

Tips:

Difficulty in eating and drinking

Eating and drinking are more than a necessity to stay alive: dining together has a social, emotional and gastronomic dimension and the opportunity to do so largely determines the quality of our lives.

When someone is faced with swallowing problems, this often leads to withdraw from family and social life. Swallowing problems are a combination of motor disorders, a weakened sensitivity and a decrease of reflexes

At the onset of the disease, the ALS patient only chokes occasionally. Due to the limited impact of these problems most of the patients do not report them immediately. After a while however the swallowing difficulties become more serious and more difficult to treat. Early registration and a quick therapy prevent many problems.

Together with the other counselors and with your family and friends (that are involved in your diet and therapy) we want to help you reduce the discomforts of swallowing difficulties when eating.

Swallowing occurs unconsciously, quickly and precisely. It is an extensive process whereby voluntary and reflex movements are coordinated.

The swallowing occurs in three phases.

What happens when we swallow?

Oral phase.

Correct.

The food chunk is formed by the chewing that converts the food to a solid mass. The tongue and the palate contract and thus push the food back in the mouth. The palate is raised so that the food cannot go to the nose.

Incorrect.

If the food chunk is not converted to a solid mass, you get a lot of small chunks in the mouth. This increases the risk of choking.

Pharyngeal phase.

Correct.

Here the swallowing reflex is induced. This consists of the sinking of the epiglottis, the rising of the larynx and a movement of the tongue whereby the food chunk is pushed in the throat (larynx). The epiglottis closes off the larynx and thus assures that the food chunk enters the esophagus while protecting the trachea.

Incorrect.

A delayed or absent swallowing reflex (in fact a motor and/or sensory disturbance) enormously increases the risk of choking and aspiration (food in the trachea) because the closing of the trachea is not guaranteed. If you have a fragmented food chunk, the risk is even bigger because it makes it difficult to induce the swallowing reflex.

Esophageal phase.

Correct.

This phase is just like the last fully reflexive. The food chunk goes down the esophagus to the stomach. This phase terminates the automatic swallowing.

Incorrect.

- The food particles which are not ingested may be inhaled.

The swallowing problems oblige you to adapt your meal and the preparation of it. By making simple changes and different degrees of emphasis in the preparation, you can again enjoy your meals.

A pleasure for the eye.

Try to present your meal as attractive as possible through more color variation and a good plate settlement.

Enjoy the fragrance.

Before tasting, you smell the meal. The smell of the food and its preparation tickle your memory for tastes and allows you to enjoy your meal.

That delicious taste.

For people with swallowing problems, the taste is a precious thing because it stimulates the sensitivity of the mouth.

There are a lot of ways to preserve the taste of food:

- Use simple cooking techniques such as steaming and grilling
- Prefer light sauces over cream sauces that disguise the original flavor of the food
- Take care of variation in the food
- Feel free to use herbs in cooking to give more flavor
- Serve meals at the right temperature (a meal that is too cold or too hot loses its flavor)

Advice to swallow safely

For the patient.

- Get a good sitting posture
- Keep your head up
- Bend your head slightly forward when swallowing to stimulate the swallowing reflex
- Avoid as many distractions as possible while eating
- Take into account fatigue in ALS and try to plan your meals accordingly
- Brush your teeth after each meal

When choking: no panic!

1. Close your mouth and block your breathing for a while
2. Breathe in slowly through your mouth
3. Cough as hard as possible
4. Empty your mouth
5. Repeat 2 and 3 if required.

For the environment.

Never leave a person with swallowing problems alone during a meal. Choose, for the safety, a place at the table that the patient can easily and quickly leave in case of problems.

Take care that the position of the patient in the chair or in bed is correct when you feed the patient, keep in mind the following tips:

- Sit down in such a way that the patient does not have to turn his/her head
 - Make sure that the denture is secure
 - Make sure that the nose of the patient is properly cleaned
 - Do not distract the attention of the patient
 - Do not cut the pieces too large in the preparation of the meal
 - Do not give a big mouthfuls
 - Take your time to feed the patient and make sure that breathing continues smoothly after each swallow
 - Ensure that no food particles remain in the mouth after the meal
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- Help the patient to follow the 5 tips
 - Facilitate coughing, if necessary, by pushing just below the ribs during the coughing
 - If breathing remains locked, apply the Heimlich maneuver.

