Rethinking Dementia Care:
A person centered approach to behavioral expressions

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Disclosure

Carol White is a full-time employee of Brookdale Senior Living, and a shareholder in the company.
Objectives

• Recognize un-met needs in persons living with dementia and develop problem-solving skills for behavioral expressions.

• Discuss a 7-step problem solving approach and how to reduce psychotropic medication reliance while providing dementia care.

• Identify resources and successful general interventions.
Quick Review of stages of dementia and possible behavioral symptoms

• Mild/Early Stage:
  – Forgetful, word finding issues, may confuse time, dates and names.
  – Shorter attention span.
  – May see person socially withdraw.
  – May be unable to adapt to changes in life routines.
  – Loses or misplaces things.
Quick Review of stages of Dementia and possible Behavioral Symptoms

Moderate/Middle Stage:

- Language becomes much more affected.
- Lacks sound judgment—safety issues when left alone.
- May become suspicious or paranoid.
- Changes in personality and demeanor.
- Agitation and irritability may surface.
- May see, hear, smell things that are not there.
- Will need but may resist assistance with toileting, showering and dressing.
- Sexual expressions may be inappropriate to setting.
Quick Review of Stages of Dementia and possible Behavioral Symptoms

**Advanced/Late Stage:**

- Language is significantly affected, may only understand one out of four words, may speak with automatic speech or “word salad.”
- May resist care or become afraid.
- May refuse to eat or have difficulty (choking).
- Will likely need total assistance with activities of daily living.
- Sleeps more.
- Unsteady or may even be completely unable to walk.
Points to remember about Behavioral Symptoms

• Persons with dementia have a disease and cannot always control their responses--brain damage.
• They do not have the same cognitive abilities we do.
• However, abilities, skills, and talents do remain- we need to embrace those.
• Every person is different and has unique set of needs and we need to honor preferences, habits, and routines.
• We can have daily moments of success.
• Being in a care partner relationship is not always easy - for the carer or the care recipient.
It's time to change our thinking about Behaviors

• We are moving away from a strictly biomedical interpretation of behaviors towards a more experiential understanding.
• We need to begin thinking differently about dementia as a cognitive difference rather than a decline—different world view.
• What we used to coin as “challenging” or “negative” behaviors should be viewed as the person’s attempts to communicate their unmet needs to us.
It's time to change our thinking about Behaviors

• If the behaviors are the only form of communication, is it fair to “silence the voice” with sedating medications? Restraints?

• It is up to us the care partners to make changes and adaptations--the person with dementia is not capable of making changes.

• They’re doing the best job they can.
Problem-Solving Behavioral Expressions

How do we do this?

• Begins with changing our language and our thinking.
• Teaching others to create an understanding of:
  – Disease process and how the brain is effected.
  – Possible triggers for behavioral expressions.
  – Our role in reducing triggers and possible irritants.
• Person centered care & programming are the key:
  – Commit to doing things differently and meeting unmet needs.
Changing our Language

• Start with changing language.
  – Language is the place to start with any culture change.

• A “behavioral expression” instead of challenge or negative behavior.
  – An expression of an un-met need.

• Stop judging the behavior and become curious.

• The person should never be defined by his/her behavior (ex: she is a “wanderer”, a “hitter”, or a “spitter”).

• Remember the person behind the behavior—care for them individually.
Person Centered Care

• Focus on the Person.
• Seeing the person with dementia as an individual human being with a distinct personality.
• Asking who was/is this person behind the disease?
• Really “know” the resident and honor the resident’s habits, routines and preferences.
• Meet the person at their point of need and support their highest level of capability & participation.
Create Understanding of Disease & Behavioral Expressions

• Persons with dementia are trying to communicate an unmet need, trying to express something—to tell you something

• Thinking about the issue as an unmet need assists us to be less judgmental and encourages us to ask “why?”

• All care partners must become detective and commit to doing something when the behavioral expressions are made.
  – “What is she telling me?”
  – “What does she need?”
  – “Is she uncomfortable?”
  – “How can I help?”
Common Behavioral Expressions

- Hitting
- Resistance
- Name calling/swearing
- Exit seeking
- Refusing to eat
- Refusing care
- Restlessness

- Repeating
- Urinating in plants/corners/closets
- Late day restlessness
- Calling out
- Sexual comments/acts
- Sleep difficulties
- Disrobing in public areas
Psychotropic Medications

• Have been used for dementia because a person with dementia may develop abnormal thought processes at some point such that resemble:
  – Paranoia, delusions, and hallucinations associated with psychosis.

• However, the majority of people with dementia are medicated with antipsychotic medications for other resolvable behavioral symptoms:
  – Agitation, resistance to care, anxiety, pacing and repetitive speech

*Dementia Beyond Drugs, G. Allen Power
Psychotropic Medication

• Research findings suggest that between 35% and 53% of assisted living residents receive one or more psychotropic medications.

• Voyer and Martin (2003) found that more than half of community-dwelling older adults who are admitted to nursing homes receive psychotropic medications within 2 weeks of their admission (Smith, Buckwalter, Hyunwook, Ellingrod, and Schultz, 2008).

