

If you are living with ALS or COPD and either use or need a non-invasive ventilator (NIV) to support your breathing or are a caregiver for someone who does, we want to hear your story!

Your story can help raise awareness about the importance of access to these life-saving devices for individuals with chronic respiratory failure caused by conditions like COPD and ALS. Certain Medicare Advantage plans are denying access to ventilators for people who meet the coverage criteria, so the American Association for Homecare is collecting stories to help insurance companies and government officials understand the importance of protecting people's access to NIV as prescribed by their physicians to manage their medical needs.

SHARE YOUR STORY

We ask that you provide a short video or letter to share your story. Be sure to provide your name (first name is fine), state, and diagnosis in your story. Here are some prompting questions that you can use:

If you currently use NIV: Your story can help others understand how important it is to have access to the equipment you need when managing ALS.

- **How has your quality of life been impacted by having a NIV?**
For example, have these devices improved your ability to breathe and live more comfortably?
- **What would your life be like without access to NIV?**
Help others understand the critical role NIV plays in your daily life and well being.
- **What do you wish that others understood about the importance NIV in managing ALS?**
Help others understand and support individuals with ALS.

If you were denied access to NIV: Your story can shed light on the challenges faced by many in accessing necessary medical equipment.

- **Have you been denied access to NIV by your insurance company?**
Tell your story about the denial, such as how long you've been waiting since prescribed NIV, if you are going through appeals, etc.
- **How has the denial impacted your daily life and health?**
For example, are you having greater trouble breathing and performing activities of daily living?
- **What do you wish that others understood about the importance NIV in managing ALS?**
Help others understand and support individuals with ALS.

You can provide a short video testimony or a written letter. Videos may be taken on your phone, or the American Association for Homecare can set up a Zoom call to record your message. **For next steps or to learn more, please reach out to ashleyp@aahomecare.org.**

Together, let's make our voices heard and advocate for better access to non-invasive ventilators for individuals with ALS and COPD with chronic respiratory failure.