



Some people living with neuromuscular disease use non-invasive ventilation and other mechanical devices like cough assist machines to support their breathing. It is important that you continue to use these devices if you need them to breathe well. NMD4C is distributing this document created by pulmonary experts from the CHEST Home-Based Mechanical Ventilation and Neuromuscular Disease NetWork to provide guidance on how to use these devices safely during a time when we are all trying to avoid spreading COVID-19.

This guidance may be updated as we learn more about COVID-19 and NMDs. You can check for the latest version of this guide [HERE](#).

COVID-19 Resources: Care Recommendations for Home-Based Ventilation Patients

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As COVID-19 continues to affect our daily lives, it's critical that we try to limit the spread of the virus as much as possible. This is especially applicable for patients who use non-invasive positive-pressure ventilation (NIPPV), mechanical airway clearance devices, or are supported by home ventilation for other chronic respiratory failure syndromes.

Chronic respiratory failure conditions include:

- Amyotrophic lateral sclerosis (ALS)
- Chronic obstructive pulmonary disease (COPD)
- Complicated pneumonia
- Cystic fibrosis
- Duchenne muscular dystrophy
- Myotonic dystrophy
- Severe obesity hypoventilation syndrome

<https://neuromuscularnetwork.ca/news/covid-19-resources-care-recommendations-for-home-based-ventilation-patients/>

- Spinal cord injuries
- Spinal muscular atrophy
- Thoracic cage disorders

NIPPV devices can increase the risk of infectious particles being dispersed into the environment, which can then infect the people around you. This risk is especially concerning with poor fitting mask interfaces, high leak, and open ventilation systems with tracheostomy.

To help limit the spread of these particles, our network of pulmonary and lung health experts, along with the Home Mechanical Ventilation and Neuromuscular Disease NetWork, has provided recommendations and guidelines to help keep you and your loved ones stay as healthy as possible.

Limit the spread of infectious particles

- Use a well-fitted full-face mask (covering nose and mouth). Add an additional combined bacterial/viral (hepa) filter between the mask and device tubing (non-vented mask → filter → CO₂ exhalation port on tubing device).
 - Device humidifier needs to be off.
- Or, place a mask over the CO₂ exhalation port of your mask (if you are using a *vented mask*). Caution will need to be exercised to ensure the mask does not stick to the exhalation port of the mask and occlude it, as this would cause CO₂ retention.
- Or, change tubing to a closed system with a double lumen tube and non-vented full-face mask for compatible home ventilators (e.g., Philips Evo, ResMed Astral, VOCSN).
- Need to discuss with your DME provider for set up of above options.

Caring for your disposable ventilation device

- **Mask interface:** Leaking from your mask can be a significant source of infection. Consider cleaning your mask daily with a cleaning wipe (mask cushions made from foam cannot be exposed to water and should not be used when sick).

- **Hoses:** Clean your hoses with sterilizing solution (e.g., sodium hypochlorite solution of 0.1% or 1000 ppm) every other day. This could be done with commercial solutions (i.e., Control III Disinfectant) or by using a 50% hydrogen peroxide solution.
- **Humidity chambers:** Place fresh water into the chamber daily (distilled, bottled, or boiled). Clean the chamber and the hose every other day.
- **Filters:** Consider adding an additional viral/bacterial filter in-line with the device (see above). These filters help to reduce droplets and spread of infection to caregivers. (filters can be obtained from on-line sources but are likely available from your DME provider). You should change the filter every 3 days while sick.
- Also see cleaning guides (ResMed or Philips).

How to make disposable cleaning wipes at home

You will need:

- 1 sealable container large enough to fit a roll of paper towels cut in half
- 1 roll of the THICK paper towels (take the center tube out)
- 2 cups of water, boiled and cooled
- 2 tablespoons concentrated dish soap
- 2 tablespoon white vinegar

Instructions: Put towels in container and saturate with the solution. Keep container sealed.

Caring for your ventilation device

- **Cleaning:** This should be done by your DME provider when you are better.

Caring for your oral and nasal suction device

- **Cleaning of the suction device:** Clean your suction canister daily with a commercial sterilizing solution or a 50% hydrogen peroxide solution.
- Cleaning and changing tubing and Yankour tip:
 - **Yankour:** Clean daily with a commercial sterilizing solution or a 50% hydrogen peroxide solution. Between oral suctioning, consider wiping down

with a paper towel or gauze with a chlorhexidine solution. Replace Yankour tip at the end of your illness.

- **Suction catheter:** Clean after suctioning with a 50% hydrogen peroxide solution. Use one catheter a day and then discard.
- Consider adding additional suction adapters
 - **Nose:** Consider adding a small **silicone adapter** for nasal suction. Clean after suctioning with a 50% hydrogen peroxide solution.
 - **Deep pharyngeal suctioning:** Consider using a directional aid (i.e., No BiteV). Clean between uses with a 50% hydrogen peroxide solution.

Preventing secondary infections (e.g., pneumonia)

- Keep the head of your bed elevated to 35°.
- Keep oral care aggressive; use a chlorhexidine solution.
- Consider in-line suction and once weekly tracheostomy tube changes for *invasive* mechanical ventilation.

