

PERFECT PORTIONS FOR PRADER-WILLI SYNDROME

Review Draft for Comment

This **draft** resource is being prepared by Prader-Willi Syndrome Association UK and specialist health professionals. The content is **draft** only. Before being published, it will be updated based on feedback from professional peers and relevant patients, and then go through full graphic design.

Aim

To support weight management and a healthy diet by providing visual information on age-appropriate portion sizes for people with Prader-Willi Syndrome (PWS).

Learning outcomes

The reader (parents/carers of children, young people and adults with PWS) will:

- Be aware of age-appropriate portion sizes for people with PWS and feel confident in managing and providing a balanced diet.
- Feel reassured that they are getting enough nutrients to grow and develop.
- Feel supported in the choices they make regarding portion sizes.
- Be aware of strategies they can apply to reduce stress and support eating out.

With support, the resource may also be used by adults with PWS.

Request for comments

Please send comments to jenni.henderson@ndr-uk.org by Tuesday 14th May on:

- Clarity of key messages
- Suitability for purpose
- Length and amount of detail given.

Perfect Portions for Prader-Willi Syndrome

Prader-Willi Syndrome (PWS) is a rare genetic condition causing an overwhelming and uncontrollable drive to eat that can be life-limiting.

This combined with the fact that people with PWS need about 30% fewer calories than their peers, means that managing portion sizes is crucial for quality of life.

More information about PWS can be found from Prader-Willi Syndrome Association UK. Visit www.pwsa.co.uk



This portion size resource provides practical guidance on how to regulate food intake, ensuring that individuals with PWS can lead healthier lives.

Portion size management is important for individuals with PWS:

1. **Hyperphagia:** People with PWS experience an **overwhelming drive to eat**, known as hyperphagia. This intense hunger can lead to excessive food consumption, which in turn contributes to rapid weight gain. Effective portion control helps mitigate this challenge by limiting the amount of food consumed.
2. **Hypotonia:** PWS is characterised by **low muscle tone** (hypotonia). This affects physical activity and metabolism. Proper portion sizes ensure that individuals receive adequate nutrition without overburdening their muscles or causing excessive weight gain.
3. **Health risks:** Hyperphagia makes it very difficult for people with PWS to make their own choices about food. Without proper dietary management, individuals with PWS can become obese, leading to serious health issues. These health risks include diabetes, cardiovascular problems, and joint strain. Portion control helps maintain a healthier weight and reduces the risk of associated complications.
4. **Quality of Life:** Managing portion sizes allows individuals with PWS to enjoy a better quality of life. It helps them maintain a healthy weight, participate in physical activities, and avoid health-related limitations.

About this booklet

Who is it for?

The information in this booklet aims to support anyone with Prader-Willi Syndrome (PWS) or who cares for a child, young person or adult with PWS.

What will it help you to do?

It will help you and your family to choose a balanced diet for good health now and in the future. It can also help you to explain and illustrate your child's low-calorie diet to others.

Why is a healthy diet important?

A healthy diet provides the variety and quantity of food and drink to support growth and maintain health throughout life. Getting into the habit of choosing healthy foods and appropriate portion sizes now helps limit the risk of health problems such as heart disease and type 2 diabetes later. Considering diet quality is also important. The Eatwell Guide shows the food groups that form a healthy balanced diet.



Source: Public Health England in association with the Welsh government, Food Standards Scotland and the Food Standards Agency in Northern Ireland

What is the right portion size for your child?

The photos and information on the following pages provide guidance based on estimates of what is needed for people with PWS at different ages. Work with a dietitian to select the right portion sizes for your child.

The exact number of calories a person with PWS needs is hard to define and can be very individual. However, it is estimated that people with PWS need about 30% fewer calories than their peers.

The right size of portion (and therefore the right number of calories) will depend on many factors including age, weight gain pattern and activity levels. Adjustments will be needed as these factors change with time. In adolescence, during the growth spurt, boys may have a higher calorie requirement (approximately 250 calories more a day).

Regular reviews of weight are essential to guide intakes and optimise health in people with PWS.

Helpful hints for measuring the correct portion size

In this booklet, each photo shows a portion with the name, description, weight and handy measure. These photos are examples of foods from each food group. To have a balanced diet, your child will need to eat a wider variety than this. If there is something your child likes to eat which is not shown, please discuss this with a dietitian.

