

# Patient and Family Resource Guide to ALS

## Section 7 Speech

7

LES  
TURNER  
ALS  
FOUNDATION

5550 W. Touhy Avenue, Skokie IL, 60077  
847 679 3311  
lesturnerals.org  
info@lesturnerals.org

# Speech/Communication

ALS often affects the muscles used in speaking and swallowing. These muscles include the lips, tongue, soft palate, larynx (voice box, throat), and the muscles used in breathing. Weakness and/or poor coordination of some of all of these muscles may lead to difficulty in pronouncing words clearly. In some cases, language and thinking skills may also be affected.

## Problems in Communication May Include:

- Hoarse or strained voice
- Soft voice
- Unclear or slurred speech
- Nasal or muffled-sounding speech

In some persons with ALS (PALS), speech difficulties remain stable or relatively mild. In others, communication problems progress from mild to severe. At times, the PALS will perceive his or her speech problem differently than the listener does. Both the speaker and the listener should identify the factors that affect communication and work together to manage them. Speech-Language Pathologists (SLPs) at the Lois Insolia ALS Clinic at the Les Turner ALS Research and Patient Center at Northwestern Medicine can help people with ALS manage their changing communication skills for as long as possible. SLPs also can assist clients in adapting to alternate forms of communication, if necessary.

## Tips for Maximizing the Communication Environment

- **Get the listener's attention before speaking.** Agree on a special signal the individual can use when ready to speak.
- **Speak face-to-face.** Most listeners use lip reading to help them understand speech. This is especially important when the speaker's mouth and face muscles do not move well.
- **Identify the topic of conversation (or interest).** Identify this at the beginning of the conversation, so the words chosen may be more familiar or expected.
- **Speak in a quiet environment.** At home, turn down extraneous noise such as the radio, TV or music. In a restaurant, find a quiet place for conversation.
- **Rephrase if you are not understood.** It may be necessary to change the words that you use if you are not understood.

## Techniques to Maintain Communication

- Speak slowly and distinctly.
- Pause between phrases or thoughts, and even between words, if needed.

- Over-articulate speech by exaggerating consonants, especially the first consonant in the word. Learn whether the lips or tongue or both are involved.
- Clearly pronounce each syllable in longer words.
- Use energy saving ideas. Rest your voice if you know you will need to talk later in the day. Techniques that work in the morning may be less effective later in the day.
- Project your voice. Think of listeners as being farther away than they are.
- Use non-verbal strategies to add to your speech.

ALS communication specialists generally advise against rigorous, traditional exercises designed to strengthen weak or uncoordinated muscles, particularly when there are detectable speech disturbances. Exercises designed to learn and utilize speech strategies may help a PALS' changing communication needs. Some people will need just a few lessons to learn them. Others will be able to incorporate new strategies on their own. Ask your Speech-Language Pathologist for specific advice for your concerns.

## Assistive Communication Devices

Assistive communication devices are any devices that may enhance a person's ability to communicate effectively. Communication difficulties in ALS vary and can change over time. Some individuals may need only one type of device; others may move from one device or access method to another as symptoms change and progress. SLPs assist in the selection of specialized equipment for a specific communication need. The types of devices available may be discussed at your Clinic visit.

### Types of Assistive Communication Devices

- **Amplification:** A personal voice amplifier is used to make speech louder in people with soft or whispered voice. It is usually portable and works with a microphone placed near the mouth. Sometimes, increased volume is all that is needed for better understandability, but it cannot make less clear speech more intelligible.
- **Low technology devices:** Low technology devices include alphabet (letter) boards, word boards, picture boards or notebooks that can be used by pointing to the desired letter, word, picture or phrase. Anything goes! Some families create their own boards; others purchase a commercially produced product. Including a place for identification of a topic also helps to narrow down the ideas. These boards can be used with partner-assisted communication techniques, as explained below.
- **Moderate technology devices:** Moderate technology devices include smartphones and tablets (e.g. iPad, Android-based tablet, Kindle, etc.) that can serve as a communication device through various applications (apps) which are downloaded to the device. Many personal computers (desktops, laptops) can be modified to be used as a communication device.

