CLINICAL GUIDELINE

Cleft Lip and Palate

Scope (Staff): Nursing and Medical Staff
Scope (Area): NICU KEMH, NICU PCH, NETS WA

This document should be read in conjunction with this DISCLAIMER

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Background
Cleft lip and/or palate malformation is caused by a failure of the normal oro-facial development between 6 and 12 weeks of embryonic life. The incidence is 1:1000 Caucasian births and higher in Asian populations. It is more common in males and can be associated with other anomalies.
All infants born with a cleft lip and/or palate should be assessed immediately after birth by the paediatric team. This assessment should determine if there are any airway concerns (such as seen with Pierre Robin Sequence), and if so, what is the appropriate form of monitoring, where the baby should be monitored and if there are any other associated anomalies. At this review a feeding plan also needs to be formulated with parents and midwives. All but the mildest, isolated cleft lips will be transferred to PCH NICU (Ward 3B) for further assessment by the ‘Cleft Team’. Admission to Ward 3B is usually for 4 to 5 days and parents should be resident with the infant for that time.

The aim of this assessment:
- Meet the plastics surgical team to determine the need for an orthodontic plate, bonnet and upper lip strapping any other immediate procedures.
- Discuss the timing of definitive surgery for the lip and palate. Repair of the lip occurs at approximately 3 months and repair of the palate at 9 months.
- Orthodontic review to form and fit a plate if needed. This takes 1-2 days and often requires adjustment of the plate.
- Educate parents to specific care requirements of the plate, strapping and feeding to ensure optimal growth and development

Transfer to PCH
Contact the Cleft Clinic Coordinator at PCH via switchboard or Vocera, as well as Ward 3B regarding plan for transfer. Most commonly, there is no immediate urgency for a Cleft Team assessment at PCH, which is generally a Monday to Friday service. Therefore, if the initial paediatric assessment is reassuring immediately after birth, the infant can generally stay with their mother at referring hospital over the weekend or until the mother is well enough to accompany the infant, usually at 24 to 48 hours of age.

If the infant has a cleft lip only and is feeding well and gaining weight, it may not need to be transferred, but the Cleft Coordinator must still be notified to organise an outpatient assessment and follow up by the Cleft Team.

Notify the Cleft Coordinator on admission to Ward 3B to enable coordination of the Cleft Team which includes the Plastic Surgeon and Dentist.

Equipment - Admission Pack Found In Cleft Cupboard
- Pigeon (squeezie) bottle - ordered from milk room
- Laryngoscope
- Paper cups
- Chlorhexidine gel
- Soft white paraffin gel
- Plastic medicine spoon
- Boiled water (kept by patient bedside, replenished every 24 hours)
- Shortened buffered swab sticks
Feeding

Infants with cleft lip and or palate are routinely fed with a pigeon (squeezy) bottle with a short, fast teat as they are generally unable to create an adequate seal to feed with a normal bottle or “strip” the breast with the tongue against the hard palate whilst breast feeding.

- When feeding a baby with a pigeon (squeezy) bottle, the bottle is gently squeezed as the baby sucks. Squeezing the bottle ceases when the infant is not sucking.
- Infants should be fed in a sitting up position to prevent the risk of aspiration. If a baby is fed in the more usual cradled position, milk may pool in the oral cavity and aspiration may occur.
- Milk needs to be warmed to body temperature to reduce the incidence of vasovagal episodes from cold milk entering the nasal cavity. Warming the milk also softens the bottle making it easier to squeeze.
- As infants with clefts do not maintain a good seal, they tend to swallow a lot of air with the feed and therefore require winding/burping at the middle and end of the feed.
- Feeds should take approximately 30 minutes; extended feeds limit the baby’s ability to rest. Feeds should be given 3 to 4 hourly to demand.
- Breast feeding, although difficult, may be possible for infants with minor clefts, especially after a good milk supply has been established. Mothers should be encouraged to express breast milk. Expressed milk can be given via a pigeon bottle. Please discuss with the Lactation consultant on Ward 3B after admission.
- Mouth care should be given after each feed for the first 48 hours then twice daily.

