

FEEDING AN INFANT WITH A CLEFT by Luis Cuadros MD

Breastfeeding

Breastfeeding an infant with a cleft lip only but no cleft palate is usually successful, but sometimes requires more upright positioning so that mother's breast tissue fills the gap in the lip or gum. Breastfeeding an infant with a cleft palate is quite challenging unless the infant's cleft palate is very far in the back of the mouth and very small. Nursing at the breast is best limited to 10 minutes, and supplemental bottles are needed if breastfeeding alone does not supply enough food for adequate satisfaction and growth. For most mothers of infants with cleft palate, breast pumping should begin in the birth hospital using a high quality electric breast pump and continue each time after the infant eats. A lactation consultant is a breastfeeding mother's best resource for correct positioning and pumping technique. Discuss your feeding plan with this specialist before discharge from the hospital. Weight gain must be followed closely.

Bottle Feeding

Small, frequent feedings are usual in the first weeks of life for an infant with a cleft palate. Give yourself and your baby time to learn how to eat, and expect longer feeding times. Try to limit feedings to 30 minutes with an additional 10 minutes for burping and changing. Hold your baby upright or slightly tilted back (in your arm with a fat pillow under your elbow) to limit the amount of liquid that enters the nasal passage. Some infants totally ignore drainage into the nose, and you should not be alarmed to see a trickle come out. If there is a great amount of liquid in the nose, tilt the baby forward. Your baby will swallow any extra milk in the back of the throat and the extra milk in the front of the mouth and nose will drain by gravity. You may use a bulb suction to help, but the positioning is most important to prevent any extra liquid from sliding to the back of the throat.

Mead Johnson Cleft Palate Nurser

Special feeding bottles and nipples work by allowing the milk to come out of the nipple with little or no suction needed. Some cleft palate bottles need compression, or squeezing, along with an enlarged opening cut into the nipple to help the infant get enough flow of milk. Hold your baby up in a semi-upright seated position with the head and shoulders in one hand and the bottle in your other hand. If you are more comfortable with the baby in the crook of your elbow, place a blanket or pillow under that elbow to hold the baby more upright. Tickle the baby's lower lip or corner of the mouth with the nipple and place it over the tongue when the mouth pops open. You may need to pull the lower jaw down gently to get the baby's tongue down and out of the way. When the nipple is placed in the mouth, allow your baby to suck and breathe a few times before beginning compression of the Mead Johnson Cleft Palate Nurser bottle.

Begin with gentle compression and slowly increase the pressure while watching your infant's face. If the baby takes more than 40 minutes to eat, or if there is leakage from the nipple ring, it may improve feeding efficiency to increase the crosscut about 1/16th of an inch. Any time the nipple opening is enlarged, take care to squeeze less hard until you know how much the flow of formula has increased. There is little you can do to control the amount of air swallowed during feedings. Your baby will need to burp frequently, but don't interrupt the feeding too much. For very young infants, all you will have to do to is straighten up the baby by pushing gently up at the back of the waist and lifting the front of the chest with the other hand. Any commercial nipple can be used with the compressible bottle if the tip of the nipple is cut in a 1/8 to 1/4 inch "X" (see diagram).

