



# Home Mechanical Ventilation

Most infants with BPD get better during their hospitalization and need little to no breathing support after they are discharged from the NICU/hospital. Some infants with more severe BPD may still need help breathing from a ventilator (breathing machine) after being discharged from the hospital. In this chapter, we describe the benefits and some practical points of caring for your baby who needs complex, respiratory support at home.

Just like in the hospital, the ventilator helps to keep your baby's lungs expanded/open, while decreasing how much they need to work and use energy to breathe. If your baby spends less energy to breathe and has safe oxygen saturation levels, they can grow and develop better. Over time, some children need the ventilator all the time while others may only need it during part of the day or night. Your medical team will discuss if your baby needs a home ventilator, and ways to prepare for that, which would include discussing tracheostomy placement. Most often, this need becomes clear if, after several attempts, your baby cannot come off the ventilator, grow, and thrive while still in the NICU.

**Once it becomes clear that your baby needs a home ventilator, you will meet the Pulmonary Habilitation Program (PHP) team. This team helps with a successful transition to home and with consistent follow-up after discharge.**

Before going home, the team will help train at least two caregivers in the family to care for your child at home.

The caregivers will learn how to:

- Manage the home ventilator
- Care for the tracheostomy tube
- Troubleshoot minor issues
- Manage an emergency situation
- Reduce the chances of a future infection

**This team has lots of experience teaching families to recognize emergencies and help you successfully care for your child at home with this medical technology.**

At home, your baby on a ventilator will need at least 2 trained caregivers, and will need to have an awake and fully-trained caregiver with them at all times. Home nurses will provide some of this care. Some nursing is essential when you are discharged, but it can often be difficult to get enough staffing for all the shifts. This is why it is important to have 2 caregivers that are fully trained to take care of all your baby's medical needs.

## **A durable medical equipment (DME) company will provide these supplies:**

- Home ventilator
- Ventilator batteries
- Equipment to deliver breaths to trach with a self-inflating bag
- Portable suction machine
- Humidifier for the ventilator
- Oxygen tanks and an oxygen concentrator
- Nebulizer machine to give inhaled medicines
- Pulse oximeter for measuring oxygen saturation



## PATIENT AND FAMILY EDUCATION

The home ventilator is much smaller than the ventilator that is used in the hospital. With another adult, you will be able to take your baby with the ventilator outside of your home along with other necessary equipment that is portable. The best way to travel with your baby and all the necessary equipment and supplies is by using a double stroller. The team will help you determine the best stroller to fit your baby's needs. Several other supplies will be delivered to your home at the time of discharge. These are similar to the supplies your baby is using in the hospital. The details of this pathway will be discussed in another chapter.

After discharge, your baby will need to follow-up with the pediatrician for well-child or routine sick visits. Before you see them, our medical team will have already talked with them and summarized your baby's medical issues and hospital



events in detail. The PHP nurse practitioners, pulmonologists, nurse coordinators, and respiratory therapists will continue to care for your baby's lung issues in the outpatient clinic.

Depending on your baby's condition, they may need less ventilator support over time and may eventually wean completely off the ventilator. Weaning off the ventilator is a slow and steady process that is monitored closely by the PHP team.

It is difficult to know how long your baby will be on a ventilator, with some children needing it for 2 – 4 years after discharge from the hospital, and others needing it almost indefinitely. The PHP team will continue to manage your baby's lung needs for as long as they are on the ventilator.

We recognize the pathway of home mechanical ventilation is not for everyone. It is life-changing for a child and for the entire family. Your medical team, along with other families with similar experiences, are happy to discuss the benefits, drawbacks, and the alternatives to pursuing home mechanical ventilation.

**Our team is here to help make these decisions for your son/daughter in the short-term, and to provide long-term care and advice for your child and family.**