5

LIVING WITH ALS

Adjusting to Swallowing and Speaking Difficulties

ALS Association™
Fighting Lou Gehrig's Disease

Cover: *April Bloom* by Mary Louise Hartnagel.
The artwork on the covers of the *Living With ALS* Manuals was created by individuals with ALS or their family members.

About the Artist

"Mary Louise Hartnagel, my only sister, died in 1994 from the bulbar form of ALS. Art was everything to Mary. She had an Associate's Degree in Art and could see beauty, *artistic beauty*, not only in known works of art, but also in everyday life.

Mary worked in real estate sales and was very active in the community and family real estate management and development. She lived close by, but caring for my small children prevented me from being with her constantly, so we rigged up a communication system with a TDD machine. This compact TDD was invaluable during Mary's illness—her fingers could work the light pressure keys, so she could retain her communication with the outside world that she was deprived of by her failing voice. She could call me anytime on her TDD and leave a typed message on my TDD that was hooked up to a printer. Business could go on, and due to our personal closeness, we also could touch on emotional challenges and rely on each other for the mental support we both needed during her illness.

I deeply thank The ALS Association for honoring Mary's memory by sharing her work and her intense personal love of art with others, who may be facing the same path in life that she did."

Robin Hartnagel
Loving sister and caregiver of Mary Louise Hartnagel

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Manual 5

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Table of Contents

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Introduction

Most people take the acts of swallowing and speaking for granted. These abilities are both necessary in everyday life and important in many aspects of social interactions. When dealing with the challenges of ALS, be aware of how you can make simple modifications in your diet – food and fluids – to help assure that you meet your body's needs for proper nourishment, and also how you can modify your communication methods in order to maintain effective communication. The first section of this manual addresses the impact that ALS can have on swallowing and eating and how you can effectively manage the problems that occur with these functions. The second section discusses the speaking difficulties that can occur with ALS and covers the methods and devices that are available to assist and enhance communication.

Swallowing

HOW DOES ALS AFFECT NORMAL SWALLOWING?

The act of swallowing, usually done automatically without thought or planning, often can be affected by the muscle weakness that occurs in ALS. The ability of the jaw, lips, tongue, and the muscles in the throat, that help guide foods and liquids into the **esophagus** (a muscular canal extending to the stomach) and protect the airway, may be diminished.

Usually, the jaw, lips, and tongue function to control food, liquids, and saliva in your mouth by moving them around for chewing, then shifting them toward the throat for swallowing. Many structures from the mouth to the stomach are involved in the act of swallowing.

The first phase begins when the food is ready to be swallowed, and is rolled into a **mass** (**bolus**) and forced into the **pharynx** (**throat**) by the tongue; the pharynx is the area behind the mouth which is connected to the esophagus. At this point, a reflex-like response is triggered causing the **soft palate** (which separates the mouth and pharynx) to rise, thus preventing food from entering the **nasal cavity** (nose).

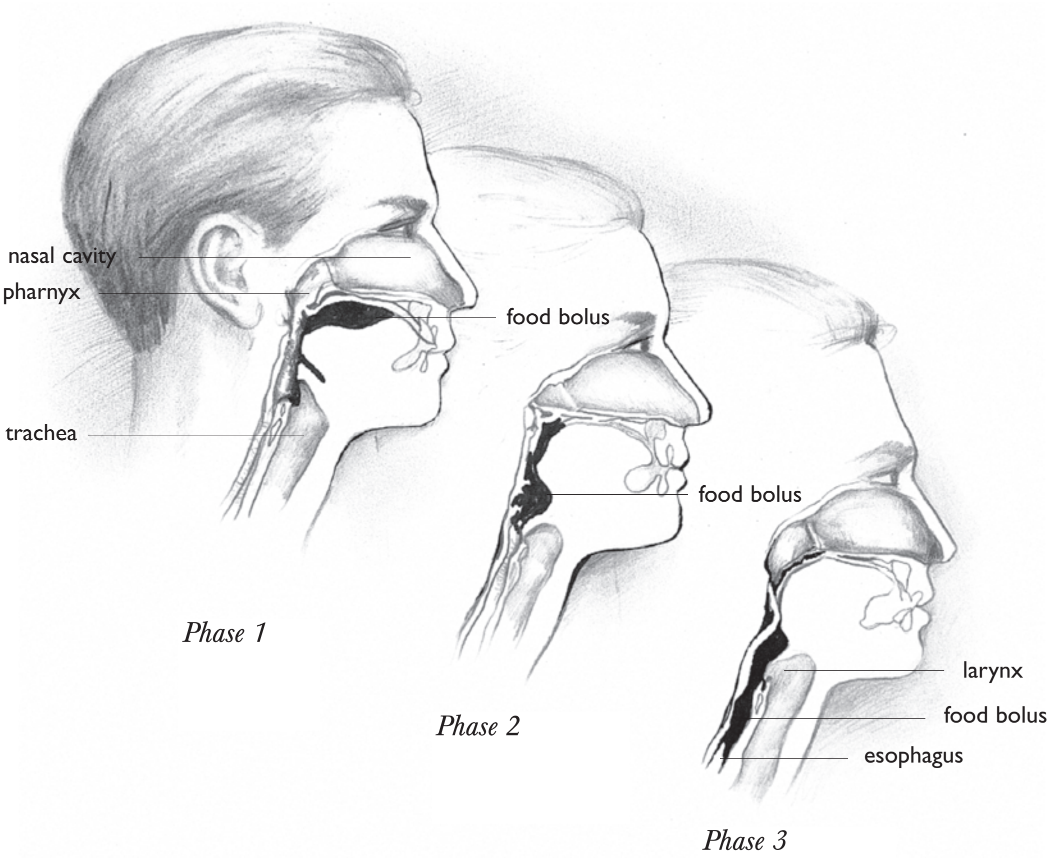
In the second phase, the **larynx** (voice box) is elevated, helping prevent food from entering the **trachea** (windpipe). The tongue is pressed against the soft palate, sealing off the oral cavity from the pharynx.

