When You Forget That You Forgot: Recognizing and Managing Alzheimer’s Type Dementia, Part II

Goals for Today

- Review common sources of stress for people with dementia
- Review care principles based on the Progressively Lowered Stress Threshold (PLST) model
- Apply basic principles to care routines and approaches
Behaviors in Dementia

- New “language” of dementia care
  - Behavioral and Psychological Symptoms in Dementia (BPSD)
  - Need-Driven Dementia-Compromised Behaviors (NDB)
  - PLST Behaviors
- Avoid negative labeling; focus on unmet needs
PLST Behaviors

- Increased anxiety
- Night awakening
- Catastrophic behaviors
- Sundowning syndrome

More likely to occur as stress increases

- Purposeful wandering
- Confusion, agitation
- Combative behavior
- Diminished reserve
- Resistance
PLST: Sources of Stress

- Fatigue

- Multiple competing stimuli
  - Noise, confusion
  - Television, radio, public address
  - Too many people
  - Too many things going on at once
    - Eating dinner
    - Taking medications
    - Meal-time entertainment
PLST: Sources of Stress

- Physical Stress
  - Illness, medication side-effects
  - Hunger, thirst, discomfort

- Changes
  - Caregiver
  - Routine
  - Environment: Internal (hunger, pain) and external (noise, confusion, stimulation)
PLST: Sources of Stress

- Demands that exceed abilities
  - Decisions that are too complex
  - Tasks that are outside abilities

- Negative and restrictive feedback
  - “Don’t do that!”
  - “Your parents are dead”
  - “But this IS your house”
  - “No, you’re not going to work”
GOAL - To act like a “prosthetic device” that supports the person do what he/she is able to do

- Interventions serve like memory “crutch” that fills in for lost abilities
- Supports person to be autonomous in spite of lost abilities
- Keeps stress at manageable level throughout the day
PLST: Care Planning Goal

- Normal Stress Threshold
- Lowered Stress Threshold

A.M.

Dysfunctional Behavior

Anxious Behavior

P.M.
Prevention is truly “the best medicine” in dementia care!!
- Keep stress at a manageable level
- Use person-centered approaches
Interventions

- Person-Centered care: Think about the person “behind the disease”
  - Lifelong habits, preferences, coping methods
  - Long-standing personality
  - Personal history
  - Life experiences
  - Personal strengths, abilities, resources
Interventions

- Multiple factors influence quality of care and life!

  - Environmental influences
    - Personal: internal feelings; unmet needs
    - Physical: objects, activities, sensory input
    - Social: people, interactions
  - Facility and care routines
  - Disease-related disability
  - Person’s strengths/limitations
Interventions: PLST Principles

Underlying Assumptions:
- All people need some control over themselves and their environment
- All behavior has meaning
- Behavioral symptoms are a sign of discomfort
- Persons with dementia live in a 24-hour continuum
Interventions: PLST Principles

Six basic ways to improve care:

1. Maximize safe function by supporting losses in a prosthetic manner
2. Provide unconditional positive regard
3. Use anxiety and avoidance to gauge activity
4. “Listen” to the person with dementia (what does the behavior “tell you”?)
5. Modify the environment to support losses and enhance safety
6. Encourage caregivers to participate in ongoing education, support, self-care, and problem-solving
Interventions: PLST Principles

- Many ways principles are applied in practice
- Highly individualized
- Basic strategies reviewed here
PLST: Care Planning

- Reduce **ENVIRONMENTAL STRESS**
  - ✔ Caffeine
  - ✔ Misleading stimuli
  - ✔ Unending spaces
  - ✔ Unneeded noise
  - ✔ Extra people
  - ✔ Large rooms, unending spaces
Compensate for lost abilities by adjusting APPROACHES
- Use calm consistent approach & routine
- Do not try to reason
- Do not ask to “try harder”
- Do not try to teach new routines
- Do not encourage to recover lost skills
Compensate for lost abilities by adjusting routines:

