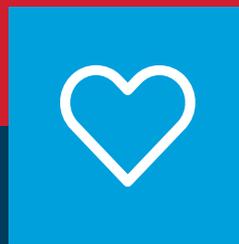


Changes in Speech and Communication Solutions



LIVING WITH ALS
RESOURCE GUIDE



Changes in Speech and Communication Solutions

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Table of Contents

Introduction	4
Communication Support Partners	5
Psychological Impact Of Loss Of Communication	8
Planning in Advance	10
What Can You Do If Your Speech Sounds Slurred?	12
Tips for Speaking Difficulties	14
Using the Telephone	16
Communication Devices And Computer Access	18
What Types of Aids Are Available to Help You Access Computers?	27
The Role of the Family Caregiver	32
Summary Statement	33
Bibliography	34

A NOTE TO THE READER: The ALS Association has developed the *Living with ALS* resource guides for informational and educational purposes only. The information contained in these guides is not intended to replace personalized medical assessment and management of ALS. Your doctor and other qualified health care providers must be consulted before beginning any treatment.



Introduction

Expressing needs, feelings, ideas, preferences and opinions allows people to control and modify their environment. Changes in speech can have a definite impact on everyday expressions, from saying “Hello” to asking for a doctor’s appointment.

How well you speak is affected by the strength and coordination of your breath, vocal cords, tongue, lips and jaw. ALS can alter the muscle control of the physical aspects of speech, thus presenting various challenges to communicating.

While the progression of speech disturbance varies in each person with ALS, most people will experience a significant communication disorder at some point during the disease. You are encouraged to adapt to ALS continually to meet the demands of work, home and other needs.

With perseverance, ingenuity, technical assistance and support from others, you can continue to be an active participant in communication. Staying motivated and interested can help you to identify strategies to improve your communication in the face of changes in speech ability.

What we will cover in this resource guide:

- Your communication support team
- Psychological impact of loss of communication
- Planning in advance
- What you can do if your speech is slurred
- Tips for speaking and listening difficulties
- Using the telephone
- Communication devices and computer access aids

Communication Support Partners



Speaking partners, who include spouses, companions, roommates, children, colleagues and healthcare providers, can supply moral support and help you in being understood.

Speech Language Pathologists (SLPs) are educated and trained to plan, direct and conduct programs to compensate for your swallowing and speaking difficulties. Those who are specially trained in ALS impairments and have experience

working with adults and Alternative and Augmentative Communication (AAC)—assistive devices that help express thoughts, needs, wants and ideas for people unable to communicate using oral speech—can suggest strategies that are the most effective.

These experts, along with Occupational Therapists (OTs), assistive technology professionals (ATP's) and computer specialists who work with adaptive devices, can help you choose tools for augmentative communication. This equipment can be as simple as an alphabet board or as advanced as a computer with special accessories to compensate for poor hand control or the absence of hand function. Other people living with ALS can offer solutions and strategies that have been successful as well.

Sometimes you or your family members may need to ask your physician to refer you to an SLP or ATP to learn about alternative communication strategies. These assessments can be done via telehealth or in person. Doctors and other healthcare providers may not adequately address these issues because they are concerned with so many other aspects of your care.

Communication, although vital to your well being, often gets lost among more medically pressing issues; however, your emotional state is dependent on how well you can communicate with others. Prevention of social isolation is paramount in maintaining a healthy psychological adjustment.

Helpful Hands, Helpful Voices

Your family and friends can help you compensate for your speaking difficulty. They can explain to others that you may need additional time to respond, but that you understand everything and should be included in conversations.

Moreover, your friends can emphasize to your listeners the importance of being straightforward and sincere.

Because your regular speaking partners are more familiar with your speech, they may be able to translate for you. However, keep in mind that even spouses and close friends may have difficulty understanding your speech. Try to be patient and not become upset as this will further impair your speech. If you are using a speech generating device, arrange for someone to maintain and transport the device. A communication partner who provides moral support and serves as your advocate

is extremely valuable in situations with high communicative demands, such as a doctor's appointment, benefits office or financial institution.



Contributed by a person living with ALS, you may want to consider establishing these or similar ground rules for family and friends, or when attending social events:

“Helpful Hints for Talking to Me”

- I may speak in the regular way sometimes and use alternate strategies such as writing or a speech synthesizer when I am able.
- Understand that my speech is slow and using alternative strategies is even slower.
- I can't control my muscles for speech so sometimes my voice or the voice synthesizer can sound terse and detached, but that doesn't reflect what's going on inside me.
- Yes/no questions are easier for me to answer than open ended ones.
- In regular speech, we talk over each other constantly and that's natural and OK! But, I speak very slowly and quietly and it takes much effort. So let me finish my thought before you say anything.
- If I ask a question or say something that needs to be responded to, please wait for me to respond before changing the subject. I have to conserve my energy and repeating things creates additional fatigue.
- If you do not understand what I'm saying, please ask for clarification. (Don't just smile and nod if you do not understand.)
- Assume that I literally mean everything I say. I have to be economical in speaking and in using the voice synthesizer, and I try not to say things that I don't mean exactly as said.
- Don't watch me type my responses and try to guess what I'm saying while I am typing; wait for me to complete my thoughts. Also, I need practice in becoming proficient with the speech synthesizer, so please be patient!
- I'm OK with one sided conversations if you are. Feel free to talk with me about anything, and I will nod my head, smile or frown to let you know I'm engaged.
- If I want to enter a conversation at some point I may wave my arm or rap on the table to let you know.

