

Understanding Cleft Lip and Palate

- Being born with a cleft lip, palate or alveolus (gum) affects one in seven hundred babies (1 in 700) born in the United Kingdom each year¹. A baby can be born with a cleft lip, cleft lip and palate, or an isolated cleft palate.
- Most babies born with a cleft are born to families with no family history, although there can be a family link, and some babies have the cleft alongside other conditions and anomalies².
- A cleft is another way of describing a 'gap' in the lip, palate or alveolus that should have joined together by week twelve of fetal development².
- A cleft lip and/or alveolus can be described as 'complete' or 'incomplete' depending on the severity, and it can affect one or both sides of the lip - this is referred to unilateral or bilateral.
- A cleft palate can involve the soft or soft and hard palate.
- A cleft lip and alveolus are usually identified during the fetal anomaly scan at 20 weeks gestation. However, the presence of a cleft palate cannot reliably and consistently be detected during an ultrasound scan². A Magnetic Resonance Imaging (MRI) Scan is sometimes used to further assess palatal involvement.

Diagnosis

Early diagnosis is important for the baby and family as any delay may affect the baby's growth and development and health care. Below, we list the opportunities for diagnosis.

Routine:

- Antenatal – Ultrasound scan
- Newborn and Infant Physical Examination (NIPE) which occurs within 72 hours of birth. The Royal College of Paediatrics and Child Health (RCPCH) recommends that a baby's hard and soft palate are visually examined within the NIPE, and it has produced a guide to support healthcare professionals do this³. It has also produced support guides for parents.

Other Opportunities:

- Review of an infant who has faltering growth, prolonged feeding, and an inability to attach to the breast* or standard infant feeding bottle or who makes an audible clicking sound during feeding, are all indications of cleft palate.
- Review of a child over 2 years who is unable to produce 'pressure consonants' in speech (such as 'b', 'd' and 'p') or whose speech sounds unclear or nasal.
- Investigations into certain hearing difficulties, such as glue ear, could be indications that the palatal muscles are not working effectively.

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For additional resources see www.ihv.org.uk

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Good Practice Points relating to diagnosis:

- Within the antenatal period, if a cleft lip has been identified by ultrasound scan, it is important that parents are made aware that their baby may also have a cleft palate to prepare parents appropriately. Once the baby is born, they should be referred to the cleft team and a full assessment provided.
- If a baby has an isolated cleft palate, this is ideally diagnosed within the first 24 hours of life but sometimes it can be missed. There is variation in how a cleft palate may present, for example, it may present as a large gap or as a bifid uvula which is where the uvula is split into two.
- It is important for health visitors to be aware that a baby with a cleft palate is unable to breastfeed directly because they struggle to achieve the necessary intra-oral negative pressure to draw milk from the breast and to adequately stimulate supply of breastmilk. If a baby is offered infant formula, they will struggle to suck from an infant feeding bottle. In these cases, a specialised bottle is used to feed the infant following assessment by the Cleft Clinical Nurse Specialist (CNS).

Impact of diagnosis for parents

Parents of children with a cleft may have many concerns, such as:

- Parents worry that they have done something wrong to cause the cleft and the impact on the wellbeing of their baby.
- They worry that the cleft is linked to other conditions.
- They may be apprehensive about caring for a child with a cleft and managing other peoples' reactions and expectations.
- They may worry that the cleft will be painful for their baby.
- They may worry about their baby's ability to feed or develop and talk.
- Some may worry about the surgery involved and possible facial scarring.
- They may worry that their child will be considered differently because of their facial difference.
- For parents who wish to breastfeed, being unable to feed their baby directly can lead to profound upset. Parents may need to be supported and helped to express milk. There can be feelings of guilt if they are unable to or choose not to offer expressed milk. During the antenatal phase if a cleft is known, a feeding plan can be discussed and recorded, and parents encouraged to hand express colostrum for use following delivery.

Treatment

Care for staged repair is proposed on a case-by-case basis depending on the surgical team and health of the child. It is important to understand from the cleft team and the family the treatment plan for each individual. Treatment may involve the following support:

- Lip repair – completed at 3-6 months of age.
- Palate repair – completed at 9-13 months of age.
- Some cleft services offer a toddler clinic review at 18 months of age where the cleft nurse, cleft psychologist and speech therapist completes a developmental assessment. This is additional to the routine developmental assessments undertaken by HV teams.
- Between 18-24 months of age, children with a cleft palate are reviewed by the cleft specialist speech and language therapist for assessment and possible therapy. Some children may require further palate surgery to improve speech clarity.
- Care from other specialists such as surgeons and orthodontists are considered via clinics held at the specialist cleft centres. Some children may need alveolar bone grafts or jaw surgery.
- A child may be offered support from a clinical psychologist who specialises in the care of children and families affected by cleft. They are available in all cleft teams.
- Patients referred to the cleft service are routinely reviewed until aged 20 years.

