**Swallowing Guidelines for Patient & Caregiver**

**Diet Texture:**
- Puree
- Mechanical Soft

**Hydration:**
- IV
- Non-Oral Hydration
- Thickened Liquids
- Thin Liquids

**Meal Schedule:**
- Training Meals Only
- Regular Schedule
- Supplements
- Serve ___ Times/Day

**Medications:**
- Non-Oral
- With Food
- With Water
- Crush
- Liquid Form if possible

**Head Positioning:**
- Chin Down
- Turn Right
- Turn Left
- Chin Neutral
- Chin Retroflex
- Other

**Body Positioning:**
- 90°
- Forward
- Reclined Degrees
- Other

**Solids:**
- 1/3 Teaspoon / Bite
- Place in: Right side of mouth
- Left side of mouth
- Midline of mouth
- Re-swallow
- Alternate a bite with a sip throughout the meal
- Slow Rate
- Encourage chewing cycles/bite

**Liquids:**
- Liquids from spoon only
- May have small sips from cup/glass
- Re-swallow
- One sip then swallow
- May use continuous cup sip (more than one sip before taking cup away from lips)

**Additional Suggestions:**
- Reflux precautions needed:
  1. Don't lie flat for ___ minutes after eating/drinking.
  2. Nothing to eat/drink within 2 hours of bedtime.
  3. Decrease/eliminate caffeine, chocolate, smoking.
  4. No restrictive belts/clothing across abdomen.

**Special Things Needed:**
- Dentures
- Hearing Aid
- Glasses
- Adaptive Equipment

**Patient Name:**
- Take medications at least ___ times a day
- Take medication ___ times a day

**Additional Instructions:**
- TEETH AND TONGUE BRUSH AT LEAST AND IF POSSIBLE
Introduction

When a person has trouble with swallowing or is not able to swallow, it is called dysphagia. This is often caused by a traumatic brain injury (TBI) or stroke. TBIs and strokes can happen without warning and harm areas of the brain that control parts of the body.

Most of the time, swallowing happens in a smooth and timely way. When you swallow, you are not aware of how complex a function it really is.

While in the hospital, the patient gets therapy to learn how to swallow and eat again. When the patient is ready to go home, the role of the caregiver becomes very important.

This book is written for you, the caregiver. It will help guide you and answer questions as you take on this role when your loved one comes home.
How Swallowing works
What to eat and drink

One of the first things a person wants to know is, "What can I eat?"

The type and firmness of food and liquids given depend on the swallowing problem. A member of the health team, most often the Speech-Language Pathologist (SLP), will review your loved one's progress often to see if he is ready for an upgrade in his diet. If there are problems with any food or liquid, talk to the SLP as soon as you can.

Work with your SLP to make a list of the foods and liquids your loved one can eat. They will come from one or more of the groups listed below.

- pureed foods: mashed potatoes • blended vegetables
- ground foods: ground beef • ground rice • ground grapenuts
- chopped foods: Cut no larger than a little fingernail.
- cut foods: Cut no larger than a thumbnail.
- soft diet: Size of food is not important. Food must be soft enough to be eaten with no teeth-
- extra thick liquids: milkshakes • baby cereal icecream • Jello* • pudding .
- thick liquids: milk • thick nectar instant breakfast • tomato juice
- thin liquids: water • broth - Sahka* • skim milk
Many find that these items give them trouble for a time after they are able to eat and drink everything else:

- bread-type foods
- rice
- stringy vegetables
- tart or tangy foods that increase saliva
- plain water

"I can't eat rice; it is one of my favorite foods. Cheese sandwiches ball up in my throat. When I stop having trouble with other things, I will try rice again."

With the help of a dietitian, the SLP will decide what your loved one needs to eat and drink. He must get enough calories and liquids each day to stay healthy. If you see that your loved one is not swallowing well, is taking too long to eat or becomes less alert, then he most likely isn't getting enough to eat and drink. Talk to the SLP if you notice any of these.

Once your loved one goes back on a regular diet, it is still important to make sure he swallows in the right way.
Silent aspiration

Before your loved one leaves the hospital, the SLP should assess his swallowing process. He will check to see if your loved one has a problem with the aspiration of food or liquid. At times you can tell right away when a person has aspirated, but other times you can't tell. This is called silent aspiration.

