

PROTOCOL FOR: Cleft Lip and/or Palate

POLICY: All parents with infants born with cleft lip and/or palate will be referred to the craniofacial team and given instructions in the care of their infant by the nursery nurses, developmental specialists, and medical team.

SUPPORTIVE

DATA: Cleft lip and palate facial malformation results when fusion involving the first brachial arch fails to take place during embryonic development. The lip and palate develop independently; thus, any combination of defects can occur. General management is focused on closure of the cleft(s), prevention of complications, habilitation, and facilitation of normal growth and development of the child. The focus of nursing care and parent education is to provide guidelines for appropriate care of the infant prior to and after surgery to alleviate adjustments in behavior for both parent and infant, i.e., learning to comfort infant without applying pressure to surgical site.

DESIRED PATIENT

- OUTCOME:**
1. Infant demonstrates adequate feeding ability and nutritional intake as evidenced by weight gain.
 2. Infant remains free of infection and aspiration as evidenced by normal vital signs and laboratory values.
 3. Parents show appropriate interaction, attachment and ability to care for child as evidenced by their actions, verbalization and demonstration of care giving competence.

- ASSESSMENTS:**
1. Document type and extent of defect.
 - a. *Report any signs of infection or breakdown around cleft.*
 2. Note any respiratory difficulties, associated stimuli and/or activity, i.e., during sleep, feeding prior to, during, after, if after, how long.
 - a. *Report any signs of respiratory distress.*
 3. Feeding ability - involve developmental specialists early in hospitalization for this evaluation.
 - a. *Report feeding problems or poor weight gain.*
 4. Parent-infant interaction; parent competency handling/feeding infant.

**FEEDING AND
POSITIONING**

- DURING FEEDING:**
1. Infants with cleft lip should be evaluated to determine which bottle and nipple is best for that particular infant. Many infants with an isolated cleft lip will be able to feed with a standard nipple. Some infants will require a different nipple and bottle.
 - a. Infants with cleft palate will almost always require a cleft palate bottle such as the Haberman feeder, the Mead Johnson nurser, or the Pigeon bottle.

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b. For Mead Johnson Nursers:

- 1) Check each new bottle and nipple assembly for defects before use.
- 2) Be sure the cross cuted on the nipple is fully opened by pulling nipple apart in both directions.
- 3) Take filled bottle and squeeze into sink or burp cloth to judge your strength when squeezing into infant's mouth. While squeezing, also check that milk is not draining out around bottleneck. Always overfill bottle, otherwise, it is difficult to keep milk constantly in the nipple.
- 4) Wash bottle and nipple assembly with hot soapy water after use and allow to air-dry. Bottles can be used.

c. Haberman Feeder:

- 1) Make sure slit in nipple is open fully.
- 2) Fill bottle.
- 3) Place valve onto bottle then screw on nipple. Refer to package instructions.
- 4) Squeeze nipple firmly and then turn bottle upside down.
- 5) Release nipple and allow it to fill with formula.
- 6) Repeat process until nipple is full. Nipple holds 27cc. See manual.
- 7) Line up the appropriate flow line on the teat with the infant's nose.

Short line = minimum flow
Medium line = moderate flow
Long line = maximum flow

Adjust the flow according to how the infant is feeding.

- 8) You may need to squeeze nipple gently (supplemental squeezes) to increase the amount of formula flow. If necessary, remove the nipple from the infant's mouth and gently squeeze the nipple into a burp cloth to judge your strength when squeezing into infant's mouth.
- 9) If squeezing the nipple, angle nipple towards the infant's right or left cheek to avoid choking the infant.

d. Pigeon Nurser:

- 1) Assemble nipple and nipple ring.

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- 2) Place the valve (the flat side toward the tip of the nipple) into the nipple. If the valve is difficult to insert into the nipple you may wet it with water.
 - 3) Feed keeping the air vent up and let the baby suck on nipple. The thicker side of the nipple should be placed against the roof of the mouth.
 - 4) If suck is ineffective, the bottle can be squeezed slightly as the baby sucks.
2. With cleft palate with or without cleft lip, the infant will not be able to create suction/negative pressure and thus will have an ineffective suck. Use feeding techniques as instructed by the feeding assessment (OT) or the craniofacial team recommendations. Feeding should take no longer than 30 minutes (except for last burping), after 30 minutes you are losing ground, infant is using more calories to feed than they are consuming. This is the general guideline for all oral feeding.
 3. Many infants with cleft lip will breastfeed well. The soft breast tissue may seal off the cleft lip. Breastfeeding with a cleft palate is more difficult due to issues with sealing the oral cavity to create suction/negative pressure required for milk expression.
 - a. Many infants with cleft palate will not be able to breastfeed. Mothers with infants with cleft palate wishing to breastfeed should be given the opportunity to work with our lactation consultants, developmental therapists, and/or craniofacial team on this issue.
 - b. Depending on the mother's desires/wishes to breastfeed and the projected timing of repair, lactation may be supported by pumping in anticipation of later breastfeeding.
 4. If the infant does not have the ability and/or energy to nipple all feeds, use nasogastric tube feedings until the infant shows readiness to attempt bottle-feeds. Leave N.G. tube in, do not remove, offer bottle, let infant p.o. feed until tired, not to exceed 30 minutes then N.G. feed the remainder. If leaving a N.G. tube in is irritating, an OG tube may be passed and removed.
 5. The feeding assessment should include recommendations for positioning. Generally, infants with cleft palate are fed in a bolt upright sitting position. This position decreases the possibility of fluid being aspirated or returned through the nose. This position also prevents fluid collection into the ears, thus minimizing the risk of ear infection, which is increased with cleft lip and palate. Alternate positions may be utilized (prone, side lying) upon consultation with the OT/CF team.
 6. If the infant has a cleft lip, put the nipple to the side opposite the cleft. When using the supplemental squeezing, direct the angle of the nipple toward the cheek. Avoid directly squeezing formula/breast milk into the pharynx.

