



Supporting people with cleft lip and palate and related disorders

Over 1,000 babies are born each year in the United Kingdom with cleft lip and/or palate¹ while others may be born with a submucous cleft palate. In addition, some children present later in childhood when they start talking, with speech that sounds as if they have a cleft palate. This is known as velopharyngeal speech disorder. Speech and language therapists play a crucial role in supporting these children and their families. They can also support adolescents and adults with these conditions.

The palate and speech

The palate is essential for speech production. It forms the roof of the mouth and is made up of two parts: the hard palate and the soft palate. The muscular soft palate moves upwards and backwards towards the back of the throat (pharynx). At the same time, muscles in the back and side walls of the throat move towards the soft palate to close the nose off during speech, so that most of the sound comes out of the mouth. We use our tongue, teeth and lips to shape the air to make different consonant and vowel sounds.

- Most of the sounds that we use in speech are made with the palate raised up, closing off the nose. Sounds made in this way include p, b, t, d, k, g, s, z, ch and j.
- Some sounds, such as m, n and ng, are produced with the palate relaxed (lowered) allowing air to flow up through the nose.

What is a cleft?

A cleft is a gap in the lip or palate where the muscles have not come together properly when the baby is developing in the womb. There are different types of cleft which affect speech:

- unilateral cleft lip and palate (UCLP);
- bilateral cleft lip and palate (BCLP);
- isolated cleft palate (CP).

In addition, submucous cleft palate (SMCP) occurs when the muscles in the palate have not joined together properly but the membrane of the roof of the mouth, known as the mucosa, has grown over the top, so it is not obvious to the naked eye. Sometimes this can be missed as it is difficult to spot in a baby.

A velopharyngeal speech disorder can occur in the absence of a cleft if there are issues with the muscles in the palate or a large space between the soft palate and the very back of the throat (pharynx). Sometimes this can occur after an adenoidectomy. There are also children who develop this type of speech through mislearning rather than a problem with the structure.

