

South Australian Perinatal Practice Guideline

Cleft Lip and Palate in the Neonatal Period

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Note:

This guideline provides advice of a general nature. This statewide guideline has been prepared to promote and facilitate standardisation and consistency of practice, using a multidisciplinary approach. The guideline is based on a review of published evidence and expert opinion.

Information in this statewide guideline is current at the time of publication.

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Health practitioners in the South Australian public health sector are expected to review specific details of each patient and professionally assess the applicability of the relevant guideline to that clinical situation.

If for good clinical reasons, a decision is made to depart from the guideline, the responsible clinician must document in the patient's medical record, the decision made, by whom, and detailed reasons for the departure from the guideline.

This statewide guideline does not address all the elements of clinical practice and assumes that the individual clinicians are responsible for discussing care with consumers in an environment that is culturally appropriate and which enables respectful confidential discussion. This includes:

- The use of interpreter services where necessary,
- Advising consumers of their choice and ensuring informed consent is obtained,
- Providing care within scope of practice, meeting all legislative requirements and maintaining standards of professional conduct, and
- Documenting all care in accordance with mandatory and local requirements

Explanation of the aboriginal artwork:

The aboriginal artwork used symbolises the connection to country and the circle shape shows the strong relationships amongst families and the aboriginal culture. The horse shoe shape design shown in front of the generic statement symbolises a woman and those enclosing a smaller horse shoe shape depicts a pregnant women. The smaller horse shoe shape in this instance represents the unborn child. The artwork shown before the specific statements within the document symbolises a footprint and demonstrates the need to move forward together in unison.



Australian Aboriginal Culture is the oldest living culture in the world yet Aboriginal people continue to experience the poorest health outcomes when compared to non-Aboriginal Australians. In South Australia, Aboriginal women are 2-5 times more likely to die in childbirth and their babies are 2-3 times more likely to be of low birth weight. The accumulative effects of stress, low socio economic status, exposure to violence, historical trauma, culturally unsafe and discriminatory health services and health systems are all major contributors to the disparities in Aboriginal maternal and birthing outcomes. Despite these unacceptable statistics the birth of an Aboriginal baby is a celebration of life and an important cultural event bringing family together in celebration, obligation and responsibility. The diversity between Aboriginal cultures, language and practices differ greatly and so it is imperative that perinatal services prepare to respectively manage Aboriginal protocol and provide a culturally positive health care experience for Aboriginal people to ensure the best maternal, neonatal and child health outcomes.

