

Midface Distraction

Using Your Child's External Midface Distractor

Answers to the most common questions families have about external midface distractors

Midface distraction is a way to slowly and gently move the bones of your child's face forward after a surgeon makes the bones loose in surgery. This is called "distraction osteogenesis." New bone is created by cutting and stretching apart pieces of existing bone:

- Distraction means pulling apart
- Osteogenesis means making new bone

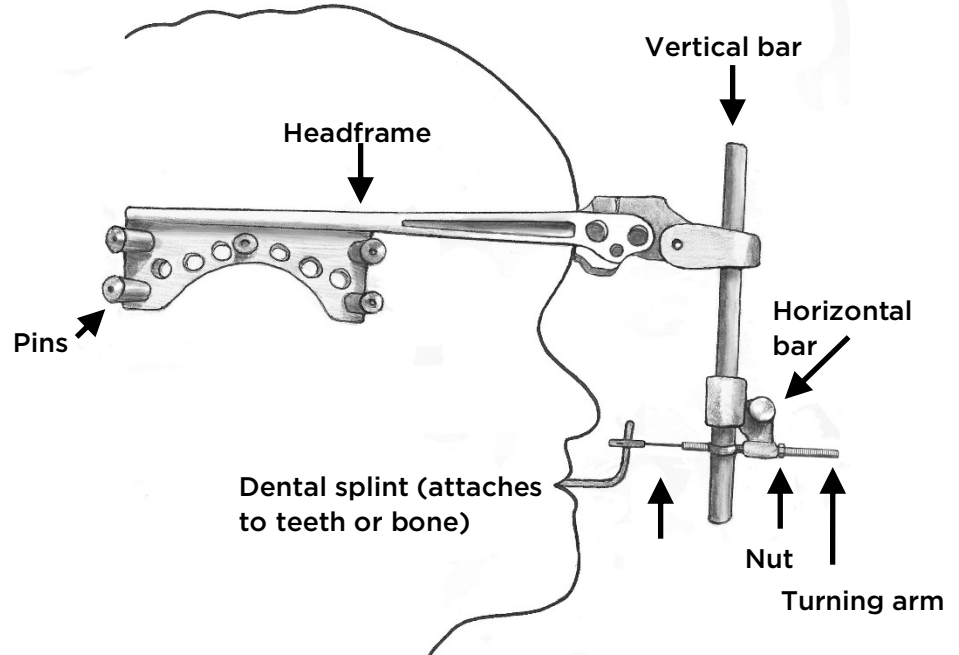
An external midface distractor is the device used to move the bones.

What does the device look like?

The external midface distractor is a U-shaped headframe attached to your child's skull with special screws called "pins." When in place, these pins are designed to keep the headframe from moving or coming loose.

In the front of the headframe there is a vertical bar. A horizontal bar is attached to the vertical bar at the level of the mouth. Turning arms on the horizontal bar are connected with wires to a piece called a "dental splint" in the mouth.

The distractor is made of lightweight materials. It weighs about 10 ounces, about the same as a child's bicycle helmet.



External Midface Distractor

1 of 6

To Learn More

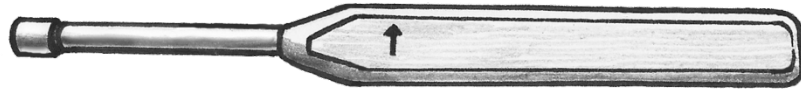
- Craniofacial
206-987-1117
- Ask your child's healthcare provider
- seattlechildrens.org

Free Interpreter Services

- In the hospital, ask your nurse.
- From outside the hospital, call the toll-free Family Interpreting Line, 1-866-583-1527. Tell the interpreter the name or extension you need.

