Evidence-Based Best Practices - Dementia Care in Long-Term Care

I. Introduction

a. Overview [1][2][11]

Dementia is a general term for declining mental abilities (including memory loss, difficulties with language and communication, problems with concentration and executive functions) that interfere with a person’s daily life. A number of progressive neurocognitive disorders are considered forms of dementia, including:

- Alzheimer’s disease, the most common form of dementia, affecting an estimated 5.3 million people in the United States; over five million of those cases were in people over the age of 65 (one in nine people 65 or over), while approximately 200,000 people under the age of 65 were diagnosed with younger-onset Alzheimer’s. Over 80% of the people with a diagnosis of Alzheimer’s are aged 75 or older
- Vascular dementia, another common cause of dementia, accounting for approximately 10% of all dementia cases.
- Lewy Body dementia, accounting for between 10% and 25% of dementia cases.
- Frontotemporal dementia often occurs in people under the age of 65, and may account for between 10% and 15% of all dementia cases.
- Huntington’s disease, a hereditary disorder caused by a defect in a single gene. Symptoms generally develop between the ages of 30 and 50, with an estimated 30,000 cases in the United States.
- Creutzfeldt-Jakob disease (CJD), a prion disease occurring when prion proteins begin folding into abnormal shapes, leading to the death of brain cells. Unlike other forms of dementia, CJD progresses rather rapidly. CJD is rare, occurring in approximately one in 1 million people annually worldwide.

By some estimates, up to 50 percent of individuals living in residential care facilities (Assisted Living and Nursing Facilities) have some form of dementia or other cognitive impairments; that number is expected to increase with time. A number of factors can increase the risk of developing Alzheimer’s disease or other dementias, including age, genetics/family history, cardiovascular disease and history of traumatic brain injury.

Other conditions can mimic the symptoms of dementia, and must be ruled out before a diagnosis of dementia can be made, including:

- Delirium or depression,
- Adverse effects of medication,
- Infection,
- Endocrine or metabolic disorders,
- Excessive use of alcohol, and
- Certain vitamin deficiencies.
When these conditions are present, appropriate treatment can lead to a resolution of the dementia-like symptoms, returning the individual back to his/her baseline.

b. Vision/Mission Statements

**Vision:** Through individual assessment and person-centered care planning, every resident with dementia will receive enhanced quality of life.

**Mission:** Provide the tools and resources necessary to implement person-centered dementia care systems utilizing evidence-based best practices.

c. Definitions of Key Terms: [3][4][5]

**Behavior:** The response of a person to a wide variety of factors, generated through brain function that is influenced by input from the rest of the body. Behavioral responses are often triggered by a resident’s unmet needs and are influenced by a variety of factors, including the environment, personal experience, past learning, inborn tendencies/genetic traits and responses to the actions or reactions of other people.

**Behavioral Interventions:** Individualized approaches, including direct care and activities, that are provided as part of a supportive physical and psychosocial environment, and that are directed toward understanding, preventing, relieving, and/or accommodating a resident’s distress or loss of abilities.

**Dementia:** A descriptive term for a collection of symptoms that can be caused by a number of disorders affecting the brain. Dementia is diagnosed only if two or more brain functions (such as memory and language skills) are significantly impaired without a loss of consciousness.

**Delirium:** An acute confusional state with symptoms similar to those of dementia and certain psychiatric disorders. Delirium develops over a short period of time (hours or days), and is associated with an altered level of consciousness.

**Excess Disability:** The loss of ability to function due to factors other than those due to the disorder itself (e.g. dementia, Traumatic Brain Injury, etc)

**Person-Centered Care:** Care that is individualized, keeping the resident at the center of the care planning and decision-making processes. The care is tailored to all relevant considerations for the individual, including physical, functional and psychosocial aspects, helping him/her achieve highest practicable level of well-being.

**Behavioral or Psychological Symptoms of Dementia (BPSD):** Behavior or other symptoms in people with dementia that cannot be attributed to a specific medical or psychiatric cause. This may include symptoms such as disturbed perception, thought content, mood or behavior.
d. Drivers

**Nursing Facility Quality Review 2013**

Percentage of residents with a diagnosis of dementia, Alzheimer’s Disease or other cognitive impairment: 68%

Percentage of residents receiving at least one antipsychotic medication: 30%

Of residents who were prescribed antipsychotics, those who were given atypical antipsychotics to manage dementia-related behavior: 49%

Of residents who were prescribed antipsychotics, those who were given typical antipsychotics to manage dementia-related behavior: 59%

**Centers for Medicare and Medicaid Services (CMS) Quality Measures – Texas**

Residents who received an Antipsychotic Medication (Long Stay): 22.49% - June 2015

National Partnership to Improve Dementia Care in Nursing Homes: Launched in 2012

**Advancing Excellence in America’s Nursing Homes**

Goal: Person Centered Care. [https://www.nhqualitycampaign.org/goalDetail.aspx?g=PCC](https://www.nhqualitycampaign.org/goalDetail.aspx?g=PCC)

Person-centered care promotes choice, purpose and meaning in daily life. Person-centered care means that nursing home residents are supported in achieving the level of physical, mental and psychosocial well-being that is individually practicable. This goal honors the importance of keeping the person at the center of the care planning and decision-making process. Care plans are living documents that are revised to reflect a person’s changing needs. When providing person-centered care, staff places a premium on active listening and observing, so they can adapt to each resident’s changing needs regardless of his/her cognitive abilities.

Goal: Medications. [https://www.nhqualitycampaign.org/goalDetail.aspx?g=med](https://www.nhqualitycampaign.org/goalDetail.aspx?g=med)

Medications, when used appropriately, can help promote the resident’s highest practicable mental, physical, and psychosocial well-being. Medications used inappropriately can compromise a resident’s well-being and even cause death. Ensuring that residents receive medications that are needed and appropriate for their medical condition is a critical component of safe and effective care.
e. **Regulatory Standards**


**42 CFR §483.15 (f) Activities (F248)** The facility must provide for an ongoing program of activities designed to meet, in accordance with the comprehensive assessment, the interests and the physical, mental, and psychosocial well-being of each resident.

**42 CFR §483.15 (g) (1) Social Services (F250)** The facility must provide medically-related social services to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident.

