[Author]Plastic surgery and Husuke outpatient clinic

STARTING LIFE

WITH A CLEFT LIP

Introduction

Congratulations on your new family member!

The HUS Cleft Palate and Craniofacial Center (Husuke) is a national center of expertise that focuses on treating cases of cleft lip and palate, defective fusions of the cranial sutures (craniosynostoses), and associated syndromes in patients from all over Finland.

The internationally acclaimed Husuke began operating already in 1948 at the Red Cross' Plastic Surgery Hospital. Today, it is part of the Plastic Surgery Outpatient Clinic and Cleft Palate and Craniofacial Center in the Musculoskeletal and Plastic Surgery division of HUS. Children's surgeries are performed at New Children's Hospital.

This Starting life with a cleft lip guide contains information about your child's cleft lip and its treatment. The guide also contains contact information for the Cleft Palate and Craniofacial Center (Husuke).

The purpose of this guide is to provide information on the child's cleft and support the family in a new life situation. The guide is a good tool for families at the early stages of a child's life and offers practical tips for a smooth everyday life.

We hope this guide provides the opportunity to read important early-stage information about clefts at your own pace and to enjoy your baby.

Husuke

Contents

The impact of cleft lip and palate on the family and the child's development

Learning that a newborn baby has a cleft lip and/or cleft palate can be a shock to the family. Adapting to the child's illness and the life change it involves takes time. In the early stage, parents may experience a variety of emotions, such as confusion, grief, anger or concern. Other people's attitudes towards the baby's appearance may be concerning and increase a parent's desire to protect their child. Parents may also feel unnecessary guilt about a child's illness. It is important to give yourself time to adapt to the new reality and its requirements

The most important thing for the baby is to establish and develop a good interactive relationship with their parent. The foundation for a safe attachment relationship is the parent's curiosity about the baby and observation of their needs. Responding to the baby's messages and sounds by providing care, chatting, playing, singing and reciting rhymes builds a common language between the parent and baby.

Development of a child with cleft lip and palate

Children who have a cleft mainly learn and develop in the same way as other children of the same age. However, they have a somewhat higher possibility of experiencing learning difficulties, especially in the linguistic area. Differences observed in early childhood development often level out as the child grows.

In most cases, a cleft does not significantly interfere with psychosocial development. No differences in psychological development have been observed between children of daycare age who have a cleft lip and palate and healthy children of the same age. In primary school, caution related to social relationships, nervousness and dissatisfaction with appearance are somewhat more common than in other children of the same age. Supporting the child's speech development and interaction skills is important in terms of preventing challenges. Encouragement from parents and setting an example help a child develop positive self-esteem, play skills and social courage. The cleft and its treatment gradually become part of the child's wider self-image.

Supporting the child during examinations and procedures

A child with a cleft lip and/or palate needs treatment provided by many different professionals during their growth. It's important to maintain the child's sense of security during hospital visits and procedures. You can help your child in many ways during hospital visits.

It’s a good idea to talk to a child in advance about the reason for going to the hospital or outpatient clinic in an age-appropriate way. A small child observes their parent to assess the safety of events from their own perspective. A parent's calm attitude and sense of security are reassuring to the child in treatment situations. A child can react to treatment procedures by, for example, crying, but the support, comfort and proximity of a parent help them manage even the difficult situations. The procedures may also seem difficult for a parent, so focusing on exhaling slowly or calming thoughts can help in a stressful situation.

A visit with an older child requires more detailed preparation. The child should know why the procedures are being done and how the visit will progress from one step to another. It’s important to answer a child’s questions honestly. Play and drawing are good ways to prepare for procedures. During the procedure, the parent's proximity, verbalisation of emotions, calm speech, a soft toy to provide a sense of safety, and focusing attention on something pleasant may make the situation easier. After the visit, you can reward your child with a treat or by spending some pleasant time together. It’s important to talk about difficult situations and the feelings experienced during them with the child afterwards so that they aren’t afraid of future treatments. You can ask a professional for support if necessary.

