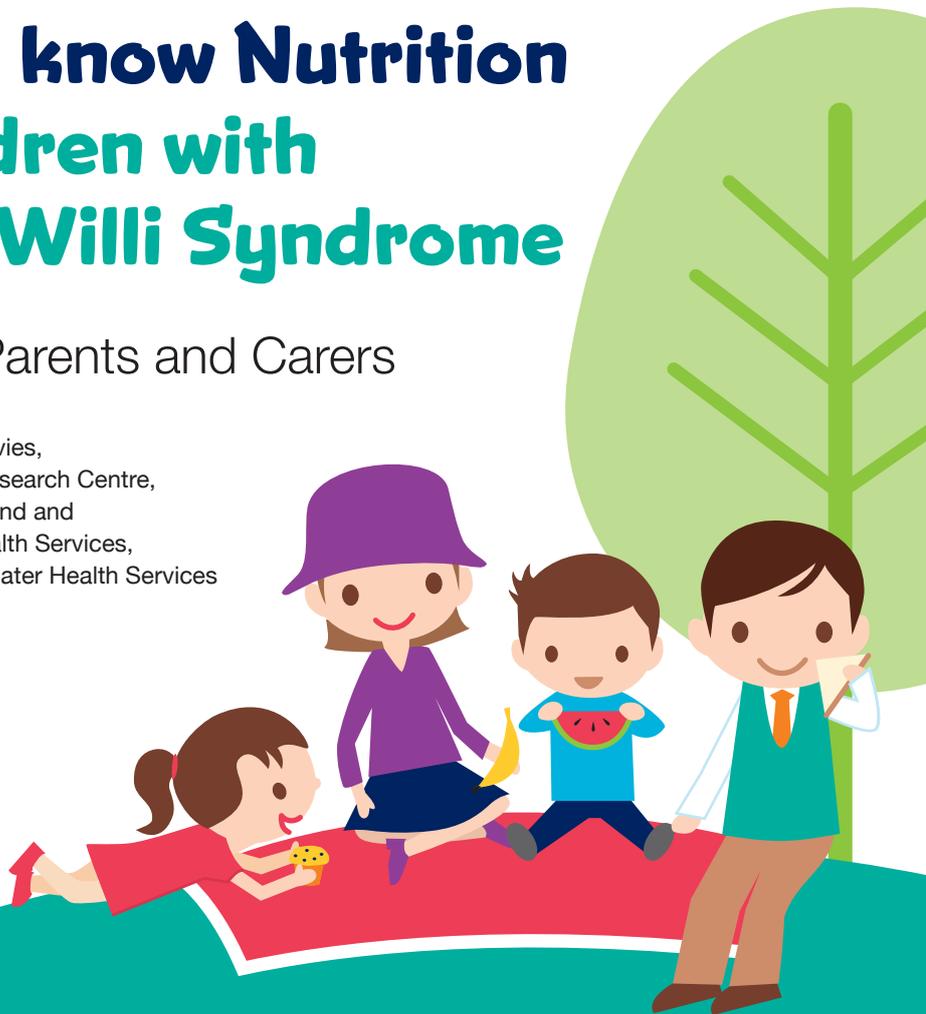


Need to know Nutrition for children with Prader Willi Syndrome

A Guide for Parents and Carers

By Professor Peter SW Davies,
The Children's Nutrition Research Centre,
The University of Queensland and
Helen d'Emden, Mater Health Services,
Co-author Brigid Knight, Mater Health Services



The information provided in this Guide is not intended to be medical advice and is provided as general information only. If you have a particular question or concern about your child's health you should see a qualified medical practitioner.

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Foreword

I am very pleased to introduce you to another very handy and useful guide on one of the major disabling aspects of Prader-Willi Syndrome (PWS) – the issue of managing diet. As parents we have the difficult task of finding a balance between limiting our child's food intake, while at the same time, ensuring that their diet is nutritious, with enough energy, vitamins and minerals for healthy growth. We also have to develop strategies to cope with their longing for food, their asking for more food and their food seeking behaviour.

This booklet will provide parents and carers with many hints about how to manage the diet of a child with PWS. This is no easy task in a society where we are bombarded with food, snacks and drinks.

Children with PWS usually have less muscle mass and lower muscle tone than other children, and are therefore more prone to avoid physical activity. The authors will help you understand that without strictly managing their diet, they may become overweight, and this may be the start of a vicious cycle of wanting more food and less activity.

Professor Peter Davies, Director of the Children's Nutrition Research Centre at The University of Queensland, Helen d'Emden and Brigid Knight, both Dietitians at the PWS Clinic,

Mater Health Services, Brisbane, have a wealth of knowledge on nutrition. Having worked with children with PWS, they will share their experiences with you and help you understand the problems of obesity in PWS. More importantly they will give you practical strategies to help prevent a child with PWS from becoming overweight. They will guide you from the infant years to the teens highlighting important aspects of managing their diet at each stage and a food exchange system is explained with practical examples. Throughout the booklet, it is stressed that good habits, once established, will be of great benefit in the long term.

I thank the authors for their thoughtful discussion of nutrition in PWS and trust you will put many of the useful ideas into practice.

Elly Scheermeyer, PhD

President of the Prader-Willi Syndrome Association of Australia

Preface

This guide to diet and nutrition for parents and carers of children with Prader Willi Syndrome, complements a booklet that was released in 2010, titled 'Exercise and Physical Activity for children with Prader Willi Syndrome – A Guide for Parents and Carers'. Both guides are available for free download from the website of the Children's Nutrition Research Centre, under the *Facts for Families* section, www.uq.edu.au/cnrc.

One of the key characteristics of children with PWS is their tendency to eat excessively. This behavior becomes apparent in most children as they progress through primary school. Individuals with PWS are unable to sense when they are full after eating. To help a person with PWS to control their weight, it is essential to understand why they are prone to obesity. Obesity associated with PWS is life threatening and does result in serious health problems which will affect an individual's quality of life.

Most importantly, parents and primary carers need to understand that taking control of the food environment and implementing effective behaviour management will be essential to ensure a child with PWS can maintain a restrictive diet, healthy eating routines and regular exercise. Good habits established early will minimise resistance from children and maximise their chances of maintaining a healthy weight in the long term.

In turn, it is equally vital for grandparents, extended family, friends, carers and teachers to support parents/carers with behaviour management. A special food treat (even occasionally) might seem kind, but will undermine any efforts to maintain a restrictive diet and good habits, and make it more likely that the child with PWS will gain weight.

PWS is a condition that is not broadly understood throughout the community, and is not commonly seen by your usual medical providers and health professionals. Sharing this guide with your extended family, carers, friends, educators, and health providers will assist in a coordinated approach to caring for you and your child.

