

Chapter 6

Speech & Communication



HOW DOES ALS AFFECT SPEECH?

ALS can lead to weakness in the muscles of articulation — the tongue, the palate and the lips — and in those that provide breath support. These changes will eventually affect your speech.

Your tongue, which is composed of multiple muscles, is primarily responsible for shaping the sounds that you make into words. So, with a weakened tongue,

even if you can produce sound, you may come to find it very difficult to form sounds into words that can be understood.

Your *soft palate* (back part of the roof of the mouth) normally works by elevating and closing off your nasal passage and separating your mouth from your nose. When the palate doesn't elevate, as often occurs in ALS, almost all sound will go up into the nasal cavity and be resonated there. This is called *hypernasality*.

The "energy" for speech and for sound is breath support. When you breathe in and prepare to speak, the vocal cords come together and you build up pressure below them. When you begin to speak, they come apart, allowing the air to rush between them and causing them to vibrate quickly, which generates sound.

As the vocal cords weaken in ALS, they fail to separate, and the voice develops a strained and strangled quality.

As ALS progresses, you may have difficulty getting good, deep breaths, resulting in reduced breath support for speech. Without adequate breath support, you'll be unable to talk very loudly or produce long sentences.

THE ROLE OF THE SPEECH-LANGUAGE PATHOLOGIST

A *speech-language pathologist* (SLP) is a health care professional trained to diagnose and treat disorders of speech. Unlike traditional speech therapy that targets oral exercises, the role of the speech-language pathologist in treating people with ALS is to assist in maintaining functional communication throughout the course of the disease.



An SLP also is educated in the assessment and treatment of swallowing disorders. In this role, the SLP works closely with a dietician to help you reduce the risk of aspiration (getting food and liquid in the lungs) and provides recommendations to ensure that you receive safe and adequate nutritional intake.

SPECIAL NOTE: If you see an SLP who wants to give you exercises to strengthen your tongue and mouth muscles, get another opinion. Some people with ALS have exhausted their weakened muscles with these exercises, without benefit. Speech therapy for ALS *never* focuses on strengthening oral muscles. These exercises may be tiring and actually hasten deterioration. Speech drills can be so fatiguing that you could become too tired to use speech for communication.

One of the most disturbing changes in ALS is the progressive decline in speech intelligibility. An SLP familiar with ALS can provide strategies to improve intelligibility and prevent speech fatigue — such as slowing speech, emphasizing articulation and avoiding competing noise.

If your speech reaches the point that others can no longer understand you, the speech pathologist can help you select and learn to use *augmentative and alternative communication (AAC) devices* (see page 81).

Difficulty with swallowing generally accompanies difficulty with speech. You may find that liquids make you cough or that it's hard to chew food and move it around in your mouth. Mealtimes may become lengthy, and fatigue can reduce your ability to finish a meal. This can result in weight loss and malnutrition.

The SLP and dietician may recommend diet changes such as thickened liquids and softer and/or chopped foods. Initially only some food consistencies are affected, but over time it may become difficult to swallow even pureed foods. At that point, your physician may recommend a feeding tube to reduce the risk of aspiration and the pneumonia that may result. (See “Spotlight on Feeding Tubes,” page 75. Also see the **MDA ALS Caregivers Guide**.)

Easier swallowing methods and other advice from your dietician can guarantee that you get proper nutrition, which will enhance both longevity and your quality of life.

The SLP is a vital member of your ALS health care team. The progressive loss of the ability to communicate with family, friends and medical team can be fright-

ening and isolating. But with the help of a speech pathologist, you'll be able to continue communicating through a variety of means.

ASSISTIVE TECHNOLOGY

Our society's achievements with computers and technology in recent decades has been nothing short of astounding. Fortunately, one especially promising segment of this revolution is *assistive technology*: products, devices and other equipment that are used to maintain, increase or improve the functional capabilities of individuals with disabilities.

This broad definition can apply to even the simplest items you read about in Chapter 1. But in this chapter, we're applying the term *assistive technology* to devices that involve advanced electronic and computer-based technology.

From communication devices that will generate speech to high-tech wheelchairs that can stand or recline, assistive technology can dramatically, positively affect the quality of your everyday life with ALS.

Assistive technology should be an important consideration in your planning and information gathering about ALS, and it's never too early to begin investigating the many choices available. For example, the months it can often take to secure funding for a speech-generating communication aid, plus the time it takes to learn how to use some of these items effectively, mean that anticipating your needs well in advance can

prove the difference between adapting to changes in your condition and experiencing enormous frustration.

This chapter describes assistive technology devices that are available at the time of this printing. With technological advances occurring rapidly, there may be newer, and even more sophisticated, equipment available at the time you're reading this. Your SLP can help you select the best devices for your situation.

