Nutritional Guidelines:

Infants through Toddlers with Prader-Willi Syndrome

By
Melanie R. Silverman, MS, RD, IBCLC
Roxann Diez Gross, PhD, CCC-SLP

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

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NUTRITIONAL GUIDELINES: INFANTS THROUGH TODDLERS WITH PRADER-WILLI SYNDROME

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This information does not replace the advice from your pediatrician and other health professionals involved in your child's care. Please contact your local health care professionals for individual help for your child.

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Introduction

Feeding any newborn child is not an instinctive or simple experience. Babies born with Prader-Willi syndrome (PWS) have especially unique needs, and each child has their own set of abilities and challenges. Be patient with your baby and the slower pace of development that is common in this first year. It does get better.

In infancy, you will focus on making sure your baby is getting enough calories to grow and develop. It may take extra effort and timed feedings, or even tube feedings for a while. You will work closely with your feeding team. Parents will have to feed a baby who often does not act hungry. Well-meaning people may not always understand or approve. It is the beginning of your role in educating others about PWS.

After this year of coaxing your baby to eat, feeding your child will change significantly. Your child will enjoy eating and not need coaxing. Your role will be providing healthy, well-balanced meals, on a schedule. You will not be feeding your toddler as many parents do – when the toddler asks for food. By providing a predictable pattern and a planned diet, you will be supporting good behavior along with controlled weight gain.

PWSA | USA is here to help support and educate you. We hope you enjoy this booklet of general guidelines, working with your home team to make it fit your child. We are grateful to the authors for their time and dedication to children with Prader-Willi syndrome.

Sincerely,

Kathy Clark, RN, MSN, CS-BC
Coordinator of Medical Affairs for PWSA | USA

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Experts

Nutrition is important in children with PWS and you will read and hear advice from everyone on what and how you should feed your child. The information can be overwhelming and confusing. There are medical professionals, in addition to your pediatrician and endocrinologist, who can help you with your child:

• **Registered Dietitian (RD):** A dietitian, sometimes referred to as nutritionist, can evaluate your baby's growth and nutritional needs using growth charts and other measures. Dietitians also can advise what types of formulas and foods to introduce as your baby grows and can provide guidance on preventing obesity in later life.

• **International Board Certified Lactation Consultant (IBCLC):** A lactation consultant is an expert in breastfeeding and can offer techniques to enhance your breastfeeding experience. Some babies are too weak to nurse at birth, but a lactation consultant is skilled at helping moms maintain and/or increase milk supply. IBCLCs can also help teach you how to pump for your baby, if that is what you choose to do.

• **Speech and Language Pathologist (SLP) or Occupational Therapist (OTR):** Speech Pathologists are trained to evaluate swallowing function, including the esophageal phase, and to identify safe feeding methods. Occupational Therapists specialize in activities of daily living, which can include feeding. Depending on where you live, an SLT or OTR may be assigned to your child. These therapists can help with positioning your baby to feed, provide strategies for safe, efficient swallowing, and recommend special bottles or nipples to optimize feeding. Throughout this booklet, we will refer to these experts as feeding therapists.

• **Physical Therapist (PT):** A Physical Therapist specializes in gross motor skill development, which includes muscles that help children roll over, sit, crawl and walk. Because your child has low muscle tone, a Physical Therapist can be helpful to support physical development.

Contact your insurance company for detailed information about your policy for all the professionals that may be involved in your child's care. Most insurance policies require a written referral from your primary physician prior to starting any therapy. Your state may also have other financial programs available for your child such as Medicaid or a program called Children's Special Health Care Services. These programs have specific criteria for enrollment. Your child's therapist and dietitian may be familiar with the various insurance companies and availability of help in your area. Ask your doctor, therapist and/or dietitian to assist you with a phone call or letter, if necessary.

Your Newborn: Birth to four months

All babies with PWS have low muscle tone and that can affect how your baby eats, but not all babies with PWS have feeding problems. Talk with your doctors, dietitian and feeding therapist for evaluation and support if issues arise.

Growth

How do I know if my baby is gaining enough weight?
Babies will lose weight after they are born, sometimes as much as 7-10%. This is common, but it's important the baby gains the weight back by about two weeks of life. Weight gain is about 5-7 ounces per week for the first 6 months. The most important way to know if your baby is growing is to have him/her weighed on a scale and plotted on a growth chart in the pediatrician's office.

How often should I take my baby to the doctor to check growth?
Weight and length need to be monitored closely every 2-4 weeks for babies this age.

Should my baby's doctor use standard growth charts or are there special growth charts for children with PWS?
We have included charts (pages 28-29) for birth to age three years which show the growth patterns of children who have not been treated with growth hormone. Growth charts were published in 2016 which are specific to children with Prader-Willi syndrome from birth to age 18 years who are being treated with growth hormone (GH). {These are available on the PWSA | USA Web site under Medical – Medical Issues A-Z – Growth Charts}

These special charts can be very helpful for your health care providers, and we recommend you bring a printed copy to your next visit. The important role of the growth chart is marking the speed of changes over time, for both weight and length. Children do not grow smoothly, so one point in time is not as important as a pattern. Your doctor or nurse and dietitian can help you understand this in more depth. Children with PWS have low muscle tone and should be measured lying down until age three years, even if they can stand easily. Standard infant growth charts use length, not standing height, until that time. Babies born early need adjustments on a growth chart to account for this, which will be taken into account in assessing growth. Keeping your own copy of a growth chart can be very helpful to all the health care providers your child will see in these first years.