To be an effective speaking partner for a person with ALS:

- Check your hearing. If you have hearing loss, recognize that it will be more challenging to understand slurred speech, so please use a hearing aid or amplifier.
- Give the person your full attention and concentrate on their face before you start listening. It is easier to understand the person when it is quiet and you can see their face.
- Be honest. If you did not understand, do not pretend you did.
- Give feedback about what you did hear correctly so that the person can fill in the missing word(s); for example, "You want to go for a drive, but I missed where."
- Have the speaker write words that are not clear, if they are able.
- Remind them to state when the topic is changing so you will know the context.

Psychological Impact Of Loss Of Communication

ALS is often described as a disease of losses, most obviously loss of independence. Some are losses of function, of the ability to walk, eat and breathe. These losses can occur on a daily basis and demand constant change on the part of the person with ALS and the caregiver. A person diagnosed with ALS is also going through catastrophic psychological losses: of dreams, of the expected future, of life itself. These can lead to deep grieving (Luterman, 2001). Dealing with multiple losses can interfere with making decisions or accepting changes.

Among the many losses of ALS is the loss of communication. Under any circumstance, loss or impairment of communication is deeply personal. An acquired communication disorder can devastate the family unit as family roles change and the emotional balance of the family unit is upset (Hinckley, 2008). When communication loss occurs as death approaches and the disease progresses, a critical tool for relationships and for conveying needs and preferences is disrupted. The artificiality of electronic AAC devices may be seen as a barrier to needed social closeness (Murphy, 2004).

Communication is associated with personhood and identity (Shadden et al., 2009). The loss or anticipated loss of speech and communication can be like the loss of humanity, and having to face this loss when confronted with a terminal illness is even more challenging. How each individual with ALS reacts to the loss of communication will be unique, and may change over time. Those reactions, however, may influence one's decisions about AAC specifically.

All persons with ALS should understand that they may, at some point, become unable to communicate. In some cases, cognitive changes may affect the individual's ability to spell, read and compose messages. Even with simplified wording, pictures and basic communication topics, the person with cognitive decline may not be able to communicate effectively or reliably, and therefore, may not be able to participate in their care or make decisions regarding long term care or life support.

ALS can also lead to "Locked In Syndrome" (LIS), which is defined as the absence of all other movement except for eye movement. In rare cases, one may become completely and totally paralyzed and unable to control any movement, including eye movement, which is known as "Totally Locked in Syndrome" (TLS). While difficult, some individuals may say that they would not consider living worthwhile if they should lose the ability to communicate. Therefore, it is important when you have ALS to consider advanced care planning and establish advance directives as to your "stopping point" when you would like all treatment withdrawn. Do this while you can still communicate your wishes to your family members or designated power of attorney.

Because ALS is progressive, people with ALS may need assistance looking into the future to consider what communication equipment they may need in a few weeks or months.

Among the many losses of ALS is the loss of communication. Under any circumstance, loss or impairment of communication is deeply personal.

Planning in Advance

Planning in advance for speaking difficulties will make it easier for you to adjust to the changes that occur. Research shows that people who start using and exploring speech devices before they actually need them experience higher rates of success in using a speech generating device.

If your speech is starting to become slurred, begin to use different types of technology or modalities depending on the communication situation and try to be open to alternative ways to communicate.

If your speech is starting to become slurred, begin to use different types of technology or modalities depending on the communication situation and try to be open to alternative ways to communicate. For example, you might consider a writing tablet or LCD tablet to supplement your communication when talking with someone face to face, whereas you might opt to use texting on a smartphone to communicate with someone at a distance instead of talking on the phone. Good preparation allows you to become skilled and comfortable with strategies and devices before you need them as your primary means of communication.

Some people may choose to “bank” their speech with a software program using a computer application or tape recorder for future use by recording certain words, phrases or statements while speech is still clear. This is called message banking and messages you save in an electronic sound file can be used in the future on a tablet, laptop and some communication devices.

Banked messages will only be able to reproduce what you have recorded, in other words, if you record, “I need my glasses,” your recorded voice will only utter that sentence in the same exact intonation and sound every time. With this method, only recorded messages will use the person’s natural voice. It does not allow you to

have free thought, meaning the process of typing a new message and using the device to produce audible messages in your own voice. Newly created messages will use the artificial voice of the speech generating device (i.e., synthesized speech).

There are various programs available for voice banking listed on the ALS Association website: <https://www.als.org/navigating-als/resources/fyi-guide-voice-banking-services>.

You will typically need a Windows computer with a wired, USB, noise canceling microphone to be able to make the recordings. Check with your local ALS Association office to see if they have a specialty microphone you can borrow as you will only need it to record the sound files to create your unique voice. It is important to begin this process as early as possible in your diagnosis and best before any noticeable speech changes. Difficulties in producing speech sounds and maintaining a consistent rate of speech and breath support for speaking up to 10 words in one breath may inhibit the ability to participate in this program and to create a unique synthetic voice for later use in a speech generating device. New advances in applications and technology have greatly reduced the number of phrases you will need to record to create a unique voice; however, the more samples you provide in recorded phrases often improves the quality of the unique voice. If you already have significant speech changes, you may opt to have a voice proxy record the phrases and messages for you, especially if you have a family member whose voice sounds like yours.

Trying to think of messages that you may want to have in your own voice can be an overwhelming task. You can start by thinking of phrases or standard sayings that are your "trademark" or that would convey only a certain meaning in your own way, or by using family



members' nicknames or very touching personal phrases such as, "I love you." There are documents available through your SLP, local ALS Association care team or internet sites that also provide suggestions and guidance regarding message banking.

