

Bulbar ALS: Unique Management Issues (Part IV)

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“Bulbar ALS” is a term commonly used to refer to those patients in whom ALS affects muscles of speech and swallowing. Bulbar involvement presents its own unique set of problems. These are most commonly the following: 1) difficulty controlling saliva; 2) extreme, uncontrollable laughter or crying, also known as emotional lability; 3) impaired swallowing; 4) impaired speech. In previous newsletters, I discussed items 1 and 2. In today’s column, I would like to discuss impaired speech. My sincere thanks to Jackie Wardle, our augmentative communication specialist, for her help with this column.

Speech is such a natural part of everyday life that most of us take it for granted. Slurred speech, or dysarthria, is usually very mild at first, but becomes gradually and progressively more severe over time. The affected individual eventually must begin repeating him or herself in order to be understood, and may reach the point where speech is so slurred that it is not understandable at all, or is understandable only by the individual’s primary caregiver. The effects of this can be devastating. Well-meaning friends and family members often begin addressing their questions and comments to the caregiver rather than the individual with ALS, expecting that the caregiver will speak for the person with ALS. This can be frustrating and humiliating for the person with ALS, leading to a sense of isolation and powerlessness. Maintenance of the ability to communicate is an important means to maintain self-esteem and improve the quality of life in persons with ALS.

At first some simple adjustments may make speech more easily understood. Some examples of this are speaking very slowly and carefully with exaggerated lip and tongue movements, using as few words as possible, breathing before each word or phrase to add more power to the speech, and using gestures to supplement speech. Eventually, understandable speech may be lost, and the person with ALS may benefit from the use of an augmentative communication device. These are devices which augment, or supplement, the person’s speech and gestures. It is convenient to think of them as being classified in two categories: low-technology devices and high-technology devices.

Low-technology devices are simple, and have been used for many years. If hand function is adequate, the simplest means of augmentative communication is writing, usually on a piece of paper, an erasable board, or a "magic slate." An alphabet board on which the individual with ALS can point to letters or words, or can acknowledge through head or eye movements the correct letter or word while a partner points is another effective means of communication.

High-technology augmentative communication devices are a more recent development. Dedicated communication systems are devices which speak a message using a synthetic voice after the user types it out. Various abbreviations and phrases can be programmed into these to minimize the amount of typing. These are commonly small and highly portable. An example of this is the Link. Desktop and laptop computers can be used as augmentative communication devices. They usually are larger and therefore somewhat less portable than dedicated communication devices, but have broader capabilities as well. Programs are available that permit persons who cannot type or use a standard mouse to still communicate effectively using various types of switches. Some of these require only minimal movement of a finger, eyelid, the head, or other body part, for example. Some respond to eye gaze. These devices also perform the other usual computer functions, such as the ability to access the internet and send e-mail. The right switches can make these functions achievable even by those with very limited mobility.

Of course, as with so many other aspects of care for individuals with ALS, technology alone is not the answer. The key to maximizing communication is a health care professional with expertise in augmentative communication. Such a person can help determine the best balance between portability and function, and can assess the level of technology with which the person with ALS is comfortable. Most multidisciplinary ALS clinics teams have such an individual as an integral member of the team.