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## Review Article

## Cleft Lip and Palate Newborn Care and Feeding: A Primer for Bedside Nursing Providers

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### Abstract

**Purpose:** This article reviews the important educational role of the pediatric nurse in managing the newborn with a cleft lip and palate. Although congenital clefting conditions of the lip and/or palate are relatively common, they remain an infrequent problem for the average bedside provider. Cleft lip and/or palate may pose substantial challenges to establishing effective and efficient feeding. An unexpected cleft diagnosis can also provide additional stressors for the family. The importance of effective support for these infants and their families cannot be understated.

**Practice Implications:** Pediatric and post-partum nurses are in an excellent position to help with many issues of feeding and lactation. Understanding some basic facts about cleft occurrence and management will help families feel more comfortable in caring for their infants. Familiarity and facility with common specialized cleft bottling systems can also help families learn to feed their child with a cleft palate in an efficient way. With appropriate support these children can grow and thrive while family stress levels will be lower.

**Keywords:** Bottle; Breast feeding; Clefting; Lactation; Neonatal nursing; Nutrition

### Introduction

Cleft lip and/or palate are some of the most commonly seen birth differences in the United States and worldwide. Despite the frequency of occurrence, however, congenital orofacial clefting is still likely to be an infrequent challenge for an individual bedside caregiver. Misinformation about the causes, recommendations, and outcomes of clefting is quite common. The associated feeding problems are frequent. There can be quite significant in some infants creating real risk for poor weight gain and failure to thrive [1-5]. The altered cleft facial form and struggles with feeding can create much anxiety for both the parents and caregivers. Early

education and appropriate follow-up can mitigate many of these problems [1,3,5,6]. Confusion or inconsistencies among healthcare recommendations, however, can have a negative impact on feeding and adaptation [1,5,7-9]. For instance, it is important to know that weight gain and growth for an infant with a cleft should mirror that of an unaffected infant. Giving parents directed feeding goals is critical. Specifically, newborns with cleft lip and/or palate should be expected to take a typical amount of milk (e.g. 60-90 mL) in less than 30 minutes at each feeding. They are also expected to gain approximately 25-35 g/day of weight during the first 3 months of life [10,11]. This article is intended to review the basics of cleft lip and palate including appropriate newborn management strategies. Individualized feeding plans are emphasized.

Understanding the basic issues of a cleft diagnosis is important because it affects so many aspects of the infant’s health and development including growth, hearing, speech, and appearance. The incidence of congenital clefting conditions is approximately 1:500 to 1:1000 live births depending on ethnicity and locale. It is more common in Asian and Native American populations and least common in African and African American populations [12-14]. Depending on the type of cleft involved, 10-40% of affected individuals may also be found to have an associated syndrome or genetic difference (Table 1) [13,15,16].

<b>How did this happen?</b>	<b>Embryology</b>
No single cause has been identified for cleft lip and/or palate	Congenital clefting occurs during first 5-7 weeks of gestation
Results from a combination of inherited and environmental factors	Embryo is developing into its earliest fetal form
Folate deficiency or prenatal tobacco use may play a role for some families	Often occurs before most mothers know they are pregnant
Maternal diabetes can increase the risk of orofacial clefting	Central face is created from lateral nasal prominences migrating medially to join the medial nasal prominence
Prenatal use of antiepilepsy drugs can increase the risk of orofacial clefting Often, the cause cannot be definitively explained	Disruptions in migration or fusion process can result in a variety of clefting conditions of the lip and/or palate
<b>Associated Syndromes</b>	<b>Genetic Counseling</b>
20-40% of patients with a cleft are found to have underlying syndrome or genetic abnormality	Can help determine if an underlying syndrome is involved
More common with isolated cleft palate	Can help a family determine the risk for recurrence in a future child
More than 200 different syndromes have been associated with orofacial clefting	Blood work may be recommended based on family history, medical history, or clinical findings
Common cleft-associated syndromes include: Van der Woude’s Syndrome, Stickler’s Syndrome, 22q11.2 Deletion Syndrome, and CHARGE Syndrome	Counseling can happen over time if other issues are identified as the child develops
Trisomy 13, 18, and 21 have all been reported with concomitant cleft abnormalities	New genetic findings may help explain causes that were previously not explained
Goldenhaar syndrome, Treacher Collins Syndrome, and Pierre Robin sequence are frequently seen to co-occur with cleft palate	During family consultation before or after delivery it is important to provide reassurance to the parents that this was not their fault

**Table 1:** Cleft Lip and Palate Facts.

Historically, congenital clefting conditions are diagnosed at birth, but prenatal diagnosis is becoming much more common. The use of 3-D and 4-D ultrasound technology can give a good view of the upper lip and nose to allow diagnosis of unilateral and bilateral clefts of the lip. The palate, however, is difficult to visualize on ultrasound. Even with a known cleft of the lip, it is hard to accurately estimate the extent of palate co-involvement prenatally [15,17,18]. Even with modern ultrasound techniques clefting can still be missed altogether depending on the baby’s positioning. Prenatal diagnosis is beneficial because a family can be offered prenatal counselling. A multidisciplinary prenatal consultation will provide information about the condition and help the family anticipate the baby’s needs after delivery. This type of prenatal counselling has been shown to positively impact feeding outcomes and increases the chances the infant will be provided human milk after delivery [3,18-21]. Depending on the presence of other significant health concerns identified prenatally, arrangements may be made for in-hospital delivery or direct transfer into the NICU after birth. Typically, though, infants with cleft lip and/or