FEEDING

How do I know if my baby has feeding challenges?
Your feeding therapist can provide a swallowing diagnosis and help your baby to eat safely. There may be a feeding issue if your baby presents with these problems:

- Gains no weight or gains weight very slowly
- Closes mouth and turns away during feeding
- Eats very slowly (taking 30-45 minutes or more to finish a feeding)
- Has swallowing difficulty indicated by struggle coordinating the suck-swallow-breathe pattern, and/or frequent coughing, or choking
- Does not wake for feedings, or falls asleep early during the feedings
- Tires easily during feedings
- Is happy at the beginning of the feeding and then may become fussy or distressed before finishing the feeding
- Has larger amounts of milk or formula leaking from the mouth while feeding

Can I breastfeed my baby?
You are encouraged to breastfeed your baby because nursing can increase oral strength, but if he or she cannot, there are ways to help your baby take advantage of the benefits breast milk offers. The first thing to do is locate an IBCLC (International Board Certified Lactation Consultant). An IBCLC may be available through your local hospital, pediatrician office or public health clinic. You can also find a lactation consultant at this website: http://www.ilca.org/why-ibclc/falc or you can call 1-888-452-2478.

IBCLCs can help you nurse and/or teach you how to pump your breast milk and give your baby a bottle. An IBCLC can also help you locate a breast pump to pump your milk. A feeding therapist may be called upon for help too. Your baby may need a special nipple attached to a bottle to help him/her feed.

What is a supplemental nursing system?
This is a small bottle filled with breast milk or formula that is connected to a small tube. The end of that tube is placed at mom's breast. As your baby nurses, he/she receives milk from the breast and from the supplemental nursing system. You can purchase the system online at www.amazon.com or Target.

What if I don't have enough breast milk to feed my baby?
There are a variety of excellent formulas that can be used to give your baby the nutrition he/she needs. A registered dietitian can help with the choice.

Which formula is best for my baby?
All feedings must be individualized. Standard infant formula is 20 calories per ounce, but your doctor or dietitian may recommend 24 or 26 calories per ounce to help with weight gain. It's important to follow the mixing directions you are given. If your baby has problems tolerating the formula, speak to your pediatrician or registered dietitian for advice.

Does my baby need vitamins and mineral supplements?
Newborns usually don't need vitamin or mineral supplements. Breast milk or formula usually provides enough vitamins and minerals. Pediatricians or dietitians may recommend Vitamin D in certain areas of the country and sometimes iron or fluoride. Speak to your pediatrician about supplements before you start any of them.

What do I do if the baby is not gaining enough weight?
All of your baby's diet formula changes should be made under the supervision of your pediatrician or dietitian. Formulas come ready-tofeed, powder form or liquid concentrate. There are specific mixing instructions on the cans of formulas that should be followed closely. If you are giving breast milk, you can add a certain amount of formula to the breast milk to increase the calories.

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If you are giving formula, mixing instructions can be altered to increase calories. Adding cereal or other foods to your baby's formula or breast milk is not advised.

How much does my baby need to drink?
Babies with PWS often do not let you know when and how much they need to be fed so it's important to watch closely. On average, young babies need to be fed about 1½ to 3 ounces every 2-3 hours, but this can vary. This amount will increase as your baby grows. Some babies need more or less depending on their pattern of growth.

Should I wake my baby for feedings if he/she is very sleepy?
Usually, babies want to eat every 2-4 hours. Because babies with PWS are sleepy, you may need to wake your baby for feeding. Breast fed infants tend to eat more often than formula fed infants. Sticking to a schedule early on may be a good idea.

When can I let my baby sleep through the night?
Babies with PWS are very sleepy, but many are at risk for low blood sugar levels. Talk to your endocrinologist about feeding schedules and how often the baby should eat to make sure blood sugars 9 remain stable. During this period, babies usually eat every 2-3 hours, but should probably not go longer than about 4-5 hours.

How do I keep my baby awake long enough to finish a feeding?
A feeding therapist can help, but here are a few tips:

- Talk to your baby while feeding.
- Changing the baby's position during feeding, including breaks for burping.
- Diaper change just before feeding.
- Make sure baby is not bundled up and too warm. The coziness may make him/her fall asleep.
- Gently wipe baby's face with a wet cloth.
- Use cooler formula.
- Feed in an active, stimulating environment.
- Turn the lights on for nighttime feedings.
- You will learn over time what works best. Watch your baby closely and never force feed. Force-feeding can cause your baby to dislike feeding and develop an aversion.

Why can't my baby suck?
Low muscle tone and weakness includes the muscles used for swallowing. The tongue muscles "drive" sucking, and the lip muscles "seal" the mouth to the nipple. Breathing muscles and muscles in the throat and voice box are also important for swallowing, and they may need time and practice to strengthen and coordinate together.

How can I help improve my baby's ability to suck?

- The best thing for sucking and swallowing is practice. A feeding therapist will help you to find the best method to safely feed. Examples of available options include different bottle types and nipples, and/or evaluating different Nipples have a wider base that is more like the breast and can help positions, such as holding the baby more upright, side lying, or feeding in a bouncer chair.
- Oral motor stimulation such as providing pacifiers or toys can give "non-nutritive" sucking opportunities outside of feedings.