The walls of the pharynx are composed of muscles which assist with swallowing. In the third phase, these muscles contract, pulling the pharynx upward toward the food; the lower muscles of the pharynx relax, which opens the esophagus. A final muscle contraction forces the mass into the esophagus, where the food is further moved toward the stomach by a rhythmic squeezing action of the muscles along the esophagus (Fig. 1).

In summary, the lips, soft palate, pharynx, and larynx function to keep food and liquids in your mouth while they are being prepared for swallowing, and to close off the nasal cavity and windpipe when you do swallow. This process assures that food and liquids move down into the esophagus instead of up into the nose or down into the lungs. Weakness in any or all of these muscles can lead to difficulty with swallowing, handling the saliva in your mouth, and speaking.

FIGURE 1

Phases of swallowing



WHAT SHOULD YOU DO IF MUSCLE WEAKNESS AFFECTS YOUR EATING HABITS?

If any of your muscles involved in swallowing become weak, this can affect your ability to maintain an adequate diet. Food (especially dry, crumbly solids) or liquid (mostly thin) can fall out through the lips or can fall back over the base of the tongue into the unprotected airway, causing choking. You may become frustrated with eating if it is difficult to move food and liquids around in your mouth normally, or if there is discomfort or fear of choking.

Should your swallowing ability change, you must pay attention to which types of foods/beverages have become more troublesome for you. If there is weakness in your mouth, taking small bites of foods and sips of liquids will help you maintain control.
Eating foods that are made of a single consistency rather than mixing solids and liquids also may prevent choking. Examples include:

- oatmeal or cream of wheat, *not* cold cereal in milk
- thick cream soups (tomato), *not* broth-based soups with meat and vegetable pieces

Soft foods or those processed in a blender also may be easier to manipulate in your mouth. Additionally, you may find it easier to control and swallow **thicker liquids** such as nectars and milkshakes rather than thinner liquids.

A good rule to follow is to swallow two or three times with each mouthful in order to make sure that all food is cleared from your throat. Moistening food with sauces and gravy is helpful in preventing the feeling of pieces being stuck. Taking a sip of liquid after each bite also may help move the solids.

Moreover, try tipping your chin downward as if you are looking at your plate, so that you shift the structures into place which protect the airway, as opposed to tilting your head backward. For some people with ALS, however, holding the chin upright is safer and more comfortable. A speech pathologist can evaluate the exact area of weakness in the swallowing mechanism and suggest the best position for you.

WHAT CAN YOU DO TO CONTROL YOUR SALIVA?

The body produces about four-to-six cups of saliva every day. Normally, this saliva is being moved in the mouth and swallowed unconsciously. If your swallowing muscles are weakened and your lips and jaw are not in control of the saliva, you may have difficulty keeping it in your mouth (**drooling**), or experience some occasional coughing or choking.

If your saliva is thick, it is important to take in enough fluid to make your saliva thinner. It is easier to swallow thin rather than thick saliva.

While some people keep tissue or a handkerchief handy to dab their mouths during the day, there are medications available which cause the body to produce less saliva. If excessive saliva becomes a problem, you should talk to your doctor about the possibility of using medicine to control it (see Manual 3). There are also **suction machines** available which are used to dispose of excess saliva; you can get more information about these aids from your nurse or doctor.

WHAT SHOULD YOU EAT TO MAINTAIN A BALANCED DIET?

