

LIVING WITH ALS **9**
RESOURCE GUIDE



Changes in Speech and Communication Solutions



CHANGES IN SPEECH AND COMMUNICATION SOLUTIONS

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Living with ALS
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TABLE OF CONTENTS

| | |
|--|------|
| INTRODUCTION | 9-4 |
| COMMUNICATION SUPPORT PARTNERS | 9-4 |
| PSYCHOLOGICAL IMPACT OF LOSS OF COMMUNICATION | 9-6 |
| PLANNING IN ADVANCE | 9-7 |
| WHAT CAN YOU DO IF YOUR SPEECH SOUNDS SLURRED? | 9-8 |
| USING THE TELEPHONE | 9-10 |
| COMMUNICATION DEVICES AND COMPUTER ACCESS | 9-11 |
| SUMMARY STATEMENT | 9-20 |
| BIBLIOGRAPHY | 9-22 |

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 course of the disease. You are encouraged to adapt to ALS continually in order 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 also 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) and assistive-technology 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 member may need to ask your physician to refer you to a SLP to learn about alternative communication strategies. 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 as well. **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 with ALS from Texas, 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 a bit more challenging to understand slurred speech, so please use a hearing aid or amplifier.
- **Give the person your full attention** and concentrate on his/her face before you start listening. It is easier to understand the person when it is quiet and you can see his/her 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 him/her 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, 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 his/her 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 to consider, 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" at which time 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.

PLANNING IN ADVANCE

Planning in advance for speaking difficulties will make it easier for you to adjust to the changes that occur. If your speech is starting to become slurred, think ahead and choose an alternative way to communicate. Good advance 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 computer 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. 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). 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, or internet sites that also provide suggestions and guidance regarding message banking.

If you want the ability to use free thought in generating speech that resembles your own voice it is recommended to use a method called **voice banking**. Software is available to create a synthetic voice that sounds much like your own personal voice. You can bank your voice on a tablet or laptop using this unique software. As of this writing, a popular method of voice banking is via a program called **ModelTalker**. This program requires the user to record 1,600 phrases that are then used to create a synthetic voice that sounds very similar to your natural speech. **It is important to begin this process early in your diagnosis before any noticeable speech changes.** Difficulties in producing speech sounds, maintaining a consistent rate of speech, as well as 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.

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, jaw movement, soft palate, 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.

The term that is used to describe this condition is **bulbar symptoms**, which refer to the weakness and lack of coordination of the muscles that control speech, swallowing, 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 he/she is 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 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 more loudly 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 make your voice more powerful and may also be helpful**; 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 overuse of the muscles for speaking, which results in conservation of energy. Typically, the listener may comprehend the first few words of the utterance, but as the speaker becomes more fatigued, he/she 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 also might 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.

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 multi-tasking.
- 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.
- A **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, at retail telephone and electronics stores, or online internet resources.

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

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.alsa.org or call your local ALS Association chapter representative to assist you with the latest technology and funding information to assist people with ALS.** You can also find many helpful videos about communication issues and ALS on The ALS Association website and also YouTube. Many people are visual learners, so these sites help people see the technology we are describing 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 in order to justify the cost of any expensive aid, it should offer access to both typing and alternative access in the case of poor hand movement.

To determine the most appropriate device for you, a communication assessment/evaluation needs to be completed by a licensed speech-language pathologist.

The assessment/evaluation is usually a covered benefit under your health insurance plan, even if the actual aid is not covered. Since communication devices come in many different shapes and sizes, receiving a proper evaluation is essential prior to selecting a device.

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 larger stationary 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?

- 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 he/she 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.** Your local ALS Association chapter 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.**

When Medicare began paying for communication devices in 2001, they decided to refer to AAC devices as SGDs—Speech Generating Devices (the acronyms are interchangeable). **AAC includes systems such as sign language, symbol or picture boards, and electronic devices with synthesized speech.** 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 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.** These people must completely rely on another method to make all their ideas, wants, or needs to be known.

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 (Contributed by The ALS Association Golden West Chapter)

There are various augmentative communication devices, ranging from the simple alphabet board to more advanced computerized speech systems. You are encouraged to seek the advice of SLP in the field of augmentative/alternative communication when choosing your equipment because he/she 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 in order to try the systems.

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

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 easier to read than script.

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

When speaking and writing abilities are lost, 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 in order 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.

Other alphabet board strategies, known as **partner-assisted scanning**, can be used with a little bit of 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. To indicate “yes,” 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,” or “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, it should be noted that eye blinks are not often reliable with a person with ALS due to slow, uncoordinated or lazy 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 him or her.

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!

Spouse of person living with ALS
(Contributed by The ALS Association Golden West Chapter)

| | | | | | | | |
|---|------|------|-----|-----|-----|------|-----------------|
| 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.)

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 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–\$15.) 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, etc. 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.