**42 CFR §483.20 (d) (F279)** (A facility must...) use the results of the assessment to develop, review and revise the resident’s comprehensive plan of care.

**42 CFR §483.20(k) (1) Comprehensive Care Plan (F279)** The facility must develop a comprehensive care plan for each resident that includes measurable objectives and timetables to meet a resident’s medical, nursing, and mental and psychosocial needs that are identified in the comprehensive assessment. The care plan must describe the following:

(i) The services that are to be furnished to attain or maintain the resident’s highest practicable physical, mental, and psychosocial well-being as required under §483.25; and

(ii) Any services that would otherwise be required under §483.25 but are not provided due to the resident’s exercise of rights under §483.10, including the right to refuse treatment under §483.10(b)(4).

**42 CFR §483.25 Quality of Care (F309)** Each resident must receive and the facility must provide the necessary care and services to attain or maintain the highest practicable physical, mental, and psychosocial well-being, in accordance with the comprehensive assessment and plan of care.

**42 CFR §483.25 (l) Unnecessary Drugs (F329)**

1. **General.** Each resident’s drug regimen must be free from unnecessary drugs. An unnecessary drug is any drug when used: (i) In excessive dose (including duplicate therapy); or (ii) For excessive duration; or (iii) Without adequate monitoring; or (iv) Without adequate indications for its use; or (v) In the presence of adverse consequences which indicate the dose should be reduced or discontinued; or (vi) Any combinations of the reasons above.

2. **Antipsychotic Drugs.** Based on a comprehensive assessment of a resident, the facility must ensure that:
(i) Residents who have not used antipsychotic drugs are not given these drugs unless antipsychotic drug therapy is necessary to treat a specific condition as diagnosed and documented in the clinical record; and (ii) Residents who use antipsychotic drugs receive gradual dose reductions, and behavioral interventions, unless clinically contraindicated, in an effort to discontinue these drugs.

**42 CFR §483.60 Pharmacy Services (F425)** The facility must provide routine and emergency drugs and biologicals to its residents, or obtain them under an agreement described in §483.75(h) of this part. The facility may permit unlicensed personnel to administer drugs if State law permits, but only under the general supervision of a licensed nurse.

(a) Procedures. A facility must provide pharmaceutical services (including procedures that assure the accurate acquiring, receiving, dispensing, and administering of all drugs and biologicals) to meet the needs of each resident.

(b) Service Consultation. The facility must employ or obtain the services of a licensed pharmacist who--

1. Provides consultation on all aspects of the provision of pharmacy services in the facility;

**42 CFR 483.60 (3) Drug Regimen Review (F428)** (1) The drug regimen of each resident must be reviewed at least once a month by a licensed pharmacist.

(2) The pharmacist must report any irregularities to the attending physician, and the director of nursing, and these reports must be acted upon.

**42 CFR 483.75 Administration (F490)** A facility must be administered in a manner that enables it to use its resources effectively and efficiently to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident.

**f. Evidence-Based Highlights [2][3]**

When developing systems for dementia care, a facility must focus on the delivery of care that is person-centered, comprehensive and truly interdisciplinary. This may require a rethinking of the approaches that are utilized in dementia care, understanding not just what is important for the resident, but more crucially what is important to the resident. Caregiving strategies must be based on an individualized, person-centered plan of care; identifying retained abilities, with input from the resident, family and others who know the resident well and understanding the resident’s preferences and needs. This concept applies to all areas of care, including but not limited to:

- Activities of daily living – bathing, dressing, toileting
- Daily routines – time of waking, going to bed
- Dining and food preferences
- Activities programming
Person-centered care requires adequate staff: both in terms of quantity (direct care and supervisory staff) and quality to meet the needs of the residents as determined by resident assessments and the individualized plans of care.

Residents with new or worsening behaviors must be evaluated by the interdisciplinary team (including the primary physician/practitioner), to identify and address any treatable factors that could be contributing to the behaviors.

The use of first-line non-pharmacological interventions for BPSD is recommended, unless clinically contraindicated or in documented emergency situations. Staff must understand that the behaviors are a means of communicating an unmet need, and utilize a process that recognizes that concept to focus on the resident’s individual needs. This will help reduce the incidence, duration and intensity of the behavioral symptoms.

In some situations, a resident may benefit from the use of medications, including antipsychotic drugs. The medication is given only if clinically indicated and to treat a specific medical or psychiatric condition and target symptoms, such as those causing harm or significant distress to the resident themselves or to others, as diagnosed and documented in the medical record. If an antipsychotic drug is deemed necessary, initial doses should start low and then be titrated slowly to maintain the highest level of functioning with the lowest effective dose. Antipsychotic drugs must never be used for staff convenience or as a form of discipline. When antipsychotic drugs are used, facility staff must attempt gradual dose reductions and implement behavioral interventions in an attempt to discontinue these drugs unless a clinical contraindication is documented by the attending physician.

To the extent possible, the resident and his/her family/personal representative must be involved in any discussion of potential approaches for managing behavioral symptoms, as well as other aspects of care. These discussions are documented in the medical record.

II. Evidence-Based Best Practices [2][3][4][5][11]

a. Operational/Administrative Functions

Policies and Procedures

Comprehensive, well-designed policies and procedures will guide the facility’s staff in providing care to residents with dementia. Policies and procedures must be evidence-based, clearly outlining a systematic process for the care of residents with dementia and drawing upon nationally recognized resources and guidelines such as:

- The National Partnership to Improve Dementia Care in Nursing Homes
- The Centers for Medicare and Medicaid Services (CMS) Hand-in-Hand series
- The Centers for Disease Control and Prevention (CDC)
- OASIS Curriculum/ Massachusetts Senior Care Foundation
Resident care policies reflect the facility’s overall approach to the care of residents with dementia, including a clearly outlined process for their care. Specific policies and procedures may include, but are not limited to:

- Wandering and elopement
- Management of new or worsening behaviors
- Appropriate use of antipsychotic medications
- Preventing and identifying abuse, neglect and exploitation
- Provision of care, including ADL’s, etc

**Staffing and Staff Training**

Research has identified a correlation between insufficient and undertrained staff with an increased use of antipsychotic medications. There are currently no specific federal regulations related to the number of staff required, however the facility must ensure there is sufficient staff to meet the needs of the residents (as determined by their assessments and individual plans of care), and that the staff is adequately trained to provide the necessary care. As CMS states, “if the approach to care requires a different staffing level or training, such changes must be made.”

