

## Your Child's Special Nutritional Needs

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It's very important that babies and children with congenital heart defects follow the age-based American Heart Association recommendations for a heart-healthy diet. Your doctor, nurse or other healthcare provider can give you more information. Sometimes babies and children with heart disease need a higher-calorie diet or have special dietary requirements to grow well and stay healthy.

Feeding your baby is challenging and rewarding, and provides nutrition for your baby's physical and mental growth. It is also an opportunity for you to love, touch and communicate with your baby. When your baby gains weight steadily and is content and thriving, it's reassuring and rewarding. A baby born with a congenital heart defect, however, may not gain weight as rapidly as other infants, despite your hard work and persistence, and at times this may be frustrating.

*Your Baby's Growth.* Healthy babies usually double their birth weight between four and five months of age. Infants and children with congenital heart disease and congestive heart failure or cyanosis (blueness) tend to gain weight more slowly. An eight-ounce to one-pound gain in a month may be an acceptable weight gain for a baby with a heart defect.

Some factors related to congenital heart defects that may interfere with your baby's growth include:

- excessively rapid heart beat
- increased respiratory (breathing) rate
- poor appetite
- greater caloric needs
- decreased food intake due to rapid breathing and fatigue
- frequent respiratory infections (bronchitis, pneumonia)
- poor absorption of nutrients from the digestive tract
- decreased oxygen in the blood (hypoxia)

A baby's growth may also be influenced by hereditary or genetic conditions. Some conditions such as Trisomy 21 (Down syndrome) have different growth charts. The most common reason for poor growth is that the baby isn't taking in enough calories or nutrients. But even if your baby seems to drink enough formula or breast milk, he or she may still gain weight very slowly due to the increased caloric needs. You need not weigh your baby at home. Your baby's pediatrician or cardiologist will weigh your baby with each office visit. These weight measurements will show how well your baby is growing.

*How To Feed Your Baby.* Either breast- or bottle-feeding works well for babies with heart problems, but it's important to be flexible about your feeding method and schedule. Some babies with heart disease may also require feeding supplements to their formula or breast milk, or require feeding through a feeding tube (usually placed into the nose).

Babies with congenital heart disease typically do best when fed more often and on a demand schedule. They tend to tire quickly during the feeding, so frequent feedings tend to work best. Initially, feeding your baby every two hours may be best, and you may find that you need to wake your baby at night several times to feed until he or she is able to tolerate a larger volume of breast milk or formula less often. Some infants do best with a combination of breast- and bottle-feeding.

*Breast-Feeding Your Baby.* If your baby is diagnosed with a congenital heart disease either before or immediately after birth, you probably won't get the opportunity to nurse your baby at delivery. You'll need to start pumping your breast within the first 12 to 24 hours after birth to maintain your milk supply. You should use a hospital breast pump and pump every 2–3 hours for the first week. Once your milk supply is well established, you can decrease pumping to 4–5 times a day. You may want to consider renting an electric pump for home use. If your baby needs surgery after breast-feeding has been established, you can pump your breasts to maintain your milk supply during times when your baby can't nurse.

**Isn't breast-feeding too hard for my baby's heart?** The “work” of breast-feeding is actually less than the work of bottle-feeding. Sucking, swallowing and breathing are easier for a baby to coordinate, and the amount of oxygen available to your baby is greater while breast-feeding than when bottle-feeding. In general, when compared to bottle-fed babies, breast-fed babies with congenital heart defects have more consistent weight gain.

**Once my baby is breast-feeding, how can I tell if he or she is getting enough?** Your baby is probably getting enough milk if you're nursing 8–12 times a day, the baby is latching on well, and you can hear the baby gulping and swallowing. Your baby should have at least 6–8 wet diapers per day. A consistent weight gain will also tell you that your baby is getting enough milk.

If you have questions or need help with either pumping or getting the baby latched onto your breast, contact a lactation consultant. Before you're discharged from the hospital, the lactation consultant will watch you breast-feed your baby to make sure it's going well.

*Formula-Feeding Your Baby.* Bottle-feeding may provide a little more flexibility, particularly if your child remained in the hospital for treatment after birth. Bottle-feeding also allows the baby's father and other family members to become more active in feeding the baby.

**How much is enough?** All infants are individuals, and they vary in how much formula they take each feeding. Try not to compare the amount of formula your baby takes to the amount other babies take. The goal for feeding an infant with congenital heart disease is consistent weight gain. Most babies gain 1/2 to 1 ounce of weight per day. However, babies with heart disease tend to gain weight at a much slower rate.

*Choosing a Formula.* Commercial formulas, available at most supermarkets, are made to be as similar to breast milk as possible. You and your baby's healthcare provider can decide which formula is best for your baby.