Nipples have a wider base that is more like the breast and can help to compensate for weak lip closure.

Here are examples of sip cups that can have a valve in place (for those who can coordinate the suck / swallow). The valve can be removed for those who don't have the coordination, strength or skill.

A specialty flow valve at the base of the nipple can help with poor lip seal and reduced suck (the valve does the work for the baby).

What is gastroesophageal reflux and is it harmful?

Babies with PWS have very low muscle tone throughout their bodies. They will sometimes experience problems with gastroesophageal reflux (GER) or the esophagus may be slow to transport food and liquid to the stomach. GER is the return of stomach contents back into the esophagus. It is usually caused by a weakness or relaxation in the muscles at the lower end of the esophagus, called the lower esophageal sphincter. GER or an esophageal phase swallowing problem should be addressed if it causes:

- slow or no weight gain.
- choking and/or coughing along with difficulty breathing.
- frequent upper respiratory tract infections or pneumonia.
- irritation of the esophagus; infants who experience pain ordiscomfort from GER or esophageal transport difficulty may limit their food intake or refuse to eat.

What can be done to treat GER or slow esophageal transport if it becomes a problem for my baby?

This is a situation that should be discussed with your pediatrician. There are medications available to help with GER. Offering smaller feedings may help as well. Taking breaks during feedings to suck on a pacifier may give time for the esophagus to clear as the baby swallows saliva.

TUBE FEEDING

How do I know if my baby needs to be temporarily fed by a tube?
Your baby's pediatrician, dietitian, and feeding therapist can help you decide, but there are some signs a tube may help your baby. If your baby…

- cannot take enough breast milk or formula to grow along his/her own growth curve.
- has swallowing difficulties that severely limit the amount that the baby can safely take.
- spends more than 30 minutes at most feedings during the day and almost always needs to be woken for feedings.

While it may be sad or frustrating to think of a feeding tube for your baby, the tubes can be extremely helpful and, over time, help parents feel much less stressed about feeding and meeting caloric goals. Also, there are ways tube feedings can be used to keep your baby taking some nutrition by mouth.

- • Your baby can breast or bottle-feed as much as he/she is able to and then the rest of the feeding can be given by tube.
- • Your baby may be able to feed during the day and need tube feedings only overnight from a small electric pump.

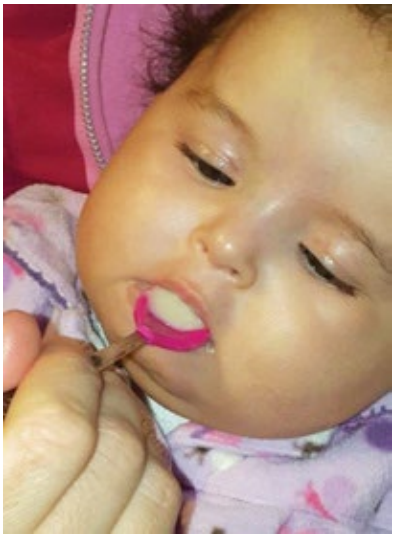
What is the difference between an NG and G-Tube?

- NG (nasogastric) tube: An NG tube is inserted through the nose to the stomach. The tube isn't in the mouth so it doesn't get in the way when a baby tries to suck. This type of tube doesn't require surgery. A doctor or nurse can teach you how to correctly insert the tube and teach you how to keep the tube clean.
- G-Tube (gastric tube): Gastric tubes require surgery for placement, but the advantage is they are hidden. These tubes may be recommended if tube feeding is needed longer than 2-3 months, but it varies child to child. If the tube is accidentally removed, reinsertion will have to be taken care of by a doctor.

How long will my baby need a feeding tube?
Your doctor, feeding therapist, and dietitian need to determine this answer. Feeding tubes provide a way to nourish your baby when he/she cannot eat enough from breastfeeding or bottle to grow and thrive. Usually, with close medical and nutritional attention, tube feedings are decreased as bottle or breast feedings are increased. During this time you will likely be required to bring your baby in for frequent weight checks to make sure the baby is gaining good weight as tube feedings are slowly discontinued. It's a gradual process that takes time. Feeding therapy can continue after the tube is out.

Should I try to breastfeed or bottle-feed my baby if he/she needs a G-tube?
Yes, it depends on your child's strength and safety in swallowing. Talk to your doctor or feeding therapist for advice.

Your Older Infant: Four to twelve months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During this period of growth, your child will likely become physically stronger. Table foods will be introduced. Even though your child is still very young, habits formed are important.

GROWTH

How do I know if my older baby is growing normally?
Growth charts at the pediatrician's office are the best way to monitor your child's growth. Weight and length need to be monitored closely, every 2-4 weeks, for infants this age. Your doctor and dietitian should evaluate weight, length and head circumference frequently. Here are estimates of growth at various ages.

- Birth to 6 months: Weight gain is about 5-7 ounces (~140-200 grams) per week and ½" to 1 inch (1.5-2.5cm) per month.
- 6 to 12 months: Weight gain is about 3-5 ounces per week (~85-140 grams) and about 3/8" (1 cm) per month.

FEEDING

When should I introduce foods?
Your baby's readiness to accept solid foods depends on his/her ability to hold his/her head upright and steady without support. Your pediatrician will tell you when your child is ready to take solid foods safely.