The Texas Administrative Code (TAC) §19.1002 does address staffing levels in nursing facilities; specifically setting out the staffing ratios that must be met for licensed nursing staff (RNs and LVNs).

Staff members trained specifically in dementia care will be able to provide a better quality of life for their residents and will experience more personal satisfaction with their jobs. Staff training must take into account the principles of adult learning, understanding that the staff members will learn best when they are convinced of the need for the information being taught. The facility must provide for on-going continuing education, as well.

At a minimum, the recommended training for staff members includes:

- Introduction to Alzheimer’s Disease and other types of dementia, stages of dementia
- Diagnosis, prognosis and currently available treatments
- Identifying depression and other conditions that could affect residents with dementia
• Appropriate and inappropriate use of antipsychotic medications in residents with dementia
• Management of BPSD, applying non-pharmacological interventions
• Communicating with residents who have dementia, their families and other caregivers
• Provision of care, including activities of daily living such as bathing, toileting, dressing, etc
• Pain management principles, assessment and treatment
• Nutrition and hydration practices at mealtime and throughout the day
• Impacts of the environment on residents with dementia and changes that can be considered
• Activities programs for residents with dementia
• Preventing and detecting abuse, neglect and exploitation

While not required by regulation, the facility may wish to designate an individual to coordinate dementia care throughout the facility and assist with training of other staff members; this person should be qualified by licensure and have received dementia care training.

The nursing facility could consider implementing consistent assignment; consistent assignment occurs when the same caregivers consistently provide care to a resident. According to Advancing Excellence in America’s Nursing Homes, “The Advancing Excellence Campaign believes a nursing home is successful when staff are caring for the same residents on at least 80-85 percent of their shifts. This means on at least four of five days, evenings and nights, the resident has the same caregivers”. Consistent assignment is particularly important for CNAs and nurses, increasing their familiarity with the resident, including his or her preferences, routines and needs.

b. Resident Care Practices

CMS Fundamental Care Processes

CMS has identified six fundamental care processes for residents with dementia. When implementing these processes, the interdisciplinary team approach is key; a holistic approach focusing not only on the needs and preferences of the resident with dementia, but also on the other residents in the facility.

Recognition and Assessment

Recognition and assessment involves the collection of detailed information about the resident, including but not limited to:
• Past life experiences – job experience, education, family/social interactions
• Preferences - daily routines, bathing, foods, music, exercise, activities/hobbies, etc
• Communication of needs and preferences – How does the resident communicate his or her needs, preferences and wishes? How does the resident communicate physical needs – pain, hunger, thirst? How does he/she express feelings of boredom, frustration, anxiety or fatigue? What about his/her desires to do something that he/she is unable to articulate?
• Medical history, including chronic medical conditions, pain, falls
• Usual and current cognitive patterns, mood, and behaviors
• Medication regimen - including antipsychotic drugs
• Religious and cultural preferences

A number of structured assessment tools are available, and can help guide facility staff in gathering this information. An example of this type of assessment tool is the Preferences for Everyday Living Inventory (PELI), developed by the Polisher Research Institute:
• Preferences for Everyday Living Inventory-NH Full (PELI)
• Preferences for Everyday Living Inventory-NH Mid-Level

Residents with dementia may not be able to articulate their needs or preferences verbally; staff must understand that behaviors are often the resident’s only way to communicate his/her needs and preferences. When the resident expresses distress, including new or worsening behaviors, those behaviors need to be thoroughly described in detail in the medical record including:
• Potential underlying causes
• Onset, duration and intensity
• Precipitating events or environmental triggers
• Any related factors, such as appearance, cognitive status - alertness

Accurate and detailed information can help the interdisciplinary team identify the underlying cause of the behavior and develop individualized interventions.

For example: documenting “violent,” ”agitated” or “aggressive” does not identify a specific behavior. Noting that the resident begins yelling or throwing furniture during crowded group activities could help staff identify alternative activities that meet the resident’s needs and also ensures the safety of the resident and those attending the group activities.

Cause Identification and Diagnosis

The information gathered during the assessment process can help facility staff identify the underlying causes of behavior and related symptoms, including how those factors interact with each other. Those factors include:
• Any co-existing medical or psychiatric conditions, such as pain, constipation, delirium, worsening mental function
• Adverse effects of the resident’s current medications
Facility staff must recognize, identify and document the new onset or worsening of behavioral symptoms, including any risk of adverse consequences to the resident and/or others.

Once medical causes have been ruled out, facility staff needs to look for other root causes of the behavior, using the individualized knowledge gained during the assessment process (including information from the family and/or previous caregivers whenever possible). This requires a systematic analysis and consideration of the possible causes, such as:

- Boredom, due to a lack of meaningful activity or stimulation during customary routines and activities
- Anxiety related to changes in routines, including shift changes, changes in caregivers, changes in roommates, inability to communicate
- Care routines that are not consistent with the resident’s preferences (bathing, waking, sleep)
- Unmet personal needs, such as hunger, thirst, constipation, pain
- Fatigue, lack of sleep or changes in sleep patterns
- Environmental factors, including noise levels
- Activities that are inconsistent with the resident’s cognitive and other abilities, leading to frustration

**Development of Care Plan**

Care planning is an interdisciplinary process, and must include input from staff members (including the CNAs), the resident and/or family members who have knowledge of his/her routines, preferences and abilities. The comprehensive care plan includes the approaches, therapies and other interventions necessary to provide care to a particular resident. The care plan must be individualized and person-centered, with well-defined problem statements, measurable goals of care and timeframes. The interventions identified on the care plan must be individualized, based on the assessment of the resident, his/her preferences and previous routines.