Professor Peter SW Davies, *Director, Children's Nutrition Research Centre, The University of Queensland*

Helen d'Emden *Dietitian, Mater Health Services*

Co-author Brigid Knight, *Dietitian, Mater Health Services*

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“THE BIG ISSUE”

Control of the food environment and effective behaviour management will set the scene for good dietary habits

When we look at diet for an individual with PWS, there are four key aspects important to maintain a healthy weight:

1. Remove temptation – access to food should be controlled at all times, other than the food provided for meals and snacks. It is often necessary to lock cupboards, fridges and prevent access to rubbish bins. Controlling the food environment is very important to ease the pressure on the child with PWS and will help your child’s behaviour, reducing temptation, tantrums, guilt and sense of failure.

2. Behaviour – you will need to establish good eating routines, offer a wide variety of healthy food choices from an early age, and be consistent. Don’t reward with food, and don’t give in to tantrums.

3. Quantity – your child will need to stay on a highly restricted diet with a lower quantity of kilojoules (kJ) than children without the condition.

4. Quality – it is best to offer your child high quality foods which are low in fat, but high in nutrients.

This book has a wealth of information and practical strategies to assist parents and carers to manage the food environment to enable good diet and eating behaviours of children with Prader Willi Syndrome (PWS). Daily exercise should also be mandatory.

Children with PWS don’t have the sense of “fullness” when they eat compared to people without PWS. Furthermore, their body composition is different to that of other children. A highly restrictive diet is necessary for them to maintain a healthy weight and good overall health. This diet is very different to that recommended for children without PWS. As the diet is so restrictive by necessity, it is best to remove all temptation of obtaining additional food, and children will need to be trained from an early age about the importance of healthy eating and exercise behaviours.

The most important message to take away from this guide is that a multifaceted approach is required to control the weight of a child with PWS. Attention must be given to diet and exercise, but adults can assist greatly by managing the food environment and ensuring **effective behaviour management** so the child develops good eating and physical activity habits from an early age.

Parents and carers of infant children with PWS will struggle with this concept, as babies with PWS fail to thrive. Parents will be focused at this stage on maximising their food intake to ensure good health. As children move into the toddler years, their eating behaviour and body shape will be more like that of children without the condition. However, at this stage, it will be vital to establish good dietary habits and to resist treating children with foods – particularly unhealthy ones. Good routines and habits established during the toddler years will ensure that children will eat a wide variety of healthy foods without challenging parents and carers. This will reduce the likelihood of daily battles, maximise harmony in the home, and improve the chances that a child will stick to these habits as they mature and gain greater independence.

A message for parents and primary caregivers

Communicate to your extended family, friends, teachers and other carers that your child's health will depend on a restricted diet, strict food routines, healthy eating behaviours and daily exercise. Their support and understanding will prevent them from undermining the good work that you are doing to help your child maintain their diet and long term good health.

It will be hard for many people to understand why your child doesn't have as much food in their lunchbox as other children – or why little food treats here and there will really cause a lot of damage in the long term.

If you experience difficulty in getting support from those around you, please talk to your paediatrician, dietitian, PWS clinic coordinator or other health professional.



Who is best to treat my child?

PWS is a complex condition that requires a multifaceted approach to manage the condition successfully. For this reason, a range of health professionals may be involved in treating your child including paediatricians, endocrinologists, dietitians, physiotherapists, and others.

However, not all specialists have experience in treating children with PWS. For this reason, a number of PWS Clinics have been established throughout Australia and New Zealand to manage PWS holistically. Most children's hospitals in capital cities have endocrinology units which specialise in PWS care. Please see your GP or care provider for a referral to a specialist clinic nearest you.

They may be able to offer support to help explain the condition to teachers, friends and extended family, and to reinforce the necessity of a restricted diet, and how their support is vital.

This guide is a helpful resource. Pass it around to friends, family members, carers and teachers to help them understand the importance of establishing a restricted diet and healthy eating behaviours for your child.



A message for grandparents, teachers, carers and family friends

It is vital that teachers, grandparents, carers and family friends are supportive of parents/primary carers of children with PWS. Your support is needed to help ensure that children adhere to their prescribed diet, eating routines, healthy eating behaviours and daily exercise. This will be difficult because the diet is very restrictive and because a child with PWS does not feel satisfied after eating. Well-meaning teachers and grandparents may secretly supplement the food intake of children for fear that they may not be getting enough to eat. Be assured that the diet for each child with PWS will be prescribed and monitored by health care professionals.

Please resist giving food treats, even if the child does not look overweight. As they mature into adolescence, a child's growing independence may increase their access to food, and weight gain will be rapid. This will be less likely if strict habits are established early.

Remember, by supporting children to stick with their diet – and by supporting parents to establish rules and routines around food and physical activity - you will be playing a big part in ensuring a child with PWS maintains good health in the long term.

What is Prader Willi Syndrome?

PWS is a genetic condition affecting between 1 in 10,000 to 1 in 15,000 live births. PWS occurs equally in males and females, affects all races, and is the most common genetic cause of obesity.

There are subtle differences in the genetic problem causing PWS in some children, but the characteristics of the syndrome remain similar in most.

There are distinct phases of PWS Syndrome – the “Failure to Thrive” phase, the ‘Setting the Scene’ or Toddler phase, followed by the “Hyperphagia” phase (excessive eating/insatiable appetite). These different phases will be introduced here but described in more detail in the pages ahead.

Infants with PWS are commonly diagnosed with “Failure to Thrive”. They are often hypotonic (floppy) and lethargic, with a poor suckling reflex and a weak cry. They are also slower to develop motor skills, taking longer to sit up, crawl, walk and talk.

During the toddler stage, parents can find it difficult to appreciate that preventing their child’s weight gain will be an ongoing struggle. This is because, during a child’s infancy,

parents of children with PWS have to work hard to achieve adequate nutrition and satisfactory growth for their baby.

As the child gets older, anytime onwards from the toddler years, most children will enter a pattern of hyperphagia, and a preoccupation with food develops. This phase is often characterised by increased appetite and excessive weight gain.

Children with PWS often have a shorter stature, small hands and feet, poor muscle tone, hypogonadism (a condition where the male testes or female ovaries do not produce enough hormones), and often carry excess weight around the abdomen, buttocks and thighs. Increased body fat has been noted in all stages of development, along with decreased lean mass, bone mineral content, and bone density.

Individuals with PWS have distinct facial characteristics including almond-shaped eyes, narrow nasal bridge, narrow forehead and thin downturned lips. Other characteristics may include altered temperature sensitivity, high pain threshold, delayed puberty and behavioural problems such as temper tantrums and obsessive compulsive behaviour.

Many believe that children with PWS have a lower basal metabolic rate (amount of kilojoules (kJ) burned at rest) than other children. This belief is unfounded. Studies have shown that once a child's height, weight, body composition and age are accounted for, the basal metabolic rate of a child with PWS is similar to that found in other children.

However, it is true that children with PWS have more fat mass and less lean body mass (or muscle, bone and organ tissue) than other children. Muscle burns a significant amount of energy at rest. This means that children with low muscle mass will burn less energy throughout the day than others with high muscle mass. Therefore, children with PWS are unlikely to use as much energy throughout the day as other children simply because they have less muscle to burn energy.