- Limit choices to ones person can make
- Monitor changes in environment
- Reduce, eliminate changes in pace

» Routine = Familiarity and comfort
  » Repetition does not become “boring” to person with dementia
PLST: Care Planning

- Allow for **LOWERCED STRESS** threshold
  - Plan rest periods in morning and afternoon
  - Maximize routines
  - Alternate low and high stimulus activities
  - Reduce stimuli when reactions occur
  - Look for triggers
  - Document incidents in specific terms: *Be descriptive!!*
PLST: Care Planning

- Provide unconditional POSITIVE REGARD
  - Use 1:1 communication, gentle touch
  - Eliminate “you are wrong” messages
  - Distract vs. confront
  - Simplify communication
  - Use Validation vs. Reality orientation
  - Don’t confront hallucinations or delusions
Positive Regard: Communication

- Adjusting communication strategies shows respect and helps increase
  - Cooperation
  - Comfort
  - Dignity
First, simplify the MESSAGE!

✓ Short, understandable words
✓ Simple sentences
  » One noun + one verb = ENOUGH
  » No lengthy or complex messages
✓ Take pronouns out
  » Avoid “there, that, those, they, him, her, it”
  » Use nouns instead
  » “Sit in the Chair” vs. “Sit here”
Communication Strategies

Simplify the message, continued…

- Tell the person who you are
- Call the person by name
- Cue the person by providing information

Next, simplify your STYLE!

- Slow down
- Say words clearly
- Avoid slang or other unfamiliar words
Simplify your style, continued…

- If you increase volume, lower tone
  - Increase volume ONLY if hard of hearing
  - Speak directly to person: Allow lip reading

- Ask a question? WAIT for a response
  - Give time to think
  - Be patient

- Ask ONLY ONE question at a time
Communication Strategies

*Simplify your style, continued…*

- If you repeat a question, repeat it EXACTLY
  - Do not “re-phrase” to clarify
  - Ask same simple question again
  - Wait for an answer

- Go ahead - Laugh
  - Self-included humor is okay
  - Don’t be afraid to laugh at yourself or the situation -- just don’t laugh at the person!
Third, pay attention to NONVERBAL messages

- Pretend a room of people are watching, listening to your nonverbal style
- Use gestures to help them understand
  - Point
  - Demonstrate
  - Use your hands, face, body to help them get the meaning
Communication Strategies

- Make sure you have and keep their attention
  - Stand in front of the person
  - Make eye contact; smile
  - Move slowly
    - Don’t threaten with sudden movements
    - Avoids catastrophic reactions
  - Walk with the person
  - Over emphasize & exaggerate expressions
Last, AVOID “You are wrong” messages

✓ No, you’re not going to work today.
✓ No, you can’t visit your father. He’s dead.
✓ No, this is your home now.
✓ No, that isn’t yours. Put it back.
✓ No, you can’t go now.
✓ No, we just talked about that!
Positive Regard: Validation

Show respect through use of “validation”

- Caregivers are often taught to use “reality orientation” (RO)
- In dementia, Validation Therapy principles are more valuable

So what is the difference?!
Reality Orientation

Basic Beliefs:

- Disoriented person needs to be in “here and now”
- Orient person to surroundings
  - Time, place, person, things
- Assumes disoriented person can return to present if given enough information
Advantages

✓ Works well with person who is “temporarily” confused
  » Delirium (acute confusion)
  » Disorientation due to relocation

✓ Gentle, “conversational” orientation useful with chronically confused
  » Tell person what is going on
  » Avoid “Do you know . . .?” questions (testing)
Reality Orientation

- Disadvantages
  - Person with progressive memory loss not able to retain information
  - Contradiction of their “reality” functions as negative and restrictive feedback
    - Increases frustration, anxiety, anger
    - Reduces self esteem
  - Can feel like “being tested”
Validation Therapy

