

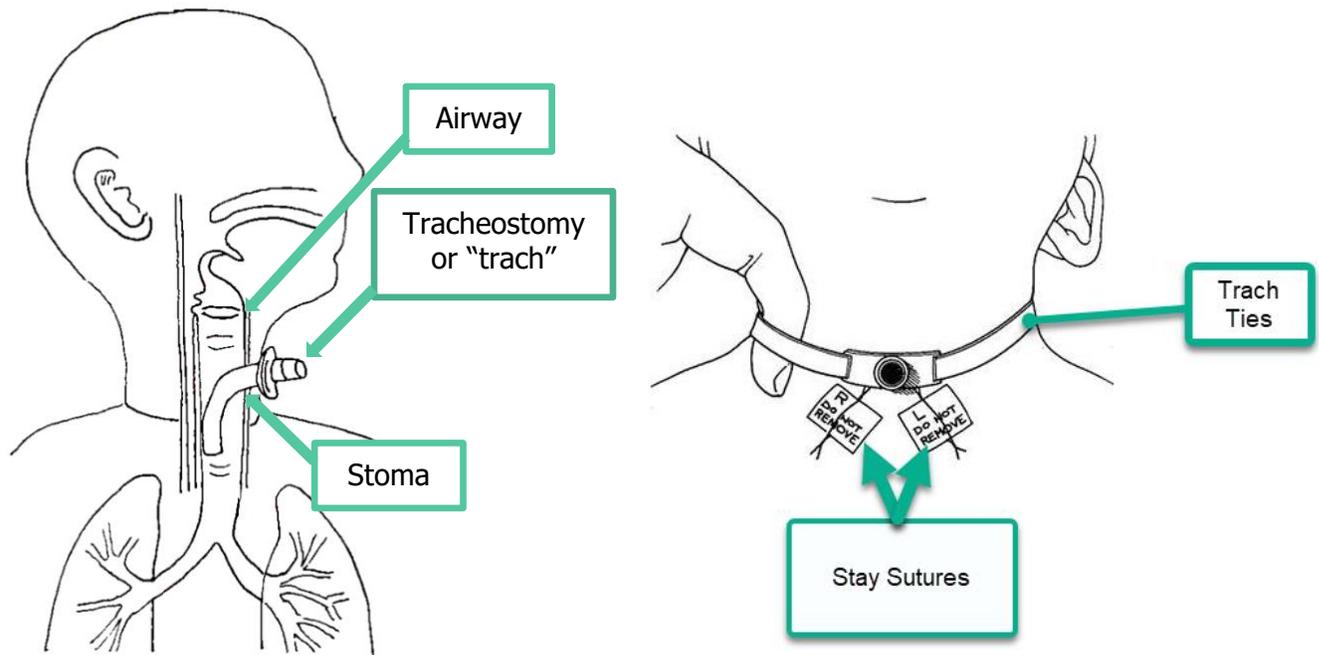
This guide was adapted with permission from: HSC Winnipeg, a Shared Health facility. Child Tracheostomy Decision Guide, c2011.

Step 1: Introduction

This guide is for families with a baby in the NICU whose care team thinks a tracheostomy ("trach") could be an option for their baby.

What is a trach? A trach is a more stable breathing tube. A surgeon creates an opening ("stoma") through the neck into the airway. The tracheostomy tube is then placed through the stoma into the trachea to maintain the airway, help babies breathe, and/or remove fluid from the lungs. Once the trach is tied into place, the breathing tube can be removed from the baby's mouth. Your baby will then breathe in and out through the trach.

Getting a trach is a big process. This guide will give information about a trach, how it might help your baby, and other options instead of tracheostomy. It can help you talk to your care team, family, and friends about a trach and other care options.



Step 2: Understand the Tracheostomy

Why does a baby need a trach? There are several reasons why your baby may need a trach. These include:

1. The airway is blocked, and baby is unable to breathe without a breathing tube.
2. Baby has bronchopulmonary dysplasia (BPD) or another lung disease, where the lungs are sick and need help from the breathing machine ("ventilator") to breathe.
3. Baby has another illness that keeps them from breathing on their own without a ventilator, like a problem with the brain or muscles.

How is a trach placed?

