LeadingAge Wisconsin
Health Issues Forum
on Dementia Issues
10:00 a.m. to 2:00 p.m.
Tuesday, April 29, 2014
Comfort Inn & Suites, DeForest

AGENDA

I. Introductions and Agenda Review (**please go to this link to access the April 29, 2014 meeting materials, the LeadingAge Wisconsin Draft Dementia Standards: www.leadingagewi.org/media/11072/hiforum.pdf. A Word version of the Draft Dementia Standards also has been posted at: www.leadingagewi.org/media/11075/draftdementia.doc)**

II. Update on the DHS Dementia Redesign Plan: Kevin Coughlin, Policy Initiatives Advisor in the DHS Division of Long-Term (invited)

III. Review of the LeadingAge Wisconsin Workgroups' Draft Document

- Overview of the six sections and comments
- Are the draft standards supported by the membership?
- How should the draft standards be used by the Association in discussions with DHS officials?
- What is our position on DHS-sanctioned draft standards?
- Discussion on Related considerations

IV. Further Discussion on the DHS Redesign Plan

- Facility–Based Services & Specialized facilities
- Training Certificates—Education
- Discussions with MCOs
- Ongoing impact of the *Helen E. F.* Decision
- Other Items within the DHS Plan

V. Other Business/ Next Meeting Schedule & Topics /Adjournment

Directions to Comfort Inn and Suites, DeForest: From I-90-94, take Exit 126, the Dane-DeForest exit, which is County Highway V. The Comfort Inn & Suites is on the left hand (south) side of County Highway V, ¼ mile west of I-90-94.

LeadingAge™ Wisconsin

Better Services for Better Aging

Draft Dementia Care and Services

Standards/Guidelines

April 14, 2014

Note: The attached draft document is the collective product of six workgroups of the LeadingAge Wisconsin Health Issues Forum. The document was drafted in response to the WI Department of Health Services call for the establishment of voluntary provider dementia care and services standards (See *Wisconsin Dementia Care System Redesign: A Plan for a Dementia-Capable Wisconsin*, www.dhs.wisconsin.gov/publications/P0/P00586.pdf, February 2014)

This document has been made available to LeadingAge Wisconsin members only. It is working draft and available to assist in the Association's ongoing discussions on provider standards/guidelines related to dementia care and services. At present, the Association has not established a position on the value of DHS-sanctioned dementia care standards.

LeadingAge Wisconsin is indebted to the individuals listed on the following page for their exploration of possible dementia standards/guidelines.

LeadingAge Wisconsin Health Issues Forum
Dementia Work Groups

Dementia-Specific Behaviors (Phase One)
Dementia Care Fundamentals; Food & Fluid Consumption; Pain Management; Social Engagement

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Dementia-Specific Behaviors (Phase Two)
Resident Wandering; Resident Falls and Physical Restraint-Free

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Admission/Transfer/Discharge and Philosophy

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Food & Fluid Consumption, Pain Management, and Social Engagement Standards

Deb Bergen- Attic Angel Community
Lisa McGlynn - Attic Angel Community
Anna Howick - Attic Angel Community
Barb Kroda – Skaalen Nursing and Rehab Center
Jennifer Stollenwerk – Pleasant View Nursing Home

Our Charge: Create Training Guidelines for the care of persons with dementia in facilities – Best Practices

Recommendations: Dementia Care Fundamentals Related to dementia care in a facility:

Food and Fluid Consumption

Cognitive Health- Potential to complete OT and Speech evaluations to assist in determining baseline. Work with dieticians to help create a brain healthy diet. Consider hydration status as related to electrolyte balance.

Physical Health- Evaluate for effects of chronic disease processes and their treatments (medications) on appetite and overall intake. Complete oral assessment to assure oral health and properly fitting dentures, etc. Recognize and honor end of life.

Physical Functioning - Encourage independence by providing utensils that can be managed. Help train to use non-dominant hand when unable to use dominant hand for eating and drinking. Create an interdisciplinary approach to minimize limitations. Hand over hand as needed to assist.

Behavioral Status - Switch to finger foods or those easily and quickly managed. Keep over stimulation controlled. Know residents and their behaviors. Know seating preferences and arrangements.

Sensory Capabilities – Try different things – Remove talking from the television at meal time. Play music or DVDs with scenery only. Bake cookies before the meal. Bake bread. Provide color contrast--table, placemat, plates. Don't overwhelm with too many choices in front of the at once. Point out location if vision loss. Rotate plate as the meal progresses. Keep stimulation controlled by placement in the dining room if needed. Use social setting/ example of peers to promote eating and drinking through modeling. Use healthy spices to stimulate taste/appetite. Ensure comfortable seating and physical needs are met.

Decision Making capabilities – The resident may not be able to communicate likes and dislikes or preferences; may not process feeling of hunger; and may not be able to initiate eating. Staff must balance in the offering of choices and assistance. It is important to do our due diligence to include residents as much as possible in choices

they are able to make as their disease progresses. For example, offer two cups and let them choose or bring a different choice if the first is not consumed, don't just let it go if they do not eat. Continue to offer choices throughout the day, not just traditional meal time.

Communication Abilities – Works closely with decision making. Use all cues from the resident regarding choices and preferences. Include verbal and non-verbal. Speak simple, direct language. Use pictures, gestures, written words or verbal and auditory cues. Give ample time and opportunity to respond and express themselves.

Personal Background – History and lifestyle may affect daily routine. Need to know routine of long ago past as well as recent past. – Growing up, raising family, work life, retirement. It is likely the resident's behavior may revert to past decades.

Cultural Preferences- Must be recognized and respected. May revert to earlier times in their life that are not known to present day caregivers. May be regional. May change over time and must be reassessed. Need flexibility within the facility to provide what is needed.

