



ALS & COMMUNICATION

A Les Turner ALS Foundation Guide for People Living with ALS

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Disclaimer Statement: The information in this guide is not medical advice. Talk to your ALS care team before making any decisions about your health or treatment. Together, you and your care team can find a treatment plan that works for you.

Last Reviewed: October 15, 2021



How ALS affects communication

Amyotrophic Lateral Sclerosis (ALS) can weaken the muscles you use when speaking and breathing.

This can lead to speech changes ranging from mild to severe. ALS can also cause a loss of strength in the fingers, hands, and arms, which may impact your ability to communicate by writing or typing. With today's technology, you have options to communicate with the people who are most important to you.

In this ALS & Communication guide, you will learn about the speech changes that can occur with ALS. You will also learn tips for navigating through those changes. Your ALS care team can customize the best way for you to meet your communication needs.



With today's technology, you have options to communicate with the people who are most important to you.

Your ALS care team can customize the best way for you to meet your communication needs.

How ALS affects speech



Hoarse or strained voice



Soft voice



Nasal or muffled-sounding speech



Unclear or slurred speech

Improving speech



Speak slowly.



Pause between words, phrases, or thoughts.

ar·tic·u·late

Over-articulate speech by exaggerating mouth movements (particularly the first sound of the word).

Shhh!

Rest your voice if you know you will need to talk a lot later in the day.



Project your voice. Think of listeners as being farther away than they are.



Point or use gestures in addition to speaking.



Get the listener's attention before speaking so they know you are ready to talk.



Speak face-to-face for added facial cues to improve understanding.



Identify the topic of conversation or interest.



Speak in a well-lit and quiet environment.



Rephrase if you are not understood.



Perform breath stacking exercise before a planned conversation.



Consider using non-invasive ventilation (NIV)

NIV is a special type of medical equipment to support breathing. Non-invasive means that it does not break the skin or require any surgery. You'll wear a mask that's attached to a device. NIV is the preferred and most used form of ventilation in ALS care.

You can use My ALS Decision Tool™ to learn if NIV is the right choice for you.

MY ALS DECISION TOOL™

alsdecisions.org/breathing

Then, talk with your ALS care team. Together, you and your care team can find a treatment plan that works for you.

Watch this video, bit.ly/ambu-bag for instructions or ask your pulmonologist during a clinic visit about breath stacking.

For more information on ALS & Breathing visit, lesturnerals.org/breathing

Specialists to help with communication

Speech-Language Pathologists (SLPs) and Occupational Therapists (OTs) work together to help you keep up with your changing communication needs.

SLPs can help in the following ways, even if you have not noticed changes in your voice:



Start the voice/message banking process to record your voice



Provide strategies to enhance speech clarity and introduce exercises if appropriate



Provide education, training, and financial resources



Recommend adaptations, tools and devices.

OTs work with SLPs to determine what devices and techniques are going to make communicating easier for you. This is important if you are experiencing decreased hand function and as well as diminished ability to speak.

Options for recording your voice

Recording your voice is highly recommended once you are diagnosed with ALS. You can use your recorded voice with different devices in the future to communicate with others.

The effort and cost to record your voice varies. The technology changes often, so please contact your ALS care team. They will help you stay up to date on your options.



If you would like an idea of words and phrases to record, the Jay S. Fishman ALS Augmentative Communication Program has a great list.

bostonchildrens.org/ALSA



Voice Banking

The process of digitally recording your voice to create a custom synthetic voice. This new custom voice can be used with a speech-generating device (SGD). The process needs to begin when your voice is relatively unchanged. The earlier in the disease process, the better. A family member can also complete voice banking for you if you desire.

There are several different software systems that you can use to bank your voice. There are two main ones:

My Own Voice Acapela (aka Acapela) is more expensive, but many people find it easier to use. For more information visit, mov.acapela-group.com.

ModelTalker can be harder to use but is less expensive. For more information visit, modeltalker.org.



Message Banking™

Recording messages using your natural voice. These messages sound more natural than voice banking by keeping the tone of your voice. For more information visit, mymessagebanking.com.



Legacy Messages™

The process of recording phrases and sentences. These are usually phrases that you frequently use or are meaningful to you. Record catchphrases that you are known for. For more information visit, legacymessages.com.



Double Dipping™

The process of recording your voice only once for both voice banking and message banking. This technology was developed by the Jay S. Fishman ALS Augmentative Communication Program at Boston Children's Hospital. For more information visit, bostonchildrens.org/ALSAugComm.



Voice banking is not covered by insurance. The nonprofit group, Team Gleason, will pay for Acapela or ModelTalker. This applies for anyone in the United States who has with ALS.

For more information visit teamgleason.org/need-assistance/.

Alternative and augmentative communication

Alternative and augmentative communication (AAC) are tools and strategies that aid you in speaking. AAC can also replace your speech when you are no longer able to speak on your own. AAC ranges from low-tech tools to high-tech computers and tablets.

Types of AAC that are available include:

Low Tech AAC



Adaptive writing tools

- T bar or flexible stylus
- Writing bird- writing helper
- EaZy universal cuffs



Using a stamp or electronic signature to “sign” your signature in cards or documents



A whiteboard and dry erase marker or pen and paper



LCD writing board (aka boogie board)



Picture, word or letter boards

- You can point to letters, words, or pictures to aid communication
- Partner-assisted scanning can be used to communicate if you cannot physically select a word or phrase.
- A partner will point to different items on the communication boards for you. When the partner has pointed to the desired item on the board, use a standard signal or sound. This is the “switch” to notify them that this is what you want to say.



