

Questions About Respiratory Symptoms & Care

ALS causes progressive weakness in muscles including those responsible for breathing. The following are a few questions to ask a respiratory therapist, pulmonologist or other qualified healthcare provider on your care team to better understand how they can support you throughout your ALS care. These questions may be answered over a series of visits.

There is often a lot of information to absorb during a clinic visit. Take a family member or friend with you who can take notes, and ask your care team whether you can record your visit so you can listen to their answers and advice again at a later time.

Provider Name:

Provider Contact Information:

1. Can you tell me about your experience working with ALS patients? How will we work together to monitor my care?

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2. How will ALS affect my breathing?

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3. How will you monitor my breathing?

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4. What can I do at home to support my respiratory strength?

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5. When will I need to start using a respiratory device? What are signs that my caregiver or I should watch out for?

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6. Will oxygen help me to breathe better? Why or why not?

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7. What are invasive and noninvasive respiratory devices? Will insurance cover these devices?

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8. I would like to learn more about the experience of living with both noninvasive and invasive respiratory devices. Can you connect me with a patient and a caregiver who have used each option?

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9. I have heard that having multiple devices can be cumbersome. Are there options for multiple devices in one machine that could be right for me?

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10. What is my lung function?

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11. What does FVC mean? What do the numbers mean?

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12. Can you help me understand more about tracheotomy and the potential physical, mental and emotional impact on me and my caregivers?

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13. What breathing exercises do you recommend for a weakening diaphragm?

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14. What milestones should we look for & what action will be taken when those are met?

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Write down other questions you have:

- 1.
- 2.
- 3.
- 4.
- 5.

I AM ALS does not provide medical advice. Please discuss questions and decisions related to your diagnosis and medical care with your health care team.

