Non-pharmacological Strategies to Bring Purpose to Residents with Dementia

Lisa Milliken, MA, CCC-SLP
Education Director

Background

• Estimated 5.4 million Americans suffer from dementia
  — More than 15 million provide caregiving
  — 18.1 billion hours of unpaid care

• Costly to treat ($236 Billion in 2016)
• Caregiving is the most costly aspect of dementia care
• Projections for 2050: 13.8 million will have dementia

(RAHQ, 2017)

Risks of Antipsychotics with Dementia

“The absolute effect of antipsychotics on mortality in elderly patients with dementia may be higher than previously reported and increases with dose.”

Donovan, et. al, JAMA Psychiatry. 2015

Number Of People Treated For Each Death

Source: Donovan, et. al, JAMA Psychiatry. 2015

The lower the number, the riskier a drug. A

EX: 1 in 26 pts expected to die within 6 months of starting Haldol for symptoms of dementia

Dangers/Risks from Antipsychotics with Dementia

• Sedation, lethargy
• Gait disturbance, falls, fractures
• Rigidity and other movement disorders
• Constipation, poor nutrition/fluids intake
• Urinary incontinence
• Weight gain
• Elevated blood sugar
• Increase risk of pneumonia
• Increased risk of stroke
• Increased risk of death

(Ballard et al. 2009)

New CMS Reform of Requirements for LTC Participation

• Resident Rights (483.10)
• Freedom from Abuse, Neglect, Exploitation (483.12)
• Resident Assessment (483.20)
• Person-Centered Care Planning (483.21)
• Quality of Life (483.24)
• Quality of Care (483.25)
• Nursing Services (483.35)
• Behavioral Health (483.40)
• Pharmacy Services (483.45)
• Administration (483.70)
• Training Requirements (483.95)

New or Revised CFRs Related to the care of residents with dementia
**Pharmacy Services (483.45)**

- Residents do not receive psychotropic drugs pursuant to a PRN order unless diagnosis supports and condition is documented in medical record.
- PRN order for a psychotropic drug is limited to 14 days unless physician documents in the medical record the rationale for continuation.

**Psychotropic Drug Definition in New Rule**

Taken from the November 2002 OIG report, “Psychotropic Drug Use in Nursing Homes” (OEI-02-00-00490):

- A drug that affects brain activities associated with mental processes and behavior.
- Includes, but are not limited to:
  - Anti-psychotic
  - Anti-depressant
  - Anti-anxiety
  - Hypnotic
  - Opioid analgesic
  - Any other drug that results in effects similar to the drugs listed above.

**Many Types of Dementia**

The most common cause: Alzheimer’s disease, responsible for at least half of all cases.

- As many as 50 other known causes of dementia.

**Effects of Dementia**

Types and levels of decline will vary by type of dementia.

**Cortical Dementia**

- Most common symptoms:
  - Severe Memory Loss
  - Problem Solving & Reasoning
  - Aphasia

**Subcortical Dementia**

- Most common symptoms:
  - More complex
  - Changes in speed of processing
  - Changes in ability to initiate activities, Clumsiness
  - Attention
  - Emotionality (Depression, Irritability, Apathy, etc...)

**Examples:**

- Alzheimer’s Disease
- Creutzfeldt-Jakob Disease
- Frontotemporal Dementia

**Examples:**

- Parkinson’s Disease
- Huntington’s Disease
- ALS

**Treatable Forms of Dementia**

- Chronic alcohol or drug abuse (if the person stops the abuse early enough)
- Tumors that can be removed
- Subdural hematoma
- Normal pressure hydrocephalus
- Metabolic disorders, such as a vitamin B12 deficiency
- Hypothyroidism
- Hypoglycemia
Person-Centered Care Approach

- Emphasizes placing the person with dementia as the focal point of caregiving (Kitwood & Bredin, 1992)
- Treatments and interventions should be very individualized and person-centered
- Is a most recognized Theoretical Framework of care, & is recommended by the National Partnership to Improve Dementia Care in Nursing Homes

Person-Centered Care

“Person-centered care’ means that individuals’ values and preferences are elicited and, once expressed, guide all aspects of their healthcare, supporting their realistic health and life goal.”

