## Care pathway “isolated cleft palate”

<p>| Planning interventions or other | Team members | 0 w | 3 m | 6 m | 9 m | 1 y | 2 y | 3 y | 4 y | 5 y | 6 y | 7 y | 8 y | 9 y | 10 y | 11 y | 12 y | 13 y | 14 y | 15 y | 16 y | 17 y | 18 y | 19 y | 20 y |
|--------------------------------|--------------|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|
| First contact with cleft lip and palate team | Prof. Vander Poorten; Prof. Schoenaers; M. Breuls; Y. Antonis; A. Brever; A. Verdonck |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| Human genetics consultation | Prof. Frijns; Prof. Devriendt |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| Soft palate closure + insertion of grommets | Prof. Vander Poorten; Prof. Schoenaers |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| First cleft lip and palate consultation – treatment planning + annual check-up thereafter | The entire team |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| Conservative dentistry | Chr. Vergalle |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| Feeding advice | M. Breuls |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| Speech and language therapy / pharyngoplasty | M. Breuls |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| Hard palate closure | Prof. Schoenaers; Prof. Vander Poorten |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| Orthodontics (once permanent teeth come through) | An Verdonck |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |</p>
<table>
<thead>
<tr>
<th>Other final corrections (possible osteotomy)</th>
<th>Prof. Schoenaers</th>
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<tr>
<td>Psychological support if needed (available at any age)</td>
<td>Y. Antonis</td>
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Cleft palate

Feeding with a cleft palate

From birth

After soft palate closure

After hard palate closure

From birth

Feeding problems affecting children with a cleft 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 cause:

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

Breast or bottle feeding
Tube feeding
Solid food
Breast 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 will be 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. Sometimes it is easier if the teat is offered more to the left or to the right side of the mouth.
- 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.
  NB: the milk must not flood into the mouth! It is important that the baby should suck actively. That is why we advise against using a lamb teat.
- 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 the feed can be thickened slightly (e.g. using rice flakes or 3-grain or 7-grain flour, depending on the age of the baby).
- 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 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 flakes or "koekjesmeel" (sweetened biscuit flour) and given with a spoon.

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

- 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 will have 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 cleft palate

Admission to hospital

Your child will be admitted to the Paediatric ward at UZ Leuven, Gasthuisberg campus. 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)

The extent of a cleft palate can vary from a cleft uvula to a cleft that runs from just behind the dental arch right to the back.

For a cleft soft palate extending no more than 1 cm from the rear edge of the hard palate, surgical closure requires a single operation at the age of 12 months. If the lower jaw (mandible) is also smaller, the operation may be delayed until 18 months to prevent tongue swelling as a result of pressure during the operation leading to the upper airway being narrowed and breathing difficulty (breathlessness) after the operation.
If the cleft extends all the way to just behind the dental arch (complete cleft palate), the soft palate and the rear part of the hard cleft palate will be closed at 12 months.

The front part of the hard palate will usually be left open,

- partly to allow the soft palate to grow backwards normally,
- and also to cause as little interference as possible with the growth of the upper jaw (maxilla).

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 or 6 years of age.

During the soft palate operation the muscles of the soft palate, which are very important when it comes to closing the nasal outlet and thus forming speech properly, are carefully aligned and reoriented. The palate is also lengthened as carefully as possible to optimise the closure between 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.

In our ward we give one week of antibiotics (Amoxicillin). Other medicines your child will be given include painkillers and nose drops. If grommets are inserted, ear drops will also have to be given.

Feeding can begin on the first day after the operation, but you are asked to give liquid food at first using 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 one month after the operation everything will be healed to such an extent that no more special precautions will be needed when feeding.

If an opening is left at the front, this will be closed at about 5 years of age, as mentioned above. 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.
In exceptional cases the restored palate may not close off the nasal outlet sufficiently at the rear despite good speech and language training. This will have an effect on comprehensibility as air will escape through the nose, causing incorrect articulation. These children may need an additional operation on their palate, usually at about the age of 6, which is called a pharyngoplasty.

**Pharyngoplasty**

Sometimes, despite the palate being adequately lengthened during surgical closure at the age of one, and despite speech and language therapy to train the muscles of the palate, there may still be a difficulty closing the nasal outlet. As a result air continues to escape through the nose when speaking, which causes problems with articulation and comprehensibility. If this happens, a pharyngoplasty should be considered.

In this operation either the nasal outlet is narrowed by fashioning a sphincter from the muscles of the lateral wall of the throat (sphincter pharyngoplasty) or the palate is lengthened, while also inserting a piece of muscle from the back wall of the throat into the nasal outlet to make it easier to close off afterwards.

After opening and releasing the palate a small flap of muscle from the back wall of the throat is stitched into place.

View of the nasal outlet:
the opening in the nasal outlet that has to be closed off is changed from a single large oval space into two sideways openings which are easier to close off when speaking. This closure is necessary in order to be able to speak clearly.