Spiritual Needs and Preferences- Know potential religious affiliations related to what may be eaten and when. Offer a variety of diets relate to lifestyle choices.

Pain Management

Cognitive Health – May not be able to communicate or recognize that they are in pain. Interpret their actions. Pain can affect their ability to interact, respond and process information.

Physical Health – May cause a decline in physical health if not detected and treated. May negatively impact participation. Assess for changes in mobility, movement and participation. Consider diagnosis history related to possible pain concerns.

Physical Functioning – Support physical functioning with pharmacological and non-pharmacological interventions -- massage, aroma, heat therapies, etc.

Behavioral Status – Look into how pain and discomfort may be impacting behaviors. Look at effectiveness of pain management interventions; uncontrolled pain may lead to negative behavior. Consider if self-identified pain may be an emotional versus physical need.

Sensory Capabilities – Consider the side effects of pain medication on the senses. (Impact on tactile senses, visual spatial) Use alternate pain scales such as PAINAD. Be aware residents may not be able to process pain sensation.

Decision Making Capabilities – pain is what they say it is. Be willing to use different alternatives for intervention. Consider scheduling pain medication versus as needed.

Communication Abilities – Recognize individual communication styles and abilities. Interpret vital sign results to help determine/gauge level of discomfort. Approach them to treat pain. Ask direct/simple questions. Interpret non-verbal communication.

Personal Background – Residents may have had a previous bad experience or may have misconceptions about pain medications. Know how they previously managed pain.

Cultural Preferences – recognize that cultural backgrounds or emotional status may affect communication of pain. Some

cultures frown upon pharmacological interventions.

Spiritual Needs and Preferences – Consider non-pharmacological approaches related to spiritual well being. Make hospice referrals as appropriate.

Social Engagement

Cognitive Health – Impacts their ability level related to participation. Offer activities that accommodate resident's level of functioning. May have depression related to their recognition of their decline. Design interactions to do with them, not to or for them. Actively engage residents. It is the responsibility of all staff in all disciplines to provide social engagement. Make sure activity supplies are available to all staff at all times.

Physical Health - Impacts their ability to participate. Embarrassment related to current physical health may impact residents' comfort with social engagement.

Physical Functioning – Offer/provide activities that promote physical health and encourages residents to use remaining skills. If being treated by therapy, use interdisciplinary approach and use activity programming to assist in increasing physical function – both fine and gross motor skills.

Behavioral Status – Assure group size and location match resident abilities and preferences. Consider environmental impact: Careful consideration of color, layout, lighting, decoration, noise, privacy spaces.

Sensory Capabilities – Engage in activities that match sensory abilities. Utilize adaptive devices to help residents participate. Ensure adaptive devices are in working order. Capitalize on strengths related to senses – provide activities that focus on all senses they are able to utilize. Keep the focus on the process versus the end result/outcome of an activity.

Decision Making capabilities – Use the "come with me" approach. Keep invitation simple. Not too much explanation.

Communication Abilities-- lack of verbal communication skills does not prevent a resident from being socially engaged.

Personal Background-- Offer as many opportunities as possible each day to provide context which has personal meaning. Encourage sharing of Life Stories and use to engage and interact with the resident.

Cultural Preferences – Know what traditions and activity are important to each resident.

Spiritual Needs and Preferences – Offer religious outlets including church, devotional reading, religious music, clergy contact. Respect religious preferences or lack thereof. Connect with community resources as appropriate.

Wandering and Falls Standards

The Dementia Care standards workgroup for Wandering and Falls has concluded its task. I am submitting the document with the group's recommendations. We have adopted the Alzheimer's Association standards almost verbatim. {*Alzheimer's Association "Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes,* www.alz.org/national/documents/brochure_dcprphases1n2.pdf}. The changes we recommend to the language are highlighted in red.

These standards would be appropriate for nursing facilities and assisted living facilities. In addition, it should be noted that these standards are guidelines for providing competent care for residents with dementia and should create no presumption that every facility will adopt every recommendation. Facilities should also always retain the ability to implement programs according to their population and culture.

If you have any questions, please feel free to contact me. I appreciate the support that you and LeadingAge Wisconsin provide to me and all of your members.

Dementia Standards; Wandering and Falls work group:
Barbara Beardsley, Jane Hooper, Shari Kellog, Grace Hayden, Michelle Putz, Lauren Hartlaub, Nancy Johnson, Katie Quintanilla, Kathleen Mertz

Wandering-- Recommended Practices

Assessment

• Upon admission, collect information from family, friends or the transferring facility about the resident's history and patterns of wandering and strategies the family used to prevent unsafe wandering or successful exiting.

• Assess each resident's desire and ability to move about, and associated risks, such as becoming lost, entering unsafe areas or intruding on another resident's private space. While evaluating the triggers of wandering and a resident's wandering patterns, it is essential to determine:

- Whether wandering is a new occurrence
- Wandering patterns
- Medical conditions that may contribute to
- wandering, such as urinary tract infections,
- pain and constipation
- Cognitive functioning, especially safety awareness
- and being impulsive
- Vision and hearing
- Functional mobility status: balance, gait and
- transfer abilities
- Sleep patterns
- Resident life history, including past occupation,
- daily routines and leisure interests
- The resident's own toileting routines
- Emotional or psychological conditions that
- may be related to wandering, such as depression
- and anxiety or need for companionship

- Social considerations, such as interest in
- involvement with others
- Environmental hazards (e.g., poor lighting and
- uneven floors)
- History of recent falls or near falls
- The resident's footwear and clothing
- The resident's access and response to safeguards (e.g., video monitors, sensors, door alarms, access to handrails and places to rest)

• Determine if unsupervised wandering presents a risk or benefit to the resident and others in the residence.