This choice is very personal to you and it is OK if you don't want to have your voice preserved. Some people don't like the sound of their voice and feel even more self-conscious when that voice has changed and no longer sounds like it did prior to being diagnosed with ALS. Think through your feelings about having a voice that is still "yours" as compared to a computerized synthetic voice and make the choice that feels right to you.

What Can You Do If Your Speech Sounds Slurred?

Slurred speech is a symptom of dysarthria, a neurologically based speech disorder that results from weakness or spasticity of the lips, tongue, soft palate, jaw, and respiratory muscles. Because ALS is a progressive disorder, the slurred speech may eventually become severe, particularly if it is present early in the disease. Due to the nature of the diagnosis, it is not always possible to achieve improvements in voice production or speech intelligibility through standard speech therapy intervention. Research studies have published conflicting evidence regarding the use of oral motor exercise and long term benefits in progressive neurologic diseases. Some people may have some positive gains while others may find these exercises increase fatigue and worsen vocal quality and speech intelligibility. This is due to the extreme variability in people living with ALS. You should consult with your ALS neurologist and therapy team to talk about specific strategies that might be beneficial to your specific form of ALS.

The term that is used to describe these speech and swallowing changes is bulbar symptoms, which refers to the area of the brain that controls the muscle movements for speech and swallowing, as well as the ability to maintain an open upper airway and the ability to clear away saliva. Bulbar symptoms involve the

part of the brain known as the medulla oblongata (the “bulb like” structure) at the top of the spinal column. Essentially, the brain is not able to send signals to the muscles in the tongue, lips, mouth and throat. Over time, the muscles become weak and nonfunctional. In order to adjust to these weakened muscles in the mouth, you can make changes in how, where and when you speak and what you do to be understood.



To be an effective speaker

with ALS:

In general, it will be easier for people to understand you if you talk while facing your listener in a place that is quiet and well lit. This arrangement helps listeners hear you more clearly as well as see your mouth and facial expressions. Recognize that your speech may be clear in one situation but not in others. For example, when you are tired, emotionally stressed or when there is background noise, your speech may be more difficult to understand.

- Try getting your listener’s attention before you start. Say the person’s name or give a tap on the shoulder to provide a cue so they are ready to pay close attention.
- State your topic first in order to help listeners understand the meaning of what you are saying, even if they do not catch every word. If you change the topic, alert your listener. Sometimes your speech may be more easily understood if you write the topic or keywords, such as “medicine.”
- Ask your listeners if they understand you. Sometimes people will pretend to do so because they do not want to embarrass you or themselves. If you are unsure, ask them to repeat or explain what you said. This effort by the speaker generally is a very welcome suggestion for the listener.

- You also should be prepared to shift to writing or texting using a smartphone if you are able or use other communication devices, as needed.

Tips for Speaking Difficulties

The following are some very specific tips that can help you communicate your message:

- Take a breath before each phrase or set of words because breath is the power behind your voice, making your words easier to say and hear.
- Convey your message in as few words as possible, realizing that those at the end of a sentence are lost more easily.
- Speak slowly and carefully; repeat your words if necessary.
- Carefully pronounce all the syllables in words; if you have trouble speaking slowly, tap out each syllable with your finger as you say it. For example, "re...frig...er...a...tor."
- Emphasize the final sounds of each word because slurred speech can omit them. For example, boo"k" or ha"t."
- Say the most important words louder by taking a breath first.
- Use a different word or phrase if the one you tried is not understood, such as "something you read" for "book"; often words that contain b, g, k and p are more difficult to say and understand.
- Try adding facial expressions, hand gestures or pointing.
- A voice amplifier or portable microphone may help make your voice more powerful; a speech pathologist or electronics store clerk can assist you in selecting an appropriate amplifier, but note that as your symptoms change, so will your need for this type of item.

To understand the speaker, the listener should:

Repeat the words they understood so that the speaker can confirm the message. This strategy also helps to reduce the need for repetition, allowing for conservation of energy by reducing the risk of overuse of the muscles for speaking. Typically, the listener may comprehend the first few words, but as the speaker becomes more fatigued, they may be unable to produce the end of the phrases/sentences. Multiple repetitions increase fatigue and may result in the speaker "giving up."

After trying the suggestions mentioned above, you might also want to use writing and spelling to facilitate the communication process.

The following are some helpful tips:

- Write key words on paper to identify the topic.
- Use an alphabet board (described later) or write the alphabet on a 5"x7" index card. Point to the first letter of each word you say.
- If you have repeated the words twice and they still are not clear, spell them on paper. Spelling the letter out loud may not be helpful since so many letters may sound the same when the lips and tongue become weak; it is difficult to hear the differences among "t," "d," "b," "p," etc.

It is never too early to begin to explore alternative communication strategies when you have ALS or when you begin to notice changes in your speech.

Using the Telephone

As your speech abilities decline, talking on the phone may be challenging because you cannot use your face and gestures to assist your speech. As an alternative, you may choose to use other forms of communication such as written methods, electronic email or texting to preserve communication independence. When telephone communication is required, you should consider the use of a text to speech application, speech generating device or an interpreting service such as a relay service.