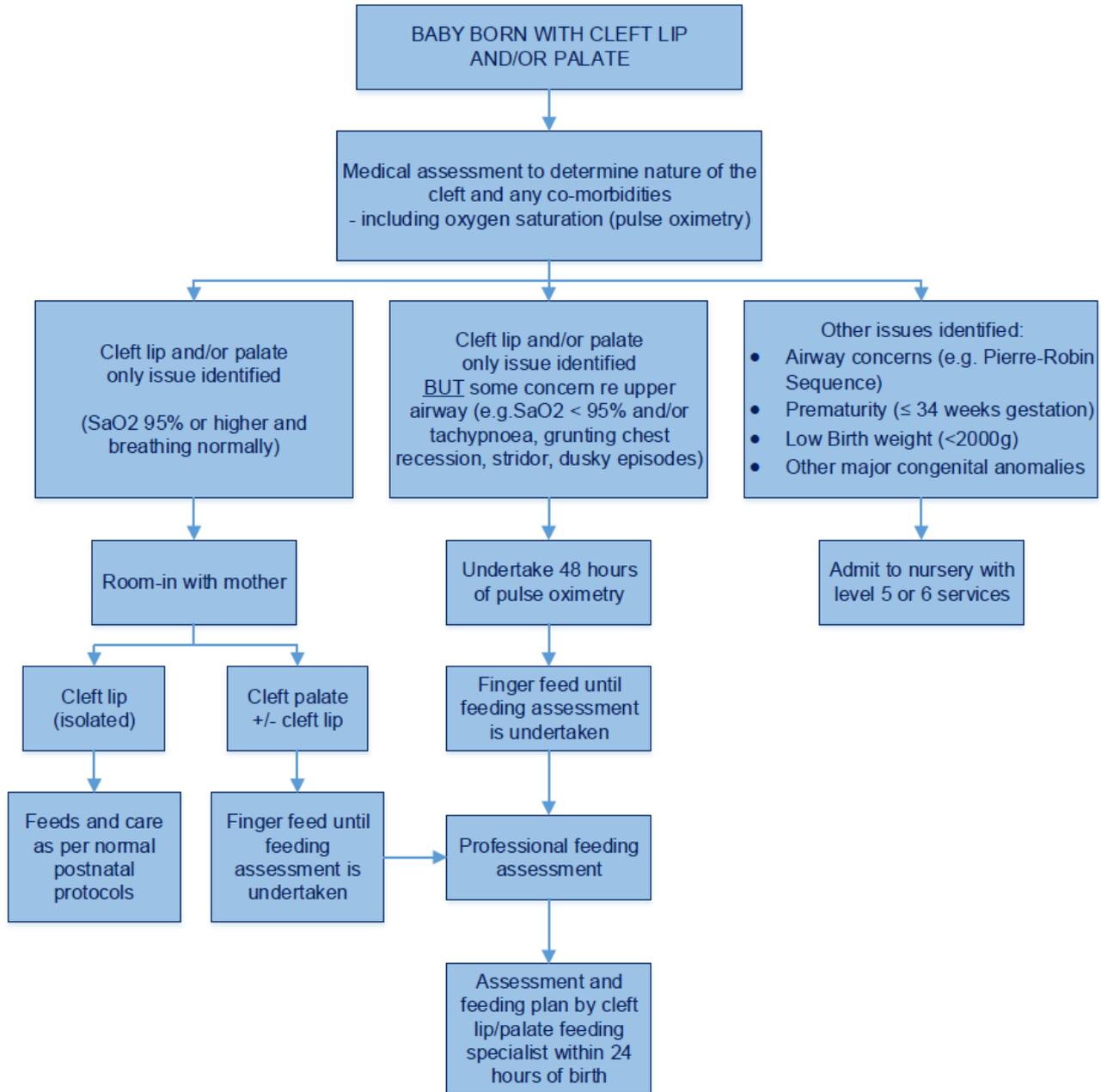
Purpose and Scope of Perinatal Practice Guideline (PPG)

The purpose of this guideline is to provide clinicians with information on the initial management of babies with cleft lip and/or palate. It includes details on assessment, transfer, feeding, referral and useful websites for parents.



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Flowchart: Initial management of babies with cleft lip and/or palate



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Summary of Practice Recommendations

Where there is an antenatal diagnosis of cleft lip and/or palate, antenatal counselling with a plastic surgeon experienced in cleft lip and palate surgery and a specialist in cleft lip/palate feeding is recommended.

Following birth, babies should have a medical assessment to determine the nature of the cleft and any associated abnormalities or co-morbidities.

Assessment of oxygen saturation using pulse oximetry should be undertaken soon after birth and repeated if clinically indicated.

Consider extended pulse oximetry if there is any concern re upper airway obstruction.

A feeding assessment by a professional experienced in feeding babies with cleft lip +/- palate should occur as soon as possible following birth. They should then initiate a feeding plan.

Babies with isolated cleft lip can generally be nursed safely with the mother on the postnatal ward with routine postnatal care.

The support of parents by professionals experienced in feeding babies with cleft lip +/- palate during the establishment of feeding is essential and has been shown to improve weight gain.

Referral to and follow-up with the Australian Craniofacial Unit at the Women's and Children's Hospital is required.