What foods do I start with first?
For years, enriched rice cereal was the starting point in solid food introduction. This is not the case anymore. For example, you can start with pureed meats or vegetables.

How should I introduce solid foods?
It's a good idea to introduce one single-ingredient food at a time and wait 3 to 5 days before introducing another new food. The reason is to make sure your baby isn't allergic to the food. Also, when starting solids, your baby will be experiencing new flavors, textures and temperatures. Starting solids is easier for your baby if changes are made gradually. Make sure the baby is sitting up and is opening his/her mouth when the spoon comes at him/her. If he/she turns his/her head, do not force feed. You can always

talk to a feeding therapist if your child is not progressing during this phase.

What is the food consistency and texture supposed to look like?
This is a general guideline, but talk to your feeding therapist for help.

- Smooth pureed such as baby sweet potato: 4-6 months
- Thick pureed like pudding, or with mixed textures (small lumps) such as cottage cheese: 6-8 months
- Soft mashed table foods such as a baked potato: 7-9 months
- Soft, bite-sized table foods like cheese or cooked green beans: 9-12 months

How much does my older infant need to eat?
This is a great question, but a difficult one to answer. All babies are different. Below is a starting point; your baby may eat more or less. Offer these amounts and see how he/she does, but never force feed.

Food/Drink	4-6 months	6-8 months	8-12 months
Grains	**3-5 tbsp**	**3-5 tbsp**	**5-8 tbsp**
Vegetable	**1-2 tbsp**	**2-3 tbsp**	**2-4 tbsp**
Fruit	**1-2 tbsp**	**2-3 tbsp**	**2-4 tbsp**
Meat/Protein	**1-2 tbsp**	**1-3 tbsp**	**2-3 tbsp**
Milk	**28-32 ounces**	**26-32 ounces**	**24-32 ounces**

**tbsp = tablespoon*

What foods should I avoid giving my baby at this age?
Honey: It can cause botulism, a serious illness, if introduced before one year.
Cow's Milk: Stick with breast milk and formula; both are rich in iron, unlike cow's milk.
Choking hazards: large hard pieces of fruits, vegetables, meat or cheese, nuts, popcorn, raisins, gum, candy, hot dogs.

Should I give my baby juice?
No, it's not a good idea and nutritionally not helpful. Juice is full of sugar and there is no reason nutritionally that juice should be given at this age or as your baby grows into toddlerhood.

When should I change from breast milk or formula to milk?
Breast milk or formula is recommended throughout the first year of life. Once a child turns a year old, you can slowly switch the child to whole milk.

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When is the best time to introduce a cup?
It depends upon the skill of the child. If able to sit up, lift and hold the cup, some babies can begin to work on drinking from a cup around 7-12 months, but the introduction varies greatly. When your baby is first learning to use a cup, you may notice that he/she loses a good deal of liquid. This is normal as he/she learns to handle the amount of fluid in the mouth. There are many different types of age appropriate cups as shown.

Does my older baby need vitamin and mineral supplements?
Not all babies need vitamin and mineral supplements and this should be discussed with your dietitian or doctor. If your child is eating foods from all the food groups, there is no reason a multivitamin or mineral supplement is needed. It's a good question that can be asked again as your child grows and develops.

If my baby is underweight, should I force feed him/her to gain weight?
It's never a good idea to force feed your child, at any age, to help with weight gain. There are other, more gentle methods that a dietitian can provide. Supplements of powdered formula can be added to breast milk or formulas and made at higher concentrations to provide more nutrition for your baby. Food can be made higher in calories with oils and other additions. A dietitian can help maximize your baby's intake if weight gain is an issue.

What if my baby continues to refuse solid foods?
Decreased muscle tone, strength and control may affect your baby's ability to eat foods from a spoon. During the first year of life, breast milk or formula provides most of the nutrition that your baby needs. Solid foods can be placed gradually and increased based on your baby's development. Your feeding therapist can continuously assess, treat, and monitor your baby's progress and customize a plan.

If my baby is tube fed, how do I know when he/she is ready to wean from the feeding?
Weaning is a gradual process. The first step is the amount given by tube is decreased to hopefully cause an increase in appetite. If your baby responds by taking in more by mouth, tube feedings are decreased again. It's important to have your doctor and dietitian closely monitor your baby's weight during this transition.

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Alejandro

Your Toddler: One to three years

Feeding skills gradually improve throughout the toddler years so that feeding tubes are usually no longer needed. Table foods and cups replace baby foods and bottles.

The toddler years are important in establishing good dietary habits. How you handle food in your home and in social situations sets a pattern for behavior for the later years. Weight control is possible in PWS, but it requires careful attention to diet, the food environment, behavior and exercise.

Some children with PWS may start to become preoccupied with food during their toddler years. Meal planning, setting meal and snack times and expectations about behavior are crucial to develop positive lifelong habits around food.

Growth

How do I know if my toddler is growing normally?
During the second year of life, growth slows. Children between the ages of 1 and 3

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usually gain about 4-5 pounds per year and grow about 3-5 inches per year. The growth charts remain important to monitor. Weight and growth checks should be done every 1-2 months at this age and diet intake adjusted based on what is happening with weight-forlength for your baby on the growth charts.

When should I be concerned about my child's weight?
The growth chart gives you insight into how your child is growing. If your child is not gaining weight or growing slowly, he/she may need more calories. If your child is gaining excessive weight and crossing percentiles (from the 25th to the 50th or 75th in a very short amount of time), it may be important to adjust calorie intake.

