

Family Education Sheet

Home Care for Infants and Children After Vascular Ring or Airway Related Surgery



Boston Children's Hospital

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When to call your health care provider

Call your child's cardiologist or primary care provider if your child has:

- Signs of an infection: fever, pain, redness, swelling or drainage at the incision site
 - 1 year or younger—Fever of 100.5°F/38°C or higher
 - Older than 1 year—Fever of 101.5°F/38.6°C or higher
- Extreme tiredness
- Fast breathing or a hard time breathing (shortness of breath)
- Poor eating or drinking
- Problems taking medications
- Skin color changes (pale, blue or gray skin)
- Vomiting (throwing up)

When to call 911

- If your child is having a medical emergency
- If your child experiences:
 - Chest pain that does not go away
 - Dizziness or a feeling like he or she is going to faint (pass out)
 - Heart palpitations (fast heartbeats)

For questions or more information

- **If you have questions about your child's health after going home,** contact your child's cardiologist or primary care provider.
- **If you have not yet met with your child's doctor since their surgery:**
 - During regular business hours, contact Boston Children's Hospital Vascular Ring and Airway Team through email or the MyChart Portal.
 - Outside of regular business hours, contact the CV surgery fellow at 617-355-3212.

You can expect your child to have these follow-up appointments. **It's very important to keep all of these appointments.**

	Cardiac surgery post-op visit (virtual visit)
	Follow-up with cardiologist (1 to 2 weeks)
	Follow-up with primary care provider (1 to 2 weeks)
	Follow-up Vascular Ring/Airway Team (1 month, 6 months virtual visit)
	Follow-up Vascular Ring/Airway Team (1 year, virtual or in-person visit)

Care at home

Behavior changes

Your child may act differently after heart surgery. This is normal. This stressful experience may cause your child to be clingy, have nightmares, wet the bed or cry. Stay calm and support your child through this time. Then, slowly begin to set the limits you had in place before surgery.

Things to watch out for

Pain

Pain after surgery is normal. Your child may have pain from muscle aches in their neck, shoulders and back.

- **Give all pain medications to your child as directed by your health care provider.**
- If your child still has pain after taking pain medications as directed, call your child's primary health care provider.

Dysphagia

What it is: Dysphagia is difficulty swallowing.

Likelihood of happening: Many children with a vascular ring or compression have dysphagia before surgery. These symptoms sometimes last after surgery.

What to do: Please **call us** if you see an increase in these symptoms:

- Not eating /drinking according to the feeding plan
- Noisy breathing with feeding
- Coughing while eating
- Increased retching or gagging not related to illness
- Feeling like food is getting stuck in the throat
- Acting like swallowing is painful or stressful

Reflux

What it is: Food or formula comes back up either as vomit or as a “wet burp.”

Likelihood of happening: Children with esophageal issues may have reflux and need to take medications to reduce the acidity and lessen the risk of further esophageal injury.

What to do: Please **call us** if you see an increase in these symptoms:

- Arching of the back
- Frequent spit ups/vomiting causing discomfort
- Fussy after feeds or while lying flat
- G-tube or G-J tube feeding intolerance for more than 1-2 days
- Increased coughing when lying flat on back
- Increasing coughing or hoarseness in voice
- Major changes in eating/drinking or behavior
- Not gaining enough weight
- Taking longer to feed than usual, not eating/drinking as much or refusing to eat/drink
- Blood in stools

Respiratory issues

What it is: difficulty breathing, chronic (ongoing) cough or frequent respiratory infections.

Likelihood of happening: Some children have breathing issues before surgery. These issues may last a few weeks after airway surgery.

What to do: Please **call us** if you see an increase or return of these symptoms:

- Recurrent respiratory infections (multiple colds)
- Wheezing and/or persistent “barking” cough
- Major changes in eating/drinking or behavior
- Shortness of breath with activity or decreased endurance
- Blue spells

Incision care

- **Watch incisions for an infection.** Call your child’s provider right away if you see any signs of an infection (fever, redness, pain, swelling or drainage from the wound).
- Most sutures (stitches) are dissolvable.
- If your child has non-dissolvable sutures (black, green or blue colored), they will be removed in the office during a follow-up visit with us or your primary care provider.
- You may see a piece of white stitch or a white knot sticking out of the incision. This is part of the dissolvable suture, and you should leave it alone. If you have questions or concerns, call your provider.

