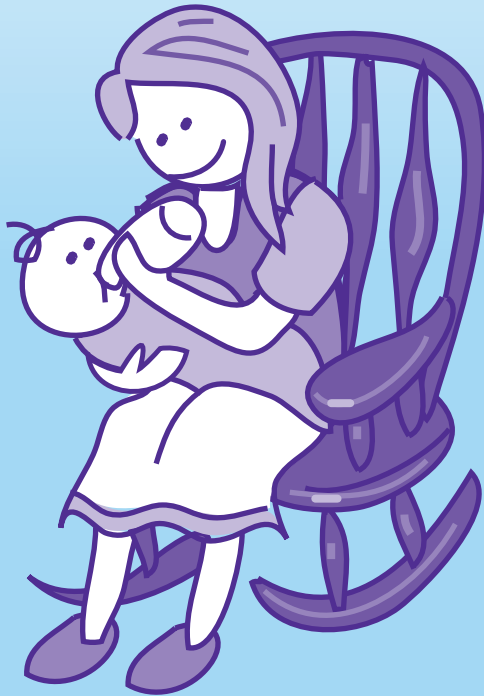




Cleft Palate FOUNDATION

Feeding Your Baby



Cleftline

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Feeding Your Baby



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Foreward

The information in this booklet, along with that given to you by your health care providers, will help you understand how best to feed your baby. This information is provided solely for educational purposes. It is not a substitute for medical advice provided by a physician. **It is intended for use by parents, caregivers, and nurses caring for infants with cleft lip and/or cleft palate, not for infants with more complicated craniofacial conditions.**

This content does not represent the only, or necessarily the best, feeding method or equipment appropriate for your infant's situation. You should consult with your health care provider before proceeding to use any of the information presented here.



Feeding Your Baby is also available on CD-Rom. Contact the Cleft Palate Foundation at 1.800.24.CLEFT (1-800-242-5338) to request a copy or visit www.cleftline.org to view the video online.

Parents and Caregivers: You Are Not Alone

Having a baby can turn anyone's world upside down. Having a baby with a cleft is no different — there will be delightful, joyous experiences and stressful times. And for parents of babies with clefts, feeding can be difficult.



This booklet will give you the facts about feeding a baby with a cleft. It will guide you through the confusing times so you can spend most of your time loving and enjoying your new baby.

Who should read this? That's easy--EVERYBODY who comes in contact with your baby. Hospital nurses and new parents; pediatricians and grandparents; siblings and babysitters; lactation consultants and midwives—all will benefit from this information.

No one anticipates that feeding a baby may be challenging. Most parents and many professionals have had little to no experience with the special techniques and bottles for feeding babies with a cleft. Well-meaning, but inaccurate, suggestions can make you and your baby more frustrated.

As parents try to do the right thing they can find themselves consumed with every aspect of feeding— how long, how much, how often. This booklet will help you find the best way to feed your baby. Keep in mind, finding what works for you will take some trial and error because every child is unique. Here, you will find help from experts and parents who deal with these very same feeding issues on a daily basis. You don't need to reinvent the wheel and you don't need to feel like you are all alone.

Before you know it, your baby will be a first-grader demanding grilled cheese sandwiches! Enjoy the journey of parenting. Sometimes it's fun. Sometimes it's not. But it is wonderful and important, and the journey moves more quickly than you can imagine.



REMEMBER...

Feeding not only provides nourishment for growth and development and exercises the oral muscles, it also promotes caregiver-infant bonding. Suckling at the breast for pleasure makes active use of the tongue and other muscles of the baby's mouth. Developing these muscles will help the baby successfully achieve future oral motor tasks such as cup drinking, chewing, and speech and sound production.

Getting Started

A baby born with cleft lip and palate, or cleft palate only, has an opening in the roof of her mouth -- between the mouth and nose. This prevents her from making the suction or vacuum, which is needed to pull milk from the nipple. As a result, even though a baby with



a cleft has normal sucking and swallowing reflexes, she needs special bottles and nipples to allow the formula to flow without the help of adequate suction. During a feeding, formula may come out of the baby's nose. This is called "nasal regurgitation". The baby may also swallow too much air while feeding.