After stitching the muscle flap above the palate into place the palate is closed again and this time it is shifted backwards. This makes it possible to position the nasal outlet closure further back, which is necessary for proper speech development. After this operation speech and language therapy is always needed to help the child to learn and use the new anatomical situation correctly.

Prior to this operation a video pharyngography is usually carried out to assess the additional length that is needed. After the operation speech therapy is always needed, which is "muscle training" to optimise functioning of the closure after it has been surgically improved.

**Video pharyngography**

This is an X-ray test to look at the anatomical relationships between the soft palate and the throat cavity. During this test the mobility of the soft palate and the pharynx muscles is also assessed. This means that a contrast fluid such as nose drops are dripped into the nose so that the soft tissues in the throat can be seen clearly during the test. Afterwards, during the X-ray test, video recordings are made while the child is pronouncing a few specific sounds. The child does not need to fast for this test.

The test is carried out by Professor Bob (Robert) Hermans, radiologist

**Teeth with a cleft palate**

**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 from the age of 2½ or 3. Dental abnormalities may occur in children who only have a cleft palate, although these children rarely have any serious dental problems. These dental abnormalities can vary considerably: HERR

- too many or too few many teeth may have come through
- 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 dental arch is not interrupted, the palate is usually narrow and quite shallow due to the original defect and perhaps also partly due to surgery, which very much depends on the type of surgery that has been used. Usually the upper jaw (maxilla) is too narrow in relation to the lower jaw (mandible), especially in the sideways direction.

Mixed dentition

From the child’s sixth birthday, permanent teeth begin to come through. Some milk teeth are replaced and some permanent teeth are added at the back. 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.

Permanent teeth

On average all the 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 who only have a cleft palate will usually not have many dental abnormalities. Nevertheless it is very important to keep the teeth and gums healthy, both for 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 three 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 treatment or extractions cannot be carried out by your own dentist, the dentist from the cleft lip and palate team will talk to your own dentist and the other members of the team to find the best treatment option. Treatment may be combined with another operation under general anaesthetic or light sedation.

Orthodontic treatment

Some children with a cleft palate may have (limited or complex) width-related problems with their upper dental arch (due to the width of the upper jaw (maxilla)). Some of these problems can be solved by the orthodontist alone. Others need to be discussed with a maxillofacial surgeon.

Milk teeth, first transition and intertransitional stages.

During the milk teeth, first transition and intertransitional stages a patient with a cleft palate will only rarely need orthodontic treatment. The growth of the child's face and the relative position of the jaws are monitored until all the permanent teeth are in place and facial growth has finished.
Permanent teeth

Orthodontic treatment may be recommended once all the permanent teeth have come through. From that moment work can begin to optimise relative jaw positioning and improve the positioning of individual teeth using a fixed appliance.

If the upper jaw (maxilla) is clearly underdeveloped, the relative position of the two jaws cannot be treated by orthodontics alone. In that case the orthodontist and the maxillofacial surgeon will need to work together. If the upper jaw is very narrow, it may sometimes be necessary to make it wider by means of surgery. At present it is still preferred to normalise relative jaw positioning surgically in adulthood.

As soon as the relative positioning of the jaws (“bite”) and the positioning of individual teeth have been normalised any abnormal shapes and missing teeth can be treated using crown and bridge work and implants.

Hearing with a cleft palate

Patients with a cleft lip and palate often 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. 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 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 properly. 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 by means of a tube. This is done by fitting a small tube across the eardrum (a grommet). 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 improves the health of the ear itself.

This small operation is done for the first time when the child is 12 months old. 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. You can use soap and shampoo, but you should avoid getting them in your child's ears.

Speech and language development with a cleft palate

Children learn to talk by imitating the speech behaviour in their immediate environment, because people are speaking around them from the time they are born, and because people also specifically talk with them and to them. Your child’s first cries and babbling sounds come by themselves – these are unlearned, spontaneous sounds. From then on, interaction with the people around them becomes very important for real speech and language development. Children gradually begin to produce more different sounds and then their first words. They learn these variations in sounds and words through imitation. Speech and language develop from this process of imitation. Good hearing, a good environment for listening, sufficient sensitivity to language and an environment that stimulates the use of language are all vital for your child’s speech and language development.

Speech development
Language development
Speech and language therapy
Pharyngoplasty

Speech development with a cleft palate

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 move 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 the 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 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”; “panel!” “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 the mouth muscles.

Language development with a cleft palate

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 caused by the cleft lip and/or palate, but is 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 etc.
Speech and language therapy with a cleft palate

The speech and language therapist from the cleft lip and palate team will monitor your child's speech and language development. If problems arise in these areas, the speech and language therapist will suggest additional tests 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 by GON (Geïntegreerd ONderwijs = Integrated Education).
- if problems with nasality cannot be resolved through speech and language therapy, an additional operation may be necessary.