

Safe Swallowing for PALS: What I Need to Know and Why it Matters



Understanding Safe Swallowing

- ✓ The Swallowing Process Explained
- ✓ Swallowing Difficulties & Safe Swallow Strategies
- ✓ What is a Swallow Study?
- ✓ When and How to Use Thickening Agents
- ✓ Maintaining Nutritional Needs
- ✓ Modified Diets and Products
- ✓ Why is Oral Hygiene Important?
- ✓ Resources for PALS Experiencing Swallowing Difficulties

Swallowing Difficulties in PALS

Swallowing is one of the most complex processes in the body. It involves the precise coordination of over 26 pairs of muscles and 5 cranial nerves to safely and effectively move food from the mouth to the stomach. The swallowing process is divided up into four stages. Weakness or spasticity of the muscles needed for safe and efficient swallowing can lead to difficulties during any of these stages in people with ALS (PALS).

Oral Preparatory Stage: Involves the transfer of food and liquid from a plate or cup into the mouth. Efficient hand to mouth movement is required during this stage. PALS with weakness in the arms and/or hands may have trouble moving food or liquids into the mouth.

The use of adaptive feeding utensils, straws, raised feeding trays for drinking, and assistance with feeding are useful strategies for PALS experiencing difficulties during this stage.

Oral Stage:

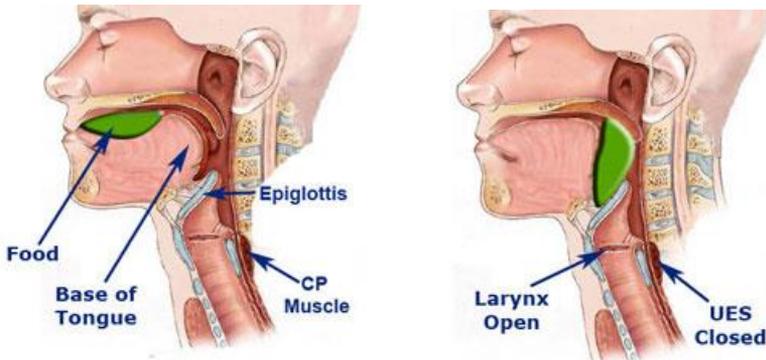


Image courtesy of Babak Larian, MD, FACS - larianmd.com

Oral Stage: Once the food is in the mouth, chewing occurs, and foods are mixed with saliva to form a cohesive piece that is ready to be swallowed. The tongue pushes the food toward the back of the mouth. When it makes contact with the back of the throat, the swallowing reflex is triggered. PALS may experience difficulties keeping food and liquids in the mouth due to lip weakness. Chewing can be difficult due to weak jaw and tongue muscles. This may result in leftover food in the mouth and cheeks.

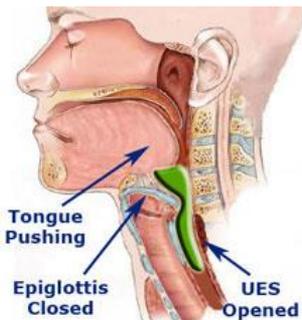
Covered drinking cups with spouts and straws may help control and direct liquids to the back of the mouth. Changing your diet to softer foods that require less chewing will minimize effort and potential fatigue of the chewing muscles.

Pharyngeal Stage:

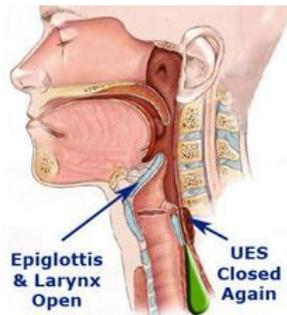
During this stage, throat muscles contract to push food down into the food pipe (esophagus). At the same time, the epiglottis flips and the vocal folds close to protect the airway and prevent food and liquid from entering the lungs. PALS may have difficulties protecting their airway resulting in material entering the windpipe during swallowing (aspiration). Signs of aspiration can include coughing, choking, shortness of breath, wet/gurgly vocal quality and spikes in temperature. Chronic aspiration can lead to pneumonia. Due to throat muscle weakness, foods may hang-up in the pockets of the throat. Changing head and body posture and using recommended swallow strategies may help protect the airway and limit food collection in the throat.

