



# Feeding Your Baby

Fourth Edition

## Fourth Edition

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## Table of Contents

<b>Forward</b> .....	<b>1</b>
Welcome.....	1
<b>Parents &amp; Caregivers: You Are Not Alone</b> .....	<b>2</b>
<b>Getting Started</b> .....	<b>2</b>
<b>The Enfamil Cleft Palate Nurser by Mead Johnson</b> .....	<b>4</b>
How to Use.....	4
<b>The Haberman Special Needs Bottle Made by Medela</b> .....	<b>5</b>
How to Use.....	5
<b>The Pigeon Bottle Made by Respironics</b> .....	<b>6</b>
How to Use.....	6
<b>Adapting Your Bottle</b> .....	<b>7</b>
<b>FAQs About Feeding</b> .....	<b>8</b>
Can I find feeding information on the Internet?.....	8
Why does a baby with cleft palate have problems with feeding? .....	8
How much should my baby eat? .....	8
How long should a feeding take? .....	8
How long do I stay with a feeding system that’s not working before I try something else? .....	8
How long can I let my baby sleep between feedings? .....	9
I see milk coming out of my baby’s nose. I’m scared – what should I do?....	9
Does my baby have acid reflux? .....	9
What is a Cleft Palate Team and why should I have one?.....	9
<b>What About Breastfeeding?</b> .....	<b>9</b>
<b>Connect With A Team</b> .....	<b>10</b>
<b>Ordering Information</b> .....	<b>11</b>
<b>For More Information</b> .....	<b>11</b>

## Forward

# Welcome

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.

## Parents & 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 challenging. 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. 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

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.

way to feed your baby. Finding what works for you will take some trial and error because every child is unique.

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.

## 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 to take formula or pumped breast milk from special bottles and nipples to allow the formula to flow despite the lack of suction.

During a feeding, milk may come out of a baby's nose. This is called "nasal regurgitation". The baby may also swallow too much air while feeding. These can be minimized with proper feeding positioning and frequent burping.

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 a semi-upright position, with the tongue level to the floor.
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 away from the cleft. The nipple should be positioned so that it makes contact with intact palate tissue or the bone that runs down the middle of the palate. The nipple should be held firmly in place while the infant suckles to prevent irritation or ulceration of this sensitive nasal tissue.
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 and consider reducing the flow rate of the milk flow by either changing the nipple or reducing pressure in the can of the Haberman or Mead Johnson nursers. 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 2-3 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.

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

## Dr. Brown's Specialty Nursers and The Enfamil Cleft Palate Nurser

### How to Use

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 and the Dr. Brown bottles are assisted delivery bottles — it's a soft bottle that's easily squeezed in rhythm with your baby's suck and swallow pattern.

This feeder should not be pulsed. An appropriate amount of pressure should be applied to the nurser while the infant is actively suckling. The pressure should be removed when the infant stops suckling. This allows for consistent flow of formula minimizing gulping swallows which can cause coughing or choking. Each infant requires a different amount of pressure but in general if you hold the bottle horizontally and apply pressure to the nurser if you see mild right at the nipple opening without it dripping this is a good place to start. Pressure can be increased or decreased depending on your child's speech and coordination of feeding.

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



The Enfamil Cleft Palate Nurser by Mead Johnson

after the bottle is emptied, then everything's going fine.

### To clean the bottles:

- 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.

## The Haberman Special Needs Bottle Made by Medela

### How to Use

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, provide consistent pressure, and release when he rests. Flow rates and amount of nipple pressure will need to be adjusted so your infant sucks and swallows efficiently without gulping or being overwhelmed with flow. Your infant should swallow without coughing or choking and feed efficiently in under 30 minutes when the flow rate and pressure is optimized.

### 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.



The Haberman Special Needs Bottle Made by Medela



## The Pigeon Bottle Made by Respirationics

### How to Use

There are 2 nipple sizes. The smaller has a slower flow rate as its diameter is smaller while the larger one has a faster flow rate.

### 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 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.



The Pigeon Bottle Made by Respirationics

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. If your baby seems to be overwhelmed with milk flow with the larger nipple change to the smaller nipple as the slower flow may be helpful.



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.

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

Cutting nipples and bottle liners should be short term solutions until you consult with your cleft team who can recommend the best bottle and nipple combination for your infant.

**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! Information from the internet can be used in the short term until you consult with your cleft team, who can recommend the best feeder for your child.

Go to [www.ACPAcares.org](http://www.ACPAcares.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.

### 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. Thickening can be challenging when using specialty nursers, so other alternatives for reflux management should be considered first. Thickening, frequent burping, upright positioning during feeding and for up to 30 minutes after feeding can help.

### **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.ACPAcares.org](http://www.ACPAcares.org) or calling 1-919-933-9044.

## **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.

Regardless of what feeding system you choose for your baby, most health care providers agree that breast milk is the best food for newborns. 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 American Cleft Palate

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. When in doubt, always contact your local care provider, your cleft palate/craniofacial team, or the American Cleft Palate Craniofacial Association.

Craniofacial Association. 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.

## Ordering Information

Bottles and other products manufactured for infants with cleft palate:

### Enfamil Cleft Palate Nurser by Mead Johnson

Haberman Special Needs Bottle by Medela, and Pigeon Bottle by Respironics, can be widely found online and through some ACPA Approved Teams. ACPA recommends you speak with your team prior to purchasing.

## For More Information

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

This publication and many others have been produced by:

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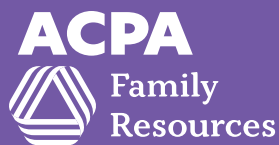
The American Cleft Palate Craniofacial Association (ACPA) maintains a growing collection of booklets and fact sheets that present an introduction to and explanation of many elements of cleft and craniofacial care and treatment. All publications are authored and revised by representatives of professional 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 on [www.ACPACares.org](http://www.ACPACares.org) or by calling ACPA at 1.919.933.9044. 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@ACPACares.org](mailto:info@ACPACares.org) or by calling.

To date, ACPA has shared over 7,000 Gund Teddy Bears with repaired cleft lips with children and families all over the world. Please visit [www.ACPACares.org](http://www.ACPACares.org) for more information about the bears.

If you are interested in helping us continue in our mission, please contribute to ACPA. Visit [www.ACPACares.org](http://www.ACPACares.org) or call to make your donation today! Thank you.





## For More Information

This booklet and many others have been produced by:

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