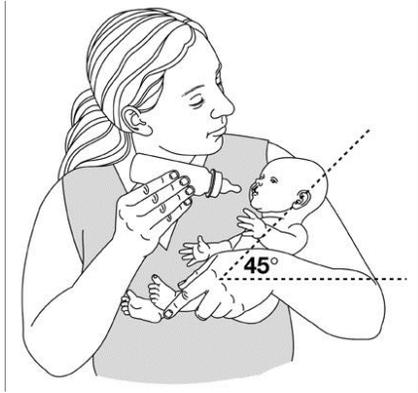
Pigeon Cleft Palate Nipple

There is a Y cut in the tip of the nipple. Roll the tip with a clean cloth to loosen the opening. Notice the V in the base of the nipple. This is the air vent, and must be positioned on the top of the nipple under the infant's nose for the nipple to work properly. If the nipple collapses or leaks from that hole, remove the nipple from the cap and massage that area to unclog the vent. You may need to poke a toothpick through the vent to clear it. If the bottle system is purchased, follow package directions for assembly. If only the nipple or valve is purchased, the nipple ring from the Enfamil bottle may be used, but not all nipple rings will fit the valve. Put the valve in the base of the nipple, flat side toward the tip. Make sure the nipple lies flat inside the ring and the valve is level with the rim of the nipple. Put the nipple in baby's mouth normally. The infant's tongue will activate the flow. If the nipple collapses, you can unscrew the cap and re-tighten it.

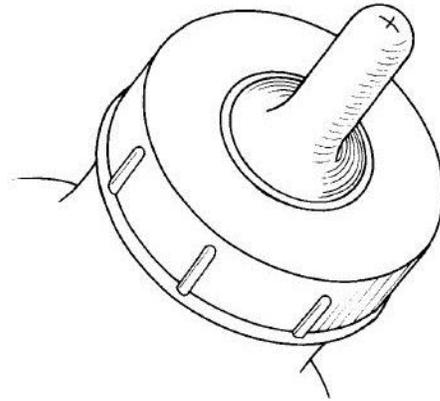
Haberman Feeder

Assemble the bottle and fill with breast milk or formula according to package directions. Line up the shortest line on the compressible reservoir with the baby's nose and tickle the lower lip. Insert the nipple when the mouth opens. Position the nipple on the center of the tongue with the tip turned under the intact part of the palate. The infant will begin to suck. Rotate the nipple until the longest line and greatest flow is under the baby's nose. If your infant cannot tolerate the flow, rotate the bottle back to a slower rate of flow. You may compress the reservoir every second or third suck, or put gently continuous pressure on the section so that more milk will come out of the nipple when the baby compresses the nipple between the palate and tongue.

Feeding a baby with a cleft



Holding the baby at 45 degrees can assist the flow of formula or breast milk. It is normal for some food to come out the nose until the baby learns how to direct the food.



Cross-cut nipples, used with compressible bottles, offer the advantage of controlling the flow of liquid when feeding. Also, because the container must be compressed, you have more control of how much milk your baby is getting. The infant aids the feeding process by gumming the nipple after the lip and the bottle make contact.



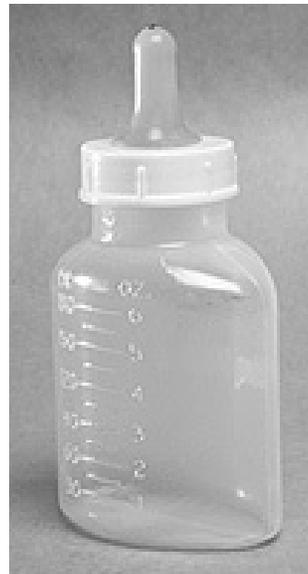
NUK nipple, NO.2



Pigeon Nipple



Haberman Feeder



Mead-Johnson Bottle

RESOURCES for PARENTS and HEALTH CARE PROVIDERS
for referrals and information call Dr. Cuadros at any time
505-243-7670 or toll-free in New Mexico **1-888-217-6120**

LOCAL RESOURCES:

Dr. Luis Cuadros, MD, FACS, Plastic Surgery. Sue Saiz, RN, Plastic Surgery Nurse
1-505-243-7670, or toll free in New Mexico 1-888-217-6120. Our office is available at any time to discuss issues regarding cleft management. We will arrange for consultation, provide feeding information and supplies.

Susanne R. Hays, MS, RN, CRRN. Pediatric Rehab Nurse and Feeding specialist is able to consult by phone or home visit for all feeding issues in newborns and babies.
1-505-294-8338

Presbyterian Ear Institute - Cleft Palate Craniofacial Center for Speech, Language and Hearing. Comprehensive evaluation, diagnostics and treatment.
415 Cedar St. S.E, Albuquerque, NM 87106
Telephone: (505) 224-7020, Fax: (505) 224-7023
Email: pei@oraldeafed.org
<http://www.oraldeafed.org/schools/pei/index.html>

Children's Medical Services - Cleft Palate Clinics (CMS)
CMS offers evaluation, diagnosis and treatment for congenital deformities using an interdisciplinary team approach.