Cutlery and crockery

The cutlery and crockery shown here are the size of those used in the photographs. You can use similar household utensils to help measure your own food portions.

This circle is the same size as the plate used in the photos (22cm/8½ inches diameter). Serving food on a small plate like this, instead of a large plate, can make portions look bigger.

The bowl used in the photos is 17cm (6½ inches) diameter.

All tablespoons are heaped unless otherwise stated.

>Insert full-size illustrations of plate, bowl and spoons here<

How much food does your child need every day?

The table below shows the recommended number of portions from each food group your child needs every day.

Food Group	Number of portions each day
Fruit and vegetables	5
Potatoes, bread, rice, pasta and other starchy carbohydrates	6-8
Beans, pulses, fish, eggs, meat and other proteins <i>Include at least 1 portion of oily fish such as salmon, herring or mackerel every week</i>	2-3
Dairy and alternatives	3
Oils and spreads	3
Foods and drinks high in fat, salt or sugar	Not recommended

The photos on the following pages provide examples of foods, and typical portion sizes for different ages. Use these examples as a practical guide to help you provide balanced and appropriately sized meals and snacks for your child. Always try to offer a variety of foods from each group so that your child gets all the nutrients they need to grow and stay healthy.



















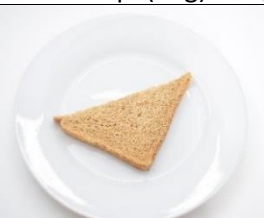
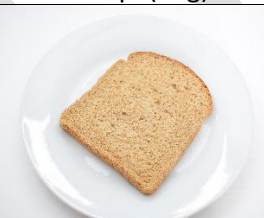




People with PWS have lower calorie requirements but the same vitamin and mineral requirements as people without PWS. Therefore, taking an over the counter, age-appropriate vitamin and mineral supplement, and separate vitamin D supplement, is recommended.















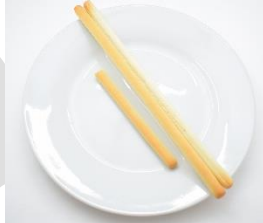
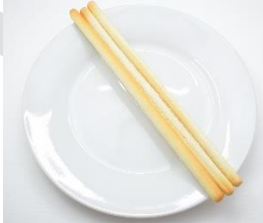
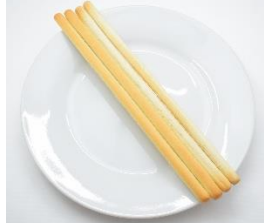
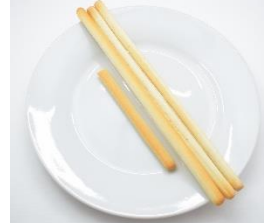






This booklet was designed to illustrate commonly eaten foods. Some of these foods should be limited or avoided as they are unhealthy. We have highlighted these with a (◆) symbol. Sauces such as ketchup and mayo are not included as they contain extra calories, sugar and fat and are best avoided.

























Cooking methods









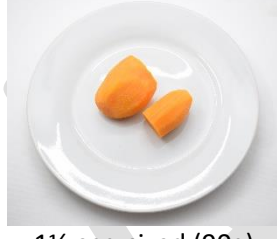

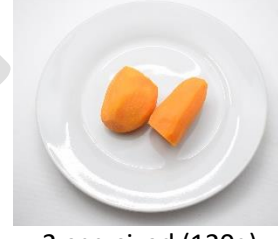
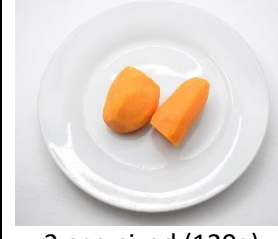




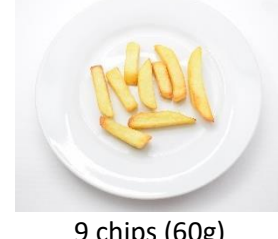

Try to choose healthier cooking methods. For example, steaming, baking, grilling, boiling and microwaving are all better than frying.

