

### Activities for Individuals with Frontotemporal Degeneration (FTD)

People with FTD disorders have impairments that affect their participation in activities differently than people with Alzheimer's. While the loss of executive functions (planning, organizing and initiating) and awareness of social behavior challenge traditional activity planning, trying individualized strategies will prove rewarding.

#### Who is Hope Ann Lynn?

Hope moved into a memory care assisted living facility four months ago. She just turned 50, and her primary diagnosis is behavioral variant FTD (bvFTD). She has been married to Rick for 25 years. Hope enjoyed a solid career as a reading specialist and was a devoted mother and grandmother. She had many friends, loved music, was an avid reader and baker, attended Mass every Sunday and was an accomplished equestrian.

Hope retired early due to increasing symptoms of her illness. She did not report to work as scheduled, assigned repetitive reading assignments and inappropriately laughed at or ignored her students. Her behaviors escalated after retirement. She read the same book continuously, had her driving license revoked due to several accidents, walked in circles in the horse corral and was verbally belligerent to her family and friends. When she began grabbing food from her granddaughter, her family sought assisted living placement.

Prior to moving into the facility, Hope's family completed the "Daily Care Snapshot" tool from AFTD to describe her background, current challenges and the interventions they learned to help her function best. This facilitated conversation and team planning.

#### Challenges Become Apparent

Fairly soon after admission, the staff, residents and visitors began voicing concerns about Hope's behaviors. The facility offers dementia-specific programs that provide structure and socialization. Hope enjoys group activities sometimes; at other times, she shouts and sings. She has begun resisting invitations to join these groups or leaves quickly after making disruptive comments. Because Hope is 20 or more years younger than most residents, she does not relate to the music, TV programs and movies that form the core of the group activities. The apathy and decreased empathy that are characteristic of FTD mean she has little motivation to be with others. A lively group can be too much stimulation.

Because it is so difficult to engage her in structured activities, Hope often stays in her room, watches TV, sleeps and ignores staff. At other times, she paces, sings, and looks for food throughout the facility. Both staff and residents have started to become frustrated with Hope because her needs and way of interacting are different from the older residents. She is not easily redirected, refuses personal care and does not positively respond to pharmaceutical interventions.

Yesterday, Hope tried to take another resident's snack. Staff intervened to avoid having the resident potentially push Hope. Staff needs assistance with understanding and intervening

*Partners in FTD Care is an education initiative of the Association for Frontotemporal Degeneration that brings together health professionals, experts and families to promote understanding of FTD and to develop best practices in community care.*

### TELL US HOW WE CAN HELP

A brief (five-question) survey is available to tell AFTD what information and resources you need most. Take just 2-3 minutes to complete the online survey today and help expand the Partners in FTD Care education initiative for community healthcare providers.

<https://theaftd.wufoo.com/entries/partners-in-ftd-care-survey/>

### HAVE A QUESTION ABOUT CARE?

The Partner's in FTD Care Forum is open to help. Join over 60 colleagues and AFTD's experts to share questions, interventions and successes about serving people with FTD and their families in home health, day, assisted living and other community care settings. This members-only bulletin board allows professionals to exchange questions and ideas to help develop best practices in the field. Register today at <http://www.theaftd.org/support-resources/forum-registration>

with Hope's behaviors, addressing the other residents' concerns and engaging her successfully in activities. The director arranged a follow-up meeting with the family and caregiver to discuss these challenges and to develop an Activity Care Plan.

### Follow-Up Family and Team Meeting

Hope's family and caregivers met to share observations and discuss the following questions to develop an individualized Activity Care Plan:

#### *What are Hope's behaviors?*

Hope talks and claps hands while others are talking; takes food and drink from other residents; ignores/walks away from others. She often sings, shouts, or isolates herself at the back of the room during activities and yells when someone is too close to her. Noise and larger group activities overwhelm her; she's slow to respond and has difficulty processing information.

#### *What behavioral interventions have been successful?*

Staff escort Hope from the activity when she displays initial signs of being overwhelmed, i.e., becomes rigid or hums. They avoid therapeutic manipulation/fibbing techniques that frustrate her.

Provide a quieter environment, i.e., soft music, serve her snack first or serve her individually. Provide ample personal space; she does not respond well to touch; provide one direction and explanation at a time; initiate an activity; sit with her to help her to start; schedule consistent caregivers; if feasible, schedule private duty caregiver during her most active time; monitor exit doors (due to her younger age, visitors may not recognize her as a resident and open the door.)

#### *Which activities are less successful with Hope?*

Large group food activities; she takes other residents' food, and grabs baking ingredients; discussion group: too much information and not relevant to her age; loud music or entertainment overwhelms her; bingo or other card games-- family shared that she never enjoyed these.

#### *Which group activities are successful most of the time for Hope?*

Music programs/entertainers (not too loud); responds to music from the 60s and 70s, as well as hymns; book club; Catholic devotions; small baking groups; in-room pet therapy, as she loves animals. *(cont. on pg. 3)*

## TROUBLES & TIPS

**Q: People with FTD don't respond to planned activities the way our older Alzheimer's residents do and it's frustrating. What can we do to engage them?**

A: The effect of disease in the frontal and temporal lobes is seen in social behavior, information processing and self-regulation of behavior. This is very different from someone with primarily memory difficulties. A resident in his 50s or 60s is likely to have robust health and appear more capable than they are.

