

Cleft Lip and Palate Newborn Referral

Guideline Responsibilities and Authorisation

Department Responsible for Guideline	NICU
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Document Owner Title	Clinical Director
Target Audience	Neonatal Team, LMC
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Guideline Review History

Version	Updated by	Date Updated	Summary of Changes
3	Chantelle Hill	Jan 2016	Due for review
4	Lyn Curnow, Speech Language Therapist, and Manju Mathew	Aug 2021	Include responsibilities of the multidisciplinary team

Cleft Lip and Palate Newborn Referral

1 Overview

1.1 Purpose

To provide a guideline for health professionals working with a baby diagnosed with a cleft lip and/or palate at birth or in the antenatal period.

1.2 Scope

Midwives, Registered Nurses, Speech-Language Therapists, Clinical Midwife/Nurse Specialist, Neonatal Nurse Practitioners, Discharge Facilitator, Lactation Consultants, Paediatricians, Registrars, and Cleft and Craniofacial Nurse Specialist.

1.3 Patient / client group

Infants diagnosed with a cleft lip +/- palate in utero or after delivery.

1.4 Definitions

Breastfeeding	Direct placement of the infant to the breast for feeding.
Breast milk feeding	Delivery of breast milk to the infant through bottle, cup, spoon or any other means except the breast.
Cleft lip	An opening in the upper lip present at birth. May be unilateral or bilateral.
Cleft palate	An opening in the roof of the mouth that may affect both the hard and soft palates. May be unilateral or bilateral.
CMS or CNS	Clinical Midwife/Nurse Specialist
LC	Lactation Consultant
LMC	Lead maternity carer
NICU	New born Intensive Care unit
Neonatal Team	They include SMO, NNP, CNS, RMO, SHO, RN, LC, and Discharge Facilitator
NNP	Neonatal nurse practitioner
ORL (ENT)	Ear, Nose and Throat Specialist
PFM	Waikato DHB Patient Flow Management programme
SLT	Speech Language Therapy
RCC	Regional coordination centre
SMO	Senior Medical Officer
RMO	Registrar
SHO	Senior House Officer

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1.5 Roles and responsibilities

Clinical Nurse Specialist Plastics

- Oversees a regional service for the Midland region
- Is available on mobile phone (0273090534) during work hours(Monday- Friday 0800-1630 hrs)
- Visits on behalf of the cleft team
- Undertakes an oral assessment
- Co-ordinates cleft clinic appointments
- Referrals to the Cleft Support Group can be made on behalf of family with the mother's consent.
- Provides the 'Blue Book' Parent information book on cleft lip and palate and contact details.

Speech Language Therapist (SLT)

- Based at Waikato District Health Board (DHB)
- Referral-based service
- Undertakes evaluation of feeding sufficiency and safety
- Supports decision-making re: non-oral feeding appropriateness/options
- Provides information, support and education on feeding including oral assessment
- Completes Enable funding applications for provision of specialised feeding equipment as required.
- Will make arrangements for ongoing Speech Language Therapy follow-up in the community.

Lead Maternity Carer (LMC) / Lactation Consultant

- Based at regional Secondary / Tertiary Maternity Facilities
- Full palate check on birth /admission by LMC/medical team
- Offers antenatal consultation for early advice including antenatal colostrum collection, early and ongoing skin to skin, expressing and feeding in the first few days.
- Assists mother to make informed choices with regard to breastfeeding, supplementing and lactation, including use of donor breastmilk.
- Ensures mother knows how to recognise early feeding cues and normal input/output
- Undertakes an oral assessment, preferably in conjunction with the SLT.
- Provides close support and expertise where complex care is required.
- Reviews and updates feeding care plan in conjunction with ward staff, LMC and paediatrician (where applicable). Documents feeding plan in baby's clinical notes.

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- Ensures that information on hand expressing and a hospital grade electric breast pump is available while in hospital, plus advice on breast pump availability in the community
- Provides advice on positioning of baby at breast
- Recommends breast compressions when baby is at breast to facilitate milk transfer
- Advises on volumes for bottle feeds/top ups
- Use Habermann bottles if suckle feeding is safe and does not compromise baby's airway and safety. Do not change to other bottle unless advised by the speech language therapist.
- Refers to outpatient Lactation Consultant for ongoing support with breastfeeding and/or expressing and lactation.