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Role and considerations for health visitors relating to care and support

1. Working together with the cleft team

- Cleft services are organised in a hub and spoke model, with each team having a specialist team within a specialist centre. See Cleft Lip and Palate Association's (CLAPA) website for full list.
- A cleft CNS will be the initial contact for all children and families who have a diagnosis and will make contact or see the babies within 24 hours of receiving the referral. Contact is a combination of hospital and home visits. It is advisable to contact your local cleft team and establish good links and understand the local service offer.
- Collaborative working including joint home visits can occur between cleft CNS and HVs to understand family needs and agree a joint plan of care. This approach can support families, promote responsive parenting, identify difficulties for parents such as coping or their mental health, and needs of the baby.

2. Supporting feeding in babies with cleft

- It is important for health visitors to support parents and explore how to promote their choice of infant feeding.
- If a parent wishes to offer breast milk, the cleft CNS can provide advice on breast pumps for expressing breast milk. The HV can also provide support and advice around this.
- Expressed breast milk will be offered to the baby using an assisted-feeding method bottle. The most suitable specialist bottle will be identified by the cleft CNS following a feeding assessment.
- For babies with a cleft lip and/or alveolus only, breastfeeding may be possible if a good seal is achieved. These babies will require close monitoring of weight gain and may need to use a specialist bottle alongside.
- Parents may have been supported by a hospital-based infant feeding team and require ongoing support once they leave the hospital, such as community infant feeding support.
- Please always consult the cleft nursing team before considering division of tongue tie in an infant with a cleft, as this may be contraindicated.

3. Additional care needs of babies diagnosed with a cleft

- Babies and their families may require enhanced health visitor care to ensure their needs are met.
- It is good practice that infants with a cleft are reviewed by a paediatrician within their first 6 weeks of life to consider any additional conditions.
- Despite the use of a specialist feeding bottle, babies with a cleft will use more energy during feeding. It is therefore important to monitor feeding and growth regularly, especially during early weeks. A small number of babies will require additional nutritional support.
- Babies with a cleft palate and a small lower chin (micrognathia) may have a condition known as Pierre Robin Sequence. This is where the tongue can fall back into the cleft and cause upper airway obstruction. These patients will require close monitoring of their breathing and may need strict positioning guidance or an airway adjunct, such as a Nasal Pharyngeal Airway (NPA).
- Infants with a cleft palate may be advised by their cleft nursing team to sleep in a lateral position rather than supine (as per current NHS Guidance on reducing the risk of sudden infant death syndrome)⁴. Ongoing research is investigating optimum sleep positioning for this cohort of patients. If you are unsure which position a patient has been advised to sleep in, please contact the local cleft team.
- Children with a cleft palate require audiology reviews until the age of 5 years. A cleft palate can increase the risk of glue ear which can impact speech and language development.
- Once a baby has teeth, they need regular monitoring by a local dentist. Research suggests that children with a cleft are more likely to have dental caries.
- For babies with a cleft palate, the introduction of solids can be considered from 17 weeks when clinically indicated, are developmentally ready, and they can be supported by the cleft CNS. This is because babies with a cleft palate often find an oral puree diet easier to manage, especially during their post-operative recovery.
- If a baby is due vaccinations near to the time of their surgery, it is important to discuss this with their cleft team.

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Support/ Organisations for families

- Cleft Lip & Palate Association - <https://bit.ly/48CVwGz>

Further reading

- NHS Choices: Cleft lip and palate - Treatment - <https://bit.ly/48C3QGy>
- RCPCH: Cleft Palate: Examination in the Newborn - <https://bit.ly/3Hlx94b>
- Transition from children's to adults' services for young people using health or social care services. NICE guidance [NG43] - <https://bit.ly/3l3z9Pe>
- Public Health England Guidance. Cleft lip: information for parents - <https://bit.ly/3uB2du9>
- For a gallery of images of cleft lip before and after surgery see; <https://bit.ly/49D0BPn>

** We refer to breastfeeding and breastmilk but recognise terms such as chestfeeding, bodyfeeding, nursing, lactation, or providing human milk may be more preferable for and accurate to some of the families we support.*

References

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3. Royal Collage of Paediatrics and Child Health. Palate examination: Identification of cleft palate in the newborn. 2014. [Accessed 11.01.2024]. Available from: <https://bit.ly/3HnlfH3>
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Author:

Helen Moreland

Lead Clinical Nurse Specialist, SPIRES Cleft Service
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An extended version of this GPP will be available on the iHV website soon.

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