Here are some practical suggestions to improve your ability to be understood on the phone when using your own voice:

- Right away, tell the listener that you have a speech disorder and that you will repeat a word or phrase if necessary.
- Ask the listener to concentrate on what you are saying and avoid multitasking.
- A voice amplifier/personal portable microphone can increase the loudness of your voice over the phone.
- A speaker phone allows you to talk without using a handheld receiver; it enables you to be part of any conversation because a nearby friend can clarify or repeat what you said without worrying about transferring the receiver.
- TTY (Teletypewriter)/TDD (Telecommunications Device for the Deaf) is a telephone relay system that is available if you cannot use speech to communicate on the phone; it is used by people who can type. The devices transfer your typed conversation to the person on the other end of the phone who has a TTY or to an operator who reads the message to your listener.
- The telephone company often provides customers with assistive communication devices (speaker phones, phones with large numbers on the buttons, voice amplifiers/personal microphones and relay systems) free of charge through its deaf and disabled services. A doctor's signature certifying that you have a speech or motor disability is usually required, but if you are unable to obtain such certification, you can purchase these aids through the telephone company, retail telephone and electronics stores or online internet resources.

Consult with your SLP or local ALS Association care team to see what is offered in your area.

When To Consider Using AAC

The timeline of how long your speech may remain functional varies depending on your symptom onset. For example, those with bulbar onset ALS typically have severely impaired speech even before learning of the diagnosis of ALS. Those with spinal onset ALS may have difficulty with breath support to produce audible speech as well as speaking long sentences or for lengthy conversations without noticing shortness of breath. It is never too early to begin to explore alternative communication strategies when you have ALS or when you begin to notice changes in your speech; however, insurance funding is not typically available for AAC until speech has become moderately or severely impaired, impacted your independent daily communication needs or has been unimproved despite traditional speech and language therapy strategies. Research studies have published guidelines recommending formal AAC assessment and intervention begin when speaking rate has decreased to 125 words per minute or less and speech intelligibility has fallen below 80%. Often there is an urgency at this time to obtain an assessment, develop recommendations and procure insurance funding prior to the need for daily use of AAC. (Yorkston K, Strand E, Miller R, Hillel A, Smith K. Speech deterioration in amyotrophic lateral sclerosis: implications for the timing of intervention. *Journal of Medical Speech Language Pathology*. 1993;1(1):35 to 46. [[Google Scholar](#)])

Remember that insurance funding can often take 8 to 12 weeks or more to receive prior authorization (i.e., approval). There may be additional delays in production resulting in further delayed shipment of the device. Furthermore, you will not be able to move to a nursing home or enroll in hospice services until the device is delivered. Moving to a nursing home facility or enrolling in hospice prior to the actual delivery date will result in denial of payment by your primary insurance. (Exceptions may be if a client qualifies for Medicaid.) Choosing to accept the use of a communication device has been linked to improved connection with loved ones while also reducing caregiver stress. Fried Oken et al. surveyed AAC caregivers. They reported very positive attitudes toward AAC technology. Those with greater AAC technology skills reported greater rewards associated with caregiving. They reported increased perception of social closeness to the individual with ALS and less difficulty in providing care. (Fried Oken M, Fox L, Rau MT, et al. Purposes of AAC device use for persons with ALS as reported by caregivers. *Augmentative and Alternative Communication*. 2006;22(3):209 to 221. [PubMed] [[Google Scholar](#)])

Communication Devices And Computer Access



Assistive Technology is a dynamically changing field with new advances and products being introduced at an astounding rate. With products constantly changing, so is insurance funding. Specific products or insurance information are not listed in this resource guide, but you are urged to visit www.als.org or call your

local ALS Association representative to assist you with the latest technology and funding information available to people with ALS. You can also find many helpful videos about communication issues and ALS on The ALS Association website and YouTube. Many people are visual learners, so these sites help people see the technology that is described in this guide.

Choosing the Right Device

How Do You Choose A Communication Device?

Choosing the right communication device and the most appropriate method to access the device (in the case of poor hand movement) can be challenging because there are many factors to consider. Be aware that your needs may change over time, and to justify the cost of an expensive aid, it should offer access to both direct touchscreen, keyboard, wired/wireless keyboard, mouse and alternative access in the case of poor hand movement.

Communication devices come in many different shapes and sizes. To determine the most appropriate device for you, a communication assessment/evaluation needs to be completed by a licensed SLP.

The assessment/evaluation is usually a covered benefit under your health insurance plan, even if the actual aid is not covered. The AAC specialist you see should perform a careful case history, including questions related to your experience with technology and computers, other types of technology for which the AAC device should be

compatible, the types of activities the device will be used to perform in addition to face to face communication and audible spoken messages such as integration with texting device, email and other forms of communication. Exploring your expectations of the AAC device before you begin equipment trials will help your AAC team match you with an appropriate device. Even with the feature matching, it is recommended that you try several different devices from several vendors. Each vendor has developed eye gaze hardware and software specifically for their devices, and one device may seem like a better fit for your communication needs; therefore, it may not be realistic to think that an evaluation may be completed in one visit. You may need to download free evaluation copies or trial versions of the software to explore their use on your at home computer to be sure that the software is a good match. You may also need to try out the various access methods to be sure your preferred software version will be compatible with use of the eye gaze hardware and that the device is capable of adapting as your disease or skills may change.

Questions to ask before you purchase a communication device:

- Where/when will you use the device?
- Do you want a small portable device that can produce pre programmed phrases and short, typed responses, or a system that allows you to write, store and say anything you choose? Do you need a device to be portable and attached to mobility devices?
- Is it easy to use?
- Is it functional/appropriate for you? How will you use the device if you lose hand function?

- If it malfunctions, can it be repaired quickly, easily and inexpensively? Do you have access to local or online tech support?
- Is there someone who can help you maintain the device, charge batteries, turn it off and on and help with programming?
- What are your budget/funding options?
- Will it adapt to your needs as the disease process continues?

