

Myths and Misconceptions

MYTH: Exercises to strengthen my tongue, lips, and jaw muscles will improve my speech.

FACT: Exercises only further weaken and fatigue muscles, which may make your speech even worse.

MYTH: If I can no longer speak or write, I will be "locked in" and unable to communicate.

FACT: SLPs, as well as AT specialists, can introduce methods and equipment that will allow you to communicate throughout the course of the disease. For payment coverage of devices, insurance companies and funding organizations require written documents from an SLP that are based on their evaluation of your communication status and needs.

MYTH: I don't plan to use an AAC device, so I really don't need to work with an SLP.

FACT: SLPs enable people with ALS to maximize the effectiveness of the speech that remains, and they provide assistance with eating and swallowing. Even if you choose not to use equipment such as an AAC device, an SLP can still help you and your family with communication strategies and low-tech aids.

MYTH: My arms are too weak to type, so I can't use an AAC device.

FACT: Individuals with little or no movement of their limbs are able to use AAC equipment. Alternative access techniques and technology allow you to create messages using the limited movement of almost any part of the body. The AAC team can help select the appropriate method and teach you how to communicate using the physical ability available.

MYTH: I don't need an SLP because I found a great device on the Internet that the sales representative feels will be perfect for me.

FACT: There are dozens of AAC devices on the market. An SLP is a non-biased professional, trained to evaluate your current needs and anticipate ones you may have in the future. An SLP will provide education about device features, offer equipment demonstrations, and help you select a device that will best support your needs now and in the future. An evaluation by an SLP is required for health insurance payment.

MYTH: I can still understand my loved one's speech and I translate, so we don't need AAC yet.

FACT: The process for obtaining an AAC system should be initiated long before an individual's speech is unintelligible. Your ALS team can help you determine when to begin the process by carefully tracking and evaluating your speech symptoms. Advance time is needed for ordering, learning strategies, and for becoming skilled in how to use the equipment.

MYTH: I have heard that my insurance does not pay for AAC equipment.

FACT: Many insurance companies, including Medicare, cover the cost of AAC devices and alternative access systems. Your ALS team can assist you in fulfilling the requirements for insurance coverage and taking advantage of other funding sources. Your ALS team may have AAC and alternative access equipment available for loan while funding issues are pursued. Your local chapter of The ALS Association is a resource for equipment loans and, in some cases, help with funding.



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The ALS Association is the only national non-profit organization fighting Lou Gehrig's Disease on every front. By leading the way in global research, providing assistance for people with ALS through a nationwide network of chapters, coordinating multidisciplinary care through certified clinical care centers, and fostering government partnerships, The Association builds hope and enhances quality of life while aggressively searching for new treatments and a cure.

THE ALS ASSOCIATION SPEAKS! *Communication and ALS*



A brochure to assist people with amyotrophic lateral sclerosis (ALS) understand their speech difficulties and to describe solutions and resources available to help them communicate.

Speech and ALS

Just as ALS may cause weakness of the arms and legs, it may also cause weakness in areas such as the face, mouth, throat (for swallowing) and the muscles used for breathing. When weakness develops in these areas, activities such as speaking, eating and/or swallowing may become difficult.

You may experience some of the following symptoms:

- WEAKNESS, SLOW MOVEMENTS, STIFFNESS in your lips, tongue, soft palate and jaw.
- WEAKNESS, MUSCLE ATROPHY (wasting) and FASCICULATION (tiny “twitches”) of your lips, tongue and soft palate.
- CHANGES IN VOICE QUALITY—it may be hoarse, breathy, or nasal sounding. Your voice volume may be low, or your rate may be slower and others may have trouble understanding you.
- DIFFICULTY MAKING YOUR SPEECH UNDERSTOOD, especially on the telephone or in noisy places. The technical term for speech problems experienced in ALS is dysarthria.
- DIFFICULTY EATING AND SWALLOWING which is called dysphagia.
- INCREASED DIFFICULTY WITH SPEECH AND SWALLOWING at times of the day when you are tired and/or stressed.

Who can Help?

A speech language pathologist (SLP) is a person trained to help with the speech, communication and swallowing difficulties that accompany ALS. An SLP is certified by the American Speech-Language Hearing Association (ASHA) and may be licensed in your state. The ASHA web site lists SLPs by geographic area (www.ASHA.org). As speech pathology has many sub-specialties, make sure to ask if the professional you are considering has experience with Augmentative and Alternative Communication (AAC) and ALS.

The ALS Association’s chapters and centers have additional qualified ALS team members who can assist you if an SLP is unavailable in your area. These team members may include a nurse, social worker, assistive technology (AT) specialist or other healthcare professional.

While you may be tempted to “do it yourself” using the web and other resources only to find communication solutions, with the help of trained professionals who know the latest devices, instructional aids, resources and ways to personalize your communication strategies, you will be better prepared to meet the communication challenges that ALS can present.

The ALS Association offers a consultation program that can assist you in finding local resources and answer questions about technology and funding of devices. Contact Alisa Brownlee at abrownlee@alsa-national.org

What is AAC?

Augmentative Alternative Communication (AAC) refers to a system used either to augment existing speech, or to serve as an alternative when there is no speech. There is a misconception that AAC means a “computerized talking device.” AAC actually refers to everything that can be used to make communication easier for a person who has speech difficulties.

An individual may use several different ways to communicate during the day. For example, a person may use a computer for e-mail, a communication device while talking with visitors or on the telephone, an alphabet/word board with a laser pointer for informal conversations, and a system of gestures and educated guesses. Different strategies work in different situations.

Your needs for an AAC system will change over time, as speech and physical abilities change. The ALS team may refer you to an SLP to work together throughout the course of these changes, monitoring abilities to ensure that you can communicate what you want, when you want.

COMMUNICATION STRATEGIES

No-Tech Strategies

- Gestures or sign language
- Talking slowly
- Exaggerating your movements
- Conserving your energy

Low-Tech Strategies

- Communication boards
- Laser light pointers on alphabet boards
- Writing – notebooks, tablets, dry erase boards

High-Tech Strategies

- Computers
- AAC Devices
- iPhone
- iPad
- iTouch

Internet Resources

- www.aac institute.org
- www.aac-lerc.org
- www.atia.org
- www.abledata.com
- www.alsa.org
- www.ASHA.org
- www.cini.org
- www.resna.org
- www.usaac.org

FOCUS ON COMMUNICATION

Your communication team offers people with ALS and caregivers many communication strategies. Assistance in choosing strategies that result in the most effective communication is widely available.

Use every strategy possible to communicate!

There can be more than one “right” way.