An Ear, Nose, and Throat (ENT) surgeon will do the procedure in the operating room. Your baby will be under general anesthesia ("asleep") and will not feel anything during the procedure. Your baby will receive pain medication so that when they wake up, they will be comfortable. He/she will continue to receive pain medication until the pain completely goes away and until the stoma heals.

What are the risks of placing a trach? The risks of the surgery include:

- Problems breathing after anesthesia
- Reactions to the anesthesia
- Bleeding
- Infection
- Damage to the airway
- Nerve damage

If your baby needs a trach, the surgeons and anesthesiologists will discuss these risks with you before the surgery and answer your questions.

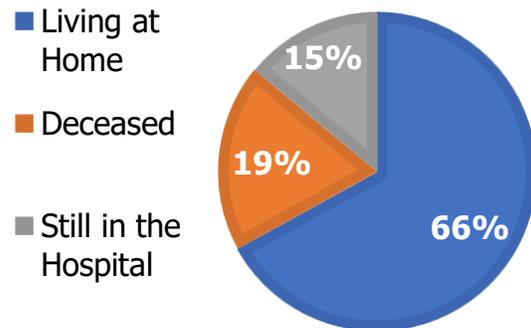
How long is the recovery after a trach?

A trach changes the airway in many ways, and it can be hard to predict how a baby will respond. Time to recovery can be from days to weeks. It's oftentimes many months before baby is ready to leave the NICU.

One NICU group studied thousands of premature babies and found that only a small group received a trach (mostly for BPD).¹ At 1-year of age, 66% of the babies were living at home, 19% had passed away, either from their disease or a trach-related complication, and 15% were still admitted in the hospital. These outcomes are shown in the pie chart on the right.

Han, S. M., Watters, K. F., Hong, C. R., Edwards, E. M., Knell, J., Morrow, K. A., ... & Modi, B. P. (2020). Tracheostomy in very low birth weight infants: a prospective multicenter study. Pediatrics, 145(3).

OUTCOMES OF INFANTS WITH TRACHS AT 1 YEAR OF AGE



How long will a baby need a trach?

It is hard to know how long a baby will need a trach. Some need it for a few years, while others need it for life. Babies needing a trach for BPD are more likely to have it successfully removed ("decannulation") compared to other reasons because the lungs can continue to grow and improve. It's important to talk to your care team about your baby and how long they think your baby might need a trach.

Another NICU group studied 200 babies in their trach follow-up clinic between 2005 to 2015.² The below timeline shows the average age of events:



Akangire, G., Taylor, J. B., McAnany, S., Noel-MacDonnell, J., Lachica, C., Sampath, V., & Manimtim, W. (2021). Respiratory, growth, and survival outcomes of infants with tracheostomy and ventilator dependence. Pediatric research, 90(2), 381-389.

What are the pros and cons of a trach?

Pros

- You can see the baby's face.
- The trach is less likely to fall out than a breathing tube in the mouth.
- The baby can be more active.
- The trach may allow the baby to make sounds or eat by mouth.
- The baby may need less sedation with the trach and can be more awake and alert.
- The trach may allow the baby to be cared for outside the hospital.

Cons

- Some babies need more breathing support from a ventilator after the trach than they did before.
- The trach may make the lungs more prone to infection requiring treatment.
- The trach may plug at home creating an emergency that could lead to death. You will be trained on how to handle a plugged trach.
- Not all babies are able to speak or eat by mouth with a trach.
- Finding home nursing for a baby with a trach can be very hard.

List the pros that are important to you:

List the cons that are important to you:

Questions you still have:

How can a baby with a trach communicate?

As a baby gets older, a Speech Language Pathologist or Speech Therapist can assess his/her communication skills and help your baby interact. They can support use of:

- A speaking valve.
- Strategies to coordinate breath and voice.
- Different ways to communicate, such as with pictures, signs, or tablets.

How can a baby with a trach take a bath?

A sponge bath or use of an infant tub are safe ways to prevent water from entering the trach or stoma.



NEVER leave your baby unattended in the bath.

The water level should be well below the neck.

If water enters the trach, suction the tube right away.