The Heimlich maneuver.

When one chokes on solid food, breathing can completely block. In that case the maneuver of Heimlich is the first act that can offer salvation.

The patient has to bend his head forward. Stand behind the patient and let him rest on your arm. Embrace the patient and put your left fist in your right hand on the abdomen. The maneuver consists of pushing on the abdomen with a strong upwards movement.

Repeat this several times so that the diaphragm goes up strongly. In this way, remaining air is pushed out of the lungs and thus takes food rests along.

If the patient is in bed, lay him on his side and lie behind him to execute the maneuver of Heimlich. You can eventually lay the patient on his belly, across the bed while head and torso hang forward beside the bed. If breathing doesn't become normal quickly, beat vigorously with the side of the hand on the back of the patient, from the waist to the shoulder blades. Always immediately remove the food residues from the mouth.

If the patient has lost consciousness, call service 100 without hesitation. Lay him on the back, the head turned sideways. Take place on top of the patient with a knee on each side. Practice with both hands crossed on each other, a strong force, starting with the diaphragm and rising to the sternum.

For more information regarding the Heimlich maneuver [Click here](#)

How to sit while eating?

For the patient.

Try to make the position as comfortable as possible, the back against the backrest, the head straight in the extension of the spine. In order to facilitate the swallowing, bring the head slightly forward before swallowing the food.

What if the patient is bedridden?

Put the head of the bed up between 60 and 80 degrees. Make sure that the back of the patient is resting as much as possible against the bed and bend the head slightly by placing a pillow behind the head. Place a pillow under the knees.

For the relief worker.

Put the patient at the table. If you are right handed, have a seat to the right of the patient, opposite him. Try to offer the food straight without the patient having to turn his head. Foresee enough space around the patient if you need to intervene when swallowed.

Source: Brochure MS Liga

Tips for dining-, drinking- and swallowing problems

Food is a complex process in which various muscle groups are involved. Muscles in the hand and the arm hold the cutlery and bring it to the mouth. Facial muscles fit the mouth to take the food in and then keep the mouth closed. Jaw muscles control the chewing. The tongue makes a little ball or "bolus" of food and saliva and pushes the bolus down the nose. Throat muscles make the swallow movement whereby the food enters the throat. Throat muscles also close off the airway so that the food would not fall into the wrong pipe. Eventually the esophageal muscles move the food down to the stomach. Weakness or poor coordination of one of these muscles can cause problems in eating and swallowing.

Here are some ways to overcome these problems.

Coughing and choking

With weak throat muscles one can feel that the food is stabbing or it can go the wrong way to the airways that are incompletely shielded.

By coughing and choking the body loses food and drinking that is likely to be inhaled. If one gets out of breath when swallowing, the food that is visible has to be removed from the mouth with the finger. If no food is visible in the mouth, one may not reach in the throat and should not knock on the back. The best approach if swallowed is trying to stay calm and to breathe slowly and steadily through the nose and to strengthen the cough reflex. Abdominal splints when coughing helps the food stuck up, work up. To splint the abdomen the arms should be crossed over the abdomen and should be pressed firmly downwards when coughing. A helper can do that by standing behind the ALS patient and pressing his hands flat on the abdomen of the ALS patient at the time of coughing.

This important technique should definitely be practiced.

In case of noisy breathing or a gurgling voice after eating or drinking, the doctor should be consulted as these symptoms may indicate that food or fluid got into the lungs.

Each patient with swallowing and speech problems should regularly be seen by a speech therapist.

Dietary adjustments

Food is a very important part of health care for everyone, also for people with ALS. A dietician should be consulted for an adapted diet. Some change too quickly the solidity of their diet where they should enjoy a normal diet with minor modifications such as chopping meat, etc.

Recommended foods

The easiest type of food for ALS patients with swallowing difficulties has a semi-solid consistency.

Stews, chopped meat, scrambled eggs, yogurt, bananas, pears, fish and jelly are soft enough to be easily swallowed.