Emergency communication devices

- Use noise-making items like a bell or buzzer to get the attention of others in case of an emergency.
- A slightly higher-tech version would be a CallToU wireless caregiver pager system for the home (calltou.com).
- A wearable medical alert device such as Life Alert can also be used in an emergency if no one is around to help you (lifeline.philips.com).

Low tech options are less expensive options if you are able to write or point. Adaptive styluses or universal cuffs are ways to adapt writing utensils if you have decreased grasp.

Amplification



Microphone

Increase the volume of your voice. One example is Chattervox (chattervox.net).

Moderate tech (this is not a complete list)



Text-to-Speech

- **Text to Speech!:** Free on iOS
- **Text to Speech:** Free on Android
- **Tell Me- Text to Speech:** Free on Android



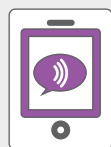
Text-to-Speech with additional features

- **Speech Assistant AAC:** available through iOS with payment and free on Android
- **Proloquo4text:** available through iOS with payment. *Can be used with Message Banking™*
- **Talk for me:** Free on iOS
- **Verbally:** Free on iOS
- **Predictable:** On iOS with payment. *Can be used with Message Banking™*

Moderate tech apps are a great bridge between low tech and high-tech devices. The apps can be downloaded on your existing smartphone or tablet through your app store at a wide range of price points.

High tech

A **Speech generating device (SGD)** is a device that is used for communication. These devices are usually computers or tablets. They allow you to browse the internet, email and send text messages. SGDs also change text into speech through specialized programs. The device will allow you to select what you want to say through various tools. These tools include a computer mouse, head mouse, touch screen and eye gaze.



Commonly recommended speech generating brands

- Tobii Dynavox: us.tobii-dynavox.com
- PRC-Salttillo: prc-salttillo.com
- Talk to me Technologies: talktometechnologies.com

SGDs can be changed to suit your communication needs. For more information, talk with your SLP, care team, and insurance provider.

Using speech generating devices?

Direct Selection



Touch

Touch the item on the screen to select it.



Mouse

Click with a mouse to select an item on the screen.



Head mouse pointer

Use head motion to select an item on the screen.



Eye access selection or eye-tracking

Use eye movement and eye-tracking software to select an item on the screen.

Indirect Selection



Switch Scanning

The computer highlights different items on the screen by first highlighting groups of objects, letters, or words, and then narrowing them down within the group.



As your abilities change, you can also change your selection method.

Insurance coverage

- Medicare usually pays up to 80% of the cost of a SGD.
- Private insurance will usually cover most or all of the cost of a SGD. Coverage will depend on your type of insurance.
- Insurance will not cover the cost of an SGD if you live in a nursing home or if you are receiving hospice care.

How can I get evaluated for assistive communication devices?

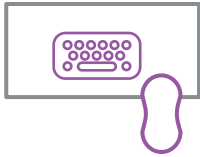
Shirley Ryan AbilityLab's Assistive Technology Program offers a variety of services. The services available will enhance your independence and quality of life. (sralab.org/services/assistive-technology)

Asyst Communications Co. Inc. offers accessible technology to help you communicate and control your environment. (asyst.us)

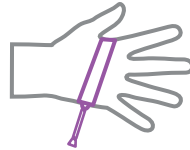
The Marianjoy Assistive Rehabilitation Technology Institute will evaluate you to maximize your independence and communication options. (www.marianjoy.org/rehab-technology/marti)

Talk with your ALS care team to get a referral to a technology center near you.

Adaptive devices for computer use



Computer arm supports and accessibility features for keyboard modification



Keyboard aid (pointer)



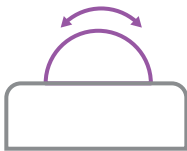
Head- or eye-control electronic/computer device



Futuro wrist brace

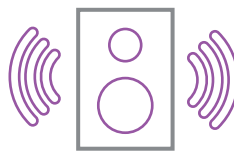


Voice-activated programs such as Dragon Speak



Adaptive computer mice

- Foot-operated computer mouse
- Trackball mouse
- Vertical style mouse
- Roller mouse- allows you to keep hands on keyboard at all times to decrease arm movement and fatigue



Smart speaker

capable of streaming audio content, relaying information, and communicating with other devices

Technology centers often have a large selection of state-of-the-art, commercially available devices on hand to assist in assessing the best equipment for you.

Talk to your ALS care team for adaptive computer equipment recommendations.

Telephone and in-home communication

Telephones can be adapted in many ways.



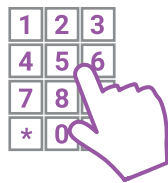
headset



Receiver holder



Speakerphone



Speed dial



Voice activated phone

In-home communication



Infant monitor



Walkie-talkie



Portable doorbell



Voice-activated house controls

(Google Home, Alexa, etc.)
paired with smart items
such as doorbells, light bulbs,
outlets, and kitchen appliances.

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.

My ALS Decision Tool™

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. To learn more, visit: alsdecisions.org.

**MY ALS
DECISION
TOOL**

ALS Learning Series

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. To learn more about ALS care and research, visit: alslearningseries.org.

**ALS
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SERIES**

My ALS Communication Passport to Quality Care

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. To find out more, visit: lesturnerals.org/passport.

**MY ALS
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TO QUALITY CARE**

Support Groups

We facilitate support groups to provide people living with ALS and 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.