Parents and children can receive psychological support at different stages of a child's development. A psychologist from the Pediatric General Hospital Psychiatric working group consults and cooperates with Husuke. If necessary, we can also help organize support with your local service network.

Kati Havo, Specialist Psychologist in Development and Education, Psychotherapist
New Children's Hospital

Clefts and heredity

Cleft lips and palates occur at the beginning of fetal development, during the first three months of pregnancy. The onset mechanism is multifactorial in most cases, meaning that it is simultaneously influenced by several predisposing genetic factors and several external factors that usually remain a mystery.

The factors affecting the development of clefts are still largely unknown, but we do know that genetic factors play an important role in this process. Thus, an important risk factor for clefts is their occurrence in the immediate family. The role and impact of environmental factors and so-called external factors in the development of clefts are poorly known. However, estimates suggest that the pregnant mother's lifestyle or nutrition has very little impact on preventing clefts. A folic acid deficiency in nutrition has been suspected of increasing the risk for clefts, but studies have produced contradictory results and no convincing evidence has been obtained.

Flu or an infectious disease in the mother has not been found to increase the risk of cleft either.

Most medications do not contribute to the development of a cleft. Anti-epileptic medications include some products that can increase the risk of clefts. However, safe epilepsy medications are available for pregnant women.

Multifactorial inheritance

The majority of clefts are inherited in a multifactorial manner, which means that both genetic factors and so-called external factors play a role in the development of clefts. The risk of cleft recurrence is determined according to the probability of recurrence based on experience from large sets of patient data.

If a child with a cleft palate has been born into the family, the risk of the next children having a cleft is 2%. In the case of cleft lip and palate, the risk is 4%. If a child has a cleft, their risk of having children with clefts is 3–4% in the future.

The same type of cleft is usually inherited within a family. However, the degree of severity can vary. Siblings who do not have a cleft have no increased risk for having children with a cleft.

Syndromes associated with clefts

Clefts resulting from multifactorial inheritance are not usually associated with other congenital structural anomalies or they occur as isolated additional symptoms. On the other hand, syndromes associated with clefts usually involve several other structural anomalies and findings in addition to the cleft. In this case, a geneticist should evaluate the situation in order to determine the precise diagnosis and assess the risk of recurrence.

Syndromes associated with clefts may be caused by an error in a single genetic factor, and heredity patterns and the risks of recurrence can vary depending on the precise syndrome diagnosis.

Although hundreds of syndromes associated with clefts have been identified, most of them are very rare. In some syndromes, the clinical picture may be very serious. On the other hand, in addition to a cleft, Van der Woude syndrome only involves missing teeth and small pits in the lower lip, which are additional salivary glands.
Van der Woude syndrome accounts for 2% of all clefts. According to some estimates, syndromes associated with clefts account for 20-30% of all clefts.

Genetic counselling in Finland

Each Finnish university hospital in Helsinki, Turku, Tampere, Oulu, and Kuopio operates a clinical genetics unit, where a geneticist can assess an individual family's situation and risk of recurrence.

In situations where a possible syndrome associated with cleft or hereditary cleft is suspected, the attending physicians at Husuke may refer the patient to their own clinical genetics unit.

Sirpa Ala-Mello
Docent, Specialist in Clinical Genetics

The effect of cleft lip on feeding a child

After the birth of the child, eating is one of the fundamental functions in terms of nutrient intake and development of the attachment between a baby and parents. The aim of feeding is to provide sufficient nutrition in the most natural way possible in a safe and secure environment. A baby with a cleft has the same need for sucking and similar reflexes as other newborns. Every parent has the right to receive the support and guidance they need, regardless of whether the mother breastfeeds or the baby receives expressed breast milk or formula in another way. The functional adverse effects on the muscles of the mouth and pharynx vary depending on the structure of the cleft. As a result, the solutions to eating problems are individual.