Feeding

What is a healthy diet?
Fresh food is best and it's also important to offer a variety of foods too. Shopping the perimeter of the grocery store and visiting farmer's markets remains the best way to find fresh food. For farmer's markets near you visit:

www.ams.usda.gov/local-food-directories/farmersmarkets

What about food that comes in packages?
It's a good idea to learn how to read a food label to determine what is on the healthier side. Take a look at these two websites for help:

http://www.fda.gov/Food/IngredientsPackagingLabeling/LabelingNutrition/ucm274593.htm

http://www.eatright.org/resource/food/nutrition/nutrition-facts-and-food-labels/the-basics-of-the-nutrition-facts-panel

You also have to look at the ingredient lists. A good rule of thumb is that if you cannot recognize the ingredients on the lists, the food is probably not very healthy for you or your family. A dietitian can offer further help and answer more questions.

Landen

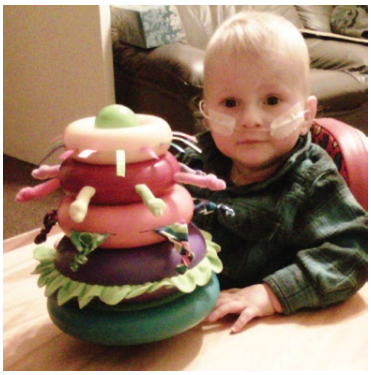
What are Carbohydrates, Protein and Fat?
Carbohydrates, protein and fat are the nutrients that give food their calories. Each has a different role in the body.

- Carbohydrates: provide energy and disease protection
- Protein: support growth and muscles
- Fat: provide energy and support vitamin metabolism

What are examples of Carbohydrates, Proteins and Fat?

- Carbohydrates: fruits, vegetables, brown rice, whole wheat pasta, whole wheat bread
- Protein: meat, fish, chicken, turkey, pork
- Fat: oils, butter

There are also foods that contain a combination of carbohydrates, protein and fat like milk and beans, which has all three. Eggs have protein and fat. Reading food labels will help you understand the makeup of foods.



Jason

I heard carbohydrates are bad for my child. Is that true?

Carbohydrates provide energy for growth and development and are rich sources of vitamins and minerals. That said, there are "good" carbohydrates and "bad" carbohydrates. When you serve your child carbohydrates, choose from the "good" suggestions. **"Good carbohydrates":** vegetables, fruits, whole grains bread/ crackers (>3 grams of fiber per serving), beans, peas, lentils, brown rice and quinoa. **"Bad carbohydrates":** candy, cakes, cookies, juices, muffins, white flour, white rice, white pasta, donuts, crackers.

Should I feed my baby a low fat diet to prevent future weight gain?

Fat is a very important part of a healthy diet for growth and development. Fat should not be avoided. Foods that contain fat are oils, avocado, nuts, cheese, eggs, fish and ground flaxseed. All should be part o a healthy diet.

What is the best way to offer healthy meals for my child?

At each meal and snack it's best to offer a source of carbohydrate, protein and fat. For example, egg, cheese and fruit would be a complete meal. Offering toast and cereal would not.

How much does my toddler need to eat every day?

Below is a starting point; your toddler may eat more or less. It's important to monitor overall growth and development and not worry i eating varies day to day. Offering a wide variety of fresh food is the most important goal for optimal nutrition.

Food Group	Amount	Serving/Equivalents/Notes
Milk	**2 cups (16 ounces)**	**1 ½ ounces cheese or 1 cup yogurt = 1 cup**
Meat	**2-4 ounches**	**¼ cup cooked beans = 1 ounce**
Fruit	**1 to 1 ½ cups**	**Soft and cut into small pieces-fresh or frozen is best**
Vegetables	**1 to 1 ½ cups**	**Soft and cut into small pieces-fresh or frozen is best**

Grains	**3-5 ounces**	**½ cup cooked oatmeal, ½ cup brown rice, 1 cup cereal (>3 grams of fiber per serving), 1 slice whole grain bread = 1 ounce**

Should I count calories for my child at this age?
Calorie counting can be cumbersome. Most toddlers need about 1000 calories per day, but this can vary widely. If your child starts to gain too much weight, a dietitian can look at your child's diet. Your dietitian should be able to review a food record you keep and reduce food that may be contributing to weight gain while making sure all nutrients are still met.

Can I have examples of breakfasts, lunches and dinners for my toddler?
Below are a few examples of healthy meals and snacks. Pay close attention to how well your child chews and swallows. For some toddlers, these foods need to be pureed and others will be able to chew the food.

Breakfast	Lunches	Dinners	Snacks
Scrambled Eggs Berries Milk	**Tuna Salad Fruit Vegetables**	**Chicken Broccoli Corn**	**Cheese Wheat Crackers**
Cottage Cheese Wheat Toast Apples	**Turkey Carrots Corn**	**Fish Mushrooms Asparagus**	**Sliced avocado Fruit Milk**
Oatmeal Ground Nuts Milk	**Lentil Soup Fruit**	**Beans Brown Rice Milk**	**Full Fat Yogurt Fruit**

What kind of milk should I give my child?
Once your child turns one year old, with permission from your pediatrician, you can gradually change to whole milk. You can speak to your dietitian about other options if you have questions.