The care plan must clearly identify identifies the responsibilities of various staff members/disciplines in implementing the interventions. Other components of the care plan include:

- Baseline and on-going details of any behaviors, such as frequency, intensity and duration, as well as the expected responses to the interventions
- Specific goals for and monitoring of the effectiveness of interventions in responding to the targeted behaviors
- Rationale and indications for use of any medications, as well as the specific target behaviors, expected outcomes, dosage, duration, monitoring for efficacy and/or adverse reactions
- Plans for gradual dose reductions when antipsychotic medications are used, when applicable
Non-pharmacological interventions are the first line of therapy before prescribing antipsychotic medications, using a consistent process to address behaviors. Facility staff must focus on the resident’s individual needs, understanding that the behaviors are a form of communication. Certain behaviors can be anticipated and can sometimes be prevented if the underlying causes and triggers have been identified and individualized approaches are implemented. Non-pharmacological interventions include activities designed for residents with cognitive impairments such as music, memory books, reminiscence therapy and many others.

In a few specific situations, a resident may benefit from pharmacological intervention. If staff has conducted a thorough evaluation, and other potential causes have been ruled out, the interdisciplinary team may determine that a low dose of antipsychotic medication may be warranted.

When an antipsychotic medication is initiated or continued, the interdisciplinary team must determine and clearly document in the clinical record:

- What is the resident trying to communicate through the behavior?
- What are the possible reasons for the behavior that led to medication being ordered?
- What other approaches and interventions were attempted prior to the use of antipsychotic medications?
- Was the family member or responsible party contacted prior to the initiation of the medication?
- Is the medication clinically indicated and necessary to treat a specific condition and target symptoms as diagnosed and documented in the clinical record?
- Has the medication been adjusted to the lowest possible dosage to achieve the desired therapeutic effect?
- Have gradual dose reductions been planned and behavioral interventions (unless contraindicated) provided in an effort to discontinue the medication?
- Has the interdisciplinary team, including the primary physician/practitioner, been involved in the care planning process?
- Does the staff monitor for the effectiveness and possible adverse consequences of the medication?

If the resident experiences a decline in function, increased or worsening behavior or less than anticipated level of improvement in response to the interventions, or if he/she has refused or resisted the interventions the care plan will need to be reviewed and revised as necessary.

When a resident receives an antipsychotic medication, the facility must also attempt non-pharmacological interventions, unless contraindicated. More information regarding antipsychotic medication use can be found on the Texas Quality Matters website Antipsychotic Medications and Alzheimer’s Disease web pages.
**Individualized Approaches and Treatment**

Implementation of the care plan interventions is the next step, ensuring the needs of the resident are met. It is important for the facility to have processes in place for communicating information about a resident’s care plan, any changes that have been made or any other pertinent information to all staff members involved in the care of the resident. Methods could include staff “huddles” at the beginning of each shift or behavioral rounds that include the CNAs or any other staff members who have information.

This also includes addressing the underlying causes and consequences of the resident’s behavior, as well as staff communication and interaction with the resident and family members in an attempt to prevent distressing behaviors or other symptoms of distress.

Observations of resident and staff interactions can help determine if the care plan has been implemented as written. Observations should focus on whether the staff:

- Identify and document target behaviors, expressions of distress and desired outcomes
- Implement appropriate, individualized, person-centered interventions and document the outcomes/responses
- Communicate and consistently implement the care plan over all shifts and disciplines

If potential medical causes of behavior or other symptoms (such as those that may indicate delirium or infection) are identified, the primary physician/practitioner must be contacted in a timely manner and a work-up and/or treatment initiated. If the resident presents with new or worsening behaviors, the interdisciplinary team needs to identify and address potentially reversible causes, revising the plan of care accordingly.

**Monitoring, Follow-up and Oversight**

The next step in the care process is ensuring the care plan is implemented on a consistent basis, and evaluating the effectiveness of the interventions. The interdisciplinary team must review the resident’s progress toward the goals identified in the care plan, then revise and update the interventions as needed and determine when the care objectives are met. The process includes:

- Monitoring and documenting the implementation of the care plan, including the effectiveness of the interventions as related to the target behaviors and/or psychological symptoms, any changes in the resident’s behavior and any adverse consequences that arise
- Adjusting the interventions based on the effectiveness and any adverse consequences related to treatment
- Notifying the physician/practitioner if concerns are identified related to the effectiveness or potential/actual adverse consequences of the resident’s medication regimen and initiating changes to the resident’s care according to the physician’s response
• Contacting the Medical Director if the physician/practitioner does not provide a timely and appropriate response to the notification

When contacted, the Medical Director must respond and intervene as necessary, with actions taken documented in the clinical record.

**Quality Assessment and Assurance (QAA) and Quality Assessment Performance Improvement (QAPI)**

The facility must have a process in place to evaluate the systemic approaches to care delivery for all residents, including those with dementia. The QAA committee is responsible for evaluating how dementia care is coordinated, and ensuring the facility’s policies and procedures are consistent with current standards of practice.

The QAA Committee is responsible for monitoring and oversight of other areas related to dementia care, including:

• Ensuring resident care policies reflect the facility's overall approach to the care of residents with dementia including a clearly outlined process for their care
• Monitoring how well staff follow policies and procedures when identifying and implementing individualized interventions for the care of residents with dementia
• Staff education and training in dementia care principles, including communicating with residents and managing behaviors
• Ensuring adequate number of staff to support the implementation of non-pharmacological interventions, instead of using antipsychotic medications
• Evaluating data collected and analyzed by staff to monitor the pharmacological and non-pharmacological interventions used to care for residents with dementia
• Responses to issues and concerns identified by the consultant pharmacist through the medication regimen review

When issues are identified, start a performance improvement project (PIP). The facility can use the QAPI process (including the Plan, Do, Study, Act cycle) to develop solutions and improve their systems for providing comprehensive dementia care.

c. **Specific Areas of Care [2][5][7][8][9][10]**

**Activities of Daily Living (ADLs)**

As dementia progresses, several of the brain functions required to perform ADLs are impacted, including executive functioning, memory, judgement and visual-spatial perception. Resident’s with dementia experience a steady decline in their ability to perform ADLs independently, requiring more assistance from caregivers.
When providing care to residents with dementia, facility staff must:

- Identify the resident’s previous habits and routines, and adhere to those as much as possible (e.g. bath vs. shower, bathing in the morning or evening, time of awakening and going to bed)
- Focus on the resident’s abilities, encouraging him/her to participate as much as possible
- Ensure a safe environment for the resident, while promoting autonomy and independence to the extent possible
- Keep distractions to a minimum
- Remain calm, being aware of the tone of voice used when talking to the resident
- Break the task down into steps, providing only one or two directions at a time
- Allow adequate time for the resident to complete tasks
- Model the task alongside the resident (buttoning a shirt, brushing hair, etc)
- Be flexible, take a break if things are not going well and try again at a later time

Bathing, Nail Care and Hair Care

Residents with dementia may be resistant to bathing for a variety of reasons. Bathing is one of the most intimate areas of personal care, and many residents may perceive it as unpleasant or even frightening. Residents may experience increased sensitivity to water temperature or pressure, triggering disruptive behaviors. Staff must never take the behaviors personally or argue with the resident; if the resident is resistant to bathing, leave and try again later.