Nasogastric tube (NGT) feeding is not generally required; infants should be encouraged to suck all their feeds. If NGT feeding is required, the NGT should be inserted into the unaffected nostril. If placed through the clefted side, the NGT is more difficult to stabilize and can migrate between the nasal and oral cavity, causing possible erosion to the mucosa.

Dummies are discouraged as they can cause erosions around the cleft and cannot be used in the later post-operative phase as it puts strain on the suture and may interfere with the healing process.

Breastfeeding and Use of Expressed Breast Milk for Infants with Cleft Lip and/or Palate

Clefts can range considerably from a small notch of the lip to complete opening bilaterally from the lip and extending to the nasal cavity.

The ability to breastfeed is related to the ability to generate suction which is necessary for attachment to the breast, maintenance of a stable feeding position and the mothers let down reflex.

There is a relationship between the amount of oral pressure generated during feeding and the size/type of cleft and maturity of the baby, therefore babies with Cleft Lip (CL) are more likely to breastfeed than babies with Cleft Lip and Palate (CLP) or Cleft Palate (CP).

Recommendations to Assist with Breastfeeding Support

- Mothers should be encouraged to provide the protective benefits of breast milk, in preference to formula milk.
- Counselling is required about the likely success of breastfeeding. There is moderate descriptive evidence that babies with CL are able to generate suction and
successfully breastfeed. Evidence suggests that direct breastfeeding is unlikely to be the sole method of feeding for babies with CP or CLP as they may have difficulty generating suction and have inefficient sucking patterns.

- Babies with CL/CLP should be assessed individually for their ability to breastfeed successfully, including type of cleft, mother’s wishes and previous experience.
- Monitoring of hydration and weight gain is important, if inadequate, supplementary feeds should be implemented or increased. These should ideally be expressed breast milk and given via a squeezy bottle.
- A small or preterm baby with a cleft will have less reserves so may also have more difficulty breastfeeding.
- The negative consequences of inadequate feeding include fatigue during breastfeeding, prolonged feeding times, and impaired growth and nutrition.
- Consideration should be given to allowing smaller volumes of expressed breast milk for healthy term babies in the first 48 hours as this is what they would be receiving if normally breastfeed. This should be monitored closely by weight and assessment of hydration during this period.
- Modification of breastfeeding positions may increase the efficiency and effectiveness of feeding.
- Skin to skin can provide comfort for the infant and aid lactation especially when breastfeeding is difficult.
- There is no strong evidence that plates (prosthesis used for palate alignment prior to surgery) significantly increase feeding efficiency or effectiveness.

**Suggestions for Positioning the Infant for Breastfeeds**

- Infants with CL should be held so the CL is orientated towards the top of the breast.
- The mother may occlude the CL with her thumb or finger and/or support the infant’s cheeks to decrease the width of the cleft and increase closure around the nipple.
- Positioning should be semi upright to reduce nasal regurgitation and reflux. This may be facilitated with a football hold with infant’s shoulders higher than the body.
- Mothers may need to manually express breast milk into the baby’s mouth to compensate for absent suction, and compression and to stimulate the let-down reflex.

**Orthodontic Appliance (For Cleft Palate)**

The orthodontic appliance (OA), “dental plate”, facilitates moulding of oral structures. It acts as an obturator and assists with feeding by creating a false palate. It also prevents the tongue from migrating into the cleft and protects against erosions due to the activity of the tongue. The dentist will take an impression with alginate for an OA if considered necessary. The neonatal nurse assists ensuring oxygen and suction, with a Yanker sucker, and forceps are available.

