



Home Ventilation Program Guide



Riley Children's Health
Indiana University Health

rileychildrens.org

Caregiver Agreement

1. At least two specifically trained caregivers will be fully trained in all aspects of the child's care, including the care of and replacing of the tracheostomy tube.
2. All caregivers need to complete a minimum of one 8-hour and two 24-hour caregiver shifts. Each caregiver will independently complete an 8-hour shift. This shift may begin at any time of the day or night but must include either the 8 am or 9 pm timeframe. It may be scheduled on any day of the week. Please note that it is common for a caregiver to have to repeat a shift.
3. Will need to be available to meet with a Patient Financial Counselor, as needed, to have the necessary resources in the home.
4. Telephone/utility companies and local emergency medical services should be made aware of the child's presence in the community.
5. A functioning phone, either a landline or a devoted mobile phone, should always remain with the child in case of emergency.
6. Must have a crib (not a pack-n-play) at home and must bring a car seat to bedside prior to vent class. (Age applicable).
7. The durable medical equipment company must inspect the home to ensure that the home environment and electrical systems are adequate to support the needed equipment.
8. An in-home professional caregiver will attempt to be identified. I am aware that home nursing may be limited in Indiana.
9. All caregivers need to be present for vent class. Vent class starts at 9 am and is held on a weekday, Monday through Friday.
10. All caregivers need to complete a vent check off day at bedside. Checkoffs start at 9 am and are held on a weekday, Monday through Friday.
11. Caregiver needs to identify a pediatrician/family doctor. Caregiver needs to confirm with the clinician that they are comfortable taking on patient's level of care.
12. Children with trachs and who use chronic ventilation at home should always have a fully trained caregiver with them. A patient cannot be left home alone with anyone other than a Riley Children's Health trained caregiver or a nurse from the identified home nursing agency. Failure to follow this guideline could lead to a trach or vent emergency that could result in death.
13. I understand that it is highly recommended that my child receives all routine well child vaccines to keep my child healthy and to prevent life-threatening illnesses. We will strongly recommend the annual influenza, and RSV vaccines in addition to other vaccines your child may qualify for. I understand that it will be discussed annually. I understand that my child is at higher risk of infection due to their tracheostomy dependence.

By signing below, you understand the expectations above and agree to be proactive in the discharge planning process. Please keep this agreement and utilize it as a reference tool throughout the discharge process.

Caregiver 1 _____ Home Vent Team _____

Caregiver 2 _____ Date _____



Program Overview

The Home Ventilation Program at Riley Children's Health was developed in 1984 to meet the discharge needs of ventilator dependent children and their families. Today, the program provides support for over 150 children and young adults on various types of ventilator support at home. The Home Ventilation Program provides discharge planning, education, long-term treatment and follow-up care. Our multidisciplinary team consists of two physicians, a nurse practitioner, a clinical nurse coordinator, a respiratory therapist, a registered dietitian and a social worker who will follow your child for as long as mechanical ventilation is needed.

Meet the team



A. Ioana Cristea, MD, MS, Medical Director, is a pediatric pulmonologist who will work with you and your child's primary care doctor to develop an individualized treatment plan for your child.



Amanda Pickett, RRT, is the respiratory therapist who will work as a liaison between your child's respiratory DME company and the hospital. She trains each family on their child's individual home equipment needs.



Sarah Bauer, MD, Associate Medical Director, is a pediatric pulmonologist who will work with you and your child's primary care doctor to develop an individualized treatment plan for your child.



Katie Barrer, LCSW, is a social worker who assists families in navigating the many aspects of care, including advocating for community resources and providing support to families.



Thao Merrell, NP, is a nurse practitioner who specializes in managing the care of your child's tracheostomy and ventilator while your child is in the hospital. She will help you understand your child's plan of care before discharge.



Becca McNelis, RD, is the dietitian for the Home Ventilation Program. She will monitor your child's growth and establish the best nutrition plan for your child. She works with other providers to ensure the best plan to support growth and development for your child.



Lauryn Ulate, RN, Nurse Navigator, is a registered nurse who works closely with other team members to help manage your child's care and support you in transitioning your family and child from hospital to home. She will review the care plan and answer any questions you have during your follow-up visits after discharge.

Training Overview

Step 1: Individual bedside checkoffs

All caregivers must complete all bedside checkoffs before moving on to Step 2. It is recommended, but it is not mandatory, that each caregiver attend both Trach Class Part 1 and Part 2. The family educator will contact you about registering for this class. It is very helpful, but not required, as a reinforcement of what you will be learning at the bedside. Checkoffs can be completed at any time of day. It is best to complete checkoffs during normal awake hours, but not around the RN change of shift (6 – 8 am and 6 – 8 pm). It will take a considerable amount of time to complete all checkoffs, so please plan to be present at the patient's bedside consistently. Checkoffs cannot be done in one day. A checkoff is not considered completed until a nurse documents that the checkoff item was completed correctly and independently.

Step 2: All caregivers home vent classroom day

This is a scheduled full day that must be attended by all caregivers. You must arrive at the patient's bedside no later than 9 am. This class must be scheduled Monday – Friday. Please bring a writing utensil with you to the class. There will be a break for lunch.