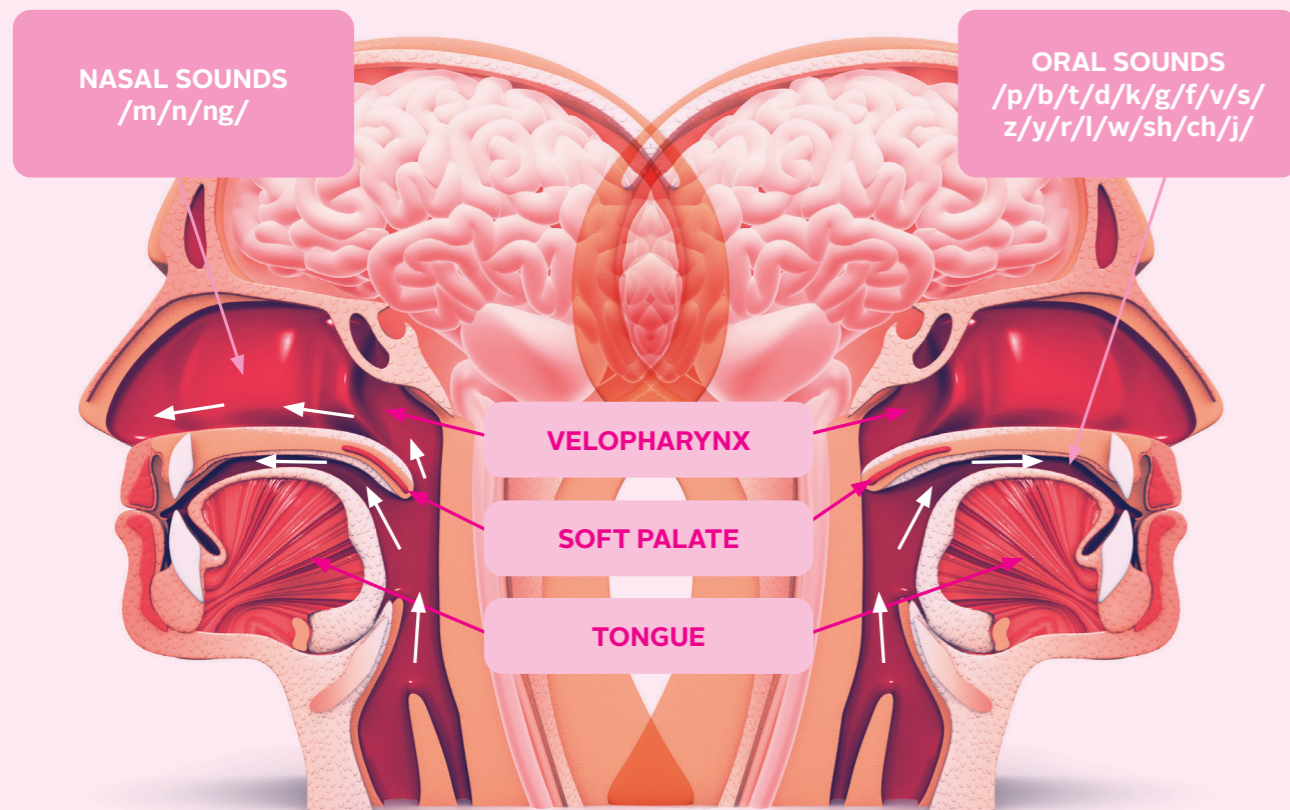


The impact of cleft lip and palate

Cleft lip and palate can have a range of impacts.

- **Speech:** it can affect speech, resulting in too much air in the nasal cavity (hypernasal resonance), air coming down the nose when talking, and articulation difficulties, such as using sounds in the throat or incorrectly making front sounds further back in the mouth (e.g. /t/ is produced as /k/).²
- **Language development:** it can affect language development,³ including the onset of talking in words and sentences being delayed and the number of words in the child's vocabulary being smaller.
- **Academic attainment:** children with cleft lip and palate may need support to achieve their academic potential.
- **Feeding:** it can affect feeding⁴ – an unrepaired cleft palate makes it difficult for babies to create adequate pressure to suck. Breast feeding is difficult and most babies will be seen by specialist nurses and fed using specially adapted bottles and techniques. Ongoing velopharyngeal problems may lead to problems of food and drink coming down the nose (known as nasal regurgitation).

ORAL VS NASAL SOUNDS



Ben's story

Ben was referred to the Regional Cleft Lip and Palate service aged 2 years 10 months by an ENT consultant, whom he had seen due to recurrent ear infections. As a baby he struggled to breast feed and had milk coming down his nose. Ben's mother consulted her health visitor and GP but no onward referral was made. Ben was slow to talk but this was put down to his frequent ear infections and associated hearing loss. As his talking developed nasal speech became apparent and a referral to the community speech and language therapy service was made. The ENT consultant diagnosed a bifid uvula and suspected a submucous cleft palate. When Ben finally saw the team at the cleft lip and palate centre he was diagnosed with a cleft of the soft palate, which was repaired when he was aged 3 years and 2 months. The specialist speech and language therapist at the cleft centre and the community speech and language therapist worked together to provide a package of intervention to work on his articulation. At 4 and a half, Ben needed further specialist investigations for his speech. These were carried out by the specialist speech and language therapist. After liaison with the surgeon, it was decided Ben needed further surgery to his throat wall to correct his speech. Speech and language therapy continued until Ben was 5 years old, at which time his speech was within normal limits and he settled into reception class well. His speech and development will continue to be monitored by the speech and language therapists at the cleft centre until he is fully grown.

Velopharyngeal speech disorder

Babies and young children may present to their health visitors, GPs or local speech and language therapy departments with signs of velopharyngeal speech disorder. These may subsequently be diagnosed as a submucous cleft palate or a cleft of the soft palate, but velopharyngeal speech disorder can occur if there is any disruption in the ability to close off the nasal cavity from the oral cavity. This might be due to problems with the muscles in the palate or a large nasopharynx. Sometimes, however, this is due to mislearning and may not be a structural problem at all. In all cases, a referral should be made to the specialist speech and language therapist at the nearest regional cleft centre.

