### Care pathway “unilateral cleft lip, alveolus and palate”

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<th>Planning interventions or other</th>
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<td>First contact with cleft lip and palate team</td>
<td>Prof. Vander Poorten; Prof. Schoenaers; M. Breuls; Y. Antonis; A. Brever; A. Verdonck</td>
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<td>Lip closure + poss. grommet insertion</td>
<td>Prof. Schoenaers</td>
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<td>Soft palate closure + grommet insertion</td>
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<td>Hard palate closure</td>
<td>Prof. Schoenaers; Prof. Vander Poorten</td>
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<td>Bone grafting to dental arch</td>
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<td>Prof. Jorissen; Prof. Schoenaers; Prof. Hellings</td>
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<td>Y. Antonis</td>
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Unilateral cleft lip and palate

Feeding

From birth

Feeding problems affecting children with a unilateral cleft lip, alveolus and palate depend on the size of the cleft as well as on other factors. Since there is a connection between the mouth and the nasal cavity, children with a bilateral cleft lip, alveolus and palate cannot vacuum suck (create low pressure in the mouth) which is normally necessary to suck effectively.

This can result in

- choking
- quickly getting tired when drinking
- regurgitating food through the nose
- not drinking enough
- drinking very slowly
- swallowing too much air

Breastfeeding or bottle feeding

Breastfeeding is not always possible, but it is certainly worth trying. Your speech and language therapist, nurse, paediatrician or gynaecologist can advise you about this.

If you bottle feed we recommend using a wide-based three-position teat, for instance a Dodie three-position teat ("second age"). Normal motor development of the mouth is stimulated best by using an ordinary three-position teat, making it easy to vary the speed of feeding by turning the bottle. If feeding is not successful using this method, it is best to try a Haberman bottle with a special teat. A Haberman bottle is a hard plastic bottle with a membrane and teat. Due to the special valve structure you can squeeze the teat along with the baby’s drinking rhythm. This means the baby does not have to
suck hard and feeding is quicker and easier.

Additional tips:

• Try changing posture: keep your baby as upright as possible when feeding, with the head inclined slightly forwards. This prevents regurgitation through the nose and swallowing too much air.
• Try putting the teat in the mouth in different positions.
• Try an ordinary teat – because it stimulates oral motor function best – and try changing the size of the hole or cutting a cross in the end of the teat: the milk will then spray out of the teat and spread over the whole tongue. An older teat may be the solution to sucking problems.
• If your baby chokes this is a sign that the hole in the teat is too large. Try a different teat with a smaller hole. Sometimes choking may be remedied by trying a different feeding position. If necessary feed can be thickened slightly.
• Regurgitating milk or food through the nose is not serious, but it is annoying for the baby. Clean the nose with physiological solution after feeding.
• Burp your baby more often when drinking.
• Take your time, but do not allow feeding to last longer than thirty minutes (it is better to do it more often for a shorter time).
• If you continue to have problems with feeding and you are worried about it, do not hesitate to contact your speech and language therapist or your GP or paediatrician.

Tube feeding

If your baby is not able to take enough food and fluid using normal feeding methods, it is sometimes necessary to use tube feeding for a time. If this is done discussions will take place with your ENT doctor, paediatrician and speech and language therapist on going back to oral feeding as quickly as possible to develop the feeding reflex and mouth function. As long as your child is being tube fed we recommend using a dummy to satisfy and maintain the sucking reflex.

Solid food

Changing over to spoon feeding usually does not cause any problems. It is best to follow the advice of Kind en Gezin (“Child and Family” agency) or the GP/paediatrician looking after your child:

• pureed fruit or vegetables from about 4 months
• drinking from a cup from 6 months
• chewing food from about 8 months

Remember that all children have to get used to eating from a spoon and get used to food with different tastes and textures. In particular you should make sure you use a soft spoon and start with just one taste. When you see that your child is getting used to this new way of feeding, you can vary the taste and texture.
When using pureed fruit we advise against using citrus fruits because they can be irritant if the food regurgitates through the nose (reflux through the nose).