SLPs, OTs and assistive technology and computer specialists can assist you in choosing the appropriate devices. Be sure to see someone who has experience working with people who have ALS because they will be able to explore communication options that are right for you. Trust your intuition; if the person you are working with does not seem familiar or knowledgeable with your problem, seek advice elsewhere. While it is important to consider what your goals are now, you will also need to think about how your disease may progress in the future. A professional with experience in AAC can help you with planning for these changes since insurance will typically only fund one device every five years. Your local ALS Association care team or rehabilitation department at your community medical center can help you find a professional in the area who specializes in assistive communication devices.

What Types of Communication Devices are Available?

Communication devices are referred to as “AAC.” The term “Augmentative/Alternative Communication” (AAC) refers to any mode of communication other than speech but is specifically used for methods to augment (i.e., supplement) or alternate (i.e., replace) a non functioning speech system.

When Medicare began paying for communication devices in 2001, the term “speech generating devices” (the acronym SGD is interchangeable with AAC) was used; however, AAC includes systems such as sign language, symbol or picture boards and electronic devices with synthesized speech, while SGD refers to a device that produces auditory speech output through a (usually) synthetic computer voice. Although the same systems can be used for either augmentative communication or alternative communication, there is a difference between the two. Augmentative systems are used by people who already have some speech but have challenges in getting their message across to their listener. In these cases, the speaker may need

to supplement speech production with non verbal strategies (i.e., gestures, writing, etc.) because they are either unintelligible or have limited abilities to use their speech. In such a case, other modes of communication are used to support or supplement what the person is able to say verbally. Alternative communication is the term used when a person has no speech. The speaker must completely rely on another method to make all their ideas, wants or needs be known.

There are various augmentative communication devices, ranging from the simple alphabet board to more advanced computerized speech systems. Each system may have a role in your communication plan as each device may be used to meet different types of communication situations. For example, in some situations it might be faster to write a few words or phrases on a tablet or LCD board, but if you are riding in a car, your communication partner may not be able to shift attention to read a tablet; therefore, you may need an audible speech output device to communicate while riding in a car. You are encouraged to seek the advice of an SLP in the field of augmentative/alternative communication when choosing your equipment because they can perform a careful evaluation and present a wide range of options. If a specialist is not available, you may want to educate yourself about various vendors and resources. You may view manufacturers' websites, download demonstration versions of software or schedule a home visit to try the systems. You may also want to talk with others who use SGDs to determine why they chose their device, what other options they considered and what they like/dislike about their system. Spend as much time researching this topic as possible to be an educated consumer.

Your local ALS Association care team can assist you in locating resources and qualified professionals.

Although there are many new high-tech speaking alternatives, be prepared to accept some level of frustration. I prefer to head off humiliation by beginning phone conversations with: "I have a breathing/speaking impairment, please be patient—I'm smarter than I sound!"

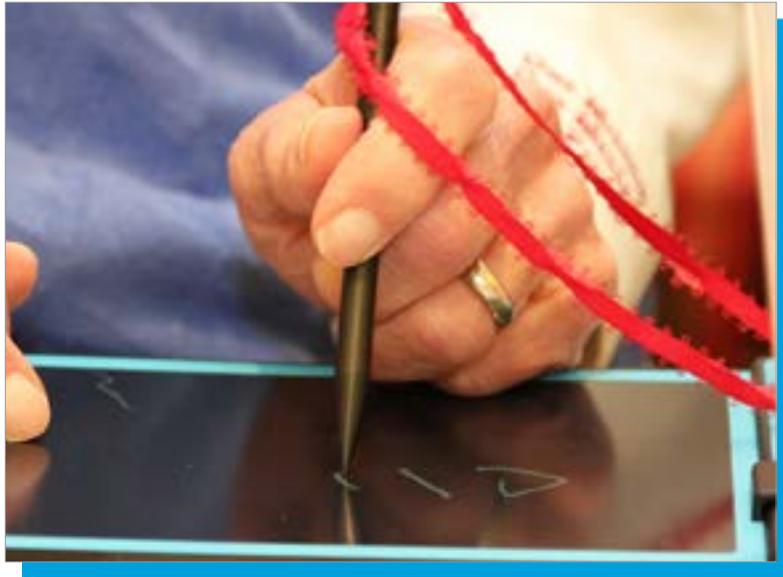
– Daniel T.

What Are Simple Options?

For most people, if you are able to use your hands, writing is the easiest alternative to speaking, and print is usually easier to read than script. Using these methods to communicate can often be nearly as fast as spoken speech.

Writing options include:

- A small notebook. Keep this with you wherever you go so that you are always ready to express yourself.
- Dry erase memo board.
- Electronic LCD writing tablets or writing/drawing apps on the iPhone or iPad.
- Pencils or felt pens. These are often better to use than ball point pens, and thick pens are sometimes easier to grip and control than thin ones.



Alternative Communication Methods

Thinking about AAC as a multimodal communication system can help you understand that we use many different forms of communication each day. These include spoken speech, hand gestures, facial expressions, texting, email and writing to name a few. Likewise, when your speech is affected due to ALS, you'll want to have many tools available to you to meet many different communication needs. For example, when speaking and writing abilities are severely impaired, or when a computer or communication device is not available or practical, alphabet boards (Figure 1) are among the most useful aids. These boards are helpful in any setting because they are portable and can be used effectively with your hands or eyes.

Note: You do not need to be able to use your hands to use a letter or picture board.

