

Dietary management for teenagers with PWS 13–18 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.

It is therefore very important to try to help your son or daughter realise how important it is that they do not become obese and also to learn to control their diet as much as possible for themselves, or to appreciate that others need to control their diet for them. Currently, the only effective long-term prevention or treatment of obesity in PWS is a low-calorie diet and restricted access to food, coupled with regular exercise.

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 people 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 are capable of preparing their own meals with little or no supervision; for others, time spent in the kitchen is time to eat as much as they possibly can, and even to secrete food on their person for later. 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 person with PWS will require a different level of help and support to another, although all will require some support.

Counting calories?

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

If your son or daughter 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 dietitian who can give you more detailed information and support tailored to your son or daughter's needs.



Please Note

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



The effects of obesity

Some of the most common outcomes of severe obesity in PWS are:

Illnesses

Diabetes (usually non-insulin dependent, but sometimes insulin is needed to control the condition), heart problems, breathing problems, sleep apnoea (cessation of breathing for short periods whilst asleep), oedema and lymphoedema (water retention), which can lead to cellulitis, a serious skin infection which can cause blood-poisoning.

Limitations on lifestyle

The ability to move about, already limited by poor muscle tone, becomes very difficult. Problems are experienced in using public transport, getting into cars, cinema seats, plane journeys, climbing steps and stairs, using the toilet, etc. Ordinary wheelchairs will not take the weight of a very obese person. Sleeping during the day becomes more frequent. Clothes to fit become increasingly difficult to find.

Psychological and behavioural effects

Self-esteem may become very low and depression may result. Sleep apnoea causes breaks in the sleeping pattern, resulting in irritability, tiredness and increased behavioural problems during the day.

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.



How 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 need fewer calories than those of the same age.

If you are in doubt about how to ensure that your son or daughter 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** <https://www.pwsa.co.uk/about-pws/publications/> 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 enclosed with this pack.

The issue of self-control becomes all-important as the person becomes an adult. If control over food at home is impossible for the person with PWS, control in many other environments, such as shopping and going out independently, is also very limited. This lack of personal control in so many areas of life may be one of the contributory factors to behavioural problems. It is therefore important to give back some control to older teenagers in other ways, for instance, in agreeing a contract about food and diet, or consulting them about the day's menu. Some people become very upset by the word "diet", so you may need to use another term such as "healthy" or "sensible" eating. Responsibility and control can be provided in other ways, such as asking them to do their own laundry and keeping their room tidy.

Environmental controls

Environmental control means the removal of accessibility to food and thus temptation. If food is not available, your son or daughter is less likely to seek it. Environmental controls can take several forms, depending on level of need, and they will be needed for those people 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. You could consider giving back control to your son or daughter by providing them with their own locked table-top fridge (with their own code), stocked with small amounts of, for example, diet drinks or fruit). Even more control can be given by suggesting that older teenagers buy the fridge and lock with their own money.

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). 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 son or daughter 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 son or daughter with PWS as well, who should have his own private space.

Agree food shops and restaurants are out of bounds if unsupervised

This is a difficult contract to make unless the individual is never allowed out on their own. For those older teenagers who do go out independently, the risk is always there. A sudden increase in weight may indicate illicit visits to food shops, but it may also mean the person has been obtaining food by some other means, such as stealing from shops, foraging in bins, or asking strangers for food or money. You can minimise some of the risk by alerting local shopkeepers and neighbours, but you may also need to agree with your son or daughter that going out independently is a privilege which they can have as long as they keep to the contract, which will be withdrawn if they do not. Regular weighing is the best way of monitoring whether someone is getting outside access to food. It is important not to make your son or daughter feel as if they are failing if the contract is not kept - emphasise what they *can* do whilst suggesting that next time someone goes with them.

Dietary management for teenagers with PWS

Eating out

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.

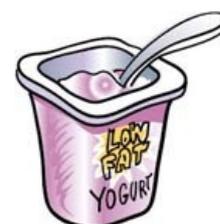
There is no reason why your son or daughter should be left out of the celebrations, but some advance planning and agreement may be required. These are a few options you could consider:

- 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 with your son or daughter that they have only two of the courses on offer. Ask them to identify the healthier options on the menu for themselves, and praise them when they get it right.



Preparing, cooking and serving meals

- There are many ways in which you can help your son or daughter 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 son or daughter'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 son or daughter has less in the first helping so that they can have a second helping along with everyone else.



Looking at food labels

per 20g serving					
16	ENERGY 460kJ 110kcal	FAT 0.7g	SATURATED 0.1g	SUGAR 5.1g	SALT 0.2g
SERVINGS 8%	8%	LOW 2%	LOW 2%	HIGH 10%	MED 4%
Typical values per 100g: Energy 1030kJ/246kcal					

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.

Social and educational controls

As the young person 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 son or daughter how important it is for people with PWS to stick to a healthy eating regime.

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

Continued ...

Social and educational controls (continued)

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

Many people can also be taught to recognise foods which are high in calories and those which are lower in calories, and your son or daughter may enjoy shopping with you for healthier options. Some people will be able to read food labels for themselves.

It may be advisable to ask your son or daughter 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.



Dietary management for teenagers with PWS

Exercise

Regular exercise is very important for people with PWS and whenever possible it should be incorporated into their 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.



