

Preparing for Surgery

First Edition

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The American Cleft Palate Craniofacial Association gratefully acknowledges the generous contributions of the patients, families, organizations, and professionals who help us learn how to better serve those affected by cleft and craniofacial birth defects.

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Introduction

What is cleft lip and/or palate?

A cleft is an opening that occurs when the skin, muscle, and bone of the mouth do not come together early in pregnancy. A cleft lip is an opening in the lip. A cleft palate is an opening in the roof of the mouth. A child may be born with a cleft lip, a cleft palate, or both. A cleft can occur on one side of the mouth, called a unilateral cleft, or on both sides, called bilateral. Cleft lip and palate can be diagnosed through prenatal ultrasound or at birth.

Will my child need surgery?

Children born with cleft lip and/or cleft palate need special medical care and support services during the first year of life and for some, during childhood and adolescence. Most children born with clefts undergo one to three surgical procedures during their first year: cleft lip repair and/or cleft palate repair surgeries. Cleft lip repair, an operation to close the lip, usually takes place in the first few months of life. Cleft palate repair, an operation to close a hole in the palate, commonly occurs just before a baby turns one year old. The timing of these procedures will vary from child to child, depending on the diagnosis and other factors. Both procedures take place in a hospital or surgical center. Typically, a child will spend at least one night in the hospital for each procedure, with his or her parent staying as well. Sometimes a child can go home on the same day as his or her cleft lip surgery.

The best way to find out about your child's particular needs is to speak with his or her surgeon and

team (described below). These two procedures are major milestones in a child's treatment and in the life of a family. It is important to feel as informed and supported as possible during this time.

Who performs the surgeries?

A cleft palate or craniofacial team is a group of professionals who specialize in treating cleft lip and/or palate. These experts work together to care for and support a child from birth onward. A cleft palate or craniofacial team includes a cleft surgeon who performs a child's first cleft lip and cleft palate surgeries (the first surgeries of this type in a child's life are called primary surgeries). The team may also include a speech-language pathologist, orthodontist, ear/nose/throat specialist (ENT), pediatric dentist, audiologist, nurse, psychologist, geneticist or genetic counselor, pediatrician, sleep medicine doctor, social worker, and others. These professionals coordinate the operations your child may need, as well as treatment of related issues, including speech, eating, hearing, breathing, dentition, social and emotional functioning, and other concerns. The ACPA can help you find a cleft palate or craniofacial team in your area.

What is a parent's role in a child's surgery?

A primary caregiver plays an important role in a child's treatment. You are the main advocate and spokesperson for your child, both before and after a procedure. It is important to speak openly with health care providers. As questions and concerns arise at home, be sure to ask about them when you meet with the

team (see page 7 for a list of possible questions to ask). Appointments with the team are critical opportunities to learn about your child's treatment and to prepare for procedures.

What is pre-surgical orthopedic treatment?

In addition to performing surgery to close a cleft lip and/or palate, a child's team may use other forms of treatment. Some teams recommend a technique called pre-surgical orthopedics. This non-surgical treatment takes place before cleft lip repair. Its purpose is to reduce the size of the cleft before surgery.

There are a few forms of pre-surgical orthopedics. A Nasoalveolar Molding (NAM) device molds the tissue around the cleft to reduce the size of the opening. With NAM, a custom-made plate is placed in the child's mouth and held in place with tapes that attach to the child's cheeks. NAM treatment requires daily home care and regular adjustments (usually weekly) by the dentist or orthodontist on the team. Another example is the Latham device, which is a type of custom-made plate that is placed in the mouth surgically, rather than taped, and is tightened in the office and at home. A third option is face-taping. For this method, adhesive tapes are placed on the face to move the tissue of a cleft lip. These techniques are used before the lip repair and may require several visits with the team. They may or may not be part of your child's treatment.

How much does surgery cost?

Most health insurance policies (but not all) will pay for cleft lip and cleft palate

operations. These procedures are considered "reconstructive surgery." To find out about coverage for your child, contact your insurance company directly. The insurance company should be the primary source of information about coverage.

It may also be helpful to talk with someone on your child's cleft palate or craniofacial team. Some teams have a financial counselor who advises families on health insurance matters (the team coordinator or social worker may play this role). This person may be able to help you find out which services are covered and help provide information to your child's insurance company about his or her treatment needs. Some states have programs which help cover the costs of treatment for children with special healthcare needs. Cleft is typically considered for coverage in these programs.

Some insurance policies require a copay before surgery, even if the procedure is covered. For more information, contact your child's cleft team and/or see the ACPA factsheet, *Paying for Treatment*.

Cleft Lip Repair Surgery

What is cleft lip repair surgery?

