

Dublin Cleft Centre Team - Supporting information for Maternity Site HCPs when referring new babies for Cleft Management Services

Family Details

- Standard information essential for registration to Cleft Services.
- Completing this record ensures timely contact with the family and initiating appropriate supports for their first consultation with the team. Ensure contact phone & email for parents included.
- Please include baby's Christian name if known.
- Nationality & language information can assist if an interpreter needs to be booked for the initial cleft clinic consult. It can also direct the Cleft Nurse Specialist/Co-ordinator regarding the provision of verbal and written information to families.

Medical Details:

Date of Birth / Time of Birth / Gestation / Cleft type / Birth Weight / Length / OFC / Apgar Score:

- Information assists in determining health of baby at birth and on-going liaison with GPs & Public Health Nurses for growth monitoring.

Delivery Mode / Parity / Maternal Health / Medications during pregnancy:

- Information provides the Cleft Team with an insight of maternal health, previous experience as a parent and if there may have been a medication contributing to increased risk of clefting.

Cleft Family History

- Provides information regarding parent's previous experience of cleft conditions or potential hereditary patterns. Can assist the Cleft Team's delivery of information on Cleft Pathway.

Airway Assessment: (this should be completed prior to 1st oral feed)

Micrognathia / tongue position / SaO2 / Tick box description of Airway Symptoms

- Important information in determining if Robin Sequence is a possible added diagnosis.
- Feeding and Management advice offered by the Cleft Team depends on the details provided.
- Infant's ability to oral feed safely can be determined by the clinical picture provided.
- Transfer to CHI as in-patient for multidisciplinary assessment and management may be required.

Feeding: (airway assessment should be completed prior to 1st feed)

Mother's Feeding Preference:

- The cleft team encourage breast feeding and the mother's choice. Breast feeding rates /EBM provision are documented annually by the team in line with "Breastfeeding in Ireland, Action Plan 2016-2021" and "The National Maternity Strategy 2016-2026". The effect that a cleft diagnosis has on a mother's feeding preference is noted. Realistic goals and feeding support are provided.

1st oral feed offered by breast / standard bottle / Other:

- The 1st oral feed should always be by breast/standard bottle to ensure the infant has the necessary oral skills. Once the infant has demonstrated safe suck, swallow, breathe co-ordination then an assisted feeding bottle can be introduced under supervision (not required with lip only clefts).

Feeding at time of referral /Describe present feeding /Bottle Type:

- Important information for the Cleft team when providing on-going feeding support and determining how soon the infant should attend a cleft clinic consult.

Investigations:

Bloods reserved / Other investigations/Other referrals

- Information provided can help avoid duplication of investigations/referrals by the Cleft Team. Referring hospital is responsible for communicating results to parents/Cleft Team.

Neonatal Audiology Screening

- Babies with palatal involvement are at increased risk for hearing loss and otitis media. All babies with palatal involvement require targeted follow up Audiology before 1st birthday as per Neonatal Audiology Screening Programme (NAST). Maternity hospital responsible to ensure babies with a late diagnosis of cleft palate are linked back in for follow up services.

Cleft Diagnosis:

Antenatal Diagnosis / Antenatal anomaly scan available in unit / Antenatal Cleft Team referral

- The Cleft Team audit the rate of antenatal diagnosis against UK standards and offer to liaise with parents before the birth of their baby. Antenatal cleft referrals advised as soon as possible after the 20 week anomaly scan.

Time of Diagnosis post Birth (in hours of age) / Birth -24hrs / 24-48hrs / 48-72hrs / 72hrs-1 week / 1week-1month / 1month-6months / >6months

- Birth diagnosis times are audited by the Cleft Team against both the UK Cleft Nurses 24hrs standard and the 72hrs RCPCH standard.
- Late diagnosis after 72hrs may have lasting effects on the parents and may constitute a risk to baby's feeding, weight gain and general health.

Referring Professional Information:

Name of Referrer/ Title of person 1st recognizing cleft / Team Consultant / Neonatologist / Paediatrician / Referring Hospital or Centre Address / Contact No. / Fax / Email:

- All important information for liaison in the event of queries on the referral. The Cleft Team record details annually on cleft cohort numbers, types and diagnosis time from all 19 ROI Maternity sites.

Date/Time referred to Cleft Team:

- The Cleft Team record time from diagnosis to referral to monitor any delays & make necessary improvements in communication between sites. The Cleft Team advise referral as soon as possible following diagnosis to ensure healthcare staff and families have the most up to date information on cleft care.

Initial Cleft referral mode by Phone / Email / Fax / Post / Referral communicated to Co-ordinator / Nurse Specialist / Secretary / Plastic Surgeon / Plastics Registrar / Speech & Language / Other:

- The Cleft Team audit their lead time from receipt of referral to 1st contact with family against their standard of 24hrs lead time.

Plan for local follow-up arrangements:

- Important information for the cleft team who advise local paediatric monitoring of growth & development for at least 1 year of age (clefts with palatal involvement), along with continued communication between all healthcare providers.

References/Recommended Reading:

- Bannister, P. (2008) 'Management of Infants born with a Cleft Lip and Palate. Part 1'. *Infant*, 4 (1): 234-236.
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- Butcher, S. (2007). 'Cleft palate: the value of early diagnosis'. *Midwives*. 10(8): 382-383.
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- Martin, V. and Bannister, P. (Eds) (2003). *Cleft Care: A Practical Guide for the Healthcare Professional on Cleft Lip and/or Palate*. Wiltshire, APS Publishing.
- Williams J. (2012). 'The recognition and management of isolated cleft palate'. *Community Practitioner*. 85(10): 28-31.
- Royal College of Paediatrics and Child Health (2014). 'Palate examination: Identification of a Cleft Palate in the Newborn'. Available at: www.rcpch.ac.uk
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- Tierney, S., Blackhurst, M., Scahill, R. & Callery, P. (2015). 'Loss and rebuilding: A qualitative study of late diagnosis of cleft palate'. *Journal for Specialists in Pediatric Nursing*. 20(4): 280-289.
- Young, JL., O Riordan, M., Goldstein, JA., Robin, NH. (2001). 'What Information Do Parents of Newborns With Cleft Lip, Palate, or Both Want to Know?'. *Cleft Palate-Craniofacial Journal*. 38 (1): 55-58.

Useful Websites: www.cleftcareireland.ie

www.cleft.ie www.clapa.com www.childrenshealthireland.ie
www.pierroerobin.org www.ern-cranio.eu

CONTACT CLEFT CO-ORDINATORS/NURSE SPECIALIST AT CHI SITES

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