Potatoes, bread, rice, pasta and other starchy foods







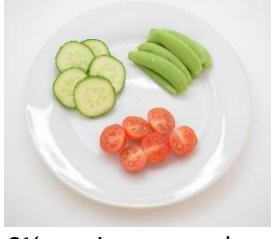


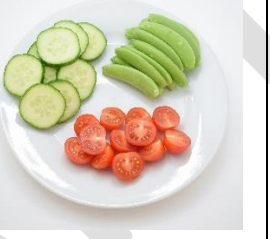








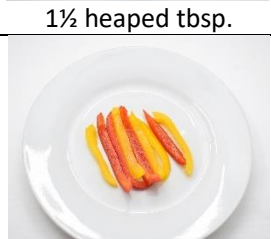

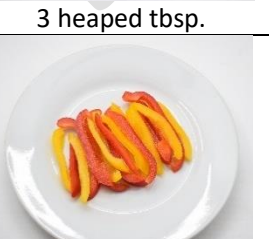



Age range	2-3 years	4-6 years	7-10 years	11-13 years	14-18 years	19-64 years
Wheat biscuit (cereal)	 ½ bisk (10g)	 1 bisk (20g)	 1 bisk (20g)	 1½ bisks (30g)	 1½ bisks (30g)	 1½ bisks (30g)
Porridge oats, uncooked	 1 tsp. (10g)	 1½ tbsp. (15g)	 2 tbsp. (20g)	 2½ tbsp. (25g)	 3 tbsp. (30g)	 2½ tbsp. (25g)
Rice crispies	 2 tbsp. (10g)	 3 tbsp. (15g)	 4 tbsp. (20g)	 4 tbsp. (20g)	 6 tbsp. (30g)	 5 tbsp. (25g)
Brown bread	 ½ medium slice (20g)	 1 medium slice (40g)	 1 medium slice (40g)	 1 medium slice (40g)	 1 medium slice (40g)	 1 medium slice (40g)

























Age range	2-3 years	4-6 years	7-10 years	11-13 years	14-18 years	19-64 years
Tortilla wrap	 1/3 wrap (15g)	 1/2 wrap (20g)	 2/3 wrap (25g)	 3/4 wrap (30g)	 1 wrap (40g)	 3/4 wrap (30g)
Chapatti	 1/4 chapatti (15g)	 1/4 chapatti (15g)	 1/3 chapatti (20g)	 1/2 chapatti (30g)	 1/2 chapatti (30g)	 1/2 chapatti (30g)
Breadsticks	 1 1/2 breadsticks (10g)	 2 breadsticks (14g)	 2 1/2 breadsticks (17g)	 3 breadsticks (21g)	 4 breadsticks (28g)	 3 1/2 breadsticks (24g)
Brown rice, cooked	 1 heaped tbsp. (25g)	 2 level tbsp. (40g)	 2 heaped tbsp. (45g)	 3 level tbsp. (60g)	 3 level tbsp. (60g)	 3 level tbsp. (60g)

























Age range	2-3 years	4-6 years	7-10 years	11-13 years	14-18 years	19-64 years
Couscous, cooked	 ½ tbsp. (15g)	 1 tbsp. (30g)	 1½ tbsp. (45g)	 1½ tbsp. (45g)	 2 tbsp. (60g)	 1½ tbsp. (45g)
Quinoa, cooked	 1½ tbsp. (35g)	 2 tbsp. (50g)	 2½ tbsp. (65g)	 3 tbsp. (75g)	 3½ tbsp. (90g)	 3½ tbsp. (90g)
Egg noodles, cooked	 ½-1 forkful (20g)	 1 forkful (30g)	 1½ forkful (45g)	 2 forkfuls (60g)	 2 forkfuls (60g)	 2 forkfuls (60g)
Wholewheat pasta, cooked	 1½ tbsp. (30g)	 2 tbsp. (40g)	 2½ tbsp. (50g)	 3 tbsp. (60g)	 4 tbsp. (80g)	 3½ tbsp. (70g)

Age range	2-3 years	4-6 years	7-10 years	11-13 years	14-18 years	19-64 years
Potatoes	 1 egg-sized (60g)	 1½ egg-sized (90g)	 1½ egg-sized (90g)	 2 egg-sized (120g)	 2½ egg-sized (150g)	 2½ egg-sized (150g)
Sweet potatoes	 ½ egg-sized (30g)	 1 egg-sized (60g)	 1½ egg-sized (90g)	 1½ egg-sized (90g)	 2 egg-sized (120g)	 2 egg-sized (120g)
Oven chips, baked (◆)	 3 chips (20g)	 5 chips (30g)	 6 chips (35g)	 7 chips (45g)	 9 chips (60g)	 8 chips (50g)