Step 3: Individual caregiver vent skills assessment day

This is a scheduled full day that must be attended individually by all intended caregivers. Unless prearranged, you must arrive at the patient's bedside by no later than 9 am. This bedside vent skills assessment must be scheduled Monday – Friday. There will be a break for lunch. Note: No visitors will be allowed at the patient's bedside during this training.

Step 4: Individual 8 hour home vent care shift

Each caregiver will independently complete an 8-hour shift. This shift may begin at any time of the day or night but must include either the 8 am or 8 pm timeframe. It may be scheduled on any day of the week.

Step 5: Individual 24-hour home vent care shifts

Once a caregiver has completed the 8-hour home vent care shift, the caregiver must then complete two full 24-hour home vent care shifts. These shifts may be scheduled any day of the week and may begin at any time of day. Note: No visitors may be at the patient's bedside during any of the home vent care shifts.

IMPORTANT REMINDERS

1. If you are running late or unable to attend a scheduled training/shift, please contact the PICU (7East) at 317.944.7428 by no later than 9:15 am. Additionally, if you are more than 30 minutes late for a vent skills assessment or home vent care shift, you may be asked to reschedule.
 2. You are only considered a qualified caregiver if you have successfully completed all of the above steps.
ONLY PERSONS DEEMED AS QUALIFIED CAREGIVERS BY THE RILEY HOME VENT TEAM MAY BE LEFT ALONE WITH THE CHILD
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Frequently Asked Questions

1. Who can be trained as a caregiver for my child?

We require a minimum of two fully trained caregivers and can train up to four individuals. This is a strict rule and there are no exceptions. Your second caregiver can be any adult (18+) in your child's life who has the capacity and ability to commit to training. This person must live within 30 minutes of your child.

If you have others in your child's life who want to help, they are welcome to participate in some of our training; however, these individuals cannot ever be left alone with your child.

2. How long is the typical training process?

Your child's medical status and your commitment to training will be the largest components in deciding how long the process takes. We encourage daily and active involvement with your child's care to learn all required skills to care for your child at home. All training must be complete, your child must be on the home ventilator and medically stable, and the home must be ready before discharge can occur.

3. What should my family expect as we approach discharge?

Beginning about a week before your date of discharge, please pack any unnecessary items and take them home. When we tell you it is time, you will go to the Riley Outpatient Retail Pharmacy (located between Radiology and the Over the Rainbow gift shop) to pick up your child's prescriptions. The Respiratory Durable Medical Equipment (DME) company will complete a home inspection before discharge. You will also be required to schedule an appointment with your child's primary care provider, ideally within the week immediately following discharge.

Please arrive early on the day of discharge. The DME supplier and home nursing agency (if available) will meet you at home. Discharge only occurs Monday – Thursday for an initial discharge, usually prior to noon.

4. How frequently will my child have appointments after discharge?

Your child will have many appointments after discharge, including monthly appointments with the Home Ventilator Program, follow-up with your primary care provider, and ongoing follow-up with multiple specialties.

5. What does traveling look like with my child?

In the car, a fully trained caregiver must always sit next to the child in the back seat. The driver does not need to be a trained caregiver. Children will travel with equipment; please see the photos on the following page for an example of what travel may look like with all your child's equipment. Travel will require planning and extra time. If you need help with transportation, please contact our office.

6. What can and can't I do with my child?

We want your child to be a full member of your family. Pets, cooking and candles are usually not a concern. Smoking is strongly discouraged; if someone in your child's life smokes, they should do so outside, away from your child. After smoking, we recommend that hands and clothing be washed before interacting with your child.

We require that families absolutely abstain from two things when their child is trach/vent dependent. First, the child cannot be around large bodies of fire, such as a bonfire. Second, the child cannot be submerged in water (to swim or to bathe). We will teach you how to safely give your child a bath during training.

Traveling with my child

Families will need either a wagon or a medical stroller to travel with their child. Both can fit all required transport-size equipment, as shown below. Families who are unable to purchase their own wagon/stroller should let the team know prior to their initial discharge from the hospital.



Photo "A" Shown:

- Patient
- Stroller
- Home ventilator
- Pulse oximeter
- Emergency bag
- Ambu bag
- Oxygen tank
- Suction machine



Photo "B" Shown:

- Patient
- Stroller
- Home ventilator
- Pulse oximeter
- Emergency bag
- Ambu bag
- Oxygen tank
- Suction machine
- Car seat



Important phone numbers

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|---|--------------|
| After Hours for all services | 317.944.5000 |
| Pulmonary (Home Vent Program) | 317.948.7208 |
| Cardiology | 317.274.8906 |
| Developmental Pediatrics (formula/feeding issues, feeding supplies) | 317.944.4846 |
| Endocrinology | 317.944.3889 |
| ENT | 317.944.8592 |
| General Surgery | 317.944.4681 |
| Gastroenterology | 317.944.3774 |
| Neurology | 317.948.7450 |
| Neurosurgery | 317.944.6201 |
| Ophthalmology | 317.944.8103 |
| Palliative Care | 317.944.3478 |
| Urology | 317.944.8896 |
| Wound Team (Concerns with g-tube/trach sites) | 317.944.5018 |
| Riley Pharmacy | 317.944.2335 |

Other important phone numbers



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