

HELPING WITH DIET MANAGEMENT

Children With Prader-Willi Syndrome at School

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What is Prader-Willi Syndrome (PWS)?

Prader-Willi Syndrome (PWS) is a genetic disorder characterized by hypotonia (low muscle tone) and poor feeding in infancy, incomplete puberty, short stature, behavior problems, and some degree of mental retardation or learning disability. Poor eating and even failure to thrive due to hypotonia in the early months may later become preoccupation with and a powerful drive for food, often resulting in extreme obesity.

Children with PWS are typically sociable, outgoing and good-natured with a desire to please adults. Most have a good sense of humor and a strong sense of empathy. They can also be persistent, perseverative, stubborn and very self-centered. Transition and change can be challenging for them.

A noninherited birth defect, it is estimated to affect 1 in 12,000 to 15,000. PWS is found in both sexes and is not associated with any specific racial/ethnic groups, socioeconomic classes or geographical regions.

What are the Nutrition Concerns?

Most children with PWS are unable to “feel full”. Thus they have a continuous urge to eat, and they will eat as long as food is available. Since their appetite is never satisfied, excessive weight gain can begin in early childhood unless intervention is provided.

Children with PWS have been found to have lower energy (calorie) needs compared to children of similar age, height and sex. Therefore, a lower energy intake is required to maintain appropriate weight for height. To accomplish this, these children need constant and very careful supervision at all times around food. Children with PWS are extremely clever and quick at obtaining food.

Excessive weight gain can lead to medical problems such as diabetes, heart disease and asthma. These conditions tend to appear during adolescence unless weight is controlled by intervention involving all caregivers. If weight gain reaches morbid obesity, it can be life-threatening.

What are the School Issues Related to Nutrition and Eating Behavior?

Most children with PWS must be supervised at all times, food is everywhere today. This includes supervision before, during and after school, during lunch and between classes. Without supervision, the child may be able to take food from others, search through trash cans, pilfer food from a cupboard or refrigerator, or buy it from a vending machine or school

store. Older children may steal money to buy food, get peers to get them food, or accept food their classmates don't want.

Some preschools and most Head Start programs serve food family style (i.e., food is placed on the table and children serve themselves). This can cause a problem for children with PWS because, unsupervised, they can serve themselves large portions of food. They will require help and very careful supervision to see that their servings are appropriate for their energy needs.

Adolescence with more independence brings even greater challenges in managing their access to food, both at home and at school. Providing supervision of food and diet while allowing them opportunities to make good food choices can help set the stage for lifelong success.

Can a Child with PWS Participate in the School Lunch Program?

Yes, all children with special needs are assured a modified school lunch, if needed, according to Section 504 of the Rehabilitation Act of 1973 and the current Individuals with Disabilities Education Act (IDEA). A written prescription for the child's modification can be obtained from a medical provider. The diet prescription should include the child's medical condition, why it restricts his or her diet, and appropriate substitutions (e.g., changing texture, omitting foods, altering energy intake).

Receiving modified school meals that are reduced in energy is very appropriate for children with PWS. If local schools or districts are not familiar with modified school meals, parents and educators should contact the state USDA Child Nutrition Program (National School Lunch and Breakfast Programs) in their state education agency. Some states have developed forms for modified meals that can be given to the medical provider.

Children with PWS have an energy requirement of approximately 8-9 kilocalories per centimeter (kcal/cm) of height for weight loss, and 10-11 kcal/cm for weight maintenance. This is approximately 20-30% less than their same age and sex peers. Although the ranges of appropriate intake vary, the majority of them will have a specific energy amount that they are to be served at each meal. For example, a child may need a 200 calorie breakfast, 300 calorie lunch, and one 100 calorie snack during the school day. There are

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many ways to reduce the energy level in the school lunch and still provide similar foods. See accompanying chart for specific examples.

CALORIES IN COMMONLY SERVED FOODS*

FOOD	CAL.	SUBSTITUTE	CAL.	CAL. SAVED
8 oz. Whole Milk	150	Nonfat Milk	90	60
Fried Chicken (4 Chicken Nuggets or 1/2 Breast)	200	Baked Chicken (1/2 Breast w/o skin)	150	50
Vanilla Ice Cream (1/2 cup)	150	Vanilla Frozen Yogurt or Low Fat Ice Cream (1/2 cup)	100	50
1 serving Apple Cobbler	300	Unsweetened Applesauce (1/2 cup)	55	245
20 French Fries or Tater Tots	235	Baked Potato (1/2 large)	105	130
Taco w/ Cheese	370	Taco w/o Cheese	270	100
Large Peanut Butter Cookie	150	10 Animal Crackers	115	35
Banana Bread (1 slice)	200	1 Banana	100	100
Ranch Dressing (1 Tbsp.)	95	Low Calorie Ranch Dressing (1 Tbsp.)	40	55

* Calories from Food Values, Bowes and Church, 1994

How Can an Individualized Education Plan (IEP) Help Children with Prader-Willi Syndrome Meet Their Nutrition Goals?

An IEP is a written plan that describes the educational goals and objectives for a student, program modifications and/or adaptations, and services that will be provided. The parents, by law, are members of the team that forms this plan. For children from birth to 3, this plan is called the Individual Family Service Plan (IFSP).

Following are examples of nutrition objectives that can be included in an IEP or IFSP of a child with PWS:

- Sarah's mother will provide all regular snacks for her daughter. For special occasions (i.e., holidays and birthday parties), Sarah can have 1/2 portion of a single treat, and this will be reported to the family.
- Food is not to be used as reinforcement for LaMar. LaMar's teacher will record his food intake at breakfast and lunch in the daily journal, which is sent home.
- Since Head Start meals are served family style, the teacher will help serve Rachel's food. Parents will review the monthly menu ahead of time and will mark appropriate foods or portions (i.e., 1/2 portion of spaghetti, nonfat milk instead of 2%).
- The school nurse will weigh Ashley monthly, record it on the appropriate growth chart, and report to family.
- Michael will be supervised at all times, before and after school, in the classroom, at lunch and between classes.
- Adam will receive a modified school lunch of 350 calories, according to his diet prescription, in the high school cafeteria.
- Armando's vocational training at school or in the community will not include food service or situations where there is food handling or access.
- Joshua will participate in adaptive PE three times a week.

Summary

Children with PWS must be supervised at all times; they can be clever and quick in obtaining food!

Food should not be used as reinforcement in the classroom.

Parents and school staff need to work together to meet the nutritional needs of the child.

Nutritional needs and diet management can be incorporated in an IEP or IFSP.

Children with PWS can participate in the school lunch program and receive lower energy (calorie) meals.