“Person-centered care is achieved through a dynamic relationship among individuals, others who are important to them, and all relevant providers. This collaboration informs decision-making to the extent that the individual desires.”

(J Am Geriatr Soc 64:15–18, 2016)

Early Dementia

- Appear more apathetic, with less sparkle
- Lose interest in hobbies, activities
- Unwilling to try new things
- Unable to adapt to change
- Show poor judgment and make poor decisions
- Slower to grasp complex ideas and take longer with routine jobs

Early Dementia

- Blame others for “stealing” lost items
- Become more self-centered and less concerned with others and their feelings
- Become more forgetful of details of recent events
- More likely to repeat themselves or lose the thread of their conversation
- More irritable or upset if they fail at something
- Have difficulty handling money

Early Dementia

- Looks “normal”
- Good speech/language/social skills
- Immediate memory relatively intact
- No changes in posture and/or gait
- Knowledge of past, present and future
- Believes still has responsibilities
- Doesn’t believe needs assistance

Early Dementia

- Wandering
- Exit-seeking, eloper or runaway
- Delusions, suspiciousness, anxiety
- Tearfulness, depression and catastrophic outbursts
- ADL relatively intact
- Visual field: 21-24 inches
Middle Dementia

- Very forgetful of recent events; memory for the distant past generally seems better, but some details may be forgotten or confused
- Confused regarding time and place
- Become lost if away from familiar surroundings
- Forget names of family or friends, or confuse one family member with another
- Forget saucepans and kettles on the stove; may leave gas unlit

- Wander around streets, perhaps at night, sometimes becoming lost
- Behave inappropriately, for example going outdoors in nightwear
- See or hear things that are not there
- Become very repetitive
- Neglectful of hygiene or eating
- Become angry, upset, distressed or frustrated

Middle Dementia

- Looks “unfinished”
- Ambivalent about social graces
- Noticeable speech/language deficits
- Difficulty using common objects
- Changes in posture, gait, balance, vision
- Knowledge past and immediate present
- Gives up previous “responsibilities”
- Unconcerned about whereabouts
- No longer able to think abstractly

- Wandering, self-stimulation
- Becoming sensory oriented
- Visual field: 12-14 inches
- Searching for things/persons
- Repetitive “tasks”
- Delusions, suspiciousness, anxiety
- Catastrophic outbursts
- Resistance to care, ADL simplification

Late/End Stage Dementia

- Unable to remember, for even a few minutes, that they have had, for example, a meal
- Lose ability to understand or use speech
- Incontinent
- Show no recognition of friends and family
- Need help with eating, washing, bathing, using the toilet, dressing
- Fail to recognize everyday objects

- Disturbed at night
- Restless, perhaps looking for a long-dead relative
- Aggressive, especially when feeling threatened or closed in
- Have difficulty walking, eventually perhaps becoming confined to a wheelchair
- Have uncontrolled movements
- Immobility will become permanent; in the final weeks or months the person will be bedridden
Late/End Stage Dementia

- Looks “abnormal”
- Severe speech/comprehension deficits
- Severe difficulty using common objects
- Appears “lost in thought”
- Difficult to get and keep attention
- Significant posture, gait and/or balance deficits
- Downward restricted gaze
- Visual field: 6-8 inches

Late/End Stage Dementia

- Awareness limited to field of vision
- Senses heightened significantly
- Retains some over-learned skills from past
- Wandering, self-stimulation
- Sensory-oriented, hyperorality
- Doesn’t recognize familiar persons
- Cannot communicate needs
- Resistance to care, almost total care
- Accepts but will not initiate interaction

The Global Deterioration Scale (GDS)

- Developed by Dr. Barry Reisberg
- Provides an overview of the stages of cognitive function for those suffering from dementia
- Broken down into 7 different stages.
  - Stages 1-3 are the pre-dementia stages
  - Stages 4-7 are the dementia stages
- Beginning in stage 5, an individual can no longer survive without assistance.