As part of the assessment process, facility staff must determine the resident’s previous habits and routines regarding bathing, and honor those preferences to the extent possible. Some of the questions could include:

- Did the resident prefer a bath or shower?
- Would he/she rather bathe in the morning or evening?
- How often did he/she bathe?
- What much is he/she able to do when bathing?

Create a pleasant, spa-like atmosphere in the shower room. Ensure the temperature of the room is warm enough. Facilities could consider investing in a towel warmer to increase comfort. Play soft music in the shower room; choosing music the resident would enjoy and place art on the walls.

When preparing to assist a resident with bathing, the staff first gathers all necessary items, including soap, shampoo and towels. The resident should never be left alone in the shower room. Provide large towels or a shower cape to provide privacy and warmth.

Encourage the resident to wash themselves if able, breaking the tasks down into simple steps. That independence can restore some of the resident’s feeling of dignity that is lost when help is needed with bathing. If a resident is embarrassed, or becomes sexually
inappropriate during bathing, the facility may want to assign a caregiver of the same sex to assist with bathing. If the resident is resistant to bathing, staff can postpone the bath and return at a later time. In some situations, a sponge bath may be sufficient if the resident does not wish to shower or bathe; a daily bath may not be necessary.

Finger and toe nails may become long and unclean without routine care. Nails that are not properly cared for can lead to infection, pain or discomfort. For some residents, the facility may want to enlist the services of a podiatrist, particularly for those residents with diagnoses that place them at high risk for injury, such as diabetes. Many residents may enjoy a manicure and pedicure as part of a “spa day.” Staff must ensure nails are clean, with no jagged edges that could lead to skin tears or scratches. Staff must be familiar with the facilities policies and procedures regarding nail care.

Facility staff may need to try different methods for washing a resident’s hair; some residents may become distressed when their hair is washed during a shower or bath. In those situations, separating bathing from hair washing may be helpful. The resident may be more comfortable having his/her hair washed in a “beauty shop” setting, or in some situations using a no-rinse shampoo may be necessary.

Dental Care
Residents can be encouraged to perform as much of their own oral care as possible; however the task will need to be broken down in to small steps – one or two specific instructions at a time. Modeling the task may be helpful to the resident. The resident’s teeth should be brushed at least twice a day, allowing adequate time to complete the task. Most dentist recommend daily flossing; if the resident does not permit flossing, the facility may want to suggest using alternate methods for removing food debris from between the teeth such as a “proxabrush”.

If the resident wears dentures, they can be rinsed with plain water after each meal and brushed daily to remove food particles. At night, the dentures are removed and soaked in denture cleaner. After removing the dentures, the resident can be assisted in using a soft toothbrush or moist gauze pad to clean the gums, tongue and other soft tissues of the mouth.

Facility staff must observe for and investigate any signs of mouth pain. Refusing to eat, or grimacing while eating may indicate mouth pain or poorly fitting dentures. A referral to a dentist for evaluation may be necessary.

Dressing
Choosing and putting on clothes can be a frustrating task for residents with dementia. Choices can be simplified, keeping the closet free of excess clothing. The resident should be given the opportunity to choose his or her clothing, but staff can assist by offering just two choices.
The process is organized, laying out the clothing in the order each item should be donned, based on the resident’s preferences. Breaking the task down into small steps may keep the resident from becoming overwhelmed. Modeling the tasks may help the resident as he/she completes each step. Staff can assist as needed, but should encourage the resident to do as much of the task as possible and allow adequate time for the resident to get dressed.

Clothing should be comfortable and simple for the resident to don; shirts, blouses and sweaters that button in the front are easier for the resident to work with than pullover type garments. Shoes should be comfortable, with non-slip soles.

Staff must be flexible; if the resident wants to wear multiple layers of clothing, staff should make sure he/she does not get overheated. When outdoors, staff must ensure the resident is dressed appropriately for the weather conditions.

If the resident wants to wear the same clothing repeatedly, the staff should ask the family to purchase duplicates or have similar options available.

**Incontinence and Toileting**
A number of factors can lead to incontinence, including:
- Inability to recognize the need to use the bathroom
- Forgetting where the bathroom is located
- Clothing that is difficult to remove
- Physical conditions, such as UTI, constipation or prostate issues
- Medications, such as diuretics, sedatives/hypnotics, anticholinergic medications
- Mobility impairments

Identifying the underlying cause of incontinence can help facility staff develop an appropriate plan of care. In some cases, the incontinence may be reversed when the underlying causes are treated; in other situations, an individualized continence promotion plan can decrease the number of incontinent episodes and decrease the risk of adverse consequences.

As part of the assessment for incontinence, the resident’s normal voiding patterns are identified and used to determine the schedule for toileting. Ensure the resident is given adequate time to empty his/her bladder and bowels.

Other actions that can help residents with incontinence include:
- Learn each resident’s triggers that indicate the need to use the toilet – may be a specific phrase, or action like pacing, pulling at clothing or increase in agitation
- Use adult words, not “baby talk” to refer to using the toilet
- Make it easy for the resident to find the toilet – keep the door open so the toilet is visible, place a sign with a picture of a toilet outside the door
• Change the color of the toilet seat if the resident has difficulty seeing it
• Keep the pathway to the toilet clear of clutter
• Consider removing plants, wastebaskets or other objects that could be mistaken for a toilet
• Make sure lighting is adequate – use nightlights to illuminate the toilet at night
• Choose clothing that is easy to remove for toileting

Additional information on developing managing urinary incontinence is available on the Quality Monitoring Program website’s Continence Promotion page: http://www.dads.state.tx.us/providers/qmp/evidence-based-best-practices/generalbp/continence-promotion.html.