- **Communication apps:** Communication apps can be purchased and/or downloaded for personal devices. Apps can be text-based or picture-based. Most provide text-to-speech features where the PALS types a message or part of a message that is then “spoken” when the item is selected. Offerings change regularly and are too numerous to list here.
- **High technology devices:** High technology devices include “dedicated” computers with voice synthesizers, usually called “speech generating devices” (SGD). These specialized products can be used through a variety of access methods as described in the next section. When a specialized SGD is being considered, an SGD evaluation by an SLP familiar with these systems is required before purchase. The SGD market changes regularly regarding products and funding so it is best to consult with an SLP. Many SGDs and apps are available in languages other than English.
- **Palatal lift:** A palatal lift is a dental apparatus, similar to a retainer, which is worn to keep air from escaping out of the nose during speech. It is an intervention for select speech problems, though recommended infrequently. It works by lifting the soft palate. Several visits to a specialized dentist, called a prosthodontist, are required for proper fabrication and fitting. This device is most appropriate for PALS whose speech problems progress slowly and who have primarily excess nasality during speech. It is not appropriate for those with rapid speech decline or weakness of the speech muscles, such as the tongue, which affects the majority of PALS. Insurance may cover a portion of the palatal lift but it is best to check your individual coverage.

## Input Selection Methods for Communication Devices

### Direct Selection

Direct selection is the most efficient selection method. It requires accuracy of the upper extremities, head or eyes.

- **By touch:** The user makes direct contact with the device, such as typing or touching a computer/device screen. A stylus also can be used.
- **By mouse:** The user moves the mouse around the screen and uses a “click” to select the desired target. There are adapted mouse devices for those with less dexterity.
- **By head mouse pointer:** This method requires the use to wear a specialized “dot” and move the head to the desired target letter or phrase on the SGD or computer.
- **By eye access selection or eye tracking:** This method involves directing one’s “gaze” to an on-screen keyboard or display and “dwelling” on the desired target letter or phrase. The “dwell” feature then selects the target to the text box or for the message to be spoken. This method is needed when other body movements are not possible.

- **Other:** Creative solutions may be developed by families to help with access. A laser pointer rigged to glasses or a baseball cap brim can also serve as a head pointer on a communication board or poster. If a laser pointer is used, though, care would be needed to avoid direct contact with someone's eyes.

## Partner Assisted Communication

Partner-assisted communication is a technique most often used with a letter or word board between a person who is unable to use his or her hands and a communication partner or the "listener." The "partner" shows the board and/or reads the row name to the "communicator." When the desired row is mentioned, the communicator selects it by a mutually-agreed upon signal, such as a head nod or eye blink. Then the partner shows/reads the individual letters or words within that row until the communicator makes a selection. That selection becomes the first letter (or word) in the user's message. These actions are repeated until the message is complete.

Some letter boards are home-made. Others are available on the Internet or from an SLP. The **AEIOU** set-up is the most common and is organized by the vowels down the left column:

ABCD

EFGH

IJKLMN

OPQRST

UVWXYZ

Other boards can be arranged by quadrant or by color or by topic.

## Scanning

Scanning is a method by which individuals who no longer are able to use a keyboard by typing can operate a computer or alternative communication device. This method takes longer for creating a message than direct selection. Displays, such as rows of letters or pictures (also known as icons) or sections, are "scanned," that is highlighted in a sequence, until the user activates a switch to make a selection. A section can be a row, several rows or even a block of icons. Once the general section is highlighted, then each individual icon within that section is highlighted until the user makes his or her choice. The number of icons displayed on the main screen can vary from only a few to more than 50 items.

There are many switches available and depend of the user's dexterity. Size, shape and access for the switch vary. A switch may be round, plate-like or a joy-stick. It can be activated by touch or motion. The particular switch may be activated by any body part or motion, such as hand, finger,

foot, eyebrow or eye blink. The SLP or possibly Occupational Therapist may suggest a particular switch depending on the PALS' skill.

## Voice Banking

Voice banking is a process to preserve the PALS's voice and use it when needed on an SGD. The process needs to begin the PALS's voice remains relatively unaffected, that is early in the process. Alternatively, a family member can also complete the process if their voices sound similar.

The ModelTalker System is a revolutionary speech synthesis software package developed by the Nemours Speech Research Laboratory and designed to benefit people who are losing or who have already lost their ability to speak. It allows people who use a Speech Generating Device (SGD) to communicate with a unique personal synthetic voice that is representative of their own voice. Visit the website [www.modeltalker.org](http://www.modeltalker.org) for details. It requires recording phrases and sentences that subsequently will be synthesized into his or her voice.

As of July 1, 2017, there is a \$100 charge for users to enable download of completed voices.

