



# Brain Support Network

**AFTD 2016 Annual Education Conference**  
FTD Movement Disorders (PSP, CBD, FTD/ALS) Breakout  
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## Tips, Resources, & Gadgets

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### FALL PREVENTION

- 1- Not all falls can be prevented. We do the best we can.
- 2- As soon as falls start happening or balance problems begin, learn new ways of walking (including turning), transferring, exercising, being safe in the bathroom, etc. Ask for an occupational therapy (OT) assessment. Acceptance and adaptation are important.
- 3- “The rule” – If you find yourself reaching out to touch walls, furniture, friends or caregivers (or they are reaching to you) while walking, you are in need of an assistive device. Devices – canes, walkers, wheelchairs. Ask for a physical therapy (PT) assessment. Our family liked the UStep walker (ustep.com).
- 4- Safe walking: slow down; concentrate (one thing at a time); don't carry anything; avoid shuffling. Families and aides can learn how to use a gait belt to assist with walking and transferring.
- 5- Making the environment (bedroom, bathroom, living room) as safe as possible. Remove rugs. Add grab bars where needed. Use sturdy seating. Place light switches, phones, toilets, heat sources, etc. in easily reachable spots. Consider footwear.
- 6- Gadgets for getting in and out of bed – bed rail; SuperPole; trapeze; satin sheets.



- 7- Gadgets for getting in and out of vehicle: plastic garbage bag on seat, Handy Bar allows a safe place to hold.
- 8- Exercise is important, regardless of the stage of disease. Consider seated exercise or exercises while lying down. Caution with treadmills.
- 9- Safety gear such as: helmets, “HipSaver” (shorts with hip and tailbone pads), bed alarms, chair alarm (Posey is a good brand), and geriatric recliner chairs.

## **SWALLOWING**

- 1- Coughing during meals is a sign that the timing and coordination of the swallow mechanism may be changing. Two concerns – choking and aspiration pneumonia. Know the Heimlich Maneuver. Good oral hygiene is important to reduce chances of aspiration pneumonia. Consider Biotene mouthwash, Toothette swabs, suction toothbrush.
- 2- Beware of “silent aspiration,” where there is no coughing or choking during meals.
- 3- Consider a modified barium swallow study (aka, VFSS – videofluoroscopic swallow study).
- 4- Thickening liquids and pureed food. Thickening options – commercial (gum-based or cornstarch-based) and non-commercial. Gum-based is ideal if diabetes is a concern. Our family liked SimplyThick-brand gum-based thickener. Non-commercial thickeners include oatmeal, gelatin, bananas, banana flakes, potato flakes, tofu, etc. There are pre-thickened, pre-packaged liquids available – water, milk, fruit juices.
- 5- Cookbook suggestions: “The Dysphagia Cookbook,” “Meals for Easy Swallowing,” “Soft Foods for Easier Eating Cookbook”
- 6- Products that might help: plate elevator, flexi-cut cup, spillproof flo tumbler, Oxo-grip spoon, scooper plate, non-skid bowl. Bruce Medical, [brucemedical.com](http://brucemedical.com), is a good online medical supply store for these items.



- 7- Consider the environment – quiet and focused on chewing and swallowing.
- 8- Have feeding tube discussion early, when there's no crisis.

## **OTHER TIPS**

- 1- Exercise, exercise, exercise
- 2- Therapies: Physical Therapy (PT), Occupational Therapy (OT), and Speech Therapy (ST)
- 3- Importance of a care team
- 4- Support Group Options: in-person support groups (those with diagnosis; for caregivers only), online support groups and telephone-based support groups, counseling, friends, environments “away” from neurological decline
- 5- Social interaction
- 6- Be open to change
- 7- Please consider brain donation! 50% of diagnoses by neurologists are wrong. Brain donation is the only way to confirm a diagnosis. Donation enables medical research into the causes, treatments, and cures for FTD. See [www.brainsupportnetwork.org](http://www.brainsupportnetwork.org) for more info.

## **RESOURCE SHEETS**

- 1- Top Resources on PSP:  
<http://www.brainsupportnetwork.org/BSN-PSP-resources-2016-02.pdf>
- 2- Top Resources on CBD:  
<http://www.brainsupportnetwork.org/BSN-CBD-resources-2016-02.pdf>
- 3- “Falls and Dysphagia in PSP,” Summer 2015 issue of “Partners in FTD Care” newsletter, published by The AFTD:  
[http://theaftd.org/wp-content/uploads/2015/07/PinFTDcare\\_Newsletter\\_summer\\_2015.pdf](http://theaftd.org/wp-content/uploads/2015/07/PinFTDcare_Newsletter_summer_2015.pdf)