Fruit and vegetables




















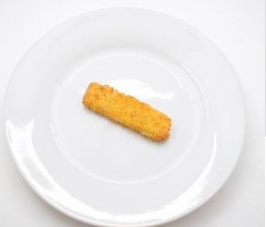


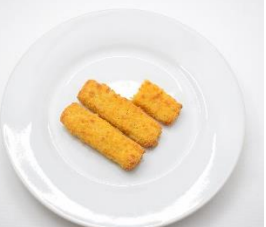
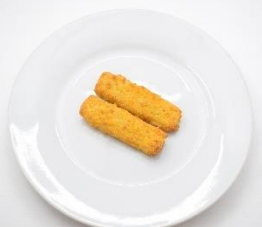
Age range	2-3 years	4-6 years	7-10 years	11-13 years	14-18 years	19-64 years
Carrots, swede, parsnip or beetroot	 1½ heaped tbsp.	 3 heaped tbsp.	 3 heaped tbsp.	 3 heaped tbsp.	 3 heaped tbsp.	 3 heaped tbsp.
Cucumber, cherry tomatoes or sugar snap peas	 2½cm piece cucumber, 3 cherry tomatoes or 7 sugar snaps	 5cm piece cucumber, 6 cherry tomatoes or 14 sugar snaps	 5cm piece cucumber, 6 cherry tomatoes or 14 sugar snaps	 5cm piece cucumber, 6 cherry tomatoes or 14 sugar snaps	 5cm piece cucumber, 6 cherry tomatoes or 14 sugar snaps	 5cm piece cucumber, 6 cherry tomatoes or 14 sugar snaps
Broccoli, cauliflower or cabbage	 1½ heaped tbsp.	 3 heaped tbsp.	 3 heaped tbsp.	 3 heaped tbsp.	 3 heaped tbsp.	 3 heaped tbsp.
Peppers	 ¼ pepper	 ½ pepper	 ½ pepper	 ½ pepper	 ½ pepper	 ½ pepper

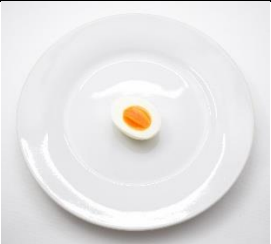
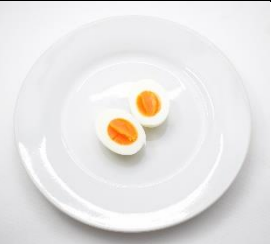
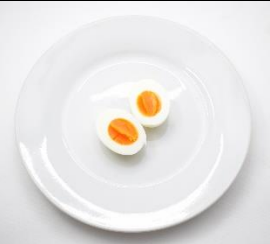
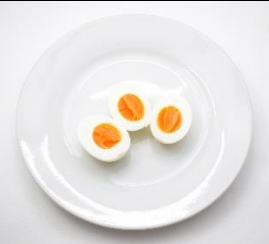
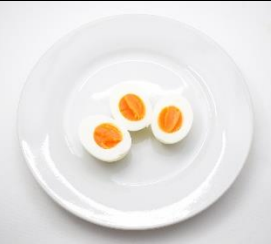
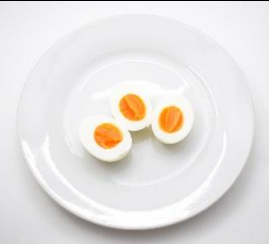















