Suggestions and Information about Speech Changes & Augmentative Alternative Communication (AAC)

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Speech Changes in ALS

Changes in speech are common with ALS and progress over time. Learning about and implementing timely strategies and proactive steps will enable you to maintain optimal communication. Beginning work with a speech therapist (i.e. speech language pathologist or SLP) familiar with ALS at the earliest sign of speech or voice changes, and even prior to changes, can be invaluable. In this article we look at what causes speech and voice changes and the important steps to take at various stages of ALS to insure you can communicate effectively.

ALS leads to speech problems when it attacks bulbar neurons. These are the nerve cells responsible for bringing messages from the lower parts of the brain (bulbar region) to the muscles that move the lips, tongue, soft palate (back of roof of mouth), jaw, and vocal folds (voice box). As nerves are lost to the disease, the muscles they control become weak and tight. This causes dysarthria – the term used to describe slow, effortful, slurred speech, and breathy or hoarse voice. Weakening lung muscles affect speech as well. Speaking may make you tired, especially later in the day. You may find yourself speaking in shorter sentences and that projecting your voice is difficult.

There is an important distinction between the dysarthria associated with ALS and the dysarthrias resulting from other conditions like a stroke. In ALS the muscles that are receiving signals from the brain must compensate for the muscles that are already weak. This means the functional muscles are doing extra work all the time to compensate and therefore, require more frequent and extended rest. In fact, rest can often help temporarily improve speech. Therapeutic oral exercises designed to strengthen muscles for people with other forms of dysarthria have not been demonstrated to improve speech for people with ALS. The movements required for speaking provide ample exercise. Stretch and massage may be recommended to reduce tightness or maintain range of movement.
Timely Interventions

I. Prior to or at the First Sign of Speech Change:

Prior to or at the first sign of speech changes, two important steps can be taken to prepare.

First, have a speech therapist measure your speech rate. This is an important baseline number that assists in determining timing for interventions.

Second, begin Message and Voice Banking so that your own voice can be used in a speech generating device (SGD) or text-to-speech (TTS) app if ever required. More information on SGDs and TTS apps is provided later in this article.

Message Banking is a process of recording phrases and expressions that are meaningful to you and those you love. Recording words of affection, your own quintessential expressions, and phrases that you often repeat, like greetings, are especially important. Banked messages preserve your cadence and unique delivery of each expression. Examples of phrases I often recommend include, “How are you doing?”, “It’s great to see you.”, “I use this device to speak but my thinking and hearing are fine. Please speak directly to me.”, “Give me a break.”, “Thanks for everything!”, “Hold on! I want to add something.”, etc. Speech therapists can assist you with lists of popular messages but the best phrase ideas often come from the people who know you best.

The Voice Banking process creates a custom synthesized voice for you based on samples of your speech. There are different programs for Voice Banking that range in cost, time expenditure, and clarity of speech required.

Your speech therapist can make recommendations for Message and Voice Banking programs and apps. Scheduling an appointment or two with a speech therapist to provide assistance with Message and Voice banking can be a great way to get started!

II. When Changes in Speech Begin to Cause Challenges with Communication:

At the point at which speech changes can be readily detected it is vital that you meet with a speech therapist. The therapist will document your speech rate and listen to your speech characteristics. Together you and your speech therapist will
choose the best strategies to help you and your communication partners enjoy improved and less frustrating communication. Oral motor exercises are not recommended for speech changes resulting from ALS but there are many strategies that can help including the following:

1. Be certain partners are looking at your face when you speak. Lip reading and other facial and gestural cues add immensely to a listener’s ability to understand. You may experience more success communicating in groups of 3 or less friends at a table as they each can see your face clearly.
2. Be aware of your fatigue level which directly impacts your speech. Plan phone conversations or gatherings for your high energy times and allow for breaks.
3. Avoid noisy or dimly lit rooms for important or extended conversations.
4. Slow down your speech and exaggerate the sounds, especially at the ends of words where they are more likely to be dropped.
5. Alert your partner if you are shifting topics and name the new topic. Distorted speech is much easier to understand once the context is established.
6. If your speech is slow, conversations may move too quickly for you to fully participate. Develop a clear, turn-taking signal or gesture that lets listeners know when you have something to add.
7. Meals are often a valuable time for socializing. If combining eating and speaking becomes challenging, consider eating and drinking prior to social gatherings. With a satiated appetite, you can focus on enjoying the company. You may want to order something small and easy-to-eat (e.g. a thick soup, ice cream, cheese cake) just to nibble on.
8. Teach frequent communication partners who occasionally don’t understand some of your words to repeat back any part of a sentence that they DID understand rather than saying, “What?”. They can substitute the word “blank” for the word they missed. Then you simply repeat back the word or words in question rather than saying the whole sentence thus saving you energy and frustration.
9. If you have repeated a word two times and it is still not understood, consider spelling it aloud or using your finger to spell on your palm or on a table. Often just providing the first letter of the word in question is enough to help others.
10. If your speech is clear but volume has decreased, ask your speech therapist about a light, wearable voice amplifier and hands-free microphone. These tools can significantly improve people’s ability to understand you, reduce the effort required to project your voice and conserve your energy so speech lasts throughout the day.
11. If excess saliva is interfering with your speech, consult with your doctor who may prescribe a portable suction machine, similar to what dentists use, and/or a drying medication or treatment.
12. If the primary factor distorting your speech is a nasal quality, your speech therapist may suggest a removable, palatal lift appliance or other options to reduce the excessive passage of sound through your nose.
13. If a communication partner has an uncorrected hearing loss, encourage them to seek services. A hearing aid may prove helpful.
14. **Voice Banking** should be considered even if your speech is slightly slurred, as long as you have the energy for the process.