The feeding goal is to help the baby get the right amount milk in the right amount of time, and avoid taking in too much air.

Here are some simple guidelines:

1. Place the baby in an upright, sitting position to prevent the formula from flowing back into the nose area.
2. Watch for a pattern of sucking and swallowing --listen for a swallow, followed by a breath. At first, many babies suck and swallow many times without stopping to rest. Most will figure this process out within a few days, and develop their own rhythm of sucking, swallowing and resting.
3. Keep the bottle tilted so the nipple is always filled with milk, and pointed down away from the cleft. The infant will move the nipple into the most comfortable position for her.
4. As your baby feeds, some formula may escape through the nose. This is common, and does not mean she is choking! Hold your baby in a more upright position. This will lessen the amount of milk coming through the nose. She may even sneeze or cough. This is good, because it clears the nose. You don't have to use a bulb syringe to suck milk out of the nose--the nose clears and cleans itself. Remember -- this is not dangerous and does not mean your baby is choking.

5. Babies with a cleft need to be burped more often because they take in more air while feeding. Watch for signs of discomfort; your baby will give you signs when it's time to stop and burp.

How will you know it's working? Your baby should feed in about 30 minutes or less. Longer feedings can cause exhaustion and burn up too many calories—calories the baby needs to grow.

Secondly, your baby should return to birth weight by 2 weeks of age and gain a half pound per week. This is an average, so be sure to follow the guidelines of your primary care provider.

REMEMBER...

You may want to elevate one or both feet on a stool or support the baby on a pillow for added comfort.

How to Use the *Enfamil Cleft Palate Nurser* by Mead Johnson

Some cleft palate bottles are considered assisted-delivery bottles, meaning the parent can pulse the bottle or nipple to assist the flow of milk into the baby's mouth. The Mead Johnson is an assisted delivery bottle — it's a soft bottle that's easily squeezed in rhythm with your baby's suck and swallow pattern.



When you feed your baby with this bottle, you gently squeeze, in a pulsing manner. If you squeeze too hard or with a constant pressure, your baby may take in too much milk, or be forced to swallow milk when she's resting and not ready to swallow. This could cause her to cough and sputter. So remember, squeeze in a pulsing rhythm – when the baby sucks, you squeeze. When she rests, you stop squeezing. You don't need to take the nipple out of the mouth when the baby's resting – just leave it there and she'll start feeding again in a few seconds.



This bottle takes a little bit of practice, but once you've used it a few times, you'll feel much more comfortable. The best way of knowing how hard to squeeze the bottle is to keep track of how long it takes to feed your baby. If it's taking longer than 30 minutes, you need to squeeze the bottle a little harder. If you're staying in the 30-minute time frame, and your baby is satisfied after the bottle is emptied, then everything's going fine.

To clean the Enfamil Cleft Palate Feeder:

- The bottles are labeled disposable; however, they are reusable and can be washed.
- Wash the nipple and bottle with warm soapy water, rinse and air dry.
- Do not boil, microwave or place the nipple or bottle in the dishwasher.

Just like other nipples, you should always inspect the nipples for signs of wear and tear. Using an old nipple can be dangerous for your baby. If the nipple looks misshapen, feels soft or gummy, or has any cracks, it is time to throw it away and use a new nipple.

Ordering information can be found at the end of this publication.

How to Use the Haberman Special Needs Bottle Made by Medela

Some cleft palate bottles are considered assisted-delivery bottles, meaning the parent can pulse the bottle or nipple to assist the flow of milk into the baby's mouth.

The Special Needs Feeder is an assisted-delivery bottle. It has an unusual-looking nipple and markings that indicate the flow of milk. It also comes in a smaller size for babies born prematurely.



There are five parts to the Special Needs feeder, which can attach to any conventional, wide-neck bottle. Above, left to right: valve, disk, nipple, collar, and bottle.

To use this feeder, fill the bottle with breast milk or formula.

- Place the valve membrane into the upper side of the disk completely and facing the nipple. The valve membrane and the high rim of the disk are facing the inside of the nipple.
- Place the nipple assembly on the bottle and secure all parts with the collar/ring.
- Hold the bottle upright, squeeze the nipple between your fingers, and then tilt the bottle upside down.
- Release the squeeze and milk should start to fill the nipple-this process should be repeated until the barrel is full.