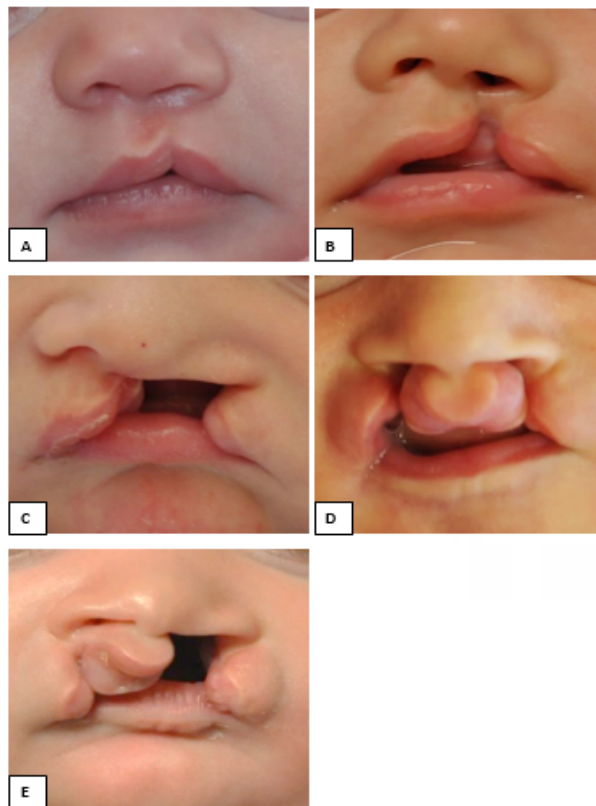
palate can be delivered locally and will not require advanced-level nursery care.

**Methods**

The content of this article is based on a formalized educational program presented to local birthing hospitals in the catchment area of our busy Cleft and Craniofacial Center. It was evident that families were commonly arriving for Cleft Team care in a delayed fashion. Infants were demonstrating poorly established feeding skills and growth patterns. Families reported receiving limited information at their birth hospitals related to cleft-appropriate care. When cleft-specialized bottles were provided, bedside providers often had limited knowledge of their use and function. This educational program, given as a hands-on lecture including practice with bottle assembly and manipulation, has been provided on multiple occasions to local and regional lactation consultants, neonatal and post-partum nurses, and advanced practice providers. All of them indicated their previous lack of exposure and appreciation of this type of education.

## Different Types of Clefts

Clefting can involve the lip, the palate, or a combination of the two. It is important to realize that no two clefts are identical so each patient will require individualized care to achieve best outcomes. In the case of an isolated cleft of the lip there is a defect within portions of the skin and mucosa of the upper lip as well as the underlying orbicularis oris muscle. A cleft of the upper lip can be unilateral or bilateral. They can be “incomplete” when portions of the upper lip or nasal floor remain intact. A “complete” cleft of the upper lip will involve a complete separation through the lip tissues and nasal floor (Figure 1). The orbicularis oris muscle of the lip will be malpositioned and insert into the base of the nose. This results in spreading of the nasal base. Distortion of the nasal shape occurs from a widened and oblong nostril on the side of the cleft. In a unilateral cleft lip, the anterior nasal septum may deviate as well causing the midline of the nose to tilt away from the cleft. When there is bilateral involvement of the lip the central lip tissue becomes separated from the lateral components. The nasal symmetry may be better in these cases since both nostrils are similarly affected. Directly behind the cleft of the lip there may or may not be a defect within the gumline. Gumline involvement can range from an insignificant furrow, deep notching, or a complete separation.

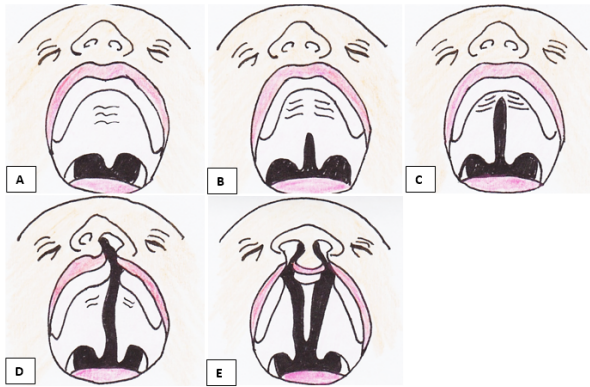


**Figure 1:** Different cleft types; A: unilateral incomplete cleft lip; B: Unilateral incomplete cleft lip; C: Unilateral complete cleft lip and palate; D: Bilateral complete cleft lip and palate; E: Bilateral incomplete cleft lip and palate.

When a cleft lip occurs in conjunction with a cleft palate there is a split through the lip skin, lip muscle, gum line, and the hard and soft palate. Clefting of the palate can also occur in an isolated fashion with an intact lip. This is in fact, the most common presentation of congenital clefting. Width and extent of an isolated cleft palate can be highly variable [22,23]. A defect in the palate creates a direct connection between the mouth and the nose. This allows food and fluid to easily pass into the nose during feeding or with reflux (Figure 2). A cleft palate creates both feeding and speech

difficulties for the child. Until the palate is adequately repaired and the mouth-nose connection uncoupled, there will be impairment in the development of normal speech. Sounds will naturally be transmitted into the nose creating nasal sounds and limiting the ability to create the necessary oral pressure required to produce numerous consonant sounds [24]. The palate defect can also affect hearing by causing inadequate opening of the Eustachian tube and build-up of fluid in the middle ear. These infants are at risk for more frequent ear infections and conductive hearing loss. Many

of these infants demonstrate early problems and do not pass their newborn hearing tests [25-27]. The defect around the cleft gumline is almost always associated with tooth abnormalities that become evident as the primary dentition erupts [28,29].



**Figure 2:** Palatal clefting; A: normal palate; B: soft palate cleft; C: soft and hard palate cleft; D: unilateral complete cleft lip and palate; E: Bilateral complete cleft lip and palate. (Images adapted from Rautio J et al., Guidelines for the treatment of cleft lip and palate; Duodecim 2010;126:1286-1294)

### Impact on Feeding

In the newborn period successful feeding is the biggest concern for infants born with orofacial clefting. Poor feeding for these infants can lead to poor weight gain, dehydration and failure to thrive. Nutrition, oral intake, and growth assessment should be evaluated at all clinic visits. The ability to feed varies significantly between infants. In the case of isolated clefting of the lip and gumline, feeding skills are not typically affected. These infants should be able to breast and/or bottle feed with minimal accommodations presuming there are no other alterations in their health [1,5,21]. Often the volume of the breast or the bottle nipple is used to fill the cleft defect allowing for appropriate latch. There may still be loss of liquids through the nose depending on cleft involvement of the anterior nasal floor.