Staff Approaches

• Assign staff to work with residents in ways that support consistent relationships so that each resident develops a sense of safety and familiarity with staff (consistent assignment).

• Ensure that staff understand whether a resident has a propensity to wander and the conditions under which this occurs.

• Staff need to understand and recognize the consequences of limited mobility.

• Ensure that residents are able to move about freely, are monitored and remain safe.

• Residents who have just moved into a new area or home may need additional staff assistance until they are comfortable in their new environment.

Example: Have specific welcome activities for new residents to help them feel comfortable and part of the community. These activities should avoid overwhelming the residents with new situations and people. Involve family members or previous caregivers to ease the transition.

• Communicate regularly with families of residents who wander regarding their need for movement. Describe resident behaviors and discuss measures to support their continued mobility, while protecting them and other residents with whom they may have contact.

• Help residents who do not have cognitive impairment understand wandering as a symptom of dementia.

• Ensure that residents who wander have adequate nutrition and hydration, which may include offering food and drinks while they are "on the go." **Note :** This is particularly important for residents who are unable to remain seated during mealtime.

• Staff may use various approaches to minimize unsafe wandering. These approaches include:

- Identifying resident needs and wishes, and then offering to help the resident engage in related, suitable activities
- Using a preventive approach to unsafe wandering

Example: For those who wander when needing to use the toilet, schedule toileting according to the resident's patterns and use cues to help the resident find the bathroom quickly.
Example: Engage the wandering resident with food, drink or activities that promote social engagement and purposeful tasks, such as sorting, building or folding.
Example: Provide regular exercise and stimulation for residents through programs tailored to a resident's level of cognitive and physical functioning. Balance physical activities with regular quiet time to allow for rest. Consider involving family or friends in these activities on a voluntary basis.
Example: Take residents outside regularly,

preferably daily except during adverse weather.
Example: For residents who are awake during the night, make activities available with an adequate level of staffing to provide encouragement and supervision.

- Accompany wandering residents on their journeys when supervision is required to ensure safety or encourage a meaningful alternate activity. Companionship is an added benefit.

Resident Example: A resident heads for an exit door at 3:00 p.m. when she sees nursing staff leaving the facility. She states that she must get home to meet her daughter after school.

DO: Begin by *offering to help* the resident.
Ask about her daughter, or ask what kind of
snack she would like to prepare and offer to help her with the preparation. The goal is for the resident to perceive the staff person as a friend and advocate.

DON'T: Begin *by telling her that she can't go out* or that her daughter is now grown up. The goal is to avoid having the resident perceive staff as an adversary.

DO: Develop a longer-term approach to avoiding exit-seeking behavior. For example, involve the resident in a 2:30 p.m. activity in a location where she doesn't see the staff preparing to leave when shifts change.

- If an alarm system is used to alert the staff when a wandering resident is attempting to leave the facility, choose the system that is least intrusive and burdensome.
  Note : For some residents, chair and personal alarm systems are a burden (as evidenced by the resident's protests or attempts at removal) and in some cases may lead to an increase in agitated behavior.

  Note : Chair, bed, and personal alarms that are audible to the resident may discourage all movement, not just unsafe attempts to stand or walk unassisted.

- Train all staff on the consequences of unsafe wandering, the protocols to follow to minimize successful exiting and the procedures to follow when a resident is lost.

- Promote identification of residents who are at risk of successful exiting:

- Keep photographs of residents who wander in a central, secure location and ensure that receptionists, security staff and others in a position to help can prevent successful exiting by recognizing these residents.
  Note : Care should be taken to ensure confidentiality and compliance with any relevant federal and state requirements.

- Provide opportunities for everyone to get to know these residents.

- Have a "lost person" plan to:

  - Account for each resident on a regular basis, such as during mealtimes, and when shifts change.
  - Establish a sign-in and sign-out policy for families and visitors when taking residents out of the residence.
  - Have recent photographs of residents and former addresses on file to provide to law enforcement personnel in case of successful exiting.

  Note : Care should be taken to ensure confidentiality and compliance with any relevant federal and state requirements.

- Notify management, family, law enforcement personnel, and state and local agencies as required immediately when a resident is missing and ensure that personnel receive information such as the resident's photo, home address, description of clothing worn and other relevant information.

- Carry out an organized search plan of the facility and its immediate vicinity and understand that a person with dementia may not respond when his or her name is called.

- Maintain local telephone numbers of nearby bus terminals, train stations or taxi services in case the search expands beyond the residence.

- Prepare a report that describes the resident's successful exit so the residence can learn from the experience as part of a quality improvement program.

- Organize routine practice searches.

- Enroll residents in the Alzheimer's Association Safe Return® program, which the Association operates with funding from the U.S. Department of Justice. Safe Return is a nationwide program that helps identify, locate and return people with dementia to their homes.

Environment

• Work to eliminate non-emergency paging-system announcements and other institutional features that make the residence feel foreign or different from one's home.

• When possible, create indoor and outdoor pathways which are free of obstructions and have interesting, safe places to explore and comfortable places to rest along the way. Pathways need to be well-lit without shadows or pools of bright light. Install window coverings to eliminate glare in key rooms and passageways. Ensure that transitions from pathways onto grass and other areas are smooth with no uneven surfaces.

• Create activity zones with recreational opportunities, such as multi-sensory theme boxes, that residents can explore with staff encouragement.

• Create a low-stimulus setting for periodic rest breaks, perhaps playing music or nature sounds that have been observed to calm the person who wanders.

• Provide substitute physical activities, such as dance, exercise or rocking.

Example: Encourage use of safe gliding chairs that have a wide base and do not tip over easily.