There are three rates of milk flow, each represented by a line on the barrel of the nipple. The shortest line means no or slow flow, the medium line means medium flow, and the longest line means regular or high flow. The desired flow line should be upward, under the infant's nose.

The barrel-like reservoir attached to the nipple may also be squeezed to increase the flow of milk. The best guideline is to squeeze the reservoir when the baby sucks, and release when he rests.

To clean the Special Needs Feeder:

- Wash the nipple and bottle with warm soapy water, rinse and air dry.
- Do not boil, microwave or place the nipple or bottle in the dishwasher.

Just like other nipples, you should always inspect the nipples for signs of wear and tear. Using an old nipple can be dangerous for your baby. If the nipple looks misshapen, feels soft or gummy, or has any cracks, it is time to throw it away and use a new nipple.

Ordering information can be found at the end of this publication.

How to Use the Pigeon Bottle Made by Respirationics

Some cleft palate bottles are considered assisted-delivery bottles; the Pigeon is NOT an assisted-delivery bottle, which means the baby compresses or sucks all the milk into her mouth without any assistance from the caregiver.



There are four parts: plastic one-way flow valve, non-latex nipple with a Y cut and air vent, collar/ring, and bottle. The nipple and collar fit standard size baby bottles as well. Here's how to put the bottle together:

- Fill the bottle with the recommended amount of formula or breast milk.
- Place the nipple into the collar/ring.
- Place the one-way flow valve into the nipple with the movable stopper towards the inside of the nipple.

- Screw the collar with the valve onto the bottle. Important: The tighter the collar the slower the milk flow. The more loose the collar, the faster the milk flow. You can make the adjustment once you know your baby's feeding rhythm. For example, if the baby doesn't seem to be getting enough milk, loosen the collar to increase the rate of flow.
- Make sure the air vent and Y-cut are cut all the way through, and after washing, cleared of any milk residue.

To begin feeding:

- Hold the bottle upright, squeeze the nipple between your fingers.
- Tilt the bottle upside down.
- Release the squeeze and milk should start to fill the nipple--this process can be repeated.
- The nipple is harder on the top, softer on the on bottom.
- Put the air vent, which is the notch in the nipple, under the baby's nose. You may also notice that the notched side of the nipple is harder. Again, this hard side should always be on top under the baby's nose.
- If the nipple collapses, the collar is probably too tight. Loosen the collar until the nipple decompresses, and then resume feeding.

To clean the Pigeon feeder:

- Wash the nipple and bottle with warm soapy water, rinse and air dry.
- Make sure the air vent and Y cut are clear of any milk.
- Do not boil, microwave or place nipple in dishwasher.

Just like other nipples, you should always inspect the nipples for signs of wear and tear. Using an old nipple can be dangerous for your baby. If the nipple looks misshapen, feels soft or gummy, or has any cracks, it is time to throw it away and use a new nipple.

Ordering information can be found at the end of this publication.

Adapting Your Bottle

Every baby is different, so sometimes you may need to be creative! You may find more success when you mix and match nipples and bottles.

While these are not recommendations of the manufacturers, here are a few combinations that parents and cleft teams have found to be successful:



- The Pigeon nipple and valve combined with a vented bottle such as the Dr. Brown bottle.
- The Pigeon nipple and valve on the Enfamil Cleft Palate Nurser.
- An orthodontic or any silicone nipple on the Enfamil Cleft Palate Nurser.
- The Special Needs Haberman nipple/valve/disk on any type of commercial bottle. With this combination, use either the ring from the Special Needs Feeder or from the commercial bottle being used. You may find that one rings leaks less than the other.
- A silicone nipple and Pigeon valve on any standard, vented or bent neck bottle with a standard, not wide neck, opening.

REMEMBER...

If a specialty feeding bottle is not available, there are other solutions to achieve effective feeding.

Crosscut Nipple -- The simplest method is to alter a standard or premie nipple with a crosscut.