**Feeding after lip closure**

After the lip operation you should first give your child a little sugar water. The paediatrician will decide when your child can be fed again. If your child was breastfed before the operation, he/she can be given the breast again after the operation. If you are bottle feeding we would suggest cutting a small cross in the teat so that your child does not have to suck hard.

During the first week after the operation it is best to start with liquid food and then liquid and/or soft food for another three weeks. After about three weeks the wound should be fully healed and you can bottle feed using normal teats again.

**Feeding after soft palate closure**

On the day after the operation your child will be given some water to drink. He or she will only be given liquid food for one week. Your child must not suck a bottle for four weeks after the operation. He or she can drink milk from a (tipping) cup. The milk can also be thickened with Nutriton, rice powder or koekjesmeel (sweet biscuit flour) and given with a spoon.

After one week of liquid feeding your child can take liquid and soft food for three weeks, for example:

- well-mixed vegetable puree (up to twice a day)
- Petit Gervais, vanilla custard or cheese curds
- Pureed fruit with crumbled cookies

**Avoid:**

- hard food products (e.g. biscuits or rusks)
- spicy foods
- acid fruits in the puree (e.g. citrus fruits or kiwi)
- fizzy drinks
- dry bread
Feeding after hard palate closure

During the first few days after surgery, feeding is usually not very easy. Your child needs to learn to swallow in a different way and often will not dare to swallow. Usually there are not many problems with swelling or pain. Once your child is eating comfortably again, he/she can leave hospital.

What your child is allowed to eat:

- soft food, mixed and without lumps
- consommé and soup
- nutridrink
- (ice-cold) milk
- ice cream
- bread, softened if necessary

Avoid:

- soured milk products like yoghurt and cheese curds.
- fizzy drinks (fizzy pop, sparkling water etc.)
- Ensini: supplementary feed that provides extra protein, vitamins and minerals. Ensini is sold in various flavours (forest fruits, peach/orange).

The mouth of your child should be rinsed out with salty water after every meal.

After coming home your child should continue to eat soft food until the wound has healed properly. This takes about four weeks.
Operation for unilateral cleft lip and palate

Admission to hospital

Your child will be admitted to the Paediatric ward at UZ Leuven, Gasthuisberg campus for both operations. It is always possible for one parent to stay in the child's room. Your child must have nothing to eat or drink after midnight.

The operation(s)

1. Lip closure.
2. Closure of the soft palate and the rear part of the hard palate.
   The soft palate and the rear part of the hard palate are closed at the age of 12 months. The front part of the hard palate is left open to allow the soft palate to extend well towards the back and to avoid interfering with the growth of the upper jaw (maxilla) as much as possible. The remaining opening at the front of the hard palate will already have become much smaller by the time it is closed at around 5 years of age.
   
   During the soft palate operation the muscles of the soft palate are carefully aligned and reoriented. The palate is also lengthened as carefully as possible to achieve the best possible closure between the mouth and nasal cavity. It is almost always necessary to insert grommets (eardrum tubes) during this operation as well.
   
   The operation takes two to three hours and the stitches dissolve by themselves after a few weeks. The child will be given a one week course of antibiotics. Your child will also be given painkillers and nose drops. Feeding is allowed immediately on the day after the operation. At first you should give liquid food with a spoon, a syringe or a tipping cup. You are advised not to use a bottle or dummy.
   
   Your child can usually go home on the third day after the operation. By that time feeding will be easy and only simple painkillers may be needed. About 1 month after the operation the wound will be healed and no more special precautions will be needed when feeding.

3. Hard palate closure
   The opening at the front is closed at about the age of 5 years. This operation is similar to the soft palate closure operation, but it generally seems to be a milder experience. Two days after the operation your toddler can go home.

4. Bone graft in the upper jaw (maxilla)
Development of the teeth

Milk teeth

On average the first milk teeth come through from the sixth month after birth. A full set of milk teeth is in place around the age of 2½ or 3 years. Children with a unilateral or bilateral cleft in the upper jaw usually have dental abnormalities. These abnormalities vary considerably:

- there may be too many or too few teeth
- the shape of the teeth may be abnormal: too small or too big
- the teeth may sometimes be blocked and may therefore not come through by themselves.
- the teeth may also be rotated or may come through crooked.
- the shape of the dental arch is often abnormal in these children. The dental arch may be interrupted in the area of the cleft and usually has a peaked shape

often the upper jaw (maxilla) is relatively underdeveloped in comparison with the lower jaw (mandible). These children therefore often have a reversed relationship between their jaws.