For Example:

Compare a plane with two engines, to a plane with four engines. While each engine might burn fuel at the same rate, the plane with four engines will consume more fuel, simply because it has more engines! In this example, the engines represent lean muscle mass. A child with more muscle mass will burn more energy – like the plane with four engines, than a child with less lean muscle mass – even though their basal metabolic rate is the same.

What is the difference between the body composition of a child with simple obesity and a child with PWS?

Simple obesity means that an individual is obese but does not have PWS. When you consider that the effort of moving a larger mass builds muscle size and strength, it is not surprising that people with simple obesity have increased fat mass and lean muscle mass. For example, a person of larger body weight will expend more effort when walking, usually causing the leg muscles to increase in size and strength. This “companionship of lean and fat”, as it has been described, is not apparent in those with PWS, or in children with Growth Hormone deficiency. Studies have shown that children with PWS have an increased amount of fat in their limbs compared with their trunk, thus reducing their total fat-free (lean) mass.

Why is obesity a major concern?

Children with PWS are at higher risk of obesity. Studies have shown that up to one third of individuals with PWS weigh more than 200% of their ideal body weight and body fat is 2-3 times higher than those without PWS. Body fat may be as high as 40-50% of their weight.

This is of major concern. Obesity is one of the major causes of disease and death in people with PWS. Obesity can lead to health problems including type 2 diabetes mellitus, high blood pressure, coronary artery disease, cor pulmonale (failure of the right side of the heart), sleep apnoea, and joint and mobility problems.

How diet will change as a child develops

There is a paradox in managing babies and children with PWS. In the first few years, it can be difficult for your baby to consume enough energy or kilojoules yet for the remainder of your child's life you will need to restrict their energy intake. Therefore, your child's diet will need to be modified depending on their stage of life.

What does the research tell us?

An Italian research team (Brambilla & colleagues) undertook studies relating to the body composition of individuals with PWS. The work confirmed what has been anecdotally suspected for some time - the body composition (amount of fat and lean body mass) of children and young adults with PWS is different to the body composition of individuals with simple obesity.

Infancy

Infants with PWS fail to thrive, are lethargic, have low muscle tone and delayed development. You will need specialist support to ensure the adequate nutrition and growth of your baby.



Toddler Stage

Children will rarely appear overweight. Establish good eating routines and habits. Encourage a wide variety of healthy foods and regular exercise.



Primary School Children & Young Adolescents

The risk of obesity will increase. Maintain very consistent boundaries, routines, a restricted diet and a daily exercise plan.



Adolescents & Young Adults

Growing independence will bring growing opportunities to access food and weight gain is likely. Success is most likely when routines are established, meals are planned, and the environment is controlled.





The Infant Stage

Infants with PWS are commonly reported as having ‘failure to thrive’. They are often hypotonic (floppy), lethargic, and have a poor sucking reflex. PWS infants are typically slower to reach milestones and delayed motor skills development means that they take longer to sit up, crawl, walk and talk. Even eating milestones are usually delayed.

Engaging your baby in feeding can present challenges - they may be uninterested in feeding, or suck poorly, then fall asleep. To assist with feeding, a range of measures may be tried such as:

- adaptive bottles and nipples,
- concentrated formulas,
- thickening agents, and
- nasogastric feeding.

Your paediatrician, as well as a speech therapist and dietitian, may be involved to ensure the adequate nutrition and growth of your baby.

If your baby is fed via a nasogastric tube, this will continue until the baby develops a swallowing reflex and can manage an adequate energy intake orally. To help develop the mouth muscles, the baby should be encouraged to suck on a dummy. Your doctor and speech therapist will usually be involved at this stage to guide you with the transition to oral feeding. They will assess your child’s oral reflexes and advise when fluids and solids can be introduced, as well as suggest special teats for bottles and cups to aid feeding.

Be guided by experts during this difficult feeding phase and remember it is short term, it will pass.

The introduction of solid foods may be delayed, but the plan for introducing solids is the same as for babies without PWS. For example, commence with rice cereals, then

pureed fruit, pureed vegetables, then meat, etc. Follow the feeding guidelines for babies as set out in current infant feeding booklets.

During this phase of introducing solids, there may be a need to supplement the oral intake with additional fats and/or commercial nutrition supplements. Eventually such supplements are reduced as the child manages more food. Your paediatrician and dietitian will be monitoring your baby's growth during this time and will advise you.

Usually by 12 months, a baby without PWS should be eating the same foods as the family, though in children with PWS, this milestone may also be delayed. Do not introduce any treat foods into your baby's diet, such as biscuits, cakes, pastries and sweets, as these foods will not be part of the long term eating plan. Babies should have full cream milk until at least 2 years of age, or until they are eating a wide variety of foods, then semi-skimmed milk can be used. Skimmed milk may be introduced by the age of 5 years.

The Toddler Stage

Diet management during the toddler years is very important as it sets a pattern of behaviour for the years ahead. During the infancy stage, parents of children with PWS struggle to achieve adequate nutrition and satisfactory growth for their baby. As the child moves into the toddler phase, parents can find it difficult to appreciate the struggle that lies ahead to prevent weight gain.

Weight control in children with PWS is possible and requires a multifaceted approach with attention to controlling the food environment, behaviour management, diet, and exercise. Additionally, other carers including grandparents, babysitters, day care staff, etc will need to be advised of the importance of following a very strict eating plan, despite the fact that your toddler will not be overweight.



Establish good dietary habits early and your toddler will reap the benefits later.

Remember, dietary habits established during the toddler years are very important. This is because a progressive rise in body mass index (BMI) has been shown in infants with PWS who are older than 30 months. Obesity may begin, even before your child exhibits a substantial increase in food intake or interest. This makes early diagnosis, and the establishment of good diet and physical activity behaviours, most important. Children with PWS who are overweight or obese early in life will find it even harder to manage their weight as they age.



Controlling access to food, providing healthy food choices, and ensuring a routine eating plan and daily exercise, is best introduced from the beginning. Feeding a toddler is the most 'normal' eating phase for a child with PWS - not too different from most toddlers. However, it is important they learn that food will be served to them and they cannot access additional food. High energy or treat foods should not be introduced into the diet as they will need to be withdrawn later on, when the need to control weight becomes obvious. It is most important to advise family members and carers of this fact too.

There are some key rules that will help to establish good eating behaviours for your toddler:

1. Concentrate on feeding your child a variety of foods from the core food groups only including:
 - breads and cereals;
 - vegetables and fruits;
 - dairy including milk, yoghurt and cheese; and
 - lean meat including fish, chicken and alternatives such as soy products/nut meats.
2. Offer a wide variety of healthy foods, particularly vegetables, salads and fruit as this will help enormously with options for variety and with weight control in the years ahead.
3. Be persistent and offer vegetables repeatedly until they become more familiar.
4. Be a good role model yourself and eat plenty of vegetables and salads and moderate servings of fruit.
5. Introduce low fat dairy food from approximately 2 years of age or the time when you feel your child is managing a satisfactory variety of foods from the core food groups.
6. Enjoy drinking water, and encourage water for your toddler too.

