

Patient Education

Neuromuscular Clinic for Swallowing and Speech Disorders



How Speech and Swallowing are Affected with ALS

This handout describes how

**ALS affects speech and
swallowing.**

**For speech issues it covers
tips for listeners and
speakers and what can be
done when speech problems
are severe.**

**For swallowing issues it
covers the warning signs of
dysphasia (a problem in
swallowing); tips for dealing
with swallowing problems,
for drinking enough liquids,
and managing saliva. It also
covers what can be done
when swallowing problems
are severe.**

What is dysarthria?

Speech requires precise, rapid and coordinated movements of many muscles. Normal speech is produced with a complex series of movements that combine:

- Breathing (respiration)
- Producing a voice (phonation)
- Forming speech sounds by constricting the airstream with the lips and tongue (articulation)
- Adding stress and rhythm

When we make the complex series of movements needed for speech, muscles must move in the right direction, with the right speed and force and at the right time for speech to be clear and precise. When there is a problem with the brain or nervous system that causes muscles to be weak, to move slowly or not to move together, speech will not sound natural and may be difficult to understand. This is called **dysarthria**. There are different types of dysarthria, depending on what part or parts of the brain are involved. Sometimes people who have dysarthria speak very slowly because their muscles are weak and do not move easily or quickly. This is often the case for people with ALS. Depending on the muscles affected, changes in speech quality also can occur. Speech can sound nasal, and the voice can sound breathy or harsh.



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How does ALS affect speech production?

ALS is a progressive disease that damages or destroys motor neurons. There are two types of motor neurons. The **upper motor neurons** start in the higher centers of the brain and carry information to lower motor neurons. If the upper motor neurons are damaged, your muscles become too tight (spastic) and your reflexes become too strong. The **lower motor neurons** in the brainstem and spinal cord carry messages to your muscles. If the lower motor neurons are damaged, muscles become floppy and weak (flaccid). You also see wasting away of the muscle tissue (atrophy). In ALS, the first speech symptoms depend on whether the damage is primarily in the upper or lower motor neurons.

Motor neurons that go to the brainstem control the muscles of your face, tongue and throat. This group of muscles is often called the bulbar muscles. When the nerve cells in the brainstem (bulbar nerves) are damaged, you will have difficulty chewing, swallowing, coughing, and speaking. Changes in your senses (touch, sight and hearing), intelligence and personality are not usually seen.

In ALS, the muscles can have too much tone (spasticity) or too little tone (flaccidity). In either case, movement of the muscles is weak and movements are slow. The changes in speech that we hear depend on what speech muscles are affected. If the muscles for breathing are affected, you may not have the respiratory power for strong speech. If this is the case, you may have difficulty speaking loudly for an extended period of time, speaking in a noisy place, or speaking a long sentence on a single breath. You may also feel tired after talking.

If your vocal folds are too tight, they will not be able to come together smoothly to make a voice. In this case, your voice may sound harsh or strained. If your vocal cords do not have the strength to come together properly, your voice may sound breathy. The pitch of your voice may also be too low or too high. When the vocal folds do not move apart as they should, you may hear a sound or “voice” when you inhale. Weakness in the muscles of the lips, tongue, jaw and soft palate (back of the roof of your mouth) may make it difficult to say consonants and vowels clearly. This makes your speech sound slurred and at times hard to understand. Your speech may also sound very nasal and air may actually come out of your nose when you speak.

What can be done about ALS dysarthria?

Treatment varies depending on the cause, type and severity of the problem. The main goal of treatment by a speech-language pathologist is to enhance participation in the kinds of communication activities that the speaker wishes. A speech-language pathologist may be able to help people with dysarthria speak more clearly through speech therapy. There are also ways to help listeners understand better. Speakers with dysarthria and their communication partners can learn ways to change surroundings to understand communication easier (for example, by cutting out noise.) Treatment may involve teaching a person ways to compensate for limitations in muscle movement with techniques such as talking in short sentences, speaking slowly or emphasizing key words. Communication is a two-way street and depends on the skills of both the listener and the speaker with dysarthria. These tips may make communication easier for both the speaker and the listener:

Tips for the listener:

- Take charge of the communication environment by making sure the room is quiet
- Give your undivided attention to the speaker, watch him or her and don't try to accomplish other tasks at the same time you are listening
- Be honest and acknowledge the difficulty you are having understanding
- If you haven't understood part of the message, repeat the part you did understand. That way, the speaker doesn't have to say that part again
- If you still don't understand, ask the speaker to write down some key words or ask questions that can be answered with a yes or no to clarify the message

Tips for the speaker with dysarthria:

- Introduce the topic of your message. Provide your listener with the context or background for what you are saying. This will help them understand you
- Ask others to let you know when they can't understand you. In that way, you will know when you need to repeat or speak more loudly and clearly

- Speak loudly and slowly, and separate words and phrases with small pauses
- Time important conversations during periods when you are not fatigued. Some people prefer to take part in important conversations in the morning

What can be done when speech problems are very severe?