A cleft in the secondary palate which occurs posterior to the gumline creates an “open system”. These are the infants that will typically have difficulty generating sufficient pressure differentials to extract milk from a breast or bottle using a typical sucking pattern [1,8,11,30-33]. They must rely on the tongue and jaw to “mash” the nipple to capture the milk that escapes. There is frequent extraoral loss of milk around the cleft and through the nose. Infants with palatal clefting with or without lip involvement are likely to require feedings away from the breast to meet their nutritional needs. This does not preclude, however, the use of expressed breast milk or non-nutritive feedings at the breast to promote bonding. These families typically require extra monitoring and lactation support due to the increased stress associated with

feeding challenges, unexpected changes to breastfeeding plans, and the potential need to express milk frequently to maintain an adequate supply [19,34-37].

It is helpful to know that feeding an infant with a cleft can be messy and time consuming compared to other infants because of the extraoral losses of milk. Feeding takes training, practice, and flexibility for infants and parents to become efficient. Newborns with an oral cleft may have a delayed return to birth weight. This is most pronounced in infants with isolated cleft palate [21]. Once effective feeding patterns are established these infants will generally be able to start cereal and other baby foods at a typical age. Children with a cleft of the palate will often be recommended for free-flow cup training to encourage transition off the bottle before one year of age and prior to undergoing surgery to repair the palate. Experienced bedside caregivers may be familiar with palatal obturators. Historically these were popular devices used to help infants with a cleft palate to feed better. These prosthetic aids are designed to sit over the cleft palate defect and artificially separate the mouth and nose [38]. The obturator provides a rigid platform for the infant to suck against, but it does not solve the problem of decreased negative pressure. Creation and fitting of a palatal obturator requires a formal dental impression and requires replacement as the infant grows. Obturators are also hard to keep in place before dental eruption occurs. Formal research has not supported claims of improved infant feeding or weight gain compared with infants that were not fitted with an obturator. As a result, our team does not recommend these for infant cleft feeding anymore. [38,39].

### Breastfeeding and Cleft Palate

As mentioned previously, infants with clefts of the palate may prove unable to successfully breastfeed. This occurs because they are unable to independently extract an adequate amount of breast milk due to difficulty maintaining a latch and difficulty creating the necessary negative pressure to remove milk. There are mothers who have reported their success with breastfeeding and there are videos circulating on the internet of infants with unrepaired cleft palates being breastfed to show that it is possible. Most typically the infant is not independently able to extract breast milk, but instead, the mother must hand express the breast milk into the baby’s mouth [40]. This can often be a frustrating and time-consuming process and does not allow the baby to develop a natural latch or paced feeding rhythms. If the process remains unsuccessful for too long, the infant may be at significant risk for failure to thrive. We support a mother’s desire to provide human milk and encourage the expression of milk whenever possible. Another option is to provide breast milk to the infant in a specialized cleft bottle which will help decrease excess energy expenditure from prolonged and inefficient feedings. Cup feeding or spoon-feeding breast milk to an infant is also possible, but these are much less efficient and do not support a natural latch or feeding

rhythms well.

Due to its protective benefits, breast milk should be provided when available and we encourage early and frequent milk expression combined with skin-to-skin contact between mother and baby [41]. In the U.S. a hospital grade double electric breast pump is well-suited to allow efficient milk expression and the ability to build and maintain an adequate supply long-term. There are also special pump settings designed to establish and build a supply for mothers who need to pump exclusively for their infants [42,43]. Once the baby's weight gain is steady, the mother is encouraged to put the baby to the breast after full bottle feedings for non-nutritive nursing to promote bonding. It is important to encourage mother self-care and relaxation to allow adequate milk flow. Helping manage external stressors as well as rapid treatment of suspected mastitis, ulcerations, or other breast symptoms can help prevent stress-related milk supply loss or decisions to discontinue pumping. This type of early lactation support has been shown to help mothers of vulnerable infants successfully navigate the common reasons for early cessation and ultimately provide expressed breast milk long term to their infants [19,34-37]. Simple solutions like using a "hands-free" pumping bra can facilitate efficient pumping while accomplishing other daily tasks. Our initial recommendation is to attempt 120 minutes of pumping each day. There are reports of infants successfully returning to the breast for exclusive feeding after cleft palate repair. This is not typical, however, for infants in the U.S. It requires a large degree of luck and persistence of the mother-infant pair [40,44].

### **Teaching the Basics**

Bedside providers who are asked to help mothers of newborns with cleft lip and/or palate are encouraged to focus on teaching the basics. Mothers need to know the signs of effective feeding, the expected frequency and duration of feedings, and the expected weight gain over time so they can help monitor their baby's progress. For mothers who choose to provide breast milk to their infant with a cleft it is important to start pumping early. Teaching and encouraging effective pumping strategies to provide colostrum and to build and maintain an adequate milk supply are important for these mothers. Exclusive pumping resources are invaluable as this experience can differ significantly from mothers who pump more infrequently for convenience or for engorgement. When a cleft palate is involved, and the baby requires a specialized cleft feeder, basic education on the design and assembly is critical. Parents should be encouraged to look for and respect infant cues for feeding such cues of hunger, satiety, or tiredness. The quality of the feeding can be as important as the quantity. We discourage force feeding the baby at any age. The goal is a happy, well-nourished child.