During these years it is also important to encourage exercise and energy expending activities with your child. Refer to pages 16 and 17 of 'Exercise and Physical Activity

for children with Prader Willi Syndrome – A Guide for Parents and Carers’ available from www.uq.edu.au/cnrc under the *Facts for Families* section.

Primary School Children & Young Teens

The risk of obesity will increase as your child progresses through primary school. This is a result of several key factors:

- **Hyperphagia (excessive eating):** this often develops during primary school years, resulting in an increased energy intake and excessive weight gain, if not strictly controlled. The core problem is not an increased appetite, but poor satiety (children can eat but will never feel satisfied or “full”);
- **Hypotonia (low muscle tone):** this continues into childhood and often occurs with poor coordination. These factors make exercise and daily activities such as walking and playing, seem harder for a child with PWS. Consequently, sedentary activities such as drawing, craft, jigsaws, or watching TV are often preferred to the more energetic activities. This can produce an imbalance between energy intake and energy expenditure, resulting in excessive weight gain;
- **Abnormal body composition:** children with PWS have more fat mass and less fat-free mass than other children. Less lean mass means that the resting energy output of children with PWS is reduced and therefore they will burn less energy throughout the day than others with high muscle mass; and
- **Reduced ability to vomit and feel pain:** children with PWS have a reduced ability to vomit or to experience gastric discomfort, even when they have eaten excessive amounts of food.

In a nutshell, excessive eating, coupled with low muscle tone, can produce a long term imbalance between energy intake (in the form of food and drink) and energy expenditure (the amount of exercise and activity undertaken) for children with PWS. This can result in excessive weight gain.



Prader Willi Support Organisations and other useful links

Prader Willi Syndrome Association of Australia www.pws.org.au

Prader Willi Syndrome Association (NZ) www.pws.org.nz

International Prader Willi Syndrome Organisation www.ipwso.org

Prader Willi Syndrome Association (UK) www.pwsa.co.uk

Prader Willi Syndrome Association (USA) www.pwsausa.org

This guide and the Exercise and Physical Activity for children with Prader Willi Syndrome: A Guide for Parents and Carers booklet are available on the Children's Nutrition Research Centre website under the *Facts for Families* section www.uq.edu.au/cnrc

However, with strict attention to diet, and encouragement with daily exercise and activity, the child with PWS can maintain satisfactory growth.

It is during this time that the benefits of a consistent meal and snack routine (started during the toddler years) will be noticed. Your child is more likely to accept that you will not provide food outside the set meal and snack times if consistent boundaries and routines have become established.

It is also during this time that the significance of the restrictive food allowances becomes more evident to you, your family and other carers. Your child's lower muscle mass and lower energy expenditure means that the energy requirement for your child to maintain their weight will be lower than others of similar age.

Where other children can enjoy daily high energy treats, you will need to limit choices to the core food groups as previously outlined. The different eating plan will also become apparent to your child at some stage too, most often during the challenging adolescent years.

Most children with PWS (approximately 90- 95%) show an increased interest in food or a large appetite, and some will go to extraordinary lengths to obtain it. This, along with learning difficulties and immature emotional and social development, can add to the difficulty of managing behaviour. It can be very challenging for all family members. By controlling the food environment to make food inaccessible, the child has no expectations of getting extra food and will not be disappointed, resulting in better behaviour.

Success with weight control is more likely when parenting styles are consistent, and when all care providers including the extended family, friends, teachers and babysitters etc, have a VERY clear understanding of the importance of the low energy diet too.

As children enter adolescence, their growing independence can present huge challenges. Reduced supervision outside the home allows more opportunities for food seeking. This needs to be addressed as weight gain can soar. Make sure you talk

about these challenges with family and friends, your child's school, and with health professionals. Seek support early to prevent problems.

The Key to Success with Diet as a Child Develops

Control the Food Environment and Focus on Behaviour Management

By making food inaccessible to your child, you are not exposing them to temptations, disappointment or failure. Additionally, eating behaviours (**when** your child eats, **how much** your child eats and **what** they eat), should be established early in life to enable them to maintain a healthy weight over time. This is important because obesity and inappropriate eating behaviours are lifelong complications of PWS.

It is important to ensure your child is eating the correct types and amounts of food and also to restrict your child's access to food to ensure they are not consuming extra energy.

Behavioural problems differ between individuals with PWS, due to varying degrees of learning difficulties, delayed or immature emotional and social skills, the environment, upbringing, family traits, etc. There is no doubt that food can be a contributing factor to behaviour problems, but don't restrict food as a form of punishment.

The following strategies may help you to manage your child's eating behaviours:

- have a daily schedule posted which includes all daily activities, including meal and snack times, exercise and leisure activities;
- discuss any changes to the routine with your child beforehand;
- teach the child about good food choices;
- teach the concept that everyone has their own meal ie 'my plate', 'your plate';
- develop strategies to deal with constant food requests;

Don't be afraid to get specialist help when needed.

Specific behaviour problems may require the help of a psychologist experienced in dealing with children with PWS. It is important to note that parents and other siblings may also benefit from consulting a psychologist. This will help to ensure there are strategies in place to care for your own physical and mental wellbeing, as well as the wellbeing of other members of the family.

Careful thought must be given to the diet.

The diet plan must be:

- > low in fat,
- > low in energy/kilojoules (kJ),
- > tailored to the child's needs to enable growth in height,
- > healthy – to ensure nutrient requirements are met,
- > sustainable in the long term,
- > manageable for the whole family, and
- > reviewed regularly as the child grows.

- do not offer second helpings at home as it may raise expectations in other situations;
- avoid grocery shopping and eating out or have very clear rules about how these occasions are to be managed;
- inform all teachers and other caregivers of food rules and check to ensure they are following them (give them a copy of this book, so they will understand the importance of your requests);
- praise good behaviours with immediate tangible rewards (stickers, cuddles);
- ensure that the rest of the family enjoys food treats in private;
- don't try and reason with the child; and
- limit food rewards...use non-food related rewards.

The ideal diet for a child with PWS

Work with your dietitian to determine your child's allowances from each of the core food groups to allow for satisfactory growth. These allowances need to be reviewed and adjusted at least once a year as your child grows. Plotting progress with height and weight on growth charts will help to determine the adequacy of the prescribed diet. Programs such as the Food Exchange System (page 28 of this guide) may assist you to manage your child's diet and help them understand how much food they should be consuming for good health.

While diet is important to prevent weight gain, it is also critical that your child gets sufficient exercise and activity, or weight control will be an uphill battle. The guide 'Exercise and Physical Activity for children with Prader Willi Syndrome – A Guide for Parents and Carers' available from the website of the Children's Nutrition Research Centre, under the *Facts for Families* section, www.uq.edu.au/cnrc is a valuable

resource to guide parents and carers of the importance of exercise and activity for maintaining energy balance. It has many ideas to help you manage your child's energy requirements and to motivate them to undertake exercise. It may be helpful to plan exercise prior to a meal or snacktime to help motivate your child to complete the activity – this is not considered a reward as it is the usual meal or snack that follows.