For example, a laser pointer attached to a hat or eyeglasses can be used to point to the desired letter, or your communication partner can be taught other ways to use a letter board to maintain communication if you cannot speak or move your hands or head. This strategy, known as partner-assisted scanning, can be used with a little training and practice. While the partner calls out the first letter in each row, you can indicate “yes” when your partner calls out the desired row. Then, your partner points to each letter in the row waiting for a “yes” response to indicate the desired letter. Use a consistent movement to represent “yes,” such as nod or shake your head, look up or down, raise your eyebrows or select any method of communicating your responses that is consistent and reliable. The phrases “yes,” “no,” “maybe,” “I don’t know,” “end of word,” “space,” and “mistake” should be listed on the board as well.

It should be emphasized that having a “yes/no/maybe” communication option is critical in the medical management of ALS. This is the simplest form of communication, yet most people limit the choices to “yes and no” only. If you have asked the question wrong, there is no way for the person with ALS to say “maybe.” Receiving a “maybe” response could indicate the need to ask the question in a different way or to provide other choices. These other choices could be “I don’t know” or even “I don’t care.” While many professionals and communication partners rely on eye blinks for a “yes/no” communication system,

Fortunately, there are many tools and products that can help people overcome communication obstacles, and we have used several of them throughout the years. The simplest and cheapest of the tools we have used and continue to use is Ismail’s spelling chart. It may be low tech, but it sure does get the job done!
– Cheryl T.

1	A	B	C	D	to	for	New word
2	E	F	G	H	the	with	Start again
3	I	J	K	L	M	N	Space
4	O	P	Qu	R	S	T	please / thanks
5	U	V	W	X	Y	Z	.
6	What	When	Who	Why	How	Yes	No

Figure 1: Alphabet board used for non-verbal communication. (A larger one-page size is included at the end of this guide for you to copy and use.)

it should be noted that eye blinks are not often reliable with a person with ALS due to slow, uncoordinated or unreliable blinking. It may be easier to suggest that the person with ALS look at targets—e.g., look right for “yes,” look left for “no” and look up at the ceiling for “maybe/I don’t know.” Once a system is agreed upon, write it down and post it near the person with ALS. For example, John says “yes” by looking to the left, he says “no” by looking to the right and “maybe” by looking up. This ensures that everyone interacting with the person with ALS will know how to communicate with them.

Another simple tool for communication is an alerting system. Buzzers can be easily assembled so you can get someone’s attention. Inexpensive intercom systems used by parents of young children are available so that you can call for someone in another room. Another option could be a remote door chime (i.e., wireless doorbell), which can be purchased at any local home improvement store. These devices may have a range of up to 100 feet. You hold a small transmitter with a button that is depressed when you want to alert someone. The caregiver carries the receiver portion and can be in or outside the house. The remote will chime when the user presses the button. These devices are ideal for those who have hand function but have a weak voice or no voice at all. (Most chimes average \$10 to \$15.)

If there is one piece of equipment I would recommend to others who have lost their ability to speak it would be a smartphone. Then let friends and family know to send texts. Just the ability to communicate with others helps those that become trapped in their own bodies.

– Karen B.

The remote door chimes can also be purchased with switch accessibility. Switch technology can be operated by almost any body part that is able to produce consistent and voluntary movement. Switches come in a variety of shapes and sizes depending on the action used to activate them (such as sip puff, pushing, pulling, pressing, blinking or squeezing). Some switches may only require a light touch and some may be designed to be kicked for people who have weakened or no hand function.

What are the Technology Options?

The advent of smartphones, personal data devices, laptops and tablets has dramatically changed the options for alternative communication systems, especially for those with poor speech skills but intact hand function such as those with bulbar ALS onset.

When Hand Function is Intact...

Text to Speech (TTS) communication applications are available for many formats and may be free or very low cost. These applications (or apps) are added to devices that many people use every day. For example, there is free text to speech software that

As soon as your speech is starting to change, get an iPad and download a speech to text app. You have to be able to communicate. If I didn't have this I would be so frustrated. It has made life so much better for me.

– Janine G.

will turn your existing laptop into a communication device. In about five minutes, people with ALS can begin using their own laptop and verbally communicate with family and friends. In addition, there are apps available for tablets that will enable a person to have verbal output through the tablet. These devices are small and portable and are often implemented seamlessly in activities of daily living. Unfortunately, these devices may or may not be easily adapted to accommodate alternative access methods in the event of loss of hand function.

When Hand Function is Impaired...

When hand skills become impaired so that modifications to direct finger or stylus interaction are no longer feasible, it may become imperative to examine alternative devices such as communication devices that have been specially designed to help people with speech and physical disabilities.



There are businesses that specialize in communication software for various operating systems. Technology is always changing and these companies may come and go; therefore, names of devices and companies are not included in this manual. Be aware that the specialist who works with you may favor a certain device, but it is important that you put forth your preferences.

Your choice depends on many factors:

- System familiarity
- Budget and cost constraints
- System adaptability to changing speech and physical needs

- Chance to explore multiple options

There are always new developments, so it is recommended that you consult with an SLP or technology specialist who is knowledgeable about these systems. Health insurance coverage may exist; therefore, you will need to work with an SLP and your physician to complete the required paperwork for funding. Your local ALS Association care team can assist you in locating resources and qualified professionals.

What Types of Aids Are Available to Help You Access Computers?

If your hands are so weak that you cannot type on a standard keyboard, there are several mechanical aids that can help you access the computer. Keyboards can be made larger or altered so that you can move your fingers across them more easily to identify the button you want. Some software can even speed up your typing by predicting the most commonly used words and by being programmed so that a single key represents an entire word or phrase. Onscreen and popup keyboards, touchscreen and standard mouse devices can all be used and modified to input keystrokes and text.