Neonatal Team

- Based at Waikato Hospital NICU
- Full palate check on birth /admission by LMC/medical team
- Will examine the baby in the early postnatal period, including airway, breathing and check for cardiac anomalies.
- Investigations should include
 - Detailed family history
 - Thorough examination of head, neck and extremities.
- These investigations may be included if there are concerns:
 - Chromosomal testing

Consider:

- 22q11 Deletion Syndrome, also known as Velocardiofacial Syndrome as this is the most common syndrome associated with cleft palate
- Pierre Robin sequence

Social Worker

- Based at regional Secondary / Tertiary Maternity Facilities
- Provide counselling and support for families.
- Provides funding information
 - child disability,
 - travel/accommodation assistance

Discharge Facilitator

- Provide support and discharge planning

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Lactation consultant

- Breast pump hire costs (where applicable).
- Breast pumps can be hired from Cleft NZ website for free (www.cleft.org.nz).

2 Clinical Management

- If the condition was **not** identified antenatally the parents will be unprepared and may be alarmed and concerned by the diagnosis
- Examine the oral structures carefully to assess the extent of the condition, this includes palpation and visual inspection

The mouth should be fully inspected with a good light and spatula and the palate inspected right back to the uvula to exclude minor degrees of cleft palate.

2.1 Referrals

- Lead Maternity Carer (LMC) involved in the birth of the new born baby with a cleft lip +/- palate should refer the child to the services documented below using the appropriate internal referral documents.
 - Plastics Department via RCC
 - Lactation Consultant via RCC
 - Clinical Nurse Specialist – Plastics or RN Cleft via phone **027 309 0534**
 - Speech Language Therapy
 - If inpatient at Waikato Hospital via PFM
 - If not an inpatient, Child Development Centre referral via RCC
- If baby is in the postnatal ward, midwife /LMC to refer baby to the cleft team and inform the neonatal team about the referral.
- If baby admitted to NICU due to medical problems, Neonatal team to send referral as soon as possible after diagnosis of the cleft.

2.2 Follow up

All staff working with the parents should ensure that:

- Parents have the Clinical Nurse Specialist – Plastics or RN Cleft name and contact details
- Parents are aware of cleft clinic appointments
- Parents know what follow up support is available in the community from SLT, Lactation consultant and LMC and how to contact
- Parents are provided with patient information below
- Document in the discharge letter

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2.3 Useful contact numbers

Speech Language Therapist	021-762-942
Clinical Nurse Specialist (Plastics)	027-309-0534
Discharge Facilitator, NICU	021-910-594
Lactation Consultant, NICU	021-242-8719
Clinical Nurse Specialist (Home care, NICU)	021-929-896

3 Patient information

- The 'Blue Book'- a handbook for parents of children born with cleft lip/palate - is available from the Clinical Nurse Specialist – Plastics and/or RN Cleft.
- This is given to and discussed with the parents. It is also available online, www.cleft.org.nz or 0800 425 338.
- A referral to the support group can be made with the parent's consent or they can be contacted by families directly.

4 Audit

4.1 Indicators

- All infants with cleft lip +/- palate are referred to the specialist services by their LMC/neonatal team
- All parents of a child with a cleft lip +/- palate are provided with the contact details for the Clinical Nurse Manager – Plastics or RN Cleft contact phone number
- All parents receive a copy of the 'Blue Book'.

5 Evidence base

5.1 References

- Starship (2018). Cleft Lip and Palate. *Clinical Guideline Newborn Services*. Retrieved on October 21, 2020 from <https://www.starship.org.nz/guidelines/cleft-lip-and-palate>.
- Auckland DHB (2019) Newborn examination. *Starship Child Health Newborn Intensive Care clinical guidelines* .Retrieved March 19,2021 from <https://www.starship.org.nz/guidelines/newborn-examination/>
- Counties Manukau Health (2020). *Cleft lip and palate*. Retrieved on March 21,2020 from <https://www.healthpoint.co.nz/public/plastic-surgery/auckland-regional-plastic-reconstructive/cleft-lip-palate/>

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5.2 External Standards

- Health Practitioners Competence Assurance Act 2003
- Healthy and Disability Services (Safety) Act, 2001
- Health & Disability Commissioners (Code of Health & Disability Services Consumers' Rights) Regulation, 1996.

5.3 Associated Waikato DHB Documents

- Breastfeeding policy (Ref 0132)
- Artificial milk/formula feeding for Infants policy (Ref 1901)
- NICU Medical: Use of Donor Breastmilk in the Newborn Intensive Care Unit procedure (Ref 5926)
- NICU Nursing: Labelling, handling, storage, transport and administration of human milk in New Born Intensive Care Unit procedure (Ref 2771)
- NICU Nursing: Enteral Feeding in Newborn Intensive Care Unit procedure (Ref 4945)
- NICU Nursing: Expressing Breastmilk in the Newborn Intensive Care Unit procedure (Ref 6088)
- NICU Nursing: Feeding Equipment procedure (Ref 2894)

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