DEVELOPING ENVIRONMENTAL AND BEHAVIORAL STRATEGIES IN FTD: PROBLEM SOLVING APPROACH

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- **Audience Participants**

OVERVIEW OF PROBLEM SOLVING APPROACH

- FTD is a neurological disease of the frontal lobes
- Results in profound changes in personality and behavior
- Impacts family and care partners
- Problem solving approach addresses the “big picture” of challenging and changing behaviors

AIMS

- Identify problematic behaviors in behavioral variant FTD (bvFTD)
- Understand importance of non-pharmacological interventions
- Learn principles of problem-solving approach in home and residential care settings
- Become familiar with resources

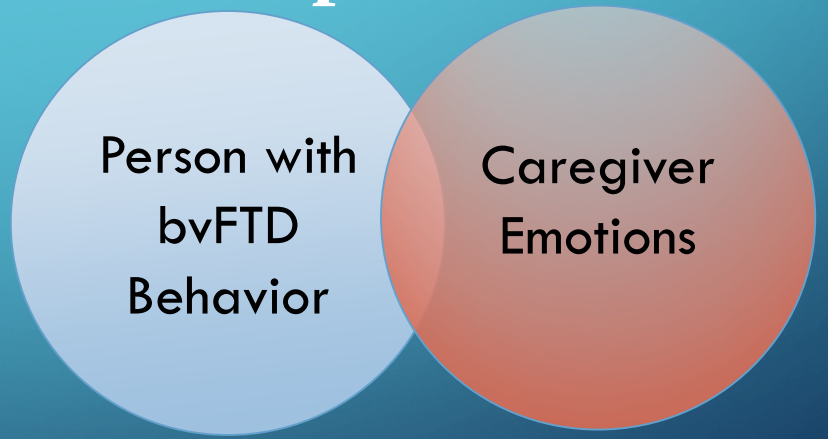
PROBLEMATIC BEHAVIORS IN (BV) FTD

- Diagnostic categories of symptoms include
  - ✓ *Disinhibition, apathy, compulsive/ritualistic, dietary changes*
  - ✓ *Decreased insight and/or empathy*
- Individuals express behaviors in unique ways
- Overlap and changing of symptoms is common
- Impact on caregiver anger, frustration, sadness

IMPACT ON CAREGIVERS: LOSS OF INSIGHT AND EMPATHY

Normal Empathy

Caregiver Response



PROBLEM-SOLVING IN FTD: *ROLE OF MEDICATIONS*

- Behavioral interventions and environmental modifications are often *more* effective at managing behaviors than drugs
- No current medication stops or slows *disease* progression
- Medications can be used *in addition* to non-pharmacological strategies

PROBLEM-SOLVING APPROACH IN FTD: *GENERAL CONSIDERATIONS*

- Challenging symptoms commonly occur together; focus on specific behaviors, one at a time
- Consider impact of brain impairment on behaviors/solutions
- Contact medical team if behavior is unsafe or related to medical illness, pain, or changes in medication
- Acknowledge emotional approach of caregiver/staff as key. Get support and help!

PROBLEM-SOLVING IN FTD: *SPECIFIC METHODS*

01 Define the behavior

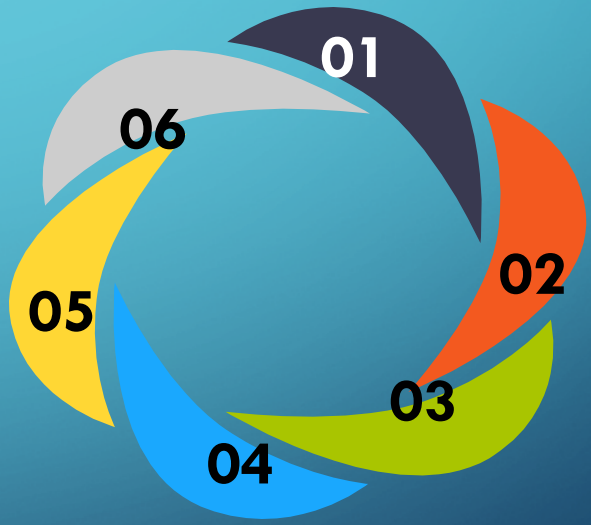
02 Assess risk

03 Brainstorm

04 Evaluate options

05 Create a plan

06 Evaluate, review, try again



EXAMPLE
JIM AND SUSAN

- Jim (age 52) was diagnosed with bvFTD two years ago; lives with wife, Susan
- No longer interested in physical activities, healthy diet
- Recently diagnosed with pre-diabetes (increased weight and glucose level)
- Became angry when denied cookies
- Unable to understand Susan’s explanations, concerns, feelings

