

Falls and Dysphagia in PSP

Progressive supranuclear palsy (PSP) is a rare brain disorder that causes problems with control of gait and balance, and problems with swallowing known as dysphagia. Whereas medications do not currently address symptoms of balance, swallowing, or cognition in PSP, non-pharmacological interventions can impact them most effectively.

Falls

- Consult with a physical therapist (PT) experienced with PSP or Parkinson's disease for falls prevention strategies, including strategies for transferring in and out of vehicles.
- Exercise! Work with a PT or personal trainer with experience in PSP or Parkinson's to develop a modified exercise program.
- If the person walks on a treadmill, use one with an "emergency off" cord to automatically stop it in case of falls. A body-weight support treadmill can also be considered. Later, move to a recumbent bike, seated pedal exerciser and other seated exercises.
- If free weights are used - even lightweight ones such as two-pound weights - they should never be lifted above the shoulders.
- Consider the [LSVT-BIG program](#) for Parkinson's disease, adjusted to the person with PSP.
- In consultation with a physical therapist, select a walker designed for people with Parkinson's disease for larger, more durable wheels, a braking system and a seat for the person to rest.
- Use a chair/bed alarm to alert the caregiver when the person stands and may need monitoring. Many people living with PSP are impulsive and may rise from a chair to walk without regard for safety.
- Consult with a mobility equipment specialist or PT about an appropriate wheelchair, giving consideration to preventing the wheelchair from tipping over backwards, and to special seat cushions for preventing pressure sores.
- Assist the person to stand every 1-2 hours, which makes blood flow upward to the heart to be circulated throughout the body.
- Consult with an occupational therapist for a safety evaluation of the environment and for recommendations for appropriate assistive devices. Consider adding bars, poles, or railings to make transfers easier.
- Pay particular attention to the risk of falls in the bathroom; install grab bars, a toilet seat riser and a shower bench.
- Learn how to closely escort someone when walking. Eliminate unnecessary talking when walking. If someone "freezes" when walking, learn techniques to help the person get moving again, such as: counting; clapping your hands to establish a beat; or tapping the back of the frozen leg.
- Use a gait belt secured around the person's waist or chest to steady the person through: transfers, sitting and standing; and walking.
- Recognize that the risk of falls can increase in the afternoon or evening, when persons living with PSP become more fatigued.
- After a fall, individuals should be made comfortable and allowed to rest as long as needed. Then help them to a sofa or sturdy chair, instruct them to get up on one knee, then with assistance help them to the chair to rest.

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Falls and Dysphagia in PSP (continued...)

Falls, *continued*

- Consult a neuro-ophthalmologist for evaluation of downgaze palsy or double vision, and for a possible prescription for prism glasses.
- Work with a physician to assess all medications for the likelihood that they may contribute to falls (usually due to sedation).
- If bladder incontinence is a problem, work with a neurologist to address this issue, especially for nighttime urination. It is dangerous for someone with PSP to get out of bed in the middle of the night to go to the bathroom. Consider medication, incontinence briefs, a catheter (including a condom catheter for men), a plastic urinal, a bedside commode, bladder training and lifestyle changes (no liquids after 6pm, no caffeine or alcohol in the evening).

Dysphagia

- Early in the disease's progression, help the person living with PSP to consider and make known their preferences about having a feeding tube.
- Reduce distraction (e.g. turn off the TV, create a quiet atmosphere for meals) to facilitate concentration needed for swallowing.
- Consult a speech-language pathologist for evaluation of swallowing difficulties, recommendation of exercises to maintain strength in swallowing muscles and other strategies to reduce choking.
- Use strategies to facilitate swallowing, such as determining the optimal thicknesses of liquids, keeping the chin tucked down when swallowing, and using a double-swallow after each bite or drink.
- Work with an occupational therapist or speech therapist to evaluate mealtime equipment, such as: thick-handled, weighted eating utensils; special cups; scoop plates; non-skid bowls; or plate elevators.
- Ensure that family and professional caregivers know how to use the Heimlich maneuver in case of choking.
- Present only a limited amount of food at any given time to limit the shoveling of food due to cognitive impairment.
- Use pre-thickened liquids or thicken with an agent such as [Thick-It®](#), which is cornstarch-based, or [SimplyThick®](#), a gum-based thickener, so that liquids can be consumed more safely. Some may prefer the taste of such liquids when chilled.
- Eliminate dry meats or cereal and things with mixed consistency (such as soup) from meals. Choose moist and tender foods, such as dark meat chicken, fish, casseroles or pastas.
- Use a blender to puree food, which may be necessary for severe dysphagia. Thicken pureed food with commercial thickeners or other products, such as oatmeal, bananas or potato flakes.
- During mealtimes, give verbal cues (such as *go ahead and swallow, eat slow, one bite at a time, small sips*).
- Learn warning signs of swallowing problems and possible aspiration, such as: coughing during meals; drooling; dysarthria (difficulty articulating sounds); mouth stuffing; holding food in one's mouth for 20 seconds before swallowing; choking (perhaps on saliva) not during meals; or pneumonia.
- Continue good oral hygiene as this can reduce the chances of aspiration pneumonia.
- Consider smaller, more frequent meals in an effort to keep meal times less than 60 minutes. Otherwise, it may be extremely fatiguing for the person with PSP to eat.