The role of specialist cleft speech and language therapy

Specialist speech and language therapists in cleft palate and related disorders typically:

- oversee children born with cleft lip and/or palate from birth to adulthood;
- assess the speech and language of children, young people and adults referred with any speech problems related to palate function;
- undertake specialist investigations of palate function. This might include an x-ray of the person talking (videofluoroscopy)⁵ or a small camera being inserted up the nose (nasendoscopy)⁶ to investigate the movements of the palate and its relationship to the pharynx;
- provide specialist interventions such as cleft articulation therapy or electropalatography (EPG);⁷
- liaise with cleft link and community speech and language therapy colleagues regarding appropriate intervention close to home, including not only speech but early communication skills and language;⁸
- train other speech and language therapists to help reduce missed cases of submucous cleft palate and velopharyngeal speech disorder, ensuring correct referral to cleft lip and palate services and avoiding incorrect referral to other services, for these types of speech disorders, and in the UK, not, for example, ear, nose and throat services;
- help in the differential diagnosis of palatal speech problems, including advising if surgery and/or speech and language therapy are needed, and the timing and sequencing of these interventions.

Cleft lip and palate care is centralised in the UK with 11 regional services delivering multidisciplinary care. The specialist speech and language therapist is a core team member.

The impact of speech and language therapy

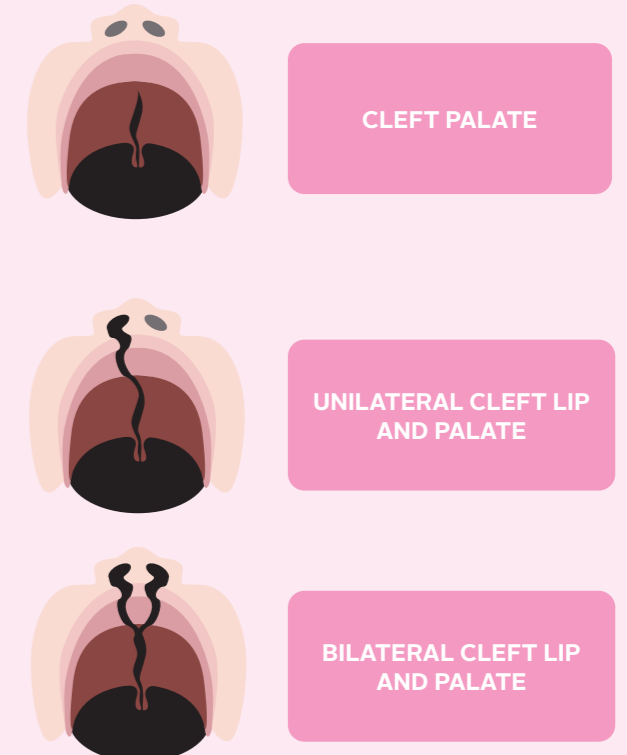
- There have been improvements in speech outcomes since the centralisation and specialisation of cleft palate services.⁹
- Early referral to specialist SLTs is beneficial. Early intervention has been shown to prevent later speech problems in some cases.^{10, 11, 12}
- Early liaison with audiology and ear nose and throat (ENT) colleagues is essential to manage the commonly found associated hearing difficulties.¹³