To prevent weight gain, we must not consume more energy in eating than we expend in physical activity. Energy in must balance with energy out.

Energy In = energy Out = no net weight gain/loss

If Energy In > (greater than) Energy Out = weight gain

If Energy In < (less than) Energy Out = weight loss



Diagram 1. Preventing weight gain - energy must balance with energy out.

Does it matter what kind of food I feed my child?

When preparing food for your child, remember that not all kilojoules (kJ) are equal.

1gram protein = 4kcal (17kJ)

1gram carbohydrate = 4kcal (17kJ)

1gram fat = 9kcal (38kJ)

1gram alcohol = 7kcal (29kJ)

A kcal is commonly referred to as a calorie

Fat has the highest calorie count per gram. Fat is also very efficient at being converted to body fat. Carbohydrate is high in energy but less efficient at being converted to body fat. Protein is the most satisfying food for people without PWS, but remember that individuals with PWS do not feel satisfied, no matter what type of food is eaten.

Resources & Recipes

Calorie, Fat and Carbohydrate Counter, Allan Borushek

Low fat cookbooks/magazines eg. Weight Watchers

Nutrition Australia's website:
www.nutritionaustralia.org/dynamic/recipes.php

Dietitians Association of Australia website: www.daa.asn.au/recipes

Nutrition Society of New Zealand:
www.nutritionociety.ac.nz

New Zealand Nutrition Foundation:
www.nutritionfoundation.org.nz

New Zealand Dietetic Association:
www.dietitians.org.nz

Low fat recipes can be useful to demonstrate low fat cooking techniques, however portion sizes are often excessive for children with PWS, and some recipes may include added sugar. You can discuss recipes with your dietitian if you are not sure they conform to your child's diet plan.

Therefore one way to minimise energy intake for your child is to offer foods that are LOW IN FAT.

The recommended diet for a child with PWS is very different to that recommended for a child without the condition. A dietitian can prepare a diet that will be suitable for your child. PWS is rare, so not all dietitians have experience in managing children with PWS. Speak to your care provider about how to contact your nearest PWS clinic or specialist for dietary advice specifically related to children with PWS.

How can I minimise fat in my child's diet?

All family members can benefit from low fat cooking techniques. Other family members will need larger serving sizes and extra snacks, while other children in the family may receive food-related treats separately. However, it is important for siblings, friends and other family members to understand the rules and routines at home that are important to manage the energy intake of their sibling with PWS. This is all easier said than done, but very important for success with weight control.

Some low fat cooking tips include:

- choose lean cuts of meat and remove all visible fat;
- remove skin from chicken;
- choose low fat cooking methods such as grilling, baking, steaming and microwave cooking;
- roast meat on a rack to allow fat to drain away;
- allow soups and stews to cool and skim off surface fat;
- avoid creamy sauces and high fat gravies;
- use low fat dairy products instead of full fat varieties;
- use low calorie salad dressings or balsamic or wine vinegars as dressings;

- roast vegetables without added fat;
- keep serving sizes small, especially if having a treat;
- limit takeaway foods;
- avoid rich cakes and pastries – use low fat products or (cake/muffin/biscuit) recipes for the occasional treat such as a birthdays;
- try rice cakes and honey or jam without margarine; and
- instead of margarine on bread, use condiments such as mustard or low fat mayonnaise.

Top tips for managing food intake

It will be important to learn clever ways to reduce the energy content of meals. Adopting low fat cooking techniques is important but behavioural strategies, routines and other methods will also assist. Here are other top tips for controlling the food intake of a child with PWS:

- offer smaller serve sizes and use smaller plates;
- follow a diet plan;
- teach the ‘my plate’ versus ‘your plate’ concept;
- maintain a routine, with consistent snack and meal times, and venue;
- serve from the kitchen, not the table;
- limit access to food - store food in lockable cupboards, lock the fridge and prevent access to bins;
- ensure constant supervision around food;
- be prepared and have low joule foods and snacks available;
- allow siblings who do not have PWS to consume ‘secret’ snacks and food treats;
- teach the child with PWS about appropriate food choices;



A good set of scales will help you to serve accurate portion sizes. Scales are an essential tool for parents and carers of children with PWS.

- reward good food choices;
- plan ahead for parties and rehearse restaurant choices;
- inform all caregivers of the strict diet and ensure they comply;
- ensure regular activity and reduce periods of inactivity;
- if food related treats are unavoidable, plan something small on an occasional basis, for example if your child's birthday is the 12th June, plan the treat for the 12th of every month. This makes it easier to say no on other days;
- always encourage your child to drink water - having a special water bottle may help;
- control your child's access to money to ensure it is not used for additional food; and
- prepare your child for unusual circumstances when food may be accessible and teach them to notify you or their caregiver if this situation occurs.

Is an occasional food treat okay?

To minimise the energy intake of your child, it is better to focus on non-food related treats where possible. However, the following can easily be incorporated as food treats:

- diet or low joule drinks contain no energy/calories/kJ so taking advantage of this by offering it as a treat is a win/win. Add lots of ice if you wish;
- diet jelly also contains no energy and can be used for a treat or dessert;
- frozen fruit can make a special change;
- ice blocks made from diet cordials;
- a small serving of low fat ice-cream;
- small amounts of sugar free lollies – they often have less than 100kJ (approximately 20kcal) so in small amounts are an acceptable treat; and
- rice cakes and honey or jam without margarine.

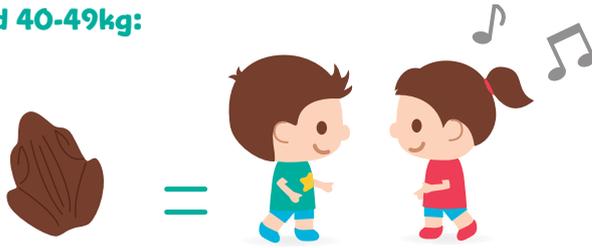


How long does it take to “burn off” some of the common foods we eat?

When trying to minimise your child’s energy input through diet, it is very important to understand how much activity is needed to “burn off” the energy consumed through food.

The pictures below, will help you to understand the energy levels of common foods and how much activity is needed to expend this energy.

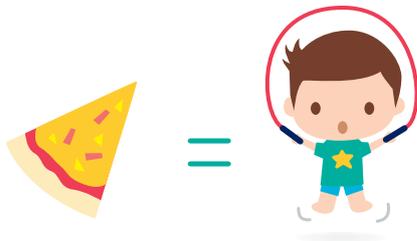
For a child 40-49kg:



Chocolate frog = 19 minutes of dancing
80kcal = 336kJ



Blueberry mini muffin = 21 minutes of swimming
110kcal = 462kJ



A slice of commercial pizza = 32 minutes of skipping
(ham & pineapple)
250kcal = 1,050kJ



Banana = 28 minutes of walking
99kcal = 416kJ

How do I manage my child's dietary needs outside the home?