I am worried about my baby's hydration. What can I do if he/she doesn't drink water?
There are ways to flavor water that may help. Soaking water with lemons/limes, apples/cinnamon sticks or oranges can help the water taste more interesting. In addition, drinking throughout meals and at the end of each meal should be taught because it can help to clear the esophagus.

My child is beginning to become preoccupied with food. What can I do?
One of the hardest tasks of parenting a child with PWS is controlling food intake. When our children tell us they are hungry, parents want to give them something to eat. To prevent obesity and the serious health problems that come along with it, parents need to ignore some natural parenting instincts. This is difficult. Meal planning and setting meal and snack times is crucial so your child knows what to expect when it comes to food.

Will my child try to eat nonfood items?

All toddlers are very curious and sometimes their curiosity leads them to taste non-food items. Toddlers with PWS may try to eat non-food items, just like any other curious child. You need to watch your child closely to make sure he/she is kept safe.

Sydney

How can I avoid my child overeating?

- Avoid using food as a reward for good behavior. Use praise, stickers, hugs, reading a book or special time together so as to avoid excess calories.
- Eat meals and snacks at scheduled times. A regular routine helps you monitor food intake and helps reassure your child that food is regularly available.
- Keep food out of sight and out of reach. If you have a kitchen door, you may find it helpful to keep the door closed and/or locked when the kitchen is not in use. A lock on refrigerators or cabinets may be necessary too.
- During mealtimes, supervise your child, especially when other children are present. Other children may offer your child food.
- Do not eat a snack in front of your child when they cannot eat.
- Remove dishes from the table immediately to prevent your child from eating extra portions or eating from other's plates.
- During meals, engage in pleasant conversations.
- Use smaller plates and cut food into smaller pieces to make it appear as if there is more.
- Encourage your child to eat slowly and help pace him/her to chew food thoroughly.
- Do not eat in front of the television or other technology.
- Post rules about behavior you expect at meals and explain to children they must abide by these rules.

Should I feed my baby in front of the television or tablet to distract him/her to eat?

The habits you form now will be important for a lifetime. What you feed your child is just as important as how you feed your child, and all family members need to follow the same rules. All meals and snacks should be eaten at a table, without technology, so your child can concentrate on the food that you provide for him or her. Televisions and tablets are distracting and don't allow anyone to tune in to their eating.

Jason1

What is Food Security?

Food Security means that your child can depend upon you to provide good nutrition with a plan for each meal, and no surprises such as extra snacks or substitutions for promised food. Reliability is the key here. Children are not expected to have to ask for food because it will be supplied as promised. It does not mean that children WON'T ask for more food or extra food – instead, a parent will always be in charge and prepared ahead of time for every snack and meal. Instead of feeding a child with PWS when they request food – which will lead to obesity and behavior problems – parents must be very organized to provide food security.

It's important to understand this concept early as your child grows and develops. These guidelines are essential to establish good food behaviors; it isn't just about controlling calories. Allowing children to be in charge of food will lead to significant challenges as they grow up.

The principles of food security are:

1. **No doubt** when meals will occur and what foods will be served – spontaneous changes are hard on children with PWS. Knowing what will be served makes them feel secure.
2. **No hope** of getting anything different from what is planned – no plate of tempting cookies on the counter, no buffet lines, no self-serving of portions.
3. **No disappointment** related to false expectations – if you promise ice cream, you must provide it.

What kinds of exercise should my child do during the toddler years?

Regular exercise is crucial and should not be underestimated, even in the early years. Once your child is mobile, avoid carrying them when possible. Move toys out of their reach to encourage movement. Avoid screen time as entertainment. Exercise helps control weight gain and improve muscle strength, but most importantly, it is essential for your child to learn, and for continued brain development. Involve your child in family games. Exercise should be fun and centered on play. PWSA | USA offers an extensive booklet "Therapeutic Interventions for the child with PWS" by Janice Agarwal, PT, CNDT which can guide parents and professionals with specific interventions.

Websites for reference and further reading

www.wholesomebabyfood.com | www.ellynsatterinstitute.org

www.kidshealth.org | www.mayoclinic.org | www.hopkinsmedicine.org

Acknowledgements

Melanie R. Silverman, MS, RD, IBCLC, is a registered dietitian and board certi ied lactation consultant. She received her Bachelor of Arts in Chemistry and Spanish from Indiana University and her Master of Science degree from Rush University, where she also completed her dietetic internship. She spent seven years in pediatric intensive care and outpatient clinics at the University of Chicago and has been in private practice since 2003 counseling families with picky eaters, food allergies, failure to thrive, tube feedings and obesity. She began her work with Prader-Willi syndrome in 2004. She is a speaker at national and international meetings. (www.melaniesilverman.com)

Roxann Diez Gross, PhD, CCC-SLP, has been an active researcher and a practicing speech-language pathologist for most of her career, and is frequently invited to lecture nationally and internationally on dysphagia (difficulty swallowing). Dr. Gross has published several scienti ic papers in peer-reviewed medical journals and has authored multiple clinical book chapters. Her primary area of research examines interactions between breathing and swallowing in individuals of all ages with neurological impairments and respiratory disease. She has the privilege of working with feeding expert, **Marybeth Trapani-Hanasewych, MS, CCC-SLP, and Patsy McMelleon, MA-CCC-SLP,** who provided advice and input into this booklet. Dr. Gross and other colleagues at The Children's Institute of Pittsburgh completed a PWSA | USA funded research study that characterized swallowing function in children and adults with PWS.

