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 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 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 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 clients in adapting to alternate forms of communication if necessary.

Tips for Maximizing the Communication Environment

1. **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.
2. **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.
3. **Get the listener's attention before speaking.** Agree on a special signal the individual 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.

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- 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 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.
- Use non-verbal strategies to add to your speech.

ALS communication specialists generally advise against rigorous, traditional exercises normally designed to strengthen weak or uncoordinated muscles, particularly when there are detectable speech disturbances. 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 by 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. Other information can be obtained from www.att.com/relay.
- **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.

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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 also have excess nasality during speech. It is not appropriate for those with rapid progression of speech or weakness of the speech muscles, such as the tongue.

- **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, often called speech generating devices or SGDs. This market changes regularly. It is best to consult with a speech-language pathologist familiar with augmentative devices when considering this type of system.

INPUT METHODS FOR COMMUNICATION DEVICES

Direct Selection

Direct selection is a method where the user makes direct contact with the device, such as typing or touching a computer screen. It is the most efficient method but requires good dexterity of the upper extremities.

Scanning

Scanning is a method by which individuals 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 person 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, the "target," 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.

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

ABCDEFG
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.

Eye gaze systems

Devices can also be accessed by eye gaze, which involves directing one's gaze to an on-screen keyboard and "dwelling" on the desired letter. The "dwell" feature then selects the target to the text box. This selection method is needed when other body movements are not possible.

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.

ABCD
EFGH
IJKLMN
OPQURST
UVWXYZ

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.

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- **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.

COMMONLY 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 several 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.

- The patient must have an evaluation from the Lois Insolia ALS Center Speech-Language Pathologist.
- ONLY patients of the Center are eligible for devices from the communication bank. A leasing agreement in the amount of $10 -25 per month (depending on the device) 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 PALS' communication needs individually.

The following are SGDs that are frequently recommended and used by PALS. It is not an exhaustive or complete listing, as new products often come on the market.

Devices that Require Direct Selection via Typing

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

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Crespeaker*** (Crestwood Co.): about $400. Small, portable device; male voice; optional external speaker ($30); English/Spanish.

LightWRITER*** (Zygo Industries; Woodlake Technoligies, Inc.): about $5000 - $6000. Medium sized, lightweight and portable; dual display; DEKtalk speech; memory storage; abbreviation expansion.

Devices that Move from Direct Selection-Typing to Scanning

LightWRITER-SL87***: same features as above, with scanning module integrated into system.

DynaWrite (DynaVox Technologies): about $4,300. Small, portable, "type and talk" system. Voice output choices of DEKTalk or VeriVox® programs. Can move to scanning with additional cost of switches.

LinkPLUS (Assistive Technology, Inc.; Woodlake Technologies, Inc.): about $2,500 plus accessories. Medium sized (12 in. x 9 in.), lightweight (2.2 lbs.), portable device; DEKtalk speech; word prediction built-in telephone/onscreen dialer.

Polyana 3™ with Persona (Zygo Industries, Woodlake Technologies, Inc.): about $ 3,500 plus accessories. Small and portable; Access via typing, touch screen or switch scanning; DECtalk speech; modem for e-mail and internet access.

Portable IMPACT (DynaVox Systems; Woodlake Technologies, 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 or other input method

CommuniMate or ASYST 3000*** (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 on loan through the Les Turner ALS Foundation. (see above criteria). Steve Wells, President of the ASYST Company, has been a provider of services for the Les Turner ALS Foundation for more than 20 years. He provides in-home installation of equipment and training for PALS and their family members. Prices range for purchase from $4,000-$6,000.

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ERICA (Eye Response Technology) and Eye Gaze (LC Technologies): are systems that are accessed using an individual's eyes to perform computer tasks such as communication output, computer access capabilities and environmental controls. A dedicated ERICA Communication System provides only for communication output. Costs range from $7,000+ to $15,000).

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.

There are a number of companies that sell various types of software to those with special needs: Qualilife (www.qualilife.com), Gus Communications (www.gusinc.com). These markets also change regularly so an all inclusive list is not possible.

MEDICARE COVERAGE

Medicare's policy on funding assistive communication devices has been in place since 2001. Many "speech generating devices," or SGDs, are now covered. For example, a synthesized SGD such as LightWriter or DynaWrite, is eligible for Medicare reimbursement. Personal computers are only eligible under this policy if fully "dedicated" to speech communication

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needs. Many companies have products which comply with Medicare guidelines. Computer software that enables a laptop computer, desktop computer or PDA to function as an SGD is covered as an SGD; however, installation of the program or technical support are not separately reimbursable.

Establishment of the need for the SGD and selection of the correct device among the many available is required and is completed by a speech-language pathologist. The SLP will prepare a formal written evaluation, which will serve as the basis for Medicare reimbursement to the provider. Medicare's policy covers 80% of the cost of the device, up to predetermined limits. The remaining 20% will need to come from other sources (secondary insurance, self-pay or grants). Additional information can be found at the AAC-RERC website. http://www.aac-rerc.com - [Medicare Funding of AAC Technology. Information obtained on June 3, 2005. Supported in part by the National Institute on Disability and Rehabilitation Research (NIDRR).]

RESOURCES FOR EVALUATING COMMUNICATION DEVICES

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

The Technology Center for Environment, Computer and 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 2005). 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, 312-655-9200.

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COMMUNICATION-RELATED INFORMATION WEBSITES AND SEVERAL LOCAL DISTRIBUTORS- not all inclusive list

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

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

Crestwood Company
Milwaukee, WI
414 352 5678
communicationaids.com

DynaVox Systems LLC
Lombard, IL 60148
630 426 0626
dynavoxsys.com

EyeGaze System
LC Technologies
www.eyegaze.com

Eye Response Technologies
Charlottesville, VA 22902
434 296 3846
eyeresponse.com

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Woodlake Technologies, Inc.
650 W. Lake St., Suite 320
Chicago, IL 60661
800 253 4391
312 655 9200
woodlaketechnologies.com

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

Chattervox Voice Amplifier can be obtained through Woodlake Technologies or ASYST. Falck Voice Amplifier can be obtained through Woodlake Technologies.

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