalanine is one of the 20 building blocks of protein. PKU is diagnosed through newborn screening (also known as the heel prick test), from a blood spot taken when a baby is five days old.

Without strict dietary treatment, the child with PKU would have severe learning and behavioural difficulties. By following the dietary restrictions, a child will be expected to grow and develop healthily and have the same opportunities that any child would have.

PKU is NOT an allergy. Children with PKU will not become sick or need urgent medical attention if they are accidentally given, or eat foods on the STOP list (see page 6).

However, if a child does have something they should not have eaten, the parent/carer must be informed on the same day, so that adjustments to the diet can be made at home.

PKU is monitored by regular blood tests, and the phenylalanine (the restricted part of the diet) will be higher if the child has eaten something extra or eaten food that is not allowed. A daily diary/record of what foods have been eaten will provide important information for the parent/carer each day. This will provide reassurance for the parent/carer that the dietary treatment is being correctly attended to. The parent/carer should discuss with the class teacher which member of staff should be responsible for completing the food diary.





What is the treatment for PKU

Treatment for PKU is a very strict low protein (low phenylalanine) diet medically supervised by specialist metabolic dietitians.

All high protein foods such as meat, fish, chicken, eggs, cheese, soya, almost all Quorn products, pulses and dairy products along with other foods like ordinary bread, pasta and cakes need to be avoided.

Aspartame (E951) is a sweetener that contains phenylalanine and should not be given.

High protein foods are replaced with a protein substitute (in powder, liquid, tablets, bars or granules) that contain "safe" proteins along with vitamins and minerals. It will be the responsibility of the teaching team to administer this rather than the school dinner service.

An individual allowance of carefully weighed amounts of protein – known as *protein exchanges* – are allocated each day.

One exchange is the amount of food that contains 1g of protein (50mg phenylalanine). These are from foods such as breakfast cereals, potatoes, sweetcorn, peas and broccoli and should be spread evenly throughout the day. The parent will advise how many protein exchanges will be allowed for the school meal.

Staple foods such as bread, pasta, rice, flour, milk, biscuits and cakes are replaced with low protein manufactured products and home-made low protein foods. These specialist foods are only available on prescription and cannot be bought in supermarkets. The parents will need to supply these to the school.

The PKU diet explained

On the following pages is a practical guide to explain how the PKU diet works using a traffic light system





Foods that need to be avoided as they are too high in protein (phenylalanine)

MEAT

All types of fresh, frozen or canned meat and meat products:

- Bacon
- Beef
- Beef burgers
- Chicken
- Corned beef
- Game
- Ham
- Kidney
- Lamb
- Liver
- Meat paste
- Meat pies
- Offal
- Pate
- Pork
- Sausages
- Turkey

MEAT ALTERNATIVES

All types of food made with soya, TVP, almost all Quorn products and tofu

FISH

All fresh, frozen, tinned and shellfish

EGGS

All types

CHEESE

All types generally need to be avoided, but there may be some *free from* or vegan cheeses that contain little or no protein that are allowed in the low protein diet.

Please check with the parent/carer or dietitian to find out which products are suitable

NUTS & SEEDS

All types

FLOUR BASED FOODS

All varieties of flour (except cassava flour):

- Bread
- Biscuits
- Cakes
- Pasta

ASPARTAME (E951)

Aspartame is an artificial sweetener, which contains phenylalanine. Aspartame can be found in many fizzy drinks, squashes, cordials, yogurts, jellies, crisps, popcorn and some chewing gums. All foods and drinks containing aspartame must be avoided.

These foods should be labelled *E951* and *contains a source of phenylalanine*.

Please note that all other artificial sweeteners are suitable to be included in the low protein diet e.g. sucralose, Truvia, saccharin, Stevia.

**GO
CAUTIOUSLY**

Foods that need to be carefully weighed as they contain some protein (phenylalanine)

The weight of each food listed = 1 exchange

POTATOES		VEGETABLES		FRUIT	
Boiled	80g	Beansprouts	60g	Figs	60g
Chips	45g	Broad beans	20g	Passion fruit	40g
Croquettes	40g	Broccoli	60g		
Instant mash		Brussels sprouts	60g		
– dry powder	10g	Cauliflower	60g		
Jacket	80g	Chestnuts	40g		
Mashed		Corn on the cob	55g		
– no milk	80g	Kale	35g		
Roast	55g	Mange tout	60g		
Smiley faces	48g	Mixed vegetables	30g		
Waffles	40g	Peas	25g		
Wedges	50g	Petit pois	25g		
		Spinach	25g		
		Spring greens	35g		
		Sugar snap peas	60g		
		Sweetcorn kernels	35g		
		Yams	60g		

BREAKFAST CEREALS*	
Kellogg's Branflakes	8g
Kellogg's Cornflakes	14g
Kellogg's Rice Krispies	14g
Shredded Wheat	10g
Weetabix	10g
Weetaflakes	10g

*If other brands of cereal are used please check exchange amounts with the parents

There are other foods that may be useful for school meals. The use of these foods will depend on their protein content and the child's daily protein allowance. Please check with the parent/carer or dietitian for the amount that can be given. These foods include:

Baked beans	Rice
Hash browns	Tinned spaghetti
Ice cream	Vegetable fingers
Quorn fishless fingers	Yoghurt

GO

Foods that contain very little protein and can be eaten without weighing

FRUIT

Most types including: fresh, frozen, tinned, raw, puréed, cooked in sugar, dried.