15. **Message Banking** requires less energy and speech precision than Voice Banking, and is worth doing even when speech has changed quite a bit, as long as your words are recognizable.

16. Consider customizing your own list of helpful communication strategies to share with frequent communication partners. It can be distributed directly, via emails or through social media. Don’t forget to explain your energy conservation needs including preferred communication times for calls and limits for visits.

A speech therapist will have other strategies to help with challenges like phone communication, emergency alerting systems for times when you are home alone, and tools for signaling to others within the home if you have a need.

At the point when speech is beginning to require repetitions or your speech rate slows significantly a speech therapist will often recommend an evaluation for **Augmentative Alternative Communication (AAC)**. A proactive approach to AAC involves obtaining and customizing the components of a complete AAC system prior to a time when you may need to rely on it for communication.

### III. When Speech Doesn’t Meet All Communication Needs Throughout the Day:

Your ability to communicate at all times is vital and must be maintained even when speech alone is not sufficient. **Augmentative Alternative Communication (AAC)** tools and strategies are available to help. Three primary AAC tools are:

1. **Speech Generating Devices** or **Text-To-Speech Apps**
2. **Low-Tech** or **Rapid Access Communication Methods**
3. **Alternative Access Methods**

A speech therapist specializing in AAC will help you review options, trial equipment, and tailor a customized and comprehensive solution for you.

**Speech Generating Devices (SGDs)** and off-the-shelf tablets equipped with **text-to-speech (TTS)** apps provide a means to produce voiced speech. Voiced speech enables you to be part of a conversation, to get people's attention, talk on the phone, speak with young children, and many other everyday needs. There are numerous factors that go into selecting an SGD or TTS app that best meets your current and future needs. Speech therapists can assist with insurance and funding choices and make sure you have the needed accessories (e.g. mounting and alternative access equipment) to make the system work optimally for you. A speech therapist can also assist you in installing banked message or personal, synthesized voice you created into the SGD or TTS app.

**Low-Tech/No Tech Communication** is sometimes called *rapid access communication*. It involves using simple or no equipment to convey messages and is an essential part of a
complete communication system. Low-tech communication systems, like paper communication boards, are an essential backup to your high-tech speech generating device. Many people find a low-tech/no-tech AAC system to be preferable in some settings and situations. Writing is the most familiar low-tech communication method. If you cannot hold a pen or are limited to only movement of the eyes, there are other easy and portable low-tech solutions. The primary difference between high-tech and low-tech AAC systems is there is no voice produced by low-tech AAC. A partner is required to speak aloud the letters, words, or phrases you write or select from a board.

**Alternative Access** refers to the tools and strategies that enable people with limited hand or limb movement to continue to use their SGDs, tablets, alerting call chimes, and low-tech communication systems. Alternative access is vital for people with ALS who may lose standard ways of representing their ideas like handwriting or keyboard typing. Some simple assistive technology modifications include:

- using a thick barreled pen if grip is reduced
- increasing the cursor speed of a mouse so less movement is required
- eliminating the need to double click on items to select them

Many people with ALS find using a mouse with an onscreen keyboard rather than touch typing can enable them to maintain use of their computer, tablet or SGD. For those with very weak or no arm movement, alternative access equipment can enable a person to operate an SGD or tablet with head, foot or eye movement.

### 7 Vital Communication Competencies & Partnering with your Speech Therapist

As your abilities change you will partner with your speech therapist to maintain or improve your communication. A speech therapist will make sure you have the tools and training to achieve each of these 7 **communication competencies** throughout the progression of ALS. It is essential though that you understand the abilities you can expect to maintain and alert your therapist when updates in your system are needed.

1. I can alert people in other rooms or outside the home when I have a need or emergency.
2. My communication partners and I can use communication strategies that improve communication speed and success and reduce fatigue (whether using speech or AAC).
3. I can use a low-tech or rapid access communication system.
4. I can produce voiced messages via speech, SGD, or TTS app.
5. I can communicate with people not in my immediate environment (email, text, phone, social media, etc.)
6. My communication partners and I can independently set up, customize, and use all of the elements of my communication system.
7. I can describe a pro-active strategy designed to prepare for typical changes in speech and/or computer access that I may experience.

Adapted from the **ALS Functional Communication Scale**, Roman 2014

*The ALS Association thanks and acknowledges Amy Roman, MS, CCC-SLP, for sharing her time and expertise on this factsheet.*