Knowing when to refer to specialist cleft speech and language therapy

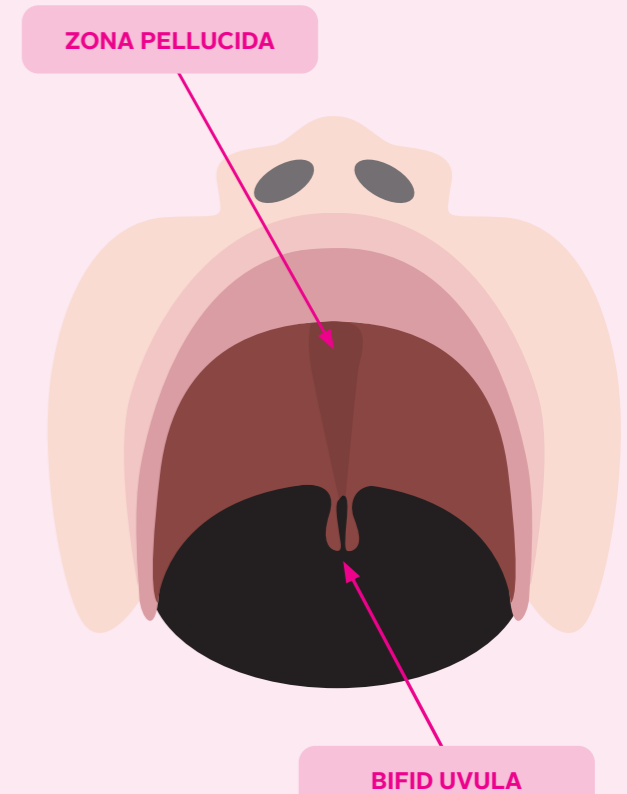
It may be necessary to refer a child to specialist cleft speech and language if there is a history of some or all of the following:

- milk frequently comes out of the nose in the first year;
- breast feeding can be difficult;
- feeding in infancy takes a long time and the baby tires and falls asleep;
- food and drink frequently comes out of the nose in older children;
- poor weight gain;
- nasal sounding speech—sounds like 'b' and 'd' pronounced as 'm' or 'n' – so 'bye' sounds like 'my' and 'daddy' sounds like 'nanny';
- air coming down the nose when speaking;
- difficulties sucking and blowing through mouth, such as blowing bubbles;
- family history of cleft or other medical conditions, especially congenital heart conditions;
- slow development of language;
- frequent ear infections;
- bifid (split) uvula – the dangly part of the palate at the back of the mouth;
- zona pellucida (midline translucency in palate).

EXAMPLES OF DIFFERENT CLEFTS



EXAMPLE OF SUBMUCOUS CLEFT PALATE



Missed cases of cleft palate

Cases of cleft lip and palate are visible on ultrasound at the 20 week routine scan and can be diagnosed before birth. Isolated cleft palate is harder to detect but should be diagnosed within 24 hours of birth. However, 28% of cleft palates are diagnosed late - 12% diagnosed after 1 week and 2% after 6 months¹⁴ with implications for feeding, attachment, healthy growth, speech and language development and parental anxiety.

To help reduce the risk of cases being missed, the Royal College of Paediatrics and Child Health (RCPCH) has produced the following NICE guidelines for examination of a palate:¹⁵

1. Healthcare professionals should examine a baby's hard and soft palate as part of the full new-born physical examination and record this in the child health record.
2. Examination of the baby's palate should be carried out by visual inspection.
3. A torch and method of depressing the tongue should be used to visualise the whole palate.
4. Parents should be informed if the whole palate (including the full length of the soft palate) has not been visualised during the new-born examination.
5. If the whole palate is not able to be visually inspected at first attempt then a further attempt at visual examination should be made within 24 hours.
6. Trusts should provide training on the correct method of visual inspection of the palate to all healthcare professionals required to carry out the new-born examination.

Associated syndromes

There are many syndromic diagnoses associated with cleft palate and velopharyngeal speech disorders^{16,17}, with more chromosomal abnormalities discovered every year. The most common are:

- 22q11 deletion syndrome (or Di George also known as Velo-Cardio-Facial-Syndrome)
- Sticklers syndrome
- Van der Woude syndrome
- Treacher-Collins syndrome

► For more information about how speech and language therapists can support people with cleft lip and palate please email info@rcslt.org and for more information about the support that CLAPA can provide, please visit: www.clapa.com.

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