AUGMENTATIVE, ALTERNATIVE COMMUNICATION (AAC) DEVICES

Team Up With Experts

Your ability to communicate often has a direct impact on independence. When ALS affects your ability to speak, an *augmentative, alternative communication (AAC) device* can help keep you connected with loved ones and able to maintain a higher quality of life.

Such methods as writing notes, asking a loved one to “interpret” your weakened speech and using letter boards may be suitable for a short time in ALS. But they don't offer the independence, speed and variety in communication that come with technology.

If you're shopping for an AAC device, both health experts and device manufacturers agree that your first step should be to consult with a team of experts. You'll want to consult your SLP, occupa-

tional therapist *and* physical therapist.

Some SLPs advise that your *rate of speech*, rather than intelligibility, is the best indicator of your need for a communication device. The SLP can measure your rate of speech, and better predict when the loss of speech intelligibility will require technological intervention.

Together they'll try out many types of devices with you, help you decide what AAC equipment is most appropriate for your lifestyle, and determine how you can continue to use it as the disease progresses.

SPECIAL NOTE: AAC experts who are knowledgeable about ALS stress the importance of not waiting until your speech is affected to start shopping around for a communication device. Shopping early gives you the advantage of time to explore the many systems, plus a chance to become confident and comfortable with the system you choose before it becomes an essential tool.

In addition, planning can allow you to record many phrases in your own voice for using with communication devices after your speech has degenerated.

Quality AAC machines can cost thousands of dollars, but some are covered by insurance (see “Spotlight on Finding Funding,” page 86). Your health care team will help guide you through the complicated funding and insurance process. They also may have information about equipment loan programs or special funding programs to help defray the costs in your community.

When selecting an AAC device, it's very important that you choose one that can

accommodate switches, which you'll probably need as your ALS progresses. The adaptable device will cost more at first but will save money in the long run because it can be modified with switches instead of having to be replaced several times.

AAC Basics

While there's a rapidly growing number of choices in today's market, most communication devices follow the same basic idea: The user inputs the information about what he or she wants to say, and the machine "speaks" it. Methods of input differ, however, and AAC systems differ by design, size and features.

Today's AAC devices include *dedicated* machines designed solely for generating speech or written text, and *software programs* for personal computers.

Specialized computer software can turn a personal computer into a speech generator. EZ Keys by Words+ is a popular program that offers a variety of access options, input methods (such as using one of the mouse alternatives described on page 84) and keystroke-saving features such as word prediction. Most people install the programs on laptop computers for added portability.

Variety of Systems

Most communication devices are designed to be portable and durable. They're generally the size of a laptop or smaller, with handheld or palmtop devices a recent innovation. But beware: Though handheld or palm computers may be attractive, their small size may soon make them unmanageable to a person with ALS.



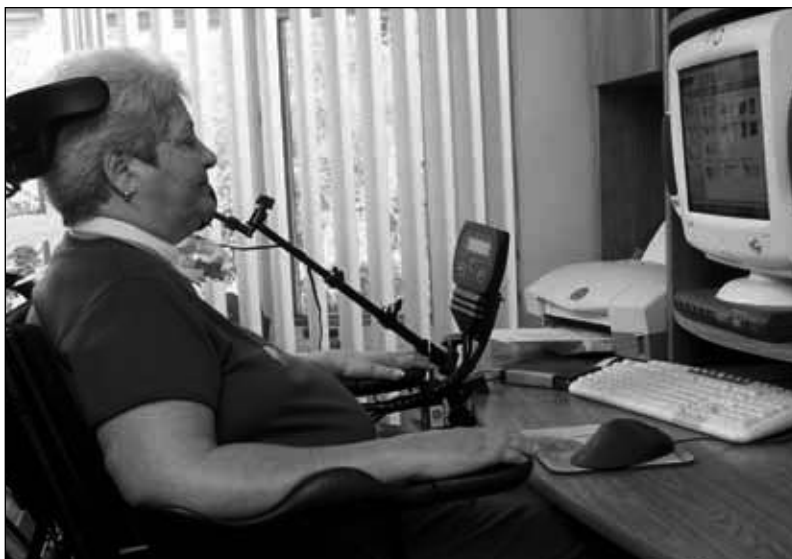
In addition to the type of machine, AAC users also must choose a type of system:

- *symbol-based*, in which the user selects from categories of symbols and pictures to form a sentence
- *text-based*, in which the user inputs text, codes or abbreviations that are converted into speech
- *text-to-speech* machines, in which you can type a sentence and the computer "speaks it."

Switches

These are another important element of AAC and other types of assistive technology. If a user's physical ability changes, often so must the input method for using an AAC machine. For example: If you lose the ability to type on a traditional keyboard or click a mouse, you might still be able to activate a switch by tapping a button or moving a joystick to perform the same functions.





on a screen in sequence, and the user activates the switch when the correct choice is highlighted.