Thickening liquids help to slow the flow of liquids through the throat and provide more time for closing the airway. The use of gravies and sauces can help moisten foods and ease passage through the throat. Alternating food and liquids after every 2-3 bites or doing a hard, effortful swallow can help to wash residual food from the throat.

Pharyngeal Stage



Esophageal Stage



Images courtesy of Babak Larian, MD, FACS - larianmd.com

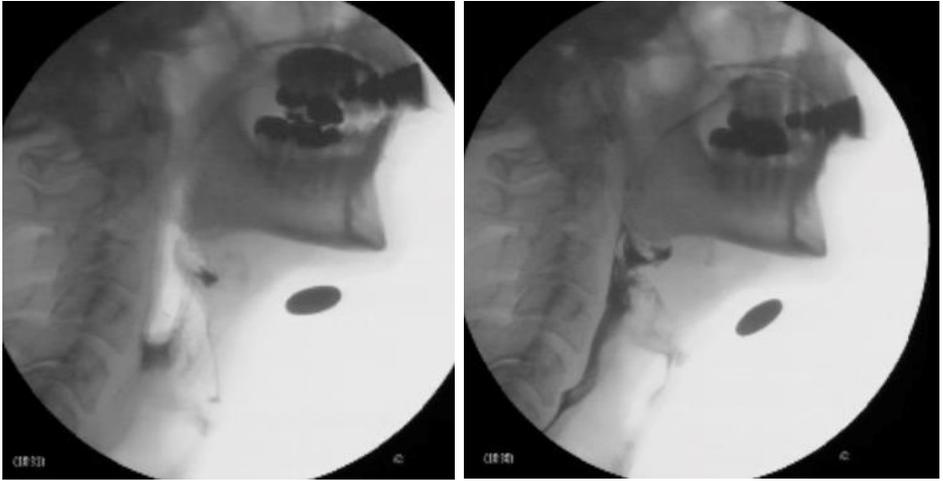
Esophageal Stage:

During this stage the food moves from the throat into a muscular tube (the esophagus) that contracts to push it into the stomach. Some PALS experience spasms of the muscle between the throat and esophagus (upper esophageal sphincter, UES) which may result in the food coming back up into the throat or difficulties with materials passing from the throat into the esophagus.

A variety of pharmacologic, surgical and behavioral treatments can be utilized to minimize heartburn, acid reflux, or regurgitation.

What is a Swallow Study?

A swallow study, also called a modified barium swallow (MBS) is the “gold standard” diagnostic exam that speech language pathologists (SLP) and radiologists perform to evaluate swallow function. This exam provides a real time moving x-ray that allows the SLP to identify areas of weakness or dysfunction, assess degree of airway protection and the effectiveness of various treatment techniques.



Two examples of modified barium swallow studies.

What to expect during a Swallow Study?

During a swallow study, you will be seated in special x-ray machine. You will be instructed to drink liquid barium of different volumes and consistencies and foods such as graham crackers, a banana or cereal that are coated with barium. Regular liquids and foods are transparent under x-ray so barium is necessary to see the food. The study takes approximately 15 minutes, however radiation exposure is typically limited to under 3 minutes and is typical of other diagnostic evaluation procedures. The SLP will record the video images and review them during and after the study. She will then review the video and highlight pertinent findings with the patient and caregiver.

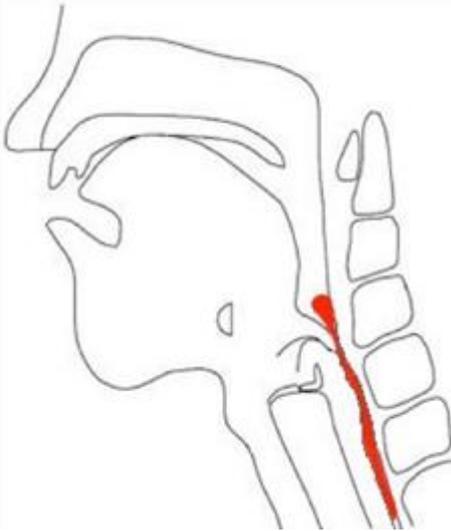


Illustration of normal swallowing with **adequate airway protection** (the epiglottis is inverted to cover the airway and the vocal cords are closed). Swallowed material (in red) is coming from the mouth, down the throat and into the food pipe (esophagus and stomach).