The purpose of cleft lip repair surgery is to close the opening(s) of a cleft lip. This operation usually takes place when a child is ten weeks of age or older, based on the needs of the child and any other medical conditions which may affect safe timing of the repair. Most often, the lip is repaired in a single operation. Sometimes, a surgeon performs this procedure in more than one operation, depending on the child's unique features such as

the width of the cleft, whether there are bilateral clefts that differ from side to side, the surgeon's personal experience, and/or the center's typical treatment protocols.

What does the surgeon do during this procedure?

During lip surgery, the surgeon cuts the tissue near the cleft and rearranges it



Figure 1: Example of incisions for lip surgery

to close the opening of the cleft and realign the upper lip (there is no need to take tissue from other parts of the body for this

procedure). The operation involves not only restoring proper lip dimensions and appearance, but also joining the muscle of the upper lip to enable a child to make an "O" shape with the mouth, which is important for eating and speech. The drawing above shows how the incisions may be planned.

After surgery, the surgeon may place small tubes called nasal stents into a child's nostrils to support the nose. The stents are held in place with surgical stitches or tape. Your cleft treatment team will provide education on proper cleaning and use of stents if this is part of their treatment protocol. They will be removed in clinic at a later date, usually weeks or months after the procedure. These tubes help maintain the shape of the nose following the procedure.

What are the risks?

Any surgery has risks. The surgeon on the team and the anesthesiologist

in the hospital should discuss the risks of surgery with you before the procedure. An anesthesiologist is a doctor who makes sure your child is asleep and pain-free during the operation. They provide sedation medications so that a person does not feel or remember anything until after the surgery.

The most common problems that occur with lip surgery are infection and problems with healing. Infection occurs less than 5% of the time. Problems with healing can be caused by bumping or damaging the incision after surgery. While bumps are not common, caregivers need to be as careful as possible to prevent mishaps.

It is possible that a child will have respiratory problems during or shortly after anesthesia. During an operation, a breathing tube is inserted through the child's mouth into the windpipe to allow for breathing while under sedation. Sometimes it can be difficult to position the breathing tube in small infants, and sometimes inflammation of the airway may result afterward, warranting observation in the hospital. Very rarely does a person have a reaction or allergy to any of the anesthesia medications. If you know of a family history of adverse reactions to anesthesia, it is important to tell your child's anesthesiologist.

Will my child need more surgery to the lip?

As a child grows, sometimes the lip or nose may become more uneven. A minor "touch-up" is sometimes performed around the time a child starts kindergarten or at the same time as other operations they may need later in childhood. It can refine the lip and deal with minor asymmetries of

the lip or nose. Parents should discuss expectations with their child, the surgeon, and the team.

A child may undergo future touch-up surgery to improve appearance of the surgical scar, depending on the opinion of the surgeon, how well the scar heals, and the family's and patient's opinion on whether they are satisfied.

Cleft Palate Surgery

What is cleft palate repair surgery?

The purpose of cleft palate surgery is to close the opening in the roof of the mouth. This procedure usually takes place between 6 and 18 months of age.

For cleft palate surgery, the surgeon cuts and rearranges tissue around the cleft to close the opening. As with lip surgery, there is usually no need to use tissue from other parts of the body. The surgeon may also rearrange the muscles in the back of the mouth, called the soft palate, to support proper speech.

In some cases, a surgeon may recommend more than one surgical procedure to close the palate opening completely. This decision depends on many factors, such as the width and extent of the cleft. The drawing above shows the incisions usually made for cleft palate repair. The cleft palate repair is often coordinated with placement of ear tubes by an ENT surgeon, depending on a child's hearing tests and exam.

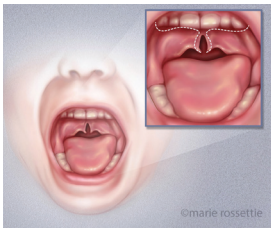


Figure 2: Example of incisions for palate repair

What happens after palate repair surgery?

As a child grows, he or she may need additional surgery to improve the function of the palate, especially near the back of the mouth, an important area for speech production. The surgeon and speech-language pathologist on the team may recommend one of several procedures to address speech concerns, depending on the needs of the child. The surgeon can lengthen the soft palate, for example, or reduce the opening between the throat and the nose.

What are the risks?

Risks of the palate repair include the possibility of infection and bleeding, which occur within the first few days to a week after repair. The palate repair may also worsen snoring or breathing problems until surgical swelling improves. Your baby may not feed as well while the palate is sore, and careful monitoring is needed to make sure they are not dehydrated. Admission to the hospital for at least one night is standard to watch for all these issues. If the repair does not heal completely, there is a possibility of developing a fistula, which is a persistent opening that may allow liquid or food to come out the nose. A fistula is usually visible within the first one to two months after repair. Longer term, there is a possibility that a child is still not able to make all speech sounds properly, even after the palate is repaired. These outcomes may require another operation on the palate to close a fistula or further enhance the soft palate for successful speech.