The following is a sample of Activity Tips for individuals with FTD. For a complete list, join the **AFTD online forum for health providers**. This private forum is a great way to post questions, share effective interventions and join professionals from various disciplines to develop best practices in serving people with FTD.

- With the loss of executive function and planning, the person with FTD cannot always initiate an activity. They may need someone to sit with them for a few minutes to get them started. Try. It may keep them busy for much longer than the time you spend getting them started.
- Early on, people may need to feel useful or helpful. Finding "a job" such as dusting, sweeping or folding papers may work. Repetitive "work" may be easiest.



- There may be loss of social rules – taking turns in games is lost, and following rules isn't important. No one else will get a turn unless you encourage it, and "cheating" is the way you play the game. They really do not see that it is "wrong." Staff can facilitate a small game with others or adapt rules for flexible play.

- They may do better with activities that are individual. Even Bingo may be hard to figure out. They may just cover all the spaces even if they have not been called. (This does not go

over well with the serious Bingo players at the table!)

- Symptoms and abilities change regularly. Look creatively at how to adapt and build on what works. If music is a favorite but the MP3 player gets lost, attach it to a firm headset that is easier to keep track of. Adjust expectations for word searches that were a breeze before. Remember, the rules don't matter, they may find the word *plane* with the "pl" on

one line and "ane" on another. It is not cheating; it is a creative way to find the answers. In later stages he may not be able to find the word, but could go on a "letter" search – find all the b's.

- Some compulsive behaviors can be channeled into activities. Sorting like things – a deck of cards can be sorted into suit; colored objects or pegs by color or shape. Matching dominoes is another sorting option. Repetitive activities may hold a person's attention.



### ***Which individual activities are successful for Hope to enjoy with her family, private duty caregiver and staff?***

Music--her husband purchased an MP-3 player with her favorite music; walks in the courtyard; photo and scrap books; family pictures and horses; in-room computer programs; TV/DVD--favorite movies, TV shows, and cooking shows; family and staff provide individual snacks.

### ***Hope's Activity Care Plan***

- Post a daily, individualized schedule, including appropriate individual and selected group activities, personal care, snacks, etc., in Hope's room.
- Staff will encourage Hope to attend posted activities, including spiritual music, Mass, book club, small baking group, pet therapy and acoustical entertainment.
- Staff and family will join Hope 1:1 to help her engage in individual activities, including age-appropriate music, movies, and TV shows, walks, photo and scrapbooks, computer programs and snacks.
- Staff will not expect Hope to attend activities that she dislikes or overwhelm her, including bingo, card games, loud music, discussion groups and large food groups.

- During group activities, Hope will be provided a chair next to the exit so that she can leave easily.
- All caregiving staff and private duty caregiver will use successful behavioral interventions, including quieter environment, serving snacks first or individually, not hovering, explaining and providing one direction at a time and initiating an activity.
- The plan will be revised regularly based on Hope's changing abilities and needs.

### ***Activities as Crucial Intervention***

An effective activity care plan is an important aspect of care for someone with FTD. Understanding how impairment in the frontal and temporal lobes affects social interaction, communication and behavior encourages staff to reach beyond traditional approaches to dementia care and develop new skills. An individually tailored plan for someone with FTD promotes consistent, yet flexible daily structure and positive interaction between staff and the resident. These are especially important when serving people who are younger and have symptoms and needs that differ from more common types of dementia.

## **RESOURCES TO CHECK OUT**

### **Partnering with Family**

Because it is most often a young onset disorder, families affected by FTD face different stresses and needs than those of older dementia residents. A positive relationship with Hope's family began before move-in. The "Daily Care Snapshot" was completed by the family to introduce Hope and her life accomplishments, current abilities, activities and hobbies to the staff. Download the Snapshot from AFTD and share with prospective residents:

<http://www.theaftd.org/healthcare-professionals/partners-in-ftd-care-2>

### **Education about frontotemporal degeneration**

Information specific to Hope's diagnosis, bvFTD, and other FTD subtypes is available on the AFTD website, ([www.theaftd.org](http://www.theaftd.org)) under "What is FTD." Learning more about key clinical features including behavioral, emotional and neurological symptoms, is helpful for understanding unusual behaviors or reactions of someone with FTD.

Additionally, caregiving staff can be trained via an in-service utilizing the Partners in FTD Care Training Materials. Order it online through the website **Partners in FTD Care** page.

<http://www.theaftd.org/healthcare-professionals/partners-in-ftd-care-2>

## **SAVE THE DATE!**

### **Conquering Mountains**



**AFTD Conference 2013**

AFTD will host its education conference and annual meeting for 2013 in Salt Lake City on April 12th.

**What:** AFTD's Education Conference and Annual Meeting

**When:** April 12, 2013  
10 a.m. – 6 p.m.  
(social reception to follow)

**Where:** Salt Lake Marriott Downtown  
at City Creek  
75 South West Temple  
Salt Lake City, UT 84101

**CEU credits will be available. Registration opens January 18 on AFTD's website.**



The Association for  
Frontotemporal Degeneration  
Opening the gateway to help and a cure

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