- Turn the nipple inside out.
- Use a sharp, thin blade or scissors to make a small X-cut in the tip of the nipple. Turn the nipple outside in.
- After every few sucks, the size of the X can be increased until the infant is eating comfortably.
- You can test the flow by turning the bottle upside down. If it flows rapidly, but you can still see individual drops, it's usually right.

Bottle Liner -- You can also use a bottle liner inserted into a plastic bottle with the bottom cut off, or purchase the smaller 4 ounce Playtex bottle. The liners can be squeezed by the caregiver to regulate the flow of liquid into the baby's mouth.



FAQs About Feeding

Can I find feeding information on the Internet?

Just because information is on the Internet doesn't mean it's accurate or appropriate. In fact, sometimes it's downright harmful and alarming!

Go to www.Cleftline.org as your first stop on the web, and then rely on your cleft palate team to recommend other reputable sources of information.



Why does a baby with cleft palate have problems with feeding?

Because of the cleft, or opening between the mouth and nasal cavity, the baby can not create the suction which is needed to efficiently pull milk from the bottle or breast. It is like trying to drink from a straw with a crack in it. Your baby may take longer to feed or have milk come out of his nose. This is called "nasal regurgitation". The baby may also swallow more air while feeding. Because of these problems, you need to make some changes, or adaptations, in the way you feed your baby.

How much should my baby eat?

Your primary care provider will let you know how much breast milk or formula your baby should take. Usually a full term healthy newborn takes about 2-3 ounces of breast milk or formula per feeding-- about 6-8 feedings per day. It's important to understand that it's normal for newborns to lose some weight in the first week or so of life, but by 2 weeks, your baby should be back to birth weight. It's helpful to have your baby weighed once a week, on the same set of scales, for the first 1-2 months to make sure he's gaining weight properly.

How long should a feeding take?

Feedings should take no more than 30 minutes. If your baby takes longer than this, it may mean she is working too hard and may actually be burning up some of the calories needed to gain weight. Try to feed your baby every 3- 4 hours. If your baby feeds more frequently- say, every 2 hours- she may

just be “snacking,” and may have problems gaining weight. Plus, you’ll feel like you’re feeding the baby all the time and both of you will be exhausted.

How long do I stay with a feeding system that’s not working before I try something else?

When switching nipples or feeding systems, allow up to 48 hours for your baby to adjust. Switching systems too often may cause your baby to get confused and more frustrated. Be sure to consult your cleft palate team or feeding specialist during this process.

How long can I let my baby sleep between feedings?

Infants in the first weeks of life should not sleep longer than 3-4 hours between feedings. If the baby is receiving breast milk, more frequent feeds may be needed, because breast milk is more quickly digested than formula. Once adequate fluid volumes and weight gain are achieved, the schedule can be relaxed to an on-demand feeding schedule.

I see milk coming out of my baby’s nose. I’m scared – what should I do?

This is very common in babies with cleft palate. Hold your baby in a more upright position. This will decrease the amount of milk coming through the nose. Your baby may even sneeze or cough, which also clears the nose. Then continue feeding. You don’t have to use a bulb syringe to suck milk out of the nose—the nose clears and cleans itself. Remember – nasal regurgitation is not dangerous and does not mean your baby is choking.

Does my baby have acid reflux?

Reflux occurs when stomach contents back up into the esophagus. Reflux can cause vomiting, spitting up, coughing, or changes in sleeping habits. Reflux is different from nasal regurgitation, when formula comes out of the nose during feeding. Your primary care provider should be consulted about your baby’s reflux symptoms. A formula change or a thickening of the formula may be recommended, and in some cases, medication may be prescribed to manage this problem.

What is a Cleft Palate Team and why should I have one?

Babies born with cleft lip or palate often require a variety of treatments as they grow. A cleft palate team is comprised of surgery, pediatric, nursing,

feeding, speech, hearing, mental health and other specialties unique to your baby's condition. By meeting with each other, and staying in communication as your child grows, these health care providers can individualize and coordinate the best treatment options. You can find a cleft palate team in your area by going to www.cleftline.org or calling **1-800-24-CLEFT**.



What About Breastfeeding?