#1 IDENTIFY THE PROBLEM

- ✓ Define one specific behavior from overlapping symptoms
- ✓ Frequency of behavior (several times/day, weekly, less than once/week)
- ✓ Possible triggers
  - *Environmental*
  - *Time of day*
  - *Other individuals*

- ✓ Previous strategies to manage behavior
- ✓ Degree of concern for affected person
  - ✧ *Weight gain – may affect care as disease progresses*
  - ✧ *Medical concerns - "feel better" behaviors may be better*
- ✓ Emotional impact on caregiver/staff/others

#2 ASSESS RISK
PRIORITIZE SAFETY AND SECURITY

- Physical safety of individual
- Physical safety of others
- Concern about medical illness, medications, pain
  - *Sudden change may signal an illness*
  - *Medication interactions*
- Contact medical team as necessary

#3 BRAINSTORM POSSIBLE SOLUTIONS

- ✓ List all ideas, regardless of whether feasible or not
- ✓ Be creative
- ✓ **Evaluate your approach**
- ✓ Ask family, friends, support group, AFTD helpline for suggestions
- ✓ Schedule meeting to involve residential staff members
- ✓ Refer to AFTD resources

#4 EVALUATE OPTIONS

- Weigh the pros and cons of each possible solution by asking what is best for the person with FTD and the best for family caregivers and/or the residential community
- Eliminate alternatives that are not manageable or realistic
  - ***Keep in mind, unless there is a true safety concern, taking something away completely without a substitute may cause other behaviors – anger and outbursts***

#5 MAKE A PLAN

- Create a written plan from the selected option
  - *Creates a communication tool between caregivers – consistency*
  - *Allows you to look back - what worked and what did not*
- Be as detailed as possible
  - *Person with FTD often responds best to a consistent routine*
  - *Helps you communicate concerns to your physician/care team*

#6 EVALUATE, REVIEW, TRY AGAIN

- Was the solution effective?
  - *Did the behavior stay the same, get somewhat better, improve?*
  - *Did the frequency change?*
- Did the caregiver/staff's thinking or feeling change about the behavior or willingness to accept the behavior?
- Does the existing plan need to be revised?
- Is a new plan needed?

JIM AND SUSAN CONTINUED

- Unfortunately, Susan developed bone cancer and needed urgent surgery and hospitalization
- Jim was admitted to a residential care facility with experience in FTD
- The administrator visited Susan before her surgery to better understand Jim’s specific issues

JIM IN RESIDENTIAL CARE

- The Administrator shared the “Daily Care Snapshot Tool” (completed with Susan) with all staff.
- Jim has been wandering constantly in the community. He is not interested in group programs.
- He tries to eat other resident’s food at meal time and communal snacks.
- Staff is not always successful in re-directing Jim.

Partners in FTD Care

DAILY CARE SNAPSHOT FOR

_____

(Your loved one's name)

(Attach a favorite photo here)

Your input to transitioning your loved one into a health care community is very valuable. The Daily Care Snapshot will assist staff by building on your knowledge and experience. The more information you provide, the better others can get to know your loved one's needs and preferences. - Thank you.

I. ***Give a brief introduction of the person you have cared for*** - life accomplishments, key relationships with family/friends, and what your role as a caregiver has been and will be.

_____

_____

_____

_____

_____

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_____

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

www.theaftd.org
267.514.7221 / 866.507.7222

#1 IDENTIFY THE PROBLEM

- ✓ Define one specific behavior from overlapping symptoms
  - *Review "Daily Care Snapshot Tool" – Prior to Move-In*
  - *Compulsive Eating – taking other resident's food/snacks*
- ✓ Frequency of behavior (several times/day, weekly, less than once/week)
  - *Team Meeting (seven days post move-in)*
  - *Searching for food, particularly cookies, frequency - daily*
- ✓ Possible triggers (environmental, time of day, other individuals)
  - *New environment, group dining, "communal" snacks, other residents, more frequent in evening*

#1 IDENTIFY THE PROBLEM

- ✓ Previous strategies to manage behavior

  - *Explain to Jim why he should not eat cookies; Limit watching TV, "Jeopardy"; Consult physician*