As your child grows, and spends more time outside the home, you will need to consider how to manage commonly occurring activities when you are not present to supervise, or when you are in a food-laden environment with your child. Here are some strategies for managing common situations:



Schools and child care:

It will be necessary to discuss your child's dietary needs with child care staff, school principals and teachers as they progress through child care and the education system. It is not uncommon for teachers to deal with a variety of special diets including food allergies and intolerances, or type 1 diabetes, so you will not be alone in asking for help. Emphasise the importance and reasons for the low energy diet. Teachers and child care staff would benefit from reading this book. Ask about the frequency of treat foods and birthday celebrations in the classroom and establish clear management strategies. For example, a very small serve of cake could be given instead of the morning tea provided from home.



Parties and special occasions:

These need planning! Discuss your child's needs with the host. Your child should not be left alone near food and the quantity they eat needs to be carefully controlled. If possible, ask the host to focus on non-food related treats. You might also offer to help out at the party – this will allow you to supervise and manage your child's food intake.



Supermarket shopping:

Parents need to think carefully about how to manage grocery shopping with your child present. Tailor your approach to suit the individual needs of your child and to minimise stress for all involved. For many children, it may not be a problem - while for others, the temptations will be too great and tantrums are likely. If this is true for you, it may be best to conduct grocery shopping when the child with PWS is not present, or only when you have a list that can be strictly followed. Another alternative is to try online shopping, where pre-selected groceries can be delivered directly to your door.

Is my child getting enough to eat?

The diet recommended for children with PWS is very restrictive and parents can be concerned they are not giving their child enough to eat. Consequently, you should visit your doctor or dietitian regularly to monitor your child's growth. Height and weight should be plotted on growth charts and the results compared with other children of the same sex and age. Depending on the age and progress of the child, growth may need to be monitored every three months or at least twice a year. Infants and babies needs are different and they will have more frequent visits with the doctor or dietitian.

Sometimes your doctor might calculate your child's Body Mass Index (BMI). This is your child's weight divided by their height² (weight/height²) and is a way of adjusting your child's weight for height. All of these measurements can be useful, but in children with PWS, the best way to monitor growth is the simplest - just measure body weight and height and plot on a growth chart.

Ask for a copy of your child's growth chart at your doctor's appointment, and discuss your child's height and weight with your doctor or dietitian.

Even though your child's diet will always remain low in energy compared to children without PWS - exercise, an active lifestyle, and growth hormone will assist them to develop more muscle. This will increase the energy requirements a little to enable satisfactory growth.

How might a dietitian assess my child's energy requirements?

The only accurate way to determine a child's energy requirements is to measure their energy expenditure. This is time consuming, costly and not practical in most circumstances.

A dietitian or other health professional will predict your child's energy requirements. These predictions are usually based on height and weight. The adequacy of the predicted energy requirements can be assessed by monitoring growth on the growth charts. This will be discussed at your ongoing medical appointments.

Will other “off the shelf” diets help my child?

The modern media is obsessed with reporting the latest food diets and fads. Some of these diets will have merit for individuals with particular conditions, such as a low Glycaemic Index (GI) diet for those with diabetes.

Dietitians are frequently asked whether a high protein diet will help a child with PWS, as protein is more satisfying than carbohydrates. However, as children with PWS do not have the capacity to feel full, this consideration is largely irrelevant. It is important to remember that breads and cereal fibre improves bowel health and helps prevent constipation. The distribution of foods from each food group should be discussed with your dietitian.

Parents and carers should not attempt to use these diets to devise an eating plan for a child with PWS. Seek specialist advice from a dietitian who is experienced with PWS to develop an individualised eating plan suitable for the age and physiological requirements of your child. This diet will require regular and ongoing specialist supervision to ensure your child is maintaining good health.

Will my child get enough nutrients on such a low energy diet?

Choosing foods from the core food groups will help to ensure a high quality, nutrient-dense, diet for your child. A diet recommended for individuals with PWS ensures a satisfactory intake of most vitamins and minerals. However, parents and carers should be aware that a low energy diet may be lacking in fat soluble vitamins such as A, D, E and K. Iron, Zinc and calcium intake may be low as well. For this reason, it may be a good idea to include a daily multi-vitamin supplement to ensure children have adequate vitamin intake. This should be discussed with your doctor, dietitian or relevant health professional.

It is also possible that the intake of essential fatty acids in children (but not infants) with PWS may be inadequate, given the very low fat nature of the diet. Therefore, it may be a good idea to include small amounts of healthy fats, such as a monounsaturated oil or margarine as part of the diet plan determined by your dietitian.

Additionally, including at least 2 serves of fish each week will add quality fats (essential fatty acids) to your child’s diet. Essential fatty acids protect the body against heart disease, are important for a healthy immune system, and for the development of the brain and retina.

Will Growth Hormone treatment help my child?

More and more children with PWS are being prescribed Growth Hormone (GH) treatment, as children with PWS have similarities in body composition to those children with Growth Hormone Deficiency. Indeed, a large proportion of children with PWS are unable to regulate Growth Hormone due to impairment of the hypothalamus. The hypothalamus is a part of the brain that influences hormone regulation, body temperature, hunger, thirst and fatigue. Therefore, many of the features associated with PWS, namely short stature, hypotonia (poor muscle tone) and obesity, might be affected by administering GH injections.

It is widely recognised that GH will assist a child with PWS to increase their height growth. However, it is also important to recognise that GH treatment assists many aspects of growth and health for children with PWS. Other positive effects of GH treatment include: leaner body composition (higher muscle mass, lower fat mass); improved weight management; increased energy and physical activity; improved strength, agility, and endurance; and improved respiratory function.

It is important to remember that GH treatment is NOT a cure-all for the symptoms and problems often seen in a child with PWS, but it can help. Commencing GH will not impact greatly on the energy requirements of the diet recommended for those with PWS, and there is no evidence to say that GH treatment will affect the appetites of children with PWS. Parents/carers of a child on GH treatment will still need to ensure their child maintains a strict, calorie-controlled, diet.

What does the research tell us?

Latest studies show that GH injections can have beneficial effects on body composition for children with PWS. One recent study noted an increase in fat-free mass and a decrease in fat mass resulting in a reduced body fat percentage. The study also noted secondary benefits from GH injections such as improved exercise capacity, strength and agility. These benefits were likely to be caused by changes to body composition, rather than direct impacts from the GH itself. However, the changes are important if we are trying to increase the exercise capacity of a child with PWS.

Furthermore, in a small study of 37 patients, Growth Hormone therapy was associated with higher energy intake and fat intake in the early stages of puberty and had a beneficial effect on body composition, in particular fat mass. However, BMI was still above desirable levels and the authors concluded that even the GH treated children with PWS should have maintained a stricter calorie regimen.

The risk of type 2 diabetes?

Research shows that 7-25% of young adults with PWS will develop type 2 diabetes. For these individuals, diabetes is diagnosed, on average, at the age of 20 years. The risk of type 2 diabetes is increased by excess weight and a family history of the condition. Weight loss is the main aim of management, and low glycaemic index foods can also help control blood glucose levels. Sometimes, the diagnosis of diabetes can be a motivating factor for the adolescent or young adult with PWS to lose weight.