What your family and caregivers need to know

Space is needed for isolation while using NIPPV – NIPPV is known to spread infectious particles, especially with poorly fitted masks. Full face masks covering nose and mouth limit spread but may necessitate additional monitoring by caregivers in young children and/or those who cannot remove the mask by themselves. Well-fitting masks are best for limiting spread. **Allow at least 3 feet of space for isolation.**

Keeping caregivers safe

- Caregivers should **wear gloves** every time they enter your room and dispose of their gloves immediately after.
- Caregivers should **wear masks (preferably N95) and eye goggles** for protection. They should leave equipment in one location and dispose of the equipment daily.
- Caregivers should **wear protective gowns/clothing** and follow the same protocol as mentioned above.
- Caregivers should **clean surfaces** with commonly available anti-bacterial/viral sprays.

Resources to keep at home

- Extra distilled water
- One month extra supply of medications
- Extra laundry supplies

What should I do if I have a tracheostomy?

- **Tracheostomy tube change/cleaning frequency:** once a week while sick
- **Tracheostomy cleaning protocol:**
 - Get one new tracheostomy tube every 3 months and always have at least 2 tracheostomy tubes at home.
 - Change the tracheostomy tube every week.
 - Use tracheostomy cleaning kits to clean the old tube and when it is very dry, store it in an airtight container until it is needed for the next tube change.
 - At the end of 3 months, discard the oldest tracheostomy, and put a new tube in the rotation.
- **Cleaning instructions:** Clean the tracheostomy tube using the brush in the cleaning kit. Put hot soapy water (you can use 50% hydrogen peroxide solution in lieu of soapy water if desired) in the base of the kit, brush clean, and then rinse through with boiling water. When the tube is dry, put in an airtight container and save for the next tracheostomy change in 1 month.
- **Tracheostomy ties and stomal care:** Continue with daily tie changes, and change stomal dressing as needed to keep gauze and stoma dry. Remember that these are respiratory secretions and will be densely filled with infectious particles. The ties and dressings should be thrown away into a zippered bag and sealed before putting in the trash.
- Consider switching to an in-line suction system. Switching will reduce exposure to caregivers and reduce the development of secondary infections.
- **Leak Speech Ventilation: Controlling particle spread (balloon up ventilation):** Leak speech ventilation is common for those on home-based invasive mechanical ventilation. The concern is that the high leak associated with this mode of ventilation (balloon down) significantly spreads infectious particles. Work with your physician and respiratory therapist to develop a safe alternative setting that will allow you to put in a cuffed tracheostomy and put the balloon up until you are

better. If you choose this mode, you will need to plan for alternative mode of communication.

I think I need to go to the hospital. Now what?

- Avoid hospitals, if possible, unless you have a fever over 100° F and/or increasing shortness of breath that does not respond to your usual treatment. Please also contact your pulmonologist. You should be aware that if you are admitted to the hospital, you may not be able to use non-invasive ventilation.
- **Bring ALL of your home devices** as the hospital may not have what you are used to and they may be out of devices. Some hospitals will not allow use of home equipment, but it is a safe precaution to bring them.
 - Know your settings (ask your provider to give you a one-page list that includes your PAP device/home ventilator settings, cough assist, suction, nebulizer therapy).
 - **Confer with the hospital medical providers on options:**
 - **Convert the NIPPV device tubing/mask circuitry into a *closed* system, which is a double-lumen tube with a non-vented full-face mask.** This will limit risk of infectious particle spread to the surrounding. (New home ventilators are capable of double-lumen tubing (e.g., Philips Evo, ResMed Astral, VOCSN).
 - Add a combined bacterial/viral filter between the mask and device tubing to reduce particle spread (non-vented mask → filter → CO₂ exhalation port on tubing → device).
 - Know your medication regimen.
 - Know your airway clearance regimen.
 - Limit cough assist and nebulizer therapy to as needed.
 - Operator will need to wear personal protective equipment (PPE).
 - Go to the “take charge not chances” program from the International Ventilator Users Network (IVUN) and fill out the following:
 - Home Ventilator User’s Emergency Preparation Checklist
 - Caregiver’s Emergency Preparation Checklist
 - Patient’s Vital Information for Medical Staff
 - Treating Neuromuscular Patients Who Use Home Mechanical Ventilation: Critical Issues
- Advocate for frequent and scheduled airway clearance. Bring your home devices (cough assist, therapy vest, etc.). You may need to have your caregivers give you

the airway clearance treatments as the hospital may only have basic suction available.

- **Challenges around the use of oxygen:** If you have chronic respiratory failure causing CO₂ retention, the use of supplemental oxygen can be risky, causing steep escalation in blood carbon dioxide (CO₂) levels. You may have been instructed that you should never be treated with oxygen. You should be aware that in the setting of infectious pneumonia – you may need oxygen in order to maintain adequate oxygen saturation with non-invasive ventilation. As long as oxygen is delivered through your positive airway pressure (PAP) device or ventilator – you will be protected as the CO₂ will be washed out by your PAP device/ventilator.
- **Patients supported on home NIPPV infected with COVID19 will need both NIPPV and oxygen.**
- For patients who are severely ill or showing signs of deterioration, intubation and mechanical ventilation may be required.

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