### **Awareness of Feeding Goals**

Generally, infants with cleft lip and palate are expected to

maintain the same growth expectations as infants without clefting. Without the presence of a syndrome or prematurity, infant growth should be plotted on the World Health Organization growth charts from age 0-2 years (boys: [https://www.who.int/childgrowth/standards/cht\\_wfa\\_boys\\_p\\_0\\_2.pdf?ua=1](https://www.who.int/childgrowth/standards/cht_wfa_boys_p_0_2.pdf?ua=1); girls: [https://www.who.int/childgrowth/standards/cht\\_wfa\\_girls\\_p\\_0\\_2.pdf?ua=1](https://www.who.int/childgrowth/standards/cht_wfa_girls_p_0_2.pdf?ua=1)) [41]. Infants with cleft lip and/or palate should be expected to gain approximately 25-35g/day weight gain during the first 3 months of life.<sup>10,11</sup> During the first 6 months of life, energy needs are approximately 102 kcal/kg and 1.52 g protein/kg as provided by breast milk or formula [41]. Parents of these infants should also be educated on the signs and symptoms of Gastroesophageal Reflux (GERD) and encouraged to monitor for it closely as GERD can interfere with feeding success from feeding avoidance or loss of volume through spit-up [45].

In the event the infant has difficulty achieving adequate weight gain, close feeding history and direct assessment is necessary to help determine the most likely cause. Most often, for infants who appears to be latching and using good mechanics, we will recommend fortification of the breast milk or formula to provide additional calories at every feeding. We also see problems where caregivers have not increased volumes or maintained appropriate frequency of feedings. In these cases, helping them to establish a set feeding schedule and total volume recommendations will be helpful. For other infants, minor adjustments in feeding techniques or helpful bottling tips may be all that is necessary. Individualized care is important and different techniques and interventions will be discussed below.

### **An Individualized Feeding Plan**

Each mother and infant pair should have an individualized care plan. It is important to determine up front what the mother's goals for feeding are. If she wants to provide breast milk, then her supply will help dictate how soon she can provide full feeds or if supplementation will be needed. Recognizing a mother's external stressors will help one understand any challenges with supply or desire, and overall commitment to providing breast milk long term. When breast milk is not available, standard infant formula is advised [41]. Infant factors play an important role as well. Intrinsic feeding skills will determine how fast a child can take full feeds effectively. Intrinsic growth delays can skew assessments of the adequacy of feeding so knowledge of underlying syndromes or anticipated slow growth will help in management of feeding and nutrition. Comfort feeds are offered to provide mother-infant bonding time but they are not expected to provide much in the way of nutrition. Indirect feeding through a temporary or surgically placed feeding tube may also be necessary if adequate feeding skills are not achieved or failure to thrive is evidenced despite adequate nutritional intake of volume and calories.

There are many different feeding positions to consider, some

of which are more favorable for an infant with a cleft. Upright feeding positions are encouraged so that the cleft lip is at the top of the breast. For infants with bilateral lip involvement a ‘Face-on’ or ‘Straddle’ position may be more effective. A ‘Football hold’ can also provide similar positioning (<https://wicbreastfeeding.fns.usda.gov/5-breastfeeding-holds-try>). It is important to guide the nipple downward into the infant’s mouth. A mother will want to support the infant’s chin and the breast at the same time. The upright positions will help decrease milk loss from around the cleft or through the nose. Typically, the breast tissue can help fill in the soft tissue defect of the lip to prevent leakage.

Gravity drainage systems can seem like a great way to simulate feeding at the breast in these children. Unfortunately, standard Supplemental Nursing Systems (SNS) still rely on some amount of negative pressure to extract the milk from the feeder tube. Instead, active supplementation at the breast may be more helpful by using a syringe and feeding tube. This is again, not ideal for establishing infant-paced feeding, but can be an option for mothers who feel very strongly about the baby-to-breast experience. Brecht feeders, a soft flexible tube tip attached to a syringe or butterfly tubing can work similarly to provide milk. We do not formally recommend any of the devices that rely on negative pressure for infants with cleft palate due to unreliable success rate in establishing effective feeds.

### **Bottle-Feeding Infants with Cleft Palate**

In the U.S. a key component of feeding education for infants with cleft palate relates to bottling. This includes information on bottle options, how to assemble and use them, and special tips/recommendations for baby-bottle interchanges. Just as with breastfeeding, it is recommended that when bottle feeding an infant with a cleft palate the child be held in a primarily upright position during feeding. Avoiding the classic cradling position can help minimize liquid entering the nasal cavity which promotes nasal reflux. Alternately, an elevated side lying position can be helpful for similar reasons while still allowing for visualization of the feed. It is common for inexperienced caregivers to direct the tip of the nipple into the gap created by a cleft in the lip, but this then directs the nipple and milk flow towards the nose as it is in continuity with the mouth. Instead, it is recommended to direct the tip of the nipple towards the most intact portion of the palate or downwards towards the tongue to help encourage milk flow towards the oropharynx. Caregivers should monitor the infant for an adequate coordination of a suck-swallow-breathe pattern. It is also important to recognize that the infant with a cleft palate will typically swallow more air during feeds than other infants. Frequent burping is helpful to prevent large volume reflux, early satiety, and loss of interest in feeding [11]. Full feedings should typically take no more than 30 minutes, or the infant will start to expend more energy feeding than they are gaining from the

feed. Efficient feeders will be able to do this easily. This is a good benchmark for caregivers to know how well the feeding process is going early on.

There are several different cleft feeding bottles available commercially in the U.S. and many other countries. Each has its advantages and disadvantages. While all should technically work, in our experience, the infant will dictate which option is most preferred. If one does not seem to be working well it is worthwhile to try an alternate bottling system. Before the easy availability of commercial cleft feeders, it was common to recommend cutting a hole or large “X” in the top of a standard infant nipple to allow easy free flow of milk. While this can definitely allow an infant with a cleft palate to extract milk more easily, it is a poorly controlled system and often newborn infants are overwhelmed with the rate or volume of milk. Differences in cuts nipple-to-nipple can also prove frustrating for an infant used to a particular nipple. Cutting nipples in this way can also degrade the nipples quickly or small pieces can break off which can be a choking hazard.