Mixed dentition

From the child’s sixth birthday, permanent teeth begin to come through. The milk teeth are replaced and the permanent teeth come through. When the new teeth come through the same dental abnormalities may occur as with the milk teeth. The permanent teeth seem more abnormal because they are larger. The transition is not as smooth as usual. The abnormal relationship between the jaws may become more pronounced as the children grow: both sideways and front to back.
Permanent teeth

On average all permanent teeth have come through by the age of about 12 to 14 years. From then on, abnormalities in the positioning of the jaws and teeth can be finally assessed.

Dental care

Children with a unilateral cleft lip and palate usually have a number of dental abnormalities:

- there may be too many or too few teeth
- they may come through in an abnormal position
- they may have an abnormal shape

Since these children will need orthodontic treatment later, it is very important to keep their teeth and gums healthy. This applies to both milk teeth and permanent teeth.

What can you do as a parent?

1. As soon as the first milk teeth come through, you must care for them well.
2. Brush daily using a small toothbrush (“baby toothbrush”) with a little infant toothpaste
3. Do not allow your child to get used to sweet things, do not give sweet drinks or soft drinks in the feeding bottle and definitely do not let your child go to sleep with a bottle. A dummy with a sweet taste on it (such as honey) is definitely bad for their teeth!
4. Fluoride reduces the likelihood of dental caries. In the past it was often given in the form of fluoride tablets. Now it is known that applying small amounts of fluoride on a regular basis is most effective. You should therefore brush using a toothpaste that suits the child’s age.
5. Allow your child to get to know your own dentist from the age of 3 so that they can develop a good relationship. It is recommended to have a check-up every six months. Your dentist will advise you on the best ways to clean teeth in difficult positions. He will also clean the teeth professionally.
6. Particularly when wearing a brace or brackets the dentist will monitor your child’s oral hygiene. Otherwise there is a very high risk of dental caries and serious gum disease.
7. The dentist can also apply preventative sealing if there are abnormal shapes or deep grooves. He will treat any cavities if necessary. In this way premature tooth loss can be prevented. The dentist will correct permanent teeth that have enamel defects or abnormal shapes. Usually this treatment will be provided in consultation with the dentist from the cleft lip and palate team.
8. If dental care or extractions cannot be carried out by your own dentist, the dentist from the cleft lip and palate team will talk to your dentist and the other members of the team to find the best treatment option. This may be combined with another operation under general anaesthetic or light sedation.
Orthodontic treatment

Children with a unilateral cleft lip and palate usually have problems with their upper dental arch. Some of these problems can be solved by the orthodontist alone, but others will need to be discussed with the maxillofacial surgeon. Problems with tooth positioning can arise as soon as milk teeth come through. Sometimes it is recommended to use a brace at this stage. In most cases this will only be needed once permanent teeth come through.

- Postnatal orthopaedic treatment
- Full set of milk teeth
- The first replacement stage
- Mixed dentition
- Permanent teeth

Postnatal orthopaedic treatment

[View of upper jaw (maxilla) with removable plate in the mouth].

Whether treatment with plates should begin immediately after birth will depend on the size of the cleft in the jaw. If the cleft is more than 1 cm wide the orthodontist will often insert a removable plate made of soft plastic material immediately after birth. This guides the growth of the two halves of the jaw, resulting in a smaller cleft. The lip closure operation performed by the plastic surgeon then also requires less tension. After lip closure the brace will be adjusted and the baby will continue to wear it until the soft palate is entirely closed.

Full set of milk teeth
During this stage of jaw and tooth development, active treatment rarely takes place. If children are being injured by their teeth or have a seriously abnormal relative jaw position in the front-back direction, normalisation of the relative jaw position (“bite”) at this young age is sometimes considered in consultation with the maxillofacial surgeon. Normally facial growth and the child’s jaw positioning are monitored until the child begins the first replacement stage.