Good nutrition is important for everyone, even if it has become difficult because of weakened chewing and swallowing abilities or a decreased appetite. Be sure to learn what is included in a well-balanced diet in order to assess whether or not you are getting enough of the foods you need. The **Food Guide Pyramid** emphasizes the five basic food groups and includes the following recommended daily servings:

Food Guide Pyramid

	Food	*Servings*
I.	Meat, poultry, fish, dry beans, eggs, and nuts (2-3 ounces each)	2–3
II.	Bread (1 slice), cereal, rice, and pasta (1/2 cup each)	6–11
III.	Milk, yogurt (1 cup each), and cheese (1 ounce)	2–3
IV.	Fruits (1 whole or 1/2–1 cup)	2–4
V.	Vegetables (1 cup raw or 1/2 cup cooked or chopped raw)	3–5
VI.	Fats, oils, and sweets	in moderation

Keep these recommendations in mind when planning daily meals; however, you may need to change the textures of some foods for easier swallowing, or allow greater amounts of foods from Group V in order to get enough calories. A **dietitian** or **nutritionist**, who is experienced in nutrition and has the ability to identify and understand your dietary needs, can work with you to make the necessary adjustments. To find a dietitian, ask your doctor for a recommendation, contact your local ALS Association chapter, or call your community hospital. If you are attending a multi-disciplinary ALS clinic, a dietitian will be one of the team members providing care and services for you.

Why should fiber be included in your diet?

Fiber is a part of food that cannot be digested and is plentiful in all fruits, vegetables, beans, and whole grain foods. It is helpful for maintaining normal bowel function and preventing constipation. With ALS, constipation can occur for a variety of reasons, including muscle weakness, immobility, changes in the diet, and inadequate fluids. If constipation becomes a problem, try to increase your intake of fiber by consuming softer forms of fruits and vegetables, drink juices (especially prune juice), and be sure to get enough fluid in your diet. Fiber supplements are also available, such as Metamucil® or Fibercon®.

How many and what kind of fluids should you drink regularly?

Drink at least eight cups of decaffeinated fluids every day to keep your body adequately **hydrated** (maintenance of body fluid). If you take in less fluid than your body needs, you may become **dehydrated** (excessive loss of fluid), which in severe cases can result in hospitalization. Dehydration also will contribute to constipation, thickened secretions, and an overall feeling of illness and fatigue. You can recognize this condition if your urine is a darker yellow, has a more noticeable odor, is less frequent or in smaller amounts, and if your mouth is constantly dry.

Since you may choose to drink less because you are afraid of choking, you should try switching from **thin liquids**, like juice, water, coffee, and milk, to **thick liquids**, such as fruit nectars, milkshakes, puddings, gelatins, and cream soups. Thick liquids are often easier to control in your mouth and during swallowing.

You also can buy products that are in powder form and use them to change your favorite beverages from a thin to a thicker, safer consistency; Simplythick™, Thick-It® and Thick ‘n Easy® are examples. Ask your dietitian for specific recommendations on the use of these products and how to order them. Another helpful hint is to blend or puree (process through a strainer or blender) soups so that the solid parts thicken the broth, thus making it easier to swallow. Or, you can stir in dry rice cereal (for infants) as a thickener.

WHAT IS THE MOST APPROPRIATE WEIGHT FOR YOU?

Weight is a significant factor in measuring your overall nutritional status. Some weight loss may be expected in people with ALS because of a decrease in muscle mass (atrophy). However, too much weight loss may result in a lower energy level and weakened respiratory status, and may indicate inadequate nutrition due to a lack of calories.

You should keep track of any changes and compare them to your usual adult weight, *not* to standardized weight charts. It is important that you maintain your regular weight, since often people do not start the course of ALS at what would be considered an ideal body weight.

If you experience a drop in weight, your dietitian can help you find ways to increase your calorie and protein intakes safely.

Recent evidence indicates that a significant proportion of patients take in less calories than they use up, which may contribute to loss of weight and muscle. Adjusting for this shortfall of calories, by increasing intake, may improve quality of life and prolong survival.

How can you increase your intake of protein and calories?

If weight loss has been identified, you can build up calories by adding margarine, butter, cream, cream sauce, gravy, sugar, chocolate syrup, and/or powdered milk to foods, and beverages that you normally eat, without significantly increasing the total amount eaten. By supplementing with these items, you are making foods more calorically-dense without adding extra time and effort to consume them.

While fried foods, milkshakes, and instant breakfast drinks are high in calories, they are also good sources of extra protein and can be better choices than “plain” foods, but only if they are well tolerated. Do not use diet or low-fat foods, because they may fill you up without giving you the necessary calories. If you have other concerns that affect your diet, such as high blood pressure or diabetes, talk to a dietitian about how you can best supplement your meals.