Today, cleft lip is often already diagnosed in an ultrasound examination during the mother’s pregnancy, but a cleft palate is only confirmed after the child is born. If a child's cleft lip has been diagnosed during pregnancy, it provides a good opportunity to become familiar with the feeding “tips” in advance.

Feeding

A newborn child tries to obtain their nutrition using the natural eating reflex. Breastfeeding is usually possible for children born with a cleft lip. The baby should be held close to the breast and in contact with the skin. This allows the baby to search for the nipple or touch the breast. This helps the milk come in. If the cleft lip is extensive and the child is unable to close their lips to make a seal, this will decrease the child's ability to suck because escaping air prevents formation of a good vacuum. It’s a good idea to breastfeed the baby so that the cleft side is tight against the breast so that the breast closes part of the cleft opening. You can support the breast from below to help the baby get a better latch. If the baby has a cleft lip and alveolus, the mother may cover the cleft opening with their forefinger or thumb, for example, to create a better vacuum in the oral cavity.

Parents should be patient to begin with, as it takes time for the mother's breast milk to come in and the child may need time to learn the eating technique. It’s a good idea to try different eating positions and change positions. You can also ask for help from the child health clinic, for example.

If breastfeeding is not possible for some reason or the mother does not want to breastfeed, she can express milk from the breast or use infant formula and offer it to the baby using a bottle with a normal teat. If the baby finds it difficult to obtain milk with a regular milk teat you can enlarge the hole slightly. If feeding is not possible with ordinary teats, you can also try special teat, for example Pigeon or Haberman. The most important thing is that the child learns to eat and gains weight.

Each child has their own rhythm for eating and sleeping. At first, the eating rhythm may be more frequent because the amounts of food are small. Within a few weeks, the intervals between feeding sessions usually increase and the amounts of food eaten are larger. The child gradually finds a daily rhythm, meaning that they eat more often during the day and the intervals between eating are longer at night. If air accumulates in the stomach, it is important to remember proper burping while the baby is eating and when they have finished. Start offering puréed foods in an age-appropriate manner according to the instructions provided by the child health clinic.

The cleft causes the mucous membranes of the mouth to dry out quickly. Drying of the gums and lip can be dealt with by cleaning them with water and applying skin oil. The baby can use a pacifier. A pacifier and eating stimulate the motor skills of the lips, tongue and mouth area.

It is important to remember that not all eating problems are caused by the cleft.

Procedure-related information

Before the operation, the child should also practise drinking milk from a bottle, because breastfeeding does not usually start on the day of the operation. The child may start breastfeeding according to the surgeon's instructions within a few days of surgery.

The baby may not use a pacifier for one month after surgery, because the plastic part of the pacifier would put pressure on the wound of the newly repaired lip. The child should be weaned off the pacifier at least two weeks before the operation. The operation must be postponed if they have not been weaned off the pacifier.

Preparing in advance helps the child feel more comfortable after the operation, because a sudden change in eating habits is an extra burden for your child.

Husuke nursing staff

Surgical treatment of cleft lip and monitoring of the child

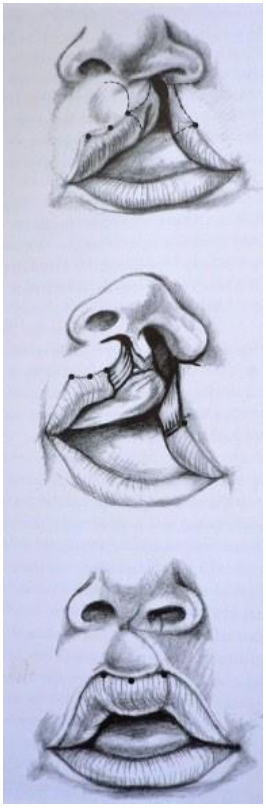
In Finland, 18–20 children are born with cleft lip each year. One in three children with a cleft lip also has an alveolar cleft, which requires bone graft surgery at a later time. An extensive cleft lip may also involve significant nasal asymmetry. A milder form is the so-called microform cleft lip, which is mainly visible only as a streak and/or type of contraction in the skin of the lip. Sometimes a cleft lip is bilateral.