Alternatives to natural speech may be needed when dysarthria is severe. Augmentative communication techniques, such as the use of simple gestures to supplement speech, or communication aids like alphabet or language boards, may be recommended. Sophisticated electronic or computer-based systems, which can be controlled with motions as simple as an eye blink or a head nod, are also available. These systems can even be used by those with very severe physical problems.

The type of augmentative communication approach you and your therapist select will depend in part on your physical capabilities. Also your specific communication needs are very important when selecting a communication system. You can imagine that a communication device that allows you to communicate basic needs and self-care requests to people who know you well would be quite different from a communication device that allows you to express lengthy, complex messages to strangers in a work setting or to talk on the phone.

When selecting assistive technology to compensate for severe speech problems, you and your therapist will review your physical abilities, your needs and the environments where you wish to communicate. Here are some examples of questions that may help you decide:

- Do I need to signal an emergency?
- Do I need to ask for basic needs?
- Do I need to prepare new messages all the time?
- Do I need to prepare long messages for a special occasion such as a doctor's visit?
- Do I need to communicate with strangers?
- Do I need to communicate in groups?
- Do I need to communicate over the phone?
- Do I need to communicate in bed?
- Do I need to communicate in a work setting?

The time may never come when you will need to use augmentative communication devices. However, knowing your physical abilities and communication needs, the speech-language pathologist will be able to help you develop a plan for communication. This plan may include selection and funding of the assistive technology that best meets your needs.

What is dysphagia?

Dysphagia is a problem in swallowing. Like speech, the process of swallowing safely is complex. Normal swallowing occurs in stages:

- Oral preparatory (chewing) stage
- Oral stage
- Pharyngeal (throat) stage
- Esophageal (food tube) stage

In the oral preparatory stage, food is placed in the mouth and chewed. In the oral stage, the muscles of the tongue, cheeks, and upper part of the throat move the food to the back of the mouth. During the pharyngeal stage, the voice box (larynx) is drawn up toward the base of the tongue, and the tongue moves back to meet the larynx. The vocal folds then close to keep food from going into your windpipe. The soft palate lifts to close off the passage to your nose. A muscle at the top of the esophagus relaxes to allow food to enter the esophagus. During the esophageal stage, food is passes down the esophagus to the stomach through a wavelike action of the muscles. Swallowing problems or dysphagia can occur at any stage of swallowing.

What are the warning signs of dysphagia?

Dysphagia is dangerous because it puts you at risk for food or liquid “going down the wrong pipe” and thus entering your airway. It may also prevent you from eating enough food and drinking enough liquids. Here is a list of some warning signs that you might be at risk for or have a swallowing problem:

- You often choke or cough when you eat or drink
- You are unintentionally losing weight
- You notice drooling
- Mealtimes take much longer than they used to
- You no longer enjoy eating
- You have difficulty chewing food

- You have to try several times to start a swallow
- Food seems to “stick in your throat”
- You have recently had pneumonia

How does ALS affect swallowing?

ALS weakens the muscles of swallowing and results in dysphagia. Your symptoms depend on where the weakness is. If you have weakness and difficulty moving your tongue, it may be too hard to move the food around in the mouth for chewing and then to move it to the back of the mouth so that a swallow can start. If the muscles of the throat are weak, there may be difficulty with the muscle action that pushes the food down. This may feel like the food is “sticking in your throat.” Thin liquid, including water, can be difficult to manage if your tongue and lips are weak. Liquid may escape between the lips, causing drooling. Because the muscles will have difficulty directing the liquid to the right place, it may “go down the wrong pipe” and cause choking.

Your vocal folds have two key functions. The first is to produce a sound when speaking. The second is to close when you swallow to keep food and drink from getting into your windpipe. If the vocal folds are weak, your cough may be weak and may not do a good job of protecting your airway.

What can be done about swallowing problems?

Just like there is no cure for the speech changes in ALS, no one can cure your swallowing problems. However, there are many things you can learn to do to compensate for swallowing problems. These suggestions might make eating and drinking easier for you and lower your risk for choking and aspiration (getting food or liquid in your lungs.)

- Sit upright. Sitting upright in your chair while eating is generally the best position for safe swallowing. Leaning backward or swallowing food when reclined is not recommended.
- Take small bites. Place only small amounts of food or liquid in your mouth at one time. If you are drinking through a straw, take one sip at a time, hold it in your mouth, then swallow.
- Think “swallow.” Hold the food or drink in your mouth and think about swallowing, then swallow forcefully.
- One bite at a time. Swallow all the food or drink in your mouth before putting more in. Bits of food can collect in your mouth, slip

backward into your throat at the wrong moment, and cause choking later.