Do I need to be aware of any health or safety concerns related to eating?

Once past infancy, children with PWS usually have no physical problems with swallowing or consuming food and often enter a phase of hyperphagia (excessive eating). For many children with PWS, the desire to eat is so strong, that they may consume rotting/contaminated food, inedible, and even toxic, substances.

As children with PWS have a reduced ability to vomit and an impaired ability to feel pain, this places them at particular risk if they do consume these substances. Parents and carers need to be on guard to keep toxic substances out of reach, to prevent children from eating food out of rubbish bins, and to prevent them from consuming inedible substances. Any sign of stomach ache or discomfort needs to be taken very seriously, and parents/carers need to seek urgent medical attention.

Constipation is also common in children with PWS and occurs when your child has a hard, dry bowel motion that is painful to pass. As children with PWS have a greatly reduced ability to feel pain, parents/carers need to be on the lookout for any signs of constipation, as children will rarely report discomfort. Constipation can occur for a range of reasons such as illness, poor toileting habits, a change in diet, or just due to a natural tendency. To prevent constipation:

- include high fibre cereal alternatives in your child's diet (ie wholegrain or wholemeal cereals and breads);
- where possible keep the skin on fruit and vegetables;
- ensure that your child drinks plenty of water; and
- ensure that your child has plenty of exercise and keeps active.

Older Adolescents & Young Adults

Diet management does not change for older adolescents and adults. Success is most likely when routines are established, meals are planned, and the environment is controlled. Involving the person with PWS is a good idea, and having routines and rules will minimise the endless questions about when food will be served, and what food is available, at each meal and snack. Where there is less supervision, weight gain is likely.

Residential care may be an option and will work well if the staff members are knowledgeable about the PWS diet and consistent with management. If not managed well, this is another period where weight can increase drastically.

Is it possible for my child to lose weight?

It is possible for individuals with PWS to lose weight if excessive weight has been gained. It requires a very disciplined approach, using many of the strategies outlined in this book. Weight loss of 20-30 kilograms or more has been seen in adolescents and young adults, with significant health benefits.

Weight loss is often associated with improved behaviour (due to the establishment of routines and rules that are clear), and a sense of pride and achievement for the individual with PWS. Weight loss is unlikely unless all care providers are supportive and working together with the same diet and behaviour management strategies. This cannot be emphasised enough – parents, siblings, grandparents, friends, teachers, and carers need to be informed and working together.



The Food Exchange System

The Food Exchange System may help to guide parents, carers, children and adolescents about appropriate quantities of food. It may also help to improve your child's understanding about food types and quantities of what they can eat. Here's how it works:

- one serve from each food group is one exchange and each exchange is equivalent to 300kJ;
- all foods can be converted to exchanges by assessing the energy content of that food;
- the number of exchanges allowed for each child will depend on their age, weight, height, activity and muscle mass – consult with your dietitian to determine this;
- as your child grows the number of exchanges will increase; and
- the distribution of exchanges across the food groups needs consideration to ensure optimal nutrition.

The System should be used under the regular supervision of a dietitian as children will need to be monitored regularly to review their exchange allowances.

*The Food Exchange System booklet is available for Health Professionals from the Mater Health Services, Brisbane.
Phone: 07 3163 2500 or
Email: pwsclinic@mater.org.au*

CASE STUDY #1

Sarah, Aged 5 Years

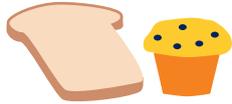
Height: **105cm** (25th centile)

Weight: **20kg** (75th centile)

Estimated Energy Requirement is approx

945kcal, 3970kJ = 13 points / day





Bread/Cereal group:

aim for 4 serves/day

A bread serve is: (1 point or 300kJ)

- 1 slice bread
- ½ bread roll/1 small dinner roll
- 1 crumpet
- ½ cup cooked rice/pasta/noodles
- ½ cup cooked porridge
- 1 cup unsweetened cereal (Cornflakes/
Rice Bubbles/Special K)
- 2 Weetbix/Vita Brits
- ¼ cup untoasted muesli
- 4 Vita-Weat biscuits

Tips

- > Good source of carbohydrate, protein, fibre, B vitamins and iron
- > Choose wholemeal or multigrain varieties for fibre
- > Choose lower fat options (eg 97% fat free)



Fruit group:

aim for 2 serves/day

A fruit serve is:
(1 point or 300kJ)

- 1 medium piece fresh fruit (apple, orange, pear, banana)
- 2 small pieces fresh fruit (apricots, kiwi fruit, plums)
- ¾ cup tinned fruit (juice drained)
- ½ cup (120ml) fruit juice

Tips

- > Good source of carbohydrate, folate, vitamin C and fibre
- > Where possible, leave skin on fruits
- > Minimise fruit juice
- > Avoid excessive dried fruit



Vegetable group:

aim for 2 serves/day

A vegetable serve is:
(1 point or 300kJ)

- 1 medium potato
- 1 cup cooked vegetables
- ½ cup legumes (baked beans)
- 1-2 cups salad/raw vegetables

Tips

- > Good source of carbohydrate, vitamins, minerals and fibre
- > Fresh, frozen or canned vegetables are all suitable
- > Avoid adding sauces to vegetables (eg cheese sauce)
- > Vegetables should occupy the majority of the plate



Dairy group:

aim for 3 serves/day

A size of dairy is:
(1 point or 300kJ)

1 cup skim milk

2 slices extra light cheese

(choose varieties that are less than or equal to 10g fat/100g)

1 small carton (200g) diet yoghurt

½ cup low fat cottage cheese



Meat/Fish group:

aim for 1.5 serves/day

A serve of meat/fish is:
(1 point or 300kJ)

40g meat or chicken

50g fish

1 egg

1/3 cup legumes

2 tablespoons nuts



Fat group:

aim for .5 serves/day

A serve of fat is:
(1 point or 300kJ)

2 teaspoons margarine, butter, oil, mayonnaise

4 teaspoons cream/sour cream

4 teaspoons commercial salad dressing

Tips

- > Good source of protein, calcium, riboflavin and vitamin B12
- > Use reduced fat versions

Tips

- > Good source of protein, iron, niacin and vitamin 12
- > Trim fat off meat before cooking
- > Grill or dry fry meat/fish

Tips

- > Minimise use of saturated fats (butter, cream, ghee, dripping, lard)
- > Use poly and monounsaturated oils and margarines
- > Reduced fat spreads are useful

Example Meal Plan

Look at Sarah's morning tea and lunch allowances. You will note this is not a 'typical' lunch box seen at school, and unfortunately the 'typical' lunch box for children without PWS is often not ideal. For Sarah, there are no packets of chips, biscuits or juice drinks. The meals are 'extended' by giving two serves of small fruit, equivalent to one larger serve of fruit, four biscuits equivalent to one slice of bread, the low calorie stir-fried vegetables and the use of diet jelly. Adding tomato relish adds flavour with minimal energy. Water is encouraged at each meal and snack.