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 Berget, father has ALS
(Contributed by The ALS Association MN/ND/SD Chapter)

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 Gerke (Contributed by The ALS Association Wisconsin Chapter)

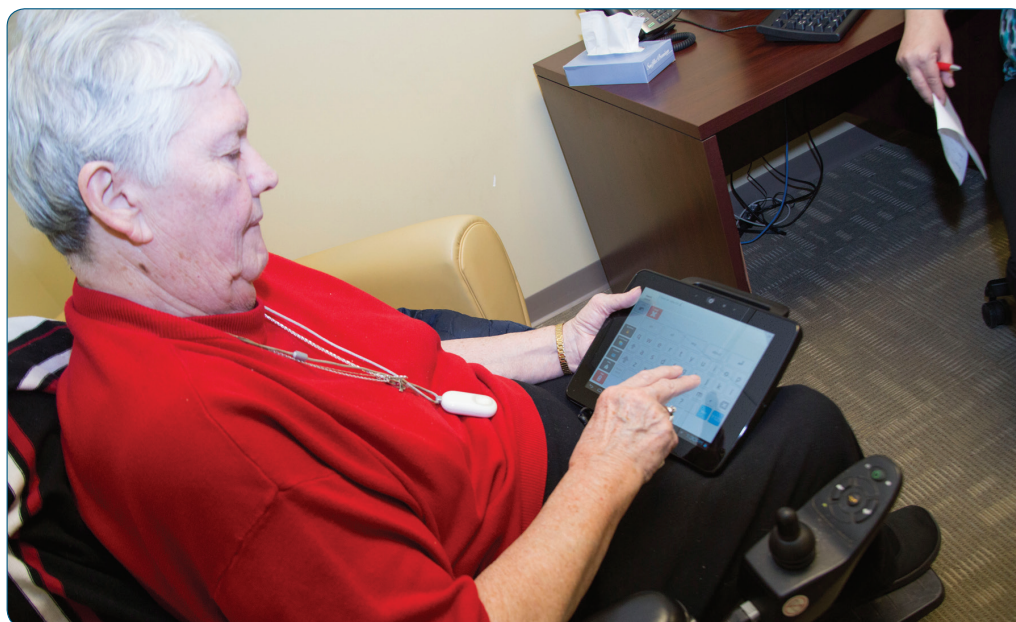
When hand function is intact...

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 will turn your existing laptop into a communication device with the download of the software. In about five minutes, people with ALS can begin using their own laptop and verbally communicate with family and friends.

There are **apps available for tablets that will enable a person to have verbal output through the tablet by simply downloading the appropriate application.** 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 chapter 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.

Headmouse Options

If you have limitations in your finger or hand movement, modifications can be made so that a keyboard and/or mouse is not required and access is gained through alternative **devices that track head movements or eye-gaze 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

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 for the letter to be typed**. 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.

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.

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. 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. Previous eye surgeries, such as those for cataracts and cornea implants, may exclude the use of eye-gaze tracking. 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 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 among other applications. 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 types 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 and 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.

SUMMARY STATEMENT

Stephen Hawking, a well-known physicist living with ALS, has used an augmentative communication device to give lectures and also has written 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.

| | | | | | | | |
|----------|-------------|-------------|------------|------------|------------|-------------|------------------------|
| 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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The following is a list of topics covered in the *Living with ALS* resource guides:

Resource Guide 1

What is ALS? An Introductory Resource Guide for Living with ALS

This resource guide provides an overview of ALS, what it is, and how it affects your body. It provides information on what kind of resources are available to help you deal with ALS more effectively.

Resource Guide 2

After the ALS Diagnosis: Coping with the “New Normal”

This resource guide addresses the psychological, emotional, and social issues that you must face when your life is affected by ALS. It provides information on how to cope with the many lifestyle changes and adjustments that occur when you live with ALS.

Resource Guide 3

Changes in Thinking and Behavior in ALS

This resource guide addresses how thinking and behavior may be affected by ALS and how these changes can impact disease course, symptom management, and decision making.

Resource Guide 4

Living with ALS: Planning and Making Decisions

This resource guide reviews areas where careful planning and decision making will be required and will provide you with resources to help you and your family plan for the future.

Resource Guide 5

Understanding Insurance and Benefits When You Have ALS

This resource guide provides strategies and helpful hints to better navigate health insurance and benefits. While understanding insurance and benefits may feel overwhelming, the guidelines outlined here should help simplify the process for you.

Resource Guide 6

Managing Symptoms of ALS

This resource guide discusses a variety of symptoms that may affect you when you have ALS. As the disease progresses, various functions may become affected and it is helpful to understand potential changes so that you know what to expect and how to manage these new changes and symptoms.



Resource Guide 7

Functioning When Mobility is Affected by ALS

This resource guide covers the range of mobility issues that occur with ALS. It discusses exercises to maximize your mobility, as well as how to adapt your home and activities of daily living to help you function more effectively.

Resource Guide 8

Adjusting to Swallowing Changes and Nutritional Management in ALS

This resource guide will help you understand how swallowing is affected by ALS and what you can do to maintain nutrition for energy and strength and to keep your airway open.

Resource Guide 9

Changes in Speech and Communication Solutions

This resource guide covers how speech can be affected by ALS and explores a variety of techniques, technologies, and devices available for improving communication. By maintaining communication with others, you continue to make a significant difference in their lives, while retaining control of your own.

Resource Guide 10

Adapting to Changes in Breathing When You Have ALS

This resource guide explains how breathing is affected by ALS. Specifically, it will teach you the basics of how the lungs function, the changes that will occur, and how to prepare for the decisions that will need to be made when the lungs need maximal assistance.

Resource Guide 11

Approaching End of Life in ALS

This resource guide examines thoughts and feelings about dying and end of life. Approaching end of life is difficult and support is critical to help sort out feelings, expectations, and plans. By talking to friends, family, professionals, and planning and communicating your wishes, you can help prepare for the best possible end-of-life phase.



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About The ALS Association

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.

For more information about
The ALS Association, visit our
website at www.alsa.org.