

Section G

SPEECH

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 or all of these muscles may lead to difficulty in pronouncing words clearly.

PROBLEMS AND SUGGESTIONS

Problems in Communication May Include

- hoarse or strained voice
- soft voice
- unclear or slurred speech
- nasal or muffled-sounding speech

In many patients, speech difficulties remain stable or relatively mild. In others, communication problems progress from mild to severe. At times, the patient will perceive his or her speech problem differently than the listener does. Both the speaker and the listener should identify the factors that most affect communication and work together to manage them. Speech-language pathologists (SLPs) can help people with ALS manage their changing communication skills for as long as possible. SLPs also can assist patients in adapting to alternate forms of communication if necessary.

Tips for Maximizing the Communication Environment

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.

Speak in a quiet environment. At home, turn down extraneous noise such as radio, TV, or music. In a restaurant, find a quiet place for conversation.

Get the listener's attention before speaking. Agree on a special signal the patient can use when ready to speak.

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 are involved.
- Clearly pronounce each syllable in longer words.
- Rest your voice if you know you will need to talk later in the day. Techniques that worked in the morning may be less effective later in the day.
- Project your voice. Think of listeners as being farther away than they are.

ALS communication specialists generally advise against rigorous, traditional exercises designed to strengthen weak or uncoordinated muscles. Exercises designed to learn and utilize speech strategies are appropriate to help an ALS patient's 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 a speech-language pathologist for advice.

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 to another as symptoms change and progress. A speech-language pathologist can assist in the selection of specialized equipment for a specific communication need. The types of devices available may be discussed at your Center visit.

Types of Assistive Communication Devices

Amplification A personal amplifier is used to make speech louder in people with soft or whispered voices. It is usually portable and worn with a microphone placed near the mouth.

TTY, or telephone relay system, is a special telephone equipped with a keyboard so speech can be typed to another person with a similar system, or read to a listener by an operator. The State of Illinois has a program that lends TTY equipment at no charge to speech-impaired individuals with a referral from their physician and an application. This program, called Illinois Telecommunication Access Corporation, can be reached at 800-841-6167 (voice) or 800-841-1055 (TTY). Individuals who have their own communication device can use a speaker telephone to serve the same purpose.

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 works by lifting the soft palate. Several visits to a specialized dentist, called a prosthodontist, are required for proper fitting. This device is most appropriate for patients whose speech problems progress slowly and those who have excess nasality. It is not appropriate for those with rapid progression of speech or weakness of the speech muscles.

Low technology devices include alphabet or letter boards, word boards, picture boards, and 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. A board can also be used with scanning, as explained below.

High technology devices include computers with voice synthesizers as well as smaller, portable (dedicated) communication systems. This market changes regularly. It is best to consult with a speech-language pathologist familiar with augmentative devices when considering this type of system.

Scanning

Scanning is a method by which patients who can no longer use a keyboard can operate certain alternative communication devices. Items, such as rows of letters or pictures, are scanned, or highlighted in a sequence, until the patient activates a switch to make a selection. The switch can be one of any number of devices connected to the communication device. The switch is activated by a single movement, such as touching a button, flicking a finger, or moving the head. Some devices can even be activated by raising an eyebrow or blinking an eye.

In the most common scanning method, each row of letters or words is highlighted in turn, until the row containing the desired letter or word is selected by activating the switch. Then the scanning sequence changes to highlight each item in the selected row. When the desired letter or word is reached, it is selected by activating the switch. It may be helpful to think of the scanning sequence as a moving “bouncing ball” which stops when the desired letter or word is selected by the switch.

In this example of row scanning, the desired letter is “M.”

ABCDEF G
 HIJKLMN
 OPQRSTU

When the second row, which contains the desired letter, is highlighted, it is selected by activating the switch.

H I J K L M

When the “M,” the desired letter, is highlighted, it is selected by activating the switch. In this way, words are created, letter by letter.

Adaptation of scanning for letter or word boards: Scanning can also be used with any letter or word board. The “listener” shows or reads the row name to the “user.” When the desired row is mentioned, the user selects it by nodding the head, blinking an eye, or another mutually agreed-upon signal. Then the listener shows or reads the individual letters within that row until the user makes a selection. That selection becomes the first letter in the user’s message. These actions are repeated until the message is complete.

Home-made or computer letter boards are frequently called AEIOU boards because they are often organized by the vowels down the left column. That way, it is easy to find the vowels.

A B C D
 E F G H
 I J K L M N
 O P Q U R S T
 U V W X Y Z

Specialized Features

Most communication devices have specialized features, in addition to scanning, that further shorten the task, and therefore reduce the energy used in creating text.

Word completion: The device anticipates how a word is spelled, based on the first few letters. For example: TEL is often followed by “EPHONE,” and WH is often followed by “AT.” Some programs automatically finish the word, others will offer suggestions 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 person or what is likely, based on English grammar rules.

Scanning and communication devices are helpful in conserving the users’ energy and shortening typing time. Even if a homemade word or letter board is used, these anticipation techniques can be helpful in improving the communication between user and listener.

RECOMMENDED COMMUNICATION DEVICES

A triple asterisk (***) indicates that the Les Turner ALS Foundation has this device in an equipment pool that is distributed through a loaner system. The ALS communication bank has developed and grown to include a collection of many state-of-the-art communication devices. At times, the demand for these devices exceeds the available supply. In an effort to effectively and fairly distribute these devices, a policy was formulated by the Les Turner ALS Foundation and the Lois Insolia ALS Center. Listed below are the established guidelines.

1. The patient must have an evaluation from the Lois Insolia ALS Center Speech-Language Pathologist.
2. ONLY patients of the Center are eligible for devices from the communication bank. A leasing agreement in the amount of \$25 per month is to be arranged between the patient and the Foundation, However, no Lois Insolia patient will be denied because of lack of funds. We reserve the right to review each patient’s communication needs individually.