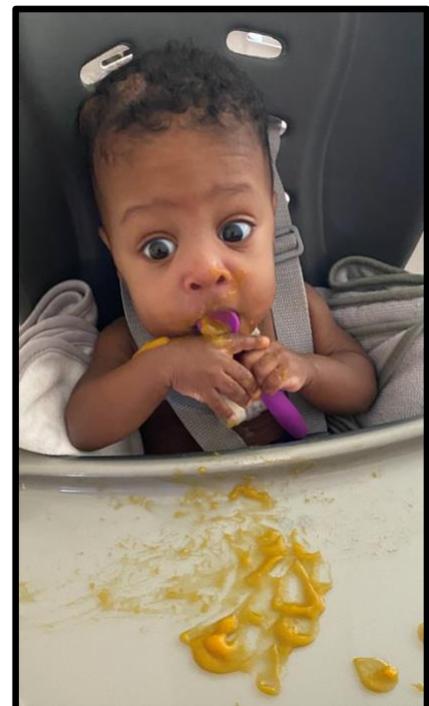
You will need to monitor your baby closely.



How will the trach affect how my baby eats?

Your care team will assess your baby's ability to eat.

- Your baby's swallowing will be evaluated by a Speech Therapist or Occupational Therapist. They will determine the safest way for your baby to eat.
- Some babies can eat by mouth in the same way as babies without a trach. However, many babies need G-tubes to get all their feeds.
- Because your baby will be breathing through the trach, instead of their nose, their sense of smell may be decreased. They may not be as eager to feed at first.
- If your baby needs a G-tube, your care team will help you learn to feed your baby and care for this tube as well.



What is home care like after a trach? Caring for a baby with a trach includes basic baby care plus caring for the trach. Training will be provided in the hospital from the care team before you leave. This will include learning:

- Routine care:
 - Suctioning the trach
 - Keeping the trach clean
 - Skin care for the stoma
 - Routinely replacing the trach
 - Managing equipment such as the ventilator, monitors, suction machine, and oxygen equipment
- Emergency care:
 - What to do if the trach accidentally falls out
 - What to do if the trach becomes plugged or blocked
 - What to do if the trach can't easily be replaced
 - How to look for signs of a lung infection and what to do in response

What you will need to care for a baby with a trach at home:

- CONSTANT 24/7 presence of a trained caregiver day and night – the baby must stay in the hospital if 24/7 care isn't available at home.
 - At least 2 primary caregivers must be trained to care for the baby and trach equipment.
 - Home nursing may be available to help with care. It is very difficult to find home nursing to cover around-the-clock care.
 - The baby can't be left in the care of a babysitter who isn't fully trained in routine and emergency care of the trach.
- EMERGENCY PLANNING
 - There must be a plan for how to get emergency help at any time.
 - Prior to discharge, notify local fire, EMS, and police departments of the baby's special medical conditions.



One Trach Journey...



This baby was born at 27 weeks' gestation and received a trach for bronchopulmonary dysplasia (BPD) and airway abnormality.

When he first came home from the NICU, he required oxygen during the day and a ventilator to help him breathe at night.

Here he is on a walk with his portable oxygen, in-line suction, pulse ox, and other trach supplies.

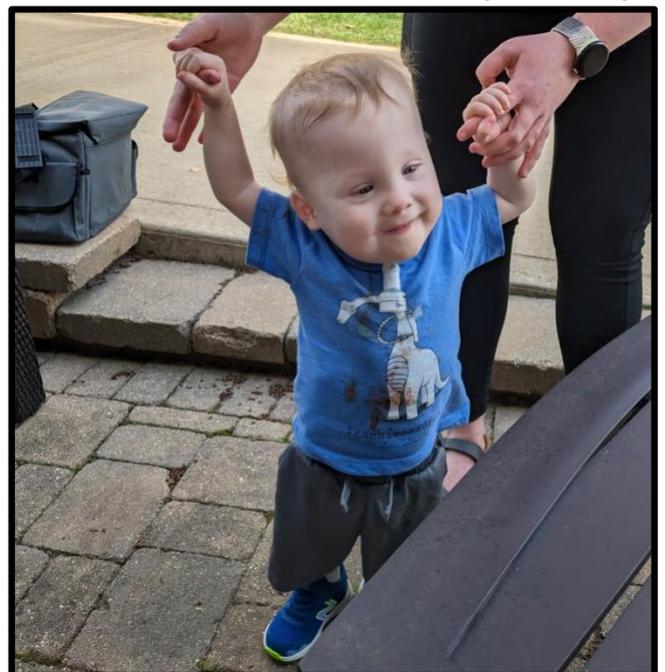
He likes tummy time.