[View of the positioning of teeth before removable plate is fitted.]

[Removable plate appliance for widening upper jaw (maxilla).]

[View of positioning of teeth after orthodontic treatment: the relationship between the jaws has been normalised.]

**The first replacement stage**

When the upper front middle and side incisors come through, these teeth usually

- have an abnormal shape
- or come through in the wrong position,
- or are sometimes even missing.

Abnormalities of tooth positioning are only treated if they have a negative impact on jaw development, for example if the upper incisors have come through behind the lower incisors. This is treated using a partial fixed appliance or a removable hard plastic plate with a number of springs that apply pressure to the tooth that is wrongly positioned.
Effect of fixed appliance on tooth positioning in upper jaw (maxilla).

Mixed dentition

Almost all children with a unilateral cleft lip, alveolus and palate are given a bone graft (from their hip, rib or chin) at the site of the cleft before the permanent canines come through [canine comes through]. Before this operation the upper jaw (maxilla) is usually widened using a fixed appliance which is unscrewed weekly or daily. This orthodontic preparation usually takes about six months. If the upper jaw (maxilla) is only slightly underdeveloped, growth of the upper jaw can be stimulated using a Delaire Mask. This appliance is fixed to a removable plate.

Permanent teeth

For virtually all unilateral cleft lip, alveolus and palate patients, orthodontic treatment is recommended after all the permanent teeth have come through. That is when work can begin to optimise the relative jaw positioning and improve the positioning of individual teeth using a fixed appliance. If the upper jaw is clearly underdeveloped, the relative positioning of the two jaws cannot be treated by orthodontics alone. In that case the orthodontist and maxillofacial surgeon will need to work together. At present it is still to be preferred to normalise abnormal relative jaw positioning surgically as an adult. Distraction osteogenesis is one way of doing this. This technique involves using an internal or external appliance to apply traction to the upper jaw. In this way the relationship between the two jaws is normalised. As soon as the relative jaw positioning and the positioning of individual teeth have been normalised, any abnormality in the shape and any missing teeth can be treated using crown and bridge work and implants.
Hearing

Children with a cleft lip and palate nearly always have problems with fluid build-up in the middle ear. The middle ear is the space behind the eardrum, in which the auditory ossicles need to be able to move freely. If there is fluid in this space the movement is reduced, which results in hearing loss. Hearing loss at a young age must be avoided because it leads to a delay in speech and language development. Long-term fluid build-up also results in retraction of the eardrum and possible damage to the auditory ossicles.

The tube that drains the fluid that builds up in the middle ear (the Eustachian tube) is normally opened by the muscles of the palate each time when swallowing. If the palate has a cleft, the palate muscles are no longer joined together in the midline and these muscles cannot open the Eustachian tube efficiently each time when swallowing. This leads to a long-term build-up of fluid in the middle ear.

To prevent the harmful effects of this fluid build-up, it is necessary to provide some help in removing the fluid through this tube. This is done by fitting a small tube across the eardrum (a grommet). This has a similar effect to making a second hole in a milk bottle: the effect is that the fluid can escape more easily through the Eustachian tube, as it is meant to do. This ensures optimum development of hearing, speech and language and optimum health of the ear itself.

This minor operation is done for the first time at the same time as surgical closure of the soft palate, at about 12 months of age. A grommet normally stays in place for 6 to 18 months and usually grows out of the eardrum leaving no injury behind. It usually has to be reinserted when the child is 5 years old.

Your child can swim with a grommet, but should not dive into deep water, which is not a problem during the first few years of life when grommets are most necessary. You can use soap and shampoo, but you should avoid getting them in your child's ears.
Speech and language development

Speech development with a unilateral cleft

Every language has its own range of sounds that belong specifically to that language. Learning to recognise, differentiate and pronounce these different sounds is what we call speech development. For proper speech development it is important for your child to be able to hear and use the muscles of his or her lips, jaws, tongue and palate properly. During the first three years of life your child will learn to listen and control the various muscles. At around three years of age most children can articulate virtually all the sounds separately, except for /s/ and /r/. During their third and fourth year your child will learn to use the different sounds correctly in words. It is therefore normal for children frequently to miss out sounds or replace them with others when pronouncing their first words.