Apples	Fruit salad	Oranges
Apple crisps	Glacé cherries	Peaches
Apricots	Grapes	Pears
Avocado	Grapefruit	Pineapple
Banana	Jackfruit	Plums
Blackberries	Kiwi fruit	Prunes
Blueberries	Lemons	Raisins
Cherries	Limes	Raspberries
Clementines	Mango	Rhubarb
Cranberries	Mandarins	Satsumas
Currants – <i>black, red, white</i>	Melon – <i>all varieties</i>	Strawberries
Dates	Nectarines	Tangerines
Fruit pie filling	Olives	

VEGETABLES

Most types including: fresh, frozen, tinned, raw, puréed.

Acorn squash	Ginger	Peppers – <i>all colours</i>
Aubergine	Green beans	Plantain
Baby corn	– <i>dwarf, French, runner</i>	Pumpkin
Beetroot	Leek	Radish
Butternut squash	Lettuce	Salad cress
Cabbage	Marrow	Spaghetti squash
Carrots	Mushrooms	Sweet potato
Cassava	Onions	– <i>uncoated chips, fries, wedges and mashed</i>
Celeriac	Pickled onions	Swede
Celery	Pak choi	Tomato
Courgettes	Parsnips	Turnip
Cucumber	Pickled vegetables	Watercress
Garlic	– <i>eg. onion, gherkins, red cabbage</i>	

PLANTS & CEREALS

- Blancmange powder
 - vanilla, fruit flavoured and chocolate, **NOT** blancmange mix with milk powder
- Custard powder
 - traditional, **NOT** instant custard
- Konnyaku
 - traditional Japanese noodles
- Sago
- Tapioca and tapioca starch
 - **NOT** ready to serve milk puddings including sago and tapioca

FATS

- Butter
- Margarine
- Vegetable fats and oils
 - liquid, solid

MISCELLANEOUS

- Angelica
- Brown sauce
- Coleslaw
 - containing fruit or vegetables only
- Fruit sorbets
- Honey
- Jam
- Marmalade
- Mayonnaise
 - if the protein content is 1g per 100g or less

BAKING INGREDIENTS

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

FOOD ESSENCES & COLOURINGS

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

HERBS & SPICES

- All varieties, fresh and dried
- Salt and pepper

SUGARS

- Boiled sweets
- Brown sugar
- Candy floss
- Candy sherbet
- Caster sugar
- Demerara sugar
- Fruit sugar
- Fruit syrup
- Glucose
- Golden syrup
- Icing sugar
- Maple syrup
- Molasses
- Ready to roll icing
 - except chocolate
- Treacle
- White sugar

- Milk shake powder
 - **NOT** containing milk powder, chocolate flavouring or aspartame
- Milk shake syrup
 - check for aspartame
- Mint sauce and mint jelly
- Mixed peel
- Salad dressing
 - if the protein content is 1g per 100g or less
- Soya sauce
 - if the protein content is 1.5g per 100g or less **OR** 1.5g per 100 ml or less

- Tomato ketchup
- Vegan cheese
 - e.g. Violife containing protein up to 0.5g per 100g
- Vegetable gravy granules
 - containing protein up to 0.5g per 100g when made up according to the manufacturer's instructions
- Vegetarian jellies
 - without gelatine and check the label for aspartame
- Vinegar

GO

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 crackers
.....
Low protein biscuits and cakes
.....
Low protein flour mix
.....
Low protein cake mix
.....
Low protein dessert mixes/custard mixes
.....
Low protein egg replacer
.....
Low protein milk
.....
Low protein chocolate
.....

These foods are available on prescription from the family's GP. They are subject to stringent quality control checks and cannot be bought over the counter. Therefore, they can only be supplied by the parent/carer to the school.

The parent/carer must order the low protein food from their GP and then place the prescription with the chemist or home delivery company. The prescription foods may take several weeks to be delivered and therefore the parent/carer should be given sufficient notice to allow the foods to be supplied to the school.

Catering staff should check that any food handed in by the parent/carer has intact packaging and is in date.

If staff do not receive sufficient supplies or a parent does not supply the foods on request, the managing dietitian should be notified or the school asked to contact the dietitian.



Useful guidance when handling low protein prescription foods:

- Check expiry dates
- Ensure adequate stocks as products may take several weeks to be supplied
- Follow instructions on how to cook the food carefully – they do not always cook in the same way as regular pasta, rice and flour

Important contacts

Please use this space for notes and to write down contact details for the child's parent/carer and dietitian:

If you are unsure, always check with the parent/carer or dietitians first.

Or you can call the NSPKU helpline for more information and advice on 030 3040 1090.



The NSPKU exists to help and support people with PKU, their families and carers. It actively promotes the care and treatment of people with PKU and works closely with medical professionals in the UK.

Additional information

For more detailed information about the PKU diet, please visit the NSPKU website www.nspku.org

Government publications on guidance for schools

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/803956/supporting-pupils-at-school-with-medical-conditions.pdf

<https://www.gov.scot/publications/supporting-children-young-people-healthcare-needs-schools/pages/2/>

<https://www.eani.org.uk/parents/school-meals/dietary-requirements>

<https://gov.wales/sites/default/files/publications/2018-12/supporting-learners-with-healthcare-needs.pdf>



The National Society for Phenylketonuria (UK) Ltd

Helpline 030 3040 1090

Email info@nspku.org

www.nspku.org

Registered in England | Company No 1256124 | Charity No 273670

Copyright © 2020 NSPKU (UK) Ltd. All information in this leaflet is correct at the time of printing: April 2020.