

Using a Home Ventilator with a Child

A ventilator is a life support machine that helps a child breathe. A mechanical ventilator is also called a respirator or breathing machine. Some children require help from a ventilator for a long time (chronic ventilation), even for many years. Children may require the ventilator all day or only part of the time such as when they are sleeping. Even young children can adjust to being on a ventilator and can breathe comfortably with it. Supporting a child's breathing with a ventilator at home can be challenging and requires a team approach to care. A ventilator-dependent child should always have an awake and fully-trained caregiver watching him or her.



Why does my child need a ventilator?

Breathing is the process of air going into and out of the lungs. When breathing, oxygen enters into the body and carbon dioxide is removed or exhaled. Respiratory failure occurs when a person is unable to maintain normal oxygen or carbon dioxide levels.

There are a number of medical problems that can lead to respiratory failure and the need for a child to use a ventilator chronically. Some examples are:

- Conditions that affect the lungs (extremely premature birth, severe infections, other lung diseases),
- Disease of the muscles and bones that may lead to weak breathing,
- Disease of the nervous system that lead to poor breathing effort or weakness,
- Airways that are narrow or collapse and limit airflow and breathing.

Sometimes there are several problems that contribute to the need for a ventilator. You can talk to your child's healthcare provider about why your child needs ventilator support.

What does the ventilator do?

The ventilator helps the child breathe better. It does this in several ways:

- By blowing air into the lungs, the ventilator keeps the airway open and helps the lung expand to avoid compression or collapse of the lung tissue (atelectasis) and improve clearing secretions.
- The ventilator can help bring more oxygen into the body and remove carbon dioxide.
- The ventilator can help reduce the child's work of breathing which can make him or her better able to do activities and grow.

How does the ventilator connect to the child?

If ventilator support is only required part of the time, the doctors may decide to try a "noninvasive" approach which means a mask is placed on the child's nose or face to provide the breaths. However, when children need the ventilator all the time, can't get enough help or can't tolerate a mask over their face, then "invasive" ventilation is more commonly used. This means that a surgery is performed to place a tracheostomy tube or "trach" in the neck that goes into the trachea (windpipe). The ventilator can then be attached to the trach with flexible tubing. This method is a more secure way to deliver chronic ventilation, but requires

special care and training since the child's life can depend on the trach remaining in place and open (not blocked with mucus). (See also ATS Patient Information Series, Use of a Tracheostomy with a Child).

What must happen before a child goes home with a ventilator?

In order to go home from the hospital, a number of "discharge criteria" should be met:

- The child should be medically stable (not sick, and with no changes to the medical plan for at least 1-2 weeks before discharge).
- The ventilator settings should be working well and able to be continued at home.
- The child needs to be able to ride in a car safely with all the necessary equipment.
- At least two (2) family caregivers should be fully trained to care for the child including how to respond to emergencies and perform cardiopulmonary resuscitation (CPR).
- Some children have in-home professionals (usually home nurses) who are experienced working with children with ventilators.
- There is a durable medical equipment (DME) company to supply the home ventilator and other supplies and also agrees to be available for questions and support 24 hours a day.
- There is a clear plan for follow-up with the child's medical team.
- Caregivers who smoke or vape should receive help to quit.

Secondhand smoke is not good for anyone, but is particularly dangerous to ventilator-dependent children. Smoking and vaping must not be allowed in your home.

How do I learn to care for my child and the ventilator?

You will get trained by the medical team before your child goes home. You need to have at least one more person who will also be trained fully to care for your child at home.

Every caregiver needs to show that he or she is able to properly perform all aspects of the child's care. Training may involve handouts, videos, and hands-on demonstrations. Practice and repetition are the key to successfully learning what to do. Simulations with dolls or mannequins can help teach emergency care without putting the child at risk. Knowing how to suction and replace the tracheostomy tube are critical life-saving skills. Before going home, caregivers should complete an independent stay (often called "rooming-in") to make sure they can comfortably care for the

child alone. You can also get updates and more training at home and in the clinic.

Can I get help caring for my child at home?