- Stresses importance of “going with the person” to their reality
- Validates feelings in whatever “time” is real to them
- Views all behavior as purposeful
  - Listen carefully for meaning
  - Respond to “emotional” message
Advantages

- Reduces risk of sending “You are Wrong” messages
- Addresses person in more positive way
- Often leads to reminiscence, review of life events
- Promotes self worth
- Person-centered approach
Validation Therapy

- **Disadvantages**
  - Person may respond to approach “in the moment” but not retain information
    - Feels reassured briefly then forgets again
    - Repeats questions over and over
  - May not be successful in reassuring person
    - Irritability, anxiety may continue
Validation Therapy

1. Don’t confront the person’s mis-belief. Distract and redirect instead.

Person: “I’m going home!”
Don’t: “Your house has been sold. You live here now.”
Do: “It’s too late to go home now. Stay here with me. We’ll go tomorrow.”
2. Validate the person’s reality. Avoid “You Are Wrong” messages.

**Person:** “Papa’s coming to get me.”

**Don’t:** “Papa is dead. He’s been dead for years!”

**Do:** “Papa loves you. Papa’s a good man.”

“I forget. Tell where Papa lives.” “Papa called. He’ll come tomorrow, not today.”
3. Listen carefully to "nonsense." What might message mean in person’s reality?

**Person:** “Hurry up! Up, up, up, up there! Go! Go! Go! Up there! Up there! Whoaaaaa!”

**Don’t:** Assume message has no meaning

**Do:** Ask family, significant other “where” person might “be” in his/her reality. Do words make sense based on history?
Validation Approaches

Misbelief vs. delusion or hallucination?

- False beliefs may be “harmless” or quite distressing to the person. All are quite real to the individual, and may be
  ✓ Frightening or upsetting
  ✓ Helped by providing information
  ✓ Reduced by reassurances of safety
  ✓ Related to “real life” events (illusions)
Validation Approaches

- Don’t:
  - Reason
  - Argue
  - Confront
  - Remind them they forgot
  - Question recent memory
  - Take it personally!!!
Validation Approaches

- **Do:**
  - Allow time for your message to “sink in”
  - Slow down. Take your time -- even when you are in a hurry!
  - Take “but” out of your vocabulary
    - “But we just talked about that”
    - “But I just told you why not”
    - “But that’s tomorrow, not today”
    - “But that’s not yours”
Validation Approaches

- **Do:**
  - Distract them to a different subject, activity
  - Accept the blame for misunderstandings *(even if when you know better!)*
    - “I’m sorry. I didn’t mean to frighten you.”
    - “I’m sorry if that hurt.”
  - Leave the room to avoid confrontations
    - “I’m going to the kitchen now. I’ll be back.”
    - “Let’s stop now. We’ll do this later.”
Validation Approaches

Do:
- Respond to feelings, not words
- Be patient, cheerful, reassuring
- Go with the flow!

You’re going to work? But you are on vacation this week. Stay home with us . . . Please?
Validation Approaches

- **Do:**
  - Listen carefully to type and extent of false beliefs
  - Monitor level of distress experienced by the person
    - Persistent, severe, and troubling beliefs may reduce comfort and function
    - Short-term, low-dose medication may be needed
    - Try all other approaches first!!
Problem-solving requires good documentation!

- Demanding? 
  *In what way?*

- Disoriented? 
  *To time? Place? Or person?*

- Delusional? 
  *What about? What did she say? Do?*
PLST: Care Planning

- Evaluate Care
  - Sleep patterns
  - Weight
  - Food & fluid intake
  - Incidents and outbursts
    - How often?
    - How long?
    - How severe?
  - Medication use
Summary

- Dementia is **INCURABLE** but not **UNTREATABLE**!
  - Preserve remaining abilities
  - Avoid unnecessary stress
  - Treat overlapping illness that makes symptoms worse
  - Provide education & guidance to families