Headmouse Options

As mentioned briefly above, if you have limitations in your finger or hand movement, modifications can be made so that a keyboard and/or mouse can be easier to use, or alternately, accessible devices may be used to allow computer control with head or eye movements.

These devices are used with special software that provides onscreen/virtual keyboards and/or mouse software that allow text input into any active text field. Head movements are translated into mouse movements and the user can hover the cursor over a target to make a virtual mouse “click” for selection.

Eye Gaze Options

As the disease progresses, many ALS patients require the use of eye tracking for several reasons. First, eye tracking is often the least fatiguing movement for AAC access. Eye gaze is natural, and eye muscles generally do not fatigue with use. Therefore, there are various types of electronic eye gaze options for people with ALS. These systems rely on eye movement to “activate” a letter on a computer screen resulting in the letter being typed in a message field. In order for the system to work reliably, the person with ALS needs to have upward, downward and side to side eye movements. This is used by people when they have little to no muscle movement capabilities. The basic premise is that a Closed Circuit Television (CCTV) camera is placed below a computer monitor. The camera tracks your eye position and eye movement. Special software is loaded into the computer and allows the user to have full access by simply moving their eyes around the screen. There are also applications on smartphones and tablets that use the front facing camera to replicate a CCTV camera and allow the user to use the device by eye movement.

After completing calibration modules, eye gaze trackers translate eye movements into mouse movements, and the cursor is held on the target letter or text entry while a “click” is performed or a dwell timer is activated. Often these keyboards incorporate rate enhancement features to allow data entry with minimal keystrokes to promote rate and efficiency. These hardware devices and software programs enable you to operate the programs just as you would with a standard keyboard and mouse.

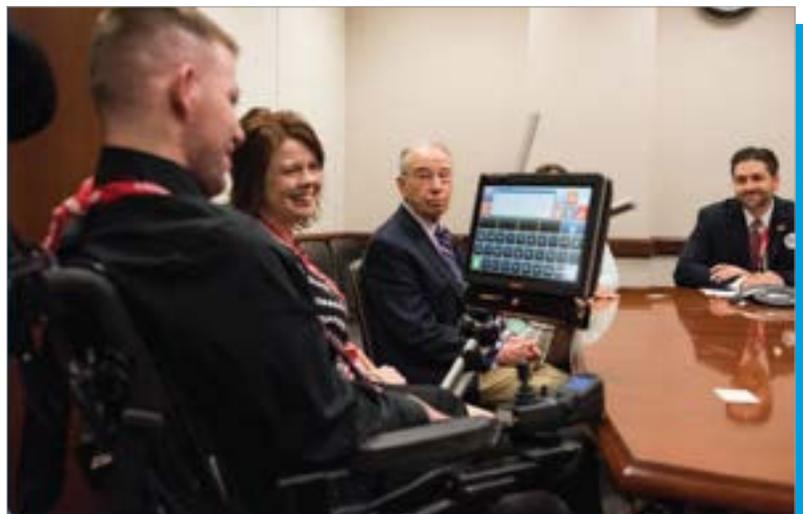
It should be noted that previous eye surgeries, such as those for cataracts and cornea implants, may exclude the use of eye gaze tracking. Other medical issues as well as the use of eye glasses and medications can all affect the accuracy of the eye gaze hardware and software to translate eye movements into cursor movements. Training and technical assistance may be necessary to adjust the angle of the glasses as well as environmental adjustments, such as positioning curtains and/or blinds to block natural sunlight, may all need to be considered in order to improve accuracy and successful use of eye gaze hardware. In addition, medications such as muscle relaxants and those used to control pain and anxiety can affect pupil dilation, which may also impede the use of eye gaze tracking technology.

Although rare, some people may lose the ability to control their eye movements and thus be unable to benefit from eye gaze tracking technology. Fatigue and changes in thinking can also limit the use. While advances in technology are improving the options available to those who have physical impairments, it is possible that technology may not be able to aid communication when a person becomes totally “locked in.”

Switch Scanning

At times, head movements or eye movements may not provide a reliable means of accessing a computer. In these cases, communication devices or computers may be controlled via a single switch and scanning settings. A switch is an electronic device that activates a communication device from even a very slight muscle movement. The switch sends a command to the communication application or computer system to start or stop. Switches may be activated with any part of the body, including hand, foot, cheek, eyebrow or eye blink. It is even possible to make a selection without any movement. See more about scanning using brain computer interface technology below.

Most communication devices and specialty computer software have the ability to scan through letters and messages. Scanning means that the communication device or computer will automatically scan the rows and columns of letters, words, phrases, or messages on the screen. If using a switch, the switch is activated when the letter you want is highlighted. Most communication devices and computer software have the ability to predict the most commonly used words and this feature can speed up the time it takes to spell out words or phrases.



Computers are an integral part of our society and activities of daily living; therefore, being able to use a computer is often very important to a person with ALS. The internet and social media now allow you to access information on any subject and to communicate with others around the world. You can “talk” with anyone, such as your doctor, neighbors across the street, or a friend in another country, by using email or by participating in various online chat rooms and networks. Visual and video communication software programs also allow you to see the communication partner, which enhances a face to face communication exchange. Through software and adaptive hardware options described above, technology exists to keep you engaged, productive, and in contact with the world around you. As with any other computer user, you can arrange for travel, pay bills, or carry on business transactions using the proper software and hardware modifications.

Brain Computer Interfaces (BCI)

(Excerpt adapted from ALS White Paper by Fried-Oken and Peters)

A Brain Computer Interface (BCI), also known as a brain machine interface, is a system that allows a person to control a computer or other electronic device by using only brainwaves, with no movement required.