## BeSpoke™ Voices

BeSpoke™ Voices are uniquely created (customized) voices for an SGD that searches the VocaliD database for a voice match. It results in a digital voice that is understandable and personalized. A few seconds of vocalization of the voice recipient's voice is needed. The TobiiDynavox company is partnering with VocaliD in this project. Information can be found on [www.tobiidynavox.com/vocalid](http://www.tobiidynavox.com/vocalid). As of July 2017, the cost for this service is approximately \$1,200.

## Specialized Features

Most SGDs and moderate technology devices, like smartphones and tablets, have specialized features that further shorten the task, reducing the energy used in creating messages. Even with a homemade word or letter board, these anticipation techniques can be helpful in improving the communication between user and listener.

- **Word completion:** The device anticipates how a word is spelled, based on the first few letters, and finishes it for you. Some programs will offer selections among which the user can select.
- **Word prediction:** The device anticipates words that come after one another in context. For example: If the phrase: "I want to" is formulated, the next word is likely to be "go." Sophisticated computer programs learn how phrases are used by a specific user or what it likely to be used based on English grammar rules.

## Commonly Recommended Communication Devices

The ever-changing nature of the speech generating device market and funding regulations makes specific recommendations challenging. However, several companies have products which may be appropriate for some PALS.

Tobii-Dynavox: [www.tobiidynavox.com](http://www.tobiidynavox.com)

Asyst Communication Company [www.asyst.us](http://www.asyst.us)

Prentke-Romich: [www.prentkeromich.com](http://www.prentkeromich.com)

## Medicare Coverage

Medicare recognizes assistive communication devices as durable medical equipment (DME) which is a covered benefit under the Social Security Act. The Steve Gleason Act of 2015 (S.984) was signed July 30, 2015 and was supposed to end October 1, 2018. It amended the title XVIII of the Social Security Act to provide Medicare beneficiary access to eye tracking accessories for speech generating devices and to remove the rental cap for durable medical equipment under the Medicare Program with respect to speech generating devices (“S. 984 — 114th Congress: Steve Gleason Act of 2015.” [www.GovTrack.us](http://www.GovTrack.us). 2015. June 7, 2017

<<https://www.govtrack.us/congress/bills/114/s984>). ALS advocacy groups were working to make this important legislation permanent and as of February 2018, the Bipartisan Budget Act of 2018 (H.R.1892) was signed. By signing this legislation, which included the Steve Gleason Act, there are no longer policy limits for speech generating devices for our PALS.

Eligibility for obtaining an SGD remains based on medical necessity, as determined by a PALS’ physician and Speech-Language Pathologist. A communication device evaluation by a licensed SLP is required.

Medicare’s policy covers 80% of the cost of the device, up to predetermined limits. The remaining portion can be covered by a secondary policy, outside funding source or self-pay.

Unfortunately, Medicare does not fund devices for users living in a skilled nursing facility or for those enrolled in hospice care. Benefits are allowable for those in palliative treatment, those living in an independent living facility or in assisted living. Medicare, at this time, funds SGD peripheral equipment, such as a wheelchair or rolling mount, or an eye access module, with proper evaluation and documentation. Medicare currently funds one device every five years, based on the date of shipment of the device.

It is best to inquire with an SLP for current Medicare policies regarding SGDs.

## Resources for Evaluating Communication Devices

Centers in the Chicago region for demonstration and/or evaluation of high technology devices include the following locations:

- **The Technology Center at the Shirley Ryan Ability Lab (formerly the Rehabilitation Institute of Chicago (RIC)):** This Center is staffed by augmentative communication specialists, usually SLPs, and Occupational Therapists. In addition to evaluation for a dedicated SGD, RIC will evaluate for specialized hardware or software for full computer access, keyboard modifications and/or alternative mouse devices, as well as for environmental controls to help with daily living issues. A physician's referral is needed. Medicare and private insurance typically pay for an evaluation and follow-up visit (though as with any medical coverage, check with your insurance carrier for details). A wide array of communication devices is available for demonstration. [www.sral.org](http://www.sral.org). Technology Center contact: 312-238-2988. Main RIC phone number: 312-238-1000.
- **Marianjoy Rehabilitation Center, Wheaton, IL:** [www.marianjoy.org](http://www.marianjoy.org). General outpatient services phone 630-909-7150.
- **VA Hospital System:** The VA Hospital System provides SLP services and evaluation to qualifying veterans. The PALS needs to be registered at his or her local VA to attend. The VA provides SGDs and access equipment as appropriate.
- Some SLPs affiliated with hospitals or free-standing centers can provide SGD evaluations with the assistance of an SGD vendor.

*Disclaimer: All care has been taken in preparing this document. This information is of a general nature and should be used as a guide only. Always consult your health care team before starting any treatments*