

The prevention of obesity is one of the most important goals for the family of a child with Prader-Willi syndrome. Obesity prevention is compounded by three major problems. First, the child may very often feel hungry. Second, he or she may have a very good appetite that is not easily or ever satisfied. Third, the child may only need about two-thirds of the calories usually needed for a child to grow and be healthy. The metabolism functions at about 50% of that of a child without PWS. The purpose of food management is to prevent the child from becoming overly fat and reduce the risk of breathing problems, heart disease, hypertension and diabetes that may develop as a result of obesity. The goal is to establish a healthy eating pattern for life. The average life span of a person with PWS used to be age 17, now it is age 27 and rising rapidly with the early diagnosis and careful food management done by conscientious parents. With good food, exercise, and behavior management our children with PWS can expect to have a normal life span.

First, let's start with mealtime behavior management. Bowls of food should not be placed on the dining table "family style" but instead the parent should portion out the food onto the plates, providing a smaller size plate for the child with PWS. Some parents praise the child when he/she has finished eating saying, "Good girl/boy, you are full." Remove the empty plate from the table and encourage the child to play away from the table or kitchen area until all food items have been cleared away.

Meals should be on as strict a schedule as can be maintained with two or three no-calorie/low calorie snacks in the mid-morning, middle afternoon. Some parents provide their child another low calorie snack just before bedtime. This schedule is the beginning of getting the child into a healthy eating habit so that food can be controlled and it becomes a part of his/her daily routine.

Hyperphagia is characterized by an unrelenting drive to eat and/or obtain food. Restricting calories is a life-time chore for the parent, but if done "matter-of-factly" the child can come to accept this as normal.

Rules for the parent are to avoid using food as a reward, use praise, stars, stickers, etc.

Eat meals at a regularly scheduled time. This helps parents monitor intake and reassures the child that food will be available. (Principles of Food Security)

Keep food out of sight and out of reach. Keep under lock and key if necessary.

If other children are in the household, make certain they understand they are not to share their food or eat in front of their sibling.

During mealtime, talk about pleasant things, distract him/her from focusing on food. Use a small plate and cut food into small pieces, spread out over the plate. Encourage the child to chew thoroughly. Be generous with low calorie vegetables.

Remove dishes immediately from the table.

Do not snack or eat in front of the child unless they are eating too.

Expect age appropriate table manners.

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Number of calories for a child with PWS

According to "The Nutrition Book for Children with PWS – Ages 3-9, daily energy needs for the young child with PWS range between 22-28 calories per inch of length or height to maintain weight. If it is necessary for a child to lose weight 20-22 calories per inch of height may be recommended. Milk should be skim only. Protein needs are about ½ to 1 gram of protein per inch of body length daily. This needs to be monitored very closely by a Registered Dietician or your primary doctor. Fat is essential to brain growth and needs to be included carefully into the diet. Fat should make up 150-300 of the day's total calories. Excessively fatty foods, sugar – laden juices, etc should be avoided. Carbohydrates should be between 100 grams and 200 grams a day. Whenever the daily calorie intake is below 1200 calories a day, a multivitamin should be given daily and your physician should be tracking the weight and physical condition carefully.

Conversion to metric: 1 inch = 2.54 Centimeters Therefore, 22-28 calories per 2.54 cm to maintain weight. 20-22 calories per 2.54 cm to lose weight.

If your child is 78.74 cm tall they should be eating about 775-800 calories a day, if s/he is not obese.

There are three nutrition books available for the three major age periods of a child's life:

- "Nutrition for Infants and Toddlers"
- "Nutrition for Ages 3-9"
- "Nutrition for Adolescents and Adults"

There is also a pictorial and text PWS Diet specific book titled, "*Red, Yellow, Green System for Weight Management*" available from Prader-Willi Syndrome Association (USA) at 800-926-4797.