• Provide cues to help residents who wander orient themselves to the residence. Cues can include memory boxes by a resident's door, personal furnishings that residents will recognize or large visual signs or pictures for bathrooms.

• Consider the following approaches to minimize the risk of successful exit seeking. Before implementing them, check with fire marshals and other relevant officials regarding safety regulations, which vary by state.

• Make exits less obvious to reduce visual cues for exiting so the resident who wanders does not realize exiting is possible.

Example: When designing a new residence or unit, place doors parallel to the walking path with no windows in or beside the doors.

- Install non-intrusive alarm systems that alert staff to resident exiting.

- Post signs at exterior doors to alert visitors that people with dementia might try to leave when they do.

Resident Falls

Recommended Practices—Assessment

- Upon admission, collect information from family, friends or the transferring facility about the resident's history and patterns of falling and strategies the family used to prevent falls.

- Initial resident assessment is critical in the first few weeks after entering a residence because of a resident's potential confusion due to relocation. After a reasonable adjustment period, ongoing assessment addresses the changing risk of falls as dementia progresses.

Example: Newly admitted residents with dementia require close monitoring. The first 24-48 hours after an admission to a new setting are critically important because staff and surroundings are unfamiliar to the resident.

- A comprehensive assessment includes both identification of resident risk factors and evaluation of environmental conditions related to falls. It also includes collecting information from a resident as well as his or her family or caregivers about the history of falling and any other factors that may contribute to falls.

- Effective resident assessment includes:
  - History and patterns of near-falls, recent falls
  - and fall-related injury
  - Cognitive impairment and capacity for safe
  - and proper use of adaptive equipment and
  - mobility aids, such as walkers
  - Functional status and factors that affect mobility,
  - including muscle tone and strength, transfer ability, balance, stance, gait and ambulatory ability
  - Sensory function, including vision, ability to sense position of limbs and joints, and tactile senses

Note : Visual impairment may be related to contrast sensitivity, field loss, and use of glasses with incorrect prescriptions. A new prescription for corrective lenses may cause falls. Residents with cognitive impairment may be unable to use bifocals or trifocals properly.

  - Medical conditions that may contribute to falls, such as pain, infections, cardiovascular disease, osteoporosis, deconditioning, and nighttime urinary frequency and urgency
  - Hallucinations and delirium
  - Presence of restraints

- Nutritional status and recent weight loss
- Current medication regimen and use or recent change in medications
- History or presence of substance abuse or withdrawal symptoms
- Psychological conditions such as depression and anxiety
- Aspects of a resident's life history, professional and personal occupations, and daily routines could lead a resident to attempt activities that might result in falls

Example: A resident previously in the furniture business might try to move heavy furniture, thus increasing the risk of falling.

- Environmental assessment includes:

  - Environmental layout (shape of space and ease of getting around)
  - Lighting and glare
  - Presence of obstructions in both resident rooms and common areas
  - Accessibility, visibility and safety of bathroom and dining room
  - Sturdiness and visibility of handrails and furniture
  - Contrast of the toilet and sink from the wall and the floor
  - Safety and working condition of equipment and fixtures (e.g., bedside commodes, shower chairs, adequacy of brakes on wheel chairs)
  - Appropriate use of personal safety devices, such as canes, walkers or wheelchairs
  - Bathing facilities with non-slip surfaces
  - Floor surfaces, textures and patterns

  Example: A blue-and-black border may look like a river or a hole.

- Fit and use of resident footwear

  Example: Examine shoes and slippers regularly for potential poor traction.

- Use of housekeeping equipment

  Example: Ensure that machines like floor buffers are run when residents are not likely to be moving about. However, they should not be used at night when residents are sleeping.

- Use documentation and a tracking tool to identify falls, fall patterns and patterns of risky movement. Follow up with a family care plan meeting to evaluate options, such as use of an individual caregiver or presence of family and friends to help during peak activity times.

- If necessary, refer the resident to a qualified professional for evaluation using a more in-depth assessment of the resident's functional mobility, and ability to use safety awareness and compensatory strategies. Upon admission to the residence, refer residents to appropriate professionals if they have any of the following:

  - History of recent falls
  - Existing or new gait disorder or other condition that may be related to falls
  - Need for restorative activity to support mobility by strengthening muscles, improving balance, stabilizing gait and increasing physical endurance

  Note : Professionals can help identify creative, individual solutions to minimize the number of falls and injuries.

Staff Approaches

- Based on the resident assessment, develop a care plan that promotes resident mobility and safety while preventing or minimizing injuries. Update the plan as the resident's falling patterns change with the progression of dementia. Involve family or other caregivers in planning to help them understand the resident's condition as it changes.

- Dementia care training is the first step to ensuring effective staff approaches to reducing risks and managing falls. Effective staff training on fall prevention addresses:

    - Resident risk assessment
    - Identifying and monitoring resident needs that may increase risk of falls or fall-related injuries
    - Identifying and monitoring behaviors that increase fall risk, such as wandering patterns
    - Understanding risks and benefits of potential interventions to prevent falls
    - Understanding the benefits of exercise for improving a resident's strength and endurance
    - Proper use of safety equipment and personal safety devices
    - Safe techniques for lifting and transferring residents

- Some key points related to falls that staff need to understand include the following:

    - Because maintaining mobility is important, resident movement should be encouraged. The more a resident is immobile, the more he or she is at risk for injurious falls.

  Example: Exercise that promotes sit-to-stand activities and walking as part of the daily routine can help preserve a resident's mobility.

- It is necessary to follow existing organizational policies and procedures relating to fall management and response.

  Example: Perform fall event assessments at the time of the fall to identify and address the specific cause for a fall, such as water on the floor or resident dizziness after standing up.

