



Emergency Information Card

ALS is a heterogeneous disease. Every person is dealing with a unique situation, what works for one may not work for another.

This is a SAMPLE of an emergency card. If you choose to use one, please personalize it to your specific medical needs and have your primary care physician review the information. **Replace any red text with personalized information.**

Additional Tips: Keep it brief. This is a quick reference card for emergency personnel. Once personalized and reviewed with your doctor, print and laminate several copies. Keep one with you at all times.

Sample Text for Emergency Card

If I am short of breath and/or have low SpO₂, do NOT give me oxygen. I need non-invasive positive ventilation to expel CO₂. Oxygen will not help and may mask respiratory failure. My lungs are healthy. My muscles - including my diaphragm - are weak. If oxygen is needed, it must be bled through my Bi-Level Positive Airway Pressure (Bi-Pap) or **Trilogy**.

Due to my weakened diaphragm muscles and compromised respiratory system, I cannot lie flat on my back. Doing so will cause further respiratory distress. Please keep me at a minimum of 30°.

Only my motor neurons are affected. I can hear you and understand you. I may use a computer to communicate. If it is not accessible in an emergency event, please ask yes or no questions. **I will indicate 'yes' by raising my eyebrows and 'no' by blinking my eyes.**

My sensory neurons are all intact. I am dependent for mobility and support. Please support my head during transfers and be attentive to any discomfort that might have come from that transfer. Thank you.

Emergency Information for Medical Personnel

NAME

HOSPITAL

D.O.B.

PHYSICIAN

EMERGENCY CONTACT

DX- ALS

EMERGENCY CONTACT #

I HAVE ALS.

If I am short of breath and/or have low SpO₂, do NOT give me oxygen. I need non-invasive positive ventilation to expel CO₂. Oxygen will not help and may mask respiratory failure. My lungs are healthy. My muscles - including my diaphragm - are weak. If oxygen is needed, it must be bled through my Bi-Level Positive Airway Pressure (Bi-Pap) or _____.

Due to my weakened diaphragm muscles and compromised respiratory system, I cannot lie flat on my back. Doing so will cause further respiratory distress. Please keep me at a minimum of 30°.

Only my motor neurons are affected. I can hear you and understand you. I may use a computer to communicate. If it is not accessible in an emergency event, please ask yes or no questions. I will indicate 'yes' by _____ and 'no' by _____.

My sensory neurons are all intact. I am dependent for mobility and support. Please support my head during transfers and be attentive to any discomfort that might have come from that transfer. Thank you.