

Dietary management for your child: 10–13 years



Introduction

Very often, if a person with PWS has been diagnosed as a baby or young child, their parents will have followed guidelines suggested by the PWSA UK or medical professionals, and controlled their child's weight by restricting access to food and serving lower calorie meals.

This is relatively easy to do while the child is still willing to comply with parental control, but it can become increasingly difficult as the child grows older and becomes more aware of how their own dietary needs differ from their peers. In typical teenage fashion, they may start to rebel against parents' wishes.

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.

Individual variations

Not everyone with the syndrome has the same problems around food. However, most have food as one of their main interests in life – so much so that some children seem to be continually asking when the next meal is due, what it is, what everyone else is having, and so on.

Some would never steal food from shops or other people; some unfortunately will. Some people will eat items such as pet food, frozen food and food from garbage bins, whilst others will not.

So far, no-one has been able to account for the reasons for these differences in eating behaviour. What is certain is that one child with PWS will require a different level of help and support to another, although all will require some support.



Note:

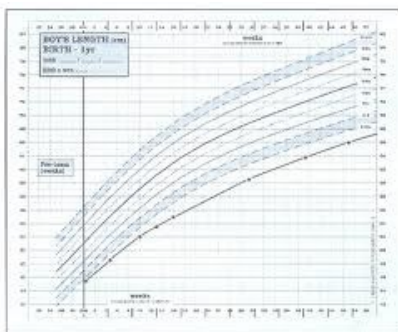
For ease of reading, the text refers to "he/him" but all the information is equally applicable to girls.

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.

How older children and teenagers with PWS can be supported to maintain a healthy weight



It is far from easy for people with PWS to maintain a healthy weight. They have the same nutritional requirements as everyone else, but because of poor muscle tone and short stature (if they have not received growth hormone), they require fewer calories than most to maintain stable weight levels - yet they almost always feel hungry. Even those on growth hormone will probably need fewer calories than those of the same age.

If you are in doubt about how to ensure that your child is getting all the nutrients they need, or are unsure about how many calories they require, it is a good idea to get a referral from your GP or consultant to a registered dietitian. The PWSA UK booklet **Healthy Eating with PWS** gives more information about the dietary and nutritional needs of people with PWS and also includes sample menus. You can order it from the order form <https://www.pwsa.co.uk/about-pws/publications/>

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 –environmental controls



Environmental control means the removal of accessibility to food and thus temptation. If food is not available, your child is less likely to seek it.

Environmental controls can take several forms, depending on level of need, and they will be needed for those children and teenagers with PWS whose self-control around food is minimal. Here are some suggestions:

Locks on kitchen, fridge and pantry doors

These can be ordinary locks and keys, magnetic locks, padlocks, or more sophisticated electronic locks. Keep tools stored away safely - these may be used to force locks.

Do not leave food lying around

Do not put sauce bottles, bread, etc on the table before the meal commences. Clear everything from the table immediately after a meal and put leftovers straight into the rubbish bin or into the fridge for later (both of which may need to be locked).



PLEASE NOTE!

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

Though expensive, it may be worth buying a waste disposal unit to deter those who forage through rubbish bins. Make sure that family members do not leave sweets, crisps etc in coat pockets or unlocked drawers.

It is important to try to teach your child about the significance of private property. If everyone in the family agrees, there should be some cupboards or rooms in the house which belong to each family member, and no one else should be allowed to go into them without their permission. This has to apply to your child with PWS as well, who should have his own private space.

Preparing, cooking and serving meals

There are many ways in which you can help your child reduce calories by adapting your methods of preparing, cooking and serving meals. These should not impinge to any great effect on the family's daily lifestyle. Here are some of the most commonly used:



- For snacks, provide fresh fruit or vegetables instead of biscuits or cakes. Buy smaller sizes of fruit such as apples and oranges. If a biscuit is a must, make it a plain biscuit and include the calories in the day's overall intake.
- Grill food, or use a microwave oven, wherever possible. Do not fry food.
- Use small thin slices of bread instead of thicker ones. Use small crackers and crispbreads and use a small amount of low-fat spread.



- Look for alternatives to desserts made with flour, sugar and fats. Try unusual fruits, low calorie jellies, sugar-free yoghurts or fromage frais.
- Give larger portions of "free" vegetables and salads, but less of higher calorie foods. Make sure there are sufficient protein foods.
- You can avoid family arguments about one person having more than another by serving separate meals on trays in front of the television.
- Add water to your child's helping of soups or stews to make it look larger. Avoid thick soups, cream soups and thickened stews.
- To prolong a meal, serve salad as a special first course, or even before dessert as in France.
- If your family is used to having second helpings, ensure your child has less in the first helping so that they can have

Looking at food labels

Look at food labels carefully. Remember that "low fat" and "low sugar" do not always mean low energy (low calorie). Make sure you read "per portion", "per pack", "per 100g" etc correctly. For example, the label on a product may say 70kcal per 100g, but if there are 250g in the whole pot, the entire contents would amount to 175kcal.

per 30g serving					
16	ENERGY 460kJ 110kcal	FAT 0.7g	SATURATED 0.1g	SUGAR 5.3g	SALT 0.2g
SERVINGS	9%	LOW 2%	LOW 1%	HIGH 9%	NEED 4%
<small>% of an adult's reference intake. Typical values per 100g: Energy 1539kJ/363kcal</small>					

Eating out and parties

Eating out is one of the pleasures of life for most people, with many outings and special occasions organised around a meal in a restaurant, or a party.

