

Tracheostomy and ALS

ALS causes progressive weakness in muscles including those responsible for breathing. There is equipment out there that can support your breathing, known as respiratory equipment. While there are many types of respiratory assistance, this document focuses on a tracheostomy, which includes a surgery where an opening is made in the neck into the trachea (windpipe) to allow for access to the breathing tube. A tracheostomy tube is then placed through the opening to allow breathing through the tube versus the nose or mouth.

Although I AM ALS does not provide medical advice, we are here to support you and have collected educational resources that may be helpful in learning more about tracheostomies. Please discuss questions and decisions related to your diagnosis and medical care with your health care team. Check out [this list of questions](#) to ask your healthcare team on respiratory symptoms and care to help you get the conversation started.

Additional Resources:

- [The Trach Decision from the Perspective of Someone Living with ALS](#) – NEALS ALS Consortium
 - Description: The decision to pursue a trach is an individual choice that does not have a right or wrong answer. This presentation is based on actual questions asked by those with ALS facing this decision. It gives insight to the steps and processes that come with the pursuit of a trach, along with an understanding of what those opting for this procedure are interested in learning.
- [ALS and Breathing Guide](#) – Les Turner ALS Foundation
 - Description: This resource provides an overview of a tracheostomy, its impact on speech and communication, implications, insurance coverage, removal, power outage/emergency planning and travel preparation. The information on tracheostomies begins on page 13.
- [Charting Your Respiratory Care Plan](#) – The ALS Association
 - Description: If you feel you're ready to begin shaping your respiratory care plan, these six tips will provide an overview of the steps to take and questions to discuss with your family and health care providers.

Connect one-on-one with our ALS Support Team for personalized support and assistance with your ALS-related needs. Email us at gethelp@iamals.org or contact us at iamals.org/reach-out

- **[Identifying and Communicating Your Values Question Checklist](#)** – I AM ALS
 - Description: Your values are the lenses through which you view yourself and the world. When you use your values to make decisions, you make a deliberate choice to focus on what is important to you. The questions in this checklist may be helpful in learning to identify your values and communicate them with your healthcare team, particularly as you consider the decision to get a trach.
- **[Lung Function Tests for ALS](#)** - ALS News Today
 - Description: This article overviews devices and measurement parameters used to evaluate the respiratory function of people living with ALS. This includes forced vital capacity (FVC), the most frequently used respiratory function test in people living with ALS.
- **[FYI: Paying for Home Care](#)** - The ALS Association
 - Description: This article discusses ALS in-home care coverage using public insurance plans (such as original Medicare and Medicaid) and private insurance plans (such as Medicare Advantage, an employer's health insurance plan or long-term care insurance).
- **[Your ALS Respiratory Guide](#)** - Your ALS Guide
 - Description: This is an educational guide on ALS respiratory challenges, support, intervention and equipment. This page is filled with trusted information, helpful tips and video clips.
- **[Bedside Percutaneous Dilational Tracheostomy \(PDT\)](#)** - John Hopkins Medicine
 - Description: Percutaneous dilational tracheostomy (PDT), also referred to as bedside tracheostomy, is the placement of a tracheostomy tube without direct surgical visualization of the trachea. This article discusses the criteria, techniques and advantages of this procedure from a medical standpoint.
- **[Traveling with a Trach and Power Wheelchair](#)** - Team Gleason
 - Description: An example of the ideal process used for Steve Gleason, who is living with ALS, when he flies. This covers flying with both a power wheelchair, ventilator and other ALS-related equipment.

- [Traveling With ALS](#) - Your ALS Guide
 - Description: An ALS diagnosis does not have to stop you from traveling. If you want to visit friends or embark on a new adventure, plan ahead and take that trip! This article offers information and tips on how to plan for a trip while living with ALS, or caring for someone living with ALS.
- [Ask Me Anything ALS - Tracheostomy Part 1](#) and [Part 2](#) - I AM ALS
 - Description: In this two part series, learn from people living with ALS and tracheostomies as they answer questions from an audience of people also impacted by ALS.