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Abbreviations

ABR	Auditory brainstem response
EBM	expressed breast milk
g	grams
mL	millilitres
SaO ₂	Oxygen saturation

Definitions

Cleft lip	A congenital opening or split in the upper lip. May be unilateral or bilateral.
Cleft palate	A congenital split or opening in the roof of the mouth. It can involve the hard palate and/or the soft palate. The opening allows communication between the mouth and nasal passages.
Cleft lip/ palate feeding specialist	A professional who has undertaken specific education and has experience in assessment of cleft lip and palate feeding issues: For example a speech pathologist, lactation consultant or nurse/midwife who has completed specific training.

Background

Antenatal diagnosis

Cleft lip and/or palate occurs in approximately 1 per 800 births in South Australia.

Whilst cleft lip and/or palate may be an isolated finding on ultrasound, it can be associated with other congenital anomalies or rare syndromes. Therefore, when a cleft lip and/or palate is diagnosed on ultrasound (usually at the 18-20 week morphology scan), referral for second opinion ultrasound with a subsequent Maternal Fetal Medicine appointment (+/- Clinical Genetics) should be made.

Where there is an antenatal diagnosis of cleft lip and/or palate, antenatal counselling with a plastic surgeon experienced in cleft lip and palate surgery should occur^{1,2}.

Antenatal counselling with a practitioner experienced in feeding management for babies with cleft/palate should also occur. Mode of feeding (including benefits of breast milk versus formula) and anticipated feeding issues should be discussed^{3,4,5,6,7,8}. Antenatal breastmilk expression can be encouraged if this is the woman's feeding preference.

Neonatal Management

Following birth, babies should have a medical assessment to determine the nature of the cleft and any associated abnormalities or co-morbidities².

Clinical assessment should also pay particular attention to possible airway compromise and associated breathing difficulties. Initial assessment of oxygen saturation using pulse oximetry should be undertaken, with a low threshold for repeating oximetry in the context of symptoms such as increased breathing effort, stridor or episodic dusky appearance.

Consider an extended period (48 hours) of oximetry monitoring if there is any concern about upper airway obstruction or if oxygen saturation is less than 95%. If there is evidence of upper airway obstruction referral to paediatric respiratory medicine will be required prior to discharge home.



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Transfer

Issues identified that require admission to a level 5 or 6 neonatal nursery include:

- Airway concerns (e.g. Pierre-Robin Sequence)
- Prematurity (\leq 34 weeks gestation)
- Birth weight ($<$ 2000g)
- Other major congenital anomalies

Note: Babies with cleft lip and/or palate may also require transfer to a facility with higher level neonatal services if there is no 'in-house' professional support for feeding infants with cleft lip and/or palate (e.g. speech pathology, specialist lactation consultant, trained nursing/midwifery staff).

Where a rural practitioner is uncertain whether transfer to a level 5 or 6 neonatal facility is required, guidance can be sought via the Perinatal Advice Line on phone 137 827.

Feeding when cleft lip and /or palate is only problem identified

Babies born with a cleft may present with a range of feeding difficulties according to the type and severity of the cleft^{6,7,8}.

Breastfeeding or breast milk feeding is encouraged for all babies.

Establish maternal feeding preference.

A feeding assessment by a professional experienced in feeding babies with cleft lip +/- palate should occur as soon as possible following birth. They should then initiate a feeding plan.

Cleft Lip (isolated)

In the majority of cases, the baby can be cared for safely with the mother on the postnatal ward with routine postnatal care.

Maternal preference for breast milk feeding

Try to facilitate a seal using the breast tissue close to the cleft (this may be easier if the cleft is facing down). Feeding and observations follow normal postnatal ward procedure,

Maternal preference for formula feeding

Bottle feeding may be commenced using a normal bottle and teat at standard volumes.

Cleft Palate +/- Lip

Suggested minimum length of stay is 5 days with routine postnatal care.

With a cleft palate, the major difficulty is an inability to create sufficient negative intraoral pressure for effective feeding, thus reducing sucking efficiency.

Breast milk feeding is encouraged as it is less irritating to the exposed nasal mucosa and gives some protection against otitis media with effusion².