### **Bottle Options**

The most common commercially available systems in wide use today in the U.S. are the Dr. Brown’s® Specialty feeding system, the Medela SpecialNeeds Feeder®, the Pigeon Nipple, and the Mead Johnson™ Nurser. These feeders have similarities and differences which are helpful to understand. Given that different nurseries may use one system over another each will be briefly discussed. The first three bottles listed have a basic design which includes a one-way valve. This valve keeps milk within the nipple creating a pressure head that allows for steady milk flow when the infant compresses the nipple without the need for suction.

#### **Dr. Brown’s® Specialty Feeding System**

The Dr. Brown’s® Specialty feeding system is the most recent arrival to the world of cleft feeders. The system works with a one-way valve in an otherwise typical-looking bottle. You can increase the flow rate of milk by changing to a higher ‘level’ of nipple. Without the one-valve inserted into the base of the nipple, it works like a typical Dr. Brown’s® bottle, so this accessory valve piece is the key for a child with a cleft palate. The basic bottles are easy to find in stores, but the valves must be special-ordered or provided by the cleft team.

To assemble the nipple-valve system the flat side of the blue valve is directed towards the top of the nipple. The center stem inside the valve should point down towards the bottle. Once inserted, the valve should be flush with the bottom of the nipple. The nipple, with the valve in place, is then inserted into the nipple ring. It is easier to place the valve into the nipple before the nipple is in the plastic ring. The remainder of the Dr. Brown’s® bottle assembly includes snapping the cream-colored reservoir into the blue (or pink) insert. This is put into the bottle and the nipple-

ring attached (Figure 3). There is a “Fill line” warning and it is important not to overfill the bottle. It is better to swirl the formula to mix it rather than shaking to minimize bubbles. When attaching the nipple ring, closing it too tightly may prevent the valve system from working. If it is too loose the ring can leak. This is true for all the valve-based systems. It is recommended that the system be primed by squeezing the nipple, inverting the bottle, then releasing the nipple. This allows milk to flow into the nipple through the valve. Once primed, the action of feeding will allow the nipple to keep filling. Additional resources for feeding therapists and families can be found at drbrownsbaby.com.



**Figure 3:** Dr. Brown's® Specialty Feeder Nipple Assembly

### Medela Special Needs Feeder®

The Medela SpecialNeeds Feeder®, once called the Haberman bottle, has been in use for many years. The advantage of this system includes the presence of three flow rates in one nipple due to changes in the orientation of the opening at the nipple end depending on how it is held. The nipple is soft and easy to squeeze which allows for parent-assisted pressure to increase the flow rate or help with pacing. This bottle tends to work even with the weakest of sucks as milk will flow with simple compression of the nipple. The one-way valve is a very small flat piece of plastic and is assembled with two pieces. The nipple is somewhat atypical in appearance which can make some families anxious. These bottles are also quite expensive and can cost upwards of US\$25 per system. The nipples do not tolerate boiling or microwave sterilization well so they must be washed by hand. Nonetheless, this bottle works well for many, many infants which is why it has

been so successful over the years. Hospitals are also very familiar with using these bottles.

To assemble the valve, the white rubber disk membrane is pressed into the upper side of the larger yellow hard plastic disk until the membrane stud goes through the center hole. The clear nipple is then placed into the nipple collar (Yellow ring). The valve components are then placed into the nipple-ring assembly. The white membrane should face the top of the nipple and the stud face towards the bottle and away from the nipple (Figure 4). The bottle can be filled and primed similarly to the Dr. Brown's® system although two or three squeezes and inversions of the bottle may be required to fill the nipple half to three-quarters full.



**Figure 4:** Medela SpecialNeeds Feeder® Nipple Assembly.

To select the flow rate, the appropriate flow line is pointed towards the baby's nose. The longest line is the fastest flow, the medium line is medium flow, and the shortest line provides the slowest flow. Technically speaking, by directing the space between the lines towards the nose in-between flow rates can be achieved, either medium-slow or medium-fast so up to five flow rates can exist with the same nipple. The nipple is also long enough to easily provide room to squeeze it and provide constant flow to assist babies with weak effort. It is helpful for caregivers to familiarize themselves with this system by practicing assembly, filling, and squeezing the nipple before first use. The packaging contains very detailed instructions on use and assembly. More information including a feeding video and downloadable instructions are available at [www.medelabreastfeedingus.com/products/576/specialneeds-feeder](http://www.medelabreastfeedingus.com/products/576/specialneeds-feeder).

### Pigeon Bottling System

The Pigeon bottling system comes as only a nipple and valve that is able to be used with any standard small-mouth bottle. It

has the advantages of being a more typical-looking system with a simple one-piece valve and minimal parts. One side of the nipple is firmer which is directed towards the roof of the mouth to mimic the firmness of the palate. Overall, it functions very similarly to the Dr. Brown's® system. The disadvantages of the pigeon system are that it has not always been as readily available as the Medela SpecialNeeds Feeder®. Some complain that the stiff side of the nipple can cause ulcerations on the palate although this can be true of any nipple. The nipple is also relatively fast flowing which may not be tolerated by some infants.

To assemble the Pigeon system, the one-way valve is placed into the nipple. The flat side faces into the nipple and the pointed stem faces down into the bottle. The valve should sit flush with the bottom of the nipple. The nipple can then be inserted into the nipple ring (Figure 5). The ring-nipple-valve assembly is then attached to the filled bottle. As with all these systems, if the ring is placed too tightly the valve may not function well and if it is too loose the bottle will leak. The nipple is primed by squeezing it and inverting the bottle to draw milk into the nipple. There is a notch located on one side of the nipple (The firmer half) and this notch is pointed towards the nose to orient the nipple appropriately. There is officially only one flow rate for this system, but some providers note that if you turn the nipple a quarter turn so the notch is directed toward the oral commissure the flow rate can be decreased. More information is available at [https://clefline.org/wp-content/uploads/2018/10/Pigeon-Cleft-Palate-Nipple-System-Product-Improvements-Information-Sheet.\\_-003.pdf](https://clefline.org/wp-content/uploads/2018/10/Pigeon-Cleft-Palate-Nipple-System-Product-Improvements-Information-Sheet._-003.pdf).