Aspiration -when
food or liquid
gels into the
lungs

The SLP will do all he can to make sure this won't happen when you take your loved one home. But there is a chance that silent aspiration can occur. If it does happen and is not treated, pneumonia can result. Because of this, you should know the signs of silent aspiration and pneumonia. Watch for these signs, and call your SLP at once if any of them occur. If caught and treated early, serious problems may be avoided.
constant, low-grade fever, most often between 99-100 degrees (Any temperature one degree above the norm for that person can be called a low-grade fever.)

• increase in chest secretions toward the end of the meal or within one hour after eating. (Coughing up mucus may mean there is a problem.)

rattling in the lungs

cold-like symptoms in the chest

chest pain

not feeling well
When to call the doctor

If you notice any of these, call your doctor or SLP at once to find out what the problem is and how to keep it from happening again.

1. coughing while eating, drinking of soon after
2. congestion in the chest after eating or drinking
3. wet sounding voice during or after eating
4. slow earing (more than usual)
5. weight loss
6. more than 1 or 2 swallows on a single mouthful of food
7. trouble chewing or swallowing (more than usual)
8. being tired or short of breath while eating
9. rise in temperature 30 minutes to an hour after eating
10. signs of pneumonia

PHONE NUMBERS:  Doctor.  SLP
Medicines

Many people with swallowing problems find it very hard to take pills. You may have to grind medicines.

Some medicines can cause problems like:

- a dry mouth that makes it hard to swallow
  The food, sip, food, sip technique helps.

- feeling sluggish, sleepy and tired
  This can make it even harder to swallow.

Tell your SIP of any problems caused by medicines. Often, the medicine can be changed or you can learn ways to handle the problem.
What Is Caregiver Burnout?

Caregiver burnout is caused by too much long-term stress. It occurs when you feel overwhelmed and can't meet constant demands. As the stress continues, you begin to lose the interest or motivation that led you to take on a certain role.

Your emotional and psychological health can affect your physical health. Many caregivers don't take time to care for themselves. They begin to show signs of caregiver burnout.

Your healthy body, mind and spirit benefit your loved one just as they benefit you. Learn the signs of caregiver burnout and seek help if you're having them.

What are the signs of caregiver burnout?

As a caregiver, you're under a lot of stress. It's common for caregivers like you to let your health suffer. So, watch out for:

• Excessive use of alcohol, medications or sleeping pills
• Appetite changes — eating too much or too little
• Depression, hopelessness, feelings of alienation, lack of energy to do new things
• Losing control physically or emotionally
• Neglect or rough treatment of the person for whom you're caring
• Trouble falling or staying asleep
• Difficulty concentrating
• Missing appointments

If you recognize the warning signs of burnout, it will only get worse if you ignore them. Take steps to get your life back into balance.

How can I avoid burnout?

It takes a combination of things to avoid burnout. Taking care of your physical health is a good way to stay emotionally healthy. Start working towards achieving your health goals. Take it one day at a time and make small changes.

Follow the ABC’s of preventing heart disease and stroke:
• Avoid tobacco.
• Become more active.
• Choose good nutrition.

This will go a long way toward healing your heart and strengthening your mind.

What do I do about depression?

Clinical depression is a serious illness and can keep you from being a good caregiver for your loved one. Depression is also common among survivors of heart and stroke events. It's important to learn the signs of depression and get help if you experience several of these
What is Caregiver Burnout?

Symptoms for two weeks or more,
• Depressed mood
• Marked loss of interest or pleasure
• Feeling worthless or guilty
• Change in appetite or weight
• Loss of energy
• Fearfulness of activity
• Sleeping too much or too little
• Lack of interest in personal hygiene
• Lack of interest in sex
• Anxiety
• Tearfulness
• Easily distracted
• Agitation or restlessness
• Inability to concentrate or make decisions

Depression can often be treated with medication. If you need help dealing with your emotions, seek out a support group, counselor or physician. If you have thoughts of death or suicide, seek help immediately.

How can I learn more?

0 Call 1-600-AHA-USA1 (1-800-242-8721), or visit heart.org to learn more about heart disease and stroke,
Q Sign up to get Heart Insight, a free magazine for heart patients and their families, at heartinsight.org.
© Connect with others sharing similar journeys with heart disease and stroke by joining our Support Network at heart.org/supportnetwork.

Do you have questions for the doctor or nurse?

Take a few minutes to write your questions for the next time you see your healthcare provider.

For example:

I think that I have too many signs of depression. Is there a treatment that will help we feel better and provide better care for my loved one?

We have many other fact sheets to help you make healthier choices to reduce your risk, manage disease or care for a loved one. Visit heart.org/answersbyheart to learn more.