- A range of interventions are available to individually tailor preventive strategies for residents at risk of falling.
  Note : Strategies informed by thorough resident assessments have the highest likelihood of reducing falls.

  Example: To reduce falls associated with urgent trips to the bathroom, consider using an individual toileting schedule or a bedside commode. Consider clothing that is easy for residents to remove when they have to
  go to the bathroom.

- Ensure staff are available to help those residents who need assistance with ambulation, dressing, toileting and transferring. Consistent staff assignment increases staff familiarity with individual residents.

- Eliminate physical restraints, unless needed for medical treatment in an emergency.

- Promote consistent and appropriate use of assistive devices, such as a walker.
  Note : Some residents may always need staff to walk with them to prevent falls.

- Promote a regular sleep-wake cycle by keeping bedding dry and ensuring residents are exposed to sufficient daylight, identifying a resident's regular bedtime routine, and matching the sleep-wake cycle to lifelong sleep habits.

Example: Ensure a comfortable sleeping environment with a good quality mattress, optimal temperature and minimal noise.

Example: Ensure that residents who like to bathe or read before bed can do so.

Example: Help a resident choose between extendedwear absorbent incontinence products to promote uninterrupted sleep or an individual toileting schedule.

- Have a scheduled and structured exercise or walking program for those residents who can safely participate in order to maintain or improve function, posture and balance.

Example: Develop walking programs around a resident's need to get someplace, such as walking to and from the dining room, instead of using a wheelchair.

Environment

There are various ways to modify the environment to help prevent falls.

- Adjust bed, wheelchair, other chairs and toilet heights when indicated to help prevent falls.

  Note: Existing safety guidelines recommend that toilet height be at about knee height.

- Understand that a person with loss of balance will grab onto anything within reach. Ensure that stable handholds are available by providing such items as grab bars and railings.

- Make sure furniture is sturdy and in good condition and adjust furniture location to match as closely as possible the resident's previous bedroom-to-bathroom path.

- Create and maintain a clear path to the bathroom.

- Whenever possible, provide non-slip floor treatments throughout the residence, especially in bathrooms and next to beds.

- Encourage use of footwear that is non-skid and provides a wide base of support.

- Ensure good lighting.

  Example: Increase resident ability to turn on lights by installing motion-activated lighting or sensor lights.

  Example: Install nightlights between a resident's bed and bathroom.

- Use silent alarms to alert staff when a resident at risk of falling attempts to leave a bed or chair.

  CAUTION: Alarm systems can inadvertently restrict a resident's movement, in which case the systems function as restraints. For example, some residents may become afraid to move for fear of setting off an alarm. Staff needs to respond to alarms by providing the assistance needed to help the resident to move.

Behavior Expressions

The workgroup was committed to incorporating a person-centered operational culture as a fundamental component to the development of care strategies for addressing the behavior changes in persons living with dementia. "Challenging behaviors" can have a paternalistic connotation and generally assumes a negative connection to these symptoms. Often these symptoms are a reasonable reaction of the person with dementia including expressions of unmet needs such as pain, boredom, loneliness, or responses to changes in the physical environment or an underlying medical condition. Behaviors expressions are a form of communication. *As a result, the workgroup recommends that the "challenging behavior" description be replaced with the person-centered language of "behavior expressions."*

The workgroup felt that these standards are applicable to both skilled nursing facilities and assisted living facilities.

With the underlying foundation of person-centered support, the workgroup recommended dementia care practices for behavior expressions to include the utilization of initial and ongoing comprehensive assessments, development and implementation of effective, personalized plans of care, and a commitment to building person-centered dementia care knowledge and skills for all staff members.

I. A **Comprehensive Assessment** including the resident's abilities, social history, and personal preferences is necessary to provide support in both proactive and responsive approaches to behavior expressions.

A. An initial, **strength-based assessment** includes understanding a resident's holistic abilities:
   a. Cognitive abilities
   b. Medical needs
   c. Physical functioning
   d. Sensory abilities
   e. Behavior expression status
   f. Communication abilities
   g. Medication review
   h. Personal preferences
   i. Cultural background

B. An ongoing assessment includes a **root cause analysis** of the potential factors that impact the behavior expression of each resident:
   a. Change in functioning
      i. Physical
      ii. Medical
      iii. Cognitive
      iv. Sensory
   b. Environmental factors
   c. Psychosocial factors
   d. Staff/family approaches
   e. Systematic approach to non-initiation, reduction, and/or elimination of antipsychotic medication usage

II. The development of an **effective plan of care** is necessary to provide individualized approaches based on the comprehensive assessment, family input, and staff participation.

A. The plan of care builds on the resident's abilities and incorporates strategies to personalized approaches to prevent and respond to behavior expressions.

B. Plan of care documents will be accessible to all staff in order to

effectively provide person-centered care approaches.

C. Suggested best practice approaches to compliment individualized, plan of care interventions.
   a. Aromatherapy
   b. Light therapy
   c. Massage
   d. Benevolent Touch
   e. Snoezelen or other sensory stimulation programs
   f. Animal assisted facilitation/visits
   g. TimeSlips
   h. Memories in the Making or other art facilitation programs
   i. Namaste
   j. Music and Memory Initiative
   k. Individualized photo albums Engagement kits/bin
   l. Sensory, themed baskets
   m. Eden approaches

D. A comprehensive plan of care also includes a specific, **support strategy** when a crisis occurs in which behavior expressions impact the safety and well-being of the resident or others.

E. An **interdisciplinary team coordinates** the ongoing evaluation, interventions, and effectiveness of the behavior expression plan of care.

III. Initial and ongoing **staff training** includes topics that promote person-centered, dementia-specific philosophy of care.