Figure 5: Pigeon Bottle Nipple Assembly.

### Mead Johnson™ Cleft Nurser

The Mead Johnson™ bottle does not work with a valve system, but rather a regular nipple and ring on a specialized soft polyethylene bottle. The bottle is wide and flexible and is designed for compression (Figure 6). By rhythmically squeezing the bottle the milk can be pumped into the infant's mouth. This does not allow the infant to regulate the pace of feeding and requires close monitoring of the infant's swallowing pattern. Because of the large size of the bottle it looks different from other baby bottles, but assembly is typical. This bottle is relatively inexpensive at less

than US\$3 each but must be special ordered. Some authors suggest this bottle system is favorable because of its ease of use [46]. In our experience, this bottle is the best option when thickened liquids are required because the valve systems typically do not work well with most thickening agents. For ordering information see [www.enfamil.com/shop](http://www.enfamil.com/shop).



Figure 6: Mead Johnson™ Cleft Nurser.

### Helpful Bottling Techniques

There are several helpful techniques that feeding specialists recommend to support successful feeding. We stress the importance of infant-driven or cue-based feeding. Feedings should be enjoyable for both baby and caregivers. If weight gain becomes an ongoing issue, then non-oral supplemental feedings via nasogastric tube or surgical feeding tube should be considered. Nearly all of the cleft feeding systems allow for some amount of squeezing of the bottle or nipple to provide flow support. This should be used with caution, so the infant is not flooded with too much milk at one time. If this support is needed the caregiver should only squeeze the nipple when the baby is actively feeding. Squeezing is released when the baby stops for breathing and swallowing. This takes appropriate attention and coordination for the caregiver. Providers can demonstrate pacing of feeds to the family to familiarize them with how this looks and sounds. Even without squeezing, respiratory pacing is helpful to improve the suck-swallow-breathe coordination for newborns. After the baby takes 2-3 sucks, the bottle is tipped down to remove the milk from the nipple (Do not remove the nipple from the baby's mouth) so the mouth is not overfilled with milk which can promote choking and reflux. After the baby swallows and takes a breath, the bottle is tipped up to fill the nipple. This cycle is repeated as needed throughout the feeding. As feeding skills improve, the need for pacing should decrease. It is important to monitor closely for signs of aspiration especially if the baby has an associated syndrome.

Chin support can be a helpful aid for infants with inefficient bottling because of excessive jaw movement. Placing a finger under the bony part of the chin will allow the caregiver's finger to



serve as a fence or border to prevent excessive jaw movement. It is important to note that some jaw movement is normal so the finger should not be used to restrict all movement. For infants with wide clefts of the lip taping may be recommended. Lip taping can be performed with Steri-Strips™ or half-inch paper tape placed across the lip after gentle compression of the lip segments together. There are also commercially available products designed specifically for cleft lip taping. Lip taping can support orbicularis oris functioning for successful latch and compression of the nipple during active feeding (Figure 7). Over several weeks' time lip taping can also help to passively narrow a wide cleft considerably which can make feeding and eventual surgery easier.



**Figure 7:** Example of Cleft Lip Taping with DynaCleft® Positioning Strips (more information available at <https://www.cranio rehab.com/DynaCleft>).

In summary, the establishment of feeding and growth are key issues for infants with cleft lip and/or palate. While exclusive breastfeeding is not generally recommended when baby has a cleft palate, the use of mother's milk is strongly encouraged whenever possible. Syndromes and other medical issues are common in these infants which can also affect feeding and newborn care. For children with significant multisystem issues, it is appropriate to

adequately prioritize cleft-related care. As a final note it is important to encourage picture taking and normalization of bonding for all parents of children affected by orofacial clefting.

### Impact to Nursing Practice

Neonatal and post-partum nursing providers are in a key position to positively impact the early feeding success of infants born with orofacial cleft conditions. Often nurses may have limited experience or exposure to children affected by clefting and nurses may benefit from directed education on understanding and assisting with these infants' early feeding challenges. Nurses can help these families in many ways including encouraging a mother of a child with a cleft palate to start expressing her milk early to build her supply, demonstrating for the family how to use a cleft-specialized feeder in the first few hours after delivery, and support with any necessary transitions to cleft-specialized feeding. Nurses can observe as parents assemble and use the bottles to help to ensure appropriate techniques. Providing parents with realistic 24-hour feeding goals can help decrease the pressure at each feeding. Bedside providers can also help establish next steps of care by referring infants with orofacial clefting to the appropriate multidisciplinary cleft team prior to discharge (Table 2). This allows early first contact between families and their future cleft-care providers, particularly if feeding remains a challenge. Cleft team providers can offer a variety of in-person, phone, or video-based assistance to improve feeding before it becomes a prolonged issue. Nurses can also provide families with resources for cleft-related bottling and exclusive pumping if the infant has a cleft of the palate and the mother wants to provide human milk. Cleftline.org managed by the American Cleft Palate-Craniofacial Association can provide bedside caregivers with many online and in-print education resources for families of children with cleft or craniofacial conditions. This site offers a wide variety of helpful and reliable cleft care information including feeding videos and cleft bottle ordering information.

