

Ask the Neurologist: Mechanical Ventilation

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The questions in today's column will focus on mechanical ventilation through a tracheostomy for individuals with ALS.

What is mechanical ventilation through a tracheostomy, and how does it differ from non-invasive positive pressure ventilation (NIPPV, commonly called BiPAP)?

NIPPV requires the patient to generate some inspiratory and expiratory forces. These act as triggers for the machine to push some additional air into or draw some additional air out of the lungs through a mask over the mouth and nose, or through nasal pillows. In contrast, mechanical ventilation through a tracheostomy draws air into and out of the lungs even when the patient is not able to produce any respiratory pressure. A tracheostomy is a surgical procedure whereby a tube is placed through the neck and into the main airway, or trachea. The tube is connected to a ventilator which is then adjusted to provide mechanical "breaths" of the correct size and at the proper rate to sustain life.

What percentage of individuals with ALS choose mechanical ventilation through a tracheostomy?

Probably less than 5 percent. Some of these persons make a conscious decision to live on a mechanical ventilator. Others have a tracheostomy performed as an emergency procedure because of uncontrolled secretions going into their lungs (aspiration) or because they cannot breathe adequately, even with the help of NIPPV.

Why don't more persons with ALS choose mechanical ventilation through a tracheostomy?

Choosing whether or not have mechanical ventilation through a tracheostomy is a very complicated decision. The individual must be prepared to accept that he or she will continue to experience progressive weakness of other muscle groups which may eventually result in complete paralysis. Caregivers are needed around the clock. Costs are very high. Some individuals with ALS are concerned as to whether their quality of life will be acceptable to them. Others worry about being a burden.

With all these negatives, why do some individuals with ALS choose mechanical ventilation through a tracheostomy?

Some see the alternative (death) as unacceptable at this point in their life. This may be because they have specific goals that they still wish to accomplish, or events that they wish to be present for, or loved ones that they wish to spend more time with. Remember that quality of life (QOL) as perceived by an individual with ALS is not the same as that perceived by someone in good health. In fact, individuals with ALS frequently rate their QOL higher than their caregiver or other “healthy” individuals rate the QOL of individuals with ALS. Most patients with ALS who choose mechanical ventilation through a tracheostomy state that they would choose it again if given the opportunity. We must be careful not to impose our concepts of QOL on the individual with ALS.

How will I communicate with a tracheostomy?

For some patients, a speaking valve or a fenestrated tracheostomy tube can permit an individual to speak if there is not severe bulbar weakness (weakness of the mouth and throat muscles). Eventually this is lost. When there is adequate arm and hand movement, individuals can communicate by writing or by using a computerized speaking device. Systems using small amounts of finger movement, head movement, or eye movement are available as well. Individuals with ALS who choose mechanical ventilation through a tracheostomy should realize that eventually they will likely lose all ability to communicate with those around them. This is referred to as a “locked in” state.

Can I ask to be removed from mechanical ventilation through a tracheostomy?

Yes. The support can be discontinued either through documents completed in advance specifying when this should be done (for example, if the individual loses all ability to communicate with others). Or, a decision to stop ventilation may be made by an individual at any time he/she is on the ventilator.

Will Medicare or other insurances cover the costs of home mechanical ventilation?

Medicare and most insurances will provide some coverage for equipment, depending on the policy. However, most of the cost of home mechanical ventilation is for round-the-clock care. A few insurance policies will cover these costs, although most will not, including Medicare. For persons under age 60 who qualify for Medical Assistance, the Michael Dallas Waiver Program generally provides 16 hours per day of care. For persons over age 60, there is no federal or state program to pay for home mechanical ventilation. Medicare pays for 90 days in a ventilator facility. After that, the individual must spend his or her own assets until they qualify for Medical Assistance, which will then pay all expenses, but only in a facility, not at home. The nearest facility which can care for someone on mechanical ventilation through a tracheostomy may not be close to that person’s family and friends.