*Choosing a Bottle/Nipple.* There are many types of baby bottles and nipples available. It may take several trials with various bottles and nipples before you find the one that works best for your baby. Some babies with heart disease have difficulty feeding from a regular nipple. You

may want to find a soft nipple or make a larger hole in the nipple to allow the formula to flow more easily. Small holes in the nipple make it harder for your baby to suck and he or she may swallow air, which may result in vomiting. You can enlarge the hole in the nipple by inserting a sterilized sewing needle into the hole, increasing the opening a little. The nipple should then be boiled for about five minutes in a pan on the stove and allowed to cool completely before it's used. An occupational therapist, clinical nurse specialist or feeding team member may be asked to assess your baby's feeding habits and make recommendations for a specific feeding schedule and nipple.

### **Additional Feeding Information:**

#### *Tube Feedings*

Some babies with congenital heart disease may not take in adequate amounts of calories with breast-feeding or bottle-feeding alone. These children may require additional feeding using a nasogastric (NG) tube. This NG tube is placed in the baby's nose and passes to the stomach. Formula or breast milk is delivered through the tube. This makes the feedings less "work" and results in your baby gaining more weight. Other methods of tube feeding include gastrostomy tube (GT) or jejunostomy tube (JT). These methods involve placing the tube surgically into the stomach (GT) or intestine (JT). You and your healthcare team will determine the best method and feeding schedule for your baby.

#### *Other Liquids*

Avoid giving your infant water, because water has no calories. You may give juice to your baby after four months, but it should not replace formula. Formula or breast milk is still the best way to meet your baby's caloric needs when solid food or juices are started, because milk has more calories than most solid foods or juices.

#### *Starting on Solid Food*

Your doctor will help you determine when solid food should be added to your baby's diet. This usually occurs around six months of age. Cereals fortified with iron are typically introduced first, followed by fruits and vegetables, and then meats. Solid food should always be fed to your baby with a spoon. Adding solid food to the formula in the bottle thickens the formula and makes it hard for your baby to suck it out of the nipple.

Parents sometimes think children with congenital heart disease need to eat special diets that are low in fat, similar to the low-fat diets recommended for adults with heart disease. In fact, since children with congenital heart disease often have poor appetites, high-calorie foods and snacks can play a very important role in providing good nutrition. Don't restrict fat in the diet, particularly in the first two years of life. It's needed to help children grow and develop properly. That's why lower fat milks (2%, 1% or fat-free [skim]) aren't recommended until children are two years of age or older.

#### *Heart Medicine and Feeding*

Many babies with congenital heart disease are given medications such as digoxin (Lanoxin) and furosemide (Lasix) to control congestive heart failure. These medications typically don't interfere with feedings. It's usually best to give medications to your baby before a feeding. Give the medications directly into your baby's mouth using a syringe or dropper from the medication bottle. Do not mix any medication in the formula bottle because your baby may not finish the

bottle. If the baby vomits after the medication, do not give that medication again until the next scheduled time.

If your baby is receiving a diuretic such as Lasix, your cardiologist may recommend a potassium supplement because some diuretics remove potassium from the body along with the excess fluid. The potassium supplement is usually given as a liquid medication added to a small amount of juice or milk to mask the bitter taste. Foods such as bananas, orange juice, potatoes and dried fruits are also a good source of potassium for older infants.

Contact your cardiologist or other healthcare provider if your baby becomes ill, feeds poorly or vomits more than 2–3 feedings per day. Your baby's medication may need to be adjusted or a formula change may be needed.

*Ways To Boost Calories.* Babies with congenital heart disease may require more calories per day than the average infant. Some babies can't eat or drink enough formula to grow. If your baby gains weight too slowly and can't tolerate an increased volume of formula, your doctor may recommend increasing the amount of calories per ounce. Your pediatrician, nurse or dietitian can prescribe ways for you to concentrate or fortify formula or breast milk. Additionally, you can view a list of examples of [high calorie baby foods](#).

*Looking Ahead.* Persistent and loving efforts to feed your baby will be rewarded. Even when your baby doesn't eat with enthusiasm, just being physically close to you during feeding times is important. Feeding your baby should be a positive experience, never a battleground. Let your baby decide when he or she is satisfied. If your baby doesn't grow normally because of heart disease, heart surgery may result in a faster growth rate, with a catch-up period in height and weight. Children with heart defects often reach satisfactory growth by the time they become adolescents. Many books on infant nutrition can help you with additional feeding techniques. If you have feeding problems or questions about your baby's growth, talk with your pediatrician, cardiologist, nurse or dietitian.