Cleft Team Care	Team Members
<ul style="list-style-type: none"> <li>• Optimum care occurs when children with clefts are treated in a coordinated fashion by an interdisciplinary team of cleft-related specialists</li> <li>• Each specialty serves different roles at different times for a particular child</li> <li>• Patients are evaluated soon after birth in order to assess the child and make initial care recommendations</li> <li>• Together the team maps out an individualized care plan based on the cleft presentation and concomitant medical issues</li> <li>• Major medical and cleft-related issues are identified and plans for feeding and any necessary early surgeries are made</li> <li>• Families are provided with education regarding appropriate feeding and growth</li> <li>• Feeding and lactation resources are provided to help support the family at home</li> <li>• The team works to identify barriers to care and connects the family with community resources</li> <li>• The team works to coordinate the child’s medical care with any outside providers</li> <li>• Cleft team follows the child regularly over time to help anticipate and manage any cleft-related issues including speech, hearing, learning, dental, or psychosocial issues</li> </ul>	<p>Cleft Team members can include specialists from all of the following disciplines:</p> <ul style="list-style-type: none"> <li>Audiology</li> <li>Dental</li> <li>Genetics</li> <li>Lactation</li> <li>Nursing</li> <li>Nutrition</li> <li>Occupational Therapy</li> <li>Oral surgeons</li> <li>Orthodontics</li> <li>Otorhinolaryngology</li> <li>Plastic Surgery</li> <li>Psychology</li> <li>Social Work</li> <li>Speech-Language Pathology</li> </ul> <hr/> <p style="text-align: center;"><b>Basic Cleft Care Timeline</b></p> <p style="text-align: center;"><b>Birth to 3 months:</b> Monitor feeding and growth  <b>3-6 months:</b> Cleft Lip Repair  <b>9-18 months:</b> Cleft Palate Repair, Ear tubes  <b>6-9 years:</b> Orthodontics  <b>6-9 years:</b> Gumline Repair  <b>16-18 years:</b> Jaw Surgery, Rhinoplasty</p>

**Table 2:** Team-Based Cleft Care Concepts.

**Conflicts of Interest**

All authors certify that they have no conflicts of interest including no sponsorship affiliations or any financial interest or non-financial interest in the products or materials discussed in this manuscript.

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**References**

1. Miller CK (2011) Feeding issues and interventions in infants and children with clefts and craniofacial syndromes. *Semin Speech Lang* 32: 115-26.
2. Goyal A, Jena AK, Kaur M (2012) Nature of feeding practices among children with cleft lip and palate. *J Indian Soc Pedod Prev Dent* 30: 47-50.
3. Baylis AL, Pearson GD, Hall C, Madhour LL, Cummings C, et al. (2018) A quality improvement initiative to improve feeding and growth of infants with cleft lip and/or palate. *Cleft Palate-Craniofac J* 55: 1218-1224.
4. Gottschlich MM, Mayes T, Allgeier C, James L, Khoury J, et al. (2018) A retrospective study identifying breast milk feeding disparities in infants with cleft palate. *The Journal of the Academy of Nutrition and Dietetics* 118: 2154-2161.
5. Kucukguven A, Calis M, Ozgur F (2020) Assessment of nutrition and feeding interventions in Turkish infants with cleft lip and/or palate. *J Pediatr Nurs* 51; e39-e44.
6. Martin V, Greatrex-White S (2014) An evaluation of factors influencing feeding in babies with a cleft palate with and without a cleft lip. *J Child Health Care* 18: 72-83.
7. Lindberg N, Berglund AL (2014) Mothers’ experiences of feeding babies born with cleft lip and palate. *Scand J Caring Sci* 28: 66-73.
8. McGuire E (2017) Cleft lip and palates and breastfeeding. *Breastfeed Rev* 25: 17-23.

