

# My ALS Communication Passport to Quality Care

*Nursing, medical staff and caregivers, please look at my passport before you do any interventions with me. This document will help you better understand my care needs and preferences.*

My Name \_\_\_\_\_

Neurologist \_\_\_\_\_ Phone \_\_\_\_\_

Pulmonologist \_\_\_\_\_ Phone \_\_\_\_\_

***If you require emergency medical attention, please call 911 to access your local emergency services.***



**Things You Must Know About Me**



**These Things Are Important to Me**



**My Likes and Dislikes**

**LES  
TURNER  
ALS  
FOUNDATION**

[lesturnerals.org](http://lesturnerals.org)



# Things You Must Know About Me



Name \_\_\_\_\_

Preferred Name \_\_\_\_\_



Phone \_\_\_\_\_ Email \_\_\_\_\_

Address \_\_\_\_\_

\_\_\_\_\_



Date of Birth \_\_\_\_\_



## EMERGENCY CONTACT

Name \_\_\_\_\_ Relationship \_\_\_\_\_

Home Phone \_\_\_\_\_ Cell Phone \_\_\_\_\_

## HEALTHCARE POWER OF ATTORNEY

Name \_\_\_\_\_ Phone \_\_\_\_\_

Location of Documents for Advanced Directive and Durable Power Of Attorney  
For Health Care

\_\_\_\_\_  
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How I communicate/what language I speak

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# Things You Must Know About Me



My support needs and who gives me the most support

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Who I live with

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Religion \_\_\_\_\_

Religious needs \_\_\_\_\_



Primary Care Physician \_\_\_\_\_

Phone \_\_\_\_\_

Address \_\_\_\_\_

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Other services/professionals involved with me

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# Things You Must Know About Me



## Allergies

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## Medical interventions - how to take my blood, give injections, blood pressure, etc.

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## Breathing/heart problems

*If I am short of breath and/or have low SpO2, **DO NOT** give me oxygen; I may need noninvasive positive pressure (bi-level unit) 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 indicated, it may be bled through BiPAP.*

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## Risk of choking, Dysphagia (eating, drinking, and swallowing)

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## What to do if I am anxious

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# Things You Must Know About Me



## Current medications, vitamins and supplements

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## My medical history and treatment plan

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# These Things Are Important to Me



How to communicate with me

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How I take medication (crushed tablets, injections, syrup, etc)

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How you know I am in pain

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Moving around (posture in bed, walking aids, wheelchair, etc)

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# These Things Are Important to Me



Personal care (dressing, washing, etc)

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Seeing/Hearing (problems with sight or hearing)

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How I eat food (food cut up, risk of choking, help with eating, etc)

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# These Things Are Important to Me



How I drink (drink small amounts, thickened fluids, etc)

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How I keep safe (bed rails, support with challenging behavior, etc)

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How I use the toilet (continence aids, help to get to toilet)

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Sleeping (sleep pattern/routine)

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# My Likes and Dislikes



## Things I do like

*Please do this*

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## Things I don't like

*Please don't do this*

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## Learn More

*The Les Turner ALS Foundation exists to guide you to answers, support you and your loved ones and advance scientific research.*

To learn more about living with ALS, visit [LESTURNERALS.ORG/RESOURCES](https://LESTURNERALS.ORG/RESOURCES).

### MY ALS DECISION TOOL™

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If you have ALS, you will need to make some important decisions about your health care. As your disease progresses, your ALS care team may recommend different care options. You can use this tool to learn about some common ALS treatments, answer a few questions to help you think through what is most important to you and get ready to talk with your ALS care team about your options.

**MY ALS  
DECISION  
TOOL™**

To learn more, visit [alsdecisions.org](https://alsdecisions.org).

### ALS LEARNING SERIES

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Our online ALS Learning Series aims to empower the ALS community through the latest information and insights. Educational webinars and interactive Q&A's covering a diverse array of topics, from nutrition to respiratory care, are offered monthly featuring members of the Foundation's Support Services team, our Lois Insolia ALS Clinic at Northwestern Medicine and other national ALS experts.

**ALS  
LEARNING  
SERIES**

To learn more, visit [alslearningseries.org](https://alslearningseries.org).

### MY ALS COMMUNICATION PASSPORT TO QUALITY CARE

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My ALS Communication Passport to Quality Care was created to make your life easier. You will be able to share health information and care preferences with caregivers. You have a lot of information to keep track of, and this tool will help you do that.

**MY ALS  
COMMUNICATION  
PASSPORT  
TO QUALITY CARE**

To find out more, visit [lesturnerals.org/passport](https://lesturnerals.org/passport).

### SUPPORT GROUPS

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We facilitate support groups to provide people living with ALS, their caregivers and family the opportunity to share their experiences, give encouragement and help each other navigate their journey with ALS.



To find out more, visit [lesturnerals.org/support-groups](https://lesturnerals.org/support-groups).