

## Dietary management for your child: 5–10 years



### Introduction

Parents often ask when the signs of an excessive appetite will begin to show.

This varies considerably between children - no-one knows why. Most children by this age will have begun to show signs, but a few may not.

The way in which it manifests also differs between individuals - some simply like talking about food or playing with toy kitchens, or eating everything on their plate; others will start to take food at every opportunity.

Sometimes there is no noticeable change in appetite, particularly in families who habitually have large portions, but the child nevertheless begins to gain a lot of weight.

It is also not unusual for children with PWS to show food preferences - i.e. refusing to eat certain types of food.

However, it is important for dietary management techniques to be set up from an early age, even before signs of increased appetite are displayed, as it may be difficult to change habits, treats and meals once your child gets older.



#### **PLEASE NOTE!**

**This information does not replace guidance from any health professionals in individual cases.**

You may find **Let's Talk about PWS** <https://www.pwsa.co.uk/about-pws/publications/> useful in helping your child to understand why healthy eating is so important in PWS.

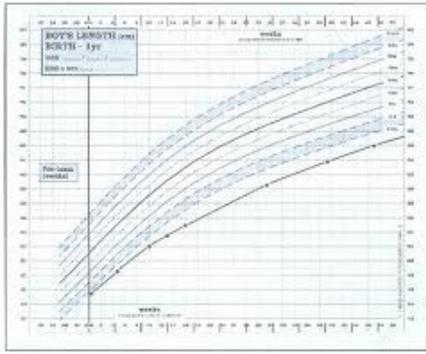
### Counting calories?

Parents and carers often ask, "Should we count calories?"

**If your child is maintaining a healthy weight on their current diet, then there is probably no need, but if they are gaining weight, you should seek the advice of a paediatric dietitian who can give you more detailed information and support tailored to your child's needs.**

#### Note:

For ease of reading, the text refers to "he, him, his", but the details are equally relevant to girls, unless otherwise stated.



## Maintaining a healthy weight and growth monitoring

Because parents and carers of younger children do all the cooking, it is easier to control what they eat. It is important that you maintain a balanced and nutritionally adequate diet for your child. This balance can be difficult, as your child needs enough energy (calories) to remain healthy and to grow, but if his energy (calorie) intake is too high, too much weight gain will result. You may also find the resources listed at the end of this leaflet helpful.

Monitoring weight and growth patterns to check that your child is gaining weight and height at an appropriate rate can be difficult in the context of PWS and you should ask your health professional to explain height/weight charts to you. Growth charts specific to PWS do exist in other countries – most recently the USA, but currently there are none which are widely used in the UK. PWSA UK can send you or your paediatrician copies of these charts if you would like to see them.

### Is it worth it?

There can be a lot of effort involved in keeping your child on a healthy diet, but this far outweighs the stresses and strains of looking after a child whose lifestyle is severely limited and whose health is put at risk by excessive weight.



### Day to day management of your child's food intake



It can be difficult for parents to deny their child food – nurturing and feeding your child is one of the great pleasures of being a parent. However, you do not have to have to restrict everything: most parents allow the occasional treat, especially at times like birthdays, Christmas and Easter. Others have a treat built into the day's food allowance.

There are some very simple restrictions that can be put in place. For instance, don't buy sweets when you go to the supermarket or local shops; it may make life easier for you in future if your child knows now that there are certain things you never buy, and

begins to learn about healthy foods. However, this might not work if you have older children who are used to sweet treats. If they do, they should not eat them in front of their brother or sister with PWS.

Help your child to appreciate the different dietary needs of other people, and support him to cope with eating situations with which he is unfamiliar. It is inevitable that you will find yourself in situations such as other people's homes or eating out which would benefit from your child being able to adapt and to accept that other people may need more – or different – things to eat.

Your child may have a tantrum or temper outburst if he cannot get extra food – but don't give in to this as he will “learn” that having a temper outburst can be rewarded by food, and this can be very difficult to manage as he gets older.

## Mealtime strategies

The following list gives some ideas to help keep down the calories when preparing food at meals. More suggestions can be found in the PWSA UK publication **Healthy Eating with Prader-Willi Syndrome** which can be ordered from the PWSA UK <https://www.pwsa.co.uk/about-pws/publications/>



- Plate up all the family's food in the kitchen (i.e. do not provide dishes from which people serve themselves unless it is green vegetables or green salad).
- Give your child larger portions of green vegetables and salads to make the meal look larger.
- Add extra water to soup portions for your child with PWS
- Use smaller plates, bowls, cups and mugs for your child with PWS
- If your family is used to second helpings, a second helping can be reserved from the first serving for your child with PWS – overall he will have correct amount, but is thus being treated the same as the rest of the family.
- Cut up fruit into smaller pieces to make the portion look bigger.
- Turn ordinary apples and other fruits into “special for you” by adding a cocktail umbrella or arranging items into the shape of a face or other object.
- Use lower calorie alternatives where available, e.g. semi-skimmed instead of whole milk.



There may not be any need to lock the kitchen, fridge or food cupboards, and as long as things are working out well, you should not feel obliged to do this. On the other hand, it might be an idea to put environmental controls into place now, so that it does not cause problems later on.

## How many meals a day?

As long as you do not exceed the overall amount of food your child needs in a day, it does not really matter whether this includes in-between meal snacks, or is limited to three meals a day. It can be helpful to have snacks, as this lessens the time (and build-up of anxiety) between meals.

If you have other children to consider, it is probably best to keep to the regime your family are already familiar with. Children with PWS often like a routine with regard to their meal-times and can be upset if this is not adhered to. On the other hand, it can be useful to teach your child not to expect too regular meal-times - there are always the occasions when this just cannot happen for reasons beyond your control.