Activities Programs

It is important the residents with dementia engage in meaningful social interactions throughout the day, every day. Both formal and informal activities can provide the resident with a sense of security and enjoyment. Formal activities are those that are generally scheduled and placed on the facility’s activity calendar (parties, religious services, games, etc.). Informal activities are those that occur during everyday interactions, such as a walk down the hall, a chat with another resident or even participating in ADLs like bathing. Access to personal space and time to relax are also important for enhancing a resident’s quality of life.

Facility staff must complete a formal assessment (involving the resident and family members/representative as much as possible), identifying the resident characteristics that could impact the resident’s involvement in social activities and interactions. Those factors include:
• The resident’s physical abilities and potential impairments
• Capacity for social stimulation
• His or her interest in social interaction
• Interest in spiritual and/or religious participation and fulfillment
• Cultural values
• Preferences, previous interests and hobbies

The resident and family members should be encouraged to share the resident’s “life story”, summarizing his or her past experiences, personal preferences and current capabilities. Once the resident’s preferences, abilities and needs have been identified, an individualized plan for meaningful activities must be included in the comprehensive care plan. The focus should be on activities that are person appropriate not age-appropriate.

The responsibility for residents’ participation in activities program does not rest solely with the activities staff; every staff member, regardless of their discipline or department has a responsibility to interact with residents in a manner that ensures residents’ needs are
met. Activity materials should be available at all times for use by non-activity staff and visitors, such as:

- Baskets of towels, fabric swatches or socks for residents to sort
- Books or calendars with photos to view and discuss
- Puzzles or games, depending on the resident’s abilities
- Multi-sensory theme boxes – fishing, gardening, etc

Even residents with limited verbal communication or those with vision, hearing or mobility impairments can participate in social interaction; however staff will play an important part in initiating that engagement. When planning activities, staff must be aware that residents with dementia may experience increased confusion and agitation at the end of the day, and consider scheduling higher energy activities for earlier in the day.

The environment can have a tremendous impact on a resident with dementia. Minimizing distractions can improve the resident’s functioning and promote more independence. Appropriate lighting, temperature and comfort will enhance the resident’s enjoyment of the activity.

Residents should always be encouraged to use their remaining skills; activities must proactively engage residents. Activities for residents with dementia should be designed to do with not to or for the resident. Offering activities that are consistent with a resident’s level of functioning will increase his or her participation in them.

When conducting group activities, staff can tailor the activity to the residents’ level of functioning. Small groups may be more beneficial, limiting the time to 30 minutes or less before transitioning to another activity. Resident preferences should always be respected, including the times a resident prefers to have solitude.

Facility staff could consider opportunities for involvement with the community, such as attending a concert or interacting with children; this will help the residents continue to feel they are part of the society as a whole. Depending on the resident’s cognitive and functional level, he or she may still wish to participate in specific activities such as voting, etc. The facility can also offer opportunities for families and other community volunteers to participate in activities.

Even seemingly meaningless actions, such as random wandering, can have purpose for the resident. The facility can consider developing indoor and outdoor spaces for residents to walk, like walking paths with areas to sit and rest. Transitions between surfaces (e.g. between a sidewalk and grass) should be level and smooth to decrease the risk of falls. The facility could also substitute alternate physical activity for the wandering, such as dancing, exercise or rocking in a rocking chair.
Dining and Nutrition

Residents with dementia may experience a reduction in food and fluid intake, in part related to a decreased recognition of hunger and thirst, changes in perception of smell or taste, vision problems, difficulty swallowing and an inability to recognize dining utensils. The loss of physical control (inability to feed him or herself) can also contribute to the problem. The resident may lack the ability to communicate the feeling of hunger or thirst.

The facility must design systems for comprehensive screening and assessment; ensuring residents with dementia maintain their nutritional health and avoid unnecessary complications. The assessment must address any nutritional problems present, as well as any resident characteristics that could impact their intake, such as:

- Poor dental health
- Swallowing issues
- Distractibility during meals
- Impairments in balance, strength or endurance
- Difficulty handling utensils
- Attempts to eat non-food items

A variety of approaches may be utilized to provide a positive dining experience for residents, while ensuring adequate intake of food and fluid. The facility can involve the resident and/or family as much as is practicable, identifying previous habits and preferences.

Whenever practical, give residents a choice about when their meal will be served. Provide opportunities for residents to engage in the mealtime experience by helping to plan menus, set the table, etc.

Facility staff should always seek to maximize a resident’s abilities; encourage him or her to eat independently whenever possible to prevent excess disability. Adaptive utensils may help a resident maintain the ability to eat independently. If adaptive utensils are needed, staff must ensure they are available and used with each meal. If the resident is unable to handle utensils, the facility may consider modifying the shape of food so it can be picked up with the fingers.

Allow the resident to eat at his or her own pace, extending the mealtime for those residents who need more time. Staff may need to give verbal cues, reminding a resident to eat and drink. If the resident is distracted by the number of choices, serving one food at a time may be preferable.

Environmental factors must be evaluated including:

- Large, noisy and crowded dining rooms
- Lack of sensory cues that could orient the resident to mealtime
• Type, color and material used for serving meals (trays vs plates)
• Adequacy of lighting in the dining space

For residents with dementia, it may be helpful to have a dedicated dining space with recognizable furniture and decor, rather than eating in a large multi-purpose room. If that is not possible, it is important to provide clear cues for when dining and non-dining activities are occurring, such as involving the residents in setting the tables. Diffusion of food preparation smells may increase residents’ appetite; for example, using a bread machine to produce the smell of baking bread before meal times.

Excessive noise or other stimuli can make it difficult for these residents to concentrate on their meals. The facility can consider removing televisions sets from the dining room and playing soft, calming background music instead.

With aging, visual changes occur; older adults may require up to three times as much light as younger people, but they may also be more sensitive to glare. Lighting that cast shadows are avoided, since residents with dementia can have difficulty interpreting them. There should be a clear contrast between the color of the dishes used to serve the meal and the table top; avoid solid white or highly patterned dishes.