Another possibility is the puree diet. Daily food can easily be processed into puree in a food processor or blender; in this way the patient can eat the same as the rest of the family, but in puree form. It is important not to grind the food too much or to add too much liquid so it becomes too watery. The ideal consistency is that of thick porridge. Food that is too watery can be thickened with flour or corn flour during cooking. It is very important to avoid clotting in the thickening. There are also instant binders about which the dietitian can provide more information.

Food that can cause problems:

- Food with a mixed texture such as soup with large chunks of vegetables or meat
- Food that becomes fibrous such as bacon, tomato peel and celery
- Food that sticks in the mouth such as white bread or by boiled cabbage
- Very hard food such as nuts, raisins, hard toast
- Spicy food that can cause saliva problems with some people
- Food that crumbles when eating such as cookies, cake or dry toast

Liquids

It is normal to drink 1.5 to 2 liters of liquid per day to prevent thick mucus secretions and constipation. Alcohol should be consumed in moderation and especially the effect of alcohol on medicines that need to be taken has to be discussed with the doctor.

Food and weight control

ALS patients often lose weight through muscle loss. Weight should be controlled once per month and communicated to the doctor or dietician. Dietary changes can help preserve an optimal weight. Prescribed supplements and sweets can help to keep the calorie supply to standard. Some gain weight due to a lack of exercise. Here also the solution is dietary changes. An excellent diet should be pursued.

Some eating tips

For people with ALS eating can be a slow and frustrating matter but nevertheless it is very important not to rush. Meals should always be taken in a relaxed way and without being in a hurry.

If eating in a family environment is perceived as difficult, the ALS patient can eat alone with his/her helper and afterwards still sit at the family meal. When eating, the following posture is recommended: sit up straight in a firm chair with high back, feet flat on the ground, and the arms on the table, head straight up and retracted chin towards the chest. This way the esophagus is in the best position to take food. A support collar must be removed. A Velcro headband, attached to the back of the chair, can be a useful alternative.

To prevent the food from moving too quickly in the throat, it is recommended to take small bites of food or sips.

Eating and talking at the same time should always be avoided.

If a whole meal is too tiring, lighter or more frequent meals per day can be tried.

Efforts just before the meal should be avoided; one should go rested and relaxed to the table because food needs to be attractive and pleasant and one should enjoy aroma and flavor in an optimal way.

After the meal it is recommended to sit straight during half an hour to stimulate the digestion

Oral hygiene

It is very important to control the mouth after the meal and to remove all food particles from between cheeks and teeth. Rinse the mouth with water after meals is also helpful. Teeth should be carefully brushed at least twice a day. Electric toothbrushes, toothpicks with soft tip, dental floss and a regular visit to the dentist also prove their worth.

Constipation

Drink less because of swallowing problems, deleting fiber food from the menu can lead to constipation. In case of constipation the fiber content of the diet needs to raise by adding well moistened bran to food such as cooked cereal, calf bread and a lot of sauces. Prune juice or stewed prunes can serve as a natural laxative.

Food that contains a lot of liquid, such as pudding or sorbet is strongly recommended.

Tube feeding

For people with serious swallowing problems tube feeding can possibly be used. There are two common types of tube feeding:

- A tube that goes through the nose and into the stomach
- A tube that is inserted directly into the stomach.

Tube feeding is a simple method to administer proper nutrition (including multivitamins) in liquid form via a thin, flexible tube. Tubes of all kinds have proved their worth, but often their use is delayed because of unnecessary fear.

Saliva and mucus

When the muscles that control the swallowing weaken, it can happen that saliva and mucus are not often enough swallowed, causing it to accumulate in the mouth. Saliva can then run from the mouth or can enter the respiratory track resulting into suffocation. As too much saliva and mucus can be annoying, most people use paper towels to dab away the excess saliva. Often this problem is transient.

Following suggestions may fix this problem. First of all the patient must be aware of the problem and must provide a very conscious effort to excess saliva or mucus every minute or so by swallowing. Also firmly closing the lips can help.

There are also medicines available that keep the mouth dry by inhibiting the production of saliva and extraction equipment for extracting the excessive saliva and annoying amounts of mucus in the back of the mouth. Extraction equipment works basically like the aspirator at the dentist; it consists of a motor pump, a collection bottle, tubing and catheters.

A dry mouth however is to remedy by sipping ice water or by using cotton swabs soaked in water or a mouthwash drink.

It's very important to have a suitable humidity in the whole house.