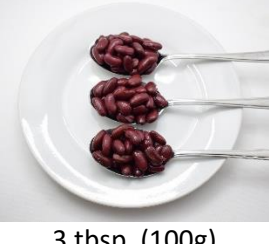

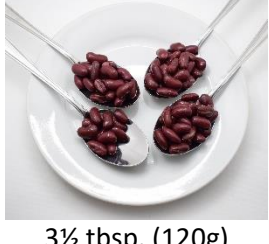
Age range	2-3 years	4-6 years	7-10 years	11-13 years	14-18 years	19-64 years
Sweetcorn or peas	 1½ heaped tbsp.	 3 heaped tbsp.	 3 heaped tbsp.	 3 heaped tbsp.	 3 heaped tbsp.	 3 heaped tbsp.
Tinned tomatoes	 1/10 x 400g tin (40g)	 1/5 x 400g tin (80g)	 1/5 x 400g tin (80g)	 1/5 x 400g tin (80g)	 1/5 x 400g tin (80g)	 1/5 x 400g tin (80g)
Okra	<i>Image to be added</i> 1½ heaped tbsp.	<i>Image to be added</i> 3 heaped tbsp.	<i>Image to be added</i> 3 heaped tbsp.	<i>Image to be added</i> 3 heaped tbsp.	<i>Image to be added</i> 3 heaped tbsp.	<i>Image to be added</i> 3 heaped tbsp.
Vegetable soup	 1/2 small bowl (100g)	 1 small bowl (200g)	 1 small bowl (200g)	 1 small bowl (200g)	 1 small bowl (200g)	 1 small bowl (200g)
Small fruit (plum, apricot, kiwi)	 2/3	 1½	 1½	 1½	 1½	 1½

























Age range	2-3 years	4-6 years	7-10 years	11-13 years	14-18 years	19-64 years
Medium sized fruit (apple, pear, orange, banana)	 1/4	 2/3	 2/3	 2/3	 2/3	 2/3
Large fruit (melon, pineapple, mango)	 1/2 slice	 1 slice	 1 slice	 1 slice	 1 slice	 1 slice
Berries (blueberries, raspberries, strawberries)	 1 tbsp.	 2 tbsp.	 2 tbsp.	 2 tbsp.	 2 tbsp.	 2 tbsp.
Grapes Whole grapes should not be given to young children due to a risk of choking.	 1/2 small handful, sliced	 1 small handful, sliced	 1 small handful	 1 small handful	 1 small handful	 1 small handful













This list of fruit and vegetables is not exhaustive. Aim to have at least 5 different portions of fruit and vegetables every day. Ideally, this should include at least 3 portions of vegetables. If you wish to have more than 5-a-day, choose more vegetables.

Beans, pulses, fish, eggs, meat and other protein













Age range	2-3 years	4-6 years	7-10 years	11-13 years	14-18 years	19-64 years
Beef minced, extra lean, cooked	 1 tbsp. (25g)	 2 tbsp. (50g)	 3 tbsp. (75g)	 3.5 tbsp. (85g)	 4 tbsp. (100g)	 3.5 tbsp. (85g)
Chicken breast, cooked without skin	 ¼ medium breast (25g)	 ½ medium breast (60g)	 ½ medium breast (60g)	 ¾ medium breast (80g)	 1 medium breast (110g)	 ¾ medium breast (80g)
Pork sausages, reduced-fat, cooked	 1 thin sausage (25g)	 2 thin sausages (50g)	 2½ thin sausages (60g)	 3 thin sausages (75g)	 3½ thin sausages (85g)	 3½ thin sausages (85g)
Fish fingers, Cooked (◆)	 ½ fish finger (15g)	 1 fish finger (30g)	 1½ fish finger (40g)	 2 fish fingers (60g)	 2½ fish fingers (70g)	 2 fish fingers (60g)



















Age range	2-3 years	4-6 years	7-10 years	11-13 years	14-18 years	19-64 years
Eggs	 ½ egg	 1 egg	 1 egg	 1½ eggs	 1½ eggs	 1½ eggs
Tofu	 50g	 110g	 130g	 165g	 200g	 180g
Baked beans	 1 tbsp. (40g)	 2½ tbsp. (100g)	 3 tbsp. (120g)	 4 tbsp. (160g)	 5 tbsp. (200g)	 4 tbsp. (160g)
Beans, tinned (red kidney, butter, cannellini, chickpeas)	 1 tbsp. (35g)	 2 tbsp. (70g)	 2½ tbsp. (85g)	 3 tbsp. (100g)	 4 tbsp. (140g)	 3½ tbsp. (120g)













