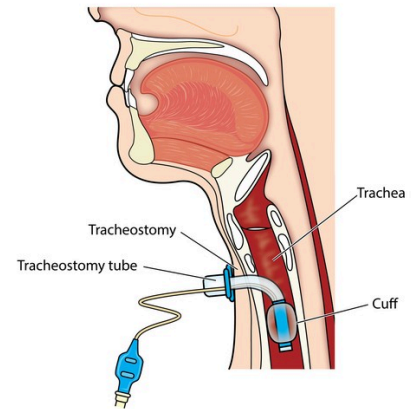


Tracheotomy and Ventilation

Some people living with ALS choose to extend their lives by deciding to receive invasive ventilation. This involves a surgical procedure called a tracheotomy that creates an opening in your neck where a tube connects to a ventilator that will breathe for you.

It is very important to learn about and discuss this option ahead of time with your loved ones and ALS professionals. Going on full-time mechanical ventilation can help you live longer, but it can also come at a great cost to you and your family. It does not slow down disease progression or reverse ALS.



Should I get a tracheotomy?

This is a very personal decision. Only you and your family will know what is best. This is a decision that cannot be reversed. If you are considering getting a tracheotomy, discuss the pros and cons with your neurologist and ALS clinic or medical team.

It is important to talk with your loved ones because once you are on invasive ventilation, you will need 24/7 assistance. Professional skilled home care is expensive and not covered by Medicare. Most families cannot afford full-time professional care, which means family members often become full-time caregivers.

Common reasons for not getting a tracheotomy include financial cost, burden to family members, and concerns about living a diminished quality of life. The vast majority of trached ALS patients remain connected to their ventilators 24/7 and are unable to speak.

Reasons for getting ventilated include the desire to continue living, spending more time with loved ones, and fulfilling a greater purpose. Advancements in respiratory and communication technology have enabled people to be more comfortable, stay connected, and have a better quality of life.

When should I get a tracheotomy?

When your respiratory muscles weaken to the point that noninvasive ventilation (breathing support through a mask that you can take on and off as needed) no longer provides enough breathing support, you can get a tracheotomy so that a ventilator will breathe for you.

Learn about your options ahead of time so you fully understand what your decision entails. Once you make a decision, be sure to update your advance directives so that your wishes are clear to loved ones and medical professionals. If you change your mind later, you can always go back and update your advance directives.

What is the surgical procedure like?

If you are considering a tracheotomy, your neurologist will refer you to a pulmonologist for consultation. The pulmonologist can answer all of your questions regarding the procedure and rehabilitation.

Getting a tracheotomy involves remaining in the hospital for 2-4 weeks after surgery, going to a rehab facility to learn how the ventilator works, and training for your personal caregivers.

Once I have a tracheotomy, how does it work?

At home, you will be connected to a portable ventilator, which will breathe for you. Your caregivers will know how the machine works and will need to make sure that it is working properly. Most ALS patients will be on the ventilator 24/7, though some patients can disconnect for short periods of time during the day.

In most cases, once you are on a ventilator, you will need to get your nutrition, liquids, and medication through a feeding tube. If you do not already have a feeding tube, you will receive one when you are under anesthesia for the tracheotomy procedure.

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