CMS Statewide Office - Toll Free 1-877-890-4692

Albuquerque - District I CMS Office - 897-5700 or 897-3311

Farmington - San Juan County Health Office - 505-327-7606

Gallup Health Office - 505-722-6830

Santa Fe County Health Office - 505-476-2603

Dr. Dan Shover - Pediatric Gastroenterology - (505) 563-6550- Presbyterian Feeding Clinic - Nutritionist Cindy Chall Silva. If your baby is having trouble gaining weight, your pediatrician can refer you to this clinic.

INSTITUTIONAL AND ORGANIZATIONAL RESOURCES

CleftLine: Managed by the Cleft Palate Foundation. 1-800-24-CLEFT .
Call this number 24 hours/ 7 days to obtain information on clefts.
<http://www.cleftline.org/>

WideSmiles: organization begun by a parent who has adopted three children with cleft palates.

PO Box 5153, Stockton, CA 95205-0153

email WideSmiles@aol.com

<http://www.widesmiles.org>

American Cleft Palate-Craniofacial Association/Cleft Palate Foundation
1504 East Franklin Street, Suite 102, Chapel Hill, NC 27514-2820 USA
(919) 933-9044 ,
info@cleftline.org <http://www.acpa-cpf.org/>

Prescription Parents - support group with cleft lip and palate information.
45 Brentwood Circle, Needham, MA 02492
617-431-1398.
<http://www.samizdat.com/cleft.html>

A Parent's Guide to Cleft Lip & Palate - University of Minnesota Guides to Birth and Childhood Disorders. Moller, Starr and Johnson. Univ of Minn Press. 1990. Available from Dr. Cuadros and from <http://www.amazon.com>.

The Cleft Advocate -providing educational opportunities, on- and off-line support networks, social interaction and advocacy guidelines, cleftAdvocate gives families the tools they need to obtain the absolute best medical care from their craniofacial team and the best service from their insurer, while encouraging children, teens and adults with cleft lip and/or palate and other craniofacial anomalies to reach their highest level of self-esteem.
<http://www.cleftadvocate.org>

The Cleft Palate-Craniofacial Journal is an international, interdisciplinary journal reporting on clinical and research activities in cleft lip/palate and other craniofacial anomalies, together with research in related laboratory sciences. Official Publication of the American Cleft Palate-Craniofacial Association (ACPA)
<http://cpcj.allenpress.com/cpcjonline/?request=index-html>

PRODUCTS

Zip-n-Squeeze bottles
<http://www.zip-n-squeeze.com/softsipp.html>

Arm restraints: Pedi-Wrap, PO Box 5398, Hemet, CA 92544. Tel 909-925-8800.
<http://www.medi-kid.com/>

Pigeon Nipples. PIGEON has developed the nursing bottle which enables a baby to suck in the same manner as they would from a mother's nipple by studying the shape, size, elasticity and structure of the nipple.
<http://www.galtak.com/nipples.htm>

Haberman Feeders
Specialized feeders designed for babies with cleft palate.
<http://www.medela.com/NewFiles/specialtyfdg.html>

Mead Johnson Cleft Palate Nurser (Enfamil Cleft Lip/Palate Nurser) - home delivery
<http://store.enfamil.com/>
http://store.enfamil.com/bottles_and_nursers.html

DONATIONS TO THE CMS CLEFT PALATE EDUCATION FUND

A charitable fund has been established through the New Mexico Medical Society to help with education resources for patients, parents and providers. The fund provides educational materials and learning experiences to improve the care of children in New Mexico. To donate please contact the office of Dr. Luis Cuadros — 505-243-7670.