9. Snyder M, Ruscello DM (2019) Parent perceptions of initial feeding experiences of children born with cleft palate in a rural locale. *Cleft Palate Craniofac J* 56: 908-917.
10. Hartzell LD, Kilpatrick LA (2014) Diagnosis and management of patients with clefts: a comprehensive and interdisciplinary approach. *Otolaryngol Clin N Am* 47: 821-852.
11. Burca NDL, Gephart SM, Miller C, Cote C (2016) Promoting breast milk nutrition in infants with cleft lip and/or palate. *Advances in Neonatal Care* 16: 337-344.
12. Mossey PA, Modell B (2012) Epidemiology of Oral Clefts 2012: An International Perspective. *Frontiers of oral biology* 16: 1-18.
13. Watkins SE, Meyer RE, Strauss RP, Ayslworth AS (2014) Classification, epidemiology, and genetics of orofacial cleft. *Clin Plastic Surg* 41: 149-163.
14. Esheti M, Butali A, Deressa W, Pagan-Rivera K, Hailu T, et al. (2017) Descriptive epidemiology of orofacial clefts in Ethiopia. *J Craniofac Surg* 28: 334-337.
15. Losee JE, Kirschner RE (2016) *Comprehensive Cleft Care*, (2<sup>nd</sup> Edition) CRC Press, Taylor & Francis Group: Boca Raton, Florida.
16. Kobayashi GS, Brito LA, Meira JGC, Alvizi L, Passos-Bueno MR (2018) Genetics of Cleft Lip and Cleft Palate: Perspectives in Surgery Management and Outcome. In Alonso N, Raposo-Amaral CE (Editions) *Cleft Lip and Palate Treatment*, Springer International Publishing 25-35.
17. William WK (2012) Prenatal diagnosis and assessment of facial clefts: where are we now? *Hong Kong Med J* 18: 146-52.
18. Levaillant JM, Nicot R, Benouaiche L, Couly G, Rotten D (2016) Prenatal diagnosis of cleft lip/palate: the surface rendered oropalatal (SROP) view of the fetal lips and palate, a tool to improve information-sharing within the orofacial team and with the parents. *J Craniomaxillofac Surg* 44: 835-842.
19. Martino K, Wagner M, Froh EB, Hanlon AL, Spatz DL (2015) Postdischarge breastfeeding outcomes of infants with complex anomalies that require surgery. *J Obstet Gynecol Neonatal Nurs* 44: 450-457.
20. Torowicz DL, Seelhorst A, Froh EB, Spatz DL (2015) Human milk and breastfeeding outcomes in infants with congenital heart disease. *Breastfeed Med* 10: 31-37.
21. Kaye A, Thaete K, Snell A, Chesser C, Goldak C, et al. (2017) Initial Nutritional Assessment of Infants with Cleft Lip and/or Palate: Interventions and Return to Birth Weight. *Cleft Palate Craniofac J* 54: 127-136.
22. Wang TD, Milczuk HA (2014) *Cleft Lip and Palate*. Flint PW, Haughey BH, Lund V, Niparko JK, Robbins KT, Thomas JR, Lesperance MM (Editions), *Cummings Otolaryngology: Head and Neck Surgery* 2915-2932.
23. Burg ML, Chai Y, Yao CA, Magee W, Figueiredo JC (2016) Epidemiology, etiology, and treatment of isolated cleft palate. *Front Physiol* 7: 67.
24. Kummer AW (2018) A Pediatrician's Guide to Communication Disorders Secondary to Cleft Lip/Palate. *Pediatr Clin North Am* 65: 31-46.
25. Jordan VA, Sidman JD (2014) Hearing Outcomes in Children with Cleft Palate and Referred Newborn Hearing Screen. *The Laryngoscope* 124: e384-388.
26. Tan EEK, Hee KYM, Yeoh A, Lim SB, Tan HKK, et al. (2014) Hearing Loss in Newborns with Cleft Lip and/or Palate. *Ann Acad Med Singapore* 43: 371-377.
27. Purcell PL, Sie KCY, Edwards TC, Lochner-Doyle D, Neidt K (2018) Identification of oral clefts as a risk factor for hearing loss during newborn hearing screening. *J Early Hear Detect Interv* 3: 21-28.
28. Haque S, Alam MK (2014) Common dental anomalies in cleft lip and palate patients. *Malays J Med Sci* 22: 55-60.
29. Sá J, Araújo L, Guimarães L, Maranhão S, Lopes G, et al. (2016) Dental anomalies inside the cleft region in individuals with nonsyndromic cleft lip with or without cleft palate. *Med Oral Patol Oral Circ Bucal* 21: e48-52.
30. Bessell A, Hooper L, Shaw WC, Reilly S, Reid J, et al. (2011) Feeding interventions for growth and development in infants with cleft lip, cleft palate or cleft lip and palate. *Cochrane Database of Systematic Reviews* 16: CD003315.
31. Ize-Iyanu IN, Saheeb BD (2011) Feeding intervention in cleft lip and palate babies: a practical approach to feeding efficiency and weight gain. *Int J Oral Maxillofac Surg* 40: 916-919.
32. Reilly S, Reid J, Skeat J, Cahir P, Mei C, et al. (2013) *Academy of Breast Feeding Medicine. ABM clinical protocol #17: guidelines for breastfeeding infants with cleft lip, cleft palate, or cleft lip and palate, revised 2013. Breastfeed Med* 8: 349-353.
33. Merrow JM (2016) Feeding management in infants with craniofacial anomalies. *Facial Plast Surg Clin N Am* 24: 437-444.
34. Chen PG, Johnson LW, Rosenthal MS (2012) Sources of education about breastfeeding and breast pump use: what effect do they have on breastfeeding duration? An analysis of the Infant Feeding Practices Survey II. *Matern Child Health J* 16: 1421-1430.
35. Corriveau SK, Drake EE, Kellams AL, Rovnyak VG (2013) Evaluation of an office protocol to increase exclusivity of breastfeeding. *Pediatrics* 131: 942-950.
36. Oakley LL, Henderson J, Redshaw M, Quigley MA (2014) The role of support and other factors in early breastfeeding cessation: an analysis of data from a maternity survey in England. *BMC Pregnancy Childbirth* 14: 88.
37. Kaye A, Cattaneo C, Huff HM, Staggs VS (2019) A Pilot Study of Mothers' Breastfeeding Experiences in Infants with Cleft Lip and/or Palate. *Adv Neonatal Care* 19: 127-137.
38. Goyal M, Chopra R, Bansal K, Marwaha M (2014) Role of obturators and other feeding interventions in patients with cleft lip and palate: a review. *Eur Arch Paediatr Dent* 15: 1-9.
39. Boyce JO, Reilly S, Skeat J, Cahir P (2019) *Academy of Breastfeeding Medicine. ABM Clinical Protocol #17: Guidelines for Breastfeeding Infants with Cleft Lip, Cleft Palate, or Cleft Lip and Palate - Revised 2019. Breastfeeding Medicine* 14: 437-444.
40. Morgan R (2018) *Breastfeeding a Child with a Cleft Lip and Palate. Women's Health Today.*

41. Academy of Nutrition and Dietetics (2018) *Pediatric Nutrition Care Manual*. Chicago, Illinois.
42. Eglash A, Malloy ML (2015) Breastmilk Expression and Breast Pump Technology. *Clin Obstet Gynecol* 58: 855-867.
43. Meier PP, Patel AL, Hoban R, Engstrom JL (2016) Which Breast Pump for Which Mother: An Evidenced-Based Approach to Individualizing Breast Pump Technology. *J Perinatol* 36: 493-499.
44. Farrow A (2014) Breastfeeding a Baby with a Cleft Lip and or Palate - The Red Carpet Treatment. *Breastfeeding USA*.
45. Sdravou K, Emmanouilidou-Fotoulaki E, Mitakidou MR, Printza A, Evangelidou A, et al. (2019) Children with diseases of the upper gastrointestinal tract are more likely to develop feeding problems. *Ann Gastroenterol* 32: 217-223.
46. Shaw WC, Bannister RP, Roberts CT (1999) Assisted Feeding is More Reliable for Infants with Cleft - A Randomized Trial. *Cleft Palate Craniofacial J* 36: 262-268.