## Dietary management for your child

### Meal planning and feeding the rest of your family

**How you plan meals depends very much on your personal situation, as well as the needs of other members of your family.**

**If your child with PWS is an only child, or the eldest in the family, it is usually easier to alter your family eating programme than if he is a younger child in the family. In the latter case you may already have established an eating pattern which is not the best for your child with PWS.**

**There are many ways of dealing with this – much will depend on the layout of your house, the ages and appetites of other children involved, and the capabilities of the child with PWS himself.**

**Most families, however, have to accept changes in the way food is eaten and served. This can cause conflict if everyone does not fully understand and accept the needs of the child with PWS, so much patience and tolerance is required.**



## The importance of exercise in weight control

The importance of exercise for your child cannot be stressed too highly. The more exercise he takes, the more calories he will burn up. A child who exercises a lot may be able to have a higher number of calories in their food intake. Ask your dietitian for advice about this.

Exercise can be incorporated into all sorts of daily activities, including, of course, play, games and walks. The booklet **Exercise and Physical Activity for Children with Prader-Willi Syndrome** included in this pack is very helpful. It can also be downloaded from [media.wix.com/ugd/a71d4c\\_083a2139228f42ceada273ffb128308f.pdf](https://media.wix.com/ugd/a71d4c_083a2139228f42ceada273ffb128308f.pdf)

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## Birthdays and parties

Birthdays and parties are important to all children, and children with PWS are no different. If you are the host or hostess, then it is easier to provide healthy, lower calorie options. If your child is going to someone else's party, make sure the host or hostess knows in advance about your child's dietary requirements and ask the host or hostess to fill their goody bag with non-food items.



## School

Make sure that your child's school knows all about PWS, and the necessity of keeping food out of sight, preferably before your child starts school. Give the school the article **Information for Primary School Teachers** <https://www.pwsa.co.uk/assets/files/primary-staff.pdf>, included in this pack, which includes information about dietary requirements.

With healthy eating on many agendas, it should not be too difficult to convince them about the need for a child with PWS to watch what they eat. It is unlikely that your child will be the only one on a special diet - there may be others with allergies, diabetes, food intolerance etc. Some schools provide a special area for such children to sit together so they can be more easily supervised.

Some schools allow children to bring in cakes on their birthdays. If this happens at your school, make arrangements with the school beforehand about how you want to handle this. Many parents find it useful to be warned in advance, so that their child can either be given less pudding or supper (or a lower calorie meal) at home that day, or so that they can bring the cake home to eat later - perhaps in two or more servings or to share with other family members.

You could also give school alternative treats to give your child e.g. a low calorie fruit bar. Everyone at the school must be made aware of the dangers of having unsupervised food around. This includes not only the teachers and classroom assistants, but canteen staff, cleaners, caretakers and taxi escorts. They should be alerted to possible problem areas (see inset panel on next page).

## Family and friends

Relatives, friends and neighbours often find it difficult to understand why they should not bring sweets for the child when they come to visit. ("Just one won't hurt, will it?") You must stress the importance of sticking to a rule of "no sweets as treats", if that is what you have decided.



## Snacks and treats

Here are just a few ideas for in-between meals snacks and treats for young children. Don't forget to adjust the rest of the day's food intake

accordingly.

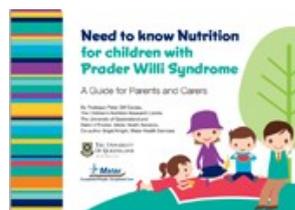
- Ice lollies - Make your own using diet squash or fruit juice diluted with water.
- Yoghurt lollies - Keep lolly sticks. Make a small slit in a low fat/low-sugar yoghurt lid. You can also use natural yoghurt with a little fruit added. Put the lolly stick into the slit and freeze.
- Rice cakes with honey - For a special sweet treat, take a plain rice cake and lightly coat with a tsp of honey. An energy-giving sweet treat! Approx. 40 kcals.

If you have any ideas for snacks and treats, especially savoury ones, please let us know so that we can share them with other parents.

## Further information

Some of this article is taken from **Healthy Eating with Prader-Willi Syndrome** <https://www.pwsa.co.uk/about-pws/publications/> which is available to order from the PWSA UK. The book has sections on calorie counting, portion sizes, nutrition, meal planning and some sample menus and recipes.

**Need to know Nutrition for Children living with PWS, A Guide for Parents and Carers** - enclosed with this pack. It can also be downloaded free from [https://docs.wixstatic.com/ugd/71d4c\\_9055a2900becfefe090122a066742f68.pdf](https://docs.wixstatic.com/ugd/71d4c_9055a2900becfefe090122a066742f68.pdf)



**Red Yellow Green system for Weight Management** - developed in Canada especially for people with PWS. You can read a presentation on this at [www.bcpwsa.com/aboutpws/nutritional\\_care.pdf](http://www.bcpwsa.com/aboutpws/nutritional_care.pdf) The book can be ordered from the Ontario PWS Association at <http://www.opwsa.com>

**PWSA USA** - also has various leaflets and books on dietary management. See [www.pwsausa.org](http://www.pwsausa.org) for more details.

## Dietary management for your child

### Possible food problem areas at school

- Other children's lunch boxes
- Uncleared plates
- Delivery vans/trays of bread
- On outings
- Travelling to and from school
- Food used in the classroom, either for cookery, or for craft work (e.g. pasta, flour dough)
- Food in coats or bags in the cloakroom
- Tuck shops
- Harvest festival displays and other celebrations involving food.

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