<table>
<thead>
<tr>
<th>Level of Impairment</th>
<th>Stage</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Cognitive Decline</td>
<td>1</td>
</tr>
<tr>
<td>Very Mild Cognitive Decline (Age Associated Memory Impairment)</td>
<td>2</td>
</tr>
<tr>
<td>Mild Cognitive Decline (Mild Cognitive Impairment)</td>
<td>3</td>
</tr>
<tr>
<td>Moderate Cognitive Decline (Mild dementia)</td>
<td>4</td>
</tr>
<tr>
<td>Moderately Severe Cognitive Decline (Moderate Dementia)</td>
<td>5</td>
</tr>
<tr>
<td>Severe Cognitive Decline (Moderately Severe Dementia)</td>
<td>6</td>
</tr>
<tr>
<td>Very Severe Cognitive Decline (Severe Dementia)</td>
<td>7</td>
</tr>
</tbody>
</table>

Assuring Purpose for Residents

- Physiological
- Esteem
- Safety/security
- Belonging and love

Responses to Stress

Typical Stress Relievers
- Go for walk
- Talk on the phone
- Take a bath
- Put on comfortable clothes
- Go shopping
- Exercise
- Read a book
- Sex

Dementia Behaviors
- Wandering
- Asking same thing over and over
- Taking off clothes
- Rummaging
- Pacing
- Inappropriate sexual behavior
Behavioral symptoms related to dementia are defined as verbal, vocal or motor activities that are considered to be aggressive, excessive or lack adherence to social standards.

Behaviors result from interactions between the resident, the caregiver and the setting.

56-66% of residents in LTC facilities exhibit behavioral symptoms related to dementia (Boustani et al, 2005).

Inappropriate, repetitive or dangerous behaviors which are disruptive to the living and working environment in the NH.

Most common disruptive behaviors:
- Wandering
- Aggression
- Agitation

Ahn & Horgas, 2013

ALL behavior has meaning and is indicating something.

Behavior is a form of communication.

Look at every behavior as unmet need.

Behaviors are considered a problem when:
- Safety or well-being of patient or others is compromised
- A trigger or cause cannot be identified

Anger/agitation
Sleep problems
Paranoia/delusions
Resistance to ADL
Continence difficulty
Getting lost/wandering
Sundowning
Catastrophic reactions
Rummaging
Repetitive actions
Crying out
Inappropriate social and sexual behavior

Health Conditions
Medications
Communication
Environment
Tasks
Unmet needs
Life Story
Staff Approach

Prevent the incidence of agitation and aggressive behaviors.

Respond to episodes to reduce severity, duration, caregiver distress.

Interventions may be:
- Patient focused: directly intervene with patients
- Caregiver focused: intervene through caregivers and environment
Non-pharmacologic Interventions

- Staff nurses under-identify behavior changes and the need for additional physical assessment
- The Serial Trial Intervention (STI) can be initiated to determine the cause of a behavior change and address it (Kovach et al., 2012)

Responding to Behaviors

- Each person is unique
- No one-size-fits-all way to respond
- Patience is key in trying a response, determining if it’s effective and, if necessary, trying a different response

Cognitive/Emotion Interventions

- Reminiscence Therapy
  - Discussion of past activities, events, experiences (Akanuma et al., 2011)
- Simulated Presence Therapy (SPT)
  - Audiotapes by family about cherished memories
  - Overall good evidence, though may cause adverse effects in some residents (Jetteker, 2008; O’Connor, et al., 2009)

Cognitive/Emotion Interventions

- Validation Therapy
  - Opportunity to resolve unfinished conflicts by encouraging and validating expressions of feeling
  - Mixed evidence (Neal, Barton, & Wright, 2009)
  - Overall, insufficient evidence to draw conclusions about the efficacy of cognitive and emotional interventions
Multi-Sensory Interventions

Increased engagement in multi-sensory environments (Heyn, 2003)

- **Sound**
  - Natural environments decrease agitation (Whall et al, 1997)
- **Sight**
  - Light intensity improves performance and sleep (Koss & Gilmore, 1998)
- **Smell**
  - Lavender oil decreases agitation (Holmes et al., 2002; Thorgrimsen, Spector, Wiles, & Orrell, 2003)

- **Snoezelen Multisensory Stimulation Therapy (MMS)**
  - Combines the therapeutic use of light, tactile surfaces, music, and aroma
  - Neuropsychiatric symptoms may result from periods of sensory deprivation
  - Short-term benefits on behaviors were significant (Chung & Lai, 2009)