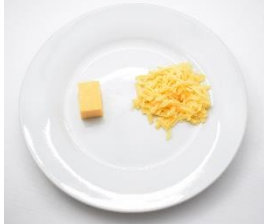
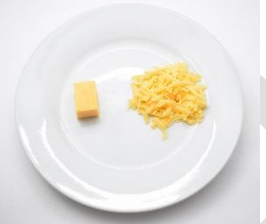
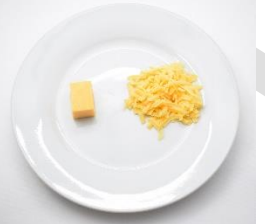
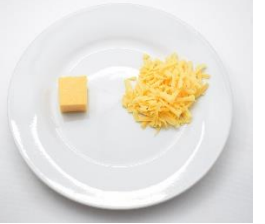
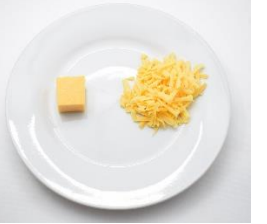
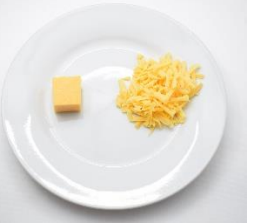






Age range	2-3 years	4-6 years	7-10 years	11-13 years	14-18 years	19-64 years
Lentils/dhal, cooked	 1 tbsp. (40g)	 2 tbsp. (80g)	 2½ tbsp. (100g)	 3 tbsp. (120g)	 4 tbsp. (160g)	 3 tbsp. (120g)
Unsalted nuts or nut butter. Whole nuts and seeds should not be given to children under 5 years due to a risk of choking.	 Smooth nut butter 1 tsp. (5g)	 Smooth nut butter 3 tsp. (15g)	 Whole nuts 2 tsp. (15g)	 Whole nuts 3 tsp. (20g)	 Whole nuts 4 tsp. (25g)	 Whole nuts 3 tsp. (20g)
Reduced-fat hummus	 ½ tbsp. (15g)	 1½ tbsp. (45g)	 1½ tbsp. (45g)	 2 tbsp. (60g)	 2½ tbsp. (75g)	 2½ tbsp. (75g)
Oily fish, oven cooked (salmon, mackerel)	 1/5 fillet (20g)	 ¼ fillet (25g)	 ½ fillet (50g)	 ½ fillet (50g)	 2/3 fillet (65g)	 ½ fillet (50g)

Age range	2-3 years	4-6 years	7-10 years	11-13 years	14-18 years	19-64 years
White fish, oven cooked (cod, haddock, plaice)	 ¼ fillet (30g)	 ¾ fillet (90g)	 ¾ fillet (90g)	 1 fillet (120g)	 1½ fillet (150g)	 1 fillet (120g)
Sliced roast beef	 1 slice (25g)	 2 slices (50g)	 3 slices (75g)	 3 slices (75g)	 4 slices (100g)	 4 slices (100g)

Dairy and alternatives













Age range	2-3 years	4-6 years	7-10 years	11-13 years	14-18 years	19-64 years
Semi-skimmed milk	 110ml	 100ml	 125ml	 160ml	 190ml	 170ml
Soya milk, fortified (non-dairy alternative*)	 120ml	 110ml	 135ml	 170ml	 200ml	 180ml

Age range	2-3 years	4-6 years	7-10 years	11-13 years	14-18 years	19-64 years
Yoghurt, plain, low fat	 2½ tbsp. (100g)	 2 tbsp. (80g)	 2½ tbsp. (100g)	 3 tbsp. (120g)	 4tbsp. or 1 small pot (150g)	 4tbsp. or 1 small pot (150g)
Soya yoghurt, fortified (non-dairy alternative*)	 2 tbsp. (80g)	 1½ tbsp. (60g)	 2 tbsp. (80g)	 2½ tbsp. (100g)	 3 tbsp. (120g)	 2½ tbsp. (100g)
Fromage frais, fruit (◆)	 1 x 45g small pot	 1 x 45g small pot	 1 x 45g small pot	 1 x 85g pot	 1 x 85g pot	 1 x 85g pot