Helping your son or daughter to lose weight

It may be necessary to support your son or daughter to lose several kilograms in weight. This will involve a decrease in daily calorie intake with, if possible, an increase in the level of physical activity.

You may need to get advice about calorie levels and calorie counting from your GP or dietitian. If they have little or no knowledge about PWS, send them appropriate leaflets on PWS in advance of the appointment.

Keep to realistic expectations: 0.5 - 1 kg (2-4lbs) per month is quite adequate. Some people find a sponsored slim a very attractive way to lose weight, whilst older teenagers may get some benefit from going to a WeightWatchers Club or similar. Check with the organisers before going ahead with this - some slimming clubs have a minimum age limit of 16 years.

WEIGHT LOSS CHART					
YEAR	MONTH	STARTING WEIGHT	END OF MONTH	STRENGTH	PERSONAL BEST

It obviously helps if someone else in the family or a friend is also attempting to lose weight and can sympathise. Some may find fitting into a fashionable outfit is a sufficient target, whilst others may need the extra support of colourful charts, and tokens towards rewards such as CDs or outings.

Continued ...



Helping your son or daughter to lose weight (continued)

Another idea is to start a "video diary" using a smart-phone or camcorder to take a few minutes of video each week, so that the person can see their weight loss from week to week, and talk about their difficulties and successes in losing weight. A successful video diary would be a very valuable resource for the PWSA UK and extremely useful for encouraging others. Alternatively, take a series of photographs, perhaps with the tape measure showing their measurements.

Whatever method of support is chosen, regular weighing is essential to ensure that it is working. If it is not, and unwanted weight is being gained, then the method needs to be re-examined to see what is going wrong, and perhaps additional support and/or different methods will be required.

Everyone who is involved in the daily life the person should be made aware of the exact level of support which is being offered and adhere to it. Many people with the syndrome will quickly take advantage of loopholes in the system, or of newcomers, to obtain extra food. This includes family, friends, neighbours, local shops, staff at schools and colleges, day centres, respite centres, youth clubs, etc.

Praise the person whenever they meet or even exceed expectations.

Weight management is usually more likely to succeed if your son or daughter is involved in the discussions regarding the level of support which is being offered.

Other weight loss diets and treatments

"Miracle" diets

Generally speaking, commercial "miracle diets" may work in the short term, but their effects do not last. Some diets are dangerously short of essential nutrients - consult a registered dietitian or your GP before embarking on any of the latest fad diets.



Appetite suppressants

To date conventional appetite suppressants have had mixed results on people with PWS, often having unwanted side effects on the nervous system, and in a few cases triggering episodes of mental illness. They do not always succeed in reducing appetite and they are rarely effective in the long term. Effects in normal people only last about 6 weeks.

Surgery

Gastric by-pass operations can be performed, but usually as a last resort. There is a risk for very obese people under anaesthetic, and the side-effects of gastric by-pass, such as continual diarrhoea and unwanted folds of skin, can be very unpleasant. Wiring of the jaws is generally considered inadvisable.

Hospitalisation

Hospitalisation may be the only alternative in cases of severe obesity. A person may need to be admitted to hospital to reduce weight under supervision This will only work if the person does not gain access to food from other patients and nursing staff are aware of the person's cleverness in obtaining food from unusual sources.

Drinks and alcohol

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 son or daughter's tea and coffee, and sweetener rather than sugar. Some people 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.

Once your son or daughter reaches the age of 18, going to the pub can be a very helpful socialising experience but, if possible, someone should go with them who understands their dietary needs. Alcoholic drinks have a high calorie content, but there are now some drinks on the market which are lower in calories.

If a visit to the pub is planned, try to make up for the extra calories by going without a dessert at mealtime. Low calorie lemonade, tonic water, etc. can be used as mixers to keep overall alcohol and calorie levels lower.

Anecdotal evidence from parents suggests that alcohol has very similar effects on people with PWS as it does on the rest of the population, although a person with PWS may become intoxicated more quickly than most people, and having drunk smaller quantities of alcohol.

School and college

Make sure that your son or daughter's school or college 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 teenager with PWS to watch what they eat.



It is unlikely that your son or daughter will be the only one on a special diet - there may be others with allergies, diabetes, food intolerance etc. Some schools and colleges provide a special area for such teenagers to sit together so they can be more easily supervised.

Everyone at the school or college 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.

Possible problem areas in school and college

- Other young people's lunch boxes
- Uncleared plates
- Delivery vans/trays of bread
- On outings
- Travelling to and from school or college
- 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
- Snack vending machines
- Religious festival displays and other celebrations involving food.



Let's Talk About PWS

You may find it helpful to use this booklet to explain to your child why people with PWS need a healthy diet. <https://www.pwsa.co.uk/about-pws/publications/>



Give the school or college the article Information for secondary schools <https://www.pwsa.co.uk/assets/files/Secondary-staff.pdf> or Information for colleges <https://www.pwsa.co.uk/assets/files/college-staff.pdf> which includes information about dietary requirements.

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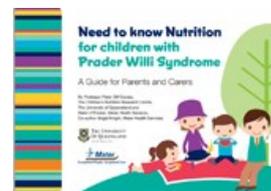
Further information

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.