If a resident requires assistance with eating, staff can guide his or her hand using the “hand-over-hand” technique. Staff must always sit while assisting a resident with eating, making eye contact and conversing with the resident during the meal. Residents should be monitored closely for choking and aspiration.

Before utilizing fortified foods and supplements, staff can first try other options such as offering favorite foods, as well as foods with higher nutritional density, calories and protein.

At the end of life, residents with dementia may no longer be able to eat and may need only comfort care. Staff must institute meticulous oral care and moistening the resident’s mouth for comfort. Weight loss is often a normal occurrence at the end of life, but should still be assessed. If artificial nutrition and hydration is being considered, the family/responsible party must be advised of all potential consequences including aspiration, infection and accidental dislodgement of the feeding tube.

The facility staff must provide opportunities for hydration throughout the day, incorporating fluids into activities, and making fluids available in a variety of forms (sherbets, popsicles, gelatin desserts, etc).

**Pain Management**

Pain is often under-recognized and therefore under-treated in residents with dementia. There are a number of challenges in managing pain in these residents, including the need...
for alternate methods for conducting assessments and communicating with them regarding their pain and possible adverse effects of treatment. Pain that is poorly managed can lead to behavioral symptoms that are misinterpreted by facility staff, resulting in the inappropriate use of antipsychotic medications.

Pain assessment must occur on a routine basis, including detailed observations of residents with dementia since they may have difficulty communicating verbally. Residents should be observed with movement, since pain symptoms may not be present when they are at rest. All staff (especially CNAs) should be trained to recognize signs of pain, and to report their observations to the licensed nurse.

Treatment for pain will vary, depending on the individual resident’s needs, however the facility’s staff needs to explore non-pharmacological interventions to ease pain. When medication is necessary for the treatment of pain, staff must be aware of and watch for any potential adverse effects.


**End of Life Care**

A diagnosis of dementia comes with a number of considerations for health care, including the resident’s wishes regarding end of life care. Optimally, a conversation regarding the resident’s preferences would begin as soon as possible after diagnosis; as the disease progresses, those decisions become more difficult.

Facility staff should begin the discussions about advance care planning and preferences for end of life early in the admission process. The resident’s cultural, spiritual and religious values must be recognized and respected; effective communication with the resident and as dementia progresses, with the resident’s family members or responsible party, can guide staff in providing care that meets the resident’s needs and preferences. Among the considerations that can be discussed and documented are the following:

- Cardiopulmonary resuscitation (CPR)
- Other medical procedures and diagnostic tests (surgery, labs, dialysis, etc.)
- Hospital admission, use of ICU and ventilator support
- Artificially provided hydration and nutrition
- Use of antibiotics, medications for chronic medical conditions
- Preventative health screenings (mammograms, colonoscopies, etc.)
- Dietary restrictions

If the resident has executed any advance directives, copies must be placed in the clinical record accessible to the entire interdisciplinary team. If the resident has not executed an
advance directive and has not designated a proxy decision-maker, state law determines who will serve as the decision maker.

Many common medical interventions have shown minimal to no benefit to people with advanced dementia, and may actually have adverse consequences. The resident and/or the family/responsible party must be thoroughly informed of the benefits and the burdens of any medical interventions. They must also be provided with information regarding the facility’s policies and procedures regarding implementation of advance directives.

Any decisions made as part of the advance care planning process must be included in the resident’s care plan and translated into physician’s orders to ensure the resident’s wishes are honored. If, after receiving information about the risks and benefits of a particular course of treatment, the resident or proxy decision-maker decides on an aggressive course of treatment the interdisciplinary team should make every effort to honor that decision. The team, however, is not required to provide treatment or care that is determined to be medically inappropriate.

The facility may wish to establish an ethics committee or work with other local providers who have an ethics committee already in place; these committees can help resolve issues when there are disagreements between family members about the care being provided or other decisions about end of life care.

III. Educational Information/Toolkit

a. DADS Created Resources
Antipsychotic Medication Questionnaire
http://www.dads.state.tx.us/providers/qmp/providers/qmp/docs/AP-meds-questionnaire.pdf

Care Planning Dementia Related Behaviors
http://www.dads.state.tx.us/providers/qmp/docs/CarePlanningDementia.pdf

Comparing Traditional and Person-Centered Models of Care
http://www.dads.state.tx.us/providers/qmp/docs/TraditionalVsPerson-Centered.pdf

Nutrition Best Practices in Dementia Care (PowerPoint Presentation)
http://www.dads.state.tx.us/providers/qmp/training/dementia-care-nutritionppt.html

Non-pharmacological Culture Change (PowerPoint Presentation)
http://www.dads.state.tx.us/providers/qmp/training/non-pharmacological-culture-change-ppt.html

Non-pharmacological Culture Change
• Non-pharmacological Culture Change
  http://www.dads.state.tx.us/providers/qmp/docs/CultureChangeActivities.pdf

• Factors to Identify Behavioral Causes
  http://www.dads.state.tx.us/providers/qmp/docs/FactorstoIdentifyBehavioralCauses.pdf

Quality Monitoring Program Website: Healthy Weight Management

Quality Monitoring Program Website: Appropriate Use of Antipsychotic Medications

Quality Monitoring Program: Alzheimer’s Disease and Dementia Care

Culture Change in Texas Long-term Care
http://www.dads.state.tx.us/culturechange/index.html

DADS Reducing Antipsychotic Medications Videos
http://www.dads.state.tx.us/providers/qmp/resources/videos.html

VN Educator Toolkit: Alzheimer’s Disease and Dementia Module
http://www.dads.state.tx.us/providers/qmp/vocationalnursing.html

b. Resources from Other Organizations

  Administration on Aging
  Dementia-capable States and Communities: The Basics

  Responding to the Wandering and Exit-seeking Behaviors of People with Dementia

  IDD and Dementia

  Brain Health Resources Page
  http://acl.gov/Get_Help/BrainHealth/Index.aspx
Advancing Excellence in America’s Nursing Homes
Resources and Tools [https://www.nhqualitycampaign.org/dementiaCare.aspx](https://www.nhqualitycampaign.org/dementiaCare.aspx)