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7. When using supplemental squeezing with an infant with cleft palate, allow the infant to guide the feeding. Offer squeezing when the infant sucks and stop when the infant stops. Attempt to establish a rhythm of feeding with the infant. As with any infant, a pattern of sucking bursts followed by brief pauses is expected. It is not necessary to remove the nipple during each pause. This may frustrate the infant and disrupt the overall feeding.
8. Avoid repeated unnecessary removal of the nipple from the mouth because of fear of choking. This frustrates the infant causing him to cry, disrupts the creation of a feeding rhythm and prolongs feeding.
9. Burp the infant frequently. Infants with cleft palate swallow a lot of air. Burp infant sitting up, facing away from the caregiver.

GENERAL

POSITIONING:

1. Some infants may benefit from being placed in an infant seat or held upright for at least 30 minutes after feeding. This position allows mucous to drain easily and prevents choking and aspiration. It also encourages burping (air to rise).
2. Avoid placing infants with cleft lip in the prone position, place side-lying and alternate from side to side.
3. Infants with Pierre-Robin Syndrome should be placed in crib in prone position. Infants should be individually assessed for the need for elevation of the foot of the bed. Do not put infant with Pierre-Robin on his back except when changing, bathing, etc. At all times, carefully assess respiratory status in the supine position.

CLEFT CARE:

1. Avoid contact with anyone who has an infection in the hospital and when discharged to home. Infection will delay reparative surgery.
2. Clean cleft as needed with clear water by squeezing a small amount of water into infant's mouth with Mead Johnson feeder and allow infant to clear oral cavity.
3. If this is not adequate, clear water and a cotton tipped applicator can be used to clear curds.
4. Prevent skin breakdown around cleft lip. Vaseline is useful if used sparingly. Because of mouth breathing, the lips may be dry and it is important to prevent a break where infection may enter.
5. Gently use bulb syringe to aspirate mucous or formula from nasopharynx only if necessary, try to gravity first. Suction only when absolutely necessary. Use gentle suction to prevent trauma to operative site.
6. Use cool mist humidity to keep mucous membranes moist.

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SUPPORTIVE CARE

- OF INFANT:**
1. The infant with a cleft lip cannot be comforted in the usual way, never put infant up to your shoulder, sit infant on lap facing outward. It is important for the caregiver to comfort the infant in a way which does not potentially cause rubbing of the lip. Measures that may cause rubbing of the lip cannot be used after surgical repair of the lip for three weeks. Providing comfort measures early in the infant's life that he/she becomes accustomed to which are appropriate for post-op care will facilitate his/her recovery post-operatively. This can prevent any difficult adjustments for both the infant and the caregiver.
 2. Pacifiers are to be avoided until after consultation with craniofacial team.

PARENT

- EDUCATION:**
1. Be supportive of parents by accepting the infant and their feelings toward him. The manner in which the nurse handles the infant may make a lasting impression on the parents.
 2. The parents need to be reassured that the infant's defect is not their fault.
 3. Provide parents with encouragement about their caretaking abilities to help them develop confidence before discharge.
 4. Involve the craniofacial team as soon as possible after birth.
 5. Show video "Growing in Unexpected Ways" to the family. They may have seen this at the referring hospital.
 6. Teach parents feeding techniques and inform them that formula often returns through the nose and this is to be expected. These infants sneeze a lot because of formula in nose.
 7. Instruct parents how to recognize signs of respiratory distress.
 8. Teach parents proper oral hygiene and prevention of injury to operative site.
 9. Provide parents with a plan for follow-up care.
 10. Initiate home nursing referral if family requires support and/or there are concerns about infant's care and follow-up.

APPROVAL: Nursing Standards Committee

EFFECTIVE DATE: 1/86

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REVIEWED DATES: 12/08