A. Overview of progressive symptoms of Alzheimer's disease and related dementias

B. Strategies to support person-centered, strength-based care

C. Approaches to effective communication

D. Techniques/approaches for prevention, elimination, and reduction of behavior expressions

E. Social engagements

F. Activity-focused support

G. Interventions to maintain independent functionality

H. Problem solving approaches to providing care and support

Staff Qualifications & Composition

The team consists of the following Leading Age WI Provider Members:

- Sarah Hubert, Pleasant View Nursing Home
- Terry Hensel, Pleasant View Nursing Home
- Monica Day, Fair View Nursing Home
- Jennifer Vossen, Sauk Co. Health Care Center
- Susan Teteak, Skaalen Nursing and Rehabilitation
- Sally Rocque, The Neighbors of Dunn Co.
- Mark Radmer, Harbor Haven Health & Rehabilitation

After extensive conversation, the team identified the following 6 primary considerations under the Core Area of "Staff Qualifications & Composition", as needing further development/discussion:

1. Need/Requirement for **Interdisciplinary Composition** of Dementia Care Team –

a. Dementia Care centers/households/nursing units in the SNF/AL environments must have staff from all disciplines represented. This would include Nursing, Activities, Social Services, Rehab, Dining Services, and Environmental Services. All disciplines must have a hand in resident-specific care-planning and implementation, in order to best meet the needs of the Dementia resident.

2. Need for **Training** to Ensure Qualifications –

a. Training designed to improve the provision of care & services for residents suffering from Alzheimer's or any form of dementia, must be covered in General Orientation for ALL new staff coming to work for an organization that provides Dementia Care.

b. Training designed to improve the provision of care and services for residents with Alzheimer's/Dementia must be part of an organization's/facility's curriculum for Annual Staff Education, for ALL staff, where Dementia Care is provided.

c. For those facilities that provide a Dementia-specific or specialty household/unit, the staff routinely assigned to these areas would be required to have more intensive training relative to, but not limited to the following areas:

- Dementia disease process;
- Dementia ADL/care approaches;
- Strategies for communicating with Dementia residents and their families;
- Medication interventions for Dementia residents;
- Activity interventions for Dementia residents;
- Nutrition interventions for Dementia residents;
- Behavioral Crisis Management & Interventions;
- Other

3. Need for **Consistent Staffing** Assignments –

a. For those organizations or facilities that have care environments where the existence of residents with Dementia is common, in these care areas the facility/organization must have consistent staffing assignments. Specifically, the assignment of staff to these areas should be such that only a limited number of individuals from any given department will work in these areas, recognizing that staffing needs and adjustments to this model may be necessary particularly in the event of a staffing emergency. This concept is of greatest importance for nursing staff in traditional care models, for both licensed and unlicensed caregivers, yet applies in the universal care worker/household model as well. Creating a sense of familiarity for Dementia residents with their caregivers is of vital importance to improving outcomes.

4. Need for formalized **Caregiver Mentorship** Program –

a. A Caregiver Mentorship Program should be in place for all Dementia-Care environments, which should include hands-on training by the mentor, with the new staff member. The mentor and trainee should be "paired-up", and working assigned shifts together, until all components of the Mentorship Program have been covered or completed by the new employee and their mentor.

The Dementia-Care Mentorship Program should require completion of a formalized Mentor training program for all assigned mentors, and Dementia Care mentors should have at minimum, the training as described in item # 2 c. of this document. Completion of the mentorship program would be necessary prior to any consistent staffing assignment becoming permanent. In other words, both brand new employees, as well as someone who has worked for an organization long-term, but is new to a Dementia-care area, must complete all training required in the Dementia -Care Mentorship Program.

A Dementia-Care Mentorship Program must be consistent with other Dementia-specific staff training, it must enforce these concepts, yet the mentorship training will also involve training/orientation which focuses on particular residents and their needs, any particular care environments considerations, and work processes unique to that area/household.

5. Need for formalized Caregiver & Organizational **Communication Platform** –

a. In Dementia-care environments, there is a need to ensure for a means of communication among staff, from all departments and from all shifts, and specific to the needs of the day for the residents, household, and outside of the household. While the communication means would include some form of a "shift-to-shift report", and care-planning meetings/discussion, it has to be more than that. Whether daily or several times per week, there has to be a routine utilization or care-management review, similar to how many SNF's review their Medicare A caseloads, so that all disciplines have the opportunity to share their assessments, observations, recommendations, plans, and goals for each Dementia resident, as well as the opportunity to be informed of the same from other disciplines.

6. Need for formalized Staff **Burnout Prevention/Treatment** Program –

a. There is a need for a formalized Staff Burnout Prevention and Treatment Program for Dementia Caregivers. Staff that work in Dementia-Care environments are arguably at greater risk for burnout due to the high level of frustration and stress that can at times be a part of working with residents who suffer from Dementia, due to many factors. Organizations providing Dementia should have a formalized program to periodically assess staff for burnout, one that can "treat" staff burnout if it occurs, and one that uses preventative measures and education designed to avoid burnout.