Commercial nutritional supplements are high in calories, protein, and various vitamins and minerals; are very convenient; and may come in beverage and pudding forms. Some examples of brand-name products are Ensure® and Boost®, both of which are available in “Regular” and “Plus” (50% more calories) formulas; usually they can be found in drug, discount, and grocery stores. These products can be more expensive than regular grocery-store items; however, it may be possible to save money by acquiring coupons or buying off-brand types, but make sure the nutrients are comparable to the brand-name varieties. Carnation Instant Breakfast® is an example of a less costly product commonly found in grocery stores.

Homemade methods of supplementing foods can be equally effective and tasty–and less expensive. The amount needed depends on how much you are eating overall and how much weight you have lost. Try not to replace meals with liquid supplements; they are best used as a snack or as a beverage with meals.

DO YOU NEED TO CHANGE THE CONSISTENCY OF THE FOOD YOU EAT?

Food and liquid consistencies may have to be altered because of possible chewing and swallowing difficulties. Continue eating foods of regular consistency, as long as you have *not* experienced any swallowing problems. If you notice slight difficulties, you might change to softer-consistency foods; for example, cut meats into small, bite-sized pieces or use ground meats, and add gravy, sauce, or broth for moistness. In addition, try smooth foods that may be easier to handle:

- mashed, boiled, baked, or French-fried potatoes (no skin)
- noodles or rice with gravy or sauce
- casseroles, pasta, and soft-cooked vegetables
- hot cereals
- canned fruit, sherbet, ice cream, and puddings

If you are unable to chew or are having more serious swallowing problems, pureeing foods may help. Many foods are of an acceptable consistency already, such as mashed potatoes and cream of wheat. If using a blender, mix in gravy, sauce, broth, juice, or milk (depending on the food) to create a smooth, moist consistency and to add calories and protein.

If you have noticed signs of choking or coughing with meals, tell your doctor so that he/she can refer you to a Speech-Language Pathologist for a complete evaluation of your swallowing problems. This evaluation will help you by providing recommendations for safe eating. A procedure, called a **modified barium swallow**, can be done with a speech pathologist and will pinpoint the exact area of difficulty, so that you receive the best recommendations for safe eating. Be sure to ask the health care professional performing the swallow study to provide you with the results and recommendations.

WHAT IF YOU CANNOT CONSUME ENOUGH FOOD, EVEN AFTER CHANGING THE CONSISTENCY AND USING SUPPLEMENTS?

If you find that your food and liquid intake is insufficient despite your supplementation efforts, or if swallowing has become too risky due to frequent choking, you need to consider another method of eating. The goal is to keep foods from passing (sometimes unnoticed) into your airway and to maintain adequate nutrition and liquid intake.

An alternate method for you to consider is a **feeding tube**, also known as a **PEG** (**percutaneous endoscopic gastrostomy**) **tube**. It is placed directly into your stomach through the abdominal wall to provide another way for you to receive nourishment and liquids. PEG tubes can be either an actual tube (made of a very soft, pliable material) which extends about six-to-eight inches outside of your stomach, or in button form which is smaller and lies flush against your stomach.

Each type of tube is inserted by a surgeon or **gastroenterologist** (a specialist in the study and care of the stomach, intestines, and related structures), usually on an outpatient basis or with overnight hospitalization. Usually, general anesthesia is not needed and the individual is awake for the procedure. This option allows you to feed yourself by completely bypassing the mouth, thus avoiding the swallowing difficulty. However, you also can choose to eat orally (through your mouth) whatever food is enjoyable, as long as those selections have been assessed as safe.

When a tube is in place, a dietitian, doctor, and/or nurse will help you to determine how much food (in the form of a liquid supplement) and water you need daily and what your feeding schedule should be. In addition, you do not have to be concerned about the adequacy of your food intake, because your new diet is designed to meet your nutritional needs and control your weight loss. Tube feeding also saves you the time and energy that was spent on trying to eat enough food.

There are several formulas available for use with a PEG tube or button, including Isocal HN®, Osmolite HN®, Boost®, Ensure®, Jevity®, and Ultracal®. Most are products that contain one calorie per milliliter of liquid, meaning that the average person would need approximately 50-to-80 ounces (6-10 cups) per day to meet all of his/her nutritional requirements. Some of these products contain fiber, and some are available in high-calorie or high-protein formulas.

Your dietitian can determine which kind, exactly how much, and what type of schedule is best for you. Because these products are not typical foods, the cost of your formula and other PEG tube supplies may be covered by your health insurance. To date, Medicare covers 80% of the expense of such formulas when they are administered via a feeding tube and are documented as your sole source of nutrition. Contact your insurance plan to see what coverage exists for feeding tubes and specific nutritional formulas.

Some home medical supply companies will ship products to your home and work directly with your insurance company, easing your burden in this area. Lastly, it is recommended that you ask your physician and/or nurse about length of hospital stay, necessary education regarding use and cleaning of the tube, as well as, possible complications.