BCIs can be used for communication, computer access or control of devices such as a wheelchair or prosthetic arm. Virtually anything that can be controlled by a computer could, potentially, be controlled by a BCI. BCI is being examined as a rehabilitation device to help people regain motor skills that are lost from stroke, as well as a prosthetic device to replace or compensate for motor skills that will never return.

There are basically two types of BCI systems: invasive and noninvasive. Invasive systems require surgery to implant electrodes on or near the surface of the brain. Most noninvasive systems use electrodes placed on the scalp, usually held in place by a cap that looks like a swimming cap. Noninvasive systems cause little or no discomfort, although most currently require the use of conductive gel, which must be wiped or washed out of the hair after use. The electrodes, whether invasive or

noninvasive, are connected to a computer (usually through an additional hardware component about the size of an external hard drive). The brain signals that are picked up by the electrodes are sent to the computer, which uses sophisticated software to translate the brain signals into computer commands.

Many people imagine that BCI will allow them to simply think of a word or phrase and have it appear on the screen or control a wheelchair by thinking about where they want to go. Unfortunately, this is not the case with current BCI technology. There are a variety of BCI systems, and each one works a little differently. Most BCI spelling systems display a series of letters, either one at a time or by highlighting letters in a grid. When the letter you want lights up, you react to it and your brain wave changes. The computer looks for that change and interprets it as a “keystroke.”

For example, if you wanted to type the letter A, you would focus on the A and count each time it flashed, or think “Yes!” when you saw it appear on the screen. Recognizing the A would trigger a spike in your brain signals, which would be detected by the BCI system. Usually, each letter must be “selected” multiple times, so typing with a BCI is quite slow. Systems designed to control a computer cursor often rely on movement imagery. You would imagine squeezing your right hand to move the cursor to the right, and your left hand to move the cursor to the left.

Although most people are capable of using BCI technology, it is not for everyone. There are also considerations involved in the timing of calibrating, learning and incorporating the technology into daily use. Current BCI systems are challenging to use and require expensive equipment and time consuming setup. People who already have a reliable method of controlling a computer or communication device (e.g., using hand, foot, head or eye movement) are likely to find that BCI is slower, more complicated and simply not worth the hassle. BCIs will be most beneficial for people who have little or no reliable muscle movement, particularly some people with advanced ALS.

Most BCI systems are still in the research and development stage and are not available for purchase or independent home use. BCI technology is quite expensive and is not yet covered by Medicare, Medicaid or any other insurance provider.

Potential Limitations to Using AAC Technology

While there are many options to help preserve communication, if cognitive changes occur, the ability to operate the technology may become too difficult. Additionally, even though eye movement is maintained for a long time, it can be lost in later stages of ALS, rendering technology that relies on eye movement no longer an option.

The Role of the Family Caregiver

While AAC specialists are professionals who provide the AAC intervention services, such as assessment and initial instruction, AAC facilitators for people with ALS tend to be family members who provide ongoing support including instruction of new communication partners and caregivers, programming new messages into the AAC device, maintaining the AAC system and interacting with the technology manufacturer if necessary. (An AAC personnel framework: adults with acquired complex communication needs. Beukelman DR, Ball LJ, Fager S, Augment Altern Commun. 2008; 24(3):255 to 67. [PubMed] [Ref list]) Therefore, it is often important to consider the needs of the caregiver and AAC facilitator, including comfort with technology, training to support the person living with ALS, integration of the device into the daily environment and routine and the ability

There is no limit to what you can communicate if you are open to adapting to change and exploring and practicing the techniques and technologies that are described in this resource guide.

of the AAC facilitator to troubleshoot and take on a role of tech support to work on challenges or to reach out to the vendor tech support line. It is important for the AAC facilitator to be present during all evaluation and training sessions and to be an integral part of the team in order for a successful integration of the AAC device.

Summary Statement

Stephen Hawking, a well known physicist who had ALS, used an augmentative communication device to give lectures and wrote several widely read texts. There is no limit to what you can communicate if you are open to adapting to change and exploring and practicing the techniques and technologies that are described in this resource guide. By maintaining communication with others, you continue to make a significant difference in their lives while retaining control over your own. However, a difficult concept to consider is that, even with advances in technology, it is possible that strategies may NOT be available if you become completely “locked in.” Therefore, it is important to involve your family and/or power of attorney in any decisions and preferences you may have surrounding advance care planning while you are still able to communicate, and to provide clear directives about any use of life sustaining interventions if you can no longer communicate.

Please keep in mind that whenever you use an alternative method of speaking, it will be slower. Other people need to be sensitive to your circumstances, and you must be flexible with how much you say at a given time. You need to remind people that you want and expect to be included in the world around you. Trying and adapting to alternative methods before you absolutely need them and practicing as much as possible will help make these tools more useful when you have to rely on them.

In most cases, by exercising patience and fortitude, you can continue talking, joking, arguing, expressing love, gathering information and carrying on the business of daily life with family, friends and colleagues.

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1	A	B	C	D	to	for	New word
2	E	F	G	H	the	with	Start again
3	I	J	K	L	M	N	Space
4	O	P	Qu	R	S	T	please / thanks
5	U	V	W	X	Y	Z	.
6	What	When	Who	Why	How	Yes	No



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About The ALS Association

The ALS Association is the largest philanthropic funder of ALS research in the world. The Association funds global research collaborations, assists people with ALS and their families through its nationwide network of care and certified clinical care centers, and advocates for better public policies for people with ALS. The ALS Association is working to make ALS a livable disease while urgently searching for new treatments and a cure.