Admissions / Transfer / Discharge and Philosophy

Admission Standards

1. Agreement of self-disclosure
   - Know what type of resident you are getting
   - What are the diagnosis
   - What are the medications
   - What type if any special care you will need for the resident such as 1:1
   - Level I required prior to admission under short term exemptions use emergency placement

2. Appropriate diagnosis for all psychotropic medications

3. Hospital buy-in-- hospitals understand what is needed for EPP admissions

4. Adult EEP staff understand the difference between Chapter 51 & 55 because of nursing home regulations. Across all processes admit/discharge/transfer so once a resident is admitted to a SNF other options are explored for least restrictive placement

5. Dementia related diagnosis for admission are assessed so appropriate residents are admitted

6. Cognitive screens done by MCOs & ADRC

7. Physician buy-in to assist in a smoother transition in the admission process

Transfers & Discharges Standards

Note: We feel it would be good for LeadingAge Wisconsin to develop plans for all SNF/AL/RCAC to follow for:

1. Develop a list of resources for placement
   - Consortium with other Counties
   - Contract with psychiatric Services

All LeadingAge members should work with DHS and County Human Services to:

1. Crisis plan development
   - Maximum information obtained from hospital and EEP

2. Have plan in place for resident; work with EPP from the county seeking placement for what the long-term plan will be for the resident

3. Communication with other facilities/counties as above in admission standards agreement of “self-disclosure”

Dementia Physical Design Standards

Based on the charge to the workgroup, we were to make recommendations on physical plant items that contribute to a therapeutic living environment for individuals with dementia. Features considered could then be used a "roadmap" that new users could take into consideration when considering the development of a dementia unit. Unless noted, all the items identified would apply to either a SNF licensed environment or a CBRF licensure level. It was the consensus of the members that a RCAC environment is not appropriate for most dementia residents. Our recommendations do not address new construction vs. remodeled spaces; rather they identify those physical features which promote a dementia appropriate area. Recommendations offered based on personal and professional experience of workgroup members.

Since caring for dementia residents offers substantial challenges, it is critical that any new resident be evaluated to determine any limitations on their physical ability to see, ambulate, or move independently. Based on that assessment, the physical environment can be modified if necessary to accommodate personal needs. Heights of furnishings, toilet fixtures, falls risk, and visual impairments can be accommodated in many ways to offset potential risk to the client.

Topics to Consider:

1. Physical Space- Size, Configuration

- Ideal unit size 10-16 people
- Single level- grade level, no steps or transitions
- Single/private rooms- able to accommodate a reasonable amount of needed equipment and personal possessions
- Preferably private toilet and bathing options
- Ideally hallway layout would offer sufficient space to residents to function as a Wandering path- eliminate dead end halls
- Common space configured to look "familiar"- i.e. Residential vs. Institutional

2. Lighting Issues

- Soft lighting colors- full spectrum lighting
- Indirect lighting, offering even lighting coverage for all resident areas
- Multiple lighting sources throughout room and living areas
- Individual controls in resident rooms to cater to person's visual ability
- Whenever possible eliminate glare off surfaces
- Use of lamps to offer additional options and resident specific lighting needs
- Wall lighting
- Use of natural lighting whenever possible
- Use natural lighting as focal point for common areas
- Allow use of blinds or drapes to control outside lighting

3. Sound levels

- Design nurse call system to eliminate call lights that blink and beep
- Eliminate overhead paging whenever possible
- Eliminate background music
- Monitor/eliminate unnecessary TV/radio use
- Limit use of chair /bed alarms

- Use of materials that absorb, rather than reflect sound

4. Flooring- Design, Materials

- More use of vinyl materials than carpeting
- Plank flooring also good-
- Neutral, glare free finishes
- Avoid very light/very dark floor colors
- Eliminate Dark transitions- consistent color/shade best
- Non-slip whenever possible
- Eliminate accent borders

5. Wall Coverings- Design, Materials

- Matte finishes on surfaces
- Neutral, earth tone colors
- Reduce glare
- No busy patterns on surfaces
- Avoid dark accent walls
- Texture wall surfaces acceptable

6. Common Spaces

- See lighting suggestions
- Small spaces/groupings of furniture
- Residential style appearance
- Limit noise pollution
- Space available 24/7
- Have toilet facilities located close to common area
- Eliminate doors into spaces
- Fireplaces to attract- must be safe to touch/no openings
- Cooking/baking close by, not directly accessible to residents
- When weather appropriate , secure , barrier free outside space
- Eliminate excess foot / cart traffic through area

7. Resident Rooms and Furnishing

- Beds- consider use of 42" beds to assist in fall prevention
- HI/Lo adjustable beds
- See lighting / sound section comments
- In-room supply space eliminates carts
- Built in furnishings will assist in decreasing falls
- When possible offer a direct view of bathroom area from bed
- Encourage height appropriate furnishings depending on physical ability of resident

8. Bathing Areas

- Encourage use of showers vs. large tubs
- Warm temperature- draft free
- Moderate lighting
- Whirlpools may be suitable for some- not all
- Use of lift assisted tub bathing to be limited

9. Dining Issues

- Food readily available 24/7
- Plated service to meet resident needs
- Layout of dining area to encourage interactions as appropriate
- Adaptive devices available in used

10. Colors

- Neutral
- Earth tones
- Eliminate sharp contrasts in colors
- Neutral patterns in upholstery

11. Way-Finding/Personal Effects

- Allow space for familiar items
- Room finding functions
- Age appropriate decorations

April 3, 2014 email from DHS Carrie Molke to
Tom Moore (WHCA) and John Sauer (LeadingAge Wisconsin)

Subject: RE: Dementia Work groups

Thanks for your inquiry, and sorry that it has taken awhile to get back to you.

There are five Implementation Teams for the Dementia Care Project, based on the components of the Dementia Care Plan: (1) Community Awareness and Services; (2) Facility-Based Long Term Care; (3) Care for People with Significant Challenging Behaviors; (4) Standards and Training; and (5) Research and Data Collection. Some of the teams will be further divided into strategy-specific workgroups.