The Last Word on Swallowing

ALS can cause a great deal of change in your regular eating habits. There may be issues of safety and food adequacy that will require you to make modifications along the way. If you work with your dietitian, speech pathologist, and other caregivers, there are many options available to ensure that your nutritional needs are met and that your quality of life is maintained.

Speaking

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 these physical aspects of speech, thus presenting various challenges to communicating.

You are encouraged to adapt to ALS continually in order to meet the demands of work, home, and other physical needs. With perseverance, ingenuity, technical assistance, and support from others, you can continue to communicate at the highest level.

Speaking partners, who include spouses, companions, roommates, children, colleagues, and health care providers, can supply moral support and also help you in being understood. **Speech pathologists** 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 **augmentative communication** (assistive devices that provide speech for people unable to communicate orally) can suggest strategies that are the most effective.

These experts, along with occupational therapists (OTs), and assistive technology and computer specialists who work with the disabled, can assist you with choosing tools for augmentative communication. This equipment can be as simple as an alphabet board or as advanced as a computer. Other people living with ALS can offer solutions and strategies that have been successful, as well.

WHAT CAN YOU DO IF YOUR SPEECH SOUNDS SLURRED?

Slurred speech is a symptom of **dysarthria**, a neurologically-based speech disorder that results in 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.

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. 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. Try getting your listener's attention before you start; say the person's name or give a tap on the shoulder, so he/she is ready to pay close attention. You also should be prepared to shift to writing as needed.

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. Sometimes your speech may be more easily understood if you write the topic or key words, 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.

Tips for Speaking Difficulties

The following are some very specific tips that can help you with your speaking difficulties:

- Speak slowly and carefully; repeat your words if necessary.
- Convey your message in as few words as possible, realizing that those at the end of a sentence are lost more easily.
- 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, since slurred speech can omit them, for example, boo**“k”** or ha**“t.”**
- 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.
- Say your 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 gestures, such as facial expressions and pointing.
- A **voice amplifier**, a small machine with a microphone to make your voice more powerful, also may be helpful; a speech pathologist or electronics store clerk can assist you in selecting an appropriate one, but note that as your symptoms change, so will your need for this type of item.

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 down 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 out loud.

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. In addition, arrange for someone to maintain and transport any assistive communication devices that you might have. A communication partner who provides moral support and serves as your advocate is extremely valuable.

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 their face.
- If you do not understand something, ask the person to please say it again slower–or louder.
- Have the speaker spell words that are not clear.
- Remind him/her to state when the topic is changing so you will know the context.
- 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.”

USING THE TELEPHONE

With ALS, talking on the phone may be challenging because you cannot use your face and gestures to assist your speech. Here are some practical suggestions to improve your ability to be understood on the phone:

- Right away, tell the listener that you have a speech disorder and that you will repeat a word or phrase if necessary.
- A **weak-voice amplifier** can increase the loudness of your voice over the phone.
- A **speaker phone** allows you to talk without using a hand-held 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, weak-voice amplifiers, 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 or at retail telephone and electronics stores. Consult with your speech pathologist or local ALS Association chapter to see what is offered in your area.

WHAT CAN YOU DO IF OTHER PEOPLE CANNOT UNDERSTAND YOUR SPEECH AT ALL?

Your tongue and lips may become too weak to produce speech. Remember that communication of your thoughts is what is important. Sometimes doctors and other health care providers fail to refer you to a speech pathologist for the necessary intervention because they are concerned with so many other aspects of your care. Communication, though 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.

If your speech is starting to become very slurred, think ahead and choose an alternative way to communicate. Planning in advance for speaking difficulties will make it easier for you to adjust to the changes that occur. 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 by recording certain words, phrases or statements while speech is still clear for future use on a computer or tape recorder.

Communication Devices and Computer Access

HOW DO YOU CHOOSE A COMMUNICATION DEVICE?

Choosing the right communication device and the most appropriate switches (explained later) or controls 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 using a switch of some kind. A communication assessment/evaluation should be done to determine the most appropriate device for you; it is usually paid for by your health insurance, even when 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. You might want to consider the following questions before you purchase a communication device:

- Where/when will you use it?
- Do you want a small portable device that can produce pre-programmed phrases and short, typed responses, or a larger stationary system allows you to write, store, and say anything you choose?
- Is it easy to use?
- Is it functional/appropriate for you?
- If it malfunctions, can it be repaired quickly, easily, and inexpensively?

- Is there someone who can help you maintain the device, such as charging batteries, turning it off and on, programming?
- What are your budget/funding options?

There are speech pathologists, occupational therapists (OTs), and assistive technology and computer specialists who 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?

There are various augmentative communication devices which range from the simple (low-technology) alphabet board to more advanced (high-technology) computerized speech. Technology is constantly changing, so specific recommendations should be made by qualified professionals.