Spare trachs and other supplies are taped to the foot of the crib.

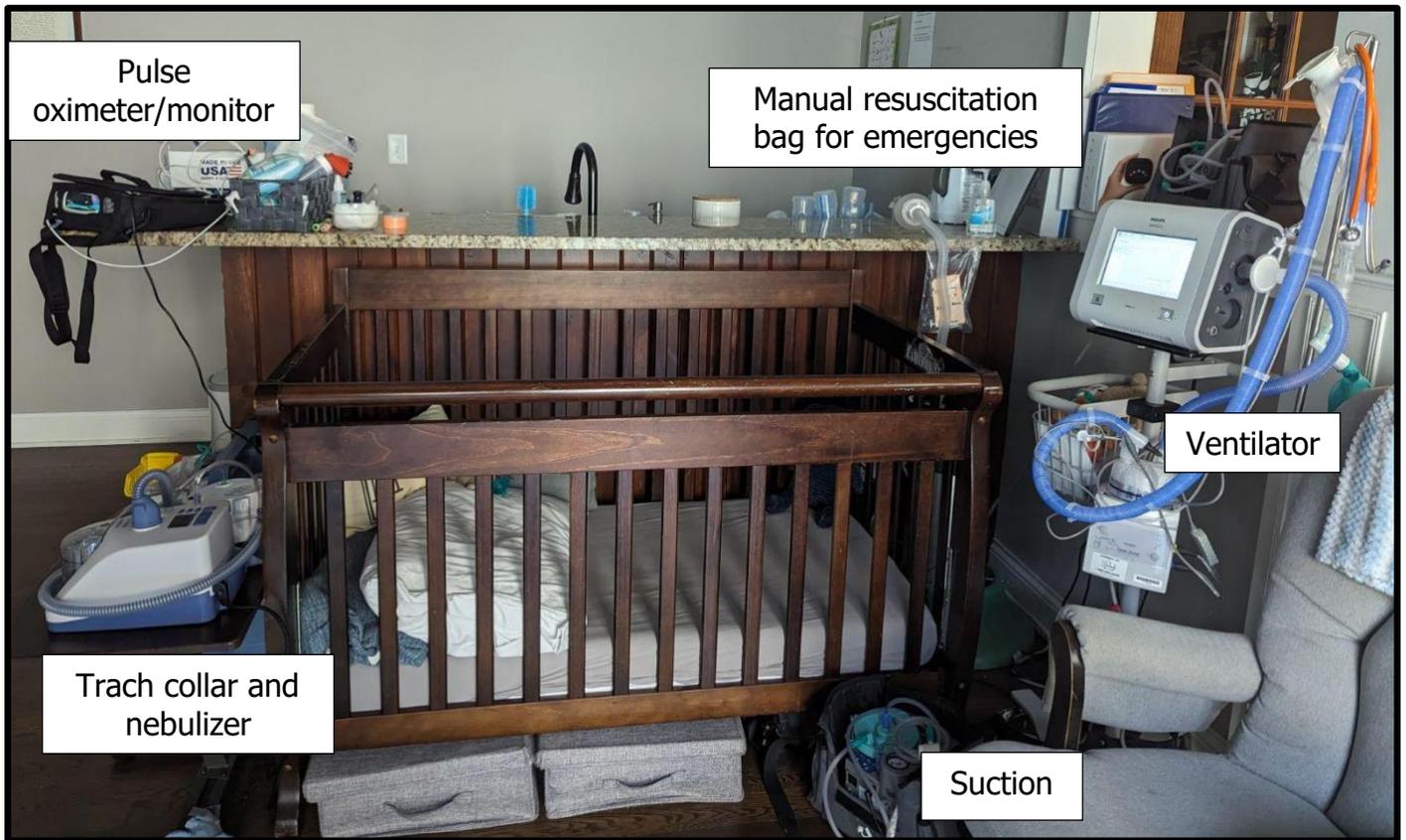
After almost a year at home, he no longer requires oxygen during the day. He can go on outings (like the grocery store) with only his suction and his Go-Bag.