La Leche League International advises that,

...except in rare cases, a baby with a cleft palate cannot get all the milk he needs by breastfeeding alone.

An opening in the palate makes it impossible for the baby to seal off his mouth and make the suction typically used to keep the breast (or bottle) in place and pull the nipple to the back of his mouth.

Over time, lactation consultants have found that feeding exclusively at the breast is a difficult goal for all but a few babies with uncorrected cleft palates.

Breastfeeding a Baby with a Cleft Lip or Cleft Palate, La Leche League International, November, 2004.



Learning that breastfeeding is an unlikely option can be a source of disappointment and sadness for some families. Give yourself time and space to grieve this loss. But remember, you can still share many benefits of breastfeeding with your child:

- Express breast milk with a pump, but feed your baby with one of the bottle-feeding methods described.
- During feedings, make sure that you both enjoy eye-to-eye, and skin-to-skin contact whenever possible.
- Once your baby has become successful feeding on a bottle, she may be put to the breast for non-nutritive sucking. Non-nutritive sucking at the breast can be a satisfying experience for both moms and babies.
- Non-nutritive sucking exercises and stimulates important muscles in your baby's mouth and tongue, and can facilitate the bonding experience. It may also help stimulate milk production for those moms who continue to pump breast milk.

REMEMBER...

Regardless of what feeding system you choose for your baby, most health care providers agree that breast milk is the best food for newborns. (The American Academy of Pediatrics recommends breast milk for children up to one year of age.) If using breast milk is not an option, your health care provider will help you select the most appropriate formula for your baby based on nutritional composition and compatibility with his digestive system.



Connect With A Team

Consult with a cleft palate team as soon as you know your baby has a cleft. You can find a list of cleft palate teams in your area by contacting the Cleft Palate Foundation. The team will guide you through every aspect of care and treatment and will be a resource when



you have questions or anxieties regarding your child. It's important to remember your baby is just like any other baby who just happens to have one of the most common and one of the most correctable birth defects.

REMEMBER...

Infants are remarkably adaptable. Given the right combination of supplies, positioning, and technique, along with reassurance, support, and information, your baby will grow and thrive. So try to relax and enjoy feeding time! When in doubt, always contact your local care provider, your cleft palate/craniofacial team, or the Cleft Palate Foundation.

Ordering Information

Bottles and other products manufactured for infants with cleft palate:

Enfamil Cleft Palate Nurser by Mead Johnson

<https://www.meadjohnson.com/app/iwp/consumer/productCategory.do?currentSubCatPath=/B2C/Accessories>

Phone: 1.800.222.9123

Email: AskMeadJohnson@bms.com

Haberman Special Needs Bottle by Medela

<http://www.medelabreastfeedingus.com/products/breastfeeding-devices/83/specialneeds-feeder>

Phone: 1.800.435.8316

Email: customer.service@medela.com

Pigeon Bottle by Respironics

<http://bottlesandfeeders.respironics.com>

Phone: 888.766.8443 (parent orders); 800.345.6443 (hospital orders)

For More Information

Las publicaciones de la Fundación del Paladar Hendido también se ofrecen en español. Favor de llamarnos para recibir copias en español.

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The Cleft Palate Foundation (CPF) maintains a growing collection of booklets and fact sheets that present an introduction to and explanation of many elements of cleft and craniofacial care and treatment. All publications are authored and regularly revised by representatives of professional disciplines serving the field of cleft and craniofacial care and treatment.

A publications order form for institutions including current pricing, bulk order rates and shipping and handling fees may be accessed at the CPF website or by calling the **Cleftline** at 1.800.24.CLEFT. All fact sheets are available at the website as open-access, PDF documents. Families, patients, students and other individuals may request complimentary packets of publications by emailing info@cleftline.org or by calling the **Cleftline**.

To date, the Cleft Palate Foundation has shared over 7,000 Gund Teddy Bears with repaired cleft lips with children and families all over the world. Please visit www.cleftline.org or call the **Cleftline** for more information about our bears.

If you are interested in helping us continue in our mission, please contribute to the CPF Cleftline Fund. Visit www.cleftline.org or call the **Cleftline** to make your donation today! Thank you.

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