Speech is assessed on the basis of comprehensibility, which means how well the listener can understand the speech. Comprehensibility is less good when there are problems with articulation or nasality. Nasality means air escaping through the nose when talking. In Dutch this should only happen when making the 'nasal' sounds /m/, /n/, /ng/ and /nk/; for all other sounds the nasal cavity is completely separated from the mouth. This is done by closing the soft palate.

Specific problems that can arise:

1. Articulation problems: due to a greater difficulty positioning the tongue correctly, some sounds are pronounced incorrectly (e.g. /s/ with the tongue between the teeth) and/or frequently replaced by others (e.g. /t/ is replaced by /k/).
2. Problems with resonance or hypernasality: due to an abnormal air flow through the mouth and nasal cavity and/or due to the soft palate not closing properly, the sounds that are made seem too nasal.

Tips on positively encouraging speech development:

1. Your baby likes pulling funny faces; this encourages him or her to imitate you and practice using his or her mouth muscles.
2. Imitate your baby or toddler's sounds and you will often start having a 'babble conversation'.
3. Pronounce the words and sentences that you say to your child correctly yourself.
4. Avoid correcting your child or making him or her say the word correctly; instead repeat it correctly yourself or use it in a simple sentence (e.g. "pi" “Yes that is a pig”; “pane!” “Have you seen a plane?”). You can emphasise the sounds that were not pronounced correctly. After hearing it many times your child will begin to pronounce the word correctly.
5. Avoid using your child's toddler language. Say it correctly yourself.
6. Do not talk too fast and use short, simple sentences.
7. Do lip, tongue, blowing and sucking exercises with your child to stimulate his or her mouth muscles.
Language development with a unilateral cleft

Language development means learning to understand the meaning of words and sentences (language comprehension) and thus learning to express your own thoughts and wishes in words (language production).

- Between 12 and 18 months your child will begin to say his/her first words.
- Between one and half and two years children learn to make two-word sentences.
- Two years is a crucial age for the speech therapist to assess language development.
- From two to five years children gradually begin to express themselves using longer sentences with a wider vocabulary and putting correct prefixes or suffixes and endings on their words (as well as using correct declensions and conjugations).

Children with cleft lip and/or palate sometimes have delayed language initiation and delayed language development. Any language delay is usually not due to the cleft lip and/or palate, but due to other related circumstances, such as hearing difficulties or incorrect articulation that inhibits general language development.

Tips on positively encouraging language development:

1. Create talking situations: talk about what your child is doing, talk about what you are doing, talk about what you can both see.
2. It is important for you to get into conversation with your child, whether or not your child can talk. E.g. “ba”, “What a nice bear”; “daddy car” “Yes, that is daddy’s car”; “wanna dink” “Would you like a drink of juice?”. Listen to your child, respond to what he or she says and ask questions about what he or she tells you.
3. Do not be too quick to use gestures. Children learn to talk because they understand that they can get things done by talking.
4. Do not force your child. Talking should be fun, so do not correct your child or force your child to pronounce something better.
5. Play ‘language’ games together: look at books, name objects, point and read, play lotto, dominoes or memory, make up imagination games together, sing songs or read rhymes and poems aloud etc.

Speech and language therapy with a unilateral cleft

The speech and language therapist from the cleft lip and palate team will monitor your child’s speech and language development. If there are problems in these areas, the speech and language therapist will suggest additional test or treatments in consultation with the cleft lip and palate team.

The following types of treatment are possible:

- support and guidance for very young children (1.5 to 3 year age group)
- speech and language therapy (starting no earlier than +/- 3 years) with a speech and language therapist in your area
- multidisciplinary therapy in a rehabilitation centre
- sometimes support may be provided at school by GON (Geïntegreerd ONderwijs = Integrated Education).
• if nasality problems cannot be resolved through speech and language therapy, an extra operation may be necessary