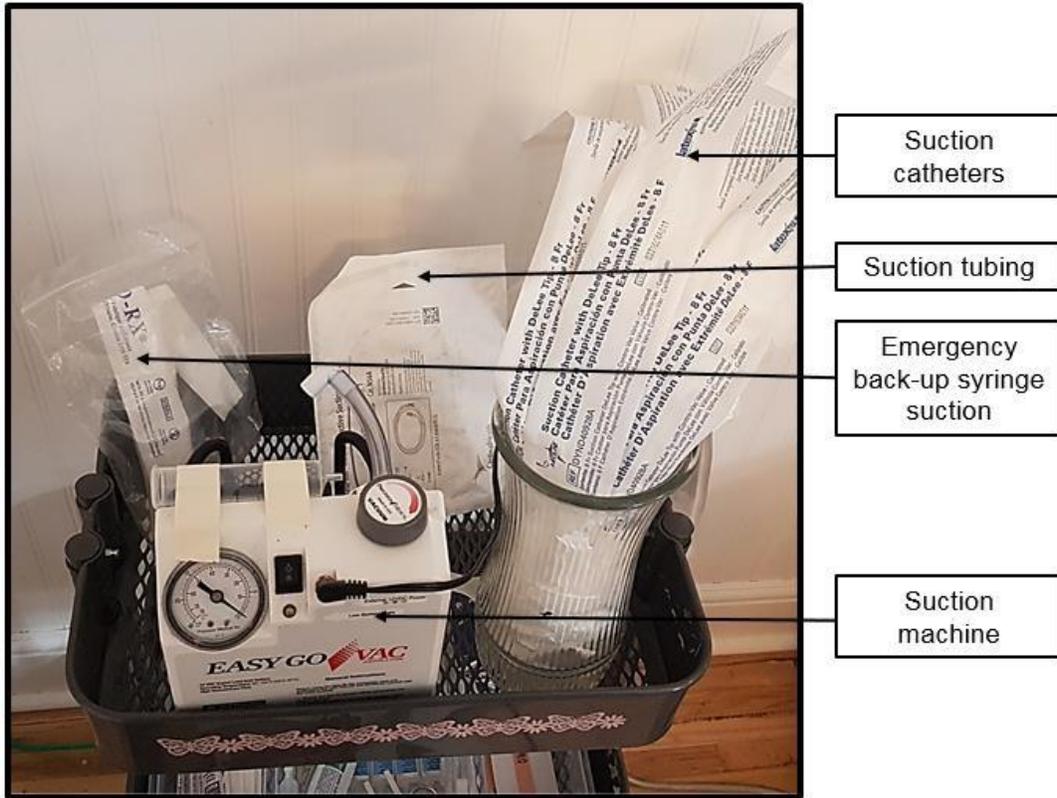
And he's learning to walk! His Go-Bag is always close by.



Equipment at Home



Examples of Suction Set-Ups



Examples of Go-Bags:



Go-Bags hold all the equipment you'll need for daily trach care and emergencies. Your Go-Bag should always be with your baby.

List family and friends who can be trained to care for your baby:

What kind of stress do families feel when they have a baby at home with a trach? Some families say that having a baby at home with a trach can:

- Change family relationships.
- Change family finances.
- Disrupt family sleep patterns.
- Affect your job.
- Require other caregivers or healthcare providers to be in the home.
- Make families desire to live closer to a Children's hospital.

What are the benefits of having a baby at home with a trach?

- The baby is always with family and friends.
- Family doesn't have to go to the hospital to visit baby.
- The baby's quality of life improves.
- The baby has improved developmental milestones.

What about your other children?

Your baby's siblings may have a hard time understanding this new trach and its care. They may have trouble coping at first.

Child Life Specialists in the NICU can help with siblings of all ages to talk about the trach.

It will be important to talk about the trach with siblings, allow them to visit (based on NICU visitor policies), and show them acceptance/comfortability around the trach.