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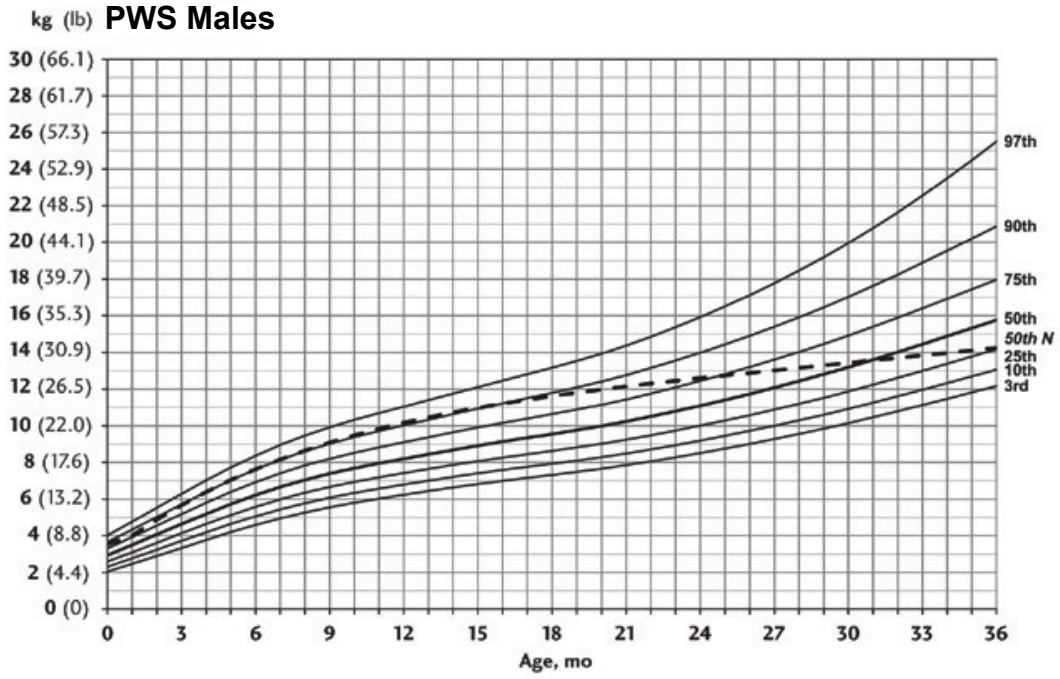
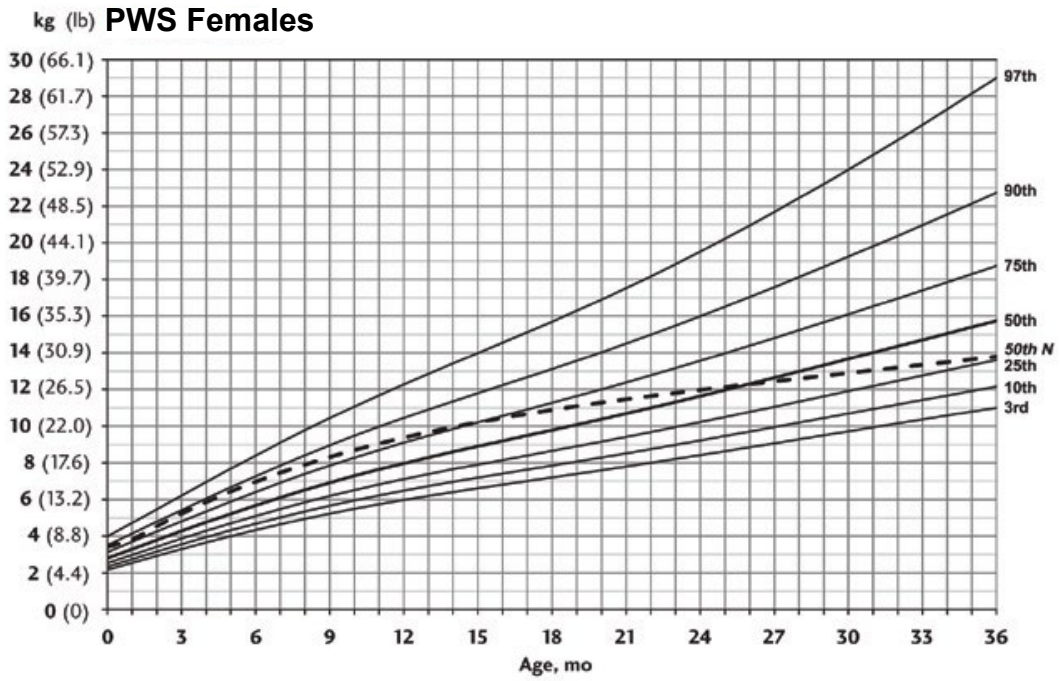
Weight of Infants with PWS
Compared with Normal Weight for Age





Standardized curves for weight of male (upper) and female (lower) infants with PWS (solid lines) and normative 50th percentile (broken line).