In many cases, in-home professionals will help the family care for the child. This is important because a child at home with invasive ventilation should have an awake and fully-trained caregiver present at all times. In-home caregivers are most often nurses. They must be experienced with the child's ventilator, familiar with all aspects of the child's care, and certified in infant/child CPR. How many hours of help you can get will depend on your child's health insurance and needs. You will need to work with your child's healthcare team to see how to request help and get connected to a home nursing service. DME company staff will also be available to help answer questions about the equipment and provide more training on the home equipment if needed.

Can a ventilator-dependent child be left alone?

No! Never. Children with trachs and those who use chronic ventilation at home should always have an awake and alert fully-trained caregiver with them. Rarely can a family do this without professional help. You always have to have a plan to manage if your home nurse or other help is not available. Airway emergencies do happen and may occur when you least expect them. A fast and proper response may prevent harm and save your child's life. However, this prompt response is not possible if a caregiver is tired, asleep, or not paying attention.

What equipment do we need at home?

The DME company will provide all necessary medical equipment for the ventilator-dependent child. The ATS clinical guideline recommends that all children must have the following:

- a ventilator (and back-up ventilator when indicated)
- ventilator back up (fully charged) batteries
- a self-inflating resuscitation bag and mask (brand example Ambu®)
- a portable suction machine (stationery and portable)
- a humidifier for the ventilator
- oxygen supply
- a medical air compressor and nebulizer to give inhaled medicines if prescribed
- a pulse oximeter and probes for measuring oxygen saturation

If the child has a tracheostomy, a back-up tube and one a size smaller should always be available.

Disposable supplies such as suction catheters will also be provided. Other equipment may be needed depending on your child's medical problems. Make up an emergency bag to keep at hand that includes items such as a back-up trach, self-inflating resuscitation bag, flashlight, and suction catheters. Talk to your healthcare team about what equipment and supplies you need.

After going home, who will be part of my child's medical team?

Children with home ventilators need a team that includes a primary care provider and a lung specialist. This team will create a "Medical Home" for your child. The Medical Home is not a specific place, but an idea that your child will have easy access to care that is well-organized, compassionate, and sensitive to your preferences and beliefs. Your child's team can also include home nurses and therapists (feeding, occupational, physical, respiratory, speech). Additional doctors may help care for your child's other health problems. Everyone wants your child to do well, achieve all he or she can, and adjust to life with chronic ventilation.

Family-centered care takes into account all of the other parts of life including the home environment, school, community life, and other

family issues to provide the best care possible.

You will be involved in decision-making and information will be openly shared with you.

Will my child always need ventilator support?

Some children improve over time and get to a point where ventilator support is no longer needed. Your lung specialist will help guide you in how to decrease your child's time on the ventilator (or the settings) over time. This is called 'weaning'. Families and other in-home caregivers should not make adjustments on their own without a plan. When a child is ready, your healthcare team will tell you how to watch your child carefully as each change is made and what tests are needed. Some changes can be made in the clinic and others require close observation. Sometimes, an overnight stay in the hospital or a formal sleep study will help see that the child is ready for ventilator support to be decreased.

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Rx Action Steps

- ✓ If your child requires chronic home ventilation, work with your medical team to make sure you are trained and have what you need for home.
- ✓ Choose the family members who will help care for the child at home and plan to be available for the training care you need and for rooming in at the hospital.
- ✓ Learn how to perform routine and emergency cares for your child before going home. If you are not comfortable with any of the skills you have been taught, ask the hospital team to show you again. Learning to care for your child may take time, but you should feel confident that you can provide the care needed before you go home.
- ✓ Remember, have an awake and fully-trained caregiver with your child at all times. Work closely with all home and professional caregivers as a team to keep your child healthy and safe.
- ✓ Take part in family-centered care and make sure you have a Medical Home and a clear care plan in place for your child. Be sure you know who you should call with questions or concerns. Go to all follow-up appointments planned by your medical team.
- ✓ Caring for a child on a ventilator at home can be challenging at times. Speak up and ask for help or support when you need it—your medical team understands.

Healthcare Provider's Contact Number:

Additional Resources:

American Thoracic Society

www.thoracic.org/patients

Global Tracheostomy Collaborative

<http://globaltrach.org/collaborate/patients-families-portal/>

National Heart, Lung, and Blood Institute

<http://www.nhlbi.nih.gov/health/health-topics/topics/vent>

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