Word Prediction:

Based on one or two letters, the system tries to guess the rest of the word the user is typing, and offers a list of letters that would go with letters already entered.

Switches, too, span a wide range of technology, from simple *plug-in buttons* to high-tech *eye-tracking systems* that follow eye movement to activate a selection. Wireless sensors/switches, which can attach to virtually any part of the body, read electrical impulses from the slightest muscle movements and translate them into mouse clicks.

Keystroke-Saving Features

Encoding:

This is a process of creating codes, abbreviations or labels to represent a letter, item or message. Example: Typing “HH” might stand for “Hello, how are you?” on one brand of machine, or touching one button might do the same on another machine. Most AAC systems use some form of encoding or *abbreviation expansion*.

Scanning:

This method of selecting items in a communication system is usually coupled with switches. Scanning programs highlight rows or sections of choices

COMPUTER ACCESS

Assistive technology isn't confined to generation or replacement of speech. It gives people with limited muscle strength or abilities many options for accessing personal computers and thus e-mail, the Internet and other programs. Here are some basic specialized equipment (hardware) and programs (software) that help make this possible.



Hardware

Mouse Alternatives

Computer users don't always need to control a traditional mouse to move a cursor or input information into a computer. Some alternatives of particular interest to people with ALS include:

Eye Tracking (Eyegaze):

This system tracks eye movements to control a cursor and put it where the user is looking. Signals such as dwelling in one place or blinking activate mouse clicks.

Head Mouse/Tracker:

The user wears a reflective dot sticker on the forehead, and a special mounted camera tracks the dot and controls the cursor according to the user's head movement. This approach is ideal for those who have limited use of their hands, but retain some head and neck control. The user can access all computer functions when used in conjunction with special software and onscreen keyboards.



Trackballs: The user rolls a ball with the palm instead of moving a mouse to control a cursor. Click buttons are usually separate but situated near the ball.

Joysticks:

The user tilts a stick-shaped lever to control a cursor.

Touch Screens:

Touching these plastic screens with a

pointing device or finger can activate the same functions as a mouse.

Keyboard Alternatives

Nontraditional computer keyboards come in many forms.

Ergonomic Keyboards:

These are intended to reduce user fatigue; some are designed to require little strength or dexterity to use.

Keyless Keyboards:

Taking the ergonomic idea even further, for example, the Orbitouch by Keybowl has the user rest his or her hands on two domes, and then slide the domes into different positions to "type" each letter.

Onscreen Keyboards:

Another option is software programs that interface with most software. Some programs are designed to reduce keystrokes, such as StickyKeys, which eliminates the need to press and hold multiple keys simultaneously.

Software

Voice/Speech Recognition

This realm of software enables hands-free use of a personal computer. Users can control many standard computer





functions by voice command, and use dictation as a substitute for typing. These systems require a microphone, with higher-quality microphones usually yielding better accuracy.

Software programs such as Dragon NaturallySpeaking or IBM ViaVoice are appropriate for people with ALS who are unable to type on a computer, but can speak clearly. If possible, this type of technology also should be explored with the assistance of a speech-language pathologist or an occupational therapist.

ENVIRONMENTAL CONTROL UNITS

Another form of assistive technology of interest to people with ALS is the *environmental control unit (ECU)*. These devices allow you to control electrical appliances or systems in your environment. Again, PTs and OTs can help you explore this technology.



ECUs offer a wide variety of options to give you more independence. For exam-



ple, an ECU can be programmed for jobs such as switching channels on the TV set, turning on lights, controlling video or audio systems, adjusting a thermostat or enabling a home security system.

Generally, ECUs can be stand-alone units or software packages for personal computers. Some AAC devices include features that allow you to interface with or control devices around you, such as a telephone or intercom.

Some systems use simple plug-in units with switches, while others employ infrared, wireless or even speech-recognition technology for advanced access. As with many devices, the level of technology will dictate the price, which can range from under \$100 for a one-switch unit to thousands for more complex units.

Spotlight on Finding Funding

Although higher-tech devices often mean higher prices, there are also many options available to help you obtain, learn about and use such technology, despite the cost. In fact, Medicare and many insurance companies cover items such as communication devices; your MDA equipment loan program may have an AAC device you can use.

Check with your insurance company for its guidelines on *medical necessity* for speech devices; they vary from one company to another, and the key to getting coverage may lie in properly completing the paperwork. For instance, if you're unable to speak and a device is necessary to communicate your needs, it gen-

erally will be considered a medical necessity by insurance guidelines.

Manufacturers and vendors of assistive technology equipment also can be useful funding resources. Some have departments or staff members whose job it is to navigate the world of private insurance, Medicare, regulations and paperwork so that you can buy their products. Funding information also may be offered through state vocational rehabilitation departments and local independent living centers.

As noted earlier in this chapter, choosing the most adaptable device will save you money in the long run.