Age range	2-3 years	4-6 years	7-10 years	11-13 years	14-18 years	19-64 years
Custard (◆)	 1½ tbsp. (55g)	 1½ tbsp. (55g)	 1½ tbsp. (55g)	 2 tbsp. (75g)	 2 tbsp. (75g)	 2 tbsp. (75g)
Rice pudding, canned (◆)	 1.5 tbsp. (60g)	 1.5 tbsp. (60g)	 1.5 tbsp. (60g)	 2 tbsp. (80g)	 2.5 tbsp. (100g)	 2.5 tbsp. (100g)
Cheddar cheese (◆) <i>Photo shows what 1 portion of cheese looks like grated and as a matchbox size piece.</i>	 ½ small matchbox size (15g)	 ½ small matchbox size (15g)	 ½ small matchbox size (15g)	 ⅔ small matchbox (20g)	 ⅔ small matchbox (20g)	 ⅔ small matchbox (20g)
Cream cheese, reduced fat (◆)	 1 mini tub (35g) or 1 tbsp.	 1 mini tub (35g) or 1 tbsp.	 1 mini tub (35g) or 1 tbsp.	 1¼ tbsp. (45g)	 1½ tbsp. (55g)	 1½ tbsp. (55g)

* If choosing dairy alternatives, always go for alternatives that are fortified with calcium. Rice milk is not suitable for under 5's.

Oils and spreads

Age range	2-3 years	4-6 years	7-10 years	11-13 years	14-18 years	19-64 years
Reduced-fat spread	 1 tsp. (5g)	 1 tsp. (5g)	 1 tsp. (5g)	 1½ tsp. (7g)	 1½ tsp. (7g)	 1½ tsp. (7g)
Oil (olive, rapeseed, sunflower, vegetable)	 1 tsp. (3g)	 1 tsp. (3g)	 1 tsp. (3g)	 1 tsp. (3g)	 1 tsp. (3g)	 1 tsp. (3g)

Snacks

Depending on how much your child eats at mealtimes, small portions of healthy snacks can help them meet their daily energy and nutritional needs.

Some people with PWS find it helpful to have a healthy snack routine in place. Others may find it easier not to have any snacks at all.

Fruit such as strawberries, raspberries and melon are good snack options – they are lower in calories than bananas and grapes. Dried fruit is not recommended as is it high in sugar.

Fluid

- Your child should drink 6-8 glasses of fluid a day.
- Tap water is the best way to quench thirst. Many parents find it difficult to get their child or young person to drink water. Try adding a slice of lemon, lime or cucumber for flavour, offer ice cubes, or choose a sugar-free drink.
- Skimmed milk is recommended unless a dietitian has advised differently. It contains calories so check the portion guidance on page X.
- Energy, caffeinated and alcoholic drinks are not recommended as they often contain high amounts of calories and provide no nutritional benefit.
- A sugar-free drink can be an alternative to having a snack.

Plated meals

Meals often include a combination of foods from different food groups. The following example shows how you can make up a balanced meal to ensure your child gets all the nutrients they need to grow and develop.



Food security and food seeking tips

Many parents introduce food security measures even before hyperphagia (increased hunger) begins. These include:

- Locks on kitchen doors and/or cupboards. Locks are not just a physical security but psychological as well. Removing opportunities to access food can take away anxiety around this.
- Routines in place for meal and snack times. Knowing when they are going to eat can be reassuring and help to reduce stress for those with PWS. A visual timetable/plan can help too.
- Meal/menu planning in advance.
- Dish up meals at the worktop rather than having bowls of food in the middle of the table.

Food seeking can be difficult to manage. However, reducing opportunities to find food can help, not just at home but in school too. PWSA UK can provide advice and guidance to schools.

Here are some tips to help:

- Ensure your child's teacher has a good understanding of the condition and is aware of the role and responsibility they have.
- Make sure lunch boxes and snacks are kept out of sight.
- Do not use food such as rice, pasta or flour dough in play.
- Ensure supervision during lunch breaks and social times.
- Ensure other children are encouraged not to swap or share food.
- Keep pet foods such as seeds and cereals out of sight.
- Ask other parents not to bring sweets and cakes to celebrate birthdays.

A message for people with PWS

This resource has been designed to help those who support a person with PWS understand what a safe amount of food is to be healthy.

You may be able to use much of this yourself, but you should ask for support and guidance using it.

Useful websites

- Prader-Willi Syndrome Association UK (PWSA UK): www.pwsa.co.uk
- International Prader-Willi Syndrome Organisation (IPWSO): www.ipwso.org

Notes