Due to the great amount of interest in the Dementia Care System Redesign Project, the variety of types of stakeholders, and the ambitious timeline identified in the Plan, the Department has been giving careful consideration of how to meaningfully engage stakeholders in the implementation process while continuing to move the process forward. Here is the general plan we have outlined so far:

- Stakeholders will be included in the ongoing work of the Implementation Teams as the Teams and their workgroups feel is feasible for their specific responsibility areas. The Teams may also identify and periodically engage with a larger group of "stakeholder consultants" to get feedback at critical junctures.
- An additional "Communications Team" within DHS will help prepare presentation materials and track stakeholder interest and engagement. In addition, the Team will be responsible for:
    a. Making regular updates to the DHS priority initiatives website;
    b. Creating and managing a listserv through which participants are notified when new items are posted to the website.
    c. Creating and managing a brief survey instrument on the website through which stakeholders will be able to submit comments related to the Project that will be forwarded to the implementation teams and workgroups;
    d. Managing a DHS "Speakers Bureau," including tracking requests for speakers and associated scheduling.
    e. Tracking additional activities related to the Project, such as meetings of Department staff with stakeholders for discussion of issues related to the Project and/or to provide technical assistance and media interviews.
- The Dementia Care Project will work with one or more partner agency to co-sponsor periodic stakeholder meetings through which participants will have an opportunity to discuss specific implementation issues and make suggestions related to the Project. The details of this approach are still under development. It will be made clear to participants that these meetings are advisory in nature and will continue only through implementation of the Dementia Care Plan.

- The Dementia Care Project will also host regional public meetings to provide updates and opportunities for stakeholder input.

I know that you are specifically interested in how your industry might be involved in the Implementation Teams and workgroups. Because there are many strategies under each Team and because the Department has decided to take a comprehensive approach to figuring out how to fairly engage stakeholders, the teams are still finalizing how their approaches to the strategies and to ensuring meaningful stakeholder input. As stated in the first bullet of the general plan, we do expect the teams and their workgroups to include stakeholders, either as members of the group and/or as periodic consultants. Each team is in the process of identifying how best to do so.

Each team has been provided with the names of the stakeholders that have expressed interest in their area. So your name has been provided to all the teams! But it is clear that we do not have the staff resources to manage discussions and decision-making with large groups of people for each and every team and workgroup meeting. That is why we expanded our strategy to include making frequent updates on the Project on the DHS website, with the opportunity for stakeholders to comment, and to sponsor periodic meetings with stakeholders at which specific topics will be addressed and stakeholder input on those topics will be solicited. We will also be responsive to requests by specific stakeholder groups for meetings and discussion.

One of the areas I am sure you will be interested in that is coming up soon relates to the Standards and Training Team. That Team is currently working with the University of Oshkosh Center for Career Development and Employability Training (CCDET) to plan for meetings with three types of stakeholder groups, including provider experts, dementia care experts, and crisis intervention experts. The purpose is to solicit input on the development of voluntary standards and training programs. It is expected that following those initial meetings a stakeholder advisory group to the Standards and Training Team will be formed to provide ongoing input. The provider industry will certainly have the opportunity to be involved.

As for specific engagement with the other teams, I ask for your continued patience as we strive to further develop processes to meaningfully engage the many interested stakeholders in the implementation of the Dementia Care Plan.

Thanks,

Carrie Molke
Director, Bureau of Aging and Disability Resources
WI Department of Health Services
608.267.5267
carrie.molke@wi.gov

From: John Sauer
Sent: Friday, April 04, 2014 9:33 AM
To: 'Tom Moore'; Molke, Carrie A - DHS
Cc: Shoup, Brian A - DHS; 'Woods, Otis L - DHS'; 'Coughlin, Kevin J - DHS'
Subject: RE: Dementia Work groups

Carrie,

Thanks for the follow-up.

A couple of things:

1. I appreciate you adding our names to the list of persons seeking representation on the 5 workgroups.
2. There is value in getting input, early on, from those in the field—I have many providers that are eagerly awaiting the opportunity to share their expertise and insights on addressing the needs of persons with dementia.
3. With respect to standards, LeadingAge Wisconsin is evaluating possible internal standards for members to consider. We are looking for a best practice approach that does not impose mandated standards.
4. We are very interesting in being engaged, soon, on the apparent vision of DHS to rely on CBRFs to serve as “specialized” dementia crisis centers. A discussion should occur soon on the relative merits and cost of using CBRFs to serve in this capacity, versus the role of SNFs. We’d like to learn more about the DHS plans on facility-based care.
5. This is FYI. Many of our members and I are attempting to erase the word “industry” from our vocabulary as it is often used to describe the long term services and supports provider community. Industry connotes a factory, rote approach to care and service delivery. We seek the language change to better reflect the dedicated mission of those who serve others……

Thanks

John Sauer
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From: Benesh, Patricia A - DHS [mailto:Patricia.Benesh@dhs.wisconsin.gov]
Sent: Tuesday, March 04, 2014 8:32 AM
To: John Sauer
Subject: RE: Dementia workgroup

John,

Sorry for the delay in getting back to you, I was checking on the topics. DHS is creating a list of stakeholders regarding Dementia Standards and Training. Both you and Wanda Plachecki are on the list. No firm dates have been established for the meetings, possibly late March. As I understand, you can nominate individuals now or wait until they send you the meeting notice. We haven't started putting together the DQA workgroup yet.

Thanks, Pat.

Pat Benesh, Quality Assurance Program Specialist
Division of Quality Assurance
Department of Health Services
608-264-9896
Patricia.benesh@wi.gov

-----Original Message-----
From: John Sauer [mailto:jsauer@leadingagewi.org]
Sent: Tuesday, March 04, 2014 8:09 AM
To: Benesh, Patricia A - DHS
Cc: John Sauer
Subject: RE: Dementia workgroup

Pat

Is this the group looking at DQA safe harbor issues? How many reps are needed and when will they meet first?

Js