The support of parents by professionals experienced in feeding babies with cleft lip +/- palate during the establishment of feeding is essential and has been shown to improve weight gain^{3,4,5,6,7}.

Babies usually require only small quantities of milk in the first 24 hours. Gentle finger feeding of the volume of breast milk able to be expressed, or 5 mL of formula where the intention is to formula feed, is safer than a squeeze bottle.

Squeeze bottles should not be used until after a feeding assessment.

Maternal preference for breast milk feeding

Transfer of breast milk by suckling at the breast is rarely adequate where there is a cleft palate and the emphasis should be on maintaining lactation and providing expressed breast milk (EBM).



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Where there is a strong maternal desire to continue to put the baby to the breast, this can be supported by providing top-ups of EBM.

- Commence breast expression as soon as possible following birth (see *Expressed Breast Milk: Safe Management and Administration in SA Clinical Directive* and the *Breastfeeding Perinatal Practice Guideline* available at www.sahealth.sa.gov.au/perinatal for more information).
- Expressing should be undertaken at least 7-8 times within a 24 hour period, including at night, until lactation is well established.
- Feed with a 4 hour limit.
- Give top-up feeds of expressed colostrum at the volume available (or 5mL formula) by finger feeds following all breastfeeds.
- Following professional feeding assessment, feeding is either by breast with full EBM squeeze bottle top-ups or solely EBM via squeeze bottle (as agreed with mother, lactation consultant and/or cleft lip/palate feeding specialist)
- Offer bottled EBM at the volume that can be expressed
- Monitor weight gain and adjust feeding plan as indicated

Maternal preference for formula feeding

- Commence finger feeding with 5mL of formula per feed.
- Following professional feeding assessment, a squeeze bottle and teat should be used.
- Volume of formula should be determined as per routine recommendations for infants being formula fed.

Referral and Follow-Up

Includes:

- Australian Craniofacial Unit at the Women's and Children's Hospital
 - Referral via fax number: 08 8161 7080
 - Surgery generally at around 3 months for cleft lip and 6 months for cleft palate (corrected age if born prematurely), depending on weight
- General Paediatrician
- Speech Pathology
- Audiology referral for diagnostic ABR
- Eye review
- Consider microarray for isolated cleft palate
- Other specialties as indicated (e.g. Clinical Genetics, Cardiology)

Advice for parents

Parents should be advised to seek medical attention if their infant shows signs of respiratory distress, such as tachypnoea, chest recession, noisy breathing or poor feeding.

Note: parental education in resuscitation is suggested.



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Additional Resources

Information for Health Professionals:

Australian Craniofacial Unit (based at the Women's and Children's Hospital)

<http://www.wch.sa.gov.au/services/az/divisions/psurg/craniofacial/index.html>

Australasian Cleft Lip and Palate Association Inc.

<http://www.cleft.org.au/>

Information for parents on cleft lip and cleft palate repair from:

Australian Craniofacial Unit (based at the Women's and Children's Hospital)

http://www.wch.sa.gov.au/services/az/divisions/psurg/craniofacial/acfu_patient_info.html

Australian Government Department of Health

<https://www.healthdirect.gov.au/cleft-lip-and-cleft-palate>

Raising Children Network

<https://raisingchildren.net.au/guides/a-z-health-reference/cleft-lip-palate>

Information for parents on feeding infants with cleft lip and/or palate

https://www.rch.org.au/kidsinfo/fact_sheets/Cleft_lip_and_palate_infant_feeding/

<https://www.rch.org.au/uploadedFiles/Main/Content/kidsinfo/cleft-lip-and-palate-infant-feeding-booklet.pdf>

<https://www.breastfeeding.asn.au/bf-info/cleft>

<https://www.clapa.com/treatment/feeding/>

Cleft Connect

Cleft Connect Australia unites cleft affected families and individuals with one another, and with the professionals who can best assist them at all stages of their journey

<http://cleftconnect.org.au/>



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