- A special glue called Dermabond may be on the outer layer of the incision. Leave it in place. It will wear off over time.
- Dress your child in loose-fitting clothing so clothes do not rub against the incision

Scar care

- Scars often look worse before they start to look better. They should start looking less red about 3 months after surgery. Most scars are completely healed in about 1 year after surgery.
- Keep scars out of direct sunlight for at least the first 6 months. It’s OK and encouraged to use sunscreen over the incision for the first year after surgery.
- In about 3 weeks after surgery, you may be able to use lotions like Mederma, Aquaphor, vitamin E or aloe. **You can use these lotions only if your child’s scabs have fallen off, the wound is healing well and there is no infection.** Massage the scar for 5 minutes, twice a day.

Activities

Returning to school or daycare

- Returning to school or daycare varies by child and by situation. Talk with your child’s cardiologist for more information. Below are general recommendations.
 - Many children are able to go back to school in about 2 weeks after discharge to home or after their first cardiology or primary care provider follow-up appointment
- If you need a note for school or daycare, call your child’s health care provider.

Going on vacation

Everyone heals differently and is ready for trips at different times. Do not go on a vacation until your child has had their first follow-up appointments. Talk to your child’s cardiologist or primary care provider before you make plans to travel.




Physical activities, sports and gym class

- After a sternotomy, the sternum takes about 6 weeks to heal. It is very important to protect the chest during this time. For the first few weeks, it is OK to do light activity like walking.
- After a Thoracotomy you may start **moderate** activity after 3-4 weeks.
- Make a plan with the cardiologist and/or surgeon before your child returns to other activities, including gym class or recreational or competitive sports.
- Your child may need to wait longer to return to full contact sports and weight lifting.
- Call your child’s health care provider if you need a note for school.

Diet

Follow the instructions given to you by the Vascular Ring and Compression Team.

Swimming and bathing

Type of Surgery	Time After Operation		
	 Shower	 Soaking in a tub	 Swimming
Sternotomy	Immediately (keep the incision turned away from the water)	3 weeks	6 weeks
Thoracotomy	Immediately (keep the incision turned away from the water)	3 weeks	4 weeks

- It's OK to give your child sponge baths if there is Dermabond. Avoid the incision as much as possible.
- It's OK for older children to shower with Dermabond as long as their incisions are turned away from the water.
- Don't let your child soak the chest area in water or swim until the Dermabond has fallen off, wounds are healed without signs of an infection and scabs have fallen off.

Newborns and infants

- Do not lift your baby under the arms for 6 weeks.** Pick your baby up by scooping underneath the head and buttocks. Once in your arms, it's OK to hold, burp or cuddle your baby in a position your baby likes.
- You can hold your baby chest-to-chest, often within days of surgery.
- You may allow your baby to roll over, push up on their arms to lift their head and pull up to stand. Your baby would not do these things if it hurt.
- If your baby has a sternotomy incision, wait 2 weeks after surgery to place your baby on their belly for tummy-time.
- Remember, all babies younger than 1 year old should always be placed on their backs for sleeping.**

Toddlers to school-age children

- Do not lift your child under the arms for 6 weeks.** Pick up your child under the buttocks and behind the shoulders carefully.
- Help your child get up and walk every day after surgery. Your child may stop when tired.
- Your child can climb stairs as long as your child holds onto the railing and is not tired or light-headed. Stay close by to help if needed.
- Younger children should not lift anything heavier than 2 pounds for the first 6 weeks.
- School-age children should not lift anything more than 5 pounds for the first 6 weeks.

Car seats

- Using a car seat is the law. **You must put your child in a car seat every time.** Do not put extra padding between the incision and car seat straps.
- Follow the manufacturer's guidelines for car seat installation and use.

Staying healthy

Infections and crowds

- It is important to stay healthy and not get an infection for the first couple of weeks after surgery.
- Wash your and your child's hands often with soap and water.**
- Consider limiting contact with visitors and staying away from crowded public places. If people in your house are ill, you may want to try to limit your child's contact with them.

Immunizations

- We recommend flu shots for most patients. Please talk about this with your child's health care provider.
- We recommend waiting at least 4 weeks after surgery for your child to get immunizations. Speak with your child's cardiologist or primary care provider if you have questions.
- Some infants may need a monthly injection to prevent RSV infections. Your child's primary care provider or cardiologist will tell you if your infant needs this.

How we will communicate with your health care provider

We will send your discharge information, including details of the surgery and blood test results, to your child's primary care provider and cardiologist.