You are encouraged to seek the advice of a speech pathologist in the field of augmentative 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 request catalogs, a demonstration disk, or a home visit in order to try the devices. The **Alliance for Technology Access**, **Local Assistive Technology Partners**

Projects, RESNA, nonprofit organizations, and valuable web sites can provide valuable help with this process, as described later in this manual.

What are the low-technology 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. Keep a small **notebook** with you wherever you go so that you are always ready to express yourself. A **magic slate board** (a black pad covered by a film sheet that allows you to write messages and then lift the film to erase) is another option. Either one is inexpensive, lightweight, and simple to use.

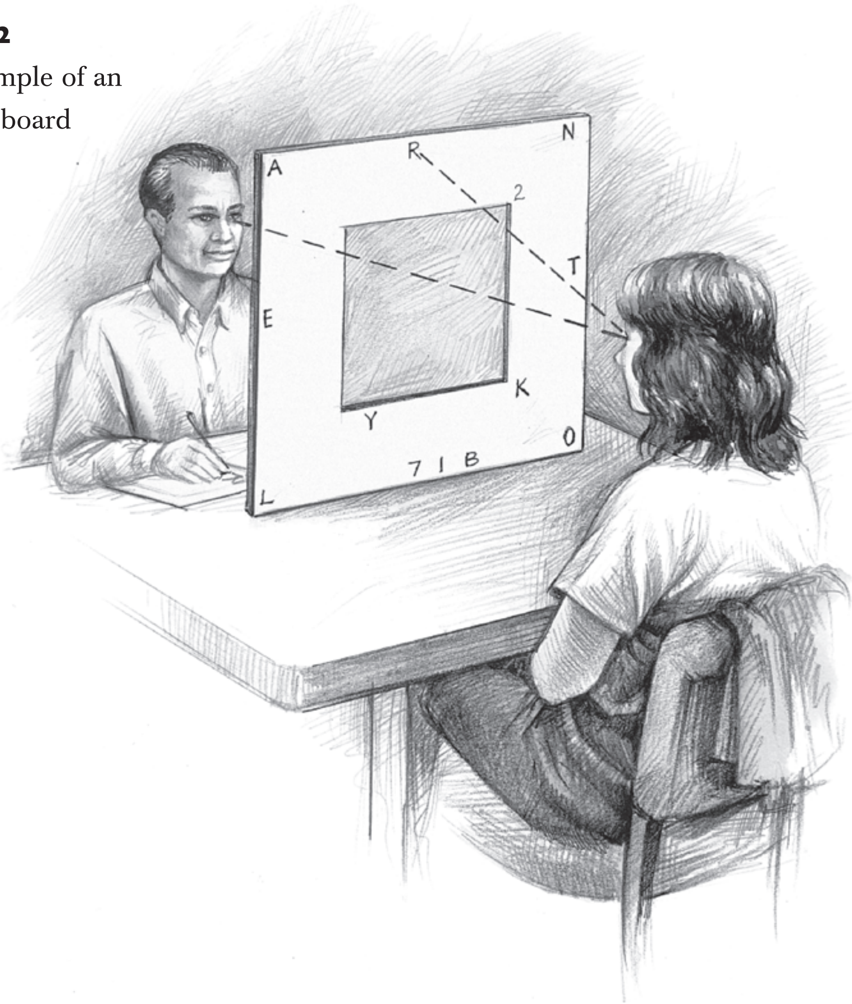
Picking the appropriate writing instrument also can influence your ease in writing. Pencils or felt pens are often better to use than ball-point pens, and thick pens are sometimes easier to grip and control than thin ones.

Alphabet boards are among the most useful aids when speaking and writing abilities are lost, or when a computer or communication device is not available or practical (when in the shower). These boards are helpful in any setting because they are portable and can be used effectively with your hands or eyes. You can spell words with a pointer, or scan the alphabet and indicate "yes" or "no" when your partner points to a row or letter; to do so, 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 "end of word" and "mistake" should be listed on the board, as well (Fig. 2).

Another simple tool for communication is an **alerting system**. Buzzers can be assembled easily 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 would be a remote door chime, which can be purchased at any local home improvement store. These devices have a range of up to 100 feet. The user has a small piece with a button that is depressed when you want to alert someone. The caregiver has the other piece and can be in or outside of 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 for people who have weakened or no hand function.

FIGURE 2

One example of an alphabet board



What are the high-technology options?

Small communication devices, such as hand-held, microchip-powered typewriters (talking organizers or language translators), allow you to type short statements and then push a small key that vocalizes what you wrote. It is also helpful to preprogram a list of frequently used phrases like “I have to go to the bathroom,” so that they can be accessed by pressing only one or two keys.