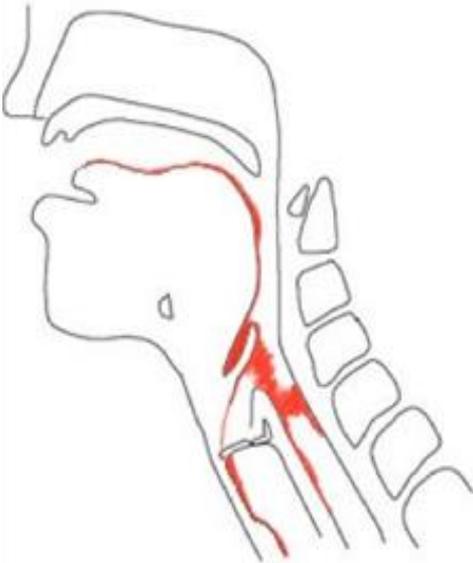


Illustration of **poor airway protection** and aspiration of material into the trachea or windpipe. The airway has not been adequately protected by the epiglottis or closure of the vocal cords and material has entered the trachea (airway) and is routed towards the lungs.

When and How to Use Thickeners



Thickeners are used to alter the viscosity of liquids and therefore decrease the speed or flow rate of swallowed liquids. This gives PALS greater control of the liquid, which can lead to a safer swallow. A qualified SLP will determine if thickening agents are appropriate for you and recommend either a nectar-thick or honey-thick thickener.

Starch-based thickeners are made of modified cornstarch or maltodextrin, and require about 1-3 minutes of vigorous stirring with a fork. They tend to produce a slightly grainy texture and do not maintain their consistency over time. They work best with purees and blended into food. **Gel-based** thickeners, made from xanthan or cellulose gum, work well in hot and cold drinks and maintain their consistency over time but tend to impart a mild slippery feel to the item being thickened and require about 5 minutes of vigorous stirring.

Starch-based thickeners:

- Thick-It
- Thick-It2
- RESOURCE ThickenUp
- Thick & Easy
- Thick & Easy 2

Gel-based thickeners:

- RESOURCE ThickenUp Clear
- Thick and Easy Clear
- Thick & Clear
- Simply Thick

Measure carefully and blend completely for best results.

Thickeners, pre-made thickened beverages, and pureed products can be purchased from the following locations:

Thick-it Products:



Local stores: CVS, Walgreens, Walmart

Online: Dysphagia-Diet.com
Walgreens.com
CVS.com
Amazon.com

Phone: 4WebMD 1-877-493-2633
Dysphagia-Diet 1-800-633-3438

RESOURCE ThickenUP



Local stores: Walgreens, Walmart

Online: Nestlehealthscience.us
Amazon.com
Walgreens.com
Walmart.com

Thick & Easy



Not sold in stores

Home Care Nutrition.com includes a full line of modified foods such as thickened foods and beverages, broths & soups and desserts.

Online: www.homecarenutrition.com
Also available at: Amazon.com
Walgreens.com

Simply Thick



Local stores: GFS Marketplace, Walgreens, Moffitt Cancer Center Pharmacy, Medical & Nutrition Supply, Bay Front Medical Center, Medical Arts Pharmacy Sarasota

Online: www.simplythick.com

Phone: (800) 205-7115

Importance of Maintaining Nutritional Needs

Maintenance of weight and proper nutrition is very important for PALS. If an individual cannot meet their nutritional and hydration needs, or is no longer safe to take their primary nutrition orally (by mouth) because of the risk of aspiration pneumonia, then a dietician or speech language pathologist may recommend a percutaneous endoscopic gastrostomy (PEG) tube. The PEG tube is a feeding tube that is surgically placed into the stomach by a physician. With a PEG tube, a patient can supplement their oral intake with nutritional supplements, such as Boost, given through the PEG. In both scenarios, the end goal is for the individual to maintain appropriate nutrition and hydration levels. An alternative to the traditional PEG is the *Mickey Button* that functions similarly to the PEG. However, it does not have a long tube extending from the insertion site so it's more comfortable and aesthetically pleasing.

