Communicating as Speech Declines

Perhaps the most frustrating and emotionally painful aspect of ALS is the ability to communicate. The good news is there is an explosion of new technology in the augmentative communication field. New, more sophisticated hardware and software systems are coming out in droves to allow PALS to continue to communicate. High tech solutions are not the only answer. Low-tech solutions such as alphabet boards, communication charts, lip reading and the use of Morse code are a cost-effective, convenient and effective ways to communicate.

Insurance coverage for augmentative communication equipment runs the gamut from good to bad. The good news is that Medicare recently revised their guidelines so that starting January 2, 2001, augmentative and alternative communication (AAC) devices that generate speech for people with limited vocal ability will be considered durable medical equipment eligible for coverage by Medicare. Although there are still limitations (laptops probably won’t be covered) this is a big step forward since many private insurance carriers base their coverage on Medicare guidelines.

Augmentative communication is an area where consulting a Speech Language Pathologist trained in assessing a patient’s ability and recommending assistive equipment is typically worthwhile. This is a fast changing and complex field. Insurance coverage will also typically require an evaluation and recommendation from both a speech language pathologist and physician before considering equipment for coverage.

Communication Charts and Alphabet Boards

In addition to lip reading, communication charts and alphabet boards are common low tech ways that ALS patients use to communicate. Communication charts are simply charts with numbered lists of commonly used phrases. The patient or character then simply points to a phrase to communicate. A alphabet or letter board is a grid of letters and symbols that one points to in order to communicate. An icon board can be made to symbolize phrases or frequently used words. A product called EyeLink is available from CINI (Communication Independence for the Neurologically Impaired). EyeLink is a clear acrylic alphabet chart that allows you to communicate with just about anyone with minimum level of training for use. The PALS begins to spell out their communication by fixing their eyes on a letter on the chart. The communicating party then just moves the chart around until both have locked gazes.

Speech Synthesis

In the case of bulbar onset, the voice is often one of the first losses experienced by the ALS patient. Many bulbar patients continue to communicate well either by writing, using a keypad device like the Lightwriter from ZYGO Industries or using a laptop computer. Speech synthesis programs are available for laptop computers to give a voice to what is typed. E-triloquist (formerly called SpeakEasy) is a free windows based computer program which provides an electronic voice for those who can not speak. It can record, save and play words or phrases as well as performing free-form text to speech synthesis. CHIPSpeaking and CHIPSpeech are free windows based computer program which provides text-to-speech synthesis and voice recording based on the Microsoft Agent voices. Commercial speech synthesis products are also available from Gus Communications, Words+ and ZYGO Industries.
Voice Recognition Software

Limb onset ALS patients often lose the ability to use their hands while their voice remains strong resulting in difficulty being able to use the computer. An excellent option to solve problems using a computer keyboard is the use of voice recognition programs such as Dragon Dictate and NaturallySpeaking from Dragon Systems or ViaVoice from IBM.

Onscreen Keyboards

Once a patient loses both the ability to speak and to use a keyboard, the use of an onscreen keyboard allows the continued use of the computer for communication. These keyboards can be operated by clicking on letters with a mouse or input device that provides mouse emulation. Many onscreen keyboards also have a scanning feature to enable operation via a single switch. When using the scanning feature, each time you click the switch, the cursor “scans” through the “keyboard” row-by-row, then column-by-column until your desired selection is reached. Many onscreen keyboards also have word prediction to eliminate the need to type entire words. With word prediction, as you enter letters, the program predicts words that begin with the letters you have entered. When you see your word on the list of predicted words, you select it and the word plus a space is placed in your text. Onscreen keyboards are available from Madentec, Origin Instruments, Prentke Romich, Words+ and ZYGO Industries. The Virtual Keyboard by MiloSoft is a free basic on-screen keyboard (no scanning or word prediction) available through the ALS March of Facles website. Also, the Windows ME operating system comes with an onscreen keyboard. Go to Control Panel > Add/Remove Programs > Windows Setup > Accessibility > Details > select Accessibility Tools.

Mouse Emulation

There are two common alternatives that provide mouse emulation: the head controlled mouse and the eye-controlled mouse. Head controlled mouse systems operate by placing an infrared camera on top of the computer display. This camera tracks a small reflective dot worn on the forehead and moves the computer mouse relative to movement of the user’s head. Head controlled mouse systems are available from Eye Control Technologies, Madentec, Origin Instruments, Prentke Romich, Words+ and ZYGO Industries. Eye controlled mouse systems work in a similar manner to head controlled mouse systems but track the movement of the eye rather than the head. The tracking cameras are either mounted on the computer display or built into a lightweight assembly attached to glasses. Eye controlled systems are available from EyeTech Digital Systems, H.K Eyecan and LC Technologies.

Switches

There are a number of innovative switches on the market that can help patients communicate even when most muscle function is gone. Switches are which can be operated by virtually any body part. As long as the patient has one muscle he or she can move, an infrared switch can be hooked up to the muscle allowing access to scanning communication software. Very often the eye muscles remain intact even though the rest of an ALS patient’s body may be paralyzed. Several systems are available which respond to eye blinks or eye movement. Good sources for switches include AbleNet, Access First and Tash in addition to most of the onscreen keyboard vendors mentioned above.