**Note: the mouth must be visualised after the impression and suctioned to ensure no alginate remains as this may be a choking hazard.**

Creation of the plate takes 12 to 24 hours and then is fitted by the dentist. Dentists usually review the plate and palate each day to ensure a good fit and to check for areas of ulceration in the mouth caused by the OA. Using an OA creates less room in the oral cavity, which can make initial feeding more difficult. The OA remains in situ at all times apart from routine mouth care and cleaning.
Routine Mouth Care

1. Performed after each feed for the first 48 hours after the OA is fitted; then twice daily thereafter.
2. Remove the OA and wash in cooled boiled water.
3. Give the infant sufficient room temperature boiled water by teaspoon to effectively rinse the mouth and keep the mouth relatively curd free; usually 1 teaspoon. **Note: a vaso-vagal reaction can occur if cold water is used.**
4. Remove the OA from the water and apply chlorhexidine gel to the plate; TDS for the first 48 hours and then twice daily thereafter.
5. The mouth should be inspected for any new areas of ulceration, bleeding and tooth eruption, using the laryngoscope. The OA may need to be adjusted by the Dentist.
6. Using a moist, shortened buffered swab sticks clean under the flattened nostril.
7. Carefully insert the OA slightly sideward for a unilateral cleft and straight for a bilateral cleft.
8. Apply soft white paraffin to all lip areas and the pre maxilla as needed and at each feed time.
9. Mouth care is not required for isolated clefts and in babies with Pierre Robin Sequence.

Bonnet & Strapping

- Commences **ONLY AFTER** the insertion of the OA. Strapping consists of a piece of soft elastic, fitted individually to the infant. It should sit on the protruding maxilla and cover the cleft lip, but it must rest on skin and never on oral mucosa.
- Pressure areas can occur if the strapping is too tight and be ineffective if the strapping is too loose.
- Bonnets should be tied snugly at the side, checked frequently and tightened when necessary.
- The cheeks should bulge over either side of the elastic. The position should be checked frequently by staff and parents.
- Each infant should be individually fitted for 3 bonnets. They are taken home and replaced in the dental clinic as required.
- Bonnets are washed at bath time and dried at the cot side.
- Strapping is kept in place at all times other than feeding and bathing.

Unilateral Cleft:
Start strapping from the non-cleft side, and pull over the cleft; fix with Velcro tabs.

Bilateral Cleft:
The strapping is placed on the pre-maxilla and should cover the width of the cleft and the tabs are affixed to both sides of the bonnet in one motion.
**Documentation**

- Feeding amount and duration
- Condition of mouth and palate
- Review by Cleft Co-ordinator, Plastics and Dentist.
- Parent education
- Visit by CleftPals

**Prior to Discharge**

- Infants must have been seen by the Cleft Clinic Coordinator, Plastic Surgeon and Dentist.
- If the parents have not been reviewed by a geneticist, an appointment will be arranged for them as an outpatient by the Cleft Clinic Coordinator.
- Dental Clinic will obtain consent and organise for photographs of the infant’s cleft for patient records.
- Parents must be competent in feeding and mouth care. The infant should be feeding well and gaining weight.
- Equipment: Parents are given 2 bonnets of appropriate size, small torch, Bonnet and Strapping Kit, Parrafin. Squeezy bottles must be purchased from the Dental department or CleftPals Association.
- Follow up appointments for Dental and Plastics Surgical clinics are made by the Cleft Palate Coordinator.

**Education (Videos)**

- “Cleft Lip & Palate Nursing Care Plan”
- “Fitting Bonnet and Strapping for Cleft Lip and Palate infants - Dental Demonstration”
- “Spoon feeding for Cleft Lip and Palate infants” (Parents will be required to spoon feed infants prior to lip repair at ~ 3 months).

**Parent Support**

CleftPals is an organisation of parents who support families of children with cleft lip and palate. They are available for hospital visits and to give advice over the phone. They also provide supplies such as pigeon bottles at a reduced cost. At parents’ request, CleftPals can be contacted through the cleft coordinator or further information obtained on line at [www.cleftpalswa.org.au](http://www.cleftpalswa.org.au).
References


Useful resources (including related forms)

www.cleftpalswa.org.au

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