• 10% of geriatric hospitalizations are related to the use of benzodiazepines (Voyer & Martin, 2003).

*Dementia Beyond Drugs, G. Allen Power*
Psychotropic Medication

• Risperidone released in 1993 and several since—thought to be “safer” than the older medications in the same class—use of these meds with dementia skyrocketed.

• A study of the 2.4 million Medicare recipients who spent time in a nursing home from 2000-2001 showed that 28% (693,000 people) were prescribed an antipsychotic med—nearly doubling the number from 5 yrs. previous.

• 17.2% of these recipients (over 100,000 frail older adults) received more than the maximum recommended daily dose.

Dementia Beyond Drugs, G. Allen Power
How do we reduce antipsychotic medication use?

• Implementing person centered care and programming.
• Establishing a strong culture of behavioral expression discussions & communication amongst care partners.
• Complete the 7- step problem-solving process.
• Resist the urge to rely on a pill.
Beginning the problem-solving process: Questions to ask

• Physical
  – Hungry? Thirsty?
  – Need to go to the bathroom?
  – Can we blame the PAIN?

• Environmental
  – Too hot, cold, full of glare?
  – Visually distracting, noisy, unfamiliar?

• Task-Oriented
  – Has the task been adapted to person’s level of dementia.

• Approach
  – Are we using prompts, cues and verbal direction based on the person’s level of dementia.
7 Step Program

- **Step One**: Describe the person and the behavioral expression.
- Use descriptive terms.
- Avoid negative judgments and terms (e.g. “he’s just nasty, mean, etc.”).
- Remember who the person is behind the behavior.
7 Step Program

• **Step Two**: Describe the actual behavioral expression. Remember these are the symptoms not the problem!

• Describe and include:
  – Who is involved.
  – Where does it happens.
  – Identify patterns of involvement.

  (e.g. someone visits the person wearing a suit and triggers a person to want to get to work immediately).
7 Step Program

Step Three: Identify when the person exhibits the behavioral expression.

- Be very specific in your description.
- Pinpoint exact times.
- Look for patterns and triggers (e.g. agitation increasing around classic movement times—5 pm).
- Don’t underestimate the effects of new care partners on the person.
7 Step Program

Step Four: Think about and describe what works to lessen the behavior?

– Include any interventions that have been effective in the past.
– Be sure to ask the person themselves!
– Be sure to ask all care partners—someone may have an answer.
– Involve and question family members and former care partners.
7 Step Program

**Step Five:** Determining the Unmet Need

**ASK:** Can we “Blame the Pain”?  

- Rule out resolvable physical issues as causes:
  - Pain (arthritis, old injury, movement), physical discomfort (lower back pain) or illness.
  - Infection (UTIs not always a culprit).
  - Changes in medications or poly-pharmacy issues.
7 Step Program

**ASK:** Is it our approach?

- It is crucial that we observe and consider the behavioral expression occurs to rule-out the following areas.

- Care partner actions that startle, threaten, cause pain, or just annoy the person:
  - Not gaining permission.
  - Not using good body language or getting too close too fast.
  - Not being gentle and calm.
  - Not respecting the person’s wishes.
  - Asking the person why he/she did something.
  - Scolding or other “tone-ing”
  - Demanding that the person be polite.
7 Step Program

Step Five: Determining the Unmet Need

**ASK:** Is it the environment?

- Physical Environment that is uncomfortable, unpleasant, or irritating.
- Too hot/cold.
- Inappropriate lighting.
- Unfamiliar-no recognition of purpose of surrounding.
- Too much noise and stimulation.
- Not enough noise and stimulation—lack of novelty.
- Crowded space.
- Agitation in other persons or care partners.
7 Step Program

Step Five: Determining the Unmet Need

**ASK:** Is it the person in a state of well-being?
- What are the Resident’s Unmet Emotional, Psychiatric, and Physical Needs.
- Emotional or Psychiatric Needs.
- Unaddressed Depression issues.
- Fear
- Anxiety
- Delusions or hallucinations
- Anger/Frustration
- Loneliness
7 Step Program

• **Step Six**: Create a plan to solve the problem and distinguish the behavior
  – What can be done to meet the unmet needs?
  – Who needs to be notified of plan for interventions?
  – How will you communicate with each other?
  – What needs to change in your approach

• **Step Seven**: Implement the plan and set up an evaluation procedure to determine if the plan is effective
General Interventions

- Keep routines structured and predictable - consistent care partners.
- One step at a time - break down the process.
- Alone time is ok.
- Meet needs through person-centered approaches.
- Monitor TV - may not understand violence or issues discussed.
- Keep visits calm and simple.
- Avoid lots of questions.
Resources

• **Dementia Beyond Drugs: changing the culture of care,** 
  *G. Allen Power 2010* (www.healthprofessionspress.org)

• Alzheimer’s Association (www.alz.org)

• Alzheimer’s Disease Education & Referral Resource (www.ADEAR.org)