Malnutrition speeds up and exacerbates muscle loss resulting in weakness of movement and further compromising the immune and respiratory systems. This muscle weakness can negatively impact an individual's ability to ingest enough calories (due to weakness, fatigue and reduced effort) that sets up a vicious cycle for malnutrition and further muscle wasting. Specific research findings indicate that: 1) Maintenance of weight early in the disease can predict a longer survival in PALS (Arahata et al., 2012; Berryman et al., 1996); 2) Malnutrition increases risk of death by nearly eight times (Couratier, et al., 1999); and 3) PALS survived three times longer and with a higher quality of life when malnutrition was prevented (Tandan et al., 2011).

When Should I Get a PEG tube?

Early PEG placement ensures a dependable means to maintain nutrition and hydration when it is needed and has been noted to increase survival in PALS. In a research study of 150 dysphagic PALS, those who agreed to have a PEG placed lived, on average, 6 months longer than those who choose not to receive a feeding tube (Spataro et al., 2011). More recently, Sterling, Plowman, Simpson and Appel (2014), reviewed medical records of 2,192 PALS and found that Peg placement extended survival by 9.5 months in spinal-onset PALS.

Current practice guidelines recommend that PEG placement should occur when: 1) a loss of greater than 10% of body weight has occurred (Berryman et al., 1996); and/or 2) **before** Forced Vital Capacity falls below 50% (Beghi et al., 2009; Miller et al., 2009) to minimize surgical risks and complications. Given the data that indicate a strong role between nutrition and wellbeing in PALS in combination with PEG survival data, ***we recommend consideration of early PEG placement so an individual can stay 'ahead of the curve' to prevent malnutrition.*** Having a PEG placed before significant weight loss ensures a 'back up' nutritional source.

Modified Diets



Delivery services for pureed food:

Blossom Foods – www.blossomfoods.com

Home Care Nutrition – www.homecarenutrition.com

Meals on Wheels Tampa – www.mowtampa.org

Smoothe Foods – www.smoothefoods.com

Top Chef – <http://topchefmeals.com/therapeutic.htm>

The Dysphagia Cookbook by Elayne Achilles

Easy to Swallow – online recipes – www.easytoswallow.co.uk

National Dysphagia Diet (NDD) – American Dietetic Association, 2002

Level 1: Pureed

All foods must be pureed and thickened to a pudding-like consistency with no lumps and requires very little chewing.

- smooth pudding, custard, yogurt
- pureed fruits and well mashed bananas
- pureed meats and eggs
- mashed potatoes with gravy or butter
- well cooked pasta, cooked cereal (farina)
- pureed vegetables

Avoid: breads, rolls, crackers, dry cereal, seeds, jello and ice cream, whole fruits, eggs, cheese, peanut butter, fish, rice, soups with lumps, un-pureed vegetables.

Level 2: Mechanical Altered (soft)

All foods are moist, soft-textured and easily chewed; meats are ground and served with gravy or sauce

- Cooked breakfast cereals and soft pancakes moistened with syrup
- Bananas and soft fruits (canned)
- Soft cakes and cookies dunked in milk
- Mac & cheese, lasagna, pasta
- Mashed potatoes and well cooked vegetables

Avoid: coarse cooked cereals, seeds, nuts, dried fruits, rice, whole fruits, dry, tough meats, peanut butter, hard cooked eggs, sandwiches, pizza, potato skins, rice, soups with large chunks, peas, corn, broccoli, cabbage, asparagus, chewy foods

Level 3: Advanced

- Includes most regular consistency foods
- Excludes hard, dry, sticky, or crunchy foods
- Foods should be moistened and in bite-size pieces
- Meats must be tender; Lettuce can be served shredded

Avoid: nuts, seeds, dried fruit, crusty bread, corn, tough meats, clam or corn chowder, rice, fried potatoes

Level 4: Regular – No restrictions

Importance of Oral Hygiene

Oral health care is very important in helping to prevent aspiration pneumonia and support respiratory health in individuals with swallowing impairment (dysphagia). The average individual produces and swallows approximately 1.5 liters of saliva daily. Individuals with dysphagia may ingest or aspirate saliva into the lungs. Saliva can carry high amounts of bacteria in individuals with poor health and therefore can increase risk of pneumonia if aspirated into the lungs.

