

Healthy Eating and Dietary Management



Hyperphagia, or feeling hungry almost all of the time, is part of having Prader-Willi syndrome (PWS), and we will explore some ways of managing this in the following document. Individuals with PWS also have hypotonia, or low muscle tone. This means that taking exercise is important to keep up muscle strength, but it can also mean that exercise can be tiring for someone with PWS. Any new exercise plan should start off gently and then build over time. walking or swimming are good examples as they are low impact. Lots of people enjoy things like yoga and tai chi too.

Low muscle tone affects all the muscles including those that help to digest food. Individuals with PWS don't burn calories as fast as the rest of the population and so need fewer calories in their daily diet.

We use the formula below as a guide to work out a daily calorie intake. It is a case of trial and error and the formula will need to be adapted to suit individual needs.

$$\begin{aligned} 6 - 8 \text{ Kcals per cm height} &= \text{weight loss} \\ 10 - 12 \text{ Kcals per cm height} &+ \text{weight maintenance} \end{aligned}$$

Some ideas for ways of keeping calories down:

- ✓ We suggest smaller portions of higher calorie foods such as fatty foods and those high in sugars.
- ✓ Use food swaps - for example, swap chips for homemade sweet potato chips with a light oil spray, or boiled potatoes. Instead of cake have some berries or a slice of melon.

- ✓ Larger portions of green vegetables, especially things like cabbage, courgettes and broccoli which have fewer calories than peas or sweetcorn. We often suggest using sachets of sauce rather than putting a whole bottle on the table for people to help themselves.
- ✓ Choose low calorie/low fat alternatives, such as skimmed milk, “lite” spreads and zero fat yogurts. These can be useful, but take care to check the calories on the label, as some low-fat foods are high in sugar.

Menu Planning

We know that individuals with PWS like a routine, they like to know what’s happening when, and to know when mealtimes are.

Here are some suggestions:

- ✓ Involve your child/adult with planning a weekly menu so you all know exactly what you’re going to have each day. This will also help them to think about what they like to eat and to make healthy choices.
- ✓ Try to eat meals at the same time each day. We know this isn’t always possible, but it can take away any anxiety about wondering what time you’re having your next meal and worrying about it being later than planned.
- ✓ If calories are carefully managed, daily meal plans can include a snack in the morning or the afternoon. We know that some people like to save up some calories during the week and have a treat on a Friday.

Managing diet:

- ✓ It’s always a good idea to seek advice from a dietitian or other qualified health professional before starting a new diet. We know that some families have had good results from ketogenic diets, low fat diets and other types of diets that seem to come and go. Some of these restrict certain food groups and it’s always a good idea to ensure a balanced diet.
- ✓ Let carers, friends and family members know that your child/adult has a special diet. They can help out by not offering extra portions or treats.
- ✓ If your loved one is currently on a weight loss plan, it can help to have a weekly weigh in to keep track of progress and make a note of weight loss.
- ✓ Take a photo at the start of the diet so you can all see the difference when they have lost some weight.
- ✓ Make sure you don’t have treats or snack foods in the cupboard – remove all temptations. When you go shopping, take a list and only buy foods that are on your list.

- ✓ Drinking plenty of water during a diet is helpful and it's important to keep hydrated.
- ✓ Homemade soups are a great way to make low calorie and tasty lunches.
- ✓ Instead of frying things, try boiling, steaming, microwaving or baking instead - for example, swap a fried egg for a boiled or poached one.

Carbs & Cals

Have you heard of Carbs & Cals?

This is a website (<https://www.carbsandcals.com/>) which has lots of information about different diets, healthy eating, portion sizes and ways to cut calories. It allows you to download up to 50 free PDFs and is fantastic if you are going down the calorie counting route as it gives portion sizes alongside the number of calories, carbs, fats, proteins and fibre. It also suggests food swaps:

Mashed Potato

For a tasty alternative mash up some butter beans and add lemon juice and garlic for extra flavour, or try roasting and mashing some butternut squash.

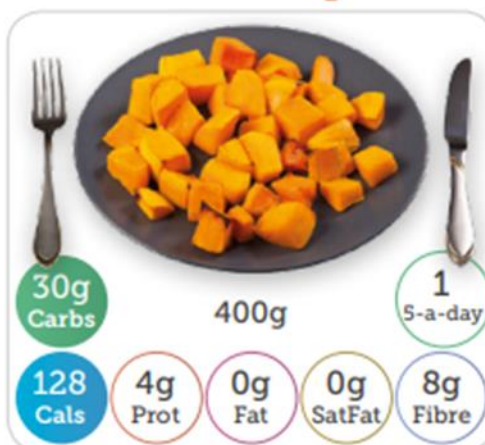
Mashed Potato (with butter)



Butter Beans



Butternut Squash



Exercise and activities

Regular exercise is good for everyone:

- ✓ Improves your muscle tone
- ✓ Improves circulation
- ✓ Improves mental health and emotional wellbeing
- ✓ Helps to keep your heart healthy
- ✓ Strengthens your muscles and increases flexibility
- ✓ It's fun and it helps to improve your mood

Good exercises to start with include:

Swimming

This is a great resistance exercise for those with PWS. Hopefully, those who enjoy regular swimming will soon be able to go again as lock down restrictions begin to lift and leisure centres open again.

Walking

There are lots of ways to make your usual walk more interesting.

Try taking some scavenger hunt sheets which you can download from the internet. You can get nature ones as well as ones for urban walks.

Bike riding

Some people may find bike riding more difficult, and trikes can be a good option.

Gardening and housework and dancing also burn calories!

Pilates

You may have heard of Joakim

Valsinger – especially if you have been to one of our conferences. He is the father of a little boy with PWS and a specialist in Pilates. You can read more about Joakim and his Pilates practice here:

<http://www.pilatesintel.com/albie/>

He is also able to offer a free 1:1 Pilates session for families with PWS. Joakim says: *"I'm always trying to raise awareness of exercise in the PWS context, because it is such a vital partner to diet."*