Multi-Sensory Interventions

- **Massage and Touch**
  - To reduce depression and anxiety
    - Hand massage with calming music
    - Tactile input during meals
    - Gentle massage 3X/day
    - Intermittent touch with talking
  - Massage and touch therapy may have beneficial effects
    - (Hansen, et al., 2009; Gleeson & Timmins, 2004)

Multi-Sensory Interventions

- **Music**
  - Reduces repetitive disruptive vocalizations and self-stim behavior (Lundy & Hofn, 1994)
  - Promotes mobility skills and body awareness (Pomeroy, 1993)
  - Improves posture, competence, and sensory awareness (Biostel, Brown, & Eleman, 2003)
  - Reduces agitation and time spent with meals (Sherrell, Thorren, & Hatton, 2004)

Multi-Sensory Interventions

- **Animal-Assisted Therapy**
  - Robotic cats, plush toys, fish tanks, resident cat/dog
    - Decreases in agitated and disrupted behaviors
    - Increases in social and verbal interactions
    - Decreases in passivity
    - Increases in nutritional intake
    - (Greer, et al., 2001; Martindale, 2008; McCabe, et al., 2002)

Other Interventions

- **Exercise**
  - No specific guidelines re: intensity or frequency
    - Increased sleep time, decreased daytime sleep, decreased nighttime awakenings
    - Improved mobility and decreased falls
    - (Alessi, et al., 1999; McCurry, et al., 2005; Alessi, et al., 2005)
**Agitation**

- Sensory interventions (aromatherapy, thermal bath, calming music, and hand massage) show decreased agitation
- Social contact, environmental modification, caregiver training, and behavior therapy showed limited effects on agitation

**Agitation Strategies**

- Do not fight, scream or scold
- If possible leave the room (tell person you’ll be back)
- Do not turn your back on the person
- Do not try to reason
- Keep your hands in view
- Avoid exaggerated gestures
- Stand to one side and slightly sideways

**Wandering Strategies**

- Illusions
  - Misinterpretations of common, everyday events and items
- Visual cliffing
  - Misinterpretation of a change in color or texture as a change in elevation
- Deterrents
  - Intentional obstacles to stop an undesired activity

**Wandering Strategies**

- Message
  - What exactly is the message you want to send?
  - E.g., DETOUR, DO NOT OPEN, DANGER
- Authority figures
  - Choose a figure that conveys respect

**Wandering Strategies**

- Camouflage
  - Make it disappear or resemble something else
  - E.g., door murals, “fake mullions”
- Diversions
  - Items strategically placed to catch and redirect attention
Wandering — Signage/Cues

• Location
  o Signs are of little value if not seen

• Readability
  o Simple, easy-to-read contrasting letters
  o Consider native language

• Backup precautions
  o Never rely on a single device or strategy when more than one is warranted

Visual Barriers/Interventions

• Concealment of doorknobs, painted doorknobs, wall mural on an exit door are effective for wandering

• Dividers facilitate engagement in activity and improve attention
  (Namazi & Johnson, 1992)

• Wall murals and posters decrease exit-seeking behavior
  (Cohen-Mansfield & Werner, 1998)

Eating

• Improved consumption when:
  o CNA allows resident to control more of the eating process (Amella, 1999)
  o Verbal prompts and positive reinforcement (Coyne and Hoskins, 1997)
  o Listening to music while eating (Ragneskog et al., 1996)
  o Small dining rooms next to living space (Day et al., 2000)
  o Consistency of caregivers and increased nutritional value of foods (Burgener and Twigg, 2002)

Fall Management

• Incidence of falls with AD is around 60% (twice that of normal elderly) (Shaw et al., 2003).