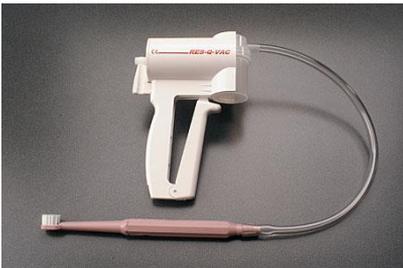
Indeed, clinical trials have identified poor oral hygiene as the number one predictor of aspiration pneumonia in older adults with dysphagia and documented that improvements in oral hygiene reduce the risk of developing aspiration pneumonia and mortality rates associated with aspiration pneumonia. (Bassim et al., 2008; Ishikawa et al., 2008; Scannapieco et al 2003; Yoneyama et al., 2002).

Oral hygiene is particularly important for PALS who have a PEG tube and who are not eating orally.

Good oral hygiene includes:

- Regular dental visits (including checkups and cleanings)
- Daily brushing and flossing before and after meals
- Oral cleaning, swabbing and rinsing with specialized products

Several products are specially designed to help with oral hygiene for PALS:



A Plak-Vac oral care system is a suction toothbrush that is used to suction out toothpaste, bacteria, fluids, plaque and debris while brushing the teeth. This can be ordered by a dentist or from Amazon.com and is helpful for people with difficulty managing oral fluids and secretions.



Electric toothbrushes are a good alternative to a traditional toothbrush as they are easier to hold, reduce arm movement, and do most of the work for you. They effectively remove plaque and bacteria.

Oral Hygiene Products



Extender and easy grip handles can easily be made by inserting a standard toothbrush into a tennis ball, bicycle handlebar grip or thick Styrofoam tubing. A toothpaste pump can also be helpful for dispensing toothpaste. A pump can be purchased at local retailers, at drugstores and on www.amazon.com.

Surround Toothbrush



The surround toothbrush cleans all surfaces of the teeth simultaneously reducing time and effort required for brushing. The Proxabrush cleans between the teeth without toothpaste. Both products can be purchase at most local retailers.

Proxabrush



Toothettes



Toothettes are sponge-like disposable toothbrushes that require no water as they are moistened by the saliva in the mouth. They can be purchased at Walmart, Amazon.com and other online retailers.

Biotene



Sometimes PALS experience excessive dryness in the mouth. Rinsing with Biotene can help to reduce dryness. For those unable to manage fluids, these toothettes with Biotene provide relief. Available at Amazon.com, Walmart and other online retailers.

Resources

The ALS Association Florida Chapter – www.alsaFL.org

The ALS Association is the only national not-for-profit health organization dedicated solely to the fight against ALS and provides a comprehensive site with a wealth of invaluable information for PALS, family members and caregivers. *Printing of this booklet funded by The ALS Association Florida Chapter.*

National Foundation of Swallowing Disorders (NFOSD)

<http://www.swallowingdisorderfoundation.com>

The NFOSD is a not-for-profit organization committed to providing individuals with swallowing disorders support, education, diet resources and updates on research related to the treatment and advancement of dysphagia (swallowing impairment).

American Speech Language and Hearing Association (ASHA)

<http://www.asha.org/slp/clinical/dysphagia/>

ASHA is the national organization for Speech-Language Pathologists. This site provides information regarding swallowing and feeding disorders, preferred practice patterns for the treatment of dysphagia, diet modifications and tube feeding issues.

Plowman Laboratory – www.plowmanlab.org

Dr. Plowman and her research team at the University of South Florida are dedicated to improving and enriching the lives of PALS suffering from swallowing impairments. This website details ongoing research efforts of her team, provides links to research articles from the lab and other useful educational and clinical resources for PALS experiencing swallowing difficulties.

iSwallow App

The iSwallow™ is a free app for use on the iPhone, iPod Touch or iPad. Intended for use under the supervision of a qualified clinician this clinical resource serves as a personal rehabilitation assistant for completing swallowing therapy exercises.

National Dysphagia Diet

www.anfonline.org/Publications/articles/2004_03_008Dysphagia.pdf

Standardized dietary management of dysphagia developed by the American Dietetic Association.

Joy McCann Culverhouse Center for Swallowing Disorders

Lauren Tabor, M.S., CCC-SLP: 813 974-3374

A Life Story Foundation – www.alifestoryfoundation.org

All product information obtained from manufacturer websites. Booklet produced independent of manufacturers of products featured with no financial compensation or implied relationship. Booklet is intended for use as a patient education guide together with education and recommendations from an SLP.

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