

# SWALLOWING PROBLEMS IN PSP

By

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Feeding and swallowing problems are very common in progressive supranuclear palsy (PSP). Dysphagia is the medical term for disordered swallowing. There are many reasons for dysphagia in PSP: difficulty looking down may limit an individual's ability to see the plate during meals; loss or defective brain cells may affect control of the swallowing mechanism; there may be a change in behavior resulting in rapid drinking or mouth stuffing; poor self feeding because of tremor or stiffness, extended head and neck posture, and dementia.

The two primary concerns regarding swallowing are:

1. The ability to swallow safely and easily, to keep food and liquid from "going down the wrong way into the trachea or windpipe", known as aspiration, increasing the risk for developing pneumonia;
2. The ability to maintain an adequate intake of fluids and calories.

There are several warning signs of a potential swallowing problem including: drooling, food collecting in the mouth, apparent increased effort with swallowing, a "wet" voice, trouble swallowing medications, increased length of mealtime, low grade fever, chest congestion, trouble talking, coughing and choking with a red face, weight loss, need for the Heimlich maneuver, or pneumonia. Some individuals with PSP may not recognize that they have a feeding or swallowing problem. This is called "silent aspiration", when the individual does not cough or choke when food, liquids or saliva go down the wrong way.

If any of these signs occur, you should notify your physician. A referral should be made to a speech pathologist that specializes in swallowing problems, and is familiar with PSP. It is often beneficial to maintain a diary of the swallowing difficulties observed, including the setting in which the symptoms occurred, and with which foods or liquids. This will make the swallowing evaluation more thorough and the recommendations more specific to your needs.

In some situations, the speech pathologist's evaluation may determine that continued intake by mouth is unsafe because of the risk of aspiration, or may be

inadequate resulting in weight loss. At this time a feeding gastrostomy tube may be considered. This is a very personal decision and should be discussed at length with family members and physicians. A feeding tube will provide adequate nutrition; however, it will not entirely eliminate the risk of aspiration.

*Feeding Suggestions:*

1. Sit upright, preferably in a chair, during meals.
2. Eliminate distractions such as television or conversation during meals.
3. Concentrate on maintaining a slow, steady rate of feeding.
4. Keep the plate of food in the line of vision, for instance, by placing it on a telephone book, if you have difficulty looking down.
5. Substitute a pair of reading glasses for bifocals, which are often ineffective in the setting of impaired downward gaze.
6. Experiment with different plates and utensils. Plates with a rim can be useful for keeping food on the plate. Using a spoon instead of a fork, or with a modified grip can make it easier to eat.
7. Experiment with different cups and glasses. Many different cups are available to restrict how much liquid you can take in your mouth at once. Safe swallowing cups or dysphagia cups help maintain your head in a safe swallowing position, usually head neutral or chin down.

*Swallowing Suggestions:*

1. Make sure the mouth and throat are clear of excessive secretions/ saliva prior to eating or *drinking*.
2. Maintain the head in a slightly chin tucked position when eating or drinking.
3. Avoid extending the head back while eating, drinking or taking medications.
4. Avoid taking too large a bite, drinking too rapidly or placing more than one bite in your mouth before swallowing.
5. Alternate swallowing food and liquids to assist with clearance of drier or more textured foods.
6. Avoid highly textured foods (red meats, raw vegetables, etc.) or dry particulate foods (rice, pretzels, potato chips, crackers, cookies, etc.). Consider changing to soft, moist foods such as canned fruits or cooked vegetables, fish and chicken, complemented with gravies and sauces.
7. Avoid items of mixed consistencies such as cold cereals, chicken noodle or vegetable soups and fruit cocktail. These items should be blended into one consistency.
8. Thin liquids may be difficult to swallow because they move faster through the mouth and throat, or because there is a slight delay in the onset of the swallow and closure of the airway. Thicken liquids with a commercial thickener (such as Thick-It, Thicken-Up, etc.), potato or banana flakes, or fruit purees.
9. It may be easier to take medications with a spoon of puree consistency such as pudding or applesauce instead of liquids. Do not crush medications unless approved by a physician.

*General Suggestions:*

1. It is important to maintain good oral hygiene.
2. Dairy products often have a tendency to make secretions thicker, so minimize these products.
3. A portable suction machine may be of value to assist with clearance of secretion, particularly at meal times. Drinking more water, or sometimes use of carbonated beverages may help reduce or thin secretions. Your physician may have suggestions for medications to thin or reduce secretions. Avoid medications that dry up secretions, making them thick and ropey and more difficult to manage.
4. It is important that the caregiver be educated in the use of the Heimlich maneuver. Ask your physician, nurse, or therapist for instructions.
5. Monitor for weight loss.
6. Monitor the medications being prescribed because some of them may cause the swallowing problem or make it worse.
7. It is important to be alert to the signs of pneumonia, including increased chest congestion, chronic low grade fevers, increased cough, and change in sputum.
8. The use of nutritional supplements such as Ensure, Carnation Instant Breakfast, Sustacal, etc may be of value to increase caloric intake quickly and easily.
9. Supervision during all meals is always a good idea.

These are cookbooks available for those who have difficulty swallowing:

Non-Chew Cookbook by J. Randy Wilson  
Wilson Publishing, Inc. P.O. Box 2190  
Glenwood Spring, CO 81602-2190

MeALS The Muscular Dystrophy Association  
810 Seventh Avenue New York, NY 10019

Pureed Food with Substance and Style  
Imaginart Communication Products  
307 Arizona Street Bisbee, AZ 85603  
800-828-1376

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