There is no reason why your child should be left out of the celebrations, but some advance planning and agreement may be required. These are a few of the options you could consider:

- **Agree in advance that only certain foods, or only a small portion of any celebratory cake or dessert can be eaten.**
- **Agree in advance that if there are no "diet" drinks on the menu, the option will be mineral water or tea/coffee.**
- **If eating in a restaurant, agree in advance that he has only two of the courses on offer. Ask your child to identify the healthier options on the menu for himself, and praise him when he gets it right.**



Social and educational controls

As children with PWS grow older, they will usually start to realise how different their own dietary needs are from those of other people. If they haven't already begun to question what and how much they eat, they may begin to do so now. So now is the time to show your child how important it is for people with PWS to stick to a healthy eating regime.

Other things he can be educated about are: what is a reasonable portion of food to have on his plate, not to eat whilst he is talking, how much food to take into his mouth at a time, and to wait until others are served before commencing the meal. Reward or praise your child when he does this correctly.

Others in the family can be supportive by not eating in front of your child, joining in with the "healthy eating" programme, and remembering not to leave leftovers lying around.

Teaching your child about healthy eating

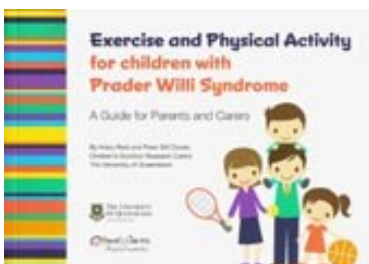
Many older children and teenagers can also be taught to recognise foods which are high in calories and those which are lower in calories, and your child may enjoy shopping with you for healthier options. Some individuals will be able to read food labels for themselves.



It may be advisable to ask your child to help you make the shopping list before you set out - this will minimise arguments in the shop. Always praise the food choices and suggest alternatives when an inappropriate choice is made. Make sure that **your** facts are correct before passing on your knowledge to your child.

However, this may not be appropriate for some children who become very anxious and/or upset when dealing with food choices or being around food.

Exercise



Regular exercise is very important for people with PWS and whenever possible it should be incorporated into your child's daily programme. It is important for several reasons:

- It helps burn up energy (calories)
- It will improve muscle tone
- It improves circulation
- It distracts from eating
- It improves alertness

Exercise can be taken in regular sessions with the aid of DVDs, exercise bikes and step machines (while watching favourite TV programmes or listening to music). It can also be taken in less formal ways: Nintendo Wii, games and sports, cycling, walking, riding, dancing etc.

The booklet **Exercise and Physical Activity for Children with Prader-Willi Syndrome** is very helpful and can be downloaded from the internet at media.wix.com/ugd/a71d4c_083a2139228f42ceada273ffb128308f.pdf

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.

Relatives and neighbours

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.



School

Make sure that your child’s school knows all about PWS, and the necessity of keeping food out of sight. 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. Give the school the article **Information for**

Primary School Teachers <https://www.pwsa.co.uk/assets/files/primary-staff.pdf> or **Information for Secondary School Teachers** <https://www.pwsa.co.uk/assets/files/Secondary-staff.pdf> which includes information about dietary requirements.

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 the 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.

Continued ...

Dietary management for your child

Drinks

There are now many diet drinks on the market, which are generally considered to be safe as long as they are not consumed in large quantities.

Cola, while OK in moderation, has a decaying effect on teeth, which are often very vulnerable to decay in PWS. Therefore, if possible, a variety of other drinks should be offered.

Use skimmed milk for your child’s tea and coffee, and sweetener rather than sugar. Some may enjoy herb, fruit or lemon teas.

If possible, use different types of sweetener in different drinks, so as to avoid a very high concentration of any one type of sweetener in the total intake.



Let's Talk About PWS

You may find it helpful to use the enclosed booklet to explain to your child why people with PWS need a healthy diet.

PWSA UK

Suite 4.4 , Litchurch Plaza

Litchurch Lane

Derby DE24 8AA

T: 01332 365676

E: admin@pwsa.co.uk

W: www.pwsa.co.uk

© PWSA UK

School (continued)

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:

- 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
- Food in coats or bags in the cloakroom
- Tuck shops
- Religious and cultural celebrations involving food.

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.

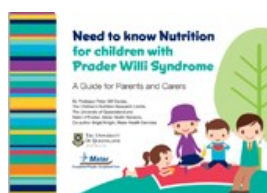


If your child is going to someone else's party, make sure the host or hostess knows in advance about your child's dietary requirements and ask the host or hostess to fill their goody bag with non-food items.

Further information

Some of this article is taken from **Healthy Eating with Prader-Willi Syndrome** which is available to order <https://www.pwsa.co.uk/about-pws/publications/>

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

- This 44 page booklet has been compiled by University of Queensland and Mater Hospital and can be downloaded free from https://docs.wixstatic.com/ugd/a71d4c_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 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 for more details.