Medication Management
[https://www.nhqualitycampaign.org/goalDetail.aspx?g=med#tab2](https://www.nhqualitycampaign.org/goalDetail.aspx?g=med#tab2)

Person-Centered Care: Seven Simple Steps to Success
[https://www.nhqualitycampaign.org/goalDetail.aspx?g=PCC#tab1](https://www.nhqualitycampaign.org/goalDetail.aspx?g=PCC#tab1)

iMPROvement Feature Consistent Assignment in Nursing Homes
[https://www.youtube.com/watch?v=HYX10i_Khn4](https://www.youtube.com/watch?v=HYX10i_Khn4)

Fast Facts: Consistent Assignment

**Cleveland Clinic**
Alzheimer’s Disease Questions & Answers
[http://my.clevelandclinic.org/health/diseases_conditions/hic_Alzheimers_and_Dementia_Overview/hic_Alzheimers_Disease_Questions_and_Answers](http://my.clevelandclinic.org/health/diseases_conditions/hic_Alzheimers_and_Dementia_Overview/hic_Alzheimers_Disease_Questions_and_Answers)

**CMS**

Review of Care and Services for a Resident with Dementia: Dementia Care Checklist (PDF)


Survey & Certification Letter 11-35-NH: Mandate of Section 6121 of the Affordable Care Act for Nurse Aide Training in Nursing Homes


Survey & Certification Letter 13-02-NH: Clarification of Guidance Related to Medication Errors and Pharmacy Services (PDF)


QAPI Land Roadmap http://www.dads.state.tx.us/providers/qmp/docs/QAPI_roadmap.pdf
Using the QAPI Land Tool
http://www.dads.state.tx.us/providers/qmp/docs/QAPI_LandTool.pdf

**Illinois Foundation for Quality Health Care**
Change Ideas for Consistent Assignment
http://aipp.afmc.org/Portals/2/images/CultureChangeHome/Library/change_ideas_consistent_assignment.pdf

**Massachusetts Senior Care Foundation**
OASIS: Reducing Off-Label Use of Antipsychotics in Nursing Homes
http://www.maseniorcarefoundation.org/OASIS.aspx

**MUSIC & MEMORY℠**
Music & Memory http://musicandmemory.org/

Alive Inside Video Clip https://www.youtube.com/watch?v=fYZQf0p73QM

**New Jersey Geriatric Education Center**
The Interprofessional Approach to Alzheimer’s Disease and Dementia Care: A 5-module web based program (Note: Web site requires registration to access modules)
http://www.rowan.edu/som/njisa/njisanganjec-downloadable-resources/

**Nursing Home Quality Care Collaborative (NHQCC)**
Learning: Resources and Tools http://qio.ipro.org/nursing-homes-hac/qapi/webinar

**NIA/NIH**
Alzheimer’s Disease Education and Referral Center https://www.nia.nih.gov/alzheimers

About Alzheimer’s Disease: Caregiving


Alzheimer’s Disease Fact Sheet

Caring for a Person with Alzheimer’s Disease

Alzheimer’s Disease Medications Fact Sheet
Forgetfulness: Knowing When to Ask for Help
https://www.nia.nih.gov/health/publication/forgetfulness

Alzheimer’s Disease: Unraveling the Mystery

TMF Quality Innovation Network – Quality Improvement Organization (TMF QIN_QIO)
Nursing Home Quality Improvement
https://www.tmfqin.org/Networks/Nursing-Home-Quality-Improvement

Pioneer Network
Consistent Assignment Tip Sheet
http://pioneernetwork.net/Data/Documents/MDS3.0/Startertoolkit/Consistent_Assignment_Tip_Sheet.pdf

Alzheimer’s Association
Basics of Alzheimer’s Disease: What It Is and What You Can Do

Brain Tour http://www.alz.org/braintour/3_main_parts.asp

2015 Alzheimer’s Disease Facts and Figures
http://alz.org/facts/overview.asp?utm_source=gdn&utm_medium=display&utm_content=topics&utm_campaign=ff-gg&s_src=ff-gg&gclid=CITTubjUgMeCFZKFaQodhgQNg

Health Care Professionals and Alzheimer’s
http://www.alz.org/health-care-professionals/health-care-clinical-medical-resources.asp

Alzheimer’s and Dementia Caregiver Center http://www.alz.org/care/

Communication and Alzheimer’s
http://www.alz.org/care/dementia-communication-tips.asp

Down Syndrome and Alzheimer’s Disease

Dementia Care Practice Recommendations
http://www.alz.org/professionals_and_researchers_dementia_care_practice_recommendations.asp


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Activities [http://www.alz.org/care/alzheimers-dementia-activities.asp]

Alzheimer’s Disease International
Nutrition and Dementia [http://www.alz.co.uk/nutrition-report]

Fact Sheet: Dementia and Your Teeth [http://www.alz.co.uk/sites/default/files/dementia-and-teeth.pdf]

Polisher Research Institute
Geriatric Assessment Instruments and Scales
[http://www.polisherresearchinstitute.org/#!assessment-instruments/c16rg]

Registered Nurses Association of Ontario
Screening for Delirium, Dementia and Depression in the Older Adult
[http://rnao.ca/bpg/guidelines/screening-delirium-dementia-and-depression-older-adult]

Caregiving Strategies for Older Adults with Delirium, Dementia and Depression
[http://rnao.ca/bpg/guidelines/caregiving-strategies-older-adults-delirium-dementia-and-depression]

University of Iowa
Dementia and Challenging Behavior Series
[https://www.healthcare.uiowa.edu/igec/resources-educators-professionals/modules-dementia/]

IA-ADAPT: Improving Antipsychotic Appropriateness in Dementia Patients
[https://www.healthcare.uiowa.edu/igec/iaadapt/]

Bibliography

[http://www.alz.org/facts/]

[http://www.alz.org/national/documents/brochure_DCPRphases1n2.pdf]


(4) National Partnership to Improve Dementia Care in Nursing Homes. Advancing Excellence in America’s Nursing Homes.
[https://www.nhqualitycampaign.org/dementiaCare.aspx]

(5) Statewide Initiative to Safely Reduce the Off-Label Use of Antipsychotics January – September 2014. Massachusetts Senior Care Foundation.
[http://www.maseniorkcarefoundation.org/OASIS.aspx]