Sarah's growth would be monitored to assess the adequacy of these allowances.

Meal	Food	Points
Breakfast	2 Weetbix plus 1 cup skim milk	1 bread/cereal 1 dairy
Morning Tea	½ Sandwich 1 slice light cheese and tomato relish (no margarine)	1 bread/cereal + ½ dairy
	Cheese stick	½ dairy
	1 Kiwi fruit	½ fruit
Lunch	4 Vita-Weat biscuits with Vegemite	1 bread/cereal
	1 Mandarin	½ fruit
Afternoon Tea	Tub diet yoghurt	1 dairy
Dinner	Chicken (60g)	1½ meat
	Stir fry vegetables	2 vegetable
	½ Teaspoon oil	½ fat
	½ Cup rice	1 bread/cereal
	Diet jelly and tinned peaches	1 fruit

CASE STUDY #2

Tom, Aged 16 Years

Height **154.4cm** (1st centile)

Weight **88.8kg** (97th centile)

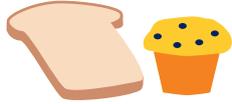
Estimated Energy Requirement is approx

1280kcal, 5376kJ = 18 points / day

Tom's weight has increased 18kg over the past year.

In response, Tom was placed on a weight reduction diet. Tom's weight should be monitored at least monthly with the expectation of a downward weight trend. Ideal weight loss would be approximately 1- 2kg per month.





Bread/Cereal group:

aim for 5 serves/day

A bread serve is: (1 point or 300kJ)

- 1 slice bread
- ½ bread roll/1 small dinner roll
- 1 crumpet
- ½ cup cooked rice/pasta/noodles
- ½ cup cooked porridge
- 1 cup unsweetened cereal (Cornflakes/
Rice Bubbles/Special K)
- 2 Weetbix/Vita Brits
- ¼ cup untoasted muesli
- 4 Vita-Weat biscuits

Tips

- > Good source of carbohydrate, protein, fibre, B vitamins and iron
- > Choose wholemeal or multigrain varieties for fibre
- > Choose lower fat options (eg 97% fat free)



Fruit group:

aim for 3 serves/day

A fruit serve is:
(1 point or 300kJ)

- 1 medium piece fresh fruit (apple, orange, pear, banana)
- 2 small pieces fresh fruit (apricots, kiwi fruit, plums)
- 1 cup tinned fruit (juice drained)
- ½ cup (120ml) fruit juice

Tips

- > Good source of carbohydrate, folate, vitamin C and fibre
- > Where possible, leave skin on fruits
- > Minimise fruit juice
- > Avoid excessive dried fruit



Vegetable group:

aim for 3 serves/day

A vegetable serve is:
(1 point or 300kJ)

- 1 medium potato
- 1 cup cooked vegetables
- ½ cup legumes (baked beans)
- 1-2 cups salad/raw vegetables

Tips

- > Good source of carbohydrate, vitamins, minerals and fibre
- > Fresh, frozen or canned vegetables are all suitable
- > Avoid adding sauces to vegetables (eg cheese sauce)
- > Vegetables should occupy the majority of the plate



Dairy group:

aim for 3 serves/day

A size of dairy is:

(1 point or 300kJ)

- 1 cup skim milk
- 2 slices extra light cheese (super slims, extra light, free singles)
- 1 small carton (200g) diet yoghurt
- ½ cup low fat cottage cheese



Meat/Fish group:

aim for 3 serves/day

A serve of meat/fish is:

(1 point or 300kJ)

- 40g meat or chicken
- 50g fish
- 1 egg
- 1/3 cup legumes
- 2 tablespoons nuts



Fat group:

aim for 1 serve/day

A serve of fat is:

(1 point or 300kJ)

- 2 teaspoons margarine, butter, oil, mayonnaise
- 4 teaspoons cream/sour cream
- 4 teaspoons commercial salad dressing

Tips

- > Good source of protein, calcium, riboflavin and vitamin B12
- > Use reduced fat versions

Tips

- > Good source of protein, iron, niacin and vitamin 12
- > Trim fat off meat before cooking
- > Grill or dry fry meat/fish

Tips

- > Minimise use of saturated fats (butter, cream, ghee, dripping, lard)
- > Use poly and monounsaturated oils and margarines
- > Reduced fat spreads are useful

Example Meal Plan

It is obvious that this is a very restricted diet for a 16 year old boy. Once Tom loses the desired weight, there would be a slight increase in the energy content of the diet to approximately 1540kcal/ 6470kJ, (21 points). Exercise would remain important and he would need to continue on a diet plan in the long term.

Meal	Food	Points
Breakfast	1 Cup cooked oats plus ½ cup skim milk and 1 tablespoon sultanas	2 bread/cereal + ½ dairy + ½ fruit
Morning Tea	Banana	1 fruit
	Rice crackers x 10	1 bread/cereal
Lunch	Sandwich with 20g ham and 20g cheese and salad and chutney no margarine	2 bread/cereal + ½ meat + ½ dairy + ½ vegetable
	Apple	1 fruit
Afternoon Tea	200g diet yoghurt	1 dairy
Dinner	Meat (100g) Potato cooked in 2 tsp oil Pumpkin, green beans Side salad	2 ½ meat 1 fat 1 vegetable 1 vegetable ½ vegetable
	Fruit – strawberries 1 cup 200g diet yoghurt	½ fruit 1 dairy

Conclusion

We hope this guide has assisted you to understand the importance of nutrition and an active lifestyle in managing weight in children with PWS. Children with PWS are at high risk of developing obesity. Therefore it is critical for parents/carers to implement a healthy diet and regular exercise routine in the household.

There are many organisations and specialists in the community who can assist you to develop a diet and exercise plan that is right for your child and your family. Most children's hospitals in capital cities have endocrinology units which specialise in PWS care. Please see your GP or care provider for a referral to a specialist clinic nearest you.

The most important message for a parent of a child with PWS is to remember the energy equations:

Energy In = Energy Out
results in no net weight gain

Energy In > (greater than) Energy Out
results in weight gain

Energy in < (less than) Energy Out
results in weight loss

If you can get the energy balance right, you will be on the way to preventing obesity and ensuring your child can look forward to a healthier future.



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The authors of this information guide are from the Children's Nutrition Research Centre (CNRC), The University of Queensland and the Prader Willi Clinic at the Mater Children's Hospital, Brisbane. The CNRC, The University of Queensland is based at the Royal Children's Hospital in Brisbane. The CNRC undertakes cutting edge scientific research to improve the nutritional health of children and young people and is particularly renowned for its studies in growth and development, body composition and energy metabolism. It is one of Australia's leading paediatric nutrition centres with an international reputation for research achievement.

The Mater Health Services Brisbane provides a multidisciplinary clinic offering a number of specialist and allied health services for children with PWS from birth to 18 years. The clinic provides a supportive environment for families to develop a network of support, learning and friendship while encouraging the children to develop and reach their full potential.



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cnrc@uq.edu.au | www.uq.edu.au/cnrc



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