• Embed physical training focused on improving gait, strength, balance, and flexibility in occupation-based intervention (Hauer et al., 2006; Oliver et al., 2007)

• Close supervision and participation in activity-based intervention (Detweiler et al., 2005)

Wandering

• Staff rewarding non-wandering behavior (Allen-Burge et al., 1999)

• Secure place to wander (Allen-Burge et al., 1999)

• Corridors with nature and homelike scenes (Day et al., 2000)

Toileting/Continence

• Improved continence when:
  o Toilets are visibly accessible to residents (Day et al., 2000)
  o Prompted voiding, behavior modification, and scheduled toileting (Doody et al., 2001)
**Sleep Behavior**

- Bright light therapy to improve circadian rhythms and increase time sleeping at night
- Higher doses of melatonin
  - Neither has solid conclusive evidence
- Environmental modification may help to improve sleep behavior
  - E.g., less noise, light, interruptions

**Bathing and Dressing**

- Improved independence when:
  - Listening to favorite music (Clark et al., 1998)
  - Environment with nature sounds, large, bright pictures, sweet food (Whall, 1997)
  - Tailor care to capabilities of the individual resident (Beck et al., 1997)
  - Verbal prompts and physical assists (Rogers et al., 1999)
  - Present clothing in sequential order (Day et al., 2000)

**Routines**

- To maintain occupational performance (Nygård & Öhman, 2002)
- To address wandering, aggression, or to prevent catastrophic reactions (Corcoran, 2003; Leary, 2003; Ward, 2003)
- Routines must be flexible to meet the resident’s needs, not staff (Skovdahl, Khlgren, & Khlgren, 2003)
- Residents should follow preferred routines (Donovan & Dupuis, 2006)

**Pain in the Elderly**

- 50-80% of NH patients are reported to be in pain (Achterberg et al., 2013; Ahn & Horgas, 2013; Patel et al., 2013; Takai et al., 2010)
- Pain is positively correlated with ↑ aggression and agitation scores (Ahn & Horgas, 2013)
- Analgesics were significantly less often prescribed and/or used for patients with dementia (Hoffman et al., 2014; Takai et al., 2010)

**Pain Management Protocol**

- Ensure all comfort needs are met
- Look for treatable conditions
- Look for other potential sources of the unusual behavior
- Try non-drug comfort strategies
- Begin an analgesic trial
- Use a pain rating/assessment tool

**Pain Behaviors**

1. Facial expressions
   - Slight frown/sad, grimacing, wrinkled forehead, closed eyes, rapid blinking
2. Verbalizations/vocalizations
   - Sighing/moaning/groaning, grunting/chanting, calling out, noisy breathing, asking for help, verbally abusive
3. Body movements
   - Rigid/tense, fidgeting, ↑ pacing, rocking, gait/mobility changes (Achterberg et al., 2013)
Pain Behaviors

4. Changes in interpersonal interactions
   - Aggressive/combative/resisting care, ↓ social interactions, socially inappropriate/disruptive, withdrawn

5. Changes in activity patterns or routines
   - Refusing food/appetite change, ↑ rest periods, sleep pattern change, cessation of common routine, ↑ wandering

6. Mental status changes
   - Crying/tears, ↑ confusion, irritability/distress

   (Achterberg et al., 2013)

Barriers to Pain Management

- Poor or absent communication
- Psychotropic meds to deal with behavior
- Lack of knowledge for pain assessment & management
- Reluctance to change/increase meds

Multi-Sensory Interventions

- Transcutaneous Electrical Nerve Stimulation (TENS)
  - Most often used for pain control
  - Positive short-term benefits on sleep disturbances and behavioral symptoms, evaluated immediately after treatment or at six-week follow-up

   (Johnson, 2008; Cameron, Loneigan, & Lee, 2009)

Verbal vs. Non-Verbal Communication

- Body Language: 55%
- Pitch and Tone: 7%
- Verbal: 38%

Factors Affecting Communication

- Family/staff stress and frustration
- Environment
- Time
- Distractions in the environment
- Medications
- As dementia progresses, the ability to correctly interpret communication decreases
- Depression and anxiety

Challenges in Communication

- Word-finding difficulty
- Repetition
- Unable to read and/or understand written communication
- Revert back to their native language
- Lose ability to speak in sentences
- Loss of ability to understand
- Unable to use words
**Communication Strategies**

- Avoid arguing or reasoning
- Ask closed-ended questions
- Observe non-verbals
- Allow time to respond
- Be ready to repeat
- Use short sentences
- Speak slowly, clearly, audibly
- Use the person’s name
- Use gestures/visual cues