Preparing for Surgery

How does a surgery get scheduled?

In most cases, the process of scheduling a surgery includes family input. During your early meetings with the team, the surgeon may give you a general idea of when a surgery should take place. Feel free to talk with him or her about your family's schedule and your needs for support.

What happens in the weeks and days before a surgery?

Before undergoing any surgery, the surgeon on the team may recommend that your child meet with his or her primary care physician (PCP). Your child's PCP should verify that your child is generally healthy. He or she should help you plan for any special health needs and confirm that your child's weight and growth are adequate for surgery. The PCP should also make sure that your child's immunizations are up to date.

Prior to surgery, your child may have a pre-operative visit at the hospital or telephone screening call. During this visit, a staff member will give you instructions on what time to arrive at the hospital on the day of surgery and when your child should stop eating and drinking on that day.

Your child may also have at least one other visit to the surgeon's office. This visit may include blood tests and other lab tests. Your child's surgeon will explain the planned surgical technique and may examine your child. The staff will ask about your child's medical history (if they have not already done so). You may also meet with an anesthesiologist, either before surgery or on the morning of surgery, who will examine your child and discuss a plan for managing pain. This visit is a good time to ask questions, such as the ones listed on the next page.

During one of your child's pre-surgical visits or on the morning of the procedure, you will be asked to sign consent forms for surgery. Based on what you learn at your pre-surgical visits, you may also have some errands to do in the weeks before surgery. You may need to buy medicine for your child. Some families arrange for childcare during the recovery period after surgery. You may also need to be ready to pay certain fees to the hospital before or on the day of surgery. This period is a good chance to prepare for the busy time ahead.

What should we bring to the hospital?

It is important to bring health insurance cards to the hospital, as well as identification like a driver's license or passport. Many families also choose to bring a notebook, file, or electronic device for asking questions or taking notes.

Some families choose to pack a familiar object, like a child's blanket or special toy, as well as plenty of bibs and sleepers. Sleepers with a central opening (like those with snaps) tend to work well after surgery because they can be pulled on and off a child without disrupting a post-operative IV tube in his or her arm. Don't forget to bring comfort items for yourself as well, like a pillow, comfortable shoes, and clothes for sleeping. Some parents recommend bringing dark shirts for themselves to wear or small towels to drape over their shoulder when they hold their baby following surgery, to avoid staining their clothing with blood or discharge from incisions. Some hospitals allow families to bring snacks and drinks; most have cafeterias and other places to buy food.

What happens at the hospital before and during surgery?

The day of surgery usually starts with check-in at the hospital, a process that involves signing forms and receiving ID bracelets. You may be asked to identify yourself and your child several times throughout the day. This is a safety measure to ensure that the surgical team knows who you are and why you are there.

Before surgery, parents usually stay with their child in a pre-operative area until he or she goes into the operating room. You may be asked to dress your child in a hospital gown. Just before surgery, your child may receive medicine by mouth that will make him or her feel sleepy.

In the operating room, your child will be given general anesthesia that causes loss of consciousness during the procedure. Usually, a baby goes to sleep by breathing a gas. Then, the IV needle is inserted. An IV is a thin plastic tube inserted into the arm. The baby receives anesthesia through that tube, in addition to fluids, nutrients, and other medicines. A baby will also have a breathing tube during surgery, to make sure he or she is breathing well. During the procedure, parents usually stay in a waiting room in the hospital.

What happens at the hospital following surgery?

When surgery is complete, the surgeon will meet with caregivers to describe how it went. Then, staff may direct you to your child in the recovery room. Your child will still have an IV inserted. He or she may also be wearing arm splints, stiff bands that prevent a baby from bending his or her arms and touching the delicate surgical area.

After cleft lip surgery, a child will have stitches in the lip and nasal

area. There will be some swelling and bruises near the lip and nose, and some bloody drainage around the nostrils. After cleft palate surgery, there may be some bloody drainage through the nose and mouth. In both cases, the drainage usually appears pink in color and stops after several hours. If you have any concerns, be sure to speak with the nurses, staff, and members of your cleft team to confirm that everything is okay.

A child usually spends a few hours in the recovery room then moves to a regular hospital room. This is where your child will rest and recover for the remainder of the hospital visit. In most cases, you may sleep overnight in this room with your child. During this period, a nurse will take your child's vital signs regularly, give pain medications, any other home medications, and assist in feeding. Following cleft lip surgery, nurses may instruct you on how to clean the surgical area. There are no special cleaning procedures for cleft palate surgery.

If your child's surgery included the placement of ear tubes (also called "myringotomy tubes" or "PE tubes") in the eardrum, you may notice some drainage from the ear canal. The hospital nurses or staff may give your child eardrops. The surgeon will give you instructions on home care for the tubes. In some cases it is important to avoid getting water in the affected ear. Eardrops may or may not be needed at home.