Dedicated communication devices are those that have been specially designed to help people with speech disabilities. From an alphabet board to a computer, they enable you to visually scan letters or to type and produce computerized speech. Different from **desktop** and **laptop computers**, they are designed for a single purpose–communication. These devices can range from a few dollars to several thousand dollars.

Laptop and desktop computers (personal computers or **PCs**) offer a wide range of effective speech alternatives. With special software, you can have a conversation using computerized speech. Once you have typed your message, you can make it “speak” or save, print, or fax it.

On the **Internet**, you can access information on any subject and communicate with others around the world who have ALS. You can “talk” with anyone, such as your doctor, neighbors across the street, or a friend in another country, by using electronic mail (**e-mail**) or by participating in various on-line chat rooms. You type in your text with your fingers or a switch, and then that message is sent over the computer lines to the person on the other end. Your computer interaction can involve either the exchange of a typewritten message or you can push a key to make it speak. And like any other computer user, you can arrange for travel, pay bills, or carry on business transactions, using the proper software.

A new technology is developing that uses brainwaves to generate electrical signals that create "communication" through a computer. As of 2003 these "thought transference devices" (TTD) are being developed and are being used by several people with ALS throughout the world. The TTD technology holds promise for people who can no longer use even the slight muscle movement that is needed to activate a switch device.

Apple Macintosh computer systems, including powerbooks, come with built-in voice capability, while hardware for speech output is available for IBM-type machines. Both offer extensive opportunities for several types of communication, written and spoken (computerized voice). There are businesses that specialize in communication software for Apple, IBM-type, or PC machines and sell it through catalogs.

The specialist who works with you may favor a certain device, but it is important to put forth your preferences–what machine, if any, you are familiar with; your cost constraints; the need for a trial period; and the request to explore all of your options. There is software available for under $100 that can provide you with a speaking communication tool to use on the computer, while others run as much as $2,500. Your choice depends on the computer and how many communication options you want and can afford. There are always new developments, so you may want to consider consulting with someone who is knowledgeable about such recent advances.

Many different electronic communication systems are available. The health care professional that performs your communication assessment can help you try out several communication systems at the evaluation center or in your home. Some communication systems are custom designed for a specific user or can only be used in specific situations. For example, a communication system that works through a desktop computer cannot travel with the patient to doctor visits, but a laptop or notebook computer is more portable and will allow the patient to travel with the system. In selecting an electronic system, the individual must understand the features offered by the system and determine if those features best meet his or her needs.

Electronic communication devices can be broken down into two categories: dedicated and undedicated systems. A **dedicated device** is strictly a communication device–the only thing the device does is speak. **Undedicated devices**, which are computer based (desktop or laptop computers), not only speak, but also feature all the functions of a regular computer so you can have a conversation using computerized speech. Computer systems can be IBM or Macintosh based.

Voice output on a device is either digitized or synthesized. A digitized voice utilizes recorded human speech. Synthesized speech devices use computer-generated speech. There are benefits and limitations to both types of devices. Digitized devices, although more “normal” sounding, are limiting because they can only say the words or phrases programmed on the device. They do not allow for free-thinking. Synthesized devices allow the user to have pre-programmed phrases or words and also have the ability to spell out novel thoughts.

Making communication efficient and quick is important. Most communication devices have pre-programmed phrases or abbreviations which can be accessed with one or two buttons or by using your switch. For example, a communication device could be programmed to say “Hello, how are you?” when the user hits the letters “hh”. Each communication device differs in the amount of storage space and memory available but most will hold 100 phrases. Some machines have no limit to the amount of pre-programmed material.

All of the items discussed in this section mention the possibility of pre-programming phrases into a communication device that can be accessed with one or two buttons. The following abbreviations are some examples for simplifying the expression of common needs when speaking or using assistive communication devices:

abbreviation	*expression*
SS	“I’d like to say something.”
ID	“I disagree with that.”
NWM	“That’s not what I meant.”
LTB	“Let’s take a break.”
LTL	“Let’s talk about that later.”
TL	“Thanks a lot.”
TF	“That’s funny.”
MI	“May I interrupt?”

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.

If you have limitations in your finger movement, computers can turn Morse code into letters by translating the tapping patterns into letters and words. Adjustments can be made so that a mouse is not required and access is gained through a single switch. 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, eyeblink, and muscle and mind activity. Most communication devices and specialty computer software have the ability to **scan** for the individual. Scanning means that the communication device or computer will automatically scan the alphabet and when using a switch, you hit your switch 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. If you have limited hand function, but good neck control, you can use a **mouth stick** to type and access buttons on a keyboard. Also, a variety of cursors are available that work like a mouse, but can be mounted or placed on your head (head mouse).

