A very reasonable goal for a neuromuscular disease patient on a ventilator following acute failure to breathe adequately could be maintenance with NIV. Unfortunately, many physicians consider liberation from mechanical ventilation to be the only acceptable goal. This is due, in large part, to lack of training experiences in managing patients with long-term chronic ventilation needs. Most pulmonary and critical care physicians are trained to manage acute illness in patients for whom complete weaning from mechanical ventilation is the appropriate goal. Unfortunately, when a patient previously managed successfully with NIV is admitted to the ICU, the previous successful experience with NIV may be forgotten and a tracheostomy-based ventilator strategy becomes the main goal.

How can we change this? Education of pulmonary and critical care physicians in chronic non-invasive ventilation is crucial. A greater understanding of the home options for ventilatory assistance patients is equally important. These clinical training experiences are difficult to come by but can make all the difference in a physician’s comfort level in managing such patients.

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The paramount goal definitely should not be to wean the patient entirely from the vent, but rather to return the patient home at the highest level of functioning possible. Especially if the patient had been a successful user of noninvasive ventilation previously, I would attempt to wean the patient from invasive ventilation back to NIV. I have done this many times, and the main considerations are to postpone the transition until the underlying process (pneumonia, for example) has responded to treatment, and secretions are manageable. Using devices like the cough inexsufflator can be very helpful during this transition.

Mask ventilation can be started with the trach plugged and NIV sessions gradually lengthened as tolerated until the patient can be supported entirely noninvasively, at which point the trach can be removed.

Sometimes patients acquire problems with swallowing and severely weakened cough and are not good candidates for returning to NIV. In this case, it is still sometimes possible to discharge patients home in the absence of weaning, but there has to be much more caregiver support available than is the case with NIV. If the patient is capable of eating and speaking, then part of the rehabilitation should focus on preserving these functions while providing breathing assistance.

Some patients are so ill they cannot wean from tracheostomy ventilation or be sent home, but this situation is acceptable only if weaning to NIV and transfer to home have been seriously considered and proved impossible.

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Do you have a question about ventilator-assisted living?

Are you a health professional with a question for ventilator users? Send it to info@ventusers.org, and IVUN will find experts to answer it.