If you're interested in meeting other families who have had babies with trachs, please let your care team know!

Quotes from other NICU parents on the trach process:

"I think a lot of the decision making around placing the trach is being in denial, and that was definitely me. I was totally in denial for how sick <baby> was and what I thought his life should look like—versus what his life is probably going to look like—and once you kind of accept that, it's hard."

"It's scary when you first get told you [have to] be there 24/7. You [have to] make sure... you know about emergency situations. There [may be] times that... you're scared, and you have to call 911."

"It was an easy [decision], but it also was a hard decision because I knew what all came with trach life. I knew that once you get that trach, if you don't have 24-hour care, you can't leave the hospital."

Quotes from other NICU parents about what surprised them:

"One of the questions I asked, was, 'Once he has a trach, can I walk in and just pick him up?' And [the answer is] 'Yes. [The trach is] considered a stable airway. You can do that.'"

"I kind of thought that he would get [the trach], and then he would get better. And that didn't really happen. I don't think I appreciated how major of a surgery it was."

"The lack of sleep and the stress on relationships, I think that that's definitely very, very [important]."

"All the things that can go wrong with trachs... that may have been somewhat of a surprise. I wasn't aware that there could be a [mucous] plug, which actually happened [to us] in the NICU."

Quotes from other NICU parents about living at home with a trach:

"You still can live a full and fulfilling life and still do the things that you want to do with your child. It's just [going to] take you a little longer to prepare for it and take you a little bit longer to get out of the house."

"Living life with a trach: [babies] can still grow, they can develop, they can still learn."

"We still went to baseball games [and] soccer games. We did everything. So, for a person to be able to see [that] you can still live a normal life. Take the trach, take the vent, take the [equipment]. Do whatever is safe for your family. Go for walks. All of these things are possible. I think in the clinical setting, that's left out a lot."

Step 3: Understand Your Baby

Now it's time to think about your own baby and your family. If you don't know the answer to something, ask your care team!

Why does your baby need breathing support?

- They have lung disease or injury to the lungs
- Air movement is blocked in their airway
- They have a disorder of the brain, nerves, or muscles needed for breathing
- They have weakness of the muscles that affect swallowing
- Other: _____
- Unsure

If your baby needs a trach, how long will they need it?

- For a short time and likely will be removed in a few years
- For many years before removal
- For life

With a trach, what else will your baby need to breath?

- A ventilator to help their breathing
- No ventilator
- Unsure

What is your baby's quality of life right now?

- Excellent – No pain or discomfort and can interact with people and enjoy life
- Good – Some pain or discomfort at times but can interact with people and enjoy life
- Poor – Pain/discomfort much of the time with little ability to interact and enjoy life
- Very poor – Pain/discomfort most of the time and no ability to interact and enjoy life

What are your hopes and fears for your baby?

Hopes

Fears

Questions you still have:

Step 4: Understand the Other Options:

What are other options for your baby? Not all options are possible; your care team will review options for your baby.

- Surgery (e.g. airway dilation) or other medicine (e.g. steroids) to improve airway/ lung problems
- Try to wean baby from the support
 - Have you tried this before?
 - What happened when you tried?
 - Is there still a chance for improvement?
 - Has enough time been given?
- Comfort care
 - Depending on their babies' diagnoses, some families choose to remove breathing machine and provide comfort care
 - Comfort is always a goal of care

How clear are the options to you?

- Very clear – I don't need further discussion
- Mostly clear – I have questions about them
- Not clear – I need to discuss again

Do you understand the reasons to choose each option? Yes No

If not, what don't you understand:

Do you feel pressure to choose any of the options? Yes No Unsure

If so, describe the pressure or why you feel unsure:

Step 5: Taking Action

As you consider your options, who would you like to be included in the discussions?

A family member

Your baby's pulmonary doctor

Your bedside nurse

A friend

Your baby's ENT surgeon

Your social worker

Your baby's NICU doctor
(Attending, Fellow, NP)

Your baby's PACT team

Your pediatrician at home

How ready are you to make a plan?

- Very ready – My mind is made up
- Somewhat ready – I need more time
- Not ready – I am not ready to make a plan

What other information do you need to make a plan?