Devices that Require Typing Skills

AYST 1000*** (ASYST Co.) about \$200. Small, portable device; male voice; keys widely spaced; may need external speaker; English/Spanish.

Crespeaker*** (Crestwood Co.) about \$350. Small, portable device; male voice; may need external speaker; English/Spanish.

CrespeakerMAXX*** (Crestwood Co.) about \$1,100. Medium sized, lightweight, and portable; male/female voice; memory storage under each letter key.

Link (Assistive Technology, Inc.; Woodlake Tech., Inc.) about \$1,500. Medium sized (8 in. 3 11 in.), lightweight portable device; male and female voices; memory storage under function keys.

Lightwriter*** (Zygo Industries; Woodlake Tech., Inc.) about \$5,000. Medium sized, lightweight and portable; dual display; male and female voices; memory storage; abbreviation expansion.

Devices that Move from Direct Selection, Typing, to Scanning

Portable IMPACT (Enkidu; Woodlake Tech., Inc.) about \$3,000–\$4,000. Hand held, Palmtop, and Tablet versions; DECTalk speech; preprogrammed phrases; word prediction; bundled productivity software; Palmtop and Tablet version work best with use of stylus (or scanning).

Devices that Are Based on Scanning

CommuniMate*** (ASYST Co.) scanning via switching; abbreviation expansion; word prediction; links to environmental Control Units. Contact ASYST for purchase. A limited number of these devices may be obtained as “loaners” for a small monthly fee, through the Les Turner ALS Foundation. Devices are available for those PALS enrolled in the Lois Insolia ALS Center, with a referral from the ALS Center Speech Pathologist. Steve Wells, President of the ASYST Company, has been a provider of services for the Les Turner ALS Foundation for more than fifteen years. He provides in-home installation of equipment and training for PALS and their family members. Prices range from \$3,000-\$6,000.

E-talk*** (Great Talking Box or Woodlake) about \$3,500. Can be used with touch screen or scanning. Symbol-word based system that can be personalized, as it provides the opportunity for recording one’s own speech.

Computers

Many programs that can be used for communication are available for standard personal computers. If the patient can type, the standard computer keyboard can be used. For patients who cannot use a keyboard, the scanning

method described earlier can be used with an on-screen keyboard. A wide variety of switches are available.

The advantages of using a computer as a communication device are many. Commonly used phrases can be saved, organized by topic, and recalled when needed using only a few keystrokes. Methods are available for adding, changing, and deleting phrases. Some programs can accept audio phrases, enabling the use of sounds to gain the attention of listeners, or even recordings of common phrases in the user's own voice. Synthesized voices can be male or female. The speed and pitch of the voice can be controlled. Most computer programs for speech implement the word completion and word prediction features mentioned earlier. And the computer can be used for other purposes. See also Section K, Useful Resources.

Software Information about the many computer programs for speech that are available may be found in the Communication Independence for the Neurologically Impaired (CINI) website, www.cini.org. Among the programs listed is one sponsored by the Les Turner ALS Foundation. Its name is E-triloquist, a contraction of electronic ventriloquist. It is available at no charge on the Internet at www.etriloquist.com, or from the Foundation office.

MEDICARE COVERAGE

Medicare is implementing a new policy on assistive communication devices. Many "speech generating devices", or SGDs, are now covered. For example, a synthesized speech output device such as Link or LightWriter, is now classified as durable medical equipment and is eligible for Medicare reimbursement. Although personal computers are not eligible under this policy, software programs that enable the computer to provide synthesized speech output are covered. Establishment of the need for a speech generating device and selection of the correct device among the many available is done by a speech-language pathologist. The pathologist will prepare a formal written evaluation, which will serve as the basis for Medicare reimbursement to the provider.

RESOURCES FOR EVALUATING COMMUNICATION DEVICES

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

The Technology Center for Communication at the Rehabilitation Institute of Chicago. This Center is staffed by an augmentative communication specialist and occupational therapists. A physician's referral is needed. Medicare and private insurance often pay for an evaluation (1 to 2 hours, approximate cost was \$500 per hour in the year 2001). A wide array of communication devices is available for demonstration. 312-238-2556.

Woodlake Technologies, Inc., 650 W. Lake St., Suite 320, Chicago, IL 60661. This business is the local distributor for a variety of augmentative communication devices and consults with companies seeking to assist those with special workplace needs. Woodlake Technologies, Inc. can demonstrate dedicated communication devices for those with fairly straightforward needs. 800-253-4391.

LOCAL DISTRIBUTORS AND COMMUNICATION-RELATED INFORMATION WEBSITES

Assistive Technology, Inc.
Chestnut Hill, MA
800-793-9227
www.assistivetech.com

ASYST Co.
Indian Creek, IL 60061
888-779-9998
Fax: 847-816-8581
www.communimate.com

Communication Independence for the Neurologically Impaired (CINI)
www.cini.org.

This is an excellent site with information covering the many communication devices for ALS patients.

Crestwood Company
Milwaukee, WI
414-352-5678
www.communicationaids.com

Enkidu Research
Lockport, NY
www.enkidu.net

Great Talking Box
San Jose, CA
www.greattalkingbox.com

Les Turner ALS Foundation
8142 N. Lawndale
Skokie, IL 60076
847-679-3311
www.lesturnerals.org

Sentient Systems/Dynavox
Pittsburgh, PA 15203
www.sentient-sys.com

Woodlake Technologies, Inc.
650 W. Lake St., Suite. 320
Chicago, IL 60661
800-253-4391
www.woodlaketec.com

Zygo Industries, Inc.
Portland, OR
800-234-6006
www.zygo-usa.com