**Communication Strategies**

- Communication skills vary
- Assume most of the conversation
- Grade the conversation
- Be an active listener
- Avoid shouting
- Use adult language
- Use eye contact
- Use touch
- Communicate through senses (smell, touch, sight, taste)

**Be Present**

- Be with a resident – see their perspective
- Giving complete attention
- Trying to understand the person’s needs
- Looking in the eye when talking
- Spend time, even when busy
- Give control

**Caregiver Approach**

- The caregiver’s approach affects the resident’s behavior
- Behavior management skills training program
  - Inservice, direct observation and feedback
  - Decreased use of ineffective strategies (e.g., arguing), decreased disruptive vocalization, restlessness, aggression during ADL
    (Burgio, et al., 2002)

**Importance of Activity**

- Tailored Activity Programs reduce behaviors and increase engagement
  (Gupta, et al., 2008)
- Activity kits improve quality of visits and QOL
  (Crispi & Heitner, 2004)
- Individualized and meaningful activities show positive results
  (Pool, 2001)

**Activity Requirements**

- Gross motor
- Repetitive
- Uses familiar motions
- Involves 1 or 2 steps
- Observable effect on environment
- Non-competitive
- Involves few or no rules
- Tailored to match skills and interests
  (Kolanowski, 2001)
Meaningful Activity
Every activity must . . .
• Have a purpose that is obvious to the participant
• Be voluntary
• Be pleasurable
• Be socially and age appropriate
• Be failure proof

Considerations When Adapting Activities
(Marchal, Copeland, Edell, 2012)
• Attention span
• Environmental scanning
• Awareness of purpose/goal
• Communication
• Physical attributes
• Quality of work
• Problem solving
• Sequencing
• Social factors
• Environment
• Ability to initiate
• Ability to choose
• New learning ability
• Direction following
• Response time

Successful Activities
1. Assess cognitive function
2. Learn about past habits and interests
3. Choose activities based on past interests
4. Adapt the activity to match physical and cognitive abilities
5. Assess success of the activity

Interdisciplinary Treatment Techniques
• Establish simple routine
  o Short simple phrases for instruction
  o Concrete, not abstract
  o Consistent with sequence of tasks/instruction
  o Predictable routine

Interdisciplinary Treatment Techniques
• Task segmentation
  o Simplify tasks
  o One-step commands
  o Hand-over-hand guidance
  o Familiar area
  o Allow for slower reaction time
  o Repeat commands
  o Limit adaptive equipment

General Behavior Management Strategies
• Keep tasks simple
• Be flexible
• Provide soothing activities
• Tolerate wandering or pacing
• Get into the person’s reality
• Validate the person’s feelings
• Keep a calm demeanor
• Distract with meaningful activity
• Use routines, keep familiar environment and approach
**Interdisciplinary Treatment Techniques**
- Provide one-step commands
- Speak slowly
- Repeat and rephrase sentences
- Utilize gestures with speech
- Praise and encourage patient often
- Limit distractions/structure environment
- Eye contact
- Avoid open-ended questions, offer choices
- Demonstrate the activity

**Cueing Strategies**
- Cues should be short and provide clear direction (Padilla, 2011)
- Verbal prompts along with positive reinforcement improve performance (Coyne & Hoskins, 1997)
- Demonstrate the activity
- Series of pictures that symbolize activity
- Provide tactile stimulation along with verbal instruction

**Cueing Strategies**
- Use hand signals, pictures, facial expressions
- Provide familiar visual and auditory stimuli
- Provide cues when changing topic
- Use of redirections
- Hand-over-hand technique
- Utilize multi-modality cueing

**Making a Difference**
- Understand and accept their reality
- What are their physical/emotional needs?
- Know where each person is in the disease process
- Honor with dignity and respect
- Be a good communicator
- Focus on what they can do
- Every interaction is an opportunity to connect

**Questions to Ponder**
- Are you present for your residents?
- Are your programs individualized?
- Do you grade your communication?
- How do you make a difference?
- Is your staff trained?
- Do your residents have a sense of purpose?

Lisa Milliken, MA, CCC-SLP
Education Director
lmilliken@selectrehab.com

Thank you.