- ✓ Degree of concern for affected person

  - *Moderate – Jim's health and safety*

- ✓ Emotional impact on caregiver/staff/others

  - *Other residents/families upset about Jim's behaviors*

  - *Staff frustrated (re-direction and supervision)*

#2 ASSESS RISK
PRIORITIZE SAFETY AND SECURITY

- Physical safety of individual – *Several verbal altercations with other residents*
- Physical safety of others – *Same*
- Concern about medical illness, medications, pain – *Gain of five pounds and increase in blood glucose level*
- Contact medical team as necessary – *Weight, labs, and behaviors*

#3 BRAINSTORM POSSIBLE SOLUTIONS

List all ideas, regardless of whether feasible or not

- Staff met to discuss Jim's past history, behaviors and possible interventions (including AFTD resources):
- Post daily schedule (group exercise, golfing, meal times, and one PM snack – 4 cookies)
- Escort Jim to dining area when others are finished eating
- Provide Jim with a specific seat (near exit)
- Educate staff re: bvFTD

#3 BRAINSTORM POSSIBLE SOLUTIONS

- Meet individually with other families/residents
- Discourage watching TV in the evening
- Encourage Jim to attend exercise and trivia programs
- “Disguise” community snacks
- Private-duty companion (3:00 – 8:00 daily)
- Explain to Jim that we ran out of cookies but have jello, etc. for dessert
- Limit magazines/pictures of food
- Consult physician re: medication, weight, behaviors

#4 EVALUATE OPTIONS

- Weigh the pros and cons of each possible solution by asking what is best for the person with FTD and the best for family caregivers and/or the residential community
- Eliminate alternatives that are not manageable or realistic

#5 MAKE A PLAN

- Create a written plan from the selected options:

Post daily schedule (include meal times and PM snack

- 4 cookies in sealed container)

Escort Jim to the dining room after other residents eat (near exit)

Provide video, trivia game while others are eating (breakfast and lunch)

Private duty companion (4:30 – 7:30 daily)

Store communal snacks in non-visible containers

#5 MAKE A PLAN

Do not reason or argue with Jim

Re-direct Jim to video golf or scrap book of family pictures if he becomes upset

Report any negative behaviors/resident and family concerns to administrator immediately

Encourage Jim’s family/friends to visit before/after meal times

Report weekly weights and blood glucose levels to physician

#6 EVALUATE, REVIEW, TRY AGAIN

- Was the solution effective?
  - *Did the behavior stay the same, get somewhat better, improve? Improved but PM still most active time; continue to observe*
  - *Did the frequency change? Four pound weight loss; BS (monitor 30 more days – possible diabetic medication)*
- Did the caregiver/staff's thinking or feeling change about the behavior or willingness to accept the behavior? *Still periods of frustration, continue to educate and support*
- Does the existing plan need to be revised? *On-going; continue private duty companion at night*
- Is a new plan needed? *Meet weekly to revise; Susan in rehab. setting*

RESOURCES

Specialized information and support from AFTD

Website: www.theaftd.org

Helpline: 866-507-7222

Partners in FTD Care Newsletters:

- Issue #1: Fall 2011: Behavioral Variant FTD
- Issue #2: Winter 2012: Communication Strategies in FTD
- Issue #11: Spring 2014: Communication Se Act Like That? Aggressive Behaviors in FTD
- Issue #13: Fall 2014: The Loss of Empathy and Connection in FTD
- Issue #14: Winter 2015: Changes in Eating and Managing Related Compulsive Behaviors
- Issue #23: Winter 2018: Understanding and Managing Apathy to Improve Care in FTD
- Issue #25: Winter 2019: Everything is Just Fine: Anosognosia in Frontotemporal Degeneration

RESOURCES

AFTD Educational Webinars:

- **August 27, 2018**: What You Should Know about Behavioral Variant FTD (bvFTD)
- May 25, 2017: bvFTD Subtypes: Divergent Anatomy: Divergent Behavior
- January 12, 2017: A Care Paradigm for Persons with Frontotemporal Degeneration

Additional Resources:

- National Institutes of Aging: http://www.nia.nih.gov/health/what-are-frontotemporal-disorders
- Savvy Caregiver Program: The Savvy Caregiver program is a 6 week training program for caregivers of someone with Alzheimer's disease or related dementias. Caregivers learn to develop and adjust strategies and approaches for effective care giving. Provided locally by various dementia care organizations.