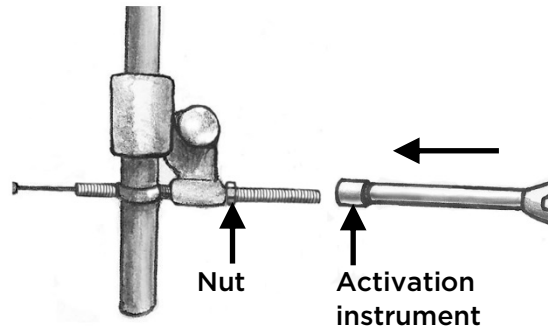
How does the external midface distractor work?

It works by slowly pulling the bones in your child's face forward. To make this happen, we will teach you to use a special tool, called an activation instrument.



Activation Instrument

The activation instrument slips over the turning arm to turn the nut. Turning the nut tightens the wires that are attached to your child's face.



Activation Instrument Detail

Turning phase

As the device is turned, the bones in your child's face move forward about 1 millimeter each day (about the thickness of a dime). This is called the activation or "turning phase." It lasts 2 to 3 weeks, depending on your child's needs.

Healing phase

When the face bones are in the correct position, you will stop turning the arms. During this phase, the headframe and wires stay in place to hold the bones in their new position. The bones heal in their new position. This is called the consolidation or "healing phase." This phase lasts 1 to 2 months, depending on your child's surgery.

When healing is complete, your surgeon will remove the distractor and any wires or splints. This is done under general anesthesia, so they will be fully asleep. Removal is usually a quick procedure that does not require any stitches (depending on your child's surgery).

When is the device put on and when do we start turning the arms?

After your child's doctor has finished the surgery to loosen the bones in your child's face, the surgeon will put the device on your child's head. Your child will still be under anesthesia in the operating room.

Your child's doctor will decide when you should start turning the arms. Timing will depend on the type of surgery and the age of your child. Most of the time, you will start turning the arms of the distractor 2 to 5 days after surgery.

Who will turn the device's arms?

Most of the time, we will teach a parent or family member how to turn the distractor. After families learn how to turn the distractor arms, they usually say it is much easier than they thought it would be.

Usually, you will turn each arm 1 full turn clockwise in the morning, and 1 full turn clockwise in the evening (twice a day for a total of 2 full turns). You will turn the arms every day until we tell you to stop. Most children need to have the device's arms turned for 10 to 21 days.

Does it hurt my child when I turn the device's arms?

During the first week of turning, most children do not feel anything when the distractor arms are turned. After a few days, some children feel aching in the face. Older children describe this feeling as close to the feeling of having braces on their teeth adjusted.

It is common for 1 arm to be harder to turn than another arm. Let us know if all of the arms become very hard to turn or if your child is complaining of increased pain after turning.

What happens if I forget to turn the arms?

As soon as you realize you have forgotten to turn the distractor arms, turn them right away. Then return to your normal schedule. Missing 1 to 2 turns during the turning phase will not change the final result. If you miss more than 1 turn or are having difficulty keeping up with the twice-a-day turning schedule, tell us right away.

What can my child eat while wearing the device?

Your child will have to eat soft foods for the entire time the device is on, including during the healing phase. Examples of soft foods include overcooked pasta and vegetables, applesauce, scrambled eggs and yogurt. You can also use a blender to make milk shakes, smoothies or other foods easy for your child to eat.

Before your child leaves the hospital, we will make sure that they are able to eat. You may also meet with a nutritionist or dietitian before or after the surgery. We may weigh your child at each visit to make sure they are not losing too much weight while wearing the device.

How will my child eat while wearing the device?

There are several ways that your child can eat while wearing the device. Small spoons work well for soft solid foods. Eating may be slow.

Squeeze bottles and squeeze bags that you can buy in stores work well. You can also put soft food in a heavy duty plastic bag with a double zipper, cut one corner off and have your child squeeze the food into their mouth. Squeezable sports water bottles work well for liquids. After a few days of practice, you will find the best method for your child.

Your child may drool during the turning phase. This usually stops by itself during the healing phase.

How will my child sleep while wearing the device?

Some children prefer to sleep on their back, while others feel more comfortable sleeping on their side. Any position your child finds comfortable is OK.

What do I do if it comes loose?