- Concentrate. Always eat slowly and carefully, paying attention only to eating. Don't watch TV or try to talk at the same time you are eating or drinking.
- Keep your chin down. Tucking your chin or keeping it down as you swallow may make the swallow easier and will lower the chance of food trickling into your windpipe.
- Place food in the back of your mouth. If moving food to the back of your mouth is difficult, put the food as far back on your tongue as possible. If the muscles on one side of your face are weak, place the food on the stronger side on your tongue. If your lips are weak, causing food to leak out of your mouth, try gently pinching your lips together with your fingers.
- Eat often. Eating six small meals rather than three large meals keeps you from tiring your already weakened muscles.
- Eat foods that are dense in calories. Make the most of your time and effort by eating healthy foods, not empty calories. It is more efficient to spend the same amount of time and energy drinking a milkshake than drinking a diet soda.
- Remain upright. It is a good idea to sit upright for a period of time after eating. That way, if food remains in the mouth or the back of the throat, it will slide down to your esophagus, rather than falling into your windpipe later.
- Drink lots of liquids. Long term dehydration can cause fatigue. Dehydration also causes thick saliva that may be more difficult to swallow than thin saliva. Drinking two quarts of liquid per day is recommended.
- Choose your foods carefully. Eating foods that are the easiest texture for you to swallow will help prevent choking problems and keep you from getting tired.

How can you drink enough fluids?

People with ALS often have more problems drinking thin liquids than eating solid foods. It is very important to provide your body with plenty of liquids (about two quarts a day is a good target.) Thick liquids, such as pear juice or apricot nectar, tomato juice, eggnog, milkshakes, instant breakfast products, supplements such as Ensure, and creamed soups are easy to swallow. Thin liquids, such as water, apple or orange juice, coffee and tea are more difficult. Thin liquids

are difficult because they are hard to control in your mouth. They have no texture and spread out in your mouth. Here are some tips for drinking enough liquids:

- Sip liquids all day long. Many people with ALS carry a sports bottle with them at all times. In this way, they can sip iced liquids all day long. It is very difficult to meet your fluid needs all at once.
- Avoid liquids that are at body temperature. Cold liquids tend to stimulate the swallow. We do not usually recommend very hot liquids because most people prefer to cool them to body temperature before swallowing them.
- Try carbonated drinks. Some people find that carbonation adds texture to liquids and makes them easier to swallow.
- Avoid caffeine. Avoid caffeinated drinks (coffee, tea, and many colas) because caffeine causes water loss and should not be counted into your two quart per day target amount.
- Drink the liquids that you enjoy. Your liquid intake doesn't need to be water. It may be easier to reach your target if you choose a drink that you enjoy.

What can be done when swallowing problems are very severe?

As your illness gets worse, you may reach a point when you cannot swallow food or liquid anymore. This may happen because the danger becomes too great that food or liquid will get into your windpipe and lungs. It may also be so difficult to eat safely that you simply cannot eat or drink enough to meet your nutritional needs. At times, people with ALS begin to dread mealtimes. If you reach this point, you may wish to consider taking your food by tube rather than by mouth. A small tube can be inserted directly into your stomach. This is called a gastrostomy. A common procedure is called a PEG, which stands for Percutaneous (through the skin) Endoscopic (using a small scope) Gastrostomy (into the stomach.)

Keep in mind that a PEG tube does not prevent you from eating by mouth. It does not change your ability to swallow. It does not make swallowing any easier or any more difficult. PEG tubes are simply a way of getting calories and fluid and bypassing areas where chewing and swallowing problems occur. Many people with ALS eat for enjoyment and supplement eating with tube feedings. Others will use the tube to meet their fluid needs or take their medications. Other people will use the tube only when they are in a hurry and would

prefer not to take the time to eat a full meal. Although the decision to use tube feeding is almost always a difficult one, most people with ALS are pleased with the result. Many indicate that it takes some of the burden of eating off their shoulders and adds to their quality of life.

What can be done about excessive saliva?

When swallowing problems become severe, people with ALS often complain that they feel that they have extra saliva. Most of the time, this is not the result of producing extra saliva, rather the result of not automatically swallowing the saliva as often as normal. Here are some tips for handling the extra saliva:

- Frequent swallows. Swallow often and clear your mouth. Because this may not be automatic, you may need to remind yourself to do this.
- Sleeping position. If you have trouble with choking on saliva while lying down, raise your head so your neck is flexed during sleep or lie on your side to allow saliva to drain out of your mouth onto a towel.
- Avoid phlegm-producing goods. People with difficulty swallowing often report that uncooked milk and milk products, such as ice cream or chocolate, increase phlegm. Boiling milk and substituting sherbet for ice cream are possible solutions.
- Papase. Some people have noticed that papaya or pineapple juice tends to decrease mucus. Dissolving a papase tablet (an enzyme made from papaya) slowly in your mouth or swabbing meat tenderizer (that contains papase) in your mouth can help thin your mucus.
- Maintain liquid intake. Thick saliva is more difficult to manage than thin saliva. Drinking enough liquid is one of the key ways to make sure that saliva is thin.
- Mints. Some people say that strongly flavored mints such as Altoid mints are helpful.
- Medications. If excessive saliva continues to be a problem, talk with your doctor or nurse about medications to decrease saliva.

Questions ?

Neuromuscular Clinic
for Swallowing and
Speech Disorders:
(206) 598-4022

Your questions are important. Call your doctor or health care provider if you have questions or concerns. UWMC Clinic staff are also available to help at any time.

Other clinics that can provide information are:

Rehabilitation Medicine/
Muscular Dystrophy
Association Clinic:
(206) 598-4295

Pulmonary Medicine
Clinic:
(206) 598-4615

Notes



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8/2001