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

FACT: AAC devices can be used by individuals with little or no movement of their limbs. 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.
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
- iPad
- iPhone
- iTouch

**Internet Resources**
- www.aacinstitute.org
- www.aac-rerc.org
- www.atia.org
- www.abledata.com
- www.abledata.com
- www.resna.org
- www.ussaac.org
- www.alsa.org
- www.ASHA.org
- www.cini.org
- www.ussaac.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.*