If your mobility is severely limited, scanning methods are also available that present the alphabet on the monitor; you touch or signal a button on the screen to indicate which letter you want. This method requires the movement of one finger, shoulder, eyelid or mind activity, thus assuring that you can communicate your opinions, questions, answers, requests, statements, and feelings. These access methods vary in price ($25–$2,500).

With computers being such an integral part of our society, being able to utilize a computer is often very important to a person with ALS. With access to the Internet, you can get information on any subject and communicate with others around the world who have ALS. You can “talk” with anyone, such as your doctor, neighbors, or a friend in another country by using electronic mail (e-mail) or by participating in various on-line chat rooms. You can type in the text with your fingers or a switch, and then that message is sent over the computer lines to the person on the other end. Your computer interaction can involve either the exchange of a typewritten message, or you can push a key or use your switch to make the computer speak for you.

WHAT ARE THE "ALLIANCE FOR TECHNOLOGY ACCESS FOR THE DISABLED" AND "THE REHABILITATION ENGINEERING AND ASSISTIVE TECHNOLOGY SOCIETY OF NORTH AMERICA" (RESNA)?

There are 39 nonprofit computer centers throughout the country organized by the **Alliance for Technology Access.** They provide an opportunity to try various communication aids before you purchase them, as well as make specific recommendations as to the type of computer software that will fit your needs. The centers, which often employ people who are knowledgeable about ALS, are free or request nominal donations for their services.

The national headquarters, located in Petaluma, California can direct you to a center in your area: call (707) 778-3011, fax (707) 765-2080, TTY (707) 778-3015, and/or web site www.ataccess.org.

The Alliance also has an online resource library that contains many useful resources.

RESNA Technical Assistance Project provides technical assistance to the 56 state and territory assistive technology programs as authorized under the Assistive Technology Act of 1998. For more information on a local chapter, go to www.resna.org or call 1(703) 524-6686.

There are many excellent web sites that provide information on products and Medicare, some include:

www.aac-rerc.com (Medicare and AAC policies)
www.cini.org
www.augcominc.com

WHERE CAN YOU FIND FUNDING FOR THESE DEVICES?

Computers and special communication devices can be expensive. Some insurance companies will cover the cost of communication devices, especially if one is recommended by a speech pathologist and presented to the insurance company as a piece of durable medical equipment (DME). In addition, most Medicaid programs will cover augmentative communication (Speech Generating Devices) with a speech pathology recommendation and physician prescription. As of January 1, 2001, Medicare will provide reimbursement for some AAC devices (referred to by Medicare as "speech generating devices" or "SGD"). An excellent web site for up-to-date Medicare policies with regard to which devices are covered, and the assessment and application process is www.aac-rerc.com. You can also call your local ALS Association chapter for more information.

Additionally, you can make a request to the community service groups in your area. Religious organizations, nonprofit social service agencies, or even groups of friends may help raise money for you. Sometimes the **State Department of Rehabilitation** will provide the assistive device, if it allows your caregiver to leave your home and go to a job or enables you to do some work. (For more details about funding resources, please see Manual 1.)

The Last Word on Speaking

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. However, there is no limit to what you can communicate. 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.

By maintaining communication with others, you continue to make a significant difference in their lives, while retaining control over your own. You need to remind people that you want and expect to be included in the world around you. With 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. It is hoped that the information provided in this manual will help you with these endeavors.

Notes

Notes

The following is a list of the topics covered in the *Living With ALS* manuals:

Manual 1

What's It All About?

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

Manual 2

Coping with Change

This manual 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.

Manual 3

Managing Your Symptoms and Treatment

This manual discusses the symptoms that affect you when you have ALS and how to treat them. It also covers the most recent breakthroughs in medications and how these treatments can improve the quality and duration of your life.

Manual 4

Functioning When Your Mobility Is Affected

This manual covers the full range of mobility issues that occur with ALS. It specifically 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.

Manual 5

Adjusting to Swallowing and Speaking Difficulties

This manual addresses swallowing difficulties and how to maintain a balanced diet with ALS. It also covers how speech can be affected by ALS and the specific techniques and devices available for improving communication.

Manual 6

Adapting to Breathing Changes

This manual explains how normal breathing is affected by ALS. Specifically, it explains how to determine if you have breathing problems and what options are available to assist you as your breathing capacity changes.

The information contained in this manual can be very valuable to people living and dealing with ALS. Please donate this manual to your local library if you no longer need it.

ALS Association™

Fighting Lou Gehrig's Disease

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FAX: 818/880-9006

Information and Referral: 800/782-4747
www.alsa.org

The ALS Association is the only national not-for-profit voluntary health organization dedicated solely to the fight against amyotrophic lateral sclerosis (often called Lou Gehrig's Disease) through research, patient and community services, advocacy, professional education and public awareness.

Member of the National Health Council and Community Health Charities (CHC)