The image above is an example of a treatment pathway. An individual treatment pathway is planned for each child.

Huulihalkiolapsen hoitopolku	Treatment pathway for cleft lip
Ensikäynti	First visit
Määräaikaistarkastukset kasvun aikana	Regular check-ups during growth
plastiikkakirurgi, oikojahammaslääkäri, puheterapeutti	Plastic surgeon, orthodontist, speech therapist
Huulen sulkuleikkaus	Lip closure surgery
Luunsiirtoleikkaus jos halkio myös ikenessä	Bone graft in the case of alveolar cleft

Tarvittaessa voidaan tehdä: huulen ja/tai nenän korjausleikkaus	If necessary, the following can be performed: surgery to correct the lip and/or nose

Lip reconstruction



Children who have a cleft lip can often breastfeed. If breastfeeding is not possible or the parents don't want to continue breastfeeding for some other reason, the surgery can be performed at the age of 4 months.

If the mother wants to continue breastfeeding without interruptions, the surgery should be postponed to the age of 6 months.

The surgery should not be postponed for very long, because once the child starts standing up using support, there is a higher risk of damage to the lip after the operation.

During lip surgery, the surgeon finds the normal soft tissue structures of the lip and nose and uses small sutures to attach them into the correct position. Most of the sutures dissolve by themselves, but sutures in the skin area of the lip may have to be removed after surgery. After surgery, the scar is often a bit hard at first, but it usually becomes softer and nearly unnoticeable. After surgery, you can apply cream to the lip scar and protect it with surgical tape.

Later operations

Children with partial or complete alveolar cleft usually require bone graft surgery at the age of 9–12. Today, we use a bone graft taken through a very small incision made in the iliac ridge (hip). The operation is relatively minor and not very stressful to the child. Bone graft surgery is preceded by orthodontic treatment of the teeth, which continues after the bone graft operation.

A cleft lip can also involve deviation of the bone and cartilage in the nose. The position of the nose is always corrected during infant surgery, but in this case the nose structures are left untouched for the time being. If deviation in the nose structures or the shape of the nose bothers the young person later, a separate operation on the nose can be performed after they have stopped growing.

Children with a cleft lip do not experience the speech problems that are associated with other cleft types.

Anne Saarikko
Docent, Specialist in Plastic Surgery

The effect of cleft lip and palate on teeth and bite

Baby teeth appear at the age of 6 months–3 years, but on average the development of permanent teeth is 6 months late. An exception is the tooth at the cleft site (tooth number two), which may appear very late in both the baby and permanent teeth. The size and shape of the cleft area and the teeth adjacent to it also vary. Extra teeth at the cleft site are not usually removed until this is necessary due to the arrival of permanent teeth.

Orthodontics

Nearly all children who have had a cleft lip or cleft lip and alveolus need orthodontic treatment. Orthodontic treatment is performed at Husuke or in the home municipality according to instructions from Husuke. The x-rays required for orthodontic treatment are also taken at Husuke. Copies of these will be sent to the home municipality.

Orthodontic treatment usually starts at school age when the permanent teeth have come in. Jaw growth in children with cleft lip is usually normal. The primary objective is to even out the cleft site and upper dental arch with orthodontic treatment. If two permanent teeth appear at the cleft site, one of these teeth will be removed. If a tooth is missing at the cleft site, it can be replaced prosthetically or the resulting space can be closed with orthodontic treatment. Bone graft surgery is necessary in cases of cleft lip and alveolus when there is bone deficiency in the alveolar ridge. In this case, orthodontic treatment is timed to coincide with the bone graft surgery.
The dentists and dental hygienists at Husuke are happy to answer any questions you might have related to dental care and orthodontic treatment.