It is unusual for the external midface distractor to come loose. Sometimes 1 or 2 of the pins loosen, but the rest of the pins keep the device in place.

If a pin starts to come loose, you can gently tighten it by using 2 fingers to turn the pin in a clockwise direction no more than one-half of a turn. If the pins continue to come loose, or the U-shaped headframe starts to drop lower over your child's forehead, let us know so we can adjust the device.

During the healing phase, 1 or more of the turning arms may shift up or down. This can happen as your child moves during sleep or supervised play. You can straighten the arms with your fingers so they return to their normal position. This will not cause a problem with your child's treatment. If the arms are difficult to straighten, or become loose, we can tighten the arms without causing any pain to your child.

What activities can my child do while wearing it?

Your child may do many things like read, draw and color, do arts and crafts, watch movies, play calmly with toys or take walks outside. You must avoid activities that could cause falls or bumps to the face.

Examples of activities to **avoid** include:

- Unsupervised play with other children, running, bicycle riding, skateboarding, skating, swinging, playing on jungle gyms or anything where there is a risk of falling. Your child's feet should be on the ground at all times.
- No sports, swimming or physical games are recommended until approved by us.

How often do I need to come back to the hospital after my child's surgery?

At first, you and your child will need to come to the hospital (or clinic) often after the surgery. We will check your child closely during the turning phase to make sure the device is working properly, and to decide when to stop turning.

Your child will need X-rays of their face at some of these visits. Sometimes we may need to make small adjustments to the device.

During the healing phase, we will not need to see your child as often. The surgery to remove the distractor is usually a day surgery with a fast recovery. Your child will not have to stay overnight in the hospital.

How do I bathe my child while they are wearing it?

- **Bathing:** Baths or showers can begin about 3 days after surgery, or when your child gets home from the hospital. Baths must be supervised. Do not allow the distractor to go under the water in the bath.
- **Hair care:** You should wash your child's hair with their usual shampoo every day. Use a showerhead or large cup to gently pour water over the hair. Let the soapy water run over the pin sites. This helps to keep them clean. Gently comb or brush your child's hair, but try not to bump the distractor. After washing the hair, gently remove any crusts that form around the pins using a cotton swab. This helps to keep the pin sites clean.

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- **Brushing teeth:** You can begin brushing your child's teeth when they begin eating. Use a soft baby toothbrush, water and a very small amount of toothpaste to clean your child's teeth. Some parents prefer to use the baby toothbrush that fits over a finger. Ask us before using an electronic toothbrush or water flosser (Waterpik).

How will my child's face change after treatment with the device?

The first day after surgery, your child's face will be swollen. There may also be bruising around the eyes. The swelling is greatest about 36 hours after surgery. It stays that way for 2 to 3 days before starting to go away.

The swelling around the eyes and temple region is the slowest to go away. As the swelling goes down, you will slowly notice changes in your child's face during the turning phase. You may notice their nose becoming more prominent and their upper teeth and jaw moving forward compared with their lower jaw. Depending on the type of surgery your child has, the area around their eyes may also change as their cheek bones become more visible.



Before



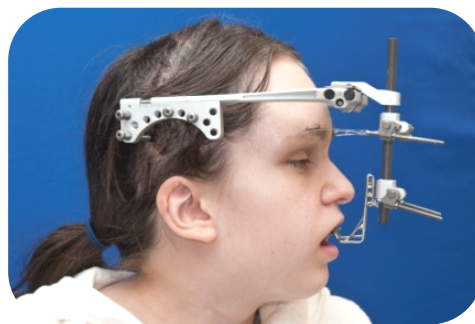
During



After



Before



During



After

Can my child return to school and normal daily activities while wearing the device?

Some children do return to school while wearing the device. Other families choose for their child to stay at home. We can give you information to help make this decision with your child's school. If your child does go to school, we will recommend that they avoid recess, physical education classes and sports until the distractor has been removed.

Please ask if you have questions. We are here to answer your questions and to support you at every step of the process.