When can we go home from the hospital?

In order to release a child from the hospital following surgery, hospital staff will make sure that he or she is breathing and eating well. Your child's surgeon or another team member should also provide you with

written information called discharge instructions. These papers list all the prescription and non-prescription medicines your child will need to have at home, including those to manage pain. The instructions also describe how to care for your baby at home after surgery. There may be special instructions for feeding. You may also be advised to watch for signs of infection. These instructions should also list a phone number to use in case of questions or an emergency (any time, day or night).

Before you leave the hospital, feel free to ask the staff as many questions as you wish. You should feel comfortable that you have all the information you need to care for your child at home.

What happens during a child's recovery at home?

After surgery, your child may be fussy or irritable for a few days and may require medication for pain. Sometimes, a child may come home wearing arm splints, the stiff bands (mentioned above) that prevent a child from bending his or her elbows and touching the surgical area. The team may also instruct you to administer a soft-foods diet for some time after surgery. It is important to bring your child to follow-up appointments as needed and to follow all the discharge instructions from the team.

For a few days after cleft lip surgery, the surgical site will be a little swollen and bruised. Surgical stitches will be noticeable at first, but will dissolve or be removed by the surgeon a few days after surgery. You may be given instructions on how to clean and care for your child's nasal stents, if placed.

During the first few weeks after lip surgery, the scar on the lip may become redder, harder to the touch, and more raised off the skin than before. These

are all positive signs of healing. Your child's surgeon will examine the scar at postoperative visits. He or she may give you instructions about scar care, including using sunscreen and massage. The scar on the lip usually keeps its reddish color for several months. Though scars may fade, they will never completely disappear. (For more information on scars, see the ACPA Family Resources factsheet, *Information about Surgical Scars*.)

What are some questions to ask the team?

Here are some questions to ask your child's cleft palate or craniofacial team before surgery. While some of the answers may be found in this booklet, others are specific to your child's surgeon, team, hospital, and/or personal needs.

Questions for the Surgeon:

- What surgical procedure will you perform? Will there be more than one procedure?
- What are the goals and benefits of this procedure?
- What are the risks and possible complications?
- How old does my child need to be for this surgery?
- Is there a weight requirement for surgery?
- Will my child need additional surgery?
- Is there any treatment needed before surgery? Why? What is involved?
- How long will my child be under anesthesia? How will my child look and behave after surgery, as the anesthesia wears off?
- How long will my child stay in the hospital?

- How will my child's pain and discomfort be managed in the hospital? At home?
- Will I need to have prescription or other medicines on hand for my child after surgery? How will I get the prescription? When will the medicine need to be administered?
- Are there any liquid or food restrictions before or after surgery?
- What medical items will I need to have to care for my child after surgery? (A surgeon may suggest hospital gauze, sterile water, creams, or other items.)
- Should I expect any changes in my child's sleep patterns after surgery?
- What should I watch for after my child comes home from the hospital?
- My child regularly attends childcare. How long should he or she stay at home before resuming a regular schedule?
- Whom can I call for medical advice (24-hour support) if I have a question?

Questions for the Team Coordinator:

- Will I need to make any payments to the hospital on the day of or before surgery? What amounts?
- At the hospital, where do I check in? Park my car? Are there parking fees?
- May I stay overnight with my child in the hospital? Where?

Questions for the Speech-Language Pathologist, Nurse, or Feeding Specialist:

- Will I need to have special bottles, nipples, or food to feed my child at the hospital?

- How do I feed my baby after surgery?
- For mothers who pump breast milk: Is there a breast pump for me to use at the hospital? (Some hospitals have breast pumps available for loan; others require you to provide your own.)

Where can parents find support?

It can be distressing to find out about a child's cleft lip and palate and related surgeries. Some parents feel better about their child's treatment after learning more about what to expect. We at ACPA recommend you talk to the doctors and other experts on your child's team. Don't hesitate to seek information from books, booklets (like this one), and trusted websites. At the ACPA website, you can find booklets and factsheets on topics like speech development, social situations, and cleft treatment throughout childhood and adolescence. Also, consider seeking support groups, either in person or online. Be sure to ask all of your questions along the way! And please contact ACPA if you would like to connect with another parent who has been through this treatment with a child. Remember, resources are available. You are not alone.

The surgeries described in this booklet usually take place when a child is very young. Following these procedures, your child's cleft palate or craniofacial team will continue to care for your child for several years, if not longer, depending on his or her needs. The team should be your family's first resource for information and advice.

At ACPA, we are ready to help and support you as you care for your child through his or her early surgeries and in the years ahead. We wish you and your child the best possible outcome from cleft repair surgery and ongoing cleft care.



For More Information

This booklet and many others have been produced by:

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