Arja Heliövaara

Docent, Senior Dentist

Cleaning and basic care of the teeth

Children who have a cleft need to take good care of their teeth and mouth from an early age. Tooth brushing should start as soon as the first baby teeth appear in the mouth, so that the child can learn good oral health practices right away. A parent should brush their child's teeth in the morning and evening using fluoride toothpaste. For children under 3 years of age, a thin layer of children's fluoride toothpaste (1000–1100 ppm) is sufficient during both brushing sessions. A good toothbrush for your baby is soft and has a small head. As your child grows, it's a good idea to familiarise them with using an electric toothbrush. Cleaning the cleft site may be more difficult because of misaligned teeth. An oral health professional will help with this if necessary, and provide instructions on selecting and using suitable devices.

Evidence shows that children who have a cleft have more cavities in their teeth. Missing teeth, extra teeth and problems with enamel development are also more common. In addition to thorough tooth brushing, cavities are prevented by means of a regular meal rhythm without snacking between meals, avoiding excessive sugar intake and choosing water as a drink to quench thirst. Another goal is to protect the child from caries bacteria transmitted through the saliva, which among other things, means avoiding eating with the same spoon.

Husuke is responsible for orthodontic treatment related to clefts, but basic dental care, such as dental examinations, preventive dental care and cavity filling, is provided by health centers in your home municipality. A pediatric dentist at New Children's Hospital will also assess the oral health situation and, if necessary, provide the local health center with treatment recommendations. It's important to ensure that the child attends regular examinations at their own health center. Due to the increased risk of cavities, we recommend more frequent examinations and preventive dental care appointments. Good oral health promotes cleft treatment and reduces the risks of complications.

The pediatric dental team,

New Children's Hospital

Medical photography

The photos required when diagnosing a disease–during diagnosis as well as when monitoring and documenting treatment, the surgical outcome and healing–are called clinical photos. These are added to the medical report as an appendix.

In plastic surgery, clinical photos supplement x-ray and laboratory examinations in accordance with good care practice. Staff at the HUS Clinical Photography Unit are responsible for photography that is directly related to patient care. The photos are patient data that is equivalent to x-ray images and are subject to the same confidentiality and communication regulations as other patient data.

A photo of the patient taken by a doctor or other medical staff member in a treatment situation is also patient data equivalent to x-ray images and is subject to the same confidentiality and communication regulations as other patient data.

As a family, you have the right to prohibit clinical photography of your child. Prohibiting clinical photography will not affect subsequent treatment in any way. Please inform the doctor treating your child about your decision to prohibit photography and a note of this will be added to their patient document.

Maisa portal

Maisa is a portal for social welfare and health care customers. It can be used either in a browser or as a mobile phone application that can be downloaded from an app store.

Maisa also allows you to act on behalf of another person if you have permission from that person. Logging in requires strong identification, i.e. online banking credenticals or a mobile certificate.

You can find the Maisa portal at www.maisa.fi. and from app stores.

Maisa includes the following services:

1. Appointment booking and cancellation.
2. A preliminary information form may be associated with your appointment. Please fill it in carefully. You can also add information about any allergies and medication. A professional will go through these with you at the appointment.
3. You can also cancel appointments in Maisa. However, we hope that you will cancel an appointment by 12 noon on the previous day at the latest by calling or sending a message via Maisa instead of using the cancellation function in Maisa. We will try to reschedule your appointment as soon as possible, but unfortunately the appointment may be delayed for quite a while in some cases.
4. Communicating with a professional.
   You can send a message to a unit where you have an appointment. The message function is intended for non-urgent matters. We will reply within three working days. The message function can be found in the 'Contact Us' menu in Maisa.
5. View test results.
6. Monitor your health information.

For more information, see the 'Frequently Asked Questions' section at Maisa.fi.

Contact information

Park Hospital, Plastic surgery and Husuke outpatient clinic

Stenbäckinkatu 11, Helsinki
Mon-Fri 8 am—6 pm, tel. 09 471 73500 (call-back service)
www.hus.fi/husuke

New Children's Hospital, Ward Avaruus

Stenbäckinkatu 9, Helsinki

Office tel. 09 471 73731

www.hus.fi/en/new-childrens-hospital