Weight of Infants with PWS
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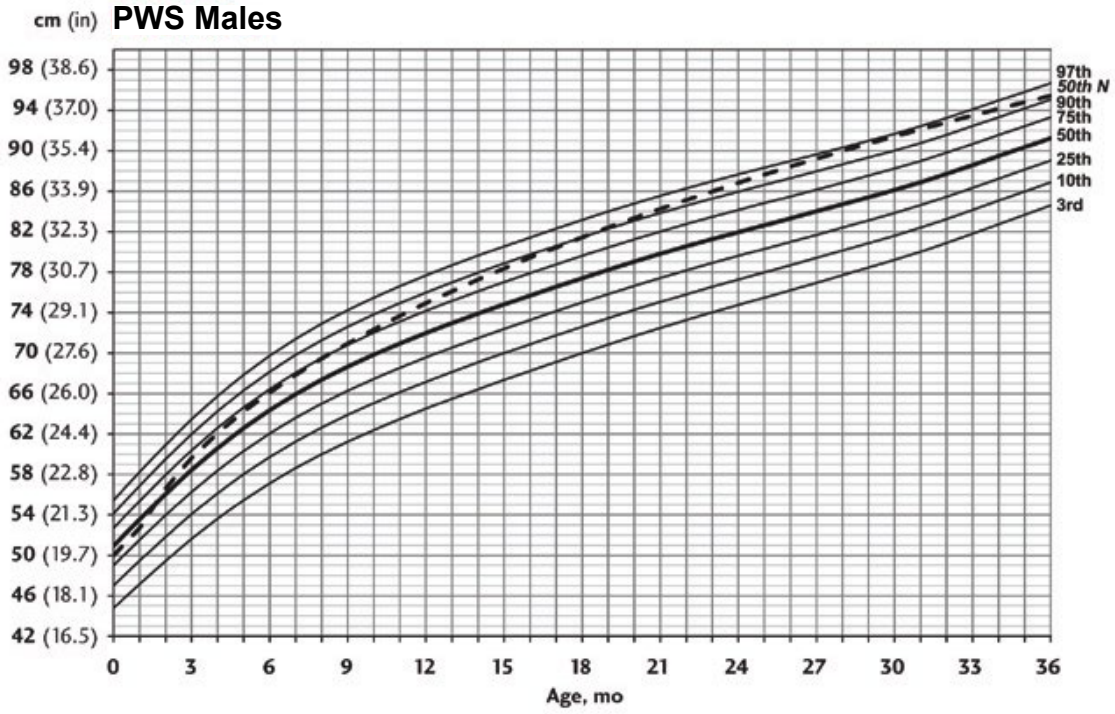

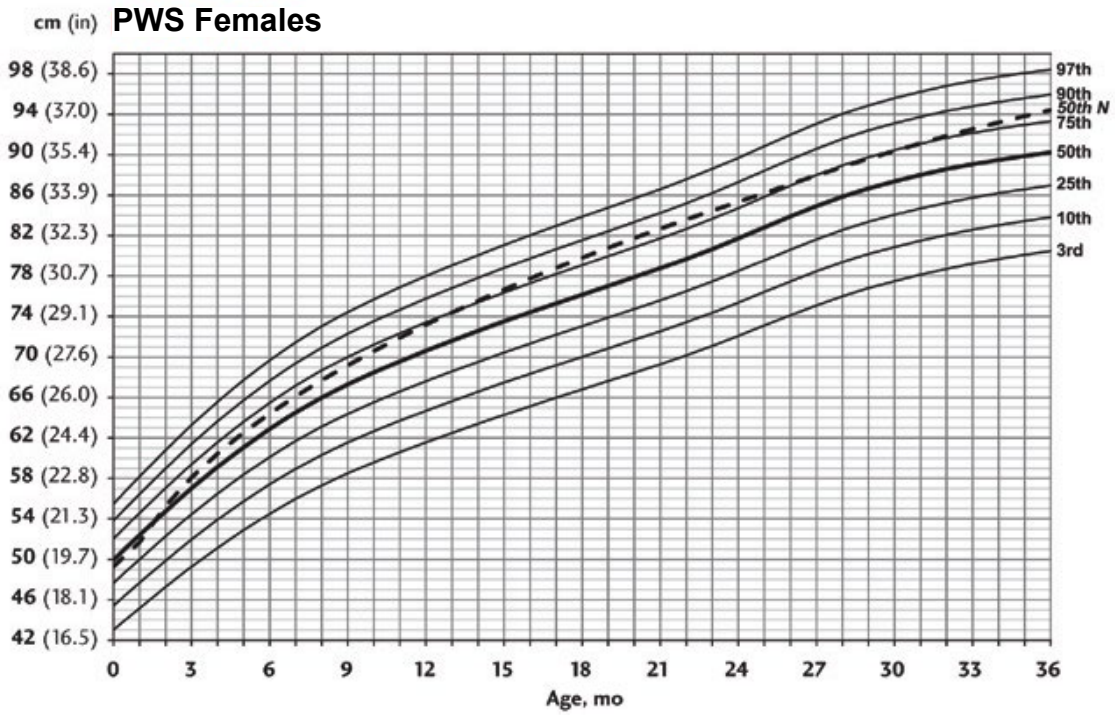

Standardized curves for length of male (upper) and female (lower) infants with PWS (solid lines) and normative 50th percentile (broken line).

Notes

Information in this publication is not intended to be, nor is it, medical or legal advice on the management or care of a person with Prader-Willi syndrome. It may not represent the opinions of PWSA | USA.

Any decision about treatment or legal options (including, but not limited to, medical, nutritional, educational services or psychiatric options) should be made in consultation with your own medical and legal team.

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